



Making **I**nvolvement **M**atter in **E**ssex

‘Big Conversation’

Report on Consultations Across Essex, Southend and Thurrock

**Service User and Carer Views on
Commissioning Priorities**

**Information on Key Work Strands Highlighted
By Commissioners**

Personalisation & Day Services

Employment Services

Accommodation

Voices of Seldom Heard Groups

**With thanks to the many service users and carers who helped us to
undertake the consultations and compile this report.**

CONTENTS

Introduction	3
Background	4
Proposal	4
Revisions to plan	5
Methods	6
Workshops	
Keeping Well	9
Future Services	15
Values	20
Communication	22
Information	25
Structure	
Childhood	26
First onset	27
Residential	28
Community	29
Moving on	35
Key work streams	
Employment Support	38
Personalisation	40
Seldom Heard Groups	42
Accommodation Issues	44
Summary & Conclusion	44

Introduction

The Mime Team strongly believe that this report is presented at an opportune time but in a very different climate to that which existed when the project was first discussed.

MIME was born from a courageous and innovative partnership between health and social care - across boundaries of responsibility, designed to give service users and carers a genuine voice in helping to design services to meet their needs in the future.

Since its inception the financial and political climate has changed. New mental health strategies have come and gone and we await more. The organisational structure of commissioning is changing and along with it we have a new government with a new ethos and approach to service delivery.

But we believe that the impetus to set up the project was sound and that it is even more important, in a time of financial challenge and uncertain future, for decision makers to build relationships with service users and carers in order to make cost effective decisions which will deliver improved outcomes for the people who rely on the work we do.

The following comments from our 'Big Conversation' stand out:

'We know what is doing us good – they may be spending on services which aren't doing us any good.' (Basildon)

'We need to identify what works/what doesn't work' (Chelmsford)
They 'can't stand in my shoes. We have a qualification they don't have. We know what it is like because we've experienced it.'
(Southend)

It is in that spirit we present our report,

Pam Hutton, Partnership Coordinator (On behalf of the MIME Team)

Background

The Mime Partnership was commissioned on 1st September 2009 to provide a user involvement service specifically to mental health and social care commissioners across Essex, Southend and Thurrock. The partnership team consists of mental health service user and academic researchers based in the Faculty of Health and Social Care at Anglia Ruskin University and service user consultants, ARW Mental Health Training and Consultancy.

The proposal for a series of broad consultations to seek the views of service users and carers emerged as a response to the potential need for service redesign engendered by a new policy framework (New Horizons 2009) for mental health and the continuing development of the personalisation agenda in a challenging economic climate.

Following an initial meeting with commissioners on 9th March and further discussions within the MIME Team on 15th March, a proposal (Appendix A) was drafted and submitted to the commissioners' meeting on 17th March where it was agreed with minor revisions. The proposal argued that:

- The conjunction of policy change and financial restraint presented both a challenge and an opportunity
- It was important to involve service users and carers as key stakeholders in planning for the future
- It was potentially more constructive to involve service users and carers in a broad consultation rather than look at individual services separately
- An open discussion might provide further information on service user and carer views on personalisation

The MIME partnership was committed to a robust and genuine process which would give people who use services in Essex and their carers the opportunity to influence the direction and pace of change within the parameters mentioned above. Service users had already raised concerns in other events about the 'management of change' and had also highlighted dissatisfaction with some consultations they had been involved in previously which had only engaged with small groups of service users who have often been described as 'the usual suspects.' These factors encouraged the team to suggest 'The Big Conversation' as a way of widening participation.

The Proposal

In order to engender as wide an engagement as possible and also to illustrate our commitment to best practice we suggested:

1. The setting up of a small Service User and Carer Reference Group (approx 8 - 10) to work alongside the team to influence and engage with process, methods, delivery, analysis and reporting.

2. A wide ranging consultation which engages both existing people who use specialist mental health services, those who are supported in primary care and those individuals who have developed the skills to manage their own well being.

In order to engage as many people as possible it was felt that a variety of methods might be needed:

- Large and small group consultation events
- Newspaper and web poll
- Employer event

In addition to partnership staff the team proposed involving service users:

- as facilitators and note takers
- in data inputting
- in the development of questions, planning, reviewing reports and giving feedback

Revisions to Plan

Undertaking the 'Big Conversation' required a flexible approach and the ability to learn and adapt in the light of experience. The initial proposal had been for 2 large consultations and a number of smaller ones. However, as both of our largest towns are in North Essex it would have meant considering a third large event in the South, which would have proved expensive. We decided therefore to try Chelmsford as our first and largest event and then plan smaller events in other areas.

The high costs and poor return from the initial newspaper advertisement for the Chelmsford event led to the decision to drop the newspaper poll and look for other ways to boost recruitment to events and widen the evidence base.

We were confident that we could attract participants who had experience of using services to our consultations but had wanted to have some input from the wider population. We had hoped that using a web poll, approaching primary care providers and a large local employer might give us that additional perspective.

However, the effort required to recruit participants to the consultation events was time consuming and so we decided to take advantage of the opportunities provided by World Mental Health Day events to gain access to the views of the wider population. Essex County Council were kind enough to allow us to organise our own event in the Atrium at County Hall in Chelmsford on 8th October and we joined the Mental Health 'Market Place' organised by 'Time to Change' in Basildon on 15th October. With the help of service users from the project the team were able to get over 250 questionnaires completed and the report on that will be sent separately.

Methods

We began by setting up our **Big Conversation Reference Group** as we wanted the consultation to be led by service users and carers. We publicised the opportunity in our Newsletter and were fortunate to secure the assistance of about a dozen members. We tried to secure representation from all the areas covered by the project and have been largely successful. Some people came to one or two meetings but the core membership were very loyal and hard working. They:

- Helped us to decide the questions we would use in the consultations and to identify venues
- Acted as recruitment champions in their areas
- Assisted with analysing the comments coming out of the events and the information from the questionnaires
- Helped to present the key themes to Commissioners at our meeting in September to celebrate our first anniversary

Many of them also undertook training to assist with their tasks, helped with facilitating groups, and are building their skills base.

In terms of **recruitment to events**, our champions were particularly useful. Our newsletter helped and we were able to draw on the relationships we had developed with other organisations in order to boost numbers. As mentioned above the initial newspaper advertisement was costly and ineffective. A short slot on the Dave Monk Show on Radio Essex provided welcome publicity and was more effective in terms of numbers for the Chelmsford event.

However, **networking** with other organisations proved far more useful in terms of publicising events. Community Development Workers (CDWs) in South Essex were particularly helpful in enabling the participation of people from BME groups. Community bridge builders (CBBs) in the North East were very supportive and other voluntary sector provider organisations enabled us to secure the attendance of people from **seldom heard groups**, such as those with dual diagnosis and experience of residential accommodation and forensic services.

We decided to hold the first event on a Saturday in the hope of enabling wider participation. In order to encourage people to attend we offered taster sessions in complementary therapies, provided by a lecturer and students from Anglia Ruskin University, which were very popular, and had displays of art and musical entertainment. For the other events we offered a small payment to participants as a thank you for their input.

Events were held in the following areas:

Date	Place	Numbers of service users and carers participating	Commissioner attending
08.05.10	Chelmsford	32	Nicola Colston
25.05.10	Grays	22	Adrian Faiers
16.06.10	Southend	25	David Bush & Jumoke Ogunmokun
28.06.10	Basildon	12	Pauline Stratford
05.07.10	Clacton	12	Emily Oliver
11.08.10	Colchester	12	Paul Rogers
01.09.10	Harlow	7	-

We were fortunate that so many members of commissioning teams were able to attend as service users see their attendance as a demonstration of their commitment to the process. Janice Cheng would have attended the Harlow event were it not for the arrival of a new grandchild.

We were very pleased with the attendance in South West, South East and Mid Essex and if the Clacton and Colchester events were combined, attendance in the North East was also good. However numbers were disappointing in West Essex and there were several reasons for that:

- We lacked the time to have more than one event in an area which has scattered populations
- We were recommended by service users at a previously successful event in Epping to choose Harlow and although we sent the publicity out to provider organisations several weeks before the event, participants said they didn't hear about it until a couple of days before it took place
- Community Development Workers in the area were unable to help with recruitment
- We had recently held another consultation event in the area on community services and it is possible consultation fatigue played a role in poor attendance

Since then we have built stronger links with West Essex Mind and hopefully future events will be better attended.

At each event we had two workshops but to enable the engagement of all the people who attended we split participants into small groups for discussions as we have found it both encourages participation and facilitates note taking. We asked the following **questions**:

1. What do you do to keep yourself well
2. We want you to dream – if you were designing a mental health service – what would it look like, what staff would work in it, what skills/knowledge would they have, what services would be provided

By using open questions which allow participants the freedom to raise issues which are important to them we attempted to generate a discourse that was not confined or restricted by questions that were too prescriptive. The aim of the first question was to get participants thinking about the different ways in which they try to maintain their own well-being. We hoped the information gathered in these sessions might provide some indicators of potential commissioning priorities in the context of personalisation. But we also hoped that the discussion might raise awareness around issues such as responsibility, agency and empowerment.

The second was an invitation to think outside the box. The introduction to sessions stressed that this consultation was an opportunity for commissioners to hear what service users and carers would like to see in the future rather than an opportunity to discuss the success and/or limitations of services in the past or present. From the outset we were anxious to encourage service users and carers to embrace the opportunity to influence commissioning priorities and minimise the danger of the meeting reverting to outdated antagonistic models of involvement which have the potential to sabotage potentially constructive attempts at engagement.

The questionnaire, on the other hand, was designed to elicit information about the general public's expectations, which might give useful indicators to feed into commissioning priorities around prevention, support for mental health in employment and personalisation.

With the exception of one group at our first event all the **groups were facilitated by service users from the project.**

NB: The quotes in the boxes are taken from notes made at the time of the events. Where possible note takers record actual phrases used by participants but where conversation is rapid summary notes are made.

Some extracts have been used to illustrate different points as they are relevant in more than one section.

