



Health content for
Local Offer/ Provision Document

Tulip Paediatric Neurodisability Nursing Service

Charlotte Conway

Paediatric Neurodisability Matron

Excellent care for all
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Version 1: December 2024



Who are the Tulip Nursing Service?

What do the Tulip Paediatric Nursing Service do?

South West London, Integrated Care Board (SWL, ICB) commissions The Paediatric Neurodisability Nursing Service (Tulip) from Croydon Health Services NHS Trust to provide support for children and young people with learning disabilities and clinical health needs. Services are delivered across five specialist pathways:

- **Special School Nursing**
- **Complex Care for CYP with medical complexity**
- **Transition from children's to adult health services**
- **Acute liaison for hospital admissions**
- **CYP with Learning disabilities that display behaviours that challenge**

Who are we?

- We are a team of NMC registered nurses across the field of Children's, Learning Disability and Adult Nursing and Healthcare Assistants and Assistant practitioners. The service is based out of the Nursing office at St Giles School.
- The team have a wide range of knowledge in supporting children and young people with learning disabilities across a wide range of areas. We also have specialist posts in the team supported by Roald Dahl's Marvellous Children's Charity and a Clinical Nurse Specialist who sits on the RCNs Neurosciences Forum as their Paediatric link nurse.

What do our pathways offer?

Special School Nursing

The Special School Nursing service support children in Croydon Local Authorities five Special Schools, St Giles Nursery and Private, Voluntary and Independent (PVI) Nursery settings. The services provides:

- The training and competency assessment of education staff delivering healthcare interventions in Special School settings.
- The clinical care of patients where it is risk assessed as not suitable to delegate to education staff either due to risk; or frequency of intervention.
- The writing of individual health care plans (IHCPs)
- School nursing input into the health section of the Education Health and Care plans (EHCPs)
- Support is also provided for children with an allocated social worker identified as a child in need (CIN) or those subject to safeguarding plans.



Croydon Health Services
NHS Trust

Melissa Clarke

Paediatric Neurodisability Nursing Service
Complex Care Clinical Nurse Specialist

"Supporting children and young people with disabilities and complex health needs birth- 25 years in Croydon community services"



COMMUNITY NURSING NEURODISABILITY PATHWAY

- Oversight of shared caseload between school nursing and community nursing
- supporting practitioners in 3-6 monthly assessments
- early identification in changes to health needs and alternate pathway requirements

COMPLEX CARE PATHWAY

- 1-3 weekly reviews of most complex patients with multi-systemic health needs
- Supporting CYP with fluctuating health needs through changes in health presentation.
- Optimising health needs
- Supporting families to implement symptom management plans
- Liaison with specialist tertiary teams and co ordination of care.

19-25 SUPPORT INTO ADULT SERVICES

- Supporting the 'Complex care' caseload into adult services.
- Joint working with the Complex Care adult DNs and rapid response following transfer into adult services.
- Key worker support at point of transition between tertiary paediatric and adult services

Complex Care

Supporting children and young people with complex fluctuating health needs across a specialist complex care pathway with frequent reviews of health, liaison with specialist teams. Working closely alongside the child or young person's local health team, liaison with local and specialist hospital Trusts and multi-agency teams to ensure a clear understanding of the impact of the child's health needs on both education and social care. Attendance at specialist multi-agency clinics and coordinating complex health needs.

Acute Liaison

Supporting CYP with disabilities during acute inpatient admissions to Croydon University Hospital (CUH) on Rainbow Children's Unit (RCU) and Paediatric ED. This role ensure reasonable adjustments are in place and supports with the training and support of acute inpatient services working with children with disabilities at CUH, and liaison with specialist tertiary services following planned and unplanned admissions and step down to local hospitals. It will support discharges from acute to community services as part of the multi-disciplinary team.

