

Key findings from an evaluation of Rollercoaster:

A parent support group for parents
and carers of children and young
people with mental health difficulties

Briefing Paper, April 2022

*“ It is an amazing group,
that I could not have
been without these last
few years. ”*

Parent,
Fothergill-Misbah et al
(2021)

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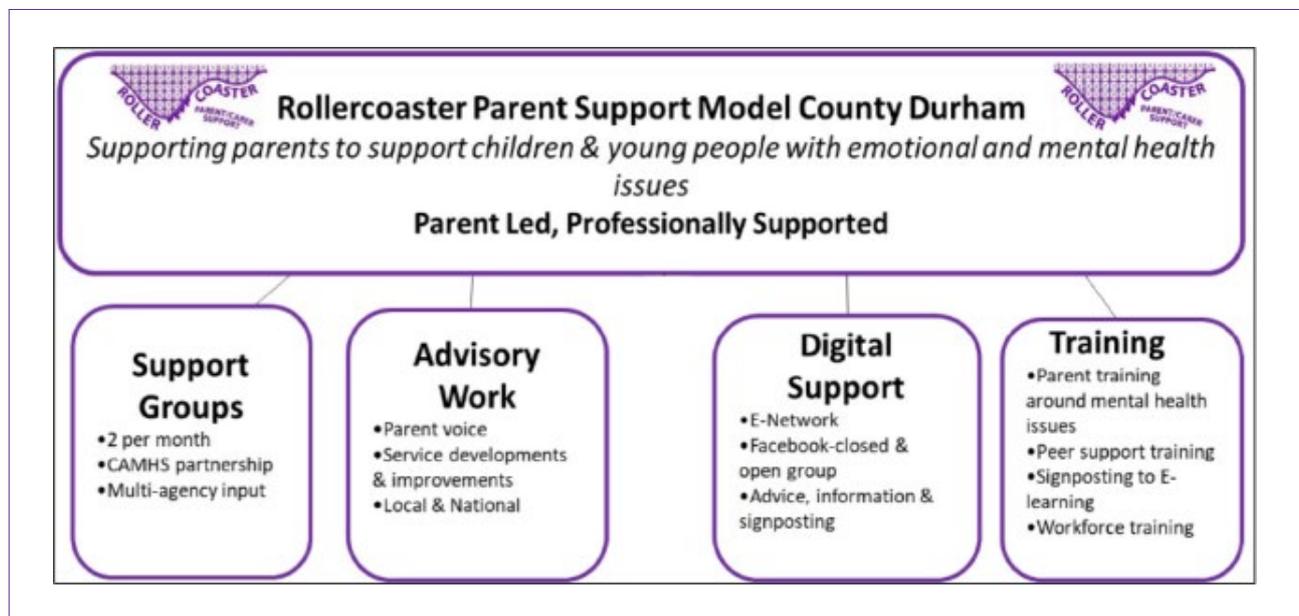
Rollercoaster graphic

About Rollercoaster

Caring for a young person with mental health problems is one of the most stressful things a parent can do. Rollercoaster is a parent support service based in the North East of England, set up to help people in this situation. Over six years of operation it has developed into nationally recognised provision for parents and carers living in or around County Durham.

The service consists of a combination of face-to-face groups, on-line groups, opportunities for training and individual email contact. Parents self-refer or are referred through local services (such as child and adolescent mental health services and social work agencies). Currently the service receives funding from County Durham NHS Clinical Commissioning Group.

The Rollercoaster Parent Support Model contains the following elements:



Rollercoaster quarterly report April 2021

About the evaluation

Northumbria University's Department of Social Work, Education and Community Wellbeing undertook a mainly qualitative process and impact evaluation of the Rollercoaster parent support service over a period of six months from the end of 2020 to June 2021.¹ The Association for Young People's Health (AYPH) was involved in the design of the evaluation, which built on earlier work that AYPH had undertaken with Rollercoaster.²

The evaluation drew on Rollercoaster's internal monitoring reports, interviews with founding members and wider partners (15), an on-line survey of parents/carers from Rollercoaster's database (82), observations of group meetings (13), and individual interviews (14) and focus groups (2) with parents/carers. In total there were over 300 separate engagements as part of the evaluation although some of these will be the same people taking part in several activities. In this briefing we pull out some of the key findings from the evaluation report and AYPH's own work with the service to highlight what we know about how Rollercoaster works.

During the period of the evaluation the UK went through the third national pandemic lockdown and both services and evaluation activities were largely conducted on-line. The evaluation report acknowledges and discusses this, but it seems that neither the core elements of intervention delivery nor the evaluation methods were fundamentally affected. It seems fair to assume these findings stand whether the service is fully or only partially on-line.

The key research questions

- How was Rollercoaster set up and implemented?
- What are the key components of the Rollercoaster model?
- What evidence is there of impact on parents, in terms of engagement, experiences and impact?
- What are some of the challenges and good practice messages for others setting up similar services?

