



Our Ref: CS/KD

12 December 2016

**By Email**

Lynne Neagle AM  
Children Young People and Education Committee

Dear Chair

**TOGETHER FOR CHILDREN AND YOUNG PEOPLE PROGRAMME**

Thank you for inviting us to attend the Children, Young People and Education Committee on 24 November 2016 and your subsequent letter of 7 December.

As we highlighted at the meeting, '*Together for Children and Young People*' (T4CYP) is making good progress in delivering a whole systems approach to emotional health and wellbeing and not just CAMHS, but we have significantly more to do.

In your letter you asked for clarification on the new CAMHS targets. In response to your questions we can confirm that:

- The current target for referral to treatment is 28 days. This brings CAMHS in line with the target for adult mental health services.
- Statistics against the new waiting times targets of 48 hours for urgent specialist CAMHS assessments and 28 days for routine assessments are not yet routinely published. We understand that Welsh Government policy officials are requesting that NHS Stats change their reporting systems. Such a change has to be agreed by the Wales Information Standards Board, a process we understand is being worked through. We are able to interrogate the current data to show individual weeks and use the 4 week position to report against the new 28 day target for routine assessments. The total number waiting 28 days from June to September 2016 has decreased by 42% (106 to 62).
- Both the 48 hour urgent and 28 day routine targets you cite in your letter refer to referral to assessment. The latter again brings CAMHS in line with the requirements for adult mental health. All health boards tell us that they are now meeting the 48 hour target and that those who are not doing so already, will achieve the 28 target by April 2017.
- The neurodevelopmental data is no longer reported within the CAMHS statistics and is being included within the revised routine reporting arrangements outlined above. As we mentioned at the session, this brings neurodevelopment in line with the rest of paediatrics. Welsh Government policy colleagues are monitoring progress towards this target. All health boards have confirmed will deliver this during the course of 2017.

During the session we also agreed to provide additional information on the wider work of T4CYP. This is outlined below, with the relevant documents attached

### ***Making Sense and our You Said We Did Report***

During 2015, mental health charities Hafal, Mental Health Foundation, Bipolar UK, and Diverse Cymru completed a consultation with children and young people to consider how mental health services in Wales could be improved. The results were published in the *Making Sense Report* (attached 1), highlighting 10 recommendations for improvement. We have taken these into account in remodelling services. Our *You Said We Did* report (attached 2) demonstrates how we are listening and acting upon the issues raised by all children and young people and not just those who use Child and Adolescent Mental Health Services. This was widely shared through our close links with the Children's Commissioner's office, Children in Wales and the High Needs Collaborative.

### ***The All Wales Baseline Variations and Opportunities Audit Report 2016***

The report (attached 3) provides the most comprehensive audit of specialist CAMHS to date, outlining current service models and provision. It highlights variations in Welsh service and identifies both areas for improvement and good practice for health boards to adopt. Recommendations from the first report are informing the work of our specialist CAMHS work stream.

### ***CAMHS National Benchmarking 2016***

All health boards submitted CAMHS data in the 2016 NHS UK wide Benchmarking Exercise. A facilitated event was held on 29 November providing health boards with the opportunity to look at the benchmarked data, review changes over the past 12 months and look at the position across Wales and in comparison with the rest of the UK. We are awaiting a final report from NHS Benchmarking UK which we will forward to you upon receipt.

### ***North Wales Adolescent Services In-patient Unit***

Following your questions at the session we asked for a report from the Welsh Health Specialised Services Committee (WHSSC) as the commissioner for Tier 4 in-patient services. Their report (attached 4) outlines the latest position on the North Wales Adolescent Services in Abergele.

I hope that this provides the Committee with the additional information it requires. We will ensure that members are kept up to date with our work through our regular newsletters which will be sent to the Committee clerk for circulation.

If you have any queries or issues requiring further clarification, please do not hesitate to contact me.

Yours sincerely



**Carol Shillabeer**  
**Chief Executive Powys teaching Health Board/Chair of T4CYP Programme**

*Cc: Siân Stewart, National Director for Mental Health/Programme Director T4CYP*

*Enc:*

- 1. Making Sense Report*
- 2. You Said We Did Report*
- 3. All Wales Baseline Variations and Opportunities Audit Report 2016*
- 4. North Wales Adolescent Services Report*



# **A report by young people on their well-being and mental health**

**A response to the 'Together for Children and Young People' Programme**

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*January 2016*



## First, let us introduce ourselves...

We are Mair Elliott and Jake Roberts. We have both used Child and Adolescent Mental Health Services (CAMHS) in Wales. This is our report.



### **Mair Elliott, 18**

*Aged 14, Mair began suffering from anxiety and depression. As her illness worsened, she developed psychosis and regularly self-harmed.*

*She needed hospital care, but the only available bed was in London, six hours from her home in Pembrokeshire.*

*Now 18, Mair campaigns to improve CAMHS, and became a Hafal Trustee in autumn 2015.*



### **Jake Roberts, 22**

*Jake first saw CAMHS after being hospitalised when he was 17. Despite numerous attempts to access services, he only received help after entering crisis.*

*Diagnosed with Borderline Personality Disorder, Jake feels stigmatised by a diagnosis he believes will hinder him for the rest of his life.*

*Now 22, Jake is keen for lessons to be learnt from his experience to improve the lives of future CAMHS users.*

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# Summary

With referrals to Child and Adolescent Mental Health Services (CAMHS) in Wales increasing over 100 percent from 2010 to 2014<sup>1</sup>, and experts saying the service is ‘in crisis’<sup>2</sup>, we are calling for change to address the over-referral of children and young people to CAMHS.

Over-referral to CAMHS is having disastrous consequences for children and young people in Wales. Our consultation, involving over 500 people, found that three-quarters of CAMHS users have a negative experience of the service. Less than half said the service helped them get better and move on. CAMHS needs to change.

As children and young people, we want support from the people we trust. CAMHS users said that given the chance, they would prefer to receive support from friends, educational counselling services and teachers.

We are calling for non-mental health professionals; teachers; school, college and university counselling services and youth groups to share the responsibility for the majority of children and young people’s emotional needs and overall development. Specialist CAMHS should support the much smaller numbers of young people with the highest needs.

To achieve this, strict referral criteria must be enforced, emotional intelligence and healthy coping mechanisms need to be taught in schools, and an absolute timescale for referrals must be introduced.

This will reduce waiting times for the most severe cases who need specialist CAMHS, and ensure that young people receive support that is appropriate to their needs - at the earliest possible opportunity.

Children and young people face many challenges growing up, but we should be wary of labelling these ‘mental illness’, diagnoses they live with for the rest of their lives.

We must not medicalise growing up.

## Key data

- Three-quarters of CAMHS users have a negative experience of CAMHS
- Less than half of CAMHS users agree that the service helped them get better and move on
- But, 75 percent of CAMHS users said that the service was friendly and approachable
- 56 percent of CAMHS users would prefer to turn to friends, 44 percent would prefer to turn to education counselling services and 39 percent would prefer to turn to teachers

## Our recommendations

1. Expand and/or create high-quality support provided by non-mental health professionals
2. Don’t medicalise growing up
3. Reform CAMHS’ referral systems
4. Embed emotional intelligence and healthy coping mechanisms into the curriculum
5. Introduce an absolute timescale for referrals
6. Review practice within CAMHS
7. Reorganise the transition to adult services
8. Improve data collection and accountability
9. Support carers
10. Listen to young people

You can find our recommendations in full on page six.



# Why we're writing this report

Like most other users of Child and Adolescent Mental Health Services (CAMHS), we have had both good and bad experiences. We have met caring professionals doing their best but we have also been let down by delays and inconsistency in support which has made us and our families fearful about whether we could cope.

But, we are not defined by our mental health problems. Like all young people\* we are most concerned about growing up to be happy and successful. We need supportive family and friends, good schools and colleges which see education in its broadest sense - not just academically but with first class pastoral care that can help when we get into difficulty; we need good GPs and other primary care staff who can help us with physical and mental health needs.

Along the way a few of us have problems which require specialist help from mental health services. When that need arises we need it quickly and we need it to be effective so that we don't hold up our education or lose touch with what other young people are doing.

Because we feel passionately about this we have been campaigning to improve services. In May 2014 we and two other young people, Rosie and James, gave evidence on our experiences of CAMHS to the National Assembly for Wales 'Children and Young People Education Committee'. Our evidence was described as some of the most powerful the Committee had ever heard and was reflected in their report 'Inquiry into Child and Adolescent Mental Health Services (CAMHS)'<sup>3</sup>.

In December 2014 we met the Health and Social Services Minister, Mark Drakeford AM, to discuss our experiences alongside the then Children's Commissioner for Wales. And, in November 2015 we discussed our current campaign with the new Children's Commissioner for Wales, Professor Sally Holland. We have also appeared on television and in the press to share our ideas.

Over the last year we have been working with partners in the Making Sense initiative, which aims to respond to the Welsh Government's challenge to improve mental health services for children and young people in Wales. The Making Sense initiative comprises the High Needs Collaborative (mental health charities Hafal, Bipolar UK, Mental Health Foundation, Diverse Cymru), in partnership with Wales Observatory on Human Rights of Children and Young People, who assist us with the human rights and legal aspects of CAMHS and wider services.

This report is ours but it is also endorsed by the organisations in the High Needs Collaborative, which represent many hundreds of service users and their carers. We have consulted over 500 people over the last few months, and are pleased to voice their experiences alongside ours.

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\*'Young people' is used from this point to refer to all children and young people.

## The 'Together for Children and Young People' Programme

In the last few years CAMHS services have come under increasing strain. In February 2015 the Minister of Health and Social Services launched a programme to review and refocus CAMHS.

"Led by the NHS in Wales, Together for Children and Young People (T4CYP) is a multi-agency service improvement programme aimed at improving the emotional and mental health services provided for children and young people in Wales."<sup>4</sup>

In terms of statistics, the heart of the problem is the doubling of CAMHS referrals in recent years<sup>5</sup>.

The Minister of Health has observed that many of these referrals are not appropriate and lead to:

- frustration for those children, young people and their families who learn that they have been sent down a route which cannot meet their needs
- frustration for CAMHS staff who spend time and resources on assessments which need not have happened
- harm for those young people who really do need the mental health expertise of a CAMHS service, but find their way to that service delayed by so many others who turn out not to have needed it.<sup>6</sup>

### About Making Sense

We are supporters of 'Making Sense', an initiative by the 'High Needs Collaborative' (mental health charities Hafal, Bipolar UK, and the Mental Health Foundation, supported by Diverse Cymru) working with the Wales Observatory on Human Rights of Children and Young People, aimed at improving support for children and young people in Wales with a mental illness.

We believe there is an urgent need to reform and refocus services for children and young people in order to clarify who is responsible for providing support at different levels of need and, through that refocus, to make major improvements in services for those in highest need.

We also recognise that we cannot consider the needs of young people in the highest need without seeing that in the context of all young people's needs.