NHS
Croydon Health Services
NHS Trust

Claire Jewell
Paediatric Neurodisability Nursing Service
Acute Liaison Nurse

"Supporting children and young people with disabilities in Croydon University Hospital"

EMERGENCY DEPARTMENT	RAINBOW CHILDREN'S UNIT	SUPPORT WITH GOING HOME
<ul style="list-style-type: none">• Support with your child's assessment• Discuss reasonable adjustments to find a safe space for your child to be seen• Support with your child's communication needs• If your child has long term health condition we can work with you to develop a hospital passport to reflect their needs	<ul style="list-style-type: none">• Review any reasonable adjustments your child may need during their stay• Ensure your child has access to all the equipment they need• Support staff with any specific training needs relating to your child's care• Training for you in any changes to your child's health needs which can continue to be supported on discharge	<ul style="list-style-type: none">• I have an active role in discharge planning within the wider MDT• Working closely with the Children's Community Nursing team to support your child's home equipment needs• Liaison with wider multi-agency teams to ensure your child has the support they need at home• Follow up post discharge to ensure your child has remained well

Transition into adult services

The transition pathway will support CYP aged 14-18 years and their families transitioning into adult healthcare services through a multi-agency approach. Support will be offered to all 14-year-olds with an opt out option. Transition needs assessments will be undertaken with personalised transition plans provided. Liaison with adult services regarding health needs of transitioning cohort with direct referrals made into the Community Learning Disability and District Nursing Teams where criteria is met.

Tulip
Paediatric Neurodisability Nursing Service

NHS
Croydon Health Services
NHS Trust

Judy Ardley
Paediatric Neurodisability Nursing Service
Transition Clinical Nurse Specialist
SEND Transition

"Supporting a co-productive approach to transitioning young people with neurodisabilities from children's to adults services"

SEND Transition- A pathway for young people with neurodisabilities moving from children's to adult services

SUPPORT	EMPOWER	NAVIGATE	DELIVER
<ul style="list-style-type: none"> • Early discussions with family around what to expect from transition children-adults. • Start complex care folder or develop personal transition folder • Identification of LD and reasonable adjustments • Discuss access to urgent care pathway • Independence goals and training package 	<ul style="list-style-type: none"> • Send letter to parent/carers introducing transition and providing named worker contact details. • Offer completion of 'transition readiness questionnaire' for YP with disabilities followed by appointment with CNS transition. • EHCP/Annual Review • Plan for adult placement 16 + and what health provision required 	<ul style="list-style-type: none"> • Referral to adult services, DN, complex care, continuing care, LD team as applicable • Identify Lead service • Move from CWD-Transition Team • Plan route into Urgent care and ward • Provide Hospital passport if not in place • Flag placed on EMIS and Cerner for LD and complex needs • Complete parental transition plan or 'navigate transition tool' 	<ul style="list-style-type: none"> • Continue with annual reviews to look at how YP/family are experiencing adult services and whether any specific pieces of work are required • YP and families to be given CNS transition as point of contact for difficulties and troubleshooting. • Joint working with adult 'complex care team' for YP with highly complex needs

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CYP with Learning disabilities that display behaviours that challenge

The pathway provides support for CYP aged 4-18 years with a learning disability who display behaviours that challenge at a Tier 2 level. The service provides support in the home settings and liaises with wider members of the MDT. Support is provided through bespoke 1-1 behaviour support plans and 1-1 work in the home, clinical psychology support through creative arts therapy (delivered by the Indigo service) and group work delivered via parent groups for specialist areas including; sleep, restrictive eating, escalating behaviours and puberty and adolescence.



Claire Green

Paediatric Neurodisability Nursing Service
Learning Disability Clinical Nurse Specialist

"Supporting children and young people in Croydon with learning disabilities and behaviours that challenge"



EARLY INTERVENTION

- Support for families in parent group settings for children who are more at risk of developing behaviours that challenge due to their diagnosis.
- Workshop support for families including, restrictive eating, sleep, continence and puberty.
- Specialist workshops managing with high risk behaviours, physical violence and absconding.

SUPPORTIVE THERAPY SERVICES

- 8-12 week sessions of therapeutic interventions from the clinical psychologists supporting CYP with LD via creative arts therapy.
- Drama/ music therapy to support with triggers including communication and accessing behavior support plans.
- Support for parents in recognising the emotional impact of having a CYP with a learning disability and strategies to support via workshops.

RISK ASSESSMENT AND INDIVIDUALISED BEHAVIOUR SUPPORT PLANS

- Initial assessment of risk following referral
- Individualised 1-1 work with children and families to identify triggers and develop strategies to support behaviour.
- targeted work around specific behaviours, including sleep and restrictive eating
- Development of behaviour support plans
- Referral onto tier 3/4 services as required

Which other professionals do we work closely with?



