Making Contact

A report on direct consultations with Service Users and Carers of people who attract the diagnosis of Personality Disorder in Somerset

For more information about the ‘Making Contact’ project or about what’s happening for people with personality disorders in Somerset please contact:

Christopher Gordon
Clinical Nurse Specialist
Personality Disorder Network
Holly Court
56 Preston Road
YEOVIL
Somerset
BA20 2BN

01935 428420 (Ext 370)
07920245395

personalitydisordernetwork@sompar.nhs.uk
ABSTRACT

Direct consultations with service users and carers of people with a diagnosis of personality disorder in Somerset provided an insightful view of their experiences of accessing and using mental health services, and a meaningful way of identifying needs and how services might be developed to meet these needs.

The experiences of people showed that they valued being treated with dignity and respect, open and honest relationships with staff who had positive attitudes and were well trained and supervised, ease of access to and from services, relatively long-term involvement, being fully involved in their care and treatment, and robust support.

A number of unmet needs were identified during the consultations including:

- Clear and accessible information
- Support groups and networks
- Training and education
- Care pathways
- Quality standards
- A cultural shift

The findings of the consultation are consistent with national policy and contemporary research and, it is recommended that the findings are used to directly inform the development of a county wide service strategy. It is also recommended that mechanisms for ongoing consultation with service users and carers are put in place.

INTRODUCTION & BACKGROUND

This report summarises direct consultations with service users and carers of people who attract the diagnosis of personality in Somerset.

The consultation process is the first stage of the ‘Making Contact’ project by the Personality Disorder Network in Somerset Partnerships NHS & Social Care Trust. The project is funded by the South West Care Services Improvement Programme (CSIP SW) and its main aims are to:

- Consult service users and carers to identify their needs
- Provide identified training and education
- Develop a support network
- Identify service users and carers who can inform and help develop mental health services
- Develop and provide a central point of information for service users and carers
METHOD

The consultation process was arranged through a series of four two-hour meetings across the county for service users and carers respectively. The meetings were held between September and November 2007 and were supported by service user and carer participation workers.

The meetings were facilitated by a member of the Personality Disorder Network who kept anonymised notes. These notes were then sorted and analysed under general themes and headings. These were then summarised with recommendations in a draft report. This was then sent to each of the participants to ensure their views were represented.

PARTICIPANTS & IDENTIFICATION OF SERVICE USER AND CARER CONSULTANTS

In total ten service users and nine carers contributed to the consultations. A further three also contributed by e-mail.

During the consultation process four service users and one carer were identified as wishing to directly contribute to service development through quarterly strategy meetings.

RESULTS & SUMMARY OF IDENTIFIED NEEDS

The consultations produced a wealth of rich valuable information about the experiences and perceptions of service users and carers of people who attract the diagnosis of personality disorder in Somerset, and their views about how services should be developed locally in order to meet their identified needs.

Listening to and validating peoples experiences of using mental health services seemed very important as it appeared to meaningfully identify what mental health services should continue to helpfully keep doing and developing and, to stop repeating what is not:

Positive experiences of mental health service

“I have regular contact with the service through my CPN. He’s sound! We have built a good relationship over the years. He is open and empathic and does not make excuses for the short comings of the service. He treats me as an equal. The help of an STR worker has also helped me get into voluntary work and back to college. I feel I am gradually becoming who I am”.

Service User
A variety of positive experiences of general mental health services were identified and discussed including:

- Regular contact
- Relatively long-term involvement
- Good relationships with staff
- Openness, empathy, sensitivity and understanding
- Focused on recovery
- Positive attitudes
- Consistency
- Being fully involved and informed
- Staff who are well trained and supervised
- Staff who are supported and who are not overburdened by excessive caseloads

**Negative experiences of general mental health services**

“My psychiatrist talked about me not to me! I wondered if there was any point being there. My treatment was medication focused and offered me no light at the end of the tunnel. I stopped communicating and began to feel that I was dead. I was never offered any psychological therapy”.

