A New Prescription for Drugs Services: giving users a greater role in recovery

A User Voice project for the Doncaster Drug Strategy Unit supported by the Centre for Innovation in Health Management, University of Leeds

A New Prescription for Drugs Services: giving users a greater role in recovery

Introduction

This report is based on a user-led consultation with the recipients of drug and alcohol services in Doncaster. The impetus for the project came from Doncaster NHS Drug Strategy Unit (DSU), who recognised that involving the people who used their services can play a vital role in effective delivery and evaluation. The project was designed and delivered by User Voice and supported by the Centre for Innovation in Health Management, at the University of Leeds.

User Voice was chosen because it has unique and effective methods of engaging with excluded groups. Run for and by ex-offenders, User Voice ensured that the research was carried out by ex-offenders who have considerable experience of drug and alcohol services. User Voice's facilitators have turned their lives around and are all fully-trained to run consultation groups. Their past gives them a special understanding and rapport with service users which encourages participants to talk openly - often for the first time - about their feelings and experiences.

Methods

Service users were surveyed at various locations across the Doncaster area. As well as undertaking four focus groups, User Voice conducted in-depth interviews with service users. Finally, a seminar was hosted in Doncaster where service users, providers and commissioners could exchange thoughts and ideas about service improvements.

The project's approach was guided by User Voice's principles. At the heart of these is a belief that effective user involvement needs to build on the recognition of the power relationships that exist between staff and service users and the difference this can make to perspective. User Voice believes that both groups have vital and distinct contributions to make and both stand to benefit from service user involvement activity.

Findings

Questionnaires

In total, 257 questionnaires were completed by service users. Over half of all respondents reported having a positive relationship with their drug support worker: comments ranged from 'fine' to 'fantastic' were expressed. Service users were asked about their relationships with their drug support workers. The majority of respondents indicated that having a compassionate or understanding key worker helped them to think positively about their situation. Conversely, service users did not feel it was helpful for key workers to be involved in influencing changes in prescription and

reported feeling powerless when they encountered a system that was unhelpful, often acting as a barrier in their recovery as a result of the focus on treatment.

Suggestions for improvements suggested a real willingness on the part of service users to put time into their recovery; many wanted more time to be allocated for appointments and for the number of regular appointments between key works and service users to be increased. When asked about service users' role in services, a number of respondents believed that users should have more of a say in their own treatment, relying less on what key workers suggested or guided them towards. It was also highlighted that face-to-face communication and honesty were essential to improving communication between service users and key workers.

Focus groups

Focus groups give more time for discussion in a structured environment. Earning the trust and respect of participants is central to successful engagement. The User Voice approach invests time, energy and effort in creating and cultivating relationships before any meaningful work takes place. This allows the space for a trusting relationship to develop; one that is based on respect and understanding. By understanding that the people leading the delivery have come from similar experiences, people are more likely to be motivated and inspired to give insight from some of their most personal experiences.

Some key themes emerged from the focus groups:

- *Positive experiences of services:* The majority of positive comments received in relation to services related to successful relationships with key workers which are based on trust, respect and understanding.

- *Negative experiences of services:* When relationships were unsuccessful it was often when service users felt that the service offered was being done 'to' rather than 'with' them. This was particularly in relation to Probation which was seen as a barrier to the treatment journey.

- *Treatment and exit plans:* Most service users expressed deep concern about being prescribed methadone for lengthy periods of time with little or no exit plans. There was great fear and misunderstanding about coming off methadone among service users with providers not seeing this as a critical step. Too often getting into a methadone programme seems to be a 'good enough' end point.

- *Improving services:* The more frequently cited improvement was the need for greater communication between service providers and service users and for service users to be central to their own treatment plans.

Seminar

The focus groups highlighted a number of key challenges that service users chose to discuss further at the final seminar. These included:

- How to improve the relationship between key workers and clients, including identifying key barriers.
- How to address treatment and in particular staff providing medication too willingly.
- How to improve services users' access to housing and ensure they were able to find stable, safe and secure places to live.
- How to improve service users' access to training and employment and developing sustainable routes back to work.

Conclusion and recommendations

Many of the participants in this project said that this was the first time they felt that their voice had ever been heard. The current system of drugs and alcohol services is led by professionals and a national drugs strategy, which has tended to emphasise – even define service provision – as treatment, rather than a more holistic approach to drug and alcohol misuse. This is perceived by the outside world as a successful model, but on closer inspection and through listening to service users in Doncaster, this emphasis results in a menu of services available is that largely limited to prescription.

This consultation underlined the importance of face-to-face communication, and not just paper-based systems. Service users stressed the importance of talking and listening and of developing empathetic and honest relationships between drugs and alcohol misusers and key workers.

We conclude that the earlier users are able to express their views, share their experiences and raise concerns, the better as this would prevent problems from arising and escalating later on. If there is one overriding recommendation from this report it is that a vehicle should be set up which will give service users a chance to express their views and feelings, and commissioners a chance to hear them. Such an inclusive approach can not only bring about improvements to the effectiveness of the service provision but it would foster co-operation and help service users to take more personal responsibility.

More specifically we recommend:

1. **Recovery and rehabilitation:** there is currently little ambition in the system to move from treatment to a life of recovery and rehabilitation. Commissioning of services needs to be driven by this impetus.

2. **Personalisation:** currently there is a one size fits all service, with little recognition of individual differences and diverse needs. Service users must become central

to their own treatment journeys and treatment plans, so that these different needs are considered.

3. **Improve links with the criminal justice system:** service users highlighted lack of coordination with the criminal justice system as a barrier. In particular they identified lack of coordination with probation as a barrier to recovery and treatment. A striking feature of this consultation was the lack of integration and planning involved in care pathways. We conclude that there is a need for treatment and recovery to be integrated with the Drug Intervention Programme (DIP), prison throughcare and aftercare.

4. **Increase (non-)service user involvement:** the report highlights our ladder of engagement which suggests that current service user involvement in Doncaster while aiming to promote degrees of user power is actually tokenism. Service users and more importantly those not engaged in services need to be given greater opportunities to be involved at all levels, and in order to achieve a deeper and more meaning level of involvement and ultimately more active citizens, not reliant on public services, our overriding recommendation is that service user groups need to be given more independence.

This needs to be considered in a national picture of the Coalition Government's focus on the Big Society, in which people are being asked to do more to bring about social change and the recent cuts announced in the Comprehensive Spending Review, which will create the need for value for money and the greater role of individuals and communities in public service provision.

Case Study A

"I have been rebelling against the establishment. I've been in care when I was 11 from then on upwards. I didn't think I was going to get out because I was just a prolific criminal. And I don't know something has just changed. I was put on a drugs course. When the course ended the feedback I got was just amazing. They made me feel really special. That's the type of feeling. I couldn't even sleep because of all these nice things that they were saying about me, the manager was on about me being an advisor for probation. It's just turned me around. They could have done this years ago when I was in jail.

