Service user views of drug treatment:

research conducted for the Audit Commission

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Undertaken by EATA on behalf of the Audit Commission

EATA European Association for the Treatment of Addiction (UK)

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Chapter 4: Summary of Findings

Chapter 1: Introduction

a) What is this paper

This paper details the findings of a consultation exercise with current users of drug treatment services. The research provides an overview of the issues and experiences of a limited number of service users and does not intend to replicate or replace more in-depth local user consultation exercises. Organisations within the field need to develop and further expand their work by taking into account the views and experiences of service users.

Service users were asked to comment generally on accessing and receiving treatment not necessarily from the service they were currently attending but from all services they had experience of.

It was evident from the discussions that the participants had a wide experience of drug treatment and were extremely knowledgeable about the area. The participants themselves raised topics such as models of care and treatment modalities.

b) Who should read this paper

The Audit Commission management report "Drug Misuse 2004" (October 2004), for which this research was commissioned, drew on the findings in recommending improvements to the local and national approach to tackling drug misuse. This paper should be read alongside it, to give fuller details of the user perspective.

This paper is primarily aimed at organisations that provide drug treatment services within all tiers of treatment provision. It will be beneficial to purchasers and others with responsibility for drug treatment strategic planning, commissioning and monitoring.

It will also be of benefit to Crime and Disorder Reduction Partnerships, Drug (& Alcohol) Action Teams, the police and other services and individuals with a responsibility for addressing drug related issues within communities.

c) Aim of the research

The consultation aimed to identify the experiences of service users of voluntary sector drug treatment providers in the following areas:

- Residential rehabilitation

- Structured day care
- Aftercare
- Street services

In particular the research aimed to:

- Trace service users journeys through the system from their first point of contact
- Explore their expectations and experiences of all the professionals they met during this time
- Explore the degree to which they felt their needs were met
- Explore the experience and any impact it had on them
- Seek ideas for improvement to the system in general.

Chapter 2: Methodology

a) Who conducted the study

European Association for the Treatment of Addiction (EATA) is a membership organisation representing the UK drug treatment sector. EATA commissioned an independent consultant with experience in the drug treatment field to undertake the fieldwork and write the report.

b) Information gathering approach

The consultation exercise consisted of an informal group discussion lasting approximately two hours. The exercise involved an exploration of service user views of drug treatment services by the use of open ended and closed questioning techniques. The main topic areas for discussion were:

- Introduction to EATA and the role of the Audit Commission.
- Overview of the aims and objectives of the study
- Reassurances given on confidentiality and permission to record
- Users experiences of drug services to date
- Initial contact with services
- First impressions of services
- Starting treatment services
- Continuing support
- Opportunities to influence
- General reflection of users experiences

All groups were recorded to ensure clarity of information received. For health and safety reasons a member of the project staff was present during the discussions. The consultant built in time at the end of the sessions where project staff were not present, this enabled clients to discuss current service experiences.

c) Confidentiality

All service users were guaranteed confidentiality in what ever remarks they gave in respect of the service they were in, previous services that they had contact with, the Audit Commission, EATA and the consultant.

In addition, to ensure that comments could not be attributed to individual services or regions the names of the services taking part have been omitted.

d) Profile and recruitment of participants

All services were contacted and a project brief and client information leaflet forwarded. Users were invited by the services to participate in the study and the project brief was discussed with users prior to the exercise taking place.

Additionally providers were asked to recruit potential participants in a way that represented the diversity of the drug using population. However, the sample worked with was representative of the agencies that took part and as a result it was noted that Black and other minority ethnic groups were under represented in services outside large metropolitan areas.

Although individuals were presented from one particular agency, they were asked their views on all agencies that they had had contact with in the drugs/ alcohol/criminal justice field.

In total 49 people participated in the study. The balance of women to men who participated was approximately 40% women to 60% men. The age for drug users was between 20 and 50 with the average participant being about 25. Of these six individuals were in treatment with their children.

Participation in the group was voluntary and no payment was given.

e) Approach to analysing the transcripts

During the groups, the consultant took notes and recorded the session. All the data was then organised into themes or issues that participants had chosen to comment on in relation to questions asked. The consultant then grouped these into logical group headings in order for the data to be presented. This paper attempts to draw out the analysis of key findings, interpretation and conclusions from the comments that were made. While these conclusions are an evidence source for the Audit Commission study, they do not necessarily represent the Audit Commission's view.

f) Layout of the paper

The paper groups the analysis comments under each theme. Some service user comments have been included to support the points made. Proposals contained within the report are based on general agreement as to what is required. Where proposals are based on an individual or minority view, these are clearly specified.

