



FULL REPORT OF THE EVENT

1. Method: How we tried to make today a success

The Date & Time

- We chose the date carefully – we wanted to tie into the publicity around World Mental Health Day.
- The date was also symbolic – putting drug & alcohol issues on the mental health map.
- We wanted to make sure it coincided with the other main plank of the Dual Diagnosis programme – the start of the training of Staff at LAU.
- We started after 10.30 – and finished before 4 - so people could pick up scripts, buy saver tickets on the bus, or drop the kids off at school.



The Invitations

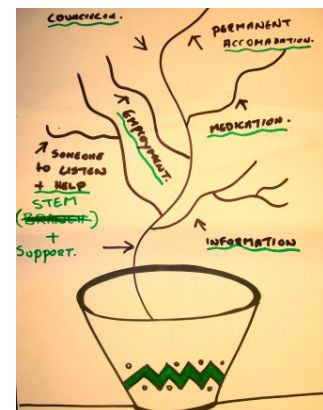
- We sent out the invites with plenty of notice.
- We asked staff to “sell” the day to Service users.
- We wrote to everyone a week before the day, to remind them the event was happening.
- We phoned everyone to see if they would need help getting to and from the venue.
- We made sure that everyone who was coming knew that spaces were limited. We didn’t want enthusiastic gate-crashers/well-wishers to be turned away on the day.
- We made sure that service users were paid for their contributions at the end of the day.

Venue

- We chose a training room at one of the core Dual Diagnosis partners, with another breakout room.
- We made sure they could provide decent catering for the day.

Content

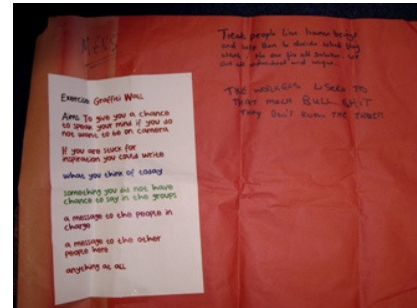
- We tried to balance the information we gave between written material, graphic-rich exercises, and ones which participants created themselves.
- We started out with small group exercises – to build confidence, before moving onto larger group discussions.
- We tried to pace the day to keep it interesting. We made sure we moved on every half an hour or so.
- When activities over-ran we asked participants to choose between stopping before we were finished, or moving on to the next exercise.
- We remembered the point of the day. The exercises were there to encourage the sharing of opinions and discussion. So when people got talking, we changed the exercises to fit in around them, not vice versa.
- We tried to make sure everyone got their say. Some people found speaking in groups easier than others, and we tried to make sure that no-one’s contribution was ignored or overlooked.
- We scheduled plenty of breaks for smokers and to give some headspace.



- We made the activities visual and interactive – we gave clear instructions in writing for people to consult, as well as explaining it from the front.
- We provided admin. support to the group leaders, to make sure everything was written down.
- We didn't use power-point, so nothing could break down.

Evaluation

- We used lots of evaluation tools. We allowed people to video or tape their contributions, and offered them a cash incentive to do so. We gave them some prompts that they could use or ignore.
- We wrote down what was said on flipcharts.
- We provided graffiti walls in the toilets so people could offer written opinions in private. It also allows us to analyse feedback by gender more easily. Again, we gave prompt sheets that people could use or ignore.



Feeding back

- We held an immediate debrief/evaluation session to capture first impressions.
- We allocated jobs to get things done quickly.
- We allocated tasks according to pressing deadlines (for print coverage).