The Minister has already pointed to some of the answers to these problems. He says the solution lies in a Prudent Healthcare approach, specifically:

- Maximum diversion
- Minimum intervention
- Systems management.<sup>7</sup>

#### Notes from Wales Observatory of Human Rights of Children and Young People

When deciding what to do about CAMHS, Welsh Ministers are required by law to have due regard to the requirements of the United Nations Convention on the Rights of the Child (UNCRC), which recognise the special needs of children growing up as well as their developing capacity. The requirements include a range of issues surrounding the holistic development of children and young people.

All legislative, administrative and other means must be used to implement these requirements. The UNCRC publishes General Comments, Concluding Observations and other information to help governments.



# Our Consultation

Over the last few months we undertook three distinct surveys:-

- An on-line questionnaire via SurveyMonkey aimed at CAMHS users, their carers and any other young people under 25
- Group surveys of pupils in two secondary schools (including one Welsh medium)
- Group surveys of adult user and carer groups with experience of mental health services

We also participated in two seminars led by the Wales Observatory on Human Rights of Children and Young People at Swansea and Bangor universities. With students and their tutors we discussed the issues concerning mental health services in Wales in the context of legal and human rights. Their expertise has been invaluable in helping inform our report.

## The findings

The table below shows the responses we had for different parts of the consultation:

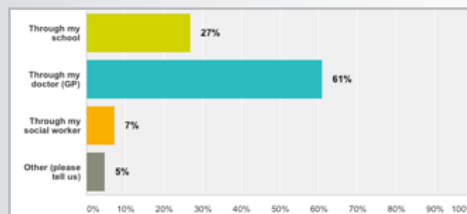
How	Demographic	Total
On-line SurveyMonkey	CAMHS users (or former)	54
	Carers of CAMHS users	116
	Other young people under 25	76
Group discussions	Pupils in schools	191
	Adult service users and carers	80
		517

The full results of the consultation have been published and are available on the Hafal website but the key results were as follows:

### CAMHS users (or former)

- Referral pathway of CAMHS users:

- 27% through school
- 61% through GP
- 7% through social worker
- 5% other



- 23% asked to be referred to CAMHS

#### What they said...

- 72% had a negative experience of CAMHS
- 75% said the service was slow to respond
- 32.5% said the service kept them safe
- 40% agreed that the service they received helped them get better and move on
- 75% rated the service as friendly and approachable

- 29% said the best part of CAMHS was getting to talk to someone

#### Who took part...

- 54 CAMHS users (or former)
- 87.5% described themselves as female, 12.5% described themselves as male
- 93% white British; 7% other/unspecified
- 60% first got involved with CAMHS aged 13-15
- 68% were diagnosed with depression and/or anxiety
- 32% had an eating disorder and/or body dysmorphia



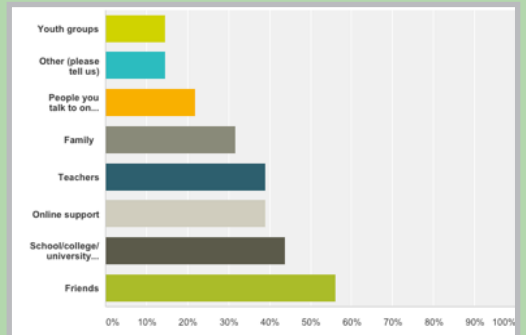


## CAMHS users (or former) continued...

### The key stats...

- When CAMHS users were asked who they would have preferred to turn to for help:

- 56% said friends
- 44% said school, college & university counselling services
- 39% said teachers
- 39% said on-line support
- 32% said family



- 46% are now using adult services
- 38% said the best way to improve the transition to adult services is having flexibility around the age young people are required to transition

*"I didn't feel comfortable with all the professionals involved"*

*"I was on a waiting list for 5 months after being suicidal. I had to phone and demand appointments."*

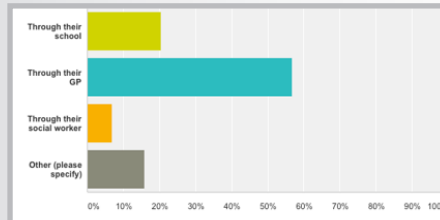
*"More support is needed for families"*

*"My transition to adult services was non-existent. I wasn't prepared for the different approach in adult services"*

## Carers of CAMHS users

- Referral pathway of the CAMHS user they care for:

- 20% through school
- 57% through GP
- 7% through social worker
- 16% other



### Who took part...

- 116 carers of CAMHS users (or former)
- 59% described the person they care for as female, 41% said male
- 98% described the person they care for as white British, 2% said other
- 51% of the people cared for were aged 13-16 when they first accessed CAMHS

### What they said...

- 75% said the CAMHS user they care for had a negative experience of CAMHS
- 80% said the service was slow to respond
- 25% said the service didn't kept the person they care for safe
- 35% agreed that the service they received helped the person they care for get better and move on
- 75% rated the service as friendly and approachable
- 35% said the best part of CAMHS was that the person they care for finally got to talk to someone

*"They don't listen to our opinion. And my son feels they don't listen to him either."*

*"School could have provided him with better care."*

*"We were made to feel like we were part of the problem rather than part of the solution."*

*"CAMHS told her nothing is wrong. She is dead now, so things were seriously wrong..."*

making sense

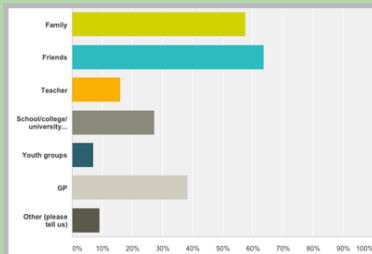
## Other young people (with no personal experience of CAMHS)

- 68% said talking about feelings is most important to maintain good mental health

### The key stats...

- When young people were asked who they would turn to for help if they started experiencing mental health problems:

- 64% said their friends
- 58% said their family
- 38% said their GP
- 27% said school, college & university counselling services
- 16% said teachers



### Who took part...

- 76 young people under 25
- 66% were female, 32% male, 2% other
- 95% white British; 5% other
- But 30% knew a CAMHS user

- 25% said education and awareness in schools needs to improve

*"I would build more help that is closer, which would mean you would not have to travel far or wait too long."*

*"My sister had to wait 20 months to be referred"*

*"I would change it so that teachers stop being so hard on students. Being extremely strict and harsh can ruin your mental health."*

*"We should learn about it in PSE."*

## Groups of pupils in schools

### What they said...

- All eight groups said speaking to friends and/or family is most important to maintain our mental health
- Five out of eight groups said they would first turn to friends and/or family if they started experiencing problems with their mental health

### Who took part...

- 119 children and young people
- 54% were female, 46% were male
- Approximately 7% were from a BME background

- Five out of eight groups said educating people through schools is most important to improve services

## Groups of adult users and carers

- Scored CAMHS as 5 out of 10 in comparison to adult services 7 out of 10
- Eight out of 17 groups recognised that specialist arrangements need to be made for the transition
- Nine out of 17 groups said there needs to be increased awareness and more information for young people

### Who took part...

- 80 adult service users and carers
- 56% were male, 44% female
- 100% white British

# Our recommendations to improve services

1.

## Expand and/or create high-quality support provided by non-mental health professionals

The majority of children and young people will face difficulties as they grow up: it's a given. Most are healthy, despite these expected high and lows. The older young people get, the more responsibility they take for looking after themselves.

All young people need the support and guidance of friends, family, teachers, youth workers and others to enjoy and sustain a healthy lifestyle. In most circumstances these people support young people to maintain their well-being even when they face significant problems: for families this normally happens instinctively; for professionals it should be a core part of their role.

Our consultation shows that young people would prefer to turn to people they trust - over half of CAMHS users (56 percent) said that given the chance they would prefer to turn to friends; 44 percent said they would prefer to turn to educational counselling services, and 39 percent said they would prefer to turn to teachers. We must empower those people so that they can help and support young people, who want and badly need their help. Nearly one-third of CAMHS users (29 percent) said that the best part of CAMHS was getting the chance to talk to someone. Often, that someone could be anyone with counselling training, not necessarily a specialist CAMHS professional.

In fact, less than one-quarter of CAMHS users asked to be referred to CAMHS, which shows that young people just want help (we accept that some young people may be too incapacitated by their symptoms to seek help, others may not be aware of CAMHS).

The Welsh Government has made significant investment in school counselling services: this should enhance the ability of schools to effectively support the majority of children who get into difficulty. In our consultation, only one-quarter of carers said that the CAMHS user (or former user) they care for also used a school, college or university counselling service. We believe this statistic should be far higher.

When a referral is made to CAMHS, the support from non-mental health professionals should not end. Children and young people should continue to lead their 'normal' lives as much as possible, and should still receive support from the services they were accessing beforehand.

The responsibility of children and young people's health lies with everyone; not just CAMHS, not just parents but anyone that person interacts with. It is everybody's business to help future generations of young people live healthy and fulfilling lives.

2.

## Avoid the medicalisation of growing up

Young people, their families, teachers and youth workers should be the experts on how young people can lead a good life and enjoy good mental health. Doctors and mental health services have an important but much narrower role in helping people with more serious problems.

We are concerned that the language and approach of mental health services should not encroach on or undermine the role of teachers and others who have always taken the lead on supporting young people, including those facing significant difficulty. We do not want those anxieties which all young people experience labelled



automatically as “depression” or the behaviour of more unruly children labelled as “conduct disorder”: we suspect this happens increasingly often and it can lead to an inappropriate referral or (worse) inappropriate treatment. We note the huge increase in mental health medication for children in recent years<sup>8</sup> and we do not believe this is defensible. Medication should not be seen as the first choice.

Over two-thirds of CAMHS users in our consultation were diagnosed with anxiety and/or depression. Mild to moderate mental illnesses such as these should be treated by primary care services and education counselling services before more complex issues develop. Some may be prevented entirely if emotional intelligence was embedded into the curriculum (more on this later).

Nothing could be more wrong than treating a troubled child for a mental health problem if their difficulty really lies externally, with family, school, or if they are experiencing normal reactions to life events such as parents separating, bereavement, etc.

We support early intervention in the sense of reacting immediately and effectively when a person displays overt signs of serious mental illness, such as psychosis or severe paranoia, or high-level eating disorder and body dysmorphia.

For example, it is well known that early intervention can greatly improve the long-term prognosis of young people suffering from the first onset of psychotic symptoms.

We should not mistake early intervention in psychosis services provided by mental health services with good quality preventative work by non-mental health professionals. Early intervention by mental health services should have a clearly defined and limited meaning, which does not involve mental health services attempting to intervene with a larger group of young people who might be ‘at risk’.

We cannot emphasise enough that the inappropriate, upward referral of young people towards mental health services is not just inefficient but is also damaging to those young people.

Inappropriate referrals harm both those young people who do not need specialist help and those who do, because they have to wait longer to get help.

