

Welcome to the Extensive Needs Service



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This resource is for caregivers who care for children with disability and medical complexity. It is not intended as medical or professional advice or opinion.

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Holland Bloorview Kids Rehabilitation Hospital

Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview) is Canada's largest children's rehabilitation hospital dedicated to improving the lives of children with disability. As a hospital fully affiliated with the University of Toronto, we are home to the Bloorview Research Institute and the Teaching and Learning Institute, allowing us to conduct transformational research and train the next generation of experts in childhood disability. For more information, please visit www.hollandbloorview.ca.



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Introduction to Holland Bloorview

Welcome to Holland Bloorview Kids Rehabilitation Hospital (Holland Bloorview), where we believe in meaningful and healthy futures for all. In partnership with children, youth, and caregivers, we deliver personalized and interprofessional care. Our goals focus on building strengths and abilities, and helping children participate in the activities that are important to them.

We are committed to providing a safe, supportive, and accessible environment with services that are culturally competent. At the hospital, we treat others with courtesy and dignity, respect different choices and values, and listen to understand without judgement and assumptions.



Getting to Holland Bloorview



Vehicle access to the building is along Kilgour Rd off of Bayview Ave. There is no access from Rumsey Rd.



Accessible parking is available on-site. The cost for parking is posted as you enter the parking lot. Credit and debit are accepted at the parking gates. Cash is accepted at the machine inside the building. On-street parking is limited.



You can walk to the hospital from Bayview Ave and Rumsey Rd.



If you are taking public transit, there are TTC bus stops on Eglinton Ave at both Bayview and Rumsey Rd and on Bayview Ave at Kilgour Rd.



Family Resource Centre

Learn about resources, find new information, and share experiences with others at the Grocery Foundation Resource Centre, which is located on the first floor (Monday to Friday, 9:00 a.m. to 5:00 p.m.).



Wi-Fi service

Wi-Fi service is offered throughout the building at no cost to our visitors. Please ask Main Reception for the Guest Network password.



Welcome to the Extensive Needs Service

The Extensive Needs Service, also called ENS, provides important support for families and caregivers with children and youth who have multiple medical, physical, developmental, or social health needs. We strive to make it easier for vulnerable children to get timely, effective, and supportive care.

Our team values the experiences of the people we work with. We encourage **you** to take part in identifying yours and the **child's** needs and help to set goals and plans. Throughout the program, we provide **trauma-informed** and **measurement-based care**.



In this resource when we say “**child**” we mean those who access the pediatric health system. This includes children, adolescents, and youth. When we say “**you**” we refer to all caregivers.

What is trauma-informed care?

Our team works to build strong rapport and trusting relationships with our **clients** (a non-medical term to refer to the person getting individualized care¹) and their caregivers. Their physical and emotional safety and dignity are always prioritized.

What is measurement-based care?

Measurement-based care involves clients and clinicians completing standardized questionnaires. The information from the questionnaires is used to track progress and make informed decisions about care.

About this resource

This welcome resource provides you with information on what you can expect during your time in ENS.

Welcome
to ENS!



You will find information on:

- the different healthcare providers involved in care
- how healthcare providers support children
- what to expect when receiving services
- planning for safe and supportive visits
- how the services are evaluated

¹Shevell, M.I. (2009). What do we call ‘them’?: the ‘patient’ versus ‘client’ dichotomy. *Developmental Medicine & Child Neurology*, 51: 770–772. <https://doi.org/10.1111/j.1469-8749.2009.03304.x>



Preparing for Your Visits



Sharing information will help the ENS team get ready for your first visit. Here is a list of some of the different types of information that the ENS team may ask you about the child:

- health history (e.g., allergies, medical conditions, medications)
- challenges affecting well-being (e.g., school attendance, missed work days)
- triggers and unsafe behaviours (e.g., sound, inability to communicate needs)
- what is important to both you and the child (e.g., social skills, independence, coping)

