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West Midlands
Regional Development Centre

In Partnerships with



Sharing and Learning Together

Understanding and learning from the experiences of people from Black and Minority Ethnic communities who use Mental Health Services

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New Possibilities

This consultation was carried out by New Possibilities; a Birmingham based training, facilitation and consultancy organisation.

New Possibilities understands that each of our customers has unique needs, which can only be satisfied through successful and supportive partnerships and specifically tailored intervention.

Our expertise lies in:

Renewing commitment and enthusiasm by dealing effectively with barriers to change, reducing fears and anxieties and motivating people

Shedding fresh light on entrenched problems experienced by our customers' using; our years of practitioner and training experience, our creative skills and innovative approaches

Walking alongside people and organisations until change is embedded, and positive outcomes are achieved



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1 BACKGROUND

This consultation was commissioned by the lead officer for delivering race equality within mental health services for the West Midlands. The Delivering Race Equality (DRE) programme is an innovative five year action plan set up in 2005 by the Department of Health. It is designed to reduce inequalities in how people from black and minority ethnic communities access, experience and achieve outcomes from mental health services.

The DRE programme includes people of Irish or Mediterranean origin and East European migrants as well as refugees and asylum seekers and works across all age groups.

The DRE Action Plan seeks to address areas of inequality in mental health by working with commissioners, providers, users and carers and the voluntary and community sectors to actively promote better outcomes for people.

The intention of this piece of work was to gather the experiences of people from black and minority ethnic heritages who have used, or who care for a family member who has used, mental health services. The purpose was to learn from people's experiences and understand the changes that need to happen in order to provide services that support the cultural diversity of people who use mental health services within the west midlands.

Methodology

A series of ½ day workshops were held within in the following areas of the region:

Stoke On Trent

Telford and Wrekin

Coventry

Worcester

Rugby

The events were advertised through local lead officers for BME mental health services and community development workers.

The group had the opportunity to consider their personal experience of services in order to identify what worked well and what did not work about the treatment/ intervention they received. The session was graphically recorded.



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Where possible, local commissioners attended to hear the issues that were raised by the group. The commissioners had the opportunity to identify action that could be taken by them in response to the points made. Representatives from Fan the Flames, the West Midlands Service User/Survivor/Carer network acted as Ambassadors for most of the events.

This report seeks to summarise the learning from each workshop. This has been done in the chronological order of events. The appendices contain individual experiences that validate the points that have been made. The learning taken from each event is then summarised and recommendations made for future service development.

This report will be circulated to those groups who contributed for final consultation and validation before the final version is submitted to Ranjit Sanghera.

2 WHAT HAVE WE LEARNT?

Stoke on Trent

There were 9 people participating in this event 2 people with experience of using services 2 family members 1 champion and 4 people who worked in services. The group had representation from African Caribbean and Asian and Irish communities.

Professionals need to know that:

Some people who experience mental ill health are good at putting on a front that masks the common symptoms of their illness. This may mean that they get mislabelled as attention seeking or aggressive. This message came particularly associated with being a woman with an African Caribbean heritage.

Young people who encounter professionals from psychiatric services can be intimidated and unable to talk about their underlying issues. If the causes of illness are not recognised and the signs missed then the symptoms may be misdiagnosed. Without an understanding of the root cause of the illness the recovery process will be delayed.

It is not appropriate to assume that people from black and minority ethnic heritages would want to have a service provided by someone who reflects their culture. A close cultural match between a person who uses services and a professional worker may cause difficulties for the following reasons:

- There is an unintentional match to a figure from the past
- Being known socially within the community raises issues of confidentiality.

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Either of these of these issues will close down the channels of communication and therefore hinder the diagnosis and make support difficult.

In some cultures it is not appropriate to speak of problems outside of the family which makes seeking help very difficult.

Educating Professionals and support workers

- Training for staff and professionals around cultural issues is necessary to raise awareness.
- There must be diversity in the workforce which represents people being supported.
- People must have their choice of support accommodated and professionals must feel secure enough to accept that they may not be the right person to support everyone.

However for other people support may work better if the support they receive comes from people who share their cultural experiences and language. This creates a tension that can only be addressed by asking the individual what would work best for them.

The Stigma

Some labels of mental ill health are highly emotive and the stigma attached to them leads to a loss of status which ultimately works against recovery for an individual.



