

# GOLDEN KEY EVALUATION: LIVED EXPERIENCE DISCUSSION PAPER SERIES

## THE INDEPENDENT FUTURES (IF) GROUP EXPERIENCE

### **Introduction to the Discussion Paper Series**

In pursuit of unlocking services and delivering lasting systemic change for the benefit of those with multiple and complex needs in Bristol, Golden Key adopts a client-led approach. Central to this, and the securing of accessible services that are more tailored to clients' needs and choices, is the input of clients and advisors with lived experience - or 'experts by experience'.

The centrality of the voice of lived experience in shaping the Golden Key (GK) programme has come to be recognised as a significant strength, and the discussion paper series aims to contribute to an iterative and collaborative documentation and evaluation of this. The subject matter of discussion papers in this series includes: 'The Genesis, Role and Impact of the IF Group'; 'The Role of Clients in Shaping GK Practice' and 'The Voice of Lived Experience in GK: Peer Mentors'.

### **Introduction to the Current Discussion Paper**

*"You're giving an opportunity to people that have considered themselves down and outs and going nowhere their entire lives to change the world"* IF Group member

At the launch of Golden Key an advisory group of experts by experience was formed with the aim of providing the voice of lived experience within the broader partnership. In April 2013, this group became known as the 'Independent Futures' (IF) group. This current paper specifically presents data analysis concerning the views and experiences of the IF group, and is intended to elicit discussion amongst a range of stakeholders. The GK partnership has invested heavily in ensuring that the IF group is an effective and sustainable voice of lived experience. This paper aims to provide some further insight in to the experiences and perspectives of the IF group members themselves, and make some recommendations to ensure the continued effectiveness and sustainability of the group.

## Executive Summary

- IF group members report pride in their role and a sense of ownership of the broader GK project. Given the range and scope of GK, there are very few areas where members do not feel consulted, and 'listened to'.
- The fundamental role of the group in relation to the broader GK project has been interpreted variously by some IF group members. This may have shaped some of the heterogeneity of views around priorities and activities within the group, and been the source of tension between the IF group and other GK partners.
- IF group members experience a parity of esteem in their membership of the broader GK partnership.
- At times the strong democratic and egalitarian ethos within the IF group gives rise to preferred practices that are not necessarily entirely synchronous with the structures and approaches of other GK partners.
- Over the duration of the programme to date the IF group have been characterised by their high levels of engagement, strong cohesion and effective functioning. However, recent tensions between individuals have caused some temporary disruption to the business of the group.
- The strong sense of purpose and social bonds experienced by the IF group appear to be instrumental in members' continued recovery. However, the vulnerabilities of other group members, and risk of relapse, are sometimes experienced as a risk to recovery.
- The shared experiences of IF group members and the GK client group are doubtless key to their considerable impact and value to the programme. However, the proximity of members and clients on the road to recovery also provides some significant potential challenges to members of the IF group.
- Commitment within the IF group to the GK project remains high. On such a long project, the continued commitment and resolve may be served by some form of recognition of temporal milestones.

## **Brief Methodology**

The experience of the IF group reported herein is informed by researchers attendance at IF group meetings during 2015 & 2016, the review of group meeting notes, and thematic analysis of interviews with seven IF group members conducted in early 2016. After conducting a thematic analysis (Braun & Clark, 2006), interviewees were then invited to return to one of two follow-up focus groups to explore emerging themes with researchers. The focus groups served to explore participants' response to initial interpretations of the data, and allow for further elucidation of central organising concepts and sub-themes. 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. Several of the most prominent over-arching themes are presented below, and each of these poses some important questions and provides points for discussion.

## **Perspectives on the Role & Impact of the Group**

Interviews with IF group members reveal a clarity in their understanding of the aims and objectives of Golden Key (GK), and a confidence in the programme's ability to deliver on them. It is clear that IF group involvement from the start of the project has paid dividends in enabling the IF group members to feel ownership of the broader project. Members also communicate a united understanding and enthusiasm for the broad role that the group serves in providing a voice of lived experience to Golden Key, and this is further discussed below. However, the interviews also reveal a heterogeneity amongst members' perspectives on the priorities of the group itself, and how that voice of experience might specifically be deployed in service of GK. Interviewees' responses to questions about the role of the group broadly cluster around the following:

- i) a central role in advocating for clients through direct contact: *"finding out what their experiences are and forwarding that through the partnership to the service providers"*.
- ii) a more strategic role: *"pointing out why services need to connect to each other, giving examples of that and hopefully show how that's benefitting people once it starts happening within Golden Key"*.
- iii) a monitoring or scrutiny role: *"holding the programme to account"*.

