VOX — Voices Of eXperience

VOX members meeting response to the Mental Health Strategy Consultation 2011-2015

1. METHODS
2. VOX'S TOP PRIORITIES
3. OVERALL APPROACH
4. SOCIAL PRESCRIBING - Isolation
5. COMMUNITY ASSET BUILDING – Stigma and Recovery
6. CHILDREN AND YOUNG PEOPLE – links to the Commission on the Future Delivery of Public Services
7. NATIONAL SUPPORT - Peer Support
8. CHALLENGING THE EVIDENCE BASE - Talking Therapies
9. FOCUS ON PERSONALISATION - Dual Diagnosis
10. LEADERSHIP - Service User Involvement, Advocacy and Participation
11. GAPS IN SERVICE PROVISION
12. LATER LIFE
13. FINANCIAL INSECURITY

1. <u>Methods</u>

VOX held members meeting on the 12th December 2011 to discuss the Scottish Governments mental health strategy consultation 2011-2015.

The findings were influenced by 78 individual participants who represented a wide range of people, up to around 3,000 people taking into account those who represented the views of local collective advocacy groups. The methodology we used was open space, and the following issues were discussed which related to the mental health strategy.

Open Space methods meant that we set the agenda on the day; members were asked to identify key issues/topics that they wished to discuss in relation to the mental health strategy consultation.

In addition to the findings which we gleaned from the event, we have also taken into account some of our group members' responses to the strategy consultation, in particular Lanarkshire Links, and HUG –action for mental health.

2. <u>VOX'S top priorities</u>

<u>THEME:</u> WHAT ARE THE KEY ISSUES THAT YOU FEEL ARE IMPORTANT IN RELATION TO THE MENTAL HEALTH CONSULTATION STRATEGY?

Individuals were then asked to use sticky dots to vote on what issues they felt should be progressed.

The following issues were identified (in no particular order) by our members;

<u>WELFARE REFORM</u>

- Priority:- Appropriate Assessment/Accurate Information
- Changes in assessment, the <u>P.I.P</u>.
- Collective advocacy should be recognised as a source of expression & influence.
- We should not be absorbed by other people's agendas.
- We need to build effective relationships between politicians, strategy makers, policy makers and service user groups.
- Changes in Staff/Service Culture. **(3 stars)**
- Illness dependency, need to argue illness to access benefit services.
- Impact of DWP assessment on individuals and services. **(3 stars)**
- Support for employment. **(1 star)**
- Availability of pre-crisis service – to avoid crisis!! **(4 stars)**
- Personalisation should be a choice, not a default **(2 stars)**

<u>BUDGET CUTS</u>

- Concern over the cuts to services (21 stars)

<u>YOUNG PEOPLE</u>

- Specific reference to transitions (14-25)
- Explore Peer support roles within that transitional period

- Skill up staff to support young people during these transitional stages or set up a service for this issue.
- Where possible, young people to be treated at home or in their community.
- Getting information to young people at an earlier stage, develop communications with young people.

STIGMA

- Needs to be a core part of the strategy. **(5 stars)**
- More productive education at school level to combat stigma/ needs to happen more widely.
- Fear factor
- More than see me!!
- More productive education at school level to combat stigma and needs to happen more widely.
- Stigma linked in with recovery (hinders recovery)
- Indicators to combat stigma in recovery. **(3 stars)**
- Changes in the media.
- People with mental health problems should be in more empowered positions in society. **(1 star)**
- Local as well as national campaigns. **(2 stars)**

ADVOCACY

- A key way of developing policy and strategy and finding out what people want is by supportive collective advocacy.
- It needs to be person centred – means what every individual wants.
- Needs to be decided by listening and doing and taking seriously the individual & collective voice.
- Government should implement legislation & implement policy decisions on advocacy collectively and individually.

ASYLUM SEEKERS/REFUGEES

- Better provision of Mental health for Asylum Seekers and Refugees **(11 stars)**
- More communication on a Government level **(9 stars)**
- More sensitivity in relation to cultural differences **(2 stars)**
- More training for professionals **(1 star)**
- Better pathways after people have been discharged from services.
- More advocacy for Asylum Seekers and Refugees **(2 stars)**
- Keeping mental health in mind and not to make things worse e.g. detaining children which increases mental health issues.
- To have services to integrate Asylum Seekers and Refugees into the community. **(2 stars)**
- Drawing similarities between people, breaking the barrier of "them and us"

MENTAL HEALTH AND LEARNING DISABILITIES

- Mental health services not a "good fit" for people with a learning disability.

