

Reference FOIAH2324/039

Number: From: Other

Date: 15 April 2024

Subject: Autism Waiting Times

- Q1 The median length of time from referral to autism services to receiving an autism assessment from Alder Hey Children's NHS Foundation Trust.
- A1 46 weeks to first attended appointment as part of the autism assessment pathway (therefore this does not include cancelled or non-attended appointments) please note there is also additional triage/screening of information at earlier stages of the pathway.
- Q2 The median length of time from referral to autism services to receiving the final outcome of an autism assessment (i.e. a positive or negative diagnosis) from Alder Hey Children's NHS Foundation Trust.
- A2 71 weeks
- Q3 The conversion rate of autism assessments to autism diagnoses through Alder Hey Children's NHS Foundation Trust.
- A3 90%
- Q4 What support and further referral is routinely offered to children who receive an autism diagnosis through Alder Hey Children's NHS Foundation Trust.
- A4 Please see attached support services list which is also available via the Alder Hey Website. In addition, the service has a Memorandum of Understanding (MOU) with Advanced solutions community network who are our commissioned partner to provide support to children, young people and families at pre and post stages of the diagnostic pathway which includes data sharing at the start and end of the process, so parents/carers can access support throughout the pathway. Referrals to other services are also completed for each individual child based on their needs identified in assessment, e.g., Community Speech and Language Therapy, Young Persons Advisory Service and other 3rd sector support, Child and Adolescent Mental Health Services (CAHMS), Community Paediatrics etc.
- Q5 What support and further referral is routinely offered to children who undergo an assessment for autism through Alder Hey Children's NHS Foundation Trust but do not receive a diagnosis.
- A5 As per A4
- Q6 What standardised tools are currently used by Alder Hey Children's NHS Foundation Trust for the screening and/or triage of children who seek an autism assessment.
- A6 The service does not use a specific screening tool currently; the clinical team review the referral form information which is based on the Diagnostic and Statistical Manual of



NHS Foundation Trust

Mental Disorders (DSM-5) criteria for autism. It is also expected that schools share evidence of the graduated response to ensure the child/young person is supported whilst they are waiting for an assessment.

Support services

There are lots of local and national services that can support children/young people and their families while they are waiting for an ASD assessment and after a diagnosis.

Support, information and training around ASD

SEFTON & LIVERPOOL (families with a Knowsley GP can access the national offers but not services which are specific to Liverpool or Sefton)

- ADDvanced Solutions Community Network
 Advice, support and training to families of children across Liverpool and Sefton (they
 also have an offer for families in St Helens, Warrington, Knowsley & Halton).
 <u>www.addvancedsolutions.co.uk</u>
- The National Autistic Society (NAS)
 The National Autistic Society website has lots of information about ASD. It can be
 used by young people, families and schools. They also offer access to training.
 <u>www.autism.org.uk</u>
- Hub of Hope Mental Health Support Network provided by Chasing the Stigma | Hub of hope
- Autistic Girl's Network Welcome to the | Autistic Girls Network
- Neurowild This is a really good resource which uses neuro affirmative language and helps explain ASD to children and YP <u>NeuroWild | Facebook</u>
- Autism Foundation Autism Foundation
- Autism Initiatives work alongside autistic people their families and carers providing specialist services tailored to individual needs <u>https://www.autisminitiatives.org/</u>
- Together Trust champion the rights of children, young people and adults across the North West https://www.togethertrust.org.uk/

Liverpool GP ONLY:

- Liverpool ASD Training Team
 Pre- and post-diagnosis training, email support and 1:1 Zoom or telephone advice
 sessions <u>https://fsd.liverpool.gov.uk/kb5/liverpool/fsd/service.page?id=8VkIJg0iBBA</u>
- Liverpool Parent & Carer Forum (LivPac) Advice, support and training to families
 <u>https://livpac.org.uk</u>

- Liverpool Children's Centres (children under 5) 'stay and play' sessions for preschool children and targeted groups for children with communication difficulties or additional needs. To find your local centre in Liverpool, please visit: <u>https://fsd.liverpool.gov.uk/kb5/liverpool/fsd/results.page?localofferchannel=2-5</u> (You can then filter by postcode)
- Liverpool Parents' Interest Group The group is for Parents, Grandparents & Carers of children with ASD, ADHD & related conditions. They meet once a month and all are welcome. They sometimes ask professionals to do talks. Contact: Babbs Blueet-Duncan (Email: <u>babs.bd100@gmail.com</u>)
- School Health Team <u>https://www.merseycare.nhs.uk/our-services/liverpool/school-health-service</u>

Sefton GP ONLY:

