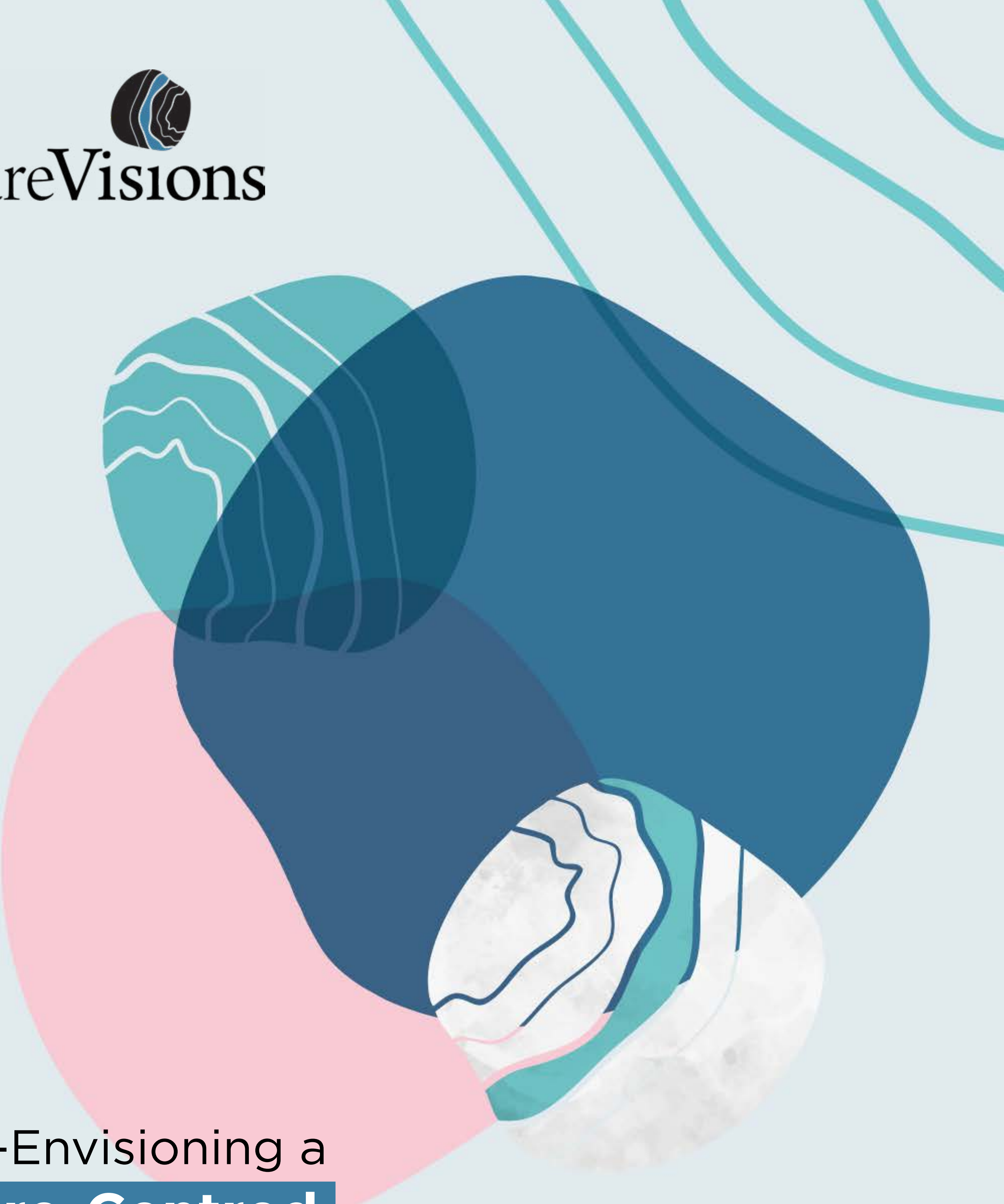
CareVisions



Re-Envisioning a Care-Centred Society in Ireland beyond COVID-19

Claire Edwards, Felicity Daly, Carol Kelleher,
Cliona Loughnane and Jacqui O'Riordan

Institute for Social Science in the 21st Century (ISS21)
University College Cork, Cork

December 2023

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

THIS REPORT CAN BE CITED AS:

Edwards, C., Daly, F., Kelleher, C., Loughnane, C. and O’Riordan, J. (2023) CareVisions: Re-Envisioning a Care-Centred Society in Ireland Beyond COVID-19. Cork: University College Cork.

ACKNOWLEDGMENTS

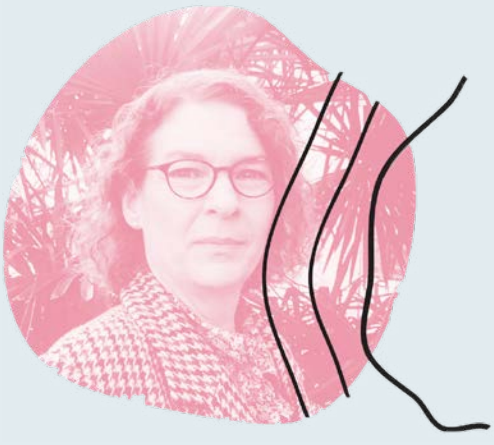
We would like to sincerely thank all the individuals who gave their time so generously to share their experiences and take part in this piece of research. We are also immensely grateful to the CareVisions Research Advisory Group who have provided a consistent sounding board throughout the three years of the project; their insights and advice at all stages of the project were hugely helpful. We would also like to thank Liam O’ Sullivan, CEO Care Alliance Ireland for believing in the CareVisions research programme at UCC. Finally, we would like to acknowledge that this project would not have been possible without the generous financial support of the Carolan Research Trust and the philanthropic funding of the late Professor Geraldine Fennell. We are extremely grateful to you all.

Contents

CareVisions Team

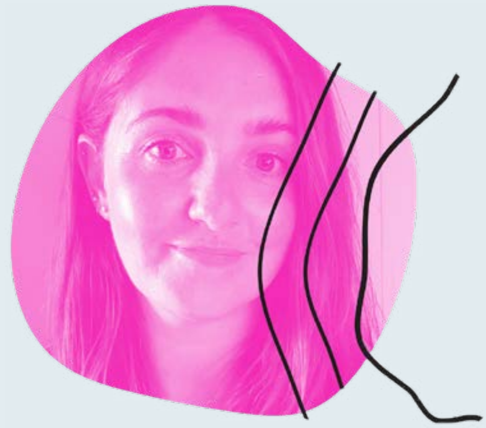
RESEARCHER TEAM/REPORT AUTHORS

Dr. Claire Edwards is Senior Lecturer in the School of Applied Social Studies, University College Cork (UCC). Her background is in urban and cultural geography, critical disability studies and social policy. Having formerly worked for the Disability Rights Commission in the UK, her research and teaching focuses on sociological and geographical understandings of disability, and addressing socio-spatial in/justice in the lives of disabled people. She has conducted research on disabled people's access to justice as victims of crime, on disability organisations' engagement in urban regeneration initiatives, and on issues of Universal Design in relation to children's play spaces.



Dr. Felicity Daly is an Assistant Professor in Global Health, Trinity College Dublin and directs the MSc in Global Health and was a full-time post-doctoral researcher on the CareVisions project. Felicity holds a Doctor of Public Health from the London School of Hygiene and Tropical Medicine. Prior to joining UCC, she worked as a researcher at the Institute for Commonwealth Studies, School of Advanced Study, University of London. In addition to her work as a researcher, Felicity has over two decades' professional experience in policy analysis and advocacy in the fields of global health and social development and as a technical consultant for UN agencies and international non-governmental organisations.

Dr. Carol Kelleher is a Senior Lecturer in service design at UCC. She co-founded and co-chairs the Institute for Social Science in the 21st Century (ISS21) CARE21 research cluster in UCC. She is committed to participatory research approaches which place carers' voices and experiences at the centre of policy and practice. Current care-related projects include the CareVisions project (2020-2023), a qualitative participatory study of teenagers with type 1 diabetes transitions from adult to self-management of their condition (in collaboration with Cork University Hospital) and a qualitative study of how parents of children with autism experience the health, social care and educational systems. Previous projects include CAREREN-GAGE (2020-2021), Caring for Family Members with Dementia (2018-2019) and Post-Caregiving (2016-2017).



Dr. Cliona Loughnane is a social policy analyst and researcher and was a full-time postdoctoral researcher on the CareVisions project. Prior to CareVisions, Cliona worked for more than a decade in research and policy positions in the health and social care sector. Her research interests include the gendered nature of care, healthcare reform and the commercial determinants of health.

Dr. Jacqui O'Riordan is a lecturer at the School of Applied Social Studies, UCC, where she works across a broad range of undergraduate, postgraduate and adult education programmes. Her research interests are largely located in qualitative participatory methodologies developed in co-operation with community participants and stakeholders. Research contributions in the care field include analysis of care and experiences of carers. She has worked with civil society organisations in researching experiences of carers, and less visible aspects and caring contexts such as supporting mental wellbeing in family and caring across home and institutions. She has also developed postgraduate seminars to further conceptual understanding of caring relations and dynamics. More broadly her work centres on a range of issues concerning gender, equality and diversity in local and global contexts. It includes analyses of aspects of women's livelihoods and conditions experienced by a range of marginalized communities.

CAREVISIONS RESEARCH ADVISORY GROUP

Suzy Byrne, Disability rights activist and Regional Manager, National Advocacy Service for People with Disabilities, Ireland.

Professor Mary Daly, Professor of Sociology and Social Policy, Department of Social Policy and Intervention, University of Oxford, UK.

Dr. Nikki Dunne, Research Manager, Family Carers Ireland.

Zoe Hughes, Senior Policy and Research Officer, Care Alliance Ireland.

Dr. Naomi Masheti, Coordinator, Cork Migrant Centre, Ireland.

Dr. Joan McCarthy, Senior Lecturer in Healthcare Ethics, School of Nursing & Midwifery, UCC (Retired).

Professor Maggie O'Neill, Professor in Sociology and Criminology, Department of Sociology and Criminology, UCC; Director, Institute for Social Science in the 21st Century (ISS21) & UCC Futures: Collective Social Futures.

Aoife Smith, Chief Executive Officer and Co-Founder, The Great Care Co-op, Ireland.

Ailbhe Smyth, Feminist and LGBTQI campaigner and activist, former academic University College Dublin, Ireland.

Summary

INTRODUCING CAREVISIONS

The COVID-19 pandemic and current social, economic, and environmental crises have brought the significant deficits and inequalities in current care practices and policies in Ireland and globally into sharp focus. The challenges exposed by these crises suggest that there is an urgent need to re-evaluate and re-envision the significance of care relations, policies, and practices in contemporary society (Fine and Tronto, 2020). Despite the 'carelessness' witnessed during the pandemic (Chatzidakis et al., 2020), COVID-19 also provided glimpses of alternative ways of care and caring, revealing interdependencies within and between communities and between those giving and receiving care.

This report presents findings from a three year (2020-23), interdisciplinary, participatory research project entitled CareVisions, based in the Institute for Social Science in the 21st Century (ISS21) at University College Cork, which explored care experiences during and beyond the COVID-19 pandemic to re-imagine future care relations, practices, and policies in Ireland and internationally. Core to the project is a recognition that we need to rethink how we conceptualise the term care itself. The project aims to advance knowledge about the meaning of care in people's lives and stimulate critical public debate about how we can envision alternative care futures.

CAREVISIONS AIMS AND OBJECTIVES

The key aim of the CareVisions project is to reflect on care experiences during and beyond the COVID-19 pandemic to explore and reimagine how we might envision future care relations, practices and policies in Ireland.
Its objectives are:

- To re-imagine and envision future care relations, practices and policies drawing on and developing a feminist ethics of care approach.
- To explore the social, political, and ethical implications of the COVID-19 pandemic for future care relations, practices, and policies in Ireland.
- To build a collaborative, interdisciplinary network of scholars, policy-makers and community/voluntary organisations committed to advancing knowledge, theory and public policy debate about the ethics and practice of care within and beyond Ireland.

UNDERPINNING PRINCIPLES: A FEMINIST ETHICS OF CARE

CareVisions is underpinned by ideas drawn from a feminist ethics of care perspective. Feminist care ethics emerged from feminist activism which sought to challenge the gendered burden of care in the private sphere and draw attention to the societal devaluing of care as a 'species activity' which is fundamental to society and human flourishing (Fisher and Tronto, 1990: 40). Feminist care ethics enables us to think about care in different ways: as a set of values, as a set of relations, and as a practice. CareVisions is underpinned by several key precepts drawn from feminist care ethics:

• CARE AS RELATIONAL.

We understand care relations and practices as made up of multiple, interconnected relationships and interdependencies. In this context, individuals are not seen as autonomous, independent beings, but exist in relation with one another. We recognise care as a relational two-way process, which disrupts the binary categories of care giver and care receiver.

• CARE AS A PERSONAL AND POLITICAL ISSUE.

A feminist care ethics approach makes explicit the connection between care relations in the most intimate spaces of people's lives, and wider political and democratic concerns about how societies operate and are configured. Bringing care into the political sphere means not only reflecting on how responsibility for care in society should be distributed, but also critically appraising the values and mechanisms which drive care provision and systems.

• CARE AS A PARTICIPATORY, DELIBERATIVE PROCESS.

An ethics of care means paying attention to the need to create deliberative, participatory spaces – not just within formal policy-making structures – but to enable debates about care to take place in a way that includes the voices of care receivers as much as care giver.

METHODOLOGY

CareVisions adopted a multi-method, participatory research design, built around two interconnected phases:

PHASE 1 involved exploring how care was understood and talked about in Irish public and political discourse during and shortly after the pandemic. Specifically, we conducted discourse analyses of two governmental processes, the Citizens' Assembly on Gender Equality and the Houses of the Oireachtas Special Committee (SC) on Covid-19 Response (2020).

PHASE 2 involved exploring care relations, understandings, and practices amongst two groups in Irish society: disabled people and asylum seekers. These two groups were chosen because their identities within the care domain have often been fraught with tension, and also because they offer the potential to challenge taken-for-granted assumptions about care relations.

The engagements with disabled people and asylum seekers were designed as discrete but interconnected strands and involved a range of different qualitative methods. In the case of disabled people, this involved a focus group process and individual (face to face and online) interviews with nine disabled people. The work with asylum seekers involved interviews, focus groups and participant observation in different spaces, including online and in community gardens. Data were analysed by the research team using a thematic approach and were brought back to, and discussed with, the participants and the Research Advisory Group as part of the analytical process.

FINDINGS

PHASE 1: ANALYSING DISCOURSES OF CARE IN IRELAND

As a way of exploring how care has been understood and spoken about in Ireland, part of CareVisions' methodology involved exploring the way in which care was represented in two political processes using discourse analysis methodologies (Chapter 3). While we should not generalise from these two analyses, they provide insights into the ways in which care has been spoken about, and who or what is invisible in discussions of care.

A feminist ethics of care lens also enables us to consider what alternative understandings of care might look like.

What constitutes care?

Analysis of the Citizens' Assembly and Special Committee shows there are constraints and limits in the ways in which care as a concept is understood in public and political discourse in Ireland. Care is predominantly understood in terms of specific services and spaces, whether in terms of healthcare settings, childcare, or care work. There is occasionally articulation of the need for care as a universal social good or a value. Overall, however, the concept of care is often ill-defined.

Who gives and receives care? Care giver and receiver identities.

A feminist ethics of care approach aims to disrupt ideas of a neat boundary between care givers and receivers, recognising that we all give and receive care at different times in our lives. However, in both processes we see evidence of assumed care receiver identities. For example, older people, children and disabled people were frequently referenced in relation to care receipt. These identities are not unproblematic and can reinforce ideas of a hierarchy of deservingness, and of paternalism for some groups who are deemed to be 'vulnerable'.

In both processes, we see some awareness of the intersection and fluidity between care giving and receiving identities. For example, they acknowledge that migrant care workers also require care; or that disabled people are also involved in caring roles in various capacities. However, they stop short of recognising the intersectionality of care relations in greater depth.

Care, privatisation and the market

Our analysis demonstrates that 'care talk' continues to be dominated by discourses around the market. This 'talk' shifts from at some points, tacit acceptance of care as in service to the market, and at other times, a recognition of the problems, challenges and deficits created by a marketized care system in which private sector interests are increasingly dominant. While there is some articulation in both processes of the need for new models of care and greater state oversight of care services, we do not see a radical or transformative break from existing policy trajectories.

Gendering and de-gendering care

While the Citizens' Assembly on Gender Equality made very explicit the interrelationship between care and gender inequality given its remit, the Special Committee illuminates the on-going gender blindness that continues to shape recognition (or lack of recognition) about care practices in Ireland. In particular, the Special Committee report failed to acknowledge the gendered burden of care experienced by women during the pandemic. Questions also remain in terms of how the gendered care 'problem' is to be solved: for example, much of the focus we see is on moving 'unproductive' women into paid work, with less attention paid to more deeply embedded patriarchal structures and assumptions that perpetuate the gendered burden of care.

Reflecting from a feminist ethics of care

Our discourse analysis leads us to suggest that there is a need for a more fundamental and wide-ranging conversation about what it might mean to understand care as a 'species activity' and place care as a value at the centre of society and politics, rather than as a practice that applies only to specific groups of people or sites and services. Moving away from the idea of binary care givers and receivers means paying more attention to the fluidity and intersectionality of care relations, practices and identities.

The analysis also indicates a need for greater reflection on how we might understand and talk about care beyond a form of exchange value in the market, and on the current challenges presented by the increasing marketisation of care provision. This is a recurring theme that raises broader questions about who the appropriate providers of care should be in configuring a 'caring society'.

PHASE 2: EXPLORING CARE RELATIONS, UNDERSTANDINGS AND PRACTICES.

Exploring And Rethinking Care: Disabled People.

Our discussions with disabled people focused around exploring meanings of care; understanding care relations and networks; examining the impacts of COVID-19; and exploring what 'good care' might look like.

Understandings and meanings of care

Disabled people had multiple and contested, understandings of the term care. Care was associated with values such as human kindness, reciprocity, dignity and respect in relationships, and with caring about and for close others in their personal networks. However, it was also associated with negative and painful experiences in the context of formal care and support systems, and the stigmatisation of certain groups in society, in particular disabled people and older people.

Participants believed there was a need to clarify understandings of care, to recognise how societal perceptions and support/care systems have restricted how care is understood, and to distinguish care from personal assistance. For some, this means rejecting the term 'care' altogether.

Navigating care relations, networks and structures

A key theme emerging from disabled people is the significance of relationships in enabling support and care. Participants had diverse family relationships and multiple significant people in their support networks, including friends, neighbours, members of their local community, and the disability community. For some, their Personal Assistants (PAs) were also part of these interpersonal networks of support.

Reciprocity is at the heart of these networks and there was a recognition that these are often 'two-way' support relationships. Disabled people were engaged in a range of support and care activities, including practical, financial and emotional support for family members, neighbours, friends and the wider disability community. However, participants were very aware that society does not recognize disabled people as giving care, only viewing them as care receivers.

Disabled people had different experiences of formal (paid) care systems and networks (including PA hours, home support hours and respite in institutional settings). Many described significant deficits and inequalities shaping these experiences, including a scarcity of service, lack of equity of access, and clientelism in the system. Participants described an unrelenting fight for support.

Participants acknowledged that formal care systems continue to make inappropriate presumptions about disabled people's informal care supports. It is assumed that family members (and particularly female family members) will step into the breach to provide support if needed.

> “**COVID-19** was also a time in which collective activism grew through the creation of online spaces and platforms. Participants described Zoom as ‘the gift of COVID-19’, which facilitated a range of activities and built connections with those who had not previously been a part of the disability community.”

Disabled people discussed the centrality of the care giver/receiver relationship, particularly in the context of PAs and care workers. Many described having very positive relationships with PAs and care workers, but also spoke about the challenges around the high turnover of staff and also expectations regarding the role. Participants were acutely aware of the poor working conditions and pay within the care sector and argued this needed to change if these roles were to be filled and valued by society.

The on-going privatisation of care was identified by disabled people as contributing to negative service experiences. They felt it was contributing to a fragmentation of services, poor conditions for care and support workers, lack of transparency and accountability in service delivery and a concern with prioritising profit over the quality of the care experience.

Reflecting on the impacts of Covid-19

Disabled people described COVID-19 as intensifying already existing deficits and inequalities in support systems. It also exposed the on-going stereotyping of disabled people as being both at risk and a risk to others. Some (but not all) people experienced difficulties in knitting together PA supports (due to an absence of PAs, for example), and a loss of service which meant that they had to move back in with family. Others described the fear, anger and isolation they felt during periods of lockdown, and in having to deal with non-disabled people’s attitudes towards them. COVID-19 was also a time in which collective activism grew through the creation of online spaces and platforms. Participants described Zoom as ‘the gift of COVID-19’, which facilitated a range of activities and built connections with those who had not previously been a part of the disability community.

Disabled people expressed a concern that their needs were being forgotten in the return to ‘business as usual’ after COVID-19. Thus, while the pandemic might be seen as being over, many disabled people are still dealing with the consequences, particularly in terms of access to services.

Meanings of ‘good care’ and re-envisioning future care relations

Disabled people’s experiences shape their understandings of what good care might look like. Good care was linked to having a choice, not having care imposed upon them, being seen as an individual with needs and preferences, and recognising the reciprocity of the care giver/receiver relationship, such that both have the right supports and are valued.

People feel there is a need for real and substantive redesign of how society plans and provides support which should be based around disabled people’s right to care and to equity of access. Such change needs to draw on the experience and expertise of disabled people in redesigning the support/care system.

Disabled people identified several key areas in terms of re-envisioning future care relations. These include:

- **Challenging narratives and representations of disabled people** as passive care receivers, by recognising the significant care giving that disabled people engage in.
- **Challenging societal presumptions** about informal care networks, that is, that family members should be ‘expected’ to undertake care.
- **Challenging the on-going privatisation** of care systems.
- **(Re)defining and clarifying** the role of PAs and care workers. Distinctions between personal assistance and care work are often unclear and become blurred within formal care infrastructures. Disabled people should take the lead in this exercise of (re)definition.
- **Building forms of collective advocacy** in a system that is very individualised. The pandemic facilitated a period of renewed activism among the disability community, but there needs to be a focus on how these spaces can be sustained.

Exploring and rethinking care: Asylum Seekers

Empirical work with asylum seekers identified three strands of enquiry to amplify our understanding of how their experiences as international protection applicants, living within the congregated settings of Direct Provision[1] (DP), could further our understanding of less widely recognised intersections of care relations. The first two strands focused on what we can learn through experiences encountered during the first COVID-19 lockdown. Strand i focused on experiences and conditions of care within DP centres during COVID-19; Strand ii focused on experiences of asylum seekers working within the care sector. In Strand iii we explored engagement with community garden initiatives as a way to explore ‘universal care’ of people and planet.

We found that participants working in the health and social care sector identified forms of ‘care’ in relation to paid care work. Outside of that context, using the term ‘care’ was not immediately recognised, understood nor well defined by our research participants. Asylum seekers expressed other terms such as support, help, assistance, and, importantly, protection.

i. Conditions in DP and carelessness during COVID-19

Our findings reveal that DP was experienced as a threatening environment where the State was unable to uphold its duty of care for international protection applicants. They reveal an increased vulnerability associated with crowded conditions within DP centres, exacerbated by lack of communication, planning and preparedness. While they highlight systemic weaknesses of overcrowded centres, they also identify a level of carelessness towards the care needs of asylum seekers.

Communication on COVID-19 precautionary measures was inadequate and information on how COVID-19 is spread was not translated into languages widely understood by asylum seekers. Practices put in place to protect the general public could not be implemented in crowded DP centres, where space sharing is common. One of the failed practices which gained notoriety during the first COVID-19 lockdown was that of transferring groups of asylum seekers between DP centres. Carelessness and lack of preparation characterised transfers: residents were not tested prior to transfers, travel to other centres was in crowded buses and receiving centres were unprepared for residents on their arrival. It also appeared that centres were hastily opened.

---

[1] Direct Provision is Ireland’s system of accommodation for those seeking international protection, administered by the International Protection Accommodation Service (IPAS).

Isolation, which was commonly experienced during COIVD-19 lockdown, was exacerbated in DP centres by the limited spaces allocated to residents who found that spending prolonged periods of time in isolation in small rooms was extremely difficult. Several spoke about this time as another experience of trauma, or re-traumatisation, in their lives.

ii. Navigating the international protection system as an asylum seeker working in care

An important objective of CareVisions is to contribute to the visibility of asylum seekers' roles in giving care. In this strand of our research, we explored the experiences of asylum seekers employed in the health and social care sector in Ireland while living in DP.

Our findings demonstrate that the International Protection Accommodation Services (IPAS) was incapable of effectively responding to the threat of COVID-19 outbreaks and unable to recognise and enable the role that some international protection applicants played in the pandemic response. Asylum seekers working in care faced tensions within centres whereby other residents were alarmed at the risks of COVID-19 being spread by those working in care settings. In particular, roommates viewed them as presenting an increased risk of infection to them. Asylum seekers' terms and conditions of employment were often short term and at entry level healthcare positions. Some employers transferred these health care workers from DP centres to short term accommodation where guidance on social distancing resulted in closing off opportunities for sharing experiences and providing mutual support for one another.

Income from paid work could be inconsistent and unpredictable and expensive travel put excessive strain on their incomes. Reliant on public transport, health care workers were concerned about COVID risks on public transport and/or how cancellation of services affected them and meant they had to augment with expensive taxis.

