

"The single thing that has made the difference is Mr Matthew Brown, Year 3 teacher at Whitton Green Primary School, Lowestoft, Suffolk"

"Minister for Education - Why do different schools in the same LEA have differing attitudes ADHD?"

"Social Services staff do not understand / accept ADHD - Parents made to feel they are at fault - bad parents"

"Jack was diagnosed a half and I feel teachers have been"

"50% of children with ADHD have a Statement of Special Educational Needs"

"Need to look at the whole child"

ADDiSS
ADHD INFORMATION SERVICES
Registered Charity No. 1070827
The National Attention Deficit Disorder Information & Support Service
10 Station Road, Mill Hill Broadway, London, NW7 2JU
Tel: 020 8906 9068 Fax: 020 8959 0727
email:info@addiss.co.uk www.addiss.co.uk



ADHD

(Attention Deficit Hyperactivity Disorder)

"Parents said that social services were obstructive and even detrimental to their children and families"

Parents, Provision and Policy
A Consultation with Parents
"If only... something would be done and more people would be aware of..."

"The one thing that has made a difference is the existence of a support group locally"

"Parents get most of their support from the voluntary sector - an activity that is neither recognised nor resourced by the local authorities"

Southport
September 2003

"To teachers: For a relatively small investment/recognition at a young age (primary school) you CAN make a real difference"

ADDiSS
ADHD INFORMATION SERVICES
Registered Charity No. 1070827
"I in... had been apprehended for... or other youth offences"



Acknowledgements

ADDISS would like to acknowledge the support of all those who worked with them on this consultation exercise, particularly **the parents** who attended the weekend conference and told their stories freely and positively.

The exercise could not have been undertaken without the expertise and skill of the **workshop group facilitators**:

Under 12s: Dr Gillian Baird, Barbara Worrall, Liz Miller, Lorraine Marer, Rita Jones, Dr David Coghill and Jenny Missen

Under 17s: Fintan O'Regan and Jan Assheton

Adults 18-25: Pippa Weitz and Margaret Alsop

Youth Offending: Steve Brown and Dr Phil Anderton

Scribes: Sharon O'Dell, Debbie Thompson, Maryla Carter

A special thank you to the keynote speakers

Jerry Mills, teacher, singer/songwriter, who travelled from Marquette in Upper Michigan USA to be with us

Professor Eric Taylor, Institute of Psychiatry, London,

Fintan O'Regan, Education Consultant, DC Education Services & ADDISS and

Chris Wall, Personal Care Consultants Ltd

We would like to thank Samantha Miller and Maxine McCarthy from the Southport Tourist Bureau and Sefton Council for subsidising the marvellous facilities of the **Southport Theatre and Floral Hall** and all the staff at the venue for looking after us so well.

Nicki and Ian Boyle and their family deserve a special mention for their hospitality and help to prepare the materials for the weekend.

We appreciate the services of **Dr Maureen Devlin** in the development of the consultation tools, for the analysis of the findings and the drafting of this document – designed by **Braden-Threadgold**.



Foreword



Services for children are in a phase of important change. The development of a National Service Framework has reflected a widespread feeling that much needs to be done before children with special needs get the kind of help that they deserve. Priorities are being set, and the voice of those using services is being listened to with new attention. The National Health Service, for example, needs good information at every stage of its work. It is no good having the best treatments in the world if they are not used. Good treatment depends upon consulting effectively with users, making sure that there is a real, informed choice for them, and ensuring that professionals know the best ways of intervening to help people at risk.

The problems associated with attention deficit hyperactivity disorder (ADHD) have challenged not only the health service but also education and social agencies. Research has led to a rapid increase in knowledge, and it is now some eight years since the recognition that ADHD was a serious risk led to the reintroduction of methylphenidate to the market, and to the increased use of psychological and other medical therapies. Very often, however, it has proved difficult to apply this knowledge in practice. There are some very good examples of successful training in the recognition and treatment of ADHD, but it must be admitted that practice is patchy and there are examples both of under-and over-treatment.

In this situation the work of ADDISS is a fine example of managing the flow of information. It has for years served as an invaluable exchange and source of information for user groups. One

result has been a good knowledge of the problems that are brought to it by people from all over the country. It supports, and consults with a variety of local groups. This paper provides the results of its latest consultation exercise. A national meeting in Southport was the setting for representatives from many local groups to bring up their own ideas and develop them in focused and facilitated discussions. It was a creative and heartening meeting. A wealth of ideas and suggestions are to be found in these pages.

Care providers will find a great deal to think about and to measure their activities against. Two of the themes that inform the whole document are the need for the highest quality of training, and for training about ADHD to extend to all those who are in contact with children with special needs. Another theme emerging in several contexts is the wish for a closer and respectful collaboration between the statutory and the voluntary sectors.

The lessons from the consultation go far beyond issues about what should be provided by specialists. Indeed, the discussions emphasise over and over again the great need of people affected by ADHD to have the condition widely recognised, and for ADHD provision to take a full place in the mainstream of health, education and social care. All too often service users find that the condition is regarded as debatable or spurious- attitudes which they rightly think to be out of date and ill-informed. Primary care trusts, departments of education and social work, local councils and higher levels of governmental planning will all find the wish expressed here, and creatively elaborated, for them to be responsive to the needs of people with ADHD. Their voice here is clear and articulate.

Professor Eric Taylor

Professor of child and adolescent psychiatry
Institute of Psychiatry, Kings College, London.



