



Adult Autism Strategy

1 October 2014



Essex County Council

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1 Our vision

In Essex we are committed to improving the lives of adults with autism. We will do so by working with families, local autism groups and partner agencies to address some of the frustrations with existing patterns of services and the difficulties in accessing support.

We are committed to bringing our approach in Essex in line with the Autism Act 2009, the first disability explicit law to have been passed in England and Wales, and in conjunction with NICE guidance.

The Adult Autism strategy sets out the overarching vision that Essex will pursue in order to improve the lives of adults with autism. A separate Action Plan will provide further detail about the individual steps we will take to address the key issues in each area.

Services for adults with autism in Southend and Thurrock are the responsibility of the respective unitary authorities for these areas. However we will work closely with these authorities to develop a consistent approach across the county to ensure a consistent all Essex Approach.

2 The needs of adults with autism, definition of Autism and Asperger Syndrome

Autism is a lifelong disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

It is a spectrum condition, which means that, while people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over – or under-sensitivity to sounds, touch, tastes, smells, light or colours. People with autism often prefer a fixed routine and can struggle with new, unpredictable or ambiguous environments. Severity of autistic characteristics varies widely across the spectrum. For this reason, it can be useful to distinguish between low functioning and high functioning autism when analysing needs. In addition an individual's capacity may fluctuate according to age, circumstance or environment.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language. It is mostly a 'hidden disability'. This means that you can't tell that someone has the condition from their outward appearance. They do not usually have the accompanying learning disabilities associated with autism, but they may have specific learning difficulties. This includes dyslexia as well as dyspraxia or other conditions such as attention deficit hyperactivity disorder (ADHD) and epilepsy. With the right support and encouragement people with Asperger syndrome can lead full and independent lives.

People with the condition have difficulties in three main areas, referred to as "the triad of impairments":

- **SOCIAL COMMUNICATION** - difficulties understanding and using verbal and non-verbal language, such as gestures, stance, and tone of voice.
- **SOCIAL INTERACTION** - difficulties recognising and understanding other people's feelings and managing their own.
- **SOCIAL IMAGINATION** - difficulties in understanding and predicting other people's intentions and behaviour and adapting to new or unfamiliar situations.

These can result in problems initiating or sustaining social relationships, obtaining or sustaining education or employment, travelling, obtaining health care and living independently.

Around half of people with autism also have a learning disability and many of these qualify for support from learning disability services. Others may be of average or above average intellectual ability, have good communication skills and show knowledge or skill in specific areas. They may still experience significant difficulties in key areas but, since they do not require support for a learning disability, find a lack of alternative support to meet their needs. This leaves people in this situation more dependent on families, universal services and community based support.

People with autism can be more vulnerable to mental illness. An inability to communicate effectively, meet self-expectation or those of others, or problems engaging in everyday life can lead to anxiety or depression. Insufficient understanding of autism can also lead to risk of misdiagnosis, such as psychosis or obsessive compulsive disorder, with inappropriate

prescription of drugs. Difficulties with communication, interaction and social imagination can also leave people vulnerable to misunderstanding others' intentions and sometimes poor judgement which can lead to exploitation, exposing individuals to risk of victimisation or criminalisation.

3 Autism in Essex – data and evidence

The prevalence of autism within the adult population is estimated to be 1% of the adult population in England, with the rate among men (1.8%) higher than that among women (0.2%)¹. Based on this, the number of people in Essex who are likely to have autism is set out below:

Population aged 18-64 predicted to have autistic spectrum disorder²

	2012	2020	2030
Essex: Total population	8,411	8,735	9,154
Colchester	1,145	1,238	1,336
Chelmsford	1,033	1,053	1,090
Basildon	1,027	1,060	1,098
Braintree	884	912	949
Tendring	799	823	868
Epping Forest	758	805	865
Castle Point	509	499	506
Harlow	499	518	542
Rochford	488	500	517
Uttlesford	470	497	530
Brentwood	433	451	475
Maldon	370	371	377

Within the autism population, 45% are estimated to be high functioning – ie they have an IQ above 70³. This will include many with Asperger Syndrome.

Population aged 18-64 estimated to have higher functioning autism (referring to individuals with Asperger Syndrome and higher functioning autism)⁴

	2012	2020	2030
Essex: Total population	3785	3931	4119
Colchester	515	557	601
Chelmsford	465	474	491
Basildon	462	477	494
Braintree	398	410	427
Tendring	360	370	391
Epping Forest	341	362	389
Castle Point	229	225	228
Harlow	225	233	244
Rochford	220	225	233
Uttlesford	212	224	239
Brentwood	195	203	214
Maldon	167	167	170

1 Health & Social Care Information Centre

2 Source: www.pansi.org.uk v6.0; accessed November 2012

3 Baird et al (2006) as cited in Knapp, "The Economic Consequences of Autism in the UK (2007);

4 Source: calculated from adult autism population estimates obtained from PANSI.

Where adults with autism qualify for support from social care, they are most likely to be supported within learning disability services. In 2014 ECC data systems were altered to include the capture of presence of autism. Research has found that within the adult learning disabled population, the likely prevalence of autism is between 20% and 30% - and within specialised learning disability services is more likely to lie at the upper end of that range⁵.

