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Learning from collective lived experience: a case study of an experts by experience group

Chris Pawson, Richard Bolden, Beth Isaac, Joseph Fisher, Hannah Mahoney and Sandeep Saprai

Abstract

Purpose – *The purpose of this paper is to present a case study tracking the development and engagement of a group of experts by experience (The Independent Futures (IF) Group) who provided a lived experience voice to the Bristol Golden Key (GK) partnership within the Fulfilling Lives programme. The case study reports the genesis and impact of the group, as well as the facilitators of impact and experiences of the group members and those they worked in partnership with.*

Design/methodology/approach – *The research adopted an iterative approach drawing on multiple data sources over an eight-year period. An inductive ethnographic analysis of stakeholder and partnership meetings was combined with documentary analysis and thematic analysis of interviews with experts by experience and service providers.*

Findings – *The voice of lived experience provided by the IF group contributed to the GK partnership through various channels. Evidence of this contribution and its impact was found at programme, city-wide and national levels of the service ecosystem. Furthermore, IF members recognised the value of the group in contributing to systems change and service improvement, but also for themselves.*

Practical implications – *This case study serves to illustrate the impact of the lived experience voice on services and systems change, specifically the provision of that voice from a formalised advisory group. The successes and challenges of the group and the experiences of its members are reported with a view to sharing learning that may influence future co-production initiatives with experts by experience and service provision for those experiencing multiple disadvantage.*

Originality/value – *The insights provided by the longitudinal observation of the group as it was formed and evolved, coupled with insights provided by the experts by experience, have important implications for facilitating and supporting sustainable lived experience input.*

Keywords *Lived experience, Multiple disadvantage, Multiple exclusion, System change, Co-production, Fulfilling lives*

Paper type *Case study*

Introduction

Golden Key (GK) was one of the 12 local partnerships within the Fulfilling Lives programme funded by the National Lottery Community Fund ([National Lottery Community Fund, 2021](#)). The partnership aimed to bring together and empower statutory services, commissioners, voluntary sector organisations and the local community to improve services for people facing severe and multiple disadvantage in Bristol. More specifically, it sought to facilitate improvement through lasting system change for those repeatedly cycling through homelessness, drug and alcohol, mental health and criminal justice services.

A key component of the GK partnership and its approach to improving services and system change was the involvement of people with personal experience of multiple disadvantage.

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People with lived experience of disadvantage and services are widely deployed in the health and social care sector within education (Cooke *et al.*, 2015), personnel recruitment and service scrutiny (Scourfield, 2010) and research (Ennis and Wykes, 2013). The value of the insights provided by these “experts by experience” (Preston-Shoot, 2007) is widely acknowledged, and from its inception, GK sought to capture these insights and incorporate “a sustainable, authentic client voice” into the development of the partnership and its services (Second Step, 2013).

The approach whereby the lived experience voice was assimilated into GK was closely aligned to models of co-production (Brandsen and Honingh, 2015; Needham and Carr, 2009, 2013). More specifically, those with lived experience (as clients of relevant services) were incorporated into partnership with the service providers to work alongside them in the design and implementation of services while also simultaneously sensitising the services to their experience. The specific vehicle developed by GK to facilitate this was the formation of an experts by experience advisory group – “Independent Futures (IF) Group”. This approach aimed to challenge some of the constraints on lived experience influence, which are often limited to consultation, and have led to accusations of tokenism (Daya *et al.*, 2020).

The purpose of the research reported herein was, therefore, to explore and document the contribution of the IF group and the experiences of its members. Where significant contributions were evident, it sought to understand the dynamics of the group and its partnerships that facilitated these contributions. Specifically, it asked what factors might enable the audibility and impact of the voice of lived experience within the partnership, as well as identifying any associated challenges. By engaging in the ethnographic study of the group, the research aimed to extend the impact of the group by spotlighting their contribution to GK, and wider systems change. However, by doing this, it also sought to elucidate the underlying dynamics of their contribution because of their implications for future programmes and initiatives seeking to maximise the impact of lived experience.

This case study provides insights into the assimilation of the lived experience voice through documenting the process of forming and building a partnership between services and experts by experience. It draws on perspectives from those both within the group, as well as those service providers working alongside them, and includes observations from an independent evaluation team working with the partnership longitudinally over eight years. The paper provides insights into the processes of group formation and engagement of the group by the partnership in its infancy. How these processes facilitated the provision of audible lived experience voices and their contribution to the wider partnership are illustrated through a range of examples. Finally, interviews with service provider stakeholders and experts by experience revealed the significant value of partnership with a lived experience advisory group for service development and system change, but also for the experts by experience themselves. The implications of this, and reflections on the challenges and solutions of this partnership, are discussed with a view to sharing learning for future projects and systems change for people experiencing multiple disadvantage.

