

# Self-Directed Support

IF IT'S SO GOOD THEN WHY IS IT SO HARD?

by Simon Duffy



# SKILLS



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by **Simon Duffy**

THE PROJECT IS A PARTNERSHIP BETWEEN ANFFAS, KVPS, EASPD,  
IN CONTROL SCOTLAND AND THE CENTRE FOR WELFARE REFORM  
TO PROMOTE SELF-DIRECTED SUPPORT (SDS) IN EUROPE.



## Publishing Information

Self-Directed Support © Simon Duffy 2018

Illustrations on pages 21-24 © Belinda Evans 2018

Figures 1 to 9 © Simon Duffy 2018

First published June 2018

Self-Directed Support is published by the Centre for Welfare Reform

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[www.centreforwelfarereform.org](http://www.centreforwelfarereform.org)

Adapted from a design by Henry Iles: [www.henryiles.com](http://www.henryiles.com)

42 pp

ISBN download: 978-1-912712-04-5

Thanks to everyone at SKILLS who offered advice on this paper.

This paper is also published in association with Citizen Network - the global community to create a world where everyone matters, everyone is equal and everyone a citizen.



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The SKILLS Project has been made possible with support from the Erasmus+ Programme of the European Union.



Co-funded by the  
Erasmus+ Programme  
of the European Union

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# PREFACE



The central idea I will explore in this paper is Self-Directed Support. This is the term some of us use to describe a system of organising help so that the person who receives help is in control. This is not the reality for many people who receive state-funded assistance. Often the person does not control the help they receive, instead they are passive and support is often institutional in character. Self-Directed Support is about organising things so that people are not passive, instead they are active citizens, able to control the assistance they receive, in control of their own lives, and able to play an active part in community life.

The term Self-Directed Support is only one word that is used to describe this new system and it may not easily translate into other languages. However it is clear that, whatever language we use and whatever term we prefer, the human rights of persons with disabilities and the principles set out in the *UN Convention on the Rights of Persons with Disabilities* (UNCRPD) demand that we develop support systems that respect people's rights and full citizenship.

This paper was written on behalf of the SKILLS Project, which is funded by the European Union's Erasmus+ programme to support learning and education on Self-Directed Support across Europe. Self-Directed Support is at an early stage of development in Europe and awareness of its benefits is low. The project aim is not only to develop useful materials for educators, but also to help advance the idea of Self-Directed Support in Europe.

One of the possible advantages of being behind is that you can learn from those who have made more progress. Sometimes this means you can go further, by not repeating the same mistakes as others. So the purpose of this paper is also to start to gather knowledge from people and places where Self-Directed Support has made some solid progress.

However this paper is not a comprehensive description of all that progress; instead the aim is to start a conversation about that progress and the difficulties of making progress. This paper is written as a provocation to deeper understanding and each section ends with questions posed to leaders in different places about their experiences. After publishing this paper we will gather written responses and carry out interviews, which we will also publish. This means that we will end up with a rich tapestry

of stories and a range of different perspectives. These then can be used to inform the development of materials and approaches for European leaders to reflect on as they begin to develop their own strategies.

Our assumption is that stories, not just theories, will help people find courage and hope for the future.

# INTRODUCTION



This paper does not start from a neutral place. The questions arise from the author's own experience in the development of Self-Directed Support in Scotland from 1996-2002 and then in England from 2002-09. In particular I am interested in uncovering the story of how changes finally emerged. Often the official story of any policy change forgets to pay attention to how ideas originally develop. Typically there are long periods of social innovation, change and conflict which precede any changes in law or policy.

For example, in the early 1980s in England, some people with physical disabilities began to organise their own support, using public funding from local government, to purchase their own support (Glasby & Littlechild, 2009). After a period of campaigning, central government created legislation, the 1996 Direct Payments Act, to fully authorise this approach. This was not a total system of Self-Directed Support, but it did give some people the ability to choose to leave the main system and to organise things for themselves.

At the same time some of us began to work with people with intellectual disabilities and their families to develop systems that would give them more control, flexibility and creativity. In Glasgow in 1996 we developed a system of individualising support and funding called Individual Service Funds and we created a new community organisation called Inclusion Glasgow to help people to leave institutions and establish themselves in their communities (Animate, 2014). Later in a small number of places in Scotland we successfully tested out early versions of Self-Directed Support. But despite these successes there was still significant resistance to these ideas (Fitzpatrick, 2010).

In 2002 we began to work with English local authorities on these same ideas. We used the term Self-Directed Support to describe a comprehensive system of changes which included new systems for:

1. Budgeting
2. Assessment and social work
3. Advocacy and planning
4. Organising assistance
5. Controlling budgets

Using the brand name - *In Control* - we managed to coordinate developments in a large number of local areas. Success stories and research evidence began

to emerge and this led to a period of policy debate at the national level. Over time political support grew and eventually this led to a policy change by central government. Some of the ideas we had developed were then built into the 2014 Care Act. However, while the new system is meant to offer Self-Directed Support to everyone, in practice it has been significantly watered down and progress towards meaningful change has slowed.

In England there is only one system of social care for all adults, and so, although these changes began for adults with intellectual disabilities, they also led to changes in the systems for older people, people with mental health problems and people with physical disabilities. However, in practice, the degree of change depends on the quality and understanding of local leadership. There is a high degree of difference between approaches in different areas and between different groups of people in the same area. Some people, for example those using residential care, have also been excluded from the system of Self-Directed Support.

Self-Directed Support has also become an important policy in social care for children and in the health system for people with chronic illnesses (Cowen, 2010; Alakeson & Duffy, 2011). However progress remains slow. Since 2010 the UK Government introduced an austerity programme which has targeted cuts on social care and on people with disabilities. The UN has severely criticised the UK for breaching the human rights of its own citizens (UNCRPD, 2016). In this context real progress on Self-Directed Support is hard to evaluate. However the general direction of travel has accepted by most people and there are only a few who would advocate taking control away from people with disabilities and their families.