People with moderate to severe learning disabilities in Essex⁶

The number of people aged 18+ predicted to have moderate to severe learning disabilities 2013		Total likely to have autism (30%)	Total known to adult social care (LD 18+)
Essex	5561	1668	4017
Colchester	762	191	624
Basildon	694	174	413
Chelmsford	678	170	334
Tendring	574	144	602
Braintree	569	142	441
Epping Forest	480	120	200
Castle Point	338	85	196
Rochford	327	82	123
Harlow	312	78	169
Uttlesford	290	73	110
Brentwood	289	72	179
Maldon	248	62	117

People with learning disability known to adult social care services in Essex by age plus likely prevalence of autism⁷

	Total		Aged 18-24		Aged 25-39		Aged 40-64		Aged 65+	
	LD	Autism est.	LD	Autism est.	LD	Autism est.	LD	Autism est.	LD	Autism est.
Essex	4017	1205	715	215	1163	349	1723	517	416	125
Colchester	624	187	80	24	190	57	259	78	95	29
Tendring	602	181	70	21	139	42	276	83	117	35
Braintree	441	132	85	26	129	39	177	53	50	15
Basildon	413	124	93	28	116	35	175	53	29	9
Chelmsford	334	100	62	19	111	33	142	43	19	6
Epping Forest	200	60	38	11	58	17	95	29	9	3
Castle Point	196	59	54	16	68	20	62	19	12	4
Brentwood	179	54	24	7	35	11	106	32	14	4
Harlow	169	51	34	10	47	14	75	23	13	4
Rochford	123	37	29	9	34	10	55	17	5	2
Maldon	117	35	23	7	28	8	54	16	12	4
Uttlesford	110	33	23	7	30	9	49	15	8	2

This strategy is concerned with adults. However there is information about children and young

5 Emerson, Baines "The estimated prevalence of autism among adults with learning disabilities in England" (IHAL / LDO, 2010)

6 Sources: Total Population – PANSI; Autism estimated according to Emerson, Baines prevalence estimate (higher range); Total known to social care – Essex County Council (Feb 2012).

7 Source: Essex County Council (Feb 2012); Autism prevalence calculated in line with Emerson, Baines at upper level (30%)

people with autism held on the special educational needs database. It is worth looking at this, particularly as these are not dependent on estimates of prevalence. Young people with severe or complex needs may be more likely to require adult services in adulthood.

Numbers of children with a statement of special educational needs with autism as the main category of need (January 2013)⁸

	Total
Essex	885
Mid	260
North East	253
South	229
West	143
Tendring	136
Basildon	118
Colchester	117
Chelmsford	116
Braintree	112
Epping Forest	68
Brentwood	48
Uttlesford	42
Harlow	33
Castle Point	32
Maldon	32
Rochford	31

Autism and mental health

People with autism have been shown to be more prone to mental health problems although research differs on whether they are more vulnerable than people with a learning disability. Affective disorders such as depression and anxiety are the most common co-morbid secondary psychiatric disorders. Rates of depression and anxiety have also been found to be higher among close relatives of people with autism. A systematic review of follow-up studies from childhood to adulthood (Howlin, 2000) concluded that depression, often associated with severe anxiety is the most common psychiatric disorder in adults with high functioning autism.⁹

There are significant overlaps between the presentation of adults with autism, particularly high functioning autism, and the presentation of adults with psychosis. Similarities between symptoms can complicate the picture and lead to misdiagnosis. This means it is possible that some long term users of mental health services who have been diagnosed with psychosis might be more appropriately supported in the context of a diagnosis of Asperger's Syndrome.¹⁰

A recent study in North Wales for the Welsh Assembly Government estimated that 1.4% of cases open to Adult Mental Health services are likely to have autism and almost half of these will not be formally diagnosed. Furthermore the probability of receiving a service from Adult Mental Health is approximately five times greater for adults with autism than in the normal population. The study suggested that this is likely to be an under-estimate of the true prevalence of autism within the Adult Mental Health caseload for a number of reasons including lack of diagnosis and poor recognition.¹¹

8 Source: School Census (PLASC), January 2013

9 Tsakanikos et al "Psychopathology in adults with autism and intellectual disability" (2005)

10 Jackson et al "Mental health services for adults with autism spectrum disorders in North Wales" (2011) summarising evidence on autism and mental health.

11 Jackson et al (2011)

Economic consequences of autism

Diagnosis is hard to obtain for anyone who believes they have Asperger syndrome/higher functioning autism but particularly hard for women with no learning difficulty due to their different presentation and current male-centric diagnostic criteria.

