Stigma: A consultation with people with experience of addiction and people in recovery.

Author – Mark Stephenson

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Contents

1   Introduction

The Collaboration Action Fund is a source of funds for North East organisations who have identified themes where collaboration with others will generate greater benefit for communities. Recovery Connections were successful in securing a grant of £5000 funded by Lily Lewis, Venture Capitalist to explore collaboration with another organisation. Recovery Connections approached The Road to Recovery Trust as a similar organisation based in Newcastle, to form that partnership. The theme of the work was to explore how collectively the two organisations could identify and address stigma associated with addiction in the North East.

Following a number of facilitated sessions to explore organisational values and commitment to work the two organisations agreed a need for community member input and consultation to determine the impact of stigma and discrimination at a grassroots level. Based on the findings of the consultation the two organisations will explore a joint project in the North East to tackle stigma and source appropriate funding. This consultation is therefore a foundational piece of work which the two organisations will use as a platform for a future project.

2   Methodology

Two consultation sessions with people in recovery and experience of addiction were held. The format for the sessions were developed in partnership with senior management from Recovery Connections in Middlesbrough and The Road to Recovery Trust in Newcastle to ensure it met their needs.

Two consultation sessions were held: one in Middlesbrough (the group was convened by Recovery Connections) in December 2019 and a second session in Newcastle (the group was convened by The Road to Recovery Trust) in March 2020. Each session was approximately two and a half hours in length.

The themes and questions discussed included the following:

- What is stigma?

- In what way have you been stigmatised?

- Why is there stigma?

- How does stigma play a part in people accessing/engaging with an addiction/recovery service?

- At what time in an individual's engagement with an addiction/recovery service do you feel that stigma plays a lesser part/reduces diminishes?

- What interventions/themes support that process?

- How does stigma play a part in the relationship between the individual and the addiction/recovery service they are accessing?

- As individuals, what can we do to challenge and eliminate stigma?

- How can organisations working with addiction/recovery challenge and eliminate stigma?

- If we were to design a service which aimed to challenge and eliminate stigma – what would that service look like?

A mixed method approach was used within the sessions. Themes for responses were elicited through individual work and the completion of post-it notes, and these were then discussed within the larger group. The facilitator took notes during the discussions. Other elements of the work were undertaken

in small groups. Other work, where time allowed (in Middlesbrough) was undertaken on a World Café basis.

More generally, the flow of the session was developed in order to build confidence, knowledge and understanding throughout the session. Two thirds of the session focused on experiences and sharing these experiences with the group - whilst the final third of the session focused on solutions.

Middlesbrough Consultation Session

Staff from Recovery Connections recruited a group of individuals who were known to the organisation, to participate in a focus group to discuss the issue of stigma. We understand that most participants were in recovery from addiction. The session was held on the afternoon of 17th December 2019.

Twenty participants attended the session. Eighteen participants identified as 'White British' and two participants identified as 'Other'.

Eleven participants were female and 9 were male.

Age distribution was as below:

Age Range	Number
18 - 24	2
25 - 34	5
35 - 44	6
45 +	7

Newcastle Consultation Session

Staff from The Road to Recovery Trust recruited a group of individuals who were known to the organisation, to participate in a focus group to discuss the issue of stigma. We understand that most participants were in recovery from addiction. The session was held on the evening of 3rd March 2020.

Fourteen participants attended the session. All participants identified as 'White British'.

Five participants were female and nine were male.

Age distribution was as below:

Age Range	Number
18 - 24	1
25 - 34	1
35 - 44	6
45 +	6

3   Findings

3.1   Middlesbrough Consultation

3.1.1   Defining Stigma

Participants were asked to define stigma and were asked the question: 'what is stigma?'

The word cloud below illustrates the key themes:

Participants defined stigma in a number of different ways. They regarded stigma as being fundamentally judgemental and based on prejudice and it was felt that stigma was essentially unfair, discriminatory and was linked to labelling and stereotyping.

Participants also identified the ways in which people can be stigmatised : race, addiction, criminal background, sexuality, age, social class and gender.

The effects of stigma were also discussed when exploring this question in this group. Participants felt that the stigma was cruel, hateful and damaging and it had the result of making those who were being stigmatised feeling ashamed and embarrassed. Others discussed how feeling stigmatised can lead to individuals 'not accessing services' and how stigma was a 'mark of shame'. Stigma was also regarded as being debiltating and had the potential to lead to further isolation.