All participants in this strand of our research were women originally from countries in sub-Saharan Africa and some shared that they experienced racial discrimination from clients, particularly elderly nursing home residents. Their response to this was compassionate and understanding of the latter's unfamiliarity with their carers, reflecting a high turnover of low paid care workers and isolation from family members and other visitors.

iii. Caring and community gardens

Our third research strand explored asylum seekers' engagement in care for the planet and people by conducting research in two gardens established by community organisations providing support to asylum seekers: one a long-established garden and the other one initiated in 2022.

Engagement with community gardens was perceived to provide access to green space outside of cramped, overcrowded, congregated settings, to enable them to 'breathe'. Either by actively partaking in gardening or just enjoying green space, current and former asylum seekers were able to enhance a felt sense of wellbeing and practically engage in social inclusion. Gardening helped to re-engage connections with nature and with culture through growing plants indigenous to their country of origin or giving them a place to celebrate cultural occasions together. Taking control of identifying and choosing plants, as well as maintaining crops and eventual harvesting brought people together in safe and open spaces. Gardens can offer a form of horticultural therapy and many participants spoke about how important access to green space is for their own and their children's wellbeing. Mothers shared that when their children are gardening or engaged in outdoor activities supported by community groups their own sense of wellbeing is improved and they are less stressed about the conditions of raising them within the DP system.

Envisioning good care

Participants strongly identified the lack of care they experience in DP and also reflected on initiatives where they feel cared for. We asked participants to recommend changes that could improve the standard of care that the State and its agents can deliver within the international protection system. Recommendations included:

> - the development of a framework where staff within the DP system be trained and educated on supporting people who have experienced trauma.
> - ensure better care by listening to the voices of asylum seekers.
> - considering not just basic material needs of asylum seekers but viewing needs more holistically.
> - greater consistency in support, and
> - simply 'being more caring'.

CONCLUSIONS: RE-ENVISIONING A CARE-CENTRED FUTURE

Drawing from a feminist ethics of care and bringing together the different strands of the CareVisions project, our research illuminates a number of key points about care relations and practices in Ireland and the impacts of COVID-19. It also enables us to reflect on the principles that might underpin a 're-envisioning' of these care relations.

REFLECTING FROM A FEMINIST ETHICS OF CARE

Drawing from a feminist ethics of care perspective, the research highlights the following key issues.

Unfixing care identities. Public and policy imaginaries in Ireland continue to 'fix' particular groups in Irish society as either care givers or receivers, with negative consequences. Disabled people were very aware of this in discussing public attitudes towards them during the pandemic, attitudes which reflect a continuation of perceptions of paternalism and dependence. For asylum seekers living in Direct Provision, they perceived that they were not necessarily seen by wider society as 'deserving' recipients of care but viewed as a burden. Like disabled people, their role as care providers was not recognised or acknowledged.

Complex interdependencies in care relations. The research demonstrates the complex intertwining of formal and informal care relations that exist in both the lives of disabled people and asylum seekers, which often remain hidden in debates about care. Asylum seekers for example draw on informal support relations (with families and others living inside and outside of Direct Provision) to enable them to undertake formal care labour. Disabled people are engaged in informal relations of support, from families to neighbours, friends, and the wider disability community, but also draw on formal systems and supports (such as PA services) to enable them to participate in social networks and provide care to the wider community. Should these formal supports cease to exist, however – if, for example, PA supports are not available to disabled people - this has a significant impact on participation and the reciprocal nature of their informal relations. In general, the dynamics and intersection of care giving and receiving - and of paid and unpaid care labour - frequently remain invisible and unrecognised.

Our research also draws attention to the centrality of the care giver/receiver relationship, and the wider dynamics of power and intersecting identities that can shape these interpersonal care and support relations. Disabled people's and asylum seekers' experiences of receiving and providing formal support services respectively reveal the intersectional dynamics and inequities of 'race', dis/ability, gender and class which shape care relations, and which need to be sensitively acknowledged and addressed.

The wider political sphere of care relations. Our research draws attention to the wider social, economic, and political processes and structures which shape interpersonal care relations. A dominating influence is the increasingly marketized and privatised model of care and support provision. Direct Provision centres, for example, run on a for-profit basis, while the provision of home care supports for disabled and older people has become dominated by an increasingly fragmented marketplace of private providers, with increasingly negative consequences. Recognising the politics of care relations therefore means asking questions about who, and what agencies, should take responsibility for care. Our research suggests that there should be a re-prioritisation of public responsibility for care which moves it outside of the market domain.

On-going carelessness in care practices and services. Both disabled people and asylum seekers continue to experience instances of 'carelessness' in services and institutional contexts, whether in terms of the re-traumatisation of living in the congregated setting of Direct Provision, or absences of support and instances of 'poor care' in the context of disabled people. For both groups, the spectre of institutionalisation looms large in terms of care experiences and past abuses. Care ethics asks us to challenge these instances of carelessness, to acknowledge how they have emerged and confront past abuses.

Spaces of (care) collectivism and solidarity. Our research demonstrates instances of collectivism and solidarity which shape care relations, and activism around care and support. Within their own communities, we can see evidence of this collectivism amongst disabled people and asylum seekers. The creation of the community gardens for asylum seekers embodied a space for developing collective solidarity; the renewal and building of social networks amongst disabled people in the online space during COVID-19, is another reflection of this community-building and solidarity. Care ethics pushes us to think about how we can express solidarity with diverse groups, not as an act of paternalism or charity, but a wider solidarity grounded in respect, dignity and equality in the search for caring relations.

THE IMPACTS OF COVID-19

The project revealed significant impacts and implications of COVID-19 in terms of current and future care relations. Our research shows that it led to the emergence of public and political discourses around hierarchies of 'deservingness' of care between different groups. Disabled people, for example, reported the (re)emergence of paternalistic attitudes which constructed them as both vulnerable to COVID-19, but also 'risky' in terms of being seen as carriers of COVID-19. Asylum seekers were also constructed as a 'risky' population, as COVID-19 outbreaks in Direct Provision centres became the focus of media attention and asylum seekers working as care workers during the pandemic were viewed as 'risky' amongst their peers in, and by the managers of, Direct Provision centres.

The pandemic exacerbated care deficits in services and enabled care abuses: we found that both disabled people and asylum seekers experienced intensified care deficits during the pandemic which emerged from a withdrawal or restriction of services, or changes to the way services were run. This included dehumanising conditions in Direct Provision centres and the withdrawal of services for disabled people which often led to isolation and a renewed dependence on family members.

It is possible to identify some ways in which the pandemic has prompted critique and led to calls for change, particularly in the way care and support systems are organised. It has led to renewed calls to end the long history of institutionalisation – including Direct Provision - as the state's response to dealing with groups deemed to be vulnerable and requiring protection and care in Ireland. It has also led to a recognition of the impact of poor conditions for low paid workers, including care workers, as evidenced in the introduction of the Sick Leave Act (2022); and it has prompted discussion about the availability and coherence of services for specific 'care groups', most notably older people. Importantly, our research shows that COVID-19 facilitated new spaces of peer-based activism, as disabled people's experiences of online organising bear witness to.

TOWARDS A RADICAL RE-ENVISIONING OF CARE

Based on our findings and analysis, we propose an agenda for a radical re-envisioning of care. We hope that this vision or agenda will be a starting point for discussion and debate about the future place of care in Irish society. It involves the following priorities and actions.

Changing the language of care

- Clarify and reframe language and narratives around care, acknowledging the diverse meanings (both positive and negative) that the term care holds for different groups in society. As part of this, the harms that have been done in the name of 'care' need to be acknowledged.

- Recognise that care is central to human life and expand understandings of care beyond particular groups of people, service settings and sites of care. Care should be considered as intrinsic to humanity and human activity and care relations should be conceived as more than the care giver/receiver binary.

- Reject and move beyond market-based discourses of care that narrowly construct care in terms of economic exchange value and recognise the implications that these market-oriented discourses have for how we think about care and care futures.

- Co-create spaces for dialogue, coalition and advocacy between diverse groups implicated in shaping care policy and practices, including those representing care givers and those representing individuals in receipt of care, support or assistance.

Care work and care identities: challenging assumptions

- Challenge deeply held normative and cultural assumptions about care that continue to pervade Irish society. These assumptions relate to the devaluing of care and care work, and to gendered, racialised and ableist assumptions about who does care 'work' and who is 'deserving' of care.

- Recognise that care giving and receiving are two sides of the same coin, and that all people should be supported to give and receive care throughout their lives.

- Acknowledge the centrality and reciprocity of the relationship between care receiver and care giver. This relationship needs to reflect a context in which:
  (i) the person in receipt of care or support has had choice and been able to determine how their support is provided; and
  (ii) the person providing care needs to be adequately supported to undertake their role (i.e through good working conditions, fair pay, understanding of their role and recognition).

Building better care infrastructures, systems and services

- Challenge the increasing privatisation of care which leads to care being treated as a commodity and source of profit, as well as increasingly fragmented service experiences. We need to restate care as a ‘public good’.

- The state needs to play a central role in ensuring care and support needs are met and should provide good conditions which enable the giving and receiving of care.

- Better care and support services need to be built around ‘seeing the person’ and placing the individual at the centre of any form of support. This should be matched by standardisation, equity of access and an end to clientelism.

- Stimulate greater conversation and clarity around different care or support roles and expectations around what these roles look like/involve. Throughout the lifecourse, people require different levels and types of care and support, and the individual in receipt of care or assistance is best placed to articulate expectations and contribute their expertise to role definitions and training.

- Those in receipt of care or support need to be encouraged to articulate concerns or complaints and to know that these will be listened to without fear of loss/change of service.

- Identifying good care can only happen by also continuing to identify, acknowledge and confront instances of bad care, and care abuses.

Creating collective spaces for care activism

- Foster peer spaces which offer opportunities to build collective activism around issues relating to care. This might include online spaces, but also other community spaces, including community gardens.

- Locate care issues at the centre of political decision making and ensure that those most impacted by care policies and practices lead our care deliberations.

1

Introducing the Carevisions Project

1.1 INTRODUCTION

The COVID-19 pandemic and current social, economic, and environmental crises have brought into sharp focus the significant deficits and inequalities in current care practices and policies in Ireland. COVID-19 illuminated the unmet care needs of those deemed to be ‘vulnerable’ or ‘at risk’, whilst also revealing hierarchies of ‘deservingness’ amongst care receivers as they were articulated within public and political discourse (Daly and Edwards, 2022). At the same time, the pandemic highlighted the on-going inequitable gendered and racialised burdens of paid and unpaid care work in multiple settings, from the home to hospitals and residential institutions. Governments were criticised for the failed responses of health and social care systems, many of which have been linked to the increasing marketized and privatised configuration of care services and the ‘commodification of care’ which has resulted in low paid and precarious care work (Cullen and Murphy, 2020; Lynch, 2022).

The challenges exposed by COVID-19 have led commentators to suggest that, more than ever, we need to re-evaluate and re-envision the significance of care relations, policies and practices in contemporary society (Fine and Tronto, 2020). Despite the ‘carelessness’ witnessed during the pandemic (Chatzidakis et al., 2020), COVID-19 also offered glimpses of alternative ways of being, revealing the vulnerability and interdependence within communities and between those giving and receiving care. New sites of collective caring were demonstrated through friendship and community networks when state systems were in crisis and people were restricted to their homes. Solidaristic street level responses to the pandemic, such as ad-hoc mutual aid groups and multilateral solidarity response funds, inspired hope for the emergence of more egalitarian responsibilities for care. Care responses such as the provision of remote healthcare and a move to online peer support groups and online activist communities, promoted more caring possibilities for ‘virtual strangers’ (Barnes, 2012: 119) providing and receiving care within lockdowns, but also across national and other borders of age and ability. State systems also began to acknowledge some of the failings of the fragmented, privatised provision of care and the need for publicly provided, collectivist welfare services (Daly and Edwards, 2022). Yet it is unclear how far this recognition and different forms of action have sustained beyond the immediate COVID-19 emergency, and there is a danger that we return to ‘business as usual’ in a post-pandemic world.

This report presents findings from a three year (2020-23), interdisciplinary, participatory research project entitled CareVisions, which addresses these debates by exploring care experiences during and beyond the COVID-19 pandemic to re-imagine future care relations, practices, and policies in Ireland and internationally. Core to the project is a recognition that we need to rethink how we conceptualise the term care itself. To that end, CareVisions draws on ideas from a feminist ethics of care perspective, which understands care as a form of universal mutual human interdependence that is central to the functioning of society. Over a period of three years, CareVisions has used different methodological approaches to critically interrogate understandings and meanings of care in Irish public and policy discourse, and explore care relations, networks and practices experienced by diverse groups in society. In presenting the project findings, we hope that this report will advance knowledge about the meaning of care in people’s lives and stimulate critical public debate about how we can envision alternative care futures.

1.2 AIMS AND OBJECTIVES

The key aim of the CareVisions project is to reflect on care experiences during and beyond the COVID-19 pandemic to explore and reimagine how we might envision future care relations, practices and policies in Ireland. Its objectives are:

- To re-imagine and envision future care relations, practices and policies drawing on and developing a feminist ethics of care approach.
- To explore the social, political, and ethical implications of the COVID-19 pandemic for future care relations, practices, and policies in Ireland.
- To build a collaborative, interdisciplinary network of scholars, policymakers and community/voluntary organisations committed to advancing knowledge, theory and public policy debate about the ethics and practice of care within and beyond Ireland.

CareVisions is also underpinned by a concern and commitment to explore moral and ethical questions about the future of care, by developing an experiential ethics of care in the Irish context which (a) advances feminist ethics of care scholarship and (b) informs future policy debate about the development of care in Ireland.

1.3 UNDERPINNING PRINCIPLES: A FEMINIST ETHICS OF CARE

CareVisions is underpinned by ideas and principles drawn from feminist care ethics. Feminist ethics of care covers a wide body of literature and emerged from feminist activism which sought to challenge the gendered burden of care in the private sphere (see Loughnane, 2022 for a summary of some of the key thinkers). In a frequently cited definition, Fisher and Tronto (1990: 40) describe care as ‘a species activity that includes everything that we do to maintain, continue, and repair our world so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life-sustaining web’. This definition suggests that care and caring should not be understood in narrow, functionalist terms, or in ways which create binary categories of people/ways of being (care giver and care receiver, for example), but rather as fundamental to society and for human life to flourish. Care ethics enables us to think about care in different ways: as a set of values (such as reciprocity, trust, understanding, solidarity embodied in caring); as a set of relations, such that we are all interdependent, and universally occupy positions of care giver and receiver at different times in our lives; and as a practice, highlighting for example the paid and unpaid labour involved in caring, and the different spaces and contexts in which it takes place.

Drawing on a feminist ethics of care perspective, then, CareVisions is underpinned by three central premises which frame the project.

- **CARE AS RELATIONAL.** We understand care relations and practices as made up of multiple, interconnected relationships and interdependencies. In this context, individuals are not seen as autonomous beings, but existing in relation with one another; neither in the context of care identities, can they be seen as either independent or dependent. We recognise care as a relational two-way process, which disrupts the binary categories of care giver and care receiver. Adopting this approach, we recognise that care has to be understood in terms of what Kittay (2020) refers to as ‘nested interdependencies’: while we may often think of care as a one to one relationship, we have to understand the wider sets of social relations involved in care practices, which ‘may include paid and unpaid care givers (family members, friends and care workers)’ (Barnes, 2015: 35), as well as more formal spaces of care, such as residential or institutionalised settings. Crucially, these networks themselves do not operate in a vacuum, but are situated within, and influenced by, broader governmental and state responses to care (for example, through care policies, and state supports for care givers and receivers). All of these require interrogation if we are to understand the full extent of care and care relations.

- **CARE AS A PERSONAL AND POLITICAL ISSUE.** As the insights of feminist theory have revealed, issues which have traditionally been constructed in terms of people’s most private, personal worlds, are also public and political (Barnes et al., 2015a). A feminist ethics of care approach makes explicit the connection between care relations in the most intimate spaces of people’s lives, and wider political and democratic concerns about how societies operate and are configured. As Barnes et al. (2015a: 5) note, ‘the transformations that care ethics seek are not solely that care provided face to face will be better, but that care thinking will impact on the way we think about politics and the way political decisions are reached’.

  Bringing care into the political sphere means not only reflecting more widely on how responsibility for care in society should be distributed, but rather also critically appraising the values and mechanisms which drive care provision and systems: this includes, for example, reflecting on the consequences of marketized and commodified systems of health and welfare for care services, practice and care work, the negative effects of which have been widely documented (O'Dwyer 2017, Liveng 2015). CareVisions therefore recognises care as both a private and public issue in terms of envisioning alternative care futures.

- **CARE AS A PARTICIPATORY, DELIBERATIVE PROCESS.** One of the implications of a feminist care ethics approach, with its focus on bringing 'care talk' into the political sphere, is its focus on 'a dialogic and narrative form of practice' (Barnes et al., 2015b: 238). A feminist ethics of care means paying attention to the need to create deliberative spaces – not just within formal policy-making structures – but to enable debates about care to take place in a way that includes the voices of care receivers as much as care givers (Barnes, 2012). CareVisions responds to this emphasis by developing participatory research approaches and spaces for deliberation which engage diverse groups and voices in re-imagining care in Ireland.

1.4 A NOTE ON LANGUAGE

We recognise that the term 'care' is far from benign and that for many groups in society, care has been seen as central to their abuse and oppression, to negative stereotyping and the creation of dependent relations. For example, scholars writing within the realm of disability studies and disabled people[2] themselves have highlighted the multiple ways in which care relations have positioned disabled people as passive care receivers, thereby contributing to their disempowerment and in some cases, to direct abuses of care (in institutionalised settings, particularly) (Fine and Glendinning, 2005; McLaughlin, 2020; Morris, 1997). Many Disabled Persons' Organisations[3] (DPOs) which advocate for personal assistance services as a route to independent living[4] therefore prefer to use terms such as support and assistance, rather than care; there are concerns that talking about care can move the political agenda away from calls for disabled people's rights, equality and justice.

In CareVisions, we recognise these linguistic challenges and tensions and acknowledge the power relations inherent within the term care. We also heed the warnings of intersectional scholars who have criticised feminist ethics of care perspectives for failing to pay sufficient attention to the classed and racialised dynamics of care (Raghuram, 2019). However, in this report, we retain the term because we see a value in seeking to expand, rethink and redefine what we mean by care, and reflect on what it might mean for alternative social futures in Ireland.

1.5 METHODOLOGY

Drawing on feminist ethics of care, CareVisions is built on participatory principles and a political orientation to research practice for social change. The project was led by an interdisciplinary team of researchers, supported by a Research Advisory Group of scholars, activists and practitioners drawn from academic and community groups. The project methodology was designed around two key strands. Phase 1 involved a discourse analysis of selected government and policy documents to critically explore understandings of care in public and political discourse during and post pandemic. Specifically, two policy processes and associated documents were chosen: the Citizens' Assembly on Gender Equality, and the Houses of the Oireachtas Special Committee on Covid-19 Response. Findings from these analyses are detailed in Chapter 3.

Phase 2 comprised empirical work with two groups in Irish society – disabled people and asylum seekers living in Direct Provision (DP)- to explore understandings and meanings of care, care networks and relations, impacts of COVID-19, and possible ways to collectively rethink 'good' or 'better' care. These groups were chosen as their identities within the care domain have often been fraught with tensions, but also because they offer the potential to challenge taken-for-granted assumptions about care relations and care giving/receiving identities.

In the case of asylum seekers, the international protection system pushes the boundaries of what is traditionally considered a space of care. Asylum seekers themselves are often not constructed by the State as a group needing care despite the fact that many contribute to the care economy as paid workers in the Irish health and social care sector. Similarly, debates around care and disability are also subject to contestation, albeit for different reasons. As detailed in Chapter 2, we worked with specific organisations representing disabled people and asylum seekers, utilising diverse participatory, qualitative approaches, including interviews, online focus groups, and participant observation in different community settings. Findings from Phase 2 are presented in Chapters 4 and 5.

---

[2] In this report, we use the term 'disabled people' to reflect the collective and political identity that comes from recognising disability as a form of oppression created by disabling societal attitudes and barriers towards people with impairments.

[3] Disabled Persons' Organisations are organisations that are led by disabled people for disabled people.

[4] Independent living (IL) is concerned with promoting disabled people's self-determination so that they have control over their lives and can participate in society like everyone else. Independence in this context is not about doing everything oneself but having control over your life, including the supports you may need for daily living. For many disabled people, a Personal Assistance Service, in which an individual is hired to assist with day to day tasks, directed by the disabled person, is central to IL.

Empirical work on CareVisions was also complemented by a series of public seminars and lectures over the course of the three-year project as a way of seeking to contribute to and build further public and academic debate around feminist care ethics, policy and practice. These were delivered by high profile national and international academics and activists within the care arena.

1.6 STRUCTURE OF REPORT

The report comprises six chapters. Chapter 2 introduces the project methodology, outlining the underlying ethical principles, research design and specific methods used. Chapter 3 focuses on a select discourse analysis of Irish governmental and policy documents as a means of illuminating the ways in which care has been understood in public and political discourse in Ireland. Chapters 4 and 5 focus on our empirical research with two groups in Irish society, disabled people and asylum seekers respectively, in the context of care relations and networks. Finally, Chapter 6 integrates the findings of Phase 1 and 2 of the project and proposes principles and actions for a radical re-envisioning of care relations in Ireland.

Methodology

2

2.1 INTRODUCTION

In this chapter, we document the methodological development of the CareVisions project, including outlining how feminist ethics of care principles underpinned the design and conduct of the project. A participatory research design was central to the project in order to foreground the lived experiences of those receiving and providing care, and to acknowledge that both are embedded in interdependent webs of care relations framed by societal norms, state policies and discourses. Below, we detail our considerations and thinking at each stage of the research process.

2.2 ESTABLISHING THE PROJECT: CO-CREATING VALUES AND RESEARCH PLANNING

2.2.1. Establishing the research team

The genesis of the CareVisions project was the philanthropic vision of the late Professor Geraldine Fennell who advocated for research to improve care relations in Ireland. In response to this commitment, we established a multidisciplinary team of five academics and researchers with prior experience, practice and current relations with diverse community groups and care organisations in Ireland. Team members had different disciplinary backgrounds (including social science, public health, and management). Two had co-established and led the care research group in UCC and all five had worked with different groups, including migrants, asylum seekers, disabled people and young carers in diverse capacities – through research, activism and policy advocacy. From the project outset, members of the research team reflected on how their background and positionality related to and resonated with CareVision's aims and objectives. For example, some team members wrote blog posts on the CareVisions website, articulating what had brought them to this project. The project embraced the concept of 'universal care' which implies that 'we are all jointly responsible for hands-on care work, as well as engaging with and caring about the flourishing of other people and the planet' (Chatzidakis et al., 2020: 96). Therefore, the project's very essence required an examination of and attention to its working relations from the outset, emphasising co-operative and supportive relations within its internal workings and external relations (O'Riordan et al., 2023).

2.2.2. Grounding the project in a feminist ethics of care

Prior to the commencement of the project, the research team informed and immersed themselves in key concepts and debates within feminist ethics of care literature, including the work of authors such as Nell Noddings, Virginia Held, Eva Feder Kittay, Kathleen Lynch, Fiona Robinson, Joan Tronto, Selma Sevenhuijsen and others. Thereafter, team members reflected on this material, discussed and debated the key tenets and their potential application to the CareVisions project at initial team meetings. Following this, two members of the research team conducted a literature review to ground the project design in key concepts of a feminist ethics of care approach emerging in different disciplinary literatures. They also foregrounded the contestations arising within, and in response to, feminist ethics of care scholarship – such as the tensions between calls for justice and care in the context of disability rights activism. This process culminated in the identification and articulation of the core values underpinning the project, namely interdependence, relationality, and recognising care as both personal and political.

2.2.3. Establishing the Research Advisory Group

To create deliberative and participative spaces to enable debates about care from diverse perspectives, we next established a Research Advisory Group comprised of individual scholars, activists, and practitioners from academia and community groups (please refer to page 5 for membership of this group). This group included carers' and migrant rights' organisations, disabled people's rights and feminist activists, social policy, philosophy, and sociology experts, as well as those with caregiving and care receiving experiences. The Research Advisory Group met six times over the course of the project and was a vital sounding board and space for discussion of key elements of the research, including decisions about the research design, interpretation of emerging findings, and discussion of possible ways to communicate and disseminate the research findings to diverse audiences. In particular, the group played a critical role in keeping the research team up to date with continuing developments happening in the care policy arena and other related policy spaces, which ensured that the emergent findings remained relevant to the dynamic care context in Ireland.

2.2.4 Ethical statement

As researchers based in a university, we recognised that we are bound by formal ethics procedures as set down by UCC's Social Research Ethics Committee (and approval for the project was granted through SREC). Through this process, we are committed to principles of informed consent, to minimising harm to research participants, respecting participants' privacy, and developing inclusive research practices. However, within the research team, we also recognised that ethical considerations extended beyond the formal processes of university research ethics committees. In conjunction with the Research Advisory Group, we therefore developed an ethical statement for the project which sought to articulate the ethical principles underpinning our research practice, including around research design and how we involve people in, and communicate about, the project (see Appendix A).

2.3 RESEARCH DESIGN PHASE 1: DISCOURSE ANALYSIS

As a way of seeking to understand how care is currently understood and referred to Ireland – and was represented and constructed during the pandemic - we chose to undertake a discourse analysis of selected policy processes. After exploring potential options, we alighted on two processes which were on-going during the first year of the project, when COVID-19 was at its height. The first of these was the Citizens' Assembly on Gender Equality (2020–2021), and the second was the Houses of Oireachtas Special Committee on COVID-19 Response (2020). The purpose and nature of each 'process' was quite different. The Citizens' Assembly on Gender Equality (2020–2021) was one of a series of Citizens Assemblies which have been held in Ireland to examine issues of public importance: it was a deliberative process in which a nationally representative sample of the population was selected to input into deliberations about different aspects of gender equality, supported by an expert advisory group and civil service secretariat. Whilst care was not the primary or only focus of the Assembly, it formed one of the 'modules' under examination by citizens. The Special Committee process was a cross-parliamentary committee established to examine the government's response to COVID-19, the end product of which was a report with multiple recommendations. Again, care was not stated as a core focus of examination for the committee, but we selected it as a way of understanding how care might be visible (or not) in debates about COVID-19. For both processes, we analysed different forms of documentary evidence, including final reports and hearings of and submissions to the Committee/Assembly. Findings from both analyses and details of the analytical approaches taken are presented in Chapter 3.

