



WITHOUT BOUNDARIES

CHALLENGES AND HOPES FOR LIVING WITH ADHD:
AN INTERNATIONAL SURVEY



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1 Without Boundaries

The World Federation for Mental Health (WFMH) is committed to heightening public awareness of mental health and to improving understanding and acceptance of mental health disorders. *Without Boundaries* seeks to address this need for families living with Attention-Deficit Hyperactivity Disorder (ADHD).

ADHD knows no boundaries and the prevalence of the disorder is consistent across countries. It is a chronic condition that requires long-term treatment and, if left untreated, can severely impact the life of the individual as well as their family, friends and society. Although inroads have been made to improve the management of this condition, there is still a great way to go in many countries to ensure that consistently well managed diagnosis and treatment programmes are in place to help people whose lives are affected.

Conducted in partnership with ADHD expert Dr. Russell Barkley, the *Without Boundaries* survey examined the impact of ADHD on individuals and families to identify strengths and weaknesses in the diagnosis and management of the disorder internationally. In contrast to much of the ADHD research conducted at an international level, our survey was undertaken from the parent's perspective.

The results of this research show how each of us can make a difference in the lives of those with ADHD.

Parents of children with ADHD have a very tough time and often face barriers to seeking medical advice. With accurate information, parents are empowered to demand appropriate medical attention from healthcare professionals. Patient groups, such as the ones involved in this survey, and The World Federation for Mental Health can provide practical advice and assistance to parents.

Healthcare professionals need to be better at listening to parents' concerns and to be open to the possibility of ADHD. Children need to be

referred for thorough evaluation and diagnosis as early as possible to minimise the disorder's impact.

Governments have to recognise and place ADHD on their national health agenda to ensure that children have timely access to care. Similarly, educators must work together with parents to ensure that children receive the care they need.

The media have a responsibility to reverse the myths that surround ADHD and ensure that accurate facts are presented to their audiences. The media can play a vital role by creating awareness of ADHD and the impairment it can cause the child, their family, and society in general, if unmanaged.

There is a great need to raise **public** awareness and understanding of ADHD to help combat the prejudices families face.

Both children with ADHD and their families need your help.



Preston J. Garrison

Secretary General and Chief Executive Officer,
World Federation for Mental Health



Dr. Russell Barkley

Professor of Psychiatry,
Medical University of South Carolina, USA



2 Family Impact

Survey methodology: a total of 938 interviews with parents of children with ADHD were conducted in Australia, Canada, Germany, Italy, Mexico, Netherlands, Spain, the United Kingdom, and the United States. The majority of interviews were conducted using CATI (Computer-Aided Telephone Interviewing). On-line interviews were completed in Canada.

ADHD Defined

ADHD is a neurobiological disorder attributed to a developmental delay in brain circuitry impacting inhibition and self control. Inattention, hyperactivity and impulsivity are the key symptoms. For example, a child with ADHD is easily distracted, finds it difficult to complete tasks and has difficulty returning to the task, if distracted. He or she may also act impulsively, move and speak rapidly and excessively, and may often respond or act inappropriately, without thinking.¹

ADHD is highly hereditary.¹ Numerous studies have indicated that the heritability of ADHD is similar to that of height.² Interestingly, our survey found that two-thirds of parents (69%) recognised ADHD symptoms in themselves or their partner, with this figure highest in Germany (84%) and lowest in the US (56%).³ Sharing these symptoms may make it all the more challenging for a parent to raise a child with ADHD.

"You cannot run a smooth household. Every day is a struggle, since there's no reasoning with her. You never relax because you don't know what's going to happen next. It's like living with a toddler again."

Eva* – Spain

Family Impact

Parents across all countries surveyed were concerned by the disorder, with the majority of parents (88%) admitting to being stressed or worried about their child's ADHD. In Spain, almost every parent (98%) echoed these concerns.³ This overarching worry relates to nearly every facet of their child's life.

