KIRKLEES METROPOLITAN COUNCIL

AD HOC SCRUTINY PANEL INTO SUPPORT FOR PEOPLE WITH ATTENTION DEFICIT HYPERACTIVITY DISORDER

OCTOBER 2005

CONTENTS **PAGE REFERENCE**

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Terms of Reference

To examine the range of services available for people with Attention Deficit Hyperactivity Disorder (ADHD) and autism spectrum disorders, including transitional arrangements from childhood to adulthood.

The ad hoc review will make recommendations to the council and other agencies as appropriate, with a view to informing the wider debate on support and intervention for vulnerable adults within Kirklees.

Background to scrutiny request

A request was received from a member of the public who had been diagnosed with Attention Deficit Hyperactivity Disorder as an adult. In order to be assessed and get a diagnosis he had to pay for a private consultation and a referral to the Maudesley Clinic in London. On receiving a diagnosis he returned to Kirklees hopeful of accessing the support that he felt he needed. However it was not as he had hoped and having tried both health providers and council services, he became very concerned at the lack of support available for people with ADHD. Any support that was available to children did not continue into adulthood.

On talking to people with Autism Spectrum Disorders, dyslexia and dyspraxia he found shared concerns about the support available, particularly at the transition stage from adolescence to adulthood.

On considering the request for Scrutiny to investigate the issue of support to people with ADHD, the Overview and Scrutiny Management Group were clear that the main focus of the investigation should be ADHD and the panel did not have the capacity to scrutinize Autism Spectrum Disorders, dyspraxia and dyslexia in the same degree of depth. However it may be relevant when looking at the findings of the panel, to consider extending recommendations to cover other learning, communication and behavioural differences.

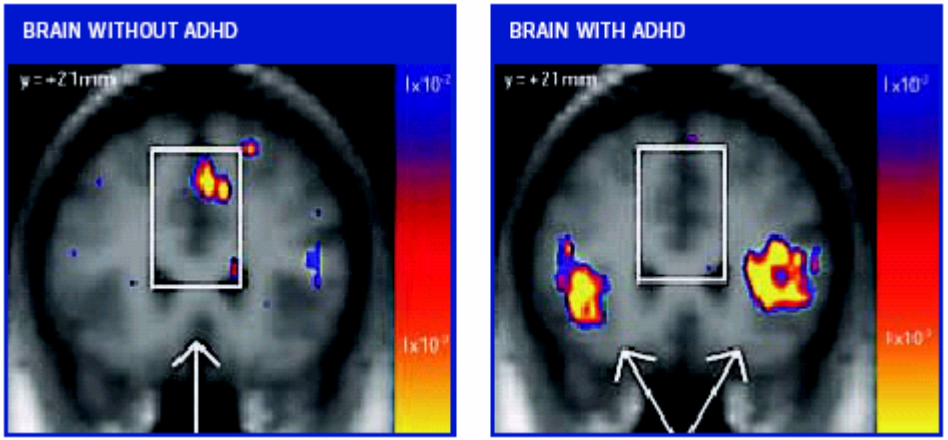
In planning the work of the Panel, members quickly recognised that early identification and intervention is critical to influencing the quality of life for a person with ADHD. The Panel therefore looked at all stages of life from infancy to adulthood.

Approach

The panel have approached this piece of work from the standpoint that there is sufficient medical opinion and research to establish that Attention Deficit Hyperactivity Disorder is a medical condition. It is not simply a case of a naughty child without effective discipline or an inattentive, disruptive adult. The pattern and chemical balance of the brain is affected and leads to a spectrum of behaviour and difficulties. For some, the symptoms may be mild and with support coping strategies can manage the condition. For others, medical intervention will help but needs to be combined with a range of support strategies.

Within the medical profession there is still disagreement and many believe that the condition only exists in childhood. However, the health representatives that the panel spoke to agreed that the condition existed in childhood. They also considered it likely that for a percentage of people with ADHD, some of their symptoms would continue into adulthood. In America, it is a diagnosed condition in both adults and children.

The panel quickly learned that it is rare for someone to have ADHD alone it is usually accompanied by another learning difference, which may include oppositional defiance disorder, conduct disorders, dyslexia or dyspraxia which further complicates a person's ability to learn and integrate. Having more than one learning or behavioural difference is known as comorbidity. The report will therefore also touch on these issues as some of the support needs overlap.



The pictures above show the differing activation of the brain in people with and without ADHD under specific test conditions.
Source: Bush G, Frazier JA, Rauch SL, Seidman LJ, Whalen PJ, Jenike MA, Rosen BR, Biederman J. Anterior Cingulate Cortex Dysfunction in Attention-Deficit/Hyperactivity Disorder Revealed by MRI and the Counting Stroop. *Biological Psychiatry*: 45 (12), 1999

Definitions

Attention Deficit Hyperactivity Disorder

Attention Deficit Hyperactivity Disorder is perceived to be a brain based condition caused by chemical imbalances that affects the parts of the brain that control attention, concentration and impulsivity. ADHD is characterised by an imbalance in neurotransmitter chemicals. Current diagnosis of ADHD is based on symptoms and not the causes of symptoms.

Attention Deficit Hyperactivity Disorder has been referred to as a hidden disability because there is no outward sign that something is physically wrong with the central nervous system or brain. ADHD affects 5% of school age children, that is 500,000 children in the UK.

Children with ADHD have developmentally inappropriate behaviour, including poor attention skills, impulsivity and hyperactivity. Children with ADHD may also experience problems in the areas of social skills and self esteem.
Adults with ADHD may have some of the following difficulties –

- poor time management
- difficulty controlling temper
- difficulty establishing relationships
- concentration difficulties
- generally disorganised
- over activity or under activity
- restlessness
- mood swings
- low tolerance of stress

People may exhibit some or all characteristics of the disorder with varying degrees of severity. Two of the most usual comorbid conditions that people with ADHD may have are conduct disorders and Oppositional Defiance Disorder.

Autism and Autistic Spectrum Disorders

Autism is a developmental disorder causing lifelong difficulties with communication and social skills. The severity varies greatly from not developing any meaningful speech and being “in a world of their own”, to subtle difficulties with the social use of language and poor empathy.

Alternatively, people with Autism may have well developed language skills, average to above average intelligence and social “clumsiness” and are often referred to as having Asperger Syndrome.

Because of the wide range of different presentations, the umbrella term “Autism Spectrum Disorders” has been adopted. It is thought that about 1% of children have autism spectrum disorders. At the mild end of the spectrum about ten times as many boys as girls may be affected.

The characteristics displayed tend to change as a child develops. There a number of key features that are always present to some degree;-

Impairment of language
Impairment of Social Relationships
Impairment of creative imaginative play
Rigidity of thought

Some authors have linked Asperger Syndrome with creative genius, suggesting that the behaviour of people such as Mozart, Beethoven, Orwell, Michelangelo and Einstein showed typical autistic traits.

Dyspraxia

Dyspraxia is generally described as an impairment or immaturity of the organisation of movement .
Associated with this may be problems with language, perception and thought.

People with dyspraxia may have a poor understanding of the messages that their senses convey and relating those messages to action, for example a series of instructions needs to be broken down into one or two at a time.
It is suggested that approx 7% of the population may have some form of dyspraxia, in a ratio of 3:1 male to female.

People with dyspraxia may have the following difficulties:

- organising thoughts
- difficulties in following routes from place to place
- delayed speech and language development
- poor motor skills
- poor short term visual and verbal memory

Examples in children may include:

- games lessons - lack of hand eye coordination
- Slow to dress , tie shoe laces
- classwork completed slowly and rarely finished
- difficulty in copying form a board, dictation and following sequences

Some traits may follow the child into adulthood and result in low self confidence and self esteem and a difficulty in pursuing a career.

Dyslexia

Dyslexia is a combination of abilities and difficulties that affect the learning process in one or more of reading, spelling and writing.

Difficulties may include speed of processing information, short term memory, sequencing and organisation, auditory and visual perception spoken language and motor skills.

Abilities of people with dyslexia can include well developed spatial, visual and creative skills. Good speaking skills and problem solving ability.

Dyslexia was first mentioned in a British Medical Journal in November 1896 as a case of Congenital Word Blindness. The case study stated that in spite of laborious training a 14 year old boy had difficulty spelling out words of one syllable. The school master who taught him said that he would be the smartest lad in the school if the instruction was entirely oral.

A study in 1984 suggested that dyslexia affected 4% of the population although it has been suggested that up to 10% have signs of dyslexia.

As with ADHD and Autism the prevalence is higher in males than females by 4:1.

ADHD - Separating the fact from myth

MYTH	FACT
ADHD is not a medical condition	Scientific research has shown that there are differences in some parts of the brain in people with ADHD. The part of the brain known as the prefrontal cortex controls mental activities that allow self control. The three core symptoms of ADHD - hyperactivity, impulsivity and inattention may all arise due to pre frontal cortex deficiencies.
ADHD is a modern condition	Not true - ADHD was first described by Dr George Still in 1902 as “morbid defect of moral control”. ADHD has also been called - minimal brain damage (1930) - minimal brain dysfunction (1960) - hyperkinetic reaction of childhood (1968) - attention deficit disorder (ADD) with or without hyperactivity 1980) Since 1987 it has been known as ADHD. In 1987 the World Health Organisation introduced a second definition “hyperkinetic disorder” for more serious cases of ADHD.
ADHD is just a trendy label to excuse poor parenting and badly behaved children and all they need is a “clip round the ear”	Poor parenting is not the cause of ADHD, although a range of different parenting styles can influence behaviour and help parents to manage difficult behaviour. As already outlined, there are differences In the chemical makeup of the brain.
ADHD does not continue into adulthood	Between 50% and 80% of children with ADHD will still have ADHD as teenagers and up to 60% will still have it as adults

ADHD cannot be inherited	Research has shown that there is a strong genetic link in ADHD. In identical twins the probability is 72 to 83% that both will have ADHD. In non identical twin this reduces to 21 to 45%. More than 50% of parents with ADHD will have a child with ADHD.
ADHD affects male and female equally	Both male and female can have ADHD, but boys are four times as likely as girls to have ADHD
ADHD is a result of poor diet and over consumption of additives and E-numbers	Poor diet is not the cause of ADHD, however diet can affect behaviour and for some people with ADHD the exclusion of dietary triggers may help to alleviate symptoms. Fish oils have improved concentration in some cases.
Parents encourage their children to display ADHD symptoms to get a diagnosis and qualify for Disability Living Allowance	The media encourages the idea that greedy parents push for a diagnosis so they can get additional benefits. However, diagnosis should be as a result of a rigorous assessment and only on the prescribing of Ritalin can Disability Living Allowance be awarded.

Data source: Netdoctor.co.uk

Methodology

When the panel was considering the best way to carry out the scrutiny investigation, it decided that it was important to look at the support available to people with ADHD throughout their lives. In this way, the panel could identify areas of good practice and gaps in support provision at all phases of life, including adolescence and adulthood. In addressing the issues in the early stages of life, there is the opportunity for people to learn to manage their differences and therefore require less support later in life.

This report reflects the panel's findings as a journey through each of the major stages of life to adulthood. The report will generally focus on ADHD, but will make reference to the other learning, behavioural and communication differences already identified.

The Panel were keen that readers of this report could see examples of how ADHD and other learning, behaviour and communication differences affected the lives of individuals. Members have therefore decided to accompany the journey narrative with anonymised case studies, shared with the panel through the course of their work.

The panel has met with a broad cross section of professionals from within the local authority and partner agencies, who are involved in the diagnosis and support of people with ADHD and Autism Spectrum Disorders. These included representatives from Mental Heath Services, Primary Care Trusts, Youth Offending Team, Education, Social Services and local support groups. The panel also held open meetings to meet with members of the public who have direct experience of ADHD, Autism Spectrum Disorder, dyslexia or dyspraxia, or are the parent or carer of someone with a learning difference.

In addition, each member of the panel undertook assigned tasks to gather additional information from a variety of sources including, Huddersfield Technical College, Connexions, Education Psychology, Families Together Project, Autism Resource Provision (in 3 schools) and Kirklees Parent Partnership Service.

The life journey has been split into the following broad areas:

Early Years	**ages 0 to 5**
Infant and Junior School	**ages 5 to 11**
High School	**ages 11 to16**
College / 6th Form and Higher Education	**ages 16 to 24**
Adulthood	

Early Years

The early years are a period of intense development in every person's life. For someone with ADHD it is usually not possible to diagnose the condition at such an early stage, although patterns of behaviour are emerging. A child may appear to be hyperactive and often act in a "naughty" way. This could be interpreted as a demanding child with an abundance of energy that requires strong parenting skills, rather than a child with ADHD.

The evidence presented to the Panel indicated that these children are never the less at risk of starting to be excluded from normal social activities. Opportunities to develop social skills and learn appropriate behaviour can be taken away from the child. For example, a child may wish to attend playgroup at age 2 years 6 months, but because they persistently exhibit challenging behaviour, the playgroup struggles to meet their needs. Finally, under pressure from other parents, the playgroup takes the decision to exclude the child.

By this stage in a child with ADHD's life, parents are sleep deprived and struggling to understand why their child has such demanding behaviour. People within the parents' social circle may start to withdraw and may believe that the perceived indiscipline is as a result of poor parenting skills. Parents have told the Panel about feelings of guilt as they question their own abilities and start to feel their self confidence eroding by their inability to help their child to fit in. They start to withdraw, feeling they cannot take their child into some environments and for many the isolation for parent and child begins.

Parents of infants with Autism Spectrum Disorders can often recognise that there is a delay or something unusual about the way in which their child is developing, as young as 18 months. The differences often seem clearer where a child has an older sibling.
Parents of children with dyspraxia also informed the panel that they were aware that their child had difficulties from around 18 months old.

During the early preschool years, Health Visitors and General Practitioners play a critical role in the early identification of any developmental differences including ADHD, Autism Spectrum Disorder and dyspraxia. Health visitors are able to make referrals for assessment if they consider it appropriate. The evidence presented to the Panel showed a mixture of experience when parent's approached their GP for help. One parent's GP said to go away and forget it, and not to bother reading books and articles on the internet as these will not help. Other GP's have been more responsive and referred the child to a Consultant Paediatrician. A number have referred the child to the Child and Adolescent Mental Health Service (CAMHS) for assessment.

However it is more likely that the child with ADHD will not be diagnosed until he or she is attending school when the behavioural differences and attention deficit are likely to be highlighted within the school environment.

Transition into Education

Starting school is looked forward to by both parents and child with an equal mixture of excitement and dread. For a child exhibiting challenging behaviour, who has already struggled to cope in learning and play settings, there is a compounded feeling of trepidation, as parents wonder how their child will adjust to the new surroundings and how the school will manage his/her learning and behavioural differences.

The key to all transition stages is communication, both of relevant information concerning the child and of information to parents so they can understand what to expect and help to prepare their child. In recent years, schools have become better at sharing information, but for a child who has not engaged in preschool provision this is difficult. The panel has heard about different levels of success in introducing a child with ADHD symptoms to school. Parents have raised concerns about a lack of consistency and some schools are not as flexible in agreeing appropriate transition arrangements to support the child. Preparation for school is critical, including familiarizing a child with new routines and surroundings. Schools try many different approaches to this settling in period, including visiting with parents, attending for school lunch and a phased starting period where children start on a part time basis and build up to full time school hours. For children with ADHD, changes in routine can lead to an escalation in inappropriate behaviour, so working with parents and all staff to minimise this is essential.

Health visitors have an important part to play in sharing information with school staff, including Special Education Needs Coordinators to help prepare the way for a child with learning differences.

The more information the school has about the child, the more likely they are to be able to respond early to provide support and develop strategies to meet the child's needs. This may include referral for formal assessment or bringing specialist services into the school to help the school work with the child.

Case Study A

Child A has developed well until at the age of 18 months he started to regress. He stopped speaking and started to display autistic tendencies.

Within the extended family are two GPs who believe that the child urgently needs to be assessed. However after an initial referral, the family found that the waiting list for a multi agency assessment with the CAMHS team was lengthy and their child's case was not seen as any more urgent than anyone else on the list.

The view of the family was that it was critical to have a diagnosis as soon as possible so a plan of early interventions can be developed and action can start to help the child. The families perception was that medical opinion indicates that at age six a child's brain cells become fixed. Before the age of six it is still possible, through intensive interventions, to stimulate the development of other parts of the brain that will help compensate for those areas that have not developed.

The family chose to secure a referral to the Early Diagnostic Centre in Nottingham. A thorough assessment was undertaken at a cost of £2,800. The resulting report recommends an intensive programme of interventions to start immediately.

The family also had a multi agency assessment with CAMHS and are told that there is no further action that can be taken at the present time and the child should be seen again at the age of four.

The view of the family was that they should not wait until the child is four and they decided to pay for private therapists to carry out a programme of interventions at a cost of £50 per hour. The child is responding well to the programme and has begun to speak and start to interact socially again.

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Case Study B

Child B was diagnosed with Autism Spectrum Disorder at the age of two and a half when his parents became aware that he was not developing in the same way as his brother. Symptoms included very faddy eating, becoming very distressed when hearing music and having speech development difficulties.

The Health Visitor made a referral to Dewsbury District Hospital Child Development Centre. An assessment took place both in the hospital and home setting.

Although the diagnosis came as a shock to the family, it opened up opportunities for their son. He obtained an early nursery place to help with his development and was statemented from the start. The parents were delighted with the knowledge and support they received from all the staff working with their son.

In addition the parents and family members took part in the Early Bird Scheme at Dewsbury District Hospital. It is a ten week intensive programme that helps family members learn how to support the child with special needs. If a child is diagnosed when at school, then the class teacher will also attend.

A place at Infant and Junior School was secured after considerable pressure from the parents. The school has an autism resource provision but child B has a place in mainstream school with a support worker. The parents are concerned that there is no resource provision at High School level in North Kirklees.
The parents believe that as a result of the early intervention work and support, Child B has made considerable progress and is growing into a confident child.

Infant and Junior School

Within Infant School the symptoms of an undiagnosed child are likely to escalate as they struggle with new routines and trying to fit into a structured environment. They have the opportunity to try and make friends but sometimes their impulsive actions and boisterous behaviour mean that other children are wary of them.

