



SUMMARY

AUDIO DIARY PROJECT

RECORDING LIVED EXPERIENCES OF CHANGES TO MENTAL HEALTH SERVICES AT THE HIGHGATE DAY CENTRE

PLEASE NOTE: This summary is presented alongside the full report which contains the full set of data charts accompanied by direct quotes from the audio diaries.

Background

The Highgate Centre Audio Diary Project is a collaboration between Healthwatch Camden and service users from the Highgate Day Centre.

Healthwatch Camden is an independent organisation with a remit to make sure that the views of local service users are heard and help to bring about service improvements.

The Highgate Day Centre is a service for people with mental health needs in Camden.

During 2015-16, the service underwent significant changes, partly as a consequence of resource constraints and partly in response to changes in thinking around appropriate models for service delivery. Before the changes, service users described their service as a therapeutic mental health day care centre based on a recovery-oriented programme. The changes aimed to reorganise the service in line with what the Camden and Islington NHS Foundation Trust and the Camden Council described as the “recovery model”.

The most significant change proposed was the abolishment of the Associate Membership, meaning those who had completed their programme as Core members would no longer be able to retain access to the Centre for support or peer contact. Other changes were also proposed. These included cuts to staffing levels, ending

the provision of the daily hot lunch prepared by a staff cook in the Centre's kitchen and making changes to the programme of groups and classes.

Service users were distressed by the changes proposed and expressed their views throughout the consultation process and at the Adult Health and Social Care Scrutiny Committee. The Council and the Trust (co-commissioners and providers of the service) provided responses to their concerns, but the service users said:

“What you say is happening does not reflect the reality for those of us who have to live through these changes.” (Highgate Centre service user, Health and Adult Social Care Scrutiny Committee Meeting, September 2015)

The aim of the project

Healthwatch Camden offered to work with the service users at the Highgate Centre to co-design a research project that would seek to capture, in real time, their lived experiences of the service changes at the Centre. Qualitative evidence from lived experience is often neglected in favour of quantitative evidence leaving an “evidence gap” around what service changes really mean for people in their daily lives. We wanted to challenge the tendency to write off individual experience as anecdotal by gathering and analysing personal testimony systematically.

We also wanted to understand how the lived experience of the service changes evolved over an extended period, starting at the time of imposition of the service changes and continuing beyond the time when the process was expected to have been concluded. All participants knew this study would not have any direct impact on plans for the Highgate Centre. Nor did the project seek to assess the relative merits of different models of service delivery: the aim was to learn from this experience to help inform approaches to service change elsewhere in the future.

A broadly representative group of eleven service users volunteered to record regular weekly “audio diaries” addressing three questions about changes taking place at The Highgate Centre.

Regular weekly diaries were then submitted, transcribed, and coded and charted using Framework Analysis (this is a recognised research method). Next the information from the diaries was sorted in accordance with key issues and themes to produce charts and graphs which demonstrate the impact of the changes across the group of participants.

Nine participants submitted weekly diaries through the full 30 week period. Project progress was reviewed in meetings with the group of participants at regular intervals and participants were consulted over decisions around release of interim findings and other matters concerning the progress of the work.

Key Findings

1. Impact of service changes on overall wellbeing

Service users were told: The new model/change to the service will be better for your wellbeing

What did service users experience?

Findings at a glance – impact of service change on overall wellbeing

- The changes at the Centre caused a gradual decline in the mental health and wellbeing of all the project participants.
- Both core and associate members experienced anxiety, uncertainty, depression, isolation and sense of loss caused by the changes.
- The assertion by the Trust and Council that people would be able to reduce their dependency on the service holds true in only in a small minority of cases.
- The very high number of reports of negative mental health including suicidal thoughts give cause for serious concern.

Service users at the Centre were told that the changes were not being driven only by the need to cut costs (although the financial challenges facing the Council due to central government funding cuts were openly acknowledged). The Trust explained that the changes were informed by new thinking around the beneficial outcomes that could be expected from a “recovery model” of service design for mental health service users. They were told that the “*intention was to promote recovery rather than to have a large number of people dependent on The Highgate Centre*” (Minutes, Scrutiny Committee, Health and Adult Social Care, September 2015) and that the objective was an overall and long term improvement in their mental health and wellbeing.

