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Social Disability as Disaster: Case Studies of the COVID-19 Pandemic on People Living with Disabilities

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Abstract: Social disability is a process or event that significantly disrupts, paralyzes, or prevents the formation and/or sustaining of interpersonal social relations required for meeting human needs. When prolonged, the ‘disabling’ of essential human interrelationships can have a destructive impact. This is especially true in communities where people are highly interdependent and where individuals living with disabilities rely upon social relationships to prevent isolation and decline in overall wellbeing. Meanwhile, disaster response systems have developed to first rescue or protect individuals’ ‘bare life’ and immediate, bodily needs. We argue that these systems, intended to mitigate disaster, can exacerbate social disability as a kind of collateral damage. We explore this problem as it unfolded amidst the COVID-19 pandemic in two research sites: one located in rural, northern Scotland and another located in rural, Midwestern United States. The Scottish research focuses on experiences, causes and risks of social disability for adults living with disabilities within a small rural community, while the U.S. research focuses on emergence of and resistance to social disability among residents of a continuing care retirement community for 55+ aged adults. We conclude with implications and recommendations for disaster intervention and future research.

Keywords: social disability; disaster; COVID-19 pandemic; disability; disaster intervention



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1. Introduction

Anthropologists have long studied how people can live in disaster-prone areas and under difficult conditions. This involves exploring how diverse groups of people, including people with disabilities, living in different social, cultural, and environmental circumstances prepare for, experience, adapt to, and recover from disasters in different ways (Faas and Barrios 2015; Hoffman and Oliver-Smith 2020). However, they also warn how capacities to cope with disasters may become overwhelmed as anthropogenic climate change increases the frequency and severity of disasters, as well as the number of locations and people likely to be affected (McGreevy and Adrien 2023; Kemp et al. 2022), and especially when this results in increased ‘disaster compression’ (Dyer 2023). Disaster compression occurs when the frequency and severity of disaster events accelerate to such an extent that ‘adaptive strategies of communities and societies to restore pre-disaster equilibrium fail’ (Dyer 2023, p. 4). This is an important consideration as research demonstrates that social support networks can break down as a result of disaster (Norris et al. 2005; Williams et al. 2021).

Pandemic disasters are relatively uncommon, typically constituting a once-in-a-lifetime experience (Yamori and Goltz 2021, pp. 10–12). Being global in scale, they are associated

with greater and more widespread mortality and morbidity than environmental disasters associated with anthropogenic climate change, such as floods and hurricanes (*ibid.*). They also tend to be long-lasting and involve large-scale, society-wide recovery processes ([Kola et al. 2021](#)). In contrast, floods, hurricanes, and other types of environmental disasters tend to have relatively location-bound impacts, be of shorter duration, and are associated with fewer deaths. People living in disaster-prone areas are also often used to dealing with and adapting to these specific types of disaster and devising effective ways to respond, especially those living in high-risk areas ([Pierro et al. 2022](#)).

Although the COVID-19 pandemic represents a different type of disaster to those associated with climate change, understanding its impacts as they emerged amongst different social groups living in different socio-cultural contexts and environmental circumstances also presents important considerations for living in and adapting to a world characterized by increasing incidences of disasters. This is because, as climate-related disasters become increasingly widespread, frequent, longer lasting, and severe, developing new interventions that are responsive to the increasing spread, duration, frequency, and severity of disaster becomes crucial ([Yamori and Goltz 2021](#)). In other words, disaster compression calls for study of how pandemic and climate-related disasters may require comparable if not integrated intervention strategies.

The COVID-19 pandemic was a disaster that the world at large was unprepared for and, as such, provides important insights as to what may happen in situations where a disaster occurs for which people and governments are un- or under-prepared, where few or no pre-existing adaptational strategies are already in place, or where established strategies and interventions become exhausted or overwhelmed. In addition, while the pandemic represented a global phenomenon in terms of its scale of reach ([Yamori and Goltz 2021](#)), the ways in which its impacts were experienced took place at a more localized level, with impacts on people's lives being shaped by and experienced within particular socio-cultural and environmental contexts ([Douglas et al. 2020](#); [Matthews and Thorsen 2022](#)). Understanding the lessons that can be learned from the pandemic as it manifested within the context of people's lives and the impacts of interventions used to mitigate its impacts thus become important for helping to ensure that interventions aimed at mitigating the impacts of increasingly widespread, concurrent environmental disasters are locally and socio-culturally responsive. In particular, the COVID-19 pandemic has called attention to disasters of global and immediate scale in which disaster systems and interventions can no longer be positioned or evaluated as securely located outside or 'external to' those needing help ([Vandenberghe and V  ran 2021](#)). Critical scrutiny of national responses to the pandemic also reveals how top-down emergency response interventions to disasters of this scale enhanced the 'totalizing' impact of COVID throughout society, placing constraints upon human agency, creativity, and expressions of socio-cultural diversity in social problem solving (*ibid.*). Humans are a social species, and a longstanding mechanism of survival and flourishing is social interdependence and support. Disaster intervention services, however, are typically constructed with the preservation of lives being positioned through dyadic relationships of a helping and managing 'self' acting upon and for a relatively helpless 'other' ([von Meding and Chmutina 2023](#)). This approach results from more egocentric, expert-led models of disaster support that dominate international policy for disaster risk reduction ([van Riet 2021](#)). These interventions are associated with unintended iatrogenic impacts, especially when insufficiently attuned to local cultures and sources of support, coping, and adaptation ([Ayeb-Karlsson et al. 2019](#)). This is, in part, because how we define and respond to 'the other' is culturally bound rather than universal ([van Riet 2021](#)). While 'the other' in the context of more egocentric Western societies is centered upon the individual, in more societal cultures, the 'other' is viewed in relation to an extended and dense social network—the family, household, or village—which become the first 'line of defense' in the event of disaster.

Governments and institutions tasked with responding to disasters need to ensure that interventions are tailored to the specific needs and circumstances of different pop-

ulation groups. People who are most socially marginalized are disproportionately at greater risk than others from negative impacts associated with environmental disasters (Kelman and Stough 2015). People with disabilities represent one of the most socially marginalized groups who are likely to be at greater risk of experiencing increased harm as disasters become more widespread, frequent, and severe. However, the perspectives of people living with disabilities remain under-represented in disaster intervention and planning efforts, with the result being that interventions are often inadequate for meeting differentiating needs and are often associated with harmful, iatrogenic impacts that also stifle creativity for devising more suitable interventions (Connon and Hall 2021). Understanding the impacts of both the pandemic and its interventions, therefore, helps provide important lessons for ensuring that new interventions are responsive to the particular needs of people living with disabilities in different socio-cultural and environmental contexts.

Given the pressures facing disaster response systems, local, socially based approaches to disaster planning and response that harness existing patterns of social relationships to deliver more favorable outcomes are becoming increasingly preferred in disaster risk reduction developments (Kruger et al. 2018; Losee et al. 2022). At the same time, questions arise about whether these social networks can be maintained or developed amidst increasing disaster compression. Devising improved disaster support interventions, therefore, requires understanding of how social interrelationships may be fostered, sustained, and nurtured amidst disaster. Equally important is how disaster systems can avoid breaking down social support networks in the process of crisis intervention.

This article addresses these problems by offering a definition of what we term social disability disasters to describe what happens when important social interpersonal relationships break down amidst disaster, resulting in the decline of normal social functioning. Using evidence from two case studies of the COVID-19 pandemic, in Scotland and in the United States, we describe the core characteristics of social disability disasters and explore how they emerged in two different contexts among people living with disabilities. We argue that the problem of social disability disasters can be triggered by both the disaster itself (the threat of contagion) and by well-intentioned yet socially isolating means of intervention. However, the case studies also lead us to possible observed solutions to the problems of how to mitigate the risk of or recover from social disability disasters.

We begin with a critical overview of the existing literature focusing on disability and disaster, highlighting the importance of focusing upon the consequences of social disability disasters for people living with disabilities. We then explain why the COVID-19 pandemic necessitates rethinking of conceptual understandings that underpin dominant models of policy and practice in disaster risk deduction, followed by outlining the key components of our theory of social disability. We then turn to the research that led to this theory; first, describing study methods and then, results from each case study. We conclude by discussing the importance of understanding social disability disasters for improving disaster risk reduction, and we offer our recommendations.

2. Literature Review and Contextual Background

2.1. Disability and Disaster Risk

Over 16% of the global population has a disability (World Health Organization 2022), with approximately 27% of people in the United States (Centers for Disease Control and Prevention 2023) and 26% in Scotland currently living with one or more disabilities (Kirk-Wade 2023). These numbers are expected to rise over the coming decades as societies age and more people live with disabilities. Research has demonstrated that people living with a disability are disproportionately negatively impacted physically, psychologically, socially, and materially by disasters and are at more risk during all phases of a disaster, from life-threatening challenges during evacuation to negative psychological consequences during recovery, than people without disabilities (Abbott and Porter 2013; Alexander et al. 2012; Kelman and Stough 2015). The existing research helps explain why people with

disabilities have been identified in disaster relief systems as especially vulnerable and in need of intervention (Wolbring 2009).

However, researchers examining the relationship between disability and disasters have long criticized the prevalence of medical models of disability that continue to underpin much of the policy and practice of disaster response (Hemingway and Priestley 2014). Application of this model leads to understanding of the disproportionate impact on people with disabilities, being understood as an outcome of ‘inherent vulnerability’ resulting from the presence of a physical, sensory, or mental ‘impairment’ or ‘divergence from a socially defined bodily norm’ (See Hemingway and Priestley 2014, for critique). This ‘assumed’ vulnerability of people with disabilities (Lid 2015) has been increasingly questioned as both research and policy have moved towards greater understandings of disability as a social and relational phenomenon (Lid 2015; Ton et al. 2019, 2021).

