Personalisation and pandemic: an unforeseen collision course?

Helen Dickinson, Gemma Carey & Anne M. Kavanagh

Published online: 01 Jun 2020.

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Personalisation and pandemic: an unforeseen collision course?

Helen Dickinson[a], Gemma Carey[b] and Anne M. Kavanagh[c]

[a]NHMRC Centre for Excellence in Disability and Health, Public Service Research Group, University of New South Wales, Canberra, Australia; [b]NHMRC Centre for Excellence in Disability and Health, Centre for Social Impact, University of New South Wales, Sydney, Australia; [c]NHMRC Centre for Excellence in Disability and Health, Centre for Health Equity, University of Melbourne, Carlton, Australia

ABSTRACT

The outbreak of a pandemic provokes fear and risk of ill health for all individuals, however, these events pose even more of a threat to people with disability who often have poorer health outcomes because of underlying conditions, have difficulties in accessing health and other services, and typically fare worse once they are in the healthcare system. The growth of personalisation schemes in disability internationally is now exacerbating those risks and could lead to high morbidity and mortality if swift action is not taken.

Introduction

The outbreak of a pandemic provokes fear and risk of ill health for all individuals, however, these events pose even more of a threat to people living with disability (PLWD), who often have poorer health outcomes because of underlying conditions, have difficulties in accessing health and other services, and typically fare worse once they are in the healthcare system. Recent changes to the structure and operation of disability services in Australia may have left PLWD even more vulnerable in the face of major global challenges such as COVID-19 and we believe this is also likely to have similar impacts in other countries with personalised disability service systems.

Over the past few decades, many areas of the developed world (e.g. Australia, USA, Northern Europe, Canada) have seen the widespread expansion of the personalisation of disability services. While many within the disability advocacy community have argued for greater choice and control over the services that they receive and the ways they are delivered (e.g. National People with Disabilities and Carer Council 2009), these schemes are not

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without challenges. The COVID-19 pandemic brings many of the limitations of these schemes into sharp relief. The intersection of personalisation and this new pandemic may have set us on a collision course where PLWD will lose their lives unnecessarily. In this article, we outline this argument and consider what might be done to rectify this situation.

Health challenges faced by people living with disability

Many PLWD are an 'at-risk' population in the COVID-19 pandemic, for a variety of reasons. A high proportion of PLWD has underlying health conditions such as diabetes, autoimmune and respiratory problems (World Health Organization 2018). Across the world, research shows that PLWD are more likely to be poorer, less likely to be in work and more likely to be socially isolated (Kavanagh et al. 2013; Milner et al. 2014; Krnjacki et al. 2016), which also makes them more likely to experience poor health outcomes within a pandemic. Evidence from previous pandemics shows that health inequities worsen during epidemics (Quinn and Kumar 2014). This means that without proactive policies to protect PLWD, we are likely to see a growing gap in socio-economic and health outcomes for people with and without disability.

Added to this, health services are often inaccessible to PLWD at the best of times because of barriers such as physical inaccessibility, lack of understanding of a person's disability and cost (MacLachlan, Mannan, and McAuliffe 2011). Health information is rarely presented in an accessible format for children and adults with intellectual disabilities, for example.

Further to the issues of accessibility, pressure for health resources as many people present with illness could mean that PLWD are de-prioritised. Disability groups have raised concerns that decisions about whether people with disabilities receive life-saving treatments will be based on judgements about the quality of their lives and/ or their reliance on support rather than the likelihood of them benefiting for the treatment. Many countries use Clinical Frailty Scores (Mitchell, Tahir, and Banerjee 2019) that automatically deprioritise care to disabled people who require support from others or have activity limitations. We have already seen different health systems around the world making decisions based on judgements about the quality of people's lives and their health that are unrelated to the likelihood that someone will benefit from treatment. If decisions are influenced by assumptions about lives and need for support, then it is likely that many PLWD will find themselves at further risk of prejudice and de-prioritisation of their access to preventative, screening and treatment measures for COVID-19.

The rise of personalisation

In many parts of the world (e.g. Australia, USA, Northern Europe, Canada), disability services have undergone significant reform. In part, this has been in

response to the disability advocacy community. PLWD have argued for greater choice and control over the design and delivery of services that they access. They argue that a one-size-fits-all approach to service delivery cannot effectively meet the needs and desires of the broad range of people disabilities (Dickinson 2017). Moreover, a one-size-fits-all approach is seen as not an efficient use of funding. In line with the New Public Management philosophy (Ferlie et al. 1996), externalising the delivery of disability services from the state to a range of private and not-for-profit disability service providers has been seen as a way to promote diversity of services and enable better choice and control.

In many places, there have also been pushes to personalise services. In some cases, this involves supporting greater self-direction of care services, working through individual priorities and expectations about activities of daily living (e.g. governments working with providers to tailor services, such as in Norway). In others, it involves the articulation of an individual budget, which can be given to an individual as a cash payment to self-manage (e.g. Direct Payments in England, National Disability Insurance Scheme (NDIS) in Australia, Cash for Care Schemes in USA), held by the state but directed by an individual (e.g. Personal Budgets in England) or held by a third party (e.g. for some in the NDIS). These different options are important as they come with diverse management arrangements. Self-managed budgets typically offer the greatest flexibility although will often require individuals (or their families and carers) to take responsibility for employing service providers and administering budgets often through quite complex schemes. In many jurisdictions, the introduction of these schemes has shifted governments from block contracting arrangements with providers, to spot contracting arrangements (i.e. contracting for singular services) according to the preferences of individuals.