The narrative concerning the role as 'scrutineers' emerged in a number of meetings and interviews with IF group members referring to monitoring the "checks and balances". However, unlike i) and ii) above, this 'scrutiny' role is not mirrored in the discourse outside

of the group and across the partnership – which has been found to be more focused on co-creation and collaboration with the IF group. Interviews with stakeholders in the initial stages of GK, reveal that there may have been something of a mismatch between members of the GK partnership board and the role of the IF group as perceived by its members. This mismatch is potentially salient given that, at times, the IF group members have reported feeling that when they have been vocal in expressing concerns about the programme, this was not well received. It is possible that some friction experienced in communication between the IF group and the partnership board may well have been catalysed by a mismatch in expectations about role.

Despite these aforementioned occasional tensions, the group and wider partnership have worked hard to resolve any issues and concerns, and they continue to enjoy a largely productive relationship. Indeed, a number of IF group members have noted the distinction between the work they do for the group and GK, and their previous less positive experiences of expert citizen or people participation activities. Many IF group members report 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"*

*"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"*

Paradoxically, there is some evidence that the parity of esteem in which the IF group are held by the remainder of the partnership may have, at times, been something of a challenge to the IF group. An interesting theme to emerge from the interviews with members, was the strong democratic and egalitarian ethos within the IF group. Decisions within the group are voted on, and all members are encouraged to get involved in all activities. However, it seems that this has not always made the group easy to liaise with as partners. The typical role-delegated structures and processes of most organisations (and indeed most GK partners) encourages distributed roles and decision making, and at times there has been evidence that partners have sought to engage the IF group in the same manner. This is manifested in non-IF group partners understandably seeking to engage with particular individuals around specific activities, and in an informal fashion. However, this is at odds with the strong collective identity and democratic approach to group activity and decision making that the IF group prizes. At times this has caused discomfort for some group members who didn't feel that they wanted to speak on behalf of the group.

Although IF group members have occasionally voiced scepticism in interviews about whether all agencies and professionals they interact with really value the voice of lived experience, the IF group members are unified and unwavering in their belief in its importance and value. IF group members highlight the empathy they are able to call on in advising GK, but also the potential credibility they bring to the GK programme through their involvement. For most members, participation in the IF group has strengthened their belief in the value of providing the voice of lived experience.

*"...we started at the bottom and now we've climbed the ladder and we're clean we can reboot back to someone...I think we are important because we've lived that experience...some people don't look at us as experts but we ... are. We are the people that have lived it and got through it"*

Beyond belief in the value of lived experience more broadly, and despite differences in perceived priorities, the IF group members also evidence a strong sense of purpose about their contribution to the GK programme. Members have often voiced pride in the "new and dynamic" role the group is providing. The group itself is viewed extremely positively by some members:

*"...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"*

*"What the group allows me to do is share the experience I've had and try and fight to help other people avoid the same situation"*

### **Intra-Group Dynamics**

From attending meetings and analysis of interviews, the overall sense of the intra-group dynamic over the duration of the programme to date is one of cohesion and effective functioning. It is notable that the IF group has not experienced some of the issues of inconsistent membership and engagement to the extent that expert citizen groups from elsewhere in the Fulfilling Lives projects have reported. However, over the last 6 months the IF group has experienced some tensions within the group. There have been differences of opinion around the direction of the group with resulting observed discord which, members have reported, has impacted on the climate of the group during some meetings. Members have reached out to other GK partners for support in managing these issues, and have voiced some disquiet about a perceived lack of responsiveness and effective facilitation. That said, group members have also acknowledged that there are benefits to reflecting on and resolving these issues internally – particularly as the group strives towards further independence.

It is important to note that recent tensions have been the exception, and have now been resolved. Furthermore, observation of meetings reveals a strong and supportive collective identity. Analyses of one-to-one interviews identified a number of examples where members made reference to the support network offered by the group: *"...checking in doing what we can to support them, letting them know they're not on their own"*. The IF group members also frequently liken the group to a family. For many members who report being estranged from their own families, they frequently reflect on the valuable social support offered by membership of the group.

