



**Glasgow Disability Alliance** Confident Connected Contributing

## Triple Whammy: Disabled Women's Lived Experiences of Covid-19

Voices, Priorities and Actions for Change

March 2022

## **GDA Sisters**<sup>1</sup>

I'm not alone y'see, I got my GDA sisters smilin' back at me. No matter where we been, No matter how we do. I look at my reflection, and I see YOU – I see you!

There's times when you get down, these dark days of feelin' low, But we just press the zoom-zoom chat and ladies off we go! To know we're not alone, and get to share our day, Laugh out loud at nothin', make challenges less grey.

I'm not alone y'see, I got my GDA sisters smilin' back at me. No matter where we been, No matter how we do. I look at my reflection, and I see YOU – I see you!

So here we are together, united hand in hand. Facin' what life throws at us, this ain't some one man band. And with your eyes and ears and voice, you too can link the chain make it stronger, louder prouder, these sisters won't refrain.

I'm not alone y'see, I got my GDA sisters smilin' back at me. No matter where we been, No matter how we do, I look at my reflection, an' I see YOU – I see you!

I'm not alone y'see. I got my GDA sisters smilin' back at me. No matter where we been, No matter how we do, I look at my reflection, an' I see YOU! I see you!

<sup>1</sup> This song was written to be performed by GDA's Purple Poncho Players for the First Minister's Advisory Council CIRCLE event for Women and Girls in January 2021. Lyrics were inspired by disabled women's experiences of Covid-19 – its restrictions during Lockdowns and beyond, the inequalities which were "supercharged" and of the support they received from GDA and each other. Lyrics were written by Anita Vettesse with music by George Drennan. The performance was stage managed by Nadia Drennan and choreographed by Darren Brownlie. The song was performed by GDA members Paula Fummey and "The GDA Sisters"- part of GDA's Purple Poncho Players (PPPs). The PPPs use sketches, poetry and songs to depict the real life experiences of disabled people.

## Acknowledgements

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- Purple Poncho Players "GDA Sisters" for contributing sketches and a song depicting real life experiences and some of the barriers faced by disabled women during Covid-19.
- Our beloved friend and colleague, the late Susan McKinstery to whom we pay warm gratitude and acknowledgement for her rich insights over many years. Thank you Susan for sharing your lived experience evidence and always saying yes when we asked you to help us come up with solutions – many of which are contained in this Report.

Thanks also to :

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- Wider academic research including Shakespeare, Watson, Brunner & Cullingworth on the wider impact of Covid-19 on disabled people in Britain.

• GDA funders.

Triple Whammy was written by Tressa Burke, CEO, with, for and on behalf of GDA

## Introduction: About Glasgow Disability Alliance

Glasgow Disability Alliance (GDA) is a thriving disabled people led organisation run by and for disabled people, with 5000+ members across Greater Glasgow. Our members are diverse disabled people, people with long-term conditions, and member organisations led by disabled people. We also have a growing network of associate members: people, partners and allies who support our aims. GDA is the biggest groundswell of disabled people in Scotland and a leading example of a grassroots community of identity and peer support.

Our Vision is a world where disabled people can participate and have our voices heard, on a full and equal basis, in all aspects of our lives, communities and wider society, with our human rights upheld and with choices equal to others.

Our Mission is to build the confidence and connections of disabled people, by delivering fully accessible programmes of learning, capacity building and support to enable disabled people's vital contributions and active participation in our own lives, in decisions which affect us, and in creating a fairer more equal society. During Covid-19 we developed additional responses to meet evidenced needs.

## **Covid-19 and GDA Response**

From March 2020 and outset of Lockdown 1, GDA took swift action checking in with our members about their wellbeing by telephone, post and email to find out how they were being affected by Covid-19 and how we could help.

From April 2020 – end March 2021 we made and received well over **30,000**<sup>2</sup> phone calls, and spoke to over **6000**<sup>3</sup> disabled people about their needs, experiences, priorities and ideas – many of them multiple times and for lengthy periods on the telephone and/ or Zoom. We analysed online surveys from over **2500 disabled people**,<sup>4</sup> many of which were completed with support from our exponentially growing Team, recruited to help us deal with Covid-19 pressures and challenges facing disabled people. The aim was to ensure that disabled people were not left to fall through the gaps.

<sup>2</sup> GDA Trustees Report, December 2021

- <sup>3</sup> ibid
- <sup>4</sup> ibid

This engagement shaped our ongoing Covid-19 response: adapting our vital services and establishing new ones to plug gaps and meet needs. In addition we referred people – and continue to refer and "ease" pathways into other services where these exist or have been newly developed and accessible to disabled people. Many are left with no services and GDA, as well as other DPOs, continues to pick up the pieces of broken services.

Through our engagement we have demonstrated that, although we may all be in the same storm, we have most certainly not been in the same boat. For disabled people there have been fewer lifelines within reach.

GDA's report **"Supercharged: A Human Catastrophe - Inequalities, Participation and Human Rights before, during and beyond Covid-19"** and continual, ongoing engagement, highlight disabled people's experiences and crucial priorities during the ongoing pandemic. Our report found that, of the thousands of disabled people we have spoken to:

<b>41%</b> faced barriers to accessing information in formats required	<b>47%</b> faced barriers to accessing food/medication	<b>57%</b> were concerned about money and hardship
82% were acutely isolated	62% were concerned about their mental health	<b>80%</b> were unaware of, or unable to access, local support services
<b>47%</b> were concerned about their social care supports	<b>90%</b> were worried about physical/mental health	<b>60%</b> were digitally excluded

90% + wanted disabled people's voices to be heard

On top of the existing inequalities and reduced life chances disabled people face, GDA's engagement clearly evidenced Covid-19 's additional, negative impact on all disabled people. Through GDA's in-depth engagement and support provided to thousands of disabled people, particular inequalities for disabled women were quickly emerging. These showed a combined and cumulative impact of being disabled, being a woman and dealing with Covid-19: a **"triple whammy"**, as one group of GDA women described it.

We have long known, from lived experience shared by GDA members and other Disabled People Led Organisations<sup>5</sup> that women are more likely to be disabled than men; that disabled women are more likely to live in poverty, have insecure and low paid employment; and be at risk of violence and abuse compared with both non-disabled people and disabled men. We also know that disabled women fare less well in education than non-disabled people or disabled men; and disabled women struggle more to access the healthcare they need.<sup>6</sup> All of this is further evidenced by academic and independent research including the Equality and Human Rights Commission, **"The 'double whammy' of being a disabled woman in the UK".**7

GDA's Covid-19 engagement and support from 2020 through to 2022 has found higher numbers of disabled women than men, not knowing where to turn for help. Disabled women also described increased challenges and pressures surrounding household responsibilities such as shopping, housework and caring responsibilities for children and relatives. Women described huge impacts on their ability to cope, as these additional challenges were, and still are, exacerbated by social care cuts, reductions in health and childcare services, as well as rising poverty, isolation and mental health impacts.

Glasgow Disability Alliance sought to understand better the specific impacts on our disabled women and wider disabled women in Glasgow, because we are aware that disabled women are frequently voiceless and invisible. We are determined to make sure that their voices are heard, priorities acted on and lives improved.

<sup>&</sup>lt;sup>5</sup> Sisters of Frida, The Impact of COVID 19 on Disabled Women, April 2020.

<sup>&</sup>lt;sup>6</sup> Engender, Dr Wiseman, Dr Ferrie, "Our Bodies, Our Rights" 2018

<sup>&</sup>lt;sup>7</sup> https://www.equalityhumanrights.com/en/our-work/blogs/%E2%80%98doublewhammy%E2%80%99-being-disabled-woman-uk

## **Disabled Women: Diversity and Inclusion**

At GDA, disabled people's equality and human rights are core to our mission, and we know this can only be achieved through an intersectional approach: recognising and empowering those who face multiple oppressions and intersecting barriers, to ensure the full strength and diversity of disabled people's voices and lived experience is at the heart of our work to build solutions.

GDA has supported diverse networks to self-organise within our membership, including a disabled women's network, disabled LGBTQIA group, disabled Black and minority ethnic people's network, younger disabled people and older disabled people's groups.

Self-identification is core to our ethos and operations: disabled people are too often required to evidence, prove and repeatedly justify ourselves in order to access the supports we need – GDA therefore asks not about conditions, diagnoses, or medical certificates, but about the support disabled people need to take part.

Our disabled women's network, and wider engagement undertaken to inform this report, are both inclusive and open to self-identifying disabled women and girls, nonbinary and gender non-conforming disabled people. Specific LGBT-led and BAME-led discussion sessions were organised for disabled women and non-binary people from our BAME and LGBTQIA members' networks. Participation on a one-to-one basis was also supported where required for access reasons (whether due to digital exclusion, impairment or confidentiality preferences) so a diverse range of voices, experiences and priorities were facilitated and included in this report.

As part of the disabled people's wider movement for social change, GDA believes that the inequality and exclusion we face is not caused by our impairments or conditions – but by the barriers we face living in a world that was not designed for us. It is not disabled people who need to be 'fixed' – but society and the barriers. Simply put, these need to be removed! This is the social model of disability.

## **Methods and Approaches**

GDA has engaged with diverse disabled women for over 20 years using community development methods and approaches to reach women and disabled people who are often isolated, voiceless and disengaged. It is our firm belief that those who experience inequalities should be involved in shaping responses - including sharing lived experience and planning solutions for change.

