



LONDON  
SELF-DIRECTED  
SUPPORT  
FORUM

*Building on the  
experience of  
Direct Payments*

# SELF-DIRECTED SUPPORT

*If we are going to do it, let's do it right!*

Report of a day conference organised by the London Direct Payments Forum now known as the London Self- Directed Support Forum

20th June 2008

**Peter Beresford**

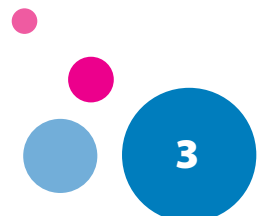


# FOREWORD

This report is an important contribution to the public debate around social care. It is an excellent synthesis of wide-ranging dialogue that happened over the course of a day in June, in City Hall. It gives a voice to a range of perspectives, that look forward to extending choice and control for disabled people using personal assistance, and is a valuable resource in the goal of transforming people's lives and truly delivering equal life chances.



**David W. Morris**  
**Senior Policy Adviser to the Mayor of London**  
**(Disability and Deaf issues)**  
City Hall



# CHAIR'S INTRODUCTION



On the 20th June 2008, The London Direct Payments Forum held a conference to discuss Self-Directed Support. The Forum which has since changed its name to The London Self-Directed Support Forum, in order to reflect the changes taking place in the world of social care, is made up of Local Authority Direct Payments officers and Direct Payments Support Service workers — many from the voluntary sector, some of whom work for user-led organisations.

We felt that, as the practitioners currently working in the closest proximity to the field of Self-Directed Support, it was essential we call such a conference.

We decided to call the conference because we were both excited and concerned about the progress towards Individual Budgets, and the personalisation agenda.

Excited, because of the real possibilities the agenda offers, but concerned because there seemed to be a lot of loose ends, and questions left unanswered. The delays in getting the Individual Budget pilot scheme reports out, the lack of clarity on support and brokerage, and the crucial question of funding were pressing issues.

We therefore sought to put together a conference, where enthusiasts, practitioners, doubters, sceptics, and critics could come together to raise questions, concerns, hopes, and make suggestions.

The conference enjoyed the participation of a wide spectrum of speakers, panellists and participants. The participants comprised largely local authority and voluntary sector workers — mainly in the Direct Payments field — and service users.

It proved to be an excellent forum for the airing of views, and it was particularly pleasing to hear the views of service users, which were articulated throughout the day.

This was the first conference we at the Forum had ever run on this scale. It is also the only conference on the subject so far that has given a platform to such a wide variety of opinions. The fact that it went so well gave us all a real sense of achievement.

It goes without saying though that its success also owed much to other groups — the speakers, and the panellists – and to the brilliant chairing of the question-time style session in the afternoon by BBC radio presenter Peter White. On behalf of the Forum I would like to thank all of them.

Very big thanks are also due to London Councils and CSIP, without whose financial and practical support the day could not have happened.

Similarly the support and participation of the Greater London Authority was of enormous importance to us.

Most of all though, my thanks go to all who attended and made it such a lively, interesting, questioning and constructive day.

I hope you find this report, which has been so skilfully put together by Peter Beresford, helpful in the fight ahead for the true independent living that we are all seeking. Personalisation, and Individual Budgets, like Direct Payments, are not in and of themselves guarantors of true independent living, but they can provide enormously important strides on the path to getting there. Therefore, as we said at the conference, **'If we're going to do it, let's do it right'**.

# SUMMARY

This report sets out the findings from a day conference organised by the London Direct Payments Forum, focusing on Self-Directed Support and how to take it forward successfully. A wide range of participants took part in the event, including service users, carers, practitioners, support services and local authority staff.

**Section One** looks at the meaning of the terms used in this field. It draws a distinction between the goal of Self-Directed Support, which aims to increase the choice and control of service users, and Direct Payments and Individual Budgets, two methods that are now being rolled out by government to try to achieve these goals.

**Section Two** highlights a series of key values or principles which are seen as crucial in developing Self-Directed Support successfully. These include:

- Values of independent living and human rights
- Linking to broader independent living policy and practice
- Being accessible to all
- Flexibility
- Effective user involvement

**Section Three** looks at potential barriers in the way of mainstreaming Self-Directed Support, as highlighted by participants. These include:

- Uncertainty
- A difficult context
- Inadequate funding
- Questions about who is in control
- The limits of consumerism

**Section Four** sets out a series of requirements that need to be in place if Self-Directed Support is to be ensured, i.e., the conditions for effective development. These include:

- **Assessment based on the philosophy of independent living**
- **Support for assessment**
- **Support for staff**
- **Support for all to access Self-Directed Support**
- **Skilled independent brokerage**
- **Access to advocacy services**
- **An infrastructure and network of support**
- **Effective planning for change**
- **Adequate funding**
- **Shared ownership**
- **Service user training and consultancy for Self-Directed Support**

**Section Five** sets out a series of priorities identified as the basis for a strategy for taking forward Self-Directed Support successfully. These include:

- **Building alliances and staying true to principles**
- **Supporting and involving user-controlled organisations in co-production**
- **Being able as service users to have an effective influence on policy and practice**
- **Making the argument for investment in support**
- **Involving key stakeholders, like service users and carers, in further open discussions at local and national level all over the country**

# INTRODUCTION

*History tells us that Self-Directed Support has been going on in Hampshire since 1983. They did their own assessment. They had to negotiate with local authorities. I don't believe there is something different here. But it should be equally good for everyone.*

**Frances Hasler, Commission for Social Care Inspection**

*The question is how we deliver support as a society for all those people who need it in a way that retains independence, freedom and dignity.*

**David Morris, Senior Policy Advisor to the Mayor of London  
(Disability and Deaf equality)**

The government says that it wants to make big changes in the way that social care works and is funded. It says that it wants to move to a system based on 'personalisation' and 'self-directed support', where people as service users have real choice and control over the services and support that they receive. The massive expansion of Direct Payments and Individual Budgets is seen as central to this change. The government is spending an additional £520 million, on top of existing money being spent on services, over the next three years, to bring about these changes.

