

# Overview of mental health services

Report supplement: Service user and carer views



Prepared for the Auditor General for Scotland and the Accounts Commission  
May 2009

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# Part 1. Summary

## Background

1. Audit Scotland published its national report, *Overview of mental health services*, on 14 May 2009. This report is available at: [www.audit-scotland.gov.uk](http://www.audit-scotland.gov.uk). As part of our review, we commissioned Ross Consulting to carry out focus group discussions to obtain the views of people who have used mental health services and carers of people with mental health problems. This supplement accompanies our national report and summarises the main findings from our work with users and carers.
2. Our research considers service user and carers' views on mental health services and includes the experiences of people with a range of conditions across varying ages, ethnic groups and geographical areas.
3. This supplementary report focuses on the experiences of people's access to services, the quality of their care, access to out-of-hours care, the coordination of services provided by various professionals and agencies and the level of information provided by services about their condition and treatment.
4. This report is organised into three parts: **Part 2** considers access to mental health services; **Part 3** examines the quality of mental health services; and **Part 4** looks at the coordination of care and information provided to services users and carers.

## Key messages from our focus groups

- Service users and carers reported long waits for mental health services.
- Wider services, such as housing services, can be a valuable support for people with mental health problems.
- Service users and carers reported that mental health services are not delivered to a consistent standard.
- Service users and carers felt that the standard of care is improving.
- Services need to better join up care to meet people's needs.
- Better information is needed to help people access services and understand their condition.

## Methodology

5. Audit Scotland commissioned Ross Consulting to speak with people in focus groups (small discussion groups) which lasted around an hour and a half. With the permission of the participants discussions were audio-taped and written notes were taken during the meeting. The researcher facilitated discussion around six broad questions (for carers these were focused on the views and experiences of carers):
  - What has been your experience around access to mental health services?
  - What has been your experience around the quality of your care?
  - How coordinated was your care and information about your care?
  - What has been your experience of other services you have required for provide support for your mental health problem, such as housing, leisure and benefits advice?
  - What is your experience of out-of-hours care?
  - Did you receive enough information about your mental health condition and your care?
6. A total of 18 service users and seven carers took part in six focus groups across Scotland, although several of the carers also had mental health problems. Participants of the focus groups were identified through a number of voluntary organisations (further details in **Appendix 1**):
  - Voices of Experience (VOX), Glasgow – a national mental health service user-led organisation
  - Highland Users Group (HUG), Inverness – a network of people with experience of mental health problems which represents the interests of users of mental health services across the Highlands

- Saheliya, Edinburgh – an Edinburgh-based service that supports the mental health and well-being of Black and Minority Ethnic women
  - Men in Mind, Edinburgh – an Edinburgh-based service that supports the mental health and well-being of Black and Minority Ethnic men
  - Scottish Transgender Alliance, Edinburgh – an organisation which aims to improve the lives and experiences of all transgender people living in Scotland through various activities including training, awareness raising, research and policy development guidance
  - National Schizophrenia Fellowship (NSF) Scotland, Edinburgh – an organisation which aims to improve the wellbeing and quality of life of those affected by schizophrenia and other mental illness, including families and carers.
7. The service users and carers included in this study are not intended to be representative of all service users and carers. We have attempted to get as wide a representation as possible across: age, gender, geographical area, deprived and affluent areas, ethnic groups, sexual orientation and mental health conditions. A more detailed description of the sample of participants is included in **Appendix 2**.

# Part 2. Access to mental health services

## Service users and carers reported long waits for mental health services

8. The most common issue raised in the focus group discussions was long waiting times to access mental health services. These long waits were reported to be months rather than weeks. This was the most frequently raised issue at all of the group discussions which participants wanted to see resolved.
9. People who had been discharged from mental health services but who subsequently needed further treatment or to contact services again expressed frustration at the difficulty of this process, especially the length of time it could take to get back into the system. These service users wanted to be able to refer themselves to services and not have to rely upon a referral from the NHS:

*“We know our own illness. We know when we are getting unwell.”*

**VOX, Glasgow**

10. Several people said that long waits to access care had led to self-harm and the use of antidepressants. Transgender people highlighted long waiting times for counselling regarding gender-reassignment which had caused significant distress.
11. Carers felt that the NHS could do more to prevent people diagnosed with mental health problems becoming unwell again:

*“The service waits for a crisis rather than trying to catch an episode before it happens. As a carer for 20 years – we are experts, we know when things are getting bad. We have been asked to catch episodes to prevent things getting bad but they don’t believe us when we do just that.”*

**NSF, (Scotland)**

12. Another issue raised by participants was the length of appointment times with NHS staff, which they felt to be too short. This caused some people considerable anxiety as they were worried that they would not have enough time to discuss their concerns. All groups wanted to see longer appointment times but without having to wait a long time for the appointment itself.