Ten years ago few people knew about Attention Deficit Hyperactivity Disorder. Over the years parents have done a great deal to raise awareness and we now have more and more children being diagnosed. But are they being recognised and helped in our schools, in our community and in our juvenile justice system? This is what we aimed to find out.

Ten years on our parents are still blamed and our children continue to be demonised by society and the media.

In the field of mental health ADHD is the poor relation, representing over 50% of referrals yet receiving less than 50% of the budget. The DfES in their ignorance continue to bury ADHD in the category of Social, Emotional and Behavioural Disorders, not recognising the uniqueness of our children or the fact that, their behaviours aside, their brains function differently to other children when placed in the learning environment or educational institutions.

The Learning Skills Council recognises and funds ADHD, but Social Services will not share that burden for children with ADHD who have to be placed in residential schools.

There is no consistency in recognition or acceptance of ADHD as a legitimate disorder across the board nor in the delivery of services.

This consultation is unique, bringing together 400 parents who travelled great distances to make their voice heard.

It would be a shame if no one listens to what they had to say nor tries to put things right.

This document is a tribute to a group of courageous parents who continue to fight for their children in the face of adversity.

Andrea Bilbow
Founder and Director



| CONTENTS | PAGE |
|---|-----------|
| Introduction to ADHD and ADDISS What is ADHD? Impact of undiagnosed and untreated ADHD What is ADDISS? | 1 |
| Headline findings | 2 |
| Why consult parents now? | 3 |
| What were we looking for? | 3 |
| What we did | 3 |
| Key Findings Questionnaire Comment Cards Consultation Groups | 4 |
| Full Findings Questionnaire Comment Cards Consultation Groups Education Health Social Services Adult Services Youth Offending Examples of Best Practice | 6 |
| Emerging Themes, Issues, Solutions and Responsibilities | 16 |
| References | 17 |
| The Board | 18 |

Introduction to ADHD and ADDISS

According to NICE guidance, the prevalence of ADHD in the UK is 5% of school-aged children, which equates to approximately 400,000 children. NICE also notes that ADHD is currently underdiagnosed in the UK¹.

What is ADHD?

Attention deficit hyperactivity disorder (ADHD), also sometimes referred to as attention deficit disorder (ADD) or hyperkinetic disorder (HKD), is a neurobiological disorder caused by an imbalance of some of the neurotransmitters found in the brain, called norepinephrine and dopamine².

ADHD is characterised by symptoms of impulsivity and hyperactivity and/or inattention. The symptoms are not seen to the same degree in all people diagnosed with the disorder and healthcare professionals recognise that there are 3 main combinations of symptoms:

- Some people have predominantly (mostly) hyperactive-impulsive type
- Some have predominantly (mostly) inattentive type
- And some have a combined type (this makes up the majority of ADHD cases³).

Hyperactive or impulsive behaviours may include: fidgeting, having trouble playing quietly, interrupting others and always being ‘on the go’³. Symptoms of inattention may include: being disorganised, being forgetful and easily distracted and finding it difficult to sustain attention in tasks or play activities³. Whilst ADHD behaviours occur to some extent in all of us, the difference between ADHD and normal behaviour is the degree of the problem and the difficulties it causes.

The consequences of severe ADHD for children, their families and for society can be very serious. Children can develop poor self-esteem, emotional and social problems and their educational achievement is frequently severely impaired. The pressure on families can be extreme. This complex condition needs early diagnosis and careful management in order to not only ease the misery and frustration that results, but also to ensure that each child reaches their full life potential.

Impact of undiagnosed and untreated ADHD

The economic, emotional and social consequences of failure to treat and manage ADHD are damaging to the affected child, their families and their communities.

It has been shown that the rate of self harm amongst 11-15yr olds with hyperkinetic disorder is eight times higher than for unaffected children⁴. Hyperkinetic children are also twice as likely to be involved in accidents, leading to greater use of NHS services⁵.

It is widely accepted that a child's life chances are harmed through underachievement at school. Those with a persistent hyperkinetic disorder are twice as likely to leave the education system with no qualifications; due in part to the fact that affected children are eleven times more likely than unaffected children to be excluded from school⁶. An Audit Commission report (1996)⁷ suggested that 42% of youth offenders had been excluded from school.

Furthermore, it has been demonstrated that children with ADHD are significantly more likely to be arrested in adolescence for delinquent behaviour⁸, with hyperactivity being recognised as a risk factor for both higher juvenile (46% versus 11%) and adult (21% versus 1%) criminality⁹. According to the British Medical Association, lack of recognition and early diagnosis of ADHD have forced up the national crime figures, with up to 48% of youth crime due to medical disorders and other mental health related conditions associated with ADHD¹⁰.

What is ADDISS?

ADDISS (National Attention Deficit Disorder Information & Support Service) works at a national level in partnership with local support groups to provide accurate, timely and useful information - reaching over six thousand parents and interested professionals. To make sure it responds to current needs, ADDISS regularly seeks their views. This report describes the findings of the most recent consultation exercise.

"To change, you must know what to change, how to change and build a structure to support that change" (Thom Hartmann)

Turning parents’ views into positive action for children and young adults with ADHD

Findings from the ADDISS Consultation Exercise
The Southport Theatre and Floral Hall
September 6-7th 2003

HEADLINES

Parents said that social services were obstructive and even detrimental to their children and families. The majority of support they receive is from the voluntary sector even though the care and management of ADHD children cuts across all public sector providers. Within the official agency bodies, schools - when ‘ADHD aware’ - were the most supportive.

| WHAT DID PARENTS IDENTIFY AS THE BIGGEST GAPS? | |
|--|--|
| Health Services | Not being able to get an early-age diagnosis, quickly |
| Education | Lack of training on ADHD for educators, teachers and all associated school staff |
| Social Services | Staff attitude - often heavy handed; parents made to feel that they are at fault |
| Adult Services | Poor continuity of services for medication |
| Young Offenders | Trained single points of contact for families |
| Media /Information | Lack of balance in media coverage of ADHD |

Note: Other areas of concern, together with suggested solutions, are reported later in this document

Why consult parents now?