These plans and changes towards 'self-directed support' are very important for everyone concerned with social care, particularly disabled people and other service users who rely on its support. These changes are likely to have big effects on how they get support and live their lives, as well as changing how social care workers work, how support is provided, and how it is paid for. People are saying that these changes may be the biggest in social care since the creation of the welfare state after the Second World War. And they are happening fast.

The aim of this report is to help everyone get a clearer idea of what is happening: what the possibilities and problems of these changes in policy may be; what barriers people may face, and how these might be overcome. It draws on discussion from a day conference on Self-Directed Support: If we are going to do it, let's do it right, held on 20th June 2008, organised by the London Direct Payments Forum. The Forum is the leading authority on Direct Payments in London and uniquely it regularly brings together Direct Payments support services and local authority staff. Key speakers in this field provided information at the conference. There were



also two panel discussions with experts to deal with participants' comments and questions.

Participants were a mixture of social services staff, Direct Payments support staff (in-house and from the voluntary sector), user-controlled organisations, consultants working in this field, carers and family members, advocates, welfare advisers and others. A large and wide range of disabled people and other service users were involved as planners, speakers and participants. The conference provided a unique opportunity for informed discussion on a subject that is becoming increasingly important and controversial. Despite the determined efforts of the conference organisers, there were two omissions in participating stakeholders. Although the Department of Health was invited to provide a speaker, and In Control, the voluntary organisation which has been a major player in developing Individual Budgets, was offered a speaker slot, neither actually contributed to the Conference. The London Direct Payments Forum is publishing this report both to share the valuable learning from the conference and also to help influence and inform future policy and practice for Self-Directed Support, particularly in London, but also perhaps more widely.

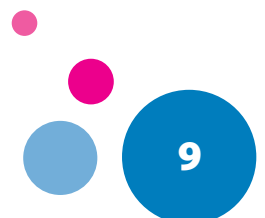
The report is organised into 5 sections. This reflects the range of issues discussed and raised at the 20th June Conference. Section one looks at the meaning of Self-Directed Support and other key concepts in this development. Section two focuses on a series of key principles identified for taking forward Self-Directed Support. The third section explores people's views on a number of possible problems and barriers that are emerging in the way of Self-Directed Support. Section four sets out a series of key things that seem to need to be in place for Self-Directed Support to work to the best. The last section identifies a series of key tasks identified by participants as necessary for taking forward Self-Directed Support successfully. This is followed by a short list of helpful resources available to complement the information contained in the report.

All the comments and quotations in the report are from speakers and participants at the conference, unless otherwise stated.

*We can do it. We have been doing it for years!*  
Service user



**Frances Hasler**  
*Commission for Social Care  
Inspection*



# EVALUATION

An evaluation form was provided for participants to feed back their views on the conference, and most completed this. Their feedback was very positive about the conference, but it also highlighted particular concerns that people have at this stage in the development of Self-Directed Support and Individual Budgets. They valued the diverse mix of participants at the event and also the wide range of speakers and other contributors.

They thought it was important that the conference was participatory and interactive. There was praise for the diversity and 'unbiased range of thought' speakers brought to the event. There was also, however, regret that neither the Department of Health nor In Control provided speakers.

Participants welcomed the fact that they were being offered not 'answers', but 'well-informed points of view' and 'fair and independent advice'. They thought it was important that there was a 'good balance' of speakers offering 'different viewpoints'. This may be a response to the polarised nature of discussion that has tended to characterise the development of Individual Budgets. Participants referred to the need to improve understanding of Self-Directed Support and to simplify its processes for people:

- There is so much that is still not known.
- Many service users had a chance to speak.
- I was pleasantly surprised that I wasn't the only one who was a little confused.
- What a big task is ahead of us.
- I got a better understanding of the issues.
- It made me confident to think outside how things are moving in my local area.



On a lighter note, some participants realised that the title of the conference came from a song by Wham. One said:

***Send all social workers and managers and commissioners to the next conference and make them dance to Wham!***

Another, however, said:

***Can we base the theme around something from Queen next time, not Wham!***

# 1 GETTING THE LANGUAGE CLEAR

*There is a lot of jargon in this area!*

**Peter White, Disability Correspondent, BBC**

*From the work of VIA, service users are confused. A lot of jargon, something happening and not knowing about it.*

**Catherine Bewley, Values Into Action**

Many new terms are now being used to describe the changes that the government aims to make to support services. These include 'personalisation', 'individualisation', 'individual budgets', 'personal budgets' and 'self-directed support'. There is a lot of new jargon!

## What 'self-directed support' means

*We need to keep it simple, stop changing the language.*

*People want the resources. It's a real opportunity to change the way support is delivered.*

**Kevin Caulfield, Development Manager, NCIL**

The main term we focused on in our discussion was self-directed support. Not everyone is agreed about what this term means. Some people clearly use the terms 'self-directed support' and 'individual budgets' as if they mean the same thing. But disabled people and service users particularly make a distinction between the two. They see Individual Budgets and Direct Payments as means or ways of trying to achieve Self-Directed Support. According to how they are run and set up, such schemes may be better or worse at helping people achieve Self-Directed Support. Service users take Self-Directed Support to be the goal or aim of service or support systems. By Self-Directed Support they mean support arrangements that people control, and which offer them maximum choice and opportunity in their lives. It is being clear what this is and how to make it possible that is our focus here.

*Self-Directed Support equals me being in control of my life for all of us who need support.*

**Service user**



**Peter White**  
Disability  
Correspondent, BBC

## Personalisation

We also need to say something about ‘personalisation’, since it is the term that the government has used most in talking about the big reforms it is making to social care and other services. What seems to be meant by ‘personalisation’ is that instead of people having to fit into services, in future services and support must match what the individual wants and needs. They must be personalised to fit them. In this sense ‘personalisation’ can be seen to mean ‘person centred support’ – support which is shaped by the rights and needs of each person.

## Individual budgets and direct payments

Similar issues are raised by the terms ‘individual budgets’ and ‘direct payments’. Direct Payments were developed by disabled people and have now been around for a relatively long time – about 30 years - in one form or another. The term ‘individual budgets’ is much more recent – it has only been used in the UK over the last few years.