Service User

A considerable number of negative experiences of general mental health service were also reported and discussed, including:

- Extreme difficulties accessing services
- Detrimental treatment which increased distress and risk of self harm/suicide
- A purely medical approach
- Unavailability of talking therapies
- Rigid, controlling and prescriptive approaches
- Rejecting/threatening behavioural approaches
- Inconsistent and infrequent contact
- Meaningless ICPA process
- Poor assessment & diagnosis
- Lack of information and understanding
- Poorly trained, supervised and supported staff
- Confusion about professional roles
- Poor communication
- Being labelled as stupid, attention seeking or a liar
- Punitive and disregarding attitudes
A number of specific themes emerged from the consultation discussions which are summarised under the following headings:

Access

“Once we are known to services we don’t want to jump through hoops to be able to access information and support. We need clear and accessible ways of communicating with those who are treating our loved ones”.

Carer

“Services seem to be fragmented and people get lost in the cracks”

Service User

Accessing services appeared to be a common difficulty. This often began at primary care with reports that GPs seemed to have difficulty recognising difficulties and not knowing where or who to refer to. Difficulties re-engaging with services after a break were also reported as well as difficulties gaining a full service as personality disorders seemed to be exclusion criteria for specific services.

SUMMARY OF IDENTIFIED NEEDS

- Clear and agreed care pathways
- Greater awareness in Primary Care and A & E departments

Treatment

“I was diagnosed with borderline personality disorder 15 years ago and it was only last year that I was offered talking therapies. I have been told that I could be waiting another two years before I get this”.

Service User

Treatment was discussed at length. In the main, there appeared to be agreement that psychological approaches or ‘talking therapies’ are the most helpful forms of treatment for personality disorders. There was general agreement that therapy should be relatively long-term. However, they were also considered not to be the ‘be all and end all’ to treatment. A psychological approach within general mental health services was perceived to be helpful. Other forms of treatment such as occupational therapy, art therapy, complimentary/alternative therapies, ‘Mindfulness’ and peer support were also seen to be most helpful. Several of the participants discussed how spiritual support and help had been useful.
Over emphasis on self-help particularly in the early stages of recovery was seen as unhelpful. Although medication was perceived by many to be unhelpful it was also acknowledged that it has its place and that more information needed to be available.

“I have no idea what’s on offer for people with personality disorder”.

“Sometimes people are so grateful for any form of help or just feel the need to please, which makes it difficult to express choice”.

Service Users

Choice and flexibility were also perceived to be an important aspect of treatment. Most were unaware of choices and some feared getting locked into certain treatments without the flexibility of changing without discrimination. Because of the acute shifts of how people are feeling, regular reviews and constant dialogue were also perceived to be essential. It was also felt that direct contact with services was not always required or welcome, and some times a telephone call, e-mail or text message was enough.

“Considering the shocking and appalling experiences of people with PD accessing and using mainstream mental health services there is a clear need to develop a dedicated service”.

Service User

“People with PD have a great fear of loss and need belonging and secure attachments”.

Carer

There was general agreement that there needs to be some form of dedicated service for people with personality disorder, although the rural nature of Somerset was seen as a limiting factor in this regard, particularly in terms of access. The basis for this need appears to be based on the poor experiences and perceptions of general mental health services and, the need for a secure base and attachments. It was suggested that developing such a service required full user involvement and needed to be managed or partly managed by people who have been diagnosed with personality disorder. The advantages to having a dedicated service included: having access to well trained, supported and supervised staff; consistency and shared care; crisis support; and, access to quality treatment and support.

“I think there needs to be more regular support during the psychotherapy day programme and access to crisis support. I left the group feeling I was a failure. In hindsight I wasn’t ready so it was not me it was the service”.

Service User
The Trust’s dedicated Psychotherapy Day Programme was mentioned by several of the participants. One of the participants felt it was particularly unhelpful as she did not know what it would involve; she finds groups difficult and felt she needed some preparatory work before starting something so intense. Another participant felt it had been a positive experience but needed a little more support following the treatment. Another said they had only just found out about the service through his carer and was concerned that his care coordinator did not inform him.

