



Dearadh agus Nuálaíocht Chliniciúil; Oifig an Príohoifigeach Cliniciúil  
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Deputy Alan Kelly, TD  
Dáil Éireann  
Leinster House  
Kildare Street  
Dublin 2

**RE: PQ 16770/21**

**To ask the Minister for Health the status of the national model of care for paediatric services in relation to transitioning plans for adolescents with spina bifida and hydrocephalus; and if he will make a statement on the matter.**

Dear Deputy Kelly,

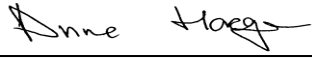
The Health Service Executive has been requested to reply directly to you in relation to the above parliamentary question, which you submitted to the Minister for Health for response. I have consulted with the National Clinical Programme for Children (Paediatrics and Neonatology) on your question who, in turn, consulted with the National Spina Bifida Team at CHI Temple Street in compiling the following response. I have been informed that the following outlines the position.

Transition is the active process of preparing a young person for adulthood in terms of their healthcare literacy and self-advocacy. The Team at CHI Temple Street have advised that, due to the absence of an equivalent multidisciplinary service for adults with Spina Bifida, children upon reaching 16 years of age do not have a natural setting within the adult services to which the paediatric services can transition children with Spina Bifida. This deficiency is a significant concern in terms of the multiple co-morbidities over the lifespan of individuals living with Spina Bifida and would benefit from a co-ordinated approach.

Approaches to transition currently in place include children transitioning to the surgical counterparts of the paediatric surgeons they currently attend. Plans to resource and develop an integrated service for adults with Spina Bifida must be prioritised. The National Clinical Programme for Children (Paediatrics and Neonatology) will seek to progress developing a Transition Guiding Principles approach in collaboration with key stakeholders, targeted at all professionals who are involved in the care of young people with existing health conditions who are preparing to move from paediatric services to adult services.

I trust this information is of assistance to you, but should you have any further queries please do not hesitate to contact me.

Yours sincerely



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**Anne Horgan**  
**General Manager**