

**THE NEED FOR SUPPORT:
YOUNG PEOPLE LIVING THROUGH A FAMILY
HEALTH CRISIS**



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Foreword

Young people living with a family health crisis are found to experience high levels of distress, anxiety, low mood and depressive symptoms and are at risk of becoming disengaged with education, socially isolated and uncertain regarding what the future will hold for them.

A body of research indicates that practical intervention, including youth work, engagement with other young people and targeted support can have a significant impact upon a young person's capacity to cope with a complex family health crisis and develop self-reliant behaviours.

Despite the plethora of evidence to indicate the need for systems of support for children and young people experiencing a family health crisis, current provision across the UK is inconsistent, inequitable and not clearly underpinned by policy intervention. This study sets out to indicate the extent and nature of need of children and young people who are living with a family health crisis in Britain, the type of support they require and the ways in which *Hope Support* meets those needs.

Throughout the report, we use short case-studies to shed light on the circumstances that children and young people are living within.

There is widespread recognition that a key way of addressing the health and wellbeing needs of young people experiencing a family health crisis is intervention and targeted support. Practical interventions can make a significant difference in tackling feelings of anxiety and distress experienced by many young people and support them in re-engaging with education and developing self-reliant behaviours. Nonetheless, evidence suggests that there is limited understanding of the extent and nature of need nationally and limited service provision of the kind required by young people.

In the absence of national figures accurately depicting the number of children and young people living through a family health crisis and the nature of their experiences, this study drew on three strands of data, two of which were quantitative and one of which was qualitative. Data were used to indicate: 1. levels of national need extrapolated from the British Millennium Cohort Study; 2. the nature of needs presenting to and service uptake from Hope Support in the localities of Gloucestershire and Herefordshire since 2010 and online nationally since 2015; 3. how young people experience living with a family health crisis and nature of the services they require based on interviews with young people.

Key findings

Millennium Cohort Study Data (MCSD): extent of need across Britain

It is possible to make some broad generalisations using both the Millennium Cohort Study Data and national population data:

- If it is assumed (using MCSD findings)¹ that approximately **20%** of all children aged 11-17 (total 11-17 year olds = approximately 5 million) have a parent or caregiver who has a longstanding illness, then this equates to potentially **a million children** aged 11-17 years currently in the UK with a parent/caregiver with a longstanding illness. Not all of those longstanding illnesses will be serious or life threatening, however.²
- Over 20% of those parents or caregivers with a longstanding illness describe their illness or condition as impacting 'a lot' on their ability to do everyday activities in MCS data 5 & 6. This equates to potentially **over 200,000 children** aged 11-17 years currently in the UK with a parent/caregiver with a longstanding illness that impacts a lot on their ability to do everyday activities, which can be assumed to be serious, although not necessarily life-threatening.
- If it is assumed (using MCSD findings)³ that approximately 0.02% of all children aged 11-17 have a parent or caregiver who has cancer, then this equates to potentially 10,200 children aged 11 and above in the UK who has a parent with cancer. However,

¹ Millennium Cohort Study Data findings 5

<https://discover.ukdataservice.ac.uk/doi?sn=7464#4> and data findings 6

<https://discover.ukdataservice.ac.uk/doi?sn=8156#2>.

² Data available from the MCSD does not differentiate longstanding illness from chronic and/or life threatening illnesses.

³ Millennium Cohort Study Data 5 & 6.

it is likely these figures do not reflect the true scale of the problem. For example, an estimated 2,273,200 people who had previously been diagnosed with cancer were alive in the UK at the end of 2013. These figures are increasing year on year, and there were around **357,000** new cases of cancer in the UK in 2014, that's **980 cases diagnosed every day** (Cancer Research UK, 2017). There were **2.5 million** people living with cancer in 2016 and by 2040, there will be 5.3 million (Macmillan Cancer Support Annual Report, 2016: 5), many of whom will have a young person living at home. Cancer is the condition accounting for most referrals to *Hope Support Services*.

Findings from Hope Support data: local service provision

- The vast majority of referrals to Hope (74.3%) are due to a close family member being diagnosed with cancer.
- The majority of close family members were either mothers/stepmothers/foster mothers (50%) fathers/stepfathers (24%) or grandparents/step grandparents (14%). However, in 9% of cases it was a brother, sister or cousin with the serious health condition.
- The most common presenting issues for young people were mental health problems (i.e. anxiety, depression, panic attacks) with over half of children referred to Hope needing support with this (55%). Issues with relationships, loneliness and problems at school were also very frequently reported.
- Hope have supported **380** young people in a variety of ways over the last seven years, through youth sessions, one to one sessions and youth activities in Herefordshire and Gloucestershire and through online support nationally.

Findings from Young people's voices: living with a family health crisis

Young people living through a family health crisis explained: the ways in which they experienced need; the consequences of their needs going unmet or being partly met; the characteristics of the support they received from Hope; and the nature of services that were required by young people in such circumstances.

- **Experiencing need**
 - Health crises of family members extended across long periods of childhood and adolescence;
 - Young people struggled to understand what was happening to them;
 - They had varied experiences of responses by service providers;
 - Their experiences had a profound effect on their daily lives
- **Consequences of [un]met need**
 - Young people with inadequately met needs risked being labelled as 'difficult';
 - Their family health circumstances impacted negatively on their educational experiences and outcomes;
 - Usual childhood and teenage social lives and friendships were difficult to maintain;
 - Young people experienced feelings of severe stress, anxiety and hopelessness.
- **Characteristics of Hope Support**

- Hope provided a powerful means of building relationships on which all other support was then based;
- Hope differentiated the support provided, allowing access by young people to meet their individual needs at different times.
- **Nature of services required by young people:** What makes Hope so valued by young people?
 - Flexibility: Young people value support that is flexible and tailored to individual needs that change over time.
 - Acceptance and understanding: Young people need to feel that their varying needs and reactions will be accepted without judgement and without the need for explanation. They just need to be 'held' in a safe space.

Recommendations

Short-term:

1. Raise public, stakeholder and government awareness as to the extent and scale of need across the UK recognising the number of children, young people and families experiencing a family health crisis and the significant long term impact that this can have.
2. Seek funding for much needed large-scale in-depth research in this area, incorporating: C&YP's experiences across a range of circumstances and from a range of backgrounds; evaluating the cost of funding much needed support for C&YP experiencing a family health crisis against the costs to young people's health, wellbeing and educational outcomes if needs continue to remain unmet.
3. Reflect on the type and quality of targeted support that Hope services provide in meeting the needs of C&YP experiencing a family health crisis and explore avenues through which these services can be expanded to meet national need.

Recommendations for stakeholders, national and local policy-makers for mid-term action:

4. Ensure that national data are collected on a regular basis on the number of children and young people who are living with a family health crisis, including
 - a. Time from diagnosis
 - b. Access to support services for C&YP
 - c. Impact on the activities, progress and achievements of C&YP
 - d. Level of service provision compared to level of need.
5. Comprehensively review and revise national and local policies, including education, health and social care, for service provision for C&YP facing a family health crisis from the point of diagnosis and continuing throughout the period of illness. Implement associated policy, provision and practice changes that recognise:
 - a. The need for additional educational support with flexibility in timing and close-to-home study.
 - b. The need for training of education, health and social care professionals with regard to understanding the needs and experiences of C&YP living through a family health crisis.
 - c. That support services nationally need to combine flexible, face-to-face support as well as access through different media such as online or mobile access.

- d. That building relationships with a small network of trusted youth workers and companionship from C&YP experiencing similar situations are vital aspects of support which should precede and enfold counselling support. Companionship and being 'held' emotionally in a safe place amongst professional adults and peers with whom relationships are formed can be more effective initially than counselling sessions with a stranger with a set start and end time over a set number of appointments.
6. Review accessibility of services available to C&YP from minority ethnic and minority language backgrounds, given that current services appear to be accessed primarily by White British C&YP
7. Consult and involve children and young people in the design and delivery of support services and policy provision. Recognise, too, that C&YP in the midst of a family health crisis may not feel able to fully recognise and articulate their own needs. They need support to enable them to do so.

1. Introduction

Lucy is 16-years-old. Her mother was diagnosed with breast cancer when Lucy was 15 and spent much of the last year in hospital undergoing treatment. Although Lucy has older siblings, she is the only young person living at home and she has taken on some of the caring responsibilities. Lucy was diagnosed with depression last October due to the stress and upset of the family health crisis. Her school work has suffered and she has found this very upsetting. Lucy has had the support of counselling and a workshop group for mental health issues as well the support of the school nurse, but she has found the online support from Hope to be of particular benefit, too. She lives too far from Herefordshire and Gloucestershire to access the face to face services.

1.1 Purpose of report/project

Hope Support commissioned the Children’s Research Centre at The Open University to undertake an initial small-scale research study to investigate the need for its services nationally. This study sets out to indicate the extent and nature of need of children and young people who are living with a family health crisis in Britain, the type of support they require and the ways in which Hope Support meets those needs. The aim of the study is to raise public, media and stakeholder awareness of the scale of need nationally for Hope Support Services (or similar) and awareness of the work Hope is currently doing with a view to securing funding to carry out further research and to lobby for policy change and funding to extend services.

1.2 Background to Hope Support Services

In 2006, Sue Trevethan was diagnosed with cancer. She set out to find if there were any services available for her three children, who were 13, 16 and 19 at the time. She soon found that no such service existed. Sue decided something had to be done to help the thousands of children and young people every year who experience the trauma and uncertainty of a family health crisis. With her background as a therapist with young people, Sue set about starting Hope Support Services (‘Hope’) from a coffee shop. The first-ever youth management team was established in 2009 as a group of young people who were experiencing or who had been through a family health crisis themselves and wanted to use their past experiences to help others. In 2010, Hope started providing free training for professionals working frontline with children, young people and their families. In 2012, having established a partnership with Macmillan, Hope’s service delivery expanded to include work with local services and organisations in the county to support children and young people.

The charity’s objectives (as set out in the Articles of Association) are to:

- To relieve the mental and physical sickness of persons resident in the United Kingdom, in particular children and young people suffering from bereavement or loss or a serious health crisis of a family member by the provision of workshops and support;
- To advance the education of professionals working with children and young people suffering from bereavement, loss or the serious illness of a family member by the provision of training.” (Hope, 2015).

Hope describes how young people come with a variety of different needs which shape the type of support Hope can provide, including ‘practical skills around anxiety, maybe around coping strategies, around boundary work and personal relationships, for young people going through their emotional development’.⁴ Coping with a family health crisis can present many challenges for young people as a Hope youth development worker describes:

If a young person is juggling hospital appointments, to then think, oh, I need to go and let the school know exactly what’s going on as well. We can bridge that gap. At Hope we work with everybody that’s around the young person.

Hope works across community and neighbourhood projects and alongside health, social care and education practitioners to provide holistic support services. Hope is unique in the support it provides to young people living in Gloucestershire and Herefordshire experiencing a family health crisis. Support is provided through a number of different media, including youth sessions, online support, counselling and a youth advocacy programme.

Hope recognises the importance of providing different types of support from a variety of different professional roles using a holistic approach. This includes youth development workers who are trained to provide social and emotional support for young people, and who also work across sectors including education, health and social care to ensure that the many different needs that young people experience are addressed.

1.3 Nature of the problem: literature review

The number of young people in the UK who are living with a family health crisis is not well documented and is currently an under-researched area. Yet small scale, localised studies indicate that a significant proportion of young people live with a parent/carer, grandparent and/or sibling who is chronically or terminally ill. Furthermore, a small body of research literature suggests that there are many young people throughout the UK who are unable to access appropriate and yet much needed support to cope with a family health crisis (Shucksmith and Hendry, 1998; Mayall, 2002; Beckett-Milburn and Jackson, 2012). This not only reflects the uneven distribution of support across the UK but an over-reliance on charitable intervention rather than policy funded programmes of support. Currently young people experiencing a family health crisis in the UK are an invisible group. Such young people are vulnerable, potentially at risk and far more strategic effort is required.

⁴ Quotation taken from an interview with a Hope Support youth development worker.

Studies exploring the impact of young people living with a family health crisis have often orientated to 'young carers' who provide care for a family member within the home (Aldridge and Becker, 2003), as well as studies of parents caring for a chronically or terminally ill child (Kennedy *et al.*, 2004) and for young people suffering bereavement (Rolls and Payne, 2007; Brewer and Sparkes, 2011; Fredman, 2011). Lenton *et al.* (2001) found that where a child or young person had a life-threatening illness, there were significant emotional and behavioural problems in 24% of their healthy siblings. Studies of young people aged between 5-15 years who had a parent or sibling dying were more likely to experience mental disorders than those who had not, (Meltzer *et al.* 2003). Other research has studied children and young people's experiences of parental substance use within the home and the strategies employed to endure such challenging circumstances (Bancroft *et al.* 2004; Backett-Milburn *et al.* 2008).

Relatively little research has been carried out exploring young people's personal concerns and experiences in living with a family health crisis (Shucksmith and Hendry, 1998) and the impact that this has upon their lives (Bockett-Milburn and Jackson, 2012). This may reflect the complexity of the field as well as the difficulties in identifying and accessing young people's views and experiences (Mayall, 2002) in such a sensitive and highly charged area. A small body of research however, does reveal that young people living with a family health crisis experience high levels of distress and anxiety (Kennedy and Lloyd Williams, 2009; Kennedy, 2010; Backett-Milburn and Jackson, 2012) and are prone to low mood, depression, isolation and self-harming behaviours (Holbrook, 2017). Studies further suggest that such issues could lead to enduring negative impacts upon young people's future lives.

Few studies have researched young people's experiences of living with a family health crisis from the point of diagnosis. Furthermore, limited research is available to examine the impact that programmes of targeted support can have for young people experiencing such challenging circumstances. The research that has been completed in related fields does suggest that support in the form of face to face and online counselling (King, Bamling, Reid and Thomas 2006.) and targeted youth work can have a significant impact upon young people's capacity to endure exceptionally challenging situations (Bockett-Milburn and Jackson, 2012) and develop self-reliant and resilient behaviours (Holbrook, 2017).

