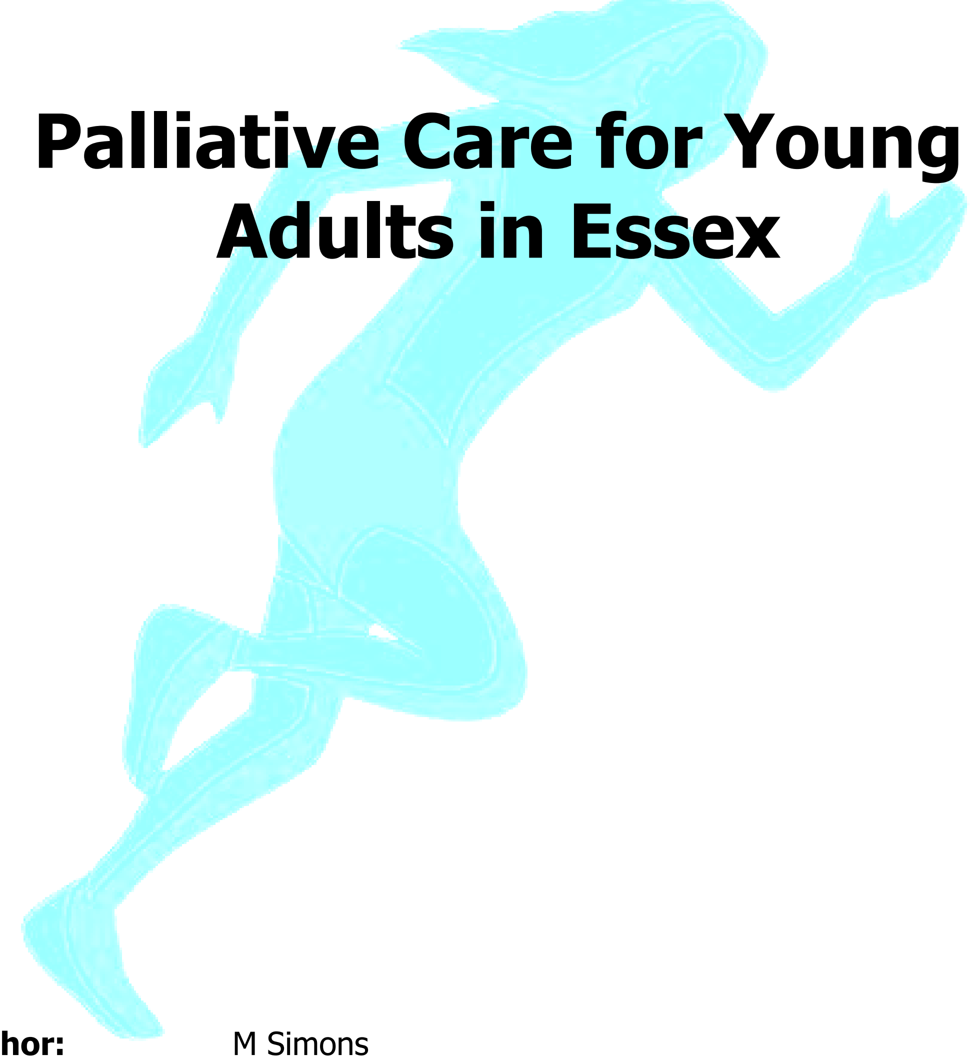
Public Health Action Support Team

Community Interest Company: A Social Enterprise Organisation

Project Report

Palliative Care for Young Adults in Essex



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Public Health Action Support Team (PHAST)

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A report like this is dependent on other people to produce information and a great number of people have done this. Some are mentioned in Section 13, "Main Contributors".

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[1] Whereas conventional businesses distribute their profit among shareholders, in social enterprises the surplus goes towards one or more social aims which the business has. PHAST will invest any surplus into development of new products and working with charities. In line with this PHAST directors and shareholders receive no dividends for their work in managing PHAST CIC. PHAST CIC is also regulated by the CIC Regulator, based at Companies House, to ensure it fulfils its Social Enterprise objectives with a mandatory requirement for annual audit.

Executive Summary

The J's Hospice is seeking to provide services for young adults (aged between 18 and 40) with life limiting or life threatening illness. For children and young people the focus of palliative care is maximising life. The questions this report tries to answer for palliative care are:

- How much?
- Where?
- In what format?
- For whom?

A) Recommendations

1. Given the "black hole" in provision for the 16 – 18 year age group, and the need for variable age transition owing to different mental development and physical need, The J's should consider an eligible age group of 16 – 40.
2. Most sections of this report discuss the type of the care needed by young adults in Essex who have palliative care needs. This should inform decision making on the service model developed.
3. The demography of Essex suggests a model of care that incorporates both a central resource for respite care, intensive symptom control and end of life care where home care is not possible, and also distributed home care or satellite centres in larger urban areas.
4. Having reviewed distance travelled and differential take up of services locally, the hospice should consider how to make their service more accessible to those at a distance.
5. A period of slowing in the number of deaths in older age groups is expected to be reversed from about 2012. A period of population growth in the 20 – 39 year age group is expected to increase from about 2025. It is recommended that service planning takes these demographic changes into account.
6. The higher prevalences of severe disability expected in some black and minority ethnic groups should be factored in when improved data is available following publication of the results of the 2011 census.
7. The J's should work with commissioners in the NHS, PCTs and GP consortia, and Adult Social Care and those constructing end of life registers (Southend and NHS Mid Essex), and the numerous projects underway defining processes for transition in statutory and voluntary children's services as well as acute units to advertise and promote care for young adults.

8. Service planning should consider the 100 deaths per annum that might have required palliative care in young adults in Essex, as a maximum number, and the amount of service that will be required prior to death.
9. Place of deaths data should be further investigated to review the higher proportion of people in Essex who died in a place categorised as "other".
10. Most people say they wish to die at home. Trend data for changes over time in home deaths in Essex should be reviewed and produced, and this information should be further investigated.
11. The J's are recommended to consider accommodation for short term independent living experience following comments in Section 8, views of young people, and plans for two self-contained mini flats at Rainbows in Loughborough.

B) Needs Assessment

The literature review indicated that annual numbers of adult deaths in England fell by 8% from 1974 to 2003, but are expected to rise by 17% from 2012 to 2030. Numbers of home deaths could reduce by 42% and if current trends continue, fewer than 1 in 10 will die at home in 2030.

In the younger adult population there is increased survival owing to the changing nature of disease management. "Least rare" diagnoses found in the literature were cerebral palsy for which conditional on surviving to age 20 years, almost 85% of the cohort survived to age 50 years when a comparable estimate for the general population was 96% (Hemming, Hutton, and Pharoah 2006); cystic fibrosis (CF) for which life expectancy for a child born in 1990 is 40 years which represents a doubling in the last 20 years, and nearly half of all patients are now adults" (Jaffe and Bush 2001) and Duchenne Muscular Dystrophy for which the estimated probability of survival to age 30 years was 85% and median survival was 35 years (Kohler et al 2009). Amongst the great number of more rare diseases was Juvenile Battens disease for which onset was between 5 and 9 years. Death can occur from the late teens to the mid 30's (Claussen et al 1992).

The literature also indicated raised prevalences of severe disability in black and minority ethnic groups (ONS 2004), (Taylor et al 2010). The demographic review noted that Essex has 116,700 residents from ethnic groups other than white and all black and minority ethnic groups make up more than 10% of the Essex population. However the data are not yet adequate to be able to make sound judgements on the effect this has on prevalence of severe disability.

The literature review also highlighted the importance of services being offered at appropriate periods when "palliative care" is a notion acceptable to parents (Erby, Rushton Geller 2006). A young adult hospice provided the estimate that "one third of families are aware of us and use us, one third are aware and don't wish to use us, one third have a child with a life threatening condition and are not aware of us or possibly not admitting to the fact of a life limiting condition".

The distribution of the population is mapped to provide some intelligence on the most appropriate distribution of service

For the proposed age range for The J's the population projections show a flattening of population rise from 2011 to 2020 except in the 25 – 29 age group which shows an earlier rise.

Deaths have been investigated using the DH document "Palliative Care Statistics for Children and Young Adults" (DH2007). The paper identified approximately 370 causes of death which might have required palliative care and applied codes from the International Classification of Disease now in its tenth revision (ICD10) to these. The document was then able to give data on

- deaths from all causes
- deaths which were likely to have required palliative care
- and place of death

Information relevant to the age group under review (15 – 39 years in five or 10 year age bands) has been reproduced here.

Datasets drawn from Essex PCT's Public Health Mortality Files by each organisation's senior public health intelligence manager gave 8 years of data for similar analysis for the Essex population to be carried out. Results are proportionately similar to the results seen for England.

A rough rule of thumb suggests about one third of all deaths in the age group would have required palliative care, approximately 100 deaths per annum between the ages of 15 and 39.

The discussion drew further on DH(2007) which used the proportion of 10 children in need of palliative care for every such death counted. This cannot be applied with great assurance to all palliative care deaths over the age of 15 owing to the heavier burden of cancer in adulthood which has a different trajectory of palliative care need from children's life limiting or life threatening illness.

However as increasing numbers of children and young people will survive childhood with those conditions, a factor will need to be applied, but this ratio is not yet available. Suffice to say that mortality is a very safe statistic which will need multiplication by a factor of up to 10 to estimate palliative care need.

Place of death data are compared for Essex with England. Most people wish to die at home and there is now an imperative to increase the number of deaths which occur at home rather than in an institution. In Essex currently about a quarter of deaths in the age group 30 – 39 take place at home, and about 23% in the age group 20 – 29.

Place of death data are presented by category, Home, Hospice, Hospital and "Other", which includes for example: psychiatric hospital, nursing home, residential home, or private home that is not the usual residence of the deceased. When Essex is compared with England, the "Other" category shows Essex having significantly higher proportions of people in the 20 – 29 and 30 – 29 age groups and it is suggested that place of death might be further investigated to explain this and also to undertake trend analysis to track change.

Local services were investigated to try to show current levels of service supplied and to note "observed" numbers to compare with the "expected" which might be extrapolated from national deaths data. However, recording was usually manual making extraction difficult, and results were uncertain. Children's Community Nurse Teams provided most complete numbers showing 54 children and young people aged 15 - 19 with palliative care needs. Twelve more aged 15 – 19 were identified at Little Haven's Children's Hospice.

At Little Havens although it is sole provider for Essex, most of the children and young people were resident in south Essex. Also, of 103 children and young people (aged 0 – 19) only two were identified as black and ethnic minority. This is an under-representation and needs investigation especially as some evidence was provided for greater prevalence of some conditions requiring palliative care amongst those communities.

In an attempt to discover more young people with palliative care needs, the county's schools for children with special needs where they provided for the most severely disabled children were reviewed. Again a few schools worked to provide data and engaged positively with the exercise, others were less able to do so and some were not contacted in the time available. One school was able to identify 7 pupils with palliative care needs of whom only two were known to Little Havens. This Head also stated that one family was very much in need of respite but felt Little Havens was too far away. The Head had recommended The J's.

Information from children's services was intended to support transition planning into young adult services. Within the age group again a number of approaches was taken. Adult palliative care services provide from age 18 but service use by those under age 20 is rare. Numbers are given for all hospices except St Clare Hospice which was unable to fulfil the information request. A few diagnoses other than cancer were recorded, but very few. These are noted. Douglas House in Oxford has 8 people in the age group but were unable to give further details.

Essex County Council's Adult Social Care Department initially seemed to be a good source for information with comments such as managers knowing that there were clients with palliative care needs. However information was not forthcoming and ultimately only one case in Essex was cited. The Essex-wide Transition Data Co-ordinator was not aware of any records being kept of young people with palliative care needs.

A CCNT nurse had commented: The 16 – 18 age period is a "black hole" when young people neither "fit" children's nor adult services. Generally this age group is nursed at home with help from either the CCNT or the District Nurses but "there can be a gap where parents are left looking for a service for a dying child".

A number of the services which submitted information added comments such as indicating that they knew there were more young people with palliative care needs than were being returned, or that they knew the numbers given were small but did not know why, and that the 16- 18 age group is a "black hole" where neither children's nor adult services would accept responsibility.

A previous collection of views of young people in transition is given. Owing to resource limitations on the needs assessment, it was decided not to repeat this qualitative survey. It was conducted amongst young people in or post transition with palliative care needs in NE London in 2010. The results showed good concordance with other similar studies undertaken by at least two young adult hospices in the UK so repeating the review with Essex young people would probably not have added much further understanding.

As the young people had looked on the children's hospice as a centre for socialising, fun and time away from the family, their identification of requirements in young adult palliative care reflected a similar approach. This illustrates one of the differences from adult hospices. Young people were looking for provision in a clear priority order: once the medical requirements and care were in place, education and employment were next main concerns then socialising and finally independence.

In common with studies in other towns they wanted to have all life's experiences whilst they were able: boyfriends and girlfriends, to be able to go on outings and eat fast food. They wanted to stay up late and get up late in the morning as their able bodied peers (not dependent on the time the carer arrives) were able to do. Recurring themes were information sharing, level of support, managing carers, education and social life, respite care, medical and therapy services changes, knowledge of rights and hopes for the future.

Information was a major topic, how to know one�behaves's rights, how to ask if it was not clear what should be available. Advocacy was recommended. Parents regretted not understanding more about transition, the loss of day centre attendance, moving from the care of the children�behaves's nurse team, the loss of regular therapy sessions at school, holidays for children organised by a charitable organisation, and greater difficulty obtaining equipment.

Finally the report gives a comparative review of other services already in place for young adults with palliative care needs. Almost every other service studied was unique; there is no "preferred model" although some were similar. All services reviewed had an allocation of beds; none was a purely home based service. Many had a catchment defined by a radius of 1½ hours car journey. Each service had some unique particular quality and these were identified as principles of good practice which might be considered for young adult services. They included working in partnership with statutory services close to the client's home, having access to advocacy to enable independent management of their own affairs, the principle of normalisation: doing what their able-bodied peers do, and allowing need rather than age to direct the suitable type of care. These principles were developed by other services seeking to provide what young people wanted so contribute to the "Views of Young People" section as well.

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1. Purpose of the Document

This report provides a public health assessment of the palliative care needs of young adults aged 18 – 40 years in Essex. Over time palliative care provision for children has developed but only to the age of 19 years or younger. Palliative care for adults has traditionally targeted much older age groups, and generally where there is a diagnosis of cancer. A new group has emerged of children surviving into adulthood and young newly diagnosed adults for whom neither model of care is appropriate. This document assesses the needs of this group.

2. Aims and Objectives

2.1 Aim:

To provide baseline data on the current and projected levels of young adults requiring palliative and end of life care in Essex and identify gaps in service provision. These data will include the numbers (quantitative) of actual and potential users and identify the needs and preferences (qualitative) of users.

2.2 Objectives:

- To measure the level of need for palliative care services for young adults aged 18 – 40 years resident in Essex, with additional details where available on geographic distribution and demography.
- To review expected and projected incidence and prevalence.
- To collate information previously presented in grey and published literature on young adults and their needs and preferences related to palliative care services.
- To map current service provision including quality and determine the role played by PCTs (and where information is available the new GP commissioning consortia), acute services, NHS community services, local authorities, and voluntary/independent sector organisations, and the interface and working relationships between them all.
- Compare need to current provision drawing upon the work of academic departments and national research projects.
- Identify areas requiring service development and improvement.
- Recommend how to respond effectively in tackling gaps and identified improvements.

3. Introduction

In March 2009 PHAST produced *Paediatric Palliative Care Needs Assessment – Outer North East London* and followed up in August 2010 with *Transition from children's to adult palliative care,* again in NE London. Needs assessment for children with life limiting or life threatening illness is relatively straightforward, dealing with children who meet one of the Association for Children's Palliative Care (ACT) four categories (ACT/RCPCH 2003) [2], but the brief for *Transition from children's to adult palliative care* begged the question of whether the appropriate area of study was the process of transition or destination – transition to what? The J's Hospice is seeking to provide services for young adults (aged between 18 and 40) with life limiting or life threatening illness who have transitioned from children's services but also for those who receive a life threatening diagnosis in their teens or twenties, but other services do not all provide to the age of 18 years. Children's Community Nurse Teams (CCNT) may not routinely work with young people over the age of 16, or they may provide until the upper age for children's health services of 19 years. Occasionally where length of remaining life is short, a "child" may be provided for beyond the age of 19, whereas a young person newly diagnosed at 17 would be entered immediately into adult services. This review has collected data for each year from age 15, for service planning purposes, and then from 20 – 39 years.

There are decisions to be made about the nature of the care to be provided. A paper published by the Department of Health, Palliative Care Statistics for Children and Young Adults (DH 2007) explains why it includes information on young adults aged 20-39:

'Children's palliative care is different from that of adults and by comparison the number of children dying is small. However, a child's need for palliative care involves much longer term provision and increasing complexity of care needs, beginning immediately after diagnosis of a life threatening or life-

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[2] Defined in 1997 by The Association for Children's Palliative Care (ACT) and The Royal College of Paediatrics and Child Health (RCPCH):

Group 1 – Life-threatening conditions for which curative treatment may be feasible but can fail. Palliative care may be necessary during periods of prognostic uncertainty and when treatment fails. Examples: cancer, irreversible organ failures of heart, liver, kidney.

Group 2 – Conditions where there may be long periods of intensive treatment aimed at prolonging life and allowing participation in normal childhood activities, but premature death is still possible. Examples: cystic fibrosis, muscular dystrophy.

Group 3 – Progressive conditions without curative treatment options, where treatment is exclusively palliative and may commonly extend over many years. Examples: Batten's disease, mucopolysaccharidosis.

Group 4 – Conditions with severe neurological disability which may cause weakness and susceptibility to health complications, and may deteriorate unpredictably, but are not usually considered progressive. Examples: severe multiple disabilities, such as following brain or spinal cord injuries, including some children with severe cerebral palsy.

limiting illness, with the potential for death to occur before adulthood but timing is often uncertain'.

This need for palliative care does not cease because the child reaches the age of 19 years, unlike children's health services. A continuation of care to complement that provided for children but adapted to the young adult would be appropriate.

For children and young people the focus of palliative care is maximising life. For people at the other end of the life spectrum, palliative care was defined in 2002 by the World Health Organisation[3]:

'Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

As will be noted this definition appears in the Cancer section of the WHO website, and the focus, although many people are now discharged from an adult hospice following a period of respite care or symptom control is on managing a good death. For children, cancer is the minority diagnosis among those receiving palliative care and the focus is on managing a good life which may be expected to be short.

The final area of confusion which needs consideration, and the most difficult, is how to count those in need of *palliative* care since a far greater number of children and young people live with complex health needs which may develop

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[3] Source: World Health Organization, http://www.who.int/cancer/palliative/definition/en/.

into a reduced life expectancy but which are not of themselves categorised as life limiting or life threatening illness for example those with severe cerebral palsy. Diseases are categorised and counted using the International Classification of Diseases, now its 10th Revision (ICD10). Normally this would help identify how many hospital admissions there had been for a particular disease, on which could be based an estimate of the number of cases in the population. The same classification identifies cause of death. But palliative care is a treatment approach across a large number of diagnoses and for this there is as yet no classification.

4. Literature Review

4.1 Introduction

Most recent government guidance and academic references to life expectancy for young people with the least rare life limiting or life threatening conditions are included here.

4.2 Methodology

Databases were searched using the keywords: cystic fibrosis, life expect*, survival, Duchenne Muscular Dystrophy, Cerebral Palsy and ethnic minor*. Limits were applied for Publication Year 2000-Current and Abstracts and Humans and English Language. The papers were scanned and information taken as necessary.

Government guidance was drawn from relevant websites (Department of Health, NHS, End of Life, and through Google searches). References from an earlier literature review (Simons et al 2010) on transition where included as they related to the present needs assessment.

4.3 Results

Approximately 120 papers were scanned in addition to the papers from the earlier transition literature review.

Children's palliative care has developed at a great rate in recent years owing to government guidance and initiatives, from the NSF for Children, Young People and Maternity Services (NSF 2004) to Commissioning Children's Palliative Care Services (DH 2004), Palliative care statistics for children and young adults (DH 2007), Aiming High for Disabled Children (DH 2007a) and Better Care, Better Lives (BCBL 2008) and the work of lobby groups such as the Association of Children's Hospices (ACT).

