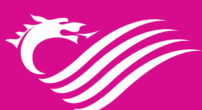
National Assembly for Wales
Children, Young People and Education Committee

Inquiry into Child and Adolescent Mental Health Services (CAMHS)

November 2014



Cynulliad Cenedlaethol Cymru

National Assembly for Wales

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Children, Young People and Education Committee

Inquiry into Child and Adolescent Mental Health Services (CAMHS)

November 2014

Cynulliad Cenedlaethol **Cymru**

National Assembly for **Wales**

Children, Young People and Education Committee

The Committee was established on 22 June 2011 with a remit to examine legislation and hold the Welsh Government to account by scrutinising expenditure, administration and policy matters encompassing: the education, health and wellbeing of the children and young people of Wales, including their social care.

On 22 January 2014, the Assembly agreed to alter the remit of the Committee to include Higher Education. This subject will continue to be included in the remit of the Enterprise and Business Committee, with both committees looking at Higher Education from their particular perspectives. The Committee was previously known as the Children and Young People Committee.

Current Committee membership

Ann Jones (Chair)
Welsh Labour
Vale of Clwyd

Angela Burns
Welsh Conservatives
Carmarthen West and South Pembrokeshire

Keith Davies
Welsh Labour
Llanelli

Suzy Davies
Welsh Conservatives
South Wales West

John Griffiths
Welsh Labour
Newport East

Bethan Jenkins
Plaid Cymru
South Wales West

Lynne Neagle
Welsh Labour
Torfaen

David Rees
Welsh Labour
Aberavon

Aled Roberts
Welsh Liberal Democrats
North Wales

Simon Thomas
Plaid Cymru
Mid and West Wales

The following Member was also a member of the Committee during this inquiry:

Rebecca Evans
Welsh Labour
Mid and West Wales

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The Committee's conclusions

During the evidence gathering process for our inquiry into specialist Child and Adolescent Mental Health (CAMHS) provision in Wales, we spoke at length with young people and their parents and carers. Some of the issues they raised with us were a cause of considerable concern. Subsequently, we wrote to the Minister to outline those concerns.

On 23 October, the Minister wrote to the Committee to provide an update on progress. In his letter, the Minister announced that he had asked Professor, Dame Sue Bailey, a child psychiatrist and past president of the Royal College of Psychiatrists, to lead a "root and branch review" to modernise and redesign the service for the future.

We are pleased that the Minister has announced an external review of CAMHS. We believe this is an appropriate response to the serious concerns highlighted during our inquiry and welcome the Minister's positive approach.

Given the commitments outlined in the Minister's letter, we consider that it would not be appropriate for us to make detailed recommendations at this stage of our work and that the root and branch review should be allowed to run its course and deliver its modernisation plan. We also note that the Minister is determined to "agree a way forward at pace" with an agreed plan, with clear deliverables and dates in place by late 2015.

We believe that this is an important moment for CAMHS in Wales. It presents a much needed opportunity to modernise the service so that it is fit for purpose and able to meet the needs of children and young people in a modern Wales. The Committee will ensure that its report and the issues raised by children, young people and their parents, are drawn to the attention of Professor, Dame Sue Bailey.

In our view, the key priorities to be addressed by the external review should be:

- Ensuring that children and young people get access to appropriate child and adolescent mental health services in a timely way;
- Resources for specialist CAMHS;
- Referrals that are inappropriate or not accepted;
- Primary Care provision;

- The configuration of services and the appropriateness of clinic based services
- Arrangements for access to CAMHS on an emergency basis and out of hours
- In patient provision
- Transition from child to adult services;
- Access to psychological therapies; and
- The use of prescription medication in respect of children and young people with mental health problems.

We are fully committed to scrutinising the Welsh Government's progress in delivering the step changes needed to improve wider child and adolescent mental health services and will return to this issue to monitor progress and to ensure that delivery of the modernisation agenda is on schedule.

Finally, we will take forward further scrutiny of its specific concerns about service provision in two key areas – prescribing trends for young people with mental health problems and primary care provision. We will undertake short pieces of work on both areas in the next year, with the intention of feeding into the external review over the coming months.

Executive Summary

1. The specialist Child and Adolescent Mental Health Service in Wales (CAMHS) is under more pressure than ever before. The last four years has seen a 100% increase in demand.

2. It is clear from the evidence we received that the service does not have capacity to meet the demands currently placed on it. Furthermore, we are deeply concerned about the impact that the difficulties within the existing "system" is having on children, young people and their families.

3. We note the Minister's position that CAMHS is a specialist, medical service and is not intended "to be the whole of the answer to young people who are experiencing difficulties as they are growing up and whose mental wellbeing needs to be attended to." However, we are concerned that:

- The level of CAMHS provision is not sufficient to meet the needs of young people in Wales who need a specialist, medical service;
- That difficulties exist for those children and young people who do meet the criteria for CAMHS, including waiting times, clinic-based services and the use of prescription medication;
- The absence of services for those children and young people who do not meet the "medical model" criteria for CAMHS means that there is a significant level of unmet need.

Specialist CAMHS

4. Our report sets out a number of concerns in key areas in relation to CAMHS.

Access to specialist CAMHS

5. The total number of CAMHS referrals to treatment in Wales doubled between April 2010 and July 2014 (from 1204 to 2342). The number of referrals waiting for more than 18 weeks saw an almost five-fold increase during that period (from 164 to 798).

6. As of May 2014, of all categories of specialty outpatient treatment, CAMHS has the highest number (2,410 people) awaiting treatment, compared to adult mental illness (1,291 people) and old age psychiatry (634). The same statistics show that 682 people (of all age groups) were waiting more than 18 weeks, and of those 652 were children and young

people. The Committee are particularly concerned that those waiting more than 18 weeks are almost exclusively children and young people.

7. Data provided to us by LHBs show that in 2013-14 there were 2,845 CAMHS referrals "not accepted" in Wales. This does not include data from Betsi Cadwaladr LHB.

8. The service is finding it difficult to cope with the current levels of demand, resulting in significant increases in numbers of young people on waiting lists. It is unclear how the service will cope if numbers of referrals continue to increase at the current rates.

Resources for specialist CAMHS

9. The spend on CAMHS remained broadly consistent between 2008-09 and 2012-13. In 2012-13, £42.8 million was spent on CAMHS (6.9% of the £617.5 million spent on mental health).

10. Welsh Government statistics on spend per head of population in 2012-13 show spending of £200.87 per head on mental health problems. Of this:

- £82.75 per head was spent on general mental illness;
- £58.18 per head was spent on elderly mental illness;
- £13.94 per head was spent on child and adolescent mental health.

11. Since 2012, 16 and 17 year olds have been included in CAMHS, rather than receiving adult provision. It would be reasonable to expect a spike in spending on CAMHS since that time as a consequence of these changes. However, as described above, expenditure has remained static.

12. The Committee was pleased that the Minister gave a commitment that the question of whether CAMHS budgets should be ring-fenced would be considered as part of a Welsh Government review into the ring-fencing of the mental health budget.

Welsh Government's role

13. The Committee noted the range of strategies, reviews and action plans relating to CAMHS published by the Welsh Government and joint inspectorates in Wales since 2001. The Minister informed the Committee about a CAMHS National Improvement Plan published in March 2014. We welcome the plan in principle, but are concerned that it cannot deliver the significant changes needed to meet the needs of children and young people.

14. The Committee questions whether the move from a child-focused strategy to an all-age strategy has led to improvements on the ground. In particular, evidence received by the Committee suggested that the introduction of the Mental Health (Wales) Measure may have had a negative impact on children and young people.

15. The Committee also considered whether there was sufficient monitoring and overview of how CAMHS is being delivered. The Minister emphasised that, in terms of monitoring, the Welsh Government had recently focused on the introduction of the Mental Health Measure. We were told that Welsh Government oversight of CAMHS had increased over the past 12-18 months. However, there is a lack of clarity about some of the Welsh Government's targets in relation to CAMHS.

16. In relation to the Annual Operating Framework (AOF) Targets, the Minister told us that while the Welsh Government no longer collects information against each of the AOF targets, "we would expect this information to be held locally by LHBs" and they are "expected to examine their performance against these requirements." Three of the LHBs we contacted told us that they had not collected this information since 2012, as they were not required to do so.

Structure and delivery of CAMHS

17. During our inquiry, a number of issues were raised in relation to the structure and delivery of CAMHS, including –

- the appropriateness of a clinic-based service for young people who are experiencing mental health problems;
- arrangements for the provision of CAMHS on an emergency basis and out of hours;
- in-patient provision;
- transition from child to adult services;
- access to psychological therapies; and
- the use of prescription medication in respect of children and young people with mental health problems.

18. We have addressed each of these issues in the body of the report.

Wider provision

19. It is clear from the increase in demand on CAMHS (based on the number of referrals) that there is a significant level of unmet need in Wales. Some of those individuals may not meet the current medical/diagnostic classification but the evidence we received was that they are either:

- having to wait until their condition worsens to access support;
- desperately seeking a medical diagnosis in order to gain access to CAMHS; or
- having their referrals not accepted and not being able to access support.

20. In relation to the second bullet point, there appears to be a potential perverse incentive to be diagnosed, so that young people can enter into the system, even though specialist CAMHS (in the context of it being a medical service as described by the Minister) may not be the most appropriate support for some of those young people.

21. We were particularly concerned about the unmet need relating to children and young people with attachment disorders, echoing the findings of our earlier report on the provision of Adoption Services in Wales

22. We are concerned in particular about the use of prescription medicines to manage young people's conditions. The evidence we heard suggests that the numbers and associated costs are increasing at an alarming rate. It was suggested that prescription medicine is increasingly being used for younger children because it is the only mechanism available to manage their conditions.

23. Capacity within the wider system, both in terms of staffing numbers and skills, was a key problem.

24. It is likely that the reduction in local authority budgets will have a significant and on-going impact on wider provision.

25. The impact of the Mental Health (Wales) Measure will need to be kept under review, particularly in the light of evidence received by the Committee regarding the disruption to the previously established referral pathways and that adult mental health staff who do not have the skills and experience are working with children and young people.

Minister's letter

26. On 23 October, the Minister wrote to the Committee to provide an update on progress in relation to CAMHS.

27. In his letter the Minister stated that he had asked Professor, Dame Sue Bailey, an internationally respected child psychiatrist and past president of the Royal College of Psychiatrists, to lead a "root and branch review" to modernise and redesign the service for the future.

