

Cross Party Group on Carers

Committee Room 4, Scottish Parliament

14 January 2014

Note of meeting

MSPs: Claudia Beamish, Graeme Dey, Rhoda Grant, Joan McAlpine, Mark McDonald, Fiona McLeod

Individuals and organisations: Alan Gow, GAMH; Dr Allison Blackett, NHS Greater Glasgow and Clyde; Bernadette White, Leverndale Hospital; Cate Bradley, GAMH; Christine Rae, Action for Children North Lanarkshire; Chrys Muirhead; Craig Smith, SAMH; Fiona Sinclair, Autism Rights; Frances Simpson, Support in Mind Scotland; George Kappler, Mental Welfare Commission Scotland; Dr Ian-Mark Kevan, NHS Greater Glasgow and Clyde; John Wallace; Jude Clark, Division of Clinical Psychology in Scotland; Julie Cameron, Mental Health Foundation; Kathleen Taylor, Renfrewshire Carers Centre; John McFarlane, Renfrewshire Carers Centre; Lisa Ross, Mindroom; Michelle Morrison, PAMIS; Nicola King, Action for Children North Lanarkshire; Rosemary Nicholson, GAMH; Sarah Ritchie, MS Society Scotland; Rosemary Moffatt; Rebecca Marek, Scottish Youth Parliament; Tom Wightman; PASDA.

Joan McAlpine welcomed everyone to the meeting. A number of clarifications to the minutes of the meeting on 25 September 2013 were discussed:

- Graeme Dey was present at the meeting
- At the meeting on 25 September 2013 Graeme Dey had asked that the group consider meeting on 28 November 2013 to coincide with a visit to the Scottish Parliament by Angus Young Carers, where a film that the young carers had made would be shown.
- The protest regarding kinship care that was being held outside Parliament on 25 September 2013 was organised by the Scottish Kinship Care Alliance. It was noted that this organisation's views on the kinship care provisions in the Children and Young People Bill are not universal and some groups support the provisions in the Bill for a Kinship Care Order.

Following these clarifications, the minutes were tentatively accepted. Revised minutes will be signed off as soon as possible.

Kathleen Taylor spoke about her caring role. She looks after two of her children who have Bipolar II disorder and both she and her elder son have received very little support and poor advice from health services. Particular issues have been around confidentiality – health care professionals have frequently interpreted confidentiality guidelines as requiring them to withhold important information from Kathleen. She also spoke about the wider impact that caring has had on her family and how she has greatly benefited from support provided by Renfrewshire Carers Centre, and feels that more support for the person who is being looked after is required as this also has benefits for the carer.

Joan thanked Kathleen for speaking and asked if any other people attending the meeting had had, or were aware of, similar experiences. A number of people indicated that this was common. Cate Bradley and Chrys Muirhead indicated that they had had similar experiences with health care professionals not recognising the expertise of the carer. John McFarlane added that this was common and that carers were often seen as an interference, and their role is not recognised by health care staff. Jude Clark recognised the issues around confidentiality and withholding of information from the carer, and stated that she had experienced similar from health care staff regarding her own son, and she was only aware of available services because she had accessed mental health support herself. Kathleen stated that when she first took her son to the GP, she was not involved in the discussion at all, and as her son was under 16 at the time, felt that the GP should have recognised that she should have been involved in discussions about her son's health and treatment. Jude Clark agreed that carers need greater support or will end up being unable to care and need looking after themselves.

Rhoda Grant MSP entered the meeting and was welcomed.

Alan Gow spoke about the unique aspects of mental ill health as opposed to physical ill health - the reasons for it can be less clear, there is not always a cure, and there is the potential to be detained – and acknowledged that stigma around mental illness has existed for a very long time. He also pointed out how it can be difficult for the carer to access support for themselves and the person they care for if the person refuses to acknowledge or does not realise that they are ill. Alan also agreed that there are many health care professionals who do recognise the importance of involving family and carers, and respect carers as equal partners, and hoped that the forthcoming carers' legislation may define carers' position as equal partners further. Tom Wightman agreed with other attendees that there was a lot of bad practice in mental health, and that for people with learning disabilities, this can cause further issues if they or their carers do not fully understand the processes or treatment.

Joan summarised that carers of people with mental health issues seemed to be given less respect than carers in other caring situations. Many people agreed and Chrys Muirhead added that the Mental Health Act is supposed to enshrine respect for carers and family members and people need to know that their rights are safeguarded. George Kappler confirmed that the Mental Welfare Commission had oversight of the mental health legislation. Chrys added that in some cases, patients' advance statements were not being adhered to. Kathleen stated that the flow of information regarding her son's condition was always from her to the healthcare professionals and never in the other direction, and she was seen as interfering. Mark McDonald spoke of his family's own experience of caring roles and how healthcare professionals had interacted with them, and stated how strange it was that mental health carers were not being given the same respect or being treated as equal partners. Cate Bradley told of attending a medical appointment with her son where despite her attempts to give the health care professional information about her son's condition, he was seen separately and told not to bring Cate to an appointment again. Julie Cameron spoke of her previous role as an advocate and sometimes being shocked at the lack of involvement for and consideration for the carer, often with the unspoken assumption that the 'blame' for the condition lay with the family. She added that common sense needs to be applied when dealing with confidentiality queries, and the family's relationship with the patient should not automatically be considered a bad one.

