



# Policy Review Report

# Document Information

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## Target audience

Members of the Children and Young People's workstream of the National Cancer Survivorship Initiative including health professionals.

Commissioners, policy makers and service providers from across the health, education and social care sectors.

## Brief abstract

This policy review looks at what guidance, practice and policy exists around the provision of generalist services for survivors of cancer in England aged up to 25, considers what young people themselves say about their needs and examines how the supply of services and the needs of young cancer survivors can be matched more effectively.

## Glossary of terms

Please refer to the glossary of terms at Appendix 1 of the report.

## Who is CLIC Sargent?

CLIC Sargent provides nursing and social work care and support when a child is in hospital, in the community and at home. This ensures that a child's care can continue at home and the family remain supported through this intensely challenging experience. CLIC Sargent funds a range of frontline care professionals such as specialist nurses and social workers as well as play specialists and youth development workers. Financial grants, free accommodation close to hospitals and holiday breaks are also provided to families.

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# Foreword

From the Chair of the NCSI Children and Young People's Workstream, Professor Faith Gibson.

A world-class service at each stage of the cancer journey – regardless of where people live – was a point emphasised in The Cancer Reform Strategy (Department of Health [DH] 2007). We know however that inequalities exist, in relation to access to services and treatment, patient experience and outcomes (DH 2010). One of our aims in the national cancer survivorship initiative (NCSI) is to produce a model of care that provides equity in terms of, for example, access to follow-up care, access to psychological support, and support with returning to education and / or employment. Tests sites across England have a shared focus on describing the various elements of models of follow-up care that will inform agreed pathways of care that can be rigorously evaluated.<sup>1</sup> One element of the pathway will be to indicate the need for self-management that ensures young people receive the support, information and ongoing guidance that will allow them to improve both their health and general well-being. Signposting and access to information and resources will be key to any model of care. We recognised early on in the NCSI that what was less tangible as an easily accessible resource available to professionals was all the policy documents that promote good outcomes, particularly around education and employment, and social care. This policy review has filled that gap.

In the pages that follow, and summarised in Appendix 2, are the many policies that together present a policy map across three main strands of influence:

- \* Education, employment and training.
- \* Emotional and psychological well-being.
- \* Health and recreation.

Here in one report is a very useful resource that presents a point in time, that will be helpful to all tests sites as they build the information they will use in their models of care to ensure improved outcomes. Our intention is that this review will both inform and influence the ongoing care of young people with cancer. Therefore recommendation two will need to be actioned. A practical guide that will support self-management will be a further important outcome from this commissioned piece of work. A guide that includes comments from the young people it seeks to inform would be even better. We know that information and access to resources are key features in achieving a high quality and person-centred service. The evidence is here to inform such a resource.

Department of Health (2007) Cancer Reform Strategy. Department of Health, London.

Department of Health (2010) Equity and excellence: liberating the NHS. Department of Health, London.

<sup>1</sup> See <http://www.ncsi.org.uk/children-young-people/children-and-young-people-test-sites/> for further details

# 1. Executive summary

## 1.1 Introduction

This policy review has been carried out by CLIC Sargent and commissioned by the National Cancer Survivorship Initiative, a programme established by the Cancer Reform Strategy. The review aims to assess the resources that are currently offered to young survivors of cancer to ensure their outcomes are as good as their peers, and to see how that matches with what young people tell us they need. It focuses primarily on policy in England.

## 1.2 Methodology

The review was conducted by means of an extensive desktop literature search to identify pertinent current research and policy, advice and guidance, both cancer-specific and that relating to children, young people and adults. The relevant evidence was then examined in depth to highlight areas where it specifically related to young cancer survivors. In addition, findings from published consultations with young survivors of cancer and their families were considered to identify what they said they needed from the policy framework, and how they thought their needs were currently being met. Interviews were then held with professionals in the field to test this information against their first-hand experience. The findings and recommendations were then formed by bringing this information together.

## 1.3 Results

The review considers the National Institute for Clinical Excellence's *Improving Outcomes in Children and Young People with Cancer: The Manual*, the 'Every Child Matters' programme and the 'National Service Framework' as overarching policies which affect young survivors. It notes that these are inclusive policies that promote good outcomes for 0 to 19 year-olds, but recognises that there is a difference between

the good practice that the policy cites and the actual practice that is implemented.

CLIC Sargent's report, provides strong evidence of a need to take a more systemic approach and to look at all the needs of young people within the context of the families and communities that they live in. It suggests a range of methods, including most notably a key-worker led model of provision, to ensure these policies are implemented on the ground.

The education, employment and training policy framework is dominated by the 2002 Education Act, which introduced the 'whole child' concept, and the 2008 Education and Skills Act, which brought in the duty to participate in education, employment or training, and devolved information, advice and guidance services – which are critical in supporting young cancer survivors – to local levels.

The policy framework is also influenced by the 2009 White Paper, *Your Child, Your Schools, Your Future*, which aimed to narrow the achievement gap between advantaged pupils and those who are in danger of falling behind – a risk which many young cancer survivors face as their education is disrupted by treatment programmes. The detail behind this initiative remains unspecified.

*Quality, Choice And Aspiration: A Strategy For Young People's Information, Advice And Guidance* (2009) set out a range of measures to help young people succeed in education and to make informed career choices, including the provision of personal tutors in schools. Young cancer survivors say that this would be particularly valuable to them.

The Special Educational Needs and Disability Act of 2001, together with individual action plans and the School Action Plus programme, have an important role to play in the policy framework, as many young cancer survivors are classed as having learning disabilities or special educational needs as a consequence of their illness or the disruptive effect of treatment on their education. The schools inspection service, Ofsted, is currently

reviewing special needs provision and is due to make recommendations to Government about how the system can be made more effective.

Reducing The Number Of Young People Who Are Not In Education, Employment Or Training (NEET): The Strategy (2007) is another important facet of policy affecting young cancer survivors, who as we have seen perceive themselves as facing a greater risk of dropping out of education, employment or training.

One effective tool for supporting young cancer survivors is the Common Assessment Framework (CAF), a standardised approach to conducting assessments of children's additional needs and deciding how these should be met. Used appropriately, it should also enable better sharing of information between service providers, which is critical to improving outcomes. It is not clear that this is happening in practice.

The Trade Union Reform and Employment Rights Act 1993 and the Education Act 1997 set the framework for careers education, advice and guidance, which again is vital for young cancer survivors if they are to fully reach their potential beyond the age of 18. There is a shortage of data about the numbers of young cancer survivors accessing advice and guidance services such as Connexions.

This also applies to the wide range of benefits potentially available to young cancer survivors who qualify for them, from Disability Living Allowance to Working Tax Credits. We do not know how many young cancer survivors are claiming benefits or what the economic consequences may be, as the data is not collected. There is a strong case for ensuring that young cancer survivors know what benefits are available to them, and that they are aware of programmes such as the 'New Deal For Young People' (1998) which can help 18 to 24 year-old job-seekers to find work.

*Access to Education for Children and Young People with Medical Needs* (DCSF, 2001) is a particularly relevant piece of policy for young cancer survivors, as it requires education providers to ensure that young people's educational needs are met as far as their medical condition will

allow. It also stresses the need for communication between education and health professionals and the families. However, there are still gaps as hospital schools are not under a legal obligation to offer the national curriculum for example.

The above has major implications for the section of the review looking at emotional and psychological wellbeing. Personal, Social and Health Education (PSHE) is now recognised as an important part of mainstream education, helping adolescents cope with a key period in their development. Young cancer survivors often say that they miss out on key elements of school-based PSHE as a result of their treatment, and the fact that hospital schools are not obliged to offer PSHE is a cause for serious concern. Young cancer survivors overwhelmingly affirm the importance of receiving emotional support following cancer diagnosis and treatment and it appears to increase with age – 96% of young cancer survivors aged 20 to 24 classed psychological support as important in CLIC Sargent's report, *More Than My Illness: Delivering quality care for young people with cancer*.

The policy framework on emotional and psychological wellbeing is governed by the Mental Health Acts of 1983 and 2007. Again there is a major gap in the legislation as far as young cancer survivors are concerned; young people aged 18 to 24 with mental health needs will be referred to adult mental health services, but these services only address the needs of adults with diagnosed mental illnesses, and most young survivors of cancer will not meet this kind of diagnosis. Younger cancer survivors, up to the age of 18, are covered by policy and guidance for Child and Adolescent Mental Health Services (CAMHS). A great deal of work has gone into this area, for example, 'Improvement, Expansion and Reform' (Department of Health, 2002) called for a 'comprehensive CAMHS', which focused on early intervention to promote resilience and emotional wellbeing among children, rather than focusing on mental illness and treatment.

