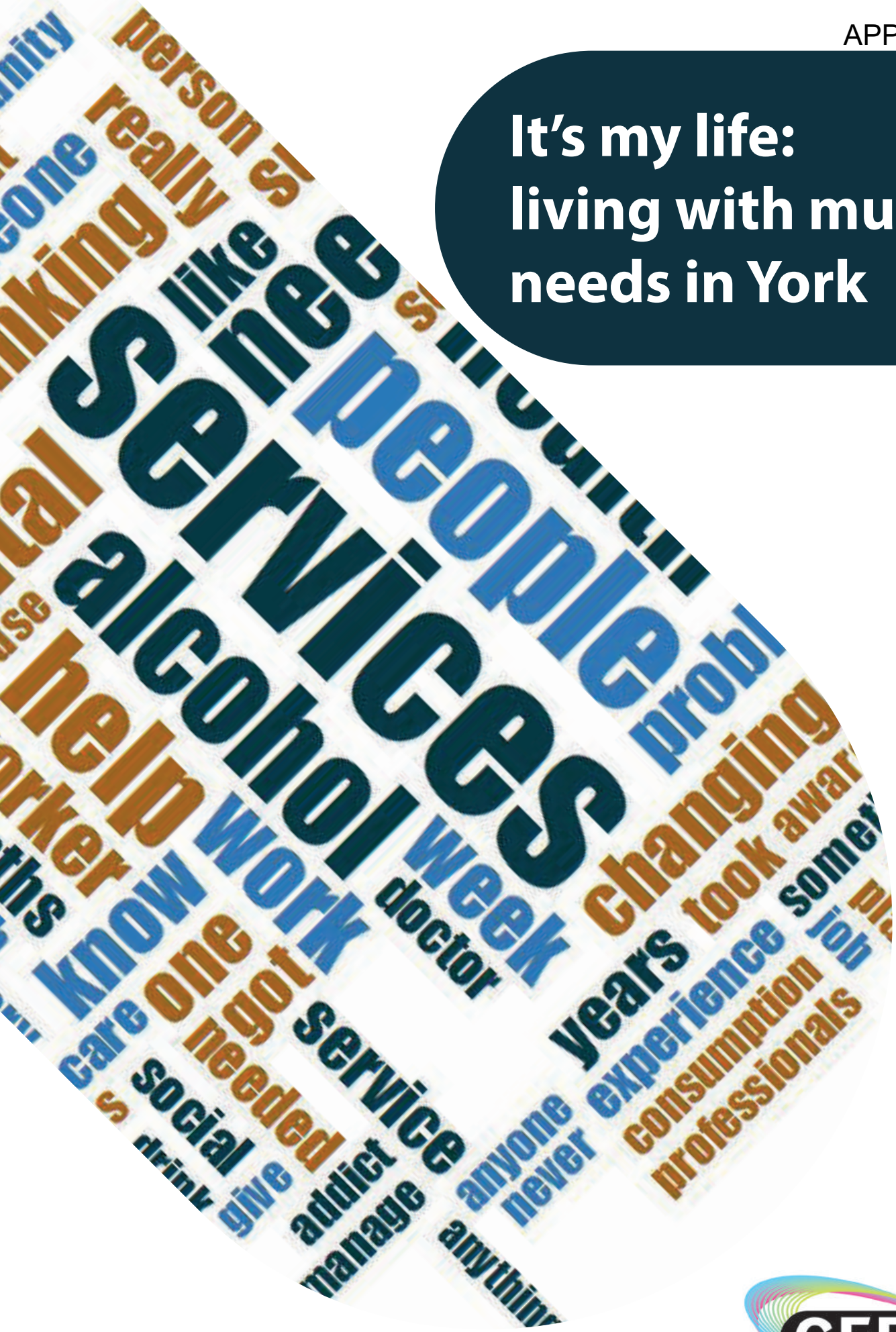
It's my life: living with multiple needs in York



CERT

Converge Evaluation and Research Team

insight through experience

York's Underbelly

APPENDIX 2

Executive Summary

In 2017, work began to create a **Multiple and Complex Needs Network** in **York**. In this report, ***'people with lived experience of multiple needs'*** refers to people who experience a combination of problems such as homelessness, substance misuse, mental health difficulties and contact with the criminal justice system. These are people who may fall through gaps in services and systems and may be offered services which do not address their needs, ultimately preventing them from leading fulfilling lives.

The **Converge Evaluation and Research Team** (**CERT**) was commissioned by the **York Multiple and Complex Needs Network** to conduct a peer research project – to go out and speak to people with lived experience of multiple needs in **York**. This was to facilitate hearing the voices and stories of people who face multiple disadvantage, and ultimately to use this data to influence how services in **York** work with people who have multiple needs.

This research has been used to create both this report, and a piece of theatre entitled, ***It's My Life!***

Methods

Our first action was to create a reference group consisting of people with lived experience of multiple needs, **CERT** members, and professionals. In our first meeting we discussed potential areas of enquiry, and possible research methods. **CERT** was particularly concerned about the language we use – we wanted to ensure it was respectful and non-stigmatising. People with lived experience of multiple needs (the term they chose) voted on alternative descriptions (see page 14). After extensive discussion, the people with lived experience selected 13 areas of importance to share with our interviewees (page 13).

After obtaining permission from **York St John University** ethics committee, we conducted six in-depth interviews, short interviews 'on the street', and interviews with two professionals. We had a very loose criteria for inviting people to interview –we contacted them through agencies which support people with lived experience of multiple needs. We did not ask people which 'needs' they have.

Analysis

Our in-depth interviews were discussed collectively by a group of people with lived experience of multiple needs and **CERT** researchers in an 'analysis group'. By involving people with lived experience at this analysis stage we can ensure the conclusions we come to about the data are valid and reflect real peoples' experiences. The discussions which occurred in these meetings are included here as data.

Findings

We asked the people with lived experience of multiple needs during their interview to choose the three areas which they think are most important from the list on page 13. Their choices are shown on page 18. The findings of this study are organised by the top 6 of 13 areas. In addition, *'knowing where to get services'* has also been included because in our initial work it came out as the most important problem.

APPENDIX 2

Access to good and timely mental health support

Many individuals we interviewed in-depth indicated that they struggled with their mental health or that they had a mental health diagnosis and discussed their experience of accessing (or wishing to access) mental health services. There was a consensus that the mental health support for people with lived experience of multiple needs are lacking, especially for those abusing substances. One interviewee expressed that:

> *Mental health services need to be more understanding [about addiction]* (participant (p) 3).

The analysis group observed that in their experience people struggling with addictions are often refused help for their mental health while they continue using substances. This puts them in an impossible position where they are required to stop their main coping strategy before they can access any support. The analysis group reflected that mental health professionals are often lacking in their knowledge and skills about working with people who abuse substances, and that there is poor communication between different agencies. There was a consensus that professionals in contact with people with multiple needs should be trained in working with people with mental health needs.

