Self-directed support and mental health

Paper 2 Evidence

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Introduction

About Self-directed support in Scotland

The Scottish Parliament has passed a new law on social care support, the Social Care (Self-directed support) (Scotland) Act 2013. The Act comes into effect on 1 April 2014.

The Act gives people more choice in how their social care is delivered, empowering people to decide how much ongoing control and responsibility they want over their own support arrangements. In practice this means:

- People can focus on the outcomes they want - what they want to achieve and what a good life means for them.

- The care and other support they get is planned to help them achieve these outcomes.

- There are more flexible ways of organising the support, to make it easier for people to get the combination of support they need.

- People choose the way they organise their support, as well as choosing the support.

  Overall, this approach is known as Self-directed support (SDS).

About Getting There

Getting There is one of the capacity building projects which is funded by the Scottish Government to support the implementation of Self-directed support (SDS) in Scotland. The project is supporting smaller voluntary organisations that deliver services and are led by the people who use those services as they get ready for the introduction of SDS. It is based at Outside the Box.

About this work

One of the gaps that the people involved in Getting There identified was that there is relatively little experience of people with mental health problems in Scotland using Direct Payments or other forms of Self-directed support. Similar arrangements have been in place for a few years already in England, and the learning from there could be useful to people in Scotland.

The Getting There project asked the National Development Team for Inclusion (NDTi) to bring together existing evidence and practice on Self-directed support for people with mental health problems. The overall aim is to share with people in Scotland an idea of how SDS can work in practice for people with mental health problems, based on what has happened before.

This paper looks at the evidence on how SDS works and the impact it has for people and their quality of life. It is one of 3 papers, which overall describe what we are learning about how SDS can be made to work for people with mental health problems. The other two papers are:

- Background to SDS and how it works for people with mental health problems.
- Practice around SDS, including ways to overcome the barriers that can limit the ways people with mental health problems use and benefit from SDS.

To download copies of any of these papers please visit the Outside the Box website: http://www.otbds.org/gettingthere/

For more information about this work, please contact us

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Note: this work has mainly drawn on practice from England, where personalisation and Self-directed support has been in operation in earnest since 2009, with much activity before then.

How available is evidence on Self-directed support for people with mental health problems?

Mental health services are lagging behind others when it comes to the implementation of personalisation, Self-directed support and associated mechanisms. The existence of inequalities does not necessarily indicate that personalisation and increased choice and control are unsuitable for people with mental health problems. Instead, it points to the need for more creative approaches to delivery and support.

One issue with understanding Self-directed support for people with mental health problems is the relative lack of evidence. This reflects the fact that smaller numbers of people with mental health problems are accessing personalised approaches compared to other client groups.

Current evidence gaps include:

- The experience of people with mental health problems using Self-directed support.
- The experiences of people with mental health problems who actively choose not take up a Direct Payment and their reasons for doing so.
- Comprehensive information regarding the cost-effectiveness of Direct Payments in mental health services.
- Whether or not using Self-directed support approaches leads to a big impact on reducing episodes of mental ill-health or leads to a reduction in service use.

Nevertheless, there is some evidence available on the difference Self-directed support makes for people with mental health problems. We describe the evidence that is available in the rest of this paper.

Trends in Self-directed support

Note: To understand the trends in take-up of Self-directed support approaches, we will look at Direct Payment usage. Though Self-directed support is more than just Direct Payments, this is where information is most readily available.

In Scotland, the uptake of Direct Payments in general was slower than in England and concentrated on people with physical impairments. By 2000, some 13 out of 32 Local Councils in Scotland operated specific Direct Payment schemes, none of which supported people with mental health problems at that time. The picture in England was similar – the National Centre for Independent Living (NCIL) could identify only 10 people with mental health problems who were receiving Direct Payments in 2000. Furthermore, during the major pilot between 2006-8 on implementing personalisation and self-directed approaches in England, only 14% of the participants had a mental health problem.

However, specific projects tend to lead to greater take-up of personalised approaches. For example, one project which lasted for 9 months in the East Midlands meant that an additional 222 people were self-directing their support – a 70% increase.

The position in 2012

The most recent picture shows that inequalities across service user groups persist. Only 5% of people who are self-directing their support in Scotland have mental health problems – compared to 37% who have physical impairments and 24% who have learning disabilities. In England, the take-up of Self-directed support in 2011/12 shows that people with mental health problems make up 7% of all those who have a Direct Payment as all or part of their Personal Budget.