Overall our research finds evidence of negative impact of the changes at the Centre on the mental health and wellbeing of all the audio diary project participants.

4. Risks arising from service changes

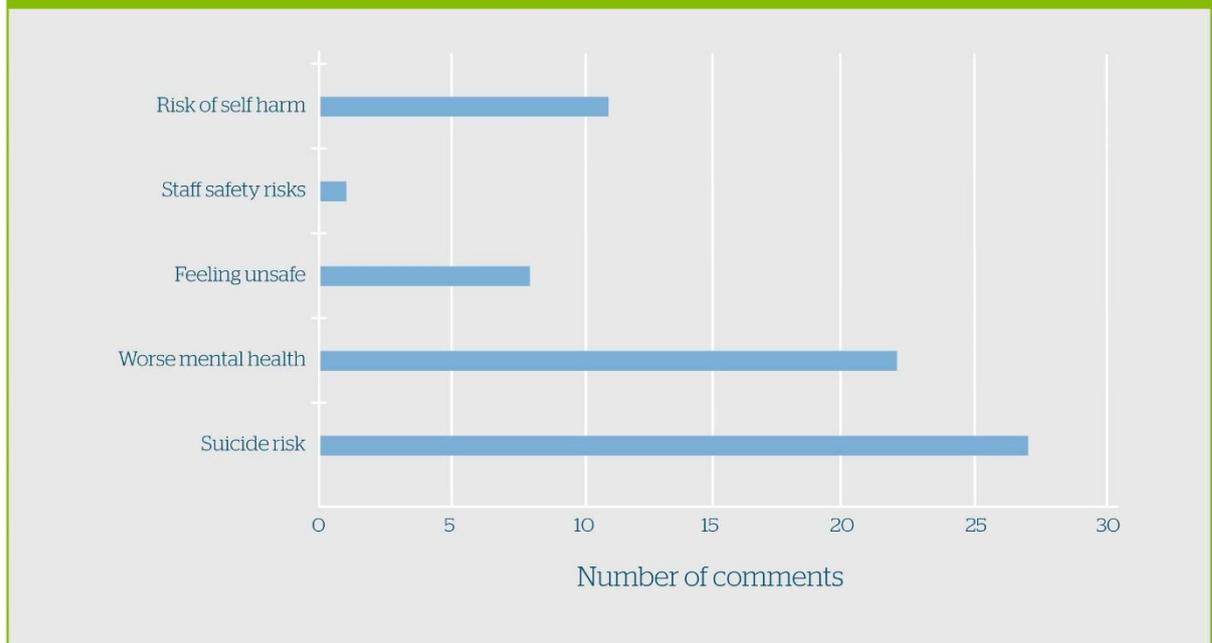


Chart 4 (numbering relates to full version report) tells us what risks the participants reported as a result of the changes to the service. The very high number of comments about suicide (27 in total) give cause for very serious concern. We know from the diary entries that these risks were not only perceived but real. Over the 30 week period of reporting, the diaries indicate that there were suicide attempts by at least three of the nine audio diary project participants. We also know from the diaries that three participants were admitted to a Crisis Centre and one participant was admitted to a mental health hospital ward. As well as these admissions, other participants also called on the Crisis Team over the period of 30 weeks. It is possible that there were critical incidents which were not reported in the diary entries, meaning that these could be underestimates.

Other charts in the full report explore the range and extent of both negative and positive feelings about the changes and the variation in these feelings over the seven month reporting period.

“I have urges to hurt myself and I just feel really unsafe.”

“I felt a lot like self-harming this week. I feel quite desperate. I don’t want to go back to self-harming and risking my life.”

“I took an overdose on Thursday. I hadn’t self-harmed since [before the changes at the Centre].”

“I was looking at getting a job. I was doing well. I feel like a lot of that is being undone.”

“I was looking at the prospect of building a life outside the Centre and a job but that’s no longer a certainty. It’s the security that I thought I had that’s just gone.”

2. Consultation and change management

Service users were told: We will consult and listen to you about how to make the changes and the changes will be made in a planned way and communicated to you.....

What did service users experience?