The idea of Individual Budgets was developed by non-disabled people. They argue that they are different to Direct Payments. They say this because, they argue, they can include a wide range of sources of funding (not just social care money), and also that they are based on the idea of the ‘RAS’ or ‘resource allocation system’ (more jargon words!).

What this means is that at an early stage the individual who is assessed as eligible to receive an individual budget, will be told how much they will receive so that they can plan the support they want accordingly. Two points need to be made here. Firstly, one of the difficulties emerging in developing Individual Budgets is the inclusion of a wide range of funding sources. Secondly, Direct Payments can include different sources of funding and can also be operated to let the service user know at an early stage how much money is available. In this sense, the two schemes, Direct Payments and Individual Budgets, may be just the same. Many disabled people feel that the development of Individual Budgets needs to take more account of all the learning and pioneering already achieved through Direct Payments.



**Catherine Bewley**  
*Values Into Action*

## 2 KEY PRINCIPLES FOR SELF-DIRECTED SUPPORT

*What are our underlying principles? We are looking at a fundamental review of the whole structure of social care – it is an opportunity and a scary place to be!*

**David Morris, Senior Policy Advisor to the Mayor of London (Disability and Deaf equality)**

*It's about shifting the whole balance of power from the state to the individual.*

**Frances Hasler, Commission for Social Care Inspection**

*We need some overarching principles, not just technical methods of what people should get.*

**Steve Dowson, National Development Team**

We already know that really good ideas like Direct Payments, that have been pioneered by disabled people to improve service users' lives, and which offer choice and control in them, can be undermined. Some local authorities have made Direct Payment schemes very bureaucratic, so that they are hard work to run. There has been a tendency to over-control them, making service users account for every penny they are given, as if they are not to be trusted. This makes having Direct Payments much more difficult, demanding and hard work. Now that the government wants all social care service users to have Self-Directed Support, it is especially important, if we are to get it right, that it is developed in the right way. People feel that for this to happen it has to be guided by a set of important principles or values. These are some of the key principles that people identify:

### **Based on values of independent living and human rights**

*People have points taken off (in calculating budgets/payments) if there's a willing and able carer and put on if not. It makes for difficult situations for families. It must not penalise people.*

**Kate Groucutt, Carers UK**

*Service users should be able to take acceptable levels of risk.*

*My life — my risk.*

**Service user**

Traditionally, access to support has been based on what is called a 'deficit model'. You have to show what you can't do, to get any help. The philosophy of independent living developed by the disabled people's movement, has a very different starting point for support. Here the idea is that people should have the support they need to be able to live their lives to the full, to be able to live lives that are as independent and interdependent as possible.

This must be the basis for providing support, not a cash-limited system of allocating money or the separate professional judgement of workers.

The philosophy of independent living is fundamental to the achievement of Self-Directed Support. Self-Directed Support on its own cannot ensure independent living, but it is one step on the way.

Historically, the provision of social care services has been based on outside experts or 'professionals' making their own judgements of what people need. This approach has been seen by many service users and their movements as paternalistic and inadequate. Instead of being defined by others' judgements of what they need, they have argued instead for support to be based on safeguarding and ensuring people their human and civil rights. Independent living is a rights-based approach to support.



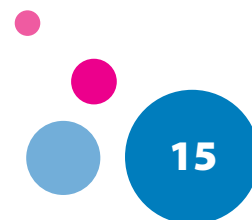
**Steve Dowson**  
*National Development Team*

*Support must be based on the individual, not a points system.*

**Service user**

## **Linking to broader independent living policy and practice**

Self-Directed Support is one key aspect of enabling independent living. But it is not the whole story. Disabled people and other service users also need to be able to access other services and live in mainstream society without barriers or discrimination. This is the

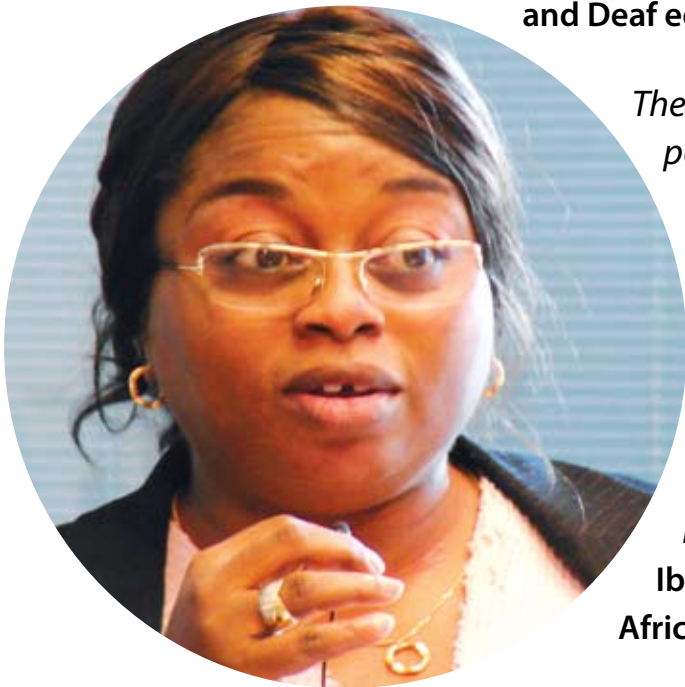


full meaning of independent living. Self-Directed Support must be coupled with this broader philosophy and policy. In spring 2008, the government published its Independent Living Strategy. This is scheduled over a period of five years and has formal support from a wide range of government departments, like education, housing, health and employment. Its aim is to move towards such independent living, and it is being monitored over this period with an ongoing process of consultation with disabled people to check what progress is being made.