Methodology

Insights into the genesis, contribution and experiences of the IF Group were gained through the deployment of an inductive ethnographic approach (Hammersley and Atkinson, 2007). Researchers sought to develop an embedded “researcher in residence” relationship with the IF Group (Marshall *et al.*, 2014; Vindrola-Padros *et al.*, 2018) and attended IF Group meetings, and accompanied members as they represented the group in meetings with the wider GK partnership. In keeping with the ethos of GK and the IF Group, researchers explicitly signalled to the IF Group that they viewed themselves in a collaborative role, adopting a co-production approach.

At the beginning of the research project, researchers requested that they be granted access to all formal meetings, and this was granted. However, it is important to note that researchers did remind IF members that if they wished to discuss anything privately, the researchers would not attend or would leave the meeting. Researchers were never asked not to attend.

The embedded researchers (one non-White female and one White male) remained the same throughout the research. They attended external meetings with group members individually, but both researchers attended IF Group meetings together on several occasions. Both researchers also reviewed associated documents, which facilitated an emic perspective on the partnership (Fetterman, 2010). The documentary analysis drew on an ethnographic content analysis approach (Altheide, 1987) which explored meeting minutes and policy documents and then sought to verify outcomes through triangulation with documents from subsequent meetings or the accounts of IF group members. Ethnographic data collection provided insights into the genesis and organisational structure of IF (see section “The genesis and organisational structure of independent futures” below) and revealed a wide range of ways in which the lived experience voice had been both provided and heard. These are presented below with illustrative examples of how the group contributed at local programmatic, city-wide and national levels (section “The influence of the IF group and lived experience voice”).

Given the length of the GK programme, and the frequent attendance of the researchers at meetings, the nature of the relationship between researchers and the group inevitably evolved. The social distance was observed to change significantly over time, and although the researchers remained silent observers during the formal discussions of meetings, data was also collected outside of the formal business of meetings as researchers travelled together with IF members to various meetings.

In addition, insights from IF Group members ($n = 8$) and GK staff ($n = 12$) were captured through one-to-one semi-structured interviews. GK staff interviewees included the GK project manager, members of the GK service delivery team and the project psychologist. Interviews ($n = 8$) were also conducted with GK partners (i.e. service providers working with GK clients and the IF Group). These included three senior managers and five client-facing support workers. All interviews were conducted by the same male and female researcher described above, and these interviews were audio recorded and transcribed for analysis. Interviews ranged in length from 24 min to 87 min with a mean length of 54 min and were analysed using thematic analysis (Braun and Clarke, 2006). The IF Group, GK staff and partner interviews were all analysed separately by the stakeholder group, and initial themes were identified. IF Group interviewees were then invited to return to one of two follow-up focus groups to explore and sense-check themes identified by researchers. The focus groups both consisted of three IF Group members and served to explore participants’ responses to initial interpretations of the data and allow for further elucidation of central organising concepts and sub-themes. We began the focus group by explaining the process of analysis and presenting the initial themes to participants. These were illustrated with quotes, but the themes were deliberately not named. This approach aimed to enable a co-production of the themes but also a check with the participants as to whether the themes felt coherent and whether our interpretation of quotes was the same as theirs; through this process, participants were empowered to critically discuss the research, extending their role to an integral part of the analysis. Also, this method ensured the interpretations reported below reflected participants’ experiences and perspectives more accurately.

The themes identified by the thematic analysis were triangulated, and several were then iteratively amended in light of IF group feedback or the identification of opportunities to synthesise sub-themes from across different stakeholder clusters. The most salient are reported below (section “The lived experience of the lived experience group”) with a view to providing insights into the experience of the IF Group. These themes are presented because the authors and our IF group co-researchers believe they provide important critical

insights for understanding how the IF Group contributed to GK and what can be learned for future projects engaging with experts by experience.

Ethical approval was sought and granted from a University ethics committee. The ethics application followed the guidance of the British Psychological Society Code of Human Research Ethics (BPS, 2014).

