



# THE CHANGING LIVES INITIATIVE



## INFORMATION KIT

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## **THE CHANGING LIVES INITIATIVE INTERVENTION PROGRAMME**

The Changing Lives Initiative is an early intervention programme to support families of children aged 3 to 7 years whose behaviour is consistent with Attention Deficit Hyperactivity Disorder (ADHD).

The Initiative consists of the following three stages:

1. An Information and Awareness programme.\*
2. A Screening Programme.
3. An intensive intervention in the form of the evidence-based ADHD focused Incredible Years Parent Training Programme.

\* The Changing Lives Initiative provides two types of Information and Awareness sessions. One is designed for parents/guardians (see below); the other for teachers and early years practitioners. The two-module Information and Awareness sessions for professionals provide information on ADHD and how it might present in children. They examine ADHD-related symptoms and learning problems, and introduce participants to techniques, interventions and strategies to enhance outcomes for children displaying behaviour consistent with ADHD in the classroom. In addition to providing practical approaches to benefit the individual child, the sessions also offer whole-of-class and whole-of-school strategies.

### **Information and Awareness Sessions (parents/guardians)**

These one-hour sessions are run in schools, libraries and other suitable venues. They provide parents/guardians with information on ADHD, what it is and is not, and what behaviours consistent with ADHD look like. They offer tips and strategies to manage the challenges of living with a child with ADHD-like behaviours. They also provide information about current research, treatment and interventions for ADHD.

### **Screening Programme**

If, after attending an Information and Awareness session, parents/guardians are concerned that their child might be displaying behaviour consistent with ADHD, they can choose to take part in the Screening Programme. Parents are asked to complete some standardised questionnaires about their child's conduct. If their responses indicate that they have a child who is displaying behaviour consistent with ADHD, they will be offered a place on The Changing Lives Initiative's Incredible Years Parent Programme.

The screening process is used solely to determine a family's suitability for The Changing Lives Initiative's Incredible Years Parent Programme. It does not in any way constitute a diagnosis or assessment. The results of the screening do not determine if a child would or would not get a diagnosis of ADHD if they were to be assessed by the appropriate professional(s).

Should screening indicate a family is not suitable for Incredible Years Parent Programme, the team will endeavour to help the family to access appropriate resources and services that may be available to them and their child.

## ADHD focused Incredible Years Parent Training Programme

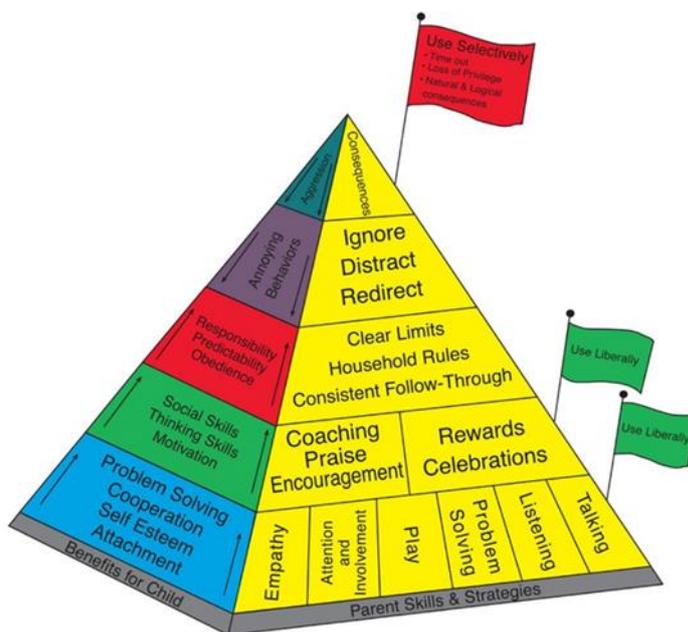
The ADHD-focused Incredible Years Programme is recognised internationally as a programme of choice for the early treatment and prevention of conduct disorders in childhood. It is designed to improve social and emotional functioning, and reduce or prevent emotional and behavioural problems.

Typically, it consists of 12 to 14 weekly sessions. However, The Changing Lives Initiative Incredible Years Parent Program consists of up to 20 weekly sessions to provide more time for participants to focus on improving their understanding of ADHD and practising the behaviour management skills they have learned.

Trained facilitators use video vignettes to structure the programme content and stimulate group discussions, problem solving and trigger practices related to participants' goals. Each session is of 2.5 hours duration.

The facilitators follow up the group sessions with a weekly phone to each participant. A buddying / WhatsApp system is also in place to provide ongoing peer-to-peer support.

