
Healthwatch response
to Stockton Borough
Council's Adult Mental
Health Services Review

An independent study
of the views of service
users and carers
affected

Healthwatch Stockton-on-Tees &
Middlesbrough and Stockton
Mind



Contents

WHAT IS HEALTHWATCH?	3
INTRODUCTION	3
PURPOSE	4
METHODOLOGY	4
OUR FINDINGS.....	5
ADDITIONAL FEEDBACK FROM SERVICE USERS AND CARERS.....	16
THEMES & RECOMMENDATIONS.....	17
CLOSING COMMENTS.....	22
SHARING THIS REPORT & FEEDBACK.....	23
ACKNOWLEDGEMENTS	24
CONTACT	24
APPENDICES.....	24

WHAT IS HEALTHWATCH?

The Health and Social Care Act (2012) established Local Healthwatch as the new consumer champion for health and social care services for adults and children in England. Healthwatch Stockton-on-Tees aims to be a strong, independent, trusted and effective voice and a champion for local people, influencing health and social care delivery and supporting people to access health and social care services. It will strive to ensure the best possible quality and choice in health, social care and wellbeing services for the benefit of all living and working in Stockton-on-Tees.

Healthwatch is unique in having statutory powers:

- It can enter and view premises where health or social care services are provided
- It has a statutory seat on the Health and Well-Being Board
- Service providers have a duty to respond to Local Healthwatch reports and recommendations within 20 working days

Local Healthwatch can escalate issues direct to Healthwatch England and through them, the Care Quality Commission and ultimately the Secretary of State.

INTRODUCTION

Healthwatch has conducted an independent study to submit to the Stockton Borough Council EIT (Efficiency Improvement and Transformation) Review of Adult Social Care Services. This report will summarise the findings from the Healthwatch study as well as highlighting the emergence of pertinent themes. The report will go on to make key recommendations on the findings in order to feed into to the Stockton Borough Council's review.

Stockton Borough Council Adult Services and Health Select Committee are currently in Phase 2 of the EIT review process.

The services under review include: day services, rehabilitation, respite, link workers, community support workers, user and carer involvement and commissioned residential 24 hour care. In-house day services are provided at 70 Norton Road, and Ware Street provides out of hours day services, rehabilitation and respite services.

Further details of the review can be found by contacting Stockton Borough Council or at:

<http://www.egenda.stockton.gov.uk/aksstockton/users/public/admin/kab12.pl?cmte=CAB&meet=104&arc=71>

PURPOSE

Healthwatch did not seek to duplicate the activity undertaken by the Local Authority; rather, the intention was to add value by providing service users and carers with an independent means of highlighting their views. This approach intends to provide the Local Authority with detailed and credible responses from service users and carers who may not otherwise feel comfortable or confident in taking part in formal consultation activity.

The Healthwatch study therefore aimed to achieve the following:

- Offer service users opportunities to feedback independently in an environment where they felt safe and comfortable to speak openly.
- Provide the Local Authority with the honest perspectives of the affected service users and carers.
- Provide opportunities for service users and carers to talk fully about their experiences and therefore provide the Local Authority with additional qualitative data to utilise in the review.
- Ensure that service users and carers felt that they had a collective voice which would be considered when decisions are made regarding the changes proposed.

Why Middlesbrough and Stockton Mind?

Middlesbrough and Stockton Mind is an independent local mental health charity. They provide a range of services for local people and are heavily experienced in the field.

Middlesbrough and Stockton Mind is a member and delivery partner of Healthwatch Stockton-on-Tees, both organisations felt that Mind was best placed to lead on this project given their specialist expertise in working with people experiencing mental health difficulties.

METHODOLOGY

The Healthwatch approach to conducting this study focused on identifying the impact the proposals may have on people currently using the services under threat of closure. This decision was made to ensure that sufficient information was collected from those people most affected by the changes within the given timescale. Emphasis was also placed upon capturing service users' comments and opinions in order to obtain additional qualitative data. The Healthwatch study is detailed below.

1. An overview was gained of the Local Authority's consultation plan. This included the questioning format and schedule of consultation.
2. Services identified for closure were contacted providing details of the Healthwatch consultation. See Appendix A. Service users and carers were offered the opportunity to take part in structured individual or group consultation sessions.

3. Relevant stakeholders were also offered an opportunity to feedback on the proposed changes.
4. A semi-structured interview was devised. This was based on the Local Authority's own questionnaire for Phase 2 of their consultation. Opportunities were added to allow service users and carers to elaborate on their comments in more depth. For example, open questions and space for service users to ask questions and raise issues.
5. A timetable of meeting events was constructed in which visits were planned to talk to service users and carers at:
70 Norton Road Day Centre
Ware Street Resource Centre
New Horizons Outreach Group
Surge Service User involvement group.
6. Service users, carers and stakeholders were offered the opportunity to feed into the consultation on a 1:1 individual basis. See Appendix B
7. Throughout the process, anonymity and ethical issues were reinforced to service users and carers, both formally and verbally. Please See Appendix C
8. Feedback the report to service users and carers involved in the study with a follow up visit to each service. (After formal submission to Stockton Borough Council)

OUR FINDINGS

A total of 43 service users, carers and stakeholders took part in the consultation-see breakdown below at Table 1.

Table 1

Consultation	Service Users	Carers	Stakeholders	Totals
Norton Road	10	1	0	11
Ware Street	16	2	0	18
New Horizons	7	0	0	7
1:1 Phone Call	0	0	1	1
SURGE Group	6	0	0	6
Totals	39	3	1	43

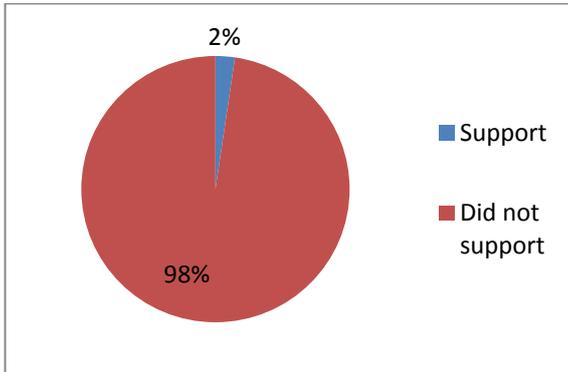
QUESTION 1



The Council say that 70 Norton Road and Ware Street (The Links Unit) are underused and cost a lot of money to run. In light of this they are proposing that these services close. If the decision is made to close the services, **would you support the proposal?**



There was a general lack of support for the proposal to close the facilities amongst service users and carers.