Increasingly researchers have developed innovative methods which aim to gain a greater understanding of the health concerns of children and young people (Christensen and James, 2000; Ogilvie-Whyte, Bockett-Milburn and Morton, 2005) unencumbered by adult power relations (Pole and others, 1999; Mayall, 2002). This current study aims to provide first hand views of young people in relation to their experiences of having a close family member with a life-threatening illness from diagnosis alongside analysis of statistical data from the large scale Millennium Cohort Study and from Hope's own records. It will supplement previous related studies in this area, but also provide an original perspective.

1.4 Existing services

Services that are available to support families experiencing a family health crisis in the UK are very much dependent upon the age and status of the service user designated as child, adolescent or adult and their capacity to access and engage with support. For many service users, particularly children and adolescents, this means being specifically referred for support, being aware of the services available and having access to appropriate information or being able to engage online support.

Whilst there are a number of organisations, including Barnardo's (<https://believeinme.barnardos.org.uk>) and Relate (<https://www.relate.org.uk>) that offer services for children and young people targeting social care, education and mental health issues, there are few organisations that deliver the range of support that children and young people experiencing a family health crisis require.

Support services that are available for children and young people experiencing a family health crisis are typically designed to address specific issues, such as bereavement, mental health issues and young carers, as well as broad based one-to-one counselling.

Support for bereavement

A number of organisations in the UK provide support for children and young people following bereavement including Hope Again (<http://hopeagain.org.uk/>) - an affiliation of the Cruse bereavement service designed for young people (<https://www.cruse.org.uk>) and Winston's Wish (<https://www.winstonswish.org.uk/>).

Young carers

A young carer is someone under 18 years of age who helps look after someone in their family, or a friend, who is ill, disabled or misuses drugs or alcohol. There are a number of organisations throughout the UK that provide support for young carers, including the Carers Trust (<https://carers.org/about-us/about-young-carers>), the Children's Society (<https://www.childrensociety.org.uk>) and Barnardo's (<https://believeinme.barnardos.org.uk>). The type of support provided for young carers varies from one-to-one counselling, to online support and advocacy work.

Support for mental health issues

A number of organisations deliver a variety of services targeted to support child and adolescent mental health, including young minds (<https://youngminds.org.uk>), heads2gether (<https://www.headstogether.org.uk>) and mind (<https://www.mind.org.uk/>). The type of support available includes online guidance, counselling and advocacy work.

One-to-one counselling

Following referral via Child and Adolescent Mental Health Services (CAMHS)⁵ children and young people can be offered one-to-one counselling following a variety of different approaches

⁵ <http://www.nhs.uk/NHSEngland/AboutNHSservices/mental-health-services-explained/Pages/camhs-information-for-children-and-young-people.aspx>.

and delivered across a number of different contexts including school counselling⁶, youth work and private sector counselling services.

The small body of available research indicates however, that despite a range of services that are available for children and young people experiencing specific issues relating to mental health issues, bereavement and the challenges of being a young carer, few services are available for children and young which address the complex issues of living with a family health crisis from diagnosis.

2. Research project: methods and data sources

Molly is aged 17 years and an only child. When she was 14 years old, her mother was diagnosed with stage 3 cancer of the kidneys. Molly's mother spent a lot of time in hospital due to the serious consequences of her illness and was diagnosed as having terminal cancer about a year ago. She currently undergoes dialysis four times a week and is very unwell. About a year ago, too, Molly's grandmother had a stroke and became very ill. The family moved to live with her to help care for her. Molly and her father jointly shared the caring responsibilities of Molly's grandmother and her mother. Molly's grandma died last year. Molly has had the support of Hope throughout, but has still found juggling school, college studies, caring responsibilities and the emotional turmoil very stressful and draining. She is now part of the Y-Team and helps to run Hope Support.

In the absence of national figures accurately depicting the number of children and young people living through a family health crisis and the nature of their experiences, this study draws on three new strands of data, two of which are statistical, the British Millennium Cohort Study and data held in records by Hope Support, and the third of which is qualitative interview data. The purpose of the three strands is to indicate: levels of national need extrapolated from the Millennium Cohort Study; the nature of needs presenting to and service uptake from Hope Support in the localities of Gloucestershire and Herefordshire since 2010 and online nationally since 2015; how young people experience living with a family health crisis and the nature of the services they require based on interviews with young people.

Analysis and audit of Millennium Cohort Study data and Hope's own records was undertaken by Dr Stephanie Bennett under the guidance of Prof Jane Payler and Dr Victoria

⁶ In 2016 the government published *Counselling in schools: a blueprint for the future* (https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/497825/Counselling_in_schools.pdf). This departmental advice from the Department for Education (DfE) was produced to help school leaders set up and improve counselling services in primary and secondary schools and recognises that effective counselling is part of a whole school approach to mental health and wellbeing. Current provision, however is highly dependent upon school funds.

Cooper. Data collection and analysis of the qualitative interview data was undertaken by Prof Jane Payler and Dr Victoria Cooper. Ethical approval for the study was provided by the Open University Human Research Ethics Committee. Details of **ethical considerations** are given in section 2.3.

Each data collection method is now explained in turn.

2.1 Secondary Data - The Millennium Cohort Study (MCS)

The Millennium Cohort Study (MCS) is one of Britain's national longitudinal birth cohort survey studies, run by the Centre for Longitudinal Studies (CLS) at the University College London Institute of Education, London. The MCS survey field of enquiry covers such diverse topics as parenting; childcare; school choice; child behaviour and cognitive development; child and parental health; parents' employment and education; income and poverty; housing, neighbourhood and residential mobility; and social capital and ethnicity.

For the purposes of this project, three main survey elements of the MCS have been focussed on: 1) parent/caregiver self-report data regarding their own health; 2) parent/caregiver responses regarding their child's health and wellbeing; and 3) child self-report data regarding their health and wellbeing. These survey responses therefore give a picture of how many parents and children have been affected by a longstanding illness, each of which constitutes what it means to live with a family experiencing a health crisis.

The MCS study has been tracking the Millennium children through their early childhood years and currently plans to follow them into adulthood. The MCS population is a population of children defined as: all children born between 1 September 2000 and 31 August 2001 (for England and Wales), and between 24 November 2000 and 11 January 2002 (for Scotland and Northern Ireland), alive and living in the UK at age nine months, and eligible to receive Child Benefit at that age. Using birth statistics (Jeffries, 2005), it is possible to estimate that there were approximately 597,400 live births in England and Wales, and approximately 83,600 live births in Scotland and Northern Ireland during these time periods (Total MCS population approximately **681,000**). Note that these figures are estimates and not exact as the sampling timeframes are not in line with published birth statistics.

Data were first collected for the MCS during 2001-2002 and information was collected from the child's main resident parent or carer and any co-resident partner from almost 19,000 babies aged nine months across England, Wales, Scotland and Northern Ireland. An additional 692 families – referred to as new families – were recruited at the age 3 survey. The total cohort (at 9 months) was 19,244 – see Figure - the MCS sample therefore represents nearly (2.82%) **3% of the population of children** age nine months at that time.

The original sample was drawn in two stages: the first stage was the selection of electoral wards and the second stage the selection of families within those wards. All the electoral wards in the UK were allocated into one of three types:

1. "Ethnic": defined as wards in England in which 30% or more of the population were 'Black' or 'Asian' according to the 1991 Census of the population.

2. “Disadvantaged”: the poorest 25% of wards (not classified as Ethnic) as defined by the 1998 Child Poverty Index which is based on the proportion of children living in families in receipt of certain state benefits.
3. “Advantaged”: all other wards not classified as ‘Ethnic’ or ‘Disadvantaged’. These are not necessarily ‘well-off’ areas.

The sample was selected from a random sample of electoral wards, disproportionately stratified to ensure adequate representation of all four UK countries, deprived areas and areas with high concentrations of Black and Asian families. A total of 398 wards were chosen for the study with proportionally more chosen in Scotland, Wales and Northern Ireland.

The two most recent MCS datasets (MCS5 2012 & MCS6 2015) were chosen to explore further for the purposes of this research project because 1) the datasets are open source; 2) the datasets contain data which is at most only five years old, so the findings can be considered recent; 3) the datasets contain health survey data on children and their families when the children were aged 11/12 years and again when the children were aged 14/15 years so directly relevant to this project, and 4) the sample size for both datasets is substantial (more than 11,000 cases), enabling generalisation to the wider population in the U.K.

*Figure 1 displays the cohort size for each of the sample sweeps and age of child when survey data were collected.

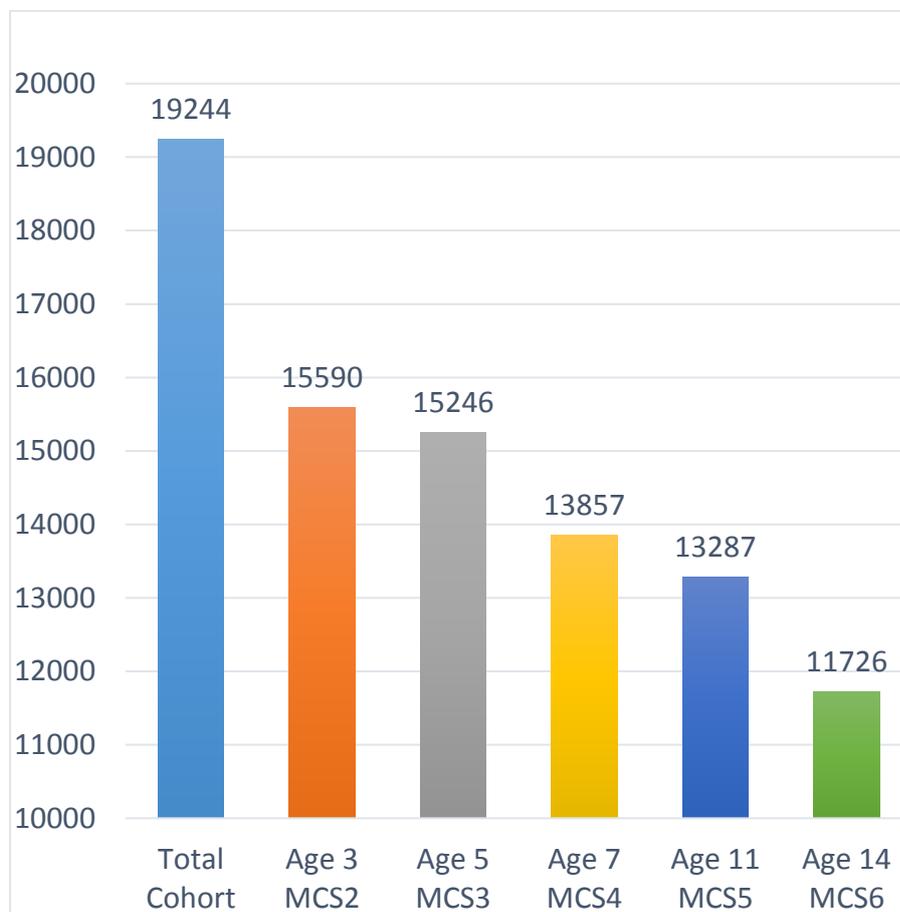


Figure 1: Cohort size for each of the sample sweeps and age of child when survey data collected.

MCS5 (Sweep 5, 2012)

The fifth sweep of the Millennium Cohort Study took place during 2012 when the cohort children were aged **11 years** and in their final year of primary school. The survey included interviews with both parents (where co-resident), cognitive assessments and physical measurements of cohort members, a self-completion questionnaire for cohort members and a survey of class teachers in England and Wales. The final number of productive interviews achieved was 13,287.

Summary

All parent/caregivers: Mean age 41.23, 59% females/41% males.
 Main interview participants only: Mean age 40.13, 96% females/4% males.

Table 1: Parent/Caregiver’s relationship to the Cohort Member MCS5

| | Frequency | Percent |
|--------------------------------|-----------|---------|
| Natural parent | 13165 | 99.1 |
| Grandparent | 53 | .4 |
| Adoptive parent | 20 | .2 |
| Step-parent, partner of parent | 13 | .1 |
| Other relative | 13 | .1 |
| Foster parent | 12 | .1 |
| Other non-relative | 6 | .0 |
| Natural brother/Natural sister | 3 | .0 |
| Half-brother/Half-sister | 2 | .0 |
| Total | 13287 | 100.0 |

Table 1 above shows that almost 99% of the *main interview* participants were natural parents.

MCS6 (Sweep 6, 2015)

The Millennium Cohort Study surveyed the cohort members and their families in 2015 when the young people were aged around **14 years**. The issued sample for MCS6 included all families: except those that were ineligible (where a cohort member had died or the family had emigrated outside of the UK) those that had permanently withdrawn from the study, and those that had been classified as ‘permanent refusals’ or ‘permanently untraced’. Interviews were conducted with 11,726 families. The Age 14 sweep was again a household based survey that collected information from parents, as well as from the cohort members (children) themselves. It combined both interviewer administered and self-completion instruments, as well as direct measurements of young people's physical growth, and assessments of both young people and their parents' cognitive ability.

Summary:

All interview participants: Mean age 44.48, 59.8% females/40.2% males.

Main Interview participants only: Mean age 43.49, 94% females/6% males.

Table 2: Parent/Caregiver's relationship to the Cohort Member MCS6

| | Frequency | Percent |
|--------------------------------|-----------|---------|
| Natural parent | 11598 | 98.8 |
| Grandparent | 56 | .5 |
| Step-parent, partner of parent | 23 | .2 |
| Adoptive parent | 17 | .1 |
| Foster parent | 16 | .1 |
| Other relative | 16 | .1 |
| Other non-relative | 9 | .1 |
| Half-brother/Half-sister | 3 | .0 |
| Natural brother/Natural sister | 2 | .0 |
| Total | 11740 | 100.0 |

Table 2 above shows that almost 99% of the main interview participants were natural parents.

The nature of needs presenting to and service uptake from Hope provide a second strand of data reflecting the methods applied for this research.

