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Official Report

EQUAL OPPORTUNITIES COMMITTEE

Thursday 10 October 2013

Session 4

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CONTENTS

EQUAL OPPORTUNITIES COMMITTEE
26th Meeting 2013, Session 4

CONVENER

*Margaret McCulloch (Central Scotland) (Lab)

DEPUTY CONVENER

*Marco Biagi (Edinburgh Central) (SNP)

COMMITTEE MEMBERS

*Christian Allard (North East Scotland) (SNP)
*John Finnie (Highlands and Islands) (Ind)
Alex Johnstone (North East Scotland) (Con)
*John Mason (Glasgow Shettleston) (SNP)
*Siobhan McMahon (Central Scotland) (Lab)

*attended

THE FOLLOWING ALSO PARTICIPATED:

Tam Baillie (Scotland's Commissioner for Children and Young People)
Tressa Burke (Glasgow Disability Alliance)
Etienne d'Aboville (Glasgow Centre for Inclusive Living)
Pam Duncan (Independent Living in Scotland)
Florence Garabedian (Lothian Centre for Inclusive Living)
Sophie Pilgrim (Kindred and for Scotland's Disabled Children)
Bill Scott (Inclusion Scotland)
Nick Watson (Adviser)

CLERK TO THE COMMITTEE

Douglas Thornton

LOCATION

Committee Room 4

Scottish Parliament

Equal Opportunities Committee

Thursday 10 October 2013

[The Convener *opened the meeting at 09:30*]

Draft Budget Scrutiny 2014-15

The Convener (Margaret McCulloch): Welcome to the 26th meeting in 2013 of the Equal Opportunities Committee. I ask everyone present to switch off all electronic devices or put them on flight mode. We have received apologies from Alex Johnstone.

I will begin with introductions. At the table we have our clerking and research team, our budget adviser and the official reporters and around the room we are supported by broadcasting services and security staff. I also welcome the observer in the public gallery.

I am Margaret McCulloch, the committee convener. I invite members and witnesses to introduce themselves in turn.

Nick Watson (Adviser): I am Nick Watson from the centre for disability research at the University of Glasgow.

Marco Biagi (Edinburgh Central) (SNP): Good morning. I am Marco Biagi, the MSP for Edinburgh Central and deputy convener of the committee.

Christian Allard (North East Scotland) (SNP): I am Christian Allard, MSP for North East Scotland.

Siobhan McMahon (Central Scotland) (Lab): I am Siobhan McMahon, MSP for Central Scotland.

John Mason (Glasgow Shettleston) (SNP): I am John Mason, MSP for Glasgow Shettleston.

John Finnie (Highlands and Islands) (Ind): Madainn mhath. I am John Finnie, MSP for Highlands and Islands.

Pam Duncan (Independent Living in Scotland): I am Pam Duncan, policy officer for the Independent Living in Scotland project.

Sophie Pilgrim (Kindred and for Scotland's Disabled Children): I am Sophie Pilgrim and am representing the for Scotland's disabled children project. I am a parent of a young man with autism and director of Kindred.

Bill Scott (Inclusion Scotland): I am Bill Scott, manager of Inclusion Scotland.

Florence Garabedian (Lothian Centre for Inclusive Living): I am Florence Garabedian, chief executive of the Lothian Centre for Inclusive Living and chair of Self Directed Support Scotland.

Etienne d'Aboville (Glasgow Centre for Inclusive Living): I am Etienne d'Aboville, chief executive of the Glasgow Centre for Inclusive Living.

Tressa Burke (Glasgow Disability Alliance): I am Tressa Burke, chief executive of the Glasgow Disability Alliance.

Tam Baillie (Scotland's Commissioner for Children and Young People): I am Tam Baillie, Scotland's Commissioner for Children and Young People.

The Convener: Thank you, everyone.

Our first and only agenda item is an evidence session to support our scrutiny of the Scottish Government's draft budget for 2014-15. I am aware that Sophie Pilgrim needs to leave the meeting early, so she should just let us know when she feels that it is time to go.

John Finnie will begin with questions on human rights.

John Finnie: Good morning and thank you for all your submissions. My first question is for Ms Duncan. Can you expand on the wish that is highlighted in your submission for a "human rights based approach" to budgeting?

Pam Duncan: Certainly. First of all, thank you very much for the opportunity to give evidence. We appreciate it and the continuing support that we get from the Scottish Government to do our work.

A human rights-based approach to budgeting means several things, one of which is participation. Participation is the first of the PANEL—or participation, accountability, non-discrimination and equality, empowerment and legality—principles of human rights. However, it is quite difficult for disabled people to participate in budgetary processes when they are so hugely oppressed by society—I think that it is fair to say that most of us share that understanding of the situation—and when the directly accountable organisations representing disabled people are stretched, to say the least. That said, as has been recognised throughout the equality budget statement and various documents that have been produced, if we involve disabled people in communities in the process, we can get things right very early on. As I have said in the past, disabled people are innovative by design; every day, they have to find solutions to lots of tricky issues, and that is something that the Scottish Government and the public sector across Scotland should enjoy.

Our submission on human rights also highlights the issue of social care, which we believe is a key infrastructure for equality and human rights. Without such care, I would not have been able to get out of bed this morning to do anything, never mind exercise my equal right to democracy and participate in this evidence-taking session. At this moment in time, the funding for the social care system is in crisis. The elastic in the budgets is not simply stretched; it has snapped. Local authorities are struggling and disabled people face huge disadvantages as a result. Staff in the sector are experiencing incredible difficulty, particularly those on the front line, who are having to tell people that there is not quite enough money to give them the support that they need to participate fully in society, lead an ordinary life and uphold their human rights. As a nation, a Scotland that was fit for purpose in 2013 could lead the way by including equality and human rights in our budgeting and recognising social care as a key infrastructure in that respect.

At the minute, local authorities are addressing the crisis in three ways. First, they are setting very high eligibility criteria that pay absolutely no regard to prevention and result in many people dropping out of the system. Across the piece, there is unmet need that is not being recorded and, because we do not really know what the real need is and we have not taken a human rights-based approach, we are finding it difficult to set our budgets in Scotland. I urge the committee to examine that issue.

Secondly, local authorities are charging disabled people more for social care services. In recent times, there has been a 12 per cent increase in charges at a time when, taking into account the extra costs of being disabled, about 47.5 per cent of disabled people are living in poverty.

Finally, local authorities are kind of robbing Peter to pay Paul by telling people, “You’ve got a Rolls-Royce package” when in fact it is just a bog-standard Corsa, or whatever the bog-standard car might be. After all, it is just about people getting out and doing what they need to do. We really should not be telling people to top-slice whatever they have and give it to someone else. We cannot empower one person simply by disempowering another.

Does that go some way towards answering your question?

John Finnie: That was a comprehensive reply, and I am sure that my colleagues will pick up on some aspects of it.

Your submission also mentions

“evidence driven by lived experience”.

I wonder whether you and the rest of the panel can talk about the importance of that and the role of advocacy.

Sophie Pilgrim: As a director of an advocacy agency, I should probably have a go at answering that from the perspective of children and families.

As you will be aware, the complex system of statutory services and benefits is a huge challenge for families who, at the same time, might have substantial caring needs. I emphasise the needs of families with children who have very severe or complex disabilities and who might need palliative care. Quite often, those families are nursing a child 24 hours a day. Such a role cannot be taken on by staff who do not have nursing qualifications. If those who have to meet that level of demand of care in their lives are at the same time having to negotiate the system of statutory services such as health, social work and education and the benefits system, they will simply not have the time or energy to get into disagreements with those services.

Research from the children’s commissioner shows that eligibility criteria across Scotland are not consistent. Parents are being put through a huge amount of assessment, but at the end of the process there is little objectivity in the decisions that are made about their care packages. As advocates for those families, we try to explain to them what has happened in their assessment and how authorities have reached certain decisions about their care packages. Where families have lost out, we support them through the process of getting the care and support that they desperately need.