Outcomes that are identified must reflect what is important to the person these will be different for everyone. E.g. regaining employment, being able to open a bank account rather than service outcomes such as reducing medication or attending an outreach service.

If the professional diagnosis of illness is not accepted by the recipient; recovery will be hampered. However, if the diagnosis is one which the person recognises they are more able to work with professionals on their recovery.

The experience of mental ill health can be hugely isolating which can be exacerbated when:

- Professionals focus solely on the label of mental ill health
- Public perceptions focus on the risk that the individual presents to society.

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There is a perception that some people find themselves in services because professionals do not know what else to do.

Understanding the carers perspective:

Carers must have confidence that any replacement support workers share their understanding of how the care needs to be provided in order to be able to put the burden of caring down. E.g. knowing the routine of making a cup of tea can allow the carer to relinquish responsibility for that task. If it is *not* done correctly then it will fall to the family member to do it again later.

For young carers other agencies must be willing to work flexibly around the carer and their responsibilities. E.g. fitting school hours around the carers needs.

Professionals need to value and respect the contributions carers have to make.

For families who have their loved one taken into the system there can be a huge sense of relief that things will get better for them all. This can rapidly be replaced by a sense of betrayal if the services which were meant to support their loved one instead causes untold damage. (See appendix Stoke on Trent Experience 4)

It is essential that support is available to carers and users of services outside of office hours as often it is at the end of the day or during the night when things can get particularly difficult.

Telford and Wrekin

This group was made up of 10 people 7 of whom had experience of using services and 3 people who worked in services. They predominantly represented South Asian women

Professionals need to know that:

People will often have been living with their mental ill health for some time before they seek help. Usually a family member or friend urges them to seek help. If the patient attends an appointment with the GP with a family member or friend as an interpreter; it is possible that the symptoms that are described do not reflect the real problem because:



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- The interpreter puts their own emphasis on the symptoms or dilutes the message
- The description of symptoms is not easily translated in many Asian Languages.
- The patient may hold back on describing exactly what they are feeling as they are passing personal information through a family member or friend. This can be a very exposing experience.

If the person chooses to attend their appointment without an interpreter it is possible that they will not fully understand the diagnosis, what medication is prescribed and the side effects that it may cause. This can have a massive impact on the person's quality of life and their emotional well being.



The diagnosis of a physical complaint can be very traumatic and may initiate an episode of mental ill health that could have been avoided if the appropriate attention had been paid to how the information is passed on. (See Telford and Wrekin appendix; experience 3).

People feel that often the symptoms of mental ill health can be missed and a diagnosis of a physical complaint or a learning disability is given in isolation.



Things that are working well:

Having a service that can be accessed out of office hours; that gives access to someone you can build a relationship of trust with, gives confidence to the sufferer.

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It was apparent that for this group of women the following things have helped them in their recovery:

- Having a nurse who speaks the same language so doing away with the need for an interpreter
- The opportunity to meet up regularly with other women who share some of their experience
- Building an informal network of support that has come out of formal organised events.
- Having opportunities to do things during the day time with this network and extending the network to include women who do not experience mental ill health.
- Having family relatives; particularly daughters to be there for support.



Things that would help more:

Having access to information in places like local shops and temples to raise the awareness of the local communities. The information would include:

- Information about what to look out for; some of the signs of mental ill health
- Side effects of medication that is taken
- The support that may be available

More support available to carers; to feel understood and to offer culturally appropriate respite services.

There is not felt to be enough support for men within the South Asian communities as there is a stigma attached to having mental ill health within their culture. It is thought that this may prevent men seeking the support that women get from talking to each other in their focus groups.



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Cultural issues for which there is no obvious answer:

There is a huge pressure place on women from South Asian Communities to have a son.

It is not appropriate to talk about personal problems for fear that information will be passed around the community.

Coventry

16 people contributed to the event 5 people with experience of using services one family member and the remaining participants were there in a professional capacity. There was representation from African Caribbean and Asian communities.

Professionals need to know:

The relationship that is built with the GP, the Psychiatrist, or other consultants is crucial to the treatment of people who experience mental ill health. The following list is the key components that the professional and/or support worker must offer:

- Taking time to listen; do not dismiss or ignore me
- Building a mutually respectful relationship; the person with the illness is the expert on how they are feeling and what would help them to recover.
- Being available ring to talk things through if necessary
- Building a relationship with the family; valuing their contribution and offering them advice and guidance.
- Keeping people informed
- A service that does not get delayed, that is efficient and punctual.

