Priority Issues for User-led Providers
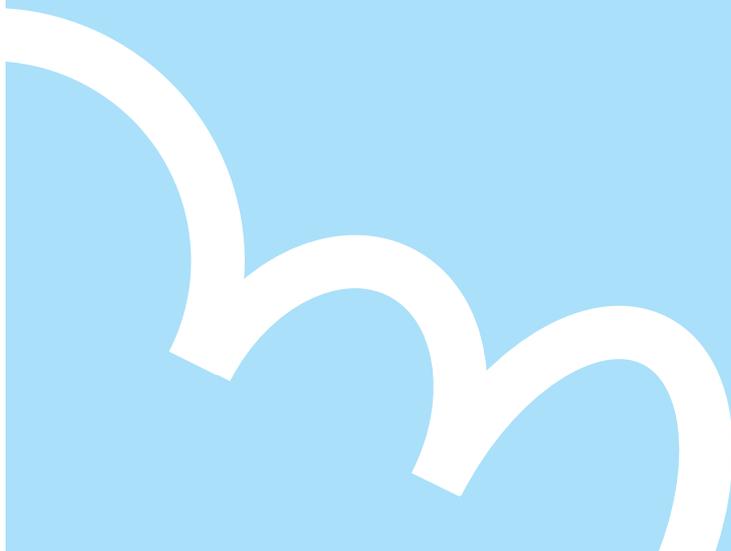
Getting There Information Note

Outside the Box

August 2012

Priority issues for User-led providers

- Understanding about Self Directed Support.
- Getting more choice for members and other people who get support.

    Increasing choices and Personalisation for individual people.

    Care Management Role.

    Discussions with local authorities and with other providers.

- Strategic direction of the organisation.
- Governance of the organisation.

    Option of becoming a user-led broker service.

- Office systems and publicity.

About Getting There

The Getting There network brings together user-led groups which provide social care services who want to learn more about Self-directed Support and what it can mean for voluntary organisations like them.

The project has grant support from the Scottish Government as part of the programme to develop the capacity of service providers as part of the planning and implementation of Self-Directed Support in Scotland.

- Several hundred people and groups are part of a wider network. They identify issues that they want to learn more about and feed in their views and experiences.
- A few organisations are part of the in-depth shared learning about SDS.

About user-led services

A user-led service is run by the people who use that particular service, or by people who share a common illness or disability or situation.

- It is usually taken as at least half the members of the board or committee being people who use services (or relatives of people with a disability for family-led or carer-led services). Getting There takes a flexible approach to reflect the wide range of circumstances of the people involved in these organisations.
- The ethos of the organisation is to reflect the views and experiences of people who use services and/or families.
- There may be opportunities for people to be part of delivering services, such as peer support groups, volunteering or workers who openly bring their experience of using services.
- It delivers care services or does other activities that are of practical benefit to people. This may be as well as representing the views of people who use services or supporting people to participate in influencing what other organisations do.

These are some ways in which these issues are different for smaller user-led providers than for other care providers.

- Many of the groups who are part of the Getting There network have less than 1 fte member of staff. So tracking down information is taking up a much higher proportion of their time than for bigger organisations.

- The types of information groups are looking for is often wider – the impact for individual service users, impact for provider organisations, and scope for new ventures.

- There are few people in the organisation who can go to meetings, so contact with other providers in that area, or with the local authority is a more significant commitment than for many other service providers.

- Groups are usually trying to keep in touch with developments that affect the members and other people who use that service as well as with developments affecting service providers.

About this Information note

This note describes issues that many of the smaller service provider organisations have said are priorities for them. It draws on the experience of organisations that Outside the Box is aware of in summer 2012.

Some of the issues are current matters that groups have to deal with now. Other items on the list are issues that groups are aware they will need to tackle soon.

Many of the points here are the same as those facing any organisation which delivers social care in relation to SDS. But others arise more often for smaller, user-led organisations, or affect them in ways that are different from other types of service providers.

Understanding about Self Directed Support

A priority for many groups is learning what SDS is and what it will mean for people who use and those who provide services. Some of the smaller user-led organisations have fewer contacts with networks that have reliable information about the development of SDS. They are beginning to get more information now through Getting There and other national capacity building projects, but it can still feel patchy on what is happening in their local authority, or for the people who are their members.

Staff and other people at many groups are dealing with some of the misunderstandings that are still around: links with budget cuts, perceptions that SDS is all about personal assistants, or purchasing care from big traditional service providers.