At the same time, increasing pressure is being brought by demographic changes on management of dying in older age. Recent work by Gomes and Higginson analysed past trends in place of death (1974–2003) and projected likely trends to 2030 in England and Wales. They found that annual numbers of deaths fell by 8% from 1974 to 2003, but are expected to rise by 17% from 2012 to 2030. They also found that home death proportions fell from 31% to 18% overall, and at an even higher rate for people aged 65 and over, women and non-cancer deaths. If recent trends continue, numbers of home deaths could reduce by 42% and fewer than 1 in 10 will die at home in 2030. There is government encouragement as well for improved end of life care as in the NHS National End of Life Care Programme, and recent publication of "Supporting People to Live and Die well: a framework for social care at the end of life".

There is also evidence of increasing survival among young people who have what used to be considered terminal childhood disease.

Strauss et al noted in 2007 that improved survival over a 20-year period was found in children with severe disabilities owing to cerebral palsy (CP) and in adults who required gastrostomy feeding. In these groups, mortality rates fell by 3.4% per year, showing an increase of approximately 5 years life expectancy if adjustments to 2002 mortality rates were made. However for other people with CP there was, at most, a small improvement over time. The results suggest there have been improvements in the treatment and care of the most medically fragile children. Hemming et al studied Long-term survival for a cohort of adults with cerebral palsy in 2006 and found that "Conditional on surviving to age 20 years, almost 85% of the cohort survived to age 50 years (a comparable estimate for the general population is 96%). Very few deaths were attributed to CP for those people dying over 20 years of age". This is key to management of patients with CP who may have received palliative care as children but whose condition may be considered stable in early adult life (see notes on Douglas House management policy). In an earlier study (2005) Hemming et al found that the number and the severity of impairments were the best predictors of survival in young people with CP and birth weight and socioeconomic status were not significant.

A number of studies have considered life expectancy of young people with cystic fibrosis (CF). In 2003 Jackson and Pencharz stated that life expectancy was well beyond 30 years and over a third of CF populations were in adult clinics. In 2001 Jaffe and Bush stated that "the median estimated life expectancy of children with cystic fibrosis (CF) born in 1990 is 40 years which represents a doubling in the last 20 years, and nearly half of all patients are now adults". These estimates are underlined in a number of journals

In young men with Duchenne Muscular Dystrophy (DMD) this trend is repeated. Kohler et al (2009) reported results of a longitudinal study they had conducted involving 43 young people with DMD aged 5 – 35 years, assessing a number of indicators of health in them annually. The estimated probability of survival to age 30 years was 85% (median survival was 35 years).

Claussen et al in 1992 produced data on a much more rare set of conditions collectively, Batten disease (Neuronal Ceroid Lipofuscinosis or NCLs) which have different age onsets and life expectancy.

- Infantile – onset between 6 months and 2 years. Death can occur in mid-childhood.
- Late Infantile and variant late infantile – onset between 2 and 4 years. Death can occur between the ages of 5 and 15 years.
- Juvenile – onset between 5 and 9 years. Death can occur from the late teens to the mid 30's.
- Adult – onset normally before the age of 40. Shortened life expectancy.

This is a rare set of conditions with a variable incidence across different countries.

The search included review of different prevalences of disease by ethnicity. However few papers were found. It is known that for example, haemaglobinopathies are more prevalent among people of Black Caribbean and Black African descent, and a paper published by ONS (2004) showed varying prevalence of severe disability in children:

Prevalence Rate/ 10,000 population of severely disabled population aged 0 to 16 years by ethnicity, 1996–2000

Year	White	Black-Caribbean	Black-African	Black other	Indian	Pakistani	Bangladeshi	Irish	Chinese
1996	6	9	16	7	3	13	10	21	2
1997	6	10	18	6	4	13	9	6	3
1998	6	11	28	6	4	15	11	3	3
1999	6	15	25	10	5	17	13	0	4
2000	6	15	18	12	6	19	9	1	6

Source: ONS (2004)

Much has also been written and studies completed on the value and improved outcomes resulting from good transition (for an overall review see Simons et al 2010).

For some diagnoses, service provision will need to continue as is the norm in children who start palliative care at diagnosis. For others (DMD) care needs to start later as the need increases. A paper in 2006 entitled "My Son is Still Walking" by Erby, Rushton and Geller reported interviews with parents of 17 sons with DMD and suggested the opportunity for discussion may exist as sons are approaching significant transitional milestones. At other times parents were not ready to consider advance care planning.

A paper by Taylor et al (2010) aims to provide a new epidemiological base of information on models of hospice care for children and young adults. The paper reviewed retrospectively all children who had been referred for care at Martin House since it opened in August 1987 until May 2008. The study found that of 1,554 children who had been referred to Martin House in that time 89.5% were accepted. The deprivation profile, referral source and distribution of diagnoses had changed over time with recently increasing numbers of non-progressive disorders (ACT category 4). The ethnicity profile had also changed with an increase in the numbers of South Asian children. They found that the length of involvement with a children's hospice was highly variable and could last for 20 years.

4.3.1 Grey Literature

Following publication of the paper by Taylor et al (2010) further discussion was held with staff at Martin House, Wetherby. Dr Mike Miller Consultant in Paediatric Palliative Medicine had reviewed usage of the young adult hospice. For ages 20-24, 53 young people used the hospice, a rate of 2 per 10,000 young adults. Martin House only accepts referrals under the age of 19 years so these young people would have had known needs at the time of transition. Looking at the overall population using the children's and young adult's hospices at the Martin House site, a local review estimated that "one third of families are aware of us and use us, one third are aware and don't wish to use us, one third have a child with a life threatening condition and are not aware of us or possibly not admitting to the fact of a life limiting condition."

4.4 Discussion

The literature cited shows extended life expectancy for a number of conditions previously classified as terminal in childhood. The expected lengths of life and variable requirements of various conditions should shape the type, quantity and duration of service that might be required:

Cerebral Palsy - Conditional on surviving to age 20 years, almost 85% of the cohort survived to age 50 years (a comparable estimate for the general population is 96%). On attaining adulthood therefore there is a case for discharging people with CP from palliative care with a view to reinstating this as it becomes demonstrably necessary nearer the age of 50 years.

Cystic Fibrosis – expected length of life for a person born in 1990 is 40 years which represents a doubling in the last 20 years, and nearly half of all patients are now adults.

Duchenne Muscular Dystrophy - estimated probability of survival to age 30 years was 85% (median survival was 35 years).

However those reviewed are only the least rare amongst a large number of very rare conditions. Palliative Care Statistics (DH 2007) lists approximately 370 codes from the ICD10 identifying conditions given as causes of death which might have required palliative care. For example, Juvenile Batten disease has an onset between 5 and 9 years. Death can occur from the late teens to the mid 30's. These results are important in planning for a new service for young adults with life limiting or life threatening illness.

Much has also been written and studies completed on the value and improved outcomes resulting from good transition (for an overall review see Simons et al 2010) and this is also of importance to a new service for young adults, where age of transition is key.

Given the increase in government support for children's palliative care, the expected rise in the numbers of deaths among older adults from 2012 with the reduction in opportunity for dying at home, and the increasing survival of younger people with life limiting or life threatening illness, a new service targeting that group has opportunity to learn from both children's and adult palliative care approaches and policies.

Elements of both services will be needed, respite care as provided for children, and the life opportunities that children with palliative care needs have come to expect, but also the opportunity to die in the place of one's choice and the support to allow that to happen.

A young adult service may also expect a burgeoning caseload as pressure increases on services to children and older adults and this needs assessment has found evidence of this occurring.

5. Demography

5.1 Introduction

This section contains demographic information to support service planning for the area of interest to The J's.

Essex is a large semi rural county with a population of 1.7 million people which has been divided into 5 PCTs, now working in clusters. Each PCT area has a major town:

South East Essex	Southend
South West Essex	Basildon
Mid Essex	Chelmsford
North East Essex	Colchester
West Essex	Harlow

The PCTs now work in two clusters, SE with SW Essex, and NE, Mid and West Essex.

5.2 Methodology

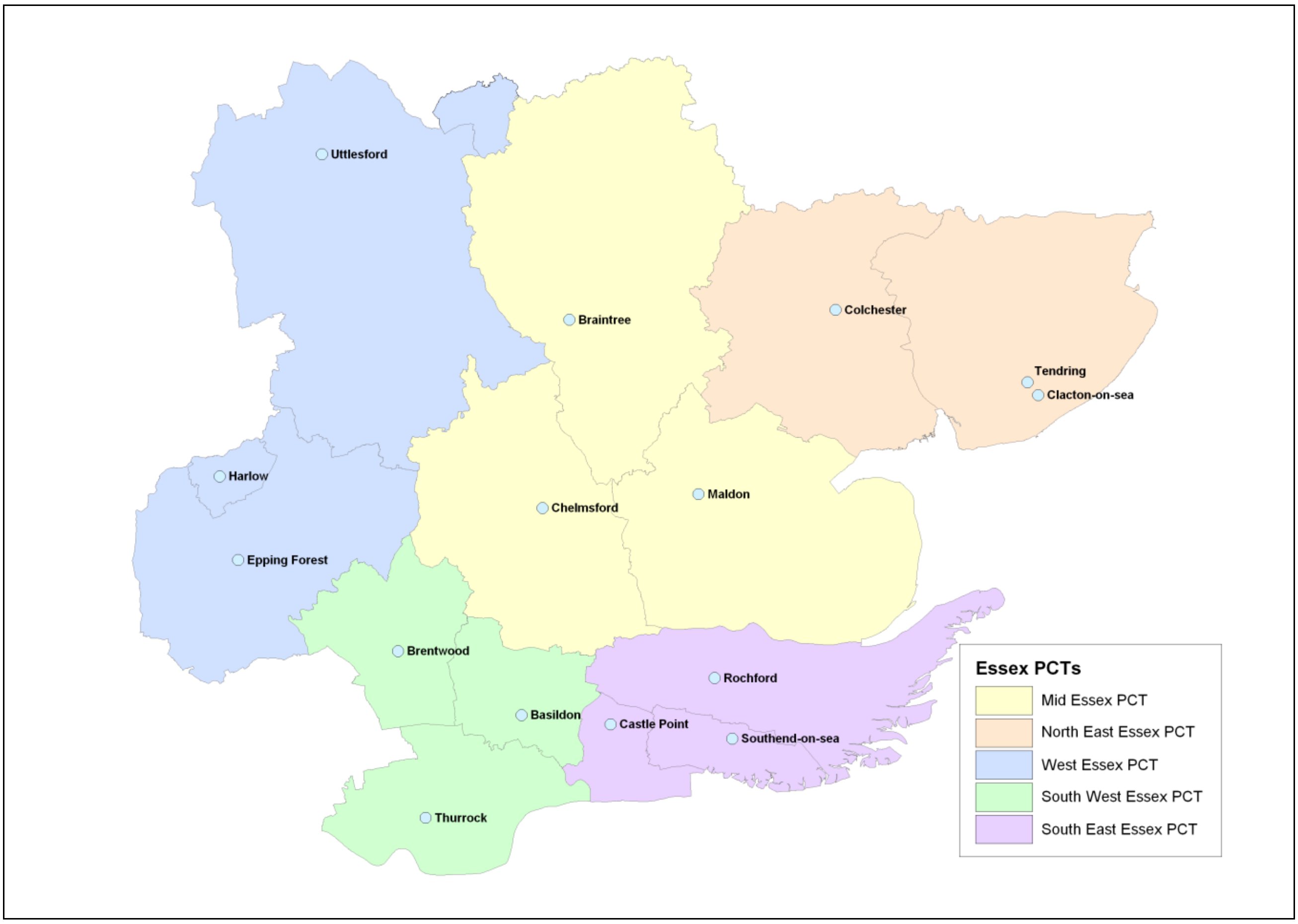
Demographic data provided by the Office for National Statistics are mainly presented in maps, and use is also made of information collected for the Essex Joint Strategic Needs Assessment. Maps are based on Lower Super Output Areas (LSOA) as these are of similar geographical size (each area has a minimum size of 1,000 residents and 400 households, but average 1,500 residents) rather than on wards which differ greatly in size (from fewer than 100 to 30,000 people).

Population maps are shaded according to population size in these small homogeneous areas. The legend on each has a figure in brackets which shows how many LSOAs fall within each category.

Information is presented on the overall population by age group, on deprivation which may increase where there is a disabled child in the family, and on ethnicity where prevalence of different conditions is known to vary, although information on the distribution of ethnic groups is very poor. Populations are also projected in order to assist service planning.

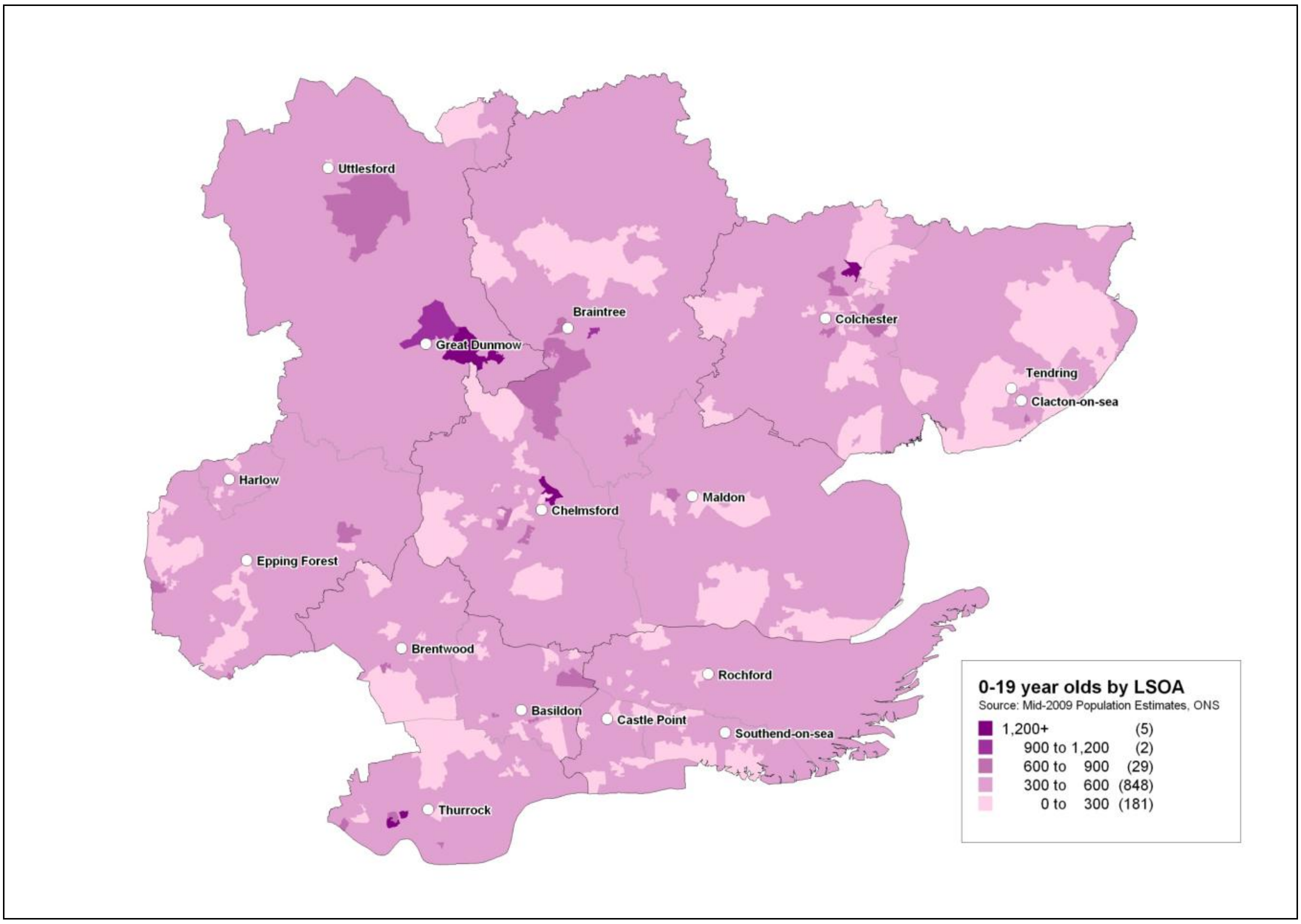
5.3 Results

Figure 5.1 Essex by PCT showing significant towns



Source: Office for National Statistics

Figure 5.2 Essex Population age 0 – 19, by PCT

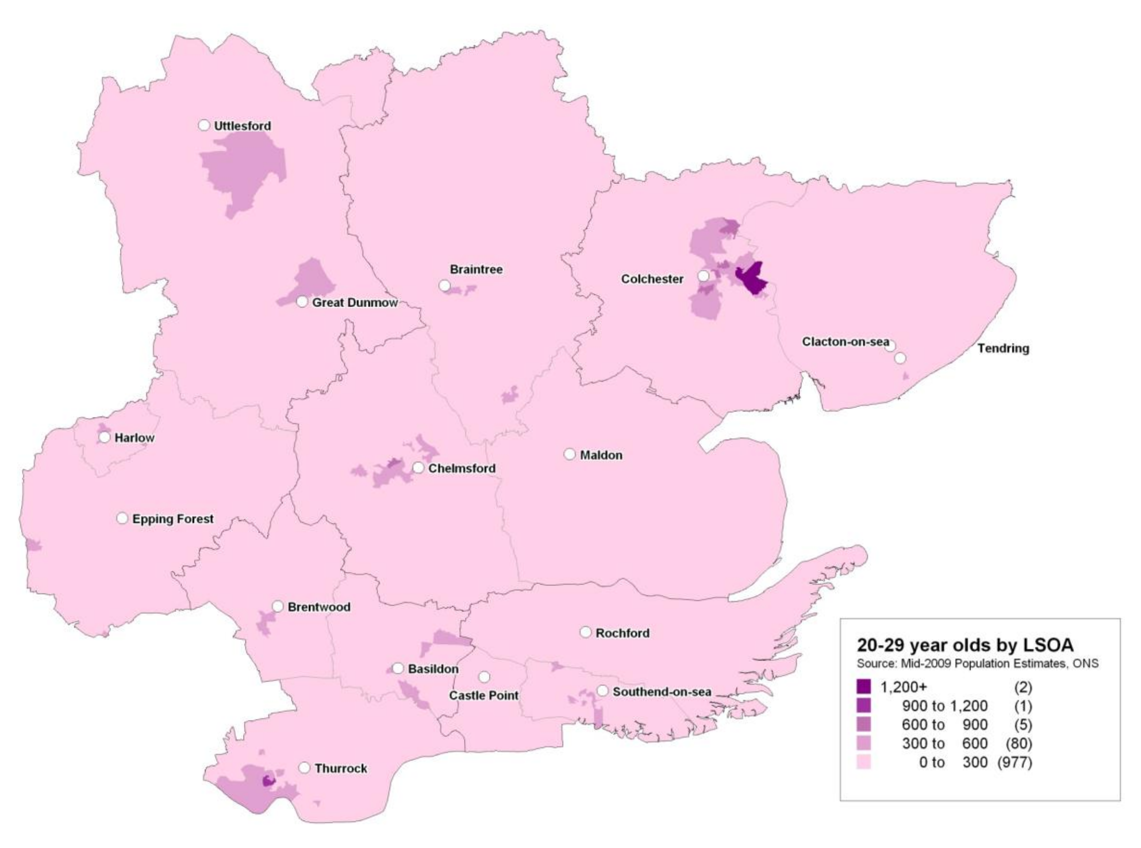


Source: Mid 2009 population estimates, ONS

The distribution of younger age groups is relevant to planning for palliative care for young people as more children with palliative care needs survive into adulthood.

As expected greater concentrations of children are found in urban centres and also around Great Dunmow, possibly within parents' commuting distance to Stansted airport, although the reasons for this concentration are unclear.

