PROGRESSING SERVICE USER INVOLVEMENT

IN THE

D12 DRUG TASK FORCE

INTRODUCTION

Occam were contracted by the D12 LDTF:

- to review the operation of the currently suspended D12 drugs forum
- to make recommendations for the establishing of a new drugs service users forum
- to suggest a mechanism whereby the forum could provide representation on the D12 LDTF
- to facilitate the first four meetings of the forum
- to do a review and progress report after the first four meetings

Methodology

In our research we visited ARC on a number of occasions and met with the Director and team leaders of Athru, Croí Nua, Phoenix and Family Support projects as well as a range of service users. We visited the two HSE clinics where we met with the nurses. We met with the Director of the Walkinstown Greenhills Resource Centre. We met with the D12 LDTF Coordinator and Project Development Worker on a number of occasions. In addition we met with Cairdeas and with the service user facilitator of Coolmine Therapeutic Community Service User Forum and spoke to the Interim Coordinator of the Tallaght DTF regarding their forum. During this period we also met with the South West Regional Drug Task Force Development Worker and the Dublin North East Drug Task Force Treatment and Rehabilitation sub-group to discuss their service user forum initiatives. We met with members of the previous D12 Drugs Service User Forum. We did a literature review of forward-thinking publications on service user involvement especially *Nothing About Us Without Us: A manifesto by people who use illegal drugs* (Canadian HIV/AIDS Legal Network 2005), *Service User Involvement Framework* (Wales Policy Implementation Group 2004), *A Guide to Consumer Participation in NSW Drug and Alcohol Services* (New South Wales Government 2005) and the *National Strategy for Service User Involvement in the Irish Health Service 2008-2013* (HSE 2008). We would like to thank everyone that we met for their willingness to give up their valuable time to share their ideas and for their openness and honesty.

Context

Internationally, the area of service user participation in decision making in drug services is still one of trial and error and is locally impacted by factors such as timing, finding the right approach for the right group of people, the right facilitation method, and even luck. Drug

users often face a range of challenges to their participation in decision making; they are more likely to be marginalised, financially disadvantaged, poorly educated and lacking in power. While these factors make the structuring of a working system of involvement more difficult they also underline the importance of actively facilitating involvement of drug users in the services that they use.

Specific challenges facing the participation of users of drug services in a forum of public discussion are: embarrassment at being identified as a drug user; current or prior involvement in illegal activity; chaotic lifestyles; mental illness; cognitive impairment associated with drug use; fear that their methadone may be withdrawn or that they might be excluded from treatment programmes if they give negative feedback about a service or its staff. Along with these hurdles are the practicalities of childcare and transport. And a good reason to attend in the first place i.e. What is in it for them?

Some words of caution are appropriate at the outset. The concept of service user participation is one that is inspiring to service users and providers alike. Initiatives such as this are often launched with great fanfare and ambitious vision but soon come up against realities of: the limits of effective power of the forum; the lack of similar experience of the participants; the challenge to the service providers of dissatisfactions not before expressed (and there tends to be a lot of this at the start) and subsequent withdrawal from engagement by the service providers; poor communication; frustration; fall-off in participation etc.

A number of interviewees expressed a view that can be summed up by the common saw: 'These things take time'. This is an important realisation that underpins the recommendations in this report. All stakeholders must accept that we 'start where we are'. The recommendations here are just the starting point for a process that will take on a life of its own once the forum is up and running. They are a framework to focus thoughts and energy but priorities will change as the group discovers its own strengths and unique challenges and environmental factors shift.

Notes from interviews are appended and these will give further insight into some of the issues dealt with in this report. All remarks in quotations in the report are taken from interviews.

ENVIRONMENT

THE WIDER D12 COMMUNITY

One person interviewed for this report observed, "The drugs issue is universal at this stage, everyone knows someone touched by it". Members of the forum will be made up of users of drug services but their work potentially will have an impact on everyone in the community. Another person expressed the view that the work of the forum could become the "good face" of drug service users in the community, driving positive change at many levels, and "in this way could be pretty spectacular".