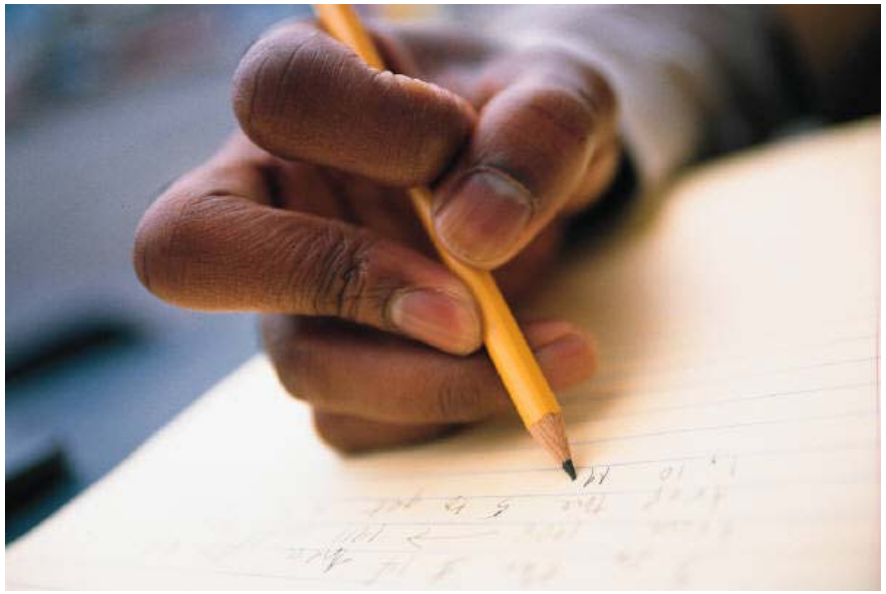
From the evidence gathered by the panel it is evident that at this stage children start to develop a self awareness of their behaviour and learning differences. For example, children with dyspraxia are expected to take part in team games and whole class physical activity. They struggle to coordinate their movements and their self confidence starts to be eroded.

Children with difficulties in learning may become disruptive due to frustration. In other cases children start to withdraw quietly as they struggle to cope. Children with ADHD can struggle to concentrate on a task for any length of time. They become easily distracted and may wander around the classroom. In most cases it will not be obvious to the class teacher that the child has ADHD, particularly where it is not at the severe end of the spectrum. Some children will start to develop their own coping strategies, for example by becoming the “class clown”. In these subtle ways children start to fall through the net and their learning differences go unrecognised. Differences can be masked, for example children may excel in some areas, such as numeracy, whilst struggling with reading through undiagnosed dyslexia. Children may just be judged as being boisterous and having challenging behaviour or just a little slower in learning.

In the current education system within Kirklees, many children with learning differences will not require a statement of special education need. Both ADHD and Autism Spectrum Disorders affect people to varying degrees. Children at the most extreme end of the spectrum are likely to have Statements of Special Educational Need. Evidence indicated that a statement was currently the only way to ensure additional one to one support and funding tailored to the needs of the child. However, additional support is critical to children with learning differences. Children with ADHD need someone to help to keep them on task and minimise the disruption caused to other pupils. The Panel has spoken to parents who say that it isn’t always essential to have one to one support, children may benefit from additional support as part of a small group, for example 1:4.

Parents reported very mixed experiences to the panel concerning their relationships with school staff. For some, the school could not have been more helpful. They were involved and informed and worked with the school to support their child. However for many parents the experience was not a happy one. The school was reluctant to recognise that there was an underlying problem and did little to help. The school was quick to criticise the child’s behaviour rather than discuss strategies to address the issue. The parent was usually made to feel that it was their fault and as such they had a responsibility to deal with it. The panel were concerned to hear from more than one parent who had reluctantly decided to withdraw their child from school because the constant friction at school was causing their child considerable distress and compounding difficulties.

A parent is generally the person who knows their child best. They can spot the subtle changes in behaviour as their child starts to struggle in the school situation. However many parents feel that the school either does not hear their views or dismisses them as being overprotective. The panel received examples of schools having dismissed parents views on a number of occasions before finally someone has recognised that there is an issue of concern and the slow process of assessment and diagnosis has finally begun.



The quality of understanding of ADHD, Autism Spectrum Disorder, dyslexia and dyspraxia varied greatly. Where a teacher does not have a full understanding then it is difficult to put appropriate support in place. The panel has heard of non teaching assistants trying to support children with ADHD with no real understanding of ADHD and how best to manage the symptoms. There is only very limited training within the Teacher Training syllabuses on learning differences. Training courses are provided by the Local Education Authority but these have to be paid for by the school and may not be considered a priority area.

The Panel shares the view of a local paediatrician, that ideally a child should have a diagnosis by the time they start Key Stage 2 (Junior School aged 7). This should enable a package of support to be put in place during Junior School to help maximise achievement and for teachers and parents to learn how to work effectively with the child.

During junior school children will start to become more discriminating in their friendship choices. Many children with learning, behaviour or communication differences can find themselves feeling isolated and in the worst cases being bullied because of their differences. In some cases, children with ADHD can use bullying behaviour to intimidate others.

Primary school is a critical time for establishing patterns of behaviour and engaging children in learning. At the age of four, the experience is new and exciting but if the school does not respond effectively in identifying and meeting the needs of a child with learning differences, then the experience sours and the child starts to disengage and fall behind in achieving. This is not only achieving in an academic sense but also in social skills and the ability to integrate.

Case Study C

Child C is five years old. He lives with his parents and 8 year old sister. He has a ten year old male cousin who has severe dyspraxia.

Child C's behaviour has always been different to his sister, who has been a "model child" at home and school. From an early age he had explosive and violent tantrums. His mother discussed this with the health visitor and GP, who both suggested that it was the "terrible twos" or "boyish behaviour" and nothing to worry about.

Child C attended play group but was violent with other children and was asked to leave. His mother persuaded her GP to refer him to a paediatrician. The paediatrician accepted that child C had severe behavioural problems, but said that he was too young to be diagnosed with ADHD.

Child C has been at school for 6 months. The school are finding it difficult to cope with him. His main problem is his violent tempers. His mother is frequently called at work to collect him. The school has now threatened to exclude child C and have suggested he only attends school on a part time basis.

Child C's mother does not know what to do. She is desperate for help but does not know where to go.

Case Study D

Child D is ten years old and in her final year at Junior School. She has been diagnosed with ADHD and dyspraxia and is very unhappy at school.

Child D feels her classmates laugh at her because of her behaviour and co ordination difficulties. Her only friend is another child with special educational needs. Her reading and comprehension are good but her numeracy is poor. The SEN Coordinator told parents that she was going to refer child D for an assessment for discalcula but this has not happened.

She is currently trying to avoid going to school and frequently complains of stomach aches and headaches. These can be genuine and brought on as a result of the child's stressed state.

The parents of child D are getting very concerned about her transition to High School. By March of the year of transfer they have had no contact from either her current school or the High School about how best to manage transition.

Child D has many concerns about the transfer and it is important that she gets a positive and supported start and that all the teachers are aware of how to meet her needs.

Transition to High School

Effectively supporting a child with ADHD, Autism Spectrum Disorder, Dyslexia or dyspraxia during the transition from junior school to high school is critical. All children are nervous about of the move to high school. Children move from an environment of childhood into an adolescent environment. They move from generally having lessons with the same teacher and pupils, in the same classroom, to having to move around a large building being taught by a variety of teachers and learning with a wider mix of pupils. Effective management of transition is key to early integration and minimising the impact of the change in environment and routine.

The evidence presented to the panel, indicates that for children with learning differences but without a statement of special educational need, the transition is not well managed. Information from one school to another seems to get buried and even if it is passed across, preparations start at a very late stage. Most parents spoke of having to start the "battle for support" all over again as funding or support does not follow the child from one key stage to another.

Communication is vital and parents told the panel that the needs of their child are not communicated effectively across all the staff that work with the child. Teacher training only touches on these areas of need and many teachers do not have a full understanding of the complexities of the learning differences and how to address them. For example, a child with dyslexia may have difficulty with short term memory, this means a teacher can verbally instruct a child on an activity but by the time the child returns to their seat to start work, the messages have already become confused.

The panel realises that the demands on teachers are intense and that many teachers are committed to trying to meet the needs of all pupils whilst balancing the priorities set by the curriculum and achievement targets. However, the evidence gathered shows that in many cases the system struggles or fails to meet the needs of children with ADHD and the co morbid conditions that can accompany ADHD.

At High School age the desire to fit in and be the same as everyone else is very strong. Children do not want to appear different and will sometimes not raise their difficulties. From the information given to the panel by parents and teachers, the panel believes that it is not unusual for the whole of the first year at high school to have passed without any additional support being put in place.

The Panel identified concerns about funding allocations in the last year of junior school and the first year of high school. There is evidence that some schools will not refer a pupil for assessment or seek funding if the pupil is going to leave the school in a short period of time.
The school is reluctant to use it's limited number of referrals if they can manage the pupil in the short term. If this situation occurs with a year six pupil at junior school, it means that when the child gets to high school in year 7 there is no additional funding to support the child. The high school has to start the process of referral and assessment and it is unlikely that any additional resources will be in place before the pupil completes year 7. As already indicated the first year at high school is a time of immense change and schools should seek to have additional support in place at the start of year 7 for pupils with learning differences. It appeared to the panel that the resistance to refer could be interpreted as doing what is best for the school and not what is best for the child.

High School

A young person has the chance of a fresh start at High School. The difficulties of primary school can be put behind them and they have the opportunity to build new relationships and have an increased variety of learning experiences.

Year 7 is a critical year for settling in all children. The Panel believe that for children with learning differences this is a particularly difficult period and recommend that there should be a key worker appointed for every child that needs additional support or reassurance. This may be a form teacher but is more likely to be a support assistant or special educational needs co coordinator who can be available to that child at break and lunchtimes to answer questions and if necessary act as an advocate for the child. This person should have a full understanding of the child's needs and ensure that these are effectively communicated to all staff. The contact worker could also try to keep parents informed and discuss any concerns the parents may have, if necessary signposting parents to appropriate members of staff.

The Panel has received positive feedback on the support provided by Learning Mentors for some children with learning and behaviour differences. A child can have an hour or two a week with this person, focussing on an area where they require additional help. Ideally the Panel would like to see one learning mentor per year group at High School. This is not usually the case. Learning mentors also need additional training to understand the nature of learning differences and agree strategies to work effectively with these young people.

From the evidence that the panel has heard, it believes that there is a high level of inconsistency of provision and support at all levels of education but this is most noticeable at High School. The Local Education Authority allocates an element of funding to meet special educational needs, the panel worries that sometimes this funding is subsumed into other areas which are seen as a greater priority. Schools then complain that they do not have the resources to buy in the support that is needed. There are examples of good practice across the district but the panel has very real concerns about how effective the current funding is in meeting the needs of children with learning, communication and behaviour differences who are not statemented.

The perception of parents is that support in education is a lottery. Some parents, through dogged persistence, have finally accessed a minimal level of additional support for their child. There is evidence that Kirklees is not proactive in keeping abreast of current learning developments in areas of learning difference. For example in the area of dyslexia, the panel were told by more than one parent that they had been unable to convince the school of the need for assessment and had paid for a private assessment which had lead to a diagnosis.

This can cost up to £300 and for single parent families, relying on state benefits, it is not an option. If a parent then feels their child would benefit from an intensive support programme offered by a private specialist organisation, then this is likely to cost at least £2,000.
Once a child has a diagnosis, Kirklees' response is that the Local Education Authority has effective methods in place to teach children with dyslexia. However, like all learning differences, every child is different and the approaches offered by Kirklees schools may not be the most appropriate. Case Study F indicates how a parent had to pay to try a method themselves in order to convince a school that it was appropriate for their child. It has been suggested that schools are not being given the flexibility to try working with private specialists to meet pupils needs.

For young people in High School with ADHD there needs to be a time out, quiet space that they can access to help them calm down. The resource provisions for Autism, attached to three schools in Kirklees, have recognised the benefits of a quiet space. Like children with ADHD, children with Autism are prone to outbursts and fits of temper or frustration. It is very difficult to remain focussed in a classroom environment for any length of time before pressure starts to build with in the child. The Panel has heard of high school age children running around corridors causing disruption to other pupils during lesson times. If there was a quiet room then there would be a place to go to "kick off" and calm down before returning to the lesson environment. There are such facilities in the Autism Resource Provision at Honley High School and it is very effective (see case study page 22).

Exclusion

The use of exclusion across education settings has seen a steady increase over the last three years. The following tables illustrate fixed term and permanent exclusions:

Fixed Term Exclusions

School Type	2002/03	2003/04	2004/05
Primary School	467	465	402
Middle School	112	177	351
Secondary School	2580	2767	2733
Special School	252	233	284
Pupil Referral Unit	14	44	71
Totals	3425	3686	3841

Permanent Exclusions

School Type	2002/03	2003/04	2004/05
Primary School	4	9	13
Middle School	2	4	3
Secondary School	30	34	45
Special School	0	1	2
Pupil Referral Unit	0	0	0
Totals	36	48	63

Children with undiagnosed learning differences and difficult behaviour are more likely to have periods of fixed term exclusion. Permanent exclusion is frequently threatened and in some cases the threat is carried out. The further into the High School career the young person is, the less likely they are to be able to secure a place at another school. The panel have anecdotal evidence that young people drop out of the education system and with the extreme pressure on LEA resources, in some cases they are not followed up.

It was alleged that in some cases, schools overlook truancy because the absence of a challenging pupil provides a break for teachers and the rest of the pupils in the teaching group form the disruptive behaviour of the absent individual. In addition the school does not have to go through the formal route to exclusion which would cost the school £6,400 if the pupil were to be permanently excluded.

Evidence indicates that some schools work harder than others to minimise exclusions. Some schools operate a cumulative system, whereby three offences, which may be as minor as wearing a baseball cap on school premises, result in a fixed term exclusion. This seems unreasonable to all parents. If a child is constantly being told off for “minor offences” it has a very negative impact on them. For a child with ADHD the reward of positive behaviour and achievement helps to engage the young person. For parents, the use of fixed term exclusions compounds the feeling that their child’s right to an education is not being met.

Many parents have told the panel that it is impossible for them to work because the school is regularly telephoning them to come and sort out a situation or to take their child home. This means that parents can be forced to continue to claim benefits even though they are seeking to improve their financial situation and want to work. It was suggested to one parent that it would be better if their child only attended school part time. All their peers were full time but because the school could not cope with the child they put forward the part time solution.

Parents have told the panel of how they are able to succeed on a 1:1 basis where the school fails in adapting strategies to help their child learn. The panel has heard of situations where parents have reluctantly withdrawn their child from school as the school is unable to meet their child’s needs. This is usually a last resort but parents have become very concerned about the effects on their child, eg very distressed by the continual conflict at school and unable to learn in the environment.

The national emphasis on inclusion means that schools are increasingly expected to take on children with complex needs. The panel queried whether this was appropriate in all cases. At the same time, the Government is wanting local education authorities to reduce the number of Statements of Special Educational Need that they issue. The panel recognised that the school had to balance the needs of one child against the needs of the majority. Schools often have differing views to parents about what is most appropriate to meet the child’s needs. It is a complex area but the panel would conclude that insufficient resources are being put in place to work with these non statemented children in the most appropriate ways.

Case Study E

Child E has ADHD and Autism. He has secured a place in the Autism Resource Provision in a Kirklees High School.

He is very intelligent and loves to learn. He is very happy at his high school because of the additional support that he is offered in the Resource Provision.
If he is becoming agitated in a lesson and knows that he is about to lose his temper, he can leave the room and go to the resource room to let out his frustrations.

If he only had ADHD then this provision would not be available to him.

He is making good progress at school and is happy that there are other people like him at the school. There are also staff who understand his behaviour and communication differences.

Case Study G

Child G was diagnosed with dyspraxia at 7 years old but could not access any support until 10 years old. With the support of a local paediatrician she received some physiotherapy. Child G has a statement of Special Educational Needs and gets a very small amount of support.
Her parents feel there were more forms of support available 8 years ago then there is today. The parents set up a support group. They have found that fish oils have a positive effect on their daughter's symptoms.

Case Study F

Child F was diagnosed with dyslexia at the age of 11 in 2004. His mother was convinced he had dyslexia as far back as 2000/2001 but when requesting an assessment was advised by an Educational Psychologist that this wasn't necessary. The Educational Psychologist felt that child F was a slow learner.

In 2001 he was assessed as having reading and literacy skills at level 1 (below average). At age 11 he had a reading age of 6.0 years.

His mother battled to get her son an assessment and once he was diagnosed with dyslexia she fought to get him a minimal level of additional support. She paid privately for a dyslexia specialist to work with her child in order to prove to the school that such support would be beneficial. With a minimum of 1 hour a week he has seen his comprehension rise from 6.01 to 8.07, his spelling from 6.05 to 7.3 and his maths and science work to above average. All this has been achieved during the final year of junior school.

His mother contacted Kirklees Parents Partnership Service to help find out about her rights regarding her son's education. She learned that the school should have provided her with a Dyslexia booklet when her son was diagnosed but that was not provided until she requested it.

Mum is concerned about the move to high school. Her son is quiet and his educational experience has made him quite withdrawn and undermined his self confidence. Because he does not have challenging behaviour his mother feels there is a tendency to overlook his needs.

Sixth Form, Further Education Colleges and Higher Education

The Panel received submissions from Greenhead College, Huddersfield Technical College, Dewsbury College and Huddersfield University on the provision that they make to help people with learning differences access further and higher education. The panel also received evidence from people who had attended these facilities or had children currently studying at them.

The panel learned that moving from High School to further education allows a greater relaxation of the structured environment. The volume of pupils with special educational needs and learning differences will decrease. There is the option for young people and adult learners to focus on their areas of strength and more vocational learning.

In general it appeared that young people with ADHD preferred the technical college environment where they could study vocational courses and perhaps try to improve attainment in key areas like maths and english. Some students with Autism Spectrum Disorders are highly intelligent and may opt for the academic courses of study offered by sixth form colleges.

It was brought to the panel's attention that some young people do not want to have their differences identified. They want a fresh start and the opportunity to try and manage themselves. Parents have been faced by the dilemma of wanting the educational institute to meet their son or daughter's needs whilst respecting the adolescent's desire for independence and confidentiality.

The panel received no information on the failure to complete courses by people with learning and behavioural differences. The evidence gathered showed that the institutions had tried to respond to the needs of the individual. In many cases the response was not immediate (see case study H) and in some cases insufficient resources meant only limited support could be offered. It was alleged that at University it was easier to access technology support for which funding was available, but other types of support were a lot less accessible.

