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Hywel Dda Community Health Council

# Child and Adolescent Mental Health Services - (CAMHS)

December 2022



# **Accessible formats**

This report is also available in Welsh.

If you would like this publication in an alternative format and/or language, please contact us.

You can download it from our website or ask for a copy by contacting our office.

# Contents

<b>About the CHCs</b>	<b>3</b>
<b>Introduction &amp; Background</b>	<b>5</b>
<b>What we did</b>	<b>7</b>
<b>Who we are hearing from</b>	<b>8</b>
<b>What we heard</b>	<b>8</b>
<b>What people said was good</b>	<b>13</b>
<b>What people said was not so good</b>	<b>14</b>
<b>What people said about how to make things better</b>	<b>16</b>
<b>Learning from what we heard</b>	<b>19</b>
<b>Recommendations</b>	<b>20</b>
<b>Thanks</b>	<b>22</b>
<b>Feedback</b>	<b>23</b>
<b>Contact details</b>	<b>24</b>
<b>Hywel Dda University Health Board response to our report</b>	<b>25</b>

# About the Community Health Councils (CHCs)

CHCs are the independent watchdog of the National Health Service (NHS) within Wales. CHCs encourage and support people to have a voice in the design and delivery of NHS services.

CHCs work with the NHS, inspection and regulatory bodies. CHCs provide an important link between those who plan and deliver NHS services, those who inspect and regulate it and those who use it.

Each CHC:



**Carries out regular visits to health services to hear from people using the service (and the people providing care) to influence the changes that can make a big difference**



**Reaches out to people within local communities to provide information, and gather views and experiences of NHS services. CHCs use this information to check how services are performing and to ensure the NHS takes action to make things better where needed**



**Gets involved with health service managers when they are thinking about making changes to the way services are delivered so that people and communities have their say from the start**



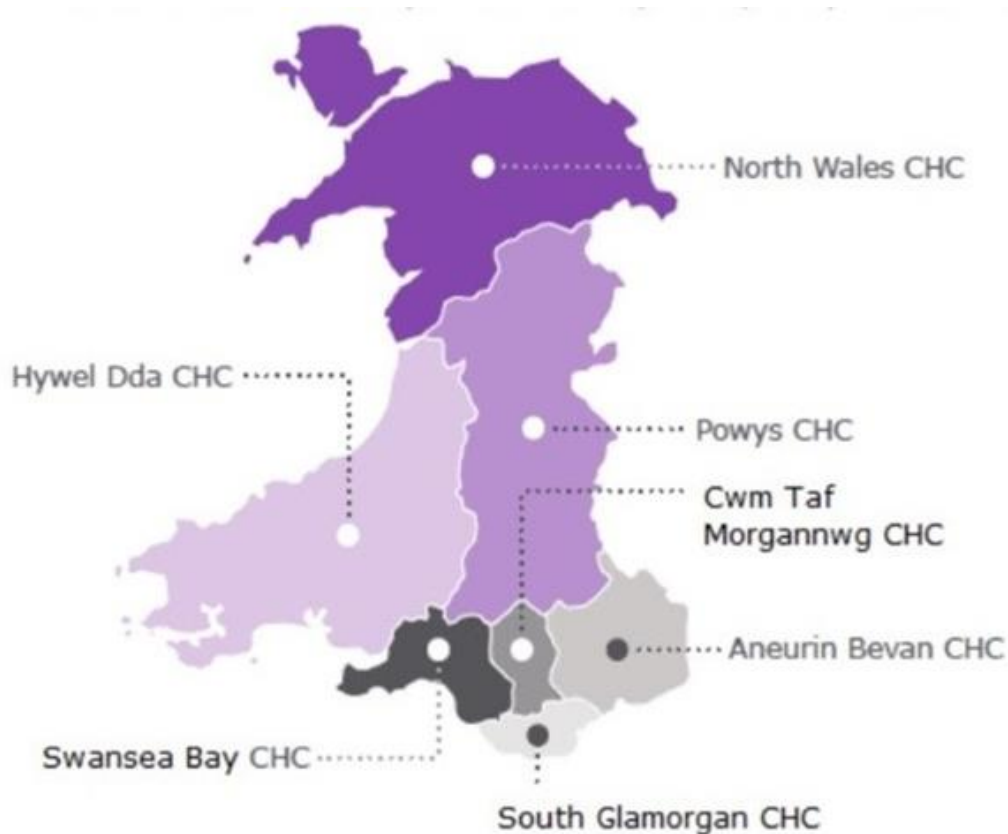
**Provides a complaints advocacy service that is free, independent and confidential to help people to raise their concerns about NHS care and treatment.**

