CLS Evidence & Learning Briefings 2020

Paper 4: Community Led Support: Learning from Stories of Change

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Community Led Support

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Community Led Support is a place-based approach to achieving change in health and social care services, through working closely with local communities and wider partners in the voluntary, community, business and public sectors. Changes made to local services and systems include a combination of interconnecting elements, all of which are essential, but which are shaped and refined to reflect local circumstances.

While Community Led Support involves a set of core principles and practices common to all participating areas, each area works differently depending on local circumstances, priorities and readiness for change across the partners involved.

www.ndti.org.uk/our-work/our-projects/community-led-support

***Acknowledgements**: Stories about change lie at the heart of community led support. They inspire us all to carry on when implementing change gets tough; they help us see what is really important in all the various aspects of implementing Community Led Support; and they help us hold onto what really matters to people so that this becomes the focus of our work on an ongoing basis. Thank you to those who have shared their story or the stories of the people they know through Community Led Support.*

Contents

The aim of this paper is to give voice to the people experiencing Community Led Support in a sample of places across the UK – providing practical examples of how people have engaged with CLS, to better understand the changes that have come about in their lives and how this has been achieved.

Capturing, sharing and learning from change stories is a key component of the Evidence & Learning activities taking place within and across all CLS sites. Every site has their own way of doing this, but the underlying approach is consistent and based on the following methodology.

Change Stories are short, straightforward accounts that help us explore and better understand the range of experiences and outcomes relating to an initiative, service, support or development. These accounts can be at an individual, community, service or system level, and can tell us what types of supports, activities, approaches or actions worked in what context and for whom they worked, and how and why they were important to individuals.

Change stories are most often written by or from the **perspective of individuals** who are affected or involved in a personal change. They can also be written from the perspective of others, so it becomes their story of the change that has occurred; for example, about the experiences and outcomes for families or carers, staff or volunteer teams, services, organisations and communities. The key thing in the change story process is being clear what it is that has changed or is different, often in relation to desired outcomes, and what/who helped to make those changes happen.

Change stories are written retrospectively when something of note has taken place. This may be something which has worked well but may also be something which has not gone well which has led to important learning. They can complement other data and provide powerful evidence for decision makers and funders, as well as being useful for internal learning and reflection.

The Most Significant Change process is a tried and tested method for capturing, sharing, analysing and using change stories in a robust and inclusive way. It involves a cross section of people involved in a change programme working individually and together to record, analyse and scrutinise each other's stories – and agree which ones best convey what is working (or not working) and what is making that happen. Over time, a story bank can grow which can be used for quantitative as well as qualitative analysis. It also provides a way of different voices to be heard and better understood. This is the aim of collecting and sharing change stories across the CLS Programme.

The remainder of this paper shares a sample of stories and the insights they generate for understanding what works in Community Led Support.

Who are these stories about?

A total of 31 change stories was analysed from 10 of the 27 CLS sites, detailing the changes achieved by individuals through engagement with the CLS programme.[1] The diversity in these stories reflects the breadth of change experienced, and both the large and small - but important - differences in how people are supported to have a good life and their needs met. The following information shows where these change stories have come from. *Note: this information doesn't add up to 31 as the detailed breakdown was not consistent across this sample.*

Bradford | Denbighshire | Derby | Doncaster | Leeds

Orkney | Somerset | Torbay | Warwickshire | Western Isles

7 stories were from young adults, aged 18-35

10 stories were from adults under the age of 60

13 stories were from older people, aged 60 and over.

