



Making Involvement Matter in Essex

EVALUATION OF THE MIME PROJECT

USER INVOLVEMENT IN MENTAL HEALTH COMMISSIONING

**With thanks to the service user members of the MIME team who
contributed to this evaluation**

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1. INTRODUCTION

Commissioners made a request at their meeting with the MIME team on 5th August 2011 for an evaluation of the project to date, to be presented at the next commissioners' meeting. It was agreed that commissioners would undertake their own evaluation based on their monitoring information, reports received and experience of engaging with the work of MIME. A suggestion was made that an evaluation by an independent service user organisation would enhance the credibility and integrity of the evaluation but commissioners did not consider it essential and it was agreed that the project would undertake its own evaluation.

Following a training session arranged by Essex County Council on 'Outcomes Based Accountability' (Friedman, 2009), which was attended by the Partnership Coordinator and four service user members of the project a decision was made to use the tool as a framework for the evaluation as the simplicity of language inherent in the model and shared understanding generated by the joint training would enable genuine involvement of service user members in the evaluation process. Before describing the evaluation methods in more detail the following section provides information about the background against which the MIME project was developed in order to provide a context for the evaluation.

2. BACKGROUND TO THE MIME PROJECT

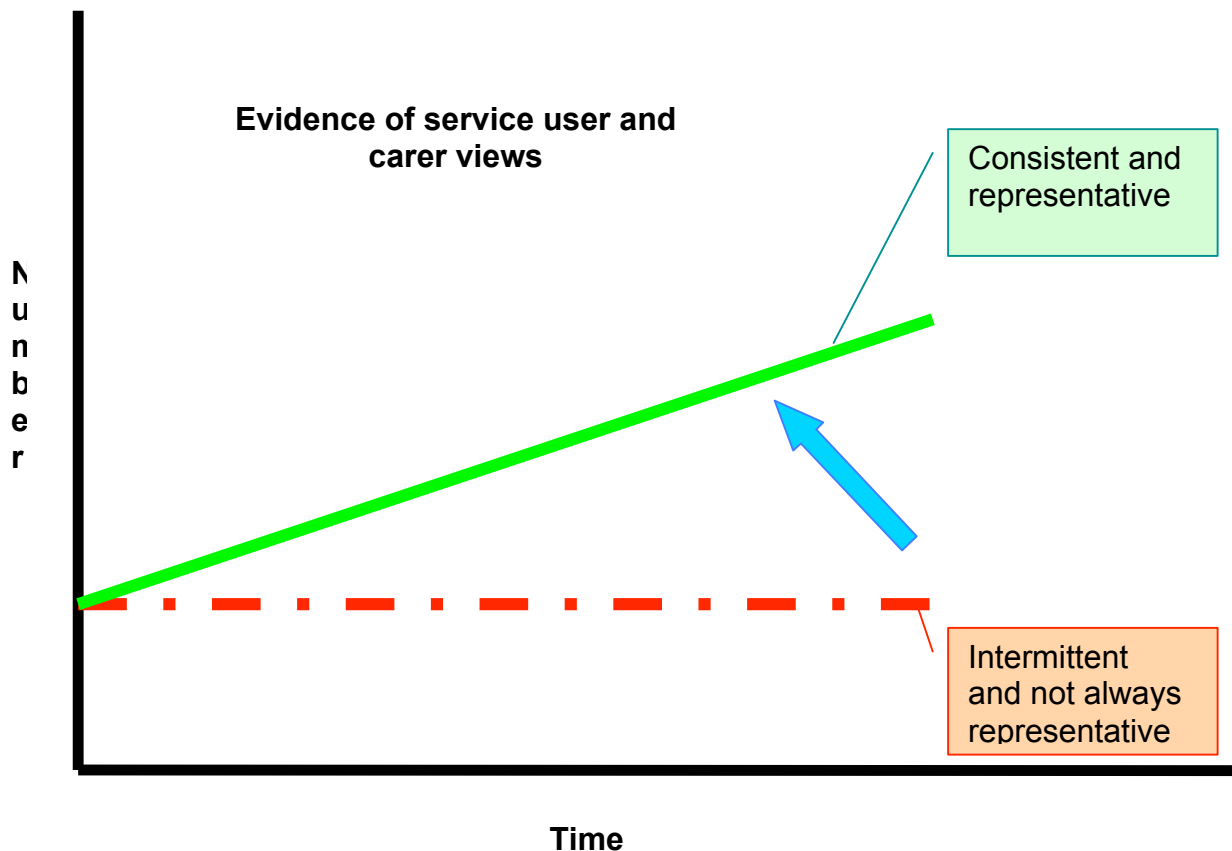
The Department of Health requires commissioners in both health and social care to demonstrate that they take into account the views of the populations they have a responsibility to provide services for. In addressing this need in the past, commissioners have adopted a number of strategies, including funding service user forums and conducting or commissioning consultations and evaluations on particular topics.

Some service users have told us that they appreciated the forums as they provided opportunities to get together which met social and peer support needs as well as providing the opportunity to raise concerns about the services they used. These concerns were often taken up directly with provider organisations. While this could enable provider organisations to respond to concerns informally rather than processing them as formal complaints, it did not always provide commissioners with consistent data on service user and carer views. The number of service users and carers involved in consultations was sometimes disappointing and on occasion they struggled to engage with seldom heard groups. Evaluations of particular services did reach reasonable numbers of people, but there was still an identified need for ongoing, consistent data.

Therefore the drivers to strengthen service user and carer involvement in commissioning included:

- The need to provide ongoing, consistent evidence of user and carer views
- A desire to increase the numbers of service users and carers engaging in involvement activities
- An aspiration to build on previous achievements through collaboration and constructive dialogue between commissioners and service users and carers in Essex, Thurrock and Southend.

Looked at through the lens of Friedman's model, a 'turning the curve exercise' was needed to improve the flow of service user and carer views:



Following a competitive tender process, the contract to deliver what became the MIME project was awarded to a partnership between Anglia Ruskin University and ARW Mental Health Training and Consultancy, a service user and carer led organisation with previous experience of working with some of the Anglia Ruskin team. The partnership brought together service user experience within both partner organisations, together with the specific skills of individual members in research, training, consultation and evaluation. A Partnership Coordinator with experience of service use, project management, community engagement and counselling skills was appointed to facilitate the work of the project, with support from a Partnership Administrator.

