SLaM Trustwide
Involvement Group:
Operations

Privacy and Dignity

Service User and Carer Consultation

March – April 2012

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South London and Maudsley NHS
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Introduction

As part of the development of a Trustwide Privacy & Dignity Strategy, Natalie Warman (Assistant Director of Nursing with responsibility for physical healthcare) approached the Operational Trustwide Involvement Group in Summer 2011.

The operational arm of the Trust Wide Involvement Group is designed to ensure that a wider range of service users are involved in the improvement and development of SLaM [South London & Maudsley] services, and to look across the Trust and externally to influence and develop good practice, innovation and service user research.

The aim of this consultation was to engage people with experience of using SLaM services in the process of identifying what is important to service users and carers about privacy and dignity.

The Process

Whilst staff were available to support the process where necessary, the management and co-ordination of the project was led by people with experience of using services:

A working group was established where service user consultants worked alongside staff to:

- Develop a consultation plan
- Develop the budget
- Identify 4 key questions that could be posed in focus groups across the 4 SLaM boroughs.

A service user consultant managed the project:

- Ensuring service user consultants were recruited, trained, briefed & supported to run a series of focus groups
- Ensuring the project ran to time
- Managing & overseeing the content analysis
- Writing the report

A service user consultant co-ordinated the arrangements for the focus groups:

- Contacting the venues
- Overseeing booking details including refreshments

A service user consultant and a carer jointly developed publicity for the focus groups.

A service user consultant and staff member delivered a training session on facilitating focus groups.

Focus Groups

We ran 10 focus groups, with at least one in a community setting and one for inpatients in each Borough. Twenty-eight people attended, and one person gave feedback by email.

Questions

1. What does it mean to have your privacy maintained?

2. What does it mean to be treated with dignity / respect?

3. Are there any barriers that prevent you having your privacy and dignity maintained?

4. What are your suggestions for improving the privacy and dignity of people that use our services and family / carers?

Emergent themes

Environment

Stigma

Patients' Rights

Communication

Interface

Treatment

Staff

Carers

Theme: Environment

Participants reported 8 main categories with respect to environment: Safety, Ambience, Access, Activities, Fabric of the Building, Visitors, Food and Drink, and Cleaning.

Safety

In terms of Safety, participants reported a number of suggestions; including privacy and needing a safe place: ”Privacy is important for people because we all need a place to feel safe.”

Some participants reported feeling vulnerable on the ward, whilst others reported that hospitals should be a place of safety. One other participant stated that feeling safe and comfortable was important. And one participant stated that property loss affected dignity.

Ambience

In terms of the ambience of the ward environment, participants reported a number of negative issues. A number of participants felt that the ward was not a therapeutic place, and one participant reported: “It is hard to feel dignified in an environment where people are agitated.”

A number of participants reported technical problems with lighting not working correctly. The noise levels were also reported as an issue. Loud alarms and doors being slammed at 3am were noted problems.

Access

In terms of access people reported a number of issues with respect to their freedom. A number of participants reported issues related to leave: ”consistent and clearer leave” was needed, and it was desired to “have a more flexible form of hospital care.”

Others reported having restricted access to the garden for fresh air: “Patients having as much freedom as possible e.g. to get fresh air” was considered important, and “not being given access to the women’s back garden” was seen as an issue.

One participant reported that locked doors were an issue, whilst another stated that Bed Blocking was an issue.

Activities

In terms of Activities some participants reported boredom as an issue impacting dignity. Others suggested more board games, and more physical activities, including Gym, Swimming, and a Walking Group.

Fabric of the Building

A number of participants commented on issues related to the fabric of the building: ”some of the buildings are terrible. The environment is a question of dignity.”

A number of participants reported issues with bathrooms. These included privacy whilst using the bathroom: ”toilets and bathrooms should have locks.” It was also seen as a problem that “one bath” had to be shared “between 20+ patients.”

Others commented on the fabric issues with bathrooms including: ”lights in bathroom not always working” and “no plug for the sink. I had to use toilet paper to plug the sink.”

One participant suggested basic toiletries to be provided on the ward.

A number of participants reported a number of issues which impact on their Privacy and Dignity. These included having more transparency on the ward, including CCTV. Other comments included having improved TV reception and a better family room.

It was seen as important to make children feel more welcome. One participant reported the lack of resources as an issue. Another suggested: ”Separate male and female sections are important.”

Visitors

In terms of visitors participants reported a number of issues related to improving access and space for visitors. The participants commented on children visiting. One suggested ”more space for visitors”.

Another suggested allowing children to visit more often. One participant reported that space should be provided to allow privacy when visitors arrive: ”visiting times should be private, with space to be provided.”