Children with ADHD require the provision of services from health, education and the social care sectors. Various policy initiatives being considered across these sectors have the potential to improve or damage the life chances for these children. ADDISS has the responsibility to ensure that policy makers hear the views of parents about what can make a real positive difference to them, their children and their families.

Although the formal consultation on the National Service Framework for Children is complete, work on the implementation of the NSF standards is in progress until the expected publication of the NSF in 2004. We believe that the NSF team need as much information as possible on how to meet the needs of children with ADHD, in line with the scope of the NSF: *"All children, whatever their age, race, sex, faith or disability should be able to receive high quality services"*¹¹. The NSF references the work being undertaken by the National Institute for Clinical Excellence (NICE) on the use of medication for ADHD. NICE additionally has work planned on the clinical/cost effectiveness of parent-training / education programmes for treatment of conduct disorders which is out for consultation until January 2004¹².

The Department for Education and Skills (DfES) is currently seeking views on its sponsored green paper *Every Child Matters*¹³. Expected in February 2003, the draft legislation was finally published in September and the consultation period extends until the end of the calendar year.

ADDISS has never received a copy nor has it been asked for the views of parents of ADHD affected children – a shocking oversight for a green paper entitled Every Child Matters !!

Additionally, the Antisocial Behaviour Bill is about to reach report stage in the autumn which could impact on the lives of many ADHD adolescents.

What were we looking for?

For parents, the lack of information and poor co-ordination of services is a major problem. They rely in the main on **voluntary** local and national support groups for help and advice and we wanted to find out why this is so – when the care of ADHD children requires input from all of the local public service agencies. We needed to learn from parents not only what the issues were that impacted on their lives, but also to identify positive experiences so that we could generate a *pragmatic wish-list* – those national and local solutions that will do most to help children and support parents.

What we did

We organised a two-day consultation conference in Southport for parents from all over the UK. The consultation employed a combination of a questionnaires, workshop-style consultation groups and free-text 'comment cards'. Expert speakers introduced the context for the consultation looking at the wider public policy framework, and included a plenary/discussion session led by representatives from the Lancashire Constabulary.

The questionnaire was designed to learn about delegates and their families; issues around diagnosis and treatment; types and levels of support; and views on the 'label' of ADHD and the role of the media.

The workshop-style consultation groups were facilitated by experts in education, health and the voluntary sector. The groups were organised so that delegates focused either on the interests of children up to 12 years old, teenagers or older adolescents.

The desired output from each group at the end of the two days was a 'pragmatic wish-list' of no more than ten items that could make a real difference to their children's lives. To reach this consensus, each group considered the following overarching themes:

| | |
|------------------------|----------------------------|
| Health Services | Social Services |
| Education | Adult Services |
| Young Offenders | Media / Information |

The groups were also asked to highlight examples of local 'best practice' that could be picked up and tailored in other areas.

Each delegate additionally received three blank '**comment cards**' in their conference pack. The cards had two functions: firstly, to allow parents an additional opportunity to put forward their views on the topics being discussed and secondly, to seek answers to two questions presented at the start of the conference:
Q: What is the single thing that has made a difference to you and your family?
Q: If you had 5 minutes with someone you believed was influential in your situation, who would that be and what would you say?

Key Findings from the Questionnaire

- Whilst some parents said diagnosis took less than 6 months, almost a quarter reported that this process took between one and five years – thereby placing those children at extreme disadvantage
- Three quarters of children with ADHD receive medication
- For 1 in 6 children, medication started before the age of 6 years
- A diagnosis is generally made by a consultant in either psychiatry, psychology or paediatrics; parents do not care who they see provided they are competent and experienced
- Very few consultants offer, let alone provide, details of a local support group
- More than half of respondents stated that a support group had been the most help to them
- Time and time again Social Services (SS) were deemed the least helpful organisation. Most parents said Social Services didn't recognise ADHD as a disability, and rarely offered support for respite care
- The parents agreed that training was vital, yet only a minority found that the teachers in their child's school received specific training on ADHD
- 50% of children with ADHD have a Statement of Special Educational Needs
- **Experience of positive change is largely dependant on individual professionals rather than through a managed organisational approach**
- 1 in 4 affected children had been apprehended for anti-social behaviour or other youth offence

Key Finding from the Comment Cards

What is the single thing that has made a difference to you and your family?

The overwhelming majority of parents replied:
"Getting a diagnosis and treatment "

But for one family:
"The single thing that has made the difference is Mr Matthew Brown, Year 3 teacher at Whitton Green Primary School, Lowestoft, Suffolk" ☺

Who would you want to talk to?

Out in front: Policy makers at national level

What about?