The programme covers topics such as: Child Directed Play; Academic and Persistence Coaching; Social and Emotional Coaching; Praise, Encouragement and Reward; Effective Limit setting; Natural and Logical Consequences; Teaching Children to Problem Solve; Adult Problem solving and working with teachers and other professionals



**The Incredible Years**   
Parents, teachers, and children training series

## **WHAT IS ATTENTION DEFICIT HYPERACTIVITY DISORDER (ADHD) AND ITS IMPACT?**

Attention Deficit Hyperactivity Disorder (ADHD) is one of the most common disorders of childhood, estimated to affect 5.29% of children in Ireland and the UK.

ADHD is a chronic and debilitating behavioural disorder that is characterised by high levels of inattention, hyperactivity and impulsivity. Many children, of course, have difficulty concentrating, find it hard to sit still, or may act before they think. However, ADHD is a long-lasting neuro-developmental disorder that causes significant difficulties throughout many aspects of a child's life, including at home, at school and with friends.

It is important to stress that while some children may experience behaviours that are consistent with ADHD, this does not always mean they will go on to be diagnosed with ADHD. For a diagnosis of ADHD to be given, a child's behaviour must exhibit a pervasive pattern of inattention and hyperactivity, excessive restlessness, lack of sustained effort/attention and unusually high levels of movement and acting without thinking, across three different settings: home, school and community.

In recent times, there has been a significant increase in recognition of the disorder and a growing number of children are presenting with ADHD-type symptoms and subsequently being formally diagnosed with ADHD.

### **Treatment of ADHD**

Society's approach to the treatment of neurodevelopmental conditions generally has remained unchanged for the last 25 years. Medication is the most common intervention for children with ADHD. It has been estimated that approximately 85% of children with ADHD are prescribed psychostimulants (in particular, Ritalin).

Drug interventions do not in themselves reduce behavioural difficulties and peer problems; neither do they equip the child with social skills, bring about improvements in emotional regulation, improve family function, parent-child interactions, or parenting skills.

Drugs provide short-term relief of the symptoms of ADHD. They are effective in constraining the child's behaviour so s/he can engage with academic institutions. This means that outside of this singular domain the majority of the child's and family's lived experience is unaffected by current treatment regimes.

In contrast, The Changing Lives Initiative places the family and school at the heart of the intervention process and recognises the different spheres of a child's life. Leading mental health experts, including those at the National Institute of Clinical Excellence and the World Health Organisation, recommend psychosocial interventions such as parenting programmes as the first line of treatment for children with ADHD who are aged under five and their

families. Medication should only be used for children in that age group who have severe symptoms of ADHD and have not benefited from psychosocial treatment.

A number of evaluations have been conducted as part of The Changing Lives Initiative and these have added to the body of evidence demonstrating significantly improved outcomes for families from this type of intervention. These include, in particular, a significant reduction in ADHD-related behaviour reported in children, a reduction in other emotional and conduct problems, a significant increase in parental skills, and a reduction in parental stress.

The Changing Lives Initiative provides conclusive evidence that community-based, early intervention parenting programmes are not only viable and effective, but provide a preferred alternative to medication in managing ADHD-consistent behaviour.

### **Cost of ADHD**

Aside from the personal, family and community costs of ADHD, the treatment of ADHD places a significant burden on health, broader social and special educational services. For example, the 2010 National Institute of Clinical Excellence report on ADHD finds that the annual costs in the UK for treating ADHD amount to £66m, including £23m for specialist assessment, £14m for follow-up care, and a further £29m on prescribed psychostimulant medication.

The cost for ADHD medications in Northern Ireland alone for the 12-month period March 2019 – February 2020 was £3,462,711. The aggregate costs of ADHD in the UK have been estimated at around £102,135 per case.<sup>1</sup>

In Ireland some 90,000 prescriptions for ADHD medications were issued in 2019 at a cost of €5,143,915 according to data extracted from the HSE Primary Care Reimbursement Service (PCRS). By comparison, the cost of providing The Changing Lives Initiative programme per family is as little as €1,155 (costs range from €1,115 - €1,555 per family across the project locations as per results of The Changing Lives Initiative Economic Evaluation).

### **Long-term impacts of ADHD**

The majority of people diagnosed with ADHD in childhood continue with the disorder as adults. In a review of its adverse occupational effects, it was found that adults with ADHD had higher levels of unemployment compared to control groups. Even amongst those who managed to sustain employment, those with ADHD experienced greater levels of workplace impairment, reduced productivity and increased absenteeism. They were also more likely to experience workplace trauma, injuries and less social engagement in the workplace.

