mental welfare
commission for scotland

VISIT AND MONITORING REPORT

Living with severe and enduring mental illness in Scotland

August 2016

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The Mental Welfare Commission for Scotland

What we do

We protect and promote the human rights of people with mental health problems, learning disabilities, dementia and related conditions.

We do this by:

• Checking if individual care and treatment are lawful and in line with good practice.
• Empowering individuals and their carers through advice, guidance and information.
• Promoting best practice in applying mental health and incapacity law.
• Influencing legislation, policy and service development.

We are an independent statutory organisation, with a range of duties under mental health and incapacity law.

Executive summary

In this themed visit we interviewed 59 people who were living in the community, and were receiving care, treatment and support from community mental health services. All had severe and enduring mental ill health and most had had ongoing contact with mental health services over many years.

We arranged to meet people who lived in each of the mainland health board areas in Scotland. We also met a small number of people living in one of the island health board areas.

We asked people to tell us how involved they felt they were in decisions about their treatment and support. We asked people to give us their views about what they felt was most important in helping them to keep well, and whether they felt their care and support was enough, including how support can be accessed in a crisis. All the information we gathered came from the 59 interviews with individuals. We did not look at mental health records. Commission practitioners also noted whether they felt the person was receiving adequate and appropriate care and treatment.

Summary of findings

Mental health care and treatment

Most people felt their mental health care and support was benefitting them and were satisfied with the level of support. Where people said they wanted more support, this was generally because they wanted to be more active or have more social contacts, or to have more practical support. They rarely said explicitly that they wanted more support to treat mental health problems. However, we know that good mental health is more than the absence of symptoms of mental illness, and that having positive relationships with others and purpose in life helps people stay well and can prevent serious mental health problems having a life-long impact.

People identified some specific things which they valued the most with regard to their mental health care and treatment. These were: having consistent relations with staff and not having frequent changes, being listened to, and having flexible support which can increase when this is needed. Some people also mentioned difficulties they had experienced negotiating the system and accessing services at the beginning, although almost all of this group were happy with the care and treatment they received after they accessed services.

A few people spoke about recovery focussed ideas when we met them. This included people who had clear personal goals and hopes, and also a very small number of people who had their own wellness recovery action plan (WRAP). One person showed us their very detailed WRAP, two people had participated in WRAP training, and another two people had contributed to a book of recovery stories. We would have hoped to see more evidence though that services are developing a stronger focus on recovery in the way care and treatment is provided, and that this is reflected in care plans.

Participation and rights

Almost all the people we met felt they were given information about their care and treatment, and a large majority felt they had all the information they wanted. People who were given all the information they wanted were much more likely to feel they were able to have a say in their treatment, and to be agreeing to all the treatment. Just over half the people we saw did not know if there was a care plan that had information about their care, treatment and support.

Most people had not heard of advance statements, or could not remember if they had been given information about this right. Fourteen people said they had an advance statement, and several people told us how they had been encouraged to make a statement by mental health professionals, and had been reminded that they might review and update their statement. It is disappointing, though, that the majority of people did not know about this right. The Commission has done work to promote advance statements, and we now have a section on our web site giving information and guidance about advance statements, along with a series of short films featuring people with first-hand experience of advance statements. We would hope that more people become aware of advance statements, and the difference they can make.

While only a small number of people said that they currently had an advocate, a larger number had used advocacy supports in the past. Most people told us they were aware that support from an independent advocate was available. When people had decided not to use advocacy supports it was not clear if there had been a discussion about the possible benefits of accessing advocacy.

Very few people we met had heard of self-directed support (SDS), which allows people to make choices about how social care support is provided. This partly reflects the fact that many were only receiving support from health services, and did not have any social care support. While we did not find significant unmet need for intensive community support, we did find people who were isolated, and whose lives had been significantly diminished by their illness. A modest amount of individualised and imaginative support to help people in that situation, reflecting the duties of local authorities under the Mental Health (Care and Treatment) (Scotland) Act 2003, could be transformative.

Availability of support in a crisis

Overall, almost everyone we spoke to knew who they would contact in a crisis, although under a third said they had a written crisis plan.

We saw some examples of very good crisis care plans, with information about what triggers a crisis, what helps the person through a crisis, and who to contact. We also heard how experiences using crisis services such as A&E departments were more positive when good information was available to these services about the early warning signs when that individual person is becoming unwell.

Most people knew their community psychiatric nurse (CPN) was the person to contact in a crisis, either as the only contact, or as one of a number of contacts.

People recognised that there were specific things that were important about support in a crisis. Unsurprisingly, they valued getting a quick and sympathetic response and the fact that, for a number of people, supports were increased during the time when they were more unwell.

Physical health care

We were pleased to find that a large majority of people told us they had regular physical health checks. We were also pleased that a large majority of people who smoked, or said they had concerns about their weight, said they had been offered support with these issues, although the number who continued to smoke remained high.

Over half the people we met said they exercised regularly. Some were doing a range of exercise activities while, for many people, walking was their main exercise. Most people who had concerns about their weight said they were not getting any regular exercise. We would suspect that many of the people we saw are not meeting guidelines for healthy levels of activity. Exercise referral schemes targeting primary care populations have been in place in many parts of Scotland for a number of years, yet no-one who spoke to us mentioned having had access to such a scheme in their area.

Activities and social support

Most people told us they had good informal support systems, and good connections in the community with family, neighbours and friends. A significant number of people were experiencing some loneliness and isolation, which can happen even when people have regular supports from family and friends. People said they can feel lonely at specific times, or that they feel lonely because they have lost social networks they had when they were in work, or have lost contact with friends who have moved on in their lives while the person has been unwell.

Some people were very active and involved in a lot of activities. Others appeared to have quite restricted lives, where their main contacts were with professional support staff. Where people were involved in more purposeful activities, they tended to have more goals and expectations which were recovery focussed.

One person, who was on a college course, told us they had completed one course and had moved on to a part-time diploma course at college. They felt that 'no-one believed I could achieve what I have managed.' Unfortunately this sense of optimism was unusual and it was more common to hear people tell us that they had accepted and were resigned to having a more limited life now, as a consequence of mental illness.

Housing finance and employment

Most of the people we met were satisfied with their accommodation, and a number of them spoke positively about how connected they felt with neighbours and their community. Some in supported accommodation had clear hopes that they would move into their own tenancies, to live more independently.

We did not hear many issues related to benefits, but several people said they knew that they were going to be transferring to new Department of Works and Pensions (DWP) allowances, and were anxious about this process.

We were disappointed to find that only three people were in paid employment.

Local authorities have a statutory duty to provide or secure services for people with mental illness in the community, and to provide assistance in obtaining and undertaking employment[1]. A number were involved in voluntary work, and many people identified having a job as one of their hopes for the future. Most people also said they did not feel that having a job was possible for them. A smaller number said that while they did not think this was possible at present, because they would struggle to manage in employment, they would want to be working in the future.

The Commission believes that having opportunities for paid or voluntary employment would aid the recovery process, and would contribute towards people feeling more positive about moving into employment being possible in the future. We saw little evidence, though, in this themed visit that current efforts to promote employability have secured positive outcomes for people with severe and enduring mental illness, or are encouraging people them to think about the possibility of work in the future.

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[1] Mental Health (Care and Treatment) (Scotland) Act 2003 s26 (2)

Recommendations

1. Managers of community mental health services should ensure their service has a clear focus on recovery, for example through the use of the Scottish Recovery Indicator (SRI 2) as a service development tool.

2. Managers of community mental health services should ensure that mental health professionals complete written care plans, with an appropriate recovery focus. Plans should be completed jointly with the person receiving care and treatment, who should contribute to the development of the plan and be given a copy.

3. NHS Boards should develop plans to promote advance statements for people with severe and enduring mental illness in the community, in preparation for their responsibilities under s26 of the Mental Health (Care and Treatment) (Scotland) Act 2015.

4. Professionals should develop a written crisis care plan jointly with people receiving care and treatment. Where appropriate this plan should identify care and support preferences in anticipation of a crisis.

5. Health and social care partnerships should develop targeted activity to promote physical exercise for people with severe and enduring mental illness in their areas, including exercise referral schemes.

6. The Mental Welfare Commission and the Care Inspectorate will discuss how the Care Inspectorate can strengthen the focus on better outcomes for people with severe and enduring mental illness as part of the inspections of care at home and housing support services, looking at how services promote wellbeing and social development.