It's really blown me off my feet. Because I have lived on the wrong side of the fence all my life. But now this empty void in my life has been filled. Me of all people. I have been on that side of the fence, and I saw the rest of my life on that side of the fence. Because I have always heard it myself, even my grandma told me from a young age that I was going to end up in Jonny Bullcock's farm. So that was all I ever got feed. So when I started getting into trouble that's what I thought my path was. But this feeling that I have got, I'm worthy. I'm not interested in the money I get pleasure out it.

I'm used to a world of hostility and people pulling you down and that's what I know of the world. So when a manager gives his office up, and there are staff queued outside to ask me questions and shake my hand I felt really special. And I still do. It's amazing the chance that I have been given. You have to start getting people to believe in themselves because where I am from, if you are starting to do good they start pulling it to pieces to make themselves feel good.

The same feeling that these peoples are giving me, through the courses, has inspired me to go and help probation. These lads aren't prepared to listen because there is a big wall up. They ain't lived our life so how can they understand and all that stuff. By me going in as a mediator, I love it. The change around is good, it's changing everything. When they have said all these wonderful things about me it's just inspired me so much to turn things around."

Involving Users in Drug and Alcohol Services

The impetus for this project came from Doncaster NHS Drug Strategy Unit (DSU), who recognised that service user involvement can play a vital role in the effective delivery and evaluation of its services. This report is based on a service user-led consultation with the recipients of drug and alcohol services in Doncaster designed and delivered by User Voice and supported by the Centre for Innovation in Health Management (CHIM), University of Leeds.

User Voice

User Voice is led and delivered by ex-offenders and former drug and alcohol users. It exists to reduce offending by working with the most marginalised people in and around the criminal justice system to ensure that practitioners and policy-makers hear their voices. It is well placed to gain the trust of and access to people involved in crime and addiction. It aims to deliver a powerful rehabilitation experience for service users, better rehabilitation services and institutions, and more effective policy.

User Voice was founded in 2009 by Mark Johnson, an ex-offender and former drug abuser, best-selling author of *Wasted* and social commentator. Mark's experiences of prison, and later as an employer of ex-offenders and consultant – taking on various roles within the criminal justice system and voluntary sector – left him convinced of the need to create a model of engagement that is fair and incentive led. His aim was to foster dialogue between service providers and users that is mutually beneficial and results in better and more cost-effective services.

All the work User Voice has done suggests offenders want to talk to people who have 'walked in their shoes'. This includes:

- **User Voice Councils** that can be developed for use within prisons or in the community for probation, youth offending teams and other related services.
- **Bespoke consultancy** where User Voice works with clients to design projects aimed at accessing, hearing and acting upon the insights of those who are hardest to reach, including prisoners, ex-offenders and those at risk of crime. These projects include staff and user consultations, workshops and research.
- **Advocacy work** aimed at engaging the media, the public, practitioners and policy-makers.

User Voice recruits qualified and talented ex-offenders to lead the organisation and to carry out its frontline work. This has a profound impact on employees' self-confidence and transforms their long-term employment prospects. More broadly User Voice demonstrates the hugely positive role ex-offenders can play given the right circumstances.

Service user involvement

Listening to users to improve public services is not a new concept; in fact, it is now commonplace. There is broad recognition that effective user engagement can help to improve services and their outcomes by:

- identifying their needs;
- highlighting current systemic failings or gaps between provision and the reality for the end user; and,
- providing ideas for change.

Marginalised groups are often missing from user engagement strategies. This is particularly true of those with substance misuse problems. This project – indeed User Voice itself – is based on the belief that we all benefit and learn when service users are engaged in the services that impact on their lives and their path to rehabilitation. Doncaster DSU have gone some way to redressing this by establishing Dream (Doncaster Recovery Empowerment and Mentoring) a service user peer support group.

The Project

The aim of this consultation was to gain an insight into the extent to which those people who use or have used the drug and alcohol services in Doncaster feel these have helped them towards rehabilitation and recovery. This report sets out the main findings of the consultation, outlining the key issues raised and some of areas where staff and service users can respond to these. The consultation also intended to provide a foundation for the future involvement of service users and ex-service users in Doncaster Drug Strategy Unit.

Methods

This project is a collaborative venture between User Voice and the Centre for Innovation in Health Management at the University of Leeds. Given its core theme, the project sought to involve service users in a way that altered the traditional dynamics of power in research activity. Too often research about service users is undertaken by academics without their involvement and with little attention given to issues of power and involvement. With this in mind, in this project User Voice took the lead role and the Centre for Innovation in Health Management were commissioned to collect and analyse the research data. This helped redress the power dynamic in favour of the user. As well as desk research, we undertook questionnaires, focus groups and a final seminar, all of which involved users in design and execution.

The questionnaire we used was designed by User Voice researchers and was completed at a range of locations frequented by service users including X and Y.

A total of 257 were completed on a face-to-face basis. A different questionnaire was developed for service providers. It total 14 were completed through face-to-face interviews.

Those service users who completed the questionnaires were invited to attend one of four focus group discussions. Three of these were held in the community and one was held at HMP Doncaster.

In total, 25 participants took part in the focus group discussions which gave participants the opportunity to discuss their experiences in more detail. Participants came from a wide and diverse a range of backgrounds and experiences, although the gender mix within the focus groups was limited: approximately 80 per cent were male in the community groups and in the one held in HMP Doncaster all participants were male. Focus group sessions were lead by a researcher from User Voice and notes were taken by a researcher from CIHM.

A final seminar was held in August 2010 and was attended by service users, providers and commissioners. The service users were selected by their peers at the focus groups and were invited to highlight issues raised in this group. Attendees were invited to identify problems, challenges and suggest ideas for change. .

Case Study B

"I have been on methadone for the past 10 years. But the thing is, when you are clean and on methadone they don't tend to want to reduce it because they are happy that you are clean. I was clean for a long time but I was still on the same amount of methadone, it was me that had to go to the doctor to ask to be reduced by 5mls.

I used to see my doctor every four to five months. When really I should have been seeing him every month so I could have my methadone reduced. He should have been talking to me, asking me if I was ready to be reduced, rather than me having to go and ask for the appointment. I shouldn't have had to ask, they should have known. If they had looked at my file they would have seen she has been clean for this amount of time we should look at reducing her.

The reason I have been on methadone for so long is that twice I tried to reduce it and I did it too quickly and I went back and ended up using again. I reduced it down to a certain amount then because I used I was put back up higher than the amount I was on originally. Because I had said I was using x amount a day. They do it like 10ml is one bag. Looking back on it I was on 120mls, there is no way I needed to be on that amount, not on this earth.

I feel like they should have a time scale of , look you have x amount of months and if you are not clean in that amount of months we are going to have to stop the methadone programme until you are ready to use it properly. Rather than be on it and then not only have to get rid of your heroin habit or whatever you are using you then have to get off your methadone addiction. Due to the fact you have been using it for that long. In my case that is a lot worse than heroin. If you are on it for a long time you get to were you need, your body don't want it, it's you that needs it.

The National Context

The National Drug Strategy is currently being reviewed by the Coalition Government, led by the Home Office and in partnership with the Department of Health, Department for Education, Ministry of Justice and Cabinet Office Policy Leads. The vision for the new Drug Strategy is to prevent drug taking, disrupt drug supply, strengthen enforcement and promote drug treatment with a focus on enabling people to become free of their addictions, including alcohol, to recover fully and contribute to society.