Huddersfield Technical College

The panel were impressed by the efforts being made by Huddersfield Technical College to support people with learning differences. They provide a range of different services to meet different needs which includes ADHD, Autism, Dyslexia and Dyspraxia. The ages range from KS4 i.e. children excluded from school in years 10 and 11, to people in their sixties that need help with independent living; similar to day care services. The college try to make learning as holistic as possible, looking at all aspects of life and providing something that is relevant. The college tailors individual plans to integrate students into mainstream classes and support them in classes.

The panel were impressed by the commitment of the 50 staff in Care Services at Huddersfield Technical College and felt that there should be more support for the staff to maintain their learning about learning differences and the disabilities that they support. Only 2 staff are trained specialists and the rest are largely self taught. This isn't because the college doesn't recognise the importance of professional development but there is a lack of information and training available. The service does have waiting lists for support in some of the more severe learning difficulties. The panel were concerned that the planned cuts to adult education would mean large reductions in the Care Services provided by the college.

Case Study H

Having struggled throughout her education, H was finally diagnosed with dyslexia and dyspraxia during 6th form. When her parents asked what support this would give H, they were told that it was too late. The GP had not been interested in helping the family so diagnosis was obtained through a private assessment by a local specialist.
Because of her condition, H has become a loner and does not mix socially. She is currently studying at Huddersfield University and her parents have secured 1:1 tutor support, although this was not made available in her first year.

Her mother was most concerned about the lack of support available when a person is newly diagnosed. She recommended a single point of contact where you can be signposted to appropriate services.

Case Study J

J has severe Autism. Her mother refers to her "falling out of Children's Services into a black hole". There was no plan in place concerning her daughter's future.

Mother arranged an appointment with the Commissioning Manager for the Children with a Disability Partnership Board and her Manager and was encouraged by how they listened to the issues she raised. After the meeting officers started to address the concerns. J's mother felt this turned a negative experience into a positive one because someone took the time to listen and understand J's support needs.

Case Study K

Child K's symptoms started at the age of 4. His father had the same behaviour differences.
His elderly GP appeared not to believe in the existence of ADHD and referred him to a psychologist.
Child K has not slept through the night since he was born. He disrupts the whole household and his behaviour is becoming increasingly intimidating. Although physically small he is very strong, particularly when angry.
He can concentrate on the computer for hours but cannot focus on formal lessons at school. He has become very disruptive and has been excluded. He gets very upset when he gets into trouble. He now attends a school for children with behaviour problems.
His sister has similar problems but to date the school has been very helpful in working with her. Child K's mother feels they did not offer her son the same support.

SCENARIO 1 - EARLY INTERVENTION				
AGE:				
0-5 PRE-SCHOOL	**5 YEARS INFANT AND JUNIOR SCHOOL**	**11 YEARS HIGH SCHOOL**	**16 YEARS TECHNICAL COLLEGE**	**19 YEARS EMPLOYMENT / ADULTHOOD**
EVENTS/ EXPERIENCES:				
Joins playgroup at 2.5 for two mornings a week. Very boisterous behaviour, including kicking and biting. Mum and playgroup supervisor agree approach, provide play to suit and monitor behaviour Younger sister born	Playgroup passes information to school. Teacher aware of behaviour problems. Consults parents. Parents go to GP. Referred for multi-agency assessment. Age 6 diagnosed with ADHD. Starts taking Ritalin medication. School informed and develop Individual Education Plan. All school staff have previous training and understand ADHD. Additional support provided for the child and family. Review diet and home environment.	Information transferred to new school. All teachers and support staff fully trained in strategies to manage ADHD symptoms. Learning mentor allocated to child 1 hour a week. School provide quiet area for time out. Support maintained throughout school life. Does reasonably well in exams. Joins local karate class and makes new friends. Continues on Ritalin but dosage starts to be reduced from 14 years. By 16 years just needs ritalin for exams.	Gets a place on a course in animal husbandry. College made aware of condition and they provide a support worker and access to a quiet area. Builds new friendships at college and enjoys socialising. No medication required. **CONCLUSION** Early diagnosis and support has a positive effect on every area of a person with ADHD's life. The need for additional support in adulthood is dramatically reduced	Successful at college and secures a job as a veternary assistant at local vets with help of college support worker. Symptoms of ADHD being self managed Has clear understanding of how to manage behaviour. Self confidence growing and able to manage with limited support from family.
RELATIONSHIPS :				
Child has difficulty making friends. Feels left out. Not invited to social events. Parents very tired and struggling to cope	Parents learn new strategies to manage behaviour. Starting to make friendships. Younger sister starts school.	Mum able to start part time work. Happy family holiday every year. Close group of friends at High School Sister dong well at school	Mum and dad celebrate 20th wedding anniversary. Good relationship with younger sister Positive relationships with college tutors and other students	Settles into a long term relationship. Looking to live independently Family is proud of what he has achieved
OUTCOMES				
Feeling isolated Parents stressed and anxious about child's behaviour	Making progress and strategies having positive impact on education and social attainment Parents coping with support	With support is able to achieve academically and integrate socially	High self esteem Hope for the future Intact family unit	Content with what has been achieved Looking positively towards the future

SCENARIO 2 - NO INTERVENTION

AGE:				
0-5 PRE-SCHOOL	**5 YEARS INFANT AND JUNIOR SCHOOL**	**11 YEARS HIGH SCHOOL**	**16 YEARS DROPPED OUT OF EDUCATION**	**19 YEARS EMPLOYMENT/ADULTHOOD**
EVENTS / EXPERIENCES :				
Enrols at playgroup at 2.5 years for two mornings a week. Very boisterous behaviour, including biting and kicking. Playgroup supervisor unable to cope. Considered risk to other children and excluded from playgroup. Younger sister born	Teacher notices behaviour problem and tries to discipline child. Teacher calls mum in to discuss behaviour. At age of 6 threatened with exclusion. Parents try to discipline child Behaviour problems continue throughout school leading to frequent exclusions. Taken to GP but parents told they need to take control and the child will grow out of it.	Nervous of new school. Reputation known and teachers already perceive him as a nuisance pupil. Feeling isolated, angry and frustrated. Behaviour patterns continue, frequent aggressive outbursts at home and school. School reacts by imposing frequent exclusions. Finally permanently excluded at 15 No other school willing to take him so he drops out of school system.	No qualifications. No lasting friendships. Feeling lonely, resentful and frustrated. Drinking increasing amounts of alcohol. Starts graffiti and damaging property - referred to YOT. Can't keep appointments, fails to complete early intervention activities.	Given ASBO. Breaks conditions of ASBO and gets a custodial sentence. No diagnosis or treatment in prison With criminal record and no qualifications cannot get a job Reliant on welfare benefits No self esteem. Develops additional mental health disorders. Behaviour leads to eviction and homelessness.
RELATIONSHIPS :				
No friends. No social invitations Mum and dad struggling to cope and feeling isolated. Relationship under strain. Younger sister born	Parent's relationship falters under stress, they separate and then divorce. Mum receiving welfare benefits. Younger sister nervous of brother and under achieving. Mum prescribed anti depressant medication. All feel isolated.	Mums health continues to deteriorate and her relationship with her son is under increasing strain. Sister resents brother, blames him for her difficulties. No constant friendship group - ostracized by many Significantly underachieving Low self esteem and insecure	Mum frightened of son, particularly physical strength and mood swings. Sister angry with brother and feels she is judged by his behaviour. Mental health of all is suffering.	Mum feels guilty but can't take anymore and disowns son. Mum has a new partner and moves away from the area for a fresh start. Mum comes off medication. Sister growing in confidence and got new friends.
OUTCOMES:				
Social isolation Strained relationships	Relationships breaking under strain Negative effects on all family	Escalation of behaviour Disengaging with education	Medical implications for all family Negative relationships	Low self esteem Self abuse Irreparable relationship breakdown

Conclusion

A lack of early diagnosis and intervention affects the short and long term quality and direction of life for a person with ADHD and their family. Costs are ongoing as a result of evolving symptoms in adulthood.

Costs and Benefits Attached to the Intervention and Non-Intervention Scenarios

SCENARIO ONE - WITH INTERVENTION	
COSTS	**BENEFITS**
Medical Treatment - Assessment and Ritalin until 16 years old	Close Family Unit maintained
Support worker to advise family on different strategies to manage behaviour	Mum able to start paid employment
Learning Mentor to support child in school	Sister achieving well at school
Support worker to help young person at college	Young person achieves independence and good quality of life. Able to gain full time employment and become a contributing member of society
Some additional cost in providing appropriate training for support staff.	

SCENARIO TWO - NO INTERVENTION	
COSTS	**BENEFITS**
Costs related to dealing with an exclusion - teacher, Education Authority and governor time	Short term savings on educational and medical resources through not providing appropriate support to the child.
Mum unable to work - cost of welfare benefits	
Parents divorce - financial and emotional costs	
On going costs of anti depressant medication and doctor time for mum	
Sister underachieving - cost of additional support	
Cost of removing graffiti and repairing criminal damage	
Cost of staff time in Youth Offending Team	
Costs associated with ASBO, legal, police and enforcement time	
Cost to victims of crime	
Cost of time spent in prison	
Cost of welfare benefits - income support, Council and housing benefit	
Housing and Homelessness costs - court proceedings, eviction, bed and breakfast, officer time	

These scenarios are indicative and based on the real life experiences of many people that the panel has spoken to

Cross Cutting Issues

There are a number of issues that the panel believe cut across all or a number of stages of development prior to adulthood.

Parenting skills and support.

Many of the parents the panel spoke to had been at the “end of their tether” in trying to cope with their child. They may have been successful in getting a diagnosis and medication but did not have any additional support to show them how to parent a child with learning, behaviour or communication differences. In addition to periods of intensive parenting skills development, many parents wanted a helpline,that they could turn to at times of crisis. The helpline would be a “listening ear” for advice and support or just someone to talk to who understands the difficulties that parents and people with ADHD, Autism Spectrum Disorders and dyspraxia are facing.

Support for siblings and wider family

The impact on the family of a person with ADHD was also identified as a cross cutting area of concern. Parents focussed a lot of their time on one child and felt this was at the expense of any other children in the family. In addition they often relied on older children to help “babysit” their younger sibling so parents could focus on household management. Most families did not qualify for any respite care and many had not had a full nights sleep since the child with ADHD had been born.

Relationships between siblings often become strained or broke down. The violent outbursts of anger or frustration exhibited by a child with ADHD can put younger siblings at risk.

Additional, appropriate support in schools.

The parents and carers that the Panel has spoken to have all suggested ways in which their child could be better supported in mainstream education. The following areas were frequently identified:

One to one support - or small group work even as little as one hour a week of appropriate tuition can make a significant difference.

Quiet rooms - accepting that children with ADHD and Autism Spectrum Disorders will sometimes have temper tantrums or outbursts due to a build up of frustration, a quiet room where they can go to have time out to calm down and minimise disruption.

The use of card systems - parents spoke about a card system that gives brief information about the child’s behaviour and needs. In addition there was also a card that could be presented to a teacher where a child recognised that they are struggling to continue in the class situation and needed to go to the quiet room to recompose themselves. However some parents had reservations about any system that identified a child as different.

Training for all professionals - Many parents were critical of the level of understanding and appropriate training for all staff that worked with children with learning differences. They felt it was critical that all staff had a full understanding of the needs of the child and appropriate behaviour management strategies.

Funding and accessing support - A frequent concern was to length of time it took to secure support for a child. Parents often had to obtain a diagnosis by paying for a private assessment. Having secured a diagnosis it then took a further lengthy period of time to secure minimal additional support in school. Once support was in place and progress was being seen, the parents then had to continually battle to maintain the level of support . Once a child left one key stage of education for another the parents had to start requesting support all over again as the funding did not follow the child through their education.

Support to families with excluded children - When a child with ADHD had been excluded, temporarily or permanently parents did not feel they had adequate or timely support. For many families the implication of exclusion was financial as it restricted the parent's ability to work.

Diet and dietary supplements - There were varied opinions from parents on the influence of diet on learning differences, in particular behaviour and concentration. It was emphasised that changing diet was not a cure but it did have a positive effect on symptoms for some children. In general parents felt it was better to give children a healthy balanced diet and avoid what appeared to be trigger foods like fizzy drinks and sugary products.

Many parents believed that taking additional omega 3 fish oils had a very positive effect on their child's ability to concentrate and learn. However it was emphasised that the quality of the fish oils commercially available varied greatly and the most effective were also the most expensive.

A research project funded by Durham County Council and lead by Dr Madeleine Portwood, an educational psychologist , worked with a group of 120 underperforming children between the ages of 6 and 12. The children were given a combination of omega 3 fish oil and omega 6 oil of evening primrose. Half the children took an olive oil placebo. Children were tested at the outset and again after three months for ADHD symptoms, co ordination and short term memory. In 12 out of 13 behavioural scales there had been highly significant improvements, including in three diagnostic ADHD features, inattention, hyperactivity and impulsivity. Short term memory had also significantly improved. Over a six month period the most dramatic improvement was in concentration and the spin off was children had better attainments so their reading score improved. Some children improved by up to four years during the six month trial and their self esteem rocketed.

Awareness raising - Many parents and professionals emphasised the need for a better understanding of ADHD and other learning differences. This included awareness raising amongst all staff in schools, frontline workers and the police so that people had a better understanding of why someone might behave in a certain way.

Adults

The dilemma faced by adults in the UK is that the criteria for diagnosing ADHD were designed for children. Many medical professionals remain sceptical that ADHD exists into adulthood. Within the UK there are only two NHS Hospitals that will make a diagnosis in adults, these are The Maudesley in London and Addenbrooks in Cambridge. There are no specific facilities for the diagnosis and treatment of ADHD in adults in Kirklees.

The diagnosis of ADHD is controversial and there is considerable debate in literature on the issue about its causes and the validity of diagnostic criteria for ADHD, particularly for adults. The diagnosis of ADHD in both adults and children is made on clinical grounds based on assessment of symptoms according to defined criteria and the exclusion of alternative psychiatric or medical causes. In addition, it is generally accepted that there must be evidence that symptoms were present in childhood (though not necessarily previously diagnosed) for the diagnosis to be sustainable in adults. The view of the local Primary Care Trusts is that while under-diagnosis of the condition in adults is possible, it would be more common for some other diagnosis to be given. There are a number of diagnostic categories that could be applied, usually dependent on the presentation of the individual and a full psychological assessment.

However, those health professionals that the Scrutiny Panel spoke to felt that it was reasonable to assume that for a percentage of people with diagnosed childhood ADHD, not all the symptoms will disappear as they enter adulthood. For some, symptoms will persist and may require medical intervention.

Statistical evidence varies greatly. At a recent National Attention Deficit Disorder Information and Support Service (ADDISS) conference attended by a panel member, it was suggested that up to 88% of people with ADHD would grow out of their physical symptoms. Other sources suggest that up to 60% of people with ADHD in childhood will carry some symptoms will persist into adulthood.

Signs and symptoms of ADHD in adulthood may include a general restlessness, impulsivity, difficulty controlling temper, mood swings, poor attention, disorganisation and the inability to compete tasks.

What has become apparent to the panel through the course of the study is that the lack of early recognition and intervention regarding a learning, behaviour or communication difficulty can have a profound effect on an individual's entire life. Employment prospects are poor and there is an increased risk of criminality and substance abuse. Relationships are unstable and often the combination of circumstances will affect mood and behaviour leading to depression or anxiety.

Services provided directly by Kirklees Social Services Learning Disabilities Resource Team are specifically for clients with learning disabilities, including an IQ of less than 70. Those who do not meet the criteria will be referred to other community support services or mental health services depending on the nature and severity of their learning disability. Adults with ADHD are highly unlikely to access any support through the current Health and Social Care Board structures.

Many of the families that have contacted the scrutiny panel to speak about their experiences have highlighted that a child's behaviour is very similar to that of another family member. This may be a parent or grandparent but almost always the adult in question does not have a

diagnosis. One parent who had dropped out of school at fifteen only realised she had dyslexia when she saw her son having similar difficulties and pushed for an assessment. As recently as the last two or three years, young people are still coming out of the education system with undiagnosed learning differences.

Adults with ADHD in the criminal justice system

The Panel heard evidence about the volume of offenders who have a diagnosed or undiagnosed learning difference. Numbers are disproportionate to the percentages in the general population. Statistics show that 23% of crime is committed by people with undiagnosed or inadequately treated mental disorders such as ADHD. 5% of the general population is estimated to have ADHD but in 2001 a report by Her Majesty's Inspector of Prisons reported that up to 50% of the prison population had a mental health need.

On attending a conference run by the ADHD Association ADDISS, a member of the Panel heard about work being undertaken by the Lancashire Police Constabulary who had identified the issue as having a significant impact on police resources. Information on the Lancashire Project, known as DAPP - Development Disorders - Achieving Potential, is set out in a report entitled "Wasted Lives - Missed Opportunities". Wasted lives states that " *Undiagnosed and untreated ADHD leaves young people vulnerable, marginalized and at a greater risk of not achieving their birthright potential*". The case study taken from the report (see page 32), illustrates the type of person that the project sought to help. In general they are people with a genetic condition that leads to a chaotic lifestyle. DDAP is designed to alter the course of a life and help people with ADHD and their carers to break the cycle.

The project developed a multi agency framework for service provision which included CAMHS, the Primary Care Trust, health visitors, social services and the voluntary sector. An anticipated outcome is that if agencies assist young people to achieve their potential then entry into crime or persistent relapses into crime will reduce as a consequence. Activities have deliberately not been restricted to a single age group.

DDAP has recognised that additional vulnerabilities and issues frequently manifest themselves within people with ADHD. Some of the other headline issues that the partners are trying to address through their work are:

- Teenage pregnancies - an additional risk of unwanted pregnancy is 41:1
- Community drugs teams acknowledge that ADHD and associated comorbidities provide higher risk of a fast track into substance abuse.
- Domestic violence groups working with offenders and victims acknowledge that ADHD leaves a person nine times more likely to be involved in domestic violence
- Youth offending teams tackling the increased risk of re-offending from 1.7% within the "normal" population to 31% within the ADHD population.

The DDAP identified through feedback from parents, carers and people with ADHD, that individual access to services was a barrier to progress. A key aim of DDAP is to provide care pathways for parents, carers and people with ADHD to reduce the maze of services into a more organised and identifiable allied service.