Research carried out for the Foundation for People with Learning Disabilities in 2007 on the economic consequences of autism in the UK¹² estimated that the average annual costs for adults with an Autism spectrum disorder and a learning disability range from £36,507 to £97,863. It was estimated that average annual costs for adults with a high functioning ASD range from £32,681 to £87,299. These estimates include about 59% service costs¹³ with the remainder accounted for by lost employment (for both the person and their family) and family expenses.

The same research estimated that 79% of adults with high functioning autism live in private residences with parents or relatives; 5% live in Housing Related Support accommodation; 16% in residential care and none in hospital. Adults with autism and a learning disability were less likely to live in their own home – the research estimated that 31% live in private residences; 2% in their own home; 2% in a private home with a partner; 7% in Supporting People accommodation; 52% in residential care and 6% in hospital.

For an adult with high functioning autism the annual cost of living in a private household (with or without family) was estimated to be £32,681, of which almost £20,000 was attributable to the cost of lost employment for the individual. Costs for high functioning adults in supported living settings or care homes were estimated to be much higher (£84,703 and £87,299 respectively) and a much higher proportion of this was attributable to the cost of accommodation and support staff.

For adults with autism and a learning disability, the mean annual costs excluding benefits but including lost employment were calculated to be £36,507 for those living in private households; £87,652 for those living in Supporting People settings; £88,937 for those living in residential care and £97,863 for those living long term in hospital. For people living in private households, the largest service cost elements are associated with day care, respite services and adult education. For people in Supporting People settings and residential care, the accommodation itself is the largest cost element.

12 Martin Knapp et al “The Economic Consequences of Autism in the UK” (Foundation for People with Learning Disabilities, 2007).

13 The research took into account health, social care, education, housing and leisure costs – but only where they related to an individual's autism.

4 Our statutory duties and national policy

Within Chapter 4 we have captured the legal and policy context for providing services for adults with autism.

Community Care Assessment	Local authorities are required to carry out an assessment of need for any adult who appears to be in need of community care services and decide whether those needs call for the provision of services. (NHS & Community Care Act 1990, section 47).
Eligibility	<p>Eligibility for a service provided by the local authority must be determined following an assessment of need in line with <i>Prioritising Need in the Context of Putting People First (DH, 2010)</i>. This sets out a national framework based on risks arising from needs associated with various forms of disability, impairment and difficulty. The guidance prioritises the risks into four bands: Critical, Substantial, Moderate and Low.</p> <p>Councils are required to use these bands to determine their criteria for eligibility for adult services. Essex will currently provide services to meet needs that fall into the critical and substantial bands.</p>
Safeguarding	Local authorities have overarching duties to safeguard both children and vulnerable adults from abuse. It is everyone's responsibility to recognise suspected or actual abuse and to take appropriate action.
Equality	The Equality Act 2010 requires all organisations that provide a service to the public to make "reasonable adjustments" to those services to ensure they are accessible for disabled people. Reasonable adjustments are not limited to removing physical barriers to accessing services but include changes to the ways in which services are delivered and ensuring that policies, procedures and staff training all enable services to work equally well for people with disabilities.
Autism Act	The Autism Act 2009 required local authorities and NHS bodies to comply with guidance issued by the Secretary of State for Health in relation to the provision of services for adults with autism.
National Adult Autism Strategy	<p><i>Fulfilling and Rewarding Lives: the strategy for adults with autism in England</i> (DH, 2010), which is backed by statutory guidance, highlighted five core areas for development and action:</p> <ul style="list-style-type: none">• Increasing awareness and understanding of autism across all public services• The development of clear, consistent pathways for diagnosis in every area, which is followed by the offer of a community care assessment• Improving access for adults with autism to mainstream public services and the support they need to live independently within the community• Helping adults with autism into work• Building capacity and capability at a local level to enable local partners to plan and develop relevant services for adults with autism to meet identified needs and priorities.

- Think Autism Update 2014 is an update on the 2010 Autism Strategy and reaffirms the importance of the 5 areas for action identified in the strategy aimed at improving the lives of adults with autism.

NICE Clinical Guideline

The National Institute for Clinical Excellence (NICE) has developed clinical guidelines for the recognition, referral, diagnosis and management of adults on the autism spectrum (Clinical Guideline 142, June 2012).

NICE Guidance (2014) CG 142

List of quality statements

Statement One

People with possible autism who are referred to an autism team for a diagnostic assessment have the diagnostic assessment started within 3 months of their referral.

Statement Two

People having a diagnostic assessment for autism are also assessed for coexisting physical health conditions and mental health problems.

Statement Three

People with autism have a personalised plan that is developed and implemented in a partnership between them and their family and carers (if appropriate) and the autism team.

Statement Four

People with autism are offered a named key worker to coordinate the care and support detailed in their personalised plan.

Statement Five

People with autism have a documented discussion with a member of the autism team about opportunities to take part in age appropriate psychosocial interventions to help address the core features of autism.

Statement Six

People with autism are not prescribed medication to address core features of autism.

Statement Seven

People with autism who develop behaviour that challenges are assessed for possible triggers including physical health conditions mental health problems and environmental factors.

