

LEARNING REPORT – SUMMARY

SURREY DOWNS COMMUNITY OF PRACTICE CHILDREN'S NEURODIVERSITY

Theory of change



Therfield School

SURREYDOWNS
Health & Care Partnership



healthwatch
Surrey



AND TO ALL OF YOU FOR
JOINING THIS
COMMUNITY OF
PRACTICE

Mental Health Investment Fund



SETTING THE SCENE



... striving to improve the lives of children and families through working collaboratively with partners



The challenge...

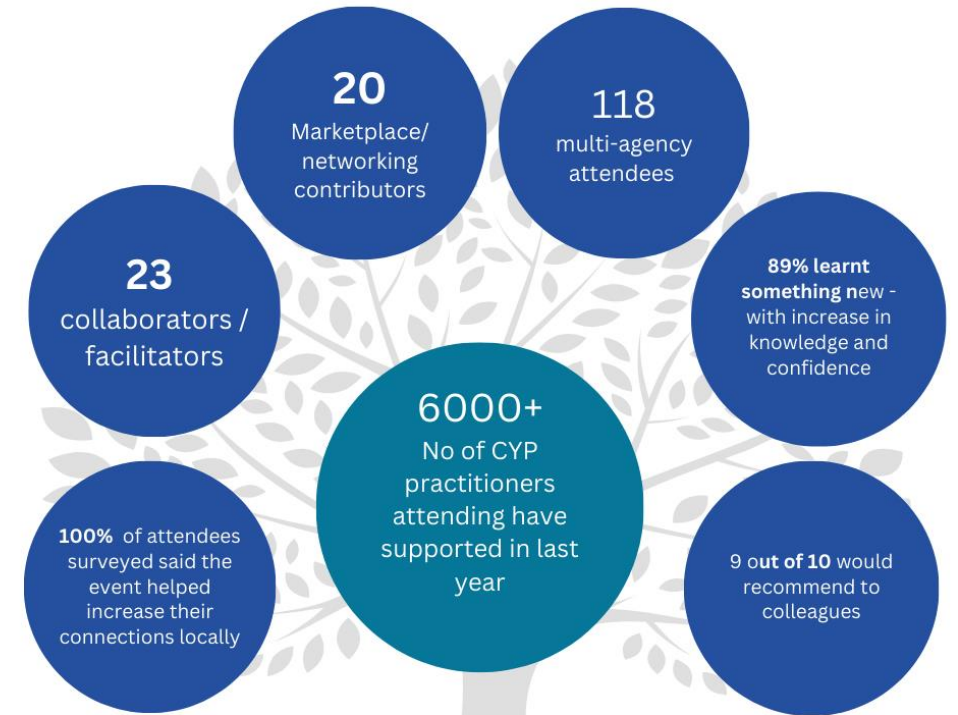
Services around ND are complex and, at times, difficult to navigate for children and young people, their families and practitioners

The opportunity...

Develop a co-created system-wide ND Community of Practice at Place with a focus on strengthening relationships, learning and new ways of working between practitioners and sectors

Building the community...

Community of Practice (Surrey Downs) - Children's Neurodiversity event held on 6th December 2024



What were the Aims for THIS Community of Practice?

Relationships & Connections

Nurture relationships and a shared purpose across teams and organisations in Surrey Downs to **join the dots, reduce duplication and improve effectiveness.**

Collaborative Learning

Participate in needs led **learning and networking opportunities.** **Share knowledge and skill** across teams and organisations in Surrey Downs.

Innovation & Transformation

We will embrace and evolve **new ways of working** by learning through others and sharing **emergent thinking to continually innovate and transform opportunities in support of Neurodivergent CYPF** in Surrey Downs.

Were the aims achieved?

Relationships & Connections

Nurture relationships and a shared purpose across teams and organisations in Surrey Downs to **join the dots, reduce duplication and improve effectiveness.**

100% of attendee reporting their number of connections had increased

Collaborative Learning

Participate in needs led **learning and networking opportunities. Share knowledge and skill** across teams and organisations in Surrey Downs.

