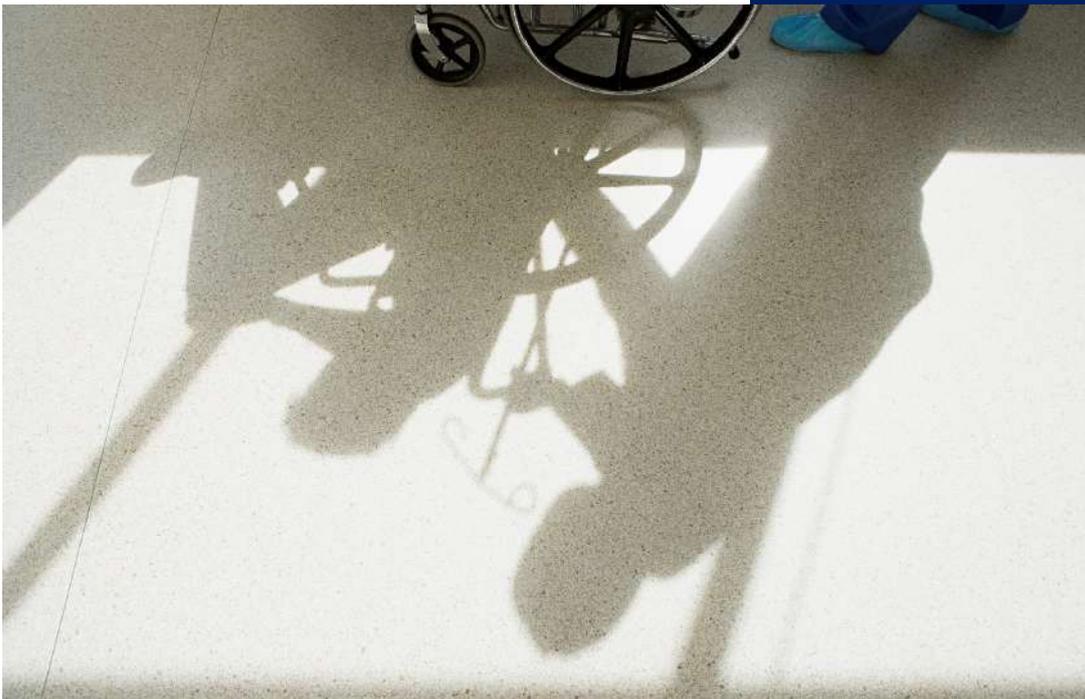


Self-Directed Support for Service Providers

Exploring the responsibilities and options
for service providers for persons with disabilities

by **Simon Duffy, John Dalrymple and Nic Crosby**

on behalf of **EASPD**



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Preface

This short report was prepared by three researchers who have also worked practically in the field of disability support, providing support services, working alongside people with disabilities and their families to design individual arrangements, and working with policy-makers to change systems.

This report is based on the combination of the personal experiences of the three researcher and our analysis of existing published research. We have also been able to build on the work of the Erasmus+ funded SKILLS project - which is a partnership between EASPD, KVPS, Anffas, In Control Scotland and the Centre for Welfare Reform.

We also carried out a very quick online survey on the subject of what needed to change in services for people with disabilities (n= 48, 35% disabled people, 37% family members). We have included quotes from the survey throughout the report to show.

We hope it provides a useful overview of the challenges and the opportunities that lie ahead as Self-Directed Support grows across Europe.

Unfortunately, even in one language - English - there are often multiple words which are often used in different and confusing ways. To make things easier for the reader we have used capital letters for more technical words like Self-Directed Support, and we have defined how we have used these words in a glossary at the end of this report.

Dr Simon Duffy, John Dalrymple and Nic Crosby



Summary

There is increasing awareness that the realisation of the human rights of persons with disabilities demands a change in the **power relations** in the human service system. In particular, ideas like Self-Directed Support, Independent Living and Coproduction have been developed on the assumption that people must be treated as full citizens, that support services must be accountable to them and that future policy must be created by a partnership between people with disabilities, families and professionals. These principles should be at the heart of deinstitutionalisation, and Europe is in a good position to build on its own best practice and the lessons from outside Europe.

Self-Directed Support involves a series of practical changes in how funding and control is organised. It does not make community support redundant and there is no doubt that service providers can and do play a vital role in securing the implementation and the delivery of positive systems of Self-Directed Support and Coproduction. In particular good community organisations are necessary to enable:

1. Personalised Support
2. Personal Assistance
3. Shared Management
4. Support Brokerage
5. Microboards
6. Microenterprises
7. Community Connecting
8. Asset Based Community Development
9. Peer Support
10. Specialised Support



In Europe Self-Directed Support is still at an early stage of development and even in countries that have been developing Self-Directed Support for decades the levels of change, while positive, has not happened quickly.

Scotland offers a good example of how Self-Directed Support creates new possibilities for deinstitutionalisation and a shared agenda between the disability movement and service providers.

In fact service providers can play an important role in advocating for Self-Directed Support - as partners to people with disabilities and families. Often there are practical and legal systems that need to change in order for Self-Directed Support to flourish, and it is important that service providers play their part in building the right systems for the future.

Now is a good time for EASPD, working with its partners and its members, to make clear its support for these human rights principles.



1. The Right to Self-Directed Support

People with disabilities have faced oppression, discrimination and exclusion from society in many countries around the world. Today, there is still a long way to go before basic human rights are met.

Many people with disabilities are still:

- Incarcerated in institutions where they have little control over their daily lives and are cut off from community life.
- Experience higher levels of poverty and are excluded from opportunities for personal development and contribution to wider society.
- Suffer higher levels of abuse, control, hatred and prejudice.

However there have been important positive changes. Since the 1960s people with disabilities and their families have increasingly found ways to demand their rights and to influence how their society has changed. In some countries institutions have been closed down completely; some people now have control over their own lives and play a full and active part in society. In some places prejudice and fear is being tackled and people with disabilities are better respected and have started to be included in every aspect of life.

1.1 Disability rights are human rights

Centrally the *UN Declaration of Human Rights* (UNDHR), the *UN Convention on Rights of Persons with Disabilities* (UNCRPD) and the *European Pillar of Social Rights* (Article 17) all reinforce that people with disabilities should be treated as **full citizens** with the right to direct their own lives.

Disability rights are not different to human rights. The *UN Convention* was designed to make clear that universal human rights must be applied to the specific **barriers and prejudices** faced by people with disabilities. These principles are powerful and they present real challenges to the way that many societies are organised. In particular, the following articles are relevant to the design and funding of support services:

Article 14 guarantees that people should not be “deprived of their **liberty**.” And one of the key messages from people with disabilities is that if they cannot control their own care or support then they cannot live the life they want.

Article 19 guarantees that people should be able to live independently and “choose their place of residence.” Despite this, most countries continue to invest in institutional and residential care services that effectively deny people the chance of a real **home** that others take for granted.

Article 22 protects people from interference with “**privacy**, family, home or correspondence.” However many people with disabilities lose all of these rights when they are forced into residential care services with limited protection of their basic rights.

Article 23 promises to “eliminate discrimination against persons with disabilities in all matters relating to marriage, family, parenthood and relationships.” Yet in both in matters of law and the practical organisation of services if it is often very difficult to people to form and maintain **relationships** and a family life.

1.2 The challenge of deinstitutionalisation

Currently the European Union has prioritised the importance of deinstitutionalisation as a central reform strategy for all people with disabilities across Europe. The *European Disability Strategy 2010-2020* aims to create a barrier free Europe and to “promote the transition from institutional to community-based care.”

However this challenge raises profound questions.

Institutional care is primarily care that shapes and organises the lives of people with disabilities through a mixture of geographical, architectural, social, legal and economic forces. In particular institutional care is marked by the control of support services by professional, commercial or administrative systems, rather than by people, families and their allies. **Power** - rather than buildings - is at the heart of institutionalisation. The experience of deinstitutionalisation since the 1960s has repeatedly reinforced the lesson that institutional control can move with people, even as people move away from the large asylums, hospitals or residential services that are typically called ‘institutions’ (see Figure 1).

In fact, what are often called ‘community services’ are just a midway point on a journey towards full citizenship. People may be living in smaller buildings, perhaps closer to family, but they are often still under the control of a service system, their relationships are limited and their access to all the opportunities offered by community life is highly constrained.

“Our biggest problem is the rigidity of care systems.” [Respondent from the USA]





FIGURE 1 FROM INSTITUTIONS TO CITIZENSHIP

Moreover institutional systems are quite effective at defending their own forms of practice; and disability campaigners, families and community support organisations are often at disadvantage in terms of access to resources and political influence. The lesson of the last 50 years or more is that deinstitutionalisation is essential, but rarely easy to achieve and it is often resisted.

Deinstitutionalisation and the realisation of human rights for people with disabilities, which is set out in the UNCRPD, demands a radical shift in the relationships between people, families and the services that exist to support them. Meaningful **deinstitutionalisation** demands both Self-Directed Support and Coproduction:

- **Self-Directed Support** - this means that support services must be led by or accountable to people with disabilities or their families.

“The support services must be controlled by persons with disabilities.” [Respondent from Montenegro]

- **Coproduction** - this means that the design of services, systems and society must be done by people, families and professionals in a spirit of equality.

