



mental welfare
commission for scotland



Carers' experiences of interaction with services

What people tell us

February 2020



**Carers' experiences
of interaction with services**

**The views of people
with lived experience of mental illness,
their friends and family**

February 2020

The views in this paper are an expression of the opinions and experiences of people that the Mental Welfare Commission have consulted on a number of occasions but do not necessarily, in themselves, represent the Commission's view on any of these issues.

With thanks to the individuals and groups that helped with this report.

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Carers' experiences of interaction with services

The Engagement and Participation Officer (Carer) at the Commission visits support groups for people looking after individuals who have mental illness, learning difficulties, autism or dementia. We also meet with carers one-to-one if they prefer, and attend relevant conferences where discussions around issues takes place. We contact new groups regularly, and revisit others when we have new issues to discuss.

In the majority of cases families and carers in new groups we visit are unaware of the Commission and its work so we provide that information for them and highlight how the Commission can help them and the people they care for.

We try to have a wide spread of locations to also represent rural and isolated areas.

Over the last six months we have met with over 60 carers individually or in small groups from all across the country. We also listened to and spoke with many more at several conferences.

In this round of visits we visited mental health carer groups in Oban, Glasgow, Renfrewshire, Aberdeen, Lanarkshire, Paisley, West Lothian and East Renfrewshire. This also included a trip to Islay where carers from Jura also came to the meeting.

We visited a specific group of individuals with eating disorders and their carers, and further carers in Perth.

The Bipolar Scotland Annual Conference provided more opportunities to hear from carers as did events run by Lanarkshire Links and Islay Links which are groups providing support for individuals and families in those areas.

We also spoke with forensic carers in the State hospital and at the Friends and Family conference for forensic carers run by Support in Mind.

We visited one group of people caring for individuals with dementia in Oban.

We attended two events run by Sense Scotland, a charity that support disabled individuals and their families where we were able to speak to staff and families on issues especially around transition.

As part of the Commission's recent themed visits we also met with several carers of older people with functional mental health problems and carers of individuals with autism and complex needs.

The carers we meet in some ways self-select, as they feel able to attend the groups or conferences. We also meet with carers one to one who are referred from carer centres as having particular concerns or issues and who do not attend groups. These carers are often at the end of their tether and we provide advice and support as appropriate. Carers often comment on how useful it is to speak to someone who has lived experience and can easily see things from their point of view.

Many of these carers are signposted to our Advice Line where they will get expert help, and if necessary the situation will be highlighted to the practitioner for their geographical area.

Not listened to

The most common complaint heard from the groups was the feeling that they were not listened to and that their concerns were dismissed by services. In some cases this has led to tragic consequences and certainly to poor outcomes for many individuals with a mental health diagnosis.

Many of the carers pointed out that they feel they can see a deterioration in their relative early and that if services responded to their concerns at that point then deterioration in their condition would not have to be inevitable.

One carer reported being told “he says he is fine” despite their relative having serious problems with self-care; and there was agreement in almost every group that their concerns were ignored if the individual gave a different version of events leading to the consultation.

Individual not engaging

One of the most difficult situations carers identified at all of the groups was that of an individual who refuses to engage with services even when clearly unwell.

Relatives are then faced with a very stressful situation watching the deterioration of their relatives but being unable to access help. They told us that GPs do not feel able to visit when the individual has not requested a consultation and Community Psychiatric Nurses (CPNs) will not engage without a referral.

One carer described this as “being left in no man’s land.”

Another carer, however, described how her son, who was known to services, refused to attend his appointments and how services responded well. His psychiatrist told his mum to come instead, as he said her account would be equally valuable. She felt that his attitude and acknowledgement of her place in the situation made it so much easier and enabled her to continue to cope. It helped her gain the confidence and skills to persuade her son to re-engage.

This is not always the case, however, and most families were not able to get this support. It is particularly difficult if the family member is not known to services. One mother described how her daughter will not speak to anyone but her, but services will not speak to the mother.

“She says if anything happens to me she will just ‘go with me’ as there will be no point. This puts even more stress on me.”

Dual diagnosis

Where relatives had a dual diagnosis, with substance abuse complicating their mental health issues, families described difficulties around gaining joined up consistent input.