Statement Eight

People with autism and behaviour that challenges are not offered antipsychotic medication for the behaviour unless it is being considered because psychosocial or other interventions are insufficient or cannot be delivered because of the severity of the behaviour.

5 Strategic Areas for Development

5a Autism awareness

Professionals need to understand how autism affects people so that they can identify and respond to the needs of adults with autism. Lack of awareness or understanding in frontline services can also lead to people with autism being treated inappropriately or failing to receive the help they need.

Lack of professional understanding of autism can create a significant barrier to accessing services for adults with autism. Staff in services can make inaccurate assumptions about individuals which can lead to inadequate or inappropriate responses to the person's needs. Lack of professional understanding also means that service providers are not able to accommodate the needs of a person with autism by adapting services or communication. More seriously professionals can misinterpret an individual's communication problems as aggression or lack of co-operation.

Poor quality interactions with professionals, deficits in social imagination and impaired social communication can lead autistic individuals to distrust services which can deter them from seeking or accepting the support they may need.

The consequences of this lack of understanding can lead to individuals with autism experiencing poor outcomes on several fronts. They can be socially excluded as a result of difficulties establishing and maintaining relationships. They can experience economic exclusion through poor educational outcomes and difficulty obtaining employment. They may face increased risk of homelessness through difficulty gaining access to appropriate accommodation or inability to manage the responsibilities associated with living independently. A range of problems arising from autism can also increase the person's vulnerability to all forms of exploitation or bring them into conflict with the criminal justice system.

It is important to ensure that there is a sound understanding of the needs of people with autism throughout services and at key points of the pathway. This does not mean that every practitioner needs to have specialist expertise in autism, but it can be helpful to ensure that within each service there are people with clear expertise who can advise and support colleagues.

Health and social care staff have particular influence over the kind of support adults with autism receive. It is therefore essential that all frontline staff receive autism awareness training. Staff who are involved in carrying out assessments, support planning or providing care or support directly to people with autism may need more specialist training in line with their role. More broadly the council has an interest in promoting autism awareness in other services and among employers as this will support our aims to achieve greater independence and inclusion of people with autism in the community.

Essex County Council has already taken action in this area. We have commissioned a range of autism awareness training ranging from e-learning that is available to all staff up to Level 3 training aimed at practitioners undertaking assessments. This training is available to practitioners in both Adults and Children's services. We have also established Autism Champions in each Essex area to provide advice and guidance to colleagues in social care. We will work with the Department of Work and Pensions to ensure appropriate training and knowledge of how to make reasonable adjustments.

Priorities for action:

Raise autism awareness

Continue the programme of autism awareness training. Ensure that frontline health and social care staff can identify potential signs of autism; understand how to adapt their communication and behaviour; and know how to make reasonable adjustments.

Assessment training

Ensure that all staff involved in assessing people with autism undertake awareness training.

Consider rollout of more advanced training for staff across all sectors (including employment services) involved in assessing people with significant autistic or communication difficulties.

Establish a register of trained practitioners so that people seeking assessment can request someone who understands the needs of someone with autism.

Develop specialist expertise within teams

Develop specialist training and target this at staff involved in support planning and providing support directly to people with autism.

Maintain an Autism Champion in each of Essex's four geographical areas who has clear expertise in autism and can provide advice, information and guidance to colleagues in each area.

Promote awareness in other services

Work with partners and user groups to expand awareness training to other services, particularly care and support providers, education, employment services, benefits advice, housing services, police, probation service.

Explore ways to develop awareness among employers.

5b Recognition and diagnosis of autism

Autism has been under-diagnosed among adults. This means that many older adults on the autistic spectrum have never received a diagnosis, their needs have not been correctly understood and, as a result, support and interventions may not have been effective.

Autism can be identified in early childhood, in some cases before the age of three years. However many diagnoses take place later in childhood or in adulthood, particularly in the case of people with high functioning autism or Asperger syndrome. Access to diagnostic services can be more difficult for adults who have less contact with education or other services that are accustomed to screen for autism. In addition diagnostic services for adults have not been widely available.

The consequence of autism not being identified is individuals and their families living for years without a full understanding of why they feel and behave the way they do. This can prevent people from developing the skills to manage their condition effectively or achieve greater independence. It also means they are unlikely to receive the most effective support or interventions for someone with autism. Some people may be assessed as having a learning disability or a mental health condition and be supported accordingly, when some of their needs may in fact be attributable to autism and require different approaches.

It can be hardest to recognise autism when there is no learning disability. This can lead to needs not being recognised or assessed correctly or people being offered inadequate or inappropriate support. People in this position can be poorly served by public services and experience ongoing problems through their communication or behaviour not being understood or being misinterpreted.

