

Supercharged: A Human Catastrophe

Inequalities, Participation and Human Rights before, during and beyond COVID19

August 2020











There have always been inequalities for disabled people in society, but I've never felt it more than now."

iPad

"Maybe after this virus, people will value and respect disabled people more – that's my hope."



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"I feel that disabled people have been abandoned and forgotten."

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Foreword

Through COVID, Glasgow Disability Alliance learned that although we are all in the same storm, we have not all been in the same boat- and we still aren't. Everyone caught in the COVID-19 storm needs a lifeline that can pull them out of danger when they need it most – but for disabled people there were, and are, fewer lifelines within reach.

Much is made about the economic recovery and this is critical to ensure that people stay in work and maintain good health and wellbeing. But we must also apply efforts on social recovery since much damage has been done to people as well as the economy for example thousands of disabled people have endured extreme isolation and had their social care packages cut. Decisions made at the start of Lockdown left disabled people with no support to wash, dress, eat, go to the toilet or take medication. And many supports have as yet, not been reinstated – despite Scottish Government providing additional funding to Local Authorities. History will recount how we all responded to the coronavirus outbreak. We must ensure that the story told demonstrates our commitment – as a society – to protecting everyone from harm: particularly those most at risk of the worst impacts of COVID19. We must design policies and practices that provide security for every member of our society – including disabled people who make up at least 25% of Glasgow: this cannot happen without our involvement.

Inequalities have been supercharged and we must now in turn supercharge the meaningful involvement of disabled people, independently supported by our own communities of interest – our disabled people-led organisations which are a model for involvement, participation, wellbeing and resilience. We are all connected – nothing has shown this more than COVID – for good and bad. Now more than ever, we must harness the voices of disabled people and take every opportunity to understand and remove barriers, to design services and responses that meet the acute and changing needs of those most vulnerable to COVID and its aftermath. In this way we will ensure- no only that disabled people are not left behind in social and economic recovery but more importantly, that we can contribute to it.

Tressa Burke

GDA Chief Executive Officer



Background: A Human Catastrophe – then COVID19

GDA is a grassroots, community-led organisation, run by and for disabled people, since 2001.

We are a diverse community, that extends across Greater Glasgow and beyond – with a membership of over 5000 disabled people and people with long term conditions, disabled people-led member organisations, and associate members including nondisabled allies, family members and supporters.

For almost 20 years, GDA has been supporting disabled people to come together and support each other, through fully accessible programmes of learning and peer support. GDA builds disabled people's confidence, connections, and contributions – supporting members to participate and speak out, collaborate with powerholders, share lived experience and expertise about the barriers we face and how these can be tackled, to build a fairer more equal society. GDA's disabled people-led model of empowerment is needed now more than ever.

12 years of austerity has increased the challenges we face, and threatens to erode hard-won progress towards equality and human rights. Welfare reform has exacerbated poverty and isolation, hostility and hate crime.



Barriers we face in education, work, housing, health and social care in turn exclude us from participating in our communities, families, societies, and even in our own lives – eroding our confidence and self-belief. The EHRC calls it 'A Journey less equal', while the UN concluded that austerity has created a 'human catastrophe' for disabled people in the UK. On top of this human catastrophe, came COVID-19. Since long before lockdown, too many disabled people have been living in poverty, facing barriers in our daily lives and struggling to access badly needed support services.

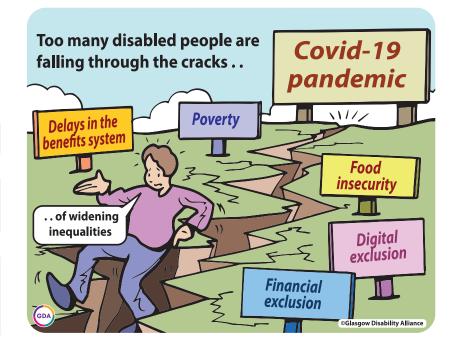
During the pandemic, disabled people have found ourselves triply at-risk:

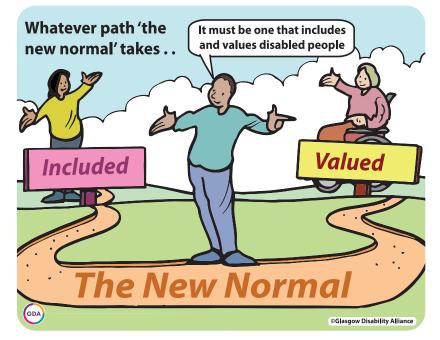
- **1.** For many, our conditions or impairments put us at greater physical risk from the virus
- 2. The barriers and inequality we face also leave us less able to respond and keep ourselves safe, and more at risk from social impacts of the pandemic and lockdown.
- Our needs, voices and expertise have long been excluded and overlooked by those planning and delivering services, meaning lockdown and COVID responses have not only exacerbated inequalities we already faced, but have also created new ones.

As lockdown eases and many people look forward to getting 'back to normal' – for disabled people, 'normal' never worked. As workplaces, transport, and social lives resume - albeit with new limitations - many disabled people are already suffering the long-term impacts of the pandemic and lockdown on our lives, our bodies, and our hopes for the future.