The groups are dealing with the understanding and the concerns of a range of people/roles – staff, committee, members, volunteers, and families/carers. Some groups have found it has taken up a lot of time and energy when different messages have been heard by different people, or by the same people through different routes.

Getting information about what is happening, or going to happen, in your local authority can be difficult.

- In some local authorities there seem to have been frequent changes in who is leading in SDS, or there are several people with slightly different roles. Staff and committee members in user-led groups are not certain who to talk to, or get passed from one person to another.

- The contact with other voluntary organisations and with other service providers also varies. Some smaller organisations are finding it difficult to learn what other providers are doing and learning around SDS.

- Several groups have mentioned enthusiastic presentations by local authority staff which left service users, including committee members, saying that SDS was being forced on people, or is the route for cutting support, and that they wanted the group to have nothing to do with it.

- Some local authority staff have told providers they also do not know what is happening and have done this in a way that has raised alarm and uncertainty.

- Some groups have not been included in meetings or presentations from local authority staff to existing providers. The possible reasons seem to include: user-led providers being on an advocacy or user involvement organisations list rather than a providers list – so not invited; meetings that have involved the large providers who are in touch with a lot of people, but not other providers; and assumptions about a few voluntary organisations cascading information to other providers.

- There can be issues about the committee members of user-led providers being part of discussions between local authority staff and providers when these individuals are perceived as being service users rather than as the managers/employers/people making decisions about future direction of the service.

The information that is available can also add to difficulties. People are trying to work out what is relevant for their organisation from experience of SDS in very different settings. Many people are feeding back difficulties when all the local examples are about support for people with learning disabilities or physical disabilities, but their group supports people who have mental health needs or older people.

The user-led providers do want to learn more about potential ways of using SDS – the idea/ approach and the practical processes – as this could create a lot more opportunities for them.

People who are part of user-led providers are also concerned that they are not being included in discussions about the future arrangements. The risk is that the perspectives of this different type of service provider are not being recognised and their values and experiences are not contributing to the collective learning about SDS.

"Our main contact has been good. Sending round updates, reassuring us that there will be no sudden changes for our grant or for people we support."

"Some of our committee were at an event for people who use services. They came back and all said there was someone from the local authority telling them that direct payments would be in place for everyone by this October. Some people in the audience got upset but the woman went on with her glossy presentation and then didn't stay for questions. That caused chaos for us for weeks and it is still difficult to have a discussion about SDS, people are still so angry."

"There are very mixed messages from different people in the local authority here. We now look to national organisations to tell us what is happening."

"There has been a roadshow for service users and carers and lots of publicity in our area. But it feels like it is too soon. They talked about it as if it was all decided, but the Bill is not even through the Parliament yet and we know there is work still happening on the implementation."

"It's been hard to find information about how SDS will work for people who have mental health problems, or any fluctuating condition. I'm spending a lot of time on the internet."

Getting more choice for members and other people who get support

Increasing choices and Personalisation for individual people

The biggest priority for most of the organisations is the impact for their members and for other people in their circumstances. Most groups think there are potential advantages and disadvantages from SDS, depending on how it gets implemented nationally and then in their local area.

The general experience is that when a group can see more advantages for the people who are their members, they are more willing to put in the extra effort to make SDS work. Some groups are already involved, or planning to get involved, in activities to raise awareness with members and other people in the area. The risk of this is spending time and resources on activities that may not help the viability of the organisation in continuing to provide care services.

Some groups are beginning to work on advocating for, and looking for, ways to extend the opportunities for people to direct their own support to benefit more people. This is a big issue for some services that are in touch with people who they feel are at risk of being overlooked, such as people who have addictions and people who are or have been homeless.

Some groups are already working to help their members or the people they support to get the best out of the opportunities SDS may bring – whatever the potential consequence for the organisation as a service provider. This includes increasing the confidence as well as knowledge of people they support to enable people to think differently and have wider ambitions. The aim is for people to have a good life and choose what support they want, as well as getting services at that group to be more person-centred.

In some organisations the increased learning about SDS and the potential arrangements has led to more people getting more choices already, as they ask for – and get – different service arrangements that work better for them.

> *"Getting information about SDS for members has been the main priority. People are so upset by what they are hearing about Glasgow and things in the papers. It's hard to reassure people that this is a great opportunity and it's what we've been arguing for over many years."*

> *"We have articles on SDS in every newsletter now."*

Care Management role

For many groups this potential impact of SDS is linked to serious worries about the availability and quality of the care manager role in their area.