#### **Notes from Wales Observatory of Human Rights of Children and Young People**

Having due regard to the UNCRC, children presenting with possible mental health issues would never receive a diagnosis as a gateway to non-medical treatment, and be offered medication only with fully informed consent and clear justification. The use, side-effects and long-term effects of psychiatric drugs on children would be rigorously monitored (Articles 3, 5, 12, 17, 24; General Comments: 14 para 77; 15 paras 38, 39).

## **3.**

### **Reform CAMHS’ referral systems**

Strict referral criteria needs to be introduced and enforced to ensure that only appropriate referrals are made to CAMHS. Training should be given to all referrers to implement Wales-wide criteria on what constitutes an appropriate referral. Referrers need to know who to refer where.

There is an overwhelming need to fix the systems and pathways, as the Minister said<sup>9</sup>.

Generalist children and young people’s services such as schools and youth services must address the problems of the majority of young people who get into difficulty, making use of their own staff and in-house counselling services. GPs should provide for those with more serious problems, making use of primary care-level services and general paediatric services. Interventions at this stage should happen quickly.

We suggest that a single point of access may be required through which all referrals (including those by GPs) must be channelled.



### Notes from Making Sense partners

There are interesting examples of this approach, for example in Derby City a multi-agency group including the Derbyshire Healthcare NHS Foundation Trust meets weekly to agree referrals for a large volume of young people in difficulty.

All referrals (including those by GPs) have to go to the group because there is no alternative route to CAMHS. The group does not assume that the young people necessarily have a mental health problem primarily (so they consider external factors) and almost all those referred are directed towards a specific source of help (not “sent back” or “rejected”) - crucially only a minority are referred to CAMHS. Other referrals are to community paediatric services, school nurses, health visitors, etc.<sup>10</sup>

## 4.

### Embed emotional intelligence and healthy coping mechanisms into the curriculum

Children and young people spend significant amounts of time at school. It is only natural that education should play an important role in their holistic development as people.

Over two-thirds of young people said ‘talking about feelings’ was most important to maintain good mental health. If all children and young people are taught how to cope with stress and other emotional difficulties from an early age then they can help support themselves. Crucially, we should not introduce unnecessarily the language of mental health services.

If relaxation techniques, body confidence, methods to deal with exam and coursework pressure and other healthy coping mechanisms were embedded into the curriculum we could create a generation of children and young people aware of their emotional needs, without thinking or being told that they have a mental illness. This would reduce the number of people requiring specialist support for their mental health.

Peer support should be encouraged. It is no surprise that nearly two-thirds of other young people (64 percent) said they would turn to their friends if they started experiencing problems with their mental health. Young people are often dealing with similar issues; we should actively encourage conversation on these matters.

If emotional intelligence and healthy coping mechanisms were embedded into the curriculum, it would destigmatise the fact that everyone has emotional needs.

We are encouraged by Welsh Government’s review of the curriculum. The Successful Futures Report (The Donaldson Review)<sup>11</sup> provides an ideal opportunity to implement emotional intelligence and healthy coping mechanisms into the everyday development of the next generation of young people. Education should not be limited to academic success; it should be seen in its broadest sense. Crucially, the experts in developing this aspect of the curriculum should be non-mental health specialists, including teachers and young people themselves.

### Notes from Wales Observatory of Human Rights of Children and Young People

Having due regard to the UNCRC, children presenting with possible mental health issues would be protected from stigmatisation and discrimination, including protection from sanctions for non-attendance at school (Article 2. General Comment 15 para 8).

## 5.

### Introduce an absolute timescale for referrals

Many young people are waiting for many weeks to be assessed, causing unacceptable distress to them and their families and



raising levels of risk. Some young people need same-day attention; others should be seen within just a few days. And, where the assessment indicates, appropriate services should be provided promptly following the assessment.

In our consultation, three-quarters of CAMHS users said waiting times are a problem. The length of time from referral to assessment and assessment to treatment must be reduced. To achieve this, a strict timescale for referrals must be implemented.

We note that from October 2015 Welsh Government expected all urgent specialist CAMHS assessments to be undertaken within 48 hours, and all routine specialist CAMHS assessments to be seen within 28 days by 1 April 2016<sup>12</sup>. We encourage this target, but believe a timescale should also be introduced from assessment to treatment if young people are to really benefit.

It should be possible to reduce waiting times by attention to the actions in recommendations 1 to 4 (above). But, there is a need to examine the systems used by CAMHS teams to manage waiting lists.

We wonder if a more sensitive system of guaranteed, swift access into a triage stage could be developed. This could enable immediate actions to be taken to support individuals, along with advice and information - even if they have to wait for further assistance.

#### **Notes from Wales Observatory of Human Rights of Children and Young People**

Having due regard to the UNCRC, children requiring specialist treatment would receive it promptly, close to home and in a developmentally-appropriate setting (Articles 3, 9, 24; General Comment 4 para 29).

## **6.**

### **Review practice within CAMHS**

We are sympathetic towards CAMHS teams concerning the pressure of referrals. Without doubt, reform of referral arrangements is vital if they are to improve not just response times but the quality of care they provide.

It is clear from our consultation that the majority of users (three-quarters) find CAMHS professionals friendly and approachable. But, our consultation also shows that CAMHS services are not very effective in delivering results and keeping people safe (or, anyway, feeling safe). One-third of CAMHS users felt the service didn't keep them safe).

We believe that in addition to reform of referral systems there needs to be a review of how CAMHS teams operate. We would like to see analysis of such issues as:-

- The proportion of working time spent by teams in face-to-face contact with clients and their carers
- How other time is used and whether efficiencies are possible
- The use of group work with clients
- How CAMHS works with other agencies to sustain their support for CAMHS clients
- How CAMHS supports young people to make their own decisions and take action for themselves
- How CAMHS works with carers (more on that below)
- How CAMHS responds to the particular experiences and needs of ethnic minorities and other minority needs
- How CAMHS sustains focus on outcomes.

All of these areas concern not only good practice but also efficient working.

Based on that review, new standards for CAMHS need to be established and delivered, building on the holistic Care and Treatment Plan prescribed by the Mental Health Measure and its Codes of Practice. All life areas need to be considered and all relevant agencies need to be coordinated to deliver on Plans, including non-mental health agencies.



In the longer term, we also think consideration could be given to shifting some of the resources devoted to CAMHS into educational services. This would enable them to take the lead with a higher proportion of young people in difficulty, leaving a much smaller number to come under the care of CAMHS.

Under the Mental Health Measure 2010 (specifically Part Two) all users of secondary mental health services (including CAMHS) are entitled to have a Care And Treatment Plan in a required format which includes sections for eight distinct 'life areas' - so there is scope to create a comprehensive and holistic plan which looks beyond treatment. There is also a requirement for the user of services to be involved in developing their Plan. The Code of Practice for Part Two (and Part Three) of the Measure sets out detailed standards for development and content of these Plans.<sup>13</sup>

## 7.

### Reorganise the transition to adult services

We are deeply concerned about the transition point to adult mental health services. This can be a difficult time because young people can find themselves dealing with different people and different services. In fact, the whole environment can seem completely different.

Efforts are being made to make this transition smoother but there is a long way to go. It is important that non-mental health professionals, as well as young people and their families, are aware of the transition point and make sure they ask CAMHS teams how the transition will be made. They need to find out who will be providing support in the future.

We really do need to find a way to end the abrupt and disruptive transition when a young person turns 18.

One key method of doing this is through improved use of Care and Treatment Plans, which apply to both under and over 18s. The Plan provides a legally-required platform ideal for organising transition and ensuring continuity. We suggest a review of current practice in "handing on" Plans between CAMHS and adult services and development of advice on using Plans to ensure continuity.

In our consultation, 38 percent of CAMHS users said flexibility over the age young people move to adult services is the most important way to improve the transition. For some young people, it may not be suitable to transition to adult services on their 18<sup>th</sup> birthday. Protocols are also required to enable staff to work across the age divide to create continuity in professional engagement.

#### Notes from Wales Observatory of Human Rights of Children and Young People

Legal protection for human rights does not end at 18. Adults as well as children have rights to be treated humanely and to have respect for their family and private life. This includes making sure they have the support necessary for essential human dignity and participation in society, and do not suffer unjustified deprivation of liberty. Welsh Ministers must comply with these requirements (Human Rights Act 1998 section 6; Government of Wales Act 2006 section 81; European Convention on Human Rights Articles 3, 5 and 8).

## 8.

### Improve data collection and accountability

We must analyse what works and what doesn't. To do this, CAMHS teams within the local health boards in Wales must collect the same data to effectively measure outputs.

Ideally, they should all use the same information and data



systems. But, crucially, the information collected within those systems must be the same. Only then will we understand what works and what doesn't.

The availability of Wales-wide data would encourage strategic, evidence-based decision-making across Wales, and encourage health boards to work in a more synchronised way.

#### **Notes from Wales Observatory of Human Rights of Children and Young People**

The UN Committee on the Rights of the Child has repeatedly made clear that systematic and disaggregated data collection, child rights-based performance indicators and effective mechanisms of accountability are all essential aspects of implementation of the requirements of the UNCRC (General Comment no. 5 paras 9, 12 and 48 and repeatedly in Concluding Observations on State Party reports). Without adequate data and transparency there cannot be effective accountability: this applies both to decision-making in individual cases and to policy decisions.

We question whether the improvements in waiting times Welsh Government expected from CAMHS by October 2015 have been met (to reduce the wait for assessment in most severe cases to a maximum of 48 hours). We call upon health boards to release their data to indicate whether this, and all future targets have been met.

We must have accountability for the decision-making that directly affects thousands of children and young people in Wales. If targets are not met, we must be able to question why.

#### **Notes from Wales Observatory of Human Rights of Children and Young People**

Having regard to the UNCRC all children requiring specialist treatment would have the benefit of an advocate capable of giving or accessing legal advice (Article 3, 12.2; General Comment 4 para 29).

## **9.**

### **Support carers**

In our consultation, we found carers to be more critical than users of services. We believe they are probably nearer the mark - many young people find that their mental health problems lower their expectations of services, whereas carers rightly expect timely and effective support for the person they care for.

No wonder they become frustrated when their reasonable expectations are not met. In our consultation, 87 percent of carers of CAMHS users said they did not feel that CAMHS valued their opinion or kept them informed.

Carers often have clear insights into what action will be most effective for the person they care for. They can often clearly see what is not working (and so wasting resources). Carers need to be listened to and treated as lead partners.

In most cases, the carer is the most important source of support for the young person and therefore, where relationships are right, CAMHS teams' greatest ally. Of course there are many instances of this collaboration between the young person, the carer, and the CAMHS team working really well: this practice needs to be celebrated and benchmarked so that it becomes the norm.

Mental health services need to establish and deliver a new standard of communication, engagement and support for carers, which recognises this. If the child or young person provides their consent, there should be no barrier to prevent a carer being involved in their treatment.