Inequalities have been supercharged: the drive towards recovery and renewal will leave disabled people even further behind, unless urgent action is taken to supercharge our meaningful involvement, with disabled people and our organisations in the lead.

Disabled people's voices and expertise will be vital to Scotland's social and economic recovery. As a nation, we cannot afford to miss any more opportunities to learn from mistakes, understand barriers, and design policies and strategies for resilience which protect those most at risk – by putting disabled people in the lead.





A COVID-Response led by disabled people

From 16th March 2020 GDA suspended all our planned programmes, and, using our well established infrastructure as a community of 5000+ disabled people, we began extensive outreach across our vast membership: to listen, support, and respond in any way we could; to enable survival, build resilience and amplify voices. Through in-depth member engagement we were able to adapt our vital services, and rapidly develop new ones to fill gaps and meet needs, diversifying our supports to disabled people during turbulent and challenging times.

Engage:

6000 check-in calls made



- 2500 calls received
- disabled people connected to 4500+ information and support
- 20,000 accessible info mailouts
- 2,100 in-depth survey responses

4000+ hours contributed by **GDA** members sharing experiences, concerns and priorities by phone and online to shape GDA response, and inform local and national responses.

Respond: new services rapidly established to address gaps and meet need **GDA Lifeline** delivering food and essentials to disabled people unable to access support **GDA Wellbeing** specialist group and individual

Rights Now: welfare rights support

GDA Learning programme moved

online, with digital support provided

remotely, by phone and online

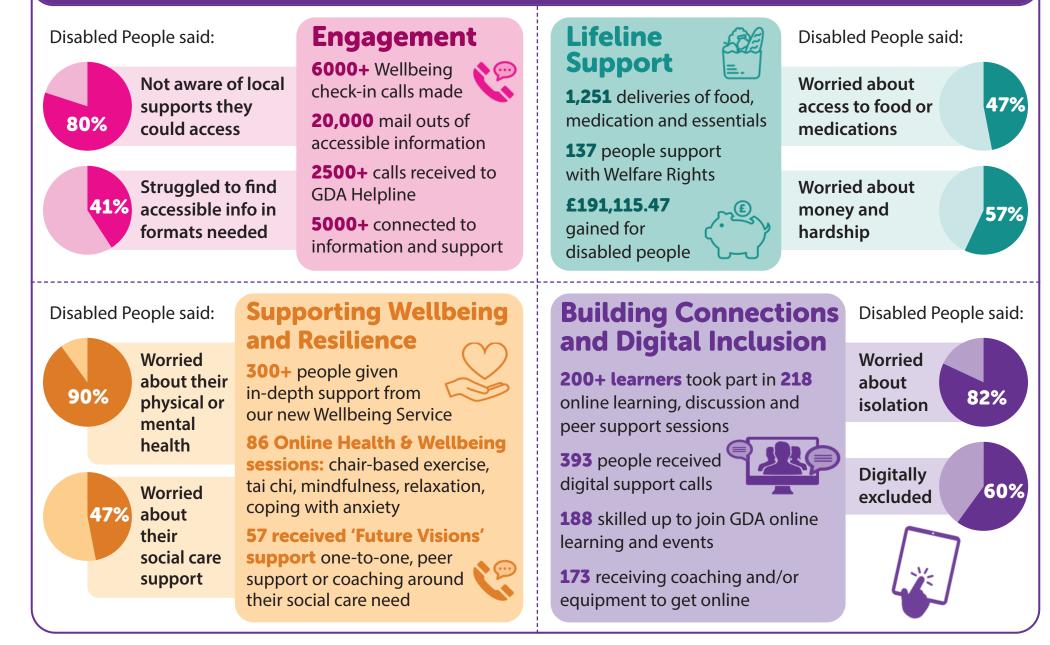
support and advice for health and wellbeing

GDA Connects equipment, connectivity and coaching to tackle digital exclusion





GDA resilience engagement and response: Snapshot 20th March – 31st July





It's so important disabled people's voices are heard otherwise we will be forgotten about, as always. "Listening to disabled people is the only way elected members, government and other agencies will know where the gaps are and what services are required now and in the future. "

90%

Over 90% said they want disabled people's voices to be heard. 85 online peer support discussions.130 disabled people supported to attend GDA's first ever online conference.

to us!

Listen

4000+ hours contributed by **5000+** disabled people speaking out, online and by phone, about their experiences, concerns, ideas and priorities for equality beyond COVID.

GDA member engagement: Headline Findings

- 1 COVID19 has supercharged inequalities already faced by disabled people.
- 2 Pandemic responses have created new inequalities and left disabled people behind.
- Recovery and renewal risk leaving disabled people even further behind unless we supercharge disabled people's involvement every step of the way.

To address these supercharged inequalities, we must **Supercharge disabled people's:**

Involvement

2 Rights

Support

Poverty: Supercharged

Pre-COVID: Disabled people were already 3 times as likely to be living in poverty.

- Disabled people face extra costs, averaging £583 per month.
- 1 in 5 disabled people and 1 in 4 families with disabled children face extra costs of **more than £1,000** per month (Scope 2019)
- Disability-related extra costs include:
 - higher bills for fuel and food
 - costs of equipment, accessible transport
 - charges for vital social care

Left Behind: COVID19 has exacerbated poverty for disabled people.