Participants also suggested that stigmatisation was based on social norms and assumptions and was linked to those with a stgmatisimg attitude being fearful and close-minded and holding pre-conconceptions.

3.1.2   The Impact of Stigma

Participants were asked to discuss the ways in which they had been stigmatised, and in this way, individuals were exploring that impact of stigma.

Participants discussed the impact of stigma in terms of low self-confidence, low self- esteem, low self-worth.

Participants had experienced stigma in a number of environments: Employment and work, the criminal justice arena, when in shops, accessing benefit payments, drug treatment services, housing, education, healthcare and from family and friends.

Stigma had included participants being subject to a range of verbal and physical abuse, had led to them feeling fearful, alone, ashamed, worthless, ashamed, guilty, and isolated.

3.1.3   The Root of Stigma

Participants were asked to discuss why they felt there was stigma; in many respects they were being challenged to explore the roots of stigma. Responses have been grouped together thematically:

Media

There was a sense amongst participants that a stigmatising view of people experiencing addiction had been 'whipped up' by the media - and there was also an element of this now being proliferated through the use of social media.

Beliefs

A number of participants suggested that stigma was as a result of beliefs - some of which were identified as deep rooted and cultural. There were a number of different contexts to this suggestion:

- Community
- Passed on knowledge
- Different generations / generational views
- Learned behaviours
- Conditioning
- Copied behaviour
- Passed on values and beliefs
- Higher ground

Historical and Societal

Several suggestions can be thematically grouped as historical and/or societal:

- Politics
- Laws
- Creates division
- Cultural norms
- Socially constructed

Issues such as social status and social class were also discussed within a historical and political context.

Within this context participants discussed the use of stigma as a tool to manipulate, create division, to create a 'higher ground' and to apportion blame.

Ignorance /lack of awareness and understanding

There was a sense that a lack of information and awareness and ignorance was also at the root of stigma. It was suggested that those who stigmatised had a negative, close-minded outlook. Some people, it was suggested, either misunderstood or did not want to understand and this had led them to adopting a stigmatising mindset. This was linked to a judgmentalism.

It was stated that stigma was as a result of some people lacking compassion and empathy.

Fear

Fear was discussed as a driver of stigma. Some people, it was stated, were angry or insecure and this led to them having a stigmatising worldview.

3.1.4   Accessing and Engaging with Addiction / Recovery Services

Participants were asked in what way stigma played a part when accessing / engaging with an addiction/recovery service. This task was undertaken in small group work settings and then shared and discussed within the larger group.

12 Steps – Perceptions of religion

Participants suggested that some individuals may not want to access a service that includes a 12 Step model, as they may have a misconception regarding the role of religion. One participant stated that they previously 'didn't want to access Mutual Aid because of the word God'.

Previous experience of professionals

It was stated that previous experience of engagement with professionals and people in authority (e.g. social services, schools, doctors, prisons) may impact on the potential for a person in need to access an addiction service.

Fear

Fear was discussed within this context in a number of ways:

- Fear of the unknown
- Fear of rejection
- Fear of failure
- Fear of commitment
- Fear - and anxiety - regarding socialising
- Fear of letting people down
- Parents with children feared accessing a service
- Fear of losing their job.

Pride

Some participants linked pride and ego with fear, with one participant stating that they feared 'admitting to what I've become' and 'admitting that there is a problem'. This was also linked to denial, humiliation and, as stated by one participant - 'not thinking they are as bad as other people'.

Anonymity

Maintaining anonymity was regarded as initially important when accessing addiction services, with one participant stating that they were in 'fear of neighbours or family seeing me' accessing the service.

Lack of knowledge

Pre-conceived ideas - or misconceptions - of services were also regarded as a potential barrier to some individuals. Similarly, perceptions of staff within services was also discussed as a potential barrier.

Shame and embarrassment

Shame and embarrassment were discussed as potential barriers to some accessing services.

<u>Labels</u>

For some, labels around addiction were also discussed as a barrier to accessing services. Some participants stated that some individuals may not attend as there may be a perception that they will be stigmatised for accessing a service - a sense that others regarded addiction as 'self-inflicted'. They may also be concerned that workers within a service may have a pre-conceived view of those people with an addiction issue.