In contrast, relational approaches to disability assert that ‘being’ or ‘becoming’ disabled is an emergent state of being, located in the interplay between the biological reality of physiological impairment, structural conditioning (i.e., enablement/constraints), and socio-cultural interaction between bodies and environments (Hall and Wilton 2017). It follows that vulnerability to disasters can therefore also be understood as an emergent outcome of these same interactions; as Oliver-Smith et al. (2016, p. 8) also notes, vulnerability is ‘seriously and dominantly conditioned by societal perception, priorities, needs, demands, decisions, and practices’ that, over time, place certain social groups at a disadvantage, meaning that vulnerability can be understood as a conditional consequence of environments that are ‘disabling’ for some more than others (Connon and Hall 2021).

While a lack of appropriate social support can increase vulnerability, effective forms of social support can offer a buffer against some of the harmful impacts of disaster (Connon and Hall 2021). In particular, the presence of strong social networks and prosocial behavior, resulting in higher levels of social connectivity, is significantly associated with better outcomes (Kelman et al. 2016; King et al. 2019; Kruger et al. 2018). Furthermore, social contexts and disaster response systems that allow greater expressions of agency, creativity, and decision-making capacities are more helpful in enabling people with disabilities to demonstrate high levels of adaptational skill in leveraging sources of social support to overcome challenges to manage risk (Connon and Hall 2021). Research also demonstrates that people with disabilities are not passively dependent on others amidst disasters either. Rather, they can display active involvement and important levels of agency in making decisions to realize capabilities (ibid.; Ton et al. 2019). However, given the importance of social connectivity for those living with a disability, including those of advanced age, it follows that if a disaster disrupts normal social interactions, they may be at greater risk of social disability as cause and consequence of that disaster.

2.2. Understanding Social Disability Disasters for Improving Disaster Intervention

From an anthropological perspective, many expert-led disaster support interventions are constructed within a classic ‘self’ and ‘other’ paradigm, with an expert or a ‘self’ positioned outside the disaster who intervenes, in a top-down manner, to rescue a passive, incapacitated, disaster-affected ‘other’. The goal of these systems is to halt or mitigate harm to individuals. This means that awareness of details of local culture and coping are often less important within these systems than having clear plans, boundaries, and determinations of what an agentive, helping ‘self’ can do to ‘fix’ disasters as distinct and discrete problems and their impacts on individual ‘others’ (see Scolobig et al. 2015). The ‘others’ who are given the greatest priority and attention are those considered to be the most ‘vulnerable’, including people with disabilities.

While these approaches may be considered advantageous in that they contain clear plans for what can be implemented and anticipated, they can also be highly disadvantageous (Scolobig et al. 2015). In particular, their failure to work with local capacities and to engage in culturally appropriate ways that validate the humanity and agency of the ‘othered’ people is especially problematic, as they fail to account for human dignity, agency,

and capabilities, as well as important cultural values (ibid.; [Connon and Hall 2021](#)). While the ‘othering’ of people living with disabilities within the context of disaster relief comes with compassion for threats to bodily survival, responses that are culturally and diversity insensitive may result in ‘iatrogenic’ problems ([Illich 1975](#)) that emerge from expert intervention and from treating people passively rather than engaging with their strengths and agency. For example, while expert-led systems may be presumed to be preferable for those with the greatest dependency on others for care and those most socially isolated, they are also associated with enhancing dependency on emergency support services and greater risk when normal arrangements become disrupted ([Connon and Hall 2021](#)).

For these reasons, ‘socially responsive’ disaster response systems and interventions that promote greater consideration of local social variation and social as well as individual strengths and capabilities and which do not privilege individual bodily survival (‘bare life’) over social survival are often considered a preferable option. It is also argued that longer-term benefits can be realized by enhancing local socially based interventions ([Aldrich and Meyer 2015](#)), thus decreasing dependence upon external systems. However, as disaster compression intensifies and as the population ages and the number of people living with disabilities increases, greater pressure will inevitably also be placed on existing local social support networks and socially based interventions. While studies show that communities with more prosocial behavior and socially based disaster responses that are embedded upon relationships and networks with others (family, friends, and carers) are associated with better outcomes ([Pacoma and Delda 2019](#)), a crucial question arises as to whether these socially based interventions can be maintained in the context of increasing disaster compression. Furthermore, if this is possible, it is likely that at least part of the support for people with disabilities in times of disaster over the coming decades will need to come from more formal social relationships, such as relationships with formal care providers, and not just friends and family.

Understanding social disability becomes important as research and policy increasingly seeks to explore ways to facilitate the enhancement of local social support systems based on social capital networks and social interpersonal relationships ([Kruger et al. 2018](#); [Losee et al. 2022](#)). A plethora of research also evidences how community groups with strong social ‘bridging’ capital, ‘bonding’ capital, and ‘linking’ capital are better able than others to access resources and support and to devise self-coping mechanisms (see [Norris et al. 2008](#); [Panday et al. 2021](#) for examples). However, although interventions based on relational social capital networks are associated with better protection against disaster, they are fundamentally premised upon the assumption that strong interpersonal social relationships that facilitate the development and maintenance of these networks already exist or at least have the potential to be developed before disaster strikes and can be maintained amidst one or more crisis events. This represents an important consideration, given that other research demonstrates that a breakdown of community relations, including in communities with previously strong social interrelationships and interconnections, may also occur in the aftermath of disaster ([Norris et al. 2005](#); [Williams et al. 2021](#)).

With this in mind, thinking of ways in which socially based response systems and interventions may be improved requires consideration of how interpersonal social relations may be protected and/or restored amidst disaster compression. In our research, we discovered this through negative examples demonstrating the short-term and potentially long-term harm of disrupting interpersonal social relations. We frame this harm as one of ‘social disability’. In the case studies presented in this paper, we explore how social disability may arise (and for whom).

2.3. The COVID-19 Pandemic: Exploring the Emergence of Social Disability Disaster

The COVID-19 pandemic, with its global reach, provides an important impetus for exploring social disability, especially amongst people living with disabilities and advanced older ages who, owing to health and physical body constitution, are often at greater risk of mortality, severe illness, and long-term complications if infected ([Kelly 2021](#)). As the

pandemic affected communities throughout the world simultaneously, responses—which were coordinated and implemented at the national or state level—often involved social ‘lockdowns’ and distancing measures that directly affected existing patterns of social life and interpersonal social interactions (Tatarko et al. 2022). These measures proved controversial, leading to public protests and the need for research investigation (Murphy et al. 2021).

The scale of the COVID-19 pandemic also provides another reason to re-examine the ‘self/other’ construction of modern, external expert-led disaster relief systems as within the global disaster context, the ‘self’ is not and cannot be located outside the disaster, separate from its impacts and threats. Consequently, those who provide and seek care, intervention, and support become potential sources of contagion for each other and positive social relationships also become part of public health measures of control and containment. This suggests that both care and community settings may be locations of heightened risk of the emergence of social disability in the event of viral outbreaks. Also, while socioemotional needs take second place to the physical need to prevent contagion within the technocratic logic of these disaster response systems, we need to critically consider whether this approach truly saves lives—or rather, whether the solution to self-isolate or socially distance shifts the wellbeing burden from a virus to the lack of interpersonal contact, thus becoming its own source of harm.

From our case studies of the impacts of the global pandemic and intervention efforts in different communities, we argue that the novelty and level of risk imposed by the virus exacerbated the emergence of social disability disaster. We also explore how intervention efforts implemented in both case study sites—which included periods of ‘lockdown’ and ‘social distancing’—contributed to the emergence of social disability. We also note that people were not entirely passive in how they responded to either the virus or the interventions and show how ‘rebellion’ and creative adaptations emerged, which proved fundamental in offsetting, reducing, and recovering from social disability disaster.

3. Defining Social Disability Disasters

Based on our analysis of our case studies, we define social disability as a disaster that occurs when any environmental process or event results in conditions that significantly disrupt or paralyze fundamental formal or informal social interpersonal relationships that underpin social sources of support and inter-relational networks crucial for everyday wellbeing and for adaptation amidst crises. Furthermore, given the significance of interpersonal relationships for individuals, communities, and societies to function healthily, we argue that the emergence of social disability can itself be deemed a ‘disaster’. If social disability takes hold, regular patterns of interaction cease, resulting in social groups becoming ‘socially disabled’. Individuals are then at risk of isolation or becoming too socially self-contained to the extent that it hinders their abilities to adapt and thrive in changed environments.

It follows that the risk of experiencing social disability is most prevalent when the scale of disruption to normal social functioning across the whole of society is wider, or for those most socially isolated. This is because if important social relations break down, there are fewer connections to rely upon to prevent disaster. Those most at risk from social disability are likely to be those most dependent on others for social support, and for whom the interpersonal social relations that become threatened are the most fundamental.

We also reveal that while social disability can result from an event that disrupts social interrelationships to the degree that normal socially based ways of coping become suspended, interventions that swiftly replace local coping and adaptation practices with the goal of ending any immediate threat to physical survival that exposure to the event imposes can also contribute to the emergence of social disability disasters. This is more likely to occur where the intervention is more focused upon meeting individual, bodily survival rather than ensuring important social needs are met and that intervention mechanisms are attuned to local ‘informal’ systems of adaptation and support provision. The effects of interventions become most apparent when the immediate crisis is over and the intervention is withdrawn, where local social networks remain inactive and social interpersonal actions

are not spontaneously restored, and where people's help seeking has changed such that they become prone to social withdrawal rather than finding or sustaining the social supports they need. Furthermore, important cultural practices and values enacted through social interpersonal relations may also become threatened, thereby enhancing experiences of ontological insecurity, including losses of previously held senses of purpose, identity, and envisioned futures.

