The development of service user and carer feedback questionnaires for community intellectual disability teams

Dr Laura Nicholson, Consultant Learning Disability Psychiatrist

Contents

Introduction 1
Method 2
Development of the questionnaire 3
Implementation 7
The role of families and carers in completing feedback questionnaires 8
Analysis of results 10
Conclusions 12
List of existing feedback questionnaires 13
List of potential questions 14
References 19

Introduction

NHS health-care policy has moved towards a more patient-centered approach over the past few decades. In mental health, there is increasing focus on listening to the patient and carer, and developing the service to reflect their needs and priorities. Service users are considered experts with respect to their needs (Biswas et al. 2009), and improving the relationship between service users and services is associated with satisfaction, better engagement, and improved clinical outcomes (Chisholm & Sheldon 2011). Larsen note that evaluation of a service is incomplete unless service user’s perspectives are taken into account (Larsen et al. 1979). Because service users are typically unable to choose an alternative service, control of the service is fully in the
hands of the provider unless there is some means of feedback. Development of service user and carer feedback is supported by Scottish and UK health policy (The future vision coalition 2009; Department of Health 2011; The Scottish Government 2012; The Scottish Government 2009).

One way of ascertaining service user’s views is by developing a service user feedback questionnaire. Typically, a number of questionnaires are sent to a sample of service users, and the responses are collated and used to support service change and development. This is a relatively cheap and simple way of collecting service user opinion. However, unless the design and implementation of the feedback questionnaire is carefully considered, the data collected may not be of value.

This essay reviews the literature investigating the development, implementation and analysis of service user (and carer) feedback questionnaires. There is relatively little published in the field of intellectual disability, and the essay therefore also draws from the fields of mental health and primary care. The purpose of this essay is to clarify the research supporting the development and use of service user questionnaires. It may therefore be used to help develop feedback questionnaires for people using intellectual disability services. This essay may also give a better understanding of the limitations of existing questionnaires.

The appendix of this essay gives a comprehensive list of all questions identified from publically available existing intellectual disability feedback questionnaires. This can be used as a base when developing future questionnaires.

**Method**

A literature search was carried out in November 2012 using OVID (Medline and Embase). In addition, the author searched the internet using Google; this was generally more successful in identifying relevant literature than the search through OVID. Finally, the author asked colleagues working in Greater Glasgow and Clyde Learning Disability Psychiatry about any experience of using feedback questionnaires, and for examples that they had used.
Development of the questionnaire

The measurement of satisfaction

Despite an extensive search, the author was unable to identify any literature that specifically addressed the theory of developing service user feedback. However, there was a small amount of literature that described the theory and measurement of satisfaction with services.

Satisfaction is defined as a “thing that satisfies desire ... settles obligation ... or compensates for injury or loss.” (Oxford University Press, 1984) It is not a tightly defined concept, and there is no gold standard measure of satisfaction. It is not possible to measure 100% satisfaction, or other proportions; for example, 85% satisfaction. Even the statement “100% of our patients are satisfied” is not necessarily meaningful. Service users may be satisfied with some aspects of a service (such as accessibility and timely response) but dissatisfied with other aspects (such as ultimate outcome.) A good feedback questionnaire should be able to identify what the service user is satisfied and dissatisfied with, but will be unable to measure “total satisfaction” with a service.

In general, satisfaction with a service will depend on whether service user expectations have been fulfilled. Satisfaction is therefore dependent on underlying expectations; and these may differ between different populations (for example, people of different ages or from different social classes). Expectations may be minimal or in some cases inappropriate. This has implications when analyzing the results of feedback questionnaires, and is discussed later in the essay.

It is important to consider why exactly satisfaction is being measured. This has implications for how the results of any questionnaires will be reported and used by a service, and should also be taken into account when designing a feedback questionnaire. As part of the development of service user feedback for older adult services, Webb (2008) used a process of consultation to agree that the three primary purposes of a satisfaction questionnaire are:
• To assess quality of care.
• As an outcome measure.
• To improve a service.

There was no other literature in this area, but the author suggests that other reasons might include:

• To keep in line with national and local policy.
• As part of clinical governance (e.g. identifying areas of high risk).
• To compare different services.

