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CAMBRIDGESHIRE

AUTISM

GUIDANCE

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Contents

Introduction

This document has been written to provide guidance to professionals and parents on the most current approaches and interventions used to support children and young people with autism to fulfil their potential. The document forms part of the wider Cambridgeshire Local Offer which covers information on the local provision for Special Educational Needs (SEN) and Disability.

For parents and carers who have received a diagnosis of autism or social communication difficulties for their child and are looking for further information, help and support, Cambridgeshire Community Services NHS Trust have some online learning sessions on their website Introduction to Autism Online Learning

A note on terminology

Terms that have been used to talk and write about autism include the following: autism spectrum disorder (ASD); autism spectrum condition (ASC); atypical autism; classic autism; Kanner autism; pervasive developmental disorder (PDD); high-functioning autism (HFA); and Asperger syndrome.

Research conducted by the National Autistic Society (NAS), the Royal College of GPs and the UCL Institute of Education in 2015 sought to elicit the views and preferences of UK autism community members about the terms they use to describe autism. Whilst the findings demonstrate that there is no single way of describing autism that is universally accepted and preferred by the UK's autism community, the most highly endorsed terms were **'autism'** and **'on the autism spectrum'**. Consequently, these are the terms that SEND Services in Cambridgeshire use.

Pathological Demand Avoidance (PDA)

A subgroup that has been suggested as part of the autism spectrum is Pathological Demand Avoidance (PDA). This was first suggested by Professor Elizabeth Newson (Newson *et al*., 2003). As an experienced clinician she identified a group who were similar to those with autism but who were much more avoidant and did not appear to respond to some of the educational approaches found to be effective in autism.

Since that time, clinicians and researchers have been attempting to establish whether there are clear and distinct differences between PDA children and those with autism. As yet, there is insufficient evidence and PDA has not met criteria for acceptance as a separate diagnosis (MacKay *et al*., 2018). Consequently, whilst Cambridgeshire SEND Services recognises that demand avoidant behaviour can be part of an autism spectrum profile, and that different strategies have been found to be effective with these children and young people, we do not use the term PDA. This position is aligned with that of our health colleagues working in Cambridgeshire Community Services NHS Trust. That said, where a diagnosis of PDA *has* been made by an appropriately qualified health professional, or where a young person self identifies as PDA we will be respectful of that. We acknowledge that different strategies have been developed for children and young people with a demand avoidant profile and there is a website developed by the PDA society which gives details of effective resources developed for this group: www.pdasociety.org.uk

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What is autism?

Autism is a developmental condition affecting the way the brain processes information. It occurs in varying levels of severity and is a lifelong condition; autistic children become autistic adults. To be given a diagnosis on the autism spectrum, there must be evidence of difference (from typical development) in the following core areas, and that the individual's everyday life has been and continues to be affected by these:

1. social communication and interaction (including non-verbal communication and the ability to use and understand body language, eye contact, facial expression and gestures; and the development and maintenance of friendships and relationships)
2. restricted and repetitive patterns of behaviour, interests or activities (including repetitive speech or movements; adherence to routines or resistance to change; or intense interests) sensory perception and responses.

The **causes** of autism are still being investigated. There is strong evidence to suggest that autism can be caused by a variety of physical factors, all of which affect brain development – it is not due to emotional deprivation or the way a person has been brought up.

There is evidence to suggest that genetic factors are responsible for some forms of autism. Scientists have been attempting to identify which genes might be implicated in autism for some years. Autism is likely to have multiple genes responsible rather than a single gene. The difficulty of establishing gene involvement is compounded by the interaction of genes, and by their interaction with environmental factors. For these reasons genetic testing to diagnose a pre-disposition to an autistic spectrum disorder is not, at present, possible.

There is no known **'cure'** for autism and the concept of a cure is controversial for some people on the autism spectrum and their families. However, there are many approaches and forms of support which can help people with autism to manage their condition and fulfil their potential.

Autism is a spectrum condition which means that while all autistic people share certain difficulties, being autistic will affect them in different ways. In addition, like all children and young people, individuals with autism will vary in terms of their intellectual ability, their personality, the presence of other conditions, (for example learning disability, ADHD, epilepsy) and their life experiences. All cultures, races, ethnicities and genders are represented within the population of those diagnosed with autism.

What should all schools be doing to support children and young people with autism?

Good quality education for all children and young people with autism

It is the position of SEND Services in Cambridgeshire that the underpinning ethos and values of developing good quality education for all children and young people with autism must focus on the need for mutual adaptation on behalf of the individual with autism *and* those who live or work with them. Parents and education professionals must reflect on the dynamic relationship between the individual and those around them, understand the way the individual processes and experiences the world, and find ways to give the individual with autism control over their learning.

Linked to this, we believe that the performance and actions of an individual with autism depend very much on their context. One can create a learning environment where the child or young person feels uncomfortable, anxious and excluded or one where they feel relaxed, included and confident. The types of environment created for typically developing pupils are often very difficult for children with autism to operate within. Without knowledge of autism generally, and knowledge of the individual with autism specifically, teaching staff and others can unwittingly create problems.

A framework

A 2019 report commissioned by the Autism Education Trust (AET) and written for education practitioners reviewed the research evidence, current policy documents, expert opinion, and statutory guidance as well as gathering accounts of autistic individuals. Eight key principles emerged for providing a framework for the development of good quality education for all autistic children and young people:

1. Understanding the strengths, interests and challenges of the autistic child and young person.

2. Enabling the voice of the autistic child and young person to contribute to and influence decisions.
3. Collaboration with parents and carers of autistic children and young people.
4. Workforce development to support autistic children and young people.
5. Leadership and management that promotes and embeds good autism practice.
6. An ethos and environment that fosters social inclusion for children and young people on the autism spectrum.
7. Targeted support and measuring progress of children and young people on the autism spectrum.
8. Adapting the curriculum, teaching and learning to promote wellbeing and success for autistic children and young people.

From Guldberg, K., Bradley, R., Wittemeyer, K., Briscombe, J., Phillips, C. and Jones, G. (2019) 'Good Autism Practice: Full Report' London: Autism Education Trust.

School auditing tool

Autism friendly policies in schools and settings are most effective when they form part of the whole school development plan and when progress towards the goals and targets on the plan are regularly monitored. A tool freely available to all schools and educational settings for assessing and developing their own good autism practice is the **AET Autism Standards** (AET schools autism standards – Autism Education Trust). The standards are a set of 40 statements which reflect good practice for those on the autism spectrum. For each standard, the user can evaluate the extent to which this standard is in place in their school or setting, using the ratings: 'not appropriate', 'not yet developed', 'developing', 'established' or 'enhanced'. Each standard is linked to resources which demonstrate examples of how a school or setting might achieve and evidence the standards.

Using SPELL

The National Autistic Society has developed a framework called SPELL, to assist professionals in understanding and responding to the needs of individuals with autism. SPELL stands for Structure; Positive; Empathy; Low arousal; and Links.

Schools in Cambridgeshire are encouraged to use the SPELL framework as outlined below.

Structure:

- Introducing **timetables** will help the child to predict what's happening next, and to tell them about any changes to the usual routine. Use **timers** to clearly label how long an activity will last.
- Ensure all planned activities are achievable. Explain tasks in **small manageable chunks** with a clear start and end point.
- Use **visual cues** (symbols and pictures) to support a child's understanding of an activity.
- Provide structure in **unstructured times**, for example, offer choice boards and structured games at lunch time and playtime. Limit choices, making them clear to avoid any confusion.
- Structure your **communication**. Use the child's name first to obtain their attention before giving an instruction and allow the child time to process this before moving onto the next. Use **language** that is clear, precise and concrete.
- **Colour code work sets**, for example, colour all science books blue and label all science equipment with a blue sticker to enable the child to organise themselves more independently.

