


AD/HD
Time for Change

Belfast City Hall, 2nd Sept. 2015, lit up purple in support of those affected by AD/HD across NI

AD/HD MANIFESTO to the NI Assembly & Executive

ADD-NI

Children's Charity



***“Why does
no – one
care about
us?”***

Introduction

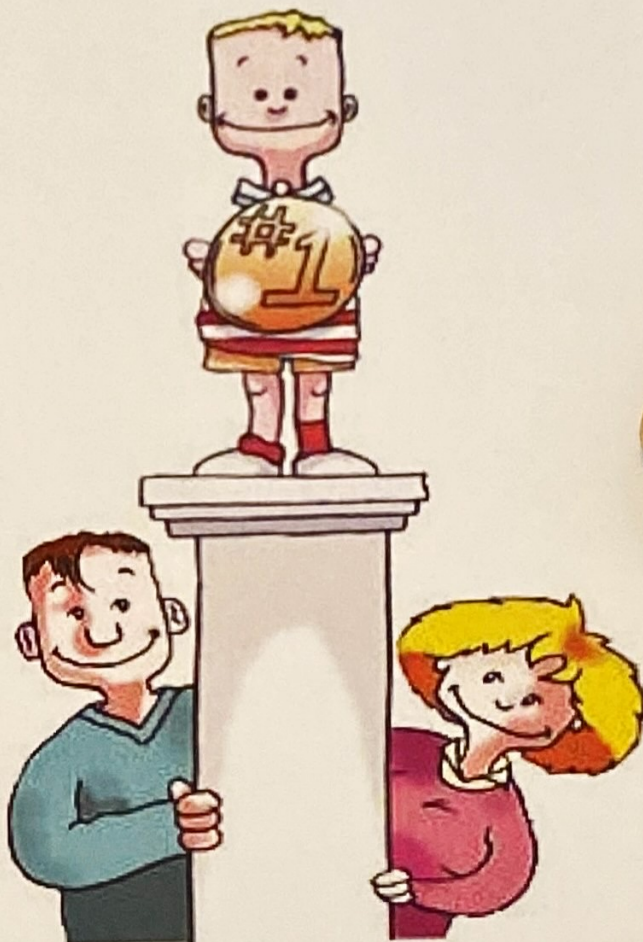
We are delighted to introduce the AD/HD Manifesto, 'Time for Change.'

The purpose of this document is to bring about change, alter perspectives and improve the quality of life for children, young people and adults affected by AD/HD in Northern Ireland.

AD/HD is a real and complex condition. Young people with AD/HD and their families are very often misrepresented and misunderstood; yet the human, societal and economic cost of untreated AD/HD is vast.

It is therefore time for the Assembly to stop ignoring these very important issues, to take notice, and to actively invest in organisations such as ADD-NI to support them to expand their delivery of services. Every political party should include a commitment in their party manifesto ensuring that all young people and their families, and adults affected by AD/HD have access to specifically tailored, evidence-based interventions that meet NICE Guidelines.

“There’s no condition on earth, other than AD/HD, where education on the condition is necessary before compassion is shown to the child.”





“People need to understand AD/HD, instead of judging us.”

What is ADHD?

Attention Deficit Hyperactivity Disorder (AD/HD) is an internationally recognised medical condition that is highly misunderstood and can have devastating consequences on a young person's life if left untreated.

Boys are six times more likely to be referred for help than girls. There have been many misconceptions surrounding what causes AD/HD. Research shows that it is a genetic condition.

Having AD/HD can be very difficult for the child to cope with. Equally, it can place significant stress on parents and siblings which impacts significantly on relationships within the family. Families affected by AD/HD often experience social isolation and stigma, which contributes to chronic family stress and can have damaging consequences on the family as a whole; "Ultimately, AD/HD has been associated with high levels of family conflict and poor family cohesion" (White Paper, 2013).



Whilst young people with AD/HD have immense strengths, they also experience isolation, struggle to cope and face mental health difficulties coupled with high stress levels on a daily basis.

It is very important that the child and family receive appropriate support and intervention to help them to cope with this condition effectively.

"You can't get rid of AD/HD, you learn to live with it."