CHCs hear from the public in many different ways. Before the coronavirus pandemic, CHCs regularly visited NHS services to hear from people while they were receiving care and treatment. CHCs also heard from people at local community events, and through community representatives and groups.

Since the coronavirus pandemic, CHCs have focused on engaging with people in different ways.

This includes surveys, apps, video conferencing and social media to hear from people directly about their views and experiences of NHS services as well as through community groups.

There are 7 CHCs in Wales. Each one represents the “patient and public” voice in a different part of Wales.



## Introduction & Background

Community Health Councils across Wales have heard, through our national surveys, that children and young people who are referred to mental health services (Child and Adolescent Mental Health Services – often called CAMHS<sup>1</sup>) are faced with a long waiting times. Child and Adolescent Mental Health Services (CAMHS) is the name for National Health Service provided services in the United Kingdom for children, generally until school-leaving age, who are having difficulties with their emotional well-being or are deemed to have persistent behavioural problems.

Identifying when young people are experiencing poor mental health and then providing them with appropriate support and treatment is important for children and young people. Without

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<sup>1</sup> CAMHS - Child and Adolescent Mental Health Services

the appropriate care at the right time, there is a risk that mental health problems continue into adulthood. These can then stay with that person and have an effect on them, their family and friends, for the whole of their lives.

During the pandemic, disruptions to school, home and life in general have affected many of the support systems young people rely on. This may have worsened their mental health and wellbeing both during the pandemic and now. This has the potential to impact their later life.

We understand from Hywel Dda University Health Board papers that recruitment challenges for suitably skilled and qualified staff to work with children and young people continue. Although more recently, there has been some success recruiting into recent vacant posts. Vacancies for the School In-Reach team to help children and young people in school settings are being advertised. It also takes time to process successful applicants, induct them and get them into their working roles.

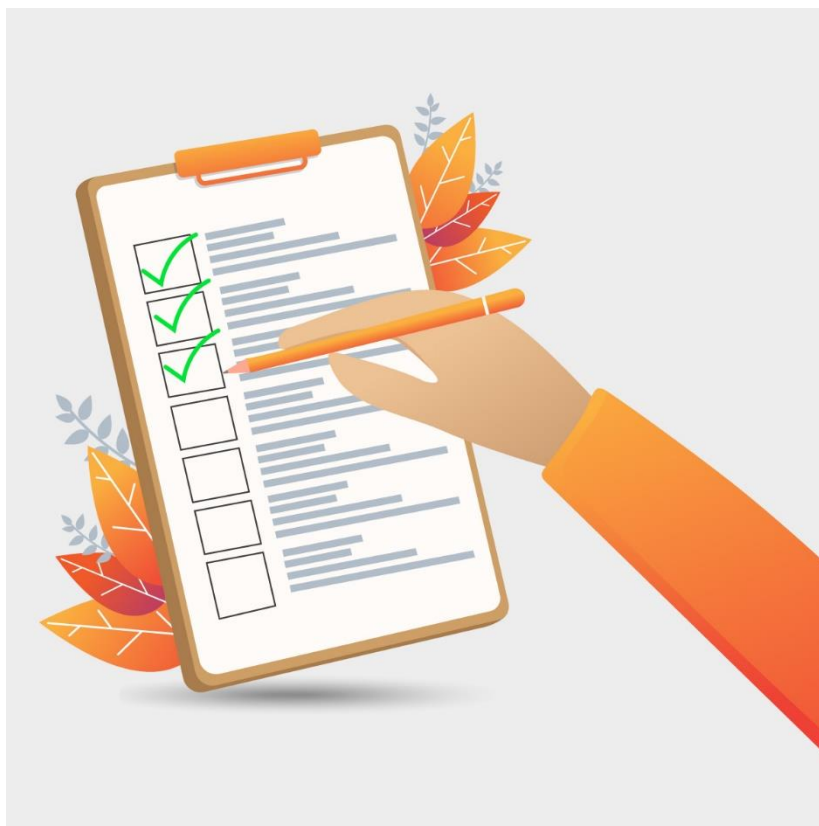
Given these recruitment issues and the effect of the pandemic, Hywel Dda CHC wanted to get a better understanding of how children and young people's mental health has been impacted and to learn more about their experiences of getting support throughout this period. We asked patients and their carers to complete our survey to tell us what their experience was like in the three counties of Carmarthenshire, Ceredigion and Pembrokeshire.

