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research article

The politics of navigating complaint: asylum seekers and disabled people challenging care deficits in Ireland

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This article explores the dynamics and consequences of vocalising care deficits within neoliberal care configurations in Ireland. We illuminate how asylum seekers living within congregated settings of the international protection system articulated and challenged systemic care injustices during COVID-19, often defying threats of retaliation. We also foreground disabled people's decision making around vocalising care deficits in support services, negotiating fears about the loss of service or erosion of interpersonal support relationships. Connecting both groups, we reveal how those who speak out can be marginalised or left to absorb institutional care failings and highlight the importance of collective activism in challenging care abuses.

Keywords care deficits • complaint • asylum seekers • disabled people

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Introduction

Over the past 30 years, feminist care ethics scholars have theorised what good care might look like through the development of a relational ontology that stresses our interdependency (Toronto, 1993; 2013; Held, 2006; Barnes et al, 2015). While offering a potentially transformative agenda that recognises care as a personal and political

endeavour, there remains a need to ‘trouble care’ (Raghuram, 2016: 515) by raising questions about the way in which ‘caring and *noncaring*, or *uncaring*, relations coexist and intersect’ (Bartos, 2019: 769, emphases in original; see also Robinson, 2011; Barnes et al, 2015; Bartos, 2018; Sihto and Vasara, 2023). Indeed, care often involves conflict and tension, which requires us to pay attention not only to moral sensibilities but also to the specificities of personal, institutional and political care practices (Tronto, 1993). There remains a need to excavate the power dynamics and inequities that shape care relations and consider how we can vocalise and resist the practices and politics of ‘*uncare*’ and ‘*noncare*’ (Bartos, 2019).

In this article, we consider care relations as conflict by asking how those who are positioned as receivers of state-funded care respond to instances of care deficit, and with what effect. In multiple jurisdictions, there has been a long history of institutional abuse, oppression and state violence enacted in the name of care (see, for example, Bartos, 2019; Dowler and Christian, 2019). In today’s mixed economies of welfare, voice or participation may be recognised or invited, but it is often circumscribed through a consumer orientation, evident in such constructs as patient satisfaction or notions of service user choice (Barnes, 1999; Yeandle et al, 2012; Bradby et al, 2020). These categories, however, fail to capture the everyday dilemmas and emotional labour involved in deciding whether and how to speak up in the face of care failings (Aronson, 2006).

Developing these debates, this article explores the dynamics of vocalising experiences of care deficits in the context of neoliberal care infrastructures in Ireland. Drawing from a wider qualitative study exploring how we might re-envision care relations in Ireland following the COVID-19 pandemic (Edwards et al, 2023), our analysis focuses on the experiences of two groups accessing different forms of care: asylum seekers living in congregated settings of the Irish state system for international protection accommodation, known as Direct Provision, and disabled people living in community settings. Recognising that care relations are always situated (Raghuram, 2016), we reveal how different institutional contexts shape participants’ experiences in terms of navigating perceived and actual fears about the consequences of speaking out. While the negative effects of voicing instances of poor care are very evident, participants’ narratives also highlight the potential for forms of solidarity and collective activism that challenge the absences and violences of state-funded care. Our research, therefore, asks how we might foreground the voices of those receiving care and build solidarities across diverse groups as a way of challenging the power relations that create ‘careless’ welfare regimes.

Vocalising care deficits and failings

In recent years, the effects of increasingly commodified neoliberal welfare systems in generating care failings and absences have become a focus of analysis (Barnes, 2011; Barnes et al, 2015; Farris and Marchetti, 2017; Woods et al, 2017; Lynch, 2022). While we should be wary of totalising narratives that ignore the situated contexts of different (national and local) care relations (Raghuram, 2016), these effects have been shown to be multiple and stark. They include: a lack of services and the deterioration of service quality as states ration public spending and for-profit providers seek to reduce costs in order to make care pay (Aronson, 2006; Woods et al, 2017); a lack of accountability for care deficits in a context where a complex landscape of multiple actors and providers (the state, private care providers, voluntary and non-governmental providers, and

regulatory bodies) creates a fragmented and faceless care system (Woods et al, 2017); a growing emphasis on individuals to take responsibility for their own care in the face of state withdrawal from provision or when the care market fails (Macpherson et al, 2023); and an erosion in the quality of interpersonal care relationships as those engaged in care work find themselves devalued and underpaid by a system that exploits their labour (Lanoix, 2009).

