

Listening to ...

The thoughts and feelings of people who use mental health services in Hampshire and the Isle of Wight

**Hampshire and Isle of Wight Mental Health Service
User and Carer Engagement and Experience
Literature Review (2016-19)**

June 2019

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1. Introduction

The aim of this project, which was commissioned by Wessex Clinical Network and Hampshire and Isle Wight Sustainability and Transformation Partnership (HloW STP), was to identify key themes from existing mental health service user and carer experience and engagement reports across Hampshire and the Isle of Wight.

Wessex Voices undertook an independent review of national and local information from the last three years to create this thematic report summarising people's views of mental health services. We have identified themes that are cross cutting (i.e. that come up across all services); and some that are specific to different areas of the mental health pathways for adults; and then for children and young people's services.

From our findings, we make recommendations about areas that the mental health system may wish to explore further with people. We also suggest some that may help improve processes around gathering people's feedback; engagement and coproduction.

2. Methodology

We asked all local mental health service commissioners and providers, including the voluntary sector, to provide us with their service user/carer experience and engagement reports from the last three years. We also researched websites and spoke to commissioners and providers. The full list of the reports we reviewed can be requested.

It should be noted that apart from the Women's Taskforce, the Hampshire Autism Consultation, notes from a consultation with 6 lesbian, gay, bisexual and trans (LGBT+) young people, and the Portsmouth Student Wellbeing report, we did not find feedback from seldom heard groups, making it difficult for us to identify themes relating to these groups. Equality monitoring information in reports was also generally limited, and usually only captured age and gender, not the other protected characteristics.

We recognise that this is an initial attempt at gathering information from a wide range of different sources and that there may be other information in existence. If other information is available, we recommend sharing it across the system and reflecting on whether it changes the nature of the findings in this report.

The exercise of finding and accessing this information itself highlighted some learning, from which we make some specific recommendations.

Learning from this process

- It was time consuming and resource intensive to source and gather existing experience and engagement feedback from services across Hampshire and Isle of Wight from scratch.
- The degree and quality of the service user and carer engagement, and the reporting of service user experience, varies widely.

Who has done this well?

Solent NHS Trust's quarterly patient experience reports are easy to find on their website and provide consistent evidence that they are listening to their patients' views and responding to them in order to shape their services. The reports include information about physical and mental health, and are easy to read and understand.

- Long reports had to be searched using common terms, such as complaints, engagement, consultation and experience, to see if they contained relevant information around mental health services.
- Finding publicly available reports was sometimes difficult because information is included in general committee reports, rather than service user engagement / experience sections of websites, or reports were poorly labelled.
- Much of the experience / engagement intelligence held by the voluntary sector and some statutory services, including schools, is anecdotal and informal.

Recommendations

Reports could be made more accessible, both for readability and transparency, by:

- Producing short, clear summaries of the report findings and recommendations.
- Clearly labelling and dating reports with relevant, user-friendly titles and publishing them on organisations' websites under 'involvement' or 'experience' sections.
- Creating a public, searchable central repository for such reports (across all services), or utilising an existing tool, like the Patient Experience Library, and facilitating access to it for staff.
- Exploring ways to share anecdotal and informal feedback, alongside planned engagement feedback, particularly to identify where anecdotal feedback needs to be researched further.

3. Key service user and carer experience / engagement themes

Section 3 covers feedback and engagement themes for those that:

- a) Cross cut all services
- b) Are specific to adult/older people's mental health services
- c) Are specific to children and young people's services.

