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## Case Report

# Case study discussion: The important partnership role of Disability Nurse Navigators in the context of abrupt system changes because of COVID-19 pandemic



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## ABSTRACT

**Background:** Rapidly implementing telehealth-facilitated healthcare services in a COVID-19 environment generates relational challenges for people with intellectual disability. Disability Nurse Navigators assume a critical intermediary role between the healthcare system and this population.

**Aim:** To discuss the impact that rapid service change, in response to the COVID-19 pandemic, can have on people with disability and the work of Disability Nurse Navigators who support them.

**Methods:** This clinical case discussion comprises two parts. First, a discussion on the impact that COVID-19 pandemic management has had on one person with an intellectual disability is framed using intersecting notions of cumulative complexity and Burden of Treatment Theory. Following, through a Latourian lens, the role of the Disability Nurse Navigator is explored.

**Findings:** During COVID-19, telehealth has proved an important tool for healthcare continuity. Yet, for some people with some disabilities who live with additional and cumulative layers of health and social complexity, the healthcare workload that is transferred to them is exacerbated as they try to interact with disabling infrastructure.

**Discussion:** The Disability Nurse Navigator recognises that people with disability are not independent of the technologies and structures that make up the healthcare system but that they are mutually constitutive. The Disability Nurse Navigator thus works to stabilise the relationships between changed service provision and the healthcare workload and capacity of people with disability.

**Conclusion:** The work of the Disability Nurse Navigator ultimately mitigated the disruption and additional treatment burden that is transferred to people with disability because of unintended consequences arising from the rapid introduction of service change.

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## Summary of relevance

### Problem

Little is known about how Disability Nurse Navigators stabilise relationships between rapidly implemented healthcare processes and the healthcare work that people with intellectual disability must do.

### What is already known

People with intellectual disability risk overburden if healthcare workload is excessive and network capacity is diminished. Fundamentally, Nurse Navigators must build capacity in stakeholder networks surrounding these people.

### What this paper adds

Rapidly introducing best practice interventions can upset complex and fragile networks. Disability Nurse Navigators must engage multifarious associations and interests to stabilise networks and realise best outcomes for patients. This complex work is largely invisible.

## 1. Introduction

In this paper, we outline a clinical case that describes some of the relational challenges that occur when evidence-based and necessary change is rapidly implemented in hospital systems in response to external conditions such as the COVID-19 pandemic. We discuss the impact that this can have on people who live with disability, notably those living with intellectual disability, and the work of nurses who support them. We frame our discussion of this clinical case using the intersecting notions of cumulative complexity (Shippee, Shah, May, Mair, & Montori, 2012) and Burden of Treatment Theory (May et al., 2014). Then, through a Latourian lens (Latour, 2005), we explore the critical intermediary role that Nurse Navigators assume between the healthcare system and people who live with an intellectual disability when telehealth was rapidly implemented in response to the current pandemic environment and the subsequent importance of robust and functional partnerships with all actors in a network of healthcare providers. Before commencing the outline of the clinical case and the discussion proper, a brief background on the development and implementation of the Nurse Navigator role is provided.

## 2. Background

### 2.1. Nurse navigator

Healthcare provision in acute care systems is challenging to navigate, and people who have multi-morbid and complex health conditions are rarely supported by health professionals to resolve dilemmas that arise at the nexus of health, healthcare systems and everyday life (Ørtenblad, Meillier, & Jønsson, 2018). Moreover, when individuals have neither health professional nor social network support to navigate health systems, their health outcomes are likely to be sub-optimal or worsen. In response to the recognition that people need support to navigate health and healthcare systems, Nurse Navigators (NN) have been employed in some healthcare settings.