My own experience suggests that the quality of Self-Directed Support is not simply a matter of legislation and central policy. In fact if the only driver for change is central policy then the Self-Directed Support will actually be implemented in ways which are much less effective. Positive change means going on a journey - together - people with disabilities, families, professionals and the wider community working together to design better ways of doing things - making it easier for people to be in control, to get good assistance and to play their full role in life of the community.

Resistance to change may be inevitable, but we can also work to create new solutions that convert fear and resistance into positive experience and better outcomes for everyone.

# SUMMARY



This paper is a provocation for discussion. You may not agree with it and we want to hear alternative points of view, but these are our first assumptions:

1. Self-Directed Support is a **new way of organising support** to people with disabilities and families in order to better respect their human rights and advance their citizenship.
2. Self-Directed Support works by **shifting control to the person** and to those close to them and ensuring they can shape the support they need to fit their lives.
3. Research on Self-Directed Support shows that it **improves peoples lives** and that it can also be more efficient than older systems of support.
4. Self-Directed Support works primarily because it better **enables people to enjoy a good life**, as member of the community, instead of being in more institutional systems that increase isolation and reduce contribution.
5. Self-Directed Support **requires practical changes in the system** used for budgeting, planning, support and assessment. There are different models and still much to learn.
6. Self-Directed Support **works well for people of all ages** and many different kinds of disability or need; however systems need to be flexible enough to adjust for those differences.
7. Changing to a system of Self-Directed Support **requires innovation**, not just at the beginning of the journey, but at every stage of development.
8. Self-Directed Support should be **built on a foundation of human rights** principles together with an awareness for the need for a respectful partnership between the citizen and community.
9. Self-Directed Support needs to be developed in ways which avoid the risk of reducing social protections and which **strengthens solidarity and community**.
10. Self-Directed Support has been developing around the world in a complex pattern and now is good time to **connect different initiatives** and to share learning.

In each section below we ask one important question - then offer some thoughts based on the Scottish and English experience - we end by suggesting some further questions. We will be using these questions in our ongoing research.

# Q1. What is it?

**At its simplest: Self-Directed Support is a system to organise the help people need so the person has as much control as possible.**

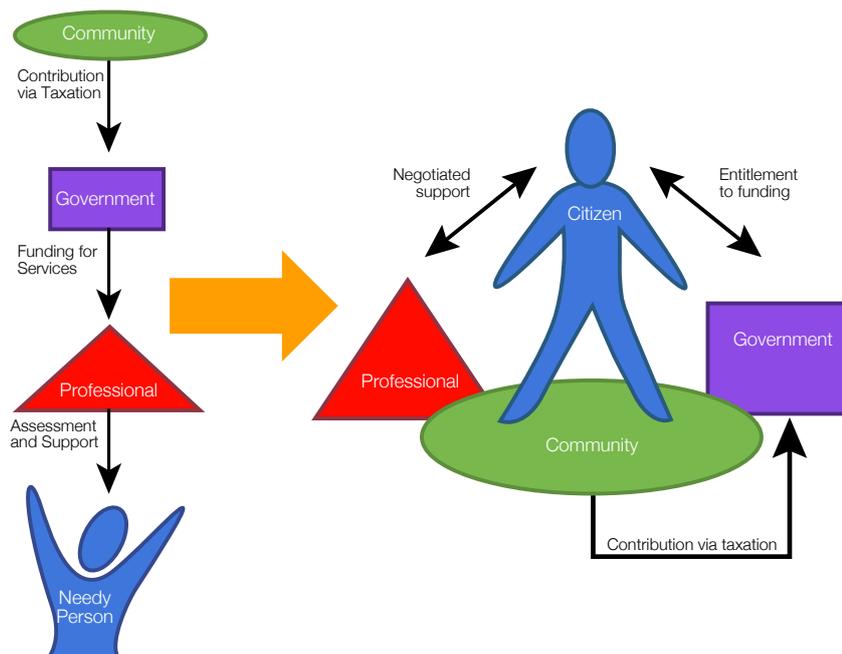
In order to help people see that this a new and important thing we often have to contrast Self-Directed Support with how support is usually organised. Many systems of support are not rooted in the idea of human rights. Instead of treating people as active citizens who have the right to shape their own lives they treat people as passive recipients or service users (Duffy, 1996).

**The old model can be considered as the Professional Gift Model of service delivery:**

1. Community funds the state
2. State funds professionals
3. Professionals decide what people need
4. Person receives support as a gift, not a right

**Self-Directed Support is organised around a different Citizenship Model:**

1. Citizens are in control of their own lives
2. Citizens live as part of a community
3. Citizen have entitlements to support
4. Citizen shape the support they need



**FIGURE 1. From the professional-gift towards the citizen model of support**

The journey towards Self-Directed Support is about taking people on a journey where people choose to deconstruct the old system and to rebuild a new system around human rights principles.

In particular Self-Directed Support is a powerful way to overcome the problem of institutionalisation and to help people disabilities and older people to enjoy full citizenship and inclusion. Where people are dependent on assistance then it seems logical to focus on making that assistance fit the aspirations and needs to the person and to put the person at the centre of making decisions.

Often the drive to close long-stay institutions led to the creation of smaller institutions. So the challenge is to create a second wave of deinstitutionalisation - to transform institutional community services into real community services.

The drive to Self-Directed Support was also part of a commitment to human rights and in particular the right to independent living described in the *United Nations Convention on the Rights of Disabled Persons (UNCRPD)* (Chetty, Dalrymple & Simmons, 2012; Dalrymple, Macaskill & Simmons, 2017).

**Self-Directed Support is relevant in almost every area of human rights, but is certainly essential in relation to:**

1. **Article 14** - Liberty and security of the person
2. **Article 19** - Living independently and being included in the community
3. **Article 22** - Respect for privacy
4. **Article 23** - Respect for home and family

However some people are not attracted to Self-Directed Support because of human rights or the desire for a more inclusive community.