2. Full Record of Participation, Analysis and Outcomes

Comments on difficulties and barriers to care

ANALYSIS OF THEMES & KEY POINTS	COMMENTS / QUOTES FROM PARTICIPANTS
<p>Access to appropriate care is difficult and fraught with barriers:</p> <ul style="list-style-type: none"> ▪ There is a concern that vulnerable people often become homeless. There is a view that some people commit crime to access support. ▪ The requirement of being abstinent from alcohol / drug use before accessing mental health care is perceived as a major problem. This can be perceived as unattainable, or in other cases as unbearable pressure. ▪ Referrals to specialist services are difficult to initiate; people are often passed on from place to place and often there is no follow-up. ▪ When people managed to access services, they found that there was very seldom aftercare provision. 	<ul style="list-style-type: none"> ▶ Concern was expressed about people who were “Too ill to sort themselves out at all, who had fallen through the net and would, therefore, be very vulnerable and sometimes finishing up on the streets”. ▶ “I had to get arrested before I could get support. I couldn't get referred for extra support with my MH until I got clean. I could have really done with the help at that time”. ▶ “I didn't get any help until I committed a crime; as soon as I got to court I was given on a script”. ▶ “No help until committed a crime”. ▶ “Court – script”. (A comment regarding lack of support until involved with criminal justice). ▶ A participant stated that “he actually had to commit a crime and get arrested to get a script”. ▶ “Support not available until clean”. ▶ “High expectations”. (A comment regarding unrealistic requirement of being drug-free before accessing support). ▶ “When they pressure you into things you don't want to do”. (Comment relating to people who are not yet ready to make changes feeling pressured into it). ▶ “Hard to get appointments to see a mental health worker but seems to be a problem if you need to change the appointment once you have one”. ▶ Most of the service users seemed to find “the first barrier to getting help was the fact that once they had made an initial visit to the doctor they couldn't seem to be able to get any further help. They had difficulty in getting referred to the services available which could be of assistance to them”. ▶ “Not getting much help when did actually access these services. Found that no one phoned back and felt that had to try and sort things out myself. Services don't actually seem to communicate between each other”. ▶ “When they let you down and pass you on to others”. (Perceived as major barrier to recovery). ▶ A gentleman who had been homeless “went to Housing Advice, who sorted him out with somewhere to live. He then went to ADS but wasn't informed of the services available. He again felt the doctor had delayed the process of getting him help”. ▶ A few people said “they found AA to be a very good service. But they needed some follow up service they could access that would be ongoing after”. ▶ “No aftercare”. ▶ “Things have not changed for 18 years”.
<p>There is a perception that prejudice and antagonism against substance users is still present in health services:</p>	<ul style="list-style-type: none"> ▶ “Services don't want the people with DD. Negative about dual-diagnosis. People don't know what to do”. ▶ “Stigma – people treat you different”. ▶ “Doctor's seeing you as a 'user', 'alcoholic', etc. instead of an individual”. ▶ “Doctors can be devils when they just turn round and say - well stop drinking then”.

