

Report on Healthwatch Wandsworth's consultation about transitions from child and adolescent mental health services to adult services.

Background

Young people who require support from mental health services can often find their care interrupted as they make the transition from child and adolescent services (CAMHS) to adult services (AMHS)¹.

Currently mental health services for children and young people such, as the Child and Adolescent Mental Health Services (CAMHS), end at 18 years of age when young people start using adult services. However, research has shown that the way mental health services are often structured can leave gaps that young people could fall through as they undergo the transition from CAMHS to AMHS. The TRACK study, for example, has shown that only 4% of young people in London experienced their 'ideal' transition from CAMHS to AMHS².

The issues explored in this consultation will affect a large proportion of our community as around 2,984 young people aged between 5 and 16 years in Wandsworth are estimated to have a clinically diagnosed mental health problem³.

The Healthwatch Wandsworth survey aimed to understand the issues young people, families, carers and professionals in Wandsworth perceive in the transition process with a view to support both Wandsworth Council and Wandsworth Clinical Commissioning Group in addressing gaps and improving the quality of the support offered to young people when they make their transition to adult services.

Our Consultation Survey

The survey was devised to collect information from service users, carers, providers and other interested stakeholders to understand the challenges for young people transitioning from CAMHS to AMHS in Wandsworth. The findings will be fed back to Wandsworth Borough Council and Wandsworth Clinical Commissioning Group (CCG) to help them improve the quality of support offered to young people transitioning to adult services.

The survey was open from 13th February 2017 to 31st March 2017. It was advertised on our website, social media and in our newsletter and it was circulated to our network of local contacts. It was available to complete online and was taken to outreach events.

Wandsworth Borough Council had already worked with the Youth Council and sought views of young people, so we decided to focus on getting some views of carers and others. Responses from people working with those going through the transitioning process on a regular basis could potentially provide a valuable representation of a wider number of service users. It was challenging to seek views and feedback from on such a specific topic, but we kept the survey open longer than initially intended to encourage responses. The responses we received, though

¹ National Advisory Council for Children's Mental Health and Psychological Wellbeing (2010) 'One Year On', London: DH/DCSF

² Transitions of Care from Child and Adolescent Mental Health Services to Adult Mental Health Services (TRACK Study): A study of protocols in Greater London, Singh et al., (2008)

³ Wandsworth Borough Council and Wandsworth CCG, Wandsworth Children and Young People's Transformation Plan 2015 - 2016

limited in number, provide some useful insights in to the transitioning process between mental health services.

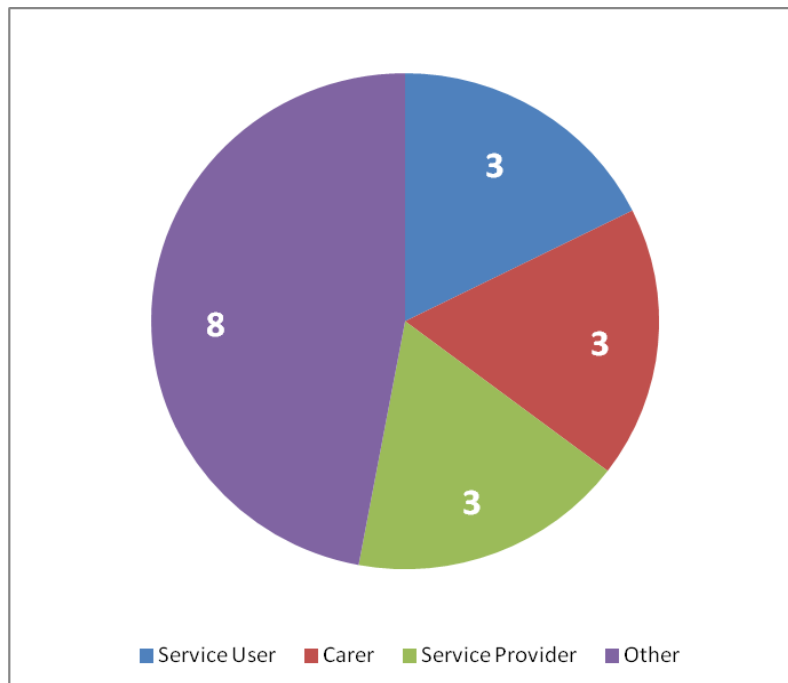
We have also analysed and included, where relevant, feedback from local residents that we have collected via our Information and Signposting Service and outreach activity since the beginning of 2016 for further insights.