Food and Drink

In terms of food and drink participants reported a number of issues which would improve the environment. Generally, food provision needs to be improved, including a better choice of breakfasts and hot milk. General improvements to the quality of food were desired: “food needs much improvement”, and it was felt that “diet is important”.

A number of participants reported the need for easier access to hot drinks for both service users and visitors. One participant suggested having more water, refreshments, and fruit. One participant reported not enough variety for individuals with specific dietary requirements: “not enough choice with food, e.g. diabetic, Kosher, Muslim, and Caribbean meals etc.”

Cleaning

In terms of the cleanliness of the environment a number of participants reported issues with cleanliness. The toilets and bathroom need improvements: it was desirable "to have clean toilets and facilities", and it was felt that "having clean quarters, i.e. toilets, bathrooms etc, is important." One participant suggested "cleaners should not lock you out of the day room for hours."

It was deemed important to "make sure everything is clean in the ward environment."

Theme: Stigma

The general feedback around the stigma theme fell into two categories: assumptions and labels.

One participant reported that the disclosure of mental health problems in employment was an issue as "relapse may result in losing your job."

Assumptions

Regarding assumptions, one participant said "it should not always be assumed that you are lying." Another said that it was desired and important "to be regarded as innocent until proven guilty, rather than the other way around." It was also cited that "being believed" and "having credibility" was a big issue.

Labels

In terms of labels there were a lot of comments around the negative effects of labelling, for example one person said it would be good "not to feel identified by your diagnosis." "Labels like borderline personality disorder are a stigma and a barrier." Also it was said that "being labelled by your mental health problem is unhelpful".

Theme: Patients' Rights

Participants reported 5 main categories with respect to patients' rights; Spirituality, Autonomy, Confidentiality, Gender, and Personal Space.

In terms of general feedback it was seen as desirable "to feel respected", and "to be spoken to as an equal."

Spirituality

In terms of spirituality participants felt that their religions were not being respected. Others also felt ignored when they asked to see a vicar: "When I first went into hospital my diagnosis was paranoia. I asked to see a Priest but was ignored."

One participant made a positive comment about dignity and the support their family member received: ”Dignity is difficult to balance. The support systems in place in [Borough], and the Consultant and Care Plan Worker’s vision have been tremendously helpful in maintaining an inner calm and dignity. And [x] himself is a remarkably resilient person. The above all has helped us to understand things.”

Autonomy

Feedback received about autonomy fell into a general category and Basic Rights.

In terms of Autonomy participants felt that their opinions must count. There were a lot of negative comments: ”Being physically restrained can be very undignified. Better options should be considered.” It was also noted that “often it can be more comfortable to speak to one nurse as opposed to another”, and “too much rigid authority” was seen as a bad thing.

Basic Rights:

In terms of basic rights most participants commented that they are not being valued: “I felt I wasn’t treated like a human being.” “I felt like I did not exist. I did not feel valued”. Others felt that they didn’t have a choice, and were being forced to do things: ”patients are not kept informed and have no choice.” It was desired “not to be forced to do things.”

Two participants commented on not being able to smoke, while others felt they were being dependant on staff to make drinks.

One positive comment was “my privacy was maintained when I was an in-patient.”

Confidentiality

In terms of confidentiality, participants commented that “service users should choose what information is shared with family etc.” Others felt that “things said to their GP should be kept confidential (except in cases where the safety of a child, another person, or yourself is at risk)”, and “staff should not discuss you (your case) in public places, e.g. on wards or in corridors.”

One participant commented that “privacy is so delicately balanced. On the one hand one doesn’t want to be isolated. But at the same time there are areas that simply cannot be shared, even with close friends and larger family, who do not comprehend what it’s like to undergo such an experience. It’s only later, when things are running more normally, that one can begin to open up.”

Gender

In terms of gender, some participants commented that they prefer to have a mixed ward rather than a single sex ward, while others said they preferred “not to have male staff on a female ward.”

Another commented that "male staff not to be involved in forcible actions, i.e. stripping, drugging, and so on of female patients, and vice versa."

Personal Space

Feedback received under personal space fell into 2 categories: Physical Space and Emotional Space.

Physical Space:

Generally the participants felt that they should have their own privacy respected: "A patient's bedroom should be their private space – where possible no one else allowed in, not even staff." It was also desired "to be treated fairly and respectably, to be able to wear decent clothes that aren't too revealing," whilst another said "everyone should have a key to their own room." Also, another participant preferred "being asked, helped, and encouraged instead. People should not be forcibly stripped and washed."

Emotional Space:

In terms of emotional space participants felt that they should be treated with respect, whilst others felt they are being treated like children: "Having respect for when someone wishes to remain silent or be alone" was desired, and "being belittled" was seen as a negative.

One participant commented "staff sometimes impose their own judgments e.g. about sexuality."

