

Cross Party Group on Carers

Committee Room 2

22/03/2102

Note of Meeting

In attendance:

MSPs:

Claudia Beamish MSP (Chair)
Roderick Campbell MSP
Graeme Dey MSP
Nigel Don MSP
James Dornan MSP
Bill Kidd MSP
Fiona McLeod MSP –represented by Drew Cassidy
John Mason MSP
Sandra White MSP
Humza Yousaf MSP

External Organisations/Individuals

Simon Hodgson, Carers Scotland
Suzanne Munday, MECOPP
Shona Bartoff, MECOPP
Wendy Laird, Carer
Linda Allan, Greater Pollok Carers' Centre
Christine McFadden, Carer, Glasgow
Janice Clark, Carer, Glasgow
Helen Dolan, Carer, Glasgow
Kathy Jagger, Carer, Glasgow
Christine McFadden, Carer, Glasgow
Teri McCue, Carer, Glasgow
Colette McCann, Carer, Glasgow
Vanessa Dallas-Ross, Direct Payments Service, Dundee Carers' Centre
Barbara McGuire, Direct Payments Service, Dundee Carers' Centre
Lynn Williams, The Princess Royal Trust for Carers
Catriona Tucker, Glasgow West Carers Centre
Linda Beazely, Carer, Glasgow
Erin Townhill, SIAA
Moirá Oliphant, Scottish Government
Craig Flunkert, Scottish Government (speaking)
Craig Scott – shadowing Graeme Dey MSP
Brett Millett, parent carer, Glasgow
Ian Hood, Learning Disability Alliance Scotland
Dougie Wands, Clerk to Health and Sport Committee
Dave Clark, East End Community Carers (Carers' Centre)
Joe Canavan, Carer, East End Community Carers
Danny McGhee, East End Community Carers
Violet Keenan, SPAEN

Lesley McLaren, PAMIS
Claire Cairns, Coalition of Carers in Scotland
Carolan Connolly (Speaking)
Evelyn MacIver (Speaking)
Cherie Rodney, Carer, East Renfrewshire
Ann McKenzie, One Parent Families, Scotland
Sharon McIntyre, First Hand
Trish Dunlop, Equal Futures
Linda McLeod, Edinburgh Carers' Council
Florence Burke, The Princess Royal Trust for Carers

1. Welcome

Claudia Beamish MSP convened the meeting and began by welcoming carers and carers' representative organisations attending. She also mentioned MSPs in attendance.

Claudia outlined the programme for the event and welcomed the speakers. She outlined the purpose of the meeting which was to focus on Self Directed Support and in particular the Social Care (Self Directed Support) Bill, currently in stage 1 of its journey through Parliament. Claudia outlined the importance of the Bill for both service users and carers and welcomed Craig Flunkert from the Scottish Government team leading on the Bill to the Cross Party Group, attending to provide an outline of the Bill, its' provisions and its timeline.

2. Craig Flunkert, Scottish Government – The Social Care (Self Directed Support) Bill

Craig Flunkert thanked everyone for the opportunity to speak to the Cross Party Group on Carers about the Social Care (Self Directed Support Bill) and emphasised that he was keen to take questions and hear people's views during his input. Craig provided hard copies of his presentation. Electronic copies are available from Lynn Williams, Secretariat for the Cross Party Group on Carers – lwilliams@carers.org.

Some of the key points from Craig's presentations:

- (i) The vision for Self Directed Support in Scotland underpins the provisions of the Bill – *"The quality of life of people who require care and support is improved through increased choice and control over the support they receive."* The Bill is about 'putting people at the heart'.
- (ii) The team driving the development of the Bill for the Government are clear about what Self Directed Support means and what it should mean for people. This is an "enabling Bill" and it should lead to:
 - Increased choice for all and increased control for those who want it – this should be the norm and should also apply even where people continue to receive direct support from local authorities and don't opt to manage things themselves.
 - A focus on values and practice, not excessive rules and regulations
 - A genuine mainstream approach at the heart of integrated health and social care
 - Choices for people – direct payment; individual service fund or more choice/flexibility in arranged services.
 - Maximum flexibility in how budgets are used to meet outcomes
 - SDS being open to all people eligible for social care.

