Glasgow Disability Alliance.

Disabled People’s Mental Health Matters Report. October 2022

Glasgow Disability Alliance and Angela Gribben

“*I can’t just ‘get more exercise and fresh air’. I don’t have the support I need to get out and do that. It’s frustrating that the system can’t see you and recognise your whole life, and how this affects you*.”

About the Authors.

Glasgow Disability Alliance.

Glasgow Disability Alliance (GDA) is a disabled people led community organisation of 5500+ across Greater Glasgow – the largest groundswell of disabled people in Europe and a leading example of grassroots community activism.

GDA has contributed over 20 years’ of disability equality expertise and lived experience to a range of policies, strategic plans and service reforms in Glasgow and Scotland.

Our foundations of individual and collective community empowerment are based on a model of peer support, developing and drawing on disabled people’s own strengths, across three levels:

* building individual capacity to take a leading role in their own life, the life of their families, and the vibrancy of their communities;

* building collective identities, voices and activism of disabled people as a community to work together and with others to challenge inequality, contribute lived experience and participate in dialogue, deliberation and solutions;

* building capacity of local & national government, local communities and the third sector, acting as strategic partner and critical friend; sharing insights, evidence, and collaborating to shape policy and codesign services.

We achieve this via 4 critical, interrelated elements that increase disabled people’s life chances, raise awareness and tackle inequality:

1. Engage and “find” disabled people traditionally labelled “hard to reach” but actually are ‘easy to ignore’, using community development methods and approaches.
2. Deliver programmes of accessible, holistic and individual supports that build confidence, improve connections and increase wellbeing and participation.
3. Deliver programmes of collective capacity building and support to develop community identity, increase awareness of rights, how to access and assert them and challenge inequality.

4. Act as Independent Strategic Partner and critical friend, to Glasgow City Council, public and third sector in Glasgow and the Scottish Government, sharing lived experience evidence and collaborating to co-design solutions.

GDA is a model of excellence of community development and exemplar community of identity.

Angela Gribben.

Angela has worked as a consultant in the Voluntary Sector since 2000 as a highly effective Facilitator, Trainer and Coach.

Her expertise in delivering facilitation, development projects and coaching to charitable organisations is widely known and held in high regard.

Angela has undertaken a range of commissions over many years around Governance and Management within the Third Sector, acting as Interim Manager, Trustee and Advisor to a range of Third Sector Organisations. Angela has also provided mental health and wellbeing insights, training and coaching across a variety of organisations, drawing on her extensive experience as well as reflecting her earlier professional knowledge and expertise as an RGN, RMN and Nurse Manager in a variety of mental health settings and in setting up and delivering a Community Mental Health Project.

Angela has worked on collaborative projects with a wide range of service providing Third Sector organisations, including mental health organisations and those that work with people who have experienced trauma. Her work is geared to making a difference for people accessing services and she is particularly interested in participatory processes that strive to embrace diversity and inclusion.

In her own words,

"I have seen many changes in how we think about mental health and in how mental health support is provided, but never, in 40 plus years, have I encountered the level of unmet need and witnessed so much distress as described by GDA members during this research project. Overall, the report is a grim read of the lack of support for disabled people who need accessible mental health services. But this is also accompanied by hope: hope given by their involvement with and supports provided by Glasgow Disability Alliance.

This report is based on a series of events and interviews to explore mental health matters with a range of diverse disabled people, all members of Glasgow Disability Alliance. The members who contributed gave of their time freely and were open in describing their experiences in the hope that this will lead to better service provision for disabled people; fewer barriers, greater respect and necessary changes to demonstrate that they were heard. Thank you to GDA members and staff for their support with this research."

Angela Gribben, BA (Social Science)

September 2022.

Executive Summary.

The findings of this report demonstrate that disabled people are aware of what is needed to support their wellbeing and how they can maintain or improve their mental health. The also demonstrate a distinct lack of support from statutory services when a disabled person requires interventions for mental ill health.

Key Findings

- 100% of participants said they do not/ did not feel heard or taken seriously when trying to access mental health services or supports.
- 45% expressed fearfulness of statutory mental health services and the resulting stigma from accessing services.
- 85% of participants expressed concern around human rights not being upheld or eradication of rights, or legislation that may diminish their rights as disabled people.
- 55% of participants expressed having suicidal feelings in the past two years.
- 100% of young disabled people knew what contributed to mental wellbeing and what actions they could take to alleviate low mood.
- 46% of young disabled people were getting the mental health support they actually needed (outwith GDA supports).

Recurring Themes

- Disabled people were not heard. They were not taken seriously and often felt not believed or dismissed.
- Disabled people found themselves having to rely on GDA and other community or third sector services when others halted at the outset of the pandemic, including at mental health crisis points.
- There was a lack of trust in, and fearfulness of, statutory mental health services which have shifted from being there to support and "take care of" people, to a new position which is felt to be about detachment and disbelief.
- Crisis intervention appeared to be offered after disabled people had taken actions to end their life, and not before. This was a cause of frustration to many participants who wanted appropriate preventative and timely support when their mental health was poor but before crisis point was reached.

It is noted with concern that many of the problems faced by disabled people stem from inequality, disadvantage, poverty and exclusion.

"The range of services and supports disabled people need is more complex and we are at the mercy of a number of systems which are all failing and this got worse during the pandemic and remains a serious issue.

Continual "micro-aggressions" such as not being believed, being dismissed and being discriminated against has also resulted in negative mental health amongst some respondents including depression, anxiety and negative view of the world. This is exponentially so with disabled people who have additional protected characteristics, such as LGBT disabled people and BAME disabled people.

Disabled people appear to be suffering from the conditions of despair coupled with societal lack of concern and othering of diversity and difference. Participants expressed concerns about their rights not being upheld but worse still, a blatant disregard and lack of care about these rights with professional burn-out resulting in a corresponding burn-out in compassion and care.

This appears to stem from belief and related behaviours that human rights obligations cannot be met due to affordability: the inevitable choice is therefore to cut or reduce provision in services and support.

Young people had hopes for the future but concerns about a range of issues, including patchy service provision and transition between CAMHS and adult services.

Disabled people were concerned that there was a lack of recognition that the provision of appropriate home support, access to care and access to services improved the quality of life of disabled people and thus reduced the risk of poor mental health.

Headline Recommendations

1. Involve and Listen to Disabled People.
2. Eliminate Barriers to Access.
3. Invest in accessible and holistic Wellbeing Services.
4. Address Gaps in Services.
5. Promote and Uphold Human Rights

Context: The Covid-19 pandemic

From the outset of the first lockdown in March 2020, GDA began a wellbeing check-in service for members to find out how disabled people and their families were being affected and what GDA could do to support them.

This was because GDA is a values driven organisation, dedicated to improving disabled people’s lives and at the outset of the pandemic was in the privileged position of being able to realign resources to conduct a massive check in with members and to carry out what became a far reaching research project.

By March 2021, there had been in excess of 30,000 phone calls and over 6,000 disabled people had been engaged in conversations about their needs, ideas and priorities. 2,500 disabled people completed GDA’s online survey- mainly supported to do this due to barriers with digital connections or confidence. This survey asked people to describe their situation and their needs. Respondents who left details or gave permission were contacted by GDA staff, who followed up to ensure they could access the support they required.

The aim of GDA's check-ins were to ensure that disabled people did not fall through gaps as services were reduced or removed due to the pandemic.

Findings were stark and included that for disabled people:

* 60% faced digital exclusion, no access to devices, WIFI and/or lacked confidence to use it.

* 80% were unaware of and/or were unable to access any local support services they needed.

* 41% were unable to get information in the formats they needed.

* 82% worried about social isolation and loneliness.

* 62% were concerned about their mental health, with many people suddenly losing statutory and community based mental health support services.

* 90% were worried about both physical and mental health.

* 57% were worried about money and hardship.

* 47% were worried about access to food due to poverty, food shortages, lack of support to get food, digital exclusion and many were rapidly running out of food supplies.

* 47% were worried about social care. Social care was withdrawn from 1884 people in Glasgow with little or no notice. Others lost the regular informal support they relied on.

As the pandemic continued, the situation for disabled people worsened, with around 80% reporting that they were struggling with mental health issues as time progressed.

