

Self-directed Support Roadtesters

My Choices:

A vision for self-directed support

Action research report

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In co-production with participants

March 2014


Glasgow Disability Alliance

Thank you

Acknowledgements

Glasgow Disability Alliance would like to offer sincere thanks to the Scottish Government for funding the Project and recognising the need for capacity building; to the excellent PAs and agency staff who worked with participants to offer personal support; to Noreen – our amazing Project Assistant who supported older participants in a variety of ways and who went above and beyond at all times; to the dedicated GDA Team members for their roles in identifying, supporting and advising participants as well as organising support: in particular, to Marianne Scobie for tireless efforts and attention to detail in collecting and editing personal journeys; to Peter Patterson for following these journeys, capturing them on film and producing the DVD.

A special thanks to Dr Sally Witcher who was involved in the project from the early stages, contributing ideas and shaping the design of the Action Research: Sally ultimately produced a report which is rich in learning, reflections and ideas moving forward. Her role went beyond that of traditional “professional” researcher in that she co-produced the participatory approach, encouraging and supporting all participants as well as GDA Team, PAs and all involved to be researchers, recorders and reporters. This ensured both that learning, experiences, views and ideas were captured and that these shaped the evolving project model. The Action Research itself had to be flexible in approach and take into account changes .e.g. the original plan for 2 cohorts of participants was abandoned for a rolling programme: thanks to Sally for being flexible and patient in response to these challenges and for her insights, consideration, passion and commitment to working alongside GDA as a disabled people led organisation and the participants themselves.

Above all, GDA wishes to thank all “My Choices” participants for enthusiastically and honestly sharing their experiences, aspirations, knowledge and reflections. This has been crucial in understanding barriers and working together to remove these: the project has established an innovative and successful model for supporting disabled people to achieve their personal goals. It is hoped that My Choices has wider lessons which inspire service planners and policy makers in relation to Self Directed Support and models of support which disabled people value and benefit from.

Most importantly these finding hope to influence models which can enable maximum choice and control, enable disabling disabled people to live the life they choose with the support they need, participating in their communities and having the same chances and choices for equality and fulfilment as other citizens.

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Summary of the project and what we found out

1. Starting point

- The purpose of 'My Choices' was not to replicate the delivery mechanisms for Self-directed Support (SDS) but to start with the vision for SDS and see what could happen when disabled people were supported to have choice and control over their lives and to find out about the sorts of support that they might need.
- As the project was all about promoting choice and control, it seemed appropriate to carry it out as a form of co-produced participatory action research. All the participants themselves were researchers, recorders and reporters. The project evolved and changed as it went along. It's an adventure! No one knows when they set out quite what will happen or where they will end up.

2. Setting off

"Disabled people don't dare to dream as they don't think things are possible – sometimes even the smallest things." **'My Choices' participant**

- Although the vision for SDS is very positive, the 'reality gap' between people's lives and that vision can be very great.
- People whose lives have come to a halt, without choice, without access to opportunities to try new things and make new friends, may not 'dare to dream'. They may need considerable support to take a first step forwards. They may therefore not respond to what might appear to others to be a welcome opportunity.
- People who ended up being recruited had often had experience of GDA before. They trusted GDA and this seemed to be an important factor in their decision to join the project and stick with it. This was explained in terms of shared understanding based on the fact that GDA is led by disabled people.
- The participants were a very diverse group (16 people), in terms of age (18 to 85), education, impairment type and household type. It was important to have a very varied group to see what impact having choice could make and whether it was important for everyone. They were put into 3 groups: younger people, employability and older people.
- The project started with the researcher meeting each of the participants and then each participant meeting with the GDA team member for their group. There was then the first of 3 events for all the participants. They talked about how they were feeling about the project and their ideas about what they wanted to do.
- Even at this early stage, and among such a diverse group, there was strong evidence of how valuable participants found sharing experiences and getting support from others. Despite their diversity, they were peers with regard to the project.
- People wanted to know what the limits were. There needs to be some boundaries within which that flexibility can take place. Of course, if there isn't enough money or not enough time, no amount of flexibility can enable people to have choice in any meaningful sense.

3. Into the driver's seat

"It's been my choice, what I do when I'm out with my PA. I always feel like I have to ask, but my PA said I'm the boss." **'My Choices' participant**

- The things participants chose to do were as varied as the participants themselves.
- There were many examples of how confidence was raised through one activity and that motivated people to do other things. Doing one thing opened doors to others. Sometimes a 'journey' was sequential – one activity followed another. It was also the case that for some people, all kinds of things happened at once as lives blossomed in different directions.
- Participants of all ages and all impairment groups took and benefited from courses. The courses participants did included: guitar, first aid, Spanish, art, sewing, computing and counselling.
- Sometimes mainstream classes worked best. Sometimes 1-2-1 tuition was the answer.
- Inaccessible transport and buildings, and not having much money, can make it difficult for older and disabled people to get out and about. One thing that came through loud and clear (unsurprisingly) was how much participants of all ages and impairment types valued being able to get out of the house, to meet with friends and go on trips.
- However, there were lots of bumps and barriers that could get in the way. Not all could be removed by support of any kind.
- Participants had experienced terrible attitudes that could discourage them and destroy their confidence. Such attitudes might come from bus drivers, teachers, driving examiners, and even parents, not to mention people who always spoke to the people with wheelchair users rather than and the wheelchair users themselves.
- Disabled people disproportionately experience poverty because they have restricted access to earned income and extra costs. It means they can have no spare money to fall back on. One participant who did a counselling course would have liked to do a diploma but it cost thousands of pounds. She said "You might as well ask me if I'm going to the moon." Another would have had to abandon her nearly completed course, or get heavily into debt, because of the introduction of the bedroom tax. Another participant had been advised by the NHS to undergo a specialist course of treatment only available in London: this was a unique programme of rehab to develop techniques and approaches to managing her condition at The Royal National Orthopaedic Hospital in Middlesex. Unfortunately, the NHS couldn't fund travel, costs to stay away from home or subsistence although they funded immediate costs of the course itself which involved a hospital stay.
- The way services are designed and delivered, and the way different services come together, can create lots of barriers to choice and control. For example rules around benefit entitlement like availability for work could have stopped a participant from having a course of healthcare treatment – which could have improved her employability.
- In addition, rules about social work eligibility may render some participants unable to qualify e.g. for SDS or in other cases, only enough to have physical care needs met. A lack of focus on preventative approaches can block support to access learning, volunteering, employability, social or civic participation.

- However, the benefits of choice were clear to see. Some people's lives had been totally transformed. Many were happier and more confident. They had achieved things they (and others) had never thought possible.
- Relationships with family members had improved. One 85 year old woman learnt to read and write and for the first time in her life was able to write to relatives in Australia. Another talked about how she could be the mother again rather than the child. By going on outings they reconnected with their former lives and their city.
- Several had improved their employability.
- Many experienced benefits to health and well-being. Sometimes their goals were specifically health-related, e.g. around condition management or more general fitness. Often improvements in health and well-being were a positive spin-off from increased self-esteem and motivation.
- Participants' journeys are not over and they were looking to the future and had lots of plans. Although there were some worries about what would happen when the project ended, there was evidence that there would be a lasting legacy for many. In some cases, improved confidence meant they were now doing things without the PA support they would previously have needed.

4. Oiling the wheels

"There's a lot of background work you have to do to make things happen"

GDA team member

- One of the striking findings of this project is the pivotal importance of a number of different relationships. All appear to play an essential role in providing support necessary in different ways to exercising choice.
- Despite the fact that the range of activities carried out by participants was very wide, the support they needed took a relatively limited number of forms.
- GDA's role was to help people develop their ideas, pay for and arrange PAs and taxis, pay costs like food, find and fund courses, tutors and counsellors, connect people with specialists and experts, buy equipment and provide a bit of spending money. At the heart of successful support were the relationships and ongoing communications between participants and GDA team members, particularly the one responsible for their group.
- The relationship the participant had with their PA was also really important. Sometimes they could both get very close. Sometimes they were or became friends. But it was important to remember they were paid to do a job. As with any relationship, it is important not to make assumptions and there can sometimes be 'boundary issues' to negotiate – affecting either party.
- Throughout the project there was overwhelming evidence of the value participants place on peer support.
- Sometimes people had particular friends. Sometimes friends were made through the project. In one case, they were close friends before and gave people the confidence to get through the door and join the project. Sometimes they stuck together; sometimes they went in different directions after that.

