MIDLOTHIAN & EAST LOTHIAN
DRUGS & ALCOHOL PARTNERSHIP

The Experiences and Views of the Users of Drug and Alcohol Services in East Lothian and Midlothian

July 2013

Summary of Comments and Implications for Future Service Design and Provision

1. Introduction

1.1 In May 2012 MELDAP submitted to the Scottish Government its three year Delivery Plan in which it set out a number of key priorities organised in four strands. Strand 4 was *Commissioning and Assuring High Quality Recovery Focused Services.* Within this priority was a commitment to, 'undertake a redesign of existing service provision to delivery an integrated recovery pathway'. The active role of service users in this redesign process was highlighted.

1.2 In November 2012 MELDAP held an Over the Horizon event to begin to explore with key partners and stakeholders what services to support people with or affected by substance misuse should look like from April 2015 onwards. As part of this process of review it was agreed to hold a series of consultation events across East Lothian and Midlothian involving staff, managers and a service users and carers. Six events, three in East Lothian and three in Midlothian were designed to provided services users with the opportunity to share their experiences of what it was like to be a user, current and past, of services designed to support people misusing alcohol and drugs. Each event was anticipated to last between two and three hours. The views of service users were recorded by the MELDAP Team on post-its. These were then grouped to identify broad themes and a summary of comments was given after each session to allow for further discussion and comment. Service users were also able to record their own comments independently and post these on the relevant sheets. Three key questions were used at each event to provide a core structure. These were:

- What works?
- What doesn't work?
- What should we do more of?

Appendix 1 provides a summary of fifty service user and carer's comments gathered during the six consultation events, Appendix 2 provides a summary of the comments from staff and service managers and Appendix 3 the comments from Stakeholders. What is reassuring is that the comments made from these different perspectives are broadly consistent in terms of what works and what needs to change. It is also clear that the comments made by these different groups as to what needs to change and thus improve opportunities for recovery mirror those made in a variety of the research literature in terms of describing the key elements and attributes of effective Recovery Orientated Systems of Care (ROSC), such as being holistic, person centred, using a strengths based approach (recovery capital), recovery orientated and outcomes focused.

1.3 Within these broad questions there was the opportunity to explore with service users:

- their journey through the treatment system from first point of contact to discharge
- their experiences and views on the service personnel they met during this time
- how they felt their needs were being met
- the impact the quality of their service experience had on their recovery

- their views about the lack of services including the challenges of accessing services because of the geography of East Lothian and Midlothian

- how service users and carers might be involved longer term in the redesign process and the work of the partnership.

1.4 At the consultation events held for service managers and service staff, all were encouraged to support their service users attend the forthcoming events. Good support was given from certain service providers and this was appreciated by both service users and the MELDAP team. At the service user's events attendees were asked whether they would like to be involved in a longer term Service User Reference Group (SURG). From the 50 service users who attended a total of twelve people expressed an interest in participating in the proposed SURG. The purpose and of the role of the SURG were outlined, possible duration of the group, frequency of meetings with the MELDAP team to discuss specific themes raised through the consultation and how it would provide an opportunity to explore some emerging issues in depth. From the system redesign timeline it was envisaged that the group would run for a year and would provide an essential forum for 'testing' possible models of service redesign. The redesign process also made clear the need to report on the outcomes of the consultation events and associated ongoing developments in the form of a quarterly Newsletter, the first such newsletter being issued in May 2013.

1.5 The first meeting of the SURG was held in July 2013. The members of the SURG are at different stages of recovery, some in long term recovery, some affected by someone else's substance misuse and two were recent graduates from the Lothian and Edinburgh Abstinence Programme (LEAP). While the majority of service users at the consultation events were males in their thirties, women were well represented at the first SURG meeting; five out of eight, two of whom were carers. There was no representation at the consultation events or on the SURG from Black and other minority groups. This may be something that needs to be explored further. It was agreed at the consultation events that members of the SURG would be reimbursed for any travel expenses incurred and for their attendance at meetings.

2. Using the views of service users

2.1 The paper attempts to summarise the views and experiences of service users through the comments they made during the consultation events. It does not represent all the comments made but identifies themes or areas that were touched on or referred to on at some of the events and/or by a number of participants, whether service provider or service user. Nearly all the views expressed stem from their first hand experience of using a particular service or set of services, for example, some had previous involvement with social work services, health services, treatment services whether NHS or third sector and mutual aid groups such as AA and NA. Most said they had previously started treatment but had dropped out, not because of the quality of service they received but usually because of their own lack of preparedness to sustain long term involvement. It is intended that the initial comments made at these events and the issues raised will form the basis of the ongoing work of the SURG in order to better understand what services should be in place, how they should interrelate and what they should do. The implications for service provision listed at the end of each section will also be 'tested' with the SURG and amended based on the comments

received. The SURG will also provide an opportunity that key issues are explored in some depth, particular those in section 1.3.

