



Centre of Excellence in Interdisciplinary Mental Health

Working for User Involvement in Mental Health Services Paper 3

TRANSFORMING SERVICES: CHANGING LIVES

A Guide for Action

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THE UNIVERSITY OF BIRMINGHAM CENTRE FOR EXCELLENCE IN INTERDISCIPLINARY MENTAL HEALTH

This Centre, based at the University of Birmingham is involved in developing a dynamic and collaborative partnership between six schools in the university and the mental health service user, practice and policy communities. Through this partnership it aims to enhance and expand the delivery and evaluation of innovative, interdisciplinary mental health programmes within higher education and the mental health sector. Service user and carer involvement as well as e-learning will be key features of programme development. The Centre can provide advice, training and further information on promoting user involvement in the mental health services.

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INTRODUCTION

Over the past seven years, Suresearch, a Midlands based, user led organisation of mental health service users and their allies, has undertaken four research projects in Birmingham and Solihull. These projects were commissioned by the Birmingham and Solihull Mental Health Trust to find out about service users experiences of the mental health services. Over 200 service users have shared their experiences with us. They represent people of all ages and from diverse communities, who use the full range of hospital and community based services, run by health, social care and voluntary sector staff. Our work has also sought the views of staff from these services. This evidence has revealed a lot about what is working well and what is not working well from the perspective of service users.

A project that we undertook in 2003 of service users experiences of services in the City of Birmingham resulted in the construction of seven user generated indicators. These are indicators of the core characteristics of services which are working positively to support service users in their recovery from mental ill health. They are:

- Valuing** service users as people and experts in their own lives
- Listening** to what service users say about what is happening to them and what they want to happen in the future
- Learning** from service users about what works for them and what blocks their recovery.
- Engaging** with service users on key issues relating to their lives e.g. employment, housing income, personal and family relationships, treatment and care options.
- Working with users** through exchanges, including care planning assessment, directed at achieving life changes that support recovery
- Connecting service users** to sources of specialist and community based advocacy and advice that will promote their rights as citizens
- Involving service users** in service development and staff recruitment.

The evidence from Suresearch research in Birmingham and Solihull suggests that some services are delivering on these areas. However, most are struggling to deliver on all of them in ways that make a positive difference to service users. We therefore wrote

this guide to action to assist staff working in the Trust to think about and change the ways they are working with user involvement in the services they are delivering.

We piloted the guide with help from a group of staff from across the service areas of the Trust, by offering them two half days of user led training on using the guide. After each session we asked the participants what they thought of the guide and the training. Both were very positively evaluated. After the first session of training staff said they had found it useful because it had been good to spend time away from work and concentrate, with others on how they can promote positive user involvement in their services as well as the geographical areas they serve. One participant commented ***'There is so much out there, that I wasn't aware of, it is good to catch up with what is going on outside of my service.'*** Another said ***'such training should be mandatory across all disciplines, It would also be good education for service users who want to know more about the concept of user involvement'***

In between the training sessions participants tried using ideas from the guide and reported that they had found it very useful in reviewing how their team is working with user involvement as well introducing them to policy and practice guidelines that they had never come across before. One participant described it as ***'an ongoing and practical resource that we need to use to get user involvement to the forefront of people's thinking'***.

This guide suggests ways of engaging with user involvement which will assist mental health practitioners in mental health trusts and the voluntary sector to improve practice in this area. It combines ideas and advice with direct quotes from some of the users and staff who contributed to the research on which it is based. We would like to thank them for the time and attention they have given to putting user involvement on the agenda.

MENTAL HEALTH : AN ISSUE FOR US ALL

It is estimated that one in four people in the UK will experience mental ill health at some point during their lifetime. (1)

How mental distress is experienced will vary between individuals. Some of this variation relates to factors such as age, ethnicity, gender and social class. (2)

For some people a diagnosis of mental ill health means that they have to cope with a life long condition.

For others it means intermittent periods of acute mental distress.

For others it means an extended period of distress which does not return.

Most people with mental ill health get their support from the primary care services who deal with 90% of diagnosed mental health problems. The remainder look to specialist mental health services for care and support. (3)

Staff working in the mental health services need to provide responses that positively help a range of individuals through crises and recovery. Recovery involves people taking an active role in making the improvements in their lives that are important to them.

Evidence suggests that responsive services are those in which staff actively listen to what service users say is important for them and work in partnership with users.

‘Staff here really listen to me, it has made such a difference to what’s happening in my life’.

Service user-assertive outreach service

Working in active partnership with service users in ways that involve them in shaping services so that they meet the needs of individuals more effectively is vitally important to the mental health and wellbeing of us all.

An important aim of user involvement is to create the kind of mental health services that any of us would want to use for ourselves, a friend or a family member, if we experienced mental distress.