1. Fair, consistent implementation of policies to ensure children achieve their potential
2. Policies to increase awareness and understanding

The Vital and Pragmatic Wish-List – Outputs from the Consultation Groups

These eight things are what parents feel will make a real difference to their children and their families. They want policy makers and local agencies to realise that things can change - ideas for 'how' this can be achieved are given in the Table on page 16

1. **Training** for all professionals concerned
2. **Improve communication** between parents, schools, health services and social care
3. **Early intervention** to get diagnosis and treatment as soon as possible
4. **Raise awareness** – of the condition, the issues, the positives
5. **Consistency** of services and policies – locally and nationally
6. **Information** – for parents and children
7. **Resourcing** – right things in the right place
8. **Roles and responsibilities** – real local partnership working



Comments from our facilitators:

"It is important for teachers working with ADHD students to see this as a learning issue, not premeditated acts of demanding, disruptive or difficult behaviour. I believe that for ADHD to be taken seriously in the UK it must have a defined place within the current Code of Practice."

Fintan O'Regan, Education Consultant

"The child, the family and the school must work together to make changes."

Liz Miller, Social Worker and ADHD Project Leader

"We must not forget that needs change over time. My group was very clear on what they need – competent, knowledgeable professionals who recognise that ADHD is not a single disorder. They need a joined up approach from all the agencies, to facilitate the patient's journey."

Dr Gillian Baird, Consultant Developmental Paediatrician

"We should ensure that children are helped to adapt to fit into the society that they live in – as children and as adults."

Pippa Weitz, Teacher and Education Consultant

"It was a privilege to be able to spend the weekend with such an enthusiastic, resourceful and knowledgeable group. I can only hope that this document allows their many thoughts and ideas to be heard."

Dr David Coghill, Consultant and Lecturer in child and adult psychiatry

"We as a service need to be more effective at signposting parents / carers towards support groups for ADHD."

Dr Philip Anderton, Lancashire Constabulary, Community Safety Department

FULL FINDINGS

1. Questionnaire

Characteristics of delegates

The majority of the delegates were parents but the conference also attracted teachers and other interested individuals such as grandparents and social workers. Most parents said that they belonged to a support group – and for those that said they didn't belong it was mainly due to a lack of local availability.

94% respondents had at least one child with ADHD. Whilst the majority had one affected child, 18 delegates have two; and three delegates declared responsibility for three children with the condition. 78% of these children are currently between 5 and 15 years old.



Diagnosis and treatment

The majority of parents reported that their child received a diagnosis in less than six months, and for more than half of these, diagnosis was achieved in less than three months. However, a significant proportion of this latter group (25%) had been forced to seek private medical care.

The GP rarely initiated the referral that led to treatment being offered. A specialist opinion was required – generally either from a paediatrician, psychologist or psychiatrist. **A number of parents actually changed their GP to get the help they needed but they didn't care who made the diagnosis – they just wanted someone who was experienced in the field.**

For those who had to wait longer than six months, one third of respondents said they had to wait longer than 1 year; for thirteen families it took a further four years for a diagnosis.

For just over a quarter this was a second opinion and it is noted that 8% of the respondents were forced by lack of help to pay for a private consultation.

Most parents had heard of ADHD before their child was diagnosed with the condition but fewer than 1 in 5 were given any details of a local support group from their consultant.

Many children with ADHD also have one or more co-existing conditions. Of these, the most commonly reported were Oppositional Defiance Disorder, Speech and Language Difficulties, Dyspraxia, Dyslexia and Conduct Disorder. Autism and Asperger's Syndrome were also cited.

75% of children are receiving medication for their ADHD.

The quality of life for most children on medication improved either 'quite a bit' or 'quite significantly'.

A small proportion of children received medication for ADHD before the age of six. One parent commented "I trusted it was necessary" while a second noted "...due to a lot of pressure on our part."

For those not on medication, nearly half were receiving no treatment at all. However, various alternative/complementary options were being used such as behaviour management, diet and occupational therapy. For others, dyslexia support, speech and language support and cranial osteopathy were being employed.

Support

When asked if teachers, the NHS or social services provided as much support as parents felt they needed, the **overwhelming answer** for each group was ‘No’. When the question was modified to find out which group had been the most help to them and their child, more than half said a support group, with teachers in second place. Social Services were felt to be helpful by only 2 delegates.

The attitude of Social Services seems also to be compounded by lack of information. Less than a quarter of parents said that their local department recognised ADHD as a disability.

Parents get most of their support from the voluntary sector – an activity that is neither recognised nor resourced by the local authorities.

Fewer than 1 in 5 said that their child’s teachers received specialist training on ADHD. This figure may explain why teachers only rarely suspected the possibility of ADHD (23%).

About two thirds of the children concerned are on the Special Needs Register, with an Individual Education Plan (IEP). Almost half of these had a Statement of special educational needs. There was no one age at which statementing generally occurred showing that for some children, many years pass before they get the help they need – in effect, a massive negative impact on their learning and life potential.

Most parents were involved with the IEP for their child although one parent noted "I have to ask to take it home, not just ten minutes at the parents evening".

Only a small number of parents had a child who was over 16 years and could respond to questions on the transfer to adult services (n=34). In the majority of cases, this was unsatisfactory often leading to the sufferer feeling "isolated and unsupported". Other comments included problems resulting from new infrastructure, medication being stopped and having to fight for adult learning support.

1 in 4 affected children had been apprehended for anti-social behaviour or other youth offence.

General views

Most respondents felt that the ADHD ‘label’ was helpful, although one parent noted "The ADHD label is helpful for me, my son hates it."

The media coverage of ADHD was generally felt to be negative, choosing the sensational option and/or the demonisation of properly prescribed medication. The attitude of certain sections of the media appears to be "Never let facts get in the way of a good circulation-building story." Only 1 in 5 thought media coverage is balanced or positive.



