

Permission to Dream 2015

Making SDS work well for people with
mental health problems



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The event

In April 2014 the new Self-directed support arrangements came into effect for every part of Scotland. We held a series of events, which brought together almost 200 people who wanted to share experiences and ideas and worries about how we could all make SDS work well for people with mental health problems.

People with mental health problems had not made as much use of the old Direct Payment arrangements as other people did, so there was less experience to build on.

Some people thought that SDS could not work for people with mental health problems.

But the evidence from people who had used similar arrangements here and in other places showed that this worked very well for people with mental health problems.

The report from the 2014 events is at: www.gettingtheresds.com/wp-content/uploads/2014/07/permissiontodreamfullreport.pdf

Rich Watts from National Development Team for Inclusion had looked at the experience in other parts of the UK and research from other places on the impact of similar approaches. His report and list of practical solutions for questions and worries are at: www.gettingtheresds.com/work-with-ndti

We held this event in 2015 to hear what was happening a year on and share ideas for ways to develop local services.

“SDS is there to give people the choice, control and flexibility of what they need and want in their lives. It allows people the opportunity to have - support to dream, to plan and to live life to the full.” Marie Johnson, Grampian Opportunities

Having dreams

The SDS arrangements are a means to people getting choice in the support they use, which in turn helps them achieve what is important to them. It is about having a better life – and it helps if you can dream and see what that better life could look and feel like. We were all hearing that many people with mental health problems still don't feel they have the permission to dream.

- It can be hard to make choices when you can't look ahead, or don't feel able to make decisions.
- Change can feel risky.
- Sometimes the people around you – staff in mental health services as well as friends and family – are cautious (or don't understand what the changes can be) and are not giving much encouragement.
- There have been stories in the press about people losing services they have, and it can feel safer to stick with what you know.

“It is not easy for people to start thinking about the things they would like in their life, if they have not had this opportunity before.”

What is your dream?

- My dream is to climb Arthur's seat, which means I need to get fitter and find a friend to do it with me.
- To help others with mental health issues from my experiences and reduce stigma.
- I want to visit my family.
- I want to be in paid employment.
- I want to live on my own so I can eat when I want, and come and go as I please.
- That mental ill health is as accepted in society as physical ill health.
- My dream is to travel the world, meet lots of people and learn about different cultures.
- To get better at playing the ukulele and be good enough to play in public if I want to.
- To have a house full of flowers grown in my garden.

Example from discussions

Some people seem to find it easier to think about bigger changes that benefit many people than about themselves.

There are ways people can use that bigger dream to then have a vision of their role. For example, if someone wants to see an end to stigma, their dream for themselves and steps towards that could be:

- Getting involved in an arts group that is working on a See Me project, as a way to tackle stigma and to get back to activities I enjoy.
- Building up my confidence enough to get involved in training about mental health and wellbeing.
- Getting involved in a community newspaper or website as a way of doing occasional pieces about mental wellbeing, and to get more friends and build my skills.

Penumbra's Let's Talk Outcomes is a good example of using someone's else's situation to help people think about dreams and outcomes: www.gettingtheresds.com/march-2015

What helps?

- Don't be too narrow in your dreams. Be open to more opportunities if they come along.
- Be open to getting help from other people and you helping them
- Courses that bring people together are having a big positive impact – see Marie's description of Strike Out: <http://www.gettingtheresds.com/march-2015/>
- Good care managers.
- Support and encouragement from staff in mental health services.

"The Strike Out project for us has been about making people aware that they have permission (and the right) to dream and think differently about how to use an SDS budget package to meet their needs." Marie from GO

How do we encourage people to dream and make their dreams real?

- Staff who listen.
- Create space and time for people to dream and think of a different future.
- Include friends and family.
- Break things into small tasks and do one at a time.
- Challenge and encourage people to do more and make changes.
- Respect people.
- Hearing from other people - for peer support and their examples.

"We give people hope and share ideas and stories."

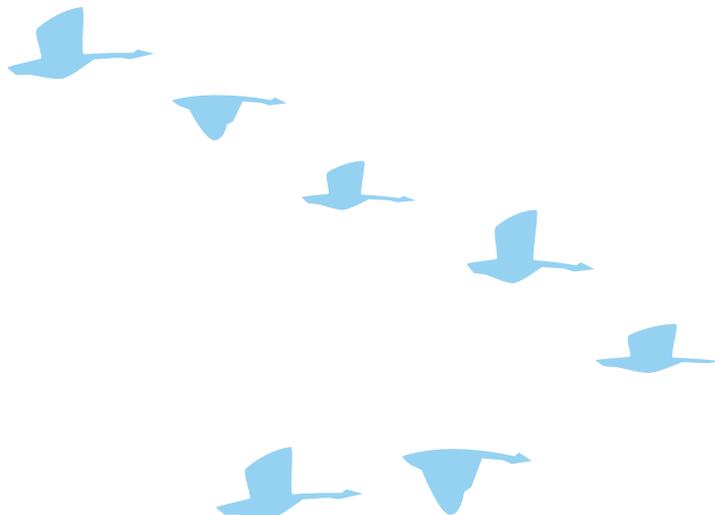
"We start by thinking of people as volunteers with something to offer and not just as service users."