5. Overview

- There is overwhelming evidence that 'My Choices' did achieve the vision for SDS described at the start of this report. Participants' lives were 'enriched through greater independence, control, and choice' and this did lead to 'improved health and well-being, and the best outcomes possible'. The participants did demonstrate that 'Everyone, no matter what level of impairment, is capable of exercising some choice and control in their living'.
- Understandings were deepened. There were avoidable and unjustifiable constraints on 'the best outcomes possible' that support alone could not always remove. Structural inequalities prevail such as negative attitudes and the ways society is designed without disabled people in mind e.g. transport, employment patterns, the built environment.
- In terms of the value of 'independence', everyone was supported to maximise their aspirations and potential. However, there might be tensions between having a right 'to be safeguarded and protected' and being able to choose to take responsibility for safeguarding and protecting yourself, or for taking risks and the consequences – just like anyone else. This highlights the balance to be struck between protection and empowerment.
- The things participants wanted to do – to pursue their interests and learn more about them, have a social life, go out and about, have good relationships with family, make new friends, help others with their skills or through volunteering, look for work – were the stuff of what goes into the ordinary, fulfilled lives of any other citizen. If their achievements were extraordinary it is because of the barriers that stood in their way when it came to doing what anyone else might take for granted.
- There were great similarities between the 3 groups, and no obvious patterns according to type of impairment or other characteristic. It emphatically showed that choice was valued and could be exercised by all, and that all were capable of developing skills, choices, confidence and achieving.
- There was no obvious or consistent relationship between the amount of money that was spent on support and the scale of its impact. The literacy classes attended by one 85 year-old participant were free, equipment bought for some people totalled £400 in one case and £2000 in another. One package was as much as £5000 for BSL and others involved mainly transport costs from a few hundred pounds to around £2000. It would be meaningless to talk about an average cost as the driving factor was that support was person centred and linked to self defined outcomes. Indeed, you can measure expenditure, but how can you measure having your life transformed?
- It was clear that, whatever the quality of support, there were barriers to independent living that require additional action to be overcome. Having flexible, well-funded support will not change other people's negative attitudes, cause buildings and transport to become accessible or services of different types to smoothly integrate.

- A new model for support emerged. It involved multiple parties including peers and friends. Key features included the importance of local knowledge and contacts, of timing - sometimes requiring rapid intervention, sometimes accommodating delay – and the involvement, as necessary of experts and specialists. The role of coaching in raising and sustaining aspirations was also evident.
- Trust was critical and related to the shared understanding of barriers disabled people face due to the fact that GDA is led by disabled people.
- It is not always obvious how these roles and features would be reflected in SDS, but lots could be relevant to improving policy and practice.
- The innovative approach taken to carrying out this project indicates how research might be genuinely co-produced. It is a model that might lend itself to the further development of participatory research methods.

“My Choices’ showed that there is nothing inevitable whatsoever about having a poor quality of life if you are old or disabled. So long as you have choice, and with the right support, your life can be amazing!”

1. Starting point

"My motto is that it's always possible." GDA team member

Defining the vision

In 'Self-directed Support: a National Strategy for Scotland' (2010), the Scottish Government and CoSLA described their 10 year vision for Self-directed Support (SDS) like this:

'The lives of people who require support are enriched through greater independence, control, and choice that leads to improved health and well being, and the best outcomes possible.

Self-directed support should become the mainstream mechanism for the delivery of social care support... every person eligible for statutory services should be able to make a genuinely informed choice...The choice should be available to all but imposed on no-one.'

They said that:

'The fundamental principles of SDS are choice and control. Choice is evident where people are able to choose how they live their life, where they live and what they do. People have control of their support by determining and executing the who, what, when and how of the provision.'

Fundamental principles also include:

Inclusion – Everyone, no matter what level of impairment, is capable of exercising some choice and control in their living, with or without that choice and control being supported by others.

Equality – Everyone is an equal citizen of the state and has the right to live life as fully as they can, to be free from discrimination, and to be safeguarded and protected.

They said that their values include:

Independence – Everyone is supported to maximise their aspirations and potential. Support focuses on the prevention of increasing dependence and enablement, or re-ablement.

Freedom - Everyone is supported to participate freely in all aspects of society, in the same way as other citizens.

All this is important because it recognises that:

- Having choice and control is good for your health and well-being.
- Choice and control should be available to everyone who gets statutory social care services. This includes older people as well as disabled people.
- People need to have information so they can make fully-informed choices.
- Everyone is capable of exercising some choice and control (with the right support).
- Everyone should be offered choice and control but they can always choose to give someone else the responsibility for making choices on their behalf, if they want.
- Choice and control over your services underpins choice and control over your life.
- We are all equal citizens.
- Everyone has the right to live life as fully as they can and should be supported to do so.
- Everyone should be supported to participate in all aspects of society, not just some.

This is very much in keeping with the vision for independent living that was originally developed by disabled people in the independent living movement. On 5 March 2013, Scottish Government, CoSLA, NHS Scotland and the convenor of the Scottish Independent Living Coalition signed up to a shared vision of independent living in Scotland. This defined independent living as:

“disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life.”¹

It also fits very well with the United Nations Convention on the Rights of Persons with a Disability (UNCRPD). Article 19 talks about disabled people living independently in the community, with choices equal to others. It says we should have the opportunity to choose where we live and who with. We should have access to a range of support necessary to support living and inclusion in the community. Community services and facilities available to everyone should be available to disabled people on an equal basis and be responsive to our needs.

This year the Scottish Government will have to report on how it has implemented the UNCRPD.

Reality gap

Unfortunately, the gap between the vision for choice and the reality of disabled people's lives has often been very great. Too often, people have not been able to make choices about even the most basic things, like what time to get up or go to bed, or even when to go to the toilet.

There are lots of reasons why older or disabled people have not had choice and control over their support - let alone their lives. For example, it might be because:

- Professionals think giving the disabled person choice is too risky and are worried about being held responsible if things go wrong.
- The way local authorities operate makes their social care services inflexible.
- Sometimes it is assumed that older or disabled people are not capable of exercising choice, or that they do not want to.
- Sometimes it isn't obvious what the best way is to support someone to exercise choice and control.
- Older or disabled people don't have enough money or enough hours support to do anything other than survive.
- Parents want to protect their disabled child from harm and are worried what might happen if their child wants to try something new.
- Older or disabled people can spend years – sometimes their whole lives – being told they cannot do things and without opportunities to try. This can mean they lose all their confidence.

¹ <http://www.ilis.co.uk/uploads/Vision1.pdf>

There are far too many examples of how awful life can be when you don't have any choice and control. But what about examples of the positive difference having choice and control can make? How could it really change older and disabled people's lives - without costing the earth? What can we find out about the sorts of support that might be needed and how to deliver it so that it promotes choice and control?

This is what we set out to explore. The project was not trying to reproduce the choices people get with SDS about who delivers support. For example, no one was paid money to buy in their own support. All the support was organised by GDA and delivered through them. Instead, the purpose of 'My Choices' was to see what could happen when disabled people were supported to have choice and control over their lives and to find out about the sorts of support that they might need.

Mapping progress

Structuring and steering

'My Choices' was one part of a bigger project called Self-directed Support Road Testers. This had four main areas of activity:

- **Information** to be provided about SDS to disabled people in Glasgow
- **My Choices** project to demonstrate the impact that having choice and control can make, and explore the best ways of delivering support
- **SDS Champions** to tell people about SDS
- **Sharing learning** from the project overall.

In keeping with all of Glasgow Disability Alliance's work My Choices was integrated into 'Pathways for Change'², which initially placed participant in one of three groups. As with this overarching project, evidence quickly emerged that these were artificial divisions as people do not neatly fit into categories and in fact, there was crossover between these:

- Young disabled people
- Disabled people of working age looking to improve their employability
- Older people

The 'My Choices' project was intended to contribute to the bigger Self-directed Support Road Testers project outcomes concerned with:

- Increased peer support and social networks
- Increased confidence and skills for independent living and accessing training, learning, volunteering and work as well as appropriate services to support their goals (young disabled people group).
- Increased aspirations and greater employability skills towards actively seeking employment and access job seeking services (employability group)

² Pathways for Change aims to support disabled people to be better able to cope, be better connected to their communities and have 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, showing leadership and innovation such as 'My Choices'.

- Maintaining independent living (older people group)
- Service providers/ agencies can plan services that better meet the needs of disabled people and help them achieve independent living

These were to be explored by developing a series of research questions to find out about underlying issues and steer the collection of evidence. Research of any kind usually starts with a series of questions that you want it to answer. On this occasion there was a lot we wanted to explore:

1. What sorts of things can older or disabled people achieve with the right support? What might they chose to do?
2. Is there a relationship between the amount of money spent on support and the scale of the impact on older or disabled people's lives?
3. What benefits can be shown to arise from having choice and control over support?
4. Is there evidence of positive knock-on effects? Does doing one new activity open up opportunities to do more things?
5. What is the value of peer support and social networks? Have they increased during the course of the project?
6. Are barriers to independent living encountered that
 - Cannot be overcome by providing support to individuals because they require others to take action?
 - Would reduce the need for support if they were removed?
7. What can we learn about delivering support in ways that promote choice and control?

