IIMHL Leadership Exchange, England, 9-14 June 2014

Consumer Leaders and Peer Services

Background

The International Initiative for Mental Health Leadership (IIMHL) is a unique international collaborative that focuses on improving mental health and addictions services. IIMHL is a collaboration of eight countries: Australia, England, Canada, New Zealand, Republic of Ireland, Scotland, USA and Sweden.
IIMHL organises systems for international networking, innovation sharing and problem solving across countries and agencies. The overall aim is to provide better outcomes for people who use mental health and addiction services and their families.
The Leadership Exchange is a week-long learning event which is held every 16 months.
Knowledge transfer through IIMHL includes not only the Leadership Exchange, but also promotion of workshops/training/education, support of learning collaboratives and information dissemination between Exchanges.
This year (2014) England hosted the exchange.
The National Survivor User Network (NSUN), a service user-led charity supporting the involvement of people with lived experience in England, was part of the IIMHL exchange project team hosted by the Department of Health. Throughout NSUN worked with partners to ensure that people with lived experience had significant roles in the exchange and that their views were taken seriously.

We achieved this in several ways:

- NSUN was part of the IIMHL exchange project team;
- With fellow charity Together we hosted the two-day 'Service user leadership and peer support' element of the exchange;
- We lobbied for four people with lived experience to present to the main gathering in Manchester;
- We were invited to facilitate a workshop led by people with lived experience at the main gathering in Manchester.

Monday 9 June – Day one of exchange

International delegates gathered at Together's offices in Old Street to be welcomed to the two-day service-user leadership and peer support exchange.

The delegates then travelled together to the Ortus Learning Centre at the Maudsley Hospital campus, Denmark Hill, South London. The venue, designed in consultation with service users, had been made available to the exchange with no charge thanks to the generosity of Maudsley Learning. A grant from the Maudsley Charity helped pay for catering and other costs. At the Ortus NSUN and Together had arranged a service user leadership and peer support festival called ***'Taking over the asylum.'***

During the day and indeed the week people tweeted using #iimhlpeer and #iimhl

Noon: Event began with lunch and networking with about 90 delegates in the atrium area.

Stallholders:
Core Arts
Mind
NSUN
Together
SLAM Recovery College
Survivor History Group

