### Autistic young people - FAQ's

### **Diagnosis**

### 1. What is the process for pursuing an autism diagnosis in primary or secondary school?

There are two routes you can take to pursue a neurodevelopmental assessment of your child: the School, or the GP.

If you wish to make the referral through the school, you should contact them in the first instance to outline your concerns and identify whether the school have any concerns or have similar observations to you. If so, the school can complete the neurodevelopmental assessment paperwork that has been provided by the Neurodevelopmental Team (NDT) and submit it to them directly. This will be shared with you prior to the referral being submitted, to ensure you are happy with the content.

If behaviours are not evident at school, but you are seeing these behaviours at home, the school will most likely ask you to go to your General Practitioner (GP). If you wish to make this referral through the GP, then you can make an appointment and request this. They will ask for as much information as possible so they can complete a referral to the appropriate team, so it may be helpful to record your concerns and take these with you to the appointment.

If there are mental health considerations, it may be appropriate to ask your GP to refer to the Children and Adolescent Mental Health Service (CAMHS). Where a Learning Disability is also suspected, a referral into the Child Development Centre (CDC) may be appropriate – this will usually be picked up quite early on by your health visitor. The NDT will not assess children who are referred to the CDC.

### 2. What is the Neurodevelopmental (ND) team?

This is a relatively new team which was set-up to aid the waiting list and processes involved for families pursuing a neurodevelopmental assessment for their child. They are able to assess for Autism, ADHD and Foetal Alcohol Syndrome Disorder – this can be done as part of one assessment rather than waiting on different lists for separate assessments. The ND team also work closely with other health professionals (Speech and Language Therapists etc.) to provide the diagnostic assessments and provide support while on the waiting list. They will also work closely with CAMHS.

### 3. What options do I have if the school feel unable to put forward my child for an assessment?

We are aware that children can present very differently in a variety of contexts. This can be as a result of 'masking', or anxiety. If your child does not present with the same behaviours or concerns within school as noted at home, it may be more appropriate to consult your GP regarding a referral for neurodevelopmental assessment. Again, it is useful to record your concerns in some way and take these with you to your appointment. Specific examples will be useful to assist the GP with the referral.

#### 4. What supports are there in EDC for families on the waiting list?

- The Local Area Co-ordinators (LACs) run a monthly parent and carer forum for families to get some peer-support and share advice and knowledge, including hearing from guest speakers about local services and also sending out a digital 'ASN newsletter'. This can be accessed by families who are supporting a person of any age and any stage of the diagnostic process. To be added to the mailing list, send your email address to the LAC team – LACs@eastdunbarton.gov.uk
- Creatovators also run information sessions throughout the year called 'You Are Not Alone' for families of an autistic person (or on the assessment waiting list https://creatovators.com/news-events/.
- You can also still get support from Carers Link if the person has not received their diagnosis
  yet. As well as offering 1:1 support you can also access the 'Supporting Autism and
  Neurodiversity' training for families <a href="https://carerslink.org.uk/">https://carerslink.org.uk/</a>
- If you live in the Kirkintilloch area and care for someone in P6-S2 then you may be able to access the new Young People's Local Area Co-ordination service which is funded through the Whole Family Wellbeing Fund. Contact: <a href="mailto:Ashleigh.Grant-ng@eastdunbarton.gov.uk">Ashleigh.Grant-ng@eastdunbarton.gov.uk</a>
- There are also some new services which have been introduced as part of the 'Whole Family Wellbeing Fund'. For more information about what services are on offer contact: <u>Elisabeth.Faulks@eastdunbarton.gov.uk</u>

# 5. What options do I have if I disagree with the outcome of the diagnostic assessment? Speak with the practitioners within the service who have competed the diagnostic paperwork. Each service will have their own way of raising a complaint or a comment. You could also request independent advocacy – *Partners in Advocacy*' is an advocacy agency who offer advocacy support to adults, children and young people - <a href="https://www.partnersinadvocacy.org.uk/">https://www.partnersinadvocacy.org.uk/</a>.