3. Information about services

3.1 Most service users had views on the quality of information they received about the range and type of services available to them, their families or partners. The feeling was that generally there was a lack of information on where to go for help, what kind of services were available, the referral process/criteria and ways of accessing services. A number people mentioned the lack of information about treatment options once they engaged with services with the sense that some of this was to do with professional control or staff beliefs about aspects of recovery such as support available through the different fellowships. A number of service users commented that an important source of information was from people within their peer group, usually fellow drug users. There were also the views expressed that no matter the quality of information provided, individuals had to take responsibility for their own actions including their unwillingness to seek help for reasons such as denial, lack of motivation, not willing to change and for some, particularly women, the implications of engaging with services when they had children. Comments were made as to how people should be helped or 'nudged' into services a role that many believed could be undertaken by those with lived experience because they could better understand the anxieties, apprehensions and concerns of making that first step into recovery as well as providing a tangible example of what was possible.

3.2 What service users said:

- *lack of information on where to go for support particularly people with children*
- *information needs to be more widely available*
- *I got information about LEAP from two other recovering addicts*
- *I heard about LEAP through Serenity Café*
- *the lack of signposting to specialist services*
- *having information on other services readily available and active signposting to these services from professionals*
- *there needs to be greater awareness by all staff who support addicts of what is out there to support them and their families*
- *my GP didn't know what was out there*
- *no information provided by GP about LEAP*
- *thirty years in addiction and no one told me about recovery*
- *professionals must be clued up about what's available*
- *no one ever told me about fellowship or rehab' services*

- *catching people at the right time and having services to support that willingness to change*
- *someone to support people into services*
- *no one explained what the options were*
- *I was terrified to ask for help because I thought my kids would be removed*
- *maybe there should be multi-agency meetings for adults-benefits, treatment, housing, family support all present*
- *make sure you maximise advertising-on the back of toilet doors and other places*
- *use local media to advertise local services.*

3.3 Areas for improvement:

- Services need to ensure that there are processes in place that are monitored and managed in relation to the dissemination of information to service users and/or carers that maximise the available options and choices.
- Service Providers [including GP's] need to ensure that there is a positive culture towards understanding available resources and promote them without prejudice.
- All MELDAP guides should be reviewed to ensure that they include description of services; referral criteria, range and type of services offered and access routes.
- The information on the MELDAP website should be subject to critical service user and carer evaluation and if required upgraded.
- Develop information for substance using parents regarding child welfare and child protection procedures and the services available to offer support.
- Improved information for service users about the standard of service they should expect in the form of a service charter.
- Improved information outlining the journey from treatment to recovery and all the services available at each stage to support this.
- Better information for all professionals about the range and type of all the available services that exist for substance misusers.
- Service users and ex-service user's skills should be utilised to develop materials for future users of services.

4. Starting Services

4.1 Two issues mentioned were the time taken to access appropriate services, the configuration of the services and how they relate to each other. In other words how joined up were services and

did they meet the needs and expectation of service users when they first engage. A number mentioned that they had to wait quite a while to get a service. A number mentioned the Recovery Gateways and how this had greatly improved access to services. It should be noted that in March 2013 services in East Lothian and Midlothian had achieved a 97% level of performance against the HEAT A11 target of, 'three weeks referral to treatment'.

4.2 Aftercare or more accurately lack of was also noted as a significant problem with some believing no one should be discharged from a service until there is appropriate aftercare support in place.

4.3 In terms of co-ordinated, integrated services, service users said that much work needed to be done in this area and services should take a holistic approach when working with new clients.

4.4 Housing needs and benefits were two areas where service users wanted stronger links. The clear links between mental health and substance misuse were also spoken of and that support had to be much more integrated. A number of clients noted the lack of aftercare support once they finished treatment, the impact on their recovery that the absence of such support would have and the lack of a 'visible' recovery community in East Lothian and Midlothian. Edinburgh was seen as having a visible recovery community and the positive work of the Serenity Café was noted by a number of service users. The lack of GP practices willing to work with substance users was identified as an issue by a number of service users.

4.5 A number of comments were made on the importance of services better understanding the range of anxieties service users feel when the first engage with services. There were issues around confidence, self-esteem, fear, uncertainty and previous negative experiences. For drug users there was they said, an imbalance in the professional-client relationship because of the need to get a script, which for some made them overly compliant. Not all of the difficulties around first contact were the fault of the service provider, client behaviour which they believed had served them well in the past, for example being aggressive, was no longer appropriate as was their failure to keep appointments.

4.6 First impressions mattered when one considers the high level of anxiety and uncertainty service users felt when engaging with services for the first time. The human face of the service in terms of reception staff could often put people at ease or in a number of cases have the very opposite effect with people feeling they were being judged or looked down on.