- (iii) The rationale for driving real change in how people access social care arises from changing requirements and expectations, the wider drive to reform public services and the fact that for many, current service configurations do not always meet people's needs.
- (iv) Craig outlined **key aspects of the Bill**, including:
- The *key principles* which underpin the Bill – collaboration, informed choice and involvement.
 - *Duties on local authorities* to offer choice (Section 3 of Bill) and to act on the choices of individuals (Section 9 [2]).
 - Duties on local authorities to provide information and advice to support the above (Section 8).
 - Power to provide support to carers, but duty to offer SDS options for that support (Section 2).
 - Assistance provisions (Section 5)
 - Bill will take account of AWI best practice
 - Bill should be about unlocking 'creativity'.
- (v) Craig also outlined that work will be carried out to provide regulations and guidance to support implementation of the Bill.
- (vi) *The Bill's provision for carers is discretionary* – local authorities will have a power to support carers following a Carers' Assessment, and on the back of this, they must offer carers the same choices as service users. There should be a focus on prevention, to support the carer in their role. The rationale for making this a power as opposed to a duty lies partly down to cost and partly down to the need to unlock the creativity of front-line social work practitioners, giving them the discretion to make their own professional judgements.
- (vii) Craig raised the issue of finite budgets within social care and that that others have a role in providing support to both service users and carers other than social workers. Professional judgement and freedom for social care professionals is important.
- (viii) Funding to support Bill implementation will be in place; funding to drive real change in social care linked to the Self Directed Support Strategy has just gone out to a range of organisations.
- (ix) A group of representative organisations and individuals have been working with the Scottish Government in preparing the way for the Bill. The Bill was introduced to Parliament in February 2012. The Bill will be scrutinised by the Health and Sport Committee; it has called for written evidence for Stage 1 and will also call for oral evidence. A site visit to meet people who will be affected by the Bill will take place in Glasgow in May. This will be for Stage 1 of the Bill. A Stage One Debate will take place in September 2012, Stages 2 (Amendments) and 3 of the Bill will take place probably between October to December 2012. Commencement of Bill/enactment Autumn 2013.
- (x) Craig opened up to the group for wider discussion and questions. MSPs and others in attendance raised the following points/issues:
- *Sandra White* – discretionary powers could lead to continued postcode lottery of support for people if local authorities interpret this in different ways. Craig highlighted that local diversity could be good as it meets the needs of local populations. However, where

there are already in place ways in which people can challenge LA decisions and appeal – complaints, through ombudsman and through judicial review. Sandra also asked about the plans for integration and how this would sit with Self Directed Support. Craig emphasised that the details around integration were not in place yet, however people do have joint health and social care budgets and that the Minister has highlighted that people who get integrated support in this way could get access to SDS.

- *James Dornan* – raised concerns about need for Bill to change Local Authority practices in providing social care, and that in some cases, personalisation of services was masking cuts in budgets. Craig responded that having a personalisation as a cover for ‘cuts’ was not a good one – people know that LA budgets are being tested. In reviewing packages of support, it is important that there remains focus on outcomes which people want to achieve.
- *Lynn Williams* asked why there was only a discretionary power to support carers given their crucial role in the health and social care system. Craig responded that the decision to include only a discretionary power was largely down to affordability but also that having a power left Local Authorities flexibility in how they offered support to carers.
- *Nigel Don* asked about how people would be supported where the individual who gets support was unable to make a decision about the support they received and what this might mean for their carers. Craig pointed out that the Bill looks at the issue of carers in situations where there are adults who need additional support to make a decision due to brain disorder or difficulty communicating due to physical disability. It recognises that people will need support in this situation to make effective choices and that local authorities should proactively involve the right people, including family members, to help an individual access the right support. This could include unpaid carers.

