

COVID-19 AND THE GLOBAL POLITICAL ECONOMY

Crises in the 21st Century

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Disability and Aged Care Services into the Future

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Introduction

When Covid-19 first arrived on Australia's shores in early 2020, the aged care and disability support sectors were already under enormous pressure and in considerable flux. This was vividly demonstrated by the fact that Australia had launched two Royal Commissions (formal public inquiries) into these sectors. Details of the many failings of these service systems were emerging almost daily from the in-progress Royal Commission into Aged Care Quality and Safety and the recently commenced hearings for the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. Dramatic reform has occurred over the past decade within the disability support sector with the introduction of the National Disability Insurance Scheme (NDIS). A series of well-documented inquiries and scandals centred on staffing shortages and abuse in residential aged care had set the scene for major reform of this system very soon. This policy turmoil was taking place amidst demographic trends predicting increasing pressure on formal care systems in the coming years.

The pandemic exposed the deep, pre-existing fault lines within Australia's disability and aged care sectors and, more importantly, the devastating consequences of these flaws. Failures to adequately include people with disability in the policy response and vaccine roll-out, the interaction of workforce shortages with quarantine rules and vaccine mandates, and fear about the speed and ease with which the virus can—and has—spread through nursing homes, disability group homes and other congregate care settings, were all fixtures in national news media during 2019 and 2020. In this chapter, we argue that the Covid-19 pandemic exacerbated existing issues within the aged care and disability support sectors and shone a spotlight on them. Given that these issues have been illuminated so vividly, there is a

responsibility on politicians and policymakers to invest in the future of the care economy through systemic reform.

In the first part of the chapter, we provide a brief survey of the pre-pandemic care sector. We then explore the experiences of people with disability, older people, and care workers during the first waves of the pandemic. We examine how various structural features of Australia's disability and aged care systems created heightened risk for care service workers and clients. Both care workers and their clients faced an increased risk of contagion due to close living conditions in congregate care settings and the mobile nature of the care workforce. Care workers faced income loss, and people with disability and older people faced significant social isolation as services were cancelled or could not be sufficiently staffed. Compounding factors include a bungled Covid-19 vaccine roll-out to people with disability and a slow roll-out of vaccines to aged care and disability support workers.

Care largely happens behind closed doors—whether those doors lead to private homes, residential aged care facilities or specialist disability accommodation settings. Australia's political economy, like that of other contemporary capitalist states, is structured by a gendered logic of labour where the sphere of visible work and public action is predominately masculine and maintenance work—the management of care and support needs and the sustaining of bodies and minds within the private sphere—is configured as a primarily feminine responsibility. But Covid-19 has dragged the care sector out from the shadows and under the spotlight, into public consciousness.

Aged care and disability support are usually treated as distinct and separate policy domains. But the common challenges in both areas, which we describe together as the Australian care sector, suggest mutual opportunities for investment that can transform the future life outcomes of millions of Australians if they can be translated into concrete policy actions. Investing in the care sector to promote empowerment and security for both care workers and care recipients is critical for securing the future quality, safety, and sustainability of these essential support services.

In the final part of the chapter, we examine opportunities for future reform in the care sector. The care economy will increase significantly in the next few decades in Australia, due primarily to population ageing but also other demographic drivers. However, the aged care and disability support workforces, which are already feminised and low-paid, appear to be facing increasingly insecure employment arrangements, and it can be difficult to attract new workers into these expanding fields. The pandemic has demonstrated that issues of low pay and insecure work conditions are not just equity issues but are in themselves a public health concern. It has highlighted the essential nature of care and support work for a vast network of workers, older people and people with disability, family members and informal carers. We identify four areas that the Australian care sectors need to undertake substantial reform within if we are to more effectively serve the care needs of the population.

