GOLDEN KEY LOCAL EVALUATION

PEER RESEARCH DISCUSSION PAPER: THE CLIENT EXPERIENCE

Golden Key background

> *"Our target clients experience a challenging mix of homelessness, long term mental health problems, dependency on drugs and/or alcohol and offending behaviour. Our aim is to find new ways to break this cycle of deprivation and dependency and create new, positive, futures for those with the most complex needs."* **John Simpson, (Independent Chair, GK Partnership Board)**

The Golden Key programme in Bristol is one of 12 initiatives across the UK funded by the Big Lottery Fund *Fulfilling Lives* programme to support improving services for people with multiple complex needs (PWMCN). The core elements of GK include:

1. A programme of **systems change** activities across the GK Partnership and citywide.

2. A team of **Service Coordinators** who engage PWMCN with services to develop a better understanding of how to support their needs effectively and improve their outcomes.

3. Activities to advance **Psychologically Informed Environments** (PIE) as a way to improve outcomes for PWMCN and other service users.

4. **Service user involvement** - including a Peer Mentoring support service for PWMCN and a group of experts by experience (the IF Group), who represent the voice of service users to shape the strategic direction and practices of GK.

5. **Improving PWMCN's experience of assessments** to access services.

6. **Innovation pilots**

Why have UWE Local Evaluation Team produced a discussion paper?

The discussion papers have been introduced by the UWE Local Evaluation Team as a tool to stimulate discussion and engage stakeholders with some of the main themes and questions arising from our peer evaluation research interviews with GK clients. This approach aims to facilitate collaborative sense-making and support the evaluation in contributing to GK's learning, particularly at relevant points for key stakeholders closest to the programme.

Collaborative peer evaluation research approach

Through co-producing evaluation research with members of the IF Group, the UWE Local Evaluation aims to sustain GK's ethos of keeping service user involvement at the heart of the programme. Considerable time and energy was invested by the UWE Local Evaluation Team alongside the peer researchers in developing a collaborative approach throughout the process, right from the design stage through to analysis and interpreting findings.

Designing the evaluation peer research

Six IF Group members joined four UWE researchers on peer research workshops that were designed to simultaneously plan the research and develop the peer researcher's skills. During three ½ day workshops, we agreed ways of working, framed the evaluation context, developed understanding of research methods and ethical concerns, agreed research aims and methodology, designed research tools (checklists, question guide, client info), developed interview questions and the interviewer's skills.

Key research aims

The key research aims were to understand from the client's perspective: their experience of GK and relationships with Service Coordinator(s), the nature of Service Coordinator's support, and experiences of services in supporting their needs.

Recruiting and interviewing GK clients

All clients we interviewed were engaged with Golden Key and had developed a relationship with their GK Service Coordinator to some extent. ***An important limitation of this research and a key challenge for the evaluation is that we were not able to interview any clients who were not engaged with GK.*** Some initial challenges in recruiting GK clients led to a range of different approaches being used, including: referrals from existing IF Group contacts, referrals from Service Coordinators, and approaching GK clients staying at a hostel in Bristol.

Four peer researchers led the nine semi-structured interviews with GK clients that were conducted during Autumn 2016. A UWE researcher was present at all interviews who supported the peer researchers and, at times (depending on the peer researcher's confidence), introduced the research and occasionally asked clients further probing or supplementary questions.

Analysis and interpretation

The peer research team engaged in analyses and interpretation during 2 x ½ day workshops, with group analyses activities and further individual analysis of own interview transcripts. A UWE researcher analysed all interview transcripts and then the research team reviewed and enhanced interpretation of preliminary findings together leading to the production of this paper.

Summary of key findings: understanding the client experience

1. When first engaging with GK, clients mainly understood and were reassured by GK being a **new** and **long-term** service **especially designed for people like them**.

2. Whilst many of the clients we spoke to went into initial engagement meetings feeling anxious and/or apprehensive, their experiences of first meeting Service Coordinators were positive and felt relaxed and easy to clients.

3. Clients described strong trusting relationships with their Service Coordinators. Key contributing factors were clients liking and respecting their Service Coordinator, also finding them genuine, consistent, reliable, accessible and responsive to their needs.