4. Methodology

The context from which our theory originates was born out of the authors' experiences of conducting research focused on other topics amidst the wake of the pandemic: one exploring people with disabilities' experiences of living in flood-prone areas of rural Scotland, the other focusing on how affluent older people in the U.S.A. avoid and mitigate the risks of vulnerability, disability, and 'becoming old' by living in continuing-care retirement communities (Crampton 2023). However, given the enormity of the pandemic's impact on people's lives, it was found that interlocutors' experiences of the topics in question could not be separated from their experiences of the pandemic. Nor could the researchers' own experiences of conducting ethnographic research in the wake of the pandemic be isolated from the pandemic itself. This paper comes out of the authors' sharing preliminary study results associated with pandemic and pandemic intervention impacts as found at each research site, and then returning to the data for more explicit data coding and analysis to explore what we now propose as a theory of social disability as a risk factor during disasters and disaster relief efforts.

The research design for both studies used an inductive, qualitative, and anthropological approach that entailed "following the ideas" and questions raised during research as much as executing a pre-planned protocol (Nader 2011). The purpose of this type of research is to learn through close examination of the interplay of details, contexts, and events that might later lead to generalization of findings through comparison with other populations and research site locations. When working with people experiencing socially stigmatized identities, such as people with disabilities and older adults, it is especially important to spend time in the field developing trust and rapport to ensure authentic exchanges when later engaging in more formal data collection through semi-structured interviews. Through direct immersion in the study site where people live and work, the researcher becomes the main 'instrument' of data collection as a participant observer of personal and social experience. Data are collected through research diaries that record events, observations, and the responses given in informal interviews. These are later reviewed for writing emergent hypotheses into analytic memos (Charmaz 2008). This inductive groundwork then contributes to more formal semi-structured interview protocols. This enables more widespread and systematic data collection that also incorporates asking respondents to speak candidly as to what research questions and data they find important (ibid). Through this more dialogic approach, researcher bias is reduced as it encourages research participants to provide critical feedback and elaborations unanticipated by the researcher (Burawoy 1998). Formal interviews are digitally recorded and transcribed. The result is a data set of research diaries, analytic memos, and interview transcriptions for later coding and analysis. This may also be supplemented by document collection.

Our first case study focuses on the experiences of 17 people with at least one daily activity-limiting disability, living independently within a small rural community in Scotland. Participants were aged between 29 and 93 years, with eight aged under 60 (with four of these being under 40) and nine over the age of 60. The community is known for being 'close-knit' and has longstanding experience with adapting to flooding, but the COVID-19 pandemic brought new uncertainty and restrictions that resulted in the onset of a social disability disaster. All participants were previously known to the researcher, who has been conducting ethnographic anthropological research in the community since 2014. Plans to conduct several months of ethnographic research within the community during 2021 to

explore experiences of worsening weather were amended so that the research could (where possible) be undertaken remotely online due to COVID restrictions on fieldwork.

To substitute for the in-person ethnographic research, video calls were arranged to hold a series of discussions with participants that the researcher had intended to meet with. These included friendly, informal 'chats' as well as focused, topical discussions related to the research topic in question. Only 10 out of the 19 participants were able to take part in the online discussions due to their abilities to access and use the required technology. It was these discussions, however, that brought participant experiences of the COVID pandemic to the fore, with descriptions of their experiences of both the pandemic and restrictions coming to dominate the discussions. The online discussions were followed by semi-structured, formal online interviews with these same ten participants between May and September 2021 when restrictions continued to prevent in-person research from resuming. Owing to the importance of the pandemic in participants' lives, interviews included four open-ended questions which asked for information about experiences of the pandemic. These specific questions were: 1. Tell me about your experiences of the first and second periods of lockdown? 2. In what ways did/has the pandemic affect(ed) your regular activities and routines? 3. In what ways did/has the pandemic affect(ed) your relationships with family, friends, carers, and/or others living in the community? 4. How do you feel life has changed for you now compared to before the pandemic? These ten interviews were then supplemented by a period of ethnographic research conducted within the community and an additional seven semi-structured, face-to-face interviews conducted in summer 2022, after restrictions ended. These later interviews also utilized these questions to find out more about participant experiences of the pandemic. Data were collected with permission and in accordance with the University of Dundee's Research Ethics Committee, with informed consent being sought and obtained from all participants.

Study limitations due to COVID restrictions were mitigated by how participants and the researcher had known each other for a number of years. Familiarity with the researcher and prior engagement in research meant rapport had already been established and participants were already comfortable talking with the researcher about experiences of living with a disability and experiencing hardships, including in an interview context. This was evidenced by how it was the participants themselves that initially raised the issue of the pandemic and, by doing so, ultimately steered the focus and development of the research towards its eventual outcome. This demonstrates that they felt comfortable raising topics that they thought were more pressing than the original topic in question. It is also important to note that the research aimed to capture the subjective experiences and views of participants, rather than objective, unbiased forms of data. Acknowledgement of people's perspectives, values, and agency in the process of conducting research, as well as in the reporting of the findings, is also particularly important within disability research for enhancing inclusion and helping to rebalance uneven power dynamics between the researcher and research subjects ([Smith-Chandler and Swart 2014](#)). While participation was limited to those who had already previously been engaged in earlier research focusing on experiences of extreme weather before the pandemic, participation in this earlier study was open to anyone living with a disability residing within the community, as long as they could provide informed consent. While additional potential participants would normally have been sought and welcomed, pandemic restrictions meant that abilities to expand networks were limited.

Our second case study explores local policies and responses to the COVID-19 pandemic in an affluent continuing-care retirement community (CCRC) located in a Midwestern U.S. state. Preliminary ethnographic research was conducted during four weeks in winter 2020. Data were collected through participant observation, document collection (such as facility policy documents), and semi-structured interviews. Formal data collection was conducted over several months, primarily through the summers of 2021 and 2022, as well as several two-week ethnographic research trips between August 2021 and January 2024. As part of research design, fieldwork immersion and participant observation was enriched by living

in apartments and guest suites in the facility during three months in 2021, 3 months in 2022, and each field “revisit” (Burawoy 1998) for further data collection and sharing of preliminary results with research participants. The principal investigator was joined by a graduate research assistant for one month in Summer, 2022. The assistant lived ‘off campus’ from the facility and conducted participant observation through daily visits and participation in facility activities. In total, the principal investigator and assistant interviewed 84 residents and 28 staff, which included follow-up interviews with several residents and staff both informally and through recorded, semi-structured interviews. Data were collected with approval by the Marquette University and University of Michigan institutional review boards and the internal research review board of the research site facility.

Participant age ranges differed in each of the case studies, with the first case study involving participants between the ages of 29 and 93 and the second case study focusing on an older population with an average age of 85. However, our study is centered upon the issue of disability rather than age per se. In the first case study, all participants were living with a disability in a wider community setting. However, acquisition of a disability is also a common feature of aging and a reason why people may choose to move into an independent-living retirement community like the one in the second case study (Reed et al. 2014). As such, the sites represent two forms of residential settings where large numbers of people with disabilities in both the UK and US may reside. However, given the large discrepancies in age range between participants in the first case study and between participants in the first and second case studies, we indicate in the findings and discussion the instances in which participant responses between those over 60 and under 60 diverged and where these divergences indicate differences in experiencing disability at different stages of the life course, as well as how the pandemic impacted upon these experiences.

In exploring social disability as a disaster intervention theory, data from each project were first analyzed separately and thematically by hand, using a ground-up (inductive) approach (Braun et al. 2019), which involved examining the contents of research diaries and interview transcripts and coding for key themes. The five general themes identified across both case studies were as follows: disruption; coping with disruption; short-term impact; longer-term impact; and silver linings (that is, any positive outcomes as systems and people responded to the pandemic). Results from coding for these themes from each project were then compared and reflected upon by the authors to identify commonalities in how social disability emerged, intensified, became entrenched, and/or was resisted, offset, and/or recovered from, in order to develop the theory, while also noting differences due to differences in community-based and residential setting, population demographics, and culture. As such, the study did not aim to test the generalizability of the findings nor test a pre-determined hypothesis but instead drew out similarities from the two case studies to devise a theoretical explanation for aiding understanding of the impact of the pandemic on people’s lives.

5. Findings: Case Studies on Experiencing Social Disability as a Disaster

5.1. Case Study 1—Becoming ‘Disconnected’ and ‘Different’: Living with a Disability and Experiencing Social Disability in a Scottish Rural Community

The research site, located in rural, northern Scotland, comprises a small village community of 477 residents. Known as a ‘close-knit community’, residents once would proudly declare how it was a place ‘where everyone knows everybody’, and ‘everybody looks out for one other’. The village contains a public house, community hall, and a local shop, which was known as ‘the heart of the community’, owing to its distinguishability to anyone passing by on account of the numbers of people gathered outside readily engaging in conversation, or as stated by one interviewee, ‘obtaining their daily supply of gossip—you know, what’s been happening in the village. What’s on, who’s ill... Everything’. Most residents live as couples or as intergenerational family units; however, a small number live in single-person households. Sheltered (amenity) houses are available, with units specifically designed for older adults (60+) and those with mobility needs; however, the

majority live in standard housing accommodation—including, in some cases, having had adaptations made to allow them to remain in their own homes.

In this study, however, all participants lived independently (in some cases, with formal service-provided or informal/kinship-based carer support) in their own homes (two in sheltered housing), either as a single-person household or with other family members. Particular disabilities reported by research participants included a range of physical, mental health, and sensory difficulties, neurodivergences, and long-standing chronic health conditions, some lifelong and others acquired later in life, with each having at least some significant identifiable impact on their individual daily activities and pursuits. All participants were White and cisgendered, with demographic information for the wider Scottish regional locality within which the community is located revealing that over 96% of the local population identifies as White ([Scottish Government 2023a](#)). In 2020, over half were entirely reliant or lived in households that were entirely reliant upon disability, long-term sicknesses benefits, and state retirement pensions as their only sources of income. The household incomes of others varied depending upon whether they lived alone or with others, the earnings of those they lived with, and whether they themselves were in employment or receiving private retirement pensions. In total, more than three-quarters of participants were living in households with incomes below the median Scottish annual income.