Findings

We received a total of 17 responses to our survey and two additional responses to our online poll. A sample of the questionnaire can be found in Appendix A. All of the individual responses can be found in Appendix B.

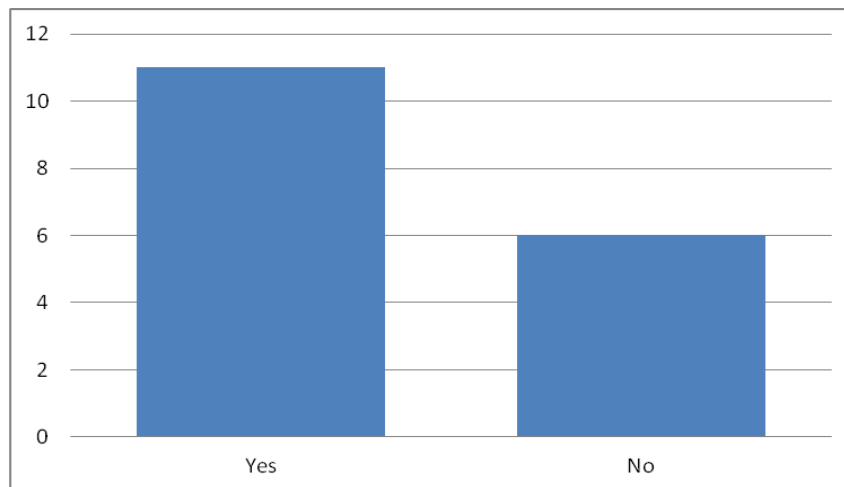
Question one: Are you a service user, carer, service provider or other?

The pie-chart below shows the proportion of the responses from the different perspectives of those involved in the survey. As the graph suggests the majority of responses (8) were received from those who identified as ‘others’, including a district nurse, a parent and a clinician. We received 3 responses each from service users, service providers and carers. One person identified as both a carer and ‘other’ as they are also a counsellor. For the purposes of this survey, this respondent has been defined as a carer.



Question two: Have you or someone you know experienced the transition from child to adult mental health service?

The following bar chart shows that more than 60% of respondents have either experienced or knows someone who has experienced the transition from CAMHS to AMHS. These respondents include three service providers, two of which were noted as *Wandsworth & Westminster Mind*, *Family Action*, *Wandsworth Young Carers*. Others included a parent, a teaching professional who knows a young person who uses a CAMHS service and a district nurse who engages with clients and parents. Of the six respondents who answered in the negative, two were service users.



Question three: If you have attended or are attending a CAMHS service, what do you like about the service?

The responses to this question were varied and included both negative and positive themes. One emerging positive theme amongst service users, carers and service providers relates to the **friendliness and approachability of services**:

“Staff are approachable and understanding” – Carer

“The service has been very friendly” – Service User

“[I like] my consultant” – Service User

“The teams are good to work with and open to joint work across the sectors. They are generally good at representing the young person’s perspective and needs” – Service Provider

However, every group responding to our survey emphasised that **waiting times for CAMHS are a barrier** to improved mental health while a number of others highlighted that, for many young people, the **high clinical threshold** means they are **unable to access help**. Moreover, some other respondents felt that that the level of **support is not adequate**.

Concerns were also raised around the **value of the service and difficulty accessing the service**:

“Not much” – Carer

“...friendly but not very helpful” – Service User

“It has taken... more than a year to receive a proper assessment” – Service User

“Too much paperwork” – Other

Question four: What don't you like about the CAMHS service?