Theme: Communication

Comments about communication fell into 3 categories: verbal communication, formal communication and poor communication.

Verbal Communication

In terms of verbal communication, the main issues were concerning how staff spoke to patients and general communication between staff and patients. It was reported that there were language barriers when staff spoke "poor English" and it was "frustrating." A suggestion was that more training was needed. One person said they were spoken to in a way that made them feel disrespected. Another view cited was that there should be regular meetings "between patients and staff regarding privacy and dignity."

Formal Communication

Formal communication fell in the areas of practice and procedure. It was reported that practices were sometimes unsatisfactory for instance one person said the "GP doesn't always have my notes up to date" and another said that "assessment can be very repetitive and sharing personal information with mental

health professionals can be frustrating when agencies don't pass information on." There was also another negative comment on "the NHS failing due to a lack of communication."

Poor Communication

Things that fell into the poor communication category were comments on "unclear communication" and a "lack of information." Two participants reported that they needed to be kept informed.

Theme: Interfaces

Participants reported the interfaces fell into the main areas of admission, advice and support, discharge, psychiatric liason and general practitioners.

In terms of general comments, participants reported that it is important to remember to respect that some people "with mental health problems also experience physical health problems and vice versa." Also to note that as a mental health patient going into A&E for a physical problem it is often assumed that the matter is mental health related.

Psychiatric Liaison

In terms of psychiatric liaison it was reported that it was sometimes, "not always effective and could be seen as a barrier." Also the psychiatric liason department, it was said, did not share personal information with the participant's GP.

General Practitioners

Regarding GPs, a positive comment was that the participant's GP "knows when I'm becoming unwell and makes the appropriate referral ASAP." A more negative comment was that sometimes when service users get "passed between GPs and A&E" and that this results in the participant feeling "unwanted and un-valued."

Admission

One participant suggested "if taken to hospital under a section, to be allowed to pack a bag and take it with you." Also another participant reported the desire not to automatically always have one's mobile phone taken away regardless of the particulars of the case on triage. One participant was treated indignantly by the police "(violence)."

Advice and Support

The question of a participants personal dignity came into the comments; "[Borough] no longer has an out of hours advice line, now being advised to contact the Samaritans," which impacts on a participant's dignity.

Discharge

Two basic points were raised that would impact the participants very positively; one suggested that some form of therapy could be devised that could help patients and carers with the transition involved with discharge. Also it was suggested that there could be ways to "remedy the loneliness upon discharge that can poorly affect recovery."

Theme: Treatment

Participants reported 4 main categories with respect to treatment: medication, recovery, input into own care and non-consensual.

Medication

In terms of medication, most comments from participants were negative, "not to have to queue for medication" and "medication to be kept confidential from other patients." Only one positive comment was mentioned that, "medications brought to patients rooms. Observations done in privacy."

Input into own Care

Generally participants felt that there was a lack of involvement in their own care and they were not encouraged to get involved. "Asked my care coordinator a question about my medication and the care coordinator blew his top saying are you challenging my professionalism?" It was also mentioned that there is a lack of one to one meetings and "inconsistent regimes on the wards."

Recovery

The overall report was that participants felt a more person-centred and more holistic approach to treatment should be implemented. While they felt life and should get better, two participants commented on respect and value, "valuing each other" and "respect is reciprocal." One participant asked for "help outside of hospital to put or remedy the possible external causes off ill-health".

Non-Consensual

Some participants felt they are being forced to take medication and treatment. "Medication is regulated without consent" and "patients still being forced and

held down to be given medication." Other patients felt that they should be encouraged or helped to do things, as opposed to being forced.

Theme: Staff

Participants reported 4 main themes with respect to staff: attitude, organisational, gender/ culture awareness and training.

Attitude

In terms of attitude, feedback from participants fell into 2 categories: Best Practice and Bad Practice.

Best Practice. Participants reported that mutual trust, listening skills and politeness were of paramount importance. Staff should take "direct responsibility" when questions are asked and a few participants commented that "trust needs to go both ways." Compassion and empathy are necessary for staff to "respect the boundaries of patients." One participant reported that staff should "not always be in a rush." "To be treated with courtesy" meant that it was possible for participants to "respect staff due to being treated well."

Bad Practice. There were a large amount of comments by participants on the ill-treatment by staff. Issues ranged from "staff interfering in our business" to "being ignored", to "confrontational in exercising their authority" and "being threatened with the section system by staff." Participants were concerned by a lack of respect, with staff "kissing their teeth", "barging in without knocking" and "being told what to do by staff who are much younger than me." It was recognised, however, that some problems were due to "not enough staff" and "staff overstretched."