4. Nearly all clients we spoke with described their Service Coordinator's support in ways reflective of an approach that was: holistic (across all services and areas of client's life), independent of services - on the client's side, pro-active, positive and flexible (depending on the client's needs).

5. The majority of clients interviewed were overwhelmingly positive about GK's role in their life and saw positive change as a combined result of GK's support and their own endeavours.

6. Most clients we interviewed appreciated the personal and emotional support that Service Coordinators provided. This included practical personal support (e.g. moving house, domestic matters) and emotional support at varying levels. Some clients appreciated the friendly style of relationship with their GK Service Coordinator.

7. Five clients commented on knowing their Service Coordinator was busy, although these individuals also emphasised they were overwhelmingly satisfied with their support from GK. This was also suggested as a potential area for improvement by several clients.

8. Clients described various situations and understanding regarding their relationships with GK support beyond their assigned worker (i.e. 'back-up' or 'second' assigned Service Coordinator).

9. Having built up a good relationship with a Service Coordinator, transitioning between Service Coordinators can be challenging for clients to handle.

10. Clients descriptions of their previous experience of services involved a recurring theme of them feeling 'let down' by services. This included various and systematic ways that client's expectations of support were not met, negative experiences through assessments, and some specific traumatic incidents.

11. Many clients we spoke with felt their experiences of services had improved during the time since they had engaged with GK. Their Service Coordinator gave them confidence to engage with services and increased client's trust that services would meet their needs more effectively.

12. During our interviews, clients described their use and access to the personal budget positively. Items these clients had purchased included those providing practical support, and items which supported longer term fulfilment, physical and emotional well-being.

13. Some clients talked about their loneliness and wanting to find positive activities to structure their time and positive people to spend time with.

Client's experience of starting to work with GK

Clients understood GK was a new long term service especially for people like them

Several key features characterised GK for clients at the point of their referral. Client interviews indicated that they had primarily understood that it was a **new** and **long-term** service **especially for people like them**.

Some clients specifically mentioned that when they were first referred to GK, the long-term nature of GK's support had positively affected their perception of the service.

> *"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 was really up for that because I'd worked with most agencies before, you know, 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."* **GK CLIENT**

Peer researchers discussed that these features especially were likely to be reassuring to clients as they reduced the perceived risk of engaging with another service.

Most of the clients who had been with GK for over 12 months looked back at the point when they engaged with GK as an especially low point in their life:

> *"… that was particularly a difficult period of my life, because around that time I was in crisis… I was really suicidal and stuff like that"* **GK CLIENT**

Clients report positive experiences starting to engage with GK despite some apprehension

Peer researchers were keen to explore how client's had experienced the initial engagement, as this can be a particular hurdle for PWMCN who have previously had negative experiences of assessments, been refused support or had unmet expectations for support. Peer researchers had often found these initial meetings with services unpleasant in the past and described their own feelings in the past when first engaging with services: this was a highly stressful situation where they needed support but did not necessarily understand the access criteria or the assessment process. They also reported that they tried to manage expectations and avoid investing too much hope in the outcome themselves, in order to deal with the uncertainty and combined potential for both positive change or disappointment in their life.

GK clients we interviewed who were able to recall the initial engagement talked positively about meeting their Service Coordinator and beginning their engagement with GK. Around half of clients reported feeling anxious or apprehensive before the meeting due to being 'let down' by services in the past. Interviewees explained that this meant that they went into the first meeting careful not to get their hopes up too much. Whilst many clients described an initial 'wait and see' attitude after the initial engagement, several described feeling hopeful:

"I came out of the first meeting on the assessment and everything with a thought, you know what, this might work. I got the impression they was taking what I was telling them very serious and they had a bit of an insight and understanding and I thought well this is definitely worth going to the next meeting." **GK CLIENT**

Whilst some clients could not recall much about their first meeting due to their condition at the time or poor memory issues, overall, we gained an impression from many clients of their initial engagement with their Service Coordinator feeling relaxed and easy.

"So when I was meeting this new worker, it was very relaxed, it was just a coffee thing… so the first few meetings with him, just getting to know him with the other person, I think we had about 3 or 4 of them." **GK CLIENT**

Several clients repeatedly stated problems with their memory and could not clearly recall the time of joining GK, suggesting a need for care when interpreting their accounts.

