Glasgow Disability Alliance
Confident Connected Contributing

Budgeting for Equality

Action research by disabled people exploring:
how can disabled people play a full and meaningful
role in participatory budgeting in Scotland?

Contents

Summary

Participatory budgeting (PB) or community budgeting, means involving community members in decisions about how money is spent.

- The Scottish Government's Community Choices Support Programme commissioned this 6-month project to explore how disabled people can play a full meaningful role in PB in Scotland. With disabled people's expertise at the heart of our approach, we explored 'What helps and what hinders' disabled people's involvement in PB and community decision making.

- GDA is a disabled-people led community of interest with 4500 disabled members city-wide and a 17 year history developing disabled people's capacity to participate and influence change, in their own lives and communities.

- GDA's specialist community development staff supported GDA members to develop and carry out our action research plan, drawing on existing evidence and external expertise. From survey design to analysing the findings and making recommendations, this project is built from the collective expertise of all our members.

- This report summarises our process, and presents our findings and recommendations for a PB framework that can reduce inequalities disabled people face, ensure meaningful participation and improve life outcomes.

Key stats: Who did we reach?

With training and support our team of peer researchers held **13 focus groups**, used **interview techniques to support 149 participants to give in-depth face to face** responses, and gathered **94 responses to our online survey**.

Ages 19-93	Range of ethnic backgrounds including New Scots	All areas of Glasgow and beyond (up to Stirling, Edinburgh Dumfries)	All impairments and conditions: physical, sensory, autism, learning difficulty, mental health, neurological conditions
Women Men Transgender and non-binary people			

- Disabled people who are working, volunteering, looking for work, or in education: all more likely to find it easier participate and feel heard.

- **The majority not in learning, work, or volunteering: found it harder to get involved and be heard.**

- Those who find it **hardest to get involved** were far more likely to **rely on some form of support at home** – formally or through friends and family carers.

Read on to hear the barriers and solutions our participants shared.

Headline findings

1 **Disabled people overwhelmingly want to be involved in deciding how public money is spent** but are prevented from doing so by a web of complex barriers.

- Disabled people want to be involved in decision making at all levels, from ward to Westminster - but **overwhelmingly prioritise the need to participate in and shape decisions about mainstream services.** Disabled people's lives are disproportionately affected by mainstream services decisions – housing, planning, education, social care. Our **unique insights** into what works well, what doesn't and what needs to change are **crucial to reducing inequality and improving our public services.**

- Disabled people actively want to be involved in local PB and decision making alongside other local residents. However, due to inequalities and multiple barriers, **we need extra support - information, access and capacity building - to level the playing field and ensure our participation.**

2 **A cycle of exclusion prevents communities across Scotland from accessing disabled people's insights and expertise.** The barriers which cause our inequality are the same barriers which prevent us taking part in decisions that could address it. Removal of these barriers is what disabled people would prioritise if given more say over resources:

- physical barriers: inaccessible transport and built environment
- unmet support needs
- poverty
- inaccessible and inadequate opportunities for work or learning
- negative attitudes and a lack of understanding of our needs and rights
- consequential isolation and corrosion of hope and confidence
- overwhelmingly feeling we have no voice and are not listened to

3 **Structural inequality cannot be addressed at the local level alone: wider culture change is essential if participation is to have meaningful impact** – GDA members have been speaking out about barriers and how to improve services for many years, yet remain broadly disempowered across our lives: without resource realignment and a willingness to do things differently, barriers persist and outcomes remain the same – or get worse.

Headline Recommendations

A transformative, deliberative PB framework designed to tackle inequalities could be the lever we need to truly amplify the expertise of those who would otherwise be unheard. Removing barriers to disabled people's meaningful involvement in PB requires wider culture change to tackle the barriers we face across society starting with:

Planning and Design:

1   **Work with communities of interest (e.g. disabled people) as well as communities of place to set Equalities Outcomes for PB at local, regional and national levels:** Lived experience is key to build solutions and improve lives. A focus on poverty and income inequality alone will be insufficient to tackle the nuanced, multiple inequalities faced by disabled people and other equalities groups.

2   **Ensure sufficient resources and timescales to remove barriers** including transport, support and accessible information.

3   Build capacity of PB stakeholders through **disability equality training**: raising awareness of rights and broader equalities issues.

4   Uphold a clear focus that the **purpose of PB** is not only working collaboratively to make the best use of resources but is **above all to improve people's life outcomes**: use Equality and Human Rights Assessments to transparently measure progress.

Delivery:

5   **Identify and involve** those who are easily ignored including disabled people: connect with equalities led organisations to redress imbalances.

6   **Empower and actively encourage marginalised voices: create space** for equalities groups to contribute lived experience to the process: Build in accessible, thematic, safe-space approaches to participation in local PB projects.

7   **Enable deliberation** to build all stakeholders' understanding of human rights and Equalities issues, to coproduce outcomes which reflect the diverse needs of the community.

Learning and Culture Change:

8   **Embed a "test and learn" culture** within and between organisations from leadership to delivery which cultivates confidence to listen, do things differently, take 'risks', and learn from mistakes as well as successes.

9   **Resource communities of interest** e.g. disabled people led organisations to build capacity of equalities groups to participate in PB locally and city wide

10 As PB evolves to explore mainstreaming, **test out new methods and approaches to embed disabled peoples' participation in decisions about mainstream services,** using Public Sector Equality Duty as an enabling framework including: transport, housing, urban planning, education, employability, health and particularly social care.

Background

GDA: Participation for Equality

Glasgow Disability Alliance was founded in 2001 by a small group of working class disabled people, with the aim of uniting and amplifying the voices of disabled people in Glasgow, to effect change and improve lives.

Across the UK, a grassroots movement of disabled activists had achieved:

- the 1995 Disability Discrimination Act (DDA) recognising that vast inequalities faced by disabled people were the result of direct and indirect discrimination - by barriers in society, not our own deficits - and enshrining a statutory duty to make 'reasonable adjustments' to prevent discrimination.

- the 1996 Direct Payments Act to finally enshrine disabled people's rights to independent living, equality, choice and control over their own lives.

Landmark Equalities legislation takes time, effort and collaboration, to effect the necessary culture change and transformation. In Glasgow the road to equality is steep, with higher rates of overall deprivation, and disabled people making up 25% of our population rising to 30% in areas with the greatest challenges.

GDA's initial 50 or so members identified that to build disabled people's confidence and capacity to influence change, the first step is tackling the acute social isolation disabled people face as a consequence of complex barriers. GDA developed opportunities to bring disabled people together through fully accessible programmes of adult learning and peer support – thus GDA's disabled-people led community development approach was born.

17 years later GDA has 4500 members across greater Glasgow, all disabled people or people with long term conditions. GDA is run by and for disabled people, (100% of elected board and 50% of staff team are disabled people) and now delivers thousands of accessible learning opportunities to around 1500 disabled people each year. GDA's Drivers for Change leadership network of around 150 members receives enhanced support and capacity building, through briefings and training opportunities, and this network, in turn, supports the wider GDA membership to participate and speak out about the issues and barriers they face.

Through this process GDA members have taken part in local and national debates, including:

- Producing GDA manifestos and hosting hustings events ahead of elections.

- Feeding into the Community Empowerment Act; Shaping Social Security in Scotland; Healthier Scotland and a Fairer Scotland for Disabled People Delivery Plan.

- Glasgow's Community Plan, Health & Social Care Integration and a Vision for Self Directed Support in Glasgow; and Local Governance conversations.

- DWP Green Paper responses, Review of Hate Crime Legislation.

Collaborating for culture change

Despite 17 years of this participation and involvement by disabled people, the UN declared last year that disabled people's rights in the UK have been eroded to the point of 'Human Catastrophe' – in particular: social care, housing, education, employment, poverty and cuts to welfare benefits. Only Scotland was praised for involving disabled people in a Fairer Social Security system and protecting the Independent Living Fund.

GDA members are well placed to help inform Local and Scottish efforts to mitigate some of the worst challenges, such as Universal Credit; however the ingrained structural barriers explored in our research require deeper collaboration for transformative change.

Our project underlines concerns that 'empowering communities', without understanding the inequalities and exclusion faced by specific groups e.g. disabled people, can actually worsen the barriers and disempowerment faced by these groups. Those who have valuable lived experience of complex barriers and inequality are the least able to participate in decisions about resources, precisely because of these barriers.