Workshops

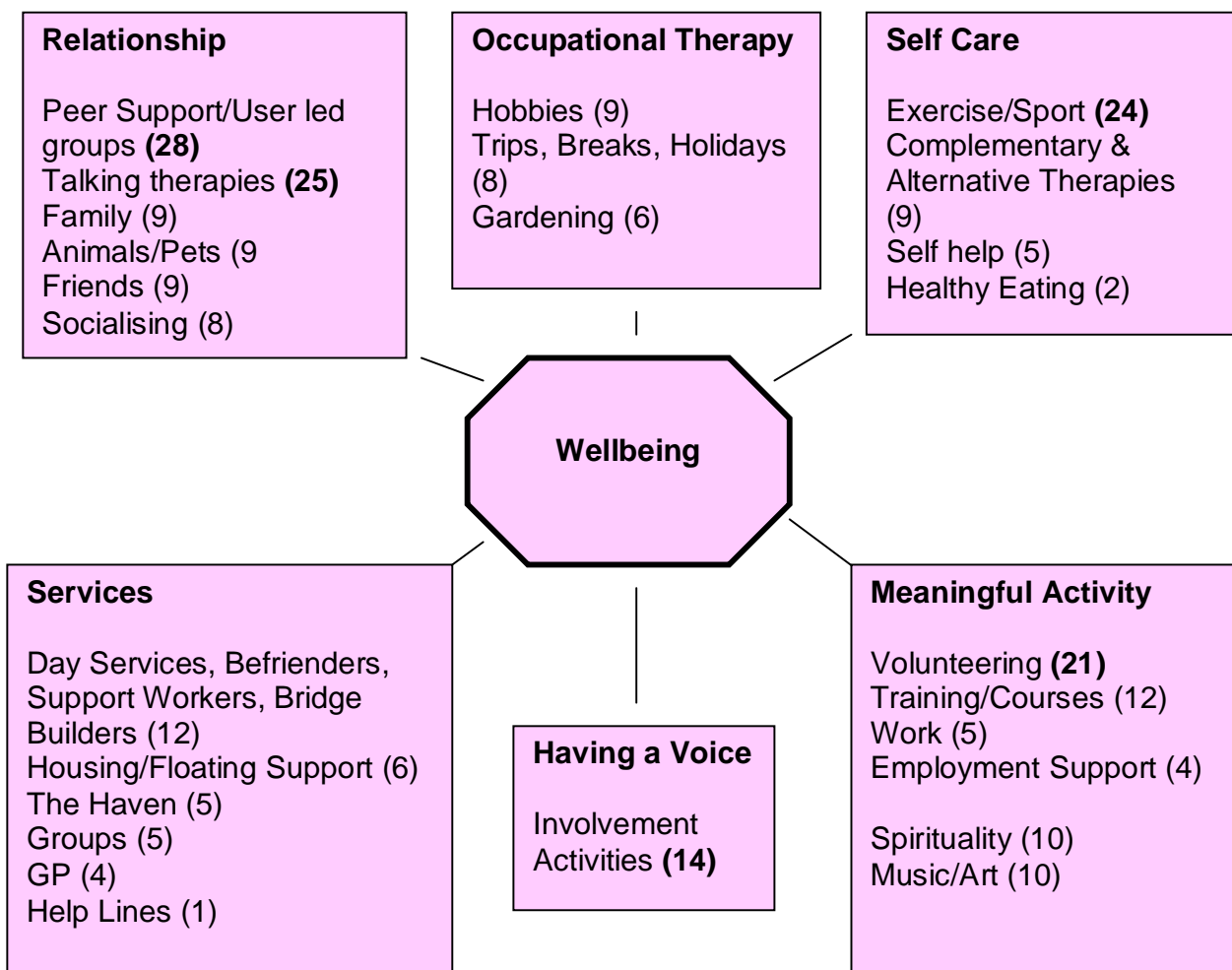
What do you do to keep yourself well?

By asking this open question we hoped to enable participants to begin to reflect on their own wellbeing and think about questions such as:

- Who is responsible for my wellbeing
- How do I seek/maintain an increased sense of wellbeing
- Who or what helps me

Inevitably some people thought of it in terms of what services do I use and wanted to discuss those which they found useful and gaps in provision if they felt their needs were not being met.

But many engaged with the discussion and were eloquent in describing what supports their wellbeing. They seemed to fall into 6 main themes:



The scores on the previous page relate to comments recorded in the notes taken at the time. However, in general discussions where several people are making a similar point numbers in agreement were not always noted. To improve accuracy we will attempt to address that in future consultations

However the scores recorded for peer support groups and talking therapies show that relationship with others is very important to service users and carers. The most frequent reason given for valuing peer support was that peers understood where they were coming from, were non-judgemental, accepting and supportive in contrast to service users' experience in the wider community where they often felt stigmatised. For participants from BME communities their experience of cultural insensitivity and racial abuse was a further reason for favouring peer support groups.

Talking to friends, family, peers and in therapy was seen as crucial to well being but there was criticism for unacceptably long waits for the latter – years in some cases. Many people mentioned the value of counselling and psychotherapy and its role in helping to prevent relapse but some participants were critical of time limited therapy which was seen as ineffective. Increased use of group therapy was suggested both as a remedy for long waits but also because of benefits they experienced in terms of peer support from fellow group members. The majority of participants made the point that there should be a variety of talking therapies available as one size doesn't fit all.

It is interesting to note that the proportion of service users quoting friends and family as important to wellbeing is significantly lower than that in our general population survey.

In terms of looking after self, exercise and sport were high on the agenda and exercise such as walking in the fresh air and outdoor activities (green therapy) were more popular than indoor such as gym or swimming.

Involvement activities and volunteering generally were often mentioned as crucial to maintaining well being. Having a voice and a sense of being heard was acknowledged as empowering and feeling useful seen as improving self esteem. When discussing something meaningful to do, volunteering was very popular and although there was some link to involvement activities a broad range of activities were also discussed. Many volunteered 'to give something back' or used their experience in a positive way to help someone else.

In relation to the financial climate there were many suggestions that service users could:

- run their own peer support groups in CMHTs
- act as buddies or provide information to people when they receive a diagnosis for the first time
- get involved in training staff from a user perspective

Many people found undertaking courses beneficial in terms of mental stimulation, socialising and boosting self esteem, although some found the cost prohibitive. Basic level courses could be accessed freely but for those with some qualifications, wishing to improve on them, funding was harder to find and sometimes impossible, although some participants reported that they had been helped by CBBs to access funding for training.

Spirituality in all its forms was cited as supportive and beneficial. Where it took the form of attending places of worship it gave a sense of belonging which was highly valued. Participants from BME groups in particular called for improved access to spaces where they could pray when they were in hospital.

But there was relatively less interest in the traditional arts and crafts activities of occupational therapy groups and some people were quite scathing of attempts to stimulate their interest in 'geriatric playschool' which was reminiscent of comments made in the North Essex Community Services review re 'card making for kids'.

A significant number found looking after animals as personal pets or through volunteering therapeutic. Alternative or complementary therapies were popular and people were willing to pay for them though for some the cost was an issue. A few were able to access them in the services they used and many called for the provision to be more widespread.

Young people (under 25) were under represented but those who did attend were more likely to call for the provision of activity groups as well as talking therapies and seemed marginally less inclined to prefer activities specifically provided for those with mental health conditions. One young single parent said that because she had a child to look after she often kept in touch with friends in the evening on the internet and wondered why services did not take advantage of new technology to support and expand existing service provision.

With the help of CDWs in Chelmsford, Thurrock and Southend we were fortunate to have several BME groups represented at events. The predominantly Indian and Pakistani group in Thurrock, who were mainly female, talked of activities within the home and seemed marginally less likely to undertake activities independently. This may be related to cultural and gender specific expectations. However, they were happy to engage in group activities organised by Thurrock Racial Unity Support Task Group (TRUST) and the CDWs. But they were keen to access training to improve their English language skills and were also interested in:

Learning skills to help with social integration... things like writing so can fill in forms, getting money out of a cash machine, how to access services etc. Literacy in Service User's native language would also be helpful so can use written materials available to them. (Thurrock)

The groups in Southend who were mainly from Southern & Eastern Europe and North Africa were also keen to improve their language skills and some seemed confident about using the library to access information about activities that were available in the community. They clearly valued the support they were given by the CDWs who are based in Southend Mind and were frustrated that statutory health providers seemed reluctant to make use of the service's expertise in culturally appropriate ways of working.

Like the groups in Thurrock, they also flagged up difficulties with obtaining interpreters for appointments and problems with receiving written communications in English even when they had made it clear that they could not read them.

One of the reasons for generating a discussion on wellbeing was the hope of providing early indicators of potential commissioning priorities in the context of personalisation and we have included comments on personalisation in the key work strands section on page 38. Service users reported using a wide range of activities to support their wellbeing, showing that there are a variety of activities available but many reported difficulties accessing them as they were costly for individuals on benefits:

Complementary therapies – acupuncture, alternative therapies, back massage etc (Chelmsford)

Weekly massage and a facial is very beneficial but expensive...Finance can be a problem in accessing some therapies (Chelmsford)

I've looked into exercise – I prefer it to therapies – but I don't want to be solitary. A gym would be good but it's far too expensive. (Chelmsford)

I like college courses but I can't afford them (Basildon)

Once you get to a certain level you can't get help (in relation to courses - Thurrock)

Some participants when thinking about wellbeing wanted to discuss services they used at present or had used in the past:

The Haven allows you to feel safe and belong and the service offers a 24 hour phone support service and up to 14 day respite accommodation. In addition, there is daily one-to-one support and the service is really empowering (not institutionalised) as there is lots of freedom to come and go as appropriate. (Colchester)

When I was very ill I came across the NSF now Rethink. I've been with them for 14-15 years. It's a good way of dealing with your illness – they can give you information and signposting. They've been my support but now I can be independent - I learned from other people in the group. Now I can give back. (Southend)

When I need help or need to know my rights, I go to Mind. The environment at Mind is better than the Taylor Centre. (Southend)

The group gives me a family feeling – I am happy to go and be there....gets me out of the house. They talk to us and make us feel better. At home I get distressed. Going out means I learn about different cultures. Balmoral community centre is run by REASON and we can do IT. (Southend)

90% of the old drop-ins were good – they signposted to other services Dorson House ~ It was called a Drop-in but it was more like a Crisis Centre. (It is now Summit House and they are developing some service user-controlled groups. It is hoped that these will progress well and that some of the original activities from Dorson House will be reintroduced) (Clacton)

Recently I joined Mind, all the services I have used are from the voluntary sector. It is a matter of trial & error to find what's out there. Swan Housing have provided practical support & provide an interface with the Job Centre (Colchester)

My daughter goes to Assertive Outreach and they will help her with things. There are/have been periods of time when I wished there was more, if she could have had an intensive programme earlier.....NACRO have been very helpful. (Colchester)

**With support like I get from Oasis I can do so much more (Thurrock)
I've been accessing not just mental health but drug and alcohol... that service got me back into recovery.... now I lead a sensible life (Thurrock)
Open Arts- that was really good it got you out doing things.
Befrienders are good for isolated people.
I go to the organisation at Panorama House, they are very good if there is a problem they will get in touch with Aston Court (Basildon).**

New CPN – ‘my CPN is now working with me for my benefit – we seem to be on the same wave length...’ (Clacton)

Mind day centre they take us on trips (Harlow)

Sadly some people seem to accept that they may be permanently dependent on services:

My illness is never going to go away – I stumble from crisis to crisis..... I was moved from the CMHT to Assertive Outreach team... I have a 365 day a year service... Even when I get picked up by the police when I’m unwell they see the card and call the AOT and they sort it. (Thurrock)

Dream Session – the Future

Although a few people seemed to find it difficult to go beyond discussing the merits and faults of services as they are, most people were willing to engage with a wider discussion on what should be the key elements of services in the future and the discussions showed that many service users are able to reflect and use their personal experience constructively to suggest priorities for service planning and delivery.