**Instead, for some the attraction of Self-Directed Support seems to be:**

- It can be **efficient** and offers potentially cheaper ways to organise support
- It opens up more **choice and competition** and fits with the ideas of consumerism
- It is seen as a **modernisation of public services** and may fit other political agendas

It may seem that Self-Directed Support fits into powerful economic models like liberalism. But for many of us these models are very problematic and they can quickly undermine the creation of good systems of Self-Directed Support. As we will discuss below, there are dangers when people implement an idea like Self-Directed Support with the wrong assumptions about what it is trying to achieve.

## Questions for leaders

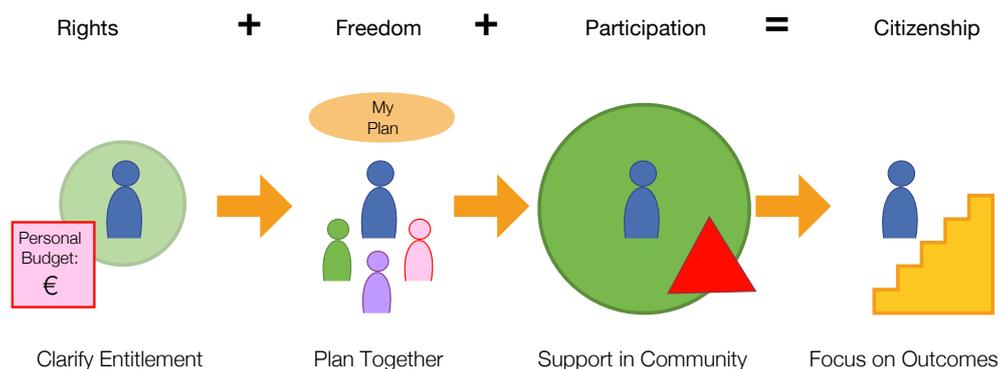
**How did you think about the fundamental shift that was involved in introducing Self-Directed Support differently?**

**What advice would you give to European leaders about how to justify Self-Directed Support?**

## Q2. How does it work?

How Self-Directed Support works will vary depending on many different factors. However it can be useful to imagine Self-Directed Support as a system that involves a series of steps (Duffy, 2013):

1. **Rights** - People find out if they are entitled to support and if they are entitled to a budget.
2. **Freedom** - People make plans, with help from family, friends and sometimes professionals to decide what they want to do, using their real wealth (which includes, but is not limited to their budget).
3. **Participation** - People live their life, getting the mixture of paid and unpaid support that works for them.
4. **Citizenship** - People meet their needs, but in a way that is consistent with their goals, and they share what they've learned with the community.



**FIGURE 2.** The core elements of Self-Directed Support

For some of us the challenge has been to stop Self-Directed Support being turned into a form of shopping or consumerism. We wanted people to understand that the value of the process lies in integrating an entitlement to funding with all the other resources, opportunities and support people could use. We did not want people to be forced to choose from a narrow list of service providers, offering all the same services as were already on offer in the old system.

**In practice there is often resistance to these ideas and systems often only partially implement the model:**

- 1.** People lack knowledge of what they are entitled to
- 2.** People are not free to plan and set their own goals
- 3.** People are not able to use resources flexibly and creatively
- 4.** People are not treated as citizens with rights and responsibilities

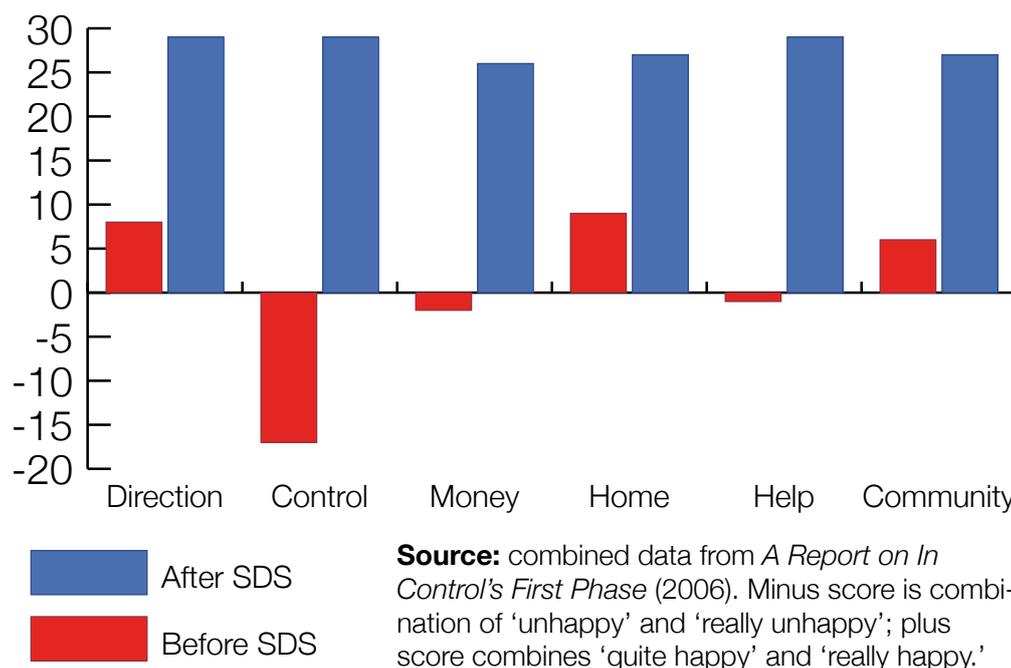
## Questions for leaders

**What do you think are the main elements of the Self-Directed Support?**

**What should European leaders think about to make sure Self-Directed Support does not turn into a form of shopping?**

## Q3. What does the research say?

In the early days of Self-Directed Support in England there was very little research available about Self-Directed Support and much of the research was generated by those involved in the early pilots. For example, this research showed improvements in citizenship for people in the first phase of *In Control's* work:



**FIGURE 3.** Research from Phase One of *In Control's* work

In England there has been many small studies on specific topics, but the critical research that has influenced policy is probably:

- **Zarb G & Nadash P (1994)** - This report showed the efficiency of direct payment arrangements and was very successful in helping win agreement to the 1996 Direct Payments Act.
- **Poll et al. (2006)** - This report was the first to demonstrate the value of Self-Directed Support for people with complex needs and led to initial Government interest.
- **Poll C & Duffy S (eds.) (2008)** - Efficiency data in this report was widely cited by Government to justify its change in policy.
- **Glendinning et al. (2008)** - This was a major academic Randomised Control Trial (RCT) which gave final official sanction to emerging Government policy.

