Involving Young People in the Development and Evaluation of Self Harm Services

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Summary of project
Evidence suggests that nurses often struggle to help young people who self harm. This project therefore aimed to engage with staff and young people in a young people’s centre to enable participation of young people in planning and delivering the self harm service. Questionnaires were used to gain staff perspectives on working with young people who self harm. A series of focus groups with young people were facilitated to capture their views and experiences. The themes from these discussions were used to inform developments in practice including the introduction of self harm feedback forms and a patient passport. Staff reported an increase in confidence and greater understanding about working with young people who self harm resulting from the feedback, training and supervision associated with the project. There is ongoing commitment to embed service user participation in service delivery and development.

Background
The Young People’s Centre in Chester is a 14 bedded inpatient treatment mental health unit and a 10 bedded acute admissions mental health ward for adolescents aged 13 to 18 years old. Young people are admitted from all over Cheshire and Merseyside to receive care and treatment for a range of mental health problems and disorders including psychosis, severe depression and eating disorders. Almost half of all young people are admitted in an emergency crisis and this often follows self harm or recognition of the risk of suicide. 60% of admissions are girls and the average length of stay is just over three months.

The unit is staffed by a multi-disciplinary team of nurses, psychologists, psychiatrists and therapists. There is also an on-site school. The Young People’s Centre has a large team of nurses including a nurse consultant, modern matron and newly developed clinical nurse specialist (self harm) post. This is in addition to several nurse team leader posts, staff nurses and support workers.

Nurses at the Young People’s Centre have more contact with the young people who self harm than any other professional group. This is in the context of assessments, treatment interventions, day to day care and consultation with other professionals.
The evidence base for what works with young people who self harm has expanded in recent years (Wood et al., 2001; Hawton et al., 2002; Miller, 2007) and this has included publication of a NICE guideline on self harm (NICE, 2004); however, despite the available guidance, nurses often struggle to help young people who self harm (Dow, 2004).

There is consistent evidence from research that young people who self harm feel that their views are not taken seriously (NICE, 2004; Mental Health Foundation, 2006). They often feel misunderstood, blamed and stigmatised by professionals (McDougall and Brophy, 2006). Therefore, to achieve improvements if practice, it was felt essential by our senior nurse team that service user involvement in planning care and treatment interventions should be strengthened by developing ways of listening to and understanding the opinions of the young people who used the service; then exploring the ways in which their views can be used to facilitate improvements in practice and incorporated into training packages for staff.

**Aim and objectives of the project**

The project aimed to enable the full participation of young people in the planning and delivery of self harm services. The following goals were identified to achieve this aim:

- Establishing a baseline of staff views about caring for young people who self harm
- Facilitating a series of focus groups involving young people to explore their views about their treatment and experiences
- Agreeing a process with service users for how the information collected through the focus groups would inform the wider development of the self harm service
- Utilising a number of approaches to use the information to inform and facilitate staff development
- Evaluating the impact of the project on staff

The project leader identified key stakeholders within the service to form the project team and to consult with during the project. The team consisted of representatives from the trust’s Patient and Public Involvement (PPI) forum, the leader in self harm services and key individuals involved in delivering care.

**Initial questionnaire to staff**

In order to form a baseline against which to assess changes in practice, the project team developed a qualitative questionnaire (see Appendix 1) based on claims, concerns and issues (from Fourth Generation Evaluation, Guba and Lincoln, 1989). The questionnaire asked staff to identify positive statements (claims), negative statements (concerns) and questions (issues) about working with young people who self harm.

In order to capture the views of all multi-disciplinary staff who worked differing shift patterns, the questionnaire was sent via email explaining the purpose of the questionnaires and how the responses would be used to influence training and development. In addition to this a short presentation was given on this at a team meeting following the questionnaires distribution.
Response via email to the project leader was positive with an 82% return rate. As the project team felt that it was important to capture the views and opinions of all staff, a member of the project team met with individuals to complete the questionnaire.

The completed questionnaires were reviewed by the project team to identify the key themes; these were:

- Staff lacked confidence in managing self harm situations
- Staff were unsure about giving young people appropriate responsibility to de-escalate their risk taking behaviours
- Staff were unclear as to how young people experienced their care giving in crisis situations

The information collected from the questionnaire was used to inform an initial training session on practical management of incidents of self harm as well as providing an overview of trust policies. As the project progressed, the training incorporated feedback from young people regarding their experiences as will be outlined below.

Focus groups
The project team felt that focus groups would be the ideal approach to enable free discussion to ensure that young people’s views formed the basis of the project. The project was therefore presented to the young service users on a number of occasions:

- Initially the project was presented to ten young people accessing a specialist outpatient self harm treatment programme within the service to invite their participation in a series of focus groups
- The same information was then presented to young people in both the acute admissions and treatment wards

By repeating this presentation periodically, 43 young people from across the service were captured in total. Following on from the presentations, letters were sent to the young service users inviting them to participate in the project and requesting those who were interested in participating to return an enclosed consent form; 16 young people responded.