The project is looking to improve the services provided to offenders, pre offenders and those in the Lancashire Farm Youth Offending Institute. Training will be given to the Crown Prosecution Service and court services regarding mental health and ADHD to ensure that interventions and sentencing decisions are made in a manner that supports the offender and gives every chance of effective rehabilitation.

Criminal Justice Case Study taken from Lancashire Constabulary Publication

M grew up in care, with no relationship with her parents. Seen as “different” at school, she had few friends. She was always “on the go”, never resting, never stopping and leading a solitary young life. At times she was outspoken in the foster home and often punished for being wilful and expressing herself with tantrums and anger. Carers could not cope with M and by the age of 5 she had been looked after by four different families as well as having time in a Council Children’s Home.

As M grew older other children shunned her, her self esteem grew lower as teachers called her stupid and punished her with endless detentions and withdrawn privileges. At the age of eleven, feeling totally humiliated by teachers for her poor academic performance, M set fire to the school. It was razed to the ground. The police caught M who had remained on the school grounds, fascinated by the fire.

M was referred to a psychiatrist and over the next five years was diagnosed with three different and conflicting mental health disorders. For one six month period she was forcibly kept in secure accommodation as she was deemed too ill to be allowed into society.

From the age of 11, M was receiving no education worth noting. She didn’t concentrate, she didn’t care and she didn’t actively participate. She became more and more defiant and was rejected by all those around her.

By the age of 19, uneducated and rejected, M was a criminal, an habitual drug taker and an alcoholic. On many occasions she had attempted to take her own life. Finally a specially trained social worker recognised the possibility of M having ADHD. After a lengthy struggle, M was seen by a specialist psychiatrist who confirmed her ADHD and prescribed medication for her.

M became motivated to do better and went back to college. In a single year she sat three A levels and passed with flying colours. She went on to study at Cambridge and remains under the care of a leading psychiatrist.

Dyslexia Association and Bradford Youth Offending Team

A study completed by the British Dyslexia Association in partnership with the Bradford Youth Offending Team has found that there are many links between undiagnosed dyslexia and the criminal justice system. The report concludes that this could also have major implications for ADHD.

In recent years a number of projects and studies have found a much higher incidence of dyslexia amongst offenders compared with the incidence in the general population. The figures indicate that between 30% and 50% of offenders have dyslexia compared with 10% in the general population. Yet appropriate educational support of dyslexic offenders remains the exception rather than the rule. In this particular project a sample of 34 young offenders were screened for dyslexia and 19 were categorized as dyslexic, an incidence of 56%.

The executive summary of the report states:

"… There is evidence of a "route to offending" among certain young people, which starts with difficulties in the classroom, moves to low self-esteem, poor behaviour and school exclusion, ends in offending. Children and young people with dyslexia are more likely to fall onto this route, because of the difficulties they face with learning …"

The project found that there were particular "hot spots" in the system at which knowledge of a person's dyslexia was critical for the best action to be taken. This included the support given by an Appropriate Adult and presentence reports. Another problem that was identified was that many young offenders were not formally excluded from school, they just did not attend. This meant that the funding for that young person was locked in the school system, while voluntary income was used to develop projects to engage the young people positively in the community.

Of the 19 young people identified with dyslexia in the sample, 7 had a statement of Special Educational Need but the statements were all related to behavioural problems not dyslexia.

The project offered a number of interventions in addition to the screening, these included ICT based literacy support for individuals, training for staff at the Youth Offending Team and partner agencies that work with the YOT. A number of recommendations were made to all YOTs. Details of the project can be found on adders.org – Research.

Evidence Gathered From Services in Kirklees

In order to find out what services were available for people with ADHD in Kirklees, the panel gathered information from a broad cross section of council services and partner agencies such as health and the police. The next section of the report summarises the key information that the panel received. It should be noted that this section reflects the views of the professionals that were interviewed and that the views were not always shared by the panel.

Health Services

The Panel met with representatives of Paediatrics, the Children and Adolescent Mental Health Service, the Primary Care Trusts and Adult Mental Health Services (SWYMHT).

Children and Adolescents Mental Health Service

The Calderdale and Huddersfield NHS Trust have management responsibility for CAMHS in North Kirklees, South Kirklees and Calderdale. The service employs 58 full time equivalent staff. The evidence reflects the process in South Kirklees which differs slightly from North Kirklees. Children with suspected ADHD are referred to the service by their GP. They are then put on a waiting list for assessment. From referral to initial appointment can take between 10 to 12 weeks. Although the panel heard from other professionals that the waiting time was approximately six months. At the first appointment a child psychiatrist, a psychologist and a community paediatrician will meet with the family and start to build up a picture of the family history, including significant issues for the family, the family structure and any family tensions such as absent parents etc. The child will usually go into a side room with support staff and use a short assessment designed to look at attentional difficulties known as the ACID test, this includes general knowledge, mental arithmetic and memory tests.

After the first visit a series of observations will take place to see how the child behaves in different settings. Information is also gathered from the school. When the information has been gathered then the assessment team will try and reach a diagnosis. The whole process from initial referral to diagnosis can take 20 weeks. It is an expensive process because of the amount of professional time involved.

In respect of ADHD in adults, there is considerable debate on the issue. Health professionals in America are currently pushing for an official adult ADHD diagnosis. Britain is usually five years behind America in diagnosis. A lot of child psychiatrists argue that ADHD is a neuro-developmental disorder and as such, as the brain develops, a child should grow out of the symptoms. However, it can be clearly seen that some adults who are now able to hold down busy careers would have had a diagnosis of ADHD as a child.

CAMHS are aware that there is an issue when clients reach 17 and leave school. Adult Mental Health Services are not used to dealing with this group of young people and there are difficulties in prescribing medication. They are more used to working with young people who are depressed or have psychosis, obsessive compulsive disorder or the traditional symptoms that Adult Mental Health work with.

CAMHS are also involved in running parenting courses. These run for a ten to twelve week period and follow the Webster-Stratton programme. The programme operates in North and South Kirklees and usually works with about twelve parents at a time.

Autism clinics are six months from referral and the assessment process is very complex. CAMHS are following the approach set out in the National Plan for Autism. Services in Kirklees are striving to meet the standards but have not yet been able to attain the targets set nationally. There is very little support for a young person with autism spectrum disorder when they have left school.

There is no treatment service for dyspraxia in Kirklees whereas there is a service available in Calderdale. It is a funding issue that the Trust are aware of but as yet have not addressed.

Dyslexia is dealt with through the Education Service, but CAMHS were aware from colleagues in the Adult Psychology Service of an on going percentage of adults in higher education who have not been diagnosed in childhood.

There is no preventative strategy in Kirklees. Agencies are generally reactive which is the traditional way of working. However, CAMHS recognises that there is an increased need for early identification, intervention and strategies for improving the child's situation.

Adult Mental Health Service

Across Calderdale and Kirklees there are different ages at which you can access adult services or more importantly are unable to access child and adolescent services. The age of transition is 17 but in some cases it may be appropriate to extend that depending on the individual. There is no formal hand over from CAMHS to South West Yorkshire Mental Health Services (SWYMHT). There are six Primary Care Trusts operating in the area and the panel felt it would be helpful if they could have some sort of commonality. (Note: The current situation regarding the allocation of PCT's is being reviewed nationally).

The Service works to internationally agreed classifications of diseases. There was no classification to enable the diagnosis of ADHD in adulthood. The last review of classifications was in 1993 and a new review is imminent.

The Adult Service deals with referrals on a case by case basis. The Mental Health Trust is under no legal obligation to conduct research into developing areas such as Adult ADHD, this is something that generally falls on academic institutes. If an adult presents with ADHD like symptoms then the service would look at developing a package of measures to meet the person's needs, but could not give a diagnosis of ADHD. The prescription of Ritalin is not licensed in adulthood but a consultant may decide that an exception should be made and Ritalin could be prescribed. In putting together a care package the service would work across agencies. CAHMS reported that of the agencies involved in the care package, Social Services is often the most difficult to engage with.

The transition to adult services is a key issue, some young people may be mature enough for transition at the age of sixteen whilst for others it may not be appropriate until they are nineteen.

The Medical Director that the Panel spoke to recognised that ADHD in adults was an emerging issue and felt it was probable that in a few years time there would be clarity of definition and descriptions of ADHD presents in adults who have not been diagnosed in childhood.

Paediatrics

The panel also spoke to Doctor Michael Sills, Consultant Paediatrician based at Huddersfield Royal Infirmary. Many of the parents that the panel spoke to had been referred to Dr Sills at paediatric out patients rather than to CAMHS. Dr Sills is a general paediatrician and has been working in Huddersfield for 22 years.
For the last ten years Dr Sills has worked increasingly with children with ADHD and their families. Initially these parents told Dr Sills that their children had seen psychologists, psychiatrists, social workers and other professionals and been told that their children had a behaviour disorder. Parents had tried all the behaviour methods and dietary advice to try and alleviate the difficulties their children had. Having made little progress, parents had carried out their own research and come to the conclusion that their children probably had ADHD.

Ten years ago Dr Sills knew very little about ADHD, so undertook his own research into medical thinking and practice on ADHD at the time. He started to prescribe Ritalin and found that the drug, that had received some very negative coverage, was in his opinion, not as bad as it was being alleged. By the end of a six month period, Dr Sills had collected approximately 30 cases. To date approximately 500 children under the care of Dr Sills have tried medication for their ADHD. An audit of Dr Sills' work was carried out and concluded that up to 70% of the children prescribed medication were enjoying some improvement.

One of the first children to try Ritalin in Huddersfield had been through six schools in a year and finally been placed in Nortonthorpe Special School. Within 4 months of being prescribed Ritalin he had left Nortonthorpe and been admitted to Mirfield Free Grammar School where he received the Achiever of the Year award. Dr Sills asks children if the prescribed medication is "any good" and the majority will say that they feel calmer and happier because they can get on with their work at school and are able to get on with their friends better. Dr Sills has prescribed medication for children as young as 3 or 4 in the most extreme cases and has seen very positive results. Dr Sills emphasised the need for early intervention to help children with ADHD as soon as possible and change their long term outlook.

As Dr Sills' knowledge of ADHD developed so did the increasing number of referrals of children who had ADHD. In diagnosing the condition Dr Sills listened to the child and parents and looked at the history of the child. He tried to gather information from schools and others to inform the diagnosis but this was not always forthcoming. Dr Sills' view is that ADHD is a combination of being more active than normal for your age, being more intensive and impulsive for your age and then considering if these factors are obstructing a child's progress towards independent adolescence and adulthood. Was the child's behaviour affecting them academically and socially and leading them to a loss of self esteem and a lack of success? Dr Sills tried to look through the "cloud of behaviour" to see if there was a pattern of poor concentration, over activity and impulsiveness that was driving the child's behaviour.

Dr Sills emphasised that increasingly research studies were concluding that medical therapy combined with behaviour therapy showed the greatest improvement in managing ADHD.

Dr Sills was part of a multi agency working group that produced guidelines on ADHD in 1997. Conferences were held and some training provided. The guidelines were distributed to all schools. In 2003, the local NHS Trusts decided that all cases should go to CAMHS however this had not significantly reduced the volume of referrals that Dr Sills is receiving. One of the possible reasons why referrals to Dr Sills are made is that he sees the child in a much quicker timescale and will not allow the waiting list to build up.

As children reach the cut off point for paediatric services, Dr Sills will be flexible in their continued treatment as he is aware that there is no adult service for ADHD. Approximately 10% to 20% of patients will continue to need support into college education (16 - 19 years). Dr Sills has declined to get involved in adult ADHD issues as he wishes to focus on the childhood years.

Dr Sills referred to a project run by the National Children's Centre called Families Together that had been run through a Home Office grant. The valuable service that provide support to people with ADHD and their parents was having to close as further funding had not been identified. Dr Sills expressed his disappointment as the loss of this valuable resource and support for people with ADHD. The project has worked with over 300 families during the three years it has been in operation.

Health and Social Care Board

The panel spoke to the joint Chairs of the Health and Social Care Board and the Partnership Commissioning Manager about the provision of services to people with ADHD and other learning, communication and behaviour differences.

The Health and Social Care Board structures are under review but at the time of writing do not include any provision for vulnerable adults. There is also unlikely to be any support available for children with ADHD. The partnership Board responsible for commissioning services for adults with learning disabilities has very strict criteria which means that adults must have an IQ of less that 70.

Representatives of the Heath and Social Care Board were aware that a number of vulnerable people, particularly adults, were currently unable to access support. Some of the services required by vulnerable adults were of a support nature to help access mainstream provision and to provide advice or advocacy support.

There had been recognition by officers that transition was a particularly difficult time. A dedicated transition team had been put in place to work for children receiving services from Social Services. The panel were mindful that with the further coordination of children's services across agencies, the separation from Adult Services could become even more marked.

Social Affairs

The panel met with Paul Johnson, Assistant Director of Social Affairs and Heath to find out what involvement the service has in supporting children with ADHD and their families.

Mr Johnson reported that social workers would respond to referred cases where there were concerns about a family being able to look after a child properly. There are specialist services to work with children with a disability and services are allocated in line with strict criteria drawn from legislation guidelines. Children with ADHD are not disabled. The Service provides a range of family support aimed at working with a family during a difficult time and preventing the need for more serious interventions at a later date. There is no one place in the service that would have responsibility for supporting families where a child has a diagnosis of ADHD and the child's behaviour is putting the family under strain.

The Service does care for a number of children in residential establishments who present ADHD type of behaviour. Mr Johnson acknowledged that there may be more young people that the service had supported who had ADHD symptoms without a diagnosis. One of the challenges facing the service is that children with ADHD may not automatically fall into one of the categories that would generate a response. An anonymous phone call saying that a child is suspected of being beaten by a family member would result in a response, but challenging behaviours are not always as clear cut in what support or intervention is required by Social Affairs. Generally a call about a child with difficult behaviour would not generate a call unless the behaviour was very extreme. Social Affairs may signpost parents to other services, such as the GP or they may have a discussion with CAMHS or officers in the Education Service.

Through the introduction of the measures of the Children Act, the services that work with children across Kirklees will have to develop a more joined up approach to the delivery of services. At the current time, the volume of high risk cases and dealing with potential abuse and abandonment situations, takes the majority of the social work resources. The implication of this is that there is unlikely to be any support available for children with ADHD other than the most severe cases.

Mr Johnson recognised that for most families the transition from child to adult services was a stressful time. This was the case across all agencies. One of the most common concerns expressed by families who have received support through social services, is the frequent change of their case worker contact. It is difficult to build an effective relationship, including establishing clear communication and trust, if the worker keeps changing.

The implementation of the Children Act will mean the introduction of a common assessment framework whereby all agencies, health, social services, education etc. will have to work to an agreed assessment process. This should help to ensure consistency of approach and early, clear diagnosis.

Kirklees Parent Partnership Service

The Kirklees Parent Partnership is an independent statutory body which provides advice and support to parents of children with special needs. The partnership was established as a requirement of the Special Educational Needs and Disability Act 2001. Part of the partnership's remit is to involve parents in the provision of special need education and to help them to influence policy.

In Kirklees the service has one coordinator, two part time officers and administration support. They support parents in a variety of ways, from explaining correspondence to accompanying them to meetings. The service can act as a mediator between the parent and the school. The service also works with schools, governors and volunteers to provide training and advice. The service has also worked with voluntary support groups including the Autism Parent Support Group, ADHD Parents Support Group and Dyslexia Parent Support Group. The nature of the work means that officers work in the evening and subsequently struggle to maintain the service in regular office hours.

Some of the parents who spoke to the panel had contacted the Parent Partnership Service and received information on their rights concerning their child's education. However the majority of parents were unaware of the partnership but would have welcomed some support and advice.

Kirklees Early Years Service

Officers from the Early Years Service met with the panel to explain the support that they could offer to parents and pre school settings in meeting the needs of children with challenging behaviour.

The service worked with children up to school age and confirmed that it was unlikely that a child would have a formal diagnosis of ADHD before starting school. However when a child started playgroup or nursery it may become apparent that they had behavioural problems and the setting could contact KEYS for officer support. KEYS could only get involved with parental consent. An officer from KEYS would go into the setting and help them devise strategies to enable a child to continue in the setting.

KEYS officers emphasised that the majority of pre school settings were private businesses and as such could decide who was able to access the provision. Playgroups and nurseries could be put under pressure by other parents to exclude a child rather than be allowed the time to work towards maintaining the child in the provision. Sometimes KEYS officers were not given the opportunity to provide early intervention strategies and advice because the provision had taken a business decision to exclude the child rather than risk losing other clients.

The panel were concerned that many early years provisions were staffed by very young Nursery Nurses. They may have an NNEB or GNVQ qualification in childcare but very little experience. The panel were concerned about the level of training and ability of these staff to recognise the early symptoms and behaviours that need additional support or should trigger a referral to enable early intervention put in place.

Education

When gathering information on the support provided by the Education Service for people with ADHD, the panel chose to speak to officers who oversee policy development and strategic approaches but also to practitioners working in the school setting who have to deliver the agreed policies and access the additional resources and support to meet individual needs. The panel also gathered an overview of the additional services available to support children with special needs.

The Panel met with Liz Dobie, Assistant Director (Pupil Support) to discuss the Local Education Authority policy in relation to supporting children and young people with ADHD. Ms Dobie referred to the work of a Kirklees multi disciplinary working group that had looked at how partner agencies could work in partnership to deliver effective support for children and young people with ADHD. A report on the findings of the group was produced in 1997 which set out information on the problem, professionals who would be involved in ADHD work, how ADHD is managed both medically and through behavioural strategies and details of successful management in schools including classroom strategies. Ms Dobie advised the panel that the report needed to be updated to reflect current practices but resources had not been identified to do the work.

In working with a child with ADHD, it is expected that the Head Teacher and the Special Educational Needs Coordinator would work together with appropriate professionals to draw up a plan to try and meet the individual child's needs. The plan would be responsive to the child's development needs and if a particular strategy was not effective then the school would look to try alternatives. The plan would encompass the child's entire time in school including breaks and lunchtimes. However, if a parent is not willing to recognise their child's needs and refuses to cooperate then there is very little that can be done.

The panel noted the limited number of referrals that a school can make to Educational Psychology in a year. There are 20 psychologists employed by Kirklees, 13 of whom are located in schools. The allocation of professional time is based on a formula that takes into consideration the size of the school and other factors. The Education Psychology Service also runs courses for school staff on understanding ADHD, Autism and comorbid disorders. The courses also include information on behaviour management strategies. In some cases the Education Psychology Service will work with CAMHS to combine resources to provide additional support.

