



Young people's community workers pilot

Evaluation report

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Summary

This report is an independent evaluation of a CLIC Sargent two-year pilot to test the effectiveness of a new community worker role in enabling 16–24 year-olds with cancer to deal with a range of challenges they face during and after treatment, so they can live life to the full.

The evaluation was conducted between November 2012 and March 2013 by Kate Gledhill, an independent consultant with 30 years experience working with children and young people in the public and voluntary sector. She used a range of approaches: evidence from 57 young people supported by the service, 10 members of NHS Teenage and Young Adult Multi-disciplinary Teams, and key CLIC Sargent staff; a case file audit; and an analysis of the pilot's needs analysis system.

Note: during the pilot project the role was known as the CLIC Sargent Community Young Adult Worker, following the results of this evaluation and CLIC Sargent's decision to continue and expand the service, the role is now known as the CLIC Sargent Young People's Community Worker, and is referred to as such throughout this report.

About CLIC Sargent

Today, 10 children and young people in the UK will hear the shocking news that they have cancer. CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide clinical, practical, financial and emotional support to help them cope with cancer and get the most out of life. We are there from diagnosis onwards and aim to help the whole family deal with the impact of cancer and its treatment, life after treatment and, in some cases, bereavement.

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Introduction

Many of those taking part in the evaluation described the developments there had been in work with teenagers and young adults with cancer over the past few years, and how important it was that this focus was now being placed on a group of service users who historically had had a second rate service to that provided to younger children. It was felt that young adults (particularly the 19 to 24-year-olds) were much harder to engage than younger children in hospitals, and that approaches to working with them had to have an investment of time, be understanding of, and flexible to, the particular circumstances of young adults and be able to remain committed to working with them despite difficulties in engagement.

Within this context, in 2011 CLIC Sargent recognised a gap in service provision for teenagers and young adults aged 16-24, many of whom were not receiving treatment as inpatients at a principal treatment centre (PTC). As a result, the charity launched a pilot initiative establishing the role of young people's community worker in five regions – Birmingham, Southampton, Cambridge, Glasgow and Nottingham. The aim of the pilot was for the new posts, which were created out of existing youth development worker posts, to offer services in the community (anywhere outside hospital) and with a particular emphasis on employment, education and training.

Birmingham, Southampton and Glasgow have taken part since the outset of the pilot, with Cambridge and Nottingham joining later. However, each pilot area had their own, distinct set of circumstances into which the initiative was launched, in terms of:

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- Existing post holders – skills, expertise, current workloads
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- Relationship to the local multi-disciplinary team (MDT) – in particular with clinical nurse specialists and lead nurses
-
- Existence of other service providers including Teenage Cancer Trust
-
- Size of CLIC Sargent team
-
- Demographics of the existing service – geography, potential service user numbers
-
- Existing resources within services for teenagers and young adults in each area (eg age specific units, drop-in facilities).

These differences have, inevitably, had an impact on the way in which the young people's community worker posts have developed in each region. It is important to say at this point, that in very few ways was the evaluation comparing like with like. What I have attempted to do in this report is to draw out themes; underlying principles/approaches to the work, workers' skill bases and other areas that are common or shared amongst the pilot areas.

The evaluation was asked to examine and report back around a range of issues. This report addresses the following areas:

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- Division of responsibilities between team members
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- The post – skills, approach and added value

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- An analysis of the priority areas of need

 - Community outreach

 - Referral pathways

 - Assessments and care plans

 - The use of the Rickter Scale as a planning tool

 - Evidencing impact

 - Participation of young people

 - Post treatment services

 - The professional network

 - Potential barriers and risks.

Methodology

A range of approaches were used to gather information about the perspective and experience of all the major stakeholders.

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- A questionnaire was sent out to 100 young people who had received a service as part of the pilot (of which 36 replies were received, approx. one third of those sent out)

 - Six young adults took part in two semi-structured focus groups

 - Semi-structured telephone interviews were held with 15 young people across the pilot areas

 - Semi-structured interviews were held with:
 - each of the five young people's community workers
 - the CLIC Sargent team leader in each area
 - the young people's social workers in four areas

 - Semi-structured interviews were held with seven MDT professionals across the regions and email contact with two consultants

 - A case file audit was carried out on a randomly selected third of the young people worked with under the pilot in each area

 - An analysis was undertaken of the priority needs identified for each young person as recorded using the tool developed for the pilot.

Copies of the questionnaire, questions used in interviews and groups and areas examined within the case file audit are attached as appendices A – D to this report.

Findings

Roles and divisions of responsibilities between team members

It was in this area that it was most possible to see regional differences and the impact that the worker in post (their experience, expertise, interest etc) had had on the way the young people's community worker post had developed. The job descriptions for both the young people's community worker and young people's social worker posts, although different, have a range of cross overs in relation to assessments and care planning, providing individual support, delivery of activities, a requirement to network and signpost and reference to employment and education issues for young people.

In all but one region, both social workers and young people's community workers undertake assessments and care planning for different young people. It is clear that all five young people's community workers have the skills and experience to undertake these tasks but the decision about whether or not they do seems to have grown out of the need of the team in which they are placed. Where referrals are very high, where the young people's community worker has a social work background or where there are high numbers of referrals from designated hospitals across a large area, it seems more likely that the young people's community worker will be undertaking a role very similar to that of the young people's social worker in terms of assessments and care planning.

In respect of the tasks actually undertaken by the young people's community worker, again there were some regional differences. There was an agreement with all that providing emotional support, particularly around issues of self esteem and confidence, was fundamental to the role of the young people's community worker (this was also borne out in the feedback from young people). Some areas had a clear concentration on education, employment and training, with others engaged in a wide range of intensive emotional support including through palliative care and seeing the more practical assistance with housing, finances and employment issues as a social work role. Other young people's community workers took on virtually any aspect of a young person's life that they needed support with.

"It's about confidence building and motivation, to feel safe in themselves in the world. Practising small steps, building on what they have, building resilience. We help them to be aware of opportunities available to them, opening up the world again. Personal development that sort of stuff. Readjustment of life plans and support with practicalities, eg going to interviews, google searching, CV writing. Helping young people see they can go for it. A move to being more of an adult and less of an overprotected child – support to take risks and move forward." (Young people's community worker)

However, it was possible to evidence a shared understanding about the underlying approach of the young people's community worker across all the areas. The young people's community worker is seen very much as being focused on, around and for the young person - "we work with the young person's views and experience"; whereas the social worker role is seen as being more systemic and working with the young people within the context of their family. Consequently, the young people's social worker would offer support to the family members of a young person and were described as being allocated cases that were requiring more complex treatment and/or had a range of other presenting issues alongside the issue of cancer. In the main, the work of the young people's community worker was seen as being part of helping a young person hold on to life outside of cancer, either post-treatment and transitioning back or maintaining a focus on keeping life as "normal" as possible through treatment, eg with friendships/relationships, employment or education.

"Their health and treatment has been everything, this helps them to remember that there is life in addition to cancer." (MDT member)

In three of the five regions the young people's community worker was described as working more with young people who were post-treatment – that being the time it was felt the young people were most likely to be needing support to look at resuming employment, education or training and were struggling with issues connected with transitioning back. However, in all areas, the young people's community workers supported young people who were in treatment and all but one would support a young person who was receiving palliative care. However, even in the region where the young people's community worker would not be presumed to have a role in palliative care, the team leader felt that if this was the worker with the closest bond to the young person then they would be the obvious person to provide that support. In one area the young people's community worker was described as doing only a small amount of post-treatment work, as cases were generally closed fairly quickly post-treatment because of referral numbers. What was clear across all the pilot areas, was the degree of flexibility, discussion and assessment about which staff member (young people's community worker or young people's social worker) was most appropriate to work with a particular young person. Although the criteria about who worked with which young people might vary across the areas, each pilot had a consistent approach to these decisions, that was shared across the team and was working, or beginning to work, locally.

Another main, and shared, distinction between the role of the young people's community worker and the young people's social worker was that of the time spent with the young person.

"Social workers can't offer the intense and focused work that young people's community workers can. They have the time to build up a young person's self-esteem, help a young person to take baby steps, help them to try things even if they don't seem like a good idea." (Young people's social worker)

This time was largely seen, by the staff and the young people themselves, as being spent building up relationships that provided support with motivation, confidence, body image, self-esteem, post-treatment anxiety and negotiating with education establishments and employers who “didn’t get it”. Another important aspect of this role for all was around linking young people into groups and activities where they could meet up with other young people in similar situations to themselves. Again this was strongly supported by the views of the young people who took part in the evaluation; the majority of whom highlighted the access to other young people as one of the most important things their young people’s community worker had made available to them.