A further letter was sent to those who had expressed an interest from the outpatient service asking them to complete a questionnaire to establish the most suitable times to run the groups, to identify a venue and to address any barriers to participation. For those accessing inpatient services, posters were placed around the wards giving information and contact details of the project leader. Young people responded by asking in person, via their named nurse or by emailing the project leader. This information was used to form the groups.

Separate focus groups were run for inpatients and outpatients as the project team felt that this would work best for the young people involved. The focus groups were held on weekday evenings from 7-8.30pm and facilitated by three members of the project team. The project team provided refreshments and an iTunes voucher as a way of thanking service users (both inpatients and outpatients) for their participation. At the initial group, the young people requested and it was agreed, that when the project team collected information from the discussions, specific individuals would
not be identified as they felt that this would allow them the freedom to express their views. The project team facilitated discussions using their experience of group work; the ability to facilitate groups being an essential part of working in child and adolescent mental health services (CAHMS). The young people were asked to generate themes for discussion relating to their experience of the self harm service; the project team had agreed that this was the most effective way to ensure the evaluation of what was important to the young people themselves. The project leader supported the young people with time keeping and allowed each young person’s views to be voiced. The young people involved were extremely keen to be involved in the process to ensure it was driven by their views. The other members of the project team captured themes and quotes from the participants.

There were a total of 18 focus groups over the period of 12 months which involved 16 young people in total (both inpatients and outpatients). The numbers in each group varied from three to seven depending on their availability. The young people from the acute admissions ward did not take part in any focus groups during their inpatient stay; however three were able to contribute following discharge.

During the focus groups, the young people (both inpatients and outpatients) were asked to identify areas of discussion relating to their experiences during inpatient stays throughout the project time span. They were then asked as a group to identify themes for discussion. Service users elected a note taker to write the themes for discussion on flip charts. Three main themes emerged which are outlined below along with an example of the discussions:

**Young people’s experience of treatment options**
Young people perceived that their journeys had been different dependent on locality and all recognised that each person’s recovery was not solely down to service provision. Family, peers, education and motivation to change were all key to how they experienced their treatment journeys.

**The perceived lack of knowledge from some care givers**
The young people identified that many of the adults surrounding them had little knowledge or understanding of their difficulties and they felt it would be more beneficial, in addition to their own treatment that others i.e. parents, teachers etc. were offered the opportunity to learn and be part of the treatment offered.

**Having to repeat their risk history when assessed for new episodes of self harm**
The young people mainly focussed on their experience of having to tell professionals the same history. An example of this from young people was; firstly meeting GP/school nurse, then repeating the information to Tier 3 CAMHS at the point of initial referral. From this they felt that they had to repeat it again when allocated a therapist and again if referred to Tier 4 CAMHS. In addition to this they would repeat their history when presenting to A&E and again when reviewed by liaison psychiatry.

**Service user stories**
In addition to the information collected via the focus groups, six service users provided feedback via ‘stories’ as they felt unable to participate in the focus groups at the time.
The idea of service user stories evolved from the focus groups as young people expressed that they were never invited to share their experiences. Although the young people are invited to complete post discharge questionnaires, they did not see these as a valid form of collecting information about their experiences. They suggested that a form should be added to the post discharge questionnaires that invited them to write their ‘story’. Guidelines and consent to share were developed by the project team to assist young people in sharing their ‘story’ should they wish to do so.

The content of the six ‘stories’ returned during the period of the project mainly focussed on their journey through services for self harm; the information reinforced the themes raised in the focus groups.

This approach to collecting service user’s experiences continues to be used as part of the discharge process and the information collected is used to inform developments in practice using the processes that will be outlined below.

**Developing practice through service user involvement**

A number of approaches were used to enable the feedback from service users to inform practice. This included feeding information back to staff, the development of a self harm incident form and the recognition of the need for a patient passport.

**Sharing information with staff to develop practice**

Information from the focus group discussions was utilised in two ways to enable staff to develop practice; informing discussions in meetings and supervision; informing the development and implementation of training sessions.

Information was fed back in ‘real time’; such that, as the focus groups were ongoing, information gathered from these was discussed with staff at team meetings and governance meetings, for example. Sharing the information in this way provided opportunities to review the amount and type of self harm incidents and the young people’s perceptions of them, thus enabling staff to identify specific learning and required actions. An example of this included changing the staff handover times to ensure that there were additional staff available to the young people on the ward. This was identified via the number of incidents around this time and also from young people’s feedback of feeling more vulnerable at these times.