5.1.1. Pre-Pandemic: Being Different, but Not Feeling Different

Prior to the pandemic, participants requiring formal care support to meet daily needs received care from a team of visiting local authority care providers, which included a community meals service, help with washing/dressing, cooking, and assistance with medication. However, most chose to receive assistance from family and friends instead of or in addition to relying on formal care services. All interviewees who received at least some formal care support also relied on friends, family, and village networks for meeting important social and health needs, including for transport to organized activities as well as for ‘simple enjoyment of life’.

Disability in Scotland is officially defined according to the Equality Act 2010 as a ‘physical or mental impairment which has a substantial and long-term adverse effect on an individual’s ability to carry out normal day-to-day activities’ ([Scottish Government 2023b](#)). However, the experience of ‘being disabled’ and of the ways that ‘impairments’ affect a particular individual’s ‘normal’ daily activities incorporates a degree of subjectivity in how this manifests, depending on what people view as ‘normal’ within the contexts of their own lives. During the online discussions and interviews that took place during the pandemic and in the face-to-face interviews that took place afterwards, over half the number of interviewees described how their experiences of ‘being disabled’ changed over the course of the pandemic, with some mentioning how, prior to the pandemic, although they were aware of their particular disabilities and how they impacted on daily activities, they did not ‘actually feel disabled’, nor feel that their disabilities limited their lifegoals or made them feel markedly ‘different from others’ within their social and community networks. Others alluded to how their disability was not central to their self-identities, commenting, for example, how they ‘[F]elt just the same as everyone else, same as my friends. . . some played football, some didn’t. I was just one of us who didn’t’. However, they also expressed high levels of gratuitous awareness of how their close, social, and familial relationships with others made it possible to achieve goals and complete tasks, by saying things like, ‘[It was] only possible because I had [name of person] to take me there—they are just great. When they couldn’t take me any more. . . it was so depressing. I hate missing out’.

This was the case for both older and younger people; however, for those over 60, perceptions of similarity to others were also associated with aging processes, with disability being viewed as ‘something that everyone will face sooner or later’. In contrast, those under 40 all referred to ‘differences in abilities’ amongst people more generally, with disability

being viewed more as part of this wider state of human diversity rather than something that marked them out as being fundamentally different to others.

While community social interpersonal relationships were important for avoiding feelings of ‘being disabled’ or ‘becoming different to others,’ these same relationships had also been of fundamental importance for reducing the risk of harm during extreme weather emergencies and flooding before the pandemic. The village is located in an area prone to flooding and although residents are ‘long used’ adapting to flooding, the community has faced increasingly severe flood-related emergencies over the past decade. However, previous research focusing on the issue of flooding in this community found that despite increasing extreme weather, the community had continued to be able to successfully cope with, adapt to, and recover from these disruptions (Connon 2017; Connon and Hall 2021). People with disabilities were also able to cope and adapt well during these emergencies, owing to a combination of familiarity with experiences of flooding in the area, strong social relationships with other community members upon whom they could depend for assistance, and confidence in the upholding of local, cultural norms underpinning reciprocal community supportive arrangements to ‘always look out for one another’ and not to assume that if someone does not directly ask for help it does not necessarily mean they are not experiencing difficulty (Connon 2017). People who had learned to live with disabilities were also able to cope and adapt when faced with emergencies rather than becoming helpless, due to their experiences in having had to learn to cope with and adapt to uncertainties to be able to live in physical and wider social environments that were excluding by not having been designed to meet divergences in bodies and human needs (Connon and Hall 2021). While disruptions to formal care arrangements sometimes resulted amidst periods of flooding, residents retained confidence in the capacities of informal, local social connections to plug any shortcomings in formal support provision that may have arisen (ibid.).

5.1.2. Pandemic Disruption: First Period of Lockdown March–July 2020

Following the arrival of COVID-19 in Scotland in March 2020, the entirety of Scottish society went into ‘lockdown’ as the First Minister announced that the country was in a state of national emergency. Schools closed, shops closed, community centers closed, people were instructed to work from home, and citizens were told to cease all non-essential (carer) social contact with members of other households and to stay at least two meters apart from members of other households outdoors. People were not permitted to gather outdoors in groups, even when socially distancing. Rules on staying at home, mask wearing, and social distancing became a legal requirement through the UK Coronavirus Bill. These strict lockdown requirements lasted until the end of May before gradually being eased through to December.

While the Scottish government pursued a ‘zero-COVID strategy’ to protect the health of all citizens living in Scotland, the entire country now found themselves situated within the emergency response protocol and, consequently, almost overnight, within the structure of a nation-wide ‘total institution’ (Goffman 1961). Warnings were issued on the national news that those who broke rules could face police action. At the time, official government and public health announcements pushed the message that these restrictions were needed to protect ‘the most vulnerable’ members of Scottish society for whom infection bore the greatest risk.

5.1.3. Coping with Pandemic Disruption

Reflecting upon this time, participants recalled how this was a particularly ‘terrifying’ time, owing to the perceived level of threat posed by the virus to themselves as well as others. One recalled, ‘I thought that’s going to be the end of my time, everyone’s time’. At this time, both older and younger people were similarly concerned with the threat posed to themselves and others, especially older people. For example, as one younger participant explained, ‘I was worried it would get me but also what would happen if the older people

I knew got it. It's bad for all older people, even if healthy. . . For younger people with no [health] conditions it's not as dangerous, but if they got it and then pass it onto someone older it's not going to be good'.

At this stage of the pandemic, requirements for formal carers to wear masks were highly welcomed as the wearing of masks was deemed to provide at least some degree of security against contagion. Efforts to minimize touch beyond 'absolute necessity', even in essential care contexts, also helped create a greater sense of security for both caregivers and care recipients; as one participant recalled, 'I could see that [the carer] was nervous and I said, 'It's okay, I don't take offence'. I was quite glad about it really. Just in case'.

However, although participants were relieved that measures had been put in place to try to contain the virus, they also described feeling helpless as a result of social distancing requirements, with one explaining: 'I was glad something was actually being done, but then I thought well what now?' Another recalled feeling like a 'naughty child', being 'punished by an overly strict nasty schoolteacher for something [they] hadn't done and being forced to sit in detention with nothing to do forever. . . that feeling, just wanting to escape, and waiting for those words 'you can go now'".

However, the placing of restrictions on social movement and interaction heavily impacted upon the lives of those relying on informal systems for support and friendship. The lack of regular social, informal interactions was also intensified by how regular social and leisure activities had ceased. Those struggling with isolation were, at this point, deterred from 'rule breaking' owing to how the national media continually promoted the notion that rule breakers were selfish for putting others at risk. While rural areas are often known for their tolerance of the minor breaking of 'official' rules, for rules which they themselves view as 'irrelevant' for applying in more isolated rural settings, instances of rule breaking during the first few months of the lockdown were few and far between. While some were deterred by the risk of infection to themselves, more were deterred through fear of putting others at risk.

Options for retaining social connections without meeting face-to-face were also often limited due to internet connectivity being poor in some village areas. For those with internet access, weak connectivity meant that attempting Zoom meetings proved 'frustrating at best; impossible at worst'. Some switched to on online text-based communication instead; however, this posed additional frustrations for those used to speaking in a local form of the 'Scots language', with experiences of messaging in Scots being less enjoyable than conversing verbally in Scots: 'Seeing it made me aye miserable as it made me miss it a' the mair. So, I stopped bothering with it'.

While isolation affected participants regardless of whether or not they were financially well off, those who were the most widely socially connected within the community experienced heightened levels of boredom and feelings of isolation compared with those who previously spent less time meeting friends and engaging in community social activities. This was particularly the case for those who lived alone but who were also previously very socially active. Those who had family and friends living in the area but who did not form part of their immediate household often reported the greatest sense of isolation, regardless of whether they lived alone, owing to how, as one participant explained: 'It's worse when they are nearby but you can't see them. It's painful because they are so close, and things happen like you are miles away. [Name of family member] lives [far away] so I wouldn't expect to see him. But when you expect it, it's a different story'. Those who lived with others also reported feeling isolated at being separated from others outside the household, even though household members helped to provide more care activities during this time. For example, as one explained: 'It would have been different if we had others come to stay even if we didn't see anyone else. When you live together as long as we have, you think more as one and you do get lonely and bored—you just get lonely and bored together'.

5.1.4. Short Term Impacts: Increased Isolation and Awareness of ‘Being Different’: Reflections on the Pandemic from July 2020–September 2021

The prolonged lack of regular social interaction resulted in feelings of loneliness, purposeless, and emptiness amongst participants. Those who relied on formal care support also felt increasingly burdensome as normal, friendly social interactions that formerly took place amidst the provision of caring activities ceased as carer visiting times were minimalized, with both providers and recipients being worried about the risk of viral transmission. One interviewee described these new arrangements as ‘skeleton visits’. This was not only because they were restricted to providing ‘essential’ care only but because ‘all the humanity had gone. It was now wash, dress, medicine, and out [they] went. No gossip, no cups of coffee. . . like a body with bones but no flesh is not a body, it’s a skeleton. The remains of what was once a body’. She also explained how this subsequently led to negative changes in her sense of identity and self-esteem, ‘I’d rather go smelly than die. . . I’ve always taken pride in my appearance, but it didn’t matter, we couldn’t see anyone. . . I got used to not washing. I became a useless lazy lump’.

Others recalled becoming ‘terrified’ by visits by formerly welcomed carers and subsequently refusing services for fear of contracting infection owing to concerns about the accuracy of testing and fears that official requirements for care staff to take regular tests were no longer being adhered to properly, combined with concerns over asymptomatic cases, with one older person recalling: ‘I didn’t fully trust the tests and I have to admit I didn’t trust that testing rules were being followed. Not always by then anyway. Because people were fed up with endless tests. But I didn’t want to ask, ‘Are you sure you are following the rules?’” A younger adult reported similar concerns, stating, ‘I knew from our earlier chats that she goes out a lot and if you miss it, maybe rules get broken. You just don’t know who they’ve been in contact with. . . but you can’t go making accusations’. This reveals both a decline in trust between care givers and care recipients, as well as a growing distrust in protective interventions. However, despite concerns about infection, after the first few months, a small number expressed frustration with minimal physical contact, which they felt had become a dehumanizing experience. For example, as one explained, ‘I was grateful initially. But when you feel you are being held at arm’s length like a dirty nappy, you feel like you’re diseased and need to be kept away from even though the point is not to catch a disease’. While mask wearing by carers continued to provide reassurance against infection, two participants also noted that prolonged mask wearing increased their sense of separation from carers. However, this was something they were willing to put up to protect themselves and others, with one explaining, ‘It can be more difficult to hear, difficult to catch what someone’s saying behind a mask. . . I like to see people smile. But I am pro-mask. It helps [reduce transmission] so yes’.

