## Briefing on Autism Services

# Health Overview Policy and Scrutiny Committee

13 January 2021



### What is autism?

Autism short for Autism Spectrum Disorder (ASD), a lifelong disability which affects how people communicate and interact with the world.

**Autism is a spectrum condition**, ranging from individuals in need of 24-hour care, to people who struggle with some aspects of everyday life including forming friendships, coping at school or managing work.

**Every person with autism is different**. Some people may share some of the following characteristics:

- communication issues;
- repetitive behaviour and routines and difficulty with unexpected change;
- anxiety in social situations and difficulty with interacting;
- sensory sensitivity to light, touch, sound or smell;
- intense and highly focused interests.

### Local authority and Health responsibilities



#### The Care Act 2014

Wellbeing outcomes

Prevention, awareness, accessible information, responsive and safeguarding



### Children and Families Act 2014

A requirement to joint commission and meet needs as identified in an Education Health and Care plan (EHC).



## The Autism Act 2009 The National Strategy

Sets out the provision for meeting the needs of adults with autistic spectrum conditions.



#### Children Act 2004

Sets out the duties to meet assessed need and the guiding principles for care and support of children..



## Preventing inappropriate admissions and discharge - Transforming Care

Development of locality wellbeing hubs across health and social care



Mental health – Access to emotional and mental wellbeing



## National Institute for 7 Clinical Excellence (NICE) guidelines

Reducing waiting lists
CCGs commission
assessment and
diagnostic services



### NHS Long Term Plan 2019

Accessing health services –
Training the workforce and
reasonable adjustments
Tackling Health inequalities –
children and adults

### 5 year All Age Autism Strategy launched in April 2020

(ECC strategy shaped in partnership with Health)



We want Essex to be recognised as an autism friendly county in which people with autism can live fulfilling and meaningful lives within communities that are understanding and supportive.



We have developed a strategy for the next five years with people with autism, family members, health, voluntary and community partners and other key stakeholders.



The strategy takes a whole life approach and encompasses children, young people, adults and older adults with autism and considers the views, wishes and opinions of carers and families.



It has been informed by people with lived experience and their families and carers, including consultation and engagement within our network and partnerships.

### Essex All Age Autism Strategy: 7 Key Priorities

A revised Strategy action plan is being shaped and implemented through the Autism Joint Commissioning forum

Read the full All Age
Autism Strategy and its
Easy Read version here

## Working towards an autism friendly county

- Professional awareness
- Planning
- Education and training
- Employment
- Criminal Justice
- Accommodation
- Diagnosis, assessment and support

## All Age Autism Joint ECC and Health Commissioners Forum established

- To support delivery on Diagnosis, Assessment and Support
- ECC commissioners and CCG commissioners from each area are invited including Southend and Thurrock
- 12-month countywide BCF funded autism navigator/support service pilot commenced in April 2020 and delivered by Summit Services (not including Southend and Thurrock) to support adults seeking a diagnosis, to support them with information support whilst they are awaiting their assessment, to known what to expect, and support post diagnosis.
   Pilot ends March 2021
- Procurement underway for longer term Joint service arrangement for April 2021 onwards
   Countywide service arrangement is dependent on future funding
- Further work to be undertaken to align with the Children's Diagnosis pathway.

# Covid-19 Autism Survey undertaken via the Essex All Age Autism Partnership

**81%** of respondents were parents

19% responded that their mental health was much worse.

31% responded that their mental health was somewhat worse.

**88%** responded that the reason was disruption of routine. The next highest reasons given were:

- Anxiety of the unknown;
- Social isolation;
- Difficulty sleeping.

When asked about positives, the majority discussed school:

- "Not having to go to school and be faced with lack of support and understanding"
- "No school!"
- "Not worried about going to school"

## Support available during pandemic for people with autism and their families

The Essex Wellbeing Service continues to provide support to Essex residents including:

- Managing and coping with change
- Managing anxiety and staying active
- Maintaining healthy relationships and accessing peer support
- Using technology
- Understanding coronavirus
- Coping with separation and loss
- Practical support including help to get food and medication

Learning Disabilities & Autism service providers including Summit Services are working within the Essex Wellbeing Service, to provide specialist practical and emotional support to individuals with Learning Disabilities and/or Autism during the pandemic and their carers.