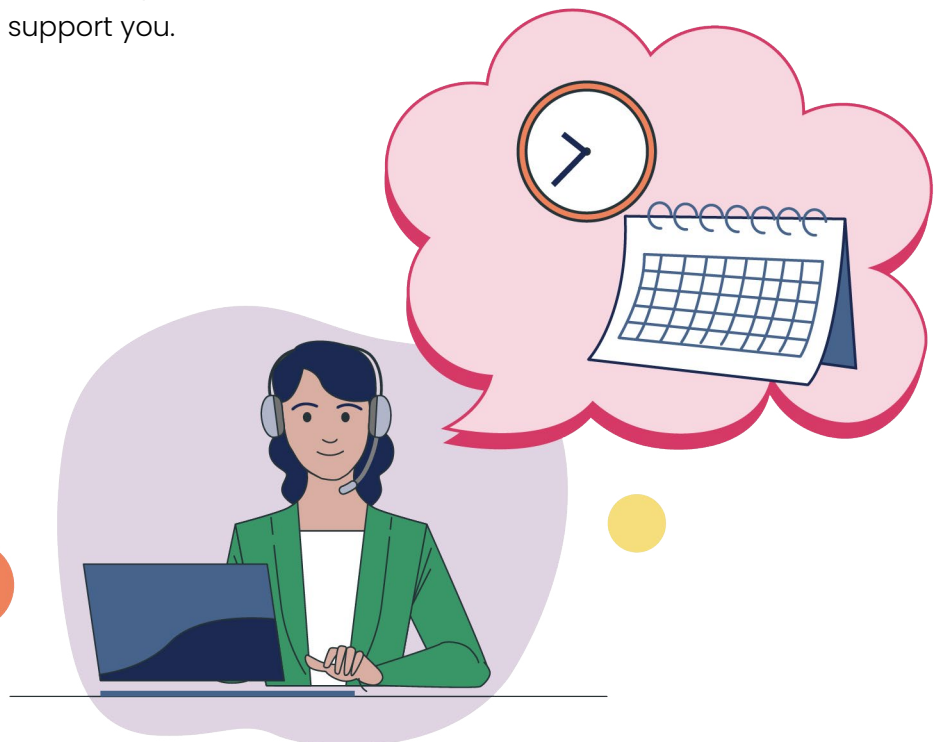
Appointments

Appointments are scheduled between Monday to Friday from 9 a.m. to 4 p.m. Participating in appointments is one way to support the child. Consistent participation by the child and caregiver is crucial to progress towards goals.

Please be sure to:

- bring the child's health card
- arrive for appointments on time

If it is difficult to attend appointments, speak to the ENS team to see how we can support you.



Your ENS Journey

For most clients, their time in ENS is approximately 9 months. At the start of care, you will meet with the ENS team. They will outline the child's needs and relevant treatment goals that can be addressed during this timeline. You and the ENS team will meet approximately every 3 months.

In between those larger team meetings, you will meet with individual clinicians for different aspects of the child's care. This is based on what the child needs to ensure progress throughout the program. Close to the 9-month mark or as the child reaches completion of their goals (whichever comes first), there will be a planned discharge meeting. Any important information will be shared with the child's community providers to ensure a safe transition after your time in ENS. Each child's transition plan and supports will differ depending on their individual needs.

Refer to the [ENS webpage](#) to learn more.