4.7 Comments were made on the need for services to be more flexible in terms opening hours and access with some saying at least one evening and weekend opening would be welcome. There was a feeling that most treatment services were better suited to people out of work; people in work wished greater flexibility and access at times that suited their work patterns, for example, people misusing alcohol were often in full time employment. Drop-ins for those who were described as being 'all over the place' and self referral were seen as positive options. The Recovery Gateways were mentioned as a positive example of this more flexible approach.

4.8 What service users said:

- *even when it appears people don't want help they really do*
- *more flexibility around appointment times and opening hours;*
- *need a drop in service*
- *you don't get long enough to talk to your GP about things that are embarrassing*
- *support for service users to access services, the need for a helping hand*
- *workers can't be too judgemental, not seen as I didn't want help-I did*
- *everyone I know wants to get off, only LEAP, need for greater choice*
- *drug addicts manipulate and lie to get what they want*
- *the importance of access to worker even if its picking up the phone*
- *Gateways are great*
- *feeling judged when accessing services.*

4.9 Areas for improvement:

- Sustain and improve the HEAT A11 standard.
- Develop more appointment flexibility to include evening and weekend opportunities.
- Explore the option of text prompts and reminders to improve attendance.
- Explore feasibility and need for a drop-in option.
- Ensure all staff that come into contact with service users are appropriately trained to ensure they promote a positive welcoming service ethos, values and that they have the required interpersonal skills.
- Service Providers should develop the use of peer "buddies" to meet and greet new service users and assist with induction, orientation and support. Consideration should also be given to the use of induction groups where new clients starting on an opioid replacement programme have the opportunity to meet with other service users to share their experiences.

5. Attitude, skills and knowledge of staff

5.1 Not surprisingly the role of staff, for better or worse was the area where most comments both positive and negative were made by current and ex service users. Apart from LEAP, CLEAR and the Serenity Cafe no service as a whole was mentioned as having made a difference, rather the comments made were about individuals within a particular service. The importance of the skills of

individual workers; CPNs, drugs worker or GPs, who were able to make significant difference cannot be underestimated. Many service users named the person who had made the difference, in the views of some service users, the person who had turned their life around. They said that such staff were willing to go the extra mile to support them. The importance of establishing and sustaining respectful, productive relationships even through difficult 'periods' was made clear. There was also a recognition that sometimes the relationship between staff and user was not good and that breakdown was sometimes a 'clash of personalities'. However, this breakdown in relationship was sometimes perceived by staff as a person not taking treatment seriously or being difficult. Most of the negative comments received were aimed at non-specialist staff, particularly but not exclusively GPs.

5.2 Stigma, particularly for drug users was still an issue within some services and certainly with certain people and groups within a service user's own community. There was a sense that even when people had turned their lives around, their previous life and behaviours still defined their identity within their community- once an addict always an addict.

5.3 What service users said:

- *individual doctors made a difference, showing they were interested*
- *had good support from my GP, called me after I had been to the Gateway, felt really pleased that he had taken the time to phone*
- *really good GP, had to go round loads before I got one who would prescribe methadone*
- *had a good CPN, couldn't pull the wool over her eyes*
- *the skills of staff and the way they work **with** clients, CLEAR at the orchard Centre were a good help*
- *staff with a passion for their work*
- *MELD staff don't judge you, want you o get on, are good at helping people*
- *staff who we feel confident in, dedicated, knowledgeable, willing to go the extra mile*
- *working with your key worker*
- *being a human being, consistent continuous support*
- *workers who do what they say*
- *workers with the right attitude who are non-judgemental*
- *quality of relationships with your key worker, showing they were interested, keeping in touch, appointment prompts*
- *GP didn't understand, happy to prescribe anti-depressants*

- *GP just wanted rid of me looked down nose at me*
- *GP didn't know what was out there*
- *GP and CPNs were clueless about addiction*
- *lack of interest by GPs/professionals about what other services can do*
- *doctors not keen to help people with addiction and mental health*
- *GPs trained by someone in recovery they need to have the knowledge and skills of working with people in recovery, all GPs should do a training day at LEAP*
- *the cliquedness of services, staff getting defensive when challenged about practice, feeling judged when accessing services*
- *the attitude of some staff and how they spoke to you*
- *better trained staff, social workers need training on how to work with women who are abused by their partners*
- *social workers threatened to take my kids away*
- *need for inspirational staff to support those in recovery like CPN in West Lothian*
- *agencies have to be educated in addiction and recovery, still issues to do with stigma*
- *staff in hospital stigmatise you because you drink*
- *challenging stigma-not being ashamed of your past, stigma affects the whole family.*

5.4 Areas for improvement:

- Service management need to ensure that all staff uphold the ethos of person centred, recovery focussed service delivery.
- Service management need to ensure that all staff uphold the values of Respect, Dignity, Privacy, Choice, Safety, Realising Potential, Equality and Diversity.
- Provide relevant training for all staff who work with service users.
- Identify and disseminate aspects of effective professional practice more effectively.
- Use supervision arrangements to ensure all staff provide the highest quality of service.
- Use the experiences and skills of service users for training purposes.
- Develop training for recovering substance users to allow them to become employees within substance misuse services.

