The Big Lottery's Fulfilling Lives Programme: Supporting People with Multiple and Complex Needs

connecting people, services and commissioners

WY-FI and Mental Health Services: 15 months on

Mark Crowe – WY-FI Project Research and Evaluation Co-ordinator. 21 December 2015

The WY-FI Project works with people experiencing three of the four following needs: homelessness, addiction, re-offending and mental ill-health. In addition they are in ineffective contact with services, if engaged with them at all. The aim of the project is to provide person-centred "navigator" support to adults who have chaotic lives to move towards a fulfilled life in their community. In particular it is the co-ordination of support from a number of agencies which is proving to be effective in dealing with interdependent issues and enabling the individual to engage effectively with them, allowing agencies to be more efficient in working with the whole person. In turn this reduces the number of inappropriate re-referrals or crisis contacts with someone who is experiencing immediate problems.

Early evidence from the project has shown that there has been most difficulty in engaging with mental health services in general. This is partly because experts and service users of the other 2 or 3 types of services are unused to or unwilling or simply unable to talk about their mental health and wellbeing. Additionally we have very few experts or service users who describe mental ill health as their primary issue, yet we know from the research we undertook that around 80% of multiple needs population are likely to experience mental ill-health whether or not it is formally diagnosed.

WY-FI has undertaken two tranches of research with interviews conducted by people with lived experience amongst people in locations which are indicative of them being probable or potential WY-FI beneficiaries. The findings help us to build a profile of the demographics of the multiple needs population.

Peer Research Summary Information

Key Findings from the 2013 Research (n=420)	***Key Findings from the 2015 Research*** (n=120)
80% were White British	84%
60% Male, 35% Female (5% not recorded)	31% male; 69% female
36% have secure accommodation,	40%
64% have temporary accommodation or sleep rough	52% (plus 8% expect to remain in prison)
30% have slept on the streets in the last month	18%
30% Don't engage constructively with services	26%
17% have been excluded from services	22%

Needs	
85% experience substance misuse	97%
65% have offending or probation needs	91%
51% experience homelessness or have nowhere settled to live	38% (range from 0% to 77%)
81% experience mental health problems	90%
71% of respondents experience 3 or 4 of these	69%
In the last month	
35.5% arrested (2.4% >6 times)	30% (5% 6 or more times)
32% spent time in the cells (2.6% >6 times)	27% (5% 6 or more times)
29% appeared in court	25% (4% 6 or more times)
17% spent time in prison	3.5% (17% 6 or more times)
30% slept on the streets – 15% >6 times (63)	8% (10% 6 or more times)
52% visited a GP or Walk-in Centre (6% >6 times)	59% (8% 6 or more times)
18% travelled in an ambulance	20%(3% 6 or more times)
18% were admitted to hospital	26% (2% 6 or more times)
26% attended A&E (3% >6 times)	30% (3% 6 or more times)

WY-FI has reviewed the first 12-15 months of the project overall and some of the findings are highlighted below. These are from a range of documents: CRESR's Local Evaluation and Year 1 Review (June 2015 the full report is in the appendices to WY-FI's annual report to the Big Lottery Fund), the Position Paper developed for the Years 3 and 4 Business Plan Review (September 2015); The Summary of Action Learning Research carried out into Women, BME and Criminal Justice System beneficiaries (October 2015); Feedback from Experts by Experience to the review of the Business Plan (October 2015); CRESR's Briefing on Multi-Agency Review Boards (October 2015).

From CRESR's Review of Year 1 of WY-FI:

- There is a high level of priority attached to improving the support of those with multiple and complex needs. Furthermore, in seeking to join-up existing support WY-FI is 'going with the grain' of recent developments. Nevertheless, interviewees frequently drew attention to the difficulties encountered in engaging **mental health service providers**. This theme was explored in more depth with mental health service providers who made a number of points, particularly about misunderstandings around precisely which mental health issues qualify individuals for support (see below 1).