It should be noted that most of the reports we reviewed focused on areas for improvement rather than what works well. We have, however, pulled out some good practice (green boxes); and are also aware that organisations may well be working on improving services based on people's feedback, for example, around peer support; restorative practice; and new quality improvement approaches.

a) Cross cutting themes from HloW's mental health services

Six cross cutting themes were identified from the feedback:

1. Service user and carer engagement is valued
2. More effective signposting is needed
3. Better training is required
4. Safe, comfortable environments are important to people
5. Support is valued, and people need this early in their experience through to recovery
6. Understanding and planning is vital, particularly at discharge

1. Service user and carer engagement is valued

People valued being engaged throughout all areas of mental health services. Service users wanted to have their input into how services worked and how they should run, and they want to see evidence of this being done through sharing with forums and 'You said, we did' reports. They repeatedly said that services needed to reflect the needs of the population that use them and their reflection was that this is not the currently case.

The themes discussed in this report reflect the reasons why people feel that the services do not reflect the needs of the user. Some organisations have had positive feedback about how their engagement shapes what they do. These may be useful examples of how to improve engagement of service users across services.

Certainly, the Children and Young People's commissioners we spoke to gave a strong verbal commitment to improve how young people are involved in shaping services. The current training by Young Minds 'Amplified' workshops and Restorative Practice training should support a developing culture of young people's involvement.

Who has done this well?

- a) Richmond Fellowship’s service users say they feel involved in the way the organisation is shaped and run.
- b) The Hampshire Mental Health Transition Care protocol was developed in partnership with key stakeholders, including young people, their families, health, education, social care and voluntary sectors, to address the holistic needs of young people who move from children’s to adult’s services. There is an ongoing group, which includes young people, who work together on ‘transition’ for 16-20 year olds to start planning and create a readiness for this process.

2. More effective signposting needed

Effective signposting is seen as the key to accessing support for mental health issues, but people said that the knowledge about local services needs to be better for GPs, other professionals, service users and carers. For example, Portsmouth University students gave positive reviews about their student support services, with 80% saying they would recommend them to a friend, yet they felt that students were not aware that those services were available.

People also said that signposting should be specific to the individual, for example directing people to groups that specialise in different cultures and conditions. More needs to be done to make children in care and care leavers aware of the types of support available to them by putting information in places where they might see it, not just on local council websites.

People recommend having one place to go for information and ease of access to relevant local mental health services. A ‘single point of access’ could bring together the NHS and voluntary sector to share information and to enable service users to have a clearer idea of what services are available. Multiple suggestions were made as to what this would look like - a phone line, online portal, and email contact.

Who has done this well?

- a) [Hampshire Youth Access \(HYA\)](#) is a partnership of 12 leading agencies providing counselling, information, advice, and support to children and young people aged 5 to 17 across Hampshire. The overwhelmingly positive response means that they currently have long waiting lists.
- b) Child and Adolescent Mental Health Services (CAMHS) [website](#) has had high use in its first year and users reported very positive feedback.

3. Better training is required

People said that training needs to be improved for both professionals and service users. People recommended “mental health first aid training” for everyone and it is understood that over 180 people have been trained in this or Connect5 in the last year.

Service users also suggested that they would benefit from training on general coping skills and emotional wellbeing. Both service users and carers wanted training in recognising symptoms early to prevent an escalation to crisis. People thought that this would be especially useful for child carers as it could help them to recognise their parent’s symptoms and get help. Carers also said they need more training in how to deal with negative feelings towards those they care for.

GPs are often the first port of call when it comes to people seeking help, but they were consistently said to need more training on mental health issues and on how to approach and support people, including for those with specific needs like those with Autism (see other sections of this report for more specifics).

Other services, such as education, were also identified as needing more training to reduce stigma and support people with mental health issues, which reflects the new NHS long term plan to invest in mental health teams associated with schools.

Who has done this well?

North East Hampshire and Farnham CCG and Healthwatch Hampshire engaged with GP practices and service users to explore how they can improve the experience of patients with mental health issues. [Click here](#) to read more.

Service users suggest that GPs should have more mental health training, or people should have access to a mental health practitioner in every surgery to be immediately referred to.

4. Safe, comfortable environments are important to people

People say that, across the range of services, the physical environment, such as lighting and seating, and the atmosphere created by staff, is really important to them. The environment can also affect how comfortable people feel to talk to a healthcare professional.