7. Local authorities and health and social care partnerships should review how they can work together to develop the provision of relevant services under ss. 25 to 27 of the Mental Health (Care and Treatment) (Scotland) Act 2003.

8. The Scottish Government should include a stronger focus on employment support for people with severe and enduring mental illness in the next national mental health strategy.

Part 1 - Introduction and background

1.1   Why we carried out these visits

One of the ways in which the Commission monitors individual care and treatment is through our visits programme. We visit people in a range of settings throughout Scotland: at home, in hospital or in any other setting where care and treatment is being delivered. As part of this programme, we carry out national themed visits each year. National themed visits enable us to assess and compare care and treatment for particular groups of people across Scotland. Our aims are to help services learn from good practice and to respond to any issues that are identified.

Policy context

Improving mental health and treating mental illness are established priorities for government policy. The Framework for Mental Health Services in Scotland (1997) described the core features of a local mental health service. *Delivering for Mental Health* (2006)[2] set out objectives to accelerate improvements in mental health services. These included a focus on improving patient and carer experience of mental health services by establishing the *Scottish Recovery Indicator* (SRI) as a tool to help services be recovery focussed, and developing peer support. *Delivering for Mental Health* also recognised the need to improve the experience of care and treatment for people with long term mental health conditions.

The Scottish Recovery Network (SRN) was launched in 2004 to promote the concept of recovery[3]. Since 2008, the SRN has supported the development of wellness recovery action planning (WRAP) as a self management tool to help people take more control over their wellbeing and recovery. SRN also promotes and supports peer support, and the use of the Scottish Recovery Indicator (SRI 2) by services, to develop a recovery approach.

The Mental Health Strategy for Scotland: 2012-2015[4] was the successor to *Delivering for Mental Health*. The strategy acknowledged the need to extend the availability of peer support, and support for self-management. It built on previous policy documents, and identified having a range of community, in-patient and crisis mental health services to support people with severe and enduring mental illness as a key change area.

The Mental Health (Care and Treatment) (Scotland) Act 2003 came into force in 2005. It was recognised at the time as a significant piece of mental health legislation, building on the work of the Millan Committee.

Importantly, the Millan Committee recommended that specific duties on local authorities to provide support for people with mental health problems and learning disabilities in the community should be retained and modernised. This was done in sections 25-27 of the 2003 Act, which oblige local authorities to provide:

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[2] http://www.gov.scot/Publications/2006/11/30164829/0
[3] http://www.scottishrecovery.net/
[4] http://www.gov.scot/Publications/2012/08/9714

- services designed to 'minimise the effect' of their mental disorder and give people 'the opportunity to lead lives which are as normal as possible'
- services designed to promote 'well-being and social development', including social, cultural and recreational activities, training and support for employment
- assistance with travel.

The Commission has a duty to monitor the operation of the Act and promote best practice. This includes monitoring how the principles of the Act are being applied in practice. While we visit people living in a range of settings, to gather information about how care, treatment and support are being provided, most of our national themed visits to date have looked at the provision of care and treatment in hospitals or registered care settings.

We recently published a report, 'Visits to people on longer term community based compulsory treatment orders.'[5]   This report looked at the care and treatment of people who had been subject to a community based compulsory treatment order (a CCTO) for more than two years. We feel it is important that we also look at the care and treatment people are receiving when they are living in the community, and may not be subject to a CCTO. We decided therefore to carry out a national themed visit during which we would meet people with a diagnosis of a severe and enduring mental illness, who are living in the community and are receiving care, treatment and support from community mental health services.

We wanted to look at how the principles of the Act are being applied when community mental health services are supporting people in the community. In particular, we wanted to see how people were involved in decisions about their care and treatment, and whether there was evidence of application of the principles of minimum restriction and maximum benefit. We also wanted to see whether people who were involved with community mental health services were receiving appropriate services, either if they were no longer subject to, or if they had never been subject to, compulsory measures. We know that severe and enduring mental illness affects over 40,000 people, and almost all of this group will be living in the community, and will not be subject to compulsory measures under the Act[6].

In this visit, as well as looking at the provision of mental health treatment and support, we also looked at how physical health care needs were being met. It is well known now that people experiencing significant mental health problems are at a considerably higher risk of developing physical health problems than the general population. This is recognised in government policy, which clearly states there is a need 'to improve the physical health of people experiencing mental illness[7]'.

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[5] The Mental Welfare Commission for Scotland (2015) Visits to people on longer term community based compulsory treatment orders
http://www.mwcscot.org.uk/media/243429/ccto_visit_report.pdf
[6] Audit Scotland, in the 2009 report 'Overview of mental health services' said that data from GP registers in 2007/08 showed that 43,135 people in Scotland were recorded as having severe and enduring mental illness. (**ref –Audit Scotland, Overview of mental health services, May 2009)**
[7] Scottish Government (2008) Mental Health in Scotland: Improving the Physical Health and Well Being of those Experiencing Mental Illness
http://www.gov.scot/Resource/Doc/251663/0073699.pdf

1.2   Planning and consultation for this themed visit

In this themed visit, which took place from November 2015 to February 2016, we wanted to make sure we were looking at the issues which were most important to people using community mental health services, and to their carers.

We held three consultation events, one with families, friends or other carers, and two with people using community mental health services. These events were held in Perthshire, facilitated by Support in Mind, in Lanarkshire, facilitated by Lanarkshire Links, and in the Borders, facilitated by Penumbra. We are grateful to these services for hosting these events.

People at the consultation meetings identified a number of things they felt we should look at, including:

- Staffing in community services, and consistency of staff
- Availability of support in a crisis
- Support to help people become active and connected where they live
- Support when someone has financial problems and debts
- Discharge planning when people leave hospital.

The issues raised in these meetings helped inform the questions we asked in this themed visit.

1.3   Making contact with individuals in the community

In 2008[8] and 2011[9] we visited individuals with severe and enduring mental illness in rehabilitation and continuing care wards in hospitals across Scotland. *(Ref: Greater expectations revisited (2008) and Left behind (2012))* In 2011 we met with, or examined, the case notes of 144 people in rehabilitation and continuing care wards. We hoped that a significant number of this group would have moved on from hospital over the previous four years, and we planned to visit at least 50 of the individuals we had previously seen, to assess the care and treatment, and look at their experiences living in the community.

When we tried to set up visits to this group of people we found out that many of them were still in hospital, and that a number of them had died since our previous visit. It would not have been possible to meet our minimum target of seeing at least 50 people by trying to visit individuals from this group who were living in the community.

We then decided we should visit people with severe and enduring illness who were in contact with community mental health teams. We wrote to mental health service managers in all the mainland and one of the island health boards, and selected a number of community mental health teams (CMHTs) to assist us in planning and delivering this themed visit. We asked CMHTs to identify people on their case loads living with severe and enduring mental illness, and in one very rural area we also asked the social work mental health officer team to identify people they were supporting in the community.

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[8] The Mental Welfare Commission for Scotland (2009) Greater expectations revisited 2009
http://www.mwcscot.org.uk/media/53203/Greater%20Expectations%20revisited%202008.pdf
[9] The Mental Welfare Commission for Scotland (2012) Left Behind
http://www.mwcscot.org.uk/media/62802/left_behind.pdf

We asked CMHTs to give us the names of 12 individuals who had had contact with their service in the previous four weeks and who would be likely to engage with us. We said that the individuals identified:

- must have a severe and enduring illness
- must have had their diagnosis for over 12 months
- must have spent most of the previous 12 months living in the community (apart from brief episodes of inpatient care and treatment)

We also asked for brief details about their community psychiatric nurse (CPN), social work or support service contacts. We selected names at random from the lists we received from CMHTs, to give us a mix of people living in rural and urban areas, and in one of the island health board areas. We then contacted people directly, and were able to meet with 59 people, and find out their views about their mental health care and support.

Contact was made with CMHTs and visits were completed before the legislation to implement health and social care integration came into force, on 1 April 2016. The group of people we visited were receiving limited social work input or support, but this may have been because we were visiting people who were on CMHT caseloads. This legislation brings together NHS and local authority care services together under one partnership arrangement in each area in Scotland. We would hope that with integration new ways of working will develop in mental health services, with an increasing focus on delivering a wider range of support services, with more emphasis on prevention, recovery, and promoting well-being.