A good long-term relationship with one worker

A common feature emerging from our research was the importance of developing a good, strong, consistent and long-term relationship with one profession (e.g. support worker, mental health nurse, GP):

> *[You need] a helping hand who will do the journey with you until you get to the point where you can do it yourself… If you have a wobble you can talk to them* (p3)

The discussion group felt the long-term relationship was crucial for creating a truly personalised support programme which asks which services a person wants to receive and offers them in a flexible way. As such, developing trust in this relationship seems to be felt to be necessary for facilitating recovery:

> *If you're doing one-to-one work, trust is vital, and that [comes] from continuity…too much having to see different people makes [building] trust very difficult* (p2)

Analysis group members explained that one of the reasons seeing the same professional is that they don't need to constantly be re-telling their story each time they see someone new – this is particularly important if they find re-telling their story traumatic and distressing, or feel shame and stigmatised about it.

A safe place to recover

For those experiencing substance abuse, the importance of finding somewhere safe to recover, either as a day offering or residential service, was a strong theme. There are both day services and residential services offered in **York** by **Changing Lives**, **The Salvation Army** and **Sunshine Changing Lanes** (see appendix 1 for details about services mentioned in this report).

Experience of services

Several interviewees and members of the analysis group expressed satisfaction with services in **York**. One interviewee was grateful for the safety and sanctuary they experienced at the residential service at **Union Terrace**, and felt this was vital to his recovery:

> *I was in the fortunate position that I was taken in by the service at Union Terrace and able to live there while I worked on my addiction and mental health. I was fortunate that I had a base that gave me an element of safety. If I wasn't in Union Terrace, I would be rough sleeping* (p4)

APPENDIX 2

Social networks

The social network of the individual in recovery is important – sometimes, in order to come off drugs and/or alcohol, the person often has to lose their circle of friends (as they are still using). Therefore creating new circles of friends who support their recovery is crucial. Services such as **Oak Trees** require their service users to attend three fellowship (peer support) groups, which promote abstinence to develop a peer support network for people all in recovery.

Good quality aftercare

Aftercare means on-going support for service users after they have completed an intervention. Several interviewees and members of the analysis group had completed the 12-week **Oak Trees** programme (see appendix 1): after graduating, participants get just two hours per week of support and are expected to find their own way to fill their time. Some of our interviewees found this switch extremely challenging, and felt it left people unnecessarily vulnerable to relapse:

> *Oak Trees helped me a lot but at the end of the 12-week programme it was like being thrown to the wolves… I know several people who have relapsed… more safe places are needed, services to help people to maintain [their recovery]* (p1)

There was a consensus in the analysis group that a more gradual withdrawal of support would be more effective in helping people maintain their abstinence in the long-term:

> *I'd like a gradual come down with more effective support… it's very easy to drop back into the old behaviour… services should be more open ended and a bit more supportive* (p4)

What will get dealt with first?

APPENDIX 2

Stigma and respect

Many people we spoke to shared having experienced stigma from professionals working with them:

> *More education would stop people being so judgemental. Unless you seem like a decent member of society, they're [professionals] not willing to help* (p3)

Members of the analysis group shared how they had felt stigmatised by professionals They reported feeling that professionals don't always respect them, that they have been given unwelcome labels, and that they have been written them off as a lost cause or not worth helping. Sometimes they have sensed that professionals are blaming them for their difficulties.

A particularly concerning issue of respect was raised by our interviewees at both **Carecent** and **Food not Bombs** – there is nowhere safe for rough sleepers to leave their possessions during the day. It is current practice for **City of York Council** employees to remove and dispose of any unattended possessions. This seems to be especially disrespectful and undignifying.

A quicker response and shorter waiting times

A common theme throughout our interviews and analysis group was that to end their substance abuse, the person has to be 'ready', otherwise the intervention will be pointless:

> *Addiction took my life… [in this state of mind] I wouldn't have wanted to know if anything was available… I had to get to a very low point to be ready to address the problems I had with alcohol abuse* (p4)

The problem identified here is the speed of access to services which can support people when *"it comes crashing down"* (p3). The challenge of having to wait days or weeks for support when in crisis or at *'rock bottom'* was discussed at length by people in the analysis group. There was a feeling that it is crucial that when a person realises, they want support, services should respond by offering support immediately, in hours or days, not weeks or months.

Knowing where to get services

A major barrier to recovery is the lack of awareness by professionals working with people with multiple needs of services which could help them:

> *I went through my GP for referrals but now know that they don't really know what is available. Once, the doctor gave me three numbers to phone for services. None of them were relevant. There are places to go but they aren't signposted* (p4)

> *My social worker hadn't heard of Lifeline, Oak Trees or Changing Lives. If I'd got the help then, things probably wouldn't have gone any further* (p3)

The case for a one-stop hub?

Almost universally, the people we interviewed expressed the belief that there is a need for a one-stop hub for people with multiple needs. They feel that at present, services in **York** are disjointed, fail to communicate, have blurred and duplicated pathways, and in some cases are even in competition with each other for funding:

> *A safe place or hub – people just have to go to one place… it would save having to go to several different services before finding the right thing* (p7)

At a multiple needs hub, a visitor could get help to address all of their needs, beginning with the most basic ones – food, warmth, safety, hygiene, and appropriate healthcare –through to more complicated things such as help with claiming benefits, searching for work, and to getting permanent accommodation themselves. Families and friends of the people using the service could also get support there.

APPENDIX 2

Additional improvements suggested by those with lived experience

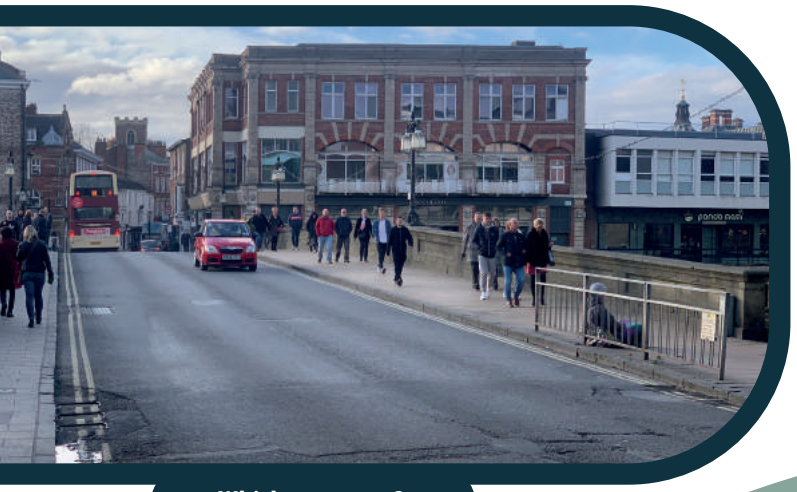
Suggestions from our in-depth interviewees:

- A welcoming, respectful service
- Somewhere to go which feels safe
- Different options for people choosing services for themselves
- Quicker responses and shorter waiting times
- Support for friends and family
- Continuity of care
- Professionals being aware of other available services
- Reduction in stigma and promotion of acceptance
- Support from people with lived experience
- Access to appropriate help and/or diagnosis for people with mental health difficulties

Suggestions from Carecent and Food not Bombs:

- Asking the person what they want help with, rather than assuming you know what they need most
- More and better accommodation
- Good quality, timely healthcare: access to GP services, vaccinations, dental services, and to specialist hospital services
- Access to day-time activities: clubs which provide for their leisure and social needs
- Financial help for travelling around the city (e.g. bus passes)
- Support claiming benefits, especially where they have to do it online and don't have an address
- Access to suitable clothing for the season, sleeping bags and tents where the person chooses to sleep rough, and replacements if they get wet or are taken away
- Better communication between agencies, raising awareness of services available
- Specialist outreach to find vulnerable people who cannot communicate their needs, especially when they have mental health difficulties
- Council workers not removing possessions from the street
- Dedicated homelessness workers who get to know people really well and help them to navigate the system

APPENDIX 2



Which way to go?