1 Fothergill-Misbah N, Perkins N, Johnson A, Rutter N, Wood M, Henderson E (2021) *Final report: Evaluating a support group for parents and carers of children and young people with mental health difficulties*. Unpublished report. Newcastle: Northumbria University

2 Hagell A and Kenrick J (2021) *Rethinking how we support the parents and carers of young people with mental health problems: policy and practice issues and emerging solutions*. London: AYPH

The implementation journey

Rollercoaster Family Support was set up in November 2014 as a parent support project, run voluntarily by two parents who were supporting their children with mental health. It was set up in partnership with Tees, Esk and Wear Valley Child and Adolescent Mental Health Services (CAMHS). Wendy Minhinnett, one of the founder parents, continues to lead the service today. Support groups started in 2015. By the end of the first year 20 parents had attended a group and 30 had been in touch for information. By the end of the second year (2016), over 50 parents had attended groups and over 70 had been in touch for information. In 2019, the year leading up to the pandemic, there was a total of 371 attendances at the face-to-face groups.

Initially Rollercoaster relied on volunteers to run the groups in partnership with a member of staff seconded from the local CAMHS department twice a month. It received its first funding grant in 2016. Since

then it has grown to become a fully funded parent support service with a range of different activities in addition to the groups, although the core staff group remains small. Its governance arrangements have evolved over time; starting as a community interest company (CIC), it is currently a limited company, with clinical supervision provided by CAMHS. The Charlie Waller Trust now works in partnership with Rollercoaster and its founder and has hosted activities that have broadened out beyond the local offer, to include running a national network of parent support services (PLACE), and contributing to policy and practice development across the country. The PLACE Network will facilitate the growth of parent-led professionally supported parent support groups and the Charlie Waller Trust is also supporting the development of parent peer supporters in the children and young people's workforce.

Key components of the Rollercoaster model

From the beginning, Rollercoaster has been framed as a parent-led, professionally supported service.

Key elements of the model include:

- Co-production and co-delivery with parents
- Mental health input, advice and supervision from the Tees, Esk and Wear Valley NHS Trust.
- Partnership with CAMHS
- A varied offer, allowing parents choice in how to participate.
- A wide range of routes into the service. Similar proportions are directed to the service through friends (22% of survey respondents), CAMHS (19%), healthcare or social workers (19%) and schools (12%). Others respond to marketing.

Parents' engagement and experiences of the service

Numbers engaging: Simply in terms of numbers using the service, Rollercoaster demonstrably filled a gap in support for parents/carers in the local area. In the first nine months of 2020, when the face-to-face groups had stopped, there were 168 attendances at on-line groups, a further 312 engagements with Facebook Live sessions, and 87 parents took part in Parent Training events. At the time of the evaluation there were 1,700 parents in the closed Facebook group. Given the focus on providing mainly just for Country Durham, these numbers are a striking reflection of need.

Experience of Rollercoaster: Both the evaluation and Rollercoaster's own regular service level data reflect that parents are very positive about the service. There was confidence among survey respondents that Rollercoaster knew how to help (82% of survey respondents agreed or strongly agreed). More than nine out of ten agreed with the statement "if a friend needed similar help, I would recommend that they use Rollercoaster". Parent/carers felt listened to (89%), could talk freely (89%) and treated well (89%). In interviews and comments parents frequently commented on the non-judgemental atmosphere and how this facilitated engagement. This is by definition a group of parents in distress, who may have been feeling desperate and let down. In that context these ratings can be regarded as very high.

Value of all parts of the service offer: In a survey of parent users undertaken for the evaluation, respondents reported high use of the on-line social media components (78% respondents regularly using this) complemented by attending training sessions (53%), making telephone support (29%), and attending online (27%) or face-to-face meetings (10%). During the Covid-19 pandemic, delivery of groups was on-line through Zoom or Facebook Live sessions. Qualitative interviews with parents confirmed that all elements of the service offer were valued in one way or another, and no service gaps were identified.

Responsiveness of the service: Qualitative data suggested that the responsiveness of the service (through telephone and email support in addition to groups), and the support offered from staff and other parents, were highly valued. Feeling there was always help available was important, and different from anything else on offer.

During the first 9 months of 2020, as the pandemic unfolded, there were

567

direct parent engagements with the service at groups and events

Fothergill-Misbah et al (2021)

“ I have been part of the group a long time now but never really expressed anything, but tonight I feel so emotionally drained I need to get this out. I know in this group I have a voice. ”

Parent, Rollercoaster quarterly report April 2021

94%

of parents agreed that "if a friend needed similar help, I would recommend that they use Rollercoaster"

Fothergill-Misbah et al (2021)

“ I can remember one night, being outside of a hospital at 3 o'clock in the morning, feeling wretched...and I can remember putting a post on [Facebook closed group], and [name] straightaway in-boxed me, one of the members, and so all of a sudden, I wasn't alone...On those darkest of times, having somebody there, it's magic. ”

Parent interview, Fothergill-Misbah et al (2021)

Parent outcomes

Qualitative interviews undertaken for the evaluation generated a range positive impacts reported by parents:

Parent wellbeing: There was extensive qualitative evidence that taking part in Rollercoaster improved the wellbeing of parents/ carers. Parents reported leaving groups more positive than when they arrived, that their anxiety reduced, and that taking part reduced the feeling of being alone. Many reported the significance of Rollercoaster support for helping them to “keep going”. Parents attributed this largely to the peer support received.