<u>Increases substance misuse</u>

One participant stated that stigma would make some people 'use more' substances.

3.1.5   Engagement and impact on stigma

Participants were asked to explore at what time during an individual's engagement with an addiction/recovery service did they feel that stigma started to play a lesser part. This task was undertaken in small group work and then shared and discussed within the group. Responses have been grouped together thematically:

<u>Trust and relationship</u>

One participant accepted that perceptions of stigma had made it hard for them to 'open up'. Many participants suggested that once receiving support, the barriers reduced, relationships started to grow – as did trust. This was particularly the case when people based within services shared their own experience of addiction and recovery. It was suggested that trust and relationships built honesty:

> *'When you are honest – accept have an issue, not alone, require support, willing to engage'*

<u>Progress and confidence</u>

Growing confidence, self-acceptance, progress, and growth were regarded as important features in terms of engagement:

> *'Self-acceptance. Learn to accept we may get things wrong and that's okay'*

> *'Once you learn to accept your problem and become open minded and want to help others and change stigma and become visible recovery'*

> *'When you feel more stable – when positive things begin to happen in life – feel less stigmatised'*

Participants also discussed issues which may prevent an individual initially accessing an addiction/recovery service:

- Fear of fitting in within the service
- Fear of other people finding out that you require the service
- Lack of experience and empathy from people at the service

3.1.6   Interventions/themes that support the engagement process

Participants were asked what interventions / themes supported engagement and strengthened a sense that stigma was playing a lesser part. This task was undertaken in small group work and then shared and discussed within the group. Responses have been grouped together thematically:

- Opportunity to contribute and 'give back'

- Growth and self-worth

  Where there was personal growth and a greater valuing of self, then this helped to promote the engagement process:

  '*When Personal Care Plans show results'*

- Feeling gratitude

- Being with others in recovery

  Many participants stated that being with others in recovery promoted the engagement process. This provided opportunities to support and focus on others (which was regarded as important). Group work was also discussed within this context:

  'Realising that you are not alone in making a life in recovery'

- Trust and acceptance

  Acceptance, 'feeling a part of' and belonging were all regarded as important. Love was also discussed within this context:

  'Being relaxed in environment'

  'Sense of family in Recovery Connections'

  Linked to trust was the ability of workers to follow up on promises and carry out what they said they would do.

- A culture of visible recovery and valuing lived experience:

  'More empathy in peer led services. More empathy and knowledge'

- Service understands stigma and how that applies in practice and in the real world

  'An open door and support because they are aware of stigma'

  'Understanding of stigma and a strong bond of trust'

3.1.7   Stigma and the impact on the relationship between the individual and the addiction/recovery service they are accessing

Participants were asked to discuss and identify the ways in which stigma plays a part in the relationship between the individual and the addiction/recovery service they are accessing. This task was undertaken in small group work and then shared and discussed within the group:

- Fear of being judged

  'Trust and fear of being judged'

- Fear of rejection

  'Fear of being open and honest and being rejected'

- Concerns over confidentiality

- Promises unfulfilled by the worker /service

  'False promises'

- Feeling that the worker/service is not listening

  'Nobody listened'

- Fearing a lack of empathy

- Needs/issues not 'passing criteria'

  'Feeling my issues are not as valid as others'

'Not passing criteria to deserve help'

'Don't want to be categorised into the same group as drug addicts'

- Lived experience

'Not trusting staff and services who haven't experienced addiction'

- Belief in recovery

'That people will not believe you have the ability to change so you don't think you can say how you feel'

3.1.8   Challenging, addressing, and eliminating stigma

Individuals

Participants were asked to discuss and explore the ways in which individuals can eliminate and challenge stigma. This task was undertaken using a World Café approach. Responses fell into two categories:

An approach that **all individuals** can adopt to challenge stigma in general:

- Being empathetic

'Showing emotion'

'Be human'

- Practical support

'Identifying minority groups, people in isolation'

An approach that **people in recovery** can adopt to help challenge stigma:

- Raise awareness and challenge assumptions/assertions

'Arrange groups with addicts and the public'

'Make people aware of the disease of addiction – most stems from childhood'

'Promoting open mindedness to people – learn about the disease of addiction. And as an individual being willing to learn'

'More advertising/publicising'

'Challenge people's perspective with love and compassion'