Towards the beginning of the second year of the project, the MIME team agreed that a Service User Advisory Group (SUAG - formerly the Big Conversation Reference Group – see page 13) would be invited to provide additional representation alongside the service user and carer members of the MIME Steering Group.

All those involved in setting up the project were aware that it would provide a wide range of challenges. In particular, past experiences of involvement activities made team members aware of the challenges of engaging representative numbers of service users, ensuring dialogue was honest and open in order to foster trust between all stakeholder groups, and being forward looking rather than focusing on the past. It was recognised that involvement needed to be genuine and not tokenistic, and that training and support for different stakeholder groups would be necessary to achieve this.

It was felt that networking would be crucial to the success of the project and the following organisations were identified by commissioners as key partners:

- Local Involvement Networks (LINKs)
- Community Development Workers
- Service user and carer groups and forums.

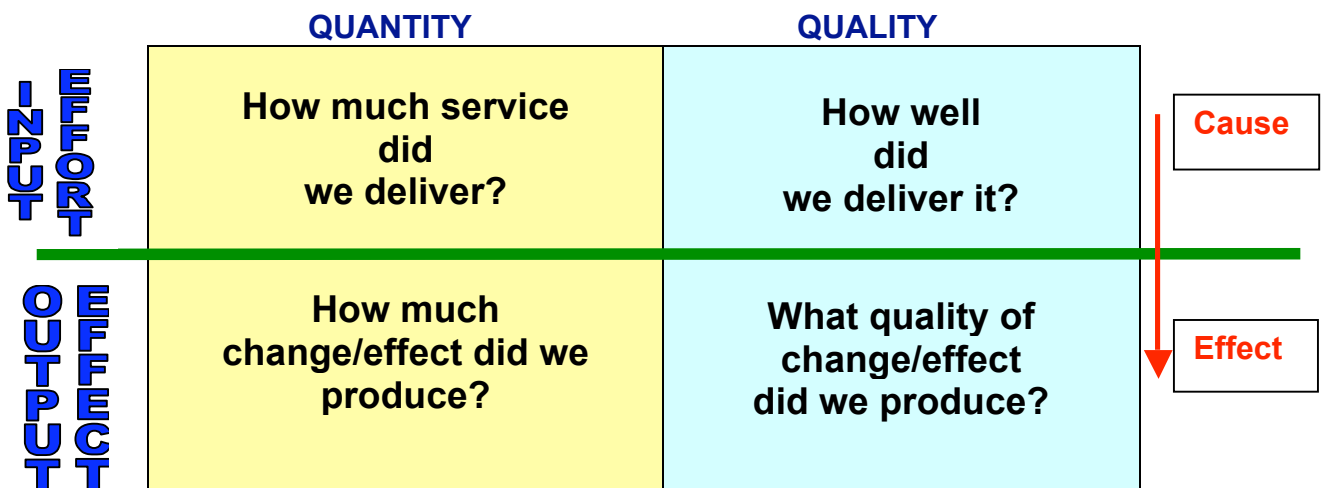
3. EVALUATION METHODS

The evaluation was led by the MIME Partnership Co-ordinator working with the Service User Advisory Group (SUAG). This section first outlines the evaluation process. Information is then provided about the way in which the Outcomes Based Assessment model was applied.

3.1 Evaluation process

The first stage of the evaluation involved:

- Explaining the Outcomes Based Assessment process to members of the SUAG and the MIME steering group (see diagram below)
- Asking SUAG members to provide qualitative data on their experience of engaging with MIME.



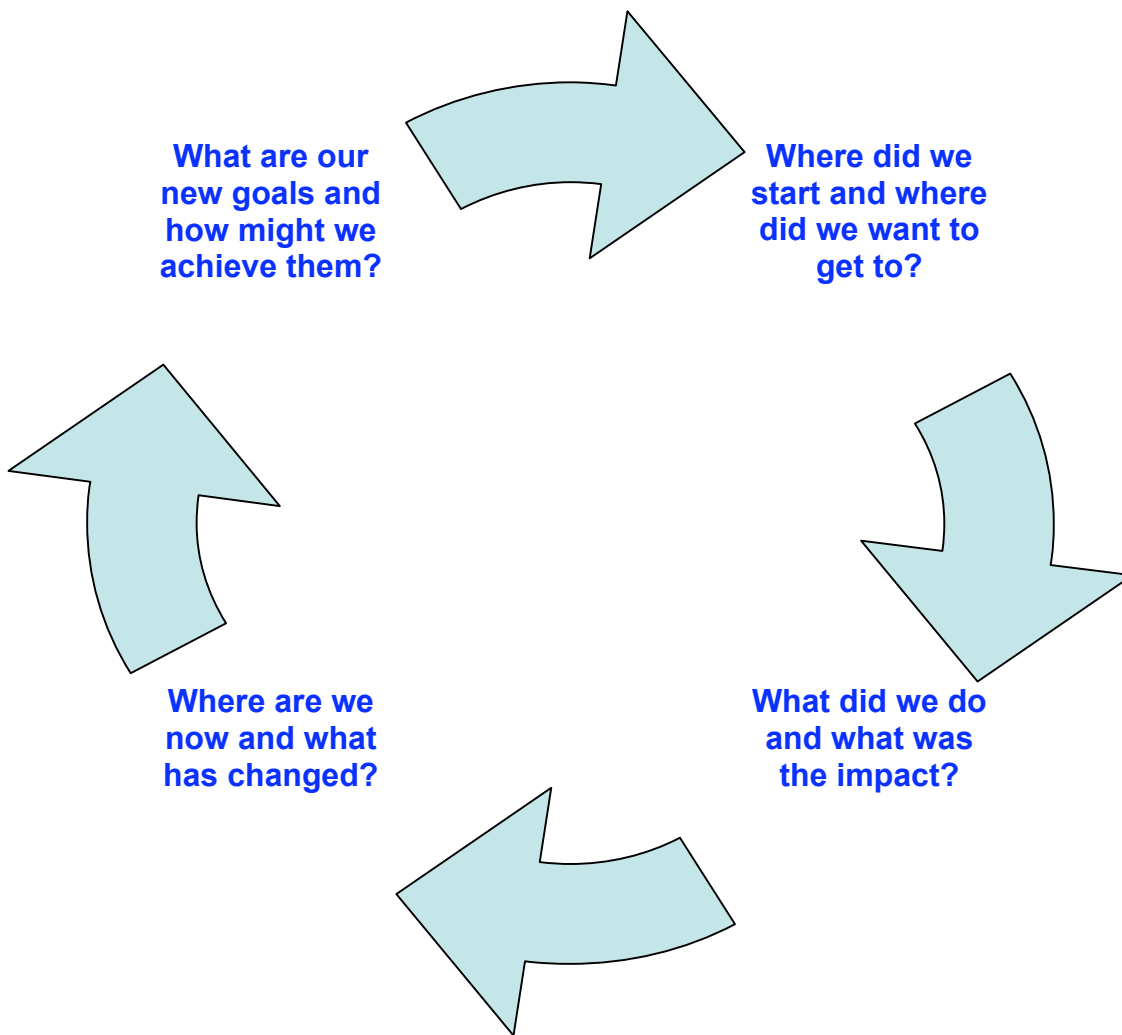
The second stage involved identifying:

- The data sources which could provide information
- Relevant outcomes
- Indicators
- Performance measures.

The third stage was:

- Using the data collected to populate the outcomes framework
- Assessing the quantity and quality of what has been delivered using Friedman's model.

The fourth stage consisted of a reflective cycle, depicted on the next page, to assist with planning for the future (Schön, 1983).



Following feedback from commissioners on a first draft of this report, the final stage consisted of revising the report with input from other members of the Anglia Ruskin/ARW team (MIME Steering Group). The revisions have been made with the aim of keeping the integrity of service users' views and comments at the heart of the report while addressing commissioners' feedback.

The first draft had concluded with recommendations from SUAG members. Because these were dealt with when the report was presented at the commissioners' meeting on 28th October 2011 they have not been included in the main body of the revised report but have been retained as an appendix to this draft so that a record of SUAG members' views remains. This is not intended as in any way dismissive of the views expressed, but simply reflects the fact that commissioners have already had the opportunity to respond to them. The sustainability of the valued role played by SUAG and other MIME members is an important focus during this final year of the project.

3.2 Applying the Outcomes Based Assessment model to MIME

Population

The first stage of Friedman's model is defining the population that the intervention is for and in the case of the MIME project commissioners identified adults of working age

requiring support for mental health/wellbeing issues and their carers in the areas for whom the following bodies have responsibility:

- Essex County Council
- Thurrock and Southend unitary authorities
- The PCT clusters of North and South Essex.

Outcomes

The desired outcome was that the views of people who use services and their carers inform the mental health commissioning strategy in Essex, Thurrock and Southend. The aim was that MIME would support a wider group of service users than was previously the case to develop the confidence and skills they would need to engage with commissioners and enable other service users' views to be heard by carrying out research and consultations for commissioners.

Indicators

Consideration of indicators involves asking the simple question, 'how would commissioners know that the project had achieved the outcomes identified above?' We would suggest that the following are key indicators:

1. Commissioners have an evidence base of service user and carer views to inform commissioning strategies during the life of the MIME project and potentially into the future.
2. Commissioners, service users and carers have the skills to engage in constructive discussions around service planning and delivery.
3. Service users and carers have the skills to carry out future research, consultation and evaluation.
4. User and carer involvement in mental health commissioning involves a wide range of participants including those from seldom-heard groups.
5. Commissioners can demonstrate to service users and carers that their views have informed commissioning decisions.

Performance measures

The final stage in designing the evaluation was to identify key factors commissioners could use to measure the performance of the project. We have used the performance criteria outlined in our contract to identify appropriate factors, linked to the indicators listed above as shown in column 3 of the table on the next page. The relevant sections of this report are identified in column 4.

In the following section the factors listed above are used to evaluate MIME's progress to date in terms of the quantity aspect of the Outcomes Based Assessment model before going on to examine quality and impact. Some evidence relating to Indicator 5 is considered in relation to quality and impact. In addition, it is anticipated that commissioners will provide feedback relating to this indicator in their own evaluation of MIME and service users and carers will be particularly interested to learn how their views have shaped decision-making.

Factors for performance measurement		Indicators	Section
Involvement needs to be:	Representative of the population	4	4.1 (pages 7-10)
	Relevant	1, 4	
	Data driven	1	
Involvement should empower & support service users through:	Training and support to enable service users to engage in relevant activities	2, 3	4.2 (pages 10-12)
	Health promotion and anti stigma activities	2	
	Building peer support capacity	2	
The service provided should include:	Representation at meetings	1	4.3 (pages 12-14)
	Lay assessing	1	
	Data collection via consultations, research and evaluation	1	
	Reports and presentations	1	
	Developing a website	1	

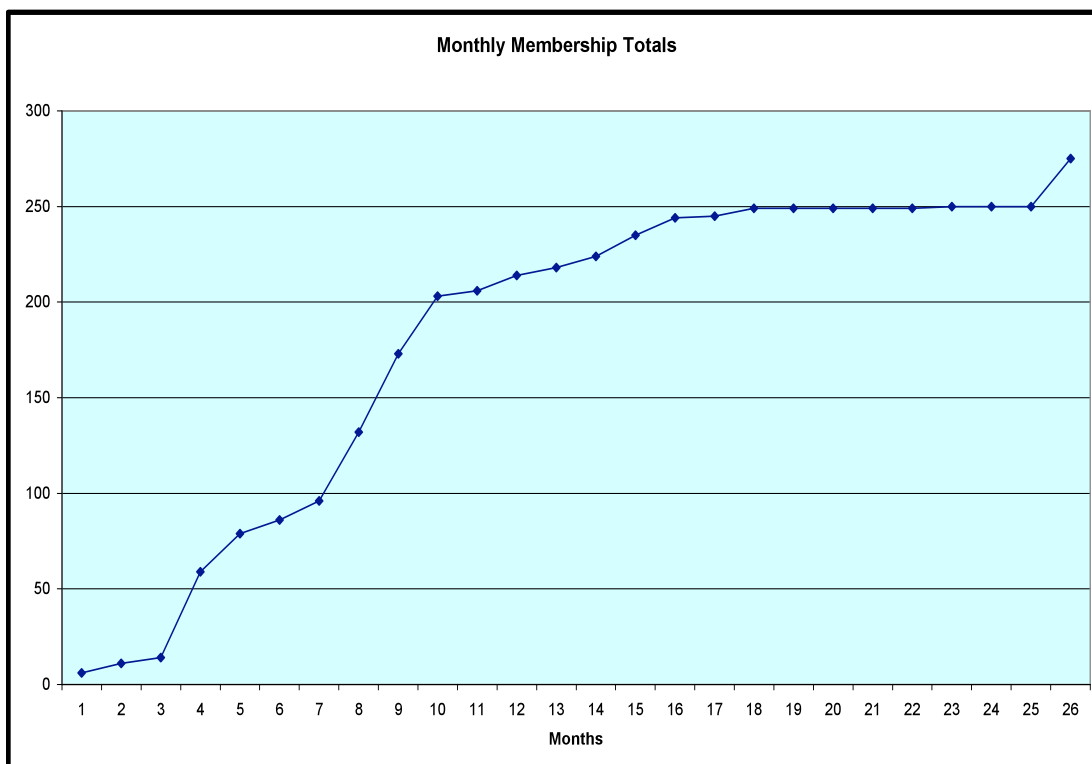
4. HOW MUCH HAS MIME DELIVERED?

