Hard Edges Scotland:
Lived Experience Reference Group

May 2017

Glasgow Homelessness Network

1. Lived Experience Reference Group: Role and Membership

1.1 The Lived Experience Reference Group was established as a core part of the Hard Edges Scotland project to support the qualitative element of the research. The central function of the group was to help shape the content of the qualitative interviews by people using their own experiences of severe and multiple disadvantage – as well as their often extensive experience of answering the questions of staff and researchers – the topics they would prioritise.

1.2 Two parallel reference groups were facilitated to capture the specific priorities of men and women with experience of severe and multiple disadvantage, and to ensure that space was provided sensitive to specific needs and allowing all voices to be heard safely.

1.3 Both groups met three times between the end of April and end of May 2017 with each following the format of:

- An introduction to questions: why they are important, what makes a question good or bad?
- What topics should be prioritised in the Hard Edges research: based on your own experience what would you ask about?
- Consolidation and review.

1.4 15 people participated in the reference groups, 8 men and 7 women. Of the 15:

- 11 had experience of homelessness, addictions and offending;
- 3 had experience of homelessness and addictions;
- 1 had experience of homelessness and offending;
- 15 had experience of mental ill health (in a small number of cases severe enough to lead to hospital admissions).

1.5 Care was taken to invite membership from as wide a range of services as possible, covering all aspects of severe and multiple disadvantage. The 15 participants were recruited from:

- Sacro, Tomorrow's Women (criminal justice);
- Turning Point Scotland, Aspire, Chara Centre (homelessness);
- Local recovery networks (addictions).

2. Key Themes to Explore in Qualitative Interviews

Both groups were encouraged to think of missed opportunities in their own lives to either prevent situations getting worse or to help them get better.

2.1 Missed Opportunity: You are judged on your past, not your future

This was a common theme across both groups, although particularly strong amongst men, that staff in services look at your past before your future, judging you on 'bits of paper' rather than getting to know you and taking you 'at face value'.

This was identified as a missed opportunity as it immediately builds a feeling of mistrust and a sense that services aren't really there to help, often stopping people from engaging. Nobody was looking for the language of 'goals, assets, or aspirations' (seen as remote), just the sense that there is hope for the future.

Linked to this lack of focus on a positive future, the prevailing view that 'it's all we've got and it's better than nothing' is so common in crisis service provision that it gets in the way of finding lasting solutions, creates the impression that nobody is looking for lasting solutions, and deters people from asking for or expecting more.

2.2 Missed Opportunity: The system is there to test you

The complexity of the system – with services focusing on a single issue and staff working to tightly defined remits – leads to people experiencing severe and multiple disadvantage often finding themselves going in the 'wrong door' and speaking to the 'wrong person'. Finding your way to the 'right door at the right time' was seen as a test that few people manage to pass.

As a member of the men's group noted, 'the system itself is a missed opportunity.'

It was clearly identified by both groups that the implications of this can be very serious.

One particularly difficult example was raised of a young woman disclosing sexual abuse by her brother but to someone who did not have that 'remit'. With the information not being shared the young woman, following a period in hospital as a result of mental ill health, was discharged back to the care of her brother.

Even if such serious consequences are avoided, both groups were clear that it is not unreasonable for people at their most vulnerable to believe that disclosing sensitive experiences once would be enough but that saying it to the 'wrong person' was the same as not saying it at all. Which in turns means people won't say it again, missing the opportunity to get at the root of the problem.

One final aspect of this as a missed opportunity is that all participants identified that the one question they are very rarely asked is 'how can we help you?' Staff either tell you 'what they will do' or offer little unless you directly ask for it. Like many elements of the system this stops people asking for help.

2.3 Missed Opportunity: You only get help in a crisis

Linked to the complexity of the system there was a common view that you will only get help if you are in a real crisis – the example of multiple suicide attempts over one weekend before 'getting anyone's attention'. Everyone recognised the importance of early intervention, but the men's group prioritised a

discussion around what it is that makes you ready to accept help from someone or understand that you need help.

One example was of a young man who described 'going to rehab, doing the wrong thing, kicked out. Going back to rehab, doing the wrong thing, kicked out. Back again, did the right things. But what was different?'

Another member of the group described the first time, after many years of severe and multiple disadvantage, that they 'opened up' to an addictions worker in a way that had never been able to before.

When discussing why the time felt right and they were ready to move forward, common themes included feeling safe, feeling like they weren't being judged, focusing on positives rather than negatives.