## Accessible to all

*There may be some difficult questions we have not engaged with about how we deliver effectively for everyone. There is inequality in the system now. How do we get the balance right?*

**David Morris, Senior Policy Advisor to the Mayor of London (Disability and Deaf equality)**



*The test will be when significant numbers of older people are taking up Self-Directed Support... At present older people with money are often sent away with no help or information.*

**Frances Hasler, Commission for Social Care Inspection**

*We need more funding to encourage more black and minority ethnic service users to access Direct Payments.*

**Ibukun Olashore, Director, Organisation of Blind Africans and Caribbeans (OBAC)**

If there is to be equity in Self-Directed Support — that is to say if everybody is to have support that ensures choice and control — then it must be available for everyone, regardless of age, impairment, sexuality, ethnicity, class, culture, gender, family status and so on. This is particularly true for groups facing particular barriers, like people who communicate differently - travellers, asylum seekers, homeless people and others. It cannot be assumed that there will be family members able or willing to operate schemes like Individual Budgets for service users. People will need support, information, advice and advocacy to make having such

**Ibukun Olashore**  
*Director, Organisation of Blind Africans and Caribbeans (OBAC)*



support possible at zero cost. Different people may want to take on varying degrees of responsibility, from a lot to very little, for running such schemes. This must be made possible.

## Flexibility

*The lack of portability now is an absurdity. We need to change it.*

**David Morris, Senior Policy Advisor to the Mayor of London (Disability and Deaf equality)**

*You need flexibility and sufficient funding.*

**Steve Dowson, National Development Team**

*It took me seven years to get Direct Payments. My condition isn't stable. I couldn't get my local authority to realise I needed different support at different times.*

**Service user**

Flexibility is key to Self-Directed Support, if it is to match the reality of people's lives. People's situations and conditions change, sometimes regularly, sometimes imperceptibly, sometimes unexpectedly and suddenly. Arrangements for support must be capable of matching this, and resource allocation changed sensitively, speedily and helpfully. A key aspect of flexibility is 'portability'. What this means is that if and when people move, then their scheme of support can travel with them with the minimum of difficulty and bureaucratic hassle. Equally important is that people can spend their individual budget or direct payment in the way that they want to, to make the most of their lives. Some funding sources and some local authorities impose narrow and unhelpful restrictions on how such money can be spent. This is contrary to the spirit and purpose of Direct Payments and Individual Budgets, their particular value being that they can make it possible for people to be imaginative and innovative in how they spend payments to improve the quality of their lives.

*The upfront allocation of resources needs to take account of flux of needs and conditions.*

**Service user**



**Linda Jordan**  
*Valuing people*

*We should have crisis planning as part of assessment, taking account of reserves for a crisis.*

**Service user**

## **Effective user involvement**

*The whole issue of Self-Directed Support is about us controlling it.*

**Service user**

*Quite a lot of people find involving service users difficult. They need to change their structures to make it possible.*

**Service user**

User involvement is a key principle among service users. Being able to get involved and have a real say over their lives and in the support and services that they receive has always been a key goal of disabled people's and other service users' organisations and movements. This inspired the development of self-advocacy groups and organisations and people's desire to speak and act for themselves, instead of having other people talking on their behalf. Many of the most important developments and ideas in social care have grown out of this involvement, including the idea of Self-Directed Support. Over the years, however, there have also been increasing concerns among some service users about 'tokenism', or of being asked to get involved without really being listened to. There is a clear distinction between being consulted – just asked for your views – and being involved – where you really have a say in what happens.

### 3 KEY PROBLEMS

A number of key difficulties in the way of taking Self-Directed Support forward were identified. Speakers called these ‘the elephants in the room’ and ‘elephant traps’, meaning problems that aren’t always talked about but are nonetheless important and may create barriers in the way of Self-Directed Support. By identifying them, it becomes more possible to overcome them. The traps or barriers talked about, included:

#### Uncertainty

*There are all sorts of different views about the development of Self-Directed Support and how money should be found. What is it we need to learn in order that Self-Directed Support becomes a fundamental step in the direction of independent living rather than choice and control being lost?*

**Pat Stack, Chair of London Direct Payments Forum**

*If we don't get it right, more likely we'll see a loss of direction, certainty and what will be left is a mechanism for government to control public expenditure. We need a counter balance of people making demands.*

**Steve Dowson, National Development Team**

*We needed to start again to get Self-Directed Support.*

**Members of afternoon panel**

One of the questions raised at the conference was asking why government was talking about the radical transformation of social care and a move to Self-Directed Support at this particular time? Until recently, central and local government support, for example, for Direct Payments, has been limited. Could current commitments and official enthusiasm be taken at face value? There is still uncertainty as to whether there is real political commitment to transforming support services, or whether the government instead is primarily concerned with saving money and restricting expenditure.

Different people have different views about this. The government



is currently committed to the radical reform of social care based on personalisation, but it is also reviewing the funding of social care, with a forthcoming Green Paper looking at this. There is widespread agreement that existing funding is inadequate, but there are no commitments to substantial increases in funding for the future. The government highlights the problems of maintaining current levels of expenditure on social care with the big increase taking place in the numbers of very old people.

## A difficult context

*They make you go to 17 different places and the person doesn't know the answer. It is very disheartening.*

### Disabled woman

It is never an easy matter to make big changes. But there are now many difficulties facing social care. A large number of social care service users, nearly half a million people, particularly older people, are still living in residential institutions. Two-thirds of social care service users are older people. The number receiving support from the state has declined and some studies suggest that service users are also receiving poorer quality support. Big demographic changes are coming which mean that there will be a larger number and proportion of older people, particularly very old people. Existing services, according to service users, are often inadequate, unreliable and of poor quality. Governments are now restricted by increasing funding constraints. The government has also set itself a tight target for trying to mainstream Self-Directed Support and personalisation. Its programme for transformation is only three years.

## Inadequate funding

*We get nervous seeing our lives talked about in the press and on TV, for example, about how we fund social care. People are starting to talk about how much it costs for our freedom... We must understand the economics,*  
**David Morris, Senior Policy Advisor to the Mayor of London (Disability and Deaf equality)**

Funding has long been identified as a big problem for social care. Social care does not get the same funding support as health services. The service system has sought to deal with these constraints by developing increasingly restrictive 'eligibility criteria',

restricting more and more who gets support, as well as imposing charges and increasing the charges that people have to pay for support, unless they are on low incomes. There is no political commitment to more funding for social care. While Self-Directed Support may improve the quality of support for people, few people believe that it can be provided more cheaply.