Client's previous experiences of services

Common experiences in the past of clients feeling 'let down' by services

Many clients described how they felt they had been repeatedly 'let down' by services in the past. Some reoccurring themes included:

− Services ending support at a point where the client felt they still needed help, sometimes where a client felt that a relationship they had built with a service worker was important to their support.

− Services raising hopes of helping, but not meeting the client's expectations.

− Personal information being misinterpreted or used in ways that affected the client negatively (e.g. to deny access to services, disclosing personal info to peers).

"Some services are very short lived, you just get or you get comfortable and you start building up a relationship and then they drop you." **GK CLIENT**

Some clients described specific important traumatic incidents they had experienced with services in the past that had severely affected their confidence and trust in services overall.

"I think I'd had a few bad experiences, maybe in a row with stuff... towards the beginning, with housing and people that were meant to be key workers and stuff, I had a few bad incidents that made me not trust or to want to work with anyone, to think this will just be the same... one of the reasons why I'd gone on the streets and gone back to drugs." **GK CLIENT**

Clients dislike telling their story many times to access support from services

Clients described their history of negative experiences going through assessment processes to access services:

"I got put on some waiting list, I'd started to work with some people, met someone, gone through all of the paperwork then about 3 or months later, the

person would either leave and it would be a new person so I would have to start working with or…. I remember that, starting with a new organisation, I didn't enjoy, going through all that paperwork and it was the same type of question every time, 'what is wrong with you?' you know, 'what makes you qualify for it?'… "I knew the questions off by heart so it was kind of like a thing I didn't like doing that I had to do... then you go and the people they're just seem to be interested in filling out the questions and want to get all this stuff down." GK CLIENT

Clients raised their past disengagement from services as a crisis sign/symptom

Several clients mentioned that their disengaging was a sign or symptom of them having a difficult time and appreciated their Service Coordinator recognising this.

"If they [their Service Coordinator] don't hear from me for a while, if I miss an appointment, they'll check in with me, they'll even come round… it was also part of actually listening to what we had at the initial interview, that if I withdraw from services, it's usually the time that I need it the most, and I think they took it on board" GK CLIENT

Peer researchers shared their own experiences where they had felt at times in the past that services had interpreted missed appointments as a sign of disengagement and then assumed that they had given up or couldn't be bothered. This was a point where peer researchers considered it was particularly meaningful and helpful in the past when a service worker had reached out to them.

Client - Service Coordinator relationships

Clients describe strong positive trusting relationships with their Service Coordinators

All clients who were interviewed described having a positive relationship with their GK Service Coordinator and nearly all described this very positively in terms of having very high levels of trust. Key contributing factors to building this trusting relationship included:

– Client feeling that their Service Coordinator is genuine in their relationship and desire to help them.

– Service Coordinator demonstrating they are consistent and reliable over time.

– Client feeling that their Service Coordinator listens to them and takes them seriously.

– Service Coordinator is considered responsive and accessible to the client (appropriate to their level of need at the time).

– Service Coordinator is very positively regarded and respected by the client

"Maybe it's just the person I've found to work with, I get on with them very well and I trust them completely and they know about all the stuff that's gone on…. one of the ways that I built up trust with him because he always took me

seriously and never led me to think is this person just going through the motions but really they don't like me as a person and they think I'm attention seeking or just trying to get, lying about stuff, I hate that." **GK CLIENT**

"Reliable, yeah, somebody reliable in your life that's not on drugs and not got loads of mental health problems." **GK CLIENT**

Several clients felt there was something akin to friendship in the relationship.

"Well [Service Coordinators give] every sort of support really... and they help me with my brain, just everything, they're just like friends but they're not friends if you know what I mean." **GK CLIENT**

"You kind of get to be friends and talk about stuff and have a laugh... yeah it's good, nice like that I think." **GK CLIENT**

Peer researchers commented that people without a positive and stable social support network may confuse the relationship with friendship when their Service Coordinator is nice to them. However, it was not felt that clients were saying Service Coordinators **are** their friends, but that a 'friendly' style of relationship is appreciated. We reflected during our discussion on how we sometimes tended to separate 'personal' and 'professional' relationships and that the English language lacks a word to adequately describe the nature of the Service Coordinator relationship.

