

## **CPG on Carers 8<sup>th</sup> October 2014 – Note of meeting**

**MSPs and their representatives:** Joan McAlpine, Mark McDonald

**Individuals and organisations:** Florence Burke, Carers Trust Scotland; Paul Traynor, Carers Trust Scotland; Rebecca Marek, Scottish Youth Parliament; Lauren King; Scottish Youth Parliament; Jude Clarke, Division of Clinical Psychology in Scotland; Lorraine Allan; Gillian Reid, Enable Scotland; Sarah McDermott, Dementia Carer Voices; Lesley Jeffrey, Dumfries and Galloway Carers Centre; Janey Macdonald, Helensburgh and Lomond Carers SCIO; Daniel Short, Helensburgh and Lomond Carers SCIO; Penny Stafford; Jacqueline McShane, Barchester Healthcare; Andrea Donoghue, Barchester Care; Helena Kelman, PRT Lanarkshire Carers Centre; Cath Logan, Big Lottery Fund; Lesley McLaren, PAMIS; Ian Hood, Learning Disability Alliance; Celia Sweeney; Mig Coupe, Mindroom.

Joan McAlpine welcomed everyone to the meeting. The minutes of the previous meeting were accepted and there were no matters arising. As the meeting had been delayed due to chamber business, the Scottish Youth Parliament were invited to update on their campaign at the beginning of the meeting.

### **Scottish Youth Parliament: “A Costly Youth” report**

Lauren King explained that the Scottish Youth Parliament’s campaign had produced a report ([link](#)) that showed how many young carers are struggling financially. The report made several conclusions about how to improve the situation for young carers.

Cath Logan asked if the report had explored the different experiences of young carers based on who they were caring for; it was explained that the impact of caring often seemed more relevant than the particular role.

Mark McDonald asked if support across Scotland for young carers was too fragmented, as this seemed to be the case. Lauren King confirmed this, stating that it is because different services and different levels of funding are available. Florence Burke said that Carers Trust Scotland is doing lots of young adult carer work at the moment, some of which builds on existing work with Scotland’s Colleges. Work on implementing GIRFEC is also being done in conjunction with the Scottish Young Carers Services Alliance to make sure that good practice relating to young carers’ transitions is publicised. (Information and links will be circulated to the group separately.)

Helena Kelman informed the group that a feasibility study around a young adult carer service would be taking place in Lanarkshire very soon. She asked if the research had looked at young adult carers who were not receiving services. Rebecca agreed that there needs to be a higher awareness of services for young adult carers and confirmed that the research asked about support already received rather than the ideal support scenario, but there was some supplementary data on ideal services and specialised services for young adult carers. Jude Clarke asked if the research participants wanted to identify as condition-specific carers; Rebecca said that some focus groups had revealed that young carers in situations with actual or perceived stigma (such as looking after someone with an addiction) could be reluctant to identify.

Although the SYP has now chosen a new campaign for 2015, work will continue on the current campaign until the end of the calendar year. There was some discussion about the campaign’s achievements; education maintenance allowance guidance has changed to be more inclusive of young carers, and SYP have meetings lined up with Keith Brown, Minister for Transport and Veterans and Mike Russell, Cabinet Secretary for Education and Lifelong Learning, to discuss ongoing issues from the campaign. Joan McAlpine said that when she attended the Scottish Young Carers Festival in

July 2014, she was surprised at how many of the invited guests were not education professionals. Florence said that this had been a consistent issue since the first Festival in 2008, and that the young carers who attend had also commented on this. Joan asked if the Scottish Youth Parliament could raise this issue with the Cabinet Secretary for Education and Lifelong Learning when they meet in November.

