Arolygiaeth Gofal Iechyd Cymru
Healthcare Inspectorate Wales

Thematic Report

How are healthcare services meeting the needs of young people?



Review date: 2019

Publication date: 29 March 2019

This publication and other HIW information can be provided in alternative formats or languages on request. There will be a short delay as alternative languages and formats are produced when requested to meet individual needs. Please contact us for assistance.

Copies of all reports, when published, will be available on our website or by contacting us:

In writing:

Communications Manager
Healthcare Inspectorate Wales
Welsh Government
Rhydycar Business Park
Merthyr Tydfil
CF48 1UZ

Or via

Phone: 0300 062 8163
Email: **hiw@gov.wales**
Website: **www.hiw.org.uk**

Mae'r ddogfen yma hefyd ar gael yn Gymraeg.
This document is also available in Welsh.

 WG37493 Digital ISBN 978 1 83876 099 1

Contents

Healthcare Inspectorate Wales (HIW) is the independent inspectorate and regulator of healthcare in Wales

Our purpose

To check that people in Wales receive good quality care.

Our values

We place patients at the heart of what we do. We are:

- Independent
- Objective
- Collaborative
- Authoritative
- Caring

Our priorities

Through our work we aim to:

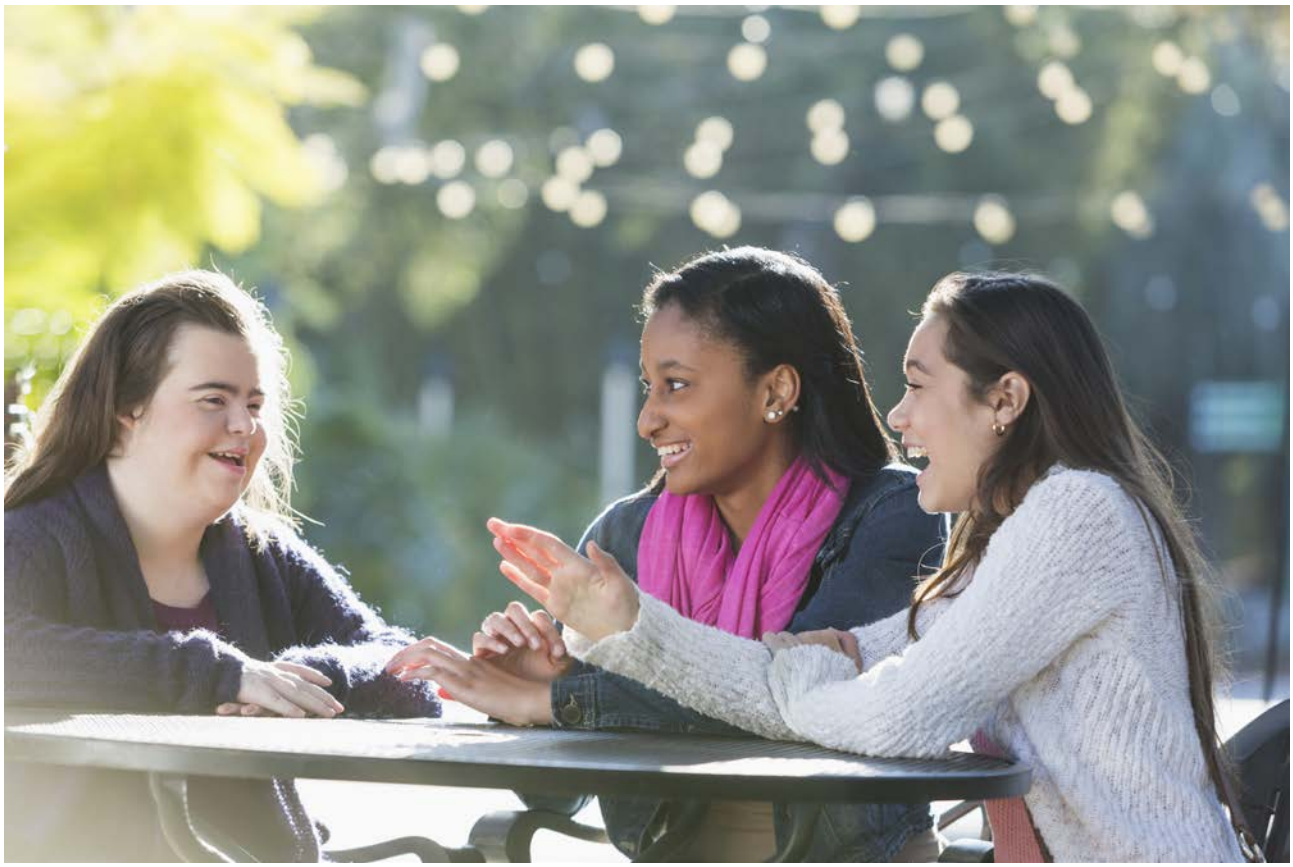
Provide assurance:	Provide an independent view on the quality of care.
Promote improvement:	Encourage improvement through reporting and sharing of good practice
Influence policy and standards:	Use what we find to influence policy, standards and practice

1. Foreword

Healthcare Inspectorate Wales (HIW) committed to undertaking a review of how healthcare services are meeting the needs of young people, including those who need to transition from child to adult services. This work is part of wider thematic work undertaken jointly by Inspection Wales[1]. Our review will contribute to a wider evaluation of services which support young people's healthy development, wellbeing, and access to education and employment.

In conducting this review, HIW has looked back across its inspections over the last two years relating to children and young people, including in-patient Child and Adolescent Mental Health Services (CAMHS), treatment for physical health conditions in hospitals and care within children's hospices. In arriving at our conclusions, we have also considered a range of legislation, strategy, standards, guidance, and reviews.

The intention of this report is to identify key themes, issues and good practice in relation to youth healthcare services. We hope the findings from this review are used to improve services and to inform further work and investigation around the areas we have highlighted.



[1] Inspection Wales consists of the four inspectorates/audit bodies in Wales, Healthcare Inspectorate Wales, Care Inspectorate Wales, Estyn and Wales Audit Office

2. Summary

Within the three in-patient CAMHS units we inspected, it was positive to find that staff worked hard to provide compassionate, dignified and person-centred care. We also saw evidence of positive multi-disciplinary team working within the units.

However, across our inspections, we could not always be assured patients were receiving safe and effective care within CAMHS units. This is because we identified weaknesses around systems for ensuring safe care, including a system for locating emergency equipment. We also found improvements were needed to patient records, care planning and statutory mental health documentation. In the Regis Healthcare CAMHS unit, it was of particular concern to find excessive use of full physical restraint which compromised patients' safety, rights and dignity. We found there were ongoing challenges across CAMHS units to ensure there are sufficient numbers of staff with the right skills to meet the needs of young people.

Overall, HIW has significant concerns about the ability within CAMHS units to accommodate young people who are high risk due to challenges with staffing, environment and effective management and leadership.

General healthcare services for young people

We looked at the care provided to young people with acute, long-term and chronic physical health conditions in our inspections of Noah's Ark Children's Hospital and Morriston Hospital Emergency Department. We found staff were caring and talked to young people and their families about their medical conditions. Environments were generally suitable for young people and there were facilities to support families and carers.

In general, we found children and young people received safe and effective care. However, services needed to make improvements to ensure young people received timely care in emergency departments and for invasive procedures. We also found aspects of care documentation were not always completed and a number of staff had not completed training in how to safeguard children at risk. Despite attempts to recruit new staff, there were ongoing challenges in both hospitals to ensure they had sufficient numbers of staff with the right skills.

As a result, we found that in the emergency department, there was not always sufficient staff for children and young people to be treated in the designated children's area.

Supporting young people with life-limiting conditions and palliative care

We looked at the care and treatment provided to children and young people in the two children's hospices in Wales. Although we identified some areas for improvement, overall, we found that young people received safe and effective care. We found staff were kind and caring and there was good support available to families. Young people received care that was tailored to their specific needs and were supported with an extensive range of facilities and

programmes to enhance their well-being. Children, young people and their families were involved in decisions about their care, and hospice staff were particularly respectful of their wishes for end-of-life care and after death.

We also found evidence of good management and leadership at the hospices.

Transition from child to adult healthcare services

We found a varied and inconsistent picture across Wales in respect to transition. It was positive to find health boards generally worked to national guidance on transition, including having a named key worker, joint meetings with other services and typically starting transition at an appropriate age.

We found variation across services and health boards regarding the age at which transition usually starts. Although there should be no arbitrary age for transition, in practice, age appears to be the main determinant. We found examples where transition could be rushed and did not always start early enough. We were told that transition works very well for a small number of patient groups. However, in practice, particularly for young people with complex needs, this can be more fragmented and can feel like 'falling off a cliff edge'.

We found that differences between child and adult services meant that individuals did not always receive the same level of care and there may not be an equivalent adult service for a young person to transition to.

There also appears to be a lack of a formal and consistent mechanism to involve young people in monitoring or reviewing the effectiveness of transition processes. Some health boards said they had plans to engage young people in future within some services once transition pathways had been developed.

We found variation in how young people aged 16 or 17 years old are treated across healthcare services in Wales. Of particular concern were the occasions when young people would be treated on non-designated adult wards which may not provide suitable environments and staff to meet their needs.

Conclusion

Overall, it was positive to find young people had predominately good experiences of care within services. However, we are concerned about the current ability of CAMHS units across Wales to accommodate young people who are high risk, meaning some young people need to be placed out-of-area. This is not acceptable and we believe Welsh Government needs to take firm steps to address this problem. Many of the issues we have identified around transition are well known and greater consistency is needed across Wales. Health boards must take responsibility for ensuring there are clear transition pathways across all services they provide and have a robust system for monitoring their effectiveness. Further work is also needed to understand the experiences of young people with complex needs and life-limiting conditions.

A list of our recommendations can be found in Appendix A of this report.

3. Background

Focus of the review

This review considered what we know about how healthcare services meet the needs of young people in the following areas:

- Child and Adolescent Mental Health Services (CAMHS)
- general healthcare for young people (considering young people with acute, chronic, and long-term physical healthcare needs)
- supporting young people with life-limiting conditions receiving palliative care
- transition between child and adult services.

In this review we have identified key themes and issues from available evidence, drawn conclusions and made recommendations for improvement. Throughout this report we have highlighted areas of good practice, and in order to share learning across Wales, we have also included specific good practice examples around transition in Appendix B.

Context

There are a number of strategy, legislation, standards and guidance documents which relate to healthcare services for young people, in addition to a number of published reviews.

Some of the key legislation and standards include the following:

- Mental Health Act 1983[2]
- Mental Health (Wales) Measure 2010[3]
- Mental Capacity Act 2005[4]
- Social Services and Well-being (Wales) Act 2014[5]
- Well-being of Future Generations (Wales) Act 2015[6]
- United Nations Convention on the Rights of the Child[7]
- Independent Health Care (Wales) Regulations (2011)[8] and National Minimum Standards for Independent Health Care Services in Wales[9]

[2] https://www.legislation.gov.uk/ukpga/1983/20/contents

[3] https://www.legislation.gov.uk/mwa/2010/7/contents

[4] https://www.legislation.gov.uk/ukpga/2005/9/contents

[5] https://www.legislation.gov.uk/anaw/2014/4/contents

[6] https://www.legislation.gov.uk/anaw/2015/2/contents

[7] https://www.unicef.org.uk/what-we-do/un-convention-child-rights/

[8] https://www.legislation.gov.uk/wsi/2011/734/contents/made

[9] https://gov.wales/legislation/subordinate/nonsi/nhswales/2011/4927892/?lang=en

- Health and Care Standards 2015[10]
- All Wales Child Protection Procedures[11].

