

## **Cross party group on carers**

**22 February 2017**

### **Committee Room 6, Scottish Parliament**

**MSPs and their representatives:** Claudia Beamish, Graeme Dey, Monica Lennon, Sheena Cleland (office of Roseanna Cunningham MSP) Martyna Napierska (office of Roseanna Cunningham MSP)

**Individuals and organisations:** Alexis Hay, Standard Life; Andrew Muir, Psychiatric Rights Scotland; Arvind Salwan, Care Inspectorate; Barry Gale; Ben Hall, Shared Lives Plus; Carolynne Hunter; Chris Doyle, Health and Social Care ALLIANCE Scotland; Claire Cairns, Coalition of Carers in Scotland; Don Williamson, Shared Care Scotland; Elizabeth Morrison, Life Changes Trust; Fiona Collie, Carers Scotland; Gill Westwood, CAS Kinship Care; Greg Hill-O'Connor, Health and Social Care ALLIANCE Scotland; Hayley Wilkinson, B-Eat; Janet Hill, Support in Mind Scotland; Jean Campbell, Support in Mind Scotland; Kate Hogarth, Shared Care Scotland; Kelly Munro, Enable Scotland; Layla Theiner, Disability Agenda Scotland; Lindsey Currie; Louise Morgan, Carers Trust Scotland/Scottish Young Carers Services Alliance; Oonagh Brown, Scottish Commission for Learning Disability; Pauline MacIntyre, Children and Young People's Commissioner for Scotland; Robert McGeachy, Camphill Scotland; Sara Preston, B-Eat; Sarah Cox, Support in Mind Scotland; Cath Logan, Big Lottery Fund; Evelyn Menzies, Headway Scotland; Geoff Kitchener, Centrica Carers Network; Tom Wightman, PASDA; Lesley McLaren, PAMIS; Jodie Gordon, Newington Communications

**Apologies:** Alex Cole-Hamilton MSP; Jackie Baillie MSP; Paul Edie, Care Inspectorate; Angela Lombardi; Kathleen Taylor, Mental Welfare Commission; Christine Farquhar, Upward Mobility Project; Lynn Williams; Harry Robertson, North Lanarkshire Carers Together; Roseanna MacDonald, Scottish Youth Parliament; Angela McLeod, Stroke Association

Graeme Dey welcomed everyone to the meeting. The minutes of the previous meeting on 6 October 2016 were accepted.

### **1. Support in Mind Scotland**

Sarah Cox spoke briefly to Support in Mind Scotland's circulated paper on "Recognition Rights and Advocacy: Understanding and Supporting Mental Health Carers" (Appendix 1). This briefing paper has been written in collaboration with other mental health organisations, whose wish is to strengthen the voice of mental health carers in policy and to develop awareness of the specific needs of mental health carers that mark their experiences out from the experience of others in caring roles.

Jean Campbell and Janet Hill, both carers with Support in Mind Tayside, spoke about their caring role, as a parent to their adult sons who have a serious mental illness. They both spoke about the lack of support that some carers can experience, as well as difficulties with information sharing between the professionals involved in providing care and themselves as carers. The recognition of the caring role of family members can be under acknowledged, as well as the stigma which carers can feel or be aware of in their communities.

The involvement of mental health carers should happen routinely in both the community mental health services, and if the person is admitted to hospital. Carers should be seen by the professionals as "equal partners" in care/support provision, whilst still respecting the professionals need to maintain the patient's confidentiality. Carers' knowledge, experience, and ability to support needs greater acknowledgement and recognition. The carer's rights should be recognised, which would include their wish to continue to care.

In addition both carers spoke about their involvement with Support in Mind, and the support they receive and appreciate through the services provided such as regular local support groups, information sessions on mental illness such as specialist knowledge on mental health legislation, and coping strategies.