28. The Minister stated that this "transformational work" should:

> "[…] move CAMHS services significantly forward to make them fit for the future needs of young people, rather than services, which in some areas, developed from a model first designed as Child Guidance Clinics, many decades ago."

29. In relation to the timescale for this work, the Minister said that the major redesign work would commence on 5 December, with a national conference planned for March 2015. The Minister said:

> "[…] that work aims to have an agreed plan with clear deliverables and dates for delivery by late 2015."

30. The Minister also informed the Committee that health boards had agreed to establish community Crisis Intervention and Treatment Teams and they should be operational across Wales from April 2015.

1. Introduction

31. The Children, Young People and Education Committee agreed to undertake an inquiry into Child and Adolescent Mental Health Services (CAMHS), focusing on some key issues around CAMHS in the context of the Welsh Government's reforms as set out in *Breaking the Barriers*; the implementation of the *Mental Health (Wales) Measure 2010*; and the Welsh Government's 2012 mental health strategy *Together for Mental Health*.

Terms of reference

32. The Committee was particularly interested in exploring:

- The availability of early intervention services for children and adolescents with mental health problems;
- Access to community specialist CAMHS at tier 2 and above for children and adolescents with mental health problems, including access to psychological therapies;
- The extent to which CAMHS are embedded within broader health and social care services;
- Whether CAMHS is given sufficient priority within broader mental health and social care services, including the allocation of resources to CAMHS;
- Whether there is significant regional variation in access to CAMHS across Wales;
- The effectiveness of the arrangements for children and young people with mental health problems who need emergency services;
- The extent to which the current provision of CAMHS is promoting safeguarding, children's rights, and the engagement of children and young people; and
- Any other key issues identified by stakeholders.

33. Based on the written evidence received and the discussions the Committee held with service users and their parents or carers, the Committee decided to focus initially on some key areas of these terms of reference. This focused report identifies our key areas of concern.

Our inquiry

34. We would like to thank all those who have taken the time to contribute to this inquiry by giving evidence. A list of those who gave oral evidence is

included in Annex A to this report; a list of all written submissions is included in Annex B.

35. The Committee was grateful to receive information from a number of sources which helped inform its inquiry. Following a request from the Committee in November 2013, the Children's Commissioner for Wales provided a paper outlining concerns about CAMHS. This, together with information provided informally by Barnardo's Cymru and a recent joint Wales Audit Office and Health Inspectorate Wales follow-up report, provided the Committee with a fuller picture of some of the issues with CAMHS.

36. The Committee notes that this inquiry into CAMHS services received 64 written responses, the highest number of responses to any policy inquiry undertaken by the Children, Young People and Education Committee of the fourth assembly or to the equivalent Committee of the third assembly. The volume of written evidence helped us to identify the areas on which to direct the initial focus of our work.

Service users and their parents or carers

37. In addition to gathering formal written evidence, the Committee was eager to hear from young people and their parents about their experiences of the system. To this end, we held several informal evidence gathering sessions across Wales.

38. We are particularly grateful to the Children's Commissioner's Office for facilitating visits to projects run by Hafal, Barnardo's Cymru and Action for Children. With their support, we heard directly from more than 20 young people aged 12-24 from different parts of Wales - young people we would normally not be able to reach.

39. These informal sessions gave us an invaluable insight and ensured that young people and their parents and carers were at the forefront of our minds throughout our inquiry. We would like to thank all those who participated and who were willing to share their personal experiences to help us with our work.

40. Summaries of what young people and their parents and carers told us have been published on the Committee's website and can also be found at Annexes C and D respectively.

2. Access to specialist CAMHS

Introduction

41. Difficulties in accessing specialist CAMHS was a key theme in the written evidence submitted to the Committee and in its discussions with young people and their parents. Concerns were raised about a number of issues, including referrals not being accepted; the criteria for accessing the service; and long waiting times between referrals and treatment for those children and young people who were deemed to be eligible for support.

42. The majority of parents, carers and young people reported a negative experience of trying to get support from specialist CAMHS. Many parents told us of the significant impact of their child's mental health problem on their child and their family and said that this was made worse by not being able to get the help they felt they needed.

43. Written evidence pointed to an increase in the number of children and young people being affected by diagnosable mental health problems. However, we were told that there is no accurate picture of need in Wales and that there is a need for data collection on the prevalence and incidence of mental health conditions in children and young people.

44. The written evidence overwhelmingly suggested a perception of a significant under-capacity within specialist CAMHS and this was leading to long waiting lists and increasing difficulties in accessing the service. It was suggested that this had resulted in the criteria for accessing specialist CAMHS being tightened. A number of professionals informed the Committee that they "don't bother" to refer to CAMHS, as their experiences suggests that "there is no point".

45. Although our inquiry focused on specialist CAMHS, we also considered how these specialist services are set within the context of a broader "CAMHS concept" (set out by the Welsh Government in its 2001 CAMHS strategy, "Everybody's Business") where a range of agencies play a role in delivering wider CAMHS services, in particular education and social services. Written evidence suggested that, largely due to a lack of resources, there has been a diminishing input from social services into the wider provision of CAMHS. Evidence also suggested that the role of educational psychologists and their potential to play a key role within broader CAMHS provision is not valued sufficiently.

46. Respondents also pointed to significant variation across Wales in the way children and young people are able to access support from specialist CAMHS. We were told this was particularly noticeable in certain settings, for example the support that specialist CAMHS provide via Youth Offending Teams.

Referral rates

47. The total number of children and young people referred and waiting for treatment from CAMHS in Wales has increased by 100% in the last four years, from 1,204 referrals in April 2010 to 2,410 referrals in May 2014. Aneurin Bevan Local Health Board experienced the largest increase (241%) in people waiting for CAMHS outpatient appointments in this period, from 190 in April 2010 to 648 in May 2014.

Referrals not accepted

48. Parents and carers told the Committee about referrals to specialist CAMHS being rejected "without explanation" and GPs told us referrals had been rejected without CAMHS having seen the child. Parents spoke of feeling they had to "lobby" to access services for their child. One parent said "children and young people don't get seen until there is a crisis and often not even then".

49. In response to these concerns, the Committee sought information from LHBs (Local Health Boards) on the number of CAMHS referrals which were "not accepted".

50. All LHBs responded to our request for information; however, they supplied data for different time periods and three LHBs did not start collecting data on "referrals not accepted" until November 2013. The year in which the most complete data was provided showed that in 2013-14 there were 2,845 CAMHS referrals not accepted in Wales. This figure does not include Betsi Cadwaladr LHB and is therefore likely to be an underestimate. Of the referrals not accepted, Aneurin Bevan LHB did not accept 1,033 referrals to its specialist CAMHS services in 2013-14.

51. The data suggested a potential level of "unmet need" over a longer period. Betsi Cadwaladr LHB told us that over the five year period 2009-10 to 2013-14 they recorded 3,950 referrals as "not accepted". In the same period Hywel Dda LHB recorded 2,767 referrals as not accepted and Powys LHB recorded 963 referrals as not accepted. The other LHBs did not start

collecting this data until November 2013 or did not provide a complete data set.

Criteria and thresholds for accessing specialist CAMHS

52. A number of respondents to our consultation raised concerns about the criteria for receiving a service from specialist CAMHS.

53. In relation to this, respondents were concerned that the current "medical model" of delivering CAMHS results in young people needing to have a diagnosable disorder to receive a service from specialist CAMHS. It was suggested that this model of service provision excludes many children and young people who need support for their mental health. This point was made by a number of LHBs and by professional groups such as the Royal College of Psychiatrists.

54. In reference to this "medical model", Action for Children told us that it means that "we overlook the enormous psychological needs of children who have experienced trauma, abuse, neglect, attachment difficulties and losses". Some of the young people we met had previously been looked after by the local authority. Referring to trauma experienced by some looked after children, one young person said "we've all seen things we shouldn't have seen and got no help with it".

55. Several responses from Local Authority children's services or looked after services also point to how the "medical model" results in children with attachment disorders being excluded from receiving a service. The Applied Psychologists in Health National Advisory Group referred to "a growing body of evidence from neuroscience research which demonstrates that the brain is structured to develop healthy attachments".[1] They went on to say:

> "The emphasis in both PCMHSS and later in Tier 2 CAMHS services is directed by a medical model of health care which identifies deficiency and disorder rather than on promoting mental health. Evidence of effective early intervention would therefore dictate a change in the model used to one which supports secure attachments within the family and wider community."[2]

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[1] Written evidence, CAM25
[2] ibid

56. Much of the written evidence supported a perception of a tightening of the exiting criteria and thresholds to access support from specialist CAMHS. For example NSPCC Cymru said:

> "Threshold levels are felt to be rising with our services reporting concern that unless a child presents with life-threatening behaviours they are less likely to receive a service."[3]

57. Dr Rachel Williams, representing the Applied Psychologists Specialist Advisory Group, spoke of her concerns about the thresholds for accessing support and said that CAMHS is being delivered "like accident and emergency"[4]. She said "it is hard enough to get a child onto a CAMHS waiting list, but what is happening in reality is that only the urgent cases, where there is a significant risk of self harm, are being seen".[5]

Referral to treatment times

58. Welsh Government statistics show that, as of May 2014, of all categories of specialty outpatient treatment, CAMHS had the highest number (2,410 people) awaiting treatment. This compares to adult mental illness (1,291), and old age psychiatry (634). At a Wales level, this means that 3.8 of every 1,000 children and young people are waiting for treatment compared to 0.5 of every 1,000 adults. Waiting times varied according to LHB, with 754 children and young people waiting for treatment in Betsi Cadwaladr LHB – the highest of all LHBs.

59. In the context of the total number of CAMHS referrals to treatment in Wales increasing from 1,204 in April 2010 to 2,342 in July 2014, the number and percentage of referrals waiting over 18 weeks has increased from 164 (13.6%) in April 2010 to 798 (34.1%) in July 2014.

60. In relation to the number of young people waiting more than 18 weeks for treatment in Aneurin Bevan LHB, information provided to the Committee by the LHB shows that the total number of referrals to treatment has increased from 191 in April 2010 to 695 in July 2014. Of these referrals, the number of those waiting over 18 weeks for treatment has increased from 0 (0%) in April 2010 to 507 (73%) in July 2014. The majority of this increase was seen in the period between February 2013 and July 2014.

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[3] Written evidence, CAM42
[4] Oral evidence, 2 April 2014
[5] ibid

61. In our discussions with them, young people and their parents told us that this was a key concern for them. They told us that not getting help when they first needed it had made their mental health problems worse and resulting in several of the young people being admitted to specialist inpatient units. One young person told us that "It's too long to wait to see CAMHS – why can't they help you from the start".