As a disabled-people led community of interest with a 17-year track record of empowering ourselves, it is our hope that Participatory Budgeting could present the opportunity for Scotland's agencies to truly harness the expertise of disabled people, to help meaningfully realign resources to tackle inequalities.

Putting disabled people on the PB map: context so far

Participatory Budgeting is championed around the world as a transformational approach to decision making, where citizens' involvement and expertise are harnessed to ensure funds get to where they are most needed.

Scotland has embraced Participatory Budgeting as a tool for **engaging communities, building their resilience, to improve outcomes and deliver public services more effectively** – local authorities aim to commit 1% of budgets to PB by 2021. "First Generation" PB work has mainly followed a 'small grants' model: a community – usually place-based - is awarded a pot of money; community members develop ideas and submit proposals, and the wider community is invited to vote for the proposals they want to fund. Programmes of support are essential to help community members develop their proposals and capacity to deliver on them.

Engagement — What do you think?

Time to participate

Fatigue

Communication

Never knowing when meetings are on. Not enough notice

(1) Class (2) professionals making decisions (3) ignored

Taken seriously

How to get involved, where to hear about it

Accessibility

Again, it's hard finding out what is on.

Lack of communication

How to get involved, where to hear about it

Lack of support

I can rarely get out and I never see anything acknowledge that my issues have been heard

However Participatory Budgeting without an equalities approach could easily exacerbate inequalities within and across communities: the community members who are best placed to take part and win support and resources are those who already have greater influence and resources, while those who are isolated, marginalised, or face multiple inequalities, experience much greater barriers to accessing these processes and resources, and winning support for their issues to be addressed.

What Works Scotland[1] warn that **communities of interest facing multiple complex inequalities** – disabled people, LGBT people, black or minority ethnic people – **are often excluded** from community engagement initiatives, precisely because of the inequalities they face in society. Existing within and across geographical communities, they are not "hard to reach" but rather **"Easy to Ignore" – due to the scale of challenge** involved in unpicking the web of barriers and addressing the **ingrained structural inequality** at the source.

Interim evaluation of PB in Scotland[2] found that to fulfil its transformative potential, **PB in Scotland will require a much clearer** emphasis on addressing inequality, along with a wider **culture change** towards more inclusive and shared decision making: broadening PB beyond small grants models to **involve communities in decision making about core service provision.**

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[1] http://whatworksscotland.ac.uk/

[2] Evaluating Participatory Budgeting Activity in Scotland – Interim Report Year 2, Angela O'Hagan, Clementine Hill O'Connor, Claire MacRae, Jennifer Broadhurst and Paul Teedon: https://www.gov.scot/Resource/0052/00527483.pdf

With austerity and increasing demand for public services as our population ages, the 2011 Christie Commission found that community **participation would be crucial to future-proof** our services, build resilience and stronger partnerships, and invest in prevention.

What Work's Scotland's Review of PB[3] and **"Participatory Budgeting in Scotland: The Interplay of public sector reform, community empowerment and Social Justice"**[4] recently outlined ambitions for "2nd Generation PB" to be a clear enabler in this process, driving a **concerted focus on tackling inequality**; more emphasis on informed, **deliberative dialogue**, and changing culture; and shifting participation away from small grants, **towards the mainstream.**

The concurrent review of Local Governance[5] faces the same challenges in ensuring that devolving power and decision making does not further increase inequality for communities of interest e.g. disabled people.

For disabled people living through a "Human Catastrophe" with rights continually eroded, the need to be heard and influence decisions is as acute as ever – harnessing disabled people's expertise to help shape a transformational PB framework is an excellent starting point.

> **"A cycle of exclusion prevents communities across Scotland from accessing disabled people's insights and expertise.**
>
> **Our participation is crucial if we are to truly tackle inequality"**

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[3] Review of 1st Generation Participatory Budgeting in Scotland, Escobar, Harkins, Moore, GCPH: https://pbscotland.scot/blog/2016/10/19/review-of-participatory-budgeting-in-scotland?rq=what%20works%20scotland%201st%20generation%20PB

[4] http://whatworksscotland.ac.uk/wp-content/uploads/2018/07/WWSHopeForDemocracyPBinScotland.pdf Page 333

[5] https://beta.gov.scot/policies/improving-public-services/local-governance-review/

Action Research: Community-led Evidence and Solutions

Community-led Action Research means supporting communities themselves to use their lived experience to decide on what to research and how, so they can evidence the need for positive change for their community.

GDA's core work is supporting disabled people themselves to identify barriers they face and work with power-holders to achieve solutions – so GDA members' experience and expertise is a major asset in in co-producing a robust PB framework for Scotland: our Community-led Action Research approach kept our members' expertise firmly at the heart of the project.

1. Collaborative research design

GDA's Drivers for Change steering group was supported by staff to:

- explore PB background and existing evidence
- Reflect and draw on own experiences of involvement in local communities vs a city-wide community of interest
- develop initial research questions, draft survey ideas and outreach plan
- identify necessary training and support
- Pilot draft survey and information with wider DFC network
- Finalise Survey and briefing materials based on feedback, and consultation with external researchers[6].

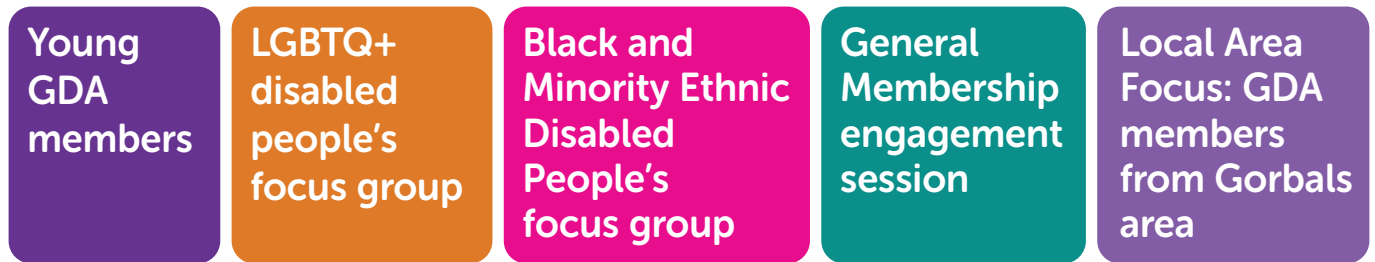## 2. Training and Capacity Building throughout project:

- In-depth PB familiarisation
- 3 x Research Skills workshops with Dr Richard Brunner from What Works Scotland (Interview skills; research ethics; reflective practice sessions)
- Facilitation skills
- Digital Skills
- Intersectionality Awareness
- Tailored briefing and support sessions ahead of researchers' engagement sessions
- Research Analysis principles

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[6] With thanks to Glasgow Caledonian University, Glasgow Centre for Population Health and What Works Scotland / Strathclyde Disability Research Centre

3. Outreach/Fieldwork

GDA's diverse membership of 4500 disabled people is a rich resource for engagement in our research. As well as sharing the survey at our general learning events, we convened 5 specific focus groups within our membership:

Young GDA members	LGBTQ+ disabled people's focus group	Black and Minority Ethnic Disabled People's focus group	General Membership engagement session	Local Area Focus: GDA members from Gorbals area

To get a more general cross-section of the disabled population of Glasgow, we had to look beyond GDA's members, who all receive regular communications, support, information and engagement opportunities, by being part of GDA. As well as sharing the survey widely online, DFC members were supported to identify participants within their own networks and other groups and organisations they were aware of.

Mental Health Network	Capability Scotland Junction 52 Centre	Possobilities, Possilpark	Flourish House

Capability Scotland Service User Network meeting	Interfaith Glasgow's 'One Big Picnic' event on George Square	People First Glasgow	Glasgow Gladiators Powerchair Football club

4. Researchers' Debrief and Reflection

Further support from What Works Scotland to reflect and share learning on the challenges and successes of the research process; what the researchers had gained and learned from the experience; and how our approaches shaped the body of data we collected.

I've gained a lot of confidence- it felt good to demonstrate what disabled people are capable of.

It was like a dam getting unleashed: I was blown away by how desperate people were to be listened to about their issues.

I'm even more aware now of the scale of these problems – it's not just me in my area, the barriers for disabled people are the same everywhere.