- Look at their experience and learn from it e.g. stigma, involvement in treatment, protection and rights, person centeredness and transitions.
- Scottish Government to undertake a piece of work looking at experiences of adults with a learning difficulty in the mental health system with a view to developing a separate strategy plan.

THE USE OF TECHNOLOGY

- Get it recognised in the strategy and its use in mental health care.
- By the end of the strategy, using technology in mental health services/support should be as accessible as other forms. **(10 stars)**
- Look at innovation and IT more. **(1 star)**
- Use of personal devices and QR codes for advanced statements.

MILD TO MODERATE MENTAL HEALTH PROBLEMS

- Include regular feedback for mental health (not included at the moment) **(1 star)**
- How long did it take the patient to get the help?
- More use of the telephone and internet consultations to speed up access. **(1 star)**
- More use of telephone counselling.
- Self-stigma – more awareness raising. **(1 star)**
- Quicker assessments.
- Earlier intervention.
- Peer support whilst waiting. **(1 star)**

PEER SUPPORT

- It is an old concept that needs to be included within the strategy that also includes benefit and employment issues.

DUAL DIAGNOSIS

- Staff should be retrained to enable them to deal with the whole person i.e. all issues treated at the same time.
- Allocate each person a "team", addiction/mental health/employment/further education/family problems. Money issues (wider social issues should be looked at).

RECOVERY

- Recovery means different things to different people and groups of people.
- It's not a service **(8 stars)**

SOCIAL CONSEQUENCES OF MENTAL HEALTH PROBLEMS

- 85% of people with mental health issues face isolation. **(1 star)**
- Acknowledge social isolation as a key challenge to mental well-being. **(2 stars)**
- Raise awareness of this.
- Design services to challenge this.
- Commit to address the social dimension of mental ill health. **(2 stars)**

LATER LIFE ISSUES

- Treat the condition not the age of the person. **(3 stars)**
- Continuation of psychological therapy access post 65 years and post diagnosis of dementia.
- Recognition of early onset of dementia e.g. Korsakoff, Downs Syndrome in learning difficulties.

MEANINGFUL PARTICIPATION AND LEADERSHIP

- Need to be listened to and taken seriously
- Who should represent us? VOX SIAA
- Service users need to decide their own outcomes.
- VOX needs to be more representative i.e. Scotland wide. **(2 stars)**
- Government and decision makers need to evidence any decision made and be answerable to service users.
- Service user representation at the table.
- Government and local authorities should be held accountable. **(2 stars)**
- Stand firm together and unite mental health groups in Scotland so that necessary services i.e. services that promote well-being and prevent mental illness, are not closed. **(2 stars)**

Some of the discussions were repeated if a number of members wanted to engage in the topic and others had only one or two people who were interested. Those who raised the topics facilitated the discussion on those topics, members input into any discussion they felt they wanted to get involved in. The weighting of this has been stressed in the emphasis placed on the particular topics.

Due to the methods we used (where we were keen for our members to find the topics they felt to be important to them, and not to feel limited to what was in the strategy) not all questions in the consultation arose.

From these discussions we have developed some suggestions for how they could be addressed.

3. <u>Overall Approach</u>

Overall there some discussion around the fact that members would have liked to have been involved in thinking through some of the key outcomes, and that they would have had more of a slant towards people's lives more broadly rather than a strong focus on services. For instance social outcomes could be mentioned more frequently and inequalities should also be considered in relation to outcomes.

Members felt that much of the work which has taken place through Towards a Mentally Flourishing Scotland should continue to be developed, for example work on stigma, recovery and work with young people.

It was felt that the strategy was possibly trying to answer too many complex issues - for example in trying to influence service design – members felt this should be jointly worked through with individuals who would be affected by these changes. They suggested that this can be a role for service user led organisations to utilise co-production models of change, and that this would need dedicated time and involvement.

There should also be links within the strategy to other key developments for example self directed support. Furthermore the integration between health and social work should be outlined.