62. According to the Welsh Government's statistics on specialty outpatient treatments, those waiting more than 18 weeks for treatment are almost exclusively children and young people. In May 2014, of the 682 people waiting more than 18 weeks, 652 were children and young people.

63. A Principal Child and Adolescent Psychotherapist told us:

> "Specialist CAMHS are woefully under-resourced and case-loads are congested with families who have long-term, complex needs. Consequently waiting lists are long and only those who present with acute need or crisis are seen as a matter of priority. Many receiving short-term treatment to resolve the presenting symptoms will return with a different set of symptoms requiring further interventions: 'revolving door children'."[6]

The expansion of access to the service in 2012

64. The Committee received evidence to suggest that the significant increase in demand for the service may be, in part, a result of the inclusion of 16 and 17 year olds within the CAMHS remit since 2012. Written evidence suggested that this change had placed significant pressure on specialist CAMHS, in particular as there were no specific additional resources allocated by LHBs.

65. The Committee raised this issue with the Minister by letter during its inquiry. The Minister responded that a "specific impact assessment of the change in the age coverage of CAMHS was not undertaken' but that "it has become clear that some refinement in policy may be required".

Early intervention and the impact of the Mental Health (Wales) Measure

66. The written evidence suggested that there are very limited early intervention services to meet the needs of children and young people with mental health problems, both from specialist CAMHS and wider services. It

[6] Written evidence, CAM10

was suggested that whilst Welsh Government strategy emphasises early intervention "ironically, the drift seems to be in the opposite direction".[7]

67. Whilst school counselling services were seen as important and helpful for some children, one respondent told us:

> "A serious lack of NHS CAMHS means that children in great distress, who even 10 years ago would have seen a clinical psychologist, psychiatrists or family therapist in CAHMS (…) are now directed to school counsellors who do not have the skills or training or infrastructure to deal with the severity or complexity of many children."

68. Some examples of "good practice" in early intervention were cited such as a clinical psychologists and clinical psychotherapists being employed by Flying Start Services and the Action for Children Family Intervention Team in Caerphilly.

69. The *Mental Health (Wales) Measure 2010* came into force in 2012 and has a specific focus on early intervention though Primary Mental Health Services.

70. Some written evidence, for example from the Royal College of Nursing, suggested that the all-age *Mental Health (Wales) Measure* had led to an inferior CAMHS service for children and young people. Other evidence suggests that the Measure better reflects adult orientated services and that Primary Mental Health Workers who are not trained or experienced to work in child and adolescent mental health, are expected to do so.

71. The Children's Commissioner said that the approach whereby only GPs can refer to CAMHS does not take account of the fact that they are often not the first point of contact for young people. Referring to the *Mental Health (Wales) Measure's* focus on supporting GPs, Cwm Taf Health Board stated:

> "CAMHS do not get the majority of their referrals to primary mental health via the GP, and there is a risk that the valuable services that are provided by our existing primary mental health workers will be lost due to pressure to meet a Tier One target that is not appropriate for children and young people."[8]

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[7] Written evidence, CAM14
[8] Written evidence, CAM 49

72. In reference to this issue, Hywel Dda UHB told us:

> "As an age inclusive service little account has been taken of the significant role that child and adolescent PMHW delivered historically across all Tier 1 agencies and has led to confusion as to their role. This undermining of the role is of significant loss and steps should be taken to address it before the role becomes completely devalued."

73. The Welsh Government is required to review the implementation of the Measure. The first report, published in March 2014, contains limited references to children and young people.

Minister's evidence

74. In reference to the significant pressures on CAMHS services, the Minister emphasised the importance of not only considering whether supply is sufficient to meet demand, but the nature of that demand. He said:

> "There has been a 100% increase in referrals to the system over a four-year period. I cannot imagine that anyone would think that the amount of mental ill health among young people in Wales has doubled since the year before the last Assembly election. Derek Wanless told us a decade ago that, in the health field, if you think that the answer is always to go on ratcheting up supply to meet demand, you will never reach a point where the system is in balance."[9]

75. He went on to stress that CAMHS is a specialist, clinical service:

> "It is not intended, nor was it ever intended, to be the whole of the answer to young people who are experiencing difficulties as they are growing up and whose mental wellbeing needs to be attended to. [...] we should always be attending carefully to that border line to make sure that those people who need a CAMHS service get it and that those young people whose needs can be better attended to by the more universal and general services get the help that they need there."[10]

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[9] Oral evidence, 17 July 2014
[10] ibid

76. The Minister also commented on the need to ensure that young people who need to access general services are provided with the appropriate support:

> "[…] one of the reasons why we get this volume of referrals to CAMHS, and a high proportion of those then rejected by CAMHS as not being suitable for what they can provide, is because we need to strengthen the ability and the confidence of a wider range of lower-tier professionals to respond to the needs of those young people."[11]

77. The Minister rejected the suggestion that professionals were not referring to the service because of long waiting times and the high number of referrals not being accepted. He said :

> "If you have a service to which the referrals have doubled in a four-year period, and then argue that people are not bothering to make referrals—the two things cannot both be true. The actual evidence, rather than the opinions that people have put to you, is that people are referring to CAMHS like they have never referred before. So, the idea that people are thinking that it is not worth bothering is simply not borne out by the practice of people on the ground."[12]

78. The Minister said that not every CAMHS service "has been brought up to date in the way we would like it" and announced that a "national CAMHS improvement plan" had been introduced. He also gave the example of Aneurin Bevan LHB investing an "extra investment" of £80,000 and said:

> "The investment has not just tried to turn the handle faster on the service that it provides; it has been to remodel the service so that it is sure that it is dealing with the young people who really need the service, to strengthen other parts of the system to respond to other young people's needs, and to change the pattern of the professional workforce so that you have more people available to see young people. I think that it has succeeded in reducing those over-18-week waits quite quickly."[13]

79. In a further letter to the Committee, the Minister referred to the improvement plan and said that:

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[11] Oral evidence, 17 July 2014
[12] ibid
[13] Ibid

"Welsh Government will also be funding service change expertise to support the Plan. This will take the form of a nationally recognised clinical leader to shape and inform CAMHS strategic development in order to promote service change. This role will be supported by a senior 'turnaround manager', […]. Work has already commenced including leading Welsh academic input, activity by the NHS Delivery Unit and national benchmarking work. Activity will be funded over the remainder of this year and next, and is expected to cost around £100,000."[14]

80. In response to a question on waiting times, the Minister said:

"I recognise that there is a problem in that regard, but more children are being seen within the target times than at any other time since we have had CAMHS."[15]

81. The Minister was questioned on the Measure's impact on children and young people and whether an appropriate amount of the money allocated by the Welsh Government to implement the Measure had been targeted at children and young people. He said that he had been informed that "where the Measure has had its greatest impact in relation to children has been in the provision of a care and treatment plan for young people in secondary care". The Minister said that 94 per cent of children and young people have a care and treatment plan. He went on to say:

"We have not, as I said, done an across-Wales analysis of young people using primary mental health services as a result of the Measure. However, where we do have solid evidence, it is that they are receiving a service there in considerable numbers."

82. Dr Watkins, an official accompanying the Minister, referred to additional Welsh Government funding to implement the measure across all ages and said that:

"[…] broadly speaking, children should be accessing more services, because £3.5 million is a lot more money, and we think that it does help children and young people and their families to have a written care and treatment plan that shows you who to contact in a crisis and

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[14] Letter from the Minister for Health and Social Services
[15] Oral evidence, 17 July 14

> what the name of your key worker is. Service users, over and over again, tell us that that is what they want."[16]

83. She went on to say that LHBs and voluntary sector bodies had been asked to make sure that people of all ages took part in a service users' satisfaction survey as part of an interim review of the Measure.

The Committee's view

84. The Committee is concerned about the following issues relating to access to specialist CAMHS:

- the numbers of referrals not accepted, inappropriate referrals and levels of unmet need;
- that the impact of the "medical model" of service provision within specialist CAMHS (where children and young people need to have a diagnosable disorder to receive a service) is excluding significant numbers of children and young people who need support for their mental health; the waiting times for children and young people (in particular those waiting more than 18 weeks for treatment are almost exclusively children and young people);
- whether there have been any unforeseen negative consequences on access to CAMHS resulting from the Mental Health (Wales) Measure.

[16] Oral evidence, 17 July 14

3. Resources for specialist CAMHS

Introduction

85. A key concern in the written evidence was the level of resources available for specialist CAMHS, particularly in relation to the appropriateness of the amount of expenditure on the service by LHBs; and also whether staffing levels are sufficient to provide an effective service.

Funding

86. Latest Welsh Government statistics show that £617.5 million was spent on the category of "mental health problems" in 2012-13. This is the largest single programme budget category within the NHS. Of this, £42.8 million was spend on CAMHS (6.9% of total mental health spend).

Table 1: Expenditure on mental health services 2008-09 to 2012-13

NHS expenditure	2008-09	2009-10	2010-11	2011-12	2012-13
Child & adolescent mental health (£m)	42.2	43.8	41.9	42.8	42.8
Child & adolescent mental health spend as a percentage of total mental health spend (%)	7.2	7.2	6.6	6.7	6.9
General mental illness (£m)	282.4	306.6	327.7	316.4	254.4
General mental health spend as a percentage of total mental health spend (%)	48.0	50.5	51.5	49.3	41.2
Elderly mental illness (£m)	158.0	167.4	176.3	186.4	178.9
Elderly mental illness spend as a percentage of total mental health spend (%)	26.9	27.6	27.7	29.0	29.0
Other mental health (£m)	105.8	89.6	90.7	96.3	141.4
Other mental health spend as a percentage of total mental health spend (%)	18.0	14.8	14.2	15.0	22.9
Total mental health spend (£m)	**588.3**	**607.4**	**636.7**	**641.8**	**617.5**

Figure 1

Source: NHS Programme Expenditure Budgets, published June 2014

87. Information provided by LHBs shows that in 2012-13 the percentage spent on specialist CAMHS as a proportion of total spend on mental health varied from 3.4 per cent in Hywel Dda LHB to 10 per cent in Betsi Cadwaladr LHB.

88. The Welsh Government has published statistics on spend per head of population in 2012-13. These show spending of £200.87 per head on mental health problems:

- £82.75 per head on general mental illness;
- £58.18 per head on elderly mental illness;
- £13.94 per head on child and adolescent mental health.