Commencing in January 2015, in Queensland, the Queensland Government introduced a policy for the roll out of 400 NN positions over four years. A novel role in the Queensland public healthcare setting, the intention was to utilise advanced practice nurses (APNs) with expert clinical knowledge and in-depth understanding of the healthcare system to assist patients with complex, chronic conditions to move more efficiently and effectively through the healthcare system in acute, subacute and community settings (Office of the Chief Nursing and Midwifery Officer, 2017). Four key practice principles guide the functioning of the NN role; 1) coordi-

nating patient care, 2) creating partnerships, 3) improving patient outcomes and, 4) facilitating systems improvements (Office of the Chief Nursing and Midwifery Officer, 2017).

### 2.2. Disability nurse navigator

The NN role has been appointed in the disability context in recognition of the significant challenges experienced by people with disabilities (Cooper et al., 2017; Australian Institute of Health and Welfare, 2019). While there has been a limited, but growing, body of evidence on the advanced practice profiles and work activities of NNs to date, limited understanding of the role in the disability context exists. Anecdotally, however, the Disability Nurse Navigator (DNN) provides a person-centred approach to the healthcare journey of those living with a disability, with a focus on supporting client-identified, health-related goals that aim to enhance self-agency. In the context of intellectual disability, the immediate health focus relies on the formation of a nurse-client relationship that has as its focus understanding and adjusting the complexities the health system to enhance healthcare access.

While the DNN role is relatively new in the Queensland healthcare setting, the role differs slightly to other DNN-like roles more prominently found in the United Kingdom. The role, for example, of learning disability liaison nurse is most commonly affiliated with a team (Brown et al., 2012), and community intellectual disability nurses are most notably positioned in the community (Backer, Chapman, & Mitchell, 2009). The DNN role reflects a hybrid of the established UK roles. Employed by the public hospital and health service, the DNN operates autonomously and fluidly between hospital and community settings to support the healthcare experience of people with intellectual disability. The role also frequently intersects with different sectors such as Non-Government Organisations (NGOs) and agencies such as the National Disability Insurance Agency (NDIA) in an advocacy capacity, particularly at the time of commencing the National Disability Insurance Scheme (NDIS) process, to facilitate urgent review of care plans or to support clients in their efforts to access appropriate services.

## 3. Clinical case study

Joe<sup>1</sup> is a 45-year-old man who lives alone. He has an intellectual disability and attends the outpatient department of a medium sized hospital in a metropolitan city because he needs specialist intervention for a clinical condition. Paid service providers operating under the NDIS comprise the sole people in Joe's social network. Joe does not have family to support him. Services provided to Joe are limited to once a week as per his NDIS funding arrangement. Otherwise, Joe maintains responsibility for his healthcare management.

Joe was experiencing increasing anxiety because of institutional responses to social distancing requirements associated with the COVID-19 pandemic. Prior to the pandemic, his social interactions were entirely dependent on attending groups organised by NGOs, who also transported him to those groups. At the beginning of the pandemic, NGOs withdrew all social interaction groups, they were visiting him less frequently and he was increasingly feeling 'shut-in'. Joe did not understand what was happening. His answer to the pandemic was simple – 'the doctors should just fix it', and he did not understand why this could not happen. As his anxiety increased, Joe was accessing the local hospital more frequently

<sup>1</sup> The clinical case presented in this discussion paper is not a specific case but rather is an exemplar of the healthcare experiences of people with disability during the initial responses to the COVID-19 pandemic. Details such as patient name, age and gender have been changed to ensure anonymity. Ethical approval to prepare this discussion paper was not sought given its non-case-specific approach.

for support. Under duress, Joe has an abrasive nature, becomes increasingly vocal and loud and uses expletives in response to high levels of frustration. On one visit to the Emergency Department, Joe was referred to the Disability Nurse Navigator (DNN), who had become an important source of support to him.