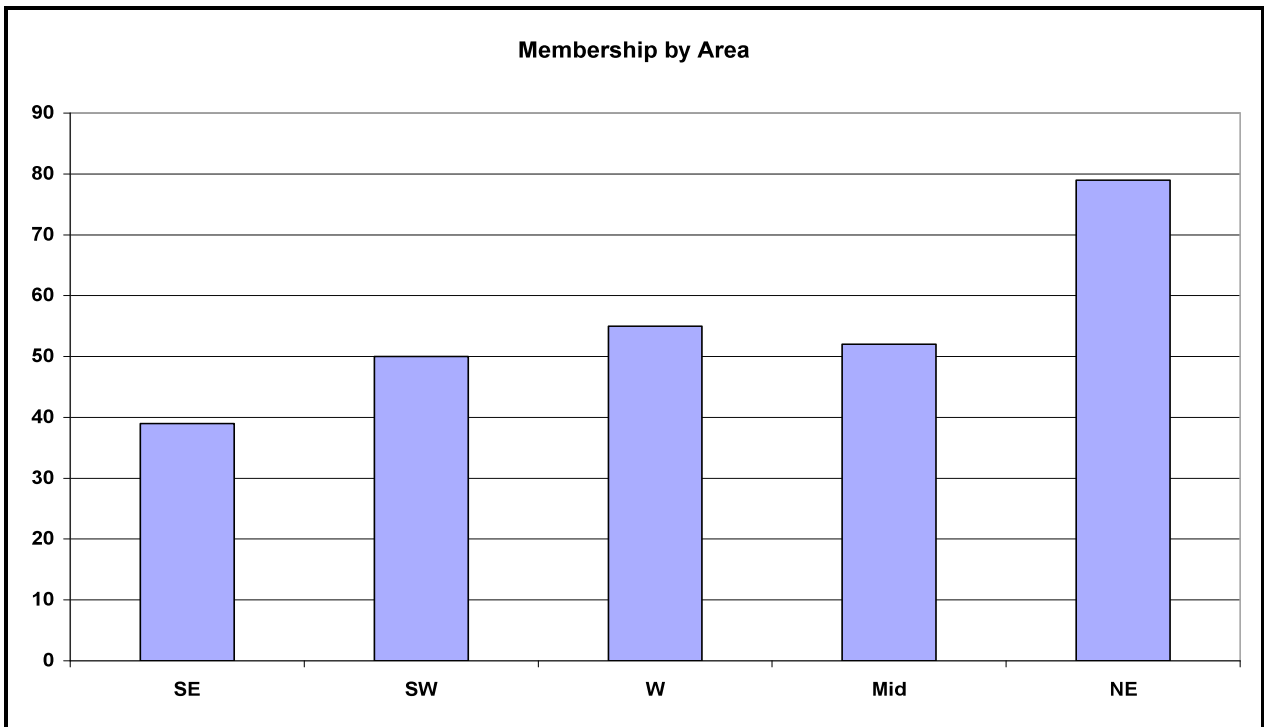
Evidence of MIME's performance is presented below in relation to the performance criteria and factors listed on the previous page.

4.1 Involvement should be representative, relevant and data driven

Representation

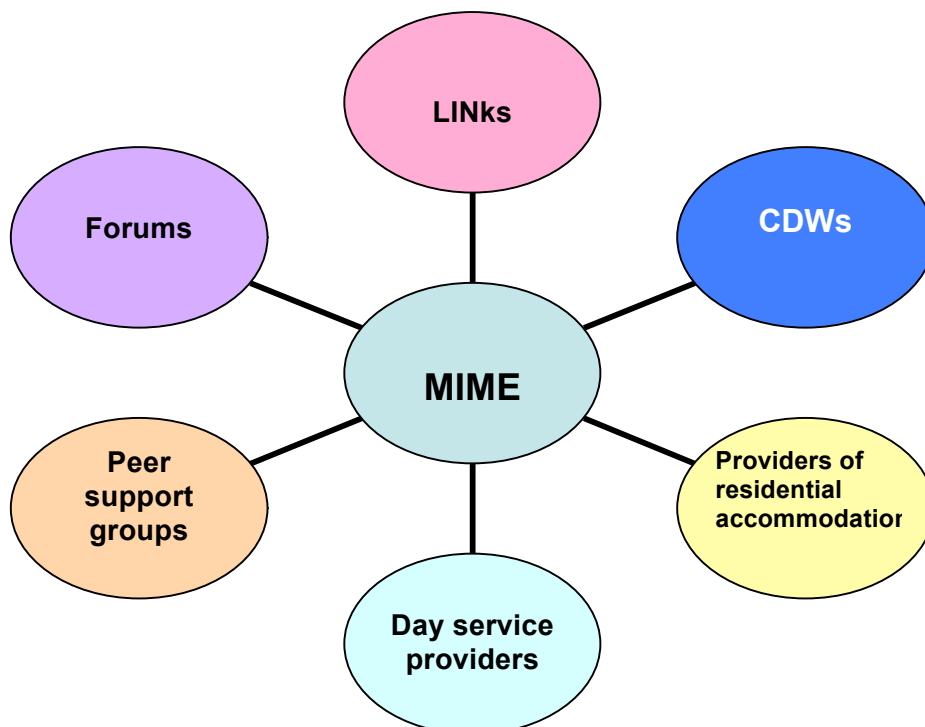
The following charts show our recruitment trajectory and the geographical spread of membership.