Social Isolation: some limitations of our data

Our Action Research methodology supported researchers to use their own networks as a starting point to gather responses and conduct interviews. Our actions researchers found this enabling and empowering but one consequent bias in our data is therefore, that respondents **were almost all already connected to a community of disabled people**: either as a member of GDA, or another disabled people's organisation or service, or through being known to a GDA member. While our participants still reported high levels of frustration and disempowerment, the proportion who have connected with accessible, supported opportunities to get involved and be listened to is inevitably skewed upwards because of this approach.

Many GDA members tell us that before joining GDA - where access, transport and support are guaranteed - they had not left the house for a long time - even years. For some of our members, GDA events are still the only time they are able to leave the house, as their **needs for support, transport and access are not being met elsewhere in their lives**.

While we took steps in this short project to engage disabled people beyond our 4500+ membership, an unknown proportion of Glasgow's 150,000 disabled people remain acutely isolated with scarce access to information.

5. Participatory analysis, write-up and dissemination

Through our 243 responses and copious notes from discussion groups, our researchers gathered a wealth of information about disabled people's experiences, views and priorities, to feed into shaping meaningful participation in PB in Glasgow and beyond.

- Through 4 wide-scale analysis workshops, initial emerging themes were identified, our researchers arranged anonymised qualitative responses into themes, and reflected and discussed their implications.

- Barriers were overlaid against solutions, and priority issues raised by participants were mapped against areas of decision making and potential influence.

- Through this process, key findings were debated and established, and recommendations mapped against existing PB policy with support from GDA Board and staff Team.

- Drivers for Change collaboratively gathered and analysed the evidence, developed recommendations, and had on-going input to and oversight of the final written report.

- To widen accessibility of our findings we have produced a short film to share the insights and key messages from our project.

- Ongoing capacity building will enable wider GDA members to continue the dialogue they have initiated, equipped with co-produced evidence and recommendations for removing barriers and enabling meaningful participation.

Our Findings

Do disabled people have enough say in how money is spent in Glasgow?

Across Scotland 80% believe people 'definitely or probably should be involved' in decisions about how services are run and how budgets are spent.

People in more deprived areas (where there are higher numbers of disabled people) were more likely to say they:

- **would like more say in how things are run**

- **would take part if it were easier to do so**

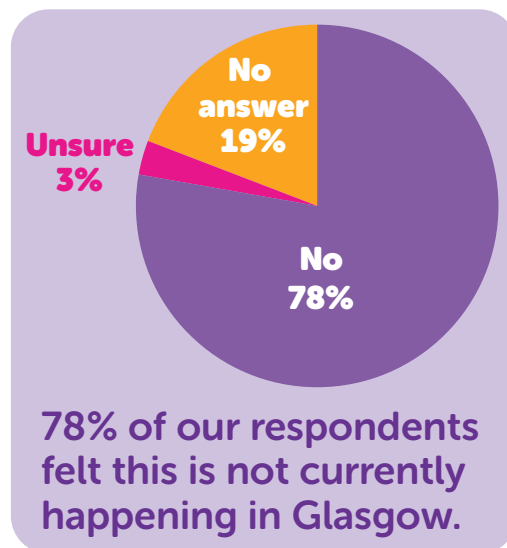Disabled people were even more likely to say they 'definitely' should be involved.

75% had never heard of Participatory / Community Budgeting before taking our survey.

No answer 19%

Unsure 3%

No 78%

78% of our respondents felt this is not currently happening in Glasgow.

Some had heard of specific projects run in different areas of Glasgow, but only 7 had been involved – with mixed results:

- "Our womens' group applied for funding with Spirit of Ruchill. It was a really good event, and now I attend all the Spirit events."

- One group had twice failed to win enough votes for their art group, but **workers intervened to prioritise and secure other funds for them**.

- Another had tried unsuccessfully to get £100 through their local participatory budgeting project, to seedcorn their idea. They told us they felt the system was unfair as they were 'up against people who had marketing skills: *"The system is skewed in favour of people who are confident speaking up already".*

- One described it as a *"daunting ordeal for only a small pot of money - I was terrified having to go up and speak to all these people – then I never got the money."*

The cycle of exclusion

To paraphrase What Works Scotland[7]: "The Inequalities faced at large in society" are often the very things which prevent people from taking part in decision making and engagement – this very much rings true with our respondents' experiences.

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[7] http://whatworksscotland.ac.uk/publications/hard-to-reach-or-easy-to-ignore-promoting-equality-in-community-engagement-evidence-review/

How easily can disabled people take part in things in our local areas?

71% Sometimes difficult, quite difficult or very difficult to take part in things in my local community.

Less likely to be working, volunteering or looking for work.

More likely to be receiving support at home (through family or paid support)

There's nothing accessible in my area.

I can't get out or travel without support and I have none.

I'm not part of my community.

13% Quite easy to take part e.g. through GDA or another Disabled Person's Organisation but still face significant barriers.

I take part in my local club because transport is provided.

Depends what it is and how you get treated – GDA is always accessible.

...but sometimes I'm afraid to leave home as I have troublesome neighbours.

6% Very easy to take part.

Already active and connected in their community, working or volunteering in housing associations or community councils, chairing committees

Easier access to information and opportunities, as well as the **confidence, skills and self-belief** to take them up and speak out.

I feel comfortable speaking out at meetings etc as I have spent time as an adult tutor.

Through my volunteering I can access information easily e.g. about budgeting events.

Years of community involvement developed my skills.

10% No answer.

Across Scotland **70% of people have taken part** in an activity to register their views on an issue… (2015 Scottish Social attitudes survey)

In contrast, of our respondents **62% had never taken part** in decisions about local issues or had tried unsuccessfully.

Of the rest, half said they had taken part:
- Only through GDA or another disabled people's organisation
- Only in decisions about their club or housing association
- Only by voting in local elections
- Or only before they became disabled.

No connections, no info

66 Don't know what is happening.

No idea how to get involved.
Don't know who to contact.
I've never been asked.
Most information is not accessible and we don't know where to find it. 99

Structural Barriers

66 It's hard to engage when your health is poor and you don't have the care or support you need, to enable you to participate.

We can't take part because we can't get out

Events rarely cater to disabled people. So often held in old inaccessible buildings – staff can be impatient or unaware of wider access issues like hearing loops, quiet spaces. 99

Stigma and low expectations erode confidence

66 Not enough disabled people are encouraged to put forward ideas.

They presume we don't know what we're talking about.

Seem to think disabled people can't make a difference to this city and our lives.

We get made to feel as if, being disabled, we aren't clever enough to have any thoughts or opinions of our own.

Disabled people are treated differently – with no respect.

There is a real shortage of disabled role models in positions of power to change things or inspire others with confidence. 99

How much do you feel you are listened to?

76% A little or not at all

13% Some of the time

11% A lot or all of the time

"Inequality does not stop at the door"

Even the few who felt they could take part easily felt their contributions often went unheard and unheeded.

Many who felt listened to 'sometimes' explained: 'Only at GDA' or another disabled people's organisation, or 'If my sister speaks for me then I'm taken seriously'.

The right support, the right attitudes and access throughout are vital.

'Hard to Reach' or 'Easy to ignore'?

What Works Scotland warns that groups facing acute inequalities are **'easy to ignore due to the complexity of their situation and the difficulty of reaching solutions'.**

This very much rings true with the experiences reported by our respondents who felt:

"Disability isn't popular – we seem to be a low priority."

"The cost of involving us puts them off – decision makers have bad stigma that disabled people are expensive - they don't see us as an asset or an investment."

"It's hard for others to listen to you about meeting the needs of others, like benefits etc – there's so much stigma."

Despite this, disabled people strongly believe in the difference their expertise could make to equality in Glasgow. Despite low awareness of 'PB', disabled people deeply understand and live the principles:

"It's obvious when disabled people's voices aren't being heard because needs are not met e.g. housing and transport. Disabled access has got worse instead of better."

"We need active participation at all levels in the decision making process, in equal partnership with the decision makers."

"Help lives improve by giving people some choice / power."

If we had more say on how the money is spent in Glasgow:

"…people's lives will improve financially and would lead to better health."