- Interviews with staff from mental health services revealed perceptions that:

- **Navigators may not have an adequate level of understanding of the severity of mental conditions required to meet thresholds for support**: *'There's different levels of understanding around mental health. The other thing we can do from an organisational point of view is to give Navigators a single point of access for that advice and guidance so that they could at least have a discussion to determine whether they are within the mental health pathway or it's more a psychological intention pathway. My experience has seen people say someone's got*

mental health issues, mental health aren't doing anything. When you unpick it, they may have a severe and enduring mental diagnosis, but often there are [just lower level] *psychological issues'.*

- **Navigators have unrealistic expectations of mental health services which compromises the development of positive working relationships.** '*From my discussions with Navigators, I think their expectations of mental health services is probably too great, therefore they're getting very frustrated thinking that mental health services aren't doing anything'.*
- **Navigators should be given appropriate advice and guidance about mental health services to give them a better understanding of the issues and to reduce frustration.** This seems to be occurring in Leeds: '*They are drawing on our knowledge and experience to do some of the work but I like the fact they are respectful of other agencies'*.
- **The dual diagnosis service in Wakefield has been helpful in fostering closer relationships with mental health service providers and the criminal justice system.**

Recommendations from the **Action Learning Research Summary**:

In general:

- The desire for mental health teams and agencies to become more involved with other organisations e.g. through joint support planning was also a view expressed by a significant number of service users.
- Early recognition of multiple needs in individuals' contact with services and the causes and consequences of them was viewed as an important factor in each of the research findings. Research found that participants saw this as vital in order to recognise the early signs of developing multiple needs and consequently access services early before the point of crisis and chaos.
- Many participants had accessed services multiple times throughout their lives or had been involved with a service for a number of years. This was especially so for mental health and the criminal justice system.
- Many participants in the research felt they would not be in their current position if they had been more effectively supported earlier in their life, possibly when the point of crisis was not around a HARM issue but around, for example, relationship breakdown, bereavement, trauma or another personal experience.

BME Communities, Prison Leavers' and Women's support:

- Women: There is a need for [these workers] to develop pathways to services, especially to access suitable accommodation and seamless transfer to mental health services in the community as evidenced in the research.
- Male Prison Leavers: The younger, more chaotic participants with 4 HARM needs had accessed mental health services 3 times more often than the older group in the dataset who had 3 HARM needs. The younger group had been in the mental health system consistently longer than the older dataset with 3 HARM needs. This is an indication that older beneficiaries tend to lose faith and trust in services and therefore stop them accessing them
- Male Prison Leavers: Individuals with multiple needs within the prison leaver population are not given access to the services that they require on transition back to the community due to poor interagency working and a lack of knowledge on behalf of the services. For example, when asked if there were any housing services that weren't accessible for any reason, 42.8% stated that they were barred due to having mental health problems. However, when accessing mental health services, **6 out of 8 did not access due to having dual diagnosis of mental health and substance misuse concurrently**. This kind of circular referral (particularly prevalent in the case of dual diagnosis) presents a barrier to access one service or the other, meaning that for those experiencing both three or four multiple needs as a prison leaver, they are pushed from one service to another.

- BME Communities: In terms of multiple needs and directly associated issues, the priorities of BME communities seem to be:
    - Employment
    - Lack of Money
    - Benefits
    - Mental Health
    - Physical Health/ disability
    - Offending
    - Housing
    - Debt
    - Homelessness
    - Addiction

Distinct areas of need where people did not access services were in relation to: racial discrimination, relationship breakdown and segregation from community.