A key concern of this article is what happens to voice within contemporary (neoliberal) care regimes and how those on the receiving end of state-funded care can vocalise care deficits and failings. While notions of voice and choice have been core to the health and social care strategies of many nations in the Global North (Yeandle et al, 2012), important questions remain about whose voices get heard and in what spaces (Barnes, 2008; Barnes et al, 2015). Embedded in notions of the citizen as consumer, voice is often only invited through institutionally determined spaces of policy involvement or constructs of service user (dis)satisfaction and complaint (Aronson, 2006; Grootegoed et al, 2013; Bradby et al, 2020). However, poor care experiences ‘do not necessarily or usually translate into the explicit expression of dissatisfaction’ (Bradby et al, 2020: 741), and most people do not enter formal complaint systems or seek redress (Allsop and Jones, 2007; Gulland, 2011). In many cases, negative experiences of care remain unsaid or unheard, despite the distressing and sustained impacts that they have on people’s everyday lives.

To address this lacuna, we focus on uncovering informal expressions of *noncare* and *uncare* (Bartos, 2019), which often exceed formal spaces and/or categories of complaint. We do so by drawing on disabled people’s and asylum seekers’ narratives of negative care and their dilemmas about whether to articulate these more publicly within Ireland’s welfare regime. Following Grootegoed et al (2013), we suggest that this negotiation is a form of emotional labour that is often rendered invisible and yet forms an ongoing part of many care users’ navigation of contemporary welfare systems (see also Tonkens et al, 2013). Studies that explore why disabled people and older people do not complain in the face of care deficits highlight feelings of fear (that their service will be stopped or reduced, that they may be moved from home into institutionalised care, or that their care workers may be targeted for criticism), hopelessness (that there is no point in complaining), shame (of being seen as too needy) and, indeed, stoicism (not wanting to be seen as a troublemaker and ‘putting up’ with poor care) (Aronson, 2006; Grootegoed et al, 2013). All of these can act as obstacles to articulating poor care experiences.

Crucially, these studies illuminate how expressions of emotion and feeling must be read through the lens of broader structural and discursive changes that feed into particular care subjectivities and identities (Aronson, 2006). Groups such as disabled people, older people and asylum seekers have frequently been perceived as vulnerable and voiceless within care systems, yet they are very aware of societal perceptions about them, including their competence to speak out (Jingree and Finlay, 2013). Within a context of state narratives about welfare retrenchment, the management of one’s self-identity and emotions becomes ever more important as people seek to manage their (affective) responses within extant norms about how they should feel (Tonkens et al, 2013). For Aronson (2006: 537), the consequences of this, such as the pressure to be stoic, amount to a form of self-silencing that is ‘generated when structural forces penetrate subjectivity and narrow people’s sense of identity, entitlement, and possibility’.

Important questions exist, therefore, about what to do with these informal and yet often devastating accounts of poor care and how privately expressed emotions might be placed into the public sphere as forms of resistance. For [Grootegoed et al \(2013: 483\)](#), the transition to vocalising formally sometimes happens when individuals (with support from others) reconfigure situations of deficit or dissatisfaction through a legitimising form of anger rather than a lens of shame. Their analysis not only highlights the significance of engaging diverse emotional registers in raising concerns (see also [Barnes, 2008](#)) but also the importance of networks and relations of solidarity as central to forms of resistance. This solidarity – or what [Tronto \(2013\)](#) refers to as ‘caring with’ – may come through peers, solidarity groups, advocacy networks or, indeed, friends and family; however, we suggest that it has a crucial role to play in challenging the silencing that can occur in the face of care abuses and deficits. We therefore need to remain attentive to the complex interrelationships and contexts that shape people’s care networks and identify opportunities for collective activism that expose and resist the embedded power dynamics that underpin care injustices.

Contextualising care deficits in Ireland: situating asylum seekers and disabled people

The Irish state has a long history of enacting care failings and deficits ([Edwards et al, 2023; Loughnane and Edwards, 2023](#)). Shaped by Catholic principles, care in Ireland was historically positioned as the preserve of the (patriarchal) family and religious organisations ([Dukelow and Considine, 2017; Mercille and O’Neill, 2021; Cullen, 2024](#)), with institutionalisation a key feature of Ireland’s welfare provision for much of the 20th century. However, as numerous inquiries have exposed, these purported spaces of care were punitive sites where neglect and abuse against children, women and disabled people were commonplace ([Ferguson, 2007; O’Rourke, 2021](#)).

