RARE CONDITIONS IN NI

EXPERIENCES FROM THE RARE CONDITIONS CONFERENCE

contact

For families with disabled children

This report was supported by funding from the Pears Foundation and Dormant Accounts.

Prepared by Catherine Murnin, freelance associate with Contact as part of Dormant Accounts Funding and supported by NI Rare Disease Partnership.

CONTENTS

INTRODUCTION

This short report shares the context of the Rare Conditions Conference that brought parent carers and practitioners together at an event in January 2024. The conference was facilitated by Contact NI and The Northern Ireland Rare Disease Partnership (NIRDP), supported by funding from the Pears Foundation.

Rare conditions are characterised by a wide range of symptoms and signs that vary not only from condition to condition, but also from patient to patient with the same condition. Relatively common symptoms can often hide underlying rare conditions, leading to misdiagnosis. Rare conditions not only affect the person diagnosed, they also impact families, friends, carers and society as a whole.

Thanks to the parent carers, practitioners, facilitators and team members at Contact NI and the NIRDP for coming together to support conversations and learning around families and children living with a rare condition across Northern Ireland.

ABOUT CONTACT

Contact was founded in the 1970s by families of disabled children, who recognised that even if their child's conditions were different, they shared a common experience – that of being a family with a disabled child. They understood how important it is to support each other.

A lot has changed since then but some things haven't changed nearly enough. There is a desperate lack of services and support for the 620,000 parents in the UK who care for a disabled child. As a result, families face a huge range of challenges and many feel isolated and alone. Coping with extra financial costs and practical challenges can put an enormous strain on daily life, with families more likely to face emotional issues, stress and anxiety.

We are here for all families with disabled children:

- ***supporting families***
- ***bringing families together, and***
- ***helping families take action for others.***

Our vision is that families with disabled children feel valued and are strong, confident and able to make the decisions that are right for them.

Our Northern Ireland Team

Our Northern Ireland team offers support, advice and information to families with disabled children, no matter what their condition or disability.

Our Outreach Workers and Family Support Advisers work directly with families and professionals, providing assistance with inquiries, hosting information sessions and organising workshops to ensure that families of disabled children get the support they need.

We also offer support to practitioners through CPD-accredited courses, co-production training and guidance around working with families through consultancy to improve SEND provision and practice.

ABOUT NORTHERN IRELAND RARE DISEASE PARTNERSHIP

The Northern Ireland Rare Disease Partnership (NIRDP) was set up to ensure that no-one is disadvantaged because of the rarity of their condition. Our aim is to catalyse transformational change by working with and for people affected by a rare disease, their dependents, carers and those treating them. We do this in the following ways:

Connecting

- ***Stronger Together***
- ***Outreach to the rare disease community in Northern Ireland***
- ***Tackling disadvantage and inequality***
- ***Reaching out to those living and working with rare disease elsewhere in the UK and Ireland, and across the world.***

Advocating

- ***Strong cohesive and coherent voices***
- ***Empower our members***
- ***Embed rare disease issues in policy formation and service delivery.***

Educating

- ***Raise awareness of rare diseases and rare disease issues and impacts***
- ***Increase levels of knowledge and expertise***
- ***Act as a knowledge broker among medical, health and social care professionals, policy officials, rare disease families and the public.***

Innovating

- ***Develop and implement improved methods of managing and treating rare diseases***
- ***Improve the quality of life for those affected by rare diseases; and increase the efficiency and effectiveness of care and support.***

RARE CONDITIONS IN NORTHERN IRELAND

A condition is defined as rare in Europe when it affects fewer than 1 in every 2,000 people.

1 in 17 people will be affected by a rare condition at some point in their lives.

110,000 people across Northern Ireland.

Together, Rare Conditions Patients are many.

THE UK RARE DISEASES FRAMEWORK

Development of the UK Rare Diseases Framework was based on the outcomes of the *National Conversation on Rare Diseases*, launched in 2019. The *Conversation* gathered views across the rare disease community on the major challenges faced by people affected by rare conditions across the UK.

6,293 responses were received, which helped identify four high-level priority areas to bring about real change and forming the basis of the Framework. The four priorities are:

- ***helping patients get a final diagnosis faster***
- ***increasing awareness of rare diseases among healthcare professionals***
- ***better coordination of care***
- ***improving access to specialist care, treatments, and drugs.***

To turn these priorities into a reality, the Department of Health in Northern Ireland recognises that significant action is needed across health and social care.

In addition to the four priorities, the Framework identifies five underpinning themes to support the four priorities. These themes are:

- ***patient voice***
- ***national and international collaboration***
- ***pioneering research***
- ***digital, data and technology***
- ***wider policy alignment.***

The Framework was published on 9 January 2021 and outlines a national vision for how the UK will improve the lives of those living with rare diseases over the next five years. All four UK nations have committed to developing clear and tangible action plans to deliver on our collective Framework.