# What we did

We delivered surveys and posters with QR codes to various 3<sup>rd</sup> sector organisations (sometimes called voluntary organisations) in the Hywel Dda area. Emails were also sent to the 3<sup>rd</sup> sector organisations that we frequently link in with.

We also shared our survey regularly via our social media platforms such as Facebook, Twitter and Instagram and we also made sure people could access the survey on our website as we know people often use their phones, tablets and computers to find out and access information.

In total we received 30 responses to our survey. We asked the patients where they accessed their services and how they felt about their care.





# Who we are hearing from

Almost half of the responses were from patients living in Carmarthenshire, the other half were from Ceredigion and Pembrokeshire. Most of the responses were from patients who were past users of these services and about a quarter of the responses were people currently using the service and about another quarter were people who were still waiting to be seen.

Those who were waiting to access these services told us about waits between 2 months and a year, some had waited many years. The age profile of patients represented in the survey was on average between 13 and 17, though two were as young as 5 and 9 years old.

# What we heard

Child mental health services are found at various different sites throughout the Hywel Dda area, including Tŷ Helyg in Aberystwyth, Aberaeron Integrated Care Centre, Canolfan Gwili in Glangwili hospital Carmarthen, and the Elizabeth Williams clinic in Llanelli. Some patients accessed the services through their school counsellor.

Finding out what was available and being able to get to that service were problems in some cases even before patients were actually seen by anyone.



didn't meet threshold for support

Awful, no support whatsoever

Other services were not sufficiently aware of what they [CAMHS] do and what they don't do

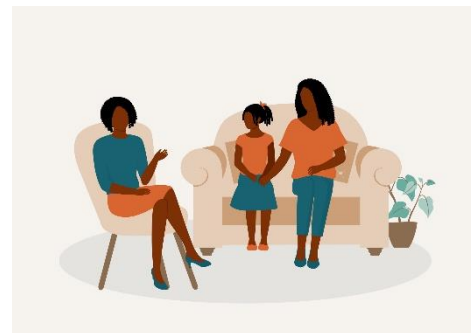
Being sent in circles when you ask for help, wait for help and then get told we can't help, go to see xyz...and it starts again....

Once people were in touch with the CAMHS service, some were then frustrated at not being able to access the services at all.

Awful. 7 refused referrals despite self-harm and suicidal thoughts. When we were finally seen after a formal complaint, the lack of understanding of autism and PDA was astounding. More harm done than good and we discharged ourselves from the service.

Lack of services...No response, left to try and manage ourselves, school unsupportive!

The waiting list was such that we had no alternative but to secure private counselling due to depression. Fortunately this is something we can afford as a family.



Others waited and were seen but then told that they couldn't be helped.

Unless your child is suicidal they do not want to know. Signposting to teams around the family / parental groups but no actual support for the child was our experience. The system is overwhelmed, the demand outweighs the support available.

She met with a CPN for initial assessment, and answered every question positively. I was brought back in at the end of the assessment, where I had to correct a few of the answers, and she was discharged from the services. While my daughter needs support, she was deemed inappropriate for the service

Referral via the G.P for self-harm and no food intake, but I had a letter after 2 weeks from CAMHS saying they can't help because she has autism.

The doctor was good on the day, seemed to understand and I felt positive we'd get some help after waiting a long time for the appointment, then after the session we got a letter saying we can't help, we had already been declined once, but our G.P re-applied.