GDA has always had more women than men in our membership, perhaps reflecting the fact that more women are disabled than men.<sup>8</sup>

Over the last 2 years (February 2020 – February 2022) we ran **16** specific events to capture the lived experiences, voices and priorities of disabled women in our Disabled Women's Network including:

- **1** face to face "Disability Spotlight" event in February 2020 to support GDA's work with the First Minister's Advisory Council for Women and Girls and establish disabled women's priorities for actions.
- **6** GDA Disabled Women's Network events to provide peer support and capture experiences, priorities and actions for change.
- **5** Disabled Women's Focus Groups drawing on our Women's Network, Disabled LGBTQIA+ Network and Disabled BAME Network.
- **2** Focus Groups to contribute lived experience of Lockdown and restrictions to the Social Renewal Advisory Board.
- 2 Collaborative "Sense-Making" events to check in again with disabled women: firstly in a face-to-face pilot event and then in an online event to cater for those too nervous or unwell to attend in person. These most recent events in February 2022 aimed to check findings against lived experience and "mop up" and plug any gaps.

In total, **131 diverse disabled women** actively participated in these meetings and events across the year and followed up by sharing reflections and contributing to recommendations – sometimes through the events themselves, or one-to-one by phone, or in interviews for research and films GDA has made during the last 2 years.

Additional data was mined from our engagement with over 6000 disabled people, **60% of whom were disabled women**. This enabled us to glean further insights e.g. from experiences of disabled parents as well as to check for gaps and sense check analysis.

<sup>&</sup>lt;sup>8</sup> Sisters of Frida, The Impact of COVID 19 on Disabled Women, April 2020.

### **Reducing Barriers and Promoting Participation**

Pre Covid-19 at face-to-face workshops, GDA was committed to meeting all access needs and supporting meaningful participation. We previously provided transport (usually through taxis) and personal assistants; accessible venues were used, information given in accessible formats and information and communication support needs were met wherever required. This was our starting point at the outset of Lockdown.

**During Covid-19 and related Lockdowns and restrictions**, face to face sessions were no longer possible. Instead, we adapted to using online sessions, events and workshops and learned to support disabled women and disabled people more widely with access to digital devices, access to broadband and intensive digital coaching to get online.<sup>9</sup> Without this, very few people would have been able to participate. The dialogue both started and ended with a face to face session.

We have offered opportunities for learning, peer support and connections with other disabled people – including events for women, parents, BAME and LGBTQIA+ disabled people, and across all ages.

To enable specific research around disabled women, workshops were designed to explore key issues that emerged from GDA's extensive engagement during COVID: this aimed to capture the experiences of diverse disabled women more specifically and identify actions for change which will contribute to building a fairer more equal Scotland.



<sup>9</sup> Funding from COVID related grants from Scottish Government, The National Lottery Community Fund, Glasgow City Council and Impact Funding has enabled GDA Connects digital support project, GDA Lifeline – food and medication and GDA Wellbeing supports.

## **Summary Findings**

Covid-19 has disproportionately impacted on disabled women, in comparison to both their male disabled peers, and non-disabled women. Many of the critical issues which have emerged during the pandemic are not new, but demonstrate the need to address ingrained inequalities facing disabled women.

These inequalities have been supercharged during the global pandemic and related crisis, creating a "triple whammy" of barriers. For disabled women, the inequality, exclusion and discrimination already faced as a disabled person, and as a woman, have been triple-charged by the unequal impacts of Covid-19.

GDA's findings about disabled women during Covid-19 echo reports from the Sisters of Frida,<sup>10</sup> the Women's Budget Group,<sup>11</sup> and the Women's Budget Group, London School of Economics and Political Science, Queen Mary University of London and the Fawcett Society.<sup>12</sup> In addition, findings reflect similar themes to those captured by Women's Policy Group Northern Ireland<sup>13</sup> and Engender, "specific issues and even deeper impacts have manifested for Black and minoritised women, young women, disabled women, unpaid carers, mothers, pregnant women, LGBTI women, and women with insecure immigration status, amongst other groups who experience intersecting forms of oppression and discrimination."<sup>14</sup>

GDA's Report demonstrates that, during the Pandemic, disabled women have faced myriad difficulties – a "triple whammy" of barriers which exacerbate existing inequalities and create new threats.

A wide variety of topics and experiences were shared which can be grouped into the following themes where disabled women's experience of the pandemic reflected this **triple whammy of barriers and inequalities**:

- Access to healthcare including mental health services as routine health services and appointments were stopped, reduced or deprioritised.
- Access to social care as many social care packages were halted or cut completely, and disabled women took on more "caring" responsibilities of children or other family members when support was withdrawn. Housing problems and lack of support increased social care needs during this time.

<sup>10</sup> Sisters of Frida, "The Impact of COVID 19 on Disabled Women -Voices of Disabled women in the pandemic", 2020.

<sup>11</sup> Women's Budget Group "Covid-19 and economic challenges for disabled women", Winter 2020. <sup>12</sup> Women's Budget Group, London School of Economics and Political Science, Queen Mary University of London and the Fawcett Society "Disabled women and Covid 19 Research evidence" April 2020 <sup>13</sup> "Covid-19 Feminist Recovery Plan: Disabled Women", Rachel Powell, Women's Policy Group NI, 2021 <sup>14</sup> Engender "Response to the call for views on the aims and principles of the Scottish Covid-19 public inquiry"

- **Poverty and financial struggles** including access to food, money, social security and vital resources such as sanitary and continence provisions. Many disabled women remain on legacy benefits and were therefore unable to access the £20 uplift awarded to those on Universal Credit.
- **Employment challenges** including lack of employment support, discrimination in the workplace including pressure to return to face to face and challenges with Access to Work.
- Social Isolation and being disconnected from local communities, being digitally excluded, lacking accessible information and support and feelings of abandonment exacerbated extreme loneliness and isolation.
- Human Rights Regressions due to pandemic responses including emergency legislation and women also faced increased risks of violence and hate crime.
- Climate Justice and Just Transitions barriers including measures taken during lockdown, such as travel restrictions and increased street furniture, which failed to take account of disabled women's needs and made accessing and using public space more difficult.

A theme, which emerged repeatedly, was the **role of disabled people's organisations** in offering peer support, access to information about human rights and creating resilience. Frequently this was referred to as **"a lifeline" and we have included direct quotes at Appendix 1**.

To "build back better", we must address the inequalities experienced by disabled women during Covid-19 but also that these were "supercharged" by entrenched and structural, long term inequalities. Our ambitions and actions are therefore thoughtful and reflect this analysis. Action now will prevent widening inequalities for disabled women and will improve their lives, opportunities and positive outcomes for them and their families.

## Headline recommendations:

- **1** Involve diverse disabled women, via DPOs in post-pandemic policies, plans and actions. We are ready, willing and able to participate.
- 2 Ensure that solutions are joined up and break free from silo thinking and silo working: "policy coherence" requires planners, policy makers and service designers to have a good understanding and analysis of the interrelated barriers which disabled women experience.
- **3** Co-design policies, services and actions: disabled women and those in power must work together towards solutions: this requires capacity building and resources.

## **Recommendations:**

## Access to Healthcare including mental health

- **A.** Urgently fast track and resource disabled women's access to vital health services cut or reduced during Covid-19 including face to face **and** online appointments, treatments, medication, lower level interventions and mental health and wellbeing supports.
- **B.** Enable disabled women to be accompanied at medical appointments including on admission to hospital for communications and/or support as well as allow us the equipment we need e.g. wheelchairs.
- **C.** Establish ongoing health care plans / passports for disabled women, which allow for continuing healthcare and uphold human rights in the context of national and global crises such as Covid-19.
- **D.** Ensure diverse disabled women's involvement in policies, services and decisions about our health care, working with disabled people led organisations (DPOs).
- **E.** Embed Disability Equality Training for health professionals at all levels drawing on the lived experience of disabled women, co-designed and delivered by DPOs.
- **F.** Resource and provide better access to specific Covid vaccines and treatments such as biological medicines and anti-virals for disabled women at highest risk of becoming seriously ill who test positive. Provide FFP2 masks to keep us safe.

## 2 Social Care and Housing

- A. Immediately reinstate, without reassessment, social care which was cut or cancelled at the outset of Lockdown or paused by disabled women through fears of the virus. Continue / restart assessments and provide additional resources to meet backlog.
- B. Embrace the legal definition of Independent Living enshrined in the United Nations Convention on the Rights of Persons with Disabilities: embed into Scottish law and Local Authorities strategies, policies and approaches including within Community Planning and Integration Joint Board (IJB)/ Social Care policies.

- **C.** Implement recommendations from the recent Feeley Review of Adult Social Care<sup>15</sup> to close the gap between good intention and lived experience, particularly:
  - I. Ensure diverse disabled women's involvement in policies, services and decisions about our care from individual service level to decisions made at the IJB and Scottish Government: build trust and relationships which embed sharing power and participate in the difficult conversations necessary to deliver change.
  - II. Plan actions to embed human rights in social care to support independent living.
  - III. Secure adequate resources for social care whether through increased investment from governments or local authorities, increased taxation or both.
- D. Co-design Social Care policies and services with diverse disabled women and our organisations: empower and embed the unique voices of disabled people led organisations as a matter of course, avoid allowing others to speak for us.
  #NothingAboutUsWithoutUs.
- **E.** Deliver disabled women's rights to accessible housing going beyond the minimum standards and specifications in new build housing and/or housing developments or adaptations and consider specific needs of disabled women.

