

Towards A Mentally Flourishing Scotland

A response from carers living in Fife

Introduction

This paper summarises the views of carers in Fife who were consulted through Fife Families Support Project (FFSP) on the Scottish Government's proposals on the future of mental health improvement in Scotland. Fife Families Support Project is managed by the National Schizophrenia Fellowship (Scotland) (NSF Scotland) and is funded by Fife Council and NHS Fife to provide support, information and advice to the relatives, partners and close friends of people in Fife with severe mental ill health. We have provided this service since 1993.

The responses are organised under four headings:

- Proposed Local Actions
- What The Scottish Government Can Do To Support Local Actions
- How To Tell If The Actions Are Working
- What Else Needs To Be Done

The focus is on the actions around *“Support to improve quality of life, social inclusion, equality, recovery and addressing stigma, prejudice and discrimination.”*

Consultation

This paper outlines the views of carers we consulted and do not necessarily reflect the views of FFSP or NSF Scotland. The views were collected through Discussion with our local Advisory Group and through written questionnaires to a reference group of carers who had previously indicated a desire to be consulted on local and national service development. The consultation took place in January and February 2008.

Demographics

18 carers in all were consulted: 3 male and 15 female and all were resident in Fife.

The person they cared for was:

Partner – 4 Adult Child – 13 Sibling – 1

Some have also been users of mental health services, but we did not record that information.

Proposed Local Actions

There is unanimous agreement with the proposed actions laid out in the paper.

However, the support is qualified:

“But I don't think they address the core of the problem.”

“(But) effort should be more.”

“But just like a written care-plan it all looks good in black and white.”

“What the Scottish Government suggests – I have heard something similar before, but what action has been taken? Very little or none.”

Everyone feels the actions are very important and relevant to their situation, but some are sceptical as to how they will translate into action on the ground.

There is a particular welcome for action to improve attitudes and behaviours within staff groups with one person saying:

“The attitude of staff is important as people are very vulnerable when mental illness appears in the family.”

Some people, but not all, have had some very poor experiences of staff attitudes.

“Staff should appreciate that it’s heartbreaking to feel so helpless at times.”

Related to staff attitudes and behaviour is the issue of Stigma. People do support the goals of existing anti-stigma campaigns, for instance:

“Recovering from mental illness needs role models and encouragement within the local community, together with an attitude of empathy among friends and neighbours.”

“Mental illness can happen to anybody. My son was studying chemistry, physics and maths at university and his illness robbed him of completing it. I also lost a son to suicide 5 years ago.”

However, there is also a desire for a shift of emphasis:

“Look at educating the public more closely. What does the ‘See me’ campaign actually say about mental illness that allows the public to fully understand the problems the illness presents and prevents. It asks for tolerance and understanding but it doesn’t present a case for it.”

“Run TV ads demonstrating recovery with case studies.”

What The Scottish Government Can Do To Support Local Actions

People are clear that central government has an extremely important role to play.

They say:

“Central Government knows better than anyone the full range of care in the country. The varying degrees from area to area should be looked at and upgrades made in necessitous areas . . . working upwards to a level playing field for the nation.”

“Central government needs to consult with local agencies.”

“Promote and fund an expansion of Community Psychiatric Nurses/Psychological practitioners in line with local statistics and need.”

“Appoint a Minister for Mental Health to whom local representation/partnership etc are reporting – with access to the same by individuals.”

“More money is required to solve the problems that exist.”

How To Tell If The Actions Are Working

Almost everyone says that the best way to find out if change is working is to ask service users and carers:

“It’s felt locally by the patients and families immediately. They feel supported and understood – through being referred quickly to the correct professionals, through a knowledgeable GP, through not having long to wait for care (even when not in crisis).”

“Well users and carers would certainly be aware of staff attitudes improving when they come into contact with staff.”

“It is likely to be a long, gradual process but sufferers could be telephone-surveyed at 2-year intervals.”

“By seeing my son’s standard of living improving – personal care – regular haircut – finding dentist (NHS) – someone to accompany him to do normal everyday things – helping him to fill his day e.g. voluntary work.”

“More time given to each client (by professionals); wider access to psychologists, users more likely to cooperate (because the service is) less stigmatic.”

“I don’t want professionals to tell me things are improving or read it in a daily paper. I want to hear from carers, about the improvement in their loved ones’ lives and what has made the difference.”

In short, *they say the best measure when it comes to supporting those people who experience mental illness is to ask the people themselves and their families about their experiences.*

What Else Needs To Be Done

Befriending and Social Support

People are extremely concerned about the social isolation of their loved ones:

“Befriending. There is not enough emphasis put on this. I don’t believe professionals realise how important it is and should be recognised as such. Also befrienders should be paid for this important job. It helps to ease the carer’s burden which is also badly needed.”

“I would like to see an initiative to encourage people to befriend the mentally ill.”

“Befriending is badly needed, although difficult to recruit for. Perhaps there has to be a large scale media advertising campaign as part of a follow up to See Me.”

Linked to this is a desire to see more emphasis on social support, for example:

“Services should be making sure that people suffering from mental illness (especially under CTOs) have sufficient food in the home – whether that means someone going with them.”

“Look closely at the role and remit of practitioners and voluntary groups. Are they comprehensive enough? Do they collectively cover all aspects of care required? Should they be interchangeable and accountable?”

“Do employers need more information/education/incentives to employ and train staff? Is there a need for legislation to enforce inclusion with percentages of the workforce applied much the same as with general disability?”

“Could a grant system be reinstated for students experiencing mental illness? Currently would have a low income but have to pay for prescriptions. Could student debt be wiped out for same?”

Improved Responses from Services

Some people feel that services need to be more responsive and that people should not have to wait as long for help as they sometimes do:

“My son hasn’t seen a social worker since before Christmas. My son phoned me 3 weeks ago at 1.30am feeling suicidal. I phoned his CPN the next morning – only last week did he visit him. (If services can’t respond more quickly) there should be someone checking daily or every second day to prevent anything happening.”

“GP education in the many varied causes of depression with more emphasis on family history.”

“Much better access for the patient in referral to psychological care (waiting times are excessive at the moment).”

Summary

The carers we spoke with are generally in agreement with the proposed actions under improving quality of life, social inclusion, equality, recovery and addressing stigma, prejudice and discrimination.

There is a strong sense that staff attitudes, responsiveness of services and supporting a social and psychological as well as a medical approach are all crucial to achieving this improvement in people’s quality of life.

Finally, there is an apparent unanimity that in order to find out if your actions are working you need to listen to people who experience mental ill health and the people who love them.

Stuart R Pryde
Carers Officer
Fife Families Support Project
Unit 3, Fraser Buildings
Millie Street
Kirkcaldy KY1 2NL

01592 641401

ffspnsf@btconnect.com

www.fifefamilies.org.uk

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