The Pre-pandemic Care Sector Landscape

The care sector is a complex landscape characterised by a mix of accountability structures and funding responsibilities. Responsibility for funding, regulation and policy development concerning aged care (which includes residential care and community-based support services) sits with Australia's federal government. Specialised disability services are predominately provided through the National Disability Insurance Scheme (NDIS), which is administered by the National Disability Insurance Agency (NDIA), a separate statutory agency. The NDIS was first introduced in 2013 in trial sites but has since been rolled out across all states and territories of Australia. The federal and state and territory governments all contribute to NDIS funding and decision-making processes. What is different to the previous system is that states and territories no longer directly provide specialised disability services. These are provided via a new care market comprising profit and non-profit organisations.

Service provision in both disability and aged care is mainly undertaken by non-government providers. Under the NDIS, eligible people with disability receive individualised funding packages to purchase support services that meet their personal needs and goals from a mixed market of non-profit, profit and government providers. The NDIS Quality and Safeguards Commission is the independent agency that regulates NDIS providers and seeks to improve the quality and safety of services. The aged care sector is similarly publicly funded but predominately outsourced to private and not for profit providers. Other mainstream services that people with disability and older people rely on, including public health services, are variously funded by the state, territory, and federal governments, and provided by a range of organisations.

In this chapter, we focus primarily on the clients of specialised aged care and disability supports because of the high impact of Covid-19 on these services, particularly on residential and accommodation services.¹ However, it is important to note that many older people and people with disability were greatly impacted by Covid-19 who were not recipients of these services. Most older Australians do not live in residential aged care, for example. From 2019 to 2020, 245,000 people were living in residential care facilities, whereas 840,000 people used the Commonwealth Home Support Program (CHSP), which includes services such as domestic and gardening assistance and meals on wheels (AIHW 2021). As of June 30, 2021, there were 466,619 participants in the NDIS (National Disability Insurance Agency, 2021, 5), which was designed to cater only to the disability-related support needs of the approximately 10 per cent of total Australians with disability assessed as having a severe and permanent disability. We lack good quality data about those who are not in these specialised services. For example, unlike in other countries such as England, there is no disability identifier in health data, meaning we have no clear picture of the number of people with disability who have contracted Covid-19 in Australia or died from it.

Australian disability and aged care services have experienced significant reform over the past decade. In much of the policy literature, it is suggested this has been

prompted in part by rising expectations of older people and people with disability about the quality and convenience of the care and support services they receive. But it is also important to note that there have been longstanding concerns over the quality of these services and the life chances of individuals accessing them. In both sectors, the dominant discourse is that systems should be more “consumer directed” and that this will drive better services as individuals demand better services from providers or move their business elsewhere. The assumption in both cases is that the market will help drive improvement as individuals tailor services to their needs.

These reforms should signal that there are different expectations of the care sector now than there were in the past and that clients, their families and the community will hold providers to higher standards of accountability now than ever before. But when we examine the reform experience, we find research showing that the benefits of these reforms for clients have been both imperfectly realised and unevenly distributed. Individuals who are well-placed in terms of socioeconomic status and ability to self-advocate—or who have a network of supporters to assist them in negotiating the aged care or disability support system—are significantly more likely to experience choice and empowerment within consumer-directed systems. Conversely, people with cognitive disabilities, complex support needs, and people who do not have access to a support network of formal or informal advocates experience significant barriers to good conditions and support (Malbon et al. 2019). In both systems, there are also significant market challenges, with gaps in markets arising due to a lack of provision. This is particularly pronounced in rural and regional areas but is also an issue faced in urban areas.

The recent Royal Commissions highlighted several major challenges impacting the future quality and sustainability of these sectors. The first of these is staffing, in terms of both securing an adequate supply of workers and proper training and capacity building of these workers. The second is around models of care, and specifically how the environment within which care services are provided influences outcomes for clients. The third key issue is effective governance. This includes interface and coordination issues with other policy areas and the need to involve older people and people with disability in planning and decision-making processes. And the final issue, which is related to each of the previous ones, hinges on the need for more robust human rights underpinning to be at the centre of both aged care and disability support. We return to these issues indirectly in the next section while exploring the experiences of older people, people with disability and workers, and directly in the final section regarding opportunities for future reform.

