

Lucy Ellis, is an Autism Pathway Navigator North Lancashire (LSCft). She started the role in March 2021 and is based in Lancaster. Lucy supports a team of learning disability nurses, speech and language therapists and psychologists who conduct school-age autism assessments. Due to COVID restrictions, she is currently working from home but can go to our office if she needs to. This works well due to her caring role.



How did you become an Autism Pathway Navigator?

I am parent carer of autistic children and have been running peer support groups and representing parent carers in local and county-wide services for 13 years. I was part of the group that formulated the current Autistic Spectrum Disorder (ASD) assessment pathway and have always championed the need for parent peer supporters in these services as a way to support families at times of need. I helped put together what service could help parent carers then applied for the role when it was advertised. Following interview, I was appointed and started in March 2021 on a fixed-term contract for 12 months. I created a Facebook group and website a few years ago which acts as a mini local offer for North Lancashire. I continue to maintain this and use it for signposting people to relevant information. You can access the website at the following link www.northlancsdirectionsgroup.com

What does your role involve?

I support families and referrers at various points including: prereferral to ensure the team receive good quality information and also ensure the referral is appropriate; post referral during their wait for assessments until the point of discharge and post diagnosis with signposting and advice.

I support the running and coordination of workshops currently delivered online for families on Behaviour, Sleep and Sensory issues. I also co-deliver a post-diagnosis workshop for families to ensure they have the right information following diagnosis. I put together e-newsletters once a month and send these to families and referrers with signposting and advice to local support and themed resources. My main role is to talk to families offering progress updates, support completing paperwork and offering advice. Some days I can speak to five to ten families but the most has been 17 in a day. I speak to a lot of referrers also asking for pathway progress.

What have been the best bits and challenges of your role?

The variety of the role. I love making a difference to families whether that is giving them advice / signposting or just being able to listen to them when they feel they have nowhere to turn. The impact I have made on families outcomes has been well received by my team and service leads. Families always appreciate speaking to someone who has been there. As soon as I mention that, they feel they can share and offload without judgment. You can often hear the change in their voice.

The length of our pathway due to COVID, staffing and time constraints means most families have a considerable amount of time to wait for a conclusion. I speak to families everyday who need support and sometimes those families go into crisis. It's extremely hard to listen to and you never know what the family needs when you answer the phone, but I have a great team who support me. I have made contact with over 250 families since I started my role which has been incredible but challenging at the same time.