2.4 RESEARCH DESIGN PHASE 2: DEVELOPING EMPIRICAL WORK WITH DISABLED PEOPLE AND ASYLUM SEEKERS

2.4.1. Choosing Priority Groups

For Phase two of the project, we wanted to explore experiences of care, care relations and networks within different groups in Irish society. Following consultations with the Research Advisory Group, community-based organisations, and respective community members, we coalesced on two priority groups for the empirical phase of the project: disabled people, and asylum seekers in the international protection system in Ireland. These two groups were chosen because their relationship with care has been fraught with tension, or in some cases rendered invisible. For example, whilst asylum seekers may come to Ireland seeking international protection, they do not tend to be perceived as care receivers – nor are Direct Provision centres thought of in terms of spaces of care. Similarly, as articulated in Chapter 1, disabled people's lives have often been shaped by negative encounters with care and the term itself can be highly problematic given its association with paternalism and vulnerability. We therefore selected these two groups as we wanted to explore some of these tensions and dilemmas and ask what a re-envisioning of care might look like for these groups.

In the case of both groups, we had four key questions that we were seeking to address:

- How do disabled people/asylum seekers give meaning to care in their everyday lives, both as receivers and givers of care?
- How do disabled people/asylum seekers describe and experience their care networks?
- In what ways did COVID-19 impact, alter or disrupt their care networks, and with what effects?
- How, if at all, has COVID-19 led to a rethinking of ways in which care practices and relations might be reconfigured for disabled people/asylum seekers?

While the research questions above guided our engagement with both groups, each strand was designed as a discrete process and we met with representative organisations and members of both groups to co-develop the research design, contexts and materials.

2.4.2 Working with disabled people

Our engagement with disabled people recognised and was deeply sensitive to the ongoing epistemic and political contestations that frame ‘care’ in the context of disability, as well as critiques of processes and social relations of research production within the disability arena. These have emanated from a prior history of potentially exploitative research relationships between (non-disabled) researchers and disabled people as research ‘subjects’ which have done little to improve the lives of disabled people (Oliver, 1992). In working with this group, we recognised the need to create and prioritise ‘a ‘discourses bridge’ between feminist and disability perspectives on care’ (Hughes et al. 2005:271; McLaughlin 2020).

Reflecting the participatory emphasis of the project, we did not begin with a prescriptive research design, but rather engaged in an iterative process and series of conversations with disabled people and DPOs. Following these conversations and subsequent discussions amongst the research team, we co-created a multi-method research process. At its heart was an online focus group process made up of a group of nine disabled people with physical and sensory impairments who were members of a DPO. Importantly, however, participants took part in the research in a personal capacity, rather than as a representative, or voice, of the DPO. Participants lived in different parts of the country and had different living and support arrangements, although all were living in the community. Five were living alone, and four were living with others, including spouses, partners, children and parents. Five received a Personal Assistance service, while others received home care hours and had had experience of using respite care/services. The majority of participants had physical (mobility) impairments; one person had a visual impairment. Ages of participants ranged from twenties up to seventies, with the majority being aged between 40 and 60.

The group met four times online for two hours over a period of nine months (August 2022 – March 2023). At each session, the group discussed a different theme: these themes were decided with the group at the start of the process. They included understandings and meanings of care; exploring care relations, networks and services; discussing impacts of COVID-19; and thinking about how we might understand ‘good care’. The focus group process was complemented by semi-structured interviews with each individual participant (some of these took place face-to-face, with others online). The purpose of the interviews was to explore in more depth some of the themes discussed during the focus groups, particularly in terms of individuals’ complex care networks and relations.

We were very cognisant in organising the focus groups and interviews of the significant time demands for participants, and of planning around the work and also the personal assistance, care and support schedules of participants. Not all participants were able to attend every single focus group, for example. While we also proposed the use of diaries to participants as a way of recording their thoughts and feelings about the issues discussed in the groups, no-one chose to take this up. On reflection, such an exercise was potentially too burdensome on top of participation in interviews and multiple focus groups. At the end of the series of focus groups and interviews, we held two meetings with the group to present initial analysis, discuss the presentation of key findings and identify possible areas for future action.

2.4.3. Working with asylum seekers

Residents in the DP system were chosen because their experiences highlight care deficits within a state protection system that are typically not considered in care discourses. The Irish State system for international protection accommodation, known as Direct Provision and Dispersal (DP), is an institutional setting which asserts control over people and the physical space they live within. It was introduced in 2000 following a rise in numbers of people coming to Ireland seeking international protection throughout the 1990s. The DP system provides asylum seekers with shared hostel type accommodation and small weekly financial allowances. There are specific house rules applied locally in centres to which residents must comply.

They include, for instance, rules on visitors – who, when and where they can visit – as well as rules on what can be stored in rooms and rules on eating/cooking times. Since its introduction, it has been widely and consistently critiqued as limiting people's freedom to integrate and as causing further trauma (O'Riordan, 2020). Two of the research team had long standing relationships with non-governmental organisations (NGOs) working with groups representing migrants and asylum seekers: specifically, Cork Migrant Centre and the Movement for Asylum Seekers Ireland (MASI) which support the wellbeing and social integration of asylum seekers. Building on this, the research team co-created the themes and approaches for our study with asylum seekers. We recognised that potential participants might wish to be involved in different ways due to a diversity of barriers and that they also might require material support to enable their involvement.

Initially, one Research Advisory Group member facilitated an introduction to six women working in the care sector and living in DP. We then held three, hour-long online exploratory meetings at various times with these six participants. It was extremely important to accommodate their schedules as they balanced work, including night shifts, some very complex and time-consuming travel arrangements, childcare and other self-care commitments. During these initial meetings, we collated and reviewed co-created topic guides relating to their experiences of care work and their lives in DP, which we agreed that we would explore further with the wider group. Separately, we began recruiting participants through Cork Migrant Centre, MASI and Clonakilty Friends of Asylum Seekers. Our inclusion criteria were people aged over 18, who were living in, or had previous experience of living in DP, and who were able to understand and to consent to participate in the research.

The next phase of this study emerged organically because of the establishment of a community garden in Cork city in partnership with Cork Migrant Centre, shortly after the commencement of our exploratory discussions with the six women. We recognised that this was an opportunity to discuss our study face-to-face with potential research participants in a natural setting.

In the end, then, we devised a research process with three strands. Strand i focused on experiences and conditions of care within Direct Provision centres during COVID-19. Strand ii focused on experiences of asylum seekers working within the care sector. Strand iii explored engagement with community garden initiatives as a way to explore 'universal care' of people and planet. **Table 2.1** summarises the three strands, the participants and different methods involved.

2.4.4. Research ethics

Approval for the research was sought and granted by UCC's Social Research Ethics Committee (SREC). In both strands of the research, we ensured that information about the project was accessible, and sought and gained informed consent from participants. We met with participants to explain about the research before seeking consent and were available to address any queries participants may have had before and during the research process. All interviews and focus groups undertaken were recorded and transcribed, and the transcripts sent back to participants for checking. We are particularly aware of the sensitivities of the topic area for both groups – sensitivities which for some individuals, involves fear about the consequences of 'speaking out' about poor conditions of care. In order to protect participants' privacy, therefore, we have used pseudonyms and provide only a generalised profile of our participant groups. Emergent themes were also regularly discussed and debated within the team and wider Research Advisory Group.

2.4.5 Data analysis

Analysis of data for both strands employed a thematic approach, identifying and coding transcripts and field notes using both manual and computer-assisted analysis (via NVivo). In both strands, two researchers took the lead in data analysis – initially coding data individually and then coming together to compare and discuss emergent themes. These were then discussed with wider team members. The thematic findings from both research groups, disabled people, and asylum seekers, are outlined and discussed in Chapters 4 and 5 respectively.

2.5 DISSEMINATION AND ADVOCACY

As part of our political and advocacy role, we prioritised ongoing communication via our website, social media and other means throughout the project. We also regularly hosted seminars with Irish and international speakers on care-related issues. The purpose of these seminars was to encourage and promote academic, policy and public conversation, participation, and debates about care issues in Ireland. A full list of project briefing papers and conference presentations is available at **www.carevisionsucc.ie**.

TABLE 2.1: PARTICIPANTS, METHODS AND TIMELINE OF THREE STRANDS OF RESEARCH WITH ASYLUM SEEKERS

STRAND THEME	PARTICIPANTS	METHOD/TIMELINE
i. Conditions and carelessness in DP during COVID	Four participants: two men and two women, three raising children in DP. Countries of origin in sub-Saharan Africa, three still living in DP in various counties at the time. All had been involved in transfers between DP centres during the initial outbreak of COVID.	Case study interviews online March - April 2022
ii. Asylum seekers working in care	Six participants: all women. Countries of origin in sub-Saharan Africa, all working in health and social care while living in DP centres in various counties, during the initial waves of COVID.	Semi-structured interviews online June - September 2022
iii. Care of people and planet in community gardens	Two locations: International Garden, Ardfoyle, Cork city; Friends of Asylum Seekers Community Garden, Clonakilty, Co Cork.	Participant observation Spring/Summer 2022 and Spring/Summer 2023
	Women participants (five in Clonakilty, fourteen in Cork), various countries of origin, either living in DP centres in various counties and participants living in their own accommodation after receiving permission to remain in Ireland.	In-person focus groups Clonakilty, November 2022 and Cork, June 2023
	Two participants, women, various countries of origin, living in and raising children in DP. One interview with two participants; one who has recently exited DP and the other a resident in DP. Country of origin in Sub-Saharan African.	Semi-structured interviews, in-person at community gardens. Clonakilty: November, 2022 and May, 2023. Cork: 22nd October 2022.

Analysing Care Discourses In Ireland

3

3.1 INTRODUCTION

As part of the analytical work of the CareVisions project, we sought to explore the ways in which notions of care have been deployed and developed in public and political discourse in Ireland. Discourse analysis can enable us to explore how particular issues are understood, interpreted and 'problematized' in society (Bacchi, 2009). By analysing specific texts, language, and indeed, policy processes, we can see who or what issues are foregrounded, while also identifying the silences in policy and public spheres – that is, what is not said.

To understand contemporary political and public understandings of care in Ireland during and beyond the pandemic, we selected and interrogated two policy or governmental processes: the Citizens' Assembly on Gender Equality (CA) which took place between 2020 and 2021 and the Houses of the Oireachtas Special Committee (SC) on Covid-19 Response (2020). It should be noted that neither of these processes is focused solely on care: the CA was a wide-ranging deliberative process which examined many facets of gender equality in Ireland, of which care was one. Similarly, the SC involved a cross-party parliamentary process designed to explore how the state had responded to the COVID-19 pandemic in multiple areas of life, from health care, to education, to the economy and so on. It is nevertheless pertinent, given the significant care challenges and inequalities illuminated by COVID-19, to explore how far, and in what ways, care was understood and referred to in this parliamentary process designed to interrogate state responses to the pandemic.

In this chapter, we summarise some of the key findings from the discourse analysis of each of these processes and bring together conclusions across the two[5] to make some key points about the way in which care has been understood in public and political discourse in Ireland. Our starting point for doing so is feminist ethics of care thinking, which as outlined in Chapter 1, seeks to reinstate care as 'the basis of citizenship, of solidarity and of justice' (Williams, 2012: 115), and move care from beyond the private sphere into the public and political domain. This analytical framework enables us to explore the silences and limits of care discourses but also what might be different if we were to apply a feminist care ethics lens. The two processes involved slightly different discourse analysis methods, but both engaged in analysis of documents, hearings, submissions and reports produced as part of the two processes. This chapter draws on findings published in Daly and Edwards (2022), Loughnane and Edwards (2022) and Loughnane et al., (2023), and more detailed discussion, including an outline of the methodologies utilised, can be found in these articles.

3.2 THE CONTEXT OF CARE IN IRELAND

An analysis of both processes needs to be situated within historical and contemporary care relations and policy in Ireland. Ireland's historical development as a gender-conservative, low-tax welfare regime continues to shape care policy and practice (Dukelow and Considine, 2017; Cullen, 2019; Cullen and Murphy, 2020). Within the State's Constitution, care has been articulated via Article 41.2, colloquially known as the 'woman in the home' clause, as a private function of the patriarchal family – and of women specifically (Government of Ireland, 1937).

---

[5] There are different methods of discourse analysis. In this study, we used two different approaches, one drawn from Bacchi's (2009) 'What's the problem represented to be?' approach (for the CA analysis), and the other from Sevenhuijsen's (2004) Trace method (for the SC) which utilises a feminist ethics of care lens to trace care discourses constructed in policy documents.

Historically, care services have developed in a residual manner, reflecting care as a form of charity bestowed by the state, rather than citizen entitlement (Fischer, 2011; Van Aswegen et al, 2019). Gendered caring expectations of women and men have remained relatively fixed (Government of Ireland, 2021). Following an 'unsupported breadwinner model' (Ciccia and Bleijenbergh, 2014: 70), the Irish state has required increased labour participation by women without equivalent public childcare provision. Marketisation is also a key and ever-increasing feature across all care sectors as a result of recent austerity cuts, competitive tendering and a significant growth in large institutional investors entering Ireland's care market (Cullen, 2019). Low wages and job precarity for formal carers have limited the attractiveness of paid care work, provided by an increasingly migrant workforce (Cullen, 2019). Informal caring is supported via means tested income supports, rather than the provision of universal care services (Hanly and Sheerin, 2017).

Ireland's policy trajectory has been shown to have explicit gender effects. National research demonstrates that, on average, women spend double the time of men caring (Russell et al., 2019), despite growing policy discourse on men as carers. In Ireland, the COVID-19 outbreak exposed the scale of care needs across society, as well as the limitations of care services and supports. Ireland's 'long history of leaving care work to women' (Dukelow and Considine, 2017: 328) was evident in the total lack of childcare, even for front-line health staff, during the first COVID-19 lockdown (Hick and Murphy, 2021). Indeed, the state was heavily critiqued for operating a 'gender blind policy response' (Cullen and Murphy, 2020: 355) during the pandemic, which failed to recognise the disproportionate informal and formal care burdens that fell on women during this time.

Notwithstanding the significant work undertaken by non-governmental organisations in the care arena, care in Ireland has not been a coordinated policy space. Rather, debates about care have focused on specific groups of care receivers (older people, children, for example), care givers (including family carers), and particular service settings. However, partly in response to the emergence of the European Commission's European Care Strategy (2021), which requires member states to submit a National Action Plan on Long-term Care to the European Commission in 2023, there is a renewed focus on rethinking and prioritising care in the policy sphere in Ireland. In particular, the Irish Human Rights and Equality Commission's Policy Statement on Care, published in July 2023, recognises care 'as a human rights and equality issue', that 'cannot be uncoupled from gender equality and the realisation of other fundamental rights, including to health, family life and full and effective participation in society' (IHREC, 2023: 10-11). It makes a number of wide-ranging recommendations, including establishing a National Planning Unit for Care, implementing a life cycle approach to care services and providing adequate recompense and employment rights for care workers. Crucially, it calls for more radical transformative solutions to the care crisis which recognise the need to 'prioritise the de-privatisation of care services by investing in a publicly funded and non-profit care infrastructure' (p.4). The proposed referenda on gender equality designed to repeal the outmoded 'women in the home' clause – one of the recommendations to emerge from the CA - is also an opportunity to reflect on and rethink the position and value of care within Irish society and is increasingly bringing care into the political spotlight.

3.3 ANALYSING THE OIREACHTAS SPECIAL COMMITTEE ON COVID-19 RESPONSE

The Houses of the Oireachtas Special Committee on Covid-19 Response (SC) was a process in which the Irish state sought to assess its response to the pandemic through the formation of a short-term parliamentary committee. The Committee was established on 6 May 2020 and was made up of 19 Teachta Dála (TDs, or members of the Irish parliament) from across the political spectrum. Its remit was broad, and it sought to explore the impacts of COVID-19 across a range of sectors of the society and economy (Daly and Edwards, 2022). Through a series of hearings and submissions, the key output of the process was a report issued in October 2020 (Houses of the Oireachtas, 2020). Our analysis of the SC report and associated documentation revealed a number of key findings, which we expand upon here (see Daly and Edwards, 2022). These are: a circumscribed understanding of care which is limited to health care and specific congregated settings; a reinforcement of categories of care receivers and givers, which draw on sometimes problematic understandings of 'vulnerability'; and a lack of gendered analysis and understanding of the impacts of the pandemic on care (Daly and Edwards, 2022).

3.3.1 Limited understandings of care

Our analysis of the SC illuminates the limited understandings of care in political discourses. The Committee's identification of care, and care discourse, was limited to specific contexts and settings. Care was not articulated as a value, for example, but predominantly discussed in relation to the formal healthcare system and spaces of care such as congregated settings (hospitals, nursing homes, and international protection accommodation for asylum seekers known as Direct Provision) (Daly and Edwards, 2022). The report briefly references the impact of societal lockdowns on Health Service Executive (HSE) home care supports. However, there was only minimal recognition of the high levels of informal care that was taking place in the more private domain of the household, and this recognition was partial; for example, mention was made of older people and people with disabilities receiving informal care in the home, but there was little recognition of childcare taking place in these spaces.

Particular attention was given to nursing homes as a site of care failures. Care in nursing homes was assessed as suffering due to 'systemic issues that led to poor outcomes for residents' (Houses of the Oireachtas, 2020: 14). The Committee acknowledged, however, that at that time it was unable to establish why deaths in nursing homes represented '56 per cent of all deaths in the State from Covid-19…totally disproportionate for a group comprising of 0.65 per cent of the population' (Houses of the Oireachtas, 2020: 12); it subsequently called for the establishment of a public inquiry on nursing home deaths (Daly and Edwards, 2022). Despite calls from bereaved families, carers and some politicians, at the time of writing, no public inquiry has been established.

Despite the narrow understanding of care articulated by the Committee due to a restrictive focus on the performance of formal health and social care systems, there was a recognition of the problematic nature of the 'care market' shaping Ireland's health system. For example, the Committee critiqued the privatised model of care provision which has resulted in 'eighty per cent of residential care being in the private sector' (Houses of the Oireachtas, 2020: 13) and lamented changes in oversight from 'a State-controlled one to a slightly distanced one' (Houses of the Oireachtas, 2020: 34). It was suggested that the fragmented care market had contributed to poor communication between hospitals, and private sector nursing home providers (Daly and Edwards, 2022).

The Committee asserted that a new 'model of care' for older people was needed (Houses of the Oireachtas, 2020: 14) and issued policy recommendations which could encourage new models of provision, including supporting older people at home through publicly funded and provided community care and creating 'person-centred integrated systems of care which support people to stay in their own homes and receive care in the community where possible' (Houses of the Oireachtas, 2020: 63). Whilst such proposals may appear progressive and reflect the existing trajectory of policy in this area to a certain extent, they remain ill-defined. The principles of person-centred care, for example, were not expanded.

3.3.2 Binary categories of care givers and receivers

Within the SC report, certain groups within society were designated as requiring care, namely older people, disabled people and those living in congregated settings. The Committee was particularly concerned about older residents of nursing homes, who were framed in the report as 'the population who were unique in terms of frailty and vulnerability' (Houses of the Oireachtas, 2020: 12). Such portrayals reflect ideas of welfare deservingness and the need to protect particular groups from risk; however, it sets older people apart as 'other' and has the potential to reinforce paternalistic notions of dependency, whilst also hiding from view other groups with support needs (Daly and Edwards, 2022). The effect of paternalism was particularly evident in the context of disabled people, who were described in the report as having been significantly affected by the suspension of home care and other services, with some choosing to limit personal assistance services coming into their homes in a bid to prevent infection. Yet disabled people's narratives were presented in the report through the voices of care givers, with a significant emphasis on the challenges faced by family carers.

Understandings of vulnerability in the Committee's report were intertwined with institutionalised care contexts, with the Committee identifying that the State is 'over reliant on institutional care for our vulnerable population' (Houses of the Oireachtas, 2020: 14). These sites of care are also where we see discourses of vulnerability emerge in relation to care workers. The Committee sought to explore 'the impact on health care workers' (Houses of the Oireachtas, 2020: 10) as a 'priority focus', and the Report drew attention to the challenges faced by 'low paid vulnerable workers' which the Committee suggested fuelled COVID-19 transmission in institutionalised settings. Drawing attention to the precarious nature of care work, the Committee found 'workers felt compelled to attend for duty even though they were potential carriers of the virus due to the absence of income support if they reported sick'; thus, they were deemed to have 'posed a high risk of unwittingly transmitting the disease to residents' (Houses of the Oireachtas, 2020: 15).

We also see glimmers of an awareness which recognises the intersecting and overlapping identities of care giver and care receiver, with the Committee acknowledging that low paid nursing home and care workers included 'residents of direct provision centres and…migrant workers who, because of the low pay in the (nursing home) industry, were forced to cohabitate with fellow workers in over-crowded living conditions and thus also could not self-isolate' (Houses of the Oireachtas, 2020: 15). On the basis of these findings, the Committee issued the recommendation to 'make provision for statutory sick pay scheme to cater for low paid workers such as those in nursing homes' (Houses of the Oireachtas, 2020: 16). This recommendation, which resulted in the establishment of the Sick Leave Act (Government of Ireland, 2022), indicates the beginnings of a greater recognition of a renewed role for the state in intervening to create a 'caring infrastructure' (Chatzidakis et al., 2020: 65).

3.3.3 Lack of gendered analysis of care

There was little recognition in the Committee's work of the gendered burden of care shouldered by both unpaid care workers and those working in healthcare during the pandemic. This is perhaps not surprising given the persistence of gender inequality in Ireland with structural barriers including the continued reliance on a 'modified male breadwinner model', and limited supports for caring (Russell et al., 2019: ix; see also Cullen and Murphy, 2017). Indicative of this was the total lack of provision of childcare in Ireland for working parents during the pandemic, even amongst critical health care workers (Hick and Murphy, 2021). The only mention of disproportionate gender burdens in the Final Report is drawn from a submission from the Irish Federation of University Teachers which outlined that, in addition to 'maintaining caring responsibilities' at home, women working in higher education also provided pastoral care for students and colleagues (Daly and Edwards, 2022). These women workers asserted that this 'aspect of gendered impacts is a reality which must be acknowledged and factored into the assessments of this crisis' (Houses of the Oireachtas, 2020: 53). This sole acknowledgement of gendered imbalances of care in the report sits in stark opposition to the narratives of many women and women's organisations at the time who illuminated the multiple ways in which the pandemic intensified and exacerbated gendered care burdens.

3.3.4 Assessing recommendations for change

The SC made 11 key recommendations as a result of its inquiry and discussions and referred a further set of matters to sectoral Oireachtas committees. There was a critique expressed of current systems, particularly in the context of privatised nursing home care, the inappropriateness of institutionalised care settings, and the consequences of low paid work. This critique could have been said to have contributed to the introduction of the Sick Leave Act (2022) and also the recent announcement by the government that they are establishing a Commission on Care for Older Persons (McHale, 2023). However, the suggestions for tackling the privatised nursing home system for example do not suggest a radical transformation in terms of policy direction (a publicly funded and provided health and social care system, for example). Rather, the committee recommended changes that tinker at the edges, such as greater monitoring of nursing homes by HIQA and more training and regulation of healthcare staff. It is important to ask questions therefore about how far the experience of the pandemic has led to any significant change of approach in terms of existing care infrastructures and policy trajectories.

3.4 ANALYSING THE CITIZENS' ASSEMBLY ON GENDER EQUALITY

The Citizens' Assembly on Gender Equality was established in 2019 by the Irish government to make recommendations to advance 'gender equality' across a range of areas, including the Constitution, gender norms and stereotypes, work and social protection and care (Loughnane and Edwards, 2022). The CA was comprised of 99 members of the public, selected by a polling company to be nationally representative by gender, age, region and social class. As part of the CA process, members received presentations from experts, advocates representing civil society groups, and individuals with lived experience. They heard summaries of public submissions to the CA, engaged in Q&As, held private member-only discussions and refined their recommendations, concluding in ballot voting. For the purposes of this exercise, our analysis was focused largely on the care module which 'covered the treatment of care and caring in the economy and society, childcare, the experience of carers and those requiring care and Ireland's system of care for children, persons with disabilities and older people' (Citizens' Assembly, 2021: 112; see Loughnane and Edwards, 2022). However, we also make reference to the work and social protection module, in which paid and unpaid care work emerged as a particular focus (Loughnane et al., 2023).

3.4.1. Care as a problem of gender inequality

In contrast to the SC, care in the CA was related to and explained as a problem of gender inequality and as central to women's dependency. Analysing the care submissions, the gender inequality at the centre of care was articulated as an over-representation of women in care, a reinforcing of gender stereotypes, the exclusion of women from public life, and poverty in the lives of women. It also articulated the dis-incentivisation of men to provide care, the lack of male role models and lack of paternity leave (Loughnane and Edwards, 2022). The CA drew attention to deeply entrenched norms which continue to associate care with women's work and highlighted the impact of care inequalities on women - including the impact of women's disproportionate (unpaid) caring activity on gendered labour market participation patterns, pay and social protection.