The charts illustrate that we are meeting our target of increasing the number of service users and carers participating in involvement activities. We acquired a few members from the mail shot to individuals who had engaged with the previous provider, although a significant number of individuals on their database were staff working in provider organisations. However, the vast majority of MIME members have been recruited via:

- Visits to service user groups, forums and provider organisations
- Publicity generated by articles in magazines, advertisements for events, training sessions and participation in anti-stigma activities
- Extensive networking as depicted below.



We would particularly highlight our success in engaging individuals from groups which are traditionally under represented in involvement activities:

- BME communities (our ethnic monitoring records 65 attendances from non White British participants in consultations and training¹)
- Refugees and asylum seekers
- People who have used forensic services
- Individuals with experience of using residential accommodation
- People who are lesbian, gay, bi-sexual or transgender (LGBT)
- Individuals with physical disabilities as well as mental health conditions
- Younger service users
- Participants with dual diagnosis – both mental health and learning disability, and mental health and substance misuse.

The approach we adopt is one of enlisting support from organisations which have knowledge and experience of the particular client group and we then seek to gain the trust of the service users they work with. It has at times involved us in adapting the way we work to fit with individuals or groups. It has been necessary to work out of hours at times and to go to some lengths to enable the participation of as many people as possible. For example:

- Visiting a pub in Harwich on a dark snowy night in December to meet members of a peer support group
- Negotiating with caterers at a training venue to provide an Indian buffet
- Talking to individuals on a 1:1 basis at the end of consultation meetings if they were unable to contribute in a group
- Ensuring that venues have access for people with disabilities
- Providing translators
- Standing up to take notes from a participant who was unable to sit or stay in a group for long as she was recovering from a recent operation.

As many of the people we work with are vulnerable and can at times attend activities when they are quite unwell we have developed procedures to follow if an individual is clearly very distressed. We have also enlisted the support of the SUAG to develop ground rules for meetings as a way of coping with behaviour which can disrupt meetings.

We would like to recruit more members in South East Essex and with that in mind are in the process of negotiating visits to two projects in that area. We hope also to gain some new members as a result of visits to Panorama House for the recent day services evaluation.

We are especially grateful to voluntary sector agencies for publicising our activities² and to statutory agencies for facilitating some of our research activities³.

Relevance

Our contract highlights the importance of gathering data from relevant populations – that is from service users who have experience of the issue under review. As noted above, organisations which have knowledge and experience of particular client groups have helped us to achieve this in our research and consultation projects. In addition, our publicity for events clearly states the criteria for participation. For example when recruiting

individuals to attend our consultations on vocational support in North Essex our publicity included the following:

Are you

- Living in North Essex
- On CPA or were until recently
- Of working age

If you have not previously accessed support for vocational activities then we would like to hear your views. We are holding consultations ...

The overwhelming majority of our members have experience of using secondary mental health services. We are aware that commissioners increasingly have responsibility for promoting wellbeing in the wider population too, so we have used our anti-stigma activities to engage with the general public, as well as engaging with Time to Change events run by the two NHS mental health trusts. In 2010, we developed a questionnaire which our service user members used to generate conversations around wellbeing at events in County Hall and Basildon.

During our project focusing on vocational support services in North Essex, service users had highlighted concerns about employers' and training providers' awareness of their obligations to support staff with mental health conditions. In 2011, we therefore 'started at home' by enlisting the support of Anglia Ruskin University's student services for an event at the university. On this occasion our members, staff from the MIME team and the university's student counselling service used a questionnaire to generate conversations around the support staff and students would expect from an education provider or employer if they were to experience mental ill health. We also provided information on support that is available at the present time. We collected about 150 questionnaires which are in the process of analysis. We will share the results with commissioners and with Anglia Ruskin's human resources and student services departments.

Data driven

When working on projects we go to some lengths to discuss and clarify with commissioners what they are seeking to discover. Then with service user members we develop questions which are designed to provide the specific information being sought. Questions can be used in the form of questionnaires or as prompts to discussions in consultations or 1:1 interviews. Following analysis, again with help from service user members, a report is compiled. This process is given strength and credibility by the support provided by research members of the team.

4.2 Involvement should be empowering and supportive

Training and support

A wide range of training and support has been developed, including initial confidence building and assertiveness training, a research skills module and bespoke research training, facilitation skills training and both individual and peer group support. Since the project began we have provided initial training sessions in Colchester, Chelmsford, Harlow, Southend, Clacton, and Grays, reaching approximately 45 members.

The sessions focus on confidence building and assertiveness skills. Further sessions have been requested in West and South East Essex which we hope to deliver this year as we have been offered free venues which will keep the costs to a minimum.

Five carers participating in a SEPT pilot took part in research skills training in the hope that they would form the basis of a MIME carer research group. Last summer we delivered a 4-day research skills module which has led to the setting up of a research group for North Essex which has already been involved in developing and testing the web survey we used for the evaluation of ECC-funded day services. About 20 people attended the sessions.

As we need facilitators for our consultations we have developed and delivered a training session specifically on facilitation which 12 people attended, four of whom went on to do a second session which gave them the opportunity to practice the skills they had learned. We subsequently delivered a specific session on facilitation for the day services evaluation which 12 people attended.

Offering training for specific tasks is a useful way of improving skills and ensuring the quality of the data collection we undertake. It is essential as a preparation for research tasks and we delivered a session to interviewers on the forensic services work stream.

We also respond to requests from service users for specific training and a session in Colchester on skills around participation in meetings was useful with four people attending.

Service users report that training in small groups with service user trainers is empowering and gives them the confidence to participate in a way they would find difficult in larger groups.

In terms of support, as mentioned above we offer individual packages depending on the skills and confidence of the person undertaking the task. We also have supervision sessions following meetings of the SUAG for individuals who have 'worked' on activities since the previous meeting. In addition, service user researchers who carry out interviews and facilitate focus groups receive specific support and supervision.

With regard to supporting our members to undertake activities which will give them useful experience and transferable skills should they feel ready to return to work, we advertise opportunities for free training in our newsletter and were pleased by a recent success when one of our members took advantage of training offered to individuals who have bilingual skills and were interested in completing advocacy training. She successfully completed the training.

