



Children's Hospices Across Scotland

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Sue Webber MSP
Convener
Education, Children and Young People Committee
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Dear Ms Webber

Further to the Committee's inquiry into the National Care Service (NCS), I wanted to write to set out some considerations from the perspective of Children's Hospices Across Scotland (CHAS).

While we are aware that a decision with regards to the inclusion or otherwise of children's services is being taken separately to the progress of the National Care Service (Scotland) Bill, we would like to stress that clarity is needed on where children's palliative care would potentially sit under any new arrangements.

For any new structures to operate smoothly in practice, they need to both preserve what currently works well, help ensure that best practice is applied consistently across Scotland, and reduce barriers people experience in getting the care they need. For children, it is important that there is a seamlessness of operation between acute health, community health, social care, social work and education.

Services for people that are already integrated

Children's palliative care is a total and active multi-disciplinary approach that embraces physical, emotional, social and spiritual elements through death and beyond. It involves support for a dying child, their siblings, parents and wider family, and is provided by both the health care and social care sectors. Support is provided in hospice, hospital or in the child's home – and often in all of these. CHAS, the NHS, and local authorities work very closely together to support families as seamlessly as possible. CHAS offers highly specialised and highly integrated services that span both health and social care.

Children's Hospices Across Scotland is the single national provider of children's hospice care. Our staff work across children's homes, CHAS hospices, and NHS hospitals, in deep partnership with statutory services. Our doctors, nurses, social workers, family support workers and others all look at the holistic needs of a child and their whole family. It is a unique, national model. It is important that these, and other organisations' similar services, continue to be able to operate fluently across health and social care even under new arrangements.

Keep the joy alive



Rachel House Children's Hospice at Kinross . CHAS at Home Team . Robin House Children's Hospice at Balloch
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Children's Hospices Across Scotland (known as CHAS) is a Scottish charity, SC019724, regulated by the Scottish Charity Regulator (OSCR).
CHAS is a company limited by guarantee and is registered in Scotland, SC136410. VAT Registration number 214 8303 34.

During any change, the new arrangements must recognise that some voluntary sector services, such as CHAS, are already integrated. We do not operate in only the social care or only the health care sectors. We take a person-led approach as to what matters to each child. We hope the new arrangements arising from the Bill recognise that some of Scotland's most high quality services include elements of health care and social care within one organisation.

It would be concerning if a shift of responsibilities from local authorities to the NCS meant that arrangements like this, which allow completely integrated health and social care services to operate across boundaries, were to become fragmented or were otherwise jeopardised. We know this is not the intention of the Bill, so would welcome further proposals on how organisations which provide *both* healthcare and social care can continue to operate seamlessly.

Interface between children's and adults services

The transition between children's and adult services is widely acknowledged to be a complex and often stressful area – something the Disabled Children and Young People (Transitions to Adulthood) (Scotland) Bill is seeking to improve.

If children's services are to join adult services under the structure of the National Care Service, this presents a welcome opportunity to address some of the long-standing issues that young people and their families face. Currently, they navigate a range of transitions across institutions and services within healthcare, education, and social work. They will move from being supported by an expert paediatric palliative care team to a wider range of adult services, which are often configured for people of a much older demographic. They may also face changes to the social care support they receive, because the availability or criteria for adult services are different to children's services.

There should be a better system in place for the children's to adult services transition... I co-ordinated all of my care and without this I am scared to think of where this would have ended. I was the first complex needs case my social worker has worked with.
(Young adult)

On the other hand, if children's services are not to be included within the scope of the NCS, then further clarity is needed on the interface between the systems of support for children and adults, particularly at times of transition. We need to ensure that further boundaries aren't erected to further complicate this already complex time for children and families.

Irrespective of where children's services ultimately sit within new structures, the real-world issues that families tell us they are facing within the social care system must be addressed – including sufficient numbers of staff within the specialised workforce, quicker assessments for Self-Directed Support, and an outcomes-based approach to social care entitlements.

Funding arrangements for organisations must reflect the needs of people using services

While the majority of CHAS' services are funded by charitable donations from the Scottish public, CHAS receives a proportion of funding from the Scottish Government's health budget. CHAS also receives some more limited funding from local authorities annually, reflecting that its work includes family support, social work, and other support that is more generally regarded as aligned to local authority social care and social work activities. CHAS has a longstanding and recurring national agreement with the leaders of all local authorities, brokered by COSLA. This national model reflects the reality of the social care element of children's hospice care – in that it is needed by children from different places, at different times, often at very short notice and in the most complex of times.

The nature of work provided by CHAS is highly specialised. Indeed, there is a strong case for CHAS' existing national model to be an exemplar of how other national specialist

services could be centrally funded by a NCS in respect of social care delivery, if the Scottish Government chooses to include children's services in the NCS.

Please do not hesitate to be in touch should you require any further detail. I have also written to the convener of the Health, Social Care and Sport Committee on this matter.

Yours sincerely

Rami Okasha
Chief Executive
CHAS