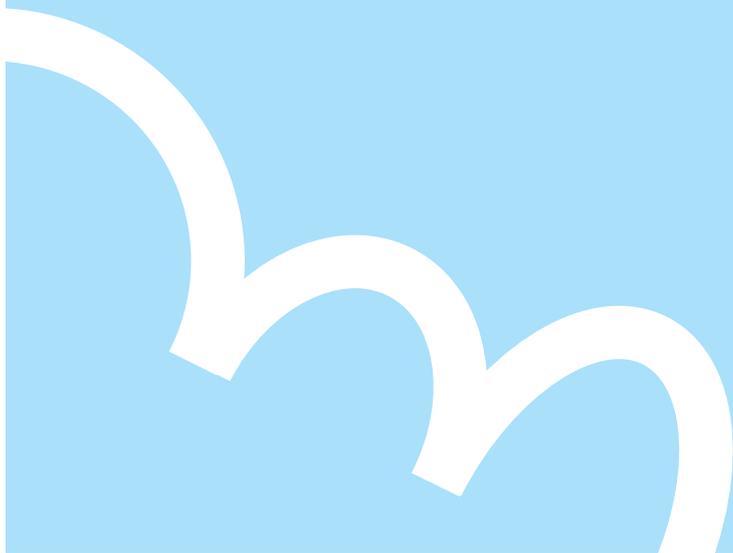




# Getting There: Our First Year



# Dedication

This report is dedicated to Geraldine McGuinness, who died on January 1st 2013.

Gerry was a volunteer with Grampian Opportunities who contributed a great deal to Getting There over its first year.

Gerry's aim was to create as many choices and opportunities as possible to enable users of direct care services to live a good fulfilling life. Having managed her own life, with limiting conditions, for many years she was well placed to advise the project about the complexities of organising domestic help and support. Recently she had successfully employed a Personal Assistant under the Direct Payments scheme and was beginning a new and more relaxed period of her life. The process was not without its difficulties and she was in a wonderful position to make suggestions and share her frustrations and joys.

Gerry was passionate about the Getting There project and, as in everything she took on, had very high standards to aim for. She had a great belief in peer support and in the importance of this approach. She brought a wonderful enthusiasm and insight whilst never losing sight of the overall vision.

Gerry was a great, inspirational lady who touched the heart of many people. We will miss her.

## About Getting There

Getting There is a network of user-led voluntary organisations which provide social care services. We are working together to learn more about how we can use the opportunities from Self-directed support (SDS) to benefit members and the people we support.

Getting There is based at and supported by Outside the Box, which is a voluntary organisation which provides community development support to people and groups across Scotland. The project is funded through the Scottish Government programme to build capacity in service providers as part of the introduction of Self-directed support.

The funding was awarded in October 2011 and the project runs to March 2015. This report describes what we did over the first year, what we have learned and what we plan to take forward into 2013 as plans for the implementation of Self-directed support in Scotland move forward.

### What we mean by user-led services

Getting There takes a fairly flexible approach to a definition of 'user-led'. This reflects the very wide range of groups which are part of the network and which expect to be involved in various ways in the development and implementation of SDS.

The people who use the services that the organisations provide have a significant role in leading the organisation and setting the scope and quality of the services that are provided.

The people who use the services usually are also involved in delivering the services, either as staff or volunteers, or through a peer support role.

The ethos and values of the organisations are based around being led by the people who use the services or share those experiences and circumstances.

The groups provide social care services which bring direct benefits to the people who get support. This may be in addition to having other activities such as representing the views of people in these circumstances, contributing to training for other organisations, working towards an inclusive community or delivering services that benefit more people within the community.

Most of the organisations that are part of the wider Getting There network work in a local area or across a single local authority area. But some have a wider spread and are supporting people in several local authority areas.

## What else was happening during this year

During this past year many of the smaller, user-led service providers said they felt that there was a lot of uncertainty for them.

Initially there was uncertainty about the timing and scope of the proposed arrangements for Self-directed support. The responses of some staff in local authorities in discussions with voluntary organisations added to the inconsistent information and sense of anxiety in some places.

The Bill to establish Self-directed support was introduced in the Scottish Parliament at the end of February and was followed by a period when people fed in views and sought to influence the final legislation.

It felt more settled once we knew what was being planned. But the message in some parts of Scotland from the local authority over the next few months was different and this again caused uncertainty. We also knew that some of the proposed changes to the Bill would reduce what many of the people involved in the user-led groups saw as the main potential benefits for both this type of organisation and for people looking for support.

