Children's Trust Approach in Essex

Putting Children and Young People First
Thurrock Children's Trust

EASTERN Development Centre
Supporting improvements in Health and Social Care in the East of England

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Supporting the emotional and mental health needs of children with learning disabilities.

CAMHS LD Commissioning Plan
January 2010

Purpose of the document

The purpose of this document is to produce the research findings of the Review Team which was commissioned to

- map out the current services available to support the emotional and mental health needs of children with learning disabilities/ difficulties
- determine gaps in services
- to develop a draft commissioning plan for Essex, Southend and Thurrock

and present the draft Commissioning Plan for 2010 -2013.

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Contents

Please note that this commission refers to the whole of Essex. Therefore where the information within it refers to the whole county it is referred to as Essex. Where it refers to Essex County Council only it will be referenced as Essex CC, Thurrock Council will be referred to as Thurrock and Southend Council as Southend.

Supporting the emotional and mental health needs of children with learning disabilities

1. Background

1.1 The Essex CAMHS Joint Commissioning Executive priorities for 2009/10 identified CAMHS LD as a key priority. Services for children and young people with learning disabilities and emotional/mental health problems were also highlighted in the Children and Young Peoples Partnership Plan (CYPP)[1] and are a proxy target within Local Area Agreement (LAA) as part of NI 51 Improving the effectiveness of CAMHS.[2]

1.2 It has been recognised that there are significant inequalities in provision for CAMHS LD across Essex, Thurrock and Southend and it was agreed that there is a need to reassess the various models of provision and develop a county wide comprehensive service based on best practice and the National policy.

2. Introduction

2.1 The Eastern Development Centre (EDC) was commissioned by the Essex CAMHS Joint Commissioning Executive (JCE), including the two unitary councils, Thurrock and Southend, to undertake an extensive review of the services available to children and young people with learning disabilities/ difficulties (LDD) with emotional and/or mental health problems.

2.2 The agreed Project Mandate states

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The EDC will:

- Map the current CAMHS LD models of provision from 0-19 years
- Identify gaps in provision based on evidence
- Produce a comprehensive commissioning plan based on best practice and the National CAMHS LD strategy which will enable the CAMHS Joint Commissioning Executive to commission a comprehensive integrated CAMHS LD service across the county.

[1] Our Children and Young People, Our Partnership, Our Plan – Children and Young People's Plan 2006-09, Summary of progress 2008. Children's Trust Approach in Essex and Essex County Council.
[2] NI 51 Effectiveness of Child and Adolescent Mental Health (CAMHS) services DCSF DSO, 2008

2.3 It is important to recognise the inter connection with other areas of work and we would particularly draw your attention to Aiming High for Disabled Children.[3]The rationale for this being that some of the children and young people will be the same, requiring support and resources from those services commissioned through the CAMHS LD Commissioning Plan and/or Aiming High for Disabled Children Commissioning Strategy[4]. Each of the authorities has already done extensive work to develop their Aiming High for Disabled Children opportunities. With this is mind we have worked collaboratively with the Project Lead for Essex CC to better understand the shared agendas and had discussion with Thurrock and Southend AHDC Leads.

2.4 When considering the data available in the report it should be recognised that the data used has been provided by Essex, Thurrock and Southend in relation to the CAMHS LDD component using the Schools Census data and by Essex CC SENCAN data base in relation to the AHDC component. This therefore means that there will be some deviation depending on the date in time and the criteria used which differs between the two databases.

2.5 In order to further maximise opportunities for children and young people with learning disabilities/ difficulties this report should be considered in conjunction with

- Essex Children and Young People's Emotional Health and Well-being Strategic Implementation Plan
- The Review of Children's Trusts arrangements in Essex
- CAMHS Transformation Project (Southend Borough Council and South East Essex PCT)
- The Review of Speech, Language and Communication Services currently underway.
- Mental health training for Essex Tier 1 and 2 children's workforce.

2.6 It should be guided by National policy and guidance including

- Every Child Matters
- The National Service Framework (NSF) for Children, Young People and Maternity Services with particular attention paid to Standard 8.
    - Local authorities, primary care trusts, and CAMHS ensure that:
        - Disabled children have equal access to child and adolescent mental health services
        - Appropriate mental health service are available for;
            - Disabled children suffering from traumatic accidental injury

[3] Aiming High for Disabled Children: better support for families, May 2007
[4] Aiming High for Disabled Children in Essex (proposed Commissioning Strategy 01.01.10)

    - Children and young people with complex health needs and life-limiting illnesses, and the siblings of disabled children
  - Assessments and services for children and young people with learning disability and mental health needs are provided by professionals with expertise in learning disability and children and young people's mental health
  - Services are planned and commissioned on a multi-agency basis
  - Local child and adolescent mental health service development include plans for improvement in services for children with a learning disability across all four tiers of provision;

and Standard 9: The Mental Health and Psychological Well-being of Children and Young people which has ten markers of Good Practice, all of which are relevant to all children and young people. However marker 6 states;

- All children and young people with both a learning disability and a mental health disorder have access to appropriate mental health services.

- Children and young people in mind: the final report of the National CAMHS Review (Nov 08)

- Do Once and Share (DOAS): National Care Pathway a mental health care pathway for children and young people with learning disabilities.

- The Royal College of Psychiatrists Quality Improvement Network for Multi-agency CAMHS (QINMAC) have developed a set of standards for measuring the delivery of Tier 3 Learning Disability CAMH services (QINMAC LD).

- Aiming High for Disabled Children

- Local Area Agreement (PSA 12) Proxy target 51; this performance indicator for local authorities also aims to ensure that a full range of CAMHS for children and young people with learning disabilities has been commissioned for the council area.

  The detailed definition of this translates to:

  - Partnership working and protocols are in place to ensure that co-ordinated and integrated packages of care are available for children and young people to meet their health, education and social needs, including links between CAMHS and other services for children with learning disabilities and special educational needs services, paediatrics and children with disability services.

- Services should be provided by staff who have the necessary training and competencies to deal with children with learning difficulties and mental health needs.
- Commissioners ensure that joint agency planning and commissioning takes place between health, children's services (including social care and education) and the voluntary sector for children and young people with LD who have severe, enduring and complex needs.

3. Methodology

In order to review the current services and develop a draft commissioning plan the following methodology was used.

3.1 Steering Group

A Reference Group was set up to act as a catalyst for information collection and sharing. This was then re focused to act as a Steering Group with representative membership from commissioners and the main providers. The role of the Steering Group was to ensure engagement at all levels through the membership.

3.2 Face to face meetings

Face to face meetings were undertaken with commissioners and providers of services across universal (Tier 1), targeted (Tier 2) and specialist (Tier 3) services within health, social care, education and the third sector organisations.

3.3 Electronic service data collection

An electronic template was developed to collect service information and distributed to commissioners and providers in August and re distributed in September. A second template for universal services to complete was distributed in September. The information returned was incomplete and therefore limited in it's usage. This may have been due to the depth of information requested.

3.4 Focus Groups

Focus Groups were undertaken with specific stakeholders including

- Paediatricians
- Speech & Language Therapists
- SENCOs
- PACT Harlow
- ASESME
- Parents
- Children & Young People

And the unitary councils

- Thurrock Council
- Southend Council

3.5 **Consultation meetings**

A series of four one day consultation events was planned, three of which were cancelled and replaced with three half day condensed workshops.

3.6 **Attendance at Parent Workshops**

Two parent events were attended with information stands offering parents the opportunity to discuss their experiences and to respond to the questions used for the Focus Group Meetings.

3.7 **Workforce Skills Audits**

- A Workforce Skills Audit was undertaken by the National Institute Adult Continuing Education (NIACE) on behalf of the EDC. This was drawn from previous audits in North and South Essex and the Eastern Region.
- A Parents' Survey of training and development was also undertaken.

Given the level of information available in the findings they form two independent appendices 1.1 & 1.2 to this report.

3.8 Stakeholders included in the review

- Children and Young People
- Parents and Carers
- 3rd Sector Organisations
- Universal services
- Specialist Health Visitors
- Speech & Language Therapists
- Tier 2 CAMHS worker
- TASCCS
- Children's Trusts
- Tier 3 CAMHS services
- Tier 3 LD services
- Tier 3 CAMHS LD services
- Children with Disabilities Teams
- Educational Psychologists
- Community paediatricians
- Acute Paediatricians

- Special schools
- SENCOs /Teachers in mainstream schools
- Nurseries / pre school provision
- Early Years
- Youth Offending Teams
- Early intervention in psychosis
- Procurement services
- Data analysts within the Councils
- Commissioners
- Advocates

3.9 There were varying levels of response across the stakeholder group and further work would be beneficial with regard to general practice and specialist roles within primary care.

4. Definitions

4.1 The Valuing People definition of learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- A reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development.

This definition encompasses people with a broad range of disabilities. The presence of a low intelligence quotient, for example an IQ below 70, is not, of itself, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder that may be of average or even above average intelligence – such as some people with Asperger's Syndrome.[5]

4.2 The Essex multi-agency definition of a disabled child is:

"A child or young person who has substantial difficulty, either permanent or temporary, in achieving his or her full potential in areas of personal or social development, emotional or physical health, family life, schooling, further education/training or employment."

[5] *Valuing People, A New Strategy for the 21st Century, 2001*

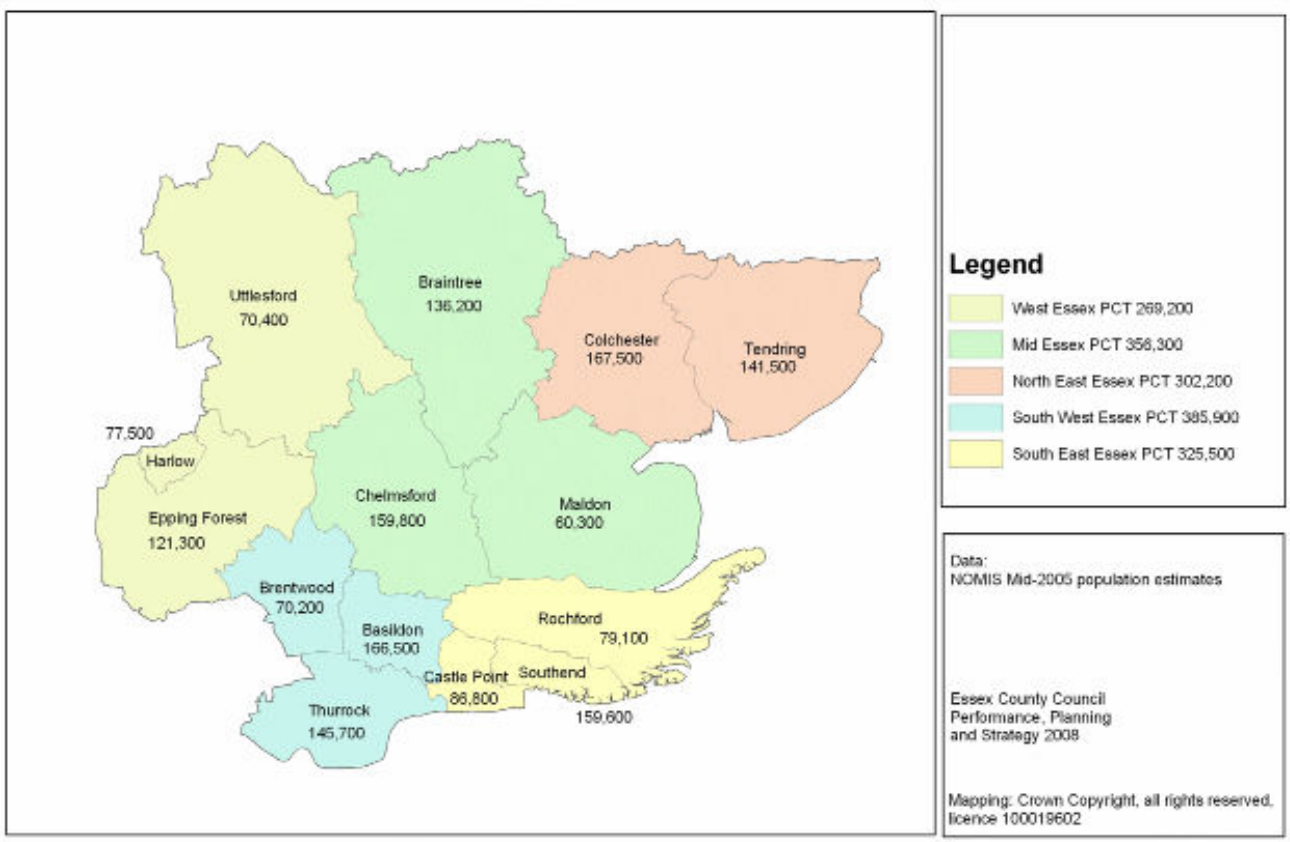
This may be due to:

- a visual impairment
- communication difficulties
- deafness
- physical disability
- a chronic or short-term or life limiting illness
- a psychological impairment.[6]

4.3 For many children with a learning disability there is a high probability that they will have additional needs which require additional support.