The post – skills, approach and added value

There was largely a clear consensus amongst both professionals and young people about what sorts of skills the young people’s community worker needed to have – and often these were the same skills as for the young people’s social worker. The young people were asked to help come up with a person specification for the post which is attached to this report (Appendix E) in full, but included: listening, understanding, someone you can have a laugh with, sociable, experienced in working with young people, ready to be there for the hard conversations, care about how we feel, respect and don’t judge, be able to ask the right questions and think outside the box.

Professionals highlighted many of the same attributes and core skills (even if they did use different terminology to describe them) – non-judgemental, willingness to hang on in there, ability to build trusting relationships, empowering, open and honest communicators, and have an understanding of the impact that having a life-limiting/threatening illness has. In the main it was also felt important that young people’s community workers had previous knowledge/experience in the areas of personal development for young people or education issues. The ability to provide emotional support was a consistent theme but had a quite a wide definition as to what this might cover, right up to requiring therapeutic training or qualifications.

The young people taking part in the evaluation had had their young people’s community worker for anything between two weeks and two years, so their answers give us a good cross-section of experience across the range. Given that the responses were almost completely positive, with only one or two suggestions for improvements, one could assume that the workers are building positive relationships and meeting needs from the outset and continue to remain important to the young people throughout their journey, wherever it may take them.

Through the evaluation, the young people were asked a number of questions aimed at establishing aspects of the post that might be specifically important to the relationship, or might mark them out from other workers involved in the life of a young person at this time. Accessibility to their workers, in addition to the community-based aspect which is covered later in this report, was seen as very important to the young people. Of the 36 young people who responded, 27 of them said that it was very easy to stay in touch with their young people’s community worker, the remaining eight said that it was quite easy. No young person expressed any kind of difficulty.

“He is always on the end of the phone.”

“Because whenever I ask him to phone me he does straight away.”

“All I have to do is pick up the phone. She also rings me when she thinks I might be down – very helpful.”

“I can text or email and always get a rapid reply.”

“She is always keeping in contact asking how I am and if I am keeping well. I have a mobile phone number and email. She never fails to reply to me within a day.”

The only more negative comment in this section was from a young person who said there had been a delay in processing their Disability Living Allowance application and that several weeks had passed without them hearing from their young people’s community worker about it.

In addition to the ease with which young people are able to contact their young people’s community worker, they described this flexibility continuing into how often they see their worker. Again there was a wide range of answers from every week/couple of weeks through to every couple of months; in line with hospital appointments or at social groups. Whatever the frequency there was a clear indication that the timing was in line with the wants and needs of the young person:

“When I need help with something, no set times.”

“When I was in hospital every other day. When at home a visit would be arranged for every other week due to my own choice.”

“Fairly regularly at the start of treatment but not as often now.”

“Once – I had a good talk with him and have not requested further help.”

“Just when I need help or advice or if we are going to talk something over, eg CV.”

“She contacts me on a regular basis. She doesn’t hassle me but she’s always there as and when I need her.”

The evaluation aimed to draw out from young people the aspects of the working relationship with their young people’s community worker that were important, different or additional to the services they received anywhere else. The accessibility and flexibility of the relationship described above, combined with the young person-focused/led approach to the work (see participation section below) clearly help with establishing trusting relationships that many

young people described as pivotal in their lives, but one that does not make them feel any sort of pressure or responsibility:

“The comfort of knowing that someone is there to give you support or any help other than family is important.”

“He is a good support worker and helps in the way that he takes some of the strain of everyday life off me. When I feel too tired and weak to handle something he always steps in and helps to sort out the problem until I am feeling better.”

“She has been there when I needed her and makes me feel that I could rely on her on practically anything in my life.”

In trying to establish the added value of the posts in the lives of young people, they were asked to comment on how different the support from the community worker was compared to support from other members of their care team, and how useful each aspect of the service was (31 young people answered this part of the questionnaire):

- The types of things the young people’s community worker helped them with – 28 said different to the support from others and all said useful
- The time the young people’s community worker spends with them – 23 said different to others and all said useful
- The amount of emotional support the young people’s community worker offers – 23 said different to others and all said useful
- The way in which the young people’s community worker works with them – 27 said different to others and all said useful.

When examining further the “types of things” the young people worked on with their young people’s community workers that were different, what came out was the focus on trying to maintain a normal life, keeping going with “life outside cancer” and picking back up and moving forward after treatment. This would seem to provide evidence that the aim for the post is being delivered and appreciated by the young people as providing an additional and valuable resource in their lives.

Meeting the need

In order to establish what service the role was actually delivering, an analysis of the priority needs recorded in the pilot tool was undertaken. To check whether this coincided with what young people felt that they most needed, and those they had in fact received from the young people’s community workers, the young people were asked to comment (both verbally and via the questionnaire) on what work they had done with their young people’s community worker.

As the tables opposite evidence, it was emotional support that was most consistently identified through both streams as being the priority need and task.

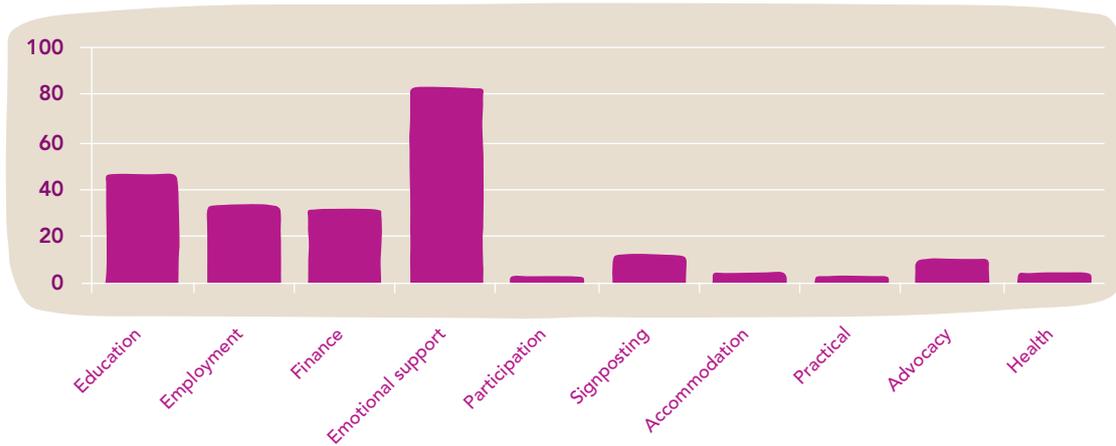


Table A: breakdown of needs identified in the recording tool. A total of 240 needs were recorded across all five pilot areas (many young people had more than one task with which they wanted help).

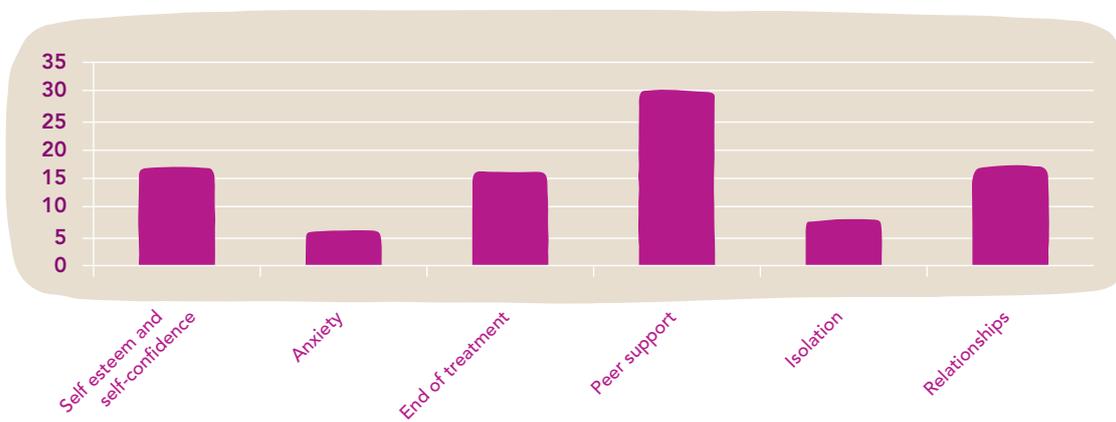


Table B: breakdown of what emotional support covered.

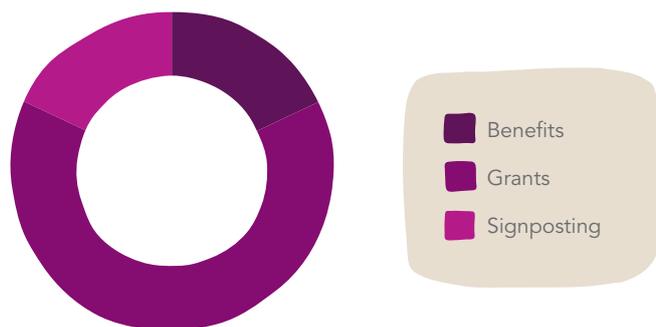


Table C: breakdown of the nature of financially-related tasks.

