



I've got cavers coming in so I'm up dressed and ready to go nowhere by 9am.  
 Its so frustrating that I can't get help to go out and do stuff

# Wisdom, Wit and a Whirl:

A Reshaping Care for Older People consultation

June 2013

# Thanks and Acknowledgements

Glasgow Disability Alliance would like to offer sincere thanks to the RCOP Strategy Group for funding the event and recognising the true costs of involving older disabled people and those with long term conditions; to the speakers who attended from the partnership on the day and took part in workshops meeting every participant; to the excellent PAs who supported older people to participate at the event ; to Brian for organising and briefing the PAs; to the fabulous staff and all who helped out on the day at Thistle Hotel Glasgow; to the wonderful and dedicated GDA Team members for their roles in planning the day, facilitating workshops and joining in the dancing; to Naheem and Alison- for dealing with bookings and access arrangements for participants; to Nick for assisting with PR and social media; in particular, to Noreen Malik for enthusiasm, energy and efforts in promoting the day and recruiting over 100 new older people to attend and to Linda Algie for outstanding organisation skills and planning the event with meticulous attention to detail. Thanks also to Marianne who managed to acquire some fabulous resources including access to a starlit curtain and candelabras. The GDA Team truly are creative and amazing!

A Special thanks to “That Swing Sensation” for providing the music and entertainment which made the day so enjoyable and for the donation which paid for this!

Above all, GDA wishes to thank all of the older participants for enthusiastically and honestly sharing their experiences, views, opinions and reflections. This is critical in assisting the Strategy Group and planning partners to move forward, taking these views and needs into account.

GDA is hopeful that services for older people can be reshaped and reformed, providing a safety net for those most vulnerable, working collaboratively with people and communities and prioritising preventative approaches: in turn these will alleviate pressure on public services. We hope that services and supports- from community, through social work, NHS and Care Home Sector will be inspired and informed by the wisdom of all the older people who took part in “Wisdom, Wit and a Whirl” .



A handwritten signature in black ink that reads "Tressa Burke". The signature is written in a cursive style.

**Tressa Burke, GDA Chief Executive**

# Introduction

Glasgow Disability Alliance (GDA) held *Wisdom, Wit and a Whirl*, a briefing and consultation event on the Reshaping Care for Older People (RCOP) agenda on Friday 14th June. 202 older disabled people and older people with long term health conditions attended. Discussions focused on the Draft Joint Strategic Commissioning Plan 2013-16, which was drafted by NHS, Social Work, private care providers and the Third Sector to plan improved services for older people in Glasgow. The event was an opportunity for the proposals to be tested with older people directly and this report summarises the views of older disabled people.



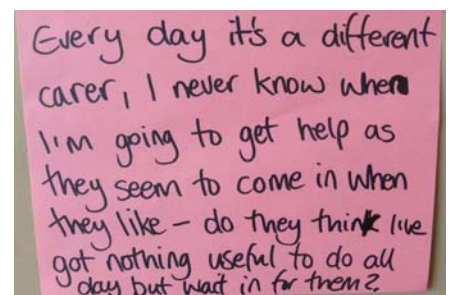
# What is Reshaping Care for Older People?

Reshaping Care for Older People is a Scottish Government initiative, designed to respond to our ageing population by changing the way health and care services are provided. People are expected to live longer in future, so we will have more older people than we do now. We therefore need to change the ways in which health and care services are provided for older people to make sure that their needs can be met in the way they would like and that the country can afford.

Reshaping care is about improving services for older people by shifting resources towards better anticipatory and preventative care, i.e. keeping older people healthier for longer and meeting their needs at home or in the community, rather than focusing on hospitals and residential care homes, where resources

are prioritised at the moment. This agenda requires a culture shift for services and for older people. There needs to be greater focus on increasing the resilience of older people, promoting social connections and participation in communities to reduce isolation and people of all ages need to take more responsibility for their own health.

RCOP is about shifting existing resources to meet future needs more effectively but there is a small Change Fund to help try out new services or ways of working, for example services which can support people at home or in the community and reduce the number of hospital admissions. These also focus on improving the resilience of older people to cope with challenges, by helping to build their social connections.



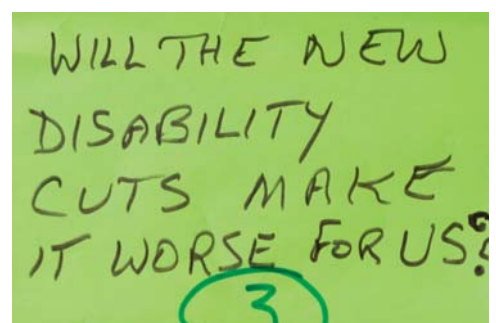
# Glasgow's Plan for Reshaping Care for Older People

The RCOP partnership in Glasgow has a vision of Glasgow being a great place for people to live and grow old safely and healthily. This means:

- Helping older people and their carers take responsibility for their own health so that people can stay healthy, active and live well, be independent, have choices and are fully involved and engaged in decisions that affect them.
- Ensuring that health, housing and social care is focused on those older people who are in greatest need because of their health, social and economic circumstances.
- Increasing the focus on prevention and anticipatory care to help people stay well.
- Delivering joined up, person-centred care.
- Building community capacity to make sure older people continue to contribute to care provision and wider society; and that there is greater community cohesion and a mutual care approach across generations and different sections of society.

## The key commitments in the draft plan are:

- Organisations working together to improve the health of Glaswegians in the longer term, and tackle health inequalities.
- Working with and listening to older people to produce new community services.
- Making sure that care is focused on the preferences, needs and values of the individual older person, giving them as much choice and control over the care they receive as possible.



