# Overview and Scrutiny Report

# Support for Attention Deficit Hyperactivity Disorder in North Tyneside



October 2016



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# 1. Background to the study

1.1. At the meeting held on 16 February 2015, the sub-committee considered a report produced by the authority's Disability and Additional Needs Service which gave an update on ADHD, detailed the recommendations of the clinical guidelines produced by the National Institute for Health and Clinical Excellence (NICE) <sup>1</sup> ('the NICE clinical guidelines') and provided some local context and information with regards to provision in North Tyneside. Also in attendance at the meeting were representatives from Healthwatch and the Parents' Support Group, All Together Better, who presented a briefing note which summarised the context of their request for the issue to be considered and highlighted questions which they considered remained unanswered.

At the end of the discussion the sub-committee agreed to establish a sub group in the 2015/16 municipal year to examine the support provided for children with ADHD and their families (minute CES33/02/14). On 16 November 2015 the Children, Education and Skills Sub-committee received a report and an initial scoping document for the establishment of a sub group to scrutinise current services available for children diagnosed with ADHD and agreed to begin work on the ADHD sub group in January 2016.

1.2. Councillors K Barrie, P Oliver, J Cassidy, M Huscroft and a church representative co-opted member, Rev. M Vine, volunteered to be members of the sub group and a work programme was agreed.

# 2. Methodology

- 2.1. The focus of the study was to be the support provided for children with Attention Deficit Hyperactivity Disorder (ADHD) and their families with the objective of scrutinising current services available for those diagnosed with ADHD, across both social care and health, and to make recommendations on how the current provision could be improved.
- 2.2. The study would use the NICE clinical guidelines on the diagnosis and management of ADHD relevant to children and young people as a template and look to see whether the Authority was meeting them and where gaps were identified what could be done to fill them.

The guidelines subject areas were:

- 1. The development of age appropriate training programmes for the diagnosis and management of ADHD by specialists.
- 2 Healthcare professionals should offer parents or carers of children access to a parent training/education programme.
- 3. As part of the diagnosis process, people with ADHD require an assessment of the persons needs as well as an assessment of co existing conditions.
- 4. Post diagnosis of ADHD advice about diet, behaviour and general care.

<sup>&</sup>lt;sup>1</sup> <u>Attention deficit hyperactivity disorder: diagnosis and management - NICE clinical guidelines</u> (Sept. 2008, updated February 2016)

- 5. Treatment for children and young people dependent upon the severity parent-training/education programmes, psychological treatment, contact with the child's teacher, drug treatment reserved for those with severe symptoms and impairment or for those with moderate levels of impairment who have refused non-drug interventions, or whose symptoms have not responded sufficiently to training/education programmes or psychological treatment.
- Teachers have received training in ADHD and its management and can provide behavioural interventions in the classroom to help children and young people with ADHD.
- Transition to adult services if receiving care, transferred to adult services
  with transition planned in advance by both referring and receiving services;
  use of the care programme approach considered if needs are severe and/or
  complex.
- 8. Every locality should develop a multi-agency group, with representatives from multidisciplinary specialist ADHD teams, paediatrics, mental health and learning disability trusts, forensic services, child and adolescent mental health services (CAMHS), the Children and Young People's Directorate (CYPD) (including services for education and social services), parent support groups and others with a significant local involvement in ADHD services. The group should:
  - Oversee the implementation of this guideline.
  - Start and coordinate local training initiatives, including the provision of training and information for teachers about the characteristics of ADHD and its basic behavioural management.
  - Oversee the development and coordination of parent-training/education programmes.
  - Consider compiling a comprehensive directory of information and services for ADHD including advice on how to contact relevant services and assist in the development of specialist teams.
- 2.2.1. The Sub Group met on a number of occasions to receive information and discuss their findings and also met with officers from the local authority. To gain an understanding of the services available in the borough the sub group also met with:
  - Members of All Together Better, a parent carer organisation charged with working with the statutory and voluntary sector to improve service provision for all disabled and additional needs children living in North Tyneside;
  - North Tyneside Parent Support Group (ADHD), a peer to peer support group
    which has been running for over ten years (with the support of the Carers
    Centre) which provide parents with a forum where they can learn more about
    the kind of support they might expect from Health and the local authority.
    Increasingly the group have recognised the need to extend this support to
    include parents whose child has ASD, a condition which frequently is co-morbid
    with ADHD.

- Peter Gannon, the head teacher of Silverdale school, a SEMH (social, emotional and mental health) school which catered for the needs of up to forty nine students between the ages of seven to sixteen who experience emotional, social and behavioural difficulties:
- The SENCo co-ordinators group which was a group which had been established in 2015 with support from the School Improvement Service;
- The manager of the Education Psychology Service; and
- Practitioners from the Child and Adolescent Mental Health Services (CAMHS).
   CAMHS offered a mental health service to children and young people aged 0 18 and their families. The team see children and young people for a wide variety of reasons including emotional problems (such as anxiety or depression), behavioural problems (such as ADHD), developmental disorders (such as autistic spectrum disorders) and educational/social difficulties (such as school refusal or peer relationship problems).
- 2.2.2. The Parent Support Group had undertaken a survey of its members, approximately 140 people, and had based the questions on issues that had been raised by their member's on a regular basis to try and have a base figure upon which to measure improvements. The survey was completed by 37 families The results were presented to the sub group; these findings are referred to in the relevant sections of the report.

### 3. Findings/Evidence

#### 3.1. NICE Clinical Guidelines

3.1.1. The NICE clinical guidelines<sup>2</sup> describe ADHD as

'a heterogeneous behavioural syndrome characterised by the core symptoms of hyperactivity, impulsivity and inattention. While these symptoms tend to cluster together, some people are predominantly hyperactive and impulsive, while others are principally inattentive...

Symptoms of ADHD are distributed throughout the population and vary in severity; only those with significant impairment meet criteria for a diagnosis of ADHD. Symptoms of ADHD can overlap with symptoms of other related disorders, and ADHD cannot be considered a categorical diagnosis... Common co-existing conditions in children with ADHD are disorders of mood, conduct, learning, motor control and communication, and anxiety disorders...

Not every person with ADHD has all the symptoms of hyperactivity, impulsivity and inattention. However, for a person to be diagnosed with ADHD, their symptoms should be associated with at least a moderate degree of psychological, social and/or educational or occupational impairment'.

3.1.2. The guidelines only made recommendations for the diagnosis and management of ADHD for children older than three years old, therefore the sub group only looked at the services available to children above three years old.

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<sup>&</sup>lt;sup>2</sup> NICE Clinical Guidelines (CG72), p4.