- (xi) Craig also highlighted that there would be training in place for social care professionals around the requirements of the Bill – workforce capacity and support is a key element of planning for implementation should the Bill become law.

3. SDS – The Carers’ Perspective

- (i) Carolan Connolly and Evelyn Maclver shared their own views and experiences of Self Directed Support. Both are from Glasgow. Carolan has undergone the review process for self-directed support for her daughter. Both have provided written copies of their input to the Cross Party Group (see appendix to minutes).

Carolan Connolly

- (ii) **Carolan** highlighted that for her and her daughter, having access to Self Directed Support was a relief as it let them access the type of support which worked best – i.e. “no more square peg, round hole” support. She emphasised that she and her family wanted SDS and saw the benefits for her daughter.
- (iii) However, as part of the review process undertaken by social work staff in the move towards personalisation, a Self Evaluation Questionnaire was used which did not ask questions relevant to the support needs of her daughter or Carolan’s needs as a full time unpaid carer. Carolan stated that there was an assumption made that she, as her daughter’s main carer, would pick up the gap in provision (see Carolan’s input in appendix).

- (iv) A subsequent reduction in the budget received for her daughter's support means that Carolan is now providing additional care. This has impacted substantially on her own health and wellbeing.
- (v) She feels strongly that there was no real choice for her daughter or her family. The SDS Bill remains a real opportunity to end the post code lottery out there. In its current form though, it adds nothing to existing rights and indeed in her situation, her rights were not taken into account. Her current situation is not sustainable –as a carer she is not being effectively supported. The budget for her daughter's care was cut despite her having the highest level of need according to existing eligibility criteria.
- (vi) Carolan pointed out the cost effectiveness of supporting carers through her own situation –

“Without my support the Local Authority has a duty to provide 24/7 care to my daughter, the average cost of £135,000 per year. This would only be to replace my support - her risk assessment of requiring 2-1 support could potentially double this figure. If the Local Authority has indeed to look at best value then currently my support is free. It will be up to them for how much longer this support is sustainable.”

Evelyn Maclver

- (vii) Evelyn talked about the Self Evaluation Questionnaire used in Glasgow, and that those overseeing the allocation of resources for care packages could override the views/wishes of both carer and cared for.
- (viii) She felt that the way the process was developing in Glasgow meant that carers had to share every aspect of their lives and their caring situation in order to get support – sometimes carers do not want to do this. For them it is about looking after a family member, being a mum/dad etc. By not sharing their full situation or outlining caring responsibilities, there was a risk that support would not be provided or indeed cut.
- (ix) Evelyn highlighted the closure of the Independent Living Fund and the impact this would have on packages of support.
- (x) Evelyn felt that in some cases, the views of carers who had powers of attorney/guardianship of a loved one had not always been taken into account. She also highlighted worries about a new charging regime for day care and rigidity in how services are delivered which meant that carers had to use more days of their respite allocation than the actual length of the break e.g. a break of five days might mean carer actually having to use double that due to how provision was planned.

4. Discussion points following input from Carolan and Evelyn:

- (i) *Rhona Maxwell*– highlighted the importance of social work training and that identifying best practice was critical.
- (ii) *Jackie Doig, Enable* – There is no real point in giving parents/carers and service users a choice if there is nothing to choose from - no providers or choice of provision. A trial voucher scheme for respite in Perth did not work as there was no real provision from which to choose. There is very little real support especially for parent carers.