*We need to look at what we spend the money on. We need to spend more on social care. Without more money we won't be able to improve services. We'll just reconfigure services with consultants getting more. We want good quality services. Look at the four nations [of the UK]; look at the way it is different across the four nations.*

**Service user**



## **Problems with the 'RAS'**

One of the particular selling points of Individual Budgets (IBs) has been the 'RAS' – the 'resource allocation system'. The strength of this was seen as enabling the service user to know from the start how much money was available to pay for their package of support. However, service users are now highlighting some serious problems with the RAS. It is calculated by dividing overall spending on support using a points system to allocate a sum for each individual. But this doesn't necessarily coincide with the cost of the actual amount of support service users may need to live an independent life.

*The RAS just doesn't seem to be working adequately and so budgets are being taken back to funding panel for more debate on how the budget can be altered. I thought RAS was supposed to stop this approach but it is not a transparent and fair way of allocating funds. We really need some questions raised about the RAS model.*

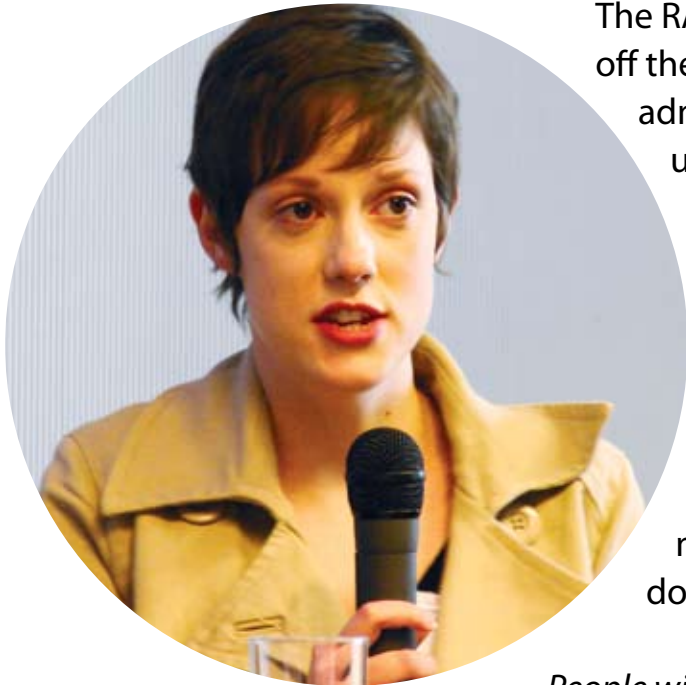
**Service user**

*There are no terms of reference for this system. The members of funding panels are making personal judgements about budget allocation, rather than this being from a value-based set of criteria and a person-centred approach.*

**Service user**

The reality is that the RAS is essentially another bureaucratic procedure shaped by the social care agency and subject to the same kind of problems as previous systems of assessment and financial allocation. Similarly, because the RAS is set differently by individual local authorities and eligibility criteria also still vary between regions, the RAS is no more portable than previous arrangements, again restricting the mobility of service users.

The RAS also tends to be 'top sliced' (a sum taken off the overall sum of money) in order to pay for the administration of IBs and any support service users need to access them - either at the level of the individual or the organisation. This means that a separate funding allocation is frequently not being provided to people for any support, information, advocacy or advice they may need to help run their individual budget or self-directed support system. They are therefore having to use some of the money intended for their support package to do this, which is a cause of real concern.



**Caroline Throssel**

*People without family support or unwilling to use them should not have to spend their RAS on buying-in this support.*

**Service user**

One service user expressed another concern about the RAS – the way it could again encourage service users to be seen as an individual cost rather than a benefit.

*Now the community is made aware of how much a disabled person is costing its local council; this doesn't actually feel very comfortable or nice.*

## **Questions about who is in control**

*You can only use a service under Self-Directed Support if it is available and you know about it. There will be a local care economy – a real challenge to how service users are involved.*

**Service user**

*My sister has had very little support. She's meant to manage, but no*

*training is offered. She had help from a local organisation, but its funding is strangled.*

**Service user**

*There are two key relationships here: the individual and services and the relationship with the state – which is much more problematic.*

**Steve Dowson, National Development Team**

While the whole point of current reforms is to offer service users more choice and control, there is some doubt about how much say service users and their organisations actually have in the development. The impetus for individual budgets came from non-service user organisations, and the development so far has been very much a top down one. A theme of this conference was the vulnerability and limited funding of service user-controlled organisations.

*The massive issue for me is ownership. Direct Payments was a drive from disabled people. It is much more unclear where the drive for Self-Directed Support comes from. People with learning difficulties and self-advocacy groups have been left out of this debate.*

**Catherine Bewley, Values Into Action**

*One of the first things people with learning difficulties say when you are telling them about Self-Directed Support is, 'can you repeat what you've said?', and 'where is the accessible information?' and 'who can offer me support?'*

**Mark Brookes, Values Into Action**



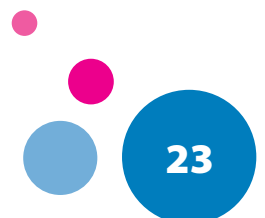
**Mark Brookes**  
Values Into Action

## **The limits of consumerism**

*The theory is that people holding individual budgets will shape the market...If it is underfunded many providers won't be interested in entering the market. The level of money in the market place will have an important role.*

*At a recent conference in Detroit the overwhelming message from 40 – 50 such projects was that it will lose its way, become bureaucratised – the freedom will get lost [without a strong user voice].*

**Steve Dowson, National Development Team**



*I have gone to three rogue traders. I had to go to Motability to get a decent scooter.*

**Disabled woman**

Some people think that the customer will be king in an individualised system of support. Others argue that this is naïve; instead, the individual consumer is likely to be limited by the power of local and central government, of bureaucracy, professionals, the existing service system, the market and traditional commissioning processes. This is likely to greatly limit their real choice and control.

*You will need informed customers and customers ready to use their purchasing power.*

**Steve Dowson, National Development Team**





## 4 KEY REQUIREMENTS FOR ACHIEVING SELF-DIRECTED SUPPORT

*It shouldn't be that all the rules change. The key difference is that under a system of Self-Directed Support, everyone should have a similar degree of control.*

**Robin Murray-Neill, Direct Payments Lead, CSIP**

If Individual Budgets are to play their part in the achievement of Self-Directed Support, a number of essentials look like being needed. A number of such requirements were highlighted in the conference. These included:

### Assessment based on the philosophy of independent living

*Assessment now is a bit of a lottery; how you are judged, how the care manager is trained up.*

**Service user**

Assessment must be based on criteria of what support people need to lead the fullest lives they can wish to live – not on the current deficit model, where they must show what they can't do to have a chance of getting anything.

