



## **Consultation Report**

# **Self-Directed Support Changes What does it mean for me?**

**6<sup>th</sup> March, 2012**

**Lothian Centre for Inclusive Living**

**Norton Park Conference Centre**

## **Lothian Centre for Inclusive Living (LCiL)**

### **Self Directed Support changes? What does it mean for me?**

**Norton Park Conference Centre - 6<sup>th</sup> March 2012**

#### **Report**

On 6<sup>th</sup> March 2012, on the afternoon of the LCiL AGM, our organisation invited individuals interested in self directed support, to attend an information event about the implications of the coming Self Directed Support (Scotland) Bill on disabled people and their care packages. The invitation also highlighted that questions and comments from participants would be conveyed to relevant local authorities representatives in the Lothian region.

A total of 24 people participated in the event. An overwhelming majority of these (22) were from Edinburgh, one from and East Lothian and another one from Dunbartonshire.

The event was structured so that the sometime complex information was accessible to all. In introducing the event, Florence Garabedian, LCiL chief Executive, explained that although the new SDS picture has started to emerge in the four Lothian local authorities, no one was exactly sure of many things and of direct or practical implications for disabled people and support organisations such as LCiL. It was, however, possible to identify a broad process and key aspects. It is these that we were seeking to invite comments on and discuss.

The brief introduction was followed by three LCiL staff members and volunteers enacting a role play introducing a new way of assessing people, the SDS four options, individual budgets etc.

Participants then went into groups facilitated by LCiL staff members where the information was broken down, more details were given and group members had the opportunity to ask questions and offer comments. Each group also had a note-taker.

At the end of the discussions, participants reconvened briefly to hear about the LCiL Development Programme and opportunities to get involved directly with the organisation.

This report is based on the (five) group discussions as reported by note-takers and without analysis of the material. Groups had the opportunity to discuss, comment and ask questions on four main changes that the Bill would make to the current social care delivery:

1. Change in the way people are assessed
2. The introduction of the Individual budget and the four options
3. Planning towards individual outcomes or person centred plan
4. New ways of calculating a care package

Facilitators made clear at the start of the session that they probably wouldn't know many of the answers to the questions but these would be recorded and conveyed to the local authorities.

**Organisational note:** Many of the comments and feedback from participants convey their fear as well as a lack of trust of local authorities and their staff to implement SDS in the spirit of the Bill. This perhaps is the biggest challenge facing local authorities: getting people to believe that they are sincere in their attempt to implement SDS within the spirit of the Bill and in meeting the aspirations of disabled people and people with long term conditions. We accept that support organisations have an important role to play in alleviating such fears, perceived or real, and in providing independent and objective information to individuals and groups. LCI will continue to do this with integrity and professionalism whilst adhering to its own values.

### **Initial Comments**

Although the event focused on the changes brought by the Self Directed Support Bill, many people expressed concerns and anxiety regarding the wider aspect of care, welfare reform and benefits. It was very much felt that, as SDS will operate within these wider issues, financial constraints would have an effect on it as well. In different ways people wondered whether they were going to have their packages automatically reduced.

Eligibility criteria for Direct Payments were also identified as a key issue by participants who felt that almost always they aimed at meeting their personal care needs and hardly ever at meeting their social needs.

**'The Independent Living Fund (ILF) is closing in 2015 and is already closed to new applicants. Local authorities can't afford the support**

**we need now. There is no point discussing Self Directed Support when the money won't be available.'**

**'ILF money should be ring fenced so that it goes to disabled people who need support.'**

**'Losing ILF is a human rights issue. Both my disabled children will lose their ILF money and will no longer be able to leave the house or do anything.'**

**'How can disabled people use the law to challenge cuts to social care and ILF?'**

**'With ILF closing, many of us are scared that Residential Care will be our only option!'**

**'What about our rights?'**

**'The Scottish Government is very positive about SDS, but the local authorities set their own budgets and don't make it a priority.'**

**'The Government should say how local authorities spend their budgets and should ring fence support for social care.'**

**'What will be different from what is on offer now. Is there anything different about Self Directed Support (SDS)?'**

**'People already have choice over support, they can get Direct Payments, choose what to do and set their own outcomes.'**

## **Change 1**

**SDS changes to the nature of the assessment**

## **Feedback**

### **► Capacity of local authorities to implement SDS in the spirit of the Bill**

- Where will the money come from – as Scottish Government is imposing new duties on local authorities will it provide more money to enable local authorities to implement changes.

