SCOTTISH RECOVERY CONSORTIUM

Lived Experience Reference Group

Residential Feedback

7th January 2021

Contents

Foreword 2
Executive Summary 3
1. Background 4
2. Summary of the reference group discussion 5
2.1 Access to treatment 5
2.2 Support from professionals/services prior to rehab 6
2.3 Funding 6
2.4 Waiting Times 7
2.5 Aftercare 7
2.6 Family Support 8

Scottish Recovery Consortium, 2/1, 30 Bell Street, Glasgow, G1 1LG
Charity Number: SC041181 Telephone Number: 0141 552 1355

Foreword

When the Scottish Government asked the Residential Rehabilitation Working Group to assess the current status of residential rehabilitation across Scotland, we were glad of the opportunity to shine a light into one of the most neglected areas of drug and alcohol treatment. We uncovered evidence of good practice, but also much that needs to change.

One vital theme in the group's work was to understand what constitutes good practice for residential rehabilitation interventions - not only for treatment itself, but also how rehab is funded, how people get there, the challenges they face and what happens afterwards. We could not do this, indeed should not do this, without involving those with lived experience.

As you will see from this report, the lived-experience members of the reference discussion group bore witness to many of the findings in our earlier publications, but because of their own experience, what they said gave colour, depth and meaning to the issues.

The group identified frustration at the lack of choice, missed opportunities, late interventions and blocks to referral. They highlighted tortuous funding systems and long waits. They also exhorted us to understand the whole journey and to make everything joined up, instead of having to silo-hop.

We are asked to accept that some people may need more than one rehab treatment because of non-linear recovery journeys. The reference group call for longer stays, enhancements in aftercare and a better deal for families as well as improved communication between stakeholders. What makes this report particularly relevant is that the group's appeals for improvement are based on their authentic experiences before, during and after residential rehabilitation. This is what currently happens in our systems. We need to do better.

Because of the Scottish Government's commitment to improve residential rehabilitation, we now have a real opportunity to raise the bar. Angela Constance MSP, the Minister with responsibility for drugs policy gave her endorsement when she said, 'I believe in the power of residential rehabilitation'.

I hope we will get to a point where rehab is seen as an integral part of our treatment system, where there are clear access pathways and full integration with other options and services, where the individual's needs are at the forefront every step of the way. Those with lived experience have to be at the heart of the process. The publication of the reference group's discussions will ensure that their voices are being heard.

As chair of the Working Group, I'd like to say thanks to the volunteers who made up the reference group for their time, reflections and opinions and to the Scottish Recovery Consortium for facilitating the group's meetings. We are grateful to Geraldine Smith and Anniek Sluiman for helping us analyse and write up the discussions.

Dr David McCartney
Chair, Residential Rehabilitation Working Group

Executive Summary

It is difficult to navigate the referral system and more should be done to ensure individuals are involved in decisions around their care. Multiple stays in rehab are normal and should be recognised as being part of recovery and should not impact on future referrals. Fear, stigma and mental health impact on an individual's ability to seek help.

The role of professionals is one of the most important factors in the success of referrals to rehab. Professionals with lived experience were seen as essential and are key to making referrals. However, the level of support provided is not consistent. Lack of resources, communication and silo working negatively impact the support an individual receives, and their recovery.

Funding routes are difficult to navigate and self-funding is simpler and quicker. Many do not have the option of self-funded care and many also would not accept family support. The perceived severity or likelihood of harm was important in securing funding via ADPs, however this is often only when an individual is in crisis. By lowering the eligibility threshold for funding and ensuring funding before crisis point will likely reduce drug related harms and deaths.

Waiting times are generally long and in reality are a combination of both the time taken to seek referral/ the referral process, and the waiting list of a rehab facility. The window of opportunity for an individual to effectively engage in treatment can be small and so everything should be done to minimise the time an individual should wait to receive care.

Aftercare is an important part of the rehab process and minimises the likelihood of relapse. A high quality and detailed discharge plan tailored to the needs of an individual is key to ensuring a good level of aftercare. This should be agreed in partnership with the individual, the local authority and the residential rehab.

The support of the family is important and opportunities should be made available to family members to engage with the rehab and the recovery of their loved one. Support for family members should be in place dependant on individual circumstances.

1. Background

This Lived Experience Reference Group was established to support the work of the working group on residential rehab and the subgroup. The subgroup's remit includes bringing together the evidence base around residential rehabilitation in Scotland to generate a set of guidelines in the form of a Good Practice Guide.

Previously, a mapping exercise was commissioned by the working group to establish a national estimate of number of beds and services provided by rehab facilities. This report raised a number of questions around pathways into rehab including how an individual accesses treatment; professional support; funding arrangements available; the impact of waiting times; importance of aftercare; and the role of family support.