Lack of ability to access the outdoors to see other people from other households with social distancing measures in place as a result of continued disruptions in support arrangements and continued fear of infection during this period resulted in both older and younger participants feeling like they were missing out on spending quality time with friends and social contacts, including one who stated, ‘I couldn’t go outside. No friendly chats with people at the gate, no going down to the shop and stopping for a chat. These things still happened, but I wasn’t part of it’. For others, exercising outdoors and at a distance posed challenges for those requiring support to be able to do so. For example, as one partially sighted respondent explained, ‘I love walking outside. But there were no arms offered for me to take’. Others, especially older people, who were able to go outdoors but who were especially afraid of infection avoided doing so. One interviewee described how this resulted in life becoming like ‘a dark black hole that when you fall down you fall further and further from where you want to be and the people you want to be with’. However, at the same time, nearly all older participants and over half of the younger participants experienced strong feelings of guilt at having these thoughts, owing to also knowing that the restrictions were in place to protect them above others.

The majority of interviewees, especially those over 60, were particularly uncomfortable being at the center of government and public health communications and, in their words, 'being used to dictate the message to people to stay home and disintegrate'. One reason why this was so uncomfortable is because of the importance placed on avoiding engaging in individual 'selfish and self-centric behaviors' in rural Scottish culture, where drawing attention to oneself or making others go out of their way for you when 'they don't really need to do so' is generally frowned upon, especially amongst older adults. Pre-pandemic, these ideas helped promote supportive behaviors towards those deemed to 'need' support while also limiting potential exploitation, with 'socially approved' support-seeking behaviors being defined loosely as acts of informal supportive interventions from friends and community-based social networks for those 'struggling' or 'who could not manage without it'. However, going from this to feeling 'like the entire nation was having to go out of their way' to protect them was considered too much of a burden that they felt others had to bear on their behalf. As one person explained, 'when I say we all support one another round here I mean just that. . .one another. . .when we need it. That's different to the whole country doing that just for a few'. Others, including all the younger interviewees aged under 40, also expressed concern that the constant official messaging to 'protect the vulnerable' would lead others to blame them as well as older people for the restrictive situation Scottish society now found itself within.

This deliberate avoidance of activities presented a moral dilemma for some, however. This was due to how they perceived that their decisions to put their own health first through avoidant behavior challenged long-standing norms about 'facing up to danger' as well as those 'of not putting individual needs above those of others', with younger interviewees more likely to express concern about their unwillingness to take risks and older interviewees being more greatly concerned about putting their own needs first. For example, one younger person described how they 'felt like a total wimp' for being afraid of the virus but 'couldn't admit it publicly' and instead made excuses as to why they could not meet outdoors. This was especially profound amongst the younger male participants who reported feeling both 'guilty' and 'inadequate' for being so anxious about the virus, while participants who were both older and female were more likely to report that they struggled emotionally owing to concerns about having become more selfish in their behavior by refusing to meet others who might be feeling lonelier than them.

By 8 August 2020, the total number of deaths in Scotland where COVID-19 was mentioned on a death certificate was 4213 ([Public Health Scotland 2020](#)) and the total number of cases recorded following a positive test was 18,890. At this time, case numbers within the wider local authority area where the community is situated were lower than 26,294—the lowest in the country (*ibid.*). However, at this time, people within the community were highly anxious about the prevalence of COVID-19 and participants described COVID-19 as being 'everywhere' and that 'everyone [knew] someone who's had it or who's got it'. Although no known deaths had been associated with COVID-19 within the community, people said that this was 'down to luck more than anything else'. However, participants also thought that living in a rural area meant that cases might be more likely 'to slip under the radar and go unnoticed' and perceived that rules about testing and the reporting of test results may not have been as strictly adhered to or enforced as they should have been. For these reasons, five participants said they did not fully trust official daily case number reports and continued to restrict contact with others as much as possible.

As restrictions for the general public gradually eased, those in households with a member considered to be more 'vulnerable' in terms of 'bodily constitution' were initially told to keep maintaining restrictions to protect their health. Consequently, some people with disabilities as well as members of their households became more restricted than others and the rest of society. At this time, some became aware of how small their informal support and care networks had become. For example, one interviewee explained that this was when she became acutely aware of her increased dependency on her husband, who became her primary caregiver for emotional survival, explaining, 'I just sort of woke up

and saw it was now just me and him. I was horrified. He helped before but he'd become my world'. Younger people were also acutely aware of how their worlds had become more restricted and expressed concern about the extent to which they felt they had become dependent on close family and household relationships. This was associated with a sense of personal failure owing to the value they placed on being or becoming independent to resist social exclusion and offset negative stereotypes about disability. For example, as one participant explained: '[When] you're disabled, being independent is so important. Like your ultimate goal. You don't want to be seen as not capable and stuck only with your family like disabled people in history or that you are a burden on others, but that's what happened'.

It was also at this time that others became more aware of their disability or of 'being different' and 'feeling more distant' from others. This was especially the case for younger adults whose immediate social circles were less likely to contain similar numbers of disabled and non-disabled people, compared with older people whose social circles were more likely to contain others who also needed to continue with greater levels of social distancing measures. For example, as one interviewee described: 'Everyone else now seemed to be getting on with things apart from me. My condition had never stopped me doing anything—not completely anyway...but at that time it controlled me completely'. Another found that others had also become more afraid of them simply because of the nature of their disability, explaining: 'I was angry because people kept away, and I found out they were frightened I would get too close because of my ADHD...I'm not going to forget to keep my distance after a year of the whole world banging on about it'. In contrast, older people, although less likely to express concern about feeling different to others of a similar age, became more aware of their age, for as one interviewee explained, 'I've always been disabled but had good health and didn't think of myself as old or frail. But all this focus on age and vulnerableness makes you feel old. Makes you feel weak and frail. Like because other folk now see you as old and frail you think like that too after a while'.

5.1.5. Longer Term Impact: Persistent Social Divisions and Senses of Disconnectedness in 2022

Further interviewee reflections upon experiences of the pandemic after restrictions ended continued to reveal heightened awareness of 'being disabled' and of being 'different to others' because of disability. This was especially the case for younger adults who continued to feel socially disconnected from others because they had 'missed out on so much' that they now felt substantially distant from those they previously had close social relationships with, for as one explained, 'So much happened when I was still distancing. I suppose you could say I fell behind...I kind of feel I'm on the outside'. However, senses of prolonged disconnection from formerly important close contacts were also described by older people. For example, as one person stated: 'It's like me and [name of friend], it's like we are both living in different worlds from each other nowadays'. Others continued to express concern and despair over having become more dependent on close family members for social pursuits and finding it difficult to resume connections with others, such as a younger participant who explained, 'I do a lot with my family as I don't get invited out as much. If it's something like someone's birthday, I'll get invited but people don't randomly come round'.

Perceptions of being 'more disabled' and of feeling 'different' to others whom participants formerly felt were very similar to themselves also continued to persist, as did increased awareness of 'age' and 'frailty' amongst older people. Although by 2022 participants had resumed more social contact, they continued to find that people treated them differently, as one described, 'like a porcelain doll'. They also explained that while they had been initially grateful for the kindness shown, it had now become tiresome, and had a detrimental impact on their sense of not wanting to be defined by their disability or by their age or a combination of the two, for as another participant explained, 'You know the expression 'kill with kindness'? They don't see me the same way anymore'.

Later reflections also revealed how important cultural norms underpinning informal, supportive interpersonal relationships at the community level were also threatened by the pandemic. In this particular community, as also evident in other rural Scottish communities, there existed several long-term subtle, yet stable, culturally specific norms surrounding the pro-offering of assistance to people who may be at risk of experiencing hardship. Many people do not feel comfortable openly admitting when they are struggling, owing to concerns about ‘being seen as selfish’, and so will either not directly ask for help or when asked directly will reply that they are fine, to avoid experiencing feelings of ‘shame’ in not being self-sufficient enough. To circumvent this, other people in the community (also aware that this is how people will respond when asked) find out how people are ‘really doing’ through regular sustained informal, social communication, paying attention to the person’s demeanor or appearance as much as to what is said (see [Connon 2017](#)). Offers of support are not pro-offered directly, upfront, but via friendly gestures of ‘offers to come and have a ‘proper chat’ soon and via friendly statements such as ‘my door is always open if you want to pop in’ to ensure that the person gently and discreetly knows that someone ‘quietly has their back’ should they need it. However, after the pandemic, people described how they no longer had ‘those sorts of conversations’ and also spoke about how ‘people [didn’t] know anymore what others [were] doing or how they [are]’ and that ‘our gossip networks seem to have vanished’. One person recalled how the absence of these informal visits and ‘local gossip’ led to her not realizing that the spouse of a friend had died until nearly a week later. She explained, ‘nobody told me, they presumed I knew. All the information that normally goes round a village in an hour wasn’t coming to me anymore’.

5.1.6. Silver Linings: Creative Rebellion and Offsetting Isolation during the Second Lockdown

Despite the disruption imposed by the pandemic and its negative legacy upon individual and collective social relationships, interviewee reflections also revealed how, as both the contagion and interventions changed, peoples’ attitudes and actions in response to these also changed to a certain degree. After the country started to recover from the first lockdown, it was again plunged into another period of full lockdown in December 2020 with the rise of the Omicron variant, before restrictions were gradually eased again over 2021. However, during this time, greater amounts of rule breaking occurred within the village, including by some people with disabilities, both old and young, and often justified on the basis that they felt ‘they simply just couldn’t take another lockdown’ and instead ‘would take the risk of COVID just to avoid having to live like that again’.

