The Foundation of Nursing Studies
Developing Practice • Improving Care

Foundation of Nursing Studies Dissemination Series 2005 Vol.3. No.1.

Making Hospitals Friendlier and Easier to Use for People with Learning Disabilities: a Project Looking at Service-Users' Perspectives

Keywords:
Learning disability, user involvement, consultation, access

Duration of project:
March 2004 – August 2005
Report received for publication: August 2005

Project leaders:
Kirsty Glaysher, Patient Information Manager (State Registered Occupational Therapist)

Contact details:
Kirsty.glaysher@stgeorges.nhs.uk

Summary of project

Background
Valuing People (Department of Health, 2001) explains that people with learning disabilities get a "worse deal" from health services than the rest of us. The World Health Organisation (2001) reiterates this by stating that people with learning disabilities have poorer health outcomes.

A learning disability means that a person has a reduced ability to understand new or complex information, or to learn new skills and a reduced ability to cope independently, which starts before adulthood and has a lasting effect on development (British Institute for Learning Disabilities, 2005 webpage).

In order to respond to these inequalities in health and access to health services, a consultancy scheme was established where people with learning disabilities were facilitated to review healthcare and make recommendations to an acute hospital trust. The project was coordinated over the course of a year by the Patient Information Manager and conducted in partnership with a local organisation (Generate) that supports people with mild to moderate learning disabilities.

Aims of the project
The primary aim of the project was to achieve improvements in access and quality when experiencing health services for people with learning disabilities and their families. Consequently, the project objectives included increasing the potential for partnership working between the hospital trust and local organisations, developing a service user-led culture of scrutiny within the hospital, and the promotion of awareness of the legislation and guidelines that exist involving people with learning disabilities.

The hospital is a member of the local Learning Disability Health Action Planning Task Group. This project was planned and conducted in line with the task group's terms of reference and framework for implementing health action planning and health facilitation.

Processes
The project was divided into succinct project steps, each one having a time frame and planned budget allocation.

Step 1 – Recruitment of a team of service users
Four members of Generate, all of whom had a learning disability, were recruited to work as project advisors, representing a range of support needs as well as a variety of previous work experience. From the outset, an involvement incentive payment and expense system was laid out and approved by the advisors as well as both organisations.

A facilitator was also appointed to provide support to the advisors throughout the project. A member of staff from Generate was identified and the service users were consulted to ensure involvement at every stage.

Step 2 – Preparation for work in the hospital
Two sessions were held with the advisors and facilitator aiming to develop skills of observation, scrutiny and evaluation. Videos, role play and group discussion was used to raise awareness of good and poor practice.

Step 3 – Reviewing the hospital site and services
The reviews, or "User Tests" as they were called, involved advisors looking at patient information, way-finding around the hospital, as well as experiencing clinical services. A breakdown of the user tests can be seen in Table 1. An actor with learning disabilities and his carer were paid using the project funds to attend simulated outpatient appointments and a ward discharge meeting, which the advisors observed as "flies on the wall".

Table 1. Details of "User tests"

A. Travelling through the hospital information journey
Advisors looked at the information sent to patients before coming into hospital (letters, leaflets, appointment cards). The information was assessed for user-friendliness and general accessibility.

B. Navigating the hospital site
Advisors were met at the main entrance of the hospital and allocated (individually or in pairs) a department/clinic and a ward to find. Arrangements were made to meet in the hospital dining room at the end of the exercise. Advisors were briefed that they could use any available resource to help orientate them, such as reception/information staff, signposts and maps on the walls.

C. Experiencing clinical services
Advisors discretely observed a "patient and carer" (actors) attending an outpatient appointment and a meeting with a nurse on a ward as if preparing to leave hospital after an admission. The communication skills of staff, physical environment, information used and time taken were all reviewed. Both exercises were pre-prepared and simulated to avoid ethical issues of having five people (advisors and facilitator) observing a "real" patient's clinical care.

Step 4 – Gathering feedback
Comments and opinions were collated by the facilitator immediately following each user test. The advisors were asked to consider the "good things" and "bad things" about their experience in the hospital that day, and give the service marks out of ten.

