# ADHD in Irish Children Parent Survey

Nationwide Survey of 150 Irish Parents of ADHD diagnosed children.

#### Dear Parent,

In 2005, 150 parents of Attention Deficit Hyperactivity Disorder (ADHD), diagnosed children took part in a survey designed to better understand how parents currently manage their child with ADHD and how the condition impacts on the family and normal daily living.

We also wanted to better understand the unmet needs in treatment options. Currently children tend to receive treatment that covers the school day only, leaving a great need for morning, evening and bedtime cover therefore increasing the strain on the child and immediate family.

The survey was commissioned by ADHD Action, a multi-disciplinary group that includes consultants in child and adult psychiatry, consultant paediatricians, representatives from National Educational Psychological Services (NEPS), Irish Primary Principals Network (IPPN) and from the Hyperactivity and Attention Deficit Disorder Family Support Group (HADD).

The group's principle aim is to educate the public and healthcare professionals about ADHD in order to improve disorder awareness levels and to dispel the myths and stigmas whilst offering support to parents and families living with the condition.

On behalf of ADHD Action, I would like to thank those parents who participated in the survey.

Lastly, I hope you find the research results interesting and hopefully re-assuring on some level that other parents are dealing with similar issues in caring for a child with ADHD.

Professor Michael Fitzgerald Professor of Child Psychiatry, Trinity College Dublin & Chairman of ADHD Action

### The Core Symptoms of ADHD

The following describes briefly the core symptoms of ADHD. Associated behaviours of ADHD can be found on page five of this booklet.

#### Inattentiveness

Children with ADHD can be easily distracted, and will often flit from task to task. They do benefit from one-to-one supervision and when it comes to schoolwork they are very slow to complete it or they forget instructions. However, a child who is extremely inattentive while doing schoolwork may well be fully focused when playing video games or when being tested by a psychologist.

#### Impulsiveness

Most children with ADHD talk over the top of others, they tend to be accident prone, and have very short fuses. They answer questions in class even before the question has been completed. Although they act without malice they also act without forethought, which can lead to problems in the playground and the child being labelled aggressive or even getting suspended.

#### **Over-activity**

In primary school, children with zADHD are restless and fidgety, they have difficulty remaining seated and find it hard to stop talking. In the playground, they very often act like they have been released from captivity, and they find it even more difficult to settle back into class when they return. At secondary school, over-activity seems to have lessened. However, the children are generally still noisier and more talkative than their peers. Over-activity combined with impulsiveness can make managing these children very difficult.

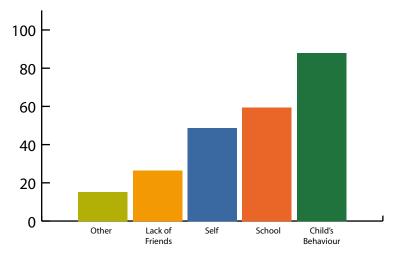
## ADHD Diagnosis

- On average, children included in the study feedback, were 12 years of age
- On average parents first noticed some difficulty at the age of four
- The average age of diagnosis is eight years
- Although there are variances, on average there is a four year lag time between parents considering some difficulty to achieving actual diagnosis
- 87% of parents said their child's behaviour brought ADHD to their attention, with 60% mentioning schools
- 54% of parents had managed to achieve a diagnosis for their child locally, the remainder had to seek diagnosis outside of their area or they were referred to a central hospital

That he can cope in school with education and with making and keeping friends

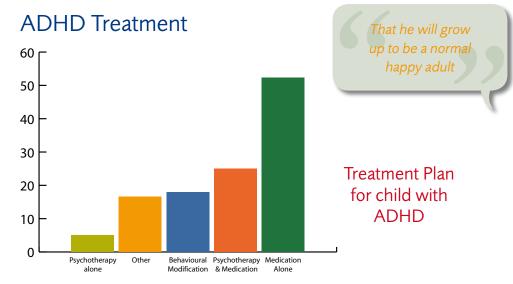
- Parents are more likely to go to their GP first, with 53% seeking a diagnosis from their GP
- Half of parents needed more than one visit to a healthcare professional (average five) before their child was diagnosed
- Access to Private Specialist care was achieved in less than four weeks for approximately 55% of those seeking it. Four-week access to Public Specialist care was only achieved in 13% of cases with 26% waiting one year for public access
- There was a great variance in approach & advice given to parents