The 'National Service Framework for Children, Young People and Maternity Services' is another important part of the policy jigsaw governing emotional and psychological wellbeing. Standards

6 and 9 of the framework govern support for young people with long-term medical conditions and mental health services for young people respectively. Although these are highly relevant to young cancer survivors, neither specifically mentions the particular needs of this group. Similarly, CAMHS has been mapped nationally since 2002 to gauge its effectiveness. However, young cancer survivors are not specifically mapped as part of this process, so it is not possible to say how well their needs are being met. In addition, 'Targeted Mental Health in Schools' (TaMHS), a programme which trains school and community staff to deliver low level mental and emotional health support under supervision to young people, is being piloted in 55 centres, but none of them are currently looking at the needs of sick children or those who have survived chronic illness.

The final area the review examines is health and recreation. Research suggests that young cancer survivors have fewer health worries than their peers in general, and that 90% believe that overall they are in good health. Studies also suggest that they are less likely to abuse illicit drugs, smoke or engage in problem drinking. This is echoed by what young cancer survivors themselves say: 84% of respondents to the CLIC Sargent *More Than My Illness: Delivering Quality Care for Children and Young People* report said a healthy lifestyle was important to them.

The key piece of policy here is the 2004 White Paper, *Choosing Health, Making Healthy Choices Easier*, which reinforced the idea that health promotion is as important as disease prevention and treatment, and that a balance must be struck between individual rights, public concern and protection, particularly in the case of children. Again, no mention is made of those who have experienced long-term illness, and the various targets set out in the White Paper are also silent on the subject.

## 1.4 Recommendations

The review finds that there are significant gaps in the current policy framework for young cancer survivors aged 19 to 25, and evidence demonstrates that the needs of this cohort are different from those of older adults but equally from children. However, there appears to be no specific policy relating to community provision that addresses the need of this age group, and it should be noted that this gap relates to all young adults with chronic health needs. Policy and delivery gaps extend across most areas of need and particularly mental health, sexual health, and routes to education, employment and training. The first recommendation of this review is therefore that a scoping exercise should be undertaken, looking at more effective models that will ensure services are accessible to the 19 to 24 age group.

This review recognises that the best way to improve outcomes for young cancer survivors is not to single them out, particularly if they are trying to reintegrate back into mainstream life, although it is acknowledged that they could benefit from targeted support in some areas. The main finding of this review is that the key to enabling young cancer survivors to better access mainstream and generalist provision is information and empowerment. Therefore the second of the review's recommendations is for the NCSI to lead on the development of a guide for young cancer survivors and community-based professionals on the information and themes covered in the review. The guide should set out what local services ought to be doing to support young cancer survivors under the existing policy framework and would provide them with targeted information on what provisions Government policy has made to ensure they get back on course. As well as providing young cancer survivors with useful information on the services available to them and their rights and entitlements in relation to these services, the guide would raise awareness of the needs of young cancer survivors and aid generalist

and community-based practitioners, including teachers and other educationalists, to support young people as appropriate. It would also aid the provision of care closer to home as well including a move towards the type of model set out in CLIC Sargent's report *More Than My Illness*.

The guide should cover the full range of areas covered within this review, including:

- \* Employment programmes.
- \* Young people's advice services such as Connexions.
- \* Benefits.
- \* Requirements on schools.
- \* Individual Education Plans.
- \* Common Assessment Framework (CAF).
- \* Child and Adolescent Mental Health Services (CAMHS).
- \* Youth services and facilities.
- \* Personal, Social and Health Education.
- \* Details of relevant specialist voluntary sector information, training and services.

This guide could ultimately be assimilated into the Department of Health's 'Information Prescriptions' programme being developed for children and young people with cancer. As the policy context for public services is being transformed at present it would be sensible to wait until the policy landscape for public services is really clear to develop a guide thus avoiding producing something that might date.

This review argues that it is critical that young people themselves have more of a say in future work around survivorship, how community services respond to young people who have had time out, and also on wider cancer services development. The third and final recommendation is therefore that the Department of Health ensures that young people's views are systematically feeding into work using the many existing consultation avenues available both with charities and the NHS.

## 2. Background

The National Cancer Survivorship Initiative, launched by the Department of Health in September 2008, was established as part of the department's 'Cancer Reform Strategy' to look at a range of approaches to the care of cancer survivors. The 'Cancer Reform Strategy' builds on progress made since the NHS Cancer Plan was completed in 2000, the first such guidance for cancer in this country. The 'Cancer Reform Strategy' addresses a number of issues facing people living with and beyond cancer, particularly focusing on psychological wellbeing and financial support. This recognised for the first time that psycho/socio-economic issues matter to cancer survivors and therefore need to be addressed more comprehensively within UK policy.

In August 2005, the National Institute for Clinical Excellence (NICE) produced the guidance, *Improving Outcomes in Children and Young People with Cancer: The Manual*, as part of its *Improving Outcomes in Cancer* series. The guidelines make a number of key recommendations about the type of treatment and prevention services that should be commissioned through cancer networks, including services delivered by Principal Treatment Centres and those delivered through shared care arrangements. Age-appropriate facilities are strongly advocated throughout. This document focuses mainly on the 'care pathway' for children and young cancer survivors during their illness and it does not address the impact a young person's illness may have on their wider lives, nor how generalist services respond to this. For example, the psychological care referred to in this guidance relates to support for the child and family during cancer treatment, long-term follow-up, palliative care, respite care and bereavement. This is vitally important, but it concentrates on the provision of holistic care at the point of treatment, rather than what happens afterwards. Care can and should continue through community-based services and initiatives such as CAMHS, school commissioned psychological support and family support services. The benefits of providing more community-based care have been widely documented. They include bringing service delivery closer to home, ensuring local services link up around the young person, and cost benefits.

NICE guidance recommends that each child or young person with cancer should have a key worker. CLIC Sargent's *More Than My Illness* report set out the critical role a key worker can play in co-ordinating care and support and enabling children and young people with cancer to spend as much time as possible at home during treatment. When a key worker-led model of service delivery is in place, it will enable much better communication and co-ordination between specialist and community-based services.

Throughout this report, the term 'generalist' policy is used to describe policy which applies to young people across the general population, for example in the community as opposed to acute settings. Generalist policy therefore refers to education and learning, employment, benefits, training, general health and wellbeing, sexual health, and fitness, including obesity, emotional and psychological health, information and advice, involvement and democratic engagement, recreation and play.

By far the most important generalist policy strand for children and young people of recent times is *Every Child Matters* (2003). This began as a Green Paper response to the death of Victoria Climbié, but resulted in a new Children Act (2004) and subsequent programme of change aimed at improving outcomes for all children and young people. One of the key objectives of *Every Child Matters* is inter-agency co-operation, and the 2004 Children Act legislates for this. For the first time, all agencies have been made responsible for considering children and young people's holistic needs across the five areas of being healthy, staying safe, enjoying and achieving, making a positive contribution, and achieving economic wellbeing, rather than viewing one aspect of them from siloed professions. Detailed policy from *Every Child Matters* will be assessed later in this review.

The 'National Service Framework', a 10-year programme launched in 2004 to improve children and young people's health, is another of the foundations on which the current policy structure rests. Standard 6: *Children and Young People Who Are Ill* is for "all children and young people who are ill, or thought to be ill,

or injured [to] have timely access to appropriate advice and to effective services which address their health, social, educational and emotional needs throughout the period of their illness". A key word in this Standard for young survivors is "timely access", along with the description of the range of needs, not just physical, which those supporting young people should take into account. However, this Standard does not explicitly require community service providers to include survivors of illness in their services.

CLIC Sargent's report *More Than My Illness* is another important part of the context of this review. It recommends a model of future service delivery that commissioners and service providers from across the health, education and social care sectors can use when developing community-based services for young people with cancer and their families. The model includes holistic, non-clinical care delivered by acute and community services, and clinical care delivered by community services.

Approximately 1,700 children aged 0 to 15 and 2,300 young people aged 16 to 24 are diagnosed with cancer each year in the United Kingdom, according to the National Registry of Childhood Tumors (NRCT). Together this amounts to 4,000 children and young people, or 0.021% of this age group (ONS population projections, 2008). This percentage may seem small, but the fact that it accumulates year on year and that survival rates are improving - now over 75%, compared to just 30% in the 1970s - means that more and more healthy young people have cancer – and everything that comes with that as part of their personal history. Each year around a thousand 11 to 19 year-olds are diagnosed with and treated for cancer, which is equal to one in 600 pupils of this age. This number has remained relatively constant year on year.

The types of cancer that affect young people are generally very different from those found in adults. For example, brain tumors account for 24% of cancers in young people, but just 2% of

cancers in adults. The most common diagnoses for young people aged 13 to 19 are leukaemia, carcinoma and epithelial neoplasms, brain and spinal neoplasms and lymphoma. In recent years there has been an increase in the incidence of childhood and adolescent cancers across a wide range of diagnoses – for young people aged 15 to 24 this is true across all diagnostic groups, according to NICE. However, there have also been vast improvements in survival rates over the last 30 years, with the overall rate at 75% (source: NRCT).