As the project was all about promoting choice and control, it seemed appropriate to carry it out as a form of co-produced participatory action research (to find out a bit more about participatory action research please see appendix 1 at the end of this report).

In traditional research there might be a professional 'researcher' who observes what the people do and/ or interviews them to find out what they have done and what they think, and then writes a formal report of her/ his conclusions. Although there was a researcher like this, the difference was that all the participants themselves were researchers, recorders and reporters. The Glasgow Disability Alliance team who were responsible for working with the participants and organising their support also contributed their perspective. So too did two of the Personal Assistants who were involved in supporting some of the participants throughout the project. It was important to find out about everyone's learning, experiences, views and ideas.

As for any project, we needed to start with a plan. Usually the aim is to stick to that plan, come what may. However, it is in the nature of a co-produced project involving multiple partners that it needs space to evolve, sometimes in unexpected ways, as it goes along. For example, a formal research report was to be just one of many outputs from the research. It was for each participant to decide what they wanted to record about their experiences and how they wanted to communicate it. For everyone, learning and adjustments can take place throughout the duration of the project. It's an adventure! No one knows when they set out quite what will happen or where they will end up.

Process

With that in mind, here is an outline of the plan we started with.

The project started in November 2012. The first thing to do was to recruit participants by sending out a leaflet to GDA's membership. It was proposed to have two rounds of recruitment, with a second phase happening around 9 months into the project.

Participants contacted the office and talked over the phone to GDA team or met with someone as agreed, to have initial conversations about ideas.

Once participants had been recruited, the next thing would be for the researcher to meet with each of them to talk about the research and their role as researchers, to ask them about the activities or outcomes they had chosen and answer any questions. The aim would also be to find out where people were starting from, so we could all see what difference the project had made. There was to be another meeting between the researcher and each participant after a year or so, to see what had happened. There were also to be meetings between the researcher and the members of GDA's staff team who were supporting each group of participants. Some Personal Assistants (PAs) might also be interviewed.

Each participant would meet with the GDA team member working with their group. They would agree outcomes, activities and timetables, review progress and keep in touch throughout the project. The GDA team member would manage budgets and put in place the necessary support.

During the project there were to be three events held for all the participants to come together, share their experiences and support each other.

The project would end with a conference for anyone who might be interested or who we wanted to tell what we had found out. This included policymakers, care providers and other disabled people.

This, anyway, is what we expected to do. What we actually did wasn't very different, but there were some important changes made along the way.

2. Setting off

“Disabled people don’t dare to dream as they don’t think things are possible – sometimes even the smallest things.” ‘My Choices’ participant

All aboard

Daring to dream

You might think that there would be a huge response to a leaflet asking GDA’s membership (around 1500 at the time) if there was anything they’d like to do, if they had support to do it. We did. We were wrong! To our surprise only a very few people came forward.

Of course, anyone might have to think twice if asked what outcomes they want to achieve in their lives. The challenge of thinking about what you might do is likely to be even greater for people whose lives have long been limited by discrimination, low expectations, low incomes, social isolation, poor health and lack of choice. Such factors destroy confidence and can create a self-perpetuating spiral downwards.

However, there were a number of disabled people who GDA had worked with before on other projects. They often attended GDA events and courses. They knew the staff team quite well and some of them knew each other a bit. Through GDA they had already successfully tried new activities and met new people. It became clear that many of them did have ideas about things they would like to try. They were already a little way down the track – from daring to dream towards daring to do.

“Even though I’ve been involved with GDA for many years, building my confidence, making new friends and learning new skills, I still lacked a lot of confidence when going out and about as I don’t have a support package. I also didn’t get to do the things other people my age would normally do because of lack of money, support and transport to get places.”
‘My Choices’ participant

There were early indications that the quality and duration of the relationship people had with GDA might be an important factor in promoting their participation. It might be because, through GDA, they had already successfully tried new things and met new people and so had gained some confidence. Perhaps they trusted GDA and the GDA team, having previously had good experiences.

“GDA always pay for transport and provide personal assistance so I trust them to make it easy for me to take part. So when I saw the information about My Choices, I felt confident to ask for a place on the project.” ‘My Choices’ participant

“Because I trusted GDA, I felt I could approach them for help and I knew they wouldn’t judge me or make me feel like I had to jump through loads of hoops to get the support I needed.” ‘My Choices’ participant

The participants made for a very diverse group of 16 people. Ages ranged from 18 to 85. One had several degrees, another had been a teacher, while another was unable to read and write. Between them they had a wide range of physical, sensory and intellectual impairments. Some – but not all – had health conditions (it is quite possible to be disabled but not unwell). Some lived by themselves, others with partners, parents or other family members. Some attended daycentres, one was at college, and a couple were in temporary jobs.

It was important to have a very varied group if we were to show that having choice can be important to anyone, can be exercised by anyone and can lead to improvements in their lives. Of course, it was possible that we would find that having choice didn't work for everyone. This is what the project was trying to test out.

It's time to start living the life you've imagined. Henry James

Comings and goings

Although the intention had been to have two clear-cut rounds of recruitment, this is not what happened. There were good reasons for this. It is an example of how the project evolved as it went along, as it became clear that a different, more flexible, approach would be better.

Firstly, one of the participants dropped out after the initial meeting with the researcher. She was one of two people who had no previous experience or relationship with GDA. Both were volunteers with the Commonwealth Games. The second of these came to the first event and was very enthusiastic about it. Both received initial support to develop ideas and outcomes and one received substantial support in his project which ran for some time: this centred around BSL interpretation to allow him to train to become a volunteer with Glasgow 2014. For example, a BSL interpreter enabled him to take part, in a training course, including the social interactions around the whole weekend. Unfortunately, these participants withdrew from My Choices and expressed frustrations and disappointment at the lack of understanding and practical support in relation to access from the volunteer placement provider. These 2 examples also highlight the gaps of Access to Work³ in not covering volunteering.

A 3rd person also withdrew at this stage for personal reasons. It wasn't long before GDA staff came across other people who had ideas about things they wanted to do. They were people who it would be possible to support through the 'My Choices' project. It seemed silly to wait for months until the next recruitment round when there were places and money available for them to come on board right away. It can be important to seize the moment. Months later the course might not be available. Confidence might have been knocked by a bad experience. Personal circumstances might have changed to make it impossible.

The idea of a fixed second recruitment round was abandoned. Instead, people identified in random ways in the course of GDA's activities were given the opportunity to join the project when they wanted to. The number of participants grew and again reached 16. This was the first example of needing to be flexible and make adjustments.

³ Access to Work is a government scheme, administered by DWP that supports disabled people in paid employment with the additional costs of equipment, support and travelling they incur.

First encounters

Introductory meetings

There were initial discussions with GDA staff about ideas and possibilities. In many cases there was already established trust and in all cases trust was built around shared understanding in that GDA is a disabled people led organisation. Encouragement, support and informal coaching were given, even at this early stage to give people the confidence to come on board.

Following this, a meeting took place between each participant and the researcher. This was an opportunity for everyone to introduce themselves, say a bit about their background and their ideas for the project. Some people had lots of ideas and some were not sure or had just one that they had firmly decided that they wanted to do. We talked about the fact that participants could also be researchers and how they might record their experiences.

These meetings were followed up with meetings between each participant and the GDA team member working with their group. They talked through ideas and supported participants to select what they would do. They each began to set up their personal project.

"I spent time with the My Choices worker planning what I wanted to do and what support I would need. I knew I wanted to explore the city, but I was afraid to do so as a wheelchair user as it's been years and years since I was last able to be a "tourist" in my own city."

'My Choices' participant

In addition, personal coaching sessions were arranged with a Life Coach for the young people to develop ideas and personal outcomes. This was important as the coaching was an enabler and a safe space to develop ideas free from prejudice and influence. In many cases this was the first time that the young people had been asked what they wanted for themselves.

First 'My Choices event'

In May, the first of three events for all the participants was held. This was the first time they had all met each other. It was an opportunity to talk to each other about the things they wanted to do and to see if other participants had ideas and suggestions.

They also talked about how they were feeling about the project and what might happen. They listed things they were nervous about, things they were excited about and any questions or ideas they had.