89. Most CAMHS funding is included within the overall mental health ring-fenced allocations to LHBs, although it cannot be separately identified. In a letter to the Committee, the Minister said that "it is the responsibility of LHBs to allocate their resources to meet the needs of their population and across all ages".[17]

90. Many respondents were concerned about the level of funding for specialist CAMHS. Some raised concerns about the allocation of resources to specialist CAMHS being proportionally less than adult mental health services. In written evidence, Hywel Dda UHB told the Committee:

> "There are significant differences in resource allocation and provision across Wales, with no clear format for considering what % of the Health Board allocation should be considered appropriate for a significant percentage of the population. A level of clarification/guidance would be welcomed."[18]

91. Referring to the "disproportionate" spending on adult compared to children's mental health, the Royal College of Psychiatrists told us that the inclusion of 16 and 17 year olds was "the last straw".

92. £3.5 million has also been made available by the Welsh Government each year since 2012-13 to support the implementation of the *Mental Health (Wales) Measure* and the Minister was questioned on how children and young people had benefitted from this allocation. Hywel Dda UHB told us of a "significant concern that the funding made available for the development of Primary Care services did not take into account the full needs of this vulnerable age group and therefore may have disadvantaged them".[19]

93. Some respondents described the benefits of invest-to-save models. Reference was made to an external evaluation of the Family Intervention

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[17] Letter from the Minister for Health and Social Services
[18] Written evidence, CAM53
[19] Written evidence, CAM53

team in Caerphilly which we were told showed a saving of £7 for every £1 spent.

94. The "CAMHS concept" was the basis for the Welsh Government's 2001 Everybody's Business CAMHS strategy**.** It highlights the importance of the role of agencies other health in delivering comprehensive mental health services, for example the importance of social services and education. Evidence to the Committee suggests that in reality this broader approach is not in place. It was suggested that there has been a diminishing input of the wider range of agencies to CAMHS, in particular from social services, and that this is largely due to resources. For example Rhondda Cynon Taf local authority told us that that the social work role within CAMHS "has been eroded" and that the "strategic links between RCT Children's Services, Youth Offending Services and CAMHS has, over the years, also deteriorated".[20]

95. RCT Children's services referred to the reduction of local authority funding for social work support for the broader provision of CAMHS. The Minister provided further evidence to the Committee on how the current financial climate had resulted in a reduction in local authority funding, in turn affecting broader CAMHS provision. He said:

> "Local Authority input has always been integral to specialist CAMHS and social workers have been core members of multidisciplinary teams. We know from a contacts audit of CAMHS in June 2012 by the Delivery Unit there were 7.5 WTE social care workers in specialist CAMHS teams. This contrasts with Durham mapping of CAMHS which showed social workers within CAMHS were 11.1 WTE in 2008 and 25.7 in 2007."[21]

Staffing

96. During our discussions with them, parents pointed to a shortage of staff being a major issue within specialist CAMHS. They suggested that limited staff and resources means that parents and carers are bridging the gap and this is having a significant impact on them and their families.

97. This view was echoed in the written evidence, which suggested significant pressures on staffing capacity, especially compared to adult services. In some areas, this was compounded by vacancies. Written evidence

[20] Written evidence, CAM30
[21] Letter from the Minister for Health and Social Services

also suggested that specialist CAMHS do not have the right skills mix, with a lack of staff able to deliver therapeutic interventions being a key concern.

98. A comparison of staffing ratios for adult and child secondary health per head of population shows a rate of 9.9 working time equivalent (WTE) CAMHS medical staff per 100,000 population compared with a rate of 15.9 WTE per 100,000 for adult psychiatry specialities.

99. In reference to these figures, the Minister told the Committee that "the mental health problems adults experience are frequently more enduring and require, for example more hospital admissions, some times at high levels of security".[22] He also referred to CAMHS being provided at community level and this not being reflected in the staffing levels. However evidence received by the Committee does not bear out a perception that specialist CAMHS, in the main, is provided at a community level.

100. The Royal College of Psychiatrists has published guidance on staffing ratios, which recommends:

> Specialist Tier 2/3 CAMHS
>
> 19.3 WTE clinicians per 100 000 total population for a non-teaching CAMHS and 24.2 WTE for a teaching CAMHS up to the 18th birthday. This does not include capacity for severe intellectual disability, youth offending and substance misuse work.[23]

101. In a letter to the Committee, the Minister stated that the Royal College of Psychiatrists Guidance is "aspirational guidance"[24] which the Welsh Government had circulated to LHBs.

102. Parents, carers and young people told us of high rates of staff turnover within specialist CAMHS, a view echoed in the written evidence. Young people told us building trust with staff is very important and this is not possible when you see different people. A young person told us "I am not good at talking – they expect you to chat straight away" [...] "then they send me to a different person – I have to say it all again". Her support worker explained that she had four different CAMHS workers in the past 6 months.

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[22] Oral evidence, 17 July 2014
[23] RCP guidance
[24] Letter from the Minister for Health and Social Services

Minister's evidence

103. In relation to the proportion of expenditure on CAMHS and whether or not it is appropriate, the Minister said

> "I am not saying that the split is right; I am not saying that 7% is the right figure, but I am saying that it is not quite as simple as saying, 'Twenty per cent of the population are children, so how come 20% of mental health money isn't spent on them?' The nature of the service that they need, and the nature of the experience that they have means that the expenditure is not required in quite the same way."[25]

104. He also referred to the fact that adults have higher rates of admission into in-patient care and therefore different patterns of service delivery.

105. On whether or not lack of finances could possibly lead to an individual being denied access to services that they needed, the Minister said:

> "It would be impossible to deny, would it not, that the system is under pressure? The system is under financial pressure, as all public services are. I would be very disappointed if I thought that a child was being denied a service because the affordability issue had determined that decision. We know that there are reductions in local authority spend on mental health services, which are causing some extra pressures in the system […] I think that we are very lucky in Wales to have a third sector that is actively ensuring that that does not happen and a very committed workforce as well. However, I could not possibly answer the question by saying, 'Oh no, money's no problem and never enters the calculation'."[26]

106. In relation to whether or not the allocations for specialist CAMHS should be ring-fenced within LHB budgets, the Minister said:

> "I know, because I have read some of the evidence that you have had, that the question of the mental health ring fence has been raised with you. You know that we have brought forward our review of the mental health ring fence, and I know that you raised the question with me in a letter from the Chair about whether the CAMHS part of

[25] Oral evidence, 17 July 2014
[26] Ibid

that would be included in the review. I can confirm today that we have decided that it will be."[27]

107. In reference to the impact of including 16 and 17year olds in CAMHS since 2012, the Minister said:

> "They were always part of the spend of local health boards. These were not new people; they were receiving a service. Whether the spend is allocated on one side of the ledger or the other, I think that you could say that you would expect that. It is a distinction without a difference, in a way, because the money was being spent whether it was entered in one column or the other."[28]

108. On the Royal College's guidance relating to staffing ratios, the Minister said:

> "There is no doubt at all that its ratios are aspirational. We do not know of any service anywhere that is meeting the guidelines that the royal college sets out. What we do know is that we have a better proportion of staff to need in Wales than they have across the border and that there was a 24% increase in staff within CAMHS during the last Assembly term. That is not to say that we would not like to strengthen the service."[29]

The Committee's view

109. The Committee is particularly concerned about the following issues in relation to the resources available for CAMHS:

- whether the level of spend per child per head of population is appropriate, given that one LHB has called for guidance in relation to this issue; whether a further ring-fence for child mental health should be included in the mental health ring-fence;
- the Minister's evidence that it makes no difference whether mental health spend for 16 and 17 year olds is within CAMHS or adult mental health services, given that in reality the costs are being borne by CAMHS services; and
- the impact reductions in local authority budgets are having on overall mental health services for young people.

[27] Oral evidence, 17 July 2014
[28] ibid
[29] ibid

4. Welsh Government's role

Introduction

110. Based on themes emerging from the written evidence, the Committee was keen to further examine the effectiveness of the Welsh Government's strategic approach to CAMHS, including how it monitors delivery of the service against relevant targets, such as the Annual Operating Framework Targets and those in the *Mental Health (Wales) Measure.*

CAMHS strategies and reviews

111. The Welsh Government has published 7 policies, strategies and reviews relating to CAMHS since 2001,[30] not including the all-age *Mental Health (Wales) Measure* which came into force in 2012 nor the 2012 all-age Together for Mental Health Strategy.

112. In 2013, the Wales Audit Office published a review, in conjunction with Health Inspectorate Wales on CAMHS: follow up-review of safety issues. The review specifically focused on the issues highlighted in the 2009 report as putting children and young people at risk. The 2013 report found that children and young people continued to be put at risk due to inappropriate admissions to adult mental health wards, problems with sharing information and acting upon safeguarding duties and unsafe discharge practices.

113. The introduction of the 2012 Together for Mental Health Strategy signalled a move from a child-specific approach to an all-age approach for mental health strategy. On this issue, the Royal College of Nursing said that:

> "The RCN in Wales is of the view that the publication of 'Breaking the Barriers (2010)' and the subsequent Mental Health Measure created an impetus for the improvement in Child and Adolescent Mental Health Services. Despite this, there is some concern from our members on the ground that the publication of the Welsh Government's 2012 all age Mental Health Strategy 'Together for Mental Health' may have stifled this impetus and that CAMHS services are now seen in some areas as 'the Cinderella of Cinderella services'."[31]

[30] Including the 2003 National Service Framework for children, young people and maternity services
[31] Written evidence, CAM39

114. The Children's Commissioner for Wales told us:

> "I am concerned that the loss of a distinct and separate national strategy for children and young people and its replacement with an all age strategy "Together for Mental health: A strategy for Mental Health and Wellbeing in Wales" could potentially dilute regard to the intentions of the UNCRC. I welcome the fact that the strategy includes the seven core aims for children and young people in Wales under the UNCRC within its approach. However I am still not convinced that this can provide stronger direction in relation to a rights-based approach to mental health services for children and young people than would have been provided in a separate and distinct strategy."[32]

Annual Operating Framework (AOF) Targets

115. The Minister informed the Committee that the NHS Annual Operating Framework 2010-11 targets for CAMHS remain in place and that "LHBs are expected to examine their performance against these requirements". In a letter to the Committee, the Minister said that the Welsh Government "no longer collect information against each of the AOF targets" and that "we would expect this information to be held locally by LHBs".[33]

116. The Committee wrote to LHBs asking for the AOF data. Three had not collected data beyond 2012 as they had not been required to do so.