NORTHERN IRELAND'S RARE DISEASES ACTION PLAN

Northern Ireland's first Rare Diseases Action Plan aims to support implementation of the Framework and was developed with stakeholders across the healthcare system, the Northern Ireland Rare Diseases Partnership (NIRDP) representing the rare disease community and rare disease researchers and educators from Queen's University Belfast and Ulster University to bring about specific and measurable improvements for people living with a rare disease.

ABOUT THE RARE CONDITIONS CONFERENCE

PURPOSE OF THE EVENT

To create a space for connections and conversations around improving health and wellbeing outcomes for parent carers of a child with a rare condition, across Northern Ireland. The event was held in The Junction, Dungannon.

AUDIENCE

Parent carers and practitioners supporting families who have a child with a rare condition.

STRUCTURE

A free half-day conversation with parent carers sharing their experiences and time for facilitated discussion in groups around co-production, support services and training needs.

WHO ATTENDED?

43 individuals with:

62%	parent carers
38%	practitioners from different parts of Northern Ireland.

OUTLINE OF EVENT PROGRAMME

Welcome and introductions

With Susan Walls, Contact.

NIRDP introduction

Plus 1 in 17 voices videos with Caroline McFerran, NIRDP and Anne Marie Hoey. Caroline McFerran is a Community Navigator in the NI Rare Disease Partnership and was a key supporter in putting the conference together. She shared some insights from the charity's Rare Stories – Voices of the 1 in 17 project, alongside Anne-Marie Hoey, mum to identical twin daughters living with the rare genetic condition, PKU.

Parent carer keynote speech

Claire O'Hanlon, mum to Luke, living with Duchenne Muscular Dystrophy. An experienced business mentor and MBE recipient for her services to Muscular Dystrophy campaigning and fundraising, Claire is passionate about ensuring that the lived experiences of parent carers is valued and listened to when services are being designed and delivered.

You could have heard a pin drop when Anne Marie Hoey and Claire O'Hanlon shared their stories. Saul, a young man living with a rare condition, entertained the audience with this humour, honesty and zest for life!

BREAKOUT DISCUSSIONS

Prior to the conference, participants had been invited to give some thought to the following areas and on the day, breakout discussions were facilitated in groups that included parent carers, practitioners and staff from Contact and NIRDP.

- ***What experiences do you have of a co-production approach? If yes, what worked well and what could be improved? If no, how do you think this could improve outcomes for families?***
- ***With challenges around waiting times and access to support services, how can families be better supported in their caring roles?***
- ***What training and support needs might practitioners have and how could we work together to meet those needs?***

SUMMARY FROM BREAKOUT DISCUSSIONS

Question 1

What experiences do you have of a co-production approach? If yes, what worked well and what could be improved? If no, how do you think this could improve outcomes for families?

Feedback

- **Concept of co-production** is positive but experiences from parent carers identified very slow processes, lack of feedback on agreed actions and parents being expected to give up their time and share their stories with no remuneration
- **Volunteering** – sometimes it seems like it's the same people volunteering their time, and this can be exhausting. Parent carers do want to share their lived experiences to educate and improve services, but it can become exhausting. Charities could involve more people in different volunteer roles but how do we hold the decision makers to account?
- **Jargon** – the terms co-production and co-design might mean very little to families. Parents might be more likely to be involved if the process was clear and there were examples of positive change. It is important to remember that some practitioners and professionals are also parent carers
- **Access to training.** If healthcare and education are serious about co-production, then those involved should have access to appropriate training with guidance and support for parents in these areas
- **Start early** and include co-production modules in training for students
- **Sounds good in theory**. We've never heard the term co-production, but I wouldn't have considered it as something related to our child's care and support for our family. It sounds good in theory but more challenging to put into practice, especially when things are rushed and we often feel that we are not respected as part of the decision-making process.

Question 2

With challenges around waiting times and access to support services, how can families be better supported in their caring roles?