Over 85% of the young people who took part in the groups and telephone consultations stated that they had had emotional support from their young people’s community worker and that this had been extremely important to them.

Approximately 85% of the young people who had emotional support recorded as a priority need were referred to peer support groups and activities. Of the young people spoken to, over 80% said that they had attended groups and really benefitted from them, with one young person saying that the group had been “the best thing about this whole business”.

Analysis of the questionnaire responses regarding the kinds of things that their young people’s community worker has helped them with are represented in Table D below.

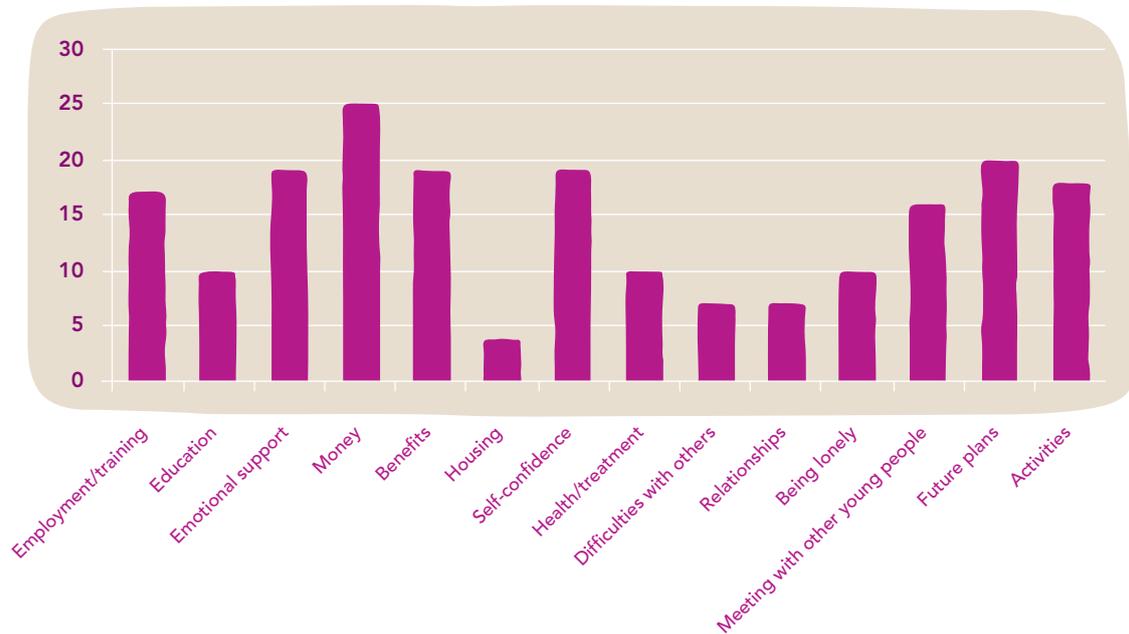


Table D

Once again we see a similar focus on financial matters, issues to do with emotional support (including self-confidence and being lonely), employment and education and the chance to meet up with others as being the primary areas of concern that the young people have used their young people’s community workers for.

Community outreach

The pilot had hoped to meet a perceived need for a service for young people with cancer that was community-based. There is clear evidence that this has been achieved and is widely appreciated by both young people and other professionals, but possibly even more important for the young person is the flexibility of the approach, in that young people’s community workers met with young people where they wanted and that varied depending on what was happening for them at any particular time.

“It seems to me that we can meet anywhere that is convenient to me.”

The range of reasons why this arrangement works well for young people is illustrated by the quotes below:

“Because I live in Ipswich and used to have my intense treatment in Cambridge I saw my worker a lot in hospital. Then with less treatment she came to mine.”

“We met in hospital because this is usually where I am at my most vulnerable so it’s nice to be reminded that the support is there.”

“I feel more comfortable in my own environment.”

“Flexible depending on where I am, it always makes me comfortable knowing they will support me wherever I want.”

“It’s easier for me because I don’t have to pay any travel costs to go to the hospital.”

“I rely on public transport and struggle to get about.”

Young people completing the questionnaire were asked to say where they met their young people’s community worker and whether or not this arrangement was okay for them. Of the 36 young people who answered this question, 23 said that they met up outside the hospital and all but one young person said that this arrangement worked well for them. This was a young person who met with the young people’s community worker in hospital and the reason given by that young person was:

“I feel I would rather have more visits at home because in the clinic it is often crowded and noisy and not private.”

This would reinforce that the drive to meet young people outside the hospital environment is right and that it is extremely important to continually check out with the young person if the arrangement is right for them, and to guarantee to meet their need for community-based contact if that is what they choose.

The young people completing the questionnaires also highlighted that the ability to meet outside the hospital setting was a factor which separated the service they got from their young people’s community worker from other services. Out of the 31 young people who completed this question, 23 said that it was different to other services and 100% of those replying said that this was a useful difference.

Professionals across both the MDTs and CLIC Sargent teams highlighted the community aspect of the young people’s community worker role as being of great value. Medical staff are largely appointment and hospital-based. The teacher at Queen Elizabeth’s Hospital in Birmingham is also hospital-based and specifically mentioned the benefits of the combined working with the young people’s community worker who can follow through and support young people in the community with homework and invigilating exams that he as a teacher can set up from the hospital. It was repeatedly stated during interviews that larger numbers of referrals on behalf of the older age group of young people were now being received and it was felt that this was in part to do with better communication with designated or shared care hospitals, and partly because of the growing visibility of this group and the accessibility of the young people’s community worker as someone who could and would travel to the young person. However, there were also some concerns expressed about being able to meet expectations and requests for services if too many referrals were received.

Referral pathways

The referral pathways have developed locally to be able to fit with existing structures and systems. In three areas the young people's community workers are part of, or attend, the MDT meetings and decisions are made at those meetings about which person is best placed to work with them. For the remaining two areas, referrals to the young people's community workers are made through the young people's social workers who receive referrals from the clinical nurse specialists.

The main issues impacting on referrals to the young people's community workers are:

- The relationship with the MDT and in particular the clinical nurse specialists. This may be an historical issue between the MDT and CLIC Sargent and based on how the charity is viewed and the priorities of the clinical nurse specialists. There is always the possibility of tension and conflict when a number of organisations come together to provide joined-up services. In some areas there are at least two charities and health services together, all with competing priorities.
- The relationship between the designated hospitals and the principal treatment centre (PTC). It was clear that some of the pilot area PTCs and MDTs were having to spend a considerable amount of time building links with clinical nurse specialists in designated hospitals and so ensuring all potential referrals were coming first to the MDT and then to CLIC Sargent staff.

It was felt that the take up by young people of referrals to young people's community workers was impacted on by a number of things:

- Timing of referral to the young people's community worker – this needs to be at a time that makes sense to a young person with respect to their treatment, their feelings about their lives and plans etc.
- The referral coming from a trusted and known source
- Introductory meetings to the CLIC Sargent Young People's Community Worker by a care professional known to them
- Direct contact being made in person or by phone.

Uptake of referrals to the young people's community workers in most areas was above 80% if the above requirements were in place. Young people themselves highlighted the importance of a direct approach rather than a leaflet or letter if they were to feel confident to take up the offer of a service. Of the 36 young people who completed these questions on the questionnaire, only one had become engaged with a young people's community worker as a result of a letter, 18 had taken up the service because of a visit from a CLIC Sargent care professional and 21 because it was recommended by a member of staff at the hospital. This would appear to further support the premise that direct approaches increase the likelihood of a take-up of a service.

When asked why they decided to work with CLIC Sargent, all the young people consulted talked about the personal attributes of their young people's community worker as one of the deciding factors:

"Approachable and friendly."

"They talk on my level."

"Laid back."

"I was the youngest person on the ward by far and it was so good to meet up with someone who knew what that was like."

"They came to me in my time of need."

"She was on the end of my hospital bed one time."

"They contacted me and seemed really helpful and I thought it would be nice to meet up with others in my position through them."

The case file audit showed that the time between diagnosis and referral to CLIC Sargent had decreased during the pilot. From records it appeared that 90% of young people were seen within one week of referral. These are positive findings that were reinforced in discussions with young people and in feedback from other professionals. Young people described meeting their CLIC Sargent community worker at diagnosis, whilst in hospital in the early stages and having a home visit within a week. All of which they felt very positive about.