CERT recommendations:

- Improved support for those with mental health needs:
  - Specialist mental health workers for people with multiple needs.
    - Training in how to work with people with multiple needs for all mental health professionals.
      - Training in mental health for all professionals who come into contact with people with multiple needs.

- Designing a system which can allow individuals to build a long-term relationship with a consistent professional who has the skills and knowledge to help them access the services they need in a timely fashion. This includes access to services offered by different agencies, and will be bespoke and personalised for each individual, and flexible to change as time goes on.

- The length of aftercare for people who have graduated from recovery programmes should be individualised and based on their needs.

- Professionals working with people with multiple needs should be offered supervision to support them to work in a way which is non-stigmatising and is hopeful for the futures of their service users. No-one should be given up on.

- The issue of rough sleepers having their possessions removed should be addressed urgently, especially with respect to York becoming the UK's first Human Rights City in April 2017. We see the disposal of possessions as denying rough sleepers' right to dignity and respect. Alternatives such as lockers or other self-storage options should be considered.

- Efforts should be made to clarify what agencies do so that referral pathways are clear, in particular, working to avoid duplication of services, and avoiding situations where different agencies are in competition for service users or for funding. This would make joined-up working more straightforward and effective.

- We concur with our interviewees that the possibility of developing a central hub should be seriously explored.

APPENDIX 2

Limitations of this report:

- We are aware that the people we spoke to in researching this report are not a comprehensive representation of people with lived experience multiple needs in **York**. In particular, we did not conduct any in-depth interviews with any rough sleepers, and only interviewed in-depth one person who described contact with the criminal justice system.

- We quickly became aware in our 'on the street' interviews, that some people were suspicious of our motivations, and were extremely reluctant to sign a consent form In future work, we need to find a way of working with people in this situation which makes them feel safe.

- Almost all of the people we interviewed in-depth struggled with substance abuse, but not all people with multiple needs are substance abusers. The perspectives of those who don't abuse substances in this system should be sought in future work.

Conclusions

CERT was commissioned by **The Multiple and Complex Needs Network** in **York** to conduct a peer research project, to seek the voices and stories of people who face multiple disadvantage in **York**. Using in-depth and short 'on the street' interviews, we identified that the priorities of people with lived experience of multiple needs are access to good and timely mental health support; a good, long term relationship with one worker; a safe place to recover; a good quality aftercare; stigma and respect; and a quicker response and shorter waiting times. Knowing where to get help also emerged as important. Various improvements were suggested by the people with lived experience of multiple needs that we interviewed, including the creation of a one-stop hub. **CERT** also made recommendations, including suggesting mental health training, facilitating long-term relationships, human rights issues, and conducting further research to hear the voices of people with lived experience of multiple needs which we did not reach in this project.

Table of Contents

APPENDIX 2

Introduction

In 2017, work began to create a **Multiple and Complex Needs Network in York**. In this report, ***'people with lived experience of multiple needs'*** (the term which they chose to use, see page 11) refers to people who experience a combination of problems such as homelessness, substance misuse, mental health difficulties and contact with the criminal justice system. These are people who may fall through gaps in services and systems, and may be offered services which do not address their needs, ultimately preventing them from leading fulfilling lives. There is on-going work within the network to bring all of the different strands of work which goes on in the city together to create a coordinated approach. This includes efforts to bring the voices of people with lived experience of multiple needs into the work which is being done in the city.

The **Converge Evaluation and Research Team** is a group of people with lived experience of mental health difficulties who have received training in research methods at **York St John University**. Supported by University academics, **CERT** offers bespoke evaluation of mental health services and community projects. Using inventive approaches, the team specialise in finding ways to support people who find it hard to express themselves. **CERT** is part of **Converge**, a partnership between **York St John University** and **Tees, Esk and Wear Valleys NHS Trust**. **Converge** delivers educational opportunities to adults who use mental health services in **York** and the surrounding area.

CERT can be contacted at **cert@yorksj.ac.uk**

More details can be found here: **www.yorksj.ac.uk/Converge**

CERT was commissioned by the **York Multiple and Complex Needs Network** to conduct a peer research project – to go out and speak to people with lived experience of multiple needs in **York**. This was to facilitate hearing the voices and stories of people who face multiple disadvantage, and ultimately to use this data to influence how services in **York** work with people who have multiple needs. In particular, to facilitate moving towards flexible, person-centred support.

This research has been used to create both this report, and a piece of theatre called ***"It's my life!"***

APPENDIX 2

Methods

Our first action was to create a reference group consisting of people with lived experience of multiple needs, **CERT** members, and professionals who work with people with multiple needs invited by the **Complex and Multiple Needs Network**. In our first meeting we discussed the direction of the project, considering different potential areas of enquiry, and possible research methods we could use. We narrowed down 10 areas which people present thought were important.

Members of **CERT** were particularly concerned about the language we would use in the process of the evaluation and in our report. We wanted to ensure it was respectful and non-stigmatising. To address this, in our second meeting we invited suggestions from those present for different terms which are used in the field. We then invited people with lived experience of multiple needs to vote on which term they would like us to use in our report to describe them (excluding from voting **CERT** members and professionals without any lived experience). It was clearly decided that they wished to be known as ***'people with lived experience of multiple needs'*** (see ***figure 1*** overleaf).

To help us focus our research plan on what is important to people, the next step was to invite those in the room with lived experience of multiple needs to rank the ten areas of enquiry suggested in the first meeting by their **importance** (***figure 2***). Collectively, the list was refined and expanded to 13 areas which were shown to our interviewees:

- A quicker response and shorter waiting times
- A good long-term relationship with one worker
- Good quality aftercare
- Support for family and friends
- Personal knowledge of available services
- Professionals' knowledge about available services
- Reduction in stigma – acceptance and respect
- People with lived experience in support roles
- A safe place to recover
- Help to understand what has happened
- A central hub for support
- Relationship with Department for Work and Pensions (accessing benefits)
- Access to good and timely mental health support

