Self-directed support and mental health

Paper 3 Practice

NDTi
National Development Team for inclusion

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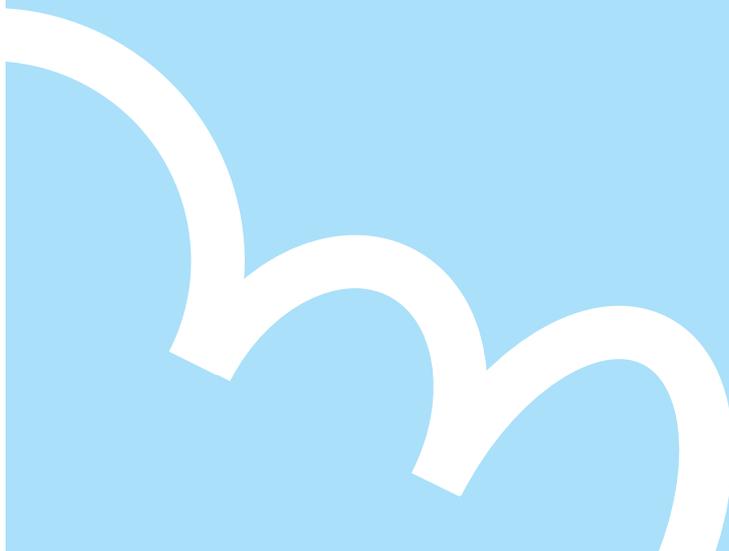
Introduction

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 practice around SDS, including ways to overcome the barriers that can limit the ways people with mental health problems use and benefit from SDS. 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.
- Evidence on how SDS works and the impact it has for people and their quality of life.

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.

Practice

The literature on personalisation and Self-directed support regularly shows that, despite widespread agreement with the underlying principles, a number of attitudinal and structural barriers challenge the implementation of SDS. Between the gap in national policy and local reality, a lot of anxiety and worry can be found. Though some of the problems are related to more general issues relating to social care (particularly the level of funding available and eligibility), some are related specifically to Self-directed support and its implications.

However, through understanding how SDS has worked well in practice, we know that many of fears and problems highlighted are often based in myth or misunderstanding. These lists bring together the main barriers/issues that are regularly mentioned with regard to Self-directed support, and highlight information from practice and the evidence base that can support everyone – users, providers, commissioners – to challenge and overcome these barriers.

Information

What the barriers are thought to be	Information from practice about the barriers
There is a lack of awareness amongst people with mental health problems and staff about Self-directed support. Where there is awareness there is confusion and misinformation – the majority of people are unaware of the flexibility and the variety of arrangements possible in their use.	Most people with mental health problems and carers hear about Self-directed support from their social worker or community psychiatric nurse, so these professionals need to be informed about SDS.
Access to information on Self-directed support is patchy – many local councils lack a centralised place that lists both universal and paid-for services. This means that it is difficult to signpost people to services.	Make sure there is good access to advocacy and support services for people.
	Encourage interest in Self-directed support with real life examples – knowing about examples can help to increase knowledge and awareness of Self-directed support, amongst both people and mental health professionals.
	Target people with mental health problems, for example by providing a pack of information for all those using secondary mental health services.

Capacity and eligibility

What the barriers are thought to be	Information from practice about the barriers
There are a variety of reasons why it is thought people with mental health problems aren't eligible for Self-directed support. These can include: People with mental health problems being seen by frontline mental health staff as not having the capacity to self-direct or manage their support, and so resulting in a reluctance to promote Self-directed support. People can be concerned at having to manage any financial arrangements associated with SDS, such as employing personal assistants. Access to assessment may be dependent on whether an individual is eligible to access a service There is an assumption Self-directed support, especially Direct Payments, are only for people with physical impairments, older people or learning disabilities.	The vast majority of people using mental health services have the same rights as everyone else. Only a small proportion of people are subject to legislation which limits their freedom to self-direct their own care.
	Self-directed support isn't about having only one opportunity to make a choice. There are a range of decision-making points in setting up and managing Self-directed support, so if someone lacks the capacity to make a particular decision their ability to make decisions on other matters should still be assumed. Throughout, the person's views should be sought.
	There are a variety of ways in which people can arrange for proxy-decision making, for example by a carer, user-controlled trust, advocate or circle of support. Ensure you offer these options to people and their support networks.
	It is broadly true that the language used in relation to Self-directed support is not as familiar to mental health professionals (e.g. independent living, social model etc.) and examples used in the literature typically relate to physical care. However, good and regular staff training – as well as sharing examples and good practice – can address this.
	Employing a Personal Assistant is just one way that people can use Self-directed support – it is used in many other ways. If people do choose to employ a Personal Assistant, or need any form of support in managing their support, a range of support structures can be put in place (including third parties).