The Experiences of People with Disability, Older People and Care Workers During the Pandemic

It was within the context of a care sector landscape already subject to considerable change and pressure that Covid-19 arrived on the scene, a virus with much deadlier consequences for older people and people with disability than many others in the community.² Some of the increased vulnerabilities and adverse effects experienced

by these groups during the pandemic were due to disability or impairment related reasons, such as the presence of underlying health conditions or an inability to enact social distancing because of the physical nature of the care and support they might require. However, many were the result of contingent economic, political, and social arrangements such as barriers and discrimination within the health system (Dickinson, Llewellyn & Kavanagh, 2022) and more still were a result of structural features of the care and support sector that were exacerbated in the context of the pandemic.

From almost the very beginning of the pandemic, older people were identified as a population at high risk of contracting the Covid-19 virus and of becoming seriously ill or dying if they did so. In particular, the high proportion of older people with acute health conditions living in residential aged care settings led to the well-founded fear that the virus would spread rapidly through these facilities with devastating consequences. At the time of writing, 1,841 people in total had died from Covid-19 in Australia. The vast majority of these people were over the age of 70 (1,483 in total), and close to half (45 per cent or 835 people) were residents of government-subsidised aged care facilities (Australian Department of Health 2021). As outlined above, we do not know what proportion of those who have contracted COVID or died from it are people with disability because Australia lacks a consistent disability identifier in health data.

The recognition that older people were an “at risk” population allowed health authorities, aged care services, and older people and their families to take steps to mitigate this risk through infection control strategies such as limiting visitors to aged care facilities and priority access to protective equipment and vaccines. However, early recognition of their heightened vulnerability to Covid-19 also meant that older Australians experienced profound disruption to their lives over a long period. One of the key strategies adopted to reduce the risk of infection in residential care facilities was to restrict visitations from family and friends. Older people living at home with the support of community care services such as domestic assistance, community nursing, and meals on wheels also experienced reduced services, with some service provisions ceasing altogether. Others cancelled services themselves due to fear of infection (Pachana et al. 2020). Families were advised to not visit their older family members.

Several academics, advocacy groups and people with disability had seen what was unfolding in terms of people with disability being an “at risk” group in other countries and stressed the need for a tailored response (e.g. Kavanagh et al. 2020). However, the Federal Government was slower to identify that people with disability, like older people and First Nations people, were a priority group for developing policy. Many people with disability have pre-existing, underlying health conditions, which impact the intensity and duration of illness upon contracting the virus and the incidence of death. People with disability are also more likely to live on or below the poverty line and to live in poor quality and insecure housing or institutional settings than other Australians (Green et al. 2020), factors that contribute to the likelihood of exposure to Covid-19 and increased morbidity and mortality

if infected. Even before the pandemic, people with disability had trouble accessing health and health services information in accessible formats, experienced low levels of participation and access to preventative health programs and encountered discriminatory practices within healthcare settings (Kavanagh et al. 2021).

Despite recognising these heightened risks, the early policy response in Australia largely failed to address people with disability. Left out of initial communications and consultation strategies, they found it difficult to access reliable information about Covid-19, the effects of the virus, and who was most at risk (Yates & Dickinson 2021). As Kavanagh et al. (2021) note, when guidelines for the management of outbreaks in residential care facilities were issued by the federal government in March 2020, disability accommodation was not mentioned at all. A range of commentators including people with disability, disabled people's organisations, families and carers and their organisations and academics, had been vocal about the dangers of the virus spreading rapidly through disability accommodation settings such as group homes and respite services from the very early days of the pandemic. The lack of concrete action on the part of governments to mitigate risks was galling and frustrating for many in the broader disability community, particularly in the face of the mismanagement of the federal government's vaccination program. But for many, it was also unsurprising and simply a reflection that people with disability are all too often forgotten about and deprioritised.