Graeme Dey thanked Jean and Janet for their contributions and asked if either Jean or Janet had Power of Attorney had over their children's affairs. There was a discussion about how difficult this can be in cases of mental health where the person does not recognise that they are ill or is unwilling to make provisions for PoA. Problems around being the 'named person' were discussed and the need for carers to be confident and tenacious in order to get information from professionals and make their voices heard. Carer involvement should happen automatically if a person is admitted to hospital, and it was discussed whether stigma or prejudice around mental health admissions made this less likely to happen. Carers' experiences and abilities to support need to be recognised more, including the right to continue to provide care if this is what they want to do. The forthcoming Mental Health Strategy and the acknowledgement of unpaid carers in this were discussed and it was hoped that this would lead to change.

Ben Hall asked Jean and Janet if they had been offered respite or a break from caring. Neither had been able to take a break, and this was in part due to lack of appropriate accommodation and support for the cared for person.

Tom Wightman spoke about unmet need, and whether the Carers Act would encourage unmet need to be recorded so there would be evidence of the gap between support required and support provided.

## **2. Young carers health and wellbeing research**

Pauline McIntyre from Children and Young People's Commissioner for Scotland introduced "Coping is difficult, but I feel proud: perspectives on mental health and wellbeing of young carers" a research report published earlier that week by CYPCS and Carers Trust Scotland. (The report can be downloaded at <https://www.cypcs.org.uk/ufiles/CopingWithCaring.pdf>) The main findings of the report

were that although young carers were often proud of their caring roles, those who spent the most time caring experienced the most negative wellbeing issues such as stress, anxiety and poor sleep. This research compared the experience of young carers with young people who did not have caring roles, allowing the wellbeing indicators to be attributed to the effect of caring roles.

Graeme Dey asked if the number of young carers in Scotland was an underestimate and whether schools were more aware of young carers and able to support them. Louise Morgan stated that some surveys have indicated that 1 in 10 young people have some level of caring responsibility, which is much more than the 29,000 young carers figure given by the Scottish Government, but must recognise that there is a spectrum of caring roles, which the new research also examined. Monica Lennon asked what kind of support young carers would need in schools, as CAMHS waiting times and school-based counselling can vary in both provision and waiting times. Generally, young carers prefer someone in schools that they can trust, and to approach a member of staff that they have a good relationship with. The cuts to counselling and CAMHS services have been noticed by young carer support services who are struggling to keep up with demand. Louise Morgan highlighted good practice examples of young carer services working with schools, such as in Stirling.

Claudia Beamish asked if there had been any progress on widening teacher training on young carer issues. Louise Morgan stated that due to the time pressures on in-service days opportunities were limited, but there is some success and individual young carer services that work with schools can also access student teachers and probationers if they are placed in these schools. Claudia asked that this issue be followed up.

The research's focus on young carers' needs for time and space to have fun and have a childhood were mentioned, particularly as the most common caring activity that young carers provided was company and companionship. These young carers can be seen as not having a burdensome caring role as they are not always doing tangible, practical tasks, but still need support. The need for continued awareness and education about what young carers do was highlighted. Fiona Collie asked if the gap between identified and hidden young carers could include those caring for a parent with an addiction problem. Edinburgh Young Carers Project runs a specific group to support young carers in this situation. Similar issues were highlighted by Tom Wightman when it comes to adults with autism, as there can be under-diagnosis of this group and so there can be a lot of hidden carers.

Graeme Dey thanked the attendees and speakers for their contributions.

### **3. Next meeting and AOCB**

Sara Preston reminded attendees about the Scottish Eating Disorders Interest Group annual carers' conference that would take place on 4 March.

The next meeting of the CPG will take place on Thursday 25 May at 1:00pm in the Scottish Parliament. Shared Care Scotland will present on short breaks and respite.

## **RECOGNITION, RIGHTS AND ADVOCACY: Understanding and Supporting Mental Health Carers**

### **National Mental Health Carers Forum**

This Briefing Paper is a collaboration between the organisations who are members of the above Forum, set up in response to our increasing awareness that the voice of mental health carers was fragmented and was not being projected in policy arenas, and specifically in the work towards the Carers Bill for Scotland that has resulted in the new Carers (Scotland) Act 2016.<sup>1</sup>

Our aim is to strengthen the voice of mental health carers (MHC) in policy and development by raising awareness of the specific needs of mental health carers that mark their experiences out from the experiences of carers in other caring roles.