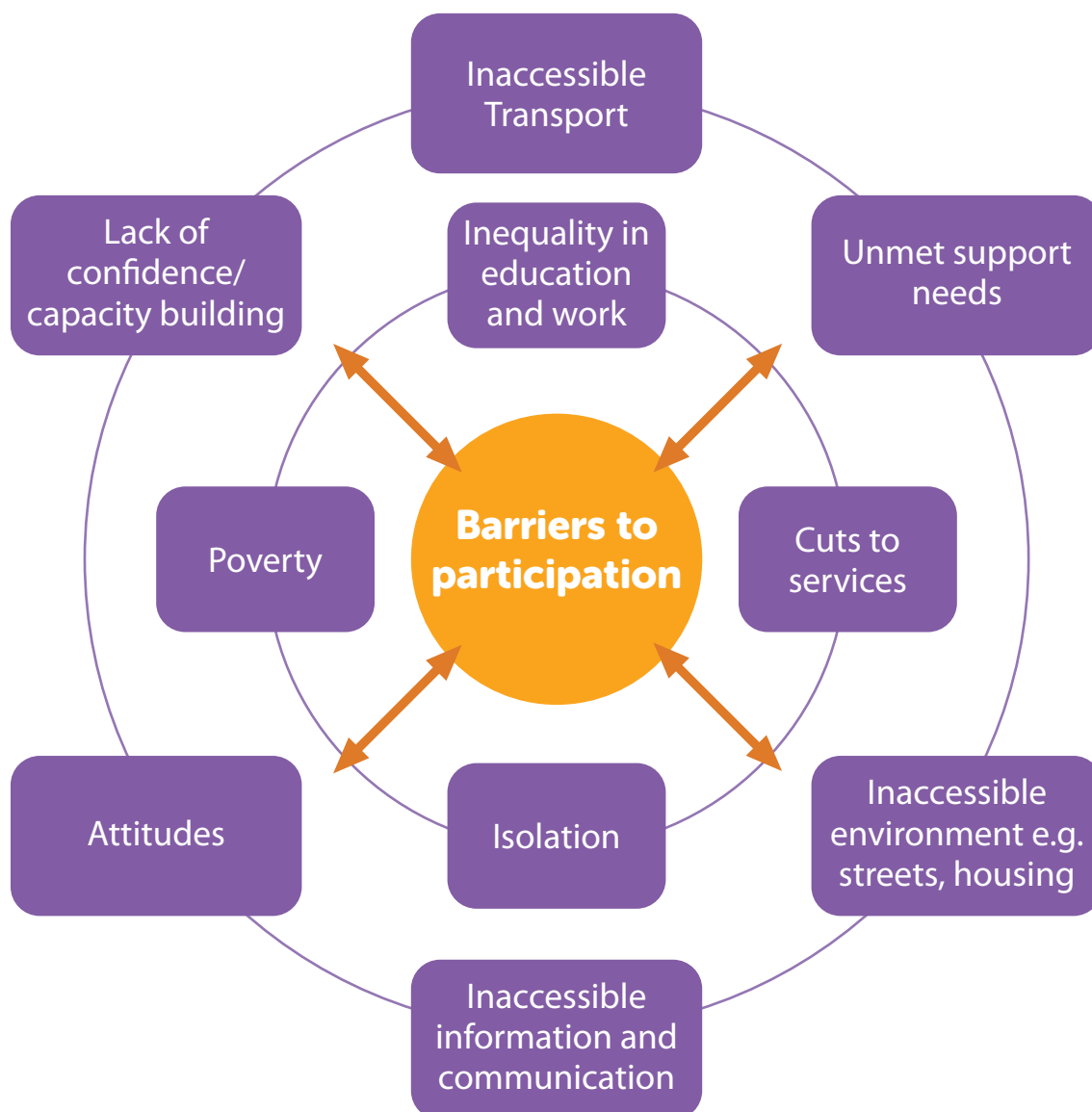*"…money would be spent on accessible amenities and making transport accessible to disabled people in Glasgow."*

"…we'd be able to live and work like any other person, whereas now we are suffering from the impact of poor accessibility and lack of budgets for support."

So what are the barriers and what can we do about them?

What Works Scotland recently reported: **"Inequalities faced at large in society (education, confidence, resources, disability) often constitute the key barriers preventing people taking part in community engagement processes in the first instance."**

It is not surprising, then, that **the barriers our respondents face to participating and being heard, are the very same things which they said they would prioritise if they had more say over spending and decisions in Glasgow.**

In other words, removing barriers to participation is essential so disabled people's expertise can be harnessed to solve deep rooted inequalities across our city.

Inaccessible Transport

Lack of confidence/ capacity building

Inequality in education and work

Unmet support needs

Poverty

Barriers to participation

Cuts to services

Attitudes

Isolation

Inaccessible environment e.g. streets, housing

Inaccessible information and communication

These myriad barriers are preventing communities all across Scotland from accessing and benefitting from disabled people's skills, knowledge and expertise.

"Recognise the skills we have. I have lived as a disabled person 24 hours a day, 365 days a year, I don't clock off at all: I have gained a lot of knowledge over the years. I am an asset."

Transport

Transport was cited 217 Times across our 243 responses – both as a barrier and as a solution to inclusion – in local decision making, as in all other areas of life.

Glasgow City Council's Strategic plan recognises that the provision of accessible, affordable **transport is fundamental** for people to access all other services and opportunities.

The **unique barriers disabled people face using public transport** affects our access to employment, benefits advice, healthcare, sport and leisure, social connections – and of course to opportunities to have our views heard and shape decisions.

What do these barriers look like?

- Too few wheelchair spaces on buses and trains.
- Limited access to underground and train stations.
- High cost of accessible taxis is very limiting.
- Community groups and services have no budgets for transport.

"I can't take part because I can't get there. I'm not an independent traveller – I need someone to take me."

"I frequently wait an hour or more 'til a bus comes by that I can get on. Buggies or shopping in the wheelchair space - drivers don't always intervene. Disabled people chained themselves to buses in the 1990's - why is this still happening in 2018?"

Benefits cuts exacerbate barriers

Disability Benefits including Disability Living Allowance and Personal Independence Payment are intended to assist with the extra costs of being disabled – while public transport requires a wholescale overhaul to eradicate barriers, many disabled people rely on taxis or accessible cars to get around.

But with the roll out of PIP seeing huge cuts in disabled people's entitlements, an estimated 90,000 people have lost Motability cars across the UK.

The New Policy Institute[8] reported in 2016 that even the full complement of disability benefits (which fewer and fewer are receiving) falls short of covering the additional costs of being disabled.

[8]https://www.npi.org.uk/publications/income-and-poverty/disability-and-poverty/

Solutions:

If disabled people had more say over budgets, what would you prioritise?

Our ideas

"More free accessible transport provision by community groups and services."

"More space on buses and trains."

"More accessible train stations and underground!"

"Better transport information – not just online."

"Projects to help people travel independently – like travel buddies."

"Taxi-card scheme like in Edinburgh."

Local Solutions

Ensure enough resources to cover transport costs as a core access need for disabled people's participation.

Mainstream Solutions

Involve disabled people in transport decisions and planning: setting and progress accessibility targets.

Support

Support was a strong determining factor in disabled people's ability to participate in all aspects of life including community involvement.

- The need for support was mentioned by **over two thirds of respondents**.

- **67% of those who find it 'very hard' to take part in things depend on some form of support at home.**

- Many others cited unmet support needs as the major barrier for them.

*"I can't get to things or communicate without support and I have no support."*

"The only time I can go out is to GDA, because they always have a PA to provide personal care if you need it."

"It is rare to get support to fill in a big form or consultation or to understand the issue in the first place."

"Are disabled people listened to? With Social Work definitely not. I can't even choose what time I go to bed, never mind what happens in my local community."

- **Audit Scotland** found that rights to Choice and Control in Social Care (Self-Directed Support) have stalled, as budgets reduce and demand keeps rising.

- The UN reported that **local authorities do not have adequate ring fenced resources** to meet their duties and uphold rights to Independent Living, under the UNCRPD.