Overarching guidance around transition of young people from child to adult services includes the following:

- NICE guidelines: Transition from children's to adults' services[12]. (This applies across mental health, general healthcare, chronic and life-limiting conditions)
- Royal College of Nursing – Lost in Transition: Moving young people between child and adult health services[13].

We are also pleased to note that Welsh Government is in the process of developing guidance on provision of healthcare services for 16 and 17 year olds and handover of healthcare from children's to adult services. This guidance aims to address the issues and concerns raised in relation to the healthcare offered to 16 and 17 year olds, and their progress into adulthood 'transition'. The intention is to provide direction for Welsh health boards and trusts.

Key strategy, standards and guidance regarding Child and Adolescent Mental Health Services include the following:

- Welsh Government: 'Together for Mental Health' strategy[14]
- Together For Children and Young People Programme (T4CYP)[15]
- Good Transition Guidance for professionals from the T4CYP (2017)[16]
- National Assembly for Wales: Children, Young People and Education Committee – *Mind Over Matter* report 2018[17]
- Welsh Government: Admissions guidance[18]
- Royal College of Psychiatrists (2013) CAMHS guidance[19].

[10] https://gov.wales/topics/health/publications/health/guidance/care-standards/?lang=en

[11] https://gov.wales/topics/health/socialcare/safeguarding/?lang=en

[12] NICE Guidelines published 2016 (and transition pathway published in 2018) https://www.nice.org.uk/guidance/qs140

[13] https://www.rcn.org.uk/professional-development/publications/pub-003227

[14] https://gov.wales/topics/health/nhswales/mental-health-services/policy/strategy/?lang=en

[15] https://www.goodpractice.wales/t4cyp

[16] http://www.goodpractice.wales/SharedFiles/Download.aspx?pageid=185&mid=326&fileid=751

[17] http://www.assembly.wales/laid%20documents/cr-ld11522/cr-ld11522-e.pdf

[18] http://www.wales.nhs.uk/sitesplus/documents/862/Item14i.WG.AdmissionsGuidance.pdf

[19] https://www.rcpsych.ac.uk/docs/default-source/improving-care/better-mh-policy/college-reports/college-report-cr182.pdf?sfvrsn=8662b58f_2

Key strategy, standards and guidance regarding general healthcare for children and young people include the following:

- Welsh Government delivery plans for specific conditions including, diabetes, cancer, heart, neurological conditions, respiratory health, stroke, critical illness[20]
- Royal College of Nursing: Facing the Future: Standards for children in emergency care settings[21].

Key strategy and guidance regarding life-limiting conditions and palliative care include the following:

- Palliative and End of Life Care Delivery Plan 2016[22]
- Together for Short Lives Guidance[23]
- Children and Young People's Continuing Care Guidance[24].

HIW inspection framework

Within this report we have referred to HIW's inspections of NHS and independent healthcare services in the last two years.

In our inspections of NHS services, HIW considered how services met the Health and Care Standards (2015).

In our inspections of independent healthcare providers, HIW considered how the service met the requirements of the Independent Health Care (Wales) Regulations 2011 and the National Minimum Standards for Independent Health Care Services in Wales.

Where appropriate, HIW also considered how services complied with the Mental Health Act (1983), Mental Health (Wales) Measure (2010), Mental Capacity Act (2005) and Deprivation of Liberty Safeguards.

Further detail about how HIW inspects the NHS and independent services can be found on our website[25].

[20] https://gov.wales/topics/health/nhswales/plans/?lang=en

[21] https://www.rcpch.ac.uk/sites/default/files/2018-06/ftf_emergency_standards_digital_-_website_version.pdf

[22] https://gov.wales/topics/health/nhswales/plans/end-of-life-care/?lang=en

[23] https://www.togetherforshortlives.org.uk/resource/guide-end-life-care/

[24] https://gov.wales/topics/health/publications/socialcare/guidance1/care/?lang=en

[25] http://hiw.org.uk/about/whatwedo/inspect/?lang=en

Specific healthcare services for young people in Wales

There are three CAMHS in-patient units in Wales:

- **Tŷ Llidiard** – operated by Cwm Taf University Health Board for 12-18 year old patients from across South Wales. The service is commissioned by the Welsh Health Specialised Service Committee (WHSSC) to provide 15 beds for NHS patients.
- **Abergele** – provided within Betsi Cadwaladr University Health Board for 12 to 18 year olds from across North Wales. The service is commissioned by WHSSC to provide 12 beds for NHS patients.
- **Regis Healthcare Ltd** – registered with HIW to provide independent CAMHS services based in Gwent South Wales for 13-18 year old patients. It has capacity to provide 24 beds. However, due to HIW's concerns[26] about the service, the number of beds available has been reduced from 24 to 12. The service had previously treated Welsh NHS patients. However, due concerns of Welsh NHS commissioners, at the time of writing, Regis Healthcare are not currently commissioned to treat Welsh NHS patients.

There is one dedicated paediatric hospital in Wales:

- Noah's Ark Children's Hospital, based on the site of the University Hospital of Wales in Cardiff provides health care for children and tertiary services for children across Wales. The service is based within Cardiff and Vale University Health Board.

There are two independent paediatric hospices in Wales that provide care and treatment to children and young people:

- **Tŷ Hafan** – located in Sully, Cardiff. Registered with HIW to provide independent and collaborative specialist palliative care for up to 10 children and young people aged 0-18 years.
- **Tŷ Gobaith** – located in Groesynydd, Conwy. Registered with HIW to provide independent and collaborative specialist palliative care for up to five children and young people aged 0-25 years.

Evidence considered

During this review we considered evidence from the following sources:

- Legislation, national strategies, policies, guidance and standards on healthcare for young people and transition between child and adult services.
- Self-assessments completed by each health board in Wales on healthcare services for young people and arrangements on transition.
- A range of published reviews and research of healthcare services for young people.

[26] Due to concerns around the governance, management and leadership of the service, Regis Healthcare Ltd is under the closest scrutiny from HIW, within which we have imposed conditions on their registration and ability to take on new patients. Further details are included under 'Timely Care' within the 'Child and Adolescent Mental Health Services' section of this report.

HIW inspections of NHS and independent healthcare services including the following:

- Tŷ Llidiard 2017 and 2018[27]
- Abergele 2018[28]
- Regis healthcare 2018[29]
- Noah's Ark Hospital 2015 and 2017[30]
- Tŷ Hafan 2018[31]
- Tŷ Gobaith 2018 [32]
- Morriston Hospital Emergency Department 2018[33].

When considering what inspections to include as part of this review, we looked back at our hospital inspections over the last two years where there were findings around the care of children and young people. We have included our inspection of Morriston Hospital Emergency Department in particular, because it highlighted challenges around the care of young people which may also be present in other emergency departments across Wales.

Terminology in this report

Throughout this report we have referred to both children and young people. By the term 'children' we mean those aged 0-12 years old and by the term 'young people' we mean those aged 13-24 years old.

When we discuss 'transition', we mean young people moving from child to adult healthcare services, including mental health.

[27] http://hiw.org.uk/find-service/service-index/tyllidiard?lang=en

[28] http://hiw.org.uk/find-service/service-index/abergelehospital1?lang=en

[29] http://hiw.org.uk/find-service/service-index/regishealthcare89?lang=en

[30] http://hiw.org.uk/find-service/service-index/children'shospitalforwales20?lang=en

[31] http://hiw.org.uk/find-service/service-index/tyhafan122?lang=en

[32] http://hiw.org.uk/find-service/service-index/tygobaith119?lang=en

[33] http://hiw.org.uk/find-service/service-index/morristonhospital53?lang=en

4. Key themes

Child and adolescent mental health services

We found CAMHS did well in the following areas:

- Staff treated young people with respect and kindness.
- There was positive multi-disciplinary team working.
- Facilities for families and carers.
- Systems to listen to young people and learn from feedback.
- Young people were involved in their care.

We identified CAMHS needed to improve in the following areas:

- Timely completion of work to improve the physical environmental.
- Communication with young people and families at referral and on admission.
- Information on raising concerns and access to advocacy services.
- Ability to accommodate patients who are high risk.
- Waiting times and access to services for young people in crisis.
- Systems to ensure the safety and effectiveness of care, including location of emergency equipment and use of physical restraint.
- Sufficient numbers of staff with the right skills, and induction of new and temporary staff.

Why this issue is important

Approximately 50% of people with enduring mental health problems will have symptoms by the time they are 14[34]. The Mental Health Act required that age-appropriate services be put in place and that patients aged under 18 with a mental health problem requiring admission to hospital are accommodated in an environment that is suitable for their age. For those young people with enduring mental illness the need for ongoing support and care from childhood into adulthood is vital. All children and young people should receive safe and effective care from mental health services which meet their needs.

What the evidence shows

In this section, when evaluating how young people with mental health needs are cared for, we have primarily considered the evidence from our inspections of the three CAMHS in-patient units in Wales. This includes our inspections of Abergele unit within Betsi Cadwaladr University Health Board, Tŷ Llidiard unit provided by Cwm Taf University Health Board and Regis Healthcare's independent low-secure CAMHS unit where people with acute, long-term and complex needs are cared for. We have also considered the evidence from guidance, research and reviews around CAMHS services more widely.

Quality of patient experience

Across the three CAMHS units we inspected, we found young people had access to a range of activities within the units and in the community, including cinema/games rooms, cooking sessions, sports, gym and leisure facilities and arts and crafts. However, we found that at times, activities provided could be ad hoc or with limited availability due to insufficient staff being available to facilitate/supervise. On other occasions, we found that access to facilities and activities was affected by environmental issues such as damage to equipment and maintenance needed to indoor and outdoor spaces. We also identified that activities were not always clearly linked to the individual patient's care plan.

Environment

We found efforts had been made by services in the design and furnishing of the units to provide a suitable environment for young people to receive care. Young people had their own bedrooms which they could personalise with their belongings.

However, across our inspections, we found issues with aspects of the physical environment. We identified areas of damage and maintenance needed to internal and external areas. We found garden areas, which were intended to benefit young people by giving them time away from the unit, overgrown and poorly kept.

We found that both Abergele and Tŷ Llidiard units were undergoing anti-ligature work to the hospital environment. This was a positive step to reduce the potential opportunities for patient self-harm via ligaturing, thus improving patient safety.

However, whilst each unit had systems in place to deal with environmental issues and ongoing programmes of maintenance, work was not always carried out in a timely way. In our 2018

[34] http://www.assembly.wales/laid%20documents/cr-ld11522/cr-ld11522-e.pdf

inspection of Tŷ Llidiard, we found environmental changes were needed to ensure the safety and wellbeing of patients with more complex care needs. However, we were told it had taken a long time for the work to be completed.

In addition to updating furniture, fixtures and fittings to be anti-ligature, services also need to ensure that there are individualised plans to identify and mitigate the risk that young people may harm themselves or others. Services should also be aware of items left unattended which could be used by young people to self-harm.

Recommendation 1

Health boards and service providers must ensure environments protect the safety and wellbeing of young people. There must be robust systems in place to monitor risks within the environment and ensure maintenance work is conducted in a timely way.

