

Critical Junctures: When children and families need CHAS most



Children's Hospices Across Scotland

Author: Will McLean, Programme Manager, CHAS

✉ willmclean@chas.org.uk



Aim

We wanted to meaningfully involve as many of our stakeholders as possible in organisational strategic planning. We faced a number of challenges in hearing these voices. CHAS is a national charity supporting families in every local authority area, operating from different locations and with a presence in hospitals across Scotland. We have staff and volunteers across the country working collaboratively with different partners.

CHAS supports children from pre-birth to 21, and their whole families, and continue to support families after their child dies. Many families we support have complex lives including many single parents. Our previous engagement activities highlighted that traditional strategy building methods don't work, especially for children.

Methodology – Most Significant Change

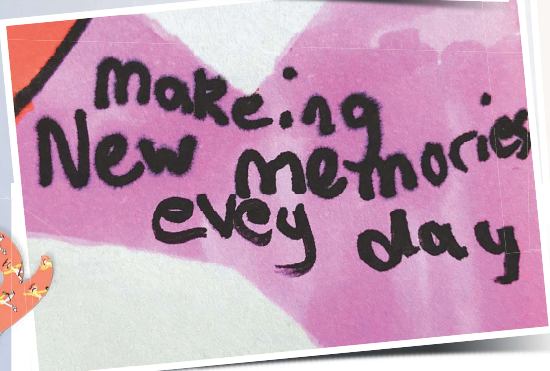
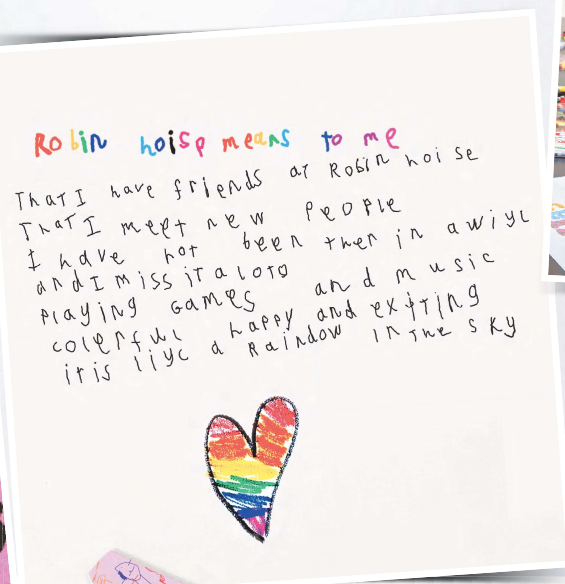
Most Significant Change identifies what matters most to people by collecting and analysing personal stories of change from the perspective of all stakeholders. An evaluation group, where all members had an equal say, was established including bereaved family members and staff representation from across CHAS. We involved volunteers with both professional and lived experience.

We asked our stakeholders one simple question and we simply listened:

- **Families:** Please tell us about an important time when CHAS helped you and your family.
- **Our People:** Please tell us about a meaningful moment in your experience with CHAS.
- **Children:** Let's make something that shows people what you think about CHAS.

We used storytelling, visual art and therapeutic play to involve children. We had group activities where younger children created their CHAS Backpack, adding what mattered to them through drawings, writing, photos and stickers.

Older children creatively told their own stories and we had hearts where they could share what was important. We engaged older brothers and sisters during residential stays, and this included a group of bereaved siblings, allowing them to share their story in their own way in a safe space.



Participation

137 families, 40% of the families supported, were involved from across Scotland, including 21% in very remote areas and 45% in the most deprived areas.

The families were representative of everyone we support and accessed our services in hospice, hospital and home.

77 children, aged 3-16 took part.

32 were referred children with very complex medical conditions, their involvement supported by our professionals and their families.

175 staff, volunteers and partners were engaged.

Data Analysis

Visual imagery was converted to wording and transcribed with all stories. A six phase Thematic Analysis was undertaken on this dataset and themes were explored, refined and organised. We further analysed the text with two natural language processing techniques - Word frequencies and Sentiment Analysis. Word frequencies helps understand the importance of what is said and determines commonalities between stakeholders. Sentiment Analysis is a field of Artificial Intelligence that enables machines to understand and interpret human language to determine the emotional tone of a piece of text.

Critical Junctures

"Throughout all the critical junctures of my life, when I have felt alone and unable to progress, when I have been scared or overwhelmed, I have always been able to access support from CHAS."

The three main themes, or "critical junctures", were identified and form the structure of the new strategy:

Learning your Child is Seriously Unwell

Living Well

Dying Well and Bereavement

Sub-themes identified the outcomes children and families wanted from our services and these change events are written in the language used by stakeholders. The Sentiment Analysis identified what children and families value about CHAS, the feelings and emotions they experience, and importantly how our services can support positive outcomes. One outcome is "**More Children Can Make New Memories Every Day**" a sentiment shared by many families and taken from a child's artwork.