

Are social and healthcare systems for self-directed support as good as they can be? Do people have better lives? What's the evidence?

A report of the London Self-Directed Support Forum conference, July 2016

“It ain't what you do - it's the way that you do it”

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Introduction

The London Self-Directed Support Forum has a membership consisting of professionals working on the delivery of self-directed support in London and the South of England. It draws its membership from local authorities, clinical commissioning groups, the voluntary sector (including Disabled People's User Led Organisations), brokers, independent trainers and consultants, and the private sector.

On 15th July 2016 the Forum brought together experts on self-directed support with disabled people and families who use direct payments from across London to discuss the state of progress. In particular they were wanting to explore some of the inflexibilities and problems that are holding back full progress.



The event was also an opportunity to launch an illuminating research report on self-directed support by Hestia. This paper brings together some of the key findings of the report with the talks, discussion and the results of a poll carried out on the day.



Self-directed support and Independent Living

Self-directed support emerged out of the revolutionary movement, led by disabled people, which campaigned for and created Independent Living. This movement was also partly inspired by the experience in the USA, where disabled people in the 1960s demanded independent living and started to organise their own systems of support to replace institutional care.

John Evans was one of the founding members of Project 81, a group of disabled people from Hampshire who engineered their own escape from residential care in the late 1970s. John said:

“Independent Living was an unstoppable force. Disabled people had a vision, and that vision was Independent Living. We wanted to be free from the shackles of the institution. We wanted an alternative solution to residential care and the answer was simple - just give us the money for ourselves and let us take control. This was not just a social policy reform; it was a revolution to free ourselves.”

In the UK one of the key moments came in 1988 with the *Rights Not Charity* March. The march was a response to the threatened termination of the Domestic Care Allowance. This was one of the largest demonstrations by disabled people and it led eventually to the introduction of the Independent Living Fund which opened up the doors to independent living nationally.

By 1991 disabled people found some local authorities were prepared to open up direct payments to disabled people. So the National Centre for Independent Living (NCIL) began to build alliances with the Local Government Association (LGA) and Association of Directors of Adult Social Services (ADASS) and began to put pressure on government to ensure direct payments were possible for everyone. This led to the 1996 Direct Payments Act. Subsequently the regulations opened up direct payments to more and more people.

By the early 2000's the language of independent living began to be adopted by central government and a series of positive policy initiatives began:

- Valuing People (2001)
- Improving the Life Chances of Disabled People (2005)
- Putting People First (2007)
- Independent Living Strategy (2008)



Today progress on independent living seems to have slowed or gone into reverse in many areas (Morris, 2014). Baroness Jane Campbell has now formed the Independent Living Strategy Group in the House of Lords. One of the key challenges is to create a right for Independent Living. Although the UK is a signatory to the United Nations Convention on the Rights of Persons with Disabilities there is no equivalent to Article 19 yet on our statute book (although it is mentioned in the Statutory Guidance to the Care Act).

The importance of flexibility

Flexibility is critical to self-directed support because people should be free to live the life that's right for them - a personal budget must not just be about services. The resources that are included in a personal budget or direct payment represent the support people need because of their impairment, frailty or mental health problem. This is the support people need to be free and in control of their own lives.

For instance, Geoff Smith outlined how he'd been able to use a direct payment to pay for time in a professional music studio. Geoff described that after years of having no life outside managing his mental health problem, playing and recording music unlocked his confidence and put him on the road to recovery. Now he works and volunteers as a mental health advocate, but none of this would have happened if he had not had the chance to return to his roots as a musician and start writing and recording music again.

“I was able to approach the studio as a musician, not as a mental health service user”

This opened up creativity, community and a positive path for him - he describes it as a transformative experience.

Only this kind of creativity keeps alive the true flame of independent living. It is not about purchasing services - it is about living a life of meaning. As Pat Stack, Chair of the Forum, succinctly put it:

“All power to the imagination!”