“Our organisations should be involved at all levels of discussions and policy making.” [Respondent from Malta]

1.3 External threats to human rights

Currently services are still evolving and moving away from the presumption of professional power and control. There are many positive and progressive forces at work, like the European commitment to the *UNCRPD*, independent living and deinstitutionalisation. However there are many negative forces which also must be addressed:

- **Austerity** - There is political pressure to reduce spending on those public programmes that support human rights and often it is support to the most disadvantaged groups that is being cut first.
- **Marketisation** - There are efforts to shift services into market models that often weaken social commitment to community, collaboration, the equal value of all lives and the practice of Coproduction.
- **Regulation** - Often systems are controlled by laws, regulations and systems of control which do not seem to allow for innovation and may encourage services not to change.

The current political ideology underpinning a particular country's government will also impact on moves to improve support and the recognition of human rights. For example, in some countries (e.g. Hungary) there has been new investment in institutional services, whereas others (e.g. Finland) are still working to close institutions. Or, while some countries (e.g. Slovenia) are establishing new rights to Personal Assistance, other countries (e.g. Greece) lack any systems to support Independent Living.

As it stands there is a wide variance in approaches to supporting disabled people of all ages to live in their local community and to move away from institutions. The shift towards Self-Directed Support is about taking people on a journey where people choose to deconstruct the old system and to rebuild a whole new system on **human rights principles**.

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

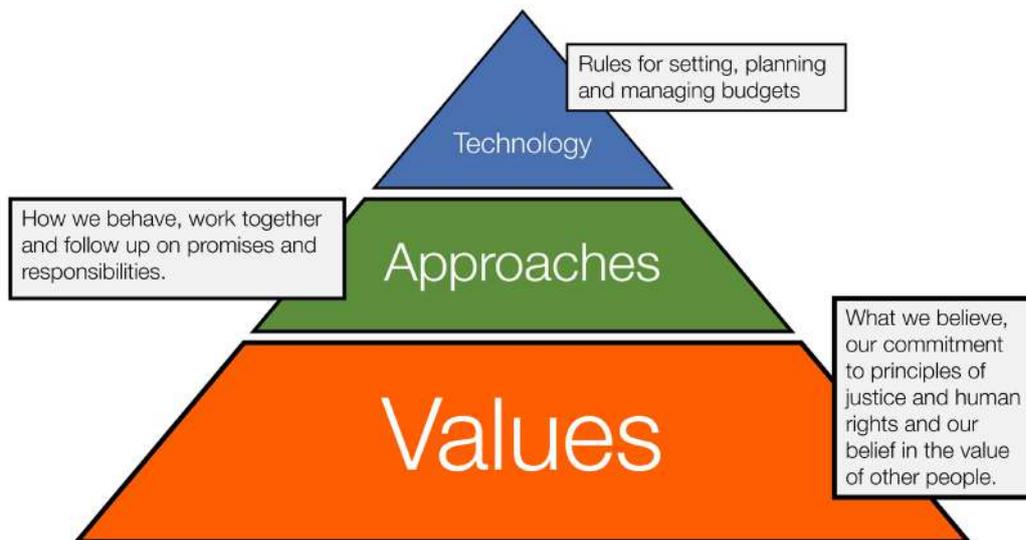
However, there is also the risk that Self-Directed Support will not be promoted because of a desire to respect human rights or to create more inclusive communities.



Instead, for some policy-makers, the attraction of Self-Directed Support lies elsewhere:

- Self-Directed Support can be more **efficient** and it may offer potentially cheaper ways to organise support.
- Self-Directed Support may open up more choice and competition and this fits with **consumerism** and privatisation of services.
- Self-Directed Support may be seen as a kind of **technocratic** modernisation of public services and it may lead to increased centralisation.

It is not the **technology** of Self-Directed Support that safeguards progressive reform. The technology (new forms of budgeting, planning, managing and reviewing support) should serve the underlying values. The implementation of this technology must be carried out using Coproduction - ensuring people and families are at the heart of learning change. At the foundation for these



changes must be the underlying values of human rights, inclusion and equal citizenship (Simmons).

FIGURE 2 THE SIMMONS TRIANGLE

In this report we have examined what can be learned from the development of Self-Directed Support over the past 50 years. In particular we have tried to draw out the strategies that seem most hopeful and positive. Organisations like EASPD, have a key role to play in enabling a stronger voice and greater participation for disabled people and families.



2. Changing Roles for Service Providers

If all the existing service arrangements were functioning well and offered people exactly what they wanted then there would be little demand for Self-Directed Support and Coproduction. Self-Directed Support and Coproduction means change, change in how power is organised and change in the kind of support people receive.

Change creates fear and resistance; until people can see that this change can be positive. In particular the changes required from support and community organisations are changes that are consistent with the values of many of these organisations. Often it is old practices and funding systems that lock people into more institutional practices. Self-Directed Support can liberate people to make changes that better reflect their true values.

The **biggest risk for service providers** is that they misunderstand Self-Directed Support and see it as merely a new way of funding what they do now. If services believe that what they do now is already good enough and that all they have to do is 'sell' these existing services directly to people with disabilities then they have profoundly misunderstood the challenge of Self-Directed Support.

2.1 Self-Directed Support as a system

Although the current organisation of funding varies across Europe there is a common pattern which involves four key interventions:

1. **Assessment** is the process, often led by a social worker, of defining someone's needs and determining any eligibility for support.
2. **Planning** is the process, often also led by professionals, of planning what services people will receive.
3. **Placement** is the process of transferring the person into the control of a service that is funded directly or indirectly to provide care.
4. **Review** is the process by which placements are monitored and possibly changed.

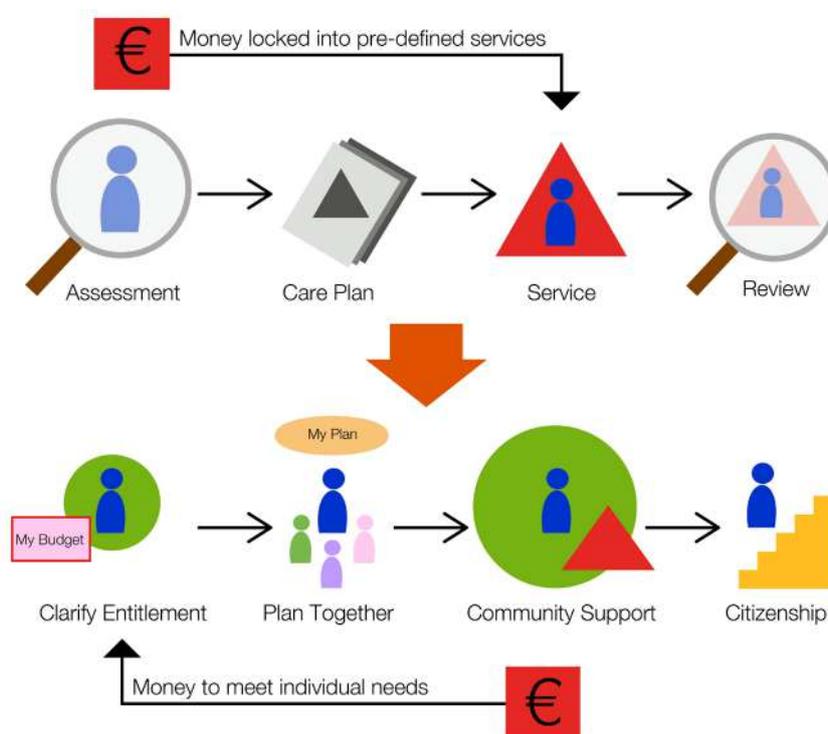
This kind of process seems rational, but it is fundamentally in conflict with the human rights of people with disabilities. The process effectively makes the person passive and assumes that professional processes should shape how someone lives their own life.

Self-Directed Support and Coproduction involves challenging and changing this process at four key points:

1. **Clarifying entitlements** - If people have rights and are entitled to support then what people are entitled to must be clear. Ordinarily this will mean knowing what budget is available for your support.
2. **Planning together** - If people are freed then they must be able to set their own objectives, and change their minds, as they learn and develop. This means planning must be done with the person at the heart of the process.

“First of all, the support should be individualised and provided in the mainstream public and private setting, and secondly, it should be given to the disabled people and not to the family in order to avoid any financial dependence in addition to the physical (need to help) and emotional (need to love).” [Respondent from Bulgaria]

3. **Support in community** - If people have the right to participate as an equal within the life of the community then their support must be organised so that it enables inclusion and contribution.
4. **Citizenship** - If people are citizens then they can be entitled to build a life that is meaningful

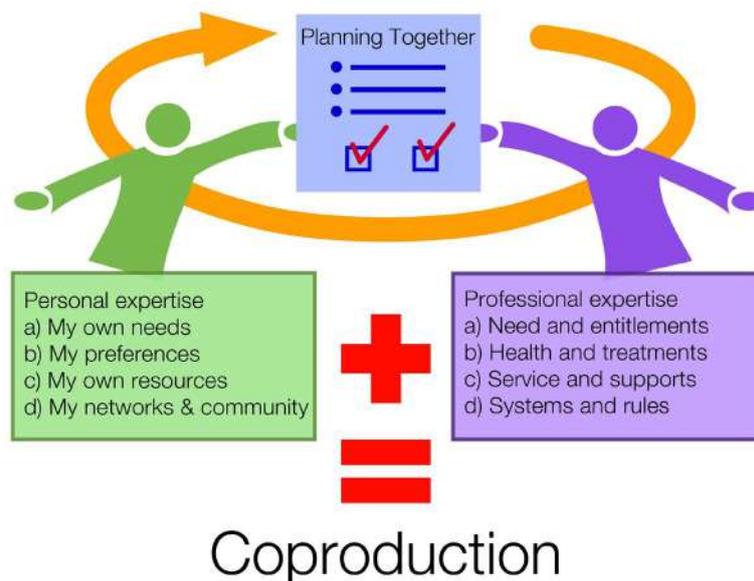


to them and where they define their own outcomes.