### Support for assessment

*How can it be 'self-assessment' when it is being checked by professionals?*

**Service user**

*In my authority, they call it supported assessment.*

**Service user**

Each person should be able to have reliable information, advice, advocacy and support to make their own self-assessment. We know that without this, self-assessment will be limited by what people have been used to, and low expectations.



**Robin Murray-Neill**  
Direct Payments Lead, CSIP

## Support for staff

*I have worked with strong care managers who'll get what's needed for service users and others less experienced or competent who'll get less.*

**Pat Stack, Chair of London Direct Payments Forum**

So that they are included and equipped to work in the new ways that will be required of them, staff will need support and training. Unless this happens, then there is likely to be a repetition of the problems that the introduction of care management brought. The move to Self-Directed Support and Personalisation will be experienced as another unhelpful burden dropped on them, rather than a role that they are helped to take on and enabled to participate in to shape it to the maximum.



## Support for all to access self-directed support

*Unless there is a circle of professionals to help people, I don't see how this can go on.*

**Service user**

*Information, advice and guidance – which should be free at the point of delivery.*

**Tony Phillips, National Brokerage Network**

Self-Directed-Support needs to be a realistic option for all service users and not depend on them having family members to operate it, or be based on the expectations that they want to take on full responsibility to run it. It must be a workable, positive option that will continue to work if people have particularly difficult times, if their condition fluctuates, or if they can't take much on individually on their own. Only in this way can people of different abilities and experience have truly equal access to Individual Budgets. Black and minority ethnic communities must be fully involved and included. There must be equity and equal access, so far badly lacking in social care.

*There are complaints about the assessment process where certain cultural needs are not taken into account. Social services need to*

*understand that if people need to get food for their culture, it may not be at the supermarket. They may have to go further and it will take more time for support.*

**Ibukun Olashore, Director, Organisation of Blind Africans and Caribbeans (OBAC)**

## **Skilled independent brokerage**

*An Individual Budgets system that doesn't have independent brokers as an option is a flawed system.*

**Steve Dowson, National Development Team**

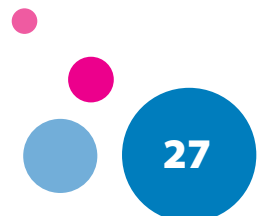
*Brokerage is about different ways people can exert choice.*

**Frances Hasler, Commission for Social Care Inspection**

To work well, Self-Directed Support will need to develop a strong practitioner group of skilled independent brokers. This role must be very different from the damaging rationing role that care management was reduced to. It is a role that will demand the social understandings, and skills grasp of independent living that social workers need, plus more. The pluses will include the ability and the skill set to support people to work out the package of support they want, under their control, but organised and maintained in a way they can handle at zero cost in terms of stress and anxiety, and without top-slicing their support funding.

### **The independent support broker role:**

- **Is independent**
- **Has good working relationships with social workers and support providers**
- **Is professional in the way the assistance is delivered - service that is task-focused, and efficiently and honestly delivered, to the person's requirements**
- **Is not 'professional' in the negative sense, i.e. remote, impersonal, disempowering, or self-serving**
- **Assists, as each individual requires, in the tasks up to the point of implementing the plan, and no further**
- **Is available and equipped to act as the person's agent**
- **Offers assistance on the basis that it is a paid service being delivered to a customer.**



- (Dowson S (2008) Custom and Control: the training and accreditation of independent support brokers, National Development Team [www.ndt.org.uk/docsN/CustomandControl.pdf](http://www.ndt.org.uk/docsN/CustomandControl.pdf))

*Accrediting and regulating brokers through boards linked with local user-controlled organisations, which won't undermine, but strengthen the voice of the service user.*

**Steve Dowson, National Development Team**

## **An infrastructure and network of support**

*We must have someone to go to when it goes wrong – because our life depends on it, even when we are living independently. We are vulnerable even if we don't want to be.*

**Service user**



*What happens when something goes wrong?*

**Service user**

Personalisation and Individual Budgets have sometimes been sold on being able to reduce 'bureaucracy' and save money. But to be truly inclusive there will need to be a new infrastructure of assistance, supporting people to access it on equal terms. This is a key lesson from Direct Payments developments.

*It is essential to make the argument for investment in support. Without it people will drop out.*

**Frances Hasler, Commission for Social Care Inspection**

**Peter Beresford**

## **Effective planning for change**

*We can't sustain this anymore unless there is capacity building, looking at rates of pay for personal assistants, employment legislation and so on. I worry about money going into local authorities and being spent on big consultancies. We've got to invest in service users.*

**Service user**

Moves to Personalisation must be properly planned at local as well as national level if Self-Directed Support is not to be set up to fail,

with realistic preparation of administering organisations, staff and service users. All will need support to develop their capacity to take on this different, valuable way of working.

## Adequate funding

It is essential to address funding issues if Self-Directed Support is to work well as part of an overall policy based on values of independent living. Self-Directed Support can't be expected to be cheaper, although it could be better. A common view is that there will need to be much more money if it is to reach all the people who need support. Otherwise we will quickly see people getting individual budgets calculated according to funding limits, instead of being based on the principles of independent living. These principles must inform the decisions.



*To say it can be done cost-neutral is ridiculous. It's nonsense to say it can be done without more money.*

**Tony Phillips, National Brokerage Network**

## Shared ownership

*So far if you've been outside the pilot process, it's felt very excluding. It's a major change happening. It has to be inclusive.*

**Catherine Bewley, Values Into Action**

Service users and their organisations must be centrally involved in developing and operating Self-Directed Support. They must be involved in an ongoing way through their own user-controlled organisations, at every level — from a local and individual level, to a strategic and national level. Otherwise, as we know from experience with Direct Payments, it is unlikely to work well. The same goes for face to face practitioners. They too must be properly involved and included.