The 3 core characteristics are:

Extreme impulsivity: Difficulty in thinking before acting

Excessive inattentiveness: Difficulty concentrating & easily distracted

Hyperactivity: Always on the go

The Forgotten Youth

"AD/HD occurs in approximately 10% of all school age children."

AD/HD can significantly interfere with everyday life and the ability to function on a daily basis. There are many associated features, which can include:

- Oppositional behaviours
- Poor school and academic performances
- Poor peer relationships
- Communication difficulties
- Aggressiveness
- Anxiety
- Mood related problems
- Emotional immaturity
- Poor self-esteem



"When you have AD/HD people think differently about you, even before they meet you"

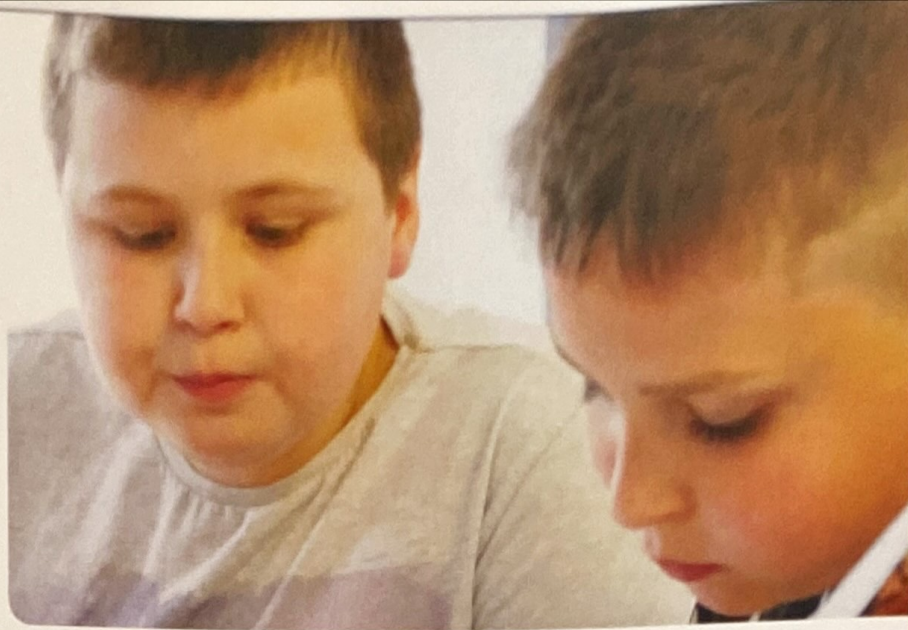


“People need to be aware that if they bombard me with information I won’t be able to understand or even hear”

KEY FACTS

1. AD/HD affects 1 in 10 school age children (CDC, 2010).
2. It accounts for over 50% of the paediatric and child psychiatry population (Cantwell, 1996).
3. There is a consistent lack of understanding about AD/HD in every aspect of the young person's life.
4. Families experience high levels of stress and mental ill-health due to the nature of AD/HD.
5. Families experience social exclusion as a result of intolerance and ignorance regarding AD/HD within the community.
6. AD/HD impacts on all areas of a young person's cognitive, emotional, and social development.
7. There is no co-ordination of pre/post diagnostic services across all Health Trusts in Northern Ireland.
8. There is a chronic lack of investment in young people with AD/HD and their families.
9. AD/HD is not just a childhood disorder; however, there are limited specialist services for adolescents post-18.
10. There are no co-ordinated, specialist services for adults with AD/HD.
11. There is an over-representation (up to 60%) of young people with AD/HD within the justice system.
12. AD/HD is not within the Autistic Spectrum.

*“You
don’t ever
grow out
of AD/HD”*



What young people want you to know about AD/HD:

- AD/HD is not because of poor parenting
- Sometimes you feel bad or left out because you have AD/HD
- It’s OK to have AD/HD
- Don’t pre-judge me
- People with AD/HD are sensitive and can be easily taken advantage of
- We need people to understand AD/HD across Northern Ireland
- We need to raise awareness of AD/HD across Northern Ireland
- More funding should be made available for services for young people with AD/HD
- Everyone with a diagnosis of AD/HD would benefit from coming to ADD-NI

**We are not
bad, lazy or
stupid.**

*“It’s unbelievable how angry you can get,
especially when people don’t understand”*

Children with AD/HD and their Rights

The rights of children with AD/HD are often overlooked, as a result of misunderstanding and public misconceptions.