- **Scotland's care crisis** is a huge gap we must bridge on our journey to a fairer, more equal Scotland, where all citizens can participate.
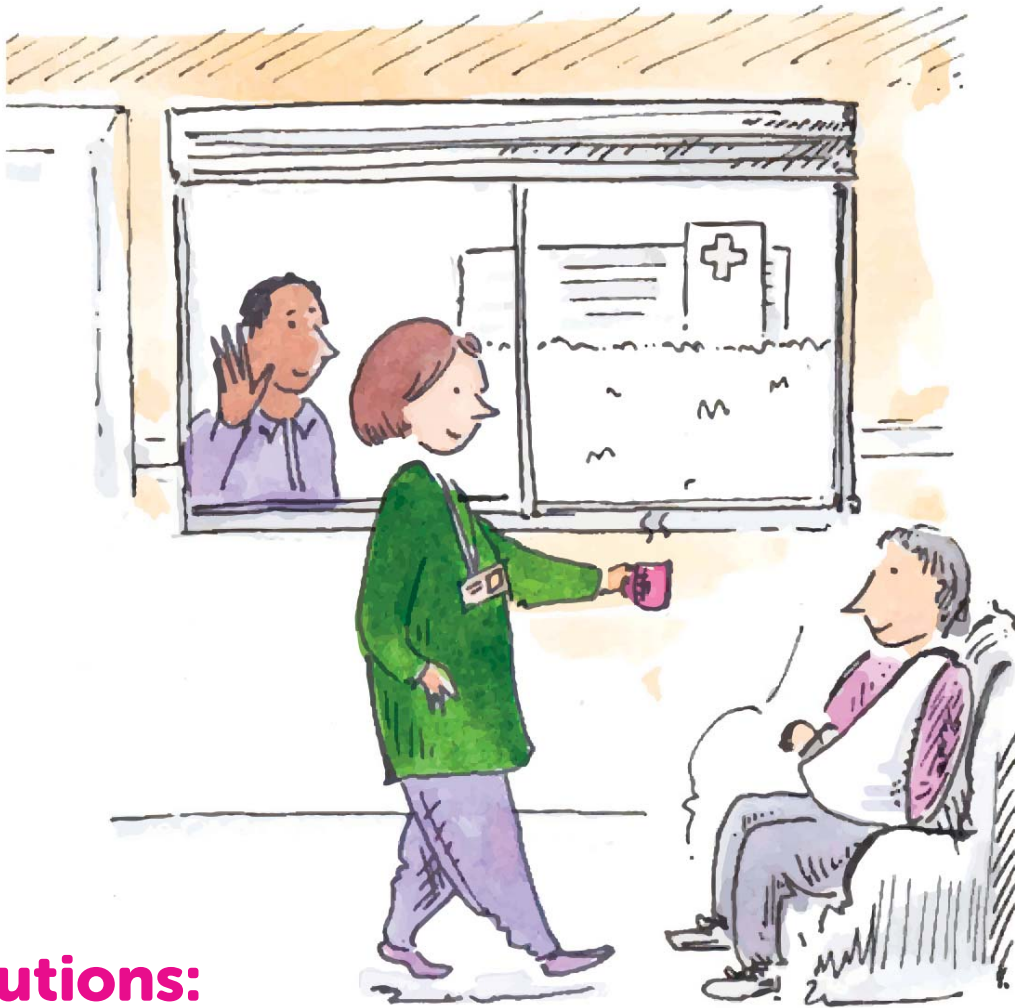
Solutions:

If disabled people had more say over budgets, what would you prioritise?

Our ideas

"More support for the folk who are isolated and can't get out themselves."

"Good budgets for care packages."

"Support and care packages that allow people the choice to live and have the same opportunities as others."

Local Solutions

- **Ask participants** what support needs they have.

- **Ensure resources to provide enough support** including a personal assistant at meetings or events if required.

- Use our Rough Guide to help ensure your **events are organised in an accessible way** – this will minimise many support needs people have. (See Page 42).

Mainstream Solutions

- **Work with disabled people to build solutions to Scotland's Care Crisis.**

- **Involve disabled people in planning health and social care services** including budget and strategic commission decisions.

- Explore solutions to **ringfence social care funds** to guarantee basic rights.

Accessible environment

Our 243 respondents gave over **400 examples of barriers in the physical environment** that stop them from taking part and being heard at all stages of the process: from getting to events, to getting in, participating, or even just getting out of their own homes. Extensive physical barriers came through as key priorities which disabled people would address, if they had more say over resources.

It was felt strongly that these barriers would be best addressed with disabled people's involvement.

Streets, pavements, public spaces

"Dropped kerbs are my lifeline – stop people parking on them!"

"Potholes and badly laid out streets take away my independence."

"More seats and benches in public places – I can't walk very far."

"More accessible public toilets."

Any non-disabled person taking a simple walk with someone with a mobility impairment quickly realises why disabled people need to be involved in planning our road and pavement layout and maintenance.

Buildings, services, events

"Accessible toilets should be standard, everywhere. How can I take part if there is no loo I can use?"

"Events rarely cater to disabled people."

"Doorways, shop counters, even some lifts are inaccessible. Nothing is designed with us in mind."

"Most places I can't get into."

Involving disabled people is the best way to ensure access needs can be understood and met.

Housing

"Disabled people are not listened to because we can't get out our houses."

"Impossible to get adaptations you need. They seem to think it's fine for me to crawl to the toilet!"

"My biggest barrier is getting out of my house."

One respondent has waited 19 years for an accessible house. Asked about PB she said *"Money should be distributed by reps from the disabled community who know our needs. Regarding disability issues we need a strong voice."*

Solutions:

If disabled people had more say over budgets, what would you prioritise?

Our ideas

"Accessibility across the city: Roads, kerbs, potholes, street clutter, lighting, parks, buildings, businesses - so we can go places like everybody else."

"Enforcement against parking on dropped kerbs – would bring in a fortune!"

"More accessible housing for disabled people."

"Better access to housing adaptations when they are needed."

"Training community workers to make their activities more accessible."

"Grants for businesses and services to become more accessible."

Local Solutions

- Involve disabled people in planning your event; use our Rough Guide (appendix 1) to ensure your events and services are as accessible as they can be!

- Take up access audits from Glasgow Access Panel and other disabled people led organisations – then broadcast your accessibility information!

Mainstream Solutions

- Involve disabled people in planning and decisions on public realm and housing (including new builds, allocations, adaptations).

- Involve disabled people in reviewing how procurement and the public sector equality duty could support accessibility improvements.
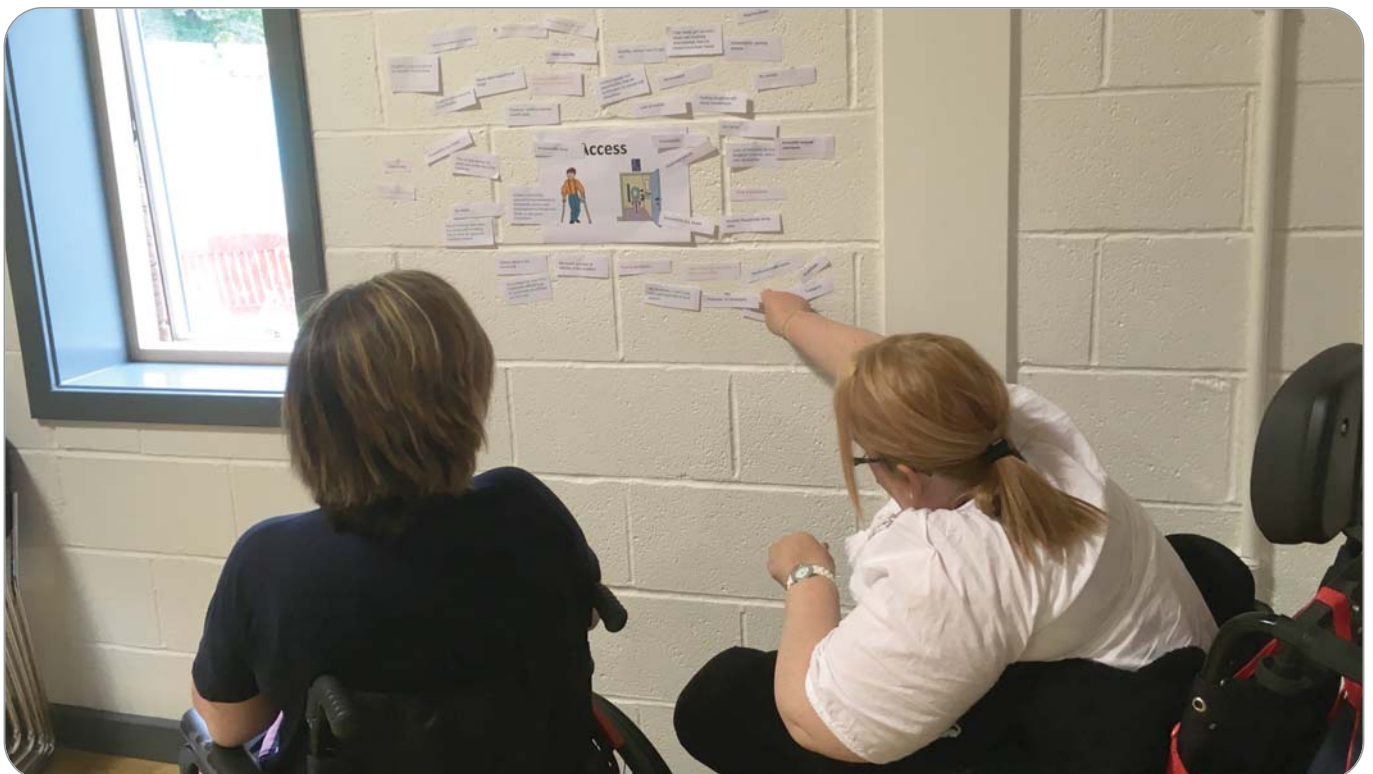
Information and Communication