5. Demography

5.1 Essex has a population of around 1.66m, residing in its twelve districts and borough councils and the two unitary authorities of Southend and Thurrock.[7] This is expected to grow by 6.5% by 2029. Based on ONS figures for 0 – 19 year old children this will increase from 412,600[8] to 439,419.

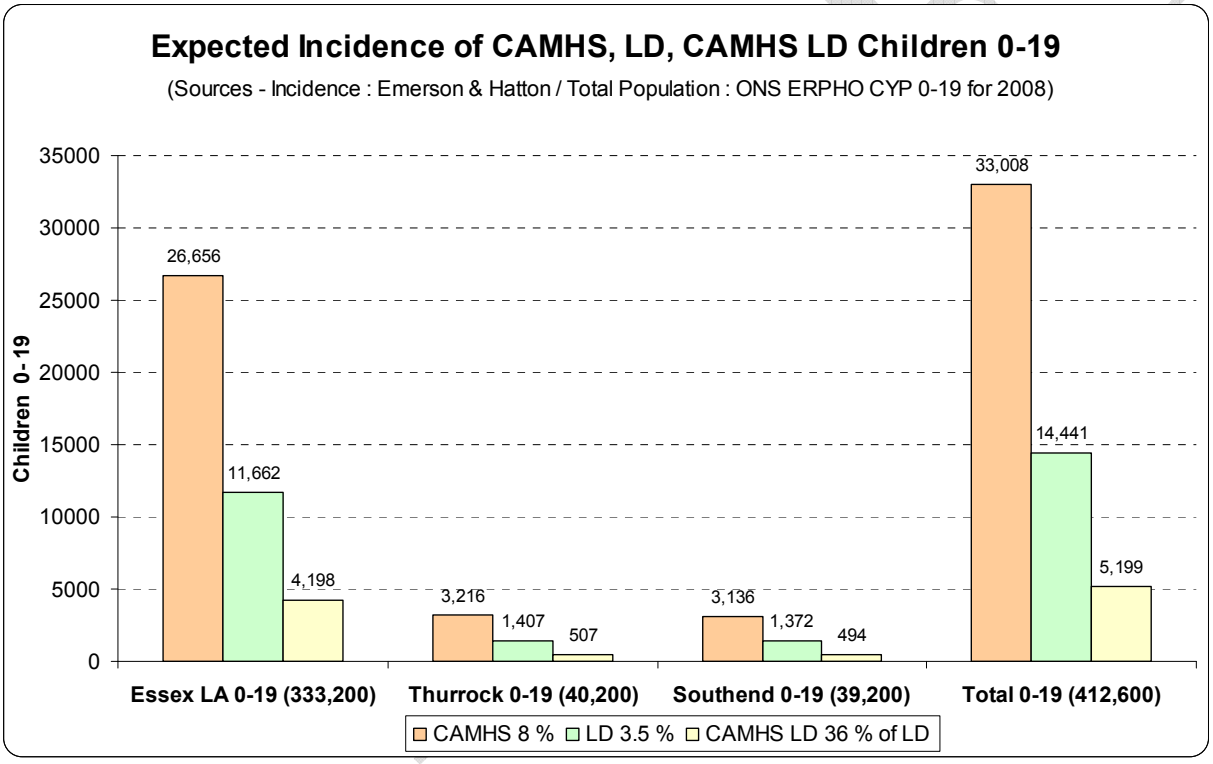


˘ Draft Essex Multi Agency Strategy for Children and Young People with Disabilities, 2009, Children with Disabilities

[7] Essex, Southend-on-Sea & Thurrock Joint Strategic Needs Assessment, 2008

[8] ONS, 2008.

5.2 The table below provides the prevalence data for children with learning disabilities who may require CAMHS. All figures are projected on the basis of 3.5% of population of 0-19yr olds having LD, and 36% of them predicted to need a specialist CAMH service.[9]



5.3 The figures are based on a primary diagnosis of learning disability. Where there is co-morbidity the likelihood of requiring a CAMHS service is likely to increase. This underlines the need for a definition and reporting system to be agreed which embraces a holistic approach.

5.4 The risk of having a mental health problem cuts across all types of psychiatric disorders. Children with learning disabilities are:

- 33 times more likely to have an autistic spectrum disorder
- 8 times more likely to have ADHD

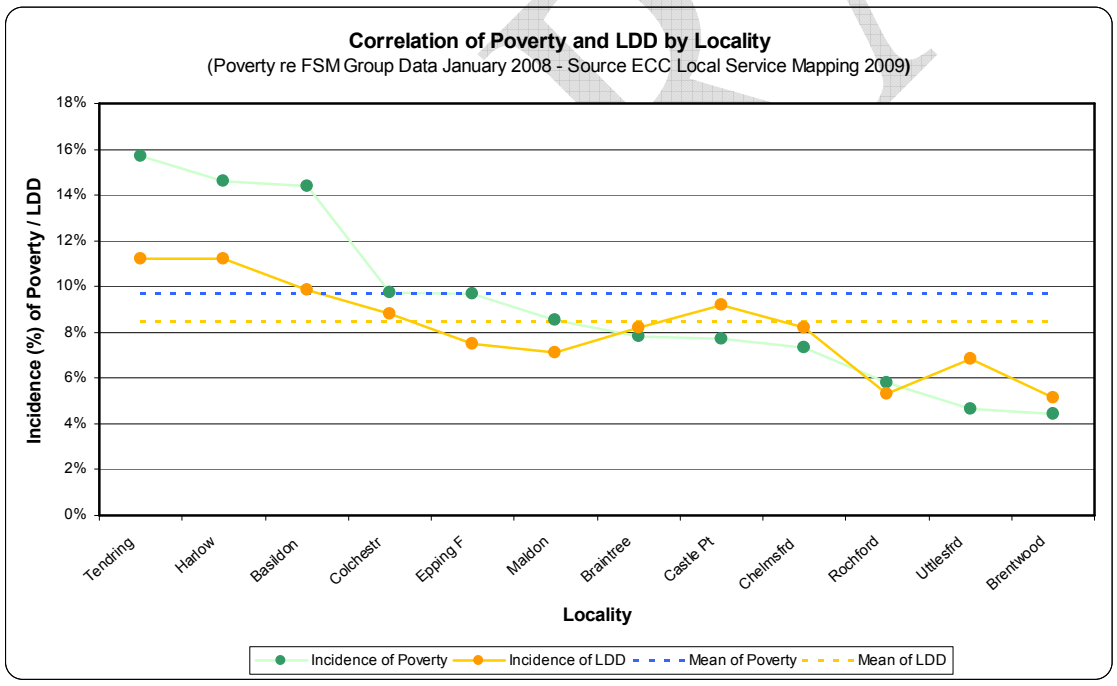
[9] Mental health of children and adolescents with intellectual disabilities in Britain, British Journal of Psychiatry, 2007

- 6 times more likely to have a conduct disorder
- 4 times more likely to have an emotional disorder
- 1.7 times more likely to have a depressive disorder.

They are also significantly more likely to have multiple disorders.[10]

5.5 Many children and young people with complex health needs or life-limiting illnesses need psychological and emotional support to minimise stress. In addition, these children and young people are significantly more vulnerable to mental health problems than other children. Prevalence suggests 11% compared to 8% of the general 0 -19 population.

5.6 There are substantial differences between districts in the percentage of children and young people with learning disabilities (from 4% to 16% based on the Essex CC Service Mapping 2009) and this is represented on the table below which shows the correlation between children and young people with learning disabilities and poverty.



5.7 In addition research shows that of the children in Britain with learning disabilities and a mental health problem:

- 53% are living in poverty
- 45% are supported by a carer with no educational qualifications

[10] The Mental Health of Children and Adolescents with Learning Disabilities in Britain, summary iii, 2007

- 44% are supported by a mother who is likely to have mental health needs herself
- 38% are living in families in which no adult is in paid employment
- 38% are supported by a single parent.[11]

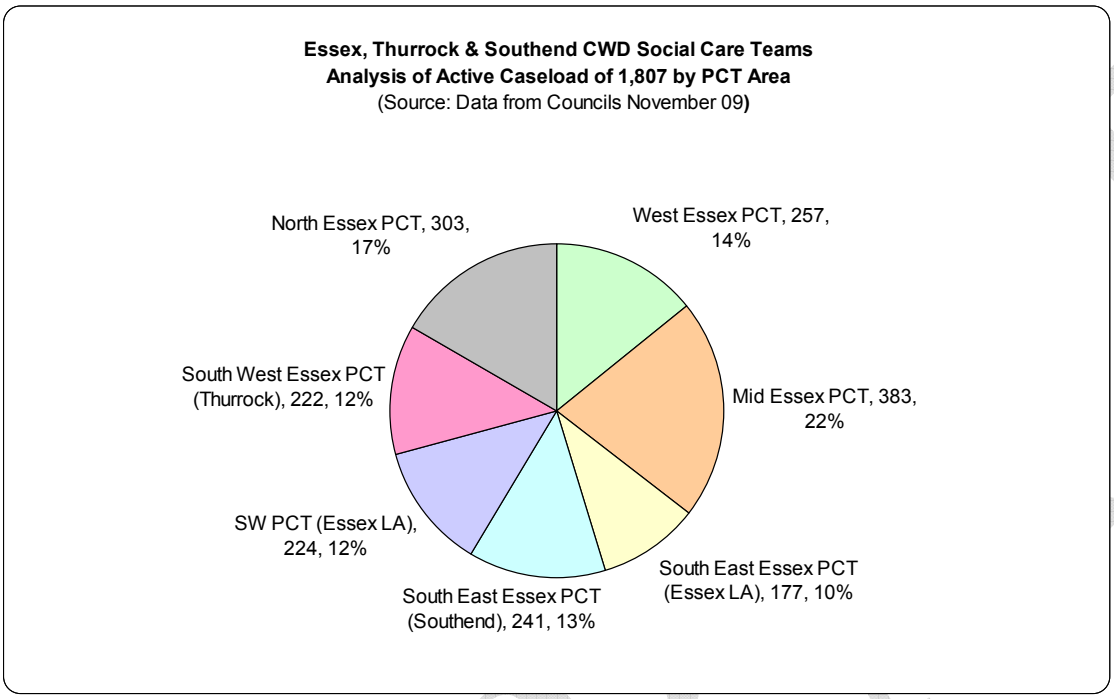
5.8 Given the evidence provided by research and the data available in Essex it is vital that when planning and developing services additional attention is paid to those areas with the greatest health inequalities. In terms of poverty and prevalence of learning disabilities in children and young people these are Basildon, Harlow, Tendring and Colchester.