89% of attendee reported they learnt something new

Innovation & Transformation

We will embrace and evolve **new ways of working** by learning through others and sharing **emergent thinking to continually innovate and transform opportunities in support of Neurodivergent CYPF** in Surrey Downs.

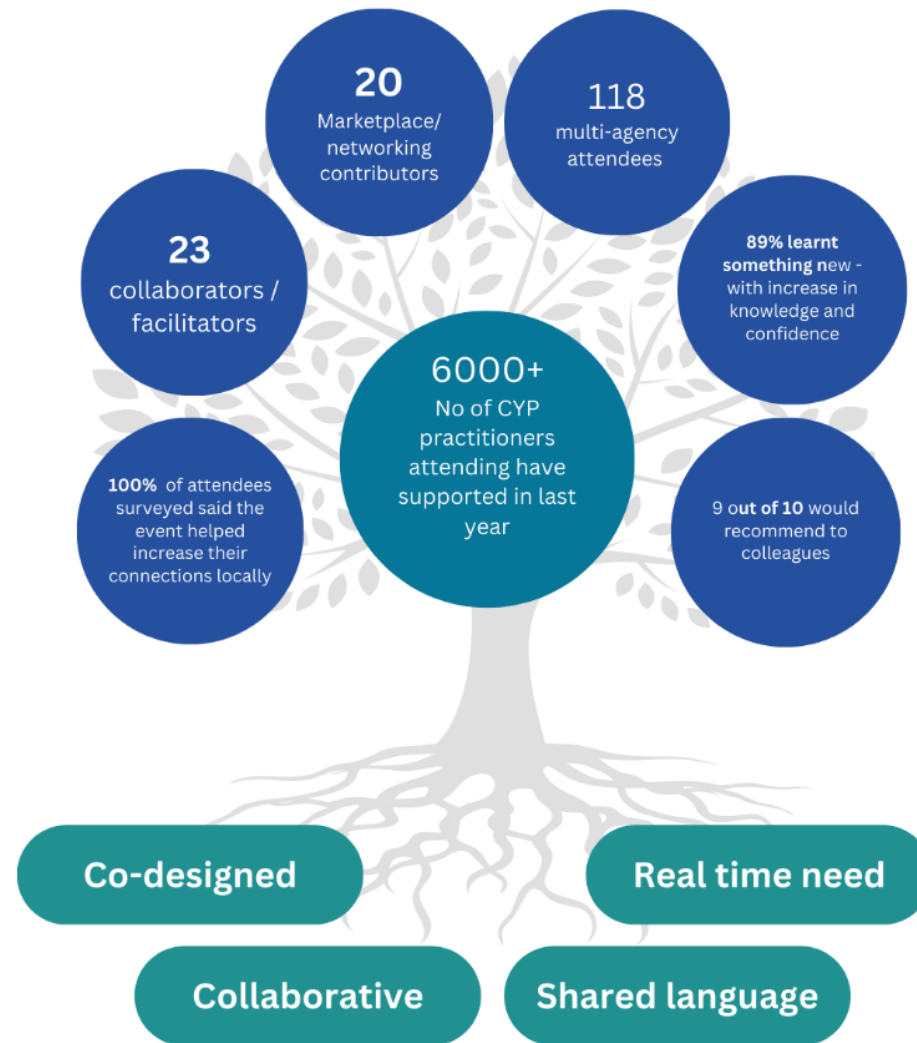
Participant and Collaborator feedback

Were the aims achieved continued ..

Relationships & Connections

Collaborative Learning

Innovation & Transformation



A further 590 colleagues have the potential to be reached as direct team colleagues of participants who attended

100% those attended received a "little black book" of colleagues to aide onward connection

What DIFFERENCE did the programme have on Relationships and Connection?