## What brought ADHD to parents attention?



# Has your child been diagnosed with another condition?

- 75% of parents whose children had been diagnosed with ADHD stated that their child had been diagnosed with another condition
- 18% of ADHD children were diagnosed with a general learning disorder, 21% were diagnosed with a conduct disorder and 33% with ODD
- Other conditions include anxiety, autism and Tourettes Syndrome



- 38% of parents agree medication always calms the child, 47% saying it often helps the child pay attention
- 35% say medication always helps the child to be better at school while 43% maintain it helps the child do better with the family
- Almost 50% of parents of ADHD children state that their child never has a break from medication during school holidays or at the weekends
- 73% of parents agree medication offers control of symptoms throughout the day
- When not on medication 87% of parents often or always claim their child's symptoms impact on family functioning and their children have difficulty playing with siblings or friends
- In contrast, research shows that there is a significant difference when the child is on medication, facilitating more 'normal' daily functioning which allows the child to perform tasks and hence play and learn with family and friends

## Impact on Family

- 83% of parents stated they often or always got stressed with their child's condition
- Parent and advocacy groups were sited as the best source of information and the greatest help with 75% in agreement, the internet was next at 48%



- Education and life milestones are the most common root for concern amongst parents.
  The child's unhappiness, lack of friends, aggressiveness and if they'll lead a normal life and be happy are all questions parents were worried about
- On reaction to a diagnosis of ADHD, responses ranged from relief to devastation for both parents and child

# Functioning for children with ADHD not on medication

- 69% had difficulty getting ready in morning
- 85% had difficulty with tasks early afternoon and/or early evening
- 58% had difficulty falling asleep
- 79% had symptoms which impacted on family

To live his life to his full potential and have all the same oportunites as any person without ADHD

# Side Effects

As with all medications, those available for the treatment of ADHD can cause side effects in some children. Some of the more common side effects of ADHD medication include lack of appetite, insomnia and sleep disturbance. The majority of these side effects became transient over time.

## Schools Impact and Influence

- Research shows a mixed response from parent's on their views of school and its approach to ADHD
- Overall there is a view that with limited resources schools do what they can
- In conjunction with social and family functioning, education is of great concern for parents with ADHD children
- Dreadful, but I always knew something wasn't quite right. Aunts, uncles and grandparents always thought he was a bold child and they don't have much time for him.

If my child has a

- 75% of parents of ADHD diagnosed children state that medication has helped their child do better at school
- 47% of parents agree that teachers really help their child out
- 19% of parents feel that the school doesn't give the child the help that is needed

Happy to know I wasn't the only parent in the same situation. Good to know there is medication available

# Improved functioning for children with ADHD on medication

- 43% had difficulty getting ready in morning
- 42% had difficulty with tasks early afternoon and/or early evening
- 37% had difficulty falling asleep
- 38% had symptoms which impacted on family

Glad to know it wasn't bad parenting that was causing him to behave this way

I finally knew what was wrong with my sons and could help them

### Associated Behaviours of ADHD

In addition to the three core behaviours, there is a cluster of behaviours associated with ADHD:

#### Persistence

Persistence is generally considered the most nerve-numbing behaviour of children with ADHD. Frequent interrogation and inflammation of situations can generate immense tension. It is often the case that children's persistence (combined with impulsiveness) causes the most stress to teachers and parents.

#### Social clumsiness / poor social skills / relationship problems

Social clumsiness causes children with ADHD to stand out in a crowd. They misread facial expressions, social clues and misinterpret the right behaviour required for a situation. They can act 'silly' in a group and "come on" too strong, often exhibiting over-demanding and bossy behaviour in one-on-one situations with friends. Children with ADHD have the capacity to make friends, but have great difficulty keeping them.

#### **Emotional Over-arousal**

Children with ADHD tend to experience the extremities of the emotional spectrum – they do not tend to get a bit cross or a bit frustrated, nor merely like people or things. Instead they love intensely, and experience great anger or frustration.

#### Hypersensitivity

Children with ADHD can be extremely sensitive to certain stimuli, showing strong aversions to certain fabrics, tastes, smells or textures. Some children react with discomfort to levels of sound and light that others find completely tolerable.

#### Variability

Children with ADHD can have dramatic mood swings, which vary considerably from day to day, with no obvious cause. This also applies to performance in school.