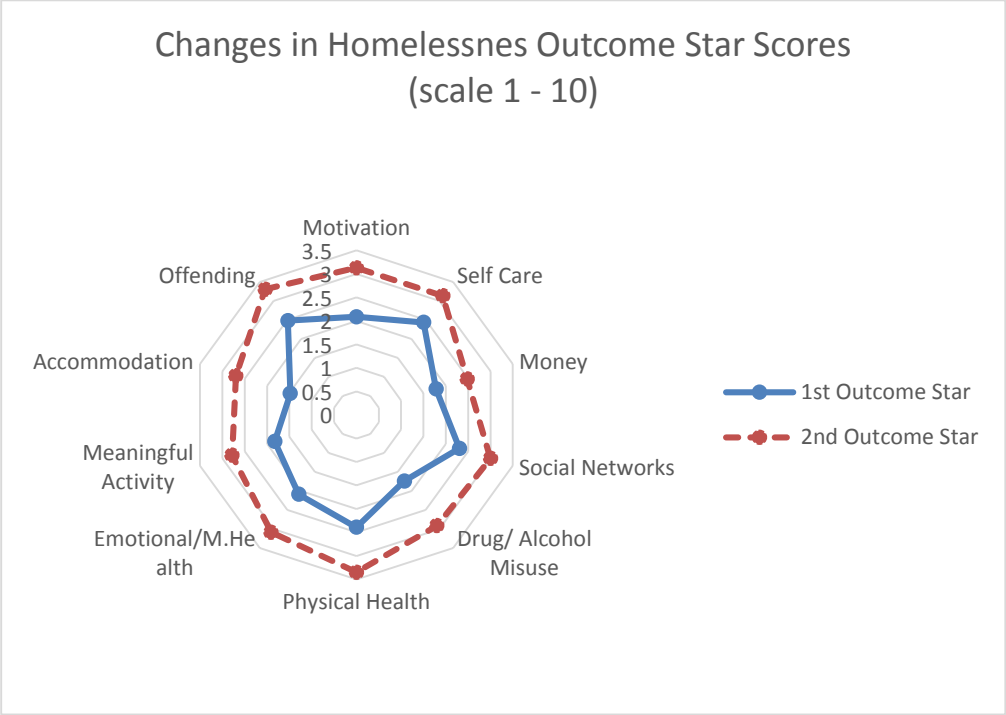
Additional blocks and barriers that need to be taken into in providing services to BME communities are:

- Stigma attached to HARM needs, especially mental health.
- A lack of knowledge regarding HARM needs, especially mental health (for example, 'depression' is not culturally defined and therefore some BME communities do not realise it exists as a clinically diagnosable condition.
- There is also an embarrassment of reaching out for 'external' support within BME communities as it is felt 'problems' should be kept within the community to avoid shame.
- BME communities are fearful of repercussions of sharing information, e.g. from social services or with professionals from within their own community.
- Often BME individuals will not access services until 'breaking point' as a result of the themes identified above.

WY-FI Position Paper:

Flex Achieved by Navigators - Early indications of flex in services achieved by Navigators identified housing/ homelessness and mental health as the two areas in which services have flexed. In mental health in particular this has been achieved through building up personal/professional working relationships with sympathetic individuals in those services. As with much of the early work it remains to be seen how much of this flex can be systematised beyond individual relationships. In some agencies familiarity and co-working with WY-FI teams has enabled certain flexed services to be offered to navigators as standard with WY-FI beneficiaries.

The Homelessness Outcome Star (HOS) is completed by the beneficiary 6 monthly to record their perception of their own progress. Average scores of 30 beneficiaries are shown below. WY-FI beneficiaries, on the whole, make progress in all areas of need in the first six months – these improvements are interrelated, not distinct from each other.



Experts by Experience Review of the Business Plan:

Specialist Services (Advocacy) In terms of improvement the majority of comments were directed towards having more capacity around these [women, BME, prison leavers and advocacy] areas of work. There was one suggestion about treating mental health, housing, benefits, education as all being specialisms in their own right. One expert pointed that other services provided advocacy and would swap that support provided by WY-FI for mental health.

CRESR, Local Evaluation Briefing on Multi-Agency Review Boards:

Leeds - For the first six months the MARB had no mental health representative but the mental health crisis team now attend. Although one interviewee felt that an additional mental health input beyond the crisis team would be helpful. There have been conversations with a psychologist who is likely to join the MARB in the near future.

Calderdale - A mental health representative which was seen as a big issue given the prominence of mental health issues in clients' lives and the lack of sufficient dual diagnosis services which means providers will not currently support clients with substance misuse issues. A range of reasons were given for this gap including organisational and staff changes as well as general pressures on an already overstretched service. However, a meeting has been arranged between Foundation UK and mental health services in November where it is hoped that this will lead to a representative being nominated for the MARB.

Case Studies, Anecdotal Evidence and Commentary

Multiple needs are very often rooted in an emotional or mental health need in late childhood/ early adulthood that has gone unaddressed or unmet, compounding and compounded by other behaviours that lead to the entrenchment of a chaotic lifestyle and complex needs.

There is a huge power imbalance felt by service users in the mental health system – and service users are acutely aware of the hierarchies and power relationships among mental health staff.

One service user commented – “psychiatry is a very young science” – in some ways it has been defining itself within the profession and the profession itself is unused to engaging more widely.

