mental welfare commission for scotland

What we should be concentrating on in the Mental Welfare Commission

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

What people tell us

September 2019

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

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

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Summary

What were we trying to find out?

We were trying to find out from people with lived experience their friends and family what they would like the Mental Welfare Commission to concentrate on over the coming months and years.

Who did we meet?

We met 191 people with lived experience of mental ill health and their friends and family and a small number of staff across Scotland.

What did we find out?

We found out a large number of issues that are important to people. In the meetings we attend we have often explained what the Commission does but, reflecting on the responses, it may be that people do not fully understand the Commission's role, or they want it to do some things differently or maybe what we ended up with was closer to a list of the most important things people are facing around mental health issues and the services they receive.

Issues to do with hospital were the most frequently mentioned, which is helpful as a major part of our role is to do with visiting hospital wards, the particular issues people see as important were very varied ranging from the widespread use of illegal drugs, to the use of restraint and the décor of a hospital ward.

The next most frequently mentioned issue and the most talked about within groups was the services young people get, especially around transitions to adult services and the need for early treatment and investment in services. After that people were keen to talk about the shortage of staff in mental health services, the problems that constantly seeing locums causes people, the need to support staff and make working in mental health an attractive proposition. They also wanted to talk about the need for help in crisis, and mentioned that A&E was not always an attractive environment to be treated in.

After that people discussed the ways in which the Commission itself works, asking for such things as more unannounced visits, more discussion about local service users experience with the Government and more powers for the Commission.

People were keen that we looked at the value of peer support, both paid and unpaid and also very keen that we looked at the impact of welfare reform on people's mental health and whether its impact has contributed to an increased use of mental health services and the increase in detentions under the mental health act over the last few years.

Underlying the discussions we had was a theme of the impact of austerity and the shortage of community facilities to use. It is interesting to note that although hospital was mentioned the most, issues to do with communities were also mentioned very frequently.

It is also interesting to see that, despite the review of the Mental Health Act being announced during this meetings schedule, only one group appeared to think that this was important although two groups did raise issues to do with mental health tribunals.

Introduction

In late 2018 and up until the summer of 2019 the Engagement and participation officer (lived experience) held meetings with advocacy and support groups across Scotland.

One of the discussion topics during these meetings was about what people thought were the key issues and things we should be concentrating on within the Mental Welfare Commission.

We felt this would be a useful addition to the mainly professional perspective provided by the practitioners, board members and others at the Commission and felt it would be a valuable resource as the Commission plans its work program.

We met with 191 people who were mainly people with lived experience of mental ill health but there were also family and friends involved and a small number of workers (who were mainly advocacy workers). Most of the meetings were group discussions but we met a small number of people separately who do not attend group meetings.

We met:

- People with lived experience of mental ill health and friends and family in Highland (HUG action for mental health)
- People with lived experience of mental ill health in Highland (Serenity: support group for women with EUPD)
- People with lived experience of mental ill health and friends and family in Argyll (Mull Safe and Sound, Acumen)
- People with lived experience of mental ill health and friends and family in Argyll (Bute Link Club and Dunoon Acumen members)
- People with lived experience in Argyll (Acumen, Our Voice meeting Helensburgh)
- People with lived experience of mental ill health and friends and family in Glasgow (Bipolar Glasgow)
- People with lived experience of mental ill health, friends and family and workers in Lanarkshire (Lanarkshire Links)
- People with Lived experience of mental ill health and friends and family in the Borders (Bipolar Borders)
- People with lived experience of mental ill health in Edinburgh (Royal Edinburgh Patients Council)
- People with lived experience of mental ill health in West Lothian (West Lothian involvement group)
- People with lived experience of mental ill health and friends and family in Dundee (Healthy Minds Network Dundee)
- People with lived experience of mental ill health and friends and family in Angus (Angus Voices, Forfar)
- People with lived experience of mental ill health and friends and family in Angus (Angus Voices, Freikheim)