Table 2. Details of project findings

The written information sent/issued by the hospital to patients, was found to:
- be poorly laid out
- contain confusing content
- have unclear instructions of what to do / where to go
- be unreadable at times with type too small
- show several numbers to call for any problems (advisors were unclear of which to use)

When navigating the site, the advisors found that:
- signs were confusing in places
- floors also called levels
- several different versions of maps of the site could be found on the walls
- colour coding for wings was helpful on signs and written materials but not when colours were faded

The appraisal of the clinical services, revealed that
- the physical environments (layout of chairs, cluttered rooms) did not lend themselves to a positive experience
- the patient not asked if they would like their carer to come in
- the time taken for the appointments was important as the patient got bored
- complex instructions (regarding medications and discharge advice)

Positive examples of good practice noted by the advisors included:
- staff speaking directly to patient (not via carer)
- nurses using pictures to explain things
- staff introducing themselves and explaining their roles
- staff around the hospital stopping to offer help without being asked
- a generally friendly environment due to the use of pictures / art around the hospital

Step 5 – Informing staff
The main project findings were divided into areas for development ("bad things") and areas of noteworthy practice ("good things") as building blocks for good practice (see Table 2). These were conveyed in presentations to staff/management via a commissioned performance from a training group who specialise using theatre to address issues facing people with learning disabilities. Three presentations were held; a drop in session in the hospital dining room (attracting around 100 staff, students and visitors), a formal "by invitation" session for staff working in key areas (for about 70 staff) and a presentation to the hospital's Equality and Diversity Group. Evaluation forms provided very positive feedback (83% of people who saw the presentations gave it 10/10) and comments included:

"this was a very powerful way to convey the message that I need to be more patient with patients"

"I have learnt how confusing and disorientating it might feel to come to the hospital if you have a disability"

Staff attending the presentations were provided with Top Tip Guides for working with people with learning disabilities providing best practice ideas for a holding a consultation/appointment, signage, providing a welcoming environment and for letter writing.

Recommendations and implementation of findings

A list of recommendations has been compiled to address the main findings of the project. This has been presented to and ratified by the Trust Board and Executive Group in the form of an action plan, which in turn formed part of a new "Policy for the Protection of Vulnerable Adults".

These recommendations were:

1. The early identification of potential support needs for patients. This has involved the integration of the community learning disability register with the hospital patient administration system, alerting staff at the first possible opportunity that a patient may need extra assistance (such as a longer appointment).
2. Guidance for staff on how to support patients with learning disabilities; "Top Tips" on how to meet and treat patients with learning disabilities have been widely distributed and are also available on the hospital intranet.
3. User-led training sessions are being piloted on the nurse induction programme and for Learning Disability Champions (staff with a special interest working in key areas of the hospital).
4. Establishment of Learning Disability Task Group to ensure that the measures above are implemented and monitored for effectiveness, represented by hospital staff, people with learning disabilities and members of the local inter-agency Health Action Planning Task Group.

Reflecting on working with service users

Delivering patient centred care goes far beyond the clinical contact between a healthcare professional and the patient. It encompasses the entire journey that the patient travels along, from the point of access (such as a referral or Accident and Emergency attendance) to the point of discharge. The project was developed around the fundamental principles of Patient and Public Involvement (Department of Health, 2004), recognising that the most responsive way of finding out what services users want is to engage with them and be directed by them.

Responding to the challenge of involving service users in a meaningful way required effective reflection, monitoring and feedback. Generate were consulted from the earliest stage, even at the point of project design (prior to the bid submission) about the most effective way to allocate potential project funds. Key stages in the user involvement included the appointment of the facilitator, preparation of the advisors for the project and looking at outcomes and evaluation.

The appointment of a facilitator was key to the success of the project, recognising that supporting and effectively communicating with people with learning disabilities requires specialist skills and experience. It was essential that the advisors were comfortable with the facilitator and responded well in the feedback sessions that followed each user test. An informal discussion was held with the advisors to ensure that they felt the facilitator possessed skills necessary to effectively support them.

Preparation for the project was carried out over two sessions; the first for getting ready for working in a hospital environment and the second for developing observation and scrutiny skills. Looking back, a more intensive approach to this aspect of the project may have been useful. One session a week over two weeks meant that the service users had significant new skills and knowledge to carry over a considerable length of time. Additional sessions offered with higher frequency might have been more beneficial, although that would have posed certain logistical difficulties in coordinating the project group (the facilitator, project managers and the advisors) more than once a week.