It aims for:

- Greater ambition for individual recovery whilst ensuring the crime reduction impact of treatment.
- Action to tackle drugs being part of building the 'big society'.
- A more holistic approach with drug issues being assessed and tackled alongside other issues such as alcohol abuse, child protection, mental health, employment and housing.
- Budget and responsibility devolved wherever possible with commissioning of services at local level.
- Budgets and funding streams simplified and outcome based.
- Financial cost of drug misuse reduced.

The 'rehabilitation revolution' and payment by results will impact on substance and criminal justice commissioning. The impact of elected crime commissioned on Doncaster Drug Strategy Unit priorities and resources coupled with the impact of the 'Big Society' and the DSU response to the broader localism agenda is an impatient contextual consideration.

The National Treatment Agency (NTA), is still operating until March 2012 and the Drug Intervention Programme (DIP) and Pooled Treatment Budget (PTB) – although may be reduced – will still focus on outcomes and drug user and offender involvement in planning, commissioning and will have more emphasis on involvement and delivery and 'patient user feedback'. The NTA's treatment and recovery function will be transferred to the Public Health Body post March 2012 and will include drugs and alcohol.

This is a prime opportunity for Doncaster DSU to review commissioned services alongside this service user consultation to strengthen commissioning of recovery, reintegration and greater ambition for individual recovery and a drugs free focus.

Doncaster DSU should consider and develop any treatment services improvement with payment by results as a key factor to commissioning and achieving outcomes. Government drug and alcohol, criminal justice payment by results will be running as pathfinders in a number of areas with outcomes key to payments.

Outcomes will include:

- Treatment completion – including drug free abstinence and potentially prescribing and methadone but with ambition and rehabilitation
- Secure housing – appropriate to need and individual family
- Training and employment – return to work
- Reduction of crime

A 36% service user involvement outcome measure will be needed. The User Voice Council model (described later) could help support that sustained need and review of Doncaster led involvement.

Findings

The findings of this project drew on desk research, questionnaires with services users and providers, focus group discussions and a final seminar (see Figure 1). All of this data was analysed and a summary of findings is presented in this report.

Questionnaires

The 257 were completed at various locations in Doncaster. This meant we were able to ask the same questions of a range of service users in different contexts and were able to engage those people who did attend discussion groups.

Approximately two thirds of respondents indicated that they lived in the vicinity of Doncaster; the majority (160) travelled less than approximately five miles to access support services (Figure 1).

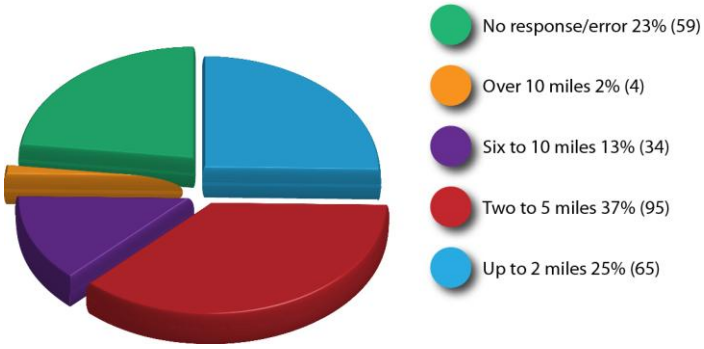

Figure 1: How far do you or did you travel to receive drug/alcohol support?

In terms of support services accessed, a number had used the Garage, DIP and the Probation service (Figure 2). Other services mentioned (but by less than ten respondents) included: a GP, Badas, Dream, Jade Centre, M25, Mind, and Clearways.

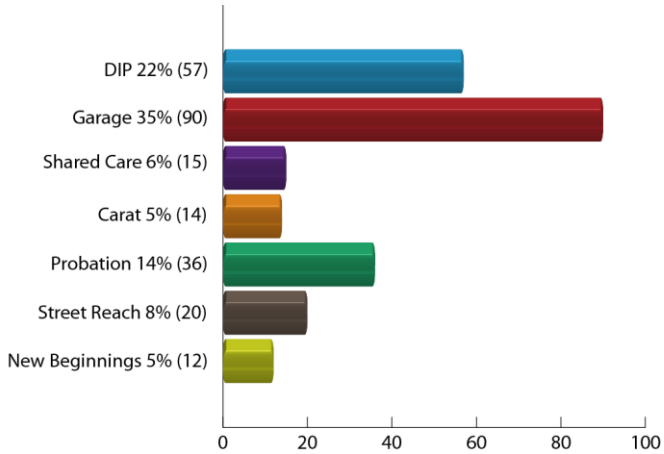

Figure 2: What drug services are you using or have you used in the past?

Over half of all respondents reported having a positive relationship with their drug support worker. Comments ranged from ‘fine’ to ‘fantastic’ being expressed (Figure 3).

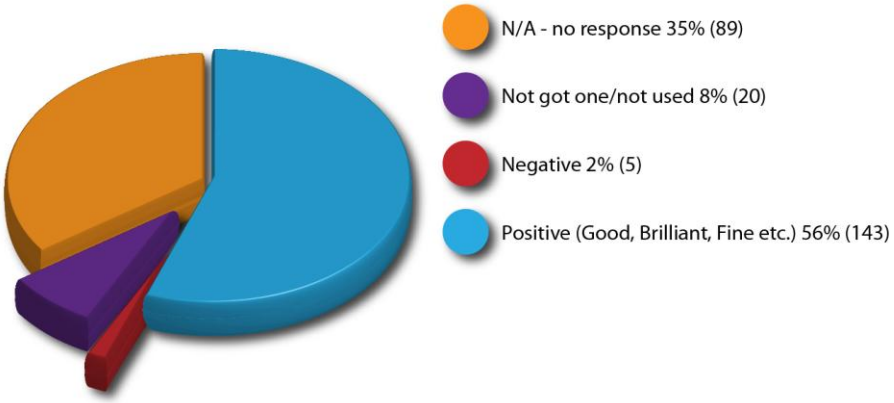

Figure 3: What is your relationship like with your drug support worker?

In terms of things that worked well in the service user/drug support worker relationship, a number of respondents indicated that having a compassionate or understanding key worker helped them to think positively about their situation. Others indicated that a positive relationship was one where their key worker facilitated recovery and change at the service users own pace.

No pressure to do what don’t want to do, and can speak to them about anything.”

“Communication with key workers. Honesty. Not being judged.”

“Having same key worker and the time so you can get to trust them and keeping to appointments and doing what they say they will do.”

“Talk to her, feel like she is listening. Takes action to improve.”

“I think it is good he travels to see me as it is too far to go and see him as they no longer give bus passes out.”

Find it really easy to talk to him.”

A number of themes emerged in relation to elements of the relationship that do not work as well as they could. These included key workers influencing changes in prescription and service users feeling as though they were part of a system that did not centrally focus on developing good relationships.

"Bad feeling if I don't speak to my worker my prescription would get stopped."

"They are a bit slow to do things."