- Ensure that all services have a visible service charter detailing the quality of service people can expect.

- Work with GPs to address some of the recurring issues identified by service users.

6. **How well did services meet their needs?**

6.1 Similar to the comments made with regards to individual staff, services user's experience of services was uneven, Again LEAP was the only service consistently mentioned in terms of the consistent quality and the difference it made to people's lives. Comments on the care planning or the less used term, recovery planning were generally negative. Service users said that there was a sense of things being done to them rather than with them, plans focused on their drug or alcohol use rather than taking a holistic review of needs and that key areas in their lives; benefits, housing, employment, education and training were overlooked. A number of service users commented on how they had to repeat information to a number of professionals and services, often being asked for the same information or being asked the same questions. Many said the need to repeat information again and again often opened up unhappy memories for them and having shared this once did not understand the need for frequent repetition.

6.2 What service users said:

- *a unified service under one banner in central location*
- *holistic approach to supporting individuals (LEAP helped me learn about myself)*
- *harm reduction, medical detox but only in the short term*
- *treating the cause as well as the symptoms;*
- *more psychological support, more alternatives, CBT, counselling*
- *services tailored to the individual (person centred)*
- *longer time to speak with key worker and longer time in services*
- *open ended services, not cut off when not ready*
- *support for widening interests, art therapy, support for mental well being*
- *services not joined up-the number of times you have to tell your story to different services*
- *services don't co-operate with other services, 'our service users' mentality*
- *you don't get a say on what you want*
- *need to make connection with staff and an element of choice with regards to the staff who support them, everyone has to work together*
- *when my psychiatrist was off ill for months, I did not get offered appointments for months*

- *no discussion of goals, short and long term*
- *too much focus on pharmacological treatment, do not focus only on pharmacological treatments*
- *need for more involvement of service users in services*
- *if you want help in a crisis-nothing local- I threw brick through window to get help.*

6.3 Areas for improvement:

- Consider how additional services such as housing, benefits, education, training and employment could be integrated more effectively into a hub type provision.
- Service Providers need to ensure that for each service user, there is a holistic and individualised Recovery Pathway
- Service providers need to ensure that there is a comprehensive menu of appropriate interventions available to each individual service user.
- Develop 'one-stop' approach to support crisis intervention.
- Increase opportunities for joint working across services to enhance communications between teams and ensure the 'best fit' pathway for clients.
- Develop a more holistic ethos looking at the range of needs to be addressed when clients first engage with services.

6.4 A number of comments were made about the lack of choice or options available when they engage with services. Some service users felt that their treatment was non-negotiable, particularly when it came to the issue of choice of medication. There was a sense from the comments made that the system was overly reliant on methadone which in turn, for some, led to its misuse. With respect to residential rehab service users understood the need for a standardised approach through a particular programme, LEAP being a good example of this, and once in it most reported that they adjusted to its requirements. Some mentioned that success levels of such rehab programmes could be increased if there was some form of pre-rehab work in order to help them better understand the requirements of being on such a programme, possibly by LEAP graduates or other peer supporters. It was therefore important that referrers explain to their clients of the likelihood that they will find treatment a challenging, difficult experience in which they have to play an active role.

6.5 What service users said:

- *the importance of a safe environment such as LEAP to recover*
- *proper intensive rehab, be completely inclusive*
- *the Ritson, gave good respite over festive period to avoid relapse*
- *the Ritson doesn't work, what changes after one week, going back to the same situation*

- *locally based pre admission support for LEAP and aftercare service for graduates similar to the one in West Lothian*
- *too much focus on pharmacological treatment, over reliance on medication by GPs*
- *people being left to rot on huge doses of methadone for years*
- *over reliance on medication by GPs*
- *methadone was horrible, I took it because it was free and I could sell it on*
- *from start goals of coming off methadone should be made clear*
- *threw methadone at me got sense I could be on it forever*
- *get rid of methadone people take it to buy other drugs*
- *long term methadone maintenance*
- *suboxone is the way forward.*

6.6 Areas for improvement:

- Develop appropriate pre and post residential rehab support.
- Improve range of psycho-social interventions provided in treatment services.
- Enhance therapeutic exploration of causes behind an individual's substance use.
- Improve recognition of the impact of trauma on adult substance misuse.
- Increase choice in types of maintenance drugs available.
- Disseminate best practice with regards to reduction and termination of maintenance prescribing.
- Increase range of treatment modalities for all service users.