The majority of service users and carers stated they would be adversely affected by the closures. People felt that if the services were to close, they would become socially isolated and they would see deterioration in their mental wellbeing.

“It’s a lifeline for me”

“I wouldn’t see anyone for weeks if I didn’t come here”

“I would have no structure and wouldn’t know what to do with my time if it wasn’t here”

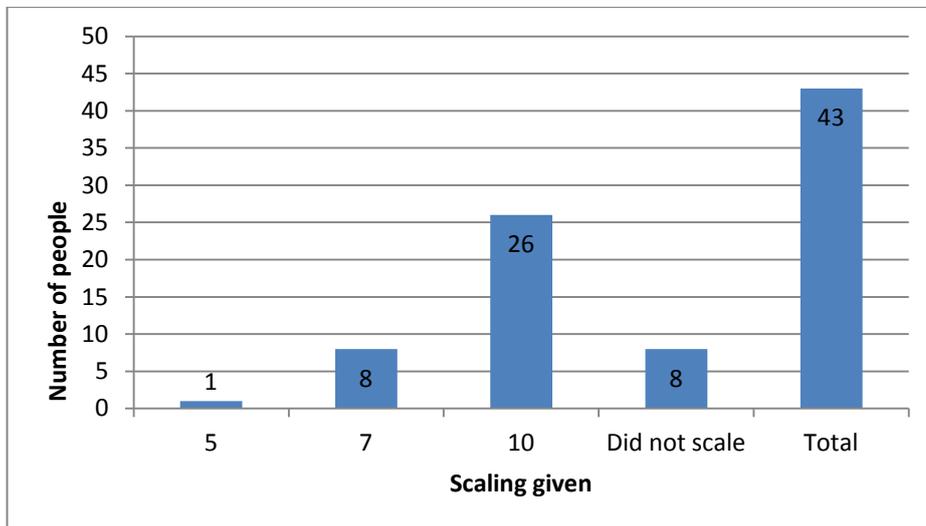
“If I didn’t have somewhere to go, I’d smash the house up and cry”

Concerns were expressed that if the services were to close, service users and/or carers may feel abandoned and would need careful monitoring or “leading by the hand” to alternative services.

Many service users felt that the admissions to in patient services would increase if these services no longer existed as a result of these factors having a detrimental effect on existing conditions.

QUESTION 2

How concerned are you about this proposal on a scale of 1-10 where 1= not at all and 10= very concerned?



QUESTION 3

Are you aware of the alternative services available to you?

There was a mixed response to this question which prompted many comments:

- The majority of service users were unaware of alternative services.
- Existing services that had been offered/signposted were considered unsuitable or inappropriate for their needs by some service users and carers.
- Some services being offered are not considered sustainable. Service users commented that they are worried about the future of other services such as Chat as they have seen some closures. People expressed that this makes them less confident about accessing alternative services.
- Service users did not feel confident and able to use other services as they had already built up trust and relationships within current services they accessed. People did not want to have to start this process with a new provider and/or staff team.

“I would not use another service; I’m used to coming here and feel comfortable and confident”

“It took a long time for me to build up trust and confidence with the staff here, I couldn’t do that again”

“Why fix something that’s not broken”

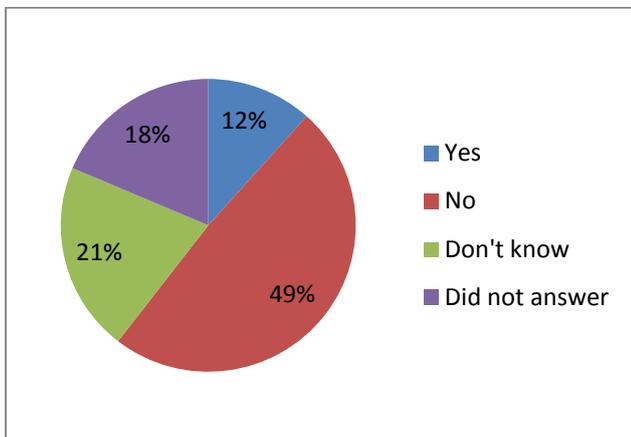
“I couldn’t use another service. I am used to coming here...comfortable, confident”

“We would prefer other options”

“Not enough information available ... if people don’t go to Norton Rd or Ware St, where is there to go?”

QUESTION 4

Would you be willing to work with the council and those who provide health and social care service to develop alternative services that may be more suited to your needs?



The majority of people were unsure about what this would mean for them and they were struggling to understand how they could contribute. Those undertaking the study felt that there was a strong feeling of consultation apathy throughout the process; service users commented that they felt sceptical about the Local Authority consultation and they were not confident that their feedback would be used in the decision making process.

In addition to this, there was a general feeling of suspicion around this particular question. Many Service Users referred to a conversation in which it had been proposed that they themselves take on the operations of the services under threat. When this was discussed, service users were very clear that they would not support this option. Some commented that they did not feel they had sufficient skills to undertake this work and also felt that the pressure would have a negative impact on their mental wellbeing.

In terms of identifying alternative provision, very few suggestions were made by service users. Many individuals said they felt current provision was effective and therefore they could not suggest better alternatives.

A number of service users and carers suggested that they would like to have a ‘menu’ of options to choose from rather than constructing service models themselves.

“We don’t know what else it out there”

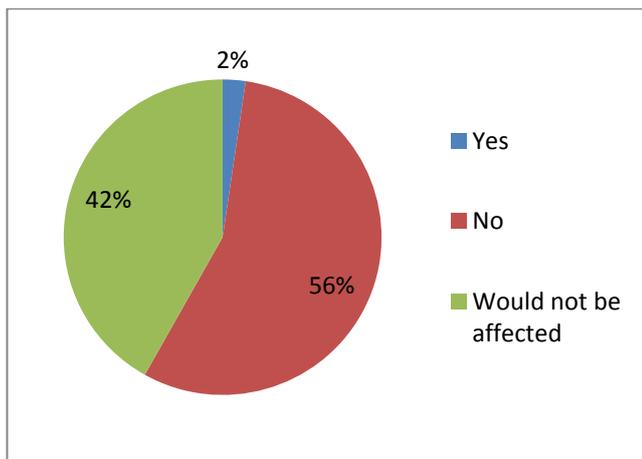
“There is nowhere else for us to go at the moment”

“It’s not our responsibility to make up new services the council should come to us -we are not the experts”

QUESTION 5



If Ware Street was to close, it would mean that respite services would no longer be available there. The council proposes to encourage service users to think about respite in a different way, such as short breaks away or someone coming to your home to offer support to carers. **If this was to go ahead, would you support the idea?**



This question was only answered in detail by those service users and carers who would be directly affected by the changes. Individuals who were not directly affected did not feel comfortable about responding.