1.4 Who we visited

We visited fifty-nine people in their own homes across Scotland, between October 2015 and February 2016, and this included seven people we had seen in hospital in 2011. Fifty-nine percent (35) of the people we saw were men and forty one per cent (24) were women. Most people were age 45-64 (56%, 33) or 25-44 years (36%, 21); one was under 25 years and four were age 65 years or over. All the people we saw had severe and enduring mental illness. Forty-six per cent (27) had a diagnosis of schizophrenia, 15% (9) had a diagnosis of schizophrenia plus other conditions, 24% (14) either had a diagnosis of a bi-polar disorder or a bi-polar disorder plus another condition. Two people told us clearly how they experienced their mental health problems, but did not tell us their diagnosis. The rest of the people we met had other specific diagnoses, including autistic spectrum disorder, personality disorder, and problems relating to drug and alcohol use.

The majority of people (92%, 54) had contact with mental health services on a voluntary basis; 8% (5) people we met were subject to compulsory measures under the Act. Four people told us that compulsory measures which had been in place had been revoked very recently, in one case just two days before we visited. Several other people said they had been detained in hospital in the past, sometimes many years ago.

A carers' questionnaire was available to be completed by the carer themselves, or in a private interview with one of the Mental welfare Commission visitors on the day of the visit, or by telephone.

This questionnaire asked for their views on the care of the person they cared for, and how involved they felt they were in decisions about care and treatment. We met with nine carers who completed questionnaires. A small number of other carers sat in on interviews with the individual people we were seeing.

We are conscious that our sample was drawn from people who are in touch with services, and we cannot draw conclusions about people who not be in regular contact with specialist support. In 2016-17 we plan to visit homeless people with mental health issues, which may provide useful comparisons.

Part 2 - Detailed findings

2.1 Mental health care and treatment

What we expect to find

We expect to see good provision of community services to support individuals and promote recovery. We expect that everyone with mental health problems who is receiving support from community mental health services gets the care and treatment that best meets their needs.

What we found

We asked people a very general question about whether there was anything they wanted to discuss with the Commission, and very few people identified issues about their care and treatment, apart from two people who mentioned delays accessing services, and one person who did not want to be subject to compulsory measures. In response to this general question, several people spoke about their care and treatment being excellent*: 'my care and treatment has been exemplary', 'everything is going pretty well at present', and 'my care is second to none. My CPN follows things up if I am unwell. I feel I get listened to....'*

We asked people for some information about the support they were getting from services, and about whether they felt this was enough to meet their needs, or whether they had any concerns about their care and treatment.

Almost all of the people we met were receiving support from two or more professional staff; one person was supported by a single professional. Twenty-two per cent (13) had two professionals involved in their care and treatment, 46% (27) had three professionals, 19% (11) had four, and 12% (7) had support from five or more people.

People were in contact with a range of medical, nursing, social work, and social care professionals. Almost all, 95% (56), saw a psychiatrist and had regular contact with a CPN (90%, 53). Half also saw their GP (53%, 31). A smaller proportion saw an MHO (19%, 11) or other social worker 17%, 10).   29%, 17) had visits from support staff, including staff on site in supported accommodation, and 14% (8) were seeing a psychologist.

When care, treatment and support is being provided by a number of people it is important that there is effective communication between them, and we would expect to see that there is an identified key worker. Fifty three interviewees knew they had a key worker they could talk to about their care and support but six people who had support from a number of professionals were not sure who their key worker was. For 64% (38) people, their key worker was their CPN (possibly due to our sample being drawn almost entirely from CPN caseloads), while 17% (10) identified their social worker or social care support worker as their key worker.

We asked individuals whether they found contact with their key worker helpful. Most (51) of those who were able to identify their key worker spoke positively about this contact, often giving us very specific details about how it helped them.

'I can tell them if anything is troubling me, if my voices have been distressing me....'

'very good, very approachable, listens to me, and monitors my mental health very effectively.'

A clear message from almost all the people we met was that they found having a key worker who was consistent and talked to them regularly was a great benefit. People identified some specific things which they valued in their relationship with their key worker. Some people mentioned their key worker helping them set goals, helping them with recovery planning, and helping them with their WRAP. Many people valued the chance simply to talk with someone who they felt really listened to them. Several people commented that talking to a key worker helps to make sure that support is increased when needed. One person told us that their contact with a key worker was helpful, but that their key worker had changed several times, which caused problems because they had to get to know a new worker.

We asked people how often they met with their consultant psychiatrist, and how helpful this specific contact was. Thirty four per cent (20) met their consultant on a three-monthly basis, and 24% (14) met them six-monthly. Fourteen per cent (8) were seeing their psychiatrist monthly or more often, and two people had annual reviews. Three people were waiting to meet new psychiatrists, and a few did not say how frequent this contact was.

People were asked if they felt this contact was helpful. Three people said they did not find this helpful, because they did not feel they had a good relationship with their psychiatrist, or because they had seen a number of different doctors. One person, for example, said that recently they had seen a different doctor every time at outpatient appointments. Twenty people simply told us how often they saw their psychiatrist and didn't tell us whether they found this helpful, but most people who gave us their view about this contact did find it useful. When people spoke about what was most valuable, they identified some consistent themes:

- being listened to and being able to discuss how they were feeling
- reviewing medication, any side effects, and discussing possible changes
- reviewing treatment generally
- having flexible contact, which is increased when people are unwell
- feeling reassured that their consultant still had an oversight into how they were managing.

One person told us how they now see their psychiatrist every two months, but that when they were very unwell and their mood was low they saw their consultant weekly.

Seventy eight per cent (46) of people felt that the professional support being provided was enough. Fifteen per cent of the 46 people didn't tell us any more about why they felt this support was adequate. Three people felt they were getting enough support, but also told us they had been referred for other supports. Most people told us they were happy with their support, but 11 people gave us very clear information about why they felt their mental health support was enough.

One person said their support had literally been life saving: *'I would have been dead if it wasn't for the mental health team. They have been so supportive, it's been a long journey to accepting my illness and learning to deal with it, they have been there for me.'*

A common theme, when people told us specifically how support had helped, was having a consistent trusting relationship with professional staff. One other theme that was mentioned by a number of people who were positive about their mental health support was feeling confident that services would respond flexibly. This was valued by several people who told us that if they phoned one of their support team, they would get a quick response, and that support would be increased when needed:

'when I take episodes of being unsettled I can get help. I get extra help when I have a bad time, less when I am okay.'

This was echoed by other people who clearly saw this as important to them.

Nineteen per cent (11) felt their support was not adequate. There was no obvious link between people who did not feel support was adequate and the level of support they were getting from different professionals: people who were in contact with more professionals were not automatically more satisfied with the amount and adequacy of their support.

One person, for example, was getting support from five different professionals, but felt support was intrusive, although the Commission practitioner who saw them felt they were getting support which was appropriate to their needs. One other person also felt they had too much interference in their life. Three people said they would like to be in different accommodation, either moving to their own flat from supported accommodation, or living in a different area. Two people were unhappy having to pay for some of the support they received, and in one case someone who said they would like more support was not willing to accept support they could get because of the financial implications. Six people spoke about wanting more practical support, or support to be more active and to get out and do things. Only one person mentioned specific support to help manage mental health symptoms, and this was someone who was very clear about therapeutic support they would like access, such as acupuncture.

Two people described experiences of poor support in the past, which they said had led to them being admitted to hospital when they didn't need this, and one person said '*I know when I am ill, they wait too long.....I end up in hospital*'. Four people also mentioned delays or difficulties accessing services, with three of these saying that they were satisfied with their care and treatment once they started getting support from services, and with the other person acknowledging that they felt the support from their psychiatrist was very good.

We wanted to know if anyone we saw had had changes to their mental health support package in the past year, either in response to a re-assessment of their needs or because there had been a cut in service provision. 75% (44) said there had been no change in their level of support, or that the support had been increased in the past year. 17% (10) did not know, or were not clear, whether there had been any change.

Five (9%) said that the support they received had decreased. Two of this group told us that they felt they were recovering, and they were happy their support was being reduced. Of the other three people, one person has not been willing to consider other support because they may have to pay some of the costs of support services, and one person had only recently been discharged from hospital, with a care plan which at the moment is focussing on managing crises. The other person who said his support had been cut was very happy with the intensive support his psychiatrist was providing, but felt if other support was available, the psychiatrist would not need to see them so often.

We also asked people if they had heard about peer support, if this was available where they lived, and if they were getting any peer support. Forty six per cent (27) said they did not want to access peer support; 27% (16) were not aware of peer support or were not sure about this support. 27% (16) were accessing peer supports; most of these attended support groups (10) and found this support valuable.