Things people were nervous about included:

- Talking to new people, finding it hard and not knowing where to start
- What happens if you come across obstacles
- People say computing is easy but we've never done it before and we're nervous about it
- Had a panic attack about budgeting
- What happens if I'm unwell when I stay in a hotel for the first time?
- Need contact details for the GDA team so you can contact them if you have a question or a problem.

Things people said about what they were excited about included:

- New friends and meeting people
- Where my project will take me in the future
- Writing a postcard to niece Sally in Australia
- Top of the world confidence and feeling good within yourself
- Writing a story and getting it published
- Got a job (receptionist)
- Starting social care course
- You need to be excited to push yourself forward and achieve what you want
- GDA makes us excited because they make everyone feel the same and help us be ourselves.

There were lots of questions, including:

- What barriers would we face?
- What if I want to do something in which I have no experience? Will there be funding for training?
- What happens if I cannot get my project up and running?
- Will there be after support?
- There are loads of different projects. What advice would you give to picking one and sticking to it?
- What kind of time span are we looking at to start? How long will I have to work on my project?
- If my plan doesn't work, how flexible can we be? Can I change to something else?
- How much do you have to report back to GDA? Can I phone Nick [GDA team member] at any time?
- Will there be more days like this?

Ideas they had about their individual projects and the project overall included:

- Doing counselling having heard someone else's idea.
- Personal safety - would like a course on this.
- Set up a counselling service in an accessible building to prevent mental illness. Maybe a holistic therapy centre for disabled people working on their mental wellbeing.
- Exchange emails and contact details of participants.
- Could we link in with each other if we are doing the same/similar project?
- Give people a chance to speak about their own project in front of the group.

People clearly got a lot from the day. Even at this early stage, and among such a diverse group, there was strong evidence of how valuable participants found sharing experiences and getting support from others. They said:

"It was great to meet other people and to hear about their projects and plans" "It is helpful to hear how other people have overcome their problems. People may come across as confident and in control but it is reassuring to hear that this was not always the case and that they had similar problems to me"

"I found it really helpful to have the opportunity at the last session to ask questions. We helped one another to resolve issues. It is good to share experiences"

"Already the project has taken away a lot of stress for me – I am less anxious"

"Everyone's projects are fantastic!"

But there were worries too. The group felt anxious about not knowing key things about the project, like spending limits or when the project will end. Some were reluctant to ask for additional support or help to achieve new outcomes:

"I'm not sure if there is money available and if you should ask for it. You don't want to ask for too much and you don't want to ask for too little"

"You need to know what the limits are"

While the aim is to be as flexible as possible in the way support is provided, to remove rules and restrictions that just get in the way, it seems that people want to know what the limits are. There need to be some boundaries within which that flexibility can take place. Of course, how wide or narrow those boundaries are could make all the difference. If there isn't enough money or not enough time, no amount of flexibility can enable people to have choice in any meaningful sense.

"Don't let anyone rob you of your imagination, your creativity, or your curiosity. It's your place in the world; it's your life. Go on and do all you can with it, and make it the life you want to live." Mae Jemison

3. Into the driver's seat

"It's been my choice, what I do when I'm out with my PA. I always feel like I have to ask but my PA said I'm the boss." 'My Choices' participant

Where we went

The things participants chose to do were as varied as the participants themselves. Some of their choices might seem more ambitious than others. However, each needs to be seen in the context of the participant. For example, one of the younger participants had never spent so much as one night away from her family. To spend a night in a hotel with just her PA was, therefore, a major step. There were many examples of how confidence was raised through one activity and that motivated people to do other things. For example, for two older participants their journey took in a First Aid course, a Glasgow bus tour and the People's Palace, volunteering with Cancer Support Scotland, sewing classes and saving money by making clothing and soft furnishing.

"We definitely have found that everything we do results in other doors opening for us and we now have full diaries – our families will soon need an appointment to see us!"
'My Choices' participant

There was lots of evidence that doing one thing opens doors to other opportunities and activities.

"My teacher is amazed at the progress I have made. I can now play some songs on the guitar and feel confident enough to practice on my own. This project has opened up further doors for me. I now have increased confidence to go back to a singing group I was part of years ago. I also felt able to take part in GDA computer courses and creative writing which I also enjoy." 'My Choices' participant

Other evidence showed that things did not always happen in a linear or chronological order – it might be that all kinds of things happened at once as lives blossomed in different directions. For example, another participant (from the younger people/ employability group) had been supported to go swimming and join her local gym, to go to the theatre, bingo, the cinema, out for dinner and around the shops. She developed a real love for the theatre and drama (her favourite experience was a trip to see the Rocky Horror Show) and had joined a drama company. She's also now got a part-time job with a care agency and totally loves it!

The activities pursued were, therefore, many and various. They also included taking up specialist healthcare treatment that would otherwise not have been possible, seeking out volunteering opportunities and many more.

There were two broad areas in particular, though, that many people chose to pursue.

Courses

Many of the participants wanted to do courses. It might have been expected that younger people, and/or those seeking to improve their employability, would be most interested in these. Nothing could be further from the truth. Those in the older people group were just as likely to do courses and just as likely to benefit from them in a whole range of respects. This perhaps reflected previous good experience of learning and capacity building on GDA Programmes. There was also no pattern regarding type of impairment. Participants with learning difficulties, physical impairments, visual impairment, head injury, or mental health issues all took and benefited from courses.

The courses that participants went on included:

- Guitar
- First aid
- Spanish
- Art
- Sewing
- Computing
- Counselling

In some cases mainstream classes worked well. One participant (older people group) commented on how supportive and nice the other people on the First Aid course were. There were two lovely young men from the railways, one from a cinema and a secretary, who were renewing their certificates. She couldn't get on her hands and knees to do CPR but they were happy for her to direct them.

"I got on really well with the folk in the class. I also passed the exam to get my qualification. I'm delighted with myself!" 'My Choices' participant

Others thrived better with one-to-one tuition. A participant in the younger people's group had been to Spain on holiday a lot, really liked Spanish food and culture and had always wanted to learn the language.

"I planned it out with a My Choices worker and we found an evening class on basic Spanish. I went with a PA to the class and it was going ok, but after a while I felt the class was too long for me and it wasn't holding my attention even though I was keen to learn. Normally, I'd just give up, but GDA staff helped me to stay focused and find a solution – a one to one tutor. I now have lessons with the tutor every week... When I started the lessons I had a PA with me, but I now go on my own as I'm much more confident and getting on really well with the tutor." 'My Choices' participant

The courses were valuable in their own right in broadening people's horizons, their enjoyment of life and their self-esteem.

"I met with an art teacher who helped me to develop an art project. I had transport and personal assistance to visit museums and galleries for information and inspiration. I was also given a budget to buy art materials for my project. I also got an animation app and learned how to use this. It was so exciting and I'd never been able to do anything like that before." 'My Choices' participant

While any activity might lead to another, in some cases they clearly led on to something else:

"I am making good progress on my counselling course, with only 2 modules left to complete. I feel that I have gained transferable skills from the course and my social skills have also been further developed. I have attended a number of job interviews recently and although these have not yet resulted in a job offer, I feel I am now at least being considered." 'My Choices' participant

Socialising and going out

Inaccessible transport and buildings, and not having much money, can make it difficult for older and disabled people to get out and about. One thing that came through loud and clear (unsurprisingly) was how much people valued being able to get out of the house, to meet with friends and go on trips. Again, this applied to participants of all ages. For older people it often meant once more being able to do things they used to do. For younger people, it was about doing what others of their age would usually be doing.

"For the first time in ages, I could go out and meet friends for lunch, go to the cinema, theatre or just to the supermarket to choose my own shopping. At Christmas time I was able to buy some cards and gifts to send on to family. I was even able to volunteer at a fundraising stall at a Christmas Fair. I've also found out about other organisations and services that support disabled people, like the cinema card that entitles a PA or carer to get into the pictures free of charge." 'My Choices' participant

"I love to do social things and meet up with friends, but I find this so difficult. As well as transport, lack of money is often a barrier to me. Through My Choices, I got transport, personal assistance and sometimes even some spending money to help me get back out and socialise as anyone else my age would do." 'My Choices' participant

Bumps and barriers

"The path to our destination is not always a straight one. We go down the wrong road, we get lost, we turn back. Maybe it doesn't matter which road we embark on. Maybe what matters is that we embark." Barbara Hall

Disabled people routinely experience barriers that stop them doing what they want to do.

"I love getting out and about but inaccessible transport and not having access to personal assistance made it difficult for me to go out and do what I want to in life."
'My Choices' participant

As we discovered, with the right support it is possible to overcome a lot of them. However, there are many that can remain to be tackled.