Another barrier very commonly raised was the lack of information about where or how to get involved, or who to contact to share your views or seek assistance. A huge majority of respondents cited insufficient information as a barrier to taking part and being heard.

The Digital Divide:
In 2016 across the UK, 25% of disabled adults had never used the internet compared with 10% of the general population.[9]

"We can't have our say because most information is not accessible."

"A huge barrier is finding out about things in the first place – the meetings, the issues, what's happening."

"Information can be hard to understand or you don't know where to find it."

Solutions:

If disabled people had more say over budgets, what would you prioritise?

Our ideas

"More information about what help and support is available – not just online but everywhere."

"More accessible information about our rights and what is happening: easyread, audio, braille, large print."

"More hearing loops – BSL and notetakers provided when needed."

"Help with my computer at home."

Local Solutions

Ensure **basic accessibility standards** in all printed materials and offer alternatives.

- Size 14 sans serif font as standard.
- Horizontal text left aligned against plain background with adequate contrast – do not justify text.
- Leave white space.
- Use bullet points, sub headings and plain English.
- Where possible, use supporting images.

For more info about producing audio, braille and easy read, contact The Scottish Accessible Information Forum: www.saifscotland.org.uk.

Mainstream Solutions

- Work with disabled people to develop thorough networks for regular, clear communications - through services, groups, Council newsletter etc.

- Involve disabled people in Digital Inclusion strategies.

[9]https://www.ons.gov.uk/businessindustryandtrade/itandinternetindustry/bulletins/internetusers/2016

Attitudes

Negative attitudes and lack of understanding from others were described by many as a major barrier to taking part and being heard: in communities, wider society, and in discussions with power holders.

"No one listens to me on my own – if someone talks for me then I'm taken seriously."

"Worrying about how I will be treated stops me taking part. In the past I've been made a fool of for not getting stuff right."

"Nobody cares about a disabled guy in my community."

"Decision makers lack understanding of disability issues and have bad stigma that disabled people are expensive. They don't see us as an asset."

"We are overlooked - They presume we don't know what we are talking about."

"In the shop they speak to my carer and ignore me. I don't have a voice in this community."

"I don't feel safe going out - I have troublesome neighbours."

Hate Crime and Harassment towards disabled people have risen steadily in recent years and are still vastly under reported. **15 of our respondents mentioned feeling unsafe** going out as a major barrier to taking part.

Solutions:

If disabled people had more say over budgets, what would you prioritise?

Our ideas

"An awareness campaign so we don't feel like nuisances!"

"Training for a broader understanding of all our rights, equality, and access issues."

"More disabled people as role models in positions of authority."

"More resources for tackling Hate Crime."

"More visibility, more air-time - disabled people employed in council and making smart decisions on how funds are spent."

Attitudes: what helps?

- Feeling welcomed and invited, being respected and included, feeling my opinion matters.

- If my neighbours treated me with respect, not judging me.

- Elected representatives who take the time to listen and understand our issues.

- When events or groups specifically advertise welcoming disabled people. This reassures me people will understand if I need to ask for assistance, so I don't feel as anxious or intimidated trying to attend things.

Local Solutions

- Intersectionality / Diversity and Equality training for all PB stakeholders and decision makers, led by those with lived experience.

- Use safe space approaches to enable marginalised voices to build confidence and contribute lived experiences.

Mainstream Solutions

- More disabled people in leadership roles – boosting accessible opportunities for work learning and progression.

- Build shared awareness of rights and equality issues, through disability equality training.

- Boost disabled people's confidence, capacity, self-belief through lifelong learning, and accessible opportunities.
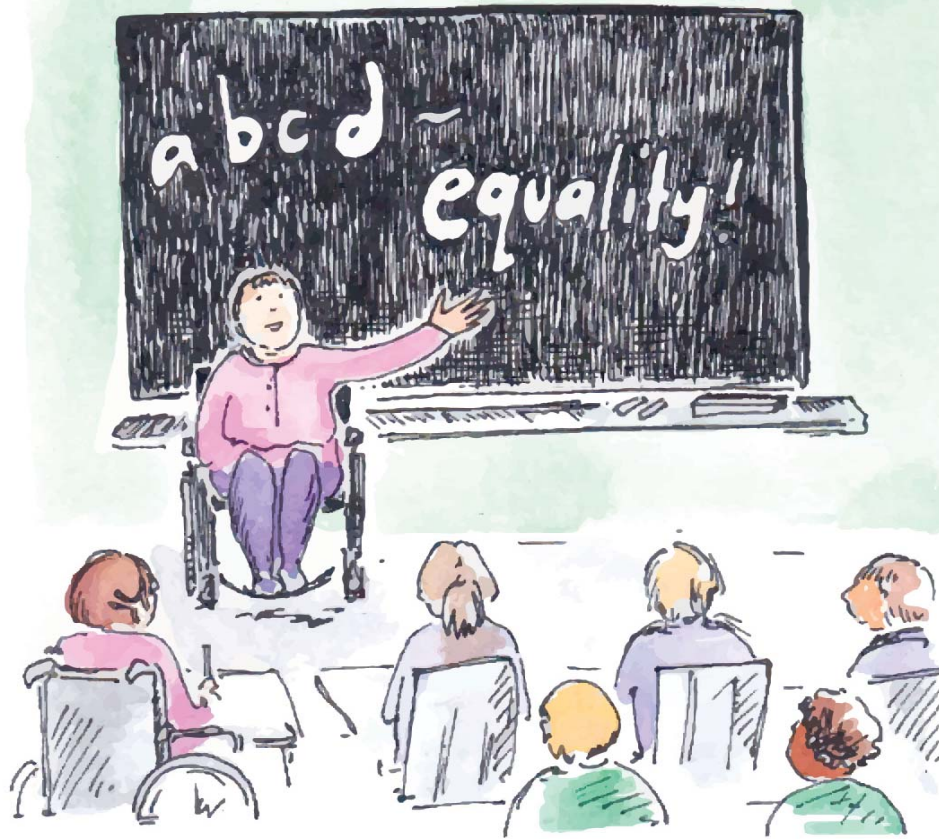
Equalities-informed participation

The scale and pervasiveness of negative attitudes towards disabled people cannot be overlooked when planning PB going forwards. The lack of understanding and compassion disabled people experience day to day sparked considerable discussion during our fieldwork.

Many disabled people feel their rights are not upheld and interests are not served even by those whom they elect to positions of power.

There were huge concerns about the possibility that PB could see powers and money handed over – by default – to powerful community members who may well lack understanding or appreciation of their disabled neighbours' lives and needs.

"It is hard for people to listen to you about meeting needs of others - like benefits etc. People may not want to know about it."

Throughout our research project we took steps to continually support researchers' awareness of and reflection on the **multiple dimensions of inequalities and the silent prejudices we absorb from the unequal world we live in.**

GDA members felt that sensitive, informed and reflexive learning about **diversity, privilege and disadvantage** – in local communities and across the city – **should be an essential component of the capacity building required to support meaningful participatory budgeting** – and should be delivered where possible, by those with lived experience of barriers and discrimination.

Confidence, Capacity Building through Peer support and social connection

Hearing in-depth about some of the greatest barriers disabled people face day to day when trying to participate, have their say or just live their lives, it is not surprising that many said these barriers erode their confidence and self-belief.