The diagnosis of cancer in childhood clearly has a huge impact on a young person's life. The treatment process can be long and complex, often requiring large amounts of time away from school, friends and family. The uncertainty of the outcome and cancer's reputation as a deadly disease can have a serious psychological impact on a young person and their family. On top of these factors, young people are a diverse cohort themselves, with their own individual levels of resilience and vulnerability. Each young person will deal with a diagnosis, and the treatment that follows, very differently to the next and so will their families.

'Survivorship' has been defined by young people themselves as the period of time from the day after diagnosis onwards, ie from day two they count themselves as survivors. This is therefore the definition used in this review.

This policy review sets out various ways in which generalist policy can be made to work better for young cancer survivors. However, this will be achieved most effectively by bottom-up action and empowerment, rather than by top-down policy imposition.

# 3. Education employment and training

## 3.1 Key findings

There is a wealth of data on this subject thanks to a report entitled 'Educational Attainment and Employment Status in Survivors of Childhood Cancer in Britain' (Hawkins and Lancashire, 2010). This report looked at findings from the British Childhood Cancer Survivor Survey, which is a long-term study of 10,500 individuals diagnosed with cancer between 1940 and 1991. The 2010 report compares the education and employment records of cancer survivors with those of the population at large.

The headline findings suggest that survivors of cancer perform significantly worse overall in GCSEs, A-Levels, teaching qualifications and degrees. However, this lower attainment is disproportionately found among survivors of particular cancers – in particular central nervous system neoplasm and cranially irradiated leukaemia – which distort the result.

For survivors of all other types of cancer there is no evidence of a lower than standard educational attainment. In fact retinoblastoma and bone sarcoma survivors performed better than the general population in their GCSEs.

CLIC Sargent has conducted its own research, based on a sample of nearly 2,000 cases studied for the 2009 report 'More Than My Illness'. Of the young people studied aged five to 15 years (the current compulsory school age), 83% participated in education. Among those aged 16+, 67% were in education, employment or training, compared to a national target rate of 90%. The rate of participation for those aged 19+ is even lower.

This study also found that 50% of young adults said the impact of their diagnosis meant they did not do as well as they thought they could at school. Of those young people employed at or since diagnosis, 51% said they had had to take a break from employment, and 41% said they had had to leave their employment, while 31% took unpaid leave to cope with their illness.

## 3.2 Young people's views

CLIC Sargent held a number of discussion groups for 17 to 24 year-olds to support this work. It was clear that school age cancer survivors wanted to see better communication between health and education services. They also wanted more co-ordinated provision, more reliable community education services, and better understanding of young survivors' needs.

**"When he was first diagnosed and needed something to distract him from thinking of his illness there was very little available due to his age – younger people seem to get more educational support, which is odd because the late teens are very important."**

Parent of young cancer survivor

**"There was a total lack of communication within my part-time workplace – the doctor that worked for the company would phone me to see if I was fit to return to work yet, but then my boss would not be informed of this phone call or my current state of health. I also felt my boss was rather unsupportive of me needing to be off work for a long period of time, even though I was only 16 at the time."**

Young cancer survivor

## 3.3 Policy

The existing policy framework is strongly influenced by the 2002 Education Act. This Act was one of the first pieces of legislation to consider the 'whole child' in an education setting, and not their academic abilities alone. It argued that other aspects of a young person's life will influence their academic performance and learning in general. This is of course crucial for young survivors of cancer, and for their experience of education. The 2008 Education and Skills Act introduced two significant shifts

in policy. The first placed a 'duty to participate' on 16 and 17 year-olds in England. This duty to participate (due to come into force in 2013 for 16 year-olds and 2015 for 17 year-olds) reflected a number of policy concerns, including:

- \* the need for a highly skilled workforce;
- \* fears of a projected skills deficit;
- \* the desire to reduce the number of young people not in employment, education or training.

Participation in education, training, or apprenticeship – or a combination of these – was seen as crucial to addressing these concerns, and a range of new 14 to 19 qualifications were envisaged to increase participation levels.

The second major policy shift in the 2008 Act saw responsibility for information, advice and guidance services such as Connexions devolved from national to local levels. The aim was to encourage these services to work more closely with other local agencies such as schools, local authorities and the health service. It is hugely important that schools, job centres and other local agencies providing advice and guidance are able to work together to support young cancer survivors who are at risk of underachievement or face economic difficulty.

Within the Act a new duty was placed on local authorities in England to make available services that would assist the effective participation of young people up to 19 (24 in the case of those with learning difficulties) in education or training.

### 3.4 Personalised education

The schools White Paper *Your child, your schools, our future*, published in 2009, aimed to ensure that every young person achieves high standards of schooling and stays in education or training until the age of 19. This was seen as a way of narrowing the achievement gap between advantaged and disadvantaged pupils. It introduced the pupil guarantee: that there is good behaviour and strong discipline; pupils are taught a broad and flexible curriculum, in a way

that meets their needs; that they take part in sport and cultural activities; and that their health and well-being is promoted.

'Taught in a way that meets their needs' meant the following:

- \* Personal tutors would give support to every secondary school pupil, from September 2010.
- \* High-quality careers education, information and advice would be given to all secondary school pupils.
- \* Schools would identify pupils with additional needs quickly and ensure effective co-ordination with health and specialist services.
- \* Children who have fallen behind during Key Stage 2 would be entitled to extra support, including the guarantee of 10 hours one-to-one catch-up tuition. Those pupils who are not at the expected level in English and Maths at the start of secondary school would have the guarantee of one-to-one or small group catch-up tuition in Year 7.
- \* Schools would give written confirmation of the extra support to be given to pupils who have been identified as gifted and talented (to be implemented by September 2010).
- \* Every pupil would have the chance to express their opinion on their school and how it could be improved.
- \* Every young person would participate in education and training up to the age of 17 from 2013, and up to the age of 19 from 2015.
- \* There would be a review of the Dedicated Schools Grant (the principal source of funding for schools in England) from 2011 in order to establish a funding framework that improves the outcomes of disadvantaged children, better enables partnership working and raises standards overall.
- \* The Government would carry out a consultation exercise in early 2010 on proposals resulting from the review.

- \* The increase in participation in education and training for 16 and 17 year-olds would need extra funding, and as a result the former Department for Children, Schools and Families was tasked with developing a national formula for 14 to 19 provision in the long-term.

A Timetable for Action document was also published in 2009 setting out when the objectives of this document will be implemented. However, much of the detail behind these proposals was unspecified. For example, it was unclear what the one-to-one catch-up would mean in practice for children who had fallen behind, and how it would be implemented.

### 3.5 Information, advice and guidance

*Quality, choice and aspiration: a strategy for young people's information, advice and guidance* (2009) set out a range of measures to help young people to succeed in education up to the age of 19, and to make informed choices about their careers. It aimed to raise young people's aspirations and fulfil their potential while overcoming barriers to achieving their goals.

This strategy built upon a number of other documents, including *Youth Matters*, which gave local authorities strategic responsibility for providing integrated youth support services such as Connexions, and the *New Opportunities* White Paper, which set out measures to increase social mobility, particularly in relation to access to higher education, as well as the report of the Panel on Fair Access to the Professions.

The strategy promised to provide young people in schools support from a personal tutor who knew them well and who could help them to access specialist advice and ensure any learning needs or issues were quickly addressed. Survivors of cancer and other illnesses are not mentioned by name, but it was intended that this guarantee of information, advice and guidance would be available to all young people in schools.

Young cancer survivors have said they would welcome impartial advice from someone who knows them well when they are making decisions about their future.

### 3.6 Special educational needs

Young people who have had cancer often feel their education suffers as a result. Research backs this up – particularly for young people whose cancer or its treatment has affected their cognitive functioning. This can mean such young people are classed as having a learning disability or a special educational need. The Special Educational Needs and Disability Act of 2001 served two key functions; providing a statutory framework for special educational needs, and extending the coverage of the Disability Discrimination Act (1995) to education.

A number of policies have been introduced since 2001 to take this forward, including Individual Education Plans and the School Action and School Action Plus programmes. Individual Education Plans set out:

- \* the short-term targets set for or by the young person;
- \* the teaching strategies to be used;
- \* the provision to be put in place;
- \* when the plan is to be reviewed;
- \* success and/or exit criteria;
- \* outcomes (to be recorded when the plan is reviewed).

The recent Children, Schools and Families Act (2010) places a new duty on the schools inspection service, Ofsted, to report on how well schools are meeting the needs of young people with special educational needs and/or disabilities. Ofsted is currently undertaking a review into special needs provision and will be making a number of recommendations to Government about how the system may be made to work better.