ARC FORUM

ARC is establishing its own service user forum with an independent facilitator and this has pros and cons in terms of the D12 forum. The pros are that (i) the D12 forum can clearly establish itself as separate from the ARC forum with a different level of operation (ii) issues of local concern to ARC projects (which have the lion's share of drug service users in the D12 area) will be processed at local level (iii) ARC will have a mechanism through which representatives for the D12 forum can be easily identified (iv) at times the ARC forum could operate as a virtual sub-group of the D12 forum liaising with ARC service users on particular issues of D12 concern. The cons are (i) there is room for confusion among service users when there are two fora in the area (ii) ARC staff may feel that the D12 forum is irrelevant since their primary responsibility is to their service users and they already have this forum in place to get that feedback.

MEDICAL SERVICES

At the previous forum dissatisfaction with medical services was high on the agenda. At the first meeting issues with medical services accounted for eight of the nine topics raised. Interviews for this report elicited very low satisfaction levels with GP services and a disconnect and miscommunication between the HSE clinics and the other drug services. Service users felt poorly served and disrespected by GPs. There was low awareness and uptake among service users of the counselling and holistic services offered by the HSE. The clinics were enthusiastic about involvement in the forum. The forum could have a role to play in shifting entrenched positions between services and improving awareness of how they can support each other. The HSE have developed excellent guidelines for service user

participation and this forum could provide a tailor-made opportunity to begin implementing them in the D12 area. This opportunity is referenced in more detail in the recommendations section below.

OTHER FORA

A range of approaches to managing drug service user fora are being tried in Ireland at the moment. There are fora run by facilitators and at least one which is run by service users. There are fora which are open to all comers and others which are area-specific. A challenge faced by all is the inconsistency of attendance at meetings. We have designed this proposal to secure regular attendance for the first year of the forum in the hope that this will allow it to establish a profile and a truly representative culture to help its evolution towards a secure self-facilitated future.

Degree of independence of the forum in a D12 context

A meeting for the 'Development of a National Network of Drug Users' in December 2007 (attended by Development Workers from LDTF's and RDTF's with service user forum representatives and a representative of the NDST) agreed some key principles in relation to drug user fora, the first and second of which are:

- Drug users' fora must be independent and run by the members themselves, in the same way as community and voluntary organisations are independent.
- It is essential that the fora have access to funding and support but the funders and/or agencies providing the support e.g. task forces, should not direct or control the forum.

The first of these principles – to be self-run and independent as a community or voluntary organisation – must be aspirational at the initial stage as the forum needs the support and funding described in the second principle. The task force cannot be expected to offer this funding and support without having a hand in shaping the forum. While an independent drug service user forum run by its own members is the goal, getting there will be an incremental process. At the outset the reality is that the forum is being set up by a statutory organisation which is governed by a national drugs strategy.

The task force is concerned that service users in D12 have a voice and a medium through which to formulate views and address issues that may arise for them. Service user

representation on the task force will ensure that the task force is informed of issues as they arise and so inform the task force plans for future service developments. To this end it is proposed that the forum will provide service user representation to the task force. In this light the relationship of the task force to the forum and related expectations should be made clear to all at the outset *along with* the clearly stated goal of moving to self-facilitation when the task force consider that the foundations are secure and the necessary skill sets are present.

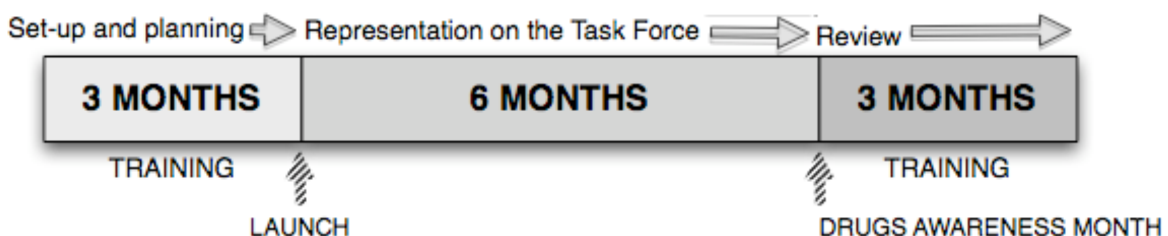
PERCEPTIONS OF THE TASK FORCE

A challenge faced by the task force is that there is poor awareness even among many staff of services about what its role is and service users tend to associate it solely with the Gardaí. However this obstacle can be overcome through the communications described in the recommended steps below.