- What if service user is happy with support arrangements currently in place – will that all have to change after this new assessment?
- Assessment is most important, it is unfair that it is done by complete stranger who do not have proper understanding of service user's disability.
- Suspicion/concern new assessment implemented/used by LAs as a means to cut costs, reduce packages. Where does financial assessment sit in this – will personal contributions increase?
- There will, presumably, be different costs involved in each choice and this will have a profound effect on where influence is brought to bear on the service user – how will this be prevented?
- In the case of higher support needs will the local authority try to move support towards NHS and medicalisation?
- What sort of input should there be from medical authorities in cases of high or multiple and complex needs cases? Will medical authority 'trump' the wishes of the individual?
- Currently it took LA representative long time to finalize budget. Prefers one Social worker to be involved with one individual case, rather than frequent change of social worker's and starting updates numerous times when new Social worker introduced. It would avoid a lot of miss-communication if they could have one dedicated person.
- One SU in the group thought talking opportunity assessment method would be better. However, others felt if it is based on what they want, social workers will never approve funds, so this will not work for them.
- Annual assessments – will LAs have resources to deliver annual assessments? Are annual assessments necessary for everyone?

**'I can't see that things will be any different. ILF is closing, local authorities are only paying for people with critical needs. There won't be any funding for SDS.'**

**'Social work will come up with all the outcomes that you want, but then say we can't afford to pay for the support you need to these things. We don't live in an ideal world and disabled people can't have the same aspirations as other people. There is not enough money.'**

**'I am worried this will mean they cut my care package and hours.'**

**'It all comes down to costing (not outcomes for service user). Budgets are being restricted. Social needs are not going to be met.'**

**'Local authority will only pay for critical support and those with highest support needs. Outcomes won't be important.'**

**► Person centred approach and individual outcomes**

- A person centred approach is much talked about and is a very good principle, but will it be applied?
- It is good to be offered the opportunity to think about what we would like to do with our support, rather than about need as long as the finance is made available!
- Will assessment system be flexible enough to meet expectations (deliver on outcomes) and offer real choice?
- Given the above, how can the choice be made from a 'level playing field'? Will the local authority be able to veto choices made by the service user and so constrain their horizons? Will the service user be allowed to make a choice that the local authority disapproves of (again how 'free' is the choice offered)?
- Local authorities' representatives are scared of disabled people, they don't understand their need and could not communicate. Mixed responses emerged from SU group whether dialogue assessment would work, some thought engaging/talking could possibly work.
- Are full assessments going to be included at reviews?

**'Assessments should still be needs based. My needs are for 24 hours a day, 7 days a week. My needs don't change.'**

**'It is important to still assess needs for personal care etc. and to assess hours of support, or new assessment will mean less hours of support.'**

**'Who will measure whether outcomes are being met?'**

**'Will the assessment be based on medical needs or the social model of disability (focus on barriers to accessing society)?'**

**'Community Care Assessments should already be outcomes based. A good social worker should already ask about the person's whole life and have a conversation.'**

## ► **Support with the process**

- It is crucial that service users are well informed about all the options pre-assessment.
- Social work and LCiL should both be engaged and involved in assessment (especially for SU's with down syndrome, learning disability, who have higher threshold of pain and limited understanding. Some disabilities prevents to express one's feelings/wishes as well).
- Who does the assessment – service users need someone to help them understand options, help them consider and explore possible outcomes, in preparation for assessment to ensure they can communicate effectively with social workers.
- Independent advocate should be part of assessment but it is unlikely that LAs would allow anyone independent to do this.
- The people doing the assessment should be the people who knows us like support organizations, individual disabled people who have similar issues with daily life, day centre staff who knows us.

**'An Independent Person should be involved at the beginning of the assessment process, including pre-assessment stage!'**

**'LCiL or independent organisation should be at assessment. No one should go for community care assessment on their own.'**

## ► **Capacity of local authorities' staff to work within the spirit of the Bill**

- Social workers tend to try and take control – will there be additional training for social workers so that they are less prescriptive?
- How is the new process going to overcome what has often been felt in the past as a negative response from social workers in relation to Direct Payments? Are adequate **training programs** being implemented for social work staff?
- Group agreed that disabled people should be involved in training social workers to promote better understanding of their needs.
- Social workers' training is the key, Lcil should have a bigger role to play with training or helping social worker's with assessments. Disabled people should also be encouraged to get involved.

