

5 Role and Impact of Lived Experience in Golden Key

Evaluation approach...

The purpose of this evaluation activity was to better understand how Golden Key (GK) has facilitated lived experience to shape the programme, and beyond GK to shape wider services. We aimed to capture GK's learning about developing the approach to lived experience involvement during the programme.

The nature and impact of lived experience involvement was explored by researchers' attendance at a range of GK meetings, and using existing local evaluation interview data collected between 2015-2021 (with experts by experience group members, GK staff and stakeholders). Finally, the evidence from interviews was triangulated with a desk-based review of programme documentation.

Learning...

The local evaluation activity identified multiple examples where lived experience shaped the design and delivery of the programme. From the earliest stages of the programme the lived experience voice shaped Golden Key strategy and vision, personnel, and client selection.

The Independent Futures (IF) group were the predominant voice of lived experience in the early stages of the programme, and particularly in relation to strategic design. We also found evidence of their influence on GK partners and delivery of the programme.

The influence of the IF group appears to have been increased by the provision of additional support, and the IF group were provided opportunities to feed in at a strategic level on the Partnership Board. However, dedicated workshops and consultation meetings were likely more effective channels for capturing lived experience expertise - particularly compared with the competing voices of a Partnership Board that increased in size over the course of the programme.

While we found evidence of the IF group's influence on operational aspects of the programme, it is less clear to what extent these directly influenced client outcomes. However, it is clear that the GK infrastructure evolved in ways which enabled lived experience insights to be shared and, on many occasions, assimilated into design and delivery.

5.1 How lived experience shaped GK's design and delivery

5.1.1 Lived experience involvement in funding bid development

From the earliest stages of Golden Key, lived experience was instrumental in several key areas of programme design and delivery. Experts by experience were involved in the formulation of the initial bid through the involvement of a Citizens with Experience Advisory group (CEAG), and this was commended by the Big Lottery as a key strength of the Bristol Fulfilling Lives project. In the early stages of the GK programme, we also found evidence of lived experience input being sought on strategic developments in multiple areas, primarily the business plan and GK vision.

In April 2013 several members of the CEAG re-branded as the 'Investing in Futures' (IF) group, which was then re-named as 'Independent Futures'. This group would go on to become the key formal source of lived experience for the remainder of Golden Key. Experts by experience were instrumental in the choice of name and branding of 'Golden Key', as the Partnership Board (the strategic multi-partner and stakeholder leadership board) began to develop, and the programme began to forge its own identity.

5.1.2 Lived experience involvement in GK's strategic leadership

We found evidence of IF group members' involvement with a range of workstreams and sub-groups, and attendance at a range of associated meetings, including:

- GK Partnership Board
- GK Creative Solutions Board
- GK Audit, Legacy and Sustainability Committee
- GK Equality Diversity and Inclusion Committee and workstream
- Housing First Board (merged to Audit, Legacy & Sustainability Committee in May 21)
- GK System Change Group
- GK Transition & Legacy Group (merged to Audit, Legacy & Sustainability Committee May 21)
- GK Evaluation Advisory Group
- Change for Good Steering Group
- Livelihood Programme Group
- Homelessness Prevention Board

"...we are getting our voices out there and they are listening and it is working"

Independent Futures group member

"I cannot say that I ever really felt like a token gesture 'service user group'... Independent Futures (IF) has always felt like an equal partner in this Golden Key project" ***Independent Futures group member***

The contribution of experts by experience was evident in the planning stages of the programme, and in the first year of the programme when key issues around decisions were being discussed, experts by experience frequently made up a substantial proportion of the Partnership Board. For the first three years of the programme, there was evidence of at least 2 (and often 3 or 4) experts by experience present at Partnership Board meetings. During an initial discussion of the Terms of Reference of the Partnership Board, the IF group were specifically invited to consider how the terms might reflect an evolving role for them and the lived experience voice.

Experts by experience were involved in the development of both the GK Business Plan and Vision document through their involvement in the Partnership Board. However, the IF Group were also explicitly

asked to contribute to these work streams through auditing the Business Plan and Vision documents for language accessibility. Similarly, we found evidence that the IF group had been involved in working with the GK partnership and Service Coordinator team to develop the client complaints handling process.