### **Mental Health Carers in Scotland**

There is no data giving us a definitive total number of MHC in Scotland but the Carers Trust estimate that around 1 in 40 people is a mental health carer. That means that there could be as many as 150,000 MHC in Scotland.<sup>2</sup> This paper also tells us that MHC make up to 25% of the estimated 6 million carers in the UK, with 7% of those carers caring for people with serious mental health conditions such as psychosis, schizophrenia and depression and 8% caring for people with both mental and physical illness.

In terms of the impact caring has on carers' own physical and mental wellbeing, a Scottish Government statistical report in 2015 showed that 32% of carers experienced poorer physical health<sup>3</sup>; however, the Scottish Schizophrenia Survey<sup>4</sup> found that 69% of those caring for people with serious mental illness believe caring has had some/significant impact on physical health; and 94% believe has had some/significant impact on mental health.

### **The Specific Rights and Needs of Mental Health Carers**

This is important because this perception that all carers have the same needs is leading to funding decisions that are eroding the specialist help and support that MHC actually need.

We believe that although all caring roles can provoke a range of issues and needs that are common to all, people who are caring for those with mental health problems and particularly more serious mental illness, do experience very specific issues that require very specific specialist information guidance and support.

---

<sup>1</sup> Carers (Scotland) Act 2016. Definition of a carer: "an individual who provides or intends to provide care for another individual (the "cared-for person")".

<sup>2</sup> 5 key facts about Mental Health Carers, Carers Trust (as Princess Royal Trust for Carers) 2007

<sup>3</sup> Scotland's Carers: An Official Statistics Publication for Scotland, Scottish Government, 2015

<sup>4</sup> Scottish Schizophrenia Survey, Amanda Larkin and Frances Simpson, 2015

In gathering together the experiences of MHC from our organisations the specific needs can be summarised as follows:

**Unpredictability of the illness:** The fluctuating nature of mental illness can often mean that MHC have to cope with unpredictable behaviour, mood swings, low motivation, paranoia etc, not knowing what may happen next.

**Stigma:** Stigma still exists against people who experience mental ill health and this can extend to their carers as well. Stigma can come from other carers, from the public, the media and even from within their own circle of friends and family.

**Isolation and reluctance to seek help:** MHC can be less open about their caring role and less likely to seek help, because of the fear that they or the person they are caring for will experience discrimination, particularly if psychotic symptoms (eg as in schizophrenia) are involved or if their relative is detained in secure care.

**Confidentiality:** MHC are less likely to be given sufficient information about the service user's condition due to professionals fear of breaching confidentiality as the service user will have capacity to make decisions for themselves. However, although they have 'capacity' they won't necessarily have the insight to fully understand the impact of those decisions on themselves and on their families.

**Carers not believed:** carers feel that professionals do not take issues seriously enough and carers' concerns are dismissed with carers being seen as 'over-reacting' or 'over-protective'

**Denial-lack of insight:** MHC can find themselves having to support/care for someone who denies that there is anything wrong and who refuses to seek help or support. The carer may try to seek help for the person concerned but find they are not believed, and help isn't given unless and until a crisis occurs.

**Lack of Specialised Respite:** Conventional respite services are often not appropriate for mental health service users and carers, due to a lack of understanding and a lack of specialist training. This means that MHC are even less likely to get a break from their caring role.

**Lack of appropriate services for the person who is unwell:** there are few services for people with mental health problems putting more pressure on families to provide support.

**Unrealistic Expectations of capacity and speed of 'recovery':** People with mental health problems experience enormous pressure to conform to work or volunteering as the reality of living with a serious mental health problem is not understood. MHC often absorb this pressure by trying to support the person and protect them from this pressure.

**Increased physical illnesses:** People with serious mental health problems are likely to experience greater physical illness but the causes and the solutions to this are not understood. MHC also experience greater physical illness due to the stress of caring for someone who is unwell.