Ms Dobie also discussed the review of SEN funding that had been undertaken in Kirklees over the last five years. The Audit Commission had identified that considerable funding had gone into SEN work but the LEA could not always demonstrate the outcomes or impact of the funding. Schools now have to be able to demonstrate that progress has been made as a result of putting SEN funding in place.

Ms Dobie confirmed that not all children with ADHD will have statements. Ms Dobie felt that children with Autistic Spectrum Disorders could do well in mainstream school if there was a resource provision. Children with Autistic Spectrum Disorders who attended Special School needed to have a statement. Kirklees was trying to pt more into supporting a child's individual needs rather than putting time into lengthy statementing processes and lots of paperwork.

Ms Dobie told the panel that data collection enabled the Education Authority to keep a check on the numbers of children being excluded and look for trends, for example black and ethnic minority children seemed to have more exclusions. Ms Dobie said that ADHD would also be an area of focus. The panel subsequently asked for the data but was told it was not available. Total exclusion figures were available and have been

included in this report. The panel also requested details of numbers of children with diagnosed ADHD in Kirklees schools in order to assess trends, but the information was not readily available.

Ms Dobie recognised the importance of managed transition, particularly in the change from primary to secondary school and the transition to post 16 education. It can be a difficult time for young people and work on managing the process for people with special educational needs is on going. The work covers health, social services and education to look at a common transition period.

Psychology Team
The Psychology Team within the Education Service has a number of smaller teams that work with young people, carers schools and other agencies to provide advice and support on education issues. Services include, autism outreach, child and family consultation, childcare portage, parent partnership, portage, portex, psychology and the service for children with a sensory impairment. Set out below is outline information on some of the services provided.

Autism Outreach Service
The Autism Outreach Service is part of the Psychological Service. The team consists of an Educational Psychologist, two teachers and three support workers. The primary role is to provide specialist support and advice to school staff and parents of children with Autistic Spectrum Disorders. . Referrals to the service can be made by school staff, parents and other professionals. The criteria for referrals are that a child has a diagnosis of autistic spectrum disorder and parental permission has been given to access support.

Portage Service
The Portage Service is a home based teaching programme for pre school children who show some sign of delay in their development. Officers told that panel that it was a very successful service in Kirklees. The service helps parents to teach their own children and see their child in a positive way.

Portex Service
Portex is for children aged 3 to 7 who attend nursery or infant's school and have learning or communication difficulties. They also present management problems associated with these difficulties. The service provides short term support for parents, teachers and classroom assistants through regular visits from a Portex teacher and regular reviews of progress. There is the facility for parents to make referrals.

The Psychology Service also provides a weekly helpline /surgery that the public can access. People can ring up without an appointment to get advice on a particular issue.

The panel also met with a range of education practitioners and professionals who are involved in the school setting. Those attending included headteachers for Junior and High School, Special Educational Needs Coordinators, representatives of school support services and the School Nurses Service. Graeme Sunderland, Auditing and Monitoring Manager for Pupil Support also took part in the discussion.

The Panel heard evidence of the support services provided by Claremont which worked on early intervention, not necessarily focussed on children with challenging behaviour, but to look at general effective teaching and learning, using strategies that can be used by everybody.

These strategies could be applied to children with ADHD or Autism. Individual children can be referred to the service. They may have an ADHD diagnosis but the service tends not look at the medical model, instead they look at strategies on how to manage the child in the setting and positive behaviour management.
Behavioural Support Workers (BSW) only work in the primary sector. If there were a Key Stage 3 BSW it would be an additional resource for schools to access. Claremont funding is only delegated to primary schools and only 87% of schools buy in the service. In addition 50% of High Schools buy in and 6 out of 7 middle schools.

Schools can refer pupils to the support provision at Westfields, however a school can only refer up to six pupils in a year and of those only one Key Stage 3 pupil at a time. The implications of this are that if the needs of a child mean time at Westfields would be beneficial, the school is not always able to refer them. There is some additional provision for children with ADHD at Nortonthorpe Hall School. For children who are on the point of exclusion there is the Exclusion and Reintegration Service (EARS). Children who are excluded are supported into their next school if requested, by a BSW and a teacher.

There was evidence of different services working together to provide early support, for example KEYS using Claremont to provide a support worker and give advice on appropriate strategies. CAMHS Commissioning Group partially funds a post at Claremont to undertake development work around emotional well being etc.

Those present recognised that the biggest challenge was the management of the children with very challenging behaviour. Schools try to get extra support to support the very challenging pupils whilst ensuring that the rest of the children are continuing to learn well. Some schools will have a greater number of more challenging pupils than others. From one year to another, schools have always got to have the relevant support in place. It takes a long time to gather the evidence required to be able to get extra help and support. It was stated that schools could feel very vulnerable and often felt unsupported by the Local Education Authority. Schools were left to make very difficult decisions when allocating limited budgets. It was also suggested that the speed with which additional support could be accessed was critical to being able to maintain a child in school. At present the process was not immediate enough.

Practitioners agreed that it was essential that all the staff who worked with a child with ADHD or any other learning or behaviour difference were appropriately trained. This included support staff, learning mentors and out of school club staff.

Practitioners raised concerns about the impact of current national and local funding models. It was stated that current methods lead to an inequality in provision, for example two children with identical needs would receive different provision in different parts of the authority. Base level funding can vary by as much as £1,000 per child. Special needs funding is allocated on top of base budget funding but a school may already have £1.2 less than another High School. Allocations take account of issues such as social deprivation but the size of the difference in funding levels had a serious impact on some schools. The ultimate implication is that if a child with additional support needs transfers from a high school in one area to an area with a lower budget then they could lose all their additional support.

Practitioners also raised the issue of the impact of reputation on school numbers and performance. Where a school has a resource provision it will start to develop a reputation for good practice and attract additional pupils with special needs. The additional resources are soon at

saturation point and the school starts to struggle to manage the needs of the pupils. The school will have a disproportionately high level of pupils with special needs, many of whom have to be catered for with mainstream pupils and support staff are overstretched.

It was suggested that secondary schools did not always have adequate information on the needs of children transferring from junior school. This means that staff are not prepared for the type of behaviour they may encounter. It was recommended that a higher level of funding be put in at transition phase to support the child through a very big culture change. The panel were informed that a new transition document was being introduced that set out the information that should be passed from one school to another but the emphasis is on giving a child a fresh start and not weighting transition with details of problems. The panel heard that post 16 there are no formal arrangements for passing information on. Staff felt that at the current time they are being reactive rather than proactive in preparing to meet the needs of young people with ADHD and comorbid disorders.

The practitioners discussed the use of the ADHD label, which they saw as a medical term. Some disliked the label while others acknowledged that without a diagnosis a child could not start the statementing process and will have problems in accessing higher levels of funding. There was some concern about diagnosis, particularly through the paediatric route where the assessment process was not multiagency. Schools gave examples of children on high doses of Ritalin who still exhibited unacceptable behaviour. . Practitioners also considered that whilst they believed there was misdiagnosis of in some cases, there was an equal number without diagnosis but who clearly exhibited ADHD symptoms.

The practitioners identified that some parents were more able than others to know where to go and who to talk to in order to access support. A lot of parents feel isolated and desperate and those present recognised their role as the initial link in supporting the parents as well as the children.

On the issue of exclusion the practitioners present felt that there was room for improvement in the management of exclusion. Many High Schools in Kirklees will not take permanently excluded pupils onto their roll. Practitioners were concerned about the ability of the authority to support these children and their families. The panel were informed that some schools had funded their own inclusion units where a child could spend time apart without having to travel to an alternative provision. Children with ADHD can access this provision but there are some children whose behaviour is too extreme for these units. It was suggested that the best way of meeting children's needs was to enable a school to bring in the professionals that were needed and for agencies to work together. Practitioners stated that they did not know if one of their pupils was being seen by the Youth Offending Team and were therefore not able to share information on what strategies had been tried and which approaches were the most successful. It was suggested that there was a "vacuum of information" that meant that support was not coordinated.

Practitioners identified Surestart as good practice because of the parent centred approach. It was suggested that some parenting support was too intensive and not very accessible to parents.

With regard to ADHD being confined to childhood and adolescence, practitioners felt that there was no common pattern. Some children did see an easing in the effect of their symptoms but others saw an escalation in aggressive behaviour. In the past two years, one High school has had four young people referred back to the school by the special provision unit who said they were unable to manage them.

The overall conclusion of the practitioners was that there remained a problem with children who exhibited the most extreme behaviour and possibly may have severe ADHD. Through no fault of their own, these children had been misplaced in mainstream education and the question has to be asked as to whether we are setting these children up to fail.

The Butterfly Project

The Butterfly project was identified by the panel as an example of good practice. The Butterfly Project is lead by Education Psychology and involves other Education, Social Services and Health professionals in the project. The project works with children aged 3 to 7 who are experiencing behavioural difficulties at home and in their educational or preschool setting. Together they provide an intensive support programme for children with behavioural difficulties, including ADHD. The programme lasts for a year and works with the child, parents, siblings, class teachers and the whole class. The aim of the programme is to provide children with a consistent and coordinated approach to their behaviour by all the key adults in their lives. The programme helps children to develop skills, strategies and techniques to positively access family and school life.

Among the techniques used by the project are relaxation techniques. A lot of children have very chaotic lives and don't experience quiet times during their daily routine. The project encourages parents to develop quiet time and to interact with their children, for example by reading stories. The centre emphasises the need for limits and boundaries and the need to notice positive behaviour.

For the first term of the project the child and parents will attend the Greenfield Family Centre in Dalton for a day a week. In the second term the Butterfly Team will spend time in the home and school helping the child and key adults to model strategies. In the third term the Butterfly team withdraw to let the child and key adults manage, but the team can be contacted at any time during the third term for advice.

There is always a waiting list for places. In the current year, 35 referrals were received for 8 places. There would usually be 10 places, supported by a team of nine staff. The provision is very resource intensive but staff feel this is justified as the short term, intensive, early intervention costs led to savings in resources in the longer term. A project in Swindon that was the inspiration for the Butterfly project in Kirklees, had calculated that the annual cost of a child with an untreated conduct disorder was in the region of £15,000 per annum if they remained in education. The Project Manager is currently considering piloting a project in High Schools aimed at year 7 pupils.

Many of the professionals that the panel spoke to said that current responses were mainly reactive rather than proactive. Some of the reasons for this were around the short term nature of the funding streams that were used to establish initiatives for a few years but then struggled to identify mainstream funding to continue. There is evidence that Kirklees employs caring and capable professionals who are committed to improving the quality of services for children and young people with learning, behaviour or communication differences. All the officers and practitioners recognised the critical need to focus on early intervention to start to influence behaviour at the earliest opportunity. There was evidence of some additional workers that could be targeted at this area, for example KEYS inclusion workers, but generally the picture was of limited resources.

Key Stage 4 (KS4) Alternative Provision

If young people in year 9 are in potential danger of permanent exclusion in Key stage 4 (GCSE years), the school will be encouraged to undertake preventative work; this is often on a short term basis. If the young person does not respond, they may be referred to KS4 Alternative Provision before they reach year 10. The key stage 4 projects are two year courses. Similarly students in year 10 in danger of failing their KS4 courses may be referred for year 11 alternatives.

Referrals can be made by schools, Education Access, Youth Offending Team and any other agency with responsibility for young people in KS4. There are slight differences between the referral process for young people with statements and those without, but mostly it is based on an annual review. The referral form is purposely detailed and long to ensure that the Panel that decides about whether to allocate a place, has sufficient information from all parties involved (including parents and pupils) on which to base decisions.

The KS4 referral panel consists of professionals from various LEA services, Social Services, CAMHS, YOT and Careers. They will decide whether to accept the referral or refuse it and if the referral is accepted, what alternative provision would best suit the needs of the young person.

There are 8 KS4 Projects in Kirklees: Futures and Futures Plus; Include Programme; LIFE – New Start Programme; Pathways; Project Cool; Project Nexus; Rathbone's Choices and Westfields' KS4 Centre. The number of places available varies from 8 to 36 and three of the projects focus mainly on Year 11 pupils. The young people seem to respond better to the more flexible and practically based programmes offered by the projects. The Projects have access to the MAST (Multi Agency Support Team), comprising of an Educational Psychologist, an Education Access Social Worker, peripatetic dyslexia and literacy specialist, a school nurse, behaviour support workers and the Careers Service. Indirect access to CAMHS and Social Services is also available.

Numbers are very limited and the projects are not obliged to accept the young person.
The number of children referred during:

- 2001/03 (not including re-referrals) was 312;
- 2003/04 the number was 172;
- 2004/05 this has risen to 185.

It could be said that all have special educational needs in that their education is not being met in mainstream school. However:

- the number of students undergoing Assessment during 2004/05 was 1;
- the number of students at School Action Plus 2004/05 was 70 (38% of the total intake for the year);
- The number of students at School Action during 2004/05 was 22.

The number of pupils with a Statement of Special Education needs (SEN) that were offered a place during:

- 2001/03 was 77;
- 2003/04 the number was 45;
- 2004/05 this has risen to 50 (27% of the total intake for the year).

Funding for Educational Special Needs

The panel had many concerns about the current methods of funding for special educational needs in schools. Although there is currently a Fairer Funding Review being carried out in Kirklees, the panel are concerned that the focus of funding will be skewed by the desire to reach Government targets.

The panel believe that it is very important to identify the needs of the individual child and design a package that gives that child the best opportunity to learn. Currently the only way that most families receive the attention they need is by receiving a Statement of Special Educational Needs. However central government are directing LEA's to reduce the amount of Statements being issued.

Currently the New Approaches C & D Funding is allocated in a block amount to schools to reduce some of the time consuming bureaucracy of bidding for funding. The amount allocated to each school is estimated on amounts required in the past. Additional New Approaches funding may be available for children with Statements but is subject to a bidding process and not all bids are successful. If a child makes significant progress and no longer needs additional support, funding is withdrawn at the end of the term. The panel has heard evidence that the withdrawal of support has caused problems for many children and their families.

The panel were told that on occasions a Junior School may be reluctant to apply for support for a child in their final year, year 6, as the school would not see the benefit of the funding before the child moved to High School. Parents told the panel how they battled to get support for the child and if they moved to High School or changed schools for another reason, they would have to start the fight all over again. The panel believe that the support package, in whatever format is needed, should follow the child through every key stage.

The proposal from the Fairer Funding Group is that there will be two levels of funding, level 2 would be for the most complex needs and allocated on a needs basis. That means that if the child transfers schools the funding would move with them. Level 1 funding would be formula funded to the school to meet SEN; statements in themselves would not generate funding but would safeguard the rights of our most vulnerable children. Funding would be allocated for the whole of the key stage to give continuity and stability. The panel believes this may go some way to addressing some of the currently difficulties associated with funding but, they are concerned that many individuals with special needs will go unidentified.

The panel appreciates the need to not label young children if possible but there needs to be a mechanism that can identify the individual needs and the package of interventions required to support those needs.

In discussing funding allocation for special needs with headteachers, the Panel was made aware of the differences in the allocation of special needs base budget. The allocation of the budget takes into consideration issues such as social deprivation. Allocations can vary by as much as £1,000 per year per child. A school with a high base budget should be able to meet a child's needs. A school with a lower base budget will have to prioritise the allocation of the budget. Based on the evidence that the panel have heard, children with ADHD, other than the most severe cases, will struggle to receive any allocation of additional support.

Autism Resource Provision

As part of the panel's investigations, panel members undertook visits to the Autism Resource Provisions attached to Moldgreen Community Primary School, Honley High School and Headlands CE Junior and Infant School. The members of the panel who visited the provisions were impressed by the dedication and expertise of the teachers and support workers who worked in the provision.

In general the provisions consisted of a dedicated space where children could get away from the mainstream school and de-stress. Children could access one to one support from specialist teachers, including speech and language therapists. Children could also discuss any problems they were experiencing and receive appropriate support. The resource provisions were able to use different learning strategies for the pupils and closely monitored individual progress.

One of the added benefits of having the resource provisions was that it meant the understanding of autism and skill levels of teachers through out the school were enhanced. In addition pupils had a greater understanding and acceptance of fellow pupils who had communication differences.

Honley is the only High School in Kirklees that has an Autism Resource provision. It is able to accommodate four children per year group, a total of 20 throughout the school. Children travel from across Kirklees to access places. The teacher in charge of the provision estimated that they could fill the places three times over. It was reported that both parents and children are happy with the support provided by the resource provision.

Honley High School also told the panel member about a card system that they operate for children with Autism. If a child is in a class and cannot cope, they hand a card to their teacher and go to the resource provision room to calm down.

In talking to the specialist teachers the following comments were also noted:

- There should be a special provision to enable young people with Autistic Spectrum Disorders to progress into adult education
- There is over subscription and reliance on medication - specialised provision can be more effective
- There should be a specialised resource provision as part of a high school in north Kirklees
- There should be additional capacity in the current provisions
- There should be a greater awareness of Autistic Spectrum Disorders across professionals including teachers and GPs.

Voluntary Sector

Support Groups

The panel has spoken to representatives of local voluntary support groups to find out their views on the availability of services to support people with ADHD, Autism Spectrum Disorders and Dyspraxia. Many parents spoke of their increasing anxiety as their children reached adolescence and neared the end of their formal education. There parents perception was that there was no early preparation or advice about what future options were. Young People attending the Autism Group and other groups spoke of the lack of understanding by employment and careers advisers about how their particular learning difference affects them, both in terms of their strengths and the type of employment that is appropriate to them. There was criticism of the inflexibility of processes, particularly interview processes. People with Autism do not respond well in formal question and answer interviews and wanted to see employers trying other approaches, such as trial work periods.

Young people with Autism also highlighted the difficulties they have in using public services, such as buses, where they have difficulty communicating and the drivers are not always prepared to try and help them. They advocated that a card system should be made available to those people that wanted to use it to succinctly identify that they had a communication difficulty. People employed in frontline services should receive training on different communication and behaviour differences to prevent discrimination taking place through ignorance.

Parents reported that they often needed the assistance of local support groups to help them in communicating with schools that wanted to exclude their child. The support groups were able to attend meetings with members and suggest alternative ways forward as well as questioning what support had been put in place or was necessary to maintain a child in education.

The support groups appeared to be undertaking the advice and support role as far as they were able with little or no funding support from mainstream services. Most needed help with room hire costs and photocopying to help share information. The Autism Support Group also coordinated social visits and holiday play schemes which were very popular with members.