APPENDIX 2

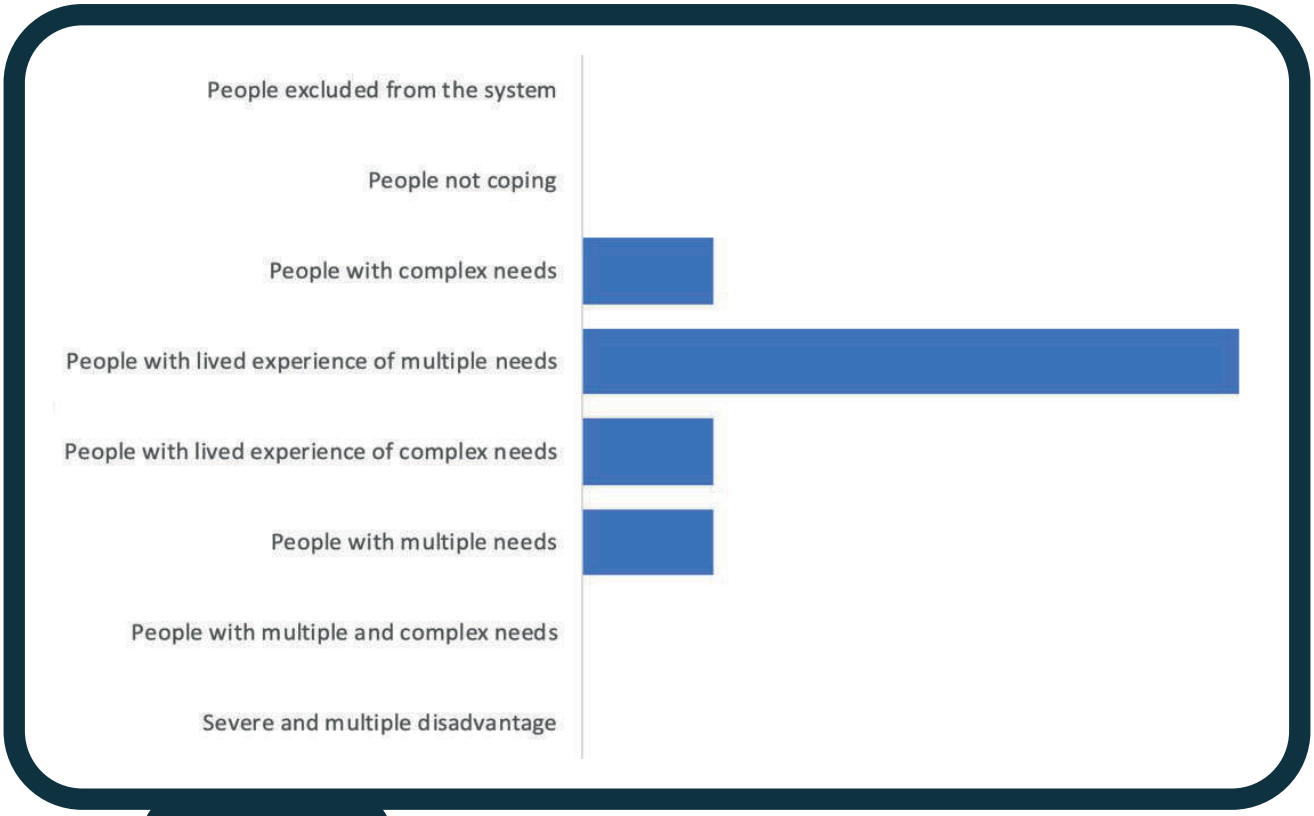


Figure 1

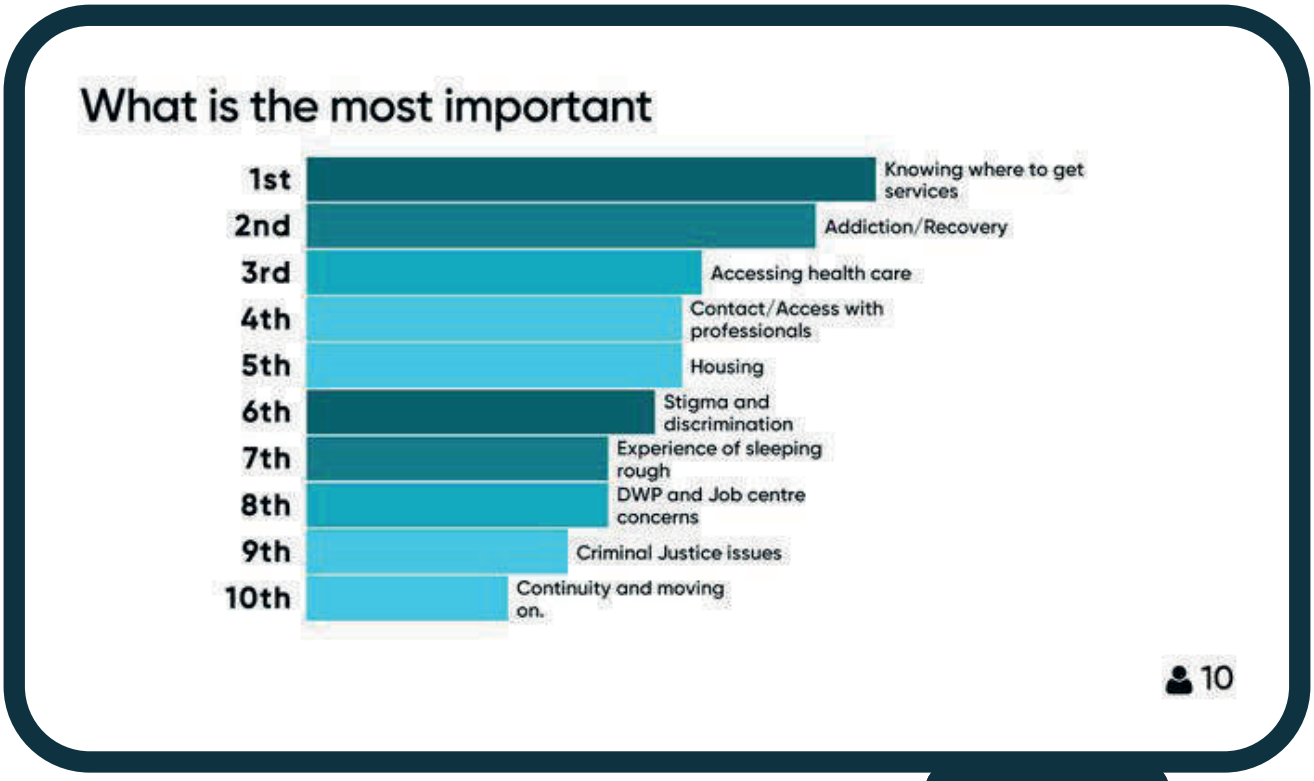


Figure 2

APPENDIX 2A

We got permission from the **York St John University Ethics Committee** to conduct interviews with people with lived experience of multiple needs and professionals who work with them. We decided to:

- Conduct in-depth interviews at the University with people with lived experience of multiple needs, with a focus on their experience of services provided to them – what was helpful, what could have made things easier or better for them, and about any issues they faced when seeking support.
- Conduct very short interviews 'on the street' at sites in the city with people with lived experience of multiple needs, asking about their experiences of services as above.
- Conduct interviews with professionals who work with people with lived experience of multiple needs about their experience of providing services.

We had a very loose selection criteria for selecting the people approached for permission to interview. We contacted people using services which would be accessed by people with multiple needs. However, we did not ask our interviewees which 'needs' they experienced, for example, whether they were homeless, struggle with addiction, struggle with their mental health, or have contact with the criminal justice system. We asked interviewees to choose what they think are the three most important areas from the list of 13 shown on page 12.

Food or Spirit?

In-depth interviews

Successful recruitment for the in-depth interviews was via word-of-mouth from members of the reference group. Posters and flyers were not successful. In total, we completed 6 in-depth interviews at the University (one of which was two people at once as they asked to be interviewed together), four female and three males. Due to the time pressure for completing this evaluation, we did not think we had enough time to address the ethical and safety concerns around approaching people on the streets, for example, people begging or sleeping rough. Therefore, none of the people we completed in-depth interviews with were in that situation. Almost all of our in-depth interviewees indicated they had experience of substance abuse. We are aware this means they are not necessarily a reflective sample of people with lived experience of multiple needs in **York**.