Barriers in transport, the environment, unmet support needs, and negative attitudes all combine to exacerbate acute isolation felt by far too many disabled people on a daily basis.

Adults who are disabled or have long term conditions are twice as likely to report severe loneliness.[10]

"Disabled people of all ages don't know what their rights are – that has to be the starting point, for people to believe things can change, and their lives can be better."

"I don't have the confidence to go places on my own or speak out."

"When you've never had choices your whole life, you need a lot more support to say what you think – to find out your rights and what your options are."

Solutions:

If disabled people had more say over budgets, what would you prioritise?

Our ideas

"Funding for groups run by disabled people, who understand what people are asking for."

"Projects to help people build up confidence and independence."

"More money for peer support groups."

"More places and opportunities for disabled people to meet and feel part of a community together."

Local Solutions

- For meaningful participation, essential capacity building must include raising aspirations, self-belief and awareness of rights.
- Connect with user-led groups in local areas Build-in safe space approaches.

Mainstream Solutions

As UN recommends, work with and resource disabled people led organisations to provide peer support and capacity building, for a strong collective voice.

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[10] Teuton J. Social isolation and loneliness in Scotland: a review of prevalence and trends. Edinburgh: NHS Health Scotland; 2018.

Self Segregation or Safe Spaces?

Some community power holders challenged our researchers to justify why disabled people should have our own meetings or events, suggesting this was divisive, assuming that disabled people don't join wider community events because they cannot be bothered or are not interested.

Our research clearly demonstrates that disabled people try very hard to take part in things in their local communities – often finding their efforts thwarted.

GDA members and our respondents testify that peer support - connecting with people 'in the same boat' 'who don't judge you' or make you feel 'other' - is absolutely essential for people's confidence and capacity building.

Solutions:

- **awareness raising of the scale of barriers and structural inequalities** faced: without checks and balances, traditional community power holders may easily dominate and exclude others.

- **convening safe space discussions with equalities groups within a given place** (locally or regionally) where possible led by people with lived experience.

GETTING TO KNOW EACH OTHER BETTER – MEANS WE SUPPORT EACH OTHER.
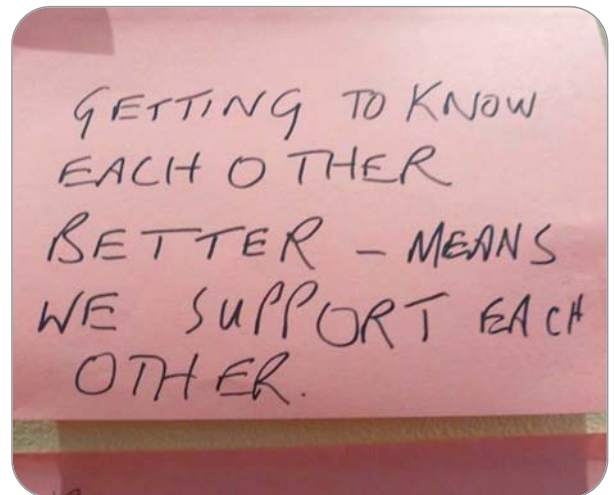
Peer support is essential to quality deliberation and enabling contributions of marginalised groups. It enables people to name their experiences, recognise oppression, develop understanding of their rights and tools for claiming them - including, most fundamentally, the right to expect and demand better treatment and envision a better future. GDA itself is testament to the power of peer support for enabling a flourishing dialogue and affirming energy.

Tackling poverty – of income and opportunity

Poverty and an acute lack of accessible opportunities are tightly entwined with all other barriers described in this report.

As well as stopping disabled people from participating and being heard, poverty contributes to isolation, eroded confidence, poor mental and physical health, inability to access other services, food, childcare or essential equipment.

Participation in decision making develops skills and opens doors – but for disabled people, while structural inequality persists, progression is thwarted. Enabling disabled people's participation and reducing their poverty go hand in hand with improving access to:

- Welfare rights and financial inclusion.
- Employment, training, volunteering and learning opportunities.
- High quality inclusive education, attainment and progression from school.
- Social Care and services to support disabled people.

Disability, poverty and participation

48% of everyone living in poverty in the UK is either disabled, or in a household with a disabled person.

At the root of this is the disability employment gap, the skills gap, low pay, extra costs, and social security cuts.

To reduce poverty overall, a concerted focus is needed on removing the barriers that cause disabled people's poverty.

Joseph Rowntree Foundation and New Policy Institute 2017[11]

[11] https://www.npi.org.uk/publications/income-and-poverty/disability-and-poverty/

Solutions:

If disabled people had more say over budgets, what would you prioritise?

Our ideas

"More support and advice with the benefits system."

"Reduce disabled people's poverty by improving job opportunities and a living wage."

"Abolish universal credit as it makes life harder for disabled people."

"More opportunities for meaningful work, volunteering and learning, with the access, flexibility and support we need."

Local Solutions

Inclusive deliberation equipping communities with **evidence and knowledge of rights and inequalities and areas of unmet need:** to co-produce outcomes that reflect diverse needs of the community.

Mainstream Solutions

- Mainstream participation of disabled people in core services including employability, education, Community Learning and development, financial services, social work services and social care (particularly care charges).

- Consider cumulative impact of austerity for disabled people.

Mitigating cuts to frontline services

In addition to highlighting lack of support as a priority issue, a significant number of our respondents said that if given more say over spending decisions, they would like to see funding realigned into core services which have seen enormous cuts in recent years: in particular Social Care, and Mental health services.

"Participatory Budgeting in Scotland: The Interplay of public sector reform, community empowerment and Social Justice" [12] warns of the risk that PB could be used as a tool to administer spending cuts and disabled people felt strongly that they should not have to compete for votes to resource vital services which they need to live their lives - services which are essential to deliver human rights.

Embedding disabled peoples' participation in mainstream budget planning is crucial if we are to achieve Christie's vision of improved participation, partnership, prevention and performance, address inequalities and improve life outcomes.[13]

Solutions:

If disabled people had more say over budgets, what would you prioritise?

Our ideas

"More support for folk who've got no one."

"Put those 60 hours back in my care package."

"Not enough Mental health services for adults or young people."

"Fund social care which we need to access all other rights."

Local Solutions

Inclusive deliberation equipping communities with **evidence and knowledge of rights, inequalities, and areas of unmet need:** to co-produce outcomes that reflect diverse needs of the community.

Mainstream Solutions

- Mainstream participation in core services including Social Care and Integrated Joint Board decision making
- Involve disabled people in meaningful Equality & Human Rights Impact Assessments as part of deliberative democratic process.

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[12] http://whatworksscotland.ac.uk/wp-content/uploads/2018/07/WWSHopeForDemocracyPBinScotland.pdf Page 332
[13] https://www.gov.scot/Publications/2011/06/27154527/0

Conclusions:
Headline findings

1 **Disabled people overwhelmingly want to be involved in deciding how public money is spent** but are prevented from doing so by a web of complex barriers.

- Disabled people want to be involved in decision making at all levels, from ward to Westminster - but **overwhelmingly prioritise the need to participate in and shape decisions about mainstream services.** Disabled people's lives are disproportionately affected by mainstream services decisions – housing, planning, education, social care. Our **unique insights** into what works well, what doesn't and what needs to change are **crucial to reducing inequality and improving our public services.**

- Disabled people actively want to be involved in local PB and decision making alongside other local residents. However, due to inequalities and multiple barriers, they **will need extra support - information, access and capacity building – to level the playing field and ensure their participation.**

2 **A cycle of exclusion prevents communities across Scotland from accessing disabled people's insights and expertise.** The barriers which cause our inequality are the same barriers which prevent us taking part in decisions that could address it. Removal of these barriers is what disabled people would prioritise if given more say over resources:

- physical barriers: inaccessible transport and built environment
- unmet support needs
- poverty
- inaccessible and inadequate opportunities for work or learning
- negative attitudes and a lack of understanding of our needs and rights
- consequential isolation and corrosion of hope and confidence
- overwhelmingly feel they have no voice and are not listened to

3 **Structural inequality cannot be addressed at the local level alone: wider culture change is essential if participation is to have meaningful impact** – GDA members have been speaking out about barriers and how to improve services for many years, yet remain broadly disempowered across their lives: without resource realignment and a willingness to do things differently, barriers persist and outcomes remain the same – or get worse.