5.9 Children and young people who are currently on the Children with Disabilities social care teams' active caseload per PCT area:

North East Essex PCT	303
Mid Essex PCT	383
South West Essex PCT (Essex local authority)	224
South West Essex PCT (Thurrock local authority)	222
South East Essex PCT (Essex local authority)	241
South East Essex (Southend local authority)	177
West Essex PCT	257

Source: Essex draft Strategy for Aiming High for Disabled Children, Thurrock & Southend CDW Team Managers.

[11] The Mental Health of Children and Adolescents with Learning Disabilities in Britain, page 22,2007



5.10 Overall, countywide 19% of children and young people from a white background are on School Action, School Action Plus or have a Statement of Educational Needs compared with 14% of non white children and young people. This statistic is mirrored in Essex and Southend but in Thurrock the gap widens with 27% of white compared with 16% of non white children and young people requiring support.

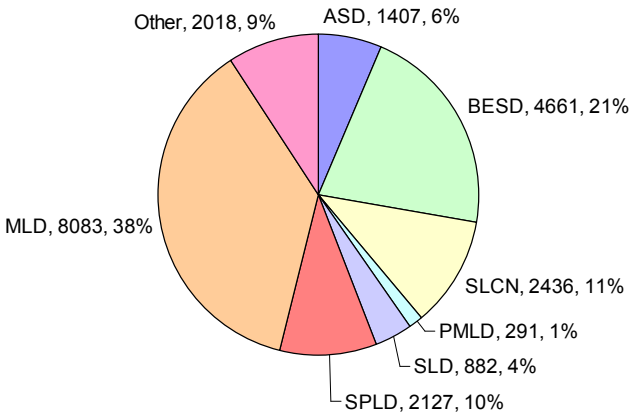
Ethnicity and Special Educational Need				
	All County	Essex CC	Thurrock	Southend
All	19%	18%	26%	19%
White	19%	18%	27%	19%
Non White	14%	13%	16%	15%
Unknown	18%	17%	24%	24%

Source: School Census January 2009

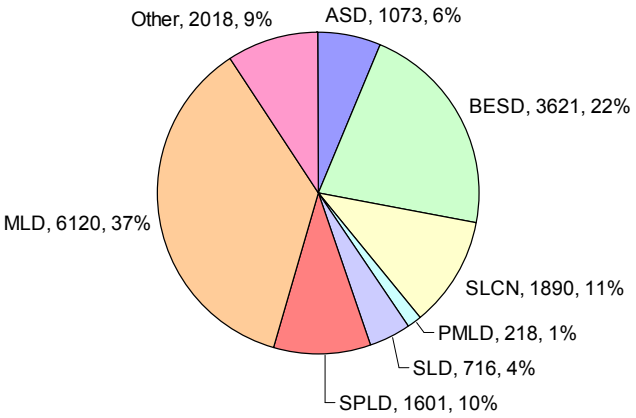
6. Special educational needs of children

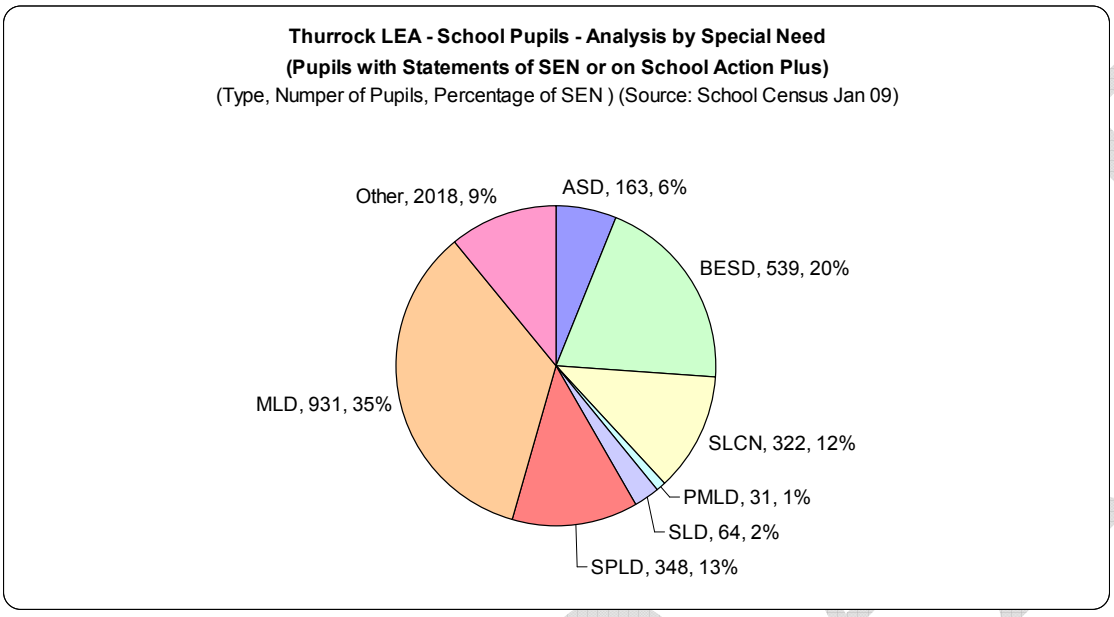
6.1 The tables below show the numbers of children requiring special schools in Essex, Thurrock and Southend or on School Action Plus including BESD and those with speech, language and communication needs.

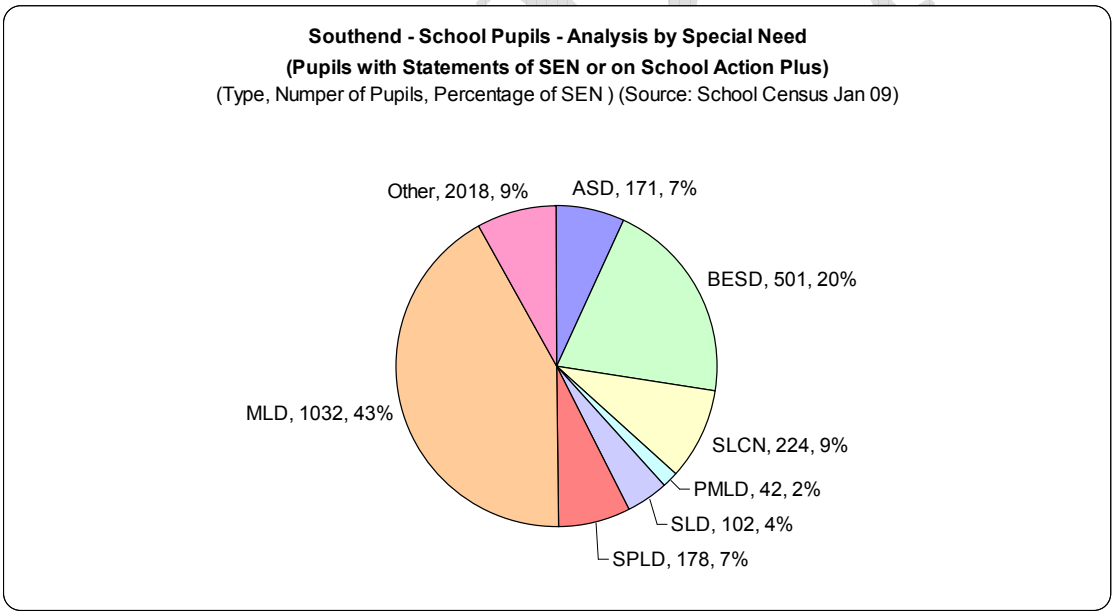
Essex, Thurrock & Southend - School Pupils - Analysis by Special Need
(Pupils with Statements of SEN or on School Action Plus)
(Type, Numper of Pupils, Percentage of SEN) (Source: School Census Jan 09)



Essex LEA - School Pupils - Analysis by Special Need
(Pupils with Statements of SEN or on School Action Plus)
(Type, Numper of Pupils, Percentage of SEN) (Source: School Census Jan 09)







7. Commissioning Resources

7.1 The Commissioning of CAMHS Services is undertaken by commissioners from Essex County Council, Thurrock Unitary Council, Southend Unitary Council and the five Primary Care Trusts (South East, South West, West, Mid and North East Essex). The CAMHS Joint Commissioning Executive brings together all above plus specialist commissioners including SENCAN, Youth Offending and DAT.

7.2 There are gaps in the financial information submitted and the level of detail varied between commissioners. Commissioning arrangements varied in terms of who commissioned services for the PCT with four out of the five PCTs commissioning CAMHS through their children's commissioner. In North East Essex the mental health commissioners are responsible for CAMHs commissioning with additional services commissioned by the children's commissioner and the public health commissioner. The information received demonstrated a coordinated and robust knowledge of services commissioned.

7.3 With the exception of the South Essex CAMHS LD service and the Learning Disability Outreach Service in Mid (located within the CWD Team) and the North East Outreach Team, there is no specifically commissioned service provision to meet the needs of children and young people with learning disabilities and emotional or mental health conditions.

7.4 There is however provision commissioned where the providers state that their service supports all children and young people or their emotional and mental health. In order to ensure that provision has the capacity to support children with learning disabilities, contracts should be explicit in their expectation for provision for children with learning disabilities with outcome measures to evidence delivery.

7.5 Within the Essex CC CAMHS Tier 2 service there are two workers who offer support to children with learning disabilities but this is not specifically commissioned so has risk attached to it. There is no CAMHS LD specific support at Tier 2 in Thurrock or Southend.

7.6 In terms of the South Essex CAMHS LD service this was initially commissioned by the Department of Health as a pilot which has continued and is funded through the Essex CAMHS Commissioner. Stakeholders have identified a capacity issue given the size of the team and it's limited age scope. Staff have raised concerns as to whether this service will be mainstreamed and recommendations regarding this will be discussed later in this report.

7.7 With regard to the children's learning disability service provision in Mid and North East Essex their funding historically was drawn out of the closure of Carlow (Witham) and Kingsmead Court (Colchester) when New Possibilities NHS Trust closed their children's inpatient services and as there was no children's learning disability service, was placed within the adult service. As of the 1st April 2010 the adult learning disability service will transfer to a new provider. The current funding of £290k for the children's LD service will transfer to the CAMHS Commissioner. There is a marked lack of provision in West Essex and an additional £60k has been allocated to start to address this. It is recommended that the £350k is ring fenced for CAMHS LD and transferred to North Essex Partnership Foundation Trust; further recommendations are discussed later in this report.

7.8 With the reduction in the Children and Young People Strategic Partnerships from eleven to four quadrants based Children's Trusts in Essex, there is the opportunity to strengthen the joint commissioning at a local level to ensure there is a balanced and robust approach to commissioned services in the localities. This will enable commissioners to take into account local health inequalities and reduce duplication of provision, providing value for money services. There is a Children's Trust within each of the unitary authorities.

8. Funding Streams

8.1 The needs analysis identified substantial gaps in service provision across the whole of Essex at each tier and therefore in terms of funding recommendations it is important to draw upon funding streams from across the tiers to demonstrate commitment and recognition at all levels.

8.2 Funding streams to be considered are:

- The CAMHS Joint Commissioning budgets funded by the Local and Unitary Authorities and Primary Care Trusts
- Local priority fund
- Community Voluntary Sector Budgets within Primary Care Trusts
- The Local Area Agreement (LAA) Funding
- Transferring funds from adult learning disability commissioners to CAMHS commissioner of £350K and the current CAMHS LD service in South Essex £197k.
- Aiming High for Disabled Children (LA, unitary authorities and PCTs)
- Early Years Funding
- Public Law Outline (PLO)
- Speech & Language
- SENCAN Budgets
- Mandatory training and development budgets i.e. Public Sector Single Equality Scheme training.

8.3 Further consideration is required to determine the workforce and training & development budgets within each organisation which is allocated to mandatory training and that will be linked to the recommendations. In addition training has been commissioned through the AHDC commissioning arrangements (Essex).