- Sefton Autism & Social Communication Team. Training for parents and schools. <u>https://www.seftondirectory.com/kb5/sefton/directory/advice.page?id=XtBcf2jlbXo&lo</u> <u>calofferchannel=0</u>
- Sefton Family Wellbeing Centres 'stay and play' sessions for pre-school children and targeted groups for children with communication difficulties or additional needs. To find your local centre in Sefton, please visit: <u>https://www.sefton.gov.uk/schoolslearning/family-wellbeing-centres/</u>
- Sefton Carers Centre If you care for someone under 18 years old who has a physical disability, learning disability or emotional/behavioural condition (diagnosed or undiagnosed) then Sefton carers provide a variety of parent advice and support <u>www.sefton-carers.org.uk</u>
- Aiming High (school need to refer) This group provide sessions during term-time and holidays for young people with needs. They give support when young people reach key 'transition points', such as moving from school into work https://www.sefton.gov.uk/aiminghigh
- Sefton Council for Voluntary Service (CVS) A charity that provides a project called 'Buddy Up'. This is a mentoring & befriending project for young people aged between 13 and 18 who have additional needs & are at risk of social isolation <u>www.seftoncvs.org.uk</u>
- South Sefton School Health Team <u>https://www.merseycare.nhs.uk/our-</u> services/south-sefton/school-health-team
- North Sefton School Health Team <u>https://www.merseycare.nhs.uk/our-</u> services/southport-formby/school-health-team

Support with mental health/emotional wellbeing

- Alder Hey Mental Health Hub <u>https://www.alderhey.nhs.uk/services/mental-health-hub/</u>
- Young Person's Advisory Service (YPAS) YPAS support the mental health and emotional wellbeing of children & young people aged between 5 25 years & their families. They provide support and therapeutic services such a counselling, psychotherapy & family work. <u>www.ypas.org.uk</u>
- **Parenting 2000** They provide information about a range of topics, therapeutic services & counselling to children, young people, families, adults & groups. They run Alchemy Youth Club for young people to meet friends and increase their confidence www.parenting2000.org.uk

Support with education/finances/legal

- Special Educational Needs & Disability Independent Advisory Service (SEND IASS) Free and confidential, impartial information around Special Educational Needs. Advice on legal rights, the EHCP process and advocacy support. Liverpool & Knowsley <u>https://barnardossendiass.org.uk/liverpool-and-knowsley-sendiass</u> Sefton <u>https://barnardossendiass.org.uk/sefton-sendiass/</u>
- Liverpool SEND Law Clinic A service which provides free and confidential legal advice to members of the public in the Liverpool area https://www.liverpool.ac.uk/law/liverpool-law-clinic/clients/children-with-sen-or-disability/
- Turn to us Tackling Financial Insecurity Together | Turn2us
- DLA Disability Living Allowance (DLA) for children claim form GOV.UK
 (www.gov.uk)
- Carers allowance Carer's Allowance claim form GOV.UK (www.gov.uk)
- Cerebra DLA guide Disability Living Allowance (DLA) Cerebra
- Blue badge <u>Thousands with hidden disabilities benefit from extended Blue Badge</u> <u>scheme - GOV.UK (www.gov.uk)</u>
- **Newlife** A charity that helps families to get equipment they may need to improve their child's quality of life <u>www.newlifecharity.co.uk</u>
- Boparan Charity Home Page |The Boparan Charitable Trust

- Family Fund Family Fund
- Disability social worker <u>Help if you have a disabled child: Overview GOV.UK</u>
 (www.gov.uk)
- EHAT <u>Early Help Assessment Tool (EHAT) | Liverpool Family Information & SEND</u> <u>Directory</u> and <u>Early Help (sefton.gov.uk)</u>

Support with sensory differences

- ADDvanced Solutions Community Network Understanding sensory processing difficulties workshop: <u>https://www.addvancedsolutions.co.uk/our-offers/family-</u> learning-programmes-and-workshops.html
- Liverpool Children's Occupational Therapy: <u>https://fsd.liverpool.gov.uk/kb5/liverpool/fsd/service.page?id=wcz_pXKyJCY</u>
- Sefton Children's Occupational Therapy: <u>https://www.alderhey.nhs.uk/services/occupational-therapy/occupational-therapy/</u>
- Sensory Hive: Specialist Sensory Integration Centre | The Sensory Hive | Whiston

