



***Children, Young People and  
Families (CYPF) Wellbeing  
Collaboration Programme -  
“Discovery” Report Autumn  
2024***

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Surrey Downs Health and Care

# High Level Outcomes



## Health and Wellbeing Strategy Priority 2 (P2) outcomes that the project is aligned to:

- Adults, children and young people at risk of and with depression, anxiety and other mental health issues access the right early help and resources
- The emotional well-being of parents and caregivers, babies and children is supported
- Isolation is prevented and those that feel isolated are supported
- Environments and communities in which people live, work and learn build good mental health

### Problem statement:

Services are complex and difficult to navigate for CYP, their families and practitioners. This may contribute to delays in receiving the right support at the right time.

Staff feel they don't have the skills, knowledge or experience to help children and look for "specialist" services

### Solution:

Creation of a system-wide programme of activity to build connection and relationship, shared learning and support innovation and transformation:

## Connection and Relationships

**Enable multi-agency connections and relationships to strengthen how we work together**

## Learning and Development

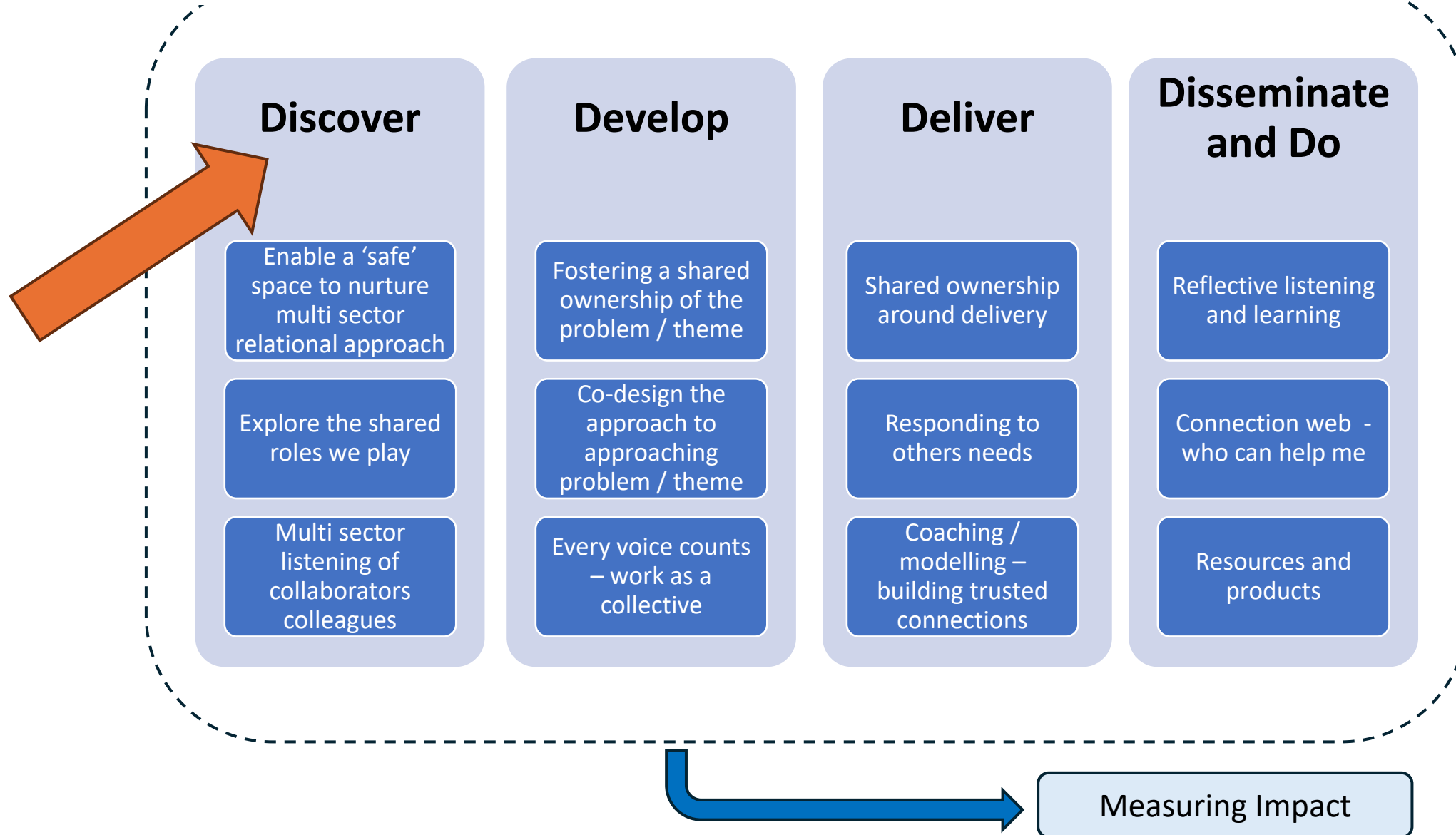
**Helping our workforce build confidence in what they know, how to find out more and responding to needs in a timely and meaningful way**