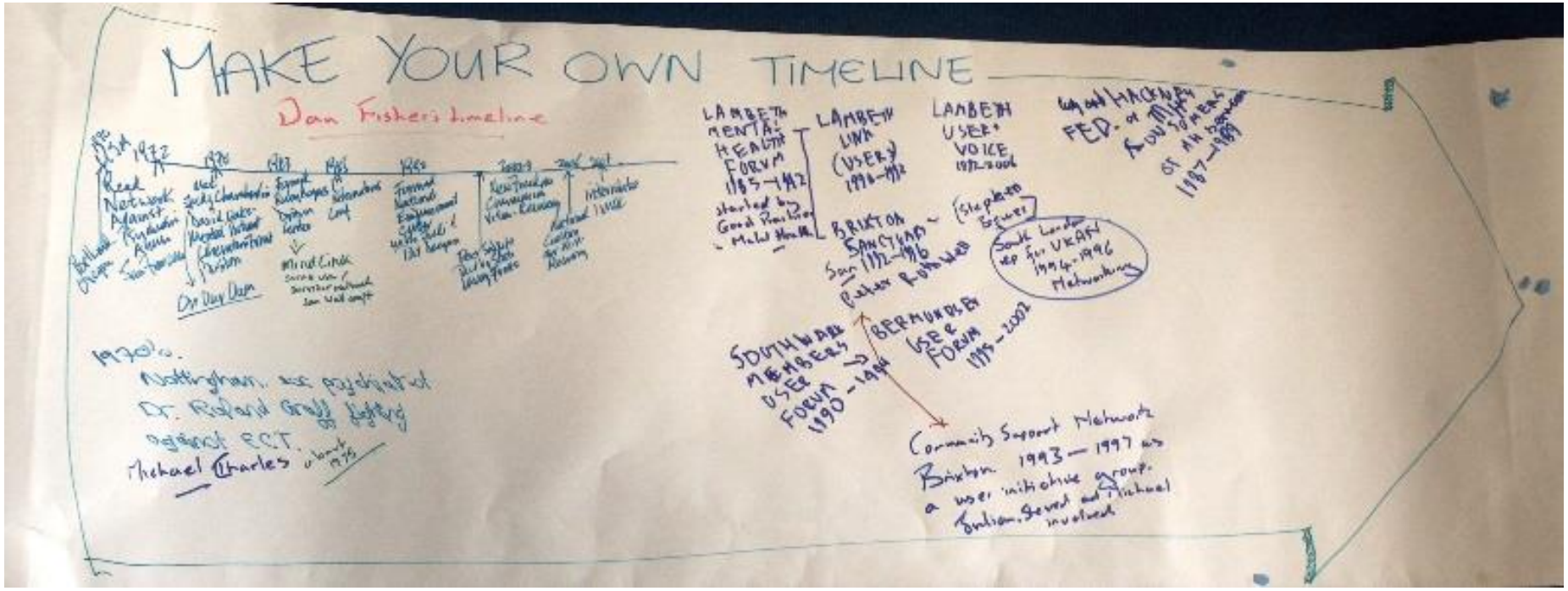
1pm: Plenary in Connect room downstairs

Introduction
Event chair **Sarah Yiannoullou**, Managing Director, NSUN welcomed everyone and introduced the day. As well as celebrating and showcasing service user/consumer leadership and peer services, it was the 'soft launch' of the **4PI national involvement standards** http://www.nsun.org.uk/assets/downloadableFiles/4pi.-ni-standards-for-web2.pdf.

Presentations
The afternoon began with two speeches to set the scene.

- Survivor History Group key note presentation: **Clare Ockwell**
- Guest presentation: **Dawn Hastings** (New Zealand) Peer Support Workforce Development

Display
Survivor History Group time-line and exhibition – **Andrew Roberts**
'Solidarity and diversity in our mad world' http://studymore.org.uk/madworld.htm



1.30pm: Soap Boxes (three-minute slots to talk about service user leadership and peer support)

Speakers:

Alison Faulkner presented the 4Pi involvement standards as part of the 'soft launch' for this work (http://www.nsun.org.uk/assets/downloadableFiles/4pi.-ni-standards-for-web2.pdf)

Daniel Fisher talked about the work of the National Empowerment Centre (USA) and his international work (http://www.power2u.org/).

Anjie Chappia spoke about her experience on the London Leadership programme - a film of the London leaders programme was shown after the Soap Box session (https://www.youtube.com/user/nsunformentalhealth?feature=watch).

Nigel Moyes spoke about his work as an NSUN volunteer and his use of Together's housing services and their training opportunities. These included mental health awareness, train the trainer, and the leadership course. As a member of his Local Involvement Network (LINK), he was part of a team of volunteers, who during a six month period between October 2012 and March 2013, help to set up Healthwatch Suffolk. During this time, I also attended a three-day patient leadership course, run by NHS East

and Midlands. Nigel now volunteers locally for Suffolk User Forum and Norfolk and Suffolk Mental Health Foundation Trust. Nationally, he volunteers for NSUN and Time to Change.

Clare Dolman, Chair of Bipolar UK (http://www.bipolaruk.org.uk/) and a trustee of APP-Action on Postpartum Psychosis, spoke about the power of peer support and how Bipolar UK runs an e-community with nearly 9,000 registered users where - day and night - people with bipolar disorder help and support each other. She spoke of her own personal experience of the illness, and how it had helped her at Bipolar UK, especially running workshops for mothers with bipolar and their partners who want to have children and can't find any advice or information. This sort of peer support - helping each other and at the same time growing in understanding of our own condition - is priceless. Shocked how ignored the subject has been by researchers, Clare decided to do the research herself and is currently studying for a PhD at the Institute of Psychiatry, interviewing other women with bipolar about childbirth issues. As another excellent example of the value and importance of peer support, she described the newly-formed charity APP - Action on Postpartum Psychosis, which offers peer support to women who have suffered this traumatizing and highly stigmatized illness after childbirth. They provide advice, support and encouragement to women, their partners and family members who are devastated when a new mum is taken into psychiatric hospital soon after giving birth. Many people on the e-forum view it as a lifesaver.
Clare concluded by calling for more recognition of the enormous value of peer support, to individuals but also to society as a whole, as it's definitely a contributor to keeping people well, and therefore out of services, and therefore less of a financial burden on the state. With just a small initial and maintenance investment, the power of volunteering and supporting your peers could be harnessed for the greater good of everyone. It's about time the government woke up to this.