As the comments below show they are also aware of the impact of the current economic climate and can be pragmatic as well as aspirational.

We know what is doing us good – they may be spending on services which aren't doing us any good. (Basildon)

We need to identify what works/what doesn't work (Chelmsford)

In every group suggestions were made, which service users felt were not only useful in terms of meeting people's needs but could also be justified in terms of cost effectiveness.

Discussions covered a wide range of issues:

- User involvement and the value of experiential knowledge
- Mental health promotion and prevention
- Services – community based and residential
- Peer support and self help
- Support offered by services both statutory and voluntary
- Medical and psychosocial interventions
- Staff skills and training
- Personalisation
- Employment

Inevitably, in such a wide ranging discussion, concerns were raised around some existing services:

- Anxieties about GPs' lack of training and expertise in mental health
- Concerns around poor communication - both interpersonal & inter-agency
- Crisis services which do not address the expressed needs of service users

However, where concerns were expressed, constructive suggestions on how issues might be tackled soon followed.

The diagrams on pages 17 to 19 attempt to show in summary the main themes which emerged.

When thinking about the shape of services in the future service users and carers tended to think about their own life journeys and the stages they were at in the present. Their comments reflected that perspective.

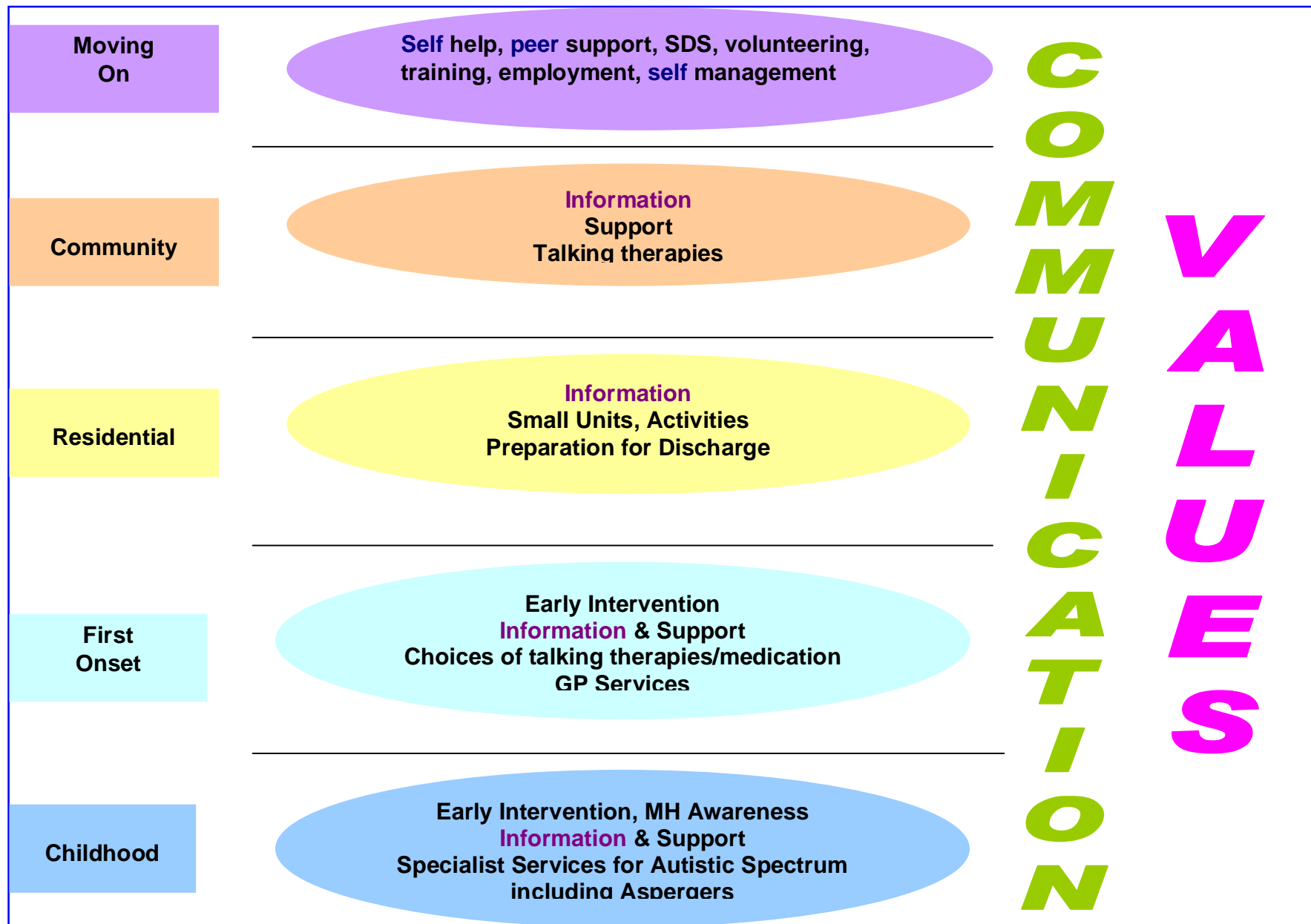
In attempting to capture and deliver a summary which reflects their collective views it seemed relevant to present their ideas in a way which reflected the different stages and concerns represented by the participants in our workshops.

However, it is important to note that some of the comments, although presented in one particular section are equally relevant for others and this applies in particular to comments in the 'community' and 'moving on' sections.

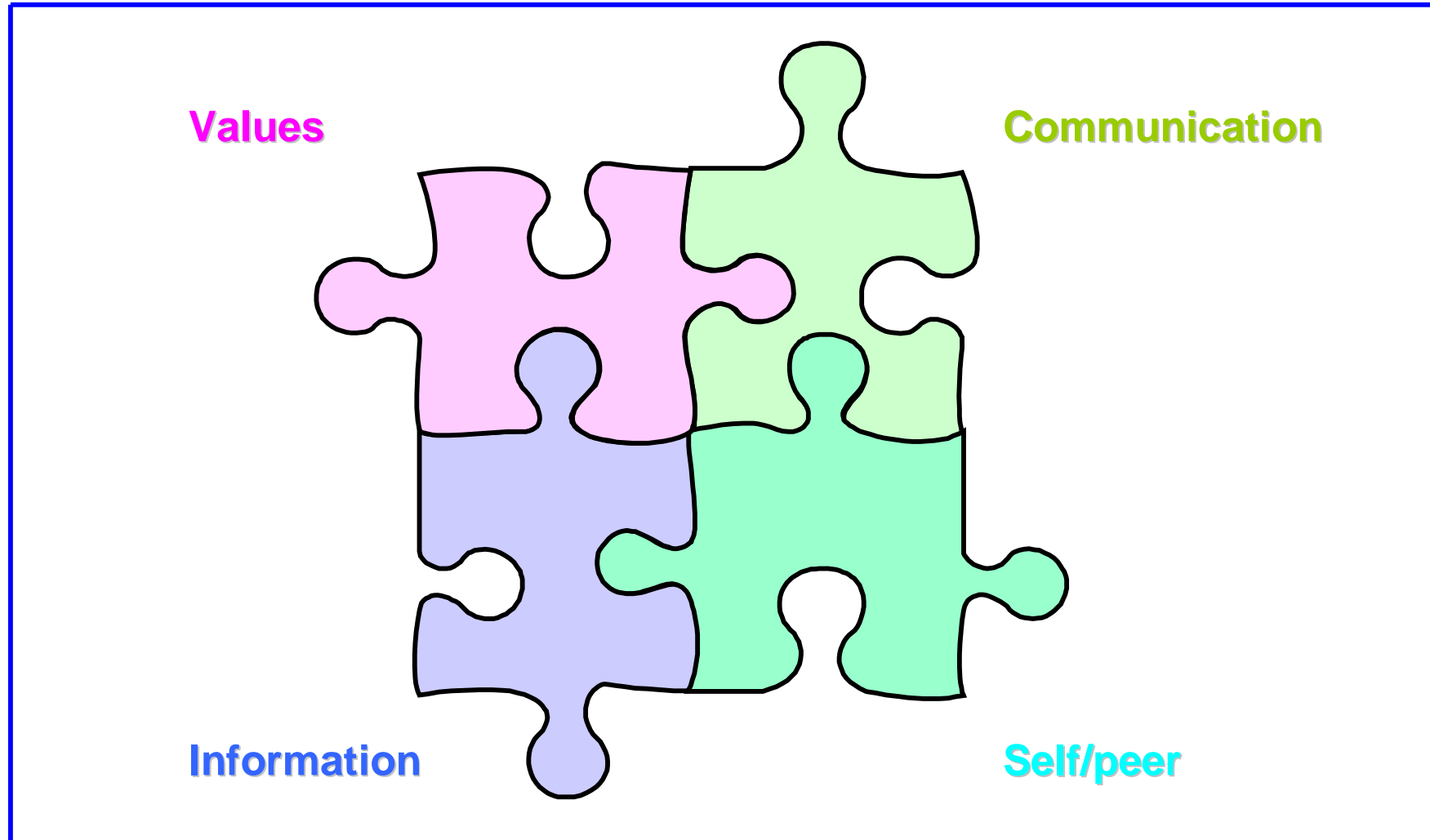
There may be an argument for not presenting them separately but the decision to do so emerged from the messages that we heard from service users about their individual stories and the importance of recognising that each person moves through their recovery journey at their own pace and there is a time when their need for care and support is greater.