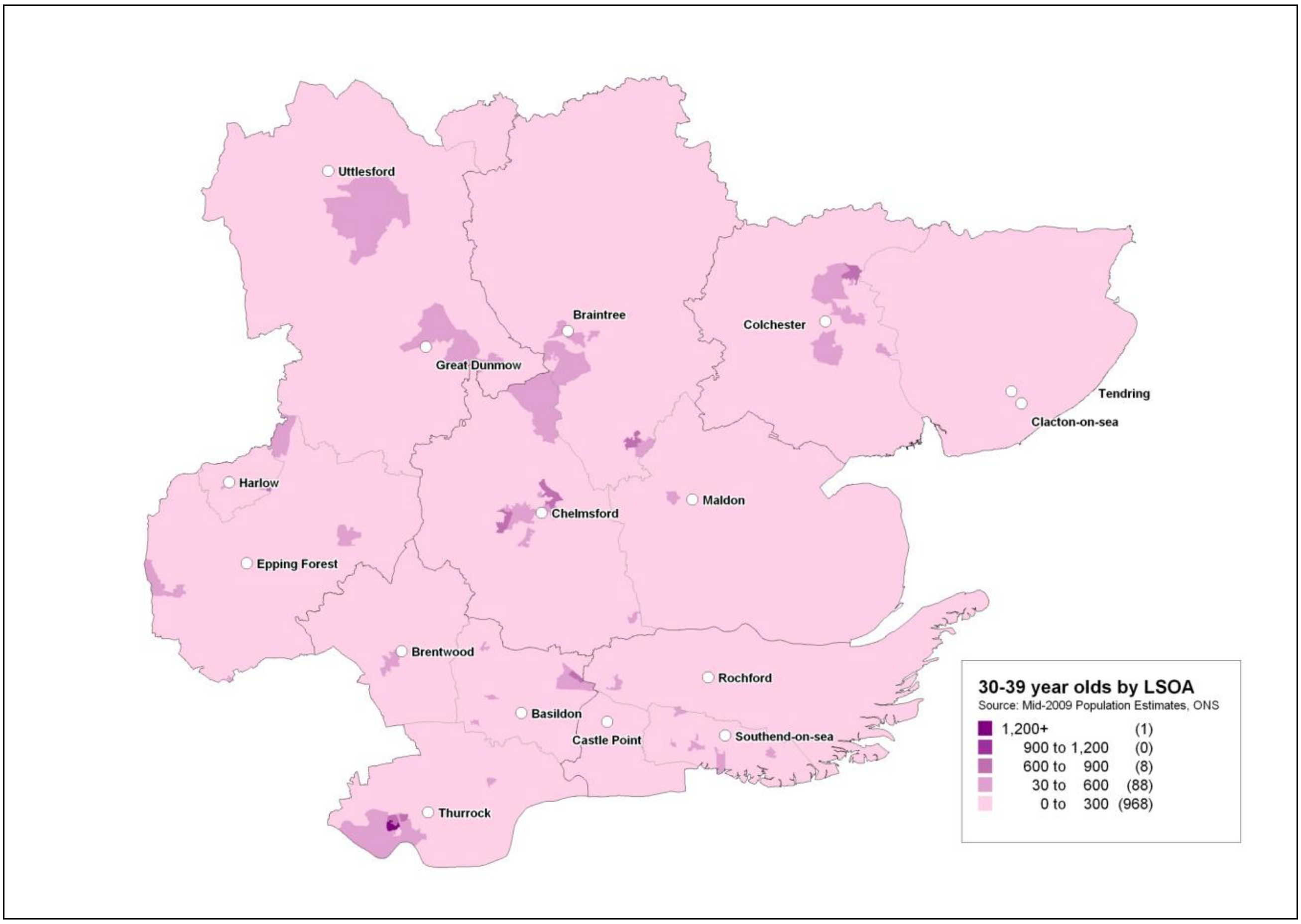
Figure 5.3 Essex Population age 20 – 29, by PCT



Source: Mid 2009 population estimates, ONS

The concentration of young adults in the 20 – 29 age group is seen clearly in Colchester and Thurrock.

Figure 5.4 Essex Population age 30 – 39, by PCT

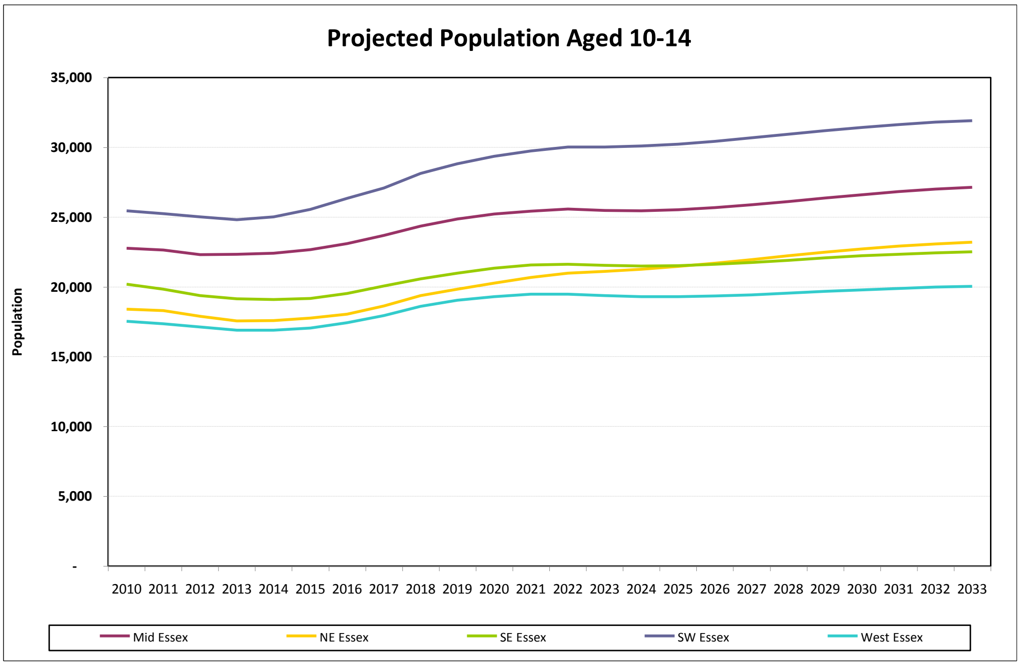


Source: Mid 2009 population estimates, ONS

The concentration of people in the 30 – 39 year age group is more evenly spread but still high in Thurrock and in urban centres especially Chelmsford and Colchester, and probably in other areas of greater employment for example near to Stansted airport but also around Uttlesford, "one of the most affluent areas in the country".

Populations are set to increase in the period 2010 – 2030, shown in the following charts by age group:

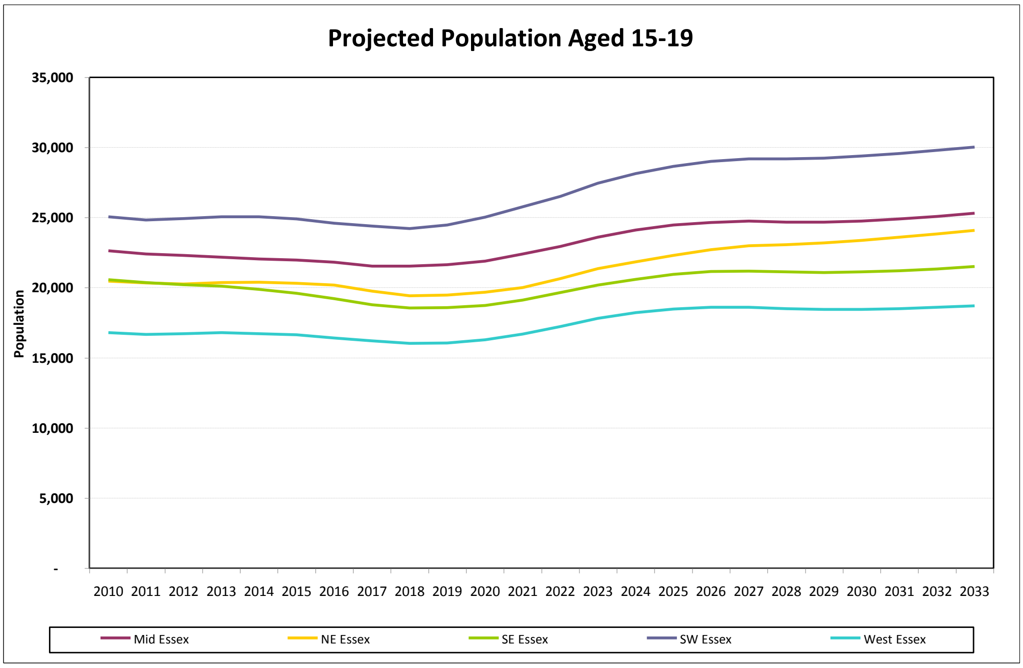
Figure 5.5 Essex Projected Population aged 10 – 14 years



Source: ONS mid-2009 population projections

This shows the relative population levels by PCT and the projected changed between 2010 and 2033 in the "feeder age range" to The J's Hospice. After a slight drop to 2014, the 10 – 14 year age group will increase quite steeply to 2022 before continuing to grow more slowly.

Figure 5.6 Essex Projected Population aged 15 – 19 years

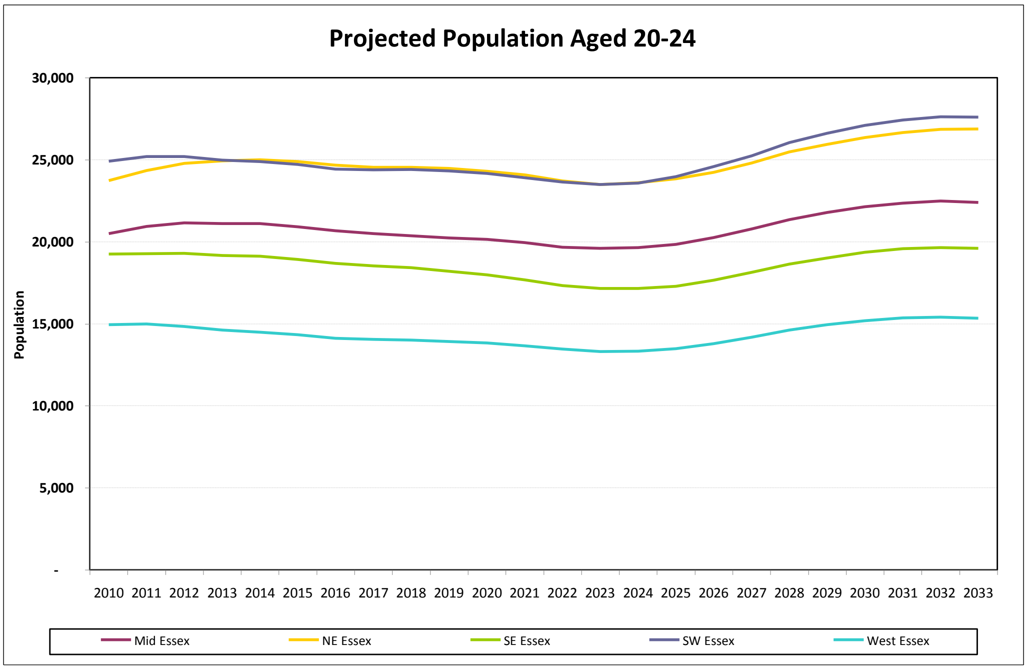


Source: ONS mid-2009 population projections

Numbers in this age band will remain steady and even drop slightly until rising again in 2020 when quite a steep curve will ensue. The similar pattern seen in the 10 – 14 year age group suggests that based simply on overall population projections, The J's wil see steady demand until about 2018. This does not take into account other factors such as increasing survival, and new service provision both of which would be expected to increase demand.

The population differences are also worthy of note, with a larger young population in SW Essex, and growing at a greater rate than in other parts of the county.

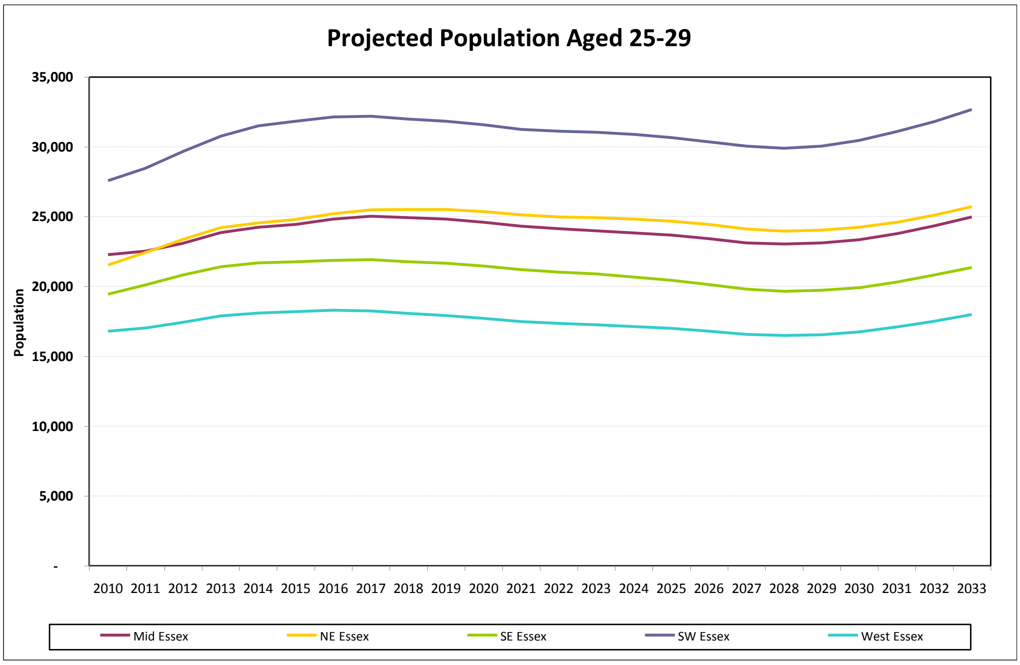
Figure 5.7 Essex Projected Population aged 20 – 24 years



Source: ONS mid-2009 population projections

This chart shows a longer period of slight reduction in the age group 20 – 24, expected to begin a steep rise from about 2026.

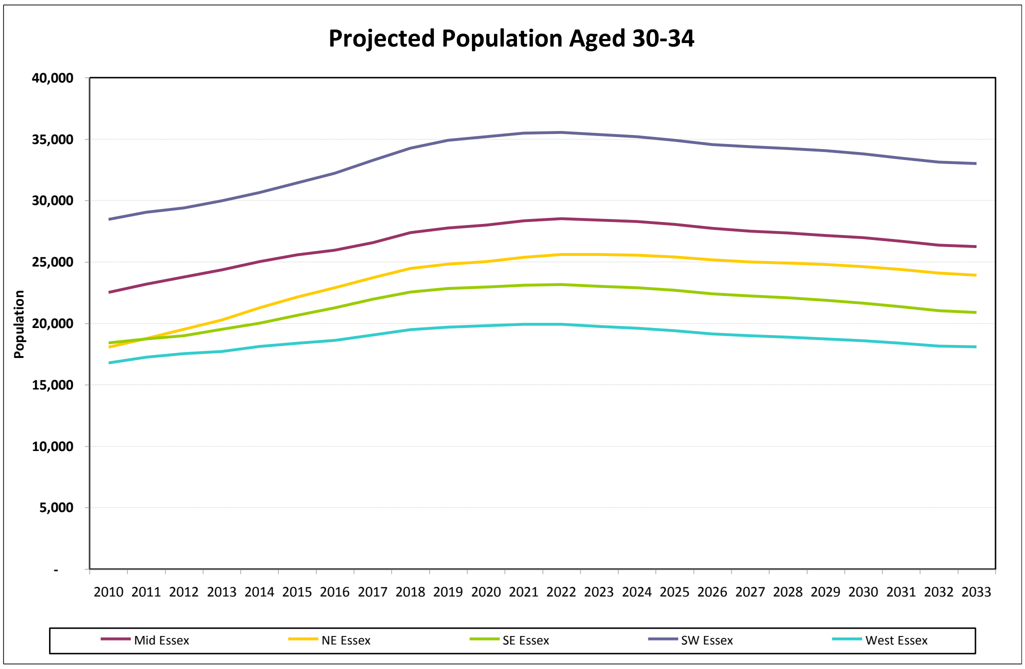
Figure 5.8 Essex Projected Population aged 25 – 29 years



Source: ONS mid-2009 population projections

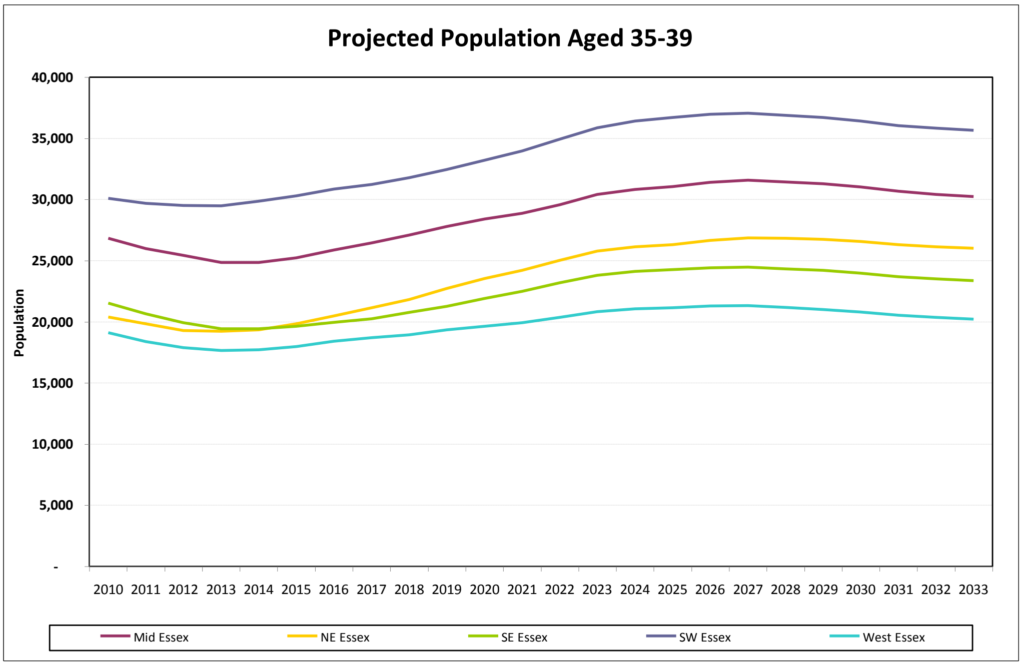
Amongst the 25 – 29 age group, population growth will start earlier than in younger age groups, peaking in 2016/17 to drop before beginning to rise again in 2030. The peak is correspondingly later in the 30 – 34 age group, peaking in 2022/23 before falling.

Figure 5.9 Essex Projected Population aged 30 – 34 years



Source: ONS mid-2009 population projections

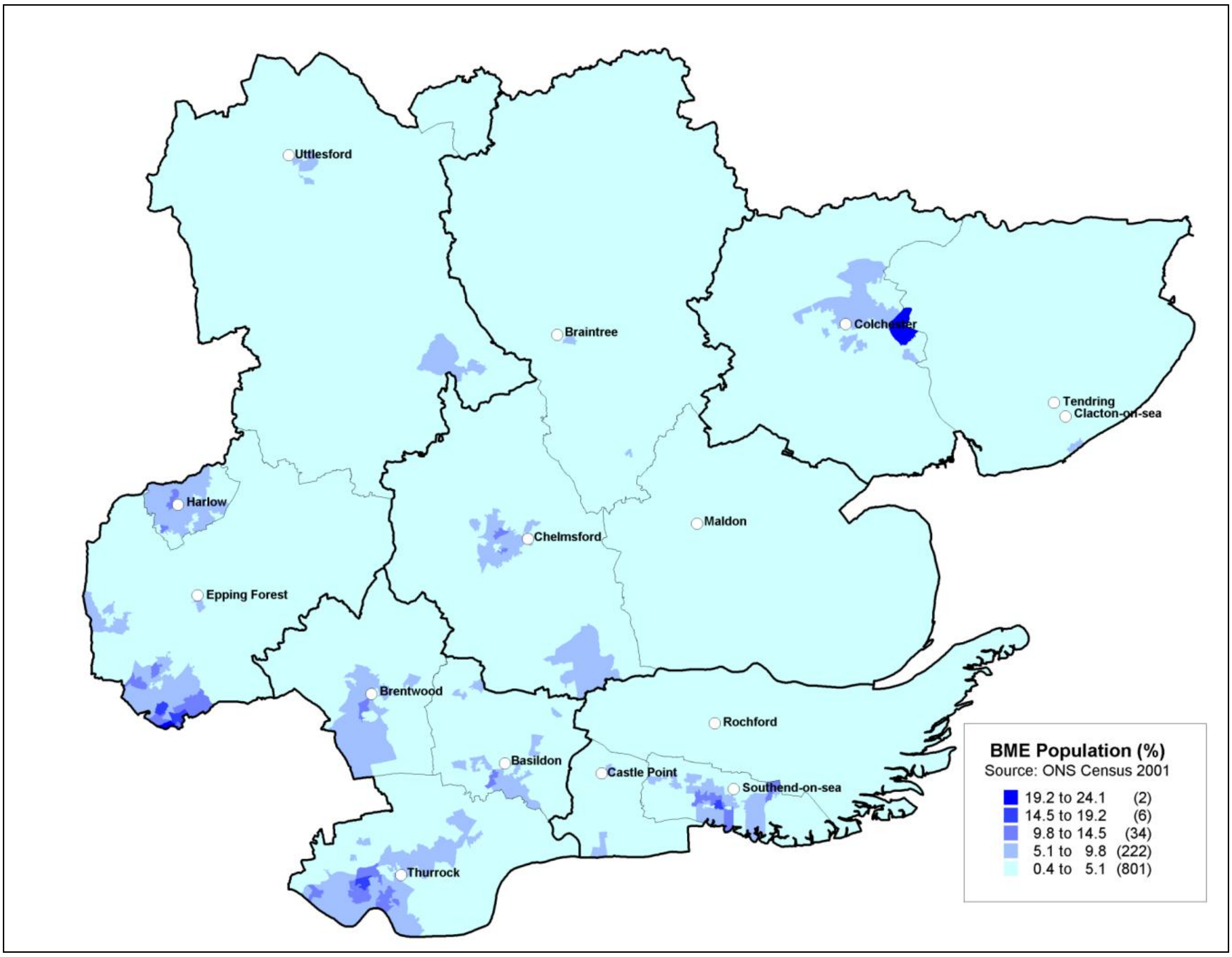
Figure 5.10 Essex Projected Population aged 35 – 39 years



Source: ONS mid-2009 population projections

The trajectory for the 35- 39 age group is dropping to 2013 before rising quite steeply to peak in 2026/27.