Issues and priorities raised by people with lived experience, their friends and family

Hospital

Issues to do with hospital were the most frequently mentioned priority (mentioned by 12 groups) for us to carry out work on. The issues people raised were:

Issue	Remarks
Easy access to illegal drugs when patients in hospital	"We raised the issue with staff but the situation did not change."
Bed numbers are reducing in some areas	"Be vigilant about more hospital beds being taken away; we should not see hospital as draconian and community good. (Hospital can be very good and community very isolated.)"
Acute wards seen as toxic	"Has the culture of acute wards changed? They seem more toxic and this may increase sections."
Smoking in hospitals	People said policies on e-cigarettes were unclear and that people who had to withdraw from nicotine experienced problems with this.
Long term hospital care	"People in longer term care: getting step down care and learning living skills and accessing community more. How does it work across the country? There are still some people who have been in hospital for many years."
Dormitories	Some people wish that dormitories were a thing of the past and that everyone had access to a single room.
Out of area placements	"Out of area placements can be really isolating; you cannot get visitors. It is hard to get contact with your local professionals and there can be funding issues." "The Intensive Psychiatric Care Unit in Lochgilphead: it was meant to have an IPCU. Going to Inverness makes it impossible for people to get visited." "NHS Highland pays for a certain number of beds at Gartnavel and it is common for the number to be exceeded and for people to be transferred as far away as Aberdeen. Are there enough bed spaces being paid for?" "It was a bad move to close Christie Ward in the Vale and make people travel to Glasgow for services."
IPCUs	There was concern about how people are treated in IPCUs.

In-patient suicides	"People who have been in-patients who have managed to take their own life; you would be astounded at the amount of people that do this in [hospital]: XX was hearing voices and her parents were trying to keep her in and she walked out and killed herself."
Nutrition	There was concern about nutrition in hospital, especially for people with eating disorders. There was also mention made of the links between nutrition and psychiatric issues and the need for attention to be paid to this. There was also concern about the quality of the food being offered.
Restraint	"Restraint - is it done right? Are people trained well? Is it used too often? Do they know alternatives and do they re-traumatise people?"
Activities	"What activities can people do on the wards? Is there Occupational Therapy, gym, swimming, third sector etc, and are the in-patient services and community connected?"
Observation levels	"The role of constant observation: it is a paradox in that it can make you more suicidal and more at risk. Because you are being prevented from doing something you become even more determined to do it and end up focussing even more on things like self-harm and suicide."
Private hospitals	"If the funding runs out you might not get the service you need."
People with additional needs	There were worries about how people with disabilities, physical illnesses, autism, deaf people etc are catered for.
Décor and the ward environment	There were worries about the décor and physical environment of some wards.
Discharge	"There appears to be a key focus on discharge from hospital whether the patient and/or carer feels that they are well enough to go home." "There is still considerable work that can be done to improve discharge planning. Carers identified that family members should be involved fully in the process. Not just told the person is getting home in two days' time. There remain waiting times for follow up by statutory and voluntary sector service providers." "There can be a wait of many weeks to see the Community Mental Health Team after being discharged from a first admission to [hospital]."

People getting stuck on acute wards	"People are being retained in acute wards for prolonged periods because there are no appropriate long term or rehabilitation places available to them."
Hospital provision and investment	"[Health board area] mental health hospital wards are not fit for purpose. There requires to be major capital investment to address the shortfalls."

Young people and mental health

This group of people was frequently mentioned in eleven groups.