9. Current Workforce

"All those involved in this work have a valuable role to play. Educational psychologists are fairly distinctive in having a foot in both areas of concern here i.e. learning difficulties and mental health/wellbeing." [12]

9.1 As part of the review substantial effort has been put into mapping current services and the workforce. However this has proven inconclusive as the returned electronic questionnaires were incomplete and the information was limited. Where the information was lifted directly from procurement information the criteria may have stated 'all' as the client group but this was, on the whole, unsupported within the project description for children with learning disabilities.

9.2 In order to ensure information is available to commissioners it is recommended that additional detail is requested when tendering work to ensure that all services clearly state the client group they offer a service to, the skills of the workforce, and how this will be delivered.

9.3 All staff need to have the competencies to support the child first and to do this the whole children's workforce needs to have core competency training to support the needs of children and young people with learning disabilities in order to offer early intervention and minimise the risk of developing an emotional or mental health condition.

9.4 Whilst the Early Years Services and Paediatricians were actively engaged in the Review there was little response received from other universal services. This may have been for a number of reasons. However if an integrated care pathway is to be developed it is important to ensure that universal services, including GPs and specialist primary care staff, are consulted as part of the consultation period.

9.5 Through the Workforce Skills audit it became apparent that many providers were unaware of the various tiers or levels of service or where the service they work in sits in the overall provision available to children, with or without a learning disability or difficulty. This was particularly apparent among the operational workforce.

9.6 The need for staff to be trained in the manifestations of particular conditions was highlighted by parents of a child with an ASD as certain characteristics could be mis read as safeguarding issues, i.e. flinching or disengaging when approached could be seen as someone being abused when it is a characteristic of the child's condition.

9.7 Concerns were raised by Paediatricians who felt that with the absence of a specialist learning disability service, they were seen as the service to provide it whilst not having the appropriate training. There was a request for clinical

[12] Workforce Skills Audit, NIACE, 2009

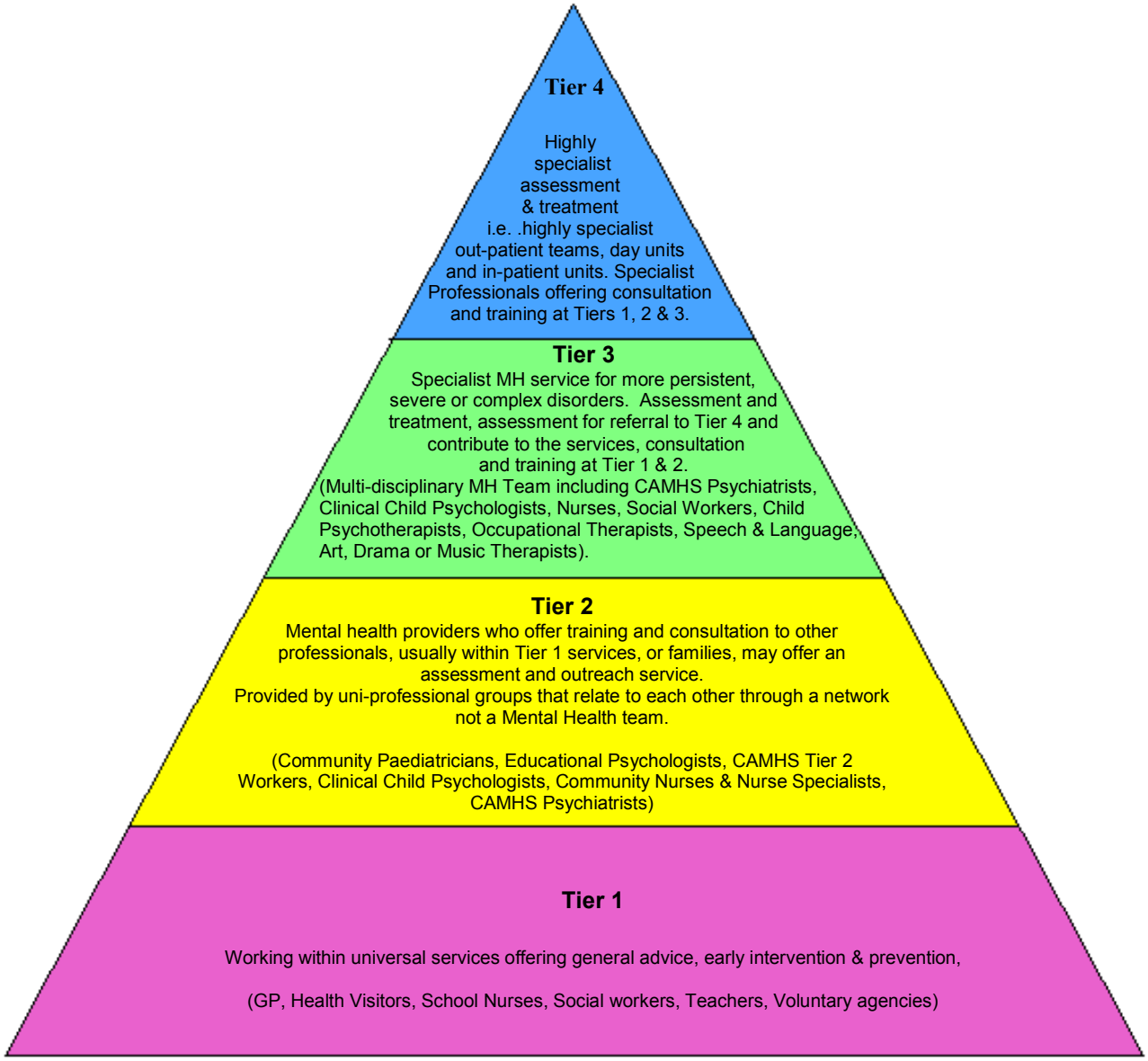
psychology input by paediatricians. This was a particular issue in West Essex which has no LD service and North East Essex where the service has been drastically reduced due to limited capacity.

9.8 Prior to the service in North East Essex being reduced, it was a respected and highly commended service that other professionals are keen to see revitalised.

9.9 In North East Essex there were concerns raised with regard to being able to access the CWD service; this was not the case elsewhere.

9.10 The CAMHS Tier 2 services hosted by Essex CC has just two staff to offer support to children with learning disabilities in Special Schools and these posts are not specifically commissioned to do so. This effectively shows an inequity in services for children with learning disabilities requiring support at Tier 2 and should be considered as the workforce is developed in this service.

The diagram below sets out the four tiers of support for children and adolescents with mental health problems. (*See Appendix A for a more detailed flow chart*)



Primary Mental Health Workers in Special Schools

As part of the Essex Tier 2 PMHW service, 2 Primary Mental Health Workers are attached to Special schools.

Their function is to offer schools

- direct intervention with pupils
- work with parents and families
- casework consultation and supervision
- training
- shadowing/joint work
- group work, relating to the emotional health, wellbeing and behaviour of children with learning disabilities and difficulties in special schools.

This service is highly valued by those who use it regularly as it

- recognises, challenges and develops skills in school staff
- increases confidence in staff's ability to recognise and respond to the emotional and mental health needs of pupils
- gives support on a regular basis, with access to consultation and advice from experienced and skilled workers
- enables decisions to be made swiftly when specialist services are required.

This service has been mentioned regularly throughout the review as an exemplar of good practice, and one that they would like to see extended.

Good Practice Example from Essex

9.11 Within Tier 2 in the third sector many services stated that they were able to offer a service to children with learning disabilities if the child had verbal communication. However, limited support is available for children with learning disabilities if they have no verbal communication. An exception to this is the Youth Advocacy Project at The Junction in Colchester where one member of staff is able to offer support to children with non-verbal communication.

Support @ The Junction: Youth Advocacy Project (YAP)

The Junction is a third sector organisation run by Colchester MIND, and offers a service to young people with emotional, behavioural or substance misuse issues in the Colchester area, with an outreach service in Tendring, and is a CAMHS Tier 2 service.

The service came out of the findings of a National CAMHS needs assessment which concluded that young people want their services to be more accessible, less stigmatising, services provided out of hours, flexibility of location and young person-friendly in approach and setting.

The Youth Advocacy Project has a part time worker specialising in working with children with disabilities, using Makaton and puppets to facilitate communication. He runs

sensory and communication groups in local special schools for children with severe LD and complex needs, and who have limited or no verbal communication.

Good Practice Example from North East Essex

9.12 Throughout the consultation events it was apparent that cross pollination of multi agency working was dependent on the relationships individuals have with peers rather than any formal processes or recognition to work in an integrated and multi agency way. This was not this case where BAMS were in place or MAAGs are being piloted (Basildon Town and Colchester).

Behaviour Assessment Meetings (BAM)

Meetings between CAMHS Psychiatrists and Paediatricians where there is concern about the presenting behaviour of a child, often pre school, and where the underlying cause may be ADHD, Learning Disability, Learning Difficulties, Developmental Disorders.

The function of these regular meetings is to ensure that correct and appropriate decisions and interventions are made for the child without the need for "bouncing" referrals between Specialists.

It also ensures that where doubt remains as to the best care pathway, the child's progress can be monitored.

This service is successful, well used, and valued by the professionals involved.

Good Practice Example from South West Essex

9.13 With regard to the specialist services at Tier 3, practitioners tend to stay within their own discipline with limited interaction across learning disability services and CAMHS.

9.14 The Tier 3 CAMHS LD service in South Essex is recognised as good practice and is favourably received by children, young people and their parents and carers. It is also considered a valuable service by other health organisations, social care and education. However, in order to provide an effective and efficient service additional resources and funding will be required over the next three years.

South Essex CAMHS Tier 3 CAMHS LD service

This small specialist Tier 3 CAMHS LD service, based in Basildon, started in September 2006, hosted by the South Essex Partnership Foundation Trust, funded by the Department of Health. They assess and work with children

- aged between 5 and 11 years of age
- with a severe to profound Learning Disability
- in a special School in South Essex

These children will have mental health problems that are manifested through e.g. sleep disorders, challenging behaviours and stereotyped behaviours. The referred "problem" is usually focused on a change in level of functioning or behaviour, which may be linked to a Mental Health need, (for example long-term enuresis will not be seen but secondary enuresis might be assessed for services). Many children seen by the team will have had behaviour issues for a long time, but these are closely linked to mental Health issues.

The Team

- Consultant Counselling Psychologist (Team Manager) 4.5 days p.w.
- Consultant Child and Adolescent Psychiatrist, half day per week
- Senior Clinical Nurse Specialist – full time
- Assistant Clinical Psychologist –full time
- Volunteer Assistant Psychologist
- Team Secretary

The Team's ethos follows the "This is what we want" report from the Foundation for People with Learning Disabilities:

- Parents "want professionals to assess our needs by observing our family in familiar settings rather than always seeing them in a clinic type setting." The majority of parents of children seen by the Team agreed with this idea.
- They want "flexibility in where they see their therapist and flexibility as to when they see them". They want "access to professionals who have expert knowledge about their disabilities and difficulties, with lots of ongoing support rather than short episodic treatment approaches."
- The strength of the current LD team lies in the very strong partnership links it has developed and the collaborative care plans spanning the different agencies involved with these children. This is in line with the NSF Marker for Good Practice.

Scope of the Team's work

- 60 children referred in the last year. Not all of these children met the criteria for direct work, but the Team also provided consultation to professionals, social workers, health professionals, and school staff.
- Supporting referrals to appropriate services, with the possibility of joint

assessment and intervention
- Involving service providers and users.
- Investment in development of CAMHS staff
- Assessing the impact on the family system
    - sibling issues
    - Parental Relationships and Stress
    - Family Roles

This is a service that is highly valued by the professionals and families who use it. There is a high assessed need for this level of service (which only exists in South Essex) across Essex, Thurrock and Southend, of which the Team are only able to meet a small part.

