

PHOTO REDACTED DUE TO THIRD PARTY RIGHTS OR OTHER LEGAL ISSUES

A spotlight report into educational provision for children and young people in healthcare settings in Wales



**Comisiynydd
Plant Cymru**

Children's
Commissioner
for Wales

Foreword

by Rocio Cifuentes MBE, Children's Commissioner for Wales

All children have a right to education under article 28 of the United Nations Convention on the Rights of the Child (UNCRC). In Wales, the entitlement in law to an education is inclusive of children and young people with healthcare needs.

This means that children with healthcare needs should be supported to receive appropriate provision that meets their educational needs. This may be in hospital, home or another setting.

However, information received by my office in 2021 suggested that in practice not all children were getting opportunities to learn when they were receiving inpatient healthcare. My team learned that some children were being offered no education at all, despite being well enough and wanting to learn. Others were only receiving very limited provision.

My team and I decided that this needed further exploration. Over the last year we've listened to children and young people about their experiences, and engaged with healthcare settings, healthcare professionals, and local authorities in Wales. We've also researched approaches in other nations.

We heard about the importance of education in a healthcare setting. This included keeping up with school work and qualifications of course, but it also included learning for pleasure, having something to focus on other than illness, and having activity and engagement away from the ward.

Teachers in healthcare settings also highlighted the role teaching and learning has in creating a daily structure, building relationships and keeping children and young people connected with their school community where possible.

But our research has shown us that not all children have equal access to their right to education under the UNCRC.

Some children in healthcare settings receive an education that develops their talents, skills and supports their wellbeing (article 29, UNCRC). But the picture across Wales varies greatly, and Welsh children who need to stay in a healthcare setting have reduced entitlements to education compared to children in England.

This isn't fair. Children who need extended periods of in-patient care, frequent day care or need to stay at home due to their healthcare needs also need every opportunity to develop and learn. In these circumstances, children need extra support, not less!

But we've heard examples of where the system isn't working as it should for children and families. One parent told us that her child's school had made her aware of a bill they'd received following her child's short stay in hospital, after she'd taken part in some learning offered there. This had left her shocked, anxious, and embarrassed, and made her feel like she'd done the wrong thing by accepting the hospital's education offer. In circumstances like this, parents need less things to worry about, not more.

In another example, one setting we spoke to described how a child had received some education in their bed because they were unable to go down to the setting's dedicated classroom. The child's local authority then refused to pay for the education the child had received because it had taken place outside of that classroom, which breached their funding agreement.

I urge Welsh Government to do better for children who need to stay in a hospital, another healthcare setting or at home due to their healthcare needs. Clearer expectations need to be established with local authorities so that children can access a full programme of learning when this is in their best interests.

The voices of children themselves in this report tell us how important this is:

It gave me something to look forward to when I am poorly in hospital.

Keeps me up to date with work from mainstream school, decreasing stress and anxiety about returning.

It made such a difference on making me feel 'normal' on the days we did tuition together.

Thank you

I want to thank all the children and young people who shared their experiences with us, their parents, and all the professionals we engaged with for their contributions, and for supporting and enabling the participation of children and young people in this research.

Welsh children who need to stay in a healthcare setting have reduced entitlements to education compared to children in England.

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There is little consistency in how the relevant people are notified when a child is eligible for education in a healthcare setting.

Key messages

- Young people value the education they receive in a healthcare setting for a variety of reasons. There is the value of continuing their studies, but also in allowing the joy of learning to distract them from their medical treatment.
- Variations in funding across Wales can result in unequal experiences for children. Healthcare settings have different funding arrangements with local authorities, resulting in inconsistencies in children's experiences on a national level. Local authorities fund varying amounts of learning hours per week, and there is no consistent understanding of the amount of funding that should be available for a child.
- There is a desire amongst local authorities and healthcare professionals for more effective multiagency communication. There is little consistency in how the relevant people are notified when a child is eligible for education in a healthcare setting, and most local authorities said communication could be improved to help a child transition back to the community.
- Some young people are more likely to miss out on educational provision. This includes young people over the age of 16, young people with additional learning needs, and young people who wish to receive their education through the medium of Welsh.

Our recommendations

Key recommendation

1. I recommend that the Welsh Government reviews Local Authorities' legal duties to provide **full-time** education to children who, because of illness, would otherwise not receive suitable education. The guidance must be clear that local authorities are responsible for ensuring Welsh children receive the same legal entitlement as their counterparts across the UK.

Further recommendations

2. I recommend that Welsh Government revises the guidance for providing Education Other Than At School (EOTAS) to include an expectation that local authorities facilitate the delivery of the equivalent of a full-time education offer for children who are receiving ongoing or acute healthcare, unless it is not in the best interests of the child.
3. I recommend that updated guidance places a duty on EOTAS leads in every local authority to routinely collect children's views on the education they receive.
4. I recommend that Welsh Government review current funding arrangements for education in healthcare settings across all local authorities and engage with stakeholders to enable a universal approach for funding to be embedded across Wales.
5. I recommend that transition and reintegration plans are included in guidance to strengthen the links between education, health and local authorities for children and young people who receive education in a healthcare setting and will be returning to their previous educational arrangements. These plans must be co-produced with children and young people.
6. I recommend that guidance is updated to reflect the new curriculum to ensure continuity of education for children and young people with health needs within whatever setting education is provided.
7. I recommend that the current EOTAS framework is updated to ensure all children and young people under the age of 18 can access educational provision when they are an in-patient in a healthcare setting.
8. I recommend that an integrated impact assessment (including a children's rights impact assessment) is undertaken by Welsh Government in relation to the guidance, including the needs of disabled children and those accessing post-16 education.
9. I recommend that Welsh Government support settings to enable children and young people to receive their education in the Welsh language when in a healthcare setting. This should be included in any commissioning framework.
10. I recommend that guidance is updated to reflect new entitlements under the ALNET Act for learners to receive support with their education, wherever it is being delivered.