- Cost of living has increased, along with additional costs for disabled people: Universal Credit was topped-up but not disability benefits, deepening inequality.
- Employment impacts if you or your family shielding /high risk: forcing disabled people and their families to choose between safety and income.
- Extra barriers to social security 58% drop in PIP applications; lengthy delays to claims up to 10 week wait for Mandatory Reconsiderations; advice and support services harder to access
- Social care budgets restricted during lockdown flexibly during lockdown, while still paying charges for cut services.



57% of disabled people we spoke to have been worried about money and hardship during the pandemic.

"Food and bills have all gone up sharply, but no increase to our disability benefits. My money gets quickly swallowed up and I'm left short." "I can't get out to collect my pension, pay bills or top-up my energy cards. Worried about getting into debt if I miss payments."

"I'm a taxi driver with severe asthma, caring for my high risk wife and mother - but I've had to go back to work because we've run out of money. It's terrifying, but we've got no choice."



"I got a letter about PIP asking me for paperwork but everywhere is shut and I can't get through on the helplines."

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GDA Response: Rights Now in action

GDA's Welfare Rights project

- **137** individuals supported, through:
- **199** remote appointments
- 99 new referrals
- £191,115.47 gained for disabled people

Disabled people are facing many of the same Welfare Rights issues as before, but lockdown has made them even more challenging to solve. Our Rights Now team has worked flexibly to find workarounds e.g. phone appointments and permissions instead of postal mandates.

Welfare Rights when you need it most:



- "At the start of lockdown, we found out my son got zero points in his PIP assessment, so we'd lose his DLA and my carer's allowance.
- You start spiralling, thinking will we lose the house, and how do I fight this with everything that's going on? I get so anxious on the phone to them in case I say the wrong thing.
- I called GDA and they got back straight away it's the first place that's really listened to me and helped.
- Ian helped me write letters to challenge the decision and get it fast tracked they said it was taking up to 10 weeks for some folk to hear back, but with lan's help we got our award back within 2 weeks.

It was such a relief to know that was sorted, and I know where to go for help next time!"

Disability Employment Gap: supercharged

The punitive UK benefits system claims to incentivise work – however, since long before COVID, disabled people have faced additional barriers to finding and sustaining employment.

In Glasgow 45% disabled people age 16-65 are in work, compared to 67% of their non-disabled peers. The pandemic has already posed additional barriers for disabled workers and jobseekers, and a post-COVID recession will only worsen this, as job opportunities shrink.

GDA has continued to:

- Provide one to one employability advice and coaching, remotely, during this time.
- Support disabled people to have their voices heard within Scottish Government Employability Action Plan, including a focus on disabled parents; and in the 'Glasgow Guarantee' Employability Partners' Forum.



JOBS

Food Insecurity: Supercharged

Pre-COVID: disabled people were already 3 times as likely to be facing food insecurity.



47% of disabled people we spoke to have been **worried about their access to food** during the pandemic.

Left Behind – extra barriers linked to:

- Emergency food provision not always accessible.
- Supermarket delivery slots overwhelmed, minimum spend barrier.
- Delays, hurdles and gaps in accessing eligibility status for shielding support / delivery priority slots.
- Lack of support and **negative attitudes** faced by those with sensory and invisible impairments.
- Barriers to accessing medications, hygiene products, masks add to increased health risk.
- Support lines withdrawn as shielding paused, leaving many cut off with no support, expected to rely on the goodwill of friends, family or neighbours, who may be returning to work.

"I'm visually impaired and supermarket staff can no longer guide me, the virus means I can't safely navigate by touch – but I don't qualify for help with deliveries."

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

"Lack of nutritious food suitable for my diet is a worry, and the impact on my health and my condition." "GP told me to shield but I never got a letter. Now my parcels are stopping – but I'm still high risk!"

"They're saying shielding will stop in August, but I don't know what I'll do without that support."

"There's volunteers helping people with shopping in my area but I've no money to pay them, and the foodbank doesn't deliver."

"I got verbally abused in the shops because I can't wear a mask – then they asked me to leave!" "I can't stand in long queues for shops but I was shouted at and humiliated by supermarket staff because I didn't have a government letter."

"My shielding packages have stopped but I still can't physically get to the shops."



GDA Response: Lifelines in action

Food, medications and essentials delivered to 1,251 people in 874 households, including many regular weekly deliveries.

Filling Gaps: referrals from British Red Cross, Glasgow Helps, Glasgow Mutual Aid, Social Work services, for clients they could not cater for.

Flexibility required: restricted diets, lack of social care, and other barriers mean some food aid provision has not been suitable for disabled people. GDA Lifeline referrals are increasing as Shielding has paused and support services wind down – but disabled people still face longstanding barriers to food security, that require a long term solution: Tackling poverty and inaccessible environments, reviewing longterm support for shopping must be part of recovery and resilience planning.

"The Shielding helpline rang out. When I got through they said it would take a week and they were too busy to pick up my medication."

"I emailed GDA to share my experiences of lockdown – I was not expecting yous to come back with such amazing offers of kindness, help and support – it is so nice to know someone cares about all us folk who are high risk and shielding."