Mental health support needs were exacerbated by the conditions arising from the pandemic; isolation; diminished services and lack of access to basics such as food and safety at home. Feelings of fear of illness and death compounded all of this and National Records of Scotland reports that almost 60% of all people dying of COVID were disabled people, confirmed that fears were justified.

The NRS Report was shocking but not surprising to disabled people because disabled people's lives are already less equal and these inequalities have been supercharged by Covid-19. Disabled people have both more chance of dying from the virus and more chance of living with inequalities - with barriers and challenges - if they do not contract the virus.

This was the context for disabled people's mental health and wellbeing and GDA's engagement as well as wider research and data, including the NRS and Glasgow University findings, all of which shaped GDA's response.

GDA covid-19 Resilience Response

The abundance of evidence and disabled people lived experience, led to the adaptation of GDA's existing programmes and services and establishing new programmes and services to plug gaps and meet needs:

* Information: clear, easy to understand, accessible information in a variety of formats; signposting into services and supports where these existed and were accessible;

* Lifeline: providing deliveries of food, medication and other essentials;

* Connects: providing IT equipment, connectivity e.g. MiFi, 1-2-1 and group and individual digital coaching;

* Learning: online learning sessions, programmes, peer activities and events;

* Rights Now: welfare rights information, support and representation;

* Wellbeing: specialised mental health and physical wellbeing support on phone/online;

* Voices: sharing experiences, capacity building sessions, capturing and sharing lived experience, feeding voices into policy and decision makers, bringing disabled people together with policy makers, service designers, planners and decision makers.

GDA Wellbeing

The findings from GDA check-in calls and survey highlighted the need for a service specifically to support disabled people's physical, emotional and psychological wellbeing.

A senior member of GDA's Leadership Team with existing expertise in mental health support provision, led the development, set up and delivery of GDA's Wellbeing service. Her previous experience of running a mental health user advocacy organisation and a Healthy Living Project was invaluable in analysing and interpreting findings of the GDA engagement work and survey along with the GDA senior leadership Team. It was agreed that the service required the appointment of two experienced Wellbeing Advisers who were recruited to complete this new team, funded by emergency Covid monies from the Scottish Government and National Lottery Community Fund.

GDA Wellbeing aims to reduce isolation and loneliness by providing a listening ear, supporting disabled people over the phone or online to boost their own mental and physical wellbeing and offering regular 'check-in' calls, the frequency of which are determined according to individual needs. GDA's Wellbeing team provide support and advice around coping strategies, relaxation techniques and ways to stay as well as possible. The service also makes referrals to community based supports, services and professionals as required and by assisting people to connect into wider GDA supports, the Wellbeing service also addresses loneliness and isolation, hunger, poverty and digital exclusion.

When resources have allowed, GDA Wellbeing has also provided online group sessions to bring people together for peer support around Wellbeing.

Topics included how to improve sleep, looking after your health, trying out wellbeing tools and sessions that explore anxieties and concerns about going outside again for those fearful about leaving the house as protective measures have been removed.

"The 'sleeping better' group sessions have been amazing and have changed my life. I have been using the techniques every night since your session and I am now getting to sleep. Everyone in the group opened up and shared, due to the way you led the group. It was very welcoming and kind"

GDA's Wellbeing service was described as critical during the pandemic, providing ongoing telephone calls to disabled people, along with emails and texts to check-in with disabled people worried about their mental health.

This included those with a diagnosed mental health condition, those who have developed anxiety during and/or because of the pandemic and those dealing with loss and bereavement. This also included those coping with acute mental distress and suicidal thoughts.

"I could not get in touch with my CPN – they seemed to disappear and no-one would help me, even though they knew I had a suicide plan. GDA Wellbeing saved my life, quite literally. There's no doubt I would not be here if I hadn't called them."

From April 2020 – end of March 2021vi, 529 disabled people were contacted by the Wellbeing service, with 432 receiving ongoing bespoke support to establish and maintain mental and physical wellbeing, including advice and support on keeping well and ways to manage anxiety, including professional counselling.

The need for this vital support has not waned since then, and in fact, sustainability of the Wellbeing service remains a key priority for GDA in 2022 and beyond to meet the "supercharged" inequalities and need identified.

"It's so much more than just a phone call. Someone to talk to and listen means the world. Just speaking to [wellbeing advisors] takes my mind off my worries. I feel so much better afterwards. My family will know if I've spoken to you or not because they can tell my mood is lifted. It means a lot."

From crisis support to core service

The delivery of GDA's new reactive services, which had responded to Covid needs identified by disabled people, further highlighted the issues experienced by disabled people in relation to mental health matters.

Every Team within GDA was confronting, and continues to deal with, mental health and wellbeing issues as presenting factors when meeting disabled people and working with them - from giving advice on welfare rights, to support with finding work, to learning and training programmes. Even in the more collective work to shape and influence policy decisions and build disabled people's confidence and capacity to share lived experiences, mental ill health and issues with poor wellbeing have manifested, for example within GDA's Social Care Expert Group, Drivers for Change, Purple Poncho Players, BAME network, LGBTQIA+ Network and Young Drivers for Change.

The digital inclusion team, staff delivering wellbeing, and the welfare rights team, experienced an ongoing rise in people reaching out for mental health support.

Disabled people were not able to access suitable, timely support in their communities, or from statutory services, so continued to take up offers and reach out to GDA staff as trusted persons when they were facing mental health challenges. This included and continues to include people who are in real crisis situations, some of whom have active suicide plans and regularly indicate wishing to act on these.

Staff have found this challenging to deal with and have described this as having an impact on their own mental health: the situation for those they are supporting often seems so acute and desperate, with little scope to refer people on.

"It was easier being a counsellor than handling the distressed calls made to the GDA Wellbeing service; disabled people really had a sense of hopelessness based on their experiences" GDA Wellbeing team member, who is also a qualified professional counsellor."

At the same time, funding for GDA's Wellbeing service has come to an end and emergency resources secured due to the pandemic have been expended. It is clear that the Wellbeing service is now core to the organisation's holistic support provision and longer term sustainable funding is now an urgent priority, to the extent that the GDA Board have agreed short terms funding of the Wellbeing service from its reserves at this time.

Mental Health Matters research project

Disabled people told GDA they were left out and forgotten in mental health initiatives and campaigns. The Mental Health Matters research aimed to highlight disabled people's specific issues in relation to their mental health and the barriers faced by disabled people seeking to access mental health programmes and support services.

GDA secured funding from NHS Greater Glasgow and Clyde, Mental Health Anti-Stigma small bids fund to carry out an in-depth piece of work in relation to mental health, stigma and discrimination face by disabled people. This was matched by additional funding from a variety of sources to widen the breadth and depth of the research.

The project explored three main themes:

1. How disabled people can better understand their own mental health needs and highlight the additional barriers, discrimination and stigma faced by disabled people around mental health, including the contributory factors discrimination plays in causing or exacerbating disabled people’s mental health issues.
2. How disabled people can be better supported to talk about their fears around suicide and suicidal feelings; how disabled people could be supported to discuss loss of friends and family due to suicide, and the specific bereavement support required to enable them to process and recover from these losses.
3. To engage with young disabled people and explore stigma and discrimination around access to mental health services and the barriers faced in seeking to access support services. The work with young people explored what works and what needs to change to enable young disabled people to experience better mental health.

Additional match funding and slightly extending the timeframe, enabled us to consider previous GDA research project findings, academic research and public policy research and evidence to ensure a more robust project report.

Methodology

The project was delivered by Angela Gribben, independent consultant, working closely with GDA Senior Team. Angela engaged with six GDA staff and 37 diverse disabled members. The project engaged via group sessions with young disabled people; LGBTQ+ disabled people; Black, Asian and Minority Ethnic disabled people and disabled people with a range of impairments and long-term conditions.

Each group session was organised so that disabled people could fully engage with the research. GDA members were invited to participate and provided with information about the research, the range of session options and how to register their interest.

There was some degree of selection by GDA, as some members, although having much to contribute, were currently too distressed to participate and it was felt that their mental health could potentially be exacerbated by the discussions.

In-person and online activities were supported by personal assistants, language interpreters and communication support. After each group session there was a wind down activity, such as yoga or Tai Chi. In-person groups were held in a fully accessible space with good ventilation and access to an outdoor space. Masks and sanitiser were provided. Transport to and from the venue was provided; hot and cold drinks, snacks, and lunch were available. One to one interviews were offered to those who felt uncomfortable talking in a group setting.