Positive:

- Ensure **expectations are realistic** and individual to the child. All work given must be achievable to ensure continued motivation and success.
- Use **rewards** and **motivators** to ensure positive behaviour is continued. Use a low arousal (dead pan) response when dealing with unwanted behaviours.

- Maintain **consistency** when dealing with behaviour that challenges through the use of behaviour support plans. Provide **positive alternatives** to behaviour, for example, allow the child to use a time out when he/she becomes anxious in class.
- Identify and use a pupil's **strengths** or **special interests** when planning activities.
- Build **self-esteem** by creating opportunities for pupils to develop independence, have responsibility and make a contribution to a group.

Empathy:

- Develop a **pupil profile** to increase staff understanding of an individual child. Include triggers to behaviour, phobias, motivators and anxieties. Include a **sensory profile** to understand which stimuli are highly sensitive. Share this information with all school staff likely to come into contact with that child, including lunchtime assistants and school caretakers, to try to avoid situations which may lead to distress.
- **Educate** staff and peers through training and strategies such as "circle of friends".
- Offer **practical help** for problem areas such as social scripts and understanding social rules.
- See **behaviour** as a means of communication – what is he/she trying to tell me?
- Ensure **actual comprehension** has been achieved – understanding may be masked by learned phrases or echolalia. Use communication strategies such as visual supports to assist this.

Low arousal:

- Check **environment** for potential distractions specific to the individual (flickering lights, strong smells, noises)
- Create a **workstation** or space free from distractions for work tasks or learning new or complex skills.
- **Filter out** irrelevant stimuli, for example, unnecessary illustrations on worksheets.

- Use **resources** to address individual needs (ear defenders to block out sounds when working, tangle toys, weighted blankets etc).

Links:

- Ensure **parents** are involved throughout the process to help monitor progress and review targets. Share information through home school books and draw up behaviour support plans together. These can then be used consistently across home and school.
- See the child themselves as a **partner** in the education process and consult with them and their parents on developments.
- Ensure all **staff** are informed of support strategies and current issues.
- **Share** information with other professionals such as Speech and Language Therapists, Occupational Therapists, Educational Psychologists and so on.

Workforce development

Autism friendly schools recognise that teaching staff, as individuals, are key to the success of students overcoming their difficulties. It is therefore important that all staff working in schools complete a basic level of autism awareness training, and that staff working directly with children and young people with autism are trained to understand and meet the needs of learners on the autism spectrum. This could be achieved through school staff attending a course about autism, whole school INSET, or training from an external agency including SEND Services 0-25.

Since 2013 Cambridgeshire County Council has been an Autism Education Trust (AET) training partner, holding a license to deliver their modular training programmes for professionals in educational settings including Early Years settings, schools, and Post-16 settings. The AET is a 'not for profit' programme led by two national autism charities – the National Autistic Society and Ambitious about Autism. Established and supported by the Department for Education (DfE) the AET training modules form part of the enhanced support that schools and settings in Cambridgeshire can purchase from SEND Specialist Services. Under the current time allocation model, schools may wish to use their Specialist Teacher or Educational Psychology hours to 'fund' training. Alternatively, schools, Early Years settings and Post-16 providers can

purchase training for their settings, or send individual members of staff to the open courses held throughout the year (schools should contact their Link Educational Psychologist / Specialist Teacher or see the SEND Traded Booklet for further details and costs). To book AET training contact the Bookings and Courses Team at SEND.Training@cambridgeshire.gov.uk.

A tool freely available to practitioners in schools and educational settings for assessing and developing their own good autism practice is the **AET Autism Competency Framework** (AET schools autism competency framework – Autism Education Trust). The framework is designed to be used as an ongoing self-reflection tool to help focus staff on which aspects of their autism practice require further developments. Its format enables practitioners to rate their knowledge, skills and personal qualities against a set of 58 descriptors outlining best practice that is recognised and valued by individuals on the autism spectrum, their families and professionals. The 58 competencies are each linked to web resources and articles to support the self-reflection process and further development in that area.

It is recognised that while most of the needs of individuals with autism will be met through good quality education, some children and young people will require more personalised support. This may involve seeking specialist advice, and/or the use of specific interventions or approaches that have been identified as likely to be most effective in meeting an individual's needs. This will be explored further in the next section.

IN SUMMARY a checklist for schools and settings working to provide good quality education for all children and young people with autism:

- ☑ Implement the 8 key principles identified by the 2019 Good Autism Practice Report (pages 7 and 8)
- ☑ Audit your school using the AET Autism Standards
- ☑ Implement the SPELL framework (pages 9 to 11)
- ☑ Train your staff to understand and meet the needs of learners on the autism spectrum.

Approaches and Interventions

As specified in the 2015 SEND Code of Practice, decisions about which approaches or interventions to use will be informed by effective cycles of Assess, Plan, Do, Review as well as by the insights of parents and of the young people themselves. Education professionals must *'ensure that the approaches used are based on the best possible evidence and are having the required impact on progress.'* (SEND Code of Practice 2015, p.25).

Overviews of the research into autism interventions conclude that there is no evidence to suggest that any single approach is superior to any other for all children and young people on the autism spectrum, or that a single approach will meet the needs of all learners *(Parsons et al. (2011).* Research reviews have shown that there is insufficient evidence to make strong claims about specific programmes, as there are many variables that can influence outcomes. Expert views therefore indicate that a range of approaches are needed in order to suit and address individual needs and preferences. (*Bond, C. et al. (2016)*

Some interventions are designed to address the core features of autism (persistent difficulties with social communication and social interaction, along with restricted, repetitive patterns of behaviour, interests, or activities) whilst other interventions are designed to address other issues frequently associated with autism (such as anxiety, aggression or self-injurious behaviour).

When considering which areas of need to target with intervention it is important to be mindful of an alternative conceptual framework arising from activism on the part of people with autism and their supporters: **neurodiversity** (Mackenzie, 2011). From a neurodiversity perspective, it may be appropriate to treat certain aspects of autism when these are experienced as *impairments* (such as developing skills needed to read social cues) but to refrain from intervening in those behaviours that are atypical, but *not* experienced as impairments (such as intense focus on single activities or placing objects in patterned arrangements). Support and management of children and young people with autism may thus involve implementing strategies to alleviate

disadvantage using autism-specific strategies and modifying the environment while respecting difference. This perspective chimes with the social model of disability, in which the emphasis is placed on how appropriately the wider physical and social environment adapts to individual difference, rather than viewing the differences of individuals as solely medical problems to be 'treated' (NICE Clinical Guideline, 170)

In March 2018 Research Autism and the Westminster Commission on Autism* reported on their inquiry into the issue of harmful interventions for people with autism. The findings enabled them to publish some **recommended principles for choosing an intervention**:

1. The intervention is based on a good understanding of autism.
2. The people who deliver the intervention know the person well and respect their feelings and views.
3. The person's capacity for consent is taken into account.
4. The intervention is adapted to the needs of the person receiving it.
5. The intervention is based on a theory that is logical and scientifically feasible.
6. Research evidence shows the intervention can work for people on the autism spectrum.
7. The intervention works in the real world, not just in a research laboratory.
8. The intervention is delivered by, or supported by, appropriately qualified and experienced professionals.
9. The people delivering the intervention follow established guidance.
10. The intervention is carefully monitored and reviewed on a regular basis.
11. The intervention provides significant benefits.
12. The intervention does not cause significant physical or emotional harm.
13. The benefits outweigh any costs (including risks).
14. The intervention is good value for money and time invested.

