ADHD is REAL
ADDiSS FAMILIES SURVEY

A study of over 500 families whose children have a diagnosis of ADHD

- 82% of children diagnosed were receiving treatment.
- 71% were receiving medication.

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FAMILIES HAVE THEIR SAY
The Survey

The ADDISS Families Survey was conducted by ADDISS in July and August 2006. Questionnaires were distributed by ADDISS to parents of children with ADHD who had called the helpline and also through the local affiliate groups and some NHS clinics. 526 responses were analysed on behalf of ADDISS by Branding Science in August 2006.

Key Learnings

ADDISS surveyed 500 parents of children with Attention Deficit Hyperactivity Disorder (ADHD) and 39% reported that their child had been ‘fixed term’ excluded from school as a result of their condition, with 11% excluded permanently. It is no surprise that the ADDISS Families Survey also found that a staggering 80% of parents questioned felt that their child with ADHD had low self-esteem compared to other children.
**Education**

Clearly coming through in the survey as one of the key issues affecting children with ADHD is education. Almost half of the children with ADHD surveyed had received a Statement of Educational Needs, with 92% of parents stating that their ADHD child’s ability to achieve at school was affected by their ADHD.

**Social Impact**

The survey results indicate that families with ADHD children often exist on the edge of society. Over half of the parents surveyed reported that their child’s ability to make friends was very affected by their ADHD, with even more children’s ability to keep friends being affected by their ADHD. Almost 20% of children with ADHD have been involved with the police.

- 39% excluded from school due to ADHD, 53% more than twice
- 19% of children with ADHD have been in trouble with the police due to their ADHD
- 92% of parents reported their children’s ability to achieve at school was affected by their ADHD, 65% severely affected.
- 45% had a Statement of Educational Needs (SEN)
- 80% of parents reported low self-esteem in their child compared to other children without ADHD.
- 83% said ADHD affected their child’s ability to make friends
- 84% said ADHD affected their child’s ability to keep friends
- 86% were not invited to parties or to visit friends
- 37% had more than one visit to A & E
A distressing picture of how ADHD can affect family life was painted by the parents of these children with ADHD. Almost two-thirds of the parents had divorced, separated or experienced marital distress due to their child’s ADHD. Almost 80% of families had been offered no help from Social Services, despite the fact that 15% of the parents had lost their job as a direct result of caring for their ADHD child, and almost half had been treated for depression due to dealing with ADHD in their family.

• Nearly two-thirds of parents had divorced, separated or experienced marital distress due to their child’s ADHD
• Nearly half had received treatment for depression as a result of their child’s ADHD
• 33% of parents were unable to seek employment as a result of their child’s ADHD. 15% of the parents questioned have lost a job as a result of dealing with ADHD in their family
• 80% were unable to take their children shopping or eat in restaurants
• 60% were unable to go on day trips or visit friends and family
LACK OF RESOURCES AND SUPPORT FOR CHILDREN WITH ADHD

Diagnosis

Over half of the parents surveyed did not receive any written information about ADHD or medical treatment options for ADHD when their child was diagnosed. Although for almost 80% of children a diagnosis took longer than 3 months from the time of referral, almost two-thirds of parents questioned were happy with the consultation process.

- More than 66% of parents had no access to a local ADHD clinic, nurse or ADHD advisory teacher
- Only 4% had access to an ADHD Advisory teacher
- 15% had access to a dedicated ADHD Nurse
- 23% had access to a dedicated ADHD Clinic

- Only 45% of parents were given written information for families dealing with ADHD when their child was diagnosed
- 79% of parents were offered no help from Social Services
- 7% offered respite
Treatment

Parents of children with ADHD have tried numerous different strategies, both medical and non-medical, to try and manage their child’s ADHD; from diet changes to exercise, behavioural therapy and prescription medication. However, half of the parents surveyed had not been offered a Parenting Programme as support, and over two-thirds of parents had no access to a specialist ADHD clinic, nurse or teacher.

- 89% of children’s performance at school had improved as a result of treatment
- 80% of children had improved relationships with other children as a result of treatment
- 84% of children had improved relationships with their teachers
- 89% of families reported an overall improvement in ‘quality of life’
- 79% of children had improved relationship with parents
POSITIVE IMPACT OF TREATMENT

- 78% of the parents surveyed tried diet change to manage their child’s ADHD, and 13% found these changes very helpful and 41% fairly helpful.

- 79% of parents surveyed tried fishoils of which 12% found them very helpful and 30% fairly helpful.

- 89% of parents who tried medication prescribed by their healthcare professional as a strategy (376 of the parents surveyed) found it was helpful in managing their child’s ADHD symptoms.
  - 57% found it ‘very helpful’
  - 32% fairly helpful

- Of the 239 parents who tried behavioural therapy for their ADHD child, 26% found it very helpful and 51% found it fairly helpful.

Of a total of 500 parents, 256 had tried exercise to manage their child’s ADHD symptoms. 28% of these parents found exercise very helpful and 30% fairly helpful.
The following therapies were offered to families in addition to medication:

- 46% of parents surveyed had been offered a Parenting Programme
- 25% Speech and language Therapy
- 17% Occupational Therapy
- 15% Anger management
- 11% Social Skills Training
- 7% Respite Care
Parents describe the way that they feel about the impact ADHD has on their child.

"That my son has a considerable ‘disability’ that affects every aspect of his life, sad that he cannot do lots of things that other children his age take for granted and are able to enjoy."

"I spent most of his school life defending and protecting him from people who had not the slightest idea how to treat my child and I was made to feel a bad person for doing this."

"At the moment it breaks my heart to see my little girl all alone at school."
Sad as he is getting older the gulf is getting wider with his peers and there are more and more limits on his life compared to them.

“I feel I have let him down. He should have been diagnosed earlier. It would have made a big difference to his school life.”

“Very sad that my son has lost out on a happier childhood; often he was so misunderstood.”

“Very sad that other peers turn their back on him, when they themselves do not understand why he is the way he is and is not explained to them by their parents, due to ignorance.”
Parents describe how they felt when their child was first diagnosed with ADHD.

“Relieved with the fact that it wasn’t my parenting skills because we all try hard with our children.”

“The diagnosis was like the missing piece of the jigsaw, everything just slotted together.”

“We were worried about his future and what ADHD would mean for him, past, present, future. We remain proud of him.”
Parents explain how misperceptions about ADHD have impacted on how other people view them.

“I feel angry when I read articles saying ADHD is not real and it is just bad parenting – some believe what they read in the press – fortunately I have a supportive family and friends.”

“I feel saddened by the negative publicity ADHD received. These children have a hard enough time without being given so much negative publicity – ‘what about positive role models with ADHD’?”

“People view that what they read is gospel – therefore they feel that ADHD is NOT real which makes me very angry!

I live with it every day!”
Parents of a child with ADHD explain the single thing that has made the most difference.

“"The whole point of my son’s success has not been a single thing – it has been medical, school, family and my son all working together."

“"My son with ADHD for trying his hardest!"

“"One of the most understanding teachers at school who saw him as a challenge rather than a nuisance."
Parents highlight the special things about their child with ADHD.

“He has successfully sat 10 G.C.S.E’s this year when we didn’t expect him to sit for one (passed or not – HE SAT FOR THEM).”

“Ability to get knocked down emotionally by peers and get back up again. (aged 12)"

“What they ARE is charming – what they DO is problematic.”