### 6. Are private diagnostic assessments accepted by health professionals?

Advice from the ND team is that private assessments should be accepted, as long as they meet national standards (ie. NICE guidelines) and local standards for NHS Greater Glasgow and Clyde. Some private assessment centres do <u>not</u> meet these standards, therefore their assessment outcome would not be accepted by health professionals. If you are considering pursuing a private assessment, do some research into the most appropriate assessment centres to ensure that they follow agreed procedures.

### 7. My child received their autism diagnosis - what support is now available?

You can contact the Local Area Co-ordinator team to get some advice about what local services you can access. They will be able to put you in touch with the right teams depending on your situation – LACs@eastdunbarton.gov.uk

# 8. If my child receives an autism diagnosis does this mean that they will be able to receive social work input?

The Local Area Co-ordinators can provide you with more information about social work services in EDC – LACs@eastdunbarton.gov.uk

#### **Education**

1. What support is available within Education (including specialist provisions)? Should you have concerns about any areas of your child's development or education, it would be important to highlight this to the school/EYC in the first instance. They may wish to arrange a Team Around the Child (TAC) meeting in order to discuss this with you. Your child may require a Wellbeing Assessment or Action Plan to allow for targets to be identified and appropriate strategies to be implemented. There will be regular monitoring of their progress throughout this process. The school may request permission from you to discuss your child at their Pupil Support Group (PSG) which is typically attended by the school and Educational Psychologist (EP). The EP can provide consultation and advice to the school, which can be fed back to you. In some cases, it may be appropriate for the EP to become more involved, and a referral can be made to this service via the school following discussion at PSG. In these cases, the EP would meet with you through the TaC meeting process and may gather assessment information to support the identification of appropriate strategies.

The school can make a referral to the Locality Liaison Group (LLG) to access wider supports within EDC. These may include Language & Communication Outreach, Wellbeing Outreach or Outdoor Education. If the TAC are in agreement, a referral to the GIRFEC Liaison Group (GLG) can be made. This group will consider the child's profile of need and may recommend that their needs can be met within a specialist placement (Enhanced Learning Resource, Primary or Secondary Wellbeing Support Service, or standalone provision).

Please see the 'Including Every Learner' (IEL) policy for more details – can be found on the EDC website.

# 2. What are my options if I disagree with a decision about specialist education services for my child?

If your child is referred to GLG you will receive an outcome letter via email when the decision has been made. The letter will detail the process of requesting a review of the GLG decision should you be unhappy about the decision that has been made.

## 3. How can I request a meeting with the school to discuss concerns I have about my child?

You can request a meeting with the school at any time. There will be an ASN Lead in all schools who may be best to discuss your concerns with. If your child has involvement from other agencies e.g. Educational Psychology, Occupational Therapy, Speech and Language Therapy, etc. it may be appropriate for the school to organise a Team Around the Child (TAC) meeting with the relevant professionals and yourself to discuss concerns and appropriate supports.

#### 4. Can I access any advocacy services for my child for matters relating to school?

• *'Partners in Advocacy'* is an advocacy agency who offer advocacy support to adults, children and young people - <a href="https://www.partnersinadvocacy.org.uk/">https://www.partnersinadvocacy.org.uk/</a>.

- 'My Rights, My Say' is a service specifically for 12-15 year olds who need advocacy for issues relating to school <a href="https://www.partnersinadvocacy.org.uk/my-rights-my-say/">https://www.partnersinadvocacy.org.uk/my-rights-my-say/</a>
- Also, 'Carers Link' can provide advocacy support for meetings in school, however this is advocacy for the parent and not the student - <a href="https://carerslink.org.uk/carers-advocacy/">https://carerslink.org.uk/carers-advocacy/</a>
- 'Govan Law' have an Education Law unit https://govanlawcentre.org/education-law-unit/
- 'Cairns Legal' also offer legal advice relating to education law https://www.cairnlegal.co.uk/education-law.html

### 5. How can I request an enhanced transition for my child?

Each establishment will have their own processes for organising enhanced transition. It is best to contact your child's directly to discuss how they can best support your child through the transition process. The Scottish legislation regarding enhanced transitions for children with Additional Support Needs can be accessed here: <a href="https://www.gov.scot/publications/supporting-childrens-learning-statutory-guidance-education-additional-support-learning-scotland/pages/7/">https://www.gov.scot/publications/supporting-childrens-learning-statutory-guidance-education-additional-support-learning-scotland/pages/7/</a>.