#### **B** Poverty and Financial Struggles: Access to food, money and resources

- **A.** Work with DPOs to co-design Disability Poverty Reduction Targets such as free bus pass, blue badges, taxi card scheme, and fuel poverty measures and plan strategic actions to address the specific impacts of poverty on disabled women.
- **B.** Ensure that Covid-19 response, recovery and renewal plans are inclusive of and accessible to diverse disabled women e.g.:
  - I. Ensure accessible communication for all to reach disabled women who need specific information and access to nutritious, appropriate and affordable food and essential resources.
  - II. Collaborate with disabled women and DPOs to address barriers and gaps in accessible food provision, and roll out solutions highlighted during the pandemic.
  - III. Equality proof pandemic food chain measures: build plans which ensure priority access / assistance is available to all disabled women who need it in future Lockdowns – not based on narrow clinical criteria.
- **C.** Invest in flexible, accessible welfare rights advice, information and representation services so that disabled women can access our entitlements.

<sup>&</sup>lt;sup>15</sup> https://www.gov.scot/publications/independent-review-adult-social-care-scotland/documents/





- **D.** Urgently uprate Disability Benefits in response to Covid-19; review adequacy of disability benefits ongoing once these transfer to Scotland.
- **E.** Strengthen Child Poverty Targets with co-designed actions to tackle specific causes of poverty for disabled children and young people, and children of disabled parents.

# 4 Employment and Support

- **A.** Co-design urgent actions to stop the Disability Employment Gap widening further. Mitigate unequal impacts Covid-19 on disabled women and jobseekers:
  - I. Overhaul employability supports: prioritise funding for accessible and effective employability services that meet disabled women's particular needs and aspirations.
  - II. Recruit and retain more disabled women in jobs with decent pay aligned to the Fair Work Framework amongst Scottish Government and public sector at all levels.
  - III. Increase availability of accessible childcare and social care for disabled children and disabled parents.
- **B.** Urgently co-design actions and targets to tackle inequality in access to education, qualifications, employment and training for disabled women and girls.
- **C.** Review and improve Access to Work to better assess and meet the support needs of all disabled people including disabled women.
- **D.** Embed lived experience in disability equality training for employers, supports and access to work.

#### **5** Tackle Social Isolation and increase Participation

- **A.** Develop and resource inclusive, accessible methods and approaches to participation both digitally and face to face to enable meaningful involvement.
- **B.** Promote inclusive, accessible communication for all, involving disabled women from the outset.
- **C.** Invest in disabled people led organisations to develop "community" connections, facilitate peer support and sense of belonging, build capacity and resilience amongst disabled women and empower us to take up rightful roles at all levels including leadership.
- D. Improve understanding and 'equalities literacy' in local "place-based" communities and across policy development, service planning and decision making.
- **E.** Co-design policies, strategies, plans and actions e.g. Outcomes setting, EQIAs and budget decisions, working with disabled people led organisations and resource participation.
- **F.** Ensure diversity and intersectional experiences of disabled women and related insights inform plans and actions for social and economic recovery and renewal.



#### **6** Uphold and improve Human Rights

- **A.** Engage with DPOs and make available Disability Equality and participation training for public sector leaders.
- **B.** Embed Human Rights provisions and protections from the UNCRPD, CEDAW, CERD and UNCRC into Scots Law. Resource capacity building for rights holders and duty bearers, and co-design robust, accessible infrastructure for recourse and redress where rights are not upheld.
- **C.** Work with DPOs, Women's Organisations and Local Authorities to increase understanding of disabled women's needs in relation to violence and abuse particularly the need for accessible accommodation, communication and support.
- D. Co-design a new approach to prevent and eradicate Hate Crime and harassment including a revised Third Party Reporting scheme, improving police and community responses, and a national awareness raising campaign.
- **E.** Continue to prioritise the safety and right to participation of diverse disabled women when public health measures are reduced: disabled women must feel safe and be protected in terms of social distancing and wearing masks where practical.
- **F.** Urgently establish data collection, analysis and an Inquiry to capture unequal impacts of Covid on diverse disabled women, in relation to intersectional needs and impacts for policymaking.

# **7** Climate Justice and Just Transitions

- A. Ensure meaningful involvement of disabled women and DPOs in local, regional and national plans, actions and decisions to tackle climate change e.g. Low Emission Zones, Active Travel Schemes, Liveable Neighbourhoods.
- **B.** Support disabled women's meaningful participation in co-designing policies and actions to achieve a Just Transition across the full range of interrelated policy areas including employment, social care, childcare, transport, housing and education.



### The disabled women who shared lived experiences painted an alarming picture when it came to healthcare and keeping healthy during Covid-19.

Participants covered everything from routine medical interventions being suspended, causing harm in the medium to longer term, when concerns and issues have gone unchecked, to emergency hospital admissions.

Most disabled women respondents expressed appreciation for the work being done by the NHS but described feeling extremely hesitant to access healthcare services for fears around Covid-19 itself:

"On the one hand you're at risk of catching Covid-19 but on the other hand the consequences of not getting treatment might be just as bad."

There was also a sense of being seen as a burden on an overworked system:

"They are dealing with so much and there is a pressure being put on us all not to contact GPs or turn up at A&E – the problem is knowing when things are serious as we already live with an ongoing condition."

Disabled women reported being left without ongoing medical care, including medication during the pandemic, which has had both immediate and long-term consequences:

"Not being able to pick up my prescription for weeks and getting no support from shielding services. The first prescription was picked by GDA Lifeline."

Disabled women described feeling overlooked and left even further behind during the pandemic, with the usual barriers and inequalities faced then triple charged by gaps and barriers in Covid-19 responses:

"It was hard enough day to day, before all this - being both disabled and a woman – then with Covid-19, losing all your supports when you need them most - that's been a Triple Whammy!"

This interacted with disabled women's previous experiences of not being taken seriously by medical professionals pre- Covid-19 and has permeated into Covid-19 interactions with health professionals:

"Before Covid-19 when you weren't taken seriously you just kind of accepted it as how things are but now, with Covid-19, you've left it so long it might actually be something really serious." This reflects findings of pre-COVID research by Engender, Glasgow University and the Scottish Learning Disabilities Observatory, into lived experiences of reproduction and reproductive rights of disabled women in Scotland:

"... women experienced having their real symptoms and concerns de-legitimised and dismissed. This was so systematic that it left many women feeling unable to access advice and support."<sup>16</sup>

Participants reported that remote consultations have removed some barriers for some disabled people but added more for others:

"It's great that I've been able to speak to my GP on the phone but it took quite a bit of persuasion as the receptionist kept telling me to phone 111."

#### Halted healthcare

A recurring story across sessions and events was healthcare being halted overnight with no indication of when or if services would become available again. People spoke of being left in pain, without necessary medical supplies or medication,

"I called up my GP to get a repeat prescription - the receptionist asked me loads of questions and made me feel guilty bothering them during the pandemic."

Many women spoke of the impact of the withdrawal of routine but vital interventions including chiropodists, dental cleaning, podiatry, rehabilitation, audiology, orthotics, aids to daily living, wheelchair services and physiotherapy,

"Regular appointments were cancelled and no information was available e.g. dentist, podiatry."

Lengthy delays in accessing these services has already had significant health and life implications, including loss of function and mobility, missing potential problems or conditions and opportunities for preventative interventions:

"I rely on podiatry to keep up my mobility. If I don't get support soon I'll not be able to walk and will need even more support."



<sup>&</sup>lt;sup>16</sup> Engender, Dr Wiseman, Dr Ferrie, "Our Bodies, Our Rights" 2018.

This in turn places pressures on families and those providing care, a disproportionate number of which are women. This point was raised in particular by parents of disabled young people during our check in calls, and continues to be raised through ongoing engagement, as well as ongoing research examining the impact of Covid-19 on disabled people, their lives and the services they receive:

"People described how their health care and support had changed significantly. Routine physiotherapy, speech and language therapy and occupational therapy were cancelled, causing particular problems for young disabled people. Attempts to replicate these therapies either via video conference or phone were not perceived to be particularly successful. The young people with disabilities and their parents/guardians we spoke to commented on how they have lost up to a year of therapy, education and socialisation."<sup>17</sup>

Examples given by participants included difficulty walking, made worse by regression in physical health due to not being able to exercise in the same way as non-disabled people. Some women voiced fears about irreversible deterioration of conditions - or unknown new ones - where they felt deterred from reporting or seeking help for changes or issues including lumps which they were worried about, bleeding or other impairment or medication related issues,

### "There was a real lack of consistency and I couldn't get access – there was no one to ask – no access to decision makers."

A shortage of medical supplies left one woman battling significant UTIs which had been previously managed with a minor intervention.

A particular area of frustration was dentistry, with many reporting their surgeries were only treating patients who could pay privately - not an option for most disabled women as increasing poverty was an issue. Some women reported dealing with tooth pain and loss unnecessarily.

Access to medication was raised frequently and there were particular concerns around mental health treatment:

"It's worrying when you run out of medication and can't get new supplies or if you're having issues with reactions to changed dosages affecting you - you feel there is nowhere to turn."

<sup>&</sup>lt;sup>17</sup> Shakespeare, Watson, Brunner, Cullingworth et al, 2021, "Disabled people in Britain and the impact of the Covid-19 pandemic"



Many of the participants found Zoom and telephone consultations helpful in many ways as these removed barriers around travel and perhaps take less time all round. However, for some women the system didn't work- they found it difficult on the phone if there was a need to be examined or if they had communication impairments. Critically, support to secure and use technology and broadband was not available:

"I received a text telling me to click on the link for "NHS Attend Anywhere". Had no idea what this meant and didn't know how to use this so missed the appointment as I couldn't get through to talk to anybody."

These emergent barriers have stemmed from the presumption of digital by default i.e. access to the IT devices, broadband and skills required to take part in online appointments. For a significant proportion of the participants, it was only because of the support that they had received from GDA around equipment and skills for technology that they had been enabled to access health care:

"I was offered an appointment with "NHS Attend Anywhere" which was online. I was able to see the continence nurse and get support which was really great but if GDA hadn't given me an iPad and a LOT of training to use it –and I mean I had about 12 sessions with them –this would have not been possible."