Scottish Recovery Consortium (SRC), work closely with those in recovery providing support and representation across different forums. The SRC facilitated this lived experience reference group discussion, bringing together a varied group of people from different socio-demographics and different stages of recovery. Ten people with lived experience were involved and were led by a facilitator also with lived experience. There were 6 men, 4 women and a range of ages (from under 25s to over 60s) were represented. Across two sessions, the group discussed individual experience of residential rehab and views on the above mentioned points. The SCR communicated the overall objectives and discussion points to the reference group in writing in advance and group members were reminded that individuals were under no obligation to discuss/ contribute to discussions they did not want to/ feel able to and that they were under no obligation to attend.

The SRC-led discussion generated a number of key points as summarised within this report. This main discussion points will be presented to the subgroup of the working group with a view to feed into the drafting of the Good Practice Guide and allow the views of those with lived experience be represented.

2. Summary of the reference group discussion

2.1 Access to treatment

The process of **navigating the referral system** and pathway into rehab was difficult and dependant on factors out-with the control of the person seeking help.

Many had the experience of family members having to **search for rehab facilities via the internet** on their behalf. This was not always straight forward and often lead an individual to believe that self-funding was the only option to them.

Individuals **do not feel as though they have a choice** in when they are referred to rehab as referrals are only made when a person seeking help becomes a danger to themselves or others, for example attending A&E or other crisis services.

The pathway for those seeking residential care with children involves the need for social work involvement, regardless of individual circumstances. This barrier for referral into residential care was complex and based around the **fear of what social work would do**, the impact on their children, and stigma attached to social services for both the individual seeking help and the family.

Access of treatment through justice system due to court order was a relatively established pathway into rehab, and less challenging to navigate than other pathways from within the community.

Poor mental health and associated behavioural issues prevented access to treatment and individuals were often turned away from services. Individuals reported a perception that mental health issues can often only be addressed after an individual is in recovery for their addiction. However, recovery from addiction is dependent on addressing underlying mental health issues. This leads to vulnerable individuals potentially being excluded from both residential rehab and mental health services.

It was discussed that at times **individuals resorted to lying about the nature** of their circumstances to allow them to gain access to treatment. This was generally only after a number of failed attempts and becoming aware of the referral process.

There is a need to recognise that as part of the process of recovery, it **is common to have multiple rehab stays and that for some this is a necessary part of recovery**. It was felt that in general rehab stays were too short and that this should be reviewed in light of the fact that considerable numbers of people require more than one stay in rehab. In addition, it may be useful to review what is meant by aftercare and consider it more like an outpatient service, where once an individual transitions back to the community the rehab continues to engage in a structured way. This may include the continuation of therapy and monitoring, funded as part of the stay, with the possibility of returning to rehab should this be necessary.

2.2 Support from professionals/services prior to rehab

Professionals who had lived experience of rehab and who were in a position to make or support a referral into rehab played a major role in individual referrals to rehab. This was discussed as being key in helping prepare and motivate people seeking help for their addiction. The group recognised the need to encourage the employment of those with lived experience in these roles as they are expertly placed to reach out to individuals needing assistance, have experience of navigating the referral system and are best placed to recognise when rehab might be a suitable option for an individual seeking help.

There was a general consensus that on the whole **GPs did not consistently provide enough support** to those seeking treatment. For those that did not have opioid based addiction or were seeking help for addictions that involved bingeing it was difficult to be referred, as the periods of abstinence in between binges were seen as evidence that an individual was able to control their addiction themselves.

Community Psychiatric Nurses (CNPs) play a key role in referrals for individuals receiving mental health support and who often have multiple complex needs. For individuals who are already in contact with mental health services this was discussed as being how they accessed residential rehab.

The discussion around the role of social work in individual recovery was mixed. Involvement of social work, in some cases, provided assistance and guidance for individuals seeking referral to rehab. However, the **degree of engagement was not consistent and the role played by social work for individuals entering and transitioning out of residential treatment was not clear**. In some cases the fear of not knowing what social work would do, and the stigma associated with social work involvement prevented referrals to rehab.

The importance of recognising that residential treatment is not just the actual time spent in rehab was discussed. **This process can be described in three stages: starting when an individual seeks help / the referral process, time spent in residential care, and the transition back into the community.**

A key barrier to this recovery journey was the lack of communication between services. It was felt that **silo working impacted both the pathway into rehab, the stay, and transition back into the community**. The importance of joined up working and continued support throughout the course of care is vital to the success of individual recovery. It was felt that **lack of overall resource may impact on the capacity to support individuals** and that this also impacts on the likelihood of recovery.

