

WHO REALLY GETS TO CHOOSE?

CONFERENCE REPORT

“My daughter has severe learning disability and needs support 24 hours every day of the week. She has had the support of a well known and respected service provider for years and my family knows them well.

“I was given 6 days notice that her service was to be put out to competitive tender. I am happy with the existing service. No one has evaluated the effectiveness of her service.

“I went to Council as part of a delegation in February. I told my story and it hasn’t made a bit of difference.

“My daughter’s service is joint funded by both Edinburgh and Midlothian. Only Edinburgh is doing tendering and as a result of the tender, there may be now 2 different providers delivering her support. I don’t think she can cope and neither can I. What is going to happen next?”

Sylvia Lawrie, parent, Question and Answer session

As you get used to a carer you build a relationship and knowing the carer makes a difference to the service. Even things like involuntary movements can be understood better if you have a regular carer. Individuals who build up relationship can experience grief when a carer leaves. It is really a form of bereavement.

Graham Monteith, Opening Session

MORE THAN JUST A CHANGE IN PAYMENT METHOD

Johann Lamont, MSP for Possil and Equalities Spokesperson for Labour in the Scottish Parliament spoke first.

The driver of policy in this area must be those who are affected. This is not an academic discussion but a practical discussion that affects real people.

The move towards Direct Payments represents a shift in care but there still is a long way to go.

- Only 2600 in Scotland get a Direct Payment
- Only 700 people with learning disabilities get a Direct Payment.
- In 9 local authorities less than 5 people get a Direct Payment.

Why are things so slow? There are lots of possible reasons but one reason might be shown by a former nurse that she met who had to fill in lots of forms and keep charts on the wall to monitor the expenditure. This is a huge burden on those who want to care and to have the time to live a life.

Self Directed Care must also be about what personalised care and choices, not just a different payment method.

The emphasis must be on delivering change. The recent Panorama programme on home care and competitive tendering showed inadequate levels of support. Lots of issues emerged from this such as E-auctions and the role of the care commission but the fundamental problem is what was in the contract and how care was specified. Local authorities have to do more.

Johann recounted a visit to a project in the Gorbals. People received care but were also active in the local church and all its activities. This showed that people had lives that were more than their care package. Taking part in the church and other activities were important to their identity.

If we change the language of care to use words like Self Directed Support but disabled people still have to battle and struggle every day then we will have failed. Personalisation must focus on individuals and a partnership with carers. We must do more than sustain people in their own homes.

This is not just about funding but about what we value. Equality doesn't come by accident it comes from listening and taking action.



I am a father who is a legal and financial guardian for my son who has learning disabilities. I had to fight for 6 years to get a Direct Payment to get the right care for my son. But there is little support for me in managing this. Two of the carers employed have left falsely claiming I dismissed them and I have had to face employment tribunals and being sued by them for up to £75,000. Direct Payments aren't magic. As an employer I am getting tired of the challenges. What kind of support or protection can I get as employer? In Blairgowrie there is no support agency in the area. It's alright having a Direct Payment but what kind of help is there for me?

Question and Answer session

In the original vision for Direct Payments there should have been support agencies in each area. We must invest more as a society in making sure that we get real choices and that carers, families and service users are properly supported when they take a Direct Payment.

Response from Karen Jackson

Summary of main points

- **Too many people feel that don't have choice or control over their own lives.**
- **There is not a single solution to the problem.**
- **Choice must be built into the plans for care and support for each person.**
- **There needs to be more investment in support services for those managing Individual Budgets.**
- **Many voluntary organisations and services are developing new and exciting ways of involving people in having more control over their lives.**
- **The development of competitive tendering is undermining moves towards choice in services and support**
- **Local authorities must involve more people in talking about and planning new and existing services. .**

On Wednesday 15th April, 150 service users and carers met in Edinburgh to discuss “Who really gets to choose” in the supply and provision of social care in Scotland. The aim was to explore the issues that confronted people who needed support and to look at what might be some of the solutions. The conference was chaired by Ian Hamilton, journalist.



The conference looked at aspects of personal care and of the effects of competitive tendering. The host city, Edinburgh is currently undertaking a competitive tendering process and this featured strongly in contributions from the floor. No official speaker was available from the council but they did deliver a 2 page leaflet for every delegate.

This report is a summary of the speeches by the main contributors and some highlights of the busy discussion period that took place. Cllr Maggie Chapman from Edinburgh had been billed to speak but was called abroad at short notice for family reasons.

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www.ecas-edinburgh.org



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CHOICE—SOME IMPROVEMENT BUT A LONG WAY TO GO

Community Care Providers Scotland member organisations have been working for many years to improve the involvement of people in their services. The Care Commission now expects organisations to show evidence of this involvement and how people can influence their service. The Commission uses gradings to show how good a service is. You can only get high grading if you involve people well.

Members of CCPS are working to improve things. Some people are supported to recruit support workers. Others help people to choose the gender of their staff. Sometimes you get to choose the time of day for your support or sometimes you might not.

This choice depends on how the organisation is run, what the council has asked the provider to do and what the National Care Standards say.

The Care Standards say you should know what you are able to choose but that you have no absolute right to choose.

A consensus has emerged that people should get as much choice as they can manage. People are working towards this but there may be some way to go. Learning Disability organisations are developing person centred services. Some care for older people organisations have further to go.

