



Friday 4th May 2018

Deputy Michael McGrath,
Dail Eireann,
Leinster House,
Kildare Street,
DUBLIN 2.

PQ Ref. No 16732/18 - To ask the Minister for Health the position in relation to parent representation on the HSE primary care steering group for children with special needs; and if he will make a statement on the matter.

PQ Ref. No 16733/18 - To ask the Minister for Health the position in relation to the loco parentis clause in respect of paediatric home care packages; if the matter will be reviewed; and if he will make a statement on the matter.

PQ Ref. No 18585/18 - To ask the Minister for Health his plans to remove the in loco parentis clause from all HSE homecare nursing packages for sick children; and if he will make a statement on the matter.

Dear Deputy McGrath,

The Health Service Executive (HSE) has been requested to reply directly to you in the context of the above Parliamentary Questions, which you submitted to the Minister for Health for response.

Paediatric Home Care Packages (PHCPs) are in place to support the discharge of seriously ill children from acute hospital into the care of their families. They are designed to maximise a child's quality of life and developmental opportunities while also helping to keep children out of hospital as much as possible. The loco parentis rule reflects the fact that PHCPs are intended to serve as a clinical support and is in place to ensure that a second person will be present in the event of an acute emergency such as respiratory arrest, decanuation of a tracheostomy or status epileptus.

I recognise that respite can be an issue for parents of children with complex medical needs and this matter is already being examined as part of the Quality Assurance Process for PHCPs that was commenced in 2017. This process will inform how PHCPs should be delivered, including the operation of the in loco parentis provision. Many parents have already contributed to the Quality Assurance Process, and further engagement will take place in the coming weeks and months.

Parental Reference Group - PHCP Steering Group is a clinical group which, as part of its remit, scrutinises commercially sensitive issues relating to the business process. Representation on the group is therefore not the best or most appropriate means of securing the views of parents. It is for this reason that the HSE will establish a Parental Reference Group that will feed directly into the work of the Steering Group.

Although some details are still to be finalised, it is intended that the Reference Group will have an independent Chair, up to 10 parent representatives and will include the National Lead for Children with Complex Medical Conditions as a member. The Group will meet up to three times per year, including meeting with the Steering Group itself. The proposed structure will ensure that the voices of more parents – and parents from across the country – can be heard directly to help us shape how we deliver care to their children. It is the intention that this group will be established by the beginning of July.

It is also important to note that as part of a **National Quality Assurance** process, individual meetings have taken place between the HSE and parents in respect of the provision of paediatric care packages, and these meetings will continue throughout the year. The HSE will also be holding workshops with parents, again enabling parents to be heard in respect of the needs of their children.

I trust the above is of assistance.

Yours sincerely,



David Walsh,
Head of Operations Primary Care