Their priorities at that stage are naturally different to those which emerge as they become stronger, more independent, better able to make use of choices and engage more with their wider communities.

In essence the message often seems to be that 'we need to experience being cared for, feeling safe and supported, before we are able to begin to care for ourselves again. In order to move to that stage we need the people working with us to understand the stage we are at and to foster hope and self belief rather than push us along a path they have drawn and we are not yet ready or do not wish to walk. If we can feel safe and supported then we are better able to draw our own map.'

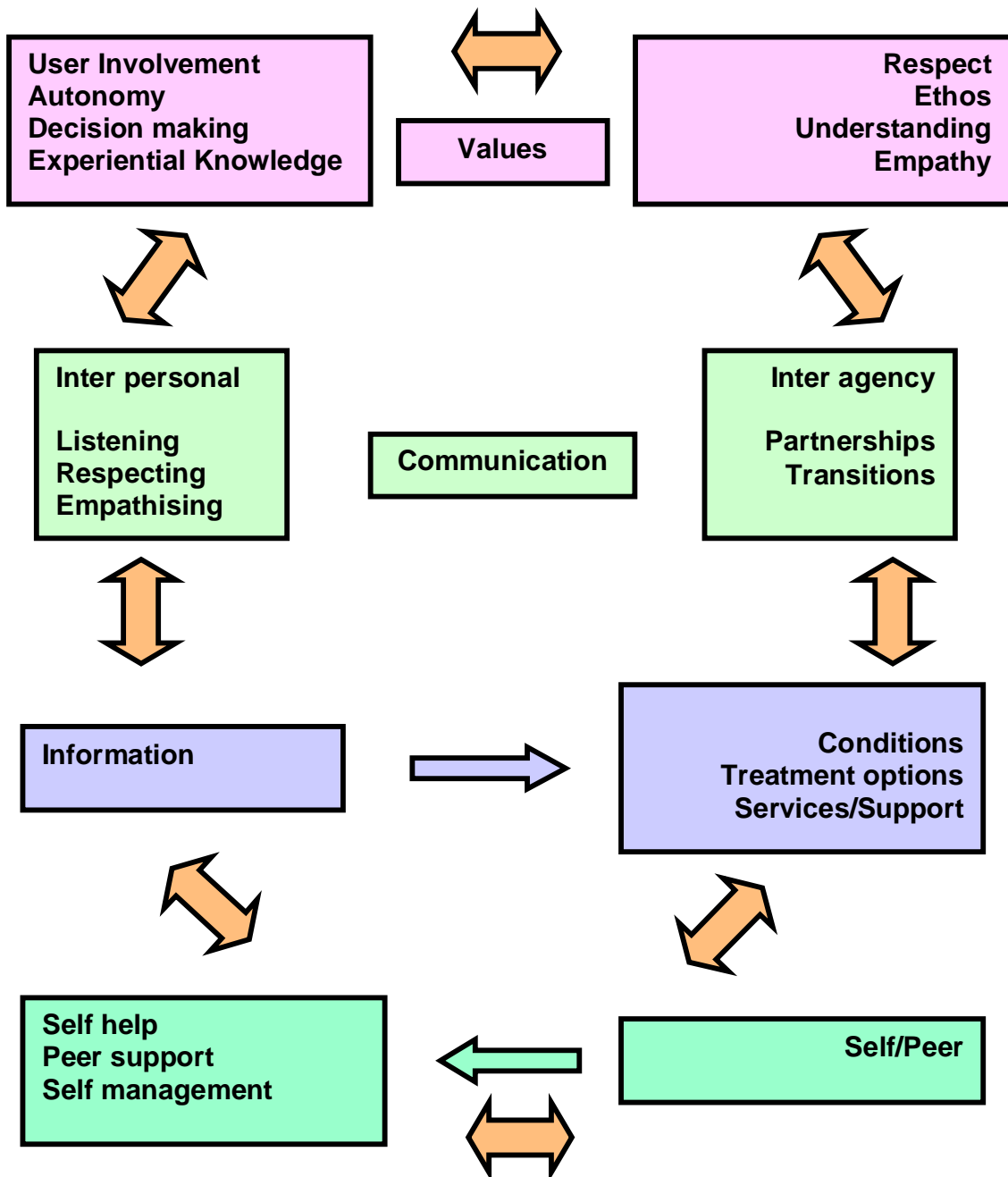


Within the diagram key words are highlighted which are of crucial significance to service users and could be seen as both underlying and major themes. These are presented first and the stages follow:



The following pages attempt to accurately convey the views of the service users and carers who worked so hard in the consultations to articulate what they felt were the key themes which should inform commissioning decisions.

As the diagram on the previous page shows the key words are intertwining and closely linked. The words which came up most frequently in the discussions relating to them are shown below:



As the diagrams attempt to show, the issues are connected and interlocking. For example, if a professional has poor listening skills, service users and carers can sometimes make the assumption that it stems from a lack of respect rather than training deficiencies.

Similarly poor experiences in user involvement activities in the past can increase service user and carer scepticism about developments now.

Values

Consultations on service planning or reviews often tend to concentrate on practical issues like what is offered and whether it works. But, given a brief to dream up a new service, one of the most important discussions in all our events was around values and they centred on two issues – user involvement and the values which should underpin mental health service delivery in the future. Service users and carers are aware that policy, education and research discourses increasingly use affirmative language in relation to the value of lived experience and they welcome these developments.

However, this apparent acceptance of the value of experiential knowledge is juxtaposed with what they experience in every day interactions with practitioners where the value of ‘expert’ knowledge is assumed and attitudes and behaviour can at times lead individuals to suspect that their experiential knowledge is little valued and sometimes dismissed altogether.

A further complicating factor is that professionals in health services are trained to maintain boundaries and distance even within some psychological therapy models. Many service users in secondary care have negative life experiences which can go back to early years which contribute to feelings of ‘difference’, social exclusion and isolation. Professional distance and challenges to their perception of their personal experience, needs and emotions can inadvertently reinforce rather than mitigate that distress.

They seek feelings of connection which may have been missing in their life experience and therefore respond better to helping relationships which involve listening and empathic responding, mentoring and affirmative dialogues – hence the interlocking nature of values and communication issues and the strong preference for peer support opportunities reported in the section on keeping well.

However, In spite of many previously frustrating experiences in the world of user involvement, service users and carers who engaged with the ‘Big Conversation’ are beginning to overcome their scepticism and welcome the opportunities provided by the MIME Project:

Asking our views is really helpful (Clacton)

Speaking of commissioners – they used to sit in their offices and make decisions based on what they thought was cost effective... there has been some change however... I think they come out and listen more now’ (Clacton)

They strongly believe that their experience of using services gives them a unique and valuable perspective on what works and what is less helpful in current service provision. In all our consultations they assert their value as stakeholders and call for more involvement in decision making:

Service user and carer involvement is paramount – need customer led services – doing what people want. (Basildon)

There needs to be more service user and professional involvement in decision making by commissioners. Service users are experts in their own needs. Professionals also have a lot of useful knowledge because they work on the ground. If this happens more it will be more economical because then services will better meet peoples needs.

In decision making groups service users should have equal votes. (Clacton)

Many see user involvement, not as something which is bestowed by a benevolent and powerful stakeholder but as a right or entitlement. In addition to a seat in decision making groups, service users see a role in staff recruitment and training as a further method of influencing service planning and delivery:

People with mental health issues should be put on interview panels (Colchester)

You need to take care in picking the right person for the job... Service users and carers should be involved in staff selection (Chelmsford)

As well as advocating for increased representation on decision making bodies and additional roles in staff training and selection as a way to effect change, many service users believe that the only reliable way to change the ethos of mental health services is to employ more people with experience of mental ill health:

More service users to be employed within services and on the Boards of Trusts (Clacton)

People who work in mental health services should/need to have the experience of mental illness themselves – unless you have been in the pit... (Colchester)

We need more people with lived experience working in the system and opportunities for clinicians to have one-on-one conversations with SU's with mental health problems – not as a doctor-SU interaction, but as a person to person discussion about what it is actually like to experience mental health problems. This would help to develop real empathy, not book-based problem solving. (Thurrock)

You can go to College and learn about mental health problems from books but you don't know what it is like from the inside if you do that.... Service users do... service users are expertsthey support each other - one participant mentioned setting up a service user support group (Clacton)

Service Users being employed within services, such as on wards, in the community, on phone lines, etc - a good mix of staff is needed... Service users and professionals should work along side each other and learn from each other – they could be useful to each other – service users often relate better to other service users. (Clacton)

Many believe that user led services, self help and peer support groups are the best guarantee they have of services which are centred on their needs rather than those of the service provider. Although some service users continue to phrase calls for peer support opportunities in terms of regret around the loss of drop-ins there is a growing awareness amongst practitioners as well as service users and carers that peer support can be both enabling and empowering.

There are benefits in terms of greater independence and improved self esteem as participants are able to offer as well as receive support. They also offer opportunities for exchanging information on services and coping strategies which are perceived as valuable.

Service users and carers see user led services, self help and peer support groups as an integral part of services in the future and call for commissioners to recognise and acknowledge the value of peer support and prioritise the provision of opportunities to access it. They quote the stigma and discrimination which they experience in their daily lives as one of the reasons why they value spending time with others who have shared experiences and can offer 'safe' spaces where they will not feel judged. This may also link to the need for 'connection' referred to on page 20.

Communication

This issue is discussed at every consultation we have engaged in at both the inter-personal and inter-agency/team level. When discussing services in the future and what they hoped for, there was universal agreement that the staff working in them should have good listening skills which they are able to demonstrate.

'They don't listen', came up in various forms about staff working in provider organisations to illustrate the point individuals were making. It occurred most often in comments relating to clinical staff and statutory services generally but also occasionally

in relation to staff working in the voluntary sector. It applies to all levels from receptionists to psychiatrists and senior managers.

Being listened to is important. (Basildon)

Workers listening to you – recognising that you are the expert in yourself...they tend to be judgemental, say that you have to put up with what you're going through. CPNs were cited as an example of people who do not listen to you, nor recognise your expertise. (Clacton)

The psychiatrists don't understand our point of view. They should first listen. There should be more staff training around communication. People with mental health problems don't get respect from psychiatrists and they don't understand different culture... (Southend)

Staff need to talk to patients and listen to them ...Social workers need to communicate. (Southend)

Sending staff not to a charm school But so they can talk and listen to people...They need communication skills. (Thurrock)

Comments about poor communication skills, as mentioned above, are closely linked not only to skills but to the attitudes which reflect the value base which service users think should underpin services:

If people feel comfortable they can connect. (Colchester)

A&E staff need to receive more training on self-harm issues - Although they say they are trained in this area, their response to self-harm is often poor. (Colchester)

Attitude of some staff is poor particularly if you self harm (Basildon)

I hate the Taylor Centre – they come out and talk to you in the waiting room. I don't want to talk to staff in front of everyone – it's disrespectful.