#### **Poor Co-ordination**

Occasionally poor co-ordination presents a major motor clumsiness e.g. riding a bike, catching a ball; but more often it presents a subtle difficulty in performing two or more actions at the one time such as handwriting. Most children with ADHD have very

untidy handwriting as a result of a combination of their difficulty with fine motor control, and with their impulsivity.

Hard news, but glad there was an answer for his behaviour

#### Disorganisation

Children with ADHD are unaware of the mess they create. At school, they are disorganised, they do not structure their work, they may have difficulty in starting work, and may be confused as to what is required of them. Books and notes are not brought home for homework, schoolbags are left on the bus and gym bags are constantly getting lost. In secondary school, having the right books and being in the right classroom at the same time is a particular problem.

#### **Poor time management**

Children with ADHD have a very poor sense of time. As a result, they regularly need support to help them achieve targets. They regularly procrastinate and find it hard to get tasks started. They have great difficulty in completing assignments in the time available. In exams, they spend too long on one question and do not have time to finish, and often do not even tackle the other questions.

#### **Specific learning difficulties**

Many children with ADHD will have significant weaknesses in certain academic areas, such as reading, comprehension –oral and written, writing, spelling, language or mathematics.

#### **Motivation difficulties**

Children with ADHD find it hard to focus on tasks which do not grab their attention. They simply do not have the self-regulation that other children have to apply themselves to tedious tasks. They may develop an antipathy to school and lack the motivation to try and overcome their difficulties.

#### Low self-esteem

While children with ADHD can appear to have high self-esteem, many of them are exceptionally sensitive, and their self-esteem can suffer greatly. This is because they typically experience failure, and are at the receiving end of frequent negative feedback, despite putting effort into schoolwork. They want to be popular but are often treated like annoying outcasts and their co-ordination difficulties can leave them on the sidelines in team sports.

Low self esteem can become a significant problem for the child as he gets older, and can have implications on the rest of their lives.

#### Stubbornness

Children with ADHD frequently express opinions and views that are non-negotiable to them. If they believe black is white then nothing will change their opinion. Producing concrete evidence will often not sway them in their convictions. At another point in time, they may hold an opposing view just as firmly.

#### Local Support Groups

Group	Contact Name	Phone
HADD (All-Ireland support group)	Stephanie Mahony	01 8748 349
ADHD Midwest Support Committee Limited (Limerick)	Betty Downes	061 312621
ADHD Parents Support Group NYP Neighbourhood Youth Project (Blanchardstown)	Moira Hyland-Doyle	01 820 5253
Ballyfermot ADHD Support Group	Michelle Hayes	01 623 4829
CLADDA (Clare)	Miriam Donnellan	065 6839827 or 087 6610534
Drogheda ADHD	Geraldine Lennon	041 9846614
Finglas/Cabra Partnership	Pauline Hazel	01 868 3806 or 087 9700034
Galway ADHD	Rose Kavanagh	091 798266
HADD Child & Family Group (Cork)	Joe Jeffers	021 4515032
Mayo ADHD	Stephanie Joyce	087 9572311
Meath ADHD Support Group	Anne O'Dwyer	086 1568209
NIADD Support Centre (Belfast)	Sarah Salters	048 90200110
North Fingal ADHD Parents and Adults Support Group		01 802 0484 085 1448600
South Tipperary ADHD Support Group	Susan Long	052 29529
The Association for IADD (Co. Donegal)	Sara Anderson	086 2545669
TRADDS (Kerry)	Michael Kelly	066 7128789

#### Notes:

1. Research Company: Lewis Grant

Cohort: Postal Survey of 150 parents of ADHD diagnosed children. Research Date: Questionnaires were dispatched throughout November and December 2004. Replies were received up to February 2005

- 2. ADHD ACTION is a multi disciplinary group whose principle aim is to educate the public and health professionals about ADHD. It hopes to dispel myths and stigmas attached to ADHD and offer support to parents and families living with the condition. The group is chaired by Professor Michael Fitzgerald, Professor of Child Psychiatry, Trinity College Dublin and includes the following members:
  - Dr Eddie McGrath, Consultant Paediatrician, South Tipperary General Hospital
  - Dr Amanda Burke, Child Psychiatrist, Child Guidance, Roscommon
  - Stephanie Mahony, Hyperactivity & Attention Deficit Disorder Family Support Group (HADD)
  - Siobhán Cartúir, Irish Primary Principals Network (IPPN)
  - Anne O'Leary, National Educational Psychological Service (NEPS)

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