“There is no support following therapy. During therapy I learnt to leave some of my old self and ways behind. Therapy finished and left me wandering who I was, where to go and what to do. Without some form of support or guidance after therapy it is so much easier to return to the old ways. We need to be prepared for therapy and supported afterwards”.

Service User

“It seems a matter of getting all or nothing!”

Carer

Several of the participants discussed some form of graded approach to and from psychotherapy in order to ‘step up and step down’ from this form of intensive treatment. Many of the participants referred to an ‘all or nothing service’. Several said they had entered into intensive treatments without knowing what they were about or what was expected of them. Most felt that there was a need for more information and some form of preparation. Support following psychotherapy was also considered to be essential, particularly social support.

“As carers we do not feel tied in with the ICPA process”.

Carer

Carers felt they were not properly involved in planning and reviewing treatment and support and were often kept in the dark about what treatment involved and what the effects or impact of treatment might be.

**SUMMARY OF IDENTIFIED NEEDS**

- Consistent and accurate assessment
- Availability of treatment in the long-term
- Full service user and carer (as appropriate) involvement
- Dedicated services
- Access to and availability of psychological therapies
- Treatment choices
- Graded approach to and from treatment
Support

“Any type of support group for people with personality disorder would be fantastic. I have a great need to share my feelings in a safe and supportive way. Meeting people with the same diagnosis today has been really helpful and I don’t feel so alone”.

“Support outside of mental health services is hugely valuable in terms of just being able to off-load and cope with day to day life”.

Service Users

Support was a theme common throughout the consultations and appeared most important to participants, particularly crisis support. The need to share, and to be themselves with people with similar difficulties appeared to be as important if not more important than formal treatment. Several of the participants also believed that a support group would help manage and reduce the risk of self harm and suicide.

“I think there is a need for graded support. Sometimes it is too frightening to mix with real flesh and blood people. It might be a matter of accessing internet support first, then attending a meeting with some one-to-one support, and then perhaps attending a regular support group”.

Service User

It was acknowledged that some people may have difficulties in accessing or making use of support groups including: anxiety about opening up, a need or pressure to look after other people, or carers denying the difficulties of those they care for. A graded support network was proposed by several of the participants, including some form of internet support, one-to-one support and group support. It was also strongly felt that a support group needed trained facilitation, particularly in the development stages and then perhaps run by service users once established. It was agreed such a group should be run democratically.

“I would be prepared to travel as long as people used it”.

Service User

In terms of practicalities it was commonly felt that an open group was necessary as a closed group would be too exclusive and more difficult to access. This would also allow access to people who no longer need formal services, but still required some form of support. Furthermore it would allow flexibility in terms of frequency of attendance. There was also agreement that the group should not be too large.
Considering the rural nature of Somerset it was agreed that a central group would be best in the first instance and could be widened to other parts of the county as needs be. However, a central group could potentially be exclusive and some sort of travel arrangements might need to be considered. It was also generally agreed that a support group would best be independent of the Trust, although the facilitation might be arranged through the Personality Disorder network.

“Because of my difficulties with men, I strongly feel the need for a women’s only support group, facilitated by a woman”.

Service User

One of the participants felt strongly that a dedicated women’s support group was needed.

“Sometimes carers are uncaring and do not have our best interests at heart, so I have no trust in carers. Perhaps support groups for service users need to be kept separate.”

Service User

“If there was a support group I do not think it is a good idea to combine it with a service user group”.

Carer

Whether support groups should combine service users and carers or be separate was discussed by many of the participants. Most agreed that they should be kept separate. From the carers consultation it was apparent that a support group for carers was generally not necessary as they felt their needs were being met in existing support groups and networks. However, it was commented that a choice would be good. Some of the participants thought that it may be appropriate in some instances for carers to support service users accessing groups.

“I think the greatest need for support groups is for service users. This in itself would be a support to carers”.

Carer

**SUMMARY OF IDENTIFIED NEEDS**

- Support groups for service users
- Web-based support network
Crisis support

“We need a 24 hour, 7 day per week crisis service, and someone to call who we know and who understands. It could be run by trained service users with the support of dedicated staff (reference to SUN project in South London)”.