13. Counselling was widely seen as being of great benefit to enable people to begin the process of returning to a more healthy state of mind. However, long waiting times to access counselling provided by the NHS was again highlighted as a problem. Some people had paid for counselling in the private sector because they could not wait for NHS counselling but they said that this was an expensive option.

## **Crisis and out-of-hours services can be difficult to access**

14. Many examples were given in the groups about feeling they had to convince services that they needed to respond to a crisis situation and the subsequent stress this placed on carers and family members. Several people said that the police were often the first service to attend a crisis situation out-of-hours and they were impressed with their sensitivity and understanding of people with mental health problems. However, many people were not happy with the lack of out-of-hours care provided by other statutory services:

*“You have to become ill Monday to Friday between 9-5. If it was any other condition, like a heart attack, there would be a riot.”*

**NSF (Scotland)**

## **Wider services, such as housing services, can be a valuable support for people with mental health problems**

15. As well as specific mental health services there are a range of other services which may support people with mental health problems, such as help to get back into employment. Wider services are also important for promoting well-being, including leisure, recreation and community regeneration.
16. Housing services were frequently mentioned in discussions. Some people had good experiences with supported accommodation and others had mixed experiences with council housing services. One group (VOX in Glasgow) talked about the efforts local housing associations were making for people with mental health problems and said they were generally good at looking after their needs:

*“The housing association went the extra mile to move us to a ground floor flat with a garden. For mental health and well-being this has just been the best thing – previously we were in a high-rise.”*

**VOX, Glasgow**



17. Libraries were mentioned as a good source of information and that staff had helped people to find relevant information. Some people mentioned the importance of leisure and social activities for improving well-being and that there was not enough emphasis on this by service providers. One service user who had spent several months in a psychiatric ward would have liked to have used the gym in the hospital but staff did not encourage him to use it and there was no instructor in the gym to demonstrate how to use the equipment. The transgender group praised staff who had run a trans-swimming group which ran for six months at a public swimming pool in Edinburgh but funding had not continued:

*“It made a huge difference – it was intensively moving to be part of a group where you had trans-men and trans-women without attracting any undue attention or hostility – joy I think really. I felt good and I felt safe.”*

**Transgender Group**

# Part 3. Quality of care

## Service users and carers reported that mental health services are not delivered to a consistent standard

18. Participants said that there was a lack of consistency among individuals who work in the NHS in terms of their understanding about mental health problems, the time they spent with people, empathy with service users and their carers and knowledge about what services were available. Some people had lived in different parts of Scotland over the years and experienced varying levels of care. It was felt that staff working in general practice did not always have a good understanding about the needs of people with mental health problems or the full range of services available, particularly those services provided by voluntary sector organisations.
19. Several people felt that there are unacceptable levels of misunderstanding and prejudice among professionals regarding mental illness. Participants with black and minority ethnic backgrounds talked about a lack of understanding among professionals of cultural issues. One person who had been referred to counselling said the counsellor admitted that she had not had experience of counselling for ethnic minorities before and was unable to provide appropriate treatment. There was a general feeling that service providers were not fully aware of how cultural issues can impact on mental health:

*“The main thing is that no-one realised the problems I was going through – the language, the food, the weather – I don’t know if GPs are aware of those needs.”*

**Men in Mind, Edinburgh**

20. The transgender group were unhappy about the lack of understanding they had encountered around transgender and mental health issues:

*“Once I am in the appointment I have to do the educating and I don’t feel up to it. It annoys me intensely – you end up spending the time discussing your identity and who you are and why you have the right to exist.”*