## The importance of service user training and consultancy for self-directed support

User-led and user-provided consultancy and training have a vital role to play if Self-Directed Support is truly to be that — to be developed in a true spirit of co-production.

The government has made a significant sum of money, over half a billion pounds, available over three years to transform social care and develop Self-Directed Support. A significant part of this funding needs to go to the service users and their organisations who are already informed, expert and up to speed on Self-Directed Support, to help take it forward; to enable their involvement in supporting capacity building, educating staff, equipping managers, re-educating commissioners, and undertaking necessary research and evaluation.

*Co-development ought to mean learning by doing. People running services should be sitting down with service users and being trained. I am hoping that's where some of the £520 million goes.*

**Frances Hasler, Commission for Social Care Inspection,**



# 5 WAYS FORWARD

*Direct Payments are the independent living movement's gift to the community.*

**An Independent Living worker in Scotland**

*We need to create assumptions about the basic minimum of what everyone should have.*

**Frances Hasler, Commission for Social Care Inspection,**

*People are not used to this whole world [of choice and control]. We need to act as ambassadors to show how this way of working is revolutionary for us and can be for them [as workers].*

**David Morris, Senior Policy Advisor to the Mayor of London (Disability and Deaf equality)**

*Raise your expectations. The government wants us to reduce them.*

**Tony Phillips, National Brokerage Network**

Conference participants were anxious to make sure that the move to Self-Directed Support really happened. A number of key ways to move forwards as effectively as possible towards mainstream Self-Directed Support were identified at the conference. These included:



**Tony Phillips**  
National Brokerage Network

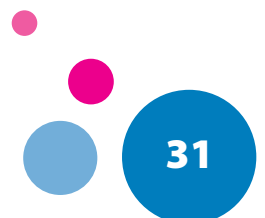
## Building alliances

*As we develop centres for independent living (CILs), it is an opportunity to develop links with other communities and other groups of disabled people.*

**Kevin Caulfield, Development Manager,**

*We as disabled people need to build alliances; with older people, with all for whom this agenda is important, the huge army of people who provide unpaid support – these are allies. There are some difficult questions we may not have engaged with about how we deliver effectively for everyone.*

**David Morris, Senior Policy Advisor to the Mayor of London (Disability and Deaf equality)**



*In our area we are all trying to work together; service users, PAs (personal assistants) and unpaid carers. There is a big issue of some older people not wanting to do Self-Directed Support. We're wanting to do training with both service users and PAs. There are older people who don't want to do the supervision side but do want to be part of our group. It offers circles of support.*

### **Local carers support organisation**



**Simon Stockton**  
*Leading Total  
Transformation  
Sites in Richmond*

Participants placed a big emphasis on the importance of developing alliances with other groups if Self-Directed Support is to progress successfully. Issues were raised about breaking out of the different 'silos' in which groups had been put by the system and policymakers, and communicating more with each other. It's important to learn from different traditions. Different groups used different language and talked in different ways about things. This is true of people involved in the fields of supported living and criminal justice,

housing and social care, who may have different ways of describing and understanding things. But there are shared goals and objectives, so it is important to learn to communicate better with each other. Service users and carers have often been set against each other in the past.

The feeling expressed at the conference was that it was important that these different groups learn how best to work together for the sake of their common rights and interests, without departing from their fundamental values and principles. This is seen as very important. While the aim is to build alliances, it is also essential not to lose sight of or weaken the principles that have underpinned service users' efforts to develop Self-Directed Support as part of the philosophy of independent living. The value of developing links and alliances with face to face practitioners was also talked about. Good practitioners face many of the same problems as service users, in terms of low income, little say and under-membership of black and minority ethnic and other marginalised groups.



*What concerns me is polarisation between workforce and service users. We want a united front once these issues have been worked out.*

**Helga Pile, National Officer, UNISON**

*We need new alliances with service users in the development of this agenda.*

**Simon Stockton, Leading Total Transformation Sites in Richmond**

*The carers movement is with you on this agenda. Self-Directed Support works for carers too, if it is done ok. The fundamental direction is right. We've got to make it work.*

**Kate Groucott, Carers UK**

## **User controlled organisations**

*Always in these government developments, there's a lot of talk of advocacy and user-controlled organisations, but there isn't the money there and a lot of groups are quite fragile.*

**Catherine Bewley, Values Into Action**

*We need consistent equal funding of organisations controlled by those who use services... In order for people to get choice, dignity, information, support, we need structures – the whole issue of Centres for Independent Living – resources controlled by service users... There is very good evidence that where there is a well-resourced user-controlled organisation that people are placed in less vulnerable positions. Evidence shows we support each other and build networks of support and it solves the problems much better than organisations or professionals, but it's not often funded.*

**David Morris, Senior Policy Advisor to the Mayor of London (Disability and Deaf equality)**



**Helga Pile**  
National Officer, UNISON

User-controlled organisations, that is to say organisations which are democratically controlled and run by disabled people and other service users, were seen as key to the positive development of Self-Directed Support. Participants felt that it was crucial that these were properly developed and supported, to play a central role in taking Self-Directed Support forward. In line with the

government's Independent Living Strategy, a network of local user-controlled organisations need to be adequately and securely resourced. This policy needs to be developed speedily. As yet service users feel not enough is being done to support the large scale development of such organisations, despite official rhetoric. Instead, many such organisations are vulnerable and insecure and in recent years, more have closed than have opened. Self-advocacy among people with learning difficulties is being put at risk.

Such user-controlled organisations are felt to be vital if Self-Directed Support is to be rolled out effectively, for a range of reasons:

- They provide the base for service users to get together, to gain in skills, confidence and empowerment.
- They provide the basis for all groups of service users to have an independent, ongoing, collective voice.
- They provide the basis for entering into discussions and negotiations with government, policymakers and services on more equal terms and at all levels.

Additionally:

- Such organisations need to be represented at local and national levels, at all levels in decision-making, and in strategic organisations and bodies.
- They are the location for the development of user-controlled support and services. Research has highlighted that disabled people and other service users particularly value such support.
- They have expertise and are particularly well-suited to provide the support structure, advice, information and advocacy that are essential for Self-Directed Support to work well for a wide range of people.
- They offer a key source of user-led training, consultancy and expertise.