Attitudes

Past experience of negative attitudes could have a major impact on people's confidence and their willingness to risk repeating a bad experience. One that was mentioned several times was bad experiences with trying to use buses. Drivers could be hostile and refuse to take people in wheelchairs. There could be difficulties caused by competition for limited space with people with buggies and prams. The alternative was to use taxis but this was a lot more expensive. One participant commented that:

"I don't "look disabled" so other passengers and even bus drivers are often very unhelpful, and can even sometimes be quite abusive. This really knocks my confidence and makes me scared to go out on my own." 'My Choices' participant

One participant talked about a bad experience she had when taking her driving test. The attitude of the examiner was terrible and she was certain she had been failed unfairly. It was very discouraging - not that this would stop her trying again if she could find money for more lessons. If she could drive she could go on courses and apply for jobs that were further afield.

Another talked about her experience of starting to use a wheelchair when she hadn't looked visibly disabled before. As is very commonly experienced by wheelchairs-users, people don't speak to the wheelchair user but to the person accompanying them, even if they are asking a question that only the wheelchair user can possibly know the answer to!

"I do find I'm treated differently if I'm in a wheelchair. Get over it!" 'My Choices' participant

There were other examples too. In most cases, parents of younger participants were positive about the impact of their involvement in the project. But one had been very discouraging, and seemed to want to destroy new-found confidence and aspirations.

A couple of participants remarked on the lack of encouragement they had received from their teachers.

"I'm always drawing and coming up with ideas for short films, but my art teachers at school didn't do much to encourage me to pursue art as a career."

'My Choices' participant

Another who was doing a course on counselling was told by her lecturer that because she was disabled she should not bother completing it. She got little support or encouragement, but she was accepted onto the course like everyone else, and paid for it like everyone else too. And, with GDA's support, she successfully completed the course and graduated!

Is it any wonder that disabled people can lack confidence? What is more surprising is that some of us manage to stand up to the negative attitudes that disable and discourage us and go on to achieve our goals regardless.

Poverty

Disabled people are disproportionately likely to experience poverty. We have restricted access to earned income, due to such factors as discriminatory attitudes, inaccessible environments, transport and communication methods – and of course many disabled people are older people who have retired. We can also experience extra costs, for taxis, PAs, equipment and so on. For people with no cash to spare, the impact of cuts to benefits and services can be a very significant barrier to choice and control.

One participant was, through 'My Choices', doing a counselling course and would have liked to go on to do a diploma.

"I'd just not have the money to pay fees and support myself - the fees for a diploma course are in the thousands. You might as well ask me if I'm going to the moon."

'My Choices' participant

Another had almost completed her studies when the introduction of the bedroom tax threatened to bring them to an abrupt halt. She could not afford to pay the tax and pay for the supervision that was essential to completing the course. Introduction of new costs like this, or loss of existing income, must either be picked up by funding from other sources, or individuals will bear the brunt by getting into debt or going without.

It is ironic that the Department for Work and Pensions (DWP) should both force people to take action to improve their employability and seek work, and simultaneously introduce a cut that, without GDA's support through 'My Choices', could have stopped her from doing just that. Moving house was not a practical option and, to continue the course would have meant getting into serious debt:

"I'd have been having toast and beans every night!" 'My Choices' participant

Another participant had been advised by the NHS to undergo a specialist course of treatment that was only available in London. Unfortunately, although the NHS could fund the treatment and training, they weren't able to fund other costs e.g. travel, accommodation, subsistence.

"I live with a number of health conditions including Ehlers-Danlos Syndrome, Meares-Irlen Syndrome and Adult ADHD. I describe my daily challenges as "trying to climb a 20 foot wall without a ladder!" I recently got a place on a unique programme of rehab to develop techniques and approaches to managing my EDS at The Royal National Orthopaedic Hospital in Middlesex. The thought of having to arrange travel and stay away from home filled me with dread – not only the travelling, but the financial aspects too. Through the My Choices programme I wanted to explore ways to manage my condition more effectively so I can concentrate on living my life and develop a career. GDA assisted me to make the transport arrangements and I got some My Choices funding to meet the costs of travelling and staying away from home." 'My Choices' participant

Service design

There were barriers to choice caused by the way in which services were each designed and delivered, and by the way in which different services interacted with each other.

One participant described her experience of home-care services. She said they have so many clients they 'have to fit people in' at times that suit the service rather than the people. It wasn't always the same person that came in the morning but, whoever it was, it was straight off with the nightie and into the shower. It wasn't very nice, but she was used to it because she'd spent time in hospital and that's how it was there.

"I'd be fully washed and dressed by 8.00am then sit there with nothing to do and nowhere to go." 'My Choices' participant

This is the kind of problem that SDS is supposed to address by letting people choose who provides their care.

Some participants described a concern that social work services might not assess them as eligible for Self Directed Support others had fears that packages might only service the most basic of care needs and nothing more meaningful. This raises questions about preventative approaches and the funding available in social care to realistically achieve this in some areas. Perhaps there is a role for the NHS within the new integrations frameworks to become involved in such interventions.

Another participant had been ready with a host of activities, including moving out of the family home to live independently. However, following a setback that occurred, for personal reasons, she withdrew from the project and moved back in with her parents. Although it is difficult to be specific about its contribution to this situation, she had to undergo an Atos assessment around this time. She was very worried about losing her income and her car and found the experience so upsetting that she described the situation as triggering depression. It may not be enough to sort out any one service in isolation from others. There was strong evidence that better integration is needed, between social care, health care and rules around benefit entitlement. Indeed, the previous examples show how the approach to benefit assessment can have an adverse impact on health and social care needs.

The participant who went to London for a course of specialist treatment not only had to deal with the fact that the NHS couldn't fund her travel or subsistence but she had also found herself caught up in benefit rules around being available for work and actively seeking work. As the course lasted 3 weeks she was told she'd have to stop claiming benefits. Her doctor offered to write a letter of support and explanation and GDA managed to negotiate for her to go for 2 weeks, with the DWP treating her as 'unwell' for that period. But what was DWP doing, effectively dictating what medical treatment she could have? Given that the treatment could make a considerable difference to her ability to cope with work, this seemed particularly counter-productive and evidenced real gaps in joined up, strategic thinking.

New horizons

"Though the road's been rocky it sure feels good to me." Bob Marley

The experience of participating in 'My Choices' had opened up new opportunities and new possibilities. There were a lot of general comments echoed by many of the participants.

They said things like:

"My Choices has been really liberating. Being able to make all the arrangements myself, meant I could be flexible about where I wanted to go and when."

"I feel like I can basically have a go at anything"

"I feel more comfortable in myself"

"I'm excited at trying new things"

"I'm much happier"

There were achievements of many kinds that would not have been possible without My Choices support.

"I've got learning difficulties, ADHD and depression...I was supported by My Choices to go to a radio station to read my poem to be broadcast on air. I was so excited but really nervous and I'd never have been able to do it without support." 'My Choices' participant

With regards to one young person who had had a brain injury and who was learning to drive:

"When she started, she couldn't pass the theory test, but through helping her with different ways to learn she has come on leaps and bounds and is far more confident. At first she was only getting 12 out of 50 on the online test, now it's full marks every time!" (PA)

There were many benefits that arose from the experience, not just for participants but for their family members, friends, communities and, on one notable occasion, a complete stranger!

Relationships with family

There were many accounts of how relationships with family members had improved as a consequence of participating in the project. Parents and other family members frequently commented on the positive change they saw in the person participating.

"I'm 85 and have cerebral palsy... I have no family in Glasgow anymore, but I have relatives in Australia who write to me every month. No-one had ever taught me to read or write so when a postcard comes in from Australia, I sometimes have to wait days for someone to read it to me and I have never been able to send a postcard back... My tutor said my progress has been incredible. I completed my first letter to my family in Australia and was able to write and send Christmas cards to each of them for the first time."

'My Choices' participant

One who had been on lots of outings said that it had given her something to talk to my husband about:

"I feel as if I'm quite intelligent again!"

There was also a feeling that relationships had been 'normalised':

"When you're a mother and you're disabled, you swap roles with your kids, and they are the ones that look after you. Now I have some of my independence and confidence back, I feel I can be the mother again." 'My Choices' participant

Reconnecting

For people in the older people's group in particular, the opportunity to go on trips around Glasgow enabled them to reconnect with their past lives and their city. It brought back memories of outings with their kids and even of their own childhood:

"From the Kelvingrove Museum, to the Charles Rennie Macintosh tea rooms, to a Play, a Pie and a Pint, I have seen more of Glasgow than I ever had before...I feel more connected to my city again." 'My Choices' participant

"We went to the People's Palace and that was the first time I had been there since I took my kids many years ago." 'My Choices' participant

Employability

Several participants had improved their employability, either directly or indirectly.