Findings at a glance – consultation and change management

- Service users felt they were consulted in theory but were not really listened to.
- Communications from the Council and the Trust felt dishonest and conflicting.
- Service users were not always negative about the changes that were planned meaning better change management could have produced a better outcome.
- Contact with Council and Trust about the changes had a significant impact on the mood of the service users, demonstrating the power of consultation to be either constructive or destructive.
- Events such as attendance at Adult Health and Social Care Scrutiny Committee and departure of staff from the Centre influenced the depth of positive or negative mood among all the service users (including those who had not been part of the delegations).
- Service users accurately predicted the risks and challenges that would be involved over the period of change. This insight could have been used to better mitigate the damage through good change management.

The Council and the Trust notified staff and service users at the Centre about their intention to change the service. Several meetings were held at which the proposed changes were explained and views sought. Meetings between the Council, the Trust and the service users continued throughout the period of change. The Adult

Health and Social Care Scrutiny Committee received deputations of Highgate Centre members on several occasions and called representatives of the Trust and the Council to respond at the meetings.

The project participants acknowledged that there was consultation about the future options. Analysis of the audio diaries shows a high number of comments that refer to meetings and discussions with either Centre staff, the Council or the Trust. A common theme is that participants felt they were consulted in theory but were not listened to and that communications from the Council and the Trust were characterised by dishonesty and conflicting messages.

“The trust said it was the council and the council said it was the trust.”

“An abusive relationship is when someone tells you they care for you while hurting you. This is how the Trust and Council dealt with us.”

“There is a complete discord between our lived experience and the Trust’s explanation of the cuts and reduction of the service”

“Definitely the whole insecurity around Highgate is being felt now... you’re much better if there is clarity.”

10. Concerns about the proposed changes

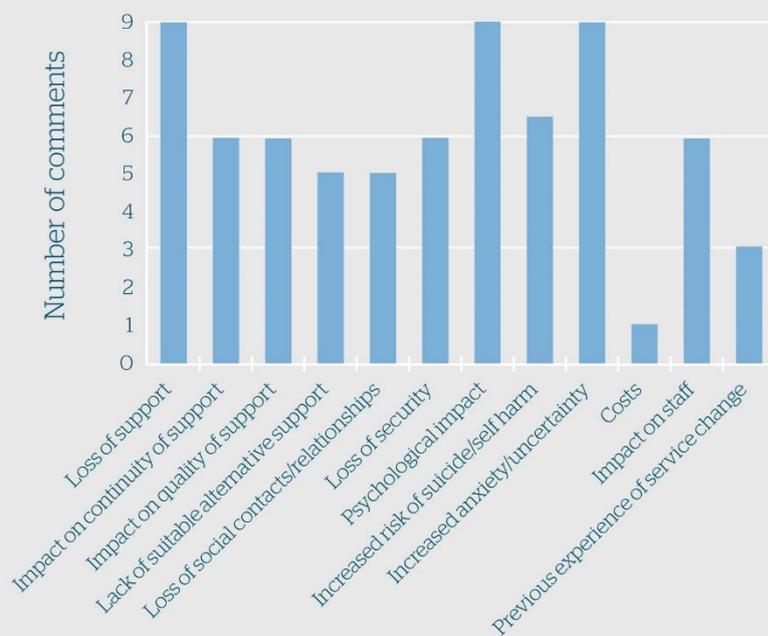


Chart 10 draws on data from the baseline interviews to show the concerns recorded by participants at the onset of the change process. We can see that participants were particularly worried that the changes at the Centre would mean a loss of support, would have a psychological impact on them and would involve a high degree of anxiety and uncertainty. Cross referencing this chart with findings from throughout the 30 week period of the audio diaries we see that the participants proved very accurate in their predictions of the challenges that would be involved over the period of change. If members concerns had been taken seriously in the early consultation stages, these could have provided the Trust and the Council with helpful guidance on where to invest effort to mitigate the damage through good change management.

Other charts in the full report explore the way views about the services changes varied over time and the extent to which events taking place contemporaneously with peaks and troughs of positive or negative feelings might help account for them. The report also explores the impact on different groups of service users and the changes in the response to the consultations over time.