Food Insecurity and Social Care

Many disabled people were already struggling to physically access groceries and essentials before COVID. Help with shopping has long since been scrapped from 'life and limb' social care eligibility, yet online shopping is rarely an option for those without internet or on low incomes.

GDA has provided lifeline deliveries to many families whose social care has been cut during COVID.

While we were unable to bridge gaps left when personal care was withdrawn, lifeline deliveries helped ease the strain on disabled people suddenly left with no support, or fully reliant on family, friends or neighbours who may themselves be high risk or unable to provide the support needed.



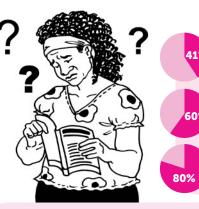
Information Gap: Supercharged

Pre-COVID: disabled people already faced persistent barriers to accessing information and services.

Disabled people are nearly 4 times as likely to be digitally excluded; and with the UK average reading age between 9 and 11, lack of accessible info has widened the unequal impacts of the pandemic.

Left Behind:

- Isolation, digital exclusion and a lack of accessible information mean many disabled people do not have the vital information they need to stay safe and access support.
- Delays and gaps in Shielding letters, and specific information relevant to disabled people widened this disadvantage e.g. guidance for social care users, disabled workers, disabled pupils and students.



Of disabled people we spoke to:

41% had **difficulties accessing information** in formats required.

60% were digitally excluded.

80% were not aware of any local support services they could access.

"I got a letter from the government and I'm severely dyslexic so I couldn't read it – I panicked not knowing what it was – I thought I was in trouble."

"There may be supports out there, I just don't know about them. If someone put a letter through my door I would know." "Information isn't available for me in a format I can understand. It needs to be clearer so everyone can understand: using pictures, info-graphics, sign language."

"I don't know about anything that goes on in my community. I wouldn't know where to look for info on this." "Services have closed – everything is moving online now and I don't have internet."

"I don't know what group I'm in or what advice I should be following. The GP says one thing, the government says another, the Council helpline is ringing out."

"Helplines and phone appointments are no use for Deaf people like me, and facemasks mean I can't lipread so I'm even more cut off."



"I've got lung cancer, and the hospital kept sending me to get my own prescription. It was GDA who told me I should be shielding, and went to collect it for me".



GDA Response: Engagement in action

GDA's community infrastructure

Built over 20 years of community development led by **disabled people – connects 5000+** of us across Glasgow to vital information and support which many struggle to access otherwise. Through:

- 20,000 mailshots
- **8500+** phone calls (made and received)
- **5000+** signposting referrals

GDA has prevented thousands of disabled people from falling through the cracks.

Inclusive communication methods are key – online, and offline: phone, letter, SMS, Easyread, braille, audio, BSL – and involving disabled people in planning communications – or disabled people get left behind.

"I don't have internet or TV so it's GDA that keeps me informed of my rights and what's happening in the world - talking to staff and members."



"The Housing office is closed and no-one's been in touch - I don't know who to call if I have an emergency. Probably GDA!" "I've been let down by every service, except GDA. No one else will provide me with accessible information, even though I've asked. So I have no idea what support there is in my area – GDA are the only ones who've helped."

GDA Connects: tackling digital exclusion

60% of the disabled people we spoke to lacked the technology, connectivity or confidence to get online.

GDA became one of the Scottish Government's first Connecting Scotland pilots, with GDA Connects.

393 people have had digital support calls.

170 devices being procured, set up and distributed to disabled people, along with coaching and support.

150 additional pieces of equipment to meet digital access needs.

11 visually impaired learners connected to specialist coaching through GDA's networks.

Social Model of Digital Inclusion

GDA's digital coaches are not IT specialists: they use patient, person-led, flexible approaches, to support disabled people to **remove barriers to digital**, and build confidence in their own abilities.



"I was worried at first I wouldn't be able to

learn because of my dyslexia and learning difficulty – but for the first time in my life, someone stuck with me to help me understand instead of just giving up. Now I'm really proud of myself for learning something new, and I can videocall my friends while we are all in lockdown".

Isolation and Exclusion: Supercharged

Pre-COVID, disabled people were already twice as likely to experience isolation and loneliness; and too often excluded from our local communities.

Leaving the house and connecting with our communities was already much harder for disabled people, due to inaccessible houses, transport, environments; lack of support; and negative attitudes.

Left Behind: for many, isolation and exclusion have soared:

- COVID 19 made going out too risky for most of us.
- Lockdown saw vital supports we rely on withdrawn or reduced.
- Digital exclusion meant for many disabled people, social contact dropped to zero.
- Some rules for public spaces, such as 'exercise only' and face coverings, have led to **hostility and hate crimes against disabled people** unable to observe these.
- Disrepair, flytipping going unaddressed, as well as hospitality expansion onto our pavements have created fresh barriers all around, by overlooking access needs.
- Fears of catching the virus were escalated by discussions of **Do Not Resuscitate files and rationing of treatment** which put disabled people at the bottom of the pile, threatening human rights.

GDA's 2018 action research found 71% of disabled people we spoke to have difficulty taking part in things in their local communities due to a lack of access, support or information, as well as negative attitudes.

During the pandemic 82% have said isolation is a major concern.

"I'm worried about loneliness and falling into depression and anxiety - that's why I called GDA -There's nobody in the world that knows about me, and I'm worried about dying alone in a room."