**‘There are no specialist social workers any more. There are no expert social workers who understand DPs or SDS.’**

**‘Who will train the staff on how to do outcomes based assessments? Will they ask us (disabled people) about what the assessment should be like and what questions to ask us about our support needs? Will the local authority just make it up themselves?’**

## **Change 2**

**→ You should be told the value of your care/support package in £. This is called an Individual Budget**

**→ SDS changes the options you will be offered when you have been assessed (or your package is being reviewed). You should be offered Self Directed Support which is a range of options. These options are:**

- 1. Direct payment (DP)**
- 2. Individual Service Fund**
- 3. Direct service**
- 4. A combination of the above**

## **Feedback**

### **► Capacity of local authorities to provide information**

- Concerns were expressed over the professionalism and accountability of care service providers (agencies).

**‘Social Workers are too over worked to do proper advice and assessments for SDS!’**

**‘Local Authority staff would not know about advising on these 4 options. Social workers will need training. I already have to tell the social worker what to do with Direct Payments’**

### **► How far is it a real change?**

- Knowing the value of your budget will definitely give more insight and control.



- Will Scottish Government set up review process for few years down line to check effectiveness of legislation – how well it's working for service users?
- In principle it looks great, in reality not good as it is probably going to continue as it is.
- 4 options do not really represent any change

**'These are not new options! Disabled people should already be offered these when they get assessed. You can already have a Direct Payment or a care provider or a service from the council.'**

**'These 4 options are already available to disabled people.'**

**'I asked for Direct Payment because I was fed up fighting with local authority about my support. Now I am in control of own support.'**

**► How much will it be for the benefit of people?**

- With regard to the four 'options'
  - Will there be monitoring process or quality control over the dissemination of all the information?
  - Will it be a tick box exercise?
  - Will there be real opportunity to negotiate revised budget if indicative figure is not enough to meet agreed outcomes?
  - Final amount – right to appeal?
- Will all of the options offered lead to opportunities for the personal growth and development of the individual or will some prove to be a means of control and containment?
- There is a fair amount of suspicion/anxiety re change – is it really change to improve quality of life for service user or a means to cut costs?
- If I am in charge, don't have other social workers r telling me what to do.

- It was feared that squeezing the service users' budget will result in the lowering of PA wages and a devaluing of the work they do and, by implication, their worth to their employer as an individual.

**'Money is not there to support the four options available under SDS. Local authorities have no money for this.'**

- How flexible will system be to allow service users to change between options if what they originally chose does not suit/work for them?
- Will individual budgets provide more flexibility regarding use of unspent funds - instead of LAs simply clawing back underspend?
- Re-ablement Team –will people be able to choose to retain support from this team rather than change to other support providers once reablement process completed?
- Some choices might be subject to the availability of places – therefore the choice would be circumscribed and not free.
- What choice of services would be available for payment from the Individual Service Fund (ISF)? Will the budget be fixed and what happens if a person goes over-budget? What happens if a person with ISF is planning, bit by bit, to put enough money by to eventually purchase something in the far future (possibly over years) will the LA, as they currently do, claw back what the LA regard as 'excess' money?

**► Support to navigate and manage options**

- The person may overwhelm with options of many service provisions. LCiL should be involved from the beginning, value of the package should be transparent and shared with the service user. Close involvement of social workers with service users for a week or more is required to understand their care need.
- One service user had high dependency needs, then money was accumulated over a period when needs went down and consequently had difficulty managing consistency in budget. It is always good to have LCiL type support organizations to provide support to manage package.
- SU need to understand their budget. SU need help to work out budgets but still retain day to day control of their support.

- Disabled people's package could go into mess as it is not easy to manage disabled people's budget. DP works well but managing support is tricky. **Peer support could help in managing funds, DP package.** I SU thought 4 options is not enough, it requires peer support and people with understanding of disability/disabled person's package related issues. Social workers need to look at bigger picture rather than 4 options.
- Regarding Individual Service Funds, group participants were happy for support organizations like LCIL to manage, but were insistence that it should NOT be Social work or other service providers who do not have relevant experience.
- Some SU want/need financial management support
- Independent Advocate, friend/family/LCIL/ independent org. would be the best placed to manage Individual Budgets
- Independent financial advice required regarding the Indicative Budget – e.g. would you have to purchase your own equipment with this?
- How is the person to know what the best choice for them is? Once a choice is made, how difficult will it be to reverse?
- Should the SDS Bill include provision of an 'ombudsman' type recourse for those service users that are dissatisfied with the way their choices have been implemented or presented – what would be the grievance procedure?