3. The new or alternative service offer

Service users were told: Your service will be replaced by other support services in the community (Associate members) or a different offer in The Highgate Centre (Core and Transitional members).

What did service users experience?

Findings at a glance – new or alternative service offer

- Some new or different activities were introduced for members (and on a time limited basis for Associate members) at the Centre.
- The new offer reduced the therapeutic orientation of the service and peer support was eroded.
- Alternative support in the community was generally not easily available or suitable for Associate members who were leaving the Centre.
- There was very little take up of alternative provision in the community by Associate members.
- Both Core and Associate members experienced reductions in social contact and peer contact as a result of the changes.
- Associate members made initial efforts to access alternative activity and support outside centre but it appears that their ability to do things was eroded and reduced as time went on.
- Lack of planning and support meant the strategy for transition to alternative forms of support through universal services available in the community largely failed.

At the consultation meetings, and at meetings of the Adult Health and Social Care Scrutiny Committee, elected members of Camden Council and members of the senior management team at the Trust told service users that the support Associate members had been receiving from the Centre would be replaced by other support available to them in the community. Core members were told that the service provided by the Centre would remain in place for them although provision of lunch, prepared by a staff cook at the Centre, would be replaced by other options for food such as cookery classes or peer-group food preparation using the Centre's kitchen.

At the Health and Adult Social Care Scrutiny Committee meeting in September 2015, the then Deputy Chief Executive of the Trust explained that *“part of the treatment involves developing a support network and these changes would provide an opportunity to explore that wider network”*. (Minutes and recording of HASC Scrutiny Committee meeting, September 2015.) He added that the service had made a commitment to talk through the plan for ongoing support with every individual service user and that, where the Highgate Day Centre had been a crucial contact point for a service user, care co-ordinators would look at how to replicate that support in other ways.

Our research aimed to record whether service users experienced these changes in the way they had been described by the Trust.

The evidence from the audio diaries suggests that some new or different activities were introduced for Core members (and on a time limited basis for Associate members) at the Centre but that these were generally not considered satisfactory by the project participants. In particular, they noted a shift in focus from care and support to a focus on returning to work. Associate Members did make efforts to seek alternative support through activities available in the community but the data show that these alternatives often fell short, either because they were costly or short term or did not provide a therapeutic framework.

Charts presented in the full report explore the limitations of alternative services in the community, the impact of the changes to the service at the Centre and the efforts made by members to take personal initiatives to find alternative support outside the Centre as well as the extent to which their will to do so declined over time.

“I haven't spoken to a soul or seen anyone. I've just been here at home.”

“..... but they're really expensive.”

“I've started this new pottery class.....but it's only five sessions.”

“I left after a couple of sessions because there were people sort of picking on me and I just couldn't cope with it.”

4. Supporting service users through the service changes

Service users were told: There will be support to help you make the changes (including personal plans and follow up)

What did service users experience?

Findings at a glance – supporting service users through the service changes

- There was a lack of consistency in the planning and implementation of the changes which had a negative impact on service users.
- The psychological support provided through the changes was inconsistent and in many cases ineffective.
- There was insufficient support for Associate members through the transition.
- Tensions and complications in the management relationships between staff at the Centre and senior managers at the Trust and between the Trust and commissioners at the Council interfered with the effective management of the service change.

Associate members were assured that each would have a personal plan, agreed with staff, which would identify the services available to them and any support they could expect in accessing new services in the community. These assurances were repeated publicly by representatives of the Trust at Health and Adult Social Care Scrutiny Committee meetings. These assurances, and the process of transition, were complicated by the fact that the Trust made revisions to the plans for change throughout the period between December 2015 and March 2016. For example, in a change from the early announcements it was decided that Associate members would be permitted to attend the traditional Christmas lunch at the Centre. Then Associate members were offered the chance to access some limited services at the Centre for a further period of months after their Associate membership was originally planned to have ended.

The audio diaries show that this lack of consistency in the planning and implementation of the changes had a negative impact on the project participants.

“I felt quite angry. I felt as if no one had thought through the effect this extension would have on my mental state, We’re going to have to go through the whole thing again.”

“Having geared myself up to leaving The Centre I now have to deal with a different scenario.”