Priorities for action:

Recognition	All front line practitioners need to be able to recognise potential signs of autism, including in people with a learning disability or a mental health condition, and know how to refer someone for assessment.
Screening tools	Develop effective screening tools and / or triage systems to help social care, mental health and other services identify adults who need access to a diagnostic service from an earlier age.
Referral pathway	Review existing pathways and establish a clear referral pathway on an "All Age" basis that links social care, primary health and mental health services to diagnostic services.
Develop diagnostic capacity	Increase capacity around diagnostic and assessment services in Essex. This is entirely dependent on co-operation with Health.

Because autism spans such a wide range of needs and can co-exist with other disorders (or be mistaken for them), a diagnosis of autism alone is not helpful. Diagnostic services need to be able to undertake a comprehensive assessment that can take alternative diagnoses and co-existing disorders into account. They also need to be able to identify specific needs relating to communication, behaviour, physical or sensory conditions that might, regardless of diagnosis, suggest a need for further assessment. A diagnostic assessment also provides a critical opportunity to identify risks to the individual or to others and initiate action under safeguarding protocols or a risk management process.

Priorities for action:

Scope of diagnosis	Diagnostic assessments need to be able to identify alternative diagnoses and make links to other services.
Identify specific needs	Ensure diagnostic services have capacity to identify specific needs that might require further assessment, regardless of diagnosis.
Safeguarding and Risk	Ensure diagnostic services incorporate full risk assessment and establish clear links to safeguarding processes.

5c Improving diagnostic pathways

Autism spans a broad spectrum of need, there is no single service that meets all the needs of people with the condition and pathways between the various services that do provide support are not integrated. This creates confusion both for people with autism, their families and for professionals in different services.

At the same time, some people can fall between gaps between services and find it difficult to access support when they need it.

Diagnosis is not an end in itself but should be part of an integrated process that assists adults with autism to access the support and services they need. However, because autism crosses a number of public service boundaries, such as health, social care, mental health, education, it can be difficult for people with autism – and for the professionals supporting them – to navigate between services and individuals can fall into gaps between services.

As a large county Essex is particularly complex with adult social care services, two mental health trusts and seven NHS clinical commissioning groups. There are also a range of voluntary organisations and user groups providing support and services across the county. A key aim of this strategy is to clarify pathways between services and make it easier for people to find and gain access to the right level of support. The current pathway is shown in Figure 1.

Diagnosis needs to be followed up with information, advice and guidance about autism, plus signposting to sources of help and support.

When an adult is diagnosed with autism, diagnostic and assessment services need to be able to provide the individual and their family or carer with relevant information to help them understand the condition and how it affects people. It is also important that individuals receive information about sources of help for them and their family. This includes contact details for local autism support services, voluntary organisations and signposting to sources of information, such as the *Living with Autism* section of the NHS Choices site.

Priorities for action:

Information, advice and guidance

Map sources of support for people with autism in Essex. Develop autism specific IAG, which includes provision for mediated access to sources of support, to which all partners can refer.

Build on existing partnerships with voluntary sector and user groups to provide specialist information, advice and guidance across Essex.

Diagnosis must be linked to further assessment of individual need.

A diagnosis of autism does not provide a guarantee of support but it should lead to a fuller assessment of needs. It is important that there are clear pathways from diagnostic services to further assessment by health, mental health or social care services and that practitioners know how to make referrals.

We will ensure that adults receiving a diagnosis of autism are offered a full Community Care Assessment to determine whether they are entitled to support from Adult Social Care. Essex

will currently provide support to meet needs that fall into the critical or substantial bands (as defined by “Prioritising Need in the Context of Putting People First” (Department of Health, 2010). Where people are found to have lower levels of need, they may not qualify for support from Essex County Council, but we will guide people towards alternative sources of help in the community. If an individual’s circumstances change (eg health, housing, support from family) they are entitled to a new assessment.

People with autism may experience difficulties with assessment processes as poor communication or social skills may lead them to give incomplete, narrow or stereotypical responses to standard assessment questions, thereby masking the real extent of their needs. In line with our duties under Equalities legislation, we will explore ways of making reasonable adjustments to their assessment processes to accommodate communication difficulties.

Priorities for action:

Referral Routes	Map referral routes between diagnostic services and other services. Develop a clear pathway showing routes between services for adults with autism. Explore developing joint working protocols between health, social care and mental health to streamline the pathway. Ensure that Integrated Plans between Health and Social Care include provision for autism pathways and services.
Reasonable adjustments	Review social care assessment processes to identify reasonable adjustments for people with autism in line with equality duties. Develop guidance for staff on reasonable adjustments and on interpretation of eligibility in relation to autism.

Build risk management / crisis support into diagnosis and assessment pathway

Many adults with autism only come to the attention of services when they reach crisis point – in the form of a severe mental health problem, physical illness, homelessness or contact with the criminal justice system. This can be a particular problem for adults with autism whose needs do not meet the criteria to receive support from adult social care but who may be vulnerable to abuse or exploitation or whose needs can fluctuate or rapidly escalate in the face of changing circumstances.

Diagnosis and assessment provide an opportunity to identify adults who may be at risk of reaching crisis and putting in place mechanisms or contingency plans to manage risks and prevent crises from developing. This would establish a preventative approach and has the potential to reduce reliance on institutional care maximise, access to support in the community and increase the individual’s independence.