<ul style="list-style-type: none"> Judgemental attitude and lack of empathy of professionals has led some service users to feel de-valued, rejected and unable to develop trust in relationships. 	<ul style="list-style-type: none"> ▶ “When they assume you are stupid because you are in care service”. ▶ “To lack empathy and not place themselves within yourself”. (<i>Perceived as negative</i>). ▶ “Not understanding the illness as a whole – seem to judge because of the illness”. ▶ “Often after seeing someone for help – professionals end up teaching you how to behave badly because they don’t listen to you”. ▶ “When they point out the obvious”. (<i>Perceived as unhelpful</i>). ▶ “Not (able) to trust”. (<i>Comment on the result of feeling judged</i>).
<p>There is a perception that waiting times are a significant barrier to care:</p> <ul style="list-style-type: none"> It can take months to be assessed by professionals and when it happens, this doesn’t always result in suitable care. There is a perception that appointments may not be long enough. 	<ul style="list-style-type: none"> ▶ One lady said that “after going to her GP to try and get some help she had to suffer for two months before anything was done, in which time she felt she could have been dead”. ▶ “Difficulty getting convenient appointments”. ▶ “Waiting times, services not getting back in touch”. ▶ “I was left hanging with no follow up in the beginning. I was told I would have to wait months but wasn’t contacted”. ▶ “Not honest about referral times or realistic”. ▶ “It was felt that care programmes came too late and if they were implemented earlier their situations would not be as bad”. ▶ Referrals can take long. “There should be better links between LAU and other services, like having addiction workers at GP’s and other community receptions”. ▶ “Long waiting lists – 6 months plus”. ▶ “One service user having to actually wait six months before getting any real help. Appointments not long enough”. ▶ “Time restrictions and financial restrictions – adversely affect my progress”. ▶ “Sometimes they don’t give you enough time because appointments aren’t long enough”. ▶ “Not given adequate time to talk to counsellors – half an hour once a fortnight is not nearly enough time”.
<p>Lack of Drug & Alcohol knowledge and lack of awareness of existing services are major difficulties:</p> <ul style="list-style-type: none"> There was a general perception that both professionals and service users are largely unaware of sources of support for drug & alcohol use. There is a perception that there is a lack of drug & alcohol awareness within health services. 	<ul style="list-style-type: none"> ▶ “GP’s haven’t a clue about alcoholism or drugs, so it’s up to you then, it’s frightening”. ▶ “You can feel on your own if you don’t know where to get help”. ▶ “GP – clueless about all”. ▶ “GP’s don’t believe you – only found out about LAU later on”. ▶ “Counsellors don’t always have experience”. (<i>Specifically in dealing with addictions</i>). ▶ Not enough information given by the professionals to steer people to AA and NA who people commented were a lifeline. “If it wasn’t for these groups some felt they would not be here today but felt that they aren’t promoted enough”. ▶ “Also there was not enough public information about what services were in place, and how they could help”. ▶ “Lack of info about services”. ▶ “Not enough understanding of lapses and relapses”. ▶ “Drugs worker don’t always know what’s best, they can only advise”. ▶ “Not always helpful when they think they know what’s wrong”. ▶ “Not understanding – complicating little problems”. ▶ (<i>some professionals</i>) “Don’t understand reasons for using”. ▶ “Turning their back on me and cutting me off because of my behaviour. Understandable, but left me feeling vulnerable and alone”. ▶ “The workers listen to that much bullshit that they don’t know the truth”. ▶ “Not enough recovering alcoholics / addicts working in Drug & Alcohol services”.
<p>Other factors & unmet needs which hinder recovery are:</p> <ul style="list-style-type: none"> There is a perception that overstretched capacity of services and an excessive preoccupation with monitoring & recording hinders effective care. Financial difficulties can be an obstacle to accessing services. Mental health & addiction can perpetuate unemployment and have a negative impact on self-esteem. Poor accommodation can deteriorate overall health. 	<ul style="list-style-type: none"> ▶ (<i>Services often have</i>) “Too many clients for good support”. ▶ “Professionals are more interested in statistics than people and their problems”. ▶ “They can intrude on my personal life by asking too many questions”. ▶ “Unable to afford telephone calls”. (<i>To contact services and follow-up appointments</i>). ▶ “They also struggled financially after being put on job-seekers allowance and felt this was an unfair benefit because they had little chance of getting a job”. ▶ “Finding employment was very difficult as most of the service users had no confidence in even getting to the interview stage after being off work for a considerable amount of time and having to state on the application form that the reason for their absence from work was because they had been alcohol/drug dependent or because of mental health problems. They felt they would be stigmatised”. ▶ “Social security benefits – don’t have the money available to access services”. ▶ “Accommodation – only got accommodation with support worker after 4 years”. ▶ “Bad when you have to complain to get something done”. ▶ “Low self esteem is major problem”. ▶ “Self-sabotage”. (<i>Comment regarding service users unready or unsure about making changes</i>).
<p>Lack of consistency is a barrier to appropriate care:</p> <ul style="list-style-type: none"> Problems found with poor follow-up, unsuitable meetings and constantly changing practitioners. 	<ul style="list-style-type: none"> ▶ “Not phoning back”. (<i>Comment on services not following-up referrals</i>). ▶ “Expected to be proactive – left hanging – no follow up”. ▶ “Consistency – not getting weekly counselling”. ▶ “When the doctor changes my appointments therefore prolonging my detox and difficulty in recovery”. ▶ “Sometimes they go on leave or on holiday so I wish they would have a stand-in”. ▶ “Problems with building up trust, getting to know counsellors who keep changing constantly”.