Lorraine Allan asked if the research had looked at welfare reform issues. It was explained that the Scottish Youth Parliament cannot campaign to change reserved powers even though young carers are affected by welfare changes, and that specific welfare support services for young carers were beyond the scope of the research. There was a discussion about benefits and welfare services for carers, which do exist in some areas of Scotland: Lesley Jeffrey mentioned that the service offered by the Council in Dumfries and Galloway was used by carers from the carers' centre but the services different throughout Scotland. There are a lot of services for people with disabilities that may also provide some support to carers, but again these are not guaranteed in all areas of Scotland. Joan McAlpine suggested that general advice services should be aware of carers' issues rather than bespoke services for carers. Florence Burke mentioned the Equal Partners in Care (EPiC) programme aimed to inform NHS staff about wider carer issues and that best practice from this programme and others similar should be shared more widely.

Jude Clarke mentioned the problems with communicating and publicising the existence of these kinds of support, particularly as people need to recognise the need within themselves before seeking a support service. Connections between support services need to be strengthened so that no one falls through the net. The general problem of identifying carers was discussed, with reference to the Carers' Parliament which had taken place earlier in the day. Lesley Jeffrey spoke more about the work that Dumfries and Galloway Carers Centre does with schools; they participate in assemblies and also provide drop-in services for older children. There is knowledge of similar input across Scotland but again, this varies in different areas.

It was suggested that now that Scotland's colleges have become regionalised, the group could write to these regional boards and determine their strategic and operational support for carers.

### **Transitions**

The group moved on to discuss transition issues for parent carers and young adult carers. Lesley Jeffrey, who cares for her daughter, spoke about her role as a parent carer and how she felt that she was able to be proactive in transition planning due to her professional role working at Dumfries and Galloway Carers Centre. The biggest problem with transition was worrying about what would happen when her daughter left school, as the health support that is provided to young people stops when further education begins. There was also a discussion about how further education is considered to be full-time but in reality can be about 15 hours, so this can affect the carer's employment or finances as well if further care and support needs to be found. Difficulties of leaving well-known child services were also discussed, as well as the problems with finding an equivalent specialised service in adult services. It was agreed by some parent carers that the support provided by colleges is not as good as the support available to school pupils, not everyone needs further education and the opportunity is often taken up due to the lack of other available services, even though disabled young people may not have a good experience of attending college.

Joan McAlpine asked about self-directed support and how this fitted in with transition planning. There had been varied experiences; Lesley Jeffrey had had a good experience but had wanted to take the lead due to her own knowledge and experience. Helena Kelman said that through speaking

to parents at parent carer support groups, it became clear that transition planning often did not start until parents instigated it, and if this doesn't happen until the age of 16-17 then it could be too late to get sufficient support in place. Self-directed support had benefited her family but it had taken a long time to organise; her daughter had left college in May but services had not been put in place until the following February and only after significant intervention. Hopefully new legislation around SDS (from April 2014) would help with this, but the amount of SDS awarded may not be enough to cover the services needed. The situation in Glasgow with the learning disability day centres was discussed, and other lack of opportunities for young disabled adults, such as the closure of the Engine Shed social enterprise project in Edinburgh.

Mark McDonald said that although local flexibility was important, the lack of a minimum standard of service meant that different areas of Scotland had different services available. There seems to be a lack of recognition that disabled children will grow up into disabled adults and not planning for long-term services. Parents of disabled children also get older – Mark referenced an experience he had shadowing a parent who was caring for her teenage son and struggled to lift and carry him now he was almost an adult. A roundtable that he had hosted for adults with autism spectrum disorder who had been diagnosed as adults showed the stark difference, & showed how transition to appropriate services is extremely important.

Joan McAlpine asked how positive experiences of SDS could be shared. Those who had experience of SDS agreed that it had been a valuable learning process and there were some issues still to address. Carers' centres and services were cited as examples of places to share good practice and good experiences. Helena Kelman spoke about a project from [C Change](#) in Lanarkshire which will be looking at sharing knowledge of SDS and how carers can support other carers who want to find out more. Penny Stafford said her son had received a direct payment since the age of 17 but had found there were some issues with which services could be purchased. Lorraine Allan agreed & spoke about how it was difficult in some areas to access a real choice of services. Lesley Jeffrey had experience of a good choice of service in a rural area, but acknowledged that Dumfries and Galloway was an SDS pilot site and that providers in the area were used to the SDS system. It was agreed that agencies must be more proactive. Jude Clarke raised issues around the lack of involvement of carers (and therefore care of carers) when the service user is a mental health patient and the potentially negative effects this can have all round.

