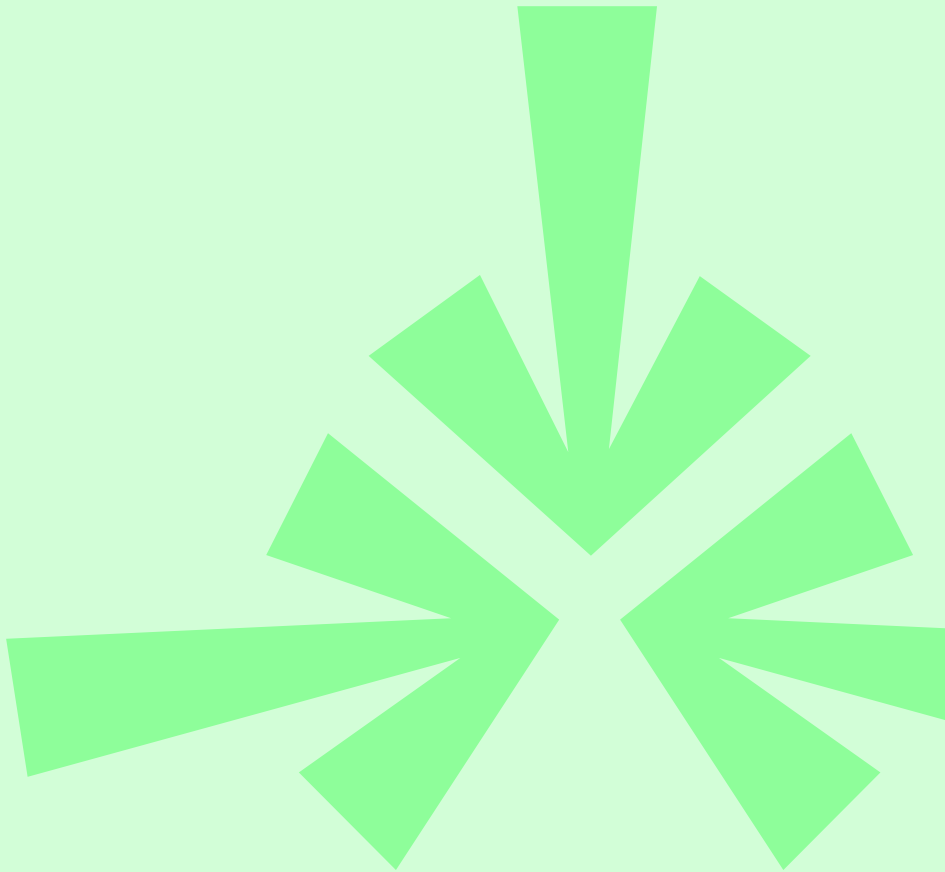




# Keyworker Schemes for children and young people with autism or a learning disability



# Introduction to Barnardo's

Leading children's charity Barnardo's is one of the most comprehensive providers of integrated health and social care services for children and young people, with more than 150 years' experience of supporting them through a variety of challenging circumstances.



We work with a range of commissioners and partners including NHS England (NHSE), Integrated Care Systems (ICSs), Department of Health and Social Care (DHSC), Department for Education (DfE) and local authorities (LAs) to deliver cost-effective and innovative integrated health and wellbeing services across prevention, early intervention, targeted and specialist support in a variety of place-based settings throughout the UK.

Our services take a trauma-informed and inclusive approach based on the principles of personalised care and shared decision making. We put the voices of children, young people and families at the heart of what we do to ensure all our services are accessible and appropriate.

## Our offer

Since the first Keyworker pilot sites were announced in 2020, Barnardo's has played a key role in their successful roll-out to support children and young people with a learning disability, autism or both. We currently deliver seven Keyworker Schemes across England with some being delivered at scale across multiple local authority (LA) boundaries within an Integrated Care System (ICS).

Keyworker Schemes focus on transformational change. They not only support the young person and their family or carer network but they also bring together partners from across the system to drive significant change in the way we work together. Co-production is at the heart of all our models, and we work with both parent-carer forums and young people from day one to ensure their views are heard and acted upon.

Barnardo's can support ICSs to develop and host Keyworker Schemes as well as other models of support for children and young people with Special Educational Needs (SEND). As a voluntary sector partner, we can reach communities, co-produce with families and young people, lead successful recruitment campaigns and provide expertise on child-centred models. In all of our models, we sit as part of NHS and LA governance structures and, as an independent voice, we can provide supportive and constructive challenge to the existing system.