There is very little evidence to support the use of satisfaction questionnaires and service user feedback for any of these purposes. For example, it is assumed that giving feedback will improve practice, but there is no evidence of this. In fact, a large commissioned review by the Picker Institute quotes two papers as showing that giving doctors feedback about their individual performance did not improve practice. They conclude that “Service users have a valuable perspective on practitioners’ performance but their views need to be taken in context (financial, organizational, political, environmental and the individual).” (pp 3, Chisholm & Sheldon 2011)

**What questions should be included?**

The author was unable to identify any literature that systematically explored what should be measured in a community intellectual disability service questionnaire. The Picker Institute (Chisholm & Sheldon 2011) advises building on existing questionnaires. Although there are a number of service user questionnaires specifically developed for community intellectual disability teams, none of those identified had any theoretical basis and none had been evaluated or validated.

Extending the search to the field of mental health identified two potentially useful service user questionnaires. First, under contract to the Care Quality Commission, the Picker Institute developed the national community Mental Health Service Users survey in 2012. This is a large and comprehensive questionnaire that looks at a number of aspects of mental health services as well as collecting comprehensive personal data; it remains to be seen how the results will be analysed and used. Second, NICE developed clinical guidelines for the service user experience in adult mental health with the intention of improving the experience of care for people using adult NHS
mental health services (National Institute for Health and Clinical Excellence (NICE) 2011). They developed 15 Quality statements, and provide a number of toolkits to audit these. Questions from both of these have been included in the appendix to this essay. However, neither of these questionnaires was developed to evaluate intellectual disability services, and they were therefore not entirely appropriate or relevant in full.

Although in the field of mental health rather than intellectual disability, Larsen et al. describe a systematic attempt to develop a service user feedback questionnaire (Larsen et.al 1979). Following a literature search in mental health, the authors generated a list of general categories under which questions might fall. They then asked 32 mental health professionals if they agreed with these categories (and went on to develop and validate a short questionnaire based on this). There was no theory underpinning the categories, but there was at least a professional consensus agreement as to what should be included. Their list of categories includes a number of areas not covered by other existing questionnaires, and have therefore been included in the appendix to this essay. The categories were broadly as follows:

1. Physical surroundings.
2. Friendly/appropriateness of support staff such as secretaries.
3. Treatment staff - competent, knowledgeable.
4. Appropriateness of service.
5. Quality of service.
6. Quantity of service - did you receive the help that you needed?
7. Outcome of service.
8. General satisfaction with the service - an overall rating.
9. Time to be seen.

In the absence of alternative supporting literature, it may be worth ensuring that the priorities of key intellectual disability policy documents are covered by feedback questionnaires. For example, questions could cover:
• Respect and feeling valued.
• Choice and inclusion in decisions about care.
• Involvement of carers.
• Absence of discrimination.
• Access to services and opportunities.
• Treatment and support for physical and mental health needs.

(From Department of Health 2001; NHS Greater Glasgow and Clyde 2011; NHS Scotland 2004; Scottish Executive 2000)

Other forms of service user feedback

This essay only looks at service user questionnaires. The main advantage of using questionnaires is they are low cost to administer and analyse. However, there are limitations of using questionnaires, particularly in this client group. Many people with an intellectual disability are unable to read, and will need support to fill out the questionnaire. This is likely to affect the results as discussed below, and it may discourage some service users from participating at all. People with more complex needs are less likely to complete the questionnaire themselves, and this may bias the results or may lead to exclusion. Simple quantitative questionnaires are unable to capture the complexity of human experience and important feedback may be lost.

Other forms of service feedback include:

• Individual interviews.
• Open-ended questions and supported conversations.
• Focus groups.
• Storytelling and acting.
• Art and sculpture.
• Forums.
These are more flexible forms of gathering feedback, and have the potential to provide a much greater wealth of insight and material. However, they are all more costly and require more time and expertise from the service gathering the feedback. There may be problems with maintaining anonymity. Although they may include some clients who are excluded from completing questionnaires, there is likely to be significant sample bias, especially if numbers are small.

The Picker Institute advise where possible allowing service users the choice of how to give feedback (Chisholm & Sheldon 2011).

Finally, it is important to distinguish between conducting a full service evaluation and individual service user feedback. A full service evaluation may engage several means of obtaining service user, carer and professional feedback (for example, Moore & Thorley 2011), with the intention of making significant changes to a service. A full service evaluation may not be achievable by a single community intellectual disability team, especially if additional managerial and admin support is not available.