# 3.2. **Pre-diagnosis support**

- 3.2.1. This section will consider the processes and experiences for children and their families prior to a referral for diagnosis.
- 3.2.2. The lack of support available before formal diagnosis had taken place was seen as a significant gap in the support for children with ADHD by the parents, they had to rely on an individual's perseverance to progress things; it could take a long time for diagnosis and they needed 'the label' to receive support. One example was a family who had to wait for almost four years and until the child was eight years old for a formal diagnosis; the child had been identified as requiring assessment by the school when he was four years old whereas another family had received a diagnosis within five to six months.
- 3.2.3. The parents support group reported that the lack of support was one of the main frustrations reported to the peer group and it was perceived by the parents that there was a lack of integrated support between the local authority and health services and also that there appeared to be no single record of the children in the borough with ADHD or ADD (Attention Deficit Disorder).
- 3.2.4. The All Together Better group informed the Members that as soon as they expressed concern regarding their child's behaviour, barriers were put up and the people who they had hoped would provide guidance and support went into denial. They were being told on one hand that they were the people who knew their child best but that on the other hand they were imagining it.
- 3.2.5. The impact of the lack of signposting at the beginning of the diagnosis process was that parents were trying a strategy at home which, in one circumstance, was counterproductive for the child and they had been told that their actions 'had minimised it' which had led to a delay in diagnosis. They were then told to look things up on the internet; a more signposted, targeted approach would have helped them to feel more supported. Parents made reference to the <a href="Additude">Additude</a> website which provided strategies, suggestions and a forum for parents to seek support from but this was an American site. Something similar from the local professionals with advice on what to look out for, the processes of diagnosis, including a CAMHS referral, what the doctor needed to know and how to get the child to attend the appointment would have helped enormously.
- 3.2.6. Guidance on interim behaviour strategies, de-escalating techniques, signposting for other sources of support and also what possible next steps were available if it wasn't ADHD were suggested as improvements to the current situation to help parents to feel less isolated whilst awaiting diagnosis. Also, if the child was diagnosed at an older age, sign-posting for appropriate services and support that they could access themselves independently would be beneficial. This information would also help children who had grown up with the condition when they reached 16/18 years old to help them adapt to adulthood, particularly as, according to the parent's group, at this age there was an increased risk they would stop taking their medication.
- 3.2.7. Sleep, or lack of it, was identified as a significant issue and any advice on how to facilitate a good night's sleep for their child (and them) would have been gratefully received because it impacted on everything and everyone in the home. Scope ran a very effective course called 'Sleep Solutions' but there wasn't a centre in the

North East although workshops could be ran anywhere as the practitioners would travel.

- 3.2.8. The All Together Better group were willing to organise and deliver training and be consulted on what other training programmes could be developed. They key for them was that the training should focus on what needed to be done differently to help the child rather than making the parent feel small for the way they had been doing things up until referral. The approach should be collaborative not dictatorial.
- 3.2.9. The Lead SENCo co-ordinators group could not emphasise enough that parents needed the support of other parents and facilitating the support of a parents network in the school would benefit all as the communication with the parents was such a significant part of helping the child with ADHD.
- 3.2.10. There were a number of North Tyneside parenting courses which could be accessed before diagnosis and for some, for example the Solihull Parenting Programme, it was helpful if that work had begun before referral. However, running these programmes cost money and there was a long waiting list for some of the more popular courses. Behaviour issues are a symptom of ADHD and behaviour management was a key component of treatment but not all children with behaviour issues had ADHD, also behaviour can deteriorate if other needs are not being met; therefore it is important the family understands what is and what is not the ADHD.
- 3.2.11. The parenting programmes did not need to be driven by or delivered by CAMHS. Schools could establish support groups or parents themselves; peer mentoring from other children with ADHD would also be an effective strategy. The power of the parent factor course was in the networks established by parents; they kept in touch with each other. Family partners and staff groups could be used to facilitate some of these support programmes.
- 3.2.12. Both parents support groups stated that referral to the Parent Factor training could only be made by CAMHS. Some parents report being advised that parent training was a pre-requisite to the child being offered medication, which was in line with the NICE clinical guidelines, and had been discharged from CAMHS until this was completed and then having to wait again to be seen by CAMHS.
- 3.2.13. Having talked to parents, healthcare and education professionals the sub group considered that there was a difference of opinion on whether a referral of a child for parent-training education programmes without a formal diagnosis of ADHD could be made (NICE guideline subject area 2) Parents valued access to the current parent factor training and valued the ongoing demand analysis, delivery and review process. It would be of value to consider how to provide information and advice using website / local offer facilities.
- 3.2.14. The sub group makes the following recommendation:

#### **Recommendation 1**

Cabinet requests the Head of Health, Education, Care and Safeguarding works with colleagues in Health to review the information and training available to parents with and without a diagnosis of ADHD paying particular attention to

- Review of pre diagnosis access to parent training
- Review of speed of access to parent factor training

- Access to training in relation to sleep solutions
- Arranging drop in sessions for parents to understand the pathways for children with ADHD and other additional needs.
- Give consideration to the creation of a webpage with techniques, strategies and links for further support and information about support groups etc.

# 3.3. Diagnosis

- 3.3.1. In the parents' survey, the time taken to complete the assessment seemed to vary quite widely with 44% under 3 months, 26% under 3-6 months and 29% taking more than 6 months. Many parents reported instances where the rating scales used by parents and school came up with differing results i.e. parents reporting difficulties but school recording few, if any difficulties. In some of these circumstances parents have been told a diagnosis cannot be made because of the discrepancies, and are discharged from the service. On other occasions, CAMHS did send members of staff into school to observe the child, but this was not felt, by the parents, to be universal.
- 3.3.2. The CAMHS team were appointed by Northumbria Healthcare Trust and commissioned by the Clinical Commissioning Group (CCG) and the local authority. They also had funding for early intervention and preventative work, which would include training others to deliver certain aspects of the work. CAMHS used the hyperkinetic diagnosis which judged the functional impairment on the individual of the disorder, in other words it was affecting their lives.
- 3.3.3. The sub group was informed that no child had the same identical symptoms as another child and ADHD was rarely unaccompanied by other difficulties, for example OCD or sensory disorders, which created additional issues relating to sleep, food and clothing. ADHD was genetic and interplay between a parent and a child with ADHD can exacerbate the difficulty; the practitioners would not hesitate in asking parents if they had been diagnosed or considered being assessed for ADHD If they believed them to also have the disorder.
- 3.3.4. The sub group was informed that ADHD is a heterogeneous condition, in that it presents differently in each individual. It was noted how it frequently presents with other neurodevelopmental conditions including ASD, dyslexia, dyscalculia and tic disorder as well as with increased anxiety. There is a strong genetic link (up to 70%) and it is not unusual for parents of young people with ADHD to seek assessment from the adult ADHD clinic. If parents receive a diagnosed of ADHD they then have access to support and treatment, which can have a positive impact at home.
- 3.3.5. Parents of young people often view diagnosis positively, particularly when associated to developing a greater understanding of the young person's specific needs and they gain access to support and treatment.
- 3.3.6. The sub group was informed by CAMHS that there was a waiting list and it could be twelve to fifteen weeks before an initial assessment has been completed, however children could be seen urgently within 24 hours if needed. Before 2014 the wait had consistently been under twelve weeks but now there was an increased pressure on the service due to an increase in referrals and the increased complexity of the difficulties children had. The more complex cases were often identified and referred early but it was not unusual for them to have been referred for another diagnosis.