QUESTION 6

How would this affect you directly?

Feedback centred on the effects of the proposals on carers including:

- An increased pressure on carers
- Mental Health of carers would deteriorate
- Mental Health of service users will deteriorate

Service users and carers commented that closing Ware Street would be unsettling, unfamiliar, stressful and “like starting all over again”.

Many service users and carers commented that the closure of Ware Street would have a direct impact on their individual mental wellbeing and lifestyle.

Service users and carers were unsure how to spend their personal budgets particularly on respite services and were unsure of alternative respite provision available.

There were a number of comments relating to inappropriate offers of respite provision. Some service users had been offered Residential Care Homes for elderly people and people with dementia. These were felt to be extremely inappropriate both in terms of the staff experience and skills level and also the age of the other people accessing the service.

“Respite service going would have a direct impact on my mental health - you may as well throw me to the wolves”

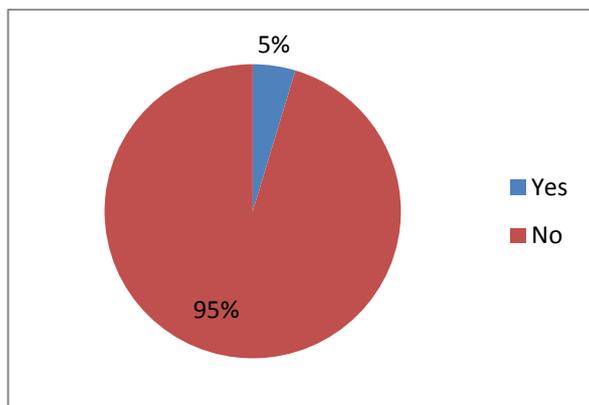
“We trust this place and the staff - we are like a family, we get a lot of peer support and we are like a community”

“As a carer I would have a meltdown if this place wasn’t here - come and live in my house and see what it is like”

“I have been offered alternative places but due to my age, they tend to be places with all elderly people. I don’t want to go there”

QUESTION 7

Would you be willing to work with the council and those who provide social care services to develop alternative respite services that may be more suited to your needs?



The feeling of consultation apathy was again apparent in relation to this question. Service users voiced suspicions about working with the Local Authority, suggesting the consultation was “tokenistic”.

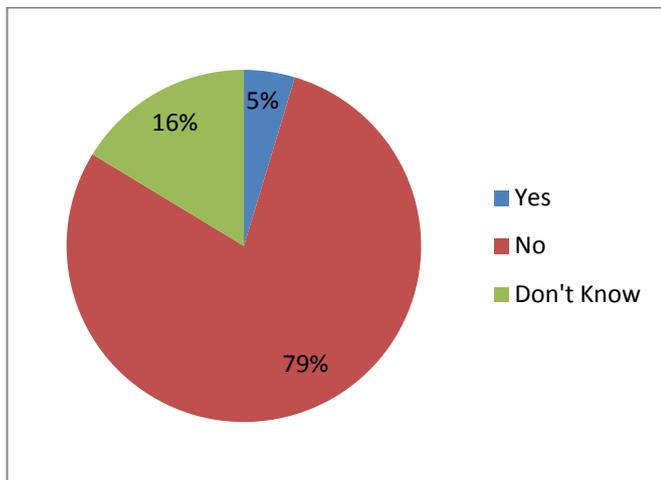
Service users and carers did not feel they had sufficient skills to be able to fully design their own provisions and also felt that the pressure would have a negative impact on their mental wellbeing. Very few suggestions were made by service users about possible future alternative respite service.

Many individuals commented that they felt current provision was effective and therefore they could not suggest better alternatives. As discussed in question 4, a number of service users and carers suggested that they would like to have a ‘menu’ of options to choose from rather than constructing service models themselves.

Question 8



The review proposes that Community Support and Link Workers support will now be offered for a maximum of 12 weeks to focus on recovery, with a view to longer-term support if it’s assessed that people require it. **Would you support the idea?**



The majority of the people engaged would not support the idea.

QUESTION 9

Will it affect you directly? Do you understand the term recovery?

The majority of service users and carers expressed anxieties about this proposal and felt that 12 weeks was too short a space of time. In addition:

- Many service users and carers did not understand the term recovery and what that meant for their treatment.
- They worried that relationships with existing key workers would become disjointed.
- Some service users were worried about getting to week 6 then spending the following weeks worrying what would happen when they got to week 12.
- There was an expectation amongst service users that at week 12 they would be dropped out of the service.
- The majority of the people engaged commented that this change and how it would be implemented, had not been effectively communicated to them.

“I would be counting down the days”

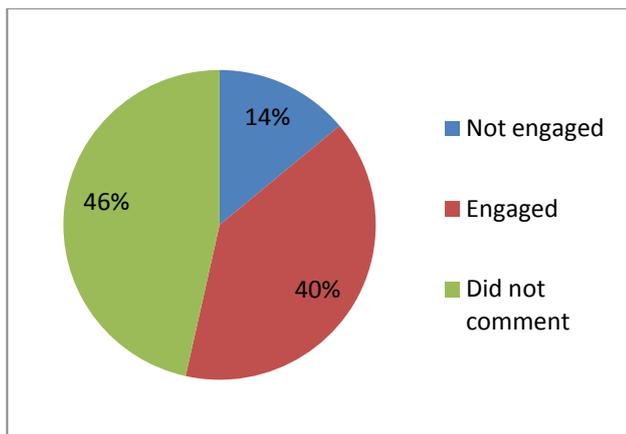
“I would feel as though we were getting fobbed off onto another service - we can’t mend you, so off you go to another service”

“How can you put a time limit on people getting better? - people are going to end up back in hospital”



Question 10

The council proposes that dedicated service user and carer involvement posts will cease. (A new strategy was published on 7th June 2013 supporting carers. The council plans to develop new services to support carers which are more flexible.) **Does this affect you directly?**



Service users and carers had engaged with the Involvement Posts in different ways. All the carers spoken to had engaged with the Carers Involvement Worker and over half of the service users were aware of the Service User Involvement post.

Of those service users who engaged fully with the posts, many gave emotional responses to the possibility of the roles ceasing. Emphasis was placed upon the advocacy provided and

support given to service users. Service Users commented that they had built up trust in their relationships with the post holder; should the post cease, they would be less likely to engage in services in the future.

QUESTION 11

How concerned are you about this (the involvement posts ceasing) on a scale of 1 - 10?