2. Comment Cards

Q 1. What is the single thing that has made a difference to you and your family?

"Private school -smaller classes and more attention"

"Changing school to one where the head and staff 'understood' ADHD"

"Medication" "Medication"

"Diagnosis" "Diagnosis"

"Having grandparents that take my daughter for a weekend away to us to give us a break"

"I feel this (consultation) weekend has been and will be historic in moving the awareness of ADHD forward focusing resources and attention on helping both family and child. Thank you, I feel privileged to be part of it"

"Mr Matthew Brown Yr 3 teacher, Whitton Green Primary School, Lowestoft, Suffolk"

"...was having an excellent GP who believed me that my son had ADHD even though he had never heard of it. He gave us the support and services we needed after looking into and gaining an understanding of what ADHD is"

"The single thing was the special needs nursery my daughter attended following diagnosis aged 3 and half to 5 years. It got her ready for school"

"My determination and the ADHD group and their constant support"

"Outside groups like Calder kids"

"The one single thing that has benefitted my son and family is the support and encouragement from Mrs Bilbow who had the courage to set up the first support group in London!"

"The one thing that has made a difference is the existence of a support group locally"

"When my son was diagnosed with ADHD he was so much happier. The most traumatic statement he came out with prior to this was when he sat in a ball in the middle of the floor crying and saying "I'm mad aren't I." Thank God for the label"

"The single thing that has had a profound effect for my child was the Diagnosis"

Q 2. Who would you like to have five minutes with, and what would you say to them?

Tony Blair

"When will the government realise that the genius of this country is being wasted in the current education system and when will the system be reformed to benefit the entire population of the UK"

"I would like to spend 5 minutes with Tony Blair and ask him to live my life for one month without his present level of support and then defend the government's position on care and development of those for whom we care, without spin"

"ADHD has the capacity to wreck a child's life and the lives of their family. It also has the capacity to produce extraordinary individuals. We need to ensure that everyone involved in the lives of children (with ADHD) understands the condition and is able to provide the understanding and support to enable these children to reach their full potential. The long-term effect of this strategy can only be positive and could be dramatic"

"If Tony Blair had a son or daughter with ADD or ADHD something would be done and more people would be aware of it"

"I would like Tony Blair to be totally aware of the problems ADHD causes and much more awareness in schools. Also money needs to be put into social services so that these children are properly assessed before being put up for adoption and fostering. These children were let down in their earlier lives and are being failed again by inadequate support"

"If children were diagnosed at an early age and got help, the government would spend less money with people in prison as lots of these people have ADHD, it affects every aspect of life"

"Does he personally accept that ADHD exists, does his government accept that ADHD exists – can he get it onto local authority agendas"

Cherie Blair

"As a barrister she could take a court action to support all parents who couldn't speak for themselves. I would ask her to live with an ADHD child for ONE day and night! That would do it!"

Government & Specific Ministers

"Government - Please recognise and understand ADHD and comorbid conditions as disabilities and put policies in place to make children and parents lives easier – especially education"

"The Minister for Hidden Disabilities - the current provision for ADHD and learning disabilities both for children and adults is grossly inadequate. How do you propose to change this in the future?"

"Minister for Education - Why do different schools in the same LEA have differing attitudes to ADHD?"

"Minister for Education - Scrap SATS/league tables; small mainstream schools and training for all school staff in SEN"

"To Charles Clarke and Gordon Brown - Will you put the funding in to support the needs of ADHD sufferers of all ages educationally in order to ensure that they fulfil their full potential in their adult life?"

"Ministers - We need more positive information, we need more help in schools"

"I would speak to the minister for help and diagnosis for ADULT ADHD"

"Ian Duncan Smith - In your next manifesto for the next election could you make a policy for ADHD to be made more aware in the education system and for provision to be put in place so that their needs would be met i.e. every SENCO to go on courses to learn more about ADHD. This would lead to less crime, young offenders truancy = saving money!"

Teachers and Headteachers Unions

"For a relatively small investment/recognition at a young age (primary school) you CAN make a real difference"

"To the chief of education - To support our children in their life’s most important challenges within the education system and to give them specific help"

"Teacher (s) is the one who would make a difference to our children. We would say to them: please find out more about ADHD, help them to build up their self-esteem and to develop their potentials. (Our boys’ self-esteem was crushed in their old school)"

"Jack was diagnosed at six and a half and I feel that his teachers have been a big influence and help"

"Class Teacher - Be patient, be fair. Understand it’s not rudeness, they can be a lot of fun and extremely interesting given a chance"

"I would like someone to spend 5 minutes with the headteacher at my son’s school as he doesn’t have a clue!!!"

"I would get the whole Education department and heads of teacher training colleges to see Jerry Mills lecture and ask them to adjust the way they train teachers. I honestly feel at the present time that systems are so corrupt and everyone is so anxious about their jobs no one is prepared to stand up and the bottom line is it all comes down to money, but what a sad indictment of our times, but who could I say this too?"

Named Celebrities

"To Billy Connolly or Richard Branson - To talk about how they cope with ADHD-support strategies and persuade them to become ambassadors for ADHD"

"Richard Branson - That as a high profile successful likeable man who did not "achieve" at school who could inspire and restore hope to young people who struggle with ADHD. He could also create a more positive viewpoint of ADHD to the public in general"

"Robbie Williams or Billy Connolly - Talk about ADHD and your fortunate lives, your failures and your successes and how you came through"

Additional written pleas

"Consistency across all authorities"

"Consistency in education"

"Consistent training in education"

"More awareness in schools"

"Fostering and adoption - Having adopted my children from the age of 5 and 7 we are still struggling to obtain the support and help they require"

"To everyone - Listen to what we are telling you and take the appropriate action that will benefit all ADHD people without passing the buck!"