Lack of support

What the barriers are thought to be	Information from practice about the barriers
Support available for people to navigate their way through the new Self-directed support approach can often be inadequate, unsuitable or unacceptable. This can include a lack of support services.	When people get good support it is largely because of the individual care coordinator or supporter. They need to be supported themselves to provide this good support.
	The introduction of Self-directed support shouldn't result in losing or reducing contact with mental health professionals if this isn't what the person supported wants. Furthermore, self-directing support does not replace the rights people have to the best possible health treatment.
	Having available support is a vital part of the Self-directed support process. This can be provided by a wide range of people and organisations – not just a care coordinator. User-Led Organisations can be a particularly effective way of providing support – see the section below on User-Led Organisations.

Bureaucracy

What the barriers are thought to be	Information from practice about the barriers
The current system for getting a provided service, or a Direct Payment, is too bureaucratic and/or sluggish. It depends too much on gatekeepers to help with access, and this often does not work effectively.	Good practice shows that a wide range of organisations should be involved in supporting someone to self-direct their support. As such, the system shouldn't be reliant only on care coordinators to support someone.
There is a lack of a simple, streamlined process. Instead, there's a danger that the associated paperwork will appear overwhelming for hard-pressed frontline staff.	While procedural models have a role to play, it is important to ensure they do not promote too narrow a focus on process. If they do, they will undermine flexibility, innovation and real engagement with people who use services. Self-directed support is a person-centred approach, not a process-centred one.
Staff are concerned about their jobs and roles in the light of SDS. Reasons for this include: Because they think they will lose their jobs if services such as day centres close or if assessment and monitoring become the reasonability of third sector bodies. Because they think they lack the professional skills to work within this framework. Because they don't want to relinquish professional control. Because they are resistant to system change in general. Because of the administrative burden any new system brings, particularly the complexity of administrative procedures. Such concerns are often compounded by a lack of sufficient investment in training required to either raise awareness of Self-directed support or to support mental health practitioners to understand and support people to use it.	There are many examples of good training that has been put in place for mental health practitioners, some of which has been delivered either by user-led organisations and/or people with mental health problems themselves. Providing regular training opportunities, including being integrated into other training programmes or as part of new staff induction programmes, helps. Furthermore, embedding discussion of Self-directed support and good practice examples into supervision and relevant meetings can support sharing good practice as well as enabling staff to share and explore their concerns. Whilst training on its own does not secure the successful implementation of Self-directed support, evidenced good practice suggests it is a necessary component.
The lack of information to and involvement of finance and IT staff department staff as a barrier to the successful implementation of Self-directed support.	Good practice sites typically involve and engage both finance and IT staff in the roll-out of Self-directed support, especially through including them in any Steering Group arrangements overseeing the implementation of SDS locally.

Assessments led by services not needs

What the barriers are thought to be	Information from practice about the barriers
Some potential recipients of Self-directed support may not have had a community care assessment, or might have assessments that are 'service-led' rather than needs-led.	This type of approach can often reflect prevailing views of mental ill health, whereas the successful implementation of Self-Direct Support would understand and reflect the social model of disability.
Some service users can express a lack of confidence that self-directed approaches would help change their experiences of services to date or the outcomes they've achieved.	Again, real-life examples can show people what is possible through SDS. Research and good practice suggests people's fears and anxieties are largely dissipated once they start using (for people) or enabling access to (for professionals) Self-directed support.

Fluctuating conditions

What the barriers are thought to be	Information from practice about the barriers
There are particular concerns that fluctuating conditions may be a significant barrier to using Self-directed support for people with mental health problems. It is thought people may be unable to express what they need when they need it, or that they become ineligible for services when they begin to recover and need more basic support.	The flexibility of Self-directed support means that it is better suited to deal with fluctuating conditions than the existing social care system. SDS means people can tailor services and supports to suit them, at times and in ways they feel would be most helpful.
	Advance directives and forward planning agreements about another party – such as a family member or friend – taking control when necessary can be put into place, and are becoming more standard. These can link to formal "Crisis Plans", too. Advance directives can also enable people to still exercise choice, by enabling someone to write down and/or discuss in advance, for example, what someone should do in particular circumstances, or you write guidelines on how to assess risk.
	Another way of keeping control of Self-directed support is to set up a user-controlled trust. This is a small group of people who the person supported knows well, and who will follow their wishes and ensure that these are carried out, even when it may seem that they are unwell or requiring a high degree of mental health or emotional support.
	It's also important to note that people receive some support when they are well to ensure that they stay that way.