It was noted that the CPG had written to health boards in early 2014 to enquire about uptake of Triangle of Care (about carer involvement in mental health support services) and that this needed to be followed up. Heather Noller will enquire about these letters and collate replies.

There was some discussion about lack of support for carers, particularly carers of people with mental health issues, and it was mentioned that the Mental Health Act can sometimes cause conflict between service users' rights and carers' rights. It was agreed that even if carers are feeling stressed due to their caring role, the cared-for person is prioritised.

The need to standardise transition planning was discussed. The forthcoming carers' legislation will make provisions for more joined-up transition planning, and it was noted by Joan McAlpine that GIRFEC support plans should also include information about transition. Mig Coupe highlighted that [Arc Scotland](#) were sharing best practice on transitions. Ian Hood discussed the benefits of preventative support, noting that there is often a diagnosis spike in adulthood because of eligibility criteria for adults and good quality preventative support often means that long-term support needs are reduced. Lesley McLaren said that it can be difficult to get a service even if a person's need is critical; she is aware of SDS packages reducing and costs for services like transport are frequently

being cut, or the transport provided is not suitable. Integration of health and social care should help with this as miscommunication between agencies is one of the main problems, but there are other issues such as lack of funding for PAs to be trained in managing complex conditions. There was some further discussion about why services have to stop at 18 if a person's need has not changed, and how people who were less able to make their voice heard could be disadvantaged. Lorraine Allan spoke about difficulties in accessing appropriate mental health services and there was a wider discussion about awareness of available services. Mark McDonald agreed that support services for mental health issues were not always well known and in many cases a diagnosis could be isolated. It was suggested that the group could highlight the need for good quality signposting and referral to statutory bodies; there will be some provision in the forthcoming carers' legislation for more joined-up information and advice services but there needs to be a focus on sharing information as widely as possible.

Helena Kelman mentioned specific difficulties in health care transition, particularly if the service user has been under the care of a paediatric specialist but there is no adult service equivalent. The need to showcase good models of best practice was discussed; Joan McAlpine spoke of services in Inverclyde for people with learning disabilities where health, care and support, independent living and other services were delivered jointly by an integrated team and this seemed to work very well. It was acknowledged that Inverclyde CHCP had been integrated for a number of years. Ian Hood said that even if there were different models in different areas, teams should still be able to focus on the particular issues that arise for their service users. Lesley McLaren reiterated that low awareness of services and opportunities could be restrictive, and Joan acknowledged that Inverclyde's learning disability day centres are the hub for the joined-up services and people who didn't use the day centres may not know about the services available.

Mark McDonald mentioned day centres in his constituency and how this type of service does not work for everyone; one size fits all does not work but a minimum standard of service with local variation could result in only the minimum standard of service being provided. However, a standard service will allow for a change in mindset. It was acknowledged that social work services are under pressure to be more cost-effective and that identifying carers who need support services is still difficult. The impact of funding cuts was discussed.

### **Future topics for discussion**

The next meeting of the Cross Party Group on Carers will discuss issues for older carers and caring for older people. Members of the CPG on Older People, Age and Ageing will be invited to attend. As many carers had spoken about SDS, it was suggested that there should be a specific meeting on SDS in the future, perhaps in Spring 2015 when the legislation will have been in place for one year. It was also noted that the forthcoming Carers Bill should be discussed.

### **Next meeting**

The next meeting of the Cross Party Group on Carers will take place on Tuesday 13<sup>th</sup> January at 12:30 (approximate start time) in Committee Room 1.