Where specific areas for development were identified by the young people in relation to individuals, these were followed up with the appropriate members of staff via clinical supervision. In addition, group supervision was also introduced. This was facilitated on a monthly basis for staff across both wards as well as when required following serious incidents. This offered the opportunity for staff to reflect on incidents and evidence of applying information gleaned from the young people’s feedback aided discussion.

As a direct result of these approaches, the young people’s feedback was able to positively influence care plans regarding effective communication during incidents of self harm. This involved including a section of the care plan in which young people could identify which styles of communication were most helpful to them in crisis situations. This positively influenced the confidence of staff in managing difficult
situations as they felt that the care plans gave them a greater understanding of what would help the young person.

Training was mainly offered to nursing and support workers, i.e. those directly involved in the day to day management and care of the young people. Sessions were repeated and adapted over a period of time to ensure that as many staff as possible could attend. Content of the sessions was informed by the content of self harm incident feedback forms (see below), for example communication styles and environmental risk factors. The training also included practical skills in managing observations and incidents in line with Trust policy and procedures. In addition to this the use of role play in looking at recurrent themes proved effective in increasing confidence and skills.

In addition to the above mechanisms, it was agreed with service users the following two themes would form the basis for development of tools to facilitate practice development encompassing user involvement. This was decided by identifying the most frequent topics of discussion amongst all the focus groups. Service users decided themselves who would be involved in which development, ten in total were involved.

Self harm incident feedback forms
Stimulated by young people’s views, it was agreed to design a way in which staff could receive ongoing feedback from service users which could be evaluated and change tracked. Whilst staff feedback forms already existed for reflecting on self harm incidents, nothing was in place for service users to feedback their experiences of the incident to staff.

In consultation with service users and staff, feedback forms were designed by the project team and four young people who had volunteered from the focus groups, to capture evidence of practice and facilitate reflection (see Appendix 2). The forms were piloted in the acute admissions ward where they were given to service users following an incident of self harm/suicide attempt by the project leader and then reviewed by the project leader. Approximately 30 were returned during the pilot period. In addition to this young people welcomed the opportunity to reflect. General themes were fed back to the team in the clinical governance meetings. A good example of this was how the feedback was used to make environmental changes to the ward which reduced potential for further incidents. Specific learning for individuals was addressed in clinical supervision. This enabled ongoing qualitative data to be obtained and become custom good practice.

Patient passport
The second strand of development to arise from the project addressed issues service users had with the amount of assessments they had when either in crisis or in chronicity of their difficulties. Whilst it was accepted that the assessment process could not be altered it was agreed that it may be helpful for service users to have pre agreed written information with their therapist that they could choose to present whilst attending A&E departments.

Initial work relating to this involved the service users who designed “A patient passport” (see Appendix 3) that included information with regards to previous risk
taking behaviours, contact details of those involved in their treatment as well as a space for individual comments. Whilst it is acknowledged that this places ownership on the service user to provide this information it was felt that a pilot of implementation would provide additional information to aid new ways of working to address the complexities of the journey of service users who self harm. Currently the document is only used as a prompt for young people to offer to share with emergency care staff to aid in their treatment. For those who have presented this, their feedback is that it has made the initial engagement process easier.

The development of the patient passport, although triggered by this project and involves six of the young people who were involved in the focus groups, has developed into a project of its own and the work relating to this is ongoing.

Staff questionnaires
The questionnaire that was used at the outset of the project was given to staff again after six months and response rate from the staff team was 100% at the first attempt. The responses were read and analysed by the project leader. The key themes to emerge from this process were that staff:

- Had increased their confidence in working with young people and understanding their difficulties and differences with each case
- Noticed that they were move reflective about incidents and more open to the process of group supervision
- Remained concerned regarding risk but were more skilled in positive risk management

In addition to the questionnaire, feedback from Trust training evaluation forms was included to form the basis of tracking change. This generally followed the themes from group supervision and were notably more positive regarding training and outcomes.

Project outcomes
There are two main outcomes from this project. Firstly, a variety of new approaches to collecting feedback from young service users have been implemented; and secondly, staff confidence in responding to self harm incidents appears to have increased.

Generally feedback from the service users involved was extremely positive and the way in which young people embraced the opportunity to give detailed feedback was invaluable. The focus groups enabled the team to really listen and hear the service users’ vision and experiences. It has provided them the opportunity to have a voice to improve the service which is delivered. It also provided the evidence to demonstrate the outstanding dedication and good practice of the team working with this group of service users.

The introduction of the self harm incident feedback system has enabled the team to celebrate good practice and learn and develop new ways of working. It assists individual practitioners in reflective practice and ensures that the staff are consistently involving young people in shaping the delivery of care. The staff team
report the benefits in care planning effectively in collaboration with young people using the service.

