Emergency Care Impact Assessment (ECIA) Project: Claire House Children’s Hospice

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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)

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.

Balancing the provision & availability of planned & emergency respite care is challenging. Participants ranked the importance of the three core services as (1st) end of life care, (2nd) emergency respite care & (3rd) planned respite care, whilst recognising the value of planned respite care for building trust & continuity of care in an emergency.

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.

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 unavailable, 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)