Professionals (particularly consultants) need to be aware and sensitive to the status and power they hold which can make it difficult for people who use services to challenge views and opinions.

When you have experts they will either get it right or wrong. It is then very easy to blame that person if it does go wrong. If you share responsibility for making a decision then it is less likely to wrong or blame be attributed to it. Shared responsibility will promote a more learning and solution focused approach.



There is a tension between the pressure placed on professionals within social work to assess quickly and close cases within 6 weeks whilst also giving people the time they need to recover.

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Cultural issues:



The use of interpreters:

Relying on family members to be interpreters raises the issue of whose perspective you are hearing. Family members are not specialist in mental ill health. Interpreters need to have in depth understanding of mental ill health. They need to be able to help people describe the symptoms that they are experiencing not just to translate between parties.

Receiving psychotherapy and counselling services from an organisation that has cultural knowledge and professionals who speak community languages does away with the need for interpreters. This is an experience found at Nafsyat.



Cultural identity:

It is becoming more difficult for people to identify their primary culture. For example a person may class themselves as being as British/ British Asian/ Asian dependent on their environment. There are different rules and expectations applied depending on what culture you identify with. This can then cause difficulty when there is a clash between the expected norms in different situations. As the UK becomes more diverse this problem will deepen.



Professionals need to be able to acknowledge the strain that is placed on an individual when they are trying to conform to different and conflicting cultural expectations.

There are a lot more men and BME workers' coming into the profession of Mental Health however there still needs to be an element of choice as to who

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people are supported by and that may not be by people who reflect their culture and community.

Professionals/ staff need to have an awareness and understanding of cultural norms however; the fear of getting it wrong often prevents staff from asking individuals how cultural issues affect them directly.

Stigma

People will cope at home for as long as possible to avoid the label of mental ill health. However once they reach crisis and need services it can be difficult to get the support that is needed because they are not known to the system. Consequently people need to weigh up whether they are prepared to accept labels of mental ill health in order to qualify for support.

The following stigmas need to be addressed to make services more accessible:

- The fear of mental health services; what happens once you get inside?
- Medication, treatment and the side effects on your personality
- Being over medicated and the treatment of ECT.
- Once you get in you may not get out.
- “A fear that the symptoms of my illness are attributed to the stereotype that I am Big, Black and Bad not to the circumstance of my illness.”



Support workers and service based issues and views:

If there is a high turnover of staff it inhibits the ability to form the relationship that is needed to support recovery.

There must be flexibility in when community based support is available. There are times when support is not wanted.

Voluntary services have their hands tied to time limited outcome focused responses. This does not take account of the time that people need to recover from a mental illness. Service based outcome focused work does not take account of sporadic recovery that people experience. It focuses more on outputs rather than outcomes for the individual.

More of the same doesn't work there needs to be innovative approaches to the delivery of services.

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An opinion was expressed that there is a vested interest in keeping the “industry” of mental health services alive in its present form. If there were greater emphasis placed on the social recovery of patients there would not be such a great need for health services.

Getting the balance between the Human Rights act (privacy) and involving the family member to support the person’s recovery is a difficult tension to address.

Pressure is experienced by workers from BME communities who feel that they should be able to help their community but feel ineffective in doing so.

Worcestershire

Make up of group: 20 people participated in this event. 2 people had experience of using services, 10 workers and 8 people from the local community who were interested in finding out more about mental health services.

What have we learnt:

Often people who are beginning to become unwell do not recognise that they have a problem. This means that the first sign is that other people notice that there is something not right about your behaviour.



“It isn’t just treatment that makes life feel better– it’s work and life and all the other things”



There must be a respectful relationship between the patient and professionals. People are the experts on themselves they need the opportunity to speak; and to be involved in decision making. The role of the doctor should be to help make sure that your health does not deteriorate.



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Therapy is better than drugs having time to share with people who have similar experiences works well. "Creative Support" got me involved in activities sometimes just with the support worker other times in small groups. I was doing ordinary things with them.



People need the option of involving family in mental health reviews not everyone will want this but the option must be offered because not everyone knows to ask. We all experience mental health differently.

People need to be encouraged to highlight the problems they are experiencing with services without fears of any come back.

Use of Interpreters and language issues:

Not all GP's refer to interpretation services to support people describe their problems. The telephone interpretation service isn't always the answer e.g. a male voice may not be appropriate.