Support for families and carers

CAMHS units typically had rooms for families and carers of young people to stay overnight. This was of great benefit to families and carers, particularly those who are located some distance away from the hospital.

Where appropriate, young people could also spend time with their families in private and could use their mobile phones or hospital phone to maintain contact with family and friends.

Dignified care

Overall, we found staff treated young people with respect and kindness. Staff made every effort to maintain patient dignity. Patients told us staff knocked on their bedroom doors before entering to respect their privacy.

For their safety, each bedroom had a see-through vision panel that could be used by staff to observe patients, without disturbing them. However, there were occasions when we found issues with repair needed to these observation panels and window coverings to promote patient's privacy.

During our March 2018 inspection of Regis, we were concerned about the impact of excessive use of restraint on young people's rights and dignity. We have addressed this further below under 'safe and effective care'.

Patient information and communication

On the whole, we found young people were provided with a range of information about their stay in the units.

Through our observations of staff-patient interactions it was evident that staff ensured they communicated effectively with young people. We also saw positive relationships between staff and young people.

Staff took time to undertake discussions using words and language suitable to the individual person. Where information remained unclear or misunderstood, staff would patiently clarify what was said. However, there were occasions when young people told us they didn't understand aspects of their treatment, including the next steps following their admission.

Within CAMHS services, health boards told us that young people are asked to provide written consent to treatment. However, there is also evidence to suggest that young people and their families don't receive adequate general information about CAMHS services at the point of referral to services. An Aneurin Bevan Community Health Council[35] report found that approximately half of the parents who had a child referred to CAMHS did not have the process explained to them and were not aware of what to expect. People also reported that when a referral was not accepted they were not told the reason for the rejection or offered the option of being referred to a more appropriate service elsewhere. The report also identified a misunderstanding of what CAMHS does and who is eligible for the service, which may then result in inappropriate referrals.

Recommendations 2-3

Health boards and service providers must ensure there is clear communication with young people to help them understand their treatment.

Welsh Government, health boards and service providers need to improve the communication with, and information available for, young people and their families at the point of referral.

Timely care

Capacity in services

In line with the findings of the *Mind Over Matter* report, produced by the Children and Young People and Education Committee, we also found a mixed picture of CAMHS in-patient capacity in Wales, to enable young people to receive timely care close to where they live. We are particularly concerned about the overall ability of units in Wales to accommodate young people who are high risk.

In our 2017 inspection of Tŷ Llidiard, we found the service was under significant pressure to provide care for more patients than the number it was commissioned for by the Welsh Health Specialised Service Committee (WHSSC). The hospital is commissioned for 15 patients but during our inspection there were 18 patients being cared for. In 2018, we noted the ongoing work to make environmental changes in order to reflect the increased complexity of patients care needs compared to those patients that were referred when the unit first opened. Due to these necessary changes, Tŷ Llidiard is operating a restricted criteria for referrals until the work is completed in 2019.

[35] http://www.wales.nhs.uk/sitesplus/documents/901/Child%20and%20Adolescent%20Mental%20Health%20Services%20in%20Gwent%20September%202018.pdf

In North Wales, the *Mind Over Matter* report also identified similar concerns regarding the restricted capacity within Abergele unit, which is commissioned to provide 12 beds. This was due to ongoing issues with recruiting and retaining the appropriate number and skill mix of staff.

Due to serious concerns regarding the quality and safety of the service provided by Regis Healthcare CAMHS unit (which treats young people from England and Wales), Welsh patients were removed by NHS commissioners in July 2018. The service operated under restricted regulatory conditions between July and December 2018 which prevented any new admissions. Whilst new admissions have been permitted since December 2018, the number of beds available have been reduced from 24 to 12. At the time of writing this report, 11 of those 12 beds were occupied by English patients and the service had not yet been placed back on the list of providers approved by commissioners to provide treatment to Welsh NHS patients.

As of February 2019, Regis Healthcare remains a service of concern, and is under the highest level of scrutiny from HIW. Until the service can demonstrate that the improvements made in recent months can be sustained it is unlikely that any increase in capacity will occur.

Due to the issues above, we are concerned that all three units in Wales are currently operating under restricted capacity and/or admissions criteria. This means CAMHS units in Wales may not effectively meet the needs of high risk patients. As a result, some high risk patients are treated out-of-area. It is also disappointing that the limited capacity within CAMHS units and need for out-of-area placements was also identified in a report in 2013 by HIW and the Wales Audit Office[36]. On an all-Wales basis, Welsh Government needs to review the demand for these services against the ability and capacity within CAMHS units to ensure young people can receive the treatment they need in Wales.

Waiting times and access to services

The current target for specialist CAMHS is that 80% of patients should wait no longer than 28 days (four weeks) from the date the referral is received by the clinic to a first outpatient appointment. However, this target has been consistently missed since April 2017, with an average of 57% of patients who waited no longer than four weeks, whilst the majority of patients waited between 4-26 weeks for their first appointment.[37]

The Aneurin Bevan Community Health Council report stated '… that many referrals are rejected, with the young people feeling that they 'weren't bad enough' to be seen by CAMHS and that 'serious' suicide attempts were the only way that young people could get any support through the health system'.

Furthermore, the *Mind Over Matter* report highlighted 'A&E becoming a "default" option, especially for cases of overdose and/or self-harm, because of historical/continued difficulties accessing support from specialist CAMHS and/or primary care'.

[36] http://hiw.org.uk/reports/natthem/2013/camhs2013/?lang=en

[37] Source – StatsWales, Waiting times by specialty and patient type – outpatient waiting times. https://statswales.gov.wales/Catalogue/Health-and-Social-Care/NHS-Hospital-Waiting-Times/Inpatient-and-Outpatient-Waiting-Times-for-Non-RTT-Specialties/waitingtimes-by-specialty-patienttype

The *Mind Over Matter* report also highlights the 'missing middle' where urgent work was needed to address the lack of services for young people who need support but do not meet the threshold for specialist CAMHS. It was also identified that 'many young people may not require CAMHS provision; however, with no obvious alternative for young people experiencing mental ill health, referrals may be being made inappropriately'.

Recommendations 4-5

Welsh Government needs to consider the capacity within CAMHS services across Wales to ensure this meets the needs of young people, including those who are high risk.

Welsh Government and health boards need to review the waiting times for CAMHS services, ensure there are timely referrals to other organisations to support young people and how young people can access support at times of crisis.

Listening and learning from feedback

Each unit had arrangements in place for dealing with concerns or complaints raised by young people but, in our inspections, we found information about these processes was not always clear and prominent.

We found young people could often provide feedback on the care they received through surveys undertaken by the units. Several units had used online surveys to try and engage young people. Responses were then considered by the service with a view to making improvements. Staff also told us that young people had the opportunity to provide feedback in meetings about their care.

All units confirmed that there is independent mental health advocacy available for young people detained under the Mental Health Act. We found information provided for patients within the units typically included information about advocacy services, and representatives from advocacy services would visit the units on a regular basis. However, we found information on the Mental Health Act, independent advocacy provision, how to raise a complaint and information on HIW could have been clearer and displayed more prominently.

On one occasion, young people told us that timescales for independent advocacy visits did not always allow an advocate to attend all individual meetings. Young people felt it would be beneficial if advocacy visits were based on individual needs rather than set visiting times.

Recommendations 6-7

Health boards and service providers must ensure there is clear information for young people on advocacy services and flexibility to enable young people to meet with advocacy services at a time of their choice.

Health boards and services providers must ensure young people know how to raise a concern.

Delivery of safe and effective care

Across our inspections, whilst we found staff worked hard to provide compassionate and dignified care, we could not always be assured that young people were receiving safe and effective care within CAMHS units.

We generally found that care and treatment plans, developed as part of the Mental Health (Wales) Measure 2010, were completed to an appropriate standard and focused on individual needs. We also found that staff made efforts to involve young people and their families (where appropriate) in the development of their care plan.

However, we identified a number of areas of improvement needed to patient records, care planning and statutory mental health documentation, including the need to ensure:

- Correct and timely completion of statutory Mental Health Act detention documents by relevant staff to effectively maintain legal compliance.
- There are systems in place for managing, organising and auditing statutory documentation and patient records.
- Unmet needs are identified and recorded within care and treatment plans.
- Care and treatment plans are reviewed in accordance with their review dates.
- Individualised plans are developed on how the young person would like to be treated in the event of any challenging behaviour.
- Restraint risk management and implementation plans are in place to assist staff members to consider the young person's physical conditions and behaviours whilst implementing restraint.
- Appropriate plans are developed in response to findings from risk assessments and risk assessments are kept up-to-date to help identify patients' needs in relation to promoting their safety and wellbeing.
- Information on physical health needs are appropriately recorded, including chronic illnesses and allergies, and care plans for physical injuries.
- Observation records are complete and accurate.

During our inspections we identified weaknesses and concerns around systems for ensuring safe and effective care. We found issues with the location of emergency clinical items, including a delay in locating ligature cutters. Any delay in locating equipment in an emergency could impact the safety of a young person. During one inspection of Regis Healthcare, we also found some members of staff lacked knowledge on how to support and monitor patients before, during and after mealtimes. This is important particularly for young people with eating disorders.

Of particular concern was the excessive use of full physical restraint, identified in our Regis Healthcare inspection in March 2018. Consequently we were not fully assured that the young people were being cared for safely and outcomes monitored effectively. This resulted in HIW issuing a non-compliance notice[38] to the service. Where a form of control or restraint is used there must be suitable arrangements in place to protect the young people against the risk of such control or restraint being otherwise excessive. Whilst any form of restraint should be seen as a course of action used in exceptional circumstances only, it can be a potential breach of young people's rights[39]. Any restraint must be a considered, last resort decision, which is fully risk assessed.

Since the March 2018 inspection, Regis Healthcare has provided staff with further training on restraint and has developed additional documentation for recording when attempts are made to de-escalate challenging behaviour prior to restraint. However, during a follow-up inspection of Regis Healthcare, we found inconsistencies in the quality of incident reports being completed and identified improvements that could be made in the analysis of incidents and records.

Whilst we did not identify similar concerns regarding the excessive use of physical restraint at other units, it is important that all services maintain awareness of the appropriate consideration and use of this approach.

Recommendation 8

Health boards and service providers must ensure that:

- patient records, care planning and statutory mental health documentation are comprehensive, accurate and completed in a timely manner
- emergency clinical items, including ligature cutters can be located without delay
- staff have sufficient knowledge on how to support and monitor patients before, during and after mealtimes
- any restraint must be carefully considered, risk assessed and monitored, with the involvement of the young person to ensure their safety, rights and dignity are protected as much as possible.

[38] If, following an inspection, HIW find that a service provider is compromising patient safety and failing to comply with the terms of their regulatory requirements and registration, HIW will take immediate action by issuing a non-compliance notice http://hiw.org.uk/providing/enforce/?lang=en

[39] Human Rights https://www.legislation.gov.uk/ukpga/1998/42/contents, Children Act 2004 https://www.legislation.gov.uk/ukpga/2004/31/contents, Rights of Children and Young Persons (Wales) Measure 2011 https://www.legislation.gov.uk/mwa/2011/2/contents, Mental Capacity Act, United Nations Convention on the Rights of the Child

Safeguarding children at risk

There were established processes in place to ensure units safeguarded children and young people appropriately, with referrals to external agencies being made as and when required.

