

All Age consultation
requested by RPCF
members

Access to Rotherham Mental Health services consultation April 2021





Background

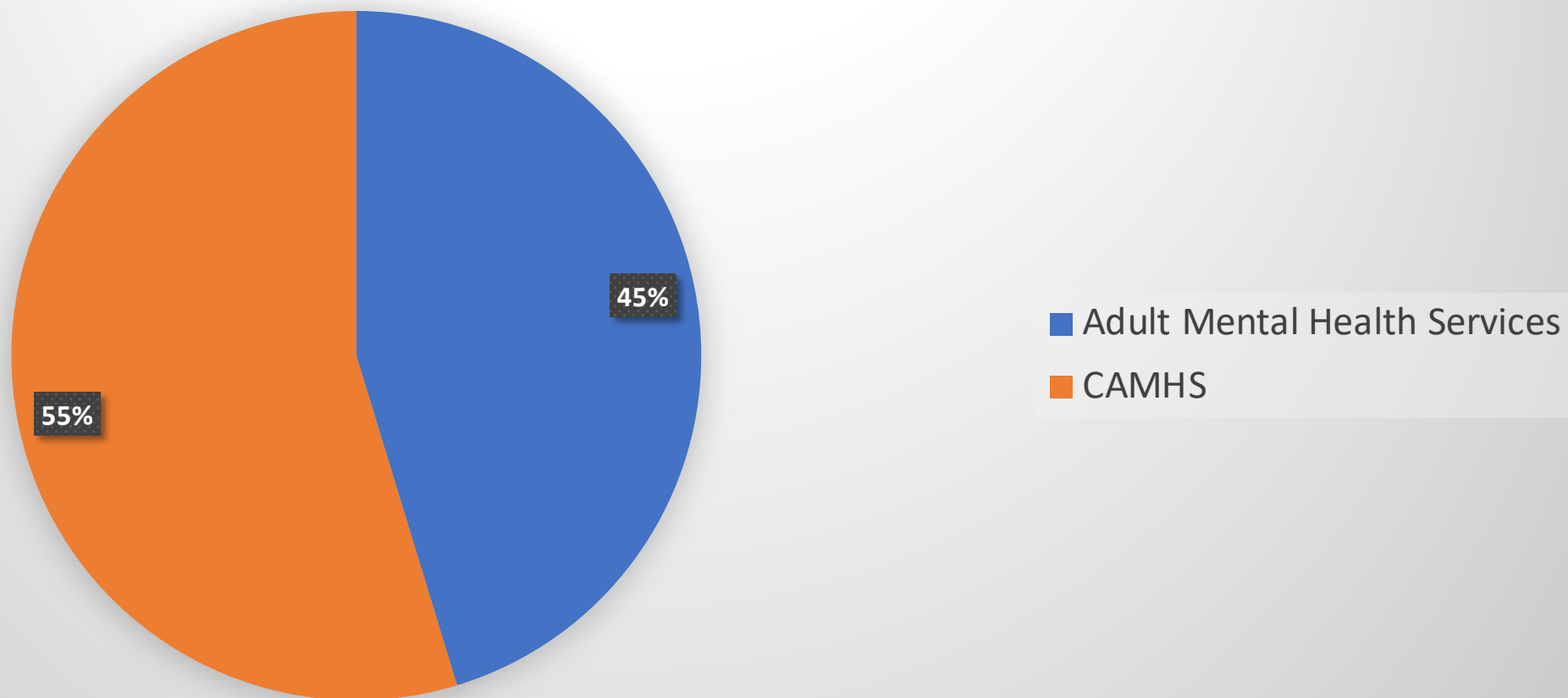
RPCF members highlighted a priority via social media and direct contact with management of the difficulty of accessing mental health services both for their children and young people and for themselves and adult members of their family.

To ascertain the main themes, resulting from lived experience, an initial consultation was carried out and these are the findings. NB: This is an overview of the raw data provided.

53 responses were submitted, with an even split of experience from Adults services and from CAMHS

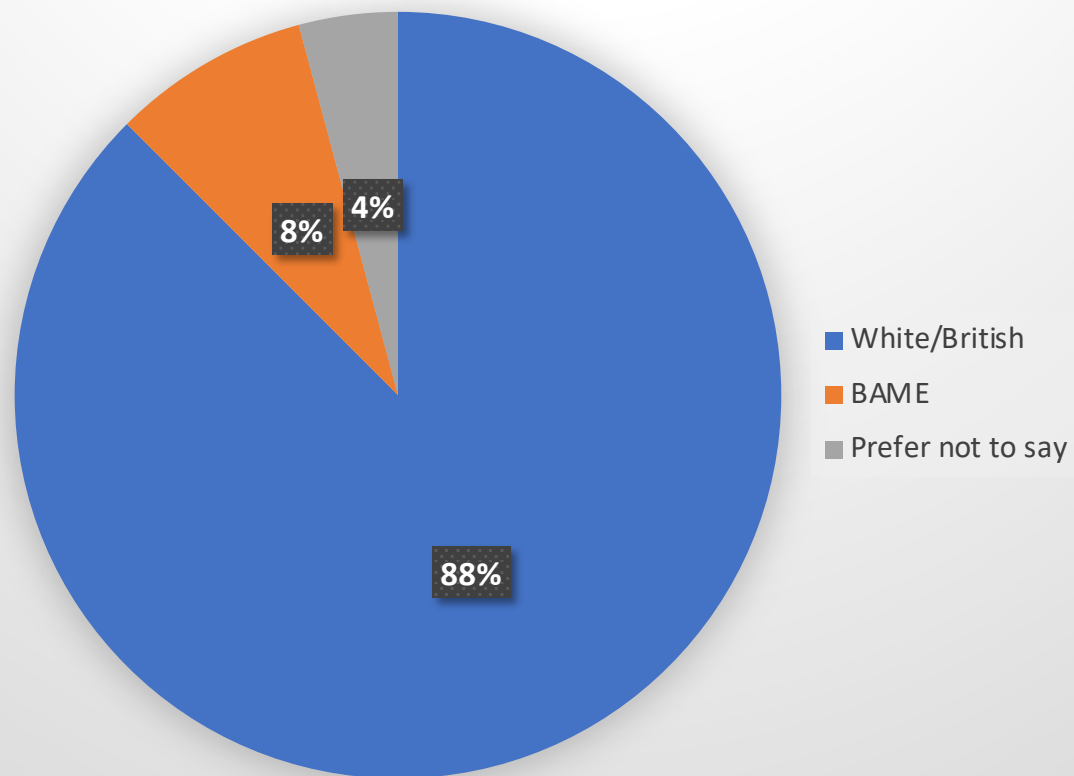
In regard to governance the SEND strategic board and SEMH strategy group were informed of the consultation and findings will be submitted.