Implementation

The only literature that considered implementation of service user questionnaires comes from the National Community Mental Health Service Users Survey (Picker Institute 2012). This comprehensive body of work was developed by the Picker Institute for the Care Quality Commission, and the survey is in the process of being rolled out in community mental health teams and inpatient units across England. All people accessing mental health services across the country will be asked to participate. There was considerable expertise and experience in the commissioned organisation, and they gave the unequivocal following advice regarding implementation:

Large-scale surveys such as this should not be carried out in-house unless there is sufficient experience; instead, an approved contractor should be used. Conducting large surveys is an administratively complex task requiring dedicated resources for several months. It requires money, resources and staff time; these are usually underestimated. Staff time in particular is one of the largest expenditures, and is often overlooked. If data are entered and checked manually then this will also take staff time. Finally, producing reports and recommendations based on the results will also take skilled staff time.
Implementing a service user questionnaire across an intellectual disability service is on a much smaller scale than the national mental health survey described above. Nevertheless, given the expertise behind the report, it is worth considering their advice carefully. For example, a typical intellectual disability service may have an open case load of around 400 - 500 clients. Across a health board this may be around 2000 - 3000 clients. If all service users are invited to complete a questionnaire, and assuming a response rate of around 40%, data from up to 1200 service users may need to be analysed. Sending out questionnaires and analyzing data on this scale is a significant piece of work. This may not be manageable within existing job plans. If a smaller sample of service users is used, then care will have to be taken to avoid sample bias.

Sending out feedback questionnaires and collecting and analyzing results should all be carried out within local and national information governance policy. All data should be stored in line with the Data Protection Act. Consideration should be given to whether the questionnaire and implementation protocol should be approved through the relevant Research and Development office; if there will be centralised analysis of the results, if the results will be analysed in a way that permits a research question to be answered, or if the results will be published, then application for ethical permission should be also be considered. All of this will take skilled time at a planning level.

It is important that the administration of feedback questionnaire is standardized, as this has been shown to affect the data collected. For example, in primary care, questionnaires completed immediately after consultation showed greater satisfaction than those completed later at home (Kinnersley et al. 1996 from Chisholm & Sheldon 2011). Postal surveys were found to be more critical than surveys completed immediately on leaving a service (Richards et al. 2010 from Chisholm & Sheldon 2011). The Picker Institute state that absolute consistency in administration is difficult to achieve, and this should be taken into account when comparing results.

It may be useful to run a pilot questionnaire before rolling a questionnaire out over the whole of an intellectual disability service. It will then be possible to get feedback from professionals and services users before proceeding with what may be a significant piece of work. Speech and Language Therapy should advise on the format and language of the questionnaire so that it is as accessible as possible for people with intellectual disabilities.

Finally, there needs to be a robust way of ensuring that the results of the feedback questionnaires (and any ensuing recommendations) are fed back to individual teams.
It is also appropriate to consider giving feedback to service users. This would be a requirement if the questionnaire was approved through a National Ethics Committee. In addition, there is some evidence that giving feedback to research participants may improve future participation (Nicholson et al. 2011).

The role of families and carers in completing feedback questionnaires

The only literature identified in this field comes from a substantial body of research by the Personal Social Services Research Unit (Malley et al. 2010). The authors carried out a number of evaluations in the context of social services care homes, some of which were for people with intellectual disabilities. They found that when families and carers responded entirely on behalf of the service user (i.e. as proxy respondents), they did not answer questions consistently. Answers tended to be more reliable when asking about concrete facts, but random error was introduced when asking about feelings. Carers tended to answer these questions from a political or moral standpoint rather than try and guess how the person that they supported was feeling. These findings were so strong, that the research team recommended that service users who were unable to express opinions about their care or who lacked the capacity to consent to take part in the survey should be excluded from the sample.

In the context of community intellectual disability teams, it would be difficult to exclude all service users who were unable to express opinions about their care or give fully informed consent to participation. This would lead to exclusion of a large and important number of clients whose opinions should be valued within the service. However, the above work was large and robust, and needs to be acknowledged. It highlights the need to know whether questionnaires have been completed by service users or carers; this should then be taken into account when analyzing the results.