Specifically, a large portion of parents reported that they found it difficult to go places with their child (43%); experienced difficulties finding a babysitter (46%); felt uncomfortable inviting friends and family to their home because of their child's symptoms (32%) and that their child frequently caused trouble with others in the neighbourhood (37%).³

"He can be very loving but very nasty as well. He is a twin. His sister feels neglected because of his tantrums, and I feel like a failure, fighting a losing battle. My husband just disappears when it comes to confrontation."

Lina – Netherlands

"The family is dysfunctional. The mood of the child affects the family because you're not sure how he's going to walk into the room when he wakes up in the morning. We live on the edge."

Elena – Italy

The resulting strain on families living with a child with ADHD can be significant. Half of parents believed their marriage had been negatively affected by their child's symptoms, rising to two thirds (65% and 61%) in the UK and Australia.³ Among parents who recognised symptoms in themselves or their partner, this figure was even higher in all countries except the Netherlands.

"The relationship with his father has broken down. We've now split because my ex-husband could not cope with his condition."

Christina – Spain

"He stands between you and your partner. All family life is controlled by him. He has a very demanding and dominating presence..."

Anke – Netherlands

*Parents' names have been changed to respect privacy

“This important international report on ADHD not only underscores the fact that ADHD is universal in nature, but just as important, that it produces a pervasive, adverse impact on many domains of major life activities over the child’s development into adulthood.”

Dr. Russell Barkley – Professor of Psychiatry, Medical University of South Carolina, USA

Impact at School

School life, both academically and socially, was a key area of concern for parents. A majority of parents (87%) worried that their child’s ADHD would threaten his or her academic success. Up to 70 – 80% of children with ADHD are likely to continue to display symptoms into adolescence⁴ and the concerns of parents for their child continue beyond the school years. Many parents (83%) worried that their child’s ADHD symptoms would limit his or her future career. Long-term fears for their child ranged from almost universal in the UK (94%) to 74% in the US, where there is a greater level of awareness and treatment of the disorder.³

Studies confirm the fears of many parents. If untreated, children and adolescents with ADHD are less likely to complete high school, further their education or remain employed, but are far more likely to be involved in drug abuse, and traffic accidents.⁴

As much of a child’s time is spent in school, there is a certain amount of responsibility placed on teachers for recognising and managing ADHD. Therefore, it is important that parents collaborate and partner with teachers to ensure the child’s ADHD is correctly managed and that appropriate support services are made available for the child.

“It’s hard for my 16 year old to concentrate in the classroom and he is unable to sit and do anything. For us as parents, we get constant complaints from his school regarding his attention problem.”

Marilyn – Canada

Social Impact

The impact of ADHD is not confined to the child and success at school – it can touch all members of a family and their daily activities. The majority of parents (60%) reported that family life had been disrupted by their child’s ADHD symptoms, with parents in the UK expressing the greatest concern (89%). Many parents (57%) claimed their child had been excluded from social activities as a result of their ADHD symptoms, with parents in Mexico (77%) and the UK (70%) expressing the greatest concern.³ Exclusion at a young age can have a long-lasting impact on a child’s self esteem. Research in the US suggests more than 50% of children with ADHD have poor peer relations.⁴

“For my son our major concern is for him to be accepted at school, because in the past he has been rejected by his classmates and teachers.”

Juan – Mexico

“His behaviour makes it hard for him to conform. He doesn’t fit into a crowd because he’s always doing silly things. People don’t want their children playing with mine. The greatest problem for us is to try to improve his self-esteem.”

Susan – Australia

3 Delay to Diagnosis

Diagnosis – An International Issue

ADHD is not restricted by geographical boundaries. Regardless of cultural backgrounds, ADHD has a prevalence of 3 – 7% of school-aged children.¹ Research has shown that the prevalence rate of ADHD is consistent across the world.⁵ However, the pathway to diagnosis in different countries varies greatly, and discrepancies in diagnosis can be linked to local attitudes about mental health.

Delay in Diagnosis

Our survey found the average length of time from first physician visit to diagnosis by a specialist was just under 2 years overall, rising to an average of just over 3 years in Italy. Time to diagnosis was shortest in the US, where it averaged at just under 1 year.³ As our survey interviewed primarily parents who were active members of advocacy organizations and whose children had already received a formal diagnosis of ADHD, we are aware that the true length of time to diagnosis may well be longer. Two or three years is a very long time during a child's formative development, when their self-esteem and education may be severely compromised. While some children were diagnosed in as little as 3 months, others took more than 5 years before receiving diagnosis and treatment.³

"Everything came together after the diagnosis. It gave us a lot of peace."

