



People's Health Trust believes in a world without health inequalities. The Trust funds small and local projects in neighbourhoods that are most affected by health inequalities with funding generated through The Health Lottery. Active Communities is one of its funding programmes and grants aim to support people to create or shape local projects that will help their community or neighbourhood to become even better, and require local people to design and run these projects. Typically lasting up to two years, the grants are between £5,000 and £50,000 for each project. The programme's main intended outcomes are:

- **Collective control:** Ideas designed and led by local people. Regular participation of residents, who are empowered to lead and take ownership of the project design, delivery and development.
- **Social links and ties:** Stronger connections between people. Decreased social isolation and loneliness, and improved connection, friendships and collective support networks among participants.

Drawing on face-to-face interviews with participant volunteers in spring and autumn 2019, the case study explains how people came together to shape and lead the **Inclusion4All** project. It also shares what they have learnt and achieved as part of the 2018-19 Active Communities evaluation.



**FibroFamily@ Stanley:**

**Inclusion4All**

Stanley, County Durham

**£11,190**

of People's Health Trust funding, through Health Lottery North East and Cumbria

**Main activities**

Providing alternative therapies; training to provide therapies; meeting for conversation

**Key outcomes**

- Improved social links and ties
- Individual and collective action and control
- Increased confidence, knowledge, skills and assets

## About the project

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The project funded work by Inclusion4all, a support group for those living with fibromyalgia and their carers. Fibromyalgia is a long-term condition that causes chronic pain and can affect the whole body. The condition is often difficult to diagnose and people with the condition may wait a number of years to receive a formal diagnosis.

The group members meet once a week in a local social club. There are around 25 core members who attend the weekly meeting, but it is estimated that there are up to 50 people whom they have regular contact with. The group offers peer support and therapeutic treatments including Reiki, Indian head massage and hot stone massage. As part of the funded project, participants had the opportunity to train in therapeutic treatments which they could then deliver to the other group members during the weekly meet-up.

## How did local people shape and lead the project?

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The participants were involved in all aspects of running the group, the basis of which was to cooperatively provide free-to-all access to therapeutic treatments. All members of the group could receive training to be able to deliver treatments to their peers within the group.

*“We all work together and we all do everything. Nobody tells anybody else what to do”*  
(Project lead)

The group was described as “democratic”, with the voice of all participants being heard. The group had regular, well-attended, meetings to discuss issues such as grant applications, finances and future training opportunities. These informal weekly meetings encouraged participants to speak openly and discuss their views.

A more formal committee was later formed, made up of eight group participants. This group met ahead of regular sessions along with the project leads. Forming the committee was an important step for these participants, demonstrating their growth in confidence through group membership: taking part in a decision-making committee at the beginning of the project would have been very difficult for them. Whilst the individuals on the committee took on a more formal role in decision-making, the project leads remained certain that *“the whole group is the committee”* and that the views of all participants continued to be considered.

### Participant case study

One lady who attends the group regularly said that becoming a member of Inclusion4all had increased her self-confidence. The member has sensory loss as well as fibromyalgia which had led to her feeling socially isolated. She was very dependent on her husband who is her carer. When she first joined Inclusion4all she attended with her husband, however over time she has grown in confidence and built friendships with her peers so she no longer needs her husband to stay with her at the weekly meetings. This has given her a sense of independence.

“I’m glad the club is here. You can talk about how you feel that day. Everyone is so friendly. We share ideas and remedies – there is a lot of craft work, or pottery and things like that. You don’t feel pushed out.”

(Participant)

“It gives members the confidence to take the bull by the horns, actually, and if something's wrong to go and sort it out.”

(Project lead)

## What has the project achieved?

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There has been a clear benefit to participants in joining a new social network made up of people with shared experiences of this challenging condition. The benefits of improved social links were seen in participant personal wellbeing, the wellbeing of their wider social networks (e.g. family) and also in the increased confidence that participants experienced which meant they were able to take on greater responsibility themselves, perhaps training to provide therapies. The cooperative structure of the group's delivery, as well as the feedback mechanisms have strongly supported collective control.

### Improved social links and ties

Fibromyalgia can lead to symptoms including fatigue, poor quality sleep and chronic pain; therefore, some people living with the condition can struggle to complete day-to-day activities. Many project participants had experienced social isolation. One person said that before joining the group she would spend several days without speaking to anyone at all, particularly when she was unwell, so knowing she had the support group was very important.