Chapter 3: Analysis of findings and proposed improvements

a) Background

i) New to treatment services

All participants had considerable experiences of the various drug treatment modalities and no one was new to treatment services. Participants reported specifically on their first experiences of services and these are contained later in the report. All participants were asked "from your experience of different services over time, do you think that services are improving?" Overwhelmingly the majority of participants felt that services were improving and that this was particularly noticeable over the last few years. On further questioning as to why they thought this to be the case the following comments were made;

- *"there are more services now, in my area there were no detox, now there are"*
- *"waiting times are better but still need improving"*
- *"there must be more money now"*

ii) On a criminal justice related treatment programme

The recent government initiative, the Criminal justice Intervention Programme (CJIP)[1] with the aim of combating drug related crime through treatment was raised with the groups. Over 60% of participants had been involved in the criminal justice system at some point. This involvement ranged from arrest referral to prison based treatment interventions. Most were aware of the increased emphasis on criminal justice based treatment services and were regarded positively. There were however, mixed views and experiences in relation to criminal justice interventions and drug treatment:

- *"if you want rehab sorting for when you leave prison, social services won't come in to assess you, what's the point"*
- *" prison was one of the only places that helped me become drug free, I had a good worker though"*

[1] This was renamed the Drug Intervention Programme from September 2004.

- *"CARAT[2] workers are a good thing because they follow you through"*

Resources and seamless service delivery were also cited as being issues depending on area, magistrate attitudes, police awareness and prison location:

- *"the problem is when you are in prison and get transferred, my CARAT worker never sent my notes to the new prison, I had to start it all again"*
- *"when I was arrested I wasn't offered any arrest referral"*
- *"there are not enough services in prison, everyone is using, they need the money in there, more drug workers"*
- *"its not connected, when you come out, you have no housing, you're using and you have to go and put it all together"*
- *"my probation officer helped me more than anyone, they sorted out all my referrals, everything"*
- *"you need to train prison workers and the police so they understand what you are going through"*

Respondents also reported that it was difficult to remain drug free whilst in prison and that there were few opportunities to be in a drug free environment. Waiting lists for criminal justice based treatment interventions were also noted as an issue:

- *"in some prisons they try to separate drug users from non-drug users, it's a joke because if you are trying to stay drug free the drug free areas are full of drugs, they should have proper rehab units in prisons"*
- *"there are long waiting lists even in prison"*
- *"places on waiting lists are reallocated if people are detained or remanded and people are put back to the bottom of the lists"*

With a minority of respondents there was a perception that involvement in criminal activities would quicken or enable treatment interventions to be provided:

- *"it seems that you have to do a crime so that you can get treatment"*
- *"if you are not an order you don't get anything"*

[2] A scheme operating in prisons.

The following improvements are proposed:

- An increase in resources for prison-based treatment is required.
- Drug free units within prisons.
- Prison based rehabilitation units need to be developed further.
- Arrest referral should be offered to all who have drug problems and are arrested. This should be monitored as it is felt to be ad-hoc and patchy.
- Better prison based treatment and onward referral for those on short sentences.
- Increased recognition of the needs of "non criminal justice" drug users should be given equal importance by the treatment services and purchasers to ensure equality of access.
- All services need to work together to offer an holistic discharge package that includes treatment, housing and employment/occupational activities.
- There is a need for improved training in issues relating to problematic drug misuse and treatment options for the police, prison officers and magistrates
- Increased control of the supply of drugs into prisons.

Individual/minority proposed

- CARAT teams in particular are generally under resourced.
- Community care assessments need to be conducted whilst you are in prison

iii) Have experiences of services in different geographical areas

Participants reported that this was a significant issue. One even reported that he had relocated in order to access services that were not available in their area. Some participants held a belief that there is greater provision and of a better quality in metropolitan areas:

- *"why do we have to wait different times for detox? A friend of mine got in, in two weeks I had to wait 4 months, she lives in London "*
- *"I went to a rehab that was miles away, this was good co' it got me away from everyone but then I had to go back to where I came from, everyone was using there"*

Rural areas in particular were noted as having problems in terms of treatment availability, location, appropriateness or simply non existent:

- *"they should have mobile drug services these should also include chemists where you can collect your script, they have them in Ireland"*
- *"pharmacies don't do methadone where I live, I have to travel to get it"*
- *"they don't want to pay for services in some areas, my social worker would not pay for me to go somewhere out of my area, I ended up in a rehab that was no good for me"*

Participants additionally reported that there were differences in levels of prescribing maintenance drugs and drugs prescribed to assist in combating withdrawals across different areas. This was of particular significance for people who had moved house.

- *" the CDT in our area hasn't had a GP for 2 years"*
- *" what is it with doctors, its like they are scared of giving you what you need"*

The following improvements are proposed:

- Reimbursement of treatment related expenses for service users and their families/carers. This is especially true for rural areas.
- Decentralisation of treatment services from metropolitan to rural areas. Mobile prescribing/dispensing services.
- Increasing chemist's willingness to dispense methadone in rural areas.
- Increased accessibility to all services no matter where you live.
- More even spread of services at all tiers across all areas.
- Increased needle exchange facilities across all areas, to include flexible opening times and mobile services where appropriate.
- Harmonisation of admission criteria, especially for rehabilitation services.