Even the service users we have talked to seem more highly "medicalised" in terms of their language about their own journey and interventions – to a greater extent than for other services.

Continuity of care and re-direction into appropriate services is an ongoing issue – leading to frequent calls to the police or frequent attendance at A&E

Rapid access to crisis care including hospital stays is difficult to obtain.

Access to assessments and having other professionals' judgements about someone's mental state accepted are also blocks to timely care/ support/ interventions

Good working with MH teams in Bradford (Navigator is an ex-CPN); Leeds (AOT involved in MARB, also York St Practice), Wakefield (Dual Diagnosis Worker sits on MARB) offering flexible or fast-tracked services to WY-FI beneficiaries.

Bradford – CMHT and drugs service are doing a training swap to each other's teams.

In some ways it would be good to find out about people who have had referrals made but not attended appointments and then had their case "closed" – these are people for whom a service was felt appropriate but have not received one and are still in the community.

Discharge from in-patient stays has meant that support in the community has not always been appropriate and beneficiaries have had to return to hospital.

In Bradford WY-FI, through the Locality Chair, has been invited into the Crisis Care Concordat partnership

Findings from work undertaken with Out of Character Theatre Company

WY-FI worked with Out of Character which is an established theatre company whose actors have all had direct experience of mental health services. The Company is based at York St. John University (in the Drama Department) and employs its own director. The Company performs in mainstream theatre (such as York Theatre Royal) as well as performing "experience pieces" to health and social care professionals and students. They also deliver workshops for example to Psychiatric Nursing students at the University of York the model for which WY-FI used to develop a way of working with a mixture of participants.

The aim of this piece of work was to explore people's experiences of mental ill-health and mental health services through a series of vignettes or tableaux which were built into scenes by the company. This was achieved through improvising around key words, feelings and emotions. The insights are therefore subjective rather than comprehensive but by taking the workshops round West Yorkshire over a period of months we believe that they are commonly felt experiences, even taking into account the different services that are provided and the different styles of service provision.

Scene 1

A man identifies the beginning of his illness as a boy of 14, separated from his father. He became withdrawn and confused about his identity. He goes into psychoanalysis and despite the analyst's presence being a positive influence (he takes the time, interest and care) the young man has a nervous breakdown – he still feels that he is a timewaster, stubbornly resistant to analysis. The breakdown manifests itself in a loss of humour and a loss of friends leading to him (labelling himself as) being serious and boring. In his isolation his attention becomes focussed on himself, placing himself at the centre of external events, culminating in the belief of an eerie presence and ritualistic behaviour. These symptoms become increasingly florid and his GP refers him to a psychiatrist and the young man receives medication.

This experience is completely different "care doesn't need to be sold" but the young man found himself being given depot injections of sedatives finding himself pleading with doctors and in

desperation (of another kind) at not being understood. He refused the medication for his own good but there were “no other solutions”. Doctors were telling him that it he had to take the medication as if they didn’t care about the side effects, it was if “they had tunnel vision”. It seemed as if they were as fixated he himself was in their view of the world.

This scene revealed the different nature of the power relationships between psychoanalyst and patient and the psychiatrist and patient. The power relationship between psychiatrist and patient being structured within an institution is magnified by the hierarchies of power inside the institution. Revolving doors of medics and the constant retelling of one’s story leads to defensive game-playing just to maintain one’s own interest in the processes. The doctors seem more interested in the drugs than the patients. Judging the ego of consultants and the unwillingness of juniors and registrars to go against the consultant is part of the game playing of the patients but which because of the power imbalance ultimately feels dehumanising. Patients do understand that psychiatry is a young science and that drug treatments undergo a lot of chopping and changing.

Scene 2

If you haven’t got a smile on your face you don’t get a full bag of chips

People with experience of mental ill-health told us that on the wards in psychiatric hospitals that it was often the least “medicalised” healthcare professionals that were the most effective in helping patients. *“The occupational therapists were really helpful – they listen to what you want.”* These were the people who would do anything that was asked of them by the patient. They are truly person-centred, picking up on interests (and interesting things) such as photography or relaxation. They weren’t all about the medications. *The support workers would ask me “how are you?” they treated me as a person. Them (the support workers) just being a friend put me back on the track.* What seem to be most important were their interpersonal skills *“walking, engaging – not talking down or being in role. Just talking and doing things with me.”* Feelings of belonging and of community were really important along with workers who were not only proactive but also caring – listening and understanding. These were the qualities for people who experienced mental-ill health that produced compassion. When doctors were good it was because they showed compassion – they took the time to listen and to focus on the person and not on the drugs.