By this time, fears about being reported to the police or authorities for rule breaking had lessened due to beliefs that ‘the police wouldn’t have the capacity to enforce the rules anyway’, given ‘the numbers doing it’. However, others continued to voice concerns about putting others at risk by breaking the rules. To avoid the risk of being reported, people met as discretely as possible through ‘backdoor chats’ whereby visitors would enter homes via the back door of the house to avoid being visibly observed entering homes or via ‘tunneled visits’ where people would meet discretely later in the day—with ‘tunnelling’ being a colloquial term chosen by local people to describe these activities owing to perceptions of their association between this and legendary practices of legendary historical characters digging secret tunnels under castle buildings to enable ‘illicit’ meetings to take place. While many with mobility difficulties could not ‘tunnel,’ they were willing to receive ‘a tunnelling mole’—a visitor to their homes. Ultimately, those who participated in some ‘tunnelling’ activities recalled that ‘a sense of vibrancy... of people, just enjoying being alive’ returned to their lives and village life from doing so.

Concerns about ‘being selfish’ and being viewed by others as selfish had also lessened by this time. Those ‘fit and healthy’ who previously avoided breaking rules sometimes became more willing to break rules out of concern for the wellbeing of others, explaining how people would first ask the person with the disability if it was okay to do so ‘out of politeness and respect’. However, younger participants reported that social contacts of a

similar age were often more reluctant to tunnel to visit them than older contacts owing to concerns about putting people they deemed to be more vulnerable at risk, while older people reported that younger contacts were also more reluctant to do so compared with those of a similar age, for the same reason. People had also become increasingly critical of government messages that ‘rule breaking was selfish’ as well as earlier fears about their risks from infection, because as one 71 year-old bluntly put it: ‘[W]hit’s selfish is leaving someone dying of boredom and what’s more cowardly than being feart of dying is not doing this [sticking up their middle finger in an insulting gesture] to the rules and saying aye I may be deed next week but I’ll hae’ a bloody good time a’fore I go makin’ sure a’body else goes happy too’.

5.2. Case Study 2—U.S. Continuing Care & COVID-19: From Independence to ‘Birds in a Gilded Cage’

The research site, located in a U.S. Midwestern state, is one of three continuing-care retirement facilities run by a nonprofit foundation. The site is in a rural area and caters mainly to affluent older adults seeking “independent living” (IL) options, with apartments and houses connected via a large campus to dining, wellness, and social activities, as well as “assisted living” (AL) apartments. Agency statistics show that nearly all residents identify as white and cisgender. Women outnumber men by 2 to 1 (about 65%). The average age of residents has risen from age 82 when it first opened fifteen years ago to age 85 by 2023. When it first opened, residents had to pass a fitness test, with the ability to live ‘independently’ being a requirement for entry. No one lived in AL, which to this day can provide housing for up to only 40 of the 200+ residents. There is 24/7 concierge and security, with nurses available during business hours. There are nearby walking trails and grocery stores. The facility is also near major hospitals with a highly ranked health care system. As stated previously, the larger research study was conducted among independent living residents about how they define transition from an experience of aging to one of growing ‘old’. An underlying question was about how people who are unusually privileged socioeconomically and who have optimum access to health care address and encounter the risk and potential reality of frailty, disability, and dependence during their residence in this facility.

5.2.1. Pre-Pandemic: Residence as Insurance against Disability and Dependency

While residents were highly aware that one day they might require greater levels of support with their daily activities, the desire to retain independence was highly motivational in their choice to live at this site. As one resident explained: ‘You come to live here as a kind of insurance policy’. This is a policy against losing one’s independence and requiring the care of AL or skilled nursing. Before the pandemic, clear policies and social structures separated IL from AL residents. Despite moving into the facility to improve access to care, IL residents hoped that they would never have to trigger their insurance policy. Many IL residents also actively avoided association with those in AL unless their spouse lived there, with one commenting, ‘we make jokes about that place—no one wants to live there’. In other words, by moving into this facility they aimed to avoid any debility that would shift their sense of self and wellbeing from that of a person who is admittedly aging to a person who has become ‘old’. For many research participants, becoming ‘old’ was not something that merely impacted their capacity for physical survival, but something that could negatively impact their ability to thrive as ‘a whole self’, with residents explaining that: ‘Aging is when you lose a part of you, one piece at a time’ and as ‘when you are no longer the person you prepared yourself to be’. Although age-related frailty was often an ever-present fear, it was also not yet a central part of self-definition or daily preoccupation among most IL resident research participants; becoming ‘old’ was perceived as both a potential disaster and a fact of life that had to be faced.

5.2.2. Disruption: Pandemic ‘Lockdown’ Mid-March 2020–June 2020

The COVID-19 pandemic came to the United States in January 2020 through an international traveler. What made headline news was infection and death spreading from a nursing home in Washington state (Sacchetti and Greene 2020). By mid-March, the governor of the state where the CCRC was located began issuing executive orders. Disaster intervention descended upon the facility as the administration decided to expand state-level “lockdown” policies for AL onto the entire community. From a biomedical perspective, the key was to prevent infection and its spread, especially among older adults and other vulnerable populations. One administrator also explained that these early days of uncertainty meant they did not know how strict to be, nor how infections most likely spread. Thus, they imposed severe restrictions for 63 days until they had a better sense of how to balance between the needs of IL residents to be independent and facility efforts to reduce risk of infection. There was a large public meeting called to announce what residents came to call “lockdown,” and full implementation a few days later. Visitors were restricted to ‘essential workers’ (caregivers and dog walkers) and ‘end-of-life situations’. This meant that families were not allowed to visit. Family visits were only permitted for residents in the hospice who were dying.

Residents were no longer allowed to leave campus, with warnings issued that those who did put ‘the community and neighbors at high risk’. Memos stated that those who left and tried to return might find that ‘we may not be able to allow entry to the campus for the protection of residents living in our communities’. In other words, protection of life, especially those most vulnerable, warranted a ‘lockdown’ in which younger, healthier, and more able-bodied older residents would also ‘shelter in place’. Administrators closed all activities and activity centers and restricted use of the restaurant and coffee shop to take-out. Staff were asked to help order and deliver groceries, meals, and medicine. Residents with family nearby were allowed to pick up items at a designated ‘checkpoint’ that was otherwise closed to traffic. A checkpoint was put in place at the other entrance which required a temperature test and explanation of why a person was arriving/leaving.

Therefore, within a short timeframe, the underlying structure of a ‘total institution’ (Goffman 1961) was realized. Triggered by a virus, the underlying system of the CCRC shifted from supporting people’s desire to prolong living independently to federal and state requirements to ‘shelter in place’. Administration also sent out daily updates with any known infections, any deaths from COVID-19, health ‘tips’ such as the importance of social distancing, and words of encouragement. For example, an April update provided clarification of what ‘quarantine’ and ‘isolation’ were, explaining why residents might be required to stay in their apartment but for different reasons—the former being for those who might have been exposed to the virus, such as by leaving campus, and the latter for those who had COVID-19 symptoms and/or a positive test. This left some residents feeling relieved while others felt helpless or enraged, with anger partly being a response to feeling that they were treated ‘like children’.

At the same time, there were residents who were able to “pivot” and lean into the use of technology to connect. For example, one resident’s family organized daily phone calls from grandchildren. Churches and other social groups began providing online connections, and residents developed greater capacity to use Zoom and other meeting apps.

5.2.3. Coping with Disruption: Lockdown Reflections during Summer 2021

When interviewed during summer 2021, more than one member of staff when asked to look back on the “lockdown period” complained that the residents, in fact, initially behaved like children. Although not all residents were difficult, many took their fears and frustrations out on staff, who were scrambling to address their own fears of infection while now also engaging in public health surveillance and basic needs support. One staff member commented on how the residents seemed to accept restrictions and simply follow the rules. Some residents reported having felt very afraid of infection owing to initial uncertainties about the degree of health risks and transmission pathways. For example,

one couple explained: ‘We totally isolated ourselves. We didn’t even see any neighbors to speak of because we were just so concerned that if either one of us would get COVID.’ Another resident explained fear observed in others: ‘[There were] people that were number one petrified to come out of their apartment. There are people here who never left their apartment for those 63 days [of the lockdown]’ Another said: ‘[N]obody knew what was going on. We couldn’t touch things. We had to wipe absolutely everything off. It was something new for everybody. Nobody in the world knew what was gonna happen. So, it was fascinating, interesting, but also scary in that regard’. In interviews, people who had been afraid of infection expressed gratitude that they could shelter in place and not have to worry about anything. They were also impressed by the speed at which administration had provided vaccines on site. They valued the use of masks and social distancing. Others simply expressed that masking and social distancing were part of the rules that they willingly followed.

5.2.4. Short Term Impacts: June 2020–May 2023—Restrictions Lifted for Independent Living but Retained for Assisted Living

Although one independent living resident recalled “lockdown” as lasting a year, a facility administrator explained that they realized after the first 63 days that they could not restrict independent living residents any more than public health restrictions in the general community. Policies remained regarding quarantine for symptomatic and COVID-19-positive residents or staff, health checks for any person (staff or visitor) entering the facility, and both masking and social distancing restrictions in public spaces. In addition, most activities that had been completely suspended were only gradually reintroduced. Previous efforts to invite community members to attend were suspended, and some restrictions were placed on family member participation as well. The most enduring change was restricted access to dining. Prior to the pandemic, two restaurants had been major centers for making social connections and socializing. As happened across the hospitality industry, restrictions on use of dining were due both to public health restrictions (gradually lifted in keeping with policies under state laws in the area) and lack of staff. Ongoing staff shortages restricted in-person dining. Residents were encouraged to order take-out and free delivery was provided to their apartments. They were learning to entertain themselves at home and through small gatherings permitted between residents of specific apartment buildings and small “neighborhoods” of houses clustered around campus. Meanwhile, those living in assisted living continued to be cut off through greater surveillance and restrictions of movement into and out of the AL. Visitors were limited, subject to health checks, and required to sign in/out. One staff member described AL as a “pretty prison”. The last of the restrictions were not lifted until May 2023.