In response to pandemic management, the outpatient department rapidly implemented telehealth. Joe is contacted by outpatient department administration staff, who were not necessarily aware that Joe lives with intellectual disability, and advised that his upcoming appointment would be by telehealth. Joe did not understand what he was told. He explained that he has trouble understanding and asked that the DNN, who is familiar with his circumstances, be contacted, but his request was not acknowledged. In frustration, Joe cancelled his appointment. At this point, the cascade of complexity and burden that was associated with this simple action of changing Joe's appointment from face-to-face to a virtual environment became apparent. Joe did not have video capacity or a smart device. The internal processes of the hospital, which exist for sound reasons, meant that once an appointment was cancelled it was not a simple matter to reinstate it. Rather, for Joe to reinstate his appointment, he needed to attend his General Practitioner to source a new referral and wait to be triaged by the outpatient department again. Joe would end up at the back of the queue to access a specialist appointment for the required intervention. Joe managed to reach out to the only person who he believed understood his situation – the DNN, who needed to draw on all the relationships, connections, advocacy and navigation skills they possessed to support the healthcare of this client.

#### 4. Discussion

##### 4.1. Navigating health systems in circumstances of rapid change—the importance of understanding that complexity is cumulative and the need to ameliorate treatment burden

Many people who access healthcare systems have multi-morbid health conditions that intersect with social and life circumstances in cumulative and complex ways (Shippee et al., 2012). If health systems are to respond effectively to this cumulative complexity and optimise health outcomes for individuals, health professionals must take into account the interaction between the health-related work that patients are required to do and their capacity to do that work (May et al., 2014). The capacity to undertake health-related work is affected by the material and cognitive resources that are available to patients and their social network/s (May et al., 2014). The person at the centre of this case study was described as having both an intellectual disability and a medical condition that became even more complex than usual when rapid changes in social support and healthcare processes occurred in response to the COVID-19 pandemic. Intellectual disability confounds complexity for some people who access health systems, especially when they have pre-existing impoverished social networks and support systems. In response to the pandemic, Joe's impoverished social network contracted even further. In addition to the disruption to Joe's access to care through service closures, availability of support personnel diminished. This is consistent with recent research that demonstrates people who are accessing emergency care for minor illnesses and injury (such as Joe) in the pandemic environment have contracted social networks (McKenna, Rogers, Walker, & Pope, 2020). Impoverished availability and capacity of social networks to support people with health conditions has important ramifications for acute care services.

People have varying levels of cognitive and material resources which impacts their capacity to respond to health-related work (May et al., 2014). When health-related work exceeds individual and network capacity to perform that work, treatment burden en-

sues and the ability of people to perform even simple tasks becomes tenuous (May et al., 2014). Therefore, care providers must adopt fundamentally person-centred approaches that are minimally disruptive for patients, and that relieve rather than compound treatment burden (May, Montori, & Mair, 2009; May et al., 2014; Shippee et al., 2012). This means that health professionals need to understand who they are interacting with and they need to understand the intricacies and complexities of individual circumstances at points of interaction with the health and social care systems if they are to realise best possible health outcomes for people (see, for example, Boehmer et al., 2016). However, the pandemic has disrupted all levels of society and responses to these disruptions have occurred in multiple directions simultaneously. Not only were Joe's social networks depleted because of the pandemic, but care processes in all his usually familiar health services also underwent urgent and disruptive responses.

