

South Gloucestershire and Bristol Local Involvement Networks (LINK)

Open Space Workshop Event for Mental Health Services Users and Carers

Follow up meeting; January 11th; 2pm until 4pm

Notes of the meeting

Present: Nola Davis; Rowena Hastings (Service Manager , Avon and Wiltshire Mental Health Partnership Trust; Jean Grant (Mental Health Services Commissioning Manager for NHS South Gloucestershire and South Gloucestershire Council); Andrew Millener* (Service User Representative, South Gloucestershire); John Langley (Chair of Bristol LINK and Chair for meeting); Amanju Manilla, Tim Dunton (South Gloucestershire Network), Warren Sneary, Stephen Osgood, Joi Demery (Operational Services Manager for Bristol and South Glos – AWP NHS Trust), Jan Cave, Selina Postgate, Caroline Postgate (Selina's Personal Assistant), Diana Elliott (National Autistic Society; Chair of South Gloucestershire LINK Mental Health Services Working Group), Catherine Wevvil* (Joint Mental Health Commissioning Manager NHS Bristol and Health and Social Care), Ian Popperwell (Planning & Commissioning Manager – Mental Health, NHS Bristol), Glen Townsend (User Monitoring and Development Coordinator – Mental Health, Bristol City Council)

Apologies: Jude Carey (Contract Manager for IAPT, Bristol), Helen Hamilton (AWP NHS Trust)

In attendance: Sarah Booker (Development Worker, South Gloucestershire LINK); Caroline McAleese (Development Worker Bristol LINK)

Caroline McAleese gave a brief introduction to the Local Involvement Networks and to the nature and outcomes of the Open Space Workshop event.

The purpose of the meeting was to follow up from the Open Space event in December to ask Mental Health commissioners and providers for South Gloucestershire and Bristol their response to the issues raised and recommendations made in response to the question:

How can Mental Health Services in Bristol and South Gloucestershire be improved?

The actions from the follow up meeting are described first:

Actions

Recommendation 1:

1. Issue of specific lunch clubs and issue about social spaces - should be dealt with through commissioning for older people in South Gloucestershire and Bristol

Recommendation 2:

1. Invite Service provider managers responsible for Increasing Access to Psychological Therapies (IAPT) programme to take questions on the programmes in Bristol and South Gloucestershire
2. Write to local providers of professional training, suggesting that local Universities could take it up the issue of training in communication, listening and Counselling skills need for separate building for those with mental health issues but not dual diagnosis

Recommendation 3:

1. There is a need for separate crisis provision for people with mental health issues but who do not misuse drugs or alcohol – recommend to commissioners and providers

Recommendation 4:

1. A directive to all professionals with whom they may come in contact to give all people who are self diagnosed as Autistic or having Aspergers syndrome the benefit of the doubt and refer them on to specialist services or clinicians
2. A directive and information to be given to all professionals making them aware that there are a large number of undiagnosed autistic people within their services

3. raise awareness and increase training and improve shared knowledge – give professional relevant skills and raise awareness

Additional Recommendations:

1. Invite expert from Bradford to speak about the effects of Neuroleptic drugs to both LINKs

All notes from this meeting will be disseminated via the following platforms: South Gloucestershire and Bristol LINK Mental Health Services Working Task Groups; South Gloucestershire and Bristol Local Implementation Teams for Mental Health; South Gloucestershire Network; The Care Forum Voluntary Sector Networks

This next meeting of this group will take place in 6 months time: July 2010.

The following notes represent a summary of the conversations that occurred in this follow up meeting and are intended to contain the main points of the discussions that took place and the agreed actions that resulted from them

There were 4 Main recommendations from the Open Space event and these were discussed as follows, the actions from all are reported at the end of this document:

Recommendation 1

Lunch clubs are the most valuable way of the carer and the client to attend together where the carer is relieved of stress and able to obtain information beneficial to the clients carer

(This refers specifically to a service for people with Dementia and Alzheimer's)

- Can also be about a social space for people, they are about social space and social contact
- Going somewhere where you can have a meal means a meal is provided and removes stress from a carer

- Mental illness in general is quite isolating – a lot of day support for individuals and carers has gone. If not able to work most of the people you know are at work. There is a need for more social space during the day in mental health services; could be provided by statutory and voluntary services
- Sitting down and eating with people is a fundamental human activity
- Really important that people who have been traditionally isolated should have choices about who they eat with, where and what they eat
- People being supported to get together for a common interest. Historically have done things to people who have level of health or social care needs – need as commissioners to make judgements, be clear on bottom line and what vision is
- Could agree that lunch and social interaction is a priority
- Lunch clubs services are for older people: this is issue was repeatedly raised at the event in December who were concerned with older people services and Dementia services
- There is a clash between what has been provided by voluntary sector and what statutory sector feels should be provided – careful about mixing up agenda of ‘chucking out’ older types of services and push for new style services
- Issue that some people who need a lunch club (older adults) – for respite etc. Then people from adult services who may want something else – wanting to work with people more individually; this can in turn broaden people’s experiences and be part of a recovery. For older adults their path may be that they gradually deteriorate
- Important to identify need – what are the gaps. Lunch clubs may be one solution – commissioners need to balance that. Everyone comes up with solutions – basis of Local Implementation Teams and Bristol Vision. Lunch clubs are not only answer to this need; may be more than one solution