Medical interventions are perceived to be inadequate in the absence of additional behavioural and psycho-social support:

- There is a view that reliance on medication can become problematic.
- Some service users were sceptical about diagnostic & treatment and were concerned that medication masks psychological issues which could be addressed via additional emotional and practical support.

- “Reliance on medications”. (*Perceived as negative*).
- “If having had a problem with a doctor/psychiatrist they found it just about impossible to change to another one. Felt they were being doled out medication which kept them quiet, but the underlying problem to their addiction/illness was not addressed. Another complaint was that they were baffled with lingo they didn’t understand. They also felt that sometimes the professionals got things wrong and would not admit to this”.
- “The answer always seems to be to throw medication at the problem. If one medication isn’t working, try another and then add another on top of that until some service users could be taking 5/6 types of medication which they feel are all fighting against each other”.
- “It makes it worse if you see a psychiatrist. It makes it worse with the medication”.
- “They don’t do anything with us, apart from giving us medication. They expect us to get on with it.”
- “Side effects of the medications given are not explained clearly enough and most people taking medication feel worse than if they weren’t taking any medication”.
- “Medication given is not always relevant to the symptom”.
- “Medication is given to dampen emotions instead of being offered practical advice. People are suppressing anger and upset from years of abuse but no-one wants to know about people’s past, they just want to cover up the problem by prescribing medication to dampen people’s feelings”.
- Someone commented that ‘Silence is golden’. “Doctors prescribe medication to quieten the person and that way they take up less time and are less trouble”.
- “Silence is golden”.
- “Medication masks the problem”.
- “If you’re quiet, you’re cured”.
- “Medication makes you keep your mouth shut!”
- One person stated that “in 21 yrs of working in the nursing profession she only knew 2 nurses who didn’t drink or use drugs. This she felt was due to the enormous pressure they are under which she felt led to nurses/professionals not doing their jobs properly and often giving wrong diagnosis”.
- “Service Users not given enough support to be taught how to cope in the ‘real’ world”. (*Comment relating to insufficient social and practical support*).
- “Psychiatrist’s make flash diagnosis without even knowing people properly. It’s wrong”.
- “Jargon, technical language”. (*Perceived as unhelpful*).
- A service user felt that psychiatry “caused more harm than good, nothing positive to say about this profession”.
- “A psychiatrist should be a choice of help not make bigger problems”.
- “Everyone here today has a reason for using whatever they use and medicating us into oblivion is protecting our persecutors and making us responsible for the distress they cause us. They are listening to the wrong people and abusing and imprisoning (chemically) the innocent!”
- One service user who had been ‘clean’ for many months said “he couldn’t cope with people and couldn’t stand being on his own, how was he supposed to live a normal life? He heard voices in his head and around him and was prescribed medication which often made things worse. He himself cut out medication and was coping but felt lost without the support he was trying to get to enable him to cope without taking medication. He had lost all faith in the medical profession and felt that because he gave the impression he was coping, he was dismissed as being better”.
- “In prison they just give you a box of tablets”.