2.2 Secondary Data - Hope Support data

Amy is 20-years-old. Her aunty was diagnosed with multiple sclerosis (MS) when Amy was aged about 10 and then, the following year, her mother was also diagnosed with MS. Amy has two older brothers who have helped her through her childhood and teenage years. However, she found the caring responsibilities, school and the uncertainty surrounding her mother's ill health very challenging. Her experiences of school were not good and led to her leaving to be home educated at age 13 years. The lack of understanding and support she experienced throughout her education left her feeling very negative about school. Although she was offered counselling as a child, she did not find it helpful. She first accessed Hope Support when she was around 15-years-old. She is now part of the Y-Team and helps to run Hope Support.

Hope Support keeps detailed data on all children they currently support or have supported in the past, with their records going back to December 2009. Hope have supported **380 young people (233 females and 147 males)** in a variety of ways over the last seven years since its inception. Anonymised case data were released to the research team and used for the purposes of enabling the reporting the nature of need and the nature of support Hope has already provided to young people both in the area local to the charity and further afield (online support).

2.3 Primary Data – Young people’s voices

Hope already has a number of public-facing case studies to help raise awareness of its services and the need for them. Through interviews with young people, we aimed to supplement these further by seeking young people’s stories relating to: the circumstances that brought them to Hope; their experiences and what they consider to be the effects of those experiences; the services they would like to see in place and what they think of current service provision.

We carried out **seven** interviews, three of which were face to face and four of which were by telephone at prearranged times to suit the young person. Each interview lasted between **20 to 40 minutes**, most lasting 30 minutes.

Ethical issues were given careful consideration. Ethical approval for the study was provided by the Open University Human Research Ethics Committee, in particular for the interview aspects of the data collection. Mindful of the sensitive nature of the questioning, how we approached the interviews was guided by Hope in consultation with a youth worker who works with and supports the young people on a regular basis. The interviews took place during routine youth sessions with the youth worker present at all times or at pre-arranged times by telephone, brokered by the trusted youth workers of the young people. Young people were given an information sheet with indicative questions before the interviews so that they felt prepared and could make an informed choice about whether or not to participate. Information sheets were also provided for parents of young people aged under 18 years. Consent to participate was given by the young people verbally, via email and/or via text, as guided by Hope Support to match their usual ways of working with young people. All interviews were audio recorded and transcribed. The transcription of each interview was sent to the appropriate young person to give them the opportunity to make alterations or additions to the information they wished to share. Each young person was given a pseudonym to preserve anonymity, with the opportunity to choose their own.

3. Findings: Extent and nature of young people’s experiences

Emma is 20-years-old. Emma’s mother died when Emma was in secondary school and Emma found that there was no support for her other than bereavement charities, which didn’t help in the run up to the death and didn’t meet Emma’s needs. She found the inadvertent lack of sensitivity in school in dealing with a young person living through a family health crisis and then bereavement a very negative experience. She couldn’t access Hope support at the time as it wasn’t available in her area. She is now part of the Y-Team and helps to run Hope Support.

In section 3, we detail the findings in turn from each strand of data. Section 3.1 reports the findings from the analysis of the Millennium Cohort Study data initially for sweep 5, 2012, when the children were aged 11 years, and then for sweep 6, 2015, when the children were aged 14 years. Section 3.2 uses the MCS data and national population data to estimate the

national need for support services for children and young people living through a family health crisis. Section 3.3 reports the statistics from Hope Support and looks at what can be ascertained from Hope’s own records about the nature of need and the uptake of services. Section 3.4 reports the findings from the interviews with young people, setting out the cross-cutting themes and categories from across their experiences and their thoughts on effective services.

3.1 What do national statistics tell us? Analysis and Findings from the Millennium Cohort Study

Millennium Cohort Study 5 (Sweep 5, 2012) – children aged 11 years

Targeted data from the MCS5 has been selected for presentation reflecting the aims of the project to examine scope of family health crisis in the UK:

1) Parent/caregiver self-report data

- Whether parent /caregiver has a long-standing illness, the nature of the illness, and the impact of the illness on their day to day activities.

2) Parent/caregiver data about their child aged 11.

- Whether child has a long-standing illness, the nature of the illness, and the impact of the illness on their day to day activities.
- Whether the child appeared to have many worries/often seem worried.
- Whether the child appeared to be often unhappy, downhearted or tearful.

3) Child self-report data (In Appendix).

- Whether the child felt worried or sad in the last four weeks (a measure of mental health).

Parent/Caregiver Data – Questions directly about the Parent/Caregiver

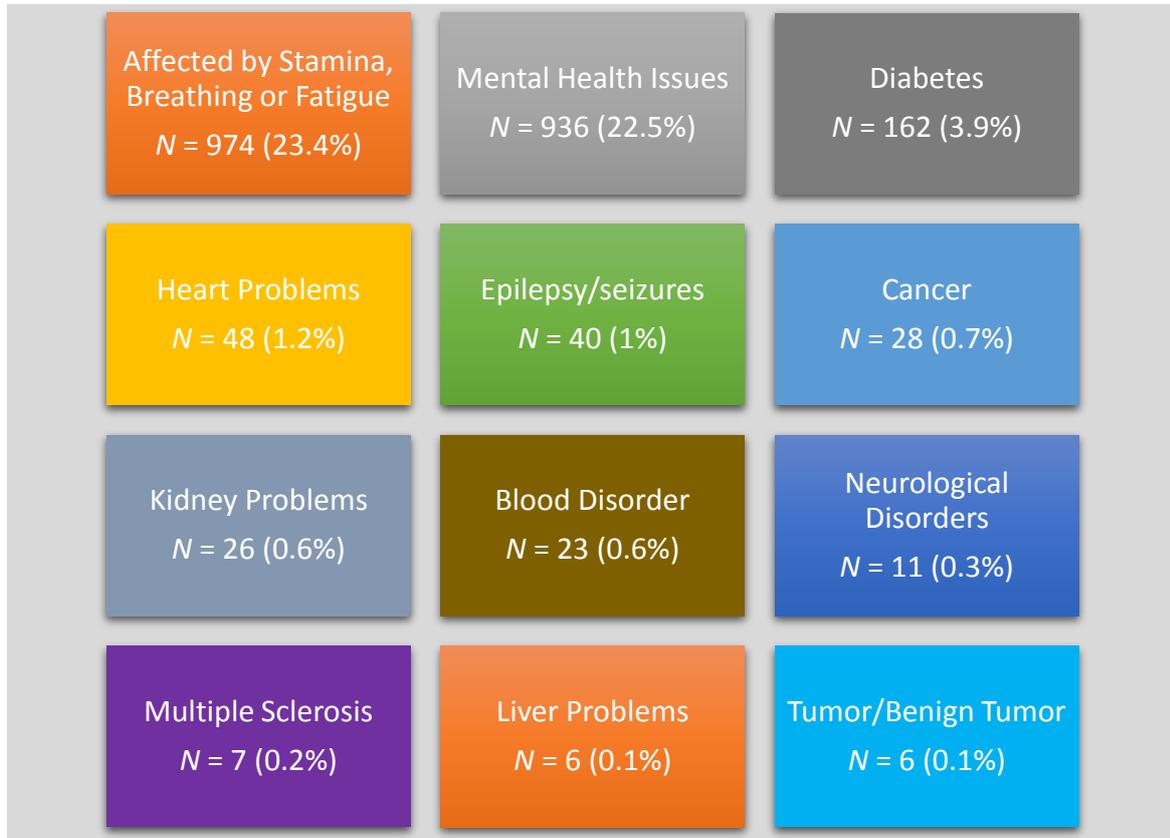
Table 3: Whether parent/caregiver has longstanding illness MCS5

| | Frequency | Valid Percent |
|------------|-------------|---------------|
| Yes | 4162 | 18.9.0 |
| No | 17824 | 81.1.0 |
| Total | 21986 | 100.0 |

Table 3 above shows that nearly 19% (or almost 1 in 5) of parents/caregivers were reported to have a long-standing illness when cohort member was aged 11. This figure is 20% for main interview participants and 17.3% for partner interview participants. Scaling up this figure to indicate the national (see section 3.2 page 25) level of long-standing illness amongst parents/caregivers that has had an impact on their abilities gives a potential total of **131,452 children aged 11 years** nationally with a parent or carer with a long-standing illness.

Of those **4162** who responded ‘Yes’ to this question, 2085 (50%) said that the illness had had an impact on their own abilities for more than 12 months, and 920 (22.1%) said that

their own illness/condition impacts ‘a lot’ on their ability to do everyday activities. Follow up information was given about the nature of the longstanding illness. In particular:



Parent/Caregiver Data – Questions about the child aged 11

This data regarding the child’s own health is important as 9% of referrals to Hope are due to a brother/sister/cousin (often younger) being diagnosed with a serious health condition.

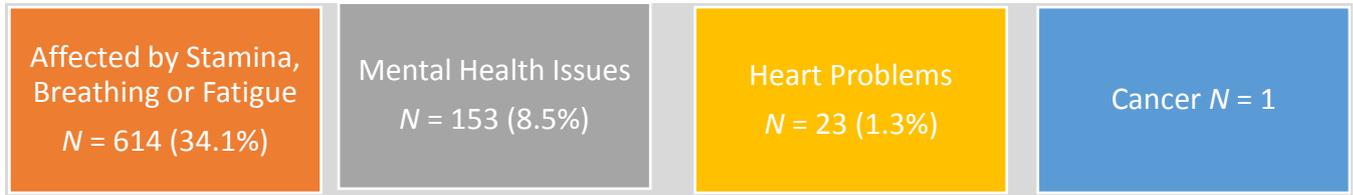
Table 4: Whether Cohort Member has longstanding illness - age 11 (*Valid data available from 13539 families).

| | Frequency | Percent |
|------------|-------------|-------------|
| Yes | 1802 | 13.5 |
| No | 11552 | 86.5 |
| Don’t know | 5 | .0 |
| Total | 13539 | 100 |

Table 4 above shows that 13.5% (or 1 in 8) of cohort members were reported (by their parent/caregiver) to have a long-standing illness when aged 11. This scales up to 93,894 of 11 year-olds nationally as an indicative figure.

Of those 1802 who responded ‘Yes’ to this question, 899 (50%) said that the illness had an impact on the child’s ability for more than 12 months, and 345 (19.1%) said that their child’s

illness/condition impacts ‘a lot’ on their ability to do everyday activities. Follow up information was given about the nature of the longstanding illness. In particular:



As the Millennium Cohort Data is available in separate databases (one for each survey), it is not possible to explore *directly* the relationship between parent longstanding illness and child wellbeing. It is possible however to explore the association between child longstanding illness and perceived child wellbeing at age 11 (and later aged 14).

Table 5: Impact of child longstanding illness on perceived (by parent) wellbeing – child has many worries, often seems worried MCS5 (missing data N =103)

| | | Not true | Somewhat true | Certainly true | Total |
|--------------------------------|-----|----------|---------------|----------------|-------|
| Child has longstanding illness | Yes | 816 | 685 | 257 | 1776 |
| | No | 7232 | 3286 | 585 | 11188 |
| Total | | 8048 | 3971 | 842 | 12964 |

Table 5 above shows that of the children who have a long standing illness at age 11, 53% were considered by their parents to often seem worried (somewhat true and certainly true responses combined). In comparison, 34% of children *without* a longstanding illness were considered by their parents to often seem worried.

Table 6: Impact of child longstanding illness on perceived (by parent) wellbeing – child often unhappy, downhearted, tearful MCS5 (missing data N = 83).

| | | Not true | Somewhat true | Certainly true | Total |
|--------------------------------|-----|----------|---------------|----------------|-------|
| Child has longstanding illness | Yes | 1215 | 428 | 116 | 1776 |
| | No | 9492 | 1407 | 223 | 11188 |
| Total | | 10707 | 1835 | 339 | 12964 |

Table 6 above shows that of the children who have a long standing illness at age 11, 31% were considered by their parents to often seem unhappy (somewhat true and certainly true responses combined). In comparison, 15% of children *without* a longstanding illness were considered by their parents to often seem unhappy.

Whilst unsurprising, this data does show a clear link between a child’s physical health and perceived child wellbeing/mental health.

Millennium Cohort Study 6 (Sweep 6, 2015) – children aged 14 years

Targeted data from the MCS6 has been selected for presentation:

1) Parent/caregiver self-report data:

- Whether parent /caregiver has a long-standing illness, the nature of the illness, and the impact of the illness on their day to day activities.

2) Parent/caregiver data about their child aged 14:

- Whether child has a long-standing illness, the nature of the illness, and the impact of the illness on their day to day activities.
- Whether the child appeared to have many worries/often seem worried.
- Whether the child appeared to be often unhappy, downhearted or tearful.

3) Child self-report data (In Appendix).

- Whether the child felt 'satisfied with themselves' (a measure of subjective wellbeing).
- Whether the child had self-harmed in the last year.