FIGURE 3 THE SHIFT TO SELF-DIRECTED SUPPORT

As Figure 3 makes clear these human rights principles imply fundamental changes in the way we think about services, funding, the roles of professionals and their relationship with people with disabilities and their families. Professionals do not become redundant, they have important roles to play at every stage, but their role is to support and protect the human rights of the person with disabilities and they must build relationships in **a spirit of equality**.

From the point of view of the person with a disability Self-Directed Support should put them in charge of their life and the support they need to live their life. From the point of view of the service provider Self-Directed Support should make them **accountable** to the person. However the purpose of this arrangement is not to make the professional passive. Instead the professional can become an active partner who uses their expertise to help the Coproduction of better outcomes. As Figure 4 suggests, this model is about combining different forms of expertise and different



perspectives.

FIGURE 4 THE MEANING OF COPRODUCTION

“They all need to listen to disabled people more and rely less on big providers, “consultants” or even moms like me. We don’t have the full picture. Only disabled people do.” [Respondent from Canada]

“The thing I would most like to see is a philosophical shift from a medical model of disability to a social model. I would like not to be treated like a problem that needs fixing, but as a person who needs support as a result of living in an inaccessible world (or better yet, an additional focus on making the world more accessible so that disabled folks can be better integrated and participate in their communities without barriers). I would like

access to medical professionals who understand my autism within a neurodiversity framework, and not as a disease that needs to be cured or a set of problematic behaviours to be eradicated.” [Respondent from Canada]

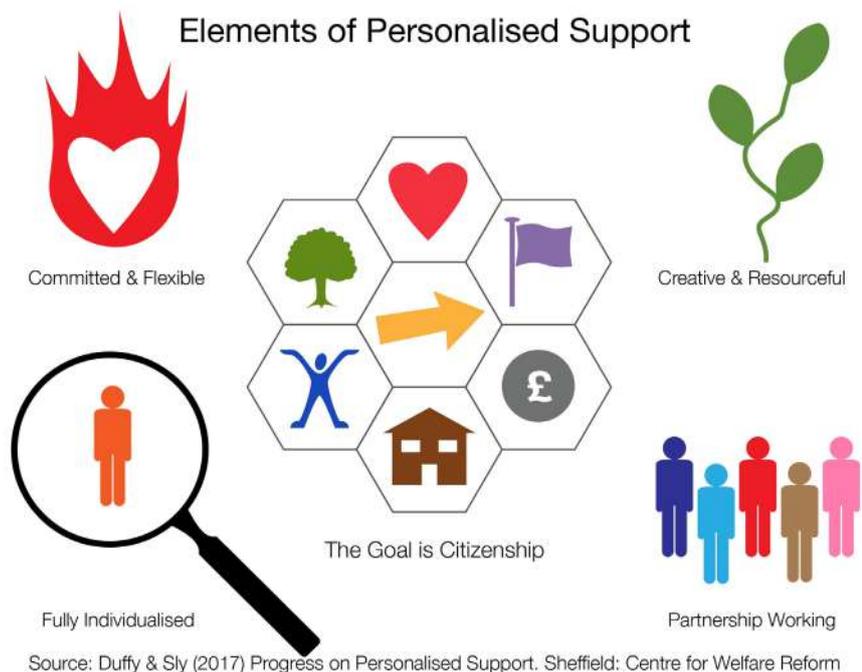
2.2 New models of support

But if it is true that Self-Directed Support is not just about selling existing services directly to people with disabilities, if it requires different kinds of changes in community support, then what are those changes? There has been 50 years of progress towards Self-Directed Support, but during that time **no one model of support has emerged**. Instead there are a range of different innovations in support that have developed in and around the evolving system, as follows:

Personalised Support

Many people want individualised and flexible support that is designed around their lives and which enables them to lead the life that they want. They do not want to employ their own staff, but they still want a high degree of control over their support (Fitzpatrick, 2010; Hyde, 2012). In some places support is being radically redesigned around the needs of the individual with extreme flexibility (Ellis et al, 2014). This means the support provider will:

- Protect the individual’s budget (Animate, 2014)
- Develop plans and support arrangements that are totally individualised
- Employ assistants who are recruited by and for the person



- Support people and families to have authority and control of key decisions

FIGURE 5 ELEMENTS OF PERSONALISED SUPPORT

The report *Progress on Personalised Support* describes how this model is developing internationally, but it still remains an unusual approach and funders have struggled to understand the value of a truly personalised approach (Duffy & Sly, 2017).

Personal Assistance

Some people want to employ their own personal assistants, but do not want to take on all the specialist services involved like finance management, payroll, recruitment and personnel services. Others may happy to purchase support from an organisation like Buurtzorg, which reduces management and helps support highly autonomous teams working in small neighbourhoods (Sheldon, 2017)

“Services should become less special, more personal.” [Respondent from Belgium]

This kind of model is the dominant model for people with physical disabilities and for those people and families who are ready and willing to become employers of their support staff. This model is often combined with Centres for Independent Living, which are run by people with disabilities and which provide peer support and other auxiliary services that make employing personal assistants



easier (e.g. payroll, recruitment or employment advice) (ACL, 2019). Sometimes new forms of service emerge which help people help people find staff more directly online.

Accessible Housing

One of the most important changes that people seek when they take more control is a home of their own. Sometimes the challenge is to access appropriate and accessible housing in the community in which you want to live. This may require very different strategies for going development - instead of building new care homes money may be better spent helping people access ordinary housing by every means possible (e.g. private renting, public sector housing or home ownership).

“What I need most is qualified customer assistants according to my needs and affordable accessible accommodation.” [Respondent from Spain]

This is also an important challenge to the idea of residential care, which tends to be the dominant model that replaces institutional care. Many advocates have proposed that we need to think about the idea of Supported Living - enabling people to enjoy the same housing rights as everyone else. In particular the challenge is to encourage support provider not to be housing providers, because combining these two functions creates a conflict of interest (Kinsella, 1993).

It often seems, when people take control of their own support, that they seek to leave residential care and it is noticeable that, in England, residential care providers have effectively lobbied to to exclude themselves from the system of personal budgets in order to avoid this risk (Poll et al., 2006).

Shared Management

Some services are developing ways in which people can take different levels of control and support, to suit their needs and preferences. This is a flexible model which has been developed in Australia and it bridges Personalised Support and Personal Assistance (WAIS, 2012). It meets an important concern, which is that if implemented badly Self-Directed Support can **load responsibilities** on to people and families with no consideration of how reasonable those extra resources really are (Baxter et al, 2013).

Support Brokerage

Some services focus on helping people plan, negotiate or organise their support, but don't get involved in direct support. In some places this becomes an essential part of every person's support, in others it is just used by a minority. There has been a lively debate about this function. In Canada there is an important that argues that everyone should have a Support Broker and that



this Support Broker should be independent of services and of any social work or assessment function (Brandon & Towe, 1989). Others have challenged this model and suggested that a new professional role may not be necessary - at least not for everyone - and that it would be better to adapt existing professional roles (Duffy & Fulton, 2009). There is possibly inadequate empirical research to determine whether there is a right approach, but the importance of good planning and creativity is undeniable and many people will benefit from a fresh perspective (Leach, 2015).

Microboards

Some families use networks of community support to provide a long-term foundation so that people will have guidance and support even if close relatives are no longer around. For example, the Vela Microboards model has enabled people with complex disabilities to get the support of families, friends and community members to manage their support in Canada and Northern Ireland. Similarly the Plan Institute in Canada supports families to establish robust systems of support and decision-making around people with highly complex needs. It is also important to note that sometimes these systems are effective vehicles for managing budgets and by creating boards or trusts it is often possible to create a legal vehicle which funders find easier to accept as a recipient of funding.

Microenterprises

Some people design very small local organisations or small businesses, including some people with disabilities who use their Individual budget to start a business. In fact one of the most positive elements of Self-Directed Support is that it often allows people to reimagine their current support as the basis of a business or social enterprise which can be used to support the passion and interests of the individual. Here, effective support combines with community inclusion as people become important agents of change in their community (Hill O'Connor & Rendall 2017).

Alternatively some people want to provide support to others, but they want to do so in a way that is highly focused and local - so instead of creating a significant business they can create a small business, perhaps with only a handful of employees to provide flexible and local support to a small number of people (Duffy & Catley 2018).

Community Connecting

Some community organisations help build support and connections across the community so that people have networks of friends and unpaid support in their lives. Organisations like KeyRing and Neighbour Networks enable people to live independently in the community while staying connected to others (Simons, 1998). Others focus on tackling issues of isolation through training, skills or friendship and dating services (Mills, 2015).

Asset Based Community Development

Others focus on enabling communities themselves to solve problems and be more inclusive places. Local Area Coordination is one model that starts by offering support that is embedded in a community and seeks to reduce reliance on services (Broad, 2012). This approach starts with making positive assumptions about the capacity of local communities and enables people to develop solutions based around the strengths of the local community (Gillespie, 2011).

Peer Support

People with disabilities are coming together to build their own systems of mutual support and self help. In some places whole systems are being redesigned so that people with disabilities own the system. Centres for Independent Living are often organised as a system of Peer Support, but there are also other approaches. For example, in Alaska the Nuka approach is transforming the relationship between people and services by making people “customer-owners” of the whole system (Harrison, 2015). In England organisations like PFG Doncaster are helping people with mental health problems to transform their lives through mutual support (Duffy, 2012).