Suggestions and comments regarding service improvement

ANALYSIS OF THEMES & KEY POINTS	COMMENTS / QUOTES FROM PARTICIPANTS
<p>Suggestions to improve access to care:</p> <ul style="list-style-type: none"> Lengthy support from a consistent, known practitioner. Easy access to support via drop-in, day services and comprehensive treatment available locally. Improved information on drug / alcohol and mental health services available locally. 	<ul style="list-style-type: none"> Length of time – permanent worker @ GPs. “That services such as detox would be available in all areas, not just certain areas and that all areas had the same services”. (<i>Access to</i>) “A day care service would be brilliant”. “More info about LAU and ADS etc. in GP surgeries”. “Standard list of services”. It was suggested “it would be helpful if posters were displayed in Doctors’ Surgeries, Housing Advice and Community Services”. Better communication in future. (<i>Between practitioners / services, to enable referrals to go to the right place</i>). Better communications to get everyone on the same wavelength.
<p>The following factors were considered useful skills, attitudes and values that enable services to offer adequate care:</p>	<ul style="list-style-type: none"> “I would much rather work with a person that cares; to be there for me”. “Someone who gives a shit – with experience – volunteering opportunity”. “Do their best to listen and try to understand your problems”. “They (<i>practitioners</i>) try not to discriminate”. “Treat people like human beings and help them to decide what they want. No one fix all

<ul style="list-style-type: none"> ▪ Caring, person-centred, non-judgemental approach. ▪ Listening skills, ability to empathise and to offer 'personalized' care based on individual needs. ▪ Consistency of care and continuous support including aftercare. 	<p>solution. We are all individuals and unique".</p> <ul style="list-style-type: none"> ▶ "Good when you're not judged for your past". "Listening skills / ear". ▶ "Someone to talk to when you have a problem". ▶ "Good when they listen". ▶ "For people to pick up on people's distress at an earlier point in time before things begin to spiral out of control". ▶ "If you connect with a worker it's 100% good for you". ▶ "Only come for help – we just need some support". ▶ "Bit of support" – so you don't feel you're on your own ▶ "Try to be there to help". ▶ "To offer support with my life changing situations". ▶ "They help monitor my moods and drinking". ▶ "Consistency". (<i>Comment referring to having a steady, known practitioner</i>). ▶ "Continuous support". ▶ "Being provided with a long term consistent service that addresses all aspects of my needs – behaviours – feelings – treatment options – education and learning appropriate living skills in an accepting and empathetic environment". ▶ "Aftercare: staff made the difference – with experience". ▶ "To see more trained people working in services and for appointments to be longer". ▶ "More people working in this field with experience". ▶ "That people could help each other and for the services to understand exactly what people want, need and require. Also to have appropriate help to get the benefits that people are entitled to".
<p>Other factors that support recovery:</p> <ul style="list-style-type: none"> ▪ Having a positive attitude, self-belief and being proactive can help people on their way to recovery". ▪ Being aware of what sources of support and treatment are available. 	<ul style="list-style-type: none"> ▶ "Being pro-active as a service user". ▶ "Taking responsibility with your addiction, building confidence" ▶ "You are worth it" (<i>comment on attitude that enables recovery</i>). ▶ "Self-help". ▶ "Accessing money – benefits and finding out what you are entitled to". ▶ "Getting in touch with housing and other agencies". ▶ "Going private". (<i>Comment on other care options</i>). ▶ "My daughter and Community Links". (<i>One person's comments on most important sources of support</i>). ▶ "AA is helpful but not for everyone". ▶ "I never knew I could get clean until I met someone who had done it." – Specific reference to AA, a comment which could have been made by myself.
<p>The top 5 treatment options that service users considered needed further financial investment are:</p> <ul style="list-style-type: none"> ▪ General Practice. ▪ Structured counselling / drugs treatment. ▪ Psychotherapy. ▪ Community Detox. ▪ Hepatitis & HIV support. 	<p>[NOTE: Participants were given the task of 'investing money' in a range of possible treatment options. The figures below illustrate the distribution of the 'fake pound notes' that were used as part of the activity.]</p> <ul style="list-style-type: none"> ▶ GP Support (£360) ▶ Structured counselling and treatment £340) ▶ Psychotherapy (£300) ▶ Community detox (£300) ▶ Hep/HIV services (£260) ▶ Structured day programme (£220) ▶ 12 step/peer support (£180) ▶ Alcohol detox and rehab (£180) ▶ Counselling (£120) ▶ Counselling (£120) ▶ School awareness programme (£120) ▶ Harm reduction (£100) ▶ CRI – training addicts to help other addicts – to work in other services (£100) ▶ In-patient detox (£60) ▶ 12 step programme run by people who've recovered via 12 step (£60) ▶ Maintenance/sub prescribing (£60) ▶ Training therapies (£60) ▶ Needle exchange (£40) ▶ Psychosocial Interventions (£40) ▶ More help for young people living in addictive/alcoholic households (£40)