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<sup>1</sup> 2012/13 prices; Parsonage M. The Lifetime Costs of Attention Deficit Disorder. Centre for Mental Health (2014).

Other problems associated with adult ADHD include increased rates of substance abuse and criminality. Those with ADHD are more than twice as likely to have served prison time; next to anti-social personality disorder, ADHD is markedly higher amongst the prison population than the general population.

**Note:** *Further information about ADHD and related issues – together with academic references – is available in the [Project Report](#)*

## **THE CHANGING LIVES INITIATIVE – NORTHERN IRELAND**

The prevalence of ADHD has increased in all age groups and ethnicities over the last 20 years in Northern Ireland. Referral numbers have risen across all five Health and Social Care Trusts, with an over 25% increase in referrals over the two-year period 2016/17 to 2018/19

Treatment pathways and waiting times vary greatly across the Health and Social Care Trusts. Average waiting times for ADHD assessment in the South Eastern Trust, for example, ranged from 65 to 78 weeks in 2018/19. The estimated wait time in the Belfast Trust was 168 weeks (over 3 years) for the same period.

While national and international guidelines recommend high quality group-based parent programmes as the first course of treatment for young children with ADHD, these programmes are not currently available to many families in Northern Ireland. There are, therefore, limited treatment options offered to children with ADHD / queried ADHD and the focus in many instances is on pharmaceutical treatment.

It is clear that the limited availability of ADHD-focused parent programmes means that the principle of universal access - which underpins the provision of mental health services in Northern Ireland – is necessarily compromised.

Over the past three years, The Changing Lives Initiative has helped to address this anomaly. The Colin Neighbourhood Partnership, which delivers The Changing Lives Initiative in Belfast and Lisburn, has worked with more than 800 families with children displaying behaviour consistent with ADHD. Two hundred and fifty of these families have also benefited from the intensive ADHD-focused Incredible Years Parent Programme. A further 500 education, health and social care professionals have participated in The Changing Lives Initiative's Information and Awareness training workshops.

The Changing Lives Initiative has become embedded within the greater Belfast and Lisburn areas with a steady stream of families being referred from paediatric services, GPs, Family Support Hubs and other agencies.

### **The Changing Lives Initiative supports NI government policy**

The Changing Lives clearly aligns with key cross-cutting outcomes in Northern Ireland's draft Programme for Government, notably: 'We give our children and young people the best start in life'; 'We have a more equal society' ; 'We enjoy long, healthy, and active lives' and, 'We have more people working in better jobs'.

With increasing referral numbers, costs and waiting lists for mental health services in Northern Ireland, there is widespread agreement that a new approach is needed.

A core outcome of Northern Ireland's 'Making Life Better: A Whole System Strategic Framework for Public Health (2013-2023)' is to give 'every child the best start in life'. Through strengthened coordination and partnerships, the framework aims to create the conditions for individuals and communities to take control of their own lives, and move towards a vision of Northern Ireland where 'all people are enabled and supported in achieving their full health and wellbeing potential'.

The Changing Lives Initiative, through its early identification and intervention approach, is strongly aligned not only with the public health policy's core outcome to provide every child with the best start in life, but also other important objectives. These include, for example, the empowerment of communities (The Changing Lives Initiative is community-led) and strengthened collaboration (The Changing Lives Initiative involves a range of statutory and community services and stakeholders).

The Changing Lives Initiative approach is also strongly aligned with a number of other government policies in Northern Ireland, including the Children and Young People's Strategy 2019-2029 which aims to ensure that all children and young people are physically and mentally healthy. The strategy recognises that the provision of help and support at an early stage, intervening early and focusing on preventative actions, can improve outcomes for children and young people and result in reduced public expenditure. It is clearly more difficult - and more costly - to intervene later when issues have become more entrenched or complex.

In addition, The Changing Lives Initiative supports the new, cross-departmental Family and Parenting Support Strategy currently being developed. This aims to build on the strengths of the 2009 'Families Matter' family and parenting strategy, which helped to embed early intervention programmes across the sector. The new Strategy will also reflect the achievements of the Family Support Hub network and the Early Intervention Transformation Programme in supporting families through the use of a multi-agency approach.

### **The Changing Lives Initiative not only works, but is sustainable and cost effective**

The Changing Lives Initiative has collected a compelling body of evidence over the last three years demonstrating that the early intervention and treatment of ADHD contributes significantly to key public health indicators, such as educational attainment, unemployment, mental health and suicide rates.

