



## The New Normal

### An Evaluation of CLIC Sargent's Social Care (Enhanced) Service for Young People with Cancer

#### Executive Summary

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*"What I really needed was someone to help build a bridge back to normality. You can see what's there [on the other side] and CLIC Sargent helps you to get to it....It's about moving into and becoming comfortable in the new normal."*

#### Purpose and scope of the evaluation

CLIC Sargent commissioned Insley Consulting to carry out an evaluation of its Enhanced Service for young people with cancer between March and June 2015. The purpose of the evaluation was to assess and analyse how well the service has achieved its intended outcomes for beneficiaries; if it is fulfilling their needs; the extent to which beneficiaries were involved in reviewing and improving the service; and the views of wider stakeholders about the service itself and the policy context in which it operates. This report is an Executive Summary of the full evaluation.

The Enhanced Service operates UK-wide. In order to align with the external environment, particularly the NHS structure, this evaluation focuses on England, specifically: London, Leicester, Manchester (including Preston), Birmingham (including Stoke), Bristol (including Exeter) and Sheffield. Learning from this evaluation will be applied to the design and delivery of the service throughout the UK.

#### Key Findings

The key findings from the evaluation are outlined below, and are expanded in this Executive Summary of the evaluation. For the full context, see the main report.

- **1,173 young people were registered for the service** in 2014-15, although the number of open cases was almost double, at 2,270 (because the service is led by the needs of the young person and can be provided for up to two years).
- Most young people said that **the timing of CLIC Sargent's first contact with them was "about right"**; many described the referral process as **"easy"**.
- The service is **accessible "at the worst time of your life"**; staff get straight back to young people when they reach out for help. It is **tailored** to each person, so that it delivers the help that each individual wants and needs. It is **flexible and need's led**: The service has

been designed to enable Young People workers to adapt their offer to meet each person's needs.

- The service is **highly respected by professionals** who work with young people with cancer. They recognise the benefit of CLIC Sargent having **long-term contact** with young people, as well as Young People workers collaborating with external partners to provide **holistic care**. The **outreach service** was seen by many as one of CLIC Sargent's unique selling points.
- Young people engaged in this evaluation reported **99 incidences of a positive outcome** being achieved through the service, an average of three outcomes per young person. Emotional and financial support were most valued by young people.
- The support made them **"less stressed"**, **"able to look to the future"** and helped to **"rebuild confidence"** after a shattering diagnosis and sometimes debilitating treatment.
- Most young people experienced the negative financial impact of cancer; welfare reform, particularly delays to the receipt of Personal Independence Payments, was becoming a problem for some young people. They were **extremely grateful for grants** to help pay for increased phone bills and transport at a time when they were unable to work. Providing access to benefits and welfare advice gave young people **more independence, feel "less needy" and "more normal"**.
- When young people were in education, training or employment prior to their diagnosis, CLIC Sargent negotiated time off, or for their circumstances to be taken into account with grades; **returning back to college or work was a significant milestone for many**.
- CLIC Sargent is piloting the use of the Outcomes Star to monitor outcomes achieved through the service. Until this, or another suitable system is rolled out, there is a **lack of robust evidence of achievement of outcomes** for all beneficiaries.
- **Potential duplication** with Teenage Cancer Trust was identified in some areas through the development of a youth support outreach service within both organisations, although both are seeking to avoid duplication in order to maximise outcomes for young people.
- The service has completed phase one of a three-phase planned growth. Therefore, **not all aspects of the service are operating in all areas, and the service is not yet accessible to all young people diagnosed with cancer**. Therefore, the service should be extended, to reach all young people diagnosed with cancer who need and want it.

## Research methods

Young people were at the core of this participatory evaluation and were engaged through focus groups and one-to-one telephone interviews. They helped to devise interview questions and focus group plans, and results from the evaluation will be shared with young people.