Figure 5.11 Essex Black and Minority Ethnic Population, by PCT



Source: Office for National Statistics, Mid-2007 Ethnic Population.

These data are of particular importance to palliative care planning for younger age groups as the frequency of some diagnoses varies by ethnic group. For non-metropolitan counties, information is dependent on the 2001 census. For extrapolation of prevalence data, numbers of black and minority ethnic groups by specific ethnic group would be needed and this level of detail is not yet available.

"Essex has 178,000 residents from black and minority ethnic (BME) groups (including Irish white and other white). There are 116,700 residents from ethnic groups other than white and 61,300 from white minority groups. People from all BME groups made up 10.2% of Essex residents - across England, 16.4% of people belonged to BME groups. People from ethnic groups other than white made up just over 8% of Essex residents[4]".

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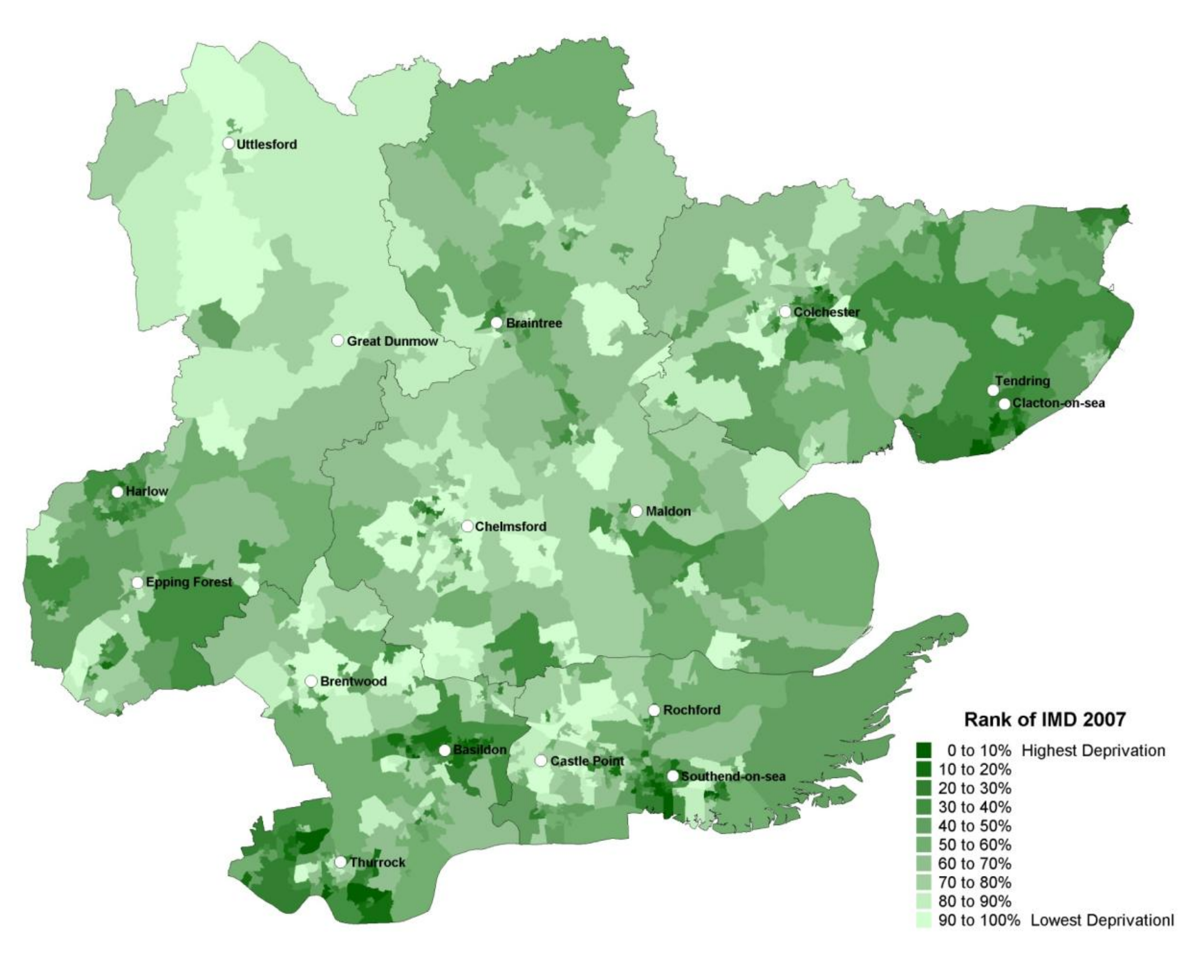
[4] NeSS Geography Hierarchy, Resident Population Estimates for mid-2007 Quoted in Essex JSNA, v 1.4 Sept 2010

Figure 5.12 Essex Population showing deprivation, by PCT



Source: Communities and Local Government.

The map shows 10 levels of deprivation, with 0 - 10% being the most deprived and 90 - 100% least deprived. Highest levels of deprivation are seen around Tendring and Clacton compared to the rest of Essex. The map shows that Tendring and Clacton are in the top 10% of LSOAs that have the highest levels of deprivation across Essex.

5.4 Discussion

The purpose of this information is to assist in planning service type and distribution. The importance of demography is seen in the type of area to be served. Essex is largely rural with small and larger towns quite large distances part. Numbers of young people requiring palliative care are relatively small and may be widespread, young adults seen as typically inhabiting the small towns or areas suitable for commuting to London. The service to be established and its style and patterns of proposed distribution will need to account for these demographic factors.

All the projections show a window of opportunity for The J's to establish as a new service, before the steeper rises in population occur. The immediate increases will be in the 25 – 34 year age group. It is also useful to note the difference in population size between the PCTs.

The population increases in the 10 – 14 year age group quite steeply from 2012 – 2022. Sharp rises are also seen in the 25 – 29 and 30 – 34 year age groups.

The needs assessment cannot address the specific needs of black and minority ethnic groups because lack of data on individual groups and their geographic distribution does not allow extrapolation of prevalence estimates by individual ethnicities. It is recommended that this be reviewed in much finer detail following the publication of the results of the 2011 census.

6. Epidemiology

6.1 Introduction

Problems with definitions and counts were described in Section 3, Introduction. Actual numbers and estimates are considered for England and for Essex. This section draws heavily on DH 2007 Palliative Care Statistics for Children and Young Adults.

6.2 Methodology

Nationally calculated data have been used to describe the number of childhood deaths that might be expected and also those which might have required a palliative intervention. This work is freely available (DH 2007).

Recording of actual cases of palliative care need among children and young people is not very precise because there are no uniform electronic systems, many different services (or none) become involved with each young person, and there are lack of diagnoses and difficulty in predicting death. The results that have been obtained are included in Section 7 below, Stakeholder Reports (Current provision and known need)

To establish normative need (what might be expected based on definitions agreed by experts), deaths data have been used. Mortality is a dependable statistic and information on deaths is produced by ONS and issued to the Director of Public Health in each locality in Public Health Mortality Files. Only this source contains underlying causes of death which may have needed palliative care. Death is frequently caused directly by an infection such as pneumonia (the first cause of death). The secondary cause of death will mention the life limiting or life threatening illness with which the young person lived.

ONS would only allow these files to be used by an NHS organisation, so the senior information analysts in each of the five Essex PCTs have very generously provided the needs assessment with data files showing only anonymous data but including all the data items required for our analysis.

6.3 Results: National

Since survival is improving in children with life limiting or life threatening illness, DH 2007 includes information on young adults aged 20-39.

Table 6.1 Deaths of children and young people from all causes, by age group, England, years 2001 - 2005

Age group	2001		2002		2003		2004		2005		All Years	
	No.	%	No.	%	No.	%	No.	%	No.	%	No.	%
15 - 19	1,313	10	1,303	10	1,222	10	1,243	10	1,235	11	6,316	10
20 - 24	1,748	14	1,777	14	1,833	15	1,751	14	1,695	15	8,804	14
25 - 29	2,239	17	2,111	17	2,029	16	1,949	16	1,856	16	10,184	16
30 - 34	3,256	25	3,151	25	3,085	25	2,868	24	2,771	24	15,131	25
35 - 39	4,351	34	4,263	34	4,258	34	4,317	36	4,108	35	21,297	34
Age 15 - 39	**12,907**	**100**	**12,605**	**100**	**12,427**	**100**	**12,128**	**100**	**11,665**	**100**	**61,732**	**100**

Source: DH 2007 Palliative Care Statistics for children and Young Adults

This shows deaths for ages 15 - 39 in England, from all causes. In 2001 10% of those deaths occurred in the 15 – 19 age group, 14% of them in the 20 – 14 year age group and so on. The proportions are consistent over the years.

As discussed in Section 4.4, DH 2007 identified approximately 370 ICD10 codes identifying causes of death which were likely to have required palliative care. In children most deaths occur in the neonatal period. Statistics are given which either include or exclude that period for fair comparison.

Applying these codes to deaths which occurred in England 2001 – 2005 gave the following result. These numbers exclude neonatal deaths, and in the first line, ages 0 – 19 of course covers two decades.

Table 6.2 Deaths from causes likely to have required palliative care excluding neonatal, by age group, England, years 2001 – 2005

Age Group	2001	2002	2003	2004	2005
0-19	1,965	1,913	1,932	1,815	1,787
20-29	1,079	1,060	1,099	1,119	1,056
30-39	3,588	3,443	3,415	3,399	3,185
0-39	6,632	6,416	6,446	6,333	6,028

Source: DH 2007 Palliative Care Statistics for children and Young Adults

These numbers were then converted to rates:

Table 6.3 Deaths from causes likely to have required palliative care per 100,000 population, England, years 2001 - 2005

Age Group	2001	2002	2003	2004	2005
0-19	15.9	15.5	15.6	14.7	14.4
20-29	17.1	17	17.7	17.8	16.4
30-39	46.2	44.3	44.3	44.8	42.7
0-39	25.1	24.4	24.5	24.2	23

Source: DH 2007 Palliative Care Statistics for children and Young Adults

This shows for example that in a population of 100,000, 17 young people aged 20 – 29 would have died in 2001 from a cause likely to have required palliative care.

The following table shows for example that 32% of all deaths occurring in young people aged 15 – 19 were likely to have required palliative care.

Table 6.4 % of deaths in age group from causes likely to have required palliative care, by age group, England, years 2001 - 2005

Age (years)	2001	2002	2003	2004	2005	All Years
15–19	32%	31%	33%	32%	31%	32%
20–24	26%	25%	26%	28%	27%	26%
25–29	28%	29%	31%	32%	33%	30%
30–34	41%	41%	41%	42%	39%	41%
35–39	52%	51%	51%	51%	51%	51%

Source: DH 2007 Palliative Care Statistics for children and Young Adults

This shows that of all deaths that occurred in the 15 – 19 age group, 32% were likely to have required palliative care; for those between the age of 20 and 24, 26% were likely to have required palliative care and then this proportion steadily rises to 30% of those aged 25 – 29, 41% of those aged 30 – 34 and 51% aged 35 – 39 years.

Table 6.5 Deaths from causes likely to have required palliative care, by place of death and age group, England 2001 - 05

Place of Death	**Age Group**					
	15 - 19		20 - 29		30 - 39	
	No.	%	No.	%	No.	%
Home	1811	19.2	1052	19.4	4073	23.9
Hospice	393	4.2	402	7.4	1889	11.1
Hospital	6985	74.2	3592	66.4	10048	59
Other1	223	2.4	367	6.8	1020	6
Total	9412	100	5413	100	17030	100

Source: DH 2007 Palliative Care Statistics for children and Young Adults

6.4 Results: Local

The following tables show deaths by PCT in Essex over an 8 year period:

- deaths from all causes in 5 year age bands between 15 and 39
- those with a cause of death likely to have needed palliative care
- place of death of those likely to have needed palliative care (totals given for eight year period)
- place of death where palliative care was likely needed comparing England and Essex

Data are presented in three year periods to preserve anonymity as some numbers are very small.

Finally, deaths likely to have required palliative care for this 8-year period among younger adults aged 15 – 39 are mapped to show geographic distribution across Essex.

Table 6.6 Deaths of Young people, all causes aged 15 - 39 by age group, Essex PCT 2002 – 2009, in 3 year groups

	Mid Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	21	24	32	33	32
20-24	38	45	35	24	19
25-29	33	35	37	43	45
30 - 34	53	55	53	45	41
35 - 39	52	62	63	63	68
Total	197	221	220	208	205

	SE Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	22	21	21	19	25
20-24	35	35	35	25	24
25-29	38	33	32	32	35
30 - 34	62	67	62	55	52
35 - 39	100	112	114	120	106
Total	257	268	264	251	242

	SW Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	26	30	21	15	15
20-24	25	22	25	21	22
25-29	33	25	25	29	30
30 - 34	65	56	59	49	41
35 - 39	82	79	75	66	65
Total	231	212	205	180	173

	NE Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	21	20	16	16	15
20-24	46	45	36	33	35
25-29	38	45	46	45	43
30 - 34	67	74	62	49	40
35 - 39	76	81	94	83	80
Total	248	265	254	226	213

	W Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	28	31	26	23	16
20-24	31	33	27	23	16
25-29	38	34	31	42	36
30 - 34	49	45	34	28	29
35 - 39	80	85	77	83	76
Total	226	228	195	199	173

	All Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	118	126	116	106	103
20-24	175	180	158	126	116
25-29	180	172	171	191	189
30 - 34	296	297	270	226	203
35 - 39	390	419	423	415	395
Total	1159	1194	1138	1064	1006

Source: Public Health Mortality Files, ONS

Table 6.7 Annual average Deaths of Young people aged 15 - 39, all causes Essex PCTs 2002 – 2009

Mid Essex	51
SE Essex	62
SW Essex	51
NE Essex	58
W Essex	50
Essex	271*

Source: Public Health Mortality Files, ONS

*doesn't add due to rounding. The average is obtained by the sum of the total for 2002/05 and 2006/09 and divided by 8 to give a single year score.

Table 6.8 All deaths of Young people from causes likely to have required palliative care aged 15 - 39 by age group, Essex PCT 2002 – 2009

	Mid Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	11	10	11	13	12
20-24	11	12	10	7	6
25-29	10	8	10	11	15
30 - 34	25	25	25	21	23
35 - 39	24	30	33	32	37
Total	81	85	89	84	93

	SE Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	7	6	7	7	10
20-24	8	11	10	8	6
25-29	7	6	8	12	12
30 - 34	24	28	25	23	23
35 - 39	39	43	42	39	36
Total	85	94	92	89	87

	SW Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	13	16	12	8	9
20-24	8	7	6	5	5
25-29	7	5	6	7	8
30 - 34	22	22	21	19	19
35 - 39	41	38	34	31	31
Total	91	88	79	70	72

	NE Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	6	6	6	4	4
20-24	10	8	8	7	8
25-29	12	15	12	13	13
30 - 34	17	22	20	19	16
35 - 39	30	32	39	36	34
Total	75	83	85	79	75

	W Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	10	8	10	10	6
20-24	8	10	5	5	3
25-29	7	6	6	13	12
30 - 34	14	13	12	11	11
35 - 39	36	35	28	32	28
Total	75	72	61	71	60

	All Essex				
Age Band	2002-2005	2003-2006	2004-2007	2005-2008	2006-2009
15 - 19	47	46	46	42	41
20-24	45	48	39	32	28
25-29	43	40	42	56	60
30 - 34	102	110	103	93	92
35 - 39	170	178	176	170	166
Total	407	422	406	393	387

Source: Public Health Mortality Files, ONS

Table 6.9 Annual average Deaths of Young people aged 15 - 39, from causes likely to have required palliative care, Essex PCTs 2002 – 2009

Mid Essex	22
SE Essex	22
SW Essex	21
NE Essex	19
W Essex	17
Essex	99

Source: Public Health Mortality Files, ONS

*doesn't add due to rounding

This table shows the annual average of deaths that have occurred in Essex populations in an 8 year period. These numbers are further commented on in the discussion section following.

Table 6.10 Deaths from causes likely to have required palliative care, by place of death and age group, Essex PCT 2002 – 2009

Place of Death	**Age Group**					
	15 - 19		20 - 29		30 - 39	
	No.	%	No.	%	No.	%
Home	23	26.1	41	23.3	106	20.3
Hospice	4	4.5	23	13.1	81	15.5
Hospital	51	58	88	50	280	53.7
Other[1]	10	11.4	24	13.6	54	10.4
Total	88	100	176	100	521	100

Source: Public Health Mortality Files, ONS

[1] .Including for example: psychiatric hospital, nursing home, residential home, private home that is not the usual residence of the deceased.