RECOMMENDATIONS

Plan

The task force agree a plan to develop the forum on a phased basis. The graphic below shows the three phases in which it is recommended to develop the forum. These phases are described in detail below.



Champions

One of the most important supports that the forum can have from the task force is to have a champion who is a decision maker, somebody who is recognised and respected by the service users and staff and management. This person – who might be the chairperson or the coordinator of the task force for example – should visit forum meetings, publicise achievements and promote the forum among the projects in the D12 area. This high level champion could have counterpoints in management and staff at local level to promote and advertise the forum among their clients. Of course champions among the service users are also important and these will be found among the representatives (see below).

ACTION: Identify a task force champion of the forum. *Since the coordinator of the forum is going on maternity leave it is recommended that the chairperson of the task force should fill this role for the task force.*

Position and communication

Establish the authority of the forum as an adjunct to the task force and the responsibility of the service providers to communicate with the forum.

ACTION: The Project Development Worker to agree lines of communication between drugs services and the forum, should a complaint arise or a suggestion be made, from the forum to the project and from the project back to the forum. The independent facilitator could provide one useful communication link.

Harmonisation with local initiatives

To have meaningful representation on the forum, and to avoid the misconception that the forum is the primary place to discuss issues of local concern there should be routes in local projects to process these issues, such as suggestion boxes (regularly checked and maintained) and complaints procedures which are advertised and monitored. It would be optimal if local projects had meetings where local issues could be discussed and representation on the D12 forum decided. The D12 forum could then become a place where issues that get stuck or are not addressed at local level could be progressed more effectively.

ACTION1: The Project Development Worker and the forum to engage with projects to encourage good practice regarding service user involvement on a local level (which can be done for treatment projects in accord with the standards set down in QuADS as recommended by the *interim National Drugs Strategy*).

ACTION2: The task force to work with the HSE Clinics and the forum to publicise and promote the guidelines in the HSE's *National Strategy for Service User Involvement* and in this way to create greater awareness of HSE services among drug users in the area and to foster supportive relationships between HSE and voluntary and community services.

Training plan

ACTION: The Project Development Worker to commission a package of training and mentoring which will introduce participants to the conventional mechanisms of meetings

such as the roles of the chair and secretary and the function of an agenda, minutes etc. These trainings to happen concurrently with Phase1 of the forum.

Advertising

ACTION: The Project Development Worker to visit projects to advertise the set-up of the forum through brief presentations giving clear information including the benefits and supports for participants in the forum e.g. the opportunity to have a voice in the community; to directly benefit those with drug issues and to change services for the better; financial and childcare support for meetings; the training on offer etc. The package to be promoted as part of a D12 wide push for good practice in terms of service user participation. The role and work of the task force and the relationship of the task force to the forum to be clearly explained.

Representation

ACTION: Drug services to be asked to encourage at least two service users each to attend the first forum meeting and to publicise the meeting. If more than two wish to come from any service that is even better but after this meeting there will only be room for two from each service. The criterion for attendance at the meeting is that you are capable of participation and service users are asked not to arrive at the meeting under the influence.

ACTION: The Project Development Worker to explore whether services are open to allowing participants time off their programmes or considering the forum as part of a programme to allow the forum to meet at a convenient time when childcare and other arrangements have already been made by participants.

Remuneration

ACTION: Task force to budget for childcare support, transport costs and remuneration for attendance at the forum or task force meetings. The voucher system that was used for the last forum could form one aspect of this support.

IMPLEMENTATION PHASES

Phase 1. Three months.

Initial set-up with Occam as facilitator/chair working with the task force Project Development Worker as secretary for four meetings. Four fortnightly (two hour) meetings for the first two months and a final fifth meeting and a launch at the end of the third month.

Meeting 1:

- Introduce the task force plan to move towards a self-facilitated group with a review of progress towards this goal after one year and after that at six monthly intervals or another interval decided by the forum.
- Clearly communicate that the forum is a space to discuss issues of general interest to the task force area at a macro level such as identifying emerging trends and planning appropriate responses, suggesting priority for investment of resources in drug services, identifying ways in which drug service users can gather data and feedback.
- Agree ground rules and ensure that it is clear that there is no expectation of confidentiality at these meetings.
- Be open to any ideas to make meetings more enjoyable while getting business done as well.
- General Q&A.