When we asked respondents specifically what they didn't like about the CAMHS , responses expanded on the feedback in the question above. The following themes emerged from responses:

High Thresholds

- *"They are trying to limit as much as possible the number of patients who need to do further assessments for their conditions"* – Service user
- *"The main challenge...is that their thresholds are so high that they rarely accept referrals"* – Service provider
- *"Can be difficult for young people to access – high thresholds"* – Service provider

Lack of early intervention

- *"Lack of staff that can provide teenagers with early intervention therapy"* – Carer
- *"We really need early intervention to prevent our young people from becoming more needy clients"* – Service provider

Limited support

- *"...Often time limited support"* – Service provider
- *"The limited number of sessions"* – Other
- *"From what I've heard they need more staff support"* – Other

Waiting times

- *"Waiting times"* – Service user
- *"...Long waiting times..."* – Service provider
- *"The waiting period and no contact or lack of communication to those waiting"* – Other
- *"Having to wait for an appointment"* – Other
- *"The lack of availability of consultant"* – Carer

As above, service providers and carers noted that **earlier identification and intervention could better support** young people but that this is not currently prioritised. One highlighted that this would bring better outcomes for young people and could prevent escalation of problems. Early intervention could also help the health services manage conditions more effectively.

Feedback we had received via our Information and Signposting Service and outreach activity also mentioned long waiting times, leading to months without support. One person also added that they felt there was a lack of confidentiality because they considered their family too involved.

Question five: At what age do you think a Mental Health Transitioning service should begin and end?

There were a wide range of views from respondents on when a mental health transitioning service should begin and a lack of consensus on the whole.

Of the carers responding, one carer believed that the service should be between 16 and 25 while another felt that 23 - 25 was more appropriate. However, one carer noted that a young person should be supported through their entire journey:

“From detection and ongoing if needed”

The three **service providers** who responded to the survey provided broadly similar views, arguing that the service should begin at 16/17, and end at 25 if appropriate.

Service users suggested ages that started later than the current service provision and the ages suggested by other stakeholders.

Those identifying as ‘**other**’ provide a very broad range of age ranges for an ideal Mental Health Transitioning service. Some believe that 5 years old and ‘nursery school’ age is a suitable age to begin such a service, echoing the desire for ‘early intervention’ in mental health care. However, other respondents believed that 18 or 21 would be more appropriate.

The variation in responses reflects the ongoing nature of mental health concerns and that adequate provision is needed for an individual whatever their age. Responses to other questions suggest that there is variation between people’s needs and the age at which they will be at different points of their journey. This suggestions provision might need to meet the needs of individuals, ‘when needed’, and in a tailored way.

Question six: What continual support do you think young people would like after the age of 18?

The main themes arising from this question relates to **understanding a young person’s needs as part of multiple aspects of their lives** and that perhaps a key worker or someone to **help navigate** using different service would be useful.

Carers noted that:

- *“[There needs to be] more understanding of their need...mental health teams do not seem to understand this need...”*
- *“[Therapy needs to be with] people they are familiar with”*

Service providers noted that:

- *“Young people either don’t know or feel unable to express their needs. If we don’t equip our young people with the language and skills that they need then we will not be able to find a way out of the crisis we now have.”*

Many stakeholder groups emphasised the need to **promote healthy environments** and to address other **key pressures which affect a young person’s world** to improve their mental health.

According to some respondents, improving access to housing, employment and education could better support young people once they reach 18.

Service users noted the importance of:

- *“Support with housing, employment, education”*
- *“Social buddy, travel buddy”*

Others highlighted:

- *“Day centres, help with jobs and social activities”*
- *“Emotional, educational and financial”*
- *“Help with finding a permanent job and home”*
- *“Young people would like Family support, financial support...”*

Service providers focussed upon a:

- *“Welcoming space to meet with others and to take part in organised activities (leisure, sport, education etc.)”*

A response to the web poll on this question emphasised that young people should receive greater support from family and friends. A local resident told us in feedback we collected at Information and Signposting and outreach that there was a need for consistent keyworkers and social workers to support many aspects of life including getting a freedom pass and support to stay in higher education.

Question seven: Do you think the transitioning age should be higher for those who have learning difficulties/disabilities?