Introduction

Setting the scene

We know that children with long-term health needs can spend considerable time away from their typical educational setting and that educational absenteeism can impact health and wellbeing outcomes^{1,2}. This highlights the importance of children and young people with healthcare needs being able to stay connected to their education: keeping connected to their learning helps to optimise their social and emotional wellbeing³. If they are unable to do this, we know the impact this can have - children in healthcare settings can be left feeling isolated and with a fear of falling behind their peers if they do not stay connected to their learning⁴.

Medical advances means the number of children living with long term conditions is increasing.

¹Recent data highlights that 18% of secondary school in Wales report living with a long-term health issue or disability, which makes the education of children and young people with long-term health conditions of increasing importance⁵.

The United Nations Convention on the Rights of the Child (UNCRC)

The UNCRC is an international human rights treaty that applies to all children and young people up to the age of 18. The Rights of Children and Young Persons (Wales) Measure 2011 places a duty on Welsh Ministers, in exercising all of their functions, to have 'due regard' to the UNCRC. The Welsh Government sets out how it feels it meets this duty in a Children's Rights Scheme⁶.

There are important considerations regarding the education of children and young people in healthcare settings, which are outlined in the UN Convention on the Rights of the Child. These include:

- **Article 2 (non-discrimination):** the right to be protected against all forms of discrimination
- **Article 12 (respect for the views of the child):** the right of the child to express views on all matters which affect them
- **Article 23 (special care for children with disabilities):** the right for a child with a disability to have a full life and to have the independence to play an active part in decision making about their care
- **Article 28 (right to education):** all children have the right to access education
- **Article 29 (goals of education):** the right to access an education which develops the personality, talents and mental and physical abilities of the child to their full ability.

¹Mintz, J., Palaologou, I. and Carroll, C. (2018). A review of educational provision for children unable to attend school for medical reasons. University College London. [online]. <https://www.hhe.nottingham.sch.uk/wp-content/uploads/2019/10/A-review-of-educational-provision-hospital-and-home-education-services-UCL-2018.pdf>.

²Vanneste, Y, Loo, M., Feron, F, Rots – de Vries C, Goor, L.D., (2016). Attitudes towards Addressing Medical Absenteeism of Students: A Qualitative Study among Principals and Special Education Needs Coordinators in Dutch Secondary Schools. *PLoS ONE* 11(2): e0148427. <https://doi.org/10.1371/journal.pone.0148427>.

³Gilmour, M., L. Hopkins, G. Meyers, C. Nell, and N. Stafford. (2015). School Connection for Seriously Sick Kids. Who are They, how do we Know What Works, and Whose job is it? *Canberra, Australia: Australian Research Alliance for Children and Youth*. https://www.aracy.org.au/publications-resources/command/download_file/id/331/filename/School-connection-for-seriously-sick-kids-full-report-web.pdf

⁴Sextou, P. (2021). Theatre in paediatrics: can participatory performance mitigate educational, emotional and social consequences of missing out school during hospitalisation? *Research in Drama Education: The Journal of Applied Theatre and Performance*, pp.1–18. <https://doi.org/10.1080/13569783.2021.1940914>.

⁵Page N., Angel, L., Ogada, E., Young H., Murphy S., (2023). Student Health and Wellbeing in Wales: Report of the 2021/22 Health Behaviour in School-aged Children Survey and School Health Research Network Student Health and Wellbeing Survey. Cardiff University. <https://www.shrn.org.uk/wp-content/uploads/2023/04/SHRN-2021-22-National-Indicators-Report-FINAL-en.pdf>

⁶Welsh Government (2021) Children's Rights Scheme. <https://www.gov.wales/sites/default/files/publications/2021-12/children%27s-rights-scheme-2021.pdf>

The legal framework in Wales

Local authorities are responsible for the provision of a suitable education for children of compulsory school age who live in their area. This includes education provision for children who are in-patients in hospitals, or who cannot attend school for other reasons, including ongoing medical needs. This is set out in Section 19A(1) of the 1996 Education Act.

The Curriculum and Assessment (Wales) Act 2021 amended section 19 by inserting section 19A. This sets out that:

(1) Each local authority in Wales must make arrangements for the provision of suitable education at school or otherwise than at school for children within the authority's area who —

(a) are of compulsory school age, and

(b) by reason of illness, exclusion from school or otherwise, may not receive suitable education for a period unless such arrangements are made for them.

Guidance

In fulfilling this legal duty, local authorities must have regard to [statutory guidance](#)⁷ issued by Welsh Government in March 2017. This guidance sets out the following at 2.10.

In the case of a short absence (likely to last for less than 15 school days) the learner's school should provide work to be completed at home, if the learner's condition permits, and support the learner to catch up on their return. The local authority should be ready to make arrangements for learners in cases where it is clear that the learner is likely to be absent from school for a significant period, e.g. more than 15 school days, whether consecutive or cumulative over the course of an academic year. However, the local authority might still need to make arrangements if a shorter absence is anticipated, depending upon the circumstances.

⁷Welsh Government (2017) Supporting Learners with Healthcare Needs. <https://www.gov.wales/sites/default/files/publications/2018-12/supporting-learners-with-healthcare-needs.pdf>

However, the 2017 guidance does not include any information about how much educational provision this could or should involve for children and young people in a healthcare setting. Once a child is deemed to require alternative education outside of school, the relevant guidance is the Education otherwise than at school Framework for Action (2019) [Education Otherwise Than At School Framework for Action](#)

The EOTAS framework for action has not been updated to include the new curriculum requirements, and does not reflect the 2021 amendments in order to define what a 'suitable education' means for children who are in hospital, or an in-patient in another healthcare setting. The guidance does not make clear the requirements for children who need to receive their education at home due to healthcare needs.