Analysis and discussion

The genesis and organisational structure of independent futures

You're giving an opportunity to people that have considered themselves down and out and going nowhere their entire lives to change the world. (Dan, IF member)

The voice of lived experience was evident in the infancy of the GK project. The bid to the National Lottery Community Fund included experts by experience from Bristol, and particularly a local client voice organisation (Bristol Reconnect), who would later be commissioned to facilitate the development and coordination of the IF Group.

In its first incarnation, at the launch of GK, the group was known as the Citizens with Experience Advisory (CEAG) group. In April 2013 it was subsequently renamed, in consultation with members, the 'Investing in Futures group' (which would later become the IF Group). Recruitment to the group was facilitated by Bristol Reconnect, who, in the initial stages of the project, sought to recruit members with lived experience of multiple disadvantage from their existing client group. The initial members of the group had lived experiences of homelessness, mental health services and drug or alcohol use. However, there was no stipulation as to the duration or currency of engagement. The group continued to recruit members throughout the course of the project and specifically sought to diversify membership through recruitment drives to ensure they continued to be representative of the GK client group.

In early meetings, the IF group developed its identity and mission statement, which were as follows:

Who we are: we are an independent group of individuals who have experience with a variety of complex needs.

What we do: we work with service providers to develop and implement improved services for people with complex needs in Bristol. This includes:

- helping to monitor the quality of services;
- offering advice, guidance and training to services; and
- being positive role models, showing that change is possible.

Over the eight-year duration of GK the membership of the IF Group has changed significantly. Over that time, the group reflected on their membership and developed a recruitment approach that enabled them to better engage a wider and more diverse group of members with experience of multiple disadvantage. At different points, the IF Group raised concerns that their membership did not reflect the diversity of the lived experience voice. Indeed, at times they also questioned whether the group was only attracting potential members who were significantly well advanced in their recovery journey. We also found this sentiment reflected in the GK service delivery team interviews:

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 Delivery Team Member).

In response to this, the IF group approach was the creation and dissemination of a presentation for service providers to give to their own in-house lived experience groups –

but also to client populations. The IF group achieved some success adopting this strategy and were actively able to recruit from specific populations they felt were under-represented at different points e.g. women and people from minority ethnic groups (particularly Eastern European experts by experience). The group also worked with stakeholders across the partnership to develop their own in-house training for newly recruited members.

In the early stages of the GK project, the IF group developed its governance structure and guidelines for group meetings, which were held every two weeks on premises provided by Bristol Reconnect. The group elected a Chairperson and Vice Chairperson to chair meetings, and over the first two years, the group identified specific roles aligned with tasks and the need for lived experience representation in the sub-groups of the wider partnership. Members of the IF group were assigned to the overall GK Partnership Board, as well as sub-groups focused on system change and psychologically informed environments (PIE). They were delegated specific roles within the group (e.g. communication and social media). In the latter stages of the programme, these roles became increasingly specified, including IF Group members focused on peer support, consultancy and research. This specificity enabled the group to capitalise on the strengths of members and addressed a concern of GK staff around the high workload and diverse demands made of the IF Group members.

It is perhaps salient that a key functional shift for the group was reported by IF Group members, GK staff and local evaluators during the project. In Year 4 of the project, the group facilitator (provided by GK) became co-located in office space with the GK operational team. This was partly driven by a change in the facilitation contract and partly in response to IF Group members feedback that they wanted to be more closely linked to the operational team. This co-location also moved IF Group members closer to the service delivery team and is widely recognised as increasing contact time and fostering improved relationships. GK staff report that this was influential in enabling contemporaneous consultation with experts by experience but also enabled project managers to be more responsive to any changing dynamics or concerns raised. Despite this shift being widely reported as beneficial by the service delivery team and IF Group, some members of the IF Group did question the extent to which this compromised the ability of the group to remain independent and represent the voice of lived experience. The research team invited the IF Group interviewees to reflect on how this had ultimately impacted their role, and they reported that while they felt confident the group retained its ability to represent the lived experience voice, concerns persisted that perceived lack of critical distance may well have challenged the IF Group's legitimacy in the eyes of some of the wider client community.

The influence of the IF group and lived experience voice

IF Group members are represented on all GK forums and report a genuine sense of equity and influence. (Isaac *et al.*, 2017)

As the IF Group evolved and developed, so too did its contribution to the project. The lived experience voice provided by the group served the GK partnership at a strategic programme level but also increasingly proved influential within the work of individual partners (including recommissioning of services). Ethnographic data collection and analysis of project documents and minutes from partnership meetings revealed contributions to a range of programme-, city-wide and even national activities. This also included offers of external funding to commission the IF Group for additional projects and initiatives. The contributions to policy and practice at these various levels are illustrated with examples below.