2.3 Funding

It was discussed that although not an option for the majority, **paying for private residential rehab is easier than navigating other funding routes**. Some felt that this was the only option available to them and that this was primarily because their condition was not seen as severe enough. There was discussion around the notion of having to fight to be taken seriously, or having to resort to dishonesty to have someone make a referral on an individual's behalf. The group discussed the concept of **only receiving funding if they are considered to be at a crisis point, a danger to themselves or having exhausted all other options.**

Although for some this added to the motivation to engage in services, for some this was an unnecessary and harmful point which could have been avoided should they have been offered a place earlier on.

There was **reluctance in accepting family support for funding** residential care, even if this was available.

The group discussed **different funding pathways** including: via the criminal justice system, as part of a treatment order, and via housing support. Funding from the local authority was more difficult to secure and the system is different now compared to the 1990s, when a number of group members were in rehab. The group also discussed comparisons with European models of residential care where walk in services were offered as part of the healthcare system.

2.4 Waiting Times

In general, the group found the **waiting times to be lengthy**. Waiting times are often thought of as the time taken to reach the top of a waiting list at a rehab facility. However, the group discussed the importance of considering **the process from first seeking help to starting rehab as a better measure of overall waiting times**. Key barriers to this include the administration process and time taken to receive funding decisions.

Important factors discussed as contributing to waiting times included having to **wait for a decision on funding before treatment could start.** An individual stated that there was even a 3 month wait as part of a 'fast tracked' funding application.

It was discussed that **GPs are reluctant to refer** and for one individual this took over 18 months. This is in stark contrast with a self-referral/ self-funded placement which reportedly only took 4 days from referral to being in treatment.

It was felt that **timings around when an individual enters rehab are key to the success of rehab**. The notion of chance and luck was discussed as something that the group related to in relation to how they entered rehab, and the group felt that the waiting times seemed to be arbitrary and not specific to individual circumstances. It was agreed that an individual should be empowered to choose when rehab is right for them as opposed to a referee making that judgment, which is often when all other community based approaches are exhausted.

The window of opportunity to get a person into rehab and into recovery may be small and **overly long waiting times is likely to have a detrimental effect on a person's recovery** and may increase the likelihood of a person experiencing significant harms such as overdose.

2.5 Aftercare

Good aftercare was one of the most important aspects of rehab and should be carefully planned out before an individual transitions back into the community.

The group discussed their experiences of aftercare and thought **in general this could be improved**. Some mentioned that there was little or no communication between rehab service and services in the community prior to admission. Others received 6 weeks of support post

rehab followed by monthly phone check-ins for 3 months. Those who transitioned to supported accommodation found aftercare to be more comprehensive. The group felt that **a support package and a discharge plan should be discussed prior to leaving rehab** and by having a clear plan, which includes practical advice, tool-kits, information on local support groups as well as short-, medium-, and longer-term goals was important.

The group felt that more **structured and consistent engagement and communication between rehab facilities and the local authority** would reduce the risk of relapse and harms in the immediate period of returning home after being discharged. **Returning home is a critical time** point where individuals are particularly vulnerable and at a high risk of retuning to past behaviour if they feel abandoned, lonely or without support.

As a number of the group had recently left rehab, **the impact of the COVID-19 pandemic was discussed in relation to the then imposed restrictions**. During this time key workers provided telephone and online support to individuals only. It was felt that face-to-face support would have been better, especially as an integral part of many residential rehab programs includes group work and that the social aspect of rehab was important in their recovery.

2.6 Family Support

It was felt that although some families may feel unable to be involved in the recovery of a loved one, and that for some individuals the involvement of their family may not be helpful; the overall consensus is that **family support is an important element and can be very helpful in an individual's recovery**.

Opportunities for families willing to engage with rehab and community services should be made available and support should be given to the family to ensure they are able to do so.

Families should be provided support themselves to help with their recovery from the impacts of their loved ones addiction. The group discussed the impact of addiction on the family and how this has changed relationships and dynamics. It was felt that supporting families to help rebuild relationships was important in creating a support network for the individual in recovery.

The group also discussed that **family members may also struggle with their own alcohol and drug use** and this may impact on the degree and nature of their involvement. Support should be available to family members affected by drug and alcohol use and this may have a key, indirect effect on longer term recovery for an individual in rehab.

The **nature and intensity of family support is dependent on a number of key variables including the location of the rehab in relation to their home and ability to engage with online platforms**. Even if the family are welcome to visit or engage, if the rehab is too far away or they do not have phone or internet access this is difficult. The group felt that structured family support and engagement in the form of weekly visits, family therapy sessions, face-to-face support groups or virtual support groups such as WhatsApp is vital.

For some, **family members were integral in accessing rehab on behalf of their loved one**, especially when those seeking recovery were in crisis and not in a fit state to navigate the referral systems themselves.

SCOTTISH
RECOVERY
CONSORTIUM

Scottish Recovery Consortium
2/1, 30 Bell Street
Glasgow
G1 1LG

Telephone: 0141 552 1355
Charity Number: SC041181

www.scottishrecoveryconsortium.org