- 3.3.7. CAMHS had undertaken work to assess the referrals process to ensure it was robust and a new model would be in place in February 2016. This would involve organising the clinic along the geography of the Coast Road, with a north clinic and a south clinic. An initial assessment would be undertaken at a clinic appointment and then be referred to a specific clinic once it had been established which would be the best one for the patient. The idea was to establish if this allowed a more streamlined approach to appointments and allow general assessors the opportunity to develop wider skills and also assists the parents and families to improve their self help skills. This should then reduce internal waiting times.
- 3.3.8. The usual age of a child presenting with ADHD symptoms was 8/9 years old but CAMHS had received referrals for 17 year olds. When a patient was referred the assessment looked for everything, including emotional problems like bullying, there was no pre-disposition towards an ADHD diagnosis. They had very few inappropriate referrals however, neurodevelopmental disorders, emotional disorders and eating disorders often overlapped; it was not unusual to have 70% of diagnoses for ADHD to overlap with another disorder. It was important to establish whether the child was not learning because they could not concentrate or if the child was not learning because they had a learning need.
- 3.3.9. A referral usually came from a GP but it could come from any health professional involved with the family.
- 3.3.10. The CAMHS team preferred to do their observations at school rather than the home as they wanted to observe the child's relationship with other children and parents give clear representation of events taking place at home. Also, there was an advantage in having their discussion with the family in a clinical setting; the act of attending a meeting, making that commitment to the appointment and the process did make the work and support being offered more effective
- 3.3.11. School input to diagnosis was very important as school staff have the experience in the classroom of behaviour management and experience of the history of the child and of other children as comparators
- 3.3.12. Parents perceived a lack of co-ordination between schools SENCo's and that CAMHS would benefit from a SENCo to support schools to produce a proper plan for the children and SENCo's having an understanding of the side effects of medication and what the intended outcome of the medication was so they could observe if it was working or not. Parents also expressed concern that school could not directly refer to CAMHS as sometimes GPs could be reluctant.
- 3.3.13. The Lead SENCo co-ordinators group were clear that having to have a doctor's referral to CAMHS caused unnecessary delay and was a major frustration to the teams. They could support parents with letters and making appointments but it was up to the parents to attend the appointment and then push for the referral. Once there had been a referral there could be a wait of up to twelve weeks and it was a lengthy process; in addition if parents don't attend three appointments they're taken off the list.
- 3.3.14. However, the sub group was informed by the Lead SENCo's group that a lot of the schools have their own SENCo networks within their own pyramids which shared best practice and helped with transition. If all schools used the local authority SEND support plans template then all staff would recognise it as such and all the

information would be held in one place which would make the management of the child's additional needs easier. The SENCo's the sub group met with were all part of the Senior Leadership Team at their schools and felt that this allowed for a coherent message to be spread throughout the school.

- 3.3.15. Having talked to parents, healthcare and education professionals the sub group considered that whilst the length of time taken for diagnosis differed on a case by case basis, the sub group considered that the diagnosis of ADHD was always made on the basis of a full clinical and psychological assessment of the person including observations and assessments (NICE guideline subject area 3).
- 3.3.16. The subgroup makes the following recommendation:

#### **Recommendation 2**

Cabinet requests the Head of Health, Education, Care and Safeguarding in consultation with appropriate health commissioners to consider whether a procedure could be adopted to allow Lead SENCo's to refer to CAMHS with parental approval instead of requiring a Doctor's referral.

#### 3.4. Schools

- 3.4.1. Parents noted that in a busy class environment, it can be difficult for teachers to identify difficulties when the child did not make their presence obvious and this was a particular problem for those children who presented as predominantly inattentive. In addition any parents reported their child as "being able to hold it together" in school but for them to express their frustration and anxiety, in quite explosive terms, when they got home.
- 3.4.2. Parents suggested that too many teachers lacked the training to understand the way ADHD may manifest itself in a classroom setting and cannot always be relied upon to give an accurate response to rating scales
- 3.4.3. The sub group met with a Headteacher of a special school, Mr Gannon, and a group of lead SENCo's to understand how the relationship between schools, CAMHS and parents worked in practice after listening to the views of the parents' groups views. They also discussed what services were available for school with the manager of the Education Psychology Service.
- 3.4.4. School and their staff are a key part of the support available for children with ADHD and their families as they were often the initiators for the child to be assessed. In light of this the parents expressed a view that it would be useful if all primary school teachers had an understanding of, and could give advice on, the process to be followed from referral to assessment to diagnosis. The level of awareness and understanding of the conditions at schools was described by the parents to be a 'postcode lottery'. Some schools were described as 'fabulous... went above and beyond' whilst others still had staff that denied ADHD was a condition at all. It was suggested that more training for teachers, particularly new teachers to help them recognise identifying behaviour and also to respond to the child's need by adapting their behaviour too would have a significant beneficial impact.
- 3.4.5. When asked by the sub group about the training available for teachers and teaching assistants, the Lead SENCo's all referred to the Parent Factor training. In addition schools could invite someone in (usually from CAMHS) to talk about

behaviour strategies for a particular child and all new teachers received training on special educational needs, which included ADHD, and received targeted training if it was required.

- 3.4.6. The parents support group explained that having received a diagnosis many parents struggled to explain to schools how this might affect their child's ability to access education and how a joint meeting with parents, schools and CAMHS after diagnosis would make the treatment of the child more successful, unfortunately 43% of parents who responded to the survey stated that this meeting had not taken place.
- 3.4.7. It was reported to the sub group that many parents felt schools concentrated solely on improving educational attainments but struggled to provide children with in-school support which addressed their emotional and social difficulties. A parent commented that the in-school support was generally focussed on education and how to keep her child on track educationally, also an example was given of when a parent wanted advice on how to help her children play together (one with ADHD, one without) and was told no-one could help her with those issues.
- 3.4.8. The sub group asked Mr Gannon's view on the awareness of teachers of ADHD in mainstream schools. Mr Gannon stated that it depended on the sector, most primary schools handled it well and at primary/first schools there was the advantage of the child having the same teacher for the majority of lessons which allows the child consistent support and time to develop relationships. If the diagnosis had come late and there could be a preconceived idea that the child was "just a naughty" then it was too late to build a good relationship with the teacher, this was more likely in secondary/middle and high schools with the worst case scenario of the child being placed in the pupil referral unit. Information from primary/first schools should be passed on but the schools are that much bigger; some schools are very good and pick it up through the special education needs route and strategies are created by the SENCo, if teachers have picked it up it is because of their behaviour.
- 3.4.9. One parent related her experience of having to move schools to receive the support and strategies her child required.
- 3.4.10. One of the key messages from the survey was that it was not at all clear to parents how schools and the local authority decided on what level of interventions children should receive or whether there was a consistent response across all schools. Many parents said they were dissuaded from asking for more help because "the child doesn't fit the criteria". The responses indicated inconsistencies on whether or not a parent played any part in setting up an education plan or if the education plan was written down. Also many parents felt their views were not written into the plan (56%) with variations in the way plans are reviewed, ranging from termly (21%) to never (25%). Parents are also not confident that all teachers who came into contact with their child are aware of their diagnosis.
- 3.4.11. Parents very much felt that the support they received from schools was a lottery and not enough staff understood the symptoms of ADHD or what to do if they suspected it. Schools often took the view that the children shouldn't be treated any differently which helped no-one; a learning mentor to follow the children throughout their school life would help with communication issues with the child, the family and the school. Parents found it much easier to discuss their concerns

about their child when they attended primary school and because of this it was much more likely school and parent could negotiate appropriate additional support for the child. However, as the child moved through the education system of middle/secondary school parents found increasing difficulties in ensuring the schools acknowledged their concerns and responded with appropriate additional support.