Examples were that the atmosphere in GP waiting rooms can provoke anxiety due to uncertain waiting times; and some people said that they were reluctant to go to Safe Havens because they feel judged by the staff.

Young people want to access community support, with age appropriate activities and environments. For example, despite the Safe Haven Café, Aldershot, being a short walk away young people said they are not keen to access these because adults also use them.

Who has done this well?

Reviews of older people's mental health by Solent showed that GPs made them feel comfortable and took the time to understand them.

5. Support is valued, and people need this early and until recovery

People highly value and need support when experiencing mental health issues. When facing difficulties, they want to access support quickly but feel they have to wait for a long time for appointments and referrals. If this is a repeat crisis they often go back to their GP and have to start from the beginning of the process again. Other users suggested that if preventative measures were in place while waiting for support, their situation would not have escalated to a crisis point. An example of where this is now happening is on the Isle of Wight, where Barnardo's will be providing support to children on the waiting list for an autism diagnosis.

There are many types of support but the most highlighted form was peer support. People want to access to peer support from the beginning (accessing treatment) to the end (post recovery), and they would like to see it offered throughout all pathways. Many of the services have begun to introduce peer support, however service users have said that they want to see more of this.

Peer support was valued so highly because service users felt that only people who had been in their situation could truly understand them.

Children and young people also highly value meaningful and supportive relationships, including young listener or peer to peer approaches, as well as with mental health professionals. They also highlighted it was important for them to remain autonomous and independent rather than adults taking control.

When young people are given the opportunity to share their experiences with their peers it leads to greater support.

Who has done this well?

Solent's Friends and Family Test results showed older people felt that they were seen for appointments and diagnosed fairly quickly, however there was no explanation as to why this process was quicker for older people.

6. Understanding and planning is vital, particularly at discharge

Services users highlighted their need to be able to understand the ‘system’ when it comes to mental health issues; and find planning vital so they know what to expect and aim for at the next stage of their recovery. Two key themes were:

- They would like more understanding of their rights and entitlements.
- They would also find it helpful if letters and discussions were in plain language and jargon free.

Service users’ feelings were particularly negative about the discharge process. They outlined that it is often sudden and unexpected, leaving them feeling abandoned and unsupported.

Who has done this well?

Healthwatch Isle of Wight’s Annual Report looked at patients’ reviews of discharge from inpatient wards. Patients on the Isle of Wight positively reviewed their discharge due to their extensive planning.

b) Themes specific to adult mental health services

Here we identify some key themes in the feedback and engagement about adult mental health services.

Pre-crisis

Lack of effective signposting

There is a lack of awareness by both the public, and GPs and other professionals, about information and local sources of support for people who are beginning to experience mental health issues. People highlighted that it is difficult to access support when they don’t know what is available, pointing to the need for a “single point of access” as previously outlined.

Difficulties accessing services

There are more services, such as well-being cafes, available in the bigger towns. People who live outside these areas find it harder to access a support network that will prevent them from reaching crisis. This is often due to poor transport links.

Effective communication between service users and primary care staff is also key, but this is sometimes hindered by language barriers and specific communication needs. Autistic people, and people whose first language is not English, reported communication barriers with their GPs, which prevented them accessing appropriate support.

Not being understood

A general finding across all areas of Hampshire and Isle of Wight was that adults with mental health issues felt that they were not understood, particularly by GPs.

- Service users said the extent of their conditions are not fully understood.
- They want GPs to understand that each person with the same condition will be different, which would require a them to listen and understand people's individual needs.

Autistic people found that when they sought help for a mental health concern they felt it was treated as a symptom of their autism as opposed to a separate issue, which meant they could not access the support that they needed.