Specialised Support

There are also examples of people focusing on specific areas of life and providing specialist support with help to:

- Get a job
- Start a business
- Find a boyfriend or girlfriend
- Learn new skills, like travelling independently

People are often looking for something special or different to meet their individual lives:

“Support is still so generic and needs to be further funded to be fully individualised to allow for better social integration and employment opportunities.” [Respondent from UK]

It is not always clear whether these kinds of support should be built into the infrastructure or support and provided for free to everyone or whether they should be treated as a services that should be purchased. In general terms there is little empirical evidence to help us be certain where to draw the boundary between infrastructure support and the kind of personalised support that must be purchasable tends. This is an interesting issue where there needs to be more experimentation and research.

No change

Most people do not change the support they receive immediately when they gain some control over it. The process of taking control can take time and it tends to be a minority who try new models. These early innovators usually set the path for others who follow their example. In fact one of the best approaches to growing Self-Directed Support is to focus on those with the greatest need or passion for it and then let those early champions show others how to do it. Treating the change process as human, social and therefore organic - not mechanical - is very important in ensuring that the changes made are consistent with the underlying values. Where government pushes the pace of change artificially it runs the risk of distorting Self-Directed Support and undermining Coproduction.



3. Progress on Self-Directed Support

Although there has been some important research on progress towards Self-Directed Support there is still much to learn. Moreover while research tends to focus on the benefits of Self-Directed Support there is much less research on its impact on services or on the precise details of how Self-Directed Support is implemented. However as the rate of change has been slow it is likely that most services should be able to adapt and find new positive roles.

One of the most important recent publications is a wide-ranging systematic review of **73 studies on Self-Directed Support: Individualised funding interventions to improve health and social care outcomes for people with a disability** (Fleming et al., 2019). It is worth quoting some of the main conclusions:

“Overall, the evidence suggests positive effects of individualised funding with respect to quality of life, client satisfaction and safety. There may also be fewer adverse effects.

There is less evidence of impact for physical functioning, unmet need and cost effectiveness...

Recipients particularly value: flexibility, improved self-image and self-belief; more value for money; community integration; freedom to choose ‘who supports you; ‘social opportunities’; and needs-led support.

Many people chose individualised funding due to previous negative experiences of traditional, segregated, group-orientated supports.

Successful implementation is supported by strong, trusting and collaborative relationships in their support network with both paid and unpaid individuals. This facilitates processes such as information sourcing, staff recruitment, network building and support with administrative and management tasks. These relationships are strengthened by financial recognition for family and friends, appropriate rates of pay, a shift in power from agencies to the individual or avoidance of paternalistic behaviour.

Challenges include long delays in accessing and receiving funds, which are compounded by overly complex and bureaucratic processes...

Staff mention involvement of local support organisations, availability of a support network for the person with a disability and timely relevant training as factors supporting implementation....”

These findings from the international evidence are supported by our personal experience of Self-Directed Support. Significant positive progress is achievable, but there are many important

matters that must be addressed in order that the implementation of Self-Directed Support is effective.

3.1 Who benefits from Self-Directed Support

There are also no obvious limits to the groups who benefit from Self-Directed Support, although often different groups may need some differences in approach. In the report *Progress on Personalised Support*, based on a global survey of good practice, examples of Self-Directed Support were identified for members of all these groups (Duffy & Sly, 2017):

- 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



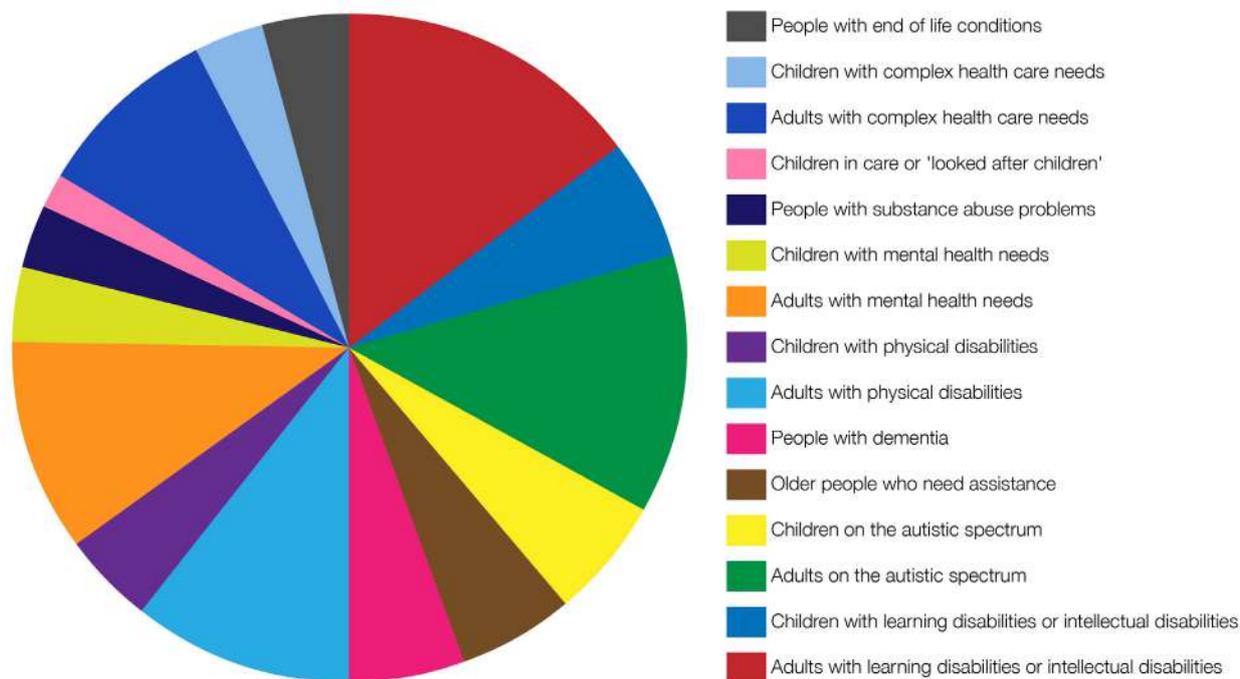


FIGURE 6 DIFFERENT PEOPLE USING PERSONALISED SUPPORT

However different people may need very different kinds of help and sometimes different systems emerge around particular groups. For example:

- 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.

- Children especially, but not only children, need support that respects their need for love and family; any practical assistance must be integrated into family life in a way that respects the integrity of the family.

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

3.2 Where Self-Directed Support is developing

The SKILLS Project is in the process of mapping the development of Self-Directed Support around the world. This work is still in progress and these findings must be treated with some caution. In particular it is important to recognise that there are multiple approaches to Self-Directed Support and there is variety in:

Progress - Even where systems aim to create a universal system of Self-Directed Support it can often take many years for the whole system to shift to Self-Directed Support. For example, in England, where Self-Directed Support is supposed to be underpinned by national law the number of people who are reached is about 25%.

Breadth - Systems vary in breadth, for example some exclude children and families, some exclude older people, some exclude people with cognitive disabilities and mental illness. For instance, in Australia there is an emerging system for children and adults, but this system does not extend to older people. Germany, on the other hand, has a very well established system to give older people choice and control, but this does not extend to younger people. Many countries have systems of personal assistance which achieve a form of Self-Directed Support, but which tends to be restricted to people with physical disabilities who want to employ their own staff.

Quality - Often systems are designed in ways which may seem like Self-Directed Support but which actually fall far short. For instance, many Scandinavian countries do have systems of individualised funding, but the rights of people and families to spend that funding creatively are more limited.

A further complication is that countries may have systems of income security (benefits or disability pensions) which do given people some money which they can control and some times this money is enough to purchase modest assistance (e.g. in Italy, Spain and France). However these systems are distinct from the Social Care system which continues to provide distinct funding that people cannot control. In other countries (e.g. the UK) significant levels of funding for support exist inside other public services (e.g. health and education) and they are not subject to the same rules.

Overall what we can see is that there are many different systems of Self-Directed Support, at different stages of development across the world, and to some extent in Europe. Progress remains slow - but it is happening. However there is certainly a lack of:

- International understanding of what counts as good practice
- Weak networks for sharing international and European learning
- On-going divisions between different groups and no shared vision for reform

These problems are also opportunities and the existing commitment of EASPD to collaborate on new forms of international learning is very welcome.



4. Case Study: Scotland

Scotland provides an interesting example of a country where Self-Directed Support has evolved as a strategy which is intentionally linked to progressive ideals, such as human rights, equal citizenship and the values of independent living. It is also a country where some service providers have played a role in positively promoting Self-Directed Support and where the positive role of the service provider is clearly recognised in legislation and policy.

4.1 Rooted in values

Self-Directed Support is a values-based technology designed to assist an ultimate goal that can be stated in terms of Citizenship or Independent Living:

- **Citizenship** means all people, without exception, should have the support and finance they require to live a purposeful life to the full, in a home of their own, without restriction on their basic freedoms, and in loving relationships with others of their choice (Duffy, 2006).
- **Independent Living** means all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life (ILiS).

Self-Directed Support has therefore been constructed as a means of enabling the most severely disabled or stigmatised members of society achieve for themselves the vital human rights outcomes of Citizenship and Independent Living, so frequently denied them both historically and in the present day. This is an approach that has much in keeping with basic Social Work values and principles especially in relation to their concern for “individualisation” and “client self-determination” – and for their injunction that the worker should be constrained “to follow for the demands of the client task” (Biesteck, 1957).

For the United Kingdom, in the post-World War II period, much of the support, finance and practical assistance required to live independently as a citizen has been mediated by the state, through the medium of its local government departments of Social Work. So this Scottish case study considers the development of Self-Directed Support within the context of modern Scottish Social Work. It begins with the *Social Work (Scotland) Act 1968* (which was based on the work of the Kilbrandon Committee culminating in the *Kilbrandon Report* of 1966. It has found its most



recent expression is the *Self-Directed Support (Scotland) Act 2013*. However, as we will see, the journey to Self-Directed Support has been long, and is still incomplete.