In each group there was discussion from the outset and agreement reached about how members would work together as a group.

The research project considered three themes:

1. General Mental Health Anti-stigma and Discrimination Work:

* Supporting disabled people to understand their own mental health needs.

* Highlighting the additional barriers, discrimination and stigma faced by disabled people around mental health, including contributory factors discrimination plays in causing or exacerbating disabled people’s mental health issues.

2. Reducing Stigma and Discrimination around suicide issues:

* Supporting disabled people to talk about their fears around suicide and suicidal feelings.

* Supporting disabled people to discuss loss of friends and family due to suicide and the specific bereavement support required to enable them to process and adjust to the loss of a loved one.

* Highlighting the issues and barriers faced by disabled people in relation to suicide and access to services.

3. Reducing Stigma and Discrimination related to disabled children and young people’s Mental Health:

* Specific work with young disabled people in relation to their mental health and the barriers faced in seeking to access support services.

* Highlighting what works and what needs to change to enable young disabled people to experience better mental health.

Timing of Research Work

The research was carried out as mandatory pandemic protections were being eased. It was clear that disabled people had been disproportionately affected by the pandemic, with 6 out of 10 deaths being those with ‘underlying health conditions’.

Reports from the National Records of Scotland highlighted disproportionate impact in that 60% of deaths were of disabled people, even though they make up only 20% of the overall population in Scotland.

Furthermore, the previous two years have been a time when societal changes themselves have had a unequal impact on disabled people. GDA members reported:

* housing repairs being left unattended;

* housing officers seemed to disappear;

* GP appointments were in very short supply;

* community services seemed to disappear, or were simply inaccessible;

* social care was removed or rationed; contracts seemed to provide only short-term interventions and fell short of delivering what people needed, if at all.

Disabled people expressed feelings of being "a burden on the public purse;" and spoke of "being told off" if asking for services or a variation in a contract.

Despite the retrenchment of social care at the outset of the pandemic, charges continued, plunging disabled people into further poverty. Food banks expected people to attend in person but for many disabled people this was not possible. GDA staff reported many disabled people expressing hopelessness with their situation and a complete lack of control. Covid was of course challenging for everyone, but for disabled people, so many determinants of good mental health and wellbeing were undermined or withdrawn, including any sense of control of their lives.

At the time of the research, the general narrative in the Western Media appeared to report as if the pandemic was over. All protections were removed from public life. This further discriminated against disabled people those who could be more vulnerable to the harm caused by the virus. Disabled people became outliers in a world of people socialising and behaving as if the pandemic has passed. This also impacted negatively on mental health as many disabled people continued to be cautious and take measured risks.

"We've been told for nearly two years that we're vulnerable, we're high risk, we need to shield, or we'll die. Now, even though the virus is still out there, we're told it's safe to go out because there's vaccinations – even though we've also been told vaccinations might only be 40% effective for folk like us. And not all of us are getting the extra vaccinations either. I'm more terrified now than I ever was. I'm exhausted and people out there just don't understand."

During the pandemic, GDA received, and continues to receive, an increasing number of referrals from Community Connectors, Links Practitioners, HSCP and community organisations who struggle to find accessible, longer-term supports for disabled people who require physical and/or mental wellbeing supports.

It seemed that health services have not recovered and remain under pressure. It appears that while projects such as GDA's Wellbeing Service are continuing to plug gaps for longer term mental health and wellbeing supports, many disabled people appear to be in need of specialist mental health services, and remain unable to access these.

Key Findings

- 100% of participants said they do not/ did not feel heard or taken seriously when trying to access mental health services or supports.
- 45% expressed fearfulness of statutory mental health services and the resulting stigma from accessing services.
- 85% of participants expressed concern around human rights not being upheld or eradication of rights, or legislation that may diminish their rights as disabled people.
- 55% of participants expressed having suicidal feelings in the past two years. 100% of young disabled people knew what contributed to mental wellbeing and what actions they could take to alleviate low mood.
- 46% of young disabled people were getting the mental health support they actually needed (outwith GDA supports).

Unmet support needs in daily living led to, or exacerbated, disabled people's distress which was medicalised for many, resulting in mental health diagnoses and prescriptions for medications.

Disabled people wanted to be treated with respect and their wider needs understood and met. They were clear that they wanted recognition of their needs and of them as a whole person. They wanted services to adopt a holistic approach, to see them as a person and treat bits of them and their conditions or characteristics in isolation.

"Disabled people are not a homogenous group, we have individual needs, hopes, fears and aspirations."

"I might be disabled but I'm still human. I need care and attention (mental health) same as a non-disabled person".

Findings are discussed thematically. Within these themes specific groups are referenced: the Young Disabled People's Group; the LGBTQIA+ Disabled People's Group, and the Black and Minority Ethnic Disabled People's Group.

Project Findings

1. Wellbeing, staying well and support for mental health

Disabled people in all groups demonstrated knowledge of how to look after their wellbeing and stay mentally well, whatever their starting point. Principles clearly stood out in terms of the importance of having connections with others, feeling a sense of purpose and something to look forward to and of having meaningful things to do including learning new things, keeping active and giving back to others-making contributions.

The techniques people described using included connecting with other people; participating in GDA classes and interest groups; participating in enjoyable activities. These were as diverse as the members themselves and included, for example: art and photography; going to the gym and physical activities; getting out into nature; spending time with pets; reading; films and outings; spending time with family and friends; connecting with GDA friends and activities.

Examples of self-care included the use of Mental Health Apps, techniques including relaxation and tools advocated by cognitive therapists.

However, the evidence gathered demonstrated patchy access to the very resources that contribute to staying mentally well. Access to in-person support services and classes all but ceased at the start of the pandemic and many disabled people were left with little or no support, except from GDA.

Mental Health Apps were used by some participants and generally thought of as useful, up to a point. However, it was noted that use of these required literacy, IT skills, and access to devices with an internet connection - not something many people were able to take for granted.

"Some of the Apps are useful, but I can't always afford to top up my phone, so it's not much use to me. Even when we were allowed out, going to a public place to get Wi-Fi isn't very easy or appropriate as you need privacy to use these."

It was noted that GDA delivered services online and by phone during the period of lockdowns and public health restrictions and some of the participants had joined these activities.

GDA also provided support for digital access which was described as a "lifeline" by many. Through this support, there were examples of disabled people being able, for the first time, to access WhatsApp and Facebook.

The digital connections opened up a new world to many disabled people enabling them to connect with their interests, long lost friends and even far flung or closer family who they simply could not see due to restrictions. There were positives described in relation to getting together with like-minded people which had previously been unavailable.

"I've been a GDA member for some time, but couldn't come along to in person activities due to my mental health. For the first time ever, I've been able to join in all the classes, make friends and get great support for my mental health too."

2. Fear and Stigma

45% of participants expressed fearfulness of statutory mental health services and also of the resulting stigma from accessing services.

Many of the participants had been in crisis - some described not wanting to live anymore; not "seeing the point"; not knowing where to turn; not seeing a future and having exhausted all hope. Participants questioned the appropriateness of some of the tools being advised when someone was in a crisis situation.

"I can't just 'get more exercise and fresh air'. I don't have the support I need to get out and do that. It's frustrating that the system can't see you and recognise your whole life, and how this affects you."

One young disabled person recounted a story of being advised to have a bath, go for a walk or make a cup of tea when she phoned a crisis helpline. The person had limited mobility and no practical support because she was completely isolated. The advice was inappropriate and did not take into account her need for support with these activities. The advice also ignored how desperate she was at the time of the call and that she had already exhausted many self-help techniques.

"No amount of cognitive therapy and thinking differently about my rotten situation is going to make my mental health better. Isolation, poverty, where I live, exclusion, discrimination and not being listened to by health professionals all impact negatively on my mental health."

This was a recurrent theme with almost everyone interviewed. When disabled people were in a mental health crisis there was a general perception that there was little, inadequate or no support from statutory mental health services.

GDA staff endorsed this view drawing on experiences of there being no-one to refer onto as "services were either absent or on their knees". They had sought support for people who were in crisis and were repeatedly told that talking about suicide or having a suicide plan was not an emergency. If the person had not carried through on a suicide plan, there was no help available. This suggested that services were struggling beyond capacity and had moved far from any preventative role.