- Visible recovery

'Visible recovery will challenge and eliminate stigma'

'Being open and honest'

'Being proud of recovery'

'Start from the inside out. Recovery's not a one cap fits all – we're all equal'

'By sharing our stories with the public'

Within communities

Participants were asked to discuss and explore the ways in which communities can eliminate and challenge stigma. This task was undertaken using a World Café approach. Responses are grouped together thematically:

- Raise awareness, educate, and challenge assumptions/assertions

  'Services to go and promote in other organisations'

  'In schools, colleges and university about addiction'

  'Public information team to go out and publicly announce about Recovery Connections and what the service is doing for people'

  'Prisons and probation'

- Promote recovery and 'tell stories' about recovery

- Be accepting

  'Showing acceptance'

  'Everyone's journey is different'

  'Showing love and empathy'

  'Treat everyone equally'

- Be honest

  'Be honest and show how we feel about recovery'

- Practical support

  ''Rolling sleeves up' and work with those who are excluded / minorities / people in isolation / people who are lonely'

  'Bring different communities together'

The role of organisations

Participants were asked to discuss and explore the ways in which organisations can eliminate and challenge stigma. This task was undertaken using a World Café approach. Responses have been grouped together thematically:

- Raise awareness and educate

  'Constant education to broaden knowledge / offer opportunities'

  'Challenge historical deep-seated views'

  'Organisations (addiction treatment services) - should go into schools / prisons / hospitals / talk to parents / teachers / police/ lack of education in other services / institutions'

  'Raise awareness and raise the profile and move it up as a public health priority'

- Consultation

  'Focus groups, giving people opportunity to talk – their opinion matters'

- Be open-minded

- Adopt a Peer Approach

  'Form peer networks / training / volunteering / employment'

  'Stop pretending organisations are experts'

- Promote visible recovery

   'Better advertising – more awareness – recovery games /walks /events'

   'Visible outreach – on the front line'

   'Peer led people with lived experience leading under a national /global framework'

   'Public health issue not in the criminal domain – led bottom up'

Designing a service that challenges and eliminates stigma

Participants were challenged to design a service which aimed to challenge and eliminate stigma. This task was undertaken using a World Café approach. There were a number of key themes discussed by participants:

Education, aware raising, and promotion

These factors were discussed within a number of contexts:

   'Better promotion and advertising'

   'Big bus on frontline going around housing estates'

   'Police, prison staff, hospitals – give them workshops on addiction'

   'Addiction is more than drugs – gambling, eating'

   'Teach empathy, compassion from a young age'

   'More information for school to inform children'

Promote visible recovery

It was felt that promoting visible recovery was important and using the experiences of people in recovery was vital, including those in long term recovery.

3.2 Newcastle Consultation Session

3.2.1 Defining Stigma

Participants were asked to define stigma and were asked the question: 'what is stigma?'

The word cloud below illustrates the key themes:

Marginalised Loneliness Uninformed Assumptions attitudes Prejudice Discrimination Self-loathing conceived solutions Stereotypes assumption individuals Ignorance procedures Depression lies Judgemental Fear-based Negative Reinforces ShameHealth ideas Paranoid Based practice low Labelling others Judging opinion Immobilising Lack Pre. division Judgement education discrimination Degrading Peoples Blinkered Exclusion Class group Aversion self-esteem treating myths Assumption polices Mental Intolerance Guilt beliefs Hostility Institutional understanding Stereotyping misconceptions knowledge hearsay/media

Participants defined stigma in a number of different ways. They regarded it as being fundamentally negative, based on prejudice and assumptions and linked to labelling and stereotyping.

The effects of stigma were also discussed when exploring this question and participants felt that is made those being stigmatised feel excluded, marginalised, lonely, depressed and had an impact on their mental health and reinforced low self-worth.

There was a sense that those who had a stigmatising mindset lacked knowledge and education and were stigmatising others based on negative myths, misconceptions, per-conceived ideas, a lack of understanding and uninformed opinions.

3.2.2 In what way have you been stigmatised?

Participants were asked to discuss the ways in which they had been stigmatised, and in this way, individuals were exploring that impact of stigma.

Participants discussed the impact of stigma in terms of feeling judged, feeling ostracised and ashamed. Some participants had internalised some of these perspectives: 'Felt that I was not good enough'.