7. Ongoing and aftercare support

7.1 Not surprisingly that lack of aftercare services and support for families were two of the major areas of concern particularly for service users at the early stages of their recovery. Comments were made on leaving treatment, support provided by the fellowships, the need for local based services and the need to build a visible recovery community across East Lothian and Midlothian. Comments were made about the recovery community in Edinburgh and a number of service users accessed these services, some because there were no equivalents, for example, a Serenity Cafe in East Lothian or Midlothian, some because transport links into the city were better than across the two council areas and others because of the opportunity to meet with a larger and more diverse group of people in recovery. Comments were also made with regards to ongoing support particularly

around housing but also in the areas of education, training and employment with others highlighting the need to 'fill their time' in a meaningful way.

7.2 There were a number of comments made on the lack of support for families supporting someone with an addiction, a feeling of being isolated, on one's own or who were kinship carers for a child of a substance misusing daughter or son. The lack of support for young people who cared for an adult misusing substances was also noted and that there was nowhere for young to turn to for support as contact with statutory services would risk splitting the family. The difficulty of undertaking a residential rehab when you had children, particularly if you were a lone parent was also noted.

7.3 Comments made by service users:

- *open ended services, not cut off when not ready*
- *SMART Recovery especially for people who don't want to go to AA or NA*
- *support groups, social activities, AA/NA (they're free)*
- *NA/AA works- inspiring, the Fellowships(but too many men not enough women)*
- *residential rehab- more people should be offered a chance to go; residential rehab works (but need lots of support in aftercare)*
- *support for widening interests, art therapy, support for mental well being*
- *too quick discharge from SMS with not enough aftercare*
- *more help with education , training and employability*
- *lack of things for people to do, not enough aftercare;*
- *LEAP aftercare in East and Midlothian*
- *got help into treatment but nothing when I left, needed support with the simple things in life such as paying bills, keeping tenancy*
- *lack of family support groups*
- *there is a need for Serenity café type service, a safe place for adults and children*
- *if you want recovery you have to go to Edinburgh*
- *aftercare support for both individuals and families*
- *support for families that are coming back together, for example, people in recovery rejoining family group*

- *aftercare after rehab is essential*
- *it would be good to have an East and Midlothian recovery conference, open days/meetings*
- *supported accommodation for people with substance misuse issues, the supported accommodation wasn't great drinking/anything goes, better recovery housing support in Midlothian ensuring that any such houses were well run;*
- *dry house (council housing-sheltered accommodation) for people in recovery*
- *develop recovery house in East and Midlothian supported by willing PO and people in recovery.*

7.4 Areas for improvement:

- Improved support with housing needs for clients completing residential rehab.
- MELDAP and its partners need to ensure that there are accessible tenancy support services for those in recovery.
- Increase range of aftercare support generally and specifically for education, training, volunteering and employment.
- Ensure staff and services are aware of range of aftercare services available including the role of and support provided by the different fellowships.
- Key workers should be trained from first engagement in considering the needs of and planning for aftercare support with service users.
- Ways of keeping in contact, the use of IT to keep in touch and following up clients once discharged from services should be considered.
- Linked to its CAPSM Needs Assessment, MELDAP should review the current level of, ways of working with and type of service provision for families affected by substance misuse ensuring the needs of all family members are supported.

8. Service user participation

8.1 Many service users felt that they had skills, which were underutilised when they were engaged with services. They felt that there should be a stronger participative role for service users within services with a belief that this would aid their own recovery and that their skills could be better used to support other people in recovery. There was a real sense of willingness to give something back by helping others. Most felt that they had little opportunity to influence service provision and no one had actively sought their views. Many spoke that services would benefit from having people with lived experience as part of the staffing complement. Peer support and the skills peers in recovery had; seeing people at different stages of recovery, seeing what others had

achieved and hearing how they had achieved this were all noted as important features of building a recovery community. The positive response to longer term involvement in the SURG was evidence of that willingness to become involved.

8.2 Comments made by service users:

- *more peer support, use of people with lived experience*
- *group formats, encouragement, being able to speak with someone in the same situation*
- *using the life skills of people in recovery*
- *more peer support, paid peer support*
- *better use of people recovering to support others*
- *GPs trained by someone in recovery they need to have the knowledge and skills of working with people in recovery, all GPs should do a training day at LEAP*
- *services that don't have an element of peer support should get it*
- *need for more involvement of service users in services*
- *it would have been good if couple's therapy had been available*
- *more celebration of success, develop more hopeful outlook*
- *better recovery network, more events.*

8.3 Areas for improvement:

- Services should harness in a productive and creative way the desire of service users to be involved and their first hand experiences using services.
- A service user's charter for substance misuse services should be developed, which would also include information on the responsibilities and conduct of service users.
- The development of, or access to advocacy service to support service users should be explored.
- Service users should be more actively involved in the design and evaluation of service provision.
- Training for staff in substance misuse services should at appropriate points include inputs from service or ex service users.
- Celebrate success of people's progress in their journey to Recovery
- Celebrate effective delivery of service that supports people in their Recovery.