"Putting you in groups in the community when you are drug-free with a full group of people that's using drugs doesn't work well."

"My key worker likes talking about herself a lot."

In terms of improvements to the service, respondents put forward a number of suggestions. These included providing more time for appointments, holding these more regularly, as well as allowing service users to develop a relationship with key workers over time (and not changing or replacing staff). There were also comments about providing more support for travel costs for those coming into Doncaster from its out-lying areas.

"Like to see them a lot more, more than twice a week."

"Give me bus fares to get into town."

"In general more time given if needed. Sometimes key workers are rushed off their feet."

"Staff to learn more about user and their place in the community."

"If they could come to you, because travel can be expensive."

"It could be better if I was to keep the same worker throughout my treatment and to know that I could contact without cash problems i.e. travel."

A range of reasons were put forward in relation to why some people choose not to attend drug support/treatment services. These included embarrassment and a sense that users were admitting they had issues with drugs by making an appointment. Some respondents commented that waiting times could be long once appointments were made. This put some off from coming forward for support and help.

"It is too far away and costs a lot to get there and when I go to the town centre I want to get some drugs if I have the money."

"Don't trust key workers not to talk to other people about them."

"They feel embarrassed."

"Nervous about approaching people of authority. Don't like waiting as when I first got help I was waiting 13 months before I got my script."

"Because we need to get cash to get there and I can't always get on time, then my appointment is cancelled and sometimes put to the bottom of the list

In terms of service users taking a greater part in services, a number of comments focused on respondents having more of a say in their own treatment rather than relying on what the key worker suggested or guided them towards. Others mentioned more practical actions that could be taken, such as providing services more locally to service users and supporting or subsidising travel costs.

"More local services. Pay expenses. Help with childcare. It's difficult for women, they usually have the children."

"Not really sure. Perhaps having more local 'offices' – it costs me a lot to get to town."

"We could have more of a say and not what we are told or how to do/use our treatment."

"To attend whilst not under influence."

"If I could tell them a time I know I can make that way it's my fault if I don't attend."

"Because I work I don't get the chance to go to services and I am expected to leave a days work for appointments just to get on a script which means losing out on a wage."

The term 'service user involvement' generally meant very little to respondents, although some did provide useful definitions and interpretations which highlighted notions of engagement and consultation in relation to decisions about service availability and delivery.

“Means nothing to me.”

“Addicts getting together to talk about drugs. Means the users getting involved in services.”

“The level of effort put in by someone looking for help.”

“Involvement of the drug and alcohol treatment programme.”

A number of suggestions were put forward by respondents in relation to the most effective way for service users and key workers to communicate. Honesty and talking to each other, face-to-face was a common suggestion. Other ideas put forward included the organisation of more social events, such as attending a football match together.

Focus groups

Experiences of services

It's like experiencing a birth – if you haven't been there you don't know what its like. The key workers that I've had – said 'if you do anything in this programme, take charge of your own recovery'. I set off on that footing. He made me think about what the costs of undertaking recovery – and that isn't just cost in terms of financial. I've felt very supported by my key workers. I think it's important to get on with them – I haven't had a bad experience with them."

My key worker is brilliant – he knows a lot of people and can open different doors for me. He suggested college to me and I'm now addicted to that. He is helping me get a computer and that – that's part of my college courses. Other key workers have come in – give me the urine test and that's been it. The communication between me and him has been really good. Built up a really good relationship with my key worker."

"I regularly use the Garage and occasionally use Streetreach. They provide help with housing etc."

"Been going to Garage for a long time – it has changed an awful lot since it started. It has become much better now – better drug intervention programmes."

"I'm only just opening up to my key worker – and building trust once every three weeks is difficult."

"New Beginnings helped me to stay clean for about 6 months. They have aftercare that, as long as you stay clean, you can live there for up to 2 years. You can go out and do activities with them. It really helps."

Some positive comment were received in relation to services; many key workers are seen as providing a useful service and being empathetic. Some participants did recognise that key workers need to operate within a support framework and that this bought with it some inevitable limitations. Some also stressed the need for service users to take charge and more responsibility of their own recovery and there was widespread recognition that there were advantages to be had from working with those who have similar life experiences.

A number of participants listed a range of negative experiences with some services, particularly in relation to probation. A number also outlined limited support in terms of finding suitable housing.

I've never got on with my probation officer – I've had to. I've never trusted her – I only see her because if I don't then I'll get sent back to prison. I've never had any kind of trust there – they've put me on courses I didn't want to go on. I went on the courses when I was in prison. I think they may have been setting me up for a fall – why did they send me onto the same courses time and again? What was the point of that? When I got out of prison I had nowhere to live after a couple of nights in a B & B. I asked my probation officer if she could help me find somewhere to live (which was a condition of my license from prison) and she said it wasn't her problem. I ended up using again because I couldn't get any help – particularly in relation to housing.

I went to Probation and they weren't very helpful. They don't seem to be willing to help – for example I got released from prison early and they didn't help much. The place I was supposed to be staying at fell through and Probation didn't help much.

My key workers were always fantastic when I could see them. My only big problem was with the doctors – they over-prescribed me on my methadone. They gave me anti-depressants which nearly killed me – they nearly gave me a heart-attack.

If you got in a circle of people or a living situation where using is the norm – then it's much more difficult to give up. If you receiving support with good housing then this can help greatly."

Treatment and exit plans

Variable accounts were received from participants in relation to the treatment plans offered to them. A number expressed concern about being prescribed methadone for lengthy periods of time, and others felt it would be useful to outline to service users the dangers of specific treatment options.

'I think there is a set time that you should be on it – if you are on it too long you are going to become dependant on it too much.

The myths should be explained as that – need to educate people – not listen to crack-pot theories. Bones will turn green is a common story that does the rounds of users.

Never mind an exit plan, there should be an entry plan – you need to know what the real story about it is. People are told that it gets into their bones, causes illness etc.

You've got to drink the methadone in the chemist – you can't say: 'can you only give me 40mil today please'? You can leave it in the cup at the chemist but if you do that they can say that you don't need it and they'll take you off it

I'm terrified of coming off it – it really scares me. If I come off it I worry that I'm going to go back onto heroin."

Improving services

Many participants highlighted the need for more communication between service providers and users. Again this was particularly thought to be the case in relation to the Probation Service. Some felt that key workers and other providers needed to have a better understanding of the realities of life faced by service users. In addition, they felt that the provision of less-centralised (including out-reach) support should be provided to help service users to access services and support. One suggestion was offering services through dedicated days to 'users' and 'non-users' and that this would help those who are working towards staying clean.

Sometimes it sounds like you working with a key worker who is reading her advice from a textbook and doesn't really know about it.

There's not enough dedication in the job – key workers have too many people on their books – their caseloads need to be managed better.

More key working sessions would be really helpful – it would help to develop the relationship. When you are in bad place you need to be seeing someone once a week really – or perhaps have group sessions where services users can speak with each other and share experiences and views.

There should be some kind of support group where people can come in, have a coffee and talk with each other.

Services need to have a clear boundary between days for users and days for those who are clean. For example, you have one person coming in for the fix and there'll be another person playing pool in the same building who would rather be doing something else.