Meetings 2&3: Development of vision, mission, values and key strategic aims.

Meeting 4:

- Development of a twelve month work-plan. Plan to include a few key areas which the task force wants the forum to report on. The task force to identify a couple of opportunities for the forum to achieve something in the short term that will also gain good publicity. The D12 Drugs Awareness Month scheduled for October 2010 would mark nine months of the forum's operation (assuming the forum has started in February) and the staging and supporting of events and activities during that month should form a key goal in the planning of the forum's work (see Phase 2 below).
- Establish a launch sub-group to work with the Project Development Worker on a public launch for the forum.
- Occam's last meeting. Occam to prepare a review and progress report

Meeting 5:

- The Project Development Worker facilitates this meeting.

- Group to decide whether continued monthly meetings are sufficient or whether they need to have more frequent meetings. *It may be that the forum decides to continue to meet monthly while sub-groups assigned particular tasks through the work plan meet more frequently.*
- Task force to secure an independent facilitator for the next six month period.
- The Project Development Worker will continue as the task force representative.
- Launch: At the three month mark the launch planned by forum with the Project Development Worker should be an event including community leaders and decision makers in drug services in the area as well as invited members of other fora, UISCE and other relevant organisations. The launch should be a social event.

Phase 2. Six months.

- The forum to nominate two representatives to the task force who will hold this post for the next six months. They will only attend for a designated period of one hour which will be dedicated to service user led issues.
- Forum to carry on with its work plan and explore ways in which it can gather feedback from and get information to more chaotic or disengaged service users.
- The D12 Drugs Awareness Month in October should become a milestone for the forum. Events that could be sponsored with the task force include guest speakers, health promotion drives, socials, art shows, fundraising events for the forum, a speak out etc. A range of such events could be staged or supported by the forum with the task force.
- At the nine month mark the work of the forum to be evaluated by an external evaluator.

Phase 2. Three months.

- Review of arrangement for task force representation with an option of trying a new arrangement for the next three months.
- New training to be offered.
- Work plan review and new priorities set for next three months.
- Begin to look at initiatives that could be sponsored by the forum, such as speak outs, surveys, focus groups, school visits, publications (a newsletter is better now than earlier as these tend to use up an awful lot of energy and cause divisiveness in less well established groups) etc.

FINANCIAL IMPLICATIONS

The potential financial implications for the task force of these recommendations are:

- room hire
- remuneration for forum members including childcare and transport
- consultant support re writing procedures and negotiating protocols
- training
- independent facilitation costs after meeting four
- independent evaluation at the nine month mark
- costs associated with events such as the launch and events during Drugs Awareness Month

NOTE: The forum could move towards independence by establishing a fundraising sub-committee

SUPPORT

It is envisaged that tasks described as being undertaken by the Project Development Worker will to some extent be delegated by him with support being provided by the task force administrator or another supporting worker in the same way as he was supported in the previous forum's work by a JI worker. The task force should consider creative solutions to this including the possibility of community employment or volunteer support while bearing in mind the need for some experience of having worked with drug users.

UNEDITED EXTRACTS FROM NOTES TAKEN DURING INTERVIEWS/MEETINGS

Problems with the previous forum:
90% participants in the previous forum were from Athrú
attendance was cliquey
forum got embroiled in work procedures from ARC… needs to have a clearly separate identity… too closely linked to ARC in the past and got a bad reputation
service users got together had great ideas and enthusiasm but no plan…
no system of representation
lack of clarity re roles and responsibilities
people leaving or just not turning up to meetings
forum had a negative profile as a 'naming and shaming' body rather than as a forum to bring constructive suggestions to the table
perception of confidentiality in the room – previously this became an issue with criticism of a GP which was reported back to a forum member
last forum was a bad experience as nothing changed
bringing in a service user representative from outside the forum was a major mistake; took place outside of CE hours
service users reluctant to turn-up to meetings which are only held when they have time off
forum attendees had to make a choice between the gym and forum
monthly was too often.