Our CAMHS Community worker was coming to the house each week to support my child; this went on for a couple of months and now she's disappeared

Those families that were able to get care told us how long they had waited. Some had been waiting years, although others didn't have the same experience, and were able to access care in a more timely manner.

They have been unhelpful, difficult to get hold of and the waiting list was ridiculous. She was only seen when she threatened her own life.

Waiting 2/12 so far for support with severe anorexia

Following referral from G.P, very well informed and had an appointment within 2 weeks

Moved things from very alarming to fairly manageable without a very long wait.

The waiting list was not as long as we had feared so we were happy with 2 months. My daughter has seen a worker twice within the last 1 ½ months for an hour session each time.

The recent pandemic meant that the ways that patients accessed care was different. Some people were seen in person and others were seen online using tablets, phones and other devices.

# What people said was good

We asked people what they felt was good about the services. Almost all said positive things about the staff. They described them as friendly and approachable, professional and that they clearly wished to help. Many people told us that staff were experiencing workload pressures because of the high demand for the service.

The staff were good but they are under resourced

The staff involved were good, all very caring, but so understaffed

Others praised the staff and how they delivered the service.

Effective and initially kind counsellor

The practitioner was amazing. She spoke to my daughter on her level



The assessment occurred within 1 month of referral. The CBT therapist was great and my daughter responded to her well

Once we got to the top of the waiting list our experience with our allocated therapist and practitioners were extremely positive

They were friendly, reassuring and professional. Tŷ Helyg is a comfortable, safe place.

People also told us that reception staff and communication about appointments were also good.

## What people said was not good

When we asked people to tell us about the things that were not so good about the service, we often heard that there were limited resources, This meant that people had to wait a long time to get the support they needed and often found that the support they had come to an end very quickly.

We heard that people were not clear about the criteria for receiving any assistance at all

Some mentioned that it took some time for the child to adjust and trust staff delivering care, and that longer periods of help would be beneficial and care often ended too soon.

Waiting list times, admission criteria, lack of specialist help for neurodiverse children, poor staffing level, how you've got to be at crisis point to get any help

Others would like to see more parental input, as they felt their child could “mask” problems and that the parents should have more involvement in the process.

The service is child and adolescent, but I feel they need to listen more to the parent. Children are experts at masking problems

There was no communication with me as a parent. The wait was ridiculous. Their limited resources didn't work for my daughter and there was nothing else

Some comments were made around times of mental health crisis, and the lack of clarity around who and how the services could help, with one patient being signposted inappropriately.

Nobody actually listens. It is difficult to get an appointment and the number of sessions is never enough especially for an ASD child who take time to build relationships.

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The counselling my daughter had took a couple of weeks for her to adjust and to trust and like her counsellor which was great.

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<sup>2</sup> ASD – Autism Spectrum Disorder



On a particular day of crisis, we were told by Bronglais to take our son to Glangwili A&E. We were told CAMHS didn't deal with children with learning difficulties. It would be useful if other services were aware of this so we weren't sent there needlessly on a day of huge crisis.

## What people said about how to make things better

Some parents asked that the referral system and criteria for help be looked at. This meant making sure that GPs<sup>3</sup> knew more about when and how to refer to the CAMHS service.

We also heard that people wanted better links between the crisis team and CAMHS so that people were not left in the lurch or trying to chase things up themselves.



<sup>3</sup> General Practitioners

Most people wanted more funding, resources and qualified staff, and to provide training and support for those staff to allow the service to be able to cope with the demand.

A reduction in waiting times and clear communication was also a common theme with parents wanting quicker access to help (particularly in crisis).

Some clarity was asked for regarding supporting children with learning difficulties. This area did not seem to be clear for parents or those delivering the service.

It was raised that "one size out of the box does not fit all" and that each individual should be assessed on their specific needs, and parental input was also deemed paramount.

More therapy needs to be on offer and each child needs to be treated as an individual. They should have a bespoke therapy package and therapists should encourage their clients to talk openly about the service they are receiving and if it is helping.

Need a more comprehensive assessment with the parent to understand daily problems the child is facing.

Listen to parents. If we say there's an issue, there's an issue!

