



## Northern Ireland Rare Disease Partnership 'Stronger Together' – June 2021



**Organisation name:** Northern Ireland Rare Disease Partnership (NIRDP)

**Project name:** Stronger Together

**Location:** Newtownards, Northern Ireland

**Grant amount:** £112,124

**Award date and duration:** September 2017, 2 years

**Project context:** More than 100,000 people in Northern Ireland live with a rare disease. The NIRDP was set up in 2014 and aims to support these people. Until the Stronger Together project, it was entirely volunteer run.

**Project aims:** The aims of this project were to: support people living with rare disease; develop the network of support available to people living with rare diseases; and raise the profile of rare disease in NI.

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## Project aims

The aims of this project were to:

- Provide face-to-face emotional and practical support to people living with rare disease across Northern Ireland;
- Raise the profile of rare disease across Northern Ireland;
- Develop partnerships to strengthen the support network for people living with rare diseases; and
- Connect people living with rare diseases with others in the same situation.

## About the grant

The NIRDP aims to offer emotional and practical support to people living with rare disease. The grant was used to employ two part-time 'Project Officers' who would offer direct support to beneficiaries and raise the profile of the project. Each Project Officer was responsible for half of the geographical area of Northern Ireland.

The two Project Officer roles were advertised via the Community NI jobs website, the NIRDP website and social media channels. In the recruitment process, the NIRDP Board had two priorities for applicants:

- soft skills, in particular someone who was supportive and an active listener
- experience of working with vulnerable people including those with lasting health conditions.

It was hoped that this skillset would ensure Project Officers were able to understand and provide the emotional and practical support beneficiaries needed.

## Project set up and delivery

Project Officers were on hand to offer emotional support to people living with rare

"[The job was] meeting people who were affected by rare conditions and just supporting them with whatever way they wanted."

**Tanya, Project Staff**

diseases and their families. For example, the daughter of one beneficiary received a Parkinson's diagnosis, alongside her existing rare disease. The Project Officer had talked them through the diagnosis and supported them as they came to terms with it.

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Some of those living with rare disease had suffered social exclusion, both due to the nature of their illness and associated mental health and wellbeing issues that came with living with a rare disease.

Stronger Together offered a pathway to greater social inclusion through contact with Project Officers and the wider support network. For example, one individual who came in with little social

contact, spent an hour a week with a Project Officer, going out for coffee or walking the dog. Alongside this the Project Officer arranged for her to attend a 'social farm', which gives adults with a long-term health condition the opportunity to help on a farm and socialise with the other attendees.

"Tanya organised for her to go once a week... They work with the animals and there's an occupation therapist who helps with her posture, so that's been absolutely fantastic."

**Jane, beneficiary**

Project Officers assisted beneficiaries in navigating the NHS and other care structures. Tanya, one of the Project Officers, was a nurse by profession and was able to offer guidance on how to pursue necessary appointments and what to expect from them. They were also able to offer support in other areas, such as supporting individuals with Personal Independence Payment applications or making adjustments to their home necessitated by their condition.

The Project Officers also acted to promote a wider network of support for people

"A lot of it was attending meetings and just getting the project out there and letting people know that there was support available."

**Tanya, Project Staff**

living with rare diseases. For example, one volunteer, Jessica, ran a support group in her town for people living with rare disease and their families. Tanya arranged for a number of speakers to come to events to talk about different health and care support options, as

well as coming to meetings herself to offer her support.

## Project impact

### Key Highlights

Numbers supported

- 350 people living with a rare disease

Key impacts

- Improved the mental health and wellbeing, reduced the loneliness and improved the confidence and resilience of people affected by rare diseases.
- Helped people living with rare disease to access more information and support.
- It has helped develop partnerships across the health and social care sector and the rare disease community in both Northern Ireland and the UK.

Website

[Northern Ireland Rare Disease Partnership \(nirdp.org.uk\)](http://nirdp.org.uk)

### Reduced social isolation; improved mental health and wellbeing, confidence, self-esteem and resilience

Beneficiaries had previously felt unsupported in managing the emotional demands of living with a rare disease.

The direct support offered by Project Officers, typically through supportive

conversations and visits, was a significant help. This impacted positively on the mental health and wellbeing of those with rare diseases and on their family members. For example, Jane's daughter went out once a week with Tanya for a social support visit. Jane found that her previously reclusive daughter was more confident and social as a result with a positive impact to her wellbeing. The time her daughter spent with the Project Officer also meant Jane had some time for herself, a rare luxury as her daughter's full-time carer.