References

1. See MIND Factsheet- *Statistics 1: How common is mental distress?* Downloadable from <http://www.mind.org.uk>
2. See MIND Factsheet –*Statistics 3: Race, culture and mental health.* Downloadable from <http://www.mind.org.uk>
3. Goldberg, D. and Huxley (1992) *Common mental disorders* London, Routledge

WHY BOTHER WITH USER INVOLVEMENT?

These are changing times for people working in mental health services and those using the services. Change can create difficulties for staff as well as service users.

Staff are often working with all kinds of pressures and stresses. These come from the puzzling and challenging nature of mental ill health, from the misunderstandings of people who are unfamiliar with mental health problems and from the changes that are taking place in the way in which services are organised, financed and managed. Staff have to deal with all of this as well as the pressures that they may have in their own lives.

So why- on top of all the things you are being required to do should you take on the work of involving service users in developing services? And how can you do it?

One of the main reasons for getting involved in user involvement is that as an employee of mental health services you are being asked to do it by the government and your employers. The NHS Plan states that

'patients are the most important people in the health service. ...Too many patients feel talked at rather than listened to. This has to change. NHS care has to be shaped around the convenience and concerns of patients. To bring this about, patients must have more say in their own treatment and more influence over the way the NHS' (1)

The Birmingham and Solihull Mental Health Trust, in their User Involvement Strategy 'Everybody's Business' states:

'All clinicians, managers and staff within the trust must see User Involvement as an integral part of their working lives. Only then will service users have the opportunity to influence planning and development of services, to properly influence the way their care and treatment is decided and delivered, and to offer an invaluable insight into the effectiveness of that care' (2)

But there are also other reasons for doing it that staff have shared with us. Here are some of the things that that staff have said about user involvement

'I've found that the more involved our clients are in what is happening here the more they feel it is their centre and they feel responsible for making it work. They have taken charge of day to day things like the look of the building, how to organise tea and coffee services, the use of the TV. This has meant that staff can concentrate on what they do best and it has taken pressure off of them'

Day Centre manager

'Our user group is a constant source of new ideas which has helped us improve our service-making it more valued by our service users'

Rehabilitation and Recovery worker

'Checking out with our service users regularly what is and what isn't working for them keeps us on our toes and helps us introduce changes when they are needed'

Assertive outreach worker

Service users have also shared with us their views about the difference that user involvement could make to them. As one user of a day service commented:

'Staff spend their time chatting with each other in the office now. They need to join in with us service users like they used to. We know that staff can be stressed when they come to work, their minds on family matters and worries about the future. Problems with their spouses or children can weigh heavily on their minds distracting them from working with service users. If they came out of the office and had regular meetings with service users they would be in the picture about our needs, they would find out how service users are feeling. It would make such a difference to everyone'

Another important outcome of user involvement that are regularly mentioned by service users is that being involved is a therapeutic experience-it increases self esteem and confidence and gives them a feeling that they are valued as thinking people despite their

problems. They feel their opinions are respected and they are making a positive contribution to improving mental health services.

Involving service users can have positive outcomes for staff. Building better relationships with service users and developing a deeper understanding of their difficulties as well as working with them to problem solve and move into recovery can make your job easier and more enjoyable!

‘One of the outcomes of our growing service user involvement has been that in discussion with service users our staff decided to change the way they worked. Instead of giving service users a few minutes of our time, when we could spare it we decided that each staff member should be responsible for a small group of service users. We are now able to give each group an hour or two of our undivided attention regularly. We have been astonished and delighted at the difference this has made to us all. It was like a light had been suddenly switched on. Our job satisfaction has really improved’.

Voluntary sector Day Service worker.

References

- (1) Department of Health (2000) *The NHS Plan: a plan for investment, a plan for reform*. London, DoH
- (2) Birmingham and Solihull Mental Health Trust (2003) *‘Everybody’s Business’: a user involvement strategy*.

A HEALTH CHECK FOR YOUR USER GROUP

Staff and service users suggest that an important first step towards user involvement in a service is to establish a user group in your service. A user group can provide a regular opportunity for service users to meet together, discuss issues and exchange views and ideas with staff about what is happening in the service. If it is working well your user group should provide a lively forum for discussing what is working well and what needs to change to improve your service.

If your service has a user group we suggest you sit down and review how healthy it is by asking yourselves the following questions:

1. Who has the responsibility of running the group?
2. How often does the group meet and who sets the time for the meetings?
3. How do service users find out when and where a meeting is taking place?
4. Is it staff and/or service users who encourage people to attend the group?
5. How many service users attend the group? Do they reflect the diversity of people that use the service?
6. Do staff attend the group for some or all of the time?
7. Who chairs the group and how is this decided?
8. Do you have an agenda for these meetings? Can service users as well as staff provide items for the agenda?
9. Do service users speak at these events more or less than staff members?
10. Is your user group an enjoyable event? Is the atmosphere one in which people feel comfortable about expressing their views?