Etienne d’Aboville: My experience is of working with people using self-directed support—about 400 to 500 people in Glasgow and another 120 plus in East Dunbartonshire. There is a link between advocacy and the human rights issue that was referred to earlier. What is often at stake for disabled people when engaging with and trying to access services is power. It is basically a power issue about who has all the information, who holds the cards and who has got the money. To empower disabled people, we should enable them to exercise more power to even out that relationship. For instance, in relation to social care, rather than challenge decisions, budgets or assessments, countless people just accept the outcome because they do not have access to support.

As a support organisation, we help people to negotiate their packages and make best use of the money. We do not explicitly advocate on behalf of people, because we are funded by the local authority, but we refer people to external advocacy organisations all the time, and it is well recognised that there is a huge need for more advocacy organisations that can play that role. Unless someone is very articulate or part of a family that can advocate for them, they will not necessarily get an equal shot at access to services. We tend to find that it is the most articulate and able individuals or families who get the results and who can challenge decisions successfully.

Tam Baillie: On the theme of rights, Pam Duncan has eloquently outlined why budgeting is tied in with people's realisation of rights. I note that the Government's equality statement says that in future years it will look at what it calls a children's rights checklist, but I think that it has to go way beyond that. Anyone who has heard me speaking about the Children and Young People (Scotland) Bill will know that we have made repeated calls for child rights impact assessments, and that is the level of scrutiny that I think should be given to the budgeting process in particular, for all the reasons that people have given about the impact on people's rights.

If the committee is to make any comment on the budget for future years, it should urge the Government to go way beyond a checklist of children's rights. The budget would bear scrutiny at the level of a child rights impact assessment. Whatever processes are in place next year, I hope that there will be a much greater focus when setting the budget on the impact on children's rights. There is not a lot of specific comment in the budget about children, and it is particularly light on children with disabilities. If the committee commented on that, I would appreciate it.

Bill Scott: We support the Scottish Human Rights Commission's suggestion that the budget should be not only outcome focused but focused on the achievement of human rights. The rights of the child and the rights of disabled people are known and the Scottish Government has signed up to them. The other evening, I was at an event that was run by Oxfam, which has developed a tool to look at whether what people on the ground in communities want to be achieved is actually being achieved by any legislation or policy that affects their lives. That is a way of referring to people to see whether the budget spend is actually advancing the achievement of their human rights. We know that we will not do that overnight, but making progress would be a start.

09:45

Tressa Burke: In relation to advocacy, it is important to emphasise that, at a time when disabled people are potentially experiencing the welfare reform impacts and the loss of the independent living allowance, with more cuts to services coming, and when they are suffering terrible stigma and discrimination following the media coverage of those things, disabled people need to be at their most assertive and articulate ever. It is the very time when all those things are impacting and causing a complex perfect storm of interrelated barriers that make disabled people at their weakest.

The disabled people's movement would argue that we need different types of advocacy. Disabled people need access to legal representation and welfare benefits advice about the technicalities of the barriers and discrimination that they experience. They need the kind of advocacy that might be sought through advocacy projects such as Bill Scott's. They also need peer support and the ability to build up their confidence in their skills and sense of autonomy so that they can speak out in negotiating care packages and the services that they need. I suggest that disabled people not having advocacy services, peer support and self-advocacy support at this time would be like disabled people not having welfare rights support in relation to welfare reform.

The Convener: Let us move on. John Mason is going to ask about employment opportunities for disabled people.

John Mason: I will start with the linked question of targeted funding and then move on specifically to employment.

There is an argument that more funds should be set aside by the Government, local government and health services for disabled people. In its responses, the Government has tended to say that it is providing free prescriptions, which helps everyone, including disabled people. In the same way, it is providing the affordable warmth scheme, the energy assistance scheme, modern apprenticeships and free bus services. Its general argument seems to be that the provision of those things somehow advantages disabled people more. I am interested in your reaction to that. Do we need more emphasis on funding for disabled people?

Bill Scott: Yes. I would go further than that and say that disabled people's needs require to be addressed within the mainstream schemes that already exist. For example, modern apprenticeships have signally failed young disabled people, with only 4.5 per cent of available places going to young disabled people. To be honest, that is a disgrace. It is also a systematic failure, because there were no targets for equalities groups in the scheme. Young women have been failed, as well as young disabled people. The issue is not that we need to shift the funding but that the funding should be used to advance the needs of those people within the overall target of increasing the number of young people in modern apprenticeships, with specific targets for the number of young disabled people and young women involved.

There could even be targets in particular areas to prevent job segregation building up over time. For example, young women are almost completely unrepresented in construction and are overrepresented in care. The tools already exist in the budget and in overall Government policy. It is not about spending more or spending specifically. It goes back to an outcomes-focused approach and is about thinking through how, within the budget stream, we can achieve what we want to achieve and reduce inequality.

I come from a community health and anti-poverty background. The reduction of health inequalities is a huge aim of Government, and it has often been thought that improving the general health of the population and increasing life expectancy will reduce health inequalities. However, that is not the case—it can intensify them. If those things are improved for the general population but the marginalised groups are left behind, the gap grows and the life expectancy of those at the top end of the income bands is much greater and grows at a faster rate than the life expectancy of those at the bottom. With all such general policies, it must be remembered that an inequality can be intensified rather than reduced by raising the numbers that are involved in a policy.

John Mason: The target is to have 25,000 young people in modern apprenticeships but, as you say, only a tiny number of poor disabled people are benefiting from the scheme. Is it more expensive to get a young disabled person into a modern apprenticeship? Should the figure of 25,000 be reduced to, say, 24,000 within which 1,000 places would be aimed specifically at young disabled people?

Bill Scott: It might cost more or it might not—I cannot say without doing the costings. However, the support is supposed to be provided mainly by the employer once the young person has been placed. A lot of funds could be accessed through access to work support, which is underutilised and underspent in Scotland. There are fewer Scottish disabled people on access to work support from the Department for Work and Pensions than there should be. I know that the access to work service is working with disabled people's organisations to improve awareness that that support exists, but more work should also be done with employers.

John Mason: Do you think that employers do not know what they can do and what is available?

Bill Scott: Employers do not know what is available and they think that there are barriers although no barriers exist. The problem could be overcome with relatively modest expenditure, most of which would be provided by the DWP. I do not think that the numbers necessarily need to be reduced. The issue is that the existing support needs to be utilised better. If the DWP is making the funds available, it is wrong that they are not being accessed by young disabled people in Scotland.

Etienne d'Aboville: Bill Scott has said most of what I wanted to say. I endorse the view that we need a more robust approach. So far, the approach has mainly been about trying to raise awareness of the need to recruit disabled people through encouragement, the provision of information and case studies, and so on. That is fine as far as it goes, but it would be possible to use the contracting relationship to be a bit more direct than that and to require organisations and companies to take on a proportion of disabled people. Training and development programmes could be offered to employers as part of that process, which they would take up as part of the contractual requirements. Positive action could be taken that is a bit more direct and does not leave things to chance so much. It would be crucial for the correct information and data on that to be collected with a view to monitoring targets much more closely, rather than finding out at the end of the programme that we are nowhere near where we need to be. We need some sort of positive action programme, although that may have budgetary implications through provision of organisational support to companies that need it.

Tam Baillie: My answer is, "Yes, but" to the first question, which was about whether we should have targeted, ring-fenced—if I am allowed to use that phrase—funding. I understand the rationale behind wanting to build as much flexibility as possible into funding at the local level. However, if the evidence is that policies are not benefiting specific groups—for instance, young people with disabilities—there must be remedial action to correct the laissez-faire, flexible approach because the funding is not reaching the parts that it needs to reach. The committee is hearing some alarming evidence about young people's access to employment. Some consideration must be given to how the Government can ensure either that the universal approach ups its game or that something specific is done with the funding to rectify the situation.