The majority of respondents (70%) believed that the transitioning age **should be higher** for those with learning difficulties or disabilities. Service users were unanimous in supporting a higher age for those with disabilities. Others highlighted that **each case should be assessed** according to an individual need rather than specifying an age.

- *“all cases should be fully assessed” - Carer*
- *“...should be judged on individual basis” - Service provider*
- *“No - but the support available needs to be tailored to reflect additional needs” - Service provider*

One of the ‘other’ respondents suggested that a “separate team” should assess and work with disabled young people who require mental health support.

Question eight: What do you think Wandsworth Council and CCG can do to better support transitioning from young to adult mental health services?

A number of themes emerged relating to supporting young people transitioning from children’s to adult mental health services.

One key theme relates to the need for **holistic, person-centred care** to ensure that the needs of the young person are being met, and that they feel **involved and engaged in the process**. As has been noted, young people can be reluctant to engage in the service, and require dedicated and tailored support. A more “personal” process, which includes the service user could better support transitioning.

Further opportunities to improve transition relate to **earlier intervention and avoiding crisis**, which links into the **need for greater support for young people before they turn 18**.

Service users note the **importance of informing key influencers** in the young person's world, such as **families and education services** to ensure a **joined-up and coordinated approach** to transition.

Other responses relate to previous themes, including the **significance of healthy environments**, such as providing housing and employment opportunities.

Holistic, person-centred pathway

- *“Make it more personal. Have a meeting with the patient together with his current and future service provider and include the patient in the process”* – Service user
- *“Communicate at a better and more appropriate level with young adult”* – Carer
- *“Provide the necessary support to enable young people to recognise and talk about their needs”* – Service provider
- *“Adapt the service so it is more user friendly”* – Other
- *“Keep talking to those using the service”* – Other

Greater support before 18th birthday

- *“Much better support for YPs referred ‘close to their 18th birthday as at present these YPs are often ‘left’/then they turn 18 and are lost trying to access the higher threshold of adults services”* – Service provider

Early intervention

- *“Fund staff resources and make therapies available before crisis”* – Carer
- *“Earlier identification of young carers”* – Service provider

Alternative settings

- *“Liaise with school...liaise better with family members”* – Service user
- *“Hold clinics in more suitable settings”* – Carer

Conclusions and Recommendations

The responses to our survey provide interesting pointers about potential issues for young people in Wandsworth making the transition from children and adolescent's to adult mental health services.

Respondents identified **challenges relating to waiting times, high clinical thresholds and inadequate levels of support**. Other key points for consideration are summarised below:

Person-centred pathway

There was a wide range of views from a variety of stakeholders highlighting the need for a holistic and personalised pathway. An overriding theme relates to understanding a young person's individual need, and responding appropriately. Individualised assessments and support could apply to prevention and early intervention, age of discharge and transition and tailoring would

then also incorporate consideration of specific needs, such as learning difficulties or disabilities, and a variation in how and when an individual might progress along their journey.

In order to better support young people making the transition, it will be important to include them in the process and ensure continuous communication. Involving relevant people in a young person's life where appropriate, such as schools and family, could also be important.

Meaningful cross-system working

Recognition of personal needs includes the interactive influence of many aspects of a person's life, which can have an effect on or be affected by mental ill health. It is important that this recognition of a person's whole world is addressed by the whole system. Better coordinating strategies to improve mental health across departments could support young people to live as independently as possible and could support recovery from mental distress. A number of responses revealed the importance of housing, employment, financial stability and access to education as indicators of mental health.

Appendix A - Sample questionnaire

Mental Health Transition Service for 17-25 year olds

Wandsworth Borough Council and Wandsworth Clinical Commissioning Group (CCG) would like to improve the quality of the support offered to young people when they make their transition to adult services.

Currently services for children and young people such as child and adolescent mental health services (CAMHS) ends at 18 years: this is the time when young people have to start using adult services.

We would like to know your view and experiences to provide feedback to Wandsworth Borough Council and CCG to help them better develop the best Mental Health Transition Service for young people in Wandsworth.