The pandemic exacerbated challenges that already existed at the intersection between healthcare and social support systems. The NDIS was introduced into Australia to provide reasonable and necessary support to people who live with permanent disability (Commonwealth of Australia, 2020; Foster et al., 2016; Wallace, 2018). The NDIS does not fund the diagnosis and management of health conditions, including chronic conditions (Commonwealth of Australia, 2013). Instead, the NDIS funds evidence-based reasonable and necessary support that relate to an individual's functional impairment and that enables them to live and participate in the community (Commonwealth of Australia, 2013). However, determining what is reasonable and necessary functional health support, how it is valued, and who funds it, are unclear and contested across jurisdictional boundaries (Venning, Hummell, Foster, Burns, & Harris Rimmer, 2020; Wallace, 2018). In the context of this case study, reasonable and necessary health support was determined prior to the onset of the pandemic. In the confusion that occurred, especially in the emergent stages of the pandemic, system complexity increased and workload shifted. The pandemic shifted health work into social support spaces (i.e., who could support Joe to navigate changes that occurred in the health system in response to the pandemic) and social support was shifted into healthcare spaces (i.e., when social support was withdrawn in response to the pandemic, then Joe accessed the local hospital and health service more frequently). There did not appear to be an easily identifiable person within Joe's support network who was accountable for coordinating the health support needs required for managing his chronic health condition. Indeed, Joe was crossing between Commonwealth and State funded health systems when he was moving between his general practitioner and medical specialist. This additional layer of healthcare complexity added to the health workload that was being shifted in response to the pandemic.

Within the health system, changing from face-to-face appointments to telehealth shifted work to patients, despite the fact that technology such as telehealth is promoted as one way of connecting healthcare in person-centred ways (Kuziemy, Gogia, Househ, Petersen, & Basu, 2018). Telehealth has been promoted as a reasonable and important response to reduce treatment burden and also one that increases staff safety (Schwamm, Estrada, Erskine, & Licurse, 2020) and reduces mental health concerns for patients (Zhou et al., 2020) in circumstances such as the current COVID-19 pandemic. However, rather than alleviating mental health concerns, Joe experienced increasing anxiety and frustration, which was compounded when his appointment was changed to a telehealth appointment. Although there is robust evidence for telehealth across health conditions and delivery contexts, in the presented case study, it was the telehealth implementation environment (Totten et al., 2016) rather than telehealth itself that was challenging and which required detailed attention by Joe. Without

intervention by the DNN, the cascade of ensuing events would arguably have culminated in adverse health outcomes for Joe. When people, such as those who live with intellectual disability, do not have high level cognitive resources, and when impoverished cognitive resources are compounded by an absence of social support, as was evident in the presented case study, then there is a greater onus of responsibility on the healthcare system and health professionals employed within it to ensure that treatment burden is not excessive. The only way to do this is to reduce the healthcare workload that is transferred to patients. It is this 'space' that the DNN plays a critical intermediary role.

The fundamental point here is that the cascade of complexity associated with the change to a telehealth appointment and the subsequent cancellation of an important specialist appointment by Joe was not immediately apparent to actors in the interaction. Indeed, once the appointment had been cancelled (legitimately and at the patient's request), the patient's voice was effectively silenced, and the likely trajectory of declining health and treatment burden was rendered invisible to the healthcare system. This trajectory was already invisible to the social care system, because social support had been withdrawn in response to the pandemic and because the social care system which was funded by NDIS did not have responsibility for healthcare interventions. However, the DNN had established a trusted relationship with Joe, which allowed his silenced voice to be heard. In the absence of a comprehensive support network (the service providers within the patient's network had temporarily withdrawn due to COVID-19 precautions), the DNN became the person to whom Joe turned – not as an inpatient, not because of an internal referral process, but because of the relationship that the DNN had developed with him during previous presentations. This relationship-based approach has been identified as a fundamental feature of nursing care for people with intellectual disability (Coyne et al., 2020; Wilson, Wiese, Lewis, Jaques, & O'Reilly, 2019).

To this point, we have discussed the relevance of cumulative complexity and treatment burden when health-related work is transferred to patients, particularly in the circumstance of rapid change such as pandemic situations. The discussion has been situated in the context of person-centred understanding about patient's experiences. What is identified is that DNNs have an essential role in supporting people with disability to navigate and negotiate the health system. Next, we explore the complex and mostly invisible work that the DNN engaged in to reduce treatment burden, support Joe's individual agency in a person-centred way and avoid a negative health trajectory in the context of a disrupted service environment. The perspective that we take here is solely to explore the impact that rapid introduction of telehealth had on the DNN role within the health system. We do not seek to explore the additional complexities that arise at the intersection between health and social care systems, nor do we explore the concept of reasonable and necessary support within the context of the NDIS. However, we acknowledge that exploration of these intersections at times of rapid change is warranted in future studies.

