

Introduction

1. We welcome the opportunity to contribute to the Children, Young People and Education Committee consultation on the general principles of the Additional Learning Needs and Education Tribunal (Wales) Bill (hereafter, the 'ALN Bill').
2. The ALN Bill provides an opportunity to create and provide a unified legal framework for Wales which will put learners, their parents and carers at the heart of the process to identify and plan how to meet their individual needs, including their health and well-being needs. With the introduction of the ALN Bill we hope that there will be improvement in the multi-agency partnership response surrounding the identification of additional learning needs (ALN) and the planning and delivery of effective additional learning provision.
3. While we support the Bill there are a number of barriers to implementation which should be considered as the Bill progresses, including; workforce pressures; uncertainty around the DECLO role and the skills required to fulfil this role; that the Bill clearly defines what a 'health' need is and that referrals for relevant health treatment are only made when there is a clinical need; that prudent healthcare principles are considered; and that the complaints avenues and processes are clarified.
4. The Welsh NHS Confederation represents the seven Health Boards and three NHS Trusts in Wales. The Welsh NHS Confederation supports our members to improve health and well-being by working with them to deliver high standards of care for patients and best value for taxpayers' money. We act as a driving force for positive change through strong representation and our policy, influencing and engagement work.

Questions

- **The general principles of the Additional Learning Needs and Education Tribunal (Wales) Bill and whether there is a need for legislation to deliver the Bill's stated policy objectives;**
5. We supports in principle the overarching policy objectives and core aims of the ALN Bill. The ALN Bill has the potential to help improve health and well-being outcomes, and ultimately life opportunities, for children and young people with ALN in Wales. While legislation is necessary, it must be recognised that the ALN Bill is but one part of Welsh Government's wider ALN Transformation Programme.
 6. The ALN Bill is welcomed because it will meet the holistic needs of children and young people. We are aware that the role of the NHS received criticism from a range of stakeholders during the consultation in 2015 on the draft ALN Bill. The criticism around a perceived lack of engagement and commination by health practitioners within the special educational needs (SEN) process; poor information sharing and multi-agency working; the lack of statutory duties placed on health and the disparity between the responsibility on local authorities compared with health bodies has been taken on board by the NHS. This Bill will encourage improved collaboration and information sharing between agencies, which are essential to ensuring that ALN are identified early and the right support is put in place to enable children and young people to achieve the best possible outcomes. We also support the strengthened statutory requirements which will have the effect of ensuring that practice is applied consistently for all learners across Wales.
 7. A jointly developed integrated, multi-agency single plan is to be welcomed, particularly one that reinforces the child and family voice in the production. While there is nothing in existing legislation

that prevents that, it is clear that the interpretation and practice of the Bill is to ensure the delivery of a co-ordinated plan across agencies.

8. While we welcome the ambition of the Bill to improve outcomes for children and young people and the general principles of the Bill, we do however have a number reservations. These include;
 - a) The engagement and provision, or availability, of adult health services;
 - b) Appropriate Information Technology structures for communication and sharing of information;
 - c) Identifying what is a ‘health need’ within the ALN Bill and the capacity for the NHS to support everyone identified as having a ‘health need’; and
 - d) A stronger reference to the UN convention on the Rights of the Child within the Bill would be welcomed.

9. Finally, we need to ensure that the ALN Bill focuses on outcomes rather than entitlements to duties and inputs. In the ALN Bill we note the strengthened section on duties placed on Health Boards to consider whether there is a relevant treatment or service that is likely to be of benefit. In line with prudent healthcare principles, health must always be a matter for clinical judgement, based on person centred, individualised plans with realistic prognosis for outcomes from any input. This principle must be reflected within this legislation because it will then be more consistent with the existing duties on health. We recommend that section 18 (4) of the ALN Bill includes the words **“based on clinical need”** to provide further clarification for the NHS when referrals are made e.g. section 18 (4) of the ALN Bill be amended to state *“If the matter is referred to an NHS body under this section, the NHS body must consider whether there is a relevant treatment or service that is likely to be of benefit in addressing the child or young person’s additional learning needs, based on clinical need”*.

- **Any potential barriers to the implementation of the key provisions and whether the Bill takes account of them;**
10. There are some potential barriers to the implementation of key provisions that need to be considered as the Bill progresses through the Assembly.