Australia's Covid-19 vaccine program commenced in late February 2021. The program initially prioritised staff and residents of both aged care and disability care and accommodation settings (see Table 8.1), in recognition that they were

TABLE 8.1 Australian government vaccination program priority groups 1a, 1b

<i>Order of priority</i>	<i>Priority group</i>
Phase 1a	
1	Quarantine and border force staff; frontline health care workers
2	Other frontline health care workers
3	Staff at residential aged care and shared disability care settings
4	Residents at aged care and shared disability care settings
Phase 1b	
5	People aged 80 years and over
6	People aged 70–79 years
7	Other health care workers
8	Aboriginal and Torres Strait Islander people aged 55 and over
9	Adults with an underlying medical condition, including people with disability
10	Critical and high-risk workers, including defence and emergency services workers

Source: This information was widely published by the Commonwealth Department of Health and other outlets during the first part of 2021 but is no longer available on government websites.

in a similarly vulnerable category due to living arrangements, reliance on paid support staff, and the high likelihood of pre-existing health conditions. The draft Commissioner's report from Hearing 12 of the Disability Royal Commission, which focused on the experiences of people with disability during the Covid-19 vaccine rollout, documents the many significant delays, miscommunications and implementation issues that occurred with the rollout of the vaccine program.

Official government announcements indicated that Phase 1a of the program, which included the priority vaccination of aged care and shared disability accommodation residents, would be largely completed within 6 weeks. It soon became clear that all phases of the vaccine program were delayed due to the failure of the federal government to secure a consistent vaccine supply. However, representatives from the Australian Department of Health further admitted³ that despite the initial policy prioritisation of people with disability, the on-the-ground vaccination strategy had "pivoted" to focus solely on residents of aged care facilities, effectively de-prioritising people with disability (and by extension disability support workers). This "pivot" occurred without public notification, meaning many clients of disability housing and care services were still waiting for on-site vaccines well after members of the wider community could get vaccinated by their local General Practitioner (GP). Many disability support workers missed out on priority vaccination altogether and many of these ended up being one of the last groups in the community to have access to vaccination as they were in the younger age groups that were eligible later in the roll-out. Victoria and New South Wales are the states that have had the largest proportions of infections and deaths from Covid-19. These both have had heavy public health restrictions with extended periods of lockdowns. These restrictions were progressively lifted as the proportion of the population that had been vaccinated reached particular benchmarks. However, in both states, the vaccination rate for the general population ran ahead of the priority groups. That is, despite having been prioritised for nearly a year, people in the priority groups were, on average, less vaccinated than the general population. Without proactive government outreach, particularly to people with intellectual disabilities, people living in supported accommodation settings, and people who are geographically isolated, these groups experienced major barriers to getting vaccinated, including difficulty accessing information about when and how they could get a vaccine and difficulty getting to vaccination sites (Kavenagh et al. 2021).

Throughout the pandemic, aged care and disability support workers also faced higher risks from Covid-19, and these risks were further exacerbated by failures in the Australian Government's vaccination program and other aspects of the Covid-19 policy response. Care and support work often involves close physical contact with clients, and workers may come into contact with multiple clients over one day. This amplified the risk of workers catching the virus, given that care work by its nature usually has to be performed on-site and in close contact with other bodies. It also amplified the risk of workers transmitting the virus to others—to their own families after returning home after shifts, and to the people with disability and older people they work with, who may have health conditions that place them at high

risk of dying should they catch it. Disability support workers were not included in groups receiving priority access to Personal Protective Equipment (PPE) at the start of the pandemic, which increased the risk of exposure for them and their clients. Support workers reported significant anxiety in the early stages of the pandemic about the lack of PPE and PPE training, and the limited and sometimes confusing information and guidance they received from their employers and health authorities (Cortis & van Toorn 2020).