- Stay Connected Sport for Confidence are providing Occupational Therapy intervention to vulnerable adults, primarily
  those with Learning Disabilities and/or Autism, at risk of social isolation due to Covid-19 restrictions / reduced access to
  ordinary services
- Digital outreach Day Opportunities providers are providing digital outreach via use of technology including wellbeing telephone calls and Zoom sessions for cooking, dance, craft and other peer activities
- Essex Carers Network are working to connect families/parents caring for people with learning disabilities and/or autism, to share experiences, information and for peer support
- Mental Health services including Futures in Mind are making weekly wellbeing calls and services including ACL Mental Health Wellbeing & Recovery Programme, The Family Innovation Funded services and Triple P parenting programme for clients known to them including people with autism are continuing.

## SEND and Autism Services



## Education Health & Care Plans and Autism - as of December 2020

- Essex County Council currently has 10,108 Education, Health and Care Plans (EHCPs);
- 3,613 EHCPs primary need is listed as Autistic Spectrum Disorder (ASD), which is 35% of the EHCP population (this is a 67% increase from 2015);
- Autism Spectrum Disorder is the highest proportion of our EHCP population with Social, Emotional Mental Health (SEMH) needs having the second highest proportion (16%);
- ECC currently has 22,518 pupils on SEN Support; 2004 (8.9%) of these children and young people (CYP) have their primary need identified as autism. This is an increase from 2015, where ECC had 684 CYP identified with autism on SEN Support (3%).

# Essex All Age Autism Strategy Priority Area: Education & Training 2020-2021

VISION: Person Centred Whole system approach Early Intervention All Age approach Empowerment Strengths Based Co-production

### Objective: People have the foundations to build and live meaningful lives

#### Where do we want to get to?

- ✓ Inclusive educational provision for young people with autism across the county;
- ✓ A good level of awareness and understanding of autism across the education sector;
- ✓ A range of suitable educational provision across Essex including both mainstream and special schools;
- ✓ Good autism practice underpinned by understanding the individual, positive and effective relationships, enabling environments and learning and development.
- ✓ Early and accurate identification and assessment of young people's needs.

We will work together to develop educational provision for young people with autism which enables them to achieve to the best of their abilities. This includes:

- Effective training and development for education professionals.
- Autism Education Trust (AET) training delivered by professionals to early years, schools and post 16 settings.
- A holistic approach using the AET's evidence-based support programme and practical resources.
- Identifying learning priorities and measuring progress in areas which relate to young people's social, emotional, independence and learning needs.
- Developing the support available for mainstream schools in supporting young people with autism.

### **Autism Provision Update**

#### **New Schools**

#### The Hawthorns School

- 70 place school in Chelmsford for children and young people with ASC;
- 10 residential places;
- Opening 2022/23.

#### The Chatten School

- 75 place school in Witham for children and young people with severe autism;
- Opening September 2021.

### **Autism Support Centre Review**

The purpose of the review is to:

- Gather evidence and a thorough understanding of what works well and less well currently, for who, where and why;
- Determine the future vision and ambitions for the enhanced provisions in order to build our requirements for future commissioning and delivery;
- Develop options to meet our future ambitions.
- Ensure Enhanced Provisions are fairly funded.
- The review is being approached in three workstreams:
  - Understanding the current operating model;
  - Determining the commissioning requirements;
  - Exploring the options for future delivery.

## Health and Autism Services



### CCG diagnostic referral statistics

CCG area	Sep 2019–Mar 2020	March 2020-Sep 2020	Sep 2020 to Dec 2020
Mid (Adults)	48	19	18
West (Adults)	47	20	14
North East (Adults)	76	63	17 Oct only
South East (Adults)	35 (10 Castle Point and Rochford, 25 Southend on Sea)	31 (9 CPR, 22 SOS)	13 (4 CPR, 9 SOS)
South West (Adults)	37 (30 Brentwood Basildon Wickford, 7 Thurrock)	42 (38 BBW, 4 Thurrock)	22 (20 BBW, 2 Thurrock)

### CCG diagnostic assessment statistics

CCG	Sep 2019–Mar 2020	Mar 2020-Sep 2020	Sep to Dec 2020
Mid (Adults)	27	28	10
West (Adults)	19	12	9
North East (Adults)	103	40	7 Oct only
South East (Adults)	27 (11 CPR, 16 SOS)	2 ( 1 CPR, 1 SOS)	5 (3 CPR, 2 SOS)
South West (Adults)	29 (20 BBW, 9 Th)	1 (1 BBW, 0 Th)	7 (6 BBW, 1 Th)