Individual/minority proposed

- Reimbursement of travel expenses for families and carers not just service users.

iv) Previously not completed a treatment programme.

All participants reported that they had previously had unsuccessful treatment outcomes, the majority however reported that this was due to an issue of personal responsibility rather than treatment failure. Related to this was a feeling amongst respondents that they were simply "not ready" for that stage of treatment:

- *"the first two times I did rehab were a mess, I don't think I was ready…third time I was lucky, I think this is because I knew what to expect"*
- *" you cant be made to change you have to do it yourself"*

However, on further exploration reports suggested that this was in some cases due to lack of preparation, inappropriate treatment regimes, the service itself or the mismatch between the client and the service.

- *"I was told to read through a book of rehabs to see which one I wanted to go to, I had no idea what to expect"*
- *"the staff treated you like you were an idiot, they did not listen to me"*
- *"I have kids, how was I supposed to attend a day programme with no help to look after them, its all I was offered"*
- *" I could not afford the travel costs, it was 15 miles away, I had to give up in the end"*
- *"my methadone was reduced too quickly, I used on top and lost my script"*
- *"there can be such a big wait between detox and rehab that you just start using again"*

The following improvements are proposed:

- Visiting treatment services prior to starting treatment would assist in ensuring a "client to service" fit. It was noted that this would assist clients in what to expect. This was particularly pertinent to residential rehabilitation services."
- "End to end" service delivery – detoxification completion aligned to residential rehabilitation admission date.
- Reimbursement of treatment related expenses for service users and their families/carers.
- Development of post residential rehabilitation facilities in order to resolve social issues such as housing and additional aftercare services.

- Training for all staff involved with drug treatment on areas such as inter-personal skills and engagement skills.
- Harmonisation of admission criteria.

b) Initial contact with services

Participants reported a variety of routes into treatment. These ranged from self-referral to involvement in the criminal justice system. A common theme for all however related to a lack of service information whether in the community or prison. Participants also mentioned personal issues as being a barrier to not accessing services in particular denial, motivation and potential child protection consequences:

i) Effectiveness of publicity

All service users commented on this area as being an issue in some way. There was a general feeling that for service users who were accessing help for the first time or for those that had been using for a number of years that a general lack of information is available. Information relating to where to go for help, what services exist, access criteria and referral processes were all deemed to be ineffective. Participants commented that there were not enough posters and advertising for services and that what was available tended to be of a "shock" nature and something that they could not identify with.

The following improvements are proposed:

- Development of guides to local services. This should include: referral criteria, services offered and access routes.
- General increased publicity regarding the effect of drugs on individuals; this should not just be about 'scare mongering'.
- Increased preventative material especially for young people.
- Materials should detail consequences and causes of drug use.
- Increased information detailing the standards service users should expect from services.
- Clear pathways through treatment services – visible documents showing potential 'journeys'.
- Development of a guide to services for use by professionals so that they are aware of the range of services that exist, including GPs.
- Increased information of services available in prison and on release.

ii) Word of mouth, peer recommendation

All service users commented that the greatest source of information came from people within their peer group, usually fellow drug users.

Participants made only one proposal regarding this item;

- Service users and ex-service users should be involved in developing materials that better inform potential users of services.

iii) Reasons for not contacting services sooner – client expectations

There were a variety of reasons why participants did not contact services sooner, ranging from fear and "not being ready" to previous negative experiences of themselves and/or friends.

- *"You have to be ready in yourself, if you don't feel ready then it's a waste of time"*
- *" one of my friends was badly treated, you are not a person"*
- *"services want you to not be using, I wasn't ready for that I just needed to sort me head out"*

Personal barriers such as denial, stigma, fear of exposure, low self-esteem, pressure from peers to continue, boredom and fear of the implications of drug dependence being recorded in medical records. Women in particular reported fear of child protection services as a reason for not contacting services and some reported not telling services that they even had children:

- *"I have kids and I was scared of having them taken away, I did not know my rights when I went last time, you need a solicitor there to help you"*
- *"I didn't know what was around, I went to my GP and he didn't know either"*
- *"I used to work, I'd have been given the push if they found out"*

The following improvements are proposed:

- Accurate and up-to-date legal advice/legal advisors should be available, especially in relation to child protection issues. Specialist family workers in tier 2 and 3 services.