The pandemic also heightened the effects of the often-poor employment conditions of aged care and disability support workers (Kavenagh et al. 2020). Disability and aged care workers are overwhelmingly female, and most are insecurely employed under part-time or casual contracts (see Table 8.2 for more detail). In many cases, the reforms to the care sectors over the past decade have worsened these conditions. Employment has transferred from state and territories to private and non-profit organisations and there is greater variety in the employment arrangements these providers have their staff. In the disability sector, the demand for flexible, person-centred support, while very positive for clients, has resulted in the increased casualisation of the workforce, as support may only be needed for a couple of hours at a time. These factors meant that during the pandemic, workers faced major blows to their financial security. If they came into contact with the virus, workers were required to cancel shifts while self-isolating to follow the directives of health authorities. One recent survey of disability support workers showed that only 47 per cent of those who took time off due to illness were paid sick leave (Kavanagh et al. 2020). Although some states (e.g. Victoria) moved to institute paid pandemic leave if people were required to isolate themselves for fear of infection, this was not common practice. This situation incentivised risky behaviours such as working while ill during a pandemic (Dickinson et al. 2020). The same survey of disability support workers found that during Melbourne's 2020 lockdown last year, one in ten disability support workers did not get tested for coronavirus after possibly encountering someone infected with the virus (Kavanagh et al. 2020). The health advice at the time stipulated that if you were deemed to be a "casual contact" you should self-isolate until you receive a negative test result. For people employed on a casual basis who may not have a savings pool to draw on, the loss of shifts these public health policies induced would have had a significant impact on financial security.

The impacts on care workers had flow-on effects for clients. At the height of the second wave of the pandemic in Melbourne, Victoria, staff shortages in some aged care facilities led to neglect of residents. For example, in one senior care facility, only six staff members arrived one morning to care for the facility's 115 residents (Curnow et al. 2020). At this point in the pandemic, we saw significantly higher numbers of Covid-19 in Victoria's privately run facilities than we did in those run by the state (Handley 2020). In part, this might be a reflection that state-run facilities were more likely to be in rural areas that had lower infection rates but it is also likely a product of the fact that there are strict staff ratio requirements in state facilities that are not mandated in the private sector. People with disability also missed

out on essential support services due to a lack of available staff (Yates & Dickinson 2021). Some government initiatives were introduced to address these issues: the Department of Health established the Temporary Surge Workforce Support initiative to assist with worker shortages in residential aged care, and in late 2020 the NDIA contracted the Recruitment, Consulting and Staffing Association (RCSA) to provide a linking service connecting NDIS service providers to temporary staffing agencies should they need to fill Covid-19 related staffing gaps. However, shortages continued throughout the sector and information on the uptake and success of these initiatives is not yet available.

The experiences of older people, people with disability and care workers during the pandemic highlight specific aspects of several well-known challenges for the care sector in Australia in the future. Firstly, the challenge of ensuring adequate *supply* in the care sector workforce, a pre-existing issue that was particularly exposed by the need for a surge workforce in aged care and disability support to fill staffing gaps during the pandemic. Secondly, the challenge of the care *setting*, or the physical environment within which supports are delivered, was brought into the spotlight during the pandemic due to the rapid spread of the virus in some specialised care facilities. Third, the challenge of creating effective governance structures: the existing coordination and interface issues within aged and disability services predictably worsened in a public health emergency scenario, and older people and people with disability were too often excluded from consultation and planning processes directly impacting their lives. Finally, the need for a common core commitment to human rights to underpin future planning and reform of the aged care and disability support sectors. When service systems are stretched to capacity and those who work within them face challenges they have never faced before, violations of individual human rights can occur more easily. But it is precisely in emergencies that a baseline awareness of and commitment to upholding the human rights of older persons and persons with disability is needed, especially amongst government decision-makers and service providers. In the following section, we deal with each of these challenges in turn, exploring opportunities for future reform.