I want to make another point, because it is not just about employment. The committee received written evidence from Lead Scotland on the reduction in places in higher education for young people with additional needs, and that is part of a bigger problem. The evidence that we have on what happens when young people move from child-focused services into adult-focused services shows that the transition causes children with disabilities and their families and carers a lot of grief, because there is a gap in care and support services, which do not continue as children move into adulthood.

We struggle generally to support children as they move into adulthood, but we struggle particularly to support youngsters with disabilities in that regard. I know that from the inquiries that come to my office. The issue requires specific attention; it has been around for a long time and the situation is not improving. The committee might well want to make recommendations about the transition to adulthood for children with disabilities.

John Mason: I think that Mr Scott said that colleges and universities could and should be doing a bit more. Do you agree, or should someone else be doing it?

Tam Baillie: The trick is to find the method of exerting influence that will get the outcome that we are looking for. It might be about targets, it might be about expectations about the courses that our colleges and universities provide, it might be about culture change; I suspect that it is about all those things. The fact remains that we are seriously struggling to provide properly for children with disabilities as they move from child-focused services into the adult world. It has been a problem for a long time and it is not getting any better.

Bill Scott: The period between the end of school and young adulthood is a key intervention period, because for many young disabled people there is no transition and they are just parked for the rest of their lives. We hear about the 20,000 or so modern apprenticeships. All the people who have been apprentices have an advantage over young disabled people, who are competing in the same job market. The people who have been apprentices have had training and work experience and they have skills. That leaves young disabled people even further behind and even less likely to be able to overcome the barriers that they face.

If investment is made at the point that we are talking about, it can change a person’s life and reduce dependency, which is what we all want. No one wants to be dependent on the state, and young disabled people want to be able to go out and have the same life experiences as their non-disabled peers have; many, many young disabled people want to work. Investment can make a difference to the rest of a life. It can reduce expenditure on social care and on health, because we know from health studies that when people are parked at home they become ill and depressed and their existing conditions get worse.

Florence Garabedian: From our experience with our service users, we find that young disabled people are often protected within children’s services. Often, the services are free and there is good support and care. When young people reach the transition period, the services either have to be paid for or are no longer accessible, which shakes their confidence.

We have a programme with disabled people in which we look at how they can lead more independent lives. We have seen that, through their having certain types of support, some young people become almost institutionalised and when the transition time comes, they do not have the confidence to go out and look for a job. They almost park themselves—they ask how, as disabled people, they could have a job. A key aspect is to build the capacity of individuals—of young people, in this case—to act for themselves and to have the confidence and ability to look for a job.

10:00

Pam Duncan: I will add to what my colleagues have said. The barriers that disabled people face to getting into employment and into apprenticeships, which John Mason spoke about, are complex. I suggest that the barriers do not relate only to employability—they also relate to segregation in schools, for example. I do not suggest that we should get into a huge debate about mainstream education versus special education, but if people do not see their friends at school, can they expect to see them in the boardroom or the workplace? If people are not out participating in the community—for example, in sport on a local playing field—and if disabled people are not seen as much in the community as they should be, how can we expect employers’ attitudes to change? We need to think about disabled people’s visibility and their participation generally.

John Mason: Changing attitudes is a long-term process. In the short term, should we focus on employers?

Pam Duncan: My message is that we need to focus in the short term on various things, one of which is employers—absolutely. Elsewhere, the focus has been on telling disabled people that they can go out and get work, and little has been done for employers. That is the wrong approach.

A short-term intervention could be a national Government-funded campaign with positive images of disabled people. Many disabled people face a crisis of identity these days. People must play strongly to their impairment to secure their benefits, but they must play down their impairment to get work. The time to address that huge crisis of identity is now. Something along the lines of the see me campaign, led by and for disabled people, could have a massive impact on how employers and society in general view disabled people.

Transport issues are relevant. I am pleased that investment is going into transport schemes, but we would very much like the concessionary pass to be usable on community transport. In some cases, public transport is not suitable for disabled people. If I am with my partner, we cannot travel on the same bus, because we are both in wheelchairs. Late at night, I am not particularly comfortable with hanging about at a bus stop on my own, and neither is he. There are issues to address, and transport is a crucial aspect of employment.

Disabled people's organisations have a crucial role to play. Statistics that we gave in our submission show the huge benefits of an employment service that is run by disabled people, in comparison with the workfare and work choice programmes. The statistics are staggering—when a programme was directed by a disabled people's organisation, 82.4 per cent of participants gained full-time employment, but when that was not the case, the figure was 3.7 per cent. I go back to the principle of participation, the user-led voice and user control over support systems.

Sophie Pilgrim: Most of the staff whom we employ are parents of children with disabilities and we have tried hard to employ young disabled people to run our young people's service. That has brought massive challenges for us as an employer, but it has also brought incredible benefits. We have a high-quality service because we gain from the knowledge and experience of disabled people. There is no doubt about that.

I have to consider that at any one time a quarter of our staff will be off because of the impact of disability—because they or their children are ill. I am under pressure from funders that ask why I employ parents of children with disabilities.

We also support parents whose employers are brutal about the fact that their child has a disability. Employers will not hesitate to hand someone their P45 if they perceive that they will have considerable time off work. That is happening.

To go back to apprenticeships, you have to protect places for children and young people with disabilities because, out there in society, those young people will not be given a helping hand. We will have much better institutions and employment places if we have a caring environment in which people take on board those things. That will be to the good of everybody in the longer term. The morale among everybody that comes from supportive employment is amazing.

The Convener: I am about to bring in Etienne d'Aboville, but I am conscious that Sophie Pilgrim will be leaving shortly, so I ask her whether she would like to add anything before she leaves.

Sophie Pilgrim: I will mention that, although some people are very against self-directed support, I see it as the end of institutionalisation. Some people and children are not necessarily keen on self-directed support because they might fit into a particular group or school, but many children and adults do not fit into groups, and need an individualised service because otherwise they will not get what suits them. My son has a package of care that costs about £30,000 each year. We have been able to do something very individual, which he needs because he has extreme levels of anxiety.

The packages of care for children with very high levels of disability are unjust. There is an assumption that parents will care for their children, but generally people really do not know what the impact on a family is of caring for someone with high-level disability. We see many families that are at the point of breakdown. The fundamental thing is that they do not get enough sleep because they do not get respite. I am not sure how this would work in the budget, but there needs to be greater protection for the families with the highest level of disability or medical need, because the current resources are not adequate. If the committee heard personally from those families, you would agree that the issue needs to be addressed.

The Convener: Your son is fortunate that he has the support of you and your husband, but many vulnerable people of various ages do not have the information on self-directed support to hand and do not know where to go for it. What help do those individuals need that is not there now but should be?

Florence Garabedian: As a centre for inclusive living, we provide information and support to disabled people to access self-directed support. Often, the information is there but the local authorities, for example, do not take a strategic approach to ensure that people have the right information at the right time. That is a big setback. People need independent information and they need to know about all the options in SDS. People can choose to buy a service within a group or to have more individualised support. People need the information at the right time, independent of what any of the organisations that give the information want. When we work with people we are not saying, "That would be better for you." We support the person to make the right choice, which is key.

In Glasgow and in the Lothians, the centres for inclusive living are able to give information—they do a good job. A lot of areas in Scotland do not have that information. When a person does not have the information, they do not have the options because they do not know about them. That is a huge setback.

In our written evidence, we make the point that a national scheme to ensure that each local authority has an independent service, preferably run by disabled people, to provide information and support would go a long way to making SDS successful.