Emily Cubbitt, Core Arts worker talked about her service user-run charity in Hackney and showed delegates a video (available on homepage of their http://corearts.co.uk) about how they use the arts to support people with experience of mental health distress**.** Core Arts was set up in 1992 by an artist using vacant space in the old Hackney Hospital. His studio became a haven for artistic expression, as curious patients seeking refuge from the monotony of life on the psychiatric ward immersed themselves in a world of paint and colour. Core Arts is now well-known as an innovative leader in mental health creativity, cultural diversity and social enterprise. With no analytical or clinical agenda, their expansive programme and member led ethos focuses on what people can achieve, supporting them to increase their capacity for innovation and learning, problem solving, confidence and leadership skills.

Dominic Makuvachuma-Walker, NSUN trustee and Mind Engagement Manager, reminded people of the tragedies involving black mental health service users like Sean Rigg, who was killed in 2008 when restrained by police officers. He made a rousing plea for all of us to stand up, join forces and challenge the practices that harm.

Workshops: 3pm and 4pm

Black and Minority Ethnic (BME) leadership workshop

Facilitated by Jacqui Dyer and scribed by Raza Griffiths

The current situation is that there is significant under-representation of black people in many areas of life, including representations in Parliament, the senior civil service, and senior management in NHS Trusts, other public services and business. The socio-economic profile of black people shows them to be worse off than the general population. The service user voice was not as strong at Ministerial Advisory Group level as it should be and Jacqui and NSUN negotiated for more meaningful involvement at this senior level.

- It is important to have black and Asian service users in leadership positions.
- Time to Change anti stigma campaign is doing some work around African communities.
- The term 'BME' is a reductionist term for a broad range of diverse communities.
- In the workshop groups were assigned the task of coming up with a key message around the need to be inclusive of a disenfranchised group (not limited to BME), the target audience it was aimed at and the outcome of putting the key message into action.
- Key message: Achieve – listen – commission based on service user requirements. We know what helps us feel better and helps us to recover. Lack of service user voice
- Target audience: Local Clinical Commissioning Groups, Minister for Health
- Key message: First point of access is GP so create a better environment for people with mental health issues to access information and guidance about local provision by having a volunteer (or PAID person) to offer information and signposting. GPs don't have this understanding
- Target audience: Clinical Commissioning Groups, GPs, local counsellors
- Outcome: people get information about their condition and about local provision which may be an alternative to medication. N.B There are pockets of good practice in some surgeries where this already happens
- Key message: Inclusive holistic approach – personalised not just medical e.g. challenging life-long diagnosis, through inclusion in art based activities as part of a therapeutic recovery based approach. Holistic strengths based report
- The 4PI principles of involvement that NSUN has been developing are very relevant to all these scenarios. Recommendation Independent Commission on Mental Health and Policing 2012(?)
- Key message: BME young people are not getting enough support for carrying the issues of society and older generation and young people are being blamed for that. We need to redirect these issues away from young people and back up to policymakers and we need to direct young people to training opportunities etc.

- Target audience: Society, policymakers
- Outcome: Tackling high youth unemployment will also help reduce crime rate which is disproportionately connected to this group.
- Key message: People from travelling communities have limited access to services like housing, GP surgeries and there is a link with stigma against travellers. We need to break the stigma against travellers. Services are usually only geared for the benefit of majority communities.
- Outcome: Equal access to services for diverse range of communities
- The 4PI principles of involvement that NSUN has been developing are very relevant to all these scenarios.

Service user leadership in community support services workshop
Facilitated by Ross Baker and Sonia Sem and scribed by Nigel Moyes
Together, for mental well has been providing support and services for 135 years. The development of the Your Way services over the past five years has been built on an ethos of personalisation, service user leadership and peer support. (http://www.together-uk.org/our-mental-health-services/community-support-resource-centres/)

- Outcome measures are good evidence to commissioners.
- Monitoring- qualitative rather than quantitative data used.
- Peer support courses - 85 per cent success rate.
- It helps to self-direct your life.
- It is not a cure, compliments other therapies.
- Meaningful and user led outcomes.
- Cost effective.
- Re-ablement builds capacity with limited resources.
- Peer support in reality solves part of the economic problem. Who will take ownership of it?
- There must not be too much formalization.
- It can complement other pieces of work, for example recovery colleges.
- Future goals - get people back into employment.
- This model in Southwark is one of 17 Together has introduced across the country, can potentially alleviate some of the ‘revolving door syndrome’.

