

CPG on Carers 11th March 2015 – Note of meeting

MSPs and their representatives:

Claudia Beamish

Joan McAlpine

Graeme Dey

George Adam

Individuals and organisations:

Shona Macgregor, Social Work Scotland

Lesley Jeffrey, Dumfries and Galloway Carers Centre

Lindsay Sim, Dumfries and Galloway Carers Centre

Sarah McDermott, Health and Social Care ALLIANCE Scotland

Ian Hood, Learning Disability Alliance Scotland

Gillian Fergusson, Health and Social Care ALLIANCE Scotland

Linda Jackson, The Borders Carers Centre SCIO

Sue Whisler, PKAVS

Pauline Campbell

Harry Robertson, ENABLE Scotland/North Lanarkshire Carers Together

Cat Purdie, PASDA

John Macfarlane, Renfrewshire Carers Centre

Kathleen Taylor, Renfrewshire Carers Centre

Colin Young, Health and Social Care ALLIANCE Scotland

Pauline Munro, ENABLE Scotland

Apologies

Clare Lally

Jude Clarke

Jess Wade, Self-Directed Support Scotland

John Dougan, Relationships Scotland

Claudia Beamish welcomed everyone to the meeting. The minutes of the previous meeting were proposed by Ian Hood and seconded by Harry Robertson. There were no matters arising.

It was acknowledged that the Carers (Scotland) Bill had been introduced to the Parliament on 9 March and time should be made in this meeting for initial discussion. This was agreed by the group.

As no nominations had been received, Claudia and Joan were re-elected as co-conveners unopposed. Heather Noller will continue in the secretariat role.

Shona Macgregor from Social Work Scotland spoke about the national approach to SDS implementation – learning exchanges for local authorities are taking place, and the SDS policy team at the Scottish Government are able to identify challenges as a result of these learning exchanges. Option 2 has been difficult to implement and there are specific working groups that are looking at the issues. It is difficult to capture qualitative data, but that which has been captured is very valuable.

Lindsay Sim and Lesley Jeffrey from Dumfries and Galloway Carers Centre spoke about SDS from a carer's perspective, presented in the form of a story where a carer could follow one of two pathways – the pathway with choice and control for the carer had good outcomes, but the pathway where the carer struggled did not end well. This illustrated the benefits of well-implemented SDS to carers and their families. The role of the carers' centre in supporting the carer was also explored through this pathway. The need to review the support package at times of change or transition was also highlighted. (See Appendix for full details of the pathway story.)

There was discussion about SDS based on the perspectives given by the speakers. Issues with locally defined eligibility criteria were highlighted, as examples were given about different levels of support provided in different areas. Some local authorities reduce people's budgets if they have an unpaid carer. Joan McAlpine said that there seemed to be a fear of SDS from some groups, particularly if the responsibilities were not explained well. Lesley Jeffrey confirmed this and stated that there was a lot of misinformation – the paperwork and planning associated with SDS did not always have to be difficult. It was agreed that local support infrastructures were key to this. Challenges of raising the general public profile of SDS were discussed, and the recent promotional campaign around adult support and protection was mentioned as a potential model that had raised awareness of the issues. The potential conflict of interest within local authorities was discussed, alongside knowledge that not all local authorities have been able to implement SDS fully yet.

Colin Young felt that SDS had missed two key opportunities for change – the introduction of national eligibility criteria for support, and (as a knock-on effect of local differences) issues caused when people wanted to move between local authority areas but couldn't not be guaranteed the same level of support. Claudia Beamish asked if more clarity was needed on eligibility criteria. Graeme Dey suggested that the CPG wrote to local authorities and asked what SDS signposting they undertook. The group agreed that this would be a good idea.

On the topic of carers' assessments and assessments for the cared for person, Claudia Beamish referred back to earlier discussion points and asked about people's experiences. The need for the cared for person to be assessed separately to the carer was discussed, but it was also acknowledged that if the carer is willing and able to provide care, then this would be taken into account. Shona Macgregor confirmed that assessments are about the person, but a carer is often a significant aspect of someone's life, and therefore they became a part of the assessment. Lindsay Sim discussed the differences between a plan based on available budget and a plan based on the need for support, and it was recognised that not all local authorities prepare plans that are wholly focused on need. Ian Hood pointed out that national guidance for local authorities was in place, and this should be reviewed if there were such significant disparities between local areas. Claudia Beamish suggested that the group could also write to the Scottish Government about a national approach to eligibility for support.

Discussion moved on to the Carers (Scotland) Bill, which had been introduced to Parliament on 9 March. Not many people had had a chance to read through the Bill in detail, but it was noted that emergency planning provisions were not on the face of the Bill but proposed to be in guidance. Difficulties in interpreting the crossover between provisions in the Children and Young People Act 2014 (the Child's Plan) and the proposed Young Carers Statement were also discussed.