- Expectation from services to be aiming for abstinence, this is not realistic for all users.
- Provision of crèche facilities available in services and promoted.
- Development of low threshold stabilisation programmes.
- Effectiveness of publicity – as above.

c) First impressions of services

By far the greatest concern expressed here was around how welcoming services and whether participants felt that they gained something from accessing the service. Comments focused on the fact that on first access to a service a user is often experiencing high levels of fear, paranoia, uncertainty and low self esteem. Perception of staff attitudes were critical to a users experience as were information and choices given. All Staff in services, in particular reception staff, should be as welcoming and non judgemental as that expected of counsellors and drugs workers.

i) Ease of getting to be seen

Appointments were the most cited issue; many felt that appointments were rigid and inflexible especially for 'chaotic' users.

- *"its not that you don't want to see them, you're all over the place"*

Opening times were also cited as being problematic especially for people in employment. Drop-ins and self-referral were felt to be positive examples in relation to speed of being seen.

- *"mornings are a waste of time because you are up all night"*
- *" you are a user 24/7why aren't services".*
- *"I had detoxed myself and was made to wait in a room that was full of people of their faces, it really did me in".*
- *"at my GP's the receptionist was a right one, she never looked you in the eye its like she was scared of me".*
- *"you go to one place, then they send you somewhere else".*

The following improvements are proposed

- Increased appointment flexibility including evenings and weekends.
- Increased drop-in facilities.

- Separation of users from non users in waiting areas.
- Environmental improvements to make services less clinical.
- Development of crèche facilities.
- Interpersonal and engagement skills training for all staff that come into contact with potential service users.

ii) Attitudes of staff – experience of discrimination

There were mixed views on this question, many users had experienced both positive and negative experiences of staff. The more negative comments concentrated on the attitudes of non-drug specialist staff including GP's, reception staff and other medical practitioners and key workers.

The following comments were made:

- *" you feel judged by staff"*
- *" GP receptionists are the worst, some GP's won't take you on if they know you are using"*
- *" they always know better than you, more than you do"*
- *"some staff are really supportive, there is always one though"*
- *"we should be told that we can change our doctor and that you can do this by the PCT, that's what I did"*
- *"if you want to change your key worker they always say it is because of you…… it's about never about them"*
- *"the best drug workers are ex users, they know where you are at"*
- *"without us they wouldn't have jobs….they should remember that"*
- *"prison workers don't understand drugs or drug users, this is really important when you are inside because this when you really want to change your life……you need all the help you can get"*
- *"I had to keep kicking on the door of the cell, this went on for ages before they would get me a doctor, they should listen to you rather than taking the piss"*

The following improvements are proposed:

- Review of GP policies on acceptance criteria.
- Training for all staff that come into contact with drug users.
- General review of staffing levels and supervision of staff across all services so as staff can fulfil their responsibilities.

- Published advice on how to register and change your GP.
- Published advice/guidance on how to make complaints.
- Training for all staff in generic communication skills, diversity and service user engagement.
- Ex drugs users should be encouraged to become drugs workers. Training programmes to be developed.
- A 'patients charter[3]' should be developed and implemented.

iii) How helpful was the experience?

Understandably respondents had a diverse range of experiences in relation to perceptions of "helpfulness" and first experiences of services.

Lack of choice was a critical element in negative service experience and covered areas such as the diversity of services offered or available e.g. residential rehabilitation and child friendly or family specialist services.

- *"we are all different so why can't services be like that"*
- *" all they had to give me was counselling, I needed more than that, I needed to get away"*
- *"it was difficult to make appointments in the school holidays, crèche's should be set up especially if you are on a day programme"*

Variations in staff attitudes and perceptions of helpfulness also differed between the treatment tiers. It was generally felt that structured services such as day programme and residential within tiers 3 and 4 were more supportive as these enabled stronger relationships to be developed. Tier 2 services were sometimes perceived as more of a hurdle to get through rather than an intervention in themselves.

- *"once you are in rehab things improve because staff want you to do well, it's just the getting there that's the problem"*
- *"you get looked after better if you are on an order"*
- *"it would be better if you knew what the staff did, you don't know who is a cleaner and who is a counsellor"*
- *"it would be good if drugs workers could come to your house"*

[3] The Alliance has developed a charter for drug treatment services. Participants in this research did not appear aware of this.

iv) Are client views listened to?

Responses in this area break down into the following categories:

Client views accounted for in individual treatment planning process

This is covered within the care planning section.

Client views accounted for in broader service planning and delivery

This is mainly covered in the opportunities to influence section of the report. However some respondents reported that they had been involved in being: invited to opening days for new services and participating in residential group meetings concerning day to day running of the service they were in. A minority reported that they had involvement with DAT consultation events and in one case that they had met the DAT co-ordinator a number of times.

- *"we have met our DAT man a few times, he really listens to what we say and tells us the truth"*

On the whole it would appear from the feedback given that there is limited involvement or consultation on service development and delivery. Where clients had been involved they felt that this had given them a greater chance of successfully completing treatment as they viewed themselves as a stakeholder in the service or broader system. On further exploration of this some service users expressed the opinion that they were in effect customers and should be treated as such.

