

CASE STUDY #5

Golden Key's lived experience involvement in the local mental health strategy

Improving access to mental health support for people experiencing multiple disadvantage

Evaluation of Fulfilling Lives:
Supporting people with multiple needs

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CFE Research and
The University of Sheffield,
with the Systems Change
Action Network



Golden Key is the Fulfilling Lives partnership for Bristol.

What was the problem?

People with lived experience of multiple disadvantage are increasingly consulted in the design of local services, but have limited opportunity to affect broader strategic work. The strategic vision around mental health often misses the needs of people experiencing multiple disadvantage. This in turn leads to commissioned outputs and outcomes that aren't focused on their needs.

Golden Key identified a gap in mental health service provision for people with experience of multiple disadvantage, particularly between primary (day-to-day healthcare such as GPs, pharmacists) and secondary services (specialist healthcare such as hospitals, clinics).

How did the partnership address it?

Bristol, North Somerset and South Gloucestershire Clinical Commissioning Group (CCG) are writing their new ten-year mental health strategy. Golden Key Bristol have facilitated the involvement of Independent Futures (IF), a group made up of Golden Key beneficiaries with lived experience of multiple disadvantage, alongside Bristol Independent Mental Health Network (BIMHN), another group of people with lived experience of mental ill-health. Golden Key were approached by the CCG due to their broader range of experience working with people affected by multiple disadvantage and their relationships with relevant partners. The IF group are well-known in the area and members are regularly invited to meetings and consultations.

Group members have been involved in all stages of the strategy development. IF group members took part in consultation workshops with the CCG. Two workshops were run with 20 to 30 attendees, including people with lived experience. Participants contributed their experiences and thoughts firstly to contextualise problems and issues and secondly in identifying potential solutions. In-depth interviews were held in between the workshops to look at life journeys of people engaging with mental health (and other) services.



We spoke about what we would like to change when [the strategy has] gone through this commissioning, you know, what would we like to see different?

Following the workshops, one Golden Key beneficiary also agreed to compile and contribute some detail of their life experiences to the consultation process to bring a real and personal account of the link between early life experience and adult complexity into the strategy document.

As the strategy has developed, Golden Key and members of the IF group have been invited to follow-up meetings to test what is being written and asked for further input. The beneficiary who contributed their life story remained involved in the editing process. The role of Golden Key is not limited to providing experts but has continued in reviewing the strategy as it is developed. This has ensured that the expert voice does not get lost or diluted.

“ At these times when people are writing these big documents, there tends to be, sometimes, a bit of tokenistic consultation process. Then, stuff gets written into the strategy and then it doesn't really turn out like that, but... each time they've produced the outcome from the days, they've come back to us to make sure that they've got it right, and asked us if they think there's anything else that hasn't been included, or is there a different perspective on this?

What difference did it make?

The strategy is still being written so any impact that Golden Key's contribution might have is solely on the development process at present.

Ensured the strategy incorporates lived experience

Genuine lived experience involvement in strategic work like this has the potential to change how mental health and related services support people with experience of multiple disadvantage. In this case the depth of involvement went beyond a token consultation and reflected a more genuine approach to co-production. It is hoped that there will be a tangible impact on the system as a result.

“ Having the voice of lived experience absolutely brings home the points of the strategy. It really enhances the messaging.

“ I don't think there's any substitute for having people with lived experience [involved] ... I thought they brought a lot, and I think they brought a very real perspective.

Raised awareness of the contribution people with lived experience can make

By working closely with the CCG, Golden Key have demonstrated that it is possible – and beneficial – to work with people with lived experience when designing health strategies. It is hoped that this will be recognised across the area and even contribute to a shift in the way other strategies are developed.

“ The work that we've been doing in raising awareness about multiple complex needs has, moved people away from apathy or ignorance to a place of urgency about the need for doing something different, and that might be driving some of the engagement with the strategy and shifts in the way behaviours are happening.

Impact on experts

Involving people with lived experience in this type of work can have a positive effect on them. IF group members appreciated being invited to contribute their thoughts and enjoyed the respect afforded to them in speaking alongside professionals, and being treated as equals.

“ What was nice about it is, when you go to the workshop, you had to sit with people that you don't know... what I like about all of this is, there's no stereotyping, and that's really important. You feel like everybody's on the same boat.

