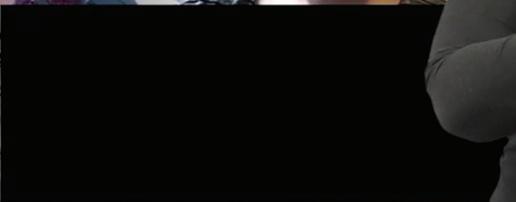




I've got my GDA sisters smilin' back at me



Glasgow Disability Alliance
Confident Connected Contributing

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

Voices, Priorities and Actions for Change

Key Findings and Recommendations
March 2022

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."

Introduction

From the outset of Lockdown 1 in March 2020, GDA checked 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.

By the end of March 2021, we made and received well over **30,000** phone calls, and spoke to over **6000** disabled people about their needs, experiences, priorities and ideas. We also analysed online surveys from over **2500** disabled people.

The aim was to ensure that disabled people did not fall through the gaps as services were reduced or removed due to the pandemic. This engagement shaped our ongoing Covid-19 emergency and ongoing response: adapting our vital services and establishing new ones to plug gaps and meet needs.

Our engagement 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.¹

Through this engagement and support, particular inequalities for disabled women were quickly emerging. One group of GDA women described the “**triple whammy**” of:

- being disabled
- being a woman
- and dealing with Covid

Disabled women’s experiences show that:

- women are more likely to be disabled than men
- disabled women are more likely to live in poverty and have insecure or low paid employment
- disabled women are at greater risk of violence and abuse compared with both non-disabled people and disabled men
- 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

¹ See GDA “Supercharged: A Human Catastrophe - Inequalities, Participation and Human Rights before, during and beyond Covid-19” 2020.

Methodology and Key Themes

GDA is aware that disabled women are frequently voiceless and invisible. We are determined to make sure that their voices are listened to, priorities acted on and lives improved. To address this GDA ran **16** specific events from **February 2020 – February 2022** to capture the lived experiences, voices and priorities of disabled women.

GDA drew on our intersectional approach, recognising and empowering women who face multiple oppressions and intersecting barriers, to participate. In this way, diversity of disabled women's voices and lived experience was at the heart of identifying themes and building solutions.

As part of the disabled people's wider movement for social change, GDA also drew on the social model of disability as we believe that the inequality and exclusion we face is not caused by our impairments or conditions; rather, by the barriers we face living in a world that was not designed for us. It is not disabled women who need to be 'fixed' – but barriers instead must be removed!

In total, **131 diverse disabled women** actively participated in meetings and events across the year and followed up by sharing reflections and contributing to recommendations. These events included:

- **1** face to face "Disability Spotlight" event to support GDA's work with the First Minister's Advisory Council for Women and Girls
- **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, Disabled BAME Network, and younger and older disabled women
- **2** Focus Groups to contribute lived experience of Lockdown and restrictions to the Social Renewal Advisory Board.
- **2** Collaborative "Sense-Making" events: one face-to-face another online

Additional data was mined from our engagement with over 6000 disabled people - **60%** of whom were disabled women.

Key Findings

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. Access to housing and related supports was also raised repeatedly in the context of increasing social care needs.
- **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** including disconnection from local communities; digital exclusion; lack of accessible information and support; and feelings of abandonment and loneliness.
- **Human Rights Regressions** due to pandemic responses including emergency legislation. Women also faced increased risks of violence and hate crime.
- **Climate Justice and Just Transitions barriers** as measures taken during lockdown, such as travel restrictions and increased street furniture, failed to take account of disabled women's needs and made accessing and using public space more difficult.

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.

1

Access to Healthcare including mental health: Key Issues

- Routine medical interventions suspended leaving women in pain, without necessary medical supplies or medication,
 - Delays in accessing e.g. chiropodists, dental cleaning, podiatry, rehabilitation, audiology, orthotics, aids to daily living, wheelchair services, physiotherapy and reproductive health scans.
 - Lack of access to medical treatments including cancer, diabetes and pain management and “gate-keeping of GPs” to access antibiotics.
 - Lack of accessible information on when services would resume.
- Deterioration of existing conditions and missing opportunities for preventative interventions leading to decline in mobility and physical and mental health.
- Disabled women’s own hesitancy to access healthcare services for fears around Covid-19.
- Hospital refusal to allow support from family member, carer or personal assistant on admission and similar refusal by ambulance service and hospital to allow disabled women to take their wheelchair on admission.
- Disabled women worried about being seen as a burden on an overworked system.
- NHS reliance on remote consultations adding barriers to those digitally excluded or with communication impairments.
- Disabled women had unequal access to Covid-19 treatments and were pressured to sign Do Not Resuscitate Notices (DNRs).
- Disabled women reported being turned away from mental health services, or ongoing supports being cut or curtailed due to heightened demand, Covid-19 related service constraints, and a lack of contingency planning.