What did work with previous forum:
Previous forum people had been given a €10 voucher for Dunnes Stores as an incentive; Problem is resources and time and money; Croí Nua set-up good example of success of service user initiative; went to forum from Athrú because given time off; advertising for forum was good enough there was awareness of it.

What is important
Confidentiality issues, clarity understanding; procedures? Skills? Training?; people need and want the forum… clear its not a Garda enterprise
Access to service users and Staff
In house systems and relationship to task force
Needs to have consistent attendees
How the forum is structured is an important issue
Should be advertised & there needs to be something in it for people
Need to address financial concerns of the service users regarding issues such as child-minding, travel expenses for buses etc.
Facilitator should be someone people are familiar with and comfortable with and can contact
There is a necessity for management to want the forum
There needs to be consistency of 'membership' or attendance
There should be a mix of people who are active and people who are clean
UISCE a useful conduit to connect with other forums
People need to have a stable commitment to the forum and if not clean at least to be stable in their use (*clarify groundrules re presenting i.e. they must be capable of participating*)… *issue raised by NED task force re asking someone who is under the influence to leave*

Importance of building a relationship as people move our of their addiction and into recovery (Cairdeas have a weekly Tuesday night)
Would be interested in the feedback
Importance of doctors being involved to inform the strategic plan of the task force, because of shortages etc.
Forum opportunity for service users to have a voice and express their grievances
An independent facilitator – to bring things to the services – involvement of independent facilitator to be time-delimited… facilitator to be the conduit of information to ARC services to staff and service users
Independent location
Issue of those actively using and those under the influence
Need to have a strong confident core who understand the process and purpose of the forum
It will take a long time
Training and education re meetings and the programme
    What is acheiveable
    What already exists
    Understand the process of a meeting
There should be minutes and actions against timelines
Importance of ownership, joint leading of the project
Action on input
Relationship with ARC needs to be clear from the outset
Concern about the timing of this so there is no confusion with the internal forum re identity: ARC one is looking in to the organisation *(So no conflict as such they can be mutually supportive) Establish link with ARC Forum to look at the broader issues*
Need for a level of trust
Set-up short term visible gains
Not to be the same thing as the ARC forum, possibility of the ARC forum sending elected reps to the forum
There has to be a policy or service level agreement in place to give the forum 'teeth'… for the benefit of the service users
Follow-up procedure to check some months down the road
Define levels of power etc. at the outset
Make it fun
More creative approach to forum meetings, days away
Partnership of service users with the task force (*necessity to introduce the task force to service users)*
Need for time to become an informed representative… take time
Carefully thought through process
Could take up to two years to establish itself
Active promotion through direct contact
Begin by targetting people with good support systems
Caution against providing a template and then it will happen… needs to be organic

Challenges
ARC forum a challenge and opportunity
In ARC there is enough trust so that they can resolve all problems internally (*contrast with concern that issues might be swept under the carpet)*

No need for a forum *attitude which misses the point of the forum having a policy input rather than replacing local communication, this is a tier above*
Commitment issue v important
Can their concerns be addressed? *Be clear about what the purpose and power of the forum is*
GP's is a major issue – you can't be honest with doctors for fear they will cut your methadone… the power balance is uneven
Two groups of service users (ARC and others)
Medical issues to Forum
Problem is resources and time and money
Get people from outside ARC to participate or a volunteer to help facilitate
Have regular meetings beween the D12 forum and ARC forum, the ARC forum might be sweeping issues under the carpet
Problem is it is outside hours of the CE places people have on programmes… can there be a commitment from projects to release people from their programmes during the day to attend the forum (*this means that the forum has to be recognised for its therapeutic benefits)* part of their role is to represent their project/programme on the forum
You need to build in flexibility, accepting that there will not be consistency of attendance
Challenge is getting people in and maintaining their involvement
Once people are in you need a plan to maintain their engagement
Watch the lingo bingo (use of exclusive terminology)
HSE based projects offer methadone and GP and counselling
Wonders if Crumlin/Drimnagh gangs are an issue as there is fear of shooting etc. around the clinic
HSE: ARC wish to dispense, they can get their script at ARC but no methadone
No office or base for nurse visiting ARC: have a clinical role taking bloods, doing dressings etc.
Chaotic and homeless users have a lot to say and offer to any forum, how to capture their input?
Feel at the clinics that clients go there to get methadone not to get well
Problems with ARC… perception that if someone has a slip and is booted off a programme that they are blackballed and cannot get onto other programmes
These people are vulnerable so beware of creating pressures or triggers
Segregation can occur according to addiction
Attitude now is that Service users don't have a voice and should just accept services as delivered
Demands of two forums will be difficult as attendance at one is hard enough
Evening time once a month people won't go
Nobody knows what the task force is
Some rules service users don't agree with but have to remain as rules
task force is not the catchiest term, associated with Gardaí
Absence of supports for people who have finished programmes… loss of wealth of 'graduates' of programmes
Resistance to change from service providers – we know best we have been doing this for years
Could be conflict of interest between clients and the task force board etc.
Different issues have different importance for service users for instance needle exchange and issues like that are of interest to the more chaotic users