Malley et al. make some sensible recommendations in the event that family and carers do assist service users to complete questionnaires. For example, they suggest that there are specific instructions on the questionnaire cover sheet for people assisting with the questionnaire. These should make it clear that the answers should reflect the opinions of the service user rather than the carer as far as possible. Questions should be added to establish who gave assistance, and to explain any differences in opinion. Their role (e.g. family, support worker or professional from within intellectual disability services) should be clarified, as this may bias the answers.
given. Finally, consideration should be given to a separate survey for carers, and this should be highlighted within the service user questionnaire. Providing carers with a separate opportunity to comment on services themselves may reduce their need to give their own opinions when assisting with service users questionnaires.

Analysis of results

Sample bias

Feedback questionnaires in mental health typically have low response rates (20% - 40%, Larsen et.al 1979) and questionnaires from community intellectual disability services are likely to have similarly low return rates. (For example, the response rate from a Bristol Community Learning Disability Service survey was 27%, and that of a Glamorgan Community Learning Disability Service survey, 40%). It is not known whether people who are satisfied or dissatisfied with services are more likely to respond, and this low response rate is likely to lead to significant bias in the results. In addition, a number of factors have been shown to affect satisfaction with health practitioners and services (table 1).
### Table 1: Factors associated with satisfaction with health services

<table>
<thead>
<tr>
<th>Factors found to affect satisfaction with services</th>
<th>Factors NOT found to affect satisfaction with services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>Age</td>
</tr>
<tr>
<td>Gender</td>
<td>Gender (but women more polarized in responses compared with men)</td>
</tr>
<tr>
<td>Social class</td>
<td>Social Class</td>
</tr>
<tr>
<td>Race (non-white clients significantly less satisfied)</td>
<td>Family income</td>
</tr>
<tr>
<td>Employment status (unemployed less satisfied)</td>
<td>Marital status</td>
</tr>
<tr>
<td>Interaction and communication with an individual practitioner may be the most important predictor of satisfaction with the entire service.</td>
<td>Rurality</td>
</tr>
<tr>
<td>Attributes of the individual practitioner including their age, gender, graduation within/without the UK, training and social class.</td>
<td></td>
</tr>
<tr>
<td>Health and prognosis</td>
<td></td>
</tr>
<tr>
<td>Rurality</td>
<td></td>
</tr>
</tbody>
</table>

(From Chisholm & Sheldon 2011; Larsen et.al 1979; Nicholson 2012; Scottish Executive 2003; Scottish Executive et al. 2006; Shucksmith et al. 1996)
Some of the evidence in Table 1 is contradictory. All of these studies were conducted in the general population, and it is not known how intellectual disability might impact on these factors. In addition, it is not known how the demographic characteristics of carers and families answering questionnaires on behalf of service users may bias results. Unless service user and carer characteristics are known and accounted for, it will not be possible to fully interpret the results of feedback questionnaires. In particular, it will not be possible to compare and standardize results across different intellectual disability services.

**Statistical analysis**

Data could be entered and analysed using a simple program such as Excel. However, much more useful information could be drawn from the data if a statistical package (such as SPSS) were used to analyse the data. Use of a statistical package would be essential if different services were to be compared. This would require a relatively skilled employee to analyse the results.

In addition to analysis of the data as a whole, it would be important to have a way of flagging up serious concerns. For example, feedback may suggest that there is significant risk to patients, or that there may be serious professional misconduct of a single member of the team. Once again, this requires the data to be analysed at a relatively senior level.

**Conclusions**

This essay has reviewed the literature investigating the development, implementation and analysis of service user (and carer) feedback questionnaires in the context of community intellectual disability services. Even drawing from the fields of mental health and primary care, the evidence base to support the development of service user questionnaires is limited. There are a number of difficulties inherent in the implementation of obtaining service user feedback, and also a number of considerations to be accounted for when analyzing the results of any feedback. Before developing a questionnaire it is important to decide what the purpose of the questionnaire is, and also what resources (both time and money) can be invested in the questionnaire. Despite these potential hurdles, the development of service user (and carer) feedback is likely to become an important part of the way in which future community intellectual disability services work. It is hoped that this essay will help the service user questionnaire to be as valuable as possible.
List of intellectual disability feedback questionnaires:

(This is a list of all intellectual disability service feedback questionnaires identified locally and through Google.)