Other changes happened unexpectedly and suddenly during the period of change. In particular, the sudden departure of the long term director of the Centre and other staffing changes had not been communicated to the members as part of the planning and consultation process. Some revisions to the planned changes appeared to be made “off the cuff” by representatives of the Trust when they were publicly questioned by the Health and Adult Social Care Scrutiny Committee. For example, an announcement that the kitchen could continue to be used for preparation of hot food was made at a Scrutiny Committee meeting, contradicting what members had been told by Centre staff.

“They are all just passing the buck.”

“They told us we’d have to leave at the end of November. Then they said we could hang on until Christmas lunch. Then the manager negotiated an extension until the end of January. Then yesterday [January 11th] the Trust Director of Operations said that definitely from next week onwards we won’t be able to come in.... except on Tuesday.”

Evidence from the diaries suggests that there were tensions and complications in the management relationships between staff at the Centre and senior managers at the Trust and between the Trust and commissioners at the Council. These were played out to the detriment of the service users themselves.

The lack of consistent and effective support for participants and high levels of confusion and distress appear to be, at least in part, an adverse consequence of the relationships between Commissioners, Trust managers and Centre staff. For example, despite the implications for their own employment and emotional wellbeing, Centre staff were made responsible for much of the communication with service users and the practical implementation of the changes. One-to-one meetings for the preparation of personal plans for Associate members leaving the Centre were conducted by Centre staff, often in the final days of their own contracts. The inadequacy of many of these plans was a significant factor in the poor transition arrangements and outcomes for participants. Yet the ability of the participants to ensure that their own needs were met was undermined by their loyalty to the long term Centre staff.

Conclusions

The audio diaries provide strong evidence that the changes to the service at The Highgate Centre were implemented in a way that had an overwhelmingly negative impact on the people using the service.

The justification behind the changes was that Associate members had regained sufficient resilience to use universal services and no longer needed the specialist services provided by the Highgate Centre. The evidence shows that this assumption was borne out over time in a small number of cases. However, it is clear that this was not the case for most of the Associate members involved in this study. Indeed, evidence presented in this report demonstrates that the process of service change eroded the resilience and recovery of some of the Associate members, potentially increasing their need for support.

A second justification for the changes was the need to cut costs due to resource constraints beyond the control of either the Council or the Trust. Evidence of increased use of emergency services, hospital, and crisis house admissions that appear to be a direct consequence of changes at the Centre suggest savings may have been absorbed by increased use of alternative more expensive provision elsewhere in the health and social care system.

Of further note is that the impact of the changes was negative across all groups of service users including Core members. The widespread negative impact appears, in part, to be linked to the loss of peer support previously provided by Associate members as part of the ethos of the Centre. The importance of peer relationships and support in mental health services is well documented yet this impact appears to have been underestimated by commissioners and providers.

Overall, the study findings expose a failure of those managing the service change to recognise and address the potential impact on all existing service users.

The evidence of the audio diaries shows that the negative impact could have been reduced by better management of the change process because we can see that members were not all or always negative about the changes that were planned. Mitigation could have been achieved through better initial consultation with service users, through clear, transparent and consistent communication and leadership throughout the process, and through the provision of adequate support for service users with attention to individualised personal plans (which should be properly researched and monitored).

Poor change management appears to have been driven or compounded by tensions and complications in the management relationships between staff at the Centre, commissioners at Camden Council, and senior managers at the Trust which were played out to the detriment of the service users themselves.

The high level of satisfaction with the existing service (evident from entry interviews) indicates a high likelihood that there would be concern about any proposed changes. This could and should have alerted Trust and Council to the fact that that investment in excellent change management would be essential to

ensure a smooth transition and to sustain the wellbeing of those currently using the service.

Mental health services have a duty of care to service users and reduction of risk is of paramount importance. The level of risk suggested by these data must be considered unacceptable as a consequence of service changes in a mental health service and should have been better mitigated.

A key finding from this study is the accuracy of the predictions and concerns of the service users about the risks involved in the planned service change. This extent to which these predictions proved accurate tells us that full and meaningful service user consultation at the outset could have furnished the commissioners and service providers with valuable insight to help guide the planning, good management and successful implementation of a challenging service change.