We note that in our consultation, less than one-third (32 percent) of CAMHS users said they would have preferred to turn to their family for support. This contrasts with young people without experience of CAMHS, 58 percent of whom said they would turn to their family if they started experiencing problems with their mental health (the





second most popular after friends, 64 percent). We wonder if CAMHS users would be more willing to turn to their carers (who are often family members) for support if they were more involved in their treatment.

In our experience, carers' main priority is the provision of effective services to the person they care for. But, of course they have important needs themselves too. Meeting those needs is a duty for social care providers, but, it is also cost-effective: a well-supported carer is good news for the CAMHS team.

Similarly, siblings should not be neglected. We do not necessarily expect CAMHS teams to provide this support; if emotional intelligence and healthy coping mechanisms were taught in schools, they would be empowered with the knowledge and information to be able to help.

#### **Social Services and Well-being Act 2014**

Carers in Wales already have a right to a carer's assessment but the Social Services and Well-being Act 2014 will reinforce this. The new Act, which comes into force in April 2016, imposes a duty on local authorities to offer all carers an assessment where it appears they may have need for support. This is a major change as previously the onus has been on carers to apply.<sup>14</sup>

## **10.**

### **Listen to young people**

We obviously haven't in this report offered the last word on mental health services from a collective young people's perspective. We are conscious in particular that we have had difficulty getting boys and young men to participate in our consultation - that's a challenge we all need to face. We did manage to reach a number of people from ethnic minorities, so their views are reflected in the consultation. But, of course there is a need for direct dialogue with those and other minority groups to ensure we understand their particular experiences - and to meet their concerns and needs.

One point of reference for a specific group - African Caribbean boys and young men - is the Diverse Cymru report "Better Outcomes - New Approach"<sup>15</sup>, which points to the problem of under-representation of African Caribbean boys and young men in therapeutic, preventive services and over-representation in crisis or compulsion-oriented services. We note in particular the call for better communication between agencies which engage with African Caribbean boys and young men.

We hope we have illustrated that young people have much to offer, not just in complaining about services (although that is legitimate and needs to be heard and acted on), but in offering practical and realistic ideas to improve services.

Nationally and locally, mental health services and others need to sustain dialogue with young people on a collective basis - we have much more to offer in detailed planning, not least concerning efficiencies.

But, even more important than hearing the collective voice of young people is the need to listen to individual young people when services are being planned and delivered to support them. This isn't just about listening and then going away and making a plan and deploying the services: it means literally making the plan jointly with the young person in the room and then involving them in delivery - maximising those areas where the young person takes responsibility themselves. For CAMHS users the platform for this is the Care and Treatment Plan as we set out above.

#### **Notes from Wales Observatory of Human Rights of Children and Young People**

Having due regard to the UNCRC, all children presenting with possible mental health issues would be listened to, given information and supported to exercise choice and control according to their age and understanding (Articles 5, 12; General Comments: 4 para 39(b); 14 paras 77, 89).

# Signing off

It is unacceptable that three-quarters of CAMHS users in our consultation said they had a negative experience of CAMHS, and only 40 percent agreed that CAMHS helped them get better and move on. It's clear that CAMHS needs to change.

We welcome the investment by Welsh Government in young people's mental health services<sup>16</sup> but we know that there will not be enough to overcome the difficulties through funding alone. In this report we have made specific suggestions about how services can be provided more efficiently.

Only by addressing the over-referral of young people to CAMHS can we improve services in Wales.

Non-mental health professionals, including education counselling services, teachers and youth groups must play a significant role in addressing the majority of children and young people's emotional needs. Young people go through ups and downs in their lives - we must normalise those and not label them 'mental illness'. Diagnosis at an early age can have a devastating impact on a young person's life.

Meanwhile, specialist CAMHS should support the much smaller number of young people with serious mental illness.

It has been really exciting producing this report. We passionately want to help those involved with the review of CAMHS to get the best outcomes for children and young people in Wales.

Young people told us they want support from the people they trust. Let's listen to them!

*Mair Elliott and Jake Roberts*

## With thanks to...

*We'd like to thank everyone who took part in our consultation, including CAMHS users, carers and other young people. We'd also like to thank Dwr-y-Felin and Bryn Tawe schools - where we had some great discussions with the pupils.*

*We are grateful to Wales Observatory on Human Rights of Children and Young People, who have not only provided expertise on human rights and law, but also organised the events at Swansea and Bangor universities, where we shared knowledge and ideas with students.*

*Lastly, we'd like to Hafal and our partners in the High Needs Collaborative, who let us speak to their service users and carers and helped organise the consultation.*



Above: Meeting the Children's Commissioner for Wales, Professor Sally Holland, to discuss the findings of our consultation.



Left: With our partners Wales Observatory on Human Rights of Children and Young People at one of the two 'Making Sense' events at Bangor University.



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## YOU SAID....WE DID REPORT OF THE PROGRAMME MANAGER

### Purpose

This report highlights the action being taken by the Programme to respond to issues raised by Children and Young People (CYP).

### Background

In June 2015 the Programme board agreed that the most effective to ensure that CYP were influencing its priority setting and work plan was to link into existing mechanisms across Wales. These include those of the Children's Commissioner's office, Children in Wales and the third sector 'High Needs Collaborative'. Board members felt it was important to provide feedback to those CYP who contribute their views and to provide them with assurance that these were leading to tangible action and service improvements.

Initial priorities for action were identified at the programme launch in February 2016 through consultation with CYP and with individuals from across health, social services, education and the third sector. These have subsequently informed the scope and action plan for each of our work streams. Since that time, Young Wales have identified 7 priority issues for CYP through their engagement work. The following 2 major consultations have also directly sought the views of CYP:

- '*Beth Nesa/What's Next*' survey by the Children's Commissioner to inform her three year plan;
- '*Making Sense*' survey as part of the third sector High Needs Collaborative initiative to support improvements in the delivery of mental health services for CYP.

### Progress to Date

Following the extremely powerful presentation by the 2 lead campaigners of the '*Making Sense*' initiative, at the January programme board, members agreed to use the 10 recommendations outlined within that report to benchmark performance. To demonstrate how the programme is listening and acting upon the issues raised by all CYP, and not just those who use Child and Adolescent Mental Health Services (CAMHS), key messages from the recent consultations and high level reports have now been mapped together with the priorities identified through the Young Wales forum. This is outlined in **Appendix 1**.

This has resulted in an over-arching list of the following 12 key areas:

1. Expand and/or create high quality support provided by non-mental health professionals
2. Don't medicalise growing up
3. Reform CAMHS referral systems
4. Embed emotional intelligence and healthy coping mechanisms into the curriculum.
5. Introduce an absolute timescale for referrals
6. Review practice within CAMHS
7. Recognise the transition to adult services
8. Improve data collection and accountability
9. Support carers
10. Listen to young people
11. Improve mental health, wellbeing and tackle bullying
12. Adhere to the rights of the child under the United Convention on the Rights of the Child (UNCRC)

### **Addressing the Priorities**

Early work being delivered by the work streams to address the 12 priorities is outlined below.

#### ***1 Expand and/or create high quality support provided by non-mental health professionals***

All work streams are considering the full range of cross sector support available to CYP within their work stream. An example of this is the directory of projects and schemes delivered by third sector and non specialist CAMHS that represent good practice across Wales. This is being compiled by the Early Intervention and Enhanced Support work stream. These schemes will be reviewed to provide guidance to Local Authorities and social care on recommended services for vulnerable CYP.

The work stream is also reviewing the roles of the Local Primary Mental Health Support Services (LPMHSS) to ensure the service is available to support other agencies in managing CYP effectively and improve training available.

#### ***2 Don't medicalise growing up***

Work is being delivered through the Resilience, Wellbeing and Early Years work stream that will focus on increasing the resilience of CYP through an awareness raising training module for front line staff. The training will be delivered through a sequence of slide presentations, together with a DVD following a young person's story. The training pack contains slide presentations as well supplementary factual evidence and is designed to equip staff with the tools to engage with both parents and CYP. This will promote positive mental health and wellbeing and build resilience to enable young people to cope with the inevitable challenges encountered in different settings.

### **3 Reform CAMHS referral systems**

During the first year of the Programme, a comprehensive audit of current CAMHS services has been undertaken with all health boards in Wales to recognise and minimise variations in Welsh services. This is providing an opportunity to share good practice, highlight investment opportunities and develop delivery plans if necessary. This comprehensive picture of services across Wales and demonstration of variations of practice has been shared with key CAMHS colleagues. A national report identifying key areas for action will be published at the conference in June.

The Quality Delivery Framework for specialist CAMHS (see point 6) will establish clear definitions and pathways. It will provide a framework to improve the current service model and enhance access and referral mechanisms for specialist and primary mental health care services. This should help to ensure that there is regular dialogue and collaboration between services and that relevant information is passed on directly. Information for professionals and families and carers to be developed later this year will help to ensure that only those CYP needing specialist CAMHS are referred to that system.

### **4 Embed emotional intelligence and healthy coping mechanisms into the curriculum.**

*Successful Futures* (the Donaldson Report) published in 2015, proposed a radical overhaul of what children in Wales are taught with a new structure for the curriculum for 3-16 year olds. Evidence considered during the review reinforced the need for a broad education that results in healthy resilient children. This is strongly aligned to the work of T4CYP and discussions have taken place to ensure the two programmes of work are joined up. Products developed by the Resilience, Wellbeing and Early Years work stream will be tested with young people through the Donaldson 'pioneer schools'

### **5 Introduce an absolute timescale for referrals**

The priority for the first year has been to improve waiting times and access, ensuring that targets for CYP needing specialist CAMHS are equitable with those required for adults. Welsh Government has set new targets that all urgent referrals are to be seen within 48 hours, routine referrals to CAMHS within 28 days and for neurodevelopmental services within 26 weeks. This will bring waiting times for CAMHS in line with those for adult mental health and those for neuro development in line with paediatrics.

The Neurodevelopmental and Co-morbid Mental Health/Learning Disabilities (NDMHL) work stream is working specifically to improve services for young people with neurodevelopmental conditions, including Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD).

During this first year, work is concentrating on reducing the time from referral to assessment and diagnosis of conditions; the production of a toolkit to standardise the quality of assessment and diagnosis and the development of a common care pathway towards an integrated 'neurodevelopmental' service across child health, CAMHS, Local Authority and third sector service providers.

### **6 Review practice within CAMHS**

As identified earlier, one of the key products identified from the programme in the first year is a Quality Delivery Framework (QDF) for specialist CAMHS. This has been developed by the specialist CAMHS work stream and will be formally launched at the conference in June.

The QDF will be a live document that will be continually refreshed. The first edition will contain an overarching definition of specialist CAMHS and the following three priority pathways:

- Crisis Care
- Early Interventions in Psychosis
- Eating Disorders.

Further pathways will be developed following discussions to agree priority areas with stakeholders at the workshop session of the Annual Conference in June. Primary care has already been identified as a potential priority area.

Three major reviews of prescribing practice for medication for children in South Wales have been completed by Dr Ann John, Associate Professor of the College of Medicine, University Swansea. The results are currently being shared with the service to assist CAMHS Clinical Leaders to revise the service models for the prescribing of antipsychotics, antidepressants and stimulants.