*"It's like a little family of brothers and sisters.....You know some are naughty some are good and we are all trying to get on together"*

*"...we are a family and when you don't have that family around you, you struggle more... people forget just how supportive group members are"*

*"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"*

The social support offered and sought by members of the group is almost universally valued by the group members who have been interviewed. However, the strong social bonds within a group who have evolved in to a support network is not without its difficulties.

*"Because in the group you've got so many people in different stages of development....there's a lot of issues going on....you know and I find it quite hard work sometimes"*

Analysis of interviews reveals how highly motivated IF group members are 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, the journey of recovery, and the fragile nature of progress was also frequently acknowledged by members of the group.

*"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."*

This fragility raises two key issues in relation to the IF group. Firstly, group members are at varying points on their recovery journey, which can mean that some members are in a more vulnerable position with regards to their needs than others. At times, the

vulnerabilities of other group members have been 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.

*"Some are very supportive of others, but some are quite damaging for others"*

*"It was very hard for someone else 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"*

A second related issue pertains to the work, albeit limited, that IF group members have done with clients. A number of IF group members have reflected that those participants they have interviewed as part of their audioBoom project may be only "just behind them on their recovery journey", and that this can be a testing experience. More specifically, IF group members report 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"*

*"We were so intent on thinking about the client.....we didn't have any emotional support...we weren't supported."*

If the members of the group feel that adequate training and support has not been provided, or the ability to reflect or debrief is absent, then it is perhaps unsurprising that members have found this difficult. This experience outlined by some members of the IF group has informed the approach to the ongoing peer research, and should serve as a salient reminder of the duty of care the broader partnership and evaluation team has to the IF group members.

### **Personal Development & the Ongoing Evolution of the IF Group**

A final noteworthy theme emerging from the interviews with IF group members is the personal development that members report, and the role that they attribute to the group in their continued recovery. This has important implications for the individual members and the sustainability of the group. Feelings of positivity about the influence of group membership are prevalent in the discourse of members, and the group is credited with having a strong developmental impact on its members.

*"...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"*

*"you're giving an opportunity to people that have considered themselves down and outs and going nowhere their entire lives to change the world"*

Members also recognise the development of the group itself. The sense of shared satisfaction and 'coming of age' is evident in the interviews with members.

*"You know, there's a certain sort of grown-upness about the group that wasn't there previously and I'm quite proud of that you know, and I'm now working with my family and they're adults! You know we're no longer pre-teens. You know need to be guided in that way, we can think for ourselves!"*

If the partnership were seeking to adopt a strengths-based approach in exploring how it may further evolve, one opportunity might be to celebrate the ongoing commitment of all stakeholders – but particularly the experts by experience at the heart of the programme. This sentiment is clearly reflected in the words of one of the IF group interviewees:

*"we've not really celebrated our successes in a real way, there's never been like someone in this group's got a plaque or a you and a picture taken saying oh thanks for the two and half, well four years...Celebrating our successes in a real way. You know 'cos that helps with your self-esteem, you know"*

### **Recommendations:**

The following recommendations are broad recommendations emerging from discussions in the GK evaluation advisory group. However, it is hoped that other opportunities for facilitating the impact and sustainability of the IF group will emerge from discussions elicited by this paper in other fora.

- As the GK programme evolves, inevitably so too will the role of key stakeholders such as the IF group. It is recommended that members of the partnership board and the IF group membership provide opportunities to formally recognise the contribution of the group annually, and co-produce the IF group agenda for the next 12-24 months. This will be particularly useful in optimising the contribution of the IF group, and clarifying the expectations of all parties - including the extent to which the IF group are expected to act as project scrutineers.
- As part of the appraisal of distance travelled, and future agenda setting for the IF group, it is recommended that the partnership board and IF group carefully consider the needs of the IF group members. Particularly as the IF group increase

their contact with GK clients, it would be prudent to explore mechanisms for formalised support of IF group members. One possibility would be to offer regular debriefing sessions for the IF group, or facilitate a mirroring of the reflective practice sessions that are common to many of the frontline teams across the GK partnership.

- Many of the IF group are now contributing to a range of other organisations and diversifying their contribution across the partnership. It is recommended that the partnership board consider ways in which they may be able to work with the IF group to devise formalised development opportunities and pathways for IF group members that could be of mutual benefit to both IF group members and partners.
- Finally, it is also recommended that members of the IF group consider the make-up of the group, and particularly how new members are identified, inducted, and then invited to contribute to the broad range of group activity.