## 3.7 Not in education, employment or training

Four key themes underpin 'Reducing The Number Of Young People Who Are Not In Education, Employment Or Training (NEET): The Strategy' (2007):

- \* careful tracking to identify those young people who are not currently participating in education, employment or training, or who are at risk of dropping out;
- \* personalised guidance and support to enable young people to access suitable provision, and to tackle barriers to learning;
- \* a flexible mix of learning provision, both pre- and post-16, designed to meet the needs of every young person in every area; and
- \* an emphasis on rights and responsibilities, so there are clear incentives for young people to re-engage quickly if they do drop out.

The latest figures – for the end of 2008 – show that the proportion of young people aged 16 to 18 participating in education or training had reached 79.7% – the highest ever rate. At 5.2%, the proportion of 16 year olds who are not in education, employment or training is at its lowest level for more than a decade.

The 'NEET' strategy acknowledges that young people with learning difficulties and disabilities are more likely to be outside of education, employment or training as those without. One of the programs currently aimed at addressing the needs of young people who are not participating, or at risk of dropping out, is 'Entry to Employment'. This is a work-based learning programme for those young people aged 16 to 18 who are not yet ready, or able, to enter an apprenticeship, employment or further learning opportunities.

As CLIC Sargent's research with young people has shown, young people perceive and report that as young survivors of cancer they are more likely to be outside of education, training and employment than their peers. However, this is contradicted by other research, such as

Hawkins' and Lancashire's study. This may reflect the fact that the educational issues faced by young survivors do not just relate to educational attainment, but also to routes to further education and employment.

## 3.8 Common assessment framework

Some young people need more targeted support because they have potential barriers to learning, and young people who are not in school due to illness or treatment fall into this category. One key to supporting such young people is ensuring their needs are properly assessed and then met through the development of more integrated and responsive services. The Common Assessment Framework (CAF) – a standardised approach to conducting assessments of children's or adults' additional needs and deciding how these should be met – is one of the most effective tools for ensuring that this happens.

Through the CAF, services can be accessed. Furthermore, a CAF assessment should ensure that the young person's needs, and those of their families, are evaluated across a whole spectrum of domains. The implementation of a common assessment also enables better sharing of information, which we know is crucial to improving outcomes. However, there is little evidence that this is being used as a tool to assess and access services for children and young people with cancer. In addition, it is known that accessing additional support in the community through adult services can be very difficult.

## 3.9 Careers services

The Trade Union Reform and Employment Rights Act 1993 requires the Secretary of State for Education and Skills to ensure that school and college students, and those leaving education, are offered careers advice and guidance. This duty has been carried out since 2001 by the emerging Connexions partnerships. The Education Act 1997 says that maintained schools must provide pupils with a programme of careers education during years 9 to 11 and allow Connexions advisers access to pupils. In its response to the 14 to 19

Green Paper consultation '14–19: Opportunity and Excellence', the Government announced that it intended to extend the duty on schools down to Years 7 and 8.

All of these pieces of legislation emphasise the importance of young people having good quality careers information and guidance to support their entry into education or employment. Young people with cancer or any serious illness can access these services.

Connexions services were established in 2001. They were originally independent organisations. Now individual local authorities commission the information, advice and guidance services that fulfil these duties. Their main role is to provide information, advice, guidance, advocacy and brokerage (including brokering access to targeted youth support services) for all young people aged 13 to 19 regardless of need, and those aged up to 24 with a learning difficulty or disability. There is a particular focus on those who are at risk of dropping out of education, employment and training, or of being socially excluded. This focus means that survivors of cancer, or those undergoing treatment through their teenage years, should receive support. However, there is no specific data on the numbers of young cancer survivors who are who are in contact with Connexions. Finally, the 'New Deal for Young People' was introduced in 1998 as part of the Government's welfare to work strategy. The programme is targeted at 18 to 24 year-olds who have been claiming Job Seeker's Allowance for six months or more, and provides opportunities to work or gain work experience. This is another route to participation in employment and training which may need to be promoted to young people who are survivors of cancer.

### 3.10 Benefits

There are a number of benefits which young survivors of cancer and their families can call on for support. These vary according to individual circumstances, but the main options outlined by current policy are as follows:

- \* Disability Living Allowance. This can be obtained if there are care or mobility needs

lasting for at least six months. A young person under the age of 16 must show they need a lot more care or supervision than other children. The allowance is not means tested but it does depend on the severity of the illness or disability (physical or mental).

- \* Employment and Support Allowance. This is for young people over the age of 16. It replaced Incapacity Benefit and is to support people of working age who are unable to work because of their illness or disability. It can be contribution-based or income-based.
- \* Education Maintenance Allowance. For young people aged 16 to 18 to help with their learning costs. It is intended to enable young people to remain in education or training and is only available to those who regularly attend a course. It is means tested and available to young people who live in families where there is a combined income of less than £30,000 per annum. A young person can be eligible for an allowance of up to £30 per week, and it does not affect other benefits for the recipient or their family.
- \* Income Support. This is available to young people who are over 16, in special circumstances, and on a low income or not working. Young survivors of cancer could be eligible for this, depending on how their treatment has affected them. Young people are automatically eligible if they are registered disabled.
- \* Job Seeker's Allowance. If a young person is over the age of 18, is unemployed, not in education and is looking for work, they can claim Job Seeker's Allowance. It can also be claimed if the young person is working less than 16 hours per week
- \* Working Tax Credit. Usually available for people over the age of 25, but it may be available to 16–25 years olds with a disability that affects their ability to work or look for work.
- \* The Social Fund. This may be applied to for one-off expenses, which otherwise would be unaffordable. It is means tested and intended for those on very low incomes.

- \* Help with transport costs may be available to a young person aged 16 to 18 to get from home to school or college. This is, however, dependent on each local authority.
- \* A young person may also be entitled to housing benefit, council tax benefit and child tax benefit depending on their circumstances.

We do not know to what extent young cancer survivors and their families are claiming these benefits, and what the economic consequences of the current system may be for this group. There would certainly seem to be a need for services providing information, advice and guidance to be well aware of the benefits available to young people with complex health needs and/or disabilities, and able to support young people in accessing them; and for information on the benefit options available to be publicised on websites accessible to young people.

Finally, the 'New Deal for Young People' was introduced in 1998 as part of the Government's welfare to work strategy. The programme is targeted at 18 to 24 year-olds who have been claiming Job Seeker's Allowance for six months or more, and provides opportunities to work or gain work experience. This is another route to participation in employment and training which may need to be promoted to young people who are survivors of cancer.

### 3.11 Specific guidance

*Access to Education for Children and Young People with Medical Needs* (DCSF, 2001) is the most recent guidance issued to local education authorities, head teachers and governors to ensure young people's educational needs are met. It asks that young people have access to as much education as their medical condition will allow, and sets out the types of alternative provision – including hospital schools, home education and pupil referral units (specialist school provision) – available for young people with medical needs. It also stresses the importance of communication between these services, the young person's

home, the home school and the home children's services department – a point reinforced by young cancer survivors themselves.

The Department for Education is also in the process of revising its 'Managing Medicines in Schools' guidance and this will include a specific section on cancer. The 'Access to Education for Children and Young People with Medical Needs' guidance says that hospital schools are subject to the procedures laid out in the School Standards and Framework Act (1998), but they are not under a legal obligation to offer the national curriculum; instead they have their own local management and delegated budget arrangements.

Local authorities have a legal duty to provide education welfare services, which work to resolve attendance issues. Young survivors of cancer are often absent from school, and unless the communication between the school and local authority is good, it can sometimes result in families being contacted in relation to their child's absence from school as if it were deliberate absconding.

The 'Access to Education' guidance also specifies the local authority's role in providing transport for a young person to a school or college, and says this is preferable to home schooling for young people's social and educational development, as well as facilitating their school reintegration.

Local Authorities now have a duty to ensure that young people aged 16 to 19 who have missed out on education due to prolonged illness have the best possible start to their working lives, including taking part in further education. The guidance states that an individually tailored, multi-agency plan should be in place for all pupils before they return to school. It suggests what this plan might include, but does not give stronger guidance on this.

# 4. Emotional and psychological well-being

## 4.1 Key findings

The most comprehensive study of mental illness in children undertaken in Britain (Meltzer et al, 2005) found that in 2004, 10% of children between five and 15 had a clinically diagnosable mental disorder. A sample of the children from this study was followed up between 2004 and 2007 to find out more about the factors associated with the onset or persistence of disorders. This found that children who face three or more stressful life events (eg illness, bereavement, divorce) are three times more likely to develop psychological problems. This indicates that some young people who have experienced cancer are more vulnerable to psychological problems than their peers.

Many researchers have also found that young survivors may experience neurocognitive impairment as a result of their treatment, which may result in problems such as memory deficits, spatial processing problems, and learning difficulties (Mulhern and Palmer, 2001).