Users and non-users should be kept as far apart as possible – it can be a really little thing that trips people off back into using – a wrapper, tin foil, a needle or something.

Services need to communicate more with each other – much more. One provider doesn't know what the others are up to. We have put posters for peer support up in Probation centres and they have been taken down. They actively work against us.

Service providers

A paper-based stakeholder questionnaire was developed by researchers from User Voice and administered at service provider locations in Doncaster. Fourteen completed questionnaires were collated. All rated user involvement in drug-related support services to be important. However, there were variable levels of user-engagement in services with no involvement of service users at commissioning and planning groups of forums, either as members or observers.

Commentary received from the stakeholder group recognised that it was important to improve service user engagement and some were aware of specific service user involvement/peer support programmes (such as Dream and the Garage Alcohol Support Group), although the majority did not know how to include service users. Clearly there is a gap here between the importance service users gave to engagement and the reality on the ground. Indeed there was also a disparity between the importance providers placed on engagement and what happened in practice.

Final seminar

The final seminar was attended by service users, service providers and commissioners. The aim of this was to showcase the benefits of providing a forum for service user representatives – selected by their peers – and to feedback the main issues from the consultation process. The representatives made groups presentations which communicated common issues to the service providers and commissioners, highlighting not only the problems but also the solution and associated benefits. These have been reproduced below:

Relationship with key worker/probation officer

Problem
Service users feel that there is a serious breakdown in communication especially where trust is concerned. They feel that when they do have genuine challenges such as lapses, domestic issues and are honest about them rather then getting support they get punished, especially with probation, which in some cases leads to a full relapse or even back to jail.

Solution
We could have a service user representative placed into probation to act as a link. This would enable both the client and worker to build up trust and eventually their rapport. This way the client feels like he or she can be honest.

Benefits
For service users
They become a lower risk to society, they feel like they are been supported to make positive changes and that they are not just seen as another criminal. All this will improve their wellbeing and have a positive effect on their life.

For service providers
People go from high risk to low risk to the public because that is what it's all about, public protection. Therefore they don't have to be seen as much so more time can be spent on high risk cases. Crime rates reduce which is cost effective because less money has to be spent in sending people to jail. Also workers get better communication with their clients because there is more time to spend on their individual needs.

Treatment and Recovery

Problem
Services are far too willing to give out medication and in the amounts the client asks for. We have heard about an ignorant fear about reducing and coming off methadone and other meds. This is through lack of education and information about medication the clients are on.

Solution

Services need to be more careful about dishing out medication. They need to be sure the client is ready to stop using is ready for methadone and other meds and amounts should be monitored more closely. There is also a need to educate clients about entry into treatment, what to expect from services whilst on treatment and what to expect when they are reducing and coming off meds. This can be done through better early interventions and aftercare. Here are a few examples:
Early interventions:

- Education about medication to help dispel the myths about methadone from the start
- Make sure the client gets the right meds
- Building a proper rapport between client and key worker from the start to get a genuine outcome

Aftercare:

- Continued education
- Continued support and monitoring to help change their views about themselves and their mindset from a life of substance misuse and abuse
- Continued referral to other services

Benefits

For service users

Clients won't be thrust into a treatment programme which isn't right for them. They will have the right information and support as the staff and service providers will have had proper and up to date knowledge, so they will be more able to tailor a treatment plan more suited for each client.

For service providers

Having more stable minded clients will help relieve key workers work load so they will hopefully have more time for training and for clients which will benefit both groups.

Housing

Problem
There is insufficient housing for substance users in Doncaster and the bit there is you are evicted if you are still using substances.

Solution
The solution is to help substance users acquire and secure stable housing in order to give them some stability in their lives to aid them in the recovery process. Supported housing is ideal as long as they are not evicted for using and forced back into the bad cycle of life but supported back into recovery processes, and when ready helped and supported with move on long term accommodation.

Benefits
For service providers
It's easier for people to get out of the vicious circle. Homelessness leads to substance misuse which leads to crime then to jail, which we can all agree is a huge drain on services and tax payers.

For service users
Helps with health and hygiene, being in a stable way of life can help with building with family and getting back into employment.

Education, Training and Employment

Problem
The problem is sometimes people are pushed into work they don't feel they are ready due to confidence and self esteem. Also a lot of services users struggle with interviews and CVs. This could be because they haven't been in work for a long time or maybe never worked.

Solution
There should be more therapy sessions and counselling to help people build up confidence and self esteem in order for them to want employment.

Benefits
For service users
The client will have the confidence and motivation as well as knowledge to go into and maintain mainstream employment.

For service providers
The services will have more time to motivate and help other chaotic clients and the clients who have successfully left the circle and shown to be steady and stable over a period of time could go back in to help others, for example peer mentoring and support.

Commissioners, service providers and service users then separated into a number of mixed discussion groups under the four headings on which service users had presented. The main issues raised are summarised below.

i) Relationship with key worker/probation officer

The group highlighted that one of the major barriers to developing a positive relationship was the huge case loads that both key workers and probation officers face. As a result it was felt that there was more of an emphasis on paperwork rather than providing support. As a result there is often a lack of engagement with the service user to discuss their treatment or rehabilitation journey, so that it is not tailored to the individuals needs.

Discussion for probation centred on the eagerness to breach service users for late appointments and breaches, without looking into the reasons why.

A number of solutions were discussed. Overall, there was a clear emphasis on the need to take responsibility and to not blame everyone else. Practical solutions focussed on the need to break down the barriers between service user and their key worker or probation officers. For key workers and probation officers it was felt that a lot more training was required in certain areas to enable them to offer more counselling and support. It was suggested that this support should be available once in aftercare, when the need is potentially more than when accessing services. Service users suggested that they could act as the link in bridging the gap in some relationships. There was also a suggestion for a local forum where service users and offender managers to develop solutions and actions together.

ii) Treatment and Recovery

The main problem identified was the ease with which service users could access methadone with no clear aims for an exit plan or journey into recovery and rehabilitation. There was a large degree of consensus from service users that treatment is not commissioned to ensure recovery and rehabilitation needs. There emerged a big problem around the fears and lack of information and education about getting on to and off methadone which people felt stopped users from moving on. Those who were able to progress found that there is a severe lack of aftercare. This was held partly responsible for the fact that so many ended up substituting their drug of choice for another, most commonly alcohol.

