

# ON OUR OWN TERMS

## General Meeting 29<sup>th</sup> June 2005 Report

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## Background

In 2001-2002 the Sainsbury Centre for Mental Health funded a research project which culminated in a Report entitled **“On Our Own Terms – Users and survivors of mental health services working together for support and change”** which was written by Jan Wallcraft with Jim Read and Angela Sweeney.

### Key Recommendations were:

To build the capacity of the movement to support and represent service users/ survivors

- Enabling stronger local, regional and national service user/survivor networks
- Development of a national voice for the black service user/ survivor movement
- Increasing the user movement’s capacity to represent diverse experiences

To strengthen and develop user involvement nationally and locally so that it can have a real impact on service provision

- Development of national good practice guidelines for user involvement
- Revision of the NSF for mental Health to include user perspectives on services

To develop a new integrated prevention, self-management, recovery and inclusion focus for all mental health services and related social and employment services.

- A national forum to refocus mental health services towards prevention, early intervention, recovery and social inclusion

The Sainsbury Centre continued to fund a Steering Group which met three times in London, Manchester and Sheffield to take this work forward. Their work culminated in the general meeting described below which was held in London on the 29<sup>th</sup> June 2005 for a wider group of stakeholders.

Although service users come from a hugely disparate range of experiences, backgrounds, cultures and viewpoints it emerged that there are clear common currents of both aspirations and concerns. There was a strong feeling in the meeting of the potential power of a united national user voice.

Lisa Haywood July 2005

# ‘ON OUR OWN TERMS’ and beyond ...

## Programme

10.30		Arrive, light refreshments
10.45	Lisa Haywood Martin All	<ul style="list-style-type: none"> <li>o Welcome</li> <li>o Aim of the meeting and programme</li> <li>o Opening round</li> </ul>
10.55	Jan Wallcraft	<u>Where the user movement has come from ...</u> <ul style="list-style-type: none"> <li>o Highlights of ‘On Our Own terms’ and what it could mean for mental health</li> </ul>
11.10	Patrick Wood, OOOT Steering Committee	<u>How a strong and united network of mental health user organisations could help shape our future</u> <ul style="list-style-type: none"> <li>o Where we are now - money ... resources ... people ... energy ...</li> <li>o What the network could do</li> </ul>
11.20	Pairs or small groups	<u>Highlights</u> <ul style="list-style-type: none"> <li>o Highlights of the last ten years</li> <li>o The most important thing to help us shape our future are ...</li> </ul>
11.45	Break	
12.15	Pairs or small groups	<u>Highlights</u> <ul style="list-style-type: none"> <li>o Highlights of the last ten years</li> <li>o The most important things to help us shape our future are ...</li> </ul>
	Feedback	
1.15	Lunch	
2.00	Pairs or small groups	<u>Recommendations to OOOT Steering Group about</u> <ul style="list-style-type: none"> <li>o What the network could do</li> <li>o How will the Network be organised?</li> </ul>
	Feedback	
2.45	Groups Feedback	<u>OK so what next?</u> <ul style="list-style-type: none"> <li>o What will be our first steps in that direction?</li> </ul>
3.00	Break	Tea and coffee
3.15	All	<ul style="list-style-type: none"> <li>o Confirming next steps</li> <li>o Review of the meeting</li> </ul>
4.30		Close – have a safe journey

*All times other than start and finish times are approximate and will be varied in the light of how things go*

# Notes of the General Meeting

## Introduction

The Co-ordinator of the conference, Lisa Haywood, welcomed delegates to the meeting and introduced the facilitator for the day – Martin Farrell from get2the point.

The initial session encouraged delegates to exercise some visionary thinking and share their thoughts on a newspaper headline which would encapsulate the positive outcomes from our work two years from now.

Many were connected with stigma – “1 in 4 worldwide unite to combat stigma”; “Stigma associated with black and ethnic mental health services banished”. Others were connected with services – “Service users unite to revolutionise the face of mental health services”; Service users and the statutory sector working together to improve mental health nursing”. Of course the ‘Bill’ was there – “Unworkable Mental Health Bill finally dropped through service user’s action. Ministers seeking dialogue with service users to plan the future”. We also could not ignore the use/ overuse of psychotropic drugs in current services – “It’s the final nail in the coffin as pharmaceuticals offer self-help alternatives”; “Giving up drugs and returning to well being”.