Issue	Remarks
Transition to adult services	"Transition between children's services to adult services: people get lost in this. It all changes overnight."
Getting help at an early stage	"Very many people have tried to get help for themselves or relative since they were little. Had it been dealt with then they wouldn't be in that situation now: young people's early intervention services."
Children in care	"Kids coming out of care with a mental illness especially the transition to adult services and other support."
Exploitation of young people	People were concerned about the sexual abuse and trafficking of young people.
Avoiding the 'system'	People were keen that attempts were made to avoid young people becoming a part of long term care in the 'system'.
Investment in CAMHS (Children and Adolescent Mental Health Services)	People were concerned about the funding of children's mental health services and felt that different areas attracted more funding. "More resource allocated to children's services to identify and treat problems early."
Attitudes	"They give a diagnosis and then discharge. I phoned to say my daughter was suicidal and they said 'She is not on the books now and if she hasn't attempted it to not worry.'" "There is no continuity and the people are always new – my daughter having new people; she wouldn't speak to CAMHS at all and they decided not to speak to her. They do not take into account the whole person." "When she was ten we were told she had high anxiety and were told to go away and get on with it. They said she will not engage with anxiety programs so there is no point in trying. They did not even try to engage her though." "Stop seeing kids as naughty and look for the problems behind it."
Variation in professional practice	"I had one who was very straight with me and made sense and didn't say medication immediately and then the new one was going straight onto putting her on medication. Each professional seems to have their own beliefs."
Increasing levels of mental ill health in young people	"Young people; especially teenagers. It is becoming endemic, there is a huge upsurge."

GPs and their response to young people	"…taking young people with eating disorders seriously; a GP made light of my friend's eating disorder." "I was told when I was 16 and depressed that I was very bright and it was normal to have depression if I was bright. I avoided services for the next ten years."
Accessing help	"Young people who are crying out for help and not getting support; especially those with less severe problems."
Being sent out of area	There was concern about young people being sent out of area and away from home and possible visitors, to young people's units.
Young people's units	There was concern about some of the treatment in young people's units.
Young people on adult wards	There were worries about the times in which young people were treated as inpatients on adult wards and suggestions that there be specialised wards for young people between 18 and 25.
Counselling in schools	People wondered where the counsellors were in school, they thought there had been a commitment to provide them.
Choice	"Medication should be the last resort for young people –there should be a range of options for them."
Waiting times	People believed that CAMHS sometimes didn't meet waiting list targets.
Understanding	"Games about mental health: computer ones; for young people to understand it."
Information provision	"CAMHS don't give information to show you what to expect as a patient."
Help for very young people	People felt that people as young as six or seven years old often had a need for support, and that early support could prevent problems later in life.

Staff recruitment, retention, continuity and wellbeing

In eight groups people raised concerns about access to and continuity of care. They worried about access to a variety of staff but made especial mention of the reliance on locum psychiatrists which was becoming more and more common.

People felt that seeing locums was counterproductive and meant that trusting relationships could not be established, that the doctor had limited knowledge of their patient and sometimes relied more than was helpful on the views of the nurses.

People wanted to see national and international initiatives to recruit staff and to be sure that staff recruited from abroad intended to stay for some time to practice.

Some people said that practice among doctors varied and that they were more likely to want to see doctors who had a good reputation for the work they did and that they much preferred cooperative rather than controlling practice.

They also felt that psychiatrists were increasingly reluctant to apply for specialist or consultant posts.

They felt that many staff were overstretched, stressed and at risk of burn out, they felt that they can have low morale, be at risk of bullying and that some staff should be paid more than they currently are.

They wanted the knowledge of junior staff to be respected and wanted staff to feel cared for themselves and wanted to be sure that when recruiting; the right staff were employed and that recruitment did not suddenly occur when there was money left at the end of the year.

Help in crisis

Eight groups raised the issue of the support that they got in crisis, they had difficulties in getting help and felt that there was variable provision of things like out of hours services, home treatment teams and crisis service and cafes across the country.

Sometimes when seeking help they had long waits, without the needs of their dependants being considered and were in the end not assessed as needing the sort of help they felt they needed. For some people crisis services act as gate keepers to services and feel damaging when they don't respond in the ways people would have liked.

Some people didn't think A&E departments were the best places to provide crisis support and that attitudes there could be difficult.