- 3.4.12. CAMHS staff had delivered direct training to a number of schools in North Tyneside on ADHD. CAMHS staff with Education Psychology had also delivered a number of sessions to special schools. CAMHS staff and Educational psychology delivered a series of sessions open to all schools on ADHD and aspects of education. School staff have been supported in these sessions to view ADHD as a neurodevelopmental condition and gain an understanding of their role they have in supporting students to engage in learning and minimise the impact of ADHD.
- 3.4.13. Help to remove the stigma could begin at school with posters of people or books about people who have succeeded in their field who also have ADHD.
- 3.4.14. The manager of the Education Psychology Service informed the sub group that behavioural psychological intervention was available in schools and the service would support and facilitate the treatment. Each school had a service level agreement with the Education Psychology Service which was split between the statutory services provided by the local authority for the support of children with EHC Plans and other work to support families in the context of school which will vary from school to school. Managing the team's capacity against the demand was a challenge and the service had to be self-funding. The budgets and Service Level Agreement's were agreed at the beginning of the financial year but often school would not identify where they needed additional support until the third term and then there was a significant stretch on resources because the additional work was unknown and resources couldn't be made available 'just in case' at the beginning of the year.
- 3.4.15. Each child the service worked with had a tailored managed approach. The educational psychologist would talk to the child's teachers to understand their behaviour in lessons, during group work and in the wider school context of assemblies and lunch times. Relationships were key which meant if the teacher could make accommodations for the child to enable them to remain in the classroom it was very helpful. This could include the way the work was delivered and handed out, in small chunks with timescales and list of tasks to be completed with the opportunity to leave the seat once a task is finished. One parent cited the adjustments made for their child which included extra time for the SATS and his timetable being presented in pictures instead of words which had been such a simple change but had been so effective. These methods can be worked into lessons in a positive way. Children need to be able to feel they can ask for a break if they have identified that they need a break, this can be done with one-to-one cards and time-out cards or cool-down zones where they can go and speak to a mentor. Peer mentoring and support is important as it can help children work in groups and keep on task by being reminded of the instructions. Older children of ADHD can do this for younger children with ADHD as it can help them focus and increase their self-esteem because they are helping someone. Current thinking is directed towards the development of the whole child in a holistic approach and understanding the impact stress can have on development, learning and acquiring skills.

- 3.4.16. The earlier the work can begin with the child the better and giving the child the knowledge and strategies to manage their own ADHD involving their family and schools is the most systematic and cost effective method. Also mentors at community level, seeing older people with ADHD doing well and prospering, encourages the young people to manage their diagnosis.
- 3.4.17. The Educational Psychologist stated that medication was never the only intervention, psychological and social interventions were always the first steps unless it was a severe case; if a child was under five, medication was not considered. Support offered for children included intervention and prevention work with individuals, group and sometimes parents, CBT was available and other support if there were other related difficulties which meant that the support had to be more bespoke. This could include therapeutic intervention where children were given a safe space where they could explore their feelings but this was not just for children with ADHD. The aim was to help children manage their condition at school and to build resilience to improve their relationships with their peers and significant others, like teachers, in the school. Work with adults included understanding and increasing empathy.

#### 3.5. Silverdale

- 3.5.1. Mr Gannon informed the sub group that the approach at the school was behaviour modification for their students. The majority of children with additional needs managed at mainstream schools and those who couldn't, in North Tyneside, went to Silverdale. The children often had other social difficulties and learnt behaviour in addition to their ADHD. The school attempted to manage their school without sanctions and with no exclusions, it was a praise based and increasing selfesteem system to make the children feel liked, wanted and cared for. It was a myth that a child with ADHD cannot concentrate, if they are interested they will concentrate until it's done. Behaviour is communication and environmental factors impact on that, for example people behaved differently in church to how they behaved at St. James' Park football ground.
- 3.5.2. If a child has been placed at the Additional Resourced Provision School (ARP) the aim was to get the child back into mainstream school because outcomes are better, if children are in the ARP for longer than a year they probably need a special school, like Silverdale or Benton Dene. The primary school years at Silverdale are run on the mainstream model as far as possible as it is hoped the child will be able to be placed in a mainstream school at some point. Older students do leave with qualifications and the school tried to create a pathway for their adult life. Classes were usually between 6-8 pupils. Modern foreign languages are not taught, however if a child wanted to learn a foreign language when they were 13 or 14 years old, attempts are made to facilitate this and support had been forthcoming from Churchill School.
- 3.5.3. Silverdale offered a four hour training session for primary schools on behaviour management. Praise was key and also when discipline was required it was important to follow up to explain why the sanction had been imposed; behaviour happened in the classroom and can only be resolved in the classroom, otherwise it was only containment.
- 3.5.4. Mr Gannon acknowledged that ADHD can be misdiagnosed or ignored as only disruptive behaviour and did predominantly affect boys. ADD was more prevalent in girls, disruptive behaviour was not symptomatic of ADD and can be missed

- because the girls are not causing a problem in class; but they are not concentrating and are often daydreaming.
- 3.5.5. Parents often had a negative view of the school and this needed to be turned around. An ADHD friendly school would not be that different, the difficulty was that most teachers are not given help to modify their style to help children with additional needs.

### 3.6. Behaviour and behaviour policies

- 3.6.1. Mr Gannon believed that the behaviour policies at school contributed to the difficulties of the children with ADHD as they did not take into account children's additional needs and this needed to be accommodated. There particularly needed to be non-sanction based behaviour management systems for secondary schools.
- 3.6.2. The Educational Psychologist agreed that punitive behaviour sanctions in school would not work for children with ADHD. Consequences need to be restorative, with empathy and systems in place to resolve conflict with flexibility appropriate to the misdemeanour to prevent children becoming increasingly resentful, angry and opting out altogether. Every school should have a nurture room which would be a comfortable safe space for children to go to when they were experiencing frustration and difficulties.
- 3.6.3. CAMHS agreed it was important that the behaviour policy and exclusion policies of schools did not discriminate against children with ADHD and had been involved with the consequences system for Longbenton High School. Children at primary school noticed children being taught differently but don't mind if they know why; it is not seen by the children as unfair, this does change at secondary school and would need to be communicated well.
- 3.6.4. It was acknowledged by the Educational Psychologist, CAMHS and SENCo's that some schools and teachers can be more responsive than others. Children can have challenging early years which can leave them prone to mental health difficulties or some teachers may think the poor attendance has lead to the difficulties and that it is not an educational difficulty.