"If we ask a different question we get a different answer."

"Taking part in new activities, like art groups, can be useful for thinking about things differently and achieving different things."

"Keep things simple. It's about a well life, safe life and a good life."

"Talking about outcomes with individuals is really difficult because it's not everyday language. Instead we ask people 'what's important to you in your life?'"



Example: James' story

When James was asked what was important to him in his life, his reply initially surprised the staff at that service. "I would like new teeth" said James.

At the time we (as workers) were not sure what the long term outcomes would be for James getting new teeth but it was amazing to see the difference it has made to his life.

Firstly, we could see how James' confidence had increased because he smiled and talked more. But there were also outcomes for James we had never considered, with new teeth James was able to eat better food and so felt and looked better. He took on more activities and met more people, improving his mood and sense of wellbeing. All of these things we realised are measured outcomes.

Finally it has also meant that he needed and wanted less support from us and was having a better life.

An outcome for us is learning that when we ask about 'what's important in your life' we think about the wider impact it can have on all aspects of people's lives.

What gets in the way?

- Staff in mental health services who focus too much on people's needs and what they can't do, or on the risks.
- Forgetting about all the other community opportunities that are there.
- People not having other people in their lives to encourage them.

How SDS is working

The overall picture that people described is that it is mixed, still with pockets of good experiences rather than good experiences everywhere. The good news is that the pockets are getting bigger and there are more of them than a year ago.

"Self directed support is helpful for our wellbeing."

What helps?

- Good care managers.
- Good support from staff in mental health services.
- Staff in services thinking about how they can use the flexibility SDS brings and giving people they support encouragement to try things.
- Local authorities thinking about how to make it work, and trying new approaches.
- Local projects that support members to ask questions.

“Participating in your local community and being an active citizen can also have impact on wellbeing.”

“It helps when a care provider is enthusiastic about SDS. More people like Lisa from Penumbra.”

Example: ENeRGI

- ENeRGI helps people in North East Fife to have a good life.
- Day-to-day support for individual people.
- Benefits advice, support and assistance.
- A food project.
- Working from the main base and at other locations that people find convenient.
- Access to phones and the internet, so people can contact other services.
- Complementary therapies and relaxation, to help people cope with the hassles of getting services as well as with their wellbeing.
- Listening to what people need and coming up with practical solutions, such as people getting together for shopping trips to the town when transport is difficult in the rural area.
- Helping people through the SDS process, from thinking about what you want before any assessment, and then the assessment or review process.

Example: Falkirk Short Breaks Vouchers

Falkirk Council knew that people with mental health problems were making less use of the Short Breaks Scheme than were other people. This meant people who were assessed as needing breaks were not getting them.

They talked to people who could have used the support and to their carers, to find out what people did want and how things could be better.

The solution they have tried is vouchers. 1 voucher = 1 hour of support.

- The person can use the voucher for activities that they want: art classes, sports, days out, comedy and music concerts, and more. There are currently 5 providers who accept the vouchers.
- The person uses the vouchers when they want to – which means it is when they feel they need a break, rather than planning something far ahead and finding it is not a good time.
- The person gives the vouchers to the provider, who then gets paid by Falkirk Council.

The impact has been very positive.

- People say it is flexible and easy to use, and reflects what each person wants.
- Outcomes for people include increased confidence and help with engaging in social activities as well as for people's wellbeing.
- It is avoiding hospital admissions, as people can use the vouchers for support at difficult times.

The team at Falkirk Council have learned from using the vouchers and are now looking at increasing the number of people benefiting from the scheme.

www.gettingtheresds.com/march-2015

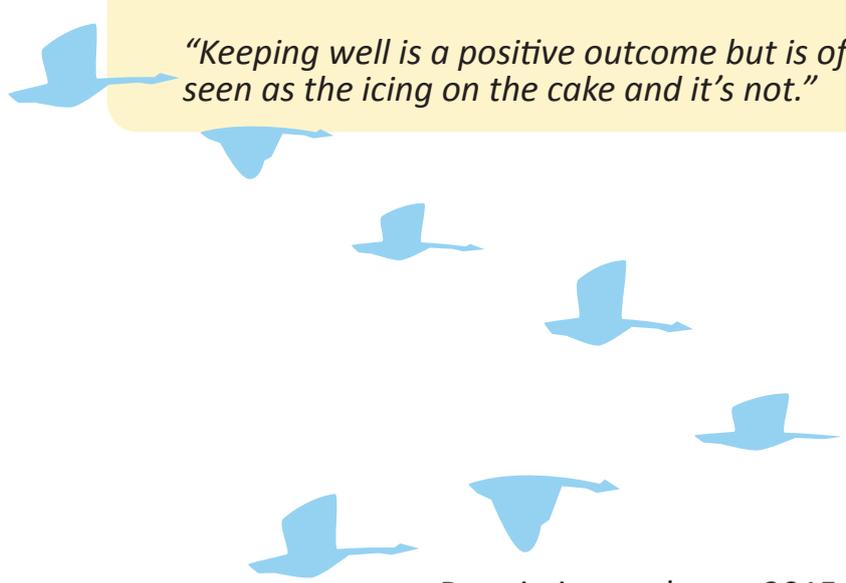
What gets in the way?