*"It makes life so much more bearable."* (Participant)

Other members of the group said that knowing they could attend the support group and receive a treatment on the Friday was motivation for them to leave the house, even if they were feeling unwell. If it were not for the group, they said they would remain at home and feel increasingly isolated from society. For times when members are unable to attend the weekly meeting, there was a WhatsApp group to access support remotely.

Finding support from those with a shared experience of the condition was important for participants, some of whom said that this supportive group of peers allowed them to share their feelings with people who understand. Family members may struggle to understand the chronic condition in their loved one, and group members said having a hidden illness can be very difficult for others to understand. The project presented an opportunity for carers and family to learn more about the condition and gain a greater understanding of the fibromyalgia experience of their family member and others. Meetings also provided a good support network for family carers experiencing social isolation themselves.

*"I have learned more about the condition. I used to say, to my daughter who has fibro, 'Oh, are you still in bed?' I didn't realise how bad it could be. I realise now that she has to have a rest: it suddenly flares up and she can be in bed for two days."* (Participant)

As well as the creation of new friendships and a new social circle with shared experience, the group provided some members with the confidence to reconnect with their existing social groups. One participant said she had regained some of her independence through the group and had developed more confidence to go out with her family and friends.

*"Socially we have a really good network now haven't we? We see each other outside the group as well."* (Participant)

"My husband doesn't want to listen to me whinge on, he hasn't got the first idea. So just having somewhere that you can talk, where people understand. It is just having that outlet"

(Participant)

## Individual and collective action and control

At Inclusion4all, the roles of participant and volunteer are not separated. All of those who attend the group are a volunteer in some form, whether they deliver treatments or help to make drinks: everyone can be involved.

"Everybody just helps each other really." (Participant)

Beyond the therapies, participants at one point decided that they would like to involve more craft activities in their weekly meetings. This feedback is offered either through the group meetings or more informally during discussion. On the basis of this feedback, the project leads invested in resources to make it a possibility.

"The girls decided they wanted to do certain crafts and things like that... and I was able to say right well if we do this we need arts and crafts stuff and sewing machines." (Project Lead)

Participants' views were valued throughout the project, and everyone was included in decision-making at both formal and informal meetings. Participants were also key to promoting the group within the local community, via awareness stalls at supermarkets, handing out flyers, or putting posters up in locations such as GP surgeries.

A further collective control outcome discussed with interviewees was the referral function of the group. When participants saw that others in the group living with fibromyalgia were able to do things beyond the project and to have positive experiences, it acted as powerful encouragement. For example, several participants attended a local 'gentle exercise' session after the instructor came to do a taster demonstration. Also, one member successfully applied for a disabled bus pass, helping a number of the other members become aware that they could do so too and subsequently did. These are good examples of how this referral function has helped members of the group become more active in society and less isolated, in addition to the project's weekly meetings.

## Improved confidence, knowledge and skills

Paying for private therapeutic treatment is costly and for most people unaffordable on a regular basis. Those living with fibromyalgia often benefit from regular therapeutic intervention and Inclusion4all has been able to make treatments accessible to all its group members by providing cooperative services 'in-house': training up participants in a wide range of therapies. At the time of the second visit, participants had been trained to deliver treatments including: Reiki, hot stone massage and Indian head massage.

"I would say we share information and get access to a treatment at a reasonable cost and it is social to stop the isolation really." (Participant)

One aim of the group was to offer training and skill development to all those who wanted it, and project staff feel they have been able to achieve this. Whilst it is noted that training courses can be expensive, the positive impact makes them a worthwhile investment for this community. The delivery of treatments is inclusive for all participants, and even those with severe physical symptoms or physical limitations may be able to receive gentler treatments such as Reiki, crystal healing and aromatherapy and to go on to partake in training and subsequent delivery of treatment to others. This strengths-based approach was important to members of the group:

"They focus on what you can do, not what you can't do. It's really good to be able to share information." (Participant)

"I can honestly say that prior to my flare... I had stopped taking my Tramadol because I had pain under control with therapies, the massages, things like that"

(Project Lead)

For those who have trained, gained qualifications and are able to deliver therapies, there is a clear sense of fulfilment in being able to give back to others. However, the project focus has been more on mutual support than upskilling. Fibromyalgia can lead to a reduced sense of self, due to the physical and psychological side effects of the condition. Those living with the condition can often focus on what is “lost” and the negatives of having to adapt to life with fibromyalgia. In contrast, the Inclusion4all project takes an asset-based approach. The emphasis is on what the individual can do, rather than what they cannot.