- Doubling spend on preventative care by reducing resources allocated to hospitals and long term care home placements.
- Supporting older people to live at home for as long as possible, reducing the length of time people stay in hospital and developing new models of care in homely settings.
- Helping people make informed choices and plan ahead for their care needs, including Power of Attorney.
- Supporting the health and social care workforce to work in new ways to meet the needs of older people.
- Providing high quality, cost effective and responsive services which meet older people's needs within available resources.
- Taking stock of the impact of the changes made, learning from experience, with an annual report on progress towards goals.

**The partners see there being a number of benefits of the plan:**

- More older people will be cared for at home or in a homely setting, rather than in hospital.
- More older people will have a say in their care and support arrangements.
- Carers will have the support they need, for example information, training, respite and short breaks.
- Hospital beds will be available for those who really need hospital care.
- Better use of combined resources in Glasgow, by partners working together to deliver care and support to older people.



There are over 80,000 people aged over 65 living in Glasgow, around 15% of the population of the city. By 2033, the population of Scotland aged 75 and over is expected to increase by 85%, “Draft Joint Strategic Commissioning Plan 2013-16” Glasgow City Partnership, 2013. In addition, it is anticipated that the number of people aged 85 and over in Glasgow will increase by 10% over the next three years. There are also huge inequalities in Glasgow with healthy life expectancy in North Glasgow nearly eight years less than the national average, (“Let’s Make Glasgow a Great Place to Grow Old”, Consultation on Joint Strategic Commissioning Plan, 2013).

There are huge health inequalities in Glasgow. On average people suffer 11-12 years of ill health in their lives, far more than in other areas. Poverty continues to be a real challenge for older people in Glasgow, particularly for women, disabled people and ethnic minorities. More people aged 50 and over will also live alone. The social and health impacts of isolation and poverty are shocking. Researchers have established a strong link between social isolation and early death: it is even more dangerous to health than a lifetime of smoking.

*“Being lonely and isolated is not only miserable, it is a real health risk, increasing the risk of an early death. Disability, poor health, poverty and no access to transport all contribute to older people feeling cut off from their family, friends and local community meaning many older people have little or no social interaction. We all need to do more to bring older people into the heart of our communities.”*

Michelle Mitchell, Age UK, on research with 6,500 older people published by University College London, March 2013.



# GDA's role

Glasgow Disability Alliance is a membership-led organisation, with over 1800 individual disabled people and groups as members (at June 2013). GDA's mission is to act as the collective, representative voice of disabled people in Glasgow, promoting equality, rights and social justice. The organisation uses community development and human rights based approaches, supporting older and disabled people to be more resilient by being better connected to their communities and having more fulfilling lives. Activities include wide scale engagement, programmes of learning and development to build skills, knowledge & confidence and fulfil potential; providing information and signposting to services; policy development using voices of disabled people and working in coproduction – working together, working differently and being open to new ideas and ways of doing things.

Over recent years GDA has developed a Manifesto for Action on Independent Living, co-producing this with over 1600 disabled people and their organisations in Glasgow as of the 2013 version. 15 rights have been analysed as 'essential pillars' necessary for full and equal participation within society.

## **Our manifesto asks for:**

1. A decent income, (standard of living) including state benefits for those unable to work
2. Accessible and adapted housing
3. Personal assistance
4. Accessible and readily available information
5. Communication support
6. Advocacy and working towards self advocacy
7. Technical aids, equipment and technology
8. Inclusive education and lifelong learning
9. Equal opportunities for employment and training for work
10. Accessible and inclusive healthcare provision
11. Peer support including from disabled people and their organisations
12. Full access to our environment
13. Fully accessible and affordable transport
14. Full social, civic and judicial participation
15. Legal Rights and legal advice





Staff and members are involved in many partnerships and groups across the city to ensure that the views of disabled people are taken into account when developing and delivering services and policies. GDA believes not only that for policy and practice to truly change and improve, professionals must be informed and empowered but also, more importantly that the voices and experience of disabled people are essential in this process: they offer critical insights, analysis and solutions. Involving disabled people in service planning, implementation and evaluation is crucial for services to be more appropriate, effective and valued.

GDA has been involved in the RCOP agenda so far via:

- being part of the RCOP Strategy Group, which wrote the Draft Plan;
- chairing the Capacity Building workstream;
- along with lead partner GCVS and others, supporting the establishment and delivery of the Transformation Fund;
- feeding in views of older people including the consultation event on 14th June which was part of a wider programme of consultation on the Draft Plan.



# GDA's consultation with older disabled people and older people with long term conditions

GDA is committed to the disabled people's ethos "nothing about us without us!" With this in mind, GDA held its *'Wisdom, Wit and a Whirl'* event on 14th June 2013 in central Glasgow for older disabled people, older people with long term conditions and those representing user led organisations. The morning focussed on RCOP and participants enjoyed an afternoon of music and dancing, courtesy of *That Swing Sensation* band and professional dancers.

## The aims of the event were:

1. To provide information about the RCOP Draft Joint Strategic Commissioning Plan 2013-16
2. To get older disabled people's input to this process
3. To consider ways of sustaining the involvement of older disabled people and those with long term health conditions



# How did it all happen?

This event came hot on the heels of the GDA Learning Festival (which brought together over 400 disabled people for accessible learning programmes). Staff involved older people and used their community engagement expertise to ensure that the event was well-attended, achieved its aims and provided an opportunity for older people who had not been involved with GDA before to participate.

**This relied on three key things:**

## 1. Making the event interesting

The afternoon of music and dancing was offered as a 'hook' to encourage people to attend and to provide an opportunity for them to make new connections and build resilience, in addition to having fun.