Family support services for vulnerable families are enshrined within the Children Order and are viewed as being a valuable preventative service in order to act as an arrester of any further deterioration within the home situation and to bring about a tangible improvement of the home dynamics and well being for the child involved (Pinkerton, J. QUB, Belfast).

Families Matter Strategy focuses on "preventive and early intervention services to support parents at particular times of need and at particular stages in the development of their child" and enabling children to "reach their potential".

The Government's Change for Children programme focuses on the link between the "right kind of family support and the ability of children and young people to reach their full potential".

The Families Matter strategy; "We will promote integrated partnership working to develop & deliver appropriate, seamless services for families & children."

DUP Manifesto emphasizes enhanced resilience, greater coping skills and strategies.

Sinn Fein's Cherishing Childhood Strategy focuses on ego-enhancing and self-esteem building, helping young people and their families to identify their strengths and to achieve their full potential.



"You don't think before you do something and then you're in trouble"

The United Nations Convention on the Rights of the Child (UNCRC) outlines within the following articles issues needing urgently addressed to assist children and young people with AD/HD.

“I have to work twice as hard as everyone else.”

Article 17

Children have the right to reliable information from the mass media.

As the current negative portrayal and trivialization of AD/HD in the mass media are damaging to children & young people affected.

- **Article 29** - Education should develop each child's personality and talents to the full. The varied and unique learning styles of young people with AD/HD should be taken into account.

- **Article 31** - All children have a right to relax and play, and to join in a wide range of activities. Young people often are unfairly excluded from leisure activities within the community, due to lack of understanding and management of complex AD/HD behaviours.

- **Article 37** - Children who break the law should not be treated cruelly. The lack of understanding of professionals within the justice system, can often result in the cruel treatment of young people with AD/HD. Education within the justice system will safeguard the rights of these young people.

Article 23

Children who have any kind of disability should have special care and support so that they can lead full and independent lives.

This is especially the case for young people with AD/HD, who are often overlooked.

Article 28

Children have a right to an education. Discipline in schools should respect children's human dignity. The education system is often difficult for young people with AD/HD, discipline often involves isolating young people from peers and taking away free time. As a result many become disaffected from the education system at an early stage

“People who care know AD/HD's real – You aren't just a bad kid.”

The NI Executive's Duty to Children & Young People affected by AD/HD

This document sets out the key demands for the Northern Ireland Executive based on our experience, and evidence of the needs of children, young people and adults who are affected by AD/HD residing in Northern Ireland.

ADD-NI has used a rights based, bio-psycho-social approach in which to address these issues, which are the specific remit of government. Each is directed at the relevant government departments and is within their purview.

We will seek to work in partnership with the Assembly and the Executive to address the issues raised, and furthermore to articulate and represent the views of those individuals who live with AD/HD.



The Assembly's Duty

- Ensure the establishment of specific legislation enshrining the rights of young people with AD/HD within Northern Ireland.
- Establish an all-party group to address the needs of those affected by AD/HD within Northern Ireland by December 2015.
- Ensure that relevant research into specific areas of AD/HD is commissioned.
- Provide increased opportunities for people with AD/HD to influence the policies and programmes in Government including the delivery of this Strategy and the subsequent Action Plan.
- Improve interaction between all sectors to achieve the social inclusion of people with AD/HD, promoting better integration and acceptance within their community.
- Work effectively in partnership with representatives from all government departments to access awareness training, which will support the public and private sector in providing better quality and level of services to people with AD/HD, their families and carers.
- Increase awareness and understanding about AD/HD amongst the general population, promoting positive attitudes toward people with AD/HD, through the specific use of the Public Health Agency, along with PHA campaigns and conferences.

The Department of Health's Duty

- Promote the physical, psychological, emotional and overall wellbeing of those living with AD/HD, their families and carers.
- Enhance the commissioning and provision of health and social care services for those living with AD/HD throughout their lives, ensuring an early assessment and diagnosis process within a twelve week period for a child aged 4 years and upwards where the index of suspicion exists regarding the possible presence/existence of AD/HD.
- Enhance the present level of commissioning and the development of Tier 2/3 therapeutic, evidence based, psycho-education intervention programmes for children, young people and their families, throughout Northern Ireland.
- Ensure that children/young people with AD/HD and their families are provided with and have access to, effective and appropriate support, where required, to help them with the everyday challenges of family life.