Many of the women spoken to felt unable to seek healthcare due to a mix of reasons: to avoid taking up resources during a pandemic; fears and risks of catching the virus by going out, especially to access healthcare settings; and guilt associated with needing things from an overstretched system. Unfortunately, a small number of participants encountered healthcare staff acting as gatekeepers to medical care, particularly GP receptionists who – in some cases - had questioned their medical needs and deterred women from seeking professional help.

Many of the women described fears that when services resume, they will be back at "ground zero" having to explain their needs all over again.

Given that, at this point, we were almost one year into Covid-19 and related impacts on services, women unanimously reported that that they were likely to experience long-term consequences from gaps in healthcare provision. One participant was diagnosed with diabetes immediately before the pandemic and a year later had not received any follow-up information or support with managing the condition:

"I got diagnosed with diabetes just before the pandemic, I've had no guidance or follow-up I'm just doing what I can based on research on the internet but not everyone has access to this." Participants felt strongly that there should be measures in place to ensure ongoing care for those already in the system – this could help minimise the need for disabled people to continually explain and justify needs, and repeat information multiple times:

"It would actually save time and money and would be more effective all round if the information was stored so you weren't continually starting from scratch."

A number of participants unfortunately still required treatment or hospitalisation during the height of the pandemic - such is the nature of some impairments and long terms conditions but, also a fact of life for us all:

"My neighbour spent months trying to get a cancer screening. As she was in remission she was ignored and, when she finally got one, new cancer had appeared and basically it is too late to address."

One issue arising multiple times was the lack of consideration around support to be in hospital: not all disabled women can navigate the health system without support yet due to virus concerns a number of the participants were placed in situations they could not navigate safely alone and were refused permission to access support from a family member or carer:

"The lack of support in the way I need it really affected my experience and meant it took me longer to recover. I was both dealing with the medical issue and also being undermined as a disabled person with rights to support but there was a real lack of knowledge and understanding about disability or how this affected my needs on top of having to be in hospital."

This lack of disability specific knowledge in hospital and healthcare settings- and more widely - has been long been reported to GDA by disabled people pre-Covid-19, and has been described as detrimental to physical and mental well-being, undermining autonomy and negatively impacting health outcomes.

The global pandemic has made it harder for disabled women in Scotland to access women's healthcare because many people have more complex needs than can be met through their GP surgery. Many participants advised of a 'freeze on referrals' during the Covid-19 crisis, meaning preventative programs such as smear testing are unattainable for disabled women:

"I was due a smear test at the start of Lockdown in 2020 but it was cancelled and I'm still waiting. I'm a bit concerned because I've had issues in the past."

A number of participants identified wheelchair services not functioning which led to being forced to use unsafe equipment or being trapped in bed for days, weeks or even months at a time. Final concerns were most harrowing around women reporting that equal access to Covid-19 treatments had been threatened – phone calls were received in some cases from GPs asking women to agree to "Do Not Attempt Resuscitation" notices,

"My mum who is fit and well was called by her GP and asked 'If you die do you want us to bring you back?' She said no because of how it was framed. When we spoke it through later she realised what it meant and felt very differently. She phoned back to tell them – but not everyone has support to understand these decisions."

These types of interactions have left disabled women feeling fearful, more at risk, and left even further behind.

#### **Mental Health**

Almost all of the women we spoke with reported that repeated Lockdowns, restrictions and isolation had impacted their mental health and wellbeing significantly. GDA's Supercharged report engaged with 5000+ disabled people and found that:

- **90%** worried about their physical or mental health since treatments stopped and this has had impact over the year.
- 62% were specifically worried about their mental health and many women spoke about how this was exacerbated by services stopping with no alternatives. This left many women struggling with far less supports and less safety nets than before the pandemic and this finding is also supported by further Covid-19 research.<sup>18</sup>

Mental health and well-being services were raised as being particularly crucial and under-resourced currently. Many participants reported that, despite having previously met thresholds for support, during Covid-19 they were turned away, or had ongoing supports cut or curtailed - due to heightened demand, Covid-19 -related service constraints, and a lack of contingency planning,

"I called up to say I needed access to a community psychiatric nurse and I was told that I was coping too well."

"I was lucky I managed to see my psychiatrist the week before the lockdown, I don't think I'd get an appointment now."

Some women described being unable to access the support they need to stay well,

"My appointment was cancelled and I've been waiting months to see my psychiatrist. I really need to review my medication- I'm not sure if I'm feeling a normal response to Lockdown or something more worrying." Women were fearful about catching the virus but also about going out into the outside world,

"I feel like a prisoner in my own house but as soon as I go outside I'm terrified and just need to get back inside."

The women discussed the lack of accessible information available and the consequences on mental health,

"I heard of one young woman with learning difficulties drinking bleach because she thought that would protect her from Covid-19."

All of the women we spoke to were excited at the prospect of a Covid-19 free Scotland. However, almost all participants raised concerns that the rest of society would forget about disabled people and disabled women as soon as a return to "normal" is possible,

"Each time restrictions have eased I've been wary. It feels so unfair because now it's down to me to make the choice or take the risk and I can't be sure how safe others are being – like are they testing? Will people continue to wear masks?"

There was an overwhelming sense that disabled people's rights have regressed and that we will be left further behind.

## Health Recommendations – including mental health

- A. Urgently fast track and resource disabled women's access to vital health services cut or reduced during Covid-19 including face to face **and** online appointments, treatments, medication, lower level interventions and mental health and wellbeing supports.
- **B.** Enable disabled women to be accompanied at medical appointments including on admission to hospital for communications and/or support as well as allow us the equipment we need e.g. wheelchairs.
- **C.** Establish ongoing health care plans / passports for disabled women, which allow for continuing healthcare and uphold human rights in the context of national and global crises such as Covid-19.
- **D.** Ensure diverse disabled women's involvement in policies, services and decisions about our health care, working with disabled people led organisations (DPOs).
- **E.** Embed Disability Equality Training for health professionals at all levels drawing on the lived experience of disabled women, co-designed and delivered by DPOs.
- F. Resource and provide better access to specific Covid vaccines and treatments such as biological medicines and anti-virals for disabled women at highest risk of becoming seriously ill who test positive. Provide FFP2 masks to keep us safe.



A common thread running through responses was that both health and social care services assumed that disabled women had access to informal support to pick up where services were reduced or cut.

While this was true for some in the immediate / short term, the enduring pressure on disabled women to rely on friends, family or neighbours, or to make do without basic personal care – has had long term impacts:

"I completely understood Covid-19 was an emergency – no-one saw it coming. But what you can cope with for a few weeks then turns into months and this is not sustainable – I didn't have a shower in 7 months."

GDA's Covid-19 Report<sup>19</sup> based on 6000 calls with 5000+ disabled members plus others calling our Helpline has previously found Covid-19 to have highlighted the fragile ecosystems of services and supports which disabled people rely on to access their human rights and live their lives. This includes the Social Care System, which was already overstretched and under resourced in Glasgow pre-Covid-19.

Specifically, disabled women reported that care packages were reduced or cut – in many cases completely – with little or no notice, no information and creating challenges to make alternative arrangements,

"We were literally given three hours' notice of our care package being cut - they didn't even bother to tell me - they told my partner."

This affected disabled women in many ways and in particular:

- Pressure to depend on family, friends or neighbours who were often in high risk groups themselves.
- Pressure to "step up" to support other family members.
- Fears about long-term consequences of going without support: at the time of writing, many care packages have not been reinstated. There was a widespread fear amongst participants that pandemic conditions will be used as the baseline for reassessment, with a perception that "you managed without support and therefore you don't need it!"
- Many disabled women whose care had been cut or reduced, reported increased risks from having to rely on neighbours, family or friends who were themselves shielding, or were also frontline workers.

<sup>19</sup> Glasgow Disability Alliance. 2020. "Supercharged: A Human Catastrophe Glasgow", Glasgow Disability Alliance https://gda.scot/wp-content/uploads/2020/08/GDA– Supercharged-Covid-19Report.pdf



In one case, a woman reported that she had stopped the care package herself due to fears about catching the virus from carers working in and out of many people's homes. She had originally been assured that the social work service understood her concerns about contagion and that the package would restart on her request. Months later, she discovered that this was not the case and that she will need to undergo a full needs assessment again, "It's like starting from scratch, as if my needs have changed which they haven't. If anything I have physically regressed and need more support but it's like you're not believed and it's another way of making cuts."

This finding was echoed in a UK wide research project where many respondents reported concerns about the impact social care cuts would have on "the security and stability of their care in the future".<sup>20</sup>

A number of women reported that unmet care needs pre-Covid-19 meant that lockdown conditions were already all too familiar:

"Lockdown really isn't that much different. Obviously there's fear and the limitations are on everyone but I was already stuck at home most of the time."

Women reported that the cuts to social care had changed relationships with families and loved ones and had taken away their independence and sense of control:

"I feel like a burden on my family, I don't know how much more they can take and it's so upsetting. None of us chose this."

Social care was not only a consideration to those in receiving it: some disabled women had to take on caring responsibilities for family members as a result of the support cuts at the outbreak of the pandemic, often whilst struggling with their own needs:

"We are both at high risk but have had to step in and care for my Mum. We've just been left to get on with it and the risks are increasing every day but there is no alternative - her support has been completely cut."

Many of the women reported care packages being cut or frozen with no notice and no alternatives put in place. Information was not forthcoming and women described social work as "disappearing":

"I was phoning and phoning and never getting through. When I did eventually get through, there was no one who could actually help and no one got back to me."