12 individuals had a physical disability or health issue

10 individuals were facing age-related health issues

10 individuals have a learning disability

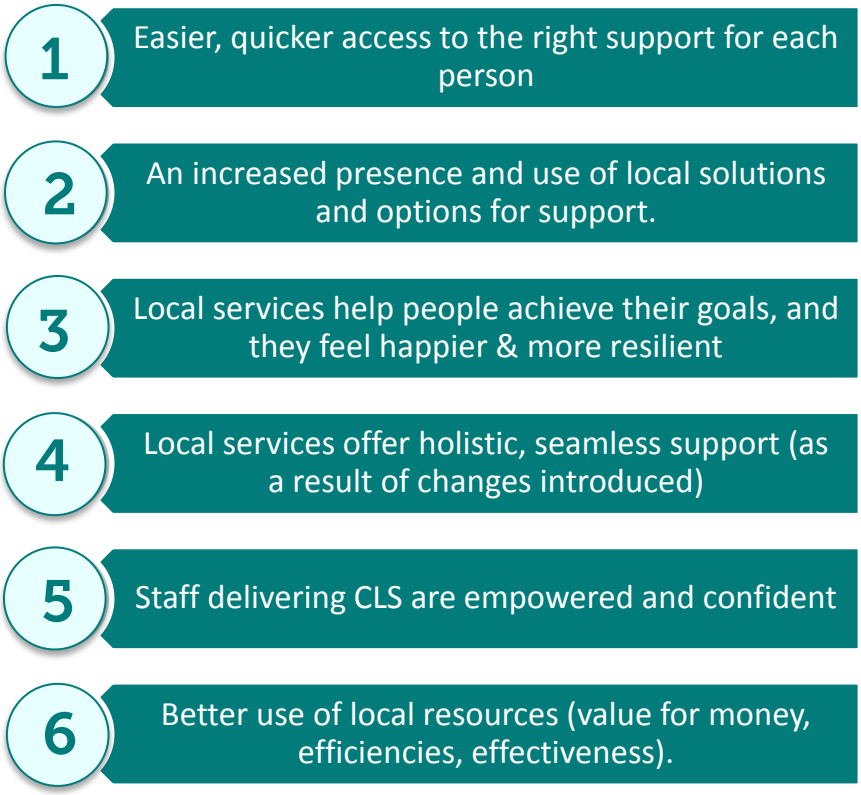
10 individuals were living with mental health issues

9 individuals were experiencing loneliness and social isolation.

Of the change stories received, equal numbers came into contact with CLS through directly approaching a community hub (8), through a referral to the council (9) and through ongoing support from their council worker (10)

What outcomes do these change stories highlight as being achieved through CLS?

The CLS outcomes that all sites are working towards are summarised below:



The majority of change stories analysed (19/33) demonstrate that the CLS approach is enabling people to **achieve their goals and improve their resilience and wellbeing** (**Outcome 3**). In many cases, this support has resulted in **people feeling less socially isolated and more connected with their community**, which in turn has **increased their confidence and resilience**. Often this is achieved through connecting individuals to existing formal and informal community-based support, such as signposting to relevant clubs and groups and informing people of support they could be entitled to and helping them to access this. For some individuals, the process of being supported through CLS has **improved their sense of confidence and ability to tackle problems going forward**. Knowing where to access advice and support if needed clearly provides a kind of security blanket for some people and **empowers them to live more independently**.

Carla's story

Carla is a young woman who has learning difficulties and lives with her parents in Denbighshire. She did not have much interaction with people outside her immediate family and increasingly felt like she had nothing to offer; she was feeling low and socially isolated. One day she received a letter inviting her to attend a Talking Point drop-in hub. At the hub she spoke with a Community Navigator about her life, what she was struggling with and about her interests (arts and crafts) and aspirations to do these activities again. She also spoke about her self-consciousness, and that she felt like she would not fit in to a community art group. The Community Navigator arranged to meet Carla the following week to accompany her to a group, in order to build her confidence. Prior to attending the art group with Carla, the Community Navigator visited the site for suitability and advised the group leader that Carla was a little shy and would need support and encouragement. In the end Carla loved the group and began attending regularly. Her confidence grew as she started to make new friends, and she began to attend other activities, including a craft class and a dance group. Carla now feels that she has a full diary which gives her purpose, her confidence has grown beyond recognition and she is feeling much less socially isolated, being able to connect with people her own age.

Christopher's story

Christopher is a veteran who lives with his wife, Angela in Somerset. As well being cared for by Angela, Christopher also has support three times a day as his mobility has been greatly affected by a brain tumour and recent stroke. His mobility issues mean he cannot leave the house and he sometimes feels quite lonely, as their family all live far away. Angela was keen to find a two-week respite break for Christopher so she could visit her daughter. Their initial application for respite had been denied by the peer forum who asked that they look for community solutions first. The CLS team met with the couple and got to know them, asking Christopher about his interests and history in the RAF as well the challenges they face now. The community agent was able to arrange for Christopher to be enrolled in a Royal Voluntary Service befriending scheme, and they helped the couple apply for respite care through the Royal Air Forces Association at a military residential home, which was eventually approved. As a result of this Angela was able to visit her daughter and Christopher was able to socialise with other ex-service men and women, while continuing to have visits from a military befriender at home, who he enjoys talking to about his RAF days. This has improved his mental wellbeing, helped him feel less isolated and introduced something new into his life.