On our inspections, we found most staff had completed mandatory training on safeguarding. However, there were occasions when we found not all staff had completed this. This is important to promote and protect the welfare and safety of young people.

Due to the excessive use of restraint found at Regis Healthcare, HIW referred this to the safeguarding team at the local authority for it to be dealt with formally under multi-agency safeguarding procedures.

Recommendation 9

Health boards and service providers must ensure CAMHS staff have up-to-date safeguarding training.

Quality of management and leadership

Across units, the staff we spoke to commented positively on multi-disciplinary team working. Staff said the multi-disciplinary teams worked in a professional and collaborative way and individual views were sought and valued.

At both Regis Healthcare and Tŷ Llidiard we found there were a number of staff vacancies, including registered mental health nurses. Although considerable effort had been made to recruit to these posts, there appeared to be difficulties with recruitment. We are also aware of ongoing issues with the recruitment of nursing staff and consultant psychiatrists at Abergele. At Regis Healthcare, we identified insufficient staffing numbers on wards with a high reliance on agency staff. In our subsequent follow-up inspections, we found that staffing levels had improved but we remained concerned about a number of other areas of governance, management and leadership at the hospital.

Across inspections, we also identified improvements were needed to ensure there is appropriate induction of all bank and agency staff working within units to ensure they are familiar with the environment and day-to-day running of the wards so they can best care for young people.

Recommendation 10

Welsh Government, health boards and service providers must consider how issues around workforce within CAMHS units can be addressed to ensure young people receive care from the right staff with the rights skills to meet their needs.

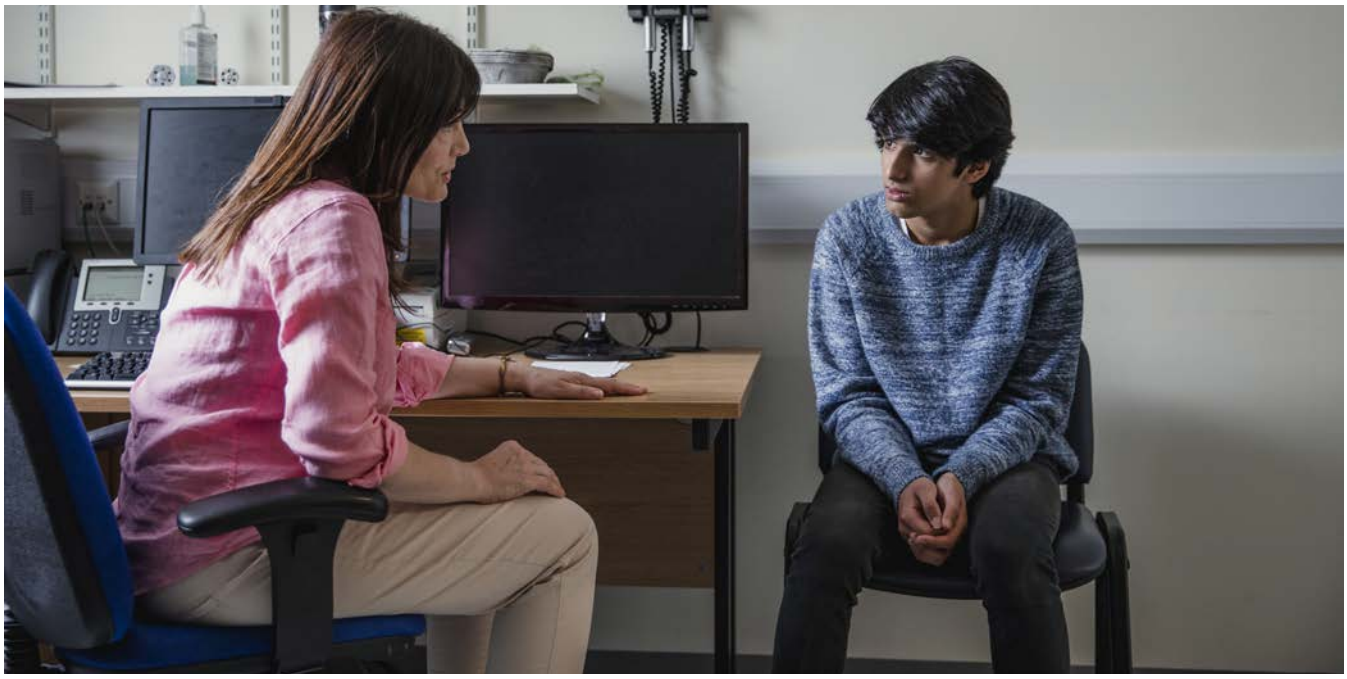
General healthcare services for young people

We found hospitals did well in the following areas:

- Feedback from patients, families/carers about their care was positive.
- Physical environments were generally well maintained and suitable for children and young people.
- There were facilities to support families and carers, including overnight accommodation at Noah's Ark Hospital.
- Staff explained to young people who they were and talked to them about their medical conditions.
- Services had ways to seek feedback from young people, including the use of age-specific questionnaires.
- We saw evidence of strong management and leadership within services.

We identified hospitals needed to improve in the following areas:

- Ensuring children and young people can be consistently treated in designated areas in emergency departments.
- Consistent timely care in emergency departments and for emergency invasive procedures.
- Completion of risk and pain assessment documentation.
- Staff in emergency departments have up-to-date safeguarding training.
- There are sufficient numbers of staff with the right skills to meet the needs of children and young people.



Why this issue is important

The number of children and young people with long-term conditions and/or complex needs is rising. Children and young people are also more frequent users of emergency departments than adults[40]. It is important that young people needing to attend hospital receive age appropriate, safe and effective care in a suitable environment, whether they need treatment for acute care or for chronic and long-term conditions.

What the evidence shows

In this section, in considering how young people with acute, long-term and complex needs are cared for, we have primarily considered the evidence from our inspections of Noah's Ark Children's Hospital within Cardiff and Vale University Health Board. As stated earlier in this report, we have also considered evidence from our inspection of Morriston Hospital Emergency Department (ED) in particular, because it highlights challenges around young people's care which may also be present in other emergency departments across Wales.

Quality of patient experience

During our inspection of Noah's Ark Children's Hospital, we received positive feedback from patients, families/carers on the care and treatment they received.

In our inspection of Morriston Hospital ED, we highlighted the experience of children and young people attending for urgent treatment. Whilst this inspection did not focus solely on the care for young people, overall, patients and their relatives commented that they were content with the care and treatment provided at the department.

Environment

We found the environment within the wards we visited at Noah's Ark hospital to be generally clean and well-maintained, although some maintenance issues remained in regards to emergency call buttons by bedsides, which had been identified on our previous inspection.

During our inspection of Morriston ED, we found children and young people were seen and cared for within a protected, appropriate environment, away from other areas of the department. It was also positive to find a play area had been created within a section of the main outpatient area as a result of the views of, and collaboration with, one family who had experience of visiting the hospital.

Standards developed by the Royal College of Paediatric and Child Health for children in emergency care state that settings should be designed and provided to accommodate the needs of children and young people and their parents/carers and they should be provided with separate waiting and treatment areas. However, during our inspection, we saw occasions when children were not able to receive care in the designated paediatric area. This was because of the lack of paediatric trained nurses available at that time. Whilst we were able to confirm that ED staff ensured children and young people were seen and assessed away from the main waiting area to ensure their safety and wellbeing, this was a disappointing

[40] Royal College of Paediatric and Child Health – Facing the Future: Standards for children in emergency care settings – 2018 https://www.rcpch.ac.uk/resources/facing-future-standards-children-young-people-emergency-care-settings

finding considering this situation was also highlighted by the local Community Health Council during their visit to the department in 2016[41].

Recommendation 11

Health boards must ensure that children and young people can consistently be treated within designated areas.

Support for families and carers

We learned that a new facility had been created at Noah's Ark Hospital to enable the parents/carers of 30 patients to remain close to their children. It was hoped the facility would provide parents/carers with the extra support and comfort they may need. It was also positive to find a dining room table and chairs, and a television had been added to the family room in direct response to comments made within a monthly patient experience survey.

We also found that relatives and families were encouraged to remain with patients and we saw a relatives' room was available for private discussions within Morriston ED.

Dignified care

At Noah's Ark Hospital, we held discussions with parents in each of the four clinical areas visited and were provided with many positive comments about the kindness and respect of staff. Parents and carers also told us staff were very attentive, explained aspects of care provision very well, and that they took time to listen to what they had to say.

Within Morriston ED, we heard from a range of patients about their experiences. Whilst feedback was not specific to children and young people, most patients and their relatives/carers felt staff were always polite and listened to them, and to their friends and family.

Patient information and communication

We found Noah's Ark Hospital had addressed our previous recommendation to ensure that staff always introduced themselves to patients and their families ahead of any discussions or clinical interventions. Staff were regularly reminded of the need to introduce themselves to children, young people and their families.

Patients, families and carers at both Noah's Ark and Morriston ED told us that staff had talked to them about their medical conditions or helped to understand them.

We also found that patients were offered the option to communicate with staff in the language of their choice and felt their language needs had been met.

Through the completion of our self-assessments, health boards confirmed that their policies to guide staff on the consent to examination and treatment included arrangements for children and young people. Health boards confirmed that clinical staff were aware of the

[41] http://www.wales.nhs.uk/sitesplus/902/page/45235

legal issues in gaining consent, including parental responsibility for under 16s, assessments of Frazer and Gillick[42] competency and the mental capacity of the young person.

Timely care

Overall, we found that every effort was made to ensure that children received timely care and treatment.

Staff worked to ensure that children were seen promptly by a paediatric nurse for triage purposes within Morriston ED. There was, however, a period during day three of our inspection, when a paediatric nurse was not available. This resulted in children being assessed outside of the paediatric area (but still apart from adult waiting zones). This resulted in some delay in the children concerned receiving further advice, care and treatment.

We also learned of an isolated instance at Noah's Ark Hospital whereby a child had needed to wait for seven days to go to theatre for an invasive procedure (re-insertion of a long-term vascular access device for feeding purposes). We found that there were no formal, current National Confidential Enquiry into Peri-Operative Deaths (NCEPOD)[43] emergency theatre arrangements in place for children's services. In addition, we could not find evidence of dedicated vascular access services[44] available at the University Hospital for Wales (for adults or children).

Recommendation 12

Health boards must ensure young people consistently receive timely care and treatment within emergency departments and for emergency invasive procedures.

Listening and learning from feedback

In our inspections of Noah's Ark and Morriston ED, we were informed that patients and their families/carers were encouraged to raise any concerns they had with members of staff. Both hospitals had ways to seek and regularly review feedback, either through comments cards in reception, or through patient and family surveys. We also found evidence of additional facilities being provided for families and children following feedback.

We noted good practice in Noah's Ark around the use of three types of questionnaires for different age groups of children and young people (up to three years of age, age four to nine and 10 to 18 years). This was in acknowledgement of the different care and support needs of children.

[42] https://learning.nspcc.org.uk/research-resources/briefings/gillick-competency-and-fraser-guidelines/

[43] National Confidential Enquiry into Peri-Operative Deaths (NCEPOD) relates to the provision of 24 hour operating theatre time (and supporting standards) for emergency surgery..