'It's a lifeline, being able to share worries, having someone to talk to' and that *'talking to others who have walked the same journey is so helpful.''*

This is not a form of support which everyone finds useful though, with several people saying that they had been to peer support groups in the past and had not found them supportive or helpful, or didn't feel they could join in the group.

As we said in the introduction to this report only 8% (5) of the people we met were subject to compulsory measures under the Mental Health Act. When someone who is subject to compulsion under the Act is prescribed medication, there are safeguards when that medication is administered for more than two months. The person either gives written consent on a T2 form, completed by the psychiatrist, or has treatment authorised by a designated medical practitioner (DMP) on a T3 form. Appropriate forms were in place for the five people, where this was needed.

A number of people did mention their medication at other points when we were talking to them. Several people spoke about medication when we talked about how involved they were in decisions about their treatment, and we discuss this in the next section of this report, **Participation and Rights**. When we asked what people felt was helping to keep them well, 31% (18) didn't identify anything. Others identified a range of things that were helping them stay well, including keeping busy, support from family and/or friends, or looking after their pets. Just under a third of the people who gave us information about this also said that their medication was helping them to stay well.

Carers' views

Six of nine family, friends and other carers were either very or fairly satisfied with the care and treatment of the individual they cared for: *'now very happy with the care and treatment especially recently (since) changed medication. The CPN is very responsive if I need to contact them with any concerns.' 'I feel he is getting all the help he needs....was well for most of the last twenty years.'* For some the current situation was good, but they said they felt it had taken a long time to get the right kind of care and support, with one carer saying '*once he got into the psychiatric system and got a diagnosis things worked well and he got the help he needed, but it took two long horrible years to get there.'*

Summary of findings

Most people felt their mental health care and support was benefitting them, and were satisfied with the level of support. Where people said they wanted more support, this was generally because they wanted to be more active or have more social contacts, or to have more practical support, not because they wanted more support to treat mental health problems.

People identified some specific things which they valued the most with regard to their mental health care and treatment. These were having consistent relations with staff and not having regular changes, being listened to, and having flexible support which can increase when this is needed. Some people, and some family, friends and other carers, also mentioned difficulties they had experienced negotiating the system and accessing services at the beginning, although almost all of this group were happy with the care and treatment they received after they accessed services.

A few people spoke about recovery focussed ideas when we met them. This included people who had clear personal goals and hopes, and also a very small number of people who had their own Wellness Recovery Action Plan. One person showed us their very detailed WRAP, two people had participated in WRAP training, and another two people had contributed to a book of recovery stories. We would have hoped to see more evidence though that services are developing a stronger focus on recovery as care and treatment is provided, and that this is reflected in care plans.

Recommendation

Managers of community based mental health services should ensure their service has a clear focus on recovery, for example through the use of the Scottish Recovery Indicator (SRI 2) as a service development tool.

2.2 Participation and rights

What we expect to find

The Mental Health Act sets out a number of important principles which people working in mental health services must take into account when providing care and treatment. The Act stresses the importance of individuals participating as much as possible in decisions about their care and treatment, and getting as much information as they need to allow them to participate. The principles reflect good practice. We expect to see these principles applied in practice whether someone is subject to measures under the Act, or whether they are involved with mental health services on an informal basis.

We expect to see appropriate care plans in place when someone is receiving care and treatment in hospital. When care and treatment is being provided by community services, we would still expect a care plan to be written in partnership with the individual person, with information about treatment and social care and support to be provided to support the person's needs, and with details of who is responsible for providing this.

Under the Act, people have a right to access independent advocacy and to make an advance statement. We expect to see that people are given information about their rights, and about how to exercise these rights.

The Social Care (Self-directed Support) (Scotland) Act 2013 allows individuals to arrange some or all of their support instead of receiving directly provided care services from the local authority social work department. This legislation is designed to encourage more participation by allowing people to decide how much control and responsibility they want over their support arrangements. This Act only applies to social care support, provided or arranged by local authorities, and not to health care services.

We expect people with a mental illness receiving care and treatment in the community:

- to feel involved as fully as possible in decisions about their treatment
- to have care plans which have information about care and treatment to be provided to meet agreed needs
- to have regular reviews of care, treatment and support plans, with clear partnership working between individuals and professionals
- to have access to advocacy
- to have been given information about advance statements
- to be aware of self directed support options if they would benefit from social care support.

What we found

We asked if people felt they were given enough information about their treatment, including medication. We also asked if they knew if there was a plan for their treatment and support, if they felt they had a say in their treatment, and if they had agreed to the care and treatment being provided.

The majority of people said they had been given all (69%, 41) or some (25%, 15) of the information about their treatment that they wanted. Three people said they had not been given information.

When we asked if people had a care plan and if they could see their plan we found that just over half did not know if there was a care plan in place. Forty nine per cent (29) said they did have a care plan, and almost all of them (24) told us they could see their plan if they wanted.

We asked if people felt they had a say in their treatment, and 76% (45) said yes. Seventeen per cent (10) said they didn't know, or didn't answer, while 7% (4) told us they didn't feel they had a say. When people were asked whether they had agreed to all the treatment they were getting, 92% (54) said yes. Of the five people who said they had not agreed to treatment, three were subject to compulsory measures with T3 forms in place to authorise medication, and one of this group was very clear in stating they would not take medication without compulsory measures in place.

We gathered a lot of information about participation in decisions about treatment. We heard some good examples of how people had been involved and felt they had a say in treatment:

'I am informed about medication, learning to self manage. My CPN, psychiatrist and psychologist all discuss treatment with me.'

One person spoke about a hospital admission last year to change depot medication, and said *'I agreed to a voluntary admission because everything had been fully discussed with me in advance.'*

A few people said that having a poor relationship with a professional worker - for example feeling that they are judgmental - makes them feel they can't participate in decisions. One person spoke about anxieties they had which were barriers to discussing their care and treatment:

'but sometimes I can't discuss downs or suicide in case they take me into hospital.'

We asked for examples where people felt they had had a say in treatment. Many people could not give specific examples, or simply said they felt they were listened to. Some people spoke about being asked if they wanted to use certain support, such as going to a specific group or to art therapy. One person said that they didn't want their family to know all the details about relapses as they become over anxious, and professionals respected this view. Eleven people gave issues about medication as examples. The people who mentioned this spoke about medication changes being discussed and agreed, often because they were experiencing particular side effects such as putting on weight. One person said *'(my psychiatrist) listens to me and has reduced my meds as low as he can without making me ill again.'*

The Act clearly says in the section on principles that it is important to provide information to people to enable them to participate as much as possible, or as much as they want, in decisions about care and treatment. From what interviewees told us, there was a clear link between people being given information and people feeling they have a say in their treatment, and that they agreed with their treatment.

Where people were given all the information they wanted, most felt they had a say in their treatment (38 of 41), and were agreeing with their treatment (40 of 41). The one person who did not agree felt they should be getting other, very specific, treatments. In contrast, under half of those receiving only some or no information felt they had a say in their treatment (7 of 18).

We asked if people had had any information about self-directed support (SDS)[10] and if they were receiving SDS. We heard from four people who knew about SDS; two were not interested in SDS, with one person saying clearly they wanted social work to continue arranging and funding services. One person had just been allocated a social worker, who had spoken about support and SDS. One person is getting SDS and using it to employ their own support worker, to help them get out and be active.

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[10] Information on SDS is available at http://www.selfdirectedsupportscotland.org.uk/

The limited awareness may reflect the fact that the people we visited were in contact with community mental health teams, and many did not have any package of social care support. To that extent, SDS would not have been an option for them. However, as we go on to discuss in sections 5 and 6, we believe some people could have benefited from support for activities, social engagement and employment. Such support needs to be personalised, individual and imaginative, all of which would fit the SDS model.

Advance statements

An advance statement is a written statement made when someone is well, setting out their preferences should they become mentally unwell in the future. In advance statements, people who have received treatment for mental ill health can say what treatment or care they would like, or would not like, if they get ill again. They are about planning ahead - stating what you would prefer in case you get too ill to be able to make the best decisions for yourself.

The Commission will have a new duty, under the Mental Health (Scotland) Act 2015 (the new Act), to hold a register of people who have made an advance statement. We have said in a previous themed visit report[11] that we were disappointed that the majority of people we saw on that visit had not heard of advance statements. In that report we also made a specific recommendation that services should actively promote the use of advance statements.