4.2 The framing of Social Work (1964-79)

As elsewhere in the United Kingdom, the period from the mid-60s through to the mid-70s saw Social Work make a planned transition: from specific, fragmented services, encompassing stigmatised public 'welfare' services and more benevolently regarded civil charitable initiatives; to a more unified, generic and professionalised approach, located firmly within the reformed two-tier local government structures created by the *Local Government (Scotland) Act 1973*, as anticipated by the *Wheatley Report* (Pincus & Minahan, 1973).

However, distinctive to Scotland was the more overtly stated aspiration that this reform of Social Work would contribute to positive social change within the country, an aspiration articulated politically by individuals such as Judith Hart (Labour under-Secretary of State for Scotland at the time the Kilbrandon Committee sat) and professionally by people like Kay Carmichael (a policy advisor to the Labour government and later deputy chair of the supplementary benefits commission) and Richard Titmuss (Professor of Social Administration at the London School of Economics, 1950-73) who with others were consulted during the process of reform.

In keeping with the bold aim of addressing big 'political' issues of poverty and inequality, the new Social Work profession was located within the more strategically-oriented nine regional and three islands councils, as distinct from the fifty-three more locally focused 'district councils'. Section 12 of the *Social Work Act* of 1968 had made it the unambiguous duty of each of these strategic authorities not simply to respond to the social problems and issues arising in their midst but instead to actively "promote social welfare" within the communities they served.

In broad terms professional Social Work in Scotland was framed by this ambition and within these structures for the next 20 years, and in this context the first shoots of what we might now recognise as Self-Directed Support began to appear: at first through the sketchy programmes of de-institutionalisation that began to emerge for people with physical disabilities, learning disabilities and mental health conditions; and later through the related UK-wide campaign that people with disabilities should have access to a system of Direct Payments (which would have its culmination in the *Community Care (Direct Payments) Act 1996*).

More generally, the Social Work system's bold and overt commitment to social change and emancipation from poverty was of course fertile ground for the expression of the goals of what would later be described as Self-Directed Support. However there was also a more statist set of assumptions about how this change could and should be achieved, which would not always sit



comfortably with the notions of Independent Living and Citizenship which were developing within civil society. This is not simply because the newly unified Social Work profession was firmly embedded within the structures of local government, but there is no doubt that the identification of Social Work with 'the Council' has established a perspective that continues to impact on both professional mindset and public perception up to the present day.

4.3 The wind shifts (1979-98)

Of course the framework for Social Work in Scotland in place by the mid-70s did not remain fixed. The original political ambition implicit in the Social Work act was diluted in the course of the 1980s by the imperatives of Conservative Government and their consequent impact on the thinking of *New Labour*. The *Griffiths Report* and subsequent *Community Care and NHS Act*, in addition to introducing a more business-oriented managerial approach and a different set of neoliberal political parameters, began to chip away at the dominance of local authority service provision and permitted the emergence of a diverse third sector, still largely not-for-profit in its constitution in Scotland, but dependent on the local authorities for determining the policy boundaries within which it could work and for allocating the bulk of its funding.

The Griffiths reforms did, however, strengthen the hand of local authority Social Work in one important respect by clearly allocating to the local authority the lead responsibility for community care services. This meant that for the first half of the 1990s (until disband in 1996) the Scottish Regional Councils, through the vehicle of their Departments of Social Work, began to engage with their local co-terminus Health Boards in some serious attempts at joint strategic planning for future provision. Although dominated to an inordinate extent by negotiations about the amount of money to be transferred from health services to Social Work, to facilitate a shift from hospital to community, these joint planning activities did set the ground for much of the de-institutionalisation activities that were implemented in the course of the following 10 years.

In turn, the actual practice of assisting some severely disabled people to leave long-stay institutions after perhaps 30-40 years residence afforded some practitioners to demonstrate the universal applicability of community-based citizenship and independent living; and also to experiment with the technology of Self-Directed Support, albeit at the margins, and to some extent 'under the radar'. This saw the creation and management of some of the first 'individual service funds' not instigated by the local authority and its Social Work commissioners, but instead initiated by the service providing organisation itself (Animate, 2014). Out of this grew a small federation of not-for-profit service providers and other associated practitioners determined to extend this methodology and its inherent values, which is called Altrum.



They were undoubtedly assisted in this by the development elsewhere in the UK of the concept of Supported Living which provided some of the conceptual tools by means of which broader citizenship ideals could be realised (Kinsella, 1993; Simons & Watson, 1999). Central to this was the insistence of these writers of the separation of 'housing' from 'support'. This ended the need to persist with the disempowering conflation of the functions of 'landlord' and 'support provider'. But also, and more importantly, it meant that people with severe disabilities could no longer be denied their right to have a home of their own on the grounds that they level and type of support they required could only be provided in 'special', non-domestic, typically institutional types of accommodation. Many would continue to be denied this right for other attitudinal and quasi-financial reasons, but the iron law that compelled people to live in places other than their own home in order to obtain the level of support they required had been broken.

4.4 The devolution of Social Work (1998-2010)

Of course, everything described up to this point took place within the context of the limited devolution afforded Scotland by the Westminster Parliament through the role of the Secretary of State for Scotland (a cabinet office from 1926 onwards) and the Scottish Office. *The Scotland Act* passed by the incoming Labour government in 1998, and implemented on 1st July 1999, radically changed the situation. Responsibility for Social Work and health matters was no longer reserved to the Westminster parliament but instead devolved to the first Scottish Parliament to sit since 1707. From this point onwards Scotland was free to make legislative decisions and to develop policy distinct from the rest of the UK.

What was to become of some significance for the administration of what we now call Self-Directed Support, was the early adoption by the Scottish Parliament of the concept of “free personal care for older people,” proposed by the Sutherland Committee, and legislated for through the of *Community Care and Health (Scotland) Act*. This is often cited as a distinctively Scottish and egalitarian approach: but it begs the question why the ability of local authorities to levy a charge (in reality an additional tax) for services, introduced by the Griffiths reforms and eagerly taken up local authorities throughout the UK, has not been more fundamentally challenged by the Social Work profession itself on the basis of the principles of universality and basic justice; all the more so given that the amounts charged are locally and differently calculated and disproportionately severe in relation to the disposable income of the individuals concerned. Instead, the charging system continues to be adjusted on an incremental and ad hoc basis in the face of opposition from the *Campaign for Frank’s Law* and *Scotland Against the Care Tax*.

More positively, however, one of the most influential first steps of the new Parliament was its early adoption, in 2000, of the first ever specifically Scottish policy paper on learning disability: *The*



Same As You? (Scottish Executive, 2000). In addition to recommending the development of better advocacy services and extending the availability of Direct Payments to people with learning disabilities, the report led to the creation of the Scottish Consortium for Learning Disability (SCLD) and contained the first ever strategic commitment to the closure of all long-stay learning disability hospitals by 2005. Prior to the *Scotland Act*, and the adoption of *The Same As You?* each individual proposal for the closure of one of these institutions required the sanction of the Secretary of State for Scotland, and was vulnerable to local political lobbying. Now the way ahead was clear, and despite the fact that the 2005 deadline was not entirely met (and despite the fact that at the time of writing some similarly constituted institutional provision can still be found within the country) a watershed moment had been reached. The Parliament's adoption of similarly progressive strategic policy documents for other groups soon followed.

Also settled at this time was a longstanding debate between the proponents of quality control by means of the registration of the buildings occupied by people receiving support and those favouring the greater use of regulation. In 2001 the Scottish Commission for Social Care (SSSC) was created to set standards for, and regulate, the social care workforce. The following year the Care Commission (later renamed the Care Inspectorate) was created to perform a similar function in respect of those agencies and organisations providing social care.

One major irony arising in the post-devolution context, however, was the fact that, as described above, the Social Work (Scotland) Act (1968), conceived within the much more limited devolved scope of the Secretary of State, was already distinctively Scottish in its scope and ambition, whatever we judge to be the extent of the erosion and dilution of its bold aims over the intervening years. The 1968 legislation remains the foundational legislation relating to the practice of Social Work in Scotland: even if viewed and interpreted in light of the related legislative and policy changes introduced both before and after 1999; and notwithstanding the now largely overlooked *21st Century Review of Social Work in Scotland* commissioned by the fledgling Scottish Executive in 2004, and published in 2006 as *Changing Lives*, which, while seeking to reaffirm and extend a professional understanding of Social Work, also sought to chart a course away from social-work-as-a-universal-service towards its more 'targeted' and 'personalised' application.

There was, however, one piece of work carried out to inform the Review which pointed to the need for a shift in the balance of power, away from the local authority based Social Work professionals and towards the people relying on the system the Social Workers sought to administer. Undertaken by Charles Leadbeater, the architect of new-Labour's policy of public service *personalisation*, and his associate Hannah Lownsbrough, it represented a first-hand survey of the views of the end-users of the Social Work system in Scotland at the time. What they wrote



could hardly have been more prescient in its anticipation of the drive towards Self-Directed Support that was to follow:

“A version of personalisation is already the goal of the Scottish social care system. But it is a goal the system fails to reach consistently. The *1968 Social Work Scotland Act*, which inaugurated modern generic Social Work, set the goals of Social Work that most Social Workers still ascribe to today... Yet the testimony of both professionals, care staff and clients is that the Social Work system often fails to deliver on these goals. In practice Social Workers seem to be risk managers and resource allocators, gatekeepers and controllers, often working with clients in crisis when the task is to save them from harming themselves or others... our workshops and interviews with service users also uncovered a feeling among many that the service they receive is driven not by what people need but by what the system can deliver: it feels as if the professionals and system make all the decisions that count. Many of the clients feel as if the professionals are in charge and they have no choice. Social work is formally committed to deliver a set of goals – which embrace the ideals of person-centred support – and yet the system works to a completely different logic to control risk and resources.”