#### 4.2. Explicating the fundamental importance of fostering robust and respectful partnerships that support individual agency of healthcare consumers

In the above case study, it is the 'disruptive' role that telehealth pandemic management played in the work of the DNN which, when explored within a networked sociomaterial lens (Latour, 2005; Callon & Latour, 1992), enables a rich understanding of the complex, nonlinear reality in which the DNN operates, fundamentally to facilitate patient agency. In contrast to understanding the work of the DNN from a socially deterministic perspective, a perspective that characterises much of the nursing literature

(Booth, Andrusyszyn, Iwasiw, Donelle, & Compeau, 2015), examining the network interplay between the DNN, Joe, the telehealth implementation environment and various other human and non-human entities, offers a way to understand the means by which patient outcomes are produced through the complex, mediated routes of DNN work.

Understanding the complexity of DNN work in this way is important given the lack of value placed on nursing in the intellectual disability field (Sheerin, 2011). As to why a lack of value exists is a complex topic, one beyond the scope of this paper but suffice to briefly state, lack of value mostly stems from three socially constructed, interrelated reasons; 1) the work of these nurses is not visible to others, it happens in invisible spaces, for example, *behind the curtain* (Lawler, 1991), 2) the work of these nurses is taken for granted, therefore rendering it invisible and 3) the person with intellectual disability is invisible in the system (Krahn & Havercamp, 2019; Allen, 2015). Powerfully pervasive, such lack of value means that it is not an uncommon occurrence during austere times that seemingly unimportant nursing roles are relinquished. Hence, unlike other frameworks, a Latourian lens provides an ability to capture the dynamic and ever-changing qualities of DNN work, understood in this context as a moving target of networked hybrid relationships that *make up* DNN work. Drawing on Latourian concepts of multiplicity, effacement, symmetry and convergence, a praxiographic (Mol, 2002) *teasing out of what happens* in networked hybrid relationships, or networks, that assemble and structuralise DNN work is presented.

Consistent with Latour's concept of multiplicity (Callon & Latour, 1992; Law, 1994), which assumes that what we practice is 'ways more than one' (Law, 1994, p. 4), the DNN may hold membership in multiple networks. Local hospital and health networks, primary healthcare agencies, government agencies, information technology networks, policy networks, advocacy and consumer groups, teaching institutions, professional nursing organisations and research groups are just some of the networks in which the DNN may be a member. Any of these networks can be multiple. Similarly, individual components of these networks can be multiple. Moreover, the DNN forms a network in and of themselves, mediated by an elaborate multi-contextual arrangement of relationships and interests. Therefore, while the core structure in which the DNN is situated is unavoidably material and consistent across multiple networks of membership, analysis reveals that the operation of the DNN is highly malleable.

Normally, everything that has contributed to forming a given network is not seen – it is 'punctualised' – so that the daily flow of life within a network can continue without having to consider the myriad things that tend to make a situation more perplexing (McCarthy & Martin-McDonald, 2007, p. 88). However, in view of telehealth and the COVID-19 pandemic, despite the *prima facie* successful integration of telehealth in contexts such as cancer care (Chan et al., 2020) and general practice (Calton, Abedini, & Fratkin, 2020), telehealth and by extension the telehealth implementation environment can be construed as a disturbance in the DNN networks. It was a disturbance that disrupted existing relationships and created new ones, while enrolling new actors in the process.