The NHS Long Term Plan has made a very specific commitment to providing keyworker support for **children and young people with a learning disability, autism or both:**

“By 2023/24 children and young people with a learning disability, autism or both with the most complex needs will have a designated keyworker, implementing the recommendation made by Dame Christine Lenehan. **Initially, keyworker support will be provided to children and young people who are inpatients or at risk of being admitted to hospital.** Keyworker support will also be extended to the most vulnerable children with a learning disability and/or autism, including those who face multiple vulnerabilities such as looked after and adopted children, and children and young people in transition between services.”

## Parent Carer Forum

In Leicester, Leicestershire & Rutland (LLR), our Keyworker service works with three family carer forums across the LA. We have five parents and carers regularly represented on the Keyworker Steering Group who also participate in various meetings with commissioners. The Barnardo's team has focused on building trust and creating safe spaces for parents and carers. Recently, the forums wanted to raise an issue about the referral process in the Dynamic Support Register (DSR) and advocate for the new self-referral process, having previously felt like they hadn't been listened to. Barnardo's staff supported them to have their voice heard and to positively challenge the Integrated Care Board.



## Parent Carer Forum Feedback

“A manager and I attended the Leicestershire SEND Ofsted CQC reinspection to provide feedback around the Keyworker Project. Manager presented an overview of the Keyworker Project statistics and a graph to report on outcomes to date.”



“I was able to speak around the co-production with health and the LA and parent / carers of the project from the beginning, from the bid through to the co-design of the project, recruitment and training of the Keyworkers, publicity and evaluation.”



“Although the outcome of the inspection has not yet been published, Leicestershire Head of SEND, has reported that the Ofsted CQC Inspectors mentioned the Keyworker Project as a successful example of joint commissioning.”



## Service feedback

“ Just wanted to say a huge thank you from us all for everything you have done over the last few months. I think as parents we had been going through so much when we met you. Desperately trying to get support for YP but just being lost in the system. Your involvement kickstarted everyone into action, and I genuinely don't think that would have happened without the DSP. Living each day is often a battle and sometimes you don't have the energy to keep fighting the system. But having you on our side to fight the fight with us has massively eased the pressure. The battle will still continue with some professionals, but YP is at least now getting the support that they need, and I always said right from the start that YP WILL be ok when they have the right support around them.

I'm sure our paths may cross again in the future as we both know that life may sometimes become a challenge for YP but until then I will always think of you when I tuck YP into bed at night under their weighted blanket. Thank you. x ”

**Parent / carer feedback to LLR Keyworker Service**

“ This doesn't feel like a tick box exercise anymore. You are really listening to what we are saying. This is really encouraging and exciting.

**Carer receiving support** ”

# Spotlight on the Leicester, Leicestershire & Rutland (LLR) Keyworker Service

## Case Study 1

YP was referred via an online referral to the LLR Keyworker DSR by the school SENDCO over an escalation in behaviours at school. YP has a diagnosis of ASD and ADHD. YP started talking about voices in their head making them do hurtful things and that they were having less control over these, school felt there was an urgent need for more input and support and decided a DSR referral could support this.

The Keyworker built a relationship with the mother which allowed them to gain more information and perspective of the home situation and needs. From this, the Keyworker submitted, with parents' consent, another Multi-Agency Referral Form (MARF) to Social Care to access Short Breaks to support YP through the summer holiday as parents had identified this as being a cause of anxiety for them.

The Keyworker made direct contact with the family on average twice per week through phone calls, texts and emails. A home visit was offered to the family, but they declined this due to other family members being in the home.

A Multi-Agency Meeting (MAM) was set up a couple of weeks after starting the case to get everyone's perspective on needs and to create actions for a route forward. In total 4 MAMs were held in the 18 weeks the case was open which allowed for proactive action setting and reflection on next steps.

The process of having other professionals involved and the regular MAMs helped school and family feel supported and gave them ideas and strategies to see through the last 12 weeks of term before YP moved to secondary school.

On closure, mum felt more supported, felt their needs had been listened to and was hopeful for the new start in a new school but was made aware of the route back into the service if this was needed.

**4 MAMs**

were held in the 18 weeks the case was open.