Later the methodology developed by *In Control* was used to create a regular tracking system to describe progress in the development of Self-Directed Support in England described as the *Personal Budget Outcomes Evaluation Tool*.

Unfortunately research from other countries (e.g. USA and Canada) was largely ignored because people were unfamiliar with the context and so the research did not seem relevant. Over time this has somewhat changed and there is now a significant amount of research and greater awareness of the relevance of research from other countries. However, confusion about different terminologies and differences in approach continue to obstruct international learning.

### **There are two major sources of tension in discussions of research and Self-Directed Support:**

- 1. The problem of development** - Many people value academic rigour, RCT approaches and large and well-funded pilot programmes. However Self-Directed Support is inevitably a complex and emerging innovation, developing within existing complex human systems. Often it cannot be tested with the necessary rigour until it has a chance to be developed. This creates a vicious circle - there can be no progress because there is no evidence - there can be no evidence because there is no permission to make progress.
- 2. The problem of purpose** - For some, the critical question is whether Self-Directed Support is efficient. For others, the question is whether it increases satisfaction or advances citizenship. Still others are more interested in questions of detail and on how best to implement Self-Directed Support.

It some times feels like research is carried out, not to discover how to make things better, but as a way to delay progress. The tendency not to pay attention to research from other countries is particularly unhelpful as it means that there is no application of learning from elsewhere.

## **Questions for leaders**

**What do you think is the most important research we've seen to show that Self-Directed Support works?**

**What advice would you give to European leaders if they wanted to start developing their own research?**

## Q4. Why does it work?

The tendency of some policy-makers to think of Self-Directed Support as a form of consumerism also leads to false or highly limited understandings of why Self-Directed Support works. In general what research shows us is that:

1. Self-Directed Support **improves outcomes and satisfaction** across a wide area
2. Self-Directed Support sometimes **leads to improvements in efficiency** - better outcomes and lower costs

However if you assume that Self-Directed Support is only more efficient because of consumer competition you will not only misunderstand why Self-Directed Support works you will also implement Self-Directed Support incorrectly.

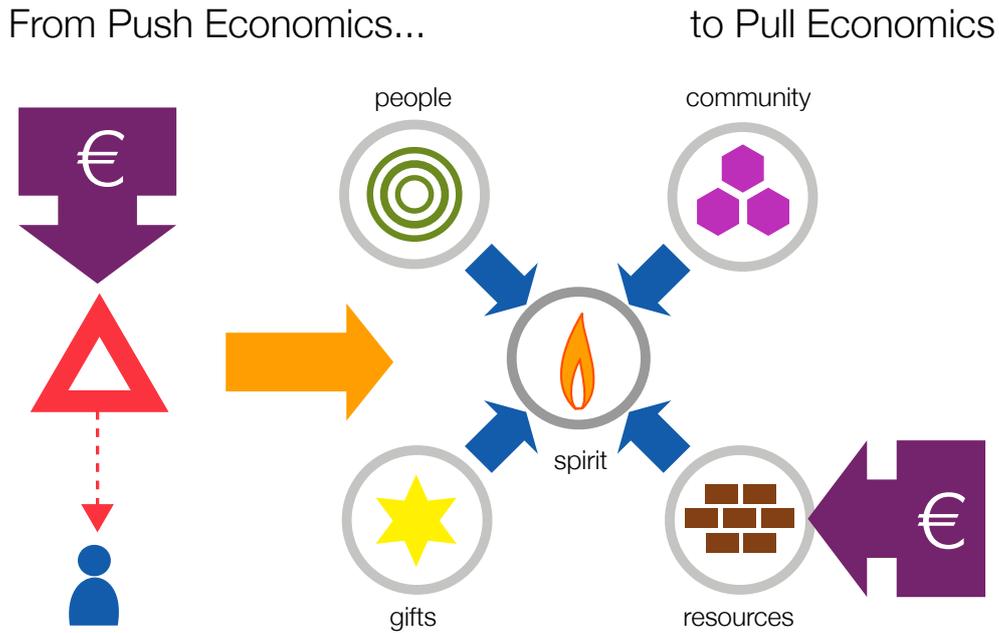
**What the research suggests is that Self-Directed Support works because:**

1. People can **focus** on the things they really want to do with their time
2. People can **choose** to stop doing things they don't value
3. People can **select** the professional or paid support they really value
4. People can **use** their budget creatively to enhance their community life

Notice that these factors have very little to do with market competition. It is not driving prices down or creating more consumer options that is important. What is important is the ability to use resources flexibly and creatively and to target the use of those resources on activities that really add value to people's lives.

It can be helpful to see Self-Directed Support in terms of our capabilities or our real wealth, the economic model developed by Amartya Sen (Sen, 1999). Instead of thinking of the person as a consumer of services we should treat them as a citizen who is using their real wealth to enhance the lives. Self-Directed Support is then an enhancement in at least one area of that life, but it is essential that the person can bring any additional resources into harmony with their ambitions, relationships and community life (Murray, 2010).

This is also consistent with the pull model of economic development set out in Figure 4 (Hagel & Seely Brown, 2005).



**Sources:** Push vs. Pull Economics is an idea developed in Hagel J and Seely Brown J (2005) *The Only Sustainable Edge*. Boston: Harvard Business Press; Real Wealth was first defined in Murray P (2010) *A Fair Start*. Sheffield: Centre for Welfare Reform.

**FIGURE 4.** From push to pull economics

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If this issue is misunderstood then policy-makers can be persuaded by powerful interest groups to give people choice - but only a very limited choice between professional and regulated services. In the end this approach tends to nullify the value of Self-Directed Support.