Emotional CPR (E-CPR)
Facilitated by Daniel Fisher and Jenny Speed

Daniel Fischer works at the National Empowerment Centre, in the US which exists to carry a message of recovery, empowerment, hope and healing to people with lived experience with mental health issues, trauma, and extreme states,. Dan is also a member of Interrelate.
Jenny Speed works with women and children in the criminal justice system in Australia where at least 80% of prisoners have mental health problems. Jenny also has her own lived experience and is also a member of Interrelate.
E-CPR (http://www.emotional-cpr.org/) is a public health education program developed in 2008 with a goal to train people to support each other through emotional crisis.
CPR stands for:
C = Connecting
P = emPowering
R = Revitalizing
E-CPR is heavily influenced by Tom Anderson's Open Dialogue approach developed in the 1990's in Finland. 'Fundamental to the approach is the shift away from an immediate emphasis on trying to eradicate symptoms. The conversation, or dialogue, is not "about" the person, but a way of "being with" them and living through the crisis together.' At present does not have a handbook, and we would like to bring to the US. There is resistance, as they believe by manualising it you might ruin it. This is being piloting in North East London Mental Health Trust. Emotional CPR grew from a need to see people through crisis when the mental health system is not doing a good job as it medicates, sections and escalates.

Dan and Jenny engaged in a role play during the workshop was a perfect illustration of the above quote - 'a way of being with them, living the crisis together'. Emotional CPR is not about learning skills it's about being yourself. It is really unlearning this idea of managing and fixing people. In this way it is really counter-cultural. The more authentic you can be the more healthy you can be, as without being authentic you can't really be of much assistance. Clinical training tends to take away what it means to be yourself. They say don't share yourself, but for many people who have gone through severe distress, what people want first and foremost is human being. We are creating a system that makes people more remote. The image in the photograph behind Dan and Jenny is a visual description of listening with your heart as well as your ears. One person described this *"two people developing one circulatory system; an emotional circulatory system."*

Emotional CPR is trauma informed it is more about what has happened to people rather than what is wrong with people. We don't feel there is an intrinsic biological deficiency and we tend to reject the term mental illness all together. It so often turns out that the people with the lease formal training like the secretaries, cleaners that they were the most helpful people – this is crazy!
We are creating a system that makes people more remote. So we have been asking ourselves from our own lived experience what was important and what we most wanted when we were in distress. What we have come up with is people, present, in the moment. We try to make the approach really empathetic by emphasizing the fact that you don't know what the other person is experiencing and should deepen the conversation and deepen the ways of connecting with another person. You must always be in the position of not knowing and living with that uncertainty.

Peer support in inpatient settings workshop
Facilitated by Clare Ockwell, Simon Betts and Jonathan Upton
Simon Betts is a peer support worker for Capital currently working in one of the three inpatient units
Katia Nesbit has used peer support and Capital
Clare Ockwell is the Chief Executive of Capital