“I mean, obviously you know about us being on the commission board so we go to the commissioners meetings, to the Golden Key so I mean we’re really involved now and it’s really, it’s like at last we are there with them and it’s nice; it’s a really nice feeling.”

Independent Futures group member

There was evidence of consultation with the IF group within the contexts and meetings outlined above, but also evidence of specific consultation workshops with the IF group around particular strategic areas early in the programme. These additional and specific forum for input appeared to pay dividends in capturing the lived experience voice. An example of this was around the development of the Vision and Mission statement. Similarly, the Equality & Diversity Strategy and Action Plan where an additional dedicated workshop in collaboration with SARI (Stand Against Racist Incidents) was held. The IF group noted that there were several areas where their comments were incorporated to the Equality & Diversity Strategy – including the importance of monitoring impact for different groups. We found evidence that the IF group alerted the Partnership Board to the importance of monitoring outcomes for LGBT clients.

As GK developed, the Partnership Board ensured that feedback and updates from members of the IF group were included as a standing item. A further sign of the early commitment to the IF group from the Partnership Board was the inclusion of IF members to the required quoracy. There is evidence in the first 2-3 years of the programme, of questions being raised by the IF group and potentially shaping the programme. For example, an IF member asking whether representation on the Partnership Board for young people was needed. Although not taken forward, this query posed by the IF group was followed up for discussion and did give rise to a pilot piece of work looking at supporting young people.

It is important to note that we also found evidence of IF group requests for additions to key strategic documents being noted and actioned. An example of this was the IF group’s request to include reference to a zero tolerance for homelessness in the GK position statement. The Partnership Board was also responsive to the IF group’s request to limit the use of acronyms in documents. A less positive example was the request from the IF group that the GK programme and partners change their terminology from ‘service user’ to ‘client’. We found evidence that the Partnership Board acknowledged the potential issues with the term service user and began to use the term ‘client’, but the use of this term persisted in some forums.

5.1.3 Lived experience involvement in GK’s recruitment and procurement

Throughout the duration of the programme, we found evidence of experts by experience involvement in the development of several GK job descriptions. IF group members received training in staff recruitment and most members of the group were involved on staff interview panels during the programme. Their involvement was sought on appointments to positions related to the IF group, but also the secondments to the service coordinator team, and the appointment of the Independent Chair for the GK Partnership Board – as well as roles within GK partner organisations.

Lived experience was also evident in several of the procurement processes, including the development of the brief for communications and evaluation partners, peer mentoring and volunteer coordination. IF members reported that this involvement gave IF members an understanding of the process, but also a sense that their voice was important in decision making.

5.1.4 Lived experience involvement in GK's client selection

The IF group requested to be involved in client selection, and two experts by experience from the group sat on the referral selection panel. We found evidence that the IF group were particularly keen to ensure that diverse groups traditionally invisible to services were selected for GK support. It is not clear to what extent it was as a response to the lived experience voice pressing for this inclusivity, but the GK partnership did subsequently engage in identification of clients through assertive outreach with partners such as St Mungo's and Bristol Drug Project (BDP). Golden Key also worked in partnership with specialist agencies in Bristol, including Bristol Refugee Rights and Bristol Hospitality Network, to identify and start to tackle the blocks and barriers that asylum seekers with overlapping complexity face in Bristol.

The IF group were also keen to ensure that clients who they felt would gain most from GK's support would not be precluded due to an invisible need on one criterion. There were key discussions around the definition of clients and criteria for referral. For example, the IF group were evidently instrumental in flagging that clients with complex needs may appear to not meet the criteria of needs in at least 3 areas, but those with undiagnosed mental health conditions (or reticence to disclose due to stigmatisation), could then potentially be excluded. It is not clear to what extent this ultimately influenced the selection criteria, but we found evidence of the IF group concerns around this issue being discussed at the GK Partnership Board.

5.1.5 Lived experience involvement in GK's client support

We found evidence that IF group input developed into areas of innovation, including shaping the use of personal budgets for clients. We also found examples where lived experience perspectives were instrumental in guiding the development of initiatives. For example, IF group members' experiences of the repetition of their story, and its re-traumatizing effect, played a significant part in attempts to develop a central initiative (Tell Your Story Once).