Appendix1

Emerging issues from consultation

The following points are ones that were made by a number of the service users and carers who attended the various events across East Lothian and Midlothian. The numbers attending in East Lothian have been disappointingly low compared to the numbers in Midlothian, which have been much more encouraging. To date we have engaged with some 50 service users of whom the vast majority were people with or recovering from substance misuse. There was a small number of adults (2) who supported someone in recovery or who were the main carer for the child of a substance misusing adult (3). There was also one carer who had supported a substance misusing parent for a number of years

The format was a presentation followed by group discussion around three key questions.

Question1: What works?

Even when it appears people don't want help they really do

- Holistic approach to supporting individuals (LEAP helped me learn about myself); harm reduction, medical detox but only in the short term; treating the cause as well as the symptoms; psychological support; services tailored to the individual (person centred)
- Unified service under one banner in central location; joined up services
- Family support services/support for the whole family
- The importance of a safe environment such as LEAP to recover; proper intensive rehab, be completely inclusive
- The importance of seeing people at different stages of recovery-seeing what is possible and achievable
- Peer support, use of people with lived experience; peer support, people with lived experience helping others; group formats; encouragement, being able to speak with someone in the same situation; using the life skills of people in recovery
- Catching people at the right time and having services to support that willingness to change; working with people before crisis occurs, not after; if you feel ready and want to-it works!
- The Ritson, gave good respite over festive period to avoid relapse
- Going to your GP first-if GP has time to listen, individual doctors made a difference, showing they were interested, 'really good GP, had to go round loads before I got one who would prescribe methadone', 'had a good CPN, couldn't pull the wool over her eyes', the skills of staff and the way they work **with** clients; staff with a passion for their work; staff who we feel confident in, dedicated, knowledgeable; workers who have the right attitude and are non-judgemental

- LEAP; coping skills**;** good relationships with workers, honesty, non judgemental; working with your key worker; being a human being, consistent continuous support; therapeutic relationship between client and worker; workers who do what they say; quality of relationships with worker, going the 'extra mile', keeping in touch, appointment prompts
- 'Good support from my GP, called me to find out how I got on after my visit to the Gateway, felt really pleased that he had taken the time to phone'
- Locally based pre admission support for LEAP and aftercare service for graduates similar to the one in West Lothian
- Longer time to speak with key worker and longer time in services; open ended services, not cut off when not ready; follow up time, time to listen and explain, treated with respect
- Recovery gateways; SMART Recovery especially for people who don't want to go to AA or NA; support groups, social activities, AA/NA (they're free); needle exchange and harm reduction services; NA/AA works- inspiring, SMART works
- Networking, effective communication, need to link services; all services need to talk to each other; having information re other services readily available and active signposting to these services from professionals
- People need to be nudged in the right direction within integrated service; someone to support people into services; someone to speak on your behalf, advocacy
- The Serenity Café, the Orchard Centre and CLEAR project; crisis centres supportive and avoid having to go to hospital locked ward
- Residential rehab- more people should be offered a chance to go; residential rehab works (but need lots of support in aftercare)
- Support for widening interests, art therapy, support for mental well being

Question 2: What doesn't work?

- Too much focus on pharmacological treatment, over reliance on medication by GPs
- People being left to rot on huge doses of methadone for years
- Too quick discharge from SMS with not enough aftercare
- Attitude of some staff and how they spoke to you; you don't get a say on what you want, no discussion of goals, short and long term
- Thirty years in addiction and no one told me about recovery; professionals must be clued up about what's available; being closed minded; no one ever told me about fellowship or rehab' services

- Ritson doesn't work, what changes after one week, going back to the same situation
- Services not joined up-the number of times you have to tell your story to different services; services don't co-operate with other services 'our service users' mentality
- GP didn't understand, happy to prescribe anti-depressants; GP just wanted rid of me looked down nose at me; GP didn't know what was out there; GP and CPNs were clueless about addiction; no information provided by GP about LEAP; lack of interest by GPs/professionals about what other services can do; doctors not keen to help people with addiction and mental health
- The cliqueness of services, staff getting defensive when challenged about practice, feeling judged when accessing services
- Methadone was horrible, I took it because it was free and I could sell it on; from start goals of coming off methadone should be made clear; threw methadone at me got sense I could be on it forever; get rid of methadone people take it to buy other drugs; long term methadone maintenance
- Attitude of some staff and how they spoke to you; you don't get a say on what you want; no discussion of goals, short and long term; put off by worker's judgemental attitude

Question 3: What should we do more of?