Telehealth and its associations of human and non-human entities 'disrupted' the extant relationship between the DNN and Joe. Compounding disruption in the relationship was the cancellation of the specialist appointment by Joe and subsequently his relationship with the organisation of the healthcare system more broadly. In keeping with Latour's approach, investigating the integration of telehealth in the context of people with disability would involve an examination of the ways in which clinical settings (from tertiary through to the community setting) and related actors and non-human actors are assembled and configured. While such an examination is beyond the scope of this paper, suffice to say that

associations between Joe and others (human *and* non-human actors) in the environment with whom he interacted shifted from what he had known and was competent and comfortable with to an environment of exacerbated treatment burden, which Joe managed by severing treatment ties. Some associations even dissolved and reformed in ways that were not anticipated. For Joe, his “dis”ability with the cancellation of his face-to-face appointment to a telehealth-facilitated appointment was an effect of changing associations in his relational networks.

This moves to Latour’s concept of effacement (Prout, 1996), which connotes a tendency to treat each element in a network as an isolated, unconnected point in that network. In this case study, the integration of telehealth into healthcare processes effectively amounted to treating elements in the healthcare system as isolated, unconnected points in the network. However well-meaning the telehealth implementation environment was intended to be, an assumption prevailed that all people, even those with intellectual disability, have the technical competence and material resources available to them to pivot from face-to-face appointments to appointments by telehealth. Joe experienced disassociation in the complex interactions that ensued and simultaneously with many other elements in his networks, many of which would not have been immediately apparent to the administration officer at the time of contacting Joe to advise of the change in mode of appointment.

Careful configuration of the telehealth implementation environment would have served to reduce the likelihood of the situation that unfolded for Joe. However, for such configuration, preparatory work was required to ensure that services (e.g., specialist appointments) and processes were designed, implemented and unfolded in ways that were consistent with the capabilities and capacity of people with intellectual disability. In the COVID-19 context, despite the benevolent intentions and considerable energies expended to facilitate the telehealth environment, the luxury of time for preparatory work has not always been available (Bhaskar et al., 2020). Certainly, in the outpatient department that Joe attended, at the time of the onset of the COVID-19 pandemic, there was mass roll out of alternative appointment arrangements in an effort to reduce patient flow through the department, to decrease the potential for COVID-19 infection.

Joe’s story thus underpins emerging literature that telehealth and the telehealth implementation environment have not been particularly successful networks for people with disability (Annaswamy, 2020). This is, however, in contrast to literature that reports the integration of telehealth into pandemic-managed healthcare environments is yielding good patient outcomes (Gilbert et al., 2020; Chan et al., 2020; Calton et al., 2020). Notwithstanding the involvement of the DNN, the yield of good patient outcomes for Joe is questionable given some of the entities involved in Joe’s networks did not necessarily act in the required – or expected – ways to achieve such results.

Joe’s experience reflects the antonym of Latour’s third concept, symmetry (Rioux-Dubois & Perron, 2016); dis-symmetry. Latour’s concept of symmetry conveys a situation of networks that appreciate the non-human resources in the networks as not the polar opposite of the humans in the networks, but that they are a form of, and a contribution to, the human condition. In Joe’s case, for example, his relative networks *would* entwine the human elements, such as the DNN, the administration officer and the medical specialist, with the non-human elements used by humans, such as telehealth technologies and telehealth-facilitated processes. In turn, these elements are appraised in terms of their contribution to the formation and sustenance of Joe. Drawing on an example by McCarthy and Martin-McDonald (2007), from this perspective, Joe’s world would thus be produced through a variety of symmetrical associations between the human and non-human elements that comprise his net-

works within which he is situated. The fear, frustration and consequences experienced by Joe in response to the introduction of telehealth exploited his previously symmetrical networks.