There were two young people who responded to the questionnaire who had only found out about CLIC Sargent at the end of their treatment and this was a very disappointing issue for them.

"I was put in touch via my hospital, however they only passed the details on at the end of my treatment when I would definitely have benefitted if I had known sooner ... I would have loved someone to support me through all my hospital appointments and someone to ask questions to, but unfortunately I was at the end of treatment before I knew about CLIC Sargent."

"When I was diagnosed the first time with cancer I didn't have any knowledge of CLIC Sargent and I felt frightened all the time."

It would appear from the rest of the questionnaire that these young people were not treated at one of the principal treatment centres, which would again strengthen the argument for the amount of work that is currently being put in by many to raise the profile of CLIC Sargent, and the young people's community workers in particular, in designated and shared care hospitals.

Whatever the referral route, the CLIC Sargent care professionals, including the young people's community workers, were evidently viewed as integral, professional and vital parts of the network by the other professionals.

Assessments, care plans and recording

The links between assessments, care plans, the pilot priority needs recording tool and recordings on contact sheets were reviewed as part of the case file audit and a range of issues identified:

- Inconsistency in recording of assessments and development of care plans
- Assessments sometimes completed several years ago and no record of them being updated
- Difficulties in identifying a thread between the priority needs recording, the assessment, the care plan and then evidence in the contact sheets that the care plan is being actioned
- Needs identified but limited information about how the need will be met and actions to be taken as part of the care plan.

From talking with young people and staff, and from the files themselves, it is clear that needs are being identified, tasks being agreed to meet those needs and action being taken on those tasks. For example, contact sheets record discussions with young people that establish the areas they want help with and then later contact recordings provide evidence of steps taken by young people's community workers to carry out those tasks, but this has not been transferred into an assessment or care plan – so undervaluing and misrepresenting the work that is actually happening. There were, however, also some examples of a clear link between all the various aspects of assessment, planning and delivery.

This is by no means an unusual situation and one that young people's community workers and managers were very aware of. Young people's community workers often struggled with the notion of an "assessment" with some saying that they never used that term in their work with young people.

"We don't use the word assessment. We go and meet and find out what's been going on. Let them lead and if something comes up we offer help. We ask questions because we know what to ask based on our previous experience, but it's about finding out from them."

As is said above, in all but one of the pilot areas, both young people's social workers and young people's community workers undertake assessments. This may in part be because of the type of assessment being less like a formal social work assessment and analysis, and more of assisting young people with identifying their own needs and where CLIC Sargent can offer assistance.

Questions were raised by two health professionals about why CLIC Sargent undertook their own assessment, given that a very detailed assessment had just been carried out and was shared with CLIC Sargent care professionals.

During the case file audit, it was found that in 80% of assessments reviewed there were no comments recorded from the young people. This would imply that the service offered is not based on partnership and participation – rather one that is done to, as opposed to for, the young person. However, this was not borne out in any other part of the evaluation. In fact, the opposite was found to be true when discussing the approach with both CLIC Sargent care professionals and young people. Once again recording issues are misleading and providing false evidence about the nature of the work actually being undertaken.

One of the difficulties cited by staff in completing the required recording for assessments and care plans was the recording procedures themselves. They were experienced as repetitive and often duplicated one another eg the priority need recording tool and the assessment. One young people's community worker stated that she spent about 30% of her time carrying out admin.

There was also a concern that the recording systems encouraged a more task-focused approach to the work.

An important aspect of the approach of young people's community workers as identified by young people, was their flexibility and their informality, a clear sense from the young people that they were in charge of the work, that they led. Although fully understanding the organisation's need to be able to evidence impact and outcomes, the young people's community workers were concerned that this need might take over and impact on the delivery to young people:

“Performance indicators won't take account of the value of building a relationship.”

“It's the journey not the task, young people feel very out of control and this is about helping them to have more control.”

During the evaluation a number of staff raised questions about how much young people themselves were aware of what was recorded and why. Some young people's community workers said that they told young people that they wrote notes so that they (the young people) wouldn't have to keep repeating themselves and other people in the team would be able to help them. But there remained for some contributors the issue of “why we record what we record” and a feeling that as an organisation this was not necessarily clear.

The use of the Rickter Scale as a planning tool

The Rickter Scale had been used by each of the young people's community workers on at least one occasion. None of the young people's community workers felt that it was an ineffective tool, however they did think that rather than being “an assessment tool of choice” it was more like one in a “bag of tricks” that they could pick and choose from. They described the tool as being particularly useful when working with young people who appeared to be stuck, or who found talking about themselves and their feelings very difficult. However, the young people's community workers also felt that thought had to be given

to the young person (a few young people had had it offered to them and had felt quite patronised by the idea) and where the meeting was taking place, for example it wasn't easy to use in a public space like a coffee shop.

“Not appropriate in all settings and with all young people. But one time I did it, it worked really well, uncovered things and it gives young people control over what they see as the issues and where they want to go.” (Young people's community worker)

The feedback from the young people who had used the Rickter Scale was also very positive:

“It helps you think through things, helped me to see links.”

“It helped me because I was blocked and just going round in circles.”

“I was able to say how I felt with it – it helped me see stuff.”

“It was good, it was an easy way to put how you feel without talking or writing.”

“It's good to get to the bottom of problems, go through them one at a time and sort out a solution.”

Evidence wasn't seen of a review of previous scoring and one young person did mention that they had never gone back to it and so that had limited the impact in terms of being able to see what had improved.

Other, more unexpected benefits of the scale mentioned by young people's community workers were that whilst completing it there was no need for eye contact between them and the young person, which for some was a positive when trying to talk about difficult things. Another young people's community worker said that because the young person was occupied it was possible for the community worker to be writing and reflecting as they were working together rather than having to make notes following the meeting.

The evidence found would lead to the conclusion that it is a useful tool, when used at the appropriate times, at the choice of the young person and by a young people's community worker who is confident to use it. However, it is one of a number of similar tools or ways of carrying out direct work (eg the feelings thermometer, the mind map, or solution-focused brief therapy approaches) and that young people's community workers feel most confident about being able to use it in that way. It was not felt to be a good tool to use to provide evidence of impact and outcomes. The perception was that to use the scale in this way would be too prescriptive and end up leading the work with young people rather than being on offer to assist them with their thinking and exploring.

Evidencing impact

It is universally difficult to provide evidence of the sort of “soft outcomes” that are fundamental to the pilot. There are a number of tools that have been developed as assessments that can then be revisited at regular intervals to see if improvements have been made and to be able to provide evidence of outcomes met. However, as described above, there was a repeatedly expressed concern amongst staff that the need to gather evidence and prove outcomes should not by default end up leading the work with young people.

As part of this evaluation the young people themselves were asked to rate the impact working with their young people’s community worker had had on their lives. To provide a focus for the rating exercise, the domains of Resilience theory were adapted. Young people were asked as part of the questionnaire to rate the impact between one and 10, where one was equivalent to no impact and 10 was major impact/help:

Education/training or employment

Score	1	2	3	4	5	6	7	8	9	10
No. of young people	2		2	3	3	3	5	1	1	11

Friendships and social life

Score	1	2	3	4	5	6	7	8	9	10
No. of young people	5		2		4	4	5	8	1	7

Confidence to manage your life

Score	1	2	3	4	5	6	7	8	9	10
No. of young people	2	2		2	3	1	2	9	5	9

Ability to take up or continue with hobbies or leisure interests

Score	1	2	3	4	5	6	7	8	9	10
No. of young people	3		3		7	4	5	5	3	2

Support and contact with family and friends

Score	1	2	3	4	5	6	7	8	9	10
No. of young people	4	1		4	6	1	3	1	6	9

Feeling that you have at least one person who you can trust and rely on to be there for you

Score	1	2	3	4	5	6	7	8	9	10
No. of young people	1			1	1			3	6	23

These findings are obviously not an exact science, nor pure research, and like many assessments of “soft outcomes” are affected by the mood and other external circumstances of the person at the time of completing the questionnaire. However, it is important to note that of the 34 young people completing various sections at least 55% scored six or above in each area. Given that one of the main objectives for the pilot was to provide support with education and employment, it is encouraging to see that this scored highly. And given the emphasis on emotional support evident within the needs analysis, and feedback from young people, it is also important to see that “having someone there for you” is the area in which young people feel most clearly that there has been a significant impact:

“Definite impact on my future and what I may do.”

“Most definitely have benefited in how I feel about myself thanks to talking.”

“It’s given me motivation. I have targets each time and because I know I’m going to meet my community worker I know I have to do the things I’ve promised. And bit by bit I’m doing more – I had a hair cut today and that’s big for me.”