There are issues of confidentiality with the use of interpreters from within the community and therefore the use of interpreters outside of the community would be preferable.



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This in turn presents a problem of finding an appropriate interpreter.

There must be continuity with the interpreter that is used. It does not work if you have to start again from the beginning each time.

A diagnosis of Dementia is not always picked up because information is diluted and it is difficult to pinpoint the problem.

If the physical problem is not identified and treated appropriately there is a greater risk that people will develop mental ill health, particularly if the system that they need to navigate is complicated and frustrating.



Understanding of cultural issues:

Male nurses may not be acceptable for female patients.

Support workers need to be able to offer support around skin care and diet.

Staff need to be patient and take time to make sure that there is a shared understanding of the situation particularly where there are language barriers.

There is a general assumption that the family will provide within BME communities but this cannot be the case if there is no support for carers or a support mechanism does not exist for the person or the carers.

If you are expecting family members to provide support then information about their relatives care needs to be shared with them.

There is a cultural expectation that people will not talk about their mental ill health, however in order to be supported people need to understand what you are going through. This highlights the problem of assuming that the family will be able to provide the support for a person.



The assumption that people will have family around to support them may be misguided.

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Rugby

There were 27 people at this event. 1 person had experience of using services 2 people had family members using services approx 9 workers and the remaining participants were interested members of the community. There were representatives from African Caribbean and Asian communities.

Professionals need to know

People who are experiencing Mental Ill Health may well present a physical symptom to their GP. The GP needs to be able to recognise the seriousness of emotional symptoms that may be present but effectively masked; rather than waiting until a crisis is reached before responding.



People's experience is of the professionals being the expert; who decides what course of action to take. Professionals need to find ways of putting the person in control of the treatment they receive.

Social recovery is a positive experience.

Bringing people together in positive ways to support their recovery and participation in the wider community to help keep them well is more effective than treating people at home.



isolating

Being treated at home can be a very isolating experience as you don't have the opportunity to spend time with people who have shared the same experience as you.

There may be times when people want to be with people who share interests rather than their experience of mental ill health.



The best time to involve people in thinking about their package of care is when they are feeling well. People should have the opportunity to think about who they would like to be informed or should not be informed of any significant changes in their mental well being.

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It is important for people to keep a record of what medication has previously worked and what hasn't.

Above all people who experience mental ill health value professionals who are honest, who say when they are not sure of the answers; who will sign post to more appropriate services; Who will do what they say they are going to do; who are able to apologise if they get it wrong.

Accessibility

For people who live in the Rugby area of Warwickshire the distance to travel to receive hospital services on the Rugby ward at the Caludon Centre can be very isolating. It is difficult for people to know what is available to them there and it is difficult for family and friends to visit.

Cultural Issues:

Language differences:

Where there are language barriers it can be difficult to describe the symptoms of mental ill health; the physical illness is easier to describe.

Cultural Differences

It is necessary to take account of what is normal for different cultures; this includes being aware of both the family culture and the wider cultural expectation. E.g. Black women being seen as being strong and indomitable increases the likely hood of help being looked for at the point of crisis and not before.

“The patient has one culture and services have another”

The Rugby Ward at the Caludon Centre has an appropriate cultural diversity within the nursing team, however there were no other black service users and the environment was devoid of any culturally appropriate images on the walls, books, music or food that would help people to reminisce or feel at ease while they are there.



Stigma

There are many fears that are attached to being admitted into psychiatric services that are exacerbated by the stigma that exists.

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These include:

- Not taking your business out of the house/ immediate family unit
- It is more acceptable to say that you have stress rather than depression
- There is a fear of taking medication for mental ill health because of the side effects
- Professionals can be too quick in handing out labels of mental ill health e.g. black men being given the label of Schizophrenia and being detained because of your heritage rather than your symptoms.



Support for Carers:

Carers often feel that they do not get the support that they need; they feel guilty about not being able to cope and meet family responsibilities.



Families can feel disempowered in supporting their loved one because service bureaucracy gets in the way. E.g. Health and safety implications are used to prevent families contributing to the person's emotional well being or recovery. In one instance; family members were prevented from bringing in food that brought cultural comfort and familiarity when their loved one found themselves in a stressful and scary situation. The food that was served in this service was not culturally appropriate but because of the health and safety policy family members were they told that they could not bring externally prepared food into the premises. In this instance physical wellbeing took precedence over the emotional wellbeing.