Many groups are describing the difficulties that their members and people they support are facing in getting a care manager at all, or getting a review when circumstances change. People also describe frequent changes in the care manager, with staff not knowing or understanding what has happened before.

People are also describing their contact with current care managers who are saying direct payments are not available, or not to people over a certain age, or only in certain circumstances. The general view is that this may reflect a lack of knowledge and skills on the part of that worker, or a systematic resistance to the approach behind SDS. But either way, it does not give people confidence for the future.

> *"Several of our members have been waiting for over 6 months to get a care manager, or for a review after a major change in circumstances."*

> *"It seems as if the current care management system is not able to cope at present. How will the new SDS arrangements work if it is the same people who do – or fail to do – the initial assessments?"*

Discussions with local authorities and other providers

Some groups are finding that they are not part of discussions about personalisation, and how this is built into the work of all service providers, in the same way as they are left out of the information and discussions about SDS.

Discussions are taking place among service providers that are initiated by them, when people are planning how they can use the opportunities that SDS will bring. This includes two or more care providers looking at how to work together and provide an overall better service for the people they support – a wider range of services, or wider geographic coverage.

Identifying gaps in what is there are the moment – including enabling people to get access to mainstream activities and preventative/early support – and thinking of ways to work together to meet the need.

Another way in which small user-led providers are working with other providers and local authorities is raising awareness among people who use services and their families about SDS. People have been involved in setting up meetings, giving presentations, distributing information and gathering people's views as part of informing future publicity campaigns. Issues here include the amount of time it is taking up - which is a large proportion for small organisations; the costs in terms of travel and other expenses; and the level of influence these and other user-led groups have on the specific activities or the overall agenda.

Strategic direction of the organisation

The opportunities that SDS is expected to bring and concerns about risks are both leading some groups to reconsider what the organisation does. This is probably the third main priority for user-led providers.

The options that many groups are considering are one or more of these options.

- Remain a service provider much as they are now. Learn to cope with SDS and move to having more people buying services direct or choosing this provider as part of an overall package.

- Form a partnership with another service provider which has similar values. This can put the group in a better position to reach more people or have more capacity, or share the costs of setting up the office systems that will be needed.

- Be a service provider but use the opportunity to refine what they do. So they may drop some elements that are part of a current Service Level Agreement and build up other responses that better reflect the needs and preferences of the people they support. People describe this in terms of being a niche provider rather than trying to compete with or duplicate what bigger providers will do.

- Focus on preventative support and social inclusion, rather than care services that will be organised through a care manager. Here, they expect to effectively drop out of the range of support that people are expecting will be purchased through SDS. Instead they would fund this through charitable grants or social enterprise activities. Some groups already do this for a proportion of their services.

- Move to becoming a user-led SDS broker or advice service. There are several options within this: stop being a care service provider and move to being a broker; go into a partnership with other groups to form a separate organisation that is a user-led broker; look at ways to do this role as part of the range of ways they enable people to have choices and control in their lives.

> *"We think that we have most impact when we are doing the low-level stuff that keeps people well. The initial information looks as if this won't be a part of SDS, or at least not in this area. So we are looking at other options."*
>
> *"Looking ahead to SDS has encouraged us to reflect on what we do. In the beginning we felt we would have to compete with the big national service providers – voluntary and for-profit. But now we are thinking that we have to make the most of our skills and expertise, and develop what we do better than anyone else."*

Option of becoming a user-led broker service

Some user-led service providers are giving a lot of thought to becoming a broker service – either as well as the range of work they currently do, or instead of that. People are aware that at this stage they do not know whether any organisation will be able to find a way of keeping on both roles, or have to choose only one role. People are aware that this will depend on the national implementation and/or local implementation arrangements.

Some people feel that the talk of broker services is too limiting, and that it makes more sense to think of broker support as one of a range of support that people who need extra services or support draw on from a range of people. Getting There is drawing together a discussion paper to look at the options that people involved in user-led services are considering in terms of the type of broker support they could offer, if they decide to go down that route.

These are the main issues that user-led services are raising around whether they should get more involved in any type of broker support.

- Whether the range of services that are available in that area would be reduced of the organisation was no longer a service provider – for example, when they are the only organisation providing some types of support, or working in certain places and times.

- How a broker service could reflect the underlying aims of giving people more choices and enabling them to have a better life.