53 Respondents Across CAMHS and Adult Mental Health Services

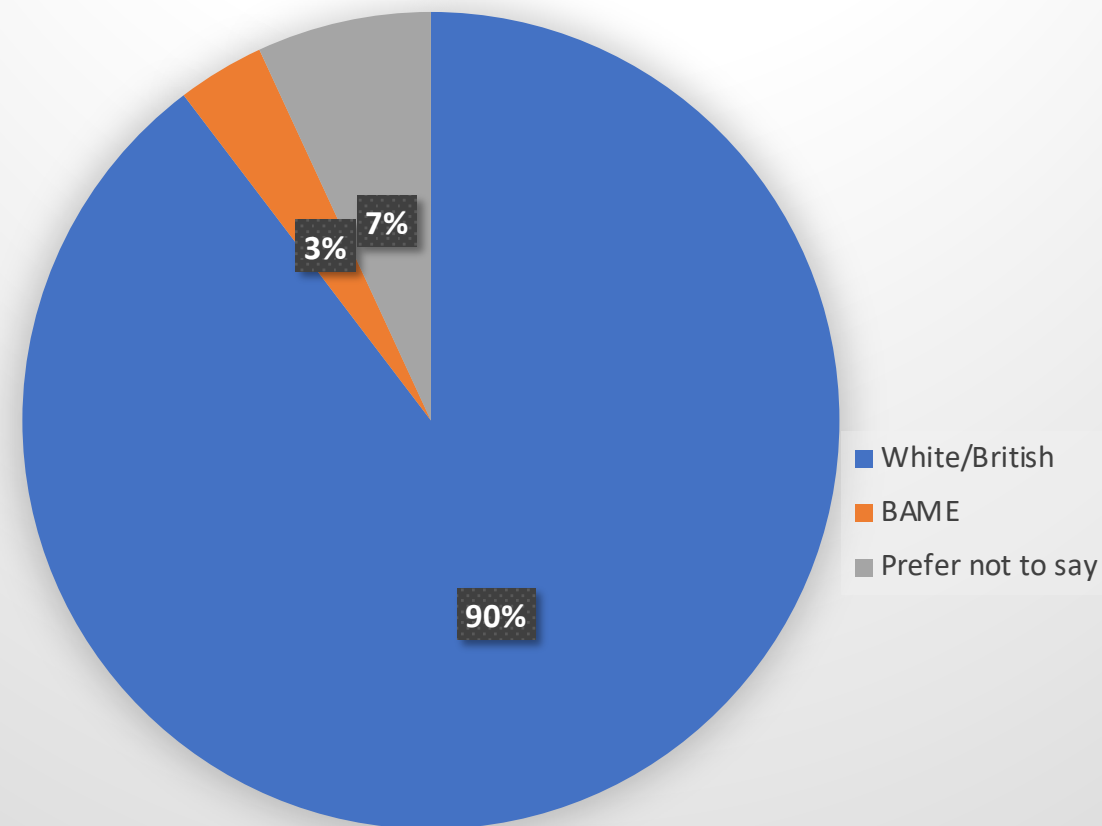


Ethnicity of Respondents Accessing Mental Health Services

Adults accessing Mental Health Services



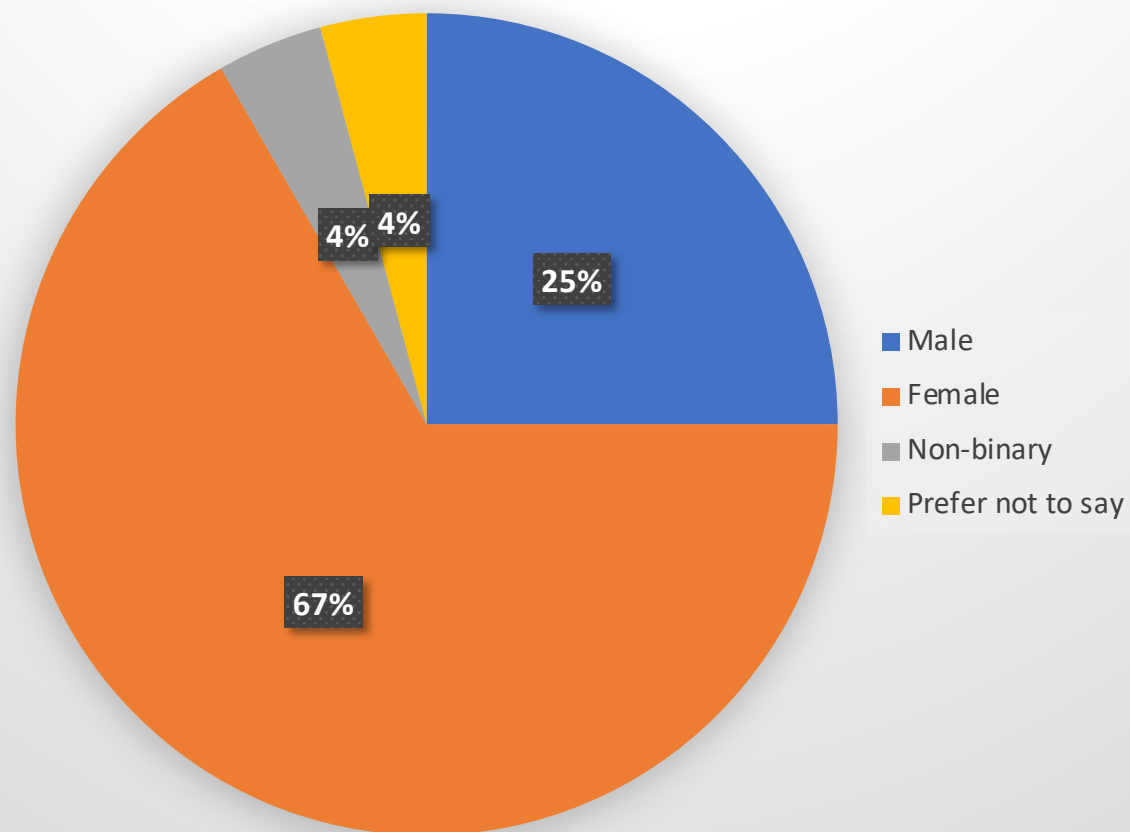
Children and Young People Accessing CAMHS