- Trying to get away from services being seen as only way – alternatives like encouraging peer groups and shared activities; so the service is the way into that
- Would rather encourage services to look carefully at meeting needs around recovery and social inclusion; trying to pinpoint a need
- In Bristol did extensive work around Bristol Vision for Mental Health Services– took around 2 years, looked at quality issues, and specifics around need and what needed to be addressed. Included service users, providers, carers. Continue to have forums where needs are brought to the commissioners. Assessing need is always fraught due to change, movement and development
- Bristol has many lunch clubs; many funded by voluntary sector, perhaps need to invite people who commission and provide older people services

Recommendation 2

Better training in responding to mental health needs. Professionals need to listen more and not hear what they want to hear.

- There is lack of training in how to listen and how to set aside own assumptions Experiences vary widely – felt by some people that professionals needed better listening skills. Experience of one person who went to a care meeting where she was being talked about and being excluded from the conversation; perhaps psychiatrists, social workers, ward staff, GP's
- Active listening is a skill which can be learnt – actually training the individuals in active listening skills and how to set aside their own beliefs and experiences – like counselling skills, not necessarily best taught by service users as is a professional skill
- Failure of people to listen – can't recall anyone saying I am experiencing this or I need this – what do you mean by that, do you mean this or would this. That lack means that people are not listening – needs to be included in training and ongoing training, also hostel workers, and housing workers

- You are often not able to empower yourself and if feel if someone is not listening to you then that is worse
- Mixed package – referring to is people saying it's ok to have a whole range of different provision. Choices are where people get a choice as citizens and the choice of the kind of support they get to do it. Many traditional services have not done that and people learn to be grateful for what they get and then don't understand how to get choice
- May also be about training services users to deal with professionals; might help where people feel lost or unable to explain themselves; can be very difficult dealing with professionals
- South Gloucestershire Network (service user network for South Gloucestershire) has tried to get people involved in piloting a scheme, and to do a whole package about awareness for professionals
- The National Institute for Clinical Excellence (NICE) – first line of intervention is Psychotherapy
- Department of Health (DH) have put money into psychotherapy for common mental health problems which will be rolled out by the end of this year
- Programme has been rolling out on a gradual basis – offering 4000 interventions in one year (4000 people), is a stepped care approach, some will be signposting, low intensity and high intensity. Also fund a number of counselling projects – around specific issues such as sexual abuse all of which is free
- Amongst 4000 people – quite a lot will be told to go to a book, and not be given counselling

Recommendation 3

Heavy burden on carers when individuals are particularly ill; a 'Halfway house' or hospitalisation might be needed and appreciated

- Feels like a convalescing type model
- Could have more crisis houses that wouldn't be specific
- Have commissioned crisis house that came directly out of Bristol Vision – due to open in few weeks, is a single sex unit. Its intended to be alternative to inpatient care – reducing amount of stays in inpatient units. No medical input into crisis house but is intended to be a different choice than an inpatient service rather than a convalescence
- What benchmarks would you use to provide another facility?
- External evaluation over its first year – one of the arguments for having it is that people will stay for a shorter period of time and will spend less time away from home. Staff will be trained and supervised by professional organisation and provide crisis house for women who have experienced domestic violence and services users have had input. A qualification does not necessarily mean something is professional
- Didn't ask for any specific qualifications for staff working at the new facility. Missing Link is providing training for staff. Think it is vital and at least need an NVQ
- If you have no one in a crisis centre that is restraint trained aren't people at risk of violence?
- People will be thoroughly assessed before they are admitted. People are trained just not professionally qualified
- Can someone who is in crisis go into a crisis house without having to deal with people who are using crack, or cocaine, or heroin?
- Is there a problem with running a dual diagnosis service? Think people who have mental health problems and have remained without illegal drugs or alcohol and have to deal with the physical, emotional and financial effects of sharing a hostel with those people

- Don't want to exclude people with a dual diagnosis, this has been our important drive as people with dual diagnosis get excluded from both kinds of services. 80% of people who use secondary mental health services have a dual diagnosis (Commissioner's Comment)
- No one should have to put up with being victimised or bullied in a hostel. Given numbers of people with dual diagnosis it would fill up in minutes if had specific service – so 2 types of services should work better with people with dual diagnosis
- Should be finding it through carers assessments, South Gloucestershire do not use the existing beds there are alternatives in South Gloucestershire as it seems like needs are very different.
- People are generally offered support from crisis and home treatment scheme, numbers are not so great, the amount of services users that have dual diagnosis are less than in Bristol. Are working towards improvement and implement strategy for people with dual diagnosis
- Would think there would be a choice of being able to go somewhere where the issues brought by people with dual diagnosis are not there

