

## Case study: Using HealthGuidance to support children newly diagnosed with autism

**Organisation:** Leicestershire Partnership NHS Trust

**Service:** Community Paediatrics - Neurodevelopmental specialist nursing team

At the height of the pandemic, the neuro-developmental specialist nursing team at Leicestershire Partnership NHS Trust were one of the first services to use HealthGuidance to move away from in-person workshops to a digital solution to engage with families of children with specialist health needs.

### The situation

Regular in-person workshops were held by the Community Paediatrics Service at Leicestershire Partnership NHS Trust for the parents and carers of children and young people newly diagnosed with neurodevelopmental disorders, such as autism spectrum disorder (ASD) and attention deficient hyperactivity disorder (ADHD).

The three-hour workshops, led by the neuro-developmental specialist nursing team, were held twice a month in a central location with up to 40 parents in attendance. The workshops offered parents an opportunity to learn more about the condition, management strategies and useful resources for further support and services available. Parents and carers that attended could ask questions to address any concerns they had, and gave feedback that this was the most valuable aspect of the workshops.

However, when their child was referred to the service, parents and carers had to wait up to 10 months for a place on the workshop. Sarah Baines, Neuro-developmental lead nurse specialist explained the challenges faced in running in-person workshops to deliver information to families:

*“There was a shortage of suitable venues, so we tended to use the same place for in-person workshops. But this made it difficult for people living further away to reach. Others could not attend due to commitments such as work or childcare. As a service, we started to think more creatively about how we could better meet people’s needs.”*

In addition to the sporadic attendance rates, there were also significant costs in hiring a venue, staff costs, admin time and transport for each in-person workshop session that took place. The team had considered using a bigger venue and holding more frequent sessions, but this put greater demands on staff, added to costs and did not do enough to reduce the increasing waiting times.

The neurodevelopmental nursing team had started to think about how the workshops could be offered digitally to share important information that parents and carers needed to support their children with specialist needs. Then in March 2020, the in-person workshops had to be immediately suspended due to the outbreak of the COVID-19 pandemic. Sarah explained the urgent need to find a solution despite the ongoing pandemic.

*“We were running in-person workshops until the COVID-19 pandemic hit, but immediately had to suspend these. As patients continued to be referred to our services our waiting lists became huge. Our plans for a digital workshop were already in the infancy stage but the pandemic meant it needed to happen sooner.”*

## The solution

Sarah and her team approached the Digital Health Transformation Service (DHTS), also based at Leicestershire Partnership NHS Trust, to discuss the potential options for producing a digital workshop for the families of children newly diagnosed with ASD. The first online content library had recently been successfully produced and piloted on HealthGuidance by the Children's Occupational Therapy Service at LPT. This team had run similar workshops and the neurodevelopmental nurses were interested in exploring how HealthGuidance could likewise meet their service needs.

Sarah explained why HealthGuidance was chosen as a solution to help them support the families they worked with:

*“The HealthGuidance support team were incredibly helpful. We knew we needed to deliver our workshops differently, but the realities of that were not clear to us at that point. One service had recently launched their content on HealthGuidance. We were able to take a look to see how it worked and how it was put together. This gave us better clarity of what we could offer on the platform.”*

HealthGuidance provided the neurodevelopmental nursing team with a secure, interactive platform to offer an online library of workshop videos and useful resources. This enabled them to produce a digital workshop for the families of children with newly diagnosed ASD and continue sharing important information, which had been halted by the COVID-19 pandemic. The ability to make the digital workshop content available to families by invitation-only would also bring a greater level of security and professionalism to the offer.

Working alongside the DHTS project management team and professional video producers, the neurodevelopmental nursing team were supported to plan and film the ASD workshop content during the summer of 2020, with COVID-safe restrictions in place. A total of 10 different videos were produced, based on the ASD presentation content delivered in the in-person workshop formats. The professionally produced videos were uploaded to the HealthGuidance platform, where they could be securely accessed and watched by parents and carers at a suitable time and pace.

Since November 2020, invitations have been sent via email to the parents and carers of children newly diagnosed with ASD, living within Leicester, Leicestershire and Rutland, as soon as they are referred into the service. This enables them to start accessing the ASD content library on HealthGuidance immediately after diagnosis. Parents and carers are given the opportunity of a one-to-one telephone contact with a neurodevelopmental specialist nurse within 6 weeks of gaining access to the digital workshops. This direct contact between families and the specialist nursing team replaces the interactive element of the in-person workshops which parents had valued, providing equitable access for further support if needed.

## The results

LPT's neurodevelopmental nursing team have seen a number of positive outcomes since introducing their digital workshops for the families of children newly diagnosed with ASD via HealthGuidance.

- Significantly improved accessibility to expert advice and information from nurses specialising in ASD.
- Empowered families to learn about ASD and management strategies at their own time and pace, and re-watch and share with others involved in their child's care, such as grandparents and teachers.



- Eliminated waiting time by providing immediate access to information, previously there was a 10-month waiting list.
- Increased staff capacity by freeing up time to spend where it's most needed.
- Over 1,000 video views across the ASD digital content library since launched.
- Saved £13,000 per annum by moving on from delivering in-person workshops, enabling funds to be redistributed.

Overall, Sarah is delighted with the positive impacts of switching from in-person workshops to a digital delivery via HealthGuidance:

*“HealthGuidance has done wonders for our service! It has given us extra staff capacity, deliver targeted interventions, reduced waiting times and families are now receiving information faster for their children diagnosed with ASD.”*

## Key learnings

The neurodevelopmental nursing team had a sharp learning curve in implementing a digital solution into their service, as it was a new experience for all those involved. There were lessons learnt about not spending too much time on the planning process and how their confidence would improve as they became more experienced in speaking on camera. The professional film crew helped the team to feel more at ease and impart their expert knowledge in a natural, rather than scripted manner. Sarah explains how she engaged the team to get involved in the filming process:

*“We encouraged colleagues to come on board by helping them to understand that the knowledge imparted is not changed by a different delivery method but is, in fact, more efficient. Instead of presenting to a room of people at a time, they are sharing information with hundreds of people.”*

Sarah is also clear that the digital delivery of their workshops is not a replacement for face-to-face treatment and care, but is intended to enhance the resources and support available to the families they are caring for:

*“Ultimately, we have a team of great nurses that want to help. We wanted this to come across in the videos by saying to families, “we are here to help and to care and this is the information we need you to know”.”*

The success of the ASD content library on HealthGuidance has led to the opportunity for the neurodevelopmental nursing team to jointly work with colleagues in children's and young people's mental health services (CAMHS) to produce a series of video content on Sleep and Anxiety for the parents and carers of children experiencing troublesome anxiety or sleep disturbances. The service is also extending their digital library by producing digital content for the families of children with newly diagnosed ADHD.

Services are benefiting from continued development of HealthGuidance. The latest new features include a feedback feature to ask users if they found the page useful, with links to an online survey for more specific feedback from service users. Subtitles and video transcripts are being applied to all videos, which will further improve accessibility.



## Recommendation

*“Our team are very proud to be part of HealthGuidance and it’s been well embraced by our service and the families we work with. The team behind HealthGuidance have been so supportive and very mindful that we’re clinicians first and faces on camera second. We really couldn’t have done it without their technical expertise. It’s been a great opportunity.”*

**Sarah Baines, Neuro-developmental lead nurse specialist**