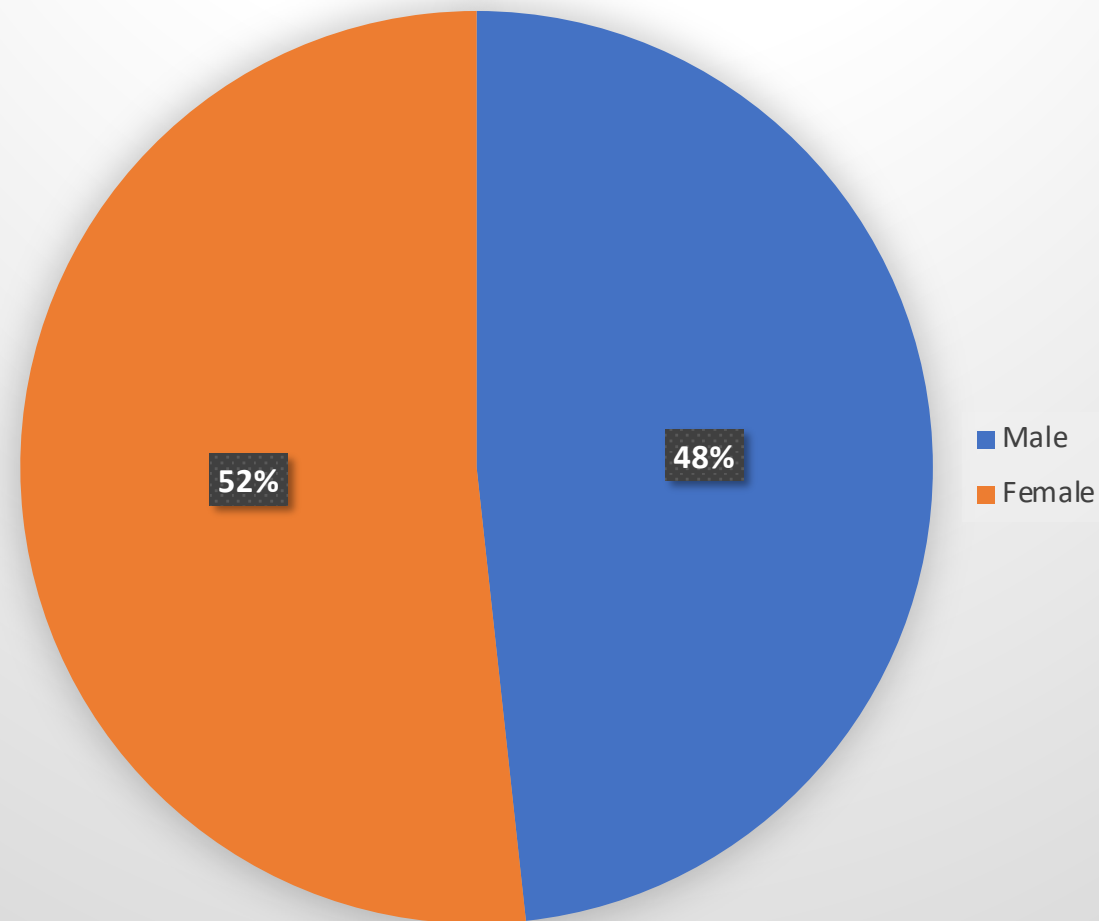


Gender of Respondents Accessing Mental Health Services

Adults accessing Mental Health Services