## 2. Removing barriers to participation

The Thistle Hotel in Glasgow is central and accessible, with parking, level access entrance, a welcoming reception, accessible toilets and plenty of space. GDA also provided taxis to transport people to and from the event, personal assistants and information in accessible formats (note takers, British Sign Language interpreters, a closed loop system, audio CD, Braille and large print).

## 3. Using different networks and publicity to extend GDA's reach

GDA invited its members but also advertised the event programme through other organisations within the disability field, via equalities organisations focussing on women, black and minority ethnic communities, LGBT networks, and by targeting older people's clubs and organisations across the city. 103 participants were new to GDA. The Herald also covered the event, publicising it further.



# How did it work on the day?



The event was chaired by Tressa Burke, Chief Executive of GDA, with the following speakers to talk through the changes being proposed:

- Lindsay Forrest, Housing Services Division, Glasgow City Council
- Helen MacNeil, Chief Executive, Glasgow Council for the Voluntary Sector
- Ranald Mair, Chief Executive, Scottish Care
- James Thomson, Glasgow Social Work Services
- David Walker, Director South Sector, Glasgow Community Health Partnership

Participants were then split into groups and invited to take part in three different workshops discussions, led by the speakers. The speakers visited each group, rather than the participants having to change rooms, so everyone had an opportunity to focus on each aspect of the draft plan and to give their views. The workshops took feedback on the challenges older people face and the proposed changes, in addition to focusing on the following questions:

## Third Sector workshop

1. What are you most concerned about as an older person and what would help?
2. What community based services work and what services are missing?
3. How do we get the views of older people about services?



## NHS and Social Work workshop

4. How do we make sure that older people can find the right information about the services and support available?
5. What would help you now or in the future to remain at home with choice and control over your life?
6. What health and social work services work and what services are missing?



## Independent Sector and Housing workshop

7. What needs to be in place to help a smooth transition into and out of care – either homes or respite?
8. How can we make sure older people stay connected to their families and communities when in care or sheltered housing for short or longer periods of time?
9. What new services should we be developing to meet the future needs of older people in Glasgow who may need residential care or supported accommodation?



Facilitators and personal assistants helped to make sure everyone was able to contribute their thoughts and comments were recorded in each workshop.



# What did people tell us?

Participants had a lot to say! The tone of the discussions could be described as 'cynical/realistic whilst hopeful' and some strong feelings were expressed. Before going into the detail of views given, it is important to note that:

- Participants generally agreed with the direction of travel suggested by the Draft Plan and they understood the need for change.
- Participants were articulate and vocal about the value and contribution of older people in Glasgow... to communities, families and wider society, and the part that older disabled people can and should play in shaping services.
- Participants also recognised the contribution that can be made by taking responsibility for their own health.
- However, there were concerns about the level of resources required, particularly the challenge of shifting to preventative spending whilst still meeting more intensive needs.
- The importance of joining services up better was also stressed.



The following issues were raised by participants:

## 1. Independent Living including Dignity, Privacy and Choice & Control over life

Overwhelming fears were expressed about the potential to lose choice, control, dignity and independence related to growing older with impairments or conditions. People were afraid of *“going into a home”, “ending up in care with no choices over my life”* and *“not getting out of hospital due to my house not being accessible”*.

Losing personal freedom in residential care was repeatedly raised as a concern, particularly for those who had longer term disabilities and who had experienced this in the past.

*“I grew up in care – I’m terrified of going back into care, not being treated with dignity, wearing incontinence pads because there is no support to change you. It’s disgusting and degrading.”*

*“I’ve been in care and know what it’s like to have no privacy, dignity or control over my life. I never want to experience that again.”*

Anxieties were expressed specifically around costs:

*“if it is seen to be cheaper to put me in a home than staying in my own home with support, do I have rights - human rights?”*

While there was a positive reaction to ‘reablement’ type services, many older disabled people were keen to point out that Independent Living is about choice, control and quality of life, not just the number of self-care tasks someone can perform without assistance. This must be understood when planning and providing services.

IF I'M IN NURSING CARE WILL MY HOME BE USED TO FINANCE IT.





## 2. Loneliness and Social Isolation

Many older people reported being very lonely, despite some living close to family and friends. Losing connections as one becomes older and frailer was a real concern, even with those older people who attended the event as members of clubs or with existing friends. Going home to an empty house, coping with someone who needs support and losing close family links can be depressing and lead to poorer health and isolation. Particular concerns were losing the use of a car and lack of support to follow religious or cultural activities, particularly among BME groups. Modern technology and the faster pace of life seem to magnify older people's concerns:

*"My family are all so busy now and live much further away. Years ago families lives within the same few streets. It's fine for the young ones, keeping in touch with texts and online, but that's alien to me."*

The need for human contact and meaningful relationships and connections was emphatically stated.