Interviewees were provided with an information sheet explaining our aims, and full written consent was gained. Interviewees were assured of their confidentiality and anonymity and reminded that they could withdraw at any point or take a break if they wished. With the permission of the interviewee, the in-depth interviews were audio recorded and transcribed.

APPENDIX 2

'On the street' interviews

To try and access a broader range of people with lived experience of multiple needs, we attended **Carecent** on 7th October, and **Food not Bombs** on 28th October (see ***Appendix 1*** for details of the service). A **CERT** researcher also attended an addiction fellowship group. To recruit interviewees, **CERT** researchers approached people using the service, introduced themselves and the project, and asked if they were willing to speak with them. A simpler consent form was used, and written notes only were taken.

Interviews with professionals

We interviewed the manager of **Carecent** to get her perspective on the needs of people using their service and ideas she might have for improving things. We also interviewed a **Local Area Coordinator** who works for **City of York Council**. Local Area Coordinators work with individuals and families of all ages, in a flexible person-centred way, to help them access resources within the community to help them get to where they want in life. The professionals were provided with an information sheet explaining our aims, and full written consent was gained. Written notes only were taken.

What we didn't do

We would have liked to conduct in-depth interviews with a broader range of people, in particular rough sleepers, and with people in contact with the criminal justice system. However, given the time constraints of this project, we were not confident that we had time to negotiate the ethical and safety considerations of working with these groups of people. We hoped to get some access to this population through our interviews at **Carecent** and **Food not Bombs**.

Analysis

The in-depth interviews were discussed collectively with a group of people with lived experience of multiple needs and **CERT** members in an 'analysis group'. It was important to us that people with lived experience were involved in this process to help us ensure the conclusions we reach about our data are valid and reflect real peoples' experiences. The discussions about the in-depth interviews which occurred in these meetings are included here as data.

APPENDIX 2

Findings

We asked the people with lived experience of multiple needs during their interview to choose the three areas which they think are most important from the list on page 5. Their choices are shown below in figure 3. The findings of this study will be organised by the top 6 of 13 areas. In addition, 'knowing where to get services' has also been included because in our initial work it came out as the most important problem and it was felt to be an important point to include.

- Access to good and timely mental health support
- A good, long term relationship with one worker
- A safe place to recover
- Good quality aftercare
- Stigma and respect
- A quicker response and shorter waiting times

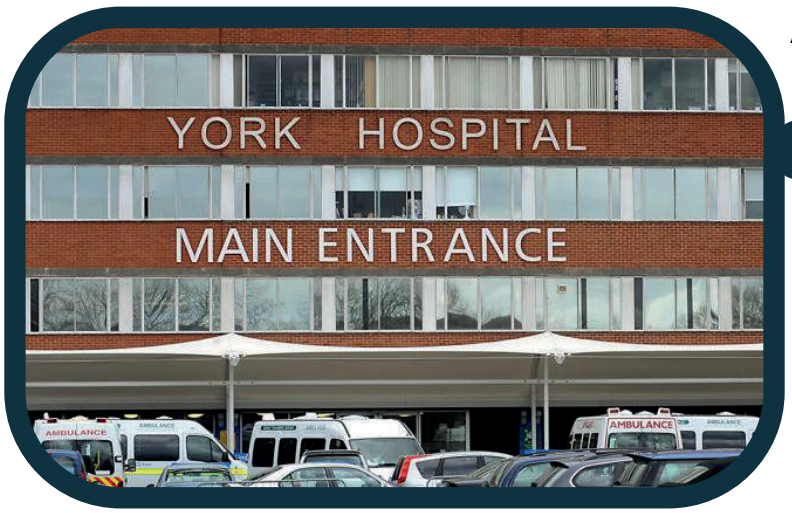
Access to good and timely mental health support

Many of the individuals we interviewed in-depth indicated that they struggled with their mental health or that they had a mental health diagnosis. They discussed their experience of accessing (or wishing to access) mental health services in **York**. Mental health also featured heavily in our 'on the street' interviews and interviews with professionals. It is worth being clear here that not all of the people we spoke to have mental health difficulties, with or without problems with substance abuse. However, for many people with lived experience of multiple needs we spoke to, poor mental health and substance abuse co-occur.

There seems to be a consensus that the mental health support for people with lived experience of multiple needs are lacking, especially for those who abuse substances. One interviewee expressed that *"mental health services need to be more understanding [about addiction]"* (p3). Others were frustrated that services often *"[need to go] through all of the service users's history yet again"* (p6&7) each time they are seen.

Mental health was discussed at length by the analysis group. Members felt that mental health services should be involved sooner where the individual has mental health difficulties in addition to substance misuse, as the mental health problem may be the cause of the substance misuse.

APPENDIX 2



First port of call?

The analysis group observed that in their experience people struggling with addictions are often refused help for their mental health while they continue using substances. This puts them in an impossible position where they are required to stop their main coping strategy before they can access any support. One member had personal experience of not being able to access support for their mental health while they continued to drink, despite believing their drinking to be a consequence of a mental health problem – meaning he needs mental health support in order to recover. Others described how getting a formal diagnosis for their difficulties facilitated them getting the support they needed.

The analysis group also reflected that in their experience, mental health professionals are often lacking in their knowledge and skills about working with people who abuse substances, and that there is poor communication between different agencies. There was a consensus that professionals in contact with people with multiple needs, for example, housing workers, should be trained in working with people with mental health needs.

One member of the analysis group described how he had needed to push very hard for mental health support, reflecting that many people in his situation may be too unwell or too intimidated to push for it. Another described being repeatedly rejected by mental health services because they were still using drugs and did not have stable housing. Members also experienced feeling stigmatised by mental health professionals because of their substance abuse. Other problems discussed by the analysis group were not getting appointment letters because they do not have an address, and then being discharged because of missed appointments – which they missed because they never received the appointment letter.

Another interviewee expressed the importance of counsellors who support them having lived experience of multiple needs:

> *Counsellors without lived experience don't know what it's about… I had help from those who had got to the other side, back from alcohol* (p3)

For people struggling with addiction, alongside mental health is the importance of understanding the cause of the addiction, and understanding this is the only way you will recover:

> *You can't deal with addiction if you don't know what caused it… It's like a wound, you've got to clean it out properly, not just cover it up* (p3)

Members of the analysis group also described the 'lottery' of which professional you get assigned (this extends beyond mental health support to all professionals who work with people with multiple needs). The variables in this lottery include the personality of the worker (whether they get on with you), the professional skills of the worker in both developing a therapeutic relationship and being able to offer appropriate interventions, the time they have to see you and understand your difficulties, the prejudices/assumptions the professional has, their power or willingness to act, and their knowledge of services which might be able to help.

APPENDIX 2

The start of a new journey?