Paid care work itself was represented as precarious, low paid and devalued as a feminised profession, and in the work and social protection module particularly, there was some recognition of the complexity of care identities as fluid and intersectional. For example, it was acknowledged that disabled women, in addition to receiving care and support, were also carers themselves and parents. Paid migrant carers were also identified as requiring care services and supports (including access to affordable childcare) to be able to live their lives. Care however was frequently presented at the meetings as a pathway to get women into employment by creating care jobs and providing care services (such as childcare) that would enable women to participate in the labour market. While this recognition is clearly significant, there is a danger here that care becomes understood predominantly as in service to the labour market – that is, as something to be accessed and activated to enable more involvement in non-care employment (Loughnane and Edwards, 2022).

A focus was placed in the CA's representation of gender inequality on the role of men and also those beyond the gender binary in changing current care relations and practices. For example, in an open letter written by citizens at the end of their deliberations, they state: 'While there are still many inequalities in women's lives that need to be eliminated, we also recognise that gender inequalities are intensified by discrimination on other grounds. Men also suffer from inequality, lack of opportunity and discrimination' (Citizens' Assembly, 2021: 8). It was asserted that addressing gender equality would benefit men through such mechanisms as better parental leave and more balanced representation of women in public life, resulting in 'more balanced and inclusive policy and decision making' (p.88). Rather than addressing the systemic and structural basis of gendered care inequalities, however, attention was particularly focused on the possibility for salaries and career ladders to encourage gender equality. Solutions such as showing role models of different genders in different jobs, including care jobs, were proposed, and the goal of shared caring between women and men was strongly endorsed. Men were to be 'encouraged' to take up family leave and reference was made to the need to support men into care (Loughnane and Edwards, 2022). That it is still the case that women carry the burden of care in a world that undervalues caring was largely left opaque. Evidence shows that while there have been some generational shifts in men's engagement in caring (Hanlon, 2012), men's involvement is still often regarded as 'helping out' (Hoang and Yeoh, 2011). There was little recognition that some men, despite future supports, may not engage in care, and in particular in unpaid care work.

3.4.2 Care as a problem of the market

The second way in which care was represented at the care module was as a market 'problem'. Care was broadly constructed as services within a care market. This representation reflected both the make-up of current care provision which is dominated by the private sector and the way in which care thinking in Ireland, and consequently at the CA, appeared to revolve around the market (Loughnane and Edwards, 2022). At the CA, the need for care provision and services to be commercially viable was evident. For example, an advocate representing childcare providers stated that 'Even with the current level of state subsidies, providers face low and unpredictable profit margins'. Not-for-profit charitable disability providers were also constructed as having to maintain their market position and be competitive as an employer. Here, pay for care work was an outcome of market competition, rather than a reflection of the value of care as an activity.

The interweaving of the family and care provision was also consistently viewed through the lens of remunerated and unremunerated work. The CA's solutions to the challenges faced by carers was summarised by the call to 'recognise care as vital social employment and to pay carers for the value of the work done on behalf of the state' (submission excerpts). While improving supports for carers is essential, the CA's focus on paid care work and on monetarily valuing unpaid care work made care into a remuneration problem to be solved. Care value, it seems, could only be expressed in terms of recognition in the market (Loughnane and Edwards, 2022)

As in the SC, however, a critique of this marketized system increasingly emerged into view through the process of the CA. Critiques were expressed of a dysfunctional care market dominated by private providers and state subsidies, in which some private providers were described as making profits at the expense of low paid staff (Loughnane and Edwards, 2022). Citizens discussed preferences for greater public investment in care services and increased responsibility of the state around caring. Ultimately, the CA recommended that public services and social protection 'should be funded firstly though greater efficiency and accountability for public funding and reprioritisation between current spending and revenue raising' (Citizens' Assembly, 2021: 138). Yet despite recognition of market failings in current care provision, the care module largely proposed new managerial solutions, to be achieved via increased state investment and regulation in tandem with private providers.

3.4.3 Reflecting on the CA: recommendations and care silences

The CA's care module made a number of key recommendations as a result of its work. These included better pay and conditions for paid carers, improvements to welfare payments for unpaid carers, moves towards a publicly-funded childcare model, and improvements in person-centred services for disabled people and older people to live independently. In the work and social protection module, it also called for the piloting of a Universal Basic Income, as part of a 'fully individualised social protection system to reflect the diversity of today's lives' (Citizens' Assembly, 2021: 14). These recommendations sit alongside others, which include the amendment of the Constitution including Article 41.2 – an amendment that the CA deemed 'should be deleted and replaced with language that is not gender specific and obliges the State to take reasonable measures to support care within the home and wider community' (Citizens' Assembly, 2021: 53).

These recommendations can be seen as progressive in the context of Ireland's historical policy trajectory, particularly insofar as it challenges the state to take on greater accountability and responsibility for caring. However, reflecting from a feminist ethics of care perspective, we can see some on-going limits and silences in terms of care discourses. Discussions of care remained largely focused on particular services and specific groups of care receivers, while care as a practice was predominantly associated with employment (through care jobs, or by freeing up those with caring responsibilities to enter the labour market). In so doing, the CA paid less attention to the relational nature of caring and the universality of care needs.

3.5 DISCUSSION: BRINGING THE ANALYSES TOGETHER

Across the two processes, we can identify some common threads, limits and silences in terms of how care is spoken about and constructed in public and political discourse in Ireland. In the next sections, we identify some of these themes. It is important to note that the intention here is not to generalise findings from these processes; they each had different emphases and involved a range of different actors. Nevertheless, they shed light on to some of the assumptions and meanings accorded to care in the public and political arena.

3.5.1 What constitutes care?

As we outlined in Chapter 1, a feminist ethics of care perspective can help us understand care in multiple ways: in terms of values, relationships, but also care practices (the labour of care work, for example). Our analysis of both processes illustrates that there are often constraints and limits to the ways in which care as a concept is understood. In both the CA and SC, the predominant way in which care was understood was in terms of specific services and spaces, whether in terms of healthcare settings, childcare, or care work. There was occasionally articulation – in the CA, particularly – of the need for care as a universal social good or a value; some voices from advocacy groups also broadened the discussion by connecting care with rights-based approaches (Loughnane and Edwards, 2022). Overall, however, the concept of care was often ill-defined. In this context then, there was not wider thinking evident about what it might mean to place care at the centre of society, as a key societal value with political implications, or indeed, even as an activity and practice that has relevance beyond specific spaces and groups.

3.5.2 Who gives and receives care? Care giver and receiver identities

One of the key areas of our analysis across both processes related to who was understood and referred to as giving and receiving care. In both processes, we see some evidence of assumed care receiver identities. For example, older people, children and disabled people were frequently referenced in relation care receipt. These identities are not unproblematic and can reinforce ideas of a hierarchy of deservingness in terms of care, and of paternalism for some groups who are deemed to be 'vulnerable'. In terms of caregiving and care workers, the CA in particular acknowledged women's role and the significance of migrant women's (care) labour.

A feminist ethics of care approach aims to erase or disrupt the neat boundary between care givers and receivers by recognising that we all give and/or receive care at different times in our lives, and indeed simultaneously. In both processes, we see some awareness of the intersection and fluidity between care giving and receiving identities: for example, both the SC and CA acknowledged that migrant care workers (including those living in Direct Provision) also require support with care; or that disabled people are also involved in caring roles in various capacities.

However, they stop short of recognising in greater depth the intersectionality of care relations, or what IHREC (2023: 24) defines as 'a framework for understanding how dimensions of diversity interact with each other to shape people's experiences of care, whether they are carers or care receivers'. This analytical lens is vital however in enabling us to explore the compounded nature of care inequalities, including how marketisation increases gendered, racial and other inequalities in care (Loughnane and Edwards, 2022).

3.5.3 Care, privatisation and the market

As demonstrated by both analyses, 'care talk' continues to be dominated by discourses around the market. In both processes, this 'talk' shifts from tacit acceptance of care as a market-based service to a recognition of the problems, challenges and deficits created by a marketized care system in which private sector interests are increasingly dominant. The privatised and fragmented nature of the nursing home sector, for example, was recognised as having had stark implications for older people's care during COVID-19, whilst the CA also questioned whether 'good care' was achievable through the market. While there was some articulation of the need for new models of care and greater state management of care services, we do not see a radical or transformative break from existing policy trajectories (Daly and Loughnane, 2022; Loughnane and Edwards, 2022). There remains a tension in both processes then, of articulating the value of caring as a core function of society, whilst continuing to operate within, and support, a marketized care model. Fundamentally, this relates to Murphy's (2011: 46) assertion that 'Some areas of social life should remain outside market relations, because putting a market value on them destroys the very essence of what they are'.

3.5.4 Gendering and de-gendering care

While the CA made the interrelationship between care and gender inequality explicit as part of its remit, the SC illuminates the on-going gender blindness regarding care practices in Ireland. The SC report failed to acknowledge the gendered burden of care experienced by women during the pandemic, nor did it meaningfully identify or address the unprecedented challenges faced by a women dominated health workforce. We might understand this blindness as part and parcel of a situation in which 'male control of state institutions impact on women as primary carers, both institutionally and ideologically' (Lynch, 2022: 47), including through a lack of public debate about and investment in care infrastructure flowing from a (masculine) inattention to caring concerns (Loughnane and Edwards, 2022). Even within the CA, we can ask questions about the way in which the gendered care 'problem' was to be solved. For example, much of the focus within the care module was focused on moving 'unproductive' women into paid work, while there was little or no attempt to examine what Tronto (1993) has referred to as 'privileged irresponsibility' – that is, how certain individuals, including men, excuse themselves from caring activities by using 'passes', such as the pass of being a productive breadwinner.

3.6 CONCLUSIONS: REFLECTING FROM THE FEMINIST ETHICS OF CARE

Our analysis of dimensions of the Citizens' Assembly on Gender Equality and the Houses of the Oireachtas Special Committee (SC) on Covid-19 Response leads us to suggest that there is a need for a more fundamental and wide-ranging conversation about what it might mean to place care as a value at the centre of society and politics, rather than as a practice that applies only to specific groups of people or sites and services. Moving away from the idea of binary care givers and receivers means paying more attention to the fluidity and complexity of care relations, practices and identities: this should not however ignore the significant gendered, ableist and racist harms that have been enacted in the name of 'care' or the multiple ways in which care inequalities can intersect in people's lives. Indeed, feminist ethics of care perspectives acknowledge the need to confront and acknowledge the troubling or 'dark side' of care if we are to challenge and unsettle stereotypical ideas of care givers and receivers (the passive, dependent care receiver or the selfless, 'heroic' care giver, for example) and alternatively identify and define 'good care'.

Our analysis further indicates a need for greater reflection on how we might understand and talk about care beyond a form of exchange value in the market, and on the current challenges presented by the increasing marketisation of care provision. This was a recurring theme in both processes and raises broader questions about who the appropriate providers of care should be within a reconfigured caring society.

Finally, the operation of both processes also raises questions about how we engage the voices of those who give and receive care in public conversations and deliberative fora. Feminist ethics of care scholars refer to a need to undertake 'care full deliberation' (Barnes, 2012) in participatory spaces which involve focusing on how deliberation takes place (not just through conventional committee fora or modes of communicating, for example, but through other modes that might include narrative, story-telling and space for emotion). There is evidence that whilst both the CA and SC provided some space for diverse voices to be heard in the deliberative arena, there were also limits and closures to these discussions (Daly and Edwards, 2022; Loughnane and Edwards, 2022).

We therefore need to ask how a diverse range of voices – including those most affected by care experiences – might be brought to the centre of public and political debate.

Exploring And Rethinking Care: Disabled People

4

4.1 INTRODUCTION

In this chapter, we discuss the findings from our research process with disabled people. As outlined in Chapter 2, this process involved working with a group of nine disabled people who were members of a Disabled Persons Organisation (DPO) in Ireland. Central to this process was a series of four online focus groups which took place over a period of nine months. These group discussions were complemented by individual online or face to face interviews with each group member. After providing some context to debates about disability, care, and the Irish disability policy landscape, we address the findings in four sections: disabled people's meanings and understandings of care; exploring care relations and infrastructures; examining the impact of COVID-19; and exploring meanings of 'good care'. We conclude by outlining potential areas for action which were identified in collaboration with the group participants, and which contribute towards forming our re-envisioning of care at the end of this report.

4.2 CARE AND DISABILITY: AN UNEASY RELATIONSHIP

As we outlined in Chapter 1, debates about disability and care do not sit comfortably together. Internationally, there has been widespread critique from disabled people and DPOs about abuses and oppression that have been perpetrated against disabled people in the name of 'care' (Hughes et al., 2005; Kelly, 2014; Morris, 1997). Ireland is not exempt from this, as the abuses perpetrated in institutional settings bear witness to. Care has been associated with disabled people's passivity and dependence on (non-disabled) care givers, whether they be formal paid care workers, or indeed, family members. Building on these critiques, disabled people and the international Independent Living Movement (ILM) in particular have sought to re-assert the autonomy and rights of disabled people to make choices about their lives, including choices about how and in what form to receive support or assistance. Core to the vision of the ILM are personal assistance services, in which the disabled person is in control of their support needs and directs a personal assistant (PA) (rather than a care worker) to enable them to live as they wish. This model of service has been the policy trajectory in many European states, including Ireland, although there are variants of the model (for example, direct payments, personalised budgets) which have taken different forms in different state contexts (Nally et al., 2022).

Personal assistance promises a way of supporting and acknowledging disabled people's self-determination and rights to live independently. However, there have been some concerns expressed about how what we might term the 'personalisation agenda' is being understood and implemented in different states (McLaughlin, 2020; Power et al., 2022). Some critiques have come particularly from the UK, which has a long history of the use of direct payments to enable disabled people to purchase support services. Commentators have raised concerns that in a context of welfare austerity and service cutbacks, personalisation is a way for the state to save money and place responsibility back on to disabled people for their own service provision in an absence of collective welfare services (Dodd, 2013; McLaughlin, 2020). There is a danger that personalisation simply constructs disabled people as individual consumers in a marketplace, which is very far away from the ILM's collectivist roots and ethos and what it intended personal assistance to be (Dodd, 2013).

While the need to assert disabled people's rights and independence is without doubt, a more philosophical tension continues to occupy some scholars within disability studies, and indeed, those within the ethics of care. This is that the 'self' envisioned by the disability rights movement, and the personal assistance model, is very much an autonomous, individual self (Power et al, 2022).

This is a rather different understanding to that articulated by feminist care ethics, which recognises that we are all embedded in networks and relations which support our independence. It is for this reason that a number of commentators have suggested that it might be helpful to think in terms of a 'relational self', which recognises that 'autonomy is achievable only when support, advocacy and enablement are collectively in place' (Power et al., 2022: 226; Davy 2019). Thinking about dynamics of independence in this relational way may help to reassert the need for collective supports and societal responses and help to move away from individual consumerist logics in our approach to the provision of assistance and support.

4.3 SETTING THE CONTEXT: CARE LANDSCAPES AND DISABILITY POLICY IN IRELAND

The history of disability policy in Ireland is one in which institutionalisation and medicalised, paternalistic understandings of disability have dominated. Services for disabled people were traditionally provided by religious orders and charities, while there was also an expectation that families would take on caring roles for disabled family members. Only since the 1990s, with the publication of the Report of the Commission on the Status of People with Disabilities in Ireland (Commission on the Status of People with Disabilities, 1996) and a growing number of disabled activists and organisations (including the Independent Living Movement Ireland)[6] advocating for, and lobbying, successive governments, have discourses and policy trajectories underpinned by rights-based understandings of disability emerged. Ireland ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2018, but only after a significant delay due in part to Ireland's outdated and incompatible capacity legislation (the Lunacy Regulation (Ireland) Act 1871, which has since been replaced by the Assisted Decision-Making (Capacity) Act 2015.

Over the past 15 years, the government has published a flurry of policy documents stipulating the need for disabled people to transition from institutionalised settings and to lead independent lives in the community. This is underpinned by a recognition that there is a need for service support models based around individualised, personalised models of service delivery (Department of Health, 2012). Yet despite these policy pronouncements, progress remains painfully slow, and to date, government resources have not provided the necessary supports to enable significant change to happen. In the context of personal support at home, for example, the Health Service Executive (HSE) provides two forms of support: Personal Assistance (PA) hours and the Home Support Service. The former is used largely by disabled people with physical and sensory impairments but is not available to disabled people over 65; the latter is largely targeted towards over 65s, although as Carroll and McCoy (2022: 695) note, 'there may be a degree of interchangeability between these two services for persons with disabilities'. However, as research has shown in the context of PA hours, there are significant shortfalls and deficits which prevent disabled people deriving maximum benefit from the support. These include a significant lack of resources from the state which limits the number of PA hours that can be funded; disparities across the country in how many hours are allocated and what they can be spent on; and a lack of clear processes about how to apply for PA hours in different geographical areas (Carroll and McCoy, 2022). These deficits have led advocacy groups to argue that there is a need to place access to PA services on a legal, rights-based footing, in tandem with a cost of living payment which recognises the significant costs associated with disability (Independent Living Movement Ireland, 2023). Current deficits in PA services, combined with lack of access to suitable housing and community supports continue to lead to instances where disabled people are inappropriately accommodated in nursing homes (Pierce et al., 2018).

Research carried out in Ireland illustrates that these service deficits and disparities were also exacerbated during the COVID-19 pandemic. As Flynn et al (2021: 6) summarised at the time, 'Disabled people have been denied services, expected to isolate in their own homes, detained in nursing homes, and faced a higher mortality rate'. Many services were closed, and PA services were restricted meaning that some disabled people had to revert to moving in with family as their support network (Flynn et al., 2021; see also National Advocacy Service for People with Disabilities and Patient Advocacy Service, 2021). While restrictions have now lifted and many services have recommenced, the National Advocacy Service for People with Disabilities and Patient Advocacy Service (2023: 2) has drawn attention to the on-going impacts of the COVID-19 pandemic, noting that 'the residual impact will require significant management for some time to come'. This is a theme which we explore in more detail later in the chapter.

---

[6] ILMI is a rights-based, campaigning organisation led by disabled people. It collectively promotes disabled people's equal participation in society through independent living, choice and control, and challenges charity-based understandings of disability (see www.ilmi.ie).

4.4 FINDINGS

In the remainder of the chapter, we outline four key themes which emerged from the interviews and focus groups conducted with disabled people. All participants are referred to using pseudonyms.

4.4.1 Meanings and understandings of care

Participants had multiple, complex, understandings of the term care, that were sometimes held in tension. These understandings related to people's lived experiences and often changing understandings of the differences between care, support and assistance. Some participants described care in terms of specific values or positive elements of human nature such as kindness, reciprocity, or as Marie said, 'showing kindness and goodness, you know, the best of humanity'. Neil similarly stated:

> *'Yeah, I suppose it probably sounds silly but caring about someone, and it's about understanding and empathy and relationship, positive relationship-building and I think even dignity. And respect and I think, you know sometimes it can be very viewed very much as we only see maybe the medicalized side of care. But then there's also caring for each other. And you know the whole piece around relationships, whether it's intimate or not intimate and I think that's really important, as well of care'.*

While some participants recognised these positive values, they also identified the way in which the term attached to different groups in different ways. Drawing on personal memories, Aoife for example linked notions of care to older people, stating 'I hate the word 'care'…I don't know, I think it's because I grew up and my granny was in care for a long time. So—I think 'care' just kind of brings back horrible memories for me and kind of I always think about older people when I hear that word'. Others also recognised that while the idea of a parent caring for a child was seen as positive, care was perceived less positively in relation to groups such as older people and disabled people:

> *'… when Marie said about care of a child. That brings up in my mind straight away this very positive thing, you know, caring, loving, you know, for an infant, you know, especially now that I have a very young grandchild. You know, that loving caring. The same cannot be said for the, you know, for the idea of the older person looking for care or the person with a disability looking for care; that it brings about a negativity. There's a negative response' (Helen).*

Indeed, for many of the participants, care was understood in the context of care services, in the fight to access support and assistance, and in care deficits as they have been experienced by disabled people: these understandings were overwhelmingly negative and led people to question the usefulness of the term. Drawing on her experience of fighting for services, for example, Mary stated:

> *'Yeah, I would just say that when you said about, you know, what do you think about care, the first thought that comes to my head is pain. I feel completely betrayed by people who call services care services or carers. I've huge pain around it. But on the opposite end of that spectrum, I need to care for myself to live healthily and well. I need to be able to care for people, for the planet, for my life'.*

Recognising the historical disempowerment of disabled people within 'care' systems, Declan also stated:

> *'For disabled people, care is a loss of independence, a loss of power, being in a systematic structure, usually a private business arrangement where they undervalue you and you cover the costs… using the term care you are already starting from the backfoot'.*

Others agreed, and suggested care should be rejected as a term; it was simultaneously described as a 'very loaded word' (Marie) with 'too much baggage' (Declan). Sandra for example stated as a member of a DPO:

> *'We don't want care, you know, and that's our mantra. We want personal assistance. We want support. Like, carers in turn, in certain—in the old way of thinking, in that we need to be cared for, so we can't do anything by ourselves for ourselves, and we certainly don't have an opinion…the whole concept of care in the ordinary system of support is detrimental to the people that need that support because it's power over people. It's telling people what to do and not giving them any choice and control'.*

A key point to emerge from the group discussions then was a need to clarify understandings of care, in terms what it was and what it was not. Participants noted that discussions about care were constrained by societal perceptions and support/care systems which have restricted how care is understood, what care is, the value placed on it and to whom it is available: as Sandra said

> *'I think we have a sort of a system and ideology of what care is and I think an awful lot of people buy into that without thinking about it and then without thinking about the consequences of it'.*

These debates – and how disabled people can engage in redefining care and support – particularly came to the fore in discussions about distinctions between personal assistance and care, as we discuss here.

Meanings of care in relation to personal assistance

Debates around the meaning of care emerged particularly in discussions about the distinction between 'care' and personal assistance. Tara said:

> *'I'm very clear about it [difference between PA and carer], I wish everybody else was. To me, a PA is like literally the clue's in the name. They're a personal assistant to one or possibly two, but ideally one disabled person, like. And they are literally, you know your arms and legs—say you're blind, they could be your eyes'.*

While some participants described being 'irked' by people not recognising the difference, Tara stated 'I think as a society we need to be aware that people can choose to use whatever language they want and not be frowned upon if they use the word 'carer' as opposed to 'PA'. 'Carer' isn't a term that I like to use, but if somebody I'm working with says their carer, I can't jump down their throat'.

Many participants made a distinction between what they saw as care in the context of interpersonal relations with family, friends and others, and personal assistance – or 'what I need to lead the best life that I can' (Linda), - which they did not perceive as care. As Sandra said:

> *'I use personal assistants. It's important for me to live and work…they support me to do what I want when I want. So, I direct them in telling them how to, you know—what I wanted doing, how to do it, and I provide backup and training and make sure it's a very comfortable environment. Yeah, so like caring for me is like I care for my kids. You know, I looked after my kids when they were young. And obviously I care for my family. So caring is very different in my head, you know'.*

Neil similarly recognised this distinction, but also the importance of not jettisoning the term 'care' completely:

> *'And no, I think it's important to say as well, that care is and there are carers out there. You know when people do provide care and I think that's important. But what I would say is that my PAs provide me with assistance and support. But I do understand that there's care as well, and I think I said that in the first meet up, is that like I provide care for my parents and my siblings and my wife, whatever. So, I think care is important in our lives as well'.*

In drawing distinctions between that care provided by family and close others, and support provided by PAs, others indicated the fluidity and complexity of the care relationship at different points in people's lives. Marie recounted an example of this in stating:

> *'Well, actually it was a disabled friend, like—she's since passed away—who said, like, you know, when she was really sick she liked to—she lived in an apartment with her sister and PAs coming in and out. But when she was really sick she used to love to go to the family home to have her mother taking care of her, because—but then as she got better it was PAs and it was managing her life and so on'.*

Such an example illuminates how care provided by a close other can become important at particular times and is perceived as distinct from the support provided by personal assistants. However, as we discuss later, personal assistance services are also described by participants as having a socio-emotional dynamic or relational element, beyond what Shakespeare et al. (2018: 165) terms a 'commodified support relationship'. Understandings and meanings of care then are complex and while some participants wished to reject the term completely, others saw value in rethinking understandings of care that have been captured in societal narratives and stereotypes. As Neil stated :

> *''Yeah, I think again because it's the way that it's framed in Ireland, definitely. That it's just this idea that care is only for that 'the disabled', 'the elderly'. Whereas, no actually, care is for everyone. We're all gonna become disabled at some point in our lives'.*

4.4.2 Navigating care relations, networks and structures

A key contribution of a feminist ethics of care perspective is that it enables us to see the interconnections and networks that shape people's lives and contribute to relations of support. We can understand these networks at different scales or levels: for example, there are one-to-one (care) relationships which exist – with family, neighbours, friends, but also with paid support workers, for example – but these relations are also situated within wider systems, services and policies that shape people's lives (for example, care and support services and infrastructures). These relations cannot always be neatly bracketed off. Formal (paid) and informal care/support relations are intertwined and impact on each other – so for example, when paid support services are inadequate, it may have an impact on people's informal relationships with family or friends. We explore some of these dynamics in this section, focusing first on more intimate, interpersonal relations, and then exploring the wider context of care services and support infrastructures.

Relationships: with family, neighbours, PAs, care workers and community.

A key theme emerging from the research was the significance of relationships in enabling support and care. Participants had diverse family relationships and also spoke to us about other significant people in their support networks, including friends, neighbours, members of their local community, and the disability community. For some, their PAs were also part of these interpersonal networks of support. A key feature of much of the discussion surrounding these networks was the theme of reciprocity and the recognition that these are often 'two-way' support relationships. However, participants were very aware that society does not recognize disabled people as giving care, only viewing them as care receivers.