Priorities for action:

Risk Management	<p>Work with partners to ensure that diagnostic and assessment services screen individuals for risks relating to:</p> <ul style="list-style-type: none">Self harm / self neglectHarm to others; anti-social or criminal behaviourExploitation or abuse by othersRapid escalation of problems or recurring crisesSignificant risk of homelessness, family breakdown or carers unable to cope <p>Develop a system of risk management planning for individuals at risk that draws on support available in the person's wider circle and community. Embed this within the social care assessment process. Work with partners to embed within health or mental health diagnosis / assessment.</p>
Crisis Response	<p>Work with adult mental health services to develop a 24 hour crisis management response, plan or escalation route for individuals at risk.</p>

Transition from children's services

Autism is a lifelong condition and many adults with autism will come into adult services via the transition process. Children with autism and their families will usually have support through the Special Educational Needs System. However, unless the individual meets the criteria for support from adult services, this support often disappears once they reach adulthood, leaving them isolated and their family unsupported. The Department of Health and the Department for Education have been working to improve transitions for young people and the *Transition Support Programme* under *Aiming High for Disabled Children* aims to ensure that all local authorities have arrangements in place to meet their statutory duties around transition.

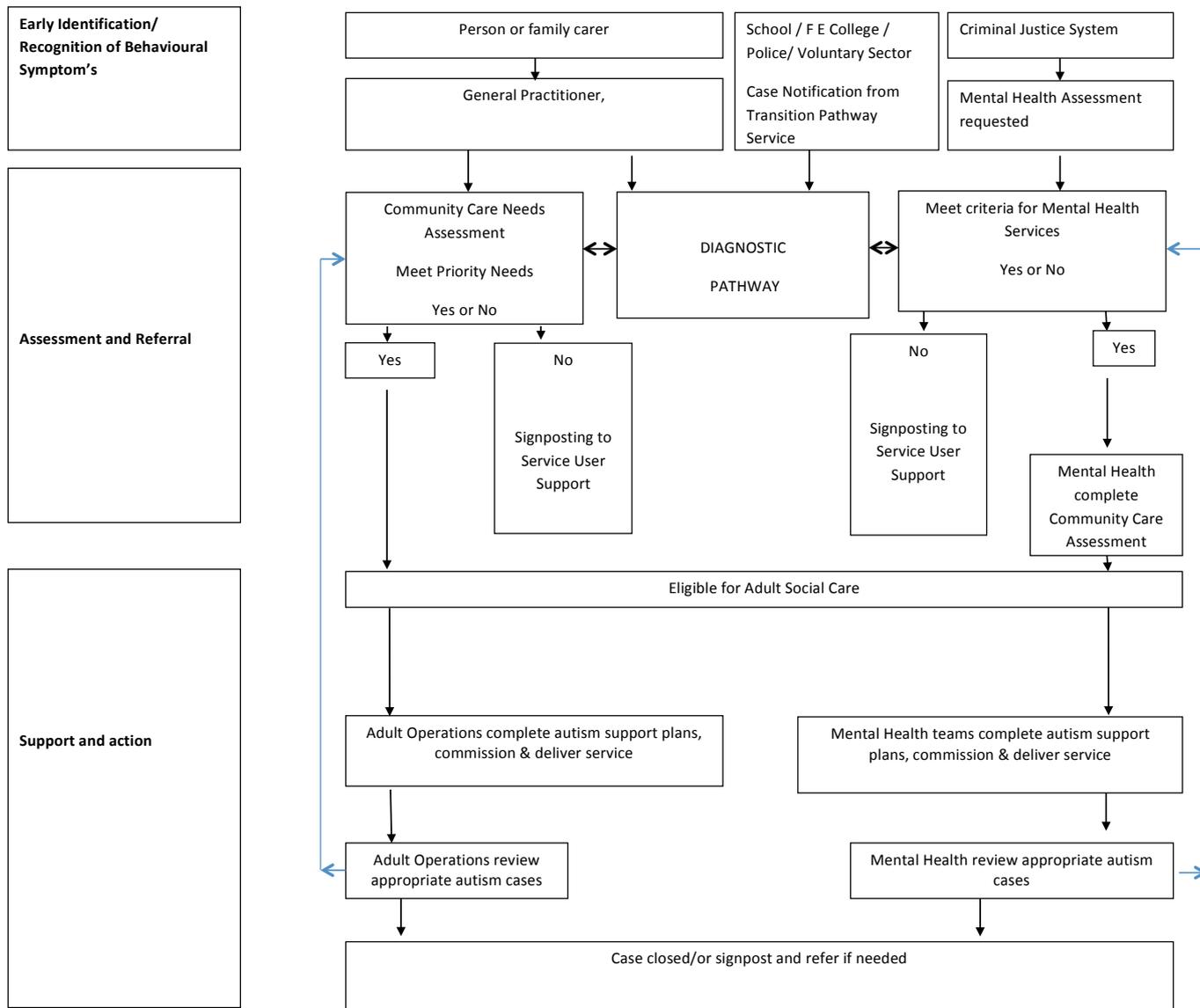
Essex has a multi-agency Transition Protocol covering all local authority and health services involved with young people making the transition from children's to adult's services. This includes young people with autism. The Transition Pathway Services works with services to ensure that young people progress smoothly through transition and referral between services.