So then, what actions and interventions were enacted by the DNN to facilitate realignment in Joe’s health-related networks? How did the work of the DNN meet Joe’s needs, facilitate his agency and improve his actions? These elements in Joe’s world needed to converge somehow to reinstate symmetry in Joe’s being. Convergence, the fourth and final Latourian concept used in this paper, promotes the restoration of harmony in one’s networks, in turn to produce network energies and efficiencies (McCarthy & Martin-McDonald, 2007; Mol, 2002). As Mol (2002) indicates, convergence in one’s networks is important, “...however fuzzy they [one’s networks] may be... [they] may well prove obdurate and tenacious. After all, they concern daily lives. And daily life is what, when it comes to it, matters most to people. It is where patients... have to live with [their] doubts and [their] diseases” (p. 183).

Themselves an actor, the DNN embodies and is subject to certain codes, discourses, meanings and concerns that make them act in certain ways in the course of their practice and, moreover, provide their actions with social significance (Rioux-Dubois & Perron, 2016). Such codes and concerns, for example, are embedded in healthcare protocols that govern nurses’ scope of practice and day-to-day activities. These protocols mediate inter-professional interactions and interactions with patients, as well as mediating interactions with a range of non-human entities such as use of time. Such protocols therefore establish certain conventions and requirements through and by which the DNN integrates and operates in health system networks. However, in the context of COVID-19, as the case study demonstrates, the DNN must at times operate innovatively within their scope of practice but perhaps outside the organisational competencies outlined in protocols, competencies that are designed to support the purpose and function of the network/s – in times arguably not characterised by pandemic.

Through the enactment of what might be coined “off label” practices, the DNN served as an extension of Joe’s capacity to restore symmetry in his health-related networked relationships. While the COVID-19 pandemic and by extension telehealth and the telehealth implementation environment constituted perturbations and depletions in Joe’s health networks, the DNN mobilised a range of human and non-human entities to offset disturbances experienced by Joe and, ultimately, the reinstatement of his specialist appointment. Through established collegiate and trust-based relationships with health professionals across different healthcare settings and including the NDIA, the DNN activated *their* relevant networks to remove, reduce or manage unpredicted and possibly ongoing unpredictable events for Joe, which could further destabilise him, further impoverish his networks and jeopardise his health outcomes. In other words, the DNN substituted their networks for Joe’s impoverished social networks. This action was necessary because health work that arose because of the change from face-to-face to telehealth appointments was unable to be shifted to Joe or to his social networks. Apparent that the responses to the pandemic impacted all systems of healthcare support that were in place for Joe, the DNN “chipped away” (McCarthy & Martin-McDonald, 2007, p. 95) at incompatibilities and resistances in regard to telehealth technologies, re-set alliances between Joe and administrative and clinical staff, and shored up small alignments with various new processes for Joe before addressing larger new processes. Addressing larger new processes included, for example, re-setting Joe’s relationship with the NDIA, particularly assisting him to redefine his support package because it was clear that, while it had been adequately supporting him prior to the pandemic, it was inadequate post the onset of the pandemic. The DNN was aware of what was happening for Joe in the liminal space

between what was needed prior to the pandemic and what was needed post the onset of the pandemic. For the DNN, it was thus not simply about what were reasonable and necessary adjustments required to processes but about navigating the intricacies associated with numerous networks in the space between past and future.

Effectively, the DNN reconfigured Joe's health-related networks in the acute and community healthcare arenas and across sectors by re-setting the parameters, thus re-setting meaning. This sort of steady change or process of translation (Latour, 2005) ensured Joe some control over the energy shifts (McCarthy & Martin-McDonald, 2007) within his networks and the directions they in turn took. For Joe, the change affected by the DNN was not something completely different or discontinuous with what he knew, but a system more suited to his needs and context.

