

## Freedom of Information Request

### Response from Paediatric ASD Service, NHSC

- **What services are provided by your Trust for children with autism**

In line with the Regional Autistic Spectrum Disorder Network (RASDN) 'Six Steps of Autism Care' & NICE Guidelines the Paediatric ASD service within the NHSC aims to provide and deliver a high quality assessment and diagnostic service for children and young people where concerns regarding ASD have been identified, provide support to children / young people with a diagnosis of ASD and their families, and support professionals within the NHSC working with children / young people with ASD

The Paediatric ASD service offers an Assessment & Diagnostic service, Post Diagnostic Support & an Intervention service. In addition a telephone consultation service is available to support families referred to the ASD service (pre & post diagnostic).

Please see enclosed leaflet – (Professional Leaflet) which provides further detail regarding the range of services provided by the Paediatric ASD service for children & young people with ASD & those awaiting assessment.

- **The number of children in your Trust area waiting to be assessed for Autism. The length of time they have been waiting already. The average length of time a child has to wait to be assessed. The above information broken down by age and gender.**

As of 11<sup>th</sup> January 2021 – 1691 children/young people are awaiting for ASD assessment to be commenced.

As of 11<sup>th</sup> January 2021 -The current waiting time for assessment to commence is 445 days. The average waiting time for the last 12 months (Jan20-Dec 20) is 330 days.

For referrals received over the last 12 months (Jan 20- Dec 20) 62% were male & 38% female

Please see table for a breakdown of those awaiting assessment to commence by age:

| Age (years) | Number Awaiting Assessment to commence |
|-------------|--|
| 2           | 101                                    |
| 3           | 208                                    |
| 4           | 212                                    |
| 5           | 176                                    |
| 6           | 142                                    |
| 7           | 132                                    |
| 8           | 145                                    |
| 9           | 104                                    |
| 10          | 87                                     |
| 11          | 69                                     |
| 12          | 60                                     |
| 13          | 73                                     |
| 14          | 63                                     |
| 15          | 48                                     |
| 16          | 37                                     |
| 17          | 25                                     |
| 18 - 19     | 9                                      |
| Total       | 1691                                   |

- **How are services for children with autism publicised by the your Trust**

The Trust publicises the services provided for children with Autism through the Trust's website, Social Media sites such as Facebook & the Family support NI website.

## Paediatric Autism Spectrum Disorder (ASD) Service

### Professional Service Information Leaflet

In line with the Regional Autistic Spectrum Disorder Network (RASDN) ‘Six Steps of Autism Care’ & NICE Guidelines the Paediatric ASD service aims to provide and deliver a high quality assessment and diagnostic service for children and young people where concerns regarding ASD have been identified, provide support to children / young people with a diagnosis of ASD and their families, and support professionals within the NHSCCT working with children / young people with ASD

### The Paediatric ASD team

This is a multi-disciplinary team with therapists from a range of professional backgrounds including:

- Community Paediatrics
- Speech & Language Therapy
- Occupational Therapy
- Psychology
- ASD Therapist (Social Work, Speech & Language Therapist & Nursing Professions)

The team is supported by a full time administration and clerical officers.

The Paediatric ASD service offers an Assessment & Diagnostic service, Post Diagnostic Support & an Intervention service. In addition a telephone consultation service is available to support families referred to the ASD service (pre & post diagnostic)

### Telephone Consultation Service

The telephone consultation service aims to provide timely support to children, young people & their families to meet their immediate needs regardless of a diagnostic label allowing intervention to be provided in a timely fashion, based on need rather than a diagnostic label.



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This service also provides a consultation role in supporting other practitioners to enhance the intervention & support they offer to children/young people with ASD (or those awaiting assessment) & their families, thus delivering intervention in a more holistic & integrated manner.

The telephone consultation service offers support & early intervention to those families, children & young people even before a formal diagnosis of ASD has been made alongside supporting those with a diagnosis of ASD.