11. Is there a comfort break during the meeting?
12. How are issues for further action identified in the group?
13. How do you let people know what has happened at these meetings?
14. What has changed in your service over the last six months as a result of ideas generated by the user group?

When you have answered all these questions discuss what you think needs to change to make your user group work better. Make a space at your next user meeting to share your views with your service users and see what they think.

WHAT ARE YOU AIMING FOR?

Working towards service user involvement in services means being clear about where you are starting from and what you want to achieve.

The following schedule can be used by staff teams to share where they think their service is in relation to user involvement and where it might be heading. Use it to decide what level of user involvement you have and what level you would like to achieve.

Level 1 *No Involvement*

The service is planned, delivered and managed and care plans are drawn up without consulting or involving service users.

Level 2 *Limited Involvement*

User groups are given limited information concerning the service and are occasionally consulted by staff, on changes to the service. No opportunity is provided for users to become actively involved in shaping the service as a whole. Users are sometimes involved in their care and treatment plans but this is not systematic.

Level 3 *Growing Involvement*

User groups are regularly consulted on aspects of the service e.g. decisions about activities, decoration and design of the premises that service users use. Comments are sought from service users by staff on referral and admission policies and practice. Most users are involved in meetings about their care and treatment plans. However, key decisions on service planning, staff recruitment, financial decisions, changing service delivery current management problems and organisational pressures are made in forums in which service users are not represented.

Level 4 *Collaboration*

Service users are fully involved and regularly contribute to a full range of service issues e.g. their care and treatment plans, staff recruitment, service planning, referral and admission policies. The service has a statement of values and aims in relation to service user involvement. Payments are made to cover the time and expenses of service users who become involved in service change outside of the regular user meetings. Opportunities are provided for service users to meet up together, and appropriate training and

support is made available to them so that they gain the skills needed to collaborate with staff. Positive steps are taken to encourage service users to access job opportunities within the service and beyond.

Level 5 Partnership

Service users and staff work in partnership across all service areas. This work is underpinned by an explicit statement of partnership values and service aims. Key decisions are made jointly. Service users are involved in the evaluation of the service. An infrastructure is in place to provide induction, support and training for service users. Service users have opportunities to be recruited to work in the service. Positive steps are taken made to encourage service users to work voluntarily within the service with a view to finding employment in the service or a similar environment.

The Birmingham and Solihull Mental Health Trust's User Involvement Strategy states that there are three areas of activity where user involvement is essential:

Individual- service users should be involved in their own care and treatment plans

Care setting- service users should be involved in exchanges about how the services they are using are being planned and delivered

Policy- service users should be involved in decision and policy making groups within the Trust.

In each of these areas user involvement can be developed in a variety of ways. Think about how you currently involve service users in each of these areas and then think about how you might increase this involvement in each of these areas.

The grid on the next page can be used to summarise your achievements in relation to the five levels and the three areas as well as to plan further developments

WHAT ARE WE ACHIEVING?

AREAS

INDIVIDUAL

CARE SETTING

POLICY

LEVELS

1			
2			
3			
4			
5			

GETTING THERE

When you have decided what you want to achieve it is vital that you find ways of working with service users to achieve the level you all think would work for you. This means that your ideas and work need to be fully informed at the outset by the views that service users have about what kinds of services work well for them.

The user generated service indicators mentioned in the Introduction to this guide can be used to do this. Once it has been used to evaluate where you are now there are other steps you can take to build on the evaluation.

STEP ONE: USING SERVICE USER INDICATORS TO EVALUATE YOUR SERVICE

The following user generated indicators list the characteristics of services which are working positively to support service users in their recovery.

Valuing users as people and experts in their own lives

Listening to what service users say about what is happening to them and what they want to happen in the future

Learning from service users about what works for them and what blocks their recovery.

Engaging with service users on key issues relating to their lives e.g. employment, housing income, personal and family relationships, treatment and care options

Working with users through exchanges, including care planning assessment, directed at achieving life changes that support recovery

Connecting service users to sources of specialist and community based advocacy and advice that will promote their rights as citizens

Involving service users in service development and staff recruitment.

These user generated indicators of a service that is responsive to, and inclusive of its users, can be used to help service users and

staff think about how the services they are involved in can move in directions that they have a positive impact on service users lives.

To do this service users should be asked to evaluate the service they are receiving by talking about whether each of these indicators is being met at an individual and a service level. If service users think that an indicator is being met they need to say how. If they think it isn't being met they need to say what they think is standing in the way and how it could be changed.

The staff team need to undertake the same exercise together.