Parent/Caregiver Data – Questions directly about the Parent/Caregiver

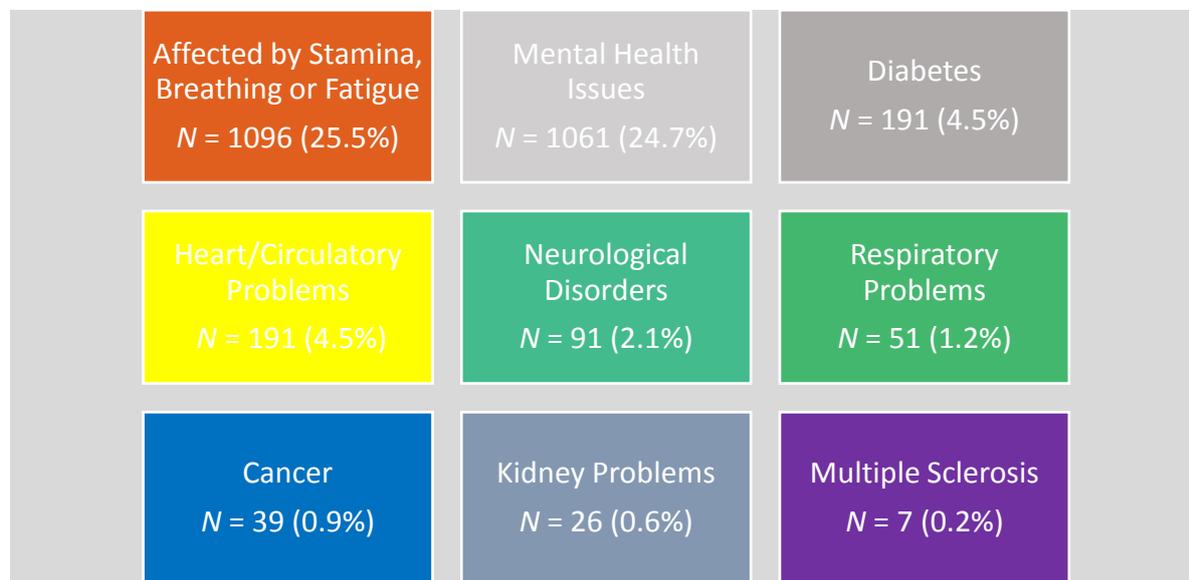
Lisa is 23-years-old. Her mother was diagnosed with terminal cancer in 2014 while Lisa was at university. Although Lisa's mother was a palliative care medical consultant and felt that there was little need for any additional medical advice and support through Macmillan, Lisa herself needed support but found it difficult to access. She found university procedures unhelpful for a young person living through a family health crisis and subsequent bereavement and felt that she had to leave eventually without completing her degree, although with time she feels she might have managed it part-time if the option had been more accessible.

Table 7: Whether parent/caregiver has longstanding illness MCS6

| | Frequency | Percent |
|------------|-------------|-------------|
| Yes | 4290 | 22.8 |
| No | 14547 | 77.2 |
| Total | 18850 | 100.0 |

Table 7 above shows that nearly 23% (or over 1 in 5) of parents/caregivers were reported to have a long-standing illness when cohort member was aged 14. This figure is 24.1% for main interview participants and 20.7% for partner interview participants. Scaling up this figure to indicate the national level (see section 3.2 page 25) of long-standing illness amongst parents/caregivers gives a potential total of **164,673** children aged 14 years with a parent or carer with a long-standing illness.

Of those 4290 who responded ‘Yes’ to this question, 2224 (51.8%) said that the illness had had an impact on their own abilities for more than 12 months, and 996 (23.2%) said that their own illness/condition impacts ‘a lot’ on their ability to do everyday activities. Follow up information was given about the nature of the longstanding illness. In particular:



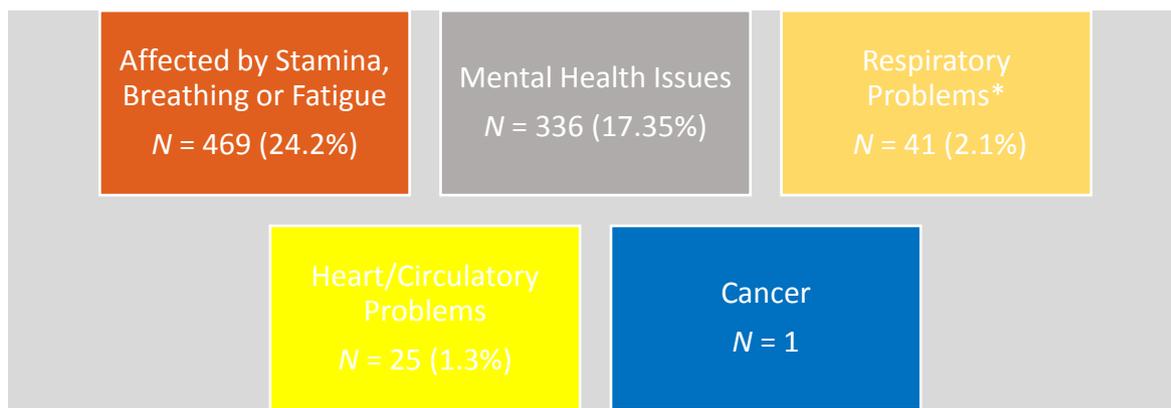
*Epilepsy/seizures, Blood Disorder, Liver Problems, Multiple Sclerosis and Tumor/Benign Tumor not recorded in MCS6.

Parent/Caregiver Data – Questions about the child aged 14.

Table 8: Whether a child has longstanding illness - age 14(*Valid data available from 11738 families).

| | Frequency | Percent |
|------------|-------------|-------------|
| Yes | 1941 | 16.5 |
| No | 9796 | 83.5 |
| Don't know | 1 | .0 |
| Total | 11738 | 100 |

Table 8 above shows that 16.5% (or 1 in 6) of cohort members were reported to have a long-standing illness when aged 14. Of those 1941 who responded ‘Yes’ to this question, 979 (50%) said that the illness had had an impact on the child’s ability for more than 12 months, and 406 (21%) said that their child’s illness/condition impacts ‘a lot’ on their ability to do everyday activities. Follow up information was given about the nature of the longstanding illness. In particular:



*Note that Respiratory Problems was not a question specifically asked about in 2012.

Table 9: Impact of child longstanding illness on perceived (by parent) wellbeing – child has many worries, often seems worried MCS6

| | | Not true | Somewhat true | Certainly true | Total |
|--------------------------------|-----|----------|---------------|----------------|-------|
| Child has longstanding illness | Yes | 763 | 716 | 398 | 1877 |
| | No | 5894 | 2935 | 620 | 9449 |
| Total | | 6657 | 3651 | 1018 | 11326 |

Table 9 above shows that of the children who have a long standing illness at age 14, 59% were considered by their parents to often seem worried (somewhat true and certainly true responses combined). In comparison, 38% of children *without* a longstanding illness were considered by their parents to often seem worried.

Table 10: Impact of child longstanding illness on perceived (by parent) wellbeing – child often unhappy, downhearted, tearful MCS6

| | | Not true | Somewhat true | Certainly true | Total |
|--------------------------------|-----|----------|---------------|----------------|-------|
| Child has longstanding illness | Yes | 1190 | 503 | 171 | 1864 |
| | No | 7736 | 1305 | 397 | 9438 |
| Total | | 8926 | 1808 | 568 | 11302 |

Table 10 above shows that of the children who have a long standing illness at age 14, 36% were considered by their parents to often seem unhappy (somewhat true and certainly true responses combined). In comparison, 18% of children *without* a longstanding illness were considered by their parents to often seem unhappy.

Again this data does show a clear link between child physical health and perceived child wellbeing/mental health.

3.2 Estimating the national need for support services

Brian is 19-years-old. His mother first became very ill when he was aged eight years. She developed Crohn’s disease and aplastic anaemia as a result of a procedure during a Caesarean section. She has since had an amputation, has been in and out of hospital for years and has had a stroke. Brian took on the bulk of the caring responsibilities from a very young age, caring for his mother, brother and his younger sister who is 7 years his junior. He has had support from Hope and from Young Carers, but nonetheless he has found his childhood and adolescence challenging in trying to deal with caring, the demands of education and dealing with the emotions of his mother’s ill health. He is now part of the Y-Team and helps to run Hope Support as well as working with Young Carers.

Using both the MCS5/6 data and national population data, it is possible to estimate how many children and young people in the UK are potentially living with a family health crisis.

The Office of National Statistics (ONS) records show that there were nearly 5.1 million young people living in the UK aged 11-17 in 2014. See Figure 2 below for the breakdown of how many young people there were at each age.

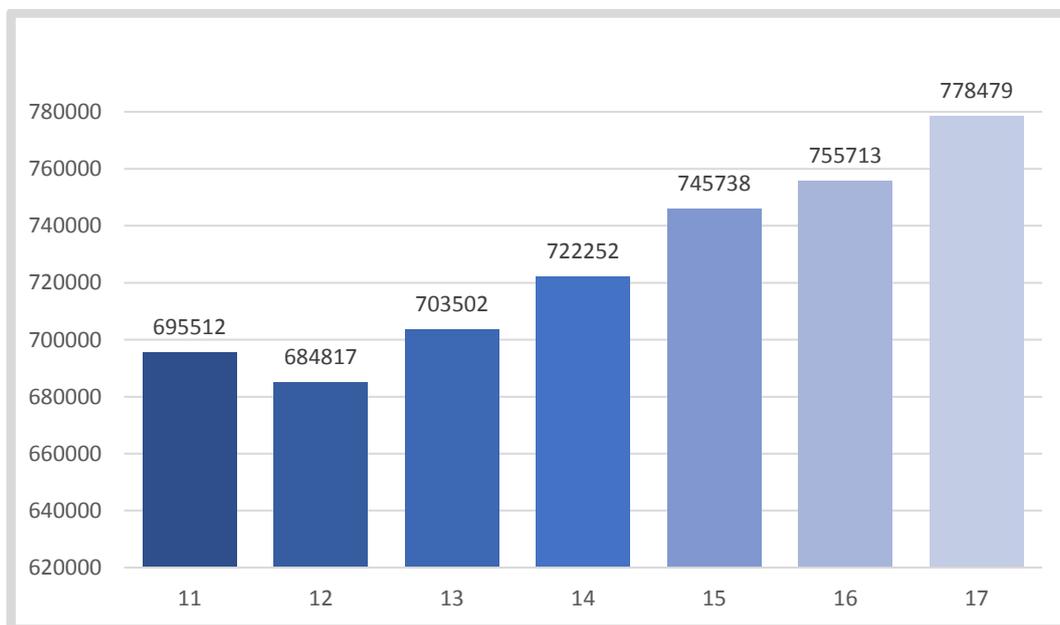


Figure 2: Population data – number of young people aged 11-17 living in the U.K (ONS, 2014)

Extrapolating from MCS5 dataset (when children in the MCS were 11).

Parent or Caregiver with Longstanding illness

The MCS5 dataset showed that 18.9% of the sample of 11 year olds had a parent or caregiver with a longstanding illness – therefore it is estimated that **over 130,000 11 year**

olds in the UK could be experiencing a situation where they have a parent or caregiver who has a longstanding illness.

Parent or Caregiver with Cancer

The MCS5 dataset showed that 28 parents or caregivers of 11 year olds in the cohort had/have cancer - this corresponds with an estimate of 905 current parents of 11 year olds across the UK.

Extrapolating from MCS6 dataset (when children in the MCS were 14).

Parent or Caregiver with Longstanding illness

The MCS6 dataset showed that 22.8% of the sample of 14 year olds had a parent or caregiver with a longstanding illness – therefore it is further estimated that **over 160,000 14 year olds in the UK** could be in a situation where they have a parent or caregiver who has a longstanding illness.

Parent or Caregiver with Cancer

The MCS6 dataset showed that 39 of the parents/caregivers themselves had/have cancer - this corresponds with an estimate of 1445 current parents of 14 year olds across the UK.

Extrapolating from both the MCS5 and MCS6 datasets to all children aged 11-17.

It is possible to make some broad generalisations using both the Millennium cohort data as already reported above and population data which shows that there were 5.1 million children aged 11-17 in the UK in 2014.

- If it is assumed (using MCS5 & 6 data) that approximately 20% of all children aged 11-17 have a parent or caregiver who has a longstanding illness, then this equates to potentially **a million children** aged 11 and above in the UK with a parent/caregiver with a longstanding illness.
- If it is assumed (using MCS5 & 6 data) that approximately 0.02% of all children aged 11-17 have a parent or caregiver who has cancer, then this equates to potentially **10,200 children** aged 11 and above in the UK who has a parent/caregiver with cancer.

3.3 Statistics: What do Hope Support services data tell us?

Hope have supported **380 young people (233 females and 147 males through to November 2017)** in a variety of ways over the last seven years, through youth sessions, one to one sessions, youth activities and online support. See the map below to see the geographic range of support provided up until June 2017, (N = 285). Note that the data in figures in this section is based on the data as of June 2017.



| | | |
|-------------|----|-------|
| Hereford | 73 | 25.6% |
| Ross | 42 | 14.7% |
| Gloucester | 36 | 12.6% |
| Forest | 26 | 9.1% |
| Kington | 14 | 4.9% |
| Cheltenham | 14 | 4.9% |
| Other areas | 68 | 23.9% |

Figure 3: Map to show where Hope support has been provided. See Appendix B for full data table.

Figure 4: Types of support Hope has provided over the last seven years (some children receive more than one).

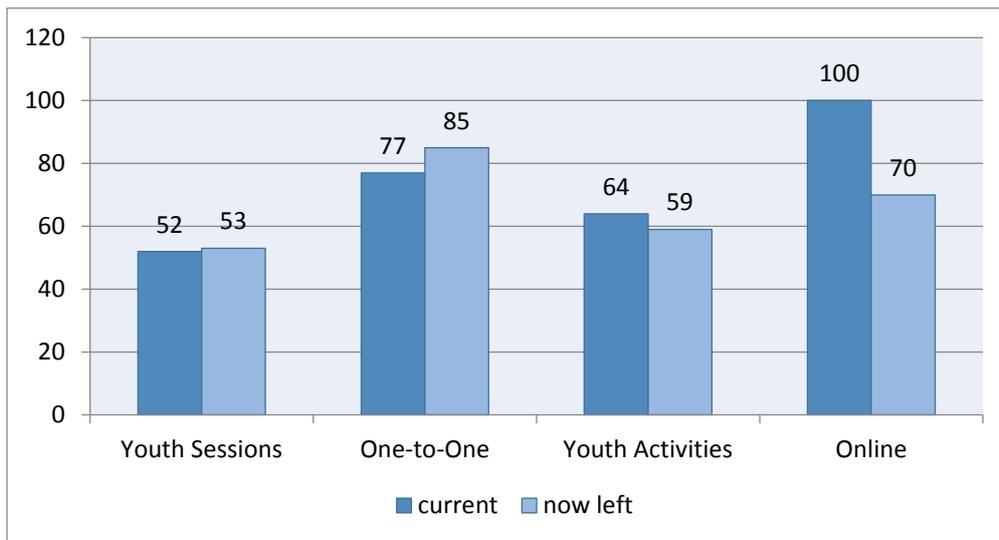


Figure 4 above show that online and one to one sessions were the most commonly delivered type of session.