"Support seems to be for elderly folk, not younger disabled people like me. I've had really nasty reactions so I gave up trying to ask for help." "I often feel isolated – social isolation is my normal - but this situation has taken my depression to another level."

"I feel I've been completely let down by the society that was supposed to care for me."

71%

82%

"Some people are in total isolation and relying on care which might not be stable – we need to remind people we exist!"

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GDA Response: Connections in Action

GDA's accessible learning programmes

tackle isolation and build connections across our community of interest – so we knew it would be vital to maintain this remotely as much as possible, moving sessions online and supporting members to build their skills to connect in this way.

- 188 disabled people supported by GDA Connects to get online and connect with others.
- 218 online sessions run by GDA Learning, with over 200 learners.
- **85 online peer support** meetings and discussion sessions about priorities & solutions.
- 300+ supported through GDA Wellbeing to access other supports such as telephone befriending.

"GDA are the only people I've heard from since staying home." "Most of us disabled people are being isolated so much in the communities – they just do their own stuff and exclude disabled people. I can't volunteer or join groups, nothing is accessible - except GDA!"

"The course helped me cope with lockdown – it gave me confidence in my abilities, and some structure, a reason to talk to others – so I don't feel so alone."

It's empowering, meeting new people! And learning new technology – using zoom, I feel a bond with all these people in these wee squares! "I saw the helpline on TV and got linked to GDA – it's really good to see people at the online sessions. It motivates you, gives you focus and takes you away from bad thoughts you might have."

"My local Housing Association wouldn't help me because I wasn't shielding, but wouldn't let me volunteer because I'm 'vulnerable'!"



Mental Health Crisis: Supercharged

Disability and mental health are closely linked.

Having a long term physical condition makes us more likely to experience poor mental health, and vice versa: those of us with long term mental illness are more likely to also have a physical impairment or condition.

 Many GDA members report barriers to accessing support for their mental health, often feeling dismissed.

Barriers we face across all areas of life – housing, work, education, social care and independent living – impact badly on our mental health, confidence and self-worth.

Left Behind:

- Many with existing mental health conditions have had care and support disrupted or 'paused' during COVID-19.
- Many who were **already struggling to access Mental Health support** are in even greater need now.
- **'Relaxation' of laws around detention** under Mental Health Act sparked fear over rights protections.
- **GDA has received over 676 referrals** to our new Wellbeing Service since May 2020.

62% 676+ Of disabled people we spoke to 62% were **worried about their mental health** during the pandemic.

GDA's Wellbeing service has had over 676 referrals since April, with referrals increasing each month.

"Nothing extra put in place for those with mental illness in fact our services have been removed. I've never felt so worthless and unvalued."

"I can't get any help – I'm 100% isolated and terrified to say how bad I'm feeling, as mental health laws are a danger, they've gone backwards under COVID."

"COVID19 has exacerbated the chronic depression I've had for years. The CPN is not taking calls – they pass you to 111 who are only dealing with COVID. I've called Breathing Space every night for 79 days." "I have really struggled with my mental health since my ma passed away. Was just starting to get back out a bit and then this happened. It is really hard now."

"I waited 4 months for my mental health appointment and now received a letter that they cancelled all appointments for next 12 weeks."

"I lost my brother to COVID, I'm high risk so I couldn't go to his funeral and I stay alone so finding it hard to cope – having someone to speak to really helps."

GDA Response: Wellbeing in Action

Our engagement quickly picked up the need for dedicated wellbeing support during the pandemic, with services reduced or overwhelmed, and isolation, poverty, discrimination and uncertainty hitting disabled people harder.

COVID emergency funding allowed us to recruit 2 wellbeing advisers to support the huge numbers of disabled people contacting us in distress, overwhelmed by fear, isolation, complex barriers and lack of available supports.

GDA Wellbeing (April – July):

- 676 Referrals received, most through our own engagement.
- 563 Wellbeing Follow up calls made: our wellbeing advisors check in, listen and provide advice and resources to improve mental and physical wellbeing.
- Over 300 disabled people connected to specific Wellbeing supports including counselling, peer support, life coaching, telephone befriending, GDA Wellbeing programmes online and by phone.



What has worked well?

While many have struggled to access mental health support during the pandemic, some exemplary support has shone through:

- **User-led, community based groups provided a lifeline:** "Being connected to GDA, Flourish House, the Mental Health Network, who understand the challenges, and check in so you know someone cares."
- For those whose support remained steady, this proved essential: "Regular support from my CPN and psychiatrist is getting me through."
- **A listening ear boosts resilience:** "Just having someone to talk to I didn't know I could call the crisis lines when I'm really struggling, til GDA gave me the number."

Health inequalities: Supercharged

Disabled people and people with long term conditions had **crucial healthcare cancelled** during lockdown; **equal rights to access COVID treatments** were threatened; and the **health impacts of lockdown** have set many disabled people even (further back.

Left Behind:

NHS Scotland cancelled 73% of planned treatment in the month of April, including treatments for heart and respiratory conditions, neurological conditions, and 53% of cancer treatment (Understanding Society).

Pain management services curtailed.