We are human beings, they act like robots & automatons (Southend)

People should be treated with respect. If you have mental health issues it's often assumed that you're unintelligent and as a result patronised. An individual's level of understanding and intelligence should be recognised. (Chelmsford)

As a non English speaker has experienced prejudice... feels people come to criticise what she has done when she did what she thought was right, rather than to help her understand what is expected of her. Opportunity to have a chance to talk to people who understand is very important. (Chinese participant via interpreter – Chelmsford)

What makes the real difference is the individuals, ethos (how they approach you – their qualities) - sometimes have problems because the professionals are under pressure themselves. It's crucial that you are served by good people.

A constructive suggestion was made in Clacton:

It would be helpful for professionals like social workers and CPNs to come and explain to service users what their roles are and what they can offer because service user and professional perceptions of duties can be very different.

Comments such as these cut to the heart of the continuing argument about the relative value of objective empirical knowledge and experiential learning from lived experience.

Many also highlighted the importance of good communication between different agencies:

Better communication of government agencies, job centres & housing, benefits & GPs all to liaise (Clacton)

There is no coordination between voluntary and statutory services (Harlow)

They also suggested that improving communication could help to reduce waiting times. Service users and carers see long waits for appropriate interventions as costly in terms of greater distress for the individual and potentially longer episodes of treatment as symptoms deteriorate.

We need help when it first arises not later when it costs more because of delays which allow deterioration and worsening of condition (Thurrock)

Need to be seen when needed. Services which offer help and support when needed may for some result in faster recovery or not becoming so unwell as to need admission or more intensive support and so should be cost effective. (Chelmsford)

Information

Both service users and carers highlight the importance of having access to good quality information in a variety of formats at all stages of their journey through services on:

- Conditions
- Choices of interventions and decision making processes
- The variety of support available
- Services in both statutory & voluntary sector including self help and peer support

List of local practitioners/peer support to be available on the ward/GP notice boards (Thurrock)

There should be information about where to get help in the library, doctor's surgery etc (Basildon)

There needs to be more information & access to advocacy (Colchester)

1 stop shop for information with a directory of services (Southend)

Information drop-ins run by people with lived experience so they can tell it like it is. (Thurrock)

Having addressed the underlying themes, the following pages look at comments within a framework of the stages participants identified.

Services – Childhood

Although the focus of discussions was on adult services many individuals suggested that prevention and early intervention in childhood was a cost effective method of minimising the need for expensive services for adults and potentially preventing a life time of dependence on services. The comments may also be valuable for commissioners with responsibilities for public health and prevention agendas:

An educational programme in schools – to help children build their resilience... good mental health starts before the child is born.

Young people need information about mental health within the education system. For young people there needs to be ... early intervention (Colchester)

Early recognition before a child gets a big problem – GPs singled out

Leeway at school for young people with mental health problems, e.g. more time to hand in work/ having a supporter to help at school, as for other disabilities

Work with schools to address stigma

More should be done in schools ... they need to understand how much they need to look after themselves and look after others

... schools and colleges need to educate young people about mental health issues and this would stop stigma too (Chelmsford)

Carers also suggested more help for parents:

I have a huge amount of guilt surrounding my daughter... on one of her admissions to hospital I wanted more – needed clarity – what was expected... something should be available at home (Colchester)

Services – First onset

Early intervention across the board, and not just in terms of presenting issues like psychosis, was felt to be crucial in terms of preventing deterioration and escalation of need.

Need to be seen when needed. Services which offer help and support when needed may ... result in faster recovery or not becoming so unwell as to need admission or more intensive support and so should be cost effective

(Chelmsford)

Problems to be dealt with as soon as possible with a focus on preventative approaches (Clacton)

GPs were felt to be important in this process but it was suggested that they needed more training:

If your GP is interested in and knowledgeable about mental health it is helpful. But GPs generally lack knowledge and need greater awareness – great difference between individual GPs and surgeries. (Basildon)

GPs don't always know enough about mental health issues (Chelmsford)

GPs need more guidelines on MH issues (Harlow)

In order to assist GPs many felt that there should be nurses with expertise in mental health working in primary care:

**Access to professionals e.g. a half day CPN drop in service in all GP surgeries
More training needed for GPs – surgeries should have dedicated MH nurse or worker within the team (Chelmsford)**

Psychiatric nurse in surgery so GP has someone can send new patients to straight away (Basildon)

Nurses in GP surgeries need dual training. They lack the knowledge to spot deterioration in a person's mental health (Colchester)

GPs should work more with MH teams and have more MH training. Would be good to have CPNs in GP surgeries (Southend)

It was felt important that GPs offered choices:

GPs should offer choice – psychological services or pills (Basildon)

Talking therapy to prevent need for secondary service – sometimes better & easier to talk with a stranger/a counsellor, someone independent... Carer described how counselling had helped her. (Chelmsford)

But there was some recognition that people are sometimes reluctant to seek help:

I didn't want to go to my GP because I was worried about it being on my medical records and I thought that employers could see these and I was worried it would affect my work. I needed someone to speak to – get information before I would seek help. (Basildon)

Services - Residential

It was interesting that few participants initiated a discussion on what types of residential support/hospital units there should be. However, when prompted by a commissioner the following emerged:

They need to be safe and there should be smaller units.

Participants felt that it was important that service users should be treated with respect and be involved in decisions about their care (Basildon)

The question of gender specific services was discussed. Although current policy requires separate provision, one service user in Southend had a different view:

Sometimes you like to be together and sometimes men and women need separate spaces (Southend)

However, female participants from BME groups asked for:

Same sex wards, female doctors for female patients, separate bathrooms... (Thurrock)

There were also suggestions from service users who have conditions which sometimes necessitate a return to hospital about how this could be managed to maintain their autonomy as far as possible whilst paying due attention to risk management:

Advance directives for self harm and crisis situations – personal safety plans where you can write ‘what helps me to feel safe’ so staff don’t do the wrong thing and make things worse (Southend)

Activities on the wards are viewed as essential in the future as at present some people felt:

Too much emphasis on drug therapy, occupational therapy always seems to be in short supply (Colchester)

Managing transitions well is vital – having information on the wards on support available in the community (see above) and working with service users to plan and manage their discharge and the level of support they will require on an ongoing basis is crucial. There was also a suggestion:

When coming out of hospital to have a buddy (Basildon)

This also links to the benefits of volunteering mentioned on page 10. Many service users think that volunteers could be used in statutory services as a way of improving services with minimum cost implications.

Services - Community

As highlighted above the provision of good quality, up to date information and a variety of support, tailored to individual needs, is essential for future community services. Service users value their autonomy and need to know what services are available in order to make informed choices about how to maintain their own well being.

In a time of economic restraint it is important that services find ways to communicate with each other in order to develop holistic packages of support. Service users agree that 'mental health is everybody's business' and suggest that the following priorities should be addressed in order to meet the needs of a diverse population of users.

Access

Statutory service providers at present organise their community support in community mental health teams. However, as the consultations undertaken for the review of community services in North Essex showed, in addition to comments made in this series of events, many service users would prefer to access support in their GP surgery if the issue of GPs' lack of expertise in mental health can be addressed. Too many specialist buildings are seen as expensive and wasteful in the current economic climate.

They need to integrate services – all these buildings are wasteful (Thurrock)

Access to professionals – e.g. a half day CPN drop in service in all GP surgeries (Chelmsford)

Would be good to have CPNs in GP surgeries (Southend)

In addition service users highlight problems they have experienced using services which divide physical and mental health needs. They prefer holistic services and some go so far as to suggest:

Combine both physical and mental health (Chelmsford)

Health should be all one service not separate physical and mental health – it shouldn't be divided (Southend)

... others preferred to access support for their mental health in a generic centre covering both physical and mental health – I don't want to go to a mental health place. (Thurrock)

They see holistic services as a positive constructive solution to the well documented difficulties mental health service users can experience when trying to get their physical health needs met. The significant difference in life expectancy rates for those with severe and enduring mental health diagnoses should make this an issue for serious consideration.

Service users recognise that there are already a variety of different providers in the community but finding out about them isn't always easy, so some suggest that statutory and voluntary sector providers should be situated in one place to improve cooperation, reduce wasteful duplication and make it easier for service users to make informed choices about the support they can use to maintain their own wellbeing.

I would love to see... there are different services scattered around... why not have like the new NHS walk-in centre... Why not do the same.... Everyone in one place NHS and voluntary sector. (Thurrock)

One building where people are caring, friendly... information resource centre (Southend)

One stop shops where everything that is needed is all in one place (Clacton)

Information on services in one place (Harlow)

Service users are also consistent in calls for services to be more accessible in terms of time and distance.

24/7 365 days a year services (Clacton, Chelmsford, Thurrock, Colchester, Basildon)

24 hour helpline manned throughout the night and support groups in the evening and at weekends (Southend)

Being seen / treated locally - People don't want to travel long distances to appointments ~ some people have to travel two hours each way by public transport! (Clacton)

It should be noted that most of the calls for the provision of round the clock services related to crisis services. Service users at every event quoted anecdotal evidence of deficiencies in the provision of support to individuals who identify themselves as experiencing a sudden deterioration of mood, often accompanied by suicidal ideation, and wishing to avoid hospital admission. This has led to calls for reforms of the existing service and suggestions include:

A&E departments should have their own specialist mental health departments/area with trained staff – this would prevent inappropriate admissions and reduce distress caused by long waits (Colchester)

... when in crisis should be able to go to a mental health unit rather than A&E

... a suggestion was that community mental health team (CMHT) members might take on the crisis role because they know you and that makes them better able to assess the situation accurately (Basildon)

There should be special Mental Health A&E departments set up (Clacton)

Service users and carers are aware of the difficulties of providing services in urban and rural areas but feel strongly that post code lotteries are indefensible and services should do everything they can to address historical disparities in service provision:

Unequal spending of the budget is not fair – some parts of Essex have much better resources than others (Clacton)

Often good things are provided but not in each locality

Greater consistency of provision across Essex/sharing good practice (Chelmsford)

There should be consistency of services – all areas the same. At the moment everywhere is different. (Basildon)

Consistency

There were also calls for services in the future to be centred on the needs of the client rather than those of the service provider. Service users and carers prefer to see the same professional consistently as they feel that helps to build a trusting therapeutic relationship. However, provider organisations increasingly offer appointments with teams rather than individuals in an attempt to manage pressures on time caused by staff absence due to sickness and annual leave. The importance of consistency was raised at every event, although there is space for only a few comments here:

...Seeing different people and going through story again and again very distressing... (Clacton)

It just makes you want to shut up and not speak to anyone - this is not good for recovery/wellbeing (Chelmsford)

When attending appointments important to see the same person... not seeing the same psychiatrist or CMHT worker makes things worse (Harlow)

Time limited help - You are told to go. You are dumped. The answer is that we don't want you to be dependent. You can't turn around years & years of suffering in 3 or 4 weeks. What sort of a system does this? You are told you can come back if you relapse! What use is that? (Chelmsford)

In addition to providing suggestions on access and consistency service users also gave detailed suggestions on the type of support they felt should be provided in a good community service.