In some cases, it is through **fundamentally changing care and support arrangements that people's sense of wellbeing has been improved** - as highlighted in Emily's story below.

Emily's story

Emily is a young mum living in the Western Isles. Emily has multiple sclerosis and had a large package of care in place to support her (9 hours per day). In conversation with her social worker, it appeared this level of care was disabling Emily in some ways and getting in the way of her most important outcome, which was being a good mum and being able to carry out daily household tasks. Taking a positive risk approach and looking at the least restrictive options, Emily was helped to redesign her support, reducing her hours to four each day, and using different kinds of technological support including a telecare system, a 24 hour response alarm and text reminder service for meals and medication. These changes mean she is much more able to be independent for example with cooking and cleaning, and most importantly, look after her children.

Improving people's sense of wellbeing also has an impact on their wider support network. These change stories emphasise the positive outcomes being achieved by family members through more creative support arrangements (in place of rigid care packages based around timed visits). People have shared how different conversations and support are **helping to reduce the physical and emotional stress they experience as carers,** that relationships have improved, and that they feel happier and healthier as a result.

For example, a young woman with Downs Syndrome living at home with her parents was feeling isolated and dependent on her family carers. She was supported to independently attend a local social enterprise, enabling her to meet other people outside her family and develop her own relationships. This has been significant for the young woman and her family: the young woman's confidence, happiness and relationship with her parents have all hugely improved, which in turn has reduced their concern about their daughter's wellbeing.

Other stories share the **importance of empowering people to help themselves**, with the right support and tools in place.

"My husband had his stroke in July 2016 and since then we have had to fend for ourselves and try and find out our own information etc. Finally, after all this time I feel that we have had some genuine and meaningful support… You came into our lives at a time when I was feeling overwhelmed with everything. You took a lot of that burden away from us…. For the first time in years I feel more positive about our future."

Just under half the change stories analysed (14/33) provide evidence of outcomes that focus on the **increased presence and use of local solutions and options for support** (**Outcome 2**). In most of these, this has meant using community-based support as an alternative to statutory support, or a mixture of both. In all cases, community-based options were considered first, and for some, this approach has meant **individuals have been able to stay in their home** rather than move into residential care. The stories below show how community-based services can meet often quite complex needs and provide positive outcomes for people without resorting to traditional residential care.

Charles and Hilda's story

Charles and Hilda are a couple in their early 70s living in Denbighshire. Charles has early onset dementia which they have both been struggling to adjust to, and which has impacted Hilda's mental health. Hilda was desperate for some respite support and wanted to arrange for a sit-in service for Charles. They were linked up with a Community Navigator to explore other community options before a sit-in service was arranged. The Community Navigator visited the couple at home, and asked Charles about all the things he had enjoyed in the past, his hobbies and interests. Charles said he had lost a lot of confidence in recent years, though would like to get out of the house. Together they discussed a variety of local opportunities which he might like to try, and now Charles is attending two local community groups every week, adapted to his needs. By leaving the house and having the opportunity to socialise with different people, Charles' confidence has improved, arguably more than it would have done if he'd just been helped at home. His time out gives Hilda a much-needed break, and as a result she is feeling much more positive and resilient.

Simon's story

Simon is an older man living in Somerset who has dementia. He remains very active and enjoys walking. He lives at home and has support from his family, social care and community organisations. Over time those involved in his care were feeling that his set-up was becoming unmanageable, with reports from the local community police that Simon was at risk of retaliation from community members due to inappropriate behaviour, including attempts to direct traffic. His daughter was finding this hard to manage and agreed that her father should move into residential care for his own and the community's safety. Through a 'What Matters to Me' conversation, it transpired that it was Simon who was at risk of abuse from others in the community, and that he was very reluctant to more into residential care. The social worker helped Simon to get a wearable tracker and put in place a small amount of support at home to relieve the pressure on his daughter. Working with different community stakeholders, including the police, the social worker also did some dementia awareness training. As a result, the community are more understanding of Simon and calls to the police have reduced. Simon's favourite café has also become 'Dementia friendly', thereby helping other community members and providing a safe and supportive space for people to meet and socialise.

10 of these stories share examples of impactful changes to personal living arrangements, including help for people to remain living in their own home through more tailored support arrangements which also demonstrate a better use of local resources (**Outcome 6**). Jack's story below shows how a simple community solution can have significant consequences for people's wellbeing and support arrangements; without first considering community-based solutions, more intensive and possibly restrictive residential support may have been considered for Jack, along with the financial implications of this for him and/or the council.