*"I don't want to stop making new friends just because I'm older. And I might need a bit of support to keep the ones I've got!"*



### 3. Practical Support - Health & Social Work Services

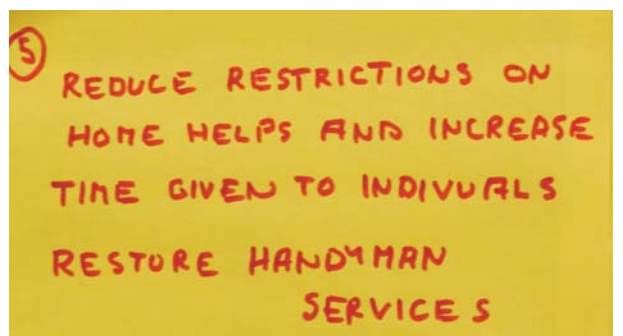
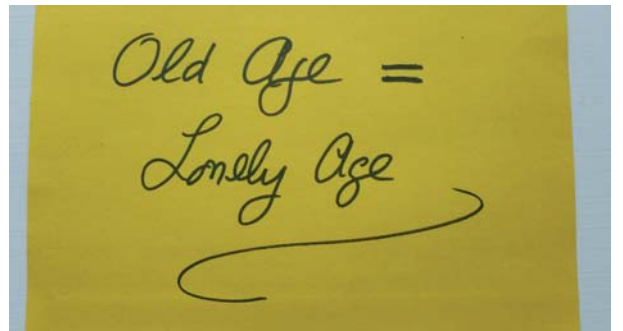
There was much comment around Health and Social Work services generally around the need for:

- resources, as there was concern these were too low
- better choice and control over what services are provided
- older people to be involved
- services to be needs-led, not resource-led
- joined up services and reduced duplication, e.g. a single assessment and less bureaucracy
- a person centred, flexible and responsive approach
- more information

The lack of involvement and communication were critical issues. Older people fed back that they don't feel involved in the services they receive and the withdrawal of GCC's handyman service - a "lifeline" - without notice had affected the majority of participants:

*"It was brilliant knowing that if I needed a lightbulb changed or a pair of curtains hung up, I could call the Handyman and not put myself at risk by climbing a ladder."*

*"It's that wee bit of help with odd jobs that keeps us independent and not feeling like a burden on our families."*



## NHS services

Comments on NHS services included lack of trust in NHS 24, long waiting lists for treatment and GP services not being willing to conduct home visits or 'keep an eye on' more vulnerable patients. Older people felt that locally based services such as podiatry and physio services were being centralised, causing transport issues.

Participants were full of ideas for new and improved services, such as:

- A 'Health Visitor' role to visit older people regularly, ensuring they were staying well and have basic checks completed, e.g. mental health, weight, blood pressure, blood tests, etc. This could also be a route for referrals, for example to social work or housing support services and improve joint working across agencies.
- People felt strongly that NHS services should be more holistic, including alternative and complementary services.
- There should be more opportunities to self-refer, e.g. for podiatry, physio and occupational therapy (OT) services.
- More cooperation between health and social work services, particularly in relation to discharge from hospital and aids/adaptations to the home environment, including stair lifts, wet rooms, specialist furniture, etc.

*"I know I need a stair lift and a walk-in shower, but I feel like I am being passed around like a parcel between my GP, housing association and social worker with endless assessments and form filling. I wish they'd just get their act together as I am truly suffering as a result."*

## Social Work Services

Older disabled people expressed numerous specific concerns about the poor quality of home care services provided by Cordia:

*"Inflexible, unreliable, restrictive – on the odd occasions I do manage to get out socially, I've got to rush home or I miss my evening meal and support to get to bed."*

*"Access to personal assistance is not a luxury. It is fundamentally important for independent living, for having choice and control and for living a full life."*

Older people want to see more flexible, responsive and quickly implemented services to enable them to be supported to remain at home. Many participants felt uninformed and nervous about Self Directed Support (SDS) and view social work services only in terms of "home helps, meals on wheels and home carers".

To redress this balance, much more needs to be done to encourage and support

older people to understand and feel confident in the range of support available. For example, older people repeatedly said that they want help with things which aren't provided by social work, such as:

- housework
- shopping
- cleaning, including tenement stairways
- washing and ironing
- odd jobs around the house such as hanging curtains, decorating, gardening
- social participation
- accessing activities e.g. clubs, courses, events

I WOULD LIKE SOME ONE TO GET SHOPPING AND THAT WOULD HELP MY



Although Self Directed Support can be used more flexibly, it is not likely to be made available to those with lower levels of impairment. Older people were very clear in articulating the support required to remain safe and well in their homes, but more importantly that they needed support to live fuller lives with meaning beyond this: the Strategic Plan must take into account the need for lower level, flexible, support services.

I've got canvas coming in so I'm up dressed and ready to go nowhere by 9am.  
Its so frustrating that I can't get help to go out and do stuff like meet my friends, go to bingo etc.

Some older disabled people also fear the transition from adult to older people's services, in case current support is reduced following reassessment.



A lack of joined up working was frequently mentioned, with people giving specific examples of being 'stuck' in hospital because social care packages were delayed. People frequently experience multiple assessments from different agencies, where one holistic assessment should be sufficient:

*"I'm up to here with assessments for this, that and the next thing – they should know my needs by now!"*

WHAT COMMUNITY SERVICES?



#### 4. Practical Support - Community based projects and services

Participants were positive about local services and clubs, would like more of these (including those which encourage greater integration of age groups, faith and cultural groups) and more of a say in how these are run. Some community based organisations were specifically named as providing good services: lunch clubs, church groups, CABs, Alzheimers Scotland and GDA in particular (notwithstanding the bias that this day itself may have brought with the promise of lunch and dancing!). Welfare rights services are very much needed, although these were reported to be more difficult to access. Church based services were seen to be proactive, well run and friendly, whilst those who have personal alarm services value the reassurance these bring. There was also:

- concern about resources for such services, as we need more community based services and supports
- support for community approaches and the need for preventative ways of working/preventative services
- a need for more joined up working with public sector agencies
- a call for better commissioning processes for the Third Sector
- interest in Change Fund projects (a directory was given out) and emerging learning from these
- and the closure of local projects and services was also cause for concern, as were reduced levels of service and charges for services.