<sup>&</sup>lt;sup>20</sup> Shakespeare, Watson, Brunner, Cullingworth et al, 2021, ,"Disabled people in Britain and the impact of the COVID-19 pandemic"

Unprecedented challenges with staffing resulted in some Local Authorities having to cut packages of support. The lack of alternative provisions or explanations for how cuts were made left disabled women confused, let down and feeling extremely vulnerable:

"I don't understand why it's ok to withdraw support when I can't eat, wash or go to the toilet without it! It seems inhumane – you wouldn't be allowed to treat animals like this."

Some women were able to rely on family members, reporting stories of relatives moving in for periods to reduce risks all round. At one year into Covid-19 and in Lockdown – this already felt unsustainable. As life resumes into more ordinary patterns and rhythms – like physical presence in workplaces – this will become unsustainable,

"It's been two years and it's just not possible for most families, neighbours or friends to sustain caring for people on top of working, studying or bringing up their own families."

There was widespread concern amongst participants that the pandemic has driven up social care eligibility thresholds even higher than before, with care packages cut to even more basic 'life and limb' support at best. If this does not change, disabled people feel they will be excluded from any 'post-pandemic' world. Disabled people who have been shielding for almost 2 years – many of whom were already housebound pre-pandemic due to a lack of access and support - want their lives to restart and be able to participate in post-Covid renewal, along with everyone else, once it is safe to do so. It was felt that social care has reduced to a state of "keeping people alive, but not living" and that this is contrary to independent living:

"It used to be that social care enabled me to live a fuller life and I got support to go out and about and see people. Then came the cuts - and that was before COVID. Things had already been stripped back but I'm worried sick what support will be left at the end of this."

This last point came up repeatedly where women spoke about feeling that their human rights had regressed significantly - first because of austerity and now because of Covid-19. There are ongoing fears around survival and what surviving Covid-19 means not only for social care support but also for disabled people's participation in their own lives and in society. Many women stated that they felt let down by a society that has forgotten disabled people, despite legislative responsibilities to take care of the most vulnerable. Some women blamed this on the emergency Coronavirus Act which enabled delays with assessments of needs and provision of support.

Participants described feeling that their experiences as disabled women were not being acknowledged or recognised and that public services and healthcare providers saw them as dispensable:

"At the start people kept saying 'but they had an underlying

#### "... an accepted casualty of Covid? ... "



condition anyway' when someone died. As if that made it ok... Then there was pressure put on disabled people to agree to DNRs if they got COVID. This really frightened me – it's as if disabled people were, and are still, acceptable collateral damage."

Connections between social care and other supports were also made repeatedly. Women spoke about housing with some saying that their Housing Associations had been wonderful and others saying that housing supports had retrenched and/or halted:

"My Housing Association was wonderful – providing food within weeks and then an iPad within a few months."

"Housing for people with mental health problems and distress is non-existent. Not one member from my housing took on board the vulnerability of my mental health or my needs – I felt there was no understanding that I was a disabled woman."

Particular concerns were raised around housing in relation to adaptations and accessibility for disabled women:

"We live in a supposedly accessible house but we can't reach the cooker, the cupboards or the sink. The windows are above our heads...mirrors above our head... All of this means that our social care needs are higher and undermines our right to be in control- even in our own home. And to add insult to injury, I've just got a letter from the housing to say the rent is increasing by £15 a month cause we're paying for a Closomat<sup>™</sup> toilet!"



## Social Care Recommendations – including Housing

- A. Immediately reinstate, without reassessment, social care which was cut or cancelled at the outset of Lockdown or paused by disabled women through fears of virus infection. Continue / restart assessments and provide additional resources to meet backlog.
- B. Embrace the legal definition of Independent Living enshrined in the United Nations Convention on the Rights of Persons with Disabilities: embed into Scottish law and Local Authorities strategies, policies and approaches including within Community Planning and IJB/ Social Care policies.
- **C.** Implement recommendations from the recent Feeley Review to close the gap between good intention and lived experience, particularly:
  - Ensure diverse disabled people's involvement in policies, services and decisions about our care from individual service level to decisions made at the IJB and Scottish Government: build trust and relationships which embed sharing power and participate in the difficult conversations necessary to deliver change.
  - II. Plan actions to embed human rights in social care to support independent living.
  - III. Secure adequate resources for social care whether through increased investment from governments or local authorities, increased taxation or both.
- D. Co-design Social Care policies and services with diverse disabled women and our organisations: empower and embed the unique voices of disabled people led organisations as a matter of course, avoid allowing others to speak for us.
  #NothingAboutUsWithoutUs.
- E. Deliver disabled women's rights to accessible housing going beyond the minimum standards and specifications in new build housing and/or housing developments or adaptations and consider specific needs of disabled women.

## **3 Poverty and Financial Struggles: Access to food, money and resources**

Disabled people were already three times more likely to face poverty and food insecurity as non-disabled people pre-Covid-19.<sup>21</sup> For example they face an average of £570 per month additional cost of living related to their impairment or condition. This is on top of welfare payments designed to help meet these costs.<sup>22</sup>

In the cases of families with disabled children, costs rise to £581 on average and in some cases for both disabled Individuals and families with a disabled child, extra costs rise to over £1000 per month.<sup>23</sup> These costs can include higher fuel or food bills, paying for pieces of equipment, using taxis and paying towards social care amongst others.

During the first Lockdown, food costs were hiked along with other household goods. The UK Government recognised challenges people were facing and topped up Universal Credit by £20. However, most GDA members and many disabled people are on legacy benefits which did not receive any such support: consequently, inequality was deepened.

The disabled women we spoke to faced specific challenges in getting access to basic necessities during the pandemic. This was exacerbated by pandemic responses which did not take account of their needs which include multiple sometimes interrelated issues.

There was a lack of consideration of women's needs (and disabled people's needs generally) when it came to Covid-19 emergency food provision. For example lack of continence pads, sanitary products, hygiene products or allergy information meant that this was not accessible:

"I suppose we shouldn't be surprised that disabled women's needs aren't considered. I remember being told that they couldn't award points for struggling with putting a bra on during my PIP assessment because it didn't apply equally to men and women. I said to the woman 'Exactly. So women are worse off because we have to wear clothes that we can't manage and it isn't recognised as a support need because it doesn't apply to men?' You couldn't make it up!"

<sup>&</sup>lt;sup>21</sup> Joseph Rowntree Foundation. Disability and poverty: Why disability must be at the centre of poverty reduction. JRF; 2016.

 <sup>&</sup>lt;sup>22</sup> Scope – equality for disabled people. The Disability Price Tag 2019 Policy report. Scope; 2019.
<sup>23</sup> Ibid

Many disabled women were either shielding or at high risk and therefore unable to go shopping which was routinely described as part of their "ordinary" family or relationship role – participants identified a strong gendered bias underlying this assumption. This point was also highlighted by Sisters of Frida, in their report examining the impact of Covid-19 on disabled women.<sup>24</sup>

With food and essential goods availability reduced due to panic buying, shortages were an issue and supermarket delivery slots were overwhelmed. Digital exclusion was a concern for many of the women. In addition, minimum spend barriers were created. Many women reported facing barriers to accessing shielding "status" needed to be eligible for the official support available:

"When you can't get out yourself and when there's nothing on the shelves, you're left with the option of home deliveries – but only if you have access to the internet which I didn't. So then I had to rely on GDA to deliver food parcels – this was a godsend and I don't know what I'd have done without them because I didn't qualify for shielding support. I also got an iPad and digital coaching from GDA which has opened up ways to connect with my family and GDA friends as well as other opportunities. But it shouldn't be down to an organisation like GDA, should it?"

Social care cuts also impacted on food security: some disabled women rely on social care for shopping, cooking and preparing meals. When social care packages were reduced or cut completely, food security became a huge issue for these women: accessing adequate, appropriate food, and being able to prepare it, became impossible for many:

"I got a bag of potatoes in my shielding box but I can't physically cook them, and my care has been cut."

Many described being expected to rely on the goodwill of friends, family or neighbours - people willing to volunteer- who were sometimes balancing this with working on the frontline or were indeed disabled themselves:

"I'm blind so rely on supermarket staff to guide me but this has all stopped. I've got family but they are mostly all working in frontline jobs and my Mum is shielding due to a lung condition so it's not ideal."

For those who were not shielding and therefore not eligible for food parcels but still identified as high-risk there were, and are, additional concerns about how to get to shops and minimise risk as well as the long-term financial impact e.g. relying on taxis,

"The only way would be to get a taxi but even then there are risks and I just can't afford either the money or the cost to my health."

Other challenges included rising costs of basic goods such as toilet rolls and canned goods; some retailers switching to "card only" use instead of cash; and minimum spend thresholds for grocery delivery.

<sup>24</sup> Sisters of Frida, "The Impact of ovid-19 on Disabled Women -Voices of Disabled women in the pandemic", 2020.

This was especially the case for disabled women who struggled to access "shielding" status and the associated supports; and also for those who had no access to online resources such as banking and shopping:

"Everything has been hiked up in price - but not the money we get as disabled people. I don't really understand why when other benefits increased and ours didn't."

Additional costs of being at home full time was raised by a number of women – and a lack of additional fuel payment support was a particular problem for disabled women whose conditions require them to keep warm:

"It's so frustrating listening to people talking about all the money they are saving, when Covid-19 is costing disabled people MORE money!"

There are also concerns that measures put in to support social distancing created unintended consequences and additional barriers for disabled women and disabled people generally. These included one-way systems around shops, reduced pavement size to accommodate expanding outside space for cafes and pubs and queuing:

"I didn't have a Shielding letter but couldn't stand in the queue. When I tried to explain, the shop assistant shouted at me and people in the queue started giving me a hard time."