- Existing conditions deteriorating due to lockdown – lack of mobility, therapies stopped.
- Environmental hazards not addressed also threatened health during lockdown.



90% of disabled people we spoke to have been worried about their physical or mental health during the pandemic.

"They should make it clear that GPs are still here

for you, you're not wasting any of their time..."

"Lockdown is worsening my condition and wiping out all the work I have done to build up my health and stamina."

"Heath care has been cancelled and I have to manage my pain on my own. I know I won't get the surgery I've been waiting on for a long time."



"I'm terrified of losing care for my degenerative condition – I could lose my sight." "I have waited 7 months for a lung scan and now it's cancelled."

"A sewer burst in my garden and I can't get anyone to help. I'm shielding after chemo, and it's my only outdoor space but it's not sanitary to use." "I've just finished cancer treatment and all my appointments have been cancelled so I don't know if it's worked, or if the cancer has spread."



"There's black mould all round my house making me ill, but housing are ignoring my calls. GP told me to get out for fresh air each day even though I should be shielding."

GDA Response: Voices in Action

GDA's Learning and Wellbeing teams have supported 100s of disabled people to address some of the gaps and health impacts of lockdown connecting people to health and wellbeing sessions online and by phone, including gentle exercise, coaching, and pain management.

But long-term impacts require deeper action, Our health to highlight and challenge these inequalities.

Through our holistic model, GDA builds disabled people's capacity to not only tackle barriers and access vital supports, but to have our voices heard, claim our human rights, and influence wider change towards disability equality.

Equal Rights to Health and Healthcare

Many GDA members spoke of fears that they would not be prioritised for treatment, or may have 'Do Not Attempt **Resuscitation'** notices filed without their consent. This increased disabled people's sense of fear, risk, and being left behind.

"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."

"It's a human rights issue our lives matter just as much!"

Our rights

"They see a wheelchair and assume you've got nothing to live for!"

Through GDA's phone, online and postal engagement, disabled people have contributed at least 4000 hours since 20th March, sharing their views, experiences, concerns and priorities during this pandemic and beyond.

• 83 online peer support discussions, covering:

- Barriers in lockdown
- Employability
- Challenges of shielding
- Social security • New police powers

Mental health

Social Care

and including peer group support for

- Disabled women
- Young disabled people
- LGBT disabled people
- Disabled Parents
- BAME disabled people
- 130 people supported to attend GDA's first ever online conference, sharing their experiences directly with Scottish Government and City Council leadership.
- GDA's Purple Poncho Players developed and rehearsed new material remotely to bring disabled people's experiences to light, even as one of the cast lost their life to COVID.

Social Care Crisis: Supercharged

A stark sign of COVID-lockdown's unequal impact on disabled people is the near-total collapse of our Social Care system, while all emphasis focussed on protecting the NHS.

Pre-COVID, disabled people's rights to independent living were already being eroded by austerity and cuts to social care, with the UN reporting Local Authorities across the UK lacked the Social Care funds needed to meet their Human Rights duties.

Deep reforms, long overdue, are now underway in Scotland, and GDA has been part of this dialogue. Learning from COVID will be vital if we are to build a robust, resilient social care system that responds to needs and protects rights before, during and after any crisis point.

Left Behind:

Emergency Legislation allowed Local Authorities to relax certain duties to prioritise urgent services. The duty to provide support still applied under Section 12 of the Social Work (Scotland) Act and related laws, yet:

- Approx. 2000 disabled people in Glasgow had their care reduced or completely withdrawn from March onwards many with no notice and no follow up.
- Many forced to rely on other vulnerable family members or neighbours for vital care including washing and eating or go without.

High risk disabled people left even more vulnerable by social care system collapse / withdrawal.



47% of disabled people wespoke to have been worriedabout their social care supportduring the pandemic.

"Losing more independence and feeling more of a burden than usual is really hard."

"I used to get 3 showers per week and they cut it to zero. Had to ask my daughter-in-law, who's a nurse on the frontline, to come help me on her days off."

"My wife and I are both high risk and had to take on full time care of my mum, whilst still working. We're doing what we can but noone's been in touch and we can't cope with this indefinitely." "I was just about managing before my care was cut, just before lockdown. Now, after months with no support, I'm struggling so much I feel I have no choice but to move into a care home."

"I'm terrified my care won't be reinstated as they'll argue I've 'survived' without it. But my mum was forced to move in with me, at the other end of the country, because they cut my care – that's not sustainable!"

"4 days before lockdown, our care package was cut completely with three hours notice. Nobody after that checked in to we were managing for personal care, toilet and showering."



GDA Response: A Model for Reform

"Social care was already

absolute bare minimum.

meant there is nowhere

else to go and nothing

Cutting it further has

operating at the

left."



COVID has highlighted how crucial yet how fragile our Social Care System is. Austerity has driven up eligibility thresholds, leaving vast unmet needs and eroding disabled people's resilience. When the pandemic hit, too many people were already in crisis – and too many had vital support withdrawn, leaving them even more trapped and vulnerable.

GDA members have been sharing their experiences over recent years, to help shape Scotland's national **Shared vision for social care reform** – and continue to speak out with crucial learning from their experiences during COVID19.

The Shared Vision emphasises the need to empower people to access support before they reach a crisis.