Problems with doctors and intimidation by people with higher education
If there is less funding it is putting the cart before the horse making this network
Everyone is very busy doing their own thing so hard to support this
Some will have an interest and a capacity for involvement others won't want to be public in their addiction Walkinstown Greenhills centre is where it is by default but it is discreet
Would have concerns about it being a top-down structure
Problem of ARC dominating the scene, have a balance with smaller groups being represented
What is in it for service users? why should they go?
Would you be interested in giving something back? (ask this question)
Child-care issues re attendance

Opportunities
Link with CE scheme, Brendan attracted by an hour out of the routine
Needs to be clearly sponsored by the task force
Get someone to publish the magazine, also communicate through email
Good to be connected in with UISCE, get a united voice to talk to the doctors
Include all service users including those who are active or in recovery and their families
Introduction of a 12 week plan (*advantage as it is not a long time… maybe monthly meetings are too far apart to keep focus*) identify a focus such as some other event 12 months down the road
Remuneration is a possibility to keep people involved
Issues raised include harm reduction, needle use etc. service users delivering presentations on harm reduction
Issues raised can influence policy, policy makers can consult re the issues they want raised
Both clinics V Positive feeling towards this initiative, hearing how the clients feel… lodge have Have a Health Promotion Board to get people's opinions on their priority issues i.e. sleep patterns… C Rd Open communication is already there, service users well able to voice their opinions and love talking
Clinics restricted to methadone scripting at the projects Restricted by HSE
Service users are unwanted in the clinic area
Clinics have a lot to offer including counselling and psychiatric services but poor awareness of these among service users of projects in the area
Integrate feedback and response… communication and action e.g. 'snow' on website
Could be useful if you consider that service users are the people with the information re trends of use etc. e.g. their input could be useful to have a coordinated response to the emergence of crysytal meth as a problem in the area *Partnership & Trust*
Meetings between the two forums *issue here is that ARC are not seeing the D12 area forum as relevant to them*
Eventually after development of the forum they will be able to have good input to debate and build up their self-esteem
Good for people to have a moan and to have it minuted
If the forum is run properly and the service users see results then it will work
Make the forum part of the programme (*is it possible to get agreement across projects for this?)* get staff to encourage attendance

ARC staff training meeting once a month there could be an interface with that and spokespeople

Opportunity for explanations to service users so they know how things work or why they work or don't

Focus groups / role plays… how would you do things?

Promote openness.

SU – "Interested in specific areas of the programme such as the continuation of wood-carving to be continued

Would like to get on daily doses of methadone was getting from doctor…

Opening hours on Curlew Rd. would like to change them

Would like opportunity to address issues of perceived Garda intimidation in the community"

How the task force relates to the SU on the ground is an issue that can be addressed through the forum, for instance officers of the task force rarely ask to meet with individual service users directly so are out of touch. Perception of task force as only about money, red tape and suffering from a lack of experience and understanding of the issues faced

Would welcome anything that would improve service and opp's for feedback to & from clients

Improve the relationship between ARC and the task force

The forum's role should be to influence the direction of the organisations serving the area

Opp to influence opinion in the community, through the task force to change the way that Service users are perceived, sway community perceptions of people who are battling with addiction