In relation to the 2017 statutory guidance, an evidence paper provided by the Education Minister to the Senedd's Children, Young People and Education Committee⁸ explained how Welsh Government provided information for children who undertake their education in a setting other than in school (EOTAS). An Independent healthcare plan (IHP) should outline the support needed by a child or young person, which is agreed in conjunction with the child or young person, parents and practitioners. Welsh Government highlight that these children should be supported through an EOTAS placement: this includes education in a healthcare setting. Furthermore, a reintegration plan is cited as good practice to help a child or young person to transition back into mainstream education provision.

In 2019's *Education otherwise than at schools (EOTAS) framework for action*⁹, Welsh Government commit to, in the short term, 'develop non-statutory guidance on the development of commissioning frameworks and quality requirements for EOTAS provision which includes ongoing monitoring of placements'. And in the longer term, Welsh Government will 'consider introducing a statutory requirement for local authorities to establish commissioning frameworks'. The COVID-19 pandemic has affected these timescales, but we expect Welsh Government to now undertake this work. Guidance on commissioning frameworks should include reference to children learning in healthcare settings, and to Welsh Government's expectations of offering a full education offer.

In a June 2023 report¹⁰, the schools inspectorate in Wales, Estyn, stated that the Welsh Government's expectation is that 'all pupils, regardless of where they are educated, should receive a full-time education'. The report goes on to say that while a full time education might not always be appropriate for the learner, 'this should not be a unilateral decision by the local authority or provider but in agreement with the parents, carers and pupil'. Estyn outlines its concerns over the inconsistency of local authority processes for agreeing the length of EOTAS placements, and reviewing the arrangements. This provides a barrier to the successful reintegration of learners. Estyn recommends that local authorities ensure placement decisions are taken promptly and identify an agreed duration, clear roles and responsibilities and a review date.

The Welsh Government's expectation over the provision of a full-time education, or the appropriate provision of education to suit the individual learner, therefore, must be more clearly set out in statutory guidance to local authorities.

The wider UK context

⁸Senedd Cymru (2020). Evidence paper from the Minister for Education, Welsh Government - National Assembly for Wales Children, Young People and Education Committee Inquiry into Education Otherwise than at School. <https://business.senedd.wales/documents/s99922/EOTAS%2032%20Welsh%20Government.pdf>

⁹Welsh Government (2019). Education otherwise than at schools (EOTAS) framework for action. <https://www.gov.wales/sites/default/files/publications/2019-09/education-other-than-at-school-framework-for-action-2019.pdf>

¹⁰Estyn (2023) Equity of curriculum experiences for pupils who are educated other than at school (EOTAS). https://www.estyn.gov.wales/system/files/2023-06/Equity%20of%20curriculum%20experiences%20for%20pupils%20who%20are%20educated%20other%20than%20at%20school%20%28EOTAS%29_0.pdf

¹¹Department of Health and Social Care, UK Government (2015). Guidance – Hospital Education: a guide for health services. <https://www.gov.uk/government/publications/hospital-education-a-guide-for-health-services/hospital-education-a-guide-for-health-services#legal-responsibility-for-providing-education>

[hospital-education-a-guide-for-health-services/hospital-education-a-guide-for-health-services#legal-responsibility-for-providing-education](https://www.gov.uk/government/publications/hospital-education-a-guide-for-health-services/hospital-education-a-guide-for-health-services#legal-responsibility-for-providing-education)

¹²OFSTED (2018) 'Outstanding' report of Great Ormond Street hospital 2018. <https://files.ofsted.gov.uk/v1/file/2786545>

¹³OFSTED (2018). 'Good' report of Manchester Hospital School 2018. <https://files.ofsted.gov.uk/v1/file/2778699>

¹⁴Scottish Government (2015). Guidance on education for children and young people unable to attend school due to ill health. <https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2015/06/guidance-education-children-unable-attend-school-due-ill-health/documents/00479700-pdf/00479700-pdf/govscot%3Adocument/00479700.pdf>

In England there is a legal requirement for education other than at school to be full time, unless not in the best interests of the child¹¹. In Wales, local authorities and governing bodies must have regard to guidance which states that learners '**should have full access to education...**'. This is not the same. Recognised good practice examples in hospitals in England^{12/13} suggest that this full-time requirement can be met through a range of learning activities over the course of a week, which might include elements of individual tuition, group work, online activities, and self-led learning, and which together constitute a full-time education programme. It also recognises the intensity of individual tuition, and indicates that 'full time' must be suitable to the child and their needs.

This legal requirement for England is set out in the Education Act 1996 at Section 19 3.A. The Education Act 1996 is also the law that underpins the provision of education other than at school in Wales. However, the 1996 Act, and the amended 19A, does not specify an equivalent entitlement for children in Wales to have full time education other than at school.

In Scotland and Northern Ireland, duties appear broadly similar to those in England, with legal duties on the authority in which the child is resident to secure a suitable education for the child. In Scotland this duty begins immediately if a child or young person's illness is 'known or reasonably thought to be likely to extend to or beyond 5 days' and they are well enough. When the length of stay is less clear, the education provision should begin after 'no more than 15 working days of continuous or 20 working days of intermittent absence'¹⁴.

We include examples from across Europe of different approaches taken to supporting learners in the appendix to this report. We encourage Welsh Government to review practice from across Europe as well as within the UK.

Methodology

Through our research we heard the views of children, families, and professionals on the topic of education within healthcare settings.

We gathered data from 18 children and young people, aged 5 to 16, who were in a healthcare setting during July and August 2022. We wanted to find out what they think and feel about their education when they are in a healthcare setting. We made a specific participation pack to gather their views. This included a resource for healthcare professionals to use on our behalf in one-to-one sessions with children and young people. We adopted this particular methodology in consultation with education professionals, taking into account the need for a flexible approach to engaging with children in a healthcare setting. The activities supported children to tell us what they like about their learning, and what they would like to change or improve.

It is important to remember that children and young people who have not been able to or well enough to receive education in their medical settings or are unable to access it, have not had an opportunity to give feedback.

