

A Story That is Still Being Written:

Our Tale of Developing Co-Produced Services for People with Personality Disorder in Birmingham

Speakers - Birmingham & Solihull Mental Health Foundation Trust (BSMHFT):

Service User Network Steering Group:

Hollie Berrigan, Ren Jassal, Barbara Norden, Simon Overend, Sally Woodcock

Tamar Whyte - Service User Network Co-ordinator, BSMHFT

Daniel Quinn, Psychotherapist, Specialist Psychotherapies, BSMHFT

Amanda Gatherer, Associate Director of Psychological Services & Lead for Personality Disorder Pathways, BSMHFT

The entire process of our journey to #BIGSPD16 is part of a learning process which informs this story. Much of the process has been led by members of our service user network steering group, including submitting the abstract, developing the talk, arranging travel and funding from four different sources for all 6 members, and inviting involvement from the team we are currently working with to develop services for personality disorder in Birmingham. We have developed relationships and received support financially and practically from staff and teams within BSMHFT which has made this talk- which has been so much more than a talk – happen. The story is indeed ‘still being written’, as the process did not end with the talk itself. We made new friends and allies within the conference, and in particular were able to make links with other service user consultants, researchers, and networks working within this field. We also entered Junior Scientist of the Year Award. For the first time ever, the conference included a ‘Highly Recommended’ award in this category, which we were presented with. The organisers had been impressed with our presentation, but also wanted to recognise the hard work of bringing together so many people, both staff and service users, for this project. On our return, we were asked to co-author an article for Occupational Therapy News by another BIGSPD16 speaker. We have been recognised by the Chief Executive of our Trust, who mentioned this project within his weekly bulletin. We are currently working on a dissemination event, and will look to use the knowledge we have gained from the conference within future service development work we do. We will continue writing the story, and hope to include further chapters within future #BIGSPD conferences.*

**We recognise that the term ‘personality disorder’ can be controversial and laden with stigma, and this is something which we have discussed both within our own group and which our Trust has debated during the initial stages redeveloping services. We use the term as it is a label which people recognise but use it to include complex mental health difficulties, trauma and people without a diagnosis but who identify with the issues we face as a group, and are open to different ideas/terminology as this debate continues.*

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A Story That is Still Being Written;
Our Tale of Developing Co-
Produced Services For People with
Personality Disorder in
Birmingham



Tamar Whyte, Hollie Berrigan,
Ren Jassal, Barbara Norden,
Sally Woodcock, Simon Overend,
Amanda Gatherer & Dan Quinn

Introduction:

During the development of our talk, we noted the similarities between the development of the network for people who have personality disorder & the development of a person may receive a diagnosis of personality disorder. We have used this as a framework for the talk.

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Traumatic Birth

• The Network's Beginning

Traumatic Birth

- An individual doesn't remember their own birth.
- No current members of the network were present at its initial conception, the knowledge we have of this is sketchy, and mainly from secondary sources as key staff have since left the organisation or work elsewhere
- The network was initially situated within a team that specialised in working with personality disorder, which later merged with a team specialising in psychotherapy
- Initially service user involvement was limited and was stop-start, there was some consultancy at recruitment and possibly the development stage.
- There was what could be termed a 'Previous Miscarriage' – the first 'lived experience' Service User Co-ordinator post lasted only a few weeks within the team and the post was re-advertised.

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Difficult Childhood

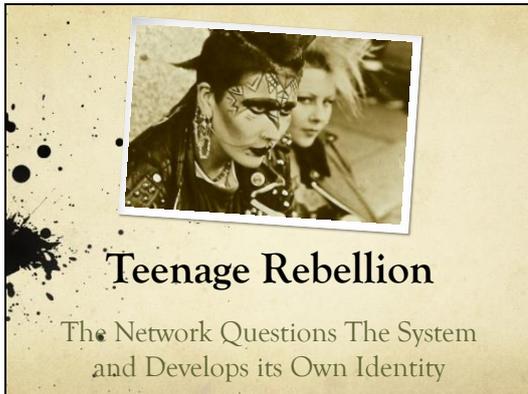
The Network's
Early Life
Experience

Difficult Childhood

- There was a second phase of recruitment and staff members with a two lived experience of personality disorder were employed in a job-share to work within the team as service user network co-ordinators
- Starting with a research phase: desk research of other models and meetings/conversations with external services.
- Barbara Norden relayed her experience of working within the team. In particular, she felt that the team had already been subject to an enforced change (a 'forced marriage' of two teams), and that the service user involvement posts may have been part of this change. Barbara highlighted the importance of developmental work needed

to introduce service user posts within a team, and the extra support and reflective supervision that is needed to make this work.