It was challenging to elicit accurate responses to this question. The proposal to delete the posts prompted emotional responses from those individuals who currently engage with the service. However, approximately half of those asked were entirely unaware that the posts existed. Discussion between these two groups therefore overshadowed the scaling process and the decision was made to omit the specific scaling findings from the report.

QUESTION 12

If you've used this support in the past, did you find it helpful?

Two of the carers who were interviewed stated that they had not found their engagement with the post particularly useful for their needs.

Some of the service users who engaged with the service user post found it extremely useful and valued the support they had received. In particular, comments were made about the post holder's knowledge and experience and how this had supported them to resolve issues and make progress.

Service users struggled to explain the full function of the service user involvement role. However, service users valued the advocacy support element of the post but were not able to describe the other responsibilities such as website and newsletter development.

"Built up my confidence speaking and stating my opinion. It encourages me to integrate in groups".

Some service users commented that the service user involvement post had supported them to attend the Patient & Carers Involvement meeting held at Ware Street and that they had found the Stockton User Representative Group for Empowerment (SURGE) Group to be supportive of their needs.

QUESTION 13

Would you still like to be involved in groups like SURGE if the service user and carer involvement posts didn't exist?

The majority of people who engaged with the posts felt that they would still like to engage in involvement groups. However they felt that they did not have the capacity and skills to continue, if a service user involvement lead wasn't available.

The majority of service users and carers interviewed felt that groups like SURGE would fold if the service user involvement post wasn't there.

The majority of service users and carers interviewed were not aware of other mechanisms to get involved and stated they would be reluctant to do so, due to the relationship they have with the current post holder. They also commented that they did not feel confident in their ability to have their voices heard without support.

Service users struggled to explain how they would be affected if the post ended. The majority of service users explained the role as more of an advocacy support role and did not describe the other features of the post.

“I wouldn't be involved if the post wasn't there I wouldn't have the confidence to complain or give my opinions”

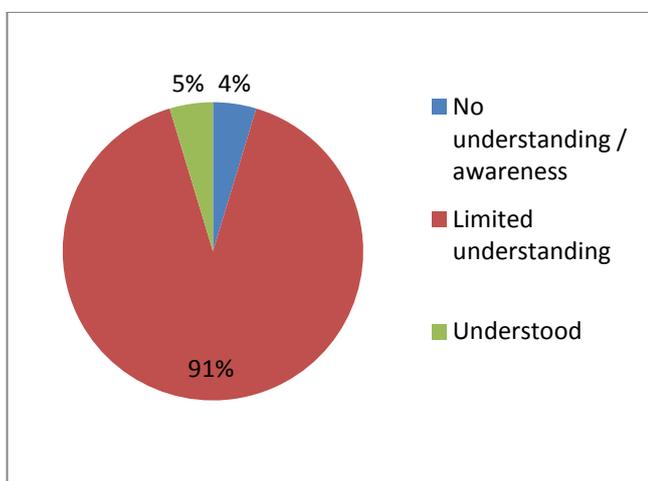
“How are people who are not well supposed to pick up all those extra responsibilities?”

“A lot of service users don't have the confidence to speak to people who they don't know especially those in positions of authority”

QUESTION 14



The council is encouraging service users and their carers to think about personal budgets and if they may be eligible for one, specifically to pay for future support and services. **Are you aware of personal budgets?**



The majority of the people interviewed had **limited** or **no understanding** of personal budgets.

QUESTION 15

Has anyone explained personal budgets to you?

A general anxiety existed around Personal Budgets. This was due to limited understanding and inconsistent experiences of the process. Personal Budgets was another topic which prompted emotional response from service users and carers. People described feeling anxious and scared for what the changes would mean for them as well as frustrated about the inconsistencies in the messages they had received.

- Some service users commented **“no one has talked to us”**. Service users and carers felt they were given mixed and inconsistent messages by professionals involved in their care.
- Service users and carers felt that professionals such as social workers did not always understand the process themselves.
- Service users lacked confidence in professionals’ expertise about personal budgets.
- The majority of people interviewed felt that there was nothing to spend their personal budgets on and that suitable options were not available.
- There was fear about using personal budgets for employing personal assistants due to employer’s responsibilities.
- Service users felt that existing services were of varying quality and not always appropriate for their needs.
- People felt pressured into using them and didn’t know how it would benefit them in the future.
- Service users and carers felt too much was expected of them regarding the management of the payments etc.
- Service users who had been involved in the process felt it took too long and that the process was very complicated. They felt this was more difficult if an individual was unwell.

QUESTION 16

How can the council help you to understand how to use personal budgets to get the right services and support for you?

- Some service users and carers interviewed would like the process to be explained to them in “layman’s” terms with less jargon to reduce confusion.
- It was felt that additional training for professionals was needed to ensure consistency of message.
- Service users and carers commented that they needed training on how to utilise their personal budget.

- Some service users and carers felt there should be a single point of contact within the council who was the expert on personal budgets again to reduce confusion.

QUESTION 17

Is there anyone else who you would like to help you to understand how to use personal budgets?

There were few suggestions as to who could support people in using their personal budget. Some Service Users suggested that family and friends could help them and others suggested key workers.

“I filled in the forms but didn’t hear anything for ages”

“No one talks to you about personal budgets”

“My partner couldn’t manage to set up a support plan by herself - there is too much pressure”

“No one really knows what we get out of it and what we can spend the money on - and if we don’t spend it we lose it”.

ADDITIONAL FEEDBACK FROM SERVICE USERS AND CARERS

Structure and Delivery of Services

- Some service users and carers asked if the local authority could combine Norton Road and Ware Street to save money and resources.
- People asked whether the option to combine services had been considered before the proposal to close all services was introduced.
- It was suggested that the services had been ‘run down’ over recent months and therefore services are operating under capacity levels. This led to the belief that this was a strategy put in place to justify closing services.
- A number of comments were made relating to a reduction in numbers of referrals being made to services; it was suggested that this was a deliberate move by the Local Authority to show services as operating under capacity.

“No referrals are getting made there anymore”

“Norton Road use to be good when we went camping and had dinner there. In the last year they have been running down Norton Road and not getting referrals anymore”

“Could you combine Ware Street and Norton Road? - Save costs by combining”

“The numbers are down - no referrals in the last year”

Feedback on the Local Authority Consultation Process

- Service users and carers were generally unhappy with the Local Authority's consultation process. Some people felt they had not been listened to.
- Some people felt the settings for the Local Authority consultations were too formal and they were therefore inhibited from making contributions.
- Individuals commented that in a particular Local Authority consultation session, they had raised their hands to make a comment, but this was ignored. They also commented they felt this was due to the events being chaired inappropriately.
- There was a general feeling that the Local Authority's consultation was tokenistic.
- Individuals commented that in a Local Authority consultation session, they felt that where an individual's comments supported the proposals, they were recorded. However, where comments did not support the proposals, nothing was recorded.
- People commented that some of the consultation minutes did not adequately reflect the conversation held.
- There were comments made by a large percentage of people interviewed that they felt the proposals were "a done deal", "rubber stamped" and that they felt the council was just "going through the motions" by consulting.