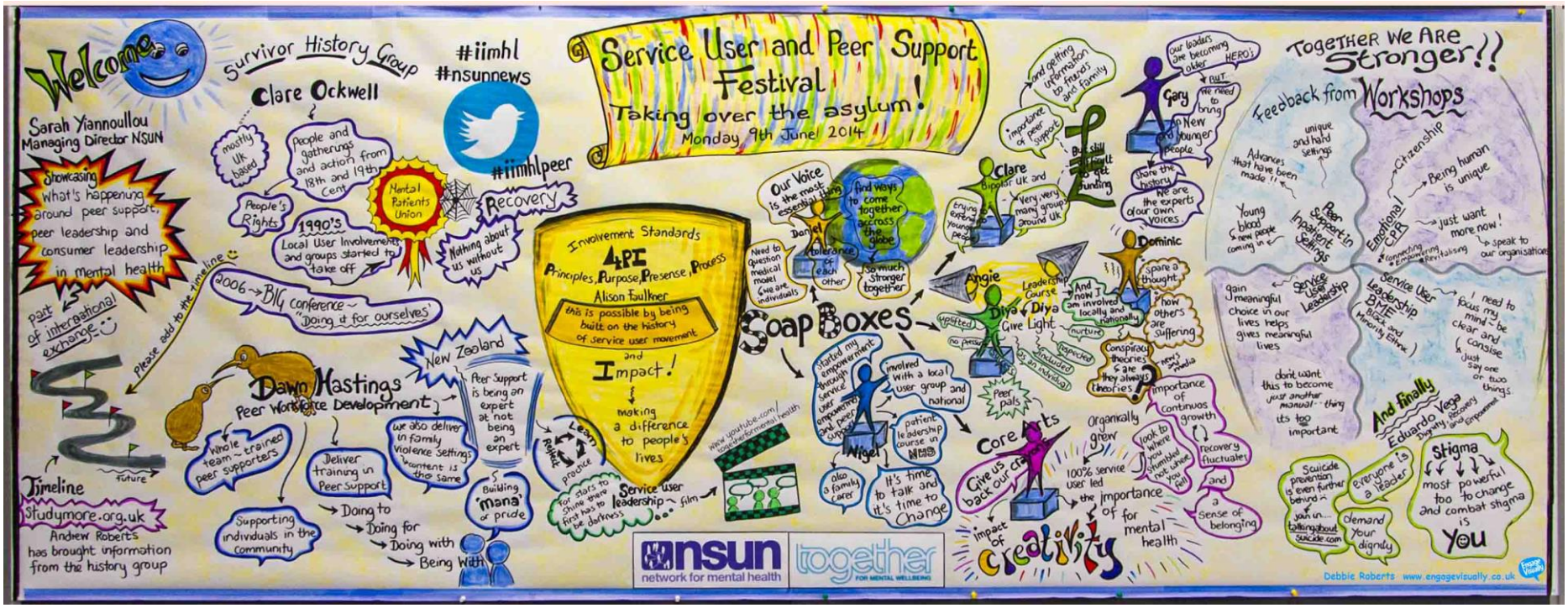
Capital (http://www.capitalproject.org/) is a West Sussex wide completely service user led charity. Capital is an acronym and stands for clients and professionals in training and learning and is now in its 17th year. Originally Capital was set up as a training organisation and peer support happened as a by-product very quickly. When Clare first joined she was agoraphobic and door-to-door support was arranged and still is in place for anyone that needs it otherwise people are excluded.
The formal peer support project started in 2010. In 2009 Capital was approached by the local commissioners to set up a peer support project on local wards saying that people would do this as volunteers. Clare successfully challenged this on the basis that this was not valuing that people would be expected to work in a high stress environment and have specific experiences and qualities. Posts with short weekly hours of work were set up so that people could do it as permitted work. In each ward across West Sussex there is now 10 hours of peer support that is independently managed. Peer supporters with Capital don't write notes that are shared with other staff. They are role models for recovery and they have the time to listen, each doing it in their own way. An important part of this work is for the peer supporters across all of the wards can peer support each other.

Simon described the peer support peer support *"we spend all of our 5 hour shifts with people either talking informally in social areas or, where helpful, we offer people a 1-1 in a quiet room for example if they want to talk more in-depth. We do a range of activities*

including the wellness workshops, music, art and crafts, knitting and crochet and mindfulness for example. We share coping strategies, wellness ideas that have worked for us and we also signpost people to other helpful people for example an advocate. We empathise which is one of the most important things as we are here to learn from each other and think about how we can get through it."

The workshop included a taster session of a group peer support session. Looking at the theme of choice, flash cards are used with different wellness ideas on them, star shaped cards that have recovery-focused questions and another set with triggers and early warning signs. The sessions last for up to 45 minutes once a week.

Plenary session: Sarah Yiannoullou invited participants to feedback what people had learnt and how it might apply where they live. During the afternoon people's contributions were 'graphically recorded' by Debbie Roberts (see below) this visual record was then transported to Manchester so that it could be seen by all the 300+ delegates at the main gathering.



Feedback forms

At the end of the event people were asked to fill in forms with the following results:

- Over 90 per cent of survey respondents understood the purpose of their involvement in the event.
- Everybody felt listened to and their opinion valued.
- Everybody felt the information given to them was clear.
- Over 90 per cent felt able to participate fully.
- Everybody found the event useful.
- Just over 20 per cent found it difficult to take part.
- Nearly 80 per cent said that they had gained new ideas and would be trying new things as a result of the event.

Comments included:

Inspired! - It can be daunting initially as a service use but I quickly felt comfortable and valued as an intelligent person with a contribution to make - Great to meet others - I intend to work in collaboration with other groups I met at this meeting - Really useful to hear how peer support is working in other contexts - I will be promoting peers support and consumer-led services

Dragon Café

After the Ortus event international delegates were invited to the Dragon Café which is user group called Club's latest creative project: a relaxing café and imaginative space, open to all, located in the Crypt of St George the Martyr Church. Delegates took part in a discussion with young psychiatrists, a drumming workshop and sampled the superb food on offer.

Tuesday 10 June

Leaders with lived experience from across Ireland, England, New Zealand, Australia and United States of America gathered at Together's Old Street office to share thoughts, ideas and develop messages to take to the main IIMHL event in Manchester later in the week.