A number of participants experienced giving and receiving care within their family as a positive experience. This is care – and relations of care - experienced without externally imposed obligation. The reciprocity in these relationships was very evident. While some participants described having lived with their family for periods of time, or drawing on their support when it was needed, they in turn also offered support in a context where the caregiver role shifts between family members due to life circumstances, such as illness, ageing and bereavement. Where people have a PA service this can support them to be more actively involved in caregiving within their families (caring for older parents, nieces, nephews and so on), indicating the interweaving of informal and formal care/support.

Disabled people's caregiving within families took multiple forms, including helping out with childcare, providing financial support, and undertaking household and practical tasks, including organising hospital appointments for older parents. Highlighting the reciprocity of relationships, Marie for example spoke about the significant support her older sister gave her when she first acquired her impairment and was living at home; however, when she got older and left home, Marie provided financial support to her sister. Neil similarly described supporting his sister when she was sick, providing practical support, accompanying his sister to hospital appointments or doing school pickups.

Not all participants experienced family support in a positive way; they also described an enforced reliance on family care which can result from the scarcity of formal support and can cause difficulties within family relationships. People described how reliance on the family can create dynamics of control for some disabled people, such as where a family relies on carer and disability payments. These tensions in informal care arrangements – and within the care sector – can be difficult to confront. As Sandra stated 'An awful lot of disabled people don't have supports and they do have to rely on their parents or siblings, and that distorts their family relationship—mother, daughter, son, father, whatever. And that's wrong'. Similarly, Tara said, 'When you're relying on family members it's really hard for someone to go, 'I'm not happy, like.' Or like, you know, 'I don't want you to do it that way.' Because like—an awful lot of the ones [disabled people] that I've been working with at the moment they are living at home and their aspiration is to get out of home'. As we discuss later however, the 'formal' support system continues to make presumptions that family members will act in a caring role.

Participants also spoke about the mutual support relationships they had with friends and neighbours, and the other people, communities and even pets that they cared for. As Linda said, 'It isn't only family you take care of. You take care of animals. And I take care of a friend of mine. I do meals for him and stuff like that'. A key source of support for many participants given the profile of the group was also the wider disability community. Participants engaged in both giving and receiving this support from other disabled people in a range of different contexts: this included providing support (including peer support) around accessing services; support around experiencing a new medical diagnosis; creating infrastructures and spaces for disabled people to come together; and activism for practice and policy change. Aoife recognised the importance of sharing her individual experience as a disabled woman, saying, 'I have the experience, if you've got somebody who's coming up behind me to give it'. Pointing to the importance of collective action, Sandra also said: 'I do know how dark it is for an awful lot of people. I do think that individual activism doesn't work because it only works for the individual and not for collective. So we need collective change, I really do. I do—it's my lived and my learned experience that we need to build the capacity of disabled people to want more and to ask for more and to demand for more'. Indeed, a number of the group spoke about political activism as a form of care, illustrating how we might think more broadly about, or redefine the parameters of, what society understands care to be.

Relations with (paid) support workers and Personal Assistants

Participants reflected on their experiences and relationships with paid support workers, carers and Personal Assistants. Many described the very positive relationship they had developed through working with particular individuals over a period of time in the PA role, and it is clear that participants took their role seriously as leaders in terms of looking out for the welfare of their PAs. As Linda said:

> *'Because when you're a leader, you're not only looking after the day-to-day care of your PAs or are directing them, but you're also looking after their wellbeing, you're looking after any HR stuff, resolution stuff, you know, and there's—you're a manager. You're a manager. I'm a manager'*

Disabled people often described engaging in 'care' for their PAs; one participant, for example, described a situation in which they provided emotional support for their PA during COVID-19. Another described helping their PA out by lending them their accessible van to take other disabled people to appointments. However, they were also conscious of not over-stepping the boundary in terms of these relationships, and there could be significant emotional labour involved in managing them:

> *'I feel with my PAs I need them more than they need me...for example, I have a PA coming in at half-nine tonight and then, you know, I would just feel obliged to talk to her. And it is a sense of obligation. Because I feel like if I'm just sitting there reading my book, I'm ignoring her. Not that she'd quit the job, but I just feel like there's always that thing of kind of you have to engage with her and—whereas I've another PA...but she's the kind of person who will read her book, happy if I'm—if I'm just ignoring her and—you know, all sorts—we've worked together a long time, so we would even be in cranky moods around each other and nobody's going to take it personally, whereas when a PA's relatively new you can't—it's not fair on them.'*

Relationships with care or support workers were not always easy to manage when there was a high turnover of staff and different faces coming into the home. Participants described instances where workers were too busy to talk or where they felt dismissed or unseen. As a way of dealing with this, Mary said:

> *'One of the things that I insist on doing with the HSE is using names of carers when they're putting out a schedule for me. I'm a cover. Well, I'm not a cover, I'm a person who needs to get cover for tonight. And using the name, I've used it in order to humanise the situation. And I've asked them, at least give me initials so that I can put a face to who's coming into my home and not the other way. And I found it softened with the people that I talk to when you humanise it'.*

One of the particular tensions emerged around how the care worker – and the agency they work for – perceive their role, and what the participants expected from them. Some participants felt that the FETAC (Further Education and Training Awards Council) Level 5 training provided to care workers was not helpful in terms of developing the ethos and practice of Personal Assistance and independent living. Others felt that care agencies and organisations were overly concerned with issues of health and safety in the home and about 'trying not to be sued' (Helen). Some participants also recognised that where care workers or PAs may be coming from different cultural contexts that there could be divergent understandings of disability. Marie recounted a situation where a disabled person was staying out late, and the PA *'was horrified. 'But you can't go out that late. You have to be in bed by 9 o'clock.' And the disabled person was livid, you know, and she made a complaint about her. But like it was—you know, and I think when it was explained to, you know, the PA, she understood. It wasn't meant to offend, but it was a cultural—you know, like, you know, disabled people maybe are considered like sick people or needing that kind of looking after.'*

Participants identified that abuses could operate both ways within formal (paid) care and support relationships and acknowledged the racism that many care workers from migrant communities in particular can experience. One participant suggested that there was a need for disabled people to be aware of racism in the support relationship, as Linda said:

> *'We were brought up with racism. You know, and disabled people were all brought up with racism, so. But there was no chance of kind of—like, we haven't done any kind of programmes around racism, awareness around racism or around disablism or violence or—you know. Because we haven't done any training around that. And, you know, and I think that should happen.'*

More generally, participants were acutely aware of the poor working conditions and pay within the care sector, and argued that this needed to change if these roles were to be filled and valued by society:

> *'—if I was ruler of the world —!— The managers' wages would go to the carer coming in. I'd swap it all. I'd turn it on its head. I would give them the respect that they need...I would highly train them and pay them in accordance and give them the respect that they need. And that would change—be a game-changer, you know. If you've got a job that people respect, society respects, you know, and says, you know, wow, God, oh my God, you're a carer? Wow. How do you become one of them?' (Helen).*

Experiencing formal (paid) care systems and networks

Participants described their experiences in the context of wider (formal) care and support infrastructures, - that is, in seeking access to and using paid support services, which took different forms (PA hours, home support hours and respite in more institutional settings). It is very apparent from their narratives that there were significant deficits and inequalities shaping their experiences. These included a scarcity and uneven distribution of services and issues in terms of the more day-to-day relations with personal assistants or care workers

Participants also spoke about the increasing difficulty of recruiting PAs, which has intensified since the COVID-19 pandemic. There was a clear sense that the system of supports for disabled people has become increasingly fragmented, privatised and under-resourced, and that disabled people constantly have to engage in a battle to advocate for, and obtain, the support that they require to live in the way they wish. Indeed, fighting for services can be seen in and of itself as a form of care labour (Østerud and Anvik, 2023).

The inequity of support services and hours was visible within the group, with individuals having different levels of support, in part depending on where they lived in the country. Participants described a lack of transparency in how access to support hours were allocated, and the postcode lottery that existed within the HSE. As Neil stated:

> *'But I think that the way the HSE is split up in the nine CHO [Community Healthcare Organisation] areas. That doesn't lend itself at all, so there's no standard, no standardized approach. There's no centralized service. So, it's all a postcode lottery…So, one CHO gets way more money than the other. Then they can provide more, provide less. And then there's a lot of people blockage as well, like it depends on your who you are dealing with in the HSE. There's no standard assessment tool. That's massive. Like, you know, it's those who shout the loudest'.*

As he continued:

> *'Yeah, I would say like they're not really transparent in their policies, even like, you know, even if you look at the CHO areas in the HSE, they have policies where they provide support or care is priority 1,2,3,4,5. So priority one being personal care, showers, toilet or that priority five could be social care or social hours. Whereas, I disagree with that because my social hours are my social life which is just as important as me going for a shower because that's where you integrate, where you meet people, etcetera. You blow off steam after long working week, but the point is that these policies are not on the HSE websites…You have to request them'.*

The scarcity of services, opacity around the assessment process, and clientelism that exists within the system – in other words, trying to find that 'one good person' within the HSE who will assist – has a number of significant effects. It leads to situations, described to us by disabled people, where people acquiesce to or feel forced to accept forms of care or support that they are not happy with because there are no other options available to them (for example, being forced to go into respite as there are no PAs available). It also creates situations of inadequate support, lack of dignity and independence: many participants described new forms of 'domestic institutionalisation', where people are trapped within their own homes due to a lack of support hours and are required to live within rigid regimes of care to meet the demands of private care providers. For example, Mary described going to bed at 8pm every day because that is when the support workers come: 'I haven't seen a sunset for years' (Mary). Others described situations where, if they had the means, they would end up paying privately for services, without a personal budget from the state:

> *'But the fact is that for an awful lot of people they cannot get out of bed. They're left in wet beds. They're left to fend for themselves. I've had to pay out a lot of money for private care just to get up, just to get to bed, just to have my pad changed. It is criminal what's going on' (Mary).*

Another effect of service scarcity is the unrelenting fight to obtain support – as Helen stated, 'you have to fight for services, fight for every single thing' – which in turn makes access to services a competition that you have to 'win'. This has the potential to create divisions and tensions between disabled people themselves, and participants described a system that is engaged in a 'divide and conquer' (Helen) strategy. Moreover, engaging in constant advocacy and fighting takes an emotional and physical toll; some participants spoke about the dangers of making complaints about the lack of support, or the quality of the support available, as this could lead to the withdrawal of any existing service and being positioned as 'difficult' by decision-makers.

Despite the mantra of personalisation underpinning recent policy pronouncements, then, it was very clear that services are failing to provide many disabled people with dignified, independent lives. These failings in turn have an impact on disabled people's (family) relationships and other networks and illuminate the intricate intertwining of informal and formal care/support networks. As Neil stated, 'And when I was younger, living at home, my mother was my carer. Still really is sometimes when in lieu of PAs. So, for example, I have staff that work for me. But if push comes to shove and I'm really stuck I know my mother would step in, you know, and in a kind of an informal role, if that makes sense'. However, for others, reliance on family care, resulting from scarcity of formal support/care, was simply not available, or not appropriate given family relationships and circumstances.

It was clear that care systems continue to make presumptions about informal carers, and participants articulated that there was still an assumption from the HSE that family members would step into the breach if needed. Many recognised that there is an expectation on female family members in particular (mothers, sisters, daughters) to be available to care. This expectation is so strong that some disabled people do not disclose they have relatives to care managers.

As Helen said,

> *Yeah, I kind of think that the HSE, as being the body of care, or is supposed to be, you know, they use a kind of a secret kind of, you know, guilt on getting your family to care for you, you know. And it's usually if you're fortunate enough to have daughters, like I have. They never mentioned my son, you know… It's kind of a guilt trip. It's subtle. It's not outwardly said, but it's a subtle undercurrent'.*

Linda also stated:

> *'Even, you know, like I didn't get on with my family for a long time. I wouldn't have one of them caring for me, but there's still that expectation. And it's like are you f****** real?'.*

Long held gendered stereotypes about family caring and carers therefore persist, and as the group suggested, need to be challenged.

The impacts of privatisation on care and support services

Participants drew particular attention to the growing privatisation of care and support services, which they perceived as contributing to negative service experiences. Disabled people were conscious of the historical underpinnings – care as private family activity, care as charity – of current care regimes. They perceived that at the heart of provision for disabled people was a

> *'a state that only thinks about money… And we know that from every other issue they've dealt with, with babies, mother and baby homes, Magdalene Laundries. It's money, money, money' (Helen).*

Recognising that today, care is 'usually a private business arrangement where they undervalue you and you cover the costs' (Declan), participants suggested that there was an on-going retreat of the state from ensuring good care: 'without the backing of the state and the funding of the state to do it and the willingness of them [service providers] to do it's never going to happen' (Helen).

The state was perceived as hands-off from private providers: 'They don't get involved in the administration of the service once they've signed a contract, so then they leave it to the companies. And they are so afraid of the companies…' (Mary). Care services, increasingly reliant on HSE 'outsourcing' have developed into a 'a big moneymaking machine and we're the product of that machine' (Helen). Thus, the system was described as one in which 'the HSE has the money and they create private organisations who provide a service and get paid so much' (Declan).

Participants suggested that there was an intensification of the privatisation of care. As Marie stated, 'it seems like every month there's a new private agency opening up… and it seems to be a race to the bottom'; 'there's nursing homes opening every day of the week' (Tara); 'they're growing like grass' (Sandra).

People described increasingly feeling at the mercy of service providers and often unregulated 'private business-for-profit vultures' who are in the business of 'containment of individuals' (Helen) rather than of care/support. They perceived service providers as going where the money is; there was a strong sense that 'There's lots of money' and you can 'follow the money… to the big institutions' (Helen) but in 'the private companies there doesn't seem to be any accountability' (Marie). Simultaneously, there are shortages for those who need care/support and very poor conditions for staff. Helen, with her own history of working for private companies and for the HSE, reported

> *'If you worked for the private companies, they were interested in working you to death'.*

Participants were aware of better conditions (mileage expenses, cover for sick leave, etc.) and salaries for care/support workers in the HSE and some not-for-profit organisations.

In addition to prioritising profit over care, participants also felt that privatisation was contributing to the fragmentation of services, and a lack of oversight of care relationships and arrangements by authorities (often in a context where services were 'delegated' from the HSE to private agencies). For some, if they were unhappy with a service, this made complaining difficult, and often there appeared to be no long-term support worker or stable service provider to resolve issues with.

4.4.3 Exploring the effects of COVID-19

A key question for CareVisions was exploring the impacts of COVID-19 on care relations. The impacts of COVID-19 have been well-documented in a number of studies and our discussions very much reinforced these findings (Flynn et al.,2021; Shakespeare et al., 2021). Participants described being impacted in different ways, not just in terms of the practicalities of how support relationships and services were affected, but also in terms of the emotional impact of the pandemic. Feelings of fear, anger and isolation at the way disabled people were treated was accompanied by a growing awareness of the need for collective activism and online peer support.

Some participants described being relatively little impacted by COVID-19 in terms of their PA arrangements, as Linda said:

> *'… because I've PAs you know. It wasn't difficult for me, I have to say. Like, the only bit that was difficult, like, if a PA got COVID. There wasn't enough other spare PAs around. That was one difficulty. Other than that, like, I didn't feel any difficulty. I was very much in control'.*

However, others were impacted by the closure of services and experienced difficulties in trying to find staff to come into the home; they had to try and knit together a rota from an increasingly small pool of support workers. For some, this enhanced their feeling of vulnerability. Others described the isolation they experienced as they were increasingly confined to the home, whilst some spoke about being forced to move back in with family in the absence of support services, which reignited feelings of dependency. As Aoife stated:

> *'Yeah, it's kind—well, being in COVID and being in all the time I realised that the only way to get out was to be out with my mam and dad because I don't have a friendship group down here. …But it was hard to ask for them because I've been so independent for so many years and then—suddenly you're relying on your parents. It felt like I was going back to nearly being a child again…'.*

While participants identified specific impacts of COVID-19, they also recognised that the pandemic had exacerbated existing challenges in the care system. There was a sense that COVID-19 had exposed the state's lack of concern for disabled people's rights and independence, and participants were conscious of the re-emergence (or increased articulation) of negative attitudes towards disabled people. As Neil stated,

> *'But there was this generalisation that we were all high-risk, we were all vulnerable. If I had a euro for every person that said to me, 'Why are you out?', you know, during this… So, I think language was really important around Covid.'*

Disabled people were simultaneously viewed as vulnerable to, and potential carriers of, the virus, and narratives of perceived vulnerability and dependence of disabled people re-emerged in families, the community and wider society. As Tara said,

> *'And I think the whole perception of disability is never great now, but I think because of Covid the non-disabled people out in the world really are fearing disabled people'.*

Despite these negative impacts, participants also outlined the significant developments which had taken place in the space of disabled people's collective activism, facilitated by online communication platforms such as Zoom, described by one participant as 'the gift of COVID':

> *'Yeah, I did think there was one thing that was really positive. [Disabled Person's Organisation] set up Zoom groups and we started meeting about PA stuff. And that was great. That was great meeting other people from around the country who have PAs. And we weren't only talking about PAs, like, but it turned out that we were talking a lot about PAs. And as a result of that then I continued my—I made friends, you know, and we support one another' (Tara).*

Online spaces opened up opportunities for peer support, friendship, the running of specific courses (in yoga, for example), and also contributed to collective activism and policy development. For example, Neil noted how an online PA peer group came together and was able to input into a policy document produced by the HSE. As he also stated:

> *'some policies and spaces have kind of been engaged with, whereas beforehand it would have been difficult to get to those spaces in a physical format'.*

More broadly, the online space was seen as a vehicle for strengthening and bringing together the disability movement and disabled people who had never been able to get involved in collective activism before.

Participants however also expressed concern that some of these online spaces, opportunities for engagement and societal learning about disabled people's experiences during COVID-19 would be lost in the return to pre-pandemic 'business as usual'. Neil for example described how he hoped that:

> *'people might care a little bit more after the pandemic because they've realised what disabled people's lives are actually like every day… even around the vaccinated versus non-vaccinated getting in places and not getting in places, that's disabled people's lives every day, we can't get in some places because of the step'.*

However, many participants cautioned that these lessons had not necessarily been learnt and that COVID-19 had left a problematic legacy for disabled people in terms of a more restricted access to services, greater difficulties in recruiting PAs, and for some, the challenges of moving on from experiences of isolation and exclusion during the pandemic.

4.4.4. Defining 'good care' and imagining future care relations

Participants characterised the 'good care' that they give and receive in multiple ways. At its heart, good care was, firstly, care that is available and that is provided in a form the disabled person has chosen and secondly, that it is provided by a worker/ family member with good conditions of their own.

This core understanding of good care relates to ideas from a feminist ethics of care assumption that good care can only happen where support relationships are recognised as needing wider public and social supports. Defining ‘good care’, Linda stated:

> *‘Well, I think for me, what it [good care] means for me is that someone cares for me in the way I want to be cared for...That is good care, like. Not in the way they think it should be done. And that’s where you kind of like have to keep reminding them that, you know, that’s a very medical model or that’s very disablist or that’s very whatever’.*

Linking it to good conditions for both the care giver and receiver, Marie agreed:

> *‘I was going to say, like, good care is care that you actually want and is not imposed on you... So, I guess when it’s your choice, when the type of care that you’re receiving is the one that you actually choose. And I know there’s the receiver and then the recipient. And I guess from the person who’s doing that caring job, like, whether it’s, you know, voluntary, when you’re caring for a parent that you have the right supports. Not just in terms of getting sufficient maybe respite breaks, whatever, but like training in terms of patient handling and the kind of training that somebody would get if they were in a paid capacity’.*

There were relatively few examples of when the system itself facilitated good care; instead, good care was often seen to be provided in spite of the system and defined in terms of what it was not. As Helen said:

> *‘So how can I speak about the care that I think would be good care when you spend your—I’ve spent nine years looking for it, you know. I’m sorry, I just—just every time I think about it, it just gets me so angry...So, you know, I would say to you that good care is not having to fight like this’.*

Some people identified good care in terms of being seen and known as an individual with particular needs and preferences. People described moments of kindness, of human connection and touch which are often reliant on ‘one good person’ going out of their way. However, this also connected with times participants described support workers being exploited, for example when workers’ values and the relationships they built with disabled people would be leveraged by the system to encourage them to go way beyond their contracts, hours and responsibilities. This reiterates the importance of relationships between those receiving and giving care and highlights how these relations are undermined by the fragmentation of service provision and the time pressures on formal and informal support staff.

A focus on rethinking care often emerged from concerns about what the support/assistance future held for people. Rethinking is therefore often situated in concern and negative experiences. This connects directly to the current scarcity of services and the increasing shortage of PAs and care workers.

Two key approaches to rethinking care emerged from our conversations: individualisation of supports/care and standardisation of access/service provision. People in the group talked about the need for individualised packages of supports (linked to being seen as an individual with their own choices and needs) and a standardised approach to this provision, where equity would be achieved regardless of where in the country a disabled person lives (relieving the pressure to fight for care and overcoming the fragmentation of the current system). Participants also spoke about a one-stop system, that would be fully responsive to an individual’s needs. As Helen said:

> *‘The system is activated based on need, based on what is happening to that individual, and not leaving that poor individual stuck to go and try to find the care and the supports that they need themselves...One phone call, based on need, based on everything, sort of, in that blanket that would be wrapped around you...So the care coming into the house, the OT that needs - and that you are not expected to go and hound people yourself or to be made feel, you know, that you’re asking for the impossible or to be made feel guilty that you’re asking for some help or to be treated with disdain’.*

In the wider system, personalisation continues to evolve as a way to rethink care, but it only appears viable for people with a high-level PA package and if there is better availability of staff. There is a desire to embed the experience and expertise of disabled people in redesigning the support/care system. In particular, participants saw potential in training devised by disabled people for disabled people and for support/care workers. As Linda said

> *‘I think it’s—I think disabled people need to devise a programme, what caring is’. Marie concurred, saying, ‘I think it should—well, I think it would start with disabled people articulating what their vision of good care is or what they know bad care to be. But that would have to be the starting point’.*

A recurrent theme throughout our conversations was a desire to move away from the system’s expectations that families will provide a high proportion of care/support. This was connected with people’s desire for a strongly articulated and fulfilled right for disabled people to care/support services; for some, this right (to a PA service, for example) would only be achieved through legislation.

4.5 CONCLUSIONS AND IDENTIFYING AREAS FOR CHANGE

As we have shown in this chapter, care has contested meanings for disabled people. Many participants acknowledged the positive meanings that can be ascribed to the term – associating it with human kindness, reciprocity, dignity, and respect within relationships. These values were particularly evident in participants' descriptions of 'caring about' close others in their personal networks. Some participants also spoke about the reciprocal and interdependent nature of their relationships with personal assistants. However, it was also acknowledged that these values were absent from their experiences of receipt of formal care and support, such that care had become associated with negative and painful experiences. More broadly, participants highlighted on-going societal negative perceptions of care associated with particular groups in society, including disabled people and older people.

Countering these perceptions, it is very evident from our analysis that disabled people's support networks are built around relations of reciprocity – of care giving as much as care receiving. However, we also have to understand the complexity of how informal and formal care and support contexts intersect, and the implications this has for these networks of relations. Participants for example described how receiving a PA service enabled them to participate equally and engage in reciprocal relationships, including providing support for others (including family, friends, neighbours and the wider disability community). However, where failures by formal care and support services exist (for example, a lack of PA services or not enough hours), this creates barriers in terms of enabling reciprocity and can lead to renewed relations of dependency. To that end, disabled people's recognition as equal citizens also need to reflect and incorporate their practices of 'caring citizenship' (Sevenhuijsen, 2003: 193).

While a key focus of CareVisions was to explore the impact of the pandemic, it is notable that many disabled people did not see its impacts as surprising or new. Rather, they were seen as an intensification of already existing processes and social relations that had been taking place before the pandemic, including the diminution of services and an on-going undercurrent of paternalism still evident in societal discourses about disabled people's lives. The pandemic nevertheless had significant effects for many in the group, exposing a range of care deficits, many of which are perceived to have not gone away. More positively, it also enabled new spaces of collective activism and an opportunity to politicise disabled people's experiences.

Overall, these experiences shape disabled people's understandings of what good care or support might look like. Good care was linked to having a choice, being seen as an individual with needs and preferences, and recognising the reciprocity of the care giver/receiver relationship, such that both have the right supports and are valued. Envisioning the future, people feel there is a need for real and substantive redesign of how society plans and to provide supports which should be based around disabled people's right to care and to equity of access. Such changes need to draw on the experience and expertise of disabled people in redesigning the support/care system.