One client described their Service Coordinator relationship as having 'ups and downs'. In this case, the client acknowledged that they themselves had changed significantly since changing medication and viewed these 'ups and downs' in the context of learning about relationships:

"I've my ups and downs mind, I've had rows with my worker and not spoke to them for a few months... I don't know, it's like any relationship innit …I didn't know how to have relationships, I've got, well I'm supposed to have a personality disorder but I did not know how to have a relationship, you have your ups and downs… but on the whole I really don't know what I'd do without them… So, I haven't got a bad word to say about them really." **GK CLIENT**

Transitioning between Service Coordinators can be challenging

Peer researchers were aware that a number of Service Coordinators had left GK and were interested to explore any client's experiences if a Service Coordinator had left GK or if a client was not happy with their Service Coordinator.

Two of the nine clients we spoke with had a change of Service Coordinator during their time with GK. One client was very positive about the experience, and though differences in levels of support were noted, it was unclear whether this was due to the client's move from prison to hospital.

"Well [current SC] became more involved than [previous SC] did... I've been seeing [current SC] more regularly than I saw [previous SC] I think, yeah... because I haven't been in prison, I've been in hospital."

The second client talked about how well they had got on with their first Service Coordinator who had subsequently left GK. This client had not been happy with the replacement they were

assigned and felt that it had taken a while for GK to find an alternative Service Coordinator (with whom they were then happy with at the time of interview).

> *"In fact... when he kept turning up, I said ain't you getting the message, I got a little bit rude in the end."* **GK CLIENT**

Service Coordinator's approach to working with clients

In terms of understanding the Service Coordinators approach to their client practice, there were some strong themes that emerged from client's descriptions of the Service Coordinator's way of working with them:

- Holistic - working across all services and client's personal life

- There for the client and on their side, being independent of other services

- Proactive and positive

- Flexible support, depending on client's needs

> *"My GK worker oversees all of that and because they can work with different agencies, so to me they feel separate which is good because if I've got problems with something or there's something I don't understand or things, they can interact with all of those different agencies... they seem to work with everyone and be involved with everything... they always seem to be able to say yes to help me, there doesn't seem to be a barrier or problem to anything."* **GK CLIENT**

> *"Yeah, I'd see that as a, that would be a big one [positive] for me, being in control, feeling that I can go as fast or slow as I want."* **GK CLIENT**

Clients were almost entirely and overwhelmingly positive about GK's role in their life.

> *"I don't know if I'm meant to be treating GK like that but, yeah, that's how I view them, they're always there and they can help with anything."* **GK CLIENT**

Clients expectations were exceeded but clients were aware Service Coordinators are very busy

Most clients were overwhelmingly satisfied with their support from GK and felt it had far exceeded their expectations. We gained the impression that Service Coordinators manage client's expectations with great expertise so clients felt very well supported. However, five clients also commented on their Service Coordinators being busy:

> *"He is a very busy guy and I understand that, so I don't, unless something's really going bad, I don't want to trouble him over my sort of paranoia you know, little things that's not actually something serious."* **GK CLIENT**

> *"She might be too busy I think sometimes..."* **GK CLIENT**

> *"Obviously it's not possible to say oh I need you this morning when they've got other appointments, but they react great when I'm in a crisis or really need the*

support we arrange very quickly how I can get access to that support." GK
CLIENT

Service Coordinators provide personal and emotional support

Clients talked positively about the personal and emotional support that their Service Coordinator provides. Service Coordinators were often described as someone on the client's side who listens, understands and supports them. This includes practical and proactive personal support that other services often don't provide (e.g. moving house, arranging practical domestic matters). Clients described emotional support that extended from having someone to talk with to a more therapeutic role:

> *"They're constantly there if you need help, and he was there…. you know, through all the crap, which really helps you know because you feel that there's always an avenue even if it's just to vent about it, there's someone there on your side, it's a good thing."*

Varying approaches and understanding of back-up/second Service Coordinator

Clients described a range of situations regarding their relationships with GK Service Coordinators beyond their assigned worker. Several clients were working closely with two Service Coordinators, whilst others were unaware if they had any second/backup worker assigned.