In comparison, the young people’s community workers were asked what impact they were aiming to have on the life of a young person by their intervention. Generally they were not particularly prescriptive, more providing an approach to the work that responded to the needs and circumstances of the young person:

“For this age group there is so much going on they can get left behind. We are helping them cope with life as they knew it and know it now. It’s about keeping in touch, supporting them through diagnosis and treatment and helping with difficulties arising – friendship, employment etc.” *(Young people’s community worker)*

Participation of young people

The evaluation considered two aspects of young people’s participation in the pilot:

- Participation in service development within CLIC Sargent and the wider cancer field
- Participation within the context of their individual work with their young people’s community worker.

The amount that young people’s community workers were involved in creating or supporting young people to take up participation opportunities varied greatly throughout the pilot areas. All of them saw the chance for young people to meet others, and to get support from their peers, as an essential part of the service, but this would not usually fit the criteria of a participatory activity. However, sometimes out of the activity groups and conferences, the young people went on to access various opportunities to use their experiences and views. Some young people’s community workers were very active in advertising participation activities through local Facebook pages and newsletters.

Examples of the range of activities on offer:

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- Sitting on the CLIC Sargent Children and Young People's Advisory Group

 - Involvement in development of policy, publications, website and Facebook

 - Cross-party group in the Scottish Parliament

 - Sharing their story and media interviews

 - Attending focus groups

 - Responding to questionnaires about service design

 - Involvement in recruitment of staff

 - Presentations at events and open days.

And opportunities to participate in partner activities for example:

-
- Jimmy Teen videos

 - Contributing to the design of a new Teenage Cancer Trust ward.

11 young people who responded to the questionnaire, and took part in interviews or focus groups, had been involved in various participation activities (a further four said they would like to and one said that although s/he hadn't so far s/he had been offered lots of opportunities). Of these young people, 10 said that they thought the involvement of young people in participation activities had made a difference. The remaining one had not been sure.

If the underlying principles of good practice within participation are taken as being child/young person-led, providing new skills for young people, increasing their confidence and having a sense of contributing to improvements; clear evidence was found of all of these.

"I was very proud to be part of designing a ward, my ideas went to make things better. Having a ward where people of similar ages can talk to people around you – helps you settle in – makes it so much better."

"It was useful to do the presentations. I thought it was important that people hear from real people."

"I wanted to be able to give back, I wanted to make sure some things improve."

There were some suggestions from a small number of young people and staff that the information coming from the wider organisation about participation activities could be a little more descriptive and detailed; that the communication from the charity's head office teams to young people was not as informative as it could be and this impacted on whether or not they chose to get involved in CLIC Sargent activities across the UK.

Another difficulty in areas with a lot of local participation activities was that of competing priorities. For example, in some areas a young person may have a CLIC Sargent Young People's Community Worker, have an involvement in CLIC Sargent UK-wide participation activities and use Teenage Cancer Trust services or units. In these situations there were problems experienced by the young people's community workers in knowing what to tell the young people about, or ask them to do, and concerns that the young people might become overstretched or overloaded by demands on their time.

In terms of levels of participation in individual work with young people, there was considerable evidence that the young people were enormously engaged in all aspects of decision-making around the service that they received. This evidence was found in the views expressed by all the young people taking part in the evaluation and through talking with young people's community workers and partner professionals about the approach adopted by the young people's community workers. Of the 31 young people who completed the section of the questionnaire asking who made decisions about what they were going to work on with their young people's community worker, 26 stated that they decided together, five said they made the decision and none replied that the work was led by the young people's community worker alone. It was also evident in many of the contact recordings that illustrated pieces of direct work (including the use of the Rickter Scale) where the young people were instrumental in setting the agenda for their work together. However, formal recording of the views and opinions of the young people was largely missing from case files. In the audit, only 20% of the assessments reviewed had entries recorded in the young people's comments section. This omission provides a misleading picture of services being offered and the high quality and level of active participation young people have in the individual services they receive from CLIC Sargent.

Post-treatment services

A range of practices exist between the pilot areas with regard to how long, post-treatment, a young people's community worker will continue to work with a young person. Largely there did not appear to be a set length of time or specific exit strategies in place, except in one service where the offer is one-to-one support for one year post treatment and then a further year of engagement in regular support groups. After the two years the young person is invited to quarterly groups until they are 25. The young people's community worker in this area stated that they are very open about endings right from the beginning so that young people know what is being offered to them. One young person from their area, who was about to move into the quarterly groups category, stated that he understood the rationale for the change even though he was concerned that it would be hard not to have that regular support.

The length of time other young people's community workers continue to provide support was found to be linked to capacity and caseloads and the necessity to close a case in order to be able to offer a service to a new referral. The pilot area where the service that had most emphasis on the young people's community workers undertaking focused work specifically around education, employment and personal development worked longer-term post treatment. This would be expected given the focus of their work is about supporting young people to establish post-cancer lives.

There was an underlying (implicit and explicit) feeling that it was preferable for young people to phase out their contact with the young people's community workers rather than to have fixed endings. This was in order to recognise the different experiences and journeys that young people had. It was also widely accepted throughout the pilot areas that post-treatment was in itself a time with specific challenges to manage and that this needed time and support to help young people manage the transition:

"We prefer young people to close us than us to close them." *(Young people's community worker)*

"With young people, brain tumours stay longer – there are more long-term changes for them, it's a new life." *(Team manager)*

"No formal cut off after treatment and we have groups available, so there is somewhere for people to move onto." *(Young people's community worker)*

"They need time to get back to where they were. When you have looked at life and death, it takes time past treatment and some still need help after several years." *(Young people's social worker)*

This viewpoint was largely reflected within the responses of medical staff who took part in the evaluation:

"The big need is around survivorship – getting back to normal lives, dealing with depression, careers, body image, fertility, relationships, living with cancer and moving on psychologically."

"Post-treatment support has to be the next part of the overall teenager and young adult service development."

"Post-treatment for young people in shared care is the gap – we need youth activities to address that in the regions."

As might be expected, given the importance of the relationship described above, young people were very clear that they did not wish to have a service that was cut off swiftly after treatment. The main message from both the questionnaire responses, and through discussions with young people, was that the timescale should be indefinite and led by the young people. For some this meant continuing indefinitely in one way or another, and for others it meant that it should not be defined or set but flexible to meet the needs of young people. Where a timescale was given they stated various times between one and five years, but the quotes below more commonly reflected the responses:

"As long as you need to – everyone is different with what they need."

"As long as it takes to get over cancer."

"As long as it takes for someone to get back on their feet."

“As long as you both think it’s appropriate.”

“It matters because everyone is different. Finishing is sometimes scarier than the actual treatment. Technically you are better but terrified it will come back. It’s crucial to know they are still there until you can let go yourself.”

A number of the young people talked about the need to have something to move on to, a reducing package of involvement and the importance of group support within that. For some this also included them taking on a different role in terms of moving on to mentor and support other young people.

The professional network

In each of the pilot areas, the feedback from both the CLIC Sargent staff/management, and their partners from Teenage Cancer Trust and the NHS, was that the service and the individuals in the post were seen as integral parts of the MDT and the overall teenager and young adult (TYA) services. Even where relations between medical staff and CLIC Sargent had been difficult and were still being worked on, there was clear respect expressed for the work undertaken by the young people’s community worker and young people’s social worker:

“Her input into the MDT is invaluable and fits well with the holistic functioning of TYA services” (MDT member)

The degree to which partners felt involved and included in the development of the pilot did, however, vary from area to area. In every area it was felt that the change in the age range served by the youth development worker post, and the creation of the young people’s community worker pilot post, had had a profound effect on those under 16 who had previously had access to the service. However, in the main, the professional networks were very positive about the pilot whilst recognising it had also created some difficulties. There were concerns that:

- 13 to 15-year-olds were now without a service leaving a huge gap for them, particularly in hospital
- Those young people under 16 who had been previously supported by youth development workers were now being left unsupported
- There was no “joined-up planning” and so other members of the MDT were left unsure exactly about the role of the new post and therefore what to expect of it and how to use it
- The timing was wrong for that particular area and sufficient work had not been carried out in designated hospitals to be able to make full use of the community aspect of the role.

There was an expression in some areas, that, whilst recognising CLIC Sargent’s right to reorganise as it desired or felt necessary, doing so with little or no consultation with the wider TYA partners had resulted in unnecessary confusion and frustration. What was perceived as a disregard for the local context in which the posts would be sited meant that

the fit of the new role had not been as effective as it could/should have been. The area in which there was greatest collaboration between the three partners involved in the TYA service had had a very smooth transition and the post was evidently completely embedded within the TYA structure.