Another member, who has been responsible for building the MIME website, was also able to take advantage of a course in how to deliver training which has opened up volunteering opportunities and will enhance his CV when he is ready for employment

Health promotion and anti-stigma activities

As mentioned on page 10 we engage with Time to Change events organised by both NHS mental health trusts, but we have also held our own events around World Mental Health Day. These have been useful in generating conversations around wellbeing and challenging stereotypes. They have also been helpful in building the confidence of service users to speak openly about mental ill health and thereby make their personal contribution to challenging stigma.

Undertaking these activities in a group and attending the SUAG offers a peer support opportunity which improves confidence and gives members a sense that they can make a difference, which is crucial in building self esteem and promoting social inclusion. They also report that it gives them a sense of being part of their communities.

We include web links to useful health promotion sites on our website and use the newsletter to:

- Pass on information about events put on by the NHS trusts
- Provide links to research and articles on wellbeing initiatives.

Building peer support capacity

Peer support opportunities are mentioned at almost every meeting we hold. They assumed greater importance in the minds of many service users and carers with the changes in day service provision and the reduction or phasing out of drop-in centres. Partly as a result of the strength of service user opinion on peer support expressed in our consultations, we were asked by commissioners to offer a presentation to voluntary sector day service providers as their contracts require them to support the development of peer support opportunities.

Discussions at the presentation showed that both commissioners and professionals seemed very interested in the self help aspect of peer support but less aware of service user preferences for the full range of peer support opportunities, which service users had highlighted in the Big Conversation and other consultations. Therefore we decided that a 1-day workshop at which the full range of activities associated in service users' minds with peer support could be explored. It also provided the opportunity to extend the training to staff from the NHS trusts. Feedback was very positive, with many participants pledging actions they would take as a result of information they had received at the workshop.

We also publicise information about the schemes which are available through bridge builders to provide financial support to the development of small self help groups. In this way we can raise awareness around peer support for both service users and staff in provider organisations.

4.3 Services provided

Representation at meetings

When commissioners were discussing the tender specification, representation at meetings was felt to be an important component of the service they required. Requests to meet this requirement most frequently take the form of an invitation to the Partnership Coordinator to attend.

This can be a useful way of providing an opportunity to discuss the relevance of service user involvement in a particular meeting and gain advice on what might be involved. Service user views as expressed through the work of MIME can also be fed through to participants at a meeting by the Partnership Coordinator.

In this way MIME has provided representation to:

- North and South Essex Partnership Boards

- North Essex Transformation Board
- South Essex Public Inquiry into how mental health and housing can cooperate better
- BME LIT
- Step Down Working group
- Outcomes Working Group
- Planning group for N Essex Networking event
- EGPC working group
- N Essex Community Review Steering Group
- Mental Health Commissioning Delivery Plan working group.

We also meet with consultants tasked with individual projects by commissioners in order to share the work we are doing and advise on service user involvement in their work if necessary. In that way we have fed into:

- JSNA working group
- Recovery Workforce Consultation
- Short Life Project
- ECC development of service user involvement policy.

We have also provided:

- Service user participants for staff interviews
- Service user representatives to sit on tender panels
- Responses to research enquiries when asked to do so by commissioners.

We respond to consultations and publicise opportunities for our members to give feedback on consultations and research projects by advertising them in our newsletter, for example:

- ECC Accommodation Strategy
- ECC Consultation on future of Healthwatch
- Thurrock Council Consultation on future of Healthwatch
- ECC Consultation on Healthwatch Executive
- ECC Consultation on SDS Support Planning Spec.
- NICE, Department of Health, National Improvement Partnership, Mind etc.

Lay assessing

When the project began we were asked to engage with ECC's quality and inspection department in order to provide service users to act as lay assessors. We advertised the opportunity in our Newsletter and several individuals expressed interest. We met with the team at ECC to discuss training, support and payment issues and committed to developing a training package in collaboration with the new members of staff they anticipated recruiting to cover what was for them a new venture as they had not previously been responsible for inspecting mental health residential accommodation.

However, there were delays in recruitment and although we have made contact with a new member of staff on the team we understand that intentions within the team have changed and it is unlikely that we will be required to pursue this work stream further at this time.

Data collection via consultations, research and evaluation

To date we have collected data for seven projects requested by commissioners:

1. A 'Big Conversation' consultation, aimed at seeking the views of service users and carers and the wider general public as a response to the potential need for service redesign engendered by a new policy framework for mental health and the continuing development of the personalisation agenda in a challenging economic climate.
2. A consultation designed to ensure service users' and carers' views informed the Joint Strategic Needs Assessment.
3. A review of community services in North Essex.
4. An evaluation of the Essex personalisation pilot.
5. A qualitative study exploring the accommodation and support needs of women leaving forensic services.
6. A review of employment support services in North Essex
7. An evaluation of day services commissioned by Essex County Council.

We are able to draw on the research skills within the MIME team and on the skills of service user members who have received training in research and facilitation in order to design data collection methods appropriate for each project, including questionnaires, topic guides and semi-structured interview schedules.

Reports and presentations

Our project work may be the most familiar aspect of our work to commissioners generally and has produced the most tangible outcomes in the form of our reports, most of which relate to the projects listed above. In addition, we have developed Standards on Service User Involvement for inclusion in provider contracts.

Our reports are circulated to commissioners and subsequently published on our website when it is appropriate to do so. Sometimes a delay is necessary. For example the work we carried out on vocational support in North Essex was undertaken to inform the development of a tender and it would not have been appropriate to publicise the information collected before the tender process was completed. For copies of our reports please contact pamela.hutton@anglia.ac.uk.

We have provided presentations as requested, for example for the review of community services in North Essex.

Website

Our contract required us to develop a website which could be used as part of our data collection. As we are a service user involvement project and aspire to best practice in terms of our values and ways of working we chose to work with service users we met in one of the provider organisations we were visiting for recruitment purposes rather than commission a consultant to develop it.

Although this meant the task took longer to accomplish it was worth it in terms of both the end result, ongoing website support and the positive impact on the service user consultant who did most of the work. The website, www.mimeproject.org.uk, can be used for providing information, publicising training and consultation events and currently carries links to our first web survey.

