



CYNGOR IECHYD CYMUNED  
COMMUNITY HEALTH COUNCIL

BWRDD CYMRU | WALES BOARD

## **Managing the transition from children's to adults' healthcare services**

CHCs are the independent watchdog of NHS services within Wales and we seek to encourage and enable members of the public to be actively involved in decisions affecting the design, development and delivery of healthcare for their families and local communities.

CHCs seek to work with the NHS, inspection and regulatory bodies to provide the crucial link between those who plan and deliver the National Health Service in Wales, those who inspect and regulate it, and those who use it.

CHCs maintain a continuous dialogue with the public through a wide range of community networks, direct contact with young people, patients, families and carers through enquiries, our Complaints Advocacy Service, visiting activities and through public and Patient surveys. Each of the 7 CHCs in Wales represents the "Patient voice" within their respective geographical areas.

CHCs routinely monitor the performance of NHS services in their area as well as respond to service developments and changes.

Community Health Councils (CHCs) across Wales are pleased to have received the consultation document 'Managing the transition from children's to adults' healthcare services' and been provided with an opportunity to share their comments.

CHCs have undertaken a number of pieces of work involving children and adult mental health services over the past three years.

An example is that in November 2017, the Board of CHCs provided a positional paper on Children and Adult Mental Health Services CAMHS in response to the National Assembly for Wales Children, Young People and Education Committee Inquiry into **The Emotional and Mental Health of Children and Young People.**

One of the comments in that paper indicated:

**“Transition to adult services continues to be a significant issue, and CHCs continue to hear from young people who do not feel that their transition was properly supported.”**

In 2018, Aneurin Bevan CHC undertook a review of data from its advocacy and enquiries service. This sought to determine what the key issues with the CAMHS had been over the previous two years.

The survey revealed that these included:

- Communication
- Support while waiting.

Our work with young people indicate that adolescents with mental health problems often require transition of care from child and adolescent to adult mental health services. The literature indicates that, adolescence is a risk period for emergence of serious mental disorders. To date child and adolescent mental health services and adult mental health services use rigid age cut-offs to delineate service boundaries, creating discontinuities in provision of care. Adolescent mental health services have been described as being are patchy. Several recent studies have confirmed that problems occur during

transition in diverse settings. In physical health, there are emerging models of practice to improve the process and outcomes of transition, but there has been very little comparable models for mental healthcare.

Another important aspect of transitioning from child to adult services is deals with gender identity issues. The only centre offering gender identity treatment to young people in England and Wales - which have seen a sharp rise in recent years, is the Tavistock Clinic in the Tavistock and Portman Trust in London. About 2,000 children and young people were referred there through the NHS in 2016/17 - an increase of 42% on 2015/16. The increase in referrals from Wales was 79%.

Since April 2019, a new Adult Gender Identity Service set up in Wales has been commissioning by the Welsh Health Specialist Service Committee (WHSSC). The newly developed Welsh Gender service will include Local Gender teams in each Health Board, was launched in the Cardiff and the Vale University Health Board area in September 2019. The service will only see patients aged 17½ and over. Patients currently on the waiting list to be seen at the London Gender Identity clinic are currently waiting 26 months to be seen. Welsh patients can expect to also wait 26 months to be seen in Cardiff. It is hoped that this waiting time will reduce.

CHCs work actively with this initiative, has a representative on the Wales Gender Identity Group, and actively participate in developing the service.

It is hoped that the introduction of the principles of the transition process as indicated in the consultation will underpin the delivery of individualised care to plan and deliver the move from children to adult services.

In the main, CHCs feel that the guidance seeks to address the typical issues that children and young people have encountered whilst transitioning into adult services in the past. It is therefore immensely valuable for that reason. The CHC consultation response form is appended below.

**Consultation  
Response  
Form**

Your name: **Desmond Kitto**

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**Consultation questions**

<p><b>Q1.</b></p>	<p><b>Is the guidance clear as to the management of Transition and Handover within the Health Board?</b></p> <p>Children and adult mental health services, especially the specialist Child and Adolescent Mental Health Service (CAMHS) have been scrutinised by Community Health Council (CHC) for many years. The significant struggles commonplace across Wales have been identified as long communication, waiting times, difficulties accessing the service and transition for children to adult services. Therefore, CHCs welcome this consultation and appreciate the opportunity of responding to its contents.</p> <p>The consultation documents were circulated to all the 7 CHCs in Wales and the consensus was that they were clear and concise. One comment received indicated, <b>'I have read this document and it certainly has elements of clarity which is an improvement on what was available.'</b></p> <p>Therefore, in the main, the guidance appears both clear and comprehensive, covering all areas of transition from child to adult services. It was easy to understand and follow from an adult perspective. It is also noted that the Children and Young People's version of the consultation is well prepared and appreciated.</p>
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Equality, empowerment, human rights and participation are values at the very centre of the CHC movement in Wales. We also welcome the section on accountability with its emphasis on the importance of collecting data and service user feedback on transition and handover arrangements.

CHCs may also collect feedback but there is a clear obligation for Health Boards to undertake this and to **"...ensure that feedback from the young person is captured so that the voice of the young person is heard and at the centre of care"**

It is also good that it mentions complaints and states **"Health boards/Trusts should ensure that there are adequate arrangements for responding to any complaints made about transition and handover services by young people."**

**Q2. Do you agree with the principles that underpin the delivery of individualised care to plan and deliver the move from children to adult services?**

CHCs agree with the principles that underpin delivery of individualised care.