A good long-term relationship with one worker

A common feature emerging from our research was the importance of developing a good, strong, consistent and long-term relationship with one worker (e.g. support worker or mental health nurse), and the same GP to people with multiple needs (aftercare from therapeutic services is covered separately later):

> *[You need] a helping hand who will do the journey with you until you get to the point where you can do it yourself… If you have a wobble you can talk to them* (p3)

> *Weekly meetings with someone to talk to… not always like a treatment, but it can lead to feeling better* (p6&7)

The discussion group felt the long-term relationship was crucial for creating a truly personalised support programme which asks which services a person wants to receive and offers them in a flexible way. As such, developing trust in this relationship seems to be felt to be necessary for facilitating recovery:

> *It's essential to build up trust… you need someone who knows. [Without this] I'd clam up and wouldn't talk* (p3)

> *If you're doing one-to-one work, trust is vital, and that [comes] from continuity…too much having to see different people makes [building] trust very difficult* (p2)

Longevity of support was discussed extensively in the analysis group. Members shared stories of whilst being desperate for help, struggling to get GP appointments in the first place, not being able to see a GP which knows them, and then feeling like they didn't have enough time with their GP to start to work on their problems and get adequate support. The members explained that one of the reasons seeing the same person (GP or other worker) is that they don't need to constantly be re-telling their story each time they see someone new – this is particularly important if they find re-telling their story traumatic and distressing, or feel shame and stigmatised when talking about it.

Hope for the forgotten few?

APPENDIX 2

Participant 5 describes frustration at never experiencing the consistency of having a single, long-term relationship with one person, focusing specifically on her needs: *"I feel like I'm being passed from pillar to post."* Members of the analysis group shared this feeling, for example, feeling like they are being bounced around the system between different services with no-one taking the lead in, or responsibility for supporting them.

Others discussed what happens when you struggle to build a relationship with their worker:

> *If you don't feel comfortable with your worker, you need to find out why, not just be written down [and dismissed] as 'not engaging'* (p6&7)

Your accommodation is ready!

A safe place to recover

For those experiencing substance abuse, the importance of finding somewhere safe to recover, either as a day offering or residential service, was a strong theme in the interviews, and also in the analysis group discussions. In **York**, Changing Lives offers both formal day (**Oak Trees** and **Blossom Street** – formerly **Lifeline**) and residential services (**Union Terrace** – men and **Robinson Court** – women and young people) and an outreach service for people who are multiply excluded and have complex needs. The **Salvation Army** has an **Early Intervention and Prevention Team** for homeless people (see appendix 1 for more details about services mentioned in this report). **Sunshine Changing Lanes** also offer support to people with multiple needs in **York**. These services all seek to offer their service users a safe place to recover.

APPENDIX 2

Experience of services

Several interviewees and members of the analysis group expressed high praise for the 12-week **Oak Trees** programme. They felt it was an opportunity to address their difficulties in a way they had never experienced before:

> *It wasn't until I got to Oak Trees that anyone asked me why [I had an addiction]. I'd ended up addicted to alcohol and no-one, not one of the doctors [I had seen], had asked that* (p1)

One interviewee was grateful for the safety and sanctuary they experienced at the residential service at **Union Terrace**, and felt this was vital to his recovery:

> *I was in the fortunate position that I was taken in by the service at Union Terrace and able to live there while I worked on my addiction and mental health. I was fortunate that I had a base that gave me an element of safety. If I wasn't in Union Terrace, I would be rough sleeping… I had security because Union Terrace has rather challenging residents. I had the sanctity of my own room…* (p4)

One member of the analysis group described a potentially serious problem which happens occasionally – housing people in recovery from addiction with people who are still actively abusing substances. This inappropriate housing obviously puts them at extremely high risk of relapse.

Social networks

The analysis group discussed another component of a safe place to recover – the social network of the individual in recovery. Sometimes, in order to come off drugs and/or alcohol, the person often has to lose their circle of friends (as they are still using), which leaves them vulnerable and isolated, which can impact on their mental health and put their recovery at risk. Therefore, creating new circles of friends who support their recovery is crucial.

Services such as **Oak Trees** require their service users to attend three fellowship (peer support) groups. Fellowship meetings such as **Alcoholics Anonymous** and **Narcotics Anonymous** follow the 12-Step programme, and involve a meeting format where people dealing with addiction meet and lend each other support. This helps to develop a fresh peer social network of people all in recovery who are abstaining.

Good quality aftercare

Aftercare means on-going support for service users after they have completed an intervention, such as a recovery programme. Several interviewees and members of the analysis group had completed the **Oak Trees** programme (see appendix 1). This programme comprises of 12-week full-time intensive therapy. After graduating from it, participants get just two hours per week of support from **Oak Trees** and are expected to find their own way to fill their time, including attending the fellowship groups they found. Some of our interviewees found this switch extremely challenging, and felt it left people unnecessarily vulnerable to relapse:

> *Oak Trees helped me a lot but at the end of the 12-week programme it was like being thrown to the wolves… I know several people who have relapsed… more safe places are needed, services to help people to maintain [their recovery]* (p1)

> *It's tricky… it can lead to relapse… you go from intense [support] to nothing… there needs to be more aftercare. Oak Trees only has two hours per week. You make friends with people on the programme, but then you're out on your own.* (p3)

APPENDIX 2

Aftercare is once a week. In my opinion it's not enough. You've had three months of intensive work, then there's a certificate and the door. One and a half hours per week is not enough… I knew a guy who came out after 12 weeks and went on a bender that night (p4).

There was a consensus in the analysis group that a more gradual withdrawal of support would be more effective in helping people maintain their abstinence in the long-term. Participant 4 described how they would prefer a more phased reduction in support:

I'd like a gradual come down with more effective support… there isn't anyone to check on me but I am in a position to be able to check on myself… it's very easy to drop back into the old behaviour… services should be more open ended and a bit more supportive (p4)

Stigma and respect

Many of the people we spoke to in both our in-depth interviews, street interviews and among the analysis group, shared having experienced stigma from professionals working with them:

More education would stop people being so judgemental. Unless you seem like a decent member of society, they're [professionals] not willing to help (p3)

If society keeps working to decrease stigma, it's all for the good… It's an illness. If services do more about that too, it would be a massive leap forwards (p2)

For some interviewees, this stigma was internalised:

I wasn't able to let it out… I couldn't even discuss it with my wife (p2)

I was just a pathetic person who couldn't cope (p1)

Another interviewee felt the **Police Service** discriminated against her:

People keep treating me like a criminal, but what has happened to me is criminal (p5)

My decision today pick up or leave behind?

Members of the analysis group shared how at times they had felt stigmatised by professionals and those around them, and experience 'feeling like everything is against them'. They reported feeling that professionals don't always respect them, that they have been given unwelcome labels, and that they have been written them off as a lost cause or not worth helping. Sometimes they have sensed that professionals are blaming them for their difficulties. Importantly, they observe that the first contact of a service with an individual is particularly crucial – if the person is unhappy with the contact they may withdraw and never ask for help again. Participant 2 suggested that professionals should keep an open mind and be welcoming and supportive in their first meeting:

If the first engagement with a service isn't welcoming, it will frighten people off. There's lots of fear already… I have always felt desperate, lonely and isolated (p2)

A particularly concerning issue of respect was raised by our interviewees at both **Carecent** and **Food not Bombs** – there is nowhere safe for rough sleepers to leave their possessions during the day. It is current practice for **City of York Council** employees to remove and dispose of any unattended possessions. This seems to be especially disrespectful and undignifying.