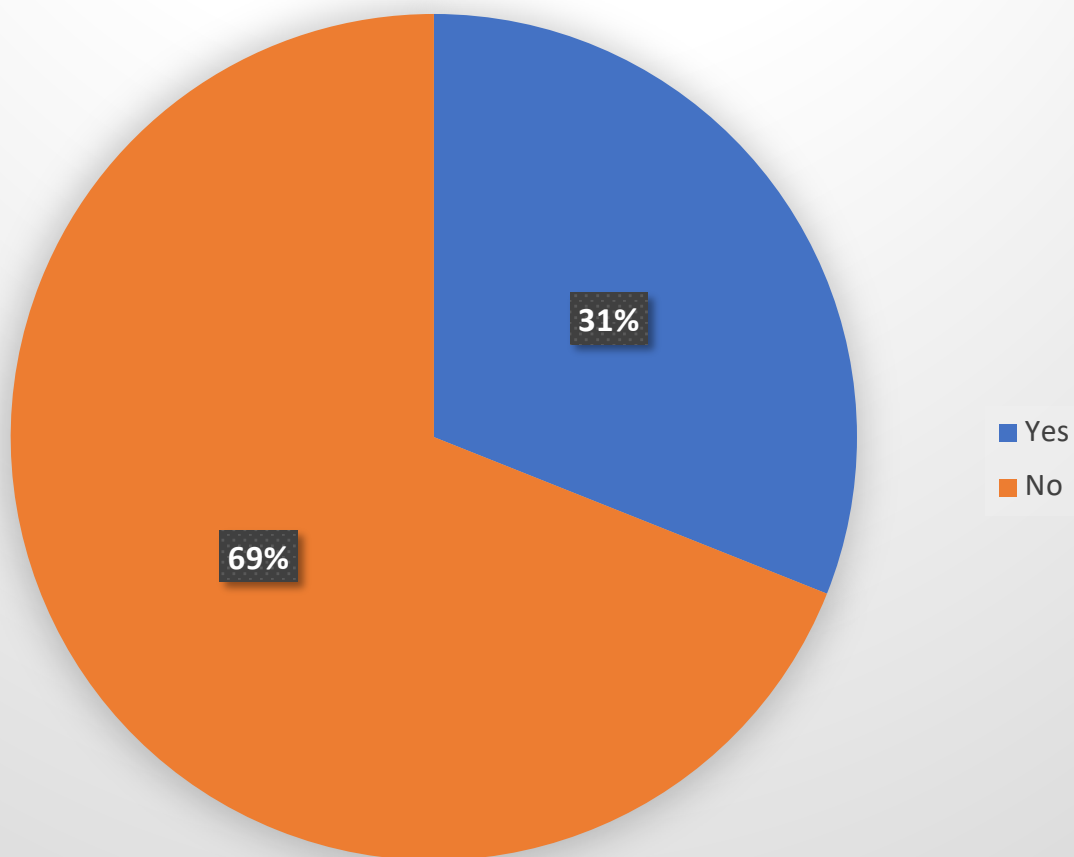


Children and Young People Accessing CAMHS

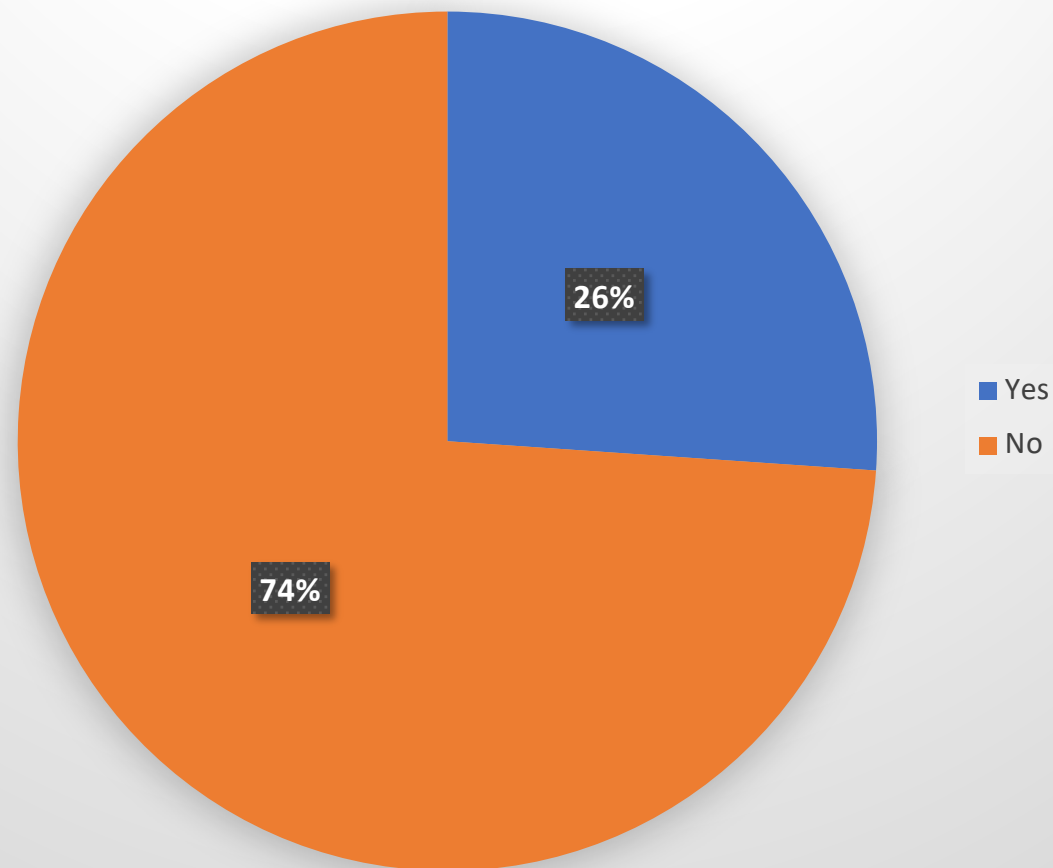