STEP TWO: SHARING YOUR IDEAS

When both groups are ready they should exchange their evaluations as well as their ideas for possible change. This can be done as part of a regular user meeting or as a special event which might be chaired by an external user facilitator.

STEP THREE: AGREEING TARGETS FOR CHANGE

When the evaluations have been shared both groups should agree on one or two targets for change. They should work out how they can deliver on them in partnership which means that service users and staff take responsibility for making change happen.

STEP FOUR: REVIEWING PROGRESS

A date should be set for when the agreed service changes should happen. When this date is reached service users and staff should discuss whether it has happened and what the outcomes have been. They should review how they felt about working together for this change and how they might build on their success in other areas of the service.

Our experience of using this approach to involving service user in service improvement suggests that the ideas for change that emerge are important and do not require extra resources but the use of existing resources in different ways.

An example

A day centre decided to adopt this method of involving users in service development. They did not have a very active user group in the Centre so they used an outside facilitator to support service users undertake a service evaluation using the user generated indicators and make suggestions for change. The service users who became involved came up with ten ideas that they thought would make the Centre more welcoming and positively valuing of service users.

When these ideas were shared with staff the outside facilitator helped everyone decide what they might do to make a change. It was decided that staff and service users would make a welcome pack for new service users which explained what the Centre could offer them and they would provide a service user buddy to support new service users through their first days at the Centre. The work undertaken for this meant that established service users and staff exchanged information which proved mutually beneficial. Everyone learnt a great deal so it was not only new service users who gained from this change!!

LOCAL RESOURCES

When you are working out how to promote user involvement in your service, it is important to identify local user organisations that can provide you with additional resources and expertise. **Use this page and the next to list the organisations that you have identified with their contact details.**

In developing this Guide in Birmingham and Solihull, we identified the following key organisations :

USER VOICE

User voice is a project that promotes greater involvement of service users in the planning and delivery of mental health services in Birmingham and Solihull.

What does User Voice Do?

- Represents users at key Trust meetings
- Organises local user meetings
- Runs a user forum where user representatives meet with Trust staff
- Encourages users to get involved in research, training, education, employment and volunteering
- Ensures there are strong communication networks between users and Trust staff

The purpose of User Voice is to make sure that service users are involved in all aspects of our Trust's work.

Contact User Voice at :

User Voice BSMH NHS Trust
PALS House number 3
Ardenleigh Way
Ardenleigh Site
385 Kingsbury Road
Erdington
Birmingham B24 9SA
Tel: 0800 694 0212

SURESEARCH

Suresearch is a Midlands based user led network of mental health service users and their professional and academic allies.

Suresearch members are involved in education, training and research activities, based in the University of Birmingham Centre of Excellence in Interdisciplinary Mental Health they hold regular monthly meetings which are open to all those that are interested in the network.

For more details contact :

Adrian Fisher

Centre of Excellence in Interdisciplinary Mental Health,
University of Birmingham

Tel : 0121 414 8170

Email : a.fisher@bham.ac.uk

Website : www.suresearch.org.uk

NATIONAL RESOURCES

When you are working out how to promote user involvement in your service you may find some of the following national organisations helpful.

Mental Health in Higher Education (mhhe)

Aims to enhance learning and teaching about mental well being and ill health.

www.mhhe.heacademy.ac.uk

MIND

Leading mental health charity for England and Wales that works to create a better life for everyone with experience of mental distress. It has a range of publications and training opportunities that relate to user involvement

Tel: 0845 7660163

website: <http://www.mind.org.uk>

RETHINK

A leading mental health charity working together to help everyone affected by severe mental illness recover a better quality of life. It has a range of publications and activities that relate to user involvement.

Tel: 0845 4560455

website: <http://www.rethink.org>

Sainsbury Centre for Mental Health

A charity working to improve the quality of life for people with severe mental health problems. It has a range of publications and training opportunities that relate to user involvement.

Tel: 02078278300

website: <http://www.scmh.org.uk>

Use the next page to add the details of any other national organisations and individuals who you have found useful for your work



CEIMH PUBLICATIONS

Titles in the series:

Paper 1 - Ann Davis, Alex Davis and Martin O'Kane (2008) Claiming Disability Living Allowance: An Information pack for people aged under 65 using Mental Health Service, their Carers and Advocates.

Paper 2 - Jean Betteridge & Ann Davis (2008). Mental Health & Incapacity for Work: An Information Pack for People Claiming Incapacity Benefit, Income Support & Severe Disablement Allowance.

ISBN NUMBER 0 7044 1354X

Copies of all of these reports can be downloaded from www.ceimh.bham.ac.uk alternatively send a stamped addressed envelope with a large first or second class stamp to: Nicola Young, Centre of Excellence in Interdisciplinary Mental Health, The University of Birmingham, Edgbaston, Birmingham B15 2TT.