Marten – The Netherlands

Diagnosis Around the World

ADHD can be effectively diagnosed and treated, but the diagnosis should be performed by a specialist or a physician with appropriate knowledge and experience with behavioural disorders. There are no physical tests for ADHD, although Magnetic Resonance Imaging (MRI) studies have found differences in brain structure between ADHD patients and individuals who do not have the disorder.⁶

Doctors will use one of two criteria to diagnose ADHD: the American Psychiatric Association's DSM-IV-TR¹ and the World Health Organization's ICD-10.⁷ Although similar, ICD-10 is used to diagnose the more narrowly defined 'hyperkinetic disorder,' not identifying children who experience the distinct inattentive or hyperactive/impulsive subtypes of the disorder as defined by DSM-IV-TR.

Both the DSM-IV-TR and the ICD-10 criteria stipulate that:

- Individuals have their ADHD symptoms for at least six months
- Symptoms have developed to a degree that is not normal for the child's age
- Symptoms have developed before the age of seven
- They occur in more than one setting (ie home and school)

When diagnosing ADHD, it is also important to ensure that other possible causes for the child's behaviour are considered. ADHD is frequently confused with other conditions such as Asperger's Syndrome, depression and anxiety⁸ – or it may occur in conjunction with these or other disorders. Our survey reflected this, with nearly a third of parents (31%) reporting that their child was initially diagnosed with a different condition. This problem was particularly acute in Mexico (53%) and in Italy (44%), where almost half of the parents originally received a different diagnosis for their child.³

"He was diagnosed at five as having epilepsy. Later someone else questioned the medication and confirmed he didn't have it. We've had to pay privately for the correct diagnosis."

Lucy – UK

“In Germany, diagnosis and treatment of ADHD has improved in the last few years. Awareness of the disorder has grown and paediatricians have shown an increasing open-mindedness towards the disease. However, the current diagnosis process still leaves a lot to be desired. Early symptoms of ADHD are still disregarded by some doctors and as a consequence, children are diagnosed too late. Cooperation between teachers and the circle of experts, which is the key for an early diagnosis and successful treatment, barely exists. Parents still have difficulties finding support and advice.”

Barbara Högl – Chairperson of BV AÜK e.V. (Bundesverband Arbeitskreis Überaktives Kind e.V.), Germany

Healthcare Professional Awareness

National protocols exist to guide healthcare professionals on ADHD,^{1,9,10,11} yet parents overall (59%) were dissatisfied with their primary care doctor's level of ADHD knowledge. For instance, only 7% of parents in Italy were satisfied with their family doctor's awareness of ADHD, with 13% satisfied in Mexico and 17% in the UK. This finding may help to explain the long delay in diagnosis. Additionally, nearly a third of parents (31%) reported difficulties securing a specialist referral, rising to half of parents in Mexico (50%).³ Family physicians must be well informed to make an appropriate specialist referral, opening the door for access to care.

“It was very difficult at the beginning. He was just seen as a child with behavioural problems. In Mexico, the culture is very narrow-minded – they think that if you go to the psychologist you are mad, so we didn't want anyone to know that we were sending him to a psychologist.”

Frieda – Mexico

ADHD and Parenting

Like many mental health or behavioural disorders, stigma has often been associated with ADHD, perhaps discouraging some parents from seeking treatment. In our survey, most parents were not concerned about the potential for stigma, with only 18% of parents feeling uncomfortable visiting a specialist due to the stigma attached. While not an overriding issue, concern that their child would be ‘labelled’ was felt most acutely by parents in the UK (30%) and Mexico (35%).³

A diagnosis of ADHD is not only beneficial for the child; it can also provide parents with the reassurance that the child's behaviour is not a result of ‘bad parenting’. Overall, two-thirds of parents (62%) were satisfied with the process for diagnosing their child, with the majority of parents (84%) reporting they felt involved in the decision making for the child's diagnosis and treatment plan.³

“My son was not diagnosed until he was 10 years old, although we knew there was a problem from kindergarten. He was difficult and inattentive and he became very depressed – but our doctor did not recognise the disorder for a long time. I tried to learn about ADHD but there was limited information available which made it challenging for our family to provide our son with the help he needed.