Scene 3

There’s a bomb under my bed

In Halifax we talked about mental ill-health and substance use. People with lived experience in Calderdale shared with us the difficulties in accessing mental health services if they had a substance use problem or even if they had a history of substance use.

When people who aren’t mental health professionals talk about nerves, anxiety and paranoia they are interpreted differently to when professionals use those terms. Nevertheless the person experiences overwhelming feelings such as a fear of crowded places or of bearing the weight of the world. Pressures on services means that access is limited, people talked about a cycle developing where drink and drugs were forms of self-medication used in the wait for treatment but because of their use of drink and drugs they became ineligible for treatment.

What the mental health professionals didn’t seem to appreciate was – how much courage and effort it takes to seek help and the window for effective help is determined by the person’s ability to stay in a position to receive help, not on a timetable of waiting lists and assessments.

That cycle, that’s the bomb under my bed.

Scene 4

No fucking whale noises, it doesn't do owt for me

In Leeds we tried to find out more about what an ideal service would look like. Where people were at in terms accessing mental health services was not good. People described having to put up with quite extreme problems/ symptoms before getting any help. This often led to accident and emergency where their *"experiences were a nightmare"*. Even when in services the pressure on staff was such that they kept getting referred on to other services or workers *"retelling my story was a complete nightmare".* People's experience was that they had to accept that they were the problem, not simply that they were a person with a problem. The provision of a quick fix (not finding the root cause) was defeating for people- it just led to them not trusting anyone any more. People were clear about textbook responses to their symptoms rather than a willingness to engage with them about their needs and what would work for them. Whale music did not figure highly as an effective response to the chaos in their heads.

- The pressures for this individual stemmed from wanting and needing a job but being prevented from getting one because of anxiety and paranoia. They identified what was needed among employers was education and empathy about how people experiencing mental ill-health could work and what individuals themselves were most frightened of was finding out they were mentally ill. These pressures forced themselves out in distinct ways:
- Frustration with the service provided leading to referrals to other services, re-telling their story but not making any progress on their own recovery, they felt they simply got "textbook" feedback.
- Reflection on their own experience led to some objective enlightenment about their own situation. This turned to feelings of anger for other people who also suffer.
- Attempted dialogue with services about the care/ treatment they provide is met with professionals' indifference to patient experience. Then "the system" directs patients to executive levels or to political levels within the supply chain of services to try and effect change.

When everyone is playing at their roles (performing) the person at the centre needs to feel hope when they go into see a professional.

What does a good service look like?

It's a service that balances regular everyday care and medication delivered by one CPN alongside another CPN who deals with more practical issues on a day to day basis. The latter CPN would focus on the patterns of behaviour and troubleshooting problems before they occur. This would be done by not dwelling on where the beneficiary had come from (their past) but focussing on the future. This requires a high level of understanding and empathy on the CPN's part, which is used to hold the situation together using the beneficiary's assets and capabilities to let the beneficiary progress on their journey. Impending (or sensed) crisis can be managed by listening to the beneficiary and acting immediately – naturally this is intensive but it prevents small problems escalating out of control. If the beneficiary does get to see a psychiatrist, then it is someone who listens, doesn't judge and has the people skills to engage the beneficiary in the management of their own mental health and communicate effectively with other agencies.

The anxiety is that it will all break down but the reality is, that everyday gets better.