Clarity of Pathways and Service Criteria

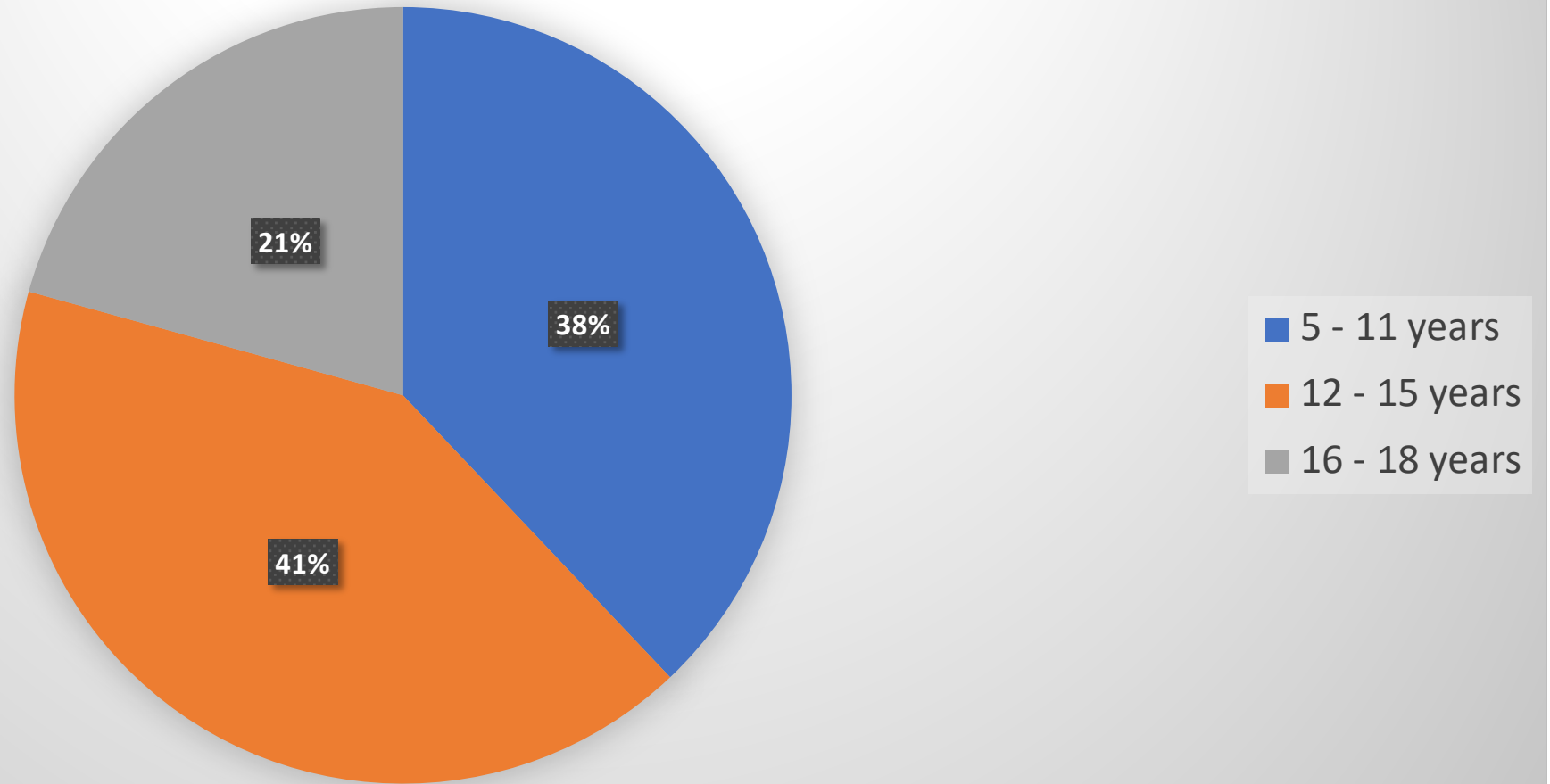
Do you consider CAMHS Pathways and Criteria Clear?