11. The barriers to the implementation for Health Boards for key provisions include:
 - a) Consistency of interpretation, definitions and expectations across different Local Education Authorities (magnified possibly by school governing bodies’ variance). The Code of Practice needs to be robust in developing agreed definitions for “health” needs as per Part 2 of the ALN Bill. Health Boards’ experiences is that there is a difference of understanding of what may be considered “health” issues in other agencies, such as education, which results in over-referral, an over-estimation of what therapy is able to do and, more importantly, develop an unrealistically high expectation from teachers, families and children on the importance of a “diagnosis” or the availability of a “treatment” to the whole process, the provision of care and the eventual outcome. This counters the policy of prudent healthcare, which is being implemented across the NHS, and the key principle of *“Do only what is needed, no more, no less; and do no harm”*.

 - b) The ALN Bill separates educational needs from health and social care needs which is likely to promote disagreements between funding organisations. For example, if a child is challenged with toileting and this means they cannot access their classes, would this be considered a health or education issue? There are many other examples of where the distinction between a health need and an education need is unclear and this is particularly unhelpful for children, young people and their families accessing services. The ALN Bill does not always appear to support other public service policy to increase and improve integration for a seamless service for citizens in Wales.

- c) Availability of resource in terms of finance and individuals with the necessary competencies to fulfil the role of the Designated Education Clinical Lead Officer (DECLO). There is a national shortage within most child health professions and the burden of work relating to safeguarding and child care legal work is expanding. Working through the role in the pilot areas and preferably working in Local Education Authorities clusters that match Health Boards' footprints would go some way towards alleviating this situation. The principles behind the DECLO role are excellent and we would support its development and the move to a role focussing on co-ordination, liaison and troubleshooting as this would enable clinicians already involved with the child or young person to contribute specific clinical advice. However, the training requirements that the ALN Bill will place on NHS staff to enable them to provide informed advice into the new system will require resources, both in relation to time and finance, and could decrease the clinical availability of frontline services in the short term.
- d) We feel the Individual Development Plans (IDP) will be labour intensive, particularly in terms of the logistics of sharing the Plans without an IT system across the various agencies. We are currently unable to predict how many IDP's will require health contribution and feel that there will be a significant increase in demand on services which are already stretched in their capacity. While having the health referral considered at a planning meeting, with health professionals present, consulted with and support the referral, can potentially reduce the likelihood of problems and disagreement, the capacity of the present workforce must be considered.
- **Whether there are any unintended consequences arising from the Bill;**
12. There are a number of unintended consequences arising from the ALN Bill that need to be considered, including:
- a) Confusions as to which single unified plan is applicable, given the requirements under the Social Services and Well-being Act 2014 and the Mental Health (Wales) Measure 2010 to provide one. Some clarity around unification of templates may be helpful for families and young people;
 - b) Inadequate support and early intervention could result in increased costs to accommodating children and young people away from home and addressing chronic health conditions in the long term;
 - c) As highlighted previously, identifying what is a 'health need' versus an education need is often ambiguous within the IDP;
 - d) How is "benefit" defined within the ALN Bill? The Minister stated to the Children, Young People and Education Committee on the 12th of January; *"if an NHS body identifies a treatment or service that is likely to be of **benefit** in addressing the child's or young person's additional learning needs then the NHS body must, not may, secure treatment"*. The precise meaning of the term 'benefit' is ambiguous and not presently clearly defined. When considering the principles of prudent healthcare this causes a conflict, as many treatments may be considered of likely benefit but not robustly evidence based or considered to be clinically effective in achieving the best outcome for the patient. The broader impact of this is around the longer term implications for funding for therapy services/allied health professionals if treatment must be provided, especially with the age range increasing to 25 years, and the present capacity within the service;
 - e) Despite the ALN Bill, public bodies, including the NHS, are still working to different targets, including waiting times, across agencies which could cause conflict and disagreement;

f) There will be administrative consequence for the NHS, and other public bodies, with the increase in contribution to IDP's.

- **The financial implications of the Bill**

13. Overall we believe that the financial implications of the ALN Bill have been underestimated, especially for the additional duties around supporting 16-25 year old and the recruitment costs to recruit for the Designated Education Clinical Lead Officer (DECLO) role.

14. The DECLO role sits within health and is considered to be cost neutral. However, Health Boards do not have anyone fulfilling the components of this role currently and therefore no capacity to release a member of staff for this role. The limited components undertaken by Health Boards are currently provided by Paediatricians. These are not defined sessions which could be released to provide anything else, and therefore investment in this role would not be cost neutral. Furthermore, where a treatment is defined as being of 'likely benefit' and Health Boards must therefore seek to provide it, but does not have trained professionals, or the resources, to provide the necessary treatment. Thus the outsourcing of this service will have financial implications on Health Boards.