However the decisions about which organisations can provide care are now decided by tender. Organisations have to apply to the council and bid for work. There is a tender process ongoing in Edinburgh right now. This affects people with a range of disabilities and support needs. The conference organisers are worried that there has not been much consultation in Edinburgh about what people want or have not been given good information on Direct Payments.

CCPS has looked into lots of tenders all over Scotland and usually the people have not been asked or involved in this area. This needs to get better and CCPS is talking to the Scottish Government about how this can be improved.

Annie Gunner Logan, Director of Community Care Providers Scotland.



As a mother who has always cared for her daughter I am worried about the future. We get a Direct Payment which helps her live in her own home. I am impressed with the organisation that supports her, she can now do things that I never thought she would. But this group that I have chosen and know and trust, may be stopped from supporting her.

I am angry about the way the tender is being carried out. Edinburgh council issued a brochure for service users which was meant to tell people what was happening. As it said in the back, I phoned Social Care Direct to ask for more information about the booklet. The man who answered the phone hadn't heard about it. Neither had his manager. They promised to find out more. But after a week I had to phone again and then discovered they had only learned about the brochure when I called the first time. I then spoke to the information manager and he didn't seem to know much either. His name also appears on the bottom of the leaflet the council gave out today before the meeting. I worry about what is going to happen in a year's time if the council didn't know what is happening today.



Questions And Answer session

RELATIONSHIPS ARE CENTRAL TO GOOD CARE

The Care Commission may set minimum standards and they are helpful but they do not meet the full range what people need. I use a leg bag and staff don't have training to change it. My wife has to help out. There are lots of situations like this that are not covered in the minimum standards.



I think you need be wary of Direct Payments and want to give you a health warning about them. I receive funding from the Independent Living Fund to buy my own support but I do not take a Direct Payment for the care that the council provides me.

I think too much responsibility passes over to the individual without enough funding.

Care services are human services. Once you are used to a carer, you build a relationship. Knowing the carer makes a difference. If you have a range of carers coming who don't have time to spend with you, you cannot build a relationship. Even things like involuntary movements can be understood better if you have a regular carer. They know what to expect and how to support you.

Relationships like this are undervalued. Individuals who build up a relationship can experience grief when a carer leaves. This is really a form of bereavement and like all bereavements it can be very upsetting.

I would also say Don't shoot the messenger. Carers do their best in difficult circumstances. They work at a low rate of pay and this seems to only ever go down. They seem more harassed now than ever and are unable to meet the needs of the people they support.

Services could be better organised. Even I can forget what needs to be done last thing at night. I go through a checklist. We need to train staff how to organise their time. This will use the time best. Care plans can help but they are only as good as the people that write them. In hospital there are nurses plans. These make the difference between getting fed or not. Care Plans should be the same in the home. It is important that we develop ways of making good Care Plans which say what is appropriate and inappropriate. You need to take hold of the care plans and involve others in writing the plan. Do not leave them just to the social worker.

Graham Monteith, Chairman of Ecas



Two things are happening. The Credit crunch is affecting business. This a sharper shrinking – more like a V. The shrinking of public expenditure is a much slower process and gradually slows down. When we come out of the recession then there will still be cuts in public spending. This may be driving a lot of the retendering in an effort to save money. Councils can involve people in the process or they can just carry on pretending that they are doing things well.

Annie Gunner-Logan, Q&A reply.

NOT JUST CHOICE BUT IN CONTROL

Karen Jackson said she was going to talk about IN Control. ARC support this because they want people to have more say over their own lives.

For the last 3 years ARC has been working with 60 service users and 25 organisations to develop a National Charter for Involvement. Even though a lot of the people involved get good support they still have problems meeting all their needs. Simple things such as holidays are difficult and expensive to arrange.



Karen asked the audience if anyone knew how much their service cost. Only three carers said they knew what the care for their sons and daughter cost because they were going through the process of getting a Direct Payment. Karen said she had found that very few people knew what their services cost.

In Control can give you money instead of a service. You fill in a self assessment form and then you are told how much you are going to get. You spend the money on your support by employing a worker or paying a service provider but you can also do a number of creative things. It is much more flexible way of creating support than Direct Payments. One example was of a young man who used his individualised budget to pay for a ticket for a neighbourhood friends to accompany him to a football game on a regular basis.



While this was a creative and less expensive way, it also helped to make new friendship and support. Such creativity is at the heart of In Control.

Karen put a video on which showed Bob Jamieson from Essex who has an In Control payment. He has good support and can make his own choices. The video finished with Bob taking off in a plane that he piloted himself [with some help!]. This was a good example of what In Control was about.

One mother said it was important to remember that you can also get good choice and control through support from voluntary organisations.

Her choice was being taken away from her because of the tendering in Edinburgh. Her son was very happy with his service and relationships. The only way she could be sure of maintaining this service was to get a Direct Payment. Whatever way you get a service should allow you choice and control.

Q&A

I work for a private care company in East Lothian and they have recently lost the contract in the tendering process. A lot of people who I support are unhappy and confused. The transfer of care is delayed and there is a lot of confusion.

People don't know how to access Direct Payments. If they don't have capacity then someone has to have guardianship first. Information from the council on this has been poor and puts people off. For the clients it is the relationship with carers that is important. There is a problem with not knowing if staff can TUPE over. This is a disgrace.

Q&A