Influencing programmatic strategic direction

Our job is to point out why services need to connect to each other, give examples of that and hopefully show how that's benefitting people once it starts happening within golden key. (Dan, IF member)

IF Group members' voices and lived experience was instrumental in the development of the aims and vision of GK, and group members acted as consultants on the business plan. They were also influential across the partnership in tendering and commissioning processes for GK partners. For example, the IF Group was invited to evaluate tenders submitted to Bristol City Council by organisations wanting to provide residential rehabilitation services. They were particularly influential in critically evaluating how bidders intended to engage with experts by experience, and therefore, contributed to ensuring that those commissioned to provide rehabilitation services in Bristol understood the importance of, and were equipped to listen to, the lived experience voice.

The IF Group's contribution to GK also included the co-production of specific strategies and initiatives for the programme, including the GK Equalities Strategy. In terms of practice and procedure within the GK programme, the IF group also co-produced best practice guidance for the involvement of experts with experience in recruitment; and informed a number of specific initiatives related to the client journey.

Influencing the GK client pathway. The IF Group was influential in the recruitment of clients in a number of ways, including making referrals themselves and signposting GK staff to potential clients. IF members also sat on the client panels where referrals of potential clients were reviewed for eligibility for GK support. Indeed, through their involvement in these panels IF Group members were influential in flagging concerns about how harder-to-reach clients might be identified. Their input and critical insights were central to discussions around several operational matters, including inclusion criteria and the ways in which the GK client-facing team (Service Coordinators) approached and gained consent from potential clients. IF Group members increasingly worked closely with the Service Coordinator team over the course of the programme. This included the development of jointly hosted events with clients and roles for members of the IF Group to shadow Service Coordinators. At times during the project, there were GK staff dedicated to a specific GK-IF Group liaison role to assist with administrative tasks and link IF Group members with specific consultancy and lived experience input opportunities. When these liaison roles were first funded by GK, the IF Group contributed to the role specifications and selection processes.

The IF Group's insights into the strengths and weaknesses of services, the interface between service providers and pathways, and the challenges of navigating them proved particularly beneficial in the development of a number of GK initiatives. This is illustrated in the IF Group contribution to GK's "Creative Solutions Board" which was set up in response to clients where the current service provision was not working, and a different approach was required. IF members were involved in the case referral process to the Creative Solutions Board and were able to offer hypotheses as to why the existing solutions were not proving beneficial for the client.

IF group members were also pivotal in the emergence of an initiative to improve the assessment process for clients in homelessness pathways. An analysis of the process of the assessment revealed clients were being asked up to 550 questions by housing providers during the assessment. Given the commonalities in assessment across agencies, but also the potential re-traumatising effect of clients repeatedly being asked to tell their story, IF Group members were instrumental in driving forward a unified assessment process that could be shared across services, whereby clients could limit the re-telling of their story. This provided the foundations of the "trusted assessment" approach, which was to become central to GK's client pathway.

As a member of IF, I was asked to sit on all aspects of the planning, creation and development of the Trusted Assessment approach, to give my lived experience. The importance of not repeating your trauma was essential for me; for others it is the importance of being listened to by services. It was also important for us to ensure organisations worked together – no more silos of working.
(Sam, IF member)

Lets 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. (Sam, IF member)

City-wide influence. IF were also active in raising awareness and promoting the work of GK and its other partners. This included the promotion of city-wide initiatives that raised awareness of the issues confronting GK clients (e.g. St Mungo's Woolly Hat day and The Big Sleep Out). As their input to GK policy and practice and contributions to the Partnership Board increased, so too did their prominence in the wider city. The IF Group was increasingly asked to contribute to homelessness events and initiatives in partnership with statutory services and attended a range of City Office meetings and events with Bristol's Mayor. Significant contributions included highlighting the inadequacy of one-size-fits-all solutions, advocating the "human touch", acknowledging client diversity and highlighting the importance of services that strive to raise public awareness of multiple disadvantage and stigma:

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)