Stigma had led to some participants being subjected to a breadth of violence and abuse, feeling fearful, alone, ashamed, worthless, ashamed, guilty, and isolated. Stigma had also led to some participants experiencing self-hate, depression, suicide attempts, and being a victim of crime.

Stigma had also led to some participants becoming isolated, it had impacted on their honesty with services, stopped them asking for help, being rejectied from family and friends ('people avoided me'), led them to missing employment opportunities and being 'written off'; indeed, a number of participants stated that stigma had led to them being refused help

Two participants also discussed the way in which they had been stigmatised by their previous peer group, once they had started to address addiction and to embrace recovery.

3.2.3   The Root of Stigma

Participants were asked to discuss why they felt there was stigma; in many respects they were being challenged to explore the roots of stigma. Responses have been grouped together thematically:

Human Nature

Several participants regarded a key root of stigma as being 'human nature'. One participant stated that it was 'survival of the fittest'.

Historical and Societal

A number of responses can be grouped together thematically as historical and/or societal/political. This included including an instinct of some within society, to 'ostracise groups' of people and 'othering'.

Class was also discussed within this context.

The use of stigma used as a tool to manipulate, create division, and to manipulate minority groups was discussed. As discussed by one participant:

> 'Sometimes used by government to push their agenda through'

It was also felt that stigma was used to create division ('them and us') and for some groups to maintain status and achieve a sense of superiority over other groups. For some people, it was asserted, stigma was used to avoid some people 'looking at themselves'. It was suggested that there were cultural roots to stigma.

Ignorance /lack of awareness and understanding

There was a sense that a lack of knowledge, ignorance, misinformation, and misunderstanding was also at the root of stigma.

Fear /Hate

Fear or hate was also discussed as a driver for stigma for some people.

3.2.4   Accessing and Engaging with Addiction / Recovery Services

Participants were asked in what way stigma played a part when accessing / engaging with an addiction/recovery service. This task was undertaken in small group work settings and then shared and discussed within the larger group.

Perceptions of the service

Perceptions of the service - and the process of engagement was regarded as a barrier to accessing the service:

- Would the individual be subject to forced abstinence?
- Perceptions of religion linked to NA
- Previous experience of workers lack of knowledge

Fear

Fear was discussed within this context in a number of ways:

- Fear of how the individual would be treated
- Fear of failure
- Fear of anonymity being broken ('frightened of people seeing me going in')
- Fear of judgement
- Fear of authority
- Fear of social services becoming involved
- Fear that admitting fault would lead to reprisals

Fear that the individual may leave the service in a weakened position, as there was a perception that they would then need to carry the stigma linked to addiction after leaving the service, was also discussed. This was a view supported by another participant who stated that they had previously not asked for help because of the potential of being stigmatised following engagement with an addictions service.

Shame

Shame was discussed as a potential barrier for some people accessing services.

3.2.5   Engagement and impact on stigma

Participants were asked to explore at what time did they feel that during an individual's engagement with an addiction/recovery service did they feel that stigma started to play a lesser part. This task was undertaken in small group work and then shared and discussed within the group. Responses have been grouped together thematically:

- Once the individual was able to be honest

- Peer support within the service

  'When addicts help other addicts'

  'When a recovery worker 12 stepped me – told me they were a recovering heroin addict'

- Trust and relationship

  'When the individual can trust the person/people at the service'

  'When I had enough time behind me to judge whether I could trust'

  'When you become familiar with surroundings'

  'Develop rapport'

- Acceptance

  'Once the individual accepts they are an addict'

- Meeting the requirements of the service

  Two participants felt that previously their sense of stigma within a service had been reduced when they had engaged in the service - 'be a good person' and 'tick their boxes'' and 'when they approve of you and you feel worthy of their treatment'.