It was apparent that some clients have quite a well-developed understanding of the drug treatment system, terminology used and mechanisms that exist. This highlights that drug users are not an homogenous group and that there is a danger in underestimating or patronising them and their views.

- Patients charter for drug services
- Increased, creative and effective models of service user involvement concerning service planning and delivery.
- Contracts should be two way between the service and service user

- Full service user involvement in the treatment planning process

d) Starting treatment services

Significantly the most common issue was one of waiting times and the configuration of services and how they relate to each other. Overwhelmingly all participants reported they that they had all at some point had to wait significant times before accessing treatment or moving on to the next treatment stage. Aftercare was also quoted as a significant issue.

i) How joined up were services?

Participants felt there was more work needed in this area, whilst it is evident that models of care is having an impact, gaps between treatment stages and tiers still exist. A number of people commented that there are very few services available to them once they have finished treatment and that aftercare was critical for them in maintaining treatment gains, they emphasised that they should not be discharged from treatment unless such services were in place. Shared care was also viewed as being a positive approach to treatment management. The lack of GPs willing to work with drug users was identified and participants felt that shared care should be increased where possible.

- *"I leave here on Monday with my six year old son, I have no where to go, different departments and different councils don't work together"*
- *"its quick to get in to rehab but you have to wait ages for detox"*
- *"when I finished my detox I had to wait three weeks for rehab, I was still in the same area, surrounded by the same people, they were all using, there should be somewhere to go in between"*
- *"finishing rehab is only the beginning not the end of treatment"*
- *"there are not enough services for when you finish"*
- *"its getting better in prison, you have one person that follows you through and sets everything up for when you leave"*
- *"housing is rubbish, they don't want you in housing association flats, you end up in a hostel full of people using"*
- *"I am in shared care and this has been really good, you know who you are dealing with all the time"*

- *"workers should involve other workers before you are discharged because you have to start it all again"*

The following improvements are proposed:

- Alignment of treatment stages – end to end services need to be developed or configured so that they are streamlined.
- Integration of additional services such as housing and employment and training.
- Increased joint working between services in relation to referral right and pathways, response times and communication between teams.
- Increased shared care arrangements.
- Development of one access point without limiting choice.
- Development of post rehab stage accommodation services to enable appropriate onward referral.

ii) Effectiveness of the care planning process

Reporting on effective care planning processes was in the main negative, the majority of participants reported that it concentrated on their drug use and omitted other key areas of their life such as housing, employment and relationships.

- *"they never really look at why you using, like the other stuff…. its all about drugs"*
- *"it doesn't really work unless someone helps you sort out your housing too"*

Additionally it was widely perceived that there is continual assessment by a variety of professionals who ask the same questions (assessment hoops) and that it was rare for other relevant professionals to be involved in their assessment which would eliminate the need for multi assessment. Care planning was also mainly seen as something that is done to you rather than with you.

- *"I never had an assessment when I went to my rehab, they just used the one my social worker did (in twenty minutes)"*

- *"I had an assessment for one hour, its just assessment and assessment, it seems to be all they do, I even said they could share my files but they still keep assessing"*
- *"they never let me see my notes, I thought they had to show them you if you asked for them"*
- *"I was given a copy of my care plan, I am shown my notes at the end of every one to one…..this really helps me because I can see how well I'm doing"*

The following improvements are proposed:

- Development of standardised joint assessment formats where possible, especially for same authority services.
- Increased client information in relation to access to medical records.
- The care planning process needs to be clear and transparent and a partnership between client and worker.
- Better understanding of confidentiality and consent issues so that information can be more easily shared between professionals.
- Increased multi disciplinary assessment and review processes where possible.
- Move away from prescriptive care planning.
- Standardisation of assessment and care planning practice across all services.
- Expanded choice of treatment modalities for all users.
- Improved assessment in matching client with service.

iii) How much user choice was there?

In relation to choice over treatment programme or elements of treatment some participants reported that they felt that their treatment was non-negotiable. This especially concerned prescribing doses and choices over medication.

- *"I wasn't given enough information about what meth would do to me, I wouldn't have taken it if I'd have known"*
- *"there should be more choice over scripts like physeptone and subutex"*

In respect to residential treatment, respondents understood the need for a standard programme for all residents and reported that once on a programme they

eventually adjusted to what was required from them. There were however a number of counter responses:

- *"I don't feel safe talking about my problems in groups, I don't mind talking with my key worker though"*
- *"You just don't need some services like counselling"*

As a percentage of respondents were resident in a children and families service the availability of such services was raised as an issue. Due to the limitation of bed spaces in this type of provision it was unsurprising that respondents felt that there should be further investment into resourcing for children and family services.