For the beneficiary who contributed their life story to the strategy, this was a positive and therapeutic process and continued involvement in the editing stage has allowed this to continue as the strategy has developed. It is hoped that when group members can see how their contribution has shaped the final strategy document this will have an even bigger impact.

Learning from experience

Although the strategy development is still ongoing, there are a number of learning points that should be considered when involving lived experience groups in similar activity.

Get buy-in at all levels

All partners involved in the strategy need to buy into having lived experience involvement and be committed to this from the start. Golden Key have a close relationship with the CCG, as a commissioner sits on the Golden Key partnership board. This has helped to build a positive relationship between them and develop understanding of what Golden Key do and the importance of involving people with lived experience.

“ There's a real buy-in to thinking differently at a commissioner level [...] and really embracing that, right down to the nitty-gritty of user-experience as well.

Bring in external expertise where required/ respect what different players bring

The consultation workshops were designed and delivered by an external company. This helped to add credibility and independence to the process.

It is also important when a range of different agencies and organisations are involved to understand and respect the strengths that each partner brings. Golden Key were involved as an organisation with in-depth knowledge of working with people with lived experience; others had expertise elsewhere and a recognition of this was deemed essential to the success of the process so far.

 **We've had quite a healthy relationship around acknowledging each-others' subject matter expertise.**

Ensure good understanding of multiple disadvantage before starting work

In the early stages of the strategy development, the CCG insights team worked with Golden Key to harness what they had learnt over four years of working with people with lived experience. This ensured the CCG had a good understanding of people affected by multiple disadvantage and how best to work with the lived experience groups.

 **I guess, with anybody who doesn't really work with this client group, they really underestimate the complexity.**

Ensure genuine, varied and recent lived experience involvement

People with lived experience giving up their time and energy to contribute want to know that it will make an impact. Involving people with lived experience needs to be central to the work rather than a token offer or an add-on. Golden Key felt that the CCG understood this and as a result, they could give reassurance to IF group members who were asked to attend.

“ I think what [IF group members] wanted was persuading while they were there that it wasn't just going to be water off a duck's back, and this wasn't some tokenistic effort.

The partnership highlighted the value of having a diverse range of voices represented. Lived experience should also not be understood or portrayed as a generic experience, but one that is experienced differently by different individuals. It is also important to ensure that contributors have recent experience in order to be able to comment on current services.

“ I would get people more with lived experience in there. People that are using the service. Like, fresh heads, not stale ones, because there's something about, you always have to be up-to-date with services to know what's going on. If you're not up-to-date with it, you can't get the right information.

Make sure contributors are properly supported

People in lived experience groups are likely to have a range of needs that can fluctuate over time. While someone might be in a good place to contribute at the start of the process this can change. It is important to manage expectations and ensure people are not asked to do too much. There is always a risk that people are adversely affected by discussing difficult experiences.

“ It's really scary when you go into those places... when you go into a room, it's like, sometimes, they expect you to have all the answers because you're lived experience and sometimes, you don't.

Meetings and consultations can be intimidating. Organisations like Golden Key can provide valuable experience, knowledge and advice on how to ensure people with lived experience are sufficiently prepared and supported. But, with enough time and resource, it is possible to involve even those with high levels of need.

“ It is really difficult to capture the genuine client voice of people who are at the highest level of need, [...] So, I think that seeking the guidance of organisations who work closely with people who are working with the clients, letting them lead that process and giving them enough time for that is really important.

Keep timescales realistic but swift

The consultation process, from initial planning meetings, through the workshops to writing a final draft strategy, took approximately three months. This demonstrates that the necessary depth of consultation required can be achieved in a relatively short timeframe. Keeping the work moving swiftly is efficient but also important in reducing the risk of the lived experience voice being lost in an extensive revision process.

“ I feel that if the change comes from anywhere, it comes from the energy, and what we're seeing, through this bit of work, is ideas that have come from practice going to strategy, in quite a quick and efficient way. It's not got diluted through going through managers and reports and all this sort of thing.

Taking it further

Following the consultation process, the findings are being presented back to stakeholders (including people with lived experience) for final comments. Golden Key continue to be involved and are hopeful that the final strategy will have a direct impact on how services are commissioned.

Find out more

Find out more about Golden Key: <http://www.goldenkeybristol.org.uk/>

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