- (iii) *Linda Allan, Pollok Carers Centre* – The capacity of organisations supporting carers must be considered. Carers will look for effective information and advice around personalisation/SDS. The centre is already gearing up for this and delivering training for carers around SDS. This could not have happened without additional investment through Carer Information Strategy funding.
- (iv) *Kathy Jagger, carer* – Kathy pointed out that SDS had not been a bad experience for all carers. She had a good relationship with her social worker and has a good package in place for her son. But package is not perfect and is not necessarily meeting outcomes identified for her son around development of life and independent living skills.
- (v) *Cherie Rodney, carer* – SDS has worked extremely well for her son who has a brilliant package of support. Her son lives independently.
- (vi) *Ian Hood, LDAS* - All local authorities are taking different approaches to developing the Self Evaluation Questionnaire mentioned by both Carolan and Evelyn. All have different Resource Allocation Systems too. The postcode lottery of support continues. Can we learn from streamlined guidance in England?
- (vii) *Suzanne Munday, MECOPP* – For BME communities, SDS can be used to transfer support which can be managed e.g. as a cooperative. There is still a strong discretionary element to SDS in terms of being able to employ a family member to provide care. For some in BME communities this is a solution which meets their needs and which under current guidance they may not be able to access. Another element which the Bill needs to address is around portability of care assessments/packages, especially for gypsy travellers.
- (viii) *Evelyn McIver* – A lot of families and carers are still not aware of SDS and what it can mean. In Glasgow it will affect everyone. Communication remains a key challenge therefore, e.g. despite going through the review process and being awarded a personal budget, some individuals are turning up for day care places and being turned away as they are no longer funded by the LA. People need to fully understand the implications of SDS for their current packages of support.
- (ix) Other points raised included:
 - The transition from children's' to adult services remains a significant issue for many families.
 - John Mason MSP highlighted that there remained a tension between SDS and provision through day care centres – shouldn't there be a place for both? Evelyn and Carolan highlighted that in some cases review of day care provision actually took away some the genuine choice for families which used and valued this type of support. Local Authorities need to create choices for carers and cared for.

5. Date of Next Meeting

Lynn Williams summed up key points from the meeting as both Co-Convenors had to leave due to parliamentary business. She asked all attendees to express their thanks to Craig, Carolan and Evelyn for their input and for taking the time to attend the meeting today.

Date of next meeting - This is still to be confirmed. It is likely to be in June. There was a willingness amongst those in attendance to focus on the Self Directed Support Bill again. Suzanne Munday

from MECOPP has agreed to deliver her planned input on work with BME carers/self-directed support to this meeting. Details will be confirmed.

Appendix - SDS – The Carers' Perspective

1. Carolan Connolly

Personalisation

Control, Choice, and Independence no one on the Earth could refuse this!!!!

From the outset my family knew the Local Authority Day Services that was offered would not be able to support our daughter however as this was the only option on offer when she left school that would provide the transport, high ratio of staffing and activities she required we had no choice but to accept it. .

It was clear to everyone involved in her care including Health and SWS that without access to activities and the stimulation these offered, her health physically and mentally would deteriorate. As carers, our life was already stressful, caring for someone with very complex need such as those our daughter presents require a lot of multi-tasking. She has numerous Physical disabilities; is profoundly deaf and registered blind. She also has health needs such as epilepsy, asthma and water on the brain. These among numerous others present us with very challenging caring responsibilities. I have multiple hats, the cleaner, nurse, social worker/care manager, chiroprapist, lawyer, accountant, although I have no qualifications for any of them. My only qualification is to be mum.

The hardest part in supporting her is she does not understand she is disabled, no one can tell her she has limited balance, she just stands up and walks, It could be said this is also due to a severe learning disability and due to this she is functioning mentally at the age of 1 years and 9 months. She has never slept through the night from she was a baby and is still up between 4 and 5 times a night. When my daughter left school the choice was not easy but we knew in order for us to continue supporting her and adequately parenting our other children we could not support her care 24/7 365 days per year. The day service opportunities for her were a mechanism for us coping or not coping. I have received direct payments on her behalf for the past 7 years for respite and home supports. It was our wish all along to have the same for the day service. For us it was simple, move the funding from the building based service and transfer it to a direct payment. But the Authority found it difficult.