Establishing ground rules for the project was another important part of preparing service users for the project. This was carried out at the beginning of the project looking at what was required from the advisors and how the payment/reward scheme would operate. It was also useful to cover ground rules immediately prior to each user test as a 'refresher' about conduct in hospitals (for example trying not to swear, not touching equipment in clinical settings).

Rewarding service users for involvement is an area that has typically generated considerable discussion in PPI circles. It is essential that any payment to service users does not affect benefits or social support entitlements. It is also important that any agreement between an organisation and a service user would not represent a contract of employment (and consequent employee entitlements). For this project, Generate were remunerated directly for the facilitator's time, whereas the advisors chose "gifts" (such as jewellery, mobile phones) to the value of previously agreed rates for each session, for which Generate invoiced the hospital. The advisors became frustrated on several occasions due to the delay between their work in the hospital and the availability of their gifts. Recommendations from this project would include fully briefing service users about realistic timescales for transferring money from one organisation to another.

Evaluating the project was a critical aspect of the work and it was decided from an early stage to present the findings to the hospital in a usual way to create maximum impact. One of the project advisors suggested using a drama company and once one had been identified, arrangements were made for all the advisors to see a performance. The decision to use Movable Feast was a unanimous one. Working long distance with Movable Feast (they are based in Durham) meant that a lot of the preparation work was conducted by telephone. Therefore the first opportunity for the service users to properly meet the performers who were conveying their important message (the project outcomes) was the day before the first performance. In the absence of being able to meet up, discovery interviews with the advisors were also videoed at the end of the project. This provided Movable Feast with in-depth feedback about how the advisors felt about the project, the hospital and their experience of service user feedback.

Conclusion

Working with people with learning disabilities provided valuable insight into issues of access to services. It highlighted the fact that healthcare providers can really only claim to offer choice when equality exists in service provision. Most importantly though, it has been a key philosophy and focus throughout the project, that "getting things right for people with learning disabilities means getting things right for most people". Other groups who stand to benefit from improvements in practice are patients with other support needs and those who do not speak English.

The findings and outcomes of the project are essentially transferable in several ways. The lessons learnt from reviewing specific services have been rolled out to form Trust wide recommendations, which have in turn been shared with other organisations.

References

British Institute of Learning Disabilities (2005) *What is a learning disability?* Web Factsheet Number 001, page 1 (last viewed 18.7.05).

Department of Health (2001) *Valuing People: A new strategy for learning disability for the 21st Century* http://www.valuingpeople.gov.uk/ValuingPeople.htm (last viewed 18.7.05).

Department of Health (2004) *Patient and Public Involvement in Health; the evidence for policy implementation* http://www.dh.gov.uk/assetRoot/04/08/23/34/04082334.pdf (last viewed 18.7.05).

World Health Organisation (2001)World Health Organization Healthy Ageing: adults with intellectual disabilities; summative report. *Journal of Applied Research in Intellectual Disabilities;* Vol.14: pp 256-75.

Acknowledgements

With special thanks to:
Our project advisors John, Simon, Anne-Marie and Jason; Jo Giles of Generate, who jointly led this project and Susan McGuiness of Generate who facilitated the advisors throughout the project; Sue Cooper, Deputy Director of Nursing and Learning Disability Champion at St George's Healthcare NHS Trust; Movable Feast who helped us present the findings of the project through such a powerful performance.

To the Foundation of Nursing Studies for funding and supporting the implementation and dissemination of this project.

To the Freemasons' Grand Charity for supporting the dissemination of this project.

How to reference this report

Glaysher, K (2005) Making Hospitals Friendlier and Easier to Use for People with Learning Disabilities: a Project Looking at Service-Users' Perspectives. In Shaw, T. and Sanders, K. (Eds) *Foundation of Nursing Studies Dissemination Series.* Vol.3. No. 1.

The Foundation of Nursing Studies Dissemination Series

ISSN 1478-4106
Editors: Theresa Shaw and Kate Sanders
32 Buckingham Palace Road
London SW1W 0RE
Tel: 020 7233 5750
Fax: 020 7233 5759
www.fons.org
Reg. Charity No 1071117