1. Are you a service user, a carer or other?

Service user Carer Other, please state: _____

2. Have you or someone you know experienced the transition from child to adult mental health service? Yes No

If yes please comment: _____

3. If you have attended or are attending a CAMHS service, what do you like about the service?

4. What don't you like about CAMH service?

5. At what age do you think a Mental Health Transitioning service should begin and end?

6. What continual support do you think young people would like after the age of 18?

7. Do you think the transitioning age should be higher for those who have learning difficulties/disabilities?

8. What do you think Wandsworth Council and CCG can do to better support transitioning from young to adult mental health services?

Thank you for taking the time to complete this questionnaire!

What happens next? We anonymise all the information and use your responses to help us formulate our formal submission to Wandsworth Council and Clinical Commissioning Group. We will also publish an anonymised report to our Healthwatch Wandsworth website.

Sign up to our mailing list: Become a member to receive our e-bulletins, invitations to our events and to take part in local and national consultations.

Name: _____ Email Address:

Appendix B - All Individual Responses

Question 1: Are you a service user, carer, service provider or other?

Carer

Carer

Clinician not in management

Service Provider/Wandsworth & Westminster Mind

Service User Service Provider/Family Action Wandsworth Young Carers

Service User

Concerned member of the public

Carer/Counsellor

Teaching profession

-

Parent

Service User

None

Support service

District nurse

Service Provider

Question two: Have you or someone you know experienced the transition from child to adult mental health service?

No

Yes

Yes

Yes - We provide a peer support service for young adults who have come into services either through CAMHS or Early Interventions but who may be transitioning into adult services. The service is a regular peer support group that works to provide routine and structure where these may be lacking, combat isolation, develop coping skills and resilience, share information on local services and activities. We also provide services in schools and colleges: • working with teachers/professionals to raise their awareness and understanding of MH problems • support CYP presenting with emotional and psychological difficulties through art/creative therapy programmes and peer mentoring

Yes

Yes - We work with young people up and until the age of 17.11 years. We like to start talking about transition from the age of 14 years and try to actively involve them in their transition from the age of 14 years. Our stats show that the caring role has a particularly high emotional impact on young carers along with the physical impact on some

No

No

Yes - I have counselled as well as cared for a young person.

Yes - Young person who used CAMHS service.

No

Yes - My daughter

No

No

Yes - Many young people I have worked with

Yes - Client and parent coping, lack of resources from the authorities, delayed organising resources and help for the client.

Yes - Many of our youth group members

Question three: If you have attended or are attending a CAMHS service, what do you like about the service?

The staff are approachable and understanding.

not much

not applicable

N/A

My consultant

"In my experience the teams are good to work with and open to joint work across the sectors. They are generally good at representing the young person's perspective and needs in TAC meetings too"

"The service has been very friendly but not very helpful. It has taken us more than a year to receive proper assessment."

Too much paper work

-

-

-

-

No

I have not attended a CAMHS service

N/a

-

Am service provider - so can not answer this on behalf of clients

Question four: What don't you like about the CAMHS service?

"The lack of availability of consultant and lack of staff that can provide teenagers with early intervention therapy. "

"the psychiatrist my son saw was rude/abrupt and did not want to communicate through me-the carer."

not applicable

N/A

Waiting times

"I don't think that I like the way this question is phrased as I don't dislike anything about the service. The main challenge however is that their thresholds are so high that they rarely accept referrals. We really need early intervention to prevent our young people from becoming more needy clients who require the help of the CMHT. "

They are trying to limit as much as possible the number of patients who need to do further assessments for their conditions.

Too many management personnel and not enough hands on.

Young people often refuse to engage.

The waiting period and no contact or lack of communication to those waiting. Attitude of organisation.

From what I've heard they need more staff support.

Having to wait for an appointment. The limited number of sessions.

-

-

Too rushed not young person centred. 21

-

Can be difficult for young people to access - high thresholds, long waiting times and often time limited support

Question five: At what age do you think a Mental Health Transitioning service should begin and end?