Feedback

- **A postcode lottery** in accessing support and services still exists in Northern Ireland, everyone feels this is unjust and unfair. Every family should have access to the information and support that is right for them, no matter where they live.
- **Take account of the whole family**. Families' journeys span from pre-birth to end of life and there are a lot of experiences to navigate along the way. It can feel very isolating and overwhelming at times. It feels like some professionals just look at the diagnosis, not taking into account that this child lives in a wider family dynamic where everyone is impacted.
- **Life before diagnosis.** Living in limbo before diagnosis, assessment, and access to support creates huge pressure, uncertainty, fear and anger and it can feel like parent carers have to fight all the time. Parent carers can become labelled as troublemakers. If professionals took a step back to understand and see the bigger picture, it might support better relationships.
- **Dealing with red tape.** Practitioners want to understand and recognise the red tape that exist across many services, they feel frustrated by this too but often don't have anywhere to go to vent those frustrations or take positive action themselves.
- **Juggling different professionals.** Parent carers talked about fitting it all in, that an appointment with a professional often focuses on one small piece of their/their child's life and it can feel like all the other stuff doesn't matter, and isn't taken into account.
- **Everyone is an individual** with their own unique needs, and this can be a challenge for everyone involved, but it is not an excuse to avoid the difficult conversations and we all must strive to do the right thing.
- **Waiting lists are unacceptable**. Some people can pay to go privately, and others can't. Some services aren't available privately. It is an unequal system. We can recognise the challenges and understand that it is a complex situation but feeling listened to and guided in the interim could go a long way to reducing stress.

Question 3

What training and support needs might practitioners have and how could we work together to meet those needs?

- **Lack of awareness and training** in some settings, for example A&E, around the needs of a child with a rare condition and parent carers often feel that professionals don't value what knowledge and expertise they have around their own child.
- **Communication challenges** mean parent carers have to keep repeating their story and it feels like no-one is listening to them. This is time consuming, emotionally draining and supports the criticism about ineffective statutory processes. It seems like some small changes could improve outcomes for everyone if communication is better.
- **Acknowleding parents' expertise**. Some staff are unable (or lack confidence/training) to use some equipment on the wards. Parents should be listened to and their expertise welcomed. We understand the challenges around risk and safeguarding but there must be a better way to work together for children/patients. Some parent carers highlighted a disconnect between NI and other UK services, when their child travels to England for treatment.
- **Awareness of the impact of caring**. There is much more awareness needed on the impact of caring on parent carers. Often, we are dealing with emotional, physical, mental and financial pain of our own but we have to keep going. It is exhausting at times and some kindness and compassion from professionals would make a big difference, even if they can't provide a specific service.
- **Student and workforce training.** We would welcome training for students, especially hospital staff and social workers. Even though suitable education places are a challenge, there is usually good awareness from staff around the challenges that families are facing.
- **Times of transition** are difficult, and it seems that some professionals don't take this into account. Having no prior experience as a parent carer can make these times very hard to navigate and we found that some professionals either didn't know what process we should follow or just gave us a number and left us to it.

OTHER KEY MESSAGES

When parent carers and practitioners shared positive outcomes, they were based on good communication, respect, partnership and truly putting families at the centre of the planning and decision-making process. Parent carers felt informed and empowered, less stressed and more in control. Practitioners felt motivated and supported, enabled to provide services in a way that meets the family's needs. Unfortunately, there were just a few examples of this approach during the conference discussions.

There were powerful reflections from parent carers around the impact of caring on their overall health and wellbeing. Very strong emotions, fatigue, uncertainty, fear, anger and lack of energy were described:

- ***"Fighting every day for survival"***
- ***"I don't want to be the angry person all the time"***
- ***"Some days it's an achievement when I get up and get dressed"***
- ***"I am living on the edge all the time".***

"It felt like something special happened today. Listening, laughing and having a chance just to talk with others. I enjoyed the informal discussions over the comfort break and lunch. Everyone was so supportive and I would like to join something else again in the future."

"This was one of the best events I've attended to give us a balance of information, social time, learning with others and hope that something might change for the better."

FEEDBACK FROM ATTENDEES

"Thank you for giving us this opportunity today. I really enjoyed meeting other parents and felt that the professionals at my table really listened to our views."

"I was a bit nervous about coming along today as I am new to my role but felt welcomed and learned a lot from what the parent carers shared. I hope this will improve my practice and how I share with other professionals"

NEXT STEPS

1 **CONNECT WITH INFLUENCERS AND DECISION MAKERS**
across services, including stakeholders across government, business, community and research.

2 **SHARE CONTACT'S AND NIRDP'S OFFERS FOR FAMILIES & PRACTITIONERS**
in Northern Ireland through our networks, media and social media.

3 **REFLECT AND BUILD MOMENTUM**
by capturing lived experiences and learning from parents and practitioners.

4 **DELIVER A FOLLOW-UP EVENT**
in May 2024 to share the report and create a space for parent carers, professionals, influencers and decision makers to come together and aim for positive change.

We are Contact, the charity for families with disabled children.

We support families, bring families together and help families take action for others.

GET IN CONTACT

Visit our website to find out about help in the early years, diagnosis, benefits, education and local support.
We also have a:

- ***benefits calculator***
- ***grants finder***
- ***Live Chat service***

contact.org.uk/northern-ireland

If you can't find what you need on our website you can call our free helpline.

☎ **0808 808 3555**