*"Let's face it not many people can be, you know, talking about rape or domestic violence or things like that, or emotional abuse or anything like that, must be very hard to sit and tell someone once, let alone every service you go to for support." **Independent Futures group member***

Tell Your Story Once was first proposed in 2014, and although it experienced significant obstacles due to data sharing restrictions, the Partnership Board continued to persevere with it. This led to work developing a Trusted Assessment approach and to some extent tackles the issue which was raised by experts by experience.

*"I think the trusted assessment is so important because that's come from clients you know, that's come from the IF group and I think and the IF group is another thing that is a really good positive aspect of it." **GK Service Coordinator***

As the sections above illustrate, the views of experts by experience were sought and incorporated into the design and delivery of Golden Key in a range of ways. This included members of the Partnership Board meeting with clients. However, the lived experience voice provided was predominantly that of the IF group. The researchers found much less evidence of activities and structures to gain Golden Key clients' views until the latter stages of the programme. This was a potentially missed opportunity, and was reflected in interview comments from both IF and SCT members.

“I think that like we do better than some places but in other areas ... we’re like in the same situation as a lot of other organisations, it’s not really good enough I would say. In terms of client voice I think we need to work harder to get client voice involved because often we go to the Independent Futures and peer mentors which is really valuable voices to be included but we need clients as well because it’s a very different experience and its very different voice from someone who’s living something now.” **GK Service Coordinator**

GK developed a Peer Mentoring service, which was eagerly anticipated by the IF Group as a means of further incorporating the voice of lived experience into Service Coordinator-client relationships. Additionally, both the IF Group facilitator and SCT Managers were keen to broaden the client voice in GK’s work with clients to include transitioning GK clients into the IF Group. Unfortunately, this did not happen, and this was attributed to a failure on the part of an external contractor. Despite initial Peer Mentoring initiatives not providing the anticipated opportunities, in 2019 the successful Emergency Accommodation Team initiative (set up to house people who were homeless or at risk of homelessness during the Covid-19 pandemic) did include peer mentoring. We found very little evidence of client-peer mentoring, nor client-IF group interactions. That said, this was not for want of trying on the part of the GK Programme Team, and there were a number of other ways in which client-IF group interactions were facilitated. Furthermore, experts by experience did subsequently join the service coordinator team in paid roles.

The SCT worked hard to organise a ‘drop-in’ sessions for GK Clients, and a social Brunch Club where they could meet IF Group members and peer mentors from a South-West service provider, ‘Developing Health and Independence’ (DHI). Furthermore, we found evidence of more direct influence of the IF Group on operational processes when they began to work more closely with the Service Coordinator Team. Examples included input to client recruitment, and have also advice provided to the SCT on their consent processes. Both of which represent direct opportunities for lived experience to improve outcomes.

Finally, we found evidence that even if the lived experience of clients was not formally or directly sought, it may still have been heard. Interviews with Service Coordinators revealed that their work with clients served to inform the programme via feedback loops. The person-centred trust and understanding the Service Coordinators developed (as reflected in both SCT and client interviews) also provided them with insights which facilitated advocacy for their client (preparing their client and services for more effective engagement), but also contributed to reflective practice discussions and team meetings where the service could be influenced by the understandings developed by the SCT.

5.1.6 Lived experience involvement in the ‘Creative Solutions Board’

One mechanism by which the IF group members appear to have impacted GK client support is through their involvement with the Creative Solutions Board (CSB). Established in August 2019, the CSB consisted of key stakeholders and IF group members who may be able to:

- meet and discuss in detail, individuals where the current response is not working and creatively action/plan a different solution, with the person at the centre
- use this individual learning to inform how the whole system might need to change and flex to deliver better outcomes

In short, IF Group members sat on this group and provided lived experience insights into the strengths and weaknesses of services, and the interface between them. In turn this contributed to the Board’s understanding of client perceptions and experiences.

5.2 GK's support for lived experience involvement to shape other local services

We found evidence of the lived experience voice reaching across the GK partnership. IF group members delivered presentations to partners, served on their interview panels, and addressed the wider partnership at a range of events, e.g. delivering presentations to partners about co-production, and a key note at the GK Homelessness Call to Action event.