In Glasgow social care support is only providing support where needs are deemed 'critical and substantial'.

Yet during and even before COVID, many GDA members report having **vital personal care cut indefinitely, leaving them unable to wash, eat or manage medications** with the expectation that family, friends or neighbours will step in. Not only is this unfeasible for many, but is also contrary to UNCRPD Rights to Independent Living.

Community supports exist – but GDA members report multiple barriers to accessing them.

Too often disabled people are required to fit in with the needs of a service – and often our lives and the barriers we face are so complex that this simply isn't possible and we fall through gaps, 'passed from pillar to post', losing confidence and hope of achieving the life we deserve.

GDA's Future Visions model offers holistic support to tackle complex barriers and access vital support.

Disabled people facing seemingly unsolvable barriers outwith their control are supported to access coaching, peer support and community connections, to help them set and achieve their own goals, with dignity, choice and control.

Future Visions pools disabled people's expertise, to help more of us find ways through the complex barriers we face, **to fulfil our potential and achieve the lives we want and deserve**.

Our holistic Future Visions model has never been more needed than during COVID19. The collapse of vital social care supports wreaked havoc on disabled people's lives, our mental and physical health, wellbeing and resilience.

Future Visions capacity building, collective voice, and collaboration has been reinforced with emergency psychological, emotional and practical support – including referrals to GDA's Lifeline deliveries, Welfare Rights, and Learning supports – to help people cope and find ways through the crisis, as many existing supports and packages have crumbled.



GDA Future Visions for Social Care: a flexible, holistic model for community-based support

GDA's Future Visions project trail-blazes the holistic, community based, person-led support that Scotland urgently needs, to build resilience and meet vast, lower level needs before people reach crisis-point.

Centring disabled people's voices is the only way to illuminate the gaps, so we can catch people falling through them. The **Future Vision approach** builds on **GDA's theory of change** that is 20 years in the making. From March – July, our Future Visions modelled has achieved:

1. Capacity building

Empowering disabled people to navigate pathways and overcome barriers to access vital supports.

- **57 people received tailored support** through Future Visions' flexible, holistic model, including: Life coaching, peer support, group CBT.
- Practical support to access vital services and equipment to cut through barriers e.g. portable ramp, talking hob, waterproof bedding, support with hoarding, housing issues, relationships.
- Support to negotiate access adjustments needed to benefit from community based services i.e. 'community connector, supercharged!'

2. Collective Voice

Gathering lived experience data and evidence from 4000+ disabled people to strengthen Social Care reform, post-COVID.

- **918 disabled people** supported to share lived experience of social care through GDA Member Engagement.
- **227 disabled people** signed up to contribute lived experience to ongoing discussions
- Gathering evidence of social care links to wellbeing, volunteering, employment, social connections, wider participation, to strengthen case for investment and reform.



3. Collaboration

Connecting disabled people with allies and powerholders, to share their voices and experiences, to raise public awareness of barriers, and the purpose and value of Social Care.

- 3 online meetings of GDA's Social Care Expert Group of around 30 individuals.
- 36 disabled people supported to speak out and raise the profile of social care, through TV, radio, print and social media, Purple Poncho Players performances, and partnership events, promoting a shared vision for social care reform.

GDA's holistic support: resilience, led by disabled people

The COVID Pandemic has highlighted the vital role played by community-led organisations – in particular, those led by disabled people, who are too often overlooked, isolated and excluded from other supports and services.

GDA's holistic disabled people-led model, demonstrated most effectively through our Future Visions Project, has proven essential to supporting our community through this crisis.

Connecting through community development:

Disabled people's voices and experiences are vital to understanding where the gaps are, what's working, and what needs to change.

GDA's vast connections built and maintained over many years, provide a channel for those of us whose voices are otherwise 'easy to ignore' – our community infrastructure enabled us to quickly mobilise outreach, build capacity, and respond to disabled people's needs.

Social Model and Human Rights

Led by disabled people, all of GDA's work is shaped by the Social Model and Human Rights models of disability:

- external barriers, rather than personal shortcomings, are the root cause of our inequality
- removing these barriers is key to achieving our human rights

Recognising disabled people's strengths in the face of inequality is key to building confidence and capacity to know and claim our rights. GDA supports disabled people to recognise that our inequality is not inevitable – and our voices and skills are crucial to dismantling it.



"I'm fighting a battle to stay positive and keep going. I hate to think where I would be without GDA, Future Visions and the coping strategies I've picked up from them over the years." "I called on GDA for support with my PIP – when I told them more about my situation, they linked me in with Lifeline deliveries, wellbeing sessions, employability support, and digital coaching."

Focus on barrier removal puts the person in the lead:

Our rapid engagement put disabled people in the lead of shaping our COVID-response. Disabled people identified dangerous gaps and barriers in:

- Information
- Food provision
- Health and Social care rights /provision
- Welfare rights
- Mental health support
- Social connections and wellbeing

Thanks to flexibility from our funders we were able to respond, connecting over 5000 disabled people to information and support they needed to build resilience during this crisis, and opportunities to speak out and share their expertise to bring about wider change and improve responses going forwards.



Long-term impacts and Lessons from Lockdown

There can be no doubt, the pandemic and lockdown responses have supercharged the barriers and inequalities disabled people already faced, as well as creating new ones.