## Innovation and Transformation

**Nurture new ways of working together to better meet the needs of children, young people and families and help inform future decision making**

# The Surrey Youth Focus 4D model – Approach Overview

Continuous learning cycle– micro, meso and macro



*Developed by Surrey  
Youth Focus – We  
kindly ask you to  
contact us prior to use*

# Discovery questions

**What is going well for neurodivergent (ND) children and their families in Surrey Downs?**

**Where are the gaps or challenges for neurodivergent children and their families in Surrey Downs?**

**What are the key issues for you working (or volunteering) in this ND space? Are there any topics, feature elements to help you feel more confident working to meet the need of ND children? (eg ND update, sensory needs, behaviour, anxiety, Child voice)**

## Area of representation

GPs and PCN and Pharmacies

Health – First Community, Mindworks etc

Early Years

Education

Social Workers, FSP, IFSP, CWD

Family First - Centres, Early Help

Vol Sector

Parent Carers/ SEND advice

AND, LSPA, Family Communication

*The summary of findings provided in the following slides were generated by AI*

# Discovery: What is going WELL



## 1. Awareness and Understanding of Neurodiversity

- There has been **growing awareness** of neurodiversity across communities, with more professionals, schools, and families becoming aware of ND conditions like autism and ADHD. The understanding of ND is **seen in a more positive light**, but the awareness often lacks follow-through in terms of actionable support.
- Training and Resources:** Several respondents mentioned that schools and professionals are **becoming better at recognising ND** and offering relevant support. However, this understanding is still developing, with more need for consistent training across all levels.

## 2. Support in Schools

- Many schools are **offering increased support** for neurodivergent students, including **ASD outreach**, and specific initiatives like the **PINS project** (likely a support initiative for ND children).
- There is a noted improvement in **inclusion in mainstream settings**, but challenges remain, especially for families who **do not know where to find help** or whose children struggle to access support.
- Specialised provisions** like outreach programs and special schools are seen as **effective**, but **there are not enough spaces** to meet demand.
- ELSA support** (Emotional Literacy Support Assistants) and the **THRIVE approach**, which prioritizes the child's voice in their support, are examples of positive steps.

## 3. Parent and Family Support

- Families report while there is **a lot of understanding**, **action and practical support** remain lacking.
- Support groups** for parents are becoming more common, though there is a sentiment that **more support is needed**, especially for those who are not sure where to turn. Some families **report that they are starting to receive the support** they need, though for others, it's still a struggle.
- Parenting workshops** and **third-sector organisations** provide valuable resources, and there are increased opportunities for parents to connect through things like **coffee mornings** and outreach programs.

# Discovery: What is going WELL



## 4. Availability of Services

- The availability of services, both within schools and in the community, seems to be improving. **There are more services** offering varied support, such as **ND parenting workshops** and **early intervention programs** like the **Enhanced Language and Communication Initiative (ELCi)** for early years staff.
- However, it is noted that **access to support is often dependent on knowing where to ask**, suggesting that **better signposting and clearer communication** of available services is needed.

## 5. Collaboration and Community

- Collaboration between schools, services, and families is being emphasised as a key factor in providing better support for ND children. There is mention of **partnerships working to fill gaps** in services. Events such as community of practice is a great way to connect.
- Community involvement** in recognising and supporting ND individuals is seen as a growing strength, particularly through **third-sector organisations** that are developing more targeted initiatives based on feedback from families and young people.

# Discovery: What are the areas for improvement?



## 1. Diagnosis Delays and Access to Services

- **Long waiting lists** for diagnosis are a major concern, with Mindworks/**CAMHS** (Child and Adolescent Mental Health Services), GP referrals, and neurodivergent assessment pathways facing significant delays.
- There is frustration that **early diagnosis** is often delayed, leaving children and families navigating systems without adequate support.
- **Lack of access to services** without a diagnosis exacerbates the issue, with families struggling to get appropriate healthcare or educational support until the official diagnosis is made.