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This disregard of emotional well being; prevents families from contributing; removes the feeling of being cared for and denied the person their cultural identity. Food is not just a functional thing.

There are many cultural assumptions made that “family will provide” but support is not available to enable them to do that.

Some family members found their experience of their GP a very isolating experience. One family member was given a list phone numbers and left to get on with it. What they needed was the GP to talk them through it and make the phone calls or have someone else make the calls on their behalf. When English is not your first language this can be very difficult. The amount of time a patient has with their GP has a big impact on whether they feel supported.



Spirituality and religion

People whose spirituality is not represented by the mainstream Church of England/ Catholicism do not have easy access to spiritual support when they are admitted to hospital.

3 SUMMARY OF THEMES

The following areas have been identified as reoccurring themes from the events that have been run across the region:

Language barriers and the use of interpreters

A tension has been highlighted between the use of interpreters and issues of confidentiality, accuracy of interpretation and the need to have support in expressing symptoms in a different language. It would appear that people’s experience of interpreters both from within the family and external interpreters is mixed.



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Who is the expert?



A number of workshops identified an issue in the relationship between professionals, the person and their family experiencing mental ill health. It is apparent that the authority that professionals hold; can seriously dis-empower people from influencing the diagnosis that is made and the treatment that is offered and received. There is a need to adjust the balance of power in order to establish a more person centred approach to service provision.

Involving family members

There is a tension between “Human Rights”; the right to privacy and confidentiality balanced with the involvement of family members to aid recovery. In order for family members to best support their loved one they must have an understanding of

- the illness,
- how it is affecting their family member,
- any side effects of medication that may be experienced
- Have an opportunity to be involved in the design of a support package that takes account of their contribution and support needs.



Assumptions about cultural matching of workers

It is important that workers have an understanding of the different cultural needs of people from black and minority ethnic heritages; however assumptions cannot be made about the most appropriate way to support an individual. People who use services must be asked directly how they can best be supported.

The stigma attached to mental health services

The negative public stigma attached to mental health services has a big impact on the point of entry into services. People who are fearful of entering mental health services will leave it until crisis is reached; at which point the intervention will be more serious and out of their control; this then confirms people’s deep-seated reservations about the stigmas that are attached to these services.



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Being able to hide the symptoms

There are a number of ways that symptoms of mental ill health can be hidden to professionals these include:

- The barrier that different languages can create in not having the same words to directly translate the emotional feelings
- Not seeing the cultural differences in the way people express themselves
- A focus placed on physical symptoms and not taking account of the emotional impact that those symptoms may have.

Social recovery

A number of the workshops highlighted the importance of social recovery for people. This included the following approaches:

- Focusing on “ordinary” outcomes for people e.g. employment, home ownership etc.
- Having opportunities to spend time with a mixed group of people, some of whom have experience of mental ill health.
- Using “ordinary places” to spend time doing activities.
- Organising informal social networks outside of the formal groups that are attended, that may provide opportunities to do everyday things e.g. going to the gym, having a massage, meeting together in a cafe for a chat.



The workshops identified these approaches as being the most effective way of supporting their recovery from illness.

4 RECCOMENDATIONS

The following recommendations were identified during some of the workshops.

Who is the expert?

People who use services need to inform the commissioning of services; in order to do this they need to feel confident that their experience is valued and they need to be able to say what is going well as well as what isn't. Talking shops alone don't achieve anything people need to know what difference consultation exercises will make.



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Mental health services need to get better at measuring how they are doing by establishing the qualitative outcomes that people who use services have identified.

Staff and service development

There needs to be support for GP's to enable them to be more supportive of people experiencing mental ill Health. People experience is directly influenced by how supportive their GP is.

Greater awareness for the general public that mental ill health is a part of all of us. The stigma of entering into mental health services comes at a very high personal cost to the individual as having that label in your notes affects your employment, finances and relationships. Information about mental health services needs to be made more available to the general public; promoting awareness in public places.

People who use services and people working in services must have the opportunity to network in order to replicate good services that are found across the region

More opportunities must be found to value the voice of the expert through experience.

Social Recovery:

Make more use of direct payments to provide some of the social recovery that individuals need.