** Until 2017 Research Autism was a charity funding research to identify and increase understanding about the best interventions for autistic people and their families. It continues to be an information service working as part of the National Autistic Society to provide up-to-date, scientifically reliable information about autism. The Westminster Commission on Autism is an independent, cross-party, cross-sector*

coalition of autistic individuals, parent-advocates, Parliamentarians and leaders from the autism 'sector'.

What follows is not intended to be an exhaustive list of approaches and interventions for meeting the needs of children and young people on the autism spectrum. Rather, it is an overview of the approaches and interventions commonly used by schools and settings in Cambridgeshire, and/or endorsed by SEND Services.

Attention Autism

Attention Autism is an intervention designed by Gina Davies, Specialist Speech and Language Therapist. It aims to develop natural and spontaneous communication using visually based and highly motivating activities. The primary objective is that the sessions are fun and offer children and young people an irresistible invitation to learn. The main aims of Attention Autism are to improve joint attention; to develop shared enjoyment in group activities; to increase attention in adult-led activities; and to increase non-verbal and verbal communication.

There is emerging research evidence that children participating in Attention Autism three times a week make significant gains in their joint attention skills, and in their attention for adult-directed activities. *(Courtman, S. 2018).* However, currently this research is limited.

Although Attention Autism is most used with Early Years and Key Stage 1 children, it can be adapted for use with children and young people of all ages.

Attention Autism *activities* (sometimes called 'Bucket Therapy' or 'What's in the Box?') are already being used in many Early Years settings and schools in Cambridgeshire. For further information and advice on how to use these activities, schools and settings should contact SEND Services 0-25.

In order to be able to set up and run the four stage Attention Autism programme in a school or setting, practitioners need to complete training. For further information see https://ginadavies.co.uk/parents-services/professional-shop/

Cognitive Behavioural Therapy (CBT)

Cognitive Behavioural Therapy (CBT) is a psychological intervention for mental health difficulties such as anxiety and depression. It is based on the idea that how we think, how we feel, and how we act, affect each other.

CBT uses techniques to help people become more aware of how they reason, so that they can change how they think and therefore how they behave.

CBT is likely to work only for those individuals who have both the capacity and the preference for monitoring and managing their own behaviour. It is therefore more likely to work for individuals with autism who are more than 8 years old without significant learning difficulties. There is good evidence to show that adapted CBT for anxiety can be helpful for anxious young people with autism.

The National Institute for Health and Care Excellence states that CBT programmes might be appropriate for the treatment of anxiety and depression in people on the autism spectrum provided that the therapists providing CBT are appropriately trained. They should also follow established best practice which includes

- Carrying out a detailed assessment of the individual, including any key strengths and weakness.
- Modifying the therapy to take account of the needs of that individual, including any strengths and weaknesses.
- Use of a longer assessment phase and an increased number of treatment sessions to help the initial engagement with the therapist, to enhance emotional literacy, and to practice, consolidate and generalise the techniques learnt.
- Using a range of appropriate measures to evaluate the effectiveness of the therapy.

CBT resources adapted for children with autism which schools can use

The CAT Kit - The CAT (Cognitive Affective Training)-kit provides a visual structure that can be used to reflect on and communicate personal experiences, and identify thoughts and feelings. The kit is currently available to buy as a printed version and as a digital app.

Exploring Feelings - clinical psychologist Dr. Tony Attwood has written two programmes: one targeting anger, and the other targeting anxiety. Each programme consists of six 2-hour sessions for individuals or small groups of children aged 9 to 12 years.

The Homunculi Approach – book: *The Homunculi Approach to Social and Emotional Wellbeing A Flexible CBT Programme for Young People on the Autism Spectrum or with Emotional and Behavioural Difficulties* by Anne Greig and Tommy MacKay offers a 10-week programme for individuals or groups aged 7 and up.

Zones of Regulation - the Zones of Regulation curriculum aims to help students gain skills in the area of self-regulation. Self-regulation is also described as self-control, self-management and impulse control. The Zones of Regulation curriculum uses lots of visual resources and teaches students to recognise which zone they are in. It also equips them with strategies to change or stay in the zone that they are in. It comprises 18 lessons and can be used for children aged 7 years and up, individually or in small groups of up to six.

Identiplay

An intervention designed to help children on the autistic spectrum, and those with specific communication disorders, learn to play using a parallel copy-and-play model with set play scripts. The approach aims to promote development of social skills, understanding, imagination and exploration. Based on the book: 'Teaching Play to Children with Autism: A Practical Intervention Using Identiplay' developed by Philips & Beavan. For an example of Identiplay watch this short video: Identi-play activity - YouTube

Intensive Interaction

Intensive interaction is an approach developed by Dave Hewett and Phoebe Nind who are teachers at a special school. It is a non-directive approach for children who are at an early stage of communication and who do not yet have consistent, intentional communication. It aims to teach and show children that it is enjoyable to be with, and interact with, other people.

Intensive interaction is a positive approach that can be used throughout the day, in most teaching and home environments. It starts from what the child can do and how they currently explore the world, so the starting point and ways of interacting are already familiar to the child. It has been used successfully with children of all ages, from infants to adults. The approach can be used by any adult working with the child including teachers, parents, teaching assistants, carers, and therapists.

When using an intensive interaction approach the child takes the lead and the adult responds to their movements and noises in a way that they understand, using noises or actions in their known repertoire. This response can often be through mirroring. This can lead to several enjoyable interaction sequences between the child and the adult. There is no aim or objective within the session, it should be fun. Studies have shown that over time children begin to demonstrate more of the 'fundamentals of communication' as their world and awareness of it widens.

Further information can be found here; https://www.intensiveinteraction.org/.

Picture Exchange Communication System (PECS)

The Picture Exchange Communication System (PECS) is a form of augmentative and alternative communication in which a child is taught to communicate with an adult by giving them a card with a picture on it. PECS is based on the idea that children who are non-verbal or with limited functional speech can be taught to communicate using pictures. The adult begins by teaching the child to exchange a picture of an item she wants. For example, if the child wants a drink, she will give a picture of a drink to the adult who will then give her a drink. The adult will then teach the child progressively more difficult skills, such as using pictures to make whole sentences or to express preferences.

The Picture Exchange Communication System was originally designed to help non-verbal children on the autism spectrum but it has also been used with adolescents and adults who have a wide range of communicative, cognitive and physical difficulties. The Picture Exchange Communication System is a key element in many multi-component programmes and approaches - such as the SPELL approach and the TEACCH programme.

To date there is a small amount of research into the use of PECS for individuals on the autism spectrum. This research suggests that PECS may be an effective way to increase the social communication skills (particularly requesting) of some young children on the autism spectrum who are non-verbal or who have limited functional speech.

PECS is a straightforward and positive approach, cost effective and not overly time consuming to implement. There is, however, much confusion regarding the correct use of PECS and it should only be implemented by appropriately trained individuals.

Talking Mats

Talking Mats is an interactive communication resource that uses three sets of picture communication symbols – topics, options and a visual scale – and a space on which to display them. This can either be a physical mat with picture / symbol cards, or a digital space, for example a tablet, smart board or computer screen using the Talking Mats app.

Topics: whatever you want to talk about, e.g., pictures symbolising ‘what do you want to do during the day’, ‘where you want to live’, ‘who do you want to spend time with’, etc.

Options: relating specifically to each topic. For example: ‘What do you feel about going for a walk? Or living at home?’

Scale: this allows participants to indicate their general feelings about each topic and option. The meaning of the visual top scale can be adapted to suit the questions you are asking the person, for example, a scale of 1 to 5, or a scale of ‘happy’, ‘unsure’, and ‘unhappy’.