"I was threatened with being sectioned when I felt I didn't need hospitalisation, but when I sought clinical in-patient care because of strong suicidal feelings, I was not offered support."

Some of the experiences recounted were harrowing. One disabled man explained that he had had good support from his GP and in-patient services after an attempt to take his life. However, it transpired that he had sought clinical intervention many times before he attempted to die by suicide. He had been dismissed with no support offered.

3. "We want people to listen to us; we want to be heard."

100% of participants said they do not / did not feel heard or taken seriously when trying to access mental health services or supports.

Not being heard; being dismissed; not being believed or taken seriously, and being ignored by services were recurrent themes.

Some participants described encountering situations where there was some perplexity that a disabled person would also require a mental health service.

“I asked if there was wheelchair access at [third sector mental health service] and they replied, ‘No, why would there be?’. I felt shocked and dismissed.”

Others said that it seemed that because of the impairment they were somehow expected to live with a mental health consequence- with the assumption being that this was ok or somehow fair.

“My GP said I should expect to be depressed due to my [physical] condition.”

“I was told that I was “frail” and therefore vulnerable to illness – as if this was ok. I’ve never thought of myself as frail and this has a big impact on my identity and sense of who I am”.

Conversely, some participants described that, because they had a mental health diagnosis, physical symptoms were attributed to their mental health. Pain was ignored and diagnosis for physical, treatable conditions was delayed or dismissed until it was too late.

One young disabled women experienced discrimination in achieving a diagnosis for a physical condition and only through her dogged determination did she eventually get a diagnosis and appropriate treatment.

“Once you have a mental health diagnosis it seems like you’re stigmatised – people don’t believe you in terms of anything else.”

Disabled people described layers of barriers and discriminatory attitudes which evidence continual “micro-aggressions”. Examples given include not being believed and being minimised or being dismissed by professionals. On top of this, some respondents reported more overt discrimination and being subjected to abuse and trauma through hateful attitudes from strangers or neighbours in relation to their physical and more obvious impairments: these amount to Hate Crimes. In particular, where disabled people were also LGBTQIA+ and/or Black, Asian or Minority Ethnic, there were increased micro-aggressions and related risks.

The combination of these interactions and micro-aggressions has resulted in negative mental health and extreme distress amongst respondents including depression, anxiety, despair and negative view of the world.

4. Social Care impacts on mental health

Mental health was adversely affected and “supercharged” by the restrictions imposed on disabled people who also experienced reductions in their care packages or in some instances these were halted. Many disabled people had limited support, delivered by a contractor with limited time and staff instructed to carry out a specific task, refusing to do anything outwith this due to strict instructions and fear of consequences. The services and support many disabled people required did not match with the support being offered.

There was abundant evidence collated by GDA as well as many other sources (e.g. University of Glasgow, Scottish Government, Sisters of Frida) that many disabled people needed support in their home but were not able to secure this. Support or help to keep their home clean; to ensure they had clean clothes; to make meals and carry out repairs timeously as well as practical help with personal care tasks like getting washed, getting dressed and going to the toilet.

The evidence GDA and others uncovered was that there was a gap in service provision and lack of support with daily living and that this has impacted adversely on mental health and wellbeing.

There was also a distinct lack of choice or personal agency described. Some disabled people were put to bed from around 6pm in the evening and stuck there until a carer visited again in the morning, or made to accept other unsuitable arrangements.

"I've been forced into using adult nappies, even though I'm not incontinent, because they can't send someone to help me go to the toilet during the night. It's totally undignified."

This echoes previous GDA research and is the subject of a funded project, Future Visions for Social Care, which is conducting action research into disabled people's experiences and needs around social care.

All of this impacts negatively on people's mental health and wellbeing, their sense of autonomy and control and their ability to engage in activities that might help maintain mental wellbeing. People also described the impact on their identity as a disabled person when they do not get the support they require for daily living, and the effect on their mental health.

"If it wasn't for my connection to GDA, my life as a disabled person would not be worth living. Until I got involved, I could see no positive outlook or identity. Who'd want to be proud of themselves living like this? GDA helped me see the problem does not lie with me – it's the system that makes us and our lives feel worthless."

5. "I know what I need"

Disabled people participating in the research were able to identify the type of services they required to support them when they needed additional mental health support, when self-care techniques had been exhausted. Some disabled people described the need for in-patient care; or a referral to a community-based psychiatrist; the need for medication, or a medication review or therapeutic interventions to help them recover their mental health.

Knowing what they needed and accessing what they needed were not necessarily achievable. However, even when support was offered it was not always actually accessible to the disabled person.

“I was meant to have mental health inpatient care but I could not be admitted because they (the hospital) could not provide the physical care I needed. I needed hoisted and that was a problem, so I could not go.”

The experience of GP services was inconsistent. Some of the participants described good working relationships with the GP practice and would use the GP as a first point of contact for mental health support. Others described a less positive experience. It appeared that where a GP knew the disabled person and trust had developed, a more positive outcome was likely. For some participants, there was no consistency and they were weary of having to retell their story and of not being believed or taken seriously.

It was noted that many of the participants did not lay blame for their experiences with either services or staff. There was a recognition that funding for services had been reduced; there was shortages of staff; fragmentation of services and staff were overwhelmed. At first, most disabled people experiencing mental ill health turned inwards and blamed themselves for the problem. However, in being involved with others in the same boat, people described being able to understand that their situation as a direct result of policy choices and decisions: the demise of services, along with the exhaustion of the workforce, were consequences of increased need reduced resources and political decisions.

These decisions, in the face of a pandemic, sadly further exacerbated the disadvantage experienced by disabled people and contributed to, or exacerbated, poor mental health and declining wellbeing. The running down of services alongside the demonisation of people in receipt of financial support (benefits) was viewed as contributory to discrimination and stigmatisation of disabled people in general and contributed to their mental distress.

Many participants had accessed mental health services from charitable organisations. GDA was mentioned in every group of participants. Although not a mental health provider, GDA stepped up during the pandemic lockdown period to mitigate some of problems disabled people were experiencing. This included providing the digital connection service, wellbeing service and food provision.

“If it wasn’t for GDA I would not be here. They literally saved my life.”

“’I’ve been getting calls from GDA for over 2 years. I don’t know how I could have coped without them. No other agency has been in touch to see how I am or if I need anything.”

“There was thought put into the GDA food packages; treats and nice things were included along with the basics. People felt cared for and treated with dignity. I felt that I was worth something.”

“In those early days when I was stuck in a bedroom shielding from my own family, I would have taken my own life if it wasn’t for GDA because there were no other services. That sounds dramatic but it’s simple and it’s true.”

"GDA is like a family… I was in a very bad state in the time of COVID, when I joined GDA; being with GDA has given me the gift of doing more things; I was given an iPad and internet and have been able to learn and widen my knowledge, which I did not have the access to do before; engagement with GDA and the BAME Network and having a safe space to share experience has improved my wellbeing, and I find that it has helped me to reduce my use of medication and been very therapeutic for my mental health"

Other organisations that were cited as supportive included Project Ability, an arts charity; Flourish House, a club house model mental health organisation; Moira Anderson Foundation, an organisation specialising in Childhood Sexual Abuse, and The Mungo Foundation, an addiction service. The common features as to why these organisations were held in high esteem included that the disabled person felt valued, heard and was treated respectfully and as though they matter.

"Moira Anderson Foundation was the only place that accepted me as a man; they listened to me and accepted me" (young disabled trans man)

6. Barriers to Access

All research participants had been involved in GDA activities and wanted more mainstream services to be inclusive. They wanted barriers to be removed and to be able to get the services they need and participate in activities without fear, especially if barriers meant they struggled to engage. For some, ongoing barriers created a vicious cycle.

"I was discharged from [NHS service] that I really needed as I could not make my appointment twice. One was due to having no carer to help me get dressed and the other being too ill to attend, but they didn't understand or seem to care. They just saw no-attendance as not needing the appointment. Now I need to be re-referred and this is having an impact on my health."

Participants recognised that disabled people have diverse needs and that some of the inclusive practises provided by GDA include: help with transport to safely arrive at a venue; the venue to be accessible for all; specific needs, for example BSL interpreters, personal assistance or a note taker to be available. Participants also wanted to feel it was a safe space to be themselves.