From 16 to 25

23-25

"I think there should be a specialised adolescent/young persons service for 15-24 year old and higher upper limit, if in full-time education."

Begin at 16 or 17/end at 25

21

"In my experience many young people experience stigma around talking about their mental health needs and there is an urgent need for early intervention to develop emotional literacy and a feeling that it is ok to discuss their mental health needs.

However 16 years is a good age to start discussing transition to MH services. But

my desire is that we can save many more young people from developing significant mental health issues.

"

19-25

10 years to when it's needed

From detection and ongoing if needed.

Should start at 18 and end at 21.

Between 5-21

Nursery school age.

26

18 years sounds appropriate. However, I have no experience or knowledge on this very sensitive issue.

21 years old

-

Starting when YP turns 17 and available up to 24 / 25 if needed

Question six: What continual support do you think young people would like after the age of 18?

Access to therapy and for to be available by people they are familiar with

"More understanding of their need to involve parents in appts and

communicating difficulties. mental health teams do not seem to understand this need for some young adults."

young people's team

"Facilitated peer support and availability of a safe and welcoming space to meet

with others and to take part in organised activities (leisure, sport, education etc.) "

A proper handover, over a period of time

"There is a desperate lack of appropriate support services and this may be down to the "chicken and egg"

situation we have. Services may be cut if people do not come forward to use them. However this is often due

to the fact that young people either don't know or feel unable to express their needs. If we don't equip our

young people with the language and skills that they need then we will not be able to find a way out of the crisis

we now have. In my experience many young carers struggle to talk and describe the impact of their role as caring is the norm for them. "

Social buddy, travel buddy

Help with finding a permanent home and job

Whatever is needed/necessary or possible.

Befriending and support networks.

Emotional, Educational and Financial.

Support group, Link worker, Mentor, Peer worker.

Support with housing, employment, education

As much support as available to them. Whatever is appropriate for the individual.

Continued support

Young people would like Family support, financial support, instinual support eg day centres, help with jobs and social activities

"At the moment the 'drop off' from child to adult services is like a cliff edge - transitional is essential - consistency

of a keyworker to support the YP to successfully access adult support if needed or 'wind ' down support in a

time appropriate manner at a pace that is right for the yp rather than 'to fit in before they turn 18"

Question seven: Do you think the transitioning age should be higher for those who have learning difficulties/disabilities?

Definitely

yes

should be separate team

No – but the support available needs to be tailored to reflect the additional needs

Yes

Yes

Yes

YES

All cases should be fully assessed.

Absolutely and include families where possible.

Not really.

Yes.

Yes.

Don't know

Yes definatly

"Yes, sometimes it becomes very difficult

to find the right setting for adults with learning difficulties (need more day centres)."

"Depends on needs - should be judged on individual basis involving family & other relevant keyworkers"

Question eight: What do you think Wandsworth Council and CCG can do to better support transitioning from young to adult mental health services?

Fund staff resources and make therapies available before crisis

"hold clinics in more suitable settings, communicate at a better and more appropriate level with young adult where needed"

"separate, also CAMHS has far more psychological treatments on offer than general adult services and perhaps there should be more psychological treatment in general adults."

Commission and fund a mental health transition service or services to meet the identified needs.

N/A

"To provide the necessary support to enable young people to recognise and talk about their needs before they become 18. This includes early identification of young carers and better emotional support. Funding more young carers services too."

"Make it more personal. Have a meeting with the patient together with his current and future service provider and include the patient in the process."

Provide permanent housing and support

"I have no knowledge of Wandsworth but in general, support all round could be greatly improved."

Keep talking to those using the services.

Employ more dedicated staff.

Continued one to one support, Counselling, Mental health education.

Liaise better with family members. Liaise with school.

I do not know much about this subject/issue. However, I think that all that can be done should be done.

Adapt the service so it is more user friendly. Easy to access.

Most boroughs need more activities and centres in place.

"Provide appropriate funds to allow the transition to take place at a pace that's right for the individual. Much better support for YPs referred 'close to their 18th birthday as at present these YPs are often 'left' / then they turn 18 and are lost trying to access the higher threshold of adults services. "