The Workforce Education and Training work stream is developing a training module that will focus on the core competencies for multi-agency staff that deliver sCAMHS and neurodevelopmental services.

### **7 Recognise the transition to adult services**

The Care Transition work stream is developing a 'transition pack' of resources for professionals that sets out a model for a good transition across the following areas:

- CAMHS to Adult MH Services
- Paediatric to CAMHS
- Referrals to and from Youth Justice
- Children moving out of the care sector, including those children that are looked after/adopted

This will ensure that there is a smooth transition for all points of transition that CYP may experience during their lifetime. Consultation with CYP is taking place in May and we anticipate that the packs will be available at the conference in June.



## **8 Improve data collection and accountability**

The QDF will provide a framework for an improved performance management of CAMHS. Data collected through the baseline audit will be used to inform reporting systems. The Programme Chair has written to all health board Chief Executives to request that the appropriate level of corporate support is provided to CAMHS colleagues across information technology, planning and performance departments.

Work to develop a core mental health data set as part of the Welsh Community Integrated Information System is currently being facilitated by Public Health Wales. This will enable services to monitor demand, capacity, provision and most importantly patient outcomes.

## **9 Support carers**

All of the work streams are working to identify best practice and resources and information that can be widely shared. Information to support families and carers is being developed through the products and resource packs previously outlined in this report. The new T4CYP website will include work stream specific pages, with shared libraries of resources that will be publicly accessible.

## **10 Listen to young people**

The Programme continues to work closely with key partners to maintain a broad based engagement that captures the wellbeing of *all* children and not just those who use CAMHS services. This approach has been endorsed by the Chair of the Expert Reference Group and the Children's Commissioner for Wales.

The Care Transitions work stream will be holding workshops across Wales during May to engage directly with young people who have used CAMHS services to discuss their experiences of transition.

Young service users will also be sharing their experiences of CAMHS and those they engaged in the *Making Sense* initiative with stakeholders as one of the key sessions at the T4CYP Conference in June 2016.

A stakeholder database has been developed to provide the central reference point for engagement across the entire scope of the programme. This will ensure that information can be widely circulated across all partner agencies working to support the emotional health and wellbeing of CYP in Wales.

The need for a communications portal and social media feed has been identified as a priority by CYP. This will be provided through the new T4CYP website that is being developed in partnership with the Welsh Local Government Agency. The website will form part of the Good Practice Wales (GPW) site; a single access online portal to Welsh public services good practice and knowledge. The main GPW portal can be accessed at: <http://www.goodpractice.wales/home>.

The T4CYP website will provide an easy to navigate on-line resource for CYP and their families as well as a live interactive Twitter feed. The website will be officially launched at the conference in June

### **11 Mental health, wellbeing and tackling bullying**

The list of best practice schemes delivered by Local Authorities and social care being developed by the Early Intervention and Enhanced Support work stream (see point 1) will include guidance and support for vulnerable CYP on a wide range of issues, not just those that are diagnosis dependent or health lead.

The training module delivered through the Resilience, Wellbeing and Early Years work stream (see point 2) will include nurturing approaches, social coaching, emotional coaching, physical and mental health.

### **12 Adhere to the United Nations Convention on the Rights of the Child**

T4CYP is based on a human rights approach and is committed to embedding the '7 Core Aims' for CYP under the United Nations Convention on the Rights of the Child (UNCRC).

Through all of its work the Programme will aim to consider how:

- the inequalities, stigma and discrimination experienced by CYP with emotional health needs and/or mental illness are reduced
- the values, attitudes and skills of those treating or supporting CYP with emotional health needs and/or mental illness are improved
- services are able to focus on the early detection of risk and the development of resilience and life skills

### **Next Steps**

Regular progress reports will be provided on our action against these key areas. This report will be shared directly with CYP through our close links with the Children's Commissioner's office, Children in Wales and the 'High Needs Collaborative'. Updates will also be featured in the T4CYP Newsletter, which is widely circulated to stakeholders across health, education, the third sector and to CYP.

The new T4CYP website will provide a live, interactive resource that will provide information for CYP, their families and carers across the entire scope of the programme.

### **Recommendation**

The Board is asked to **NOTE** this report.

**'You said ...We Did' – Mapping of Reports and Consultations**

	<b>Recommendation</b>	<b>Where Highlighted</b>
1	<b>Expand and/or create high quality support provided by non-mental health professionals</b> <i>Counselling services</i> <i>Social Services input</i> <i>Educational Psychology</i> <i>Family relationships/friendship relationships</i>	Making Sense  National Assembly for Wales, Children, Young People and Education Committee (NAfW CYPEC) Childline Review
2	<b>Don't medicalise growing up</b>	Making Sense
3	<b>Reform CAMHS referral systems</b> <i>Resources for sCAMHS</i> <i>Inappropriate referrals/access</i> <i>Primary Care provision</i> <i>Accessing Services</i>	Making Sense NAfW CYPEC  Childline Review
4	<b>Embed emotional intelligence and healthy coping mechanisms into the curriculum.</b> <i>Low self esteem and unhappiness</i> <i>school and education problems</i>	Making Sense  Childline Review
5	<b>Introduce an absolute timescale for referrals</b>	Making Sense NAfW CYPEC
6	<b>Review practice within CAMHS</b> <i>In- patient provision</i> <i>Emergency/OOH arrangements</i> <i>Review prescription medication</i> <i>Self harm, suicide and substance misuse</i> <i>Mental health and depressive disorder</i>	Making Sense NAfW CYPEC  Childline Review Young Wales
7	<b>Recognise the transition to adult services</b>	Making Sense Beth Nesa NAfW CYPEC
8	<b>Improve data collection and accountability</b>	Making Sense
9	<b>Support carers</b>	Making Sense Beth Nesa
10	<b>Listen to young people</b>	Making Sense Beth Nesa Young Wales
11	<b>Mental health, wellbeing and tackling bullying</b> <i>Bullying and hate crime/on line safety</i> <i>Abuse, Bullying/on-line bullying</i>	Beth Nesa Young Wales NAfW CYPEC
12	<b>Adherence to the UNCRC</b>	All



## **NHS Wales Child & Adolescent Mental Health Services Report on Baseline Variation & Opportunities Audit**



National Collaborative Commissioning Unit  
Uned Gomisiynu Cydweithredol Cenedlaethol



Report written by Mr Shane Mills  
Clinical Lead, National Collaborative Commissioning Unit  
*On behalf of Together for Children and Young People*

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## **NHS Wales Child & Adolescent Mental Health Services Report on Baseline Variation & Opportunities Audit**

### **1. Purpose**

This report builds on a Baseline Variation & Opportunities audit to provide a national overview of variations in Child & Adolescent Mental Health Services. It aims to act as a lever to identify areas for improvement and provide an opportunity to cascade good practice

### **2. Background**

#### **2.1. Introduction**

*Together for Children and Young People (T4CYP)* was launched by the Minister for Health and Social Care at the end of February 2015. Led by NHS Wales, this multi-agency service improvement programme is working at pace to reshape, remodel and refocus the emotional and mental health services provided for children and young people in Wales, in line with the principles of prudent health and care.

Work is being delivered through a series of priority work streams reporting to a high level multi-agency Programme Board. The Specialist Child and Adolescent Mental Health Services (sCAMHS) work stream was established to develop a Framework for Improvement for sCAMHS.

During the initial scoping it was recognised that a comprehensive picture of sCAMHS across Wales was not available. The work stream requested that a Baseline Variations and Opportunities (BVO) Audit of sCAMHS be undertaken as an initial priority. The National Collaborative Commissioning Unit was therefore asked to take this work forward in partnership with NHS Benchmarking as external advisors.

The BVO of sCAMHS in NHS Wales was based on the CAREMORE<sup>®</sup> approach and provided the following:

- a baseline position for sCAMHS across NHS Wales
- an understanding behind variation in sCAMHS service provision/ outcomes/activity across the seven Health Boards and
- an understanding of the opportunities to improve sCAMHS provision/ outcomes in a timely manner through learning from the best practice already in place in parts of Wales.

The work establishes a baseline for developing the Framework for Improvement which was launched as a key product at the T4CYP Annual Conference in June 2016. The first edition of the Framework provides a clear definition of the role of sCAMHS, together with pathways for Crisis Care, Eating Disorders and Early Interventions in Psychosis.

Additional pathways will be developed as areas of high impact change are agreed.

## 2.2 CAREMORE<sup>®1</sup>

Developed in 2012 and currently being used in commissioning adult mental health hospitals, CAMHS tier 4 hospitals, care homes and emergency ambulance services, CAREMORE<sup>®</sup> is a made-in-Wales programme for delivering prudent healthcare through a commissioning lens, with CAREMORE<sup>®</sup> being an acronym for:

**C**are standards

**A**ctivity

**R**esources **E**nvelope

**M**odels of care

**O**perational arrangements

**R**eview of performance

**E**valuation

CAREMORE<sup>®</sup> was created by Julian Baker and co-developed by Julian Baker and Shane Mills

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### 2.3 Audit customisation and engagement

In April/May 2015 the CAREMORE<sup>®</sup> Baseline, Variation & Opportunities audit, was tested with CAMHS clinical leaders across Wales and customised to take account of current best practice, localisation and models of care used in NHS Wales. In July 2015 a national event was organised to ensure full engagement by Health Boards (HBs).

### 2.4 Audit Timeframe

March 2015	Development of principal CAREMORE <sup>®</sup> audit.
April 2015	Customisation of CAREMORE <sup>®</sup> audit.
May 2015	Dissemination of audit to 7 'audit leads'
July 2015	national event to support audit completion
September 2015*	Data subject to internal validation by HB
November 2015	Data submitted to NHS Benchmarking
February 2016	Release of interim reports for comments on variation
May 2016	Return of interim reports
July 2016	Publication of single final national report.

\*Original timescale was delayed by 3 months owing to HB data collection and validation issues

### 2.5 Population figures

Population figures used in the audit are in the table below. (Population figures from Stats Wales- mid-year 2014 at <https://statswales.wales.gov.uk/Catalogue/Population-and-Migration/Population/Estimates/Local-Authority/PopulationEstimates-by-LocalAuthority-Year.>)

Health Board	0-17 yr olds
<b>Abertawe Bro Morgannwg UHB</b>	103,966
<b>Aneurin Bevan UHB</b>	123,532
<b>Betsi Cadwaladr UHB</b>	140,102
<b>Cwm Taf UHB</b>	62,455
<b>Cardiff &amp; Vale UHB</b>	100,110
<b>Hywel Dda UHB</b>	74,285
<b>Powys teaching HB</b>	25,159
<b>TOTAL</b>	<b>629,609</b>



## 2.6 Variations

A large number of reasons exist for variations in data integrity and / or performance and some of the main factors contributing to variation are identified below.