Figure 5 below shows the ages at which the children and young people were referred to Hope*.

*Note that Referral age data was missing for 54 cases. The mean age of the children aged 11-17 who have received support is 13.58 (n = 181). There were 19 children aged between 4-10 at the time of referral and 31 young people aged between 17-23 years.

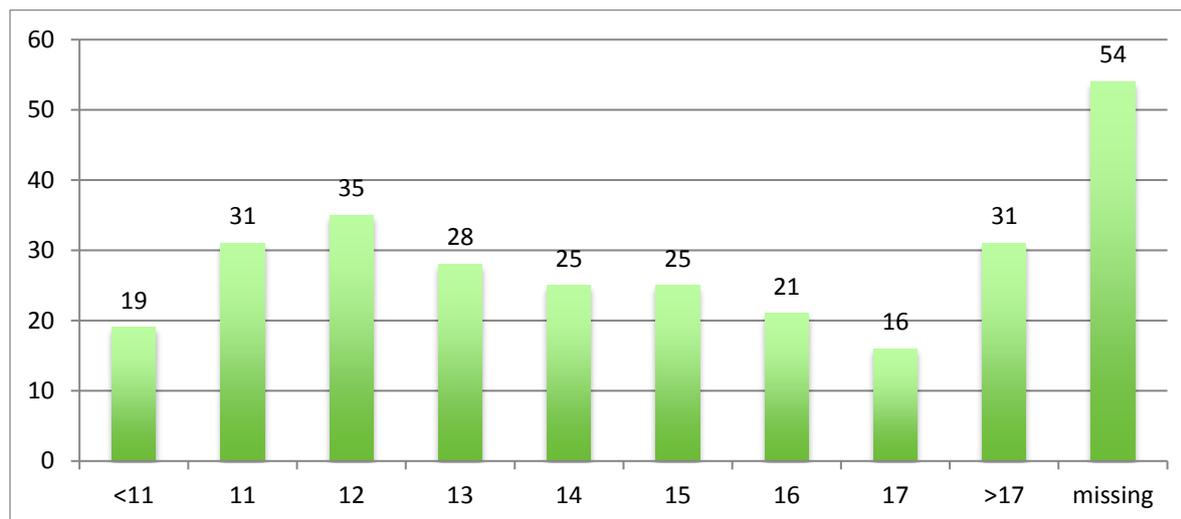


Figure 5: Ages at which children and young people were referred to Hope (total N = 285 including those cases with missing age and data).

Table 11 below shows the main condition that the close family member is dealing with.

Table 11: Medical condition that close family member is dealing with (total N = 285, Missing data n = 16).

| | |
|-----------------------|---|
| Alcoholic | 1 |
| ALD | 1 |
| Brain aneurism | 1 |
| Brain damage | 1 |
| Crohn's Disease | 1 |
| Cystic Fibrosis | 1 |
| Fibromyalgia | 1 |
| Kidney Failure | 1 |
| Liver transplant | 1 |
| Myotonic Dystrophy | 1 |
| Neuroblastoma | 1 |
| Strokes, brain damage | 1 |
| Battens | 2 |

| | |
|------------------------|----|
| Chiari Malformation | 2 |
| COPD | 2 |
| Dementia | 2 |
| Huntingtons | 2 |
| Kidney Disease | 2 |
| Motor Neurones | 2 |
| Pulmonary hypertension | 2 |
| Stroke | 2 |
| Alzheimers | 3 |
| Cerebral Palsy | 3 |
| Lung Transplant | 4 |
| MS | 5 |
| Heart Condition | 9 |
| Brain tumour | 15 |
| | 20 |
| Cancer | 0 |

Table 11 above clearly shows that the vast majority of cases (74.3%) are due to a close family member being diagnosed with Cancer.

Figure 6 below show shows the relationship between the child receiving support and the close family member going through a health crisis.

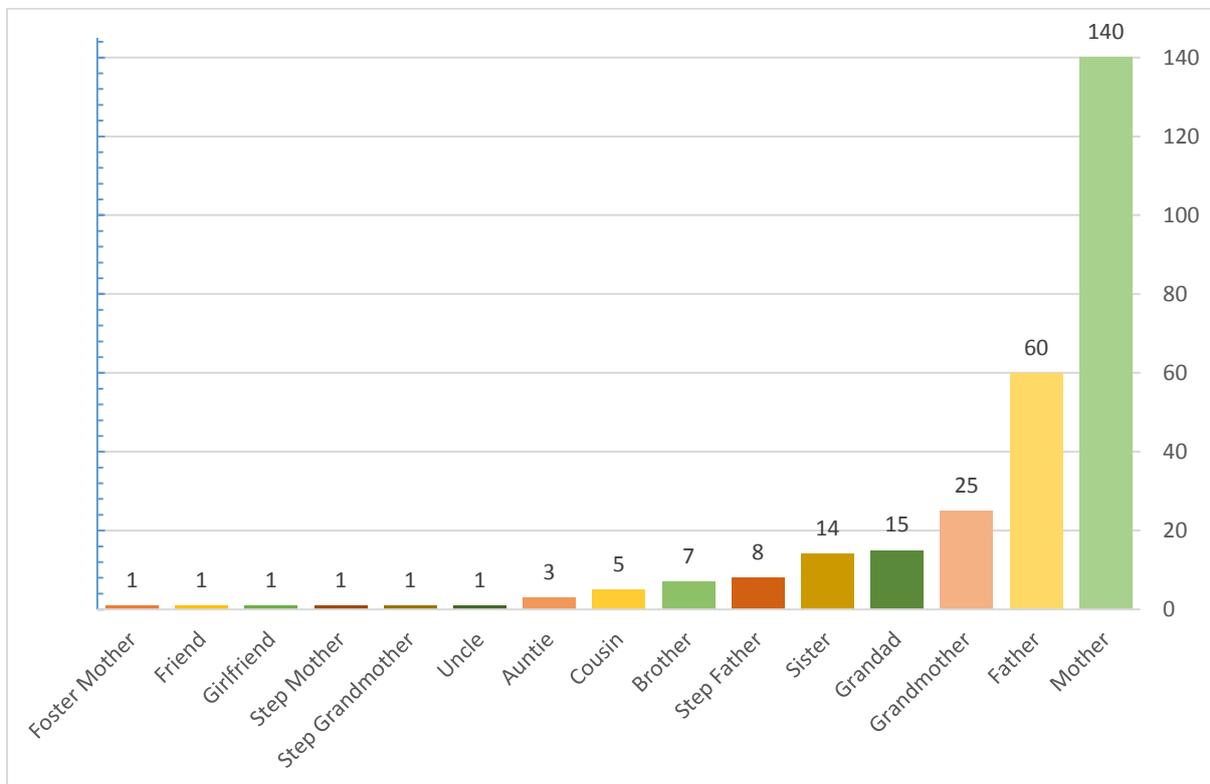


Figure 6 above shows that the majority of close family members were either mothers/stepmothers/foster mothers (50%) fathers/stepfathers (24%) or grandparents/step grandparents (14%). However, in 9% of cases it was a brother, sister or cousin with the serious health condition.

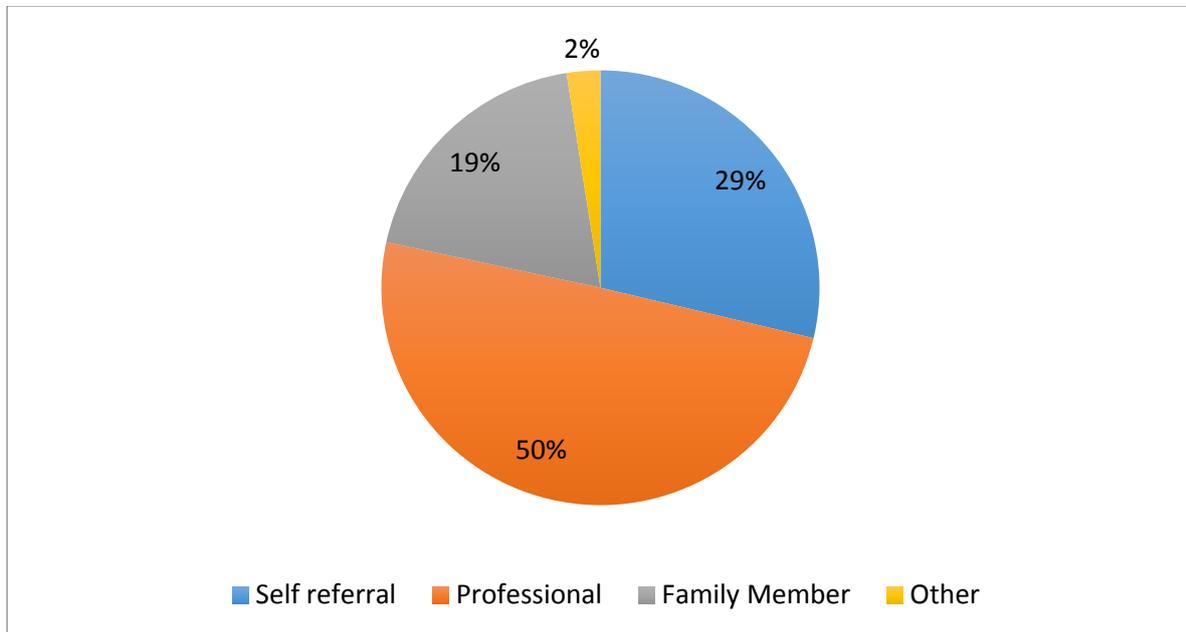


Figure7: Referral pathways.

Figure 7 above shows that the majority of referrals to Hope (50%) were made by professionals.

Table 12: Ethnicity of C&YP referred to Hope

| | |
|------------------|------------|
| White | 252 |
| Asian | 1 |
| Indian | 2 |
| Eastern European | 3 |
| Mixed Heritage | 1 |
| Other | 3 |
| <i>missing</i> | 23 |
| Total | 285 |

Table 12 above shows that the majority of children and young people referred were White.

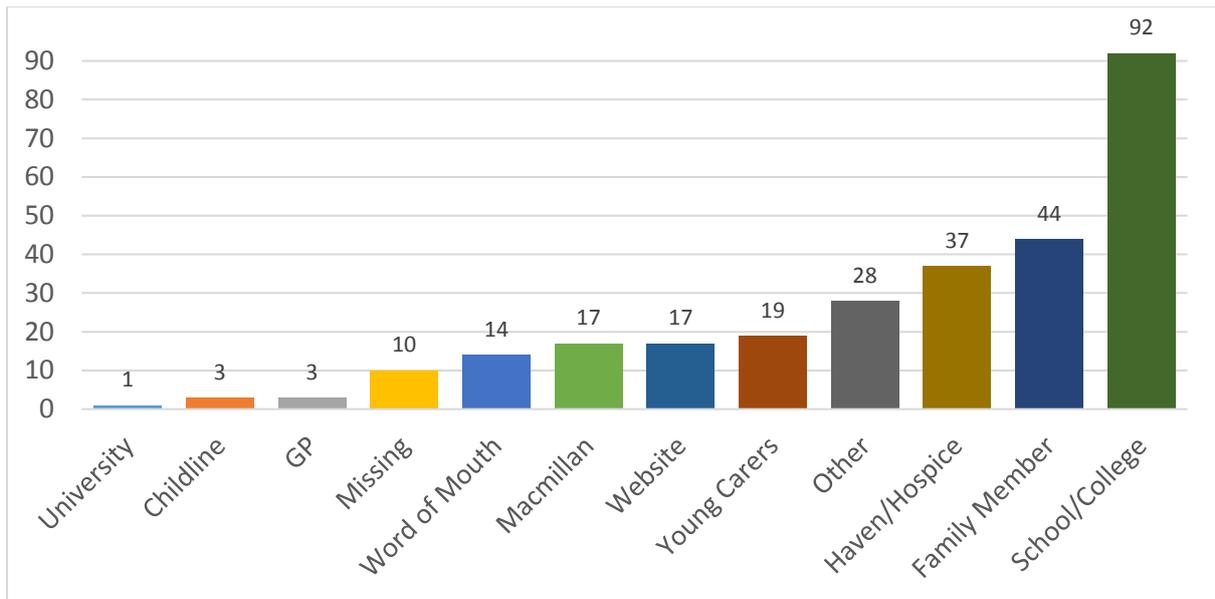


Figure 8: How the children and young people heard about Hope (total N = 285, Missing data n = 25).

Figure 8 above shows that the majority of children/young people found out about Hope from School/College (32.3%), a family member (15.4%) or from Haven/Hospice (13%).

Figure 9 below displays the range of issues the children and young adults needed support with (many presenting with more than one issue).