## 5. Personal safety

Older disabled people expressed concerns about falling and having no-one to find them, leaving cookers on and opening the door to people who would scam them. The need for peer support and courses to raise awareness of safety was identified and an evening service like the Good Morning service was suggested to check that older people, particularly those in the early stages of dementia, were okay, had eaten, turned the cooker off and locked up for the evening, etc.

There were many comments about the state of the pavements and roads, as well as poor lighting, meaning people felt unsafe going out, particularly at night.



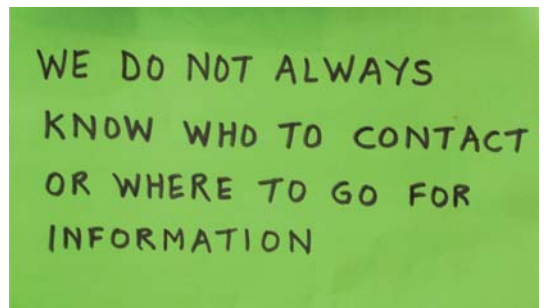
## 6. Accessible Information and advice

Older disabled people frequently cannot access information, because they are unaware of it, it's not readily available or it's not in accessible formats including easy read and plain language:

*"This is something which can be easily resolved with a bit of thought and just by asking us what works."*

*"Disabled older people are further disempowered by lack of accessible information. Organisations led by disabled people and older people can help with this and give tips."*

It was suggested that more should be made of current communications (letters, noticeboards and staff) targeting older people, for example by providing information about clubs, winter fuel allowance, emergency contact numbers, etc. Again, this relies on agencies working better together, and with the Third Sector.



## 7. Communication Support

This should be readily available so that people can participate in their own health and social care arrangements. For example, interpreters or notetakers may be necessary for deaf people, those with hearing impairments and people with cognitive processing problems to take part in an assessment of needs or medical appointment. Communication support should be a right and this would open up all sorts of other opportunities and rights which some disabled people are currently denied.

## 8. Housing, community alarms and aids and adaptations

Accessible and adapted housing (including aids, adaptations and equipment) emerged as an issue. Small pieces of equipment can make a tremendous difference to a disabled person's life and it was suggested self-assessment should be developed as a direct route to provision. Information and support should be available about housing rights and the kinds of aids, equipment and technology which might assist.

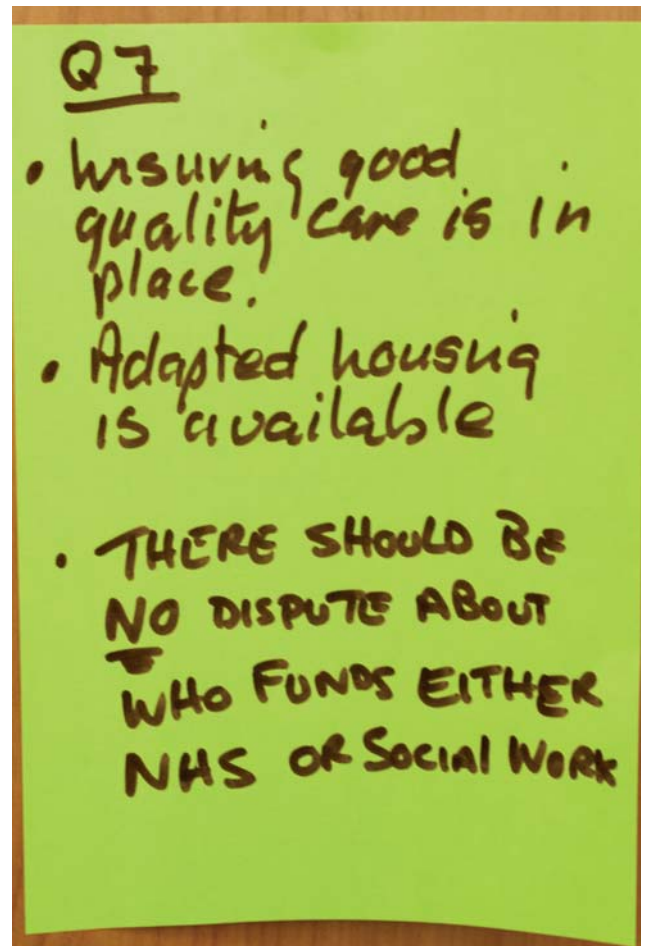
Participants also felt there needs to be a more effective system in place to return and reuse equipment and aids when no longer required. At present it is unclear where and how to return equipment so it ends up being scrapped rather than used by someone who needs it.



## 9. Benefits and Finances

The current climate of austerity measures and Welfare Reform is hitting older disabled people very hard, with participants feeling very vulnerable financially:

- Many disabled attendees were extremely concerned about losing DLA and the 'bedroom tax' which affects those over 62 who may need an extra room for family support, carers or equipment.
- The rising cost of food and fuel means many people making difficult choices between "heating or eating".
- Some older participants reported that rising charges for community services and care charges don't help and affect their standard of living.
- There were a lot of comments about family involvement in finances, including Power of Attorney and family homes having to be sold to finance residential care.
- Benefits often don't account for the additional costs of being a disabled older person, e.g. taxis, extra heating bills, adaptations, etc.
- There was recognition of the connection between poverty and disability and the consequences for reducing life chances, a lower quality of life, poorer health and greater social isolation.



## 10. Legal issues

Older disabled people also raised concerns about a lack of information and advice around a variety of legal issues:

- fear of being forced to sell their home to go into a care home
- wills and inheritance
- Power of Attorney
- DNR and living wills
- legal advice generally
- and advocacy.