For more chaotic individuals having visibility, hooking people when they are on the way in, you are there from the beginning

Forum takes the lead on debates, focus groups etc. arrange the forum programme with the team leaders of projects so that it doevtails with the programmes

Would be good to have a voice with the HSE and the Gardaí

V positive re having a forum, would provide an auditing function

Partnership aspect v good recommendations going to task force

Can be used to shape task force policy

Addressing issues related to drug use such as housing and social amenities

Do social events etc. bring life to the community through doing positive things

Use of family support groups to find participants and channel energy

Representation

Tallaght Forum anyone can go… ARC su went there and they contacted ARC *more sense to have local forum do this*

Method of representation on task force to be decided by the forum

Poss ¼ly meetings w task force

Lead-in of a year before task force rep *shoter time, say 4 months*

One consistent rep to the task force

Movement to a peer-led organisation

Participation <-> training, here is the key to the power balance… management committee training

Clinics would encourage people to go along to the Forum

Seen as a sub-group of the forum it would have teeth and respect and its opinions would be valued *communication of what the task force is is v important ie that connection with the task force will empower Service users*
Forum responsible to service users and organisations: Small group from one to help the other
Caution to people being unprepared for their role on the task force board… have two places on the task force board for Service users so there is support there, poss to rotate rep's, shared experience

Communication
The nurse would be the logical person to communicate with the forum:
Communication best through letter or phone
Complaints should go first to Susan -> manager -> Board, complaints, investogations, finsings and actions shold by communicated through letters
Inform through text messages and emails and post
Feedback via the independent faciltiator who acts as spokesperson as the service users are not going to have the level of experience necessary to do that although they may do eventually
Importance of acheivement of goals and good feedback channels
Communications to be seen and visible
Independent facilitator to be communicator between the task force and the forum if issues are raised then to go through Patsy and Susan -> team leaders -> sit-down with task force rep to work things out *(task force needs consistent rep = Cormac)*
Transparency re the minutes, who met and why
Transparency re the forum and what happens with input
Information going both ways
Use of blogs or the website – service users are very computer literate
Forum not to be hidden away can become the 'good face' of service users in the community and in this way could be pretty spectacular

Launch
One day retreat… *kick off?*
Road map for area
Competition or something else to hook them in

Facilitation
Awareness of judgements of the recovered of those in addiction
Issues and group dynamics
Not appropriate to have Service users input to hours of service delivery or staff of services… local service issues such as this are not of concern for the task force
Somebody impartial as the facilitator for a yr or more

15.2	All policies are dated and reviewed regularly (usually annually).	Policy documents.	M		

Guidance notes

This list is not exclusive and only covers non-clinical policies and procedures.

Services are recommended to refer to Alcohol Concern/SCODA guidance on equal opportunities and confidentiality. The relevant documents are: *Building Confidence: advice for alcohol and drug services on confidentiality policies* (Alcohol Concern and SCODA, 1994), *Enhancing Drug Services: a management handbook for quality and effectiveness* (SCODA, 1997), and *Opening Time* (Alcohol Concern, 1994).

Cross-references

This section cross-references with all standards and criteria which refer to policy and/or procedures

Section 2: Core service users' charter standards

16. Involving and empowering service users

Standard Statement

The service seeks to maximise involvement of service users with regard to the type, delivery and development of services.

Criteria		Evidence	M/GP	Criteria met	Comment
16.1	There are procedures for consulting with service users to inform service planning and delivery[1].	Written procedure(s).	M		
16.2	Service users are provided with information on types of services provided and the standards they can expect.	Information available to service users.	M		
16.3	Service users are represented in management structures.	Mechanism for involvement/feedback established and publicised.	GP		
16.4	The service has a charter of service users' rights and responsibilities, provided to service users on request.[2]	Statement of rights and responsibilities available.	M		

Guidance notes

1. Consultation may take the form of consultation groups, satisfaction surveys (see Standard 18: Complaints procedures), or service user representatives on the management body.
2. This could involve the service developing its own charter or subscribing to a published charter (eg SCODA *Charter of Service User Rights,* see Appendix 2).