- Care managers: not enough of them, high turnover so not enough time to build relationships, not understanding about people with mental health problems and our circumstances.
- Councils and staff getting too focussed on SDS as a process and missing the point about it being a means to people having better lives.
- Eligibility criteria that do not work for people with mental health problems.
- Not enough information, or information that is not relevant for people with mental health problems.
- Places where SDS is slow for everyone.

"There is a lot of paperwork associated with self directed support."

"It is not always easy to know how and what the SDS budget can be spent on."

"Keeping well is a positive outcome but is often wellbeing is seen as the icing on the cake and it's not."



Finding things you can change

These are Rich Watts' suggestions of what people can do to make SDS work well for people who have mental health problems.

Actions by people who use services

- Know your rights.
- Think about what you want in your life.
- Work back from this.
- Don't start with 'just' support.
- Work in partnership with professionals.
- Find out about friends' experiences and share your own.
- Be practically creative (or creatively practical).

Frontline practitioners

- Ask yourself: How many people this week have I supported to do something differently?
- Constantly ask yourself: How is what I'm doing now different from what I did before?
- If not, what's getting in the way?
- And what can I do to change it?
- Work in partnership with people
- Start the conversation – think beyond the paperwork.
- Think of ends, not means.
- Remember what most other people in your circumstances have said: "Risk management wasn't as difficult as I imagined".

Team managers

- Create space and time for people to share learning and talk through questions.
- Trust your staff.
- Support your staff: training, supervision.
- Support your senior leaders: understanding, ambitions.
- "Risk management wasn't as difficult as I imagined."
- Create space and time to build relationships with providers and SDS support services.

Commissioners and senior managers

- Get good information in place for everyone.
- Including staff and providers.
- Including real-life case examples.
- Identify and support SDS champions.
- Create space and time to work with all providers.
- Create a positive feedback loop to change patterns of spending.
- Ensure independent advocacy/support is in place.
- Value and seek input from all different perspectives.
- Including co-production with people who use services.

Looking ahead

We talked about how we can continue to help each other.

- We can all share what we are learning – disseminate this report and the social media report we made at the event, and then disseminate what happens in our areas.
- Real life examples make a huge difference. Marie and other people like her (she is unique and wonderful, but you know what we mean) are willing to share their stories to help people in other places.
- We can keep sharing resources and ideas with each other
- It helps to hear ideas and stories from other places, so we will keep in touch with Rich at NDTi.
- An event like this is a good way to bring together people who have mental health problems and are using support and staff who work in various roles.
- National networking is good too. We will plan for another event in 2016.

“Come to Aberdeenshire in 2016.”

“Permission to Dream in Aberdeen, and in Fife, Falkirk, Stirling ...”

The Getting There project supported people to be Community Reporters at the event.

- Volunteers got training and practice a few weeks before the event.
- They interviewed speakers and participants.
- They put out pieces through twitter and other social media routes before the day, as the event happened and afterwards.

You can see what happened at: <https://storify.com/RosieHopes/permission-to-dream-2015>

Contacts for the partners and speakers

Getting There brings together small social care providers that are led by the people who use the services. It is one of the projects funded by the Scottish Government to help develop SDS. You can see more at: www.gettingtheresds.com

Outside the Box provides development support for people and services that want to create more opportunities for people in their communities and in their lives. Outside the Box is the base for the Getting There project.

Outside the Box, Unit 23, 150 Brand Street, Glasgow G51 1DH
0141 419 0451
claire@otbds.org
www.otbds.org

Grampian Opportunities is led by people with mental health problems and other disabilities. They have a strong focus on people contributing through peer support and as volunteers. GO has been part of Getting There from the outset.

Grampian Opportunities, 1 High Street, Inverurie, Aberdeen AB51 3QA
01467 629675
info@grampianopportunities.org.uk
www.grampianopportunities.org.uk

ENeRGI is the East Neuk Recovery Initiative. They provide support to people with mental health and/or substance misuse problems. ENeRGI is also part of the Getting There network.

ENeRGI, 32 East Street, St Monans, Fife KY10 2AT
01333 730477
energirecovery@btconnect.com
www.energi.org.uk

Penumbra has supported a group of people who use their services as SDS Champions and has worked to raise awareness about SDS for people with mental health problems at local and national levels.

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<http://www.penumbra.org.uk/>

National Development Team for Inclusion promotes inclusion and equality for people who risk exclusion and who need support to lead a full life. They are a charity that provides development support to services and community groups. Rich Watts leads the work on mental health across the UK.

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