They felt that mental health services do not want to deal with individuals who take drugs and addiction services are reluctant to deal with those with a mental health diagnosis.

"Are people looking at dual diagnosis – is it possible to get help for this before they are sectioned? I have already been told while he is under substance misuse there are hardly any resources – but he needs to be in adult mental health where he may get a CPN – he has been discharged by substance misuse – but won't be accepted by mental health because of his substance misuse."

This was also an issue around older people where physical health problems were felt by some carers not to be adequately addressed.

One carer in particular was very concerned about what they described as services working in "clinical silos."

"Patients with complex co-existing psychiatric and medical conditions are actually exposed to risk because the hospitals don't have co-existing 'shared care' environments which can pool multi-disciplined resources and treatments into one location or plan."

They described the "it's not our problem anymore" attitude from some services as being particularly damaging.

Lack of skills in staff dealing with different disciplines was highlighted. This was also a concern raised by carers of individuals with autism, who felt staff who had training in learning difficulties did not necessarily have the skills to deal with someone with autism and complex needs.

"Staff may not be appropriately trained (only intellectual impairment, not autism specific). Staff may have the wrong attitude to either the person they are looking after and/or the carer."

Support in the community

The lack of community support for their relative was an almost universal problem raised in the groups. Many acknowledged it was due to lack of resources but led to any deteriorating health of individuals going unnoticed.

"Community support: I fight tooth and nail to get support for my husband – I have had no support – all I get is support from the carer centre."

The carers were often just looking for support for their relative and not themselves. Some said they need the burden of overall responsibility for a situation often out of their control taken away or at least lessened.

*"Some people have psychiatrists and some people have CPNs – I had to make an issue of it to get a CPN – it seems arbitrary."
"He has attempted suicide twice in the last two years which would have justified a CPN – I am constantly stressed with the worry of it all."*

Having someone to turn to for advice was a valuable asset for carers. Many highly praised the support they received from the carer's centres and importantly from their peers in the group.

*"Everyone is so supportive."
"This group has been a lifeline for me."*

The STEPS programme for individuals with a personality disorder was praised by two carers in one group but they felt it did not go far enough.

"Steps was marvellous – if that could run longer and there still be a maintenance course afterwards- it is not that she doesn't need services – when she is in crisis she needs help. People need contact with services – people will need constant help still not as intense – something every three weeks to maintain contact – not run by peers alone."

Another positive support was highlighted around dementia care. While the group members were fairly dissatisfied with statutory services they were full of praise for the community dementia team which they described as invaluable.

"Don't think we could manage without it."

This comprises joint working with the CPN, Occupational Therapy and link workers from Alzheimer Scotland, and carers were delighted with the service.

"Immediate support at the end of a phone."

The quality of community support is, however, an issue for some, and one carer described that her daughter's CPN took her to do the CPN's own shopping.

"I feel the contact should be more tailored to therapeutic activities for my child."

All the groups agreed that improved community support would reduce relapse and prevent readmissions by early interventions.

Crisis

We heard that accessing out of hours care in an emergency is often left to family and the stress of managing this can be immense.

Some carers said that looking after individuals whose level of care need is just below that for admission is equally stressful. Individuals turned away from A&E rely on family to pick up the pieces and poor communication means the family often have to highlight the issues to community teams themselves.

"Last admission meant multiple unsuccessful phone calls to CPNs then seven hour wait in A&E with daughter 'up to high doe', hallucinating, trying to leave, screaming at me with whole department watching."

Families are often advised to phone the police to manage a crisis. Many describe them as very helpful but as a last resort. Having an ill relative removed from your home in handcuffs is upsetting for everyone. Most carers acknowledged that involving police imposed much more trauma on relatives and often fed paranoia and distrust of the police in the future.

One carer also described being referred to a unit from A&E with her father who had attempted to take his own life. After waiting for three hours they were told, "We have no beds – would you be ok just to take him home?"

Another carer phoned when their relative became ill while home on pass. They were advised to phone the police, "He is your responsibility on pass – just phone the police."

We discussed solutions to some of these emergency issues in some of the groups and the idea of having a separate A&E area for those in distress was a very popular suggestion. It was felt that having a distressed individual in A&E for hours is not going to help to resolve the situation. Carers told us that the general unpredictability of other patients, the noise and the chaos all builds to make the experience intolerable to many.