**More Complex Legislation:** MHC can find themselves having to deal with legal issues if the person they care for is detained under mental health and criminal legislation, and/or if they are being detained within forensic mental health services. This additional complexity, legality and restriction is very distressing. Sometimes relationships can become strained as the service user may blame the carer for “allowing” this to happen even although the carer would have no choice.

**Financial pressures:** Some MHC have had to give up their employment because of their caring role particularly if their employer is unsympathetic to the flexibility that may be required or lack of awareness of issues they face day to day. Other MHC find they are judged for working with the assumption made that that means their relative ‘can’t be that ill’. MHC also absorb impact of additional costs and family’s low income.

**Fear:** MHC, particularly of people who experience depression or psychosis can have to cope with the fear and risk of suicide or self-harm of the person who is unwell. This attracts additional stigma as self-harm is often seen to be someone’s fault – with blame falling on the family. MHC may also fear that the person they care for may harm someone else either known or unknown. Preventing or coping with the aftermath of anyone coming to harm is extremely stressful and traumatic.

**Difficult family relationships:** all caring imposes stresses on families, but MHC can experience a complete lack of empathy or warmth or understanding from the unwell person who doesn’t understand the impact of their illness/behaviour. Similarly, MHC can misunderstand mental illness and feel frustrated at their relative’s inability to change their behaviour.

## **Carers’ Advocacy**

The Scottish Government and COSLA have produced Guidance for Unpaid Carers Advocacy in Scotland<sup>5</sup> reinforcing the value of carers’ advocacy and recognising that “carers should be involved in decisions about their own care and support” and that they “can also be involved in decisions about the care and support of the people they care for”.

However, whilst recognising the need through a requirement in the Carers (Scotland) Act 2016 that information on advocacy services to be made available to carers, the legislation falls short of requiring it to be provided and we believe that this is a missed opportunity for all carers, but particularly for MHC whose relatives are being detained under mental health legislation.

For those detained in forensic mental health services, it is a long-term and even life-long impact. Individuals subject to the legislation have a right to advocacy as an important safeguard to their rights and their carers should have an equivalent right to help them understand the complexities involved and to articulate their views and needs to the many different professionals involved in decision-making concerning compulsion and compulsory treatment.

## **Mental Health Developments 2016**

---

<sup>5</sup> Guidance for Unpaid Carers Advocacy in Scotland, Scottish Government and COSLA, 2016

There are signs that mental health is being taken seriously in more general terms with the recent appointment of a dedicated Minister for Mental Health within the Scottish Government, the announcement of £150m new funding over the next five years and a pending 10 year Mental Health Strategy for Scotland. We are asking decision-makers to build on these developments and go further – to recognise the specific needs of family members and carers of every affected by mental health problems and mental illness.

## **Our Ask**

To highlight these issues and build support for our campaign to improve and increase specialist information and support services, the Mental Health Carers Forum is launching a national campaign in June 2016 that will culminate in a national event in the Autumn at which we will clarify and articulate our **Ask** of the new Scottish Government for:

### *Recognition*

MHC rights and needs should be recognised within the legislation with a commitment to protect and resource specialist MHC information and support services in every area.

### *Rights*

MHC should have a right to be provided with clear information about their rights under mental health and criminal justice legislation, and should be involved in decision-making about the person they are caring for. Confidentiality should not be a barrier to involvement.

### *Advocacy*

MHC should have a right to informed **independent** advocacy if the person they are caring for is being treated under legislation that restricts their liberty, or their capacity to make choices about their own care. This will better support the person being treated as well as ensuring they can better understand and articulate their own needs for support within a highly complex, regulated environment

### *Giving Mental Health Carers and Voice*

Support and resources for a National Mental Health Carers Forum led and managed by Carers

## **Further Information/Contact**

Frances Simpson, Support in Mind Scotland. 0131 662 4359  
[fsimpson@supportinmindscotland.org.uk](mailto:fsimpson@supportinmindscotland.org.uk)