

“I feel like I’m being punished for not engaging”

Fulfilling Lives Newcastle Gateshead Insights Report: Disengagement Keith Gibson, FLNG Data Analyst

People experiencing multiple and complex needs (MCN) are often referenced as ‘difficult to engage’ or ‘hard to reach’ and a common theme amongst services is varying levels of engagement with the people they support. Learning from Fulfilling Lives Newcastle Gateshead’s (FLNG) direct work with people experiencing multiple and complex needs provided an opportunity to explore some of the factors that contribute to disengagement. In this report these insights point to areas for discussion and further research, and we make some recommendations around approaches services might take towards building engagement.

In practice, disengagement can look like missed appointments, not answering the telephone, changing numbers frequently or a worker attending the person’s address and them not answering the door. Longer term, this can look like the person moving away without a contact telephone number and not being in contact with other services so the worker may find that they have no way to make contact with the person.

Over the course of the programme, amongst other variables we tracked people’s service use, periods of disengagement and accommodation changes. We noticed that people disengage for various reasons, regularity and for different lengths of time. Progress is often slow and incremental, with relapses and periods of disengagement for many (Moreton, Welford, Mulla, & Robinson, 2018). We recorded changes in people’s engagement status so that we might better understand people’s motivations and the opportunities and challenges relating to their engagement or disengagement.

We have also recognised differences in viewpoints, understanding and professional practice amongst our workforce when it comes to engagement behaviours, with our frontline staff demonstrating that reaching people experiencing MCN requires a person-centred approach to flexibility, intensity of contact, consistency and persistence of approach, and tools to support building a different rapport. Similarly, through our work with local and regional services and support agencies we recognised that a wide range of viewpoints and practices also exist across services, and not just within each service. The way that some services are commissioned, service pressures and thresholds can mean that they are not able to offer the flexibility or long term support people experiencing MCN can benefit from.

Our learning: a summary

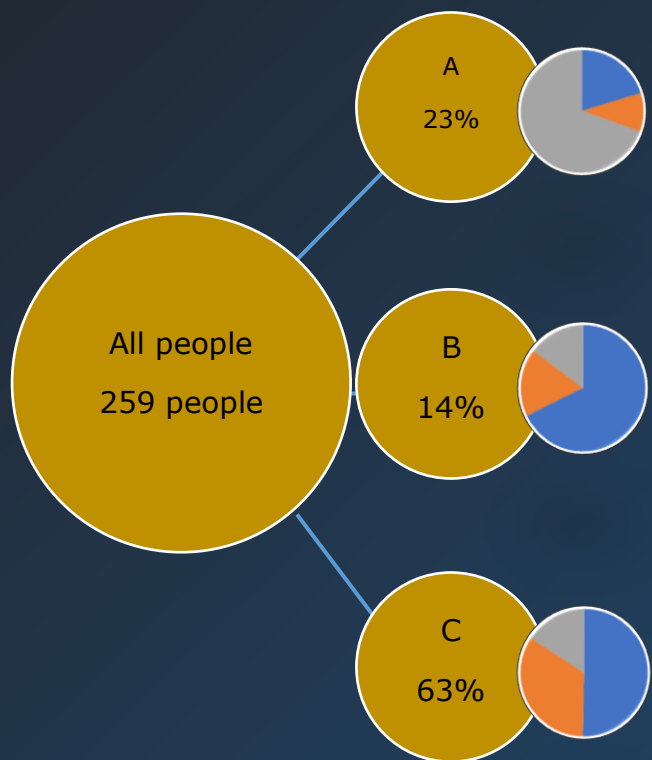
- Men and women engage in different ways.
- Disengagement is not necessarily an identifier of decline.
- Engagement is not necessarily an identifier of improvement.
- Our Experts by Experience Network, people with lived experience of multiple and complex needs, would like to see changes in how services approach dis/engagement.
- There was a significant variation in understanding, belief and approach to engagement across our FLNG workforce. Understanding this may help other agencies to explore their approaches to variations in engagement.

Disengagement in numbers

8 year project

259 people

24,000 programme days lost to disengagement



Disengaged upon time of closing

- Average 231 days per disengagement episode.
- More negative destinations.

Not disengaged upon time of closing

- Average 120 days per disengagement episode.
- More Positive destinations

Never disengaged

- Mainly positive or neutral*

Closure outcome

■ Positive ■ Neutral ■ Negative

Figure 1 - Disengagement and closure outcomes. *Note that neutral destination also includes deceased.