[44] The Association of Anaesthetists of Great Britain & Ireland – Safe vascular access 2016 http://www.aagbi.org/sites/default/files/Safe vascular access 2016.pdf. p11. "Hospital's must organise and provide the following: Timely (within 1-3 days) insertion (and removal) of long-term CVCs in specialist locations (wards, theatres, radiology) via a dedicated service."

The Royal College of Paediatrics and Child Health standards state that children, young people and their parents/carers should be invited to feedback on the service received in urgent and emergency care setting to inform service improvement. Through self-assessments, health boards across Wales generally confirmed that young people are supported to raise concerns through putting things right arrangements, with help through carers/families and professionals working with them. Health boards also confirmed they would direct young people to advocacy services, including some services specifically for children and young people such as MEIC[45]. However, we found that information on how people can raise concerns was not always prominently displayed. This meant that there may be occasions when patients and/or their families may not know how to report their concerns, or what to expect of the health board.

Recommendation 13

Health boards must ensure that young people know how they can raise concerns about their care within hospitals.

Delivery of safe and effective care

Overall, we found evidence that safe and effective care was being provided in both Noah's Ark Hospital and Morriston ED. However, we found some evidence that the health boards were not fully compliant with the Health and Care Standards in all areas.

In Noah's Ark Hospital, we found the necessary steps had been taken to ensure patients' needs were being met. Some aspects of patients' notes were very detailed and helpful to staff in providing care. However, we saw that documentation was not always completed, including paediatric risk assessment and pain assessments. This meant that we were unable to determine whether the effectiveness of prescribed medication was being monitored or evaluated.

We also found many instances at Noah's Ark Hospital where young people over the age of 16 received fragmented in-patient care due to issues around transition arrangements. We have discussed this further in the 'Transition from child to adult services' section of this report.

Recommendation 14

Health boards must ensure that paediatric risk and pain assessment documentation is comprehensive and completed in a timely manner.

Safeguarding children at risk

In our initial inspection of Noah's Ark hospital, we found there were appropriate arrangements for safeguarding children, and as such, did not identify improvements needed for follow up in 2017.

[45] Whilst not a dedicated advocacy, MEIC is the national and advice helpline for children and young people in Wales and offers a confidential and free helpline 24 hours a day, 7 days a week. www.meiccymru.org

Within Morriston ED, we were able to confirm that members of the ED team we spoke with were confident in the use of the All-Wales safeguarding arrangements associated with adults and children. We found that ED staff had ready access to details about children who may be vulnerable, or at risk. This meant that there was a particular emphasis on the provision of safe care and management of such situations.

The Royal College of Paediatrics and Child Health standards for emergency care also emphasise that all staff who regularly look after children must have up-to-date safeguarding children training. However, we found that just fewer than 50% of the ED staff had completed up-to-date training sessions on safeguarding. All staff who may care for children and young people must have up-to-date safeguarding training of both adults and children at risk and have the appropriate level of training for their role.

As young people can also be treated by adult services, it is also important that staff working in adult services also have the knowledge and skills to safeguard them effectively.

Recommendation 15

Health boards must ensure that staff working who may work with children and young people have up-to-date safeguarding training.

Quality of management and leadership

We found evidence of strong management and leadership at both Noah's Ark and Morriston ED.

Within Noah's Ark, we learned of the health board's ongoing pro-active recruitment campaign which had resulted in securing 45 new members of staff. However, we found that challenges remained in relation to ensuring sufficient staff numbers within the paediatric critical care unit. We were told that patients were not admitted to the unit unless there was a sufficient number of registered nurses present and staff (with relevant skills) were deployed to the unit from other ward areas to support the substantive team.

New staff received a comprehensive induction to Noah's Ark Hospital. However, we identified issues with the use of bank healthcare support workers on one ward, who were not familiar with children's services. This meant that permanent staff needed to pick up additional duties to support patients.

We found the staff team at Morriston ED were very aware of the challenges they faced in providing care and treatment to children and young people. We found that new staff received an appropriate induction to ensure they could care for patients effectively. Staff were working within an extremely busy environment and indicated that they weren't always able to meet all the conflicting demands on their time at work. The senior management team demonstrated a clear understanding of the issues and challenges facing the Morriston ED as a result of increased demands for unscheduled care services.

The Royal College of Paediatrics and Child Health standards for emergency care state that every emergency department treating children must be staffed with two registered children's nurses, and a minimum of two children's nurses per shift in dedicated children's emergency departments. However, one of the challenges faced at Morriston ED related to the insufficient numbers of paediatric nurses available to work within the designated children's area.
The health board indicated that it has actively tried to recruit into paediatric posts, but has been unsuccessful due to limited available workforce.

Recommendation 16

Health boards must ensure there are sufficient numbers of staff with the right skills to meet the needs of children and young people.

Supporting young people with life-limiting conditions receiving palliative care

We found hospices did well in the following areas:

- Feedback from patients, families and carers was positive.
- Hospices had an extensive range of facilities and programmes to enhance the well-being of children and families, including provision for older children and young people.
- Good support was available to families from hospice services, including emotional support and counselling services.
- Patients and their families told us that staff were kind, caring and treated them with dignity and respect.
- Young people and their families were involved in decisions about their care.
- Care was person centred and tailored to individual needs.
- There was evidence of good management and leadership at the hospices.

We identified hospices needed to improve in the following areas:

- Up-to-date environmental risk assessments and actions are addressed.
- Facilities to support people who use hearing aids.
- Young people and their families know how to raise a concern about their care.

Care for children and young people with life-limiting conditions and needing palliative care is unique and complex. These young people often become gravely ill and then make an unexpected recovery on several occasions before their death. Such episodes can be months apart, making the workload pattern different from adult care.[46]

What the evidence shows

In this section, in considering how young people with life-limiting conditions and needing palliative care are supported in Wales, we have primarily considered the evidence from our inspections of the two independent children's hospices, Tŷ Hafan and Tŷ Gobaith.

Quality of patient experience

Overall, patients and their families were very positive about their experiences of care within the Tŷ Hafan and Tŷ Gobaith children's hospices and rated the care and treatment as excellent.

Environment

We found hospice environments were thoughtfully designed, cheerfully decorated and well maintained.

Both hospices had an extensive range of facilities and programmes to enhance the well-being of children and families, including complementary therapy rooms, multi-sensory rooms, arts and crafts areas, play rooms and lounges. Both communal and private areas were provided where children and young people could spend time with staff and their families.

It was positive to find there were lounge areas specifically designed to meet the needs of older children and young people with age appropriate facilities and games, including computers.

Each patient had their own bedroom which was spacious and well maintained. Patients were able to personalise their rooms with their belongings, and beds were individualised to their specific needs for sleeping.

Tŷ Hafan had extensive refurbishment plans in place for the building, including bedrooms and communal areas. We identified some areas of improvement were needed around the development of overarching environmental risk assessments for the building and following through on actions in relations to fire safety order.

Recommendation 17

Service providers must ensure they have comprehensive and up-to-date environmental risk assessments and address any actions highlighted.

[46] https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/transition-adult-services/

Support for families and carers

We found there was good support available to families from hospice services.

The hospices provide families, including siblings, with a range of emotional support and counselling services, including bereavement and family support.

As described above, where appropriate, families are involved in the care planning for the child/young person. Families also have access to a family support worker to discuss any concerns or wishes at any time.

During end-of-life care, the wishes of children/young people and their families are considered, and facilities are available to enable the child/young person to lay, after death, in peaceful surroundings and to afford his/her family and friends the opportunity to say their goodbyes in their own time and in their own way.

Dignified care

Patients and their families told us that staff were kind and caring. We observed very positive interactions between staff and patients, with staff supporting patients in a dignified and respectful manner.

We saw staff making efforts to protect patients' privacy and dignity when providing assistance with personal care needs.

Both hospices were respectful of the wishes of patients and their families for end-of-life care and were able to provide individualised arrangements in order to best meet these.

Patient information and communication

We found that a range of appropriate information was available for patients and their families within the hospice.

Both hospices had comprehensive statements of purpose and patient's guides as required under the Independent Health Care (Wales) Regulations 2011. This provided information for children, young people and their families on the services available.

We found good practice at Tŷ Hafan which had developed a 'family contract' which clearly laid out responsibilities and expectations of families and staff during their stay. Staff explained they would discuss this information with families to ensure all parties were clear about the arrangements in place to care and support them and their child during their stay.

Staff communicated with patients in a calm, friendly and cheerful manner. We found staff members to be friendly, approachable and committed to delivering a high standard of care to patients and their families/carers.

We were assured that where possible, the wishes, preferences and consent of children/young people would be sought and they would be involved in decisions about their care. Parents and carers would also be involved in care planning discussions as appropriate.

Both hospices considered the communication needs of patients on an individual basis, including availability of Welsh speaking staff so that patients and families could communicate in their language of choice. However, we found that hearing loops were not available to aid communication for those using hearing aids and we recommended services address this.

It was positive to see information boards displaying the staff on shift and who would be working in the evening as a good way to let children and families know who was caring for them.

Recommendation 18

Service providers must ensure there are arrangements to support communication needs of children, young people and their families, including facilities to support people who use hearing aids.

Timely care

We did not identify concerns regarding timely care during our inspections. We were assured the hospices had sufficient numbers of staff to be able to meet the needs of children and young people promptly.

What was less clear from our research was how children and young people with life-limiting conditions across Wales, including those in more rural location can access the right care and support when they needed it. The number of children who need support with life-limiting and palliative care is rising[47], however, there are only two dedicated children's hospices serving the whole of Wales. This means that young people may need to travel considerable distances for in-patient hospice and respite care. Whilst we understand that hospices also work closely with GPs and paediatric and palliative care teams to support children and young people whilst they are at home, this area would be worthy of further examination.

Recommendation 19

Welsh Government needs to assess any unmet demand for palliative care services to ensure children and young people across Wales get the care they need.

Listening and learning from feedback

It was clear that hospices were open and responsive to the views and feedback from children and families. We understood that the number of complaints received were low and the hospices aimed to address any issues raised promptly.

[47] https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/transition-adult-services/

Complaints procedures were in place and patients and families were informed of these arrangements through the statement of purpose and patient's guide, in line with regulatory requirements. However, we did recommend that this information could be displayed more prominently and that details of HIW were included as the regulatory body, in relation to raising concerns about the service.

We were told about the arrangements in place to provide children and their families with access to advocacy services, if required.

Recommendation 20

Service providers need to be mindful of how they ensure young people and their families are made aware of how to raise a concern about their care.

Delivery of safe and effective care

Overall, within both hospices, we were assured that children and young people received safe and effective care. We found good practice around providing person centred care within both services.

We found evidence that comprehensive assessments of care needs were being undertaken and these were reviewed and updated on a regular basis. Care plans were also detailed with regular reviews and updates undertaken. We found that care plans were bespoke and reflected children's individual needs. Patients were involved in the planning and provision of their own care, as far as was possible. Where this was not possible, parents/carers were being consulted and encouraged to make decisions around care provision. Children and young people were encouraged to do as much for themselves as possible in accordance with their preferences and abilities.

Safeguarding children at risk

We found there were appropriate procedures and arrangements in place to safeguard children and young people. We were assured that staff had received the appropriate level of safeguarding training for their role and responsibilities.

We noted good practice around use of a safeguarding symbol on patient information boards to alert staff if there was a safeguarding plan in place for a particular child or young person.