1 ASSESSMENT



2 TREATMENT



3 DISCHARGE





Working with your primary clinician and ENS team members

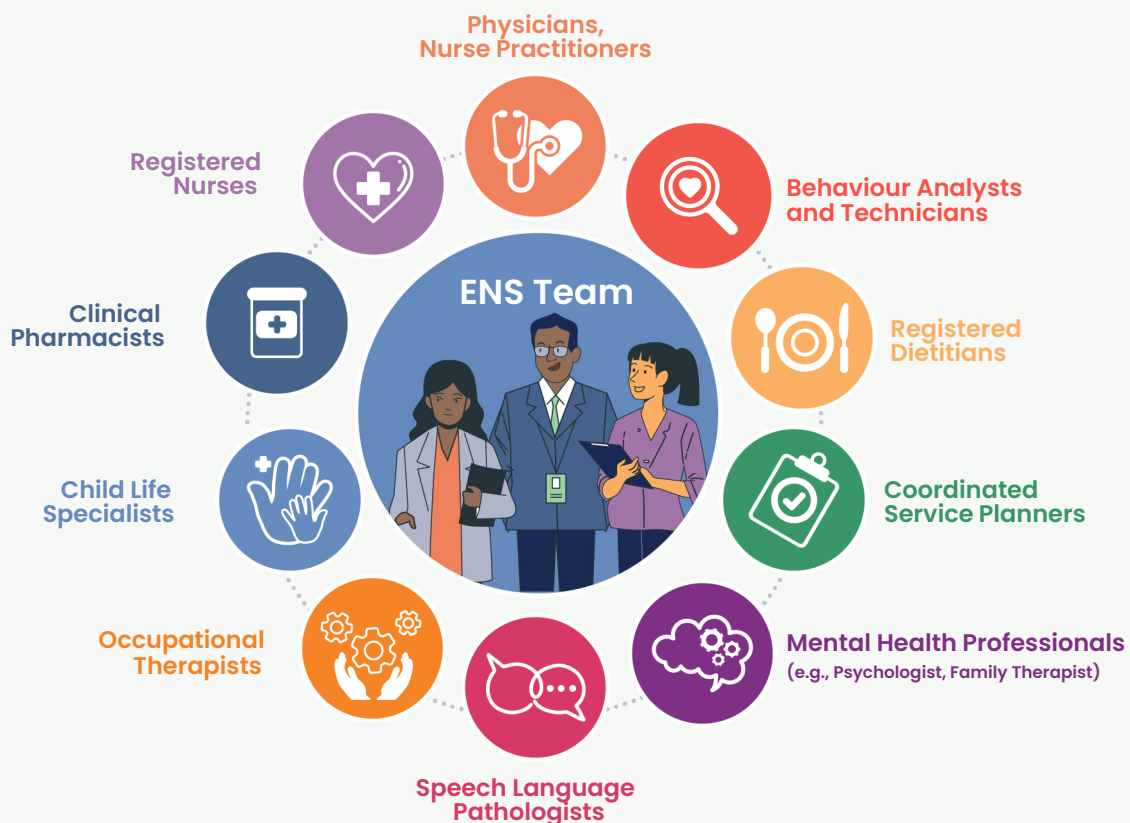
Every child will be assigned a primary clinician, who will be your first point of contact on the ENS team. How often you meet with the child's primary clinician is based on their recommendation.

Their role is to help:

- oversee treatment in ENS
- establish goals in collaboration with you and the ENS team
- work with other ENS team members to provide care that meets both your and the child's needs

The ENS team is committed to a client and family-centred care approach. This means that throughout the child's time in ENS, their independence and decision-making are respected. Together, we will create a tailored care plan and goals. The amount of care that is needed and how often it is provided is different for each child due to their unique needs.

**Many healthcare providers support children and caregivers in ENS.
Your healthcare team may include:**



The ENS Team

This table lists some of the different members of the ENS team and the type of role they may play:

Team Member Role		Description of Role
	Behaviour Analyst and Technician	• Helps to teach and practice skills that support increased participation in school, community, leisure, and daily living activities • Works with children to better understand behaviours, how to bring more joy into life, and to support the use of behaviour strategies
	Child Life Specialist	• Helps children work through the challenges of illness, hospitalization, transitions between teams and programs, injury, and disability • Offers sibling supports to help with family coping, health, and well-being
	Child Psychologist	• Creates strategies that meet mental health, emotional, social, and behavioural needs of children • Meets with schools, agencies, and healthcare providers to deliver support
	Clinical Pharmacist	• Ensures that medications are used safely • Works with the clinical team to understand how medications may help the needs, ongoing learning, and development of children
	Coordinated Service Planner	• Partners with Surrey Place (community agency in Toronto) to provide access to ENS • Provides support through referrals, assessing funding resources, and collaborating with community partners
	Physician and Nurse Practitioner	• Provides a specialized assessment and care • Reviews and prescribes medications as required