## Case Study 2

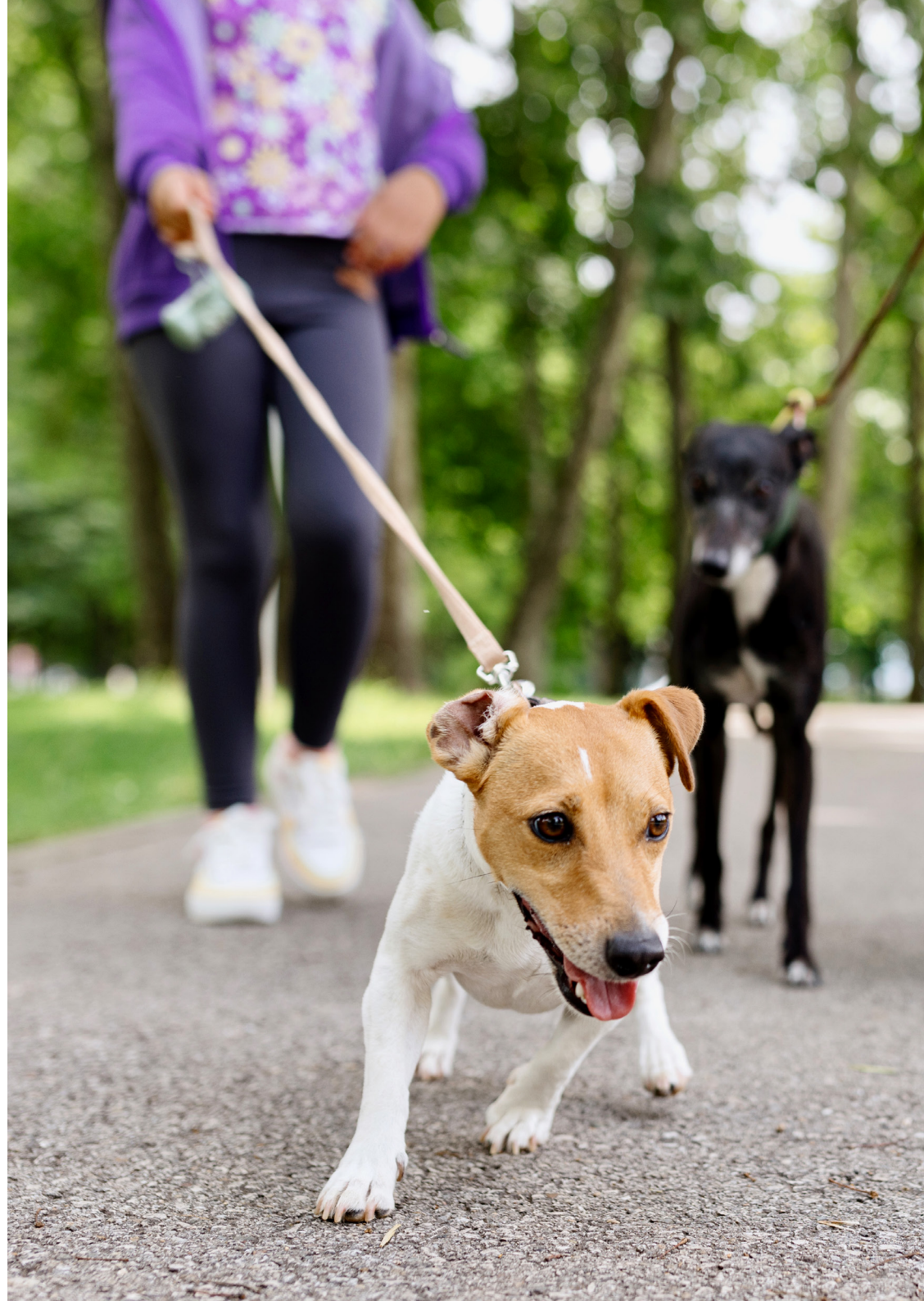
PC was referred to the service following discussion at Transforming Care and Gateway meeting. PC has been diagnosed with ASD and ADHD and is struggling with accessing school, causing extreme anxiety. Whilst PC presents as coping within school, her behaviour at home can be extreme on occasions – violent towards family and destroying property. PC also struggles with sleep and has night terrors.

The Keyworker Service completed a referral for PC to The Sleep Charity, contacted Positive Behaviour Support Service (PBSS) – offering training to mum, and organised monthly wellbeing multidisciplinary team meetings with education and other professionals involved with PC and the family. The SENDCO at school has said that these regular meetings have been “invaluable in involving other professionals and co-ordinating those involved”.

The Keyworker Service accessed Barnardo's Cost of Living Fund to the value of £480 which will be used towards a short break. PC has asked if it could be spent on Hotdog Holidays as these breaks are extremely dog-friendly and means she can access lots of things without leaving her dogs at home as this causes heightened

anxiety. This is somewhere PC has stayed previously and the family describe how lovely it was seeing PC so happy and relaxed there, more than anywhere she has been before.

The family really appreciate being able to access this funding (“we are so grateful for the grant”) and are looking forward to their holiday, which is booked for Halloween in 2024.



## To find out more

We'd love to hear from you.  
Please get in touch via  
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if you would like more information.



[barnardos.org.uk](https://www.barnardos.org.uk)



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