3.2.6   Interventions/themes that support the engagement process

Participants were asked what interventions / themes supported engagement and strengthened a sense that stigma was playing a lesser part. This task was undertaken in small group work and then shared and discussed within the group. Responses have been grouped together thematically:

- Once a routine was established

- When the individual is being open

  'Shared vulnerability – they are vulnerable back'

- Following progress being made

  'Seeing results – sober/clean time'

  'See the process working for you'

- When developing a sense of 'fellowship'

  'Seeing it work for others'

  'Seeing the same people and becoming a unit'

- When becoming motivated

- When there is an increase in self esteem

- When engaged with peer support/mentoring

- When regarded as an individual

  'When you are treated as an individual and the recovery package is tailored to your needs'

3.2.7   Stigma and the impact on the relationship between the individual and the addiction/recovery service they are accessing

Participants were asked to discuss and identify the ways in which stigma plays a part in the relationship between the individual and the addiction/recovery service they are accessing. This task was undertaken in small group work and then shared and discussed within the group:

- Power

  There was a sense that it was important for the person in recovery / experiencing addiction to hold the power and to lead on their own recovery and make plans for their own recovery. This was also linked to the need for a service to adopt a person-centred approach:

  'The service holds the power/control – don't feel like we have any input in our own recovery'

  'Putting pressure on individuals'

  'Even if the person is in 'recovery' engaging the services they (the service) can impose their own view/way'

  'Stereotypical expectations'

  'Not person centric'

  Some participants felt that there needed to be increased education within services in relation to recovery.

- Fear and vulnerability

  Fear was regarded as a barrier when building some relationships. Fear of being pre-judged was discussed. Where there was little or no trust it was stated that 'barriers' and 'defences' would be 'up'

  .

A sense of vulnerability was also discussed:

> *'Years of self-defence'*

> *'Used to hiding and lying'*

- Lack of a peer approach

It was stated that there was a lack of identification and relatability with a worker who had no personal experience of addiction.

> *'Lack of identification of someone who has learnt from a textbook'*

3.2.8   Challenging, addressing, and eliminating stigma

Individuals

Participants were asked to discuss and explore the ways in which individuals can eliminate and challenge stigma. This task was undertaken using small group work and was then discussed as a group. Responses fell into two categories:

An approach that all **individuals** can adopt to challenge stigma in general:

- Empower

- Empathise

- Be tolerant

The group also focussed on the approach that could be taken by **individuals within the recovery community** to challenge stigma (these also include the three bullet points discussed above):

- Telling our truth

- Not being ashamed

- Being an example in society

- Be aware of the language we use when speaking and referring to each other

- Create positive connections

- Carry a positive message and remain positive

- Be brave and speak up

- Waive anonymity in order to challenge and educate

- Challenge the beliefs of others

- Be aware of the language/terminology that we use

- Hold others accountable

- Report incidents at work

- Stop judging

Within communities

Participants were asked to discuss and explore the ways in which communities can eliminate and challenge stigma. This task was undertaken using small group work and was then discussed as a group. Responses are grouped together thematically:

- Raise awareness and educate

  'Educate in school/ social workers'

  'Go into schools/businesses'

  'Educate, educate, educate – building momentum – podcast/news reports in local and national papers / leaflets / fact sheet'

  'Media coverage – change to be positive not as negative'

  'Raising awareness i.e. Recovery Walk'

- Telling Stories

  'Fact not fiction'

  'Myth busting'

- Challenge

  'Challenge behaviours – not individuals'

- Inclusive communities

  'Create compassionate, inclusive communities'

- Recognise difference

  'Recognise we all have equal right to be uniquely different'

- Visible Recovery

  'Bring recovery into public domain'

  'Having a presence – therefore carrying knowledge into schools/doctors'

  'Make community aware people can recover'

The role of organisations

We asked participants to discuss and explore the role that organisations working within the addiction/recovery sector can play to challenge and eliminate stigma. This task was undertaken in small groups and was then discussed in the larger group. Responses are grouped together thematically:

- Raise awareness and educate

  'Teach kids – nip it in the bud'

  'Ted Talks'

  'Seminars'

  'Educating law enforcement including police and judges'

  'Collaboration on organisation and individual level to teach from both sides; for example, Job Centre staff and people in recovery to allow understanding on both sides without fear of reprisal'

- A Peer Approach

  'Service user involvement to share, develop and change service delivery'

  'Employ recovering addicts – recruit from the community'

- Challenge

  '*Challenge institutional stigmatisation'*

- Visible recovery

  'Need to be high profile and get the message out'

  'Be more open and in the public eye – where the offices are – not hidden away'

- Legal Protection

  One participant suggested one key structural and policy change which, they suggested, would help to alleviate stigma would be to create a sense of legal protection and ensure that addiction is regarded as a protected characteristic in the Disability Discrimination Act.