Potential barriers and risks

There were a number of concerns expressed of potential risks to the future of the young people's community worker service.

1. Imposed uniformity of the initiative across the UK

Both staff and managers within CLIC Sargent and partner agencies stated that one of the strengths of the pilot was that in the main it had been able to be developed locally to meet the needs of the particular demographics and geography. It was also felt to have been developed giving consideration and recognition to existing post-holders and their ongoing relationship to the organisation and their work. It was largely felt that a uniformed job description or remit imposed across the UK that did not allow for regional differences would weaken the effectiveness of the service offered. However, to have no connection between the posts with each area writing their own job descriptions and person specifications would present a different type of risk. With this model the organisation would not be able to provide any kind of structure with which to support or develop the posts or the area of work. It may mean that individual posts became more vulnerable and young people would risk the possibility of a very varied quality of service across the UK.

2. Raising expectations amongst young people

This concern was related to being a "victim of it's own success", in that as communication with designated and shared care hospitals became stronger and more efficient, there would be more referrals to the young people's community workers and this would have a direct impact on the quality of service they were able to provide to young people. Time was highlighted by staff, young people and other professionals as being imperative to the pilot – the time to spend with young people, time to research opportunities, to motivate and "hand hold" where necessary, and the time to follow up with young people who traditionally are not the easiest group to engage. The feeling was that with increased numbers the young people's community workers would not have the time to spend with young people and therefore the quality of the provision would be lost.

3. Balancing the group work/activities provision with 1:1 work

There was considerable evidence that the young people's community worker posts were very demanding and full. The staff in the posts were unusually very skilled in both individual and group work. All contributors to the evaluation, both young people and professionals, felt that the offer of peer support and group activities for young people outside the hospitals was vital and the young people's community workers themselves were very committed to engaging young people in participation opportunities. There was a request for further development of group work, particularly to meet the needs of young people post-treatment.

Given all these factors careful consideration does need to be given when looking at taking the initiative forward, to expectations placed on workers in meeting the needs for both offers of service.

4. The relationship between service delivery and capturing evidence of impact/outcomes

In many agencies that strive to be truly led by service users in the way that needs are met, there is often felt to be a dichotomy between evidencing outcomes and impact and being flexible and responsive in delivery. There was a clear understanding, expressed by CLIC Sargent staff, of the organisational need to capture data that could evidence positive outcomes, but at the same time staff were also concerned that an emphasis on this could have a detrimental and prescriptive effect on the work they undertook with young people. In terms of risks it is important to be realistic about the absolute necessity for the organisation to be able to prove impact if it is to be able to continue to exist, and if it is to know for sure that it is providing services that are relevant and effective. A clear framework setting out the range of services to be offered; potential benefits and outcomes a young person could expect, combined with a way to measure feedback would help to guide the young people's community workers in their work and ensure accountability to the young people. It would, however, not lose the approach that feedback from young people showed as overwhelmingly positive, in terms of the flexibility and creativity of the approach and how much they are able to impact on what they do with their young people's community worker, when and how.

5. Communication within the wider TYA service

Currently, very different levels of communication, consultation and involvement exist between the various stakeholders (CLIC Sargent, Teenage Cancer Trust, Health Trusts etc.) in each area. In some they are very integrated teams who share offices and work as one team. In others, they largely have very positive communication but work from different sites and in distinct teams, and in others communications and relations are improving but have been quite strained. In all areas CLIC Sargent care professionals use different recording systems to their colleagues in health. There was a concern expressed that unless communication was transparent, particularly in terms of service developments and who was doing what work with which young people, the effectiveness of overall TYA services would be compromised.

Summary

Overall the evaluation found that the pilot had been very successful in meeting the aims and objectives that it set out initially. It is widely appreciated and lauded by the young people and respected by professional partners. The services are creative, flexible, responsive, relevant and timely. The initial assumptions that there was a need for a service for young people aged 16-24, offered in the community and based around education/employment and providing support to resume or maintain life outside/beyond cancer, have all been proved to be correct and the pilot has successfully achieved a service incorporating all of these.

The role:

1. The young people's community worker post is seen as being focused on, around and for the young person. Although interacting with families, the clear priority is the young person, in contrast to the young people's social worker whose role may lead them to work with the wider family network.
2. The young people's community worker role is largely seen as helping young people to hold onto life outside cancer or to move on with "normal" life after treatment.
3. The combination of group and one-to-one support that was envisaged for the role is clearly on target and appreciated by young people. Several young people commented on the importance of having access to both types of support and that they complemented each other well, providing opportunities for young people to pick and choose what they needed at different points in their lives.
4. Many of the skills identified by both professionals and young people for the young people's community worker post were those most related to the building of trusting relationships eg listening, understanding, sociability, reliability, resilience, non-judgemental.
5. The young people's community worker postholders were all found to be accessible, approachable, flexible and responsive. All attributes highly valued by the young people and quoted as some of the reasons why they had decided to engage with the service and why the support they received had been so useful.
6. Young people reported a noticeable difference between services offered by their young people's community worker and other professionals in their lives in relation to:
 - the types of things they helped with
 - the time they spent with them
 - the way in which they worked with them
 - and the amount of emotional support they received from their young people's community worker.
7. All the young people's community workers were found to be offering high quality services that were, for many young people, felt to be essential and invaluable support.

The need:

1. Young people are asking for support which coincides closely with the aims of the pilot – to provide support with education and employment, money, emotional support and engaging with their peers.
 2. Although it may have been anticipated that this role would also provide a high level of emotional support, it was, perhaps, not as explicit as it clearly needs to be given the feedback from both the pilot recordings and the young people which evidences this as being the priority need.
 3. Emotional support needs cover a wide range of issues including self-esteem and confidence, anxiety, post-treatment issues, isolation, issues with relationships and the need to engage in activities with peers who have had similar experiences.
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Community outreach:

1. Community-based work is another aspect of the pilot that is on target. It works well and is well received by the young people and the wider professional network. It was said to be an aspect that was different to other types of support by over two thirds of the young people completing questionnaires and they all said that this was useful.
 2. There is concern about the distances that could need to be covered and about raising expectations beyond capacity. The guaranteed offer letter setting out the support available to young people is at present only widely used in one pilot area. It is used to a much lesser degree in other areas who at present are able to follow up all or the majority of referrals with a telephone call.
 3. If the relationships with designated/shared care hospitals (and in some cases PTCs) become more embedded, it is inevitable that referrals to the young people's community worker will increase. It would therefore be prudent to develop a strategy to deal with this consequence in advance whether through an extension of the guaranteed offer letter or further development of young people's community worker roles.
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Referral pathways:

1. In the majority of pilot areas, the young people's community worker was a standing member of the MDT and received referrals through those team meetings.
 2. In all areas considerable work was being undertaken by the MDTs in the PTC to build links with designated hospitals to ensure that they were referring all young people to them. On average it was felt that increasing numbers of potential service users were known about and referred to the MDT. As these arrangements become more embedded and the numbers of referrals to MDT increase, so will the referrals to the young people's community workers.
 3. The take-up of the service by young people referred to the young people's community worker was affected by the timing of the referral, the offer of an introductory meeting with the referrer, the referral coming from a source trusted by the young person, and most importantly direct contact being made in person or by phone.
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4. The take up rate of the young people's community worker service is very high, above 80%, clearly demonstrating that the approach outlined in point three above was being used and was successful.

 5. The personal attributes of the young people's community worker were instrumental factors in the decision of a young person to take up the service they were offering. They were cited as being approachable, friendly, laid back, there at the right time and informed.

 6. The time between diagnosis and referral is reducing (this may be in part due to the fact that CLIC Sargent staff now attend MDT meetings).

 7. The time between referral and first contact was typically short with 90% of young people being seen within seven days of diagnosis.

 8. Some young people are hearing about the service later in the process. The young people who took part in the evaluation and who were in this position had been treated outside the PTC, and had felt that they had lost out on hearing of CLIC Sargent so late on. This would again strengthen the argument to continue to build links and look at ways of advertising CLIC Sargent services as widely as possible.

Assessments, care planning and recording:

1. In all but one pilot area, assessments and care plans are completed by both young people's community workers and young people's social workers.

2. Traditional social care assessments are not a good fit with the assessments carried out for the work undertaken by young people's community workers (with some young people's community workers uncomfortable with the term) because of the young people-led nature of the intervention.

3. Electronic case files often do not accurately capture and represent the work undertaken with young people. The links between assessment (what are your needs), the care plan (what I can do for you/we can do together) and the contact recordings (doing the work) are often not evident. However, talking with young people and professionals it is clear that this work is taking place in this order and is being completed to the satisfaction of the young people. The level of participation of young people is also inaccurately represented. Again the young people were very clear that they were fully engaged in deciding what work they engaged in but this was not reflected in the assessment records.