Some people also thought particular attention should be paid to the treatment of people with a diagnosis of EUPD [Emotionally Unstable Personality Disorder] when they are in crisis.

People were also unhappy about the response time of NHS 24 and its local knowledge.

The Mental Welfare Commission

In seven groups people made particular recommendations about the way we do our work in the Commission. These included:

Issue	Remarks
Information provision	"There should be information provision to people about mental illness, including young people and young mothers and young men. There should also be videos about this on the Commission website."
Help people speak out	"Help people to speak out and encourage them to stand up and speak out and get angry. Do not penalise carers and patients who are trying to get services for people."
Additional powers	"You need teeth; make the Commission more like the Care Inspectorate."
Make sure the Commission is not used inappropriately	"I remember a Commission report with a recommendation; it was never implemented but then the NHS had another one they liked and made a big play of the fact that they should. The Commission reports can be used to organisations' own purposes."
Training	"Staff can't get released for training; could the Commission do training on some of their guides on the wards?"
Doing all the Commission could do?	"How many investigations of wilful neglect and maltreatment have been made under the Act?"
Action research	"Could the Commission engage in participatory action research? Maybe in the Commission you could look at more longitudinal long term work like this where users can both witness and experience change, rather than one off visits to places where users are involved for a short moment and are unlikely to hear of or witness any change as a result."
Promoting its role and publications	"The Commission should make further efforts to inform people of their role and how and when they should be contacted. Promote access to the Commission's reports and links to other regulatory bodies, e.g. the Care Inspectorate."
Engagement	"The Commission should meet the patients more in the ward and out in the community engaging with groups like [local mental health service user & carer organisation]. This may provide an extra incentive to [health board] to act on the Commission's recommendations."
Unannounced Visits	"There should be an increase to unannounced visits to wards with a focus on making sure proper resources are in place especially staff resource."

Influencing	"The Commission should be entering into conversations with Scottish Government to make them aware of the information and concerns that they have gathered directly from service users and carers in [health board]."
Promoting the Advice Line	"The Advice line is very valuable and helpful and is not promoted enough. I used to ring with patients and carers but most people do not know about it. It is one of the key parts of the organisation. They also always get back to you if they say they will."
Care plans	"The Commission should carry out detailed spot checks on care plans and case notes."

Peer support

In seven groups people highlighted Peer Support, both formal paid peer support and the informal support that often happens in places like self help and support groups.

This support where a person with lived experience provides (often mutual) support to another person with lived experience is very valued by some people.

They wanted to see something that recognised the value of peer support and which looked at how good its provision was in different areas of the country.

Welfare reform and the benefits system

In six groups people were keen to see the issues occurring in the benefits system looked at in more detail.

They wanted this to include the impact of being on benefits on people's mental health and whether welfare reform and poverty has resulted in an increase in admissions to hospital, as well as work to even up the emphasis between mental health and physical health when looking at benefits.

They also thought it would be helpful to look at the advice agencies that offer assistance with benefits claims.

"Parity of mental health with physical health in the benefits system – PIP [Personal Independence Payment] and ESA [Employment Support Allowance] is all about lifting things and going for walks, it does not acknowledge the ways in which mental illness stops us from doing many things including with our children and with work. There is a need for advocacy in the benefits system and an acknowledgement that going for a review is more than many people with a mental illness can manage – for instance I have not been able to attend any reviews."

Attitudes

In four groups people were keen that we look at some of the attitudes that exist within services and the wider community, feeling that some of the approaches some professionals took towards them were damaging and unhelpful.

"Listen to the patient; about what helps and what is needed. Look at attitudes towards patients, i.e. 'pull your socks up and get on with it.'"

"I was told bipolar is a good excuse for bad behaviour, by a psychiatrist."

"I wish some doctors had the humility to ask their peers when they are unsure – rather than trying to show they know the answer."