CAMHS Audit

117. The Minister provided the Committee with a copy of the Joint Delivery Unit and National Leadership and Innovation Agency for Healthcare review of CAMHS. This was undertaken in 2012 to support the introduction of Part 2 of the *Mental Health (Wales) Measure 2010.*

118. Among its findings were that: there were neither standardised practises nor controls in place for the effective delivery of services; little evidence was found in the course of this snapshot review of any systematic assessment and recording of risk; there were no standardised integrated operational policies in place and not every service had these even in draft form; there was little evidence that staff receive supervision relating to outcome focused care planning, risk management and caseload management.

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[32] Written evidence, CAM29
[33] Letter from the Minister for Health and Social Services

119. In his letter to the Committee, the Minister stated that "it is important to recognise the progress LHBs have made since the publication of the report".[34]

120. The Minister subsequently provided the Committee with a copy of the Welsh Government's CAMHS Service Improvement plan, dated March 2014. The Minister told us that the plan was developed in 2013 "with the aim of taking forward a range of actions to enable the service to adapt to meet current challenges".[35]

Minister's evidence

121. In response to a question on whether or not he thought that the overview arrangements for Local Health Boards' delivery of CAMHS was sufficient, the Minister said:

> "The one thing that I have done in the time that I have been the Minister for Health is that I have established a system where I meet every quarter with the vice-chairs of the LHBs, because they have the responsibility in the mental health area. […] Every time that we have discussed CAMHS, I have raised a number of issues with them and they feed back to me. They write to me about what they are doing and we speak again about the points that we raised at the next meeting. So, I feel that I, as a Minister, have more of an opportunity to have an impact on the system."[36]

122. In respect of the AOF targets, Jo Jordan, an official accompanying the Minister told the Committee:

> "I think that in the evidence that you have received there was some discussion over an old annual operational framework target, and they do change over time. The focus also changes. It might be true that our focus regarding what we collect in terms of what we now call our tier 1 priorities has changed in respect of CAMHS, because our focus over the last year or so has been the implementation of the Measure. […]However, that is not to say that we, at Welsh Government, are not keeping a very close eye in terms of what is happening to waiting lists et cetera."[37]

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[34] Letter from the Minister for Health and Social Services
[35] ibid
[36] Oral evidence, 17 July 2014
[37] ibid

123. In respect of the Welsh Government's broader oversight, Jo Jordan told us "you could probably say that CAMHS at the moment in Welsh Government, and over the last 12 to 18 months, has had a much closer focus and attention than previously". She referred to the Welsh Government "keeping a close eye" on waiting times and gave us an example where it was said that Welsh Government monitoring had resulted in "real improvements"[38] in reducing the number of young people being placed in in-patient facilities outside Wales.

124. In relation to monitoring expenditure on CAMHS and mental health provision for young people, particularly in light of any additional financial resource that might be made available, the Minister said:

> "I am very keen that, from a Welsh Government perspective, we track that money so that we know that it is being spent on the things we want the money to be spent on. The money that we will put into the improvement plan will certainly be tracked in that way."[39]

125. Dr Watkins outlined the Welsh Government's pilot project to monitor outcomes for people who use mental health services through the use of core data sets. This included all age groups including CAMHS but "excluding very young people" (according to the report on the pilot).Dr Watkins said that "the pilot has been successful, so it is now going to be rolled out in every LHB, starting next month".[40]

The Committee's view

126. The Committee's key concerns relating to the Welsh Government's role are:

- That there have been a number of CAMHS reviews and strategies over recent years, none of which appear to have delivered the changes needed;
- Whether the CAMHS National improvement plan will have sufficient impact to deliver the scale of change needed;
- Whether the move from a child specific mental health strategy to an all-age strategy has had a negative impact on service provision;

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[38] Oral evidence, 17 July 2014
[39] ibid
[40] ibid

- The need to evaluate the impact of policy and legislation on all age groups, including a distinct focus on children and young people; and
- The lack of clarity on the status of the Welsh Government's current targets and whether the WG has sufficient oversight of the delivery of specialist CAMHS given that some Local Health Boards no longer collect or publish data which the Welsh Government suggests they should.

5. Structure and delivery of specialist CAMHS

Introduction

127. During the Committee's inquiry, a number of key themes emerged relating to the structure and delivery of specialist CAMHS services. These included the appropriateness of clinic-based services; young people's access to emergency and out of hours mental health support; and access to talking therapies.

128. The transition from child to adult services has been an on-going area of concern and was highlighted to the Committee, along with the concerns about the increasing use of prescription medication for young people with mental health issues.

129. The written evidence pointed to a need for more consistent access to specialist CAMHS across Wales and the need for delivery models which can work both in rural and urban areas. The Royal College of Psychiatrists emphasised the importance of robust planning and commissioning.

Clinic-based services

130. Several written responses referred to the limitations of specialist CAMHS being delivered via clinic-based 9-5 services. Respondents pointed to the practical and financial difficulties which arose from specialist CAMHS being delivered from clinic bases. Evidence received from a group of clinical psychologists said:

> "We believe that most CAMHS services are predominantly based on a traditional 'clinic' based delivery of service, which does not suit some of the most vulnerable, complex and traumatised families. Reaching out to these families in a more proactive/creative way is not possible with the pressure of target driven waiting times and the capacity/demand imbalance."[41]

131. A Consultant Psychotherapist and former CAMHS Operational Manager said CAMHS is still relatively unavailable for many families, especially in rural areas, because specialist CAMHS operates an appointment-based clinic system where families attend an assessment. He went on to say: "For some of the poorest or more marginalised families in our communities there are

[41] Written evidence, CAM54

real issues to do with finance, logistics and sometimes organisation that present significant obstacles to attending clinic-based services".

132. The young people we met emphasised that clinic based services were not meeting their needs. It was suggested that models of delivering specialist CAMHS need to be more flexible and located within more suitable community settings or via out-reach provision.

133. All of the young people and parents we heard from were very positive about the mental health support they had received from specialist voluntary sector projects or from courses they had attended. However, many of these voluntary sector courses and projects had either closed or were about to end due to lack of funding. The young people we met were very upset by this.

134. It was also suggested that specialist CAMHS continues to discharge from its care young people who do not attend appointments, despite efforts by the Welsh Government to prevent this. Cardiff and Vale University Health Board told us that "the network operates a purely clinic-based model and if young people do not attend they are discharged".

135. The Head of Children's Social Services in Flintshire said:

> "Service delivery models which prompt case closure when families fail to attend pre-booked sessions do not reflect practice wisdom of the need for robust engagement techniques with this group of young people."[42]

Emergency and out-of-hours

136. It was reported to us that, as a result of specialist CAMHS provision being primarily 9-5 clinic based, many young people are being admitted to emergency or accident and emergency (A&E). It was suggested that admissions to A&E has become a "default setting" because of the difficulties in accessing support from specialist CAMHS. Many of the young people we spoke to had been admitted to A&E on several occasions as a result of self-harm or an overdose.

137. Written evidence suggested that access to CAMHS in an emergency or out-of-hours is variable across Wales. Provision in some areas was very limited and inadequate. Specific concerns included the availability of out-of-hours provision; children and young people being admitted inappropriately

[42] Written evidence, CAM63

to paediatric or adult wards; children and young people being discharged without follow up support; and a lack of inpatient beds for emergencies. Respondents suggested that emergency and out of hours CAMHS support relies heavily on adult mental health staff and paediatric staff, neither of which necessarily have the right skills to deal with emergency presentations. It was also suggested that some older young people who may be a high suicide risk are being refused an urgent mental health assessment or hospital admission due to having consumed alcohol and/or drugs.

138. Several young people told us that they had attempted suicide but it seemed to them it did not result in them meeting the threshold for services. Some of the young people had their initial contact with CAMHS after being admitted to A&E, though other young people told us they were discharged from hospital with no follow up support.

139. Many respondents to the call for evidence pointed to the unsuitability and limited support available in an emergency or out of hours. Their views echoed concerns in the 2009 WAO/ESTYN/HIW report and in the subsequent 2013 follow up report. Hywel Dda Health Board stated:

> "The current arrangements should be reviewed and could be described as ineffective or even bordering on unsafe on occasions. […] Why do we continue to admit these young people to inappropriate adult beds or send them to England?".[43]

140. Betsi Cadwaladr UHB said:

> "Out of hours mental health emergencies present a serious problem; currently they are dealt with initially by Adult mental health for 16 and 17 yr olds and Paediatrics for 15 years and below."[44]

In-patient beds

141. The Wales Audit Office wrote to the Committee and suggested we further examine the findings of the Auditor General's 2013 report which found that the limited capacity at the two CAMHS inpatient units was leading to expensive out of area placements . They told us that there had been limited progress since their 2009 report. Written evidence suggested that demand was exceeding supply leading to children and young people being

[43] Written evidence, CAM53
[44] Written evidence, CAM23

placed in paediatric wards, adult wards or being placed in expensive specialist facilities a long way from their home areas.

142. Evidence from young people and their parents also raised concerns about the lack of specialist CAMHS inpatient facilities in Wales. Several young people told us of being placed on adult wards or general paediatric wards.

143. The Medical Health Directorate of Abertawe Bro Morgannwg University Health Board raised concerns about the on-going use of Adult Mental Health wards for the placement of adolescents with mental health problems.

144. Cardiff and Vale of Glamorgan Community Health Council said "the use of children's wards at University Hospital of Wales for the assessment of disturbed children alongside seriously ill children is unsuitable for both groups".[45]

145. Some of the young people we spoke to had previously been in-patients in mental health units. Two young people had been sent to units outside Wales. Of the young people who had been inpatients, some told us they felt they were being "institutionalised" and being "held" there until they were old enough to leave. One young person reported a very bad experience of an inpatient unit saying "some of the staff spent the whole time chatting in the office – saying they couldn't wait to get home – it didn't make me feel they wanted me there".

146. Two of the young people had experienced "unplanned recall" where they had been moved suddenly to a different unit. They thought this was because it would save money not because of medical reasons. One young person we met had previously been in hospital for 9 years and was now getting more support outside hospital. Referring to this support she told us "if I had had it sooner I could have lived in my own community".

147. During the inquiry, members of the Committee visited Ty Llidiard, a mental health in-patient unit based at the Princess of Wales hospital, Bridgend. In evidence, the Western Bay Safeguarding Children Board told us that the in-patient facilities in Bridgend are insufficient to meet the needs of the population and that it has highlighted this to the Welsh Government for "urgent consideration".