Housing support:

Housing staff need training in respect of mental health issues as poor housing can cost lives! - The Council needs to be both more flexible and supportive (Colchester)

Floating support workers do help and more are needed (Colchester)

Many people value the help they receive in a variety of supported housing settings and the assistance in managing the transition from hospital to community

Practical support

Need practical help and support to do things at home. Practical skills workshops like cooking, painting & decorating, building, computers, etc (Colchester)

Better advice on claiming benefits and filling out forms (Harlow)

Support to manage every day tasks e.g. keeping home tidy... grooming... these can impact on mental health & self esteem (Chelmsford)

Being listened to and being able to access Support Workers as people sometimes need practical day-to-day support (Clacton)

Social support

The men's group keeps me well... gives me a family feeling...makes me feel I am not alone (Southend)

More social inclusion through outreach services to help us take part in the outside world (Colchester)

More bridgebuilders are needed and they need a proper base (Clacton)

Befriending schemes – everyone needs someone to hold their hand and offer support... could be a volunteer ... or care worker (Chelmsford)

Social support is often perceived as more important than medical interventions as it is so closely linked to quality of life issues.

Talking therapies

Service users consistently show that they value talking therapies. There appears to be some feeling that in the enthusiasm for IAPT, the needs of secondary care users may have been sidelined. Services in the future will need to provide better access to a range of talking therapies for individuals at every stage on their recovery journey:

Stress management courses help motivation (Colchester)

Talking therapies – they prevent relapse (Southend)

Women whose first language is not English would like psychological services they can access (Southend)

One-to-one therapy is not always acceptable to some people from BME groups but faith-based community groups would be helpful especially if group therapy could be conducted in own languages. (Thurrock)

Courses such as anger management and anxiety management (Harlow)

There should be therapists to help ease problems (Chelmsford)

There needs to be more psychotherapy and counselling, talking does help. (Colchester)

Tailor made counselling... one size doesn't fit all (Southend)

Access to talking therapies within weeks (Chelmsford)

Complementary and alternative therapies

Service users and carers value and use a huge range of therapies and activities to maintain well being as the first section of the report showed. Some felt that these should be available in community services.

Moving On

When talking about their recovery journey service users and carers felt the aim should be to promote greater independence and facilitate the recovery process. Some of the suggestions they made related to:

- The range of activities highlighted in the first workshop on wellbeing
- Self help and peer support
- Training and volunteering
- Employment support
- The role of self directed support

The activities which promote and maintain wellbeing are listed in the chart on Page 9 and some illustrative comments are in Appendix C.

Peer Support

The value of opportunities for peer support has already been discussed and it will be for commissioners to decide how this can best be supported. Many participants gave evidence of the benefits they get from accessing:

- User led services such as the Haven in Colchester, DARE in Thurrock and SODA in Harwich,
- Self help groups such as MDF's bi polar support group in Chelmsford

Without being involved with something my mental health would suffer... started getting involved with groups (Thurrock)

People want to go to self help groups (Harlow)

Participating in groups is therapeutic (Chelmsford)

Peer support is essential; we need more encouragement in this area. (Colchester)

One group of service users started own group and meet for lunch once a week they help each other. (Harlow)

Have services run by mental health service users (Harlow)

**Friends keep me going and going to peer support group... 'I hear voices – it's nice to be able to converse with them without being stared at'
Mutual support & empathy from other service users (Clacton)**

Information and advice from peers more useful – forums were mentioned...being part of something (Chelmsford)

Support for service user run/support groups

- Peer groups for friendship & fun
- Hobby groups e.g. photography, art appreciation, gardening
- Support groups like the diabetes ones
- Ways to bring people together now drop-ins gone
- Need for small scale funding for groups to form and meet. (Chelmsford)

Volunteering and Training

Many identified support for volunteering and training as a useful part of their recovery journey and felt that support to engage in it should be an integral part of recovery based services:

Volunteering can be a very useful step for some but most volunteering opportunities involve caring for others in some way. For those with mental health difficulties this may not be useful to them. There need to be volunteering opportunities which are more related to specific employment goals.

Voluntary work gets you active & gets you out / gives a sense of achievement, giving something back, self-esteem (Chelmsford)

Skills development e.g. IT... Once a month I go to the town hall and have been sent on courses at the SAVS centre... Help a charity I like...We need more activities, offer more skills courses like how to build something or sustain something. (Southend)

We've done a computer course – it's subsidised... I'd love to be able to get myself better, be one of the workers...I've done my introduction to counselling because I feel that I can give something back (Clacton)

It's important not just to go for pills, therapy... we want to do activities, volunteering – helps us move on – training... Volunteering helps self-esteem (Clacton)

Key Work Streams

The following section has relevance for other work streams that MIME is involved with.

Employment Support

Support to return to employment came up spontaneously in several discussions:

The back to work experience needs to be very flexible and understand the variation of people's moods and capabilities from day-to-day. It also needs to be flexible in respect of earnings and benefits ~ all or nothing does not work! (Colchester)

There was praise for some services and criticism of others:

I had an interview with my son at the CMHT about the Employ-ability Scheme – we had a 1hr consultation – the member of staff was very understanding and said to my son that this would be a slow process but that was ok. She managed to arrange 4hrs a week for my son to do conservation work.

When we went to see the Disability Employment Adviser at the job centre he just said 'what do you want to do?' They need to be more understanding and list some options – we didn't know what was out there. (Chelmsford)

One group in response to a prompt from the facilitator recommended the following:

- **Support at work when experiencing problems**
- **Support to get back to work**
- **Tackling discrimination on the part of the employers, within the NHS as well as other businesses**
- **Raising awareness amongst employers / understanding**
- **Recognising skills and strengths / being seen as a person not someone with MH problems**
- **Flexible work arrangements, e.g. starting on a small number of hours**
- **Work trials**
- **Volunteer opportunities within services (Chelmsford)**

And the topic of employment was also given some time in Thurrock and Southend

Would like mental health services to include access to an employment specialist who could communicate in relevant languages. (Thurrock)

Should be support to get you into work, training and volunteering (Southend)

As the comments above show there were also concerns and suggestions about maintaining work and/or the difficulties of overcoming prejudice and stigma from employers:

Mental health information in the workplace (Harlow)

Employment specialists... would help some people to access earlier to be one of first options. (Basildon)

Lot of people are in places where employers don't understand mental ill-health. Making companies more aware of tell tale signs is really important. People should be made aware as so many people suffer in silence – would be willing to talk to companies himself (Chelmsford)

Biggest barrier is that people (employers) don't understand. Companies are about making money, so will not choose people with gaps in employment because of their health

They wouldn't let me see an employment advisor as they said I didn't have a care coordinator- they didn't know that my psychiatrist was my care coordinator. (Basildon)

Several people spoke about the difficulty of gaining or keeping a job if you have a mental health diagnosis. As soon as you mention the word mental health they say bye bye... In a recession we're a liability, we're the unknown, they won't give us a chance. (Southend)

In spite of the concerns expressed there were some positive comments:

**Working and keeping occupied ... makes a big difference. It gives me contact with other people, it gives me finance. It means I can go to the gym and do aqua. All of this helps to improve social contact. It was all through an OT who reduced my dependence and encouraged me to stand on my own two feet. The structure is helpful. I have been able to take more control.
(Chelmsford)**

One thing that did seem apparent was that individuals were often not aware of the support that is available in many areas, which is of concern as the new government's 'back to work' agenda gains momentum and there was a call in Chelmsford for:

New review of how system and support to move back to work works and how individuals can be supported to move through it.

Personalisation

One of the aims of the 'Big Conversation' was to establish if there were any early indicators which could guide commissioners in their decision making in the context of the transition to self directed support (SDS). The comments made in the well being workshops may give some ideas on how people might wish to use an Individual Budget but there were also comments made specifically about the personalisation agenda.

Some people were aware of the possibilities of SDS:

**There was a discussion around funding and that acute hospital care is expensive. The group spoke about direct payments (now Self Directed Support) and what services might be purchased – attending a fitness centre, paying for petrol to attend support group meetings – even buying a dog!
(Chelmsford)**

And a few seemed positive:

Direct payments are good because my son can go out with support and I get a break. (Southend)

Direct Payments are really good, but are only possible if the service user is in touch with secondary mental health services / a named mental health professional (Colchester)

But the majority of comments were either related to the barriers involved or seemed hostile to the principle:

The Direct Payments / Personal / Individual Budgets system needs to be streamlined - more accessible (Colchester)

Most people using The Haven do not have contact with a Care Co-ordinator / named mental health professional. Therefore, access to Direct Payments can be difficult. Also, it proves to be difficult to get a bus pass / freedom pass without a Social Worker (Colchester)

Trying to access individual budgets is a nightmare – because of the barriers (Colchester)

Services can be very secretive. One group member who wanted an individual budget found that it had to go to this panel and that panel – there was a prolonged process and they would not tell him the results.

Openness and transparency are important.

Professionals also do not believe you have a mind. They should not be ruling out something that you want on the basis that it is 'a whim'. (Basildon)

There was a general discussion around personalisation. Most seemed to feel that they are pushing to put personalisation on people and it wasn't something they wanted.

In fact some viewed Thurrock's relatively late start on Individual Budgets as a positive move to protect their service users and they considered themselves lucky that they didn't live in Essex where everyone was being forced to have one and they didn't have a choice! (Thurrock)

Widening Participation - Voices of Seldom Heard Groups

We are grateful to REASON, the Community Development Worker Service in South Essex for their assistance in facilitating the involvement of members of BME communities and to a CDW from Mid Essex who brought along a Chinese service user and we would also like to thank the translators who helped those who do not speak English to have a voice

The group in Thurrock were mainly, though not exclusively, women from India and Pakistan – most of them were not fluent in English.