The shame of institutional abuse continues to stalk contemporary Irish care systems, which have witnessed the diminishing role of charitable religious orders in the provision of services and, for some groups, a move away from institutionalisation ([Mercille and O’Neill, 2021](#)). Ireland now operates with a mixed economy of welfare in which a continuing reliance on unpaid family care is coupled with the increasing dominance of for-profit care providers contracted by the state ([Mercille and O’Neill, 2021; Cullen, 2024](#)). Within home care, for example, government outsourcing, competitive tendering and tax allowances have created a system that is ‘largely unregulated, fragmented, and uneven in quality’ and in which there is no entitlement or statutory right to support ([Mercille and O’Neill, 2021: 608](#)). This leads to opacity for those on the receiving end of care and a struggle to gain access to services ([Carroll and McCoy, 2022](#)). Within this climate, we know relatively little about whether and how those who receive care services vocalise concerns and complaint, and with what consequences. A recent study of personal assistance services for disabled people, however, provides some clues; it pointedly states that ‘Putting in place channels for service users to provide feedback and report problems without fear of retaliation is ... vital in ensuring that services are performing as they are intended to’ ([Carroll and McCoy, 2022: 712](#)).

In this article, we specifically focus on the experiences of disabled people and asylum seekers within contemporary Irish care infrastructures. At first glance, these two groups may seem disparate and contested in terms of their relationship to the concept of care.

For example, many disabled people concerned with rights and independent living actively reject the term ‘care’ (Hughes et al, 2005), while the international protection system is rarely conceived of in terms of care policy. However, commentators have sought to bring understandings of care informed by feminist care ethics into conversation with disability rights (McLaughlin, 2020) and, indeed, humanitarian responses to asylum seekers and refugees (Fritzsche, 2024). Foregrounding expansive conceptualisations of care that stress the interdependency and relationality of human (and non-human) life, such analyses critique the individualising imperative at the heart of neoliberal state responses to care that prioritise autonomy and ‘self-sufficiency’ over ‘collectivity, interconnection, safety and belonging’ (Fritzsche, 2024: 1). Echoing these analyses, our focus on disabled people and asylum seekers is a purposive choice not only to expose and challenge narrow policy and service-driven conventions of what care is and who should receive it but also to explore groups for whom the concept remains unsettled.

Notwithstanding their different positionings within Ireland’s welfare regime, we suggest that there are intersections and commonalities between disabled people and asylum seekers that have the potential to reveal complex dynamics of voice and silencing. For example, both groups have been subject to institutionalisation and oppressive relations at the hands of the Irish state and continue to struggle to gain basic rights to services. The state’s response to asylum seekers and disabled people also bears hallmarks of Ireland’s growing neoliberalisation of care in the context of both Direct Provision and disability services and has been criticised for a lack of adequate complaints procedures (Carroll and McCoy, 2022; Hewson, 2022).

For the purposes of this article, the specific policy and service contexts that shape asylum seekers’ and disabled people’s lives in Ireland require explanation. Ireland’s measures to accommodate asylum seekers are enacted by the system of Direct Provision, which, in an echo of the state’s institutional past, entails asylum seekers living in congregated centres, including repurposed hotels, convents and other settings (Murphy, 2021; Hewson, 2022; Daly and O’Riordan, 2024). Reflecting Ireland’s wider trend towards privatisation in welfare systems, Direct Provision is a ‘highly commercialized system of institutionalised living’ (Murphy, 2021: 1), in which the state outsources accommodation provision, largely to private entities, via the International Protection Accommodation Service (IPAS).

Within Direct Provision, residents are provided with meals, accommodation, a weekly allowance and entitlement to a medical card but are ineligible for other welfare entitlements and must wait six months until they can seek employment. Living within strictly controlled conditions in which they may be relocated at any time, where their movements are under surveillance and mealtimes are prescribed and/or cooking facilities are limited, Direct Provision centres have been described as dehumanising, carceral spaces, in which overcrowding is common and there is little place for privacy (Hewson, 2022; Daly and O’Riordan, 2024). Despite constant criticism of the system spearheaded by a growing lobby of migrant rights organisations and the tabling of a government white paper in 2021 to end Direct Provision, what was initially established as a temporary system in 2000 stubbornly persists.

Disabled people have also been involved in complex care relations, albeit in a different context. Reflecting the influence of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and growing disability activism within the state, Irish government policy is increasingly centred around a rights rhetoric,

with processes of deinstitutionalisation seeking to support disabled people to live in the community. Ireland has trialled individualised budgets to enable disabled people to employ a personal assistant to support them to live independently (Barnes, 2011), but many disabled people remain reliant on more traditional home-care services, in which a care worker rather than a personal assistant supports them. Moreover, in a context where the funding of disability services constitutes only a fraction of overall health spending (Carroll and McCoy, 2022), disabled people continue to live with insufficient support hours due to a rationing of public funding and a postcode lottery in terms of services (Loughnane and Edwards, 2024). Calls for greater government resourcing have therefore been central to activist campaigns spearheaded by disabled persons' organisations,¹ while studies also point to the need for greater clarity about how to access services and complaints systems that do not penalise people for vocalising concerns (Carroll and McCoy, 2022). Such recommendations speak to the fraught dynamics experienced by disabled people in negotiating Irish care systems.