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[45] Written evidence, CAM21

Transitions to adult services

148. Problems in the transition from CAMHS to Adult Mental Health Services are well-documented. In written evidence, many respondents suggested that it continues to be a problem despite efforts to ensure effective transition processes. A Clinical Psychologist told us:

> "This is an area of extreme concern. Speaking from an adult services team with both health and social care staff we have exceptionally poor links with CAMHS. There is limited positive experience of transfers of care from CAMHS to our service. Transition from CAMHS to adult services is hugely unpredictable".

149. Many of the young people we spoke to referred to their concerns about transition to adult services. One young person said he had received services from CAMHS and when he became too old he "suddenly dropped out of the system".

150. Parents also highlighted concerns about transition to adult services, with comments such as: "There is no transition at all"; "it's completely up to me to do it all over again"; and "my daughter will be 18 soon and I keep asking what's happening?".

Access to psychological therapies

151. Much of the written evidence suggested that access to psychological therapies limited and, as a consequence, is becoming increasingly restricted. A clinical psychologist told us:

> "Our experience has generally been that individuals have received limited psychological therapy, often not having had access to an adequate psychological assessment to determine the need for psychological therapy."

152. In written evidence, Cardiff and Vale University Health Board stated that:

> "Access to Psychological therapies in CAMHS is extremely limited and does not comply with NICE guidelines for common conditions".[46]

153. Betsi Cadwaladr UHB stated:

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[46] Written evidence, CAM24

> "In BCU we deliver training in CBT[47], DBT[48] and Family therapy but there is a gap in the provision of child psychotherapy and therefore we cannot fully respond to the NICE guideline for depression."[49]

Prescription medication

154. In written and oral evidence, psychologists expressed concerns that children with behavioural difficulties were being prescribed drugs without exploring strategies that could be used instead of, or at least alongside, medication.

155. A group of Clinical Psychologists from across Wales said that "medication is also being seen as a frontline approach, partly because of the lack of availability of Clinical Psychologists, other therapists and psychological therapies such as family therapy".

156. Dr Rachel Williams referred to medication as being seen as "an easy solution" and told us:

> "It is probably a scandal that we will look back on in 20 years' time and think, 'What were we doing to our children?' Obviously, the effects of drugs on a developing brain are massive and frightening, but also, psychologically, what are we teaching our children? Are we teaching them that their behaviour and their mood can be controlled only by drugs? That is a really frightening message to give to our young people, and we do not know what the consequence of that will be."[50]

157. Several young people referred to being given prescription drugs rather than the help they wanted, such as talking therapies. One young person told us:

> "My GP put me on medication aged 14 – when I wanted to try talking therapies first."

158. During the scrutiny of the Draft Budget 2014-15, the Committee wrote to the Minister referring to the fact that in the previous financial year,

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[47] Cognitive Behavioural Therapy: a form of talking therapy which aims to help people manage problems by the way they think and behave.
[48] Dialectial Behavioural Therapy: a psychological therapy for people with borderline personality disorder (BPD), especially those with self-harming behaviour or suicidal thoughts.
[49] Written evidence, CAM23
[50] Oral evidence, 2 April 2014

£880,000 had been spent on the two drugs that are most often prescribed for young people identified as having ADHD. We asked for further information on the work the Welsh Government is undertaking to monitor the increase in uptake of such medication and to evaluate the causes or reasons for such increases. The Minister told us that officials routinely monitored prescribing patterns for all medicines but had not commissioned specific work to evaluate the causes or reasons for increases in medication to treat ADHD. The Minister committed to undertake further analysis of prescribing trends over the past three years.

159. In April 2014, the Minister told the Committee that work had been done to analyse prescribing trends for children and young people and that "issues of confidentiality and consent" have emerged which means that "it is likely to be necessary to commission a separate analysis" by October 2014.

Minister's evidence

160. Responding to questions about the suitability of clinic-based services, the official accompanying the Minister told us that "new community intensive treatment teams being rolled out across Wales". She said that "all of the new ones are planned to be extended hours, so they will work a little bit later and they will be available at weekends".

161. The Minister subsequently wrote to us referring to the establishment of community intensive treatment teams and said:

> "I see these as central to the future development of specialist CAMHS. Evidence shows that community based treatment could reduce admission rates and length of stay for severely ill adolescents. Research is increasingly endorsing the benefits of assertive outreach and supports the need for the development of local partnership arrangements across agencies. This is in line with prudent healthcare and wherever possible, when risk allows, young people should be cared for in the community as near to home as possible. Young Minds research shows that young people and families want CAMHS to be delivered flexibly and in a variety of settings including youth clubs, and the home."[51]

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[51] Letter from the Minister for Health and Social Services

162. Referring to children and young people being discharged from specialist CAMHS if they did not attend an appointment, the Dr Watkins told us:

> "We have stopped that. As that was an issue that the WAO raised, the delivery unit audited that and will be re-auditing it. So, in terms of the did-not-attend policy, we are insisting that services make sure that they examine why somebody has not attended, because it is critical that we do not discharge people just because they have not turned up. Services are being expected to audit that, and to make sure that they are also reaching out more."[52]

163. In respect of inappropriate admissions to adult or paediatric wards, Dr Watkins told us:

> "We are looking at inappropriate admissions guidance quite closely. We know that we have to get it right for young people. It is possible that a 17 and a half year old who needs an admission has the capacity and is able to make a choice as to where they feel would be the better place. So, broadly speaking, we need to be sure that young people are placed on children's wards whenever possible and appropriate, and we recognise and count those instances where it is inappropriate. We also need to be sure that older children are allowed to express their right in law to be able to say where they want to be."

164. In relation to out-of-area placements, Dr Watkins said:

> "For the first quarter of this year, the number of out-of-area replacement referrals was just three. We are anxious to watch that that trend continues for the rest of the year. It does not happen that, today, you make a decision that you are going to increase an occupancy rate and it happens within a week or a month. You have to staff the unit up, et cetera; you have to get the appropriate referral in. It takes time to work through."[53]

165. When asked about access to psychological therapies, the Minister said

[52] Oral evidence, 17 July 2014
[53] ibid

"There is no dispute that we are not yet able to provide psychological therapies on the scale that we would like to see in Wales."[54]

166. He went on to say:

> "The report that the Welsh Government commissioned that was published last year demonstrated that. We were able to find some money last year; we found £635,000 this year for investment in psychological therapies. It has to be on the basis not that we are going to be able to employ a huge new cadre of people, but that we use the people who are already in place and give them the skills and the abilities they need to be able to deliver psychological therapies. We are very clear that a proper proportion of that money needs to be provided in the CAMHS side of mental health, as well as in other areas of demand."[55]

167. The Committee subsequently wrote to the Minister asking how much of the £635,000 invested by the Welsh Government in psychological therapies has been spent on therapies for children and young people. The Committee was informed that:

> "We are expecting plans for the use of the psychological therapies funding by LHBs to be submitted at the end of August. We have been clear that funding should be equally distributed across service users of all ages in accordance with the local population's age profile. Plans must be agreed by the local Psychological Therapy Management Committee (which includes CAMHS representation) prior to submission."[56]

The Committee's view

Our view:

168. In relation to the structure and delivery of CAMHS, the Committee is concerned about the following issues:

- The appropriateness of clinic-based services as the model of provision for specialist CAMHS;
- Arrangements for the provision of CAMHS on an emergency basis;

[54] Oral evidence 17 July 2014
[55] ibid
[56] Letter from the Minister for Health and Social Services

- Whether availability of in-patient provision is adequate and the need to avoid expensive out of area placements which potentially add to the pressure on young people and their families;
- The transition from child to adult services;
- Access to psychological therapies; and
- The levels of prescribing of medication for children and young people with mental health problems.

Annexe A – Written evidence

The following people and organisations provided written evidence to the Committee. All written evidence can be viewed in full at: www.senedd.assemblywales.org/mgConsultationDisplay.aspx?ID=109

Organisation	Reference
Jason Hughes	CAM 01
Conwy County Borough Council Children's Services	CAM 02
North Wales Department of Psychological Medicine	CAM 03
The Neath Port Talbot (NPT) Looked after Children's Health Team	CAM 04
Julie Wallace – Principal Child & Adolescent Psychotherapist	CAM 05
Social Worker, Adoption Team, Caerphilly	CAM 06
Service User	CAM 07
NCN lead Caerphilly North ABUHB	CAM 08
Practice Manager, Markham Medical Centre	CAM 09
Dr Maddie McCulloch – Principal Clinical Psychologist	CAM 10
Service User	CAM 11
Service User	CAM 12
Estyn	CAM 13
Rachel Williams – Consultant Clinical Psychologist	CAM 14
Dr C Grantham GP	CAM 15
The National Deaf Children's Society	CAM 16
Dr Penny Goss on behalf of Greenhill Special School, Bryn Y Deryn PRU and The Court Special School	CAM 17
Pembrokeshire Coast National Park Authority	CAM 18
Royal College of Paediatrics and Child Health Wales	CAM 19
Dr Elspeth Webb – Reader in Child Health – Cardiff University	CAM 20
Cardiff and Vale of Glamorgan Community Health Council	CAM 21
Llamau	CAM 22
Betsi Cadwaladr University Health Board	CAM 23
Cardiff and Vale University Health Board	CAM 24
Applied Psychologists in Health National Specialist Advisory Group	CAM 25

Mental Health Directorate - Abertawe Bro Morgannwg University Health Board	CAM 26
Torfaen Flying Start Service	CAM 27
Prospects for Young People	CAM 28
Children’s Commissioner for Wales	CAM 29
Rhondda Cynon Taf Children Services	CAM 30
Conwy BIG Community Voice	CAM 31
General Practitioner	CAM 32
Royal College of Psychiatrists in Wales	CAM 33
Welsh Language Commissioner	CAM 34
Vale of Glamorgan Youth Offending Service	CAM 35
Action for Children	CAM 36
Hafal	CAM 37
YOT Managers Cymru	CAM 38
Royal College of Nursing Wales	CAM 39
Integrated Youth Services, Wrexham County Borough Council	CAM 40
Dr Charles Twining OBE	CAM 41
NSPCC Cymru / Wales	CAM 42
Youth Justice Board Cymru	CAM 43
Public Health Wales	CAM 44
British Association for Counselling and Psychotherapy (BACP)	CAM 45
Western Bay Safeguarding Children Board	CAM 46
Dr Mike Davies	CAM 47
Neath Port Talbot Council for Voluntary Services	CAM 48
Cwm Taf Local Health Board	CAM 49
Association of Educational Psychologists	CAM 50
Afasic Cymru	CAM 51
Diverse Cymru	CAM 52
Hywel Dda University Health Board	CAM 53
Group of Clinical Psychologists	CAM 54
Adoption UK	CAM 55
Child & Women’s Health at ABMU	CAM 56
Dr Rachel Ann Jones C Psychol AFBPsS	CAM 57
Children in Wales	CAM 58
SNAP Cymru	CAM 59