Priorities for action:

Preparation for adulthood	Promote education / support that builds capacity to live independently in the community in adulthood. Emphasise development of independent living skills; communication skills; employment skills and early intervention to address health or behavioural issues.
Information and advice	Ensure young people with autism and their families receive information and advice about the support available to enable them to plan for the future and make decisions.
Assessment / support planning	Ensure young people with autism are assessed effectively in line with the Transition Protocol and draw up a person-centred plan to identify the support they need to achieve independence in line with their needs.

Overview of Autism Spectrum Condition Adult Social Care Pathway – ECC Adult Social Care

Figure 1



5d Developing support for people with autism

We want to reduce barriers to support that could meet people's needs effectively, whatever their diagnosis. We want mainstream services to be accessible to people with autism and a range of support and interventions to meet specific individual needs to be available. Sometimes this will mean a specialised service is required.

We want more people with autism to be enabled to enter employment and to have the right support to live as independently as possible in the community.

General principles

As well as issues arising from lack of awareness or understanding of the needs of people with autism, many adults with autism can struggle to access the services or support they need because of issues relating to communication difficulties; sensitivity to light or noise or other issues arising from the condition. This can result in adults not accessing help that they need from health, education or community services or amenities which can result in an escalation of need.

A key aim of this strategy is to make it easier for adults with autism to access mainstream public services and support in the community. This will improve the range of support available, especially for people who are not eligible for direct support from social care or mental health services. Under the Equality Act 2010, all organisations that provide a service to the public are required to make reasonable adjustments to those services to ensure they are accessible for disabled people. This includes people with autism.

In some cases it will be necessary to commission or provide autism specific services. As far as possible we want to design services that support people according to their specific needs rather than their condition. This reduces the need for people to have a diagnosis in order to access the support and also ensures that services are inclusive of people with different conditions. However, we recognise that autism specific services can play a major role in enabling adults with autism to manage their condition, develop independence and access mainstream services more effectively.

Adults with autism who also have a significant learning disability (IQ below 70) are likely to receive support from learning disability services. The Learning Disabilities Observatory estimate that between a fifth and a third of adults known to learning disability services also have autism. The risk of this is that the support people receive may not be appropriate or effective in relation to needs arising from their autism condition.

Priorities for action:

Reasonable adjustments across services and the community

Develop guidance on reasonable adjustments for people with autism.

Explore scope for developing alternative access routes and communication channels that are accessible for people with autism, including social media.

Ensure that services we commission or provide are accessible to people with autism and know how to make reasonable adjustments or meet their needs.

Commissioning services	Commission services that are based on meeting specific needs and are inclusive of people with different conditions, unless an autism specific service is significantly more effective or appropriate.
Learning Disability Services	Ensure that learning disability services develop the skills to recognise autism, distinguish needs relating to the condition and develop autism appropriate support and responses.

Develop capacity in services to support people with autism

We know that we need to do more to make sure that people with autism can find the support they need to live fulfilling lives over which they have real choice and control, irrespective of whether they qualify for ongoing direct support from social care. We will be working with people with autism, those who support them, voluntary and community organisations and health partners to develop and deliver the services needed to achieve this.

We expect services to range from low level interpersonal support services, open to all who need them, to more complex support solutions for those who have more specialist needs. This approach reflects what our service users, their families and supporters have told us they want to see, and we believe reflects both best practice and the relevant national guidance and standards.

Priorities for action:

Community-based support	Work with voluntary sector and user groups to develop community-based support, particularly low level interpersonal support, structured leisure activities and information, advice and guidance services.
Person-centred support planning	Explore better solutions in communicating low level interpersonal support services for people who do not qualify for a care and support service.
Social Skills	Develop capacity in social learning programmes (both individual and group-based) in line with NICE guidance.
Life Skills	Develop capacity in structured training programmes in activities of daily living in line with NICE guidance
Managing anger and aggression	Develop capacity in anger management interventions, adjusted to the needs of adults with autism in line with NICE guidance
Anti-victimisation	For adults with autism who are at risk of victimisation, develop interventions based on teaching decision-making, problem solving and personal safety skills, in line with NICE guidance
Challenging behaviour	Develop pathways to support from the Behavioural Advisory Team and related services in Health or Mental Health to support adults with autism to address issues leading to behaviours that challenge services.

Supporting adults with autism into employment

Research by the National Autistic Society found that only 15% of adults with autism in the UK are in full time paid employment, as opposed to 46% of all disabled people. This has financial consequences for people with autism but also means that they miss out on a core route to independence and social inclusion.