Opportunities for Future Reform of the Care Sector

Invest in the Care Sector Workforce and Improve Pay and Employment Conditions

Australia, like many other high-income countries, is facing a crisis in the care sector within the next decades, with steadily increasing demand for formal care services but limited funding and workforce supply to meet this demand under current policy settings. The Australian Bureau of Statistics predicts that the proportion of people aged 65 years and over in the overall population will increase from 15 per cent in 2017 to between 21 per cent and 23 per cent in 2066, almost a quarter of the population (ABS 2018). Around one in eight (13 per cent) people aged under

65 have some level of disability, rising to one in two (51 per cent) for those aged 65 and over, which means the proportion of people with disability will be rising significantly as well (AIHW 2020). At the same time, the working-age population (people between 15 and 64 years) is projected to decrease from 66 per cent to between 61 per cent and 62 per cent in 2066, which works out to be well below two out of every three people (ABS 2018). The sector is likely to lose some workers because of the pandemic, with some reporting burnout and feeling unsupported and others who refuse to comply with vaccine mandates choosing to leave the profession.

There is significant reliance on unpaid family carers to bridge the gap between the care and support people with disability and older people need and what is currently provided through funded care services. This stopgap is unlikely to remain in place to the same degree into the future, however. Lifestyle and demographic trends such as increased rates of workforce participation amongst younger female cohorts, increased family dispersion, changing family structures and changing expectations about familial care (Cullen 2019) are likely to reduce both the availability and propensity of younger generations to provide unpaid care at the same rate and intensity that their parents and grandparents did. This means the demand for formal care services is likely to continue to rise.

Feminist philosophers and political economists have long critiqued what they view as a systematic undervaluing of the role and importance of care work in society (Davy 2019; Hughes et al. 2005). Because caregiving has traditionally been a feminine responsibility, workers in the care sector (whether male or female) experience the low status associated with “women’s work” (Hughes et al. 2005), and indeed, disability and aged care workers are overwhelmingly female (see Table 8.2). In the contemporary capitalist neoliberal state where independence and self-sufficiency are celebrated, people with disability, older people, and those who provide care to them are all marginalised by their association with the body, the private sphere, and the feminine. Despite the high demand for trained and experienced staff highlighted during the pandemic, care workers experience low pay, poor employment conditions, and limited opportunities for training and career development. The introduction of individualised support packages through the NDIS has only

TABLE 8.2 Profile of workers in major industry sectors in Australia

<i>Industry</i>	<i>Workforce median age</i>	<i>% Employed full-time</i>	<i>% Female</i>
Retail and Trade	33	50.4	54.1
Education and Training	43	62	71.5
Construction	38	84.6	13.2
Disability support and aged care	47	20	80

Source: Australian Government Labour Market Information Portal (2021a; 2021b; 2021c; 2018).

intensified these trends, leading to the creation of somewhat of a gig economy within the sector (Dickinson et al. 2020).

These conditions directly impacted the risks these workers and their clients faced from Covid-19, particularly given the delays in the vaccination program rollout. As Peisah and colleagues note, while restricting visitors was one of the key infection control strategies mandated by governments and adopted by residential care facilities, it was mainly staff who brought Covid-19 into these settings: “Around the world, despite restrictions on visitors through front doors of facilities, the virus quickly came through the back, carried by health care workers forced by low wages to work at multiple facilities simultaneously with insufficient PPE” (2020: 1201).

As well as bringing employment conditions to light, the pandemic also offers us the opportunity to reflect on these and the training and incentives that could foster good care and support, which have been seriously neglected in the shift to consumer-directed care in the aged care and disability support systems. A growing body of research demonstrates that positive relationships with paid support workers can lead to substantive improvements in the quality of life of people with disability and older people, particularly for people who have limited informal social support networks, people with cognitive disabilities, and people with complex support needs (Robinson et al. 2021). Providing enabling and empowering care and support requires complex skills in augmenting and supporting a person’s ability to communicate and make decisions, managing social and emotional dynamics and boundaries, as well as personal traits such as patience, flexibility, attentiveness and responsiveness (Fisher & Byrne 2011; Marquis & Jackson 2000). For the benefit of both employees and clients of the sector, the specialised forms of practical knowledge and expertise that are central to supporting and empowering care work need to be recognised—and invested in.