By spring 2022, when many restrictions had been lifted, people had adapted to limited activities being restricted to residents, checkpoints, on-site surveillance, mask wearing, and health (temperature check) monitoring. Others had simply left the facility for extended stays or moved out. Among those who remained, the stress and recent casualties of the pandemic at times lurked in the background of conversations, with more than one person stating that: ‘We are dropping like flies’. Although administrative records indicate there were few COVID-19 infections on site and no deaths due to COVID-19 infection, the death rate had noticeably increased without many new residents moving in. In fact, the death rate amongst residents doubled from about one a month to two on average. One resident was still especially upset to have made the difficult decision to place their spouse in AL only to have COVID-19 “lockdown” prevent contact. That spouse died before the lockdown period ended. Meanwhile, ambulances were a common albeit unpredictable presence on campus—what a resident described as ‘the little red wagon’. Due to HIPPA restrictions, residents never knew who was going or what was wrong, unless they happened to find out through personal connections. This official not-knowing also impacted COVID-19 contact tracing. In addition, when alerts of cases were issued to residents, specific details were never provided, including how many or who it was that had tested positive, which meant

that residents could not ascertain their risk of having been exposed. This contributed to perceptions of a sense of distance from the official authority of the facility as well as their sense of being treated like children.

5.2.5. Longer Term Impact

Over time, as the worst of the pandemic impact and policy restrictions lifted, residents increasingly attributed any physical or mental decline to aging rather than the impact of a disaster. The death rate settled down to pre-pandemic levels (rising again in winter 2022–23), and residents commented that many people seemed to have aged faster. There were comments of people going “downhill fast” and speculation that men were especially susceptible. In one interview, a resident said, ‘People here are slipping. I noticed it when I came back (from a long trip). People have slipped’. When asked for clarification, the respondent provided an example of a person in their building who was invited to dinner but said they could not get there alone despite this only requiring a short walk of several minutes from their residence through an attached building. The respondent was shocked by this as the person had been highly ‘independent’ pre-pandemic. Another resident, a retired professional, explained how they used to enjoy lecturing as a professor emeritus, and had been once again invited to a graduation. However, they found themselves surprised by how hard it was to accept the invitation, and how intimidating it now was to go up to the stage and participate without any railings. This resident was never observed during the study period to rely on any device to walk and always seemed ‘able-bodied’. Without a touch of regret or acrimony, this resident described current life in the CCRC as like that of a ‘bird in a gilded cage,’ explaining that this was a reference to life in foster care as another total institution.

Residents also alluded to how the pandemic affected their own perceptions of their age, with one explaining that prior to the pandemic she ‘[A]lways felt [she] was 36, but that now she did not ‘feel that way anymore’, now feeling like she was in her 60s. When asked, in response, what changed, her response was, ‘COVID, I think changed it, made it change to more my age. . . it’s very scary’. Others explained how people still continued to avoid regular, social face-to-face activities, with one saying: ‘People are anxious, you know, they don’t go to church on Sunday, they do a lot by Zoom. . . It’s a convenience to stay here (and) who wants to get COVID?’ She also then explained how concerns about infection continued to prevent resumption of normal social interactions with those in her social network. She gave an example of having to “dis-invite” two relatives from an annual visit invitation because they refused to get vaccinated. Another resident explained that she had felt her ‘world shrink’ and felt that her own needs, aspirations, and sense of self had ‘shrunk to fit in’. The issue here was that although she did not feel isolated as such, she became well-contained—actively but only pursuing her wants and needs within the social support, activities, networks and events of the community—with the effect that it had a stifling, narrowing impact on her sense of self, her world, and her place within it.

5.2.6. Silver Linings

However, this is not a monolithic story. There is also evidence of residents’ ability to “pivot” as others also adapted to pandemic conditions around the country, as well as examples of recovery and rebellion. One resident, unhappy about ‘being treated like a child’, described in an interview how some people ‘cheated and beat the system’ by inviting family and friends inside and meeting them outside restricted allowances during lockdown. Others learned that security staff did not monitor the checkpoints until 9 am each morning and would ‘sneak’ social interaction during the hours when security was absent, expressing both relief and delight in being able to rebel. Technology also helped people to stay in touch and to also form new connections, with some who had family who lived farther away being able to meet with them more via Zoom. Another was able to start attending the men’s group only once they switched to Zoom, with mobility challenges having previously prevented them from attending.

In addition to rebellion, there were residents who worked within the rules and with the administration to create social connections and thereby limit social disability. A resident-led association organized one person per “neighborhood” to call on each neighbor to check on their wellbeing. This was coupled with a staff-led “hallway holler,” in which residents were told to leave their apartments once each day to greet neighbors (while social distancing and wearing masks). These practices led to informal happy hours and potlucks organized within the designated neighborhoods. For example, residents who complained of boredom were given tasks to help staff distribute news information to residents, a practice that continues today. This helps integrate residents as part of formalized support. These practices have helped create a greater sense of community among residents and have allowed residents to promote their own independence by relieving adult children of potential care responsibilities by serving as a kind of disability or old-age insurance scheme.

5.3. Comparative Discussion of the Case Studies: Convergences and Differences in Experiencing Social Disability

5.3.1. Drivers of Social Disability

The two case studies reveal important similarities that demonstrate how social disability disaster emerges. In both communities, the combination of the risk of contagion and uncertainties resulting from the novelty of a global pandemic created an increased fear of others, which disrupted interpersonal interactions. In addition, interventions that were designed to protect human life further disrupted interpersonal formal and informal social support and community network relations that were fundamental for human wellbeing.

In the U.S. case study, we can see how intervention measures shifted relationships between residents and staff from ones where independently living residents were the dominant agents in decision making about their wellbeing, leveraging support from care and medical staff if required, to ones where staff became the authority in imposing strict public health measures and means of controlling health outcomes amongst residents. Although this was aimed at promoting their survival, in effect, this potentially threatened their survival, owing to the detrimental impact the loss of social interpersonal interactions had on their overall functioning, wellbeing, and ability to avoid ‘old age’. In the Scottish case study, we see that restrictions transformed formal and informal caring and socially supportive relationships to the extent that relationships that were once perceived as being ‘friendly’, ‘close’, and ‘familiar’ became increasingly distant and alienating.

The Scottish case study also shows the impact of inequalities in intervention measures across the wider population. Although these interventions were aimed at mitigating risk, in effect, they had an unequal, detrimental impact on the wellbeing of individuals with disabilities and the structure of the social community as a whole, transforming the social positioning of people with disabilities from one being marked by similarity with others to one more centered upon difference. Here, we also see how the centering of pandemic interventions upon individual lives was insensitive to local, long-standing cultural values about the positioning of the needs of the individual self in relation to others, thus magnifying the questions they now had about their existential relationships with others.

5.3.2. Experiences of Social Disability

Both case studies evidence how local social networks within each respective setting became inactive, that social interpersonal actions were not spontaneously restored, and that over the longer term, people’s help seeking changed to the extent that people become prone to social withdrawal. In addition, the temporality of experiencing social disability was notably similar, with social disability becoming increasingly apparent as restrictions eased. Both case studies also reveal how disruption to regular social and community interactions led to profound changes in peoples’ understandings of their self-identities. However, each case study demonstrates that the ways in which these profound changes to

identities manifested were also unique owing to specific differences in community-based and residential settings and culture.

In the Scottish case study, people experienced states of ‘becoming disabled’, ‘becoming more disabled’, or becoming ‘disabled and old’ as disruption to social interactions continued, thus evidencing disturbances to their self-identities. In this context, a social disability disaster manifested as a formerly close-knit and inclusionary community became replaced by an absence of informal social support networks and social interactions now premised upon dialectical ‘othering’ of people with disabilities on the basis of risk to ‘bodily’ survival, oftentimes regardless of whether a person’s disability actually made them more vulnerable from infection. Furthermore, we also see how important socially supportive cultural practices and values enacted through social interpersonal relations became threatened and transformed, thereby enhancing experiences of ontological insecurity, including losses of previously held senses of purpose and envisioned futures.

Similarly, the U.S. case study also evidences how the loss of social interactions contributed to residents’ feelings of loss of important self-identities. Within this residential and cultural context, these losses manifested as losses of ‘self,’ of ‘their whole lives’, as well as changes to their experiences and perceptions of aging, their envisioned futures, as well as a marked shift towards physical, bodily decline. Furthermore, this loss of life—not as in a total loss but as that loss of life ‘wholeness’ or ‘completeness’ marked by loss of energy, curious engagement, and acceptance of ‘getting old’—reveals the manifestation of social disability as a disaster from the perspective of how residents experienced it.

5.3.3. Factors Influencing the Risk of and Risks from Social Disability

The case studies reveal that those most at risk from social disability were those who were most dependent on others for social support through social interaction, and for whom the interpersonal social relations that became threatened were the most fundamental for maintaining wellbeing. The first case study reveals how those who were more socially interconnected within the wider community before the pandemic and for whom having greater levels of social interaction formed a fundamental part of their normal social routines often experienced greater senses of isolation than others because of disruption to regular social activities. Having family living nearby also appeared to compound rather than reduce the risk of isolation associated with social disability as interventions enhanced awareness of the lack of regular contact to which they were used. Living with others also apparently did not help to reduce the risk, owing to how restrictions led to increased dependency upon family members and to how whole households became increasingly self-contained. Having access to online technology did not always help to reduce feelings of distance, owing to how online communications differed from long-standing culturally specific forms of face-to-face interaction.