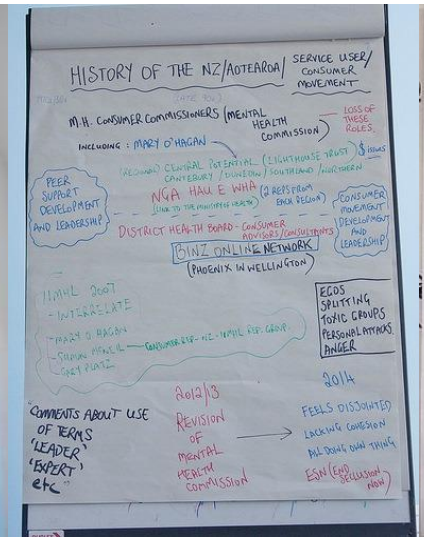
The main aims of the day:

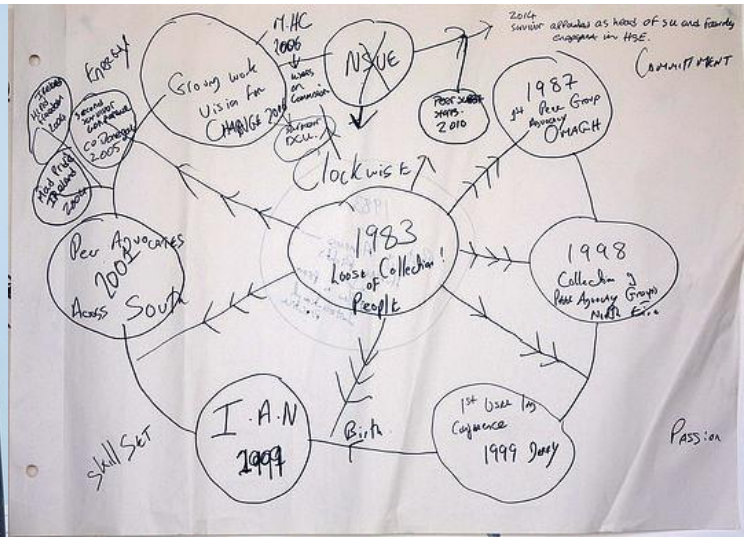
- Feedback on event
- Learning so far
- Sharing of challenges, identifying solutions
- Exploring, checking understanding of common terms
- Key messages to take to the Manchester conference

Everyone presented on **'*Our histories*'**
Some key and common themes included:

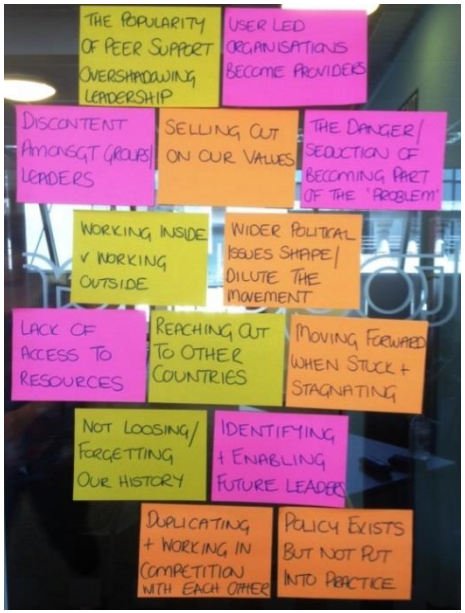
- Reflecting back and understanding our roots
- The consequences of historical struggles
- Working within systems of pressure and the dangers of being co-opted or bought out
- Strategy for working inside and outside – activists versus conformists
- The forming of national action / movements
- Working across groups – pan disability coalitions
- The language of consumers and survivors
- Telling our stories – communicating narratives
- Common challenges and solutions need to be shared locally, nationally and internationally
- Succession management
- Not handing on divisive, fragmented or fractured history – coherent vision
- Replicating the diversities of the system and understanding how to appreciate differences
- Respect and trust – essential


2014
SUICIDE RATES
LEADERS
ALIEN INVOLVEMENT!!!
LEADERSHIP
CO-PRODUCTION
MEDICAL MODEL
ANTI-PSYCHIATRY
SURVIVORS SPEAK OUT
PETER CAMPBELL
COMMUNITY SUPPORT
NATIONAL
ANTI STIGMA
DISRESPECTED
SUSPICIOUS
SOCIAL INCLUSION
PERSONALISATION
ANGRY NOT MAD
COMMUNITY CARE ACT 1990
DIRECT ACTION
PARTNERSHIP WORKING
HUMAN RIGHTS
NETWORK
LEADERSHIP
MAD PRIDE
NO HEALTH WITHOUT MENTAL HEALTH
NATIONAL SERVICE FRAMEWORKS 1999
INVOLVEMENT
EMPLOYMENT - INVOLVEMENT WORKERS
PEER SUPPORT PROVIDERS
RADICAL
FUNDING OF GROUPS
POLITICAL MODEL = SOCIAL MODEL