"I went to a GP who said 'I know nothing about mental health' and that he couldn't help at all, I felt deflated. It takes bravery to go in."

"Recognise the individual with mental illness – they have the ability to self-manage and express themselves and to value and be valued; in some places we are not equal and are not respected."

Mental health in rural areas

Four groups wished that we could do some work around the issues people face when living in rural areas.

They felt that people often found it hard to access services and that in some places there were little or no services for them to use and that with the impact of austerity among other things, some communities were losing the infrastructure and resources that keep communities together and thriving.

"[Village] had the library and it went into the schools and they took that away too. There is less community spirit. There were places you could chat but there is nothing for young people with a mental illness or a learning disability in rural areas."

"I have to go to Aberdeen for a ten minute medical appointment. It takes all day."

"Drop in centres and accessibility of these to people. How to get help in rural areas. Access to places to go to, without needing referred to them."

Information provision

In three groups people were keen to see more work on information provision about:

- Mental illness;
- Things to do;
- Services that exist; and
- Ways of overcoming isolation and loneliness.

Parity of esteem

In three groups people were keen for work to be done to ensure equity of services and investment, between services for people with mental health problems and services for people with physical issues.

> *"Mental health should have the same importance as physical health and should have the same resources allocated to it."*

Physical health and mental health

In three groups people were keen to see some work around people with both mental health problems and physical problems.

They wanted to know that:

- Services could work with people experiencing both issues;
- That physical health concerns were taken seriously and not dismissed as psychological problems; and
- Help people who also had issues to do with weight around mental health and physical health.

Community facilities

In three groups people would like to see an emphasis put on looking at the declining number of community facilities, the funding of community mental health services and community resources and the pressure on community mental health services.

> *"Closure of community facilities for people with mental illness. We need the link club reinstated."*
>
> *"The Community Psychiatric Nurses tend to be very good but it feels like they are under increasing pressure. It is rare to see them nowadays, they used to attend many of the community meetings but now never come along to events like that."*

Psychological treatments

In three groups people were keen for us to look at access to psychology and talking treatments.

They particularly emphasised the long waiting list for psychology in some areas.

Education and mental health

In three groups people wanted to see work on:

- Setting up education classes for people with a mental illness;
- Including people with a mental illness in mainstream education; and
- Teaching about mental ill health in schools.

Friends and family

In three groups people wanted work around the caring role some friends and family have. This took two main themes.

On the one hand people wanted the pressure carers were under recognised and respected. They wanted carers to have support, practical help, education about their relatives and assistance with developing skills. On the other hand some people felt that some families can be well meaning but, because they are ignorant of some of the issues, inadvertently damaging.

Advocacy and advice

In three groups people wanted more work carried out around advocacy (and advice over things like forms too) which they thought was very important and probably merited increased funding.

> *"Advocacy for the very vulnerable in hospital. I know about advocacy but when I was last a patient I did not know how to get advocacy on the ward. Advocacy needs to reach out to people and to recognise that when people are ill they may not be able to take in what is said or to recognise what they need advocacy for. Although on reflection, I did meet an advocate who seemed to say there was nothing they could do for me, which was probably right as I was very high. But if you are high or low it can be hard to trust or speak with a stranger even if they are an advocate."*

Trauma

Three groups had strong views that trauma should be incorporated into the work we do, feeling it was now gaining wide recognition as being at the cause of many mental health problems and illnesses and that acknowledging it would also address some of the assumptions behind some people's behaviour.

Issues raised by two groups

The following are issues that two of the groups we consulted thought we should be looking at.