Jack's story

Jack lives in Derby and is in his 70's. He has dementia and is cared for at home by his family. Recently his family has been struggling with his support after a series of episodes where Jack became lost after going for a walk, and becoming very unsettled in the night. His family felt the best solution would be for Jack to move into residential care, and they attended a Talking Point to get some advice and information. Through the conversation it was discovered that one of Jack's hobbies used to be walking. The family decided it would be a good idea to support Jack in attending a local walking group where he could safely exercise, and the Talking Points coordinator helped to arrange this. Being part of the walking group has had a big impact on Jack and his family. Jack is happy to be able to get out on accompanied walks and sleeps better as a result, and family relationships have improved. As a result of this, everyone agrees that he does not need to move into residential care, Jack still lives at home as he wanted.

What do these stories tell us about how these outcomes are being achieved?

CLS is promoting a smoother, more personalised experience for people through **joined-up working and improved local knowledge** of staff, as well as better partnerships between professionals and organisations across areas. This means people are getting quicker, easier access to fully rounded, holistic support **(Outcome 4)**. Many stories demonstrate how person-centred support is being provided through a mixture of social care and community organisation involvement, as illustrated in Sheila and Colin's story below.

Sheila and Colin's story

Sheila and Colin are a couple in their 60s living in Somerset. Colin was struggling with mobility and sight issues following a stroke two years ago, and Sheila had given up work to be his full-time carer. They did not have any outside help. Both were finding this major life change difficult; Sheila didn't feel ready to give up work and felt they were struggling financially, and Colin was experiencing low moods as a result of losing his independence. All of this was putting a strain on their relationship. Eventually, Sheila and Colin attended a local Talking Cafe and talked through their various challenges and goals with a Community Agent. The Agent was able to link them to various community-based support services based on the specific challenges the couple had outlined. This included various activities to help Colin get out of the house, such as a shooting club provided through Somerset Sight and Riding for the Disabled, as well as working with Colin's GP to get a referral for reduced membership rate at the gym and a personal trainer which has greatly improved his mobility. Sheila was also linked up with a voluntary organisation supporting people back into employment, and a personal assistant was sourced to support Colin while Sheila is at work. They were also supported to apply for a community grant to help with home equipment. As a result of this varied support and signposting, both Colin and Sheila are feeling much more positive. Colin's mobility has greatly improved through the gym exercises and he is now able to walk around their garden with a mobility aid. Sheila has been able to get a job which will ease financial pressures while Colin has been supported to get out of the house through community activities and with the help of his Personal Assistant.

These stories also emphasise the importance of the **community hubs** which allow people to connect with local support services in different and positive ways. A key aspect of this is the location – moving drop-in hubs out of local authority buildings and into familiar community spaces (GPs, library, cafes, job centres etc.). This changes the dynamic and tone of meetings and appointments that people would previously have been invited to in formal settings.

"I grew up here, I'm local. This is my patch. I really care about this".

This feedback from colleagues in Torbay emphasises a pride in local delivery which CLS promotes, resulting in a genuinely place-based approach from everyone involved.

In most stories (17/33), individuals became engaged with CLS through a hub. In six cases, individuals turned up at a hub without being invited or 'referred' and received support they otherwise may not have had, potentially only coming into contact with social care at the point of crisis **(Outcome 1)**. Miranda's story below clearly demonstrates the importance of CLS hubs being available in the local community, as without the pop-up hub taking place in her GP practice, she would have continued to make GP appointments which would not have addressed the root of her problems. In Alice's case, the location of the hub in the library was crucial, as it was through building relationships with regular library users that the Community Navigator was able to easily draw on local informal networks and connect Alice with other members of the community.

Miranda's story

Miranda is a woman in her 50s living in Doncaster. Miranda has mobility difficulties and was also struggling with debt problems. Miranda had been making several appointments with her GP. One day she received a message telling her about the drop-in CLS hub in the Practice so rather than making a doctor's appointment, Miranda spoke with the Stronger Communities Officer at this hub. Miranda was listened to and able to talk about her various concerns in a more relaxed setting, where it was realised that the key issues upsetting her were around her debt problems and the fact her bed was broken, which was impacting her mobility and ability to leave the house. As a result, the stronger communities' team and wellbeing support officer helped Miranda to have her bed fixed and connected her with local community groups to improve her sense of belonging. She now attends a 'knit and natter' club and has a new group of friends, and a reason for leaving the house. The team also supported Miranda to establish repayment plans with some of the companies she was indebted to. The biggest change in Miranda has been her renewed desire to help herself, knowing she has the support from the Stronger Communities team, and her improved resilience and confidence in dealing with everyday matters.