**Transgender group**

21. Service users in some groups had been involved in providing training to social workers and others said they had received positive feedback from staff who had been on courses being provided to generalist staff to improve their understanding of mental health:

*“A&E staff said the training [mental health first aid training] had brought back the basics to them.”*

**VOX, Glasgow**

## **Service users and carers felt that the standard of mental health care is improving**

22. Service users and carers who had been using mental health services for a number of years said that the quality of care had greatly improved. It was reported that the NHS is now more of a listening service and actively engages with the needs and views of service users and carers more. Carers in particular thought that in recent years the NHS has engaged with them in a far more positive way.
23. Examples were also given in the groups of staff moving to new jobs and who had made efforts to ease the transition process for the service user. One service user said that their community psychiatric nurse (CPN) took them out for a coffee to tell them about their new job and explain why they were leaving. The CPN had made arrangements to ensure that continued support was in place for the service user before leaving and this was greatly appreciated.

## **The voluntary sector provide support to service users and carers**

24. Many people had used services provided by the voluntary sector and were generally positive about the response they had received. A key feature of the voluntary sector which was mentioned by all of the groups was that it tends to employ service users and organisations are often led by a service user management committee. Most people said they got a quick response and that the people working in voluntary organisations had a good understanding of their mental health problems:

*“I think that without Saheliya I don’t know if I’d still be here – I would have given up. They listen, they take an interest in you as a person. Things were immediately put in place and I remember thinking: ‘Oh my God someone is actually doing something’.”*

**Saheliya, Edinburgh**

# Part 4. Coordination of care and information

## Services need to better join up care to meet people's needs

25. Most people said that aspects of care and information were not coordinated between services or between different parts of the same service. The main complaint from service users was having to constantly retell their patient history to each professional they came into contact with which they found frustrating:

*“NHS 24 passes you to a psychiatric link – the problem is having to constantly repeat your situation to each person you are passed to when the person you are caring for is in crisis in front of you.”*

**NSF (Scotland)**

*“It has happened to me all through my life [having to retell my history].”*

**Transgender Group, Edinburgh**

26. The group from HUG in Inverness said they thought that living in a more rural area provided some advantages in the care they received because the pool of health care professionals was generally quite small and service users were more likely to be known to staff. They did not seem to have the same problem with having to retell their history.
27. The carers group from NSF (Scotland) had many positive comments to make regarding the improvement in the coordination of care and information. They talked about the benefits of Integrated Care Pathways (quality standards developed by NHS Quality Improvement Scotland for mental health services) and multidisciplinary teams. However, they did still identify some areas for improvement:

*“Hospitals are lagging behind in terms of joined-up information – it falls apart when they (the service user) move from the community into the hospital.”*

**NSF, (Scotland)**

## **Better information is needed to help people to access services and understand their condition**

28. Participants from all focus groups reported the difficulty they had in accessing information from the statutory sector. Carers highlighted that it is important they are made aware of the implications of mental health conditions in relation to their caring role, and the side-effects of prescribed medication for example, but they are not always included in these discussions. Service users and carers reported that information was not always provided on the condition (eg, schizophrenia), services or help and support available:

*“No-one told me what I should do or where I should go.”*

**Men in Mind, Edinburgh**

*“I had to find the side effects of my medication myself.”*

**Saheliya, Edinburgh**

29. Some service users said that they found themselves educating staff about what services are available and about their own condition. Staff in general practice were particularly highlighted as being unable to provide information on where further help and support could be provided by voluntary organisations. Some people also noted that their information needs have changed over time:

*“Carers have cared for people over a long period of time – the hospital needs to come back and ask us again about our information needs.”*

**NSF (Scotland)**

30. Service users felt that when counselling is offered people may need help with understanding the process of counselling itself and how it may be able to help them. The therapies provided, such as cognitive behavioural therapy, are predominantly used in Western societies and people from other cultures may not be familiar with them.