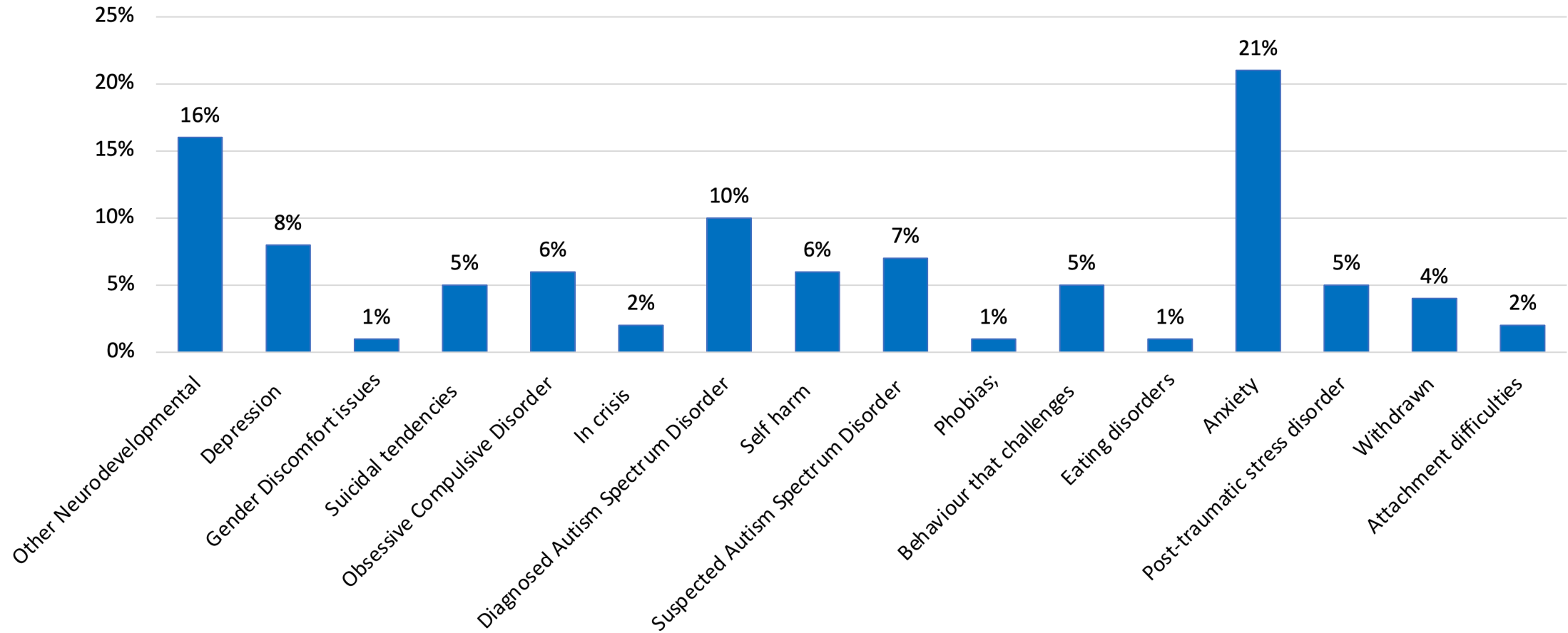
Do you consider Adult Mental Health Service Pathways and Criteria Clear?



Age Ranges of Respondents Accessing CAMHS



Main mental health conditions of the children/young people attempting to access CAMHS





On a rating scale of 1 to 10 (1 being negative and 10 being excellent), those who responded to the consultation rated their experience of CAMHS as an average of 3.

11 parent/carers expressed an interest in being involved in working with RPCF and services to inform future development of services in CAMHS including further consultations resulting from this initial one and focus groups.

When asked about their experiences, the following main themes emerged from the voice of the families in relation to CAMHS
(the full transcript of shared experience verbatim can be found at Appendix A)

Common themes were identified, **Believe Me, Get me help quicker, Diagnostic overshadowing, Pathways and Criteria**

CAMHS Theme – Believe Me

“CAMHS took notice of school staff saying he is fine in school rather than listening to me as he masks in school.”

“Was made to feel it was bad parenting and did not take me seriously with the concerns we had”

“My middle son was referred to camhs for his anxiety, we suspected he had autism, adhd, etc but camhs wouldn't even assess him and then we had to spend thousands of pounds funding private assessments. He was diagnosed privately with autism, adhd, an anxiety disorder, sensory processing disorder, dyspraxia”

“My child told numerous professionals she was suicidal from the start but as yet she hadn't got the courage to actually do it. But when (never if) she did then there was nobody who would be able to stop her. Yet she wasn't considered suicidal or a risk.”

“It took me multiple attempts to get CAMHS to accept my son onto the neurodevelopmental pathway and they only accepted him after I paid for a private SALT assessment as a second opinion.”

CAMHS Theme – Get Me Help Quicker

“Only through sheer grit and determination did I finally get her onto the pathways for assessment but we are faced with huge waiting lists. Mental health issues don't go on hold for 2 years whilst waiting. Where is the support whilst we are waiting?”

“Had to go to formal complaint to finally get a diagnosis. Whole process took almost 10 years”

“After a very long battle - over 10 years my daughter has finally been referred and is on a waiting list. More needs to be done around autism and girls especially for schools and early years health services.”

“The waiting list for an assessment is far too long.”

CAMHS Theme – Get Me Help Quicker

“The waiting times are far too long, and families are suffering and conditions are worsening whilst waiting for support and therapy.”

“CAMHS Worker didn't even show up for the appointment she arranged, no contact from camhs to let her know there had been a problem etc nothing, just left my daughter sat waiting. Bearing in mind her mental health was already rock bottom, this just made us lose all confidence in camhs and ultimately my daughter and myself felt alone with no where to turn.”

“Long waiting list & basically once diagnosed, not much help from CAMHS, always a fight to get anywhere.. Feel like we're abandoned by services once diagnosed. Only help when at crisis point & that's too late for many.”

“Overall, the experience was very negative, I felt that my child has been offered very little, to be honest no support at all whilst in crisis.”

CAMHS Theme - Diagnostic Overshadowing

“My daughter has been in the cycle of camhs since 9. She is 13. They keep discharging her when she requires talking therapy or art therapy. It has to escalate to crisis 3 times before she is helped. They use the excuse that her autism is a cause for anxiety so her anxiety can't be treated which is unfair and discriminatory.”

“Daughter has debilitating anxiety, but CAMHS refused to support stating she is asd and comes with the territory”

“Tried to access support for my daughter who is autistic, I was told it's just part of her autism and she cannot access Camhs to get help with her anxiety. Her Anxiety impacts significantly and really needs supporting.”

“It was impossible to get past the Autism label. Everything was 'the autism' rather than looking deeper. Left us all exhausted, frustrated and on our own to sort everything out.”

“now because she has a diagnosis of asd they won’t help with anxiety and told me they don’t deal with attachment issues”

“Our child is at breaking point and his anxiety is affecting all levels of his life. Camhs did nothing but excuse it with the unlawful blanket policy of saying that it’s due to his autism and that they can’t treat it because of this reason.”