4.5.1 Identifying areas for change

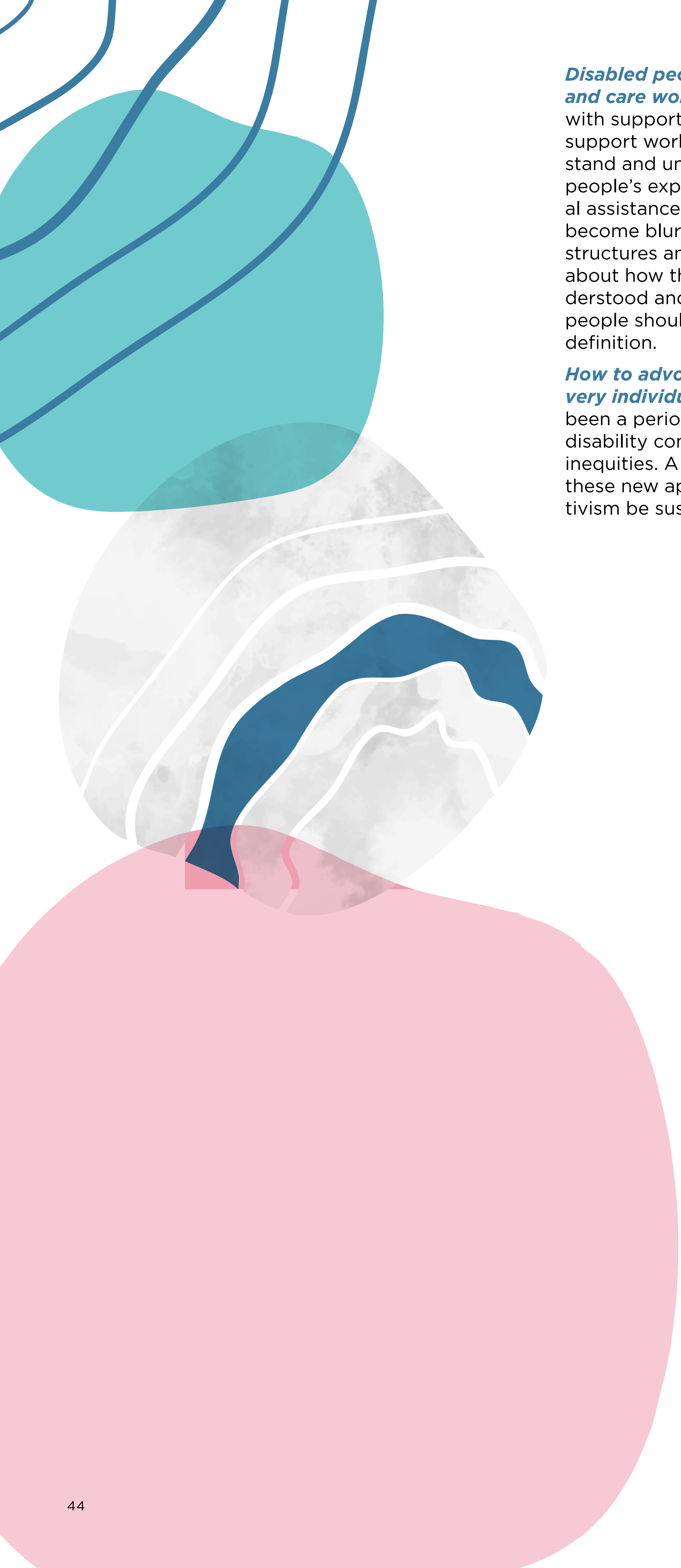
In our meetings with the group where we discussed emergent research findings, we identified several actions as a way of challenging ideas about care in disabled people's lives.

Challenge representations of disabled people; recognise caregiving. The research shows how active disabled people are as caregivers, to family, friends, community, society, the planet. Yet, this expertise disabled people have as caregivers, as well as their insights into the support other disabled people require and how it could best be provided, is not readily noticed or accepted by many non-disabled people. As a society, there is a need to move away from the binary of people as either carer or cared-for and recognise multiple and fluid roles. In particular, there is a need to challenge representations of disabled people as passive care receivers and highlight the significant caregiving they undertake.

Critique presumptions about informal care networks. Many disabled people in the group pointed to on-going societal expectations on family members (often mothers, sisters, daughters) to be available to care. This expectation is so strong that some disabled people do not disclose they have relatives to healthcare managers. There is also an awareness that not all families (or family members) have the capacity or the temperament to provide care or support. Group members therefore felt that there is a need to challenge these presumptions about informal care networks.

Challenge privatisation of care. Disabled people suggested that we need to challenge the on-going privatisation and marketisation of care which they perceive to have significant negative effects for those receiving care. They pointed to the increasing number of private service providers, accompanied at the same time by significant declines in the amount and quality of support which individuals are receiving. It would be beneficial to the public to really understand how the care/support landscape is changing.

Related to this is the impact of clientelism on how services are accessed. Many people described a reliance on individual health managers or politicians to gain necessary support services. This means that access is not based on the right to supports, or on people's needs. It creates power and control dynamics which are opaque and results in delays in getting basic necessary services.



Disabled people (re)defining the role of PAs and care workers. The importance of relationships with support workers and the ways in which PAs, support workers, care workers and others understand and undertake their role is vital to disabled people's experiences. Distinctions between personal assistance and care work are often unclear and become blurred within care and support infrastructures and services. We therefore need to think about how these distinctions can be better understood and re-stated and suggest that disabled people should take the lead in this exercise of (re) definition.

How to advocate collectively in a system that is very individualised. The pandemic appears to have been a period of renewed collectivism among the disability community and of advocacy to address inequities. A key question therefore is: how can these new approaches and new spaces for collectivism be sustained?

Exploring And Rethinking Care: Asylum Seekers

5

5.1 INTRODUCTION

This chapter presents outcomes of our research with people who arrived in Ireland as applicants for international protection. As outlined in Chapter 2, this involved three strands of research involving a range of methods including online and in-person interviews, in-person focus groups and participant observation. When undertaking each strand, we partnered with community-based migrant rights organizations that facilitated outreach and engagement with asylum seekers. Prior to commencement, we met with prospective participants to give them an opportunity to identify themes that we could explore with them. The three strands consider psycho-social aspects of asylum seekers' experiences of: living under the State's 'duty of care' for those seeking international protection during COVID-19 lockdown; providing paid care work on the frontlines of the pandemic response in Ireland's health and social care sector; and participating in care for planet and people through community gardens. The findings discussed herein are based on analysis of the outcomes of the three strands.

The chapter begins with a brief review of feminist ethics of care perspectives applied to migration studies and provides context for the Irish international protection system with our policy analysis of recent reform efforts. Then we present key findings regarding conditions and carelessness in the international protection system; navigating the system while working in care; and contributing to 'universal care' in community gardens. We conclude this chapter by outlining potential areas for action, including points that our participants wished to re-emphasise after reviewing emerging findings. These recommendations contribute to the re-envisioning of care that we offer at the conclusion of this report.

5.2 FOCUSING AN ETHICS OF CARE LENS ON INTERNATIONAL PROTECTION

Theorists have suggested that feminist ethics of care perspectives can underpin an ethic of international solidarity expressing human care relations (Held, 2006, 2018), promote a feminist approach to international human security (Robinson, 2011) and convey a 'global ethics of care' (Robinson, 1997). A growing body of research has adopted care ethics perspectives when considering the experiences of people within international protection systems. Increasingly, this work is challenging the construction of people seeking international protection as receivers but not givers of care. A recent study of the role of women volunteers in refugee support work in Germany demonstrates how they enact care values such as responsibility and attentiveness as an alternative framework to integration (Schmid, 2019). Other work has applied a feminist ethics of care lens to considerations about the need to ensure a duty of care in offshore immigration detention and refugee camps and led to the development of concrete recommendations to improve refugee accommodation (Namer, 2022). The caring relations of refugee women have been identified by examining the unpaid care labour they provide in their homes, volunteering for community organisations and caring transnationally for families who have yet to be reunited (Larios, 2019). Research has also considered how the informal care provided by asylum seekers to one another is central to responding to a high level of care needs exposed by the barriers that they and their families face when attempting to access state welfare systems and formal care services (Herz et al., 2022).

CareVisions seeks to extend such efforts to reveal how asylum seekers give care and deploys a feminist ethics of care lens to examine how Ireland's international protection system could improve a standard of care for asylum seekers. Within this work we utilize a vision of 'universal care' which suggests that 'we are all jointly responsible for hands-on care work, as well as engaging with and caring about the flourishing of other people and the planet' (Chatzidakis et al., 2020: 96). Previous scholarship in Ireland has asserted that the State should be seen as 'having a public and care responsibility in developing supports for vulnerable populations, and in being politically accountable for its national and international care responsibilities' (O'Riordan, 2020: 4). The following section examines how Ireland has failed to enact an adequate standard of care for international protection applicants.

5.3 CONTEXTUALISING THE CARE DEFICITS OF IRELAND'S DIRECT PROVISION SYSTEM

International protection in Ireland is influenced by the legacies of institutionalization and the State's attempts to integrate increased arrivals of people seeking international protection over the past two decades, which have been equated to 'warehousing' (Vianelli, 2022). Ireland's Direct Provision and Dispersal (DP) system was introduced in 2000 as an 'emergency response' to accommodate asylum seekers and to disperse them across the country while they wait for the Department of Justice to make a decision on their application for international protection. The International Protection Accommodation Services (IPAS) is responsible for identifying, organising and overseeing placements in DP. Initially a part of the Department of Justice, the Department of Children, Equality, Disability, Integration and Youth (DCEDIY) acquired oversight of this agency in 2021. Since 2002, over 80,000 people have applied for international protection in Ireland (Government of Ireland, 2020; McGee, 2023). By 2020, only 20,000 people had been granted permission to remain in Ireland, representing a minority of 3.1% of non-Irish nationals and only 0.4% of the population of Ireland (Government of Ireland, 2020).

Initially, it was envisioned that international protection applicants would stay in DP for six months, but the reality is that people typically wait much longer for a decision on their application. Waiting times are a minimum of two years, as there is a severe backlog of claims within the system. This time of uncertainty has been described as 'living liminality' (O'Reilly 2018; Isaloo 2020) and evidence demonstrates that life in DP exacerbates mental distress. Individuals experience higher levels of self-reported PTSD (Post Traumatic Stress Disorder), depression and anxiety the longer they are confined to DP (Toar et al, 2009). While awaiting the State's decision, some applicants experience a complex interplay of pre- and post-migratory traumas and exhibit mental distress that are precursors of suicidal behaviour (Murphy, et al, 2021).

DP centres in Ireland mainly operate within former hotels and lodges that continue to be run on a for-profit basis, overseen by IPAS and managed by staff who have not received trauma-informed training in advance of interacting and engaging with asylum seekers. A few DP centres are purpose built and State run. Accommodation is congregated, individuals share bedrooms and families are typically confined to one room, bathrooms and washing facilities are communal. A minimum weekly financial allowance and communal catered meals are provided though an increasing number of centres residents have access to cooking facilities. Many DP centres are isolated from the communities they are located near and in rural areas, asylum seekers are reliant on limited public transport links. In summary, life in DP is marked by a lack of privacy, personal space, autonomy and social integration.

From the outset of operating this system, Ireland has been severely criticised on a broad array of human rights indicators and found to not be complying with international obligations (Breen, 2008). In 2015, a review was undertaken by the Working Group on the International Protection Process which issued recommendations for reforms, some of which were implemented. Ireland only signed EU Reception Conditions protocol in 2018 after a supreme court case was fought by an asylum seeker to gain the right to work (Irish Refugee Council, 2023). Individuals must still wait 6 months after they make an international protection application before they can seek employment. Furthermore, asylum seekers can only apply for a driver's licence since December 2021, following another legal case taken against the State, and only gained the right to open a bank account in April 2021.

Concerns about conditions within the congregated setting of DP were heightened by the impact of the COVID-19 pandemic (Gusciute,2020; Irish Refugee Council, 2020; Murphy, 2021; Isaloo, 2021). In addition to findings of the discourse analysis of the Houses of the Oireachtas Special Committee on Covid-19 Response reported in Chapter 3, the research team conducted further analysis of relevant policy discourse. This analysis centred on the pandemic-informed State proposals to provide a more caring international protection system. Documents analysed included the Report of the Advisory Group on the Provision of Support Including Accommodation to Persons in the International Protection Process (Government of Ireland, 2020). This State mandated review commenced before the onset of the pandemic and continued during the initial waves. The review found that COVID-19 had a 'direct impact on direct provision centres, underlining their unsuitability as long-term accommodation for large groups of people' (Government of Ireland, 2020: 5). Furthermore, the report contends that

> *'a system which places applicants for long periods in segregated, congregated accommodation with little privacy or scope for normal family life is not fit for purpose. The arrival of COVID-19 in Ireland highlighted the risks of congregated living in direct provision and emergency centres and has added emphasis to the need to end the current system' (Government of Ireland, 2020: 7).*

Moreover, the Advisory Group recommended that applicants suffering from trauma 'should have access to appropriate expert care' (Government of Ireland, 2020: 133).

When Ireland's coalition government issued a new Programme for Government, it included a priority of the Green Party election manifesto and committed to 'ending the Direct Provision system and will replace it with a new International Protection accommodation policy, centred on a not-for-profit approach' (Government of Ireland, 2020: 76). To provide a framework for that commitment, in

February 2021 the Government published a White Paper to End Direct Provision and to Establish a New International Protection System (DCEDIY, 2021). The White Paper provides further identification of care deficits of the DP system and outlines a vision for reform and the State's aspiration to centre a human rights perspective in international protection. The White Paper assessed DP as 'expensive, inefficient, and ill-equipped to respond to shifting trends in international migration…it failed to respect the dignity and human rights of individuals (DCEDIY, 2021: 12). It also acknowledges that 'one of the repeated criticisms of DP is that problems were allowed to escalate and become chronic before being addressed. The new model must ensure that it identifies and addresses issues affecting applicants' wellbeing at the earliest possible stage' (Ibid: 71). This proposed new model, which would do away with congregated institutional living, was intended to be fully operational by the end of 2024.

During the course of the CareVisions project, implementation of proposed reforms to DP were not observed. In reality, pressure on the international protection system intensified following Ireland's intake of over 70,000 Ukrainian refugees since the Russian invasion of Ukraine in February 2022. Stakeholders have intimated that in this context, ending DP can no longer be achieved by the end of 2024 (Bray, 2022). Given the care deficits that are well established in policy documents and other literature 'care' is a challenging term of focus when discussing asylum seekers' lived reality. We found that participants working in the health and social care sector identified forms of 'care' in relation to paid care work. Outside of that context using the term 'care' was not immediately recognised, understood nor well defined by our research participants. Asylum seekers expressed other terms such as support, help, assistance, and importantly protection. Thus, the term 'care' needs to be more specifically articulated and expanded as we convey our research findings.

5.4 FINDINGS

In the remainder of the chapter, we outline the key findings from the three strands of research with asylum seekers.

5.4.1 Conditions in DP and carelessness during COVID-19

Given the difficulties in averting the spread of COVID-19 within DP, as revealed in policy documents analysed, CareVisions sought to learn more about asylum seekers' lived reality of this care crisis. One of the failed practices which gained notoriety during COVID-19 was transferring groups of asylum seekers between DP centres. While this measure was ostensibly taken to avert outbreaks, in reality, it exacerbated health risks. We wanted to know how these failures in the State's duty of care affected people seeking international protection. A preparatory stage for this strand commenced in late 2021, with support from the Movement of Asylum Seekers in Ireland. They helped identify potential research participants who had lived in DP centres throughout the pandemic, including those who had been transferred between DP centres during the first wave of COVID-19. Initial discussions were held with a few potential participants wherein we spoke about the issues raised in our policy analysis and provided them with an opportunity to shape our inquiry as it related to their experiences.

Our group of four asylum seekers adds to the public record, revealing the vulnerability associated with the lack of consideration of their care needs in congregated DP settings. Participants conveyed a lack of communication, planning and preparedness within DP settings, which precipitated care crises during and after the COVID-19 pandemic. At the onset of the pandemic, asylum seekers became aware that COVID-19 had begun to spread in Ireland through news reports, social media and the shifting patterns of movement in their communities. A change in how DP management interacted, maintaining distance from asylum seekers and having to shout through masks and barriers that strained communication led to asylum seekers feeling less understood and more vulnerable than in pre-COVID times. All participants reported that information on how COVID-19 was spread was inadequate and was not available in the languages widely understood by asylum seekers. Participants suggested there should have been greater public health outreach into DP centres to help people understand the precautions to take. Moreover, DP management took decisions that were not in line with the measures developed to protect the general public from COVID-19.

Participants stressed that the situation in DP was not the same as what they knew Irish people had to adhere to. One participant told us, 'I'm gonna be frank. We did not see any strong measures being undertaken like testing your temperature when you're coming in…the situation in the asylum DPs are not the same'. Residents still shared rooms, bathrooms and laundry facilities and a key disconnect in the COVID-19 prevention guidance was the ongoing provision of communal dining. This meant that asylum seekers and their children were still standing together in lines to collect catered meals and eating together at tables.

Moreover, COVID-19 prevention guidance issued by the HSE was not easily available nor translated into languages commonly understood by populations that are resident in DP centres. A participant told us that,

> *'There was no adequate information at that time…Some of the people that were there they couldn't speak English…they don't even know or understand how the COVID spreads…the HSE put a leaflet there, but nobody will read… they should talk to them; 'please do this'. Like someone telling people in their language'.*

In one DP centre, residents insisted that they wanted to be able to bring meals to their rooms and when DP management refused, some residents began a hunger strike. An Garda Síochána (Irish police force) were called and eventually tempers settled, but DP managers were reluctant to change practices. The inability to implement the COVID-19 prevention guidance within DP centres was based on the systemic weaknesses of these overcrowded settings but these findings also identify a level of carelessness towards the needs of asylum seekers.

To address risks inherent to overcrowding, IPAS organized the opening of new DP centres and arranged group transfers of asylum seekers to new locations in other parts of the country. All participants included in this first strand of our research were transferred during the early wave of COVID-19 and they reported that 'proper care' was not taken in these processes. They detailed that IPAS did not test residents for COVID-19 before boarding transport between the centres; that there was a lack of masks or other basic PPE available during travel; and there was no social distancing on buses. Several participants who were transferred to a new DP centre commented that on arrival that there was no PPE or sanitising gel, and a lack of cleaning and disinfection of common areas at the new accommodation centre. Furthermore, the new centre was hastily opened and not ready when residents arrived, leaving them to spend over two hours in the reception area, enough for the virus to spread, and then forced to share rooms too small for two people to be able to socially distance. Unsurprisingly, consequently there was an outbreak of COVID-19 at this DP centre, representing infections among close to a quarter of residents.

A participant detailed a frustrating account of this experience:

> *'There was no social distancing on the bus. We were just packed like sardines!... Like everything you need [was not put in place]: to be away from someone for a certain amount of meters... to wear a mask...to sanitise...We were packed up...There were about three or four buses. And we left like that'...A lot of things weren't OK... we weren't given any sanitizers. There was nothing there, literally...it was just like, 'move out of Dublin because...we're trying to keep you people safe. Let's take you all somewhere else'. So, we coop you up in the bus, there's no space, we coop you up in a reception area for longer than two hours. Enough for the virus to spread around to everybody, and after that will give you these small rooms...and you're just going to have to make it work'.*

During COVID-19 outbreaks, participants, including those with children living in DP, found spending prolonged periods of time in isolation in small rooms extremely difficult. Several characterised this time as another experience of trauma, or re-traumatisation, in their lives. One participant recalled that, after an outbreak, he kept his young child isolated in their room for 60 days. Another participant with a young child shared that they had experienced traumatic life experiences before seeking asylum in Ireland. However, they considered lockdown in the DP centre over a four-week period to be the most horrible time of their lives. Participants reported limited access to space outdoors for themselves and their children to be active and breathe fresh air. Given IPAS's inability to arrange further transfers at the height of the pandemic or to provide oversight to effectively sanitise affected DP centres, residents advocated for changes with support from local community members. This led to media coverage and visits from TDs and we identify this activism and the solidarity expressed from community members as forms of care.

In the aftermath of these care crises, some asylum seekers received letters of apology from the Minister for Justice, but this did little to assuage the long-term impacts of living in DP. One participant lamented that they couldn't understand exactly what the State was apologising for, given that their life in DP continued to be a struggle. Such accounts depict DP as a threatening environment where there were significant disparities regarding the ability to enact similar levels of public health guidance that the general population were subjected to. During the COVID-19 pandemic, the State was unable to uphold its duty of care for international protection applicants. The findings place on public record the care deficits and health impacts of the pandemic experienced by asylum seekers within an international protection accommodation system judged to be unfit for purpose. We hope that, by centring the perspectives of asylum seekers, that we can offer an alternative vision of the care that could and should be delivered within a renewed and reformed international protection system.

5.4.2 Navigating the international protection system as an asylum seeker working in care

An important objective of CareVisions is to contribute to the visibility of asylum seekers' roles in giving care. In this second strand of our research, we did so by exploring the experiences of asylum seekers employed in the health and social care sector in Ireland while living in DP. As discussed, asylum seekers gained the right to work in Ireland in 2018 and a growing number have found an initial entry point into employment through vacancies that are common within low-paid, devalued care work. While care ethics scholarship has extensively examined the international political economy of migrant care work, asylum seekers are not economic migrants. Their employment in the care sector is not facilitated through transnational recruitment and we know less about their experiences as care workers. Moreover, there are few studies that examine how asylum seekers navigate living within international protection systems while working in care. Given that we conducted our research following the initial waves of COVID-19, the context is shaped by unprecedented challenges facing care workers during the pandemic and compounded by the deleterious conditions of DP which were revealed in our work.

We partnered with Cork Migrant Centre to facilitate contact with women working in the health and social care sector and held preparatory discussions with potential research participants. This allowed the women to suggest themes that we might explore in interviews wherein they expressed that they hoped to 'make some noise' to influence change. With our final sample of six participants, we explored multiple, intersecting vulnerabilities that increased during the pandemic related to living in DP while working on the front lines of health care, during the initial waves of the COVID-19 pandemic. Again, participants shared their experiences of inconsistent application of COVID-19 restrictions within DP centres which heightened all residents' vulnerability. The risky setting of DP presented unique problems for care workers, including dual forms of discrimination. Initially employers would not hire workers living in DP to contribute to the health and care sector's response to the COVID-19 outbreak because of perceived risks inherent to congregated living.

After asylum seekers were hired to fill the emerging gaps in the workforce of hospitals and nursing homes, other residents of DP were alarmed at the risks of COVID-19 being spread by those working in care settings. This led to tensions, particularly amongst roommates, with care workers' roommates feeling that care workers' contribution to the care sector was something that they should not be doing and that they should have chosen to do other kinds of work. Care workers living in DP felt that they were not cared for and that they were perceived as a problem, embodying health risks that other residents needed to protect themselves and their children against. Our findings demonstrate that IPAS was not only incapable of effectively responding to the threat of COVID-19 outbreaks, but it was also unable to facilitate the role some international protection applicants played in the pandemic response.

As the pandemic intensified, employers introduced a short-term solution, designed to meet their needs, by relocating care workers to temporary accommodation. They liaised with IPAS and DP management, not care workers, when making these arrangements. This left care workers little time to prepare and no idea how long they would be away from DP centres and their own care relations. Again, participants found inconsistencies in COVID-19 prevention such as rules that care workers could not socialise in one another's rooms even though they all travelled to work together in cramped transport. Moreover, changes to temporary accommodation threatened the security of asylum seekers' state provided accommodation.

Participants reported that IPAS was often unable to respond in a timely manner to re-accommodate them in DP after returning from short term contracts at hospitals and nursing homes. In one incident an asylum seeker had to sleep rough after making an invaluable contribution to the COVID-19 response and it was a community group supporting migrants, not IPAS, which stepped in to rescue this care worker from homelessness.

Working on the front lines of the pandemic, asylum seekers faced a range of challenges, some common among care workers responding to this unprecedented challenge but other precarities unique to their migration and socio-economic status. The conditions of short-term employment threatened a basic benefit of international protection, access to free healthcare through a medical card. Yet, after they were earning a certain income level, they could no longer avail of this benefit, even though shift patterns changed weekly and income levels were inconsistent. This resulted in some participants not being able to afford care or medication without a medical card. Participants also identified inconsistencies in managing COVID-19 risks in the workplace, such as lack of consistent access to PPE and delays in access to COVID-19 tests. Furthermore, as low paid workers they were reliant on an already limited public transport system to get to work. Many participants reported how they were concerned about COVID-19 risks on public transport and/or how cancellation of services affected them and meant they had to augment with expensive taxis.

This cadre of workers did not set out to have a career in care and entered the sector at a time when the pandemic exposed gaps in the care workforce. All participants in this strand of our research were women originally from countries in sub-Saharan Africa and some shared that they experienced racial discrimination from clients, particularly elderly nursing home residents. We found their descriptions of such incidents quite generous, wherein they wanted to convey the perspective of the people they were caring for. They expressed compassion in understanding how nursing home residents were missing contact with their families during COVID-19 lockdown and also missing being cared for by people who had worked there for years.

> *'Care to me was like really giving back to the community and…I was really happy doing. Yeah, like that time I didn't see all these challenges. But I see this care not even about the work. It's like being involvement person to person. So for me, I take it is something like a calling. It's not even like a work, it's something I enjoy. I like doing it…You feel happy that you have done something. You have put a smile to somebody who was weak… It made me to be part of the community and I was really happy. And this is where you get to see, like most of us in Direct Provision, they could see that we are involved. They could understand. Like people some people could say like 'oh, why these people coming? You are taking the taxpayers' [benefits] or what?' But they could see now like these people are becoming part of the community they're participating'.*

Furthermore, there was little opportunity for sharing the emotional impacts of the unprecedented challenges of paid care giving during the COVID-19 pandemic in their domestic contexts, as there, they had to isolate from others. One participant emphasised the importance of personal relationships and support in this context and the absence of them in their work:

> *'COVID had hit, like, really hard and as much as you try to detach yourself from your work you can't avoid building relationships with people that you work with or people that you care for. So at that time, seeing a lot of people dying was really hard. It was emotionally, mentally draining. It was mentally disturbing us. And you know, you go home, you don't have anyone to talk to or anyone to vent about what's going on. Oh yes, at work they say they were providing counselling services for anyone affected by COVID. But I mean it's different from when you have someone to really talk to and they understand what you're saying'.*

Overall, while our findings indicate how asylum seekers working in care settings were exposed to increased vulnerability, we identify the important contribution they made to Ireland's health and social care sector's response to COVID-19.