- 37 young people participated from six areas in England: London, Leicester, Manchester (including Preston), Birmingham (including Stoke), Bristol (including Exeter) and Sheffield.
- Three Focus Groups were attended by 14 young people; 23 participated in telephone interviews.
- 33 out of 37 young people were age 19-24, only three were age 16-18, and one was age 25.
- 49% were male and 51% were female.
- 19 had received treatment in a local hospital, and 18 in a Principal Treatment Centre (PTC).

Information about the wider context of the service came from interviews with eight external partners. Two senior staff from CLIC Sargent staff were interviewed, and 15 delivery staff completed an online survey.

# INDEPENDENT EVALUATION OF CLIC SARGENT'S SOCIAL CARE SERVICE FOR YOUNG PEOPLE WITH CANCER

Delivered in England by

**28** Young People's Social Workers

**7** Young People's Community Workers

who helped **2,270** young people in 2014/2015

Young people described the difference made to their experience of cancer:



## EMOTIONAL SUPPORT

*"You want to speak to someone who isn't going to cry!"*

Less stressed and more relaxed

Able to look to the future

Less confused



## ACCESSING EDUCATION

*"They got Uni to recognise my essays so I could graduate."*

Motivated to go back to University

Grades boosted based on previous work

Received funding for course materials

## ACCESSING EMPLOYMENT OR TRAINING

*"I did voluntary work for CLIC Sargent. I want to do this sort of work now."*

More confident about return to work

Held on to job during treatment

Support received influenced career aspirations



## FINANCIAL ASSISTANCE

*"I felt less poor, less needy and more normal."*

Less financial strain on family

Received grants and benefits advice

More affordable debt plan negotiated



## PRACTICAL SUPPORT

*"She organised childcare so I could go to chemo without worrying about my boy."*

Secured better housing

Received wigs, which improved confidence

Re-negotiated contracts for gym & hire purchase



Supporting young people with cancer

Registered charity number 1107328 and registered in Scotland (SC039857), 15KF111



## The CLIC Sargent Young People's Programme

Around 1,800 young people aged 16-24 are diagnosed with cancer in England each year. CLIC Sargent registers around two thirds of these young people (1,173 in 2014-15), and has a longer-term aim of reaching all of them. It has developed a two-tier service model for young people with cancer, based on a *Universal Service*, which is open to all young people rather than being delivered according to assessed need, and an *Enhanced Service*, which is targeted at a higher level of need. Neither service is funded by the NHS.

The **overall aim** of the Enhanced Service is to enable young people diagnosed with cancer to both cope and live life to the full – during treatment and in preparation for survivorship (see over for the intended outcomes of the service). The service is delivered by a **skilled team** of Young People Social Workers (YPSW) and Young People Community Workers (YPCW), all of whom deliver needs led, holistic support for young people with issues including emotional support, family support, financial issues, education and employment.

The Enhanced Service is distinguished by the offer of face-to-face meetings with young people, often backed up by regular phone or text contact. The support offered is needs led by the young person and can be provided for up to two years (or one year after the end of treatment). In most areas, staff members have developed peer support groups for young people. In all areas, staff work within the Multi-Disciplinary Team (MDTs) and with a number of other agencies including the Teenage Cancer Trust and Macmillan.

## Policy and legislative context of the Enhanced Service

Although the service is not commissioned by the NHS, it operates in a challenging commissioning environment. The **Health and Social Care Act 2012** introduced national specialised commissioning of Teenage and Young Adult (TYA) cancer services, which is the responsibility of NHS England through the national TYA Clinical Reference Group (CLIC Sargent is a member). Local areas also commission certain services that young people access during and after treatment. National Service Specifications establish the commissioning arrangements for specialised TYA cancer services. Other measures and guidance that shape the delivery of services are NICE Guidance and the Peer Review Measures.

The complex nature of the health system and the wide range of professionals involved, who are subject to a variety of guidance documents, service specifications and reviewing mechanisms, means that it is difficult to have clarity about the national picture of delivery of young people's cancer services. The commissioning landscape was described as "*chaos and confusion*" by one Consultant.