It is also cost effective. The cost for ADHD medications in Northern Ireland for the 12-month period March 2019 – February 2020 was £3,462,711. The aggregate costs of ADHD in the UK have been estimated at around £102,135 per case (2012/13 prices; Parsonage, 2014<sup>1</sup>). By comparison, the cost of providing The Changing Lives Initiative programme per family is as little as €1,155 (costs range from €1,115 - €1,555 per family across the project locations as per results of The Changing Lives Initiative Economic Evaluation).

1. 2012/13 prices; Parsonage M. The Lifetime Costs of Attention Deficit Disorder. Centre for Mental Health (2014).

## **THE CHANGING LIVES INITIATIVE – REPUBLIC OF IRELAND**

The number of children presenting with ADHD has increased significantly in recent years. According to a growing number of clinicians, this increase in ADHD cases may be attributed to the condition having been previously under diagnosed and undertreated.

There is some evidence to support this assertion. In 1997, hyperkinetic disorders (including ADHD and other attention disorders) constituted less than five percent of referrals to Child and Adolescent Mental Health Services (CAMHS). It is now the case that hyperkinetic disorders constitute the most commonly reported primary diagnosis of all children in contact with mental health services. In 2018, hyperkinetic disorders accounted for some 35.7% of cases of all CAMHS referrals.

ADHD is, therefore, a serious public health issue in Ireland. While usually first diagnosed in childhood, ADHD often lasts into adulthood and is associated with ongoing mental health problems, substantial long-term depressive outcomes, higher levels of unemployment, and a higher risk of offending and incarceration. It is well documented that the long-term consequences of untreated childhood disorders are costly, in both human and fiscal terms.

In Ireland some 90,000 prescriptions for ADHD medications were made in 2019 at a cost of €5,143,915 according to data extracted from the HSE Primary Care Reimbursement Service (PCRS)

By comparison, the cost of providing The Changing Lives Initiative programme per family is as little as €1,155.

The Changing Lives Initiative not only reduces costs to the public purse but also reduces pressure on busy services and long waiting lists. This in turn frees up staff to deal with urgent issues, not least those overwhelming the health service during the current pandemic. The need to reduce pressure on staff is a particularly pressing issue in Ireland where staffing levels in statutory mental health services are less than 60% of what the Government says they need to be to provide an effective service.

The Genesis Programme (Louth Leader Partnership) has served to reduce these pressures in Louth and surrounding border areas through the delivery of The Changing Lives Initiative. Over the past three years, over 600 families and 610 professionals have benefited from its early intervention approach, which offers the best chance of improving both the educational attainment and social functioning of children displaying ADHD-like behaviour.

### **The Changing Lives Initiative supports government policy**

The Changing Lives Initiative strongly aligns with the objectives of the Irish Government's 'Sharing the Vision: A Mental Health Policy for Everyone.' These include reducing the prevalence and severity of mental health disorders through early intervention and prevention work.

The Changing Lives Initiative aligns strongly with proposed outcomes under Domain 1: Promotion, Prevention and Early Intervention, in particular Outcome 1c and 1d

- *Outcome 1c: Reduced stigma and discrimination arising through improved community wide understanding of mental health difficulties*
- *Outcome 1d: Reduced prevalence of mental health difficulties and/or reduced severity of impact(s) through early intervention and prevention work*

‘Sharing the Vision’ also recognises the need to provide services that ‘deliver consistently high quality person-centred supports that meet the needs and have the confidence of service users and family, carers and supporters’.

The Changing Lives Initiative would enable the Irish Government to achieve numerous other objectives in ‘Sharing the Vision’, including to ‘*increase the ability of service users to manage their own lives (self- determination) via stronger social relationships and sense of purpose*’, ‘*to be respected, connected and valued in their community*’, and to ‘*provide service users with timely, evidence-informed interventions*’.

The invaluable contribution of The Changing Lives Initiative is brought into further relief when considering the following target outcomes and recommendations of the Irish Government’s most recent mental health policy:

Outcome: Social Inclusion

- 3a: ‘*Service users are respected, connected and valued in their community.*’
- 3b: ‘*Increased ability of service users to manage their own lives (self- determination) via stronger social relationships and sense of purpose.*’

Outcome: Accountability and continuous improvement

- *Outcome 4c: ‘Services that deliver consistently high quality person-centred supports that meet the needs and have the confidence of service users and family, carers and supporters.’*
- *Outcome 4d: ‘Continuous improvement is future focussed and driven by adequately resourced innovation across the mental health system and related sectors.’*