Alice's story

Alice is in her late 60s and recently moved to a new area in Denbighshire after she retired. Despite being very independent and enjoying active hobbies such as hiking, Alice had found the move harder than she anticipated and felt very socially isolated and lonely. One day Alice started chatting to the Talking Point (CLS hub) Community Navigator, based in the library foyer. After a while she explained she was struggling to socialise and felt lonely. Due to the position of the Talking Point, the Community Navigator was able to not only give Alice information on popular walking routes and transport options, but also connected her to a group of women who meet at the library. This informal group regularly meet at the library to go for walks and have coffee together, and the Community Navigator asked them if they would welcome a new member. Alice was initially quite nervous but after being introduced she felt encouraged to join. As a result, Alice has been able to resume her passion for walking and meet some like-minded people, as well as knowing where to get more information from the Talking Point hub in future.

Stories can help shed light on how a CLS approach can facilitate change to happen quickly, enabling people to easily access the support they need within their community. As highlighted in the stories shared above, providing a physical space to make connections and build relationships is an important aspect of CLS, as also illustrated in Bert and Rosie's story below.

Bert and Rosie's story

Bert and Rosie are two older people living alone in Orkney. Despite living in the same area, they had never met before. One day, they both came along to a CLS Taster session. As they began talking, Rosie told Bert about some DIY problems she was having trouble in fixing by herself but didn't know of any local service that could help. Bert knew of someone and was able to put Rosie in contact with them. The conversation led onto hobbies and interests, and Bert spoke about his love of books and reading. Rosie invited Bert along to a small book club that she helps organise locally with a few of her friends. By providing a welcoming space for conversations, both Bert and Rosie were able to make valuable new connections in their local area which quickly made a positive impact on both their lives.

As well as the community hubs, these stories emphasise that it is through person-centred, honest **conversations** that people feel listened to and through **building relationships** that people feel valued. In some cases, people have shared that this is the first time they feel they have been properly listened to. In many cases it is clear that by informing individuals of their different options and exploring these with them, the onus and power in decision-making is shifted back to the person. Emily and Tom's story below shows that building trusted relationships and arranging productive support can empower people to help themselves and increase their independence.

"There's a feel-good factor for both staff and clients, having people say, 'I feel so much better that someone has listened.'"

Torbay CLS staff

"[The CLS approach] has definitely broken-down power and control within the relationship. It feels honest and real… most people know what they want to do, or what is best to do when they feel safe enough to talk with you about it."

Bradford CLS staff

Emily and Tom's story

Emily and Tom are a couple in their 40s who live in Leeds. Tom has autism, and both have a mild learning disability. Emily also struggles with physical health problems due in part to her obesity. The couple live in a supported living property and had a fairly large care package including staff supporting them with household tasks such as cleaning. Through the CLS approach, Emily and Tom's social worker wanted to make changes to their support, to empower them to be more independent and connected with their local community. The social worker felt that the support they were receiving was undermining their independence, having tasks done for them that they could do for themselves. Over time, Emily and Tom's support hours have been significantly reduced, and this resource is now used in a more productive way, focusing on their strengths. For example, getting help with meal planning, Emily feels she is learning a life-skill rather than feeling like she is being dictated to about what to cook. Over time, Emily and Tom have also been supported to be more connected with their local community: Emily goes to church and both meet people at Connect in the North sessions in which they are both very involved - recently delivering their own presentation. They are now both able to do things on their own which they previously had support for, like shopping and attending church. As a result, they are much more confident. These changes were achieved by building a trusted relationship with the couple and their family over various meetings, and ensuring that their support reflects Emily and Tom's needs and strengths. It took time to get to the understanding that the social worker was not trying to take things away from them, and that a reduction in their hours would not mean a reduction in the quality of their support and happiness. Emily and Tom felt that this was the first time a social worker had really taken the time to listen to and value them. As a result of these changes, their support costs have also reduced by £126 per week.

The personal stories shared in this paper illustrate the range of ways in which the changes associated with Community Led Support have led to better outcomes, more positive experiences and improved relationships for different people in just a small number of places across the UK. Many more stories are collected and shared across the CLS Programme than we have had the chance to do justice to here. The story-bank for community led support continues to grow as the Programme itself evolves and grows. We will be finding more ways of collecting, sharing and learning from these stories in the third and ongoing round up of evidence and learning from April 2020.

Community Led Support

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