Some of the direct feedback:

- I was able to identify so many more services within Surrey
- Lots of new learning of services, charities who I could go to when supporting families
- New services I wasn't aware of
- Community connectors were very helpful
- Networking and knowing the right people and services
- Meeting directly the different services
- I have met new connections that are going to support my families in future practice
- Meeting new people and connections to be able to support families
- It has been very helpful to network with other professionals and their services
- General collaboration was so helpful.
- Meeting new teams and services - faces to names!

100% said event helped increase connections

After the event 81% of attendees had 6+ connections
(prior to event 68% attendees had <6 connections)



What DIFFERENCE did the programme have on collaborative learning?

This programme helps us have a shared “systemwide” understanding of both the challenges and opportunities in supporting neurodivergent children and young people to “thrive”.

This Community of Practice is key system change programme and part of a wider drive towards a new vision focussing on need. For some this may involve a diagnosis, but for others it may be around understanding, adaptations, strategies and control, accessing additional support.

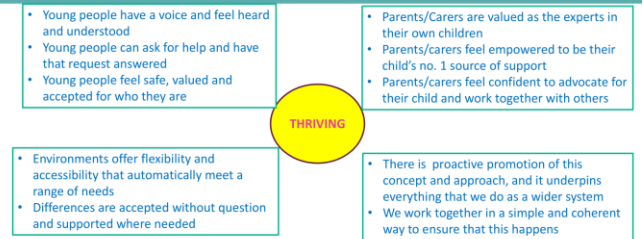
- “Although we’re time restricted **we can still make a difference**”
- “Importance of **working collaboratively**”
- “**We must share this with other agencies / charities**”

The Role of the Practitioner

Aims of the Session

- To explore what we can do individually and collectively to enable children and young people who are Neurodivergent to thrive and feel a sense of belonging
- To explore a shared understanding of the Thrive Approach
- To explore a shared understanding of the roles of practitioners

What does Thriving look like ...



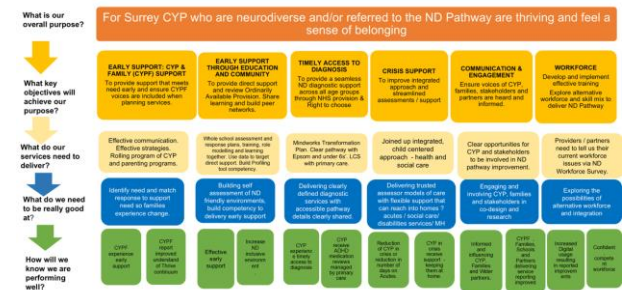
Implementing a strengths and needs based approach to keep CYP Thriving

Diagnosis – 4 benefit areas



Themes are qualitative, and the benefits are often emotional and intangible; there is considerable blurring and overlap and a complex web of connections between them.

ND System Wide Transformation Map



What DIFFERENCE did the programme have on collaborative learning?

Summary of feedback following the morning session: The difference made includes:

Shifting perspectives: Gained insights on shifting from a focus on diagnosis to understanding needs, along with learning about specialised teams like the Specialist Teaching Team and Team around the School.

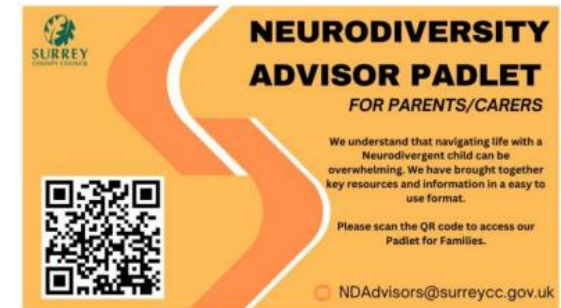
New services discovered and awareness of available services: Many professionals and parents learned about the variety of services available in Surrey Downs for children with neurodiverse (ND) needs, including community connectors, Braain, the Edge of Care service, Barnardo's, and the Family Information Service (FIS).

Networking and collaboration: Networking with different service teams and professionals helped build new connections to better support families and children in the future . Increased understanding of the support networks available, including local community services and charities, as well as specialised helplines for parents.