However, other common phrases people used that helped explain why was 'I was beat' and 'the penny finally dropped' that things had to change. A sense that, as much as a positive environment can help, sometimes the motivations for change are negative and that you never know when the personal realisation will come. And just because you haven't always done well in services in the past doesn't mean they should 'close their doors to you' in the future.

2.4 Missed Opportunity: Conflicting priorities and motivations within the system

A particular complexity of the system when you are experiencing severe and multiple disadvantage is that the constituent parts (homelessness, criminal justice, addictions) do not always have a common, or even complementary, goal.

This conflict was most commonly identified, particularly in the men's group, in the example of people entering rehab with the sole intention of avoiding a prison sentence. Several men in the group described having done this with only one identifying any kind of positive impact ('it pointed me in the right direction'). For everyone else it was a case of 'sitting it out' until the prospect of prison was gone and you had 'made a good impression, looking like you're trying'. There was no judgement of people making this choice, just the common observation that avoiding a prison sentence was a 'negative rather than positive motivation' for entering rehab, and without positive motivation 'it won't work.'

The missed opportunity was seen as services being full, but not by people who need or want to be there. Rehab being full of people trying to avoid prison, emergency accommodation full of people waiting for a place in rehab … services are stretched to capacity but people are in the wrong place.

2.5 Missed Opportunity: Overreliance on medication and prescriptions

Whether for addictions or mental ill health there was a common agreement, most strongly in the women's group, that the first port of call for staff is to 'medicate you, whether you want it or not'. There were examples of people having to fight not to be prescribed medication they did not want, but not getting anywhere because 'medicating us is easy.'

Furthermore, both groups agreed that in such circumstances, the decision is made before you even walk in the door, it is not even a personalised medical response to your circumstances.

People realised it is a difficult balance to strike as there are others out there not getting medication they need, but when people are in crisis it is seen as a 'quick fix' that can solve problems 'for staff but not people.'

For some, the resistance to medication was that 'they knew themselves' how it made them feel and wanted to avoid it. Others noted a fear of addiction to other kinds of pills. But when it came to alternatives such as counselling, very rarely would this be discussed.

2.6 Missed Opportunity: Staff know best

This thread runs throughout many of the themes, with the missed opportunity being that people are rarely asked what is important to them or what they think will help them.

However, there were mixed views amongst the two groups about this with women being clearer that 'you know yourself' and that people should be trusted more rather than assuming that 'you don't know anything because of where you are'. There was also a very strong view in the women's group that staff are often unqualified to make any professional judgement about you – 'they don't know what they are doing.'

While the men's group did recognise this, there was also the view that, when your life is chaotic you often don't know what it is that you need – 'you just need help' – and that you are completely reliant on services understanding what you need and providing it (made difficult due to the common lack of trust, and that you might have gone back in the 'wrong door').

But overall, both groups agreed that decisions should be two-way, even if it's 'not easy when you are at rock bottom.'

2.7 Missed Opportunity: Family and children as part of the solution

Contact with family and children was identified by both groups as a sign that things are improving. But the role of services in helping rebuild or protect positive relationships was highly sensitive.

Members of each group could describe 'burning bridges' with family and friends when things were at their worst, with one in particular noting that 'staying away was the only way I could protect them.'

But would it make a difference if services asked you about your family and whether you wanted contact with them? All members could see difficulties as 'family might have caused your problems' or you might not have any close family (one young man in the group became homeless after losing both of his parents and not being able to maintain the family home on his own).

But aside from these circumstances both groups discussed whether it would make things better if family relationships were raised earlier. A key observation, particularly from the men's group, was that professional services never ask about your family, but peers (either formally or informally) almost always approached the subject in some way, and that there was a far higher level of trust amongst peers.

On the issue of children, there were split views between the groups. Both men and women taking part were parents and there was agreement that children are not part of any discussions unless there are ongoing legal/custody issues ('another problem to solve').

The parents within the women's group were clear that children should be considered more centrally as part of support plans as they are the 'motivation for getting better' and not being with them 'makes everything worse'.

However, the men's group saw their parental role as something they would think about once they'd 'sorted themselves out' and that it might be added pressure to think about it when you are vulnerable.

2.8 Missed Opportunity: Not enough peer support

The lack of trust in services and the system as a whole was equally shared across both groups, as was the view that peer relationships are often more positive as they are built on a shared understanding of:

- the damage caused by being judged;
- the importance of hope for the future; and
- the reality of the fear felt by people every day.

Even though peer support models are becoming more developed and more commonly available people felt they were still thought of as 'second class' when they are often the most important, and not prioritised.

All 15 members of the reference group identified the positive impact that a peer (either just someone else using a service or someone in a formal support role) had played in helping them, and the same could not always be said for services or professional staff.