3. Outputs from consultation groups

The delegates were split into five groups, chosen through self-selection. These were:

| | | | | |
|--|---|---|--|---|
| Under 12 years | Under 12 years | Under 12 years | Adolescents (under 17 years) | Young adults (18 – 25 years) |
| Facilitator: Dr Gillian Baird <i>Consultant Developmental Paediatrician</i> | Facilitator: Liz Miller <i>Social Worker & ADHD Project Leader</i> | Facilitator: Dr David Coghill <i>Consultant & Lecturer in Child and Adult Psychiatry</i> | Facilitator: Fintan O’Regan <i>Education Consultant</i> | Facilitator: Pippa Weitz <i>Teacher & Education Consultant</i> |

Each group worked together for four sessions spread over the two days and considered the following areas:

| | |
|----------------------------|---|
| Health Services | Issues around diagnosis and treatment e.g. prescribing under 6 yrs; is there a place for alternative therapies; role of diet; did their children get offered therapy before medication? What type, did it help? Attitudes of GPs What kind of written information were they offered about both ADHD and the treatment options? Waiting times and referral routes |
| Social Services | Do local Social Services departments recognise ADHD as a disability – identify differences in geography. Any learning? Experiences of concerns of child abuse |
| Education | Good experiences – why? Any differences in the approach taken with ADHD children in the same family? Improvements in children’s abilities as a result of treatment – whether medication or other Examples of support from other parents through the school environment |
| Adult Services | Experiences – what would parents advice be to other parents whose child is due to be transferred to adult services? Experiences with employers, further education providers |
| Young Offenders | Experiences of children being apprehended and / or charged with offences such as anti-social behaviour. How did the police handle the situation when informed of child’s condition? Good experiences – why? |
| Media / Information | Media issues – impact of local and national coverage. Have parents been alarmed by things they have read – what did they do? Who did they talk to? In general, where do parents go to get the information they need? |

The facilitators led the groups to examine the issues underpinning these themes, to suggest solutions and focus on the key actions that should be tackled first, and who should be involved. The groups considered the national policy level, but also captured the good ideas parents had for local ‘hands-on’ solutions, and examples of ‘best practice’.

EDUCATION

"The classrooms with the most behaviour problems are the ones where the teacher sees ‘off-task’, inattentive or disruptive children as problem children instead of children with problems that haven’t been addressed" (Unattributed)

| The Gaps | |
|---|--|
| Training on ADHD for educators, teachers and all associated school staff | Education authorities do not recognise ADHD as genuine condition |
| Schools should be ‘ADHD friendly’ – everyone has responsibility from head teacher, through all staff and pupils | Inclusion should mean inclusion |
| Children lack information to help them understand their own condition; and that of their peers | Information for parents (services, treatment and support available) |
| Statemnting process is complex, and is not implemented or policed effectively within the Code of Practice | Child’s statement funding not used well or appropriately. Should be used for the child |
| Parents need more open access to schools; poor communication prevents parents getting involved | Need early intervention (before crisis) |
| Need differentiation of teaching styles | College / University systems are inconsistent, support is patchy |
| Lack of consistency in implementation of policies | |

Suggested Solutions

- Smaller class sizes – supports the teacher and aids the child
 - Buddy system, particularly for transition between primary and secondary schools
 - Positive school reports
 - League tables – publish SEN results separately so that schools are not penalised
 - Give praise – operate a reward system in classroom i.e. computer use, monitoring tasks
 - Reduce number of subjects the child has to concentrate on. Break tasks down
 - Schools to provide nurture groups and ‘chill-out’ rooms
 - Out-of –school activities and safe play (including summer holidays) for children with ADHD and their siblings
 - Specialised key-worker to support the child/ families through the health/education/social care systems
- Schools to involve parents earlier and regularly e.g. shared diary. Parents should be free to call in
 - Parent-Partnerships for tribunals
 - Restorative justice
 - Review of statemnting process – streamline
- Things happening that don’t help

Use of blue tabard at break periods to indicate a challenging child.
Remember Charles Dickens and David Copperfield’s stepfather who hung a sign round his neck – "BEWARE – HE BITES"

HEALTH

| The Gaps | |
|---|--|
| Early age diagnosis essential | Diagnosis needs to be within 6 months of referral |
| Clinicians need more training – greater insight and awareness | Detailed multidisciplinary assessment to eliminate other reasons first |
| Poor communication between professionals | Lack of consistency between professionals e.g. some GPs will prescribe, others not |
| Information lacking on best treatment; including side effects of long term medication and complementary options | Specialists not providing details of support groups |
| Lack of respect for parents – often blamed as bad parents | Need to look at the whole child |
| Not adhering to national guidelines | Services are patchy for adults |
| Services need to grow with the individual | |
| Poor support for adults on medication who may use other drugs – legal issues | |

Suggested Solutions

- Trained Health Visitors to pick up possibility of ADHD at 3 year checks
 - More specific training for all health professionals – ensure parents are taken seriously
 - Detailed multidisciplinary assessments
- Directory of health professionals and their expertise (national and local)
 - Information for the child to help them understand why they are different
 - Support provided (by health service) immediately after diagnosis
 - Parent and sibling support groups
 - Adult volunteers to liaise and co-ordinate between all three services (key worker)
 - Options for alternative, supportive treatments such as anger management, behaviour therapy
 - Regular appointments – actively involving the child