Periods of disengagement from our programme were logged on a timeline, and this timeline event was closed off if the person re-engaged with FLNG; after three months of trying a range of activities to make contact if we had no contact with the person their case would be closed, their case would be re-opened if they returned after this period of time.

We found that 63% of our people did not have a record of disengagement, that is to say reasonably regular contact was maintained with programme staff during their time with us. We categorised the remaining 37% into those who were closed after a period of disengagement and those who were closed at a time when they were no longer disengaging, Groups A and B, respectively. The graphic above shows the proportion of positive, neutral and negative closures within each group: a positive closure indicates the person has moved on to other support, or no longer needs support; a negative closure indicates the person disengaged from the programme; and a neutral closure denotes an event out of the control of the programme including a long prison sentence.

A key take-away is that Group B has a very high number of positive destinations despite the fact that they disengaged on average for three months per episode – a strong indicator that people who disengage from services for long periods of time still benefit from long term support.

Who disengages?

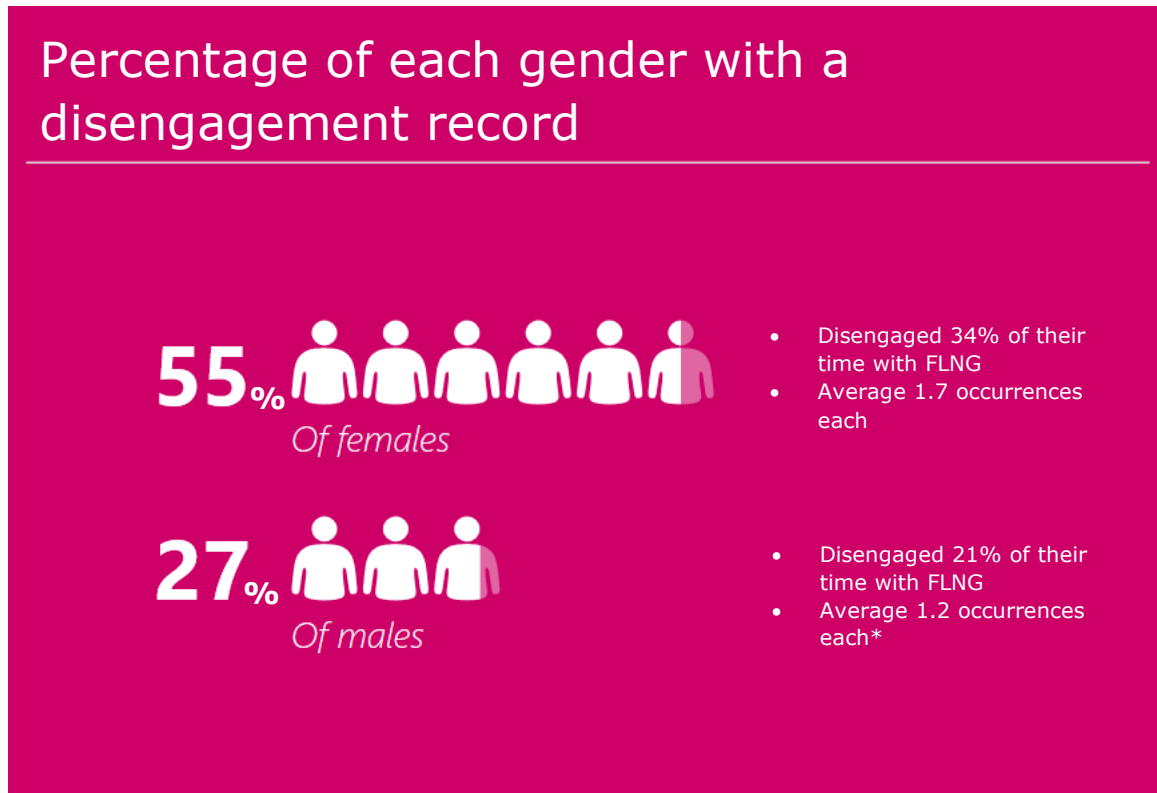


Figure 2- Proportion of females and males with a disengagement record. Females disengage for longer periods of their registration length and more regularly. *Adjusted in line with average female length of registration.

We looked at the gender breakdown within groups A, B and C. FLNG has a gender ratio of 66% males to 34% females. When comparing groups A, B and C we found that women were represented more in groups A and B than the programme average – 56% and 42% female, respectively, whereas group C consisted of more males – 76% male against 24% female.