Easier access- discussions with parents

Some requested more support for parents, such as training, support packs and advice lines. Others mentioned access to services closer to home. People told us that the length of the support available could be longer and early discharge was a concern. Having these services available at schools and arranged through the schools would also help parents and those using the service.

She had 6 sessions following sudden onset ticcing and anxiety and self-harm after lockdown. The therapist worked with her on her anxiety. The sessions and the work my daughter put in made an enormous difference and turned her life back round.

When she was finally seen it was great!

She was really lovely for my daughter to talk to, she really helped with the OCD in particular.



# Learning from what we heard

The CHC fully appreciates that recent increased demands for mental health support for children and young people as well as staffing issues have put a great strain on the service leading to long waits for support.

Better communication with families whilst they wait for support should be put in place with other avenues of support available during this time eg training, support packs and advice lines

The results of this survey show a mixed picture of people satisfied with the care they had as well as those who were unhappy, mostly about waiting to have care and getting the right care. It was very clear and reassuring that once children were receiving support from the CAMHS service, they felt they benefitted greatly, patients and parents alike commended the service. It shows that despite the staffing issues and high demand that staff have provided a positive experience for those using the services.

We continue to work closely with the Health Board and understand the enormous challenges they face.

The CHC acknowledges that this report may not be the experience of all patients that received care during the time period of our survey. We would welcome hearing further experiences and our contact details are at the end of this report.

# Recommendations

**01** Long waits for assessment and treatment to be improved and systems developed to better maintain contact with service users and their families, parents or carers.

**02** Any application for help should be responded to in a timely manner.

**03** Enhancement in support and information for service users if they are deemed not suitable for CAMHS services

**04** Better information and knowledge of the support available from CAMHS to be displayed by primary care and other healthcare providers

**05** Improvement in the services, support, and interventions offered to neurodivergent children and young people and their parents or carers.

**06** Ending of any support (or an individual giving support) must be clearly communicated to the service user.

**07** Development of a CAMHS specialist at Primary Care (or at cluster level)

**09** All medications to be explained to parents /carers

# Thanks

We thank everyone who took the time to share their views and experiences with us about their health and care services and to share their ideas.

We hope the feedback people have taken time to share influences healthcare services to recognise and value what they do well – and take action where they need to as quickly as they can to make things better.

# Feedback

We'd love to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.





## Contact details



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@HywelDdaCHC

Recommendation	Concern	SCAMHS Response
R1	Long waits for assessment and treatment to be improved and systems developed to better maintain contact with service users and their families, parents or carers.	<ol style="list-style-type: none"> <li>1. The S-CAMHS service has established a waiting list monitoring group which meets monthly to provide governance of demand and capacity across the service, identify any key areas for improvement and reduce long waits. Managers review any waiting lists periodically to review any risk and also to ascertain if S-CAMHS remains the most appropriate service.</li> <li>2. Robust recruitment is ongoing to recruit into vacant posts and ensure retention of key staff.</li> <li>3. S-CAMHS has undertaken demand and capacity planning provided by the Welsh Government Delivery Unit.</li> <li>4. S-CAMHS will continue to ensure “Keep in Touch” letters are sent to all clients waiting for an appointment every 12 weeks to reassure them they await an appointment.</li> <li>5. S-CAMHS will advise all clients &amp; families in this letter to contact the service should their concerns escalate whilst waiting an appointment to expediate appointments.</li> <li>6. All clients / families will be provided with information on local support, websites and Digital help available.</li> <li>7. S-CAMHS has commissioned Kooth -On line Digital Counselling Service to provide ADDITIONAL support when waiting for appointments / treatment .</li> </ol>
R2	Any application for help should be responded to in a timely manner	<ol style="list-style-type: none"> <li>1. All referral agencies will be provided with the S-CAMHS Service Specification which outlines both the Operational and Governance framework for the Specialist Child and Adolescent Mental Health Service (S-CAMHS) provided by Hywel Dda Health University Board.</li> <li>2. S-CAMHS will introduce a response time standard of a return call within 3 days for non-urgent, or same day for urgent calls.</li> <li>3. The service has a Single Point of Contact (SPOC) for all referrals and this is operational 5 day a week and will ensure the service responds to referrals within the Welsh Government performance targets of 48 hours for emergency and 28 days for routine referrals.</li> </ol>