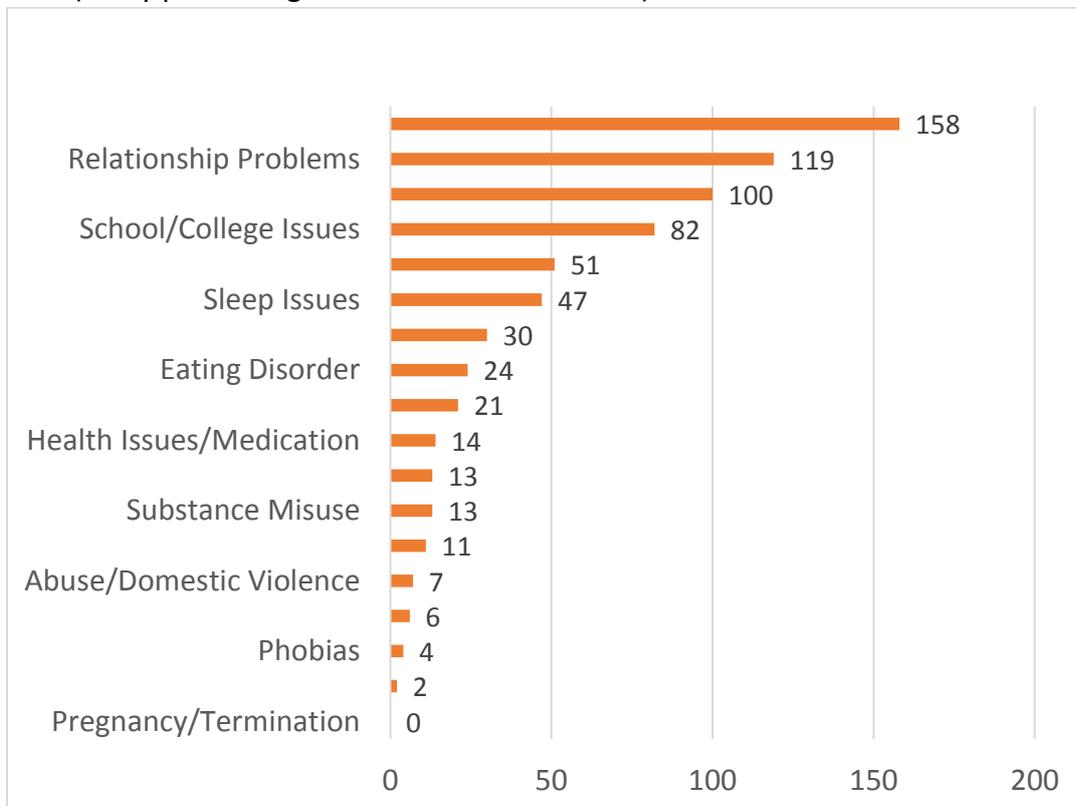


Figure 9: Range of issues the children and young adults needed support with (many presenting with more than one issue).

Figure 9 above clearly shows that the children and young people accessing Hope support encounter a variety of issues including anxiety, depression, panic attacks, relationship problems, loneliness, isolation, behavioural problems and sleep issues as well as challenges relating to their education at school and college and broader family problems. Figure 9 indicates that anxiety, depression, panic attacks, relationship problems and loneliness as the most prevalent issues.

3.4 Young people’s voices: our experiences

Bill is 20-years-old. His mother was diagnosed with breast cancer when he was in primary school, aged about 9 years. Although the school was sympathetic, there were no local services at that time for him to be referred to. His mother’s cancer became terminal and she died when Bill was in year 9, aged 14 years. Although Bill had the support of family and friends, his mother’s struggle with cancer has been a difficult and long part of his childhood and adolescence. He is now part of the Y-Team and helps to run Hope Support.

Although each young person’s experiences are unique as they face different family health crises and they each respond in different ways, there were nonetheless consistent categories discernible across the interview data, which have been amalgamated into themes. To give a rough sense of the weighting of each theme, table 13 below notes the number of quotations from the transcribed interviews that were ascribed to each category. The themes presented here are: experiencing need; the consequences of met and unmet need; the characteristics of support received/available from Hope; and the nature of services required – what makes Hope so valued by young people?

Table 13: Themes and categories from coded interview data

| Theme With categories included in theme | No. of interview excerpts ascribed to theme |
|--|--|
| Experiencing need Categories: <ul style="list-style-type: none"> • crises extending across long periods of childhood • young people’s understanding of what was happening • experiences of service responses • experiences in daily life | 42 |
| Consequences of [un]met need Categories: <ul style="list-style-type: none"> • being labelled as ‘difficult’ • impact on educational experiences and outcomes • impact on social life | 31 |

| | |
|---|----|
| <ul style="list-style-type: none"> feelings of stress and hopelessness | |
| Characteristics of Hope Support Categories: <ul style="list-style-type: none"> Relationship building Differentiated support to meet individual needs | 40 |
| Nature of services required by young people: What makes Hope so valued by young people? Categories: <ul style="list-style-type: none"> Flexibility Acceptance and understanding | 28 |

3.3.1 Experiencing need

The experiences of need for support while living through a family health crisis manifested themselves in different ways for different young people. Categories within this theme included: crises extending across long periods of childhood; young people’s understanding of what was happening; experiences of service responses; and experiences in daily life.

Crises extending across long periods of childhood

Although the phrase ‘health crisis’ is used throughout this report, it became apparent during the data collection and analysis that crisis does not indicate a short-term difficulty. Rather, for many of the young people interviewed, their parents had been diagnosed with a serious illness while the young person was very young and the effects of that diagnosis were felt not only then, but over long periods of time throughout their childhoods as illnesses progressed.

Brian, for example, described how his mother developed Crohn’s disease and aplastic anaemia when he was eight-years-old, had had continuing severe health problems over the years including an amputation and had recently, when Brian was 18-years-old, had a stroke. Throughout that time, Brian had taken on the role of carer for his mother and siblings. Molly’s mother had been diagnosed with stage 3 kidney cancer when Molly was 14-years-old. Now 17, Molly had spent the last three years in a caring role alongside her father. Amy’s mother was diagnosed with multiple sclerosis while Amy was at primary school in year 6 (approximate age: 11 years) and had experienced continuing poor health as a result over subsequent years. ‘In year 5, my aunty was diagnosed first and then my mum a year later. So my aunty was diagnosed in 2007 and my mum in 2008’ (Amy). Now aged 20, Amy’s late childhood and teenage years had been spent in the context of her mother’s illness. Similarly, Bill’s mother had been diagnosed with breast cancer when he was in year 4 at primary school (approximate age: 9 years), which had subsequently been diagnosed as terminal when he was 14 years-old. Bill, now aged 20 years, reflected on the variable nature of living with the illness.

It started at primary school when my mum had breast cancer diagnosed when I was in year 4 and it became terminal when I was in year 9 at age 14. And because its cancer it has phases so it wasn’t like all those years my mum was in a bad condition. There were times when it did get worse (Bill).

Emma, aged 20, whose mother had died during her teenage years, echoed others' experiences of living with difficulties over an extended period.

You reach different points in your grief through the years and even ... its difficult ... well I joined Hope at the point when I have already lost my Mum..... I suppose it's just when you hit a certain point and feeling a certain emotion that you can just relate with other people who might be feeling that as well (Emma).

Young people's understanding of what was happening

Having faced a health crisis at a very young age, young people had a limited grasp of the situations they found themselves in.

I didn't really understand what was going on either because I was so young...Just knew that mum wasn't very well and was spending a lot of time at doctors' appointments and stuff. That's all I knew then. (Amy)

Emma described what it felt like to face her mother's serious illness and then her own bereavement.

It's confusing and lonely (Emma).

Partial knowledge for a child about serious, complex illness is a daunting prospect to come to terms with, emphasising the value of regular information for children in forms appropriate to their levels of understanding throughout their childhoods and adolescence.

When I started to understand what was wrong with mum, I didn't really understand what MS was, I knew it was a disease that attacks the nervous system, I was like 'she's going to be paralysed, she won't be able to walk. (Amy)

Experiences of service responses

Before accessing Hope Support services, the young people described the ways in which they experienced the responses of other services such as education, counselling and community youth services to support their needs. Some of those experiences were positive and some not so positive. Amy in particular felt that she had had a negative response from her primary and secondary schools and that the counselling service that her parents had been able to arrange didn't offer what she needed or understood at the time.

They [school] didn't ever try getting help for me. Mum and dad tried, like when I was in primary, I had a counsellor, but I didn't really understand it then either, so I didn't get why I was being taken into a room on my own for an hour to talk about my problems (Amy).

Further, her trust in counselling was undermined when she discovered that the confidentiality she had been assured of didn't extend to her parents.

I went [to counselling] in primary and was told that everything I told her was confidential and then I went home one day and found letters and that everything I'd been telling her she'd been telling mum and dad. Obviously because I was younger

and because of safeguarding and things, she had to do that, but it kind of put me off counselling. She'd told me she wouldn't say anything (Amy).

Emma, too, explained her experiences at school as far from helpful.

Me and another person in my class were going through the exact same thing and I remember when my Mum died when I went back to school and even though they were aware what was going on they took me out the classroom, informed the class and then put me straight back in. It was just completely. Well the teachers just didn't know what to do (Emma).

The lack of training for teachers and a lack of sensitivity in dealing with such a delicate situation had left a lasting impression on Emma.

My experience that I had been through was such a negative one. There was nothing out of it that was positive at all (Emma).

Her brother had, however, had some support from the school.

But it wasn't really targeted support. There wasn't someone there to talk to. To talk about what you are going through. Just someone to listen to you. There was no-one really to talk to. Not like at Hope. There was no one either to talk to about what it was like to go through this ... who was passed that (Emma)

As an older young person at university, Lisa felt that she fell between being an adult with all of the independence and self-sufficiency that it implied and being a young person who was seen as vulnerable and for whom support should be available.

I was in a weird place in my life. I wasn't an adult as such. Like I didn't have a car, I didn't have a house and I didn't have a job but I wasn't a child in school. I wasn't under 18 when they do offer quite a bit of support. And I wasn't a parent of the ill person as there is some support for them and I wasn't the spouse of the ill person as there is some support for them too. There is nothing for someone whose parent is terminally ill who was not really an adult and not really a child (Lisa).

Amy's contact with a youth centre had been more positive: 'I think the youth centre knew a little bit because one of the youth workers was a family relative' (Amy). But even there, Amy had found it hard to obtain the support she needed, partly because of her own difficulties in articulating what she was experiencing.

When I went to the youth centre, they never referred me to young carers. But I also don't talk about things. I do now, but I used to not talk. Only in about the past 3-4 years. So I don't think the youth centre really knew what was going on either (Amy).

Lucy, whose mother had breast cancer, found the response of the school nurse particularly helpful.

Well last year I was seeing the school nurse quite a lot. She's been really amazing. I don't know what I'd do without her. She was the person who mentioned to me to go to the doctors about everything, so that's what I did (Lucy).

For Amy, though, her experiences at school shaped much of her later teenage years.

In the end they had to take me out of education all together and then I calmed down a lot because I wasn't going through stress of school, homework, GCSEs, going to school just to be shouted at, stuff like that. I had a horrible time at school (Amy).

Lisa, too, found the lack of support for someone in her circumstances and flexibility in educational procedures, in her case at university, troubling. As her mother was diagnosed with terminal cancer, she tried to access flexible support.

But even things like ... I tried to go part time at one point and that wasn't an option. My supervisor was great and met with me and tried really hard. And the lecturers were really great but the university system just wasn't set up for it. I then had the decision to. Well do I leave my life and go home for however long Mum's alive for or do I... cos you don't know if it's going to be four years or four months (Lisa).

Following her mother's death, Lisa herself suffered further mental ill-health, compounding an existing mental health condition, as a result of her mother's illness and death, but found the opportunities to maintain contact with her studies and return to her degree in a way she could manage unavailable.

But at uni if you take a week off cos your ill the you are completely out of your depth...It really felt like you are kind here all the time or you come back in a year. A year is a really long time because the other thing is if you take a year's leave of absence you are not allowed to live in halls. You are not allowed to use their counselling system. You are not allowed to work in a job – if your job is with them. So when I went on a year's leave of absence I lost my accommodation, my counsellor, my occupation all in one go having lost my Mum. It's very cut throat. It made me feel not at all supported by the uni. It wasn't my supervisor, they stayed in touch. It wasn't my counsellor they stayed in touch. But the only service I was technically allowed to use was the student unions support centre. Co they weren't under the university (Lisa)

Lisa goes on to describe how she felt let down by the inadequacy of support available at the time,

I was under mental health services as well for a previous condition and I was actually discharged after mum was diagnosed and they said they couldn't do any work with me when my mum was dying because I wouldn't be able to focus on the work they were doing. None of them would do any work with me at that time. Even though I was under them I was then in a worse state. And then they said they couldn't do it with me when my mum died. So I was actually discharged when my mum was diagnosed even though I was already under them at the time for a previous mental health. Which of course you would think would be made worse by my mum's illness. You are just let down at every single step.

Experiences in daily life

Not surprisingly, young people found it difficult to understand not only the health problems their parents faced and the implications of these, but also to understand their own situation within that. Some described the impact on their daily lives, but without having any sense at all, at the time, that their lives were far from typical for other children.

Everything was hard before Hope. I struggled ...I'd have to help mum in the morning, then I'd have to go to school, come back from school and then helping her. It was like was going to school, but like I also had a full-time job if you know what I mean... I'd have to give my mum her meds, I'd have to clean the house, I'd have to cook for the family, I'd have to sort my sister out and get her to bed, I'd have to help mum in the shower, help her get to bed, help her get up out of bed if she needed to go to the toilet and help her to the toilet... I was 7 or 8 when I started caring (Brian).

Similarly, Molly described her role in caring for her mother who has terminal cancer and her grandmother who had had a stroke and who died last year.

When my grandma was alive, I'd have to help sort her out with her breakfast, make sure she took her tablets, help her get up, all that sort of stuff, but then when she got bad, she was bed-bound, so like dad would take mum to dialysis in the morning and I would stay and feed grandma her breakfast. And help sort the carers out, so get all the things ready for them so they could just do their jobs. Then when they'd gone she was under constant supervision as well, so when I wasn't at school I'd be there most of the time just giving her some company and stuff. Making sure at the moment that mum's okay because she's struggling a lot with her memory as well and she's finding things hard. She's on oxygen quite a lot as well as the cancer has spread to her lungs so she can't breathe very well, so I have to do a lot of things for her (Molly).

Molly also explained how trying to maintain a brave face for her family led to breakdowns once outside the family home.

I struggled a lot at school and I started to have massive breakdowns in lessons and stuff. And then my student mentor referred me to Hope. Before that, I couldn't cope, I'd literally just be crying all the time. I didn't want to cry around family because I wanted to be strong but as soon as i was away from family and with friends or whatever, I just wouldn't be able to hold it together. It was just really difficult (Molly).

Others describe how difficult it was to share their experiences with friends and how isolating that could be.

They [friends] had no idea. [R: Did they know your mum was ill?] Not many of them, one or two knew (Amy).

There was some reluctance to tell friends because of a worry that they would be seen as different in some way. When friends shared similar circumstances, however, it provided a connection based on understanding.

One of my friends from school, her dad passed away from cancer when we were younger. We were seeing each other at youth centre, but she went to a different school and her dad passed away. She and I got on really well and to this day she's still one of my friends. But most didn't know because I didn't talk about it (Amy).