As Kelly and Gibson (2008) note, the normal psychological development of adolescents is complex and involves obtaining a personal identity, an increasing independence, the development of body image, and peer approval. Studies have shown that teenage survivors of cancer experience greater psychological problems than their peers – including depression and somatic distress – which corresponds with Melzer et al's study above. However, there are conflicting findings. Langeveld et al (2002) reviewed 30 studies on the matter and concluded that most young survivors of childhood cancer functioned well psychologically and did not have significantly greater emotional problems than their peers. What this study did find, however, was that being female, being older at follow-up, having a greater number of relapses, physical impairments or cranial radiation all lead to an increased risk of emotional problems.

Body image is a key issue for many young people, regardless of previous illnesses. However, when you include amputations, alopecia, asymmetry,

scarring, obesity, and an altered perception of body appearance – it can become an overwhelming issue for young survivors of cancer. Body image may also vary over the course of the treatment and length of time after treatment. Pendley et al (1997) found that body image concerns and social anxiety may not develop until several years after the end of treatment.

Adolescence is a key period for the development of sexuality, which usually begins at the onset of puberty. This happens differently for each individual, but involves understanding desires, attractions and feelings, learning about our bodies, and understanding loving and equal relationships. It is crucially important that children who are undergoing treatment – and are therefore absent from friends, family and opportunities for social development – experience these crucial life stages, and are provided with a robust level of personal, social and health education (PHSE) during treatment, and that extra efforts are made to ensure they are included in PHSE once they reintegrate back into mainstream education.

As highlighted earlier, hospital schools are not obliged to deliver the national curriculum – or personal, social, health and economic education – to the young people in their care.

Evans (1996) found that a diagnosis of cancer places young people at risk of psychological and emotional problems, because it disrupts the formation of independence and identity – two key functions of the adolescence life-stage. Gibson and Kelly (2008) note that in transition from “patient” to “survivor”, young people must establish a new identity that incorporates their cancer experience, but does not let it define who they are. Hollen and Hobbie (1995) wrote that they must redefine themselves as an individual, not as a patient who is part of a medical team and treatment system, but as a person who is now part of a different society. They must rejoin a whole new world of “well” people, despite having missed out on time spent in this society and with their peers. The challenge now is to

reintegrate and find a place again. Adjustment, therefore, to this new identity for young survivors is a key issue for their mental wellbeing, and one that takes some time. It needs to be supported by all those in the community setting around that young person.

Madan-Swain et al (2000) undertook research into the formation of identity among adolescent survivors of cancer. Their results indicated a greater number of survivors with 'foreclosed identity status' (a lower 'formed' identity) compared to their peers. Factors associated with this included cancer diagnosis, symptoms of post traumatic stress disorder, and conflict in family functioning. They concluded this was a way young survivors were protecting themselves in order to cope with their cancer diagnosis.

## 4.2 Young people's views

In CLIC Sargent's report, *More Than My Illness: Delivering quality care for young people with cancer*, respondents were asked how important it was to receive emotional support following cancer diagnosis and treatment; 88% said it was important, with 18% suggesting this should be in the form of counselling or psychological therapy. In this survey, the importance of psychological support increased with age, with 75% of 11 to 15 year-olds classing it as important, compared to 96% of 20–24 year-olds.

**"Being treated with cancer has made me less independent, less confident and I don't like trying or doing different things. It also affects my mum and dad as well because I need them more than usual."**

Young cancer survivor

**"Much more [emotional support is] needed, there is almost no information about recovery patterns given once treatment stops, and if psychological difficulties are mentioned at clinic appointments everyone nods their heads and says yes it is very difficult and seems to know that it is an issue that cancer sufferers have to face, but can offer no real practical help in dealing**

**with it. But the psychological support is non-existent and has been difficult and expensive to obtain."**

Young cancer survivor

## 4.3 Policy

The Mental Health Acts of 1983 and 2007 cover the reception, care and treatment of mentally disordered persons, in particular the legislation by which people diagnosed with a mental disorder can be detained in hospital and have their disorder assessed or treated against their wishes. No mention is made in this legislation of the needs of young people with long-term physical conditions. Young people aged 18 to 24 with mental health needs will be referred to adult mental health services. These services only address the needs of adults with diagnosed mental illness. Most young survivors of cancer will not meet this kind of diagnosis.

Child and adolescent mental health services (CAMHS) provide assessment and treatment services for children and young people aged 0 to 18 years where there are concerns about their behaviour or emotional wellbeing. Policy and guidance for CAMHS is often issued jointly from the Department of Health and the Department for Education – indicating the cross-cutting nature of child mental wellbeing. CAMHS have been funded in the past via the CAMHS Grant, but now are jointly funded through Primary Care Trusts and local authority mainstream budgets (often via the Children's Trust). CAMHS can also receive grant funding for specific projects, such as to provide parenting support, or to provide targeted mental health services in schools. The Department for Education has developed guidance for commissioners around how to commission effective 'comprehensive' CAMHS including early intervention services and how to deliver on the emotional health of children and young people.

Improvement, Expansion and Reform (Department of Health, 2002) first set out the expectation that areas deliver a 'comprehensive CAMHS' which removed the focus from 'mentally ill' children and a treatment model, to an early

intervention model that worked to promote resilience and emotional wellbeing among all children – with a focus on vulnerable children, including those who are or have been ill.

This approach is being adopted by schools across the country to promote the social and emotional skills that underpin effective learning, positive behaviour, regular attendance, and the emotional health and wellbeing of all who learn and work in schools (DCSF, 2007). The guidance issued to secondary schools describes social and emotional skills as forming positive relationships with others, and understanding and managing our own emotions, thoughts and behaviours. It suggests that when people have those skills, they are more likely to (inter alia):

- \* Be effective and successful learners
- \* Be self motivated
- \* Make and sustain friendships
- \* Deal with and resolve conflict effectively and fairly
- \* Solve problems with others or by themselves
- \* Manage strong feelings, such as frustration, anger and anxiety
- \* Recover from setbacks and persist in the face of difficulties

'New Horizons' (Department of Health, 2009) is a cross-departmental programme of action for the whole population's mental health, not just children. It builds on the previous 10 years of the 'National Service Framework for Mental Health', and has the twin aims of improving the mental health and wellbeing of the population and improving the quality and accessibility of services for people with poor mental health. It defines wellbeing as "a positive state of mind and body, feeling safe and able to cope, with a sense of connection with people, communities and the wider environment". Young people are the focus of a substantial amount of the programme, with 'Targeted Mental Health in Schools', 'SEAL' and the 'Family Nurse Partnership' (targeted, intensive support for teenage parents) forming part of the action plan. The programme does suggest it

intends to improve care for specific groups such as people with physical illness, but makes no reference as to what could be offered to young people recovering from chronic illness to promote their resilience and mental health.

Mental health services for young people are mainly governed by Standard 9 of the 'National Service Framework for Children, Young People and Maternity Services'. This Standard aims to improve care for children and young people with mental disorders, but also says that all children, especially those who are vulnerable, should have access to mental health care. Children and young people who have been seriously ill, or who have made the transition from patient to survivor (with or without long lasting physical effects), are not specifically mentioned in Standard 9, although those with learning difficulties are.

Standard 6 of the 'National Service Framework' offers more detailed guidance for young people with long-term conditions, stating that good mental health input is needed to maximise their emotional wellbeing and prevent or minimise problems. However, it doesn't detail what that might look like, or provide guidance for the longer term care and transition of sick children back into the 'mainstream' world, and the effect this might have on their psychology.

A review of CAMHS was recently commissioned and undertaken which made several recommendations aimed at improving services, many of which are being taken forward through the guidance described earlier. The Government published a response to this review, setting out clearly what they intended to do with each recommendation. This review was particularly interested in the mental health and psychological wellbeing of vulnerable children, including those with complex needs or chronic illness. Recommendation 12 of the review suggests that these young people have their mental health needs assessed alongside their other needs, and that an individualised package of care be made available to them. There is no data yet available on implementation of this recommendation.

National mapping of CAMHS was first undertaken in 2002, and the subsequent information it provided is a way of gauging what is being delivered across England and Wales. Survivors of cancer were not specifically mapped as a part of this process. However, children with life-limiting, life-threatening illnesses, and services offered to children with learning difficulties were mapped. It is difficult to extract meaningful data from this work as the database is developing, and therefore categories change, making comparison challenging. It provides a picture of services for children with learning difficulties, but does not describe those services, the number of children receiving the services, or the hours offered. As the data develops, it may be possible to use the information to support the identification of gaps in service delivery for those affected by cancer even without specific information.