IF Group reach across the city was also illustrated by IF members' role in the work of the GK PIE group. IF Group members worked with stakeholders and practitioners across Bristol from multiple services to encourage the development of Bristol as a more psychologically informed city. This included taking on an advisory role with Bristol Royal Infirmary on the support of homeless patients and their contribution to the development of the Bristol Recovery Forum set up by Avon & Wiltshire Partnership NHS Trust. IF members also contributed to two consultations with Avon and Somerset Police, providing advice on the issue of failures to turn up to court. Their feedback helped to improve attendance at court by shaping the way court summons letters were worded and designed:

I've had um people get in touch from XXXX 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 Delivery Team Member)

Influence beyond Bristol. The IF Group's provision of lived experience benefitted the GK partnership and the city but was also deployed beyond Bristol. IF group members represented GK at a number of national events, including the national Fulfilling Lives conference in 2015. IF Group members also attended National Expert Citizens Group (NECG) meetings in Stoke-on-Trent, Liverpool and Birmingham and hosted a Bristol meeting where lived experience groups from across the broader Fulfilling Lives projects shared ideas and considered ways to unify the voice of lived experience. One of the IF Group was subsequently nominated to chair the NECG.

IF Group members have also taken on active and prominent roles in national research, including contributing to the peer research for the Big Lottery National evaluation partner (CFE Research) and the national campaigning and research work of the Revolving Doors Agency. There are also several examples of the IF Group contributing to meetings and helping to amplify the lived experience voice to reach national policymakers and government. This included IF Group members meeting Home Office representatives and Public Health England to discuss the National Drug Strategy Review published in 2016. Members provided input on their experiences of drug services and how they felt they could be improved. Another IF Group member attended Westminster to provide insights into her experience at a seminar entitled: "Next Steps for Tackling Homelessness". The same IF member was then invited to the All Parliamentary Party Group on Domestic Violence, where

women with lived experience of domestic violence were able to speak about their experiences.

Being able to literally sit with politicians on a normal level, in the same room, is something that does not happen every day. It made me feel so empowered. By enabling politicians to listen to us and understand us, we can hopefully influence change. (Syeda, IF member)

The lived experience of the lived experience group

The considerable achievements of IF were reflected in the interviews with group members, who reported a sense of ownership of the programme and significant pride in their contribution. For most members, participation in IF strengthened their belief in the value of providing the voice of lived experience, which was also reflected in consistently high attendance at key meetings. Interviews revealed a strong sense of shared purpose and confidence in the role the IF Group played in the partnership.

[. . .] overall there is so much good will from the group members and the desire to see it succeed, and Golden Key succeed and change the world. (Ash, IF member)

Although the aims of the overall programme clearly resonated with members of the IF Group, their individual motivations and perception of their roles often proved diverse. Some members reported their key motivation to be capturing the client's voice and advocating for them to ensure they were heard by services.

We need to get their stories, find out what their experiences are and forward that through the partnership to the service providers. (Paddy, IF member)

Others saw their own lived experience as more valuable at strategic levels of the partnership. For them, the lived experience voice served as a reminder to services of what the rationale was for a more joined-up approach to service provision. This often also included references to a monitoring or scrutineering role, ensuring the partnership were "held to account" and were "keeping it real".

We have to get them to see how beneficial it is for them to work together for service users. (Dan, IF member)

Interviews with service provider partners and IF members in the early stages of the programme revealed a potential mismatch between their perceptions of the role of the IF Group. This mismatch is potentially salient given that, at times, IF members reported feeling that when they were vocal in expressing concerns about the programme, this was not well received. It is possible that some friction experienced in communication between IF and other areas of the partnership may well have been catalysed by a mismatch in expectations about role. However, despite these occasional tensions, the group and wider partnership worked very effectively to resolve any issues and concerns. Indeed, a number of group members noted the distinction between the work they did for IF and GK and their previous less positive experiences of expert citizen or people participation activities. Many IF members reported having previously felt as if they were being deployed in a tokenistic fashion, as if they were only there to "tick a box", or because they met a particular demographic criterion. However, this is not something experienced working with GK, where many participants report a generally more positive experience and a feeling of being "really listened to":

[. . .] we are getting our voices out there and they are listening and it is working. (Ash, IF 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. (Paddy, IF member)

A noteworthy theme emerging from the interviews with IF Group members was the personal development that members reported through their involvement with the group. Feelings of positivity about the influence of group membership were prevalent in the discourse of members, and the group is credited with having a strong developmental impact on its members. This is reflected in the following quotes from IF members:

From the beginning, I always knew I wanted to capitalise on this [IF]. I kept coming and over time whether I was up or down I've been building the skills I've needed to do that. (Nancy, IF member)

[...] the experience of being involved in the group is giving me everything I need [...] I get a lot of self-worth out of doing something meaningful (Dan, IF member).

you're giving an opportunity to people that have considered themselves down and outs and going nowhere their entire lives to change the world (Ash, IF member).