Each group can be further broken down into positive, neutral and negative outcomes.

Within Group A we noted that females are more likely to experience a positive or neutral outcome. Within group B males are more likely to experience a negative outcome.

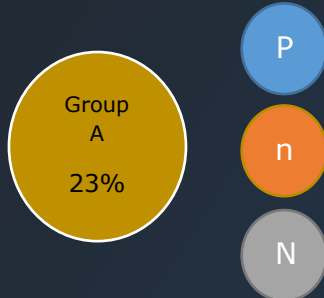
Finally, in group C, which is generally more male than female, the outcomes are quite balanced for across the three outcome groupings.

Gender breakdown

Programme baseline
66% Male and 34% Female

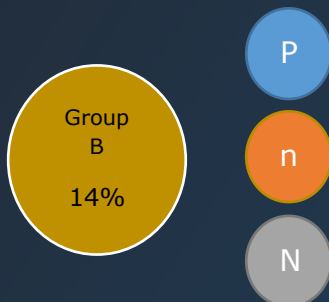


Disengaged upon time of closing



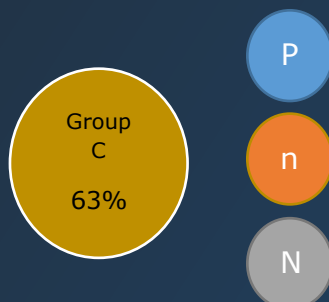
- Increased proportion of females in Group A compared to programme average (Group A baseline 44% Male : 56% Female)
- Positive - 33% male : 67% female
- Neutral - 33% male : 67% female
- Negative - 49% male : 51% female

Not disengaged upon time of closing



- Increased proportion of females in Group B compared to programme average (Group B baseline 58% Male : 42% Female)
- Positive - 56% male : 44% female
- Neutral - 50% male 50% female
- Negative - 80% male 20% female

Never disengaged



- Increased proportion of males in Group C compared to programme average (Group C baseline 76% Male : 24% Female)
- Positive - 77% male : 23% female
- Neutral - 73% male : 27% female
- Negative - 81% male : 19% female

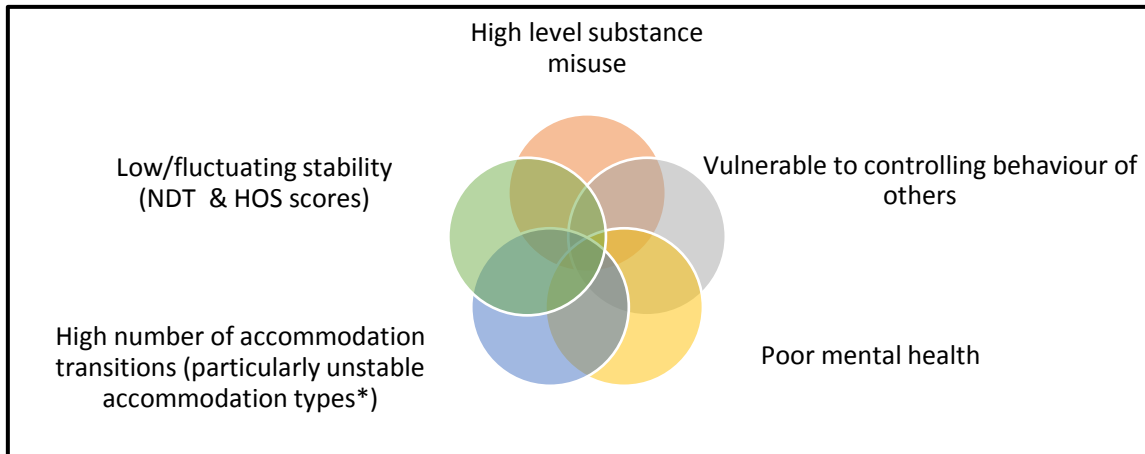


Closure outcome

■ Positive ■ Neutral ■ Negative

Common themes

A review of our case notes identified some common themes around people with a disengagement record.



We also identified and then themed different types or signifiers of disengagement as outlined below:



Pen portraits: three experiences of disengagement

Key to our methodology for understanding engagement was the analysis of client stories, mapped and showing accommodation, outcomes and key themes occurring in case notes. Here we present shortened pen portraits to show varying experiences of programme disengagement (see Fig 4 below).