Methods

The material presented in this article is drawn from a three-year qualitative, participatory project that sought to explore and re-envision care relations in Ireland following the COVID-19 pandemic. The core element involved work with disabled people and asylum seekers to understand and explore meanings and understandings of care, their care networks and experiences (particularly during COVID-19), and how we might envision better care (Edwards et al, 2023). The two strands involved a suite of different methods (for a detailed discussion, see O'Riordan et al, 2023), but both included in-depth interviews. For asylum seekers, we spoke to individuals currently and previously living in Direct Provision about their experiences of care during and after COVID-19 (ten in total). We also spoke to nine disabled people about their experiences during and after COVID-19, all of whom were living with mobility and sensory impairments in the community and were members of a disabled persons' organisation. Participants had different living arrangements: all were living in their own homes, some alone and others with family members (parents, partners, children or siblings). Members of the group either received a personal assistance service or support from care workers. All fieldwork took place between March 2022 and June 2023. Analysis of data for both strands employed a thematic approach (Clarke and Braun, 2017), coding transcripts and field notes to identify key themes. Ethical approval for the research was granted by the University College Cork Social Research Ethics Committee.

In presenting participants' experiences here, we are extremely cognisant of the sensitivities and risks that exist for participants in narrating accounts of poor care and complaint. Following consideration of the challenges of anonymity within research on sensitive topics (Wiles et al, 2008) and reflection on our responsibilities as feminist researchers (O'Riordan et al, 2023), the research team decided not to engage in any identification of individual participants where they are quoted for fear of their identity being exposed. Broadly specified, the sample of disabled people included people with mobility and sensory impairments, aged between 20 and 70, who were living in the community in different parts of the country, and included a mix of men and women. The sample of asylum seekers included a mix of men and women who were currently living or had previously lived in different Direct Provision centres in

Ireland and who were predominantly from sub-Saharan Africa. Some participants also had their children living with them in the centres. While we recognise that not providing further details about participants may temper some of the rich context and nuance of their situations, we felt that it was a necessary compromise, particularly given the relatively small population of Ireland, where individuals and communities can be easily identifiable. In the next section, we explore their accounts and experiences of *uncare* and complaint.

Asylum seekers and disabled people negotiating concern and complaint

In the sections that follow, we explore disabled people's and asylum seekers' accounts of their dilemmas surrounding whether and how to vocalise experiences of poor care and what happens when they do so. In our analysis, it became apparent that these dilemmas are shaped by and are affective responses to the particular ways in which neoliberal imperatives shape the state's treatment of both groups' care needs (Tonkens et al, 2013). While on the surface, the configuration and delivery of care may appear very different, the two contexts of Direct Provision and disability service provision bear common imprints of neoliberal processes and effects. We define these as: an increased marketisation and rationalisation of care built around concerns for cost-saving and efficiency; a complex and often opaque configuration of agencies and actors involved in the delivery and management of care; and the promulgation of an ideal, self-responsible care recipient who does not transgress the boundaries of the good care citizen.

We use these three themes as organising devices to explore disabled people's and asylum seekers' experiences of *uncare* and complaint. Thus, we first contextualise complaint by exploring participants' accounts of care deficits within the state's current 'debilitated landscape of care' (Macpherson et al, 2023: 140). In the second section, we explore how the opacity of fragmented care systems shapes participants' responses to *uncare* and decisions about how and whether to vocalise concerns. Finally, we consider how participants' decisions about (not) speaking out are intertwined with negotiations regarding their subjectivities as care recipients, particularly regarding how they are perceived and positioned by key actors within the care system. As part of this, we also explore the potential for solidaristic relations to reconfigure concern and complaint away from an individual and individualising practice to a collective endeavour and mode of expression.