It would be helpful for the strategy to consider how the on-going monitoring and development of the strategy involves service users so that the essence of the views of VOX's members is not lost.

4. SOCIAL PRESCRIBING - Isolation

Members felt that the strategy should consider how the issue of isolation is addressed. Many members are not in relationships, do not have family and friends around them and feel isolated.

Members suggested that this should firstly be acknowledged and secondly reflected within the outcomes of the strategy as it would offer a wider recognition of the influence of social and economic factors.

Members highlighted a range of activities which they found beneficial, for this reason looking at social prescribing within the strategy may be helpful. This could include access to supported education and employment; community arts based activities and various group activities etc.

Interestingly the topic of suicide did not come up directly because the focus was often more on how to improve lives of those with mental health problems rather than to reduce suicide.

5. COMMUNITY ASSET BUILDING – Stigma and Recovery

It is suggested that communities build upon the skills which exist, one example of this is to support local mental health groups to challenge stigma and promote recovery within schools, or develop community arts based events which promote recovery. In other words that advocacy groups can play a key role in informing and empowering people to challenge stigma and promote recovery.

Members felt that the anti-stigma work which has been in the media was beneficial, and felt that this should be a core part of the strategy. In order for the anti-stigma campaign to be fully effective they also felt that that there should be a focus on the community level. Public Mental Health messages should therefore also be taking place at a local level.

Ideas given included more school level education and creative community events to achieve social awareness and reduction in stigma. In addition to this that key indicators to combat stigma should be developed.

There was also a feeling that stigma and recovery should be linked together in terms of their aims. Links should be made in relation to 1st level change where the service someone

receives is recovery focussed and 2nd level change where conditions are created within the community (e.g. less stigma) to help to allow recovery to take place.

Members agreed with the principles behind recovery such as hope, control and choice and felt that a focus on these principles was very helpful. However, it was felt that people with mental health problems are the ones that should guide how recovery as a concept grows and develops in the future. Improving wellbeing and good quality of life were terms our members related to more effectively.

Members felt that recovery work should focus on the following areas;

- Having a Purpose e.g. Meaningful activity/work/education
- Feeling validated through services e.g.gp's or accident and emergency services listening and understanding.

Much of this related to a community that didn't stigmatise mental health on a work or community level.

6. CHILDREN AND YOUNG PEOPLE

Members felt that a focus should be placed on involving young people in shaping services and that they are not developed in a top down way. Some suggestions members gave included - Young people's transitions, setting up a young people's health services which has an emphasis on young people 's mental health, and a focus on keeping young people within the community where at all possible. Overall it was felt that there should be generic understanding of young people's needs, and that all staff should be trained in issues of relevance to young people.

Members suggested that preventative approaches such as emotional literacy in schools should be focussed on. This links to the Report on the Future Delivery of Public Services by the Commission chaired by Dr Campbell Christie as it stipulates the need to focus on preventative measures.

It was felt that we could make more of technology within mental health particularly for young people who utilise modern technology on a daily basis, and that some work should be carried out to consider how this could best be developed.

Areas where this could be developed included the development of advanced statements, consideration of telephone and internet counselling to speed up the system.

7. NATIONAL SUPPORT - Peer Support

It was felt that peer support should be included in the strategy. Members felt that there are many situations where support from someone who has "recovered" can be inspirational in terms of their own recovery.

This was discussed in terms of talking therapies but also in terms of social issues such as housing, benefits and employment issues.

Members felt that both informal and formal peer support are very helpful, and felt that this could be a way to improve the difficulties currently seen in accessing psychological/talking

therapies. Continued National Support is required to help to develop this valuable approach further.

8. CHALLENGING THE EVIDENCE BASE - Talking Therapies

There is a need to raise awareness of the variety of talking therapies which exist and allow individuals to have a certain degree of choice into what they feel might work for them.

Members felt that the choice and empowerment in itself can help them to recover. They suggested that evidence based research may not consider the effects of control and choice and that this in itself negates some of the foundation for using evidence base when choosing talking therapies.

9. FOCUS ON PERSONALISATION RATHER THAN SPECIALISED SERVICES

It was felt that basic training in addictions should be rolled out to mental health staff so they have an understanding and awareness of addiction issues. It was also suggested that individuals who had mental health and addiction issues should be treated by a team of experts.