Full data on how the number of people accessing Self-directed support has grown in Scotland from 2002 to 2012 is available on the Outside the Box website: http://www.otbds.org/gettingthere/

Resources

The total amount spent on Self-directed support in Scotland by people with mental heath problems has increased from £60,000 in 2002 to £1.93million in 2012. This is 3% of all money spent on Self-directed support packages – compared to 44% spent on all packages by people with physical impairments and 13% spent by frail older people.

Working age adults with mental health problems in England who were part of the 2013 Personalisation Outcomes Evaluation Tool (POET) survey chose to manage their Self-directed support as follows:

- Direct Payment (59%)

- A Direct Payment looked after by someone else (21%)

- An individual service fund (12%)

- A council-managed personal budget (4%)

- Two per cent did not know if they had a personal budget and 2 per cent stated they did not have a personal budget.

What is Self-directed support spent on?

Individual level

During the piloting of self-directed approaches in England between 2006-8, the average budget for people for mental health problems was £5,500 per year, or a little over £100 a week. Across all impairment groups the average was around £11,500 per year.

Of this £5,500 per year, it was spent on average as follows:

- £3,600 on Personal Assistants.
- £1,500 on mainstream services.
- £1,000 on leisure activities.

As self-directed approaches have developed, we have seen the ways people use their funding change. Now there is a more varied use of SDS, reflecting the increased knowledge and practice of more personalised approaches in mental health. Ways in which people use SDS include (in approximately declining order):

- Leisure activities/socialising (e.g. arts courses, cinema, hobbies)/holidays/breaks.

  A self-directed approach to support is one that recognises being connected socially is a key to good outcomes for people. Having access to mainstream activities that were not focused on mental health and so weren't non-stigmatising was often most valued.

- Assistance with everyday tasks (including care and support, respite, night sits, shopping, financial planning).

- Home improvements/cleaning services/domestic tasks.

  People with mental health problems often record having a good environment around in them supports them in achieving good outcomes. Self-directed support has been used regularly to achieve this.

- Gym membership or exercise/sports-related activities.

  Physical fitness is often seen as a particular goal through Self-directed support, especially since good physical health can contribute to achieving better mental health.

- Computing/IT equipment.

  Having a computer makes many opportunities available, and can be secured through Self-directed support. For example, easier access to the internet can support people to maintain social contact, get peer support or to access information. Others have used their Self-directed support to pay for courses to develop their computer and online skills.

- Therapeutic services (such as counselling, aromatherapy, acupuncture, Reiki).

  People regularly use self-directed support in order to access alternatives to formal healthcare they couldn't otherwise easily access.

- Travel and travel independence.

  Transport is a means by which people can support other activities. Since public transport can cause anxiety for some people, Self-directed support is a means by which they have put in place support. Similarly, access to other types of transport is particularly useful for people living in rural locations. Others have used self-directed support to buy driving lessons.

- Education/skills courses.

  Achievement of educational goals is something people with mental health problems regularly identify as an outcome they want to achieve. Within a Self-directed support system, people take up more opportunities for learning.

- Volunteering opportunities and support to achieve paid employment.

  There is some evidence that people use Self-directed support as a means of providing flexible support for employment, both in gaining or retaining a job.

- People also seek to purchase activities with each other, in "pooling budget" or joint commissioning arrangements.

  Group activities are also important, and many people want to be able to access peer support – especially as an opportunity to share experiences and solutions to deal with any problems being encountered, for friendship and to combat the isolation that a person may be experiencing.

These figures show that Self-directed support approaches tend to result in people with mental health problems using more resources for mainstream community services than for traditional or specialist mental health services. They highlight that people with mental health problems use Self-directed support as a platform to support their mental health and wellbeing in all areas of life, not just in getting services. Indeed, in England, when people have no choice over how resources are spent in mental health, over 83% of money is spent within NHS. However, when people do have a choice through self-directed support, over 84% of money is spent outside any statutory services.

People with mental health problems use their funding allocation, sensibly, imaginatively and effectively, especially when given sufficient support. Findings from a Florida project suggests that people spent less than the funds allocated to them: on average people spent only a third of the money allocated to them and overspending was not found at all. Other findings from 4 other US states found that people with mental health problems were "good stewards" of public money. Similarly, despite worries regularly expressed by professionals and carers, there is miniscule evidence of fraud in using SDS to date. In England, an estimated £2.2m was spent fraudulently from a total spend of £960m – a total of 0.2% of all Direct Payment spend.

This reflects the example of risk, where worries of what might happen in theory because of Self-directed support don't happen in practice. In the main, mental health practitioners reflect that: "Risk management wasn't as difficult as we imagined."