5.4.3 Care for people and planet in community gardens

As we have identified, one of the care deficits that compromises asylum seekers' wellbeing while confined to overcrowded accommodation in DP is a lack of personal space. Our third research strand explored asylum seekers' access to spaces outside DP by conducting research during the Spring/Summer growing seasons in 2022 and 2023 in two gardens established by community organisations providing support to asylum seekers. We conducted this research in partnership with Cork Migrant Centre which co-founded a garden in 2022 to provide current and former asylum seekers access to land to grow vegetables, and Clonakilty Friends of Asylum Seekers which established a garden several years ago on land across from a DP centre. We explored these two gardens as sites where asylum seekers have a welcoming space outside DP, access to land and fresh air, and new ways to integrate with people from local communities. Conducting research in these gardens provided CareVisions with an opportunity to explore how asylum seekers are involved in 'universal care' that supports the wellbeing and flourishing of human and non-human life (Chatzidakis et al, 2020). Our primary method was ongoing participant observation and we held focus groups in both gardens, two 1-1 interviews and one joint interview in each garden.

One of the sites for this research was in Cork city, where a new community garden was initiated by the Cork Migrant Centre, with support from a religious order which allowed use of land on the grounds of a convent. This new 'international garden' relied on guidance from an established horticulture initiative as well as material and practical input from locally based companies and volunteers. The garden provides a way to support current and former asylum seekers and their children, to grow vegetables and herbs, including varieties from their countries of origin. While gardening, participants have an opportunity to spend more time outdoors and to get to know one another through joint action. The horticultural initiative centred migrants as the decision-makers in terms of what crops to grow with the support of their expertise. The land was initially prepared by all and, thereafter, migrant women and their children came together to take control of particular spaces and plant and tend their crops.

During the first growing season, in 2022, gardeners negotiated the trial and error of growing plants, including those they formerly used in the diet of their countries of origin. The horticultural experts negotiated their support roles for the migrant women, including challenges to accepted planting practices in Ireland exemplified by the St Patrick's day tradition of planting potatoes: the women were not all that enthusiastic about this. A lot of learning took place, from local wildlife scrounging newly planted potatoes, to the later scheduling of the planting of corn indigenous to Africa rather than an Irish variety. Over the Spring and Summer months the garden transformed from a green field site and a polytunnel, to a plentiful and abundant garden.

People appreciated the easiness of the space, having time outside of the confines of DP centres, staying active outdoors in all weathers, and being able to introduce children to fresh produce, including those important in their culture. They were able to express care for the garden through negotiating, digging, planting, tending, harvesting and enjoying the garden's bounty. Even the freshness of the controversial potatoes were very much appreciated, once tasted. Participants found gardening an enriching and expansive experience which helped forge friendships, instil confidence and improve their sense of well-being.

Conversations occurring during the activity of gardening included shared strategies for coping with the challenges of negotiating the international protection process, finding housing after receiving a decision and other practical matters. Participants commented that the international garden is good for the environment, good for improvements to their diet, improves their mood, and their sense of integration. Moreover, it is a space to be able to take time for themselves in nature.

The other site of this strand of research was in a garden established by Clonakilty Friends of Asylum Seekers on land across from, and independent of, a DP centre in a town in West Cork. This garden began several years ago as a small group of raised beds first set up to offer residents of the DP Centre a space to spend time outside and grow plants. Gardening was intended as outlet from the liminality and distress of awaiting a decision on their international protection application. There have been shifting uses of this green space and now that asylum seekers have the right to work, many adult residents of the DP centre are too busy to be actively involved in gardening. They still benefit from access to the green space and to a garden dome which provides almost year-round use of an indoor space, outside DP. Within the dome, support workers and volunteers from Clonakilty Friends of Asylum Seekers offer activities like mother and baby sessions, children's homework club and coordinate a range of external activities.

For children growing up in the international protection system, access to space outside DP provides a space to play and to learn about caring for the environment with the support of an experienced gardener. The garden and dome are a base for children to spend time in groups and one to one with support workers who respond to their care needs. These forms of activity and engagement for children provide a care respite to their parents for a few hours a week in a space where they know their children are safe and have opportunities for community integration. Mothers who are resident in the DP centre shared that when their children are engaged and happy, they are happy and less stressed about the conditions of raising them within the system. The dome serves as a community hub and the surrounding green space is used to hold various activities and mark cultural occasions where current and former DP residents can relax and celebrate with one another and connect with local community members.

One participant in a focus group held in Clonakilty spoke about how essential the access to green space outside DP is for her. She said,

> *'Because you are indoors…we are all closed in our room, the space is not enough for us here. So when you come out for the garden and you still feel you have good memories and you do not over stress yourself anymore. I think it's a lovely place'.*

Many of the participants spoke about how important the garden is for their children and that knowing their children are okay helps their own sense of wellbeing. Another participant from a focus group in Clonakilty said 'It's helping them mentally because they are kids, they won't bring other kids in the room because it is just one room and you can't adjust everything to them. And sometimes they go to the garden, the garden is a lovely place, it is… they are very supportive here'.

The garden and dome provide a space to build a sense of belonging in a new society. One participant in a focus group in Clonakilty shared that after receiving a positive outcome of their international protection application and moving into the local town she was always happy to come back to the garden. She said: 'It's become a place to meet, it's a social place… whenever anything is happening in the garden, I am always invited…even if you move out there you're still part of this community.'

In Spring 2023, a new initiative was undertaken by developing a sensory garden path along the perimeter of the green space, supported by funding from an insurance company. The sensory garden incorporates principles of horticultural therapy along a path lined with a variety of seasonal plants selected to evoke sensory responses through sight, smell, touch and sound. Children living in the DP centre were supported by experienced gardeners to help plant the pathway. The brainchild of support worker from Clonakilty Friends of Asylum Seekers who is a horticulturist, the vision for the initiative is to utilise gardening for 'therapeutic or rehabilitative goals of its participants. The focus is to maximise social, cognitive, physical and psychological functioning and/or to enhance general health and wellness' (Clonakilty Friends of Asylum Seekers, 2023). Observations of DP residents interacting with the completed garden path reveal that it harnesses a variety of positive senses and is a manifestation of care and concern for their wellbeing. The children who participated in planting and watering the pathway exhibit pride in their care as the plants thrive and also appreciate an array of the senses that are awakened by immersing in nature.

Across these two research sites and through the various methods we applied, we have found that community gardens provide access to space outside of cramped, overcrowded, congregated settings to enable them 'to breathe'. Either by actively partaking in gardening or just enjoying green space current and former asylum seekers are able to enhance a felt sense of wellbeing and practically engage in social inclusion. The gardens help to re-engage connections with nature and with culture through growing plants indigenous to their country of origin or giving them a place to celebrate cultural occasions together. We find these community gardens are essential spaces of care for vulnerable migrant adults and children forging their connections with green space allowing 'universal care' for planet and for people to be enacted.

5.5 RETHINKING CARE PRACTICES: ENVISIONING 'BETTER CARE'

Participants in all three strands of our research strongly identified the lack of care they experience in DP and also reflected on initiatives where they feel cared for. We asked participants to recommend changes that could improve the standard of care that the State and its agents can deliver within the international protection system. One participant in Strand i considering the deleterious conditions in DP recommended that a framework of care be put in place to ensure that there are 'people on ground to take care of them'. Another participant urged that DP centre management and staff should be 'educated more on handling...people (who) come from different traumatic backgrounds'.

Participants in Strand ii that explored the intersectional vulnerabilities of the international protection system and the practices of managing care labour provided their thoughts on how to ensure 'better care'. One participant asserted:

> *'Almost everyone in the asylum system has a bit of damage in them and it takes only one small trigger for that person to explode. And for me, I feel like, you know, if people can just listen. That's all that's needed. Just listen... you know, as much as they say it's the right accommodation for me and my family. Yes, I agree. But mentally, is this the right place for me? No, it's not. Cause my mental health is suffering a lot in this place. But there is nothing I can do about it'.*

Another participant discussed the care needs of applicants in the context of their forced migration saying:

> *'Maybe if there's consistency in everything, like looking after the children, after the mothers. Even the fathers, they do need support. If they can give support to everybody. It's not easy to leave your own place of growth. You're leaving everything. You leave your family. You leave your children. Even if you have no kids here you leave the other support, like the friends you have when you grow up with, your own community. And you don't know where you are going. You don't know what are you going to do'*.

Such sentiments were reiterated by a participant who critiqued the care provided within the international protection system saying:

> *'Sometimes, you feel they are just not sympathetic towards your circumstances...They don't know the gravity of what you're going through and they tend to take it with so much levity and carelessness...It was more like being put in a prison and just like wait here while I determine [an application for international protection]...you feel so alone and there was no form of counselling or anybody you could actually talk to during that time...and being in a strange land, it was just so much... it was like a crippling kind of care that they were giving'.*

Yet another participant reiterated these criticisms saying

> *'you're here as an asylum seeker looking for protection and the State is not taking care of you at all. It's actually making you worse'.*

One participant summed up what they hoped to experience within the international protection system saying

> *'Be more caring...Care for us as you'd care for your relative. We're not here to do any bad. We just want to be safe'.*

Participants suggested that there needed to be open channels of communication between the international protection system and applicants. One participant recommended:

> *'IPAS they should also try to listen to residents' complaints...they should make sure all the centers have suggestion boxes. Because they just brought us here, but they don't care what is going on here. We have a lot of complaints here. But where are we going to raise our issues? Who is going to listen to our issues?'*

A participant reflected on the potential of CareVisions in generating greater awareness of the lived reality of asylum seekers. They said:

> *'It's really important what you people are doing because I just feel like some things will just be forgotten. But...it will bring a lot of impact...when you share and you put on the table, it could be known, but otherwise it could never be realized what is going on'.*

In our final section, we offer several recommendations informed by these findings that could support better care in a reformed international protection system.

5.6 CONCLUSIONS: TOWARDS CARE-CENTRED INTERNATIONAL PROTECTION

In this section, we offer recommendations emerging from our empirical research and policy analysis. Firstly, we present recommendations that some participants provided after we shared analysis of our findings with them. We invited them to highlight issues they would like to see us raise as we disseminate our work. Thereafter, we reiterate the urgency of instituting a care oriented international protection system that does not re-traumatise applicants and summarise key conclusions identified through our empirical research.

One participant underscored asylum seekers' need for mental health care and a revised approach to improving public health.

They stressed:

> *'I do strongly feel and wish the responsible department could provide forms of counselling or at least change their approach in terms of dealing with outbreaks of infections in direct provision centres'.*

Another recommendation made highlights the need for the State to recognise and enable the contribution that asylum seekers are making as care workers in the health and social care sector. This requires learning the lessons from the COVID-19 pandemic and planning accommodation that is fit for purpose to manage infection control as well as meeting the needs of those being accommodated. A participant working in care stated:

> *'My recommendation is that IPAS should try to find a better way to accommodate asylum seekers who work in healthcare services rather than keeping us together and put other residents at risk of infectious disease. They should not wait until the outbreak comes in. This will help in reducing the numbers of infections and stigma among residents. It will also allow asylum seekers who are care workers to have a good place to isolate themselves if they are required to do so'.*

Our research and policy analysis support wider calls for the Government to implement initiatives that were set out in 2021 in the White Paper to End Direct Provision and to Establish a New International Protection System (DCEDIY, 2021). The White Paper presents the Government's vision of international protection services grounded in equality, diversity and informed by the human rights framework undergirding Ireland's obligations as a UN and EU member state. Our findings clearly identify the importance of addressing the health care needs of asylum seekers, particularly in terms of mental health care. Proposals have been made in the White Paper[7] to implement an Enhanced Model of Community Healthcare, which have the potential to address these needs.

However, the enabling environment for the proposed changes has become more strained since 2021. Ireland is experiencing an ongoing national housing crisis, is facing new burdens in managing the EU Temporary Protection Directive for people arriving from Ukraine and worryingly, there is a noticeable rise of extremist anti-immigrant sentiment and associated demonstrations. The DCEDIY has acknowledged the lack of progress in implementing proposed changes, and very recently indicated that the White Paper is to be replaced. More than ever, therefore, there is a need to uphold the aspiration to reform international protection in ways that respect human dignity and express the State's duty of care for vulnerable migrants. A consistent and worrying finding of our research is that people seeking international protection are not receiving support for the pre-migration trauma they have endured and are often re-traumatised by the conditions of their lives post-migration.

It is also essential that the Direct Provision centre staff and management have appropriate training to support asylum seekers and do not express hostile attitudes towards them. A care-centred international protection system should provide supports for asylum seekers as victims of trauma and violence, and enhanced population health and wellbeing initiatives targeting their needs. Such a system should also support the wider integration of asylum seekers which enables them to contribute to Irish communities and combats forms of racialised discrimination. Importantly, a caring society does not assume one-way integration but encourages community members to demonstrate their solidarity with vulnerable migrants, to learn about their experiences and celebrate their cultures. For many, entry into the workforce is an important part of integration and asserting autonomy over their future in Ireland. Asylum seekers therefore need to be supported in this regard, through making available training and job opportunities.

While the care giving that asylum seekers provide in the care sector needs to be acknowledged and recognised, so too does the care burden that they experience in these roles. Along with other care workers, current and former asylum seekers deserve fair employment conditions, dependable contracts, increased compensation, flexibility and supports including subsidised travel and childcare.

We suggest that the community gardens we studied could serve as a model to be included in future planning of international protection and social integration measures. Enhancing access to green space forms part of Ireland's commitment to Sustainable Development Goal target 11.7 to increase access to safe, inclusive and accessible green and public spaces particularly for women, children, disabled people and other marginalised people. Making greater use of outdoor space is essential when planning the reform and location of living spaces for people seeking international protection and the end of institutional living. Green space is essential in the envisioning of an enhanced standard of care for asylum seekers, care for the planet and care expressed by community members.

These recommendations and conclusions reflect the aspirations of our research participants to 'make some noise', to encourage practical changes to asylum seekers' lives, and inspire an ethics of care as Ireland continues to integrate vulnerable migrants.

---

[7] Proposals included in the White Paper include health screening, vulnerability assessment and supports to address vulnerabilities identified across diverse populations.

Discussion And Conclusions: Re-Envisioning A Care-Centred Future

6

6.1 INTRODUCTION

In this chapter, we integrate the different elements of the CareVisions study and draw conclusions about the context of care relations in Ireland, particularly in the light of increased attention to care or lack of care brought about by the COVID-19 pandemic. Crucially, we also build on these conclusions to begin a conversation around how we might radically re-envision care relations, policies and practices in Ireland through a set of considerations or principles and actions aimed at creating a more care-centred society. These principles are directly drawn from our empirical work and analysis on the project.

The CareVisions study began during the time of COVID-19; indeed, it was the care deficits and inequalities exposed by the pandemic that drew our particular attention to the need to evaluate and rethink how we understand and respond to care. While COVID-19 has certainly remained a key theme, we found that it was not the only thing pre-occupying participants and that many were already experiencing care deficits prior to the pandemic. In this context then, our research leads to questions about how we can interpret COVID-19 as a moment of crisis, and what, if any, changes or effects it has had in terms of changing care discourses or infrastructures in Ireland as the focus on care then seemed to promise (Daly and Edwards, 2022). COVID-19 might be seen as just one of a number of on-going societal, geopolitical and environmental crises which have potential consequences for how we think about and re-envision care relations in society.

6.2 REFLECTING FROM A FEMINIST ETHICS OF CARE

As outlined in Chapter 1, a feminist ethics of care lens emphasises the centrality of care to human experience, the recognition of interdependency in human relations and the significance of moving debates about care from the personal to the political domain. In this section, we outline some of the key findings of the research, reflecting from some of these conceptual starting points.

Unfixing care identities

Our research demonstrates the ways in which particular groups in society become ‘fixed’ in both public and policy imaginaries as either care givers or receivers. As our discourse analysis demonstrates, Irish society continues to associate and restrict care considerations to certain groups, who are often defined by their vulnerability. Disabled people were only too aware of this when discussing public attitudes towards them during the pandemic - attitudes which reflect a continuation of perceptions of paternalism and dependence. For asylum seekers living in Direct Provision, they perceived that they were not necessarily seen by wider society as ‘deserving’ recipients of care, but rather viewed as a burden on the state.

This is despite the significant care giving roles that they undertook during the pandemic and continue to undertake. Policies and services however continue to reinforce care giver and care receiver binaries, with accompanying categorisations of different groups as deserving of care – rather than recognising that all individuals have the potential to care within an enabling environment and are equally worthy of care and support throughout their lives.

Complex interdependencies in care relations

Linked to the previous point, our research demonstrates the complex intertwining of care relations that exist in both the lives of disabled people and asylum seekers, and yet which often remain hidden in debates about care. Disabled people were engaged in informal relations of support, from families to neighbours, friends, and the wider disability community. These informal relations also intersect with formal support services, such as PA supports or home care. In the same way, we reveal how asylum seekers are also embedded in informal support networks – with families, children, and others living in and outside of Direct Provision – whilst at the same time being involved in formal care labour. In both cases, we see the interaction of formal and informal care networks. For example, to enable asylum seekers to work as care workers, they often had to draw on the unpaid, informal support of fellow residents in DP to look after their children. For disabled people, formal, paid support enables them to participate in social networks and the wider community, engaging in reciprocal relationships with those around them. Should these formal supports cease to exist, however, this would have a significant negative impact on their participation and reciprocal nature of these relationships. These are the hidden dynamics of care giving and receiving - and of paid and unpaid care labour - which frequently remain invisible and unrecognised. They illustrate the importance of recognising individuals as simultaneously care givers and receivers and of focusing on the interdependencies of care relations.

Our research also draws attention to the centrality of the care giver/receiver relationship, and the wider dynamics of power and intersecting identities that can shape these interpersonal care and support relations. Disabled people, in discussing the role of care workers, recognised that care workers should be valued and treated with respect. They also acknowledged that there could be challenges to navigate with such care relations, including around different socio-cultural attitudes towards disability expressed by care workers. Asylum seekers also discussed the challenges that they faced as care workers, noting that they had experienced instances of racism, particularly from some older people. However, they approached these instances with understanding and compassion. Nonetheless, such experiences draw attention to the intersectional dynamics and inequities of ‘race’, dis/ability, gender and indeed class which shape care relations, and which need to be sensitively acknowledged. Addressing these tensions and working towards ways of opening discussion between all those involved is necessary for teasing out the underlying influencing factors at play. Here, we are reminded that good care means ensuring that all involved have a voice.

The wider political sphere of care relations

In both phases of our work with disabled people and asylum seekers, participants discussed experiences of personal care relations. However, feminist ethics of care also draws attention to the fact that interpersonal relations are shaped by wider social, economic, and political processes and structures. For asylum seekers, the Direct Provision system is a key structuring influence on their experiences and must be situated within wider state responses to those seeking international protection. For disabled people, their experiences are shaped by a changing configuration of policy and services, which, whilst stressing the move to personal assistance and the rights of disabled people, fail to enshrine these rights in the resourcing of services.

In both spheres, a dominating influence is the increasingly marketised and privatised model of care and support provision. Direct Provision centres, for example, run on a for-profit basis, while the provision of home care supports for disabled and older people has become dominated by an increasingly fragmented marketplace of private providers. The negative consequences of this were evident in the research and, to a certain extent, they have also been recognised by the State itself. Indeed, the Oireachtas Special Committee on COVID-19’s report identified the privatisation of the nursing home sector as having contributed to ‘poor outcomes’ (Houses of the Oireachtas, 2020: 14) for nursing home residents during the pandemic. It asserted that ‘future moves to support the older people at home must have, as a priority, a publicly funded and publicly provided model of care’ (14). Recognising the politics of care relations therefore means asking questions about who, and what agencies, should take responsibility for care (Murphy, 2011). Our research suggests that there should be a re-prioritisation of public responsibility for care which moves it outside of the market domain and which is accompanied with adequate resourcing levels.

On-going carelessness in care practices and services

Our research draws attention to the on-going carelessness experienced by both disabled people and asylum seekers in services and institutional contexts. For both groups, the spectre of institutionalisation looms large in terms of care experiences and past abuses. Asylum seekers experienced and continue to experience the institutionalisation of Direct Provision as, what one participant described, ‘a crippling kind of care’.

The experiences of isolation, lack of understanding of their prior experiences and circumstances before arriving in Ireland, and poor physical facilities leads to a form of 're-traumatisation' in this so-called space of protection.

Disabled people too articulated multiple instances of carelessness in care practices, particularly within the context of formal care services. This carelessness becomes manifest in absences of support, feeling dismissed or 'not seen' in some interactions with care workers, and a lack of accountability by service providing agencies. Some participants expressed concern that while institutionalisation in congregated settings may be diminishing, inadequate supports for living at home could lead to 'domestic institutionalisation', whereby disabled people are at the whim of the timetables and availability of care agencies and workers.

In both our conversations with asylum seekers and disabled people, some participants also expressed instances where they were fearful of complaining in case of negative consequences; they worried that their supports might be removed, or that their application for asylum would be denied. Feminist ethics of care perspectives require us to challenge these instances of carelessness, to acknowledge how they have emerged and confront past abuses. As Barnes (2015: 11) states 'care always has a past and how we respond to past injustices is one of the largest ethical questions we have to face'.

Spaces of (care) collectivism and solidarity

Looking beyond individual care relationships, our findings also demonstrate instances of collectivism and solidarity which shape care relations, and activism around care and support. Within their own communities, we can see evidence of this collectivism amongst disabled people and asylum seekers. The creation of the community gardens for asylum seekers embodies a space for developing collective solidarity, which help forge friendships, improve senses of well-being, and share strategies for coping with the challenges of the international protection process. They also provide a way to feel connected by providing care for the environment. Disabled people also spoke about providing care in their wider community – including for animals, pets, and the environment, as well as friends and family – as a form of 'giving back'. The renewal and building of social networks amongst disabled people in the online space during COVID-19, which facilitated information-sharing, friendships and collective action, is another reflection of this community-building and solidarity. To this end, we can witness both groups engaging in what Sevenhuijsen (2003: 193) refers to as a 'caring citizenship'.

Care ethics, while grounded in close care relations, draws attention to not just our relations closest in (with friends or family, or the space of intimate caregiving) but also to the need to care for distant others, or those unknown to us. In pushing us to see beyond our most immediate care relations, we might reflect on how we can build solidarities across diverse groups and with those who might be seen as 'strangers' (Barnes, 2015). The case of asylum seekers particularly brings this into sharp relief. Many participants expressed how undertaking care work for them was about being part of, and contributing, to the wider community from which, in Direct Provision, they were largely isolated. However, as we point out, integration is not a one way dynamic and we need to explore how societies can express solidarities with asylum seekers, and indeed other groups in society – not as an act of paternalism or charity – but a wider solidarity grounded in respect, dignity and equality in the search for caring relations.

6.3 REFLECTING ON THE IMPACTS OF COVID-19

A key aim of the project was to explore the implications of COVID-19 in terms of current and future care relations. It is very evident from our research that COVID-19 significantly impacted both groups. In the first instance, it led to the emergence of public and political discourses around hierarchies of 'deservingness' of care between different groups. Disabled people, for example, reported the (re) emergence of paternalistic attitudes, which constructed them as both vulnerable to COVID-19, but also 'risky' in terms potential carriers of COVID-19. Asylum seekers were similarly constructed as a 'risky' population, as COVID-19 outbreaks in Direct Provision centres became the focus of media attention (see also Murphy, 2021).

Secondly, the pandemic exacerbated care deficits in services and enabled care abuses: we found that both disabled people and asylum seekers experienced intensified care deficits during the pandemic which emerged from a withdrawal or restriction of services, or changes to the way services were run. In particular, asylum seekers living in Direct Provision experienced dehumanising conditions which had serious emotional and material effects; they were forced to live in inappropriate, isolated conditions during lockdowns which prompted experiences of re-traumatisation. The institutional structures of IPAS and Direct Provision centres also failed to recognise the intersectional identities of asylum seekers as care workers, as well as people requiring care in the international protection system. Neither was the significant emotional labour of asylum seekers engaged in care work during the pandemic acknowledged.

Disabled people too experienced a variety of service 'reversions' (Shakespeare et al., 2021), as some services closed and it became more difficult to access PA supports. Many, but not all, participants experienced isolation or were forced to move back in with family members, thereby reinforcing relations of dependence.

However, It is also possible to identify some ways in which the pandemic has prompted critique and led to calls for change, particularly in the way care and support systems are organised. It has led to renewed calls to end the long history of institutionalisation – including Direct Provision - as the state's response to dealing with groups deemed to be vulnerable and requiring protection and care in Ireland. It has led to a recognition of the impact of poor conditions (including lack of sick pay) for low paid workers, including care workers, as evidenced in the introduction of the Sick Leave Act 2022. The pandemic has also prompted discussion about the coherence of services for specific 'care groups', most notably older people through the recent setting up of a Commission on Care for Older Persons. Importantly, our research shows that COVID-19 also facilitated new spaces of peer-based activism, as disabled people's experiences of online organising bear witness to.

6.4 TOWARDS A RADICAL RE-ENVISIONING OF CARE

Based on our findings and analysis, we propose an agenda for a radical re-envisioning of care. We hope that this vision or agenda will be a starting point for discussion and debate about the future place of care in Irish society. It involves the following priorities and actions

Changing the language of care

- Clarify and reframe language and narratives around care, acknowledging the diverse meanings (both positive and negative) that the term care holds for different groups in society. As part of this, the harms that have been done in the name of 'care' need to be acknowledged.
- Recognise that care is central to human life and expand understandings of care beyond particular groups of people, service settings and sites of care. Care should be considered as intrinsic to humanity and human activity and care relations should be conceived as more than the care giver/receiver binary.
- Reject and move beyond market-based discourses of care that narrowly construct care in terms of economic exchange value and recognise the implications that these market-oriented discourses have for how we think about care and care futures.
- Co-create spaces for dialogue, coalition and advocacy between diverse groups implicated in shaping care policy and practices, including those representing care givers and those representing individuals in receipt of care, support or assistance.