Risk

What the barriers are thought to be	Information from practice about the barriers
Perceptions about risk have sometimes compromised access to and uptake of Self-directed support for people with mental health problems. Risk averse frontline practitioners often make decisions for people based on generalised views about the capacity or 'riskiness' of certain groups.	The main question to ask when it comes to risk is whether SDS is more or less risky than the existing system of social care for people with mental health problems. There is no concrete evidence either way that SDS increases risk. In the main, mental health practitioners reflect that: "Risk management wasn't as difficult as imagined."
	It is important to remember there is a range of options for self-directing support in practice. These enable people to build their experience and confidence over time, and so manage the level of responsibility they feel comfortable with. Similarly, there are numerous source of support someone can get to self-direct their support, including from a carer, family or User-Led Organisations.
One of the most common barriers to Self-directed support for people with mental health problems is the assumption people will incorrectly or fraudulently spend any money they are allocated.	The practice of Self-directed support to date shows that this risk is unfounded. People use their money sensibly, and fraud is negligible.
It is regularly noted that personalisation and Self-directed support are "risky", and that mental health professionals are risk averse.	Risk is not something that should be only professionally-determined. In a self-directed approach, risk can be identified with the individual themselves, their carers and others and being clear with all about the potential benefits and risks of a particular approach – making plans and actions that support the positive potentials whilst minimising the potential risks.
	Clear guidance should be in place on how issues of risk management should be included in assessment and planning for Self-directed support. This can take the form of risk enablement policies or risk enablement panels. Risks to the local council and risks to the individual should be explicitly separated.
	It is recognised there are people who manage money better than others. Local Councils must agree and monitor anyone's proposed plan for how they will use their entitlement to social care funding to meet the outcomes they've agreed. This means that if the Local Authority believes that some-one is not able to control the money directly, then an alternative way of 'holding' the money would need to be put in place. If the person themselves is allowed to have access to the money then how it is used would be monitored, as with anyone else, and if misspent can be withdrawn. Monitoring needs to be proportionate to the perceived level of risk and arrangements to review and monitor can be as frequent as the situation warrants and can be changed as the situation progresses. The main message is: use the processes that are already there!

Barriers for providers

Service providers and commissioners are encouraged by national policy to transform their approach to provision, and to focus on support to deliver outcomes for individuals. But risks and concerns also exist for providers of mental health services, particularly smaller voluntary and community sector organisations, as they do for users and staff.

A study of the implications of personalisation for the voluntary sector social care workforce found general support for the principles of personalisation and Self-directed support. However, there were concerns about pressure from local councils to cut costs, and the subsequent impact on services and training budgets. There are also worries about impact of Self-directed support on workforce, noting potential impact on terms and conditions, and that pay, pensions and reasonable working hours may not be consistent with user wishes for flexibility, autonomy and choice.

A view that is consistently expressed is that the supply of services does not keep up with the demands of people with mental health problems. A study from Australia found that, in practice, people's choice was significantly restricted by either (a) the lack of services; or (b) all available services being run by one provider. In this case, it was felt not enough was done by commissioners to channel existing budgets to types of provision that reflected user's needs and wishes. There is, however, little equivalent available research in the UK on the effects of Self-directed support on providers and contracts.

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.

Because it has only been in place in England for a relatively short period of time, less is known for certain about how the provider market across all client groups has changed as a result of Self-directed support.

> Changes that people have anticipated include the following:
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> - Existing providers of services will need to update their offers to ensure that they can respond to people self-directing them.
>
> - Demand for services might change in the way people choose to receive their service, rather than changing service. This might include, for example, choosing to receive them at different times or in different locations.
>
> - New opportunities for different types of services or activities may appear. This could include information, advocacy or supporting people to navigate the Self-directed support system.

One thing that is known to have changed is that more providers, especially small providers in the voluntary sector, have worked more closely in partnership with local Councils and with each other because of Self-directed support.

User-Led Organisations

User-Led Organisations (ULO) are typically defined as organisations that:

- Are led and controlled by disabled people and have a minimum membership of 50% of disabled people on their board.
- Actively demonstrate their commitment to disabled people by employing disabled staff and volunteers.
- Actively demonstrate their commitment to the Social Model of Disability.

User-led organisations and those providing independent advocacy have critical roles to play in Self-directed support. In England, local councils have been encouraged through policy to support user-led organisations as a key source of information and support. Sometimes this role is only available to people who have been referred to the ULO by the local council. More generally, however, ULOs see themselves as having a much wider role, always based on lived experience. Good practice suggests that the earlier a ULO is involved in the self-directed support process, the better.

ULOs have been shown to be a vital and effective source of independent information and support to everybody, including people with mental health problems, in the SDS process. Involving the local ULO in supporting someone think through what they want to achieve in their life through their social care support is often reported by people to be the most helpful input they get. This is both at the initial stages of self-directing their support and on an ongoing basis.