CAMHS Clinician working in South Wales	CAM 60
The Team Around the Family (TAF) Team	CAM 61
Barnardo's Cymru	CAM 62
Flintshire County Council	CAM 63
Service User	CAM 64

Annexe B – Oral evidence

The following witnesses provided oral evidence to the Committee on the dates noted below. Transcripts of all oral evidence sessions can be viewed in full at:
www.senedd.assemblywales.org/ieIssueDetails.aspx?IId=8676&Opt=3

Date	Witness / Organisation
19 March 2014	**Royal College of Psychiatrists in Wales** Dr Clare Lamb, Consultant Child and Adolescent Psychiatrists, Lead for Policy and Parliamentary Liaison, Royal College of Psychiatrists in Wales Dr Alka S Ahuja, Consultant Child and Adolescent Psychiatrist - Anuerin Bevan University Health Board and Chair, Faculty of Child& Adolescent Psychiatry, Royal College of Psychiatrists in Wales
	Barnardo's Menna Thomas, Senior Research and Policy Officer Sarah Payne, Service Manager for the Cadarn Service in Cardiff
02 April 2014	**Association of Educational Psychologists** Mary Greening, Welsh Representative Claire Leahy, Educational Psychologist
	Applied Psychologists in Health National Specialist Advisory group Rachel Williams, Head of Psychology in Aneurin Bevan Health Board
17 July 2014	**Welsh Government** Mark Drakeford – Minister for Health and Social Servcies Dr Sarah Watkins – Senior Medical Officer Jo Jordan – Director of Corporate Services & Partnerships

Annexe C
Summary of young people's evidence

Why the Children, Young People and Education Committee needed your help

The Welsh Government has lots of plans and policies in place to try and make sure that children and young people get help with emotional and mental health problems when they need it. These services are called Child and Adolescent Mental Health Services . Sometimes these are called 'specialist CAMHS';

- The Children, Young People and Education Committee decided to take a look at whether these plans and policies are working.
- We wanted to meet with children and young people to ask what they thought.
- We've also asked lots of adults to tell us their views – some of them wrote to us and some of them came to meet with us face to face to tell us what they thought.

We heard from more than 20 young people aged 12-24 from different parts of Wales. The main things we found out were:

- Most young people we spoke to were very negative about specialist Child and Adolescent Mental Health Services (CAMHS). A few said they had a good experience.

Some of the things which young people told us which weren't good were:

- Young people not getting the help they needed
- Young people waited too long to get any help - this made their mental health problems worse
- The rules were very 'strict' for which children and young people got help from CAMHS
- Being given medication without other types of help (like talking therapies)
- CAMHS services not helping young people to be safe
- CAMHS services not helping young people who have lots of things to deal as well as mental health issues

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–When young people reached 18 things didn't work very well to link up children's and adult services.
–Some young people who had been in special hospital units didn't get the help they needed when they were there

Some things which young people said did help were:

–Help from the voluntary sector and projects run by charities
–Having a good relationship with staff and that it's really important to build trust with people who are there to help
–To be given help which makes young people better able to deal with things by themselves

A bit about the young people who helped us

–We met with more than 20 young people aged 12-24

–One young person made a DVD to tell us her views

–Most lived in different parts of South Wales and some lived in North Wales

–All the young people had mental health problems (either now or in the past) and all had some kind of service from or contact with Child and Adolescent Mental Health Services ('specialist CAMHS')

–We didn't ask young people about the details of their medical circumstances but some young people shared their stories. These include lots of different mental health issues.

–Some examples were severe anxiety; autistic spectrum disorder; asperger syndrome; sudden onset bi-polar disorder; depressive disorders and eating disorders.

–Some of the young people had been involved in self-harm, including some young people who had made several suicide attempts.

–Some of the young people had stayed in a specialist hospital unit in the past (an inpatient unit'). A young person (now living in the community) had been an inpatient at various mental health units for 9 years.

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–Lots of the young people had other things which might make their lives more stressful - like having been in care; being the victim of sexual abuse; experiencing the death of a parent; being a young carer; being the victim of violence within the home; having a parent with mental health problems; having a disability. One young person told us she was pregnant and happy that she would now be able to focus on her baby.

What did we find out?

–Most young people were very negative about specialist Child and Adolescent Mental Health Services.

–They said they either hadn't got any help at all - or if they had, it had been from what are called voluntary projects. Voluntary Projects are not the same as councils and governments – lots of them they are paid for by charities.

A few young people had good things to say

–Some young people said that it would cost the Government a lot less to give them the right help when they needed it.

–One young person said: **'if we thought about what people needed – it would end up saving money'.**

–Young people told us they had felt scared, embarrassed, and unsafe.

–Some young people said that CAMHS services are too structured and 'strict' for young people who might have a lot going on and 'chaotic lifestyles'. Those young people said that services should be set up around what children and young people need - not between the times of 9 and 5 in a clinic or hospital.

–Some young people told us how they had lots of problems to deal with all at the same time – like having more than one mental health issue; being victims of domestic or sexual abuse; being a victim of sexual exploitation; having problems with substance misuse; not many qualifications; no money; and not being given enough help.

–Other young people had done really well at school in the past but their mental health problems were affecting their education. Some schools had been really good in helping

young people with their mental health problems but others were not so good or had not 'picked up' that children needed help.

Some of the things young people told us were:

'CAMHS is rubbish'

'CAMHS is useless – to make it better you need to start again'

'Why is the Government funding CAMHS like it is now? Let's just give up on these mental health services – they ain't no good'

'Why fund statutory services when other services work better'

'CAMHS needs a lot more staff and a lot of reorganisation of their policies and procedures'

'CAMHS were not very helpful – they were more interested in what my mum had to say than in me'

'They just passed you on to other people'

'CAMHS is just about ticking boxes'

'They are not meeting young people's needs'

'Don't treat us as freaks'

'You just need to help young people understand their minds'

'I wanted help to understand why my childhood sucked'

'Therapy helps – like mindfulness and emotional wellbeing help'

'CAMHS didn't really make a difference'

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'Politicians should extend the period of time for young people to access services – they should fund things better'

'Why do we need to have scars on our arms to remind us?'

'The way I was treated made me angry'

'CAMHS asked lots of questions but didn't listen'

'I self harmed at the CAMHS session' and the young person said they also self-harmed and drank heavily after every contact with CAMHS

'[CAMHS] told me I am supposed to be getting therapy – I don't trust that it will be delivered'

'CAMHS should work with you how you want to work'

'Waiting lists are too long – they need more staff'

'Your childhood is gone'

'Some schools just seem to want to get rid of difficult kids'.

'I want help where there are no hoops to jump through – high quality help and people who can work with my family'

Young People from one project were more positive about their experiences with a specific psychiatrist and with the help they had received from a voluntary project.

'My psychiatrist is good. I didn't have to wait long to be seen because I was a high priority'

'I've had a good experience of CAMHS – it feels like going to the doctors'

'CAMHS help you understand and deal with a condition'

'Getting into CAMHS is hard – but one you are there it is completely tailored to your needs'.

Getting help when you need it

–Lots of the young people we spoke to found it very hard to get any help from specialist CAMHS. One young person told us that CAMHS support is not flexible. Another told us that times for group therapy were very strict.

–They thought there were very 'strict rules' (criteria) for people to get help. Some had gone to their GPs many times asking for help.

–Others felt their mental health problems had got worse because they hadn't had any help when they first needed it.

–Lots of young people had waited a long time for help. Some young people told us they ended up having to go into a hospital mental health inpatient unit because they didn't get help when they first needed it.

'I went back and forth to GP for years but got no real help'

'It's too long to wait to see CAMHS – why can't they help you from the start'

'I've been told I don't meet the threshold for CAMHS'

–One young person said she had told the GP she was suicidal in May but had to wait until December for a CAMHS appointment and by then she was nearly 18 so needed to go to adult services.

–Some young people who had been in care told us – 'we've all seen things we shouldn't have seen and got no help with it'

Trust in staff

–Some of the young people spoke about adults who had helped them a lot with their mental health.

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–Being able to trust and have a good relationship with professionals was really important.

–In one project young people had been given a lot of help by a clinical psychologist who worked there. They felt that she had helped them a lot – when CAMHS services had not.

–In another project, young people told us about how important it was to have good relationships with people who helped with their mental health – and said really positive things about project staff who they felt had helped them a lot.

–They also explained they didn't always trust some staff they had met through CAMHS – because they didn't do what they said they would - or because they were just 'ticking boxes'.

– One young person referred to needing more help from school and for them to understand.

– One young person talked about the time her project support worker had taken to get to know her. This was a lot more time than she had from CAMHS.

–One young person who had faced lots of difficulties in her life including sexual exploitation and a parent misusing substances told us it takes a long time to trust people. She said **'I am not good at talking – they expect you to chat straight away' […] 'then they send me to a different person – I have to say it all again'**. Her support worker explained that she had four different CAMHS workers in the past 6 months.

Crisis / Accident and Emergency

–Many of the young people had been taken into hospital accident and emergency (A&E) more than once after self-harming or overdosing.

–Some young people told us that they had attempted suicide but that this didn't seem to make them eligible for help from CAMHS.

–Some young people had their first contact with CAMHS after being taken to A&E but some had been sent home from A&E with no support.

'CAMHS are here in a crisis and then they are gone'.

'It's all 9-5 and you can't get any help outside these times'

Whether CAMHS make sure young people get services

–One young person who had experienced trauma after an already difficult childhood had received one phone call from CAMHS and had not heard from them again, 'even though they promised to call back'. The young person said **'five years on and I am still waiting for them to call me back – even though I found my dad dead on the floor – it's not right'.** She had since received support from a project which provides mental health support to young people leaving care.

–One young person told us that they had missed appointments: 'I didn't go to CAMHS as my mum never took me'**.**

–Another young person told us **'If I don't keep appointments I get struck off'.**

Prescription medication

–Some of the older young people felt they had been given prescription medication and nothing else when they went to their GPs for help'.

–Quite a few young people told us they were offered strong prescription medication by specialist CAMHS rather than 'talking therapies' or other things that might have helped.