As parents, it is very upsetting to know that we punished him for his behaviour when he was unable to control his actions because of the disorder.

Our younger daughter also has the disorder. As we knew more about ADHD she was diagnosed a great deal sooner and as a result has had a more positive experience than my son. I wish both of my children had been diagnosed early.”

Isabel Rubió – President of Fundacion ADANA, Barcelona, Spain

4 Challenging in Many Life Areas

“In Germany there are still articles that talk about ADHD being an invented disease. Those articles are frustrating to read as they demonstrate that there is still a lot to be done to change the current perception of ADHD. There has been a positive change during the last ten years – nonetheless parents still have to face animosity when they admit that their children receive medication or the children are criticised as being simply ill bred. What we need is a more pragmatic approach in dealing with ADHD: There is a child suffering from a neurobiological disease that needs an effective and safe treatment that can enable the child and their family to lead a largely normal life. We know that there are adequate treatment options that can provide that – so why not use them?”

Manfred Döpfner – Psychologist, University of Köln, Germany



Value of Treatment

Treatment for ADHD often involves a combination of approaches, including medication and behavioural and psychological therapies, alongside educational assistance. Parents found that treatment (including medication and/or psychological therapies) improved their child's concentration at school (85%), helped their child to better interact socially (75%), relieved pressure on the family (79%) and generally enabled their child to be a happier person (71%).³

“Medication has made an amazing difference. Without it, I doubt my husband and I would still be married, and I don't think I would be as close to my son. He's known as a good kid and is not disliked by the other children's parents.”

Lisa – Australia

Even with a more conservative approach to ADHD treatment in Europe, Australia and Latin America compared with North America, an overwhelming 92% of parents supported the view that children should be given the opportunity to receive medication for ADHD, with few national differences. In both the UK and US, 97% of parents supported access to ADHD medication. Even in Italy, where medication for ADHD just became available in 2004, 75% of Italian parents supported its use.³



Experience with Treatment

It is in the classroom – where students are expected to remain in their seat, work quietly and pay attention – where many children with ADHD have the greatest difficulties. These children frequently do not understand instructions and easily become distracted, failing to re-engage in their work once the distraction has passed. Coupled with frequent expulsions from the classroom for ‘bad behaviour,’ the child's education suffers and a downward spiral of ‘misbehaviour,’ poor marks, frustration, aggression and antisocial behaviour may develop.

Understandably, many parents may prioritise the educational benefits of symptom control for their child during the school day, sometimes sacrificing quality social and family time. However, parents reported that other times of day were just as challenging as school time in coping with their child's symptoms.

“The biggest challenge for my daughter is a social one. She is confrontational, speaking out impulsively. It causes great tension in the family. As a mother, I feel anguish and despair. I don't know how to give her the tools to get along with people and enjoy life.”

Maria – Mexico

“Diagnosis of ADHD and following specific therapy has changed the world for our youngest child and our whole family. At the age of seven, for the first time in his life, he could perceive and handle the world properly, and so experience it anew. A combination of medication and further therapeutic measures have led to an enormous improvement of his quality of life and they continue to do so to this very day. We the parents have also learned through seminars and training to accept the diagnosis, to deal with it properly and to put the recommended therapy effectively into practice. Through this, the family situation has improved.”