Things happening that don’t help

Coming under Mental Health Services when reaching adulthood

SOCIAL SERVICES (SS)

The Gaps

| | |
|---|---|
| Help refused without diagnosis or if child not considered to be 'at risk' | Attitude often heavy handed and frightening to parents |
| Parents made to feel they are at fault – bad parents | Staff do not understand / accept ADHD |
| Parents believe SS staff do not care | Only seem to want to work with physically disabled children |
| Negative connotations in talking to Social Services – stigma | Only get involved at crisis level |
| Provide help only if asked for (not always given) | Patchy and limited support for ADHD adults |
| Respite care not offered – ADHD does not fit criteria | |

Suggested Solutions

- Wider criteria to include ADHD
 - Training for social workers, provided by support groups but government funded. Enable staff to be proactive rather than reactive
 - Directory of services – a resource pack
 - Wider family support i.e. for siblings and respite care
 - Supervised and safe holiday and play care – qualified support workers
 - Clearer legal definitions of ADHD for care orders etc
 - Out-of-school activities e.g. youth clubs, swimming, football
 - Consistency of benefits available – should be nationwide
 - Buddy system with qualified support workers
 - Closer working between SS and education to recognise that ADHD is a complex disability (thereby reduce conflict between diagnosis and services)
 - Drop-in centre and/or help line for advice, support
 - Support for fathers by other fathers in the same boat
- Social skills training for children with ADHD
 - Improved access to care teams, disability team
 - Outreach teams to provide respite
 - Provide clear information about where to go for adult services support when child leaves school

Things happening that don't help

Taking away support too early when families are beginning to cope

Poor transition from child to adult services

Inconsistency of services – when people move. Have to start again

ADULT SERVICES

The Gaps

| | |
|--|--|
| Negative image of ADHD prevents employers recognising how talented and diverse these individuals are | Connexions – too much waiting about |
| Job Centre Plus – needs more training and programmes to help screen for ADHD | Continuity of services for medication |
| | Poor information of services available |

Suggested Solutions

- Connexions – modern apprenticeships
- Tailor-made education to fit the child (before looking for work)
- Adopt British Dyslexia Association footprint for employment. Work with them
- Mentor support through employment. Help individual to decide on employment choices
- Support for self-employment options
- Adult buddy scheme
- Advocacy service
- Independent living skills training – with directory of support available
- Places of work to be ADHD friendly
- Foundation training course prior to release from prison
- Resettlement officers (to be assigned)

Things happening that don't help

Age limit on medication



4. Outputs from session on Youth Offending – Parents and the Police

It is noted that while the police response to these issues was given by representatives from the Lancashire Constabulary, suggested solutions could be adopted by any regional constabulary

- Parents want to see trained single points of contact for families – the police anticipate this to be provided by their Youth Involvement Officers
- Parents would welcome a voluntary database so that they could register their ADHD child to minimise problems should the child be apprehended. This needs operational staff to be trained on ADHD and how to relate to the individual.
- Parents were supportive of research being undertaken by the police that aims to assist young drivers with ADHD – to help them concentrate
- Parents really want an advice line – not felt to be the sole responsibility of the police service but as a partnership venture
- The police did not know of the ‘On Track’ scheme but confirmed that they would find out more
- A big learning point for the police was that team sports are ‘not on’ for ADHD children, they are too frustrating. Boxing and other very physical sports are best.
- Lancashire has a special pre-crime panel which enables them to spot children who may get into trouble – parents advised that this was good ADHD practice provided that the panel members understand ADHD and are aware of appropriate interventions
- They recognised that, as a service, they need to be more effective at sign-posting parents / carers towards support groups for ADHD
- **The Police noted that they need to take care with the move towards anti-social behaviour orders for ADHD sufferers as this places them ‘in the system’ perhaps too quickly with nowhere to go but the inevitable criminal breach**
- They recognised that they needed to be more effective in dealing with issues of ADHD in custody suites – are there lawful obligations that need to be administered more fully?

5. Examples of Best Practice: Parents want more like these!!

☺ Early and comprehensive support in Sheffield: Immediately after diagnosis, a 16 week course is provided; eight weeks of behaviour management and a further eight weeks of teaching the children with the specific aim of improving attention span.

☺ The Liverpool ADHD Project aims to provide accurate information on the different aspects of ADHD, and it has specially trained link workers that – through 1:1 and group work – empower families and build children’s self esteem. Parent groups are supported to liaise with local schools. The Project ensured that children were involved with the design of its work right from the start; it was set up in May 2002 as a partnership between Liverpool City Council and The Children’s Fund.

☺ Feltham Young Offenders Institute has developed a process to ensure that offenders with a previous diagnosis of ADHD are managed appropriately, including liaison with community professionals on release. Further, in instances of ‘problem behaviour’ in undiagnosed cases, staff are trained to refer the possibility of ADHD to an outreach team who meet weekly with a clinical psychologist.

☺ ADHD Working Group in Sefton, Merseyside where health and social care agencies are working together through better reciprocal communication

☺ The FACE programme in Merseyside works to tackle the issues of death and injury caused by children playing with fire. This tailored approach is directly with children over the age of five years, and jointly with parents for younger children.

☺ Parenting Skills:
A recent study¹⁴ of 100 children aged 5-12 on stimulant medication has shown that when parents and children attend classes together to help the child build better social and behavioural skills, the symptoms of ADHD are reduced.

☺ The Learning Skills Council recognises ADHD as a disability which needs funding.