They highlighted the need for:

- More translators for appointments but also the crucial importance of ensuring that written communications are in their own language
- Culturally appropriate services in hospitals but also in the community – talking therapies for example should pay attention to cultural gender issues

Like their counterparts in majority groups they also valued group activities and peer support opportunities. But they also highlighted their need for language courses in order to learn English to combat social exclusion and reduce their dependence on translators. They were keen to access training, employment support and talking therapies in their own language.

The groups in Southend seemed to be mainly males from the Balkans and North Africa and females from Southern Europe. They highlighted problems that asylum seekers face when trying to access services. They also raised issues related to translators and felt strongly that services in their area not only had little cultural awareness but compounded the problem by being reluctant to work in cooperation with the CDW service and learn from their expertise.

The Chinese service user who worked with a translator in Chelmsford graphically illustrated the severe anxieties which can be rooted in an inability to speak the language of the professionals who are working with you:

There are problems if you don't speak English. I've found it frightening ... As a non English speaker has experienced prejudice, would like equality. e.g. feels people come to criticise when she has done what she thought was right, rather than to help her understand what is expected of her. Opportunity to have a chance to talk to people who understand is very important. (Chelmsford)

But she was able to share a positive achievement:

Independence and living on my own has been the best thing – it is building me up because I have a sense of achievement. (Chelmsford)

Accommodation Issues

In Colchester a group of service users, who used the services of a specialist provider for people with personality disorder, spent some time talking about issues related to the provision of accommodation. They flagged up the importance of smooth transitions from hospital to the community:

Need practical help and support to do things at home. Practical skills workshops like cooking, painting & decorating, building, computers, etc.

Outreach is really important ~ having someone to help you settle at home and develop your daily living skills. Moving to independent living can be traumatic without support. This could then lead on to having Direct Payments so people can choose the type of support they need

And the need for mental health awareness for housing staff:

Housing staff need training in respect of mental health issues as poor housing can cost lives! (The Council needs to be both more flexible and supportive)

More floating support is needed

They also make the point that:

If you have drug and / or alcohol problems, it's no good being detoxed, getting help and then being sent back to the same location where you were drinking and / or using drugs

SUMMARY AND CONCLUSION

Individuals involved in the Service User Reference Group who worked alongside the MIME team helped to identify themes coming out of the consultation events. They also highlighted the importance of Commissioners responding to the consultation. Following discussions they decided that in order to emphasise the importance of feedback they would help to frame the final section of the report as a series of questions based on the themes they had identified.

They argued that service users and carers have set clear priorities for the issues which they think should inform commissioning in the future and they are now inviting Commissioners to reflect on the suggestions made in the report and provide feedback in line with the commitment they made at the beginning of each event to listen to what service users and carers say and report back on how their views have informed commissioning decisions.

Questions

1. What steps can commissioners take to address service user calls for the provision of more opportunities to access peer support?

When thinking about this issue, commissioners might wish to consider how they might support the development of **user led peer support groups**. But it is also related to the benefits many service users gain from volunteering. There have been consistent calls across all our consultations for support for volunteering within provider organisations. Many service users with experience of using secondary services believe that they have a valuable contribution to make in terms of providing information from a user perspective to service users and carers who are new to the system.

2. How might commissioners encourage service providers and training bodies to ensure that all staff working in mental health services have good listening skills?

This is one of the most frequently reported requests. The fact that similar calls are made by other client groups involved in social work training for example would seem to suggest that there is a gap in training which impacts on many professionals' ability to build trusting and therapeutic relationships with the people they provide a service for. Service users consistently suggest that they should be involved in training professionals.

3. How do commissioners intend to address the strong call for community services to be offered in local generic centres close to home?

Many service users who are at present supported by community mental health teams would prefer to access support for their mental health via their GP surgery. They offer a number of reasons:

- Addressing their physical and mental health needs in the same venue would minimise the risk of either one being prioritised at the expense of the other and better enable the delivery of holistic care packages
- They suggest that having community psychiatric nurses in local surgeries would help to support those GPs who lack expertise in mental health issues which is particularly important in the context of the proposed new commissioning structure
- Staff with mental health expertise in surgeries would also help to reduce the amount of time service users have to wait for appropriate help when they first present and might also prevent costly inappropriate referrals to secondary services which cause unnecessary delays for service users
- Being able to access support in their local surgery would minimise the amount of time service users need to spend in buildings owned by specialist mental health providers which they suggest would save money and reduce the stigma attached to 'mental health'
- In many cases it would reduce the time and cost of travel to specialist centres which is an important factor particularly in rural and coastal areas

One of the most frequent arguments against the suggestion is that GP surgeries have limited space but service users suggest that there are times in the day when consulting rooms are not being used and allowing those rooms to be used for other purposes would be cost effective.

4. What can commissioners do to improve the information available to service users and carers?

Both service users and carers say that the provision of information on conditions, treatment options and services at all levels of mental health service provision is patchy. Although there are some examples of good practice services need to expand the variety of formats they use to disseminate information and monitor organisations' performance in this area. Some service users have good IT skills but many still prefer paper based information and a significant number find reading difficult for a number of reasons:

- Limited literacy skills
- Difficulties in concentration caused by medication
- English is not their first language.

Suggestions were made about creative solutions involving audio visual aids and providing training to improve literacy, language and IT skills. Several calls were made during the consultation for the provision of **one stop shops/recovery/reablement centres** where service users in a particular locality can go to acquire information not only on conditions, treatment options and services but also on benefits, housing, training and employment support.

Service users, particularly in younger age groups, suggest that services could use the opportunities provided by modern technology to develop cost effective and innovative developments in service provision.

5. How can commissioners help to address the issue of poor communication between different agencies offering support – including health, social care, housing and welfare benefits?

Although there were some good examples of services working well together there were far more of weaknesses in interagency communication which can result in

- Poor experiences for service users as they move along pathways and make transitions into new services.
- Difficulties in identifying gaps in service provision
- Costly duplication

6. What can commissioners do to promote the employment of an increased number of people with personal experience of mental ill health in provider organisations?

Service users and to a lesser extent carers have consistently suggested that the only way to embed recovery approaches in all levels of service provision is to employ more service user/survivors in services. They suggest that this would be a cost effective solution to a variety of issues such as high staff turnover and a perceived lack of respect from professionals. They suggest that both staff and service users have much to learn from working together. They also assert that where deficiencies in training have been highlighted such as communication skills and GPs' lack of knowledge around mental health, service users should be involved in helping to devise, deliver and assess training.

7. How can commissioners improve services users' ability to access talking therapies?

As mentioned in the report service users consistently advocate for improved access to a variety of talking therapies and highlight its role in preventing relapse. Many secondary care service users welcome the added help that IAPT has brought to individuals in primary care but think that it does not meet the complex needs of those with more serious conditions who may need longer term therapy.

8. What plans have commissioners to continue to support the development of user and carer involvement in mental health commissioning?

A significant number of service users and carers who attended events identified involvement activities as one of the activities they felt supported their wellbeing. The majority of participants welcome the opportunities provided by MIME but some advocate for more service users on decision making bodies.

9. Service users have highlighted the importance of social support. How might commissioners encourage Trusts through their partnership arrangements to give more prominence to social models of service delivery?

In all our consultations service users have spoken most about what they see as 'quality of life' issues. Like the rest of the population they want something meaningful to do

during the day. For some it might be the range of activities identified in the wellbeing section, for others who are ready to move back towards working it might be more targeted activities like training, volunteering or support to get a job.

Many service users are ready for support to access universal services in the community but some prefer the 'safety' provided by group activities specifically for service users. In terms of maintaining their wellbeing they look either to each other and ask for peer support or to a counsellor or psychotherapist to help them understand and self manage. They do not ask for more frequent appointments to see a nurse or psychiatrist.

10. How can commissioners encourage provider organisations to widen the involvement of service users in risk management?

Maintaining autonomy throughout their journey is important to service users. They value choice and a voice in their care/recovery plans. This autonomy and choice is often compromised when they experience a crisis. Service users in every session talked of problems in accessing help when they experience what they perceive as a crisis. For whatever reason the crisis teams are not meeting that need. Service users and those working with them in the community need a clear pathway that they understand and which is available when they need it.

For those whose conditions are subject to periodic crises they need the opportunity to co-construct personal safety plans/advance directives so that they have a voice at a time when they are not able to express it.

11. How can commissioners encourage the development of cultural awareness in provider organisations?

Participants from BME communities who attended events clearly valued services provided by Community Development Workers but all quoted difficulties in accessing mainstream services for those whose first language is not English. They were also disappointed by clinicians reluctance to take advantage of the cultural awareness expertise of the CDW service.

12. How might commissioners address the problems experienced by service users when service providers change?

Some service users report long waits for services when a new provider wins a contract and can take several months to implement a service.

APPENDIX A



Making Involvement Matter in Essex

Consultation Proposal

Background

Aims

Methods

Timeline

Reports

Background

This proposal draws on the ideas generated in the planning meeting with Commissioners on 9th March and the partnership planning meeting on 15th March.

Aim

With the advent of a new policy framework (New Horizons 2009) for mental health and the continuing challenging economic climate there is a need for a wide ranging service redesign. MIME's approach to these twin policy drivers is to view it as an opportunity to engender a debate amongst all the stakeholders about the best way to manage the change. The Department of Health clearly wishes to involve clinicians and staff generally in discussions around change and there is an equal commitment to involving people who use services and those who care for them.

Essex is well placed to become an example of best practice in the area of user involvement because Commissioners have already undertaken the groundwork for a genuine consultation by setting up the MIME project.

The partnership is committed to a robust and genuine process which will give people who use services in Essex and their carers the opportunity to influence the direction and pace of change within the parameters mentioned above. The project has already identified factors which we will need to take into account when planning the consultation.

The first emerged in the JSNA consultation as a comment 'they don't manage change well' from a service user perspective. The second comes across clearly in visits. Outlying areas of Essex, Southend and Thurrock perceive themselves as neglected when it comes to service provision and the opportunity to be consulted. The third was a factor in the decision to commission MIME. Previous attempts at consultation often only attracted attention and participation from a relatively small group of service users who have often been described as 'the usual suspects.' They tended to focus mainly on existing services or proposed new ones.