Encouraging people to choose things to do that will help you keep well e.g. massage, Tai Chi going to the gym rather than anger management. Choosing who you spend your time with i.e. people who share your experience or people who share the same interests as you or both. The venue must therefore be a safe place that is open to the wider community. It must be a local service with a variety of opportunities of people to meet in "ordinary places"



Spend time thinking about how this could happen by listening to experts through experience to think about:

- What this should look like



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- The kinds of spaces or places
- How segregated or integrated, how inclusive/exclusive those services should be.

There is a need to think more holistically about the solutions for people. Working within White Europeans definitions of wellbeing does not help when anything that deviates from this would be seen as ill health and does not take account of the difference in cultures. Professionals must be supported to look beyond the physical symptoms of an illness and consider other factors that may affect a person's wellbeing. There could be learning from other cultures about the full spectrum of mental health and the systems used to support well being.

Comments on the organisation of the events:

The session in Rugby was booked to run from 11am – 3pm with lunch being provided. Some felt that this was a long day that would make it difficult for people to attend

Publicity: e-mail was used to advertise the event which is not a good mechanism for users or carers to receive information. Consequently people who used services did not find out until the last minute that the event was on. This may explain the low numbers of people with personal experience of mental health services.

The dynamic of some workshops was affected by the diverse make up of the group. Where there were few people who had experience of using services it was difficult to gather individual experiences.

Points to consider if similar events are to be run in the future:

- A small number of people who have used services and family members will give valuable contributions and do this better without an audience of professionals and interested members of the public.
- Promotion of events should not rely on email.
- Professionals receiving promotional material need an explicit instruction to pass it on to people who have used services and family members.
- People promoting the event must understand the purpose of the workshops i.e. to *gather* information from participants rather than *disseminate* it to them.

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- An experienced external facilitator will bring impartiality therefore internal facilitators need to be aware of the impact that their role and experience will have on participants' contributions.
- Information needs to be captured in an engaging and non-threatening way, which enables participants to see what is being recorded. If a graphic recorder is not available then consideration needs to be given to how else this can be achieved.

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5. Appendices

Stoke on Trent

Individual stories and themes

Experience 1

Services more than two decades ago, did not look out for the signs of child abuse in the same way as they do now. This went unnoticed for years for me. There was an opportunity for it to be picked up but the whole experience of going to see some specialists was so intimidating that professionals did not pick up on it even though the signs were there. The solution identified was to prescribe medication rather than working with the cause of my distress.

It can't be just the responsibilities of professionals to pick up on these issues, families and friends are equally important in bringing this to light but there is a big barrier with confidentiality and professionals will not listen so readily to the concerns of others. There needs to be a way for family to highlight their concerns and for this to be taken seriously.

Because I was able to mask the symptoms I did not look or present myself in a way that was indicative of a depressed person and so had a label of being aggressive and attention seeking instead.

Later on I was able to help myself by finding useful information to read and finding the right counsellor (it was like finding the right pair of shoes I had to try on lots of different ones in lots of different shops)

What didn't work was a consultant asking what he could do to help rather than offering a solution. I was not in a position to be able to say for myself – my condition was too acute.

Also my insight into my disabled son has been dismissed by other professionals because of my diagnosis.

Experience 2

Eventually caring for my parent became overwhelming. There was not enough support. I needed to be able to offload with other carers who shared my experience. I will never be able to but the burden down while I feel that I am the only one who understands what needs to happen. If I am going to relinquish responsibility you need to gain my trust, get to know me and understand the way I do things e.g. make a cup of tea and other routine tasks that I do for mum. So that I can be confident that it will be done right. Respect my expertise. Support for carers needs to be available at any time of day but probably more so at night.

What worked well?

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Other agencies willingness to support me e.g. fitting school hours around me.

Experience 3

Not knowing what depression was but not able to get out of bed during the day time, not being able to get out of the house to talk to people about it as well as not being able to talk to people about how she was feeling – a cultural thing

Feeling lonely and alone and stigmatised.

Other people noticed but didn't know how to help or were offering unhelpful suggestions

Experience 4

Initial diagnosis gave us a sense of relief that he would finally get the help that he needs. Instead we entered a whole new bewildering world of strange words and scary labels and received a diagnosis that he never accepted. As a result of having such a damaging label he lost friends. Instead of helping him they damaged him. He's not the same man he once was. He got worse; treatments got worse – he had ECT and it took a long time to get it right for him.