With the publication and implementation of *The Same As You?* having coincided with Simon Duffy's earliest articulation of the concept of Self-Directed Support (and its dissemination in England, from 2003 onwards, through the work of In Control) ALTRUM and SCLD joined forces three years later to create its Scottish counterpart and sister organisation, In Control Scotland, just as *Changing Lives* was being published – indeed it was a small amount of money from the *Changing Lives* implementation fund that allowed In Control Scotland to begin to raise awareness of the principles and concepts of Self-Directed Support via a programme of seminars and training programmes across the country.

It was, however, a separate department of what was now the 'Scottish Government' that in 2008 undertook a *Review of Direct Payments*, seeking to review the experience of those who had been using Direct Payments and to establish the means by which their administration could be improved and their uptake increased. By the time the review was concluded, however, it seemed highly significant that Self-Directed Support had replaced Direct Payments as the official terminology of government. To its proponents this seemed little short of the official appropriation of the language of Self-Directed Support to describe proposals for a new and improved version of Direct Payments which, though welcome, continued to fall well short of the levels of universality and flexibility for which they argued.

4.5 Strategy for Self-Directed Support (2010-20)

The next stage in the development of Self-Directed Support in Scotland came with the Scottish Government's publication of a 10-year *Strategy for Self-Directed Support* in November 2010. The



strategy, explicitly set in terms of Independent Living and other more general Social Work and health objectives relating to older people, the ageing population, and re-ablement of people with mental health issues.

The strategy defined Self-Directed Support in terms of informed choice, Individual Budgets, choice and control, and co-production. It no longer spoke about Self-Directed Support being accessed solely by means Direct Payments, but also allowed for the possibility of Individual Service Funds being used, and for Direct Payments and Individual Service Funds to be used in combination. One of the fundamental principles espoused within the strategy was that 'SDS and all public services are subject to Human Rights and Equalities legislation', and it elsewhere asserted the human rights principles of 'Equality and Non-discrimination' and 'Participation and Inclusion'. A small number of test sites and other related projects were established as part of the strategy and the anticipated learning was seen as crucial in bringing fostering change.

While the strategy of 2010 did not anticipate that Parliament would legislate for Self-Directed Support, the pros and cons of a legislative approach to the issue quickly became a strongly debated topic as the strategy began to be implemented. The debate concluded with the decision that legislation should be brought before Parliament, and in 2013 the *Social Care (Self-directed Support) (Scotland) Act* was enacted. It took effect from 1st April, 2014. The legislation imposed upon local authorities the legal duty to offer four routes or 'options' by which they might direct their own support:

- **Option 1** - The making of a Direct Payment by the local authority to the supported person for the provision of support.
- **Option 2** - The selection of support by the supported person, the making of arrangements for the provision of it by the local authority on behalf of the supported person and, where it is provided by someone other than the authority, the payment by the local authority of the relevant amount in respect of the cost of that provision (that is an Individual Service Fund).
- **Option 3** - The selection of support for the supported person by the local authority, the making of arrangements for the provision of it by the authority and, where it is provided by someone other than the authority, the payment by the authority of the relevant amount in respect of the cost of that provision.
- **Option 4** - The selection by the supported person of Option 1, 2 or 3 for each type of support and, where it is provided by someone other than the authority, the payment by the local authority of the relevant amount in respect of the cost of the support.



The Act and its associated Statutory Guidance articulated a number of additional legal duties local authorities were required to follow:

“...to explain the nature and effect of the four options and to 'signpost' to other sources of information and additional support.”

“to have regard to the general principles of collaboration, informed choice and involvement as part of the assessment and the provision of support.”

“to take reasonable steps to facilitate the person’s dignity and participation in the life of the community.”

The Act also introduced four statutory principles articulating the underlying aims or 'spirit' of the legislation:

1. **Participation and dignity:** “...whereby the supported person has the same freedom, choice, dignity and control as other citizens at home, at work and in the community. In some respects ...a modern interpretation of the social welfare duties provided in the 1968 Act.”
2. **Involvement:** “...the supported person must have as much involvement as the person wishes in both the assessment and in the provision of support associated with that assessment.”
3. **Informed choice:** “...the supported person must be provided with any assistance that is reasonably required to enable the person to express views about the options available to them and to make an informed choice about their options for support.”
4. **Collaboration:** “...the professional must collaborate with the supported person in relation to the assessment of the person’s needs and in the provision of support or services to the person.”

The new legislation and guidance thus created a positive new paradigm for the understanding and implementation of Self-Directed Support, establishing in statute mechanisms with the potential to shift the balance of power in favour of those directing their own support, and to transform the future of Social Work and Social Care in Scotland.

There were two factors immediately mitigating against its effectiveness, however. The global financial crash of 2007-08, and the policy of Austerity economics subsequently pursued by United Kingdom governments, had the cumulative effect of restricting the level of funding available to local authorities to spend on Social Work. Though merely coincidental with the introduction of Self-Directed Support, the coincidence created a perception in some quarters that Self-Directed Support was merely a mechanism for reducing spending and disguising the process of “the cuts;” a perception greatly assisted by the fact that some local authorities did in fact use it to those ends.



In addition, however, no sooner had this landmark legislation been enacted than the attention of the professional Social Work and social care workforce was diverted from it and towards the implications of *The Public Bodies (Joint Working) (Scotland) Act 2014*, an additional legislative framework for the seeking the integration of health and social care services. In effect the purpose of this policy was to combine many of the activities of local authorities and health bodies. Whatever the merits of the legislation and the intentions behind it, its implications were such that they quickly came to dwarf those contained within the Self-Directed Support act, and took top priority.

This was one of the key messages contained within Audit Scotland's *Progress 2017 Report on Self-Directed Support* when it took stock of the progress made since the Act took effect three years earlier. Audit Scotland also concluded at that time:

"...there is no evidence that authorities have yet made the transformation required to fully implement the SDS strategy'

"...a significant minority [of staff] lack understanding or confidence about focusing on people's outcomes, or do not feel they have the power to make decisions with people about their support."

"...changes to the types of services available have been slow and authorities' approaches to commissioning can have the effect of restricting how much choice and control people may have."

"...there are tensions for service providers between offering flexible services and making extra demands on their staff."

4.6 Lessons from Scotland

Overall the example of Scotland repeats some of the general themes from the international experience:

1. Self-Directed Support emerges naturally from efforts to organise systems according to the principles of the UNCRPD and the ideals of Independent Living and Citizenship. However progress towards Self-Directed Support is currently quite slow.
2. Service providers can be important agents of positive change, but they are also confronted with making important changes to how they work. Self-Directed Support is not about 'shopping' for services, but is about a more equal partnership between people, families and professionals.



3. Wider organisational, policy or economic changes can have big impact - both positive or negative - on the possibility of making positive progress.



5. Promoting Self-Directed Support

As we have seen Self-Directed Support creates challenges for service providers - but these challenges are achievable and they are the challenges that service providers should want to meet. However there are many factors that can push service providers away from active support for Self-Directed Support.

The development of Self-Directed Support has not always been supported by service providers. Generally we have seen four competing approaches.

1. **Direct resistance** - Some service providers and their representatives have directly lobbied policy-makers to defend old systems of funding and to resist the shift to Self-Directed Support. They may believe that this resistance is in the best interest of the people they serve, but it is also clear that this is primarily a strategy to defend older modes of power and control. It is not what people with disabilities want and it is inconsistent with human rights.
2. **No involvement** - Often service providers will stay outside the discussions and wait to see what new policies emerge. Sometimes they will seek exceptions or try to limit Self-Directed Support to particular areas of Social Care. For example, in England service providers have successfully excluded residential care from Self-Directed Support.
3. **Partial support** - Sometimes service providers will play a more positive role, but will seek to interpret Self-Directed Support in a more conservative way. For example, in Australia service providers, families and disability advocates were united in demanding both new funding for Social Care and a system of Self-Directed Support. However many service providers have been happy to encourage the development of systems that make it harder for people and families to take more control.
4. **Full support** - Sometimes, as we saw in Scotland, some service providers can work in partnership with disability leaders to advance more progressive models of support and to encourage service providers to innovate and change their own practice.

5.1 Inhibiting factors

However it is important to note that the attitude of service providers will be significantly influenced by both the nature of their current system and also how Self-Directed Support is interpreted and implemented in their home country. In fact, particularly if Self-Directed Support is interpreted narrowly, then it can often seem to be in the interests of service providers to oppose it. For example:



Total state control

In systems where all support is provided directly by state employees or where the agencies funded by the state are in very secure long-term funding relationships with the state then it seems unlikely that there will be any eagerness to move to a more fluid and individualised system. Technically, Individualised Funding is compatible with a system completely controlled by the state - but we have not been able to identify any examples where a totally state-run system embraces Self-Directed Support. Some degree of diversity and an active civil society seems like an essential condition for Self-Directed Support.

Marketised state control

In some countries the state retains control over the funding, but uses contracts or grants to fund service providers. In this case the idea of giving people choice and control can seem to threaten security of funding for service providers. However in Finland the state uses open competitive tendering to purchase services. This has led to a strong alliance between disabled people and service providers and growing support for Self-Directed Support. Some service providers prefer funding controlled by people with disabilities, rather than facing regular re-tendering of services. Marketised services do not automatically welcome Self-Directed Support; it seems there must be other perspectives.