"Decision has obviously already been made"

"They want to shut the service down"

"This is just lip service"

THEMES & RECOMMENDATIONS

1. Perceived impact of proposed changes to Norton Road and Ware Street services

Of those service users and carers that Healthwatch Stockton-on-Tees spoke to there was significant concern at the potential closure of either Norton Road and/or Ware Street citing both the value of and trust built up within these services but also the potential negative impact on service users and carers if either of these were to close. This included the deterioration in mental health of both service users and mental health.

There was considerable scepticism about the process and a number of concerns expressed that the services had been deliberately been 'wound down' with less referrals and no due consideration had been taken to amalgamate services.

Recommendation 1.1

Stockton Borough Council need to consider the lack of support and negative impact the closure of these services would have on those that currently use Ware Street and Norton Road and demonstrate how this has been considered in any future decision making process.

Recommendation 1.2

Should Stockton Borough Council make the decision to close either of these services, additional work needs to be carried out with existing service users and carers to explore what future service models could look like and the benefits to service users and carers affected.

Recommendation 1.3

Should Stockton Borough Council make the decision to close either of these services, a clear timeline needs to be made available detailing a staged process. This should include development of alternative services prior to closure. This staged process needs to be timely and consider the use of 'leading hand' support for existing service users to ensure development of trust and confidence.

Recommendation 1.4

In the final report of the Adult Mental Health Services EIT review Stockton Borough Council should demonstrate any consideration for amalgamation of Ware Street and Norton Road as part of the review process.

2. Alternative Services

Service users and carers that were engaged in this study were generally not 'bought in' to the option of either existing alternative services or the development of new services.

Existing provision: many service users and carers felt that other alternative existing services did not meet their needs and in some cases were significantly inappropriate. There was significant emphasis on the importance of building trust with staff and an organisation which may have contributed to why some service users and carers did not want to consider other provision. However, the risk to sustainability of other projects was considered unsettling and a deterring factor in accessing other services.

Developing new services: many service users and carers were unwilling or uneasy about engaging in the development of new services. Reasons given included, a perception that service users and carers were not the 'experts' and lacked confidence in their own ability and knowledge. There was also some notable suspicion about why the local authority wanted them to be involved in the service development process.

Recommendation 2.1

Commissioning of future short/medium projects needs to give consideration to the potential impact on service users and carers with an expectation on service providers to appropriately manage expectations of and support to service users and carers.

Recommendation 2.2

Stockton Borough Council needs to engage with other statutory and third sector partners to develop choice and sustainability of services for service users and carers.

Recommendation 2.3

Stockton Borough Council and other partners need to work collaboratively and with service users and carers to build confidence to encourage involvement in service design and development at a time that is right for the service user and carer. This could include individually or targeted groups.

Recommendation 2.4

Stockton Borough Council and other commissioners need to look to strengthen communications about how service users and carers have influenced both past and ongoing decision to encourage involvement in future service design and development.

Recommendation 2.5

Effective communications of what is available to service users and carers to help facilitate a 'menu approach' to choice of services.

3. Personal Budgets

Those individuals that engaged in this study did not report positive experiences or perceptions of personal budgets generally. The concerns seemed to focus around four areas; individual understanding (both to apply and how to manage a budget and potential risks), professional awareness and communication, choice of service and the process to apply for a budget. Issues around choice and development of services are highlighted in recommendations 2.3, 2.4 and 2.5.

Recommendation 3.1

Additional ongoing communication needs to take place with existing and new service users and carers. This communication needs to be clear, accurate and at a time that is appropriate for the service user and carer.

Recommendation 3.2

Awareness of personal budgets needs to be developed with professionals within the local authority and those that service users and carers come into contact with in trusted settings. This needs to ensure consistent messages regarding the benefits of personal budgets, the process, how long this may take, how the money can be used and who the appropriate point of contact is.

4. Recovery

Many of the service users and carers engaged in this study did not have a clear understanding of the term recovery and what it could mean for their treatment and access to services.

Many individuals did not seem to have been prepared for the recovery model and felt this had not been discussed by professionals. There was a perception with a significant proportion of service users that they were under pressure to think about their treatment journey in 12 week blocks and had to get better in this time - increasing stress and anxiety.

Recommendation 4.1

Service users need to know from professionals involved in their treatment how the 12 week recovery model works in practice and what happens following the week 12 period.

Request for information 4A

Healthwatch Stockton-on-Tees seeks further information from Stockton Borough Council as to how the recovery model is being integrated locally and with stakeholders as a viable treatment option for service users. Additional information is requested as to how this is intended to be communicated to service users and carers.

5. Service User and Carer involvement roles

A number of those who engaged with the service user and carer involvement roles struggled to articulate the impact on them should the roles cease. However, overwhelming those that did were concerned about the loss of an important advocate support that they received from the service user involvement post and were anxious about the impact on groups such as SURGE.

Recommendation 5.1

If the decision is made to cease the service user and carer involvement posts then service users and carers need to be given appropriate support and information on alternative ways they can continue to be involved in groups like SURGE or other involvement mechanisms including support and guidance in helping the groups be sustainable where possible.

Recommendation 5.2

If the decision is made to cease the service user and care involvement posts then those service users and/or carers who have looked to the roles for advocacy support will need signposting to other appropriate advocacy services. This needs to be explored with identified services to ensure capacity and communicated clearly to those affected.

6. Local authority consultation approach to EIT review

A significant number of service users and carers engaged in this study highlighted concerns about the local authority approach to the review with many feeling the decisions had already been made. Of those who had engaged with the local authority consultation process some felt that the public meetings had been held in settings and/or formats that were not comfortable for many service users. A significant number of individuals felt they were unable to be heard and that their views were not accurately recorded. There was a general feeling of consultation apathy based on this perception of not being heard and not having real influence.

Recommendation 2.4 needs to be considered by Stockton Borough Council when reporting on the findings of this EIT review. Additionally:

Recommendation 6.1

In future consultation activity, Stockton Borough Council should consider alternative formats for managing public meetings. This is particularly true where a proposed service change has an impact on identified vulnerable groups; these groups may struggle to be heard around those who are more confident in articulating their views and appropriate provision should therefore be considered.