This telephone consultation service will facilitate early intervention focusing on:

- Offering a telephone/email helpline (Mon-Fri 9:30am-4pm) where parents/carers can contact directly without any formal referral for support & advice.
- Specialist ASD therapist will contact parents/carers directly within 3 working days to assess their need & provide initial advice /strategies
- If required parents/carers &/or young person (if approp) will be offered a pre booked consultation slot with a specialist ASD therapist (within 10 working days) where a detailed assessment of need can be undertaken & an intervention plan agreed with the family
- Resources appropriate to the assessed need will be provided including personalised visual support e.g. social stories, visual schedules, if approp
- Detailed home programmes to work through with their child/young person can be provided
- Review appointments to follow up on strategies, home programmes can be offered where appropriate.
- Parents/carers will be signposted to appropriate voluntary/community support
- If specific ASD support offered by the ASD intervention service is required for parents/carers &/or children & young people directly they will be added to the waiting list for this programme of support (see intervention programmes)

The telephone consultation clinic is available Monday to Friday, 930am-4.00pm. Parent/carer/s or Professionals can contact this service directly via phone on 028 2563 3777(select option 2) or by email PaediatricAutismService@northerntrust.hscni.net



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## **Assessment & Diagnostic Service**

### **Making a Referral for Assessment**

Consent to refer to the Paediatric ASD service must be obtained from the person with parental responsibility. Professionals making referrals to the service must follow standardised referral criteria as indicated on the NHSCT referral form **for assessment** (available from [www.northerntrust.hscni.net](http://www.northerntrust.hscni.net)).

All referrals are processed through the children's referral service, (SPOC single point of contact) for referrals central point and appointments are offered on a chronological basis across the Trust.

### **The Assessment and Diagnostic Process**

Assessment for ASD involves a process that may occur over a period of weeks/months. The service aims to commence a child's/young person's assessment within 13 weeks from the point of referral from the point of referral with an initial assessment.

In the majority of cases the parent/s / carer/s will be offered an initial assessment clinic appointment as their first appointment.

The initial assessment clinic (IAC) appointment is to meet with parents/carers in order to record a detailed developmental history on their child/young person. The purpose of this assessment is to obtain further information on the child/young person's early history and to determine if the history supports a diagnosis of ASD. The history pays particular attention to the areas of social communication, social interaction, play/imagination and repetitive interests both now and in the past. Prior to this appointment a review of the information already provided to the service is undertaken to avoid any duplication. Consent will also be sought from parents/carers to seek information from other professionals or educational staff if appropriate.

A case allocation meeting undertaken by senior professional staff reviews the information obtained in the IAC, alongside other information to determine the most appropriate assessment for the child/young person.

Assessment can occur in a variety of formats and with any combination of professionals from the Paediatric ASD team involved. The child/young person's assessment process will depend on their age and stage of development.



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At each assessment the diagnostic outcome falls into one of three areas which are: a diagnosis of ASD; no diagnosis; or inconclusive -further information may be required or further assessment indicated.

The outcome of the assessment will be discussed with the family and documented in an outcome report which will be shared with those involved with the child/young person.

### **Intervention Service**

The Northern Trust Paediatric ASD Service provides the following intervention programmes to support children & young people with ASD and their families. These supports are accessible to all children/young people & their families across the Northern Trust residential area (unless otherwise specified)

### **Post Diagnostic Support**

Post diagnostic support is offered to **all** families once a diagnosis of ASD is confirmed by the Paediatric ASD service:

The service aims to commence a child's/young person's/families specialist ASD Post Diagnostic intervention within 13 weeks from the point of diagnosis.

In the majority of cases parents/carers are initially be invited to attend a **PACE (Parents & Carers Education) Level 1 awareness programme**, appropriate for their child or young person's age (learning difficulties, preschool, 5-12 years, Teenagers).