The Bill was finally passed by the Scottish Parliament at the end of November 2012. This meant we knew what was included, what was not included, and what would get covered in the detailed implementation arrangements. The proposed changes that would have weakened the legislation were not successful while some changes that we thought strengthened it were successful.

During this year there have been useful events and discussions about aspect of SDS and its implementation. These have been provided through CCPS (Coalition of Care and Support Providers in Scotland) and other organisations and consortia as part of the packages of capacity building programmes funded by the Scottish Government.

Groups who are part of Getting There have also been part of discussions and events organised by the local authorities. This has been more patchy: some local authorities have done much more than others to spread information about SDS; and in some places the information presented has suggested that SDS is going to focus on Direct Payments as they are currently available, which is only part of the new range of options under SDS for people using care services.

There have also been other developments which affect user-led organisations which provide care services. Many groups are worried about recent and future cuts in income through the contracts and grants from the local authorities. Many voluntary organisations are also describing a lower success rate in grant applications to other funders as charitable trusts receive more requests at a time when many have less money to distribute.

Some user-led providers have started major new projects during the past year, with funding through the Change Fund to support Reshaping Care for Older People or through grants from the Big Lottery Fund.

Some of us have been reviewing our constitutions and moving to become a SCIO (Scottish Incorporated Charitable Organisation), as this model is now available to existing charities.

We have continued to have the ups and downs that face many smaller voluntary organisations, such as changes in committee membership, staff and volunteers joining and others moving on, moving premises, and all the day-to-day activities that we deliver.

*“Local authorities tend to see SDS in terms of the way services are organised now, rather than understanding the full potential this opens up. In particular they are not seeing SDS the way we and other user-led service providers see it. It feels as if we are waiting for other people to catch up with where we are in our thinking.”*

## What we did

There are 3 strands to Getting There.

- A shared learning network, where people from a few projects undertake to do some in-depth learning about SDS and then share this with each other and with other groups.
- A wider network of organisations and people who are user-led groups or who are interested in this aspect.
- Gathering together useful materials and contacts, to give people more information about SDS and the options for them.

During the past year 3 organisations have been part of the shared learning strand: Grampian Opportunities, Stepping Stones and Stirling Users Network.

**Grampian Opportunities (GO)** is based in Inverurie and has members across Aberdeenshire, Aberdeen and Moray. Members include people with physical disabilities, sensory impairments, learning difficulties, people with mental health problems and some people who also take on carer roles.

The range of activities we provide at late 2012 includes opportunities for people to develop their skills and confidence through contributing to the organisation – such as the office roles, marketing, organising events and more, a mentoring service, and opportunities for people to contribute their views about the services available in that area. There is a strong peer support element to everything GO does. There are around 40-50 people at any time who are taking on roles of member, service user and volunteer.

GO has a team of people who are the main contacts with other networks and organisations and who lead the discussions about SDS and the potential it brings within the organisation. This includes people who have director, member, volunteer and staff roles.

We are also part of the SDS capacity building project for voluntary organisations in rural areas which is co-ordinated by ARC (Association for Real Change) and in developments co-ordinated by Aberdeenshire Council.

We identified a gap in the support available to people to plan what they wanted in their lives and to get the best from the options that will be available from SDS. We developed a plan for a training package and have received a 1-year grant from the Scottish Government to pilot and refine it. Once the resource is ready we will be sharing this with other organisations and people across Scotland.

**You can find out more about Grampian Opportunities at: [www.grampianopportunities.org.uk](http://www.grampianopportunities.org.uk)**

**Stepping Stones** is based in Clydebank and supports people across West Dunbartonshire. It is led by people who have personal experience of living with mental health problems. Around 600 people are in touch with Stepping Stones each year – some for a specific type of support over a short period, while others keep in touch with the organisation over many years.

The peer support elements run through the organisation's activities. All of the support is person-centred. Some of the ways we offer support includes counselling, peer support social and other groups, individual support, CBT (Cognitive Behaviour Therapy) approaches, and WRAP (Wellness Recovery Action Planning).

Stepping Stones spent much of the first year of Getting There making contact with people and organisations in the area who were interested in SDS, including local authority staff and other projects which are part of the capacity building programmes funded by the Scottish Government. Progress on SDS in West Dunbartonshire has been slower than in some other parts of Scotland and this initial stage took time and effort.