Disabled people said they were less able to contribute to their lives, their families and wider society because of barriers and they were very aware of the narrative, especially prominent during the pandemic, that disabled lives were worth less.

"We're not asking for much, we want to be treated as human beings of value"

This stigma around disability and ongoing discrimination culminated in micro-aggressions impacting on disabled people's wellbeing and mental health. There was significant fear expressed by participants– fear that disabled people would be harmed by policies and practices; examples discussed were the Do Not Resuscitate orders introduced at the beginning of the pandemic and conversion therapy. This was particularly emphasised in the LGBT Group session where participants also reflected personal experiences of exclusion and knowledge of historical persecution for both LGBT and disabled people.

Listening to disabled people, as already noted, ran as a thread throughout the research. People talked of taking part in many consultations, with NHS, the City Council and Government, but that these id not result in the systemic and institutional changes required to enable disabled people to fully participate in life.

"It seems that most barriers we face could be solved by people listening to us - sometimes we only need simple changes that could make a big difference."

Participants wanted to contribute to their communities; they wanted accessible volunteering opportunities, and accessible workspaces. They recognised that for some people these opportunities contributed positively to their mental health.

It was agreed that people faced many physical barriers but they also faced discriminatory attitudes - including low expectations - towards disabled people and these were a massive issue, and impacted on mental health.

"Feeling like you are helping others- even being with others- can help you feel like your worth something, that you have purpose and that you can make a difference."

Participants recognised that discrimination against disabled people was still widespread. Many recognised that there were rights and laws in place but despite these disabled people were still "othered" and treated differently. It was felt that this was at least in some case because of a lack of understanding but it was felt that the bigger problem was the culture set in public services, driven mainly by lack of resources, inadequate funding for services and a belief that these were inevitable choices.

"Workers feel that they have no power to change things - even when they know it's not right. The potential for investment to be increased- for example through progressive taxation measures exist at higher levels and are more seen to be in the hands of senior leaders or politicians. This sense of having no control has led to a culture of acceptance of the status quo amongst the public sector- people go along with it because they believe there is no alternative."

The research heard how some disabled people chose not to state they had a mental health condition or impairment on work-based equality forms, for fear of facing discrimination.

"I don't trust equality monitoring forms. My experience is that despite having qualifications and lots of experience, employers just don't want to know you if they know you're disabled, especially if it's mental illness."

"I just don't have the energy to challenge all the discrimination I face. It's just become part of ordinary life now. This is just how it is."

7. Information and Communication

Accessing mental health information in accessible formats was described as often impossible, "it simply doesn't exist and hasn't been thought about!"

One visually impaired participant described having to challenge an organisation several times, before they were given information in an accessible format.

"I repeatedly asked for information and mental health support booklets in an accessible format. They [major mental health service provider] said they did not have any."

Another shared a story of pre-pandemic support to attend appointments for someone with multiple sensory impairments but that service has unfortunately since been withdrawn by the charity provider.

It was recognised that there was useful information online, but not everyone was able to access online resources. GDA Connects, GDA's digital inclusion project staff, shared their experience of working with people with learning difficulties and/or poor literacy skills who were excluded from potentially helpful wellbeing information.

Disabled people reported feeling a sense of stigma and shame associated with having poor literacy skills and some GDA members spoke of trying to hide this from professionals in their life as they were embarrassed. There was an obvious need for relatable information in multiple formats about mental health and wellbeing.

Disabled participants reported that GDA's digital project, GDA Connects, was able to procure devices and internet access for members from the outset of lockdown and to date. They also helped disabled people to learn skills that opened up connections, learning and possibilities, which impacted positively on mental health. This also enabled disabled people to source helpful information about staying mentally well.

A subtle but important point was emphasised by some respondents in relation to using interpreters. It was described as often easier to explain feelings and distress in a person's first language rather than through an interpreter. However, some people felt there are issues of trusting people with confidential information, especially for those from small close-knit communities, where relatives, friends, or even children might act as interpreter. There was recognition of stigma around mental health in some minority ethnic communities and/or faith communities that posed an additional barrier to seeking support.

8. Human Rights

85% of participants expressed concern around human rights not being upheld or eradication of rights or legislation that may diminish their rights as disabled people.

"The blatant disregard for human rights affects our self-esteem, as you just feel powerless and see no improvement (in upholding human rights)."

Some participants appeared to have a good understanding of their rights. This was most obvious in the LGBT+ Disabled People's Group and to a lesser extent in the Young Disabled People's Group. This is likely because these groups are more highly active within GDA's Drivers for Change Network which explores oppression and builds understanding of rights and redress where rights are undermined, as well as collective advocacy.

Many participants described fears about the future for disabled people and their rights. They could see that rights were not upheld now, and were fearful of an agenda that was already in the consciousness of the public that disabled people were somehow less deserving than others and they were a burden on society. It was felt that this was compounded by evidence from early in the pandemic where some disabled people reported being contacted by their GP Surgery to ask them to agree to Do Not Attempt Resuscitation notes being added to their record, should they contract Covid. This seemed at odds with the extreme life saving measures being used for the wider non disabled public at that time. Disabled people described feeling that they were disposable and that their lives were worth less than others, due to underlying health conditions. This increased anxiety and a sense of worthlessness for many. It also greatly contributed to lack of trust in statutory services.

On top of this, the withdrawal of services at March 2020, the cuts and seemingly arbitrary removal of services, the disregard for disabled people's needs (e.g. accessing outdoor spaces, public toilets and long queues at supermarkets) and, at the time of the research, the removal of Covid-10 public protection measures, without implementation of alternative protection resources send strong signals about disabled people's value in society.

"Since Covid you now only need one doctor to be signed into a mental ward rather than two, our protections are being eroded."

Reference was made on several occasions to the Holocaust and the Nazis extermination of disabled people and how it started with propaganda. Participants drew parallels with reporting in the right-wing press.

Fears were expressed across groups in relation to euthanasia and the current Scottish Parliament Bill about the right to support to end your life. This is discussed in more detail in the next section – Suicide and Loss.

This fearfulness, based on personal experience and the dissemination of information demonising disabled people, contributed to mental distress and fear of seeking support. There was fear of abuse of power but also of being traumatised by engaging with medical services which were acknowledged to be overstretched and under-resourced.

Participants spoke of the fact that many people with learning disabilities and autistic are placed in secure units, locked away, when they could and should live in the community with relevant support.

“If you’re out of sight you are out of mind and no-one knows about your human rights being taken away.”

Some participants had seen TV documentaries of abuse in hospitals and care homes, and expressed surprise that more people do not get punished for such abuse. There was a fear that “many autistic people end up in mental wards.” However, at the same time there was also concern that autistic people with mental health issues who needed intervention, were left unsupported.

“Mental health services won’t address (my distress) because I’m autistic; the autism support can’t address my mental health - so we’re in a catch 22.”

There was a fear that mental health facilities were worse than prisons and less regulated. This created barriers to seeking support.

“I’m scared to ask for help in case I end up back in hospital – there aren’t enough resources in the community. Because of multiple marginalisation, misdiagnosis and stigma it becomes harder to access physical health services too.”

There was concern expressed about the lack of respect for rights in mental health services and the lack of appropriate advocacy to help navigate the system. It was felt that there is also a lack of sign posting to the appropriate person who could handle complaints or concerns around rights and discrimination and that lack of knowledge and understanding was an issue too.

The Covid-19 pandemic had further contributed to discrimination and stigmatisation of disabled people. The emotional pain of isolation, of holding different views and of wanting to protect yourself in a world that mainly appears to be disregarding a harmful virus, placed disabled people as outliers and impacted on work, learning, opportunities for socialisation, and ultimately on mental health and wellbeing.

“I feel like I’m no longer welcome in my family and circle of friends. I’m like the one that won’t go away. They just roll their eyes or ignore me when I mention wearing masks, or not wanting to go into crowded spaces. I feel my world is shrinking, while everyone else’s is expanding again. I feel lost and alone.”

9. Suicide

55% of participants expressed having suicidal feelings in the past two years.

Many disabled people who participated in the research had thoughts about ending their life by suicide; there were some who had taken action to end their life already.