APPENDIX 2

A quicker response and shorter waiting times

A common theme throughout our interviews and analysis group was that to end their substance abuse, the person has to be 'ready', otherwise the intervention will be pointless:

> *My mind set was controlled by alcohol… I would do what I needed to get by, and what was needed to get alcohol… It didn't matter who I hurt; addiction took my life… [in this state of mind] I wouldn't have wanted to know if anything was available… I had to get to a very low point to be ready to address the problems I had with alcohol abuse* (p4)

> *I honestly think all along help was there if I had wanted it… I decided 'enough was enough', by then I had the gift of desperation… mentally and physically I had nothing left* (p2)

> *You can preach to someone, try and help them, but they need to want to do it themselves… if you're not ready, you're not ready – it doesn't matter what your friends and family think* (analysis group member)

The problem identified here is the speed of access to services which can support people when *"it comes crashing down… it's that or death"* (p3). Participant 2 described how he was referred to **Changing Lives** in crisis. He was trying to reduce alcohol consumption by himself while waiting for this appointment, but was struggling, and was telephoning them over and over again to find out when he would get to see someone and found the delay in support very distressing.

The challenge of having to wait days or weeks for support when in crisis or at 'rock bottom' was discussed at length by people in the analysis group. There was a feeling that it is crucial that when a person realises they want support to overcome their substance misuse, services should respond to this motivation quickly by offering support immediately, in hours or days, not weeks or months. If this does not happen, the person may fall back into their addictive behaviour, and even worse, perhaps internalising stigma that they are not worthy or help or that they are hopeless and will never recover.

I don't have anywhere to get to…

APPENDIX 2

Crossroads?

Knowing where to get services

A major barrier to recovery is the lack of awareness by professionals working with people with multiple needs of services which could help them:

> *I went through my GP for referrals but now know that they don't really know what is available. Once, the doctor gave me three numbers to phone for services. None of them were relevant. There are places to go but they aren't signposted. What is needed is some sort of list or place to find out about everything available in your area* (p4)

> *My social worker hadn't heard of Lifeline, Oak Trees or Changing Lives. If I'd got the help then, things probably wouldn't have gone any further. Social workers are blind and naïve about addiction… They don't know what direction to send people… once the kids are away there's no thought to helping the mother… they have ticked their boxes* (p3)

> *In my recovery, I realise there are lots of services out there, but they are not promoted, not known. I've found out recently about 'York in Recovery', a forum set up to help people in recovery. I found out about it eight months after I graduated from Oak Trees* (p4)

Participants 6&7 commented that a better awareness of services on offer could be used to create a detailed and person-centred multi-agency plan for each service user which would help facilitate individuals' recovery. In addition, participant 3 observed that:

> *Services can't help if they don't know what they are doing… Services should work together instead of being separate all the time…* (p3)

Additional improvements suggested by those with lived experience

Suggestions from our in-depth interviewees:

- A welcoming, respectful service
- Somewhere to go which feels safe
- Different options for people choosing services for themselves
- Quicker responses and shorter waiting times
- Support for friends and family
- Continuity of care
- Professionals being aware of other available services
- Reduction in stigma and promotion of acceptance
- Support from people with lived experience
- Access to appropriate help and/or diagnosis for people with mental health difficulties

Suggestions from Carecent and Food not Bombs:

- Asking the person what they want help with, rather than assuming you know what they need most
- More and better accommodation
- Good quality, timely healthcare: access to GP services, vaccinations, dental services, and to specialist hospital services
- Access to day-time activities: clubs which provide for their leisure and social needs
- Financial help for travelling around the city (e.g. bus passes)
- Support claiming benefits, especially where they have to do it online and don't have an address
- Access to suitable clothing for the season, sleeping bags and tents where the person chooses to sleep rough, and replacements if they get wet or are taken away
- Better communication between agencies, raising awareness of services available
- Specialist outreach to find vulnerable people who cannot communicate their needs, especially when they have mental health difficulties
- Council workers not removing possessions from the street
- Dedicated homelessness workers who get to know people really well and help them to navigate the system

APPENDIX 2

Switch your lights off on the way out!

The case for a one-stop hub?

Almost universally, the people we interviewed expressed the belief that there is a need for some sort of one-stop hub for people with multiple needs. They feel that at present, services in **York** are disjointed, fail to communicate with each other, have blurred and duplicated pathways, and in some cases are even in competition with each other for funding:

> *A safe place or hub – people just have to go to one place… it would save having to go to several different services before finding the right thing* (p7)

At a multiple needs hub, a visitor could get help to address all of their needs, beginning with the most basic ones – food, warmth, safety, hygiene, and appropriate healthcare –through to more complicated things such as help with claiming benefits, searching for work, and to get a flat for themselves. Families and friends of the people using the service could also get support there.

> *A building where people from all areas can be… a safe place where you can get help here and there… people with experience* (p3)

> *A place where anyone can go. An addict could get help. Partners, friends, colleagues could go in and say 'I'm concerned about [this person], how can I help them?'* (p4)

At the hub, people would get a personalised, long-term support package, with help from appropriate professionals according to their needs (rather than the needs of the system). The service would have hope that all users can achieve a life they feel is fulfilling.

APPENDIX 2

CERT recommendations:

- Improved support for those with mental health needs:
  - Specialist mental health workers for people with multiple needs.
    - Training in how to work with people with multiple needs for all mental health professionals.
      - Training in mental health for all professionals who come into contact with people with multiple needs.

- Designing a system which can allow individuals to build a long-term relationship with a consistent professional who has the skills and knowledge to help them access the services they need in a timely fashion. This includes access to services offered by different agencies, and will be bespoke and personalised for each individual, and flexible to change as time goes on.

- The length of aftercare for people who have graduated from recovery programmes should be individualised and based on their needs.

- Professionals working with people with multiple needs should be offered supervision to support them to work in a way which is non-stigmatising and is hopeful for the futures of their service users. No-one should be given up on.

- The issue of rough sleepers having their possessions removed should be addressed urgently, especially with respect to York becoming the UK's first Human Rights City in April 2017. We see the disposal of possessions as denying rough sleepers' right to dignity and respect. Alternatives such as lockers or other self-storage options should be considered.

- Efforts should be made to clarify what agencies do so that referral pathways are clear, in particular, working to avoid duplication of services, and avoiding situations where different agencies are in competition for service users or for funding. This would make joined-up working more straightforward and effective.

- We concur with our interviewees that the possibility of developing a central hub should be seriously explored.

APPENDIX 2

CERT are aware that in researching the report, we did not get a true reflection of the different individuals in **York** who have lived experience of multiple needs, in particular rough sleepers and people in contact with the criminal justice system (see the limitations section). We suggest that with resources to facilitate a longer period of research we could address this imbalance.

Limitations of this report

- We are aware that the people we spoke to in researching this report are not a comprehensive representation of people with lived experience multiple needs in **York**. In particular, we did not conduct any in-depth interviews with any rough sleepers, and only interviewed in-depth one person who described contact with the criminal justice system.
- We quickly became aware in our 'on the street' interviews, that some people were suspicious of our motivations, and were extremely reluctant to sign a consent form (despite being very willing to talk to us). Reflecting on this, we wonder whether this reluctance comes from poor experience with authority or other formal services. In future work, we need to find a way of working with people in this situation which makes them feel safe and able to officially record their words when they share their story with us.
- Almost all of the people we interviewed in-depth struggled with substance abuse, but not all people with multiple needs are substance abusers. The perspectives of those who don't abuse substances in this system should be sought in future work.

Busy shopping day for whom?