Table 6.11 Deaths from causes likely to have required palliative care, by place of death and age group, England 2001 – 05 and Essex 2002 – 2009

Place of Death	England 2001 - 05 by Age Group						Essex 2002 - 09 by Age Group					
	0 - 19 excl neonatal		20-29		30-39		15 - 19		20-29		30-39	
	No.	**%**	No.	**%**	No.	**%**	No.	**%**	No.	**%**	No.	**%**
Home	1811	**19.2**	1052	**19.4**	4073	**23.9**	23	**26.1**	41	**23.3**	106	**20.3**
Hospice	393	**4.2**	402	**7.4**	1889	**11.1**	4	**4.5**	23	**13.1**	81	**15.5**
Hospital	6985	**74.2**	3592	**66.4**	10048	**59.0**	51	**58**	88	**50**	280	**53.7**
Other[1]	223	**2.4**	367	**6.8**	1020	**6.0**	10	**11.4**	24	**13.6**	54	**10.4**
Total	9412	**100.0**	5413	**100.0**	17030	**100.0**	88	**100**	176	**100**	521	**100**

Source: Public Health Mortality Files, ONS and DH2007

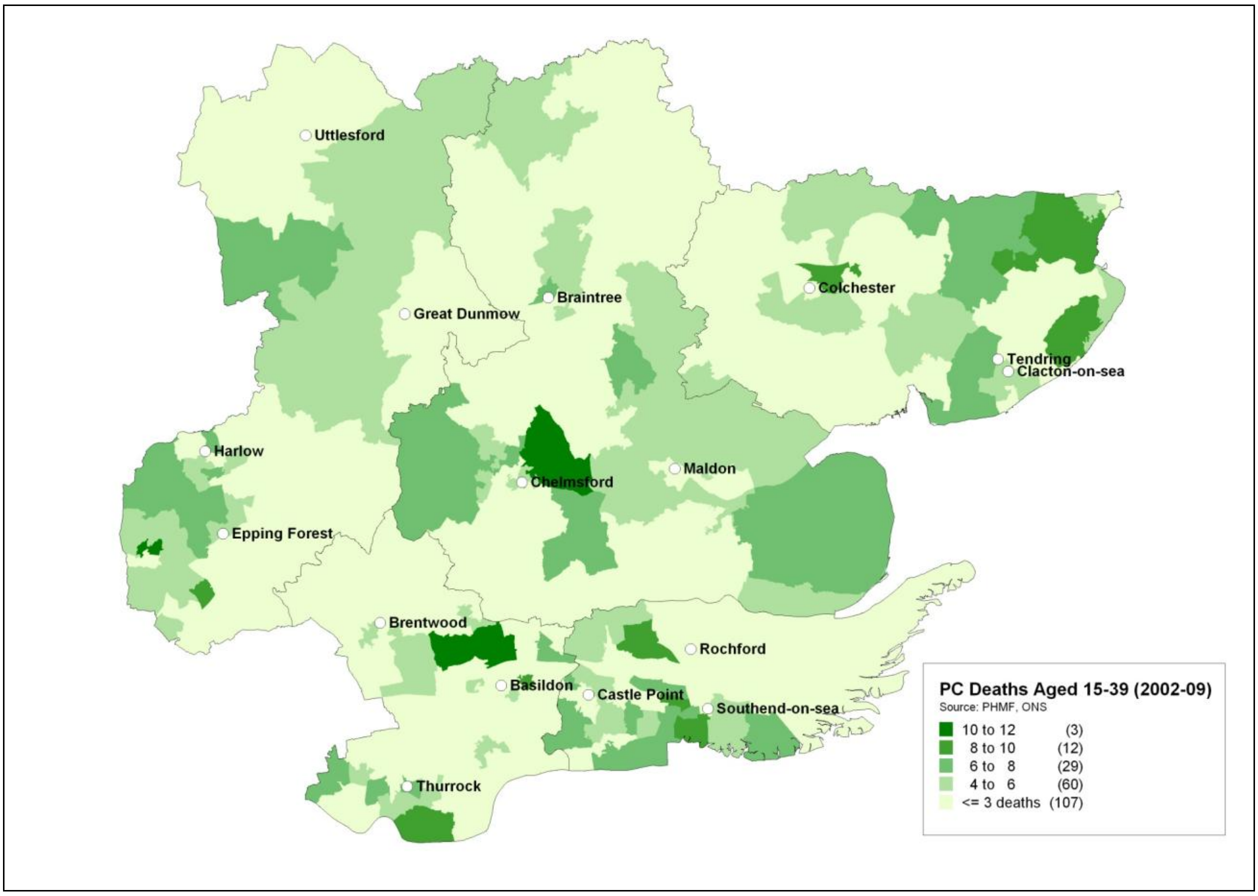
[1].Including for example: psychiatric hospital, nursing home, residential home, private home that is not the usual residence of the deceased.

Some comment is needed on place of death. The above tables have to be compared with care; they differ in time period and in age group. The England numbers were recorded for 2001 – 05 and for Essex from 2002 – 09. The first column for England records place of death of all children aged 0 – 19 and for Essex the group is 15 – 19. These therefore are not comparable.

For the 20 – 29 and 30 – 39 year age groups comparison of the percentage differences between Essex and England is useful. In Essex a higher proportion of the 20 – 29 group die in a hospice, a lower proportion in a hospital. This is the same for the 30 – 39 age group although by a smaller degree. In Essex a greater proportion in the 20- 29 age group die at home, but that is reversed for the 30 – 39 age group. The differences are not great and crucially here there are no significance measures.

Greater differences are seen amongst “other” places where the proportions in Essex are very much higher (double in the 20 – 24 year age group) and this will be considered in the discussion following this section.

Figure 6.1 Geographic distribution of deaths (by address of residence) from causes likely to have required palliative care in younger adults aged 15 - 39, Essex by Middle Super Output Areas 2002 – 2009



Source: Public Health Mortality Files, ONS

6.5 Discussion

National numbers of deaths with rates per population and percentage of all deaths by age group where palliative care was likely to be required provide expected levels of service need. However there are two specific provisos:

1. "where palliative care was likely to be required". This is based on the 370 ICD10 codes where a death was likely to have required palliative care. Many of these may have been sudden deaths where there was no time for palliative care. For many it is possible that the diagnosis was not confirmed until after death, and palliative care may not have been considered. It is also known that "denial" of a serious condition may preclude people from seeking appropriate help. So the numbers given should be regarded as maximum.

2. These numbers relate to deaths, not quantity of service. DH (2007) reviews a number of studies on palliative care needs for the age group 0 – 19 years (excluding neonatal deaths) and accepts that "on average there are 10 people requiring palliative care for every death that occurs where palliative care was needed". The deaths given here therefore, are a maximum but represent a far greater demand on palliative care services, up to a multiple of 10 to indicate the service required prior to death.

Table 6.4 showed the proportion of all deaths that occurred by age group that were likely to have required palliative care as about a third in the 15 – 19 age groups, about a quarter for 20 – 24 years and then steadily rising to more than a half for ages 35 – 39 years.

Table 6.7 shows each PCT having between 50 and 62 all cause deaths amongst people aged 15 – 39 with an Essex total of 271.

Table 6.9 shows each PCT having between 17 and 22 deaths likely to have required palliative care amongst people aged 15 – 39 with an Essex total of 99. Thus the approximately one third in need of palliative care seen in figures for England is reflected in statistics for Essex.

For a baseline measurement of need these are perhaps the most useful numbers. Each PCT records an average of between 17 and 22 deaths each year in young people aged between 15 and 39 years. These are premature deaths which will have huge impact on the individual and family and friends.

DH (2007) stated that for each palliative care supported death in childhood, there were 10 patients in need of such care. This proportion cannot be applied to young adult deaths because of the increasing prevalence of cancer in young adults which makes different demands on palliative care and the mortality rate of other life limiting or life threatening illness. However the number of deaths must be multiplied when planning palliative care input over time and with the increased survival of children with life limiting or life threatening illness, this heavier burden of palliative care need will grow.

The review in the grey literature (Section 4.2.1) from the Yorkshire service suggests that approximately one third of these deaths will receive palliative care, one third do not know the service exists and one third choose not to use it. If this held true in Essex, between approximately 57 and 73 people would be receiving palliative care in the age group. Others would decline it and the rest would not know about it.

The geographic distribution of deaths shown in the map perhaps not surprisingly places most in centres of urban settlement.

Table 6.11 compares variance in place of death between England and Essex.

The proportions shown are that in Essex, where palliative care was likely needed, one quarter of deaths occurred at home, about one sixth in a hospice and little over a half in hospital in the 30 – 39 age group. In the 20 – 29 age group the proportions are 23% (home), 13% (hospice) and 50% (hospital).

The differences in the "other" groups are greater and worthy of further investigation. There is a much higher proportion in all age ranges in Essex dying in for example, psychiatric hospital, nursing home, residential home, or private home that is not the usual residence of the deceased.

Since these are deaths likely to have needed palliative care, the question should be asked why this is the case. It could be people with long term disabilities in residential homes or nursing homes for whom that has been a place of residence for some time prior to death, and we do not know if palliative care was given.

The time difference could also be significant. The work cited in Section 4 by Gomes and Higginson (2008) found that home death proportions fell from 31% to 18% overall from 1974 to 2003, with a higher rate for people over the age of 65 years. They predicted that numbers of home deaths could reduce by 42% and fewer than 1 in 10 would die at home in 2030.

This report is not able to offer trend data for home deaths in Essex, and this information should be further investigated.

7. Stakeholder Reports (Current provision and known need)

7.1 Introduction

Up to age 16 – 18 young people receive specialist care from community children's nurse teams (CCNT), children's hospices and acute units. From that transition period, their care falls to District Nurses, adult social care, adult hospices and acute units.

Providers include those from outside the area including Douglas House, Oxford who originally accepted young people from any area. Douglas House now has a catchment of 1½ hours by car which still allows access to parts of Essex. East Anglia's Children's Hospices also provide to children and young people from Colchester and wider NE Essex for whom the Cambridge based service is nearer than Little Havens.

7.2 Methodology

Information was sought from known providers. Without time to obtain ethnical approval in the period of the study anonymised data only was sought. A number of response frameworks were devised which allowed services to identify individuals only by age, diagnosis and PCT. It was hoped that this would give enough specificity to delete double counting without requiring individual identification.

Although frequent attempts were made to gain contact with medical staff at UCLH and Addenbrookes, this was not forthcoming and reports from tertiary acute units have had to be omitted. A review is underway at Colchester Hospital and due to report at the end of March 2011 of all "open access" children. These will include those with palliative care needs, but others as well such as those with haemophilia, and further information may become available then

To provide an estimate of forthcoming need, children's services were asked for numbers of young people with palliative care needs, by diagnosis and by year of age from 15 – 18 inclusive.

There are also Macmillan Nurse Specialists and Children's Oncology Nurses who may be part of the CCNT or may be independent.

Information was also requested from children's hospices serving the Essex population.

Not all children with palliative care needs would appear in these specialist services. Schools for children with special needs were also contacted for numbers of children aged 15 years and over who might be likely to need palliative care. Where staff were unsure the "surprise question" was used: "would you be surprised if this child died in the next year?" and that gave further elucidation[5].

Those in the actual age group (18 – 40) were counted through requests to adult hospices. This is not sufficient to identify all people in the community likely to require palliative care. Further requests for information were made to adult social care and to district nurses.

7.3 Results

Commentary on results is provided in these sections. Detailed numbers by PCT, age group and diagnoses are available at **Appendix 1**.

Information from some sectors is better than from others, but none is complete and some not available at all. In particular adult social care and district nurses were difficult to access as individual professionals manage their own caseloads and information and for these teams, clients with palliative care needs are rare.

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[5] http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2518805/

7.3.1 Children's Community Nurse Teams

Services were asked for a spot check at 31 December 2010. All services responded. Services were closely aligned to PCT boundaries. A count by diagnosis and annual number by age from 15 – 19 inclusive was requested. One service added a few known to be nearing the 15th birthday (over 14½ years) and these were added with a note.

Results showed:

- Mid Essex had 13 patients
- in SE Essex had 7 patients
- SW Essex had 4 patients
- NE Essex had 13 patients
- West Essex had 17 patients.

The numbers for SE and SW Essex were low compared with the other PCTs and these were collected a second time for checking but did not change. This is a possible indicator of unmet need.

In total a point prevalence figure of 54 young adults between 15 and 19 were known to CCNTs in Essex.

The Children's Oncology Nurse at Queen's Hospital providing a service to the Ingatestone and West Hornden parts of Essex had no current cases but there had been one death each in 2008 and 2010 in SW Essex.

7.3.2 Children's Hospices

Far fewer young adults (aged 14.5 years and over) were known to Little Haven's Children's Hospice for which the catchment is the county of Essex. They knew of 19 young adults of whom 7 were probably duplicated from the CCNTs.

Little Havens and local Primary Care Trusts jointly funded EPIC (Essex Palliative Integrated Care) Children's Respite but that service would only know children already identified by Little Havens.

Little Havens has occasionally admitted a young person over the age of 19 years in special circumstances. This is with permission from the CQC but the regulator has indicated that approval for more than one at a time would not be given.

Little Havens typically has a daily caseload of 84 children and young people aged 0 – 19, and their total in any one year is 130. Although the hospice serves the county of Essex, in practice most of their patients are resident in SW and SE Essex, a phenomenon which has been recognised in many healthcare studies: uptake of service reduces in direct correlation to distance travelled.

It is also the case that ethnic minorities are under-represented; Little Havens has only two children on the caseload from these communities. This is almost certainly an under-representation, and more work is needed to understand the prevalence of conditions likely to require palliative care in specific ethnic minorities and to relate this to known populations in Essex. (see ONS 2004)

Haven House, Woodford Green provides for a small number of Essex children and had one child over the age of 15, resident in West Essex.

East Anglia Children's Hospices also provide for children and young people in the Colchester area and their current caseload includes two over the age of 15 years, one resident in West Essex and one in NE Essex. (see Appendix 1 Table App1.2)

7.3.3 Schools for Children with Special Needs

From 26 special schools in Essex, those which have children with the most severe and complex needs were identified with the help of staff with local knowledge. Attempts were made to gain information from Heads, school nurses and schools co-ordinators. Schools contacted included:

School	Town	PCT	Comments
Glenwood School 100 children aged 3 - 19	Benfleet	S Essex (not Southend)	Due to the complex health needs of pupils some children and young people will die before they reach school leaving age.
Harlow Fields 94 children aged 4 - 19	Harlow	W Essex	probably no children with PC needs or expected to die within a year
Oakview School 70 children aged 3 - 19	Loughton	W Essex	
Lexden Springs School	Colchester	NE Essex	Unable to gain response
Pioneer School	Basildon	SE Essex	
Columbus School	Chelmsford	Mid Essex	
South View	Witham	Mid Essex	7 children with palliative care needs, only two known to Little Havens.
The Edith Borthwick	Braintree	Mid Essex	2/3 of pupils between ages 3 and 11 have

School Age 3 – 19			autism
Shorefields School Age 3 - 19	Clacton	NE Essex	
Beacon Hill School (Post 16 provision). 20 children Age 16 - 19	Grays, Thurrock	SW Essex	
Lancaster 70 students Age 14 - 19	Westcliff-on-Sea	SE Essex	

Information on palliative care is difficult to obtain. An experienced Head teacher of one of eight schools in Essex providing for those with the most complex needs offered the following observations:

- This is a school of 101 pupils aged 3 – 19 years
- A very large catchment area
- Due to the complex health needs of pupils some children and young people will die before they reach school leaving age.
- This may not be from the group recognised as requiring palliative care.
- Those with a clear diagnosis indicating palliative care needs are likely to be known >30% of the children have epilepsy which may require emergency medication
- approximately 13% of the children are tube-fed
- approximately 30% have additional significant physical/sensory disability
- many children previously expected to die before school age (age 3) will now live into adulthood
- This Head expects that triple the amount of service for young adults will be required in 10 years time.
- Life for these children is very different but the quality may be no less
- Schools are very active in all transition planning – they may be the most stable partner amongst services
- As a school we are pleased with our partnership working with health; the roles of transition physiotherapy and occupational therapy provided in the child's last year at school and continued for the first 6 months into adult services is a real strength. (contact details for further information can be provided).

(with Thanks to the Judith Salter, Head of Glenwood)

7.3.4 Adult Palliative Care Services

Adult palliative care service take up by ages 19 – 40 is reported from information provided by adult hospices. Each of these has a catchment that approximates to PCT areas. Information was sought using a standard format but hospices presented data using different parameters and so are reported separately.

South West Essex
St Francis serves the Brentwood part of SW Essex, and has a small service level agreement with W Essex.

St Francis	SW Essex				Total
	19-24	25-29	30 - 34	35 - 39	19 - 39
2008/09				1	1
2009/10		1		1	2
2010 to date	2		1	1	4

Diagnoses include mainly cancer. For SW Essex and other parts of its catchment outside Essex, St Francis in this period had four non-carcinoma cases, Friedreich's Ataxia (G111), Cystic Fibrosis (E84) Heart Failure, Unspecified (I509) and Metabolic Lipid Disorders (E75).

Mid Essex
Farleigh Hospice provides in Mid Essex

Farleigh	Mid Essex				Total
	19-24	25-29	30 - 34	35 - 39	19 - 39
2009/10	1	1	4	2	8
2010 to date	2	1	3	4	10

All were carcinoma patients except one multiple sclerosis, two with motor neurone disease and one "non-malignant other". It is unlikely that these numbers reflect the need for palliative care for ACT categories 3 and 4.

NE Essex
St Helena Hospice provides in NE Essex

St Helena	NE Essex				Total
	19-24	25-29	30 - 34	35 - 39	19 - 39
2008/09 - 2009/10	2	4	5	8	19

Apart from those with cancer diagnoses St Helena provided in the two year period for patients with Cerebral Palsy, Myleodysplastic syndrome, Huntingdons disease, Renal Failure, End stage renal disease, and Motor Neurone Disease.

The catchment is North East Essex and the Colne Valley area of Mid Essex. St Helena covers the Tendring peninsula including Harwich, Clacton, Colchester, Halstead, and The Hedinghams to the border with Suffolk finishing at Bures on one side and Dedham on the other.

South Essex

Fairhaven's catchment is Southend, Castle Point and Rochford.

Fairhavens	SE Essex				Total
	19-24	25-29	30 - 34	35 - 39	19 - 39
2008/09		2	2	9	13
2009/10	1	2	3	10	16

In the two year period, two patients had unknown diagnoses, one Multiple Sclerosis and one Progressive Degenerative Neurological condition. The others were all carcinoma.

South West Essex

St Lukes Hospice has a catchment of SW Essex excluding Brentwood (all of Thurrock, Basildon, Billericay, Wickford).

St Lukes	NE Essex				Total
	19-24	25-29	30 - 34	35 - 39	19 - 39
2008/09 - 2009/10	1	3	5	16	25

Apart from cancer patients, St Lukes had one patient with Chest Infection/Epileptic/Learning Difficulties and one multiple sclerosis in the period.

St Clare Hospice has been unable to provide information so there is no information about hospice admissions for the residents of West Essex PCT.

Douglas House Hospice has traditionally offered palliative care to young adults aged 18 – 35 from any area in the country. The catchment now reaches into Essex and there are 8 young adults resident in Essex receiving care at Douglas House. No information was given on the age or diagnoses of these young adults.

7.3.5 Adult Social Care

As many services now collaborate on continuing care, information was sought from Local Authorities as well as NHS and independent services.

One manager for a learning disabilities team in south Essex, managing a team of 5 social workers and with 200 service users, and also overseeing transition for young people with learning disabilities (another 35 young service users), could identify only one with palliative care needs. Doubtless this person is also known to the NHS as the diagnosis includes ADHD, epilepsy, and a life limiting degenerative condition and he has just been placed in a long term hospital placement needed due to the requirement of constant medical supervision.

There is also a Transition Data Co-ordinator whose work is Essex-wide but he is not aware of any records of being kept of young people with palliative care needs.

It has not been possible to gain other information from Adult social care at Essex County Council.

7.3.6 District nurses

In a previous commission on a similar question, PHAST received a post hoc comment was that there should have been information from district nurses. Substantial efforts were made during this piece of work to obtain such information. However these nurses fulfil a responsive role to provide discrete symptom interventions and it has been found impossible in the current exercise, to obtain such information. A manager commented that even the general caseload for this age group was small and they did not know why that was. For children a small team would share care of those with life limiting or life threatening illness, but district nurses work as independent practitioners, perhaps called to manage a line or intubate for a feed, and there would be no central information resource logging that this is part of palliative care.

Three groups of community nurses returned information.

a) Report: District Nurses, Maldon, Dengie and Danbury

	Age Group				
Diagnosis	19-24	25-29	30 - 34	35 - 39	TOTAL
Cystic fibrosis	1				1
Ca Bowel		1			1
Total					2

b) One half of Chelmsford – no patients with palliative care needs.

c) NE Essex - no known young adults with palliative care needs at present

7.3.4 Transition

There is a potential for unmet need at the point of transition owing to differing expectations of children's and adult services. A concern of a number of respondents was provision for the 16 – 18 year age group. Although services for children in theory provide to age 19, patients referred between the ages of 16 and 19 with a life expectancy beyond 19 may not be accepted. They may also find difficulty in being accepted by adult services at that age.

During data collection, some respondents reflected on perceived unmet need:

Mid Essex District Nurse Management	We see very few people in this age group at the moment. Not sure why that is.
Little Havens	Had suggested providing social opportunities for older teens but the families have declined the offer because of the additional work involved in getting the young people to the hospice.
West Essex CCNT	Please find attached data for West Essex of the young people known to our team, I'm sure there are more out there.
Macmillan Community Children's Nurse Specialist South Essex	This service starts to transition children at age 16 having started conversation with families at age 14. No young person with cancer would be accepted after the age of 16 although those in treatment would be looked after whilst the process was completed.
Children's Oncology Nurse, Queens Hospital, Romford (Ingatestone and West Hornden part of Brentwood)	This service provides only for children aged 0 – 18 years with cancer who are generally treated until cured. The service is under review and it is likely that the cut off age will be set at 16 with an expectation that adult services will take over from then. However it is unclear as to whether adult services are party to these discussions. The 16 – 18 age period is a "black hole" when young people neither "fit" children's nor adult services. Generally this age group is nursed at home with help from either the CCNT or the District Nurses but there can be a gap where parents are left looking for a service for a dying child. Most young cancer patients do not have respite. Even though some enter a palliative period, it may be too late to introduce them to a hospice, and it may not have been possible earlier when treatment was still active and there was hope of cure. The term "Hospice" can incite refusal.