Social Skills Groups

Social skills groups are designed to provide an opportunity for individuals on the autism spectrum to practice and improve their social skills in a safe, supportive and structured environment. Social skills groups meet on a regular basis and are usually facilitated by an adult. Some groups consist only of autistic people although some may also include non-autistic people who are there to demonstrate appropriate social skills.

A social skills group session typically includes a structured lesson on a specific skill, demonstration of the skill, role playing with rehearsal/practice of the skill, discussion, and individualised performance feedback.

There is a considerable amount of strong positive evidence to suggest that social skills groups may help some children and young people on the autism spectrum practice and improve a range of social skills. Social skills groups are most likely to benefit children and young people on the autism spectrum with average or above average IQ and with existing language skills. They may also be most appropriate for children and young people who actively wish to socialise and whose anxiety levels and behaviour are manageable in situations that involve several people at once.

Caution when using social skills groups

Care should be taken to teach practical skills that children and young people *actually want* rather than abstract social refinements that other people think autistic people should have. Autistic children and young people should be taught multiple skills in situations that reflect real experiences and real settings as this is likely to be of more value to them than being taught isolated skills out of context.

Social goals need to be individualised and developed in collaboration with the various environments the child spends time, and may include (but are not limited to):

- Communication strategies: turn taking, sharing, playing games, waiting, language scripts.

- Collaborative skills: sharing item or equipment with others, accepting help from a peer, offering to help a peer, asking permission to look at or handle another's belongings.
- Taking account of others' interests, needs and feelings within an interaction.
- Friendship skills: recognising what makes a 'good friend', accepting a peer may have more than one friend or may want to spend time with other people.
- Recognising negative or bullying behaviour towards self or others.

There are many commercially available social skills programmes. Below are listed some of the more widely used programmes in the UK. However, as cautioned above, social goals need to be individualised and taught in the real-life situations they are to be used for, rather than working through a 'manual' or programme out of context.

Circle of Friends - volunteers from the child's peer group meet regularly with an adult and the target pupil. The 'circle' provides friendship, problem-solving around the social difficulties and misunderstandings the child experiences in school, and opportunities to rehearse new social skills.

FRIENDS for Life - a social skills and resilience building program. It aims to treat and prevent anxiety, increase emotional resilience, problem solving abilities and teach lifelong coping skills. The intervention is suitable for students between the ages of 8 and 11. It requires 10 – 12 weekly sessions.

Lego-based Therapy Group - young people work together to build LEGO® models and through this have the opportunity to develop social skills such as turn taking, collaboration and social communication (a guidebook for setting up this intervention is *'LEGO®-Based Therapy: How to build social competence through LEGO®-based Clubs for children with autism and related conditions'* by Daniel B. LeGoff, Gina Gómez de la Cuesta, GW Krauss, and Simon Baron-Cohen).

Navigating the Social World – a book written by Paediatrician Jeanie McAfee– a social skills curriculum including whole class lesson plans.

Socially Speaking – a manual based social skills programme (lasting a school year) for pupils aged 7 to 11 years with special educational needs.

Talkabout – a manual based program (a series of books and resources) for all ages developed in the UK by Alex Kelly Speech & Language Therapist.

The Friendship Formula – a book of 40 group social skills sessions for children aged 8-13 years.

Time to Talk – a manual based programme of 40 sessions to develop oral and social interaction skills for children aged 4 to 8 years.

PEERS (Programme for the Education and Enrichment of Relational Skills) - a 16 week-long school-based programme that teaches social skills to teenagers with autism. Developed at UCLA in the United States.

Social Stories / Social Articles and Comic Strip Conversations

These are strategies developed by Carol Gray to support students with autism by extending their social understanding and helping staff working with them to understand how the child with autism perceives their social world. These strategies can be used to accurately describe a context, skill, achievement, or concept in a way that is motivating and understandable to a child or young person with autism, and to support problem solving and to help 'un-pick' difficult situations. Social Stories / Social Articles and Comic Strip Conversations can be adapted to all needs and ages.

TEACCH

The terms TEACCH, TEACCH model, TEACCH Autism Program and structured teaching are sometimes used interchangeably, which can lead to some confusion. The TEACCH Autism Program has several key components including:

- an understanding of the culture of autism - the characteristic patterns of thinking and behaviour seen in individuals on the autism spectrum.
- the development of an individualised person (and family)-centred plan for each child or young person.

- the use of structured teaching (which consists of four elements: physical structure; visual schedules; work systems; and task organisation).
- the use of a wide range of cognitive, developmental, educational and behavioural strategies.
- co-operation between therapists and parents.

Elements of the TEACCH Autism Program are used extensively alongside other approaches within other comprehensive, multi-component interventions. It also forms a key element of the SPELL approach.

The limited research available suggests that the TEACCH Autism Program may provide a range of benefits to some pre-school and primary school children on the autism spectrum. Those benefits include increased social communication and social interaction, along with improved cognition and improved motor skills. This research also suggests that the TEACCH Autism Program may reduce stress, and improve the mental wellbeing, of some families of children on the autism spectrum.

SCERTS

The SCERTS model is designed to target 'Social Communication, Emotional Regulation and Transactional Support'. It's a comprehensive multi-component intervention which offers a curriculum incorporating the following principles

- functional, meaningful, and developmentally appropriate goals and objectives are selected
- individual differences in a child's style of learning, interests, and motivations are respected
- the culture and lifestyle of the family are understood and respected
- the child is engaged in meaningful and purposeful activities throughout the day
- supports are developed and used consistently across partners, activities, and environments

- a child's progress is systematically charted over time
- program quality is measured frequently to assure accountability

The evidence for the effectiveness of comprehensive, multicomponent approaches is mixed.

The 5P Approach

A visual and structured framework for understanding and managing behaviours, created by an Educational Psychologist. The 5P approach is a five-step pathway which progresses from understanding the individual and planning for their needs, to identifying behaviour and understanding the reason it occurs, and finally to planning and implementing a comprehensive intervention programme.

Profiling (knowing all about the individual)

Prioritising (placing behaviours in a hierarchy of colour coded GREEN, AMBER & RED)

Problem Analysis (working out what is happening)

Problem Solving (working out why it happens)

Planning (working out what to do about it - at GREEN, AMBER & RED)

Applied Behavioural Analysis (ABA)

Applied behaviour analysis (ABA) is a systematic way of observing someone's behaviour, identifying desirable changes in that behaviour and then using the most appropriate methods to make those changes. It is based on the idea that someone's behaviour can be changed by altering what happens before the behaviour occurs (known as the antecedent) and /or by altering what happens after the behaviour occurs (known as the consequence). Such methods are firmly rooted in behavioural and cognitive behavioural theories.

ABA is based upon the work of psychologists in America in the 1970s, initially working with non-verbal institutionalised children with autism, and then with children aged 2 to 4 years old in their home settings. Since then, researchers and

practitioners have developed many different interventions, programmes and techniques which incorporate the principles of applied behaviour analysis. ABA uses methodologies including:

- Task analysis and chaining
- Discrete trial teaching (performing the task repetitively in short bursts)
- Overlearning by repeating key skills and interleaving old and new skills
- Prompting, shaping and fading strategies
- Differential reinforcement.

Most of these methodologies are held to be good practice in teaching and learning for children with and without a diagnosis of autism and are not unique to ABA.

Differentiating between ABA *approaches* and ABA *programmes*?