'You're left on your own to do the best you can ...': contextualising complaint within the carelessness of Ireland's neoliberal welfare regime

Over successive years, services for disabled people and asylum seekers in Ireland have been subject to increased public resource constraint, as the state has sought cost-efficiency through processes of rationalisation and increased privatisation (Cullen, 2024). For many participants, these processes undergird their experiences of *noncare* and *uncare* (Bartos, 2019). Asylum seekers described the poor care that they received while living in Direct Provision, where standards of accommodation and food operated at a bare minimum. As one participant said: 'The management, I think to

be honest, were basically worried about you eating and as far as, you know, you being fed. I don't think they actually gave more than that.' Studies within Ireland have long identified the negative effects of living in Direct Provision on asylum seekers' mental health (Daly and O'Riordan, 2024), and this system became even more dysfunctional during COVID-19. Participants described living in overcrowded conditions, with no way to isolate, and little hygiene provision: 'We didn't have PPE [personal protective equipment], there was no supply, and we were still congested in the room, four in a room'. Reflecting the system of Direct Provision in which centres largely operate as privately owned, for-profit enterprises, asylum seekers reported how some centre managers would only allow hot water and heating at certain times of the day and provide poor-quality food to 'save costs for the owner'. Another participant described how their inability to maintain hygiene in a privately owned Direct Provision centre was compromised:

You're left on your own to do the best you can to keep yourself safe ... and in the process be humiliated.... I had an incident where I was asking for a toilet cleaner and some toilet paper, and the security guard ... said to me, 'You people are beggars!'.

Fear of being humiliated and subject to degrading attitudes was commonplace among participants' narratives – 'We get humiliation from everybody, just because you're seeking asylum' – and were perpetually reinforced by the everyday regimes of surveillance and routine of Direct Provision (O'Reilly, 2018).

Disabled people also articulated their ongoing battles to obtain care and their concerns about care quality, particularly in relation to interactions with care workers or personal assistants. Regarding the former, participants recounted the increased rationing and growing unreliability of service provision, which had only been exacerbated by COVID-19; indeed, the pandemic was described by one person 'as an excuse for bad behaviour' by the health service. One participant described how, 20 years ago, they had home help and then a personal assistant. Now, they are 'lucky if I can get to bed, get up.... I get so little now, but what I get is so insecure.' They often find themselves contacted by care administrators at the last minute on Fridays to say they have no one available for the weekend and, on occasions, have stayed in their wheelchairs overnight without eating or drinking as they cannot use the toilet alone.

Another disabled person described the vagaries of a care system that places arbitrary boundaries around who is (in)eligible for support. Receiving only minimal support hours, they noted how their allocated time enabled the care worker to do some basic tasks, for example, sweep the floors or change the bed, but 'it does not give her enough time to ask me how I am or to have a chat, or I can ask her how is *she* or whatever, and she is clocked in and clocked out', thereby diminishing the quality of the interpersonal support relationship (Lanoix, 2009). The same individual also described how the arbitrary age cut-off of 65 for access to personal assistance services in Ireland meant that their access to independent living had been curtailed: 'I don't fit the criteria – this is the language they use.... I'm just old and I don't fit the criteria.... Which is a living nightmare.' Some disabled people also highlighted negative care experiences in interpersonal support relations. This included being dismissed and 'talked over' by care workers, particularly when they were 'on the clock' and in a hurry to get their home visit done. Others feared upsetting care workers

while in their home: one individual, for example, discussed not wanting to leave out extra dirty crockery for their care worker after a friend had visited for fear that they might get angry. For both disabled people and asylum seekers, then, experiences like these led to expressed feelings of fear and anxiety, as well as anger and frustration at the carelessness of the service configurations they found themselves situated within.

'There's nowhere, right, to go with anything': negotiating complaint within the opacity of fragmented care systems

A key issue emerging from Ireland's increasingly mixed economy of welfare is the question of accountability and transparency when issues of care deficit come to light. Both disabled people and asylum seekers articulated that there was often no clear space or mechanism to raise concerns about poor care, which in some cases mitigated against individuals vocalising at all. As one disabled person stated in the case of for-profit home care agencies, 'There is no complaint procedure, you know.' Another concurred: 'There's nowhere, right, to go with anything. There's nowhere direct.' Part of the difficulty in complaining comes from an opaqueness about service availability and entitlement in a context where Ireland's postcode lottery and history of clientelism lead to a discernible inequity in what people receive (Edwards et al, 2023).

The lack of clarity about how or who to raise concerns with was also linked by disabled people to the difficulties of navigating labyrinthine administrative systems and of trying to find that 'one good person' in the Health Service Executive (HSE [the Irish national health service]) who could assist. The fragmented care system, which involves multiple actors – individual care workers, their supervisors, managers of private home-care agencies and the health service to whom they are contracted – represents a challenge to raising concerns. Despite having a good relationship with their HSE case manager, one disabled person described the 'Chinese whispers' that happen when concerns they might raise initially with their care worker pass along an administrative hierarchy, leading to 'very, very strained relationships' in which 'nothing gets dealt with'. These concerns can also become politicised within the care system:

'When something needs to be looked at or dealt with, instead of going and looking at the thing to be dealt with, it becomes an issue. And if there's an issue ... they try to put it into the complaints category. So, then you're supposed to go through a process. But in the meantime, if you have an issue with the carer ... it becomes a complaint and the person is removed from your house. So, then you're left without care.

