



# Permission to dream

## How can SDS support people with mental health problems to live the lives they want?

Ideas and themes from Edinburgh, Paisley and Perth events, Spring 2014

### About the events

During the first half of 2014 we held three events which looked at how we make self directed support (SDS) work for people with mental health problems. Over 230 people came together to share ideas and experiences and to learn from each other. The events were in Edinburgh, Paisley and Perth - one a month before the 1 April launch date for the new SDS arrangements, one 6 weeks after it, and one on 1 April. We may also hold more events in other locations in the autumn.

This is a report on all three events, incorporating the ideas and themes from each set of discussions. We wanted to increase awareness and understanding of SDS, by asking about the barriers that are faced by people with mental health problems and seeking solutions and new ways forward.

The events were aimed at people with mental health problems, their carers and support agencies and organisations that provide or commission services for people with mental health problems.

The events were run in partnership with the Getting There Project, Penumbra and the Mental Health Foundation.

#### Getting There

Getting There is a capacity building project funded by the Scottish Government. It explores what SDS will mean for smaller user-led organisations. It does this by producing helpful resources and by creating and developing opportunities for smaller user led organisations to meet, share resources and learn from each other.

**More information can be found at <http://www.gettingtheresds.com>**

We want to thank everyone who helped with the three events from the planning to at the events, and especially to everyone who took part sharing their experiences and ideas.

# Capacity building for SDS in Scotland

The Scottish Government has funded capacity building projects in preparation for self directed support (SDS). Updates were given by people who are part of projects which focus on making SDS work for people with mental health problems.

## Strike Out at Grampian Opportunities

### **Presentations by Marie Johnston, Linda Singer and Shona Owen**

Grampian Opportunities is a small user led organisation that promotes employment, volunteering, learning and enterprise opportunities for disabled people and people with mental health problems. They do this by developing relationships and by encouraging people to be involved in their community.

Strike Out is a short course developed by Grampian Opportunities to prepare people to make the most out of self directed support. It has been developed, and is delivered by people who have experience of receiving services.

It encourages people to think about their own support plan and what things they need to live the life they would like to have. It also takes time to explore ideas about planning, budgeting, choice and opportunities and decision making. It also looks at a wide range of activities and different choices for achieving a full and independent life.

*“We wanted to do something to help people prepare for the choices and opportunities of SDS so we created a course to prepare people to get the most out of SDS.”*

*“People learn from others, so sharing how it has worked for other people is so very important.”*

*“Live life to the full with the budget you have and be inventive with it so it goes further.”*

More information can be found at <http://www.grampianopportunities.org.uk/about/>  
<http://www.gettingtheresds.com/wp-content/uploads/2014/04/Marie-GO-presentation.pdf>

## SDS Champions at Penumbra

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### Presentations by a SDS Champion and Lisa lee

Penumbra is a Scottish mental health charity that supports people with poor mental health by providing a range of services that promote recovery and well being.

For Penumbra, the successful introduction and implementation of SDS is about managing change for the staff, people who receive services and for the organisation.

Part of the approach of managing change was to recruit and support volunteer SDS Champions. The SDS champions were recruited from people who receive services from Penumbra. Their role is to give first hand insight into the SDS process, using their lived experience. So far it has been very useful for finding out “where all the bumps and obstacles in the road are” and then thinking about how we address them.

The SDS champions have worked with staff to raise awareness and understanding of SDS for both staff and other people who use services. They have also been involved in designing how services are delivered.

*“To begin with there was no information for many individuals from the council in their area - it was like the secret service, not a support service. But it’s beginning to get better.”*

*“SDS is liberating but also scary for individuals and providers.”*

More information can be found at <http://www.gettingtheresds.com/presentations-information-from-events/>

## Communication Strategy at RAMH

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### Presentation by Colin Wright

Renfrewshire Association for Mental Health is an independent voluntary organisation that delivers services to people with poor mental health in their local community. Part of its approach to getting ready for SDS was to think about how it communicates with people who use its services. A key aim was to increase accessibility and the reach of its services alongside improving communication.

RAMH took a collaborative approach by working with people who use services, staff and local organisations such as colleges to develop new simple leaflets that explained what SDS is, the benefits and how it works. To support its work further RAMH also now uses a range of social media such as Youtube, twitter and facebook.