		<ol style="list-style-type: none"> <li>4. S-CAMHS will ensure there is a clear referral pathway for the NHS 111 Ring 2 service into S-CAMHS and the Crisis Assessment Team outside working hours and weekends.</li> <li>5. The SCAMHS Crisis Assessment and Treatment team will be available 24/7 to provide urgent assessments and support out-of-hours.</li> </ol>
R3	Enhancement in support and information for service users if they are deemed not suitable for CAMHS services	<ol style="list-style-type: none"> <li>1. S-CAMHS will ensure all service users/ referrals not accepted by the Single Point of Contact team are contacted and informed of the reason why the referral is not accepted.</li> <li>2. Where the criteria for a mental health service is not met, we will endeavour to provide an alternative means of support and signpost to key agencies such as School Counselling, Area 43, Third Sector services and also inform referrers and service users of the wide range of On- line support and Apps that maybe helpful.</li> <li>3. S-CAMHS will ensure information is provided on how to access Kooth: Online Counselling Service for all CYP.</li> <li>4. S-CAMHS will explore with partner agencies if a proposal for multi-agency early help panels can be developed in order to ensure better coordinated response to all mental health and wellbeing referrals. <b>(No Wrong Door approach)</b>.</li> </ol>
R4	Better information and knowledge of the support available from CAMHS to be displayed by primary care and other healthcare providers	<ol style="list-style-type: none"> <li>1. S-CAMHS will ensure all GP Clusters are provided with the S-CAMHS Service Specification to ensure awareness of service function and referral pathways.</li> <li>2. The S-CAMHS website will be updated and available to provide additional information and advice.</li> <li>3. The PMH Service Manager will attend monthly GP Cluster meetings where service developments and any key issues can be raised and addressed. We have shared new innovations and service developments via these meetings and will consider developing new literature to share information.</li> </ol>
R5	Improvement in the services, support, and interventions	<ol style="list-style-type: none"> <li>1. S-CAMHS will ensure Implementation of the Code of Practice for Autism.</li> </ol>

	offered to neurodivergent children and young people and their parents or carers.	<ol style="list-style-type: none"> <li>2. S-CAMHS will contribute and implement further service support, interventions and developments in line with the Welsh Government Neurodivergence Improvement Plan.</li> <li>3. S-CAMHS will continue to support the Regional Partnership Board in the delivery of improved services.</li> <li>4. S-CAMHS will ensure the workforce receives specific training on ASD and related Neurodevelopmental disorders.</li> </ol>
R6	Ending of any support (or an individual giving support) must be clearly communicated to the service user	<ol style="list-style-type: none"> <li>1. S-CAMHS will ensure that discharge planning / treatment endings is undertaken as preparation for discharge.</li> <li>2. S-CAMHS will provide information on community support etc on discharge and advise on re referral pathways as appropriate.</li> </ol>
R7	Development of a CAMHS specialist at Primary Care (or at cluster level)	<ol style="list-style-type: none"> <li>1. S-CAMHS has a dedicated Primary Mental Health Team for Children and Young People whose remit is to provide emotional and mental health support for mild to moderate presentations.</li> <li>2. S-CAMHS will ensure the full implementation of the School in Reach Service across the health board footprint.</li> <li>3. S-CAMHS Managers will explore with GP Clusters the possibility of additional services within the community ie expand the Pilot Family Support Service in Pembrokeshire.</li> </ol>
R9	All medications to be explained to parents /carers	<ol style="list-style-type: none"> <li>1. S-CAMHS will ensure use of the Medication Consent forms is in place for all CYP who are prescribed medication.</li> <li>2. S-CAMHS will ensure medication information leaflets are routinely provided and medication plans are discussed with client/ parent/carer when consent is provided. Explanations / information will be provided on any investigations needed to be undertaken, such as blood tests etc.</li> <li>3. S-CAMHS will also explore alternatives to medication if parents/carers and their child are not in agreement.</li> </ol>

# **Hywel Dda Community Health Council**