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Teenage Rebellion

- As service user staff grew within their roles (including research process) they began to question the organisational structure and models of team working which were restricting progress and not conducive to working with service user involvement.
- This was a particularly difficult stage. One service user network coordinator left her post, leaving half of the job share open, which was not re-recruited

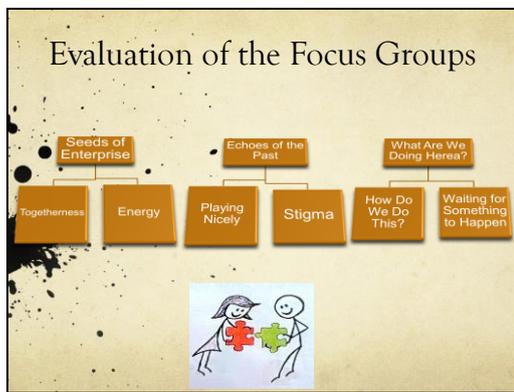
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Focus Groups

- The focus groups were a key part of the network developing its own identity
- There had been a significant amount of anxiety about service user workers establishing contact with service users, and particularly people who were accessing therapy
- After 18m we reached an agreement to conduct a series of 6 focus groups which were advertised by poster throughout Community Mental Health Team (CMHT) bases, and service users accessing therapy within the team received letters inviting them to take part
- Ren, Hollie and Simon relayed their experiences of being part of the group, and their motivations for taking part. Some of these reasons included wanting to fulfil the void left by completing group therapy and wanting to access support for the needs associated with personality disorder despite being in a professional working role
- Barbara returned to be part of the focus groups and later became part of the steering group. She wanted to continue with the project despite retiring from her post, as she felt strongly about wanting to be part of developing the network and see it become a reality

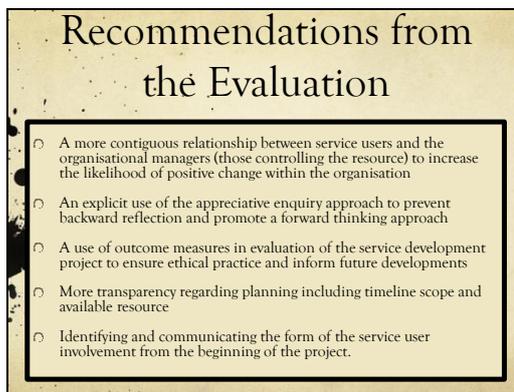
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Evaluation of the Focus Groups:

- Daniel Quinn evaluated the focus groups as part of his MSc Dissertation. He developed a model which highlighted the key themes from the focus groups:
 - Seeds of Enterprise
 - Togetherness
 - Energy
 - Echoes of the Past
 - Playing Nicely
 - Stigma
 - What Are We Doing Here?
 - How Do We Do This?
 - Waiting For Something To Happen

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Recommendations from the Evaluation:

- A more contiguous relationship between service users and the organisational managers (those controlling the resource) to increase the likelihood of positive change within the organisation
- An explicit use of the appreciative enquiry approach to prevent backward reflection and promote a forward thinking approach
- A use of outcome measures in evaluation of the service development project to ensure ethical practice and inform future developments
- More transparency regarding planning including timeline scope and available resource
- Identifying and communicating the form of the service user involvement from the beginning of the project.

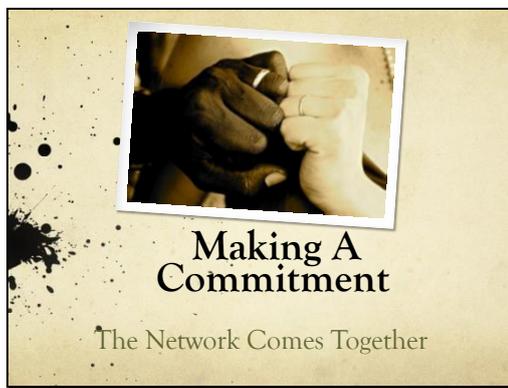
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Flying the Nest

- There was a hiatus after the focus groups – the remaining service user network co-ordinator experienced work-related stress and was absent for six months.
- On her return her post moved from to the service user involvement team, which works across the Trust.
- Tamar elaborated on the feelings and experience of changing teams. She moved from a constrained to a much looser, more organic structure. This was likened to feeling similar to being discharged: moving from an acute ward to going home. Initially, freedom feels frightening, although the move was a positive stage in the network's development.
- Simon gave his experience of how it felt to be part of the focus groups and then hear nothing for six months

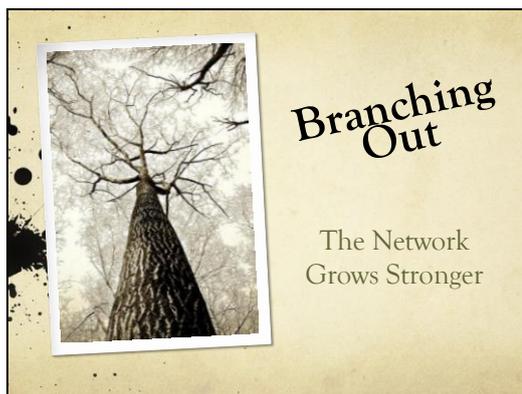
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Making a Commitment

- Each member of the network discussed why, despite obstacles or absences, they decided to continue attending
- Motivations for continuing to be part of the network included a strong desire to create something to meet needs that are currently neglected, and a strong appreciation for the emotional support which the group provided
- Sally, who joined after the focus groups gave her experience of being welcomed and becoming a key part of an already established group