Good Practice Example from South Essex

9.15 There is limited capacity within CAMHS, CAMHS LD or the Outreach Learning Disability Services to offer support to other services which with the appropriate support and consultation, may be able to offer an early intervention service.

9.16 As a result of this children with learning disabilities are often passed onto the next level of service inappropriately rather than seen as a child first and their needs supported in universal or tier 2/ targeted services. This results in their referral to Tier 3 bouncing back creating a gap in the support they receive, often not receiving a service until the child or family are in crisis.

9.17 Understanding and managing behaviour was identified as an area of concern by some parents/ carers and staff. However, it was also recognised as a means of communication by others, often escalating out of control due to frustration and anger which could have been averted if the child had alternative means of communication earlier.

The Detective Book

Purpose:
The purpose is to reorient and rework the personal and other narratives about the individual. It brings into focus the successful areas of the individual's life which might have been forgotten by attention being paid to areas where the individual may be struggling. It is underpinned by narrative therapy ideas as well as links to attribution theory, Personal Construct Psychology and Attachment.

How it works:
The significant people involved with the child such as the class teacher, parents and others develop a way of noting down the behaviours that they are keen to observe being displayed. Each one carries a small note book which is easily concealed in a pocket etc.

When the child notices that they are for example paying attention they might want to record this in the note book. This might be brought to their attention by the adults. They might say," I noticed that you were listening" and put the time and for how long this behaviour was maintained. Over the duration of the week/day all would be compiling the notes.

At a time set aside by agreement everyone comes together (this might be done separately at home and school). Notes are compared and a reason assigned for the behaviour observed. These might include remarks such as" I noticed that you were in control and had made a choice that suggests that you are a thoughtful person."

There might be other attributional statements that could also be assigned. It might be that by agreement of all present each one agrees to look out for and record observations that suggest that the person is being thoughtful etc.

Over the time of intervention different behaviours are observed and targeted to rewrite the individual story so that a different future is possible and desirable.

An example of a positive intervention used within Educational Psychology in Essex

9.18 Concerns were raised regarding the 'recruitment from the gate' of parents wishing to work as Learning Support Assistants (LSAs) for children with special needs resulting in staff with the lowest level of skills supporting those with the greatest need. This has resulted in the breakdown of placements in mainstream schools being reported.

9.19 Many stated mainstream school staff do not have the skills to support children with learning disabilities and this can have a detrimental effect on the child's emotional and mental health. This reinforced the view that more training should be provided for all so there is a universal service for children with learning disabilities.

9.20 Question 13 of the Workforce Skills Audit[13] asked 'how satisfied are you with the training and development opportunities available a) for you personally and b) for the workforce as a whole. Out of 120 responses for a), 62 respondents were not particularly satisfied and 15 were dissatisfied. Out of 117 respondents for b) 64 were not particularly satisfied and 22 were dissatisfied. Those who selected dissatisfied for self included a foster carer, a social worker and two doctors, and for the workforce as a whole a foster parent and a social worker.

9.21 Tier 2 CAMHS workers were seen as crucial, providing the 'glue' between the tiers for children with mental health problems by those people participating in the Focus Groups with regard to intervention, joint working, advice and consultation.

[13] Workforce Skills Audit, 2009 page 25/26

However, capacity to support children with learning disabilities and emotional or mental health problems is limited and inequitable.

9.22 The Workforce Skills Audit highlighted

'there is a lack of any or unifying 'core' training that is shared across the respondents to this survey from what is known to be a complex and highly differentiated workforce that seeks to work effectively across sectors and professional and organisational boundaries.' [14]

10. Age Criteria

10.1 Throughout the Review concerns were raised by stakeholders that there are no set shared age criteria when transferring from children's to adult services or across disciplines, often resulting in a disjointed service.

10.2 This has a detrimental affect on the ability of the child and their family to access services, particularly at transition from children's LD or CAMHS services where the child requires an adult LD or CAMHS service but may not meet the eligibility criteria for a service similar to that received as a child.

10.3 For many children with learning disabilities who access acute services through the accident and emergency departments, this has further distressed them and their families due to the inappropriate environment and the waiting times. Reports were received of children been sent home due to their behaviour or being placed in a children's ward where staff were unable to support them and other children were then a placed at possible risk.

10.4 For many there is a marked reduction in activities available as the child makes the transition into adulthood from full time education to limited meaningful occupation.

11. Care Pathways

11.1 Concerns were raised by stakeholders throughout the Review with regard to the lack of service provision or care pathway for children and young people with ASD. This was a particular concern of parents with children in mainstream education and in Harlow where there is limited service.

"I have had reports from our parents that local CFCS teams often refer on our children to CAMHS, but they are turned away because specialist expertise they need is not available. And again the question of too high an IQ crops up even

[14] Workforce Skills Audit, 2009 page 24

though mental health problems are obvious …there appears nowhere for our children to go. It's even worse when they reach 18.

One of the major areas of concern is how to manage the anger, frustration and aggression which seems to affect the majority of our children and frequently results in school exclusions…Many have opted out of the system completely and parents are home- educating their children. "Chair of SAFE".

11.2 Parents feel that support for their children with ASD is not always available and that staff are not skilled to offer support. They stated that short breaks are difficult to access due to the complexity of the child's needs

11.3 The exception to this is in South West Essex where the PCT Commissioners have developed a Care Pathway for children with ASD. (Cited but not provided by the Commissioners to the Review Team)

11.4 Paediatricians in North East Essex stated they are cautious to give a diagnosis too early as it provides a label that may not be the most appropriate and they prefer 'watchful waiting' to see how a child develops, and, they recognise the impact an inappropriate diagnosis can have on the child and their family.

11.5 Lack of understanding by GPs of when, where and who to refer to can lead to prolonged waiting and inappropriate referrals for children with learning disabilities and emotional or mental health needs. It is therefore important when developing the protocols to support the care pathways that there is involvement from GPs.

11.6 The consensus is that the current care pathways are poor and many children fall between the gaps due to disjointedness and lack of understanding of the eligibility criteria to access services and the lack of capacity within the CAMHS LD service in South Essex and the LD Outreach services in North East and Mid Essex, with no service in West Essex.

11.7 Throughout the Review many stakeholders felt that the tier system was no longer valid and that services should be needs-led, putting the child first and offering ' a team around the child' which includes the needs of their parents and siblings in its' approach.

11.8 Knowledge of eligibility and/or alternative support at each level was seen as a barrier to accessing a timely service, often leading to deterioration in mental health and wellbeing before a service is offered.

11.9 Access to Tier 3 is seen as particularly difficult with many practitioners no longer referring children due to the eligibility criteria and the number of 'bounce backs' leading to children receiving a limited service based on the skills or knowledge of the person supporting them.

11.10 In North Essex there is limited Consultant Psychiatry support for children with LD and emotional or mental health issues from the Adult LD Consultant in Mid Essex.

11.11 Parents and teachers raised concerns that when a child develops a mental health condition it is not seen as such but as an additional manifestation of their learning disability. Where it manifests as a behavioural problem the behavioural problem may be addressed but the underlying cause may remain unaddressed, thus representing itself in another way.

11.12 In South Essex there is sessional psychiatric support to the CAMHS LD service.

11.13 Consultation and training to universal services is limited.

11.14 The CAF is seen by some as a barrier to receiving a timely service whereas others perceive it as a pathway in to the most appropriate service. This is based on relationships rather than service provision, enabling providers who have a good knowledge of local services quicker access without the CAF.

11.15 The Early Support Package was highlighted as good practice and of value by parents and carers and practitioners.

11.16 The Unified Plan was also highlighted as good practice and seen as a useful tool by some practitioners.

11.17 It was suggested that services should offer a team around the child approach and families should have a one point of contact regardless of the number of services they access, with a Lead Professional identified.

11.18 Education and additional support in schools was identified as been an integral part of the care pathway.

11.19 Special schools highlighted the lack of CAMHS Tier 2 workers in their schools and the need to address this.

11.20 A statement of special needs or a diagnosis were seen as the only way to access a service by many parents, with many stating they had to fight to access services that should be readily available to their children.

11.21 The Review found there were huge gaps between universal and specialist services with limited knowledge or understanding of what other services provided, resulting in overlaps and gaps.

11.22 Where Tier 2 CAMHS services are commissioned within the third sector these predominantly are not commissioned to support children with learning disabilities.

11.23 Parents describe a feeling of not being listened to or their knowledge of their child being insignificant when in fact they hold a lot of valuable information.

11.24 For some parents there were concerns about the levels of service their child received from appropriately skilled staff and the timeliness of the support.

11.25 Communication is recognised as an issue for both the child accessing a service and the provider being able to offer a service, with some professionals being wary of children with a learning disability.

11.26 Access to a CWD Team was identified as problematic by special schools, particularly for children with BESD or ASD.

11.27 The Early Intervention in Psychosis team in North Essex informed the Review Team that a tiny percentage of their caseloads are young people with LD and a suspected or first time diagnosis of psychosis, but as they do not record LD they were unable to give specific information. Each EIP Team in North Essex has a CAMHS worker in it. The team provides and receives consultation to and from others.

11.28 In North Essex there is a specific post holder to develop MH & LD services. However it was unclear if this was adult only or across the ages.

11.29 Parents shared feeling intimidated by professionals who showed them little respect, often leaving them feeling like they had to fight to get a service for their child.

12. Information and Communication

12.1 Poor communication between the key organisations (health, social care and education) is seen as an issue. Information sharing needs to improve across all services with shared access to shared information.

12.2 Limited information is available to children, young people and their parents/ carers regarding information, advice and support available for children with learning disabilities, their parents and siblings.

12.3 This was a view shared by practitioners across the tiers with many relying on limited knowledge or peer relationships rather than a comprehensive menu of services.

12.4 A central source of information across tiers and disciplines available to all was seen as crucial and suggestions ranged from a newsletter, database and/or website.

12.5 Peer Networks were identified as a way of building capacity and knowledge.This was further supported by the Workforce Skill Audit responses.

13. Speech, Language & Communication

"A significant proportion of children and young people in both primary and secondary school with special educational needs have SLCN as their primary need.

In contrast, secondary SLCN are associated with other difficulties that the child may be experiencing such as autism, cerebral palsy, hearing loss or more general learning disabilities. The number of children and young people with secondary SLCN is almost impossible to quantify from the primary SLCN group. However, meeting their SLCN should be considered as part of their overall care package."[15]

"Speech, language and communication are crucial to every child's ability to access and get the most out of education and life. Children with speech, language and communication needs (SLCN) are among the most vulnerable in terms of self esteem, learning, mental health issues and adult outcomes." Diana Kelly, Senior Learning Coordinator, Essex.

13.1 Communication skills for all staff across all levels was identified by children, young people, their carers and professionals as a barrier to being able to support children with learning disabilities with additional needs including emotional and/or mental health support.

13.2 It is particularly important for non verbal communication skills to be developed with children, their parents and carers and across the children's workforce, where a child has no verbal communication.

13.3 The Review identified that communication was key for all children regardless of their disability and therefore there is a need to ensure that there are services to support this.

13.4 Behaviour was identified as a means of communication and often frustration where a child has no verbal communication. This then presents a barrier to accessing services required to support their needs, as practitioners across services do not feel able to manage the aggressive behaviours.

13.5 Many comments from parents highlighted that this became harder to manage as their children grew up and often became unmanageable as they became

[15] Bercow Review for Children & Young People (0-19) with Speech, Language and Communication Needs, 2008.

adolescents and adults, resulting in family breakdowns and the need for additional services.

13.6 Physical abuse within the family home by a youth with learning disabilities was described by a Youth Offending Team Manager as one of the reason they become involved with young people with learning disabilities.

13.7 Support for parents to enable them to communicate with their child is seen as crucial to maintain the relationship and this is particularly important where the parents have a learning disability themselves or a mental health condition.