"I have greatly improved my employment prospects by completing and graduating from the post graduate course, something I could not have done without the support of My Choices." 'My Choices' participant

"I am amazed at how much my life has changed, all thanks to some straightforward support from My Choices. The Transcard has given me more freedom, not only to actually go and look for work but to get to University for my course, take part in voluntary activities and live a life where I can afford to get out of the house. The specialist glasses that I bought via My Choices have literally changed my life." 'My Choices' participant

Health and well-being

There were countless examples of the positive impact on health and well-being that resulted from being able to exercise choice. Sometimes goals were specifically health-related.

"Through the My Choices programme I wanted to explore ways to manage my condition more effectively so I can concentrate on living my life and develop a career."
'My Choices' participant

In the case of that participant, 'My Choices' enabled her to take up specialist treatment to help with self management that would otherwise not have been possible. Furthermore:

"I am now exploring options to develop my physical strength and joint stability through joining a gym or climbing club. I'm also researching the support available from an ADHD Coach to help me more effectively manage my daily routines." 'My Choices' participant

Another found that the provision of specialist glasses completely transformed her life.

"I have a neurological impairment which makes it very difficult to be in brightly lit or noisy rooms. It is virtually impossible to sit in an office, go to a training course, event or even a visit a shopping centre. Almost everywhere in the modern world is lit by bright, fluorescent lights, and almost everywhere I go, I am affected by this poor lighting design."

'My Choices' participant

For another, it was more about general fitness:

"I was able to use the My Choices budget to pay for sessions that helped with fitness and upper body strength, plus I bought some suitable gym clothes too. This all made me feel great and I really want to keep all the exercises going."

'My Choices' participant

More often, improvements in health and well-being were a positive spin-off from increased self-esteem and motivation.

"Learning to read and write has had a positive effect on my general health and wellbeing. I feel amazing!"

'My Choices' participant

"I'm in constant pain and that causes depression. It gives you something else to focus on. You don't want to let people down."

'My Choices' participant

"For years I was very depressed, I didn't do anything and I had no motivation. The guitar lessons have made a huge difference to me. I feel so much better. I have my confidence back and feel like trying other things."

'My Choices' participant

It wasn't just the participants whose health benefited from 'My Choices'. On one occasion, so too did a total stranger! Having completed a First Aid Certificate Course, one of the older participants had an opportunity to put her newly learned skills into practice:

"A customer took ill while in a restaurant and I was able to step in and help out. It felt totally amazing, being able to be the "expert" for those few minutes and to help someone in real need!"

Future destinations

Participants' journeys are still underway, and they were looking to the future and what might come next.

"I've just got the exciting news that I'm finally going to get my own flat. I'm going to use my experiences of My Choices to apply to find out if I can get Self Directed Support to help me with day to day activities and tenancy support. I have told my social worker that I know what it's like having a PA and what's possible when I get the right support because I've experienced it!"

'My Choices' participant

Some were coming up with new ideas about things they might do next with 'My Choices', such as a yoga foundation course or taking driving lessons. For one there was a longer term goal and shorter term action through the project:

"I want to get my own house and I'd like to volunteer to build up my skills and confidence. My Choices also gave me transport and personal assistance to meet with the Volunteer Centre to find out how to apply and what's available in my area that interests me."

'My Choices' participant

There were understandably some worries about what would happen when the project eventually came to an end. One person said 'I don't want to think about it. I'd hate it to go to waste.' Others were more positive about the legacy it would have for them. Many were hopeful that friendships would continue. One was getting support to help them identify what they would need when 'My Choices' ends. One said she would continue trying to get back to work, as her health improves. One would continue working towards starting her own business. One said she'd like to have her own PA funded through SDS and not be dependent on GDA or her parents.

The legacy the project would have took different forms, depending on what support a person had received:

"So long as the glasses remain my prescription and don't break there'll be a lasting legacy."

'My Choices' participant

One of the older people who had been on a number of trips around Glasgow said that she would now know what to recommend that visitors go and see and that she could take them to places.

It was clear that some people, with the confidence they had gained, were starting to branch out on their own:

"I've very recently started trying out travelling short journeys on my local bus, and while this is a bit scary, it's fun and I'm managing to do it as I'm generally more confident."

'My Choices' participant

"I've recently joined a local mainstream poetry group and although I don't get My Choices support with that, it's because of the confidence I've built up through GDA that helped me feel able to go along and take part."

'My Choices' participant

It seems that, having gained confidence and tasted independence, this would remain with them.

As one participant said:

"I could carry on that confidence and independence I've had on the project forward for years to come."

"Life is a journey. Don't be a passenger - get in the driver's seat and keep your eyes straight ahead." Abdul Basit

4. Oiling the wheels

"There's a lot of background work you have to do to make things happen."
GDA team member

Fellow travellers

One of the striking findings of this project is the pivotal importance of a number of different relationships. All appear to play an essential role in providing support necessary in different ways to exercising choice.

Central organiser - GDA

Despite the fact that the range of activities carried out by participants was very wide, the support they needed took a relatively limited number of forms.

GDA's role could be summarised like this:

- Helping people to develop their ideas at the outset
- Coaching at the start and ongoing
- Paying for and/ or arranging Personal Assistants (PAs).
- Paying for taxis and travel cards. Arranging taxis and transport
- Paying for subsistence costs, like food
- Finding, arranging and funding courses or tutors
- Arranging life-coaching sessions
- Connecting people with specialists, experts or professionals who can help them
- Facilitating peer support
- Buying equipment, including specialist glasses, computer hardware and software and sewing machines!
- Providing a bit of spending money for social outings

At the heart of successful support were the relationships and ongoing communications between participants and GDA team members, particularly the one responsible for their group, could find out quickly if things weren't working out as hoped for. They could investigate alternative arrangements, agree the best course of action with the participant and put new arrangements in place before the situation got too bad; before arrangements or relationships broke down and confidence was lost.

Whereas sometimes it was important to act swiftly, in other cases issues arose that could cause extensive delays. The gap between paying for something, activity occurring and/ or outcomes being achieved could be substantial.

In one case, a participant was waiting for a kidney transplant. A laptop and software (including characteristic recognition software, printer and scanner) had been bought for him and he was due to have training to set it up and use it. However, he was suddenly called in for surgery, with the result that everything had to be put on hold. This is also one of many examples of the interplay between health and social care.

In another case, a participant was going to spend a night in a hotel, away from the family home for the first time. However, the PA she wanted to accompany her became unavailable. Rather than go with someone else, she chose to wait until the PA came back.

Much as on occasion it is necessary to act fast to 'seize the moment', on other occasions it needs to be possible to wait for the right time. This underlines how important it is that money is not clawed back if it is not spent within a particular time-scale. It could have implications for measuring outcomes – again it needs to be possible to hold off. Of course, there may be limits to how long it is practical to do this, and there may be judgements to be made about whether setting deadlines would be motivating or just create massive anxiety.

Perhaps GDA's previous track record of providing accessible learning, capacity building and building stronger voices of disabled people is noteworthy. Their status as a disabled person's organisation was reported to be the foundation for trust since they both understood barriers and had the commitment to work with disabled people to overcome these. Much of GDA's role entailed making arrangements, finding out about courses or tutors, administering payments, buying equipment, and so on. At times, small amounts of cash were administered where people were comfortable that reporting and accountability would be possible e.g. for spending money, to buy equipment or pay for transport. Making good arrangements was dependent on having local knowledge and contacts. This also meant being proactive in giving people connections, and extending their networks, when the participants themselves would have found it very difficult – if not impossible – to find the right people to approach.

"Using GDA's local knowledge and contacts, we managed to find a guitar teacher who has worked with visually impaired people in the past." 'My Choices' participant

Relationships with PAs

The relationship with the PA is absolutely critical. For some people they became their bedrock of emotional as well as practical support. Finding the right PA was not always easy. It could lead to delays if one could not be found or, if found, s/he became unavailable for any reason. Continuity was imperative. PAs too could become very emotionally attached to the person they worked with.

However, the fact remains that PAs are employed – and paid – to provide support. Sometimes they work for an agency and sometimes for the individual disabled person. At one extreme, the relationship could be one of 'professional friendliness'. But they might be or become friends too.

"I love playing pool, so one of the things I did was go out on a Sunday with a PA. I've loved being able to go out and about with a PA. We've been able just to hang out, go shopping, play pool and have fun." 'My Choices' participant

As with any relationship, it is important not to make assumptions and there can sometimes be 'boundary issues' to negotiate – affecting either party.