*“Improving how we communicate with people is important to us. We saw this as a good opportunity to think about how we do things and to involve more people.”*

More information can be found at <http://ramh.org/>

## ENeRGI

### Presentations by Elaine Fox and Norman Cowie

ENeRGI is the East Neuk Recovery Group Initiative. It is a Scottish charity based in Fife which provides support and information for people who have experienced or are experiencing mental health problems and their carers.

ENeRGI's capacity building project is about raising awareness and knowledge of SDS for people with mental health problems and then to support them through the SDS process. ENeRGI have a support team to assist people with each stage of organising support, from the initial referral through to reviewing the support package once it has been set up. A key part of this work has focused on the assessment stage getting people ready for assessments. Thinking about and understanding the language used, supporting people to think about support plans and what they would like to achieve with their support package and how they would like to live their lives.

*"Our project for SDS is about supporting people through the SDS journey but all the work so far has been about getting people ready for assessment."*

More information can be found at <http://www.energi.org.uk/self-directed-support-sds/>

## Perth Plus

### Presentation by Marilynne Kubath

PLUS is a local mental health charity covering the Perth and Kinross area. It is run by people who have used mental health services. It campaigns for a more inclusive society where everyone has a role and offers opportunities for individuals recovering from mental illness to participate in the work of PLUS.

PLUS is part of initiatives to raise awareness of SDS with people who receive services but also those who deliver services. It is part of a co-production planning group called Promoting Choice with the Perth and Kinross local authority, Perth Centre for Inclusive Living and Cornerstone. They have also been part of Joint Health Improvement Team Training days.

*"SDS is about change and we believe training and supporting staff to be crucial in the success of SDS."*

*"For people with mental health it may actually mean teaching people that having and making a choice is possible. Having a life is possible. Learning to dance is possible."*

More information can be found at <http://www.plusperth.co.uk/>

## Mental Health Foundation

### Presentations by Chris O’Sullivan and Chris White

The Mental Health Foundation (MHF) is a UK wide charity that seeks to improve the lives of people with poor mental health by providing information and by carrying out research and campaigns.

The capacity building project is a partnership with the Scottish Mental Health Co-operative, which brings together local organisations delivering mental health services. The project has carried out research with third sector providers and people with lived experience of mental health problems who receive services.

The last stage of the capacity building project has been to recruit and support a team of people with lived experience of mental ill health who are interested in, or have experience of SDS. Their experiences of accessing and using SDS in different areas and for different things will be recorded and shared.

Alongside this there is ongoing work with members of the Scottish Mental Health Co-operative to understand the way they involve, and want to involve service users in developing services using SDS.

*“SDS will not change issues of stigma and self- stigma.”*

*“This next stage, working with people with lived experience of poor mental health, and of accessing and using SDS, will give us a great insight into how things really work and feel for people, that we will be able share with others to develop services further.”*

More information can be found at <http://www.gettingtheresds.com/wp-content/uploads/2014/04/27th-Feb-SDS-Event-Chris-OSullivan.pdf>

## How has SDS worked for people with poor mental health in other places

Rich Watts, from the National Development Team for Inclusion, gave some examples of how self directed support has worked well in other places.

This was based on a summary of the research and experience around SDS and similar approaches for people with mental health problems which Rich prepared for the Getting There project. The full report from this work can be found at <http://www.gettingtheresds.com/self-directed-support-and-mental-health-papers/>

The main message is that SDS has made a positive difference for the great majority of people with mental health problems. In England there has been a large study which is following up the outcomes for people over the longer-term.

- 87% of people had better social care outcomes.
- 91% had improved psychological well-being.
- Overall, the support cost about the same as the services people were getting before.
- For half the people their new package cost less and for the other half it was more - but most people used just a little bit less or more than before.

Where self directed support has already been introduced people have spent their money on many different things. A few people have used Personal Assistants but most people have spent the budgets on services which provide the everyday things that everyone spends money on such as:

- Leisure activities, meeting people, holidays and breaks.
- Help with everyday tasks.
- Going to the Gym and doing exercises.
- Using and buying computers.
- Therapeutic services.
- Getting out and about.
- Learning new skills.
- Volunteering.

Self directed support works especially well for people with fluctuating conditions like mental health because:

- It's flexible.
- It can be tailored to meet your own outcomes.
- You can plan for when you need more help and for when you need less.

Self directed support also means change for everyone involved.