In this visit we asked people if they had, or would like to have, an advance statement, or if they were aware of them. Twenty-four per cent (14) people told us they had an advance statement. Eight per cent (5) people said they would like an advance statement when we explained what this was. Forty-two per cent (25) people told us they had not heard about advance statements, and 25% (15) said they were not sure if making a statement had ever been discussed with them. The proportion of people who had an advance statement was higher than we recorded in the CCTO themed visit report last year, where only 14% of people had made an advance statement. It is disappointing that 40 (67%) people said they had either not heard or could not remember hearing about advance statements.

Of these 40 people, almost half (45%, 18 of 40) did not tell us any more about their views on advance statements, apart from one person who said *'I would not need one as I feel I am always listened to.'* Commission practitioners explained briefly how writing an advance statement can help, when people wanted to know more about this. As a result, six of this group said they would talk to their CPN, or would think about it, and talk to someone if they decided they wanted to write a statement. A further six people said clearly they had no interest in making a statement, including one person who said they trusted their psychiatrist and CPN, and did not feel a statement was necessary.

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[11] The Mental Welfare Commission for Scotland (2015) Visits to people on longer term community based compulsory treatment orders
http://www.mwcscot.org.uk/media/243429/ccto_visit_report.pdf

Fourteen people told us they had an advance statement, but it was not clear from the information they gave when they had last been offered assistance to make one.

Four had written this statement in the past year, but five people who had written statements several years ago said they planned to review and update their statement, including one person who said their psychiatrist had reminded them to do this. One person also told us very clearly about how important they felt their statement had been, because it had been taken into account and as a result their medication had been changed.

Advocacy

Under the 2003 Act, people with learning disabilities or a mental illness have a right of access to independent advocacy[12]. Independent advocates are separate from mental health services and do not work for health boards or local authorities. An advocate can help someone express their views and make their voice stronger, and have as much control as possible over their life. This right of access does not only apply to people in hospital or subject to compulsory care - someone receiving informal support from community mental health services can have an independent advocate.

Health boards and local authorities have a duty to work together to make sure independent advocacy services are available in their areas, and that people can make use of this service. Under the 2015 Act, health boards and local authorities will in the future have to provide the Commission with information about how they ensure that advocacy supports are available, both now and in the future.

We hoped to find that people knew about the availability of advocacy services, and were using them when they wanted this support.

When we asked if people were aware of their right to advocacy we were told:
- 19% (11) had an advocate
- 25% (15) had been offered an advocate and refused
- 3% (2) would like one
- 20% (12) had not heard of advocacy, or were not sure, or didn't answer
- 32% (19) said none of the above, but gave us more information.

Four of the group of 19 people told us they had heard of advocacy but didn't want to use the service. Most of them said they had used advocacy supports in the past, but didn't feel they wanted or needed an advocate now. The majority of people we met therefore either told us they currently had an advocate, that they had been given information about advocacy and did not want this support, or that they had used advocacy services in the past but did not want or need to access advocacy now.

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[12] Mental Health (Care and Treatment) (Scotland) Act 2003, s259

Carers' views

Seven of nine carers felt fully involved in decisions about care and treatment, and told us for example that:

'I attend meetings and get letters/minutes......', 'CPN speaks to me. During recent admission hospital were great, gave me lots of information....', 'I did find the family sessions really helpful', and 'Care Programme Approach meetings every three months. Happy with this.'

Summary of findings

Almost all the people we met felt they were given information about their care and treatment, and a large majority felt they had all the information they wanted. People who were given all the information they wanted were much more likely to feel they were able to have a say in their treatment, and to agree to all the treatment. Just over half the people we saw did not know if there was a care plan that had information about their care, treatment and support.

Most people had not heard of advance statements, or could not remember if they had been given information about this right. Fourteen people said they had an advance statement, and several people told us how they had been encouraged to make a statement by mental health professionals, and had been reminded that they might review and update their statement. It is disappointing though that the majority of people did not know about this right.

The Commission recently worked to promote advance statements, and we now have a section on our web site giving information and guidance about advance statements, along with a series of short films featuring people with first-hand experience of advance statements. When the relevant provision[13] of the 2015 Act comes into force, health boards will have a responsibility to publish the support they offer for making advance statements. We hope that this will include working with people with severe and enduring mental illness living in the community.

While only a small number of people said that they currently had an advocate, a larger number had used advocacy supports in the past, and most people told us they were aware that support from an independent advocate was available. When people had decided not to use advocacy supports it was not clear if there had been a discussion about the possible benefits of accessing advocacy.

Very few people we met had heard of self directed support (SDS). SDS allows people to make choices about how support is provided when they are eligible for social care support, although many people were only receiving support from health services, did not have any social care support, and therefore would not have been eligible for SDS.

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[13] Mental Health (Scotland) Act 2015, s26

Recommendations

Managers of community mental health services should ensure that mental health professionals complete written care plans, with an appropriate recovery focus. Plans should be completed jointly with the person receiving care and treatment, who should contribute to the development of the plan and be given a copy.

NHS Boards should develop plans to promote advance statements for people with severe and enduring mental illness in the community, in preparation for their responsibilities under s26 of the Mental Health (Care and Treatment) (Scotland) Act 2015.

2.3 Availability of support in a crisis

What we expect to find

Having a mental health crisis will mean different things to different people. We expect mental health services to deliver appropriate support to people at a point of crisis when they need urgent help.

In November 2006, the Scottish Executive published *Delivering for Health: Delivering for Mental Health - National Standards for Crisis Services.* The government gave a commitment to achieving these crisis standards. Subsequently, the Mental Health Strategy 2012-15 recognised the important role crisis services can play, and the fact that they are valued by people who use them. Commitment 23 of the Strategy included a reference to a review of the standards for crisis services. Work is ongoing to fulfil Commitment 23, and to revise the 2008 crisis service national standards. A proposed set of indicators that any service can use to monitor the activity and effect of crisis services has been developed and is published on the Scottish Government website. A national set of key performance indicators for mental health, which will include measures relevant to crisis services, are currently in development.

Most health boards now have some form of crisis response service in place to provide support when someone is very unwell and experiencing a crisis in their mental health. Crisis response services are known by different names, such as crisis resolution teams, or intensive home treatment teams. We would expect to find that people are aware of the support they can access in a crisis, and that their experience of using services in a crisis has been positive.

What we found

We asked people if they had a written crisis plan, and if they knew who to contact for support in a crisis, if they felt unwell and needed help urgently. We asked people to tell us specifically who they would contact. We also asked them to tell us if they had experience of needing support in a crisis, and how helpful this support had been.

Thirty one per cent (18) people said that they had a written crisis plan. Twenty five per cent (15) said they did not have a written plan, while 44% (26) were not clear if there was one.

Given that many people are unlikely to be aware of support which could be available to help them get through a crisis, unless they have some written information, it is disappointing that 69% (41) people said they either didn't have a written crisis plan, or didn't know if there was one.

The increased focus on advance statements, which is discussed above, may present an opportunity to improve the development of written and agreed crisis plans. In effect, an advance statement can be a plan for one aspect of a future mental health crisis (the possible need for compulsory treatment), and could be part of a wider process of anticipatory planning for future periods of mental ill-health.

When we asked if people knew who to contact for support in a crisis, and who they would contact, whether or not they had a written plan, the information was more re-assuring. Ninety two per cent (54) people knew who they would contact. The other five people who didn't know, or didn't give us any information, told us at other points in interview that they were happy with the overall support they were receiving, apart from one person who wanted help to be more physically active. We also saw some very positive examples of good crisis planning. One person spoke positively about their WRAP plan, and showed the Commission practitioner their WRAP folder. This has detailed information about things which may trigger a crisis, and things that help the person through a crisis, along with clear details about who to contact in a crisis.

People were asked who they would contact if they needed to speak to someone urgently. Fifty one per cent (30) identified one contact person, and for 17 of these people their contact was their CPN. Some people could identify a number of crisis contacts, and 46% (27) said they had two or more contact points for when they felt unwell. Amongst all the 59 people we saw, 64% (38) recognised their CPN as a crisis contact point, 39% (23) said they could contact their community mental health team (CMHT) directly, 15% (9) would also be able to contact their GP, and 17% (10) said they could also contact NHS24. Thirty two per cent (19) told us about additional crisis supports they would use – including family and friends, their minister, the Samaritans and Breathing Space. Three people said they could access support from staff on site in the accommodation where they were living, and six people said that they could contact a specific crisis service, which was available locally.

We asked people if they had ever needed to try to get support in a mental health crisis. Twenty seven (46%) people told us they have not needed support in a crisis, while the same number said they had. Five people didn't give any information about this. Many people found it hard to remember when they had last needed support in a crisis, and a small number of people told us it had been a number of years since they had used crisis supports. Most people, though, had had some extra support in a crisis within the previous year, with several people having been unwell and getting additional crisis support within a few months before we visited them.