In this way, systems seek to turn informal concerns into fixed categories of complaint, which may be at odds with the wishes of the individual. Indeed, some participants felt that 'putting in a complaint isn't safe, for one thing. And secondly, it takes so long.' Others had attempted to raise concerns about their diminishing care provision in the past, but based on this experience, expressed a resignation and futility about doing so, as nothing changed for them. One participant described how, in their 'fight' to obtain services, they had 'written to everybody and ... they just pass the buck'. To that end, they chose to stoically 'put up' with inadequate services (Aronson, 2006).

Albeit very different to the fragmented landscape of disability services, Direct Provision also operates through a complex network of actors and agencies, which includes a centre manager and centre owner, who is contracted by IPAS. Articulating the pivotal influence of centre managers, [Hewson \(2022: 681–2\)](#) suggests that ‘whether strict or relaxed, residents and their conduct are dependent on the whims of management’. While centre managers were often the first port of call for raising concerns, participants described being ignored and sometimes threatened for vocalising concerns. One individual described a situation during COVID-19 where they approached management about changing the rules around mealtimes because they recognised that eating together contravened public health guidelines:

So, we went to him, like, ‘OK, manager, we need to talk to you.... Let’s have some discussion.’ He said, ‘No.... If you have anything to tell, you come individually and tell me all those things.’ So, I went in and told him that this is just the situation and all those things. So, he said ‘No, that’s not going to happen. You can’t take food, your meal [into your room]. You cannot do this, cannot do that.’

Frustrated with the ‘stonewalling’ and failure to address their concerns locally, others described writing to IPAS to seek action about different concerns. However, the response was often silence, as one participant noted: ‘No, IPAS is really uncaring. They can give you the number of IPAS. You will try. You will try. They won’t. They won’t [respond].’ One participant who contacted IPAS about the lack of COVID-19 protection protocols explained that it was a futile exercise that could lead to potential retaliation from centre management:

We complained, we wrote IPAS. They replied, ‘We will look into that; we will get back to you’.... And they will not do anything. And the manager will come to you ... ‘You guys are complaining to IPAS. There’s nothing you can do. If you complain, they will get back to me.’

The perceived hierarchical, closed loop of surveillance and repression in Direct Provision, in which different actors would utilise threats of reporting to others, for example, centre managers reporting to IPAS, can be seen as a way of silencing residents and stymying complaint. As in the case of disabled people, others felt that complaining was a futile exercise, which would lead nowhere. To that end, many disabled people and asylum seekers we spoke to approached vocalising concerns with ambivalence and caution, as we go on to demonstrate.

‘That’s the fear that’s instilled in us’: dilemmas around transgressing the boundaries of the responsible care citizen

It is evident from both asylum seekers and disabled people that they are very well aware of the dilemmas about how they are perceived by key actors and institutions if they vocalise concerns about poor care. As [Fritzsche \(2024\)](#) notes, neoliberal systems are premised on the self-responsible, active citizen, for whom being deemed worthy or deserving of care is intertwined with norms and expectations about how one

should behave or feel. Transgressing these norms was recognised by both groups as coming with not only significant risks in terms of their own identity but also wider ramifications in terms of service provision. Several disabled people engaged in a process of 'self-silencing' (Aronson, 2006) driven not only by a sense of futility that their concerns would be addressed but also, crucially, by fear about being perceived as a troublemaker. For example, one person described how they managed their self-identity in the face of service providers after being made to seem difficult: 'It's a small world around here. Your reputation can change. [As a result,] you don't deal with things, you just put up with them.' Similarly, another individual recounted: 'I think if you're vocal a lot of the time with a disability, you're seen as a moan because many, many times, disabled people don't speak up. And if you do, it's like, "Oh, there's your one, like"'. Another linked the act of speaking up to particular affective capacities: 'If you have the energy, and you have the personality of somebody that will just not take no for an answer and literally harass and harangue on a daily basis, you might get somewhere.... But I don't have that kind of personality. I just internalise it and keep away.'