Monika Reif-Wittlich – Chairperson of JUVEMUS e.V., Germany

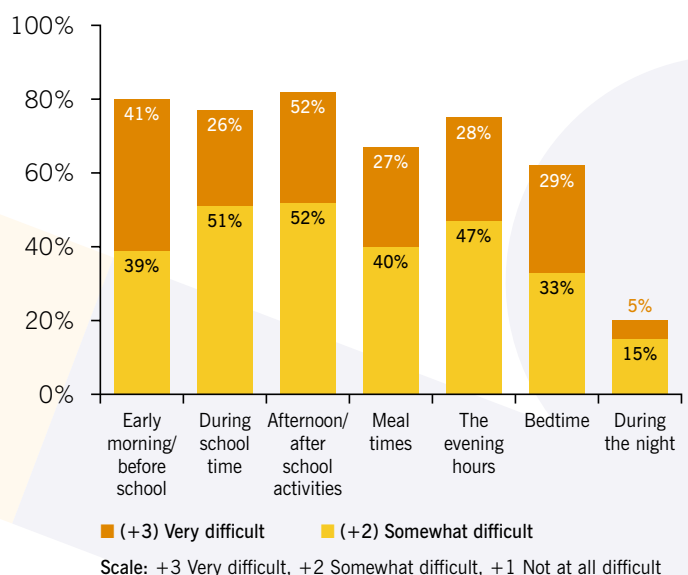
The vast majority (85%) of parents agreed that an ideal ADHD treatment would address symptoms throughout the day, with fewer than half (43%) reporting this to currently be the case. Specifically, parents reported that the treatment their child receives provides little or no control of symptoms at critical times of the day, notably early morning (42%), mealtimes (32%), evening (41%) and bedtime (42%). Looking at the level of difficulties parents experienced with their child, early mornings were significantly more difficult than other times of the day. From a parent’s perspective, school time and while the child slept at night were the only two periods of the day in which symptoms were adequately controlled.³

A deeper analysis of the data reveals that parents with older children (over 16 years) were more likely to rate school time and after school as very difficult, while parents of younger children with ADHD (less than 10 years) were more likely to rate meal times, evenings and bedtimes as very difficult.³

“In the evenings, everything falls apart. He picks on his little sister, argues with his older sister and won’t listen to his dad at all.”
Kate – Australia

Additionally, almost half (43%) of the parents surveyed would prefer not to give their child medication during the school day and a similar proportion of parents (46%) would prefer to give their child medication less frequently during the day. This was higher in Italy (63%) and Spain (67%); countries in which only short-acting stimulants (effective for 4 to 6 hours) are available, and lower in the US (27%) where a wider range of medications are prescribed.³

Difficulty coping with ADHD symptoms during the day and night³



“ADHD is a 24-hour condition, which places many restrictions on a child. Children not only learn at school, they learn at home, at after school clubs, at social events, on trips out with parents and through friends. If full-time symptom relief is available, then every child with ADHD should have the opportunity to experience an existence like their siblings and every other child. It is their right.”

Andrea Bilbow – Founder and Director of ADDISS
(The National Attention Deficit Disorder Information and Support Services), UK

5 Conclusion

“For us, at the ADHD Global Network (AGN), the message is very clear – ADHD has an enormous impact on families and parents need to take an active role in managing their child’s disorder, alongside physicians, counsellors and educators.

This survey demonstrates that ADHD associations around the world can very effectively help and support each other by sharing their experiences and building on the lessons learned.”

ADHD Global Network

If we listen to the parents who have successfully navigated the system and are now receiving support for their child, we realise what a long and difficult journey these families have had to make.

Parents in nine different countries have shared their stories about the impact of their children’s ADHD symptoms, on all aspects of family life. They have also told us about the positive difference that treatment can make. Parents recognise that ADHD is a full-time, long-term disorder and are right to demand rapid diagnosis and appropriate treatment to manage their child’s ADHD symptoms.

It is crucial that primary care physicians listen to parents, seriously consider the possibility of ADHD, and refer the child for possible diagnosis, when appropriate. Parents need to persist to find a doctor that they trust and who will listen to their concerns.

Internationally, guidelines recommend a multifaceted approach to ADHD treatment, including the use of behavioural and family therapy, educational support and medication where appropriate. Guidelines issued by the American Academy of Child and Adolescent Psychiatry (AACAP) in May 2004¹² recommend both long-acting stimulants and a non-stimulant option for ADHD as first-line medications as part of a comprehensive treatment program.