## Questions for leaders

**Why you think Self-Directed Support work?**

**How did you persuade policy makers to protect freedom and flexibility in Self-Directed Support?**

## Q5. What is different about it?

Discussion of Self-Directed Support often breaks into two kinds.

1. A lively debate between **supporters and sceptics** which focuses primarily on whether there is evidence of the benefits of Self-Directed Support and whether the benefits justify the risks of changing the current system.
2. There is a debate between **supporters** of Self-Directed Support about what kind of system of Self-Directed Support is best. This debate tends to be less empirical and is more focused on identifying the features of an ideal system.

All of this means that the development of research on how best to organise Self-Directed Support is limited. The aim of this paper and the SKILLS Project is to move towards a more empirical approach to Self-Directed Support.

**In England the model of Self-Directed Support we developed was sometimes called the seven-steps model and is described as follows:**

1. People would be **told their personal budget as early as possible** so that they knew whether they were entitled to support and if so, how much. In practice this meant that local authorities had to start developing systems to make it transparent what people could be entitled to.
2. People could **make their own plans**, with the people they wanted to. Ideally people would be able to get support from a wide range of sources, including, but not limited to their own social worker, potential support organisations in their community, peer support groups or independent experts.
3. People would finalise and **agree their plan** with the social worker who worked for the local authority. The English system is currently a locally based system and local government must agree the personal budget.
4. People could **take this budget as cash or ask for it to be managed for them** by the local authority or by a third party. In practice Scottish legislation has been much clearer than English legislation in making this possible.
5. People can **use their budget flexibly** and either organise their own support or pay someone else to organise their support for them.
6. The objective is to enable the person to get on to **live their own life as a full citizen**, actively involved in their community. Ideally funding is not restricted to services or to staff. It can be used creatively to enable to person the best chance of improving their life and contributing to the community.
7. The **review process should be human** and should focus on whether the person is safe, living well and able to follow their own goals. This means shifting away from systems that try to control how money is used and instead focusing on the real life outcomes that someone is achieving.

The seven-step model is an idealised picture. Rarely in England does the existing process of Self-Directed Support achieve this level of maturity. In practice local systems often remain wedded to assumptions that mean they struggle to give people clarity, control and flexibility. However the seven-step model did prove to be an important stepping stone which increased people's willingness to change and innovate. At each stage service leaders and family and disability leaders had to explore how they would make the step work in practice.

**The use of graphics also helped. The following images were developed by Simon Duffy, Carl Poll and the graphic artist Belinda Evans to describe the seven step process of Self-Directed Support. These images were widely used and offered an accessible way to understand what Self-Directed Support might mean in practice.**



**STEP 01.** People would be told their personal budget as early as possible



**STEP 02.** People could make their own plans with the people they wanted to

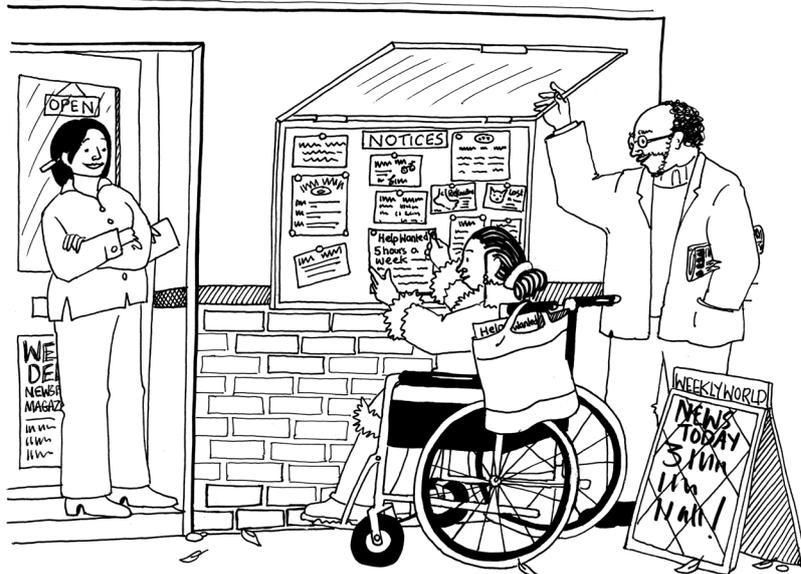


**STEP 03.** People would finalise and agree their plan with the social worker who worked for the local authority



**STEP 04.** People could take this budget as cash or ask for it to be managed for them by the local authority or by a third party

# NEWSagents



**STEP 05.** People can use their budget flexibly and either organise their own support or pay someone else to organise their support for them



**STEP 06.** The objective is to enable the person to get on to live their own life as a full citizen, actively involved in their community



**STEP 07.** The review process should be human and should focus on whether the person is safe, living well and able to follow their own goals.

## Questions for leaders

What have been the most important innovations in your systems?

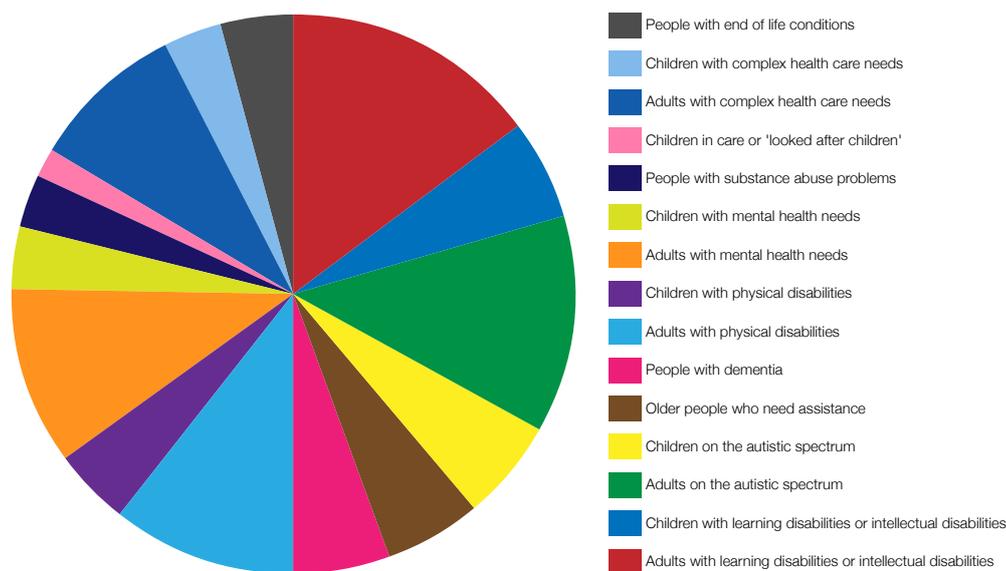
Where should leaders in Europe begin if they want to begin the process of shifting their systems towards Self-Directed Support?