It was suggested that Jamie Hepburn, the Minister for Sport, Health Improvement and Mental Health, should be invited to the next meeting where there could be a full discussion of the Carers (Scotland) Bill. It was also agreed to specifically invite members of the Health and Sport Committee to the next meeting so they could hear about issues relating to the Carers (Scotland) Bill.

Claudia Beamish thanked everyone for participating. There was no other business.

Next meeting of the CPG: The next meeting of the Cross Party Group on Carers will take place on Tuesday 2nd June at 1pm in Committee Room 5. Jamie Hepburn MSP, Minister for Sport, Health Improvement and Mental Health, will attend this meeting.

Appendix 1:

PARALLEL LIVES

For anyone who has seen the film Sliding Doors with Gwyneth Paltrow, they would see that one small change in a person's life can have a huge impact. It can set about a chain of events which will alter the course of not only their life but also the lives of those around them. Sometimes only we can change our own lives, however, along the way we need the help and support of others to help us achieve outcomes for us and the people we love and care for. I am passionate about Carers - I have been a Carer all my life, firstly for my sister who has learning disabilities then to a certain extent for my first husband who had some health issues and for my 18 year old daughter who has learning disabilities and severe autism. I am a strong, confident person who has a life outside of caring - this has been achieved with the help of my husband, my daughter's father, my son and the Personalisation budget which has been allocated by Social Work. The following story will serve to show how things can work out differently in life, depending on the actions of people. There are some elements in this story which are true of my life and I have used my children's names purely to make it easier for me. However, in this story I think lots of Carers will relate to the feelings, emotions behaviours and actions portrayed...

LIFE 1

MAY 2010 - THIS IS MY LIFE

My name is Lesley and I am 40 years old. I am married with two children, my son Kieran is 16 and my daughter, Darcy who has learning disabilities and severe autism is 14 years old.

Darcy is a beautiful girl, full of life and very active. We have had our issues over the years trying to get the support Darcy needed within Education, Speech Therapy etc. I found things quite hard when she was young, drinking too much wine to relieve stress and help me through what I now know was the grieving process. My husband is a very loving father and tries his best but I carry the weight of trying to do everything for our daughter and attending appointments, which can sometimes take its toll on our relationship. We rarely go out together anymore and it can be difficult to spend time together as a family as Darcy can be a bit disruptive and doesn't enjoy the types of things that my son likes to do. Our weekends were often spent with me taking Darcy somewhere and Kieran going out with his Dad.

I work part time and my employer is very understanding when I need to take time off for hospital appointments or school meetings.

As Darcy is now a teenager and will leave school in a few years, I'm very anxious about what will happen after that. She needs something in her life but I'm not sure what is out there. I'm getting too tired trying to do everything. Recently at a Carers Conference I heard about something called Personalisation so have asked my Social Worker to come out to visit me and tell me more.

I feel tired but hopefully something can be done to help

JUNE 2010 SOCIAL WORK

My Social Worker came to the house. She told me about Personalisation for Darcy and how this could help. I need to make up a plan which sounds a bit scary but she gave me details of the local Carers Centre where I can get some help and support.

I feel hopeful that something positive is going to happen

JULY 2010

I finally went into the Carers Centre. I was a bit nervous and was worried that they might think I wasn't coping, but they were fantastic and told me how they could support me as I am a Carer – I haven't thought of that before as I just saw myself as Darcy's Mum. I met with someone who will be my Support Worker and she was fantastic, reassuring and helpful. We are going to make up a plan together for Darcy as she said I know my daughter best (which is nice to hear) and we can look at what support Darcy needs and what things she likes to do.

I feel supported and positive

SEPTEMBER 2010 – WE HAVE A PLAN!

Darcy's behaviour has deteriorated a bit – I think it's teenage hormones! She has always been active and can get bored if we don't go out every day. Some issues have arisen at school which has meant extra meetings to try to sort this out. My Support Worker and Social Worker have helped me make up Darcy's Personalisation Plan and it's going to panel this month.

I feel a bit stressed but positive about Darcy's plan

CHRISTMAS 2010 – SUCCESS

Darcy's plan has been approved! I am ecstatic. We have met with some Workers from a Support Agency who are young and enthusiastic and have lots of ideas. Darcy loved them and has been out to a couple of social groups with them where she met some of her peers and made friends. My daughter has friends!

I feel – happy daughter happy Mum!

SUMMER 2011 - HOSPITAL

Darcy is being admitted to hospital. She needs a small operation and will be in for a few days. The Carers Centre have a Support Worker who is based at the hospital who has been fantastic. I didn't know that I could stay with Darcy overnight when she is in - this hadn't been discussed at the meeting with the Consultant. I was feeling very anxious and worried about leaving her but now know I don't have to. The Communication Passport which I have developed for Darcy with the help of her Support Workers is going with her so that the nursing staff can refer to it.

