



# VOICES for choices



A vital part of this year's conference was the service user consultation exercise that ran throughout the day. Our volunteers, armed with their clipboards, asked delegates about their personal experiences of drug and alcohol treatment. One of the main points of this was to find out if they had been offered choices – and if those choices had worked well for them. **DDN** reports on the results

**A**fter lots of relapses it's finally worked with a good script and a good key worker, but mainly because I wanted to stop. I've been three years heroin free.' For many service users this statement sums up the difference between success and failure – having the choices available and the right support at hand to help them use those choices and set 'small, achievable goals'.

The importance of a 'brilliant' key worker was obvious to respondents. When the chemistry here was right, service users saw a world of possibilities opening up. They were put in touch with the appropriate health services, given advice about their prescribing choices and options for achieving abstinence, and pointed in the right direction of support to find training, work and help with family life. The key worker also offered vital continuity of care: 'Having the option of changing

from methadone to Subutex with good support from my keyworker was essential,' said one service user, who added that the support he received following some traumatic events in his family saved him 'from complete breakdown'.

With a disinterested or poorly trained key worker, choices – and a tailored care plan to follow them up – became more remote. A service user who commented that 'relations with service users could be improved' explained how, when their drug use became chaotic, they had to attend clinic twice weekly, where 'they only did drug tests – I had no therapeutic interventions. There was no consideration of the costs of transport and other commitments, and no choice, only methadone. I did a detox twice, and they caused a setback in my treatment' – a clear case of the jointly agreed care plan not happening.

'Excellent peer support and having key workers who were ex service users

## Cheers...

'My own choice when free from alcohol was to look forward to gaining employment, but I had to set small achievable goals and now I am attending college doing HNC social care... so yes, my own choice has worked well.'

'I have seen the services change so much as I have been using methadone for 30 years and was on a heroin script before that. In the 70s there was just methadone or nothing, so to see the full range we get today is how treatment should be. I wish I had had the choice then – things might have been different for me in treatment terms.'

'I have been given a lot of choices by the services I use and this has helped me no end.'

'I think it worked because I was given the choice of medicine, psychosocial intervention etc.'

'Aftercare is good, I have felt benefits, it has cut old behaviour patterns... users run drop-ins and do tasks. It builds confidence.'

'I'm very happy with my treatment, I was given lots of service user involvement opportunities... Help people keep busy, volunteering, training, education.'

who I could relate to' took one respondent through the treatment system and into good aftercare. His experience had encouraged him to follow the route to helping others in treatment, and he had rewritten a manual for the expert patients programme and created an abstinence peer group.

Others had been coerced into treatment and felt they had been offered no choices. 'I was rushed into treatment via CJIP with a poor explanation,' said one. 'I was put straight onto methadone within 24 hours without any real assessment. They like methadone in CJIP.. now I have two habits instead of one.' Another client of the criminal justice system commented: 'The DTO was garbage – I was not treated equally.' By contrast, the same person experiencing a structured day programme said 'it was 'brilliant – it works'.

Many respondents felt they would have benefited from a different, more 'person-centred' approach from both agencies and key workers, who should be 'looking at a person's whole situation'. 'The choices were limited and owned by the agency,' commented one of many service users who had hoped for 'a more tailored care plan'. 'There is no flexibility, no manoeuvrability, it's service-centred treatment: "if you can fit your treatment around us it will be OK".' Another added: 'More individualism is needed. I feel as though I am in a cattle market or on a conveyor belt.'

There were many worries about inadequate or inappropriate treatment relating to specific drugs. The loudest complaints were about the lack of alcohol treatment, which they blamed on ignorance about clients' needs or lack of local funding. For many services users, an alcohol problem became far more significant during the course of their drug treatment, and in many cases was overlooked from their initial assessment onwards.