“AD/HD has a good side & a bad side. There’s loads of positives but also loads of hard times.”



“People think you are not smart because you have AD/HD.”

- Transform the process of transitions for people with AD/HD within the health and social care sector. Promoting and ensuring a co-ordinated approach is adopted in planning and providing for transitional needs, programs and supports for people with AD/HD across their lifetime.
- There should be a transitions support service for young people post-18 years, working a person-centred and proactive way.
- Actively involve and engage young people in decision making and ensure their views are taken into account.

The Department of Education's Duty

- Ensure that children and young people with AD/HD receive a high quality, needs-led education, which fully prepares them for life and the world of work, enabling them to fulfil their potential.
- Ensure that education provisions develop each child's personality and talents to their full potential in accordance with UNCRC Article 29.
- Provide sufficient training to equip all teachers to meet the specific needs of young people with AD/HD in the school environment through, implementing mandatory initial training for student teachers, and also, further training for post qualified teachers on a two yearly basis as part of their continuing professional development.
- Increase the opportunities for children and young people with AD/HD to attain skills and qualifications through access to appropriate services, and the use of accommodations, training and lifelong learning opportunities, with access to all user support educational aids and technology,
- Develop systematic and sustained AD/HD specific programmes by Disability Services and Learning Support Services with young people with AD/HD as early as possible.
- Colleges of FE and Universities teaching and supporting staff should have continuous AD/HD awareness training and knowledge of interventions which support young people with AD/HD, making use of accommodations and learning support as necessary for the young person to achieve their full potential.



The Department of Justice's Duty

- To ensure there is an instatement of a mandatory AD/HD assessment for all young people who enter the youth justice system, from the age of 10 years.
- Ensure all young people within a custodial environment previously diagnosed with AD/HD have access to medical supports and are enabled to live full and independent lives, in conjunction with Article 23 of UNCRC.
- Ensure access to psycho-education interventions for all young people with a diagnosis of AD/HD within a custodial environment to aid rehabilitation and to address the high re-offending rates amongst this population.
- Make available early interventions for young people at risk of coming to the attention of the Police within the community and provided with diversionary programmes.
- Ensure that young people presenting to the Police at interview are provided with an appropriate adult to assist their understanding given their vulnerability in this setting. To also ensure that they fully understand and comprehend the process of custody and the legalities involved in this matter.

"Its not an excuse for my behaviour but it affects the bad choices I make."

- Ensure that training is provided to equip, probation officers and prison staff with the specific skills necessary to work with young people with AD/HD and understand the complexities of the condition and their different communication styles.
- To ensure the provision of awareness training for the judiciary, legal representatives and police service personnel, in relation to the need for skill acquisition in the appropriate handling of individuals affected by AD/HD.
- Ensure equality within the law for people with AD/HD, that they have access to justice and the right to live safely in their own community without fear or prejudice.

These lists are not exhaustive.



About ADD-NI

ADD-NI was established in 1997 as a support network for children, young people and the families of those affected by AD/HD. We provide a regional service, and are the lead organisation in Northern Ireland offering post-diagnostic, specialist, therapeutic services for the treatment and management of ADHD. These include support and psychotherapeutic intervention services to children, young people, adults, and families affected by AD/HD on a regional basis. We provide the following;

- Specialised Parenting Programmes to improve parent efficacy and mental health
- Children and Young people's Group Programmes
- Adult's Group Therapy
- Adolescent and Adult individual counselling
- Art Therapy
- Programmes for siblings of young people with AD/HD
- Post-Intervention Programme
- Specialist training for professionals

ADD-NI's therapeutic programmes give young people the opportunity to achieve their full potential by enabling them to better cope with the effects of AD/HD. Our programmes are tailored to empower families across Northern Ireland to improve their children's lives. ADD-NI's services are externally evaluated and fully comply with NICE Guidelines in the treatment of AD/HD.

For more information about AD/HD and the support we provide, please visit

www.addni.net or call our helpline on **028 90 200 110**.

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