We also received some information from the parents of children in a healthcare setting, focusing on their knowledge of their child's entitlement to receive an education, how satisfied they were with the education provision and the role of the school during their child's stay. We did this through phone calls and emails.

We engaged with 14 professionals and 6 settings, through a combination of face-to-face meetings, and an online survey. We also sent a survey to every local authority in Wales, and received responses from 17 local authorities. Our project scope focused on inpatient provision of education where this duty belongs to the local authority (over 15 days). We wanted to include a broad context and so captured experiences of outpatient (e.g. day unit) care in our initial research phase as well as capturing case studies of those children receiving education in other settings.

Key themes from research

The value of education: What children, young people, parents and carers told us.

All of the children and young people we heard from really valued the education and activities they received.

Education is seen as an enjoyable activity that the children and young people look forward to and helps them to feel 'normal' in an otherwise scary or difficult situation.

It made such a difference on making me feel 'normal' on the days we did tuition together.

16 year old in hospital for more than 8 weeks

More hours would be better on dialysis. Dialysis sessions are boring for young children. More than one hour of fun learning with Isabel [hospital teacher] is needed. Just not long enough.

12 year old in hospital for more than 8 weeks

Keeps me up to date with work from mainstream school, decreasing stress and anxiety about returning.

In terms of improvements to education provision, responses were dominated by a desire for more: more trips; more maths; more time to go to school; and more teachers.

I would like to fly. I would like to have sessions with other children. I would like to see teachers every day.

5-7 year old in hospital between 4 – 8 weeks

There was also a desire for the education in a healthcare setting to continue after 16 years of age. This age group of young people can experience significant disruption to their education at a time when they are sitting important exams (GCSE and A Level).

[The hospital teacher] got me through my 'unusual' year 11! Without her dedication, I don't think I'd have been sitting my GCSEs this year.

16 year old who was an inpatient for over 100 days

Parents and carers told us about the incredibly difficult time they experience when their child is unwell and in a healthcare setting for a lengthy period.

For these parents, their child continuing to receive education whilst in a healthcare setting is really important for their child's wellbeing, and is one less thing to worry about.

X gets a lots of anxiety associated with hospital stays so the one thing that he loves consistently even when he is unwell during his hospital stays is having his education.

Parent/carer

You've [hospital teacher] done such a fab job and we think the services you offer are exactly what children and other people need while they have possibly long stays at hospital to help with feeling normal in some way, it greatly helps their mental health and helps prepares them for when they do go back to a mainstream school like she will be in September. She feels you made all the difference with how confident she feels with attending school again.

Carer

Similarly, to the children and young people's responses, parents and carers would love to see more time given to education when their child is unwell and in a healthcare setting. Parents mentioned their children sometimes receiving as little as 2 sessions a week of an hour's duration.

Only 33% of healthcare professionals agreed that the education provided is enough to meet the needs of all the children they work with.

Variation in funding and hours of education provided

Inconsistent funding arrangements for the education children and young people receive whilst in a healthcare setting was a core issue from the data we collected.

Our survey responses showed that for each child, the number of hours typically funded per week by the local authority varied from 5 to 20 hours across Wales. And only 33% of healthcare professionals agreed that the education provided is enough to meet the needs of all the children they work with.

One professional felt that the most important thing needed to improve education in healthcare settings in Wales was 'agreements with Local Education Authorities (LEAs) so that no child misses out due to bickering about paying for places.

Another professional said that one of the main challenges involved in delivering education was "staffing to meet individual needs due to funding".

Inconsistent Experiences

One parent we interviewed had been made aware, by her child's school, of a bill they'd received following her child's short stay in hospital, after she'd taken part in some learning offered there. This caused her stress during what was already a distressing time.

In another example of a funding arrangement that wasn't child-centred, a healthcare setting described how a child had received some education in their bed because they were unable to go down to the setting's dedicated classroom. The child's local authority then refused to pay for the education the child had received, because it had taken place outside of that classroom.

On the other hand, a response from one professional described how a funding arrangement between the setting and the neighbouring local authorities meant that all children were able to access education without any issues, including post-16 learners:

"All young people, regardless of age and stage - once admitted to the ward, attend the education centre as part of ward routine - this has been agreed through a service level agreement between the local education authorities".

Generally, many other professionals highlighted the need for increased funding, particularly around post-16 education. Other professionals highlighted the need for funding to support additional resources and specialist equipment and technology where this is needed by individual children.

Health professionals also said that they see disparity in the amount of funding awarded across UK healthcare settings, and healthcare settings offered variable amounts of education each day.

Local authority responses

76% of the 17 local authorities surveyed said they funded the education without reclaiming costs from the child's school.

The remaining authorities said they used different approaches, including: **a 'budget for hospital tuition which is paid via our Pupil Referral Unit (PRU) who are responsible for all tuition'**; and two authorities described a system where part of the money is paid for by the authority, and part paid by the school.

In response to a question asking what they would change about education in health settings, one local authority suggested that it should be funded per bed by the Welsh Government.

A funding per-bed model was also called for by a health professional, who said it would **'ensure staff are available and in place when the patient needs education'**.

Funding - Case Studies

We heard how inconsistent funding arrangements across Wales result in inconsistent educational experiences for children and young people.

In their own words, two settings in different parts of Wales describe their educational offer for children and young people.

Coed y Deryn

Coed y Deryn provides education at Noah's Ark Children's Hospital.

Here at Noah's Ark Children's Hospital in Cardiff we unfortunately do not have a hospital teaching budget for learners who live outside our Local Authority so the costs are recouped from the relevant Local Authority.

What this means in practice is that Local Authorities and often schools receive a bill for their learner's education whilst they are in hospital. Often a school will have more than one learner with us so the financial implications can be detrimental to what already is a fiscally challenging time for schools!