The group believe that there was a need to have a stronger shared understanding of what is meant by treatment; whether maintenance or abstinence or a combination of the two, and to educate both staff and service users what this meant. Once this was clear it was felt that there then needed to be a clear process of assessing service users and to then give them a clear understanding of their treatment options. The promotion of self-help programmes and advocates to provide a link and voice into services were seen as crucial in this whole process. It was suggested that service

users should be on all planning and commissioning groups as standing members, with links to service user advisory and advocacy groups.

iii) Housing

There was general agreement that the housing situation in Doncaster for service users was very poor. Again the group were keen to develop a shared understanding of what kinds of housing were most appropriate for those in recovery. It was felt that lack of assessment would improve this and could easily be improved. Often prisoners are released to unsecure addresses, such as a friend's floor, which means that they are unable to address their other problems. The group agreed that there needed to be housing suitable for those who are 'clean' away from their old networks and from those who are still using. The drug and alcohol service user 'Bond Scheme' was highlighted as a way to support the first difficult steps to securing 'quality' rented accommodation.

iv) Education, Training and Employment

A significant problem for women accessing education, training and employment was childcare. This often meant that they are unable to attend what is on offer. Transport also presented a problem with people being unable to afford travel to employment service. More broadly, it was felt that before accessing services to improve employment prospects, service users needed to build their confidence and self-esteem. The group also agreed that there is a need to look at past qualifications and skill mix, as many drug and alcohol misusers had particular educational support needs including with dyslexia, literacy and numeracy.

The group therefore suggested the need for counselling and for specific interview and CV writing sessions. It was proposed that a specific employment project be set up that had both accredited and paid training. Most importantly it was felt that targets should be set around the individual's needs and to work with Job Centre Plus and employers to understand previous convictions and offending behaviour. In order to do this they would need to be educated and trained about this specific group, which service users could offer.

Next steps

The final two discussion groups were made up of staff, service users and commissioners working in separate groups to discuss next steps from their group's perspective.

Commissioners and service providers committed to:

- Undertaking uncomfortable conversations with other stakeholders;
- Challenging the status quo;
- Leading by example;
- Visionary and strategic leadership for Doncaster;

- Enabling feedback of User Voice vision and strategy to the wider service user community;
- Introducing membership of service users on Joint Commissioning Group and Planning Groups; and
- Funding advocacy group for sustained service user involvement.

Service users committed to:

- Developing peer support and aftercare, providing they are given the necessary support;
- Offering their own experiences as support in education, training, advice and myth busting for both service users and staff;
- Offering a peer mentoring scheme to outreach places as well the town centre, providing they are given the funds and advice to set it up;
- Targeted engagement with service users from BME, disability, older, younger, LGB and 'hidden' groups such as homelessness, and victims of abuse and violence;
- Giving support to staff with clients who need peer mentoring; and
- Meeting up with service providers to discuss relevant issues or queries and provide solutions.

Case Study C

"For the first two years I didn't go to the place where it was quicker and easier for me to get services because it was where I scored from. However I got to the point when I thought I am going to have to go at some point. I did, and I got to the point where I just didn't fancy scoring.

There were originally three or four people who would turn up a few days a week. This eventually turned into a group of fourteen on a bad day or twenty five on a good day.

It used to be an old council building, and there were residents around, who obviously didn't want drug addicts coming to their door. But they had to be told, they were told that it would just be people in recovery going. It was going to be nothing but recovery. Then they opened a needle exchange clinic in the same building. They didn't ask the residents, and they didn't tell them until it was opened.

I thought from the beginning why are they doing that. There is only one door, you are in a room and you can't go anywhere else. So you may be waiting for a bit while staff are doing whatever waiting for them to buzz through to the next door. By that time 4 or 5 other people have come for needle exchange. Why would I want to see that, why would I want to be reminded of that? I am alright with it. But I know some kids who have not been alright with it. Now while the facility is not shut, no body goes to it. Can't say they have shot themselves in the foot. Because you do have people who are not going to be using dirty needles because they have been down to needle exchange but its took 6 people bad with it so was it worth it. Would them people have gone back to anyways, I don't know. It's just a big coincidence in my head, that we had a good little thriving group that used to turn up then the needle exchange opened up and now it's derelict."

A successful treatment journey?

Service users have identified a large number of issues as relevant to the success or failure of treatment journeys. The findings indicate the importance that they place on establishing a positive relationship with their key worker (indeed many had such a relationship).

However, participants identified a series of issues which they felt have the capacity to interfere with their treatment journeys. The Social Exclusion Unit identified the factors listed below as those most likely to influence reoffending and relapse rates. There is a striking commonality between these issues and the main emergent themes from this consultation, which indicates that service user thinking is in line with established research evidence.

What is also striking is that despite some service users simply blaming drug and alcohol services for all their problems, the vast majority did not. Indeed, most saw service users as needing to take a bigger role and responsibility for treatment journeys.

Key factors in reducing re-offending by ex-prisoners:

- Education
- Employment
- Drug and alcohol misuse
- Mental and physical health
- Attitudes and self-control
- Institutionalisation and life-skills
- Housing
- Financial support and debt; and
- Family networks
- Debt counselling
- Peer support and mentoring
- Equality and inclusion of need and marginalised groups

The issues from this consultation emphasise the extent to which contextual factors such as housing, benefits and employment exert a serious influence on how people can take part in and benefit from what the service has to offer.

A continuum of support relationships

The findings of the consultation indicate that a range of different relationships are important to service users in their treatment journeys. Figure 4 aims to illustrate the continuum or spectrum of those relationships with staff led support – key workers and drugs and alcohol programmes – at one end and service user led support – self help and friends/family – at the other. In between the two ends of the spectrum are those support structures that are delivered in partnership, such as peer mentoring.