#### 3.7. Transition between schools

- 3.7.1. SENCo's acknowledged that transition from one school to another was a difficult process for a child with ADHD and planning began in the October of the final school year. A meeting was held with the SENCo and class teachers of the new school. A presentation for parents was delivered with additional meetings for vulnerable groups and summer schools now took place in most primary and secondary schools. Good practice for transition had been presented to all head teachers in summer 2015 (See appendix A).
- 3.7.2. Parents expressed anxiety about the transition process and felt a lot of this was a breakdown of communication and a commitment from the schools and the health service.
- 3.7.3. Managed moves were also seen as problematic. Parents and education professionals referred to the Ofsted regime not being inclusive which meant that schools wanted the 'badly behaved' children and those who were not at an

expected level academically off their roll, the whole education climate was unfriendly to difficult children. Mr Gannon suggested that schools should be asked to state that they had done everything they could to help a child remain in school and answer why the child did not want to stay in the school before suggesting a managed move; also if a managed move had failed why would trying it again succeed? The views of the parents from the survey supported this, 37% of those asked had gone through a managed move. Whilst some would argue this was a fresh start, for a child it was frequently viewed as a rejection and was disruptive in terms of making and sustaining friendships, something which many children with ADHD struggled with.

- 3.7.4. The importance of keeping on top of medication changes and understanding what effect this would have on the child and the time it will take to be effective and communicating this to the appropriate people, for example the teacher, other teachers and support staff, catering staff and lunchtime supervisors, was emphasised. The sub group was informed of how information was shared across the school and what was expected of the classroom teacher in terms of support and to feedback any observations to the SENCo co-ordinator so it could be assessed by CAMHS.
- 3.7.5. A parent gave the example of their child having their protein shake taken off them five times because it was 'outside food' and this was not allowed by the school.
- 3.7.6. At the schools of the Lead SENCo co-ordinators group there was a good awareness of indicator signs and how to manage the behaviour of a child with ADHD and each child was treated differently. They felt that there was support and training available where it was needed and extra training was available; they had a good relationship with CAMHS and were able to receive regular feedback regarding the children at their school but the service was being reduced and it was often difficult to have a conversation.
- 3.7.7. Parents were of the view that the relationship between schools and CAMHS could be better with increased communication, it was felt that both relied upon the parent to communicate with the other instead of doing it directly and that schools should be more proactive.
- 3.7.8. Having talked to parents, healthcare and education professionals the sub group considered that care was provided by adequately trained healthcare professionals and by the SENCo's as education professionals (NICE guideline subject area 1)
- 3.7.9. That the relationship between CAMHS and schools was good and effective, particularly in light of their limited resources and schools, particularly the SENCo's were aware of the importance of their role in the treatment of children with ADHD. However there did seem to be some discrepancies between schools as to what training was provided to teachers and other employees at a school, this had an impact on how integrated the care provided to children was and fell into NICE guideline subject area 1 which was integrated care that addressed a wide range of personal, social, educational and occupational needs.

#### **Recommendation 3**

Cabinet requests the Head of Health, Education, Care and Safeguarding establishes a multiagency task and finish group to create good practice documentation in relation to assessment and management of children with ADHD

within a pre school and school environment and to review pathways for diagnosis of individual children with ADHD with particular attention to:

- The use of the universal SEN support form
- Consideration of the use of learning mentors to support young people within school.
- To ensure Education Plans are person centred to ensure instructions regarding departure from the usual school rules are included and can be communicated widely in the school environment (e.g. a child is allowed 'outside food').
- To understand the current local offer in relation to the counselling/non-medication/ universal offer strategies which are available to schools.

Once the task group has completed its work the implementation of any changes to be supported by the Health, Education, Care and Safeguarding service through the existing drop in sessions for Educational professionals and supported by Specialist services within schools.

#### **Recommendation 4**

Cabinet requests the Head of Health, Education, Care and Safeguarding establishes a multiagency task and finish group to:

- summarise the evidence in relation to a whole school approach to the management of ADHD with particular attention to behaviour policies and restorative non-punitive alternatives.
- To understand the current training packages to support teachers with its implementation and as required identify new training courses

Once the task group has completed its work to request that Specialist services disseminate good practice to schools.

#### **Recommendation 5**

Cabinet requests the Head of Health, Education, Care and Safeguarding to review how managed moves for children with ADHD are initiated and organised and compare with best practice.

#### 3.8. **Treatment**

### 3.8.1. The NICE clinical guidelines state:

'Healthcare professionals should offer parents or carers of pre-school children with ADHD a referral to a parent training/education programme as the first-line of treatment if the parents or carers have not already attended such a programme or the programme has had a limited effect'.

Teachers who have received training about ADHD and its management should provide behavioural interventions in the classroom to help children and young people with ADHD.

If the child or young person with ADHD has moderate level of impairment, the parents or cares should be offered referral to a group parent training/education programme, either on its own or together with a group treatment programme (cognitive behavioural therapy [CBT] and/or social skills training) for the child or young person.

'Drug treatment for children and young people with ADHD should always form part of a comprehensive treatment plan that includes psychological, behavioural and educational advice and interventions.'3

- 3.8.2. In the parents' survey, 88% of respondents reported medication as the most prevalent form of treatment post diagnosis. Only 15% reported receiving any psychological therapy and only 9% received a cognitive assessment, which might identify co-existing conditions. From the survey results it appeared to the parents support group that medication was being used as a first line of treatment and despite NICE issuing a Quality Standard (high priority for implementation) in August 2013, no psychological individual or group work was available to the majority of children and young people. Many parents were unaware what, if any, targeted, professionally led, psychological support was available. This was a particular problem for those parents who preferred not to go down the medication route.
- 3.8.3. The options available for treatment was also reported by parents to be inconsistent with one reporting that the only option proposed to them was medication, although the treatment had been effective and the child had made marked progress in English and Maths. A parent reported their child who was in Year 11 had just been diagnosed with ADHD at the age of 15 and a half. It had been recognised that age 9 her son needed a Statement because of difficulties related to dyslexia. As he progressed through school his reluctance to engage with education had been put down to his "behaviour" rather than an understanding that he may be struggling with undiagnosed ADHD. A medication trial was underway but he had yet to receive a medication level which was optimum for him.
- 3.8.4. Another parent reported the difficulties of trying medication to see which one was effective. The initial medication (Equasym) had resulted in nightmares and they had to wait for five weeks for the next appointment to change the prescription. When they were originally diagnosed they had to wait six weeks for the next appointment.
- 3.8.5. NICE guidelines identify the prevalence of ADHD to be between 3-5% of the school age population. Within North Tyneside around 2% of the school age population have received a diagnosis of ADHD following comprehensive assessment. This being within the range expected of a locality CAMHS team.
- 3.8.6. Medication should only be considered as part of a holistic ADHD treatment plan which should also consider support available at home and school. All plans should place the child centre.
- 3.8.7. The parents from All Together Better were positive about the crisis support available and access to services out of hours from CAMHS.