Recommendations for Healthwatch Stockton-on-Tees

As an early piece of work for Healthwatch Stockton-on-Tees the findings have highlighted key recommendations for Healthwatch development.

Recommendation H1

Healthwatch Stockton-on-Tees needs to network with identified service user and carer groups both included in this study and others across the borough to ensure awareness of Healthwatch Stockton-on-Tees and how they can get involved.

Recommendation H2

Healthwatch Stockton-on-Tees needs to promote the information and signposting function with service user and carer groups so that people can be signposted to other services including advocacy support.

CLOSING COMMENTS

As originally stated Healthwatch Stockton-on-Tees has not intended to duplicate any consultation activity undertaken by the local authority. Service users and carers who have engaged in this study are those most likely to be affected and have given full, detailed and thoughtful responses throughout. It is clear that this is an emotional and unsettling time for many and an opportunity to have an independent voice was welcomed.

It is acknowledged that due to the constraints of the consultation process overlapping the implementation of Healthwatch Stockton-on-Tees that this has necessitated a time sensitive approach focusing on those directly affected. With additional time Healthwatch Stockton-on-Tees would have sought additional engagement with other

service user and carer groups not directly affected to explore the issues further particularly in relation to the recovery model, alternative services and personal budgets.

However, Healthwatch Stockton-on-Tees has identified some key pertinent themes based around 6 main areas to feed into the EIT review process and has a series of recommendations and one request for information that will be formally submitted to Stockton Borough Council.

SHARING THIS REPORT & FEEDBACK

In addition to a formal submission of this report to Stockton Borough Council as part of the EIT review of adult mental health services, Healthwatch Stockton-on-Tees will also make this report publically available via the website www.healthwatchstocktonontees.co.uk. Hard copies of the report (including in accessible formats and other languages) are available on request by contacting the Healthwatch office.

Healthwatch Stockton-on-Tees recognises the need to feedback to those groups and individuals who took the time to feed into this study. Groups involved as part of this study will receive a copy of this report, the response from the local authority to the reports recommendations and the local authority's' final report into the overall review.

Healthwatch Stockton-on-Tees is committed to sharing its work widely as it is recognised that many of the findings and recommendations will apply to other commissioners, providers and the third sector both now and in the future. To support this, copies of this report will be sent to:

- Chair of Stockton-on-Tees Health & Wellbeing Board
- Director of Public Health (Stockton-on-Tees)
- North East Commissioning Support Unit
- Chair of Hartlepool and Stockton-on-Tees NHS Clinical Commissioning Group
- Mental Health lead Hartlepool and Stockton-on-Tees NHS Clinical Commissioning Group
- Tees Esk and Wear Valleys NHS Foundation Trust
- North Tees and Hartlepool NHS Foundation Trust
- Catalyst
- Synergy

ACKNOWLEDGEMENTS

Healthwatch Stockton-on-Tees and Middlesbrough and Stockton Mind would like to thank the following groups and individuals for freely giving their time and views to this study:

- Service users, carers and staff at 70 Norton Road
- Service users, carers and staff at Ware Street (The Links Unit)
- Previous Local Involvement Network Mental Health lead (to March 2013)
- SURGE group members and staff
- New Horizons Outreach service users

CONTACT

If you would like to discuss this report with anyone or would like to request a hard copy of accessible format, please contact the Healthwatch Stockton-on-Tees office on:

Telephone 01642 688312

Email healthwatchstockton@pcp.uk.net

Post Healthwatch Stockton-on-Tees
Catalyst House
27 Yarm Road
Stockton-on-Tees
TS18 3NJ

APPENDICES

- Appendix A: Invitation to participate letter
- Appendix B: Stakeholder organisations contacted
- Appendix C: Semi structured interview questions
- Appendix D: Participant information sheet
- Appendix E: Comments and feedback sheet

Appendix A

18 April 2013

Dear

My name is Vicki Henderson - Thynne, I work for Middlesbrough and Stockton Mind and I am working with your local Healthwatch team.

As you may know, Stockton Borough Council are currently reviewing Adult Mental Health services and are proposing a number of changes to services in Stockton on Tees. You can view the proposed changes on the Council's website at www.stockton.gov.uk/yourcouncil/consult/currentconsultations/adultmentalhealthservicesreview. We want to encourage and support you to provide the Council with feedback. You can either do this yourself or we can offer help you to contribute to the review in our role as independent consumer champion for everyone who uses mental health services in the Borough.

If you (or anyone you know) fall into this group, and would like to provide feedback through Healthwatch, please get in touch as soon as you can. We will be gathering feedback in a safe and supportive way and are happy to meet people where they feel most comfortable for example on a one to one basis or in a small group and in a choice of locations. For further information, or to arrange a discussion, please contact me in confidence by phone or by email on:

01642 688312

Vicki.henderson-thynne@middlesbroughandstocktonmind.org.uk

Kind Regards

Vicki Henderson - Thynne

Appendix B

Stakeholder Organisations contacted

Moses Project

Eastern Ravens

Bridges

New Horizons

Middlesbrough and Stockton Mind

Surge

The Link

Alliance Psychology

Former members of the Stockton LINK Mental Health Subgroup (LINK ended on March 31st 2013)

Appendix C

- Semi Structured Interview Questions for Consultation:

- It has been identified that 70 Norton Road and Ware Street (The Links Unit) are underused and cost a lot of money to run. In light of this it has been proposed that these services will close. If the decision is made to close the services:
 - Would you support this idea?
 - How will it affect you directly?
 - How concerned are you about this?
 - Are you aware of 'alternative services' and what they look like?
 - Would you be willing to work with the council and health and social care to develop alternative services that may be more suited to your needs?
- If Ware Street was to close it would mean that respite services would no longer be available there. The council proposes to encourage service users to think about respite in a different way, such as short breaks away or someone coming to your home to offer support to carers. If this was to go ahead:
 - Would you support the idea?
 - How would this affect you directly?
 - Do you have any ideas about how you would like to use respite services?
 - Would you be willing to work with the council and health and social care to develop alternative services that may be more suited to your needs?
- The changes regarding Community Support and Link Workers propose that support will be now be offered for a maximum of 12 weeks to focus on recovery, with a view to longer support if it's assessed it's needed.
 - Would you support this idea?
 - How will it affect you directly?
 - Do you understand the term recovery and what it means?
- It is being proposed that the dedicated service user and carer involvement posts are to cease. (A new strategy is to be published on supporting carers and the council plans to develop new services to support carers which are more flexible.)
 - How does this affect you directly?
 - How concerned are you about this?
 - If you've accessed this support in the past, did you find it helpful?
 - Would you still like to be involved if these posts didn't exist?
- The council is encouraging service users and their carers to think about personal budgets and if they may eligible for one, specifically to pay for future support and services.