## Q6. Who uses it?

There are no obvious limits to the groups that benefit from Self-Directed Support, although often different groups may need some differences in approach. Groups that use some form of Self-Directed Support include:

- Children with **disabilities** or **complex health conditions**
- Children in **care** or **families in crisis**
- People with **physical disabilities**
- People with **sensory disabilities**
- People with **substance abuse problems**
- People who are **homeless**
- People with **dementia**
- People with **complex health needs**
- People with **mental health needs**
- People with **intellectual disabilities**
- People with **mental health problems**
- People who are **elderly** or **frail**
- People at the **end of life**

For example the following chart, which was taken from an international survey on Personalised Support (one aspect of Self-Directed Support) shows that many different groups are benefiting:



Source: Duffy & Sly (2017) *Progress on Personalised Support*. Sheffield: Centre for Welfare Reform

**FIGURE 5.** Data on the use of personalised support

However different people can need very different kinds of help and sometimes different systems emerge around particular groups.

- People with **physical disabilities** may need much less help around decision-making and may want to employ their own personal assistants. Hence Self-Directed Support or independent living often focuses on the employment of your own staff team.
- People with **intellectual disabilities** may need more help with decision-making and this has led to a greater focus on advocacy or brokerage systems.
- **Older people** may be much less likely to employ staff and may be more willing to purchase services from existing community organisations.
- People with **mental health problems** may be focused on solutions that include counselling and peer support to provide support while making decisions.

However it is also risky to generalise too much. These groups are broad and they do not describe the most important features of people or their situation.

## Questions for leaders

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**Did you find it more helpful to focus on different systems for different groups or is one overall system better?**

**What advice would give European leaders on growing the right kind of alliances for change?**

## Q7. Where do we start?

If you want to make the change then it is not always clear how to begin. In England, and in many other countries, the first examples are usually individuals or families who have fought for a different system for themselves, but this does not really touch the main system. For example, when people took direct payments they would effectively leave the mainstream system.

Sometimes organisations or groups create small systems of Self-Directed Support inside the larger system and partially protected from it. For example, Inclusion Glasgow used a system of Self-Directed Support for many years before there was an official policy supporting Self-Directed Support.

The challenge is perhaps to find these pioneers and early examples of Self-Directed Support and to build a movement for wider change with them.

### This is useful because pioneers:

- **Inspire** people with their stories
- **Explain** how to solve practical problems
- **Imagine** what systems would have been more helpful

These pioneers are not just the people with disabilities and their families, they are often the professionals who have worked in partnership with them.

In general some leaders have observed that the following factors really help advance Self-Directed Support in its early phase:

- Permissive **legislation and guidance**
- Positive **national policy**
- Examples of **creative innovation**
- Examples of **good leadership**

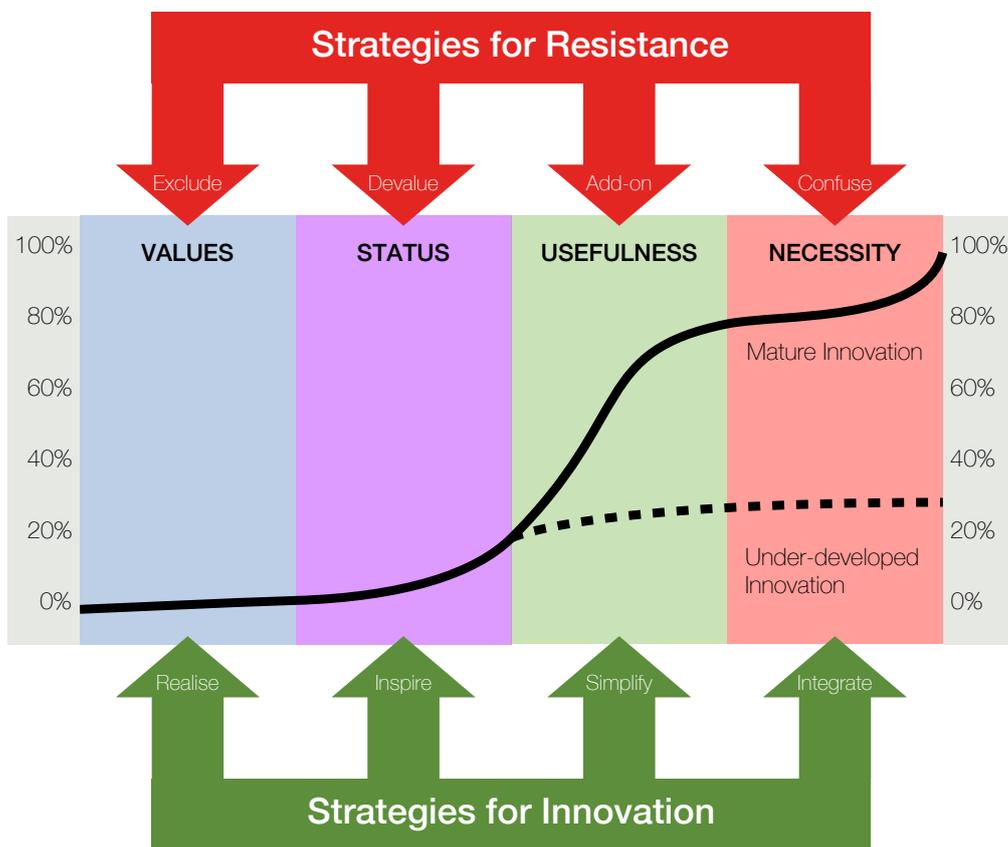
However these other factors can be very unhelpful and will hold back progress:

- A **fearful political climate**, austerity and populist rhetoric splitting the deserving and undeserving poor
- **Reducing levels** of public resources
- **Low pay** and ongoing cost pressures, e.g. personal assistants being on low salaries
- **Low level of public knowledge**, people only experience these problems when disability or illness affects their own family
- **Fears and resistance** from many professionals

- **Unequal access** to Self-Directed Support, where some groups are seen as lacking capacity or as too difficult to be able to achieve greater control
- Administrative **complexity at a local level**

It is also useful to reflect on the stages in the innovation curve. This describes the typical stages by which an innovation develops and the natural resistance all innovations face. If you understand the curve you can evolve your strategies depending on the stage you have reached:

- **Stage 1** - Pioneering - find or create early examples of success
- **Stage 2** - Inspiring - bring together a movement to share, challenge and grow
- **Stage 3** - Designing - create increasingly simple and efficient solutions to make Self-Directed Support easier
- **Stage 4** - Completion - close older systems and ensure everyone gets the ability to control their own support



**FIGURE 6.** The innovation curve for Self-Directed Support

Notice that innovation needs to be continuous. Early models of Self-Directed Support need to evolve as Self-Directed Support spread, to make it easier for more groups to use it and to make it easier for the system. Unfortunately, in England, we found that Government's approach to Self-Directed Support had the effect of freezing innovation and undermining the implementation

process. If Government starts to support Self-Directed Support then it will be important that the voice of people with disabilities and families is strong and that people continue to listen and respond with creativity.

**The following strategies may all be helpful:**

- 1. Support pioneers** - Encourage practical change in the real world or identify existing innovations and help people see them as part of the new wave of change. Unless change seems real most people will not be persuaded.
- 2. Build understanding** - Share stories, research and accessible materials that make the new ideas seem exciting and positive.
- 3. Keep innovating** - Develop a pro-innovation approach to change, instead of fixating on one model encourage people to share good examples and learn from each other. Welcome new ideas and help people to see how different ideas can fit together.
- 4. Work from the inside** - Build alliances with frontline workers and managers who want to make changes and ensure that solutions also help solve problems within existing systems. Create legitimacy for making these changes within the systems that need to change.
- 5. Go public** - Develop a social movement for change which encourages people to see these ideas as relevant to their lives. The Australian campaign *Every Australian Counts* is a good example of creating an inclusive campaign for change with a positive message.

Usually the primary focus of any change process must be based on the expectations of people and families. Unless there are people who want more control and see the benefits of Self-Directed Support, then change is very hard. This is why early developments of Self-Directed Support often focus on those who are most dissatisfied with the current system and who want to help bring about change in their lives. It is best to start where there is real willingness and energy - even if there are lots of other problems.

## Questions for leaders

**How did Self-Directed Support develop in your country?**

**What advice would you give to European leaders as they begin to develop their own strategies?**

## Q8. What are the principles?

Often there are a significant focus on the technology and practical changes to the systems that are required by Self-Directed Support. However the best test of whether Self-Directed Support is to look at whether it's meeting the rights of the person.

In England we tried to understand how this might work by developing a series of universal principles which could be used to evaluate any particular system:

- 1. Independent living** - we have the right to be a citizen with full access to ordinary lives - I have a right to live my life in a way that makes sense to me.
- 2. Entitlement** - we are each entitled to enough support to achieve citizenship - I have a right to enough support and also the right not to be over-supported.
- 3. Freedom** - we should be in control of our own lives - I have a right to make decisions about how I live my life and, if needed, I have a right to be supported by people who know me and love me to make those decisions with me.
- 4. Openness** - we should be clear about any rules or systems - I have a right to be told clearly and simply how the system of entitlement works and how the rules affect me; including how much money I am entitled to for my support.
- 5. Flexibility** - we should be free to use our own entitlements as we see fit - I have a right to use my money in any way that helps me to live my life; including the freedom to take risks, make mistakes and learn from them.
- 6. Learning** - we should share what we are learning to help everyone - I have a responsibility to share with others what I have learnt, what works for me and what doesn't work for me.
- 7. Contribution** - we have a responsibility to contribute and to build stronger communities - I have a right and a responsibility to use my skills, talents and knowledge to play a full part as a citizen in my community.



**FIGURE 7.** Key principles for Self-Directed Support

## Questions for leaders

What principles would you use to describe Self-Directed Support?

Where are the biggest risks for developing Self-Directed Support?

## Q9. What is the future?

There is little doubt that Self-Directed Support is associated with many benefits; but it also raises many fears and uncertainties. For instance some fear that Self-Directed Support will lead to or at least will not help resist:

- Privatisation of public services
- Cuts in funding or increased means-testing
- Reduced power of trade unions
- Threats to services developed by business, charities or public bodies
- Additional burdens being placed on people and families
- Increased social isolation and individualism

Some of these fears may be unrealistic. For instance, good systems of Self-Directed Support seem to increase people's community connections. However, it would seem best to develop approaches that are most likely to ensure that Self-Directed Support develops in ways which are consistent with human rights, equal citizenship, inclusion and wellbeing.

For instance, strategies might include:

1. Ensuring people always have **peer support** available
2. Encouraging the **development of cooperatives** to provide support
3. Putting in place **systems to monitor and protect** funding levels
4. Creating **systems of advocacy** in partnership with trade unions
5. Enabling businesses the ability to **develop transformation plans** to change their models of support in a planned way
6. Ensure people can use **personalised support and systems** like Individual Service Funds rather than being forced to take on all responsibilities
7. Ensure systems are **accountable** to people with disabilities and families and that they are innovating working to develop higher standards

Self-Directed Support develops in the context of a wider environment.



FIGURE 8. Self-Directed Support in a broad context

## Questions for leaders

Looking back at the strategies you used what do you wish you would have done differently?

Where would you encourage leaders in Europe to look to see the most interesting examples of Self-Directed Support worldwide?