13.8 Special schools felt that they were well equipped to recognise emotional issues in children and families.

14. Ethnicity

14.1 For those children with learning disabilities and a SLCN from BME communities this was further complicated due to cultural differences and the possibility of English as a second language.

14.2 Throughout Review meetings ethnicity was raised only three times, at a meeting with the Data Manager in Thurrock, at the Thurrock Focus Group and at the SLCN Network.

14.3 It was identified once within the workforce skills audit.

14.4 The data suggests that the greatest incidence is in Thurrock. However, it should be considered across the whole county and staff need to have cultural awareness to support children and their families who may have additional needs and are from BME communities. This was highlighted most strongly at the Thurrock Focus Group where a number of professionals related a specific case to the project team.

14.5 With the increasing numbers of people from BME communities moving into Essex consideration is needed to ensure that the workforce reflects the needs of its' community.

14.6 The CAMHS Needs Assessment undertaken in North Essex (2005)[16] identified that there was a lack of specialised services to support children with mental health problems from BME communities. This is further reduced where there is a co-morbidity of a learning disability.

[16] North Essex Child & Adolescent Mental Health Services(CAMHS) Needs Assessment , 2005

15. Early Intervention and prevention

"Paranoid mother syndrome! Premature birth and low birth weight constantly used to explain serious developmental delay, and other odd behaviours in my son. Even when I emphasised he was withdrawing from the world and had lost his speech, I was overruled."

15.1 Universal services are key to offering early intervention to children and their parents as they are often the first point of contact. However the Review highlighted universal services do not have learning disability awareness training or mental health awareness training.

15.2 Delayed development is not always recognised at child development checks as they have been streamlined. Early recognition is often missed and the Essex pilot of nursery places for children from age two and a half years where a potential problem has been identified is seen as a positive move to address this.

15.3 For parents learning that their child may have a learning disability can be traumatic, and universal services need to be skilled up to support parents and identify appropriate support. The 'Early Support Package' is identified as a positive move towards this but comments suggest a relaunch of this would benefit service providers and the service they offer. Providers feel that coordination as a child grows needs to be further considered to provide a joined up service and minimise gaps in provision.

Early Support is the Government Programme to achieve better co-ordinated, family focused services for young disabled children and their families. It is a national programme that has been introduced and used in local authorities, hospitals and community based health services across England.

It provides a standard framework and set of materials that can be used in many different circumstances, and a set of expectations about how services should work with families. Early Support is relevant to all agencies that provide services to families.
It promotes services that

- Work in partnership with parents and carers, so that families are held at the heart of discussion and decision making about their children;
- Integrate service planning and delivery, particularly when families are in contact with many different agencies.

Use of the programme is specified in Statutory Guidance on the Early Years Outcome Duty, the National Service Framework for Children and the National Health Promotion Programme. It is also incorporated within the Early Years Foundation Stage and is a natural part of the Children's Centre delivery.

Source: SEN & CO, News and views from SEN providers, Issue 16

15.4 Attachment at this crucial stage is key to maintaining a positive relationship between the child and its parents and loss of this has been identified as a key issue for the child and their family later in life.

Stepping Stones Nursery

Stepping Stones is a charity run nursery in Colchester which for the last 18 years has promoted nursery care for children of all abilities.

They are committed to the integration of children with additional needs, with 50% of the children with no additional needs and 50% with additional needs, working closely with parents, other support agencies and local schools.

There is a high staff to child ratio to ensure that each child's individual needs can be met and that parents can join in or have time for themselves with a worker. Besides general child care qualifications, staff have qualifications in Makaton, Early Years Development and Special Needs Training.

There is a sensory play area and garden for all children to use, with the aim of developing fine and gross motor skills, perseverance and concentration.

The additional services include daily after school clubs for children with challenging needs, aged 5-8 yrs and 9-16 yrs and social events to provide peer support for parents.

It is unusual for a Nursery to have such a high ratio of children with additional needs, and this service addresses many of the early identification, assessment and intervention issues found in this report.

Good Practice Example from North East Essex

15.5 Incontinence and sleep were key areas where early intervention was seen as a proactive approach to support both the child and their families' emotional and mental health, particularly nocturnal enuresis.

15.6 From the children and young person perspective early intervention and support was dependent on being listened to but they felt this was often ignored by staff.

15.7 Where children had specialist healthcare needs it was identified that parents/carers and staff felt better able to support children if they had received the appropriate training to support the child's specialist needs. This in itself offers early intervention and minimises the risk of a child or their carers developing emotional or mental health needs due to an unmet healthcare need.

16. Psychological, emotional and social development of children with learning disabilities

16.1 Lack of understanding and knowledge regarding the emotional, psychological and social development of children with learning disabilities is seen as an issue.

16.2 This is a particular issue if the child has no physically distinguishable characteristics or when their physical development was in line with their chronological age.

16.3 Accessing services where practitioners had not received child development training and the affects of delayed development on children with learning disabilities, as part of their basic training, was highlighted as a concern across all levels of service including access to acute children's wards.

17. Transition

17.1 Transition from children's services to adult services was seen as a major concern by the majority of stakeholders both in terms of health and social care, with a substantial reduction in service and new hurdles to negotiate.

17.2 From an educational perspective it was recognised that children with learning disabilities in special schools were offered transitional support but that capacity within the transitions teams is stretched. The options available to them for meaningful occupation or employment were limited.

17.3 Children and young people in special schools raised concerns about their ability to cope outside of the protected school environment particularly if they had had experience of a mainstream school placement that had failed.

17.4 In mainstream schools there were examples of 'quiet places' for children if they needed to go somewhere at break times to feel secure; consideration needs to be given to how this supports children if they choose to use this area regularly rather than mix with their peers.

17.5 Many stakeholders described the child's feeling of being different but not knowing why or how the handle it, often leading to children and young people being bullied or put under pressure to prove themselves particularly during adolescence. This would suggest that additional support is offered to meet the social and emotional needs of children during their teenage years and through their transition to adult services.

17.6 Parents highlighted their fears for their children (and themselves) as they become adults and the safe school environment is lost. This was seen by many as a pressure point in their relationship with their child and its' effect on the family.

17.7 Whilst many parents felt able to cope with their child as a small child concerns were raised as to how they would cope with an adult particularly when the child had challenging behaviour and limited support from services.

17.8 Children with learning disabilities in mainstream schools were seen as being at a disadvantage in terms of transitional support as they did not receive a service from the specialist transition team. Consideration is being given to whether the specialist personal advisors transition team in Essex co-locates with the mainstream advisors, as this would offer support and consultation opportunities to mainstream advisors.

17.9 Support during transition at other times throughout childhood were also seen as problematic particularly from pre-school to school and primary to secondary school but also from year to year as children progress through school and find change difficult due to their disability. Where children have been offered a lead in time, to the changes happening in their lives, transitions have gone more smoothly.

17.10 In a small number of examples this has back fired when the lead in was then undermined by a child being placed in a different class or with a different teacher.

17.11 Whilst TAMHS is being developed in all three areas there is nothing specific to suggest this will include special schools but if so it would provide some positive support to children and young people to equip them for any transitional issues. Particular consideration should be given to children with ASD.

17.12 Throughout the review there was limited engagement from further education organisations which given the Government's commitment to improving the life chances of people with learning disabilities and/or difficulties[17] and the provision of vocational courses offered to children and young people from age 14, needs to be explored further.

17.13 The above is further highlighted by the 'inclusion policy' in Essex to support children to access mainstream education which may then lead to them accessing further education provision which does not have the capacity or skills to support them appropriately.

[17] 'Progression through Partnership' A Joint Strategy between the DfES, DH and DWP on the role of further education and training in supporting people with learning difficulties and disabilities to achieve fulfilling lives. (2006)

17.14 Concerns were raised by children, young people, their carers and parents at the level of bullying in mainstream schools as a result of being 'different'. Given that children accessing vocational courses in further educational colleges often do so due to their limited academic skills or inability to cope in the mainstream school environment, their transition to an adult environment will require additional support often as it is being reduced in other areas of their life.

Please note the findings in the following two chapters closely align to the AHDC agenda and are included in the AHDC Commissioning Plans for Essex, Thurrock and Southend.

18. Emotional resilience

18.1 There were strong views from stakeholders that there is a need to develop the emotional resilience of children with learning disabilities, their parents and carers and their siblings.

18.2 Overnight stays were highlighted by parents as a way of offering them support but many stated that information had not been made available to them and therefore they had not had the opportunity to access the service. Information for parents is now being addressed through the AHDC Commissioning Strategies in Essex, Thurrock and Southend. It is vital that information is available not only to those families known to services, but also within mainstream services i.e. GP practices, libraries, schools and in alternative formats.

18.3 Training and development for parents has been highlighted as a key aspect to supporting their emotional resilience and developing the skills required to support their children and build their capacity; this was a particular concern regarding specialist healthcare needs, incontinence and sleep management strategies.

18.4 From the Parents Workforce Skills Audit which was limited to parents attending one of the Consultation events, eight out of ten said they would be interested in training to develop their own skills to support their child and all ten said they would be interested in training on 'how to ask for the help we need when things are not working for us.'

18.5 Other key topics for parents were practical techniques for common problems, 'my child's emotional and mental well-being', 'preparing my child for change and being able to communicate with my child'.

18.6 Through the face to face interviews a number of people working in special schools raised the need to include sex education and understanding emotions as part of the curriculum, to enable the children to understand the changes that are occurring delivered in a way they are able to understand.

18.7 Children themselves asked that they were supported to prepare for life after

school including life skills training and coping with peer pressure.

18.8 Support for siblings to understand their brother or sister and maintain their own world was also considered important and supported through the AHDC short breaks programme.

'This is what we want' guidelines stated that

- Our Families want on-going support rather than the short episodic treatment approach to care.
- To be put in contact with other local services on discharge, for example, support groups, voluntary organisations, leisure opportunities.'[18]

19. Short Breaks

19.1 Short breaks for children and young people with ASD and Asperger's syndrome was identified as of value but sometimes difficult to access due to the complexities of the condition.

19.2 Consideration should be given to parents of children with learning disabilities to support them to remain emotionally resilient and AHDC identifies the opportunity for short breaks as one means of achieving this and offering meaningful opportunities for the whole family.

19.3 AHDC funding also supports the integration to mainstream activities for children with disabilities.

19.4 Respite Care (Overnight stays) were seen as beneficial to the whole family.

19.5 Staff need to understand what normal teenage behaviour is and support the child based on the level of support they want and need in their own home or in the community.

19.6 Parents stated short breaks are crucial but are over subscribed so not readily available.

19.7 Play schemes in holidays need to include children and young people with learning disabilities with skilled staff to support their needs.

19.8 It was further recognised that for those children who attend residential schools for 38 weeks of the year it is particularly important to ensure that they have meaningful occupation and support during school holidays.

[18] This is what we want – Foundation for People with Learning Disabilities.

20. Developing a CAMHS LD Integrated Care Pathway

20.1 In order to consider the options for an integrated care pathway the Review Team visited two CAMHS LD services. Both of the services were Tier 3 CAMHS LD services.

- The Tees, Esk and Wear Service
- Telford Wrekin and Shropshire

20.2 In addition to the visits a desk top review was undertaken of other national good practice examples which resulted in the following services being identified

- Leicestershire CAMHS LD Team
- Wirral Complex Social Communication Team
- Wolverhampton Community Learning Disability Team for Children and Adolescents
- Kensington and Chelsea Children with Disabilities Behaviour and Family Support Team

Common factors in National Good Practice Examples

- All services are regularly reviewed and evaluated by either QINMAC or CORC
- They are multi agency
- Responsive Community based services
- Clarity of Care Pathways in and out of services and Tiers
- All teams have a body of tier 2 workers (LD Nurses, PMHWs, Home School Support workers) with a range of skills and functions
- Co-located with other agencies
- Joint working
- Training and consultation role with Tier 1
- Good relationships across all tiers
- Significantly reduced need for out of county and out of home placements
- Have clear definitions about function
- Have input at Regional Board level

The table above highlights the common factors shared by all six of the National Good Practice Examples identified by the Project Team.
(*See Appendix B for further information of the six services*)

20.3 The services visited were stand alone Tier 3 Services although the Shropshire example was co located in the Child Development Centre along with the Children with Disabilities Team. They also had very good links to Tier 2 workers in their locality based teams. All Teams offer consultation to Tier 1/universal services and Tier 2.