Regulated services

There is a significant tension between the idea of close regulation and control by regulatory agencies and the ideals of Self-Directed Support. While some service providers may welcome greater freedom for innovation and flexibility,

others prefer a highly regulated system which defines success and helps to justify prevalent service models.

People with disabilities and families often seek to move away from regulated services, and this can lead to a divide where Self-Directed Support is only possible for non-regulated services. On the other hand many systems of Self-Directed Support find that state control can be asserted by bureaucratic methods which remove discretion and flexibility. John O'Brien calls this the emergence of *Cog World* (O'Brien, 2015).

For many people the battle to achieve control continues even after the system has supposedly been changed to one of Self-Directed Support:

“Support is mainly decided by local authority and what they allow in the Care Plan. However, we are creative with the Direct Payments we receive and decide what suits our son best.” [Respondent from UK]

Low cost self-management

In the early development of Direct Payments in the UK and in many systems of Personal Assistance the budgets that are developed are set at levels which effectively exclude service providers. There is no funding for management costs and salary rates are set too low. Often any auxiliary assistance (e.g. support with payroll and recruitment) is provided for free by the state. The impact of this model is to create a low-cost model of Self-Directed Support which will only work for people with a high level of capacity to manage their own support and who are happy to bear the additional costs created for them by taking greater responsibility.

Different visions

Service providers are often divided by different visions of the purpose of Social Care and there can also be a significant differences of perspective between service providers, families and persons with disabilities. One common difference is between more paternalistic visions of care and a vision based on human rights. These divisions can lead to competing models of Social Care and different political and democratic pressures.

“The social workers do not understand self-determination...” [Respondent from Sweden]

5.2 Developing a shared vision

As service providers begin to consider their own position on Self-Directed Support it will be important consider some of these questions:

- Is it possible to develop a shared vision for Self-Directed Support with disability leaders and the family movement?
- Is Self-Directed Support just for people who want to self-manage and who have minimal need for service providers?
- Do service providers exists to advance human rights, citizenship and inclusion within community life?



- How best should quality of Social Care be managed to advance human rights and to reduce the risk of bureaucratic control over people's lives?
- How do we ensure that the rights of people with disabilities and the rights of support staff and employees are both protected and not traded off against each other (Dalrymple et al. 2017)?

As we have seen, in the case of Scotland it is possible for service providers to emerge as an important force supporting and developing Self-Directed Support. This has also been an important element of positive developments in Australia, where a combined campaign of people with disabilities, families and service providers called *Every Australian Counts* was able to promote the creation of a new system called the National Disability Insurance Scheme which involved:

- Increased investment in social care of 50%
- Individualised Funding for all people
- Greater levels of Self-Directed Support

This programme is now in development, and although there are many questions about the exact design of the Australian system it remains one of the most radical and significant efforts to introduce a Social Care system built on principles of human rights (Duffy, 2013). It certainly suggests that the Coproduction of a shared vision for Social Care between people and professionals is much more likely to lead to positive change.

5.3 Creating an inclusive model

The best way forward may be to focus on creating a model of Self-Directed Support which is inclusive, which recognises the basic human rights of people with disabilities, which respects the importance of family and community and which offers service providers a positive and useful role in the development of community solutions.

Given what we have learned so far about the development of Self-Directed Support then there are perhaps some obvious issues around which each of these three groups can unite:

- **Rights** - People should have the right to support and the right to control that support. Service providers who work closely with people and communities have nothing to fear from these principles. It is much better for service providers to be accountable to people with disabilities than to depend on political or bureaucratic systems, especially if those system top-down changes and control.

- **Funding** - Self-Directed Support is based on an assumption that people's entitlement to support should be properly and effectively funded. Everyone shares an interest in avoiding inadequate funding, excessive means-testing or waiting lists.
- **Flexibility** - Self-Directed Support cannot be achieved if services or people are constrained by unhelpful laws or regulations. Self-Directed Support requires innovation and everyone can become frustrated by bureaucratic systems that close-down creativity and full citizenship.
- **Management** - It benefits everyone if management costs are built into the system. Even people who choose to do more for themselves will benefit if management costs can be paid for. It is only by this means that people and families can ask service providers to help them manage their budget or provide additional support. Option 2, in the Scottish system, means that service providers are included in the wider system, but in a way that does not reduce the rights of people with disabilities.

If Self-Directed Support is seen as the organising principle for a strong and sustainable system of community support it should win support, not only from people, families and service providers, but also from the wider public.



Conclusion

Although Self-Directed Support is an important and growing policy initiative it is also clear that the pace of change is inconsistent and not fast. The critical question for EASPD is to define its own role and to explore with its membership how best to adapt to Self-Directed Support.

Clearly the authors of this paper cannot pretend to be neutral on this matter. Not only have we experienced the many benefits to people with disabilities from the development of Self-Directed Support we have also seen the many benefits for staff and communities from these changes. The ethical or human rights case for progress is strong.

The development of Self-Directed Support has not always been supported by service providers. Generally we have seen four competing approaches.

1. **Direct resistance** - Some service providers and their representatives have directly lobbied policy-makers to defend old systems of funding and to resist the shift to Self-Directed Support. They may believe that this resistance is in the best interest of the people they serve, but it is also a strategy to defend older modes of power and control. It is not what people with disabilities want nor is it consistent with human rights.
2. **No involvement** - Often service providers will stay outside the discussions and wait to see what new policies emerge. Sometimes they will seek exceptions or try to limit Self-Directed Support to particular areas of Social Care. For example, in England service providers have successfully excluded residential care from Self-Directed Support.
3. **Partial support** - Sometimes service providers will play a more positive role, but will seek to interpret Self-Directed Support in a more conservative way. For example, in Australia service providers, families and disability advocates were united in demanding both new funding for Social Care and a system of Self-Directed Support. However some service providers have supported the development of systems that make it harder for people and families to take more control.
4. **Full support** - Sometimes, as we saw in Scotland, some service providers have worked in partnership with disability leaders to advance more progressive models of support and to encourage service providers to innovate and change their own practice.

The shift from institutional models of support and the development of new models that serve and protect human rights involves going on a journey of change alongside people with disabilities and families. There is no clear end point and many more innovations and positive developments are



required. Even the countries that have made progress towards Self-Directed Support have certainly travelled no more than halfway on this journey. Some humility and a willingness to keep learning is essential.

Ideally EASPD will seek to build on its relationship with its members and with partners at a European level - especially organisations led by people with disabilities or their families - and it will be able to communicate with them a human rights vision for the future of Social Care. At the heart of this vision are the principles of the UN Convention, which are critical to the mission of EASPD. Reflecting on how to make these principles meaningful in the context of the funding and organisation of Social Care is the task ahead.

It might be particularly valuable to link work on Self-Directed Support more closely to the challenge of deinstitutionalisation. If deinstitutionalisation is primarily carried out according to the models developed in the 1980s and onwards then it will tend to replace large institutions with smaller institutions. This is far from ideal. Instead, by building Self-Directed Support into our approach to deinstitutionalisation we can short-circuit the process of change and move more quickly to full citizenship and inclusion.

Ultimately it is the values that are at the foundation of EASPD and the best service providers that offer a way forward. Values unite and bring people together. Our survey illustrated how all are saying the same things: people need to be in control, people and practitioners need to work together respectfully and support needs to be personal. Self-Directed Support is a tool to make these aspirations real at the level of the system. EASPD has a key role in taking these ideas forward in partnership with people and families.



Glossary

This is how we have used these words in the report:

Asset Based Community Development (ABCD) - an approach which assumes communities can be supported to grow their own capacity for mutual support and inclusion.

Austerity - public spending cuts that target public services and redistribute resources away from the most disadvantaged people and communities.

Centre for Independent Living - a support service, run by people with disabilities, often used to provide support to people using Personal Assistance.

Citizenship - a philosophy which stresses that each individual is unique and has the right to lead a life that is meaningful for them, both supported by their community and able to contribute back to the community.

Coproduction - the idea that public services should be developed in a partnership between the people who use them, say people with disabilities and their families, and professionals.

Brokerage - the function of helping people design and organise their own support, sometimes delivered by a broker who is independent of any form of ongoing support

Direct Payments - a system of self-directed support which means the person with a disability manages their own budget for support, often employing their own Personal Assistants

Independent Living - a philosophy which stresses the fact that people with disabilities have the right to shape their own lives and enjoy all the same rights as other people, including the right to live in their own home.

Individual Budget - a budget which is identified to meet a person's needs and which they can then choose to managed directly or ask someone else to manage.

Individualised Funding - any system which connects funding for services directly to individual people.

Individual Service Fund - a budget which is managed for a person with a disability, often by a service provider or other agency.

Microboards - when families want to establish a long-term base for decisions and management of individualised funding they often develop systems where small groups, often networked together, can oversee an individual's life and support arrangements.

Peer Support - sometimes people with disabilities or families come together to create practical forms of mutual assistance or self help.

Personal Assistance - an individual who works for a named person with disabilities, usually recruited specifically for that individual and sometimes employed by them.

Personalised Support - support that is designed around an individual to enable flexibility and control, but which doesn't require the person to become an employer.

Self-Directed Support - a whole system to organise how support services work in order to advance Independent Living and Citizenship.

Shared Management - support which helps people to take the maximum degree of control that makes sense for them, but which also offers assistance with elements where the person does not want to take full control.

