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## BACKGROUND

Service providers face difficult decisions about how best to balance & provide high quality planned respite care (*planned short breaks*) & emergency respite care to meet the needs of an increasing population of children & young people with life-limiting conditions & their families.

*(Emergency respite care refers to a family emergency – NOT a medical crisis for the child/young person)*

## AIM

To explore the impact of the hospice planned & emergency respite care on children & young people with life-limiting conditions, their families & stakeholders, to inform future service development.

## METHODOLOGY

A two-phase, mixed method, qualitative & quantitative study involving young people, families, health & social care professionals & hospice staff.

### PHASE 1

Qualitative semi-structured interviews & focus groups (n=53)

### PHASE 2

Electronic survey - Quantitative & qualitative data (n=82)

**TOTAL (n=135)**

## ANALYSIS

Thematic analysis & descriptive statistics

## SELECTED RESULTS

The excellent quality & range of hospice services were highly valued by all participants.

Participants raised concerns about the lack of other appropriate services for planned & emergency respite care when children's hospice care is unavailable, or following discharge from the service at 23 years of age.

Balancing the provision & availability of planned & emergency respite care is challenging.

Participants ranked the importance of the three core services as (1<sup>st</sup>) end of life care, (2<sup>nd</sup>) emergency respite care & (3<sup>rd</sup>) planned respite care, whilst recognising the value of planned respite care for building trust & continuity of care in an emergency.

## CONCLUSION

Families need regular respite & support to continue to be able to meet the child's complex care needs. The lack of appropriate planned & emergency respite care when children's hospice care is not available, or following children's hospice discharge, can have far reaching consequences for the child, family & society.

**"Caring for our daughter is 24/7 & exhausting & emotionally draining. We know her health needs are competently cared for whilst staying over at Claire House"**

*(FS29, family survey)*

**"The support makes you feel that you are not alone & that your children are not left in a vulnerable position at a difficult family time"**

*(FS2, family survey)*

**"Frankly I don't know how we are going to face the future without Claire House"**

*(F2, family interview)*