Crisis

Poor knowledge and access to crisis services

People are generally unaware of local crisis support and how to get to crisis facilities, particularly where transport links are poor. Using a phone when in crisis is particularly difficult for some people, e.g. those with autism, and some of the types of advice given by services, e.g. have a bath, were deemed unhelpful.

There were mixed reviews of the police by people in crisis. Some people said that they were really useful, others said that they lacked understanding.

Service users believe crisis services need further investment and development. People reported gaps in provision, e.g. between mild and severe levels of support needed when in crisis; around support lines; and support for different conditions. No solutions were proposed and there is a lack of detail in the reports.

We have been informed that since these reports, a 24/7 111 mental health triage pilot has been launched for HloW.

Staff who understand are valued

Service users really value the staff at crisis services who are patient, supportive, empathetic, and easy to communicate with.

Service users want staff to be empathetic, not sympathetic.

Rehabilitation

Continuity of care

People prefer to have stability and continuity in all aspects of treatment. This includes with staff and support services. People felt that when care has to change it was not properly explained and leads to the disruption of treatment.

Possible gaps in interventions

Service users discussed two gaps in interventions. Firstly, people said that they lacked understanding of their own treatments, and therefore choice, in treatments throughout the NHS. Secondly, they said that they felt there was a gap in treatments and support for people who were midway between mild and severe levels of mental illness, as well as for some specific conditions, such as personality disorders and dual diagnoses. However, this may need further exploration to look in more detail at these issues.

Recovery

Being in control and self-help is key to recovery

People felt it is really important to be in control of their own independent recovery. Recovery colleges and the development of self-help kits and plans are seen as beneficial to support people with this.

Who has done this well?

Service users have given positive feedback about Recovery College classes. They provide people with an understanding of their illness and how to cope in general life.

c) Themes specific to children and young people's services

Here we identify some key themes in the feedback and engagement about children and young people's mental health services.

Early Help

More clarity and better provision for mental health support

Less than two thirds of students aged 10-19 years, surveyed in Hampshire, knew who they would contact if they were 'feeling low'. 57% were unaware of the variety of services available to them (Unlock Survey Results, Southern Health NHS Foundation Trust, March 2019).

Young people report that they are not certain of who to go to for mental health support and fear they will not be taken seriously. They also have concerns around confidentiality. Several different children and young people's groups said they were disaffected by school, and an educational setting would not be the best place to find support for poor mental health. For some, it could be a contributing cause. Many, however, want more signposting to come through school.

Many also outlined that they want an identified person to speak to face to face, rather than a technological solution, and feel that they are too readily passed on to organisations that they have to contact themselves.

Better training is required

People commented that they felt healthcare professionals do not understand how to support children and young people with their mental health needs and they feel unable to speak to their GP or not listened to. Students felt they needed help with self-identifying symptoms and many do not know that they can self-refer, which they want to do without parental consent.

As well as better training for GPs, looked after children and children in care felt that social workers should have more training in mental health support and knowledge of anger management techniques.

Data from 12 local authorities in the South East shows Hampshire has the second highest number of Looked After Children (at 817 children). 29.8% of whom have a mental health problem, 32% with a learning disability, 20% with an ASD probable/diagnosis, and 11.6 % with an ADHD probable/diagnosis.

Young people in Portsmouth wanted schools to increase awareness of mental health by linking it across the curriculum, teaching metacognition and to co-design Personal, Social, Health and Economic Education (PSHE) content. PSHE was also

seen as an important vehicle to support students with LGBT+ issues.

Some parents and carers of children with autistic spectrum disorder (ASD) in Portsmouth also report difficulty in accessing courses they have been referred to by Child and Adolescent Mental Health Services (CAMHS). In addition, some Hampshire schools feel that they are not supported and want more involvement from health agencies, as some are spending around £50,000 from their budgets on employing their own mental health professionals. On the Isle of Wight, half of all Special Educational Needs Coordinators (SENCOs) felt they lacked confidence and expertise in dealing with children with ASD and Attention Deficit Hyperactivity Disorder (ADHD).