- **Data quality** -including the completeness and accuracy of data submitted by HBs. This proved a major challenge and meant that the audit process took significantly longer than had originally been anticipated. Workforce data seem to be particularly challenging for HBs to provide, hence this report is exclusively covering medical workforce.
- **Service scope** –important distinctions exist in service scope which need to be acknowledged. For example, some HBs have service models which integrate primary and secondary care; some HBs merged sCAMHS and Neurodevelopment waiting lists/ data at this point, whilst others may have a significant use of third sector, social care or other non-NHS services.
- **Case mix** –acuity and case mix present differently across HBs and are closely linked to service capacity and eligibility criteria.
- **Resource levels** –HBs have access to different levels of resource for sCAMHS which impacts directly on each system and effect the extent to which community based support can be provided.
- **Clinical processes** –the application of specific clinical pathways influences each HBs position within the benchmarking comparisons. This can include a wide range of factors such as; the impact of different systems and arrangements, the extent and approach to community based care, and the extent to which a range of treatments are available including both psychiatry and psychological therapies.
- **Reporting measures** –the measures used in this report apply specifically to the terminology and definitions used for this project and may not align with other published material from HBs which may use different specifications.
- **Validation** –each HB has had an opportunity to review and validate the data used in this report and it can therefore be interpreted as being generally representative of the organisation's position.

## 3. Local Primary Care Mental Health Services

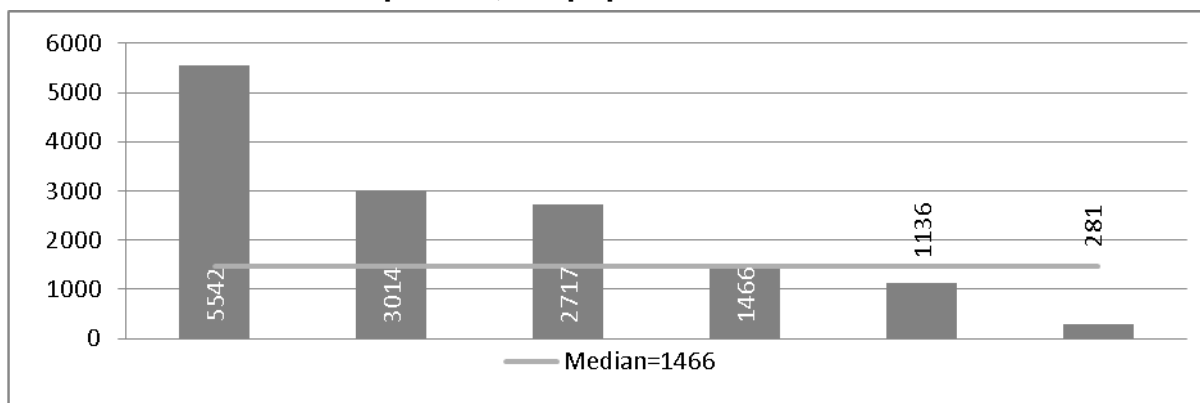
### 3.1 Number of referrals

#### Why we asked about this.

HBs need to understand the local demand for Local Primary Mental Health Support Services (LPMHSS) in order to ensure that children and young people are accessing this important service established under Part 1 of the Mental

Health (Wales) Measure 2010 and there is enough capacity in their services to ensure that young people are having the rapid assessments and early intervention provided under these schemes.

### The data: referrals per 100,000 population



### What the data tells us

- Median numbers of referrals were 1466 per 100,000 population.
- Average numbers of referrals were 2111 per 100,000 population.
- Number of referrals per 100,000 population ranged from 281 to 5542.

### We asked if there were areas of good practice in terms of collecting data on the number of referrals

- Several HBs were able to collect all referrals received by services including consultations, and school cluster meetings.
- Several HBs had moved to a single point of referral, which enabled accurate data collection.

### Improvement actions for 2016/2017

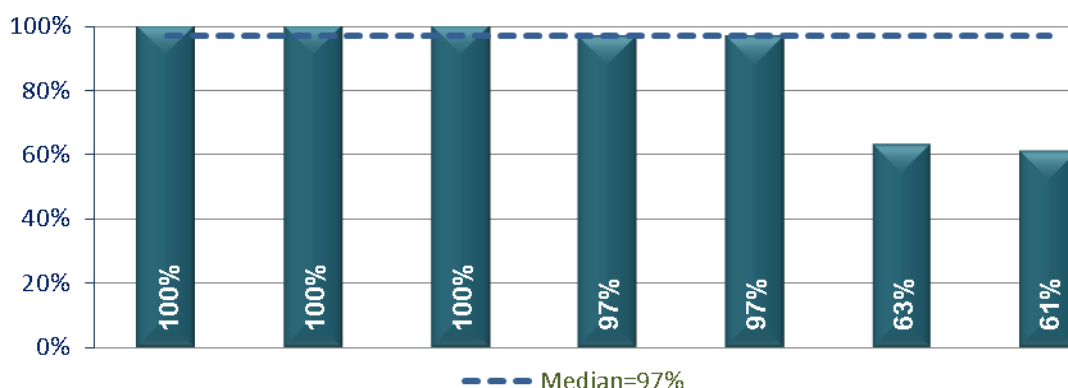
- All HBs to consider adopting a single point of referral for Local Primary Mental Health Support Services.
- All HBs to have a system in place to collect data on all referral, advice liaison and consultation activity.

### Referral Acceptance Rate

#### Why we asked about this.

HBs need to understand the acceptance rate for LPMHSS in order to ensure entry criteria is not posing a barrier to assessment by these services.

### The data for referral acceptance rates



#### What the data tells us

- Median number of referrals accepted into services was 97%.
- Average number of referrals accepted into services was 88%.
- Number of referrals accepted ranged from 61% to 100%.

#### We asked if there were areas of good practice in terms of raising the profile of LPMHSS.

- Several HBs were recruiting additional staff in order to enhance capacity and capability of the LPMHSS to meet the needs of children and young people.
- One HB was 're-launching' services to reintroduce the service to the wider community accepting referrals from professionals working with children and young people in addition to GPs.
- Several HBs had, or were in the process of, establishing single points of access which could provide advice and guidance (including links to bibliotherapy schemes, third sector, education and web based information), signposting, access to professional consultation and local primary mental health assessments.
- One HB was encouraging referrers to contact local teams by telephone to have a 'discussion' so that a collaborative agreement can be made about which outcome is best for the young person.
- Several HBs were actively engaging with possible referrers including education services, social services and GPs.
- One HB was developing better referral documentation to improve the quality of information provided by and to referrers.
- One HB was co-locating CAMHS and adult LPMHSS to deliver an integrated service model for primary care mental health to make it easier for referrers to contact services.

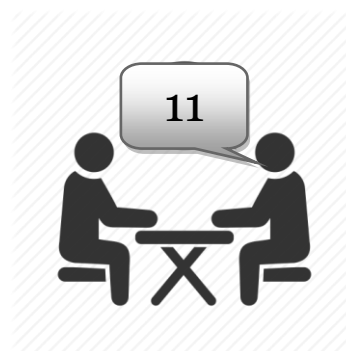
## Improvement actions for 2016/2017

- All HBs to consider adopting a single point of access for LPMHSS.
- All HBs to ensure that referrals not accepted were signposted to alternative services or written advice given to address referrers or the child and young person's concerns.
- All HBs to actively engage with local services to ensure clear understanding of purpose.
- All HBs to provide annual feedback to referrers.

### 3.2 Face to face contacts

#### Why we asked about this.

LPMHSS need to be arranged and resourced to offer accessible age appropriate assessments and short term interventions to meet the needs of children and young people in a developmentally appropriate manner.



#### The data on face to face contacts

Only a small number of HBs were able to gather this information. The median number was 11 per patient (from start of treatment to discharge).

#### We asked about the type of contacts and if there were areas of good practice in terms of increasing the number of contacts.

- All HBs offered face to face contacts.
- Several HBs had in place a telephone consultation service.
- One HB had in place link clinicians which strengthened interagency pathways to education, social care and others and able to rapidly respond to request for consultation.
- Several HBs were recruiting additional posts to increase the number of face to face contacts offered to children and young people.

## Improvement actions for 2016/2017

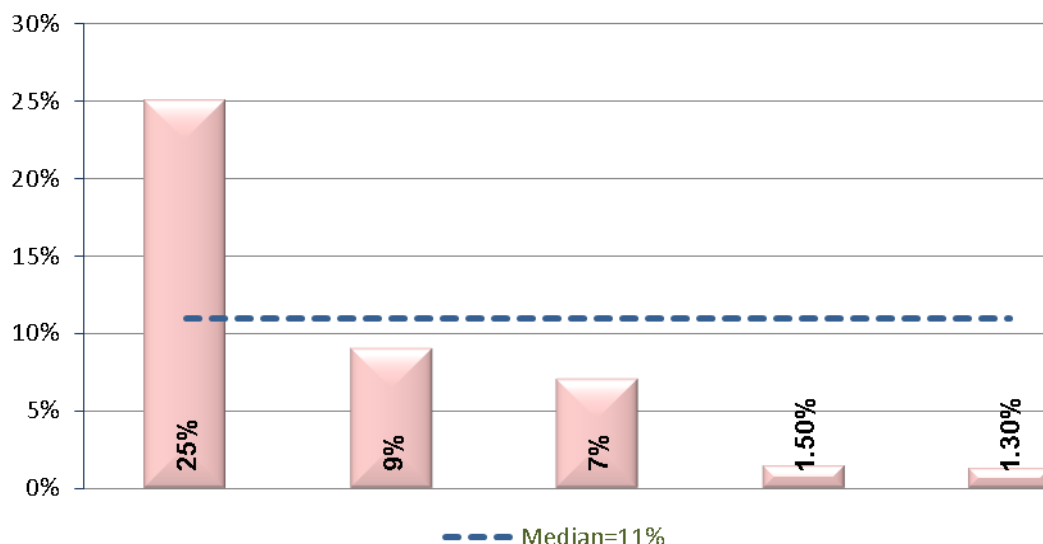
- All HBs to consider providing named or link clinicians to significant local services e.g. Schools, education, social services, third sector.

### 3.3 Rate of children and young people not attending appointments

#### Why we asked about this.

LPMHSS need to support and enable children and young people to attend their planned appointments; any missed appointments could affect the well being of the child or young person or waste resources.

#### The data on children and young people not attending appointments



#### What the data tells us

- Median number of children and young people not attending appointments was 11%.
- Average number of children and young people not attending appointments was 9%.
- Number of children and young people not attending appointments ranged from 1% to 25%.

#### We asked if there were areas of good practice in terms supporting children and young people to attend appointments.

- Several HBs are working on introducing more choice to families on convenient appointments.
- Several HBs agree follow up appointments with the family before they are booked.
- Several HB had in place or were introducing a text service to remind families of appointments.
- One HB had in place link clinicians which strengthened interagency pathways to education, social care and others.
- One HB had introduced rating scales after appointments to facilitate greater engagement and address any barriers to engagement as they arise.