We asked people to tell us if they had found the crisis support they received helpful. We heard a range of comments from people about the crisis support. Some people simply told us that the support had been helpful, and two people said they had been admitted to hospital for a short period of in-patient treatment during the crisis. Some people were able to identify what had been most helpful getting support in a crisis.

Getting a quick response to contact was seen as probably most valuable. One person told us *'(the crisis response) was great, so responsive, so helpful. I have CPN and psychiatrists mobile numbers, because I never abuse it.'* Another person was very positive about the responsiveness of CMHT reception and duty staff –*'the reception staff are good, they put you straight through to the duty CPN if your own CPN is not available.'* Several people similarly spoke about the benefit of getting a quick response in a crisis, sometimes with a person phoning back to talk, and sometimes with arrangements made for someone to visit very swiftly. One person flagged up the importance of information being shared appropriately. They had attended their local A&E department in an emergency, and told us how their health records include a record of early warning signs when they are becoming unwell. The person has a copy of this themselves, and it is also available for A&E staff. They felt that having this record available meant that A&E staff helped the person through their crisis very well.

Several people described how support was increased during periods when they were in crisis, and how this was helpful. One person told us how they had increased input from their CPN, alongside daily visits from a crisis team, and they stated very clearly that they felt this increased support helped prevent them being admitted to hospital.

Several people identified things which they felt had been unhelpful when they had tried to get support in a crisis. People were positive when they received a prompt response to contact with services, but we heard from some people who said they had phoned a service several times in one day, and got no call back, or had been given very brief telephone advice which was not helpful. One person described in some detail the initial contact they had had with NHS24. They said they had had to wait for several hours to speak directly to someone with mental health knowledge, at a time when they felt they were at risk of harming themselves.

Summary of findings

Overall. almost everyone we spoke to know who they would contact in a crisis, although under a third said they had a written crisis plan.

We saw some examples of very good crisis care plans, with information about what triggers a crisis, what helps the person through a crisis, and who to contact. We also heard how experiences using crisis services such as A&E departments were more positive when good information was available to these services about the early warning signs when that individual person is becoming unwell

Most people knew their CPN was the person to contact in a crisis, either as the only contact, or as one of a number of contacts.

People recognised that there were specific things that were important about support in a crisis. Unsurprisingly, they valued getting a quick and sympathetic response and the fact that, for a number of people, support was increased during the time when they were more unwell.

Recommendation

Professionals should develop a written crisis care plan jointly with people receiving care and treatment. Where appropriate this plan should identify care and support preferences in anticipation of a crisis.

2.4 Physical health care

What we expect to find

We know that people with long term mental health problems have greater risk, and higher rates, of a number of physical health conditions. Poor mental health is associated with an increased risk of physical illness, and a much higher mortality, with people with severe and enduring mental illness dying on average more than 10 years earlier than the general population[14] .

The Scottish Government has made commitments to improve the physical health of people with a mental illness. In 'Delivering for Mental Health' (2006) the government said: 'We will improve the physical health of those with severe and enduring mental illness by ensuring that every such patient, where possible and appropriate, has a physical health assessment at least once every 15 months.' In the 'Mental Health Strategy for Scotland: 2012-2015' the government re-affirmed this and said: 'Commitment 28: We will continue to work with NHS Boards and other partners to support a range of health improvement approaches for people with severe and enduring mental illness......'

We expect to see people with a severe and enduring mental illness having regular physical health reviews, and accessing specialist input where required.

What we found

In our recent themed visit report to people on longer term community based compulsory treatment orders we reported that under half of the people whose care we reviewed had documented regular physical health monitoring. In this visit 88% (52) people said they got a physical health check every year. Five per cent (3) said they did not get a check, while 7% (4) were not sure.

Forty three people, almost three quarters of the people we saw, had an annual physical health check from their GP. The checks which people could tell us about generally included blood pressure checks, heart tracing (an ECG), blood tests, and a weight check. Several people also spoke about other checks being done, by the GP or a specialist, because of other health conditions they had.

We asked if they were a smoker, and if they had any concerns about their weight. Fifty four (32) people were smokers, and 39% (23) had concerns about their weight. When we asked if they had been offered help to stop smoking or manage their weight, 80% who smoked or had worries about their weight had been offered support. People were also asked if they got regular exercise. Fifty eight per cent (34) said they did, but of the people who had concerns about their weight under half (11 of 23) were exercising regularly. Some people were going to a gym, or going to other exercise classes, but for most people who did exercise, walking was the main form of exercise. Some people told us that exercising was difficult for them, because of other physical health problems.

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[14] Mental Health Strategy for Scotland 2012-15 FULL REFERENCE TO ADD

Summary of findings

We were pleased to find that a very large majority of people told us they had regular physical health checks. We were pleased to find that people were being followed up and encouraged to participate in national health screening programmes.

We were also pleased that a large majority of people who smoked or had concerns about their weight said they had been offered support with these issues. That said, the high percentage of people who still smoke suggests that support to give up smoking may have had a limited effect. This is an area of considerable health inequality which requires further work, recognising the barriers faced by people with severe and enduring mental illness to living a smoke-free life. [*Add reference to ASH Scotland work on this*]

Over half the people we met said they exercised regularly, and some were doing a range of exercise activities, while for many people walking was their main exercise. Most people who had concerns about their weight said they were not getting any regular exercise. We suspect that many of the people we saw are not meeting guidelines for healthy levels of activity. Exercise referral schemes targeting primary care populations have been in place in many parts of Scotland now for a number of years, but no-one who spoke to us mentioned having had access to such a scheme in their area.

Recommendation

Health and social care partnerships should develop targeted activity to promote physical exercise for people with severe and enduring mental illness in their areas, including exercise referral schemes.

2.5 Activities and social support

What we expect to find

The Scottish Recovery Network website emphasises that while recovery is a unique and individual experience we know that certain things help in the process of recovery. The SRN describes some of these common themes *(Ref –web-site > Recovery > What helps)* and talks about how 'having good relationships and being connected in positive ways to other people' and 'having a meaningful and purposeful life' as being amongst the things which are important for recovery.

The Equal Opportunities Committee at the Scottish Parliament published a report in 2015, *Age and Social Isolation (Ref: Equal Opportunities Committee 5th Report, 2015)* While this report looked at the impact of social isolation in relation to older people and younger people the committee heard evidence from a number of mental health organisations, about how people with mental health problems lost societal contact, and about the impact and prevalence of isolation and loneliness. There had been a previous report from the Social Exclusion Unit in 2004 *(Ref; Mental health and Social Exclusion, The Social exclusion Unit, June 2004)* This report drew on a review of literature and research, and information from various consultation events, and concluded that adults with long term mental health problems are one of the most excluded groups in society and that social isolation is an important risk factor for deteriorating mental health. The recent report published by the Mental Health

Foundation, '*Relationships in the 21st Century: the forgotten foundation of mental health and wellbeing*'[15]also concluded that people who are more socially connected are happier, physically healthier, and live longer, with fewer mental health problems.

The 2003 Act places clear duties on local authorities, under ss.25 -27, to make sure that a range of services are available locally for people in the community with long term mental health issues, including services to promote wellbeing and social development. The Act also provides that local authorities should co-operate with health boards and others, including voluntary organisations, to provide this range of services.

In this themed visit, we hoped to find that people were being supported to build positive connections within their communities. We also hoped to see, with the integration of health and social care, examples of co-operation between local authorities and health services to provide services promoting wellbeing and social connectedness.

We anticipated however, that some people would feel socially isolated and may not have many positive connections with other people where they were living. A review of mental health services in Scotland commissioned as part of the Mental Health Strategy and published in January 2016 found that:

'Some participants with severe and enduring mental health conditions reported increased social isolation. This might be linked to unintended consequences of positive shifts towards more personalised approaches and centralised specialist services and needs to be monitored carefully.'[16]

What we found

We asked people about the informal support they had from people who are not paid professionals, specifically from family, friends, or others. We asked how satisfied people were with their social lives, and if they felt lonely or isolated at all. As well as asking about informal supports we asked people to tell us how they spent their time, and whether this included doing any voluntary work, participating in training or education opportunities, or being involved in any social or recreational activities.

When people had been in hospital for treatment as an inpatient we also asked them if they felt the quality of their life was better since they had left hospital, and if they could tell us what was helping to make their life better, or indeed if something was hindering their recovery.