Social Care - the support that people with disabilities or others receive in order to live safely and with dignity in the community.

Social Work - the profession that focuses on helping people maintain their autonomy if they need support, security or other changes in their life.

Support Brokerage - help to plan and organise support, but where others provide the regular support

Supported Living - the principle that people with disabilities have distinct rights to support and housing, and that should be able to live in their own home, with their own support, and must not be forced to live in group or residential care services where housing and support are locked together.

References and Further Reading

Administration for Community Living (ACL) (2019) Centres for Independent Living Make Community Living Possible. <https://acl.gov/sites/default/files/news%202018-08/ILProgramsIG.FinalWeb.pdf>

Alakeson V & Duffy S (2011) Health Efficiencies - the possible impact of personalisation in healthcare. Sheffield: Centre for Welfare Reform.

Animate (2014) Individual Service Funds. Sheffield: Centre for Welfare Reform.

Baxter K, Rabiee P & Glendinning C (2013) Managed personal budgets for older people: what are English local authorities doing to facilitate personalised and flexible care? in Public Money & Management vol 33, no 6

Biestek F P (1957) The Casework Relationship. Chicago: Loyola University Press.

Brandon D & Towe N (1989) Free to Choose: An introduction to service brokerage. London: Good Impressions.

Broad R (2012) Local Area Coordination. Sheffield: Centre for Welfare Reform.

Brown M, James E & Hatton C (2017) A Trade in People: the inpatient healthcare economy for people with learning disabilities and/or Autism Spectrum Disorder. Sheffield: Centre for Welfare Reform.

Chetty K, Dalrymple J and Simmons H (2012) Personalisation and Human Rights. Sheffield: Centre for Welfare Reform.

Children and Young Persons Scotland, HMSO, Edinburgh, 1966

Cowen A (2010) Personalised Transition - Innovations in health, education and support. Sheffield: Centre for Welfare Reform.

Dalrymple J, Macaskill D & Simmons H (2017) Self-Directed Support: Your Choice, Your Right. Sheffield: Centre for Welfare Reform.

Duffy S (1996) Unlocking the Imagination. London: Choice Press.

Duffy S (2006) Keys to Citizenship: A guide to getting good support for people with learning disabilities, second revised edition. Sheffield: Centre for Welfare Reform.



Duffy S (2012) Peer Power. Sheffield: Centre for Welfare Reform.

Duffy S (2013) Travelling Hopefully - best practice in Self-Directed Support. Sheffield: Centre for Welfare Reform.

Duffy S (2013) Designing NDIS. Sheffield: Centre for Welfare Reform.

Duffy S (2015) Getting There - lessons from Devon & Plymouth's work to return people home to their communities from institutional placements. Sheffield: Centre for Welfare Reform.

Duffy S (2013) Returning Home: piloting personalised support. Sheffield: Centre for Welfare Reform. Duffy S & Watson C (2017) Individual Service Funds (ISFs) in Dorset. Sheffield: Centre for Welfare

Duffy S & Catley A (2018) In Beyond Direct Payments: making the case for micro-enterprise, Individual Service Funds and new forms of commissioning in health and social care. London: TLAP.

Duffy S & Fulton K (2009) Should We Ban Brokerage? Sheffield: Centre for Welfare Reform.

Duffy S & Sly S (2017) Progress on Personalised Support - results of an international survey by Citizen Network. Sheffield: Centre for Welfare Reform.

Ellis R, Sines D & Hogard E (2014) Better Lives. Sheffield: Centre for Welfare Reform.

Ellis R & Sines D (2012) Better Nights. Sheffield: Centre for Welfare Reform.

Eriksson S (2014) Personal Budgeting in Municipal Disability Services: the first experiment in Finland. Helsinki: FAIDD

Fitzpatrick J (2010) Personalised Support: How to provide high quality support to people with complex and challenging needs - learning from Partners for Inclusion. Sheffield: Centre for Welfare Reform.

Fleming P, McGilloway S, Hernon M, Furlong M, O'Doherty S (RIP), Keogh F, Stainton S. (2019) Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review. Campbell Systematic Reviews 2019:3 (DOI: 10.4073/csr.2019.3)

Frank's Law Campaign <http://frankslaw.org/>

Gillespie J (2011) Positively Local. Sheffield: Centre for Welfare Reform.



Glasby J & Littlechild R (2009) Direct Payments and Personal Budgets - Putting Personalisation into Practice. Bristol: Policy Press.

Glendinning C, Challis, D, Fernandez J, Jacobs S, Jones K, Knapp M, Manthorpe J, Moran N, Netten A, Stevens M & Wilberforce M (2008) Evaluation of the Individual Budgets Pilot Programme: Final Report. York: Social Policy Research Unit.

Gregory J (2017) Parenting Chrissy: a transformational journey through the hazards of the disability system. Sheffield: Centre for Welfare Reform.

Hagel J & Seely Brown J (2005) The Only Sustainable Edge. Boston: Harvard Business Press.

Harrison, S (2015) Relationship Based Care in Action. Sheffield: Centre for Welfare Reform.

Hill O'Connor C & Rendall J (2017) Evaluation of Social Care Ideas Factory: Wee Enterprizers Project. Glasgow: Glasgow Caledonian University.

HMG (1968) Social Work (Scotland) Act, 1968

HMG (1973) Local Government (Scotland) Act 1973

HMG (1990) The National Health Service and Community Care Act 1990

HMG (1996) Community Care (Direct Payments) Act 1996

HMG (1998) The Scotland Act 1998

Hyde C (2011) Local Justice. Sheffield: Centre for Welfare Reform.

Hyde C (2012) Freedom Fighters: five stories of endurance and escape. Kilmarnock: Partners for Inclusion.

Independent Living in Scotland (ILiS) definition at <http://www.ilis.co.uk/>

Jackson R (2017) Back to Bedlam: what kind of future faces people with a learning disability? Sheffield: Centre for Welfare Reform.

Kinsella P (1993) Supported Living: a new paradigm. Manchester: National Disability Team.

Leach L (2015) Re-Imagining Brokerage. Sheffield: Centre for Welfare Reform.

Mansell J (2010) Raising our sights: services for adults with profound intellectual and multiple disabilities. London: Department of Health.



Mills K (2015) Friendship. Sheffield: Centre for Welfare Reform.

Murray P (2010) A Fair Start. Sheffield: Centre for Welfare Reform.

O'Brien J (2015) Surviving Cogworld? Supporting People with Developmental Disabilities In a Mechanistic System. Madison, WI: DD Network.

O'Brien J and Blessing C (eds.) (2011) Citizenship & Person-Centred Work. Toronto: Inclusion Press.

O'Brien J & Mount B (2015) Pathfinders: people with developmental disabilities and the allies building communities that work work better for everyone. Toronto: Inclusion Press.

O'Brien J & Duffy S (2009) Self-Directed Support as a framework for partnership working in Glasby J and Dickinson H International Perspectives on Health and Social Care. Chichester: Blackwell Publishing.

Pincus A & Minahan A (1973) Social Work Practice: Model and Method. Itasca, Illinois: Peacock Publishers

Poll C, Duffy S et al. (2006) A Report on In Control's First Phase 2003-2005. London: In Control Publications.

Poll C & Duffy S (eds.) (2008) A Report on In Control's Second Phase: Evaluation and Learning 2005-2007. London: In Control Publications.

Reekie G (2014) Testing out Individual Service Funds and Spending a Budget Flexibly: an independent evaluation of the NHS Highland ISF Trial. Glasgow: In Control Scotland.

Rose S (2017) Alternatives to ATUs. Sheffield: Centre for Welfare Reform.

Report of the Committee on Local Authority and Allied Personal Social Services (Seebohm), 1965

Scotland Against the Care Tax (SACT) <https://www.sdsscotland.org.uk/press-release-scotland-end-care-tax/>

Scottish Executive (2000) The Same As You? A review of services for people with learning disability
Edinburgh: Scottish Executive

Scottish Government (2013) Social Care (Self-directed Support) (Scotland) Act, 2013

Scottish Government (2014) Public Bodies (Joint Working) (Scotland) Act, 2014



Sen, Amartya (1999). Development as Freedom. New York: Oxford University Press. Shapiro J P (1993) No Pity: People with Disabilities Forging a New Civil Rights Movement. New York: Times Books.

Simmons H (2016) The Simmons Triangle.

Simons K (1998) 'Low support' options for people with learning difficulties. York: JRF.

Sheldon T (2017) Buurtzorg: the district nurses who want to be superfluous
BMJ 2017; 358 doi: <https://doi.org/10.1136/bmj.j3140>

Simons K & Watson D (1999) The View From Arthurs Seat: A Literature Review of Housing and Support Options 'Beyond Scotland' Bristol: Norah Fry Research Centre.

Sly S & Tindall B (2016) Citizenship: a guide for providers of support. Sheffield: Centre for Welfare Reform.

Smith S & Brown F (2018) Individual Service Funds: a guide to making Self-Directed Support work for everyone. Sheffield: Centre for Welfare Reform.

Squire A & Richmond P (2017) No Place Like Home: the economics of independent living. Sheffield: Centre for Welfare Reform.

TLAP (2015) Individual Service Funds (ISFs) and Contracting for Flexible Support. London: TLAP.

UN Committee on the Rights of Persons with Disabilities (CRPD) (2016) Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention.

Royal Commission on Local Government in Scotland, (Wheatley Commission) (Cmnd. 4150) 1969

WAIS (2012) Shared Management. Perth: WAIS.

Zarb G & Nadash P (1994) Cashing in on Independence: comparing the costs and benefits of cash and services. Derby: The British Council of Organisations of Disabled People.