Person A – Long term low level engagement

Female, late 20s, supported by programme for almost 3 years, recorded as disengaged 62% of time on programme

Person A spent their entire length of registration sofa surfing with friends and ex-partners. She had experience of sexual exploitation both current and historical. Person A spoke to her Navigator about securing accommodation on many occasions, each time appointments were made Person A missed these appointments.

The risks around Person A became heightened when she was held in a property against her will. Person A's worker noted that engagement tended to increase when some of the males in Person A's life were out of the picture – such as in the days and weeks between a 'break-up' and 'get back together' and tried to use these windows of opportunity to build a trusted relationship.

Person B - High level disengagement

Female mid 30s, supported by the programme for over 4 years, status recorded as disengaged 61% of the time on programme

On registering with FLNG Person B had very little engagement with the programme and case notes record confusion about where Person B is staying. We understand there has been contact with the criminal justice system, much of our information comes from third parties. A year into their time with the programme Person B informs various services that they wish to re-engage with FLNG, seeks assistance with homelessness applications and finding temporary accommodation and support with their high intensity drug usage. Their case is re-opened and they begin the longest and only sustained period of "engaged" status.

During this period there are frequent missed appointments, not answering or returning phone calls. Two further periods of disengagement follow. We are aware that Person B has significant health issues coming to light and immediate threat of eviction. Attempts to engage are not successful, there are occasional returned calls from Person B but follow up is limited and not sustained. Several attempts were made to meet up, Person B initiating these calls but then not turning up on the day.

Person B moves out of the area for a period then returns, re-initiating contact but does not attend appointments. Further attempts to engage initiated by worker but Person B does not make contact again and the case is closed with a disengaged status in place. Common in the notes for Person B is a pattern of engaging when a food bank voucher is needed or when support is needed to complete a form or a process, then disengaging for a period.

Person C - Medium level disengagement

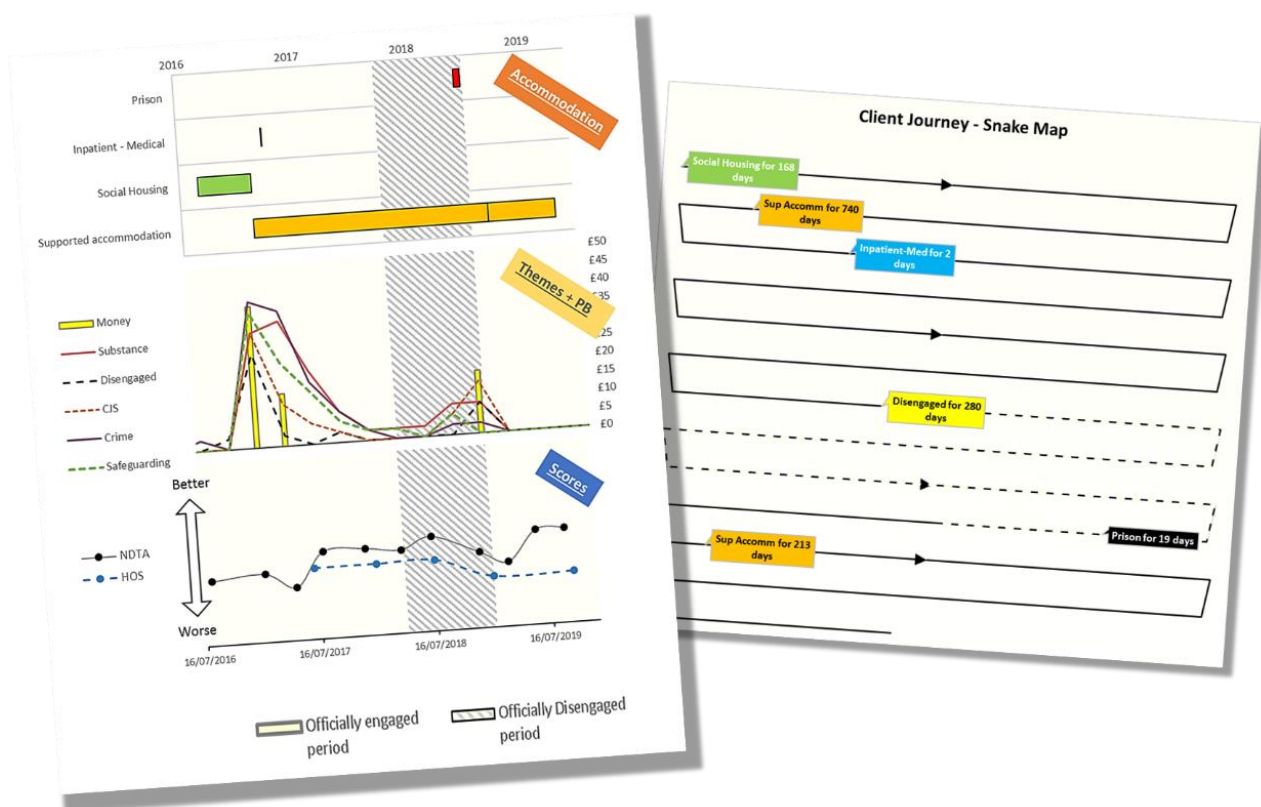
Male, late 40s, supported by the programme for over 3 years, status recorded as disengaged 25% of the time on programme