- For people who use services and their families.
- For people who work in services.
- For people who provide services.
- For people who commission services.

# Our priorities for making self directed support work for people with mental health problems

The experiences of people at the events around introducing and planning for SDS to benefit people with poor mental health raised many common issues. As part of these discussion we had a mend it café: talking over shared difficulties and worries and thinking about solutions for these issues, or at least working out how to get started on these issues locally.

One thing we did learn was that people are learning more about SDS and putting it into effect. By the time we had the Perth event in May, people were already describing more ways of tackling some of problems which had been worrying people at the earlier events before the arrangements were launched and before the detailed guidance had been published.

## Managing Change

The clear overriding theme that emerged from all three events was how to manage change for everyone involved. For some this was seen as a great opportunity, to change the way things had been done previously and also to grab the chances while they were there. But for many, both service users and people who deliver services, this change was raising concerns and uncertainty about how things are done and what they could expect from their lives and their jobs.

From the three events five priority areas with key practical suggestions for managing the changed and making SDS work for people with mental health problems emerged.

### Involve people who use mental health services by:

- Developing accessible straightforward information in a range of formats to encourage greater participation.
- Encouraging opportunities for independent advocacy.
- Supporting and encouraging everyone - service users, carers, families and providers - to be involved in the development of services.
- Developing and using co-production approaches that empower everyone - people who use services and people who deliver services - to design services and activities that people want.

### Help people prepare for assessments by:

- Having clear eligibility criteria that is published and widely available - that is transparent and clear. Describe the criteria so that people can understand.
- Having pre-assessment talks with family and friends, using support and advocacy organisations to prepare and think about choices and plans.
- Developing and using pre-assessment courses such as Strike Out – to raise expectations, generate ideas and deal with difficult issues such as dementia.
- Giving clear and explicit information to people - so they know how things work and what to expect.

- Encouraging people to think differently - have examples and case studies of how people used their money or support plan to generate ideas and offer new ways of doing things.
- Supporting and encouraging people to speak to support and advocacy organisations who will guide them.
- Thinking about the language and terms used like outcomes - most people want to live a good healthy life.
- Seeking simple solutions such as information leaflets and well informed staff, mentors and life coaches: this would make a big difference.
- Developing wider thinking and different solutions such as gardening or drawing classes.
- Making strong links with community organisations who may offer alternative activities.

#### **Develop open access and preventative services by:**

- Providing information and support to service users and providers - perhaps build local directories or use existing on line data bases like ALISS.
- Offering new or different services by pooling budgets and making strong links with other providers.
- Developing and using brokerage services for people.
- Working with local providers and community organisations to develop local alternatives.

#### **Offer real choices and range of providers by:**

- Sharing with local providers what people spend money on so they can develop local responses and services.
- Some providers working together on contracts and services.
- Marketing and promoting services and activities. Tell people about what the service achieved and the difference it has made in people's lives.
- Using micro providers to meet needs and service gaps - these could be spin offs from existing providers or brand new.
- Engaging with as many partners as possible – it's not just about paid members of staff also include service users. Use co-production approaches to develop new services and activities based upon the things that people like doing and need.
- Sharing stories and learning from each other.

#### **Make it work for people already getting services by:**

- Explaining what changes are happening and by being fair and open about services.
- Giving clear, consistent and simple explanations to everyone including people getting services and people providing services.

More information on our ideas:

**There is more information about ALISS at <http://www.aliss.org/>**

We talked about micro-providers at an event looking at how SDS can work for older people. You can see the presentation at this event at: <http://www.gettingtheresds.com/presentations-information-from-events>



## Next Steps for making SDS work for people with mental health problems

We came up with actions that will help in each area and across the country:

- Gather positive stories of the things you have done, and the things you have learnt and share them.
- Produce simple straightforward information that works for everyone, and then share it.
- Develop services, activities and ideas by working collaboratively, with people who use services and people who provide services.

*“SDS was introduced to help people achieve their dreams. The first step is to make sure people with mental health problems give themselves permission to dream.”*



Grampian Opportunities  
Finding the way forward



mental health foundation

ENeRGI



## Contacts

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### **Outside the Box - also the link for the Getting There project**

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### **RAMH**

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### **PLUS**

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### **Grampian Opportunities**

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**The Getting There website is a good place to share your stories and information – please have a look at <http://www.gettingtheresds.com>**