"Tanya was able to bring my daughter out of her shell a bit and give me a wee bit of time to myself."  
**Jane, beneficiary**

People were also connected with wider networks, including the local NIRDP support groups, which developed a support system beyond their doctors, of others with a shared rare disease experience. This provided many beneficiaries with much needed social inclusion. Living with a rare disease was described by volunteers as a lonely experience, but Stronger Together was able to bring people going through similar issues together.

"It was really good because there were other people there who cared for adults of children with rare conditions, so it felt really good to be brought together with people like that."

**Jane, beneficiary**

### **Access to information and support to improve knowledge and skills about their situation**

Project Officers provided support to ask the right questions of doctors and navigate the health and care system. As a result, some people were able to get a diagnosis or support that had been missing. Kate, the Project Lead referred to 'the rare disease odyssey'- the period of time, often 5 years plus, between symptoms manifesting and a diagnosis - as hugely damaging to people's wellbeing. Ensuring support on this journey can help people to be more resilient. This support meant some people were in a better position to secure a diagnosis with a hugely positive impact.

"A lot of time was spent trying to find the right path, so I was speaking to people in the NHS saying, 'this is what's going on with this person, what's the best way to get them a second opinion, or a private opinion, or seen on the mainland.'"

**Tanya, project staff**

"Tanya was able to refer him to urgent OT [Occupational Therapy]... this couple had been married 40 years and never spent a night apart and she [his wife] didn't sleep for fear of him falling... OT was very quickly able to assess the situation and install a lift."

**Jessica, volunteer**

Jane, a programme beneficiary, and Tanya, the Project Officer, outlined other forms of support aimed at improving people's quality of life. For example, Tanya supported one individual to get a lift installed in his home so he could go upstairs and sleep in the same bed as his wife of more than forty years for the first time in months.

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## Partnership development

Staff and volunteer Board members felt that a number of partnerships across the third sector and health and care sectors in Northern Ireland had been formed. This raised profile led to NIRDP being invited to chair the Northern Ireland segment of the UK Parliamentary event on Rare Disease, hosted by Genetic Alliance. This, and participation in other events, has helped to raise the profile of the NIRDP and the work they do.

Furthermore, the learning from the project led to a number of meetings with the NI Commissioner for

Mental Health to progress specific mental health support for the rare disease community.

"We wanted to make sure we had connections with other organisations in the community so that we could work together in supporting our rare disease folk."

**Sarah, volunteer**

## Overall reflections

The project was effective in supporting the needs of the individuals it worked with and there was a sense among board members that Stronger Together had helped to 'put the NIRDP on the map'. However, the scale of support needed, in terms of the number of people and the geographical area they were spread across, was a challenge.

One of the key factors in their success was the presence and expertise of salaried staff. Having two salaried staff members brought two benefits, which were furthered by Tanya's background as nurse at Great Ormond Street hospital. Firstly, it meant they were able to offer more direct support to beneficiaries, that simply was not possible for an entirely volunteer-run organisation. Within this, Tanya's knowledge of the NHS meant she could signpost beneficiaries more effectively to support.

Secondly, Kate and the other Board members felt that having salaried staff members gave greater weight to their profile-raising activities than they had as volunteers. Tanya's healthcare background was felt to help this.

The project also faced three challenges. Firstly, Northern Ireland was judged as having a fairly poor health and care infrastructure for people with rare diseases. This meant that there was not always a pathway to refer participants on to the support they needed.

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Secondly, the size of the geographical area they covered inhibited their ability to offer consistent support (for example, those that lived nearer to a Project Officer were able to enjoy more regular contact). Finally, having not offered this kind of outreach support before, the NIRDP were relatively unknown within the community they served. As a result, much of the early portion of the project was spent raising awareness of Stronger Together.

"Geographically it was a real challenge, it restricted in some ways how well we could deliver... one person, in a remote location, with complex needs could literally take a whole day to deal with."

**Kate, project lead**

Both a success and a challenge NIRDP came into this project with no experience of employing staff members, which meant they had to quickly develop human resources policies, more effective reporting processes and improvements to their governance. As a result of this steep learning curve, they now have more well-defined employment and governance policies and feel better equipped to "work smarter not harder" in future.

After the conclusion of the Stronger Together project, the NIRDP applied for phase two funding through the Rank Foundation, for two Support Officers. This time they tailored their approach to offer more virtual support, to overcome the geographical challenges encountered in Stronger Together (although this approach was accelerated by the COVID-19 pandemic). The Board felt that this new approach allowed them to offer more consistent support to more people, while the network of support organisations built across the lifetime of Stronger Together allowed them to do so from the outset.

### About the case study

As part of this case study, IFF Research spoke to Kate\*, the project lead and Chair of the NIRDP; Tanya\*, a project staff member; Jessica\* and Sarah\*, two volunteers who sat on the board of the NIRDP; and Jane\*, a beneficiary of the programme.

*\*Names have been changed.*