There is no single program that 'is' ABA. ABA ***approaches*** differ from what is commonly referred to as 'packaged intensive ABA' although both use analysis of behaviour in a structured manner. Packaged intensive ABA ***programmes*** tend to have the following characteristics in common:

- A trained ABA therapist (who directly oversees the intervention) undertakes a detailed assessment of the child's skills and preferences and the family's goals.
- From this assessment, a skill is analysed into steps which are then used as a one-to-one teaching programme for the child.
- The instruction plan breaks down desired skills into manageable steps to be taught from the simplest to the more complex.
- The intervention involves intensive ongoing objective measurement and frequent review of the child's progress. These are used to adjust procedures and goals as needed and discussed with staff and parents
- The daily programme may be delivered by parents/carers or by ABA tutors, or both. Parents and caregivers receive training and feedback.

- The child's day is structured to provide many opportunities – both planned and naturally occurring - to acquire and practice skills in both structured and unstructured situations.

Several UK companies market ABA programmes for children at home and/or in school.

ABA and controversy

Whilst ABA is the treatment of choice for children with autism in America and Canada, its acceptance world-wide varies considerably and many European countries do not favour this approach. Whilst there is evidence that ABA can be effective, the following issues mean that it continues to be surrounded by controversy:

- Definitions of ABA vary greatly, as do practices that fall under the heading of ABA. The range of practices under the heading of ABA has evolved over the past 30 years and now varies from traditional practices to contemporary practices. This makes it difficult to discern what is meant when reference is made to ABA as a treatment approach. (Barry M. Prizant, Ph.D., CCC-SLP). (To give an idea of the complexity of trying to synthesise the research evidence pertaining to approaches and interventions targeted at children and young people with autism: a systematic review of interventions published by French & Kennedy in 2017 found that within the 48 randomised controlled trials (RCTs) reviewed, there were 32 different models drawn from a range of treatment approaches, with a confusing variety of names and containing multiple components. The authors found that this complicated the process of comparing models and identifying the successful ingredients of an intervention).
- Most of the research evidence about the effectiveness of ABA comes from home/clinic settings outside of the UK. Therefore, there is a need for further research in the effectiveness of ABA interventions in UK schools (Lambert-Lee at al 2015 and Foran 2015)

- Most of the research evidence pertains to children aged between 27 and 56 months and indicates that ABA is more likely to work for preschool children than older children.
- Research findings tend to caution that there is a sizeable subgroup of children who do not respond as well to ABA. The characteristics of non-responders are not well understood, and there is not yet a way to predict this at an early stage.
- The intensive nature of the ABA programmes means that they are not cost effective for Local Authorities working to meet the needs of all their children with identified SEND. There is a call for research into how ABA principles could be used more cost effectively in maintained schools through low-intensity ABA-based interventions (Foran 2015).
- Autistic people in the neurodiversity movement reject the ideological goals of ABA, considering autism a harmless neurological difference rather than a pathology. They argue that eliminating benign autistic behaviour through ABA is impermissible, owing to the individual psychological harm and the wider societal impact (Kirkham 2017).
- Packaged intensive ABA typically includes 30-40 hours per week of close adult work with a child, across home and school. This can lead to concern about the child becoming highly reliant on support and, specifically, on their ABA tutor for support. This may impact on the development of independence skills, affect a sense of belonging, and restrict opportunities for social interaction.
- Linked to the point above, concerns have been raised that the intensity of ABA programmes may disadvantage the child's siblings, dominating family life and placing further strain on families (though professionals should not make these judgements on the behalf of families). (Fava et al., 2011; Strauss et al., 2012)
- Some researchers propose that group instruction is essential for skill acquisition, for observational learning and is more efficient (than one-to-one learning); it enables better generalisation of skills to other settings and provides social opportunities (Leaf et al 2016).

- There is concern that ABA's focus on observable behaviour limits its capacity to acknowledge and address the child's emotional needs; it is striking that ABA aims to eliminate 'problem behaviour' but does not focus on what the child is communicating or the needs (e.g. sensory) which the behaviour is meeting.
- Psychologists question whether the limited nature and repetition of ABA programmes satisfy the child's right to a broad and balanced curriculum.
- There is some evidence for the potentially harmful impact of ABA approaches on children and young people's emotional wellbeing. Kupferstein (2018) reported increased rates of Post-Traumatic Stress Disorder (PTSD) in individuals with ASD who had undergone ABA programmes.

Cambridgeshire position on ABA

As described above, there is no single intervention that 'is' ABA. Rather, the term ABA is used to refer to many different interventions, programmes and techniques which incorporate some shared principles. Whilst Cambridgeshire SEND Services recognise that some of the methodologies used in ABA are good practice in teaching and learning for many children with additional needs, the issues raised by research into intensive ABA programmes give cause for concern. Most concerning are the views held by some people with autism that ABA pathologises and oppresses their actions and may do psychological and emotional harm to individuals. Further, the evidence points to a risk that an intensive (30-40 hours a week) ABA programme may restrict the child's access to a broad and balanced curriculum and opportunities for social interaction, as well as impacting on their development of independence skills and their sense of belonging.

Interventions targeting sensory needs

Various factors can make it difficult for people to engage in activities that others manage easily, including differences in the way a person processes and responds to sensory information. Sensory differences are often associated with autism but can also occur separately. How people manage daily activities (occupational performance) is a consequence of the interaction between ***personal*** factors (such as

their strength, coordination, sensory needs, motivation), the ***activity*** (e.g. getting dressed, brushing teeth, shopping) and the ***environment*** (physical, sensory, cultural, institutional).

Sensory Processing Disorder (SPD) is a term that has been used to describe dysfunction in the sensory integrative process. However, there is a lack of consensus about how sensory processing can be identified and measured, and SPD is not included in the Diagnostic and Statistical Manual (Fifth Edition); sensory differences are considered a symptom rather than a diagnosis. The Royal College of Occupational Therapy do not therefore support the use of SPD as a diagnostic label. Occupational Therapists might, however, identify sensory differences and their impact on daily activities as part of their assessment of a person's occupational performance.

Performance-orientated approaches

These approaches aim to manage (not change) the sensory needs of the person through adapting the environment, modifying the task, or developing strategies for the person to self-manage their sensory needs. An example would be to alter the lighting level, noise level, visual clutter, and/or temperature of the environment to accommodate for a person's sensory needs.

Occupational Therapists have the skills to identify a person's sensory strengths and differences and to adapt tasks and the environment to enable their participation in daily activities. Interventions that focus on modifying tasks and/or the environment and that enable parents/carers/teachers/others to help individuals manage their sensory needs are effective and promote self-management. Further (free) on-line learning about sensory differences, and advice for how to support children with sensory differences is available at Sensory differences - online learning

Sensory-based interventions

Sensory-based interventions are adult-directed treatments intended to fit into daily routines (sometimes used to create a schedule and called a 'sensory diet'). They aim to change arousal states, improve the way the nervous system interprets and uses sensory information, and ultimately improve an individual's behaviour. Examples

include brushing, massaging, swinging, bouncing on a therapy ball, wrapping in a blanket, chewing on a toy, and wearing a weighted vest or using a weighted blanket. Systematic review of studies looking at the effectiveness of sensory-based interventions found the evidence to be limited and of low quality (e.g. Devlin et al. 2011). The College of Occupational Therapists recommends extreme caution if using these interventions. Interventions should be time-limited and measured through clear outcomes.

Ayres Sensory Integration Therapy (SIT)

Ayres Sensory Integration Therapy is a tool used by some Occupational Therapists to address a person's sensory needs. SIT aims to change a person's sensory processing through direct, intensive therapeutic input and is delivered by Occupational Therapists who have undertaken certified postgraduate training. The research evidence is inconclusive regarding the impact of SIT on daily life activities, although some people report that it makes a difference. The inconclusive evidence and intensive nature of this intervention, combined with the fact that it requires a specifically-trained Occupational Therapist to deliver it, means that it is not cost effective for Local Authorities working to meet the needs of all of their children with identified SEND.