While proponents of these schemes argue that they are more effective and efficient for those who use them (e.g. Leadbeater 2004), there are a number of critiques that raise concerns around a range of issues including: regulation, exploitation of care staff, exploitation of PLWD, complexity which disadvantages some groups, ideological resistance to perceived privatisation of care services and fear of closure of popular services. The evidence base is inconclusive on a number of these issues as yet, often because insufficient investment has been made into researching disability services and the added complexity of identifying the effects of disability services when they are embedded within a broader ecosystem of services and policies.

When personalisation and pandemic collide

As COVID-19 begins to hit more countries, we are seeing how these kinds of systems make it more difficult for governments to respond to public health events, and can, in fact, place PLWD at even more risk.

The main challenge posed by personalisation is that it makes it difficult to identify the workforce, train them in infection control, mobilise supplies to all who need these and upscale the workforce in face of shortages in care workers. Whereas under more traditional systems, governments had a degree of control over the workforce and levers to mobilise this to do things differently, these are lacking within a personalised system. There are fewer options for control or even the intelligence required to understand how to do this in a pandemic context.

Individuals who require support with activities of daily living can have multiple professionals moving in and out of their homes each day (and those professionals go on to other homes, in turn). This is not an issue unique to personalisation, but one challenge that emerges is ensuring whether support workers turn up for their shift. For those who do not hire workers from larger providers, instead directly employing individuals or through third party online platforms, there may be no mechanism to guarantee that individuals will turn up and, if not, whether an alternative support worker is deployed.

People working in care roles are amongst some of the lowest paid in our societies. In many systems, personalisation reforms mean that a greater number of support staff than ever are employed on a casual basis, and increasingly on a 'paid per service' basis whereby they will go without income if they do not undertake a care task/service. While criticisms of this 'gig-economy' workforce model are not unique (e.g. lack of job security, not paid for travelling between clients), they are particularly concerning in the context of a pandemic. In practical terms, our systems can be incentivizing individuals who desperately need income to take risks with their health and the health of the PLWD they are supporting, for example by turning up to work when they are unwell.

Worldwide shortages of protective gear, and the prioritisation of frontline health care staff, means that many of these workers do not have access to protective equipment. Even without international shortages, it is unclear in many of these systems who should provide protective equipment and other resources needed in a pandemic to disability workers who need them (i.e. those who are supporting activities of daily living like feeding, bathing, teeth brushing). In the Australian National Disability Insurance Scheme, for example, employers are responsible for providing protective equipment to workers. In the case of larger providers, this may be possible, but it is important to remember that where PLWD are employing their own workers directly we are asking them to go out and acquire protective equipment for their support workers. This also raises the question about who should be responsible for training workers in infection control.

As care workers become sick or are required to care for family members who are ill or forced to isolate, there is a question of who identifies a

standby workforce and how this is mobilised. As governments no longer have control over the workforce, there is little ability to create surge capacity. Governments are relying on a range of providers, some of whom are quite small and may not have the ability to scale up. Some may simply close down. This is in sharp contrast to the health sector, which in many countries remains largely amenable to control by the government. How the State supports and incentivizes the care sector to undertake activities it does not typically do is a key question.

What might be done

Clearly, challenges associated with personalisation reforms are exacerbated by pandemics such as COVID-19, and additionally, these reforms have the potential to spread such viruses further and to people at greater risk of them. In Australia, disability researchers have made a range of recommendations to alleviate some of these challenges and risks.

Information is key in a pandemic situation, particularly regarding best practice in hygiene and risk mitigation regarding transmission. Our disability workforces are now highly diversified with many casual and self-employed individuals. In Australia, we have seen efforts to push information campaigns out through large providers. This has recently been supported by a specialised information line for PLWD, their families and other carers to support those not serviced by mainstream and large providers to understand how to best protect themselves.

We have seen a great deal of mobilisation around access to personal protection equipment in areas such as health and aged care, but relatively little mention of disability workers. In extreme conditions, such as COVID-19, governments bear a responsibility to provide personal protective equipment to all workers who are in close contact with PLWD for intimate tasks such as feeding, rather than leaving this in the hands of service providers who may not guarantee such equipment or PLWD who may not be able to access it within the community.

We need to 'un-gig' the workforce during this pandemic and we would also argue for the longer term. Individuals cannot work well in care roles when they feel as though they are not being cared for in turn. Insecure work conditions do not make for a high-quality care workforce. This means governments need to guarantee income for care workers who may be sick, have caring responsibilities or have their shifts cancelled and compensate family members that need to take the time of work to provide care that is usually provided by paid staff. Governments also need to mobilise a back-up workforce, as we are seeing around the world in health care, for when carers become ill.

Disclosure statement

No potential conflict of interest was reported by the authors.

ORCID

Anne M. Kavanagh http://orcid.org/0000-0002-1573-3464

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