In Tŷ Gobaith, which also provides services to young people over the age of 18 years, we found that Mental Capacity and Deprivation of Liberty Safeguards assessments were conducted as and when needed in relation to any patients over the age of 18 years.

Quality of management and leadership

Overall, we found good management and leadership at the hospices.

We found there was a multi-disciplinary approach to the provision of care with good communication processes in place between involved professionals. There was evidence of very good multi-disciplinary working between the nursing, medical staff and therapy staff. The hospices also worked with their health board palliative care teams to ensure appropriate support and care was provided to patients.

We found staffing levels were sufficient in order to meet the care needs of the patients accommodated. Additional staff would be allocated should patients be admitted with high levels of care needs. We found there were suitable arrangements in place to ensure that any bank or agency staff used were familiar with the working environment in order to be able to care for patients. Both hospices had a pool of additional staff to draw upon, who were already familiar with the service.

Transition from child to adult healthcare services

We found services did well in the following areas:

- Health boards were aware of national guidance and used this in their approach to the transition of young people from child to adult services.
- Young people would be supported by a named key worker.
- The age of transition typically followed NICE guidelines.
- Transition works well for young people with some specific conditions such as diabetes.
- Young people can attend joint appointments with child and adult services so they are introduced to adult service practitioners.

We identified services needed to improve in the following areas:

- Consistency in approaches around transition and mechanisms to ensure these are effective.
- Effective transition pathways and support for young people with complex health needs and life-limiting conditions.
- Sufficient time, resources and capacity to support effective transition including consistent and robust systems to identify and support young people who will need to transition.
- Review the differences between child and adult healthcare services and consider how young people can continue to receive care.
- Young people are involved in the planning, design and delivery of transition process and supported to adjust to adult services.
- Clarify policies on whether young people aged 16 and 17 should be treated within child or adult services, taking into account their wishes and needs.
- Review the practice and frequency of placing young people on non-designated adult mental health wards.

Why it's important

Transition from child to adult services can be particularly stressful for young people, particularly for those with complex, long-term/chronic conditions and mental health needs. Young people between the ages of 14 and 24 years are also likely to face multiple, concurrent transitions in other areas such as education and social support services. Last-minute arrangements around transition and feelings of uncertainty and helplessness all increase stress and can reverse the progress that has been made in their care[48].

What the evidence shows

In this section, we have considered evidence from self-assessments completed by all health boards in Wales around the range of healthcare services provided for young people and the systems to support young people who need to transition from child to adult services. We have also considered key guidance, research and reviews around transition.

Examples of good practice around transition have been included in Appendix B.

Key themes

From our research, we identified the following key themes and barriers to ensuring young people have a positive experience of transition:

Variation in approaches

We found transition arrangements varied across healthcare services and health boards in Wales. Although we were told that common guidance and principles applied, different specialities had different procedures around transition.

The Royal College of Nursing publication *'Lost in transition'*[49] recommends that each service area has an agreed transition policy in place which clearly outlines transitional care arrangements, and that all staff working with young people have specific training to facilitate transition between services. However, this does not appear to be always happening in practice.

Most health boards confirmed they had policies and guidance in place for transition, alongside local arrangements or stated that they followed national guidance, such as NICE guidelines and the T4CYP Good Transition Guidance for CAMHS. However, some services told us they did not have a protocol or set of guidelines to support transition arrangements. Several health boards cited work to develop pathways for transition. Whilst others told us they had agreed transition pathways, but these were not always formalised and may vary between specialities.

Health boards told us there is flexibility within their policies for transition, but acknowledge that age restrictions apply in some specialties. We have discussed this further below under 'age of transition'.

[48] https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/transition-adult-services/

[49] Royal College of Nursing – Lost in transition: moving young people between child and adult health services 2013 https://www.rcn.org.uk/professional-development/publications/pub-003227

Recommendation 21

Welsh Government and health boards must ensure there are clear transition pathways and policies in place for each service area. Where possible, there should be consistency in approaches to transition in line with national guidelines.

Systems to monitor the effectiveness of transition

We received mixed feedback from health boards on how transition policies or pathways are monitored or reviewed to ensure they are effective. Generally, health boards confirmed they had a system in place to review policies regarding transition. However, these seem to sit within the different specialties, rather than having a higher level oversight across specialties or clinical areas. Some health boards stated they had working groups looking at transition pathways.

Overall, it appears more work is needed by health boards to ensure there is effective governance around transition pathways across all services where this takes place.

Recommendation 22

Health boards must ensure there are robust systems to monitor transition policies and pathways across healthcare services to ensure approaches are effective.

Coordination of transition

We were told that effective transition is time consuming for involved professionals. Due to timescales and limited capacity within services, we learned there can be difficulties in coordinating relevant agencies and professionals to engage in the transition process. As a result, several health boards mentioned difficulties with attendance at multi-disciplinary meetings and in joint working with housing and local authorities.

Capacity for adult services to engage in transition planning at an early stage can also be challenging. We learned that the timescale for some adult services to commence their involvement with young people can be close to their 18th birthday, which gives very little time for in-depth assessments to be completed and for therapeutic relationships to be built.

All health boards told us they have joint working practices, including transition meetings, to allow for the sharing of expertise between child and adult health services, but acknowledged that practice varies between services.

In terms of support for young people during their transition, health boards confirmed that young people with specific health needs would be supported by a named key worker to coordinate their care in line with NICE guidance. However, there appears to be variation in how this is communicated with young people and their families and a lack of a formalised system to do this. We were also told there can be delays in allocating a key worker in some areas due to issues with resources, capacity and identifying a professional best placed to do this. Some services felt that a designated role of a transition coordinator for each health board would help to overcome some of these issues.

Recommendations 23-24

Welsh Government and health boards must ensure there are sufficient resources and capacity to support effective and timely transition.

Health boards must ensure a named key worker to coordinate transition is identified promptly and consider how to best support transition, including considering designated roles.

Involvement of young people

Across Wales, there appears to be no formal and consistent mechanism to involve young people in monitoring or reviewing the effectiveness of transition pathways and policies. Some health boards said they had plans to engage young people in the future within some services once transition pathways had been developed. However, the majority of health boards said a formal approach to involving young people in reviewing transition had not yet been developed.

The Children's Commissioner for Wales[50] emphasises the need for services to take a 'children's rights approach', empowering children and young people to make choices and to affect outcomes for themselves and to involve them in the design, monitoring and evaluation of services. The Royal College of Nursing also highlights that services need to be flexible and may need to be redesigned to truly meet the needs of young people, including involving young people in co-designing services. Furthermore, a Care Quality Commission report[51] on children's transition in England, highlights the importance of services listening and learning from young people and their families as they know what works and what goes wrong and services need to learn from their experiences.

Most health boards said young people are involved in their own transition process, typically through attending multi-disciplinary meetings about their care. For young people within CAMHS, we were told they would be involved in transition arrangements through discussion regarding their care and treatment plan. The majority of other health boards said they have regular meetings, involving young people and other agencies. However, they acknowledged there is some variation across individual services.

The Royal College of Nursing also highlights young people should receive support and education to prepare them to cope with transition. Particularly as research with young people across Europe has found that many find it difficult to adjust to the increased responsibility for care they are given in adult services.[52]

[50] Children's Commissioner for Wales: The right way – a children's rights approach in Wales https://www.childcomwales.org.uk/publications/right-way-childrens-rights-approach-wales/

[51] Care Quality Commission From the pond into the sea: children's transition to adult health services 2014 https://www.cqc.org.uk/publications/themes-care/transition-arrangements-young-people-complex-health-needs-children%E2%80%99s-adult

[52] European Observatory on Health Systems and Policies 2014 – European Child Health Services and Systems. Lessons without borders http://apps.who.int/iris/handle/10665/128707

Recommendations 25-26

Health boards must ensure they have a formal systems for involving young people in the design and delivery of transition processes and learn from their experiences.

Health boards must ensure young people are involved in the planning and transition process and are provided with adequate support to enable them to adjust.

Age of transition

There is variation across services and health boards regarding the age at which transition usually starts. Although NICE guidance states there should be no arbitrary age for transition, in practice, age appears to be the main determinant of transition.

NICE guidelines also state that transition should be planned as early as possible and recommend this takes place by school year 9 (13 or 14 years old) as this can lead to a better experience for young people. The majority of health boards said transition typically begins at age 14, however, this may also begin at age 16, 17 or 18 years old in some services. It was acknowledged that the transition for young people with the most complex care needs will be over a longer period of time and may begin at an earlier age. Although we were told the age of transition is dependent upon individual needs and the type of service, many services aim for full transition by the age 18. The Royal College of Nursing guidance recommends that the timing and duration of transition is negotiated with the young person and agreed by all relevant parties. However, as described further above, we are aware of some cases when the period of transition can be very short, taking place shortly before young people reach the age of 18.

The age at which child and adult services stop and start can also be a barrier for smooth transition. A Care Quality Commission report[53] into transition arrangements for young people with complex health needs in England found that some children's services cease providing care before the equivalent adult services have started. In Wales, an example of this can be seen in mental health, where adult mental health services generally do not accept young people below the age of 18 years. However, a number of young people may need to transition before the age of 18, whilst others aged 18 and over would benefit from remaining within CAMHS for longer.

Furthermore, a recent Aneurin Bevan CHC report has stated that '…young people had a feeling that the system would delay helping them until they turned 18 as then they would go to adult services and would no longer be the responsibility of CAMHS.'[54]

[53] Care Quality Commission 2014 – Transition arrangements for young people with complex health needs from children's to adult services https://www.cqc.org.uk/publications/themes-care/transition-arrangements-young-people-complex-health-needs-children's-adult

[54] http://www.wales.nhs.uk/sitesplus/documents/901/Child%20and%20Adolescent%20Mental%20Health%20Services%20in%20Gwent%20September%202018.pdf

Recommendations 27-28

Health boards must ensure there is sufficient time to allow for effective transition and planning starts as early as possible.

Health boards need review the practices where transition starts later, particularly for services where this starts after the age of 16 and align with national guidelines.

Transition of young people with complex health needs

We found a somewhat mixed picture in relation to transition for young people with complex health needs. We were told that transition works very well for a small number of patient groups, for example children with diabetes and HIV. The transition of young people with particular conditions is also supported by a range of guidance and condition specific delivery plans[55]. However, in practice, particularly for young people with complex needs, this can be more fragmented.

During our inspections of Noah's Ark Hospital in 2015 and 2017, we found many instances where patients with complex needs (who were over the age of 16) continued to experience fragmentation in their care and support at times when they required hospital in-patient care and treatment. Although in 2017, we found parts of the children's services had well established and effective transition arrangements in place for children with some long-term conditions, in general, transition arrangements needed to be more efficient and supported by good communication between relevant professionals and agencies.

In our inspection of Tŷ Hafan, staff explained that a barrier to young people getting appropriate palliative care when transitioning to adult services is that the number of young people needing paediatric palliative care is small compared to a much larger population of older adults, particularly with an aging population. Therefore, there is not the same demand for services to provide this type of specialist support. Furthermore, many adult services lack the resources, knowledge, understanding to meet the palliative care needs of these young people.

