Post Diagnostic Support for children on the Autism Spectrum

The information below relates to children on the Autism Spectrum in East Sussex, following their diagnosis. This information applies from preschool to adolescence and support is signposted according to the age of the child/young person.

Advice offered:

- Post diagnosis information is given through appropriate written information or during a post diagnostic, follow-up appointment.
- Other support services may become involved targeted to the child’s needs.

Support available:

- **Post diagnostic clinic appointment** or individual appointment (depending on area): Within 6 weeks of the diagnosis an appointment with a specialist community nursery nurse will be offered. This is an opportunity to talk through the diagnostic findings and any concerns/questions. Information about a range of services and support groups will be supplied. This appointment usually lasts between one hour and one hour and a quarter.

- **EAST SUSSEX LOCAL OFFER for parents on all matters relating to autism:**
  Helpful information for parents about East Sussex autism services and useful links to support groups and other organisations

- **County-wide behaviour support groups for parents** on a rolling programme run by the Child Development nursing team and covering:
  - Sleep issues
  - Eating
  - Toileting
  - Behaviour

  For further information contact:
  01323 417400 extension 4850 (Scott Unit, Eastbourne) or 01424 755255 extension 8378 (Conquest Hospital, Hastings) email: esht.communitypaeds@nhs.net
• **CLASS+** works across East Sussex to support families/carers of young people on the autism spectrum. It sits within the East Sussex Inclusion Special Educational Needs & Disability (ISEND) team. **CLASS+** aims to provide support and training that enables families/carers to build their understanding of the strengths and challenges faced by children and young people on the autism spectrum and so develop greater confidence to support them.

**CLASS+** offers three levels of support:

**Tier 1**: weekly advice line, signposting to services, coffee mornings

**Tier 2**: training for parents; including post diagnostic sessions, next steps (a continuation from the post diagnosis stage), workshops covering parent identified issues such as: Autism and girls, e-safety, puberty, enskilling the wider family

**Tier 3**: time-limited, outcome focused home-based support around a specific issue.

In addition, at diagnosis or at the post diagnostic appointment, parents/carers will be given the option for their details to be passed to **CLASS+**. If parents/carers choose to take this opportunity, a member of **CLASS+** will then contact them to introduce the service, and will enter their details on a database. This enables families to be sent information on training, parent support groups and regular information on future developments.

**Contact**:  **CLASS+** 01273 336887 class@eastsussex.gov.uk

• **SPECTRUM**:

The Spectrum Service was established in 2008 and operates across East Sussex providing support to children and young people aged 0-19 years with Autism, and their families. Spectrum supports these children and young people to independently access their community, access clubs and learn everyday skills in peer group settings. The aim is to give children and young people with autism the same opportunities and experiences as their peers. Spectrum offer a range of training options available to clubs, groups, parents, schools and other professionals.

**Options Include**:

- Individual support including direct support to access clubs (including sports, social, creative and craft); guidance for travelling (catching a bus, train, plane, boat or walking to school/college); help to access every day activities (behaviour in public, meeting people, getting a haircut, home safety, personal safety, stranger danger); preparation work for health visits (hospital, doctors, dentist); support to access social events (pubs, restaurants, shopping); general life skills (applying for jobs, paper work, CV, work experience); guidance for family outings (preparation, behaviour management, trip planning).
- Autism specific information on attractions in East Sussex (Knock Hatch, Drusilla’s, Sheep Centre)
- A range of autism specific training courses
• Group/Peer sessions via the Spectrum Skills Award programme. Spectrum Skills Award (SSA), a development programme for young people at age 10yrs – 19yrs. The programme is designed as a series of twelve; six week skill building programmes that enable young people with Autism to explore, discuss, prepare for and practice life skills that enable them to actively participate in their communities, build relationships, prepare for adulthood and support other young people. The safe environment gives them the opportunity to develop social skills, build friendships and discover how autism affects them personally.

All services attract a fee. Details available upon request: spectrum@eastsussex.gov.uk or 01424 724700

• Sussex Coast College Hastings:

The group is for parents and young people with autism, to be part of a safe, supportive network. To start with, the group will meet once a month from 6pm until 9pm. Day to be confirmed.

The college is offering to provide a place for parents to meet and socialise, with refreshments, while their young people are also engaging in meaningful activities. This group will give parents the chance to provide support to each other by offering advice, a chance to talk about experiences, relax over a cup of tea and a slice of cake!