Issue	Remarks
Medication	There was a worry about the effect of medication on people's behaviour and worry about the move to decrease the number of antidepressants being prescribed, which some people felt was more motivated by cost than good practice.
National investment in mental health	Some people wanted a comparison made between what was being promoted at a national level, with the reality of life at the grassroots. They felt that there was a wide difference between high ideals and reality.
Telehealth	Some people would like to see more work carried out to see if telehealth and IT based therapies and services are helpful.
Housing and homelessness	Some people wanted to emphasise how important having their own house and front door was and how important it was to look at homelessness and mental health.
Veterans	Some people thought veterans with mental health problems got a rough deal and struggled with bureaucracy and sometimes experienced homelessness.
Change over the last ten years	Some people would like to see a comparison between mental health services that were in existence ten years ago with now. There was an assumption that we are probably in a poorer position now than then.
Gender	Some people would like to see if services are different according to gender, with the treatment of women being particularly mentioned.
Early intervention	Some people would like more work around early intervention with anyone with a mental illness.
Older people	"Older people with mental illness: they get left behind." "Transitions from acute to older peoples services. Now I am in older adults there is less involvement and more decisions made for me. It is much more paternalistic."
General practitioners	Some people would like us to look at the practice of GPs: "They rarely come to reviews and are paid to carry out physical health checks but one practice does not carry them out unless a support worker books people in herself for a check."
Mental Health Tribunals	"Mental health tribunals. Could we look at these? The success rate for not granting a section is less than 1%; I can't believe (using my own personal experience) that psychiatrists are right this often. I worry that the tribunals are so biased towards the system that sections verge on being illegal."

	"Could the tribunal have more input on supervising the conditions and powers of an order?" "Are all the panel members of a tribunal seen as equal?" "The experience of tribunals and the accuracy of what is said. We need people who can understand how frustrating it can feel at a tribunal."
Austerity	People wanted to know if austerity had resulted in an increase in the use of mental health services and if it had played a part in the increasing numbers of people with a mental illness who have been detained.
Integration	People had concerns about integration: "The negative impact of the integration of health and social care has led to tokenistic engagement with service users and carers."

Issues raised by one group

The following is a list of the issues raised by just one group.

Issues	Remarks
Dual diagnosis	There was a feeling that we should look at the experience of people who had both mental health problems and addictions.
Access to services	The need for people to get help when they feel they need help.
The workplace	Issues in the workplace and a lack of interest in people returning to work.
Third sector	The value of volunteering for self esteem and the need not to expect the third sector to have all the answers.
Built environment	The need for the buildings where people get support for their mental health to be pleasant places.
Parents	The issues parents who have mental health problems face.
Needing help and the response of services	"What about people who need help but don't get it and will not ask for it."
Life insurance	Not being able to get it or it being too expensive.
After a suicide	There was a feeling that there is little support and some very negative attitudes towards people affected by a person's suicide and a need for good practice to be shared widely.
Exploitation of vulnerable people	"Someone who has a mental health problem and is vulnerable; being targeted by people who do not have their best interests at heart."
Differing environments	"The different culture in different services: why is there one?"
Supported decision making	"What evidence is there that people are supported to make decisions?"
Human rights	Look at human rights and mental health.
Alternatives	Look at alternative approaches to mental health.
The Mental Health Act	Being sure that people with lived experience can feed in to the independent review of the Mental Health Act. Scrutinise the power of doctors and social workers. "Consistency of orders and sections: it seems to vary with different consultants: the conditions that are put in which may be interpreted differently by the next doctor." "What percentage of people are under Compulsory Treatment Orders; the evidence is that they are too restrictive. If people have been left on them for years and years what on earth is going on?"

Choice	"How much choice in treatment do people have?"
Care plans	Their consistency, or lack of.
The police	Look at the help the police give.
The 'system'	"The system: how can you trust it when it can take our children, remove our liberty and lose us our jobs?"
Inequalities	"Inequalities: bullying, being fat, being poor, working families, grandparent carers – the recognition that there should be signs that people need assistance and that these things cause poor health."
Stigma	The need for less stigma around mental ill health.
Home treatment	The need to look at home treatment services.
Isolation	The need to look at isolation and loneliness.
Using community services	"What stops people from engaging in the community? What hook is needed to get people along for help?"

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