Access to Healthcare including mental health: Recommendations

- 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.
- B.** Enable disabled women to be accompanied at medical appointments or hospital admission for communications and/or support and allow them to bring wheelchair or other vital equipment.

- C.** Establish ongoing health care plans / passports for disabled women, which allow for continuing healthcare and uphold human rights in the context of crises such as Covid-19.
- D.** Ensure diverse disabled women's involvement in policies, services and decisions about our health care.
- E.** Embed Disability Equality Training for health professionals at all levels co-designed and delivered by DPOs.
- F.** Resource and provide better access to specific Covid-19 vaccines and treatments.

2

Social Care and Housing: Key Issues

- Care packages reduced or cut with little/no notice or information creating challenges to make alternative arrangements.
 - Assumptions made that disabled women had access to informal support from family, friends or neighbours to pick up reduced or cut services.
 - Unsustainable 'choice' between trying to rely on informal support or having to go without basic personal care.
- Fears about long-term consequences as many care packages have not been reinstated leading to widespread fear that pandemic conditions will be used as the baseline for reassessment: "you managed without support and therefore you don't need it!"
- Fears that eligibility thresholds have been driven up causing people to survive rather than thrive.
- Cuts to social care changed relationships with families and loved ones and taken away women's independence and sense of control.
- Disabled women took on caring responsibilities for family members due to support cuts at the outbreak of the pandemic, often whilst struggling with their own needs and high risk status regarding the virus.
- The regression of human rights with social care provision reduced to a state of "keeping people alive, but not living" contrary to independent living.
- Housing supports retrenched and/or halted.
- The knock-on effect of reduced social care on those in unsuitable housing, e.g. not being able to cook meals in inaccessible kitchens.

Social Care and Housing: Recommendations

- A.** Immediately reinstate, without reassessment, social care which was cut or cancelled at the outset of Lockdown and continue / restart assessments.
- B.** Embrace the legal definition of Independent Living enshrined in the United Nations Convention on the Rights of Persons with Disabilities and embed into Scottish law and Local Authorities strategies, policies and approaches on social care.
- C.** Implement recommendations from the recent Feeley Review of Adult Social Care² to close the gap between good intention and lived experience, particularly:
 - I. Ensure diverse disabled women's involvement in policies, services and decisions and build 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 DPOs as a matter of course, to 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.

3

Access to food, money and resources: Key Issues

- Rise in cost of food and household goods during the first lockdown.
- Deepening inequality due to many disabled women being on legacy benefits and so ineligible for government support such as the £20 Universal Credit top up.
- Disabled women concerned they will be in more debt after the crisis and will struggle to make ends meet³, particularly as many did not qualify for shielding support.
- Lack of consideration of disabled women's needs when it came to Covid-19 emergency provisions, e.g. lack of continence pads, sanitary products, hygiene products; food unsuitable for dietary requirements and lack of allergy information.

²³ Feeley, The Independent Review of Adult Social Care in Scotland, 2021.

- Food insecurity as cuts to social care packages meant accessing adequate, appropriate food, and being able to prepare it, became difficult or even impossible.
- Gendered assumption that women are responsible for food shopping added pressure on those shielding or at high risk unable to go to supermarkets.
- Digital exclusion, minimum spend barriers and card only payments meant the shift to online shopping was unfeasible for many disabled women.
- Extra costs of being at home full time and lack of additional fuel payment support was a particular problem for disabled women whose conditions require them to keep warm.