- Are you aware of personal budgets?
- Do you understand how they affect or benefit you?
- Have you been given much advice and information about them so far?

Appendix D

Thank you!

Thank you for your help today by telling your local Healthwatch what you think about the Council's review of adult mental health services.

All information you have provided will remain anonymous and you will not be identified without your consent. We may however, use direct but unattributed quotes in our response. If you have any other questions about how your information will be used, please contact Healthwatch -details below.

What is Healthwatch?

Healthwatch is the new independent consumer champion for everyone who uses health and social care services across the borough. It aims to ensure that everybody has a voice in the way health and social care services are planned and delivered.

Healthwatch is a membership organisation which aims to ensure the widest possible range of communities and interest groups can get involved in our work and we strive to give a voice to vulnerable people and seldom heard groups.

Information and Signposting

Healthwatch Stockton-on-Tees now also provides information about local health and social care services and provides information about how to complain about a health or social care service and where to go for help and advice.

Contact Healthwatch Stockton-on-Tees

If you would like to join Healthwatch, find out more or receive a copy of the report please contact:

Healthwatch Stockton-on-Tees

Catalyst House

27 Yarm Road

Stockton-on-Tees TS18 3NJ

Email: healthwatchstockton@pcp.uk.net

Telephone: 01642 688312

www.healthwatchstockton.co.uk

Middlesbrough and Stockton Mind

Healthwatch Stockton-on-Tees is working together with Mind to help ensure we reach people who use mental health services, their carers and groups and work collaboratively with organisations who provide mental health services and support.

For more information about Mind contact:

Vicki.henderson-thynne@middlesbroughandstocktonmind.org.uk

Appendix E

Semi-structured interviews feedback sheets

Proposed changes to services at Norton Road and Ware Street

“The services are too expensive for me to attend”

“If you are on benefits you don’t have to pay so anyone not on benefits, how can they afford it?”

“People would attend the services if they were not as expensive”

“I use to go 3 times a week then it went to 2 times a week. Funding was then taken away from me and no one ever spoke to me to tell me why. I wrote to the council but never heard anything back”

“Money is put before the health and wellbeing of people”

“No referrals are getting made there anymore”

“Norton Road use to be good when we went camping and had dinner there. In the last year they have been running down Norton Road and not getting referrals anymore”

“If I didn’t have somewhere to go, I’d smash the house up and cry”

“Since putting the cost of services up, along with bedroom tax and buying food, clothes and paying for electric, I can’t afford to go”

“I use to go to Ware Street 4 times a year to give me piece of mind. If I really want respite the CPN sent me a list of places to go. The general cost was £500 per week. I would rather stay in the Travelodge for that cost”

“I would support the idea, I believe the money can be spent in better and more modern ways”.

“concerned that that service users may feel abandoned if the services were to close and believe that they may need careful monitoring or leading by the hand to alternative services”

“Service users don’t know about alternative service available or what new services could look like. Suggestions by the council weren’t suitable for this particular service user group and some weren’t sustainable.”

“if people don’t go to Norton Road and Ware Street where is there to go”

“Can we combine Norton Road and Ware Street”

“Chat’s closed - our place”

“Straight here from hospital? - 1/3 price to be here rather than hospital”

“I don’t want personal budget stuff, I just want to go to Norton Road and Ware Street”

“They want to shut the service down”

“These are humans - lives are at stake”

“Decision has obviously already been made”

“Charges are the problem. People can’t afford to come. Very expensive. £70 pw”

“Causing lots of anxiety. I’m poorly through it”

“ It’s because it’s mental health”

“Staff are invaluable”

“Where is respite?”

“How will we pay?”

“I would see nobody else for a week”

“It’s a lifeline for me”

“I trust the staff here at Norton Road”

“Been coming here for over 5 years - gets me out of bed in the morning”

“Numbers are down - no referrals in the last year”

“Norton Road → good, relaxed, family, support, unsure of alternatives, staff are really supportive”

“Could you combine Ware Street and Norton Road? - Save costs by combining”

“The activities at Norton Road are good”

"It's good here. It keeps me well"

"I get good support in all ways, good link worker, relationship, come here"

"I wouldn't see anyone - socially excluded"

"It took a long time to build up trust/confidence to even come close to Norton Road - so a big wrench to lose facility"

"Have no structure, no idea what to do with time - housework?"

"Nowhere else to go"

"There is nothing else we could go to"

"Lighthouse → can't refer"

"Housebound , I fear of going out"

"I'll get unhealthier"

"I couldn't use another service. I am used to coming here, comfortable, confident"

"I don't know if wouldn't work with other services"

"Taken a long time to build up trust and close relationships"

"Why break something not broken"

"Other services are too managed and too informal I got no help. Not suited to my needs"

*"I'm aware of other places but ***** go there and I don't get on with them"*

"I have been offered alternative places but due to my age, they tend to be places with all elderly people. I don't want to go there"

"what would happen if we needed to talk to someone? That is why we come here"

"Groups like this are what we want. The friendship in this group is valuable as everyone has been through so much"

Ware Street and respite services →

"Would put a strain on relationship with carer"

Doesn't feel alternatives like homes for dementia or equivalent are suitable for her needs and are inappropriate for some MH conditions. MH would deteriorate. Doesn't know what else is out there, not really thought about alternative ways of using respite apart from short breaks.

*“Choice taken away”
“Different people different needs”
“Trust issues”
“Don’t want to talk to strangers”
“Going over your past again if no consistency of staff”*

*“I’d meltdown” (carer)
“We need space, come and live in my house - see what it is like”
“If I didn’t get respite - I wouldn’t cope”
“Throw me to the wolves”
“It is unsettling” (the changes)
“After respite it was brilliant when got home”
“No respite will have a direct impact on my personal well-being” (Carer)
“Alternatives such as care homes for dementia. They are not appropriate, detrimental to well-being and they couldn’t meet my needs”*

*“We are like a family; we know each other and there is a sense of community”
“Current provision is essential”
“We trust these places; these staff”
“Can’t we put services into one place”
“Who is responsible for underuse? - people don’t want to pay, needs something to lure people”*

Proposal for maximum of 12 week work period with Community Support and Link Workers →

“My CPN and social worker are changing all the time. It doesn’t help my condition as I just get to know one person and then they change. There is no continuity and I feel like I am starting from square one as I have to keep explaining over again and I don’t want to keep going over it”