4. Recording systems were felt by some staff to be repetitive and task-focused, which made it difficult to record some of the emotional support given or the "soft outcomes" worked on. Concerns were expressed that in order to meet requirements to complete recording templates the work would become more task-oriented and less responsive to the changing needs of young people. However, linked to point three above, using the experience gained by carrying out the pilot recording systems could be easily and effectively amended and training rolled out to ensure that everyone was confident to use them.

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5. The detail and content of recording varied widely and it was felt by some staff that there was a lack of clarity generally about what was recorded and why.

 6. Questions were asked about how much young people knew about what their young people's community workers recorded and why.

 7. The practicalities of community-based workers having to spend a large proportion of their working week (sometimes as much as a 30%) on administration were also questioned. It was felt that young people's community workers having access to tablets and/or laptops would make a considerable difference to this – recording with young people at the time of meeting if appropriate or whilst still out in the community, and not having to return to the office to carry out admin.

The Rickter Scale:

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1. This was experienced by both young people and young people's community workers as being a useful and effective tool in particular circumstances and with particular young people.

 2. It produced an open, transparent and visual approach to the work.

 3. It increased the participation of young people who found it difficult to talk and explore their feelings.

 4. It was not thought to be a useful tool in terms of providing evidence of impact and positive outcomes because of concerns that it was too prescriptive and would end up "leading" the work with young people.

 5. It was largely used by young people's community workers as one of a number of tools and approaches they had available for them to use in their work with young people as they judged appropriate through their professional experience.

Evidencing impact:

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1. The young people who responded to the questionnaire recorded that their involvement with their young people's community worker had had a significant impact on their lives.

 2. The areas of most impact were education and employment and feeling that you have at least one person who you can trust and rely on.

 3. The areas of least impact were on friendships and social life, and hobbies and leisure interests.

 4. Discussions about ways to capture evidence of impact are ongoing. It is vital, for best practice and the continuation of the young people's community worker role, that they are addressed robustly and creatively. It is likely that this is an area that young people could help with.

Participation of young people:

1. Some young people's community workers were very committed and actively involved in promoting opportunities for young people to influence service development. All were committed to ensuring young people were offered various different options for meeting with their peers in similar circumstances.
2. Across the pilot a wide range of participation opportunities existed for young people from the advisory group, designing ward units, making presentations and taking part in media interviews, to sitting on recruitment panels.
3. The young people involved in participation activities felt very positive about their engagement and mostly felt that it had "made a difference".
4. There were more difficulties experienced in promoting UK-wide opportunities than local ones and in part this was to do with the quality of information coming from the charity's central teams for the young people to consider.
5. Considerable evidence was found that the young people were fully participating in all aspects of decision-making around their individual work with their young people's community worker.

Post-treatment services:

1. This was an area where there was considerable difference across the pilot, varying from one pilot that did very little post-treatment work to one where their work in the main began post-treatment.
2. Only one example was found with a clear structure to end contact and an accompanying exit strategy to help young people move out and away from contact with their young people's community worker.
3. Post-treatment and survivorship was felt by young people, MDT members and CLIC Sargent staff/managers as being a vitally important period for young people, with its own very specific challenges, and one where ongoing support was vital.
4. It was felt that strict cut off timescales did not account for the individual needs and circumstance of young people with cancer, for example those young people who have had brain tumours and those who have more extreme life changes.
5. The lack of thought out "exit strategies" can have a detrimental impact on young people, either by misleading them from the outset that in some way CLIC Sargent (or particular care professionals) will always be there or by preventing services being offered to newly diagnosed young people because of capacity issues for the staff. It is vital that such strategies are worked out locally and reflect the context in terms of referrals, needs, and resources in each area.

The professional network:

1. CLIC Sargent and the young people's community worker pilot are seen as integral parts of the overall TYA services across the pilot.
2. The young people's community workers are considered as effective and useful members of the TYA team.
3. The creation of the young people's community worker posts had left gaps (primarily for the 13 to 15-year-old age group) and this had caused some concerns and some frustration amongst MDT partners.
4. Different levels of engagement with partner agencies over the development of the pilot in the different areas existed. Where there had been little or no consultation or involvement in the changes, frustration was expressed that this had limited the effectiveness of the post.
5. The point was made in some areas that future developments around the pilot needed to be made with clear consideration of local circumstances and need, and therefore in discussion with partners, rather than being made centrally and rolled out from the centre.

Potential barriers and risks:

1. It was widely reported that one of the strengths of the pilot was the flexibility that there had been to develop the posts locally to meet local need and with regard to the existing post holder's qualities, experience, interests and abilities. Consequently, it was perceived that a move away from this model and an attempt to standardise the posts across the UK would be detrimental to the service provision.
2. All the young people's community workers carry large case loads and are engaged in some level of group work. They were felt to be working to full capacity. The service has been very successful in meeting a hitherto unmet need, but it has also highlighted further need within the community. There was concern expressed that as the initiative becomes better known, and links between the principal treatment centres and designated hospitals improve, the referral rate will increase and the caseloads may become unmanageable.
3. It was felt to be imperative that young people had access to both individual and group support. However, with potentially increasing numbers of referrals and if calls to develop groups more regionally are to be met, caseload management would need to be addressed within each area to ensure that this model continues.
4. The relationship between data collection and service delivery is often delicate and concerns were expressed about what the impact might be as the organisation strives to demonstrate concrete outcomes. However, there was a clear recognition and

understanding of the necessity of this aspect of the service and a desire to work together with young people to develop an approach that would suit both needs.

5. Communication between multiple agencies is often a difficult balance of partnership and autonomy. There is a need to maintain open and transparent channels that are as inclusive as possible (particularly about future developments for the pilot) if it is to be as effective as possible. The areas where there had been a greater involvement of senior managers with their peers in partner agencies had had the greatest success in terms of inclusive communication and therefore the most positive outcomes for the development of services.

Recommendations

- The existing posts of young people’s community workers should continue and funding should be secured to increase provision across all principal treatment centres in the UK, so ensuring that all young people diagnosed with cancer have access to the same responsive and quality service.
- The element of flexibility in terms of how the posts develop to fit the needs of young people and services locally should continue. However, this flexibility needs to be underpinned by an agreed framework which provides:
 - Principles and values for a common approach
 - A common understanding of the anticipated potential outcomes or impacts for young people arising from their involvement with a young people’s community worker
 - A shared offer of a range of services
 - A commitment to a community-based service
 - A commitment to the offer of peer support and group work
 - A recognition of the need to have, and transparently express, the boundaries and limitations to the services that can be offered to any one young person.
- The organisation should look at working in partnership with young people to develop recording structures and procedures which encompass assessment, care planning and review; and meet organisational needs to be accountable, provide records and be in a position to evidence outcomes, whilst maintaining the creativity and flexibility that young people value.
- To review current administration expectations in the post and consider ways to support the community-based aspect of the role.
- Promotion of communication between CLIC Sargent and partnership agencies within TYA services, from a senior level within each local area, particularly around future developments of the young people’s community worker role so that the post can achieve maximum success.
- Maintenance of group support for young people and consideration of extending groups more widely throughout regions covered by designated or shared care hospitals. This will require careful management of caseloads within each area, but the evidence is that the provision of both services is essential.
- Exit strategies for young people to be developed that incorporate local need and capacity and give consideration to the views and experiences of the young people themselves.
- The development of “self-help” type groups that are run by young people who were formally in receipt of services from young people’s community workers and have been skilled up and supported to take over developing and running local groups. This would also be a way of managing capacity issues and providing a possible option to move on to after being a CLIC Sargent service user:

“Other than my medical team, I see her as the most important role in beating cancer.”

CLIC Sargent's response to the evaluation

The evaluation has demonstrated that the young people's community worker role has the potential to transform the support available to 16-24 year-olds with cancer throughout the UK, particularly those who choose to be treated locally rather than travelling to a specialist regional hospital.

We accept all the recommendations outlined by Kate Gledhill in her report and have begun to respond to each of them as set out below:

-
- All five posts established in the pilot have been made permanent and will continue to work with young people with cancer in those five areas. We have a plan in place to significantly increase our fundraising income in the next four years, and expanding the service to every area of the UK as funds allow will be a priority.
-
- We have updated the job description and person specification of the young people's community worker to take into account the findings of the evaluation and to ensure that we take a common approach to the service model whilst allowing post-holders to respond flexibly to the needs of young people with cancer.
-
- Young people's community workers will use the charity's CARE recording system and undertake assessments and care planning as appropriate. We will develop tools to help young people's community workers provide effective interventions and models for evidencing outcomes by March 2014.
-
- We will review how we can best provide administration support to the service as we develop it in the coming year.
-
- We have developed a communication plan to inform and involve our partners in the NHS and other organisations in the development of the service to ensure it works effectively with and adds value to existing services.
-
- Group support will continue, and we have given this aspect of the role greater emphasis in the new job description. We will be able to extend the reach of group support as funds allow us to expand the service.
-
- The new service model includes up to six months support post-treatment as needed by the young person being supported.
-
- We will review if enabling young people with cancer to set up 'self-help' groups would be a useful extension of the service and consider its feasibility.