Emerging Themes, Issues, Solutions and Responsibilities

| Main theme | Underlying Issues | Possible Solutions | Who and how |
|-----------------------------------|--|--|--|
| Training | Needs to be all school staff involved including dinner ladies/taxi drivers/escorts. ADHD awareness should be part of teacher training and inset days. Health, education, social care and police professionals should have specific training. | Lobby for specific training to be included in the NSF, Green Paper and NICE Guidelines. Talk directly to teachers and schools: provide training. Consultation with DFES. | Big role for ADDISS and local support groups. Lobby directly and via local MPs. Parents to drive action locally. Head teachers and local education chiefs. |
| Communication | Needs to be between all agencies. Problems when child transfers from primary to secondary school. Parents struggle with negative attitudes, have to fight to be understood. | One Stop Shop. Local co-ordinator (link-worker). Health working alongside education and social care. | Parents and agencies in partnership working. Children’s Trusts, Director of Children’s Services and the lead council members for children. |
| Early intervention | Need to inform health visitors and GPs. Early diagnosis and treatment vital for child’s development. Without diagnosis – no help comes. | Target: Max 6 month for diagnosis under NHS. Voluntary police database. | GPs advised of local consultant expert in ADHD through Primary Care Trusts. Balanced reporting in media. |
| Awareness | Wanting to be believed. Accusations of bad parenting & child abuse. Improve understanding. Getting positive media coverage. | Need positive role models and case studies. Different learning styles need different teaching methods. | Engage local and national media with positive stories as well as the issues for ADHD children (ADDIS and local groups). |
| Consistency | Across schools and from agency to agency. No national policy implementation (e.g. SEN code of practice). Dependent on individuals being interested. | Need local willingness to change. Incentives to change in new legislation? | Local Authorities. Parents can help drive local change (with support). |
| Information | What help is available locally? What are the treatment options? How can children help themselves? | National and Local Service Directory. | Children’s Information Services. Primary Care Trusts. ADDISS & local support groups. |
| Resourcing | In the right place and for the right things. Funding doesn’t follow the child. Right people with the right skills. | After school and holiday play. Full service extended schools. £ through CAMHS. Linked to training. | Local Authorities. Education Chiefs and head teachers; SENCOs. |
| Roles and Responsibilities | Helping children and families to help themselves. Focusing and co-ordination of support group activities. Agencies don’t adhere to policy. | Include rewards for learning. Partnership between parents, child and professionals. | Parents (with information and buddy support). ADDISS. |

References

1. National Institute for Clinical Excellence: *Guidance on the use of methylphenidate (Ritalin, Equasym) for ADHD in childhood* (Q&A document). December 2000

2. Green C and Chee K. *Understanding ADHD – A Parent’s Guide to Attention Deficit Hyperactivity Disorder in Children*. Vermillion Publishing 1997. ISBN 0 009 181700 5

3. American Psychiatric Association Press. *Diagnostic and Statistical Manual of Mental Disorders (DSM-IV)*. Washington (DC): The Press; 1994

4. National Statistics Report: *Children & Adolescents who try to harm or kill themselves*. 2001. London: The Stationery Office

5. Meltzer H et al (1999). *Mental Health of Children and Adolescents in Great Britain*. London: The Stationery Office

6. Meltzer H et al (2003). *Persistence, Onset, Risk Factors and Outcomes of Childhood Mental Disorders*. London: The Stationery Office

7. Audit Commission Report (1996). *Misspent Youth: Young People and Crime*. ISBN: 186 2400 75

8. Satterfield J H et al (1982). *A prospective study of delinquency in 110 adolescent boys with attention deficit disorder and 88 normal adolescent boys*. Am J Psychiatry. 139(6): 795-8

9. Satterfield J H and Schell A (1997). *A prospective study of hyperactive boys with conduct problems and normal boys: adolescent and adult criminality*. J Am Acad Child Adolesc Psychiatry. 36(12): 1726-35

10. Dale C and Storey L. *Nursing Praxis-care and Treatment of Offenders with a Learning Disability*. ISBN 1 903625 13 0

11. National Service Framework for Children, Department of Health. July 2003

12. National Institute for Clinical Excellence: Conduct Disorder in children, parent-training/education programmes (appraisal in progress)

13. *Every Child Matters*: Department for Education and Skills, September 2003

14. Tutty et al (2003) *Enhancing Behavioral and Social Skill Functioning in Children Newly Diagnosed with Attention-deficit Hyperactivity Disorder in a Pediatric Setting*. Journal of Developmental and Behavioral Pediatrics 24(1): 51-57

Patron

Lady Astor of Hever

Founder and Chief Executive

Mrs Andrea Bilbow

Trustees

Mrs Jenny Missen (Chairperson)
Mrs Kymm Farmer
Mrs Fiona Hill
Mrs Brigit Solomon
Mrs Jill Scott
Ms Phillipa Weitz

Professional Board

Professor Eric Taylor
Professor Peter Hill
Professor Paul Cooper
Dr Gillian Baird
Dr David Coghill
Dr Nikos Myttas

Education Director

Mr Fintan O'Regan

ADDISS

10 Station Road
Mill Hill
London
NW7 2JU

Tel: 020 89069068
Fax: 020 89590727

Email info@addiss.co.uk

Website www.addiss.co.uk

All enquiries related to this document should be directed to the Chief Executive

This document has been funded by an unrestricted educational grant from Eli Lilly and Company Limited.
The views contained herein are exclusively those of the parents who attended the conference with the context provided by the author and ADDISS.