Conclusions

CERT were commissioned by The Multiple and Complex Needs Network in **York** to conduct a peer research project, to seek the voices and stories of people who face multiple disadvantage in **York**. Using in-depth and short 'on the street' interviews, we identified that the priorities of people with lived experience of multiple needs are access to good and timely mental health support; a good, long term relationship with one worker; a safe place to recover; good quality aftercare; reducing stigma and ensuring respect; and a quicker response and shorter waiting times when they ask for support. Knowing where to get help also emerged as important. Various improvements were suggested by the people with lived experience of multiple needs that we interviewed, including the creation of a one-stop hub and practical suggestions for how people's basic needs could be met and how the service could be redesigned. **CERT** also made recommendations, including suggesting mental health training, facilitating long-term relationships, human rights issues, and conducting further research to hear the voices of people with lived experience of multiple needs which we did not reach in this project.

APPENDIX 2

Appendix 1: York services mentioned in this report

Carecent:

Carecent is a breakfast centre for homeless, unemployed, or otherwise socially excluded members of the community. It provides food, clothing, Internet access and fellowship Monday – Saturday, 8.30-10.45 for people over 18. In addition to food, they work with other agencies to help move people forwards to 'an improved lifestyle'. Here, we spoke to roughly seven people, mostly men.

http://www.Carecent.org/

Food not Bombs:

Food not Bombs provides free food for everyone in St Helen's Square every Monday and Friday evening at 8pm. Here, we spoke to roughly 6 people, mostly men.

Changing Lives:

Oak Trees 12-week structured, abstinence-based programme for people who wish to be free from drugs and alcohol. It includes one-to-one counselling, group therapy, meetings, and workshops for developing life skills.

Blossom Street drug and alcohol service (**Changing Lives** in partnership with **Spectrum Community Health CIC**): Integrative drug and alcohol service comprising both psychosocial and clinical interventions, to help anyone who wants to be free from their dependency on drugs and/or alcohol.

- One-to-one support and group recovery options
- Community alcohol detoxification
- Substitute prescribing
- Support for friends and family
- Relapse prevention advice and planning
- Signposting to partner services

Union Terrace offers holistic support for men who have experienced homelessness. Alongside supported accommodation, they offer support in other areas of people's lives such as helping them access health appointments and working towards employment or volunteering. They have a 'total acceptance policy', which means accepting people for who they are, and focus on their strengths rather than the problems in their lives, and help them reach personal goals that they have set themselves.

Robinson Court offers holistic support for women and young people, with the aim of helping people build brighter futures for themselves and their families. Alongside supported accommodation, they offer further support, such as helping with accessing health appointments, and working towards employment or volunteering. They also have a have a 'total acceptance policy.'

Outreach to multiply-excluded adults with complex needs provides intensive support and multi-agency coordination to multiply-excluded adults with complex needs. People using this service often have a history of poor engagement with, or exclusion from, local services. They aim to break down these barriers to ensure they are receiving appropriate support for their individual needs.

https://www.changing-lives.org.uk/services/drug-alcohol/

APPENDIX 2

Sunshine Changing Lanes

Sunshine Changing Lanes (**SCL**) works with and offers support on behavioural and emotional reasoning, through delivering educating, experiential awareness events. Whilst not therapy our models aid in understanding personal implicit and explicit reactions that invite conflict with others or in the self esteem. Our anger management, anxiety and stress reducing model educates through emotional experience, processing from reflections over life events which invites cognitive learning and reasoning via choice and personal growth, this promoting self esteem and positive well-being.

https://www.sunshinechanginglanes.com/

The Salvation Army Early Intervention and Prevention Team

- Clients may be identified whilst conducting early morning street walks or from other homelessness services in **York**
- Client-led initial assessment which focuses on actions which can be taken immediately, including accommodation and any health needs
- Integral part of the **City of York** 'No Second Night Out' scheme
- High profile in **York** – active presence on all housing-related panels, and engages with the Police, probation and community groups

https://www.salvationarmy.org.uk/early-intervention-and-prevention-team

York in Recovery

- **York in Recovery** (**YiR**) is a group of people drawn from the community working to the common aim of promoting abstinence and visible recovery from drug & alcohol addiction in the **City of York**.
- **York in Recovery** is not a charity or delivery service, it is the name given to the group of charities, service providers and individuals working together to develop a supportive **Recovery Community in York**.

http://yorkinrecovery.org.uk

Appendix 2:

The Labour Campaign for Drug Policy Reform (LCDPR)

We are so busy in our lives which the government want of course, that issues like this one are rarely challenged. That needs to change.

I went to a meeting tonight with an agenda which wasn't quite appropriate for the agenda that was being discussed in terms of as I listened to the chair of the meeting and the panel of experts from varying fields of expertise I realised it was far more complex and a much broader discussion. Mine was focussed on the current state of services and the changes I had seen over the five years of my engagement , rather than the wider topics being discussed at the debate. It's only when you attend a meeting like the one tonight that you gain and understanding of how complicated the issue is and how so many different services are tied to drug and alcohol treatment services.

It's not just about the front line services being squeezed to breaking point. It's about social reform, the commissioning of drug and alcohol services, educating staff in hospitals and GP's and the NHS, education about drug use in schools and in the community, prisons, probation and the police , housing and street homeless, jobs, child protection issues and child trauma, attitudes towards drug use and decriminalization, harm reduction, stigmas and minorities, to name just a few of the topics that were discussed in the debate.

I learned a lot in two hours and I hope I contributed in a constructive manner without taking too much of everyone's time. I spoke out for service users and I raised the issue of the lack of mental health support given to clients who are engaging with drug and alcohol services in **York** (given I have had to re-refer myself into that system approximately fourteen times in the four years of engaging with mental health services through my G P and drug and alcohol services having not been offered specific treatment for my complex PTSD which started at the age of thirteen which contributed to the self-medicating behaviour later in life)and I would like to think I was heard.

However the one thing I didn't get to make a point on out of many I admit was of course we are not service users or clients or data or statistics, we have names and stories and histories and lives to live. We are all individuals with each of us having very individual needs and a very complex set of issues. The one thing that I came away with was that the cuts that have already been introduced and the proposed cuts in the future for **York** are unacceptable on every level and it's all of our duties to fight these cuts to budgets for drug and alcohol services now. Not next month or next year but now. I am going to go away and collate my thoughts for a few days and then write to Rachael Maskell with a more considered and prepared set of proposals to be put forward to the government and the labour party MP'S who are fighting for change in services on all levels through calling for reform to the policies for drug and alcohol treatment.

I think it's our duty as past and present clients to have an input in making a difference for the future of services for **York** and the rest of the country moving forward. Money is everything in being able to Implement the changes required and there is an urgent need for reform of drug and alcohol policies as well as other services which all link together. I would welcome anyone to contribute to that letter I propose to put together. It's such a complex issue but I do believe change is possible. It's not just about the rise in death rates related to drug and alcohol misuse for me it's about the quality of life for every individual in the community trying to access help for drug and alcohol misuse treatment. It's a about everyone receiving the same level of care, whatever their background, whatever their situation without being discriminated against. It's about being able to deliver a service that is fit for purpose, which can give the individual a set of options in tackling their misuse rather than one pathway which may not suit some people. It's about raising awareness in fighting for these much needed changes across the board from the government right down to the people accessing treatment. In the short term then it's about fighting the cuts in budgets from the last ten years and having that money reinstated to deal with the backlog of people seeking treatment, in the long term it's about a complete reform of drug and alcohol treatment policies.