Sophie Pilgrim: Florence Garabedian might not know this, but we are supported by the Lothian Centre for Inclusive Living. If you have a package of care of about £30,000 and you are employing three or four people—as well as doing your full-time day job—you are basically having to manage a payroll to ensure that people are paid on time. Things might go wrong and your personal assistants might get cross with you because of this or that. With such a big care package, you really need support from somebody who can help you with employment issues. That is often what puts people off. However, if you can get it right, you can adapt the situation to your needs much more.

The Convener: Etienne, would you like to come in on this point?

Etienne d'Aboville: I was going to make a point earlier about employment, but we have moved on, which is fine.

I suppose that I would say that we are still very much in a state of flux regarding self-directed support. Certainly what we are finding is that sometimes we get referrals from professionals and sometimes we do not. What tends to happen when people do not come to independent support organisations such as us is that they are steered towards safer options with self-directed support. As Sophie Pilgrim said, if people can make an informed choice based on what the real options are, it is much more empowering—if it is something that you want to take on—to take a much more flexible approach by putting a package together and employing your own workers. That is achievable for many more people.

We are still in a state of flux. Many professionals tend still to gravitate towards the safer options and steer people towards them. It comes back to the discussion that we had earlier about advocacy and being able to speak to somebody with no particular interest who can present the pros and cons of different options and help them make the choice that is right for them. It is about being a bit more ambitious and aspirational about the possibilities, rather than just choosing the safe ones.

Siobhan McMahon: I might come back later and ask about local authority funding. However, given that self-directed support has been mentioned, I want to turn my attention to that. The evidence that we have clearly states that the proposed budget for the roll-out of the programme for SDS will be cut from £17 million to £12 million. What are your thoughts about that, given what we just heard from Sophie Pilgrim about making individual choices? What constraint, if any, will that have on people? I heard about this recently from a public panel. Do you think that the examples that you have already given—and the examples that you will probably give—are the exception to the rule?

10:15

Florence Garabedian: The programme in the national budget is about building the capacity of organisations, of local authorities and of providers. It is not about direct care. It does not give extra money to local authorities, for example, to give more support to individuals at local level. However, the national programme is a great approach from the Government, because it has enabled a number of organisations to get ready for SDS, to have our systems ready and to ensure that we can give the right information at the right time. It is key, and we see how much thinking and co-operation has gone into getting it ready and ensuring that it works.

The funding has already dropped this year from last year, which means that fewer organisations will be able to do a good job in ensuring that SDS is a success, so again I urge the committee to highlight that. If we want people to make the right choices and to be more creative about the way in which they choose to be supported—and not necessarily in a more expensive way—they need to have the right organisations and independent information.

Pam Duncan: I am furiously looking at the statistics in front of me, but the print is far too small and I cannot read it properly—I am as well prepared as ever. The research that was done by the University of Strathclyde has found that the local authorities and voluntary sector organisations are at different stages in implementing the self-directed support agenda. It is fair to say that there is still a long way to travel, and the research recognises that. On that basis, any reduction in the budget supporting people in that transformational change is probably not good news—that is probably the softest way to put it—and something might need to be done about that.

I would like to respond to a couple of other points that have been made, before returning to local authority funding. One of the things that came up was disabled people being in employment. I would say that, if the right support is put in place for people in employment as a preventative approach, they are less likely to need time off because things will go well for them. There will be less pressure on the employees and on the employers, as Sophie Pilgrim said.

Forgive me for taking you back to another employment issue, but it must be recognised that, where social care does not meet the needs of an individual, it is often the women in the family who take on the responsibility of caring for the disabled person. In fact, what is sadder is that they expect that that will be their role, and that is something that we need to look at in terms of both equality strands—for women and for disabled people. An employment agenda could usefully look at self-directed support as a way of increasing employability across the piece for disabled people and women.

I employ PAs directly, and I do so because other disabled people inspired me to be able to do it. If I had not heard the stories directly about the experiences of other disabled people, I might have been put off—possibly not for ever, but for a while—but it was disabled people themselves who inspired me to realise that it was possible, and I had good support in place from local support organisations run by disabled people to help me do that. I employ seven people, so there are people in employment because of that. There are many different angles to self-directed support; it can support employability, and that is obviously a key agenda throughout the budget. I support that, and I think that we should consider the budget from that perspective.

Tam Baillie: Self-directed support is good in theory and gets a warm welcome for all the reasons that have been outlined, but it is a bit like the argument about the removal of ring-fenced funding. It is fine as long as there is sufficient funding, but the perception is in many instances that this is an exercise in cutting and reducing funding.

We recently hosted a conference called “It always comes down to money”, which was a quote from a parent, but given some of the other comments, we thought of calling the report “You have to fight every inch of the way” because that is what typifies parents’ experience of getting services for their children. A parent on the platform used her daughter, who has a high level of support needs, as an example. She was in dispute with the council about the level of funding and support and how, when it was converted into self-directed support, it was a fraction of the money that was required just to provide sufficient respite and care facilities for her daughter.

Some realism must be brought into what is an aspirational and excellent way of empowering people who have disabilities to ensure that they get the right care and that it is genuinely self-directed if there are sufficient funds. That is the journey that has to be taken, and people still have to be convinced that the self-directed support policy will provide better-quality services. At the end of the day, it will come down to how much money is available to put the policy into effect. I support the policy, but only if there are sufficient funds.

Tressa Burke: We welcome the SDS strategy and the act. The rhetoric around it is fantastic, but real experience is being had on the ground. I know that every local authority is in a different place, but I will take Glasgow as an example. Compared with other areas, Glasgow is dealing with extreme need and a high proportion of disabled people who have a high level of needs. There is pressure on social care budgets and it is extremely difficult to apply the eligibility criteria consistently. It is not an easy job. Many disabled people in Glasgow feel that self-directed support is a cost-cutting exercise, although that is not the intention of the bill, the strategy or the good officers who work in social work.

I am certainly not an expert and I do not know how the money is allocated internally but, from the outside, it seems as if decisions are being made according to impairment groups, and there is a perception of risk with certain groups. For example, people who have learning difficulties are seen to be higher risk and therefore in more need of social participation, whereas for people who have physical impairments, it is much more about washing, dressing and feeding and the only money that is available is for basic needs. Self-actualisation, raising aspirations, contact and civic participation have just gone out of the window. The money is just not there to do them in many cases, although I am not saying that that is true in all cases.

In relation to self-directed support and employability, there needs to be more joined-up thinking and more resources need to be put into social care. I could not tell from the budget, because I could not get into the detail of what money has been allocated for self-directed support, although I am sure that it is there. I definitely feel that it should be possible for disabled people to use self-directed support for more than just existing, which is the way that it has been experienced in some areas.

Disabled people need role models, and to have their aspirations raised and capacity built if they are even to try to think about using self-directed support or becoming employable. The irony is that, once they think about it, they might not qualify for the package of funding, there might not be a job for them, or, in the case of many young disabled people, there might be a college place for them but they have no transport and there is a battle with the college about who has to pay for it, or they might be getting disability living allowance but it is being used in a different way. People experience all sorts of complexities and barriers, but one absolute certainty is that without the support of other disabled people and disabled people’s organisations, disabled people cannot even begin to raise their aspirations to move forward.

Etienne d'Aboville: Tressa Burke has essentially made the point that I wanted to make, but let me flesh out the details a little from the point of view of the experience in Glasgow. In the past, there was a notion that self-directed support was about saving money. In my view, self-directed support potentially gives an opportunity to secure better value for money, but it is not about saving money, nor does it necessarily provide any real opportunities to save money.

In Glasgow and possibly elsewhere, as members will be aware, the local authority has tried to take a more equitable approach to the distribution of the existing money both within and between different care groups. As we understand it, the overall budget has not gone down, so what we have had is not a cost-saving exercise but a redistribution exercise. As has been pointed out, such a process will always involve winners and losers, and that is exactly what has happened. Some people now receive services who did not do so previously and some people now receive more services, but a great many people have had huge cuts in their packages.