7.4 Discussion

The most complete information is from the CCNTs. These are busy hands-on teams caring for the most frail children and young people. A "snapshot" was taken as experience of asking such staff to review caseloads over time produces very little response.

CCNTs identified 54 patients on their caseloads at 31/12/2010.

Little Havens Children's Hospice noted 19 young people on the caseload at the same date. These numbers also had to be trawled from files as there was no electronic record system in place. It appears that of the 19 only seven were also identified by CCNTs.

Little Havens identified an additional 12 young people aged 15 – 19 with palliative care needs.

However although Little Havens has Essex as its catchment area, the majority of its children are resident in the south of the county, and there is an under-representation of children from ethnic minorities. Despite SW Essex having the largest and more steeply growing population among the PCTs in Essex, the CCNT and Little Havens each only identified four SW Essex patients in the 15 – 19 age group.

Haven House takes children from West Essex PCT area but had only one in the 15 – 19 age group.

East Anglia Children's Hospice provides for children and young people living in the Colchester area and had two over the age of 15 years currently on the caseload, one from West Essex and one from NE Essex. ,

Schools for children with special needs may be a good source of identification of unmet need. One head teacher in Witham reported a family very much in need of respite but who considered Little Havens to be too far distant. Another head spoke of one death a year at her school (age range 3 – 19 years), but rarely from the group who might have been expected not to survive. Also she identified eight children aged 9 - 10 years who might not previously have been expected to live to enter school at age 3.

Areas of Essex which are more distant from Little Havens access some services across the county borders, from West Essex into London and from NE Essex into Cambridge, or even as far as Oxford. Information from all these providers was requested.

Information on the numbers of children and young people accessing palliative care services is more complete than for adults. This may be because there is a less coordinated response, less service provided, or a different focus, less holistic maybe and more fragmented. The experience for children moving into adult care is that it is very difficult to get the support to which they were accustomed as children. However the good practice developed at Glendale School for cross over services in occupational therapy and physiotherapy spanning children's and adult services, is to be applauded.

Service led information is clearly incomplete. Information from adult social care and district nurses is minimal and a serious attempt to discover unmet need would need a much more rigorous and applied attempt than has been possible in this review.

There are many research projects underway at present in Essex, in PCTs, Transition networks, in Essex County Council and there are seven funded projects at Little Havens, most reporting by the end of March 2011. It is possible that further information can be made available on service provision and take-up.

8. Views of Young People

8.1 Introduction

This work is reproduced from an earlier PHAST study at Richard House Children's Hospice in Newham, NE London where the results were found to have good concordance with similar work undertaken at Douglas House and Martin House in Yorkshire. It is unlikely that very different results would be obtained were the exercise to be repeated among young people in Essex.

Young people using the services expressed their views on what they hoped for from transition. They helped formulate the interview schedule, carry out the interviews and produce the conclusions and recommendations. Topics included access to palliative services, social care, financial support, work, education and the range of social activities common among their able bodied peers.

A full report on the study is to be found at Appendix 2.

8.2 Methodology

At a youth club night at Richard House Hospice the project was discussed by two of the researchers and the Nurse Team Lead. During that evening, two of the young service users ("research assistants") at the club volunteered to assist with the study.

Fifty-four families were invited by local hospices and CCNTs to attend a drop-in transition day at Richard House. There was also an option to take part in a telephone interview.

The study was then widened and participants sought through local acute hospitals and post-16 schools for children with special needs.

The two research assistants piloted the questions with other service users and then interviewed young people on the drop in day. The researchers took notes and prompted where necessary.

Nine people were interviewed face to face and a further 8 parents and 4 young people were interviewed by telephone. English was a second language for at least half of the families, and this may have affected not only the depth of response of the interviews themselves but also the level of understanding and knowledge of transition.

8.3 Results

Twenty-one interviews were held of which 9 were face to face (five with young adults and four with parents or carers). Nine respondents were young people and 12 were parents and carers. The young people concerned were at different stages of transition, some having completed the process.

Recurring themes were information sharing, level of support, managing carers, education and social life, respite care, medical and therapy services changes, knowledge of rights and hopes for the future. There was sometimes a struggle to maintain the necessary level of support, and training of carers was mentioned frequently. Young people needed to know how to be assertive, to teach carers how they needed to be looked after, and how to be a good employer.

Comments on social life were intertwined with regret at no longer being able to access respite care at the hospice. Social activities were lost when the young people left school or college and without the hospice, apart from the monthly youth group which was greatly valued, there were very few opportunities to meet people outside their own homes.

Information was a major topic, how to know one‗s rights, how to ask if it was not clear what should be available. Advocacy was recommended. Parents regretted not understanding more about transition, the loss of day centre attendance, moving from the care of the children‗s nurse team, the loss of regular therapy sessions at school, holidays for children organised by a charitable organisation, and greater difficulty obtaining equipment.

Lifestyle was an important topic, with young people left at home with little stimulation. In particular young men did not like to be sitting at home all day – they knew it was not good and so did their parents. Others had not anticipated that leaving school also meant losing all the social activities. There was a sense of isolation.

When the structured questions were exhausted the young people were clear about what additional support they looked for. This was to be able to live as nearly like their able bodied peers as possible. They wanted independence, a place to live, a place to meet their friends, respite with their friends, and a break from their parents. They also wanted employment, a career, more education, the opportunity for independent living. They recognised they needed all the medical support and care for their maintenance but within that they wanted to be able to have fun together and with friends who did not need to use respite care.

There was a clear priority order: once the medical requirements and care were in place, education and employment were next main concerns then socialising and finally independence.

8.4 Discussion

The study produced its own recommendations, given in Appendix 2. It was crucial that transition as a concept and then a reality was introduced early on, at age 14. Information and advice was paramount. Those who were articulate expressed their need; the information (and advocacy) was even more necessary for those who could not. The young people looked for the opportunity to break away from their parents both in terms of personal care and personal space. They looked for a replication of children's hospice arrangements to the extent of a social as well as health orientated environment - respite time with their friends not just a hospital that can cope with them.

9. Comparative Review

9.1 Introduction

Contact was made with a number of hospices in the UK already providing for young adults from a lower age of 13 - 16 years to an upper age of 30 – 40 years. Full reports on the interviews can be found at Appendix 3.

9.2 Methodology

Eight hospices offering a service to young people over the age of 19 and one community service for children and young people with non-malignant life-threatening childhood conditions who were likely to die before they were forty were contacted for information on the service offered. Three of these were not contactable. Information was obtained from 6 services. A semi-structured questionnaire (available at the end of Appendix 3) was used to elicit comparative information on the model of service, catchment, what a comprehensive model of transition looks like and what changes they might have made, given the opportunity to do things differently. As each hospice was interviewed it became apparent that each has particular features which work well and are unique. It is these which are recorded here, as good principles of practice.

9.3 Results

DOUGLAS HOUSE OXFORD opened in 2004 for young adults aged 16 - 40 to experience a high level of care in a flexible environment built around their needs. In any one year, Helen & Douglas House provide professional care and support to around 250 children and young adults, as well as their families.
Principle: Young people living with conditions previously confined to childhood are a new population and needs are still being defined. Response to need has happened over time at Douglas House.

It no longer accepts applicants from anywhere (maximum distance is a 1½ hour journey by car) and its age range is 16 – 35. The age crossover with Helen House allows some flexibility in transition. Douglas House is nearing full capacity, but over time those outside the catchment area will be replaced by people from the locality.
Principle: Distance needs to be contained for home care teams to go out, and for sick young people to reach the hospice when ill or near end of life.

The hospice has 7 beds. These are now allocated as four bookable for respite, 2 as flexi beds and one for emergency/ end of life use. The flexi beds can be used for respite but on the understanding that if an emergency arises the occupant might be asked to vacate at short notice.
Principle: Flexibility allows greater economy and best use of capacity.

End of life care is offered at home in the locality and in conjunction with the regular care team.
Principle: Work in partnership with services giving ongoing care (another reason for limiting the travelling time).

Children's respite is for the family. Here respite is for the young adult, the "guest". Young people are encouraged to make their own respite arrangements, rather than being done by parents.
Principle: advocacy is very important to enable the young people to be able to accept and manage responsibility for themselves. This extends to young people managing their own needs and wishes for their respite allocation, and helping parents to allow young people to make their own decisions.

Respite is offered for 10 – 28 nights a year with an average of 17 nights. This is based on the needs of the young person – medical, home situation, education, care package. A young person with little going on in their life might be offered more respite.

Social arrangements include a visit to the pub with friends, visit to town, shopping, the Douglas House cinema, a mixing and music room, the chance to go to bed and get up when the guests want, a bottle of beer in the fridge.

The young people say Douglas House is where they can be themselves rather than be categorised by their disease or by being in a wheelchair.
Principle: Normalisation: doing what any other young person does

MARTIN HOUSE WETHERBY ("Family House" opened 1987 for ages 0 – 19) Whitby Lodge ("the Lodge". opened 2002 for young people, 13 - 35). Serves the whole of the old Yorkshire Region. See Taylor LK et al (2010)

Children beyond 13 and their families continue using the Family House when the child functions at a significantly younger than chronological age and this is considered more suitable. An upper age limit of 30 was considered but may have required further transition. By 35 years the place is no longer needed.
Principle: Need rather than age directs the suitable type of care

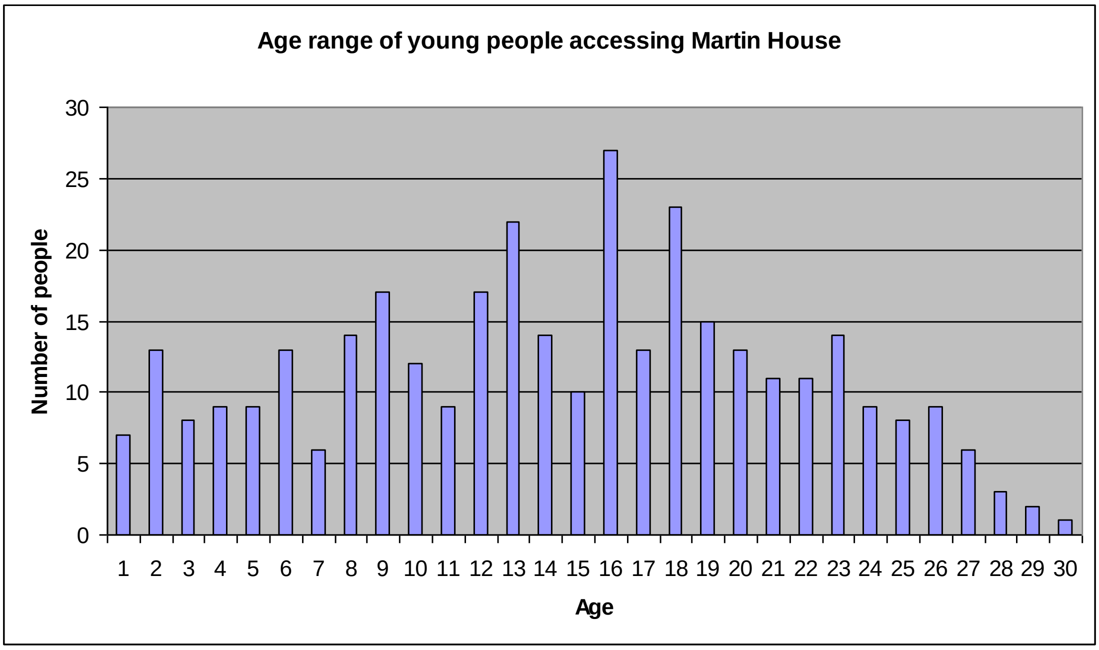
They can access the Lodge to age 35 but only if referred before age 19, except for example a young person with a very short life expectancy.

Martin House staff have observed that some young people who have very complex needs do mature when they move in with an older age group.
Principle: as with any other children and young people they need the opportunity to mature in conducive surroundings.

The Lodge has 5 beds to book out for respite and one kept for emergencies.

The majority of the young people using the Lodge at present are in their late teens to early 20s. Over time, the Lodge has had four people over the age of 30. The following chart shows the number of young people (over age 19) who would have no service if the registration ceased at 19 years)

Age distribution of children and young people using Martin House



Source: Martin House

The same medical team serves the Family House and the Lodge with a mix of general and palliative care trained, and adult and paediatric experience.

The basic unit offered is respite with a social focus (besides attendance for medical and care reasons)

Respite bookings are managed to try to bring people together who would get on. The more articulate young people are supportive of those with severe learning disabilities but there has to be a high ratio of more able people for this to work.
Principle: Social groups are formed and then supported to persist.

Activities in the Lodge include use of a den where most activity takes place – computer games etc. There is a hot spa in the family house, available but not often used by the young people. There might be a takeaway/ pizza night. Bedtimes are flexible matched by getting up late. This is a "normal" teenage pattern generally not available at home where carer's times take precedent.

There are 3 pubs in the village, one with good disabled access. Two of the young people can drive adapted vehicles so they go out for meals. There are shops close to the motorway with easy access to Leeds, Harrogate and York.

A feature of Martin House is the adapted vehicles (no logos permitted) to take young people out.
Principle: Whilst on respite most young people will go out on 1 - 2 trips.

Young people can have a friend to stay. Girl/boy friends are accepted if it is a couple in a stable relationship. With the advancing age range there had been a concern about the number of couples who might have sought respite, but it has not happened often. Sex is legal with proper consent, but some young people are quite emotionally labile so care is needed as issues are addressed, and having forums for discussion. There are no drugs which are illegal. Alcohol is permitted and again managed on an individual basis.
Principle: Flexibilty, with Choice, staffed to meet individual needs.

RAINBOWS HOSPICE LOUGHBOROUGH

Rainbows opened in 1994 for ages 0 – 19 and a unit for young people is currently under construction. This was in response to huge demand from predominantly young men up to the age of about 25years. Current registration allows for young people up to the age of 30.

The catchment area is East Midlands, including Leicestershire, Derbyshire, Lincolnshire, Rutland and Northamptonshire.

Rainbows unit for children has 8 beds. The new building will have 6 beds of which four will be for respite, symptom control, emergency and end of life care. The other two will give the opportunity to model independent living.
Principle: The opportunity to try independent living in a safe environment, for up to two months at a time.

The unit will provide for all medical conditions which are of a life limiting nature, according to ACT criteria (with the "surprise" question[6] applied with a 2 year period).

Draft policies available on transition, sexuality, alcohol, care of children alongside adults, philosophy of care of young people and a bullying policy have been drawn up.

The unit will seek to provide for the need to socialise. Once young people with palliative care needs leave school there is little opportunity to meet friends. To facilitate that they will provide a lot of day care, allowing the unit to be used as a centre where friends can meet up. The unit will provide a large room for socializing, cinema and a hydrotherapy pool is available at the children's hospice. For the World Cup, social evenings with beer will be provided. Part of the philosophy is letting go of parents, going out for a drink and generally following the lifestyle of their able-bodied peers.
***Principle: what Rainbows would have done differently was to have consulted the young people more, and talked more constantly with them throughout planning*.**

Rainbows takes the initiative in transition assessments at 14 years. Staff from the hospice liaise with education and social care services, with the aim of ensuring the children are prepared for the changes ahead.
Principle: Where no one else is doing what is necessary, Rainbows will take the key worker role in support of the emerging adult and family.

A lot of work is progressing on the Mental Capacity Act. A lot of young people are not able to act independently and parents often make decisions that may not be theirs to make for example on resuscitation. These young people are over the age of 18.
Principle: These really are independent adults.

ACORNS CHILDREN'S HOSPICE WALSALL

Acorns is a group of three children's hospices across the West Midlands, in Selly Oak, Walsall (serving mainly the Black Country), and at Worcester (for Herefordshire, Gloucestershire and Worcestershire). This note relates to Walsall.

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[6] A way of thinking about life limiting illness: "Would I be surprised if this patient died in the next year?" which was used by health care professionals in relation to patients on dialysis who were at high risk of early mortality. see http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2518805/

Principle: a network of hospices across a larger population, offering some economies of scale e.g. a shared medical director and psychosocial support and home visiting across all three, and shared outings.

Acorns has considered building a unit for young adults but currently does not have funds for that.

As there was no provision beyond that age, Acorns has been in discussions with the CQC and if they have nowhere else to go Acorns has registration to continue in-house care for the young people for short breaks, end of life care and symptom control until the 25th birthday. Separated accommodation has to be available.

Principle: Flexibility and a willingness to pursue ideals.

Referral must be made before the 18th birthday. Children can be referred by parents, or anyone but there has to be a signed letter from a consultant stating that the child is unlikely to reach the 18th birthday.

The physical layout must support keeping young adults and younger ones in separated accommodation so there is an adolescent sitting room, and one for younger children, a corridor for adolescent's bedrooms and a corridor for younger children. Dining is shared – eating as a family.

HOPE HOUSE OSWESTRY

Children and young people are accommodated in the age range 0 – 25. There are 130 children aged up to 19 and 14 aged 19 - 25. "The CQC was very clear that we cannot offer >25 years". The catchment is widespread with low population density

End of life care is offered at home in the locality and in conjunction with the regular care team.

Principle: Work in partnership with services giving ongoing care.

Have big outreach team 8.5 WTE staff. Five are nurses and 3.5 carers. The focus of the outreach service is – always terminal care in the home but they also respond to crises.

Principle: This is more of a rural model, a lot of community support because the distances are so great for people to travel.

They have launched a young adult outreach service. This includes a registered paediatric nurse purely to focus on the young adults, with an adult focus and a remit to work with local district nurses to increase their skills.

Principle: there are always more ways of improving services

Principle: Different models always worth considering. They thought about a second building for young adults, but instead launched a second children's Hospice to take the North Wales population, then provided for young adults in their own building from the spare capacity.

They saw the need of young men with DMD, and neurodegenerative young people who clearly were still deteriorating. They decided to get permission to keep young people up to 25 if they are expected to die before 25.
Principle: Where someone will live longer it is not considered in their interests to keep them with children's services. They are firmly pointed towards adult services.

JACKS PLACE WINCHESTER

Within the Trust's catchment area it is estimated that there are between 180-300 young people aged 13-24 with palliative care needs. Currently only 64 young people within this age range are known to them.

Respite care for life-limited young adults is extremely limited across the UK. Adult hospices provide an excellent service but their focus is largely on older patients with very different needs.

9.4 Discussion

Most of the young adult units discussed here have been developed, all on different models, in response to need or possibly in response by a charismatic individual or group (or funding body) and take part of their character or nature from their motivation.

Three of the hospices provided a separate building for young adults on the same site as the children's hospice. Some used a common medical team across the two, providing a mix of adult and children's specialisms, a plan favoured by service users for whom one aspect of transition was eliminated. This also allowed for flexibility in the age of transition, as mental ability did not always match chronological age.

Douglas House focuses on the independent adult moving away from the family, and provides a very different approach from the children's hospice, the separate building, a different ethos, part of a peer group with very different tastes and requirements.

It is clear from the review that take up is independent of the service offered. This was seen in Yorkshire where Martin House hospice estimated that one third of eligible people did not know about the hospice, one third knew but chose not to take up the service and only one third used the opportunities available.

Registration has been obtained in one place not where there is a separate unit, but where arrangements can be made within the same building for a different style of care. The CQC accepted the argument that there was no other provision available. This has also been seen at Little Havens where variation in registration has been obtained for a post-19 year old where risk assessment and staff provision are in place, but only for one client at a time.

What they all have in common is recognition that whether "hospice" is an inappropriate word, a centre for social gathering, with friends, is really important. This also contributes to respite, as fun and relaxation have a part to play in good health. The social group is very important to young people. It is also significant that all the hospices have pursued different styles of young adult units whether in the children's hospice or in a separate building, but not in adult hospices. The young adult model can be a continuum of the children's hospice, but other transitions would be necessary before the continuum reached the traditional older persons hospice.

The hospices for young adults around the UK had not identified catchment areas when first set up. But new catchment areas tend to have a radius of journey by car of approximately 1½ hours. The rationale for this was the time available for a home care team to visit for support or assessment, the ability to make and retain professional relationships with local carers of the young people, and the facility with which the young person could be brought to the hospice in the case of emergency for treatment or end of life care.

The following table summarises the "principles" elucidated from hospice services currently being provided for young adults in different parts of the UK.