Disabled people, then, described living in fear of the consequences of raising complaints: from being constructed as troublemakers, to potential acts of retaliation by care workers or managers, to the threat (or actual consequence) of service withdrawal. The spectre of institutional care in particular loomed large; as one person noted, the expectation is that as a disabled person, 'you're required to go to a day centre' or, worse, a nursing home. As such, perceived sanctions, such as the removal of care or a move to institutional care, frequently restricted individual attempts to address experiences of care failings in the community.

Themes of the fear and futility of speaking out and the consequences of doing so were also prominent among asylum seekers' narratives. As one participant said: 'I think as an asylum seeker, you get to that point whereby you just accept anything.... You don't challenge anything because you know when you do challenge, you are not even given an option.' Participants were acutely aware of the politics and risk that surround relations with Direct Provision centre management; as one person said: 'People will be afraid, threatened by managers or management, like that your case will be affected.... Or, they would promise some people, 'If you speak good about us, we're going to help you'. Actually, they didn't help anything.' It is heavily implied that speaking out could impact the International Protection Office's review of an application and inform the decision to either confer or deny residency status, referred to as 'papers'. As one resident stated: 'That's the fear that's instilled in us. If you say a word, you're not getting your papers.' While it is clear that many asylum seekers feared getting into trouble, some others who did complain were able to (re)construct this subjectivity of 'troublemaker' in the context of human dignity and morality. As one person who was involved in a protest at a Direct Provision centre described: 'But if you're fighting for what's right, you're not going to get into trouble.... You get into trouble if you're a troublemaker, you're just making a noise for nothing. But this was different.'

As with disabled people, it is apparent that perceived fears about vocalising are very well founded in actual experience. Illuminating how other arms of the state could be weaponised to censure asylum seekers in speaking out, one participant described how a centre owner falsely alleged that they had abused their child and reported them to Ireland's child protection agency; after a visit from the agency, the allegations were

found to be baseless. As they said, ‘Yeah, the way they went after me ... because they saw I was the only one who stood up.’ We spoke to other asylum seekers who defied threats from management by engaging in acts of resistance and protest. One of these incidents was a hunger strike, which precipitated a visit to a centre from the Gardaí (police), as tensions between management and residents escalated. The visit of the Gardaí was not only described as re-traumatising for residents but also ended in a punitive outcome for some of those involved; as one of them recounted: ‘Next day ... the manager and the owner came to give me a letter to be transferred to [another centre] ... as a punishment ... [with] less than 24 hours to leave.’

Within this example of extreme care injustice, however, it is also possible to discern the emergence of solidaristic relations that resist the individualising dynamics of neoliberal care configurations. As conditions deteriorated in many Direct Provision centres during COVID-19 and the risk of COVID-19 outbreaks overtook fears of retaliation, asylum seekers continued to engage in acts of collective protest, including hanging banners with messages such as ‘MOVE US OUT’ from the windows of centres to raise public awareness. Local community members and migrant rights organisations had a key role to play in providing support and allyship here, as one participant explained in relation to their centre: ‘And that’s when the community came in and started helping us protest, helping us speak to the media.... We would hold meetings on Zoom, you know, on what further to do: “What do you guys need? We’ll come and will drop it off.”’ With solidarity from local community members and amplification by activist groups, the concerns of asylum seekers garnered significant media attention at the time, as well as engagement with local politicians. For one participant, such acts emphasised the importance of building solidarity; as they said, ‘We need to stick together for this to happen’. However, as we have shown, these acts were also often undertaken at great personal cost.

In the context of disability, it was apparent that many disabled people felt isolated in their care struggles. However, some also spoke about the support they had received from the disabled persons’ organisation they are members of in advocating their case to the HSE and the significance of collective efforts to vocalise concerns about poor care. Acknowledging that ‘it’s [the care system] only going to change, like, if there’s enough— if there’s a groundswell of disabled people’, this solidarity took different forms, from public campaigns arguing for greater personal assistance hours to developing self-assessment forms that disabled people could submit when arguing for a personal assistance service. During COVID-19 in particular, participants spoke about the value of online forums hosted by the organisation, which enabled disabled people to share experiences of accessing and managing personal assistance services (Loughnane and Edwards, 2024). Such collective efforts created a safe peer space for disabled people to articulate concerns without fear of retribution.