It was also interesting to note the importance that members ascribed to the group in terms of their own continued recovery. Indeed, one IF Group member pointed out that the recovery rate for IF Group members was higher than those involved in mainstream services. Many members attributed this to the strong social support offered to one another through membership of the group. However, the strong social bonds and shared experiences were also occasionally a source of distress and perceived risk to members. Not everyone experienced the same uninterrupted progress and recovery journey while serving on the IF Group. Inevitably group members were at varying points on their individual recovery journeys, which meant that some members were in a more vulnerable position with regards to their needs than others:

Because in the group you've got so many people in different stages of development... there's a lot of issues going on. Peoples got mental health, peoples got addiction, peoples, you know and I find it quite hard work sometimes. (Dan, IF member)

At times, the vulnerabilities of other group members were experienced as negative and a potential risk to others' wellbeing. Specifically, the ongoing addiction issues or relapse risk of some members are experienced as a threat to their own recovery:

People forget just how supportive IF Group members are to IF Group members. But yet we see this all the time. We start worrying about them and then we see them start to decline and suddenly they've disappeared. (Syeda, IF member)

Some are very supportive of others, but some are quite damaging for others [...] and that is a problem you have when someone's issues are playing up, it can have a very negative effect on other people in the group. (Paddy, IF Member)

A second related issue pertains to the work that IF Group members undertook with clients. Analysis of interviews revealed how highly motivated IF Group members were to share their experiences of recovery for the benefit of others. A strong sense of pride emerges in the discourse surrounding their own recovery and the potential for it to signal to others that "the next chapter is possible". However, a number of IF Group members reflected that those participants they worked with in peer mentoring, or interviewed as part of research projects, maybe only "just behind them on their recovery journey", and that this can be a testing experience. More specifically, IF Group members reported that talking to clients who are struggling and with whom they identify impacts on them emotionally:

We went out to get their stories [...] it was really hard. (Syeda, IF member)

We were so intent on thinking about the client [...] we didn't have any emotional support... we weren't supported. (Dan, IF member)

GK staff were very effective in responding to this concern. The co-location of IF Group work to the offices of the operational team provided opportunities for project managers to monitor

this. However, it also provided access to the reflective practice culture of the Service Coordinator team and the psychologist working with GK.

The final theme identified from attending meetings and analysis of interviews pertains to the intra-group dynamics and their implications for the sustainability of advisory groups such as IF. The overwhelming sense of the intra-group dynamic over the duration of the programme was one of cohesion and effective functioning. Despite staff turnover and changes in membership that are to be expected over an eight-year project, the IF Group did not experience some of the issues of inconsistent engagement to the extent that expert citizen groups from elsewhere in the Fulfilling Lives projects have reported. However, that is not to suggest there was a complete absence of tensions within the group. There were differences of opinion around the direction of the group with resulting observed discord at times. Some members reported that this impacted on the climate of the group during some meetings. However, the co-location of work and facilitation of the group by GK staff have been very effective in addressing this, and it is important to note that tensions have been rare and overshadowed by a strong and supportive collective identity:

[...] we are a family and when you don't have that family around you, you struggle more. Um, people forget just how supportive group members are. (Ash, IF Member)

They got to know me and my story they wrapped themselves around me. IF Group is like a family, it's a support network for people within the IF Group. (Nancy, IF Member)

It is noteworthy that the collective identity was also reflected in a strong democratic and egalitarian ethos within the IF Group. Decisions within the group were voted on, and *all* members were encouraged to get involved. However, it seems that this occasionally made the group less easy to liaise with as partners. The typical role-delegated structures and processes of most organisations (and indeed most GK partners) encouraged distributed roles and decision-making, and at times there was evidence that partners sought to engage the IF Group in the same manner. This was manifested in some GK partners understandably seeking to engage with particular individual IF Group members around specific activities and in an informal fashion. However, this was at odds with the strong collective identity and democratic approach to group activity and decision-making that the IF Group prized. At times this caused discomfort for some group members who did not feel that they wanted to speak on behalf of the group.