Joan introduced the second presentation from Dr Ian-Mark Kevan, a consultant clinical psychologist within NHS Greater Glasgow and Clyde (GGC). His presentation reflected many of the points made by carers earlier in the meeting and he stressed that although the Scottish Government and NHS has policies in place to support carers, this is perhaps not always recognised in practice. Dr Kevan spoke about specific initiatives in NHS GGC and how families are involved in support, how families are encouraged to take part in peer support, and how 80 skilled staff who work with families have made a real difference to relapse rates. Specifically referring to the issues with confidentiality that many carers at the meeting had experienced, he clarified that health care professionals should be aware that involving the carer in discussions does not necessarily mean that confidentiality is being broken. (Slides from the presentation are available.)

Joan thanked Dr Kevan for his presentation and asked for further information on where services are in practice, as opposed to the ideal policies and situations described in the presentation. Dr Allison Blackett said that it was difficult for them to ascertain what other health boards were doing, but NHS GGC had been training staff for around two years. She mentioned that NHS GGC was using Triangle of Care, an alliance between service user, carer and staff member that promotes safety, supports recovery and sustains wellbeing. Joan asked what would be the best way to encourage a national improvement in mental health caring. Dr Blackett referred back to the confidentiality issue and stressed that all staff must be aware of the importance of the carer in supporting people with mental health conditions. There was some discussion around whether front-line staff would be aware of guidance and best practice on this issue, and Dr Blackett confirmed that in NHS GGC, training was continuing to be rolled out and the importance of staff members having access to training was well known.

Rosemary Nicholson said that GAMH have been working with NHS GGC and there is a lot to be gained by voluntary organisations working in partnership with statutory agencies to identify and support carers, particularly as these organisations can readily identify gaps between statutory policy and practice. She said that she had seen a change over time and the training provided is very good but there will still be barriers to staff being able to implement what they have learned in training. She also referred back to the discussion about confidentiality and how common sense must be used, and how there is a long term benefit in resourcing staff properly as it will prevent crisis for carers. The Mental Health Strategy needs to involve carers when it is reviewed.

Claudia Beamish asked how the number of staff who have been trained in NHS GGC fitted into the HEAT targets system, and whether it would be an idea to write to the Cabinet Secretary for Health and Wellbeing (or to another relevant Minister) to ask about how such training could be rolled out nationally. There was general agreement but it was also pointed out that targets do not solve everything, and Kathleen Taylor asked how this would help matters for people in her situation.

Fiona Sinclair spoke about a petition which has been submitted to the Scottish Parliament regarding the inclusion of autism spectrum disorders within the Mental Health Act 2003 and calling for this to change. Autism is believed to be a behavioural and neurological condition rather than a mental health issue and it is thought by some that it can cause problems for people with autism and other learning disabilities if they are included within the Mental Health Act and potentially subject to its provisions of detention and compulsory treatment.

The Petition and further information from Fiona will be circulated to the group for information. Kathleen said that for her family, diagnosis was not really a label but was the key to getting treatment and medication.

Joan asked the group what the CPG could do to help policy become good practice, as it was clear there were some good services out there. Jude Clark said that part of her role was to collate frequently asked questions and that this could be done with suggestions from the CPG and from the learning from NHS GGC and ensure that the answers are all in one place. John Wallace suggested that the group could write to health boards and ask them about whether they are using Triangle of Care and if not, why not. It was noted that MSPs could ask questions of the Scottish Government in the chamber but Joan suggested it would be quicker to write a letter. The Mental Welfare Commission's booklet on confidentiality¹ should also be referenced, and health boards could be questioned on whether their staff are aware of this publication. Chrys Muirhead noted that the Government's legislative programme for 2013-14 included a Mental Health Bill and this is currently being consulted on until 25 March 2014. It was decided that a letter to health boards should include specific questions about training for health care staff, as the Triangle of Care does not specify particular training for staff.

Nicola King asked if young carers would be included, as she is aware of situations where young carers who look after parents or other adults are refused important information. Rosemary Nicholson stated that there are different strategies and policies about young carers, but it was agreed that young carers above the age of 16 should always be given information about the adult they were looking after and for those who were younger, their skills and the specific caring role they had should be more of an indicator to the level of information they received. Rosemary also stated that as the Triangle of Care was a recently developed document that had been taken up by some health boards, we should try to increase awareness and uptake of it. Joan McAlpine confirmed that the CPG would write to the Scottish Government and health boards to find out about their implementation of Triangle of Care.

Tom Wightman said that psychiatrists needed to respect carers and realise that they are not ignorant and have a great deal of information that may help the person who they are looking after. Alan Gow reminded the group that there will be new legislation for carers introduced to the Scottish Parliament in the near future and stated that recognition of carers should become a duty under this legislation so that the importance of carer involvement was recognised.

Joan McAlpine thanked the group for participating in discussion.

Future meetings of the CPG

The next meeting will be held at lunchtime. It was decided that due to the imminent launch of a consultation on legislation for carers, the next meeting should take place in early March. Dates will be circulated to the group membership once they have been secured.

¹ Available to download from the Mental Welfare Commission's website
http://www.mwscot.org.uk/media/125263/carers_and_confidentiality_2013_web_version.pdf

Rebecca Marek from the Scottish Youth Parliament invited CPG members to attend the launch of the SYP's 2014 campaign "Care. Fair. Share" which is taking place on Tuesday 23 January. Details will be circulated to the group.

The next meeting of the Cross Party Group on carers will be held on Wednesday 12 March at 1pm in Committee Room 4, Scottish Parliament.