Disabled women described living with fears that there would be a perception that being able to "cope or manage" during this time would be used against them in future assessments for social care or social security supports.

Many of the women we spoke with described being dependent on family, Covid-19 Shielding responses or Glasgow Disability Alliance for food deliveries. The provision of Covid-19 food parcels supplied through shielding was widely praised and seen as a lifesaver by many participants. However, there were access issues around the weight of the box; where it was left; and lack of allergy information in advance of opening the box. Many observed the lack of gendered consideration around the provisions of items particularly the lack of sanitary products for menstruation:

"The food parcels were great... The problem was getting the box inside - even though they said there was help they delivered the boxes at 6.30 in the morning without knocking."

"It must have been organised by a man because a women would have thought about sanitary products - or even cleaning products!"

"The packages from GDA each week kept my family going as both myself and my husband are shielding and the kids wouldn't manage on their own. There was such thoughtful touches like continence pads and sanitary towels and a packet of biscuits which made you feel less like you were scrounging. Somehow that made me feel better – as if we were valued."



#### Access to food, money and resources – Recommendations

- **A.** Work with DPOs to co-design Disability Poverty Reduction Targets such as free bus pass, blue badges, taxi card scheme, and fuel poverty measures and plan strategic actions to address the specific impacts of poverty on disabled women.
- **B.** Ensure that Covid-19 response, recovery and renewal plans are inclusive of and accessible to diverse disabled women e.g.:
  - I. Ensure accessible communication to reach disabled women who need specific information and access to nutritious, appropriate and affordable food and essential resources.
  - II. Collaborate with disabled people and DPOs to address barriers and gaps in accessible food provision, and roll out solutions highlighted during the pandemic.
  - III. Equality proof pandemic food chain measures: build plans which ensure priority access / assistance is available to all disabled women who need it in future Lockdowns - not based on narrow clinical criteria.
- **C.** Invest in flexible, accessible welfare rights advice, information and representation services so that disabled women can access their entitlements.
- D. Urgently uprate Disability Benefits in response to Covid-19; review adequacy of disability benefits ongoing once these transfer to Scotland.
- E. Strengthen Child Poverty Targets with co-designed actions to tackle specific causes of poverty for disabled children and young people, and children of disabled parents.





# 4 Employment and Support

Covid-19's impact on poverty, education and employment is already hitting disabled people hardest. The pandemic has posed additional barriers for disabled workers and jobseekers, and a post-Covid-19 recession will only worsen this, as job opportunities shrink.

Disabled people were already facing huge inequalities in work and education, being:

- Twice as likely to be unemployed
- · 3 times as likely to have no qualifications
- Half as likely to be educated to degree level
- 3 times as likely not to be in education, employment or training by age 19.

Disabled women described multiple concerns around employment which evidences interrelated barriers. Some women described fears around the pandemic in relation to feeling pressured to return to workplaces despite being at higher risk:

"It was fine during the first Lockdown as I was allowed to work from home. But when that lifted I felt the pressure to go in to take my turn because I'd be letting them down. There was an outbreak and I caught Covid-19 and passed it to my husband. The thing is the other admin staff are in their early 20s and I'm 71 and at high risk but after the first Lockdown, there was no guidance – employers were just doing what they liked."

There were further pressures described by women who felt both vulnerable to the virus but also vulnerable to losing their employment if they weren't able to work:

"My job can't really be done from home and I was on probation at the first Lockdown so I've been in Limbo for the last 18 months. They've agreed to extend my probation but I feel like I'm on a shaky peg."

At the outset of Lockdown on 23rd March 2020, there was immediate and almost total reliance on digital connections for those already in work. Some women were well supported by their workplaces:

"They were great. I was set up with a laptop and had access to my system. We had to find a few workarounds but mainly it was fine because I already had broadband and knew what I was doing on the computer." Some women did not receive support or equipment to work from home. In addition, some women in low paid jobs who might otherwise been able to work from home could not afford broadband due to low paid jobs and so they were further disadvantaged:

"In theory I could work from home but they'd need to pay for a laptop which they didn't and I don't have broadband – I don't earn a great wage so just use my phone. This has meant I've needed to keep going in – I've had no choice."

This situation has made disabled women more vulnerable - even those in employment are disadvantaged by other barriers such as being digitally excluded, social care cuts and being a working parent:

"Not having the support means that everything is much harder and takes longer. It means I'm self conscious about appearing on Zoom at meetings because I have no one to help me getting ready – showering and fixing my hair – and I'm busy trying to get the school work done too."

Working disabled women described problems getting live signatures for Access to Work claims. Some women reported experiencing support and flexibility whilst others described experiencing rigid attitudes and having claims returned, demands made for submission of workers contracts and unable to get someone on the phone to help them due to the chaos of the pandemic:

"It seems so inconsistent. My friend and I work for the same organisation. She was informed that it was ok to email claims with electronic signatures while I was told that they had to be "live" or "wet" signatures which creates such a lot of work. It also means my PAs going physically into the post office and creates more risk all round. It's extremely inconsistent and at odds with their statement that they are fasttracking things for disabled people at this time."

For those disabled women seeking work, opportunities have dried up, and as others have lost jobs the landscape has become more competitive:

"Why would they take a young disabled person like me who's never worked when there are people with experience who've lost their jobs and are looking too?"

Disabled women described existing barriers to accessing supports to find and sustain any employment. Participants called for ambitious targets to be set within employability services; to better meet disabled women's access needs and aspirations; and to prevent the employment gap widening even further.

#### Employment and Support – Recommendations

- A. Co-design urgent actions to stop the Disability Employment Gap widening further. Mitigate unequal impacts of Covid-19 recession on disabled women and jobseekers:
  - I. Overhaul employability supports: prioritise funding for accessible and effective employability services that meet disabled women's particular needs and aspirations.
  - II. Recruit and retain more disabled women in jobs with decent pay aligned to Fair Work Framework amongst Scottish Government and public sector at all levels.
  - III. Increase availability of accessible childcare and social care for disabled children and disabled parents.
- **B.** Urgently co-design actions and targets to tackle inequality in access to education, qualifications, employment and training for disabled women and girls.
- **C.** Review and improve Access to Work to better assess and meet the support needs of all disabled people including disabled women.
- D. Embed lived experience in disability equality training for employers, supports and access to work.



## **5** Social Isolation and Participation

Disabled women reported struggling with isolation throughout the lockdowns and cuts to support networks exacerbated this. Disabled people in Scotland were already twice as likely to experience acute isolation, pre-Covid-19: the grind of repeated lockdowns of the past 2 years created new levels of isolation and loneliness for disabled women and disabled people more widely.

Furthermore, disabled people were too often excluded from our local communities due to inaccessible houses, transport and environments; lack of support; and lack of understanding and negative attitudes towards disabled people. GDA reports show:

- 82% of GDA members surveyed during Covid-19 were concerned about isolation.
- 71% of GDA members surveyed in 2017 found it difficult to take part in things in their local communities, due to physical barriers, stigma, lack of accessible information, undermining resilience.
- 80% of members surveyed were not aware of and/or could not access any local support services during the pandemic and lockdown. Many relied on GDA to provide this information and accessible supports.<sup>25</sup>

Lack of accessible information and communications combined with an over-reliance on "digital by default" contributed to disabled women's isolation and exclusion. GDA's Supercharged Report confirmed that:

- **60%** of the thousands we engaged with were digitally excluded.
- 41% had difficulty accessing information in formats required.<sup>26</sup>

This lack of access compounded disabled women's exclusion and created further challenges in relation to both understanding and following the Lockdown rules and restrictions e.g. social distancing, self-isolation, Lockdown levels etc.

<sup>26</sup> Glasgow Disability Alliance. 2020. "Supercharged: A Human Catastrophe Glasgow", Glasgow Disability Alliance https://gda.scot/wp-content/uploads/2020/08/GDA–Supercharged-Covid-19Report.pdf

<sup>&</sup>lt;sup>25</sup> Glasgow Disability Alliance, 2021, "Manifesto for Equality Now" https://gda.scot/home-page-news/act-now-to-supercharge-disabled-peoples-voices.
## Disconnection from local communities and support

Covid-19 made everyone's world smaller overnight. For disabled women, pandemic restrictions led to vital support and supply lines being cut off, exacerbating existing issues around isolation and loneliness:

"Everything just stopped overnight and if it weren't for the GDA's activities I wouldn't speak to anyone."

Services and practical support were withdrawn, further exacerbating isolation. Ordinary supports being reduced or removed left disabled women alone, with no support and, in many cases, not seeing anyone for weeks or even months on end:

"For disabled people isolation is always a worry but this is a new low – it could go either way – the fact that everyone is suffering for the first time could make people more understanding or make them shut out our experiences completely."

Lack of understanding of particular barriers facing disabled women and disabled people meant that responses did not always consider their needs:

"The community responses to food issues were great for some people – like my old neighbour, but no one came near me except GDA. I tried to find out about support in my local area but didn't know where to start."

Many spoke of the assumption being made in wider society that you can just move all services and supports online. Most of the women we spoke to were only able to get online thanks to equipment distributed and supported by GDA, backed up by intensive digital coaching and support. This was key to their success in using the equipment,

"The only people that reached out to me and made any sort of difference was the GDA. It wouldn't have mattered if I had an iPad or anything as I didn't know how to use it so the fact that the GDA got the iPads and taught us how to use them made all the difference."