> *"I've got two of them… I love seeing them both… It's good, works well because they've both got different personalities, they've got different ideas, and you know I'm feeding from them with their ideas, yeah." GK CLIENT*

Several had contact details for a second 'backup' worker as they had been introduced to another worker for holiday cover or in a way that seemed incidental to the client.

Client's current experience of services

Improved experience of engaging with services

Some clients are engaging with new services to support their needs whilst some are re-engaging with services that they have worked with before. Most clients described their experience of services improving and getting their needs met more effectively.

> *"Yeah, I believe definitely that I'm being listened to, that my needs are being listened to a lot more." GK CLIENT*

> *"I get on with everyone that I work with now, it's just part of different situations… So I'm trusting again organisations… you know key-workers stuff like that." GK CLIENT*

One client was unable to access the type of mental health support they desired (previously lost due to transitioning from young people to adult services). Another client felt their housing

situation was holding them back due to housing shortages, despite them making significant progress working on their addiction and offending.

Understanding changes in client's experience of services

The descriptions that most clients gave of their current experience of services suggested that the difference was due to subtle interrelated dynamics of the Service Coordinator's support and the client's own attitude or approach. Exploring client's current experience of services revealed some important elements of Service Coordinator support in dealing with issues that arose. Service Coordinators were perceived to:

1. Give client's confidence to go ahead and engage with services. The extra support from GK improved client's trust that the service would support them as they hoped.

2. Have extensive knowledge and experience to navigate services through signposting clients to the right support and helping clients access the support.

3. Coordinate 'joining up' services and ensured everyone is kept informed as is necessary to support the client getting their needs met.

4. Ensure other professionals listen to the client and help explain if needed so that services understand and can respond to the client's needs.

5. Advocate and negotiate with services on behalf of the client to get their needs met and held services to account.

6. Support the client through assessment processes to improve the experience of gaining access to services (may involve accompanying the client, telling the client's story for them, or supplementing important relevant details).

> *"If I've had things like PIP interviews, they've helped me with that, they've just been there as reassurance for me and been there for me, helping me, prompt me and helping me answer questions I would most probably get stressed and I would forget to ask or forget to tell."* **GK CLIENT**

Changes in client outcomes and aspirations for the future

Clients believe GK has positively affected their life

Most clients perceived significant positive change in their life due to GK, but also due to their own efforts.

> *"Golden Key has made a massive difference to my life, I'm in a lot better place now than I was 6 months down the line. Definitely, definitely, as I said before, the statistics about suicide from 2015 to 2016, one relapse in this period, from considering 6 times last year, is a lot of difference. That must be showing that I have a lot more morale and want to live more. Obviously, there's other things that comes into play with that, you know about being supported and things like that but they are the key workers on that."* **GK CLIENT**

"Since I've been with GK, that's the longest I've been out of jail… longest was a month before, and now I've been out a year…. and I've come back with negative drug tests and all that… I'm not really sure what the difference is but it's a big difference." **GK CLIENT**

"I didn't realise since I come off them [tablets prescribed for mental health] how many years I'd been on them, I'd been on them 30 years, one lot, 30 years… So like my mood is like really good at the moment and it's the first time it's been good in I can't remember since when, I'm content… now I'm happy and I've got a really good relationship with my son, I didn't see him for 9 years." **GK CLIENT**

"I've got a job recently, I've managed to complete my course, even though I had low attendance, I'm still doing things, I'm still getting on with my life… I have moved forwards since then because around that time [of joining GK] I was in crisis, I was really suicidal … so yes, my life has improved since then… I don't want to die, I did want to, but now I don't so that's an improvement in anyone's standards." **GK CLIENT**

One client who had been with GK for around 5 months, did not report any changes in his life, though they spoke of activity that was starting to engage with services.