- Children's Community Nursing Team
- Children's Therapy Services
- Rainbow Children's Ward
- Tertiary centers
- Croydon Community LD service
- Community Paediatrics
- Paediatric and Adult ED
- Children's Safeguarding Team
- Health visiting services
- Adult district nursing
- GP practices
- Social Care
- SEND
- Education and school settings
- Children's Continuing Care
- Voluntary sector
- Indigo therapy services
- Specialist CNS teams
- Croydon continence service

Referrals into our service

Referrals:

Please email ch-tr.paedsneurodisabilitycns@nhs.net for a copy of our referral form

Referrals into the service can be made by health professionals, social care or education services, consent must be gained prior to referral. Each pathway has a specific referral criteria - please email for more specific pathway details. Please note The service does not support patients with a single diagnosis of autism.

Special School Nursing: The pathway is available to children and young people aged from birth to the academic year of their 19th birthday attending Croydon Local Authority Special Schools (Bensham Manor School, Priory School, Red Gates School, St Giles School/ nursery provision, St Nicholas School). Support is available to children **2-4 years in private, voluntary and independent nursery settings** for children with a diagnosis of a learning disability/suspected learning disability supported by the SEND early years team with a healthcare need that needs to be delivered / supported while accessing a PVI setting. Children on the 2-4 years pathway must be registered with a Croydon GP and settings must be based in Croydon.

Complex Care: This pathway supports CYP from 0-25 years with highly complex health needs across three age ranges, Birth-2 years, 2-18 years and 18-25 years. Referrals under 2 years old **will only be accepted** from a **Paediatrician or Neonatal Consultant**. Referrals into the service from 2 years-18 years, a diagnosis of a learning disability or an emerging profile of a Neurodisability should be evident. There will be current or ongoing specialist reviews by at least three tertiary consultants and referring professionals must evidence fluctuating health needs. Young people cannot be referred onto the complex care pathway once they are an adult and need to already have had a referral accepted onto the pathway by 17 years 11 months.

LD behaviour support pathway: CYP 4-18 years will need to have a Croydon GP and a diagnosis of a Learning Disability alongside evidence of behaviours that challenge. Please note this is a Tier 2 service, risk assessments will be undertaken at referral triage to ensure the correct allocation of support for need.

Acute liaison pathway: CYP birth-18years will need to have a Croydon GP and a diagnosis of a learning disability and be in attendance at Croydon University Hospital in Paediatric ED or on Rainbow Children's unit. CYP admitted to tertiary ITUs can receive support remotely via MDT liaison.

Transition support: Young people identified as being in transition (14-18years) on the Special School Nursing caseload with a Learning Disability, Croydon GP, health needs and attending one of five Croydon LA maintained special schools.

Universal resources



<https://www.youngepilepsy.org.uk/>



<https://www.shinecharity.org.uk/hydrocephalus/hydrocephalus>

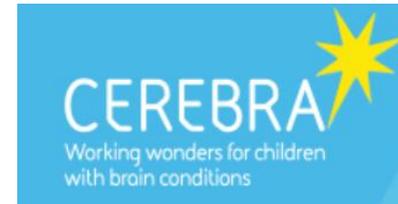


<https://www.peeps-hie.org/>



The Children's Bowel & Bladder Charity

<https://eric.org.uk/>



<https://cerebra.org.uk/>



<https://www.carersuk.org/>



<https://www.medicinesforchildren.org.uk/>



<https://www.wellchild.org.uk/>



<https://www.mencap.org.uk/easyread/annual-health-checks#:~:text=Annual%20Health%20Checks%20are%20for%20people%20with%20a,learning%20disability%20can%20get%20an%20Annual%20Health%20Check.>



<https://www.bliss.org.uk/parents/support/>



How the NHS works for young people

For parents and carers...

<https://www.cc4c.imperial.nhs.uk/-/media/cc4c/documents/how-the-nhs-works-for-young-people-parents-and-carers.pdf?rev=1b1be88776ac44715ad814927c0c3b68024&hash=38C8B1097DD17D4B3C218753B159BAC4>



<https://www.challengingbehaviour.org.uk/>