IN SUMMARY: the research evidence indicates that there is no one approach that is superior to another for all children and young people on the autism spectrum. Rather, a range of approaches is needed to suit and address individual contexts, needs and preferences.

A checklist for schools, settings and professionals choosing approaches and interventions to support children and young people with autism:

- ☑ Use the recommended principles on page 15 as a checklist when choosing your intervention.
- ☑ Be respectful of the neurodiversity perspective which holds that we should only seek to change those aspects of autism that are experienced as *impairments* and refrain from intervening in those behaviours that are atypical, but *not* experienced as impairments.
- ☑ Start with identifying the area(s) of need, and match the most suitable approach or intervention for that specific need, rather than focussing on one particular type of intervention.

Specialist Advice

"Where a pupil continues to make less than expected progress, despite evidence-based support and interventions that are matched to the pupil's area of need, the school should consider involving specialists, including those secured by the school itself or from outside agencies." (6.58 SEN Code of Practice 2015)

Schools may involve specialists at any point to advise them on early identification of SEN and effective support and interventions. A school should always involve a specialist where a pupil continues to make little or no progress or where they continue to work at levels substantially below those expected of pupils of a similar age despite evidence-based SEN support delivered by appropriately trained staff. The pupil's parents should always be involved in any decision to involve specialists. (6:59 SEN Code of Practice 2015)

In Cambridgeshire, schools can seek the support of the Cambridgeshire County Council SEND Service 0-25 which is made up of Educational Psychologists, Specialist Teachers and Specialist Practitioners. Each school (including all maintained Primary, Secondary, Village Colleges, Academies, and Area Special Schools) has an allocation of SEND Service time.

If the child is referred to the SEND Specialist Service a Specialist Teacher or Educational Psychologist may be involved in the following:

- Consultation with school staff and parents to explore interventions that have been put in place, look at pupil assessment information and make further recommendations on teaching and learning strategies. They may work with the school staff (not always directly with the child) to achieve a better understanding of the factors that may be preventing the child from making progress.
- Contribute to staff development by providing autism training and model specific interventions relevant to the child's needs.

- Work directly with the child to complete a detailed assessment of their strengths and difficulties and recommend targeted interventions based on the findings of the assessment. These would then be then reviewed.
- Be involved in Access Arrangements at secondary school and FE colleges if a specialist assessment is required and school do not have the resources. This is part of the traded offer.
- Any assessment should:

- Include the views of the child/young person
- Consider the child/young person's strengths, challenges, interests and aspirations, and use this information to inform interventions
- Include the views of the parent
- Draw, where appropriate, on the views of other professionals
- Provide recommendations, based on the assessment, to support the child to make progress
- Provide a written report
- Plan a review date

- The SEND Service 0-25 will also work at Local Authority level by contributing to research, policy development and guidance around autism.

Most children and young people with autism can be supported through School SEND Support (Code of Practice 2015). For a very small minority, an Education, Health and Care Plan (EHCP) might be appropriate. Children and young people may meet the criteria if they:

• Have severe and/or complex long-term needs which affect everyday life.

• Require provision and resources which are above those normally available from the school.

• Require intensive and longer-term help and support from more than one agency.

• Are making limited or no progress despite high levels of support and purposeful interventions.

Guidance for when an Educational Health Care Needs Assessment may be appropriate can be found here https://www.cambridgeshire.gov.uk/asset-library/Cambridgeshire-EHCNA-Guidance-2019v2.pdf.

Frequently Asked Questions for Parents

With thanks to PinPoint Cambridgeshire for submitting questions, and to Cambridgeshire Community Services NHS Trust for answering questions about autism assessment and diagnosis.

Question: What is the route to referral for an autism assessment for children in Cambridgeshire?

For pre-school and Reception Year children (0-5 years):

Parents/carers, or an involved professional makes a referral to Early Support by completing an Early Help Assessment (or Social Care Single Assessment) and sending it to the Early Help Hub.

https://www.cambridgeshire.gov.uk/asset-library/cambs-early-support-pathway-guidance-apr-2019.pdf

For children at primary school (5-11 years):

The child's school makes a referral to Community Paediatrics by completing a Neurodevelopmental Referral Form and an Early Help Assessment (EHA)

https://www.cambscommunityservices.nhs.uk/what-we-do/children-young-people-health-services-cambridgeshire/community-paediatrics/community-paediatrics-home

For children and young people at secondary school (11-17 years (or up to 18 years if they have a learning disability)):

One of the professionals involved with the child or young person and their family makes a referral to Cambridgeshire CAMH Neurodevelopmental Service by completing a Community CAMHS referral form and sending it to the Single Point of Access (SPA)

https://www.cpft.nhs.uk/training/cambridgeshire-neurodevelopmental-service.htm

https://www.cpft.nhs.uk/professionals/referrals-to-camhs

For people age 18 and over without a learning disability:

A GP or other mental health professional involved with the person will make a referral to Primary Care Mental Health Service (PRISM) for initial assessment. If your score suggests you may have autism you will be referred to Cambridge Lifespan Autism Spectrum Service (CLASS) for further assessment.

Question: My child / young person displays different behaviour at home and school – can I still get an autism diagnosis for my child / young person?

Yes. It is common for children to behave differently in different environments. However, due to the limited capacity of assessment services, children with the highest level of need are prioritised for assessment. There are children below this threshold who will ultimately reach a diagnostic threshold, but often have milder presentations and therefore can be more difficult to diagnose. To reach the threshold for assessment, there must be evidence that developmental differences are having an impact on a child's functioning, and this may only become apparent with time. Where children behave very differently at home and at school it will be important for parents to fully describe the behaviours they see at home in the Early Help Assessment or Community CAMHS referral form.

Question: Do I have to do a parenting course?

No, not for an assessment for autism. It is only where a diagnosis of ADHD is suspected that evidence of behavioural management and intervention (universal or targeted) from the Locality Team is required. For parenting and behavioural support for families, you are asked to specify dates, course name, and provide certificates if available. This must have taken place within the last 2 years. Referrals for an ADHD assessment will not be considered unless this has already been undertaken prior to referral and the response has been evaluated.

Question: My GP sends me to school and school sends me to the GP… my GP says they can't refer or don't know how to refer – who is responsible for referring?

It depends on the age of your child. For children aged between 5 and 11 years old, the school is responsible for referring. Even if school don't see the same behaviours you see at home do talk to school about how your child is presenting at home to consider whether a referral is needed. For children of other ages, it can be any involved professional (including your GP).

Question: Does the Cambridgeshire Local Authority / NHS recognise private assessments and autism diagnosis?

Yes. The school / setting / professional working with your child would ask to see a copy of the private assessment letter or report.

For the sake of the young person, we would hope and expect that the assessment meets high-quality clinical standards (as described by the National Institute for Health & Care Excellence (NICE)). According to NICE, assessment should use information from all sources, together with clinical judgment, to diagnose autism based on ICD-10 or DSM-5 criteria. Assessment should not rely on any autism-specific diagnostic tool alone to diagnose autism.

Question: Is there a waiting list for assessment?

Once it is agreed that a child will be assessed (based on the referral), the assessment appointment is offered within 18 weeks.

Question: What happens during the assessment?

Parents / carers will be asked to attend an appointment at the Multidisciplinary Social Communication Clinic, where they will provide a case history to a clinician and describe needs/behaviours/what they see and experience with their child. At the same time there is also an opportunity for clinicians to observe the child's social communication skills in the clinic. This information is considered alongside the observations provided by school and / or other professionals involved with your child, and which have been provided in writing as part of the referral.