- " *there are not enough services for men with kids, its like we don't exist, this place is fantastic though"*

The following improvements are proposed:

- Increased resourcing to and availability of children and family services.
- Enhanced choice in prescription types available.
- Enhanced flexibility in service delivery in relation to opening times and home visits.
- Expanded choice of treatment modalities for all users

iv) Family (and friends) involvement

Some users reported that recovery was faster once family members (inc. children and parents) had received help for themselves and consequently learned how to be more supportive with the user. Advertising services that could help families as a whole was noted as being poor if existent. It should be noted that individuals also discussed family in terms of other significant relationships that they referred to as though they were family members.

- *" I had drug counselling with my girlfriend, there should be more like this…. until you do it you don't really know what you are doing to others, once you know it kicks you to change" (lesbian client)*
- *"they didn't know what to do with me, they thought the police was the only answer"*
- *"I nearly killed my mam, she was worried to death about me…….she needed some help too"*
- *" my family did not want to know me, they did not understand drugs, all they saw was the bad stuff"*

In addition participants made comments regarding the role of establishing new social networks after treatment had been completed. Many felt that it was difficult to move away from old friends and social networks and that there was very little information available in this area.

- *"When you are desperate you need to phone a friend [at NA.] this helps you get support when you can't get it elsewhere".*
- *" When I'm sat at home, and friends come knocking,….they still use….. I just ignore it,. It would be good to have a group of people I could meet up with sometimes…"*

Generally it was felt that significant others should be more involved with any packages of care and support that are provided, this was especially pertinent for individuals who had children where the main carer was usually a grandparent. In relation to this drug using parents felt that the only way to access treatment was by giving the care of their children to a grandparent. By accessing children and family services with their child/children present they claimed that this had aided their recovery.

The following improvements are proposed:

- Further exploration of need for therapeutic services for same sex couples.
- Increased education and materials for families.
- Family specialists based in tier 2 and 3 services.
- Increased use of brief intervention counselling services for users and family members.
- Specific support services for family members.
- Further development of both client led and service led aftercare services, facilities and information.
- Crèche facilities should be further developed.
- Increased resourcing to children and family services.

v) Waiting times

This was the most commonly cited issue of the study, waiting times were consistently commented on as being a barrier to getting help when needed or ready. It is the main area where improvement is needed across the whole system, in particular waiting lists at statutory substance misuse services were frequently commented on. The following responses have been ordered to reflect comments made: prescribing, residential detoxification,

residential rehabilitation, day programme and prison based treatment.

Prescribing

Variations in waiting times for prescribing were cited as a common occurrence, respondents found that statutory services were particularly overstretched in some areas and that speed of access often lead to deterioration in drug use and general health and in some cases increased offending:

- *" it would help if you could attend a group or something….when you call and told there's no appointment for weeks you just give up"*
- *" I waited four months for a script, when I started using I was on about £10 per day, by the time I got my script I was on about £100 per day"*
- *"once I found out how long I had to wait, I couldn't be bothered, so I carried on using….and stealing"*
- *" I was just turned away, they did not give me a reason or any information where I could get help"*
- *"this is a nightmare, you get sicker, continue committing crime"*
- *"because I have kids and there aren't many services….i had to wait months to get in"*

Residential detoxification

Again variations in waiting times ranged from one or two weeks to 4 months in some cases. Respondents felt that access to detox was a "postcode lottery" and that some areas had no detox facilities in the area and that there was an unwillingness to fund placements out of area:

- *" when you are using you have to 'strike while the iron is hot' you could be dead by the time you get to be seen"*
- *"Where I lived before we had nothing, no detox"*
- *"its expensive, the social workers don't like paying for it"*

Residential Rehabilitation and Day Programmes

Residential rehabilitation and day programmes were less of an issue but there were reported experiences of long waiting lists in some areas. The main issue concerning this were time delays between movement from a state of detoxification and starting a rehabilitation programme. Respondents suggested that there should be a "halfway

stage" to "hold" clients in either a pre-day programme group or residential setting.

- *"it's like they don't plan things right, I had to wait for two week after detox before getting to the rehab"*

Prison based treatment

Waiting times for prison based treatment were also said to be an issue and it was noted that respondents felt that these services were overstretched in many areas yet improving and becoming more "joined up":

- *"you don't have to wait as long as you used to, things are much quicker now"*
- *" when I came out of prison I went straight into a rehab, if I hadn't I would have just continued using"*

The following improvements are proposed:

- Development of "one stop" services that can provide crisis intervention.
- Increased rapid access to treatment (prescribing services).
- Development of "holding services" for post detox/pre rehab clients.
- Alignment of stages of treatment provision to enable "end to end" service provision.
- Increased funding to treatment services.
- Equality in spread of services and service types.
- Communication with potential service users about "real" waiting list times and criteria for advancement on those lists needs to be more transparent.
- Increased number of structured day programmes provided with floating support – especially targeted at families.
- Increased investment in residential services for groups such as children and families.
- Increased resources to prison based treatment services, in particular CARATs.

vi) Challenges of completing treatment

The most cited issue concerning challenges to completing treatment concentrated on the prescribing of maintenance drugs such as methadone. A number of users complained about the current policy of cutting off prescriptions if being found to have used "on top" and the limited choice over drugs prescribed.