PAs involved with 'My Choices' were asked about their role and what they did to support choice. They made the following points:

- It's not about either bossing the other about. There has to be mutual respect.
- You need to be alert to body language and ready to adapt very quickly to any situation.
- Sometimes people can be quite negative. They say 'there's no point, I can't do it'. Problem-solving is important – or rather supporting them to solve their own problems.
- You have to think about practical issues. Is it warm enough?
- PAs don't have responsibility for ensuring health behaviours. 'If they want to smoke all day that's up to them'.
- It's fine to support people to go to parties – though helpful to be forewarned!
- If you work for an agency there can be limits regarding what you are allowed to do, or what you can support your client to do, if it is something that might be dangerous or risky. If you are employed by your client and they want to do something that might be dangerous or risky, you might talk to them to make sure they understand the risks but, ultimately, it's up to them.
- If the PA works for the agency, they are answerable to the agency. If the PA works for the disabled person, then they are answerable to the person directly. As a PA, I prefer this as nothing gets in the way of doing whatever the person needs – for example rules about tasks you're allowed to do.
- Empathy is important:
"You don't know what they've been through. They might have had a bad morning. Everyone has things going on in their lives you need to understand." 'My Choices' PA

While none of this might be terribly surprising, there are implications here for the balance between protection and safety, and empowerment to exercise choice. Could health and social care integration introduce new obligations around 'healthy' behaviour and how will this be defined and regulated? Why should older or disabled people be prevented from taking risks if they want to, like anyone else? Isn't life about making both good and bad choices and learning (sometimes!) from the latter?

Peer support

Throughout the project there was overwhelming evidence of the value participants place on peer support. The three events for all the participants were opportunities for them to talk to each other about their personal projects, as they developed.

Here are some of their comments:

- I didn't really know the people before. It feels like they're going through the same thing and that brought us together
- Other people inspired me to do things that I never thought of trying before. It was quite helpful to hear what others are doing
- Other participants understand what you're going through. I don't feel so isolated
- I was able to get advice from another participant who had done the thing I wanted to do.
- I got ideas from other participants about my project

"I have really enjoyed the My Choices peer support days and these have given me lots of opportunities to support other people and make new friends." 'My Choices' participant

"I've met loads of brilliant people through GDA and My Choices and have some fantastic new friends. We meet up and spend time together which is amazing."

'My Choices' participant

Friends

It was clear that sometime friendships had developed through people's involvement in the project. They met up on other occasions than the events and had become part of each other's wider social circle.

"I've also been supported to join a Saturday art class, where I meet up with another My Choices participant. This gives me the chance to learn art skills and get to know other young disabled people." 'My Choices' participant

However, in some cases close friendships existed before, and they were what gave people the confidence to get through the door and join the 'My Choices' project.

"We have been friends for many years and have supported each other through relationships, illness, cancer, and recovery... We wanted to work on our My Choices project together, to support each other and make best use of our budget as this was all so new to us." 'My Choices' participant

Another two who knew each other before also joined the project together:

"We met at a local day centre and one day we picked up and read a GDA newsletter that had been sent in. Even though we didn't know each other that well then, we both knew we wanted to do something more than just spending all our time in the centre. We wanted to learn new things and try to take more control over our lives." 'My Choices' participant

They both decided to do a First Aid course together. Unfortunately, on the day of the final exam, one of them was unwell, so the other had to take the exam on her own:

"I was quite apprehensive. However, I passed with flying colours, the best in the class! I was so proud of myself. At 83 years of age and having been retired from work for a number of years this is a great achievement." 'My Choices' participant

Two of the younger people group had met about a year ago on a GDA course and had both joined 'My Choices'. To start with, they were going to do the same thing. However, they then decided they would do different things. Perhaps it is helpful to have someone to help you get through the door, even if you go in different directions after that.

All this suggests a role for another form of relationship that goes beyond ordinary peer support and becomes a closer friendship or 'buddying' relationship.

"A journey is best measured in friends, rather than miles." Tim Cahill

5. Overview

Achieving the vision

There is overwhelming evidence that ‘My Choices’ did achieve the vision for SDS described at the start of this report. Participants’ lives were ‘enriched through greater independence, control, and choice’. This was shown to lead to ‘improved health and well-being, and the best outcomes possible’. People were increasingly enabled to ‘choose how they live their life, where they live and what they do’. They did have control of their support. The participants did demonstrate that:

“Everyone, no matter what level of impairment, is capable of exercising some choice and control in their living.” ‘My Choices’ participant

The project also deepened understanding of what much of this means. It showed that support alone, no matter how appropriate, could not remove all barriers. Action by other parties – to change attitudes, make buildings and transport accessible, prevent poverty and redesign the interface between different services – was also necessary. Without this, there were and will remain, avoidable and unjustifiable constraints on ‘the best outcomes possible’. That said, ‘My Choices’ showed much about the nature of the support that people controlled; that it was swift to react to change and proactive in finding solutions and sourcing what was needed, and that it could involve a number of people in different roles.

In terms of the value of ‘independence’, everyone was supported to maximise their aspirations and potential. However, there might be tensions between having a right ‘to be safeguarded and protected’ and being able to choose for themselves what level of risk they were comfortable with; to take responsibility for safeguarding and protecting themselves, or choosing to experiment, take risks and take the consequences – just like anyone else. It was arguable that the priority for support was not ‘the prevention of increasing dependence’ – if that meant dependence on support. While there were examples of increased confidence leading to a reduction in reliance on PAs, to exercise choice might be contingent on having (the right) support. Independence, defined as having choice and control over your life, might therefore only be achieved through having support, rather than describing a situation where a person doesn’t need support.

As for the value of ‘freedom’, the things participants wanted to do – to pursue their interests and learn more about them, have a social life, go out and about, have good relationships with family, make new friends, help others with their skills or through volunteering, look for work – were the stuff of what goes into the ordinary, fulfilled lives of any other citizen. If their achievements were extraordinary it is because of the barriers that stood in their way when it came to doing what anyone else might take for granted.

“You have brains in your head. You have feet in your shoes. You can steer yourself any direction you choose.” Dr. Seuss

Questions answered

The My Choices project provided clear and rich answers to the research questions that were posed at the outset.

There were many examples of what older or disabled people could achieve with the right support. Interestingly there were great similarities between the 3 groups, and no obvious patterns according to type of impairment or other characteristic. It emphatically showed that choice was valued and could be exercised by all, and that all were capable of developing skills, confidence and achievements. It also started to show what older and disabled people can contribute to their communities, transforming them into active citizens.

There was no obvious or consistent relationship between the amount of money that was spent on support and the scale of its impact. For example, the literacy classes attended by one 85-year-old participant were free. Spending a few hundred pounds on a specialist pair of glasses transformed the life of another. Equipment bought for some people totalled £400 in one case and £2000 in another. One package was as much as £5000 for BSL and others involved mainly transport costs from a few hundred pounds to £2000. It would be meaningless to talk about an average cost as the driving factor was that support was person centred and linked to self-defined outcomes. How do you measure such impacts? You can quantify pounds and pence but what value can you put on being able to read and write for the first time in your 85 years? How can you put a price on having your life transformed?

The benefits arising from having choice and control over support were clearly many and varied. In some ways it was a bit of a vicious circle, though. To exercise choice and control required confidence. And confidence grew from being able to exercise choice and control. It showed that action is needed to get people to a place where people have enough confidence to give it a go.

There were many examples of positive knock-on effects. Sometimes doing one opportunity led fairly directly to another. Confidence acquired through one success, motivated people to strive for more. Sometimes a person's journey led from one activity to another sequentially. Sometimes it was as if many aspects of their lives blossomed at once!

The value of peer support and social networks was emphatically shown, and they definitely increased throughout the course of the project. It would be possible to sustain an argument that social isolation that is so destructive and that it is relationships of all kinds that form the bedrock of people's lives. It is these, more than anything else, that require to be strengthened.

It was clear that, whatever the quality of support, there were barriers to independent living that require additional action to be overcome. Having flexible, well-funded support will not change other people's negative attitudes, cause buildings and transport to become accessible or services of different types to smoothly integrate. If these were addressed, opportunities of all kinds open up and support needs reduce.

A great deal was learnt about the nature of support required to promote choice and control. It implies a new model, distinct both from traditional approaches to services and, in many respects, that proposed by SDS.

New models

Delivering support

The approach to this project was to start with the vision for SDS and work backwards to explore the implications for the sort of support that could bring it about. It is striking that the model that emerged bears little resemblance to the four options available with SDS⁴. That is not to say that the learning from 'My Choices' about how to support choice is not relevant. There is a lot here that could be incorporated into policy and practice around SDS. Indeed, SDS could provide an excellent starting point on which to build.