Hopes and aspirations

Clients described hopes and aspirations that varied in the level of clarity (i.e. whether clients could see the steps they needed to take to get there) and vision (i.e. long term, extent to which they could envision a happy successful life). Some clients made positive statements reflecting their desire for independence, for example:

"I would like to stop taking drugs, I would like to get a handle on my mental health, I would like to get a full working job where I'm paying for myself and I don't have to be on benefits, I would like to get a flat where I can pay the rent myself…. That's the same things I've always been trying to do, but now it feels possible." **GK CLIENT**

"I just want to get, to be able to be independent, live independent, to cope and survive". **GK CLIENT**

Client's perspective on GK's positive features and areas for improvement

GK's positive features from the client's perspective

In response to the specific question about the positive elements of GK, clients highlighted the: longevity of support, independence of support (being separate and not linked to other services), consistency of support (always being there) and also the personal budget.

Some comments included:

"They're there for a long time means that they will be there even if sometimes places have closed down or ... so they're interested in everything and they try and help me with it all and for the longer term." **GK CLIENT**

The client's perspective on areas for improvement

In response to the specific question about the negative elements of GK, or things that could be improved, all clients struggled to find anything to suggest and any points made were considered fairly minor by the client. Several clients responded to the question about the negative elements by returning to earlier comments about their Service Coordinators being busy (as described previously). Some clients responded to this question by voicing their concerns about what would happen to them when their GK support ended.

> *"Make it, make it better? I mean, it's so good... the 5 year thing is great but I worry about what will happen in 5 years but maybe I wouldn't need them for longer. No I can't think of anything ... but no, no everything, all my expectations... they've been as good and better than I thought."* **GK CLIENT**

Suggestions from clients included:

- Some clients wanted to be able to refer people they knew with multiple complex needs to GK or suggested expanding GK to be able to support more people.

- Several clients suggested (somewhat humorously) increasing personal budget amounts.

- One client proposed a client coffee feedback session (this was already planned by the Service Coordinator team).

- One client would like support over the weekends.

Personal budgets

Client's perspective on their personal budget

All clients described their access to and own use of their personal budget positively. Clients who were further along in their recovery journey generally described feeling supported and empowered by their Service Coordinators in their spending choices.

> *"The nice thing is about the money… and that has been really nice to know that's there... they've never tried to hold it back from me, you know I've never been like saying, can I get some glasses and they've said, well really you should get this instead…so I've never had to feel bad about asking for stuff."* **GK CLIENT**

One client did not entirely agree with other client's spending choices (shared with them at the GK Client Coffee Morning), although there was some appreciation that items had different meanings for different people. Several clients had unclear or inaccurate understanding of their Personal Budget which is £500 per client annually for the first three years of the GK journey.

> *"I don't know the ins and outs, I know they're not supposed to tell you how much it is and it's only for something that can improve your life so, so when I have spent it on stuff to improve my life, I certainly wanted to make sure that it is something that would improve my life."* **GK CLIENT**

> *"Some of the bonus points of it are... they have a £300 a year spending allowance."* **GK CLIENT**

Clients use of the Personal Budget

Clients described examples of how they had used their personal budget for a wide range of items. These can be categorised in the following areas:

- practical support

- client finding meaningful activities /more positive ways to spend their time

- developing social networks

- Improving physical health & emotional wellbeing

Examples included: *glasses, shoes, passport to visit family abroad, nail treatments, boots, metal detector, dietary & natural health supplements, radio, TV recorder box, driving lessons, basic home appliances, music stereo, bus ticket, food, TV, clothes, cycling gear.*

Developing social networks and meaningful activities

Some gaps in local support around social networks and meaningful activities

Some clients talked about their loneliness and wanting to find positive activities to structure their time and positive people to spend time with:

> *"I do have a couple of friends but... all my friends like, they always want something, they [GK] don't want anything, they don't want any money off you, they don't want... all my other friends have got mental health."* **GK CLIENT**

> *"I really feel like I haven't got no friends though… I can honestly say, I haven't got one friend… I tend to, like, be around people that, you know, are just out there and will always be there, and I can go there and they'll be there but then they'll always treat me like shit."* **GK CLIENT**

Feedback and discussion welcomed!

We welcome feedback on this discussion paper and would be pleased to hear about any discussions or questions that the paper stimulates.

Please contact the UWE Local Evaluation Team at: beth.isaac@uwe.ac.uk.