This funding formula also has restrictions in terms of us denying offering teaching support to learners who receive private education and for those who are home schooled. Can you imagine the impact upon learners and their families when they observe a fellow patient, quite possibly in the same cubicle as themselves receiving education just because they are fortunate enough to attend a Local Authority school. It denies hospital learners one of the principles from the UN Convention on the Rights of the Child - Article 28 (right to education) "Every child has the right to an education."

Currently at Noah's Ark we have one full time teacher (increasing to 2 full time teachers from September 2023) to work with learners ranging from 4 years old up to 16 and often 17 years old (if their have an additional need). What this means in practice is that many learners are not receiving the minimum requirement of up to one hour of hospital teaching per day [this is a reference to previous Welsh Government guidance], although this will double in September 2023 and we will be able to provide Welsh medium tuition too. I'm sure you'll agree that the target of a learner receiving up to one hour each day is woefully inadequate, especially when you consider that other hospital schools in the UK might have up to 5+ staff, including staff with specialisms and teaching assistants.

Nant-y-Bryniau

Nant-y-Bryniau is an educational facility that provides education and support to the young people who are admitted to The North Wales Adolescent Service Unit's (NWAS) Kestrel Ward, and to Kite, the Intensive Community Support Team, both CAMHS tier 4. The education staff work in close partnership with both teams; assisting in meeting the needs of patients from across the whole of North Wales admitted to the services due to their mental health needs.

Nant-y-Bryniau is run by Conwy Local Education Authority on behalf of all the unitary authorities across the north of the country plus north Powys. We are situated in a purpose-built facility adjacent to NWAS in the picturesque grounds of Abergele Hospital. Upon the move to the present site, 14 years ago, a service level agreement was drawn up between heads of education for each local authority to determine responsibilities, funding and charging. Additionally, with the formation of the Kite community team in 2014, a further agreement was made to allow young people admitted to this service to benefit from Nant-y-Bryniau education provision.

Young people admitted to Kestrel ward attend the education centre for five hours of the day through term time where, if under 16 or post 16 still in education, links are kept up with the mainstream setting with the aim to continue the young person's existing curriculum as closely as possible. Where young people are post 16 and out of education, the centre works with the young person to agree a relevant personalised education experience focussing on skills to return to learning or to access employment, life skills, next steps planning, and wellbeing. Young people admitted to Kite are supported according to individual needs with some having support in the community around accessing employment, college or their mainstream school with others able to access the education centre up to 5 afternoons a week.

The education team is made up of 3 full-time teachers, 1 part-time teacher and 3 teaching assistants with full-time administrative and examinations support. The centre can cater for up to 12 full-time inpatients and 6 part-time community patients with other work to meet the needs of some Kite patients in the community as required.

Local authorities highlighted communication as the key aspect that they would want to see change in regards to education in healthcare settings

Multiagency working and communication

Overwhelmingly, local authorities highlighted communication as the key aspect that they would want to see change in regards to education in healthcare settings.

Ideas for improvement included 'better communication from schools in the first instance to alert the authority' that a child is receiving treatment and requires an educational provision, and 'improved communication between healthcare settings/school and the local authority'.

One authority suggested 'a process for developing a shared understanding between local authorities and settings', highlighting that this could bring opportunities 'to review and co-construct education offer in in-patient settings'.

Other suggestions included:

"A clear plan in place with health, parent, child, school and local authority, something which is recorded, monitored and reviewed"

"Earlier awareness raising with local authorities to enable closer working, monitoring and evaluation of the effectiveness of what is provided."

One local authority said:

"There is often no direct network/connection with Health settings to consider such care plans or to facilitate education other than at school (EOTAS)."

Transition to the community

Issues around communication was given as a particular barrier when discussing the transition of education provision from the healthcare setting back into the child's community, typically their home environment. Some professionals commented on the issue of services failing to be joined up and that a focus is needed on inter-agency communication. One example highlighted by a healthcare professional was the need for better discharge planning, saying that there should be "Immediate Team Around the Child (TAC) meetings for all learners who have been in for over 4 weeks".

83% of responses from Local Authorities said yes, there are ways that discharge processes could be improved to ensure continuous education provision when a child leaves an inpatient setting.

Suggestions for improvement of this process included a universal approach regarding notification of discharge from a healthcare setting and better communication between healthcare settings, schools and the local authority to identify any support mechanisms needed to support children to continue to engage with their education when discharged. One local authority highlighted that they only received medical discharge information about a child - not their educational needs.

Awareness that a child is eligible for provision

Our findings highlighted differences in how the relevant healthcare professionals are notified of a child's eligibility and need to access education. Some teachers in healthcare settings were notified by medical professionals in their setting, others are notified by the child's school. One professional said that they were unaware of a system in place for children in their healthcare setting to access education provision.

In terms of local authorities, some said they become aware of the need for a child to receive education in a health setting when they are notified by the school and others said they become aware when notified by the healthcare setting. One authority said that parents or guardians have informed them of this need too.

Answers demonstrated considerable variance across Wales in how a child's need and eligibility for education is recognised and responded to.

81% of the local authorities surveyed said they thought there could be improvements to the process of identifying when a child is eligible for educational provision in a healthcare setting.

Suggestions included:

"A simple compulsory notification system similar to the Operation Encompass Model that notifies schools/local authorities in a timely manner at the time the situation occurs."

"Having notifications as soon as the pupils are in Hospital and require tuition."

"It would be more beneficial to have information before the pupils are admitted. We could support more if we were informed that this is a potential option."

One authority said they are only informed when they are invoiced for the education:

"We only receive information during or after the placement. We are not informed until we are invoiced. Some of this will be our internal systems that need to improve but currently we are informed of the number of sessions, not hours, and very little about what is being provided."

There were also differences in answers from healthcare settings about when a child is eligible to receive education after notification:

One setting answering our survey said that a child would become eligible to receive an education 15 days after being admitted.

But other settings said that a child would be offered education straight away providing that they were feeling well enough to learn.