In almost all situations, mental health interventions were not provided by statutory services until the disabled person had acted on their plan. This was difficult for GDA staff who were supporting people in a profound state of distress and with no other service available to refer the GDA member on to, including in a crisis. As a result, the incidences of GDA staff having no option but to contact emergency services rose dramatically – from once or twice a year, to around once a month during the pandemic. This was treated with the utmost care within GDA with a line management structure in place and all staff being alerted to contact the senior team- day or night for information or support.

The experience of the GDA Wellbeing team and wider team was that there was no way to access a crisis mental health service that could work with a person's suicidal thoughts before they acted on these. If this is more than just circumstantial, then there is a clear gap in statutory mental health provision. From discussions with participants, it is evident that ongoing systemic, social and financial disadvantage, combined with a lack of understanding resulting in discrimination and othering of disabled people, has contributed to suicidal thoughts and actions.

Simply put, mental health services provision are not adequately equipped with knowledge and understanding needed to support disabled people effectively as this would require understanding the interrelated barriers people face.

The Assisted Dying Bill, currently being discussed in Scotland, contributed to fear for the future for disabled people and has impacted on disabled people's wellbeing. Attention was drawn to a recent Canadian example of a young women seeking assisted suicide because she couldn't get an accessible home. This impacted on her mental health to the extent that she was opting for medical assistance to die. In this woman's own words, "There is no choice, when you have no choice."

"If the very people you are expected to turn to when you're at your lowest point, are the same people who can make decisions about and help you end your life, then who can you trust? Human Rights are off the table."

10. Loss and Bereavement

There was much discussion around loss. Often disabled people experienced greater loss, and at a younger age, than the general population. There was evidence of disabled people experiencing personal loss of mobility and other physical "function" through illness or accidents, as well as losing access to opportunities.

Disabled people face the loss of disabled friends (including those with the same impairment) as well as disabled family members and colleagues. These experiences were described as 'frightening' and 'traumatic' and left some people wondering if their life would also be cut short, like their friends. Young people felt left out of bereavement support, "everyone thinks of the young person's parents and siblings, but who's supporting their friends, especially their disabled friends?" Participants highlighted that there is a lack of a specialist support service to help disabled people process their loss or multiple losses.

"When our friend died, it was only GDA who provided support. It was the start of Lockdown and they got a humanist celebrant to be with us because none of us could go and funerals weren't being streamed early in the pandemic. Then we got access to counselling if we needed it."

An obvious lack of access was within funeral arrangements which often do not consider or cater for the needs or access support of disabled people, even within their own families. A GDA staff member recalled the experience of a disabled woman, a wheelchair user, who was unable to find any accessible funeral cars for her husband's funeral and had not found the undertaker particularly helpful. They said that GDA has been asked several times to support disabled people with transport to attend funerals of their loved ones.

Bereavement was raw for many and was contributing to the exacerbation of existing mental ill health. There was a recently bereaved young person participating in the research. GDA had recently lost a valued disabled member of the staff team, and they had to cope with the loss of several well-known members due to the pandemic. Loss is more common amongst disabled people and disabled people's organisations and this has an obvious impact on mental health and wellbeing.

A key concern was that the pain and distress of bereavement would be medicalised in the absence of appropriate bereavement support services.

"It seems to be easier to give me medication, rather than provide bereavement counselling, which is what I want and need."

11. Acquired Disability (Impairment) and Mental Health

It appeared that there was no, or not enough, appropriate mental health support for someone suddenly becoming a disabled person as a result of an accident, medical incident or diagnosis.

There was discussion about the trauma, and adjustment, that was necessary for people with acquired impairments. It seems that such support is only available in certain limited circumstances, e.g. via a spinal injuries unit, or with some specific conditions (e.g. Stroke or Head Injury) but this is dependent on people getting the right information, in a format that meets their needs, and the support they need - at the right time to be able to access this. It was also suggested that you are more likely to access support if you have a family member or friend advocating for you or helping you in some way.

"My life changed in a blink of an eye. I was no longer the person I used to be."

It was suggested that early intervention and an appropriate trauma response may help with adjustment and prevent people from becoming depressed and as expressed in more than one group, suicidal.

"I was given some leaflets of where to go for help, but it was too soon and I was traumatised. No-one ever followed up or supported me to access [the support] so they just assumed I was ok. I wasn't."

It was suggested that mental health supports should be available at various transition stages as conditions progress and people have to adjust to loss - of social connections, of opportunities, of work and of involvement or feeling able to be involved in opportunities and in your own life.

12. Young disabled people

100% of young people knew what contributed to mental wellbeing and what actions they could take to alleviate low mood, but only 46% were getting the support they actually needed.

The young disabled people involved in the research articulated their needs and described using tools and techniques to stay well. However, they felt let down by statutory services when they needed mental health interventions.

As with other groups, there was evidence of being told they were "not ill enough" to access services, although participants described themselves as in crisis.

There were concerns about the quality of the CAMHS and what happened when you were too old for the CAMHS Team. Young people, who were just too old for CAMHS felt abandoned without support. This contributed to ongoing anxieties and exacerbated distress.

"CAMHS writes everyone off as too severe or not severe enough so you can't win."

Barriers to services for this group included lack of physical access and lack of support for young disabled people with sensory impairments.

There were issues around what services were available, with praise for Fife Health Board for having a range of mental health services for young people and dismay and disappointment about lack of services and inconsistency with other areas.

There were a number of young people who described being diagnosed with Borderline Personally Disorder (BPD) which impacted on access to mental health services. One young person described being treated by a psychiatrist who "didn't believe transgender was a thing" and was diagnosed as having BPD. This left the young person feeling confused and angry as well as with no support.

"It's hard enough to access support but now I don't want to take it. It made things worse with the mental health team; they gas lighted me. I don't want to be involved with them now, I tell the GP not to refer me."

A BPD diagnosis also seemed to make receiving appropriate medical intervention for physical ill health more challenging. "I'm told I'm exaggerating or imagining it - I think it's because they see the diagnosis on my medical file. It's stigmatising"

Others described being denied mental health services because they are autistic.

"I was told, of course, you're anxious and depressed – you have autism."

Despite having experienced some difficulties with statutory mental health services, there was still expressions of hope in the Young People's Group. They were collectively enthusiastic about making their voices heard and contributing to better mental health service design for disabled people. The young people recognised that this was because of the support they were getting from GDA. They wanted service providers to listen to them and listen to their hopes and fears; they wanted to be treated as an individual and have the appropriate support services to enable them to live a full and active life – one where they can both participate and contribute.

"Through GDA I'm getting the information, support and opportunities I need to stay well and fight for the rights of myself and others."

13. LGBTQIA+ Disabled People

This group was the most politically astute of the groups and had a great deal of knowledge of rights and legislation. Concerns persisted with some people that because they were members of the LGBT+ community, they were / might be discriminated against in mental health services.

"Additional labels and/or identities create additional barriers."

For most of the respondents, sexual orientation and mental health were and are linked. Some older people in the group recalled when being gay was illegal – in the not too distant past. For others in the LGBT+ Group, experiences of growing up or "coming out" during Section 28 or Clause 2a of the Local Government Act, had caused fear in the context of this legislation, which effectively prohibited the "promotion" of homosexuality in schools and public authorities, such as within social care.

People described this as an environment within which people and services had overtly discriminated and during which time peer support groups were closed or their activities severely restricted.

Group members described how they had lived in fear of being found out and how traumatic this was, and still is for some who remain unable to be themselves due to fear of being rejected or worse.

One participant shared a story of being hospitalised and encountering homophobic staff, causing fear, mistrust and more discomfort when in an already vulnerable situation. More than one talked of not being 'out' with their families and the additional strain this placed on their mental health including fear if they go into hospital of being 'outed'.

Another participant shared a story of disclosing her identity at one point as being lesbian within a routine smear consultation with a GP who had answered "But have you had real sex?" "This made me feel anxious about being honest again with any doctor for a long time".

An added factor was that LGBTQIA+ spaces are often not accessible to, or inclusive of disabled people which further exacerbates mental health issues. LGBTQIA+

disabled people then miss out on peer support opportunities as well as access to LGBT+ focussed support services.

I couldn't access mental health support at [LGBT organisation] as it was not accessible and they did not understand my needs as a disabled person. Similarly many disability spaces don't feel safe for LGBT people with the exception of GDA – they have gone out of their way to create safe space where I can feel included as my whole self."