System level

A key question regarding the introduction of personalisation and Self-directed support is whether it is a more expensive system to run than the existing social care system.

No evidence was found that the resources and costs associated with SDS in Scotland were likely to be significantly greater than those associated with more traditional services (although full costs were difficult to measure and predict). Others (for example, IRISS) have suggested that staff and money requirements for assessment and monitoring might initially increase with the introduction of Self-directed support, but that these were likely to decrease as SDS is mainstreamed and systems develop.

Where other information on this questions exists, it suggests that SDS can lead to savings. For example, in West Sussex, the introduction of SDS increased the number of discharges from residential care and appeared to reduce admissions to residential care. This reflects findings from the US: an SDS approach in Florida resulted in participants spending much less time in psychiatric inpatient and criminal justice settings compared to people not self-directing their support. Indeed, on average, participants spent a significantly higher number of days in the community (compared to inpatient or forensic settings) after joining the program than they had before.

The difference self-directed approaches make

There is a lot of consistency in what difference Self-directed support makes: though they are thought of as the most difficult group to achieve Self-directed support for, people with mental health problems have the most to gain as a result of Self-directed support approaches.

For example, on social care outcomes, the 2006-8 pilot in England was clear that improved social care outcomes were achieved for people with mental health problems – 87% of people with mental health problems reported better social care outcomes with Self-directed support than without. This result was much more positive than for people with physical impairments or learning disabilities.

Similarly, 91% of people with mental health problems reported better psychological wellbeing with Self-directed support than without. Again, this result was much more positive for people with mental health problems than any other client group.

Findings from the latest POET survey of over 2,000 users of Self-directed support reported many positive findings.

Over 70 per cent of personal budget holders reported a positive impact on:

• Being as independent as they wanted to be.

• Getting the support they needed and wanted.

• Being supported with dignity.

Over 60 per cent of personal budget holders reported a positive impact on:

• Physical health.

• Mental wellbeing.

• Control over important things in life.

• Control over their support.

Less than 10 per cent of personal budget holders reported a negative impact on any of the 14 areas of their lives.

Full details of the results are available on the Outside the Box website: http://www.otbds. org/gettingthere/

Interestingly, the inherent flexibility of SDS has appeared to be beneficial for users in remote parts of Scotland, promoting geographical equality. Direct Payments were initially found to be helpful for people in dispersed rural areas where traditional services have been more limited. Recent figures support these findings, revealing the highest rates of Direct Payment packages per population head were in two rural local councils - Scottish Borders and Orkney.

Process

The process by which Self-directed support is introduced is vital. Evidence shows that making a choice about how someone's mental health problem is managed is in its own right therapeutic.

People who use mental health services appear more likely to thrive when allowed the chance to choose what will work for them and to believe their lives can improve through Self-directed support. This is particularly the case when people have a chance to work creatively, using a range of creative media throughout the care planning process to consider alternatives to traditional service provision.

The best evidence for the importance of the process of self-directing support is from the Personal Health Budgets evaluation in England. This found that, where pilot sites encouraged choice and were transparent about the process, Personal Health Budgets were more effective than those areas which didn't encourage choice and were less transparent.

Personal stories

There is a growing body of personal stories showing how personalisation and Self-directed support approaches have made a difference in people's lives.

- Personal stories: In Control http://www.in-control.org.uk/support/support-for-individuals,-family-members-carers/personal-stories.aspx

- Personal budget stories: Think Local Act Personal http://www.thinklocalactpersonal.org.uk/Browse/Stories/IBStories/

  These videos from Think Local, Act Personal and In Control show how people have used their Self-directed support to achieve a wide range of outcomes. Videos show how people have put in place practical solutions that work for them, as well as people's reflection on the experience of taking control of their care and support. They also show how a small amount of money can have a big impact on people's lives.

- Support planning website www.supportplanning.org/MentalHealth/

- Helen Sanderson Associates http://www.helensandersonassociates.co.uk/reading-room/who-/people-with-mental-health-issues.aspx

  The support planning website and Helen Sanderson Associates have a range of practical tools that people with mental health problems can use to self-direct their support. Tools include support plan templates and examples of how other people have completed their support plan.

- Social care TV: http://www.scie.org.uk/socialcaretv/topic.asp?t=personalisation

  The Social Care Institute for Excellence has a set of films presenting the experiences of people using services and their carers, as well as social care staff. The films look at how people from lots of different background have benefited from Self-directed support.