Recommendations: Service access, coordination and continuity of care

- Recommendation 14: ‘*Where Voluntary and Community Sector organisation are providing services aligned to the outcomes in this policy, operational governance and funding models should be secure and sustainable.*’
- Recommendation 20: ‘*There should be further development of early intervention and assessment services in the primary care sector for children with ADHD and/or autism to include comprehensive multi-disciplinary and paediatric assessment and mental health consultation with the relevant Community Mental Health Team, where necessary.*’

**Note:** *Academic and other publication references used in this section are available in the [Project Report](#)*

## THE CHANGING LIVES INITIATIVE – WESTERN SCOTLAND

Approximately 10% of preschool children in Scotland display atypical and persisting high levels of behaviour that are strongly predictive of a host of poor outcomes, including school exclusion, juvenile delinquency, substance abuse and mental health difficulties later in life.

NHS Highland (Argyll & Bute Health and Social Care Partnership) deliver The Changing Lives Initiative in the Argyll & Bute Region. One hundred and seventy-four families and 527 professionals have benefited from the programme since its launch two years ago.

Prior to The Changing Lives Initiative there was no ADHD-specific parenting programme available nor any community-based programmes in place to support children with a potential ADHD diagnosis and their families in the region.

The Changing Lives Initiative is strongly aligned with Scottish Government policy in many areas. This includes:

- The Children and Young People Scotland Act 2014, which focuses on prevention and early intervention from pre-birth to eight and upholds the ‘Getting It Right for Every Child’ principles of safety, health, achievement, nurturing, activity, respect, responsibility and inclusion.
- The Scottish Government’s *National Parenting Strategy* 2012. A key aspect of this strategy is the focus on attachment and parenting support. The strategy contains a commitment to promoting and encouraging bonding and secure attachment between parents and their children. One of its main approaches is the *Psychology of Parenting Initiative*, which is delivered by NHS Education for Scotland.
- The Scottish Government’s ‘Mental Health Strategy, 2012 – 2015’, which focuses on ‘prevention, anticipation and supported self-management’ and supports early intervention to address conduct disorder in children through evidence-based parenting programmes.
- Similarly, the Scottish Government’s most recent Mental Health Strategy (2017 – 2027) highlights the importance of early intervention in mental health from pre-birth through to young adulthood. It further recognises that while Child and Adolescent Mental Health Services (CAMHS) sometimes provide the right route to achieve the best outcomes for children, at other times “an alternative would be better”. This includes providing support for families through parenting programmes where appropriate.
  - Specific actions proposed in the Mental Health Strategy include supporting “targeted parenting programmes for parents of 3- and 4-year olds with conduct disorder”, as well as “working with partners to develop systems and multi-agency pathways that work in a co-ordinated way to support children’s mental health and wellbeing”.

In addition, The Changing Lives Initiative would support the Scottish Government in delivering a number of recommendations presented by its Children & Young People’s Mental Health Task Force in 2019. The Taskforce advocates a whole system approach,

underpinned by 'Getting it Right for Every Child', to help children, young people and their families receive the support they need when they need it.

The Children & Young People's Mental Health Task Force argues that early intervention and prevention are vital to improving outcomes for children and young people, decreasing waiting times and reducing rejected referrals.

A preventative approach, with a resilient generation of children, and resilient families and communities, form the foundational building blocks in the Taskforce's model for improving the mental health of Scotland's children and families. It is envisaged that these building blocks will embed prevention and best practice in all work with children, young people and their families. To that end, the Task Force recommends that the Scottish Government and the Convention of Scottish Local Authorities should ensure that future approaches to children and young people's mental health are based on these building blocks.

The focus for delivery of the Task Force's on-the-ground recommendations are the local Children's Services Partnerships (CSPs) as they are intended to support and build on existing and developing good practice. The Taskforce recognises the importance of responding to local needs with local solutions, and that children and young people receive the right help, at the right time wherever they are. It is vital therefore that local CSPs should be actively responding to the identification of needs to ensure children, young people and their families receive the support they require.

The Changing Lives Initiative would support several specific actions proposed by the Task Force, including:

- Expansion at pace and scale of the best practice work currently being delivered by primary care professionals, the third sector and within education.
- A counselling resource and mental health support available in schools with well used and understood links to school nurses and the mental health resources within the community mental health and family hubs.
- The same improved standard of service for children & young people with neurodevelopmental conditions and their families as available to those with mental health conditions.
- Effective links to relevant children and young people services for those with neurodevelopmental conditions.
- Appropriate digital enhancement of mental health and neurodevelopment services for young people and their families.
- Enhancement of community and specialist perinatal and infant mental health services.
- More effective support for the families of children and young people experiencing poor mental health.