There were concerns that trans disabled people's mental health issues were attributed to being trans and not taken seriously. Some people expressed that invasive and unnecessary questions were asked of trans people that were morbid curiosity and not contributing to understanding the mental health issues experienced by the disabled person.

"It felt like they just asked lots of inappropriate questions about my body, rather than discussing my mental health needs."

14. Black and Minority Ethnic Disabled People

Some of the disabled people in this group worked through interpreters to share their experiences of mental health services. Disabled BAME people acknowledged fears arising from reports that there had been significantly increased COVID-19 hospital admissions and deaths among BAME populations compared to white Scottish people. They were also aware of the growing consensus that the fundamental cause of these outcomes "is rooted in longstanding, pre-existing socioeconomic and health inequalities, including those driven by discrimination and racism"

Although many in the group were grateful for the mental health services offered to them, they faced barriers to accessing these services, especially during the pandemic and the impacts of reduced healthcare resulted in declining or negatively impacted health and mental health.

A helpful suggestion was that black and minority ethnic disabled people would welcome more opportunity to get together and talk about mental health issues, including in their first language.

The main additional barriers to services (on top of those described so far) were described as language barriers and the difficulties in sharing thoughts and feelings through an interpreter. At the same time, there was some discomfort about disclosing mental health issues to practitioners within their ethnic community, even if this eliminated the language barrier. Often older people had to rely on their children to interpret for them, which presented issues over dignity, privacy and lack of appropriate support.

"I don't want my young daughter to have to interpret the abuse and trauma I've experienced, or know about my mental health struggles."

There was a definite need for more privacy due to mental health stigma within some minority ethnic communities.

“In my community you’re thought less of if you have a mental health problem”.

One member of the group described feeling defeated, and questioned if there were any services that catered well for people from minority ethnic groups. They referenced social work and housing providers. There was evidence in this group that access to appropriate care for their physical impairment led to improved mental health, but often this was not easy to secure. Examples included receiving physiotherapy for a painful injury and another participant accessing a specialist service for amputees. However, accessing these services was problematic and took longer than it should have done. Ongoing care remains difficult due to the barriers described above.

There was agreement amongst some members of the group that lack of understanding or acknowledgement of racism resulted in lack of understanding of the connections between discrimination and health i.e. that racism is a fundamental social determinant of health inequalities and adverse outcomes for black and minority ethnic people and communities.

15. What GDA is doing well that others can learn from

Throughout all of the discussions, it was apparent that participants felt the most accessible and appropriate support they received in terms of mental and physical wellbeing support, was the support they received from GDA. Obviously all participants had a connection to GDA, but all of them had previously, or were currently, also engaged with public and/or other third sector mental health services.

“Why is it that only GDA seems to be providing services that meet disabled people’s wellbeing and mental health needs? Why can’t other organisations and services do better?”

Project participants were asked what it was that GDA was doing that made a difference. The key themes were:

* GDA is a community of identity, run by disabled people, for disabled people: key elements here include GDA’s understanding of the issues and barriers disabled people face. GDA is run by disabled people. Instinctively they know what is needed in order to run / provide accessible, inclusive supports: this creates a sense of trust as people know their needs will be met.

* GDA is rooted in peer support: This trust and the more “collective” identity and voice, rooted in peer support, generates a sense of belonging and shared identity, “We are GDA” as said by a participant. There is a strong sense of ownership over the organisation which gives people a sense of hope and purpose.

* GDA is a ‘pan impairment’ organisation: they support disabled people, regardless of impairment (or type of disability), including those without a formal diagnosis.

There is no formal referral / assessment process to become a member. Membership is not a requirement to receive a service.

* GDA is based on human rights and community development approaches: they engage and support disabled people in communities, build on their talents and strengths, provide learning to increase skills and knowledge of rights, and provide opportunities to collectively tackle inequality and influence decisions which affect disabled people’s lives. GDA also works to build the knowledge and capacity of public, third and community sector organisations to create better understanding and work with disabled people to codesign better services.

* GDA provides holistic services: a vast range of services and supports are provided. The GDA team work cooperatively with each other to ensure that there is a smooth transition to other support within GDA, or joint working across GDA to support people when this is necessary. GDA staff also support referrals to other organisations where appropriate and accessible. GDA is a source of support which helps people cope with challenges.

* GDA meets access needs without question: the provision of necessary access support was a key difference, described as “a game changer” and “life saver” by many participants. For face to face activities, transport, personal assistance, communication support, interpreters, equipment, and accessible resources are provided. For online activities, GDA provides digital coaching ongoing, and, due to specific funding, has been able to provide the devices and connectivity necessary for disabled people to take part online.

* GDA support is free: recognising that the majority of disabled people live in poverty, all GDA activities and support is provided free, including all the necessary access support required. Refreshments, snacks and lunch are also provided at no cost to participants.

* GDA recognises and celebrates diversity: all GDA activities are inclusive of diverse disabled people and there are also several intersectional networks that support disabled people who face multiple barriers, e.g. disabled BAME people / disabled People of Colour; LGBTQIA+ disabled people, disabled women, young disabled people, disabled parents, older disabled people, disabled men, etc.

* GDA support is designed to meet needs: GDA understands that people’s physical and mental health can fluctuate, and other barriers in their life can also affect levels of participation. Fundamentally, GDA support is set up to meet needs and is therefore not limited to a defined amount of sessions, or time, nor do participants have to sign-up and commit to conditional supports.

"GDA is more like a family… I was in a very bad state in the time of COVID; being with GDA has given me the gift of doing more things. I was given an iPad and internet and have been able to learn and widen my knowledge, which I did not have the access to do before. Joining with GDA and the BAME Network and having a safe space to share experience has improved my wellbeing. I find that it has helped me to reduce my use of medication and been very therapeutic for my mental health. I have been welcomed into this big family, especially the BAME Network".

Recommendations

Disabled people need support to live their life to the full. Disabled people, like non-disabled people, want to be independent and do as much for themselves as possible. But many require support to manage their own health and wellbeing to the fullest extent possible and need this support to be fully accessible and non-judgemental, with easy access that does not require a medical diagnosis.

Disabled people want to build skills for self-management in ways that are informed by lived experience and led by their peers, and importantly in a manner that does not place blame or fault if their health does not improve. This is as true of people with mental health conditions as it is of those with physical conditions, sensory impairments or sensory loss. Some disabled people will always require support, be it practical or in the form of treatment or therapies.

The following recommendations were developed with research participants, based on the overall findings of the project. The recommendations chime with those made by the Social Renewal Advisory Board for Scotland which outlined a specific call to action to realise the human rights of disabled people: this called for access to vital services to be accelerated to mitigate unequal impacts of the Covid-19 restrictions and beyond on physical and mental health and life outcomes including: Healthcare; Social Care; Housing; Mental Health Supports; Wellbeing Support - including continuing support established during the pandemic.

Similarly, much of the suggestions being made here are consistent with the Scottish Government’s Draft Mental Health & Wellbeing Strategy for Scotland Consultation which is about how to maintain good mental health and wellbeing, the types of services and supports that are needed to sustain this and the interaction with other social factors, such as access to housing, education and poverty – and in the case of disabled people, social care.

The following recommendations are directed at Scottish Government, Local Authorities and public bodies, including statutory mental health services, and third sector mental health and wellbeing initiatives.

1. Listen to Disabled People and Involve Us!

Disabled people – including those with mental health conditions or facing mental health challenges, want to be involved in the development of policies, the design of services and the taking of decisions that affect their lives. They want to be heard, valued and their knowledge and skills used to enhance service provision in statutory and third sector services going forward.

To enable this, mental health and wellbeing service providers must:

* Involve, listen to and act on priorities and recommendations made by disabled people; recommendations that are informed by their individual and collective experience. Support and/or collaborate with disabled people's organisations and utilise their expertise in creating inclusive, accessible and safe spaces for disabled people to come together to share lived experience and develop solutions to the barriers they face.

* Develop and resource approaches to meaningful and inclusive participation of disabled people in planning and decision making around services.

2. Eliminate Barriers to Access

Access and inclusion is required across all aspects of society to enable disabled people to better participate in activities that contribute to wellbeing. This includes mental health and wellbeing treatments and support within public, third and community sector services.

* Access and personal assistance needs of disabled people should be met within psychiatric settings, including within in-patient facilities and at GPs.