Principles to be considered in providing for Young Adults Respite Care

Principle: Young people living with conditions previously confined to childhood are a new population and needs are still being defined. Response to need has happened over time at Douglas House. *Principle: Normalisation: doing what any other young person does* *Principle: what Rainbows would have done differently was to have consulted the young people more, and talked more constantly with them throughout planning.*	*A new approach is needed for the population of living adults with childhood contracted illnesses*
Principle: Distance needs to be contained for home care teams to go out, and for sick young people to reach the hospice when ill or near end of life.	*Recognised catchment areas*
Principle: Flexibility allows greater economy and best use of capacity.	*Bed usage*
Principle: Work in partnership with services giving ongoing	*O other teams are also*

care (another reason for limiting the travelling time).	*major providers*
Principle: advocacy is very important to enable the young people to be able to accept and manage responsibility for themselves. This extends to young people managing their own needs and wishes for their respite allocation, and helping parents to allow young people to make their own decisions. *Principle: as with any other children and young people they need the opportunity to mature in conducive surroundings.* *Principle: The opportunity to try independent living in a safe environment, for up to two months at a time.*	*Helping people to obtain and manage independence*
Principle: Social groups are formed and then supported to persist. *Principle: Whilst on respite most young people will go out on 1 - 2 trips.*	*Importance of social interaction*
Principle: Where no one else is doing what is necessary, Rainbows will take the key worker role in support of the emerging adult and family.	*Take the initiative in the key worker role until it is clear that someone else has it*
Principle: Where someone will live longer it is not considered in their interests to keep them with children's services. They are firmly pointed towards adult services.	*The key is individualised care*

Following the general principles outlined here, a blueprint begins to emerge of a hospice centre for friendships, stimulation, activities, symptom control and end of life care. There are other models. A consultant at the Royal Brompton Hospital was keen that all young people with cystic fibrosis should receive their respite care as inpatients at the Brompton. The individual needed high technical levels of skill available at the hospital and for families to have peace of mind whilst on their holiday; the young person should be in a clinical hospital environment. The outcomes, health or social care or both where possible, need to be considered.

10. Conclusion

The J's Hospice is seeking to provide services for young adults (aged between 18 and 40) with life limiting or life threatening illness in Essex. The term "palliative care" has different meanings in children's and in adult care; to children and their families it often means respite care, for the children the opportunity for some fun with peers, a place to socialize. It also means symptom control and end of life care, similar to adult hospice care. Adult hospices can be quite serene places for people who have lived their lives and now have the opportunity of a dignified end. Children's hospices are often noisy with much activity.

The literature review confirmed the growing life expectancies of a number of conditions from which in the past children have not survived to adulthood. These include young people with Duchenne Muscular Dystrophy or cystic fibrosis having a probability of living to 30 and 40 years respectively. The altered disease trajectory requires different care responses. More knowledge is being added and one paper identified that if a young person with cerebral palsy had survived to the age of 20 there is then an 85% chance of surviving to the age of 50, a likelihood which for the general population would be 96%.

The literature review also showed raised prevalences of severe disability in black and minority ethnic groups. Essex is a large county much of it rural but with small and large towns. Its black and minority ethnic groups make up more than 10% of the population. This does not seem to be reflected in current children's service uptake.

Population projections for Essex show a flattening of population rise from 2011 to 2020 except in the 25 – 29 age group which rises earlier than the other groups. A review by Gomes and Higginson found that annual numbers of deaths fell by 8% from 1974 to 2003, but were expected to rise by 17% from 2012 to 2030. They also predicted a fall in the number of deaths at home if current trends continue. Given increasing survival of younger people with conditions likely to require palliative care, and predicted increased demand for palliative care for older adults, there is potential for an increased burden on palliative care services to young adults.

The level of need is based on the DH paper Palliative Care Statistics for Children and Young adults (2007). A similar method was applied to deaths of young adults in Essex over an 8 year period, first from all causes then from causes likely to have required palliative care. Place of death was also reviewed.

Of all deaths in the 15 – 39 age group, approximately one-third of them would have been likely to require palliative care. In children, DH 2007 suggested that for each death there were 10 children needing palliative care. This proportion cannot be applied to young adults where numbers with cancer outweigh the severe degenerative neurological conditions and the different disease trajectory requires a different type and quantity of palliative care response. However this is an indication that up to 10 patients will need palliative care in young adulthood for each death which could have required palliative care occurs.

The annual average of deaths likely to have required palliative care in people aged 15 – 39 in Essex was in a range of 17 – 22 in each PCT and about 100 in Essex.

A number of routes were pursued to try to identify observed need. However the numbers were very patchy. Children's Community Nurse Teams showed a point prevalence of 54 children aged 15 – 19. Little Havens children's hospice identified 12 more. One school for children with special needs was able to identify 5 pupils with palliative care needs. In the year 2009/10 adult hospices had an approximate total of 56 Essex patients aged 19 – 39 years and the young adult hospice, Douglas House, had 8 "guests" from Essex.

The numbers seen at Little Havens suggests unmet need. Little Havens provides all children's hospice care for Essex apart from a small service provided by EACH, and equally small by Haven House at Woodford Green. Over the age of 15, Little Havens identified 19 young people and of the caseload of 130 aged 0 - 19, there were only two from black and minority ethnic groups.

Adult social care and district nurses were able to supply very little information.

Comments from people supplying information were illuminating indicating that their belief was that there were more than had been counted. There is a quite serious gap between 16 and 19 years when both children's and adult services are unwilling to take a new referral.

The views of young people showed a desire for a quite distinct model of palliative care, again emphasising the difference from adult palliative care. Once the medical requirements and care were in place, introduction to education and employment were next main concerns then socialising and finally independence. Support for these much broader elements were sought from the palliative care services.

Much can be learned from the Comparative review – other services already in place for young adults with palliative care needs elsewhere in the UK. Most of these services have been developed in a pioneering setting, often in response (as in Essex) to a growing demand for palliative care for young adults whose time of life, expectations but more importantly whose diagnoses and conditions cannot be appropriately provided for by more traditional models of care developed for older adults at the end of life.

The group addressed in the needs assessment are a unique care group whose needs are not entirely matched by adult palliative care hospice provision. Young adults newly diagnosed with cancer requiring palliative care intervention may find appropriate provision when special arrangements are made by adult hospices and some of these have been successful in Essex. However many with severe degenerative neurological conditions which form a majority in children's palliative care and the survivors with more widely recognized life limiting illness would be better provided for by a service which recognises their unique needs and limited life expectancy. It is hoped that appropriate response can be made for these young people in Essex.

11. Recommendations

1. Given the "black hole" in provision for the 16 – 18 year age group, and the need for variable age transition owing to different mental development and physical need, The J's should consider an eligible age group of 16 – 40.
2. Most sections of this report discuss the type of the care needed by young adults in Essex who have palliative care needs. This should inform decision making on the service model developed.
3. The demography of Essex suggests a model of care that incorporates both a central resource for respite care, intensive symptom control and end of life care where home care is not possible, and also distributed home care or satellite centres in larger urban areas.
4. Having reviewed distance travelled and differential take up of services locally, the hospice should consider how to make their service more accessible to those at a distance.
5. A period of slowing in the number of deaths in older age groups is expected to be reversed from about 2012. A period of population growth in the 20 – 39 year age group is expected to increase from about 2025. It is recommended that service planning takes these demographic changes into account.
6. The higher prevalences of severe disability expected in some black and minority ethnic groups should be factored in when improved data is available following publication of the results of the 2011 census.
7. The J's should work with commissioners in the NHS, PCTs and GP consortia, and Adult Social Care and those constructing end of like registers (Southend and NHS Mid Essex), and the numerous projects underway defining processes for transition in statutory and voluntary children's services as well as acute units to advertise and promote care for young adults.
8. Service planning should consider the 100 deaths per annum that might have required palliative care in young adults in Essex, as a maximum number, and the amount of service that will be required prior to death.
9. Place of deaths data should be further investigated to review the higher proportion of people in Essex who died in a place categorised as "other".

10. Most people say they wish to die at home. Trend data for changes over time in home deaths in Essex should be reviewed and produced, and this information should be further investigated.
11. The J's are recommended to consider accommodation for short term independent living experience following comments in Section 8, views of young people, and plans for two self-contained mini flats at Rainbows in Loughborough.

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13. Main Contributors

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Essex County Council Adult Social Care
Thurrock District Council Adult Social Care
Southend District Council Adult Social Care

14. Appendices

Appendix 1 Activity reported by current services in Essex

Table App1.1 Activity by CCNTs As at 31/12/10[7]

	MidEssex by year of age					**SE Essex by year of age**					**SW Essex by year of age**					**NE Essex by year of age**					**W Essex by year of age**					**Essex**
Diagnosis Description and ACT category (where available)	**15**	**16**	**17**	**18**	**Total 15 - 18**	**15**	**16**	**17**	**18**	**Total 15 - 18**	**15**	**16**	**17**	**18**	**Total 15 - 18**	**15**	**16**	**17**	**18**	**Total 15 - 18**	**15**	**16**	**17**	**18**	**Total 15 - 18**	**Total 15 - 18**
Hydrocephalus, epilepsy, scoliosis, learning difficulties	1				**1**																					**1**
epilepsy	1	1		1	**3**																1				**1**	**4**
chronic lung disease	1				**1**																					**1**
Cerebral Palsy 4	1		2		**3**											1	2			**3**	6	1			**7**	**13**
Cystic Fibrosis (CF)	2				**2**											1				**1**	4				**4**	**7**
gastro oesophageal reflux, epilepsy, cerebral palsy				1	**1**																					**1**
protius syndrome, epilepsy			1		**1**																					**1**
Acute Lymphoblastic Leukaemia L 1	1				**1**											1				**1**						**2**
Tuberosclerosis									1	**1**																**1**
DMD 2						2				**2**	1				**1**	2				**2**			1	1	**2**	**7**
Complex congenital heart condition						1				**1**																**1**
Dandy-Walker Malformation Syndrome						***1***				**1**																**1**
Galactosaemia, epilepsy, CVA						***1***				**1**																**1**
Lafora body disease						1				**1**																**1**
Spinocerebellar degeneration; Proximal renal tubular acidosis; Epilepsy; Hypophosphatemic rickets;													1		**1**											**1**
Variant Battens Disease											***1***				**1**											**1**
Cystic encephalomalacia, hydrocephalus and seizures											***1***				**1**											**1**
Demylinating Polyneuropathy 3																1				**1**						**1**
Acute Renal failure 1																	2			**2**						**2**
Congenital myopathy 2																	1			**1**						**1**
Osteosarcoma 1																		1		**1**						**1**
Brain tumour resected 1																			1	**1**						**1**
oncology																					2		1		**3**	**3**
Grand Total	7	1	3	2	**13**	6	0	0	1	**7**	3	0	1	0	**4**	6	5	1	1	**13**	13	1	2	1	**17**	**54**

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[7] Numbers in bold and italic represent young people aged over 14½ years but not 15

Table App1.2 Activity at Children's Hospices As at 31/12/10

Little Havens	Mid Essex by year of age					SE Essex by year of age					SW Essex by year of age					NE Essex by year of age					W Essex by year of age				
Diagnosis Description	15	16	17	18	**total 15 - 18**	15	16	17	18	**total 15 - 18**	15	16	17	18	**Total 15 - 18**	15	16	17	18	**total 15 - 18**	15	16	17	18	**total 15 - 18**
Complex Congenital Heart Disease					**0**	1				**1**					**0**					**0**					**0**
Duchennes Muscular Dystrophy					**0**	3				**3**					**0**	1				**1**					**0**
Sterge Webber Syndrome					**0**					**0**	1				**1**					**0**					**0**
Polymorphic Epilepsy	1				**1**					**0**					**0**					**0**					**0**
Lennox Gastaut Syndrome					**0**					**0**					**0**		1			**1**					**0**
Spinal Cerebeler Degeneration					**0**			1		**1**					**0**					**0**					**0**
Lafora Body Disease					**0**	1				**1**					**0**					**0**					**0**
Congenital Myopathy					**0**					**0**					**0**		1			**1**					**0**
Tuberous Sclerosis/ Lennox Gastaut Syndrome					**0**				1	**1**					**0**					**0**					**0**
Quadraplegia, Epilepsy					**0**					**0**	1				**1**					**0**					**0**
Cystic Fibrosis					**0**					**0**	1				**1**					**0**					**0**
Hydrocephalus					**0**					**0**		1			**1**					**0**					**0**
Scoliosis - Congenital Heart					**0**		1			**1**					**0**					**0**					**0**
Atrioventricular Sceptal Defect				1	**1**					**0**					**0**					**0**					**0**
Proteus Syndrome					**0**					**0**					**0**			1		**1**					**0**
Mixed Secreting Germ Cell Tumour					**0**					**0**					**0**					**0**				1	**1**
Grand Total	1	0	0	1	**2**	5	1	1	1	**8**	3	1	0	0	**4**	1	1	1	1	**4**	0	0	0	1	**1**
Haven House																									
Cerebral Palsy (ACT 4)																							1		**1**
EACH																									
Unknown																			1						**1**
Cerebral Palsy																					1				**1**

Table App1.3 Activity St Francis Hospice . 2008/09 and 2009/10

2008/09		Hospice total					**Hospice**		SW Essex					**SW Essex Total**
Diagnosis Description	18	19-24	25-29	30 - 34	35 - 39	40	**Total**	18	19-24	25-29	30 - 34	35 - 39	40	
Brain (Glioma, Astrocytoma) (C71)					1	1	**2**							
Breast Ca (C50)				2	1		**3**							
Cervix Uteri (C53)					1		**1**					1		**1**
Friedreich's Ataxia (G111)					1		**1**							
Hiv Pos. Asymptomatic (Z21)			1				**1**							
Liver Ca, Primary (Hepatocellular Ca) (C22)			1				**1**							
Lung And Bronchus Ca (C34)					1		**1**							
Nasopharynk Ca (C11)		1					**1**							
Sarcoma - Soft Tissue, Site Unspecified (C49)			1		1		**2**							
Sarcoma Of Bone Or Cartilage - Site Unspecified (C419)	1						**1**							
Grand Total	1	1	3	2	6	1	**14**	0	0	0	0	1	0	**1**
2009/10														
Brain (Glioma, Astrocytoma) (C71)					1		**1**							
Breast Ca (C50)					2		**2**					1		**1**
Colon Ca (C18)					2		**2**							
Hodgkin'S Disease - Histological Type Unspecified (C81)		1					**1**							
Leukaemia, Myeloid (C92)					1		**1**							
Liver Ca, Primary (Hepatocellular Ca) (C22)					1		**1**							
Lymphoma Tcell (Inc Sezary'S) (C84)			2				**2**							
Malignant Neoplasm - Primary Site Unknown (C80)			1		1		**2**			1				**1**
Malignant Neoplasm Of Bone/Cartilage Inc Knee (C40)				1			**1**							
Melanoma, Malignant, Of Skin (Unspecified) (C43)			1	1			**2**							
Nasopharynk Ca (C11)		1		1			**2**							
Non-Hodgkin'S Lymphoma - Diffuse (C83)		1					**1**							
Pancreas Ca (C25)					3		**3**							
Grand Total		3	4	3	11	0	**21**	0	0	1	0	1	0	**2**

Table App 1.3 (contd/) Activity St Francis Hospice . 2008/09 and 2009/10

2010/11 Apr_Dec		Hospice total					Hospice		SW Essex					SW Essex Total
Diagnosis Description	18	19-24	25-29	30 - 34	35 - 39	40	Total	18	19-24	25-29	30 - 34	35 - 39	40	
Brain (Glioma, Astrocytoma) (C71)				1			1							
Breast Ca (C50)				1	3		4				1			1
Cystic Fibrosis (E84)		1					1							
Heart Failure, Unspecified (I509)		1					1							
Leukaemia, Myeloid (C92)			1	1			2							
Lymphoma Tcell (Inc Sezary'S) (C84)			1				1							
Malignant Neoplasm - Primary Site Unknown (C80)						1	1							
Melanoma, Malignant, Of Skin (Unspecified) (C43)					2		2							
Metabolic Lipid Disorders (E75)					1		1					1		1
Mouth, Floor Of (C04)						1	1							
Nasopharynk Ca (C11)					1		1							
Pancreas Ca (C25)		1					1		1					1
Sarcoma Of Bone Or Cartilage - Site Unspecified (C419)						2	2							
Sarcoma Of Kydney (C49) (Pt Has Some Learning Disabilities)		1					1		1					1
Secondary Ca Of Bone And Marrow (C795)				1			1							
Stomach Ca (C16)				1			1							
Thyroid Ca (C73)		1					1							
Grand Total		6	2	5	7	3	23	0	2		1	1	0	4

Yellow highlights non-cancer diagnoses; Blue highlights Essex patients.

Table App 1.4 Activity Farleigh Hospice . 2009/10 and 2010 to January 2011

2009/10	Mid Essex					Mid Essex Total
Diagnosis Description	19-24	25-29	30 - 34	35 - 39	40	
Non Hodgkins lymphoma MS MND x2 Brain Breast Colon ovary	1	1	4	2	0	8
Grand Total						8

20010 to30 Jan 2011	Mid Essex					Mid Essex Total
Diagnosis Description	19-24	25-29	30 - 34	35 - 39	40	
Brain Thyroid Colon Hodgkins lymphoma x2 Breast x3 Ovary Colon Non malignant other	2	1	3	4	1	11
Grand Total						11

Table App 1.5 Activity St Helena Hospice . 2008/09 and 2009/2010 combined

2008/09 and 2009/10		NE Essex					NE Essex Total
Diagnosis Description	18	19-24	25-29	30 - 34	35 - 39	40	Total
		2	4	5	8	1	20
Glioma							
Melanoma							
Cerebral Palsy							
Myleodysplastic syndrome							
Huntingdons disease							
CA Testes							
Renal Failure							
Ca Rectum							
Ca Oesophagus							
Sarcoma of Bone/Cartilage x 2							
End stage renal disease							
Ca Breast x 3							
Acute Myeloid Leukaemia							
Motor Neurone Disease							
Carcinomatosis							
Non-Hodgkins 0Lymphoma							
Grand Total		2	4	5	8	1	20

Yellow highlights non-cancer diagnoses; but ages are not related to cases. They are between 18 and 40 years.

Table App 1.6 Activity Fairhavens Hospice . 2008/09 and 2009/2010 combined

2008/09 Diagnosis	19-24	25-29	30-34	35-39	Total	Known to other services
Not known		1F		1M	2	DN / UCH
Acute Lymphoblastic Leukaemia		1M			1	DN
Ca Gall Bladder			1F		1	
Ca Stomach			1F		1	DN
Ca bowel				1F 1M	2	
Melanoma - eye				1M	1	Moorfields
Ca Breast				2F	2	DN
Unknown Primary				1M	1	
Hodgkins Lymphoma				1M	1	DN
Skin Melanoma				1M	1	
Grand Total		**2**	**2**	**9**	**13**	

2009/ 10 Diagnosis	19-24	25-29	30-34	35-39	Total	Known to other services
Progressive Degenerative Neurological	1M				1	DN
Cancer – unspecified site		1M			1	
Ca Breast		1M		2F	3	DN
Ca ovary			1F		1	DN
Multiple Sclerosis			1F		1	
Oligodenroglioma			1M		1	DN
Ca Liver				1F	1	DN
Unknown primary				2M 1F	3	DN
Ca Pancreas				1M 1F	2	
Abdominal sarcoma				1F	1	DN
Renal cancer				1M	1	
Grand Total	**1**	**2**	**3**	**10**	**16**	

Table App 1.7 Activity St Lukes Hospice . 2008/09 and 2009/2010 combined

AGE	NO.	DIAGNOSIS
19 - 24	1	Cancer (1)
25 - 29	3	Cancer (3)
30 - 34	5	Cancer (2) Lung/Liver (1) Ovary (1) Chest Infection/Epileptic/Learning Difficulties (1)
35 - 39	16	Cancer (7) Bowel (1) Breast (3) (Lung 1) Renal (1) Glioblastoma Frontal (1) Cervix (1) Multiple Sclerosis (1)
TOTAL	25	

Appendix 2 Service user views

WHAT YOUNG PEOPLE AND THEIR FAMILIES SAY ABOUT THEIR FUTURE NEEDS WHEN THEY REACH YOUNG ADULTHOOD

Objectives of the Study

There is a growing number of young people with life limiting conditions who, because of the advance in medicine, are living longer. The study looks at transition from childhood to adulthood of these young people and how this impacts on access to palliative services, social care, financial support, work, education and the range of social activities common among their able bodied peers.