Parents will able to access some of the college’s facilities while their child/children are taking part in their own activities. You may like to try the gym, have some beauty treatments or maybe getting a haircut.

The young people with autism attending the college will be able to socialise with friends, meet new people, have some refreshments and enjoy lots of fun activities. This could be playing pool, arts and crafts, listening to music, playing video games or maybe watching a movie.

Contact: Lesley Watson, Head of Supported Education, Sussex Coast College, Hastings, TN34 1BA. Tel. 01424 458551 LWatson@sussexcoast.ac.uk

• Triple P parenting support:

This is a parenting intervention with the main goals of increasing the knowledge, skills, and confidence of parents and reducing the prevalence of mental health, emotional, and behavioural problems in children and adolescents. There are a variety of programmes for parents/carers depending on the needs of the family and child.

Seminars: short 1.5 hour sessions on topics like: the power of positive parenting, raising confident competent children, raising resilient children
Discussion groups: 2 hour sessions on topics like: developing good bedtime routines, hassle free shopping, managing fighting and aggression
Group Triple P: parents meet for 2 hours for 5 sessions
1:1 support: short sessions to discuss the challenges parents may be having with their children

Contact: telephone: 01424 725800 email: tripleteam@eastsussex.gov.uk Facebook: @ParentingEastSussex.
SEN and disability advice service

Impartial advice and support for children and young people with special educational needs and disabilities (SEND) aged up to 25 their parents and carers

Contact:
Phone us on 01273 337711
Email: Advice@eastsussex.gov.uk
Website: https://www.eastsussex.gov.uk/childrenandfamilies/specialneeds/send-information-advice-support-service/

I Go card:

i-go is a free cardholder scheme for children and young people (aged 0-25) with special needs and disabilities (SEND) across East Sussex. i-go aims to improve access to leisure facilities by:

- Providing information about each leisure partner including information about specialist equipment, fast-track queuing, noise, lifts and toilets.
- Special i-go rates - most leisure partners are offering special rates for i-go cardholders and their families.
- Helping with planning - a named i-go champion who can be contacted with queries before and during a visit.
- Offering i-go leisure partners (organisations who have joined the scheme) Disability Awareness training.

There are over 85 leisure partners offering hundreds of activities including leisure centres, theatres, soft play areas, clubs and much more!

Contact: https://www.eastsussex.gov.uk/childrenandfamilies/specialneeds/i-go-leisure-card/young-people/

Specialist therapy services:

Specialist occupational therapy, speech and language therapy and physiotherapy services are via referral to East Sussex Children's Integrated Therapy Service (ESCITS). If you would like to find out more about this service please check our referral guidance booklet or ring us on 0300 123 2650
Charities that can help:

**National Autistic Society (NAS):** a good starting point for information about autism

For a comprehensive list of A-Z information sheets from the NAS:

**Autism Sussex:** Autism Sussex is a charity which exists to enable people on the autism spectrum to receive the help and specialist support services they and their families need.

Financial help that may be available:

- **Disability Living Allowance for children aged under 16 years (DLA):**

  DLA is a benefit paid for children who need additional care or supervision because they have a disability or health condition. It is awarded based on the mobility and care needs of a child and is not based on having a diagnosis.

  Having a diagnosis of Autism does not automatically entitle you to the benefit, however many children with a diagnosis of autism spectrum do qualify for DLA. You can make a claim for DLA before receiving a formal diagnosis of Autism.

  For more information on DLA and how it is awarded see:


  For an application form by telephone: 08457 123 456

- **For children aged 16+ years, DLA becomes a Personal Independence Payment (PIP).** If you are already receiving DLA, you will be notified that DLA is coming to an end and information on how to apply for PIP will be included. For new claimants, you will find information at:

Disabled Facilities Grant:

You could get a grant from your council if your child is disabled and need to make changes to your home, for example to:

- widen doors and install ramps
- improve access to rooms and facilities - e.g. stair lifts or a downstairs bathroom
- environmental adaptations to support safety while in the home
- adapt heating or lighting controls to make them easier to use

An Occupational Therapist will usually visit you at home to assess what adaptations are likely to be necessary and advise on completing the application.

Further information can be found at:

https://www.gov.uk/disabled-facilities-grants/overview


We would like to thank the parent carers from iContact (www.icontactautism.org) for their time and energy coproducing this leaflet.