One of the supplementary solutions to the care crisis may be to invest in new technologies that could replace some human care activities. Robotics offers some potential here and are one of the areas that saw a significant investment over the pandemic when other areas of the industry dropped off (Dickinson and Smith Forthcoming 2022). In countries such as Japan, where significant workforce shortages are already an issue, there have been some significant advances made in these technologies. Robots can fulfil a number of roles, from manual handling, carrying and cleaning to social interaction. They are of particular benefit in the context of a pandemic, where humans can carry infections. Robots do not get sick or tired and do not need to isolate because they have contracted a virus. As we have outlined, the response for many aged care facilities was to prevent visitors from coming into the facility, which led to some residents feeling extremely socially isolated. Social robots can be one way to keep individuals engaged without risking infection. Some suggest that robotics might be part of a solution to the care crisis, although this does not come without challenges from the perspective of people working in the care sector and people accessing these services (Dickinson et al. 2021). There are concerns that without appropriate protections, the expansion of these technologies might exacerbate inequities rather than help counter them.

These technologies raise a series of ethical concerns about where they might be used, which groups might access robotic care and which groups can access human care (Smith et al. 2021).

As a result of the Covid-19 pandemic there has been increasing recognition that care and support service staff are frontline “essential workers”, providing critical services to people whose wellbeing and lives to depend on the continuation of this support. However, we have yet to see whether recognising the necessity of essential workers will translate to an increase in the respect and status associated with these professions or to an increase in their employment conditions and pay. Certainly, the recent history shows rather than being improved, the conditions and may have been substantially eroded for many, and this shows no sign of changing in the short term. Care and support work will clearly be a growing area of employment demand in the future due to the ageing population and the expanding NDIS market, but whether individuals want to move into these roles is another issue. There is an urgent need for robust workforce investment strategies to address the labour shortage, quality and equity issues that plague the disability and aged care sectors. Better career pathways and professional development opportunities are needed to attract new workers, particularly younger workers, to this expanding sector.

Invest in Supported Independent Living and Community Living Options

The physical space in which care and support services are provided played a significant role in amplifying risk during the Covid-19 pandemic. Congregate care facilities, whether in the aged care or disability support system, involve many people with heightened vulnerabilities to the virus living nearby. It is more difficult to enact social distancing practices. Combined with a highly mobile workforce working between different facilities, this makes them ideal settings for rapid viral spread. As Peisah et al. (2020: 1200) remark: “The default option of segregating older persons has exposed the heightened vulnerability of congregated settings, where it is intrinsically difficult to secure an adequate standard of health and social distancing.”

The link between smaller home-like settings and better therapeutic outcomes is well known (Bigby & Beadle-Brown 2018; Brownie et al. 2014). The built environment structures our behaviour and routines: people living in an institutional environment are more likely to be treated institutionally—as bodies to be managed rather than as individuals. The findings from the Royal Commissions demonstrate that some forms of abuse and neglect are more likely to occur in institutional facilities that are segregated from the rest of the community. For example, the interim report from the Royal Commission into Violence, Abuse, Neglect and Exploitation of People With Disability describes the high incidence of violence and neglect in supported accommodation services (2020: 24–25), and the final report from the Royal Commission into Aged Care Quality and Safety observes that physical and sexual abuse of older people in residential care is “far from uncommon” (2021: 68). Despite this, large residential care facilities continue

to be planned and built. Disability and seniors advocates have been calling on governments to invest in smaller-scale community living options for a long time, arguing that increased options about where people receive care services will enhance client choice and control and reduce the risk of abuse and neglect. Now that there is greater awareness of the heightened risks of Covid-19 transmission within congregate care settings, we hope their voices will be amplified by public health experts and officials in calling for greater investment in independent and community living options.