Brighton and Hove

Bristol Service User Questionnaire

Cheshire and Wirral Case Study

Debra Moore Associates

Derbyshire Daycare Questionnaire

Glamorgan

Gloucester NHS trust

Greater Glasgow and Clyde: Netherton Unit, and Tier 4 feedback questionnaires

Solihull Service User Questionnaire

State Hospital Care measure
List of Possible questions

These questions have been taken from a range of publically available and local questionnaires (listed above). The questions have been grouped into headings; primarily based on NICE quality statements. Almost all questions used Likert Scales in their response.

1. Effectiveness of care/outcome of service

*Did it (our treatment) help you?*

*How well do you feel that your (care plan) meets your needs?*

*The person knew how to help.*

*I have confidence in the services provided by the team.*

*Support is provided to keep healthy, safe and well.*

*Do you think the service met the needs of your relative?*

2. Do clients feel that they are treated with empathy, dignity and respect?

*I am treated with dignity and respect.*

*How good is Dr _____ at . . .*

  - Making you feel comfortable when he talks with you
  - Giving you time to think and talk
  - Really listening to what you have to say

*How good is Dr _____ at . . .*

  - Finding out what is important to you
  - Caring about you and being kind
  - Explaining things so you understand
  - Helping you to think about your future and make plans
Did we talk to you nicely?

Were you given time to talk about your problems and needs?

I felt listened to

It was easy to talk

I was treated well

My views and worries were taken seriously

Did this person listen carefully to you?

Did you have trust and confidence in this person?

Did this person treat you with respect and dignity?

Were you given enough time to discuss your condition and treatment?

Do you like the way in which the staff talk to you?

Do you like the way the staff treat you?

Do the staff listen when you have something to say?

Do staff treat you as an equal?

3. Shared decision making, self-management, involved in decisions regarding care

Do you have a say about what you want for your future?

Did we plan your treatment with you?

Did we let you ask questions?

Did we listen to what you had to say?
How involved did you feel when we made your care plan?

Did you know that you have a right to complain or provide a compliment about any services you have received?

We decided together on my goals

Do the staff include you in care planning?

Were you given the opportunity to be involved in any decisions about your relative’s care?

I feel I am in control of the services I receive from the community team.

Do you understand what is in your NHS care plan?

Do you think your views were taken into account when deciding what was in your NHS care plan?

Family carers and others who know and care for me are active partners.

Did this person take your views into account?

4. Supported by staff from a single familiar MDT with continuity of care.

(No questions identified.)

5. Confidence that their views are being used to monitor and improve the performance of services

I am involved in deciding if services provided by the team are good and what needs to be improved.

6. Access

Was it easy to get in touch with us?

The appointment times were good
The place we met was easy for me to get to.

Can you contact your Care Co-ordinator (or lead professional) if you have a problem?

7. Does client understand the assessment process, diagnosis and treatment options?

Did we tell you about how we wanted to help?

Did we tell you why this would help?

Did you receive enough information about the team when you were first contacted?

Things were explained well including my medication

The last time you had a new medication prescribed for your mental health condition, were you given information about it in a way that was easy to understand?

8. Do they receive emotional support from team?

(No questions identified.)

9. Does the client have a copy of the jointly developed care plan, with an agreed review date?

Have you been given (or offered) a written or printed copy of your NHS care plan?

10. An appropriate crisis support is available.

Does your NHS care plan cover what you should do if you have a crisis (e.g. if you are not coping or if you may need to be admitted to a mental health ward)?

Do you have the number of someone from your local NHS mental health service that you can phone out of office hours?
11. Appropriate physical surroundings
(No questions identified.)

12. Friendly appropriate support staff such as secretaries
(No questions identified.)

13. Time to be seen
(No questions identified.)

14. General satisfaction with the service - an overall rating

How happy are you with the support you get?
Have you ever wanted to complain about the support you get?
What would make the support you get better?
How happy were you with the service?
Tell us what you think of the Staff?
Is the support and help the staff provide good?

Overall, how would you rate the care you have received from NHS Mental Health Services in the last 12 months?

15. Other questions from the questionnaires reviewed

Have NHS mental health services involved a member of your family or someone else close to you, as much as you would like?
I get support from the team that helps me to stay close to my family and within my community.

My family carers feel valued and supported.
References


Nicholson, L. 2012, *The health, support needs, access to healthcare services and social exclusion of adults with intellectual disabilities living in rural areas: a rural-urban comparison*, MD, University of Glasgow.