“When I talk to my team and other colleagues that commission mental health services, they're very aware of what's happening, they're certainly aware of the IF group and that work and they talk about it a lot.” **Service Manager, GK Partner**

The IF group were also active in promoting and supporting the work of GK partners, and advising on city-wide initiatives aimed at raising awareness of the issues confronting people with severe and multiple disadvantage. These included:

- Consultations with Avon and Somerset Police, providing advice on the issue of failures to turn up to court. IF group feedback contributed to a change in the way court summons letters are worded and designed.
- Advice provided to the Bristol Royal Infirmary support team steering group.
- Working closely with a range of GK partners on several homelessness initiatives, including 'Bristol Homelessness Week', St Mungo's 'Woolly Hat Day' and 'The Big Sleep Out'.
- Feeding in to the development of the Bristol Recovery Forum set up by Avon & Wiltshire Partnership NHS trust (AWP).
- Evaluating the lived experience involvement of tenders submitted to Bristol City Council by organisations wanting to provide residential rehabilitation services.
- Working with Bristol, North Somerset and South Gloucestershire (BNSSG) Clinical Commissioning Group (CCG) on their mental health strategy (2019), providing client insights, which led to the concept of My Team Around Me (a key element of the Changing Futures programme) evolving.

A feature emerging from our interviews with IF group members, and from various meeting minutes, was the aspiration for the group to ensure diversity in its membership. Specific requests were made for partners' support in recruiting women, people from ethnic minority groups, and particularly Eastern European experts by experience. There is evidence of partners suggesting groups that IF could connect with. The IF group created a presentation to give to various client populations, other organisations and staff groups with the aim of promoting the IF group and to encourage links and involvement. We found evidence of partners inviting the group to their organisations to give presentations.

We also found several references to the aim to forge links between the IF groups and various lived experience groups and fora affiliated to GK partners in order to disseminate GK's learning in service user involvement. This linkage is also referenced in relation to ensuring the lived experience voice from across the partnership that was captured by the IF group was diversified. It is not clear to what extent these links were made, and therefore whether the IF group input reflected the lived experience of its members, or a wider voice.

5.3 How lived experience involvement brought client stories to life for GK's partnership

"I've had um people get in touch from attending System Change Group about involving IF in their particular task or project. The IF group have been really helpful about reminding people that they are you know these are services for people and that the people that use them need to you know benefit from them and there needs to be positive feedback, but that's not really a new thing but just sort of (.....) flows and focus, so I think again what Golden Keys done is just raise some of the profile again of things." GK Service Coordinator

IF group members reported that they felt a key contribution they made in discussions and meetings with partners was to 'personalise' and 'humanise' the clients. In presentations to partners the IF group flagged the importance of seeing clients as individuals on individual journeys. Client experience was brought to life for the Partnership Board through the experiences of IF group members. From the start of GK, we found examples of IF group members being provided with opportunities for GK's partner services to be sensitised to the stories of individual clients through experts by experience. For example, there is evidence of IF group members providing insights from their own experience in Partnership Board meetings. IF group members also strongly advocated for the continued use of case study examples to illustrate blocks and barriers in the systems change work, and ensure that client stories were accessible to service providers. We found evidence that this translated into the use of case study presentations at Partnership Board meetings.

IF members interviewed clients and captured client stories and experiences which were then fed back into the Partnership Board. Furthermore, the IF group also launched an initiative to capture the stories of those in Bristol with lived experience of homelessness, mental health problems, offending behaviour and drug and alcohol addiction recovery. The IF group set up the initiative with a social media app ('audioBoom') with the aim of enabling more experts by experience to share their stories with the Partnership Board. It is unclear how this developed or where it was used by GK, however, there was also a collaborative art-based project with Creativity Works which captured client journeys visually.

5.3.1 Lived experience involvement supported GK's systems change activity understanding systemic blocks and barriers

IF group members provided useful insights into the challenges facing clients, and client perceptions of Golden Key. There is evidence of the IF group flagging geographical and transport challenges to partners and advising the Partnership Board on this issue. We found evidence that this prompted a review and discussion of how outreach should be approached.