Service users’ opinions and staff feedback formed the basis of training delivered in the practical management of crisis intervention. There was a noticeable difference in the concerns of staff related to crisis intervention following delivery of training when the questionnaire was repeated. This is demonstrated by staff self-reporting increased confidence through the questionnaires. This was also experienced by the project leader who acknowledges that the team are more confident and thoughtful in their approaches, and receiving fewer requests for help.

Further evidence of enhanced confidence is provided by the stress toolkit as part of the productive wards programme. Where the number of recorded most stressful shifts involving serious incidents has decreased.

**Barriers to involvement**

It remained extremely difficult to access service users’ opinion whilst in the acute stages of their treatment. The project team reflected that our involvement in collating their opinions conflicted with our involvement in their treatment at this time. It was concluded that there remained some barriers in collaborative working that the team felt may be addressable if involvement of young people in collecting data. The introduction of the self harm incident feedback form has been the most effective way in obtaining feedback if time is spent supporting them to complete this.

It was clear from the outset that service users were not used to being asked for their opinion. The majority of participants stated that it was the first time that they had been asked for feedback face to face. Some acknowledge that they have completed questionnaires, however felt that the focus groups allowed them to identify issues pertinent to them. The majority noted that although their needs were understood generally by the service provided in Chester their journeys had had been difficult in accessing appropriate help. It was reflected that influencing change out with this organisation remains a significant challenge; however embedding the significance of user participation in this service will give this team the experience and evidence to share good practice with a view to empowering others.

It was felt that that to ensure full participation it would have been useful to have had service users as part of the project group from the onset. Although they were directly involved from the focus group point it may have been useful to access their views prior to this point. In particular the incident feedback forms have been especially helpful in identifying training needs for staff as well as extremely useful reflective feedback for service users. Given the difficulties in recruiting services users in the acute stages of their difficulties this has ensured that the still have a voice. Generally feedback has been positive and the project leader reflects that this still may be influenced by the fact that staff are asking the questions. The team would like to consider involving service users in the collection of this valuable date in the future.

**Opportunities for future development**

In addition to the project the team would like to further advance general involvement of young people. This will include dedicated workers to ensure that user participation for all aspects of Tier 4 CAMHS care is available. In addition the team look to recruit
young people to a consultation panel to ensure their expert opinion is the heart of all aspects of care delivery and service development.

**Conclusion**
The project has facilitated opportunities and processes for collecting information from staff and young people in an ongoing way. This information is used to inform practice in an ongoing way thus ensuring a consistent up to date analysis of views. Both processes are embedded into the service.

Like our service users journeys of recovery our journey to full participation has been met with challenges, resistance and difficulties. The project has given the team a strong basis in which to embed user participation in all our service delivery, evaluation and development. The ability to reflect on success and areas for improvement underpins good practice and is essential in effective service delivery.

**References**


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The project leader would like to take the opportunity to thank the young people for there hard work, commitment and collaboration on the project. You remain our inspiration to ensure best practice. The project leader would also like to thank Richard Janvier, Gemma Hayes and the staff team at the YPC for sharing your experience and inspirational work ethos.

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Appendix 1. Staff questionnaire

Know about self harm?

Your opinion counts!

Would you like to take part in a discussion group to share your views on your experiences of treatment?

Would you like to be involved in shaping the future of treatment options?

If the answer is yes then we'd love to hear your views. We will be holding a discussion group from 10-11 on the ward on FRIDAY 19th February 2010 and would be grateful for your participation. If you would like to be involved please let your named nurse know. If you would like more information please feel free to ask me when I'm visiting the ward.

Thanks
Cat.
Appendix 2. Self harm incident form

1. Please tell us the name of the ward in which the incident took place?

2. Please tell us what happened?

3. Please tell us who was involved?

4. How did you feel before the restraint?

5. How did you feel during the restraint?

6. How did you feel after the restraint?

7. What (if anything) could you have done differently?

8. What (If anything) could the staff have done differently?

9. What have you learned from this which would be helpful in the future?

10. What have you learned from this that was unhelpful?

Many thanks for taking the time to complete this. If you have any further questions or concerns please do not hesitate to contact your named nurse or clinical nurse specialist (Self Harm.)
Appendix 3. Patient passport

Patient Passport

My Full Name: Josephine Bloggs
Please Call Me: Jo

I would like: Mum: 01222-33455/07777-000111
only if mum is not available call Dad: 07999-888999
you to contact: Cat Phillips
Professionals involved in my care: Dr Jones

My treatment preferences are:

Self-harm: I normally require Paracetamol after cutting, and always need pain relief if I need stitches.

I worry about:

Having to tell my story when I am already in treatment

I prefer to be treated by:

Female staff