Stepping Stones also tracked down other people who had used SDS to support people who have mental health problems. This included services and research teams in England and other projects and organisations in Scotland.

The slower pace of developments on SDS in West Dunbartonshire and for people with mental health problems nationally has made it difficult for members to see what the issues are going to be for Stepping Stones or for themselves as individuals.

In autumn 2012 Stepping Stones decided to take a step back from the lead groups in Getting There. We may get more involved later, once the pace of development on SDS picks up.

**You can find out more about Stepping Stones at: [www.stepstones.org.uk](http://www.stepstones.org.uk)**

**Stirling Users Network (StUN)** brings together people who have mental health problems. It began as a collective advocacy project, providing a way for people living in the Stirling local authority area to have a collective view on issues that affect them. This included contributing our views on proposed service developments in the area and contributing to professional development for future staff who will be working in mental health services through links with the University of Stirling.

The service delivery aspect of StUN is growing out of the representation work. People enjoy meeting each other and we started organising regular sessions each week. Now members provide peer support for each other and people come together to work on crafts.

Over the past year or so our members have identified gaps in the range of services that are available in the area. We fed in views on this to the process for planning future services. But we also thought that one option would be for StUN to develop what we do and provide more service ourselves.

The development worker and members of the committee came to the shared learning events in the summer and StUN is now one of the lead groups in the regular sessions.

**You can find out more about Stirling Users Network at: [www.stunscotland.org.uk](http://www.stunscotland.org.uk)**

We had the first joint shared learning session in February. Since then, we have had further sessions in May, August and November 2012.

Over 200 people are on the circulation list for the wider network, many of them feeding back to others in their organisation. Some individuals and groups are more actively involved than others, feeding in questions and contributing to draft materials from the project.

We try to give groups information on specific points and questions or put them in touch with other people and groups who are interested in the same aspects of SDS. During 2012 we have met with members, committee members/directors, volunteers and/or staff at 9 user-led organisations or networks of smaller organisations to talk through the issues around SDS that affect them and hear their views on how the Getting There project can help them.

We have worked together to contribute to the wider discussion around SDS.

- We contributed written views on the Bill and circulated updates on its progress, especially on the aspects that are priorities for user-led and smaller providers.
- We developed Discussion Papers on topics that emerged from the shared learning sessions and which other members of the wider network said were also issues for them.
- We contacted people who have been leading developments in other parts of the UK to find out about their experiences, for example around the ways SDS has worked for people who have mental health problems and for older people.

## Where to get more information

We published a paper which described the issues facing user-led providers around SDS in early-mid 2012: [http://www.otbds.org/assets/uploaded\\_files/project/priorotyissuesforuserledproviderspaper.pdf](http://www.otbds.org/assets/uploaded_files/project/priorotyissuesforuserledproviderspaper.pdf)

One of the issues that people in the Getting There network said were important for their groups is broker support, to let individual people get the best from the SDS arrangements. We published a discussion paper on this: [http://www.otbds.org/assets/uploaded\\_files/project/Broker\\_paper.pdf](http://www.otbds.org/assets/uploaded_files/project/Broker_paper.pdf)

Information about and from the project will get added to our website page as the project goes on: <http://www.otbds.org/gettingthere/>

# What we have learned

*“We see this as an exciting time for organisations, and look at how we can use the opportunities to benefit people.”*

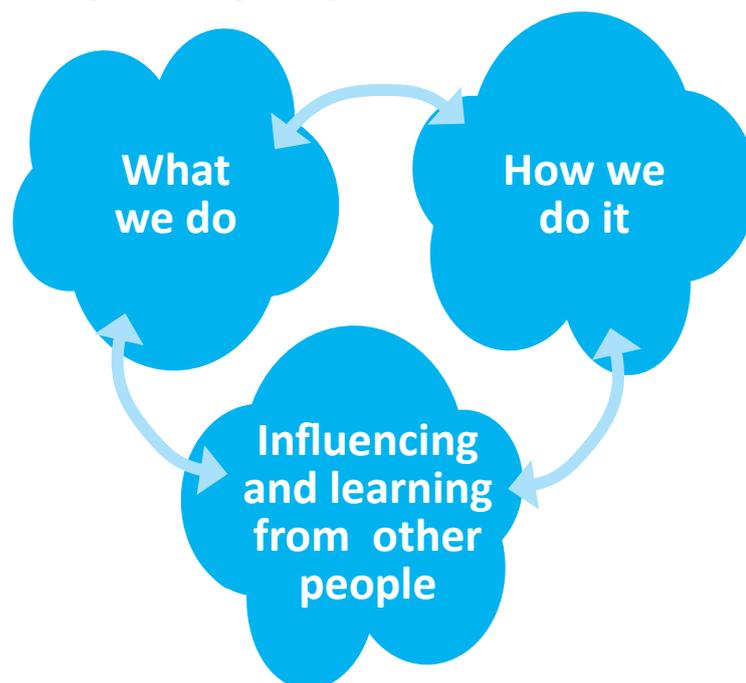
*“We are proud of what we do ourselves.”*