Families Together Project, National Children's Centre

The Families Together Project was run by the National Children's Centre and funded through a Home Office grant. The project provided practical support and advice for young people with ADHD and their families. This included dietary advice, signposting to services and advice giving. During the three year life of the project, over 300 families had accessed the support provided. The people that the panel spoke to were very positive about the support provided by the project. They were able to contact someone when they were struggling to manage the behaviour of their child with ADHD. They could also dip in and out of the support group sessions as they wished. People liked the independent nature of the project, i.e. they didn't feel they were going to be scrutinized by a Social Worker because they were struggling to manage their child's behaviour that week. Dr Sills spoke highly of the project and had signposted people from his clinics to the service for additional support. Unfortunately, during the time that the panel was gathering evidence, the funding for the project came to an end. A further source of funding had not been identified. The panel were very concerned about the loss of the project, which they felt met a number of the needs that people had identified, in particular the helpline provision and the signposting facility.

Youth Offending Team and Anti-Social Behaviour Unit

The panel were impressed with the efforts of Kirklees Youth Offending Team to work with vulnerable young people with diagnosed and undiagnosed learning differences. The team employs a full time behaviour therapist and this post is unique in the country; there are very few behaviour therapists available so it is a great asset to have one on staff.

Young people aged from 10-17 pass through the youth offending system and officers talked about the frustrations they have in trying to support these young people and their families. Many of the young people, particularly the older ones, come to the team with major learning difficulties that have not been identified before but should have been. The service works with the young person in trying to find alternative provision, build skills and match the young person to something that would continue to stimulate them.

Before employing a behaviour therapist, the service did a joint exercise with the CAMHS team in which they reviewed individual cases. They identified that 75% of the 35 young people they were working with had learning differences.

The service struggles to find support for the young people and their families and recognises the difficulties that parents have in accessing support. In some cases the child had received a diagnosis and was prescribed medication but no additional support package was provided to tackle the behavioural issues. To access support for learning disabilities the young person had to have an IQ less than 70; most of the young people the YOT work with have an IQ above 70.

The CAMHS service does not take a referral if the client is over 16. Adult Mental Health Services only take referrals if the individual is over 18. Officers said that some young people feel they have to offend to get some support, while parents talked about going round in circles looking for help.

The YOT feel that they identify issues that have been missed by other services and consequently they spend a lot of time co-ordinating things that should be done by others e.g. diagnosis, creating support packages or sign posting families to appropriate support services. The panel agrees with officers that there needs to be a better co-ordinated approach between organisations and we need to be identifying and supporting the needs much earlier.
When asked why children's needs aren't identified earlier, the service suggested a range of different possible reasons: -

- People don't always attend appointments and are therefore crossed off the list for the service.
- Behaviour can mask a lot of difficulties.
- Hidden exclusions i.e. the pupil gets a mark at registration and then run away from school and not been seen for the rest of the day.
  Young people get excluded and then get "lost in the system."
- Some young people are good at saying the "right thing" to professionals to avoid detection.
- Some young people move areas or districts and get lost in the system.
- Some think it is easier to opt out because they know they are going to fail.

Young people are referred to the YOT and the Anti Social Behaviour Unit through other services and a large number of clients are people with mental health and substance misuse problems. A percentage of these clients have ADHD, they may be taking prescribed medication as well as abusing other substances. They may take cannabis but cannabis works against the effects of Ritalin. They sometimes sell their Ritalin on and say that cannabis makes them feel better. When the service first sees the client, officers do not know if the client is taking medication or not, this is established later. The service feels that more support from the PCTs would be helpful.

Families can struggle with a range of difficulties when the children have learning difficulties. The panel were told that one of the strengths of the YOT is that they have all the skills brought by a range of services and agencies located in one team, education, health, police etc. The YOT carries out outreach and then provides one point of contact for the young people to go rather than sending them to many locations to access support. Officers stated that … *"True partnership work is important rather than just co-operation."*

If a child has ADHD they can be more likely to be put into the care of the local authority because of the stress put on parents. Looked after children have a health worker who works with them in foster placements and in homes. It is an expensive resource and the panel concurred with the Youth Offending Team that if intervention was put in place at the earliest stage then later resources could be saved and some children would remain in the family unit.

Officers felt that the police still had difficulties in interviewing people with a learning disability appropriately. The service works with referred individuals who have no idea they have committed an offence because they have not understood the processes they have been through. Sometimes, if they are over 16 they are told they don't need anybody with them in interview and they struggle with the questions they are asked. These are individuals who struggle with everyday "normal life". It was commented suggested that a greater awareness is required and the Police and the YOT are looking into this, but after 2.5 years of discussions they were just starting to achieve an understanding of the issues.

Youth Inclusion Project

The panel identified the Youth Inclusion Project as good practice. The Junior Youth Inclusion Pilot Project operated in the Newsome ward and worked with children in years 5 and 6 of junior school and year 7 of high school who had been identified as being at risk of exclusion.
The project was funded through the Children's Fund and aimed to help the pupils do better at school and manage the transition to High School. A dedicated worker provided additional support for the children and their families, including additional academic support and out of school classes. The project had seen a dramatic improvement in some children.

In Dewsbury Moor a Senior Youth Inclusion Project had been run that included individuals learning life skills such as decorating and maintaining a house in the area.

West Yorkshire Police

The panel met with Sergeant Marianne Huison and Acting Sergeant Kerri Emerson of West Yorkshire Police to gather information on the police's approach to dealing with young people and adults with ADHD and other behaviour or communication differences. The officers worked in the Domestic Violence and Adult Protection Unit.

The officers informed the panel that as part of routine police training, officers were likely to receive very little training on issues around ADHD. They did however receive a small amount of training on Autism Spectrum Disorders.

The police officers who were most likely to come into contact with people with ADHD were the Anti Social Behaviour Officers and those who worked with the Youth Offending Team. The Domestic Violence and Vulnerable Adults Protection Unit could come across adults and young adults with ADHD as victims of crime. There was guidance as part of the Achieving Best Evidence legislation about how people with Autism should be dealt with by the police. If there was an apparent mental or physical problem then special measures could be taken, such as video interviewing, considering a persons usual routine and where best to carry out an interview. The police would also liaise with carers if appropriate and take advice form specialists. Whilst there were not laid down procedures or detailed training packages, the police were trained to consider the needs of the individual in order to secure the best evidence.

The police can be made aware of people's differences through communication with Social Services or adult learning centres. There is specific legislation regarding how children should be interviewed and the Child Protection Officers who carry out this work are specially trained. However it is possible that without prior knowledge that an individual has a behaviour, communication or learning difference the issue may not be identified. There has recently been an invitation to Area Child Protection training on ADHD.

The police officers present identified that the greatest issue currently facing the police in this area was the initial identification that a young person or adult had a learning, communication or behavioural difference. The outcome of non identification was that the individual would probably be criminalised instead of receiving appropriate support. Having a criminal record compounded the difficulties that adults with differences had in gaining employment and integrating in the community.

The officers that spoke to the panel recognised that people rarely had one learning difference. Sometimes there were mental and physical health issues. Beat officers were most likely to come in contact with young people with ADHD who may have been involved in vandalism and anti social behaviour. People with Autistic Spectrum Disorders were more likely to come into contact with the police as victims of crime.

Officers recognised the opportunities that the move to Neighbourhood Policing Teams would offer, particularly when looking at adult protection training. Teams could be made more aware of the services that are available to support vulnerable adults and work more closely with other agencies.

Housing

The panel met with officers from the Kirklees Housing Allocations policy team and received a briefing note from the Kirklees Neighbourhood Housing nuisance and harassment team.

Lack of space is an issue for most families, but this is exacerbated for families with members that have ADHD. Children with ADHD can be very volatile, violent and destructive, and often have disturbed sleeping patterns, so sharing space with other siblings can be very difficult. These families are often desperate for larger accommodation, especially an extra bedroom for the family member with ADHD. For local authority housing applications, medical points are available for families who have special housing needs due to a medical condition or disability and ADHD is included within this category.

In Kirklees there has been a rise in re-housing applications on medical grounds from families who would like an extra bedroom for a child with ADHD. Between April 2004 and March 2005 there were 1,864 medical referrals for re-housing, 30 of these were from families with members that had ADHD or autism. However, just because medical points have been awarded, it does not guarantee that families will be re-housed. Of the 30 medical referrals only 5 families have been re-housed to larger accommodation. There is a shortage of large properties in Kirklees and there is a high demand for these properties, so the medical points are just not sufficient for families to be re-housed in a lot of cases.

Kirklees Neighbourhood Housing nuisance and harassment team does not have any specific policies or procedures for dealing with people with ADHD but, as part of its approved procedures for dealing with anti-social behaviour, it does have a policy for supporting vulnerable groups. Vulnerable groups can be especially affected by anti-social behaviour, both as victims and perpetrators. The Kirklees Neighbourhood Housing nuisance and harassment team work in partnership with other agencies to ensure that all measures for dealing with nuisance and anti-social behaviour are considered.

Only a small proportion of cases dealt with by the Kirklees Neighbourhood Housing nuisance and harassment team have involved children with ADHD. Examples of cases where ADHD had been cited as a reason for the anti-social behaviour are highlighted in the following page. The view of the judiciary and health experts was that ADHD was not the primary cause of the anti-social activity.

Case Study N

Two of tenant N's six children had been identified as having ADHD. Throughout the possession proceedings Kirklees Neighbourhood Housing nuisance and harassment team worked closely with Social Services and Education to resolve some of the issues which contributed to the nuisance and anti-social behaviour caused by this family.

However, the other children in the family also caused serious problems and it was noted by the Judge at the subsequent possession hearing that the problems caused by this family were as a result of poor parenting skills rather than any medical condition.

Case Study P

Tenant P is a single parent of a nine year old child who is diagnosed with ADHD and takes medication. She also has a baby and a three year old. She is currently living in two bed Council accommodation and is on the waiting list for three bed accommodation in her area of choice. Her area of choice will place her near to relatives who can give her additional support.

She is very worried about the risks posed to the younger children by the child with ADHD. He does not have his own bedroom and his behaviour is becoming increasingly aggressive and disruptive.

Because of his ADHD he has very impulsive behaviour and does not consider the safety implications of his actions.

His mother is becoming physically ill through the stress and worry of trying to manage the situation.

Case Study R

Tenant R alleged that her children were suffering from ADHD as a means of excusing their poor behaviour. Subsequent testing of the children revealed that this was not the case.

The children were not suffering from ADHD and the case progressed for legal action.

Employment and Careers

A member of the panel gathered information on the assistance available to people with ADHD in seeking work and work-related training. The information was gathered through telephone interviews with Job Centre Plus, Connexions and Worklink.

Job Centre Plus employs four Disability Employment Advisers, to whom young people with ADHD or related behavioural problems can be referred, often by school, parents or the Job Centre. There would be an initial interview with the client at which as holistic approach would be taken. The various options open to the client would be explained to them. A second interview, often with a Connexions Adviser present would try and arrange an interview for either training or employment. If necessary the Connexions Personal Adviser will accompany the client to the interview.

Connexions have created a post of Special Needs Transitional Personal Adviser, who is able to liaise with Special Schools, training providers and Job Centre Plus. Both the Connexions Adviser and the Disability Adviser at Job Centre Plus said that the main problem could Occur when the client did not have a diagnosis, and might therefore not be directed to the help available. They also agreed that some training providers are not keen to take on those with behavioural difficulties. Extra training for Advisers on ADHD and related conditions would be beneficial.

Worklink, an employment organisation for people with health related disabilities can be used if the Adviser working with the client feels that the extra support is needed, or if the person self refers because they recognise their own difficulties. Worklink help with the whole process of application for training or employment, interview and “on the job” support. They can also give advice on benefits such as Disability Living Allowance.

The Manager of Worklink felt that they were very successful, but more training on specific conditions such as ADHD would be useful for their advisers. In addition more secure, long term funding would alleviate the constant need to bid for additional funding.

Service User perspective

The panel has spoken to a number of young people and parents of children with ADHD, Autism Spectrum Disorders, dyslexia and dyspraxia. In addition a number of people have telephoned the scrutiny office to share their experiences with the panel.

For the majority of people who gave evidence to the panel, it has been a “battle” to secure support for their child with ADHD, themselves and the wider family. The major problem that people perceived was the lack of information available once they had a diagnosis. Services seemed uncoordinated and more often than not parents stumbled across provision rather than having a coordinated, signposted link to support.

It could be argued that the panel were only contacted by those people who had negative experiences to report , however this was not the case and for a minority there were examples where they praised how support services had worked very effectively to meet their child’s needs.

People were concerned at the lack of awareness and understanding of the complexities of ADHD, Autism Spectrum Disorders. Media coverage of ADHD was particularly negative and fuelled the general level of ignorance and misinformation about ADHD. No one seemed to be doing anything to address this misinformation.

The panel has heard many positive things from the Education Service but the reality for parents and children with special needs does not seem to match up. Parents expressed the view that support is a lottery. A view shared by many parents is that the move away from statementing children has meant that fewer children are getting the individual support that they need. Those parents who succeed in getting the school to secure extra support for their child constantly have to fight to maintain the level of support.

Anecdotally it appears to be the children who are perceived as having “pushy parents” that finally gain access to additional support. Parents spend time and money exploring options, having a private assessment and allowing their child to try new techniques to manage their difficulties. For many single parent families these additional options are prohibited by cost.

Parents become increasingly concerned as their children reached the end of full time education about what the future holds. Most believed that there were no services for adults, other than the most extreme cases.

Conclusions

The Panel has spent six months meeting with medical professionals, council officers, external agencies, support groups and members of the public, to discuss the issue of support to people with ADHD, Autistic Spectrum Disorders, Dyslexia and Dyspraxia. What has become evident is that this is a huge area of work and many of the learning or behavioural differences affect people to varying degrees, from very mild symptoms to severe cases that influence a person's entire life. The Ad Hoc Panel recognises that it has only "skimmed the surface "in looking at this complex issue. Therefore, some of the panel's recommendations will suggest further pieces of work to be undertaken by those with appropriate levels of expertise, to take some of the issues identified forward.

Early Years

Despite the increasing body of evidence that ADHD is a genuine medical condition, the panel encountered a continuing argument amongst professionals about the existence of ADHD, appropriate treatments and referral routes. The panel felt that further awareness raising and training in the complexities of the conditions, particularly amongst general practitioners and early years workers is essential.

Early diagnosis and intervention is critical to influencing the impact of these differences for both the individual and for their families.
The panel welcomes the recruitment of additional inclusion workers by Kirklees Early Years Service. The panel believes that if additional resources are invested in early intervention there would be savings in long term costs such as exclusion, alternative education provision, mental health services, etc.

Education

The panel realises that schools are under increasing pressure to enable as many children as possible to access mainstream education. The panel concluded that this was not always in the best interests of the child. In the more severe cases of ADHD it may be more appropriate for a child to access an alternative provision where there were likely to be smaller classes and options for a more vocational curriculum. Some of the alternative Key Stage 4 provision was identified as good practice and had provided an alternative to exclusion for some young people with ADHD. The Autism Resource Provision enables children to stay in mainstream school but have a quiet place to spend time when they felt under pressure and there are trained staff who know how to support them.

The main concerns of the panel were around consistency of provision in education. The quality of communication, parental involvement, transition and classroom based support varied greatly among schools. The evidence indicated that it is usually very difficult for parents to access support for their children. Many feel that their opinion is not given any value and a parent's understanding of their child's difficulties is dismissed. Evidence was put forward of instances where parents had gone into school to seek support and a way forward for their child, only to be criticised and made too feel wholly responsible for their child's poor behaviour.

In addition the panel were aware that schools were not passing on information to parents that may help them and their child, for example a dyslexia pack should be made available once a child has a diagnosis but one parent only found out about its existence from another source and then had to go to the school to request it .

The panel understands the reasoning behind the move away from formal statementing processes, however it is not convinced that the new approaches to funding SEN will meet the needs of children with ADHD and other learning differences, particularly where those differences are not causing major disruption in the classroom. The panel were unable to get accurate information on the number of children who have a diagnosis of ADHD in mainstream schools in Kirklees. Without accurate information it is difficult to effectively plan services and project resource requirements.

The training and awareness of support staff is key to the success of additional support. The evidence indicated that there was good and bad practice amongst support staff. Some had no understanding of how to effectively support a child with ADHD. More detailed training and understanding is required for all support staff who work with children with learning, behaviour or communication differences.

The panel is concerned about some the costs of buying in additional support and that a school must make a financial judgement before trying to meet the needs of a child. The panel is also concerned about the length of time it takes to place a child in alternative provision once they have been excluded.

The panel acknowledged that the management of poor behaviour is a problem for all schools and there are increasing demands placed on schools. Only a few of the children exhibiting poor behaviour will have ADHD and it is often difficult to distinguish the difference on the less severe end of the spectrum. The panel concluded that in some schools time was spent trying to manage poor behaviour, through fixed term exclusion etc. rather than trying to identify the root cause and help the young person in the long term.

Transition

For the purposes of this report the panel defined transition as a movement from one environment or provision to another. Times of transition represent significant change for all individuals but have particular risks associated with them for people with ADHD and comorbid disorders.

The panel concluded that effective communication was the key to successful transition. Standards varied across schools. The panel heard evidence of parents having to go into school at the beginning of every year to explain their child's needs and symptoms to the new cohort of teachers. In one reported incident a supply teacher was instructed by pupils on a child's needs and how it wasn't appropriate to treat him in a particular way. The panel felt that there should be a fresh look at what we do now to support transition, an identification of good practice and the development of a more consistent approach.

Cross Cutting Issues

Packages of Support

Packages of support should be available to families at the earliest opportunity, probably pre diagnosis, to minimise the difficulties experienced by families where a child has ADHD. The panel is very disappointed at the limited early intervention resources available in Kirklees. Each package of support should be tailored to the individual. This does not necessarily mean medical intervention in the early years although sometimes it may be appropriate to try medication. Interventions for learning, communication and behavioural differences should include intensive parenting support, followed by ongoing help for parents as required, dietary advice and access to other professionals such as

occupational therapists and dyslexia specialists. The panel concluded that more innovative practices should be trialled such as the introduction of quiet rooms in mainstream schools and trying different dyslexia teaching techniques.

Labels

In many of the panel's discussions, the issue of labels has been raised. Should we be labelling a child with ADHD and potentially exposing them to the stereotypical responses of others. Instead should services be working together to identify need and target appropriate support?