Who has done this well?

- a) Quantitative and qualitative results from the Coping and Resilience Education programme, by CAMHS at Preston Candover Primary School, helped to develop a child's understanding of their emotions, develop resilience and an ability to ask for help. It also gave parents, carers and teaching staff an increased awareness and confidence in knowing how to support children with their emotions.
- b) Parenting Programmes for children with ASD and ADHD, run by Barnardos in some parts of Hampshire, are reported to have respectful, well informed staff, which connect people and raises confidence in supporting children.

Difficulty and delays in getting an initial assessment and capacity issues

Many people think that waiting times for CAMHS support in Hampshire is unacceptable. This was common across all young service users, including a report around Looked After Children. There needs to be a bridge of support between a CAMHS referral and the first meeting. This could be done by exploring with children on waiting lists who end up in crisis what interim support could look like.

Many users felt that services would be better if they were more integrated and that waiting too long led to a deterioration in mental health, for example, a significant increase in self harming.

Tier 2-Pre crisis

Children and young people want to be listened to and involved

The extent to which the child's voice is listened to compared to the school/parent voice is reported as minimal. In the national Young Minds survey, 53% of students who were currently receiving mental health treatment didn't feel that they had been involved in the decision making about their individual treatment. Students

also want a role in the development of all the core services locally and nationally, not just mental health support teams, but they report they cannot easily find out how to be involved. Young people want their views to be taken seriously and their feedback acted upon with honesty.

Who has done this well?

Restorative Practice in Schools Project empowers families to find their own solutions, with an emphasis on listening to children. The project also aims to bring together voluntary, private and education sectors. This is being rolled out in 2019/20.

Parents and carers of students with ASD aged from 16-year-old also state feeling being shut out from decisions around care plans for their young person, and feel they need to be involved to ensure it has been understood and will be followed. Parents report their voice is not heard and there is a lack of parental guidance about expectations of the service.

Transformation of models of care

Many students want more access to holistic therapies and for treatment to be more individualised and feel that medication is too readily prescribed. They feel that therapies, such as art therapy and counselling, will be more effective in helping them resolve their poor mental health.

Who has done this well?

The ICE Project (participation in arts therapy workshops), run by Hampshire CAMHS Participation, increased confidence and self-esteem. However, it should be noted that there is no evidence of an evaluation of the long-term impact.

Lack of continuity between services

Families want greater communication between services and themselves and improved coordination across health, education and social care. Parents and carers say that services will not talk to one another about specific cases, which leaves families feeling like they are being passed around the system. Transferring between services could also be smoother. For example, The Frankie Worker Service said that their service users find it confusing meeting many different professionals and that in some cases this lack of continuity has led to inconsistencies in medication. A frequent experience cited was that having to repeat their story to different professionals increased their trauma.

Tier 4 - Crisis

High eligibility thresholds

Parents and carers feel that users need to be in extreme crisis before they are given access to relevant support.

Poor quality of care in secure units

They have concerns that hospitals can be a negative environment for a young person and these are sometimes a long distance away from family and support network. This made parents feel powerless.

In 2018, 1000 children were treated out of area nationally. The longest distance of a placement was 428 miles from home.

Challenges in getting packages of care finalised

Parents and carers felt that getting a package of care for a child in crisis finalised is difficult. No particular reasons were given. They also report a failure to recognise multiple conditions and that services are not tailored to an individual's needs, including for children and young people with special educational needs.

Who has done this well?

In 2017, although the Community Eating Disorders Service (CEDS) was not fully staffed, 78% of parents/carers described the service as very good and 90% felt that their family was receiving the help it needed. 89% of young people said their experience was good or better and 83% felt that they were getting the help they needed.

Poor aftercare when discharged

Families and carers said that they didn't feel involved in the decision-making process at a child's discharge. Young people who had been in hospital in the New Forest for their mental health report a lack of support at this point. They feel they had to be extremely proactive and seek out aftercare support.