* Information about mental health and wellbeing must be available in a variety of accessible formats across all agencies and at the same time as standard information.

* Disabled people should be able to access the support they require in order to fully access mental health and wellbeing services. This includes transport, communication support and personal support assistance as well as advocacy.

* Services should be delivered in flexible ways, able to accommodate the needs of disabled patients and service users.

* Resources to meet the needs of disabled people should be built into budgets when designing and delivering mental health and wellbeing services.

3. Invest in Accessible & Holistic Wellbeing Services

The research findings highlight that GDA are supplementing rather than complimenting mental health services without funding or recognition. As well as the general recommendations, there were some specific thoughts on how to improve the provision of wellbeing service provision:

* Wellbeing activities, alongside practical, life enhancing support, that help prevent social isolation and support wellbeing should be recognised as valuable resources and given more status within an holistic approach to wellbeing and mental health services.

* Resource longer term, bespoke wellbeing services for disabled people, such as that provided by GDA and others with specific "know-how" of disabled people and their challenges.

* Invest in holistic services that deal with the issues that cause despair including poverty, isolation, inappropriate housing or support services.

* Work in partnership across public, third and community sector services to codesign and deliver wellbeing services that better meet needs, including the needs of disabled people.

* Recognise the unique and essential nature of peer support in promoting and delivering wellbeing services, including intersectional and specific peer group approaches, and resource these to ensure those facing the most barriers can be supported.

4. Address Gaps in Services

Many participants’ mental health was adversely impacted by a lack of suitable services across a range of areas. These included lack of appropriate individual care packages, help with home care and wellbeing services for disabled people who needed mental health support but were not diagnosed with a mental health condition.

Many people felt excluded from (non-mental health) services because of their mental health issues or diagnosis. Lack of joined up approaches compounded the negative impact.

* Urgently fast track and resource access to vital mental health and wellbeing services and supports for disabled people in person, online and by phone in response to need. These support people to explore and understand their mental health, recognise what adversely affects them and know when and how to seek support and access help to promote wellbeing. Involve disabled people in mapping the gaps and exploring solutions to improve services.

* Develop and deliver accessible and safe spaces for disabled people, including peer support, to talk about and explore their mental health issues, get informal support and exchange ideas.

* Develop an inclusive intermediary service for young adults who are not in crisis but are in need of mental health support, to address the needs of young people too old for CAMHS but not deemed ‘ill enough’ to access adult mental health services.

* Evaluate the need for the provision of an holistic mental health service for disabled minority ethnic people and communities, which address language and cultural barriers to support and treatment.

* Work with disabled people to explore the development of a specialist mental health service that works for disabled people by recognising complex and interrelated barriers.

* Work with disabled people, including newly diagnosed disabled people, to explore the development of a trauma support service for disabled people who acquire impairments that they can access when ready to do so.

* Create an accessible directory of mental health services, including wellbeing services that describe services, accessibility of services and referral routes.

5. Promote and uphold human rights in mental health services.

Participants gave examples and expressed concerns about human rights not being met when receiving or trying to access mental health services. There is an urgent need to embed Human Rights into the design and delivery of acute and preventative Mental Health and Wellbeing services.

* Progress Incorporation of the UNCRPD as intended: this will protect disabled people’s right to Independent Living, as defined by disabled people and enshrined in the Convention, including access to supports that maintain good mental health and wellbeing, and prevent crisis.

* Training in Disability Equality and Human Rights, delivered by Disabled People’s Organisations, should be made available to mental health and wellbeing decision makers and practitioners, so they can better understand complex barriers faced by disabled people seeking support and more effectively plan services that meet their needs.

* Collect and utilise data in order to identify and address gaps in provision and take-up of mental health and wellbeing services by diverse disabled people.

* Co-design a new approach to prevent and eradicate discrimination of disabled people within mental health services, including lack of accessible services for disabled people seeking mental health supports, and DNAR notices added to medical notes without consent or full understanding.

* Prioritise the safety and right to participation of diverse disabled people in relation to public health measures, e.g. continuing social distancing, Lateral Flow Testing and wearing masks where practical.

* Explore a Scottish Framework for Progressive Tax to enable delivery of human rights obligations and enable more funding to flow into the system: e.gs taxes on highest profitable businesses, taxing assets like property, wealth, inheritance, reforming Scottish property taxes, addressing tax evasion/avoidance.

“The DET training delivered by GDA staff and members really helped me understand and appreciate the barriers faced by disabled people and how I could remove these barriers. It’s important that those of us who hold power have an open mind and are willing to learn.” Public sector Senior Manager.

Conclusion

GDA’s current evidence is that for disabled people, the pandemic exacerbated existing inequalities and experiences of disabled people: disabled people are still living in poverty, inequality and facing isolation in terms of the pandemic, fearful of the return of face to face activity and the loss of online opportunities as the world returns to ‘normal’.

Disabled people are now facing increasing loss of confidence and have fewer connections as a result. We know people are facing increased loneliness, bereavement, mental health impacts, deteriorating physical and mental health and continue to feel excluded from their communities.

Many of the disabled people who took part in the research, described living situations that were not conducive to good mental health and wellbeing. Poor housing examples were frequent – people unable to access washing and cooking facilities or outdoor space and people feeling unsafe due to antisocial behaviour, including from immediate neighbours. GDA staff recounted examples of many people they are supporting whose home situations are leaving them at tremendous physical and psychological danger. This included people where lack of social care support resulted in them living in dirty, cluttered homes, with no access to support to resolve these situations, causing a downward spiral into crisis.

Questions arose around societal norms that medicalise the issues arising from living with the harm of trauma, poverty, disability and discrimination against a backdrop of service reduction, austerity and demonisation of people who are diverse or different.

Disabled people need support and assistance to live their life to the full, not medical interventions at acute and crisis points that deal with the symptoms of not getting support.

Disabled people who experience mental health crises are further disadvantaged as it appears there are limited services available, and what is available is often not accessible to them, or able to meet their specific needs.

“Transforming participation for disabled people in Glasgow beyond Covid 19” outlines the steps necessary to ensure the meaningful involvement of disabled people in codesign. GDA is willing and able to both support diverse disabled people to build capacity for participation, and also to provide accessible opportunities to work together with service reform teams and decision makers to codesign services that improve lives and support mental health and wellbeing.

Changes are required and diverse disabled people want to be involved in the development of services that meet their specific needs, including mental distress, suicide prevention and bereavement services. We must work together to enable this to become a reality. Disabled people’s mental health matters.

Appendix: Case Studies

Mena experienced racism and bullying, which affected her mental health. She also experienced early trauma and had addiction problems.

Mena described struggling with her mental health against a background of an expectation to "just get on with it". She waited two years for an appointment with a psychologist and was suicidal during this time. She had previously attended addiction services but was discharged at the start of the pandemic.

GDA reached out to Mena as part of the Wellbeing check-ins and immediately was able to provide food, online learning and ongoing wellbeing support. Mena said, "if it wasn't for GDA, I wouldn't be here. Simple as that."

Charles had a long-standing condition that made day to day living tasks difficult at best and some days impossible to complete. He had carers come to his home to help with personal care. However, the care was not led by Charles and he was humiliated by carers who accused him of not trying hard enough to carry out physical self-care.

Charles had little choice or control over his life. Carers came early in the morning and evening and he was put to bed before many people would have had dinner. He needed support to keep his home comfortable and clean but that service was not available. His home and mental health deteriorated.

Charles did have some family support but they lived in a different town and visiting was limited due to distance, their work and childcare commitments. Charles struggled with his mental health as his physical health deteriorated and experienced great difficulty in being taken seriously on both counts. He eventually moved to be closer to his family and his new GP referred him for counselling. Throughout all of these difficulties he accessed telephone support from GDA, which he described as a 'life-saver'.

Leo had a history of trauma and anxiety. He was dismissed from mental health services by a psychiatrist due to 'not engaging'. He was diagnosed with a personality disorder, which made it almost impossible to get help. He approached a range of agencies to get mental health support but was turned away. He described feeling suicidal at times, without hope and helpless against the system.

Leo managed to get connected to GDA via a third party and has since had help and support through GDA wellbeing service, Digital Inclusion, Learning and Welfare Rights services. Leo described GDA support as "outstanding in terms of fast, responsive, dignified support that enabled me to have control over my life again".

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End of document.