When I heard about SDS and the opportunities this would offer relief is among many of the words to describe how I felt. Finally a chance for us to support our daughter with a service that would be personalised and tailored to her needs, no longer would we be banging on square pegs to fit them into round holes.

However it quickly became apparent we need to be very careful what we wish for.

My daughter's needs had not changed, our needs had increased due to our own health difficulties, and the funding offered was decreased. Her Single Shared Assessment was disregarded and replaced by a Self -Evaluation Questionnaire which had numerous questions she was unable to answer and did not ask the questions relevant to her support needs. We were advised we had to reduce some of the hours of support that were given during her attendance to the day service to fit her needs within the indicative budget.

When I asked the Senior Social Worker how they were proposing to support my daughter I was told she has a carer, me!! Her 2-1 support needs when she is ambulant were not taken into consideration and we were told to strap her into her wheelchair and this would save the requirement of 2 people to

support her. There was also discussion around employing a domestic as this would be a cheaper option instead of adequately trained staff and I could support the domestic.

I have highlighted these issues only to remind everyone this is not what is believed Personalisation and the SDS process offers. We know what personalisation offers, it allows us Choice, Independence and Control it will enable her to have a good life. I was hoping perhaps through adequately supporting my daughter this will also support me. I wish to return to work, or further my education for future working prospects.

My daughter requires constant care and support 24/7 we were not willing or able to provide additional supports to her yet this was forced upon us.

I have been told other Local Authorities are coming to Glasgow to find out how to move forward with Self Directed Support, through my experience my advice to them would be to come to Glasgow, and learn how not to do it. The first step of the SDS process is an adequate assessment of needs, without this Personalisation will not work.

I constantly hear from the Scottish Government and MSP's we will try our best but we can't interfere in Local Authority business. This part I clearly understand however what I can't understand is why when given the chance to be in control and fulfil a commitment to unpaid carers, Why would our Government choose not to strengthen a bill that they have control over and mean that Carers do have rights in Scotland. The SDS bill does not offer Carers anything different from the current legislation. In Glasgow I am constantly reminded I have the right to an assessment but no right to support.

This bill is the only hope that carers have in Scotland that could prevent the post code lottery.

I not only have the physical responsibility to my daughter as her Carer and the moral duty as her mother, I also have the legal duty as her welfare guardian to promote her wellbeing.

Glasgow City Council has decided they will use me as resources; they have reduced funding previously provide even though my daughters needs meet the critical eligibility.

I have advice for Glasgow and any Council who choose to use these tactics, there is not a social worker or Judge in the land who would disagree that the best place for my daughter to live is with her family. As the welfare guardian I have a legal duty to make that decision. Without my support the Local Authority has a duty to provide 24/7 care to my daughter, the average cost of £135,000 per year. This would only be to replace my support her risk assessment of requiring 2-1 support could potentially double this figure. If the Local Authority has indeed to look at best value then currently my support is free. It will be up to them for how much longer this support is sustainable.

I agree with the whole principle of Personalisation and SDS being a good step forward, and I know this because I have now been a recipient of SDS on behalf of my daughter for over a year, I can tell you it offers individuals like her who have extremely complex and changing needs a better life not just a better service. I disagree however that it is a money saving prospect and our daughters care as it currently is, is unsustainable due to our inability to keep providing additional care and support. I think through the SDS agenda all Local Authorities have been given a chance to make a difference to the lives of people who require their support, however for my family we are just unfortunate to live at the wrong post code.

Please remember Carers are only a sustainable resource with adequate support. They are not asking for a hand out just a hand up to enable them to be active partners in care and potentially save the state billions.

2. Evelyn McIver

Hopes and Aspirations for my daughter's future as regards to Personalisation

The Glasgow Model

As the single and elderly parent of a daughter with Profound Physical and Learning Difficulties, I was keen to subscribe to the idea of a better life for her after reading and being made aware of the prospects of a more individualised and person centred package which would reflect her needs and wellbeing

After being involved in various committees and meetings I am now beginning to have grave doubts about the ethos behind Glasgow City Council proposed implementation of the way forward and seriously concerned about what methods they have used to achieve their goals so far.