The lived experience of the IF group helped highlight to partners that the legacy of previous service experiences may lead to clients' reticence and potential reluctance to engage about GK. We found evidence that the IF group specifically urged GK to engage in a public relations campaign to ensure clients understood exactly what GK was, and how GK was different to other services they may have encountered previously (e.g. a more long term approach). The IF group also flagged early that there was a risk of GK client status being seen as stigmatising. The Partnership Board responded with suggestion of recruiting 'Community Champions', and this included the suggestion that IF group members should be included as potential members. Although these posts were not pursued, the IF group were central to the formation and work of GK's Communications Panel, and the subsequent communications strategy that the panel developed.

The IF group were also involved in the review of GK client pathways and experiences. They actively sought out the opportunity to feed into the identification of challenges facing the GK clients at the earliest possible opportunity. This translated into contributions to the processing of blocks and barriers. Although this ultimately proved to produce an overwhelming amount of data, this group (with the help of an external consultant) were able to identify key areas for the partners to focus on to unlock client pathways (e.g. the need for 'Interagency communications' and further 'Staff training'). Experts by experience from the IF group played a key part in identifying, processing and making sense of these blocks and barriers.

5.3.2 Lived experience involvement helped to develop a more psychologically informed partnership

IF group members also played a key role in the work of the GK Psychologically Informed Environment (PIE) group. IF group members contributed to the GK PIE strategy, and were instrumental in encouraging the partners to continue to view clients and their recovery in person centred ways. This included ensuring that GK's partners retained a view of progress as relative to the individual client's needs, rather than aligned to external drivers or expectations of progress that are not linked to the individual client or realistic progress.

The IF Group also worked with the local evaluation team to develop a PIE audit tool and highlighted areas of best PIE practice in Bristol. This contribution identified opportunities for specific partners (e.g. AWP, 1625ip) to share their practice at a city-wide Golden Key 'PIE shop' event in 2017 to increase partners knowledge of PIE and celebrate best practice. This event also included members of the IF group leading a session presenting PIE from a lived experience perspective. Feedback demonstrated that this session served to provide a crucial perspective as to what PIE principles ought to look like in practice for the development of Bristol as a more PIE city.

5.3.3 Lived experience involvement beyond local services: Fulfilling Lives wider programme, national policy, and local evaluation

The voice of lived experience provided by the IF group was not limited to the GK programme in terms of its contribution. IF members presented at the National Expert Citizen's Group (Fulfilling Lives national lived experience group) and involvement in these events was seen as a significant opportunity for them to raise the profile of their work, and communicate the voice of lived experience. One of the IF group members was elected as Chair of the National Expert Citizen's Group during the programme, and conducted peer research with the national evaluator (CFE) on the role of lived experience in recruitment.

Early in the Fulfilling Lives programme, the National Expert Citizen's Group meetings provided contextual reference points that highlighted several strengths of the IF group and its work, including the diversity of their membership, and the extent of their involvement. However, toward the end of 2014 it also served to flag a comparative shortcoming. After a National Expert Citizen's Group event, IF noted that they felt they had not had the impact other lived experience groups across Fulfilling Lives had had. This coincided with the group stating to the Partnership Board that they felt they needed to adopt a more critical eye and create some distance between IF and Golden Key. IF members instigated a National Communications Strategy for BIG (Now National Lottery Community Fund) Fulfilling Lives projects regarding Women's homelessness and addiction, and also contributed to national campaigning and research work of the Revolving Doors agency. In March 2016 IF members attended a meeting with Home Office representatives and Public Health England to discuss the National Drug Strategy Review. IF group members provided input on their experiences of drug services and how they felt they could be improved.

As the programme developed, the IF Group began to receive independent commissioned work e.g. advising a charity on how better to include people with lived experience. IF group members also

contributed to two collaborative peer research with GK clients in 2016 and 2021, conducted by the local evaluators.