In the U.S. case study, having access to online technology helped mitigate social isolation for some. However, at the same time, this also increased dependency upon remote contact, which created barriers to the resumption of normal ways of interacting socially. Those in assisted living were especially isolated through restrictions placed on outside visitors and permission to leave for social visits and activities. Independent living residents were most impacted by lack of access to in-person social activities and dining, which have only been slowly re-instated, sometimes in adjusted forms due to ongoing staff shortages. Some long-time residents and staff have observed a shift from greater activity and vibrancy of residents to behaviors more characteristic of nursing home confinement and passivity.

Both case studies demonstrate that having access to wealth may do little to reduce social disability, and suggest that income level does not necessarily mitigate risk of social disability. The U.S. study indicates a possible gender-based dynamic in terms of the impact of social disability as participants reported perceived greater levels of age-related decline in men. While no evidence of variation in extent of impact could be derived from the Scottish case study, participant responses revealed subtle gender-based divergences in self-perceptions relating to inability to be able to offset social disability owing to fear

of infection, with men being more likely to feel ashamed at being afraid of infection and women being more likely to self-shame for prioritizing their own needs.

The evidence presented in the first case study shows that being of younger age did not ultimately help to offset social disability. However, in older participants, social disability was more likely to manifest as increased awareness of age and physical vulnerability in addition to heightened awareness of disability, whereas younger participants were more likely to experience greater awareness of 'being disabled' and of 'being different to others'. In the second case study with its older population sample, social disability manifested in actual, physical age-related decline in addition to concern.

5.3.4. Resisting and Offsetting Social Disability

Both case studies provide important insights into how the risk of social disability disaster may be reduced, recovered from, or avoided. In both case studies, we can see engaging in rule-breaking activities provided an important way for people to maintain their agency, their enjoyment of life, and to be able to display their creative adaptational skills to work within their own system of cultural values and norms. In the Scottish case study, we can see this via the so-called 'tunnelling' and 'backdoor' systems and in the ways in which people balanced the perceived risks of infection against the risks from isolation for their wellbeing and the wellbeing of others in ways they deemed 'appropriate'. In the U.S. case study, we see how rebellion via rule-breaking provided an important means of maintaining residents' agency and sense of independence, as well as of expressing creative adaptational skills in a similar way to how this was also demonstrated by others who worked 'within the rules' to devise new ways to maintain social interaction. We also find in the U.S. example that residents reached out to formal care systems to request and develop informal care that had not been present previously, and which provided a way to lessen the risk of social disability.

6. Conclusions and Recommendations

Relational approaches to understanding disability and aging assert that becoming disabled is an emergent state of being which results from a complex interplay of biological and societal factors and social and culturally mediated interactions between people and environments (Hall and Wilton 2017). The COVID-19 pandemic—as an example of a social disability disaster—resulted from a combination of the risk of contagion, uncertainties resulting from the novelty of a global pandemic, and interventions that were designed to protect life having a detrimental impact on important social interrelationships fundamental for human wellbeing. Therefore, in similar ways to how interrelating factors and forces combine to produce an individual's experience of 'becoming' a 'disabled person' at the individual level, social disability disasters can also be seen to result from the interplay of multiple interrelating factors impacting at the community level, which, ultimately, creates conditions that are 'socially disabling'.

6.1. Learning Lessons from Social Disability Disaster

Our study adds to existing critiques of dominant, Western expert-led models of disaster risk reduction by showing how top-down interventions risk stifling the agency and creativity of people to successfully leverage sources of social support to overcome challenges, including for people with disabilities (Connon and Hall 2021; Ton et al. 2019), who were not passive in their efforts to try to prevent and recover from social disability disaster. Our study reveals how large-scale interventions can be especially socially destructive when they suppress local, social ways of coping and/or when not culturally sensitive or attuned to the specific needs of particular community groups. We also evidence how the 'self/other' relational construction that top-down expert-led disaster response interventions and relief systems are premised upon cannot be fully sustained within the context of global scale disasters, as the scale of the pandemic meant that the 'self' could not be located outside the disaster, separate from its impacts and threats, with those providing and receiving support

becoming both part of the threat and part of the measures of control and containment. When external systems of authority became ‘total’ in scope, social disability disaster took hold. In the Scottish example, as ‘totalizing’ interventions were relaxed to become ‘less totalizing’ for some more than others, with those continuing to face restrictions taking longer to recover than others. Therefore, where interventions involve prioritizing individual, bodily survival rather than ensuring that important social needs are met, care needs to be taken to avoid inadvertently creating a social disability disaster. As many who lived through 2020 to the present have commented, there is no ‘going back to normal’. Instead, the ‘new normal’ requires finding balance between risk mitigation and living one’s full life—including living in social relational networks with others. Social disability disaster can be argued to result from failure to find that balance.

6.2. Recommendations for Preventing Social Disability Disasters

Evidence of the ‘successes’ of minor acts of rebellion for recovery and offsetting social disability reveals important considerations about how the risk of social disability disaster may be reduced. This provides important insights into how the risk of social disability disaster may be reduced or avoided altogether by allowing space for communities to work to devise their own solutions that align with their preferences, aims, and senses of self, as well as their need for maintaining social interaction to prevent ‘decline’.

One solution would be to anticipate and not blame individuals for minor level rebellion and rule breaking. Therefore, instead of having zero tolerance for such infractions, these should be regarded like architecture with ‘give’ in the structure to help withstand challenging events and to allow the freedom for creative solutions to be developed to prevent social disability from taking hold or to aid recovery.

We also find in the U.S. example that residents reached out to formal care systems to request and develop informal care that had not been present previously, and which provided a way to lessen the risk of social disability. Therefore, in the event of a future pandemic, one way of balancing the risk to individuals’ health against the need for social interaction to ‘sustain life’ would be to encourage people to work within the rules to devise new systems of social interaction that help reduce anxieties associated with the ‘threat’ of infection from engaging in rule-breaking activities.

Another suggestion for improving national-scale interventions would be to devise ways to ensure responses work within local social systems, including locally formalized systems (e.g., the ‘friendly visitors’ or ‘local authority care service providers’) as well as informal systems of social interaction and social support practices (e.g., ‘gossip’ networks). This also brings important suggestions for disaster risk reduction more generally, particularly as disaster compression intensifies. When helping others, interventions should consider the ‘other’ as not only an individual, bodily self but also a social self and a human self. As part of one’s human self, there is need to express individual autonomy, agency, and choice. And, in cultures where the self is not solely individual and might be primarily social, the imposition of conditions that are isolating could sever these social selves, putting them at greater risk of social disability.

Best practice in disaster intervention can therefore include learning local cultures and creating local connections, which should be undertaken on an ongoing basis because local systems must also keep adapting amidst increasing disaster compression. Best practice should shift from putting total responsibility on institutions and formal governance systems to deliver interventions towards more ‘people centric’ systems (Scolobig et al. 2015), characterized by greater collective responsibility or ‘shared governance’ (Monteil et al. 2022). Based on our research, this could include, for example, working with residents in the first study community who already accustomed to delivering social support to others amidst emergency situations to leverage these supportive networks and informal ‘gossip’ networks in the event of novel emergencies posing additional uncertainties as well as to deliver important public health communications about risks in ways more attuned to local cultural values. In the second study community, for whom retaining independence is

important, this could include co-devising supportive communities of care to prevent social disability.

6.3. Suggestions for Further Research

As disaster compression intensifies, it is important to understand how experiences of social disability disaster, in turn, may also affect responses to other crises that occur simultaneously or shortly thereafter, when recovery from the initial disaster is not yet complete. Future study could involve examining the impacts of a social disability disaster upon future abilities to withstand the impacts of other disasters, including disasters associated with anthropogenic climate change, such as floods or hurricanes.

With the globality of the pandemic, the world has become something of a ‘living laboratory’ and other options might include looking at data and interventions from other countries with the aim of developing more social disability disaster-resistant forms of interventions that find a more optimal balance between risk mitigation and living one’s life. One option would be to compare the infection and death rate in Sweden, New Zealand, Pakistan, and the United States—which, by necessity and by design (through decisions of leaders and governments) took different approaches regarding public health precautions and social interaction restrictions. Among wealthy countries, Sweden was at one end of balancing social needs and individual agency through its balancing of interpersonal choice of social interaction and otherwise keeping local communities ‘open’. New Zealand was at the other end, where it was possible due to geography and population size to enforce a national ‘lockdown’. The UK and USA were somewhere in between. These countries can also be compared with those where large-scale public health restrictions were more difficult to impose, where access to vaccines was lower, and in which cultural constructions of the self as also social meant that people did not experience the social isolation found in our study.

Another option would be to consider how new approaches and methods for conducting research with more technologically excluded populations, such as older people and people with disabilities, may be devised in anticipation of future pandemics or widespread disruptions, such as by enhancing opportunities for citizen science engagement for members of these communities to participate in the research process (Tan et al. 2022). This could help enhance research by helping to capture peoples’ experiences of events as they unfold rather than retrospectively, which could help to inform the development of interventions at an earlier stage to help reduce iatrogenic effects. This would also help to enhance inclusion of marginalized groups in research and reduce uneven power dynamics between the researchers and research subjects.

Our study is limited in that the case studies from which our theory derives were located in communities within the Western hemisphere. Therefore, future research could explore experiences of the pandemic in communities living in different social, cultural, economic, and environmental circumstances in other parts of the world and compare the findings that emerge.

Furthermore, while the aims of qualitative studies based on small population samples such as this study are not undertaken with generalization in mind, the demographic homogeneity of the population samples in both case study sites is a study limitation that calls for future study to explore experiences of the pandemic within other U.S. and UK communities that have greater ethnic diversity. This becomes especially for important given that evidence in both the UK and USA suggests that different ethnic minority groups may have different, culturally specific ways of interacting socially (Williams et al. 2023; Gauthier et al. 2021), which may result in different experiences of social disability and necessitate different forms of intervention to offset risk. Further study could therefore aim to ensure that future disaster interventions are ethnically inclusive in addition to ability inclusive.

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