15. We are supportive of the development of single statutory plans and a focus on collaborative working to improve outcomes for children and young people. However we have a number of concerns about the resource implications of such a development, with particular regard to attendance at meetings. For example, learning from the implementation of the SEND reforms in England has suggested that capacity is a major issue and there are commissioning gaps in Speech and Language Therapists (SLT) support for 0-2 age group and 16-25. Under the current system, SLTs who treat children with non-complex needs attend schools to assess the needs of the child and prepare written care plans which are often shared by post and by e-mail. Under the new legislation we understand that SLTs could be invited to attend a far higher number of meetings in person given that all children with ALN will now have multi-disciplinary Individual Development Plan (IDP) meetings. Approximate calculations within one Health Boards in Wales suggest that we may move from a system where SLTs attend multidisciplinary team meetings for 25% of current case load (statements of educational need and a minority of School Action Plus) to a situation where SLTs would be invited to attend meetings for 90% of the caseload. This is one example of the increased caseload for one professional group but it is likely to be relevant to other Allied Health Professionals caseloads. Thus the ALN Bill will have an impact on workforce capacity and resources so the legislation is unlikely to be cost neutral.

- **Whether the Welsh Government's three overarching objectives are the right objectives and if the Bill is sufficient to meet these;**

16. The Welsh Government's three overarching objectives are the right objectives and the ALN Bill in its entirety is sufficient to meet these. However, as highlighted above, consideration is needed around the potential barriers and also the role of the DECLO. We feel this role is pivotal to making this work and potentially the time per population for the role is underestimated.

- **Whether the Welsh Government's ten core aims for the Bill are the right aims to have and if the Bill is sufficient to achieve these;**

17. The 10 core aims are the correct aims but there needs to be consideration as to the overlap with other legislation that similarly seeks to develop integrated, person centred and multiagency plans. Consideration in the Code of Practice needs to be given to potential dispute resolution with NHS

providers given concerns identified previously in our response as this can be given as an issue in the current system when families and education departments are at an impasse.

- **The provisions for collaboration and multi-agency working, and to what extent these are adequate;**
18. The current provisions are proportionate for legislation at this time. The underlying Code of Practice and the development of an effective DECLO role should ensure that the inter-department and interagency relationships will hopefully lead to a move away from a heavy reliance on statutory requirements to the delivery of services. Ensuring that all organisations have performance measures that ensure the aspired outcomes for the child and young person described in the ALN Bill, are achieved would facilitate this but it is important that structures are put in place, such as appropriate information technology, to create a shared interface for collaboration and communication, to improve multi-agency working. As well as technology, there needs to be further strengthening of all pathways between Local Education Authorities and Health Boards to improve multi-agency working.
 19. With fiscal pressures on all agencies there is potential for competing priorities to impact on the ability to provide what is outlined as true health provision through the ALN Bill e.g. referral to treatment waiting list targets for health versus ALN statutory requirements. In a time of austerity and stretched resource, stronger and increased legislation and duties on health runs the risk of health resource being allocated on the basis of legal requirements rather than clinical needs and outcomes, which is the underlying principle at present within the NHS in Wales.
 20. To ensure effective future collaboration between agencies, workforce planning and sustainability of all services will need to be considered, including potential investment to ensure all agencies are held to account. The responsibility for most IDP's will sit with schools but this will have an impact on health because Health Boards will be required to collaborate with individual schools on more cases.
- **Whether there is enough clarity about the process for developing and maintaining Individual Development Plans (IDPs) and whose responsibility this will be;**
21. The ALN Bill is clear in relation to education taking responsibility for developing and maintaining IDP's whilst co-opting agencies to meet children and young people's individual needs. However we suggest that there is a need for a standardised template for the IDP to ensure consistency across Health Board areas and across Wales.
 22. It is positive that the ALN Bill promotes the increased participation of the child in the IDP process. However, how this will be facilitated and whose responsibility it will be to ensure it takes place, particularly for children with communication difficulties, is unclear. Furthermore, Health Boards will have the responsibility to ensure that the information held within child and young person's IDPs is up to date, appropriate and reflective of their current need. Without defined time and workforce capacity, this is likely to be unachievable.
- **Whether Bill will establish a genuinely age 0-25 system;**
23. On its own the ALN Bill will not establish a genuine 0 – 25 year old system because many services in health and social care will continue to operate with a predominately 16 – 18 transition. It is important that strong consideration is given to transition at 25 as simply moving the age does not resolve historical problems. Furthermore, the current legislative rights and responsibilities for

children in the UK at present require transition ages of anything between 14 and 25, and whilst 25 is likely to be easier, it will not suit 100% of people 100% of the time. Flexibility is key around the strengths, needs and wishes of the young person.