'After reducing my script I found my alcohol intake increased dramatically,' said one respondent, who explained that he had to 'play down the alcohol side and play up the class A side' to be accepted by a project that was not funded for primary alcohol treatment. 'I fully realise this is a funding issue, but I feel that the correlation between drink and drugs should be better addressed,' he added.

Crack was another frequently misunderstood drug, particularly when combined with alcohol. 'It's all targeted on heroin or alcohol use as individual addictions,' said a service user who has been drug free for five years and alcohol free for a year. 'I was determined to stop crack and stimulant use, but carried on drinking for four years because the link between crack and alcohol was not catered for or acknowledged,' he explained.

One service user described how she had to visit a number of treatment agencies because she was using more than one drug. 'Agencies should be able to work across all substances,' she commented.

Many others complained of regional variations in treatment and called for services to be consistent across the country. 'If I move I should know what to expect,' said a respondent who complained that 'wherever one goes in the country treatment is different.' Another commented that he experienced the best choice when he was homeless and on the street for eight years. After many previous attempts at getting into treatment, it took the homeless outreach team to make it a reality.

Ignorance of mental health problems was another serious barrier to treatment.

## **'There can only be true choice when the service user has comprehensive information about the options available.'**

One service user said they were refused antabuse in treatment for their alcohol problem 'on the grounds of a mental health problem', and 'felt brushed under the carpet'.

Others were hampered by services' lack of knowledge around dual diagnosis: 'My partner had a mental health assessment (he was violent and paranoid) and was sent home as "just having a drug problem".'

Real choice boiled down to individually tailored treatment time and time again – and a constant fight with resources. Being part of the RIOTT (Randomised Injecting Opioid Treatment Trial) had 'worked brilliant' for one service user – 'the first time I have been stable in over 20 years'. For many others, a menu of choices that did not resort to just methadone, but which included holistic and alternative treatments, had formed a vital part of treatment and aftercare. Others had found the service user network a vital lead into life after drugs. In cases relating to all of these situations, there was high praise for inspirational and committed workers and peers who had looked beyond budgets and processes to empathise with them and spur them on – and equally, condemnation of workers and services who were ill equipped to deal with vulnerable people.

'Please employ the right people for the right job – people who care,' said one, who complained that 'people in higher management make a decision about treatment without it having a positive affect on the service user'.

'Being at the centre of my care plan, being allowed to decide my treatment route, and that decision being supported and respected,' was the ideal vision of one single mum. It's a far cry from one disenchanted service user, whose verdict was: 'I never really felt I had a choice, just shuffled through the system. Even five years clean I think "the bastards made me do it".'

Service users throughout the day gave plenty of clues on the choices that would help them, and some gave an entirely positive reflection: 'I have been given a lot of choices by the services I use and this has helped me no end.' For others, there was a long way to go: 'Nowadays there's all talk about choices, but little action. Staff are so stretched they haven't got time to sort things and would prefer the easy choices.'

One respondent summed up: 'For most first time service users, as I was, the treatment journey is a chaotic lottery,' and added: 'There can only be true choice when the service user has comprehensive information about the options available.'

## **And tears**

'The choices are limited and owned by the agency. There is no flexibility, no manoeuvrability.'

'I had alcohol dependency but I was thrown out of treatment. The biggest mistake I made was asking for help. It was why I got involved with service users.'

'At one point I had a bad keyworker. I felt that I could not ask to change the keyworker for fear of retribution.'

'I have been in treatment for the best part of 20 years. As yet my choice has not been taken into account. So far, in my experience, it's been the drug team's way or the highway.'

'There were no options, none signposted, no pharmacological interventions and very poor psychosocial interventions.'

'Peer support has never been suggested by providers. There was limited harm reduction and no aftercare – just "keep busy".'

'The service went in trends, eg methadone or detox, then rehab. There's no abstinence-based approach.'

'When I wanted a detox there was no help given, they just said don't stop the methadone maintenance due to a risk of relapse. My goal was not a consideration.'