For instance, we work with people whose package has been cut from 66 hours to 24 hours, which is a couple of days at a day centre. The impact of that is that people may lose all their social life and their opportunities for volunteering and so on. We also worked with someone whose long-standing health issues and impairment had not changed over many years, but the budget for that person, having been reviewed under the personalisation scheme, was cut by more than 22 per cent. That means that, as Tressa Burke said, the person gets access only to basic personal care and has lost all social activities. Others have been refused night cover on the grounds that they can use incontinence pads. All those sorts of issues go against the core principles of choice, control and dignity, which should fundamentally underpin the way in which self-directed support should impact on people.

That is really unfortunate, because there is no doubt that self-directed support is a good thing for disabled people. Where it works well, self-directed support is fantastically empowering, but that can be totally overridden by the lack of availability of funds. I think that the situation has become so serious that we need to take a long hard look at how we fund social care and ask questions about why, for example, we fund it differently from the way we fund health. There are perhaps historical reasons for that that we should start to move beyond. As a country, we need to take a long hard look at what our priorities are as a civilised society in providing inclusion and support for disabled people. Increasingly, I think that the only way to do that would be to set up a commission on social care that could look at such issues fundamentally. The odd percentage point here and there in the budget is just not going to cut it at the moment.

Pam Duncan: I agree with everything that has just been said. As Tressa Burke said earlier, without the support of other disabled people, it is very difficult to deal with the cuts that people are experiencing just now. I consider myself to be a particularly resilient person, but I went through the personalisation process very recently and I can honestly say that it just about broke me. It was the most demoralising, inhumane and degrading experience that I have ever had.

However, I have come out of that at the other end still believing that self-directed support is absolutely the way to deliver social care. Self-directed support delivers choice, control, freedom and dignity in a way that the disability movement has campaigned for for many years, but it does that only at the end point when you get the budget rather than at the point when you get your assessment or become eligible for support. The gruelling process that people are taken through is very difficult. Had it not been for the support of other disabled people and support organisations, I would have been broken by the system—I say that as someone who would not be broken easily.

The message that I want to convey is that, as others have said, self-directed support is the way to deliver social care at the end point. Absolutely, I think that we can mostly agree on that. However, there needs to be far more money put into the system and, as Etienne d'Aboville said, how we spend our money on social care needs to be addressed.

Regarding Etienne d'Aboville's point about existing budgets being redistributed among disabled people or service users—most of them would fall under the category of disabled people under the Equality Act 2010 definition—the money is being redistributed among an already vulnerable and particularly oppressed group of people. If we really want to consider the redistribution of resource, we need to consider redistribution across the whole of society, and not just of the resource that is targeted at or put at the fingertips of people who are already living in poverty and who are already oppressed. We must address that as a matter of urgency. I believe that Scotland can lead the way on that in Europe if we get it right.

10:30

The Convener: Does Siobhan McMahon have any more questions about self-directed support?

Siobhan McMahon: I will follow up on one point. People have answered the question about the care package and what a 30 per cent reduction in the budget will mean. I am particularly interested in the effect of SDS on working conditions for personal assistants and care workers, so Pam Duncan might be the best person to respond. Does SDS affect your PAs' working conditions given the level of funding that you have for employing seven people? The next question might not apply to you, but do you think that there has been a failure to attract the right people to the right jobs and to provide the right conditions for them when they get there?

Pam Duncan: During the process that I just described, three of my PAs changed. I lost three people and gained three new people—luckily, I attracted three other people in. There were other circumstances; that did not happen just because of SDS. My PAs' pay and conditions are pretty awful—as a person who believes in good pay and conditions for the workforce, I am embarrassed to say that. For example, they get no sick pay apart from statutory sick pay; they used to, but I cannot pay for that now.

We are experiencing that across the piece. There has been no rise in pay—my PAs have not had an increase in their salary in the seven or eight years that they have worked for me—which makes it very difficult to recruit and retain staff. Unison recently did research into the public sector workforce, and 56.1 per cent of respondents said that their pay had become worse; 59.7 per cent said that their hours had changed adversely; and 52.1 per cent said that they had been given more duties as a result of some of the funding pressures on social care. That has a huge impact on the resilience of care workers and on my PAs. I pay tribute to them every opportunity I get, as they do a very difficult job dealing with me at times, and they do not get paid enough for it. It is fair to say that that applies to disabled people across the piece.

The situation has a huge impact on disabled people themselves. When I faced a cut in my package recently, I was concerned about my own welfare—we have to be, when a cut literally means the difference between getting help to get up and go to bed or getting help to eat. I was also concerned about my PAs. I was told that, in the climate that we live in, I should realise that jobs are not for ever and that, as a responsible employer, I should never have told my PAs that their jobs were for ever. That was the attitude that I got when I asked for some guidance about what I was going to do about my staff if I lost funding.

I got two weeks' notice of the budget decrease and pointed out that my PAs were entitled to redundancy. In the end it worked out okay, but there is an adverse effect on the disabled person's ability to be resilient to some pretty brutal challenges, as well as on the resilience of the PA and whether they decide to hang about. I was lucky that my PAs hung about through all the negotiation. Because of the level of support that I and other disabled people need, PAs are often party to what is said about their jobs. I do not know how many people in this room can say that they have been party to a discussion around the reduction in their salary, before it has been negotiated. Such things are very difficult to deal with.

We must start to properly measure unmet need in the system, so that we can address it. I believe that we in Scotland are a nation of good people, who do not want to hear stories such as mine. There are good-news stories. I would like to say that mine is a good-news story, but such stories do not happen without a lot of advocacy, support, resilience and hard-won battles.

Unmet need should be recorded, and there should be serious consideration of how we fund social care as the infrastructure for equality and human rights in the future.

The Convener: Does Florence Garabedian wish to say something?

Florence Garabedian: No, thank you—Pam Duncan has covered what I would have said.

John Finnie: You mentioned unmet need earlier, Ms Duncan, but we moved on. I am trying to get my head around the issue. Did you mean need that has never been assessed, or assessed need and the difference between that assessment and what is actually delivered? Is it a combination of both?

Pam Duncan: That is an interesting question. I have sometimes been told, "Well, that is your perceived need. Your need is not unmet because we're meeting what we think it is." I pointed out that social workers are experiencing incredible difficulties, but I have also heard of situations in which they have said, "We know you need that but we can't assess you for need in that respect because our eligibility criteria are based on life and limb." When I said that I needed support to go to work, meet friends and participate in community and civic involvement and engagement activities, I was told, "We know you do but we don't fund that." Such things are never recorded in my assessment or in the assessments of other disabled people.

Although we do not want to admit failure—which I fear might happen if people start to record unmet need—we also need to be honest and say, "This is what this provision should cost us but this is all we can afford because this is the budget that the local authority has been given and this is how we've managed to divvy it up." If we do not record unmet need, we cannot begin to have honest conversations about how we are going to address the crisis in future.

Bill Scott: I just want to make a brief point about the issue that John Finnie has raised. Five or six weeks ago, I met a group of parents of disabled children in the Western Isles and was struck by the differences with regard to whether individuals and families had had an assessment. Some people had received a lot of support and had good support packages in place, while other families had been asking for assessments for six or seven years without ever getting one. How do you measure unmet need if the people concerned have not even been able to get an assessment? There is no doubt in my mind that their needs had to be assessed as parents of disabled children and as carers, and that there needed to be an assessment of the needs of siblings in the family as well as those of the disabled child. We do not know what the level of unmet need is, because those assessments are not taking place. As Pam Duncan has made clear, even when assessments take place, they do not necessarily record what the disabled person thinks their need is.