This seminar aims to provide information on ASD and how it manifests in everyday life, alongside equipping parents/carers with practical advice and techniques to enable them to assist their child/young person in their development & support & manage any behaviours of concern. Parents/carers will receive a toolkit and workbook that can be personalised to suit their child/young person and highlight strategies and activities they can try at home, over a period of time, with their child/young person.

Following implementation of the strategies and advice provided at the PACE programme, parents/carers will be asked to provide feedback to the Paediatric ASD service via a feedback form (sent out with invite to course). This form will ask questions regarding: their understanding of ASD, how it is impacting on their child/young person and the family as a whole and how they have implemented the strategies agreed from the PACE Level 1 awareness programme.



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ASD staff will then triage these returned forms to help determine if any further help is required for the child/young person or their family at this time.

It is acknowledged that many families will not require further help at this time as they are now equipped with practical advice and strategies provided at the PACE programme. However we understand that as young people grow and develop their needs may change. Therefore, parents/carers are advised that they can contact the Paediatric ASD Service directly (with no need for a formal referral) at any time in the future if they require help /support for them and/or their child/ young person, up until the age of 18. Information re contact details is provided – ie the Paediatric ASD service can be contact on 02825633777 (option 2) or via email on PaediatricAutismService@northerntrust.hscni.net

### **Intervention Support**

In addition to the post diagnostic support offered to families at time of diagnosis the Paediatric ASD Service offers additional support for children and young people with ASD and their families for those that require further help, which is accessible through a referral to the Paediatric ASD Intervention Service.

Referral forms **for intervention** are available through the trust website ([www.northerntrust.hscni.net](http://www.northerntrust.hscni.net)) / or by families contacting directly the telephone consultation service.

The majority of referrals for further intervention are offered a consultation appointment with an ASD therapist. At this appointment parents/carers will be asked to describe the current difficulties their child/young person is experiencing in relation to their ASD and their concerns at this time. Initial ASD-specific advice will be provided to help parents/carers to manage the difficulties discussed.

If required, the therapist will identify an intervention package for the child/young person and their families following this appointment.

### **Intervention Packages:**

Intervention is provided as deemed appropriate based upon the **assessed need**:

The service offers the following intervention programme identified as an assessed need following a consultation appointment :



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## Support for Parents & Carers

### **PACE Programme - Parent and Carer/s Education Programme**

There are a range of training courses available through the Parent and Carers Education Programme in addition to the Level 1 – What is ASD seminars offered following a diagnosis of ASD.

### Level 2 PACE training – Specialist training seminars on specific topics

These programmes include seminars on:

- **Promoting Communication Skills including the use of social stories –** This Seminar will explore the communication process further and will look in detail at some of the difficulties a child & young person can experience within this communication process. It aims to provide parents/carers with strategies and advice, including the use of visual supports, to help them to develop their child's / young person's communication skills. This seminar also explores the use of Social Stories and Comic Strip Conversations as a strategy that can be used to allow for the development of social communication skills.
- **Understanding Behaviour** - This seminar will explore behaviours a child & young person can engage in, that parents/carers may find difficult to understand or manage. It aims to provide parents/carers with strategies and techniques to support their child & young person to manage difficult behaviour & meltdowns more effectively.
- **Managing Feelings** - This seminar will focus on helping parents/ carers to help their child & young person understand the different emotions they experience, why they occur, and how to handle them. It aims to provide parents/carers with strategies and advice, including the use of visual supports, to help emotionally regulate the child & young person's anxieties & worries.
- **Let's make Sense** – This seminar will explore the sensory experiences of child & young person & provide an understanding of why a child & young person may have sensory needs and the stress and anxiety these



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can cause when managing their daily lives. It aims to provide parents/carers with sensory strategies to help their child & young person feel more relaxed and to provide sensory strategies to allow a child & young person the right type of sensory input in order to allow them to be calm and organise themselves for the day ahead ready in order for learning to occur.