The inclusion of advocacy support and Putting Things Right to raise a concern as well as the requirement for **"Health boards (to) ensure that the voice of the young person is heard and at the centre of care"** is a positive improvement.

Similarly, we welcome the inclusion of Dispute Resolution and the requirement for Health Board and Trusts to **"have a responsive representations and complaints system to monitor and address any problems in real time, including concerns about prolonged waiting times or clinical delay."**

CHC Advocacy services often support people complaining about treatment delays. A review of the data was undertaken in 2018 where the CHC was able to determine the key issues with CAMHS over the past two years. As well as waiting times the key themes were:

- Acceptance of referrals
- Communication
- Support while waiting.

Unfortunately, patterns are often observed in the complaints managed by advocates. Despite this, all complaint responses assure complainants that lessons have been learnt, when things go wrong. It is therefore welcomed that the requirement for Health Boards and Trusts to monitor their complaint data and use feedback to improve services. In the past, feedback received from children and young people has been reported on and CHCs will seek to work with their health boards, post implementation, to feedback what people tell us about how these arrangements are working.

**Q3.**

**Is the guidance clear about the young person's journey on the Transition and Handover process from start through to completion?**

CHCs in the main agree that the guidance is generally clear in these respects. There is however potential for confusion around different age groups; timescale and deadlines around THP and Reviews as well as entitlements – as opposed to what is stated as 'should be done' – are not clear.

One CHC questioned what remedy was there for enforcement or opportunity to ensure recalcitrant LHBs would comply.

<b>Q4.</b>	<p><b>Is the guidance clear about the process for a young person entering the healthcare system for the first time at 16 or 17?</b></p> <p>CHCs feel that the guidance is clear about the process for 16 to 17 year olds.</p> <p><b>If not, please provide details of how this could be improved.</b></p> <p>Additional comments are described in the CHC response to Q.6 below.</p>
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<b>Q5.</b>	<p><b>We would like to know your views on the effects that the draft Transition and Handover Guidance would have on the Welsh language, specifically on opportunities for people to use Welsh and on treating the Welsh language no less favourably than English.</b></p> <p><b>What effects do you think there would be? How positive effects could be increased, or negative effects be mitigated?</b></p> <p>The requirement to treat Welsh patients no less favourably than their English equivalents would require Health Boards to ensure that they have Welsh speakers or translators for both children and adult services. The CHC movement often hear of from non-English speaking patients of delays in arranging translation. We are also aware that not all Health Boards are currently meeting the requirements of the Welsh Standard. It is important to ensure that young people do not experience delay in treatment due to a lack of robust translation service arrangements, as this would negatively affect transition and ongoing care.</p>
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Some CHCs have previously engaged with children and young people extensively in respect of mental health services. Some parents informed CHCs that they felt the transitioning process to be excessively protracted, as there was the necessity for a new assessment that negatively affected the continuity of their child's care.

Some parents did not agree that their child could go into an appointment without them if they so wished. Such parents felt that not being allowed to go with their child made it very difficult to manage their ongoing care at home. It is therefore important to accurately assess a child's capacity to include their ability to manage their own treatment at home.

**Q6.**

**We have asked a number of specific questions. If you have any related issues which we have not specifically addressed, please use this space to report them**

1. Paragraph 2.3 refers to, **"Where care and treatment arrangements amount to a deprivation of liberty of the young person, the relevant Deprivation of Liberty Standards or Liberty Protection Standards (DOLS/LPS) or other procedures should be followed to lawfully safeguard their wellbeing whilst giving due regard to their human rights."**  
CHCs feel it is important to describe the limited situations when DOLs would apply to people under 18s.
2. Paragraph 4.13 states that **"If considered necessary, a named worker should be identified that will work with the young person and their family to help coordinate services."**  
The question is; considered by whom? Can a young person insist on this provision? This section might need further clarification.

2. It is felt that the THP as Passport is a great idea – it would however benefit from inclusion of timescales/deadlines for completion and review (in addition to review at age 16). The appointment of a relevant professional, as THP Coordinator might also benefit from an indication of a deadline of some sort. THP (Appendix 3) – includes young person input of key health needs – this might benefit from professional clinical summary of health needs/ treatment regime/ medication/ contraindications etc. This would ensure that its function extends to communicate to clinicians in all settings.
4. Paragraph 5.2 states that the named worker has the responsibility to convene a review meeting for this 'rising 16 THP' – but guidance - will be in place only when 'considered necessary'. This allows for a potential gap of responsibility to convene review.

The Guidance places an emphasis on under 16's review requirements but for 16/17 year olds THP reviews are not included. The guidance might also benefit from further clarity about how it extends to **'children and young people to age 25.'**

That said, CHCs feel that the guidance seeks to address the typical issues that children and young people have encountered transitioning into adult services in the past. It is therefore immensely valuable for that reason.

In January 2017, the Board of CHCs produced a positional paper in response to the National Assembly for Wales Children Young People and Education Committee Inquiry, into The Emotional and Mental Health of Children and Young People. One of the recommendations was that 'Clearer and more consistent reporting of performance is needed to better facilitate such scrutiny by the Health Boards themselves and by those who use and monitor the NHS. It is hoped that the proposed managing transition from children's to adult healthcare services will support this recommendation.

Responses to consultations are likely to be made public, on the internet or in a report. If you would prefer your response to remain anonymous, please tick here:

## Contact details



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