“The workers do not get to know the person. If I could build up a relationship with the workers it might improve how I feel”

*“If I was to recover, I wouldn’t have *****”*

“I can be okay one minute and snap the next”

“It has been explained to me that after 12 weeks I will be out of the system”

“I don’t support the idea of 12 weeks for recovery”

“Too short. People can’t recover in that time. People fall through the net and go to crisis

Isolation - if I lose support worker, I lose someone to talk to

Consistency of relationships, have to start again

Worrying for the 5 weeks before 12 = impact on my health

Long-term conditions different

12 weeks is too short - unsupportive

Counting the days down

Feeling the pressure

How can you put a time limit on getting better

Feel as though we're being fobbed off

Pushing responsibility onto SU's

We can't mend you - send you on

People will end up in hospital - more expensive than running this building

We have really good relationships with link workers and CPNs. We trust them. If this is stopped it would have an impact on MH

The model is too medical, MH takes longer to recover from, MH is different as everyone is different

Service user involvement and carer posts→

"There will be less people to talk to"

"By talking to the staff in these roles, it encourages me to integrate with others"

"Information is conveyed and explained to service users through these roles. If these roles went, there would be a lack of information and I probably wouldn't come. It is my safety net"

"The staff in these roles make me more confident about coming"

"I feel like these roles are the last link if you need support. If they went I would be by myself"

"I would like to still be involved if the roles went but it would be hard. You need someone you can trust"

"The staff in these roles support volunteers involved in the group. The volunteers encourage other service users to come along"

SURGE couldn't exist without the role the worker has too many responsibilities for them to pick up due to their capabilities, particularly when unwell.

Shooting themselves in the foot ditching position → people MH having confidence to speak up. New people you don't know - new

Carers involvement jobs not useful really for me

PPI meeting engagement - found it really useful

I grew like a mushroom - confidence

Posts - Know who and can speak to right person

Wouldn't be involved

Surge has been really supportive

Don't know if you could do the Surge role without a service user involvement worker

Encouraging services users and carers to use personal budgets to pay for services →

"The Council send people who understand but they talk in office language. We need information in plain English"

"personal budgets take a long time"

"Provide the right information and support on how to manage a personal budget"

"Local authority to put in place strategies to control and manage"

"People are very anxious as the message is not clear"

"If I'm not feeling very well, sometimes I don't make good decisions"

"A lot of service users are already in debt. A personal budget can be seen as an extra strain"

"I wouldn't feel happy holding money"

"A personal budget would have to be used at the right time for the service user"

"If it was on a credit card"

Don't feel that SU's are and have been well informed about personal budgets, feels it is improving but knowledge amongst most professionals isn't there. Feels personalisation agenda needs to take priority as there is now much pressure on other associated services such as CAB and Carr Gom (due to welfare reforms etc) which this is further impacted by this. Not confident that this will work well and feel we need professionals who have expertise and are willing to challenge local authority.

*Feels fear is stopping people from using them, particularly issues to do with hiring PA's.
Feels that SU's don't have options to spend money on quality services as there isn't any.*

They felt that more information was needed and that all professionals gave out consistent messages which were accurate.

They felt a lack of understanding would get in the way of using PB's.

The consensus was that the group did not know a great deal about personal budgets and how to use them. They did not feel that enough information had been given by professionals and that the process was too confusing and long.

It's taken me 3 years to go through the process

Far too complicated - stress and anxiety, inconsistency of message

No information given. No real clarity. Contradictory messages

Physical → mental health = different rules. Big difference in process between physical and mental health

Peoples' expectations of the process, how long, what can we get - need to manage expectations out of it?

Too many chiefs. Took one month for an indicative budget

No-one talks to you about personal budgets

General feeling of inconsistency

Staff's knowledge is poor, SU/C have to be proactive

I don't read but I have a personal budget - don't understand it

Inconsistency

Need clarity from council - especially on timing

Need to have a consistent message

We're not the experts

*They could appoint an expert officer
One set of rules - single point of contact*

Dragging their feet so you lose your budget

Admin. means we're losing out

Someone with knowledge. CPNs, not SWs

Very inconsistent messages

Keep changing format

SW champion approach - not worked, bad experience with SW - tax payers' money

Want it to be up and running, works in practice before we progress

Can't use council services

*Much more explanation needed - professionals don't seem to understand
Should not have been brought out without having a full understanding*

The money spent on other things too much responsibility

Vulnerable to safeguarding issues - what protection is in place

Being an employer. Responsible for sick, hols. Very expensive to have a personal budget PA

Not really money - virtual money?

Bank account? - clarification needed

*No-one really talked to us about personal budgets. Filled in forms then heard nothing. Money
been outlined but not supposed to use. Lack of clarity with staff about what to do next, how
to set up*

*We're unsure about what personal budgets are, people haven't had it explained, limited
understanding of personal budgets, councils should be better at helping us use personal
budgets*

Want to use personal budgets as a group - council give alternative to choose from

*How can the council help you to understand how to use your personal budget to get the right
services and support you?*

When money allocated - how money managed? Pressure

Who manages money?

*Who is responsible?
Where to start?*

Who makes decision about how to spend?

Is there anyone else you would like to help you understand how to use your personal budget?

Team at Norton Road

Care coordinator

Additional comments

“If it aint broke don’t fit it”

“The decisions have already been made, the consultations are just a formality” -

“it’s a done deal”

The notes from the meeting SURGE had with council officers in March did not reflect the conversations that were had and the quantity of conversation held. The meeting was not well chaired.

Alternatives to the SU involvement role could be regular involvement events in the town centre which would promote mental health awareness and destigmatisation

Consultation 1 - People didn’t attend as they didn’t understand potential closure

They didn’t expect so many people to turn up to phase 2 consultation

- *Leading question*
- *Why don’t you club together and run building - this isn’t realistic, they know we can’t*

Giving us lots of responsibility and pressure

This is so frustrating. Having a big impact on my health. Have felt very low since I found out.

They’ve made up their minds already. They’re not listening

Can they move to a smaller building?

Going in blind

Not informed

We would prefer options

Not enough information available

There’s just a price on your head

Options to choose from

Consultation meeting at the library:

Head of housing; mental health - what do they know

Waste of time

Felt they weren't listened to

Minutes were inaccurate - promoted personal budgets, pool money together

My partner couldn't manage to set up an alternative provision alone - too much pressure

Going to end up in hospital - all cost-cutting

No-one understands! - who could help → link workers

The information booklet was very wordy and top heavy.

Not all service users in attendance received the booklet.