The long term impacts of this crisis are now hitting disabled people, adding to what was already a human catastrophe.

Disabled people continue to speak out and challenge these inequalities – the only way to halt a major regression in Rights and Equality is to **supercharge disabled people's involvement, rights and support**.

GDA's recommendations give pressing examples of how this can and must be done – drawing on lived experience learning shared by the 5000 disabled people we have connected with since March – and hundreds more who have been challenging inequalities for many years before that.



"Hope lessons are learned that we can work remotely and do these things online that they told us weren't possible before."

"These things affect disabled people a lot more than nondisabled. They think disabled people can do things without support and don't realise how much we struggle." Disabled people's voices and expertise will be vital to recovery and renewal. GDA will build on our peer support discussions and partnerships, to ensure disabled people's voices help shape plans and responses in:

- Health and Social Care
- Employability
- Education
- Housing, aids and adaptations
- Economic and environmental planning
- Social Security
- Social Isolation
- **Digital Inclusion**

Through our diverse network and intersectional approaches we will make particular efforts to amplify the voices of:

- Disabled women and girls
- Black and Minority Ethnic disabled people
- Lesbian Gay Bisexual Transgender and Queer disabled people
- Disabled children and young people
- Older disabled people
- **Disabled Parents**

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Supercharge involvement of disabled people

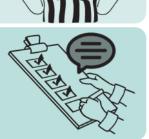
in planning recovery and renewal, to tackle supercharged inequalities

Embed lived experience of disabled people in all planning for recovery and renewal, locally and nationally, including resilience planning for future emergencies, and, urgently, in redesign of public spaces and town planning.

Ensure Place-Based Approaches are Equalities-proofed

- to avoid widening inequalities in planning and recovery. Our research shows disabled people are widely excluded within their local areas, so their voices are not heard. Ensure robust training for equalities competence in place-based approaches; and invest in parallel equalities-focussed approaches involving equalities-led community anchor organisations.
- **Drive participation: Build it in to National Performance Framework** with new indicators to capture the benefits of participation (particularly by equalities groups) for: decision making, democracy, tackling inequalities, wellbeing, social connections and contributions, sense of belonging.
- **Invest in inclusive community learning and community development** through **inclusive digital and offline** engagement and capacity building, raise disabled people's aspirations and opportunities to fulfill their potential, and strengthen participation and democracy.

Promote inclusive, accessible communication for all involving disabled people in communications planning, so that disabled people can access information on an equal basis.



Involve us!



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Supercharge Rights:

implementation and monitoring

Incorporate the UNCRPD into domestic law – starting with an **inquiry** into the unequal impacts of the pandemic responses on disabled people's human rights, including the use of DNARs and eligibility criteria for treatment. Revoke Coronavirus act and/or reinstate rights withdrawn; ensure independent scrutiny of any future temporary legislation, to protect disabled people's rights, particularly around health and social care.

Co-design a Disability Equality Action Plan: with disabled people, which builds on learning from COVID and from a Fairer Scotland For Disabled People Delivery Plan. Include a Disability Poverty strategy to deliver accessible welfare rights support, an accessible benefits take-up campaign, a new disability benefit to more effectively meet extra costs.

Urgently reinforce Fairer Scotland for Disabled People Employment Action Plan commitments and ambitions Work with disabled people of all ages to identify and mitigate impacts of COVID on disability employment gap e.g. discrimination or additional barriers to entering or returning to the workplace.

Tackle Rising Hate Crime: co-design a national public awareness campaign to tackle stigma and rising disability hate crime e.g. around face covering exemptions. Invest in a revised, rebranded Third Party Reporting scheme. Strengthen Police response processes, invest in trusted community supports, and community cohesion for prevention.

Empower public sector staff to deliver human rights, cut through bureaucracy and act with kindness: through positive collaboration with communities, including supportive equalities training to staff at all levels, particularly on disability.



UNCRPD

Rights





Supercharge support

existing, emerging and responding to gaps

Extend shielding list and develop resilience registers, building on experience; improve data collection to better understand unequal impacts of COVID on disabled people and plan actions to mitigate these in future crises.



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- Invest to maintain vital supports which emerged during COVID but address long-standing inequalities and build resilience: digital inclusion for social connections, wellbeing supports including check-in
- calls, regular food supports.
- **Elevate the role and resourcing of Social Care** to strengthen protections for disabled people's vital social care support; Re-open ILF in Scotland and establish a national Social Care agency, on a par with and working alongside our NHS. Co-design this with disabled people, modelled on Social Security Scotland and our ILF, with dignity, respect and a human rights based approach embedded.
- **Supercharge disabled people's access to vital services,** to mitigate unequal impact of lockdown on our physical and mental health: fast-track and reinstate ongoing healthcare, social care, housing, education, employability and mental health supports..
- **Invest in holistic support for disabled people to tackle barriers** faced at key stages of transition or crisis: for example, GDA's Future Visions model puts disabled people in the lead, supporting them to navigate pathways and overcome blockages and barriers to achieve their goals, participate and fulfil their potential.









we got the self isolated blues



Glasgow Disability Alliance is a registered Scottish Charity number: SC034247 Private Limited Company number: SC248467