During Person C's time on the programme we supported him to make an accommodation move from a property where he was being financially abused. He was afraid to return to the property following a physical assault. Person C moved but continued to be a victim of physical and financial abuse. Much of the work that was done to support Person C was around current safeguarding issues.

After a period of regular engagement and support Person C had a lengthy period of 280 days where they disengaged from FLNG support. During this time FLNG inputted into local

safeguarding processes but actual contact with Person C was very limited. Appointments were attended under the influence of alcohol, there were periods of verbal aggression, physical violence and threatening behaviour, and consistent during this time were reports of regularly losing their bank card which often resulted in their bank account being emptied. Person C re-engaged briefly with FLNG when their case was closed with the local Safeguarding team. They engaged well with FLNG to secure new accommodation and the case was closed by FLNG when Person C had a key worker in place, with ongoing connections with multiple services in a supported accommodation where their needs were able to be met.

Fig. 4 Client C's journey mapped thematically showing disengagement period, accommodation and key themes



What people told us about the factors that impact on disengagement

We carried out interviews with staff and a focus group with our Experts by Experience Network (EBE) to gather views around factors related to disengagement. We found some overlap in their experiences and insights:

Staff

Negative influences within the person's networks, periods of time 'hiding' from people within their own social networks, or avoidance of "authorities"

Both said:

Addiction, emotional challenges, mental health issues and crises, apathy and willpower, and conversely feeling good / doing well / concentrating on myself

Experts by Experience

Personal matters, personal priorities, staff personality, weight of expectations, low self-esteem, no money, feeling overwhelmed

Members of the Experts by Experience Network discussed emotional challenges, referring to issues that fuel disengagement, such as shame and guilt following a period of disengagement. Similarly, a feeling of embarrassment of their physical appearance and state of health could also affect the likelihood of returning from absence.

"I can't see my worker looking like shit"

Some people felt that staff personality was a factor in disengagement, the group also discussed examples of disengaging after trust broke down in the relationship. One example was about an outreach worker from a service making a comment about items being untidy around their flat, the person felt this message was delivered in a patronising way. It was agreed amongst Experts by Experience that a friendly connection, established trust, and an appropriate level of friendly banter goes a long way to encouraging engagement.

"You've got to click with them"

What people told us about how services operate - disengagement policies and practices

Both staff and EBE Network members discussed the rules that services employ and engagement thresholds that exist in some services. As outlined above FLNG operated a three month disengagement policy where our staff had the freedom and were encouraged to chase, monitor or give space and occasionally check in with a person, with a view to securing re-engagement. After three months the case was considered for closure or further action, often cases would be kept open for longer as staff started to understand people's engagement patterns and preferences for contact. The staff team told us they were grateful for the flexibility that this allowed them to keep chasing people.

In exploring how services operate, the focus group discussed other practice examples including a 'three strikes and you're out' policy whereas other services may only offer one or two warnings of missed appointments and then take someone 'off their books'. The team recognised the service pressures impacting on these policies and the practice that is borne from this.

"Other services might [have the] desire to chase, but they are often stretched and don't have resources" (frontline staff)

Interestingly when asked, EBE Network members thought three months was still too short and that it takes longer than three months for someone in crisis to find themselves in a better position to start engaging again.