Equity for all learners

93% of healthcare professionals who responded to our survey said there were particular children that did not have suitable access to education when they are a patient in a healthcare setting.

Post-16 education

Responses to our surveys suggested young people aged 16 and over as a group likely to miss out on education in a healthcare setting. Responses from professionals working in healthcare settings showed that some young people over the compulsory school age do receive an education offer, while others don't.

Whilst there isn't a legal duty on local authorities to provide education other than at school (EOTAS) to children over 16, the Supporting Learners with Healthcare Needs guidance states:

Local authorities should arrange for the continuation of education for learners over 16, but less than 18 years old, where because of illness, the learner needs to study to complete their qualifications. Where the learner has a statement of SEN, the local authority remains responsible for that learner until they are 19.

Case study | Access denied to 17-year-old

Our Investigation and Advice team was contacted by a parent whose 17-year-old child is an in-patient at a healthcare setting. When the child was 16, they were able to access education provision because they were of statutory school age. Since turning 17, they are no longer able to access the educational provision at the healthcare setting, because education is only offered up to the age of 16 due to limited resources. This is despite medical professionals involved with the child noting that the child would benefit from education as part of their care plan or therapeutic package of support.

The setting have told us they would be happy to provide the education if the appropriate funding was available.

(Investigation and Advice service, Children's Commissioner for Wales)

Some healthcare settings who do provide an education for post-16 said it isn't always easy to find specialist teachers for post-16 qualifications.

In response to a question asking how young people 16+ might be better supported, some local authorities suggested online learning might offer a greater breadth of options, as did some health professionals.

Better communication between local authorities and healthcare setting was also cited as a way to improve young people's access to post-16 education in healthcare setting.

Support for children with additional needs

Professionals with additional learning needs can also miss out because of a lack of adequate resources.

35% of local authorities surveyed said there are challenges in meeting the needs of children and young people with additional learning needs when it comes to education in healthcare setting.

Those challenges included the breadth of the learning available, not always receiving notifications from the health setting or a lack of communication to consider individual plans, meeting a child's complex needs, and having profound and multiple learning disabilities (PMLD) resources for older learners.

Our surveys also highlighted a lack of specialist equipment to facilitate education for children and young people within healthcare settings. Many children need to have adjustments made to maximise their participation within education and access their human right to education under the UNCRC. Difficulty in accessing equipment, delivering specialist education and meeting communication needs were all reported to impact upon children and young people's access to education.

One health professional mentioned that often a lack of specialist equipment impacts the education that children with additional learning needs are able to receive within their setting. One example we heard about was a young person who wasn't able to access the education centre and is using a laptop on their ward to facilitate their education access. Another professional mentioned a lack of equipment for communication needs.

Welsh Language provision

42% of Local Authorities reported issues in providing education through the medium of Welsh in local healthcare settings. Some said this was due to a lack of Welsh language tutors, and others said that it was due to the child being in a healthcare setting in England.

This highlights a language equity issue in terms of accessing education whilst a child is in a healthcare setting. Article 30 of the UNCRC states that children have the right to use the language of their choice. The UN Committee on the Rights of the Child have stated in General Comment no.11 that 'in order to implement this right, education in the child's own language is essential'.

Case study | Welsh Language Provision

A parent contacted following their child's admittance to hospital in October 2021 raising the issue of access to Welsh medium education. The child attends a Welsh medium primary school but was facing weeks, possibly months in hospital due to his medical needs without access to education in Welsh. The hospital had to request a Welsh medium teacher from the local authority and 5 hours of tuition to be taught in Welsh was subsequently agreed. This decision appeared to be made on a case by case basis and the parent shared that whilst they were glad the issue had been resolved for them that they didn't understand why the provision was not already in place within the local authority.

(Investigation and Advice service, Children's Commissioner for Wales)

Learning environment

Whilst healthcare professionals highlighted the inevitable challenges of balancing children's educational needs with their health and care needs, there were also challenges related to the learning environment itself.

In response to a question asking health professionals what would improve educational provision in their setting, there were specific answers about the quality of the learning environment.

One respondent wanted "a physical space to learn" and another highlighted the need for more funding "to improve facilities and equipment".

The learning environment was said to affect specific children in different ways. We heard that young people not in education or employment can be difficult to engage in a classroom setting and would need more facilitates that support vocational learning:

We have some young people in hospital who are not in education or employment on arrival - we do our best, but it is difficult to cater for their needs while education is not compulsory through to 18 - they are difficult to engage in a classroom setting - we would need more vocational facilities and staff.

Some professionals reported there being no physical space away from the bedside to undertake educational activities, and the negative impact this can have:

Patients who are here for a long time do not have sufficient opportunities to keep up with their curriculum. No physical space to learn away from their beds promotes an attitude of 'I am sick so I don't need to engage', which diminishes their ambition to learn and is bad for their wellbeing.

Respondents highlighted the benefits of space away from the ward setting in some incidences, whilst some services are not able to offer this environment to children and young people.

Education at home due to healthcare needs

Whilst not the focus of this report, we are aware that there are also challenges for children who receive an education at home because of their healthcare needs. One case study highlights the importance of considering those children who need to receive education at home because of their health needs:

Case Study | Home tuition

We were contacted in relation to a young person who has been receiving home tuition because they cannot access a physical building due to health needs. This has been the case for the past 16 months. During this time the young person has been allocated just three hours per week home tuition, which was confirmed by the EOTAS manager as correct and in line with the local authority policies.

(Investigation and Advice service, Children's Commissioner for Wales)

Recommendations

Key recommendation

1. I recommend that the Welsh Government reviews Local Authorities' legal duties to provide **full-time** education to children who, because of illness, would otherwise not receive suitable education. The guidance must be clear that local authorities are responsible for ensuring Welsh children receive the same legal entitlement as their counterparts across the UK.