Organisational Issues

Participants reported shortcomings in the structural organisation of staff. A number of comments were made regarding waiting times, both for requests made on wards, where 5 minutes can take 20 minutes, and being informed "exactly when our section ends". Staff discipline should also be taken more seriously. One participant mentioned complaints "should be taken into consideration in any reviews." Efforts should be made to "consider terminating the employment of rude and abusive / aggressive staff." Again it was acknowledged that there were "not enough staff to look after patients' basic care needs" but that measures should be taken to redress the "oppressive power imbalance" between staff and service users.

Gender/ Cultural Awareness

Participants reported on various themes the most prominent one being the attitudes of female nurses; "female nurses from cultural backgrounds where women are not respected sometimes seem to lack respect for women, as ironic as this may sound, and in so doing have even less respect for women with a

perceived weakness such as a mental health problem." Female nurses also sometimes fail "to show respect to female patients."

With regards to religion and cultural beliefs in hospital, "Priests and Chaplain's not easy to access". It was also noted that "staff should not impose their views on patients e.g religion". One participant commented on the fact of "CPN(s) failing to empower service users due to cultural discrimination". There was also the feeling "as though aspects of your case might be getting discussed at the pub."

Training

Staff training fell into three categories: general training, service user training to staff and involvement (SUCs).

General Comments. It was reported that there was a lack of training. It was suggested that there should be "a minimum of one day training on treating patients with dignity – mandatory." Also that there should be more "awareness from non mental health medical staff." One participant suggested "all staff to have better training in mental health e.g. nurses, occupational therapists, psychiatrists, CPNs." Participants also stated that there should be "attitude and awareness improvement" and "training in cultural awareness."

Service User Training to Staff. Participants made many comments regarding service user to staff training e.g. "service user lead training", "training delivered to staff by service users." Also that training should be given to all non clinical staff including cleaners, and that they should have training "from service user consultants re: dignity." One participant suggested that "receptionists to have SUC and mental health awareness training." Another suggested that staff should experience what it is like to be an inpatient, and that the "leaders of the CAG teams to receive training from service users."

Involvement. One suggestion was that "service users trained as secret shoppers on wards and in CMHTs." One participant said "patients find it easier to talk to linkworkers, not the nursing staff." Lastly one participant said "to not be threatened or oppressed as a service user doing involvement work (case of lead SUC being oppressive and hostile to service user consultant)-"I hope you are going to contribute more in today's meeting than you did previously."

Theme: Carers

Participants reported the theme of Carers fell into 4 main areas: communication, visiting, recovery and groups.

Communication

In terms of communication, most participants commented that carers should be better informed by staff and also informed about medication and diagnosis etc. Others commented "visitors and family members not informed that they can take service users off the ward even if they are sectioned." A participant was

"indignant to receive standard letter (to family) stating that 'carer/ family member has mental needs.' "

Visiting

In terms of visiting, participants commented "no definite defined private space for visits from family and carers." It was also noted that there were "unflexible visiting times" and "visit delays are provocative."

Recovery

In terms of recovery, participants commented that they would like to have family and carers involved as much as possible "to allow patients to have family/ carers involved at important stages throughout treatment and care." It was also suggested "to have minimal amounts of your case discussed with carers (medication & diagnosis) but not intricacies such as self-harm."

Groups

In terms of groups participants commented that they would like to have some carers and patients groups (where carers are mixed with patients).

Focus groups

Croydon:
Bethlem Community Centre (community)
Croydon (community)
River House (in-patient)

Lambeth:
SHARP (community)
LEO unit (in-patient)

Lewisham:
Catford (community)
Ladywell Unit (in-patient)

Southwark:
Maudsley Community Link Centre (community)
St Giles (community)

Carers:
Maudsley

Example flyer (carers)

We need YOU!
Help us help you

What's Privacy & Dignity to you?

Your help is needed at: **a service user run focus group**
We would like to hear your views to help shape the future of the South London & Maudsley NHS Foundation Trust

Privacy & Dignity Policy!

- **Meet other carers and join forces.**
- **Be heard and hear about privacy & dignity.**
- ***Your* view is *important***
- **Help to inform future privacy & dignity policy for the betterment of all service users and carers.**

More information

About the Privacy & Dignity Project

South London and Maudsley (SLaM) Mental Health Trust's vision is that people who use our services will be treated respectfully.

To be treated with privacy and dignity can mean many things to different people. Examples of these include, attitudes and behaviours of staff, communication, the environment, privacy to protect peoples modesty, confidentiality, to have your nutritional needs met and to be free from abuse.

People that use our mental health services are diverse; and to ensure that any strategy or policy represents the needs of service users, families and carers we would like a broad range of people to help us make things better together!

We are running some groups called 'focus groups' where people can come and give their views about privacy and dignity in SLaM services

These groups will be facilitated by people who have experience of SLaM services themselves and will ask questions like:

What are your suggestions for improving the privacy and dignity of people that use our services?