Since September 2007 school governing bodies have been under a duty to promote the wellbeing of children and young people in terms of the five outcomes of *Every Child Matters* (Education and Skills Act, 2006). In October 2008, the Government pledged to make personal, social and health education statutory within the national curriculum from Sept 2011, signalling its intent to enhance the role of schools in promoting wellbeing. A consultation took place on the ways schools might be measured against this, but the resulting indicators have not yet been published. The response to the consultation describes pupil and parent surveys as the main measure of whether the school has promoted wellbeing, although Ofsted will actually be inspecting schools with regard to this goal.

'Targeted Mental Health in Schools' is a way of making mental health services more accessible through schools. This programme trains up school and community staff to be able to deliver low level mental and emotional health support to young people while supervised by a qualified mental health worker. There are 55 pathfinder projects in operation, receiving government funding to test their models. Currently, no test sites look specifically at meeting the needs of sick children or those who have survived chronic physical illness.

Social and Emotional Aspects of Learning (SEAL) is a national, voluntary programme designed to help develop the social and emotional skills of pupils both by creating a climate across the whole school that encourages the development of these skills, and by fostering particular learning opportunities around these skills inside the classroom and outside it.

# 5. Health and recreation

## 5.1 Key findings

Monteleone et al (2009) found that young survivors of cancer had fewer health worries than their peers, but a more negative view of their health in relation to specific issues, such as secondary cancer or fertility. The *Childhood Cancer Survivor Study* (Robison et al, 2003) found that nearly 90% of adult survivors of childhood cancer believe that, overall, they are in good health, yet almost half the group also reported having at least one significant health problem develop since the cancer treatment ended. Health problems were more common among females in this study, and among those with poor educational attainment and lower household income (these latter two findings are in keeping with the population as a whole). Leukaemia survivors were less likely to report health problems.

There have also been a number of studies on illicit drug use among young survivors. Baulde et al (2005) found that 13 to 17 year-olds had an increased risk of using pain relief for non-medical purposes, but a lower risk of using cannabis or other illicit drugs when compared to their peers. Larcombe et al (2002) showed significantly fewer survivors of either sex using recreational drugs than their counterparts in the population at large. Several studies (eg Mulhern et al, 1995) have found that young survivors are less likely than their peers to drink alcohol, and that the incidence of problem drinking is low. Early studies indicated that survivors of cancer were as likely to smoke as their peers. However, more recent studies have found that in fact, survivors are less likely to smoke. An Australian study by Baulde et al (2005) found that adolescent survivors of cancer (aged 13 to 17) were at a lower risk of tobacco use than their counterparts.

Children have highlighted three specific friendship groups that are important to them: school-based peer friendships, social groups, and hospital-based friendships. Cancer often has a major impact on children's social lives and friendships, and this is often accompanied by

disruption to their education and ability to attend school (*More Than My Illness*, CLIC Sargent, 2010). The following issues were highlighted:

- \* Social isolation
- \* Being treated differently
- \* Over-protective parents
- \* Being unable to do the same things as peers/friends
- \* Friends moving on
- \* Friends becoming more cautious around them

## 5.2 Young people's views

Of the children and young people surveyed for *More Than My Illness: Delivering Quality Care For Children And Young People*, 94% found it important to keep up their social life, with 97% saying they needed to be able to socialise with their friends. Friends scored very highly in the ratings in general and were counted as the second most important issue for young survivors of cancer after spending time at home during treatment.

Maintaining a healthy lifestyle was important to 84% of respondents. Interestingly, young people were more likely to report this as important than their families. 42% of young people said they needed more help with keeping healthy and fit. With more evidence emerging of the benefits of maintaining physical activity both during and after cancer, this is an important consideration.

**"I would like more time to do fun things with my family like we used to. We used to go on our bikes for family rides for miles. We used to go for walks on the beach after school. There is nothing I can do to change this until I get better and I am not so tired."**

**Young cancer survivor**

“It was difficult to always know what to eat to help yourself, and often I found it difficult to eat so I would eat only what I could face, which wouldn’t always be great for me. I should have made a plan so I could have been more aware what I needed to achieve.”

Young cancer survivor

“Any young adult that wasn’t active before cancer will find it even harder after it so doctors etc really need to stress how important it is to lead a healthy lifestyle after cancer in order to get them back to normal again otherwise they may suffer for it for the rest of their lives.”

Young cancer survivor

## 5.3 Policy

Young people, regardless of their background and whether they have had to cope with a life-threatening condition, have a variety of health and recreational needs. These include keeping fit, living healthily, socialising with peers, playing and learning about life and what it means to be a citizen.

The public health White Paper *Choosing Health, Making Healthy Choices Easier* (2004) did not lead to a specific piece of legislation, but it did influence legislative change in a range of areas. Key themes were:

- \* Reinforcing the idea that health promotion is just as important as disease prevention and treatment (with the NHS as a service for ‘health’ rather than ‘sickness’); and
- \* Getting the correct balance between individual rights, public concern, and protection, particularly in the case of children.

The White Paper has a whole chapter dedicated to children and young people which sets out key activities in relation to healthy eating, from improving nutrition in school meals to better food labelling, and improving school health services. However, it makes no specific mention of children who have experienced chronic illnesses or who are sick. It also sets out targets for public health, such as halving the rates of childhood obesity and increasing the amount of time children have for physical education lessons in school. It describes how information offered on sexual health for young people should be broadened and improved, including developing a confidential online service by trained sexual health advisors, and the provision of targeted information for specific groups, such as disabled children. This tailoring of provision for children with disabilities is a key theme throughout the document, but there is little detail about how this might happen, and no specific reference to survivors of long-term illnesses.

The National Health Service Act (2006), The National Health Service (Wales) Act 2006, and the National Health Service (Consequential Provisions) Act 2006 summarise and consolidate most of the health legislation passed since 1977. Within these Acts the duty to promote a comprehensive health service designed to improve the physical and mental health of the people of England and Wales is set out. It is specified that after-care must be provided jointly with social services authorities for persons who have suffered from illness as part of the health service. This service should be ‘appropriate’; the full definition of ‘appropriate’ has yet to be identified, but it is assumed that this will be covered through additional guidance.

The annex to *Health Reform in England: Update and Commissioning Framework* sets out a vision for commissioning in England. This describes a purchaser-provider model for Primary Care Trusts to create an internal market and promote effective commissioning of services. This, alongside the

'World Class Commissioning' and 'Transforming Community Services' programmes, marks a major shift in NHS policy, moving towards a business model approach.

Effective commissioning should mean that services for young survivors are commissioned according to need, based on evidence and good practice, and that this happens jointly with the local authority, school and other key commissioners in their areas. Ultimately this should mean better, more joined up and responsive services for young people.

The Health Act 2009 followed the *Darzi Review of NHS services* and introduces, among other things, methods for NHS Trusts to account for the quality of their services, direct payments to be made to patients for certain services, changes to appointments and suspensions under the NHS performance framework, and control of the advertisement, display and sale of tobacco products. It legislates for a range of 'pledges' in the NHS constitution, including putting an end to the postcode lottery of service delivery. This Act should provide greater clarity to young survivors and their families as to what they are entitled to and can expect from the NHS.

The Disability Discrimination Act (DDA) defines a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. The effect should last more than a year. Young survivors of cancer will not necessarily fit into this category, and therefore will not always be covered by the Act as amended in 2005.

According to the National Institute for Clinical Excellence (NICE), young survivors of cancer run a higher risk of heart problems and should be closely screened – a routine heart trace should be done every five years and this follow-

up should be monitored robustly. Aggressive cancer treatments such as chemotherapy and radiotherapy can harm the heart, multiplying the patient's death risk by seven.

The Government published the 'Young People's Substance Misuse Strategy' in 2005 which aimed to reduce the rate of serious drug use by young people. This strategy included the 'FRANK' campaign, aimed at highlighting the dangers of drug misuse for young people. Another large campaign is 'Blueprint', the biggest drug education programme in England to date (for Years 7 and 8). Drug use by young people appears to have stabilised, but it is estimated that 20,000 young people each year go on to become adult problem drug users.

The Government introduced the 'Teenage Pregnancy Strategy' in 2000 to reduce the number of teenagers becoming parents by 50% in 10 years, and to lower the number of teenage parents who are not in education, employment or training. In 1998 the rate of teenage pregnancy was 47.1 per thousand in England and Wales, and in 2008 this was reported to be 40.6 per thousand (a reduction of 13%).

There has been some research (e.g. Surís et al, 2008) on risk taking behaviour amongst young people who have experienced chronic illness, however this is contradictory. Some evidence points to risk taking behaviour being increased amongst this group, whilst other points to it being less than their peers. Regardless of this difference it is important that the issues relating to personal, social and health education highlighted in the previous section are addressed to ensure young cancer survivors receive appropriate information and support in this area, and particularly within hospital schools.