Only 14% (8) people told us they had no contact with people who provided informal support, although one of this group did tell us they had very regular contact with a family member, but they did not seem to view this contact as part of their support system.

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[15] https://www.mentalhealth.org.uk/sites/default/files/Relationships-in-21st-century-forgotten-foundation-mental-health-wellbeing-full-may-2016.pdf

[16] A Review of Mental Health Services in Scotland: Perspectives and Experiences of Service Users, Carers and Professionals: Mental Health Foundation FULL LINK TO ADD

Eighty six per cent (51) people told us they had some informal contact and support. This could be from their partner, from family or friends, or from other people who are not paid professionals.

We tried to gather more information about the nature and frequency of this support, and some people described having very regular and helpful connections and gave us a positive picture of their informal support system. We heard from people who had frequent visits to and from family and friends, who felt they had very supportive friends and neighbours, and who met people regularly at a range of different social and recreational events. We also heard from people who had much more limited contacts and said they might only see someone once or twice a week, or even less frequently. A few people also described having practically no informal contacts: one person said 'I have no-one I would class as a friend', another said they had no friends alive now, and no family, and one person said that their closest relative had died last year, and that 'they were the only person I trusted.'

We got varied pictures from the 59 people we saw about their informal supports. For example one person who told us they had very supportive friends and neighbours, and a lot of contact with different family members, described themselves as experiencing some loneliness, while the person who said they had no family and no friends left alive said they were happy with their social life. When people who spoke about having supportive frequent contacts where they were living this did not necessarily correlate with their feeling more positive about the quality of their life.

We asked people to rate how satisfied they were with their social life. Fifty one per cent (30) people said they were happy, very happy, not lonely, or had as much contact as they wanted. Five per cent (3) people didn't answer this question, while 44% (26) indicated they had some dissatisfaction with their social life. In this group people said variously that they felt lonely, or isolated, or would like to have more contact with people, while one person did not feel safe to go out.

Interviewees' feelings about their life were varied, and complex. Some people who had a lot of informal contacts with friends and family, and were doing a lot of things, rated their social life negatively, while other people who seemed to practitioners to have limited connections with others were positive about the quality of their social life. Where people were satisfied or very satisfied with their social life they did in the main tell us they were doing a lot of things. One person spoke about a range of things they did with family and friends, and said '*in fact sometimes I feel I am too active and do too much and then feel tired*'; someone else who said their life was good said '*I go out with friends, play football, go to the cinema, go out to eat, just normal stuff*'; and someone else told us how they use their bus pass and follow their local football team to games across the country, and meet many people through this, as well as having good friendships with neighbours.

Where people rated the quality of their social life more poorly, there did seem to be some common issues. Several people, for example, talked about how they had lost their jobs, and lost the connections and the feeling of being valued that they got through work. A number of people, including people who seemed to do a lot of things during the day, spoke about feeling lonely in the evenings.

Sometimes people said they did not enjoy social settings or groups, and two people did not feel safe going outside because of traumatic events they had experienced.

A common experience for many people was that they would reflect on how their life had narrowed since they had been ill: '*a lot of friends disappeared since I became unwell four years ago*', or '*I lost a lot of friends through illness*'. Even when people had not lost contact with friends directly because these friends had stopped visiting them when they became unwell, some people recognised that friends had simply moved on in their lives –one person who had had a large circle of friends from school spoke about how many of them had married, or had moved away for further education or work.

Activities

Everyone we met told us something about the activities they did. Twenty nine per cent (17) said they were doing some voluntary work, or training towards work, or some other training or further education. Voluntary work placements we heard about were very varied, and people were doing voluntary work with recycling projects, charity shops, local church groups, and arts projects. Several people were also doing voluntary work in mental health related projects, with local mental health associations, or being involved in training professionals or peer support workers.

A few people said that they were doing further education courses at college or university, and 56% (33) spoke about being active in a number of things, visiting family, friends, or going to a variety of groups which ranged from creative groups such as art or drama groups to sport or other recreational groups. Some people, at the time we saw them, said they had stopped doing things temporarily because they felt unwell, sometimes because of physical health problems. A small number of people said they did nothing. Some people also told us they did maybe one or two things a week, but these activities mainly related to contacts with professionals. One person spoke about going to see their occupational therapist (OT) and their psychologist, and that other than that they mainly went to the shops.

We asked people who had been in hospital whether things were better out of hospital, and if so what made things better. Sixty eight per cent (40) said their life was better out of hospital. Many of the other people we met had never been in hospital so did not answer this question. The most common thing people mentioned if they told us what made life better was being free to live their own lives, to do their own things, to make their own choices, sometimes about simple things like watching TV or listening to music. Some people mentioned having social support in the community as something which made life better, and two people told us how resuming family life and their role as a parent of children was very positive.

We also asked what helped people keep well, and if there was anything they would change about their care and support. With regard to keeping well and what people valued most, 34% (20) did not give us any information. A number of other people spoke about aspects of their professional support and treatment helping them keep well. The biggest group of people, 36% (21) told us how important certain things in their social life were in keeping them well. These things were social contacts with family and friends, keeping busy, '*having things to occupy me purposefully.*'

Some people mentioned things that were solitary, like watching TV, or working in their garden, but most people did talk about the importance of being connected with other people as something they valued and helped them stay well.

Summary of findings

Most people told us they had good informal support systems, and good connections in the community with family, neighbours and friends.

Nevertheless, a significant number of people were experiencing some loneliness and isolation, and this happened, even when people have regular support from family and friends. People said they can feel lonely at specific times, or that they feel lonely because they have lost social networks they had when they were in work, or have lost contact with friends who have moved on in their lives while the person has been unwell.

Some people were very active and involved in a lot of activities, but others appear to have restricted lives, where their main contacts are with professional support staff. Where people were involved in more purposeful activities, they tended to have more goals, and expectations which were recovery focussed.

One person on a college course told us they had completed one course and had moved on to a part-time diploma course at college, and that they felt that *'no-one believed I could achieve what I have managed.'* Unfortunately this sense of optimism was unusual and it was more common to hear people tell us that they had accepted and were resigned to having a more limited life now, as a consequence of mental illness.

Although this is by no means a wholly negative picture, we believe more could and should be done to support those people who are isolated and lonely, or whose lives lack purpose and meaningful activity. We recognise the resource pressures on local authorities, but we believe the duties in sections 25-27 reflect a preventive and recovery based approach, and remain important. They should not be forgotten or overlooked.

It is striking that several of the submissions to the Scottish Government in advance of the next mental health strategy made similar points, for example:

'*For people living with mental health conditions, 'prevention' means support to live a fulfilled life, as free as possible from the disabling effects of ongoing mental ill health. This requires flexible, equitable access to health and social care services that act early, hold hope, and focus on creating the circumstances for a person to thrive, not merely exist.*'[17]

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[17] Why Mental Health Matters to Scotland's Future: a Scottish Mental Health Partnership Special Briefing Paper: Royal College of Psychiatrists and 13 partner organisations LINK TO ADD

Recommendations

The Mental Welfare Commission and the Care Inspectorate will discuss how the Care Inspectorate can strengthen the focus on better outcomes for people with severe and enduring mental illness as part of the inspections of care at home and housing support services, looking at how services promote wellbeing and social development.

Local authorities and health and social care partnerships should review how they can work together to develop the provision of relevant services under ss. 25 to 27 of the Mental Health Act.

2.6 Housing finance and employment - What we expected to find

A settled home is vital for good mental health whereas poor accommodation can make mental health problems harder to manage. When we visit people living in the community we expect to find that they are in suitable accommodation which meets their needs.

Where people were prepared to provide information we also asked about the benefits they were receiving, and whether they had had any difficulties with benefits or debts. We expect to see that income is maximised, and that people have been offered support if they have any issues with debts or financial problems.

The Scottish Government acknowledged, in the Mental Health Strategy 2012 -15, that 'improving and increasing access to employment for those with mental illness is challenging, but necessary and achievable.' The strategy also spoke about the importance of employment in promoting and maintaining health, and Commitment 29 referred to promoting the evidence base for what works in employability. We hoped to see some people, as part of their recovery plan, being supported to access employment opportunities, whether paid or voluntary.

What we found

Housing

We got information from all the people we met about the accommodation they were living in. Of the 59 people:

- 59% (35) were living in housing association or local authority tenancies
- 8% (5) were living in privately rented accommodation
- 25% (15) were living in owner occupied houses
- 7% (4) were living in other accommodation.

