

Get Involved

SPECIAL EDITION NEWSLETTER July 2021

Checking in with Ruth at York Parent Carer Forum

By **Ruth Thompson**, Managing Director of
York Inspirational Kids



York Inspirational Kids (YIK) is a support group for families of children and young people who have a disability and/or additional need and live in the York area.

YIK took on the formal role of the Parent Carer Forum in Sept 2021 and has 26 active committee members who attend meetings and contribute towards larger engagement opportunities. Having the formal agreement with both the City of York Council (CYC) and NHS Vale of York Clinical Commissioning Group (CCG) has seen us all work much closer together. We have been able to check regularly with each other before new practices are adopted and invite parent carers to speak up about issues, practices and services that have a direct impact on our children and young people.

We have welcomed the change in approach and have benefited from a greater understanding about the working of services and parameters

that sometimes need to be considered.

How does this feel for parent carers?

I wanted to share the impact this involvement has had on our parent carers. They have commented they now feel more up to date with services and progress being made. They have told us that they are made more aware of 'what is going on' and they have a greater opportunity to share their own thoughts and suggestions.

Parents have said they have felt more listened to, that the barriers are being removed and they are able to put faces to names.

As an organisation we have welcomed these changes and look forward to continuing the working relationship we have developed with both CYC and the CCG.

Welcome to our first newsletter to update you on how we are involving and supporting children and young people with special educational needs and disabilities and their families. Lots has been happening and we are working hard to ensure that you feel involved and informed about our progress.

In this edition:

- Spotlight on SENDIASS
- You said, we are doing – how we are using your feedback to make changes
- How being involved in making decisions is having a positive impact within families
- Working in partnership to help children and young people live their best lives
- ADHD and autism update
- How you can get involved and have your say

Spotlight on... SENDIASS

SENDIASS is specialist advice, guidance and support service, which offers information to all parents of children with SEND. We have a steering group which meets regularly and includes parents, parent forums, the local authority, health and social care. It has been looking at how to make the SENDIASS service sustainable. Working together has secured joint funding from Health and the Local Authority which will maintain the current staffing level until September 2021. For further information about the steering group or if you are interested in becoming a member, please email york.sendiass@york.gov.uk.

You said

We are doing

Your feedback

Families told us that they wanted news ways of knowing what has changed as a result of the pandemic.

Families have been joining us at virtual events with services from both CYC and CCG. These sessions allow families to ask questions, get to know who is behind each service and learn about possible changes that have been made since the start of the pandemic, but mostly, have a chance to stay up to date and communicate directly with those who make decisions about their children.

Families and young people told us that they didn't feel up to date with our improvement journey and wanted to be involved more with what is happening.

We have been working with families and children and young people to refresh our communication strategy and coproduce a new model of joint partnership.

You helped us to come up with the phrase 'Joint Partnership' to describe partnership with parents, carers, children and young people in decision-making. The model, designed by you, has six key principles of what we should do when working with families. This could be helping us to make changes to our services, developing new strategies or models, or on an individual level, when it comes to your child's My Support Plan, Education, Health and Care plan or annual review meetings. Whatever part of the journey you are on, we want you to get involved!

SENDIASS has been very proactive in involving families in joint partnership working, including developing a new leaflet, logo and website. As a result of being involved in this project, one young person who is currently studying media design has been offered work experience at CYC with the web design team after working with them developing the new SENDIASS site.

"The zoom meetings are helpful and great to ask questions and get answers back straight away"

"I think it's great that different key people are now willing to talk to parents. It has always felt like they tried to remain anonymous, so it's been good to meet people. I hope these sessions continue"

"It's impacted me in terms of getting me to where I want to be and it's help give me a voice about matters I'm passionate about and that's important. It's also given me a broader understanding of different types of needs and disabilities"

"I think this project has been really beneficial for me. It has helped me develop my skills a lot communication-wise"

"I was able to mention it in my university personal statement so it has definitely had an impact on my life! The project was perfect for me in terms of my future goals of going to study Graphic Design at university"

"For me it's a massive thing. It feels like someone's actually taking an interest and my advice matters. In the past nothing's really been spoken about and what should be to support those with different access needs. It's helped give me a voice and feeling like I have a purpose"

Families tell us they feel more **involved**

In July 2020, when we asked families what their experience of being involved in joint partnership was like, only **26%** of families said they felt that their involvement was positive and purposeful.

This figure is now at **85%**, meaning that the majority of families in York feel that getting involved in helping us to shape services is a positive and purposeful experience.

Working in partnership to help children and young people live their best lives

In July 2020, through a series of workshops run by the Council for Disabled Children, York developed the SEND outcomes framework. Parents worked alongside services including education, health, social care and SENDIASS to develop a group of statements that would describe key elements of children and young people living a good life:

- I am **healthy**
- I have a **choice** and am **heard**
- I am **safe**
- I **achieve** my **goals**
- I am **included**
- I can **overcome challenges and difficulties on my own** or **with support**
- I am becoming **independent**

This group of statements will help us to shape our services, know how effective our work is and together with families, always know what we need to focus on to ensure children and young people in York are living their best lives.



Autism & ADHD

You said

We are doing

You told us that you wanted us to focus on Autism and ADHD. These services are a priority for the council and local health organisations and we are working closely to ensure that your issues stay at the top of the agenda.

● Your local commissioning organisation (NHS Vale of York CCG) is putting funding into SENDIASS to ensure it continues its great work with families. We are supporting the York Parent Carer Forum (hosted by YIK) as part of its development as a key advisor on SEND, and to help your voices be heard at all levels.

● We have been working hard to respond to your feedback about waiting times for assessment. Although there is still a way to go, the average wait for an assessment at Lime Trees has reduced from 45 to 26 weeks – which is good news!

● We will be starting to review the autism offer, including all levels of support needed, under the direction of the SEND improvement board and with the involvement of the Parent Carer Forum, young people and families.

● From September 2021 keyworkers will be there to support those families where a child or young person with autism or learning disability has the most complex needs and are at risk of being admitted to a mental health unit.

● From the end of 2021, a Mental Health Support Team will start working in York secondary schools to support emotional and mental health: for some pupils with SEN, this can help avoid referrals to Lime Trees CAMHS.



NHS improvements for children and young people with SEND

As the NHS organisation responsible for commissioning health services across York, NHS Vale of York CCG has been working in partnership with City of York Council and the Parent Carer Forum to make improvements for children and young people with special educational needs and disabilities. These include:

- a new Associated Designated Clinical Officer whose sole focus is supporting

SEND at the CCG

- funding for a transition nurse coordinator at York Hospital (starting in autumn 2021)
- developing a health questionnaire which supports the request process for Education, Health & Care Plans
- running an intensive training schedule for health colleagues in therapies, nursing and mental health - most have these have been undertaken with City of York Council colleagues

- working with City of York Council on a number of projects.

Karen McNicholas, NHS Vale of York CCG's Senior Quality Lead Children & Young People, said: "This work is and has been vitally important and has significantly improved the CCG's and our health colleagues' understanding of SEND and we can already see the difference this is making to improve quality and practice."

What's coming up?



Upcoming projects that you can get involved in:

- Preparing for adulthood pathway
- Changes to the Education and Health Care Plan (EHCP)
- Special Educational Needs Strategy
- All Age Autism Strategy

GET INVOLVED

City of York Council and the NHS Vale of York Clinical Commissioning Group are working together to improve services for children and young people with special education needs and disabilities, and their families, in York.

Email jointpartnership@york.gov.uk to get involved

For more information visit www.yor-ok.org.uk/send-updates.htm