Digital exclusion and a lack of accessible information resulted in disabled women lacking the vital information they need to stay safe and access support, as well as increasing social isolation and loneliness:

"When we went into Lockdown I had no internet. I had no way of connecting to the internet. And GDA gave me this wee box that allows me to go onto the internet and I can use it as much as I want."



Some disabled women reported an interesting counterpoint in that, whilst they were immediately cut off from their local communities and outside life, a wider community of identity and interest had opened up that they could access online to share experiences:

"The GDA sent me an iPad and I was able to get connected to the world. Zoom has transformed my life!"

"Attending the events online means that you know you are not alone - you're still connected to other people who're in the same boat and we all support each other."

Whilst online participation was welcomed by some as an accessible alternative to faceto-face events – circumventing inaccessible transport and venues – at the same time, many expressed fears that this would be seen as a cheaper default for disabled people's participation in future, in place of making spaces, services and events physically accessible.

All of the women we engaged and spoke with reported that it is essential that services and support remain available offline and face to face or by phone as not all women will get digitally connected:

"I'm one of the lucky ones but there are many disabled women out there that don't know about GDA or any of these supports, and that won't ever be able to get online for whatever reason - so we need to make sure face-to-face support, opportunities and connections are still available, offline." There was also a plea for digital participation to continue beyond this essential phase of COVID's impact as this had widened opportunities for some women, particularly in learning and social participation:

"Lockdown is my normal – things going online means I can finally take part again... I hope people don't forget about us when things go back to normal."

"I had to drop out of uni 3 years ago when my health was bad, because they said I couldn't take part remotely – now everyone's doing it! I just hope this will carry on so that doesn't happen to the next generation of young disabled people."

An additional factor contributing to isolation is negative attitudes, and in some cases increased hostility, harassment and even hate crime, towards disabled people in public spaces - trying to go out for routine exercise - or go into shops, particularly if unable to wear a facemask:

"I feel safer being isolated at home than risking abuse if I attempt to go out – the one time I went into a supermarket I was shouted at for not wearing a mask. I tried to explain but the guy wouldn't listen."

Some women reported being cut off from chosen communities particularly around religious beliefs and support groups,

"I can't get to worship but I know I'm not alone."

Women reported the vital importance of staying connected to each other for peer support as well as socialising,

"I think this support is really important not just for now but also into the future because we don't know when we are going to be able to go back to face to face things and I think it ensures that we can all stay connected and meet new people just like we would at an actual GDA event. This stops people becoming isolated and gives us a lot more opportunities that we wouldn't otherwise have as disabled women."

Many of the women that we spoke to talked about the regression of their roles within their households due to childcare and other caring responsibilities emerging as existing support services ceased to function:

"I'm now the disabled Mum, the Carer, the cook, cleaner and the teacher – I don't think people understand the way this affects disabled parents and disabled women." An issue which arose in the context of our wider engagement was the increased risk of violence and abuse which disabled women experience. Sisters of Frida report that disabled women in particular are between three and four times more likely to experience domestic abuse than non-disabled women, and are more likely to experience multiple forms of abuse in their lifetime.<sup>27</sup> They also evidence that there has been a dramatic increase in calls to domestic violence helplines and support services during the coronavirus crisis.<sup>28</sup>

As a result we have a specific recommendation to address this further challenge which leaves disabled women isolated and more vulnerable with further human rights and dignity eroded.

#### Social Isolation and Participation – Recommendations

- **A.** Develop and resource inclusive, accessible methods and approaches to participation both digitally and face to face to enable meaningful involvement.
- **B.** Promote inclusive, accessible communication for all, involving disabled women from the outset.
- **C.** Invest in disabled people led organisations to develop "community" connections, facilitate peer support and sense of belonging, build capacity and resilience amongst disabled women and empower them to take up rightful roles at all levels including leadership.
- D. Improve understanding and 'equalities literacy' in local "place-based" communities and across policy development, service planning and decision making.
- E. Co-design policies, strategies, plans and actions e.g. Outcomes setting, EQIAs and budget decisions, working with disabled people led organisations and resource participation.
- **F.** Ensure diversity and intersectional experiences of diverse disabled women and related insights inform plans and actions for social and economic recovery and renewal.

<sup>28</sup> https://www.theguardian.com/society/2020/apr/12/domestic-violence-surges-seven-hundred-per-cent-uk-coronavirus

<sup>&</sup>lt;sup>27</sup> http://www.sisofrida.org/resources/stay-safe-east-da-bill-briefing-and-amendments-disabled-survivors/

# 6 Human Rights

The pandemic and related responses have overwhelmingly demonstrated the principles of utilitarianism by promoting "the greatest amount of good for the greatest number of people".

In many ways, this was inevitable in a society that has not routinely included disabled people and our rights as part of the architecture and infrastructure: the voices of diverse disabled women and our human rights are almost always an afterthought. As such, like many universal approaches, pandemic responses - albeit unintentionally - ignored the needs of disabled people, creating inequalities, injustices and eroding human rights for disabled people and disabled women.

Immediate responses to the virus included emergency legislation - the Coronavirus (Scotland) Act 2020 - which enabled Local Authorities to relax certain duties and refocus how they prioritised services. The duty to provide support still applied under Section 12 of the Social Work (Scotland) Act and related laws, yet the social care system collapsed – being reduced or completely withdrawn for many disabled women and people in Glasgow, leaving them to manage their own survival.

A recurring narrative of the focus groups and network events was this conflict between individual survival and a more 'global' or universal response to the pandemic crisis. Almost all of the women reported feeling dispensable in comparison to non-disabled people for all the reasons outlined in this report - not least of which included calls from GPs to persuade women to agree to Do Not Attempt Resuscitation notices. This made disabled women feel forgotten and like an accepted, inevitable casualty of Covid-19.

There are many opportunities to build a better future for Scotland and all its people including disabled women. As one woman put it:

"We need to work together for sure but disabled women need to be genuinely seen, heard and believed – for our lived experiences to be taken seriously. We know what's worked and what hasn't: and this needs to be valued by politicians, officers and civil servants – so we can work together for solutions, without disabled women fearing recriminations for our services or organisations. We know what we are saying is hard to hear – it's hard to talk about, and hard to go through! Sometimes the things people least want to hear are the things they most need to listen to."

#### Human Rights – Recommendations

- **A.** Engage with DPOs and make available Disability Equality and participation training for public sector leaders.
- B. Embed Human Rights provisions and protections from the UNCRPD, CEDAW, CERD and UNCRC into Scots Law. Resource capacity building for rights holders and duty bearers, and co-design robust, accessible infrastructure for recourse and redress where rights are not upheld.
- **C.** Work with DPOs, Women's Organisations and Local Authorities to increase understanding of disabled women's needs in relation to violence and abuse particularly the need for accessible accommodation, communication and support.
- D. Co-design a new approach to prevent and eradicate Hate Crime and harassment including a revised Third Party Reporting scheme, improving police and community responses, and a National awareness raising campaign.
- E. Continue to prioritise the safety and right to participation of diverse disabled women when public health measures are reduced: disabled women must feel safe and be protected in terms of social distancing and wearing masks where practical.
- F. Urgently establish data collection, analysis and an Inquiry to capture unequal impacts of Covid on diverse disabled women, in relation to intersectional needs and impacts for policymaking.



## **7** Climate Justice and Just Transitions

#### **Public spaces**

Disabled women reported that developments which had been ongoing throughout the pandemic had not taken their needs into account e.g. the introduction of new "street furniture" as well as "Spaces for People",

"When I went into town after more than a year at home, there were tables and chairs all over the place and it was impossible to navigate my wheelchair. My friend has mobility issues and struggled to manage as she's not too steady – it was really offputting and made us feel that we weren't really able to go out in the town any more."

Disabled women have often claimed they are treated as if they are invisible, and this sense of being ignored only increased during pandemic. When city centres were empty due to lockdown restrictions, it made it easy for planners to put measures in place which built around that invisibility.

It was then more difficult for disabled women to reclaim



their space in these altered and re-fitted public spaces. "We need to make sure disabled women don't disappear completely - we need to get back out their taking a lead in our own lives and in society."

Planning for low emission zones and changes to parking in the city centre also created barriers and disabled women who took part in our study described feeling excluded and dealing with even more barriers than pre-Covid-19,

"It was always a challenge to find accessible parking spaces but now they've removed lots of parking spaces and introduced more cycling lanes too. It seems that the measures to address climate change are not taking us into account- I think the intention is to reduce emissions in the city centre but they're also reducing disabled people's access and our participation too." At the same time as measures are being introduced to limit car journeys into urban zones, public transport often remains inaccessible to disabled people and does not offer a realistic alternative. Disabled women are more likely to be reliant on public transport due to taking on a disproportionate amount of caring and household roles that involves them being 'out and about', e.g. taking children to school, caring for older relatives in their homes and shopping for the household.

#### **Climate change**

In relation to this last point, disabled women commented on approaches to tackling climate change such as Active Travel and planning for low emission zones describing these as not taking their specific needs or rights into account. This particular point is backed up by Inclusion Scotland,

"Despite the obligations in international law, disabled people have been perhaps the most overlooked group in climate change negotiations, policymaking and programme implementation to date. Moreover, the growing body of legal scholarship on the intersections of human rights and climate change has failed to address the relationship between the rights of disabled people and efforts to combat climate change."<sup>29</sup>

Inclusion Scotland also evidenced that disabled people are often among those most adversely affected in an emergency, sustaining disproportionately higher rates of morbidity and mortality, and are among those least able to access emergency support.<sup>30</sup> This was also evidenced by GDA over the pandemic: GDA provided food to over 2800 disabled people who were not able to access other supports.