Addressing isolation and misinformation: Recognising that many staff members feel isolated and lack information or mis-information about available support, shows the need for better connection and collaboration within local networks.

Summary of FLIPCHART learnings later in this report!

"I've learned lots about NAS and Mindworks, ND helplines, and support available to parents"



What DIFFERENCE did the programme have on Transformation and Innovation?

Quotes:

"I felt that everyone I interacted with was really excited about meeting other people and learning about other services." "I felt there was a real buzz and excitement of people just feeling like there are people out there and different things we could try." Collaborator

"there was a really great energy about the day and certainly everyone I spoke to really felt the value in having that networking opportunity" "opportunities to connect with people that they may not necessarily have come across." Collaborator

"events like this are crucial to share knowledge and begin to solve problems" Attendee





System Learning and Key Reflections for ND next steps

WHAT DID WE FIND OUT IN THE DISCOVERY PHASE?

We asked participants of this community of practice to share what they see as currently working well, the gaps. We also asked about the key issues which included:

- Diagnosis Delays and Access to Services
- Challenges in School Inclusion and Support
- Support for Parents and Families
- Shortage of Specialist Support and Resources
- Barriers in Accessing Mental Health and Educational Support
- Barriers to Post-18 Support and Transition to Adulthood
- Improving Coordination and Access to Information
- Understanding Neurodivergence in Schools and the Community
- Resource Gaps and Equity
- Barriers to Community and External Support

Click [HERE](#) for the **FULL DISCOVERY REPORT**

While there is growing awareness and a variety of supportive initiatives, challenges remain in ensuring equitable access to services and translating awareness into concrete, consistent action for ND children and families

The key challenges include limited access to timely support, lack of resources and knowledge for families and professionals, and systemic barriers that make it difficult for ND children to access appropriate education and services. Improving awareness, support networks, and parental advocacy are central to addressing these issues and creating a more inclusive environment for ND children and families.

The key challenges highlighted include long waiting times for diagnosis and support, insufficient school provisions, a lack of specialist services, and gaps in parental support. There's also an urgent need for better understanding of neurodivergence within schools, health services, and social work, alongside improved financial support and clarity about available resources. The system remains difficult to navigate, and neurodivergent children and families often face delays and barriers to getting the support they need

WHAT DID WE FIND OUT IN THE DISCOVERY PHASE?

Potential reach of the programme:

How many children and young people do you support in your role?

6000+ Children and Young People

Within your immediate team, how many people do you work/volunteer with?

590 colleagues (118 directly)

What area/s of **Surrey Downs** are you most connected with?

Dorking, Leatherhead, Epsom, Ewell, Esher, Banstead and across Surrey

System Learning POST EVENT

Each Community of Practice is a fantastic blend of multi-agency partners, each asked to share the learning and narratives with 5 colleagues. So, for this event of 118 participants an **extended reach** of 590 further colleagues could realistically be engaged to share the change journey.

In addition, one COP participant suggested *“I think this would be really valuable training for all professionals who join organisations when they start”* This could be currently made possible via the cross system onboarding held by SYF.

Another consideration is how each of the COP participants has the potential to be seen as **“system navigators” with an increase in connections and knowledge of support locally**. By investing further in these colleagues in their role as system navigators there is potential for many more families to be effectively guiding them through their journey, answer questions, and advocate for their needs without need for new teams/services: supporting the view that “every interaction is an intervention” – this outreach support would help build resilience and confidence within families to utilise that support and feel empowered to be the number one support for their CYP - not look inward to services for a fix

Finally, one for us all to consider when planning events *“If this had been an event for ND CYP or adults how would we have done it differently? E.g. Quiet rooms/space, fidget toys on the table, take what you need approach. In order to normalise and celebrate differences we should practice that in all scenarios. The welcome pack in advance [subtitled slides, wellness room] is helping with this and was very good! Lets keep this up and make a conscious effort to create ND friendly spaces - practice what we preach”* and share what we are learning