I feel - less anxious that I could have been!

WINTER 2011 - A NEW HOBBY!

Now that Darcy has a life of her own, I decided to find something for me. My husband and I started running - although I hated it at first, I have started to really enjoy it and have entered my first race. We joined the local Harriers and I love all my new friends - they are all so positive and enthusiastic! When I go to the club I am not a Carer or a Mum - I am just Lesley. We have been invited to a weekend away to Fort William for a race - this will be our first weekend away as a couple for ten years. I'm a bit anxious about leaving Darcy but we have overnights built into her budget so one of her Support Workers is staying in our house with her.

I feel - The beginning of something new!

WINTER 2012

What a year we are having. Darcy has now been away on holiday with her friends and their Support Workers. Although I was nervous (and Darcy was agitated about leaving me for a few days) she had a ball. They went on an activity break where they went horse riding, sledging and swimming. It is so wonderful that my daughter has friends now. Her communication has improved dramatically - her Workers are learning lots of the Signalong signs and understanding Darcy more easily. Darcy's sleep pattern has improved so much - she is so busy and active that she now sleeps all night most of the time. She is so happy to go out to her various groups and activities that I get a little anxious that she doesn't want to spend time with me so much - but then I tell myself "what other 16 year old girl wants to spend time with her Mum?" - so true!

I feel - a sense of freedom!

SUMMER 2013 - TIME TO LEAVE SCHOOL!

Darcy is leaving school this week. Over the past few months I think she has been getting to the stage where she has had enough so I feel it is time for the chapter in her life to close. We had a positive review meeting with Social Work which included a budget review for Darcy's Personalisation. They have agreed the new package, although I did have to cut back on some things and be a bit more creative - I do know they have budget constraints and it's all about working together. I found out what activities are available - Darcy has been enrolled at College and there are other groups available on the days in between. As Darcy has become a bit more independent, we are now using shared support which costs less and allows her independence to develop even further. Whilst Darcy was away on a mini break with her friends I went to Barcelona with my son Kieran. We have always been close and having the time away together was fantastic, we went sightseeing, out to a show and enjoyed the ambience of the city. My husband and I are running more than ever now - I recently ran a race and came first in my age group - never in my wildest dreams did I ever think I could achieve something like this. Running makes me stronger, not only physically but mentally too. I love it now!

I feel - Ecstatic!

2014 -COULD LIFE GET ANY BETTER?

Darcy has settled into College life so well. Not everything has been plain sailing, we had some issues at the start but with one meeting we managed to resolve some issues which had arisen. Darcy also attends the Adult Resource Centre two mornings a week and is loving it. I was initially a bit sceptical but after visiting and seeing the activities that go on coupled with the fact that Darcy enjoyed it, it was a no brainer! There have been times when I have thought that Darcy maybe won't progress much more due to her age, but how wrong could I be? She can now write all her numbers and is improving with her letters. More importantly she wants to write! She wants to try to tie her shoe laces, she takes her toothbrush from me as she wants to do it herself, she now washes herself in the shower, she now chooses her own clothes and gets dressed on her own, only asking for help when she needs it. She wants to dry her own hair, she wants to paint her own nails (despite the mess!). Darcy has a really good life where she is respected, supported and loved by all around her. This has been made possible by myself, my husband, her father, her brother, her various Support Workers but also by being provided with the means to do so by the local authority.

WE ALL HAVE PERSONALISATION IN OUR LIVES

I have two friends called Caroline. I'm going away for a weekend with each of them this year. In two weeks I'm going with Caroline to Rome and we are going to run the marathon, 26.2 miles round the city. With the other Caroline I'm going to Edinburgh where we will drink cocktails, chat and go to see the new Lord of the Dance musical. Just because they are both called Caroline doesn't mean they both like the same things. Yet society has always assumed that because someone has a learning

disability they will like a particular thing. I probably wouldn't go out with both Carolines together because they wouldn't have much in common and may not even like each other. Yet because people have learning disabilities we put them together in groups and assume they will get on.

SDS and Personalisation is not rocket science. I am sick of hearing that this is a huge culture shift for professionals and it will take time to embed. Rubbish. This is life. This is what everyone wants for themselves. We go to school and college and university, we have relationships, we get married and plan a future, we have children and raise them how we see fit, we have friends and socialise, and we do activities that we enjoy. People with disabilities want those same things but they need extra help, support, guidance and yes money in order to achieve their dreams and goals. At the beginning of a marriage you may start a savings plan which will help in the event of a crisis - if you invest the money in SDS now you will prevent crises and ultimately save money but most importantly of all, you will have a more meaningful society where people with disabilities will have access to the same things that everyone else has - they will have lives that they deserve - just like you!