Recommendation 4

There is an acute shortage of trained autism diagnosticians, so mental health staff should at least give self-diagnosed autistics the benefit of the doubt rather than assuming that their poor executive functioning is the result of stress/damage/mental blocks/making excuses/laziness. They must understand that some of their clients may need lifelong support with day-to-day living tasks such as washing, cooking, cleaning and paperwork, even though they may be intelligent and articulate and may even appear socially competent in a one-to-one situation. Diagnostics of autism – Bristol Aspergers team which is a pilot scheme and has funding that will run out in March – are talks for it to be continued

- One option is to get more money other is to stop doing other things. Had a meeting to look at if could work with other old Avon authorities to develop

something. South Gloucestershire is spot purchasing for small group of people to get that done. North Somerset and Bath and North East Somerset will also do that, low numbers mean that it makes sense to work in collaboration.

- Not realistic to afford an extra services in South Gloucestershire but can work with Bristol to provide in collaboration. Would go for a hub and spoke model with Bristol as hub – there are social workers in mental health teams who are involved
- Some people who are pretty sure they are on spectrum but don't have diagnosis – do you need diagnosis to get access to specialist team, wouldn't be denied it
- Everyone met who has been self diagnosed has also been told by Social Workers that they are not; people get turned down for help from social services. The incidence of autism is similar to Schizophrenia
- South Gloucestershire has a have psychiatrist who is expert in diagnosis and can supervise others in doing assessments.
- Don't think her supervision would be enough to disentangle for an adult who believes they are autistic and has been labelled previously with other conditions. Many learned papers say it is a very specialist job. Many people cannot get access to someone who can diagnose it, find it deeply upsetting the number of people have met who have been wrongly diagnosed and whose lives have been affected by that. Took 5 years to get a referral and mental health people still say that the diagnosis is not correct. Really important autistic adults are given benefit of doubt where there are so many people having that experience
- Autism strategy asks for autism planning groups in every Local Authority; funding for pilot scheme was set up through that group in Bristol. In South Gloucestershire was a preparatory meeting to set up a planning group – first meeting in 2 weeks time and will include commissioners and make sure that its is fully representational. Will include an autistic person will be person who lives in South Gloucestershire. Regional Director did a

presentation called good practices – specified all the groups that should be representative

- Important that it doesn't become a 'them and us' discussion – partly because there has not been the expert assessment; it has got to be a joint exercise; range of people with many different needs and so need more than one person. Need to steer clear of just one person – can be tokenism
- A lot of people are being told that the autism can be left to one side and the other apparent mental health problems dealt with instead – a lot will find that autism is the key part to their problems. Once Aspergers can be identified and addressed then don't have mental health problems. But the mental health team then drops them
- Would have an amount of assessments of money but also support and training for people who are going to help – so principle is that what would be the difference in the service provided. Is no service unless they also have secondary mental health problems. Best bet is to enhance other services
- If clinicians were thinking about whether symptoms fit with autism – many people go to a health professional because they have a problem with how they feel or interact. Without that information how can you plan and work out how to work with your situation
- The National Autistic Society have a lot of trainers – others also do it, everyone involved wants everyone to know

Additional Recommendations

Over medicating upon hospitalisation in order to gain control over the patient is not always the right course of treatment. Too much medication just clouds the issues and leaves the person spaced out and without much thought processes. Then when you do get offered the chance to talk, you can't remember the issues anyhow.

- Whole are about drugs used and there is an expert in Bradford (Phil Thomas) – explains to people how specifically how neuroleptic drugs work

so when stop are over sensitised, neuroleptic drug blocks out 5 feelers so grow 10 to compensate – is illness resurfacing, much down to not having knowledge

- Majority of people with forms of dementia are being subjected to these drugs, lots of stuff about people being able to re-enter employment; would have to completely redo the drugs they were on and level was preventing them returning to work. Despite what NICE has said the number of prescriptions written for depression has doubled – something needs to be done about medical professions attitude to using medication. Need to change attitude of medical professionals about giving people pills; are wasting millions of pounds and doing a lot of damage

To find out more about either LINK or their Mental Health Working groups please contact:

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Summary of comments on the meeting

People have been very open

Good to have lots of professionals here

Good to expand on what has been highlighted in previous meetings

Valuable as operational manager to hear the issues that people are struggling with

Apparent that every issue has lots of different aspects

Hope some positive outcomes come from meeting

Comes up again and again is service users saying they want to be listened to more

More people should be involved in commissioning, it doesn't end here

Just because don't act on everything doesn't mean that commissioners don't hear them

Useful to bring service providers and users together