## Being able to influence policy and practice

*We must get into strategic discussions... We've got to be strategic to deliver something that will work in the future... We must make sure*

*these ideas aren't hijacked by a system that wants to replicate itself.*

**David Morris, Senior Policy Advisor to the Mayor of London  
(Disability and Deaf equality)**

*Some service user organisations are telling us that they are not being invited round the table to discuss Self-Directed Support.*

**Kevin Caulfield, Development Manager, NCIL**

The important role of service users' own organisations was closely linked with the importance service users attached to being able to influence policy and practice developments. The need to get more involved in strategic discussions was highlighted, in order to ask key questions from service users' perspectives. How do we uphold disabled people's human rights? How do we ensure equality of access for all who need support, that is not dependent on people's financial resources, how old they are or what different services they need, and guarantee a basic core level of entitlement and support? There was a strong sense that service users and their organisations will need to be able to think and act strategically; to have strategies worked out to take this forward. They need to be able to function at a policymaking level, while retaining and getting across what people as service users really want. People felt that their influence and involvement had to be ongoing to ensure that positive developments lasted.



**Kevin Caulfield**  
Development Manager, NCIL

*What safeguards that they don't change government policies?*

*The idea is wonderful – but keeping it funded?*

**Service user**

## **Making the argument for investment in support**

As we have seen, one of the key themes emerging during the conference, from all stakeholders, but particularly from service users and carers, was the importance they attached to there being structures of support for people to ensure that they could access and stay on schemes for Self-Directed Support, like Direct Payments and Individual Budgets. Such support was seen as essential if:

- **Everyone – all service users and service user groups – were to**

have a real and equal chance of securing **Self-Directed Support**.

- If Self-Directed Support was to work regardless of changes or fluctuations in people's situation or impairments.
- If groups unfamiliar with the idea of Self-Directed Support were to get a better understanding of it and gain in confidence, seeing it as a real option for themselves.
- If family and friends were not to be discriminated against and expected routinely to take on support and caring roles themselves, regardless of service users' or their preferences.



Recent discussions and developments around Personalisation and Individual Budgets have not always paid adequate attention to the need for such support, glossing over this with assumptions that family members or care managers could set up and run such schemes, or that people would routinely take this on themselves. But it is already clear from the experience with Direct Payments that such support is a crucial requirement for the effective and equal

operation of Self-Directed Support. This must include the provision of advice, information, guidance and advocacy. It can extend to help with running and managing schemes, taking on, where they arise, responsibilities for employing workers and the administrative tasks that Self-Directed Support can entail. There is still a job to be done to convince policymakers of the need for such support and for it to be funded. Such support clearly has cost implications and will need to be budgeted for at local and national levels if Self-Directed Support is to be rolled out on an equal basis for all. It is also important that service users' resource allocation is not top-sliced to pay for such support.

## More open discussions

Participants found the chance for open discussion that this conference offered very helpful. As yet many service users have not been able to be part of such discussions. They want to find out more, get more information and get more involved in the big changes that are taking place in social care. There was a strong feeling that there need to be more such discussions, in London and in other parts of the

country, for different groups of service users and bringing different stakeholders together. This needs to be an ongoing process, helping service users and others be part of the discussion and really engaged in the development of Self-Directed Support and finding out more about it. We heard about a learning difficulties self advocacy group in one of the individual budget pilot areas which did not even know it was happening. People said, 'we have got to widen the debate'. This was a strong message at the conference.

*[Without service users involved] it will become bureaucratised and only work if you are articulate and informed. It needs an informed, open debate.*

**Service user**

*We must uphold disabled people's human rights, equal access for all who need support, not dependent on people's financial resources, how old they are, what different services they need, and guarantee a basic core level of entitlement and support and everyone must know what it is.*

**David Morris, Senior Policy Advisor to the Mayor of London (Disability and Deaf equality)**

# HELPFUL MATERIAL

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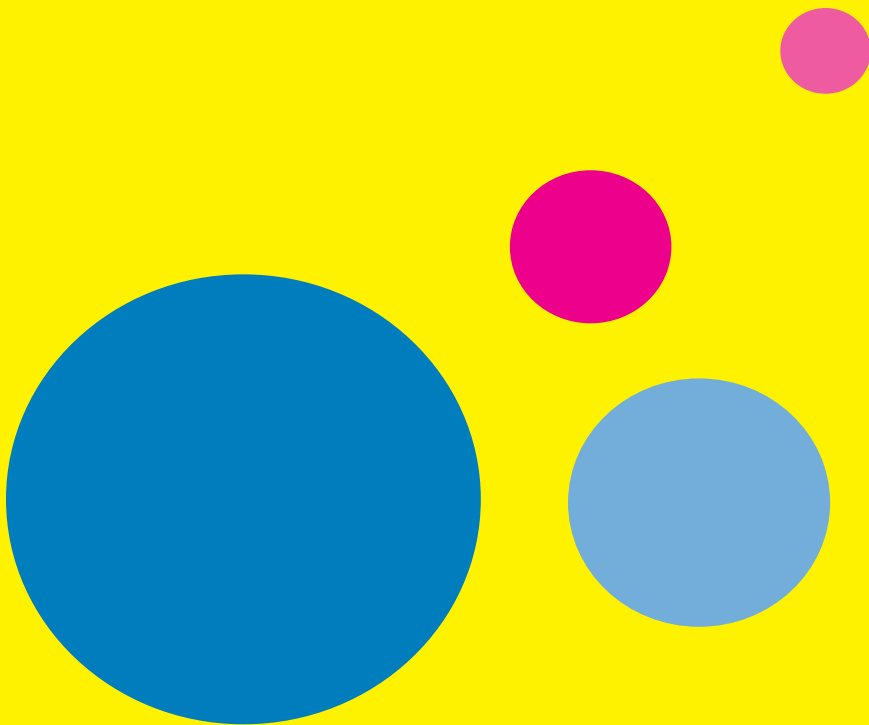
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**LONDON SELF-DIRECTED SUPPORT FORUM**  
*Building on the experience of Direct Payments*