He argued passionately that the lack of flexibility is not purely to do with reduced budgets within local authorities - but also because the systems were

too rigid and there is a growth of risk aversion often tied in with a loss of the original enabling vision of direct payments.

Ossie Stuart, a leading activist and academic said

“Systems have taken control and limited what people can do”

He reminded the audience that disabled people have always had to fight for the necessary flexibility. It may also be that different groups using self-directed support need slightly different systems to make flexibility and support easier - one size does not fit all.

“I want to send a positive message - Independent Living is great. But it must be real.”

The reality today

A recent report from Hestia outlined how these systems are being experienced in practice. Overall people are very positive about direct payments in their lives (Hestia, 2016). However, there are several ongoing problems revealed by their research:

- 77.8% of people felt there was too much administration
- 28% didn't know where to look for support
- 43.3% felt there was lack of clarity about their right to flexibility
- Only 50% families get support through transition
- pre-payment cards are still fraught with delays and complications.

In practice Hestia found that local authorities interpret flexibility very differently. What some allow, others forbid. In general things are very unclear.

A further problem was that many people (26.5%) would end the year with money left over. Rather than being able to use it flexibly to achieve different outcomes this money would be stripped out of people's budgets and returned to the local authority. Often this was because rules about flexibility or transferring money to the next financial year were not clear. Too often money was narrowly tied into some element of their care and support plan and could not be moved to where it was needed.



Maddeningly, when people experienced delays in payment, they would be reimbursed with one lump sum payment. However if it arrived too near the end of the financial year and people hadn't had the chance to spend it, the money would often be quickly clawed back.

In addition to people losing money unfairly some people (30.5%) felt that they did not have enough money to properly meet their own needs. Sometimes this was because people did not have their needs reviewed and did not know they had a right to a review. Sometimes the resources allocation system (RAS) defined an inadequate package, but people did not know they could challenge this system. Jane, who manages a direct payment for her son said:

“Both receiving and using this funding has been a gift and a curse. It has given my son access to a life that would not have otherwise been possible. But the process has been onerous, complex, confusing and full of ambiguity. The rules are complex, unclear and seem to be ever-changing. The paperwork is particularly onerous and flexibility is insufficient. Reviews have been irregular or not happened at all. Something has been lost in implementation.”

Measuring system flexibility

During the day the organisers took the opportunity to carry out a poll to measure the degree of flexibility in London's self-directed support system. Present were experts working in over 22 London boroughs and in some Clinical Commissioning Groups (CCGs).

This group of experts were asked to think about the statutory body they knew best and then to evaluate the level of flexibility in that system. They scored these systems as follows:

- Flexibility is very high: **0** (0%)
 - Flexibility is quite high: **17** (51.5%)
 - Flexibility is quite low: **10** (30.3%)
 - Flexibility is very low: **6** (18.2%)
- Total: 33**

The group were then asked to think about what is changing within the system and whether they thought things were getting more or less flexible.

- Flexibility is getting better: **6** (15.4%)
- Flexibility is getting worse: **15** (38.5%)
- Flexibility is about the same: **14** (35.9%)



- Don't know: 4 (10.3%)

Total: 39

So, overall although half of all systems were judged somewhat flexible, half were deemed inflexible, with 18% of these being very inflexible. Perhaps even more worryingly things were getting worse in twice as many places as they were getting better.

The context for self-directed support

Simon Duffy outlined the wider impact of the cuts on local government and the benefit system. He explained how disabled and older people had been targeted for multiple cuts in income and support. In particular the 30-40% cut in local government funding has led to a 30+% cut in adult social care. These problems are likely to change without wider political and economic changes.

Ellen Clifford, of Inclusion London, described the efforts of the disability movement to resist austerity and, in particular, to defend the ILF. She went on to describe what was happening to people in the aftermath of the closure of the ILF.