ULOs are particularly good at supporting people to think beyond traditional service models and to develop innovative ideas about how to meet their social care outcomes. Evidence shows that user-led approaches offer people more choice and control and a more person-centred way of working than traditional approaches. Specifically in mental health, ULOs often introduce and use more innovative, user-led approaches to support people than may otherwise be available, e.g. self-assessment diaries, advance directives, crisis planning etc.

More generally, ULOs can also be of great support to local councils as they go about introducing Self-directed support. For example, ULOs can provide training on SDS and Direct Payments, as well as collect regular feedback and information on user experiences.

There are a range of things that can be done to encourage User-Led Organisations to be involved with and contribute to Self-directed support, including:

- Local Councils need to ensure, through adequate funding, the provision of effective support at all stages of the SDS process, and service users should be offered choice about how and who provides this. Investment may be required to do this.
- Similarly, ensuring that ULOs have access to general voluntary and community sector capacity building support is important.

- Clear referral mechanisms and protocols to and from the local council to ULOs should be put in place, to help expand ULO involvement. Similarly, multiple referral routes to ULOs – from all types of organisations involved in SDS – should be put in place.

- Promotional and outreach activities should be supported to ensure people know the ULO is available to support them. Such activities can also provide a platform for peer support and to enable information and ideas to be shared.

- Ensure there are opportunities for ULO and care coordination staff to meet regularly. This enables both sharing of good practice and learning, and clear lines of communication and so effective referral mechanisms.

- As well as practical support, local councils should show backing and confidence in the role and work of ULOs. This sends positive messages to mental health practitioners, who are then more likely to engage with ULOs.

Useful resources

This is a selection of the most useful, practical resources available to support anybody interested in making Self-directed support work as well as possible in practice.

In Control, "A Voice and a Choice: Self Directed Support by people with mental health problems: a discussion paper" (available online: http://www.in-control.org.uk/media/6235/a%20voice%20and%20a%20choice%20.pdf) –Contains two useful frameworks for actions that organisations should undertake to successfully implement Self-directed support for people with mental health problems (pages 10-11 and pages 49-52).

IRISS, "SDS: Preparing for Delivery" (available online: http://www.iriss.org.uk/resources/self-directed-support-sds-preparing-delivery) - Contains explanation of the key components of Self-directed support and examples of how areas are putting it into practice.

Joseph Rowntree Foundation (JRF), "Direct payments and mental health: new directions" (available online: http://www.jrf.org.uk/sites/files/jrf/1841961388.pdf) - two lists of practical things that can be done (1) at an individual level (pages 50-59), and (2) at an organisational level (pages 69-75) to put Self-directed support into action.

Mind, "Personalisation in mental health: Creating a vision: Views of personalisation, from people who use mental health services" (available online: http://www.bristol.ac.uk/norahfry/research/current-projects/focusgroups.pdf) - Useful summary of how people have spent their Direct Payments through Self-directed support.

National Centre for Independent Living (NCIL), "Direct Payments for Mental Health Services Users/Survivors: A guide to some key issues" – includes examples of advance directives.

National Development Team for Inclusion (NDTi), "Paths to Personalisation in Mental Health" (available online: www.ndti.org.uk/who-were-concerned-with/mental-health/paths-to-personalisation/) - A whole-life, whole-system overview of what needs to be in place to support personalisation, including links to examples and practical resources.

Research in practice for adults, key information and evidence about what ULOs do and the difference they make (available online: http://www.ripfa.org.uk/publications-resources/personalisation-and-community-capacity/6-user-led-organisations-key-issue-2011 and http://www.ripfa.org.uk/publications-resources/personalisation-and-community-capacity/48-user-led-organisations-strategic-briefing-2013).

Robin Murray-Neill, "Direct Payments in Mental Health: What are they being used for?" (available online: http://www.thinklocalactpersonal.org.uk/Browse/Co-production/Equalities/mentalhealth/?parent=8599&child=6518) - A useful collection of case studies which highlights how people with mental health problems are self-directing their support.

Social Care Institute for Excellence (SCIE), "At a glance 18: Personalisation briefing: Implications for community mental health services" (available online: http://www.scie.org.uk/publications/ataglance/ataglance18.asp) – Contains comprehensive list of questions for Community Mental Health Team practitioners and other mental health professionals to reflect on in terms of their own practice.

Community Care has also published an excellent example of how one local council – Stockport Metropolitan Borough – has made Self-directed approaches its core business: http://www.communitycare.co.uk/2013/10/22/how-one-team-made-personalisation-core-business-in-mental-health/