

1 November 2013

Gill Gunn  
The Scottish Government  
Clinical Priorities Team  
Area GER  
St Andrew's House  
Regent Road  
Edinburgh  
EH1 3DG

Dear Ms Gunn

## **A consultation on the provision of specialist chronic pain services in Scotland**

Children in Scotland is pleased to respond to the above consultation paper.

As the national network and membership organisation for the children's sector in Scotland, we are concerned primarily with the impact that access to this service may have on children and their families.

It is estimated that 8% of children in Scotland experience significant pain, which can interfere with their education and quality of life. This equates to 80,000 children and young people for whom the development of this proposed specialist chronic pain service could be of benefit. Whilst there are multidisciplinary, specialist paediatric pain services available in Scotland, the proposed specialist service would be a welcome development for the management of chronic pain for this age group. Children in Scotland would advocate for this specialist service to be developed alongside the ongoing development of children's pain services in Scotland at a local level through the NHS board implementation of the Scottish Service Model for Chronic Pain.

The Scottish Government, in its current Children and Young People Bill, states that it is committed to putting children and young people at the heart of planning and services and ensuring that their rights are respected across the public sector. It is essential therefore, that the very specific requirements of children and young people are considered and acted upon from the earliest stage and that these then inform

the development of the proposed specialist service. In spite of the challenges associated with this, Children in Scotland welcome this step towards improved, integrated and patient-centred care.

Our member organisation, *The Health and Social Care Alliance Scotland*, has submitted a detailed response to the consultation paper following on from a series of public consultation events held throughout Scotland. Their response is informed by the lived experience of people who have chronic pain as well as their own extensive knowledge of the issues involved in the care and treatment of people with long-term conditions, including chronic pain. Children in Scotland endorse their response and would like to include the following comments and considerations with a specific focus on children and young people:

- It is essential that the needs of carers are fully catered for by the service and, ideally, carers (and close family members who may not necessarily see themselves as ‘carers’ such as siblings) should be explicitly welcomed and actively included in the services provided as key people in providing ongoing support to the patient.
- As chronic pain in children and young people can cause significant disruption to their education, Children in Scotland and Enquire (The Scottish Advice Service for Additional Support for Learning) would like to see how the development and establishment of a specialist, residential chronic pain service in Scotland alongside an improvement in local paediatric pain services would interact with the rights of children and young people to receive an education and any additional support that they need with their learning to help them work towards achieving their fullest potential. We are calling for a service, which causes minimal disruption to education and provides teaching and learning experiences most suited to the individual child’s needs during their treatment, particularly for those who are in the midst of taking exams. The [Hospital and Outreach Teaching Service](#), operated by the City of Edinburgh Council, is a positive example of such a service.
- It is important to be mindful not to treat children and young people as an homogenised group and to ensure that the specific needs of children are catered for differently to those of young people. Furthermore, the development of a specialist chronic pain service must account for the specific needs of children and young people who have learning disabilities; taking into consideration the challenges posed for those who struggle to communicate pain and how it is impacting upon them.
- Any technological support systems would need to be developed with children and young people in mind so that the potential for telehealth support is accessible for all age groups.
- Children in Scotland advocates for a service that is accessible for all at the point of need. Children, young people and their families will require support to access the service and consideration must be given to those for whom the

distance to travel, the cost of travel, the accessibility of the venue, time away from loved ones/carers/family members etc would preclude them from accessing the service. These barriers need to be addressed at the earliest stage so that children and young people are enabled to access and engage with the specialist service. It may be that, for these reasons, service model options 1 and 3 should be considered in conjunction: a specialist residential pain service as well as a complimentary roving outreach service for those who cannot access the former.

- It is worth noting that travel arrangements, particularly in the Highlands, for people living with a disability can be a significant barrier to accessing treatment at a specialist centre, so development of the service would need to go hand in hand with an improvement in access to suitable transport.
- Children in Scotland call for a child rights impact assessment to be carried out on the development of this service to ensure that any specialist chronic pain services, both at a national and a local level, are taking into account and enabling the rights of children and young people in Scotland. Furthermore, we would like to see the active participation of children and young people with experience of chronic pain involved in the development of the service so that the outcome reflects and is informed by their needs.

Yours sincerely,

Jeni Bainbridge  
Assistant Policy Officer (Participation and Engagement)



## *Children in Scotland receives funding from the Third Sector Early Intervention Fund*

Children in Scotland is the national umbrella agency for organisations and professionals working with and for children, young people and their families. It exists to identify and promote the interests of children and their families and to ensure that policies and services and other provisions are of the highest possible quality and are able to meet the needs of a diverse society. Children in Scotland represents more than 400 members, including most of Scottish local authorities, all major voluntary, statutory and private children's agencies, professional organisations, as well as many other smaller community groups and children's services. It is linked with similar agencies in other parts of the UK and Europe.

The work of Children in Scotland encompasses extensive information, policy, research and practice development programmes. The agency works closely with MSPs, the Scottish Government, local authorities and practitioners. It also services groups such as the Cross Party Parliamentary Group on Children and Young People (with YouthLink Scotland). In addition, Children in Scotland hosts Enquire - the national advice service for additional support for learning, and Resolve: ASL, Scotland's largest independent education mediation service.