Since the start of the Covid pandemic, the assessment happens in a slightly different way: information-gathering from parents / carers happens via video or phone. Preschool children are observed over video by a Speech and Language Therapist (SaLT) which feeds into the overall assessment. The clinician then decides whether the information (provided by the parent; the SaLT observations (for preschool children); school observations (for school age children); and also from the referral) is sufficient to come to a conclusion. In some cases, a face-to-face assessment will be offered but for most children the recognition that there are significant social communication difficulties should be sufficient to access the right support. In some cases, the level of need is apparent from a very early age. In most cases the need emerges over time as communication skills develop and as a child's emotional response mature and the child then not being able to meet the increasing social demands.

Question: What is the threshold for assessment and diagnosis?

Children with the highest level of need are prioritised for assessment. There are children below this threshold who will ultimately reach a diagnostic threshold, but often have milder presentations and therefore can be more difficult to diagnose. To reach the threshold for assessment, there must be evidence that developmental differences are having an impact on a child's functioning, and this may only become apparent with time.

Two diagnostic manuals set out the criteria for autism to be diagnosed: The International Classification of Diseases, tenth edition (ICD-10) and the Diagnostic and Statistical Manual, fifth edition (DSM-5). These manuals specify that autism spectrum disorder can be diagnosed when "persistent difficulties with social communication and social interaction" and "restricted and repetitive patterns of behaviours, activities or interests" (this includes sensory behaviour), present since early childhood, to the extent that these "limit and impair everyday functioning".

As part of the assessment, clinicians may use diagnostic tools such as the ADOS (Autism Diagnostic Observation Schedule) to collect information in order to help to decide whether someone is on the autism spectrum or not. This is considered

together with all the other information about your child to feed into the clinician's opinion. Further information about diagnostic criteria can be found at https://www.autism.org.uk/advice-and-guidance/topics/diagnosis/diagnostic-criteria/all-audiences

Question: What happens after diagnosis?

A clinic letter/report is written confirming the diagnosis and is shared with the involved professionals and your GP with your consent. Medical Investigations (including genetics tests) can be discussed with you at the appointment too.

All parents and carers of children aged 0-11 who have received a diagnosis of autism, or who have been assessed as having significant Social Communication Difficulties, are offered a place on a parenting support programme. For parents of children who are in their Reception Year or younger, this is the Social Communication, Interaction and Learning Skills (SCILS) programme. Parents of children in Years 1 to 6 are invited to attend the Cygnet programme. These programmes used to be run as weekly, group, face-to-face sessions lasting between six and seven weeks. However, due to the Covid pandemic they are currently made available online. You will be able to access and work through the course content in your own time and in your own home over six weeks. In addition, you will be invited to live online sessions hosted by local specialists in autism; speech, language and communication; sensory needs; and behaviour. At these live sessions you will be one of a small group of families which means that as well as having your own questions answered, you can share experiences with other families.

Question: What happens if I don't agree with the outcome of the ASD assessment?

Often this can be resolved with further discussion with the clinician, and sometimes further observation over time in school or by other professionals can make things clearer. Cambridgeshire Community Services don't offer second opinions within their service as they feel it is fairest to use limited resources to offer assessments to the largest number of families possible.

Question: What help is there if I don't get a diagnosis?

Parents of children who are assessed as having significant social communication difficulties, but may not have a diagnosis of autism, will still be invited to access the SCILS or Cygnet parent support programmes.

If your child needs support, this is based on their individual needs, not on a particular diagnosis. There are many children who do not fit neatly into diagnostic boxes as human development is complex and varied. Universal and targeted services are available to those who need it, and do not require a diagnosis.

Children from birth until the end of Reception Year at Primary school, who have significant and complex additional needs or disability, and require ongoing specialist support from across education, health and care can access Early Support Early Support - Cambridgeshire County Council

Children in school must have their special educational needs met, regardless of whether they have a specific diagnosis or not. This right is enshrined in the Special Educational Needs and Disability Code of Practice: 0 to 25. The Code of Practice says:

All schools should have a clear approach to identifying and responding to SEN. The benefits of early identification are widely recognised – identifying need at the earliest point and then making effective provision improves long-term outcomes for the child or young person (6.14)

Parents know their children best and it is important that all professionals listen and understand when parents express concerns about their child's development. They should also listen to and address any concerns raised by children and young people themselves (6.20)

In deciding whether to make special educational provision, the teacher and SENCO should consider all the information gathered from within the school about the pupil's progress, alongside national data and expectations of progress. This should include high quality and accurate formative assessment, using effective tools and early assessment materials. For higher levels of need, schools should have arrangements

in place to draw on more specialised assessments from external agencies and professionals (6.38)

This information gathering should include an early discussion with the pupil and their parents. These early discussions with parents should be structured in such a way that they develop a good understanding of the pupil's areas of strength and difficulty, the parents' concerns, the agreed outcomes sought for the child and the next steps (6.39)

The Autism Education Trust (AET) has produced a guide to help parents and carers identify what is important in the education of their child with autism, and to help parents to talk to staff in schools about how best they can work together AET parents guide - Autism Education Trust

In addition, local authorities must publish a Local Offer, setting out in one place information about provision they expect to be available across education, health and social care for children and young people in their area who have SEND. This includes children and young people with and without a specific diagnosis, or an Education, Health & Care Plan (EHCP). The Cambridgeshire Local Offer can be found at Local Offer - Cambridgeshire County Council

Question: How do I make contact with families in the same situation?

There are several organisations in Cambridgeshire which offer support groups for families and/or work to bring families together. Some are run by parents (for example Pinpoint), others are run by national charities (for example Contact). For further information and contact details please see 'Further sources of information and support' section below.

Question: What support will my secondary school child get in exams?

Each student with autism is an individual with a unique pattern of strengths and difficulties and the key to supporting them in assessments and exams is to put in place the correct package of access arrangements. Exam boards and educational settings have a duty under the Equality Act 2010 to make 'reasonable adjustments'. To qualify for some access arrangements (such as supervised rest breaks; extra

time; a reader; a word processor; a scribe) the school must provide evidence that the young person has an impairment 'which has a substantial and long term adverse effect'.

When planning exam accommodations for autistic students, schools should consider the strategies that have been developed and tailored to the needs of the student in their regular lessons and how that individual student achieves best. The AET has produced free guidance for teachers and examinations officers available at AET exam accommodations - Autism Education Trust

When the AET asked their Young People's Panel 'what are your experiences of taking exams? The good, the bad and what would have helped?' they gave the following answers:

'Colour-coded timetable!' (Georgia); 'Separate room for just me' (Ollie)

'Consistency - Sometimes they put me in a separate room, sometimes not' (Jack)

'Extra time, enlarged papers, laptop, scribe and a reader' (Sam);

'Rest breaks! Allowed to go outside for fresh air/walk' (Ollie)

'Laptop for writing essays / long exams' (Sam)

'Being able to walk out for a break' (Jack & Ed)

'They should be clear about the nature of exams at the start of the year so it's not a surprise.' (Jack)

'I didn't understand a lot of jargon in exam questions.' (Naomi)

'I needed help with preparation and what's going to happen in exams. Someone helped me revise with timed practice papers.' (Shane)

'Being in a room/hall with other people can be very distracting. It can be helpful to simulate exam conditions beforehand.' (Alex)

The JCQ Access Arrangements document is updated annually and can be downloaded from the website (www.jcq.org.uk)

Further sources of information and support

Local Groups

The National Autistic Society (NAS) Cambridge Branch.	The Cambridge Branch of the NAS provides support to individuals of all ages with autism, and their families including a monthly parent support group.	https://www.nascambridge.org.uk/contact-us/ **Tel: 07920 150407**
Pinpoint	Pinpoint is a parent-led support organisation for Cambridgeshire families including a wealth of really helpful local information such as:- • information and contacts with professionals and expert advisors • support groups across the county • training and workshops • speaking up on issues affecting families	www.pinpoint-cambs.org.uk Tel: 01480 877333 Email: information@pinpoint-cambs.org.uk
ASPIRE programme – Romsey Mill	The Aspire Programme is a weekly youth club for 9 - 18 year olds in Cambridge who have been diagnosed with high-functioning autistic spectrum conditions and who are in mainstream education.	www.romseymill.org/aspire Tel: 01223 521270.