Florence Garabedian: At our staff meeting yesterday, one of my colleagues told us about an older couple with a disabled child who, by chance, heard about our services and were advised that their adult child could have an assessment. Eight months later, those people now receive support and my colleague said that the dad had e-mailed or phoned to say that for the first time in 16 years he was able to go to church with his wife and take her for dinner one evening. You might think, “Aw—that’s nice,” but some of us were quite uncomfortable and angry, because it took 16 years for that to happen.

As you know, the independent living fund is closed to new candidates but when you consider the stories of those who receive money from the fund you can see that it has made the difference between having a life and not having one.

I would like to read the committee a short paragraph from a case study of a person who receives ILF funding. She says:

> “It allows me to have a life, not just be alive. My social life is a huge part of my mental wellbeing, and ILF allows me to make choices and not have to justify them to anyone.”

She then gives a number of examples and says:

> “ILF also has a big impact on my relationships with my family. Because I’m able to be independent from them and I’m not saying ‘help me’, our relationships are much more adult, much more equal.”

Another case study is of a person who is doing some volunteering work in our organisation. She says:

> “Having the level of flexibility that 24 hour support gives me”—

she has that only because of ILF funding—

> “is very important to me—it IS me—it goes a long way to shaping who I am—because I’m not stuck, I can do whatever I like”.

She then gives a number of examples:

> “I can decide what I want to eat and go shopping for food at short notice, rather than having to plan ... I can get up and go to bed at the times I choose, and I can get up to go to the toilet during the night, rather than having to sleep in a wet incontinence pad ... I don’t have to go to the toilet to a schedule, or be fed at a time I haven’t chosen ... Survival is fine, but can I not live too?”

Not only are the health and social care funds themselves decreasing but the space provided by a little bit of extra ILF funding has been closed. That leaves a lot of people with no access to any of those things.

The Convener: Thank you very much. I will call Siobhan McMahon next, but I am conscious that other members want to ask questions. I ask our witnesses to give shorter answers to allow us to get round as many people as possible.

Siobhan McMahon: The written submissions mention a lot of examples of the things that are happening, but Glasgow Disability Alliance and Inclusion Scotland, in particular, have highlighted the 12.6 per cent increase in local authority charges for social work services. Is the prioritisation of low council tax being achieved at the expense of services for disabled people and, if so, is that justified?

Bill Scott: I think that the freeze is being funded partly through increased charges on disabled people. Put simply, you cannot have an indefinite freeze funded by an additional—but stand-still—£70 million each year that does not take inflation into account and hope that services will remain unchanged and undiminished. Local authorities have only limited means of increasing their revenue from charges, and disabled people are an easy target. The 12.6 per cent increase has occurred in the past two years; that is way above the headline rate of inflation, and has come at a time when Scottish disabled people are expected to lose around £1 billion in benefits by 2015. Disabled people are under pressure from reductions in benefits and are also having to deal with increased charges.

They might be the exception, but some disabled people are losing 100 per cent of their disposable income as a result of charges. Who in society would ever envisage—never mind contemplate—putting in place a 100 per cent tax on income above the minimum a person is required to live on? Who would ever say to someone, “You can have the £3,000 or £4,000 a year that income support says you need to live on, but anything you get above that we will take in care charges”? I know of an ex-Post Office manager on an £8,000-a-year pension—which, we should remember, he paid for—who loses more than 90 per cent of it in care charges. Why did he pay into the pension in the first place? It has not done him any good or increased his living standards. He had to retire at a very early age because of the severity of his impairments and at the moment he has nothing to help him achieve a lifestyle that a lot of the rest of us take for granted. That is what care charges do. Although they represent a very small part of the social care budget—at most, 2 or 3 per cent—their impact on the lives of those on which they are levied is massive and increasing year on year.

I know that the impact of welfare reform will reduce that revenue stream, because people will not have the money that they currently have. They will lose their disability living allowance and their employment and support allowance. At that point, the revenue will drop. What will local authorities do? Will they charge those who still have benefits even more to make up for the loss of income from those who can no longer afford to contribute?

10:45

Disabled people are disproportionately paying for the council tax freeze, which cannot remain in place indefinitely. I know that the council tax is a massively regressive tax and that lifting the freeze would have a real impact on many disabled people who are employed on low wages or who are in entry-level jobs and who, because they have a small income, would not receive any relief. As we said when we were asked about this in the previous parliamentary session, our preferred option is for the council tax to be replaced with a less regressive form of taxation rather than just that the freeze be lifted, but we need to get into that debate.

The freeze cannot remain indefinitely and will need to be lifted at some point. When that happens, there will be an effect, so we should think about what will replace the current arrangement. It does not really matter whether there is a fairer form of council tax or a complete replacement, but there must be a more redistributive form of taxation than what we have at the moment, and it must protect disabled people as well as others on low incomes. We do not want those on low incomes to be hit, many of whom are disabled people who have been lucky enough to manage to get a job.

Pam Duncan: I echo much of what Bill Scott has said. This is very much about priorities. Like Bill, we see the council tax as a regressive form of taxation, but we still believe that you need to unfreeze it because the freeze is not sustainable. As Bill said, that would have a huge impact on people on low incomes, many of whom are disabled people, but at present those people face a disproportionate impact from the freeze. We believe that that should be addressed.

On the issue of priorities, research from Professor Bell of the University of Stirling suggests that the costs of care are set to rise at three times the rate of national health service costs. That is a pretty stark figure. I think that we need to prioritise social care as the infrastructure for equality and human rights, as I said before. If we see social care as being about equality and human rights—I hope that we have been able to demonstrate that we should—not only is it unfair to charge disabled people for a crucial service that allows them to enact their human rights but it is almost unheard of to ask any section of society to pay literally just to be able to get out of bed in the morning. The issue is about dignity and human rights. We believe, and have done for a long time, that community care should be free at the point of need in the same way that the NHS is.

In the context of what I said earlier about understanding the costs of care and about the need to look at how we will fund those into the future, my message is that disabled people cannot bear the brunt any longer because they simply cannot afford to do so. We need to look at how we prioritise our funding.

Tressa Burke: I echo what Pam Duncan has said. We believe in a fair and progressive form of tax, but we cannot sustain the council tax freeze, which has meant that for the past seven years, apart from disabled people, nobody has paid any money towards what are rising costs. We feel that social care should be free at the point of delivery.

Regarding Etienne d’Aboville’s earlier suggestion, perhaps a social care commission could be located within another commission such as the Equality and Human Rights Commission or the Scottish Human Rights Commission. We need that commission to undertake a specific piece of work on why social care is a rising tax paid for by disabled people and by no other part of society, whereas, due to historical legacies, the decision has been taken that education, health and other services should remain free. I am not saying that those things should not be free, but we should consider the issue by looking at how all society’s resources are allocated.

Etienne d’Aboville: I would like to make a couple more points about the impact of charges, but I endorse what has been said.

There is anecdotal evidence that people are stopping using services because charges are rising or being introduced, and in many areas they are being applied to more people. Locally, we are aware of support for mental health service users in community centres that are now being closed or users being charged for the use of support services and, therefore, choosing not to use those services. There are potentially hugely damaging impacts from people not getting the support that they require because they are avoiding it for reasons of charging. The same applies to other services. People who have used day centres for years and years are suddenly being charged for that service, which they are not used to.

How these things work does not seem to make any sense. Members will be aware that generally carers are not charged. We have no problem with that, as we want to equalise things downward rather than upward. However, there is potentially a danger in charging for some services but not others, as there may be services that are advocated by carers in a way that is not necessarily helpful, which can be disempowering for the individual disabled person who needs support. There should not be a potentially perverse incentive; charges should apply equally to everybody. Carers seem to be regarded as partners in care, so why the individuals who need care do not seem to be regarded as partners in their own care is difficult to understand.