17.6	Service user files are kept securely and can only be removed from the premises with appropriate authorisation. Computer systems are backed up and back-ups are securely stored.	Policy documents and secure location for filing systems.	M		

Guidance notes

1. The service should ensure that the policy is understood. In the case of a service user who for a number of reasons (eg. mental health, intoxication) may not understand, then the service should have in place a procedure to ensure that this non/questionable understanding is recorded.
2. This aspect of the policy should be consulted on, and agreed with, the appropriate drug action team and area child protection committee. See also *Building Confidence: Advice for alcohol and drugs services on confidentiality policies* (Alcohol Concern and SCODA, 1994).

Cross-references

Criteria 17.1 - 17.6 with Standard 15: Policy and Procedures
Criterion 17.1 with Standard 16: Involving and Empowering Service Users
Criterion 17.2 with Standards 36: Services for children and young people & 37: Services for drug and alcohol misusing parents and their children
Criterion 17.3 with Standard 5: Human Resource Management - General

18. Complaints procedures

Standard Statement

The service ensures the effective management of, and response to, complaints regarding services delivered by the service.

Criteria		Evidence	M/GP	Criteria met	Comment
18.1	The service has a written procedure for dealing with complaints. The procedure clearly identifies: • time-scales for each stage of the process • the appeals system • the identified senior member of staff responsible for managing the complaints procedure • the system for notification of serious complaints to commissioning agencies.	Complaints procedure.	M		
18.2	There are leaflets available and/or posters displayed in the service explaining the complaints procedure to service users.	Complaints leaflet and posters.	M		
18.3	The service has an system for monitoring complaints by number, nature and outcome.	Monitoring system for complaints.	M		
18.4	Staff demonstrate competence in understanding the complaints procedure.	Staff interview.	M		

Feidhmeannacht na Seirbhíse Sláinte
Health Service Executive

DEPARTMENT
OF HEALTH & CHILDREN
AN ROINN SLÁINTE
AGUS LEANAÍ

National Strategy for Service User Involvement in the Irish Health Service 2008-2013

your service
your say

WHY INVOLVE SERVICE USERS?

The literature in this area suggests that promoting greater service user involvement will result in:

Individual

On a patient-clinician level:

- Better health and treatment outcomes
- Increased patient satisfaction with care
- Increased sense of dignity and self-worth
- Empowerment of the patient, leading to greater responsibility for care
- Improvements in staff and patient relationships and increased trust
- Reduced level of complaints and safer care.

Community

On a community level:

- Improved policies to address inequalities in health
- Services that respond better to the needs of the community
- More equitable and inclusive services that help to address social exclusion
- Reduced complaints and increased trust.

National

On an organisational level:

- Ensures policies and service plans are informed, relevant, appropriate and targeted
- Cost-effectiveness promoted by delivering better service outcomes
- Improved public perception and confidence in the health services
- Greater understanding of the links between health, lifestyle and the circumstances in which people live their lives.

The Department of Health and Children hold a National Consultative Forum (NCF), the HSE Regional Health Office (RHO) supports the Regional Health Forums (RHF), and a number of Expert Advisory Groups (EAGs) have also been established by the HSE. All of the input from the approaches laid out in this strategy will be fed back and linked with the proposals from the NCF, the RHFs and the EAGs into the planning, development and service evaluation processes.

GUIDING PRINCIPLES FOR SERVICE USER INVOLVEMENT

Service users, especially those whose voices are seldom heard, have a right to be involved in the development of the health and social services that they use and this is a key element in the delivery of patient-centred care.

Commitment of management at all levels is essential to ensure leadership and delivery on this strategy.

Service users should be centrally involved in their own care.

Open dialogue, trust and mutual respect are key ingredients of successful service user involvement.

Involvement must be based on inclusion, diversity and equity – health services must engage socially excluded groups including those who are socio-economically disadvantaged, ethnic minorities and Travellers, people with disabilities, lesbian, gay, bisexual and transgendered people, children, young people and older people and users of mental health services.

Clear channels of communication with the health service for service users are essential to effective involvement.

Accurate and timely feedback and information to service users are key elements of successful user involvement.

Service user involvement initiatives must be systematically evaluated and learning from service user involvement initiatives must be disseminated across the health and social services.