### 6. Where can I get additional advice about legal rights relating to education?

- Enquire <a href="https://enquire.org.uk/">https://enquire.org.uk/</a>
- National Autistic Society https://www.autism.org.uk/advice-and-guidance/topics/education
- Education Scotland 'Parent Zone' <a href="https://education.gov.scot/parentzone/">https://education.gov.scot/parentzone/</a>

#### **Other**

#### 1. Is there any guidance on how to tell a child that they are autistic?

There is no set guidance on this, as it is a very personal to your child and what is most appropriate for them. Recent conversations with EDC parents and also local autistic residents have highlighted that it was best for them to have the conversation early, rather than wait until the person is older. It was shared that this helped the young people to better understand themselves as they were growing older, as well as making it easier for the parents to have conversations with their child about any additional supports that they might need compared to their peers. There are a number of books which help explain autism to a young person which may be helpful to use (ie. 'The Superhero Brain', 'My Awesome Autism', 'Wonderfully Wired Brains', 'What Autism means to me' and 'Being Autistic, and what that actually means')

#### 2. Where can I find out about what social groups are available in EDC?

https://www.eastdunbarton.gov.uk/health-and-social-care/disability-services/additional-support-needs-activity-groups (or Google search 'East Dunbartonshire ASN activity groups')

### 3. Are there any supports available for families dealing with behaviours that challenge within the home?

Heather Wright is a local autism specialist who runs training and 1:1 support for EDC parents and carers. Her (free) 'Supporting Autism and Neurodiversity' training has been accessed by a number

of local families and has been very positively received. This training is a 6 week block covering a range of topics relating to supporting someone who is Neurodivergent, including a session specifically on 'Arousal and Behaviour issues, causes and support'. Once you have completed the core modules, you can access other tag-on training sessions as well as the 1:1 support from Heather to discuss specific topics - <a href="https://carerslink.org.uk/carers-autism/">https://carerslink.org.uk/carers-autism/</a>

### 4. What is the procedure for prescribing melatonin for a young person?

This must be done by a paediatrician and not a GP. Have a conversation with your GP in the first instance for them to refer you on to a specialist paediatrician.

# 5. Where can I find out about local services in EDC which might be useful for me and my family?

https://health.eastdunbarton.gov.uk/services/a-z-of-services/disabilities/autism-spectrum-services/ (or Google search 'East Dunbartonshire Autism Spectrum Services')

6. Who can I speak to within East Dunbartonshire if I have got questions about services available to my family, or to get advice about any issues that we are experiencing?

The Local Area Co-ordinators (LACs) offer signposting and information-sharing to families who have a child on the autism spectrum, or on the assessment waiting list. They also offer closer 1:1 support to those with a formal diagnosis over the age of 14. You can get in touch with the team at any point if you have any questions and they will do their best to either help you themselves, or put you in touch with the most appropriate team – <u>LACs@eastdunbarton.gov.uk</u>

### 7. Where can I get more information about national services?

- Scottish Autism Advice Line <a href="https://www.scottishautism.org/services-support/support-individuals/autism-advice-line-01259-222-022">https://www.scottishautism.org/services-support/support-individuals/autism-advice-line-01259-222-022</a>
- National Autistic Society https://www.autism.org.uk/
- National Autism Implementation Team <a href="https://www.thirdspace.scot/nait/">https://www.thirdspace.scot/nait/</a>