Key reflections and next steps

<p>Framing of ND conversation and the change that is needed</p>	<ul style="list-style-type: none">• Framing of ND - including sharing the wider picture / trend of need (Healthwatch report small snapshot, what else do we know) some people like words, others prefer data (E.g. scale of the “problem”)• Develop the narrative to explain the culture change needed better – include a script for others to spread widely• What we are learning elsewhere (people working within Mindworks transformation team who have liaised with Portsmouth, Cornwall, Kent and possibly others to share learning with wider system)	<p>Consider within ND Transformation / All Age Autism</p>
<p>Maximising Resources</p>	<ul style="list-style-type: none">• There are risks for duplication/ not maximising resources where we don't have clear visibility of what other organisations are offering. Lots of similar named offers. Services offering very similar services, not working in CYPF best interest. Aim to reduce "bouncing" families between services due to lack of understanding. Consider how to give staff freedom to be flexible and creative not just confined to their roles but to help meet need.• Support available to increase mainstream inclusion in the community e.g. swimming. A lot of focus on schools but need to extend into the community	<p>Consider within ND Transformation/ All Age Autism</p>
<p>Support for Parents</p>	<ul style="list-style-type: none">• Understand the impact of poverty e.g. parents with AND themselves• A focus is needed on grief and acceptance and the family journey and needs based approach - to work towards keeping CYP thriving• Support families navigating their concerns, ensuring they feel heard and validated	<p>Consider within ND Transformation/ All Age Autism</p>

Key reflections and next steps

Involvement of Children and Young People decision-making: Increase the involvement of young people in decisions that affect their lives to help them feel more in control.

- Explaining diagnoses: There is a need for clear explanations of what a diagnosis means for Babies, Children and Young People (BCYP), tailored to their level of understanding.
- Support for low self-esteem: Create spaces similar to Leatherhead Youth Project for young people to engage, express their voice, and feel empowered, especially for those with challenges in focusing and processing information.
- Finding community: BCYP need support in finding their “tribe,” accessing mainstream activities, and overcoming barriers like transport and communication.
- Safe spaces and transport: Provide more safe spaces for young people, accessible playgroups, and transport solutions for accessing services like youth clubs.
- Feeling Heard: Ensure every child and parent feels heard, accepted, and loved by providing opportunities to connect with their community.

Consider within ND Transformation/ All Age Autism

Involvement of Education Settings in decision-making

- Myth busting/reducing blame – SEND IS part of initial teacher training and each school improvement plan. There is Named lead both in staff and on governing body.
- Encourage schools to communicate with external services they are working with to improve coordination and support (Schools to create a directory of practitioners who are working with the school/community e.g. create a template for schools to use – name the support e.g, school nurse, Stip etc)
- Consistency in schools – one point of contact for families (SENCo) frontline, senior leader buy in. Schools are not a homogenous group, lots of great practice, need to identify individual staff who need more support?
- Good quality training on neurodiversity in mainstream for neurotypical children and their parents

Consider within ND Transformation/ All Age Autism

Key reflections and next steps

<p>Surrey Downs Place</p>	<ul style="list-style-type: none"> • Consider how we share information about event to primary care to make relevant to them e.g. what they would get out of a COP • Feature event and learning in SD newsletter and potential presentation. • Discuss with primary care the Challenges with timings and support, knock on effect, quicker responses from GP and Schools for agency checks (GPs, Schools inputting information) difficult to maintain timeframes without this • Explore Parent-focused support: Develop borough-based parent directories that highlight specific resources, such as behaviour support for families dealing with high-risk situations. Networks for peer support for parent carers • Address long waiting times for respite care, such as the 5-year wait at White Lodge, and secure funding for essential services like Homestart, which has recently faced cuts. • Upscale funding for more therapies that are taking referrals 	<p>Emma Cox to take lead</p>
<p>Primary Care Engagement: improve communication and support for families without a diagnosis through Primary Care network</p>	<ul style="list-style-type: none"> • Input to primary care Practice Learning sets/networks and leaders networks, primary care around communication what is available based on needs (not diagnosis). • Consider how to use protected learning time in surgeries to share information and communication as often looking for topics • Increase understanding of reasons for referrals/diagnosis and needs based approach for community teams (social prescribers) • Language of waiting well (still suggest waiting rather than receiving support) • Consistency in services – Epsom and Ewell work flagged that CYP want to see the same person in GP/Surgery • Help parents navigate the next steps after diagnosis, including understanding school support, managing concerns, and addressing delays in services). • More signposting support in GPs (beyond social prescribers). • GP to understand autistic burn out 	<p>Kerry Clarke and Emma Cox</p>