- **Supporting Siblings of families with ASD** - This seminar aims to look at the experiences of those who have a brother or sister with ASD. It aims to explore ways for parents/carers to help siblings to increase their understanding of ASD and to share ideas and strategies that may have a positive affect on sibling relationships.

**Level 2 PACE** also includes a package of 3 training seminars for parents/carers of teenagers' called **Teenlife**. Teenlife is for parents/carers of teenagers with ASD - This 3 session seminar explores with parents/carers ways to support their young person with ASD with key issues during adolescence. This includes factors that may affect the young person's ability to emotionally regulate, self-esteem and motivation & provides strategies including the use of visual supports to promote skills in young people & develop resilience. Alongside this, the seminar further explores sensory issues a young person may experience due to ASD including strategies to manage these sensory needs more effectively, puberty and relationships & the potential issues a young person with ASD may encounter with strategies to address these.

### **Support for the Individual with ASD (one to one)**

#### **About me:**

This is a one: one time limited intervention package (3-4 sessions) suitable for those aged 10 years +. Activities and worksheets will be carried out with the young person with the focus on the following topics:

- Autistic Spectrum Disorder (ASD) – exploring and understanding the diagnosis.
- Looking further at how ASD affects the young person.
- Exploring further the positive aspects of having ASD.



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## **Group Interventions**

**Social Skills Groups** are all based on the evidence based programme – ‘Talkabout’ by Alex Kelly

### **This is me group – P1-P3**

This is a foundation to social skills training programme (6 weeks) aimed at children between P1 – P3 and facilitates the child’s development of self-awareness & self-esteem.

### **Social skills assessment**

For children & young people aged P4 + a social skills assessment (using talkabout assessment wheel) is undertaken to ascertain the social skills difficulties & identify the most appropriate social skills group from below:

### **Let’s Build it – Social Skills group – P4-P7**

This is a 6 week social skills group for children in P4-P7 where individual social skills are assessed & taught in a structured, systematic way. The topics covered include: eye contact, listening, the way we talk, questions, conversations, working as a group and friendships.

Each session is split into 2 parts:

1. Teaching the skill – the children will engage in group activities with professionals from the ASD team to learn about the targeted social skill for that session.
2. Practicing the skill – children get to play with Lego in a structured way while practicing the new skills taught & aid generalisation of the skill. This Programme is also supported with home activities to promote generalisation.



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## **Speak up, speak out - Assertive Group**

This is a 6 week social skills group for children & young people 12 yrs + where individual social skills are assessed & taught in a structured, systematic way & assertive skills are focused on as a priority.

## **Social emotional regulation groups**

This is a 6 week intervention group suitable for children & young people up to 16 yrs. This is a social emotional regulation programme that facilitates & develops the child's self-esteem, understanding of feelings, coping & communication skills. It also incorporates relaxation session plans from the evidence based 'relax kids' programmes.

Groups are delivered with children /young people of a similar age & activities tailored to their age ranges.

## **Individual Intervention Programme**

A timed individual intervention programme may be offered to the child/young person delivered by specialist ASD team members to address specific areas of assessed need such as social emotional regulation, anxiety, behaviour, sensory regulation etc.

This may include input from:

- Psychology
- Occupational therapy
- ASD Therapist

An initial assessment will be undertaken by the professional from the ASD service & a timed intervention programme will be devised. This can take the form of Home programme with review, 1:1 therapy sessions or group intervention.



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## **Northern Adult Autism Advice Service**

This service is for individuals aged 16yrs + with a diagnosis of ASD. It is made up of a small multiagency team providing a service to adults and those who support them.

The key aims are:

- To help individuals with Autism access a range of appropriate main-stream services, for example, employment, further education;
- To offer individuals with Autism one to one support for specific problems;
- To offer post-diagnostic support;
- To provide a safe place where individuals with Autism can share their experiences.

(Individuals may be supported by their carer/advocate to attend)



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