Views varied, but it was interesting to note that it was mainly professionals that said you should not need a label to access services, whereas parents were saying it was the only way to access some services. In the case of ADHD some parents said that only when their child had a diagnosis did the school start to work with them to address the difficulties. They were frustrated because the label did not mean that the needs of their child had changed but for some reason a label meant that the school now had to respond. Other parents raised the point that without a label a child was simply seen as badly behaved.

Health

From the evidence presented to the panel, it can be seen that there are strengths and weaknesses in the approaches of both CAMHS and Paediatrics to ADHD at the current time. CAMHS carries out an holistic assessment but there was little evidence that the assessment was then followed up with additional support and interventions. Evidence showed that having waited six months for an initial meeting then a further three months for assessment, parents were expecting positive outcomes from the CAMHS process but felt disappointed at the very limited outcomes.

In contrast, many parents spoke positively about the work carried out by Dr Sills, particularly regarding the time taken from initial referral to appointment and the speed of diagnosis and prescribing. However there was some criticism about the limitation of the approach, ie the child has a diagnosis and medication but no other support package. The panel have concerns about non multi-disciplinary assessment.

The panel concluded that there should be a clear pathway of care for people with ADHD, from initial referral by GP, through assessment and on going care through children and adolescent services and on into adult services. Assessment should be holistic and multiagency. However, current waiting times are too long. The panel also concluded that it was preferable not to prescribe medication in isolation but that services should work together to provide a package of interventions and support.

Medication

The panel have heard evidence of differing view points regarding the use of medication to control ADHD symptoms. Some parents and professionals are concerned that Ritalin is too frequently prescribed before any other interventions have been tried. Evidence has suggested that controlling a child with ADHD is for the benefit of the family or teacher (in a class setting) rather than the benefit of the child. However the panel has also heard evidence of the positive effects of medication to calm children and enable them to focus on tasks and build relationships better. The panel feels medication can have a positive effect and that, whilst not a cure, it is one of a range of supports that can be offered to people with ADHD.

Housing
The panel recognises that the Housing Service are facing a difficult situation in allocating a diminishing stock of council owned properties whilst balancing competing needs of prospective tenants. However, the Council needs to consider whether we place enough weighting on the implications of an ADHD child on the house hold. There are potential child protection issues, in that a child with ADHD does need their own bedroom to create a quiet area away from other siblings. The issue of adaptations should also be considered to ensure that these children can be accommodated in a safe environment, for example providing fence around the property to prevent a younger child running into the road, the removal of high trees as children with ADHD are very impulsive and do not stop to think about the consequences of their actions.

Support for Adults

Diagnosis:
The panel concluded that the greatest barrier towards making progress in the area of support to Adults with ADHD was the lack of official recognition and diagnosis. The panel has encountered many arguments about the importance of diagnosis and getting “a label” with which to access support against the current position whereby a person is treated as an individual and their needs should be met, irrespective of whether they have a diagnosis or not.

The panel would suggest that as it has been ten years since the last review of medical diagnostic criteria it is appropriate to lobby the National Institute for Clinical Excellence (NICE) for a review to take place. The review should be asked to consider worldwide evidence for the development of an adult diagnosis of ADHD. This cannot be dependant on the pre existence of an ADHD diagnosis in childhood as evidence has shown that people in adulthood now, may have been overlooked as children and will not have had a previous diagnosis. It is likely that there will be demonstrable evidence to indicate that ADHD type behaviour was manifested in childhood.

In an ideal world, the panel would like to see services and support accessed by identified need not on the basis of a diagnosis, but from the evidence gathered by the panel, the reality is that this is not the case. The Health and Social Care Board Structures in Kirklees have their own criteria which exclude all but the most severe of learning differences. It can be argued that with a finite level of resources there has to be some rationing of services. However the panel are concerned that at every stage the needs of people with ADHD, dyslexia and dyspraxia are being marginalised or overlooked as not severe enough, as a consequence people with these learning, communication or behavioural differences are not being given the opportunity to achieve their potential.

Without diagnosis and appropriate treatment and support, the evidence indicates that adults with ADHD are likely to develop additional mental health conditions such as depression and compulsive disorders.

The studies by both the British Dyslexia Association and the Lancashire Constabulary indicate the potential consequences for people who are unable to access appropriate education or employment support. The statistics regarding adults and adolescents with undiagnosed learning differences who are in the criminal justice system are alarming. Whilst the panel does not seek to excuse criminal behaviour, the lack of appropriate diagnosis and support to achieve potential is a contributory factor.

There is clearly a gap in service provision and support for adults with learning differences, but for some people this gap starts to open in the classroom when needs go unrecognised or unmet. These people have an intelligence level that is sufficient to disqualify them from receiving services through the current Partnership Board structure, yet there is recognition by professionals that support is required. The consequences of being unable to access appropriate support were obvious through out the evidence gathered by the panel. Children and adults have low self esteem and no self confidence. Adults have generally attained a poor standard of education and have little or no formal qualifications despite having average or above average intelligence levels. The on going behavioural and often mental health difficulties have isolated people from their families and society.

Evidence gathered leads the panel to conclude that in the current system the outlook for adults with ADHD is poor. Due to a lack of recognised diagnosis in adulthood, misdiagnosis is not uncommon.

The panel was extremely concerned that in a society where Dyslexia has been diagnosed for over a hundred years, we are still seeing such high numbers of adults with undiagnosed learning differences in our criminal justice systems. The issue is relevant to Kirklees as the Youth Offending Team is currently working with young people who have been through the Kirklees education system without their learning, communication or behavioural differences being identified.

Employment:
The panel recognises that there is a desire to provide appropriate support for people with additional support needs. There are services striving to provide a degree of support, for example the Connexions Advisers who specialise in disability and the staff at Worklink. The commitment of these professionals to their role was very apparent to the panel, however they can only go so far in the support they provide and agree that their understanding of ADHD and comorbid disorders is limited. The support is not co-ordinated across services and people can often get lost in the process. Services do not go far enough in providing the life skills support that is required. Because of the learning difference people can struggle to remember, or fill in a form and keep an appointment or find their way to an interview. The panel heard evidence of people being offered interviews for inappropriate jobs and then when they turned down the suggestion they were seen as uncooperative. Overall more in depth training is required to recognise and meet the needs of people with ADHD and comorbid disorders.

It is clear that there needs to be a greater understanding of learning differences and the different degrees to which they affect people. All sectors need to work together to identify where current systems are failing and how we can be more flexible in supporting people with learning and communication differences into work. For example young people with Autism Spectrum Disorder identified that they do not react well in formal question and answer type of interviews and suggested that the opportunity for a work trial may be more appropriate for both employer and prospective employee.

Social Services
Social Services would seem a logical point of contact for families under pressure and in many cases on the verge of breakdown because of the difficulties in supporting a child with ADHD. However, the evidence indicated that unless there was a child protection issue or a parent was too ill to care for a child then Social Services are unlikely to provide any support. The panel agreed with Social Services own view that it was a reactive service. The Panel were again concerned that we were in a situation where early intervention could prevent later more costly use of

resources. For example should social services be providing low level support to help a family stay together rather than waiting and having to sustain the cost of placing a child into the care of the local authority at a later date?

From the evidence gathered by the panel it appeared that many parents had expected some sort of support from Social Services to develop parenting strategies and access resources for their child. In some cases the interagency Butterfly provision had been accessed but this was the exception.

The panel were concerned that there is currently no service for children or adults with learning differences. The panel believes there is an opportunity under the Every Child Matters agenda and the review of the Heath and Social Care Board Structures to address these issues.

Police

The panel concluded that nationally there were examples of good practice, such as the work that the Lancashire Constabulary. The evidence indicates that there is a disproportionately large number with undiagnosed behaviour and learning differences in the criminal justice system. Whilst the panel does not condone criminal behaviour, the statistics are very concerning.

Evidence presented to the panel indicates that there is only a small amount of awareness training in appropriate ways of dealing with people with ADHD, Autism Spectrum Disorders and other learning and behavioural differences. The panel feels that West Yorkshire Police would benefit from looking at the work of the Lancashire Constabulary and seeing how the lessons learned could be implemented in Kirklees. This would include a review of current procedures to ensure that they do not disadvantage people with learning and behavioural differences and more in depth training on the nature of ADHD and appropriate responses for police officers who work in the community.

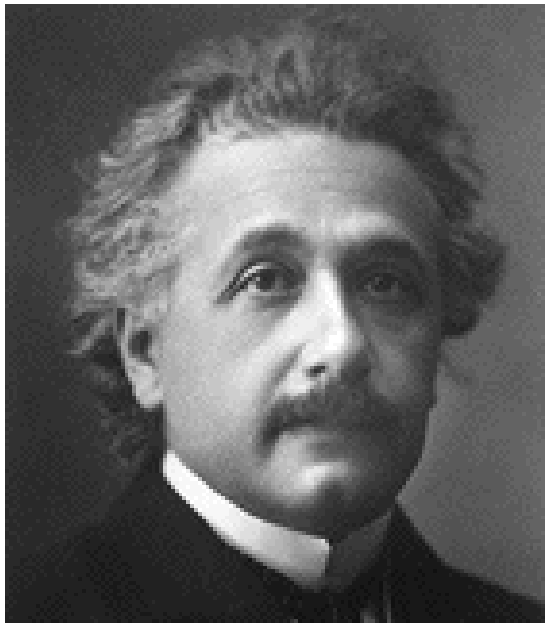
Voluntary Sector

The panel recognises the unique role that voluntary sector support groups and projects play in supporting people with ADHD, Autistic Spectrum Disorders, Dyslexia and Dyspraxia. Many of the parents that the panel spoke to had accessed the support and expertise that these groups offer.

The panel believes that the council must find more efficient ways of supporting these groups. We have a grants process to help fund room hire etc but it is lengthy and onerous. We can discourage voluntary organisations from providing their core support activity because of application, monitoring and evaluation processes. In many cases support groups are providing added value to core council services on a voluntary basis and the council should be working to remove pressures.

The panel has been very disappointed to see the closure of the Families Together project, delivered through the National Children's Centre as it was clearly providing a valuable and appropriate service to people with ADHD and their families.

The panel believe that if people are able to access appropriate support at the earliest opportunity then there is no reason why they cannot achieve their full potential. Set out below are examples of famous people who have had behaviour, learning or communication differences and have gone on to be very successful in their field.



The diagnosis of ADHD and other learning and communication differences did not exist when **Albert Einstein** was alive (1879 - 1955). However the pattern of his development has lead to the belief that he had a learning difference. The development of speech was delayed and he was unable to speak until the age of four. He was unable to read until aged 7. He failed entrance exams to the equivalent of a grammar school and gave up trying to go to university.

Yet, at the age of seven his interest in physics started as his father gave him a compass and he tried to understand why the needle always pulled to the north. He went on to be one of the greatest physicists of our time and yet he did not pass the equivalent of a maths GCSE!

For **Richard Branson,** millionaire entrepreneur and head of the large Virgin empire, school was a nightmare. He had dyslexia and found his education more and more difficult. He performed poorly in standardized tests and believed that he had been “written off”.

Once out of the formal education system he was able to use his untapped skills to overcome the difficulties that his dyslexia posed him.

Orlando Bloom also has dyslexia. He explained "….It sounds like the plague. I just have difficulties recognising some letters, so I had to work harder than other kids. School was always a bit tricky. ….Many people think dyslexic people are boneheads. Dyslexia doesn't equal a lack of intelligence…"

Michael Phelps was diagnosed with ADHD as a child. Michael struggled to confine himself to a classroom chair and grasp educational concepts.
His teachers tried in vain to cope with his hyperactivity. Michael's frustrations often manifested themselves in tantrums and outbursts.

Slowly Michael started to channel his excess energy into swimming. Most swimmers would use the break between sessions at a competition to rest but Michael was 14 before he stopped using the time to bounce on his hotel bed!

In the summer Olympics 2004 Michael became an Olympic champion by using his boundless energy to win 6 gold and 2 bronze medals.

Conclusions of Recent Research into ADHD

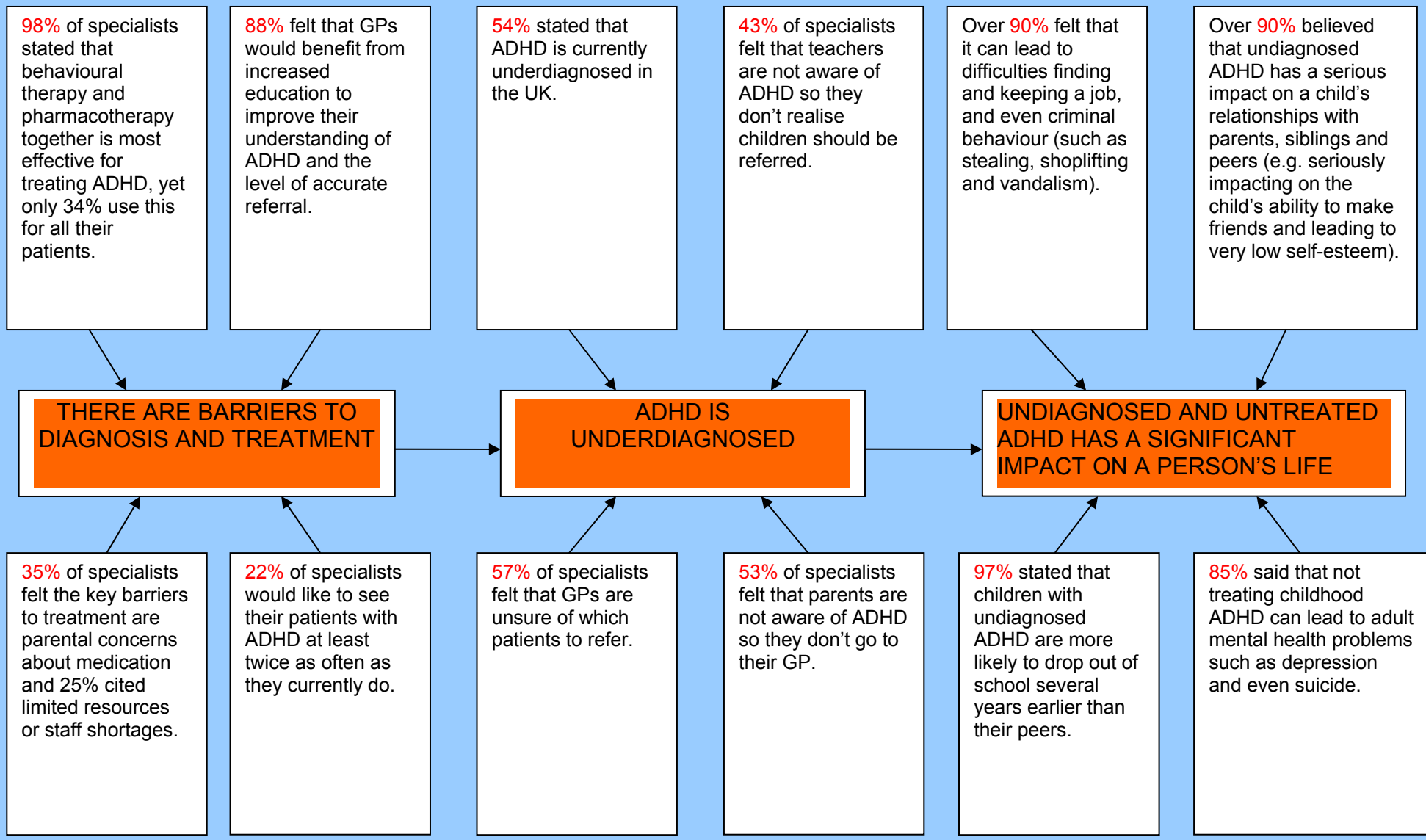
At the time when the panel were completing their work a research project investigating ADHD in the UK was publishing its findings. The report entitled ADHD: Paying Enough Attention was produced by ADDISS (The National Attention Deficit Disorder Information and Support Service). The foreword to the report states;

> *"....ADHD is a complex disorder and its management involves a wide range of organisations and individuals. Although awareness of the need for early diagnosis and effective treatment of ADHD is increasing across the fields of medicine, education and social services, there are still many areas where improvements can be made to ensure that people with ADHD do not slip through the net. Initiatives and policy changes such as the Special Educational Needs Code of Practice and the forthcoming National Service Framework for Children may go someway to address these areas but there is still much progress needed.*
>
> *Given the right support in education, children with ADHD can really succeed, which makes it even more frustrating that this is not happening at the moment. ……."*
>
> Andrea Bilbow, Founder and Director of ADDISS

As part of the research project, a survey was carried out amongst child and adolescent psychiatrists and paediatricians in the UK in order to investigate their views on ADHD and the current situation regarding diagnosis and treatment of this condition in the UK. The key findings of the survey are set out on the next page of the report.

The Ad hoc Scrutiny Panel believes that the work that they have undertaken has lead to very similar conclusions, indicating that this is not just a Kirklees problem but a national issue.

ADHD : PAYING ENOUGH ATTENTION? A Research Report Investigating ADHD in the UK



RECOMMENDATIONS OF THE PANEL

Section 1.

Pre Diagnosis

1. The Panel recommends that there should be a single point of contact for advice and support for parents who have concerns about their children's behaviour or their ability to learn and communicate.

To support the one stop shop approach the Council should work with partners to produce an information pack that is updated to maintain current contacts for support services as well as useful information about understanding the differences and parenting a child with ADHD. The information pack should automatically be made available to parents or patients at the point of diagnosis. The information pack should also include a self assessment questionnaire and next steps.

The panel recommends that the contact point should be located within Children's Services.

2. General Practitioners and Health Visitors play a vital role in early identification of potential differences and referral to access early intervention. The panel recommends that training should be given to all GP and health professionals on ADHD and comorbid disorders.

3. Nursery nurses and other people working in early years childcare settings play a vital role in the early identification of learning, behaviour and communication differences. Therefore the panel recommends that the Early Years Service investigate the quality of training available for childcare workers in working with children with behavioural and learning difficulties, and where appropriate, coordinate more in depth training to ensure a good understanding of the conditions and appropriate routes of referral to access support.

Section 2

Diagnosis

4. The panel recommends that there should be an agreed and consistent route for the diagnosis of ADHD. This should be through a multi agency assessment undertaken within a twelve week period from referral to diagnosis.

5. Diagnosis should be followed immediately with the development and implementation of an agreed support strategy that involves parents, schools, and lifestyle advice, including medication where appropriate.