#### 3.9. Post Diagnosis support

3.9.1. Following a diagnosis of ADHD a post-diagnosis appointment is offered with a specialist ADHD nurse practitioner. At this appointment the diagnosis is explored further and individual behaviours management strategies are considered – at this

<sup>&</sup>lt;sup>3</sup> NICE Clinical Guidelines (CG72) p8.

- appointment an ADHD Care Plan is agreed. This may include further liaison with school, specific behaviour strategies and if moderate/severe ADHD medication.
- 3.9.2. It was suggested by some parents that it would be helpful to make courses available for young people to enable them to understand their condition and how it impacted on them at diagnosis and also for parents of older children on how to learn to "let their children go" and gain some independence
- 3.9.3. The survey results indicated that the majority of parents received a follow up appointment within varying timescales; predominately at 3/6 monthly intervals 70% of parents were seen by the specialist nurses, 21% by psychologist and 9% by psychiatrist. Appointments were usually arranged with both parent and child present (89%). When it came to parents feeling they could talk openly 50% didn't feel they could do this. Many parents felt uncomfortable talking about negative or harmful behaviours in front of their child which created the potential for professionals not to be given a true picture, until such time as a crisis occured.
- 3.9.4. CAHMS reported that children and their families are seen four or five times a year and strategies and medication was reviewed and also support was available on the phone. It was an important relationship to maintain to ensure that practitioners could be blunt when required. If urgent appointments were required they are provided and people can be seen twice in one week if necessary.
- 3.9.5. The CAMHS team worked hard to provide continuity of care to their patients by ensuring that the patient and their family always saw the same practitioner where possible and that they worked with the family's GP, with the GP prescribing the medication which CAMHS recommended after assessment and reviews.
- 3.9.6. The importance of diet on behaviour was discussed with the representatives from CAMHS. The prevalence of energy drinks as a regular drink was commented upon and they were seen as having a huge impact on children by making them irritable and hyperactive and can also cause trouble with sleeping, which can present as ADHD, or impact more acutely on a child with ADHD. Training was key and if capacity could be developed in education, social services and parents so less fell to CAMHS, there would be a greater impact on the success of other strategies.
- 3.9.7. The educational psychologist referred to research being undertaken on mindful parenting and mindful group therapy for ADHD; the key being how people responded to each other at times of stress which can help parents recognise how their behaviour impacts on the child. People were asked to focus on their physical state, their thoughts and their emotions. It was acknowledged there was little support for parents after the diagnosis.
- 3.9.8. The representatives from CAMHS considered that helping the family cope at home was a vital first step but for improved overall outcomes for the child, achievement at school was essential. It was important to have understanding from all the people involved in the child's life, which would extend beyond their immediate family, on how ADHD affected a child.
- 3.9.9. CAMHS informed the sub group that families were referred to the Parent Factor course once diagnosis had been made and ideally there would be no wait but there could be a wait of one to two months. As referred to earlier, the CAMHS team preferred to do their observations at school rather than the home in part

because the act of attending a meeting, making that commitment to the appointment and the process did make the work and support being offered more effective.

- 3.9.10. All parents met by the sub group were very enthusiastic about the Parent Factor training course and that whilst there was no 'official' ongoing support, support networks had grown out of it as parents kept in touch with other parents on their course. One of the groups had formed a 'self-help' group which met on a Monday night and was for the whole family, not just parents or the child with ADHD. They had a Facebook page and knew of other parents' support groups too.
- 3.9.11. The Educational Psychologist confirmed that the Parent Factor was a fabulous course as it gave parents the opportunity to talk to each other about everyday things.
- 3.9.12. The parents support group suggested finding opportunities to get young people with ADHD together so they can see they are not the only one and can talk about their issues and anxieties with their peers.
- 3.9.13. Reference was made to the Shiremoor Adventure Playground which had a closed session for children with ADHD on a Monday after school and Pathways for All which ran The Tim Lamb Centre in the Rising Sun Country Park for children with disabilities and additional needs. The sub group was also informed that discussions were underway within the Council for arranging a special session at its leisure centres to allow parents to leave their children and either use the facilities themselves or spend some time with other parents in the café.
- 3.9.14. The sub group considered that the relationship between CAMHS and the local authority was an effective partnership and every effort was made to provide integrated care that addressed a wide range of personal, social, educational and occupational needs and post-diagnosis care but that communication as to what was available to users of the service could be improved. It was acknowledged that with finite resources difficult decisions on what level of service could be provided had to be taken.
- 3.9.15. The sub group makes the following recommendations:

#### **Recommendation 6**

Cabinet requests the Head of Health, Education, Care and Safeguarding in consultation with colleagues in health, education and the voluntary sector to arrange groups/drop in sessions for teenagers to help them understand their condition and how they can manage themselves.

#### **Recommendation 7**

Cabinet requests the Head of Health, Education, Care and Safeguarding and the Head of Environment, Housing and Leisure to provide closed sessions at Leisure centres for children with ADHD to give parents/carers an accepting environment to take their children and to socialise with other parents/carers.

#### **Recommendation 8**

Cabinet requests the Head of Health, Education, Care and Safeguarding, in consultation with colleagues in health to ensure that information on non-medication strategies, for example Cognitive Behaviour Therapy, is be provided to

parents at an early stage of referral and to be part of the information available in the website produced for recommendation 1.

In addition, the sub group was made aware during its work of a recommendation from the Carers Support and Respite Provision Sub Group which was:

That Cabinet ask the Head of Health, Education, Care and Safeguarding, to review the current training commitment to parent carers of children with ADHD, and to consider the submission of business case to the Carers' Centre, to provide additional training to help carers deal with the challenging behaviour associated with ADHD.

and wish to fully endorse this recommendation.