Siblings, too, were an important part of sharing the lived experience of having a close family member with a health crisis.

My brothers have always been a solid support in my life, even to this day. I mean one of them lives in [northern city] now, but he still calls me every day and checks on us. They were always supportive (Amy).

3.3.2 Consequences of [un]met need

Before finding Hope, although some of the young people interviewed had been referred for various types of support, most had not received the type of support at the time that had enabled them to cope better with their experiences. The consequences of unmet need for effective support fell into three categories: being labelled as 'difficult'; impact on educational experiences and outcomes; impact on social life; and feelings of stress and hopelessness. Even with the support of Hope or other services, young people found living through a family health crisis had a profound impact on their lives.

Being labelled as 'difficult'

Extending throughout her childhood and adolescence since her mother's diagnosis, Amy felt that her unmet need for support had resulted in her behaving in ways that were judged as bad behaviour.

I was labelled a problem child. I was sent out of lessons, I was made to sit in the head teacher's office and stuff like that. Mum and dad had to come in quite regularly for meetings and stuff but no-one could quite pinpoint what was causing it and stuff. When we look back now, coz obviously it was the time that mum was being diagnosed as well, they don't think I knew how to cope with what was going on, didn't know how to process it...then it just got a whole lot worse in secondary school (Amy)

Reasons for her behaviour were sought by the school, e.g. testing for ADHD, but there appeared to be a lack of understanding that her behaviour could be the result of the family health situation.

The school knew about my mum, but they just didn't do anything about it. They just labelled me as a naughty child and put me on report, stuff like that (Amy).

Others, however, had had more positive experiences at school, where referrals had been made to other services such as Young Carers and Hope.

Impact on educational experiences and outcomes

Several young people explained the impact that their family health crisis had had on their education. Emma, similar to other young people in the same circumstances, found that after her mother had died, being away at university was too difficult.

I went to university to study design and I dropped out. Being away from home affected me in a way I didn't really expect it to. I wasn't expecting to be so homesick (Emma).

Lisa, too, found that she could not continue with her university studies, in spite of trying to find ways to return part-time and with the support of individual lecturers. The systems themselves simply did not allow sufficient flexibility.

For Amy, education in school became impossible to continue.

I literally hate the thought of school now. I left in year 9 and was home educated in the last two years so I have no GCSEs or anything like that (Amy).

The consequences mean that Amy was having to take longer to achieve the qualifications she wanted to. Nonetheless, she felt that her feelings of greater wellbeing once out of school were more important than quickly achieving qualifications.

I went to Hall College for 4 years. I had to start at the bottom. I had to do my level 1, then my level 2 and level 3. I've only just finished college now whereas all my friends are in uni and stuff like that. I feel kind of behind, but I also feel like it doesn't really matter (Amy).

For others, maintaining caring responsibilities also made educational achievement a struggle.

Sometimes it was a real struggle like I didn't have time to do my homework because I'd have to help my sister with her homework or help my mum with something or sort out appointments or sort out the bills. But other times it was okay (Brian).

Not only did the caring responsibilities have an impact, but the emotional load that came with seeing a person they loved suffering affected their studies.

[What about your school work? Did that suffer?] Yeah it did suffer quite a lot because I were really distracted and preoccupied and weren't focusing much either. [Did it show in grades? Were you getting behind?] It did show in my grades in exams because we had mocks and the grades weren't very good at all, which impacted me quite badly because I was quite disappointed in them (Lucy).

Understanding and flexibility from teachers was important.

I was getting very behind with a lot of stuff. Very, very behind. The teachers and lecturers, coz I'm at college now they've been very good with it and really lovely about it and they've let me have extra time, which is very helpful, but it's ...there's just so much to do in a day it's just very stressful (Molly).

Impact on social life

Difficulties at home and a lack of support could make it hard to maintain a social life for a variety of reasons. Friendships could be hard, as explained above, and time for socialising limited.

It felt normal. Looking back on it now, it still feels normal because that's all I've known. But it wasn't really normal because all of my mates would be going out on a weekend and I couldn't because I had to help my sister with her homework or I had to do the washing or had to do the gardening or.. (Brian).

My friends knew everything that was going on with my mum and me being a young carer, but I didn't really have time to speak to them a lot or go out with them and things because I was too busy doing my chores and looking after my family (Lucy).

With a close family member in hospital, visiting routines meant that time outside school and hospital was very short.

And we'd go up and visit [hospital] every day so I wouldn't get much time at home or stuff. So it was straight from school all the way up to Gloucester and stuff, and then come home and then go to bed pretty much (Molly).

Feelings of stress and hopelessness

Young people described their feelings of hopelessness at the time, the feeling that no-one understood their situation or the stress that was part of living with a family health crisis.

I had I don't know how many years of feeling no-one cares. Not caring, pushing you to the side, labelling you as something you're really not, that kind of thing (Amy).

I know going through school when I was feeling things, they had no understanding at all on how to deal with me or how to deal with the situation or how I was feeling. (Emma)

There was a sense of a being alone in trying to deal with the years of illness following diagnosis.

And the help I received when I went through it was only after the worse had happened. There was nothing leading up to that point (Emma).

Family relationships could become strained as all family members tried to deal with the problems they faced, leading to further feelings of isolation.

Before at school, me and mum used to fall out a lot, that was why... It used to cause me stress so we used to argue, then me and my dad used to argue. I felt kind of isolated in the family as well. (Amy)

At the time, children and young people can feel very lost and alone in trying to deal with their family situation if they do not have the support and mediation of a service tailored to their needs and circumstances.

It's like when I was at school people would say the wrong thing and they wouldn't know to deal with that situation (Emma)

I just wish that I'd known that what I was doing wasn't normal, that not every child had to go through feeding their parents or putting their parents in the shower. That I'd have known that there was something different out there that - that I didn't have to be doing it (Brian).

Such support could ease family relationships.

I know mum tries her best no matter what. When you're young, you don't really think that. You think your mum's your mum and she should do everything for you kind of thing, but when you're coming home at [age] 11 and you're having to make tea for your family and make your dad's lunch box for work because he's doing nights and stuff, you don't really understand. You feel like mum's just asking you to do that because she doesn't want to (Amy)

Even with support, the depth of feeling engendered by the circumstances was difficult to cope with.

And it's also really upsetting seeing someone so down in the dumps as well all the time. It's just so...it's just heart-breaking really seeing her so ill. She just sleeps all day, when she gets back from dialysis, all she does is sleep. She has dialysis four times a week for four hours. But it just absolutely knackers her (Molly).

Based on their experiences, the young people identified that a gap existed in much-needed service provision prior to their involvement with Hope. Given Hope's limited geographic reach for face to face services and their limited budget, much of that need remains unmet.

I could finally help other people in a way that I hadn't been offered any help when I was going through it. [R: So there was little support for you?] No. Never... It was only bereavement charities. There was nothing to help. Not like the kind of things that we do with Hope with young people when you are going through a crisis (Emma).

But in all the blogging that I have done and I have done a lot. Well there is nothing else out there. I have had people contact me from all over the world. But I haven't found a single other organisation who work with young people who have a terminally ill family member. So if I was ill there would be stuff for me. Or if my Dad was ill there would be help for him. But Macmillan and Marie Curie were the only two. Marie Curie have an online chat room. But everybody on there is older. Sue Ryder they also have a chat room but then are all older as well. But both of those two do pick up and share my blog. And some of the support that was there - have all been cut. We did have a counselling service for young people but it doesn't exist anymore. (Lisa)

A clear need for training and information to assist friends, professionals, schools and other organisations that work with young people were identified by the young people.

There needs to be something that cos there are so many young people going through things like this that teachers need some form of training on how to deal with young people who are going through it. I thinking maybe prepping the class better would have helped. I got asked loads of questions. Some people would avoid me. Some people didn't know what to say. Exposure I think is good. ... There should be ... I don't know like some sort of session where you sit people down and talk about it. I know it's hard they have so many things to do in school but having something is so important (Emma).

Having needs met by Hope

Several of the young people articulated the difference having contact with Hope support had made to their feelings.

Hope made a big difference because once a fortnight I'd have a couple of hours out and just go and be a normal child and I could go out and relax and not worry about going home to do anything and you get once a month out, which is another relief because you don't have to worry that I've got to be back, or I need to be doing this at this time (Brian).

They listen and they have an idea of how things work at our age (Lisa)

In the following sections, we examine the characteristics of the support from Hope and the nature of services that young people want and need.

3.3.3 Characteristics of Hope

I know I can go along to the sessions or I can go along to a day out or I can just pick up the phone and talk to someone (Brian).

Living with a family health crisis can be a very lonely, isolating and exceptionally stressful experience for young people. Our research reveals that despite a variety of targeted support services tailored to meet the needs of young people facing distinct life challenges such as caring responsibilities, mental health issues and bereavementⁱ there is limited support available for young people experiencing a family health crisis from diagnosis, as Amy describes;

There isn't anything from diagnosis. Obviously there is for bereavement, but not from diagnosis. That's all I'm aware of... Hope is the only one that's from diagnosis right through and if there's a bereavement, afterwards as long as you need it (Amy).

Hope is currently the only registered UK charity that provides a variety of support programmes directly targeted to supporting children and young people experiencing a family health crisis from the ages of 11 - 25 years from diagnosis. In the interviews, young

people explained the range of services that Hope offers and the characteristics of each. The characteristics were described in different ways by the young people and yet consistent sub themes emerged to illustrate the distinct features of Hope, including; relationship building; and differentiated support to meet individual needs.

Relationship building

When young people are referred to Hope they have the opportunity to meet with a youth development leader in an informal context who then sets out the support that Hope can provide as well as allowing time for young people to ask questions or just to chat. This is an important first step in ensuring support for young people by establishing an open context for relationship building, as Amy describes;

If people are referred to Hope, Ness (one of the Youth Development workers) will meet with them beforehand either at their house or go to Tesco and buy a meal deal and go and sit at the Harbour (Amy).

The importance of establishing open and trusting relationships throughout their time at Hope is referred to consistently by the young people when describing the characteristics of Hope. This includes relationships with the youth development workers, the Hope online team and other staff at Hope as well as the other young people accessing these services, as Emma and Bill describe respectively;

The friendships I've made. The people I have met. Ness (the youth development worker) in particular is such an inspiration. It (working with Hope) has completely transformed what I want to do with my life (Emma).

Ness is available pretty much any time of the day. She's on Facebook Messenger and she's always typing away and is easy to access and it's people like that that does help 'cos kids these days are so into smartphones and having support just a message away is very valuable and can make a big difference, just knowing that there are people there to help you and they see the problem you're facing and they're happy to help in any way (Bill).

Differentiated support to meet individual needs

Hope recognises that there are many ways to provide the support that young people need which is reflected in the differentiated approaches they deliver to engage, work with and support young people, as described by Bill;

Some people prefer to just message people and not have all the bother of meeting. You know, just talking to that person on the other side of messenger. But I really like the idea of the combination, loads of different things that you can throw yourself into and use. .. you know when a really hard time hits, you might want to talk to someone because your emotions have got too much, or at other times, you might be fine, there might be an alright phase, so you don't need as close a support (Bill).

Providing a package of different types of support is a theme consistently used by the young people to describe the essence of Hope as a 'service' that 'works around you' as Bill further describes;

It's not...there is that if you want to set up a time and date to do something, it's there, for you – like this regular session that's there, but you don't have to do that. You can just do what you want and they're sort of around you to support you. So I wouldn't say it's like a set appointment where you come in and do something. It can be, in terms of coming to the session or on a day out, but the service itself is about when you want it, you reach out to them. Its self-referral or you can be referred by someone else, but it works around you. It's not a strict sort of counselling or sessions (Bill).

Hope deliver a variety of different approaches to support young people including a youth advocacy and management scheme, online support, face-to-face youth sessions, along with days out and residential events.

Youth advocacy

It's very different to other charities because it has this youth arm to it, so it's managed by youth for youth. But that's not very common... (Bill)

A core feature of Hope is the recognition of young people as advocates. Hope have established a Youth Management Team (Y Team) who play a central role in fund raising, consultation and making decisions about the structure, management and delivery of Hope services. The Y Team have all experienced or are experiencing a family health crisis and so they have insight and understanding into what this means for other young people. All the young people that we interviewed stressed the value of the youth management team in recognising how young people who have experienced a family health crisis are best placed to make decisions and inform many of the services designed to support other young people in a similar situation, as the following interview extracts exemplify;

It's getting across that even though it is a support service, a lot of it is run by young people themselves. That's very important.... we know what's needed. Everyone in the y team has gone through a family health crisis themselves, so we know what the young people might need. I know that they might need support during school because there isn't always support available in school. We can understand what people are going through. We decide where we spend the money (Amy).

The decisions that are made have a lot of backing behind them because I can put myself in their shoes because I know what it's like, so I think it's very effective in the way that decisions are made because you've got that understanding. So it's that. It's by the youth for the youth, in a way (Bill).

The stuff we do is more based around our age group. We did have an idea given to us a couple of months ago about doing an assault course for team building, but we thought that's not what any of us are into or what we'd do on a day out, so we ended up going for a walk up Robin Wood Hill and having a picnic which is what we wanted

to do, or we'll go on water activities day or go to the beach or something more for our age group, instead of having planned out for us by adults based on what they think we want to do (Brian).

In addition to youth advocacy, Hope have established an online support system which means that young people throughout the UK can talk privately to a member of the Hope online team or with other young people who are similarly living with a family health crisis.

Online support

All the young people stress how important it is to know that support is available and that they can talk to a professional or just chat with other young people, as Bill and Lisa suggest;

I think what Hope do well is the online service, the fact that there is always someone there on the end of Facebook messenger. A lot of young people now are all on their phones, so having like a digital service with plenty of people there on the other end is really important. You know, just being able to message them and what's on your mind, I think that's really helpful. Then if you want to talk to someone face to face, the people in Hereford and Gloucester are lucky that they can do that. They can meet Ness or one of the youth workers and meet for a hot chocolate or whatnot, go on a little walk, you know just sit anywhere and chat (Bill).