## 2. Challenges in School Inclusion and Support

- **Mainstream schools** often lack the resources, specialised staff, and knowledge to adequately support neurodivergent children, especially those with conditions like autism or ADHD.
- **Teaching methods** are frequently not tailored to the needs of ND students.
- **Inclusion** is often oversimplified to generic interventions that may not work for all children, making them feel like failures when the interventions fail to meet their needs.
- There is **a shortage of specialist school places** for children who cannot be adequately supported in mainstream schools. Some children with complex needs are left without appropriate school placements, especially if their **EHCP** (Education, Health, and Care Plan) indicates a specialist setting but no space is available.

## 3. Support for Parents and Families

- **Parents are struggling** to cope with the demands of raising ND children, particularly in navigating the complex systems of healthcare, education, and social support. Many report a lack of practical advice or **ongoing support** in the face of delays and under-resourced services.
- Parents often **do not receive sufficient guidance** on how to manage their children's needs while awaiting diagnosis or support. This creates anxiety and isolation.
- There is a call for more **parent support networks** and community-building activities, such as **workshops**, **parent groups**, and **outreach programs** that can provide practical tips and emotional support.

# Discovery: What are the areas for improvement?



## 4. Shortage of Specialist Support and Resources

- There is a **severe shortage of specialist resources** across both healthcare and education. Families often struggle to access appropriate support services, and **funding limitations** further limit the availability of resources.
- **Respite services (like short breaks)** are also in short supply, making it harder for families to find relief and balance their responsibilities.

## 5. Barriers in Accessing Mental Health and Educational Support

- **Mental health needs** are often overlooked or misunderstood, and **behaviours linked to neurodivergence** are not always treated as a sign of underlying mental health challenges.
- Schools also struggle to **identify mental health needs early**, and there is **patchy knowledge** about appropriate interventions for neurodivergent children, which can delay or hinder effective support.

## 6. Barriers to Post-18 Support and Transition to Adulthood

- **Post-18 support** is another area where there are gaps. Many families report that there is insufficient support as children transition to adulthood, particularly in terms of **education, employment, and independent living**.
- Access to **employment support** and **public transport** is limited, and there is little coordination between different services to help ND individuals navigate this transition.

## 7. Improving Coordination and Access to Information

- **Coordination between services** (schools, healthcare, social services) is often inconsistent, leaving families to navigate multiple systems on their own. **Caseworker support** and clear pathways to accessing the right services are often lacking.
- **Information is not always accessible** to families who need it. Many report difficulties in finding out what support is available, especially for children not yet diagnosed but still needing support.
- Efforts to improve **awareness** through initiatives like **parent workshops, support groups, and community events** (e.g., in libraries) are valuable but need to be scaled up.



# Discovery: What are the areas for improvement?



## 8. Understanding Neurodivergence in Schools and the Community

- **Training in schools and healthcare settings** is still patchy, with many professionals lacking the deep knowledge required to fully support neurodivergent children.
- There is a strong desire for **training** to improve understanding of **neurodiversity** and **autism-specific needs** within mainstream education. This includes better understanding of how to approach **behaviour, communication difficulties**, and **sensory needs**.
- **Understanding in the wider community** (including social workers and healthcare providers) is also a major gap. Many feel that **parents are misunderstood**, with a tendency for **parent-blaming** when challenges arise, particularly in safeguarding contexts.

## 9. Resource Gaps and Equity

- The **lack of specialist provision** and **insufficient funding** for services and schools is a key issue, especially as more children are being diagnosed with neurodivergent conditions.

## 10. Barriers to Community and External Support

- Access to **external support services**, such as **youth groups, playgroups**, and **specialised clubs**, is often limited, and **services outside of school hours** (such as summer camps) that are tailored to neurodivergent children are not always available.

# Discovery: Needs of Practitioners



Practitioners told us they would like the Community of Practice to feature the following:

## **1. Sensory Needs and Behaviours**

- Sensory processing issues (e.g., sensitivities to sound, light, or touch) and their impact on behaviour are key topics. Many individuals highlight the importance of understanding sensory needs to help reduce distress and support positive behaviours.

## **2. Supporting Mental Health and Wellbeing inc Anxiety**

- Anxiety is a common theme, often connected with other neurodivergent conditions like autism, ADHD, or PDA (Pathological Demand Avoidance). Managing anxiety involves understanding triggers, providing emotional regulation tools, and offering consistent, supportive strategies.

## **3. Managing Crisis and Challenging Behaviours**

- Behaviours like self-harm, meltdowns, and non-compliance can be responses to unmet sensory, emotional, or anxiety needs. Recognising these behaviours as communication rather than misbehaviour is emphasized.

## **4. ND Assessment, Diagnosis, and Support Services**

- There is concern about long waiting times for ND assessments and mental health support. Access to timely, appropriate services for children, particularly in early years and adolescence, is often limited.