Amongst EBE members a common theme was the idea that these 'triple strike' methods are not for the benefit of the person, and that services do not understand their needs, sometimes this was about needing some space from services too:

"Sometimes I just need a break" (EBE)

"It's okay to take a timeout from services" (EBE)

"I feel like I'm being punished [for not engaging]" (EBE)

One of the other Fulfilling Lives areas, Bristol Golden Key, highlights a similar viewpoint. "Freedom from restrictive timescales allows keyworkers to work at the pace of the beneficiary. Beneficiaries appreciate that keyworkers persevere with them, even if they disengage or relapse" (Moreton, Welford, Mulla, & Robinson, 2018) citing:

"One of the things that I remember that particularly made me think well this would be really good was that they said GK was a longer term thing, we'll work with you for 5 years or something. That for me was a really positive point because [...] I'd worked with most agencies before, I'd been with some of them 2 or 3 times and stuff always, it always got messed up, probably my fault, sometimes not my fault but it's always stopping and starting." [Beneficiary, Golden Key]

(Moreton, Welford, Mulla, & Robinson, 2018)

Staff training

When we asked staff about their experiences, and particularly training around engagement, most said they had never received any training around this area. Two members of staff mentioned in-house motivational interviewing training, however no one had heard of any training available specifically around engagement and disengagement, or tools and techniques to support practice in this area.

Some were of the opinion that it was not necessary to receive training on aspects of disengagement, this appeared to be a case of not knowing what could be covered as opposed to being against receiving training:

"If you're new [to this type of work] you feel guilty that you've failed your client. You take it hard." (frontline staff)

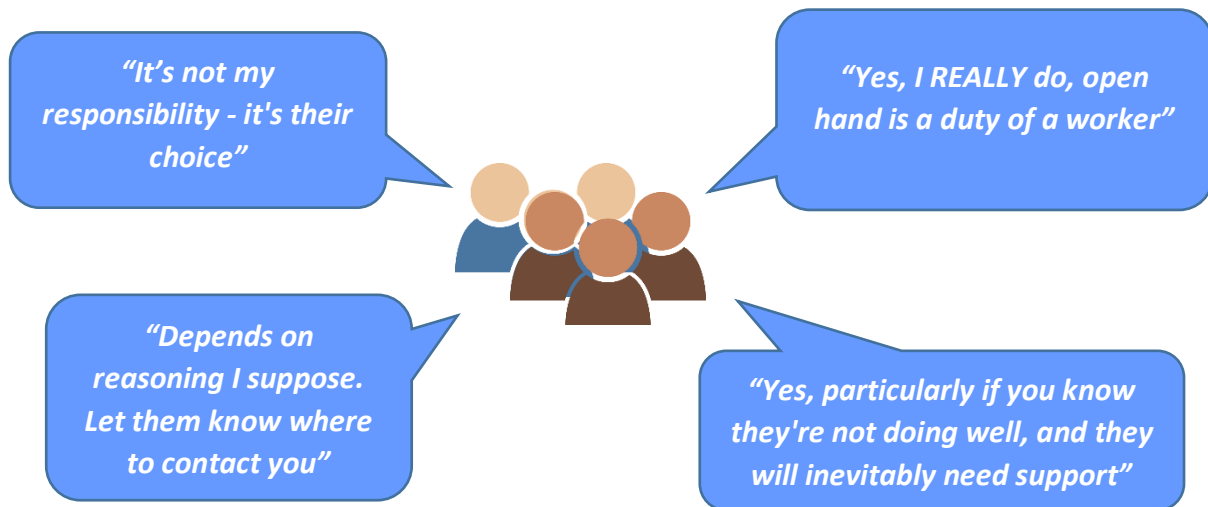
"You learn from doing and experiencing" (frontline staff)

Others felt that they had benefited from aspects of other training such as motivational interviewing, counselling skills training, training in outreach, and trauma-informed approaches and drew their engagement skills organically through their practice experience.

In addition to this, previous programme research has identified differences in the approaches taken by our staff; some spent a significant amount of time chasing a person whereas others took a more relaxed approach and felt it was important to give the person space, at least one person felt that it was "not my duty to chase".

"Do you think it's your responsibility to seek re-engagement?"