## 5. Conclusion

### 5.1. Implications for clinical practice

In the initial and emergent COVID-19 pandemic environment, changes in multiple networks occurred simultaneously. Impoverished social networks are least likely to be able to navigate and negotiate rapid change. In the healthcare context, telehealth has proved an important tool in enabling continuity in healthcare, especially during emergent and widespread pandemic conditions. Yet, for people with disability who also live with additional and cumulative layers of cognitive, intellectual, health and social complexity, the workload of healthcare that is transferred to them is arguably exacerbated as impaired people try to interact with, albeit unintended, disabling infrastructure. When disabling infrastructure intersects with impoverished networks, the consequences for individuals have the potential to be profoundly negative, unless someone is able to recognise what is happening and step in to support them. What this paper highlights is that, by shifting once standard face-to-face appointments to telehealth-facilitated appointments, the telehealth implementation environment can inadvertently render people with intellectual disability voiceless and invisible. Notably, when the DNN intervened to reinstate Joe's voice and visibility, this invisibility transferred to their work. Importantly, this invisibility does not equate to the optimal management of people with complex health trajectories or measurement of the value of nursing contributions to health outcomes (Gordon, 2006).

Invisible nursing work has previously been identified in intellectual disability nursing (Sheerin, 2011) and psychiatric inpatient settings (Hamilton & Manias, 2007), but has not been rigorously considered in the context of DNN work. In the context of this case study, although the workload of the DNN was exacerbated because of the change to telehealth for this one patient, the DNN's work was largely invisible because it was not easily accounted for in existing data collection tools or according to reductionist key performance indicators such as length of stay, waiting times, readmission rates and the like. It should not be that not achieving standardised benchmark measures relative to the role is a price that DNNs might have to pay for supporting the patient with intellectual disability – particularly in times of disruption in the networks of the patient. It can, however, be argued that the DNN demonstrated the attainment of organisational goals such as improving access to health services and treatments and patient outcomes. The invisible work that the DNN performed ultimately mitigated the disruption and additional treatment burden that had been transferred to Joe because of the unintended consequences of the rapid introduction of a process that is evidence-based and which should have reduced rather than compounded the health-related work that was transferred to him. By way of this richly textured sociological approach, complex, mediated, invisible DNN work has been 'articu-

lated', which we in turn argue 'gives value' to the role. The challenge now will be translating this value to the lexicon of DNN practice and measurement of DNN work in the aim of preventing future austerity-driven relinquishment in times of budget constraint.

What we learn from applying a Latourian lens is that Joe's experience was an inevitable outcome of a healthcare system undergoing rapid change; it was not confined to the actions taken by any one administrative or clinical staff member. We contend that the critical intermediary role of the DNN was a stabilising force in Joe's trajectory through recognition that the abilities and disabilities of people with intellectual disability are not independent of the technologies and structures that make up the healthcare system but that they are mutually constitutive. We also contend that, in the ways that the DNN brought to light the involvement and actions of numerous entities, both human and non-human, tangible and intangible, material and semiotic, including their multifarious associations, relationships and interests, this largely invisible work of the DNN stabilised the relative networks within the healthcare system and its processes. The DNN is thus the actor who follows the "disruptions" – those moments when disruptions occur for patients, the system *and* themselves – and which serve to upset the complex, and sometimes fragile, workings of the relative networks. This underscores the importance of the DNN in establishing robust and functional partnerships with all entities in healthcare networks to facilitate and support patient agency and reduce treatment burden.

### Authorship contribution statement

All authors equally developed the concept of this paper. VB and CE drafted the manuscript for publication and RB contributed to iterative reviews of the manuscript. VB managed revisions, literature and checking of the manuscript. All authors read and approved the final version.

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This work was undertaken as part of the routine work roles of the authors.

### Ethical statement

The clinical case presented in this discussion paper is not specific but rather is an exemplar of patients' experience during COVID-19. Details such as patient name, age and gender have been changed to ensure anonymity of any one patient. Ethical approval was therefore not required to produce this discussion paper. The above is made clear in the text of the manuscript (see Footnote 1 at the commencement of the clinical case study).

### Conflict of interest

The authors report no conflict of interest. The paper properly credits the meaningful contributions of co-authors. The authors report that the content of the paper is original and no prior or duplicate publication or submission elsewhere of any part of the work has been included in the manuscript.

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