- Lack of things for people to do, not enough aftercare; LEAP aftercare in East and Midlothian; got help into treatment but nothing when I left, needed support with the simple things in life such as paying bills, keeping tenancy
- Too much focus on pharmacological treatment; do not focus only on pharmacological treatments
- People being left to rot on huge doses of methadone for years; suboxone is the way forward
- Too quick discharge from SMS with not enough aftercare
- Lack of information on where to go for support particularly people with children, more family orientated activities; lack of family support groups; need for Serenity café type service, a safe place for adults and children; information needs to be more widely available, I got information about LEAP from two other recovering addicts; heard about LEAP through Serenity Café; lack of signposting to specialist services; aftercare support for both individuals and families; support for families that are coming back together, for example, people in recovery rejoining family group
- More flexibility around appointment times and opening hours; need a drop in service

- Need to make connection with staff and an element of choice with regards to the staff who support them, everyone has to work together
- More peer support, paid peer support; better use of people recovering to support others; services that don't have an element of peer support; couples therapy
- Better trained staff; need for inspirational staff to support those in recovery like CPN in west Lothian; GPs trained by someone in recovery they need to have the knowledge and skills of working with people in recovery, all GPs should do a training day at LEAP
- Need for more involvement of service users in services
- Supported accommodation for people with substance misuse issues, the supported accommodation wasn't great drinking/anything goes, better recovery housing support in Midlothian ensuring that any such houses were well run; dry house (council housing-sheltered accommodation) for people in recovery; develop recovery house in East and Midlothian supported by willing PO and people in recovery
- Agencies have to be educated in addiction and recovery, still issues to do with stigma; challenging stigma-not being ashamed of your past, stigma affects the whole family
- More help with education , training and employability
- Support for service users to access services, the need for a helping hand;
- More celebration of success, more hopeful outlook; better recovery network, more events; if you want recovery you have to go to Edinburgh; East and Midlothian recovery conference, open days/meetings
- Better distribution of resources at 3-5 year recovery stages
- Prevention activities aimed at young people; primary school education (self-esteem, confidence, trauma experiences); more support with dealing with trauma (otherwise we are just dealing with the symptoms); role of parent's behaviour in shaping children's attitudes.

Appendix 2

The Views of Service Providers

Question 1: What works?

- Services need to have real understanding and appreciation of impact of substance
- Getting in early in terms of age to promote drug/alcohol awareness – option of peer support
- Assessment and 1st treatment (maybe 2nd treatment)
- Importance of honesty between clients and service staff, good communication between services and clients
- Flexible, diverse, accessible services. Emphasis on locally based services
- Consistency of worker – build up trusting, positive relationship, non judgemental – Argument: don't mention/deal with drugs/speak of needs
- Co location (Esk & MYPAS), information sharing
- People work, person centred
- Choice 1:1; groups; peer led, AA/NA (but not so well here), SMART recovery, alternatives to drugs
- Mobilising resources – signposting/mentoring
- Family (Adult) involvement, seeing the family, supporting the family as a whole rather than disparate needs, team around child or family concept
- Midlothian screening GP major factor in bringing services together
- Substitutes prescribing, relapse prevention
- Early intervention, collaborative working – can't do it ourselves
- Better links with Prison Service. Local problems resolved locally, better links with Police, for example, SW links if drug incident. Should not be left to individuals to decide, joint work with SW (EL), consistent approach – partnership working
- Throughput from MYPAS groups into 1:1 work
- A range of options – 1:1 group, community home, residential
- Gateways! success of Kaizen event replicate as part of redesign process, Gateways, Recovery, Gateways, timing

Question 2: What doesn't work?

- Lack of choice, office hours service, timing
- Dealing with drugs/alcohol in isolation, benefits system
- More family focus approach (needed)
- Lack knowledge of individual services, what they do
- PR/communication – not good at sharing good news – need to advertise services better
- Data protection, joint work, joint working with/between Children Services and Adult Services (Midlothian)
- The way in which police referrals are made – amount that come in system
- The absence of peer support and local people using Edinburgh Recovery Community
- Lack of local visibility (people embarrassed about being seen going in), lack of positive stories, news, successes. Wider public don't know
- Access to services which is hampered by 'rural' nature of large parts of MELDAP area – AA/NA, bus fares money, geography of East/Midlothian
- Methadone as the only answer, stop people being 'parked' on methadone – challenge of 5yr + group
- Being precious about our services. Stop <u>not</u> valuing each other
- Different parts of the system working against each other

- Throughput from treatment services – need dependency on services – need greater range of other supports e.g. employability, training, structured day, rigid approaches by/of services re discharge
- Housing – no recovery houses (Oxford House) in Mid and East
- Reality of Gateway for some
- Inconsistency in levels of service offenders
- Still issues beyond access – housing, benefits, education, employability, quality of journey
- That professionals have ALL the answers, stop thinking that we always have the right medicine
- Dealing with staff issues – caseload approach, dealing with absence/change, working below skill set e.g. data entry; beyond skill set, pressures of HEAT target, stress on staff, stress on services, concern around sustainability, concern around quality
- Short term funding!