A final and obvious point is that charges differ so widely from area to area that there is an issue with portability and people having freedom of movement between different local authority areas. Some people may not be able to move because in the area that they want to move into—whether to get a job or whatever—the charging policy and other local policies relating to social care mean that it is impossible for them to do so. That speaks against the move towards an inclusive and equitable approach right across the country.

The Convener: Thank you. Christian Allard will now ask some questions about welfare reform.

Christian Allard: Bill Scott and Pam Duncan have already touched on the subject of welfare reform, which is a bit of an elephant in the room. We have received written evidence on the matter including from Aberdeenshire Council, which I will speak about because it comes from the north-east and we have an organisation from the north-east with us today. It states:

> “the move to self-directed support, the abolition of the independent living fund and the combined impact of the UK Government’s changes to welfare benefits will create budgeting challenges for those with a learning disability or enduring mental health issues.”

That is backed up by the written submission from the Scottish Trades Union Congress, which welcomes the fact that the Scottish Government is trying to mitigate the changes. Do you welcome the Scottish Government’s mitigation? Is it enough, and how should it be distributed?

Bill Scott: That is a good question. We very much welcome the support that the Scottish Government has offered, which is in direct contrast to what has been happening at the Westminster level. In Scotland, there has been at least an acknowledgement of the impact of the reforms on disabled people’s lives and an attempt to mitigate it.

We know that the resources that the Scottish Government has to deploy are much less than is available at the UK level. Whether the gap is £2.5 billion or £4.5 billion, the Scottish budget will not stretch to cover it. Moreover, the Scottish Parliament has no powers to introduce benefits to replace those that have been taken away.

I fear for people with learning disabilities as an impairment group. A lot of the reforms are aimed at reducing support for those who are regarded as having relatively low-level impairment. I say “relatively” because the support that is available for a learning disabled person who is on, say, disability living allowance is only about £20-odd a week. However, that might be the difference between their being able to socialise and their not being able to socialise, and the knock-on effect on their mental health of their being unable to get out and about and meet friends will have an impact on the health service and care services. People manage their conditions and impairments so that, although they may not lead a great life, they have some level of involvement. If that is taken away from them, it is bound to have a consequential impact on how they feel about themselves, harming both their health and their ability to manage things for themselves.

The Scottish Government and the Scottish Parliament have listened and are doing things. Could they do more? Of course. I do not want to see a single person evicted because of the bedroom tax. I would like to see £50 million going into supporting local authorities to ensure that no one is evicted. Nevertheless, I appreciate the £20 million that is being provided, because it will mean that far fewer people face that situation.

I will mention one thing that I would like the Government to focus on. At the moment, a number of local authorities, including the two largest ones in Scotland—City of Edinburgh Council and Glasgow City Council—take the disability living allowance care component into account in deciding whether to award discretionary housing payments. That means that disabled people will be put at a disadvantage in the receipt of discretionary housing payments compared with non-disabled people. Disabled people will be less likely to receive support and will be more likely to end up going into arrears and being evicted. Thereafter, if they are evicted, their care needs will be far greater than those of a non-disabled person who is put in that situation and there will be an expense for advocacy and social work support.

I therefore hope that it is part of the conditions of the extra support that is going to local authorities that they must no longer take disability living allowance into account; otherwise, a lot of disabled people who need support will be denied it. That would have real consequences for them in losing the support of the community that they live in—the friends and family round about them—and, potentially, a catastrophic impact on their lives in terms of drug and alcohol misuse, health impacts and so on.

Pam Duncan: I agree with all that Bill Scott has said. We spoke earlier about employability and transport, and those are two other things that could use some investment to mitigate the welfare reforms. If people are able to get to work, that is one way of mitigating some of the impacts of these extreme and brutal reforms. That goes back to what we said about employability and financing community transport so that people can use concessionary cards on it.

I feel as though I am saying this a lot—forgive me—but another thing that could be done is to increase the level of funding in people's pockets not only through employability and transport but by reducing or abolishing the community care charge.

Those are three tools that the Scottish Government has among its resources. I hope that it will use them in mitigation alongside the considerable resource that has already been committed to mitigating the bedroom tax.

Christian Allard: Florence Garabedian touched on the withdrawal of the independent living fund, which will close in 2015. We have received evidence saying that some local authorities think that it may be better to wait and see what the impact of that will be. Do you think that the Scottish Government has put in place sufficient funds to meet the gap created by the withdrawal of that fund?

Florence Garabedian: We do not know how much the Scottish Government will be able to add to the fund. As we understand it, the Scottish Government will try to protect the current recipients of the ILF, but that will happen only if it gets the right deal in negotiations with Westminster.

Some of our organisations have run consultation events on the situation with the ILF and to respond to the Scottish Government's current consultation. People are saying that it is really unfair that the fund is now closed to new candidates. Furthermore, if the fund is transferred, it should not go to local authorities at any cost; it should go to an independent organisation or structure of some kind, so that the funding stays with disabled people and is not lost in other big budgets.

11:00

Christian Allard: Do other witnesses on the panel agree?

Etienne d'Aboville: Absolutely. The ILF has undoubtedly been a very good thing for disabled people over the years. It was arguably the first direct payment. The key element was its ability to provide a much more flexible additional layer of support above what local authorities were able to fund under the existing criteria.

It would be fantastic if the Scottish Government could effectively fund a replacement version of the ILF that could provide that support. As we were saying earlier in relation to social care, it is difficult to see how the flexible, more social-based elements of people's packages, which are so crucial to what we understand as regards independent living, are going to be funded, although we would want that to be part of an entitlement-based system. Ideally, people would want the Scottish Government to be able to fund a full replacement for the ILF. Otherwise, we will return to a situation in which some people are getting access to the additional supports and some people are not, which is not fair.

Bill Scott: In effect, the fund has been closed to any new applicants for three years. There are people who acquire impairments or whose impairments become of a higher order as they get older.

The massive losers from the closure of the fund to new applicants have been young disabled people. That is a growing problem. The very people whom we were talking about earlier—those entering a transition phase in their lives—are being denied the support that could enable them to go out and work. Without that support, it is almost impossible for them to do that.

Pam Duncan could testify to that point. If she had lost an even larger part of her care package, she would not have been able to continue in employment, and she would not have been able to contribute as a taxpayer. All of those things are in jeopardy if people cannot get access to that support.

We very much welcome the protection—hopefully—of those who are already fundholders, but something needs to be done for the younger disabled people who will lose out and who have already lost out.

The Convener: We will now move on. Marco Biagi would like to ask some questions about children with disabilities.

Marco Biagi: We have already touched on the specifics with regard to children. Could Tam Baillie tell me which spending allocations in the budget he would identify as being crucial for childcare and support for disabled children? How could they be improved?

Tam Baillie: The Government is quite non-specific about funding allocations for children with disabilities. In the budget, they tend to come under getting it right for every child, as is the case with many other vulnerable groups for which local government has responsibility.

We have conducted our own research on the matter. In relation to questions about the impact of the austerity measures on local authority allocations, we did a freedom of information request and we carried out some analysis about expenditure at a local level. We did not find a lot of evidence about reductions in budget allocation at a local level, but we did find increased demand and that budgets were expected to go further. Therefore, despite what was said earlier regarding unmet need, budgets are having to go further.

The real lack of consistency regarding assessments and the services to be provided was touched on earlier. The conclusion, in our eyes, was that local authority services were not really being impacted but that individual families were bearing the brunt of what was occurring.

When we went back to speak to service providers, parents and young people, we got a different and much more worrying picture of what is happening. Almost nine out of 10 of our voluntary sector providers described cuts in services and said that they were having to be more frugal in the allocation of services and were having to bring in waiting lists.

In every focus group, parents described the reduction and withdrawal of services, often without any consultation or reassessment. Those changes were driven by financial considerations rather than based on the needs of children.