## **5. Role of Parents and Advocating for Children**

- Parents play a crucial role in advocating for their children's needs, but there is frustration about not being believed or not receiving adequate support. Parents' anxiety is often tied to the lack of clear information or adequate service provision.



# Discovery: Needs of Practitioners



## **6. Early Years and Transitions to Adulthood**

- Support for very young children (0-5 years) with additional needs is a priority, including sensory integration therapy, early diagnosis, and family support.
- Transitioning ND young people into adulthood (e.g., education, employment, independent living) remains a challenge. Services need to be more focused on preparing for adulthood, with practical resources and support networks.

## **7. Communication and Child's Voice**

- There is an ongoing effort to ensure that the voice of the child is heard, particularly when they are unable to verbalise their needs. Ensuring that their preferences and feelings are considered in the development of support plans is a key concern.

## **8. ND as Whole-School Approaches**

- Adopting a whole-school approach to neurodiversity that includes not just the child but also staff, parents, and the wider school community is seen as essential. This would involve training staff to recognize and support ND behaviours, including sensory needs and anxiety, and providing inclusive practices that benefit all students.



“Develop” phase of the programme includes:

- Sharing the findings and identifying delivery collaborators
- Agenda planning for community of practice to respond to the need
- Collate resources and plan marketplace
- Open bookings for workshops



# Community of Practice (Surrey Downs) - Children's Neurodiversity

Friday 6th December 2024 | ALL DAY

Therfield School, Dilston Rd,  
Leatherhead KT22 7NZ

Come and be part of it:

**Relationship and Connections:** Meet like-minded colleagues from health, education, children services, community, and hear from those with lived experience.

**Learning:** Immerse in topic-based sessions and shared decision-making.

**Transformation:** Hear latest updates and information; be part of the onward conversation.

🌐 [surreyyouthfocus.org.uk](https://surreyyouthfocus.org.uk)    ✉ [events@surreyyouthfocus.org.uk](mailto:events@surreyyouthfocus.org.uk)



**SURREYDOWNS**  
Health & Care Partnership



**Mindworks**  
Surrey



Therfield School

**SURREY**  
HEARTLANDS  
Health and Care Partnership



**HOME**  
START



**Including Early  
Help Marketplace**  
Access information  
from local charities &  
organisations  
offering support for  
Emerging Needs

BOOK YOUR PLACE TODAY



[Register Here](#)

An event for practitioners working with children and families in Surrey Downs. Anyone from Health, Education, Children's Services, Family Safeguarding, Community is welcome.

# Background info ND Transformation Plan

For Surrey CYP who are neurodiverse and/or referred to the ND Pathway are thriving and feel a sense of belonging

## EARLY SUPPORT: CYP & FAMILY (CYPF) SUPPORT

To provide support that meets need early and ensure CYPF voices are included when planning services.

## EARLY SUPPORT THROUGH EDUCATION AND COMMUNITY

To provide direct support and review Ordinarily Available Provision. Share learning and build peer networks.

## TIMELY ACCESS TO DIAGNOSIS

To provide a seamless ND diagnostic support across all age groups through NHS provision & Right to choose

## CRISIS SUPPORT

To improve integrated approach and streamlined assessments / support

## COMMUNICATION & ENGAGEMENT

Ensure voices of CYP, families, stakeholders and partners are heard and informed.

## WORKFORCE

Develop and implement effective training  
Explore alternative workforce and skill mix to deliver ND Pathway

Neurodiversity - the hidden value of diagnosis - Healthwatch Surrey



**Out of hours advice line**

**0300 222 5755**

**NEURODIVERSITY  
ADVISOR PADLET**  
*FOR PARENTS/CARERS*

We understand that navigating life with a Neurodivergent child can be overwhelming. We have brought together key resources and information in a easy to use format.

Please scan the QR code to access our Padlet for Families.

[NDAdvisors@surreycc.gov.uk](mailto:NDAdvisors@surreycc.gov.uk)

The poster features the Surrey County Council logo, a QR code, and a stylized orange and white graphic.

**NEURODIVERSITY  
ADVISOR PADLET**  
*FOR PROFESSIONALS*

We know what a minefield of information is out there. We have brought together a range of resources to help support Neurodivergent young people in their educational setting. Please scan the QR code to access our Padlet for Professionals.

[NDAdvisors@surreycc.gov.uk](mailto:NDAdvisors@surreycc.gov.uk)

The poster features the Surrey County Council logo, a QR code, and a stylized orange and white graphic.



**SURREY  
YOUTH FOCUS**

**Thank you for reading**

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