- *"its not right that they just cut you off, it could be serious….you could die from it"*
- *" all there is, is methadone, methadone, methadone its just as addictive as everything else, you are not told how long you might be on it"*
- *" if you are not getting enough meth you just go and buy it of the street….it's stupid eh"*
- *"all GP's do it different, some of them give out all types of drugs, others just cut you of for the slightest thing"*
- *" there are no leaflets explaining how you get scripted…how long you will be on it…..what will happen if you use on top….it seems that all they are interested in is urines, not how you are feeling"*
- *" as soon a I was scripted it helped me stop stealing, sometimes you need stuff on top though, like diazepam"*
- *" different places have different rules, you can be thrown out for doing something at one place but in others they keep you, its about who the staff are"*
- *" when I came out of prison there was nothing for me, I had to go and find it myself…I was given no help in sorting out the next bit, its like it was all a waste of time"*

The following improvements are proposed:

- Standardised and clear prescribing process across the board.
- Strategy development for the prescribing of drugs to combat withdrawal.
- Increased choice in type of maintenance drugs available.
- Exploration of supervised heroin prescribing/administration for some client groups.
- Enhance therapeutic exploration of the individual causes of problematic drug use.
- Increased availability of information detailing the prescribing and withdrawal process.
- Strategy development regarding good practice in termination of maintenance prescriptions.

e) Continuing support

Continued support and aftercare services were one of the major areas of concern expressed by participants. Comments focussed on leaving treatment (planned or unplanned) prison discharge and the lack of options available for continuing support.

How well are users supported to meet there aims?

Users generally felt that once they were in treatment they had positive experiences of being supported. However the majority said that they required more input to put further support in place for when they finished treatment. The support that they identified as being needed ranged from assistance in housing to employment and skills training.

- *" aftercare is left until the last minute and sometimes it just can't be sorted out in time….key workers need to be more involved"*
- *"recovery does not end when you finish treatment…it's only the beginning"*
- *" I had major problems with my housing, if this had been properly sorted at the beginning it wouldn't been so hard, this rehab has an thing with the council not to re-house you here, it's stupid cos you have to go back to where you were"*
- *"sometimes you need some respite further down the line, its really difficult to get this, lots of people relapse then"*
- *"my probation worker has been the most helpful in setting up everything for me, they put everything in place before I left prison, I had to want it though"*
- *"It is easy to be strong when you are in the clinic, but after you leave, that is when it is really tough…"*
- *" I have been introduced to NA meetings, this helps me stop worrying about when I leave"*
- *" you need to have ambitions that you can aim for, it can be really difficult to get back into things as you are always labelled as a drug user"*
- *" I attend a skills training programme, I love it because it really helps me build my confidence"*
- *" staff don't always know what is available in your area because they are from a different area"*

The following improvements are proposed:

- Key workers should be trained in planning aftercare services from the beginning of the treatment episode.
- Key workers should follow clients up after they have left treatment.
- Increased development of employment and skills training programmes.
- Establishment of ex-user support groups run by ex users for ex users.
- Telephone helpline development for ex-users.
- Access to specialist housing advice.
- Development of "holding accommodation" for post treatment clients to address social problems.

- Social workers to conduct assessments whilst suitable rehab clients are in prison.

f) Opportunities to influence

Service users reported that opportunity to influence services is virtually non-existent. They reported being disempowered in most aspects of service delivery. Where service user groups exist in local structures (DATs) many felt that this was "lip service" and that they had little opportunity to influence significantly.

i) As service users what opportunities have they had to influence the way services are delivered?

The following comments were made:

- *" When you are in services you have no say over anything really, if you do its generally over things like house rules or food"*
- *" I am involved in our local DAT service user group, its ok, you make suggestions but nothing really happens"*
- *" it would be good to be more involved, some things are just not right, the problem is that as a junkie you are a second class citizen"*
- *" we are setting up a support group for families affected by drug use, the DAT is helping us do this"*

ii) What challenges are there to service users being heard?

Participants did not directly comment on this. However the author has attempted to draw together proposals from information gleaned.

- Staff should be aware of local advocacy services so that they can signpost users to them.
- Staff should be proactive, and not defensive, about encouraging users to make use of Advocacy services.
- Drug services patients charter to be developed.
- Replication of "speak outs" as in the homeless sector.
- Service users should be involved in audit and monitoring of service standards.

Chapter 4: Summary of Findings

Service user backgrounds

Drug users seem to experience differing levels of service availability, response and staff skill in assisting them in addressing their drug treatment needs.