He had a support worker who had a similar background to him and therefore had shared experiences. Finally he is off benefits and has a label that he is more comfortable with. These two things mean that he is regaining status.

Throughout it was family that picked up on changes rather than the professionals.

Telford and Wrekin

Experience 1

I was being supported at home by the CPN visiting every 3 weeks and going between hospital and home but still keeping my job as a sewing machinist. After one visit to the GP when I was complaining of feverishness and sneezing I was unknowingly prescribed anti-depressants. I had no interpreter to support me with an explanation of what I was taking. As I did not understand the side effects I was unknowingly taking risks which resulted in me having a fall. On another occasion I was given tablets that made me sleepy and this resulted in me having to leave my job.

What worked well?

Having a personal phone number for her CPN who could be contacted at any time of the day or night. She visited in the evening

Having her daughter close by and her husband to interpret helped

Her family also had a relationship with the professionals too

Having a nurse that spoke her language. If you interpret for a family member the message is diluted sometimes this is because family do not always say what you want them to say. Sometimes it's because it's too difficult to explain and sometimes there just aren't the right words.

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Experience 2

As a family member my experience has been one of being pushed from Social Services to Health. I had no help for 2 years because no organisation would take responsibility. My son did not fit neatly into social care or health services boxes and so no one offered the right support He also needed to wait until he was the right age to receive appropriate services

Experience 3

I had been visiting the doctor with aches and pains and was sent away with paracetamol. I did not feel I was being taken seriously. I was working 7 days a week in my shop which was not helping with the physical



pain I was experiencing. I then saw a new doctor who did take me seriously and referred me to a hospital. At the hospital I was diagnosed with lupus which terrified me as my best friend had recently died from this condition. No thought had been given to how the diagnosis would affect me. It was this traumatic experience that caused me to have mental ill health.

Coventry

Experience 1

I experienced a traumatic event which affected the family dynamic. As a professional I had supportive colleagues. It was important to me to be seen as a professional who was able to cope as a social worker. I was not prepared to be a service user and this became very isolating. What I was offered when I sought help was 6-7 counselling sessions which was not sufficient and felt superficial. I needed longer; this barely scratched the surface.

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Experience 2

My son started to have problems as a teenager, that were put down to being a teenager or suffering from depression. Later on there was a question about whether this was mental health issues or autism.

As a carer the support was not there for me and as a professional I felt I should be able to sort it out. Being a professional other professionals saw me as someone who knew the system and would be able to sort it out for myself so I didn't get any help. GP was no help, reading was no help, and nobody could signpost me to places that might be able to help. Finally I found an online carers group that gave me some information.

Eventually I flew to India to get a diagnosis where I was able to talk to a doctor for 3 Hours. On return from India things began to move more quickly and there was a speedy referral from my GP to a psychiatrist. A package of support was put in place but the support workers would not recognise my contribution and did little to support my son to recover. I now have a direct relationship with the consultant who I am able to phone and talk to about any concerns that I have. This works well for me and my son is improving. This whole process has taken me 12 years.

Experience 3

I started to become ill while I was at university, I wasn't coping I was losing weight, not sleeping. My lecturers noticed, my family noticed, the nurses could see it but I couldn't. But then I had a light bulb moment when I was in hospital and I read an article that made complete sense to me and I thought "if there's nothing wrong with me why do I keep ending up in hospital". Having the right information earlier may have helped me sooner. Now I know the symptoms, I am able to recognise when I am becoming unwell and what to do about it. I also know that if I'm sleeping and eating then I'm well, if either one of these things begins to slip then I need to get help. Things that have helped me most are: Counselling, talking about my experience and CBT.

There is a stigma for the person and for the family but this illness could happen to anyone.

Experience 4

I became unwell whilst in the army and when I went to the doctor for help initially I was given repeat prescriptions and became a prescription junkie. I was sent to a psychiatrist who reviewed my situation and allocated a CPN to me. The CPN saved my life, she weaned me slowly off my tablets sent me on a lot of courses to occupy my mind and treated me as a person. This meant that she listened to me and didn't dictate. During the course of my support there were three particularly influential workers I came into contact with. I call them the three witches as they pulled me out of my dependency that I had on the service and gave me the confidence to live my life and make a valuable contribution. I now

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offer training to staff/professional on mental health related issues and am a champion for the DRE.

Further Information

If you would like further information about this consultation process please contact Anna Geyer or Charlie McAllister using the details below.