John Finnie asked about unmet need. There was a particular gap in opportunities for social interaction for children. Most of our legislation in the area is about additional support needs and education, and there is little focus on the opportunity for children to mix outside school. There is a dearth of such provision for children. If one area needs urgent attention, it is how we provide the opportunity for social interaction for children and young people with disabilities outside the school setting.

By and large, the feedback about schooling was that the children liked the schools. Despite the fact that we know that there have been some reductions in services and that there are tighter budgets, children’s feedback on their school was generally positive. However, the feedback on their lives outside school was that they are desperately lonely and isolated. That is bad for their development.

Marco Biagi asked specifically about the lines in the budget, but they are not specific enough to comment on because, although they tend to refer to children and family services with some commentary about the commitment to the enactment of additional support for learning, they do not put a budget beside that. That is the way that the budget is constructed.

Marco Biagi: If increased demand is the major driver, what does your research show is causing that increase?

Tam Baillie: Some of the increased demand is noted through the voluntary sector, because of the decision by local authorities to react to the situation by concentrating on those for whom they can provide services. That has a knock-on effect for voluntary sector providers. It may be that we are getting better at the assessment of need and that needs are being exacerbated because families are under pressure as a result of the welfare reforms. The knock-on effect is difficult to measure right now, especially when we know that families will be put in more difficult circumstances because of the withdrawal or reduction of benefit.

I do not think that there is one particular reason for the increased demand, but the general picture of people having fewer employment opportunities and benefits puts additional pressure on families and perhaps restricts their capacity to care for their children with disabilities, whereas previously they would have been in a better position to do so.

John Mason: You mentioned the voluntary sector. Is voluntary sector provision patchy around the country? At the Finance Committee yesterday, I got the impression that the relationship between the voluntary sector, the council and the NHS is good in Highland but maybe weaker in Glasgow.

Tam Baillie: I cannot comment on individual local authorities, but I can comment on two counts.

First, when we did the trawl of local authority provision it was clear that there are inconsistencies in the application of thresholds for access to services. Beyond that, when we speak to voluntary sector colleagues we find that there is consistency in the squeeze. Many areas of our provision for children and young people—not only this one—are characterised by patchy services.

One of the main challenges is to get consistent application of what is sometimes quite good legislation. For example, the application of the additional support for learning legislation is very patchy across the country, as is the implementation of many other areas of policy.

Two weeks ago, I visited the local authority in Dumfries and Galloway and learned that it runs a social evening for youngsters with disabilities. The event is heaving—actually, those who put it on almost cannot meet the demand—but the fact is that that sort of event is unusual. There are very few areas in which provision is driven by workers recognising a need and making provision for it.

In any case, these are the sorts of things that get squeezed when budgets are tight. Because they are not part of an individual assessment and do not fall within a statutory responsibility, they suffer when there is insufficient money to go around, even though we know from the very strong feedback that we get from the children in those situations that they are exactly the services that they need and want and which, as far as I am concerned, are central to their development.

Marco Biagi: I wonder whether I can seek the convener's indulgence to go on to a slightly different topic.

The Convener: Yes.

Marco Biagi: We have talked a lot about the care needs of disabled people, but what about their clinical health needs? Has that provision been tightened in the same way and have disability groups had issues in that respect?

Pam Duncan: Only 39 per cent of disabled people say that they are in good health, compared with 92 per cent of non-disabled people. We need to look at that; in fact, when we gave evidence to the Health and Sport Committee on the Public Bodies (Joint Working) (Scotland) Bill, we said that, in order to get health and social care integration right, we need to get disabled people and their organisations around the table to help make decisions.

As I said earlier, disabled people can use their ability to innovate and strengthen the decisions that are made. Their involvement should not be just a case of being able to tick a box; we can help you to get these things right. After all, if disabled people had been involved in designing buses back in the day, we would not now be having to replace the fleet. That might sound flippant, but it is an important example.

It is really important that disabled people and their organisations are resourced to represent disabled people at these levels and to be able, at the very beginning of the process, to discuss changes to the way the health or social care system works. We acknowledge that in a time of fiscal pressure a guarantee of the same funding for equalities and the third sector is better than a reduction, but we also know what it means in real terms.

Something that we have tried to get across this morning—successfully, I hope—is the value of disabled people's organisations in bringing the unmitigated voice of disabled people to the decision-making table. That is essential, and I would like to think that the Government will consider how it funds our organisations into the future, particularly through the equality and third sector budgets, to ensure that we can bring that lived experience directly to the table in the hope that we—by which I mean the public sector, not just disabled people—can get things right in the first place and do not have to spend lots of time and energy going back over things and trying to get them right at the end of the process.

Bill Scott: There is direct evidence that the health of learning disabled people, in particular, is very badly impacted; for a start, their life expectancy is 20 years lower than that of the general population.

In that respect, a number of factors are at work in the structure of the primary care side of the health service. The demand for primary care services is growing, partly as a result of the DWP's insistence on assessing every disabled person to death—in some cases, quite literally—for disability living allowance, the new personal independence payment and the employment support allowance.

Individuals will not be assessed for those benefits just once; instead, it is envisaged that they will be assessed every year or every couple of years—and there are literally hundreds of thousands of people to be assessed. If all those people lose their benefit, they are going to go to their general practitioner for medical evidence to get it reinstated. That, in turn, diverts the GP's time from healthcare into form filling and letter writing in support of the disabled people who have lost their benefit.

I do not disagree with that activity—after all, these benefits are essential to people's health—but a large amount of time will be diverted away from primary health provision into form filling. Is that really how we want to go forward with the disabled people, the sick and those with long-term conditions in our society?

11:15

As a result, the length of the consultation becomes important. For a learning disabled person or someone with a communication impairment, a 10 or 15-minute consultation might not be long enough for the GP or whoever is seeing them to identify the underlying problems—or, indeed, the problem itself. That is why many learning disabled people, who have no advocacy support in place and are unable to explain how their health is being affected, are not given the treatment that they need and therefore die earlier than they should.

The health of disabled people is being impacted on. Unfortunately, welfare reforms are part of that impact; in fact, their impact is likely to grow because a disproportionate number of disabled people live in social housing in deprived areas that have the fewest primary care services. The inverse health ratio is at work here: there are two to three times as many GPs in affluent areas as there are in deprived areas. Given that this growing demand is not going to be met by primary care providers, we need not only to restructure the benefits system but to take a fundamental look at the delivery of primary care.

Tam Baillie: Parents have reported reductions in, and longer waiting lists for, occupational therapy, physiotherapy and speech and language therapy services. Even when services, particularly in speech and language therapy, are provided, children have found their previous two hours a week becoming two per fortnight. Services are still being provided in theory, but they are stretched and are not having the same impact on or benefit for the child. In short, parents and children themselves are reporting reductions not only in social care but in some healthcare services for children.

Tressa Burke: Building on what has been said already about disabled people and health, I would like us to consider a holistic view of health and an approach in which we meet health needs in a preventative way through, for example, the reshaping care for older people model.

In Glasgow, where the need is so great and where life expectancy, particularly for those with long-term conditions, is a lot lower, health and social work, the independent sector and the voluntary sector—or what is now called the third sector—have seen the need to carry out preventative work sooner and are working very closely on that model.

As disabled people, we make a plea for that strategic approach to include the resourcing of disabled people's organisations because of the need for the peer support, advocacy, self-advocacy, capacity building and aspiration raising that we mentioned earlier to help people move on in their lives. All of that has not only intrinsic value but value in achieving positive outcomes, reducing inequality and improving disabled people's life chances.

The Convener: As members have no more questions, I thank our witnesses for coming along and giving us their evidence.

Our next meeting will take place on Thursday 31 October and will include evidence from the cabinet secretary on the Scottish Government's 2014-15 draft budget.

Meeting closed at 11:19.

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