- One HB had introduced open access to some services.
- Several HBs were providing alternative community venues for appointments.

### Improvement actions for 2016/2017

- All HBs to consider introducing text service to remind families of appointments if not already in place.
- All HBs to engage with children, young people and families to review how access and attendance can be improved with a view to implement agreed changes in next 2 years.

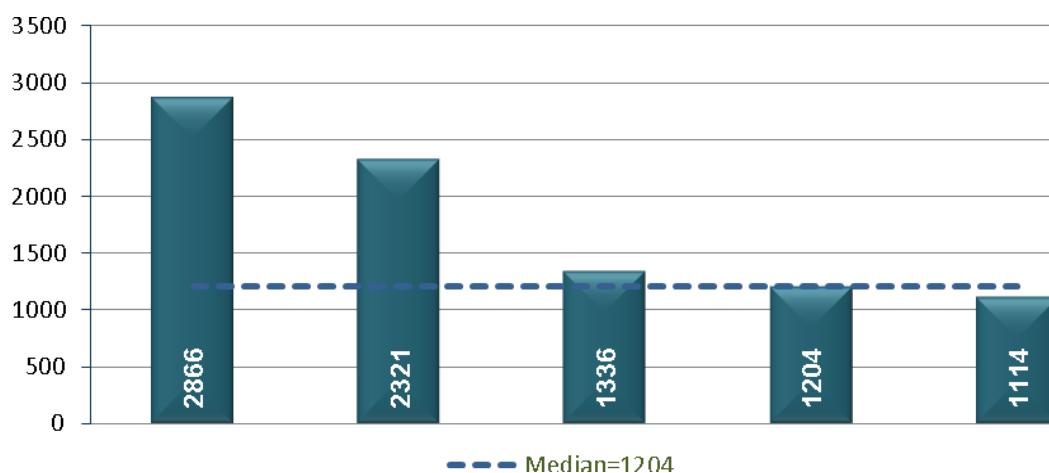
## 4. Specialist Child and Adolescent Mental Health Services

### 4.1. Caseload

#### Why we asked about this.

HBs need to understand the numbers children and young people currently under the care of their sCAMHS in order to ensure that they are meeting the needs of their local populations.

#### The data for caseload of per 100,000 population



#### What the data tells us

- Median number of children and young people on caseload was 1204.
- Average number of children and young people on caseload was 1355.
- Number of children and young people on caseload ranged from 140 to 2,866

#### We asked if there were areas of good practice in terms of collecting caseload data

- Many HBs confirmed that the data appeared accurate but reflected this information was often manually collated.

### Improvement actions for 2016/2017

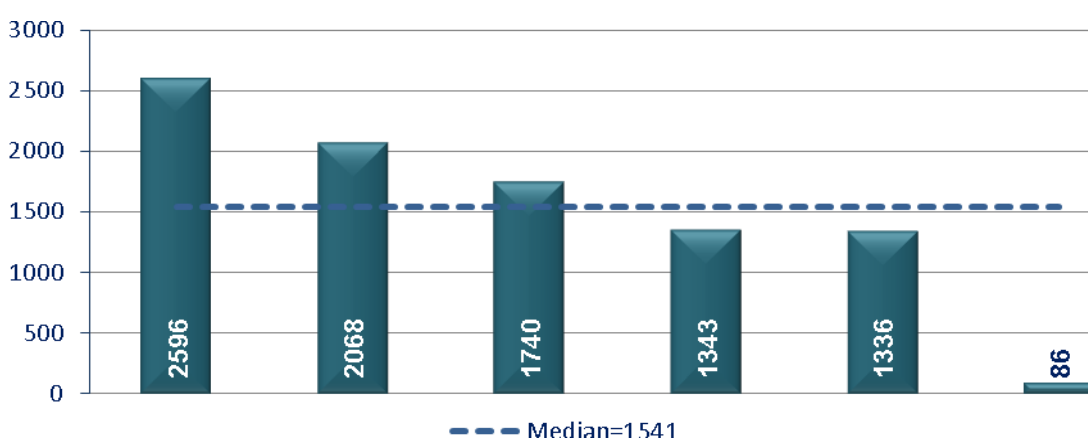
- All HBs to collect this information in a consistent manner.

### 4.2 Referrals

#### Why we asked about this.

HBs need to understand the local demand for sCAMHS in order to ensure that there is enough capacity within their services.

#### The data referrals received per 100,000 population



#### What the data tells us

- Median numbers of referrals were 1541 per 100,000 population.
- Average numbers of referrals were 1528 per 100,000 population.
- Number of referrals per 100,000 population ranged from 86 to 2,596.

#### We asked if this data accurately reflected current referrals

- Many HBs confirmed that the data appeared accurate.
- One HB was unable to separate primary and secondary care data.
- Several HBs were unable to separate Neurodevelopment referral data.

### Improvement actions for 2016/2017

- Core referral criteria for sCAMHS to be agreed on an all Wales basis. All HBs to separate Neurodevelopment referral data.
- All HBs to collect this information in a consistent manner.

### 4.3 Referral Acceptance Rate

### Why we asked about this.

HBs need to understand the acceptance rate for sCAMHS in order to ensure eligibility criteria is not posing a barrier for those children and young people needing assessment.

### The data for referral acceptance rates

#### What the data tells us

- Median number of referrals accepted into services was 56%.
- Average number of referrals accepted into services was 59%.
- Number of referrals accepted ranged from 29% to 100%.

### We asked if there were areas of good practice in terms of raising the profile of sCAMHS

- Several HBs were recruiting additional staff in order to increase the capacity of sCAMHS to accept an increase in referrals.
- One HB was re-launching the referral guidance to local stakeholders.

### Improvement actions for 2016/2017

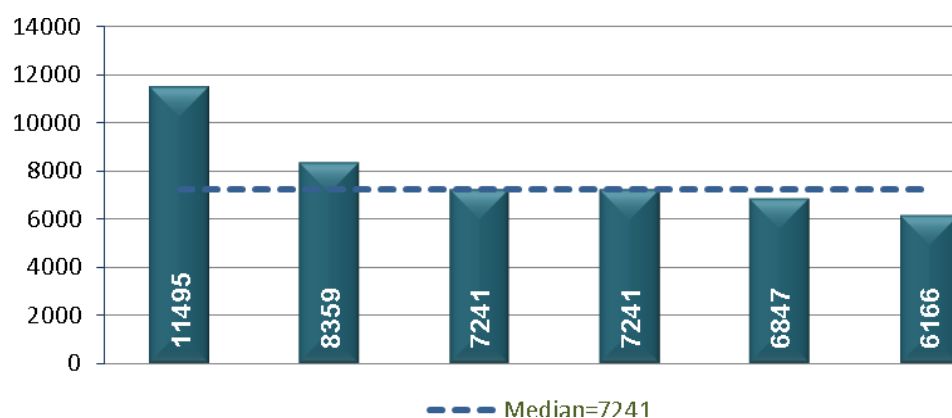
- HBs to review and launch health board referral guidance to local stakeholders (health, education and third sector partners) following on from the national agreed criteria.

## 4.4 Face to face contacts

### Why we asked about this.

sCAMHS need to be organised and resourced to offer the most appropriate care as possible in the manner that meets the needs of children and young people.

### The data for face to face contacts per 100,000 population

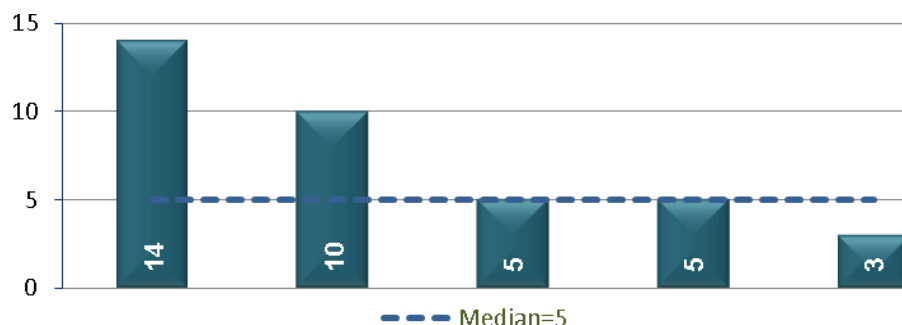


#### What the data tells us



- Median number of face to face contacts per 100,000 population was 7,241.
- Average number of face to face contacts per 100,000 population was 7,892.
- Number of face to face contacts per 100,000 population ranged from 6,166 to 11,495.

### The data for number of face to face contacts per child or young person



### What the data tells us

- Median number of face to face contacts per child or young person was 5.
- Average number of face to face contacts per child or young person was 7.4.
- Number of face to face contacts per child or young person ranged from 3 to 14.

### We asked about the number of face to face contacts sCAMHS had with children and young people and if there were areas of good practice in terms of increasing the number of contacts.

- All HBs offered face to face contacts.
- Nearly all HBs were recruiting additional staff to offer more face to face contacts.
- Several HBs were extending some services to offer 7 day support.
- One HB was developing integrated pathways for vulnerable populations.
- One HB was developing a joint adult/CAMHS 24hr urgent care model.

### Improvement actions for 2016/2017

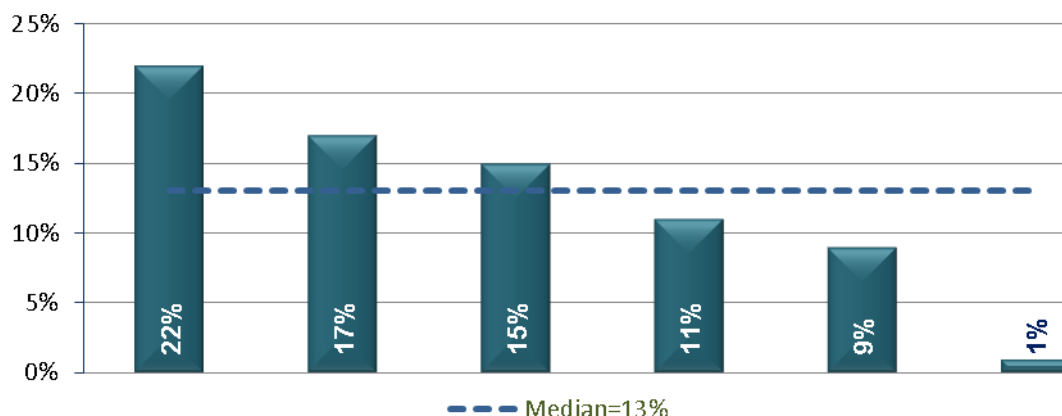
- All HBs to describe the 7 day support for crisis services and actions to ensure awareness of services by partners.

### 4.5 Rate of children and young people not attending sCAMHS appointments

#### Why we asked about this.

sCAMHS need to support and enable children and young people to attend their planned appointments; any missed appointments could affect the well being of the child or young person or waste resources.