The ENS Team

Team Member Role	Description of Role	(Cont.)
 Occupational Therapist	• Helps children do the things they need and want to do, in the places, and with the people who are important to them • Care may include: coaching, education, advocacy, skill-building, suggestions for adapting the environment, or modifying activities	
 Registered Dietitian	• Provides nutrition assessment and plan related to food intake • Works with other team members to ensure appropriate nutritional status	
 Registered Nurse	• Works closely with physicians and nurse practitioners to ensure continuity in medical care • Acts as the main point of contact for the family for medication-related goals • Connects with the caregiver at the time of referral to ensure clarity in needs and services needed	
 Family Therapist	• Provides care for the social and emotional aspects of health • Focuses on the dynamics and impact of relationships among family members and/or caregivers	
 Speech Language Pathologist	• Supports the development of speech, language, and social communication skills • Works directly with children and provides caregiver training and consultation to clinical team and community providers	

My primary clinician is:

My ENS team members are:

Dates for my progress check-ins are:

3 months:

6 months:

My discharge date is:

Questions I have are:

Additional Information



Respite

Providing continuous care for a child with complex needs can be hard. It is important to get support not only for the child, but also for yourself. Respite care can provide you with temporary relief from the challenges of providing continuous care.

Holland Bloorview and [VHA Home HealthCare](#) (VHA) are partnering to offer Extensive Needs Respite. This respite program provides short-term relief to individuals who care for a child in ENS and need some extra support and rest. Together, yourself, the ENS team, and VHA will create respite activities and goals that meet the child's needs.

Respite can improve the health of and well-being both you and the child.

Notes or questions about respite:

Safety planning

Some children may need more support for a safe visit. The ENS team has very specific training to help keep clients safe. The team will work with you to create an **Individualized Safety Plan** prior to or during the child's time in ENS. We will make sure that you know about the safety measures in the plan. This is to keep the child and our staff safe.

Physical holds will be used as the **last option** if all other strategies (e.g., removing triggers, changing the environment) do not help to improve the behaviour. If the child has a prescribed medication that is to be used at times where behaviours are unsafe, please tell the ENS team in advance.

Emergency: Security and/or 911 may be called if the child is showing unsafe behaviour that cannot be safely managed by the ENS team or hospital staff. The Individualized Safety Plan will state when security and/or 911 will be called so that you are aware. The ENS team will follow-up with you to discuss next steps and future care planning.



Additional Information



Measurement-based care

Clients, caregivers, and clinicians work together to provide individualized care. Information is collected from you, the child, and clinicians to track progress and make decisions about the child's care. Standardized questionnaires are used to collect the information. This process is called **measurement-based care**.

Measurement-based care involves:

- Sharing information early on about:
 - the child's current behaviours
 - stress experienced by the family
 - type of services used
 - quality of life
- Completing a short questionnaire every month
- Completing a long questionnaire every three months

This information will also be used to:

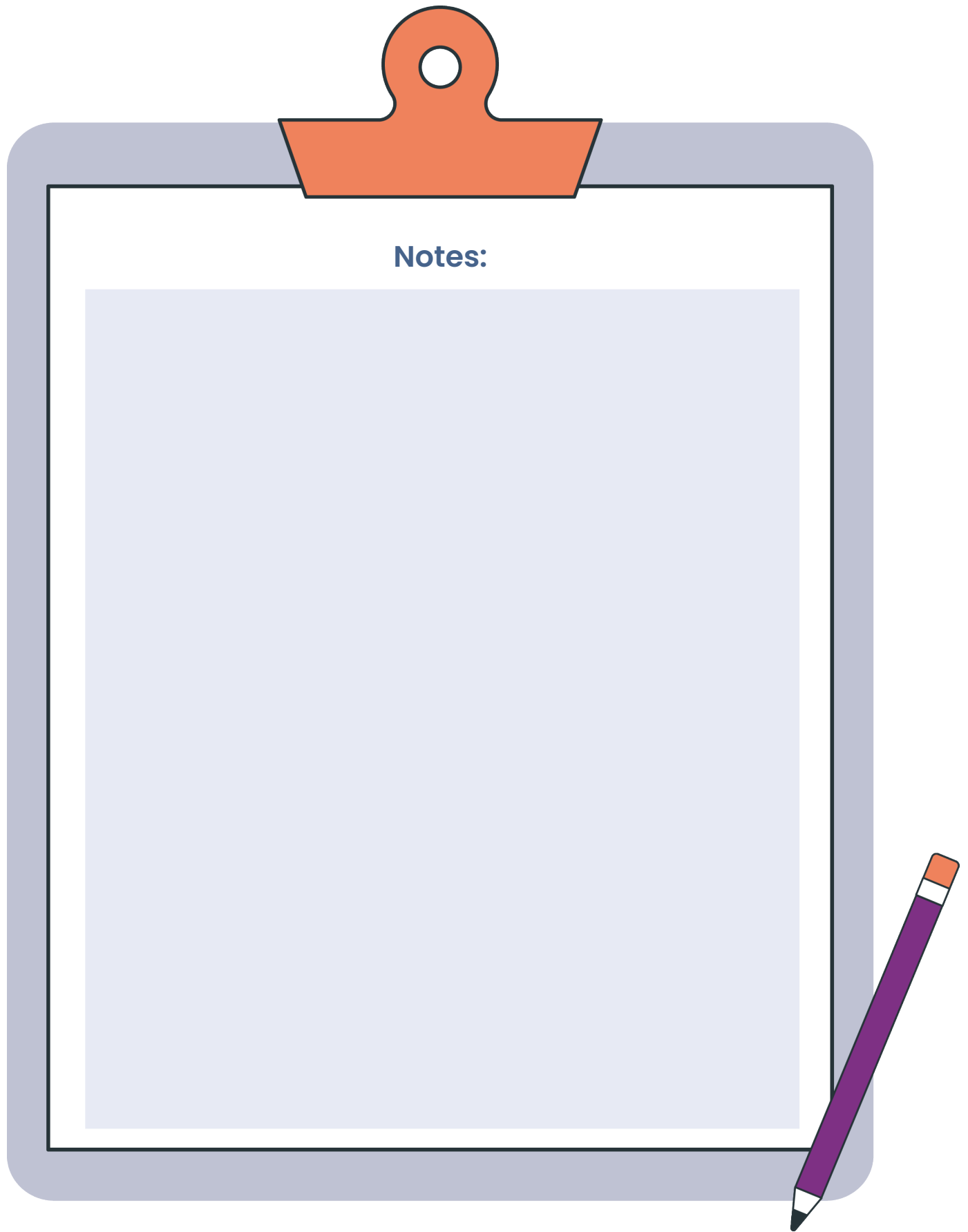
- Improve your child's care in ENS
- Change and improve programs at Holland Bloorview

The information that is collected can be used for other reasons, if you agree to it. An example of this is research studies evaluating the effectiveness of the program at Holland Bloorview and across Ontario. The ENS team will give you a letter that shares how your information could be used. You can decide if you would or would not like ENS to use your information in that way. You can also stop ENS from using your information in the future.