Further recommendations

2. I recommend that Welsh Government revises the guidance for providing Education Other Than At School (EOTAS) to include an expectation that local authorities facilitate the delivery of the equivalent of a full-time education offer for children who are receiving ongoing or acute healthcare, unless it is not in the best interests of the child.
3. I recommend that updated guidance places a duty on EOTAS leads in every local authority to routinely collect children's views on the education they receive.
4. I recommend that Welsh Government review current funding arrangements for education in healthcare settings across all local authorities and engage with stakeholders to enable a universal approach for funding to be embedded across Wales.
5. I recommend that transition and reintegration plans are included in guidance to strengthen the links between education, health and local authorities for children and young people who receive education in a healthcare setting and will be returning to their previous educational arrangements. These plans must be co-produced with children and young people.
6. I recommend that guidance is updated to reflect the new curriculum to ensure continuity of education for children and young people with health needs within whatever setting education is provided.
7. I recommend that guidance is updated to ensure all children and young people under the age of 18 can access educational provision when they are an in-patient in a healthcare setting.
8. I recommend that an integrated impact assessment (including a children's rights impact assessment) is undertaken by Welsh Government in relation to the guidance, including the needs of disabled children and those accessing post-16 education.
9. I recommend that Welsh Government support settings to enable children and young people to receive their education in the Welsh language when in a healthcare setting. This should be included in any commissioning framework.
10. I recommend that guidance is updated to reflect new entitlements under the ALNET Act for learners to receive support with their education, wherever it is being delivered.

Recommendation 1

I recommend that the Welsh Government reviews Local Authorities' legal duties to provide full-time education to children who, because of illness, would otherwise not receive suitable education. The guidance must be clear that local authorities are responsible for ensuring Welsh children receive the same legal entitlement as their counterparts across the UK.

Recommendations 2 and 3

I recommend that Welsh Government revises the guidance for providing Education Other Than At School (EOTAS) to include an expectation that local authorities facilitate the delivery of the equivalent of a full-time education offer for children who are receiving ongoing or acute healthcare, unless it is not in the best interests of the child.

I recommend that updated guidance places a duty on EOTAS leads in every local authority to routinely collect children's views on the education they receive.

A clear message from children, young people, parents and carers taking part in this research is that they would like more education for children when they are in a healthcare setting. The findings of our research also show that education for children with healthcare needs in Wales is not being thought of as a full-time education programme. 7 of the 17 local authorities who completed our survey said they typically funded a maximum of five hours' provision a week, which reflects obsolete advisory guidance from Welsh Government. Sometimes not even 5 hours were offered.

Cases in which an equivalent full-time offer is not appropriate, this must be rationalised in a child's Individual Healthcare Plan (IHP) or Individual Development Plan (IDP) and discussed with the child, parent, and guardian, their usual educational provider and healthcare setting. We are concerned that, too often, children do not have adequate input into the education they receive and whether it suits their needs. Only 1 of the 17 local authorities who completed our survey said they always gather children's views about the education they receive. Currently, the *Supporting Learners with Healthcare Needs* guidance only states that an IHP should be discussed with the child and parents / guardians.

The current guidance does not include any information about how much educational provision a full educational programme could or should involve for children and young people in a healthcare setting, nor does it include any information about the types of activities this would involve. It does not include the new curriculum requirements, and does not reflect the 2021 amendments in order to define what a 'suitable education' means for children who are in a healthcare setting, at home, or are an in-patient in another healthcare setting due to healthcare needs.

Our case study recognises the impact that unclear guidance has for children and young people who are receiving their education at home due to health needs. EOTAS guidance and the guidance, *Supporting Learners with Healthcare Needs*, must be better linked to ensure this group of children and young people are accessing their entitlement to education.

Recommendation 4

I recommend that Welsh Government review current funding arrangements for education in healthcare settings across all local authorities and engage with stakeholders to enable a universal approach for funding to be embedded across Wales.

Our report highlights the clear disparity in funding arrangements for the education that children and young people with healthcare needs receive. This is reflected by local authorities, healthcare professionals and teachers in healthcare settings. The challenging funding arrangements has clearly impacted children, parents and carers, as well as schools.

Welsh Government must advance their previously referenced work on instructing local authorities to produce commissioning frameworks for the education of children and young people with healthcare needs. These frameworks should be evidence based: our report features good practice examples of where funding arrangements have led to a positive delivery of education for children and young people. These and other examples should be acknowledged to form pragmatic funding arrangements. One example our data captured was a funding per bed arrangement.

Recommendations 5 and 6

I recommend that transition and reintegration plans are included in guidance to strengthen the links between education, health and local authorities for children and young people who receive education in a healthcare setting and will be returning to their previous educational arrangements. These plans must be co-produced with children and young people.

I recommend that guidance is updated to reflect the new curriculum to ensure continuity of education for children and young people with health needs within whatever setting education is provided.

Throughout the process, from notification to discharge and the transition back into previous arrangements, challenges have been highlighted around communication between schools, local authorities and healthcare settings. Our data highlights different notification processes, along with confusion about how and when children are identified as needing educational provision. Discharge planning was found to be a key issue for services and clearer pathways of notification and planning processes are needed to ensure there are no unnecessary gaps to a child or young person's education. There must be a shift towards a whole-systems approach that places the child or young person at the heart of their educational provision, regardless of healthcare need or setting. Services must work in partnership, recognising the strengths they can offer a child regarding their education.

Recommendations 7, 8 and 9

I recommend that guidance is updated to ensure all children and young people under the age of 18 can access educational provision when they are an in-patient in a healthcare setting.

I recommend that an integrated impact assessment (including a children's rights impact assessment) is undertaken by Welsh Government in relation to the guidance, including the needs of disabled children and those accessing post-16 education.

I recommend that Welsh Government support settings to enable children and young people to receive their education in the Welsh language when in a healthcare setting. This should be included in any commissioning framework.

Under the UNCRC, all children under the age of 18 are entitled to a full education. Our research has shown examples of how an effective funding model means that all children under the age of 18 can access full education in a healthcare setting. We have also seen examples of less effective funding models which mean that this offer isn't available to post-16 learners. Welsh Government must ensure there is equity across Wales so that all under 18s can access their human right to education.