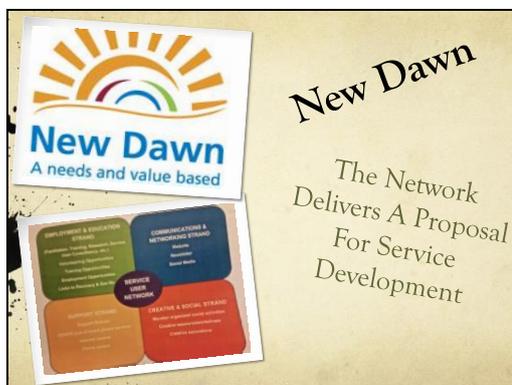
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Branching Out

- The network has developed relationships with key people within the Trust to enable the ideas and needs identified within their initial focus group research to be part of new service development
- We identified our own needs prior to the current redevelopment of services, and this has strengthened members to feel confident to play an active role in this

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New Dawn

- New Dawn is the move towards change and service redesign within BSMHFT, which incorporates all aspects of how we work with service users. This includes a Personality Disorder Pathway, now renamed as the 'Changing how we work with personality disorder' group
- Our steering group lobbied organisational leads to work alongside the Personality Disorder Pathways and be an active part of developing new services
- We are now part of the main steering group, with representation on all subgroups (which cover elements such as research, core standards, training, prescribing), including the Communications subgroup, which we lead

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Fragmented Services Result in Fragmented Service-Users

The Network Aims To Bridge The Gap

Fragmented Services Result in Fragmented Service Users

- We presented our focus group research findings to Directors and Senior managers within the Trust, inviting them to work with us to bridge gaps in services

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Pathways

The Network Paves The Way For Co-Production in Service Development

Pathways

- We are currently leading one of the pathway subgroups which looks at the ways our services communicate with service users, including the way a diagnosis is given
- We feel that actively working with people who have a lived experience – be they Peer Support Workers or Service User Consultants, is essential to developing services which meet our needs. We feel it is important to provide adequate resource, in terms of financial backing, supervision, support, mentoring and flexibility in working practice to make this work.

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The Board Challenge

The Network Wins an Award

The Board Challenge

- BSMHFT holds an annual Board Challenge. We were shortlisted to receive an award in the most subscribed category – Developing Innovation
- We wanted to showcase the work currently being done within the steering group, so we entered under the name 'Project BIGSPD'. We entered the challenge by demonstrating the process of co-producing the abstract, application and talk within the network. Part of the process included demonstrating that we were endeavouring to create and develop relationships with external services and professionals, with both lived experience and/or clinical experience within the field of personality disorder. We felt it was important to attend the conference and build these links, whether our abstract was accepted or not
- We won a runners up prize which was kindly topped up by our Chief Executive John Short, and had our first large contribution towards our costs for the conference

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BIGSPD

- We were successful in both attending and presenting a talk at BIGSPD. ****Cue an impromptu air punch from Hollie and enthusiastic round of applause from attendees****
- We received substantial funds from both BSMHFT's Specialist Psychotherapies Services and Caring Minds Charity which made attendance possible

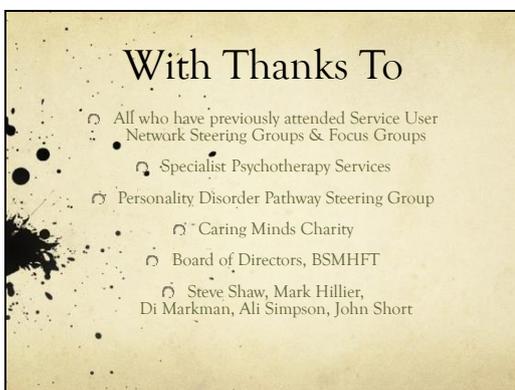
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Next On Our Agenda

- Amanda Gatherer discussed work going forward, and BSMHFT's commitment to enabling the steering group to work alongside and be an active part in decision making as services are reshaped
- Hollie closed on a positive note explaining some of the ideas and vision for the future
- There is still a lot of work to do - we are working alongside the Personality Disorder Pathways and leading it's Communications subgroup. We are working towards expanding our membership.

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With Thanks To:

- All people who have previously attended the Service User Network Focus Groups and Steering Group
- Specialist Psychotherapies Service
- Personality Disorder Pathways Steering Group
- Caring Minds Charity
- Steve Shaw, Mark Hillier, Diana Markman, Ali Simpson, John Short

Our attendance at #BIGSPD16 achieved everything we wanted, and more. The steering group bonded, made valuable contacts and learnt a lot from both the talks we attended and conversations with fellow attendees. We are also hoping to hold a dissemination event, where we will invite staff and service users to come along and hear about the work we are doing, give our highlights from the conference, and Daniel Quinn's research.

Our Chief Executive praised the project within his weekly brief, sent out to all 4000 BSMHFT staff, and we had a news item featured on our internal website. We have also co-authored an article for Occupational Therapy News, alongside Keir Harding, who has set up two Therapeutic Communities in Wales.

We enjoyed the experience, we learnt a lot from it, and we think that other people will too.