### CCG diagnostic waiting time statistics (weeks)

CCG	Sep 2019 – Mar 2020		Mar 2020– Sep 2020		Sep 2020- Dec 2020	
	Longest wait	Ave.	Longest wait	Ave.	Longest wait	Ave.
Mid (Adults)	60.9	42.3	70.7	51.7	75	66
West (Adults)	89.6	44.4	73.3	64.4	98.7	64.1
North East (Adults)	Not collected		63	43	50 Oct only	<b>24</b> Oct only
South East (Adults)	61.1	32.5	63	31	74.4	38
South West (Adults)	61.1	32.5	63	31	74.4	38

# Children's West Essex Journey of Autism Diagnosis & Early Support

West Essex
Clinical Commissioning Group

- ❖ Neurodevelopment transformation project 2018/19 JADES implementation
- ❖Integrated team consisting of: JADES Team Co-ordinator, Specialist OT, Specialist Neurodevelopmental Nurse, Specialist ADHD nurse, Paediatricians, Specialist Speech & Language Therapists, Clinical Psychologist.
- ❖ Utilises the full potential of Pre-Birth to 19 Healthy Family Teams and Children's Community Healthcare Teams from within integrated ECFWS (west Quadrant).
- ❖ Project extension 2020/21 implement Cygnets programme of support to parents/primary carers of school aged children receiving a diagnosis of Autism.
- ❖ICS review of Covid impact and scoping gap between demand and commissioned capacity across Hertfordshire & West Essex.
- Deliver the requirements highlighted in the SEND Written Statement of Action at local level, working with the Neurodevelopment Sub-Group of the Essex SEND Joint Commissioning Group.
- Average time to first assessment approx. 6 weeks; JADES care plan implemented. Both virtual and face-to-face contacts currently being offered (risk assessed).





### Diagnosis Pathway Improvement Plan

	Adults
Mid / West Essex CCGs	<ul> <li>Referral form for GP completion being developed to obtain info to support referral processing (and which also allows the provider to ensure that the referrals coming in are appropriate)</li> <li>Information sheet for GP's on what the Autism Spectrum Disorder Diagnostic Service pathway looks like (that can also be made available to those people who are referred for an assessment) being drafted</li> <li>Conversations underway with the provider on what support is needed to reduce the pressure on the existing backlog.</li> </ul>
North East Essex CCG	<ul> <li>Discussions with current service provider underway to further support increasing waiting lists.</li> <li>Current contract for Autism Spectrum Disorder ends on 31<sup>st</sup> March 2021 with HPFT /Transfers to EPUT as part of the new IAPT service.</li> <li>As part of the IAPT invitation to tender, it was outlined that the ASD service would be reviewed during mobilisation with likely change in year 1 of the IAPT contract.</li> <li>Specific mobilisation and implementation plan derived as part of wider IAPT mobilisation. This includes pathway proposal and KPI review.</li> </ul>
South Essex CCG	<ul> <li>To adapt the assessment and intervention going forward so that a virtual approach is part of the offer and not just face-face appointments</li> <li>To adapt the assessment process so that it is refined and a more streamlined assessment is offered where appropriate</li> <li>Sharing skills through training (e.g. IAPT, Custody Suites)</li> <li>Review of local neurodevelopmental service pathways and offer in the context of wider transformation of mental health services.</li> </ul>

### Diagnosis Pathway Improvement Plan

	Childrens
Mid / West Essex / North East Essex / South Essex CCGs	<ul> <li>All areas to have pathways in place for ASD/ADHD that eliminates discrepancies across Essex</li> <li>Development of MDT work streams in each quadrant</li> <li>Development and implementation of the same set of principles used to develop pathways based on NICE Guidance, good practice model's and EFF feedback</li> <li>Principles embedded for identification, coordination ,on going family support and timely assessment</li> <li>Linkages to relevant and appropriate Neurodevelopmental Pathways</li> <li>Improved Pathway outcomes that are linked to the Local Offer, IASS, EFF, Equipment, SaLT.</li> </ul>