Young people of age 15 upwards who have life limiting illness, and their families were the subjects of the study. Where possible, the young people were interviewed independently to discover their experiences, perceptions and aspirations. For some, family carers needed to be present or were the only people who could be interviewed.

Methodology

An initial meeting was held during a monthly youth club night at Richard House Hospice at which the project was discussed by two of the researchers and the Nurse Team Lead. During that evening, two of the young service users at the club volunteered to assist with the study. They subsequently assisted in defining the questions, piloting and interviewing. Some of the users interviewed were members of this group.

Forty families known to Richard House and fourteen families known to Haven House were invited via a Royal Mail letter to attend a drop-in day at Richard House to discuss their hopes for the future with respect to social and healthcare support services. At the same time, local leads of Children's Community Nurse Teams were contacted to see if they were able to forward letters of invitation to be interviewed. These teams felt that children they knew with life limiting illness would also be known through the hospices and thought they could not contribute further names. None of the families from Haven House was able to attend but 6 agreed to be telephoned. The written number of confirmed replies from Richard House was lower than hoped so the 40 Richard House families were subsequently telephoned to confirm their attendance or gain agreement to be interviewed by telephone.

The study was then widened and participants invited via the Paediatric Palliative Care Team at Great Ormond Street Hospital (GOSH), the neuromuscular service at Barts and the London NHS Trust, and through the ***JFK Post 16 Centre in Newham.*** As a result of this, two further young people were interviewed, one by telephone and one face to face.

The two service users piloted the questions with other service users and then asked the questions to the young people on the drop in day itself assisted by the researchers who took notes and asked any supplementary questions for clarification.

Due to road works and a bereavement, only four families attended the drop-in day. Two were families where the young person and parents came together, one mother came alone and one non-verbal young person came with her younger brother and carer. In addition the two service users who were helping with the project attended

Including the pilot meeting and a home visit, 9 people were interviewed face to face and a further 8 parents and 4 young people were interviewed by telephone. English was a second language for at least half of the families, and this may have affected not only the depth of response of the interviews themselves but also the level of understanding and knowledge of transition. Ethnicities include Asian, African, Turkish, White British and Greek Cypriot.

Interview process

The interviews at Richards House were conducted by one of two pairs, both consisting of a young service user and an experienced researcher. Subsequent interviews were conducted by the researchers, primarily by telephone. Face to face interviews lasted about half an hour and telephone interviews lasted between 10 and 20 minutes. Some interviewees were more willing and able to talk about their experiences and ideas while others were keen to conclude the conversation. The interviews were divided into three sections:

(1) The "Introduction" section comprised discussion of what the interview would involve, explaining confidentiality, obtaining informed consent to participation and gathering background demographic information about the young person

(2) In the "Semi-Structured" section of the interview, the interviewer asked a series of open-ended questions that explored the family's overall understanding and experience of health and social care support including what had been useful and what they would like to be different about the care they might receive in the future. In some cases the young adult had completed transition and could therefore describe the changes retrospectively. In others the young person had not yet reached 19. Participants were also asked about their understanding of direct payments, personalisation and where they might go to find out about their rights or seek further information.

(3) In the third section of the interview, families were asked if they had any other comments or questions. For many of the parents, the interview itself brought to their attention information about transition. Some used this part of the interview to seek information about entitlement and who else might be able to support their attempts to get better services.

Interview Analysis

The following is a breakdown of the 21 interviews held.

- 9 of the 21 interviews were face to face, of these:
  - 5 were with young adults
  - 4 were with parents or carers
- 9 of the 21 interviews were with young people of these:
  - 6 took place with young people over the age of 19 who had already completed transition,
  - 1 took place with a 17 year old actively aware of and going through transition.
  - 2 took place with 15 and 16 years olds who were not yet aware of transition
- 12 interviews took place with parents and carers. Of these,
  - 10 were with parents and carers of those who had not yet completed transition
  - 2 were with parents and carers of young people who had already gone through transition

Data Analysis

From the notes taken during the interviews, themes were identified and shown below under four headings.

- Themes from young people who have not yet gone through transition
- Themes from young adults who have already gone through transition
- Themes from parent or carers of young adults who have gone through transition
- Themes from parent or carers of young people who have not yet gone through transition

Results

Themes from young people who have not yet completed transition

Of the three young people interviewed who had not yet completed transition, one was 15, one 16, and one 17 years of age. The 15 and 17 year olds use Richard House, but the 16 year old was not aware of and had never used residential respite services. Both the 15 and 16 years olds were completely unaware of the implications of transition.

The 17 year old was very articulate and aware of the impending transfer to adult servcies. Both he and his mother were very concerned about the implications. In the interests of anonymity, his ideas for the future have been included below alongside the ideas of those who have already completed transition.

Themes from young adults who have completed transition

Information sharing

Six had completed (plus the 17 year old referred to in the previous paragraph). They said they were informed by their social worker that their care services were going to change and, in particular, that they would lose facilities at Richard House. One was told by her doctor that medical services would change, including new locations.. Two young adults commented that they felt they were now being treated as adults by social services. However, another young adult reported that confidential information was disclosed to her parents without her consent

Level of support

One young adult told of attempts to cut his carer services at night and that intrusive reports, as well as the involvements of his MP, were needed to maintain services despite the fact that his condition is getting worse.

Managing carers

Most young adults are now getting direct payments and selecting their own carers. In at least one case, the interviewee reported being told there was no alternative to direct payments. Two commented that more training should be given to them as employers so they know how to make their needs known and manage carers who underperform, such as turning late or leaving early. Another young lady with very good insights but who needed help to be understood felt her carer did not take time to find out what she wants, an experience that left her feeling frustrated and disempowered.

All commented how long it takes to train a carer to be competent at looking after them. This may be shortened if the carers have other relevant experience, but frequently people suggested two to three weeks of training and close supervision were needed before they had confidence that the carer could be trusted to perform key tasks without support.

Education and social life

All of those interviewed were at college or school but had limited access to social life. Their level of carer support provided meant that the focus was on personal care. There appeared to be a difference in information given by local authorities and even between social workers within the same local authority as to how many carers could be employed using direct payments and what they could be asked to do.

Respite care

The inability to continue to have respite at Richard House after the age of 18 was a huge loss or impending threat to all interviewed who had used this hospice. One young man, who previously used Richard House 7 or 8 times per year, is now using Douglas House. Though he find the new service acceptable in terms of standards, because of the distance and other factors he can only go once per year. One young woman has been to Jubilee Lodge, which she feels gives her parents a break but 'there are mainly old people there". A significant attraction at Richard House was being able to socialise with young people. Another young man said he had experienced respite care that felt 'more like a hospital", including a requirement to be in by 5pm."

Medical and therapy services changes

Services that had previously been coordinated at one hospital, i.e. GOSH, were sometimes spread over 2 to 4 hospitals that do necessarily not work together. Therapy services, such as physiotherapy previously provided via school or hospital at least twice per week, were no longer readily available. Even when needs were greater because of deteriorating health, interventions and had to be requested repeatedly rather than being provided on an ongoing basis.

Knowledge of rights

Only one person from North East London appeared to have a comprehensive picture of their rights or the organisations that might help them; others relied solely on their social worker. One person got help from the Shaw Trust.

One young man who lived in Westminster had an independent advocate whom he believed had been instrumental in helping him understand what was available.

One young lady with clear understanding but who needed assistance in being understood said that she needed one-to-one, face-to-face explanations of her rights.

As mentioned earlier, one person was quite aware that her confidentiality had been breached by her social worker making disclosures without her consent.

Hopes for the future

Questions about hopes were asked towards the end of the interview if these were still unclear.

Young female users said they would like

- 'Independent living and certainly more privacy'.
- 'Respite where I can meet my friends and not be dependent on my parents.'
- 'A private space where I can have friends round not just those who access the respite
- 'My own house'
- 'An opportunity to be with friends and do stuff together – some just for girls e.g. pampering nights and some mixed'
- 'A structured environment where I can have respite'

The young male users said they would like

- 'Discussion forums'
- 'Work place opportunities and careers advise'
- 'Workshops on independent living'
- 'Workshops on independent living including cooking, laundering and driving'
- 'Tutors and resources to help me learn including Magazines and books'
- 'Chill out zones'
- 'Opportunities to go shopping to restaurants and to cinemas'
- 'Medical facilities'
- 'Family rooms '

Themes from parents of users who have completed transition

These come from two families caring for a young person who lacked speech.

Information sharing

Both sets of parents first heard about transition when the young person was about 15 or 16. One could not recall where from, the other said they heard about it from their child's school, which held an open day on transition. They felt the open day had not really answered any questions.

Both families listed the services that had stopped or been reduced since reaching 19

Family one

- Attendance at day centre stopped
- Children's nurse visiting stopped
- Charity funded holidays stopped
- For a while palliative care nurses came and sorted out a range of issues but this has been stopped

F*amily two*

- Previously the young person had regular speech and physiotherapy via the school, this has been stopped
- The Paediatrician continued to support family for a while but made it clear that this was a favour
- Nasal feeding was handed over from children's nurses to district nurses who said they could not do it
- Requests for help from social services were reported as nearly always dealt with by the duty social worker
- Occupational Therapy services have become very difficult to access For example, getting a suitable chair for the shower

Managing carers

Both families are using direct payments, with one family finding the paperwork confusing. Both families say that training carers is difficult. One parent said that she does not believe what people say about their past experience, using as an example someone who came claiming to be experienced but did not know how to manage a wheelchair.

Education and social life

In one case school was followed by day centre attendance but this has now stopped. It was not clear in the other case what was happening in terms of social stimulation, as the responses to questions were all about medical issues.

Respite care

Both families have used Richard House in the past and have not found a replacement

Medical and therapy service changes

In one family, regular physiotherapy stopped at 16. They now only get sporadic help.

In the other family children's and adult physiotherapy services argued over who would provide support and in the end neither did

Knowledge of rights

A key source of information were special schools and both parents noted how they felt adrift after their child left school. In one case the day centre staff provided some advice but as this had now stopped. The only source of advice for both families appeared to be the social worker.

Hopes for the future

In terms of hopes for the future one family wanted suitable support at home while the other family hoped for a respite care centre that could offer the comforts of home, including a suitable bed, a garden and some stimulating activities. A hydrotherapy pool would also be welcome.

Themes from parents of users yet to complete transition

This group includes parents of ten users. In some cases, the immediate health needs of their children were such that other factors were given a much lower priority. Only where health was relatively stable were families willing and able to discuss issues of education, life skills and future social needs (see complex disability hierarchy of needs diagram on page X)).

Information sharing

Of the 10 families 4 had already heard about transition while 2 had not. Another 3 families had heard the term transition but said they did not understand what it meant.

One family had been informed about transition from a medical perspective only but complained that there was 'no road map of what would happen next'

Level of support

Nearly all families felt they had to fight for the support they had and that the current level was inadequate for their needs as carers. Some expressed worries about the future, when the level caring would be even greater. One family had their Disability allowance stopped without warning and only after much help from the hospital was it reinstated. As another family had only just discovered their eligibility for respite provided by children's services, detailed iscussion of requirements post 19 would not have been appropriate. As it was, they were were dismayed to hear for the first time that the respite they had just accessed would not be available post 19.

Managing carers

One family has some help from community nurses but the wife does most of the caring.

Six families have home carers but all say that it takes at least two weeks to train a carer, some of whom will not lift and do little more than feed.

At least two families have the understanding that they are only allowed one carer via direct payments. It is possible that the system is administered differently by different local authorities.

Education and social life

In at least one family health issues prevailed so highly that it was not appropriate to broach issues regarding lifelong learning or social needs.

One family was aware that there would need to be a transfer from school to college but have not looked into it. They assume they will 'be told what will happen'. Their daughter currently took part in after school clubs 3 times a week but they had not considered the impact of her leaving school on her need for socialising.

One mother of a 17 year old had complained that there was nothing available for teenagers like hers. The disability social worker was now trying to access suitable activities for the young person.

One family said transport to college was good but there was no transport help with social activities, which made the young person feel very isolated

Knowledge of rights

One family had been put in touch with SPINN (Supporting Parents Inclusion Network in Newham). SPINN put the family in touch with the Rainbow Trust, who had helped with transport. However it should be noted that this service is only available until the age of 18.

Most families described getting their information from school, college or social workers rather than from more independent organisations like carers services. This has led to only some information being easily available.

Respite care

Three families did not appear to be aware that Richard House service stops at 19. Another family had chosen not to use respite at Richard House because when the initial visit took place the young person associated the Rainbow Room with dying. At least 2 families were not aware of and therefore did not access the youth group.

Medical and therapy services

At least 2 families found that some medical services such as physiotherapy transferred their children to adult services at the age 16

Hopes for the future

Most of the families were so embroiled in day to day challenges that they had not given any thought to future requirements for their children. Many were unaware of how services would change including the impact of no longer being at school or of becoming ineligible for Richard House / Haven House.

It was therefore inappropriate to ask some of the questions about future needs when current needs were not being met.

One family had been anticipating changing needs for some time and has been waiting 2 years for an OT to help them with assessment for financial support to make home adaptations for a downstairs bedroom. Time was now running out for the family, who needed the funding before the planning permission they had paid for had expired

Hierarchy of needs in findings

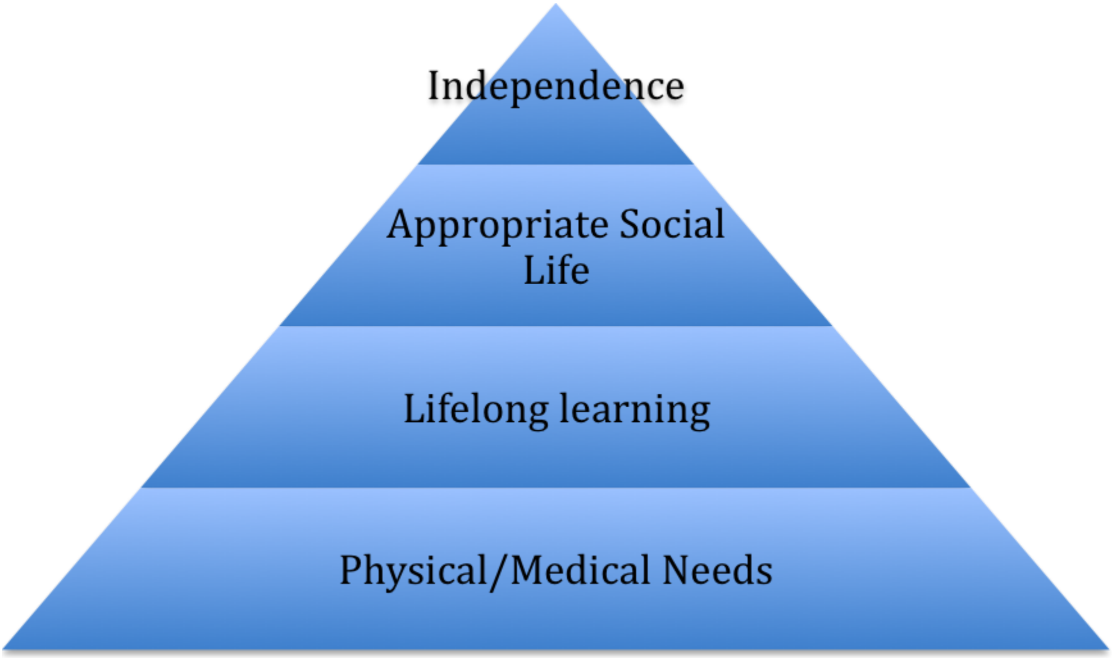
Stevens and Dunsmore (1996) describe 3 phases of transition - early adolescence, middle adolescence and late adolescence. Age 19 falls within late adolescence and by this time young adults will be looking to define themselves in terms of their career relationships and lifestyle

However the research found that where these characteristics were thwarted by circumstances a hierarchy of needs developed, that was similar to the hierarchy of needs as described by A.H. Maslow, *A Theory of Human*

Motivation, Psychological Review 50(4) (1943):370-96.. *(you have used a different way of referring here)*

Complex Disabilities Needs Hierarchy

based on Maslow's hierarchy of needs



The lowest level describes physical or medical needs and only if these are being met would education become the pressing priority. For example, where there were current issues such as chemotherapy, on going feeding problems, or impending operations little or no attention is given to other needs such as the social or educational elements of respite. Similarly, if parents are struggling to get adequate support for current physical needs from the authorities, far less attention is given to what will foster psycho-social development.

The next level, Lifelong Learning, was evident when physical safety was under less immediate threat. At this point, parents and young adults started to express their hopes in terms of educational and independent life skills development. Where these needs were still unresolved or had not yet been considered then the focus of answers was on this topic. Only where this topic was for the time being resolved would conversations move to the next level

The third level, Appropriate Social Life, comes into play when education and/or lifelong learning needs are already met. It was at this stage that the young adults raised issues of social independence.

The fourth level, Independence and Adulthood, can be particularly difficult for parents who long after infancy need to provide a high level of care, or who are aware of disability discrimination, or how difficult it can be to get adequate services. Some parents may even feel that to encourage autonomy is an abandonment of their responsibility. This topic was only broached by two young users, both female. It is hard to imagine more parental focus on user responsibility for self as an adult while the lower levels of need are either not met or demand much effort to see that they are met.

Recommendations Based On User Feedback

Access to information

1.That all professional who come into contact with young people and their parents ensure that families are aware by the time their child is 14 of the impending changes to services when the young person reaches transition and their need to be proactive in finding alternative services. This should involve both face-to-face meetings and printed information.

2.That consideration is given to the needs of young adults and their carers to have suitable access to independent information and advice about their entitlements, for example via advocacy.

3 That this information should also be provided in a format that can be understood by those for whom English is second language.

4. That organisations be invited to venues such as Richard House and Haven House to talk to young people and carers about their rights. For example to run stalls when they have fun day or open days
5. That leaflets with lists of relevant voluntary organisations, such as carers associations and disability rights organisations,

Organisation of respite care

6 That when setting up young adult respite services consideration is given to the development of maturity in young adults and their need to 'break away' from their parents both in terms of personal care and personal space. In particular that they would like :

Facilities that provide a social as well as health orientated environment- They want respite time with their friends not just a hospital that can cope with them

To have a place to meet friends and other young people in private including those friends who are not in need of respite themselves

A fuller list of desired features as described by the young adults can be found in the 'Themes from young adults who have completed transition' section of the report

Organisation of other opportunities for these young people to experience social situations independently of their parents

7. That the initiatives currently underway at Richard House to run a youth club be expanded to meet more frequently and to create a second cohort for those approaching but not yet 18.
8. That the initiatives currently underway for young adults to go on holiday breaks together be expanded

Planning for independent living

9 That consideration is given to some independent living spaces for young adults to see if and how they could cope with independent living before any longer term decisions were made.

Appendix 1- Questions for Young People

Introduction and background questions

How old are you and which borough are you from

Transition

Have you ever heard of the term transition?

How did you hear about it ?

Are you in transition at the moment?

How are you finding it /how did you find it?

Current and previous services

If you are in or past transition:

What help do you get now

How does this compare with what you had before?

What do you think you will need in the future?

If you could have a 'beyond 19' respite unit what would you like it to include?

If you have not yet gone through transition:

What services do you currently get?

How are they working?

What do you think you will need in the future?

Knowledge of direct payments, personalisation and other entitlements

Do you know about direct payments?

Have you heard of personalisation?

Do you feel you know what you are entitled to?

How do you find out / keep up to date?

Carers

Do you have your own carers?

How do you let them know what you want them to do?

Any other comments?

Appendix 2 - Questions for Parents

Introduction and background questions

How old is your child and which borough are you from

Questions about transition

Have you ever heard of the term transition?

How did you hear about it?

Is your child in transition at the moment?

How are you finding it /how did you find it?

Current and previous services

If your child is in or past transition:

What help do you get now

How does this compare with what you had before?

What do you think you will need in the future?

If you could have a 'beyond 19' respite unit what would you like it to include?

If your child has not yet gone through transition:

What services do you currently get?

How are they working?

What do you think you will need in the future?

Knowledge of direct payments, personalisation and other entitlements

Do you know about direct payments?

Have you heard of personalisation?

Do you feel you know what you are entitled to?

How do you find out / keep up to date?

Carers

Does your son/daughter have their own carers?

How do you and your son/daughter let them know what you want them to do?

Any other comments?