Conclusion

In excavating experiences of care deficits, the narratives of disabled people and asylum seekers provide important insights into what it means to vocalise and protest poor care within contemporary neoliberal welfare regimes. Complaint (or lack of) is a nexus that exposes the intersection of structural configurations of care and individuals’ emotions. Yet, as Tonkens et al (2013) note, these emotional impacts and effects are frequently overlooked in discussions of care systems and reform. The significant

emotional labour involved in deciding whether or not to vocalise care deficits – expressed through anxiety, fear, anger, frustration and resignation – was very evident in disabled people's and asylum seekers' narratives of *uncare*. We have shown how these affective responses are shaped by expectations imbued in care recipients about 'what they are worth, how they are valued and judged, and how they are supposed to *feel*' (Tonkens et al, 2013: 407, emphasis in original; see also Aronson, 2006). Thus, while some participants defied these expectations by turning their anger and frustration into active protest, others engaged in acts of self-censure, managing their emotions out of a sense of hopelessness and/or fear of retribution (Aronson, 2006; Grootegeed et al, 2013).

Connecting individual experiences to broader structural concerns and a political ethic of care, it is evident that the neoliberal logic underpinning the configuration of welfare services manifests itself in multiple ways to shape the parameters of and responses to complaint. First, it becomes evident in the fragmented structure of service provision of both disability services and Direct Provision, which leads to opacity about who has responsibility and accountability for instances of *uncare* and where complaints should be vocalised. Discussing the governance of Direct Provision, commentators note that there has been 'a lack of oversight' (Murphy, 2021: 4) of individual centres by the government and IPAS. The danger of this is that responses to complaint become dependent on the authority of specific individuals, for example, centre managers or owners, who, as Hewson (2022: 679) notes, 'may exceed laws, prescriptions and professed intentions'. Disabled people's experiences are also shaped by a 'highly individualized positioning' (Aronson, 2006: 550) in which they must find their own way through the care system. However, this approach undermines any collective sense of obligation for or right to care.

Second, speaking out is stymied by a failure of the state to clearly articulate rights and entitlements to care, which serves only to obfuscate by keeping those on the receiving end of care in the dark about what they can expect. It is partly for this reason that certain disabled persons' organisations in Ireland have called for a right to personal assistance services for disabled people to be enshrined in law (Nic Aogáin et al, 2019). More generally, systemic opaqueness about entitlements, for example, to a personal assistant, or one's 'residency status,' sows seeds of uncertainty, precarity and anxiety among recipients of care and support. It is well documented that asylum seekers are often left for years in Direct Provision to live in 'liminality' (O'Reilly, 2018) regarding their asylum application. Transferring people to other Direct Provision centres at short notice is also a purposeful act of control that destabilises the already precarious lives of asylum seekers (O'Reilly, 2018).

Third, in both contexts, we see evidence of systems that, far from engaging in acts of reciprocity with those on the receiving end of services, either have no formal complaints system or can only deal with concerns by escalating them into formal, pseudo-legal mechanisms, despite the fact that this might be against individual wishes. Indeed, escalating complaints up an administrative hierarchy was sometimes used as a threat, as opposed to a redress. This undermines any sense of trust, reciprocal listening or institutional learning, whereby concerns might be worked out informally between those giving and receiving care.

Ultimately, then, we need to ask how those on the receiving end of care can be supported to speak up, both individually and collectively, as part of a political 'praxis of care that holds the state accountable' (Dowler and Christian, 2019: 825). Our research

suggests that fundamental changes will be required within care infrastructures if voices and, indeed, emotions are to be heard and taken seriously (Barnes, 2008). This includes: actively challenging the oppressive social relations that construct disabled people, asylum seekers and other care receivers as voiceless; creating transparency about entitlements and service expectations; and creating safe dialogic spaces that facilitate the articulation of voice beyond formal complaints procedures, without fear of retribution. As we have shown, speaking out individually can be fraught with danger. In this context, we suggest that forging spaces of collective activism and resistance can play a key role. We have shown, for example, how the desperation, fear and anger of asylum seekers living together in Direct Provision strengthened solidaristic relations and led to collective protest, supported and enabled by activist networks. For disabled people, building solidaristic relations could sometimes be overshadowed by the time and energy required to fight individual care battles. Nevertheless, many participants identified the power of disabled persons' organisations, which, in not being funded by the HSE, could 'challenge the status quo' and expose systemic care injustices without fear of retribution. There are also opportunities to foreground resistances that connect groups across intersectional axes of oppression and experiences of *uncare*; for example, it is notable that some disabled persons' organisations in Ireland are increasingly engaging with disabled asylum seekers living in Direct Provision as part of their activist networks (ILMI, 2025). It is perhaps only from these activist spaces *outside* that care abuses can be challenged, and welfare configurations that do not punish but actively facilitate voice, concern and dialogue can be established.

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Note

¹ Disabled persons' organisations are organisations run by disabled people for disabled people.

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Research ethics statement

Ethical approval was provided by University College Cork's Social Research Ethics Committee.

Conflict of interest

The authors declare that there is no conflict of interest.

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