*“We are learning that we have a lot to contribute to the overall development of SDS in Scotland.”*

## What works for our members

- People need to see the potential benefits for SDS for them in their own lives and how it can make a difference to their situation before they get involved in considering what SDS can mean for the organisation.
- Once they do see the opportunities they bring their enthusiasm as well as all their experience of living with a disability or condition as well as of receiving services.
- It is much easier for people to understand about SDS when there are examples of people living nearby who are using flexible budgets or are having good experiences with Direct Payments. It is harder for people to see the potential when all the examples they hear are of people with different situations from theirs.
- It is hard for people to look ahead when they are feeling anxious about possible cuts in the services they receive or in their own income. This can be due to articles in the newspapers and what is happening to welfare benefits rather than about the specific care services that person receives.
- Regular small updates on what is happening on SDS and benefits for people in touch with the group or for others in similar situations has a better impact than one big information push. For example, Grampian Opportunities and Stepping Stones both started a regular slot on SDS in their newsletters and have an SDS section on their websites. Other groups in the wider Getting There network are also starting similar regular updates for the people they know.
- Once the changes around SDS start becoming real and people are hearing positive messages from a range of sources it will be easier for people themselves and for the organisations they are part of to get more enthusiastic and more involved.
- We are learning not to force the pace. One of the benefits for smaller organisations is that it is generally easier to make changes to structures and processes than is the case for large organisations. We are finding that it helps to remember that there is still enough time for smaller organisations to adapt when we need to, so at least for now we can go at the pace that is right for each organisation’s members and people we support.

## Aspects of how we work



- The ways in which user-led service providers work on any topic are important and are especially relevant to the development of SDS. These are aspects of how we have worked when producing information for members about SDS or developing new activities that will make it easier for us to respond to the emerging opportunities. They also apply to how we develop other initiatives.
- We identify gaps by listening to the experience of our members, so from the beginning we are drawing on and valuing the views and experience of people who use or want to use support and services.
- We make things simple – so we can have discussions with our members and other people, and many people can contribute.
- The process we use to develop things involves lots of people helping – so it brings in a range of experiences and views, and people own and understand what is produced.
- The process is inclusive – good fun, welcoming, enjoyable, valuing people, making it easy for people to contribute.
- The process is interactive. We try something, get feedback and think about how it can be improved. Then we try it out with each other and other people can also give ideas. The aim is to make it better than it was at the start.
- We also draw on the experience of other smaller, independent, user-led groups. We know that we have similar values and similar ways of working, even if the circumstances of members are different.
- We use and create opportunities to meet other people and organisations who are interested in the topics that are important for us – voluntary organisations and staff from local authorities.

- We are learning from the experiences of other people and organisations across Scotland and other parts of the UK around Self-directed support. This is showing what is possible around SDS. It also confirms the benefits SDS brings to members and people who need support.
- We find it helps when we know about the topic. For SDS, this includes finding out about the policies and legislation through the Scottish Government, information from national networks including Getting There and the Personalisation and Providers network based at CCPS (Coalition of Care and Support Providers in Scotland), and local networks in our own areas.
- We have a dialogue about different ways of doing things, rather than more examples of what is already there, which will enable the people who use services and others from the communities to be more active in providing services. For SDS, this includes a dialogue with other people about different ways services can work and different types of support.
- We look for opportunities and positive aspects of new policies and financial arrangements, while being aware of the potential risks and disadvantages.

### Discussion point

It will be good if we can find a term other than 'service user' because that reflects a limited view of how people contribute.

### Discussion point

How do we take a step back to think about people and their lives first, before we think about care services and what they do? The starting point should be: what can help anyone in that situation?