## 11. Transport and access to the environment

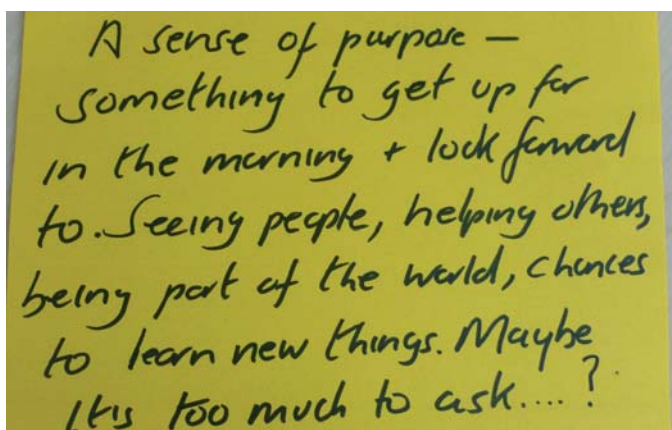
Lack of, or loss of, affordable and accessible transport is a major factor in the loss of community connections and loneliness. Most older disabled people have a bus pass that entitles them to travel free of charge across Scotland, but the reality for many people is that the timing, accessibility and routes of local transport systems do not meet their needs, so they often have to rely on taxis. Participants asked for a subsidised taxi travel card to be provided for older disabled people instead.

*“What’s the point of a free bus pass that I can’t use? Most clubs don’t provide transport. Taxis are too expensive, so I hardly get out.”*

Recent changes in bus routes and numbering were distressing for delegates, particularly as there appeared to have been no notice or consultation:

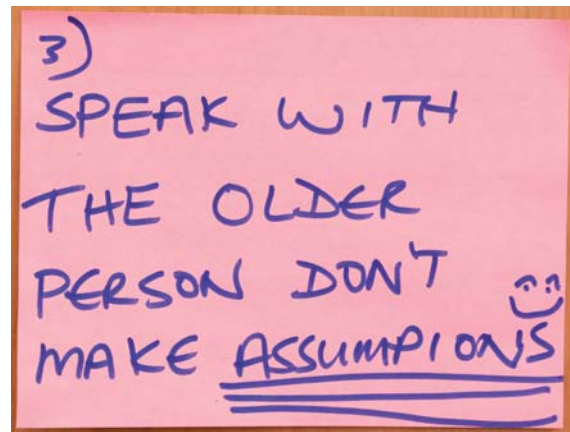
*“I used to have a bus that stopped at the end of my street, but the route has changed and I can no longer walk to the nearest bus stop. If GDA hadn’t got me a taxi here today, I couldn’t have come to the event.”*

Older disabled people’s transport experiences are often frustrating: buses are designed to carry only one wheelchair; wheelchair spaces are frequently filled with





prams; priority seating is often used inappropriately; drivers fail to stop for or assist disabled passengers; buses move off before people are seated and so on. It was suggested that older disabled people could have input to the training of bus and taxi drivers to improve their understanding/ attitudes to disabled passengers and improve the customer experience.



## 12. Support to have your voice heard individually and in relation to service design

One resoundingly positive reaction to the Draft Plan was the emphasis on 'coproduction' at all levels and stages of planning and delivery of future services. However, the use of such jargon was criticised by older people:



*"Just come and talk to us, tell us what's going on and involve us in making decisions. Treat us as equals, don't patronise us or talk to us in 'management speak.'"*

### Discussions centred around:

- involving older people and building capacity to support this
- listening better
- respecting what older disabled people have to say
- recognising that older disabled people have their own identity
- improving choice, control and older people making their own decisions
- and working together and working differently with older people



## 13. Discrimination and inequalities: culture and attitudes in organisations and wider society

Many people reported that becoming really ill and not receiving appropriate medical treatment or social services was a key concern. Older disabled people feared they would die in pain and alone, be subjected to poor end of life care, be denied treatments or subjected to lengthy waiting lists just because they were older. These fears were based on previous experience of long waiting times to see GPs, unhelpful or undignified treatment in hospital and generally poor quality treatment.

Participants also voiced concerns about potentially not being able to access Self Directed Support on the same basis as younger disabled people:

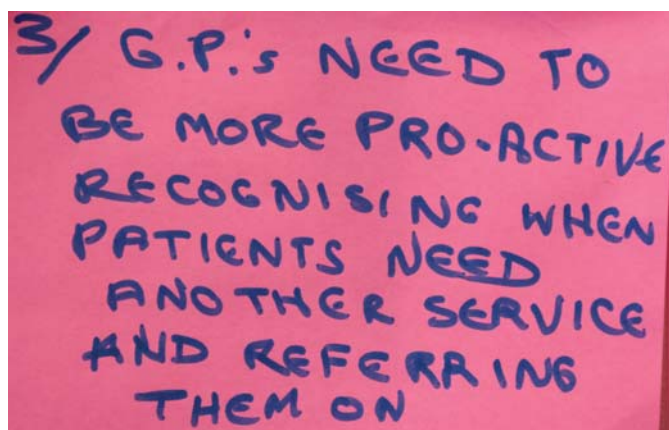
*"I'm worried about discrimination in services when I turn 65, e.g. psychiatric care, talking therapy - maybe SDS but not sure yet?"*

Older disabled people are more likely to have spent many years having medical treatment and some have very specific fears:

*"I'm sick of going into hospital to find it is not accessible to me as a wheelchair user. I need lots of support with personal care and I find unless I take a carer into hospital with me, I just don't get the level of support I need."*

*"I've got friends who've found DNR instructions on their notes. I'm terrified doctors will make a judgement about my quality of life without asking me."*

Older people are increasingly worried about the negative attitudes in society about disabled and older people. This is magnified by the effects of Welfare Reform: these negative attitudes are compounding fears and making it more likely that older disabled people will become isolated within their communities. Many delegates spoke of lack of respect from others in the community – from loud music, unkind neighbours, to people not giving up seats on buses, to businesses only “in it for the money” and seeing older people as a commodity from which to seek profit.