20.4 Consideration was given to national policy with a particular emphasis on the Do Once and Share (DOAS) project[19] and it is recommended that the whole of Essex adopt the key principles from this to develop its approach to an integrated care pathway for children and young people with learning disabilities. These principles are;

20.5.1 Holistic

The needs of the child with learning disabilities and mental health difficulties are central to any service planning and delivery. The full range of emotional, physical, social, educational and practical needs should be considered in the context of the family, with special attention paid to parents'/carers' and siblings' needs.

20.5.2 Child-centred Planning

Service development and delivery should have the child's welfare as paramount (Children Act, 1989). There should be recognition that 'children are children first', regardless of the level of their learning disability and mental health difficulties. The intention should be to develop intervention plans to meet the child's needs rather than reflect service needs. In addition, as in any work with children, their welfare should be paramount, and careful attention should be paid to child protection issues.

20.5.3 Developmental Framework

Throughout assessment and intervention, the difficulties presented by the child should be considered within a developmental framework. This should pay attention to both the child's chronological age and developmental level. Children with learning difficulties may show a more variable pattern of development than those without learning disabilities. For example, their verbal skills and emotional understanding may be above what might be expected given their cognitive developmental level.

20.5.4 Multi-agency commissioning and consideration of referrals

For care to be effective, it should be provided across health, social and educational agencies in a comprehensive and integrated manner. Avoiding duplication of service provision and ensuring effective communication between agencies is essential in offering care which is responsive to the childs and families' needs.

[19] Mental Health Services for Children with Learning Disabilities – Developing a Care Pathway, 2006

20.5.5 Inclusion and equality of access

Children with a learning disability and their families should have equal access to the full range of services that children without learning disabilities have in respect to their mental health and other areas of health, social and educational support. They should be offered appropriate support to access ordinary services where possible, and specialist alternatives where inclusion into ordinary services is not indicated.

20.5.6 Pro-active and problem solving

Services and individual professionals should take a pro-active and problem-solving approach in addressing the needs of children and their families. They should seek to equip themselves with any necessary knowledge base or skills to meet the needs of the child. Working pro-actively will require services to be flexible in several regards:

(i) Referrals on to other services should be treated as requests for service provision. Responsibility for care, or liaison with new services, should be retained by the referring service until it is appropriate to transfer responsibility to another service;

(ii) It will be important to follow up with vigour those families who find it difficult to engage with services, recognising that families may be engaged with several services at once and may find attending appointments difficult. Appointments should be offered in places which are familiar and readily accessible to children and their families, for example, school or home;

(iii) Clinicians should draw upon other resources and support the co-ordination of care in circumstances where they cannot directly meet the child's needs.

20.5.7 Collaborative practice and consent

Service development and delivery should be committed to collaborative practice, which empowers children, their families and advocates to overcome their difficulties and gain the support they need from service providers. Children's views should be actively sought throughout the care process, and information should be provided in a child-friendly manner to enable children to be informed about their care and participate in decision-making.

20.5.8 Co-operative information sharing and communication

Issues of consent, confidentiality and information sharing require careful consideration for children with complex inter-agency involvement. Information should be shared between service providers to meet the needs of the child, but this should be done collaboratively with children and families. Particular attention will need to be paid to information which may be 'sensitive' which might only be shared to protect the well-being of the child.

20.5.9 Encompassing diversity

Professionals should encompass diversity in their planning of services, and within service delivery and evaluation. Diversity relates to the child's level of disability, as well as any cultural or gender issues. Children from ethnic minority groups who have a learning disability may be more likely to face double discrimination in relation to service access.

20.5.10 Therapeutic and quality services.

The pathway should enable children to access the best available local service to meet their needs. Such services should be timely, of high quality and therapeutic for the child and family, offering both comprehensive assessments and interventions. It is recognised that services for children with learning disabilities and emotional/behavioural difficulties are currently undergoing considerable development. In developing services, one should be mindful of the above guiding principles, and should apply them in the monitoring of service quality.

20.6 These principles are recognised and adopted by the QINMAC[20] and reflected in key national documents, which aim to place children, young people and their families at the centre of service planning and delivery.

[20] QUIMAC, Quality Improvement Network for Multi Agency CAMHS – LD Standards, 2007.

20.7 To support the 'guiding principles' and monitor progress quality standards have been developed and are outlined below:

	Quality Standard	Review findings in Essex	Recommendations
Pre referral	• Clear referral criteria and processes are agreed across provider services to ensure new cases get to the most appropriate service to meet their needs • Agreements are made within the overlapping agency network about how to deal with children and young people who do not fit current criteria or are at risk of being bounced between services (e.g. CAMHS/LD services/local authority children's services/special schools/challenging behaviour teams.	• Referral criteria to CAMHS has been raised as a concern throughout the review with many children with LD being bounced back resulting in practitioners not referring children but holding them and offering a limited service. • There is a limited CAMHS LD Service in South Essex and in North Essex the LD Service is not a CAMHS Service. • There is limited interaction between the CAMHS T2 and CAMHS T3 services in Essex and capacity in Thurrock and Southend is limited. Only 2 practitioners in the Essex T2 service offer specific support to children with LD. • Tier 1/ universal services	• Referral protocols need to be established across Tier 1 -3 services taking into account all agencies, and recognising that there needs to be consistency in South Essex with regard to the two unitary authorities. • There needs to be an established CAMHS LD Service in both North and South Essex. • The children's workforce needs to be trained in key aspects to support children with learning disabilities, who may have or develop mental health problems. • The CAMHS LD Referral Pathway at Tier 3 identifies where a child may be referred to CAMHS or CAMHS LD. • A Specialist Liaison post

		do not have specific training in some key aspects to support children with LD or MH problems. • There is a pilot of Multi Agency Allocation Groups (MAAG) in Basildon Town & Colchester, and as part of the Children's Trust arrangements it has been recommended that these are rolled out across Essex CC from April 2010.	is established in both CAMHS LD Teams to support the development of the service and protocols across T1/T2/ CAMHS and CAMHS LD. • The Specialist Liaison post holder will be a member of the MAAGs or its equivalent in Thurrock (BAM) and Southend. • The MAAGs or equivalent will act as the overlapping agency network to ensure that children receive the most appropriate service and are not bounced around the system.
Referral	• First contact is made, ideally with both caregivers and referrer, to clarify referral expectations and what is possible (i.e. within team competencies). • Ideally contact takes place at home or in a setting relevant to the child (e.g. school/short break care setting)	• Throughout the Review we were told that the caregiver and referrer met to discuss the referral, however, there are limited appropriately trained staff to support children with learning disabilities across tiers 1 -3 who have mental health problems. • Where there is capacity	• Capacity to build appropriately skilled staff is required across Tiers 1 -3. • Where the child is already involved with other services the new need should be considered as part of the MAAG to reduce waiting times and minimise escalation of the need.

		either in a specifically commissioned service (SE CAMHS LD) or otherwise evidence demonstrated children are seen in settings relevant to the child or in community based settings designed for children.	
Assessment	• Assessments should be holistic and consider the child's mental health needs within the context of their learning disability and their families' needs • Assessment for mental health difficulties should follow established protocols and good practice (e.g. the NICE Depression and Self Harm Guideline, Children's NSF)	• There are established 'good practice' examples across Essex which include the use of the CAF, the Early Support Programme, the Team around the Child and Lead Professional approach and the pilot and roll out of the Multi Agency Allocation Groups. However, the level of use and the benefits are not consistently reported by practitioners across the workforce and there was limited evidence of how the mental health needs of children with learning disabilities or their	• To ensure that there is a consistent holistic assessment tool identified, the LA and PCT Commissioners should adopt a joint approach to ensure that service specifications for new and existing services are consistent across agencies and providers. • Throughout the Review practitioners stated they used evidence based practice and this was accepted. However, commissioners should ensure that this is written into service specification so that it can be

		families were supported as part of the holistic assessment. • There is not a consistent approach to an identified assessment tool in CAMHS/CAMHS LD or LD Services. Practitioners within these services are keen to develop this.	monitored against agreed outcomes. • As part of the development of an integrated care pathway for children with learning disabilities with emotional and /or mental health problems, a specific assessment tool should be agreed.
Intervention	• Interventions should be individually tailored to meet the mental health needs of the child and their family, taking into account their age, development level, and culture • Emotional and behavioural interventions should be available at all levels of service delivery (Tiers 1-4) from a variety of psychological models (behavioural, systemic, cognitive, psycho-dynamic, and humanistic) in a variety of formats (direct individual, group or family therapy and	• Where specific interventions were identified as being offered to a child in T3 CAMHS LD services, LD services or where practitioners had specialist skills they were tailored to the individual child's needs regarding their mental health. However, there were consistent concerns raised by children & young people, their parents/carers and the workforce as a whole as to the level of skills across the workforce or their confidence in their	• To develop the children's workforce it is recommended that the following core competency modules are developed 1. Mental Health Awareness 2. Learning Disability Awareness 3. SLCN Training 4. Child Development and the effects of a learning disability on normal development. • Cultural awareness should be part of the SES training in Public Sector Organisations and included as good practice

	consultation), always being mindful of the needs for evidence based practice and cost efficiency. • Interventions targeted at mental health issues should be considered within the context of other interventions (social, educational, physical) which the child is receiving. Services should develop effective interagency co-ordination to achieve this.	own abilities to support a child with learning disabilities with emotional or mental health problems. • The child's developmental stage and the effects of learning disabilities on it was raised as a concern particularly by education, educational psychologists and LD and CAMHS services • There was little evidence to suggest that cultural issues were considered with the exception of Thurrock, although this was inconsistent. • There are limited skills within T1/ universal and T2 targeted services to support children with LD who have emotional or mental health problems. However with the additional core competency training identified in the recommendations this	in service specifications with third sector organisations. • Where a child is referred to a specialist CAMHS LD service the identified Lead Professional should remain the Lead to ensure continued support and coordination of all services involved with the child and their family. • Further work needs to be established to determine the preferred assessment tool for Essex, building upon the work in both Trusts and in North Essex LD Services.

		will increase their capacity and support early intervention and prevention. • With regard to an agreed assessment being used across Essex, work is currently being undertaken by LD Services in North Essex but was not complete at the time of the review. Research suggests that assessments can be adapted that are used universally if they take into account the additional needs of the child with LD and their developmental milestones.	
What next? Discharge and re referral	• Discharge from mental health input should be clearly co-ordinated between agencies using existing review procedures. • When considering re-referrals, there should be clear definition of agency roles in relation to new	The Review Team saw little evidence to suggest that this was a robust aspect of a child's care pathway and therefore suggest this is developed as part of the protocols that will be required to support an integrated care pathway.	The protocols to support an integrated care pathway need to be developed as part of the overarching review recommendations, and should be seen as an integral aspect of the developing CAMHS LD services and the role of the Specialist Liaison post.

	concerns, and an agreed inter-agency action plan.		
Implementing the care pathway	Local CAMHS partnerships (or multi agency steering/commissioning groups) should take a significant lead role in implementing the guidance provided in this pathway, to develop local protocols for children and young people with learning disabilities and mental health needs.	• There is a strong commitment from professionals within CAMHS/CAMHS LD and LD services to develop an integrated care pathway across Tiers 1-3. • There is consultation and training offered at differing levels to various services across the whole pathway which is built predominantly on known relationships rather than an identified and pre determined care pathway. • Evidence throughout the review suggested that where services are weak there has been 'a do the best with what we can' approach which limits the support available to children and stretches professionals both in terms of their ability to maintain their own	• Drawing upon the membership of the CAMHS LD Steering Group the Review Team recommends that a Task and Finish Steering Group is established to implement the recommendations of this report and ensure that it is consistent with the DOAS care pathway whilst having a locality based approach which is consistent with mainstream practice and protocols.

		service but also in terms of the skills they have to support children with learning disabilities and their emotional and mental health needs.	