Conclusion

In summary, the data available from GK documentation and attendance at IF group and partnership meetings revealed a wide range of contributions – some of which appear likely to have been specifically facilitated by the formation of an experts by experience group. The creation of the group, and the engagement of its members, enabled the value of their expertise to reach well beyond the GK project. Contributions to city-wide initiatives and engagement with parliament far exceeded the original aims and mission statement of the group. It seems likely that the creation of a lived experience group who were assimilated into the partnership and readily accessible (rather than engaging individual experts by experience at different stages or for specific decisions) may have provided opportunities for this extended reach. Indeed, this was arguably evidenced by the range of offers they received and the commissioning of IF by other partners.

Subjective benefits of expert by experience work and co-production are reported in previous literature. For example, engagement in lived experience consultancy and co-production is associated with increases in self-esteem, self-efficacy, self-determination, self-control and gaining practical life and employment skills (Cahn and Gray 2005, Marks 2008, Slay and Stephens 2013). While interviews with IF members did reveal satisfaction in the role of sharing lived experience, individual gains reported were less likely to be

attributed to providing their individual voice and more to the shared collective identity and being a member of the group. An interesting opportunity afforded by the creation of a group was the peer support function offered to IF members. This again reflects the value of the embedded experts by experience group approach over the alternative and frequently deployed model of individual consultants offering a lived experience voice to projects (or parts of projects).

It is important to note that while there were benefits of the group, it also created some challenges for members. Where individual members experienced difficulties in their recovery journey (e.g. returning to drug and alcohol use), this had the potential to jeopardise other members' progress. Where an individual expert by experience may ordinarily be able to distance themselves from cues and triggers that may set them back, the group dynamic may pose unique risks. Group membership and the potential for members to feel compelled to remain working for the good of the group pose a potential risk to the health and wellbeing of individual group members and the sustainability of the group when other colleagues' behaviours might provide a risk to individual recovery. That said, there was also evidence of group members providing important support and solidarity for each other during times of relapse and that group membership afforded support for recovery.

The collective unity forged by the group, which provided support for members, also occasionally proved challenging for partners. The democratic ethos and preference for horizontal leadership that characterised the group were often not aligned with the preferred ways of working and culture of partner organisations. Specifically, where individuals in authority within the service provider organisations were empowered to speak on behalf of others in their team, this was not a cultural practice the IF members adopted. Indeed, the IF members preferred to always discuss and agree on a collective view, rejecting the idea that anyone member should speak on the group's behalf. Indeed, they frequently voiced concerns that partners were seeking a "lived experience voice" from one person rather than making use of the potential diversity of experiences and opinions residing within the collective. This is an important consideration for future projects engaging experts by experience groups, which is that there is a potential need for organisations to learn and challenge their own practices rather than impose their expectations and culture on experts by experience.

A final observation revealed by attendance at meetings, and particularly interviews, was that the increasing co-location of IF members within GK, and the facilitation of the group by GK project staff, was identified as key facilitator of effective IF Group work. Despite concerns that this could potentially compromise the independence of the lived experience voice, the overall assessment of IF members was that the benefits outweighed any potential costs of compromise. Future projects should carefully consider the important responsibility of safeguarding experts by experience who may be undertaking potentially demanding work and offer opportunities for reflective practice and psychological support. One way this was achieved within GK was to bring IF further "in house".

In conclusion, the IF Group provided a valuable and highly effective lived experience voice for the GK project. Their expertise was harnessed for a benefit at multiple levels and contributed to initiatives with significant potential for lasting system change. Several of their contributions, and their value to the GK partnership, were facilitated by negotiating the sometimes challenging need to strike a balance between close partnership working and independence. Future projects seeking to incorporate the lived experience voice to their work, particularly for severe and multiple disadvantaged clients, are likely to reap benefits from the formation of experts by experience groups and considering the IF Group achievements and experiences outlined above.