Service User

“Carers need flexible support in a time of crisis and easy access to an identified support worker, with who they have built some form of relationship and trust”.

Carer

The need for a full crisis service was agreed by all. It was acknowledged that accessing current crisis services was dependent upon where you lived and although it was generally perceived to be a helpful service at times it meant dealing with staff who didn’t know how to respond.

“Sometimes I need to escape from my environment. Inpatient admission is unhelpful at these times even though I may be at risk. It is the wrong environment, chaotic and noisy and I feel this pressure for discharge after a day or so. We need access to a non-medicalised crisis house. Somewhere to escape to so as to gather ourselves together”.

Service User

Inpatient admission at times of crisis was generally perceived to be necessary but often unhelpful or even harmful. The need for a non-medicalised and non-institutional approach to crisis admission was apparent.

SUMMARY OF IDENTIFIED NEEDS

- 24 hour crisis support
- Crisis accommodation

Diagnosis

“I wasn’t informed of my diagnosis; I read it on my GP records while she wasn’t looking. I know that is perhaps wrong but I just wanted to find out what was wrong with me. I asked my psychiatrist and care coordinator but nobody wanted to talk about it.”

Service User
“We were told by our son’s psychiatrist that diagnosing is not important and does not matter, which leaves us wondering about how we might help and the prognosis.”

Carer

Most of the participants were not directly informed of diagnoses. Most found out about by accident, through reading their notes, overhearing conversations or accessing dedicated services. Most of the carers were unclear about the diagnosis of the person they were caring for. One of the participants found out that she must have a formal diagnosis during the consultation meeting when she established that Main House (a service she had been referred to) was a dedicated service for personality disorder. This naturally caused participants anger, confusion and a sense of badness or blame.

From separate discussions with mental health care staff it appears that the phenomena of not sharing a personality disorder diagnoses is commonplace.

In general, the diagnosis appears to be shrouded in confusion, particularly with co-morbidity and or dual diagnosis (more than one mental health diagnosis and perhaps substance misuse). Many also felt that the diagnosis was a stigmatising pejorative label, which does not lead to any meaningful help or support and, there was concern about the language of personality disorder in terms of it feeling blaming and associations to dangerousness. There was also concern that once diagnosed, the label appears to stick and other mental health problems are not considered.

“The day I was informed of my diagnosis was my day of revelation. I could begin to make sense of my difficulties and what I could do about them”.

Service User

However, it appeared that the participants who had been informed of their diagnosis in a meaningful way benefited from this process as it provided a basis for understanding, treatment and informed choice, and an idea of limitations and what might be realistically achieved.

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<td>- Informed of the diagnosis as standard</td>
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<td>- Diagnosis shared in a meaningful way</td>
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<td>- Diagnosis to be reviewed and accurately recorded</td>
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<td>- Consider sharing the diagnosis with carers</td>
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Information

“There is no information or leaflets about personality disorder, which leaves people wondering what it is and feeling terribly isolated”.

Service User

A theme throughout the consultation was the lack of clear and reliable information available about personality disorder. Raising understanding and awareness was perceived to be crucial. Many of the participants found information on the internet a valuable resource. It was also thought that if there was more positive media coverage, such as that with ‘Personality Plus’, it would help to tackle discrimination and stigma. Everyone agreed that access to information through the Somerset Partnerships website, and possibly linked to the national website would be valuable and, that there was a need for training and education for service users and carers.

“There is a need to provide information about choices of treatment/support including complimentary/alternative approaches”.

Carer

Readily available information regarding treatment and support options was also seen to be important including what the treatment is, about what is involved, for how long and, the potential impacts including adverse affects.

“We are often given no information about what medication has been prescribed for the people we care for. When we have asked we are told it is confidential. This is a crazy and worrying situation as we are most often the one’s who are ensuring that they take it and keep it safe. We don’t know what will happen or what to do if they do not take it, and more worryingly how dangerous it might be if they overdose. This causes us a great deal of fear, anger and frustration”.