The **Welfare Reform Act 2012** is impacting on many young people we spoke to, who were facing financial difficulties as a result of not being able to work and increased costs. Professionals interviewed expressed concerns about delays to Personal Independence Payments (PiP). CLIC Sargent has worked closely with Department for Work and Pensions to shape this legislation and has used evidence of young people's experiences to raise questions in Parliament about PiP delays.

CLIC Sargent is **proactively influencing the provision of cancer services for young people**. The case for change was articulated through its recently launched policy and influencing report, 'Children and young people's cancer services: Ambitions for the next 10 years' (CLIC Sargent, 2015) and in July 2015, a new campaign entitled 'Better care for young cancer patients' will be launched.

## **Outcomes for young people with cancer**

### **Support with improved emotional resilience and wellbeing**

All of the young people who participated in this evaluation were clear about the importance of the emotional support offered by the service, and said that this had a positive impact on their wellbeing and resilience. They valued someone to talk to who understood what they were going through and so could discuss concerns, prognoses and treatments; whose *“head is still on and can help to untangle the confusion.”* Young People’s workers remain calm in the face of the storm of a cancer diagnosis, and this allows young people to express their fears. They also support parents, siblings and friends. As young people moved through and out of treatment, the service helps them to rebuild their confidence and look to the future – often to re-plan their lives in *“the new normal”*.

### **Support with the practical arrangements which make living with cancer easier**

Young people greatly value the staff role of *“resource gatherer”*. They described the many small, practical interventions that make a big difference to the quality of life. They access funding to help young people and their families with the costs of transport, including to and from hospital appointments; and to enable family members to visit. They can help to renegotiate contracts (e.g. with landlords, hire purchase agreements, etc.) to minimise the stress of having to meet contract requirements when in hospital or unable to work. In turn, this can avoid debt. Four young people in the evaluation had children. When needed, Young People’s workers arranged funding for the costs of childcare, so they knew their children were being looked after during treatments.

### **Support to be more financially stable**

Financial support was cited as one of the most important aspects of the help and support provided. It made a great difference to young people’s ability to cope with their illness, to their change of circumstance and their quality of life, and meant they could better concentrate on treatment and on recovery. Young People’s workers give advice about eligibility for and access to welfare benefits. Young people living independently have received support with Housing Benefit, which has enabled them to have a home to return to after stays in hospital. CLIC Sargent can also help with grants for practical things like wigs and clothes after treatments led to weight loss or weight gain. Young people said that this help made them feel less isolated, less cut off from their friends and *“less poor...less needy and less stigmatised.”*

### **Support to keep up with education and learning, better able to stay in work, find a job or build a career**

Many young people who are at college or university may think that their cancer diagnosis will end their education. Young People’s workers help them to stay the course, for example by negotiating extended deadlines, and making sure that essays are marked when young people are not attending classes or lectures, or helping with funding for course materials. Young People’s workers offer support with similar issues in relation to employment. They negotiate with employers for time off for treatment so that young people do not lose their jobs and help young people to get the right levels of sick pay, and negotiate phased returns to work.

Young People’s workers play an important role in informing schools, universities, employers and co-workers about the needs of young people with cancer. This enables both the institution/employer and the individual to feel more confident about a return to work or education during or after treatment, and to understand what each young person will need on their return. Young people said that the service helped them to consider their futures with a new mind-set.

## Strengths and challenges

### Strengths

**Young people value the service very highly;** it achieves its intended outcomes. Every beneficiary we spoke to benefited from emotional support, which helped them to look to the future and find their pathway through cancer. Three quarters of young people engaged in the research said that the service helped them to become more financially stable. Many were supported to return back to work or education.

**Young people's voices** are sought and heard at all levels by CLIC Sargent. The extent of young people's engagement is evidenced through the achievement of the National Youth Agency's 'Hear by Right' gold award. Through evaluations, the management and planning of services, young people's feedback and experience is being extensively used; they feel it is a good use of their time.