Looked at from an alternative perspective, it could be argued that

- People who use services are always anxious when change is mentioned.
- There are geographical and demographic reasons for differences in service provision and ability to consult.
- It is not easy to engage people in genuine discussions, particularly when they are unwell.
- There have been initiatives to engage with seldom heard groups

All these may be true but to accept them could lead to paralysis and inertia. Attempting to address them will be a measure and symbol of Commissioners' commitment to genuine involvement from a service user perspective.

Proposal

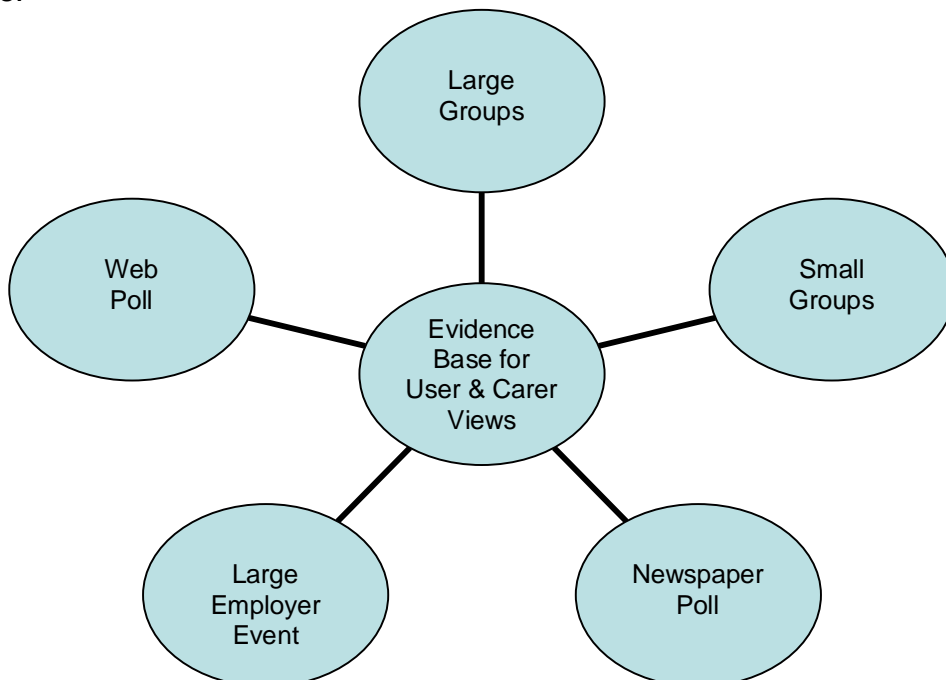
In order to engender as wide an engagement as possible and also to illustrate our commitment to best practice we suggest the following:

Service User Reference Group

Although the partnership already has a number of service users employed within the team both at ARU and ARW, we suggest the setting up of a small service user reference group (approx 8) to work alongside the team to influence and engage with process, methods, delivery, analysis and reporting. We would suggest involving people who use services and carers from the beginning is essential to the credibility and value of the consultation. The group could also be involved in writing up a report on how we organised the consultation for inclusion in an article in a professional journal and/or conference presentation with the aim of disseminating good practice.

Methods

The new policy agenda appears to signal a move away from talking in terms of mental health, which is rooted in traditional services and regrettably linked to stigma and discrimination, towards a focus on wellbeing which prioritises prevention, promoting recovery and social inclusion. This would seem to indicate the need for a wide ranging consultation which engages both existing people who use specialist mental health services, those who are supported in primary care and those individuals who have developed the skills to manage their own well being. All three groups and their carers have something to contribute to the debate on service redesign. Therefore we propose a diverse consultation which hopefully will succeed in targeting a wide range of individuals:



Large Consultations

These would be sited in Chelmsford on 8th May and Colchester on 19th June. We chose Saturdays because we felt it would be likely to attract a wider audience. St Cedds Hall in The Chapter House in Chelmsford, which can accommodate 80 café style is available for the 8th May and is holding it for us pending a booking in the near future. We are still attempting to identify a venue in Colchester but are hoping to secure the Quaker Meeting House. In order to attract attendance we are following up on the idea of offering something as well as asking. Lunch will help but we are also investigating the possibility of taster sessions of complementary therapies. We have a commitment for the 8th May from a lecturer who teaches complementary therapies at ARU for 8th and are hoping for a similar booking for Colchester.

Small consultations

In order to facilitate the inclusion of those who live in areas of lighter population we would like to offer smaller groups up to 20 people – 2 in W Essex because of the difficulties of transport and 1 each in Brentwood, Grays, Southend and either Clacton or Dovercourt/Harwich

Newspaper Poll

We will be advertising the events in local newspapers and thought of a large advertisement with details of all the methods of consultation with a few broad questions which can be torn off and answered and sent via our freepost address. This might capture those who may have used services but not disclosed it to friends and colleagues and would not dream of attending an event.

Large employers

As we are seeking broad views on wellbeing as well as data which draws on people's experience of using services, targeting a large group in the local community may help to give breadth to the consultation. We are suggesting a wellbeing event where we could perhaps give information and seek it by having a stand, with facilitators, perhaps in a staff canteen.

Web Poll

This may engage people who would not wish to give time to attend a group, were disinterested in writing things down, finding an envelope and going to a post box. They could complete it in a few minutes. It might also target socially isolated people who would find a group difficult to engage with.

We hope that using a variety of methods will help to provide data from a diverse range of individuals in terms of age, gender, race/culture, sexual orientation etc. We intend to consult with Community Development Workers for advice on engaging with the seldom heard groups they work with and will give consideration to enabling participation by addressing issues of accessibility in their widest sense.

Possible additional activities

We have not addressed the issue of the participation of people currently in hospital. We could take the view that some of the individuals that get involved in the activities we are proposing may have had recent experience of hospital. But if Commissioners feel strongly that we should have a separate opportunity to target this group then we would need to seek the cooperation of the trusts which could potentially take some time. The involvement of SE-SURG might facilitate negotiations with SEPT.

Timeline	April	May	June	July	Aug	Sep
Reference group						
Large Groups						
Small Groups						
Newspaper poll						
Web poll						
Employer mail shot						
Writing up						

Data Collection Analysis and Reports

In addition to partnership staff we would hope to involve service users:

- as facilitators and note takers
- in data inputting
- the reference group would be involved in development of questions, planning, reviewing reports and giving feedback

APPENDIX B

Comments related to Personalisation/Self Directed Support/Individual Budgets/Direct Payments. They are taken from facilitators' notes:

Colchester

There was a discussion about SDS and how secretive the process can be for the service user. 'I pay for my daughter to attend 2 classes a week, I have to pay for courses to attend ... it can be expensive (£400)

Most people using The Haven do not have contact with a Care Co-ordinator / named mental health professional. Therefore, access to "Direct Payments" can be difficult. Also, it proves to be difficult to get a bus pass / freedom pass without a Social Worker

"Direct Payments" are really good, but are only possible if the service user is in touch with secondary mental health services / a named mental health professional

The “Direct Payments” / “Personal / Individual Budgets” system needs to be streamlined
- more accessible

Chelmsford

Complementary therapies – acupuncture, alternative therapies, back massage etc

Weekly massage and a facial is very beneficial but expensive. Finance can be a problem in accessing some therapies

There was a discussion around funding and that acute hospital care is expensive. The group spoke about direct payments (now Self Directed Support) and what ‘services’ might be purchased – attending a fitness centre, paying for petrol to attend support group meetings – even buying a dog!

Financial support to access things which support wellbeing e.g. social interaction, exercise, hobbies etc- Comment that money seems to be available for carers for respite etc why not for service users?

Although everyone should be treated the same, **individual care** is very important.

I’ve looked into exercise – *I prefer it to therapies* – but I don’t want to be solitary. A gym would be good but it’s *far* too expensive. A group would be good. It’s a huge thing that is missing from services. An introduction to exercise would be a good thing.

Thurrock

There was a general discussion around ‘personalisation’. Most seemed to feel that ‘they are pushing to put personalisation on people’ and it wasn’t something they wanted. Few around the table appeared to have any awareness of the potential of personalisation or viewed it in a positive way.

When invited to think how they might use a personal budget some people said ‘I would buy a car so I can go out and not have to rely on a friend to take me’ Another said I would use it to ‘access transport so I can go to AA meetings.’ Transport to access a variety of services was a popular option.

In relation to support for training - Once you get to a certain level you can’t get help

Southend

Direct payments are good because my son can go out with support and I get a break.

Basildon

Services can be very ‘secretive’. One group member who wanted an individual budget found that it had to go to ‘this panel and that panel’ – there was a prolonged process and they would not tell him the results.

Openness and transparency are important.

Professionals also do not believe you have a mind. They should not be ruling out something that you want on the basis that it is 'a whim'.

Make personalised budgets easier and more transparent.

Like college courses but I can't afford them

Professionals need to focus on positives eg say that you will get better over time. There needs to be a focus on strengths and abilities, not just risk in a personalisation approach.

Trying to access individual budgets 'is a nightmare' – because of the barriers

Clacton

Being listened to and being able to access Support Workers as people sometimes need practical day-to-day support

One participant mentioned how much he needs a support worker eg to go out with him for a drink and talk and he can't get one – he finds it hard to put across his needs, finds it hard to articulate things which makes it difficult to explain this. He does have a social worker but.... He just feels so frustrated. – One or two other people suggesting that you clam up anyway if a worker doesn't listen

Professionals need to listen. You cannot get heard and so end up accepting something because it is the only service offered. Then you have to come back and say it didn't work when it wasn't what was needed to start with. What is needed is personalisation

Colchester

Flexibility – 'one size' does not fit all. Look at the person as an individual. Funding for other activities – not just a gym, e.g. Tai Chi
Have a 'credit facility' so you can then choose how to spend it

There was a discussion about SDS and how secretive the process can be for the service user

I pay for my daughter to attend 2 x classes a week

I have to pay for courses to attend; it can be expensive (£400)

My daughter does not want anymore services. How can we help her to become more integrated she is 'on the fringe'. Something like the Prince's Trust would have helped her. The best part of her can cope. She doesn't want to go to a centre of people the same/similar as herself. She needs a 'professional friend', something to get up for. There is an 'insight' problem, she could do with a 'buddy' system

Outreach is really important ~ having someone to help you settle at home and develop your daily living skills. Moving to independent living can be traumatic without support. This could then lead on to having "Direct Payments" so people can choose the type of support they need.