Comments on Service User Involvement and Evaluation of the Consultation Event

ANALYSIS OF THEMES & KEY POINTS	COMMENTS / QUOTES FROM PARTICIPANTS
<p>The following aspects of Service User Involvement were commented on:</p>	<ul style="list-style-type: none"> ▶ "Everyone has a voice and that each voice will be heard." ▶ "More s/u involvement – lot of empathy out there". ▶ "To see this as a regular thing – feedback where ideas are going". ▶ "To see regular meetings set up like the one today". ▶ "Too sceptical about the future feel able to decorate the room but not build the building". (A

<ul style="list-style-type: none"> ▪ Generally speaking, service user consultation is valued and participants would like to take part in future events. ▪ A number of people suggested that they would be keen to become actively involved with services and 'self-help' initiatives. 	<p><i>comment on service user involvement).</i></p> <ul style="list-style-type: none"> ▶ "We (<i>service users</i>) might have more to offer – quarterly, weekly and monthly". ▶ "For service users to be able to help set up a drop in service with service users fronting the service. Many service users would be willing to volunteer to attend". ▶ One lady suggested "setting up a voluntary organisation and said she would be quite willing to help and other people said they would also be willing to offer some of their time". (<i>Comment regarding help for people with Dual Diagnosis</i>). ▶ "To see service user's actually working in services". ▶ (<i>To engage with</i>) "People who think like I do". (<i>Comment on a positive aspect of involvement events</i>).
<p>Overall comments and Evaluation of the event:</p> <ul style="list-style-type: none"> ▪ Participants valued the opportunity to express their views and found that everybody had a chance to do so. ▪ Participants found it very helpful and encouraging to meet and interact with people who have had similar experiences. 	<ul style="list-style-type: none"> ▶ "Everyone has a voice and wants to be heard and it was felt this was achievable on this day". ▶ "Given a chance to speak, was not usually one to speak out but felt able to today". ▶ "To have had the opportunity to speak out and be heard". ▶ "More of this – everyone's had an input". ▶ "Overwhelmed and privileged; everyone has a right to be heard". ▶ (<i>Would like to see</i>) "More of this; everyone's had an input". ▶ "Advocacy – chance to talk to people and <u>make</u> services listen". ▶ "Today has proved that just because we use alcohol or drugs we have something worth saying. We might be addicts but we ain't dickheads". ▶ (<i>The event encouraged</i>) "Better connections between people". ▶ "It was good to meet other people who understood and had shared the same experiences". ▶ "Good to meet other people – did not feel so alone". ▶ "Been a privilege to meet other people who shared the same experiences and had been good to hear other people's views and opinions". ▶ "Meeting people who have been through the same thing". ▶ (<i>Has been good to meet</i>) "Other people with the same problems". ▶ (<i>Has been interesting to hear</i>) "Other people's thoughts on mental health problems – stigma attached". ▶ "Surprised myself and hearing people's point of view; I'm not the only one thinking these things". ▶ "Well done to everyone for coming to the group – it's a difficult thing to do". ▶ "Improved confidence – you're not alone". ▶ "It's a natural high" (<i>to meet like-minded people</i>). ▶ (<i>Has been positive</i>) "Opening my mouth and speaking – getting up and saying something". ▶ "Wonderful day – very enjoyable". ▶ "Intelligence, passion and goodness in the room".

Conclusions can be found in the "summary of outcomes report" which can be downloaded from:

<http://dual-diagnosis.org.uk/doc/SU.consultation.report.pdf>