For example:

- Many people are now facing having their support packages cut
- People being forced to seek NHS funding, often with no realistic hope of success
- People are losing flexibility and forced to use lower pay rates



At the same time as this the NHS is advancing its plans to open up Personal Health Budgets (PHBs). Currently 7,000 people have PHBs (about 600 in London) and progress is slow because it depends on support and commitment from within CCGs and pressure from disabled people. As Steven Pruner explained, it is still early days, but the direction of travel is clear.

In September 2016, My NHS will be publishing CCG data which will highlight the uptake of PHB's in each locality. This information is currently available but is not identifiable to each CCG.



Problems and solutions

Bringing all of this together it is clear that there are many serious threats to the principles of Independent Living that are at the heart of self-directed support:

- Overbearing bureaucracy that stifles creativity
- Austerity and a desire to take back control of budgets by local authorities
- Lack of support for people to advocate for flexible solutions
- People's inability to advocate for themselves at resource panels
- The lack of support for people to present their needs in the right way
- The failure to support effective forms of peer support
- The ongoing decline in community options
- Lack guidance about support options
- Poor communication by practitioners e.g. presenting a direct payment to clients by the number of hours of care rather than the amount of money to spend can limit people's creativity
- Marginalized communities are often not aware of the potential benefits of a direct payment

However, these are largely problems that can be solved without additional resources. Especially at a time of extreme financial pressure, there can be no defence of unnecessary bureaucracy and inflexibility which merely lowers efficiency and drives up costs.

There are wider issues that will need to be addressed with collective action and campaigning, but attendees took away a commitment to identify local solutions to make things better.

References

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- Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century*. London, Department of Health.
- Cabinet Office (2005) *Improving the Life Chances of Disabled People*. London, Cabinet Office.
- HM Government (2007) *Putting People First*. London, HM Government.
- Morris J (2014) *Independent Living Strategy: a review of progress*. London, Disability Rights UK.

Appendix - contributions from group sessions

Qn 1. Would the example given by our speaker (DP used for buying time in professional studio to make music) be accepted in your area?

- No, very hours based. Very resistant to change.
- Good practice is very patchy
- Previously no. But better now - considering new things
- Yes, but social workers often aren't aware enough
- People making decisions won't use their judgement to step outside the usual things
- If it's not a 'usual' thing, they won't agree to it
- Very rarely agreed beyond paying for a PA or agency
- Only people who shout about it get flexible use agreed
- Depends on the social worker
- Only for people with mental health needs or a learning disability
- Yes
- Several one-off payments agreed for creative and leisure activities
- Yes, the benefit of funding such things are now obvious to our local authority
- No, lack of flexibility for funded 'hours'
- Yes, using funding previously for day services to pay for some activities
- Different answers given by different practitioners - to same person and same activity
- Yes, an amount of money agreed to be able to be used flexibly
- 'Non-care' support seen as extra

[Additional question considered by one group]

Can we make a change to the way support is presented to people - that is, money not hours?

- No, this would not be possible at the moment.
- It wouldn't be agreed.
- No, council staff just think about hours not money



Qn 2. Give anonymous real-life examples of imaginative or flexible use of a direct payment that's been accepted and has worked well?

- Gym and cinema membership
- Creative writing
- Drama
- Art studio in someone's garden
- Driving lessons
- Paying for PAs when person in hospital
- ipads to help with communication
- Some people with mental health needs use an independent music studio - good outcomes. Hope to have set a precedent

Qn 3. Give anonymous real-life examples of proposals for flexible use that have been rejected? Why were they not agreed?

- Use for Pilates classes caused DP to be suspended
- DP refused for Autism assistance dog
- Paying travel expenses and accommodation for PA when person goes on holiday - working hours and food allowance paid but nothing else.

Qn 4. What prevents flexible direct payment use in your area?

- Poor communication from social workers
- Social worker lottery - depends who you get
- Heads of service not setting the lead
- Panel make final decision - not accountable
- Council take back unspent funds immediately - not possible to be flexible
- People being present in decision making meetings is successful and powerful - but rare