In previous publications we recorded that our programme ethos, rooted in open-ended long term support, prioritised an assertive outreach approach; "you have to chase them, they don't chase you" (Broadbridge, 2018); however we found that the intensity of this approach varied from worker to worker:



"Personality and empathy also play a role in your style, and it depends on what you think your role is" (frontline staff)

During our discussions with the Experts by Experience Network the topic of training was brought up by one member; it was their opinion that staff in services are not trained in understanding engagement patterns. Interestingly, one of our team shared how their own lived experience of disengagement had shaped their viewpoint and understanding:

"Personal experience of having disengaged myself has helped me to understand what people are going through, that sometimes guilt stops someone from returning, like a feedback loop. So an open hand is a duty of a worker." (frontline staff)

This is a theme that has emerged from earlier programme research, FLNG staff felt strongly that people should not feel guilty asking for support after a period of disengagement; one Navigator recalled a person being supported by a colleague calling them to ask if they could pass on his apologies after they disengaged; "he called me and said "tell her I'm sorry, I've let her down." (Broadbridge, 2018).

Common themes throughout the focus group with the Experts by Experience Network were the notions of trust, banter and connection with an assigned worker. In addition to this, Broadbridge 2018 noted that a group of beneficiaries talked about feeling let down when workers leave; one member described asking his key worker:

"Are you going anywhere? Are you going to leave?"

"[I would not engage if there was a chance of being] passed from pillar to post" (Broadbridge, 2018)

National Fulfilling Lives evaluation work also highlights the importance of flexibility and making accommodations to support people to remain supported by services:

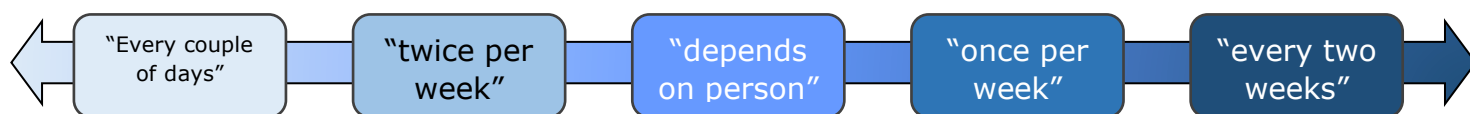
"As the evidence above shows, people with multiple needs will face setbacks and lapses in progress. It is essential that services acknowledge and accommodate this reality rather than punishing it through exclusions." (Lamb, et al., 2019)

Blackpool, another Fulfilling Lives project area, also identified that the relationship between a person and a worker was an important factor to engagement:

“...They managed to speak to 12 people who had been signed off and discovered that several of those individuals had wanted to engage with the programme, it was just that they had problems with individual members of staff they were assigned to. Within a month eight of the 12 had been signed up again to BFL...” (Findings from follow up interviews with ex-beneficiaries, Blackpool: Fourth Year Evaluation 2019)

Upon exploring our case notes it became apparent that the regularity of notes and records varied significantly across workers. Some case notes identified failed attempts at contact, others provided a brief summary whilst many records contained very little information about a person’s disengagement period.

This led us to ask staff “how often should you chase someone who is disengaged?” We received a wide selection of answers:



Feedback from staff about the different approaches they take in chasing was explored in our previous work on ‘What makes an effective multiple and complex needs worker?’. FLNG workers told us that they use a wide range of creative approaches, including text messages, letters and greetings cards.

Similarly, upon asking the Experts by Experience Network about their opinions on chasing we obtained a mixed response with a general consensus that chasing regularly is better. Interestingly one person commented that they would be happy for their peers to be contacted to find out how they are doing:



Final thoughts

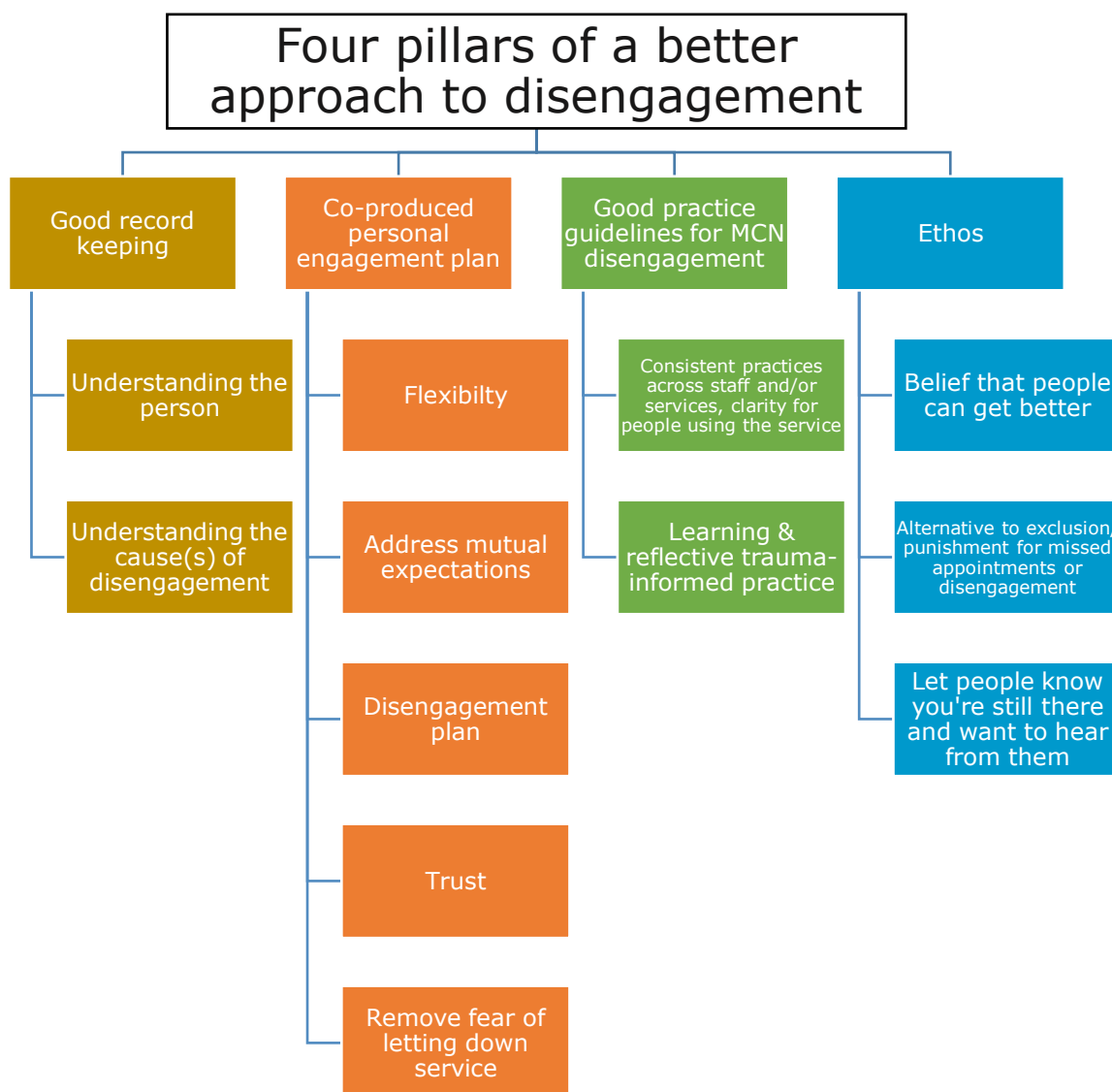
This deep dive of Fulfilling Lives Newcastle Gateshead data exploring disengagement highlights four areas for further exploration, and overleaf we start to map out how this exploration might take shape:

Good record keeping is essential for understanding the unique circumstances of a person’s patterns of engagement. Even if no contact has been made, keeping a record of attempts to make contact is useful for colleagues and the service in general when considering new strategies to engage or if there is a change of worker.

Co-produced personal engagement plan, bringing the person into the picture early to establish mutual expectations, builds trust and may assist with early engagement. By agreeing to a co-produced reasonable plan of action for disengaged spells, a worker is supported in their actions and the person knows what to expect. For example, one EBE Network member said they would be happy for their peers/other services to be contacted to help re-establish engagement. Exploring people’s preferences can help build trust and by addressing issues of guilt then we can address potential barriers to returning to the service before they happen.

Good practice guidelines – the variation of practice across services and across workers may contribute to person-centred approaches to engagement; certainly FLNG staff felt trusted to use their judgement about how and when to re-engage a person. However, our EBE Network described inconsistencies across services where rules felt unfairly implemented. Good practice guidelines available to people receiving support to understand the rules, in conjunction with a personal engagement plan, could form the basis of addressing disengagement. The differing experiences of males and females who are disengaging is worth exploring further in the development of guidelines and any training for staff.

Ethos – as shown in our analysis of destination outcomes, engagement does not always predict a positive outcome and disengagement is not necessarily a predictor of a negative outcome. A trauma-informed understanding of what day to day life looks like for people experiencing multiple and complex needs is important to understanding disengagement and patterns of engagement generally, as well as understanding the impact of trauma on people’s capacity to engage with the support.



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