Who has done this well?

My Care in Pharmacy (MYCiP), a CAMHS Community Pharmacy Project in The New Forest, is for those who require psychiatric medication. People collaborated in this service development and there is positive user feedback. It has reduced stigma and meant minimal disruption to schooling and family life, a reduction in missed appointments, and freed up clinical waiting lists.

Transition

Eligibility threshold differences

Sometimes the differences in eligibility thresholds between CAMHs and adults' services, such as around BMI for eating disorders, mean that young people who are transitioning between services become ineligible for care that they have been used to receiving.

Lack of continuity and changes in the labelling of conditions

These differences in eligibility criteria and how some disorders are described mean some young people drop out as they don't consider themselves to have the condition as defined by adult mental health services. Nationally, there is a 50% disengagement in care and treatment in transition processes and an increase in those who do not attend treatment (Young Minds, March 2019).

4. Conclusion

This report is a first attempt at pulling together and drawing themes from a wide range of service user and carer engagement and experience information from different parts of the Hampshire and Isle of Wight mental health system for people of all ages.

Whilst we searched intensively for reports, we recognise that the conclusions can only be based on the information that was available within the timescales of the project; and there may be more that could be reviewed and shared. We are also aware there is a lot of work going on to improve mental health services, based on people's feedback and with continued involvement and coproduction with them. This approach is not however consistent, and information is not easily available across all statutory and non-statutory services in the area.

We found adults have a stronger voice than children and young people. Much of the evidence reviewed was from parents, carers and the services. Whilst we heard a strong verbal commitment to involve children from those we spoke to, children and young people as well as adults would like to see more involvement and coproduction taking place.

This report explores the views of those who are in contact with the system in one way or another, rather than people who are not (including those on waiting lists who have not used services previously).

There is clearly already a rich vein of service user and carer feedback and engagement that can be used and built on to inform how mental health services are transformed across Hampshire and the Isle of Wight. Involving a broad range of people in identifying and coproducing the support and services needed can only

mean that they will be more effective and person-centred. Some parts of the system are already committed to doing this so there appears to be a ripe opportunity to use their skills, knowledge and enthusiasm to spread a more consistent involvement approach.

5. Recommendations

Wessex Voices was primarily asked to pull together the key themes from the people's experiences and engagement and recommend any gaps in intelligence to explore. However, in the process of undertaking this work we have also identified some areas that could be improved upon in terms of the process of engaging with people and gathering intelligence around experiences of mental health services.

We would therefore like to make the following recommendations to the HloW STP Mental Health and the HloW Children and Young People's Programme Boards:

1. Review the findings of this report and consider whether these gaps in intelligence should be explored as part of current system changes (if they are not already being addressed):
 - People's experiences of being on waiting lists (around support, signposting, other themes identified above)
 - Signposting under a single point of access model
 - Review with people and carers, including young carers, the training they would find helpful to better manage their/their cared for person's condition, and explore ways to deliver a sustainable programme
 - Specifics around GP and GP practice staff training around mental ill health and also around ASD
 - What people mean in terms of a gap in interventions between mild and severe crisis
 - What support people with specific conditions need at crisis and during rehabilitation
 - How to improve the discharge process in different settings
 - Experience of acute mental health inpatient settings
 - Experience of peer support and employment support services

2. Improve how experience and engagement intelligence and good practice is collated and shared across HloW to enable people to access this easily to inform future service improvement and minimise duplication (see specific recommendations on page 5).
3. Implement more effective equality monitoring for engagement activities, and actively engage with seldom heard groups, including of younger children, who experience worse mental health inequalities. This will enable service design and improvement to take appropriate account of differences.
4. Build on the existing national and local good practice in coproduction, to consider what support that the HloW Mental Health System needs to ensure there is consistency in the way people are involved in system / service development and evaluation.

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Contact us

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