Scene 5

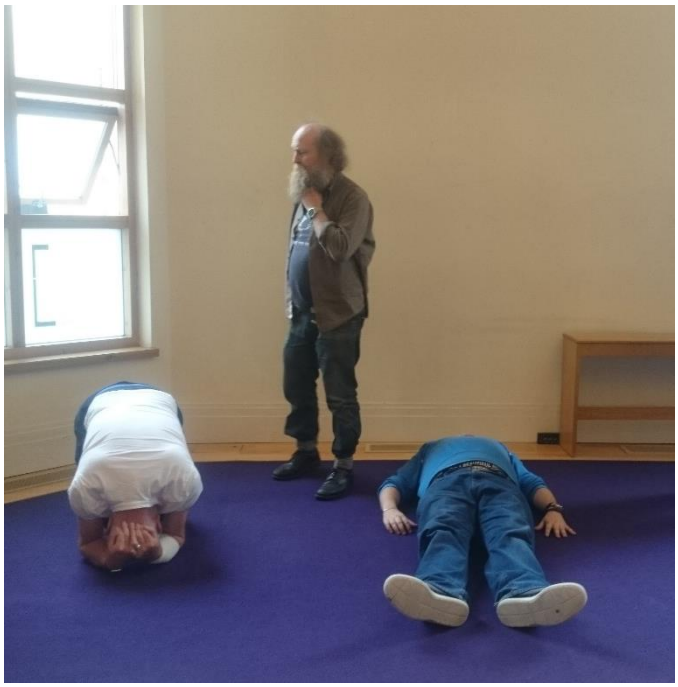
Rescue Me

In Huddersfield we tried to capture the "before" and "after" of the experience of mental ill-health. We tried to picture the loneliness of an orphan child, living in an institution whose experience of life was of physical hurt and emotional neglect. Unsurprisingly his response was to run away but

this only resulted in more of the same. Running away, though, became a theme in his life – always unsettled, rough sleeping, isolated and struggling with depression. One memory stayed with him, giving hope:

> The orphanage was empty
> I was sitting on my own
> A cleaner came
> And spoke these words to me…
> I can put a record on
> Just tell me what you'd like
> I shook my head
> So she chose one for me
>
> She rescued me…

His other rescuer was nature. Partly as a replacement for family through the "Sun Father" and "Moon Mother" but also giving him a context or a place – not just geographically but in a schema of life. *Seeing the animals and insects kept me from hiding myself … Nature brought me back … such as when I saw my reflection in water.* He had a speech impediment, a really bad stammer so he couldn't relate to talking to people. However he started to write and carried notebooks around. *Writing was my friend, it was like solving a puzzle about myself*. Through writing he was able to locate himself even if he was *at the centre of a web of confusion* and open up to feeling. The writing led to art and to music and, at the same time he was nourished by the kindness of people who shared conversations or food with him – as well as from time to time being brutalised by them - assaulted and abused. *After a while I had some poems printed … I was found in a gathering of poems.* After being homeless for many years he got a house, to begin with he couldn't sleep inside and even now he leaves the curtains open to let the familiarity of night sky in. It seems like an odd thing to say but maybe it feels unnatural to cut himself off from nature. But at least now he feels settled, connected and relaxed. Watch Laurie perform his song here.



Laurie positions the actors to capture his experience of sleeping out, exposed, and at the same time his inward feeling of hiding, trying to protect himself.

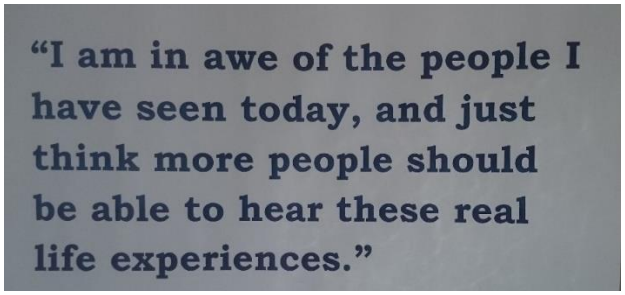
In Huddersfield we also heard how the pressures in one person's daily life came to a head in a car commute one day. That felt like a spiritual abandonment – as if the person in the car had become an empty shell without a soul. To overcome this required the biggest step of all – to

acknowledge the situation and seek help. Recovery from this situation took a number of years and involved stops and starts on a number fronts. These included medication and counselling; repairing and resetting relationships with immediate family and taking some risks (physical and emotional) and reaping the rewards. It wasn't all plain sailing but as the second scene shows a place of contentment and connection was reached.

The actors depict the pressure while Robin drives the car.

The actors show the journey (a metamorphosis) to a sense of connection, joy and achievement.

With enormous thanks to the Out of Character Theatre Company Actors: Adam, Brian, Colin, Faye, Christy, Laurie, Mark, Robin, Wayne and the Director of Out of Character, Paul who made this research true to life, enjoyable and powerful.



Poster at the Space, Leeds a venue for one of the workshops