Headline Recommendations

A transformative, deliberative PB framework designed to tackle inequalities could be the lever we need to truly amplify the expertise of those who would otherwise be unheard. Removing barriers to disabled people's meaningful involvement in PB requires wider culture change to tackle the barriers we face across society starting with:

Planning and Design:

1. **Work with communities of interest (e.g. disabled people) as well as communities of place to set Equalities Outcomes for PB at local, regional and national levels:** Lived experience is key to build solutions and improve lives. A focus on poverty and income inequality alone will be insufficient to tackle the nuanced, multiple inequalities faced by disabled people and other equalities groups.

2. **Ensure sufficient resources and timescales to remove barriers** including transport, support and accessible information.

3. Build capacity of PB stakeholders through **disability equality training:** raising awareness of rights and broader equalities issues.

4. Uphold a clear focus that the **purpose of PB** is not only working collaboratively to make the best use of resources but is **above all to improve people's life outcomes:** use Equality and Human Rights Assessments to transparently measure progress.

Delivery:

5. **Identify and involve** those who are easily ignored including disabled people: connect with equalities led organisations to redress imbalances.

6. **Empower and actively encourage marginalised voices: create space** for equalities groups to contribute lived experience to the process: Build in accessible, thematic, safe-space approaches to participation in local PB projects.

7. **Enable deliberation** to build all stakeholders' understanding of human rights and Equalities issues, to coproduce outcomes which reflect the diverse needs of the community.

Learning and Culture Change:

8   **Embed a "test and learn" culture** within and between organisations from leadership to delivery which cultivates confidence to listen, do things differently, take 'risks', and learn from mistakes as well as successes.

9   **Resource communities of interest** e.g. disabled people led organisations to build capacity of equalities groups to participate in PB locally and city wide.

10   As PB evolves to explore mainstreaming, **test out new methods and approaches to embed disabled peoples' participation in decisions about mainstream services,** using Public Sector Equality Duty as an enabling framework including: transport, housing, urban planning, education, employability, health and particularly social care.

Solutions:

	Local Solutions	Mainstream Solutions
Transport	• **Include transport costs** as a core access need for disabled people's participation.	• **Involve disabled people in transport decisions and planning:** setting and progress accessibility targets.
Support	• **Ask participants** what support needs they have. • **Ensure resources to provide enough support** including a personal assistant at meetings or events if required. • Use our Rough Guide **to help ensure your events are organised in an accessible way** – this will minimise many support needs people have.	• **Work with disabled people to build solutions to Scotland's Care Crisis.** • **Involve disabled people in planning health and social care services** including budget and strategic commission decisions • Explore solutions to ringfence social care funds to guarantee basic rights.
Accessible Environment	• **Involve disabled people in planning your event;** follow our Rough guide to ensure your events and services are as accessible as they can be! • **Take up access audits from Glasgow Access Panel or other Disabled People led Organisations** – then broadcast your accessibility information!	• Involve disabled people in planning and decisions on public realm and housing (including new builds, allocations, adaptations). • Involve disabled people in reviewing how procurement and the public sector equality duty could support accessibility improvements.
Information and Communication	• **Ensure basic accessibility standards** (see page 28) in all printed materials. • Offer alternative formats (for more info about producing audio, braille, easy read, contact The Scottish Accessible Information Forum www.saifscotland.org.uk)	• Work with disabled people to develop networks for regular, clear communications - through services, groups, Council newsletter etc. • Involve disabled people in Digital Inclusion strategies.

	Local Solutions	Mainstream Solutions
Attitudes	• Intersectionality / Diversity and Equality training for all PB stakeholders and decision makers, led by those with lived experience. • Use safe space approaches to enable marginalised voices.	• More disabled people in leadership roles. • Involve disabled people in strategy and decisions. • Build shared awareness of rights and disability equality training. • Boost disabled people's confidence, capacity, self-belief through lifelong learning, and accessible opportunities.
Capacity Building and Peer Support	• For meaningful participation, essential capacity building must include raising disabled people's aspirations, self-belief and awareness of rights. • Connect with disabled people-led / peer led groups in local areas, and build-in safe space approaches.	• As UN recommends, Work with and resource disabled people led organisations to provide peer support and capacity building, for a strong collective voice.
Tackling Poverty and Mitigating Cuts	• Inclusive deliberation equipping communities with evidence and knowledge of rights and inequalities, and areas of unmet need: to co-produce outcomes that reflect diverse needs of the community.	• Mainstream participation of disabled people in core services including employability, education, Community Learning and development, financial services, social work services and social care (re: care charges), Integrated Joint Board. • Consider cumulative impact of austerity for disabled people • Involve disabled people in meaningful EQIAs as part of deliberative democratic process.

Appendix 1: Rough Guide to Inclusive Engagement

The GDA quick-guide to making your events and services accessible to disabled people.

Our top tips for making things accessible to disabled people are…

Ask us!

Ask disabled people themselves what support they need in order to participate, and make sure that disabled people are involved in planning from the very beginning.

Let people know!

Tell us that it's accessible, or we'll assume that it's not.

nothing about us without us!

Transport:

Have you asked people about their transport needs? And have you got resources to meet those needs?

- Are you able to provide transport for people to attend? For many disabled people this is an essential for being able to take part in an event.
- Is there enough space for taxis to drop off at the entrance?
- Is there car parking at or near the venue for drivers?
- Is the venue well-served by public transport?
- Can you reimburse transport costs in cash on the day if people make their own way?

Support:

Have you asked people what their support needs are and thought about how you will meet them?

"Meetings need to go at a pace that we can follow."

A vital part of GDA's courses and events are the Personal Assistants (PAs) we have there on the day to help people with:

- Getting in & out of transport
- Finding a suitable seat or place at the event
- Reading, writing & taking part in activities
- Directions in and around the venue
- Getting refreshments
- Personal care

Have you thought about facilitation? Will there be plenty of time and support available to participants for understanding and having their say?

Environment:

Have you visited the venue yourself to make sure that it is accessible, or asked for an access audit?

- Entrance – is there level access? Do wheelchair users have to use a different entrance?

- Doorways – are doorways wide enough? Are there heavy doors which will be difficult for people to open without assistance?

- Lifts – are there lifts if rooms are not on the ground floor, and are they spacious enough?

- Toilets – is there at least one accessible toilet? Are the toilets all on one level and near the room/s being used?

- Layout – is there adequate seating for everyone? Are there tables for people to use? Is there enough space for everyone to move around comfortably?

- Lighting.

- Sound – is there a loop system, or can one be provided for the day?

- Are there rest areas and quiet spaces for people to use?

Information & Communication:

Have you asked people whether they will need information in an alternative format or communication?

"Because I don't get it in advance or in an accessible format, I can't properly take part in discussions and decisions and I can't keep up"

- Provide clear information in accessible formats; e.g. text in a minimum of 12 point sans serif font, and ideally 14 or 16 point; braille and audio copies of information available; information emailed in advance in plain text format.

- Make sure that information is available in good time so that people know what's happening and are equipped to take part.

- Use plain English.

- Book note-takers and BSL interpreters if required.

- Make sure that people can contact you via Contact Scotland BSL.

Appendix 2: Applying the National Standards for Community Engagement[14]

Inclusion
We will Identify and involve the people and organisations that are affected by the focus of the engagement.

Seek out disabled people and ask them how they want to be involved!

Support
We will identify and overcome any barriers to participation.

E.g. transport, support, accessible venues, personal assistance, capacity building.

Planning
There is a clear purpose for the engagement which is based on a shared understanding of community needs and ambitions.

Set goals which reflect the diverse needs and voices of the community.

Working Together
We will work effectively together to achieve the aims of the engagement.

Value disabled people's expertise, demonstrate respect and ensure barriers are removed throughout.

Methods
We will use methods of engagement that are fit for purpose.

Different people may need different approaches - be flexible and ask people what works for them!

Communication
We will communicate clearly and regularly with the people organisations and communities affected by the engagement.

Ask people what format of information they need and how they would like to keep in touch.

Impact
We will assess the impact of the engagement and use what has been learned in our future community engagement.

Ask disabled people for feedback - what works, what could be better? Were they able to participate fully and be heard? Were their voices reflect in the outcomes?

[14] http://www.voicescotland.org.uk/

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