HISTORY OF THE NZ/AOTEAROA/ SERVICE USER/ CONSUMER MOVEMENT
M.H. CONSUMER COMMISSIONERS (MENTAL HEALTH COMMISSION)
INCLUDING : MARY O'HAGAN
LOSS OF THESE ROLES
PEER SUPPORT DEVELOPMENT AND LEADERSHIP
NGA HAU E WHA
DISTRICT HEALTH BOARD - CONSUMER ADVISERS/CONSULTANTS
CONSUMER MOVEMENT DEVELOPMENT AND LEADERSHIP
GINZ ONLINE NETWORK
PHOENIX IN WELLINGTON
ECOS
SPLITTING
TOXIC GROUPS
PERSONAL ATTACKS
ANGER
2014
FEELS DISSIPATED
LACKING COHESION
COMMENTS ABOUT USE OF TERMS 'LEADER' 'EXPERT' etc
2012/13
REVISION OF MENTAL HEALTH COMMISSION


Energy
M.HC 2006
Glowing Work Vision for CHANGE 2010
NSUE
2014 Survivor attitudes as heads of SU and Family engagement in HSE.
COMMITMENT
1987 1st Peer Group Advocacy Otago
Clockwise
1983 Loose Collection of People
1998 Collection of Peer Advocacy Groups North E...
Peer Advocates 2004 Across South
I.A.N 1997
Birth
1st User led Conference 1999 Dunedin
Skill Set
Passion

Common issues: challenges and solutions
Some of the challenges were identified and then the solutions and collective ways forward were explored. These will be taken forward by Interrelate, the international mental health coalition. http://www.interrelate.info .



The detailed messages included:

Peer support leadership and peer services

1. Peer support leadership needs to be defined and given clarity by leaders and reclaimed where necessary, reflecting differences within different countries.
2. Peer services recognise the value of lived experience and its contribution to the recovery and wellbeing of people. They are based on an inspiring vision to build communities that embrace servant leadership as opposed to master leadership. They aspire to achieve and inspire others with lived experience, using empathy as the medium for communication.
3. Peer services are not an employment scheme for people with lived experiences
4. Peer services must be supported, facilitated and embedded across all IIMHL participating countries. This must be monitored and audited with a financial penalty for non-compliance.

Standards

1. There is a need to recognise the difference between standards of leadership for people with lived experience and standards for peer services.
2. There is a need to develop organisational standards and ethical guidelines that must be adhered to by organisations that operate peer services. Their incorporation into practice must be led by peers.
3. Ownership of standards and their associated values base must sit with people with lived experience and not be imposed by organisations.
4. Standards must be developed, implemented and evaluated by people with lived experience. This must be well resourced and supported.
5. International comparisons must be made to raise standards.

Actions for IIMHL

1. Leaders with lived experience must be treated equally and be meaningfully involved in the leadership of IIMHL to overcome marginalisation.

2. The involvement of leaders with lived experience in funding decisions must be open and transparent.
3. People with lived experience must play a vital role in training, mission, evaluation and policy formation.
4. Adequate resources to share best practice in leadership amongst people with lived experiences and peer services are essential.
5. All IIMHL participating countries must allow Interrelate to develop and draft standards in the same way that other work is developed.
6. We require all IIMHL countries to adopt and implement to standards developed by people with lived experience.
7. We require all IIMHL countries to have a full suite of well explained support options for people with lived experience to choose from
8. Previously written articles about the leadership of people with lived experience and peer services must be published.

We agreed that we had to articulate a clear vision that people with lived experience are entitled to the same life expectancy as the rest of the population. This was the overarching message and one that was deeply rooted in a **rights based** approach.

Photos of the day can be viewed by following the links below:
https://www.flickr.com/photos/89305593@N02/14268204719/in/set-72157644831879580
https://www.flickr.com/photos/89305593@N02/sets/72157645246113665/

IIMHL main event in Manchester 12 13 14 June

Far left: NSUN managing director Sarah Yiannoullou, Dr Dan Fisher, Jacqueline Dyer and Dr Rachel Perkins, after addressing over 300 delegates at the IIMHL main gathering at Old Trafford stadium

We displayed the graphic recording from the service user leadership and peer support festival and explained our key messages to delegates.