**Jan Wallcraft** then gave the meeting an overview of the background of the work and where the user movement has come from. She also took us through the highlights of the On Our Own Terms Report. This included:

- Origins of the movement
- Diversity and inclusiveness of the movement
- Common issues for the movement
- Controversial issues for the movement
- Building the capacity of the movement
- User involvement in improving services
- Integrated prevention, self management, recovery and inclusion focus for all mental health services

There was a discussion about the purposes of a network of user organisations which included:

- Offering a reference point for NIMHE, the Social Inclusion Unit etc
- Emphasising the need for a user voice which is true (generally reflecting a consensus of views) but also representative of the huge variety of diverse individual user agendas.
- It is essential that the black and minority ethnic voice is an integral part of the network otherwise there will be no real integrity of the organisation.
- Consultation with the network must not just be held in meetings but must be made in a variety of ways which encourages full participation of the widest range of users.
- The Government and strategic planning bodies say they don’t know how to access the range of users. This network can show them the way. “There is no such thing as a hard to reach group – only hard to reach services”.

- Users need their own voice and their own agenda – not the Government’s, not Rethink’s, not Mind’s - they must be independent.

**Patrick Wood** introduced the work of the On Our Own Terms Steering Group which was carried out over a period of months in three meetings in London, Manchester and Sheffield. He summarised the overarching aims of the proposed network which were:

1. Networking and information sharing/ trouble shooting for network and groups
2. Lobbying for more resources for the movement
3. Promoting and enabling service user participation
4. Facilitating campaigns on common issues

The wide ranging discussion following this introduction added a few points which the group supported as follows:

- The network needs to tell the world that we’re here; make sure they involve us; show them how to involve us; give us more money
- We need to find out what people (service users) want to change and make it happen.
- There is an overarching principle for the network which is that we are more powerful when we stand together. “United we stand: divided we fall”.
- A challenge for us is to speak with one voice while allowing diversity
- We need to use the media intelligently
- We need support/ funding from a variety of sources to enable us to maintain our independence

## **Discussion and next steps**

In the afternoon there was a challenging discussion about where we were to go from here. There had been discussion in the Steering Group that the Network could be managed by one or two current national user organisations.

Lisa informed the meeting that there was an offer and invitation from the Mental Health Foundation to meet to talk about support for the future of the Network. The group asked that Andrew McCulloch as well as David Crepaz- Keay should meet with a delegation from the group so that we can be sure of what exactly is on offer.

It was reiterated that long term there needs to be a variety and diversity of funding and support sources to ensure the independence of the network.

The discussions also included some long term aims such as a website to disseminate information as there is a clear recognition that information is power. It is also important that we learn from each others good practice and our successes so that we don’t continually re-invent the wheel.

It was emphasised that this network needs to keep focussed on the bigger picture otherwise there is a danger that our energies will get drained.

## **Agreements and next steps**

There should be three stages to the On Our Own Terms work

1. The research, report, Steering Group meetings and general meeting
2. A development stage
3. The user organisation network in action

Stage 1 is now completed with today's general meeting and agreement on the Report which will now go back to the Sainsbury Centre for Mental Health.

Stage 2 – Lisa will work up some very basic proposals for consultation with the group which will then be taken to the meeting with the Mental Health Foundation on the 4<sup>th</sup> August 2005. This meeting would be between Andrew McCulloch, David Crepaz-Keay, Lisa Haywood, Patrick Wood, Angela Linton, Louise Relton and Peter Relton. Depending on the outcome of the meeting, the development work of the network would be set up which will take two or three months. This will include:

- Lisa to work with a Steering Group to take the development phase forward
- Agreeing basic aims and objectives for the Network
- Drawing up a business plan
- Holding another general meeting to consult and agree on a way forward
- Other business/ needs to be addressed as they arise

Stage 3 – The Network in action

## **Conclusion**

The meeting was a success. The user movement as usual demonstrated how they can grapple with issues of immense complexity, underlined with strongly felt personal agendas, and end up with consensus and good feeling. The work leading up to this point had been thorough and we now have clear future plans to take the On Our Own Terms Network forward.

Many thanks to all the users who have participated over the last few months; to Beverley Taylor for her practical support; to Martin Farrel for his calm focussed facilitation and to the Sainsbury Centre for Mental Health for backing the process.

## **Delegate list**

Peter Relton

Louise Relton

Angela Linton                      Black Women's Mental Health Project

Peter Munn                          Cymar and UKAN

Philip Dixon-Phillips              UK Federation of Smaller Mental Health Agencies

Miranda Telfer                      Bruised UK

Robert Jones                        Survivors Speak Out

Millie Reed                          Southwark Mind

David Glenister                      Mental Health Action group

Diane Hackney                      PAB

Patrick Wood                        UK Advocacy Network

Sainsbury Centre for Mental Health

Beverley Taylor                      Administrator/ secretary

Lisa Haywood                        User consultant co-ordinator and Mindlink

Martin Farrell                        Facilitator - get2thepoint

Jan Wallcraft                        SCMH and NIMHE