Access to food, money and resources: Recommendations

- A.** Work with DPOs to co-design Disability Poverty Reduction Targets 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 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 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: Key Issues

- Covid-19's impact on poverty, education and employment hitting disabled women hardest and supercharging pre-pandemic inequalities in relation to access to work & qualifications.
- Lack of digital support in providing accessible equipment and assisting with cost of broadband to enable efficient working from home.
- Pressures on disabled women who were juggling work, social care cuts, childcare/ supporting education or caring for older relative.
- Pressure on disabled women to return to workplaces post- lockdown despite being at higher risk.
- Problems getting live signatures for Access to Work claims due to inflexible processes and inability to get someone on the phone to assist due to the chaos created by pandemic.
- Employment opportunities have dried up for disabled women jobseekers as the jobs market has become more competitive.

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 intersectional 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.
 - 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: Key Issues

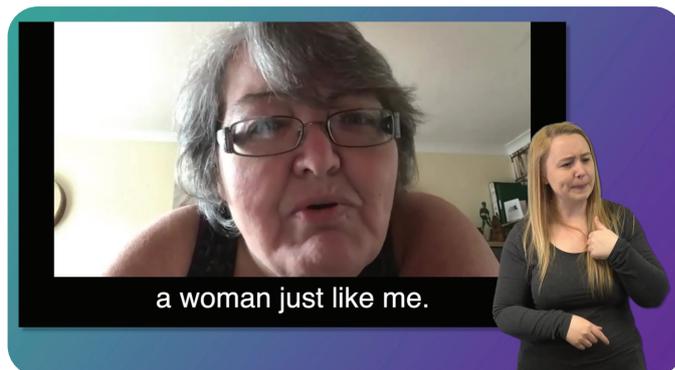
- 82% of GDA members surveyed during Covid-19 were concerned about isolation and loneliness.
- 71% of GDA members surveyed in 2017 found it **difficult to take part in things in their local communities**, due to physical barriers, stigma, lack of accessible information, undermining resilience.
- 80% of members surveyed were **not aware of any local support services** they could access during the pandemic and lockdown. Many relied on GDA to provide this information and accessible supports⁴.
- Digital exclusion and a lack of accessible information resulted in disabled women lacking the vital information needed to stay safe and access support, as well as increasing social isolation and loneliness.
- Withdrawal or reduction of services and support left many disabled women alone and exacerbated social isolation.
- Concern that online provision was assumed without back up “coaching” and 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.
- Welcome addition of online supports and “a whole new world opening up” for some disabled women.
- Increased hostility, harassment and even hate crime, towards disabled people in public spaces particularly if unable to wear a facemask.
- The regression of women’s roles within their households due to childcare and other caring responsibilities emerging as existing support services ceased to function.
- The increased risk of violence and abuse experienced by disabled women who 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 lifetime⁵.

⁴ See GDA “Supercharged: A Human Catastrophe - Inequalities, Participation and Human Rights before, during and beyond Covid-19” 2020.

⁵ <http://www.sisofrida.org/resources/stay-safe-east-da-bill-briefing-and-amendments-disabled-survivors/>

Tackle Social Isolation and increase 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 DPOs to develop “community” connections and build capacity and resilience amongst disabled women empowering them to take up rightful roles at all levels.
- 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 and actions e.g. Outcomes setting, EQIAs and budget decisions, working with DPOs 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: Key Issues

- Many universal approaches, pandemic responses - perhaps unintentionally - ignored the needs of disabled people, creating inequalities, injustices and eroding human rights for disabled people and disabled women.
- Many disabled women felt dispensable in comparison to non- disabled people, as if they were an accepted, inevitable casualty of Covid-19 e.g. the impact of deaths being minimised on the basis of 'underlying health conditions' and feeling pressured to agree to DNRs and much more recently, the lack of access to biological treatments and anti-virals.
- The withdrawal or reduction of social care support which left disabled women to manage their own survival.