- How the broker role can draw on and give people opportunities to use skills they have developed through other activities, such as mentoring.

- The potential for more opportunities for members and other people who use services through volunteer or paid work.

- The funding that is likely to be available for user-led broker services, and especially if it becomes dependent on a contract from the local authority, which could then change after a few years.

- The practicalities of that local area – whether it is big enough to be able to support several organisations taking on broker roles.

- Likely level of understanding by existing or potential broker services of the needs of the people who are the members or people supported by this organisation – will they get the benefits from SDS if this organisation does not provide some form of broker support?

The decisions that groups are making, or considering, for their future strategic direction then have a bearing on what other issues are priorities for them. In some cases, people have decided to park problems they know will arise until they are clearer what the big picture is for them.

> *"There is no broker project in our area. It is what we are effectively already doing for our members."*

> *"We have moved from saying: 'Why would we do this?' to 'Why wouldn't we?'"*

> *"The more we look at it, the more we are thinking that unless that initial advice and support to people to help them find the right combination of support is there, the whole thing will come to nothing and all the potential benefits from SDS will be lost."*

Governance of the organisation

Some of the user-led service providers have decided that this is a good time to update the governance of the organisation. Examples include:

- Reviewing and updating the constitution, to have powers to work in different ways or with a different mix of people or in different locations.

- Membership of the board or committee – looking to see if different skills and expertise are needed if/when the organisation starts working in different ways.

- Looking at the range of ways people who use the services get involved in the organisation.

- How the committee gets its information when the context is changing fast.

The experience of most of the groups who have mentioned this in discussions within Getting There is that this aspect is not posing any problems. It is a priority that is being met. The expected timescales around the implementation of SDS give groups enough time to go through the processes that are needed to change any formal or internal arrangements and get these approved.

They are also finding that the good practice policies and processes around the involvement of volunteers or employing people to work in a peer support role which were developed for one purpose will also work well if people are taking on these roles for different tasks.

> *"We've looked at our constitution, which needs some updating anyway (we've been here for over 10 years and a lot has changed). We are planning to become a SCIO (Scottish Incorporated Charitable Organisation) and have SDS arrangements in mind when we write the new constitution."*

> *"We decided to take time and get members involved and make the changes at our next AGM in June 2013 rather than rush it."*

Office systems and publicity

Some user-led providers are getting worried about office systems and how they will cope with recording much more information.

- How activities are recorded – types of monitoring that will be needed if/when the services are purchased by many individuals instead of once main source of funding.

- Finance – how to cost what the group does, what happens when people are using Direct Payments or individual budgets, especially when the group has only worked with grants for a whole service or core grants before.

- How the organisation describes what it does – will it need to attract more people to use services, as other organisations are doing?

Some of these issues look similar to those facing big service providers, but the ways smaller organisations work mean there will be different solutions for them.
One difficulty is that many user-led care providers also have grant income from sources such as charitable trusts or the Big Lottery Fund programmes, which are still project based and will still require a monitoring system that covers expenditure, scale of use and outcomes in traditional ways. People are unsure how they will deal with the need for 2 different office systems, and how they will find the resources to cover this.

"At present our Treasurer handles the grants from the Council and the Big Lottery. I'm not sure he will have time to do the same for 30 different clients, which is what will happen if everyone goes on to a direct payment-type of arrangement."

"We already have a few members who are getting support from us as part of a bigger package – some with direct payments and some in other ways. We have managed fine as each person was added separately and we had time to discuss it all with them or their carer and with the social worker. But I'm not sure how this will work if it becomes more widespread."

"Our publicity information is mostly directed at the Community Mental Health Teams and other voluntary organisations, because that is where most people hear about us – that or through an existing member. Other organisations in this area are starting to produce glossy leaflets talking about SDS. I suppose we'll have to do the same, although it doesn't feel right for the way we work."

What next and how you can help

What next and how you can help

This Information Note describes the experiences of user-led care providers who are in touch with the Getting There network over the early part of 2012.

Getting There will be producing other papers which reflect the learning and the ideas of groups in the network.

You can help us

If you are part of a user-led group which is providing care services:

- Does this reflect your experience in relation to the introduction of SDS?

- Are there other issues that are priorities for you?

- Do you have examples of good practice that we can include in future Information notes?

If you have another interest in relation to SDS:

- Can you see ways in which user-led groups might tackle the issues, such as approaches that are working in other situations?

- Do you have examples of good practice that we can include in future Information notes?

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