#### 3.10. Transition to Adult Services

- 3.10.1. The NICE clinical guidelines state 'Adult and paediatric healthcare teams should work jointly to provide assessment and services to young people with ADHD. Diagnosis and management should be reviewed throughout the transition process, and there should be clarity about who is the lead clinician to ensure continuity of care'4.
- 3.10.2. The survey included questions about moving into adulthood and accessing adult services including health, social care, education/ training/ employment. The group reported that it was 'well recorded' that many young people, between the age of 16-18, stopped taking medication. Taking out the number of young people who might be expected to stop medication because of a reduction in symptoms/impairment did not in their view account for the significant numbers of young people who dropped out of treatment at this stage. They believed that this withdrawal from treatment left many young people very vulnerable and these young people would have a long wait to access the Adult ADHD Clinic should they choose to change their mind later.
- 3.10.3. One of the parents was anxious about their son who would be 18 years old soon and was currently not on medication for his ADHD; this meant he would not get an automatic transfer as an adult to the local mental health services and would revert to 'inexpert' GP care. There was also concern about support for parents to enable them to assist their child with the transition between services and allowing them to be an adult.
- 3.10.4. The adult waiting time for assessment was 9 months to 1 year although the target was 8 weeks. For patients approaching adulthood who were being treated by CAMHS they tried to begin the process of transition for the patient when they were 17 ½ to ensure everything was in place for when the patient turned 18. However, if the GP would not prescribe medication for the patient they cannot be referred by CAMHS to adult mental health services.
- 3.10.5. The CAMHS team recognised that adolescence increased the risk of inappropriate behaviour for all young people but if parents have been able to access courses and utilise strategies early then they are better prepared for the impact adolescence has. A key thing to bear in mind is that it was 'normal' for a child to rebel at this stage and impulsivity can be a good thing for teenagers; it is

<sup>&</sup>lt;sup>4</sup> NICE Clinical Guidelines (CG72) p8.

not always something that needed to be dampened down. A lot of successful business people and sports people were successful because they were prepared to take risks; the important thing was to control the ADHD and not let the ADHD control the patient.

- 3.10.6. In the survey, 67% of parents did not feel their children had a good understanding about how their ADHD impacted on various areas of their lives and this included young children and teenagers. The vast majority of parents (93%) felt their children need additional support with this, but it appeared to them that neither Health nor the local authority could agree which organisation should take lead responsibility.
- 3.10.7. The sub group acknowledged that the transition into adulthood was a difficult time for all parents and could understand how the uncertainty about the transition of care for their children from CAMHS to Adult Services if they had been able to stop using medication as a treatment would cause parents to worry. However, the sub group considered that the process followed by the team did meet the NICE subject area guideline 6. The sub group has made no recommendation specific to transition from children to adult services because if the preceding recommendations are accepted all the people involved will have a greater awareness of process and the services available which will ensure the transition goes smoothly.
- 3.10.8. The Sub Group noted that a multi-agency support group as recommended by NICE subject area guideline 6 had not been established in the borough and believed that such a group would complement the sub group's recommendations. Whilst acknowledging that the lead for such a group would have to come from the health authority, the sub group makes the following recommendation:

#### **Recommendation 9**

That Cabinet requests the Head of Health, Education, Care and Safeguarding in consultation with appropriate health commissioners to consider developing a multi-agency group, with representatives from multidisciplinary specialist ADHD teams, paediatrics, mental health and learning disability trusts, forensic services, child and adolescent mental health services (CAMHS), the Children and Young People's Directorate (CYPD) (including services for education and social services), parent support groups and others with a significant local involvement in ADHD services. The group should:

- Oversee the implementation of the NICE guideline.
- Start and coordinate local training initiatives, including the provision of training and information for teachers about the characteristics of ADHD and its basic behavioural management.
- Oversee the development and coordination of parent-training/education programmes.
- Consider compiling a comprehensive directory of information and services for ADHD including advice on how to contact relevant services and assist in the development of specialist teams.

3.10.9. In addition, the sub group was not provided with information on the number of children in the borough with ADHD and makes the following recommendation:

#### **Recommendation 10**

Cabinet requests the Head of Health, Education, Care and Safeguarding to undertake a review of how data on children with ADHD is collated and managed to help inform future service provision and to identify trends.

#### 3.11. Other issues

- 3.11.1. There were concerns expressed by parents regarding the lack of information, support and willingness to talk about sexualised behaviour which a child with ADHD might not be able to understand as being inappropriate. Parents needed to receive some guidance early on so they could be prepared and also teachers needed to be prepared in case something happened at school. It was acknowledged that if an incident occurred it should not be minimised but that strategies for how to deal with an incident should be prepared in advance.
- 3.11.2. There were concerns expressed by parents about how the police interacted with children with ADHD. The sub group was informed that one of the Youth Offending Team officers worked with CAMHS and acted as the link with the police and saw the children who had begun drinking and using drugs and other substance misuse. The parents group considered that it would be helpful if each Police neighbourhood team had some knowledge of ADHD either through a named worker or a training session to enable them to identify if a child has ADHD so that if the child came into contact with the police the relationship with the police as an institution got off to as good a start as possible.
- 3.11.3. The sub group has not made any recommendations on these issues as they are not part of the remit for the study; however it was considered appropriate that they should be included in the report to raise awareness.

#### 4. Conclusion

- 4.1. The sub group considered that of the six NICE guideline subject areas identified at the start of the study all were being met by the Local Authority; that some aspects of each could be reviewed and improved was not disputed but plans and processes were in place to meet each one. The sub group also looked beyond these guidelines to the families and children with ADHD and how the practical realties of these guidelines were experienced by them.
- 4.2. The sub group enjoyed meeting everyone who assisted them in their work for this report and could see in all the groups they spoke to, from parents and teachers to SENCo's and health professionals, that everyone acknowledged that it was a complicated issue, that partnership working was the best way to ensure a coherent and holistic approach for the treatment of children with ADHD but that sometimes 'life' got in the way. Parents were struggling to get a referral from their G.P. or to know where to get advice and guidance for behaviour and sleep strategies. SENCo's were dealing with parents who refused or were unable to go to the doctor with their child. The team at CAMHS were struggling with funding cuts at a time of increased demand. The educational psychologist teams were trying to provide a service which met demand at the same time as being selffunding. And whilst all this was being managed (or not) children were struggling with their symptoms, not engaging with education or getting enough sleep, and

affecting others' education and sleep.

4.3. The sub group acknowledged that additional funding is not always the best solution to a difficulty and also that there were finite resources available for all local authority services. The recommendations made by the sub group are intended to allow the local authority, NHS, parents, schools and volunteer organisations within communities in North Tyneside to help and support each other; which might also reduce the stigma and increase awareness and the knowledge of people whose families are unaffected by ADHD.

# 5. Background Information

The background papers and research reports listed in Appendix B have been used in the compilation of this report and copies of these documents are available from the Democratic Support Officer.

# 6. Acknowledgements

The working group would like to place on record its thanks and appreciation to those Council officers, schools, parents and external organisations for their assistance providing the evidence on which this report is based. A full list of all those individuals who helped the Sub-group with its work is set out in Appendix C.

# Appendix A Presentation delivered to Head teachers' Briefing at Langdale Centre 10 July

Transition between King Edward Primary and John Spence	
Current school proactive in supporting families to identify likely next school through visits with staff to possible settings.	Enables transition processes to begin smoothly.
Receiving school invited to attend SEND review meeting in autumn term prior to transition.  *All SEND review dates set 6 months in advance at previous meeting to ensure family and all agencies can attend	New school able to meet parents, key worker, access an overview of needs and paperwork and needs. If appropriate meet the child but pupil views included regardless in review.
Receiving school identify a key worker for identified child and key worker begin to meet and engage with both the child and current school.	Opportunities identified for visits to current school to initially observe and then meet the child and staff. Key worker begin to understand their needs and support in place and areas of success in current school. Key worker and child begin to create a bond/relationship.
Individual visit for family and if appropriate the child, to discuss SEND needs of child and provision available.	Possibly different visits-one for adults and key workers and one for the child. Current school offer to support the child and family on visits.
Individual visits for child with current school staff to visit new school setting to familiarise child with their new school.	Opportunity for the child to meet key staff, mentor and find their way around the building.