No-one was living in temporary accommodation.

Very few of the people we met had negative comments about their accommodation. Fifteen per cent (9) people who were living in housing association tenancies were in some form of supported accommodation, with support staff available on site or on call. Two of these nine talked about how, in the future, they wanted to live in a more independent tenancy, or to have less support coming in to their tenancy.

These comments re-enforce the fact that accommodation and support needs should be reviewed regularly, to ensure that people have the opportunity to move on, where appropriate, to good quality mainstream accommodation. Three people spoke about needing to move to different accommodation. In one case this was because the person's children were all working and living away from home, and the house was too big. In another case because the person has a family and now needs more bedrooms, and in another case because the person was assaulted near their flat. In two of these cases a social worker was actively supporting applications for a housing transfer.

Finance

Although we asked specific questions about benefits, we did not get a clear picture of how benefit changes may be impact on the people we met. This was similar to what we reported in our recently published themed visit report 'Visits to people on longer term community based compulsory treatment orders.'[18]

Of the 59 people we saw, 12% (7) had a Department for Works and Pensions (DWP) appointee in place to manage their benefits. Only one person had an attorney managing their finances, and no-one had a financial guardian appointed. Eighty per cent (47) of people said they were happy to discuss finances with us. Of these 39 were managing their money themselves, and two people told us of informal arrangements they had put in place.

One person described how they identified themselves to their bank as a vulnerable customer, resulting in the bank agreeing to take action if they see any unusual or large transactions in the person's account.

People currently claiming welfare benefits are experiencing the biggest change to the benefit system for many years. A number of new benefits are replacing existing benefits, with the aim of simplifying the benefit system, and reducing the overall benefit budget. Many people will be moving over to new benefits, including the Personal Independence Payment (PIP) and the Employment and Support Allowance (ESA). There is clear evidence that poor mental health is often associated with experiencing problems with the benefit system, and that benefit problems can impact on mental health[19] .

We asked if people had had any advice in the past six months to maximise their income or benefits. Sixty three per cent (37) said no, and the other 22 had had help from a range of people, including social workers, community nurses, benefit advice workers, and family and friends.

We asked if their benefits had gone up or down recently. Fifty nine per cent (35) said their benefits had stayed the same or increased.

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[18] Mental Welfare Commission for Scotland (2015) *Visits to people on longer term community-based compulsory treatment orders.*
http://www.mwcscot.org.uk/media/243429/ccto_visit_report.pdf
[19] Centre for Mental Health (2013) Welfare advice for people who use mental health services
https://www.centreformentalhealth.org.uk/Handlers/Download.ashx?IDMF=ae91ee5e-6fe2-4c88-8909-b2756913b2fd

Twelve per cent (7) told us their benefits had decreased –in three cases this was because of changes in personal circumstances, and one person said they had had to repay an overpayment. Two people had had benefits stopped and had appealed the decision and won their appeal.

We asked people if they had had a work capability assessment, and 20% (12) had, while a couple of other people had assessments coming up soon. Most told us that it had been decided they were not well enough to work, but two people said the outcome had been that a particular benefit was stopped, and they had to appeal the decision.

Several people had also mentioned appeals in relation to other benefits, for example Personal Independence Payments (PIP), and one person told us that while they won their appeal, it took five months to get a decision. A number of people also told us they were anxious about benefit changes in the future because they knew they would be moving on to new benefits soon. One person, for example, said they knew they were going to be moved from Disability Living Allowance to PIP and had already been told they might well receive less money when their benefit changes.

The Scottish Government will receive powers over many disability and caring benefits over the next few years, as responsibility for administering a range of benefits is transferred. This will include responsibility for PIP. This is a disability benefit which claimants with a wide range of conditions may qualify for, although the most common condition for anyone receiving PIP is a mental health problem.

The Scottish Government's stated aim is that claimants are treated with dignity and respect by the new benefits agency for Scotland, which will be set up to administer devolved benefits. The government has also said there will be ongoing discussions with service users and stakeholders about the new benefit system in Scotland, and we would hope this will include people with severe and enduring mental illness, some of whom told us they were anxious about upcoming benefit changes.

Employment

Eighty three per cent (49) people told us they were not employed. Ten per cent (6) were retired or students. Seven per cent (4) were employed – one person in a full time job, two part- time, and one person was self employed, although they were not working at the time we met them.

We asked people if they would like to have a job and if they thought getting into work was possible. Fifty three per cent% (31) told us they wouldn't like to have a job at present. Twenty seven per cent (16) said they would like to be working, and 15% (9) said they would like to have a job, but did not feel they could cope with work at present. When we asked people if they thought having a job would be possible slightly more people (33) said no, seven said yes, eight said maybe, and ten said they did not feel this was possible at present. We also asked if anyone was getting support towards employment, and 7 people mentioned supports, either from specific workers, or from attending specific groups or courses, such as a course on recovery and returning to employment, and a moving on employment support project.

Some people were very clear that even if they did not feel they could return to work at present they would want to be in work in the future: one person said very emphatically *'yes. I don't want my life to be over,'* and another person said *'I can find the prospect of getting a job stressful but I want something to give me structure enjoyment and fulfilment.'* A large number of people though did not see a return to employment as possible or achievable, with one person saying very simply *'who would employ me with my diagnosis.'* Many people seemed to have a sense of resignation, which was partly linked to concerns that they could not cope with the stresses of being in work, but also possibly to worries that they would not be supported or would be stigmatised in work.

Summary of findings

Almost all the people we met were satisfied with their accommodation, and a number of them spoke positively about how connected they felt with neighbours and in their community. Several people in supported accommodation had clear hopes that they would move into their own tenancies, to live more independently, and three people were wanting to move house, for family or personal reasons.

We did not hear many issues related to benefits but several people knew that they were going to be transferring to new Department of Works and Pensions (DWP) allowances, and were anxious about this process.

The figures for the number of people in employment are disappointing, but not surprising. We found similarly low figures in our themed visit to people subject to long-term community based Compulsory Treatment Orders. The Royal College of psychiatrists has said recently that 'mental health problems have a greater impact on people's ability to work than any other group of disorders.' (Ref: http://www.rcpsych.ac.uk/usefulresources/workandmentalhealth.aspx)

We found little evidence for this particular group that the responsibilities of local authorities under s26 of the 2003 Act to provide assistance in obtaining and undertaking employment were having a positive impact.

Only three people were in paid employment. A larger number were involved in voluntary work, and many people identified having a job as one of their hopes for the future. Most people also said they did not feel that having a job was possible for them, and a much smaller number said that while they did not think this was possible at present, because they would struggle to manage in employment, they would want to be working in the future.

The Commission believes that having opportunities for paid or voluntary employment would aid the recovery process, and would contribute towards people feeling more positive about moving into employment being possible in the future.

We believe this must be a strategic priority for central and local government over the next few years, and that the devolution of employment support in the Scotland Act 2016 affords a real opportunity to develop a new approach

Recommendation

The Scottish Government should include a stronger focus on employment support for people with severe and enduring mental illness in the next national mental health strategy.

Conclusion

There were several positive findings from our visits to people with severe and enduring mental illness who were in regular contact with community mental health services.

Almost all the people we met were positive about the care and treatment they were receiving, and Commission visitors also felt that most people were receiving appropriate care and treatment and that no-one was receiving inadequate care and support. People were generally satisfied with their care and treatment, most people felt they were participating in decisions about their treatment, and getting enough information to enable them to participate in decisions. Almost everyone also knew what they would do in a crisis. We also heard very clear views about what people valued in services – feeling listened to, having a consistent person to engage with, and feeling that services are responsive, with supports increased when necessary.

While people we met, and carers we had contact with, were positive about current supports some issues came up consistently. Some people who felt their recent experience using services was positive spoke about difficulties they had experienced previously accessing services. Most people did not know if there was a care plan in place, jointly agreed between themselves and health and social care professionals, which set out details of the care treatment and support being provided and of expected outcomes. Most people did not have a written crisis plan. Only a small proportion of people had made an advance statement, and the majority of people did not know what an advance statement was, or what the benefits of making a statement could be. Very few people were familiar with the idea of mental health recovery or with specific approaches to recovery, such as wellness recovery action planning.

Many people had wide support networks in their communities, and were involved in a range of activities. However many people also said they felt their lives could be more meaningful, and that they did experience isolation and loneliness. While community mental health services may not directly provide activities which promote social inclusion there is scope for services to do more to assist people to access local resources which have a social inclusion purpose, including education, employment, volunteering or leisure activities.