6. The Panel recommends that medication should not be used in isolation but should be supported by a tailored package of interventions and strategies.

7. As part of the review of CAMHS in Kirklees (as part of the Children Act work) consideration should be given to the critical need to increase resources directed at early intervention work.

8. That CAMHS review progress made towards implementing the National Standards for Autism in Kirklees and consider any resource implications arising from the outcomes of the review.

Section 3

Adults with ADHD, Autism Spectrum Disorder and learning, communication or behavioural differences

9. The Panel recommends that as part of the review of Health and Social Care Board Structures, a Vulnerable Adults Partnership Board is established. The partnership board should co ordinate interagency working in all areas of adult life, including access to employment, benefits and further education.

10. That a clear and agreed pathway for transition from Child and Adolescent Mental Health Services / Paediatrics to Adult Mental Health Services be established.

11. That the Health and Social Board lobby central government and the National Institute for Clinical Excellence to request the updating of national guidelines and procedures in light of evidence of the continuation of Attention Deficit Hyperactivity Disorder in adulthood.

12. That Kirklees Metropolitan Council review its recruitment practices to ensure that they are fully accessible to people with learning, behavioural and communication differences.

Section 4

West Yorkshire Police

13. That West Yorkshire Police give consideration to the findings of the research by Lancashire Police on working with young people and adults with learning, communication and behavioural differences.

14. The panel strongly recommends that West Yorkshire Police provide training to raise awareness of appropriate ways of dealing with people with learning, communication and behavioural differences.

15. That West Yorkshire Police consider their processes and approaches, including completing forms and questioning techniques to ensure that they are appropriate to people with learning and communication differences.

Section 5

Kirklees Education Authority

16. That the Local Education Authority establish a working group to investigate the concerns about transition that have been raised by the panel. The investigation would include:

- Record keeping
- effective communication
- parental involvement
- child involvement
- training amongst all staff
- careful integration

The Working Group to report back to the Panel on its findings in twelve months time.

17. That there should be an increase in resource provision attached to mainstream schools for children with Autism Spectrum Disorders. A priority being the provision of an Autism Resource Unit as part of a High School in North Kirklees.

18. That all schools should identify quiet areas for use by children with ADHD and Autism Spectrum Disorders when they are struggling in the classroom setting. That the LEA should encourage all schools to develop mechanisms to identify and share good practice, eg the use of relaxation techniques and card systems.

19. That schools should be supported to try different support and learning techniques to help meet the needs of the individual child. These include behaviour management and innovative dyslexia programmes. As part of this willingness to try new ways of working, schools should have the ability to work with a wide range of external agencies as appropriate.

20. That the “time out” educational provision at Westfields is not always long enough. An individual may just be starting to respond after six weeks but is then put back into mainstream school. The panel recommends that the LEA looks to provide an extended provision for the more severe cases. The time suggested by the panel is a term.

21. That Kirklees support the Government food and nutrition in schools campaign given the positive impact it can have on learning and behaviour as well as health.

22. That the Local Education Authority review and update the ADHD Guidance booklet produced in 1997 by the multi disciplinary working group.

Section 6

Other Council Service Areas / General Recommendations

23. Housing Adaptations

The panel recommend that the housing adaptations criteria be reviewed to include the provision of adaptations in the interests of child safety, where a behavioural problem is responsible for a child's behaviour, for example the provision of secure fencing.

24. The panel recommends a multi agency awareness raising campaign to redress the level of ignorance and stereotyping of people with ADHD. To consider a positive, targeted campaign to raise the profile and levels of public understanding of learning, behavioural and communication differences.

The campaign would culminate in an ADHD awareness day which would include workshops that could be used to inform future policies.

Thanks …..

The panel wishes to thank everyone who contributed to the work of the panel. This includes those people from Council Services, the Health Service and West Yorkshire Police who attended a meeting of the panel. The panel would like to thank those headteachers and other education professionals who took time out of their busy schedules to speak to the panel.

The panel would also like to thank all those who submitted written information or participated in telephone interviews with panel members.

The panel would like to thank the local support groups for their willingness to share their experiences, in particular the ADHD Support Group, the Huddersfield Autism Support Group and the Dyspraxia Support Group.

Finally the panel wishes to thank all the members of the public who telephoned the Scrutiny Office or attended open meetings to talk to the panel.

LIST OF CONSULTEES AND EVIDENCE SOURCES

INTERVIEWEE	DESIGNATION
Mr B McCabe	Member of the Public
Mrs Stephanie Mellor-Smith	President of ADD/ADHD Support Group
Feisal Jassat	Head of Health Unit
Dr Alan English	Clinical Lead for CAMHS, (Calderdale & Kirklees)
Dr Nasreen Booya	Medical Director, SWYMHT
Fiona Jordan	Public Health for 2 PCT's - mental health portfolio
Lynne Hall Bentley	Head of Locality for Spenborough for NK PCT
Paul Johnson	KMC, Assistant Director, Children and Families, Soc.Services
Kate Faulkingham	ADHD Huddersfield Support Group
Mr & Mrs Wood	Members of the public - Parents of child with ADHD
Pauline Broughton, Lloyd Fullwood	Housing Allocations policy and Nuisance and Harrassment work
Liz Dobie	Assistant Director – Pupil Support
Bill Swap	Anti Social Behaviour Unit
Karina Hepworth	Youth Offending Team
Gina Lees	Youth Offending Team
Gill Goodswen	Head Teacher Stile Common Juniors
Graham Sunderland	Auditing and Monitoring Manager of Pupil Support
Sandra Fazakerley	SENCO – Newsome High
Sylvia Connor	School Support Manager
Joan Rock	Head Teacher – Rawthorpe I&N school
Andy Williams	Head Teacher – Holmfirth High school
Angela Horner	Central PCT, Line Management for School Nurses Service
Jill Padwell	Quality Development Manager – KEYS
Barry Seal	Joint Chair – Health and Social Care Board
Cllr Kath Pinnock	Joint Chair – Health and Social Care Board

Sue Richards	Partnership Commissioning Manager
Sgt. Marianne Huison and Acting Sgt. Kerry Emerson	West Yorkshire Police, Domestic Violence Unit
Dr Sills	Huddersfield Royal Infirmary - Paediatrician
Irene Miller	Senior Educational Psychologist – Butterflies
Janette Gruszka	SEN and Disabilities – KEYS
Karen Sullivan	(on behalf of Christine Renshaw) Inclusion Manager for KEYS
Simon Cale	Chief Executive, National Children's Centre
VISITS/ TELEPHONE INTERVIEWS	
Website for National Autism Society	
National Office of Statistics	
Visit to Superkids – National Children's Centre	
Meeting re Family Support and Parenting Strategy – Mark Feeny	
Telephone discussion with Children with a Disability Team – Kirklees Social Services	
Visit to Education Psychology – Judi Bamford	
Discussions with Connexions Service	
Discussions with Job Centre Plus	
Written submission from Probation Service	
Written submissions from: Greenhead College Dewsbury College Huddersfield Technical College Huddersfield University	
Visits to schools with autism resource provision: Honley High School Headlands JI&N school Moldgreen Primary School Lydgate School	
Pauline Swindells	Kirklees Parent Partnership Service Northorpe, Mirfield
Noreen Atkinson	Worklink
Fiona Pilgrim, Dyslexia Teacher	West Cliffe School, Keighley
Ivan York- Head of Youth Service	

REPORTS, PAPERS AND WEB SOURCES	
Papers and notes of ADDISS Conference on Challenges of ADHD in Adolescents and Adults.	
National Autism Society Publication –“ Inclusion - Is It Working”	
Wasted Lives - Report on Lancashire Constabulary’s DDAP (Development disorders - Achieving potential) project	
BBC News Website - Article - oil pills boost pupil brain power. 05.05.2002	
Research Report - ADHD: Paying Enough Attention - Andrea Bilbow, Director of The National Attention Deficit Disorder Information and Support Service June 2005	
Adders.org website – particular reference to British Dyslexia Association report on Dyslexia and Offending www. focus on adhd - ADHD Positive side.	
www. embrace dyslexia.com	
ADHD - How to Deal with Very Difficult Children - Alan Train - Human Horizon Series - updated reprint 2005	

Response to Recommendations and Action Plan

Financial Implications	Recommendation	Person to coordinate response	Recommendation Agreed yes/no Already happening/ Further work needed	Lead Agency/ Proposed Actions	Date of completion
	Pre Diagnosis				
£	**1.** The Panel recommends that there should be a single point of contact for advice and support for parents who have concerns about their children's behaviour or their ability to learn and communicate. To support the one stop shop approach the Council should work with partners to produce an information pack that is updated to maintain current contacts for support services as well as useful information about understanding the differences and parenting a child with ADHD. The information pack should automatically be made available to parents or patients at the point of diagnosis. The information pack should also include a self assessment questionnaire and next steps. The panel recommends that the contact point should be located within Children's Services.	Cabinet Member Children's Services / Director of Social Affairs an Health	Agreed This recommendation has been taken on board as part of the development of Social Services Information Points within Kirklees. Development of an information pack is agreed in principal although further work is required in who would develop the pack. Starting point would be Social Affairs discussion with CAMHS.	Director of Children's Service	
£	**2.** The panel recommends that training should be available to all GPs and health professionals on ADHD and comorbid disorders.	Chief Executives of Primary Care Trusts	Agreed in principle. A new element to be included as part of the PCT training Programme and to		

			be made available to GPs and health professionals after 6 months and on an on going basis thereafter.		
£	**3.** The panel recommends that the Early Years Service investigate the quality of training available for childcare workers in working with children with behavioural and learning difficulties, and where appropriate, coordinate more in depth training to ensure a good understanding of the conditions and appropriate routes of referral to access support.	Cabinet Member Children's Services/ Head of Kirklees Early Years Service	Ongoing as part of KEYS Training Strategy. Appointment of Training Strategy Manager 2005 to work in partnership with Inclusion Manager to deliver strategy in relation to SEN, Inclusion and equal opportunities. Training includes Social and Emotional Development / Behaviour Training Planned sessions in 2006 with Psychology and Specialist Outreach Service Ongong training SEN and Disability. Supported by 4 new Inclusion Support Worker posts . Part of the role is to promote early identification and intervention.	Head of Kirklees Early Years Service	Ongoing

	Diagnosis				
	4. The panel recommends that there should be an agreed and consistent route for the diagnosis of ADHD. This should be through a multi agency assessment undertaken within a twelve week period from referral to diagnosis.	Clinical Lead for CAMHS	Not Agreed but alternative improved targets being worked to. NHS targets are 13 weeks from referral to first appointment And 18 weeks from referral to treatments by 2008. CAMHS are working towards these targets but need to ensure equity across client groups	CAMHS Implementation Group Development of a care pathway	Ongoing
	5. Diagnosis should be followed immediately with the development and implementation of an agreed support strategy that involves parents, schools, and lifestyle advice, including medication where appropriate.	Clinical Lead for CAMHS	Need for development of family support workers and closer working with education	CAMHS Implementation Group Development of a care pathway also for those not diagnosed	Sept 2006
	6. The Panel recommends that medication should not be used in isolation but should be supported by a tailored package of interventions and strategies.	Clinical Lead for CAMHS	Agreed	Calderdale and Kirklees CAMH Service	April 2006
£	**7.** As part of the review of CAMHS in Kirklees (as part of the Children Act work) consideration should be given to the critical need to increase resources directed at early intervention work.	Clinical Lead for CAMHS	Development of Primary Mental Health Work Positive Mental Health Strategy Parenting Support Forum	CAMHS Implementation Group	April 2007

			Healthy Schools CAMHS Training Initiative		
	8. That CAMHS review progress made towards implementing the National Standards for Autism in Kirklees and consider any resource implications arising from the outcomes of the review.	Clinical Lead for CAMHS	Agreed Need for a Kirklees Wide review of Autism	CAMHS Implementation Group	April 2007
	Adults with ADHD, learning, communication and behavioural differences				
	9. The Panel recommends that as part of the review of Health and Social Care Board Structures, a Vulnerable Adults Partnership Board is established. The partnership board should co ordinate interagency working in all areas of adult life, including access to employment, benefits and further education.	Chair of Health and Social Care Board	Already Under consideration Being taken into consideration as part of discussions about the Partnership Board		
	10. That a clear and agreed pathway for transition from Child and Adolescent Mental Health Services / Paediatrics to Adult Mental Health Services be established.	Chief Executives of Primary Care Trusts	The PCT's are fully supportive of the recommendations made around adults. South West Yorkshire Mental Health Trust have expresses an interest in looking at this area and will therefore take a lead	SWYMHT	Aim for completion in 2007 (12-18 months)
	11. That the Health and Social Board lobby central government and the National Institute for Clinical Excellence to request the updating of national guidelines and procedures in light	Chair of Health and Social Care Board	Further work required The Health and Social Care Board	Chair of Health and Social Care Board	

	of evidence of the continuation of Attention Deficit Hyperactivity Disorder in adulthood.		accepts that there is a need for some updating of National Guidelines but as this is the overall responsibility of NICE , it is felt that it needs to be agended into discussions at the H&SCBd.		
	12. That Kirklees Metropolitan Council review its recruitment practices to ensure that they are fully accessible to people with learning, behavioural and communication differences.	Cllr K Pinnock / Head of Corporate HR	Work will be undertaken to identify the reasonable adjustments that are required to address the recommendation. This will be in conjunction with the Council's wider workforce planning strategy.		
	West Yorkshire Police				
	13. That West Yorkshire Police give consideration to the findings of the research by Lancashire Police on working with young people and adults with learning, communication and behavioural differences.	Chief Supt Barry South	Agreed to consider further the Lancashire Police research.	West Yorkshire Police	
£	**14.** The panel strongly recommends that West Yorkshire Police provide more in depth training to raise awareness of appropriate ways of dealing with people with learning, communication and behavioural differences.	Chief Supt Barry South	Agreed to consider and undertaken further work to look at possibilities of working with health partners to deliver appropriate training.	West Yorkshire Police - Divisional Training Officer/ Domestic Violence and Adult Protection	

			Will also consider possible inclusion at probationer training level and the financial implications	Unit	
	15. That West Yorkshire Police consider their processes and approaches, including completing forms and questioning techniques to ensure that they are appropriate to people with learning and communication differences.	Chief Supt Barry South	Agreed to be considered as part of the work undertaken re recommendation 14 and incorporated into a training package to raise general awareness	See Rec. 14	
	Kirklees Education Authority				
	16. That the Local Education Authority establish a working group to investigate the concerns about transition that have been raised by the panel. The investigation would include: • Record keeping • effective communication • parental involvement • child involvement • training amongst all staff • careful integration The Working Group to report back to the Panel on its findings in twelve months time.	Cabinet Member Children's Services / Director of Lifelong Learning (Director of Children's Services)	Not Agreed From the evidence in the report, it was felt that there was insufficient evidence gathered to warrant setting up a Working Group. The areas identified relate to Government legislation and school's individual policies and practice. Further information and evidence could be submitted to the panel to outline the way in which transition is managed For the panel to		

			balance this against information received. However the impact of work time in submitting this information needs to be considered against other priorities on local authorities and LEA at this time.		
£	**17.** That there should be an increase in resource provision attached to mainstream schools for children with Autism Spectrum Disorders. A priority being the provision of an Autism Resource Unit as part of a High School in North Kirklees.	Cabinet Member Children's Services / Director of Lifelong Learning	The LEA is reviewing its provision for children with autism, work has been ongoing, including looking at setting up a resourced provision in North Kirklees. Officers continue to work on this as an outcome from the SEN Strategy consultation process.		
	18. That all schools should identify quiet areas for use by children with ADHD and Autism Spectrum Disorders when they are struggling in the classroom setting. That the LEA should encourage all schools to develop mechanisms to identify and share good practice, eg the use of relaxation techniques and card systems.	Cabinet Member Children's Services / Director of Lifelong Learning	Responsibility for the day to day running of schools, policies and practices are a matter for the Head Teachers and governors. The LEA already offers training in relation to managing the needs of children with Autism and ADHD and sharing		

			good practice. The LEA whilst continuing to encourage good practice, is limited in its function other than to guide and influence school to develop good practice. The new self evaluation form which schools are required to complete includes the ways in which the school is meeting the needs of children with additional needs.		
£	**19.** That schools should be supported to try different support and learning techniques to help meet the needs of the individual child. These include behaviour management and innovative dyslexia programmes. As part of this willingness to try new ways of working, schools should have the ability to work with a wide range of external agencies as appropriate.	Cabinet Member Children's Services/ Director Lifelong Learning	See response to 18. Each school identifies its own priorities.		
	20. That the "time out" educational provision at Westfields is not always long enough. An individual may just be starting to respond after six weeks but is then put back into mainstream school. The panel recommends that the LEA looks to provide an extended provision for the more severe cases. The time suggested by the panel is a term.	Cabinet Member Children's Services / Director of Lifelong Learning	The provision time is as a result of consultation with headteachers and the funding of time is as a result of negotiations with schools and LEA officers.		

	21. That Kirklees support the Government food and nutrition in schools campaign given the positive impact it can have on learning and behaviour as well as health.	Cabinet Member / Director of Lifelong Learning	Kirklees has already discussed this as an issue to be addressed through the Local Area Agreement and Children and Young People's Plan		
£	**22.** That the Local Education Authority review and update the ADHD Guidance booklet produced in 1997 by the multi disciplinary working group.	Cabinet Member/ Director of Lifelong Learning	This document was drawn up via a multi-agency group. Any up-dating would require time and resources to complete and this would have to be considered alongside other priority areas.		
	Other Council Services/ General				
	23. The panel recommend that the housing adaptations criteria be reviewed to include the provision of adaptations in the interests of child safety, where a behavioural problem is responsible for a child's behaviour, for example the provision of secure fencing.	Cabinet Member Health and Social Services / Director of Social Affairs and Health	Already happening The adaptations criteria will not need to be revised as there is already provision for safe play areas in the discretionary grants policy. Such provision would be assessed by Social Workers with supporting technical advice.		

£	**24.** The panel recommends a multi agency awareness raising campaign to redress the level of ignorance and stereotyping of people with ADHD. To consider a positive, targeted campaign to raise the profile and levels of public understanding of learning, behavioural and communication differences. The campaign would culminate in an ADHD awareness day , to include workshops that could be used to inform future policies.	Cabinet Member - Children's Services / Director of Social Affairs and Health	Agreed Initial discussions with Marketing are planned to discuss possible approaches		