You may be aware that GCCSWD have at this time had ten versions of the SEQ and as yet this still does not take in the particular needs of the individual with complex needs nor gives any faith in the fact that this document, even after being completed by a "service user", a care manager/worker will still have the ability to override their and their carers opinions. There is no way of conveying accurately or indicating the actual physical requirements of the individual apart from a section on each page which you can narrate to try and advise the particular needs of that person so that the care manager/worker when putting their opinion in the document for scoring hopefully takes cognisance of .

(2)

You must remember that no-one knows their cared for like the ones who care them. Also remember that the stress that carers are under sometimes means that they do not always want to let social workers know what life is really like so it is imperative now that all carers are made aware of being "private" may mean that a further burden of care is placed upon them and what little "day respite" they have will be seriously compromised in the future.

My other and very important complaint is that although many service users relatives have Welfare/Financial Guardianship in a great number of cases this has not been taken into account and their opinion has not been sought even although they are known to the SWD and service providers. **This is totally unacceptable** There is no excuse for this total lack of procedure, disrespect or total ignorance of a legal procedure of which GCCSWD and service providers are well aware of the law regarding this They should be acting accordingly and not riding rough shod over people's rights as regards the care and decisions taken about their children/brother/sister etc.

We are still in the dark as to what the "New Charges" will be for a day service place for our cared for and what would be available to them (transport, therapy facilities etc.) GCCSWD has had at least a year and a half to get this in place and as yet has failed to do as originally

the Care Management Pathway should have started some six months ago . As of today we have not been informed of any progress that has been made in this field.

(3)

To all carers and user of services apparently there has been a Portal designed to make these choices and costs accessible to all that have access to the internet . This has been ongoing for at least a period of nine months but to no avail. We have already stated that this must be on printed option also. However Glasgow Life are rising to the challenge and are collating all "clubs" and facilities in the City of Glasgow. The same applies to Respite Care Homes and Outreach Services available . At present the system is so rigid and inflexible that respite is being wasted for service users to benefit the administration of the provider. If a carer wants to go on a holiday and the plane /bus leaves at 11am on Monday and arrives back in Glasgow at 11am on Friday you would have to take respite from the previous Friday until the post Monday. This effectively means that to enable a carer to get a holiday from Monday to Friday 4/5 nights they have to use 10 days of their respite allocation. Who benefits out of this , not the service user nor the council but solely the benefit provider. Would you buy a break like that !! The service provider has had more than enough time to work out their costs. If this was a commercial company they would be out of business a long time ago. You cannot expect people to make decision with their children for the future and agree to a personalised budget if they do not know how much it will cost and if indeed they will have the finance to enable them to take part.

(4)

Where are the service users with complex needs going to get their Physiotherapy, Hydrotherapy Rebound etc . A great number of these service users have complex needs and require therapy intervention as a necessity but the trick is to make it a fun time whilst looking after their general health. At present we are lucky to get a block of eight weeks Hydro and less if the pool heating is not working or being maintained or the physio is off or there is no transport to take them there. The rebound has been in an upstairs room or in a room whose ceiling is deemed to low. Sports facilities are unavailable to us during school holidays or competition times. No adequate facilities for changing and lowering into a number of swimming pools ETC ETC ETC

Personalisation could and should be a wonderful opportunity to ensure a fair minded and non-discriminatory example of what can be achieved for and by people with learning disabilities. The Glasgow model could be what is needed but the fact that GCC had to make substantial savings in their budget they chose to implement Self Directive Support and the budget cuts affecting the most vulnerable citizens of the city. The Scottish Executive cut of approx. 6% and it appears that the council have made swingeing cuts of an average of 20% across the board . Their justification for this is there is new demand and also that some people have gotten an increase , All of this in the name of Personalisation and Self Directed Support