In Essex improvement is needed in finding and maintaining employment for adults with autism. We therefore need to prioritise support that helps people to build on their capabilities to develop work skills and to get and keep a job. We will support people to build upon their capabilities to develop work skills and to get and keep a job. At one end of the autistic spectrum, many adults are highly skilled and often highly qualified. If support is needed at all to gain employment, it may relate to getting through the application process or developing the social skills that are required in the workplace. At the other end of the spectrum, autistic adults with learning disabilities may need more support to develop their skills to enable them to access further education and gain a variety of experiences before they are able to consider opportunities for employment.

In Essex, we are working closely with the Department of Work and Pensions to develop employment support for people with disabilities and to help individual's access flexible solutions to help them into employment.

Priorities for action:

Supported employment	Develop capacity in individual supported employment programmes to support people with autism into work
Develop employment support	Identify relevant partners and explore ways to improve employment support for people with autism.
Information, advice and guidance	Develop information, advice and guidance about support to gain employment for people with autism
Employers	Promote awareness among employers about potential benefits of employing people with autism plus information about reasonable adjustments

Housing and accommodation

People with autism need a range of different housing options. Housing authorities are already required to take account of the needs of disabled adults when considering housing provision. This includes the needs of adults with autism. Particular needs that adults with autism may have may relate to proximity to established sources of support and individual sensitivities (ie to light, noise, etc).

For adults with autism who wish to – or have to – live independently, a programme of support is almost as important as the accommodation itself. Levels of support needed could range from personal care, safety, to managing money and help with decision making.

Some adults with autism may rely on residential care. This is particularly the case for adults with severe or complex needs or for older adults who have lost their family carer and have never lived independently.

Priorities for action:

Needs assessment	<p>Develop ways to capture information about housing needs through the assessment process and ensure these are taken into account in local housing plans.</p> <p>Improve data collection about housing needs, particularly numbers of older adults and younger adults likely to need accommodation in future.</p>
Housing Development	<p>Promote the development of a range of housing options that can incorporate care and support.</p> <p>If residential care is required, ensure there is provision that is local community-based, to develop and maintain interpersonal and community -living skills, in line with NICE guidance.</p>
Housing related support	<p>Develop capacity in support services for adults with autism who live independently.</p> <p>Support people with autism to access mainstream housing options, with a range of support options.</p>
Information, advice and guidance	<p>Develop a range of information and advice to enable adults with autism and their families to understand the options available to them, including financial support options.</p>

5e Support for families and carers

People who have autism can be demanding to care for and many are dependent on their families. As a matter of principle we want people to be able to live as independently as possible in the community. This means that families and carers need support to help individuals to achieve this and to maintain their own quality of life.

Autism can have a major impact on the lives of parents, partners, siblings and carers as well as the individual with autism. Many families and carers continue to provide significant levels of support into adulthood. For many people with autism, this support is essential to enable them to sustain their independence. It is frequently when families and carers can no longer cope with the demands of caring that people with autism are obliged to move into residential care with a relative loss of independence and inclusion within the community.

There are a range of community organisations and user groups within Essex providing valuable support to people with autism and their families, but it is not clear whether this is sufficient to reach all communities in need of such support. One priority therefore is to work with the voluntary sector to develop the range of support and advice available.

Priorities for action:

Carer's Assessment	Ensure families of people with autism are offered an assessment of their own needs, including personal, social and emotional support and support to sustain their caring role, including respite and emergency plans
Information and advice	<p>Ensure families and carers are offered information and advice about autism and its management, local support groups and services for families of people with autism.</p> <p>Develop and make available information, advice, training and support to families who need help with the personal, social or emotional care of the person with autism or are involved in supporting the delivery of support and interventions.</p>
Develop peer support, counselling and advice services	Work with user groups and voluntary organisations to ensure availability of peer support and advice across the county

5f Improving evidence and analysis

We do not know how many adults in Essex have autism or how the population is distributed across the county. This makes it harder to plan and design services and means that we cannot be sure where there are gaps in support.

In 2014 ECC data systems were altered to include the capture of presence of autism. This still leaves us over-dependent on estimates of the population of people with autism in Essex based on limited academic studies of prevalence of the condition in other areas of England. We recognise that we need to improve our understanding of

- Specific types and levels of need, including people who may have additional conditions
- Numbers of people in employment or in need of employment support
- Housing and accommodation needs

We need to improve our evidence and analysis in order to understand how to develop services effectively and ensure resources are used cost-effectively to meet people's needs.

Priorities for action:

Special JSNA Report	Initiate research and analysis to establish fuller picture of adult autism population in Essex and pattern of needs. Also to identify extent of gaps in information.
Improve data collection	Explore scope to improve collection of detailed information on numbers and needs of people with autism.
User engagement	Design and develop effective user engagement to support commissioners to analyse, plan and develop services for people with autism effectively.

This information is issued by

Essex County Council/People Commissioning/Adult Autism Lead Officer

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