The *Together for Short Lives* charity has produced a number of resources and guides around transition of young people with life-limiting conditions[56]. The charity describes that 'For young people with life-limiting conditions, making the transition from children's to adult services is like falling off a cliff edge'. It also highlights the growing numbers of young people with life-limiting conditions as a result of medical advances. *Together for Short Lives* also emphasise that young people with life-limiting conditions have specific needs which differ from both younger children and older adults. However, they also report there is a lack of age and developmentally-appropriate palliative care services which can meet this growing demand. The transition these young people have to undergo from the comprehensive care offered by children's palliative care to unfamiliar adults' services can be daunting and is often not joined up.

[55] https://gov.wales/topics/health/nhswales/plans/?lang=en

[56] Together for short lives – Preventing the transition cliff-edge and securing the right care for young people https://www.togetherforshortlives.org.uk/changing-lives/speaking-up-for-children/policy-advocacy/transition-adult-services/

Recommendation 29

Welsh Government and health boards need to ensure there are appropriate transition pathways and support for young people with complex health needs and life-limiting conditions.

Getting lost in transition

We found the systems to identify young people who will need to transition varied across specialties and health boards. We also found that the arrangements to follow-up if young people missed appointments with adult services was also inconsistent.

In line with NICE guidance, most health boards confirmed that joint visits/appointments take place so that young people can meet practitioners from adult services during the transition period, but this varied between specialties.

In terms of ensuring that a young person needing transition is identified, attends their first appointment with adult services, and does not get 'lost in transition', we found there was no consistent formal 'flagging' system to monitor this. Health boards rely on practitioners and service meetings within individual specialities involved to do this. Some services felt that an IT system is needed across services to help identify these young people.

We learned of occasions where young people were discharged from adult services due to not attending appointments and this not being communicated to the paediatric service. Furthermore, in feedback from occupational therapy services, we learned that young people who are 'lost' in the transition to adult health services are more likely to present later with avoidable and treatable complications of their conditions.

The Royal College of Nursing guidance highlights the need for service providers to examine the way transition services are delivered. The guidance highlights that in order to reduce missed appointments and engage young people in their own treatment, services should be accessible and acceptable to these patients. For example, drop-in clinics and online information can make a service more accessible and approachable.

Concerns around discharge practices of services and responses to missed appointments were also identified in the HIW and Wales Audit Office joint follow-up review of child and adolescent mental health services in 2013[57]. This report identified that young people continue to be routinely discharged if there is no response from families / young people following a missed appointment with adult services. There was also found to be little evidence that the risks of discharging the young person were assessed or that clear communication routinely takes place with other agencies involved in their care.

Whilst it appears health boards are aware of the importance of ensuring that young people don't get lost in the system, and are not simply discharged for not attending appointments, it appears this can still be an issue.

[57] Healthcare Inspectorate Wales and Wales Audit Office – Child and Adolescent Mental Health Services: Follow-up Review of Safety Issues – 2013 http://hiw.org.uk/reports/natthem/2013/?lang=en

Recommendations 30-31

Health boards must ensure there are consistent and robust systems identify young people who will need to transition and support for attending appointments in adult services.

Health boards must ensure that adult services make every effort to engage with young people and communicate with other involved agencies, to ensure they can successfully transition.

Differences between child and adult services

We found that differences between the service models and provision within paediatric services and adult services can be another barrier for transition.

For example, there can be differences in service thresholds for support, meaning a young person who was supported by children's services, may no longer receive the same support in adult services. In our inspection of Tŷ Hafan, staff described that young people may not be eligible for support form adult palliative care, such as respite care, as the model of care is different. Furthermore, the environment within an adult hospice may not be appropriate to adequately meet the needs of a young person during end-of-life care.

There may also be a lack of an equivalent adult service for a young person to transition to, particularly for those with complex needs. We were also told that once a young person transitions to adult services it is on the basis of clinical speciality as opposed to a holistic approach to care.

Another key difference between paediatric and adult services is the involvement of parents and carers, which is not typically encouraged in the same way in adult services. We found the roles of parent's and carer's can change dramatically once a young person is in adult services which can be challenging to adjust to. NICE guidance also states that parents and carers should be involved in planning for transition to ensure they feel involved and know about future changes to services and care that the young person will receive.

Recommendations 32-33

Welsh Government and health boards need to review the differences between service models and thresholds between child and adult healthcare services and consider how young people can continue to receive holistic care and support into adulthood.

Health boards must ensure that parents and carers are sufficiently involved in transition planning.

Treatment of young people aged 16 and 17 years

There appears to be variation in how young people aged 16 or 17 years old are treated across healthcare services in Wales. This appears to depend upon the location and type of service they need. Some health boards told us there was no definitive policy on whether young people of this age should be treated within child or adult services as this may be dependent on their needs, consideration of the young person's choice and services available. Others

stated young people of this age would be referred to adult services, unless they are known to paediatric services. Clarity and consistency is needed across health boards and services on the approach to treating young people of this age group.

General healthcare services

Although young people may be given the choice about whether to be nursed on an adult or paediatric ward, this may not always be possible. We were told this may be affected by limited capacity and different admissions criteria for services.

In some areas, we learned that regional specialist paediatric teams will cease provision once a young person turns 16 years of age; some 16 and 17 year olds may therefore be cared for on adult wards. Health boards said they would consider the suitability of the accommodation within adult wards, such as providing a single bedroom, and carry out a risk assessment to ensure their safety and wellbeing.

We also found occasions when emergency departments find it difficult to locate suitable beds for young people aged over 16 years with acute health problems. We were told this can be because of strict adherence to admission policies for paediatric services and the inappropriate accommodation available within adult wards. In our inspection of Morriston ED, we highlighted the need for improved and timely transition of care arrangements for children who need to access adult services.

Generally, health boards do not have specific in-patient beds for young people, with the exception of some specific services such as CAMHS and the Teenage Cancer Trust. Typically, health boards said they did tend to group young people together within paediatric wards. However, from health board responses, it was unclear how they would monitor the need and provision of these beds.

To ensure that young people are cared for by appropriately trained staff when treated on adult wards, health boards confirmed that advice and support would be available from paediatric services. However, it was less clear how health boards ensure these arrangements worked effectively in practice. Health boards need to ensure staff, including those working in adult services, have the right skills to be able to care for young people.

A study[58] looking at the experience of young people aged 14 to 18 in England highlighted that young people feel that nurses in adult environments are unable to cope with their specific needs.

Mental health services

For mental health services, the Welsh Government's admissions guidance[59] and the T*ogether for Mental Health strategy* state that young people should not be admitted to adult mental health wards except in the most exceptional circumstances. This decision should be based on clinical needs, risk and wishes of the young person and should only be considered as a last resort.

[58] Dean and Black: Exploring the experiences of young people nursed on adult wards. Br J Nurs. 2015 Feb 26-Mar 11;24(4):229-36 https://www.ncbi.nlm.nih.gov/pubmed/25723268

[59] https://gov.wales/topics/health/nhswales/mental-health-services/policy/child-mental/?lang=en

Some health boards confirmed that young people of this age should not be accepted onto adult wards and arrangements are in place for them to be treated within a specific age appropriate area or 'designated bed' if required. However, in some circumstances due to urgency, acuity and capacity within CAMHS units, we are aware that young people can be placed on adult mental health wards. Health boards confirmed that maintaining the young person's safety and that of others, is the primary concern.

The HIW and WAO report on CAMHS highlighted that whilst it was common practice for health boards to have 'designated beds' within adult wards, some young people are still being placed on non-designated adult wards, if the designated beds are unavailable. It appears that this remains an issue and we have seen instances of young people being placed on non-designated adult wards in the last year through the serious incidents reported on Welsh Government. To date, since April 2018, there have been a total of 37 admissions of young people to adult mental health wards. This means that young people may be placed in unsuitable environments which may not meet their needs.

However, whilst there is reporting of underage admissions to adult mental health wards, there appears to be no such incident reporting category for young people treated on adult wards for physical health needs. Therefore, there is a lack of information on the scale and frequency of this issue across Wales.

Recommendations 34-37

Health boards must ensure there is clarity across services about how all young people aged 16 and 17 should be appropriately treated, including how they will ensure staff have the right skills to care for them.

Welsh Government needs to ensure there is clear guidance about how young people under 18 years of age, should be treated when needing care for physical health needs.

Welsh Government and health boards must review the practice and frequency of placing young people on non-designated adult mental health wards.

Welsh Government needs to consider the reporting and monitoring of underage admissions on adult (non-mental health) hospital wards to ensure there is oversight on this issue across Wales.

5. Conclusions

Although this review has identified a range of issues young people experience in healthcare across Wales, it was positive to find young people had predominately good experiences of care within in-patient services. It was also evident that services are provided by hard-working and dedicated staff who are passionate about providing care centred on young people's needs.

However, we are concerned about the current ability of CAMHS units across Wales to accommodate young people who are high risk, meaning some need to be placed out-of-area. This is not acceptable and we believe Welsh Government needs to take firm steps to address this problem on an all-Wales basis. Furthermore, the ongoing practice of admitting young people onto adult mental health wards (designated or non-designated) for assessment and/or treatment suggests further examination is required around the suitability of services to meet the needs of young people. With the recent Welsh Government announcement of an additional £7 million in funding[60] to improve the mental health of children and young people in Wales, there may be scope to use some of this additional funding to address the issues that we have highlighted.

It was disappointing to find that many of the issues around transition and the treatment of young people under 18 years of age which are well known, still appear to be present. Health boards must take responsibility for ensuring there are clear transition pathways across all services they provide and have robust systems for monitoring their effectiveness, with the involvement of young people.

Although there are a number of good examples where care and transition have worked well, we are concerned about the inconsistencies across health boards and service areas. This means that young people can experience fragmented care and may get 'lost in transition'. Effective coordination between services is vital to ensure young people have smooth transition. It should not be left up to young people to navigate their way between different services. Furthermore, it is important Welsh Government and health boards consider how services can be designed and delivered to remove the barriers to transition which the system creates, such as age restrictions and differing service models.

Our review has also highlighted that more work is needed to consider how young people with complex needs and life-limiting conditions can be better supported when transitioning between child and adult services. Whilst not included in this review, it also appears there is little known about transition for young people with learning disabilities.

We also found that whilst there has been considerable attention on admission of young people on adult mental health wards, there is not the same attention on young people who are placed in general adult hospital wards. For example, finding in-patients beds for young people who attend emergency departments for acute physical conditions. We believe this is an area which should be formally monitored across Wales.

[60] https://gov.wales/newsroom/health-and-social-services/2019/mental-health/?lang=en

This review further highlights the need for all-Wales guidance on transition and the care of young people, particularly those aged 16 and 17 years. We welcome the draft guidance around this which is currently being developed by Welsh Government which we hope will provide some much needed clarity to services across Wales.

6. What next?

We expect the Welsh Government, health boards and independent service providers to carefully consider the findings from this review and our recommendations set out in Appendix A.

Welsh Government is also asked to consider the issues we have highlighted around transition in the development of their guidance on provision of health care services for 16 and 17 year olds and handover of health care from children's to adult services.

Given the concerns we have raised around CAMHS in-patient unit provision, Welsh Government is asked to review the current arrangements to meet the needs of young people in Wales.

The following areas were not included in our review, but would benefit from further examination by other bodies:

- Continuing health care funding when a young person transitions between child and adult services.
- Sexual health and maternity care for young people.
- Transition arrangements for young people with learning disabilities.
- Capacity within services to support children in Wales with complex and life-limiting conditions, including those living in more rural locations in Wales.
- Review of underage placements of young people with physical health need on adult hospital wards.
- Detailed review of out-of-area placements of young people with mental health need and young people with complex physical health needs.