Instead, the evidence shows that the consultation was poorly managed and communication around the changes was ineffective. Indeed, the communication with service users is revealed in this study to have actively contributed to increased confusion and uncertainty, in turn driving negative responses and declining mental wellbeing. This demonstrates the power of consultation to be negative or positive and the importance of taking it seriously, being transparent, avoiding confused messages and meaning what is said.

Service users recognise that change is sometimes unavoidable due to resource constraints or other factors. Service users at the Highgate Centre were not implacably opposed to changes of any kind. A different form of user engagement which focused on seeking the help of service users in identifying how the changes could be best managed could have mitigated the negative impact on individuals.

Despite the intention to promote recovery through the service changes, the evidence from the audio diary study identifies an overall decline in the wellbeing of service users over an extended period of 30 weeks. This does not reflect the outcomes intended in a “recovery model”.

Recommendations

Recommendation 1

In the case of established services, the concerns of existing service users (identified at the outset through meaningful consultation methods) must be respected as valuable evidence for planning service change.

Evidence: The audio diaries revealed a clear match between the concerns of current service users identified before the service changes ensued and the risks that emerged as a consequence of the changes. Proper consideration of these early concerns could have informed better decision making by senior

management around where to provide additional support and invest in expertise for effective change management.

Recommendation 2

Service user engagement around changes to existing services should be rigorous in methodology and serious in intent. It should not be restricted to open consultation meetings but must also include other proven options for meaningful engagement, for example, co-design or in-depth one to one interviews with systematic analysis of findings.

Evidence: The Council and the Trust did make efforts to consult service users about changes to the Highgate Centre. However, the evidence shows the consultation approach used was not systematic and the findings were not given sufficient consideration in strategic planning. One unintended consequence was that the efforts at consultation had a negative impact on the wellbeing of service users.

Recommendation 3

The support needs of existing service users should be a priority concern during changes to services. Support provided should begin early, remain consistent, and be designed to respond to the specific concerns identified by service users themselves.

Evidence: The support provided to Associate, Transitional and Core members through the changes at The Highgate Centre was inconsistent and inadequate. Better planned and early support could have reduced the risks associated with the changes. Poor management of the changes represented a failure in duty of care.

Recommendation 4

If consultation about service change cannot achieve sufficient consensus among key stakeholders (including existing service users) then appropriate accountability mechanisms should be used to insist on robust evidence to support the arguments for change.

Evidence: A source of distress evident in the audio diaries is the extent to which the proposed change to a “recovery model” of service design was presented by the Trust as an “evidence based” strategy for the achievement of improvements in service user wellbeing. Participants felt that their existing service was recovery oriented and that evidence to support a change of approach was inconclusive. Disagreements around the validity of the claims therefore hindered joint working for constructive change management.

Recommendation 5

The Health and Adult Social Care Scrutiny Committee should take a more forensic approach to challenging contradictions in accounts given under questioning and should seek to test assurances given to service users at committee meetings.

Evidence: HASC heard deputations from service users and called commissioners, elected members and providers to respond to questioning. However, the reassuring responses given by spokespeople for the Trust at committee meetings were not always followed through in practice. This compounded the distress of service users who experienced disillusionment following the public meetings.

Recommendation 6

Change management should ensure consistency and transparency in feedback loops for the communication of decision making to service users. Senior management must do what they say, avoid making promises that can't be kept, and provide early and clear explanations for changes in plan.

Evidence: Several revisions to plans for changes at the Highgate Centre appeared to be made in a last minute in an "ad hoc" manner. While the intention may have been to ease service user concerns, the evidence shows that this contributed to service user confusion and distress and had a negative impact of overall wellbeing.

Recommendation 7

The Council and the Trust should issue a joint formal apology to service users at the Highgate Centre for the negative impact on their wellbeing that resulted from the changes and poor management of the change process.

Evidence: The distress of service users has been compounded by a sense that their opinions were sought but disregarded, that poor management of the changes increased the risks to individuals and that their wellbeing was not prioritised or protected. A formal apology will not change what has happened but will assist their capacity to move forward.

NOTE: Camden and Islington NHS Foundation Trust and Camden Council have provided a written response to these recommendations which is published in full as Annex 1 in the full version of the report.