Parent skill development: Parents reported that taking part facilitated sharing of emotions (thus helping self-management) and development of coping strategies to use at home. Parents reported better understanding about how to respond to their young person, such as strategies for managing self-harm or aggressive behaviour. Parents also reported improved understanding of how to make the most of other local services such as CAMHS. Advice from others with lived experience was seen as particularly helpful.

In addition to parent outcomes, stakeholders reported to the evaluation team that Rollercoaster promoted and became a key element of a more robust and inclusive local mental health system, and contributed to improved pathways for children & young people in the local mental health system.

Impact on young people: The evaluation did not directly assess outcomes for young people but feedback suggested that parents felt the skills and advice they received were positive for their families and for helping their young people get the services they needed. Improvements in parent wellbeing and self-esteem are likely to improve family functioning and thus may impact positively on children outcomes.

“ ...the support I have received of Rollercoaster has been my life line. I had so much going on - there was people to listen but with Rollercoaster I feel like they get me and understand without judgement and that is difference between accepting help and not. ”

Parent, Rollercoaster quarterly report
April 2021

“ I went to the one about behavioural issues, about how to handle them and calm people down. Because of the course I went on, I understand where he’s coming from, I understand that I’m not to lose my temper and shout and scream and ball, ‘cos it just makes the situation worse. ”

Parent, Fothergill-Misbah et al (2021)

Challenges and good practice messages

Evidence from evaluation interviews and questionnaires suggested that the key mechanisms responsible for Rollercoaster's success included:

- The leadership and vision provided by the group's founder
- The ethos of "parent-led and professionally supported"; a combination of co-production and professional expertise, with commitment to partnership working in all aspects of service design and delivery.
- The emphasis on empowerment of parents, giving them a platform to help themselves, help shape service provision and used their lived experience to help others.
- The provision of advice, acceptance, understanding and comfort, (as much from peers as from the service itself; this is partly what the service successfully facilitates)
- The extent to which the service is tailored to local need, is part of the wider local offer, and sits within an established and respected governance framework
- The provision of a varied offer, particularly the importance of allowing initial engagement via social media, promoting confidence 'in the background' before joining a live group. Flexibility around the degree of engagement.
- A problem-solving approach, seeking practical and strategic solutions to the issues parents/carers experience, rather than simply rehearsing distress. The regular presence of CAMHS helped with this.

All the evidence around parent engagement, experiences and impact is essentially very positive, particularly in the context of the stress Rollercoaster parents are experiencing and the challenge of getting the right help for their children. More quantitative and longitudinal data are required to confirm exactly how the service delivers impact, but the preliminary, qualitative data presented here is very promising. In terms of improvement, parents suggested more contact with adult mental health services might be useful, both in terms of the transition of their young people to these service from CAMHS, and in terms of parents own mental health needs.

The evaluation and wider discussions with the staff and stakeholders revealed that the challenges to developing the service come not from improving the offer, which is almost universally valued, but from the organisational aspects of managing sustainability and expansion. These include the reliance on the particular skills and leadership of the founding parent, funding challenges in the context of local commissioning, and coping with growth. Because of its success, demand on the service continues to increase and opportunities are arising for input into a national debate about parent support.

Conclusions and next steps

Overall the Northumbria University evaluation tells us that Rollercoaster was a successfully implemented intervention that had matured and grown over the six years, was well received by participants and stakeholders, filled unmet need, and had a positive impact on parents taking part as well as a wider impact on service provision in the local area.

The findings can be seen in the context of the literature on what works in peer support groups and parenting support more generally. Further evaluation could show us exactly how the reported impacts on parents translated into different help seeking and coping behaviours, such as accessing different services for their children, reduction in use of crisis management services, or improved mental health outcomes for young people. However, some of the qualitative data suggested all of these elements occurred.

As the evaluation report notes, *“The unanimous response to where they [parents] might seek help if Rollercoaster did not exist was ‘nowhere’, ‘there is no equivalent’ or they had ‘never seen anything like it’, demonstrating the stark gap in support for parents/carers and the need for a group like Rollercoaster”* (Fothergill-Misbah et al, 2021).

The Rollercoaster team are invested in continuing to expand the service. To do this they are building new, replicable models of parent-peer support, training up parents in a systematic way based on a knowledge and skills framework. There is considerable interest in how to distil the key elements of parent support into shareable principles for good practice that could inform other similar services, and these activities provide the next steps.





More information

This briefing paper was written by Ann Hagell, Association for Young People's Health, drawing on an evaluation undertaken by Northumbria University, and previous AYPH briefings on parent support. For more information about AYPH's work, email info@youngpeopleshealth.org.uk. To read the full evaluation report by Northumbria University, please email Dr Emily Henderson, emily6.henderson@northumbria.ac.uk

We are very grateful to the parents and stakeholders who took part in the project and shared their experiences so generously, the Northumbria University research team for their report, and the [Charlie Waller Trust](#) for funding for the evaluation.

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