- The development and introduction of new ideas is part of the continuous process of building the organisation. The SDS work has meant looking at ourselves as organisations. However, it helps when an organisation has enough funding to do this, and this can be especially difficult for smaller organisations. The Getting There grant has helped and we are also following up other sources of support for this.
- The approach of trying something, learning from it and improving on it also applies to ideas developed by other people. We can adapt what other people have done and use their experience to build up skills and experience within our organisations. One example is have someone from outside and someone inside our organisation working together as co-trainers, to get the best of 2 people's skills and experience.

- Challenging expectations and assumptions about the role of people who use services in part of what many user-led organisations do, including those which also provide support services. We try to keep doing this within our own organisations, as part of continuously trying to improve what we do. We also challenge expectations in the ways other organisations see people and organise things.
- We encourage members/service users to get involved and take on more roles. The 3 aspects reinforce each other: building confidence and skills for individuals, bringing benefits for people and achieving good outcomes for them, and learning from the process.
- The activities we provide grow out of what happens naturally between people, such as the mentoring and time banking which Grampian Opportunities has developed.
- We start with a small project, usually with a small level of funding. This then grows into something bigger as we get the evidence of need and impact and have more experience on how to make it work well.
- We are small enough to be flexible. We are able to meet a variety of needs and adapt as people's needs change.
- We are small enough for everybody to take responsibility and own what the organisation does. We don't lose sight of what we are doing and why we do it.
- We've learned that the types of funding we look for and use also need to be flexible enough to reflect the ways we work.

## **Working with other organisations**

- We see the strengths in meeting people and organisations from different circumstances and places. It is good to meet people within and outside the statutory organisations and from organisations which work in traditional ways and others with less traditional approaches.
- It is worth the cost and effort needed to use the opportunities that are available to meet with other organisations. But this is still a big commitment for small organisations.

## **What we have learned from Getting There – our advice to any user-led provider and the people who work with us**

- The ethos and values of the organisation need to stay the same in whatever a user-led provider does around SDS.
- Use the opportunities to influence local policies and practice on SDS.
- Having as much or more knowledge about SDS helps. Find what the policies are and the good practice from elsewhere.
- Remember that this is about people getting support to let them have the life they want, which is much more than receiving services.
- Take or make the opportunity to think about what SDS means for the organisation – such as delivering services in different ways, taking on different roles such as broker support, different types of partnerships, and how the internal aspects of the organisation work.

- Those involved in finding out about SDS and having conversations about it need to report back to the board and others in the organisation. Keep the internal dialogue going.
- There is an opportunity to think about what parts of SDS each user-led provider gets involved in. It does not have to be in the ways that other people expect or assume, or along the lines of what that organisation has done before. For example, GO has identified the pre-planning stage for people and the benefits of a range of options around broker support to give people choice there as gaps which it can help fill.

*“We all need to take the bigger view – the longer-term, and how SDS can benefit many people.”*

## Our vision - opportunities for people in Scotland who use support

User-led groups that provide care services as well as doing other activities are part of shaping the opportunities for people and shaping the ways in which support is organised to help make this happen.

We are doing it ourselves, doing it now, valuing our own experience, and working with other people.

There are more links with others in voluntary sector and wider community groups – social inclusion as well as care services.

There are partnerships with other projects and providers. Together we are delivering the range of supports that people want.

We are making good use of the opportunities for partnerships with local authorities to raise awareness among people currently or potentially using services and to develop new services.

There is dialogue with people who will be using services. We are having this ourselves and we are a conduit for people to be part of this wider dialogue.

There is a much wider range of types of services as well as support to use the ordinary opportunities that are there for everyone.

The range of people and organisations who provide that support is also wider.

Organisations and community groups are hearing about and responding to gaps for the people who want care and are using the potential of SDS to do this.

We are all involving more people in the process, especially people who tend to get missed out.

## Looking ahead – our plans for the next year

We will continue to share ideas and experiences through the Getting There network and the other networks we are part of.

We want to get in touch with more user-led support providers and reach groups that may not yet think of themselves in this way or see this as an option for them.

This is what we want to do over the second year of Getting There. But we want to respond to the opportunities that emerge and the suggestions and ideas that other people have. We hope that this report will encourage that dialogue.

We want to learn more about and get in touch with other user-led organisations in the UK. This includes organisations that are delivering care services and those that see themselves as mostly doing other activities such as peer support, speaking up for people and promoting and creating opportunities such as employment.

We want to find more ways to contribute to national and local implementation of SDS which are effective and realistic for organisations of our type and size.

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