Usual transition days-info sharing between receiving and current school to ensure any issues which have arisen or concerns are shared	Mentoring and summer schools
Receiving school invited to final SEND reviews prior to child leaving current school.	Enables any more next steps for planning and provision or transition opportunities for the child. Another opportunity for new school to meet and engage with family and other agencies. Pupil views also shared and if appropriate involve the child.
Current school hand deliver paperwork a full copy of paperwork to the new setting and obtain a signature of receipt.	Ensures paperwork is shared and received.
Receiving school proactive in communicating with previous school during initial weeks.	Enables any anxieties or dips in learning to be overcome using strategies known to be effective in previous school.
Receiving school invite previous school to first SEND meeting within first half term.	Ensures effective provision and support in place based on the wealth of knowledge from previous school. This supports the child and family and helps ensure the child has settled in.



In year transition of new pupils	
School receives a request for admission. School contact current school.	Head teacher contacts current school for background information on the child, family and any learning needs.
Head teacher contacts parents.	Establish parents views on child's needs.
Invite parent for visit and initial tour, may or may not be with the child.	Enables initial relationship building and information sharing. Introduce potential class teacher, SENCO and PSW.
Further information sharing between current and receiving school.	Ensures a clear picture of child's needs is emerging to enable new school to begin to plan provision, support and transition.  Meet PSW
New school arranges TAC meeting, with SARS if	Ensures an effective plan for transition and initial support is
relevant/appropriate prior to admission. to ensure an effective plan for transition and initial support is agreed and in place using the knowledge of current setting	agreed and in place based on the knowledge of the current setting. Receiving school may arrange observations or visits to current school as part of this transition. Current school may arrange further visits to the school with the child. PSW involved as part of the transition for the child and family.



# **List of Background Papers**

The following background papers have been used in the compilation of this report and copies of these documents are available from Elizabeth Kerr, Democratic Services, e-mail <a href="mailto:elizabeth.kerr@northtyneside.gov.uk">elizabeth.kerr@northtyneside.gov.uk</a> Tel: (0191) 643 5322

- Attention deficit hyperactivity disorder: diagnosis and management NICE clinical guidelines (Sept. 2008, updated February 2016)
   (https://www.nice.org.uk/guidance/CG72)
- Report of the North Tyneside Parent Support Group (ADHD).

#### Useful websites

<u>ADDitude: ADHD Symptoms, Medication, Treatment, Diagnosis, Parenting ADD</u> Children and More

http://www.scope.org.uk/support/services-directory/sleep-solutions-tailored-service-for-families

http://www.shiremooradventureplayground.org/

# **Acknowledgements**

The working group would like to place on record its thanks and appreciation to the following individuals for their assistance to the working group:-

# **North Tyneside Council**

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#### List of recommendations

- 1. Cabinet requests the Head of Health, Education, Care and Safeguarding works with colleagues in Health to review the information and training available to parents with and without a diagnosis of ADHD paying particular attention to:
  - Review of pre diagnosis access to parent training
  - Review of speed of access to parent factor training
  - Access to training in relation to sleep solutions
  - Arranging drop in sessions for parents to understand the pathways for children with ADHD and other additional needs.
  - Give consideration to the creation of a webpage with techniques, strategies and links for further support and information about support groups etc.

(page 7)

2. Cabinet requests the Head of Health, Education, Care and Safeguarding in consultation with appropriate health commissioners to consider whether a procedure could be adopted to allow Lead SENCo's to refer to CAMHS with parental approval instead of requiring a Doctor's referral.

(page 10)

- 3. Cabinet requests the Head of Health, Education, Care and Safeguarding establishes a multiagency task and finish group to create good practice documentation in relation to assessment and management of children with ADHD within a pre school and school environment and to review pathways for diagnosis of individual children with ADHD with particular attention to:
  - The use of the universal SEN support form
  - Consideration of the use of learning mentors to support young people within school.
  - To ensure Education Plans are person centred to ensure instructions regarding departure from the usual school rules are included and can be communicated widely in the school environment (e.g. a child is allowed 'outside food').
  - To understand the current local offer in relation to the counselling/non-medication/ universal offer strategies which are available to schools.

Once the task group has completed its work the implementation of any changes to be supported by the Health, Education, Care and Safeguarding service through the existing drop in sessions for Educational professionals and supported by Specialist services within schools.

(page 15)

- 4. Cabinet requests the Head of Health, Education, Care and Safeguarding establishes a multiagency task and finish group to:
  - summarise the evidence in relation to a whole school approach to the management of ADHD with particular attention to behaviour policies and restorative non-punitive alternatives.
  - To understand the current training packages to support teachers with its implementation and as required identify new training courses

Once the task group has completed its work to request that Specialist services disseminate good practice to schools.

(page 16)

5. Cabinet requests the Head of Health, Education, Care and Safeguarding to review how managed moves for children with ADHD are initiated and organised and compare with best practice.

(page 16)

6. Cabinet requests the Head of Health, Education, Care and Safeguarding in consultation with colleagues in health, education and the voluntary sector to arrange groups/drop in sessions for teenagers to help them understand their condition and how they can manage themselves.

(page 19)

- 7. Cabinet requests the Head of Health, Education, Care and Safeguarding and the Head of Environment, Housing and Leisure to provide closed sessions at Leisure centres for children with ADHD to give parents/carers an accepting environment to take their children and to socialise with other parents/carers.

  (page 19)
- 8. Cabinet requests the Head of Health, Education, Care and Safeguarding, in consultation with colleagues in health to ensure that information on non-medication strategies, for example Cognitive Behaviour Therapy, is be provided to parents at an early stage of referral and to be part of the information available in the website produced for recommendation 1.

(page 19)

9. That Cabinet requests the Head of Health, Education, Care and Safeguarding in consultation with appropriate health commissioners to consider developing a multi-agency group, with representatives from multidisciplinary specialist ADHD teams, paediatrics, mental health and learning disability trusts, forensic services, child and adolescent mental health services (CAMHS), the Children and Young People's Directorate (CYPD) (including services for education and

social services), parent support groups and others with a significant local involvement in ADHD services.

The group should:

- Oversee the implementation of the NICE guideline.
- Start and coordinate local training initiatives, including the provision of training and information for teachers about the characteristics of ADHD and its basic behavioural management.
- Oversee the development and coordination of parent-training/education programmes.
- Consider compiling a comprehensive directory of information and services for ADHD including advice on how to contact relevant services and assist in the development of specialist teams.

(page 21)

 Cabinet requests the Head of Health, Education, Care and Safeguarding to undertake a review of how data on children with ADHD is collated and managed to help inform future service provision and to identify trends.

(page 22)