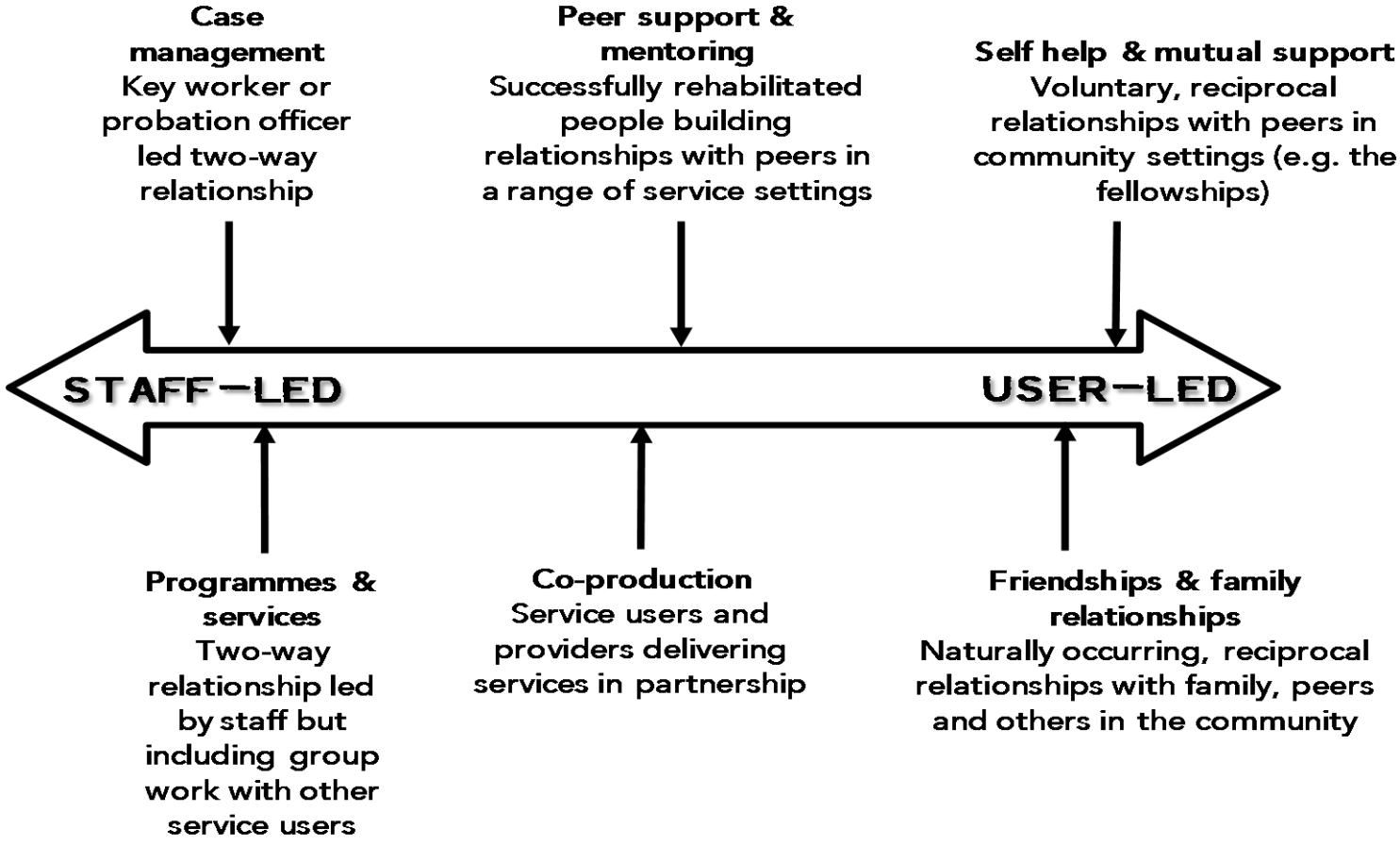

Figure 4: User Voice's Continuum of Support Relationships

Relationships
Throughout the consultation staff and service users consistently agreed that the relationship is one of the most important parts of the treatment journey. Our findings suggest that however good or bad the relationship with a specific key worker may be there is a limit to the amount of support that can be gained from it. This is because many people will only see their key worker once a week, once a fortnight or once a month and service users recognise that key workers have large case loads. This means good relationships with key workers are seen as necessary, but insufficient to support treatment journeys.

Co-producing the status quo
A theme which emerged throughout each phase of the consultation and was raised by service users, providers and commissioners was the apparent ease that people are able to access methadone, with little or no exit plan. As a result there is no ambition in the system to move from treatment to a life of abstinence. This is an example of an unhealthy support relationship in the middle of the spectrum that is co-produced by service users and providers. Users are fearful of moving to abstinence, having little awareness of the reality of moving on and few chances to dispel the myths about impacts. Providers did not see this as a critical step and too often getting into a methadone programme seems to be a ‘good enough’ end point.

Self-help and mutual support
At the other end of the continuum is the support provided by independent self-help and mutual support networks, for example fellowships like AA and NA. However many people suggested that there is not a strong recovery culture in Doncaster leaving this area of support significantly under-developed. The preference for methadone in Doncaster is an important factor in explaining why there is a distinct lack of self-help and mutual support in the area. But it is also a fundamental reason why it is so important that such groups are established and supported, so that people on methadone are able to see and speak with people who are in recovery having successfully navigated their treatment journey to abstinence.

A recurrent theme was the need for education about self-help from people who had been down it. We believe this is central to improving the services offered and raises the question of how Doncaster drug and alcohol services can support such groups to establish and grow, without them losing their ‘user led’ nature.

Peer support and mentoring
There is one group, Dream, currently operating in Doncaster, a service user and peer-mentor group developed within the Drug Strategy Unit. In the course of the consultation we met with those who set these programmes up and spoke to most of the current mentors. As a result we explored the programme.

To date it seems that the current programmes have mainly been developed and managed by staff and that there are currently quite a low number of active members/mentors. This said the mentors are currently receiving training and this programme appears well balanced in terms of its dual focus on helping current

service users and personal development. If our observations are true, the current style and focus of activity limits the potential impact of these programmes in a number of ways:

- Given the overall number of people (1800) receiving services for drug and alcohol misuse the numbers involved are currently small;
- Some service users view those involved with a level of suspicion due to the staff ownership of the programme;
- Staff sometimes choose different user representatives than service users might; this reflects that staff and service users often prioritise different elements of user involvement and benefit in different ways from user involvement activity;
- The current schemes are mainly likely to exert their influence within the drug and alcohol services; influence here is necessary but insufficient in isolation to support treatment journeys for some.

Moving service user involvement and peer-led support forward

The user involvement and peer-led support agendas are not about a simple move from service control to user control. It is about service users assuming both rights and responsibilities, something we found a real appetite for. It also involves staff and users making a commitment to the exchange of ideas in an open way. Addressing these issues locally will take time, commitment and coordination and a process of building on successes.

Some staff will understandably seek to defend programmes which they have taken time and effort to develop. They will emphasise positive initial results and the explicit benefits to those who have taken part. This is understandable.

However, we feel that despite the lack of user involvement in the design and implementation of the existing programmes it is conceivable that an ambition to user ownership and a user-led model could be implemented over time. We conclude that this needs to be independent from statutory services in order to strengthen service users' ability to self-organise and recognising the limited amount of time and resource that service providers are able to give to this agenda, especially in the current financial climate. This is particularly important in the context of needing to build 'self-help and mutual support' and the support of 'friends and family' in the area. By supporting self-help groups to grow independently, service providers will also be easing some of their current burden.

Conclusions and recommendations

Despite the low level of awareness about the term ‘service user involvement’ in this consultation, in the discussion groups people clearly articulated that they grasped the concept. They perceived value in service users contributing to the design, delivery and evaluation of services and other forms of support. These discussions continued at the seminar where both staff and service users recognised that developing this agenda will require investment, time and commitment from service users, service providers and commissioners.

In articulating our ideas for a way forward for drug and alcohol services in Doncaster on the basis of the findings from this consultation we have adapted a model of citizen engagement:

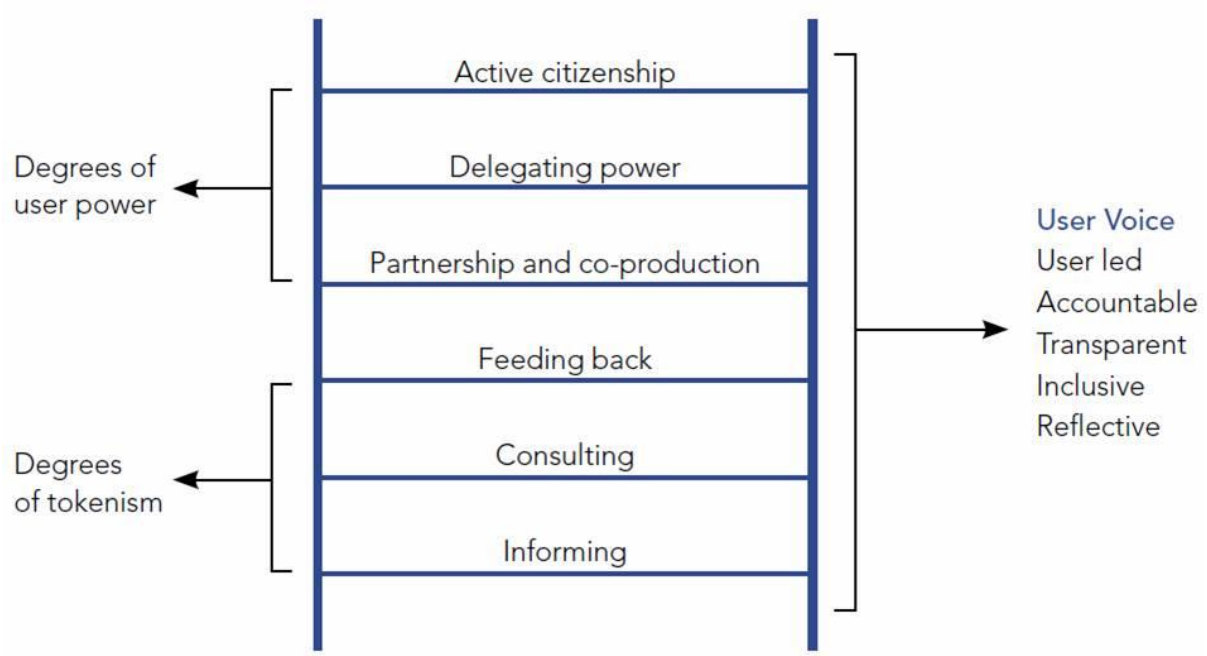

Figure 5: User Voice’s Ladder of Engagement developed from Arnstein’s Ladder of Citizenship

On the lower rung is the aim of providing people with better (but not necessarily more) *information* about changes being made in their area, the services they use and how they can access support and give feedback. In the middle are a range of approaches that aim to *consult and involve* people in shaping change. Higher up are examples of ‘co-design’ or ‘co-production’ where services are *designed and delivered in partnership* with citizens. At the top end are schemes where citizens, or service users, are encouraged to take *ownership* of community assets and, sometimes, to play a role in the running or stewardship of services.

This ladder of participation does not necessarily reflect a hierarchy. Good practice on community and user engagement stresses the need to be on the right rung for the

right job. This is important for when we come to think more about drug and alcohol services in Doncaster and what they are aiming to do. Exchange information and allow feedback? Do they suggest a deeper level of involvement? What and whose agenda is being served?

What is clear is that honesty and clarity about purpose and process from the outset are critical: if people think that they are being asked their views in order to shape a decision, they do not appreciate finding out it was in reality a foregone conclusion.

Recommendations

1. Commissioning of services for recovery and rehabilitation

There is currently little ambition in the system to move from treatment to a life of recovery and rehabilitation. This is co-created by service users and providers; service users being fearful of moving into recovery, providers not seeing this as a critical step. Instead the focus is on treatment; getting onto a methadone programme seems to be a 'good enough' end point. As a result there is a legacy of service users in treatment for a period of four years and over.

It was striking to note that one service provider commented:

"We are commissioned to deliver treatment not recovery."

Commissioning of services should be more ambitious and the focus on recovery and rehabilitation needs to be commissioned and strengthened as the entry point to treatment and services. This means developing a much clearer and stated understanding of what is meant by recovery and rehabilitation recognising individuals' needs as part of all pathways should include clear plans for drug and/or alcohol free life styles or maintenance and the recovery areas as outlined earlier (see page 29).

This requires an ambitious menu of services which should be designed and where possible co-delivered with current and former service users. This will include of course some level of prescribing but with a focus on recovery, rehabilitation and peer support, will enable the service provision in Doncaster to be more effective, efficient and most importantly successful for the service user, whatever that means to them. Membership of service users on the Joint Commissioning Group and Planning Groups will significantly improve Doncaster DSU's ability to achieve this.

2. Personalisation

Currently there is still a tendency towards a one size fits all service with all drug users treated pretty much the same and little time is given over to personalising people's individual care pathway. As a result the diverse nature of service users' environments and needs are not systematically considered. Through the consultation we found this to be especially true with regards to:

- Women, particularly in terms of childcare;
- Those not living in the city;
- Black and minority ethnic groups; and
- Those with a disability or learning need, including dyslexia, autism, learning disabilities and ADHD.

We recommend that service users become central to their own treatment journeys and treatment plans, so that these individual needs are considered.

3. Coordination with criminal justice

One of the most frequently cited problems faced by service users in their treatment journey was probation. We fully appreciate the strains currently faced by the Probation Service, but the lack of integration with care pathways and planning was a striking feature of this consultation. Criminal justice services needs to include integrated treatment and recovery with DIP, prison throughcare and aftercare.

In the final seminar service users committed to helping service providers find solutions. We suggest that including them in any committees or forums in which criminal justice and drug and alcohol services meet will enable the links between care plans and criminal justice to be stronger, more effective and ultimately aid the treatment journey.

4. Increase (non-)service user involvement

The Ladder of Engagement we cite here (see page 33) suggests that current service user involvement in Doncaster, while aiming to promote degrees of user power are relatively tokenistic. This is not to criticise the time, energy and effort that both staff and service users have invested to date – this is welcome – but to suggest a way of building on what has already been established. We suggest that without a significant shift in this respect, users will become disengaged and disillusioned. In addition, there are of course a lot more people in the area (those using and not using services) who need to be included. We recommend that for this to happen drug and alcohol misusers need to be given greater opportunities to be involved at all levels, including:

- Joint Commissioning Groups;
- Planning Groups; and
- Peer support/advocacy.

In order to achieve a deeper and more meaning level of involvement and ultimately more active citizens, not reliant on public services, a core recommendation is that service user groups need to be given more independence. By promoting greater independence and self-organisation commissioners enable service users to influence services more effectively by having the necessary structural organisation and resources, which also reduce the burden on the service provider, recognising

the limited amount of time and resource that they are able to give to this agenda, especially in the current financial climate.

User Voice has developed a Council model that could support this aim. Community Councils aim to democratise engagement with service users by providing a structure for service users select other service users to represent them across a range of issues. Councils provide a structured and effective means by which service users can voice their problems, concerns and solutions to issues and provide a point of reference for the design, delivery and evaluation of new and existing services.

This method of engagement enables a two-way dialogue that facilitates improvement s in service provision, by making them more relevant to the needs of the recipients and therefore more effective. This can ultimately lead to a better use of public funds.

This process of implementing the model will provide Doncaster DSU with a group of service users credible to both staff and their peers who are able to take forward the recommendations set out above in partnership with the drug and alcohol services. The focus on two-way exchange helps meet the needs of both service provider and service user.

These recommendations aim to provide Doncaster Drug Strategy Unit, as the title of the report suggests, a new prescription for drugs services: giving users a greater role in recovery.

User Voice
19 Buckingham Street
London WC2N 6EF
Tel: + 44 (0)20 7968 2743
www.uservoice.org
info@uservoice.org

Registered as a charity in England and Wales no. 1136047

A New Prescription for Drugs Services: giving users a greater role in recovery