HIW will also consider the areas touched upon during this review around the support for young people in mental health crisis, as part of a wider thematic in 2019-2020 around mental health crisis services.

As part of the work being undertaken by Inspection Wales, HIW will help bring together key findings around services for young people to evaluate how they support young people's healthy development, wellbeing, and access to education and employment.

Appendix A

Recommendations

As a result of the findings from this review, we have made the following overarching recommendations which we expect, Welsh Government, all health boards and independent service providers to address.

No	Recommendations	Health and Care Standards (2015)
1	Health boards and service providers must ensure environments protect the safety and wellbeing of young people. There must be robust systems in place to monitor risks within the environment and ensure maintenance work is conducted in a timely way.	2.1 Managing risk and promoting health and safety
2	Health boards and service providers must ensure there is clear communication with young people to help them understand their treatment.	3.2 Communicating effectively 4.2 Patient information
3	Welsh Government, health boards and service providers need to improve the communication with, and information available for, young people and their families at the point of referral.	3.2 Communicating effectively 4.2 Patient information
4	Welsh Government needs to consider the capacity within CAMHS services across Wales to ensure this meets the needs of young people, including those who are high risk.	3.1 Safe and clinically effective care
5	Welsh Government and health boards need to review the waiting times for CAMHS services, ensure there are timely referrals to other organisations to support young people and how young people can access support at times of crisis.	5.1 Timely access
6	Health boards and service providers must ensure there is clear information for young people on advocacy services and flexibility to enable young people to meet with advocacy services at a time of their choice.	4.2 Patient information 6.2 People's rights
7	Health boards and services providers must ensure young people know how to raise a concern.	6.3 Listening and learning from feedback

No	Recommendations	Health and Care Standards (2015)
8	Health boards and service providers must ensure that: • Patient records, care planning and statutory mental health documentation are comprehensive, accurate and completed in a timely manner. • Emergency clinical items, including ligature cutters can be located without delay. • Staff have sufficient knowledge on how to support and monitor patients before, during and after mealtimes. • Any restraint must be carefully considered, risk assessed and monitored, with the involvement of the young person to ensure their safety, rights and dignity are protected as much as possible.	3.5 Record keeping 2.1 Managing risk and promoting health and safety 3.1 Safe and clinically effective care 4.1 Dignified care 6.2 People's rights
9	Health boards and service providers must ensure CAMHS staff have up-to-date safeguarding training.	2.7 Safeguarding children and safeguarding adults at risk
10	Welsh Government, health boards and service providers must consider how issues around workforce within CAMHS units can be addressed to ensure young people receive care from the right staff with the rights skills to meet their needs.	7.1 Workforce
11	Health boards must ensure that children and young people can consistently be treated within designated areas.	2.7 Safeguarding children and safeguarding adults at risk 3.1 Safe and clinically effective care
12	Health boards must ensure young people consistently receive timely care and treatment within emergency departments and for emergency invasive procedures.	5.1 Timely access
13	Health boards must ensure that young people know how they can raise concerns about their care within hospitals.	6.3 Listening and learning from feedback

No	Recommendations	Health and Care Standards (2015)
14	Health boards must ensure that paediatric risk and pain assessment documentation is comprehensive and completed in a timely manner.	3.5 Record keeping
15	Health boards must ensure that staff working who may work with children and young people have up-to-date safeguarding training.	2.7 Safeguarding children and safeguarding adults at risk
16	Health boards must ensure there are sufficient numbers of staff with the right skills to meet the needs of children and young people.	7.1 Workforce
17	Service providers must ensure they have comprehensive and up-to-date environmental risk assessments and address any actions highlighted.	2.1 Managing risk and promoting health and safety
18	Service providers must ensure there are arrangements to support communication needs of children, young people and their families, including facilities to support people who use hearing aids.	3.2 Communicating effectively
19	Welsh Government needs to assess any unmet demand for palliative care services to ensure children and young people across Wales get the care they need.	Governance, leadership and accountability
20	Service providers need to be mindful of how they ensure young people and their families are made aware of how to raise a concern about their care.	6.3 Listening and learning from feedback
21	Welsh Government and health boards must ensure there are clear transition pathways and policies in place for each service area. Where possible, there should be consistency in approaches to transition in line with national guidelines.	6.1 Planning care to promote independence Governance, leadership and accountability
22	Health boards must ensure there are robust systems to monitor transition policies and pathways across healthcare services to ensure approaches are effective.	3.1 Safe and clinically effective care 3.3 Quality improvement, research and innovation

No	Recommendations	Health and Care Standards (2015)
23	Welsh Government and health boards must ensure there are sufficient resources and capacity to support effective and timely transition.	6.1 Planning care to promote independence
24	Health boards must ensure a named key worker to coordinate transition is identified promptly and consider how to best support transition, including considering designated roles.	3.1 Safe and clinically effective care 5.1 Timely access
25	Health boards must ensure they have a formal systems for involving young people in the design and delivery of transition processes and learn from their experiences.	6.1 Planning care to promote independence 6.3 Listening and learning from feedback
26	Health boards must ensure young people are involved in the planning and transition process and are provided with adequate support to enable them to adjust.	6.1 Planning care to promote independence
27	Health boards must ensure there is sufficient time to allow for effective transition and planning starts as early as possible.	6.1 Planning care to promote independence 5.1 Timely access
28	Health boards need review the practices where transition starts later, particularly for services where this starts after the age of 16 and align with national guidelines.	3.1 Safe and clinically effective care
29	Welsh Government and health boards need to ensure there are appropriate transition pathways and support for young people with complex health needs and life-limiting conditions.	3.1 Safe and clinically effective care 6.1 Planning care to promote independence
30	Health boards must ensure there are consistent and robust systems identify young people who will need to transition and support for attending appointments in adult services.	3.4 Information governance and communications technology 6.1 Planning care to promote independence
31	Health boards must ensure that adult services make every effort to engage with young people and communicate with other involved agencies, to ensure they can successfully transition.	3.2 Communicating effectively 6.1 Planning care to promote independence

No	Recommendations	Health and Care Standards (2015)
32	Welsh Government and health boards need to review the differences between service models and thresholds between child and adult healthcare services and consider how young people can continue to receive holistic care and support into adulthood.	3.1 Safe and clinically effective care 6.1 Planning care to promote independence
33	Health boards must ensure that parents and carers are sufficiently involved in transition planning.	6.1 Planning care to promote independence
34	Health boards must ensure there is clarity across services about how all young people aged 16 and 17 should be appropriately treated, including how they will ensure staff have the right skills to care for them.	Governance, leadership and accountability 3.1 Safe and clinically effective care 7.1 Workforce
35	Welsh Government needs to ensure there is clear guidance about how young people under 18 years of age, should be treated when needing care for physical health needs.	Governance, leadership and accountability 3.1 Safe and clinically effective care
36	Welsh Government and health boards must review the practice and frequency of placing young people on non-designated adult mental health wards.	Governance, leadership and accountability 3.1 Safe and clinically effective care
37	Welsh Government needs to consider the reporting and monitoring of underage admissions on adult (non-mental health) hospital wards to ensure there is oversight on this issue across Wales.	Governance, leadership and accountability 3.1 Safe and clinically effective care

Appendix B

Examples of good practice around transition

Although we have identified some key issues around transition, during our review, we were told of examples of good practice where transitions has worked well. Several health boards also cited transition projects in place for improving experiences for young people.

In accordance with the all-Wales transition guidance[61], several health boards talked about the development of a transition passport for young people transitioning from CAMHS to adult services.

We were told that Tŷ Hafan has a transition worker in place to support young people and families to transition from paediatric to adult health and social care services. Tŷ Hafan continue to support young people up to the age of 25 years, excluding residential stays, and facilitates peer support groups for 16 to 25 year olds. Tŷ Hafan would also support families in discussions regarding the arrangements for continuing health care needs for young people as well as linking with agencies for independent living and legal advice for power of attorney.

Powys Teaching Health Board told us it has received funding to further develop the key worker model to support and coordinate services for children and young people with complex needs to enhance the coordination between child and adult services.

Hywel Dda University Health Board explained it operates a single point of access for all mental health referrals where young people would be signposted to a service that best suits their needs, such as primary care, counselling, or CAMHS. We understand that other health boards have similar models in place or in development.

Hywel Dda University Health Board also gave an example of the role of the WellChild Transitional Care Nurse who facilitates transition to adult community practitioners.

Betsi Cadwaladr University Health Board told us there have been some very proactive positive transition cases for learning disabilities, young people with physical complex health needs and a young CAMHS case. Multi-disciplinary teams worked together to meet the needs of individuals by coordinating all agencies. In particular, we heard that the community rehabilitation team in Wrexham are good at engaging with young people to support them in transition.

Cwm Taf University Health Board gave an example of the effective transition of a young person with a learning disability and palliative care needs which was led by a Palliative Care Nurse Specialist. The Nurse Specialist arranged regular meetings that involved adult services from both health and the local authority. Meetings were also arranged with senior nurses in acute areas and the family were invited to visit and attend transition meetings. With this level of support, education and training, a successful transition to a local authority day centre was facilitated.

[61] http://www.goodpractice.wales/SharedFiles/Download.aspx?pageid=185&mid=326&fileid=752

Cwm Taf University Health Board also talked about agreed epilepsy pathways. We learnt that transition conversations are initiated with the young person and their families around 14 to 15 years of age with a plan to facilitate attendance to the transition clinic around their 16th birthday. The transition clinics are run jointly by paediatrician, paediatric epilepsy nurse specialist and adult neurologist, adult epilepsy nurse specialist and wider professional teams as may be appropriate for an individual patient.

Cardiff University Health Board told us that a multi-agency group has been set up to agree processes and improve transition for children with complex needs and disability. The health board also have an All Wales lead for transition in palliative care who works with specialist paediatric and adult palliative care teams as well as children and adult hospices, to improve transition of young people with life-limiting conditions. The health board cited examples of transition working well in specific long-term conditions, including the following:

- For young people with diabetes, a teenage diabetes clinic is being run in conjunction with adult diabetes services. It is attended by a Diabetologist from adult services and Diabetic Specialist Nurse from adult services as well as the paediatric team. Diabetes services have appointed a youth worker who will follow patients through transition aged 16 into adult service.
- For young people with heart disease, congenital heart disease services have a dedicated transition service. Young people attend joint clinics run by both paediatric transition and adult health professionals.
- For young people with cancer, at age 14, they transition from paediatric oncology to the Teenage Cancer Trust where they are cared for from the age of 14 to 24 years. There is joint working between both services during this time.

Abertawe Bro Morgannwg University Health Board told us that within paediatric services, there are databases to identify children and young people with chronic and complex needs who will need to transition to adult services. These cases are then discussed and a plan agreed between teams involved.

Aneurin Bevan University Health Board described the 'Ready, Steady, Go' model which is in development and will support the assessment of the young person's maturity and 'readiness' for transitioning to adult services. This model will assist clinicians in assessing whether the young person is ready for transition and how best they can be supported.

Aneurin Bevan University Health Board also described clinics for young people with specific conditions such as diabetes which involve both adult and children's specialists. These clinics provide opportunity for sharing expertise and practice whilst working in collaboration to meet the needs of the young person. We also heard that transition nurses within specialist services provide good support to young people.