## 14. Equalities and wider inclusion

It was highlighted that other aspects of older disabled people's identities are often forgotten, e.g. sexuality, culture and faith:

*"As a gay, disabled man, I'm terrified of being put into a care home where my sexuality will be ignored or become 'a problem'. It's difficult enough in the community to have my identity recognised and supported."*

*"I am Sikh and can't get support with practising my religion, or even simple things like care staff who can cook culturally appropriate meals."*

SEEKING PEOPLE KEEPS  
ME ALIVE + POSITIVE.  
OLD AGE IS LOVELY AGE.  
THIS HAS BEEN A TERRIFIC  
DAY THANKS TO GDA - I'D  
NEVER EVEN HEARD OF THEM!



## 15. Citizenship issues: social and civic participation

Older disabled people have a great deal to offer and want to be active in and contribute to society, continuing to learn and stay mentally and physically active:

*"I'd love to learn how to use the internet so I can keep in touch with my grandchildren. I also love writing stories and would love to share them."*

*"I'd like to keep fit and meet new people but I'm not sure what's on in my area or where to start."*

*"I'd like to do voluntary work and give something back – at the very least I've got life experience to offer"*

I've got so much experience  
+ knowledge to share - it's  
getting wasted. Why can't  
we get support to volunteer  
+ give back to our areas?  
I feel totally useless - and there's  
no need for it.



Participants want to be fully part of their communities, included in discussions and decision making, for example around the design, delivery and evaluation of services, in a more integrated way within wider society. This was seen to need greater empowerment of older disabled people, peer support and opportunities for personal development and capacity building to equip older people to participate in the ways they would wish, e.g. volunteering and being more involved in the community on a more equitable basis.

**This was supported by the positive feedback from the GDA event, where over 95% of people rated ‘being asked my opinion and taking part in group discussions’ the best part of the day (no mean feat when lunch and entertainment were provided!):**

*“Today has been a brilliant experience. No one has ever asked me my views before and I feel I have been listened to and I trust my views will be passed on. I am looking forward to staying involved and learning more about GDA and the Strategic Plan.”*

However, it must be noted that participants overwhelmingly felt that organisations such as GDA, who provide opportunities to build individual and collective capacity, are essential in assisting older people to contribute in an accessible and meaningful way. Their participation in this consultation event was only possible due to GDA’s



commitment to providing an exceptional level of access facilitation. Providing the right support and meeting access needs allows disabled and older people to truly participate in any coproduction initiative. Without this, any such involvement is meaningless and tokenistic:

“Getting a taxi meant I could attend the conference. Personal assistance gave me the independence and reassurance I needed to take part. I felt listened to and knew my experience was being valued. Often old folk are seen as a nuisance but I felt like royalty today! I want to stay involved please.”

*“I feel I was able to give my voice and have it listened to. All of us will need services from the Council at some point in our lives, and they should make sure us, the people who use them, are asked what they think.”*

In answering what would help people to remain in their own homes and have connections with their communities, a significant and pervasive finding was that some older people at first struggled to come up with ideas and options. This reflected that for some older people, having been deprived of choices and opportunities - sometimes for their whole lives in the case of longer term disabled older people - they need support and encouragement not only with information but to build confidence to “take the first steps” to access other opportunities which can benefit their health, wellbeing and sense of fulfilment.

GLASGOW DISABILITY ALLIANCE HAS BEEN ONLY MEETING PLACE WHERE I FEEL I CAN MANAGE, REGARDLESS OF DISABILITY



# Summary conclusions

Over 200 older disabled people and those with long term conditions participated in a morning of wide-ranging discussion around future support for older people in Glasgow. Participants generally understood the reasons for change and were in agreement with the direction of travel proposed, although there was concern that resources would be insufficient so support to older disabled people would effectively be cut.

Having a meaningful life through having purpose, choices and control, social connections and interactions, participating and making a contribution were seen as vital in keeping older people healthy and well. Older people were clear that independent living for them went beyond doing things by themselves, keeping safe from harm and physical rehabilitation- whilst these were important, they also wanted opportunities to meet people and make friends or sustain friendships, to participate, to learn, to be active including “getting out and about” and to contribute- helping others at times or simply taking part and giving their views and experiences: these are the things which keep them really well and give their lives meaning.





There was acknowledgement that support may be required to do these things and that this could take many forms e.g. with medication, with care at home, personal care and support to go out e.g. Self Directed Support, support to raise aspirations and come up with ideas since they may have lost confidence and been deprived of choices and chances to try new things or make new friends, support to organise transport or activities including learning, accessing community groups, aids and equipment and support from neighbours, friends and family. There was overwhelming consensus that older people must also be supported to have their voices heard- individually and collectively. Critically, older people believed that with the right support, they could achieve a great deal and would in turn be much healthier and well.

The collective definition of Independent Living established was not about older people doing everything by themselves in isolation but more importantly, about participating fully in life, with whatever support is needed. This is about having choices and a sense of purpose- equal to others and not “less” because they are older and disabled- having diversity, strengths and being individually valued, taking account of experience and identity, and being treated as an equal citizen with the same rights as others.