We'd arrange a time and meet for an hour and have a chat and there is now a Facebook group which people post in if they've got an issue like – I don't know what to do about – and people will post back. And then every other Monday night from 8 or half 8 we have a group Facebook chat for an hour. I think that they might do two. Ours is for university upwards. Most of us are at uni. I'm working. I am probably one of the older ones I think. I think it's really important even from my perspective that if there is someone who is younger who is going through what I was going through. I know what it's like. (Lisa)

Further to the support delivered by the online team, Hope also facilitate a number of online forums designed to address particular issues that young people are experiencing, including exam stress and transition to university. Again, the different layers of support are noted in distinct ways by the young people. For example, Amy talked about the online support that she accessed on Hope's Facebook page during GCSE exam time.

It was quite useful. People just talked about their ways of coping with stress and anxiety and that. Which is quite good because it's kind of like talking to strangers but although its people you've never met before you trust them even though you've never met them before because they're part of Hope, so you know, that was a quite interesting thing to be part of (Amy).

In addition to the online support, Hope staff, along with the Y Team organise, and deliver a range of days out and residential events in conjunction with the Hope youth sessions.

Youth sessions, days out and residential events

Youth sessions are organised and led by the Hope team of youth development workers. These sessions are delivered locally within Herefordshire and Gloucestershire and are designed to provide a safe space for young people experiencing a health crisis to come together. It's an opportunity to meet with other young people who are facing similar challenges and as Amy and Bill describe respectively, a chance 'to just forget about it for a while' and to 'take your mind off things ... and have some fun', for example;

So when you're out with lots of fun people, it makes it go away for a while (Amy).

All the young people talked about the value of the youth sessions, days out and events in enabling them to make friends, have some fun and take some time out from many of the challenges at home, which can allow the young people to step away from their home situation for a while.

The days out, they are essentially that, there are not really points at which we sit down and talk. It's just very much enjoying the activities. So for instance we went to Cotswold Wildlife Park and we just get there and everyone just enjoys the day. And you know if you are feeling down, there's 3 or 4 workers around, and they'll talk to you anyway and check on you and you might want to tell them something or you might not, but they can just monitor you. In terms of like counselling and so on, the days out are essentially a day out that anyone would have, which is exactly what it's meant to be, it's not fabricated at all, but there are people looking out for you and if you want to talk, yeah. And there's also the option that if you're not feeling up to it, you don't need to come. The days out are just essentially trying to recreate a day out like you'd go on with your family. The youth sessions again it's just sort of can be just time to chat or talk to people or do fun things like we're doing today. We do one residential a year, where it's like the same as the days out essentially (Bill).

3.3.4 Nature of services required by young people: What young people value about Hope

It means that if you don't want to be doing anything when you get to Hope, you can just sit down and chill out and do nothing. I've gone to a Hope session before and just slept (Brian).

In talking at length about the different ways in which they valued the services provided by Hope and the particular gains pertinent to their individual needs, young people outlined the nature of services that they considered to be required for *all* young people living through a family health crisis. The broader theme of value was further differentiated to reflect categories raised by the young people including: flexibility; acceptance and understanding.

Flexibility

All the young people stress that Hope is much more than just about coming together with other young people and with practitioners but talk about the ethos of Hope which provides flexible layers of support which young people can choose to engage with in very different ways to suit their own needs, for example;

It's just so individual, isn't it, Hope, and there's not really many charities like it out there. Just that it is totally unique in how it supports young people. I know with other charities it is quite formal. So you go there and you have to sit and talk. Whereas at Hope they can talk about as much or as little as they want. So they can find their feet before they talk about things that are going on. Making friends before you have to talk about anything, like finding trust before you have to talk about anything. In other places you have to talk about it before you've built the trust, if you know what I mean? I think that's quite important (Amy).

Several of the young people talked about how they can 'dip in and out' of the different youth sessions and events to suit their needs at particular stages in their lives. This theme is exemplified by Bill;

For the young person it's such stressful time at home that a flexible service that you can dip in and out of and you want to have full commitment or you don't is really important because everyone is different and they handle it differently. Some people will want to spend their whole time with Hope and that's what they'll do. Others might want to be a little bit disconnected (Bill).

The extent to which Hope facilitates flexible support to meet individual needs is further emphasised by many of the young people and reflects their focus on the importance of establishing an environment where young people are accepted without judgement and that they are understood.

Yet many of the young people recognise that although Hope online services are available throughout the UK the youth sessions, days out and residential events are currently only available locally to the charity in Gloucestershire and Herefordshire.

Acceptance and understanding

I've made really great friends and, you know, not only do I work with them but I also know everyone really well and it's kind of like a family, sort of thing, so it's a big part of my life and I'll keep on doing it until I'm not a young person anymore. Yeah, it's amazing (Bill).

The manner in which the young people describe Hope as a service which works 'around the young person' was evident in the way in which the services are managed and delivered in consultation with the Y Team, as Amy and Bill suggested;

I think that's important because if it were run by adults who haven't been through it and they're just going on what they learnt in uni, it might be completely different. It might not be what the young kids need as such (Amy).

It might encourage more people to come to it if it's designed by young people. Also you don't really want a group of older making all the decisions with all the money. You know what's effective, what to spend the money on. The fact that there is a group of young people who sit round a table and share the money out and organise events I think makes it more attractive for a young person to go to (Bill).

The real responsibility gave a sense of belonging and purposefulness.

And I think that for us it's great to contribute to something that's real, like it's an actual charity and we're playing quite a vital role in it. It's quite hard to describe. It's very special and unique in the way that we sort of make the decisions and a lot of the management is by the youth (Bill).

The young people talk about the uniqueness of Hope and the type of support they receive, which is quite unlike anything else available for young people facing similar challenges. As Emma and Brian described;

Everyone knows that everyone there has got something going on but you don't need to talk about it. And that's fine. It's almost like... I don't know it's unspoken but you don't need to talk about it and everyone kind of.... It's really hard to describe (Emma).

They're all going through the same sort of thing as you and you don't really have to explain anything (Brian).

This level of understanding was described at length by Amy who talks about the importance and value of Hope having a clear level of understanding compared to other professionals in other contexts such as school where this might not always be the case;

You see, this is where Hope is different, because I just wanted them [school] to understand that there is something going on that maybe I didn't want to talk about, but they should just accept the fact that there is something going on. They should understand why I was acting the way I was sometimes or why I was quiet sometimes. They should have looked past the fact that I was acting out or looked past the fact that I was quiet and realised that there was something further and realised that maybe if I didn't want to talk about it, they should still be there. In a way that maybe they didn't understand, but at least they could try to understand, if you know what I mean. The schools just don't have the time of day for it because it's not what they're there to do (Amy).

Yeah and maybe just say yes well it's really just crap. Cos the number of people say things like well things happen for a reason and blah, blah, blah. And sometimes you just want somebody to say actually I get it and its rubbish. And that makes me feel a lot better rather than oh well it will all be alright in the end. Because like, well it won't really cos my Mum is terminally ill. Actually having people who get it is really helpful. You don't have to explain. (Lisa)

For a number of the young people Hope feels 'more like a family' in the type of support it provides and all the young people emphasise the value of feeling accepted without the pressure of having to explain why they are there and what challenges they are facing. As illustrated by Amy here;

And I like that about Hope because like you accept everyone for who they are. You don't judge them on what they've been through or what they're going through at the time and I think that's good (Amy).

Furthermore, for many of the young people, such as Brian accessing the service at Hope meant they could go to a session or attend an event with the confidence that they would not be judged and could use the service in ways that suit their own individual needs.

It means that if you don't want to be doing anything when you get to Hope, you can just sit down and chill out and do nothing. I've gone to a Hope session before and just slept. So you've literally got a couple of hours where you can do what you want without a care in the world and without worrying about what you're doing...Yeah, it is really important but some people won't see how good it is or the benefits of it. It's hard to explain at the same time (Brian).

4. Conclusion and recommendations

The MCS analysis indicates that a significant number of children and young people throughout the UK are living with a family health crisis that can impact negatively upon their everyday life experiences. This study reveals that young people living with a family health crisis experience high levels of distress, anxiety, low mood and depressive symptoms and are at risk of becoming labelled 'difficult' and so disengaged with education, socially isolated and at risk of experiencing a variety of mental health issues which can have far reaching consequences.

Our research indicates that the type and quality of support that young people can access from Hope can make a significant difference to their lives. Unfortunately current provision for targeted support for children and young people experiencing a family health crisis is both inadequate and under-funded. This report details that not all children and young people throughout the UK have access to services and support systems required to meet their complex needs and, furthermore, there is a lack of awareness as to what these needs are and how best they can be supported. For example, the vast majority of C&YP who access Hope support identify as White British, which may be indicative of the demographic profiles of the geographic areas covered by Hope, but may also indicate unmet need amongst C&YP from minority ethnic groups. More in-depth research is required to examine the issues raised in this small-scale initial study.

What needs to be done

We propose that the following steps be taken in the **short term** to help set in place a strategic plan to address the issues raised:

1. Raise public, stakeholder and government awareness as to the extent and scale of need across the UK which recognises how many children, young people and families are experiencing a family health crisis and the significant long term impact that this can have.

2. Seek funding for much needed large-scale in-depth research in this area, incorporating: C&YP's experiences across a range of circumstances and from a range of backgrounds; evaluating the cost of funding much needed support for C&YP experiencing a family health crisis against the costs to young people's health, wellbeing and educational outcomes if needs continue to remain unmet.
3. Reflect on the type and quality of targeted support that Hope services provide in meeting the needs of C&YP experiencing a family health crisis and explore avenues through which these services can be expanded to meet national need.

We make the following recommendations for **stakeholders and national and local policy-makers** for mid-term action in light of the findings of this initial research:

4. Ensure that national data are collected on a regular basis on the number of children and young people who are living with a family health crisis, including
 - a. Time from diagnosis
 - b. Access to support services for the C&YP
 - c. Impact on the activities, progress and achievements of C&YP
 - d. Level of service provision compared to level of need.
5. Comprehensively review and revise national and local policies, including education, health and social care, for service provision for C&YP facing a family health crisis from the point of diagnosis and continuing throughout the period of illness. Implement associated policy, provision and practice changes including recognising:
 - a. The need for additional educational support with flexibility in timing and close-to-home study.
 - b. The need for training of education, health and social care professionals with regard to understanding the needs and experiences of C&YP living through a family health crisis.
 - c. That support services nationally need to combine flexible, face-to-face support as well as access through different media such as online or mobile access.
 - d. That building relationships with a small network of trusted youth workers and companionship from C&YP experiencing similar situations are vital aspects of support which should precede and enfold counselling support. Companionship and being 'held' emotionally in a safe place amongst professional adults and peers with whom relationships are formed can be more effective initially than counselling sessions with a stranger with a set start and end time over a set number of appointments.
6. Review accessibility of services available to C&YP from minority ethnic and minority language backgrounds, given that current services appear to be accessed primarily by White British C&YP
7. Consult and involve children and young people in the design and delivery of support services and policy provision. Recognise, too, that C&YP in the midst of a family health crisis may not feel able to fully recognise and articulate their own needs. They need support to enable them to do so.

We end the report the report with a final quotation from Molly, describing what it is like living with her very ill mother.

It's just so...it's just heart-breaking really seeing her so ill. She just sleeps all day, when she gets back from dialysis, all she does is sleep. She has dialysis four times a week for four hours. But it just absolutely knackers her.

[Researcher: And it's so hard for you to see that]

Yes. I see the deterioration of it as well. Just everything (Molly).

To receive more information and details about the evidence base underpinning this report please visit <https://discover.ukdataservice.ac.uk/doi?sn=7464#4> and <https://discover.ukdataservice.ac.uk/doi?sn=8156#2>. You can also contact our research team at the Children's Research Centre at the Open University at <http://www.open.ac.uk/researchprojects/childrens-research-centre/about-us>.

To find out more about the services that Hope provide please visit their website where contact details can be found at <http://www.hopesupport.org.uk/>.

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Appendices

Appendix A. Where support has been provided to date.

| Total | Number | % |
|--------------------|---------------|----------|
| Hereford | 73 | 25.6% |
| Ross | 42 | 14.7% |
| Gloucester | 36 | 12.6% |
| Forest | 26 | 9.1% |
| Kington | 14 | 4.9% |
| Cheltenham | 14 | 4.9% |
| Leominster | 8 | 2.8% |
| Bromyard | 5 | 1.8% |
| Monmouthshire | 5 | 1.8% |
| Worcestershire | 5 | 1.8% |
| Dursley | 4 | 1.4% |
| Tewkesbury | 4 | 1.4% |
| Yorkshire | 4 | 1.4% |
| Ledbury | 3 | 1.1% |
| Stroud | 3 | 1.1% |
| Cirencester | 2 | 0.7% |
| Bedfordshire | 2 | 0.7% |
| Birmingham | 2 | 0.7% |
| Buckinghamshire | 2 | 0.7% |
| Essex | 2 | 0.7% |
| Glasgow | 2 | 0.7% |
| Greater Manchester | 2 | 0.7% |
| Berkshire | 1 | 0.4% |
| Bristol | 1 | 0.4% |
| Cheshire | 1 | 0.4% |
| Hampshire | 1 | 0.4% |
| Lancashire | 1 | 0.4% |
| Norfolk | 1 | 0.4% |
| Overseas | 1 | 0.4% |
| Powys | 1 | 0.4% |
| Scotland | 1 | 0.4% |
| Shropshire | 1 | 0.4% |
| Somerset | 1 | 0.4% |
| Suffolk | 1 | 0.4% |
| West Sussex | 1 | 0.4% |

ⁱ A variety of targeted support services are available for different sectors within youth work, including support for young carers such as The Indigo Project; support for bereaved children and young people such as Winston's wish (www.winstonswish.co.uk) and CRUSE (<https://www.cruse.org.uk/>); support for young people experiencing mental health issues, including young minds (www.youngminds.org) and Heads2gether (www.heads2gether.co.uk).

Notes