5. QUALITY AND IMPACT

To evaluate the quality and impact of what we have delivered we look to feedback from service users and commissioners. We use evaluation forms for training sessions and feedback is overwhelmingly positive:

'A very useful training experience with good use of role play to aid learning. I feel I have learnt a lot in a comfortable environment' 26.01.11

'Thanks for all your help and support in listening to our views and passing them on to commissioners & relevant people' 3.3.11

'Any MIME event leaves me buoyed up & ready to go out and take on the world' 3.3.11

'Thank you for an informative well structured day, been of positive value: look forward to many more' 21.02.11

'I had learned a lot with the staff and also with members present. I feel very positive after these 4 weeks of training... I would definitely want to be involved with MIME – training and participation in projects' 27.07.11

'Overall, day was excellent and I rated it as a 10. I will definitely be going to other MIME Training Days and recommend them for other Service Users who want their voices to be heard.'12.02.11

We also collect feedback via supervision sessions and in meetings of the SUAG from service users who are involved in meetings with commissioners. The feedback provides an indication of how we are supporting a constructive dialogue between commissioners and service users/carers. The comments below also indicate how the commissioners involved have ensured that the service users are aware of the importance and value of their role, and provide some evidence in relation to Indicator 5 on page 6:

'From feedback received the commissioners valued my involvement in the decision making process and took on board my ideas and opinions. This gave me the feeling I was empowered to make a difference.'

'Although it was a difficult task and I felt anxious beforehand I was excited and relieved afterwards because I had managed to participate and felt I had done a good job. The commissioners were really supportive and took the time to listen to what I was saying'

'I found the whole experience to be positive and was totally involved in the whole process which made me feel valued as a service user. The commissioners clearly listened to what we had to say and made decisions as a result. This is clearly the model to follow to ensure service users voices are heard.'

'It was nice to get the opportunity as someone who had used both primary and secondary mental health services to get a chance to work alongside the Commissioners and not feel that our opinions were immaterial, for once I felt we were making a difference.'

‘I ... felt that I had been really listened to. We need more chances like this to get our views across in a constructive manner.’

Another measure of quality from a service user perspective is that many service users who came to our first event on the JSNA have gone on to become members of SUAG and participate in training. They also regularly contribute as participants in consultations when they have relevant experience and many have developed the skills to be facilitators and note takers.

Some of the most rewarding aspects of working on the project for the team are seeing the positive impact of our work on individual service users and those moments when particular individuals are enabled to participate and give their opinion for perhaps the first time.

On the community services review a particular participant was unable to speak in the group but by taking her aside quietly in a break we were able to have a conversation and the reward was not only her comment at the end of the session (‘I feel important’), but also the knowledge that the review had benefitted from additional information from someone whose voice would not otherwise have been heard.

Several participants from the BME community attended a Big Conversation event with their Community Development Worker (CDW) and talked through interpreters. One of our service user facilitators gave feedback on the session, reporting how important the opportunity to express their views had been to these particular participants. This should not of course be generalised to the wider population and taken to imply that no previous consultation had taken place with the BME communities in the locality:

‘I attended a consultation event in Grays as a facilitator. There was a large number of members from the BME community who were in tears as it was the first time their views had been sought. MIME has built up very strong ties with BME representatives and those ties have given MIME very representative data.’

Another example concerns a particular service user who has been a regular participant in training and consultations but struggles to contribute in a constructive way. We tailor our support to each individual and can usually find him something practical to do at events so that he feels involved. At our recent event for world mental health day he surprised us all by the way he engaged with students and encouraged them to fill in our questionnaires. When passing on the positive feedback, his beaming smile told us that on that day he also felt important and useful. We had never seen him smile before although he had been to numerous events.

Our aim is to operate in an inclusive way and tailor support to each individual’s needs in relation to their confidence and skills. Obviously some will need more support than others but we find that often those requiring quite a high level of confidence building at the beginning go on to really engage with the project and get involved in helping to run consultations. One service user summed it up by saying:

‘It was great ... I feel involved and I like the way MIME operates ...’

Others commented:

‘As a service user I have been greatly informed about how commissioners work to improve our services... I feel that the MIME project has helped me personally to be more proactive and be more confident in speaking about mental health issues to commissioners and others.’

‘Before I was a member – I am a ‘nobody’ but now the picture has changed – I can contribute and be helpful to others within the community – life is more positive – partly because of being a member a ‘belonging’ member partly because of the training I have been given.’

Members particularly like the way commissioners engage with the project and they also value the opportunity to support each other:

‘MIME as a project working with service users and carers by its very nature allows me to seek and offer peer support both for MIME matters and personal issues. This support can make the difference to whether I remain well or not. It gives me the opportunity to discuss issues that may be on my mind.’

We occasionally get feedback from outside organisations. For example, we were involved in providing information for the King’s Fund study on ‘influencing patient experience’ and they included our work in their report and offered the comment:

‘Such a lot of work for a small service’

A second example followed from MIME’s participation in the North Essex networking event, for which we provided the opening speaker and workshop facilitators. One participant from NEPFT described it as:

‘The best example of user involvement he had ever seen’

In terms of the impact of MIME’s activities we think that the biggest one from the team’s perspective is the opportunity for increased communication between commissioners and service users/carers. As the comments from service users and feedback from commissioners demonstrates, the resulting collaboration is viewed positively by all concerned. The work stream on vocational support services in North Essex is a good illustration. The commissioner involved sought service users’ views before preparing a new tender and the data we gathered informed the tender specification. Service users then sat on the tender panel and took part in the decision making process.

We report to service users in our newsletters when their involvement has had a positive impact. Copies can be downloaded from our website www.mimeproject.org.uk but a couple of examples are given below.

Those of you who are involved in applying for a **personal budget** or know someone who is will be aware that drawing up a **support plan** is an important part of the process. Sometimes service users value the help of an independent organisation with the process.

Essex County Council have drawn up a draft specification for the service and sent it out for consultation. We passed it on to MIME members and 2 people took the trouble to send feedback. They both received a thank you detailing how their suggestions had led to changes in the specification.

We think this is another good example of the way service user views can have a direct impact on services provided Apr 11

NEW WEBCHAT SUPPORT SERVICE

Thanks to a suggestion that came up at one of our consultations commissioners have funded a new service at NERIL. See the details on the enclosed flyer.

This is yet another example of commissioners listening to service users and acting on what they hear.
Jun 11

The following section relates to the fourth stage of the evaluation process, that of reflecting on progress to date and planning for the future.

6. REFLECTING ON PROGRESS AND PLANNING FOR THE FUTURE

6.1 Progress to date

Our reflections on progress to date relate to the three main performance criteria outlined in our contract.