**Peer support** has been arranged in all of the areas in this evaluation and is highly valued by young people. It offers opportunities to meet with others and share the experience of cancer. Many gain confidence and coping strategies from their peers and going out with others helps to rebuild lives changed by the experience of cancer. Peer support gives a clear signal "*that survival is possible*". Young People, and the staff who support them, said that the service would be improved with more opportunities for face-to-face peer support, including topic-led groups such as bereavement.

The evaluation found that CLIC Sargent **works with other services** to tailor packages of support for young people, avoid duplication of services at a local and national level, identify gaps, and seek to fill them. None of the young people we interviewed said that they had noticed any duplication between CLIC Sargent and other services. They were clear that the CLIC Sargent service is unique and highly valued because it matches young people's interests to the right resources and makes good referrals to other agencies.

Local and national stakeholders cited evidence of partnership working, a robust referral process and a commitment to filling in the gaps. CLIC Sargent was described as "*pivotal*" and "*important*" to the multi-disciplinary team (MDT), enabling the NHS to provide age-appropriate care to young people with cancer.

### Challenges

There are, inevitably, challenges with the service. The first of which is that CLIC Sargent registers around two-thirds of young people diagnosed; the service cannot yet be provided to all young people with cancer who need it. As funding allows the service to expand, CLIC Sargent will be well placed, through its outreach work to seek to **reach, engage and refer young people being treated in local hospitals** (and are not receiving TYA services), to the MDT and support available through CLIC Sargent.

Although there is evidence that there is collaboration to avoid duplication, concerns about **potential duplication of services with Teenage Cancer Trust** was flagged up as an issue, particularly as both organisations are extending outreach services for young people.

CLIC Sargent has a robust monitoring tool to assess the quality of the service. However, **evidence of impact** is not being routinely gathered in all areas, which is a weakness of the service, although the Outcomes Star is being piloted in some areas (with results not yet available for this evaluation). More detailed and up-to-date information on the cost of the service was also noted as in need of improvement.

## Key recommendations

The key 'high level' recommendations are outlined below (ordered as in the main body of the full report; the 'Section' number relates to the section of the main report in which the context of the recommendation is outlined). See Section 6 of the main report for a list of all recommendations.

**Recommendation 9, 7 and 19:** As resources allow, continue with the next stage of the phased implementation of the Enhanced Service to provide in-depth support to more young people (Section 5), particularly those living in rural areas or being treated in local hospitals.

**Recommendation 4:** Pending the results of the Outcomes Star pilot, implement a robust method to routinely gather data on outcomes achieved by young people in order to demonstrate the impact of the service using evidence gathered from all beneficiaries (Section 4.6).

**Recommendation 5 and 6:** Explore the potential to provide increased access to topic-led peer support groups and increased bereavement support, perhaps in partnership with others or as part of the online community, as part of next stages of service planning (Section 4.7.1 and 4.7.2).

**Recommendation 12 and 13:** Work with Teenage Cancer Trust to identify and avoid duplication of local services in order to maximise outcomes for young people. Continue to work with local NHS managers to ascertain how CLIC Sargent can best complement NHS services (Section 4.8.3).

**Recommendation 14:** Explore more opportunities to collaborate and work in partnership with other organisations to meet young people's need (Section 4.8.4).

**Recommendation 15:** Explore gaps in external services further in the Needs Assessment in order to understand young people's needs in more detail, and to ascertain if there is an opportunity to fill gaps through CLIC Sargent's specialist services and in collaboration with others. Where gaps are clearly outside of CLIC Sargent's remit, seek to influence others to fill gaps in services.

**Recommendation 16:** Undertake a robust assessment of the cost of providing and expanding the Service, with a Full Cost Recovery approach, in order to be able to benchmark against external data (Section 4.9.1).

**Recommendation 17:** In the context of a wider influencing programme, continue to influence improvements to welfare reform, specifically the PIP assessment and payment system, to ensure that they do not disproportionately adversely impact on young people with cancer (Section 4.11.2).

**Recommendation 18:** In collaboration with other providers, seek to ensure that all TYAs have age-appropriate care and support regardless of the medical setting in which they are being treated, by influencing the NHS to implement current guidance and update it where necessary (Section 4.11.2).