Eddies	Eddies is a family support service that provides practical help for parents/carers. There is also Happy Feet, a performing arts project for children aged 7-12.	https://eddies.org.uk/our-services/childrens-services/ Tel: 01223 883130 info@eddies.org.uk
Little Miracles	Little Miracles is a parent-led charity that supports families that have children with autism, additional needs, disabilities and life limiting conditions as well as their carers and siblings Running in Ramsey, Ely, Sawtry, Fenland, and St Neots	http://www.littlemiraclescharity.org.uk Tel: 01733 262226
Spectrum	Spectrum is a parent-led charity providing events, days out and support for children with autism, learning difficulties and additional needs.	https://spectrum.org.uk/ Tel: 01223 955404 Email: hello@spectrum.org

Local Education, Health and Social Care Services/Offer

SCILS Course	Social Communication and Interaction and Learning Skills is a 7 week parent programme for parents of a preschool child who has significant and complex social communication difficulties or a diagnosis of autism.	After assessment by a community paediatrician, SaLT or early years SEND practitioner, they will tell you about this course and how to access it.
Cygnet	Cygnet is a 6 week group parent training and support programme, for parents of primary school aged children who have recently been	After your child's diagnostic assessment, your paediatrician will tell you

	assessed as having autism or significant social communication difficulties.	about Cygnet courses and how to access them.
Local Offer	Cambridgeshire County Council's Local Offer of services and support for children who have special educational needs and disabilities.	https://www.cambridgeshire.gov.uk/residents/children-and-families/local-offer/about-cambridgeshire-s-local-offer
Early Help Hub and family workers	Early help gives children and families the support they need at the right time. Help offered might include a family worker to help you with any difficulties you are having at home.	If you think you and your family might benefit from some support, you should ask a professional who you know. This could be your doctor or a teacher at your child's school or nursery. If you don't know who to ask for help, you can contact the Early Help Hub directly: Insert weblink email: - Early.helphub@cambridgeshire.gov.uk Tel: 01480 376666
Disablity Children's Social Care	Disability Social care provides the following:- • Support for children to access the community, to develop independence and life skills.	See here for how to refer yourself and what their assessment involves: https://www.cambridgeshire.gov.uk/residents/children-and-families/children-s-

	• Provides the opportunity for children and families to have a short break (see next section). • Offers support to families and carers • The opportunity to prepare and think about the future.	social-care/disability-social-care-0-25
Short Breaks	'Short breaks' are part of the range of support available through the Disabled Children's Social Care Service. Short breaks funding enables disabled children and young people to access community activities and to also increase independence skills. This is achieved through an allocation of a personal budget that can be used for agreed activities or support. This support will provide the carer with a short break.	www.cambridgeshire.gov.uk/short-breaks 01480 379 800 dceh@cambridgeshire.gov.uk
SENDIASS – Parent partnership service	The Special Educational Needs and Disability Information, Advice and Support Service (SENDIASS) are a parent partnership service providing impartial and confidential information, advice and support to parents and carers who have a child or young person with special educational needs or a disability.	https://www.cambridgeshire.gov.uk/residents/children-and-families/local-offer/local-offer-care-and-family-support/send-information-advice-and-support-service-sendiass Email – pps@cambridgeshire.gov.uk

		Confidential helpline open during term times: 01223 699 214
SCIP data base	SCIP – the Special needs Community Information Point – is a database for Cambridgeshire children and young people aged 0- 25 years who have special needs or a disability, and their families. Information on community support and activities and weekly email updates about local groups and activities. Join SCIP and you'll get: • SCIP Card • Activity Passport • Email update on local events and activities • Information booklets on activities, support, local and national organisations • Carers Magazine	https://www.cambridgeshire.gov.uk/residents/children-and-families/local-offer/local-offer-care-and-family-support/information-and-advice-scip SCIP co-ordinator: Joan Adamson Tel: 01480 379 827 Email: joan.adamson@cambridgeshire.gov.uk

Financial Support and Advice

Contact	Advice on applying for DLA, carers' allowance and other benefits.	https://www.contact.org.uk Tel: 0808 8083555 Email: info@contact.org.uk
Disability Huntingdonshire DISH	Disability Huntingdonshire provides information, advice and	www.dish.org.uk Tel: 0330 3553 256

	support for disabled people in Huntingdonshire and South Cambridgeshire. They also support you filling in forms, support you with benefit information and appeals and tribunals.	email: info@dish.org.uk
Disability Cambridge	Disability Cambridgeshire is an advice and information service for disabled people, older people, their families and carers. They serve people of all ages in South and East Cambridgeshire, Fenland and Cambridge City.	www.disability-cambridgeshire.org.uk Tel: 01480 839192 Email: admin@disability-cambridgeshire.org.uk
Disability Living Allowance (DLA)	You could be eligible for DLA to help with extra costs in care for a child under the age of 16 with disabilities.	www.gov.uk/dla-disability-living-allowance-benefit www.gov.uk/browse/disabilities
Family Fund	Family Fund is the UK's largest charity providing grants for families raising disabled or seriously ill children and young people.	www.familyfund.org.uk Tel: 01904 550055

Disability Grants	An organisation that supports families to find grants for disabled children locally and nationally	www.disability-grants.org

Emotional Health and Wellbeing

Keep your Head	Keep your Head is a website where you can find information about mental health support in Cambridgeshire & Peterborough. This site brings together good reliable up to date information on mental health and well-being for children and young people, parents/carers and professionals.	https://www.keep-your-head.com/cyp
CHUMS: emotional health and wellbeing (not ASD specific)	CHUMS Mental Health and Emotional Wellbeing Service offers support to children and young people	You can make a referral via our website and one of our triage team will contact you to discuss the presenting issue in more detail. www.chums.uk.com/cambs-pborough-services

	with mild to moderate mental health difficulties, such as anxiety and low mood, as well as those with significant emotional wellbeing difficulties arising from life events, such as bereavement and bullying.	
Emotional Health and Wellbeing Service	The Emotional Health and Wellbeing Service offers support to children with mild mental health difficulties. They offer support in schools. A big part of their role is signposting to appropriate support.	To be referred to the EHWS please speak to your school and ask them to contact them directly: tel: 0300 029 50 50 or email: ccs.ehw@nhs.net https://www.cambscommunityservices.nhs.uk/what-we-do/children-young-people-health-services-cambridgeshire/emotional-health-and-wellbeing-services

Information and Advice: National Websites and Helplines

NAS	The National Autistic Society is the leading UK charity for autistic people and their families. Their website provides comprehensive information, advice and support for individuals and families about a very wide range of topics including:- • Diagnosis • Behaviour • Communication • Strategies and approaches • Family life • Education • Benefits and Care The NAS also have a helpline and can offer specialist advice on education rights and advice on transition support as well as a parent-to-parent support service.	www.autism.org.uk https://www.autism.org.uk/services/helplines.aspx Helpline: **0808 800 4104** https://www.autism.org.uk/services/helplines/main.aspx
Contact	Contact is a national advice and information service supporting families with guidance and information. They also bring families together to support each other. They provide advice on education, benefits, childcare, social care, medical information and more.	https://www.contact.org.uk Tel: 0808 8083555 Email: info@contact.org.uk