'Sex and Relationships Guidance for Schools', now backed by law, sets sex and relationships

education in the context of strategies to improve the health and wellbeing of children and young people. It recognises the duty on schools to promote the wellbeing of its pupils and outlines the contribution that good quality sex and relationships education makes to helping young people deal with the health challenges they face in adolescence, and in supporting their wider wellbeing. It is important that these messages are made available to young people wherever they are – in hospital, at home or in school.

In July 2005 the Green Paper, *Youth Matters*, set out proposals to improve outcomes for 14 to 19 year-olds. This included a reform of local youth support services, and the paper said that young people should have:

- \* more things to do and places to go in their local area, and more choice and influence over what is available
- \* more opportunities to volunteer and to make a contribution to their local community
- \* better information, advice and guidance about issues that matter to them, delivered in the way they want to receive it
- \* better support when they need extra help to deal with problems

*Youth Matters* identifies targeted youth support as a way to ensure that the needs of vulnerable teenagers are identified early and are met by agencies working together effectively. Local authorities have been responsible for targeted youth support services in their areas since April 2008. Connexions, or a similar provider, is often the young person's access to this more targeted support. Following an assessment of need, more in-depth services may be provided by other agencies such as a Job Centre Plus, sexual health services, or youth services.

*Youth Matters* was followed by *Aiming High for Young People: A Ten Year Strategy for Positive Activities* (2007), which set out plans to help young people to take part in “enjoyable and purposeful activities in their free time”. This strategy builds on the premise that what young people do in their leisure time can influence their future outcomes and can promote resilience. This is a welcome policy direction, although ensuring young cancer survivors participate in developing ideas for positive activities, and hosting them in accessible places for young survivors of cancer will be key. *Aiming High* also detailed commitments to invest in capacity building in third sector organisations supporting young.

The *Aiming High* strategy committed the Government to a 10-year programme of capital investment to improve youth facilities in every constituency. The training and guidance given to youth workers and other staff working in youth centres, particularly those working with young survivors, is crucial. If a young person has missed out on personal, social and health education, or key childhood life-stages, it is important that youth workers can respond appropriately.

## 6. Recommendations

This review has identified that there is a raft of solid and relevant policy that addresses the needs of children and young people who may be at risk of suffering from poor life outcomes. Although cancer survivors are not mentioned as a specific cohort in much of this policy, this is also true of many chronic or acute conditions. The fact that the word “cancer survivor” is not used does not preclude these policies being applied, and in fact these policies are targeting children and young people facing the very sorts of challenges experienced by young cancer survivors. The significant gap that has been highlighted is in the implementation of policy, advice and guidance on the ground. This is key to improving outcomes for young survivors of cancer.

Although there is adequate policy in place for under-19s, this review has highlighted a significant gap for 19 to 25 year-olds in all areas, including mental health, sexual health, and routes to education, employment and training. This is a major concern. Young cancer survivors frequently miss large tranches of their education as a result of their treatment, which leaves them vulnerable to dropping out of education, employment and training through no fault of their own. They also often miss out on the personal, social and health education that is offered to their peers in adolescence, which can have a major impact on their development as young adults. These two small examples help to illustrate why this review concludes that provision for 19 to 25 year-olds is the most urgent need identified. The next step following this review should be a scoping exercise looking at more effective models that will ensure services are accessible to this age group.

Secondly, in order to ensure that young cancer survivors are able to access the services already in place, there is a need to develop a suitable guide for use by young cancer survivors and professionals working with them in treatment settings to enable them to better access existing community based services, including advice services such as Connexions, benefits and training, personal, social and health education and a range of other services which can make a material difference to personal outcomes. Better communication is critical.

It would also be helpful to disseminate this guide to other community based professionals, including teachers and other educationalists, to assist them in understanding how to meet the needs of young cancer survivors. The young people surveyed on this subject have made it clear that they want to see more co-ordination between agencies, particularly where there are gaps in existing policy (eg hospital schools are not subject to the national curriculum requirement to offer personal, social and health education).

Thirdly, this review argues that it is critical that young people themselves have more of a say in future work around survivorship, how community services respond to young people who have had time out, and also on wider cancer services development. The third and final recommendation is therefore that the Department of Health ensures that young people’s views are systematically feeding into work using the many existing consultation avenues available both with charities and the NHS. Having young people’s views represented provides added strength to findings and greater impetus for change.

Finally, there are a number of areas where further research would be beneficial, but we would not want the absence of this research to prevent the improvement of service on the ground. Areas where further data would be helpful include hospital school provision, use of the Common Assessment Framework, the financial needs of young cancer survivors, and commissioning frameworks for local services for children and adults.

# 7. Conclusion

Any policy review can only be a snapshot of policy at the time when the review was carried out. We are now looking forward to a radically different policy environment from the one in which most of the legislation, advice and guidance described in this review was framed. Given current financial realities, it would be unrealistic to call for additional resources for young survivors of cancer.

However, this review shows three things clearly:

- \* First, that the existing framework has the potential to meet the needs of young cancer survivors, at least as far as under-18s are concerned – if only the current framework could be aligned to recognise the distinct needs of young cancer survivors. All too often they are invisible in the current system.
- \* Secondly, that small interventions can make a huge difference to the outcomes of young cancer survivors, and particularly to their chances of fulfilling their potential in terms of education, employment and training, and their opportunity of enjoying equal life chances generally. These small interventions can also maximise their chances of contributing to the wealth of the country, and reduce their need to draw on state benefits.
- \* Thirdly, that young cancer survivors are eager to take responsibility for their own futures and we need to support them in doing that.

# Appendices

## Appendix 1 – Glossary of terms

<b>CAF</b>	Common Assessment Framework	<b>NRCT</b>	National Registry of Childhood Tumors
<b>CAMHS</b>	Child and Adolescent Mental Health Services	<b>NSF</b>	National Service Framework
<b>CNS</b>	Central Nervous System	<b>ONS</b>	Office of National Statistics
<b>CRS</b>	Cancer Reform Strategy	<b>PA</b>	Connexions Personal Advisors
<b>DCSF</b>	Department for Children, Schools & Families	<b>PCT</b>	Primary Care Trust
<b>DDA</b>	Disability Discrimination Act	<b>PRU</b>	Pupil Referral Unit
<b>DH</b>	Department of Health	<b>PSHE</b>	Personal, Social and Health Education
<b>DSG</b>	Dedicated Schools Grant	<b>PTC</b>	Principal Treatment Centre
<b>ECM</b>	Every Child Matters	<b>PTSD</b>	Post Traumatic Stress Disorder
<b>EWO</b>	Education Welfare Officer	<b>SEN</b>	Special Educational Needs
<b>EWS</b>	Education Welfare Services	<b>SEAL</b>	Social and Emotional Aspects of Learning
<b>HE</b>	Higher Education	<b>SRE</b>	Sex & Relationships Education
<b>IAG</b>	Information, Advice and Guidance	<b>TaMHS</b>	Targeted Mental Health in Schools
<b>IEP</b>	Individual Education Plan	<b>TYS</b>	Targeted Youth Support
<b>LA/LEA</b>	Local Authority / Local Education Authority		
<b>MTMI</b>	<i>More Than My Illness</i> (CLIC Sargent)		
<b>NCSI</b>	National Cancer Survivorship Initiative		
<b>NDYP</b>	New Deal for Young People		
<b>NEET</b>	Not in Education, Employment or Training		
<b>NICE</b>	National Institute for Clinical Excellence		

# Appendix 2 – Policy map

General	Education, Employment and Training	Emotional and Psychological Wellbeing	Health and Recreation
Cancer Reform Strategy (CRS) DH, 2007	14 to 19 Green Paper consultation '14–19: Opportunity and Excellence	Education & Skills Act 2006	14–19 Education & Skills White Paper (2005)
Children Act (2004)	Access to Education for Children and Young People with Medical Needs 2001	Improvement, Expansion and Reform 2002	Aiming high for young people: a ten year strategy for positive activities, 2007
Every Child Matters (ECM), 2003	White Paper 'Your child, your schools, our future', published in 2009	Improving the psychological wellbeing and mental health of children and young people: commissioning early intervention support services (DCSF & DH, 2009)	Blueprint Drug Education Programme, Home Office
Improving Outcomes in Children and Young People with Cancer: The Manual 2005, NICE	Common Assessment Framework	Mental Health Act 1983	Choosing Health, making healthy choices easier 2004
National Cancer Survivorship Initiative (NCSI) DH, Sept 2008	Connexions: the New Opportunities White Paper	Mental Health Act 2007	Disability Discrimination Act 1995
National Service Framework (NSF), 2004	Disability Discrimination Act 1995	National Indicators for Local Authorities and Local Authority Partnerships: Updated National Indicator Definitions 2009	FRANK Drug Education Campaign, Home Office
NHS Cancer Plan 2000	Quality, choice and aspiration: a strategy for young people's information, advice and guidance (October 2009)	National Service Framework for Children, Young People and Maternity Services (NSF) – Standard 9	World Class Commissioning and Transforming Community Services programs
	Reducing the number of young people not in education, employment or training (NEET): The Strategy (2007)	National Service Framework for Children, Young People and Maternity Services (NSF) – Standard 6	Health reform in England: update and commissioning framework: Annex: the commissioning framework: (DH, 2006).
	Education and Skills Act 2008	New Horizons (DH, Dec 2009)	High Quality Care for All (DH, 2009)
	Entry to Employment (EZE)	Review of CAMHS 2008 and Government Response 2010	National Health Service Act (2006),
	New Deal for Young People 1998	Social and Emotional Aspects of Learning DCSF 2007	Teenage Pregnancy Strategy in 2000
	Panel on Fair Access to the Professions – Final Report, 2009, Cabinet Office	Targeted Mental Health in Schools programme 2009	Young People's Substance Misuse Strategy (HO, 2005)
	Education Act 1997	The Family Nurse Partnership Programme	Health Act 2009
	Education Act 2002		Youth Matters Green Paper, 2005
	School Standards & Framework Act 1998		Youth Opportunity and Youth Capital funds
	SEN Information Act – Research Paper, 2008		
	Special Educational Needs (SEN) and Disability Act 2001		
	Trade Union Reform and Employment Rights Act 1993		
	Children, Schools and Families bill		
	Youth Matters Green Paper, 2005		