Workshop: Service user (Consumer) standards in involvement and peer support – *To be or not to be?*

Anne Beales, Jacqui Dyer and Dan Fisher facilitated the workshop. The workshop aimed to enable participants to explore the potential and the importance of consumer led standards for peer led peer support and service user involvement and leadership. By the end of the workshop we wanted participants to have a greater understanding of the importance of consumer led standards, to be able to describe the current position of consumer led standards and identify opportunities to further develop and implements standards within their own countries and internationally.

The current position in the UK around involvement standards and peer support, and why we are developing standards' frameworks not targets was presented.

4PI national involvement standards http://www.nsun.org.uk/assets/downloadableFiles/4pi.-ni-standards-for-web2.pdf

Questions (in small groups):

- What are the three benefits of local ownership around service user involvement standards?
    - People more likely to embrace the standard and implement
    - People can adapt how they're implemented
    - Authenticity, quality and trust
    - Creates a shared approach
    - Reflective of the local population, relevant and more likely to get local support
    - Builds confidence and competence
    - Mitigate against tokenism
    - Makes people feel valued and more reflective of individual needs and views
    - Empowerment and genuine partnership in action
    - Choice, focus and integrity
    - Ownership and community emancipation
- What are the negatives around asking organisations to do things a certain way?
    - Polarises the workforce – grounds for resentment
    - Historically it hasn't worked
    - Creates a culture of tick boxing
    - Stifles innovation and creativity
    - Focusing on targets – missing the point
    - Creating silos and tunnel vision
    - Erodes skills and potential
    - Lose quality and depth

- Limits scope
- Puts statistics before people and quality
- Demotivating for workers and service users
- Not meeting individual needs
- Imposed on people – not one size fits all
- Lose sight of customer focus
- A focus on outcomes can affect quality
- Targets are not usually demographic/designed together

Introduction to the Global Standards around peer support

Questions: Where is your organisation around implementing and working to such standards?
What are the next three actions you will recommend to your organisation?
Where are you around implementing Service user involvement and leadership?

Spectrum of Involvement

Questions: Where your organisation lies on the spectrum?
What will help you progress on the spectrum?

Everyone reflected on this and then placed themselves as individuals or organisations) on the spectrum. See next page.

Discussion points:

- Challenges: resistance, demanding and conflicting priorities
- Opportunities: new roles creative and initiatives
- Definition of the word peer
- Uniqueness of a peer – bringing the real me to the table not just the 'professional part'
- The experience of an individual offers leadership – not about individuals or hierarchy
- Definitions of service user leadership vary – collective leadership/networking through independent networks
- Having a broader role in participation and sharing the learning
- Links to the Community Development movement
- Listening keenly to those on the receiving end of services and acting upon it
- Formal positions for service users and carers – representation, legitimacy and effectiveness

Dan Fisher concluded by talking about how the National Empowerment Centre 'empowers' consumer led initiatives and how consumers can work to best effect within State / Medicade services.

WHERE DO YOU FIT ON THE SERVICE USER LEADERSHIP SPECTRUM?

What does your organisation do to support service user leadership?	• Service user consultation via:
	  ○ Surveys
	  ○ Service users attending staff meetings to feedback information collected
	  ○ Meetings between staff and service users with no formal agenda and no time to plan
	  ○ Service users attending meetings where the agenda is set by the organisation
	• Staff not required to act on service user feedback
	• Quality measures use clinical standards only
	• Staff training content contains no service user input
	• Priorities determined by systems, rather than people
	• Leadership and vision is seen as the domain of staff
		• Independent service user perspectives present at all levels of the organisation
		• Service users influence governance, policy and practice of the organisation
		• Internally, service users lead some initiatives through to completion
		• Externally, service users originate and lead some organisational initiatives with minimum influence from the organisation
		• Service user groups preparing to become independent of host organisation
		• Organisation remains responsive to service user leadership even if it doesn't plan to become service user led
		• Pro-actively building local service user led organisations and initiatives (may include capacity building for a national infrastructure to support this)
			• Service users lead on governance
			• Service users lead on authentic peer support
			• Service users articulate and measure quality of practice and service outcomes
			• Service users lead policy development
			• Contributes to capacity building of service user led groups and development of a national infrastructure to support this
			• Supports independent service user led groups
			• Can host service user led initiatives through to independence
			• Leadership and vision owned by people who access mental health services and carers, as well as professionals and staff
			• Community-based or 'of the community'
			• Co-production is service user led around agreed, shared agenda

Where you are on the spectrum	**Beginnings of service user involvement**	**Good service user involvement**	**Service user led**