5.4 GK's learning: Developing GK's approach to lived experience involvement

"I think the IF group is the other thing that I would highlight really that um that's gone through different kind of phases and um and I think, I just think it's been, I've been really you know I've been really impressed with um the way they've, the group has been sort of encouraged to be involved at different times." Service Manager, GK Partner

5.4.1 Improved support for experts by experience within GK

The Partnership Board regularly acknowledged the contribution of the IF group, and IF members were very keen to share their own experiences and also celebrate how far they progressed. IF members worked closely with a charity ([Creativity Works](#)) on their business plan, and their work with an artist to communicate their stories more creatively was heralded a success. The IF group felt that this was a very important part of ensuring their stories and the lived experience voice were heard (e.g. on the event 'Vision Day'). The programme went on to explore ways in which this could be further embraced through seeking support from a collaborative storyteller through a bid to 'Awards for All'; and funding was also sought to support lived experience stories through arts-based methods, but the bids were not successful.

We found significant evidence that the GK Programme Team and Partnership Board were committed to providing support for the IF group. Second Step sought extra funding to support training for the group, and there were several offers of support from partner representatives on the Partnership Board to help prepare for Partnership Board meetings. However, the initial model of support which involved the deployment of an independent agency to support IF was piloted but was not successful. In late 2016 IF group members raised concerns that they felt there was a reduction in support available, and that the IF group coordinator role had been scaled back. In response to these concerns raised by the IF group, and their persistent concerns around the perceived distance between themselves and clients, the GK Partnership Board actioned a number of significant changes. In late 2016 two IF group members began shadowing roles within the GK team, one with operational focus working with the Service Coordinator Team, and the other on strategic and system change work. Furthermore, GK staff began working alongside IF Café Connect, and a dedicated staff member was identified with the role of strengthening day to day communications. Closer relationships being developed with the Service Coordinator Team, and staff within GK, appears to have signalled a positive change in how the IF group perceived both their support – and in turn more effective ways of working.

There was also evidence that the Partnership Board responded to interim conclusions from the local evaluation team. Through the duration of the programme, important learning took place in terms of how best to support experts by experience. Several key challenges emerged for the IF group, including managing the responsibility they felt for representing the wider client voice, and safeguarding and supporting experts by experience who are themselves on a recovery journey. We found evidence that staff from the lead agency engaged with a range of recommendations from the research, and began to develop a GK Client Voice and Co-Production strategy in 2017.

5.5 Changes to lived experience Partnership Board contributions

As the Partnership Board membership increased and attendance improved, the Board minutes indicate an apparent reduction of input from the IF group. While the IF group often made up almost half of the Partnership Board in 2013 and 2014, and there were regular references to IF member input and comment in the minutes, this reduced significantly in the latter stages of the project. There was also less evidence of the specific consultation workshops that appeared to prove useful in eliciting lived experience voice in the earlier stages of the programme. It may be that this is related to our finding that in mid-2015 a member of the IF group specifically requested that the GK Independent Chair explicitly elicit responses from IF group more often at the Partnership Board. We also found that as the Partnership Board increased in size, IF members reported they needed further support to represent their views at the Board. It is important to note that there is also evidence of the Board recognising this.

Partners explicitly acknowledged challenges to retaining lived experience voice, including the potential for: i) the power differential to become increased, and ii) the pace with which the programme was developing to become overwhelming. We found evidence of partners offering to assist in helping IF members prepare for Board meetings, and inviting IF members to suggest any further training they may need. Shortly after this invitation, we noted that IF members attended training provided by MEAM ([Making Every Adult Matter](#)) and Systems Change provided by the National Lottery. However, it appears that as the Partnership Board grew, there was a reduction in the perceived potential for experts by experience to feed in to, and have an impact on, the business of the Partnership Board. There also appears to have been a gradual decline in dedicated lived experience consultation workshops in the latter stages of the project. Both of which indicate the potential for reduced IF group impact over time. That said, it is important to note that it was the Partnership Board that highlighted these concerns, rather than the IF Group – and the Board retained IF Group consultation on the agenda of meetings throughout the project. Also, there are a range of potential explanations for this, including the changing membership of the IF Group as members developed skills and gained employment or entered further study. The successes and progression of IF members created a fluidity to the group, and resulted in changes in the IF Group representatives on the Programme Board (which can influence agency as new members develop an understanding of their role).