Treatment options and practices vary from country to country. Even with the improvements treatment brings, many parents still report being dissatisfied with the level of symptom control their children are receiving. Parents need to be active participants in their child’s ADHD treatment, considering all aspects of their child’s life that are touched by ADHD symptoms and discussing those with their child’s physician.

Parents can find a great deal of support from ADHD patient groups. National and regional groups exist in many countries worldwide, in addition to the recent formation of the ADHD Global Network. Typically run by parents of ADHD children, with the support of medical professionals, these groups deliver an invaluable service providing parents with support and guidance. Seek them out.

Finally, thank you to the twelve patient groups that worked with us on this survey and to each of the 938 parents who shared their very private experiences with us.

Preston J. Garrison

World Federation for Mental Health

6 Advice for Parents

Parenting a Child with ADHD

Parenting a child with ADHD, or any disability, can be overwhelming at times. All parents sometimes feel anger, fear, grief, frustration and fatigue while struggling to help their child. While no treatment can “cure” ADHD, the following tips can help you be the most effective parent possible for your child.

- 1 Seek up-to-date, scientifically supported information about ADHD.** There is a great deal of information available on the diagnosis and treatment of ADHD. It is up to the parent, with the help of the physician, to distinguish the “accurate” information from the “inaccurate.”
 - 2 Seek an early referral from your primary care physician.** If your primary care physician is unwilling or unable to discuss the disorder and treatment options, ask to see another physician, talk to your child's school or turn to patient groups for guidance on alternative points of entry.
 - 3 Seek a professional evaluation and treatment.** When first seeking a professional, ask questions related to the diagnosis and treatment of ADHD. What methods will they use to evaluate the child? Are they able to evaluate for co-existing conditions that are common to ADHD? Effective treatment involves the use of several therapies including an appropriate educational programme, behaviour modification, parent, child and teacher education, and sometimes counselling and medication. A thorough evaluation and assessment of your child's strengths and weaknesses will help you and members of your treatment team, your child's paediatrician, a psychologist and/or psychiatrist, and educators develop an appropriate and effective treatment plan.
 - 4 Seek parent training from a qualified mental health professional experienced in ADHD.** Being a parent of a child with ADHD can be frustrating and exhausting. You may find that approaches that work well with your other
- children do not work for your child with ADHD. Effective parent training will teach you strategies to change behaviours and improve your relationship with your child.
- 5 Seek support for yourself.** Parents can give each other information as well as support by attending local patient group meetings where available. The constant high level of parenting required can take a toll on even the very best parents. Seek marital counselling if necessary. Seek counselling if you begin to feel overwhelmed or defeated.
 - 6 Insist on regular update meetings with your physician** to ensure you and your child remain happy with the treatment plan and to allow medication and/or dosage to be monitored as your child grows. Keep a record of your child's behavioural patterns, a ‘weekly diary’ to support any concerns you may have when speaking with your physician about your child's progress. If you are unhappy with how your child's ADHD symptoms are being managed, seek a second opinion and turn to patient groups for advice. They will be able to guide you on when you should return to your child's physician/psychiatrist and are able to provide invaluable insight into alternative sources of information and support.
 - 7 Tell your child that you love and support him or her unconditionally.** There will be days when you may not believe this yourself. Those will be the days when it is even more important that you acknowledge the difficulties your child faces on a daily basis, and express your love. Let your child know that you will get through the smooth and rough times together.
- Adapted with permission from:
Parenting a Child with ADHD –
CHADD Fact Sheet #2
<http://www.chadd.org/fs/fs2.htm>

7 Further Information

For additional information about Without Boundaries and country-specific data, please visit the World Federation for Mental Health website: <http://www.wfmh.org>



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AIFA
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ADD Association, Queensland (ADDAQ)
<http://www.addaq.org.au>



AMDAH
<http://www.deficitdeatencion.org>



Balans
<http://www.balansdigitaal.nl>



Learning and Attentional Disorders Society (LADS)
<http://www.ladswa.com.au>



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<http://www.anshda.org>



ADANA Fundacion
<http://www.f-adana.org>



APNADAH
<http://www.tda-h.com/APNADAH.html>

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