It was generally agreed that many individuals in emotional distress will not need the facilities of a traditional A&E unless there is self-harm involved. Some carers felt that even in those circumstances if the individual could then be transferred to a nearby area which is calm, welcoming and staffed by mental health staff who can properly assess their needs then the outcomes would improve.

Other responsibilities

Some carers highlighted that it is easy to forget that many of them have all the other stresses in life on top of their caring role.

One described a recent cancer diagnosis that resulted in surgery, radiotherapy, chemotherapy and then complicated by septicaemia. While she was enduring this her relative did not have other support, stopped their medication and ended up back in hospital. She berated herself for having "taken my eye off the ball."

She did however report that now, with the simple introduction of a CPN, the situation is much better and she now feels she is "cushioned" by services.

Another carer highlighted the lack of support for people with autism. There was no respite available and the situation was causing resentment with their other children, "I am at their beck and call 24/7."

The impact on family life was evident in all the groups and generated guilt around the effect on other children.

Information and training

Some families were disappointed that they were given no training or even advice on how they should deal with their relative at diagnosis.

Glasgow Association for Mental Health (GAMH) did previously provide mental health first aid training but changes in funding have stopped this.

Several carers commented that they could better deal with the situation if services would talk to them and explain about the behaviour associated with a condition and how best to manage it.

"We need told what needs to happen."

Transport

All of the rural areas we visited had difficulties associated with transport.

When an individual is detained under the Mental Health Act transport is automatically arranged but when someone agrees to an informal admission relatives may be left to sort out their own transport. This can have serious consequences.

We heard that one individual who had to wait overnight with a relative before going to hospital the next morning became more unwell, attacked their relative and is now in forensic services.

There are also issues for families trying to visit relatives placed out of area.

One gentleman who has to travel hundreds of miles to visit his wife in a care home said it was only because he has concessionary travel that he is able to visit her.

The lack of secure beds in some areas is another reason for individuals having to go long distances for admission, which causes problems both at the point of admission and for relatives trying to visit, maintain contact and provide support.

One carer reported her relative was kept in prison for almost a year before moving to an Intensive Psychiatric Care Unit (IPCU) many miles away. During his stay in prison she said his mental health was "ignored." However she reported that the care he is now receiving and the engagement with her is excellent. "IPCU care has been fantastic and very welcoming to the family."

Prison

There were several reports which highlighted the issue of individuals ending up in a prison cell where staff did not engage with relatives or take any note of mental health problems. This often resulted in no medication and a subsequent further deterioration in mental state.

Lack of early intervention

Several carers gave accounts of their relatives ending up in prison, the State Hospital or IPCU after community teams have failed to act when the carers have highlighted concerns about their relative's deterioration.

Especially in forensic services, many families felt that if there had been intervention at an earlier point their relative would not be in the situation they are in.

The majority of families we heard from were happy with in-patient forensic services but nearly all felt adequate, timely support in the community would have avoided their relative ending up in forensic services at all.

We heard of several cases resulting in serious outcomes and one very distressing case which had tragic consequences which might have been avoided had services responded to family concerns.

None of these had been reported by services to the Commission in line with our guidelines.

One of the carers was a single mum with a child in IPCU who also has other children with additional support needs.

"They didn't listen to family or respond to difficulties and [relative is] now on an attempted murder charge."

Confidentiality and communication

One carer described battling to get her son admitted and then receiving a phone call from staff saying he did not want her involved in his care. Two days later he turned up at her door "on pass", saying he was allowed out if he stayed with her. She had had no communication about this from the ward.

"I wasn't consulted and did not give permission and was not asked if I was happy to look after him. I spoke to a charge nurse when he went back and said I wasn't happy; they listened to how he had been over the weekend – but did not comment on what I went through."

The Carers Act (Scotland) 2016 states that families should be involved in all discharge planning. There is no legislation for those out on pass however.

Relatives reported at most groups that they had issues with their relatives being out on pass.

Some reported being phoned to keep their relative longer and as the hospital were using their bed. Others were refused a return when difficulties arose for the same reason.