## Q10. Where are we at present?

We can identify models of Self-Directed Support that go back as far as the 1960s. However in practice these initiatives have stayed largely divided along at least three dimensions:

1. **Geographic** - there is only limited knowledge of the state of different developments of Self-Directed Support in different countries
2. **Disability groups** - many countries have very different systems for different groups of people (e.g. older people may be subject to very different rules and systems than younger people, or people with mental health problems may not be eligible for disability support funding)
3. **Systems** - even within the same group and country very different systems can emerge (e.g. the UK's ILF system was an early model of Self-Directed Support which stayed quite distinct from other systems.)

Possibly the first example would be the system of independent living developed in Berkeley, California by Ed Roberts and colleagues (Shapiro, 1993). This model, where people employ their own personal assistants, has been very influential and important, spreading around the world, but often being restricted to people with physical disabilities.

Canada pioneered systems to enable people with intellectual disabilities and their families to control personal budgets in the 1980s. Germany has a well established system to enable older people to organise their own care which was established in the 1990s. Australia has introduced far-reaching reforms, called the National Disability Insurance Scheme, to disability services, which include mental health services, and are aiming to achieve a fully funded system of Self-Directed Support for all Australians with a disability (but their system for older people is organised differently and includes means-testing.)

On top of these differences is the complexity of the emerging language or jargon. Even for people who just speak English there has been no consistent way to describe this innovation.

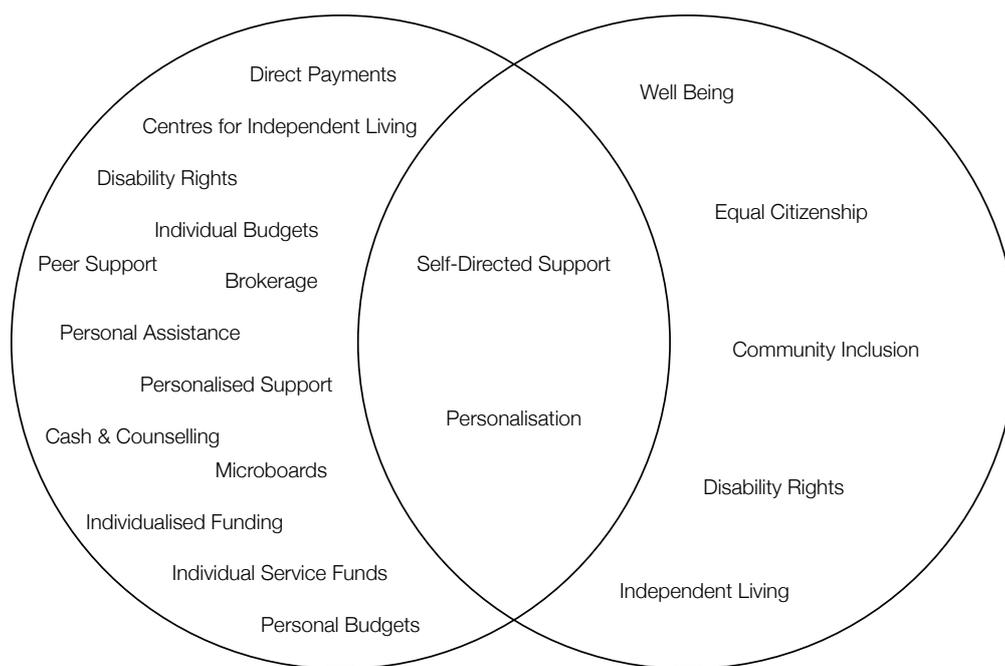
**Sometimes people talk about Self-Directed Support by talking about some part of the system for example:**

- **Direct Payments** - money transferred to the person
- **Brokerage** - independent advice to organise support
- **Peer support** - support from peers to organise support
- **Individualised funding** - money that can be controlled
- **Personal budgets** - telling people their budget upfront
- **Personalised support** - flexible bespoke support
- **Personal assistants** - helpers employed by or for the person

Sometimes people talk about the purpose of Self-Directed Support in different terms:

- **Disability Rights & Independent Living** - people with disabilities having the right to live a life of their own choosing
- **Citizenship & Inclusion** - people becoming active and respected members of the community
- **Health or Recovery** - people flourishing, avoiding crisis and making the most of life

Words like Personalisation or Self-Directed Support are somewhat intermediate for they aim to characterise the overall change in the new system both in terms of purpose and function. However both these terms are still rather narrow in their focus and may encourage people to limit themselves to thinking about the control of support or services, not their greater involvement in community life as a citizen.



**FIGURE 9.** Terminology associated with Self-Directed Support

The SKILLS Project marks an even greater challenge as many of the terms used in English may not translate well into other languages. However it may also offer us the opportunity to learn from speakers of other languages which ideas are most useful and which should perhaps be abandoned.

The most important efforts to try and connect these different initiatives include a number of important international conferences on Self-Directed Support, in particular:

- **Declaration on Self-determination & Individualized Funding** - Seattle 2000
- **Claiming Full Citizenship** - Vancouver 2015

The international global community Citizen Network has emerged from this work in order to sustain ongoing connections, learning and momentum for more profound change.

## Questions for leaders

**Do you think we should be connecting more effectively around the world to develop and improve Self-Directed Support?**

**What would you like to learn from European leaders about their journey towards Self-Directed Support?**

## CONCLUSION



As part of the work of the SKILLS Project within the wider Citizen Network community we will gather responses to these questions both internationally and across Europe. Our hope is to help people understand why Self-Directed Support is important, and to show that it is important to pay attention to how it works in practice and how it is implemented. We will be writing two further reports and publishing further information.

To stay in touch with the results of the SKILLS Project or get more involved then [follow us on Facebook](#).

### Join Citizen Network

Citizen Network is a global non-profit cooperative movement, formed to create a world where everyone matters – where everyone can be an equal citizen. We work together – locally and globally – to create welcoming communities for everyone and to form a powerful movement for change all around the world.

Membership is free, you can join [here](#).

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THE CENTRE FOR WELFARE REFORM