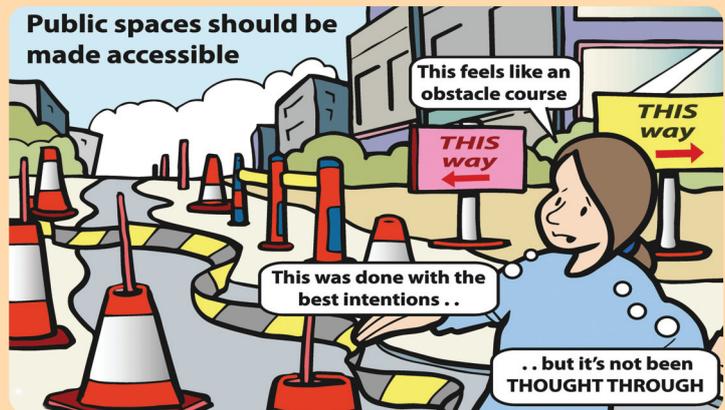
Uphold and improve Human Rights: Recommendations

- 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 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 improving police and community responses.
- E.** Prioritise the safety and right to participation of diverse disabled women when public health measures are reduced: diverse 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-19 on diverse disabled women, in relation to intersectional needs and impacts for policymaking.

7

Climate Justice and Just Transitions: Key Issues

- Changes implemented in public spaces to allow increased use of outdoor space as a Covid-19 precaution did not take disabled women's needs into consideration and have made some public spaces hard to navigate and unwelcoming.



- Increased street furniture and outdoors café and restaurant provision created hazards and reduced ease of mobility for disabled women.
- Removal of disabled parking and poor public transport accessibility has made some city/town centre areas 'no go zones' for disabled women furthering their social exclusion.
- Disabled women more likely to be reliant on public transport due to taking on disproportionate amount of caring and household roles, e.g. taking children to school, caring for older relatives and shopping for the household.
- Strategies to tackle climate change such as Active Travel Schemes and Low Emission Zones have not taken disabled women's needs into account.
- Concern that these issues are often the unintended consequences of not consulting with, and listening to, disabled women in the design stages.

Climate Justice and Just Transitions: Recommendations

- A. Include disabled women and DPOs in initiatives e.g. plans, actions and decisions to tackle climate change.
- B. Support disabled women's meaningful participation to improve Just Transition, co-designing policies, plans and actions across a range of interrelated policy areas such as employment, social care, transport, housing and education.

Conclusion

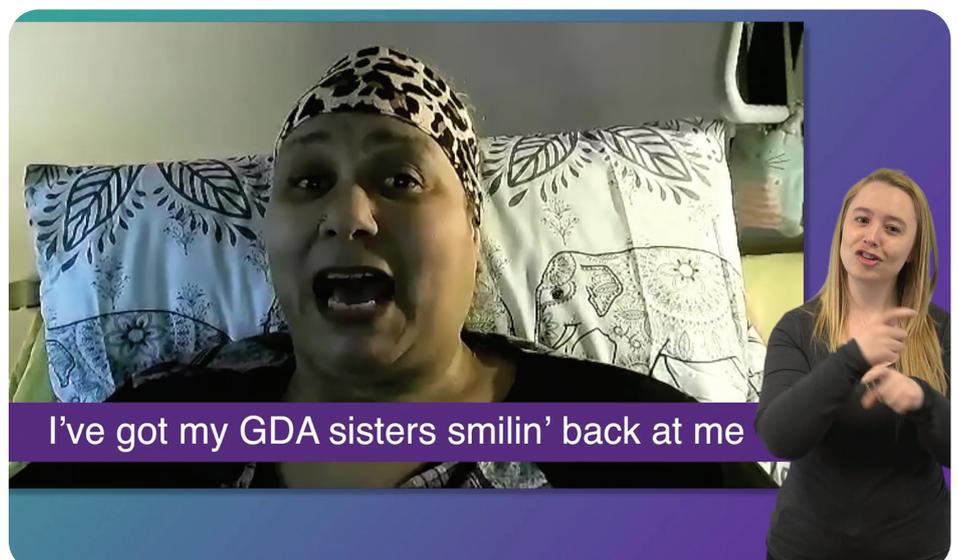
“I honestly don’t want to think about how my life would have been during Covid-19 without the support that I got. Without the other women to share with, learn from and look up to. We need to make sure disabled women don’t disappear completely - we need to get back out there taking a lead in our own lives 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, co-design policies, services and actions: disabled women and those in power must work together towards solutions: 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.”



Acknowledgements

GDA acknowledges and is grateful for the wonderful insights, resilience and generosity of the disabled women who contributed their experiences, supported each other and worked together to come up with recommendations including:

- GDA's Disabled Women's Network, Drivers for Change Network, Young Drivers for Change, Black and Minority Ethnic disabled people's network and LGBTQIA+ disabled people's Network.
- 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.

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



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