Establish Permanent Advisory Bodies to Give Older People and People with Disability a Voice in Policy Decisions

In Australia, and many other countries impacted by the Covid-19 pandemic, people with disability were left out of emergency planning frameworks, and neither group had much opportunity to participate in or inform policy and decision-making processes about how the pandemic would be managed. It was evident in the vaccine roll-out that little thought had been given to the nature of lives of people with disability. In many places, people with disability were told to attend mass vaccination settings, but these are not accessible for several people with disability for a variety of reasons. Had people with disability been involved in planning processes this would have been apparent early in the process, rather than being discovered much later. Appointing permanent advisory bodies for both groups that include a significant proportion of service users with lived experience, older persons representative organisations and disabled people's organisations, would go a long way toward ensuring this lack of voice does not happen again.

Foreground Human Rights in Future Care Policy, Planning and Practice

Although, so far, Australia has avoided the devastating numbers of deaths that occurred in other countries, harrowing stories have emerged that demonstrate how easy it is for the human rights of older people and people with disability to be suspended in an emergency pandemic situation. Cousins (2020) reports how residents in a Melbourne nursing home were left without food and water for up to 18 hours, had open wounds left unattended, and were basically locked in their rooms for the duration of the state's stay at home orders. Policies and procedures with nursing homes and specialist disability accommodation sites for allowing and managing visitors were largely left to the discretion of individual providers, which meant some older people and people with disability were prevented from seeing their family and friends for months at end. Explicitly including reference to the human rights of older people and people with disability in emergency planning frameworks is a crucial first step to ensuring that they remain "front of mind" and that policy responses adequately balance human rights with other concerns such as infection control.

Human rights awareness-raising and training amongst service provider staff and management is also critical, particularly within the aged care system. The purpose of senior care and disability support is currently couched in very different terms. Since the ratification of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2008, international human rights law has explicitly addressed the rights of people with disability in a way it has not yet done so for older persons.⁴ The aged care sector has yet to have its watershed moment towards meaningfully instituting similar rights-based reforms—unless it is the current moment, in the wake of devastating global loss of life and suspension of human rights due to Covid-19. And although there has been a major paradigm shift in the underlying philosophies of disability policy and support in recent years, many within the disability community were dismayed with the speed at which some of Australia’s human rights obligations were abandoned, including the obligation to “consult with and actively involve persons with disabilities” in decision-making processes.⁵

We argue that unless Australia embeds human rights within care services in a meaningful way, future emergencies will see these issues arise again. There are no easy solutions to this, it requires significant and ongoing work to ensure that the rights of older people and people with disability are realised.

Conclusion

While the situations of older people and people with disability are different in many ways, there are some critical similarities in the problems with the service systems designed to meet their respective needs. Without substantial investment, demand for care will soon outstrip supply. Poor pay and conditions negatively affect both care workers and their clients. Segregated and institutional environments result in poorer outcomes for older people and people with disability. In both service areas, failure to consult appropriately with those affected by public policy and public health actions results in policy and practices that are less fit for purpose and more likely to harm. The suggestions for future reform outlined above are not new. In senior care alone, there have been 20 reviews and inquiries over the past couple of decades. We hope that the confluence of factors overviewed in this chapter—and particularly the opportunity to frame these issues as matters of public health—will create further impetus for change. It is because the Covid-19 shone a light on the deep issues plaguing the sector that we have a window of opportunity now to address these issues through broad social and economic reform and investment strategies.

Notes

- 1 Specialised age or senior care refers to care for specific conditions such as MS, Alzheimer’s and dementia, stroke or Parkinson’s for example. This care is typically offered in the home by a trained health care professional.
- 2 www.cdc.gov/aging/covid19/covid19-older-adults.html (accessed November 19, 2021).

- 3 These details were first aired during public hearing 12 of the disability Royal Commission on the experiences of people with disability during the Covid-19 vaccine rollout (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2021).
- 4 There is however a growing impetus for a United Nations treaty on the rights of older people, documented in Byrnes (2020) and Quinn et al. (2018).
- 5 United Nations Convention on the Rights of Persons with Disabilities, Article 4—General Obligations