Drug users report that availability and access to drug treatment services varies widely across the country, particularly for rural areas.

It is acknowledged by drug users that personal responsibility is an element of not completing treatment, however problems with treatment preparation, staff skill levels and gaps in provision also have a role.

- Adequate levels of funding, service configuration and staff skill will aid the effective identification and treatment of problematic drug users within the criminal justice system.
- The multidisciplinary planning and delivery of holistic discharge packages of treatment and support to both short and long term prisoners will ensure the maintenance of treatment gains and a reduction in likelihood of re-offending on release.
- An audit of training needs and the delivery of high quality training to staff within the criminal justice system can do much in ensuring any perceived gaps in skill by criminal justice clients.
- Equity in the commissioning of services for "criminal justice" and "non criminal justice" clients will enable equality of access for all problematic drug users and prevent future criminal behaviour.
- Earlier interventions, before drug problems becomes more chaotic, would save resources and prevent criminal behaviour.
- The effective control of supply of illicit drugs within prisons will assist in the uptake of services and reduce the levels of problematic usage.
- Inequalities in the availability of treatment services across differing geographical areas, especially rural areas, has a negative impact on drug users seeking help or maintaining treatment regimes.
- The harmonisation of admission criteria to treatment services, especially residential rehabilitation will have a positive impact on the uptake of these types of services.
- Effective pre-treatment preparation for clients and seamless (end to end) service delivery in tiers 3 and 4 will assist in the client having increased positive treatment outcomes.

- Commissioners of drug treatment services need to explore the need for post residential treatment services that are themselves residential and would enable users in arranging their aftercare support.
- Drug treatment staff who are equipped with effective interpersonal and engagement skills are viewed as being more effective by drug users.

Initial contact with services

Access to materials and information regarding services, treatment modalities and preventative education are deemed to be ineffective by drug users.

- The publication and effective distribution of relevant and up to date materials and information relating to all elements of drug treatment provision and drug misuse prevention will increase a drug user's ability in identifying and choosing appropriate support and will assist in the prevention of tomorrows drug misusers.
- If all professionals who have contact with drug users have access to materials and information relating to all elements of local drug treatment provision, this will ensure fast and effective responses to drug users seeking help.
- Service users and potential service users need to be presented with a clear picture of their potential journey through treatment services
- The provision of diverse, appropriate and needs led services, especially at tiers 2 and 3 will assist in engaging drug users in the treatment process.
- Service users have a perception that all treatment is abstinence based and this can present them from accessing services.

First impressions of services

Drug users often experience difficulties with waiting times, in-flexibility in appointments systems and opening times.

Drug users experience discrimination in all aspects of treatment provision.

- It is desirable to limit the mixing of drug users from non drug users in all elements of treatment provision.
- Flexibility in appointment and opening times and the provision of open access services such a drop-ins would increase the engagement and retention of drug users in the initial stages of service experience and further treatment.

- Drug users require fast responses when help seeking if they are to be engaged and retained in the treatment process.
- Drug users would benefit from a patients charter allowing them to challenge poor practice in all aspects of drug treatment.
- Drug users expect their healthcare needs to be met by skilled and trained professionals when accessing primary health care services.
- Drug users believe that ex-drug users have a role in supporting drug users in the treatment process.
- Services would benefit from a regular review of staffing levels, supervision and skills so as to ensure that staff responsibilities are fulfilled.
- Increasing user participation in agreeing and implementing policies and sanctions would be more effective than enforcing "top down" decisions.
- Prescribing services, regimes and chemist services are often problematic for drug users. The implementation of evidence based, standardised prescribing practice and relevant associated information would benefit drug users who are in receipt of maintenance or substitute prescriptions and seeking to achieve their treatment goals.

Continuing Support

The planning of aftercare support services should be integral to the broader treatment planning process and should be initiated as early as possible in the treatment episode. Effective aftercare support services will enable drug users/ex drug users to maintain treatment goals and re-integrate themselves into society.

Commissioners of drug treatment services should be reviewing the aftercare support needs of drug users in all stages of treatment to ensure that adequate provision is established. This should include the following areas: housing, employment and skills training and service user led initiatives.

Opportunities to Influence

The emphasis of service user involvement is key to the successful delivery of drug treatment services and in achieving positive treatment outcomes for service users. Any service user involvement initiatives need to be relevant and seen to have impact if service users are to feel that they are being listened to.

Organisations commissioning and delivering drug treatment services should be seeking to involve service users at all stages of drug treatment strategy, commissioning and delivery in order for services to effectively respond to the diverse treatment needs of an under represented social group.

Organisations working with drug users should pro-actively signpost users to internal complaints procedures and external advocacy services and where possible influence the development of a national drug service clients charter. Initiatives of this type should have an impact on the perception held by service users that they have little power or opportunity in influencing treatment as a whole.