Key reflections and next steps

<p>Shared Language: Develop a shared language to help professionals articulate the needs of families and children without relying solely on diagnoses</p>	<ul style="list-style-type: none">• Establish a shared understanding of "needs-led approach" to ensure families can better identify and articulate their needs. (What do we actually mean by needs led approach? Jargon that we don't have a shared understanding for. Families might be able to identify their own needs if we were clearer in what we mean.) Consider creation of guide to help practitioners working with families to identify and work with needs• Reduce unhelpful language "fussy eaters" by increasing share language developed with CYPF• Avoid stereotyping parents and use inclusive, supportive language in all interactions, ensuring each interaction is positive and empathetic.	<p>Consider within ND Transformation/ All Age Autism</p>
<p>Navigating the system: many participants still unaware of local offer, padlet, community connector service etc for growing understanding of what is available in their community (services / offers changing) – live chat?</p>	<ul style="list-style-type: none">• Access inequality: Those who can navigate services easily have access to everything, while others struggle to access support, creating an unfair system. Lots of local resources and networks, what would make it easier for people to access?• Investigate Interactive tools: decision trees, FAQs, chatbots, or live chat features to help families and professionals quickly find the support they need.• Provide video on HOW to use/navigate Family Information Service• Flowcharts and visual aids: Provide clear, visual flowcharts or maps that show the support pathway, including post-diagnosis options and referral processes. <p>NOTE: some feedback about the padlet being overwhelming, need to upskill professionals to help navigate with families</p> <ul style="list-style-type: none">• Streamlined communication: Improve communication systems and eliminate the complexity of traditional "signposting" by linking various services and creating a more connected support network in person, relationally rather than online	<p>Laura Palmer, Micheal Pipe</p>

Key reflections and next steps

Training opportunities	<ul style="list-style-type: none">• Makaton training for all• Improving understanding: Offer courses for professionals and neurotypical families to build awareness of neurodiversity, not just relying on online resources) normalising differences• Sessions for Parent who are ND themselves• More training and support for mainstream organisation such as charities• Better education for practitioners on what involved in diagnosis and support pre and post• Develop a suite of resources from different viewpoints e.g. A CYP, a parent, a GP, a SENCO, a youth worker modelling discovery conversations. Empowering across the workforce to have 'curious' conversations• Emotional Support for Staff – taking on bucket full, secondary trauma	Consider within ND Transformation/ All Age Autism
Focused networking: enable more face-to-face networking events to grow and strengthen connections around key themes @ place	<ul style="list-style-type: none">• Huge demand for more face to face networks.• Showcase work of wide range of partners - Raise awareness of available organisations, key contacts, and their roles within the support system to improve overall knowledge of services.• Increase awareness of roles within organisations and their contributions in guiding families. Use library more as safe spaces.• Provide clear information and criteria for referrals to streamline access to each others services• SENCO networking meetings – more services to come and promote service there or other places where school are already, or an online session• A lot of children with ND needs might be EBSNA cases and might be out of school so families miss even more information about what's available	Surrey Youth Focus (link to MHIF skill sharing) Local Offer Showcase events Local networks (KT22 etc)

Thank you

Thank you to all the participants and marketplace contributors and Therfield School

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Any questions please contact: Cate Newnes-Smith, Chelcie Wreford, Su Freeman, Sally Stubbings (Surrey Youth Focus)

Mental Health Investment Fund