“People can lose those skills and the talents that they had when they got poorly. So this environment it is lovely to see people have the confidence to do something that they had lost you know.” (Participant)

Participants agreed that if the group were not to exist within the local area, they would not have had access to other therapies and treatment. Other available treatments and therapies are financially unattainable for many people, particularly those who cannot work due to living with chronic conditions such as fibromyalgia. The treatments available at Inclusion4all have “opened new doors” for participants, offering treatments they may not have had the opportunity to experience otherwise. This has been a huge asset.

“It is classed as a run-down place, it certainly isn’t wealthy... People don’t have the resources to travel and people don’t have the resources for therapies.” (Participant)

## Long-term outcomes

The group provides members with sustainable long-term outcomes that reach beyond the immediate boundaries of the group. One member of the group felt that the support, confidence and therapeutic treatments she has gained have led to her remaining in employment for longer. It is hoped that for others, through the confidence gained and the skills learnt, it could lead them to pursue future employment opportunities.

“Three years ago I just wasn’t functioning, so I reckon I have been at work for a lot longer because I have been coming here.” (Participant) In addition to the physical symptoms of the condition, those living with fibromyalgia are increasingly likely to experience mental health problems. Some of the therapeutic techniques that members learned can help to relieve these symptoms. As one participant said, the treatments “just lift people’s mood” and increased their sense of wellbeing.

“Medication isn’t such a major factor for us now. With alternative therapies most of us can cope with what we’ve got.” (Participant)

“It gives them pride, joy and a purpose as well if you like and if they can help other people feel well it’s good for your mental health as well. Makes you feel useful.”

(Project lead)

## What has worked well?

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- **Strong leadership.** The project lead has lived experience of fibromyalgia and was described as “positive” and “determined”. She wanted to share the positive impact that therapeutic treatments could have on those living with fibromyalgia. Although a volunteer, due to her therapeutic knowledge as a former health trainer and therapist and contacts in the field, she has been key to organising all the training courses and was seen as having a key role in facilitating the “vision for the group”.
- **Creating a culture that brings a sense of control over a chronic illness.** Living with a chronic illness may lead people to feel that they have no sense of control. The group activities allowed those living with fibromyalgia to regain a sense of control over their own condition through the cooperative delivery of alternative, non-medical options to relieve symptoms.

“It was Jackie who had the burning desire to set the group up... She was determined to make it about what we can do, as opposed to what we can't.”

(Participant)

## What are the lessons?

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- **Central location and accessibility.** The group had recently relocated to a more central location served by a regular bus route. This has had a positive effect on people being able to attend, particularly those relying on public transport. The previous location often required multiple buses with long waits, which was a difficult journey for those with a chronic illness and a clear barrier to attendance.
- **Positive group.** Some members reported past experiences of support groups that were ‘negative’. The groups were unwelcoming to new members and dwelled on negative aspects of the condition. It takes time to rebuild the trust and confidence of individuals that have experienced this, and it is something that Inclusion4all need to continue to be mindful of, particularly when welcoming new members.

## The future

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The sustainability of the project was a focus of planning from the start. The group had previously experienced financial barriers and wanted the funding to benefit them not only for two years, but to set them up for future operations. Project leads hoped to create a sustainable foundation for future cooperative treatments offered free of charge.

To create sustainability, the group used People’s Health Trust funding to make larger purchases, such as a sewing machine that will allow them to increase the number of craft activities that they can offer. They have also focused on investments that will have a long-term impact on the quality and quantity of treatments that they are able to deliver, such as massage tables and participant training.

“We are self-sufficient, on everything [now]... We only need to top up on stationery and things like that.” (Project lead)

Utilising the project funding for these large expenses enabled the project to build up a “backstop” of money from their regular income, which at the time of the second visit totalled between £800-900. Project leads said that this money would now support the everyday running of their activities long after the funding period ended.

“That pot of money, we will get at least, at least another two more years out of it at the end. We will get a lot more out of it.” (Participant)

“We have all our assets, we have pretty much what we need for the therapies, I don't see why it shouldn't be able to sustain itself”

(Project lead)