Question 3: What should we do more of?

- Housing staff dropping into Esk Centre – surgery approach, Recovery Houses
- More PR/good news stories/marketing
- More education, training projects, links to employability – local based services,
- Education older generation to challenge 'Aye' been done....
- Working with people outwith, excluded from education; better connectivity with young people
- Education more systematic for pupils, P5 onwards; consistency from councils re education, early intervention – invest more in school/education v impact of curriculum of excellence
- Confidence, self-esteem, basic skills to continue to learn and grow
- Improved pathway for service users through criminal justice particularly in and out of prison
- A moving on service (transition/WL service)
- Need to influence culture change; Scottish Government – 2 separate strategies; individuals and communities perspectives; service user perspectives, challenging social acceptance of certain drugs e.g. cannabis
- Naloxone training
- Transition between children and adult services
- Increase level of intensive family support, extended hours – work/family friendly, more flexibility, Mon-Fri had its day for certain services e.g. family based services
- Developing mentoring and advocacy services
- Encourage development of alternative Treatment not just substitute Prescribing
- Better skill mix across all agencies (↑workforce ↓resource)
- Prevent overlap, can't be allowed in present financial climate
- Improved links – mental health, more links between substance misuse services and mental health services
- More peer support, paid peer support co-ordinators – to encourage SMART/NA/AA
- Ask more questions about alcohol use – older people's service, national curriculum
- ↑access to other services – psychology/other health services, employability, training, housing
- Expectations of service users – ensure at centre of care (recovery) plan and encourage to take responsibility "it's their recovery journey"
- Stronger involvement of service users, especially young people, hard to reach groups, genuine involvement

- Activity based interventions/good links with generic services (community services)
- More ABI and follow ups
- Ask for funding review – more needed, funding – longer term funding, clear outcomes for services
- Breaking the cycle of problems
- Improve info' sharing – barriers are coming down. Info 'Commissioners' recent letter

Appendix 3: Views of Stakeholders

Question 1: What works?

- Local knowledge, locally based services, accessible services, quick access to services,
- Partnership working/Joined up services, services are safe, non-judgemental and knowledgeable
- Different treatment/support options available, one size doesn't fit all, need different things available
- Crisis Support, provide weekend outreach assessment teams for those perceived to be in crisis
- Early intervention, earlier psychosocial interventions, harm reduction , harm reduction works – Please leave it alone, continued level of BBV funding, ABI – Whole population approach
- Prevention/treatment balance, abstinence programmes ,prevention, start young, work with Peers/recovered/dry/alcohol users, Peer support, Drug and Alcohol Sessions in Schools
- Support for wider family/friends, rehab for women with children, work with 'family' to try to identify cause of alcohol/drug problem , family group conferencing, child care to ensure women/parents can attend services
- Some people want to stay in communities others not
- Culture Change – Service specific
- Employment/Meaningful activity
- Concern about commissioning process – aggressive bidders – no community links, longer timescale to re-orientate services, 10years?

Question 2: What doesn't work?

- Stop viewing dependency/addiction as the problem as it can be a consequence
- Attitudes need to do work on social acceptability of people drinking too much
- Work via licensing forum (?) re size of glasses/measures offered in pubs e.g. wine rarely see 125ml offered – huge glasses
- Lack of understanding of general public about what unit of alcohol is – more work needed
- Services not taking responsibility (people being passed around), revolving door approach
- The one cap fits all approach
- Sharing data, client info – significant barriers
- Looking at a problem from a departmental objective

- Fund outcomes (we should do this), stop funding services that are inefficient
- Redress alcohol/drug imbalance in spend, more focus on alcohol, way budget currently split, need to change way money spent
- Stop doing needs assessments and evaluations – do action research, actions and reflections to inform development
- Short term solutions, short term contracts for key services ,cutting services and cutting corners, contracts – Joint commissioning – Less small multi delivery contracts, review – historical contracts, contract performance
- Ad hoc funding applications
- Prison short sentences
- Methadone

Question 3: What should we do more of?

- Increase recovery capacity in communities , more work to support people in early
- recovery/longer term recovery depending on what they identify as they need, support through the whole recovery period, improved decision making (cognitive behaviour)
- Early interventions for families, more early and brief interventions, brief responsive at the right window of opportunity
- Work cross agency with support from the start/sure start to work children/family/community support/capacity/social capital
- More integrated services – less silos
- Intensive support Flexible 24/7 services, peer support work with communities
- Data released quickly to services, better data gathering and analysis, more data on what works, keep up to date with changing trends, improved strategic planning
- More articles local press to educate/inform people about drug/alcohol issues 'personal stories' – may help develop better community understanding support, education, improved education
- More funding to develop and sustain