Care work and care identities: challenging assumptions

- Challenge deeply held normative and cultural assumptions about care that continue to pervade Irish society. These assumptions relate to the devaluing of care and care work, and to gendered, racialised and ableist assumptions about who does care 'work' and who is 'deserving' of care.
- Recognise that care giving and receiving are two sides of the same coin, and that all people should be supported to give and receive care throughout their lives.
- Acknowledge the centrality and reciprocity of the relationship between care receiver and care giver. This relationship needs to reflect a context in which:

(i) the person in receipt of care or support has had choice and been able to determine how their support is provided; and

(ii) the person providing care needs to be adequately supported to undertake their role (i.e through good working conditions, fair pay, understanding of their role and recognition).

Building better care infrastructures, systems and services

- Challenge the increasing privatisation of care which leads to care being treated as a commodity and source of profit, as well as increasingly fragmented service experiences. We need to restate care as a ‘public good’.
- The state needs to play a central role in ensuring care and support needs are met and should provide good conditions which enable the giving and receiving of care.
- Better care and support services need to be built around ‘seeing the person’ and placing the individual at the centre of any form of support. This should be matched by standardisation, equity of access and an end to clientelism.
- Stimulate greater conversation and clarity around different care or support roles and expectations around what these roles look like/involve. Throughout the lifecourse, people require different levels and types of care and support, and the individual in receipt of care or assistance is best placed to articulate expectations and contribute their expertise to role definitions and training.
- Those in receipt of care or support need to be encouraged to articulate concerns or complaints and to know that these will be listened to without fear of loss/change of service.
- Identifying good care can only happen by also continuing to identify, acknowledge and confront instances of bad care, and care abuses.

Creating collective spaces for care activism

- Foster peer spaces which offer opportunities to build collective activism around issues relating to care. This might include online spaces, but also other community spaces, including community gardens.
- Locate care issues at the centre of political decision making and ensure that those most impacted by care policies and practices lead our care deliberations.

Appendix A

CareVisions Ethical Statement

RE-ENVISIONING CARE IN IRELAND: EMBODYING FEMINIST ETHICS OF CARE PRINCIPLES IN OUR RESEARCH PRACTICE

Aim

We aim to develop our ethical research practice and relationships in the CareVisions project based on a feminist ethics of care approach that is underpinned by the following ideas:

- that care has a central place in sustaining societies and human and planetary life;
- that care relations are interdependent;
- that care is personal and political.

This ethical statement establishes how this approach will shape how we work on the project, from the decisions we make about the design of methodologies, through to how we interact and engage with individuals and groups on the research journey.

As researchers based in a university, we are bound by formal ethics procedures as set down by UCC's Social Research Ethics Committee. Through this process, we are committed to principles of informed consent, to minimising harms to research participants, respecting participants' privacy, and developing inclusive research practices. However, we recognise that ethics is broader than the formal process of university ethics approval, and that it requires constant reflection about how we 'take care' in carrying out research and in the relationships we form within and across the project: with participants, advisors to the project and other stakeholders.

CareVisions: Ethical starting points

CareVisions takes as its starting point a number of interrelated understandings of care which will guide our thinking and practice: care as value, care as relational and care as practice.

Care as value recognises that we need to pay attention to values of mutuality, relationality, reciprocity, trust, solidarity and understanding in how we enact care and, more broadly, in our human, societal and environmental relations.

Care as relational interprets care relations and practices as made up of dynamic multiple, interconnected relationships and interdependencies. We recognise care as a multi-directional process, which disrupts the binary categories of care giver and care receiver. Interdependence in terms of care relations means paying attention to the multiplicity of diverse care relationships that exist – not just in one-to-one personal relationships, but within and between different groups, formally (through care services) and informally, and across different places and spatial scales.

Care as practice recognises the work and labour (both paid and unpaid) involved in care, and draws attention to the social, economic, emotional, political and environmental contexts in which this work takes place.

Understanding care as practice draws attention to the power relations and inequalities which shape the dynamics of 'who does' care work, and the gendered, classed and racialised dynamics which are evident in care provision.

On the basis of these understandings, CareVisions aims to:

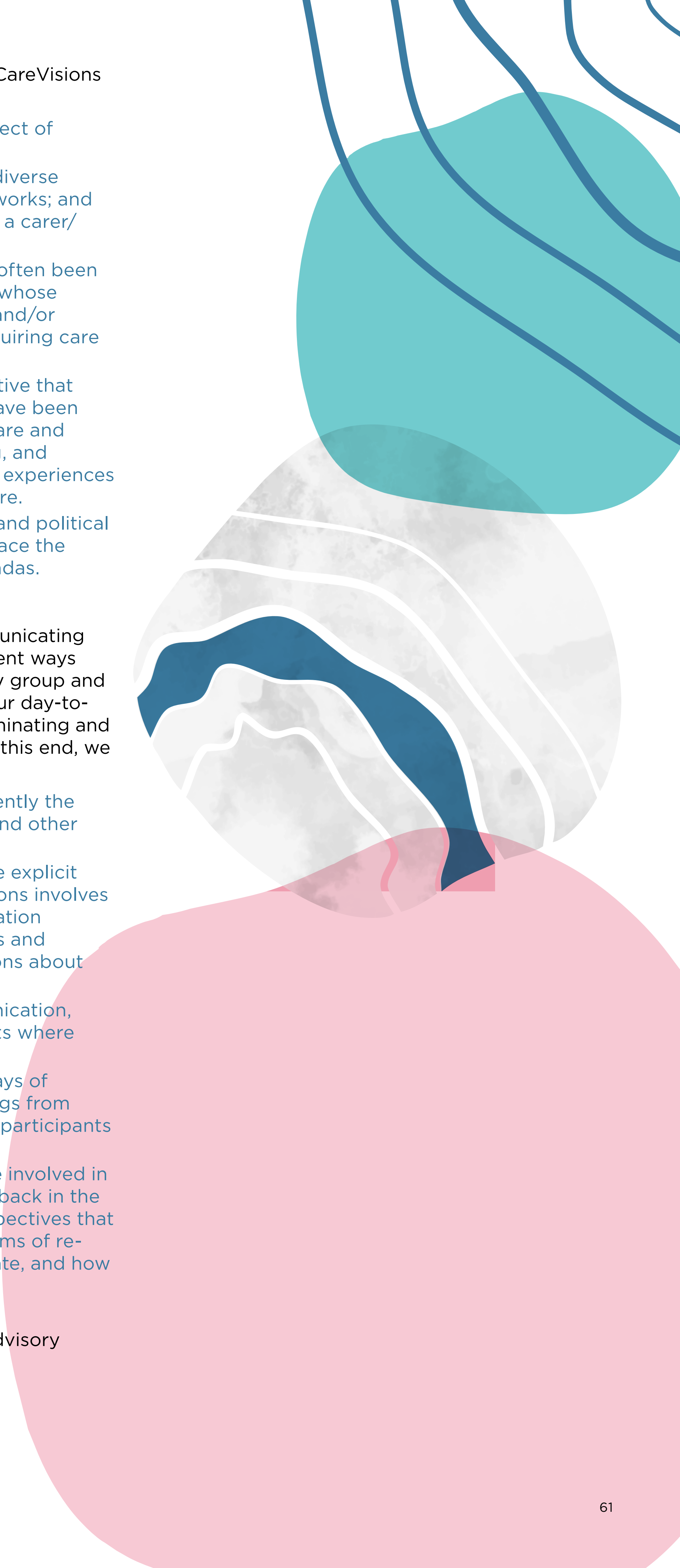
- make care a visible and valued aspect of human endeavour.
- pay attention to the complex and diverse nature of care relationships and networks; and challenge assumptions about who is a carer/ care receiver.
- acknowledge the harms that have often been done in the name of care and those whose work and lives have been devalued and/or marginalised as a result of either requiring care or working as a care giver.
- maintain an intersectional perspective that facilitates the voices of those who have been marginalised in discourses around care and commit to inviting, enabling, hearing, and amplifying diverse perspectives and experiences of those who provide and receive care.
- recognise care as both a personal and political issue and develop mechanisms to place the issue of care on policy/political agendas.

Communicating in CareVisions

We recognise the importance of communicating about the project in clear and transparent ways with research participants, our advisory group and other stakeholders - both in terms of our day-to-day communications, but also in disseminating and communicating about our research. To this end, we will:

- communicate clearly and transparently the aims of the project via the website and other media.
- in engaging participants, we will be explicit about what participation in CareVisions involves and provide clear, accessible information in different formats to enable groups and individuals to make informed decisions about their involvement.
- provide sufficient time for communication, and provide communication supports where necessary.
- develop creative and accessible ways of disseminating and sharing the findings from CareVisions, in conjunction with our participants and advisory group.
- actively invite feedback from those involved in the project and respond to this feedback in the best way we can. We welcome perspectives that challenge our ways of thinking in terms of re-imagining care, ways we communicate, and how we approach the research.

The CareVisions Team and Research Advisory Group, November 2021



References

Bacchi, C. (2009) *Analysing Policy: What's the Problem Represented to Be?* Adelaide: Pearson.

Barnes, M. (2012) *Care in Everyday Life – An Ethic of Care in Practice.* Bristol: Policy Press.

Barnes, M. (2015) Beyond the Dyad: exploring the multidimensionality of care. In Barnes, M., Brannelly, T., Ward, L. and Ward, N. (eds.) *Ethics of Care Critical Advances in International Perspective.* Bristol: Policy Press, pp.31-44.

Barnes, M., Brannelly, T., Ward, L. and Ward, N. (2015a) Introduction: the critical significance of care. In Barnes, M., Brannelly, T., Ward, L. and Ward, N. (eds.) *Ethics of Care Critical Advances in International Perspective.* Bristol: Policy Press, pp.3-20.

Barnes, M., Brannelly, T., Ward, L. and Ward, N. (2015b) Conclusion: renewal and transformation – the importance of an ethics of care. In Barnes, M., Brannelly, T., Ward, L. and Ward, N. (eds.) *Ethics of Care Critical Advances in International Perspective.* Bristol: Policy Press, pp. 233-243.

Bray, J. (2022). Plan to end direct provision by 2024 no longer possible, says expert. *Irish TImes*, 28 November.

Breen, C. (2008) The Policy of Direct Provision in Ireland: A Violation of Asylum Seekers' Right to an Adequate Standard of Housing*. International Journal of Refugee Law* 20(4): 611-636.

Carroll, E. and McCoy, S. (2022) Personal Assistance Services in Ireland: A Capability Approach to Understanding the Lived Experience of Disabled People*. Disabilities* 2: 694-714. https://doi.org/10.3390/disabilities 20400

Chatzidakis, A., Hakim, J., Littler, J., Rottenberg, C. and Segal, L. (2020) *The Care Manifesto – The Politics of Interdependence.* London: Verso.

Ciccia, R. and Bleijenbergh, I. (2014) After the male breadwinner model? Childcare services and the division of labor in European countries*. Social Politics* 21(1): 50–79.

Citizens' Assembly (2021) *Report of the Citizens' Assembly on Gender Equality.* Dublin: The Citizens' Assembly.

Commission on the Status of People with Disabilities (1996) *A Strategy for Equality.* Dublin: Stationary Office.

Cullen, P. (2019) The discursive politics of marketization in home care policy implementation in Ireland. *Policy and Society* 38(4): 606–25.

Cullen, P. and Murphy, M.P. (2020) Responses to the COVID-19 crisis in Ireland: from feminized to feminist. *Gender, Work & Organization* 28(S2): 348–65.

Daly, F. and Edwards, C. (2022) Tracing State Accountability for COVID-19: Representing Care within Ireland's Response to the Pandemic. *Social Policy and Society* 1-13, doi:10.1017/S1474746422000665

Davy, L. (2019) Between an ethic of care and an ethic of autonomy: Negotiating relational autonomy, disability, and dependency. *Angelaki* 24(3): 101–114.

DCEDIY, (2021) *White Paper to End Direct Provision and to Establish a New International Protection System.* Dublin: Department of Children, Equality, Disability, Integration and Youth.

Department of Health (2012) *Value for Money and Policy Review of Disability Services in Ireland.* Dublin: Department of Health.

Dodd, S. (2013) Personalisation, individualism and the politics of disablement. *Disability & Society* 28(2): 260-273.

Dukelow, F. and Considine, M. (2017) *Irish Social Policy (Second Edition): A Critical Introduction.* Bristol: Policy Press.

European Commission (2022) *Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions on the European Care Strategy.* Available at:
https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52022DC0440

Fine, M. and Glendinning, C. (2005) Dependence, independence or inter-dependence? Revisiting the concepts of 'care' and 'dependency'. *Ageing and Society* 25(4): 601-621.

Fine, M. and Tronto, J. C. (2020) Care goes viral: care theory and research confront the global COVID-19 pandemic. *International Journal of Care and Caring* 4(3): 301–9.

Fischer, C. (2011) Re-visioning Ireland: lessons from feminist care ethics*. Studies* 100(397): 63–72.

Fisher, B., & Tronto, J. (1990). Toward a feminist theory of caring*.* In E. E. Abel, & M. Nelson (Eds.), *Circles of Care*. Albany: SUNY Press.

Flynn, E., Phiri, J., Ní Fhlatharta, M. and Sperrin, A. (2021). *COVID-19 and people with disabilities Assessing the impact of the crisis and informing disability-inclusive next steps – Ireland.* European Commission. Luxembourg: Publications Office of the European Union.

Government of Ireland (1937) *Bunreacht na hÉireann*, Dublin: Official Publications.

Government of Ireland, (2020) *Report of the Advisory Group on the Provision of Support including Accommodation to Persons in the International Protection Process.* https://www.gov.ie/pdf/?file=https://assets.gov.ie/93440/05b40003-242c-4549-88a5-ba8fcdc20f60.pdf#page=null

Government of Ireland (2021) *Statistical spotlight #6: gender norms in Ireland*, https://assets.gov.ie/207637/1ffaa942-044a-4fbb-8ded-f4f8bf479a3d.pdf.

Government of Ireland (2022) *Sick Leave Act 2022*, Dublin, https://data.oireachtas.ie/ie/oireachtas/bill/2022/38/eng/ver_b/b38b22d-p-c-sent.pdf

Gusciute, E. (2020) Leaving the most vulnerable behind: Reflection on the COVID-19 pandemic and Direct Provision in Ireland. *Irish Journal of Sociology* 28(2): 237-241.

Hanlon, N. (2012) *Masculinities, Care and Equality: Identity and Nurture in Men's Lives.* London: Palgrave Macmillan.

Hanly, P. and Sheerin, C. (2017) Valuing informal care in Ireland: beyond the traditional production boundary. *The Economic and Social Review* 48(3): 337–64.

Held, V. (2006) *The Ethics of Care: Personal, Political, and Global.* Oxford: Oxford University Press.

Held, V. (2018) *Distributive Justice and the Ethics of Care.* In Olsaretti, S. (ed). *Oxford Handbook of Distributive Justice.* Oxford: Oxford University Press.

Herz, M., Andreasson, J., Andréasson, F., (2022) The precariousness of asylum-seekers' care and support: informal care within and because of the immigration process. *International Journal of Care and Caring 7*(1) doi: 10.1332/239788221X16456304482483

Hick, R. and Murphy, M. (2021) Common shock, different paths? Comparing social policy responses to COVID-19 in the UK and Ireland. *Social Policy and Administration* 55(2): 312–25.

Hoang, L. and Yeoh, B. (2011) Breadwinning wives and 'Left-behind' husbands: men and masculinities in the Vietnamese transnational family. *Gender & Society* 25(6): 717–39.

Houses of the Oireachtas (2020) *Special Committee on Covid-19 Response Final Report*, Dublin: Houses of the Oireachtas https://data.oireachtas.ie/ie/oireachtas/committee/dail/33/special_committee_on_covid_19_response/reports/2020/2020-10-09_final-report-of-the-special-committee-on-covid-19-response-sccr004_en.pdf

Hughes, B., McKie, L., Hopkins, D., and Watson, N. (2005) Love's Labours Lost? Feminism, the Disabled People's Movement and an Ethic of Care. *Sociology* 39(2): 259-275

Independent Living Movement Ireland, (2023) *Invest in Inclusion: Independent Living Movement Ireland Budget 2023 Priorities.* Available at: https://ilmi.ie/wp-content/uploads/2022/09/ILMI-Budget-2023-Invest-in-Inclusion.pdf

Irish Human Rights and Equality Commission (2023) *Policy Statement on Care.* Dublin: IHREC.

Irish Refugee Council, (2020) "Powerless" Experiences of Direct Provision During COVID-19 Pandemic. Press Release, Dublin: Irish Refugee Council.

Irish Refugee Council, (2023) *Reception Conditions, Republic of Ireland.* Asylum Information Database/European Council of Refugees an Exiles. https://asylumineurope.org/reports/country/republic-ireland/reception-conditions/

Isaloo, A.S., (2020) Liminality in the Direct Provisional system - Living under extreme rules and conditions. In: O'Riordan, J., FItzGibbon, M. (eds) *Direct Provision: Asylum, the Academy and Activism.* Peter Long Publishing: Bern.

Isaloo, A.S., (2021) Leaving asylum seekers in liminality: The Covid-19 pandemic and Direct Provision in Ireland. *Sociological Observer: August.*

Kelly, C. (2014) Re/Moving care from the Ontario Direct Funding Program:
Altering Conversations Among Disability and Feminist Scholars. *Social Politics* 21(1): 124-127.

Kittay, E. (2020) *Love's Labor: Essays on Women, Equality and Dependency.* 2nd edn,
London: Routledge.

Larios, L., (2019) Near and far, with heart and hands: care work in the context of refugee resettlement in Canada. *International Journal of Care and Caring* 3(2): 264-278.

Liveng, A. (2015) Paradoxical constructions in Danish elder care. In Barnes, M., Brannelly, T., Ward, L. and Ward, N. (eds.), *Ethics of Care Critical Advances in International Perspective.* Bristol: Policy Press, pp.125–38.

Loughnane, C. (2022) *CareVisions Briefing 1: Four Key Theorists of the Feminist Ethics of Care*. Cork: UCC. Available at: https://static1.squarespace.com/static/60794fe9b05e0b4b67aebfc7/t/62793ba33bddaa4d54434ef0/1652112293304/CareVisions+Briefing+Note+1+-+Key+Theorists+of+the+Feminist+Ethics+of+Care+-+May+2022.pdf

Loughnane, C. and Edwards, C. (2022). Reimagining care discourses through a feminist ethics of care: analysing Ireland's Citizens' Assembly on Gender Equality. *International Journal of Care and Caring,* https://doi.org/10.1332/239788221X16686175446798

Loughnane, C., Kelleher, C. and Edwards, C. (2023). Care full deliberation? Care work and Ireland's Citizens' Assembly on Gender Equality. *Critical Social Policy*, https://doi.org/10.1177/02610183231169195

Lynch, K. (2022) *Care and Capitalism.* Cambridge: Polity.

McGee, H., (2023). Record Number of People Sought Asylum in Ireland in 2022. *Irish Times*, Ireland, 1 January.

McHale, M. (2023) Government announces commission on care for older people. *Irish Medical Times*, 4 October. Available at: https://www.imt.ie/news/government-announces-commission-on-care-for-older-people-04-10-2023/#:~:text=The%20Commission%20on%20Care%20for,Government%20for%20their%20strategic%20development.

McLaughlin, J. (2020) Valuing Care and Support in an Era of Celebrating Independence. *Sociology* 54(2): 397-413.

Morris, J. (1997) Care or empowerment? A Disability rights perspective. *Social Policy and Administration* 31(1): 54-60.

Murphy, M. (2011). Making Ireland a Caring and Equal Society. *Studies: An Irish Quarterly Review 100*(397): 43–53.

Murphy, F. (2021) Direct Provision, rights and everyday life for asylum seekers in Ireland during COVID-19. *Social Sciences* 10(4): 140.

Murphy, R., Keogh, B., Higgins, A., (2021) An embodied distress: African asylum seekers' experiences of mental health difficulties while awaiting an asylum outcome in Ireland. *Transcultural Psychiatry* 58(2): 239-253.

Nally, D., Moore, S.S., and Gowran, J.R. (2022) How governments manage personal assistance schemes in response to the United Nations Convention on the Rights of Persons with Disabilities: A Scoping Review. *Disability & Society* 37(10): 1728-1751.

Namer, Y. (2022) Feminist Ethics of Care, Responsibility, and Refugee Accommodation: Concrete Steps Toward Improvements. In Razum, O., Dawson, A., Eckenwiler, L., Wild, V. (eds), *Refugee Camps in Europe and Australia.* Cham: Palgrave Macmillan. https://doi.org/10.1007/978-3-031-12877-6_8.

National Advocacy Service for People with Disabilities and Patient Advocacy Service (2021) *Advocacy Matters: Advocating for People Regarding Health and Social Care during the Covid-19 Pandemic*. Available at: https://advocacy.ie/app/uploads/2021/12/NAS-Impact-of-COVID-Report-3-of-4-FINAL-Web.pdf (accessed 03 March 2023).

O'Dwyer , C. (2017) Long-term care policy for older people in Ireland: a governmental analysis. In: Edwards, C. and Fernandez, E. (eds.) *Reframing Health and Health Policy in Ireland: A Governmental Analysis. Manchester:* Manchester University Press, pp.226-246.

Oliver, M. (1992) Changing the Social Relations of Research Production? *Disability, Handicap & Society* 7(2): 101-114.

O'Reilly, Z. (2018) 'Living Liminality': everyday experiences of asylum seekers in the 'Direct Provision' system in Ireland. *Gender, Place and Culture* 25(6): 821-842.

O'Riordan, J., Daly, F., Loughnane, C., Kelleher, C., and Edwards, C. (2023) CareVisions: Enacting the Feminist Ethics of Care in Empirical Research. *Ethics and Social Welfare* 17(2): 109-124.

O'Riordan, J. (2020) Introduction: the Uncaring State. In: O'Riordan, J., FItzGibbon, M. (eds), *Direct Provision: Asylum, the Academy and Activism*. Bern: Peter Long Publishing, pp. 1-14.

Østerud, K. L., & Anvik, C. H. (2023). 'It's not really Michael who wears me out, it's the system': The hidden work of coordinating care for a disabled child. *Critical Social Policy*, 0(0). https://doi.org/10.1177/02610183231199661

Pierce, M., Kilcullen, S. and Duffy, M. (2018) *The situation of younger people with disabilities living in nursing homes in Ireland – Phase 1.* Dublin: Disability Federation of Ireland. Available at: https://www.disability-federation.ie/assets/files/pdf/dfi_rr_2018_web.pdf

Power, A., Coverdale, A., Croydon, A., Hall, E., Kaley, A., Macpherson, H. and Nind, M. (2022) Personalisation policy in the lives of people with learning disabilities: a call to focus on how people build their lives relationally. *Critical Social Policy* 42(2): 220-240.

Raghuram, P. (2019) Race and feminist care ethics: intersectionality as method. *Gender, Place & Culture* 26(5): 613-637.

Robinson, F. (1997) Globalizing Care: Ethics, Feminist Theory and International Relations. *Alternatives: Global, Local, Political* 22(1):113-133.

Robinson, F. (2011) Care Ethics and the Transnationalization of Care: Reflections on Autonomy, Hegemonic Masculinities, and Globalization. In Mahon, R. and Robinson, F. (eds), *Feminist Ethics and Social Policy: Towards a New Global Political Economy of Care.* Vancouver and Toronto: UBC Press, pp. 127-144.

Russell, H., Grotti, R., McGinnity, F. and Privalko, I. (2019) *Caring and Unpaid Work in Ireland*. Dublin: IHREC and ESRI.

Schmid, S. (2019) Taking Care of the Other: Visions of a Caring Integration in Female Refugee Support Work. *Social Inclusion* 7(2), 118-127.

Sevenhuijsen, S. (2003) The place of care: the relevance of the feminist ethic of care for social policy. *Feminist Theory* 4(2), 179-197.

Sevenhuijsen, S. (2004) 'TRACE: a method for normative policy analysis from the ethic of care', in Sevenhuijsen, S. and Svab, A. (eds.), *The Heart of the Matter – The Contribution of the Ethic of Care to Social Policy in Some New EU Member States.* Ljubljana: Peace Institute, pp.13–46.

Shakespeare, T., Stöckl, A., & Porter, T. (2018) Metaphors to work by: the meaning of personal assistance in England. *International Journal of Care and Caring* 2(2): 165-179.

Shakespeare, T., Watson, N., Brunner, R., Cullingworth, J., Hameed, S., Scherer, N., Pearson, C. and Reichenberger, V. (2021). Disabled people in Britain and the impact of the COVID-19 pandemic. *Social Policy and Administration*, DOI: 10.1111/spol.12758, pp.1–15.

Toar M., O'Brien K.K, Fahey T. (2009) Comparison of self-reported health and healthcare utilisation between asylum seekers and refugees: an observational study. *BMC Public Health* 30(9):214.

Tronto, J. (1993) *Moral Boundaries: a political argument for an ethic of care*. London: Routledge.

Van Aswegen, J., Hyatt, D. and Goodley, D. (2019) A critical discourse problematization framework for (disability) policy analysis: 'good cop/bad cop' strategy. *Qualitative Research Framework* 19(2): 185–98.

Vianelli, L. (2022) Warehousing asylum seekers: The logistification of reception. *Environment and Planning D: Society and Space* 40(1): 41-59.

Williams F (2012) Care relations and public policy: Social justice claims and social investment frames. *Families, Relationships and Societies* 1(1): 103–119.

CareVisions

UCC
University College Cork, Ireland
Coláiste na hOllscoile Corcaigh

iss21
Institute
for Social
Science in the
21st Century