Representation and relevance

The information provided in Section 4.1 indicates that we have been successful in meeting this criterion. We have found that sending out details of events in a newsletter is rarely enough to recruit participants. We have to spend time seeking the support of staff in provider organisations to encourage people they work with to come along. Even then we usually have to chase people by sending out individual invitations to events or ringing members to ask if they would like to come. Often anxieties or misunderstandings emerge in those conversations and individuals can be reassured and encouraged to participate. In summary, we attribute the success of our recruitment to the following:

- The range of strategies used and the fact that we never turned down an opportunity to visit, network or talk about the project
- Adopting a non threatening approach – we only ask individuals initially to sign up to receive the newsletter and emphasise that in doing so they are not making a commitment to get involved but will be welcome if they decide to engage in activities
- The fact that recruitment is carried out by service users, which helps to build trust with potential members
- Our approach which is based on inclusion – we believe that everyone has something to contribute
- Empowering service users and carers by building their confidence and skills through training and supervision
- Having a clear vision and communicating it
- Good communication - keeping individuals in touch with what we are doing by providing information in the newsletter and on the website, and by giving feedback.

Empowerment and support

The training and support documented in Section 4.2 provides evidence in relation to this second criterion. Building confidence and skills through training helps to facilitate genuine involvement but appropriate support is what keeps individuals engaged.

Although previous experience of working with service users had led us to believe that participation in involvement activities is empowering we have been delighted and amazed at the personal development of members and their achievements. both within the project and outside.

However, our experience of offering training in research has highlighted the importance of getting the timing right. Prior to the research skills sessions mentioned on page 10 we had offered a workshop on interview skills but it was too early in the project and only four people attended. The learning from this experience helped with developing the research

skills module, which was only offered when we were sure that we had enough members with the confidence and experience to engage with it.

Services provided

Section 4.3 illustrates that we have delivered the full range of services outlined in our contract, with the exception of lay assessing, which is no longer required. The training and support we have provided for MIME members has added value in enabling a wider group of service users to become involved in designing and running consultations and evaluations.

There have also been significant benefits from hosting the project in a university in that having the support, knowledge and expertise of members of Anglia Ruskin's research team lends weight and credibility to the evidence we gather.

We attribute the success of our consultations in part to our efforts to maintain a focus on the possibility of positive change in the future rather than getting lost in recriminations over events in the past, which we acknowledge may have been distressing for some individuals but cannot change. Of equal importance is the consistent commitment of commissioners to the process and their willingness to work with service users even when they are faced with the occasional negative response from service users who have been disappointed in the past.

6.2 Planning for the Future

MIME's plans for the future over the final year of the project include:

- Developing membership particularly in the South East which is under represented
- Continuing to develop members' skills through training
- Supporting the growth of the newly formed service user research group in North Essex, now known as the North Essex Research Network
- Providing support to develop service user groups in each area, as sub-groups of the SUAG
- Building the skills of active members in order to contribute to sustainability.

7. CONCLUSION

This report has described the background to the MIME project, the development and implementation of a framework for evaluating progress to date, and the results of the self-assessment carried out using that framework. We hope the information provided is useful to commissioners in considering their own evaluation of the project and planning for the future of service user and carer involvement in Essex.

While the MIME team and many of our service user members are pleased with the achievements of the project we would welcome commissioners' feedback on the evaluation and their view on how members' involvement has influenced the commissioning agenda. Central to the MIME bid was the legacy of self-organising groups that would have the skills and potential to work directly with commissioners and others after the conclusion of the project in its current form in August 2012 and we would welcome discussion about how this might develop.

References

Friedman M (2009), *Trying Hard is Not Good Enough*, Booksurge, Charleston, USA

Schön D (1983), *The Reflective Practitioner*, Temple Smith, London

Notes

¹ This was the figure in May 11 – it has risen since then

² Essex & Southend LINK, Thurrock LINK, Southend, Colchester, Maldon, West Essex, Chelmsford, Thurrock and Brentwood Minds, Rethink, Cornerstone Trust, Nacro, Swan, Granta, SODA, DARE, CABIN, The Hope, Reason

³ South Essex Partnership University NHS Foundation Trust and North Essex Partnership Foundation Trust

APPENDIX: RECOMMENDATIONS PUT FORWARD BY THE SERVICE USER ADVISORY GROUP

Since the project's inception there has been a seismic shift in the context in which it operates due to the financial crisis and policy changes initiated by the coalition government. In the beginning we were aiming to develop links between service users and commissioners in local authorities and PCTs. Now it seems fairly certain that the plans to remove PCTs from the landscape and replace them with clinical commissioning groups (CCGs) will be implemented.

CCGs will be shadowing PCT commissioners and beginning to influence change from next April and will have control of budgets from April 2013. We are fortunate in Essex, Thurrock and Southend that commissioning teams have a great deal of experience and expertise and we hope that the quality of their work will be recognised by the CCGs and that skills will not be lost in the structural changes. We are equally fortunate that most of the CCGs in the area are engaging well with their new roles.

However, there is little doubt that GPs generally are not as experienced in user involvement or mental health as the organisations they will replace. The MIME project is due to finish its work on 31st August 2012 at a time of great transition in the way the NHS and to a lesser extent social care is delivered. Service user members feel strongly that this is a time when a consistent service user voice is needed as a strong influence not only on service planning but also on the arrangements for the transfer of responsibilities.

We are therefore recommending that commissioners give serious consideration to an extension of some funding for MIME until 31st March 2013. Service users are realists and understand the financial constraints on commissioners but would argue that is an additional driver to involvement as decision making needs to be supported by consistent evidence of what works well and less well, which service users can provide.

Their view is that continuing MIME's work for a few extra months will demonstrate to CCGs the value of user involvement in commissioning and provide the best hope of convincing them that it is crucial to commissioning in the future.

They would also suggest one of the unexpected gains from the Outcomes training was the learning from one of the case studies which showed that 'turning the curve exercises' can be spectacularly successful but frequently revert to previous states when initiatives end and attention moves away from the focus of the exercise. They are of the opinion that allowing the progress gained in developing constructive dialogue to dissipate now would do more harm to the trust that has developed between service users and commissioners than not commissioning the project in the first place. The very fact of MIME's existence raised expectations even though we were always careful to flag up that it was funded for 3 years.

Members have had a taste of making a difference and the benefits it brings in terms of enhanced well being and potentially improved services. It is understandable that they would not wish to see that disappear.