In summary, the critical issues for supporting older people identified throughout the consultation were:

1. Older disabled people want to be able to live independently, with dignity, privacy, choice and, crucially, control over their lives even if they can't do things for themselves. There is significant concern that this will not be possible, particularly if resources are limited.
2. Older disabled people were critical of Social Work Services, particularly those provided by Cordia, but also the NHS for the way older people are currently supported. They would like to see:
  - a person-centred, holistic, flexible and responsive approach,
  - better choice and control over what services are provided, including assistance with housework, shopping, cleaning, odd jobs, etc, more self-referrals (for physio, OT, aids & adaptations, etc), alternative/ complementary therapies, a Health Visitor or Good Evening service to proactively check on older people
  - older people being informed better, consulted about changes and involved in designing and evaluating services provided
  - services being driven by needs rather than resources
  - services working together better, particularly around discharge from hospital and assessment of needs, to reduce confusion, delays and stop wasting everyone's time





3. There was concern around the level of resources to support older people generally and older disabled people specifically as they move from adult services to older people's services.

4. Loneliness and social isolation has a significant impact on older disabled people's health and quality of life, so needs to be addressed more fully. Community based projects and services such as lunch clubs and welfare rights services make a difference and people would like to see more of these and have more of a say in how they are run. They would also like:

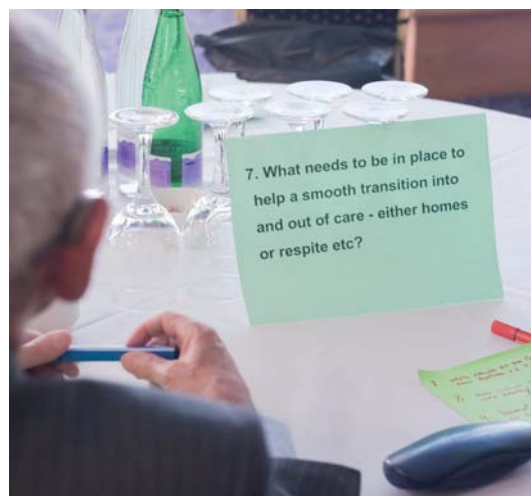
- more preventative ways of working and preventative services (public sector agencies can learn from community approaches), with interest in Change Fund activities and learning

- more joined up working between community and public sector agencies

- better commissioning processes for the Third Sector

- more financially secure community projects/services as they seem to be disappearing, reducing what they can do or charging more

5. Lack of affordable and accessible transport also reduces community connections and increases loneliness and isolation. Older disabled people would like subsidised taxi travel and to be involved in training bus and taxi drivers to improve the passenger experience.



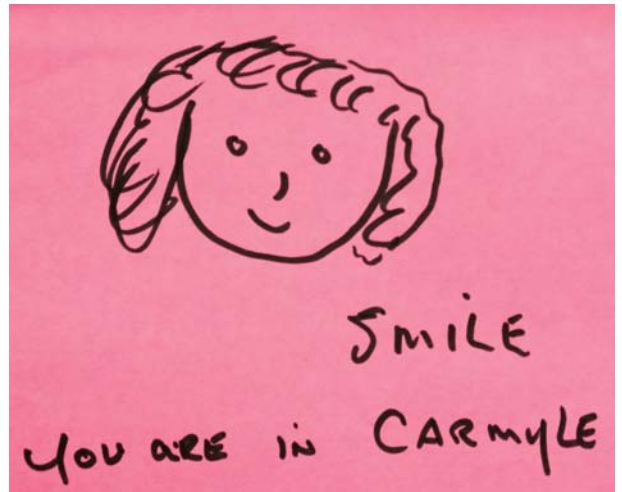
6. Raising awareness of how to maintain personal safety is important, as is improving the condition of pavements and street lighting so older people feel and are safer.
7. Efforts need to be made to ensure older people have access to the information and advice they need. This is a general point but also includes specific legal issues such as Power of Attorney, DNR, living wills and fears around having to sell one's home and go into a care home.
8. Older people should receive any communications support they need as a matter of course so they can actively participate in their own health and social care arrangements.
9. Accessible/adapted housing, community alarms and aid/adaptations can make a big difference to a disabled person's quality of life so information about these and access needs to be easier.
10. Older disabled people have been hit hard by benefits cuts and increases in the cost of living so are feeling very vulnerable financially. There needs to be greater recognition of the connection between disability and poverty, and the consequences this has in terms of reduced life chances, lower quality of life, poorer health and greater social isolation.
11. The emphasis on coproduction in the Draft Plan was very well received, as older people want to be recognised, involved, listened to, make their own decisions and their views to be respected. A human rights based approach to



services, plans and policies is required. Older disabled people have much to contribute to society and want to do so, but they may need support from peers, to develop capacity and be empowered to play their part. Services and supports needed to enable social participation, learning and other activities

12. Older disabled people are worried that attitudes within organisations which provide services to them and wider society are discriminatory – not valuing them as much as younger people. This was based on experience and there is real fear that they will not be supported, cared for or treated as well as they should be. Being older and disabled can unfortunately be a ‘double whammy’ so attitudes need to change.
13. Older disabled people can be viewed one-dimensionally but other aspects of their identity, such as sexuality, culture and faith, need to be recognised in order to provide appropriate care, support and for people to feel valued.

**Most of these issues echo GDA’s manifesto, illustrating their importance and the fact that we are still a long way from achieving them. It will take time to change services and cultures but this feedback from older people aims to provide both the motivation and the ‘to do’ list for those involved.**





**Glasgow Disability Alliance**  
 Equality, Rights and Social Justice

Call: **0141 556 7103**

Email: **info@gdaonline.co.uk**

Website: **www.gdaonline.co.uk**

Text: **0754 814 8017**

Write: **Glasgow Disability Alliance**  
**Suite 301 • The White Studios**  
**Templeton Business Centre**  
**Templeton Court • Glasgow G40 1DA**



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