Designing a service that challenges and eliminates stigma

Participants were asked to discuss and explore the ways in which organisations can eliminate and challenge stigma. This task was undertaken in small groups and then discussed in the larger group. Responses have been grouped together thematically:

There were several key themes discussed by participants:

Education, aware raising, and promotion

'Mirror / break down stigma on both sides'

'Educate change from the bottom up'

Promote visible recovery and a peer approach

'Addicts working for addicts'

Holistic and flexible

'Deal with underlying issues as well as addiction'

'Flexible recovery package to suit all an individual's needs'

'No time limits on using the service as individuals may need longer'

Supportive, inclusive, and strength-based

'Find a person's positives assets and help them to find a direction for their lives'

'All inclusive'

'Promote empathy, compassion and trust'

Non-labelling

'Have a place where people from different places could meet with just names rather than they play in society'

Structure

One participant suggested that the structure of any service could be similar to that of a Mutual Aid organisation; one in which 'Our leaders are but trusted servants - they do not govern' and 'service users are members and are the 'conscience of the service'.

4   Summary and Conclusions

Introduction

The consultation sessions were designed to support participants to travel on a journey together when exploring stigma. We constructed the workshops to have three key stages :

1. Define stigma, discuss the impact of stigma and explore the roots of stigma.

2. Explore issues in relation to access and engagment with addiction and treatment services.

3. Explore ways in which individuals, communities and services can challenge, address, and eliminate stigma.

In this way, we hoped to build a shared understanding thoughout the course of the session and, by the end of the session, move towards solutions.

The roots and impact of stigma

Stigma was defined as being negative, unfair, prejudicial, judgemental and linked to labelling and stereotyping. Stigma was discussed within a wider societal context, including race, addiction, criminal background, sexuality, age, social class and gender. The impact of stigma was profound and often long-lasting. Stigma was regarded as cruel and hateful and those subject to stigma felt ashamed, embarrassed, guilty and fearful. Stigma had the potential to impact individuals in terms of their mental health and could lead to situations in which they became the victims of abuse and crime. The debiltating impact of stigma could lead to islation, further impacting on mental health. There was also a sense that stigma could be internalised and absorbed, with further repercussions on a sense of self, self worth and self esteem, wellbeing and mental health. In a very real and practical sense, stigma had impacted on access to key services, housing, employment and educational opportunities. It had affected relationships with family and friends; as discussed by one participant : 'people avoided me'. Another stated that they had been 'written off' - further reinforcing a sense of isolation and hopelessness. Stigma therfore has the potentia to further marginalise and disenfranchise.

There was a recognition that the roots of stigma were varied. Issues such as the media, social norms and beliefs were discussed and there was a shared sense that stigma was often deep rooted and was embedded culturally, historically and societally. Stigmatisation was also linked to misconceptions, a lack of awareness and misunderstanding. In many respects, in terms of addiction, this provides an opportunity for the recovery community - and people with experience of addiction - to educate and to inform and to address myths and to tell their own story in order to challenge these misconcpetions.

Stigma and access and engagment with addiction / recovery services

Three broad themes were discussed in relation to the way in which stigma impacted on access and engagement with addiction/recovery services:

Individual: Shame, fear and pride were identified as a key barrier at an individual level, that impeded access/ engagement with a service.

Perceptions and previous experience of services: An individual's previous experience of addiction services may impede access with services. Similarly, an individual's understanding of the way in which services 'work' or their understanding of key principles of a service (such as 12 Step philosophy) may also act as deterrent to engagement.

Anonymity /Labelling: A sense that accessing an addiction service may then lead to an individual being labelled or stigmatised may also be a barrier to engagement.

Engagement with addiction /recovery services and impact on stigma

Recovery Connections and The Road to Recovery Trust were keen to gain an understanding of the time, during engagement, when an individual felt that the role and impact of stigma diminished. Both

groups interpreted this question in relation to the key themes that impacted on a sense of stigma – as opposed to a specific timeline. There were four key elements :

- Trust and relationship - both of which were regarded as promoting honesty
- Progress, growth, and the building of confidence
- Peer support available within the service
- A sense of acceptance

Interventions/themes that support the engagement process

A number of interventions and themes were identified that supported the engagement process. A number of responses reflected the themes identified above and, in many respects, focused on the approach adopted by the service, the relationship between the individual and the service and the impact of that relationship and the progress made by the individual:

- Opportunity to contribute and 'give back'

- Personal growth, increased self-worth motivation and 'progress'

- Feeling gratitude

- Being with others in recovery

- A sense of trust and acceptance

- A culture of visible recovery, valuing lived experience and a sense of 'fellowship' and an opportunity to give back

- A service understands stigma and how that applies in practice and the real world

- Establishing a routine

- When the individual is being open, honest and is regarded as an individual

Stigma and the impact on the relationship between the individual and the addiction/recovery service they are accessing

Participants were asked to discuss and identify the ways in which stigma plays a part in the relationship between the individual and the addiction/recovery service they are accessing. Many of the issues identified as barriers were linked to fears and concerns - of being rejected, being judged, concerns over confidentiality, fears that the individual won't be listened to, a fear over a lack of empathy and concerns that promises will not fulfilled by the service. Factors that would positively impact was a sense that the service 'believed' in recovery. Similarly, presence of workers with experience of addiction was also regarded as positive. A service that adopted a person-centred approach was important and this was linked to the person in recovery / experiencing addiction holding the power and leading on their own recovery and making plans for their own recovery.

Challenging, addressing, and eliminating stigma

Individuals

The role of individuals when challenging, addressing, and eliminating stigma fell into two categories. The first category was the approach that can be taken by all individuals to address stigma. This included the need for individuals to have a worldview that empowers and empathises with others – and is tolerant of others. The power of individuals offering practical support to marginalised and stigmatised groups was also highlighted. Fundamentally, the importance of the individual 'not judging others' was regarded as important.

There was also a focus on the role of individuals from within the recovery community when addressing and challenging stigma. Individuals, it was suggested, can raise awareness and challenge assumptions/assertions regarding addiction. In many respects visible recovery is also linked to this suggestion, through an approach that was discussed as 'open and honest', 'proud' and ensured that individuals were able to tell their truth and share 'stories'. In many respects, this was also linked to individuals 'not being ashamed', 'being brave and speaking up' and 'carrying a positive message'. An important part of this 'role' was also making 'positive connections'. Challenging discrimination and prejudice and holding others to account was also regarded as important, as was the importance of individuals being 'mindful of their language and terminology'.

Within communities

The role of the recovery community when challenging, addressing, and eliminating stigma was identified as important when working together to raise awareness, educate, and challenge perceived assumptions/assertions. Institutions discussed as being the focus for engagement included educational establishments – schools, colleges, universities, social services, businesses, and within the criminal justice arena – prisons and probation. Activities such as the Recovery Walk were discussed as positive and it was recognised that positive recovery stories within and across the media were valuable. Underpinning all these activities was an understanding that visible recovery was vital in terms of challenging stigma.

It was also felt that communities, in general, needed to be more 'accepting', 'honest' and inclusive, whilst recognising 'difference', to create a culture and a society that challenges and eliminates stigma.

The role of organisations

There was agreement that organisations have a key role to play when challenging, addressing, and eliminating stigma. Raising awareness and adopting an educational role was regarded as particularly important for organisations within the recovery/addiction field. There is a need for these organisations to reach out to a breadth of other institutions to undertake this work on behalf of, and with, the community that it serves. Central to this role should be challenging 'historical, deep seated views' and increasing the profile of addiction as a public health priority and challenging institutional stigmatisation. The adoption of a 'peer approach' and embedding peers within the organisation was regarded as vital, as this was also a route through which visible recovery could be further promoted, developed, and embedded – and would further challenge misconceptions.

Designing a service that challenges and eliminates stigma

A central role of any service that was designed to challenge, address and eliminate stigma was that of having an educational, aware raising, and promotional role. A range of ideas were shared on this aspect of the service and it included suggestions regarding advertising and promotion; key organisations that should be targeted; a focus on children and young people; ensuring that there was a broad understanding of addiction; and an educational process that broke down stigma and that worked from the 'bottom up'. The service should embed and promote visible recovery and use the experiences of people in recovery - including those in long term recovery. The values and the approach would be holistic, non-labelling, flexible in order to meet the needs of individuals and with no time limits on engagement. The service should be supportive, inclusive, strengths-based and would promote 'empathy, compassion and trust'. Consultation with people using the service, and with those for whom the service is aimed, is vital when designing any service.