Disabled women agreed that climate action developments had occurred without their involvement or consideration. It was felt that much of this may well be unintentional and is likely to come from a perspective which lacks understanding or insight into the issues,

"I don't think they know we have rights to be included and I think they also don't get that some of these measures are causing problems for disabled people in terms of actually going about our business. I hope that it's that rather than that nobody actually cares."

Overwhelmingly, disabled women agreed that they need to be included in initiatives e.g. plans, actions and decisions to tackle climate change, but also to improve Just Transition. This demands the meaningful involvement of disabled women in co-designing policies, plans and actions across a range of interrelated policy areas such as employment, social care, transport, housing and education. This is essential, as women remain underrepresented in this sphere in which the decision-makes, planners and architects are predominately men. This imbalance needs to be mitigated by ensuring women are consulted and involved throughout the processes.

#### **Climate Justice – Recommendations**

- A. Ensure meaningful involvement of disabled women and DPOs in local, regional and national plans, actions and decisions to tackle climate change e.g. low emission zones, active travel schemes, liveable neighbourhoods.
- **B.** Support disabled women's meaningful participation in co-designing policies and actions to achieve a just transition across the full range of interrelated policy areas including employment, social care, child care, transport, housing and education.



## Conclusion

"I honestly don't want to think about how my life would have been during Covid-19 without the support that I got. Without the other women to share with, learn from and look up to. We need to make sure disabled women don't disappear completely - we need to get back out there taking a lead in our own lives and in society."

Throughout GDA's engagement events, on which the findings of this report are based, it was evident that disabled women, in all their diversity, are determined to be active participants in the shaping of post- pandemic priorities, policies and actions. Disabled women live the **triple whammy** of being disabled, being a woman and dealing with Covid-19. These vital experiences must be listened to, and acted upon and disabled women must be involved in planning post pandemic policies and actions.

The interrelated triple whammy barriers faced require interrelated solutions in terms of policy development and coherence, service design and participation of disabled women in these processes. We must therefore ensure that solutions are joined up and break free from silo thinking and silo working. This "policy coherence" requires planners, policy makers and service designers to develop better understanding and analysis of the interrelated barriers which disabled women experience.

Going forward, we are calling for co-design of policies, services and actions: disabled women and those in power must work together towards solutions and this requires capacity building and resources.

Our society must be one in which disabled women participate and have our voices heard, on a full and equal basis, in all aspects of our lives, communities and wider society, with choices equal to others and our human rights upheld.

"We know what we are saying is hard to hear – it's hard to talk about, and hard to go through! Sometimes the things people least want to hear are the things they most need to listen to."



#### Appendix 1

### The Role of Disabled People-Led organisations

Perhaps unsurprisingly a key emergent theme was the lifeline which disabled people's organisations - particularly Glasgow Disability Alliance - had played in disabled women's lives since Covid-19. Participation bias dictates that of course the respondents were all in some way connected to GDA - thus the following comments and recommendations are within the limits and scope of this study.

Many of the participants identified the unique position of disabled people's organisations to respond rapidly, particularly in the immediate stages of the pandemic as being life-saving especially around the provision of food and medication, access to technology and broadband and a listening ear:

"The way GDA have taken initiative during Lockdown has been so helpful – even during the festive season. They identify those who are vulnerable and going to be more lonely, who are isolated and struggling and they reach out, putting in the effort to check in; wellbeing checks and any and all support that you need. Even organising little online get togethers during the festive season so people aren't just left hanging till office hours are back. It shows they continue to go above and beyond any expectations – it's not just work to them – it's genuine caring and it's life changing."

Disabled women reported the distinct support of a DPO from the outset of Covid-19, valuing them and making the support accessible, smooth and rights based – not like charity:

"GDA were there to help me 200% with the internet and technology. To get me set up with groceries. They are there like friends – like family. They see you are struggling and they offer – that is what has always made the biggest difference to me. I don't need to feel like I'm begging – like with so many other organisations I've lost count of the times GDA has shown up to me and said 'You're struggling – what can we do to help? Here's what we can offer – what would help you best?' It goes beyond words. I really can't describe how it makes you feel – like a person. You're not just a charity case; you're not just a beggar; you're not just some scrounger and they care about you beyond it just being a job. They make you feel so valued and so much less alone during this pandemic. So many people seem to forget about disabled people but we're still a priority for GDA." Disabled women spoke highly of the technology and technical support that they had received from the organisation on an ongoing basis. Women repeatedly praised the approach of GDA:

"GDA has been a Lifeline – it's not just about what they do – it's about the how. The coaching was second to none. She didn't make me feel stupid, kept encouraging me, asked what I was interested in. At times when I was about to throw in the towel I was supported to keep going and it's the best thing I ever done as now I'm connected."

The moving of activities online was greatly appreciated by the women who were able to take part. Women spoke of getting peer support, of not feeling like a burden, of being seen and heard as critical. This has been a welcome and newly accessible opportunity for many:

"I wish all the disabled women who don't yet have an iPad or broadband could see how it can transform your life. I want to shout it from the rooftops so that everybody gets the same chance."

Many of the participants reflected on the power of the wellbeing check in calls in shoring them up and helping build resilience and endurance for the sustained lockdowns and restrictions:

"That day the Wellbeing Worker called was a particular low point. I cried a bit feeling overwhelmed with gratitude that she had taken the time to call and ask how I was doing. It made me realise I wasn't alone and it helped me to get through the weekend."

Many women described the importance of the relationship with GDA and relationships through GDA sustaining them during the pandemic:

"In one of the online sessions I'd made a passing comment that my bankcard suddenly didn't work and I couldn't get shopping. I was just saying how bummed out I was. And then I got a phone call from GDA to make sure I had food, 'We heard your bankcard wasn't working and you couldn't get your shopping and we're just checking to see if there is anything that we can help with?' That almost made me cry - that they picked up on it and wanted to see if I was alright. Now that's astonishing that's a relationship - and that's what GDA has been about for me."

Others described the importance of the socialisation and peer support in giving them a sense of purpose, meaning and belonging:

"From a social point a view just seeing each other's faces on a regular basis is fantastic because we're not going to the usual community centres to meet up. You never then feel as if you're on your own. It's a bit like being on a lifeboat – yeah - you might still be adrift but at least you're with all your crewmates!"



"I enjoy getting up in the morning and I have got something to go to and I have got something to do."

"GDA has helped me tremendously in many ways and, for that I am truly grateful. In helping to alleviate loneliness and that horrible feeling of isolation. In joining in with the Tai Chi/Yoga sessions, Creative Writing, Coping with Anxiety, Singing Sessions, History and Walking groups, interaction with other people either within a group or online, all amazing for your health and well-being. Building up confidence and selfesteem plus much, much more. Also the invaluable warm friendly, staff showing care and concern and also, for helping to keep me logged on to all the fantastic courses."

Almost all of the women we spoke with highlighted the importance of disabled women having strong voices and being visible and represented in positions of leadership, power and authority and cited the vital element of peer support to sustain them:

"I honestly don't want to think about how my life would have been during Covid-19 without the support that I got. Without the other women to share with, learn from and look up to. We need to make sure disabled women don't disappear completely - we need to get back out their taking a lead in our own lives and in society."



Women shared this need for understanding their rights, having role models and peer support as fundamental to increasing self belief, self worth and aspirations,

"I don't think there are any openly identifying disabled women in the Scottish Parliament and there are a distinct lack of role models on TV or in the media. So, we need to look elsewhere. GDA is great for that – from the CEO and Depute CEO being disabled women to the Purple Poncho Players up there on the stage – well now online – on Zoom! It makes you realise you can do more. It's also great to help us understand our rights!"

(Please note that that this comment was pre Scottish Parliament elections 2021, whereby Pam Duncan Glancy MSP was elected as the first disabled woman who was a wheelchair user.)

"Such a lot of work has been done and I'm hoping that all the relevant agencies come together for the good of everyone which, would make such a difference and that people would know they are being listened to and understood. I have learned so much today and was so glad to have joined in on Zoom. Hopefully, when another event takes place I would really love to attend in person. It was so good hearing different points of view and, discussing the issues disabled women face. The Purple Poncho Players were just outstanding in telling how things really are and, how this affects disabled women's lives in so many ways."

Women also shared their feelings of safety at GDA's understanding and related approaches to intersecting barriers and intersectionality,

"They get it and they make me feel included. I'm a black woman but I'm also disabled and I just get to be who I am without worrying that I can only be one thing because people don't usually have that level of understanding of the barriers I face."



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## Special Tribute: Susan McKinstery

GDA is proud that we have involved diverse disabled women with intersectional experience. In particular we pay warm gratitude and with love we acknowledge and remember the contribution of our beloved friend and colleague, the late Susan McKinstery who died on 5th February

2022. Susan contributed rich lived experience evidence and insights towards this Report.

Susan's wisdom and legacy live on through her partner, her family and through all the people she supported and worked alongside, including GDA and our members.

Susan also left many written pieces reflecting her thoughts and the challenges she posed to a world which was designed without disabled people in mind. In one such piece, she offered the following thoughts about disabled women,

"We are individuals with skills, talents and life experiences filled with the kinds of ingenuity and adaptability which are essential attributes when living... in a still inaccessible world. Our human rights to safety, stability and the choice over how we live our lives are more than dry and burdensome obligations which must be grudgingly met; they are an opportunity to bring a richness of talent and expertise to bear in meeting the challenges we face nationally and globally. Until disability is seen as a rich and useful facet of human experience and not as an individual deficiency, this cannot happen. The person with the insight into how to tackle some of the critical social or environmental issues today may already exist but be trapped in a system which deprives them of the choice over when to use the toilet let alone share their knowledge."

#### We MATTER . . in ALL our diversity!





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