LIFE 2

JUNE 2010 SOCIAL WORKER

My Social Worker didn't turn up when she said she would. I had taken the day off work especially. When I called she said she got caught up in something else so didn't have time to see me but would call me in a few weeks. I'm a bit disappointed as she didn't seem to think I was important enough and I was way down on her list of priorities. After dinner

I feel let down

JULY 2010 - STILL NO CALL!

My Social Worker still hadn't called so I called her. She was in a meeting and I was told she would call me back. She didn't. I'm losing faith in her now.

I feel that I need support

SEPTEMBER 2010

Darcy's behaviour has deteriorated a bit – I think it's teenage hormones. She has always been active and can get bored if we don't go out every day. Some issues have arisen at school which has meant extra meetings to try to sort this out. We need to get to the bottom of things and work together to try to stop this behaviour. My Social Worker hasn't called and I'm too caught up in Darcy's issues to find the

time to call her. My husband is really busy at work so I don't want to bother him too much about it so try to pretend everything is fine.

I feel stressed and guilty that I can't make my daughter happy.

CHRISTMAS 2010 -DREADING THE HOLIDAYS

Darcy's behaviour has been even worse at school – I think she has had enough. She is frustrated and can't tell me what is bothering her. I think my stress is being passed on to her somehow although I'm trying to be upbeat about everything. We visited my family and Darcy was so bored as she had to fit in with what everyone else was doing. She was getting a bit stressed with her cousins as they are very young. I drank a bit too much but it made me feel better.

I feel that I am letting my daughter down

SUMMER 2011 - HOSPITAL

Darcy is being admitted to hospital. She needs a small operation and will be in for a few days. Someone told me there is a Carers Centre Support Worker based at the hospital but I haven't been in as I'm not sure what she can possibly do to help. I'm really worried about Darcy going in and staying overnight, she has never been away from me, won't know the nurse and they won't know her. I'm drinking more wine than usual in the evenings and being grumpy with my husband. We aren't getting on great at the moment.

I feel really worried and anxious

WINTER 2011 -DOCTORS

Darcy's behaviour at school and at home has deteriorated. She seems to have had enough of school and has started lashing out at support staff and other pupils. I am distraught. I don't know what to do and am finding it difficult to cope when she also lashes out at me. I try to keep her occupied and we seem to spent lots of time going shopping, making cakes and going for walks - but there is only so much of this a person can do and I feel she doesn't really want to do these things with me. She needs friends! I went to the Doctors to tell him how I was feeling and he has told me I have depression. I don't have time to be depressed! He gave me a prescription and has signed me off work for a month.

I feel disempowered

2012

Life as a Mum shouldn't be this difficult. I'm now off work long term sick and totally depressed. I'm not socialising, my friends are sick of me as I always get too drunk and embarrass them when I do get the opportunity to go out. I know within myself that this is a cry for help but nobody is listening! I'm trying to be a good mum but with Darcy's behaviour being so difficult I am exhausted all the time. She doesn't sleep well and being up at 5am every morning takes it's toll on me. My husband and I barely speak to each other, he doesn't know how to help and I suspect is thinking of

leaving me. My son is wonderful as always but spends all his time with his friends - and I don't blame him. This is a stressful, chaotic, miserable house.

I feel like a complete failure as a mother

SUMMER 2013 - TIME TO LEAVE SCHOOL

Darcy is leaving school and I have a complete breakdown. Months of depression and drinking have taken their toll. I've had to leave my job, which made matters worse and I was eventually admitted to local mental health facility for two weeks. Everyone is now trying to help but I have reached crisis before anyone did anything. I've been sent home with appointments for counselling, life coaching and more medication. Darcy has been put on medication by a Psychiatrist to try to control her behaviour. Maybe we should just go to appointments together! That would be too easy of course - we each have different Doctors on different days at different times! My husband has now left me and I don't blame him. My so called friends have given up on me. I am a worthless mother who can't cope. Respite has been put in place so Darcy is now going there once a fortnight for the weekend - she hates it. She will be going to the Adult Resource Centre three days per week - the College would not accept her due to her behavioural issues. What on earth am I going to do with her on the other two days. There are only so many visits to the supermarket a person can make.

I feel devoid of feeling

2014 - COULD MY LIFE GET ANY WORSE?

I have to be able to cope with this life. I have resigned myself to it. Darcy depends on me for everything. I help her in the shower, I clean her teeth, I choose her clothes, I wash her hair, I dry her hair. I am the only person who understands what she is trying to communicate - no other person knows her well enough apart from her Dad and brother. She has no friends. I have no friends. We are both isolated together. I never thought life would work out like this. I used to be a strong, confident person who worked hard to make my family happy. I have let everyone down, but people have also let me down. I can't help feeling that if only some small changes had been made at an early stage life would have worked out very differently.....