Appendix A

-
- ◉ How long have you had contact with (name) from CLIC Sargent?
-
- ◉ What made you decide to work with CLIC Sargent?
-
- ◉ How did you find out about CLIC Sargent? (Circle the one that is right for you.)
 - ◉ A letter from them
 - ◉ A visit from them
 - ◉ From my GP
 - ◉ From the hospital
 - ◉ Other (please say what)
-
- ◉ How often do you meet with your worker?
-
- ◉ How easy is it to stay in touch with your worker? (Please circle the one that is right for you.)
 - ◉ Very easy
 - ◉ Quite easy
 - ◉ Bit difficult
 - ◉ Very difficult
-
- ◉ Can you tell me why you have given that answer?
-
- ◉ I'm trying to find out how much you think working with your CLIC Sargent worker has helped or has had an impact on your life during your cancer treatment, so for each of the sections below can you score between 1 and 10:
 - ◉ Your education/training/employment*
 - ◉ Your friendships and social life*
 - ◉ Your confidence in yourself to manage your life*
 - ◉ Your ability to take up or continue with hobbies or leisure interests*
 - ◉ Support and contact with your family and important friends*
 - ◉ How confident you feel that you have a support worker who you can trust and rely on to be there for you*

** Scored 1–10, 1 being 'No impact' and 10 being 'Major impact/help'.*
-
- ◉ Is there any area of your life that you wish you had had more help with or where there had been a bigger change or improvement? (Yes, No, Not sure)
-
- ◉ If so can you tell me what?
-
- ◉ What do you think has been the biggest change or help that you have had from CLIC Sargent?
-
- ◉ Who makes the decisions about what you are going to work on together? (Please circle.)
 - ◉ You
 - ◉ Your CLIC Sargent worker
 - ◉ Both of you together

• Where do you meet your CLIC Sargent worker? (Please circle.)

- Home
- Hospital
- Other (can you say where?)

• Is this OK for you? (Yes, No)

• Can you tell us why?

• I need to find out if having support from CLIC Sargent gives you something different and extra to the services you get from other members of your care team (doctors, nurses etc). So for each area below could you say if it's the same or different, and if it's different is it useful or not:

- The types of things they help you with
 - Same as others
 - Different to others
 - Useful
 - Not useful
- Where they meet you
 - Same as others
 - Different to others
 - Useful
 - Not useful
- The time they spend with you
 - Same as others
 - Different to others
 - Useful
 - Not useful
- The amount of emotional support they can offer
 - Same as others
 - Different to others
 - Useful
 - Not useful
- The way they work with you
 - Same as others
 - Different to others
 - Useful
 - Not useful

• What kinds of things has your CLIC Sargent worker helped you with?

(Circle as many as apply.)

- Education
- Employment/training
- Emotional support
- Money
- Benefits
- Housing
- Self-confidence/self-esteem
- Health/treatment
- Sorting out difficulties with other workers
- Relationships
- Being lonely
- Future plans
- Meeting other young people with cancer
- Activities
- Other – please tell me what

• Is there anything else you would want to tell me about the service (name) has given you?

• If you also received another service from a CLIC Sargent worker, would you please tell me who this was and how they helped you?

• How long do you think you should be able to go on working with your CLIC Sargent worker after your treatment has finished?

• Have you been involved in any activities with CLIC Sargent that are about making changes and improvements for all young people with cancer across the country or within the local services you have received? (Yes, No)

• If you have, do you think young people being involved is making a difference? (Yes, No, Not sure)

• If you were talking to another young person, what would you tell them about CLIC Sargent?

Appendix B

Areas for semi-structured interviews with young people:

- The life of a young person with a cancer diagnosis:
 - Who's in your life
 - What do they do for you
 - What's different and the same between them
 - What do you like about their approach.

- The journey with your young people's community worker:
 - How did you first hear about the service
 - How did you meet
 - Why did you decide to work with them
 - What do you do together
 - Who decides what you work on
 - Groups and individual – what works for you
 - Endings and how long after.

- What makes a good young people's community worker – writing a person specification

- Participation:
 - Been involved
 - Why and what did you get out of it.

- Any messages to take back to CLIC Sargent.

Appendix C

Areas for semi-structured interviews with CLIC Sargent care professionals

- History/background:
 - How the pilot came about
 - How much has it changed the services offered.

- Roles:
 - Description of the young people's community worker and young people's social worker roles
 - Relationship to the pilot
 - Differences between the young people's community worker and young people's social worker roles.

- Skills:
 - What skills for the young people's community worker post in particular
 - What knowledge base
 - Differences to other CLIC Sargent care professionals or health workers.

- Approach:
 - The approach of the pilot
 - Difference to the approaches employed by other parts of CLIC Sargent or health workers
 - What are the strengths and difficulties of this approach.

- The professional network:
 - The place of the pilot in the network
 - How viewed by MDT members
 - Strengths and difficulties encountered.

- Referrals:
 - How and where from
 - How effective
 - Difficulties
 - Take up of referrals
 - The guaranteed offer letter.

- The process:
 - Assessments
 - Care planning
 - Recording
 - The nature of the relationship – casework, groupwork, one-off, ongoing
 - Tools – what to use and when (including the Rickter Scale)
 - Difficulties in delivery
 - Impact – what you are hoping to achieve, what outcomes and how is this evidenced.

-
- Participation:
 - Care planning and assessments
 - Wider participation and influencing agenda.
-

- Overall:
 - Strengths and difficulties
 - Risks for young people, staff and the service.

Areas for semi-structured interviews with MDT members:

- History/background:
 - How the pilot came about
 - How much has it changed the services offered.
-

- Roles:
 - Description of the young people's community worker and young people's social worker roles
 - Relationship to the pilot
 - Differences between the young people's community worker and young people's social worker roles.
-

- Approach:
 - The approach of the pilot
 - Difference to the approaches employed by other parts of CLIC Sargent or health workers
 - What are the strengths and difficulties of this approach.
-

- The professional network:
 - The place of the pilot in the network
 - How viewed by MDT members
 - Strengths and difficulties encountered.
-

- Referrals:
 - How and where from
 - How effective
 - Difficulties
 - Take up of referrals.

The guaranteed offer letter

- Overall:
 - Strengths and difficulties
 - Risks for young people, staff and the service.

Appendix D

Areas examined within the case file audit:

-
- The timescales between diagnosis and referral to CLIC Sargent
-
- The timescales between referral and first contact with the young people
-
- The quality of assessment, care planning and contact recording
-
- The existence of records that could evidence the links between assessment (including use of pilot recording tool) care planning and delivery of the service (as recorded in contact sheets)
-
- Evidence of involvement of young people in the processes of assessment, care planning and delivery
-
- Evidence of who carried out the assessments and what impact that had on the nature, quality and depth of the assessment
-
- The use of the Rickter Scale and whether this had any impact on the range, number or nature of the issues identified as areas to work on
-
- The range of issues addressed across the pilot and identifying the resulting knowledge base required of young people's community workers
-
- The numbers of young people involved in the pilot in each area who were on treatment, post treatment or receiving palliative care.

Appendix E

Person specification for the role of young people's community workers, as developed with young people who contributed to this evaluation:

"Someone who does what it says on the tin!"

Personal attributes:

- Understanding
- A good listener
- Confident enough to start a conversation with someone who's not talking
- Happy and optimistic
- Someone you can have a laugh with
- Able to read people
- Sociable
- Sensitive
- Care about how we feel.

Skills and abilities:

- Working with young people
- Able to get involved in activities and groups
- Able to relate to young people
- Able to have the hard conversations – willing to sit and see it through
- Able to be there just for you
- Able to ask the right questions.

Experience and knowledge:

- Experience of working with young people of various ages
- Experience of working with young people in emotional turmoil
- Know about the options for young people – where to go to get things sorted and get help

Generally the young people felt that the role was more about caring than the clinical aspect. There were some who thought that previous experience of working around cancer or other health issues and/or having a knowledge of the impact of cancer on families would be an advantage. But overwhelmingly they felt that these care professionals were about the "who you are" not the "what you know".



Supporting
children and
young people
with
cancer

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