## Service users and carers obtain the information they needed from a number of sources

31. The participants expected the information they required to be provided by healthcare professionals but this was not always provided or there was not sufficient time to discuss all of their information needs. Voluntary organisations are a key source of information, together with other service users and carers. This is one of the main reasons for participants to use voluntary organisations. However, many people thought that the voluntary sector was fulfilling a function which should be undertaken by statutory services.
32. The internet has improved the amount of information available for people and was widely used by all groups. However, there was concern about the trustworthiness and quality of some of the sites:

*“The internet has made a difference – the internet can be confusing because not everything is available in all countries. You try and pin down a few reliable sites that you can go back to.”*

**Transgender group**

# Appendix 1. Demographic data

## Gender

Male	13
Female	12

## Transgender/ transsexual

Yes	5
No	18
No answer	2

## Age

Under 21	1	4%
21-30	1	4%
31-40	4	16%
41-50	6	24%
51-60	8	32%
61-70	4	16%
71-80	1	4%
Over 80	0	0%

## Area

Level of deprivation*	Number	Percent
(most deprived) 1	8	32%
2	3	12%
3	1	4%
4	5	20%
(most affluent) 5	5	20%
Unknown	3	12%

\*The level of deprivation was measured by matching each participant's postcode to the Scottish Index of Multiple Deprivation (SIMD) categories. The SIMD identifies small area concentrations of multiple deprivation across all of Scotland in a fair way to allow comparisons of the level of deprivation in different areas.

## Ethnic group

Scottish	15	
English	2	
Irish	2	
Welsh	0	
Other	1	
<b>White</b>	<b>20</b>	<b>80%</b>
<b>Mixed background</b>	<b>2</b>	<b>8%</b>
<b>Black</b>	<b>1</b>	<b>4%</b>
<b>Asian</b>	<b>2</b>	<b>8%</b>

(Caribbean)  
(1 Indian, 1 did not specify)

## Sexual orientation

Bisexual	3
Gay man	0
Lesbian	1
Heterosexual	21

## Mental health conditions

Anxiety	16
Bipolar disorder	5
Dementia	0
Depression	20
Eating disorder	5
Schizophrenia	3
Self harm	9
Suicidal thoughts	13
Other	8

'Other' includes borderline personality disorder, personality disorder and gender dysphoria.

The majority of participants had experienced more than one mental health condition. Seven people had experienced anxiety, depression, self-harm and suicidal thoughts - three of these also had eating disorders. A further eight people had experienced both anxiety and depression. The distribution of people who had suffered from multiple mental conditions was fairly even across deprived and affluent areas.

## Other conditions

Long term physical illness	8
Physical disability	5
Visual impairment	1
Hearing impairment	1
Learning disability	0
Learning difficulty	2
Other	5

Three people had both a long-term physical illness and a physical disability.

# Appendix 2. Acknowledgements

33. We would like to thank all of the focus group participants who agreed to take part and share their views and experiences on a sensitive subject. We are also grateful to the following people and organisations who took part in this piece of work, identified participants and helped to arrange the focus groups:

- Akin Fatunmbi, Service Manager and Siddhartha Das Varma (known to service users as Papush), Sessional Worker, Men in Mind, Health in Mind, Edinburgh. [www.health-in-mind.org.uk](http://www.health-in-mind.org.uk)
- Wendy McAuslan, National Development Co-ordinator, Voices of Experience (VOX), Glasgow. [www.voxscotland.org.uk](http://www.voxscotland.org.uk)
- Gillian Miller, Policy Officer and Kevin Morris, Health & Education Officer, Stonewall Scotland, Edinburgh. [www.stonewallscotland.org.uk/Scotland/](http://www.stonewallscotland.org.uk/Scotland/)
- Graham Morgan, Advocacy Manager and Emma Thomas, Development Worker, Highland Users Group (HUG), Inverness. [www.hug.uk.net](http://www.hug.uk.net)
- James Morton, Scottish Transgender Alliance Project Co-ordinator, Scottish Transgender Alliance, Edinburgh. [www.scottishtrans.org](http://www.scottishtrans.org)
- Maysoon Sutherland, Community Development Worker and Pat Elmsie, previously Manager, Saheliya, Edinburgh. [www.saheliya.pwp.blueyonder.co.uk](http://www.saheliya.pwp.blueyonder.co.uk)
- Mary Weir, Chief Executive and Liz MacKay, Administrator, National Schizophrenia Fellowship (Scotland), Edinburgh. [www.nsfscot.org.uk](http://www.nsfscot.org.uk)



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