References

- Altheide, D.L. (1987), "Reflections: ethnographic content analysis", *Qualitative Sociology*, Vol. 10 No. 1, pp. 65-77.
- Brandsen, T. and Honingh, M. (2015), "Distinguishing different types of co-production: a conceptual analysis based on the classical definitions", *Public Administration Review*, Vol. 6 No. 3, pp. 426-435.
- Braun, V. and Clarke, V. (2006), "Using thematic analysis in psychology", *Qualitative Research in Psychology*, Vol. 3 No. 2, pp. 77-101.
- British Psychological Society (2014), "Code of human research ethics", available at: www.bps.org.uk/news-and-policy/bps-code-human-research-ethics-2ndedition-2014
- Cahn, E.S. and Gray, C. (2005), "Using the coproduction principle: no more throwaway kids", *New Directions for Youth Development*, Vol. 106, pp. 27-37.
- Cooke, S., Daiches, A. and Hickey, E. (2015), "Narratives of experts by experience: the impact of delivering training in partnership on the subject of personality disorder", *The Journal of Mental Health Training, Education and Practice*, Vol. 10 No. 4, pp. 234-244.
- Daya, I., Hamilton, B. and Roper, C. (2020), "Authentic engagement: a conceptual model for welcoming diverse and challenging consumer and survivor views in mental health research, policy, and practice", *International Journal of Mental Health Nursing*, Vol. 29 No. 2, pp. 299-311.
- Ennis, L. and Wykes, T. (2013), "Impact of patient involvement in mental health research: longitudinal study", *The British Journal of Psychiatry*, Vol. 203 No. 5, pp. 381-386.
- Fetterman, D.M. (2010), *Ethnography: Step-by-Step*, (3rd ed.), Sage Publications, Thousand Oaks, CA.
- Hammersley, M. and Atkinson, P. (2007), *Ethnography: Principles in Practice*, 3rd ed., Routledge.
- Isaac, B., Bolden, R., Pawson, C., Gulati, A., Gasper, R., Plumridge, A., Kimberlee, R., Tischner, I. and Stern, E. (2017), "Building connections: golden key local evaluation phase 2 report", UWE, Bristol on behalf of Bristol Golden Key.
- Marshall, M., Pagel, C., French, C., Utley, M., Allwood, D., Fulop, N., Pope, C., Banks, V. and Goldmann, A. (2014), "Moving improvement research closer to practice: the researcher-in-residence model", *BMJ Quality & Safety*, Vol. 23 No. 10, pp. 801-805.
- National Lottery Community Fund (2021), "Fulfilling lives: supporting people experiencing multiple disadvantage", UK: The National Lottery Community Fund, available at: www.tnlcommunityfund.org.uk/funding/strategic-investments/multiple-needs (accessed 18 December 2021).
- Needham, C. and Carr, S. (2009), *Co-production: An Emerging Evidence Base for Adult Social Care Transformation*, Social Care Institute for Excellence, London.
- Needham, C. and Carr, S. (2013), *Co-production in Social Care: What it is and How to Do It*, Social Care Institute for Excellence, London.
- Preston-Shoot, M. (2007), "Whose lives and whose learning? Whose narratives and whose writing? Taking the next research and literature steps with experts by experience", *Evidence and Policy*, Vol. 3 No. 3, pp. 343-359.
- Scourfield, P. (2010), "A critical reflection on the involvement of 'experts by experience' in inspection", *British Journal of Social Work*, Vol. 40, pp. 1890-1907.
- Second Step (2013), "Fulfilling lives: multiple and complex needs Bristol: 'golden key' programme business plan 2014/15 – 2022/23", Second Step, Bristol.
- Slay, J. and Stephens, L. (2013), "Coproduction: a literature review", New Economics Foundation, London, available at: www.frontiersin.org/articles/10.3389/fsoc.2019.00057/full (accessed 21 September 2022).
- Vindrola-Padros, C., Eyre, L., Baxter, H., Cramer, H., George, B., Wye, L., Fulop, N.J., Utley, M., Phillips, N., Brindle, P. and Marshall, M. (2018), "Addressing the challenges of knowledge co-production in quality improvement: learning from the implementation of the researcher-in-residence model", *BMJ Quality & Safety*, Vol. 28 No. 1, pp. 67-73.

Further reading

- Golden Key Bristol (2019), "An action experiment approach", Bristol: Golden Key Bristol, available at: www.goldenkeybristol.org.uk/news/an-action-experiment-approach (accessed 21 October 2021).

Golden Key Bristol (2021), "Practical guide to system change: tips, tales and tools for aspiring change agents", Bristol: Golden Key Bristol, available at: www.goldenkeybristol.org.uk/practical-guide-to-system-change (accessed 4 November 2021).

Isaac, B., Bolden, R., Gasper, R. and Beard, A. (2019), *Golden Key Local Evaluation Phase 3: System Change*, University of the West of England, Bristol.

National Lottery Community Fund (2019), *Changing Systems for People Facing Multiple Disadvantage*, The National Lottery Community Fund, available at: www.tnlcommunityfund.org.uk/ (accessed 21 September 2022)

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