“Camhs do not support anxiety in children that are already diagnosed autistic or adhd
They put everything under there diagnosis and do not consider that unmet needs can lead to mental health difficulties that require camhs interventions”

“As my child has a pre-existing diagnosis of asd. All issues are dismissed as part of his asd and pda profile of which camhs state they do not recognise”

CAMHS Theme - Diagnostic Overshadowing

CAMHS Theme - Pathways and Criteria

"A referral was sent but they returned with the fact that she doesn't meet criteria."

"There was nobody whatsoever who knew how to deal with a child (15+) with PTSD. We were told just take medication and when she gets to 18 there is a special trauma pathway available. This wasn't and still isn't case."

"trying to get there via doctors was the issue and only managed to get access when my son was excluded because of his challenging behaviour"

CAMHS Theme - Pathways and Criteria

“He had a recent diagnosis by Healios with Autism. Healios said to phone CAMHS about therapeutic support. Phoned CAMHS. Answer phone. Phoned GP. They said to phone CAMHS to get support and gave me more web pages. I phoned CAMHS again after a week of trying to get through and leaving messages - the admin staff said that they didn’t offer therapeutic support. Despite it saying therapeutic support on the web page. Waited a further four days for another GP appointment. In the meantime, my son phoned childline. Childline said you need a GP appointment to get a referral to CAMHS. Dr said they would do a referral to CAMHS but that it was unlikely that they would accept the referral. Waiting now.”

“Cahms do not want to know, have been told by them that anxiety is not a mental health issue and they refuse to help

“No transition from children’s to adult services, appalling, your young person certainly falls of a cliff.”

“Stuck in an endless loop between Camhs and OT.”

CAMHS service positive Feedback

"A fantastic assessment was done. My child was then diagnosed. All within a few months. The staff were amazing. Even recommended further assessment to help and signposted to other services etc. Got the diagnosis report speedily and even now they still have input and are helping my child."

"Once Allocated the service it was overall good!"

"I found everyone to be helpful and very clear with what was happening. Every step was explained well."

"xxx (from CAMHS) has been amazing when my daughter was helped by her. She also helped by sending an ocd booklet out. This was extremely reassuring and very effectively. Xxx (Practitioner from CAMHS) really understood my daughters needs. Camhs did a parent cbt programme a few years ago which has been useful."



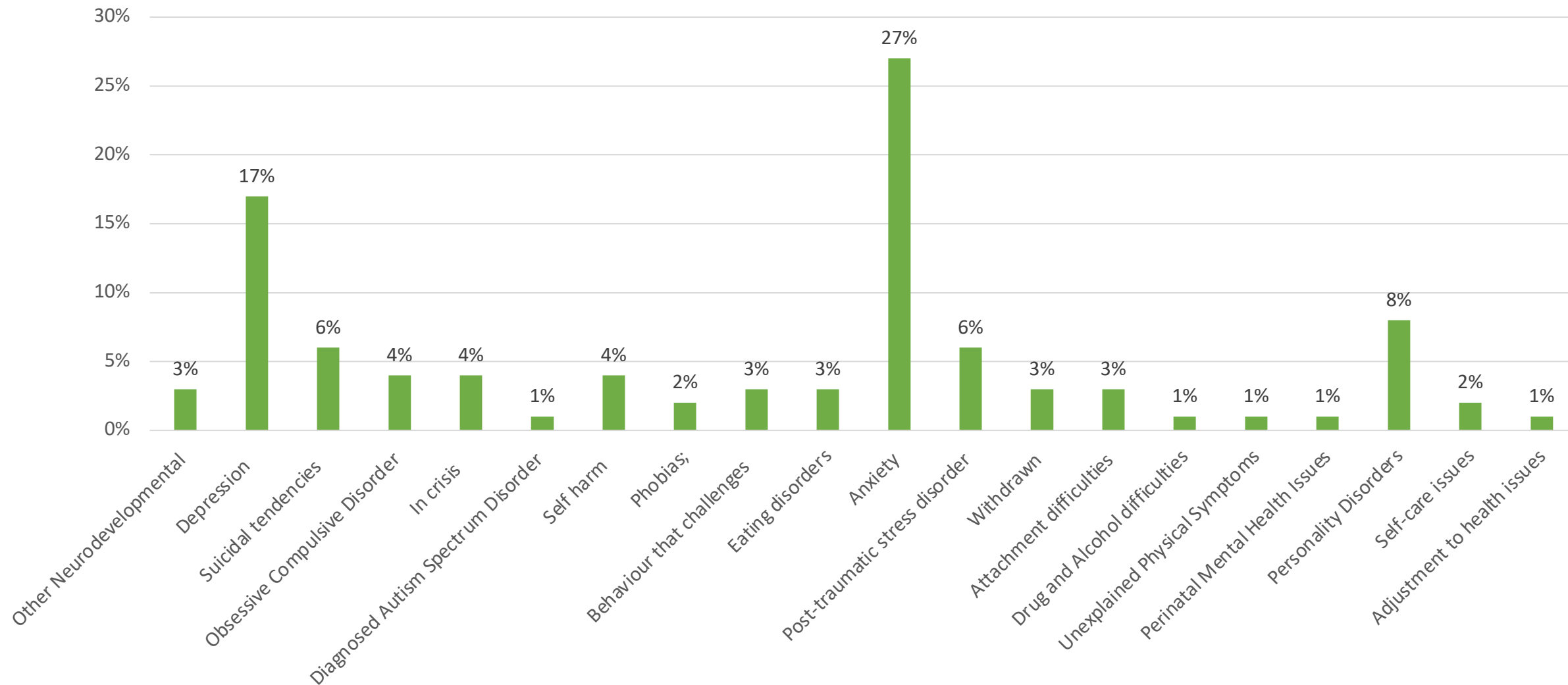
CAMHS Service positive Feedback

After a horrible experience with CDC I saw XXX at a parent forum drop in who promised to add my child to waitlist. I then had to show a need for an urgent assessment. That was successful and a fantastic assessment was done. My child was then diagnosed. All within a few months. The staff were amazing. Even recommended further assessment to help and signposted to other services etc.