#### The data on children and young people not attending appointments



### What the data tells us

- Median number of children and young people not attending appointments was 13%.
- Average number of children and young people not attending appointments was 13%.
- Number of children and young people not attending appointments ranged from 1% to 22%.

### We asked how services were supporting children and young people to attend appointments

- Several HBs are working on introducing a greater choice to families over appointment times.
- Several HBs had in place or were introducing a text service to remind families of appointments.

### Improvement actions for 2016/2017

- All HBs to consider introducing text service to remind families of appointments if not already in place.
- All HBs to consider introducing choice appointments.
- All HBs to engage with children, young people and families to review how access and attendance can be improved with a view to implement agreed changes in next 2 years.
- All HBs to liaise with the referrer when a Child or Young Person does not attend an appointment.

## 5 Quality and Outcomes

### 5.1 Health and well being outcomes

**We asked HBs to consider how they will evidence that services are improving the health and well being of children and young people**

- Several HBs are developing outcome measures in line with the Choice and Partnership Approach (CAPA) or Improving Access to Psychological Therapies (IAPT).
- The majority of HBs referenced compliance with the Mental Health (Wales) Measure 2010 as a determination of positive outcomes.
- One HB was evaluating the use of Goal Based Outcomes (GBOs)
- One HB was working in collaboration with the local authorities Emotional Health and Wellbeing Team.
- One HB was using patient stories to follow their 'journey' through care.

#### **Improvement actions for 2016/2017**

- All HBs to develop action plan to introduce GBOs as a measure of improved health and well being in children and young people.

### 5.2 Service efficiency

**We asked HBs to consider how they will evidence that services are efficient and effective**

- Several HBs are developing performance dashboards.
- Several HBs were using the CAPA processes to evidence throughput, discharge and re-referral rates.
- One HB had introduced a comprehensive set of performance and outcome indicators for their new Early Intervention and Support Service.
- One HB was mapping services facilitated by other providers to avoid duplication of interventions.
- One HB was undertaking workforce evaluations to ensure the right people are delivering the right service at the right time.

#### **Improvement actions for 2016/2017**

- HBs to develop action plan for introduction of a consolidated performance dashboard reviewing service safety, effectiveness, efficiency and staff wellbeing.

### **5.3 Training**

**We asked HBs to identify whether 90% (or above) of staff who have contact with children and young people have updated their safeguarding training.**

- One HB had reached 95% level 3 safeguarding.
- Several HBs were enhancing their internal training programmes.

#### **Improvement actions for 2016/2017**

- All HBs to achieve 90% level 3 safeguarding compliance.

### **5.4 Advocacy**

**We asked HBs to improve access to advocacy for children and young people and their carers and families**

- Several HBs did not currently commission advocacy provision.
- Several HBs were working with external advocacy groups to raise the profile of advocacy within services.
- One HB was working with their staff to ensure their role as advocates of the children and young people they care for was recognised.

#### **Improvement actions for 2016/2017**

- All HBs to improve access to advocacy for children and young people and their carers' and families.

### **5.5 Satisfaction with services**

**We asked HBs to measure and report on children and young persons (and their carers' and families) satisfaction with services**

- One HB used questionnaires to collect feedback on services.
- One HB used the CAPA scale to undertake regular satisfaction audits.
- Several HBs did not currently commission advocacy provision specifically for children and young people.
- One HB was working with the Children's Rights Unit to actively involve service users in the planning, design, delivery, monitoring and evaluation of CAMHS.
- One HB was using the Improving Quality Together silver qualification process to develop new methods of collecting and using feedback.

#### **Improvement actions for 2016/2017**

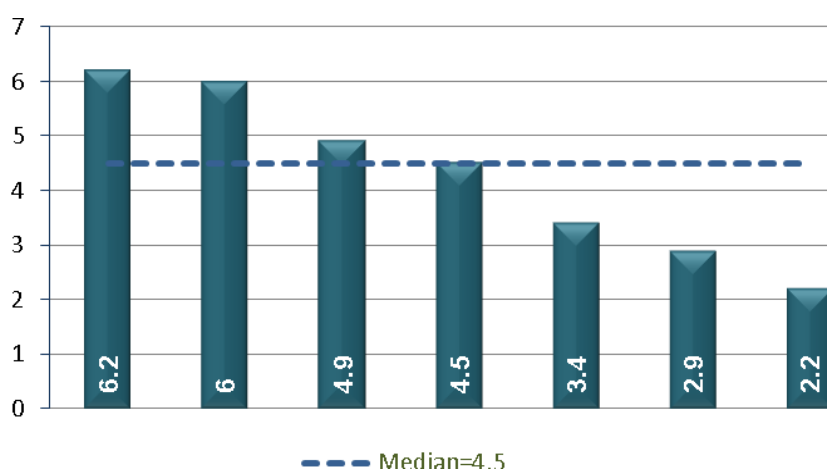
- All services to develop plan for obtaining service satisfaction measures from Children, Young people and families and referrers.

## 5.6 Workforce

### We asked HBs to measure and report on workforce profile

- There was wide variation in the workforce data which may be indicative of data capture systems. (see example table below)
- Where staff worked across areas HBs were unable to separate out sessions or portions of roles.
- Several HBs did not/ could not separate sickness/absence data for sCAMHS staff.

### Consultant Psychiatrists per 100,000 population (example chart)



### Improvement actions for 2016/2017

- All HBs to consider using the CAPA scale, or equivalent, to undertake staff satisfaction audit.
- All HBs to account for all roles, sessions or portions of roles undertaken as sCAMHS.
- All HBs to collect establishment, vacancies, sickness/absence data for sCAMHS.

## 6 Conclusion

- There are pockets of good practice in Wales in all aspects of CAMHS and initial focus should be on cascading these across Wales.
- The information demonstrates that CAMHS staff are motivated to improve service provision.
- Data collection proved a real challenge for many HBs and corporate HB support is required to ensure that CAMHS staff have access to the right data at the right time to inform service planning and provision.

- Data on outcomes and engagement is required to ensure services are effective, efficient and meeting the needs of children and young people.
- The Welsh Government has provided significant additional recurring investment into CAMHS of £7.65million. These additional monies must be targeted by HBs at improving access to services and at addressing areas of variation.

## **7 Next Steps**

- The annual NHS Benchmarking CAMHS data collection exercise will be utilised as the ongoing process to capture consistent data across NHS Wales and demonstrate improvement.
- The Framework for Improvement has documented outcomes, activity and other information to be consistently collated across Wales in order to reduce variation and enable progress monitoring.
- All HBs will consider how best to address the variations highlighted in this audit.
- All HBs will consider how best to adopt the good practice identified through this audit. To assist in this process a good practice sharing event will be facilitated by the Specialist CAMHS Planning Network.
- The improvement actions set out in this audit report will be consolidated into the Framework for Improvement and as part of that process all HBs will be requested to provide an annual statement demonstrating progress.
- All CAMHS clinical leaders in Wales have committed to adopting the Choice and Partnership Approach.
- WHSSC is offering to commission specialist training on behalf of HBs on a Once for Wales approach. Initial areas being considered with HBs include eating disorders, independent prescribing, autistic spectrum disorder and attachment.

## **North Wales Adolescent Services (NWAS)**

### **Background**

Welsh Health Specialised Services Committee (WHSSC) currently commission 12 CAMHS beds from Betsi Cadwaladr University (BCU) Health Board on a single ward basis as part of the North Wales Adolescent Service at Abergele Hospital. A second ward with up to 7 beds has only rarely been used on ad hoc basis since it closed as Psychiatric Intensive Care Unit (PICU) ward prior to 2010.

BCU developed an intensive community support team (KITE) in 2013/14 and this has operated alongside the inpatient service from Abergele Hospital. Following additional investment from Welsh Government the team will be expanded to create dedicated support to community teams in the East and the West and operate on extended hours as a 7 day week service. The full impact of this development is not clear yet as the recruitment to new posts is in its final stages and the operational development over the expanded footprint is being implemented.

The number of Out of Area (OoA) admissions from North Wales continues to be significantly greater than the South and it is hoped these new arrangements will start to have a similar impact to the intensive support teams across South Wales in the near future.

### **WHSSC Response**

In order to consider the impact of the new operational model and in response to the continued high level of use of Tier 4 CAMHS services in the North, WHSSC are holding joint strategic planning discussions with BCU. The aim of this work is to assess the longer term needs for Tier 4 CAMHS services for the North Wales population. The review is using both the Needs Assessment work published by PHW and the historic demand and capacity information held by both WHSSC and the health board.

The information will be used to review the current service provision right across the CAMHS pathway and determine the priorities for service change.

### **Options for second ward**

It was clear from the start of this review that a priority for early consideration was the future of the second ward. The NWAS developed an options appraisal looking at potential alternative uses and early discussions have been held by the group on a draft options paper. WHSSC and BCU commissioner representatives will discuss the options in further detail at the next CAMHS commissioning meeting in mid December.

### **SPEED Team**

BCU have recently launched a new development with a focus on Eating Disorders (ED). This new central virtual team brings together CAMHS and paediatric colleagues and will support the three localities in early identification of ED issues.

### **NWAS Activity**

The NWAS inpatient service has been operating in line with WHSSC targets since the start of the year in April with year to date occupancy of 97% (95% target) including home leave

and 70% excluding home leave (70% target) and in addition has occasionally utilised the second ward on an informal basis to stop potential OoA placements for existing patients.

The service does use a high proportion of its beds for patients with a primary ED diagnosis (7 of the 12 current patients) and a long average length of stay which is more typical of ED patients with 4 of these patients being admitted more than 12 months ago. In the recent national benchmarking data this led to the unit having the highest cost per patient episode in the UK. This may be a reflection of the special interest in ED of the lead clinician. The unit is basically functioning on a 1 in 1 out basis with equal number of admissions and discharges over the first seven months of the financial year.

### **Out of Area Admissions**

Due to the limited NWS bed availability the number of OoA placements from North Wales continues to be greater than the rest of Wales put together. There have been 14 OoA CAMHS placements during the year to date with 10 discharges (8 home, 1 NWS and 1 Social Services) and 2 FACTS patients.

As at the 1<sup>st</sup> December 2016 there are 4 CAMHS OoA placements all placed with providers in North West England. 1 of these patients is in specialist long stay ED bed and the other 3 (suicide risk) are due to capacity constraints.

### **Summary**

It is important to understand both the current situation and potential future demand when determining priorities for service developments. The impact of the new Welsh Government investment and expansion of KITE should reduce the demand for inpatient beds in line with the early indications from South Wales. In addition the enhancement of community ED services will also help reduce the number of ED patients needing inpatient care and have subsequent impact on NWS length of stay.

The combination of the above leads to the current assumption that additional beds will not be required in NWS over the longer term and the preferred option for the second ward at present is to open a day unit to fully deliver the CAMHS ED pathway in line with the 'Maudsley' model. There is currently little support to increase the number of commissioned Tier 4 beds especially given potential spare capacity in Ty Llidiard in South Wales.

C A Shortland  
CAMHS Planning Lead  
WHSSC  
01/12/16