'My GP put me on medication aged 14 - when I wanted to try talking therapies first'

'I was put on medication aged 13'

'Take time to build a relationship with us – don't prescribe medication'

'They just give you prescription drugs'

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Inpatient units

–A few of the young people we spoke to who were now getting help from voluntary projects had, in the past, been in-patients in mental health units.

–Two young people had been sent to units outside Wales.

–Some of the young people had been on adult wards or general paediatric wards.

–One young person we met had been in hospital for 9 years. The young person was now getting a lot of support outside hospital and said **'if I had had it sooner I could have lived in my own community**'.

–One young person reported a very bad experience of an inpatient unit saying **'some of the staff spent the whole time chatting in the office – saying they couldn't wait to get home – it didn't make me feel they wanted me there'**.

– Of the young people who had been inpatients, some told us they felt they were being 'institutionalised' and being 'held' there until they were old enough to leave.

–Two of the young people had experienced 'unplanned recall' where they had been moved suddenly to a different unit. They thought this was because it would save money not because of medical reasons.

'Instead of getting help we were just given a false sense of reality in residential units';

'They just 'hold you' in inpatient units until you are 18'.

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Voluntary Sector

–Voluntary Projects are often paid for by charities and some of them are set up to help children and young people. They are not the same as councils and governments.

–All the young people we met said very good things about the mental health support they had from the voluntary projects. Lots of the young people felt they had been given the right help with their mental health in this way.

–Young people told us that it was important to have the same support worker to help with mental health issues.

–In one project, the young people had lots of help from a clinical psychologist. She had run programmes to help young people and they were now able to help themselves much more when they had problems.

–In two of the projects we visited, the five year funding from the lottery was coming to an end. The young people were very upset that these projects were closing or parts of them were closing. They said that the only services that had helped them were coming to an end. Some of the young people were very angry about this.

'It is wasn't for Skills for Living Project we would have got no help';

'[Voluntary services] help you to make friends with people who are in the same position as you'.

–Moving from children's to adult services: For the young people who were nearly 18 or close to that age, they told us things didn't work very well to link up children's and adult services.

–One young person who was reaching 18 told us she kept asking CAMHS what would be happening next – but she told us she still didn't know. Other young people told us they had contact with CAMHS for over 10 years and suddenly 'dropped out of the system' at 18.

THANK YOU

Thank you to the office of the Children's Commissioner for Wales for helping to organise the meetings.

A big thank you also to the organisations that helped us to meet with the young people:

– Hafal
– Action for Children Skills for Living Programme
– Action for Children Family Intervention Team Caerphilly
– Barnardo's Cyfle - Children and Young People Substance Misuse Service (Conwy and Denbighshire)
– Barnardo's Cyfle – Young People's Advisory Service
– Barnardo's Caerphilly Young Carers Service

Some Assembly Members also visited Ty Llidiard Centre, Princess of Wales Hospital.

Most of all we're very grateful to the young people who gave their time to speak to us – **THANKS!**

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Annexe D

A summary of evidence from parents and carers

Below is a brief summary of the informal evidence sessions held with parents and carers. Over 25 parents and carers self-selected to take part in the informal sessions after being contacted through organisations that had already submitted written evidence to the inquiry.

Where relevant, we have directly quoted comments that were made to Committee Assembly Members during visits and informal evidence sessions.

Nature of mental health issues experienced

Those attending the parents/carers session and the young people's session were not asked to provide full detail of the child's medical circumstances. We did however learn that they included a wide range of mental health issues including **Obsessive Compulsive Disorder (OCD), severe anxiety, Autistic Spectrum Disorder, Tourette's Syndrome, Asperger, Bi-Polar disorder, Attention Deficit Hyperactivity Disorder (ADHD), Dyspraxia and Eating Disorders**. Many of the young people had been involved in **significant self-harm**, including some young people who had made several suicide attempts. Many of the young people had additional issues which compounded their situation such as being a formerly looked after child; experiencing sexual abuse; experiencing the death of a parent; being a carer; having a parent with mental health problems; or having a disability.

Emerging themes

The majority of parents and carers reported a very negative experience in respect of specialist CAMHS with two of the parents stating they had a mainly positive experience. Given that parents had self-selected to take part in the informal sessions, their evidence is more likely to reflect issues and problems with CAMHS.

Access- referrals and waiting times: Comments included: referrals being rejected 'without explanation'; several cases where GP referrals were rejected by specialist CAMHS without them seeing the child; major difficulties in accessing any support; parents fighting hard to get support; professional parents with medical backgrounds being successful in getting a referral re-assessed and accepted – 'what about parents who can't do that'; having to go through many months of 'box-ticking' to access CAMHS; CAMHS not providing specialist support e.g. to deaf children; 'it all hinges on the diagnosis'; very little or non-existent support. Parents having to advocate and lobby for services – and most of them still feeling in a crisis and not getting the services they need; problems being re-referred back into CAMHS.

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Several parents had sought input from private services. A psychologist working with some young people at one project told us of a 19 month waiting list to receive support from specialist CAMHS in their area. In another area we were told by a professional that the waiting list was 16 months.

Specific quotes included:

- 'Children and young people don't get seen until there is a crisis and often not even then';
- 'It's like the process is designed to filter people out';
- 'I've been back and forth to the GP since my child was aged 5';
- 'They are just looking for excuses not to take on a case;
- 'CAMHS rejected my son's referral without even seeing him – it's very frustrating';
- 'The onus shouldn't be on the parents to fight for services';
- 'Everything is crisis driven - we had to do 'a sit in' and refuse to leave accident and emergency so my daughter could get help';
- 'It's been a roller-coaster trying to get any help – I work in the NHS and I still find it very hard to signpost my son to the services he needs;
- 'Children just sit on a waiting list all the time';

Support provided: Comments included: very long gaps between seeing psychiatrists; services being delivered through a narrow medical model and a lack of access to talking therapies; children getting a diagnosis but no support; the difference between how physical health issues are dealt with compared to mental health services; One mother (who was not able to attend the informal session on the day) had asked workers at Hafal to tell Assembly Members that her daughter had been placed in Northampton and that this placed a big strain on everyone in the family as the mother could not drive. 'Clinic based services not meeting children's needs', nor the time they are open to help – some mental health conditions have more of an impact in the night.

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Specific quotes included:

- 'CAMHS say 'here is your diagnosis – goodbye' – why is mental health treated so differently from physical health;
- 'The service is on the verge of collapse';
- '[There is] a significant gap in services at times of crisis';
- 'CAMHS seem to 'wash their hands' of children and young people'.

Staffing: included many comments about staff shortages; there being no cover when staff go on leave or move to other roles; not enough staff or staff cover; when CAMHS staff are called to emergencies then other children miss their appointments; 'skeleton staff' – can't offer family or play therapy. Because there are no staff and limited resources – parents and carers are bridging the gap. 'CAMHS staff are not always experts'; CAMHS staff knew little more than the parents about the condition.

Transition to adult services: comments included 'There is no transition at all'; 'it's completely up to me to do it all over again'; 'my daughter will be 18 soon and I keep asking what's happening?'

Impact on family: comments that Assembly Members heard included: the 'devastation' on the family and the impact on siblings; 'violence' from the child towards parents and siblings, and this becoming more frightening as children get older. 'My child is aggressive because of their mental health issues being untreated and both parents are now on medication because of the stress'. I feel that no-one wants to help. Some parents told us they felt patronised and almost blamed for child's problems; 'I've been made to feel part of the problem – and I want to be part of the solution'; parents are not given the information they need to help their children and in some circumstances resulting in them unintentionally making the situation worse. CAMHS questioned our parenting and discipline; 'I despair for the future'. Several parents reported getting no support or respite care. One family had spent 'tens of thousands' trying to access services since their child was very young – via solicitors, private medical assessments etc – their child has ended up in an inpatient unit aged 15.

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Parents told Assembly Members: 'Social services only get involved when parents are violent to children - they won't help families when children and young people are violent to parents and siblings'; 'when I restrained my son, social services investigated'; parents worried about the future and what the teenage years will bring; my son is violent to us - his sister is afraid – I have had treatment from my GP because my child has damaged my jaw and has also split my daughters lip – if it was my partner that did it I would get help - 'my son will kill himself or someone else – I can guarantee it'. We are treated by CAMHS as though we are part of the problem. 'I wanted advice regarding whether I should hide knives from my suicidal daughter – CAMHS made me feel like I was just being difficult'; several parents were or had been off work sick. 'There is no support for parents, carers and siblings'.

Impact on children and young people: comments to Committee Members included: our children are missing 'valuable' years of their lives – school, friendships (social isolation); impact on physical health (weight loss); long waiting times to get help – wasted years e.g. from 5 to 12; parents 'pushed from pillar to post' and in the meantime 'no-one is helping my son'; because my child was well behaved in school, she didn't get help – even thought she was suffering in silence and ended up in an inpatient unit after several suicide attempts'; when young people are admitted into a specialist unit whether for children or adults, they are just 'held there' rather than receiving treatment; children are told their 'self-harming is not bad enough' to qualify for a service.

Funding / Preventative spend: Several parents noted that their child's care could have 'cost a lot less' if they had received the services they needed earlier – both emotionally and financially. 'My daughter was recalled abruptly from a specialist unit in London for financial and not medical reasons'; 'We have spent tens of thousands as a family' and the cost to the health service would be substantially higher in the end as the young person has ended up in an expensive placement outside Wales.

Schools: There were mixed experiences on the effectiveness of schools and educational psychology services. In the main, families felt their experiences were negative. Parents/carers felt that schools did not have the skills, experience or understanding in respect of children's mental health issues or accessing CAMHS. 'Teachers don't have training', '[my son was] treated as a naughty boy'; 'the secondary school is amazing, but the primary school were appalling'.

Social Services: Comments included: CAMHS don't have any social work support; there is a battle going on between Social Services and CAMHS as to who was responsible for my child; I had to take my son to Social Services aged 15 and leave him there before I got any response or support.

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Voluntary sector / wider support services: Several parents/carers had received very positive support from parenting support groups, but many said that they had found these themselves and there was no signposting had been offered by CAMHS. 'Families have to find this out for themselves'. Third sector projects outside specialist CAMHS were felt to have 'really helped' a number of parents. Many of these voluntary sector courses / projects had either ended or were about to end due to lack of funding.

Communication/ Co-ordination: Comments included that there was no inter-agency communication and it needs someone other than the parent/carer to co-ordinate the care. 'You need a multi-disciplinary team'; 'there is a lack of communication'.

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