### ► **Impact on wider social care delivery issues**

- If all local authorities develop their own processes & procedures for rolling out SDS – will service users end up in "lottery"? Some getting better assessment achieving better outcomes as result?
- It was suggested that the formalisation in the Bill of the need to provide choices might lead to a standardisation of the currently varied approaches to the same subject by the local authorities. If the Bill leads to consistency between local authorities, it was felt that that would be a good thing.

- Would the choices and personal budgets be moveable between local authorities or between areas of the UK?

### **Change 3**

**After the assessment someone may help you plan how you will achieve your individual outcomes and set your individual set up  
This is sometimes called a person centred plan**

### **Feedback**

#### **► Meaningfulness of planning for individual outcomes**

- Person Centred Plan needs to be meaningful – not just a paper exercise.
- LAs only interested in £ value, while SU need to have realistic expectations also need to be encourage to think out of the box, widen horizons when considering outcomes and how to achieve them
- If a budget is cut where does the knife fall – is it in core hours or in the PA's hourly rate?

**'How will my support change? I am 76 years old. I get home care service from local authority, I don't want a DP. But I want to have a say about who is coming into my home and what time I have to go to bed at night. I have tried complaining to council but they just say have to have home care when they can provide it.'**

#### **► Who should help with planning for individual outcomes?**

- Never social workers. Only support organisations like LCiL and other support organisation which have got understanding.
- Independent person best to help plan are advocate/friend/family/LCiL or independent support.
- Will LCIL need to become more of a crusading organisation at the cost of it giving practical help and support?
- Are local authorities going to have trained experts in planning support?'

- Service users need change – once outcome achieved is that it – box ticked?

**‘LCiL should help people plan their budgets and support.’**

#### **Change 4**

**SDS changes the way the value of your support/care package is calculated**

#### **Feedback**

- Will service users be told how the point system is allocated?
- In theory service users should have a sense that they are getting value for money is good and more choice for service users is good too, but this the reality will depend on how each LA delivers and implements SDS.
  - One of the strongest objections to the calculation of the individual budget was that the basis for the budget was unclear. Although it would be calculated as a £ figure it was unclear what the ‘unit of care’ would be or what unit of anything would be used. No-one on the table could come up with a way in which the cost of an ‘outcome’ could be quantified without reference to some common measurement unit (hours/man hours).
- Risks – LAs dictating how SU run their life, Swkrs not listen. LAs approaching this from wrong angle, they are only interested in £cost rather than what people want to achieve.
- Service users want feedback – how its working, facts, details of processes implemented by LAs, details of budgets awarded to other SUs (if Jimmy got funding for X, I should be able to claim it too!)

**‘My money all goes on paying for PAs. I pay for any transport costs myself. I can’t use my DP for anything except paying my staff.’**

**‘It would be good to know how much money you had to pay for your support.’**

**‘I only need to know how much I can pay my Personal Assistants. What is the hourly rate going to be? That is all I want to know.’**

**‘The most important thing to know is how to budget the money you have. Your needs can change throughout the year, you need to be able to pay for extra support sometimes and less support at others.’**

**On the SDS pathway, at which points would you like LCiL to help you?**

### **Feedback**

- Most participants thought they would benefit from support throughout the whole process; pre-assessment, budgeting, challenging indicative budget, negotiating with LA for larger budget to achieve agreed outcomes and helping put support plan in place (brokerage).
- Service users would rather phone LCiL than social workers to get impartial advice
- It was unanimously agreed by all participants that LCiL should help at the beginning (e.g. the pre-assessment stage onwards), **during** (e.g. negotiating the Individual Budget) and after the process (e.g. review).
- LCiL should be present at the social work assessment. No one should go for an assessment on their own.
- Social Workers should tell you about LCiL services.
- LCiL should help with planning your support, planning your budget, choosing options and monitoring budget.
- LCiL should help with managing money, employing PAs, costing support.
- LCiL is like an independent advocate and should be involved in the process from the beginning.
- LCiL can help if your needs change.

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