Notes:

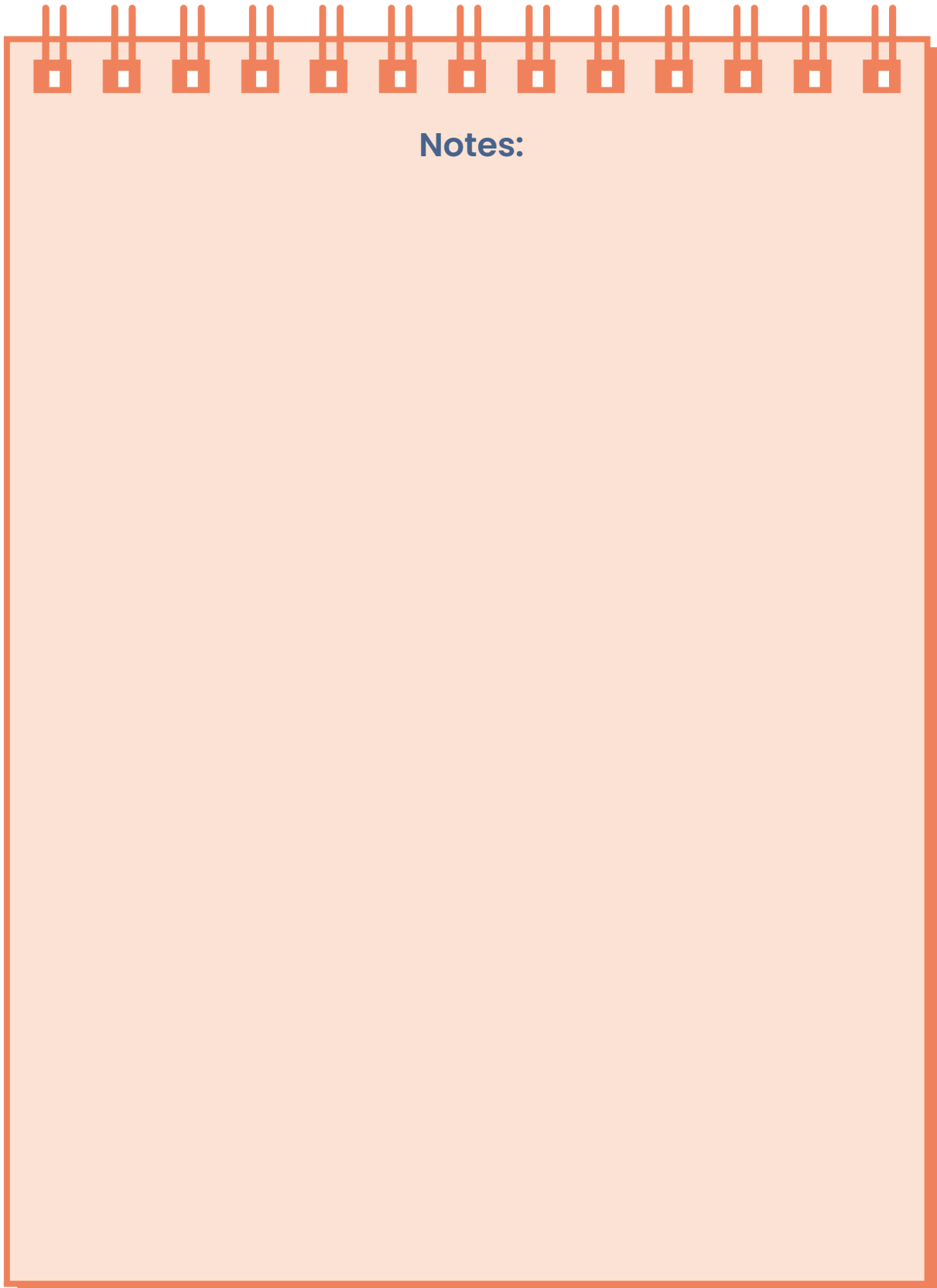
Additional Information



A clipboard with a white sheet of paper and a purple pencil. The paper has a large light blue rectangular area for notes. The word "Notes:" is written in blue text above this area. The clipboard has an orange clip at the top.

Notes:

Additional Information

A graphic of a spiral-bound notebook with an orange cover and a light orange page. The spiral binding is at the top. The word "Notes:" is written in blue text at the top of the page.

Notes:

Acknowledgements



Welcome to the Extensive Needs Service was developed by members from the ENS Team, Evidence to Care, and Family as Faculty.

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We hope this resource is useful in your
Extensive Needs Service journey.



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