On the ward

Visiting was highlighted as an issue, with the majority of carers feeling it was unfair to restrict visitors to public areas like the dining room.

While they appreciated the reason was to maintain confidentiality they felt they could listen to everyone's conversations in a communal space. One family described witnessing while in the dining room someone trying to escape through a fire escape and another being brought back by police.

Communication with relatives was patchy. Some reported excellent relationships with staff including explanations about why their relative was refusing to allow information sharing and what they could do in terms of supporting them around this.

"The key nurse explained what she could tell us and that she could hear what we had to say. The consultant even made a point of seeking me out on the ward to speak to me."

Another carer whose son was in IPCU, however, had a different experience. She has not been involved in or invited to Multi-Disciplinary Team meetings. Home visits have been cancelled at the last minute including at Christmas which upset her other children. She is having great difficulty trying to maintain a normal happy life. Staff have also passed on conversations she has had with them about concerns for her son to her son without her permission and this has now caused difficulties in their relationship.

Another family reported a much more positive experience since becoming named person for their relative. Difficulties faced during previous admissions were greatly improved and the ward was proactive in contacting them with information.

Child and Adolescent Mental Health Services (CAMHS) have faced a lot of criticism recently but one family reported an excellent experience when the CAMHS consultant kept responsibility for a young person an extra nine months because she was aware there was not an adult consultant available to take on her care. That experience was however countered with the comment that they were then "chucked into a sea of sharks with adult services."

Discharge

The Carers (Scotland) Act 2016 states that family members should be involved in discharge planning. This has been in force since April 2018 but we heard that this is not always the case.

One carer centre has a worker placed in the discharge hub of the local hospital. The worker also visits the mental health ward and collects referrals directly which provides a direct immediate link to carer support. Carers and staff report that this works very well. However several carers report their relatives being discharged without their knowledge. One carer in particular described not being informed about her relative's discharge until she had left and tried to take her own life, leaving her with catastrophic injuries.

If an individual is discharged to a new address this can cause problems. One young person was rehoused across the road from his high rise flat as he was often suicidal. This meant he was in a new geographical area and so was discharged from his community team without setting up new support. It took his relative months to get him another appointment for follow up.

Another individual was discharged when still unwell to supported accommodation. Her relative attended several meetings to try and resolve this but the individual was evicted and forced to go to a homeless hostel, where they took their own life two weeks later.

A family objected to their relative being discharged to a daughter's care when still very unwell. She had three small children but was told, "if you don't come for him we will put him in a taxi." A staff member followed them out and suggested they should make a complaint as she was very uncomfortable with the situation.

Another said that her daughter is vulnerable, has a poor memory, is easily distracted and goes out and leaves the door open. The carer found a letter post-discharge telling her daughter to contact services within a timescale if she wanted continued support. Her daughter was not capable of following the implications of this herself.

Complaints

Carers told us that the first advice carers often get when they try to address issues is to raise a complaint, which is not always helpful. The complaints process does not help at all in a crisis.

We discussed this in most of the groups and those carers who had experience of it said that they found making a complaint to the NHS to be a long winded, laborious, emotionally and physically draining process which more often than not led to an unhelpful and defensive reply.

"I eventually got a reply asking me to get my daughter to give permission to speak to me but she is too ill now to do that."

The majority of carers had no faith that going through the process would lead to anything useful.

"I think they draw it out so that you go past the time limit."

Support plans

The Carers (Scotland) Act 2016 introduced Adult Carer Support Plans and Young Carer Statements which are designed to identify carers' needs. The local authority then has a duty to provide support to carers, depending on local eligibility criteria.

We know from our own visits the uptake is low and discussions at the groups confirmed this. Many were unaware of them and those that had had one felt they were useless.

*"Yeah, I had one ages ago but it didn't change anything."
"...agree it is difficult to get an Adult Carer Support Plan. Eligibility criteria in place in West Lothian means a carer's needs must be 'critical and substantial' before they get help."*

The majority of carers we spoke to were concerned for help for their relative rather than themselves, which may contribute to this poor uptake.

Despite this most reported great difficulty in combining their caring role with family life and holding down employment.

Most also feel guilty at the impact the situation has had on other family members, especially children, and regret at the loss of the person their relative was before.

"The daughter I had is not who I have now."



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