We know that losing connection to education can impact a child's health, social and educational outcomes. This is therefore an equity issue that must be understood and tackled by all agencies involved in a child's education.

An integrated impact assessment will be an important step when considering any changes to the legislation or guidance relating to the education provision for children and young people with healthcare needs. Whilst post-16 provision has not been the focus on this report, our data showed the variation the offer across Wales. Access for young people should not vary by location. Guidance must also recognise the situation of post-16 qualifications being offered to young people aged 16 or over who are undertaking qualifications later due to health needs impacting their education.

Our case study and survey data raised concerns around the offer of Welsh language education in Wales for those children and young people who are receiving education within a healthcare setting. This must be addressed through expansion of the workforce, but also the use of external support and technology to enable children and young people to access their education in the Welsh language. The Welsh Government's forthcoming Welsh Language Education Bill should reflect alternative settings as well as maintained schools to ensure access to education through the medium of Welsh.

Recommendation 10

I recommend that guidance is updated to reflect new entitlements under the Additional Learning Needs and Educational Tribunal (Wales) Act, for learners to receive support with their education, wherever it is being delivered.

In Wales an Individual Development Plan (IDP) should set out the support a child with additional learning needs requires in school under the ALNET Act (2018). The ALN Code states that the duties under the Act apply equally to a child with healthcare needs, but that an existing IDP may be reviewed depending on the context. Under the 2017 *Supporting Learners with Healthcare Needs* guidance, children and young people should have an Individual Healthcare Plan (IHP) if they require one. These should 'capture key information and actions required to support the learner effectively', and should be populated by the learner, their parents and relevant agencies across health, social care and education. Both the existing IDP and the IHP should be considered by the local authority and arrangements made on how to honour these needs.

Our report demonstrates the difficulty some education providers faced in meeting the needs of children and young people with healthcare needs regarding their education. A lack of funding, specialist equipment and staffing were all factors that impacted this. Physical spaces, workforce and specialist equipment must be considered to support all children and young people within a hospital or another healthcare setting to receive the education that they are entitled to. Technology enhanced learning is one component of this, but a wider assessment of need is required. Including consideration of disability within an integrated impact assessment will be an important step in this work.

Appendix: practice across Europe

Wider European context

We have found that our European counterparts (Children's Commissioners or Ombudspersons) highlight some positive approaches to education provision within hospitals that could inspire future best practice guidance in Wales.

Ireland

We spoke with relevant professionals in Dublin about their local educational provision for children under hospital care. They explained the work underway for a new hospital that will contain dedicated space on each ward for hospital teachers. This will support the ability for children and young people to access their education whilst admitted to hospital.

They are a member of HOPE (Hospital Organisation of Pedagogues in Europe) which sets standards for hospital based education for children and young people.

Netherlands: regional consultants working with schools and families

In the Netherlands there are legal duties to provide education for children with healthcare needs and this is met through a network of consultants based from the regional education consultancies and the educational facilities of the university medical centres. The Ziezon network was established in 2000 for professionals to share their knowledge and experience and to work together efficiently and effectively. The common goal is to provide pupils and their teachers the best possible educational support when a pupil is dealing with a chronic illness. The school where the child is registered engages an educational support consultant from Ziezon and this consultant works with the school, the child and the family to create an education plan. The aim is to minimise interruption to education and to keep children involved in their class and in touch with their teachers, whilst at the same time providing expertise specific to the child's healthcare needs.

Flemish Belgium: additional funding for schools augmented with voluntary networks

Children in pre-primary, primary or secondary education who are ill are entitled to receive individualized instruction at home by a teacher from their regular school, for 4 lesson periods per week. This can start after the student has been 3 weeks absent from school due to the illness, or with chronic healthcare needs, this can start when the student is absent for 9 half school days. If the child is a patient at a hospital with a school then this is provided by the staff of that school, in the hospital or at home. Alternatively it is provided by the child's school, which receives additional funding to organise tuition. If needed, the school can appoint additional teachers to provide this with their additional funding. This is also supported by the voluntary sector: 'School & Ziekzijn' (school and being ill) is a network of autonomous non-profit organizations who provide teachers employed on a voluntary basis as tutors for children between 5 – 18 years who cannot attend school or who are regularly absent due to healthcare needs. Another voluntary organisation is Bednet, which is a Flemish non-profit organisation (partly funded from the Flemish Government) and which facilitates synchronous internet education for children who cannot attend school. Bednet provides the student's regular school and the student at home with IT equipment to make it possible for the student to follow class and lesson activities online while being at home, in a hospital or in a residential health care centre.

Croatia: primary schools offering support, but gaps for older young people

The Children's Ombudsman in Croatia reports that primary schools close to a hospital or healthcare provision organise lessons for the children that are patients, and that this works well for primary aged children. However, there are gaps for secondary aged pupils and the Ombudsman is recommending improvements for older children, suggesting, 'We believe that the experience of online teaching during the Covid-19 pandemic will help in overcoming the obstacles and we will certainly insist on solving the issues.'

Norway: additional authority level support for children attending frequent day visits

In Norway legal duties to secure education when a child is ill apply to the home county of the child. This can begin anytime that the child can't access their regular school, but is not expected for a short one-off stay of a few days. However, the duty begins when the stay is longer than a few days or when the visits are short but frequent. In these instances, this duty also include day patients and outpatients and in these cases the local authority should draw up a plan with the home school. There needs to be a case by case sign off by a clinician if the child is too ill to access education. The assumption is that all children will engage in education unless they clearly cannot or unless their clinician needs to write a statement to this effect. Education appears to be viewed as part of the holistic health support of the child. Exemptions to the curriculum can be obtained but these are exceptional and the parents need to consent. If an exemption is made then the student has a right to complete this at a later point if they request.