Members should therefore be looked at using a person centred approach, where staff has a wide understanding of broader issues that affect those with mental health problems.

10. LEADERSHIP - Developing Service User Involvement Advocacy and Participation

Throughout this discussion the importance of leadership was highlighted. It is felt that advocacy groups must be supportive of each other, work together in positive ways, and ensure involvement is meaningful, focussed and influential.

There should be recognition that people with mental health problems will get involved if a project/event/discussion relates to what they have experienced. Sometimes the topics they are asked to comment on feel distant from their experiences, and use terminology which doesn't help them to feel included.

Much can be understood from creative expression where those with mental health problems can explain how they feel, and then officials can work together with service users to explore solutions and appropriate outcomes.

There is a continued need to ensure that the way in which policy and strategy develops is steered by those with mental health problems.

The importance of both individual and collective advocacy was emphasised.

11. GAPS IN SERVICE PROVISION

Asylum Seekers/Refugees

It was felt that there was a lack of communication and mental health provision for asylum seekers and refugees. The social isolation, lack of networks, and barriers in terms of language and cultural differences, combined with sometimes extremely difficult circumstances for seeking asylum that this issue should be given priority.

Suggestions from a services perspective included cultural awareness, clear pathways for people who have been discharged from services and the provision of appropriate advocacy services (cultural awareness). There was also a community level perspective which related to integration of asylum seekers and refugees into the community, and breaking a barrier the "them" and "us".

Learning Disability

It is suggested that the Scottish Government should undertake a piece of work looking at the experiences of adults with a learning difficulty in the mental health system with a view to developing a separate strategy/plan.

This should be carried out utilising a co-production model where we learn from their experience of involvement, stigma, treatment, protection & rights, person centeredness and transitions.

Mild to moderate Mental Health Problems

It was felt that in order to help prevention of more severe and enduring mental health problems that some focus on mild to moderate mental health problems would be an effective way of reducing both time and severity of mental health problems. Some of the suggestions given included;

> Use of telephone and internet consultations to speed up access.

> More awareness raising work on self-stigma was also felt to be beneficial as it would assist in breaking the barriers for seeking help.

> Finally it was also felt that peer support could be utilised after the individual seeks help from their GP to provide some immediate support.

Eating disorders and Self Harm in older people

It was stated that some issues were incorrectly seen as an age related problem, in particular eating disorders and self-harm which were felt to be neglected if you don't fall into the "young people category". On-going support is required to ensure that people get the support that is required. Members stressed that problems don't just stop as soon as you reach a certain age

LGBT

LGBT VOX discussed the strategy, and it was felt that there needs to be more adequate provision of appropriate support and services for those who are from an LGB or T community, and that this should be reflected within the strategy.

12. LATER LIFE

Members felt that older people's general mental health was not focussed on adequately in the strategy. Members suggested utilising creative, community based projects, volunteering and befriending as ways to build on this area, again taking an assets based approach.

Furthermore that access to psychological therapies for older people should be included within the strategy. It was also felt that continued involvement with older people should be integral to any developments taking place within the strategy.

It is suggested that inks to the Scottish Governments older people's housing strategy should be made, where they are looking to provide support to older people to remain at home independently for as long as possible as opposed to inappropriate admissions to hospital. Clear actions relating to findings within this strategy would help to support the older people's agenda.

In the discussion on dementia, members agreed that whilst early recognition of dementia was essential that appropriate help and support was as important if not more so.

13. FINANCIAL INSECURITY

Although the strategy does recognise that the economic climate is a factor in terms of mental health problems the impact of this should be considered. Please refer to VOX's Real People, Real Cuts 2012 report.

It was stated that Collective advocacy should be recognised as a source of expression and influence in relation to challenging the spending cuts and finding the most appropriate solutions.

The importance of support for organisations essential to build effective relationships between politicians, strategy makers, policy makers and service user groups should be given precedence in this economic climate.

Changes in welfare reform were also discussed at length, and for the purposes of this consultation again the importance of effective service user groups was highlighted.

Wendy McAuslan

VOX – Development Coordinator

0141 572 1663

e-mail wmcauslan@mhf.org.uk