Carer

Information offered to carers about those who they care for including their treatment, diagnosis or any perceived risks was reported to be limited. Nearly all the carers said that ‘confidentiality’ was used by the service as a block to information and communication. While confidentiality was respected, basic information was omitted even when there was permission to share by the service user.

SUMMARY OF IDENTIFIED NEEDS

- Information leaflets
- Accessible website
- Local training and education for service users and carers
Training & Education

“There is a general lack of training and a huge need for it!”

Service User

“There is a huge cultural problem within services about the approach to people with personality disorder. I suppose it goes back to training, or lack of it. Perhaps to address this cultural difficulty there is a need to go back to basic training.”

Carer

Training or the perceived lack of it was a central theme of the consultations. It was felt that all staff should have some basic training in personality disorder, particularly psychiatrists and GP’s and, that it should be part of all professional basic training. It was also felt that service users needed to be meaningfully involved in the development and delivery of training.

A clear need for training and education was expressed by both service users and carers

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<td>• Training to be mandatory for all mental health staff</td>
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<td>• Training to be available to outside agencies</td>
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<td>• Service users and carers to be involved in the development and delivery of training</td>
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<td>• Training as a core aspect of all mental health pre-qualification courses</td>
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<td>• Advanced qualification</td>
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Culture

“Staff are demoralised by the system they work in. They are underpaid and undervalued, and lack training and support. This simply encourages poor attitudes and dealing with shitty unprofessional attitudes is really difficult”.

Service User

The poor attitudes of individual staff and the service as a whole was a theme that ran throughout the consultations. These attitudes were reported to range from simply being unhelpful and rude to punitive and rejecting. Many of the service users were told that they did not have real mental illness and that their problems were something to do with themselves or that they were attention seeking.
“Good practice all boils down to individual workers and how they relate to clients and their carers. However, this is a lottery and a matter of luck who you end up with.”

Carer

It was acknowledged that there are staff who are helpful and have positive attitudes, however it seems it is a matter of luck in terms of being allocated such a member of staff.

“Some of what happens in mental health service would simply not be tolerated in a private business. If a receptionist in private business was unhelpful, rude or unwelcoming they would be sacked. However, the NHS is full of them and they portray a really poor image of mental health services. There needs to be a better ethos! The service feels unprofessional. Basic lessons in customer service wouldn’t go amiss”.

Carer

Many of the participants discussed their experiences of generally poor customer care and the need to improve basic interactions with the public.

“It feels like there is still a strong sense social control in the mental health system. Staff seem to be happy as long as I am doing what I am told. In twenty years not once have I been asked how I feel!”

Service User

Those who did find a service were often met with rigid, prescriptive plans that were pushed upon them. Seeking to become more actively involved with their treatment was often met with being labelled troublesome or non-compliant, and actively disagreeing had been met with discharge from the services.

“There seems to be a culture of negativity about personality disorder within the mental health services”.

Service User

Many of the participants felt at odds with the service, like they didn’t quite fit in. Many agreed that this may be due to not fitting into traditional psychiatric diagnoses and being the odd ones out. All agreed that the focus of mental health services should be on health not illness.

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<tr>
<td>• Positive staff attitudes</td>
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<td>• Well supported and supervised staff</td>
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<td>• Focus on health and recovery</td>
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CONCLUSION AND RECOMMENDATIONS

The consultation process proved an effective way of identifying the needs of service users and carers of people who attract the diagnosis of personality disorder in Somerset. All those who participated valued being listened to and having their experiences validated and needs acknowledged. Many of the participants said they enjoyed the meeting, particularly meeting people with similar difficulties and issues.

The findings appear to be consistent with the national picture, existing policy and contemporary research and, it is recommended that they directly inform the development of a county wide service strategy with the involvement of the identified service user and carer consultants. However, it is acknowledged that the rural nature of Somerset places a number of challenges to meeting identified needs, particularly access to treatment and support.

It is also recommended that mechanisms for the continued process of service user and carer consultations are put in place.

ACKNOWLEDGEMENTS

Many thanks for the valuable contributions of all those who participated in the consultation process.

Christopher Gordon
Clinical Nurse Specialist – Personality Disorder