24. In addition, there are a number of practical obstacles to address. The current adult health system has few generalists to provide the necessary overview of the needs required in the process. The development of professionals to work across this age range is particularly challenging. From a professional developmental and workforce level, the skills necessary to work with this age group are different to younger children, not least the understanding of some of the legal requirements of consent etc. It is unlikely to be a genuine 0-25 system without substantial investment to ensure equity or provision for all children and young people's needs across this age range.
25. As part of considering the system as it stands there are three key issues that the ALN Bill needs to consider and address when looking at establishing a genuine age 0 – 25 system. The three areas are:
 - a) Children of non-statutory school age with defined needs who should have access to services via ALN but may not be in school. What is the plan to address this and robustness around it;
 - b) Children in mainstream school with defined needs who require access to support from health services and how they are provided across mainstream sector; and
 - c) Post 16; young people who continue within education and how their therapy needs will be provided/addressed through adult services.
- **the capacity of the workforce to deliver the new arrangements;**
26. As highlighted previously there are concerns in relation to the capacity of the present NHS workforce to deliver the new arrangements. As previously discussed, there is concern around the numbers of available staff to fulfil the role of DECLO and capacity across the whole workforce, including within allied health.
27. Overall the DECLO role is supported, if capacity and investment is provided, because the role will provide a strategic co-ordinator role in Health Boards and will support the development of IDPs. The outcome of the trials of the role currently underway across two Health Board areas will help to inform the final job description and best practice in terms of collaboration with Local Authority education and social services under the ALN Bill. Under the present Bill, Health Boards must designate an officer, who is a registered medical practitioner or a registered nurse or another health professional, to have responsibility for co-ordinating the Board's functions in relation to children and young people with ALN. As the Bill has been written, Health Boards may only designate an officer it considers to be suitably qualified and experienced in the provision of health care for children and young people with ALN. At this stage it is unclear how senior this role needs to be and the key qualifications that will be required.
28. As well as considering who will carry out the DECLO role within Health Boards, the fact that there is only one DECLO within each Health Board will lead to a significant workload for this person, especially for Health Boards with a number of Local Education Authorities to liaise with or Health Boards with a rural population covering a large geographical area such as Powys teaching Health Board.
29. The current demand and capacity plans within health only look at new referrals into services and whether there are sufficient assessment appointments to meet that flow rate across health. When looking at the capacity to deliver against the ALN Bill, we can envisage changes in demand along the following lines:

- An increase in the number of children with an IDP, which will be statutory;
 - It will be difficult to move children through health services who have an IDP as parents and other partners will be resistant to health amending the IDP to say that needs have changed, as they may be aware it will result in a withdrawal of service. Following the principles of collaborative working and agency working this will be a contentious issue. Children will therefore stay in the system for longer requiring service provision (that is statutory) for substantially longer periods of time;
 - Change in age range 0-2 and post 16 will increase demand on the present workforce;
 - Conflict around health provision will be the responsibility of health to establish redress mechanisms. Dealing with this will be a new demand; and
 - Significant training requirement for all public sector staff to increase awareness of, and participation in, the ALN procedures effectively.
- **The proposed new arrangements for dispute resolution and avoidance.**
30. While the proposals within the ALN Bill for resolution are clear in relation to lead and the roles, as indicated above, consideration of resolution over NHS provision needs to be considered as it is already a point of difference between public bodies and the new system has the potential to exacerbate this.
31. Clear, mutually understood expectations of the system and what needs to be established between all participants and agencies needs further consideration. Agreement as to which individual professionals need to be present to agree plans impinging on agencies need to be agreed across sectors. Currently health uses the 'putting things right' dispute resolution and education uses Special Educational Needs Tribunal for Wales (SENTW). Within the new arrangements the ALN Bill suggests health issues will be dealt with through 'putting things right'. However, if the IDP is being disputed, potentially it could go through both routes where representatives from authorities will be required to attend both. Having two separate avenues of complaint is potentially a very confusing situation, not least for children and young people or their parents, and tends to undermine the rationale of the ALN Bill to have a streamlined and more equitable ALN system. This needs to be clarified as to how the dispute will be resolved in a joined up way.

Conclusion

32. As stated at the outset, the NHS supports the principles of the proposed legislation which has the needs of individual learners and their families and carers at its centre. The evidence that we have provided reflects the complexity associated with this legislation and the significant costs and workforce challenges associated with the implementation of the Bill.