## Appendix 3 – Diagnosis type and area of need importance ratings as indicated by young people

Area of Need	Haemato-logical (n = 67)		Brain (n = 13)		Bone (n = 14)		Reproductive (n = 13)		Other/1 (n = 12)		Total (n = 119)	
	Count	N %	Count	N %	Count	N %	Count	N %	Count	N %	Count	N %
Spending time at home during treatment	63	94%	13	100%	14	100%	13	100%	11	92%	114	96%
Keeping up a social life	62	93%	12	92%	14	100%	13	100%	11	92%	112	94%
Medical/clinical support close to or at home	58	87%	12	92%	14	100%	11	85%	11	92%	106	89%
Emotional support	56	84%	13	100%	13	93%	12	92%	11	92%	105	88%
Maintaining a healthy lifestyle	57	85%	11	85%	12	86%	10	77%	10	83%	100	84%
Getting advice or support on money matters	47	70%	9	69%	11	79%	11	85%	8	67%	86	72%
Keeping up with education/training	43	64%	9	69%	12	86%	6	46%	7	58%	77	65%
Practical support	25	37%	7	54%	11	79%	9	69%	6	50%	58	49%
Gaining or maintaining work/a job	32	48%	6	46%	3	21%	7	54%	5	42%	53	45%
Education/training OR Employment	56	84%	10	77%	12	86%	8	62%	9	75%	95	80%
Education/training AND Employment	19	28%	5	38%	3	21%	5	38%	3	25%	35	29%

## APPENDIX 4 – List of Statutes

- \* Children Act (2004)
- \* Disability Discrimination Act (2005)
- \* Disability Discrimination Act (1995)
- \* Education Act (1997)
- \* Education Act (2002)
- \* Education & Skills Act (2006)
- \* Education and Skills Act (2008)
- \* Health Act (2009)
- \* Mental Health Act (1983)
- \* Mental Health Act (2007)
- \* National Health Service Act (2006)
- \* School Standards and Framework Act (1998)
- \* Special Educational Needs (Information) Act, 2008
- \* Special Educational Needs and Disability Act 2001
- \* Trade Union Reform and Employment Rights Act (1993)

## APPENDIX 5 – Bibliography

- Cabinet Office (2009), *New Opportunities White Paper*
- Cabinet Office (2009), *Unleashing Aspiration: The Final Report of the Panel on Fair Access to the Professions*
- Children, Schools and Families Bill (2009)
- CLIC Sargent (2010), *More Than My Illness: Delivering Quality Care for Young People*
- CLIC Sargent (2009), *More Than My Illness, Delivering Quality Care for Children*
- Department for Children, Schools and Families (2001), *Access to Education for Children and Young People with Medical Needs*
- Department for Children, Schools and Families (2007), *Aiming High for Young People: a ten year strategy for positive activities*
- Department for Children Schools and Families, (2007), *Common Assessment Framework: Practitioners Guide*
- Department for Children Schools and Families (2003), *Every Child Matters*
- Department for Children Schools and Families (2009), *Quality, Choice and Aspiration: A Strategy for Young People's Information, Advice and Guidance*
- Department for Children Schools and Families (2007), *Reducing the Number of Young People Not in Education, Employment or Training: The Strategy*
- Department for Children Schools and Families (2007), *Social and Emotional Aspects of Learning*
- Department for Children Schools and Families (2009), *Targeted Mental Health in Schools Programme*
- Department for Children Schools and Families (2009), *Your Child, Your Schools, Our Future: Building a 21st Century Schools System*
- Department for Children Schools and Families (2005), *Youth Matters Green Paper*
- Department for Children Schools and Families (2006), *Youth Matters Next Steps*
- Department for Children Schools and Families & Department of Health (2009), *Improving the Psychological Wellbeing and Mental Health of Children and Young People: commissioning early intervention support service*
- Department for Children Schools and Families & Department of Health (2010), *Keeping Children and Young People in Mind: The Government's Full Response to the Independent Review of CAMHS*
- Department for Children Schools and Families & Department of Health (2010), *Teenage Pregnancy Strategy: Beyond 2010*
- Department for Children Schools and Families & Department of Health (2008), *Children and Young People in Mind*
- Department for Communities and Local Government (2009), *National Indicators for Local Authorities and Local Authority Partnerships: Updated National Indicator Definitions*
- Department of Health (2007), *Cancer Reform Strategy*
- Department of Health (2004), *Choosing Health: Making Healthy Choices Easier*
- Department of Health (2006), *Health Reform in England: update and commissioning framework.*
- Department of Health (2008), *High Quality Care for All: NHS next stage review final report*
- Department of Health (2002), *'Improvement, Expansion and Reform'*
- Department of Health (2004), *National Service Framework for Children, Young People and Maternity Services*
- Department of Health (2009), *New Horizons: Towards a Shared Vision for Mental Health*
- Department of Health (2000), *The NHS Cancer Plan: a Plan for Investment, a Plan for Reform*
- Department of Health (2009), *Transforming Community Services and World Class Commissioning: Resource Pack for Commissioners of Community Services*
- Evans, H. M. (1996), *Resource Allocation in Cancer Care. Health Care Analysis*
- Green et al. (2005), *Mental Health of Children and Young People in Great Britain*
- Hawkins & Lancashire (2010), *Educational Attainment and Employment Status in Survivors of Childhood Cancer in Britain*
- Hollen & Hobbie (1995), *Establishing Comprehensive Specialty Follow-up Clinics for Long-term Survivors of Cancer - providing systematic physiological and psychosocial support. Supportive Care in Cancer Vol 3, No.1*
- Home Office (2009), *Blueprint Drug Education Programme: The Response Of Pupils And Parents To The Programme*
- Home Office (2005), *Young People's Substance Misuse Strategy*
- Home Office (2003), *FRANK: Drug Education Campaign*
- Kelly & Gibson (2008), *Cancer Care for Adolescents and Young Adults*
- Langeveld et al (2002), *Quality of Life in Young Adult Survivors of Childhood Cancer Psycho-oncology, Vol 12, Issue 3*
- Larcombe et al (2002), *Lifestyle Behaviours of Young Adult Survivors of Childhood Cancer, British Journal of Cancer Vol. 87(11)*
- Madan-Swain (2000), *Identity in Adolescent Survivors of Childhood Cancer*
- M.M. Hawkins et al (2007), *British Childhood Cancer Survivor Survey*
- Monteleone, P.M. & Meadows, A.T. (2009), *Late Effects of Childhood Cancer and Treatment, Emecine Journal*
- Mulhern et al, (1995), *Health-related Behaviours of Survivors of Childhood Cancer, Journal Medical and Paediatric Oncology Vol 25(3)*
- Mulhern, R.K. & Palmer, S.L. (2001), *Neurocognitive Late Effects in Paediatric Cancer.*
- National Institute for Health and Clinical Excellence (2005), *Improving Outcomes in Children and Young People with Cancer: The Manual*
- Oxford Journal of Paediatric Psychology, Vol.25, No. 2 (2002), *Improvement, Expansion and Reform - the next three years: priorities and planning framework 2003-2006*
- Pendley et al (1997), *Body Image and Psychosocial Adjustment in Adolescent Cancer Survivors, Journal of Paediatric Psychology 22(1)*
- Robison et al, (2003), *Health Status of Adult Long-term Survivors of Childhood Cancer: A Report From the Childhood Cancer Survivor Study, Journal of the American Medical Association Vol.290, No.12*
- 14–19 Education & Skills White Paper (2005)

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