Got the diagnosis report speedily and even now they still have input and are helping my child.

Once we had accessed the right service which took a lifetime of people closing doors, the service we got was wonderful, totally transformed my young person, it's a shame that if you are not resilient in your persistence then crisis happens

Main mental health conditions of adults attempting to access Adult Mental Health Services





On a rating scale of 1 to 10 (1 being negative and 10 being excellent), those who responded to the consultation rated their experience of Adult Mental Health Services as an average of 4.

11 adults expressed an interest in being involved in working with RPCF and services to inform future development including further consultations resulting from this initial one and focus groups.

When asked about their experiences, the following main themes emerged from the voice of adults in relation to Adult Mental Health Services. -

Pathways, communication and support.

(the full transcript of shared experience verbatim can be found at Appendix A)



Adult Mental Health Service Theme - Pathways

“We faced roadblocks from the beginning, all starting with the GP referral not going through as the GP failed to do it properly. My son then was denied an assessment and we had to pay for one privately as he was at crisis point.”

“I don’t know how to access help for myself, I just wouldn’t know where to start.”

“I don't recall ever seeing any information I can understand about the latest pathways.”

“No pathway for trauma and forced to do group work I mentally couldn’t cope with. Given one option of therapy which wouldn’t help my conditions at all. Fed webs of lies about everything and discharged as soon as I disagreed with anything they said. Completely ignored my individual needs and lied to throughout my whole experience.”



“I rang up was told somebody would ring me back they never did, I then received a letter from the clinic I called back and left a long voicemail and have never had contact since.”

“No one would talk to me and agency didn’t communicate and made it very stressful and hard for me to support my son”

“They didn't want to know and kept passing the buck. They wouldn't help or listen to me.”

“referred for CBT but it was a poor experience. The appointment was never the full time and I felt rushed out of the door. It all felt like a tick box without any real feeling explored. Would have preferred counselling.”

Adult Mental Health Service Theme - Communication and Support

Adult Mental Health Service Theme - Communication and Support

“The crisis line is wholly inappropriate. Getting responses such as “nothing has changed in your circumstances so why are you suddenly suicidal?” should NEVER be said.”

“The people I saw made me feel worse, made out that I was lying about the things that I experienced, told me that my diagnoses were not valid and tried to tell me that I wasn’t trying to help myself. I felt like they didn’t properly understand my mental health issues or even basic mental health issues like anxiety.”

“I have been failed and always passed about service to service or just cut off from services.”

“Just left after group work no direction on what to do next.”

“There are blanket policies in place forcing patients into group situations and if they refuse, they are discharged.”

Adult Mental Health Service Theme - Communication and Support

“It is a blanket offer using methods that are not suitable for the persons needs. The offer is not individualised.”

“I was always under the CPA, Care Programme Approach, til 2019 when I learned BY EMAIL this was being discontinued, thus contravening RDASH CPA policy. Complaint dismissed; Covid Wellbeing advice from RDASH was for dementia!!!”

“In short, the staff were rude and unhelpful, the therapy my child wanted (stipulated in NICE) wasn't available and she was offered therapy wholly inappropriate, not NICE compliant and when we researched using the website, they gave us the therapy was for eating disorders and PTSD wasn't mentioned anywhere.”

Adult Mental Health Service Positive Feedback

"Once we had accessed the right service which took a lifetime of people closing doors, the service we got was wonderful, totally transformed my young person, it's a shame that if you are not resilient in your persistence then crisis happens."

"Was good even after 2 years waiting for an appointment."

"Service was very good, much better than children's, initial appointments were quick, although there was a long wait for therapy. They understood daughters ASD but looked at her mental health issues separately (previously CAMHS wouldn't, just said it was down to her Autism) the staff she worked with were fantastic and took a person centred approach."

"I was very depressed and anxious after losing my husband.
I was given
12 sessions of bereavement counselling, which, really helped me."



Across all the common themes identified in Childrens' access to mental health services **Believe Me, Get me help quicker, Diagnostic overshadowing, Pathways and Criteria** and Adults access to mental health services, **Pathways, communication and support** is the underlying and central theme of **Effective Communication** and what services are commissioned in Rotherham for this cohort.

RPCF note that at the time of this consultation there is considerable investment and work happening around the ND pathway, With me in mind pilot, ICS keyworker pilot, Autism education training and SEN toolkit. The impact of this work on the experiences of families alongside the ongoing implementation of the SEND strategic action plan and SEMH board through ongoing monitoring , evaluation and effective communication will be realised over time.



Considerations and Next steps for RPCF

01

Share identified themes with Commissioners and relevant boards

02

Collaborate with other local organisations gathering lived experience s eg, VAR, Healthwatch -

03

Network with local and regional delivery partners, eg, VCS, RDaSH, WMIM,

04

Communicate the service development going on and plans Continue to gather lived experience and impact of new pathways

05

Promote the Consideration of the 4 cornerstones approach in service specs to embed Welcome & Care, Value &include, effective communication and partnership with people in Rotherham accessing mental health services

Together We Make A Difference