Source: Do Once and Share (DOAS) Mental Health Services for Children with Learning Disabilities: A National Care Pathway

Also see Appendix C for a flow diagram of the above approach.

This section links directly to Commissioning Plan (Independent Appendix 2) providing additional detail.

20.8 To develop a robust service the implementation needs to phased but based upon the key guiding principles and monitored against the quality Standards.This will require building capacity within current services, commissioning new components, decommissioning some services and re-investing the savings to build the CAMHS LD infrastructure.

In order to work towards this over a three year period it is suggested that the following is implemented.

20.9 Capacity is developed in Tier 1 (universal) services and Tier 2 (targeted) /Tier 3 specialist services through core competencies being established across the children's workforce to include specific modules.

- Mental Health Awareness Training
- Learning Disability Awareness Training
- Speech, Language & Communication
- The effects of a learning disability on a child's emotional, psychological and social development

For some of the workforce this will require training in all four modules but for others this may not be the case. These modules should be considered alongside the developing 'Mental Health training for Essex Tier one and two children's workforce'[21] Within this document it is recommended that the Tier 1 & 2 Workforce undertake Mental Health First Aid Training and Everybody's Business in the Essex CC catchment area.

20.10 The Workforce Skills Audit further identified additional training and development that may be developed as part of an overall CAMHS LD workforce training programme. The Workforce Skills Audit is a stand alone appendix to this report. The Review Team recommends that as further funding is invested in specialist services there is a specific requirement across disciplines to provide specific training modules to supplement the above modules and further develop the workforce.

20.11 In addition, and in line with the Public Sector Duties for Disability and Race Equality, all staff across all aspects of the children's workforce should, as part of the public sector duty, undertake mandatory training to equip them to support and understand the needs of people they are employed to offer a service to and their families.

[21] Mental Health training for Essex Tier one and two children's workforce: Care Matters 2009

20.12 Speech, language and communication was seen as one of the main barriers to children with learning disabilities accessing a service in CAMHS at Tier 2 or Tier 3. It was also seen as one of the key factors in the escalation of behavioural difficulties as a child grows.

20.13 In addition capacity within Speech and Language Therapy is limited, with private assessments being funded across the whole of Essex which are expensive and impact on service delivery.

20.14 It is recommended that the number of whole time equivalents is increased to meet demand and to provide training to the workforce. This will reduce the over all spend and enable more effective and efficient services to be developed through re-investment to local services.

20.15 There is an Essex CC plan to increase the capacity within the Tier 2 CAMHS workforce to represent 18wte per 100,000 of the population and it is recommended that within this there are 6 wte per 100,000 of the population LD skilled T2 workers to support children with learning disabilities. It is recommended that Thurrock and Southend adopt this approach. This will build capacity and ensure that there is equal access for children in special schools and also minimise the risk of escalation to Tier 3 and beyond.

20.16 Where additional capacity is built into Tier 2 regarding learning disability trained staff, their support should extend to children with emotional or mental health needs with learning disabilities in Pupil Referral Units and Youth Offending Teams.

20.17 Within Essex CC, court assessments for children with LD tend to be carried out by external assessors privately. It is recommended that these are commissioned internally by recruiting a clinical psychologist to the Core Tier 3 CAMHS service within Essex CC and reinvesting the savings to build capacity as identified in 20.10.8 and 20.10.9.

20.18 A Tier 3 CAMHS LD Service is established within North Essex and further capacity is developed in the South Essex CAMHS LD to reflect the recommended 5-6 staff per 100,000 child population, which is designated to meet the needs of young people with learning disabilities and includes 0.5 wte psychiatrist per 100,000 population.[22]

20.19 The main functions of the CAMHS LD Services will be:-

- To provide timely specialist multi-disciplinary (Tier 3) assessment, diagnosis and intervention for children and young people with LD and their families, for a

[22] QUIMAC, Quality Improvement Network for Multi Agency CAMHS – LD Standards, 2007

range of complex problems where universal children's services have proven insufficient to meet the child or young person's needs.

- To support the development of early intervention strategies across the spectrum of developmental disabilities, focussing particularly on Autism Spectrum Disorders, sleep and behavioural problems.

- To provide consultation, training and support to families, education, social services and other agencies to enhance their skills and competencies to meet the emotional, psychological and social developmental needs of C&YP with learning disabilities.

- To provide multi-agency consultation or liaison for the most complex cases at risk of exclusion or out of area placements.

- To participate in ensuring smooth and co-ordinated transition of current complex patients to appropriate adult services.

- To work in partnership with social services in the provision of respite facilities appropriate to C&YP with LD.

20.20 The CAMHS LD Team will be developed over the three year implementation period and is further detailed in the Commissioning Plan.

20.21 A Specialist Liaison post i.e. a Learning Disabilities nurse is established in each of the CAMHS LD Services. This role will act as the 'glue' across the tiers supporting

- Initial joint assessment between CAMHS and CAMHS LD
- Further complex assessments
- Multi agency work across all tiers
- Consultation and mentoring to Tier 1, 2 and CAMHS
- Training and development
- Membership on the CAMHS LD Multi Agency steering Group

20.22 As part of the care pathway, protocols will need to be established that support the child first and 'team around the child' approach that is needs led, recognising the skills within services, and establishing a care pathway which is supported by referral criteria and joined up processes.

20.23 A specific CAMHS/ CAMHS LD protocol will be established which ensures that no child or young person slips between the gaps in Tier 3 services. The Specialist Liaison post holder will have direct responsibility for managing this and coordinating joint assessments where there is not a clear need. (*See Appendix D*)

20.24 If a child requires a CAMHS service at Tier 3 and attends a special school they will be referred to the CAMHS LD service. If they attend mainstream school they will be referred to CAMHS. Children on the higher functioning level of ASD will be referred to CAMHS initially but with flexibility to be supported by CAMHS LD if this is more appropriate for their needs.

20.25 It is recommended that Tier 3 CAMHS LD, CAMHS and where possible T2 CAMHS are co-located to build joined up support and develop peer relationships, networking and enable shared training opportunities to be established.

20.26 Given the geographical spread in both North and South Essex it should be recognised that practitioners will not always be buildings-based and may work remotely to ensure that they cover the catchment area. To support this they should be appropriately equipped with IT and telephones and have appropriate support from their base.

20.27 Based on the evidence emerging from the Review it is recommended that further training opportunities are developed to support parents/ carers to enable them to support their children with learning disabilities and remain emotionally resilient themself. This is supported by the findings of the Parents Workforce Skills Survey[23] (see stand alone appendix) and AHDC work with parents.

20.28 The need to establish an ASD Care Pathway and services to support it was strongly cited throughout and it is recommended that this is considered as part of the CAMHS LD overarching pathway and it is closely aligned to the recommendations and action plan due to be released in the spring of 2010, following the Autism Bill bein passed in October 2009.

20.29 To date South West Essex is the only PCT to establish a care pathway and it is recommended that this is adopted and dovetailed into the CAMHS LD Care Pathway.

20.30 In addition the Inclusion Development Programme in Essex CC has been established which focuses on supporting pupils on the autism spectrum, and drawing upon its' good practice may offer additional support to the health and social care teams, particularly at a Tier 1/ Universal level.

20.31 To further support the care pathway it is recommended that a shared database is established that enables practitioners in health, social care and education to share information and access appropriate information which has previously been held on a separate database.

20.32 Within Essex CC it is recommended that a recruitment drive to recruit Educational Psychologists to the full establishment is undertaken and a Business Case is

[23] EDC review of CAMHS/ Learning disabilities workforce training and development: The parents survey (appendix (1.2 Independent)) 2009

developed to increase the establishment to the recommended national level of one educational Psychologist per 5.5 – 6,000 children. Currently Essex CC has 1 Educational Psychologist per 7,500 with 8 vacancies. There was no information provided from Thurrock and Southend currently have a their full establishment.

20.33 Where children with learning disabilities are in mainstream schools it is recommended that consideration is given to transition and their additional needs, which would have been provided by specialist Connexions Advisors if they were educated in special schools. This may be by offering additional skills training to mainstream Connexions Advisors, providing an outreach service into special schools or co locating mainstream and specialist advisors.

21. In conclusion

21.1 This report aims to cover the findings of the Review Team which involved a diverse group of stakeholders. Whilst our intention has not been to omit any points raised it should be acknowledged that many points were raised in various guises and have been compiled collectively.

21.2 It also covers three Local Authority areas and it should be accepted that whilst we have endeavoured to comment on the three local authorities collectively and individually the content is based on the level of information and engagement in each area.

21.3 The Review included the five PCTs in Essex, two of which work with both Essex CC and one of the unitary authorities. This therefore impacts on a number of additional reviews underway which should be considered in conjunction with this Review.

21.4 Whilst it is the Review team's intention to cover all aspects of the commission additional work may be required to embed its' recommendations and develop the integrated care pathway described over the next three years.

Glossary

ABG	
AHDC	Aiming High for Disabled Children
AS	Asperger's Syndrome
ASD	Autistic Spectrum Disorder
ASESME	Association of Special Education Senior Managers in Essex
BAM	Behaviour Assessment Meetings
BAP	Behavioural & attendance Partnerships
BESD	Behavioural, emotional and social disorders
CAF	Common assessment framework
CAMHS	Child & Adolescent Mental Health Service
CAMHS LD	Child & Adolescent Mental Health Service for Children with Learning Disabilities
CFCS	Child & Family Consultation Service
CORC	CAMHS Outcome Research Consortium
CVS Grants	Community voluntary sector grants
CWD	Children with disabilities
CYPSP	Children & Young Peoples Strategic Partnerships
CYPP	Children and Young People Plan
DAAT	Drug and Alcohol Team
DOAS	Do once and share
EDC	Eastern Development Centre
JCE	Joint Commissioning Executive
MAAGS	Multi Agency Allocation Groups
LA	Local Authority
LAA	Local Area Agreement
LAC	Looked After Children
LD	Learning Disabilities
LDD	Learning Disabilities &/or difficulties
LCTB	Local Children's Trust Boards
LSA	Learning Support Assistant
LPF	Local Priority Fund
MLD	Mild Learning Disability
NEPFT	North Essex Partnership *NHS* Foundation Trust
NHS EOE	NHS East of England (Strategic Health Authority)
NIACE	National Institute for Continuing Adult Education
NICE	National Institute for Clinical Excellence
NSF	National Service Framework
ONS	Office of National Statistics
PCT	Primary Care Trust (now identified as NHS plus the PCT area i.e. NHS Mid Essex)
PACT Harlow	Parents of Autistic Children Together Harlow
PLO	Public Law Outline
PMHW	Primary Mental Health Workers

PMLD	Profound and multiple learning disabilities
PSHE	Physical Social and Health Education
PSO	Project Support Office
PRU	Pupil Referral Unit
QUIMAC	Quality Improvement Network for Multi- Agency CAMHS
SALT	Speech and language therapy
SEAL	Social & Emotional Aspects of Learning
SENCAN	Special educational needs and children with additional needs
SENCO	Special Educational Needs Coordinator
SEPT	South Essex Partnership University NHS Foundation Trust
SLD	Severe learning disabilities
SLCN	Speech, language and communication needs
SpLD	Specific Learning Disabilities
TAMHS	Targeted Mental Health in Schools
TASCC	Team around the schools, child and community
YOT	Youth offending Team

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