Support with eating

- ADDvanced Solutions Community Network Understanding eating difficulties workshop: <u>https://www.addvancedsolutions.co.uk/our-offers/family-learning-programmes-and-workshops.html</u>
- Alder Hey EDYS <u>https://www.alderhey.nhs.uk/services/mental-health-hub/eating-disorder-service/</u>
- **ARFID** <u>WHAT IS ARFID? | ARFID Awareness UK</u> and <u>Avoidant Restrictive Food</u> <u>Intake Disorder - NEDA (nationaleatingdisorders.org)</u>
- **BEAT** <u>The UK's Eating Disorder Charity Beat (beateatingdisorders.org.uk)</u>

Support with sleep

- ADDvanced Solutions Community Network Understanding sleep difficulties workshop: <u>https://www.addvancedsolutions.co.uk/our-offers/family-learning-programmes-and-workshops.html</u>
- **Cerebra** They know how hard it can be to get a good night's sleep. They have online sleep guides and a sleep advice service <u>www.cerebra.org.uk</u>

• **The Sleep Charity** A national charity supporting children with sleep difficulties. <u>www.thechildrenssleepcharity.org.uk</u> and <u>https://teensleephub.org.uk</u>

Support with toileting

- ADDvanced Solutions Community Network Understanding toileting difficulties workshop: <u>https://www.addvancedsolutions.co.uk/our-offers/family-learning-programmes-and-workshops.html</u>
- Liverpool Children's Community Bladder and Bowel service - <u>https://www.merseycare.nhs.uk/our-services/liverpool/adult-bladder-and-bowel-</u> <u>services</u>
- Sefton Children & Young People Continence Service <u>https://www.seftondirectory.com/kb5/sefton/directory/service.page?id=jEossNyRenU</u>
- **Bladder & Bowel UK** The Bladder & Bowel UK website has a range of resource leaflets you can download for free in relation to toilet training. They have articles and resources about ASD & toilet training too. <u>www.bbuk.org.uk</u>
- ERIC Home ERIC

Support with speech and language

- Sefton Community Speech and Language Therapy: <u>https://www.alderhey.nhs.uk/services/speech-and-language-therapy/community-speech-and-language-therapy-sefton/</u>
- Liverpool Community Speech and Language Therapy: <u>https://www.alderhey.nhs.uk/services/speech-and-language-therapy/community-speech-and-language-therapy-liverpool/</u>

Jobs/careers

- Steps at Strawberry Fields <u>https://strawberryfieldliverpool.com/steps-strawberry-field</u>
- Apprenticeships <u>https://www.gov.uk/apply-apprenticeship</u>
- Bemore is a local service for searching apprenticeships <u>https://lcrbemore.co.uk/</u>
- Career Connect help young people with career options https://careerconnect.org.uk/

Accessibility

- Sunflower lanyards Hidden Disabilities Sunflower (hdsunflower.com)
- Nimbus Access Card Access Card: Making access easy
- Carers Card UK https://www.carerscarduk.co.uk/
- Carers Trust https://carers.org/out-and-about/days-out
- **CEA cinema and theatre cards** <u>Home CEA Card</u> Most cinemas offer ASD friendly hours
- Carers Discount Discounts For Carers: Exclusive Discounts, Offers & Codes

Short breaks / Social activities

- Merseyside Autistic Adults Support and social group that run regular drop-in sessions, meetings and trips out. There is a separate young adults group for 16-25 year olds <u>https://www.thelivewelldirectory.com/Services/1583</u> OR: <u>https://www.facebook.com/merseysideautisticadults</u>
- Jakes Sensory World & Garden at Netherton Activity Centre, this is a place for children to access soft play, stay & play and sensory experiences. They also help organise birthday parties. <u>https://www.seftondirectory.com/kb5/sefton/directory/service.page?id=3l1eYvgsrwk</u>
- Fusion Project (LIVERPOOL ONLY) helps children & parents/ carers access a variety of 'breaks' such as leisure & play breaks, friendship groups & holiday breaks. <u>https://liverpool.gov.uk/children-and-families/childrens-social-care/short-breaks-fordisabled-children/</u>
- Autism in Motion <u>Home Autism in Motion Liverpool, our aim is to support and</u> enhance the lives of families and children on the Autism Spectrum. (aimautism.com)
- Young Carers <u>Young Carers (sefton-carers.org.uk)</u> and <u>Young carers Liverpool</u> <u>City Council</u>
- Merlin's Magic Wand <u>Home | Merlin's Magic Wand Children Charity</u> (merlinsmagicwand.org)
- Everton in the community Everton in the Community
- Liverpool Fire Fit FireFit Hub | Home

- Autism Adventures Autism Adventures UK Ltd
- **Theatre Porto** in Ellesmere Port. Relaxed and inclusive performances <u>https://theatreporto.org/info-for-visitors/</u>
- Caudwell Children Home Caudwell Children
- Carefree Breaks <u>Take a break Carefree (carefreespace.org)</u>