The key features of the model of support that emerged can be summarised like this:

- It involves a number of different relationships with a number of different parties, each with different roles to play:
 - o a central organiser (GDA). The principles of trust, shared understanding and commitment to independent living was critical. Who would that be in an SDS set-up?
 - PAs
 - Peers – bearing in mind that people with very different characteristics can still be peers when it comes to sharing an experience. Where might people who use SDS get peer support from?
 - Close friends/ buddies. Pre-existing relationships can be important to building confidence to make a move. How could that be accommodated by SDS?
- Timing is critical. Sometimes it requires fast action – to intervene when the opportunity is there and the person ready, or where something isn't working and to put in place alternative arrangements. Sometimes it means accommodating potentially lengthy delays. SDS expenditure and outcome measurement systems need to reflect this.
- The central organiser needs to have local knowledge and contacts. Where would this come from with SDS?
- Support is required for transitions to take up new activities but also, as importantly, to maintain existing networks and activities as well as pursue new goals. Support must remove barriers to moving forward. What does this mean for an outcomes-led approach?
- There could be a key and perhaps generic role for life coaching / counselling, particularly for support around points of transition/ change. How might that be reflected in SDS?
- It is noticeable that the model of support is not just about finding the right PA but about being able to call upon a variety of experts, tutors, to carry out specific tasks. What would the implications of this be for SDS packages or support organisations? Who would find such experts?
- It also entails arranging specific activities, liaising with external bodies (e.g. art college) and events. Who would do this in SDS model?

³ People can choose if they want to

- Have money(a direct payment) to buy support themselves
- Have it allocated to a provider that they choose while the Council holds their budget
- Let the Council choose and arrange their support
- Have a mixture of these.

- Perhaps it is worth exploring health funding within the emerging context of health and social care integration. One idea is that this could fund preventative packages or top up already funded packages which cannot stretch to fund more than basic care needs. Another approach might be that health jointly funds along with social work.
- Since independent living crosses all areas of life, the possibility has emerged that other public bodies such as colleges, those responsible for Community Learning and Development and others might be part of the overall contributors to packages of support. This would require radical restructuring of services and approaches.

Lives are multi-faceted. Under normal circumstances, they are fluid, they chop and change their course all the time, sometimes in little ways, sometimes in big. But the way traditional services work is to carve a person's life up into pieces and then damn each bit up in different ways with rules and restrictions. SDS certainly promises a more flexible approach. However, there is a lot here to consider, not just about how support might be designed to enable choice and control when it comes to social care, but how it can unblock the damns created by other services and enable people's lives to flow freely.

Research methods

Participants used innovative and creative methods to gather, record and present their own evidence as they chose. Through this each made a unique contribution to the overall learning from the project. They challenged the idea of who researchers are and that research findings have to be communicated in a formal report if they are to be credible.

At the last meeting of all the participants, the researcher and the participants talked about what they had found out and what would go in the report. Participants agreed that things they had said could be included.

This report is just one of the many outputs from the research. They each tell part of the story and they tell it in different ways. The audience for this work is potentially very mixed and could have different communication preferences. Some might like to read the report. Others might prefer to watch or listen to a DVD or look at photos. Participants each had a box for keeping anything to do with the project that they wanted to collect. Some people took photos and made scrap books. A DVD was made of interviews with the participants at different stages of the project.

The conference that is to take place after a year or so of the project will be an opportunity to showcase all of the outputs. Participants had lots of ideas about how they might exhibit their work. They were involved in planning the day and will play an active role in delivering the event.

There was much about this approach which conformed to the ethos of co-production and equal partnership. But it is a first step towards a new model – there is more to explore about the implications of co-production for participatory action research.

Travellers' tales

At the last meeting of the whole group, they discussed what they wanted to tell other people about their experiences of 'My Choices'. The main themes of the messages they wanted to send (see appendix 2 for a fuller list), in particular to other disabled people were as follows:

- Have confidence in yourself, believe you can do it and be positive
- Get active, don't be passive, take charge. You're in charge of your choices.
- It can change your lifestyle – making you have a healthier life. It gives you something to look forward to and to get up for in the morning
- You'll feel better about yourself. You can increase your confidence you can improve your skills. You'll get a sense of achievement on completing an aim, e.g. certificate.
- You can overcome anxiety and barriers like inaccessible transport. GDA can help with costs, and you'll get loads of advice and help with things you would like to do
- You'll meet new people/friends and get peer support, with opportunities for sharing ideas and thoughts
- It will open doors for you – and it's fun!
- Small amounts of money and support go a long way and can be life-changing.

Ultimately, what 'My Choices' showed is that there is nothing inevitable whatsoever about being old or disabled and having a poor quality of life. So long as you have choice and the right support, your life can be amazing.

The journeys that participants embarked upon have shown what can happen with the right support and if you have the courage to dare to dream and then to do. The final word goes to a participant who powerfully talks about the impact of just a glimpse of what life could be like:

"On that trip to London my eyes were truly opened to the possibilities of what my life could become. It was only 36hrs, yet in that small window I experienced the way I would love to feel every day of my life. It wasn't perfect. I was still exhausted by lunch, and barely able to walk by the end... But it felt amazing and I cannot remember the last time I was so relaxed and totally sure of myself.

That confidence I felt on the trip, and almost complete lack of anxiety, was the polar opposite of how my daily life plays out. It shows that with the right support I can achieve far bigger things than I would have ever dared dream before."

A bit more about action research

Action research is a method often used by practitioners concerned to improve their practice. In this case, it was carried out by all parties, as fits well with Self-directed Support and its emphasis on co-production, shared responsibility and the scope for all to learn and make positive changes.

A process for action research can look like this:

- Take stock of what is going on
- Identify a concern
- Think of a possible way forward
- Try it out
- Monitor the action by gathering data to show what is happening
- Evaluate progress
- Test the validity of claims to knowledge
- Modify practice in the light of evaluation (see McNiff and Whitehead 2010 *You and your action research project* (3rd edition) London: Routledge)

This process was reflected in the My Choices action research as follows:

Take stock of what is going on	Introduction of SDS promises new opportunities for choice and control.
Identify a concern	Budget cuts, risk aversion (social work/ providers), lack of confidence (disabled people), narrow horizons (all) mean that choice and control are not realised.
Think of a possible way forward	Demonstrate value (cost/ benefit) of choice and control, what disabled people can achieve, how to deliver.
Try it out	My Choices project within SDS Roadtesters.
Monitor the action by gathering data to show what is happening	All parties gather and record evidence on an on-going basis. Regular monitoring catch-ups over 6-8 month period.
Evaluate progress by establishing procedures for making judgements about what is happening	Action research as evaluation process. Initial interviews with participants to establish baselines and desired outcomes. Research questions promote consistency and focus for evaluating data.
Test validity of claims to knowledge	Play back analyses and conclusions to participants and external parties, via dissemination event.
Modify practice in light of evaluation	Conclusions communicated to external parties, with a view to promoting positive changes to attitudes, practices and behaviours.

Appendix 2

- Improves social skills and you meet new people
- Costs are helped with taking the pressure off
- Gives you an aim and a reason to get out of bed in the morning
- Sense of achievement on completing an aim, e.g. certificate
- Overcoming anxiety helped by support and friendship
- Can feedback to other people
- Tell your family about your day
- I became a volunteer through GDA
- Small amounts of money and support go a long way and can be life changing
- Peer support
- Overcoming barriers - e.g. transport and bus drivers, GDA helped with costs
- Viewed it through a rights based approach, e.g. I have a right to be on the bus
- Sharing ideas and thoughts
- Believe in your yourself
- Increase your confidence you can improve your skills
- Great opportunities
- Let people know it's available
- Don't worry – support is there
- If you don't know, don't be afraid to ask
- Have confidence in yourself, believe you can do it and be positive
- Get active, don't be passive, take charge
- You'll feel better about yourself
- Its great fun
- You'll gain new skills
- You'll meet new people/friends
- It's given me a reason to get up in the morning
- It will open doors for you
- Giving opportunities
- Giving freedom
- You're in charge of your choices
- Confidence – makes you feel happy helping disabled people achieve their dreams
- Changes your lifestyle – making you have a healthier life. It gives you something to look forward to and to get up in the morning
- It's fun and interesting
- Don't need to worry about someone dropping you off or picking you up
- Meet new people and make new friends
- Takes your mind off of things
- Loads of support
- It's motivating!
- Loads of advice and get help with things you would like to do


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