



THE
CHANGING LIVES
INITIATIVE

The Changing Lives Initiative: An Early Intervention Approach to ADHD

Final report on Outcomes, Process
and Economic Evaluations

Summary Report | April 2021

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The views and opinions expressed in this report do not necessarily reflect those of the European Commission or the Special EU Programmes Body (SEUPB)



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Acknowledgements

We extend our sincere thanks to the Project Partners whose shared vision and commitment to supporting families led to the creation and delivery of The Changing Lives Initiative. We are indebted to the project Steering Group for their time, knowledge and determination in driving the project to success.

We would like to acknowledge with much appreciation the crucial role of the project staff, in the successful delivery of The Changing Lives Initiative, including the Project Manager, Project Psychologists, Local Coordinators, Programme Facilitators, Data and Communications, Finance and other support staff. From the outset, the project team has demonstrated outstanding dedication and skills. The innovation, adaptability and resilience they have shown, in particular during the recent COVID-19 crisis, has been remarkable and is testament to the talent and flexibility of each of the team members. We are very grateful also to our Incredible Years mentors and coach for their expert guidance and support to the team.

Our deepest thanks to the Research teams within Archways and Dundalk Institute of Technology who worked tirelessly to deliver the project evaluations and capture the impact of our work. Also to our Expert Advisory Group for their insight, support and advice throughout.

We express our gratitude also to the Special EU Programmes Body, the EU Interreg VA Fund and the Sponsoring Departments for their support of The Changing Lives Initiative. Without this support, a project on this scale would not have been possible.

Last but by no means least, we extend our special thanks to the parents/guardians, families and practitioners who participated in the project and who gave their time to take part in the evaluations. We thank you for your commitment to the programme and for the time taken to share your experiences with us and the openness with which you did so. The achievement of the project has been down to the hard work and dedication of

each of the families who took part and the practitioners who worked to support them. We hope that you will continue to feel the benefits of The Changing Lives Initiative for many years to come. We are privileged to have shared this journey with you all.

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An Roinn Sláinte
Department of Health

Match-funding for the project has been provided by the Department for Health in Northern Ireland, the Department of Health in Ireland as well as by the project partners.

Explanatory Note

ADHD focused Incredible Years Parent Training Programme (ADHD IY Parent Programme): The Incredible Years Basic Parent Training Programme (IYBP; Webster-Stratton, 1989) is a group-based intervention underpinned by the principles of behavioural and social learning theory. The Changing Lives Initiative offers a lengthened and ADHD-focused programme. The ADHD-focused programme consists of the Incredible Years Basic Parent Training Programme, extended to be delivered over 20 sessions and incorporating elements of the Incredible Years Advanced Parent Programme. The programme comprises 2.5-hour weekly group sessions, delivered by two programme facilitators to approximately 12 parents per group.

ADHD Information & Awareness Workshop for Parents (Information & Awareness Sessions): The initial part of The Changing Lives Initiative intervention. These 1-2 hour sessions were designed to create a better understanding about ADHD and associated behaviours, and to provide parents with basic strategies and effective practices to support children's social-emotional development and preventing challenging behaviours.

ADHD Information & Awareness Workshop for Professionals (Professionals' Sessions): As well as working with families, The Changing Lives Initiative offers a specialist training programme for those working with young children, in particular teachers, early years professionals and health and social care workers. These 2-2.5 hour sessions are delivered by the project psychologist and aim to help participants gain additional skills to support the children presenting with behaviours consistent with ADHD.

Project Partners: These are the five organisations involved in the management, delivery and evaluation of The Changing Lives Initiative project, namely: Archways, Dundalk Institute of Technology (DkIT), The Genesis Programme, Colin Neighbourhood Partnership and NHS Highland.

Steering Committee (Steering Group) is made up of senior representatives of the project partners and is responsible for overseeing the implementation and management of the project. The Steering Group has met every 4-6 weeks throughout the project.

Expert Advisory Group (EAG) is a committee of experts who have agreed to share their knowledge with the project partners. They are drawn from different disciplines and have agreed to provide guidance and comment on project outputs as well as on any ethical issues arising.

Project Manager is responsible for the coordination of The Changing Lives Initiative across the three project locations and overall delivery of the project plans.

Programme Facilitators – refers to the project team members on each site who deliver The Changing Lives Initiative interventions. This includes delivering the **ADHD Information & Awareness Workshop for Parents** and the **ADHD-focused Incredible Years Parent Training Programme**. When delivering the ADHD-focused Incredible Years Parent Training Programme, programme facilitators are sometimes referred to as Group Leaders – this is the title Incredible Years use to describe people who deliver their programmes.

Local Coordinators are the dedicated members of staff on each of the project sites who are responsible for the coordination of The Changing Lives Initiative in their area.

Incredible Years Mentor (IY Mentor) are highly experienced and certified Incredible Years group leaders who are authorized by Incredible Years to provide training and on-going mentoring to IY programme facilitators (Group Leaders)

T1 (Timepoint 1): Refers to when data was first gathered from participants in the project evaluations (baseline). For the three evaluations in this report, this refers to just before parents commenced the **ADHD-focused Incredible Years Parent Training Programme**.

T2 (Timepoint 2): Refers to the second time data was gathered from participants in the project evaluations. For the three evaluations in this report, this refers to just after parents completed the **ADHD-focused Incredible Years Parent Training Programme** (post-programme).

T3 (Timepoint 3): Refers to the third time data was gathered from participants in the project evaluations. For the three evaluations in this report, this refers to 6 months after parents completed the **ADHD-focused Incredible Years Parent Training Programme** (6 months post-programme).

T4 (Timepoint 4): Refers to the fourth time data was gathered from participants in the project evaluations. For the three evaluations in this report, this refers to 1 year after parents completed the **ADHD-focused Incredible Years Parent Training Programme** (1 year post-programme).

Foreword

For the past three years (2017–2020) the Interreg VA funded project, The Changing Lives Initiative, has been working to establish a new community-led early intervention treatment model for Attention Deficit Hyperactivity Disorder (ADHD). The Changing Lives Initiative is a cross-border project and has been delivered in Northern Ireland (the greater Belfast and Lisburn areas), Republic of Ireland (County Louth and surrounding border areas) and in Western Scotland (the Argyll & Bute region).

Now in its final month, the Project Partners wish to set out the results of The Changing Lives Initiative and the project evaluations. The following report sets out the context to the project, the intervention, and the results of the three project evaluations.

Research is vital in providing the evidence we need to transform services and improve outcomes. All the Project Partners recognise the imperative of robust research and evidence. Without it, we cannot improve the quality and effectiveness of our services. The use of evaluations allows us to measure the impact of our work and understand better what works well and what does not. Research can shed light on unknowns, fill gaps in knowledge and change the way that healthcare professionals work.

We hope that the evidence and learning provided by the evaluations carried out as part of this project will provide a solid basis for future discussion and decision making by Health Services, Policy Makers, Funders and Service Commissioners.



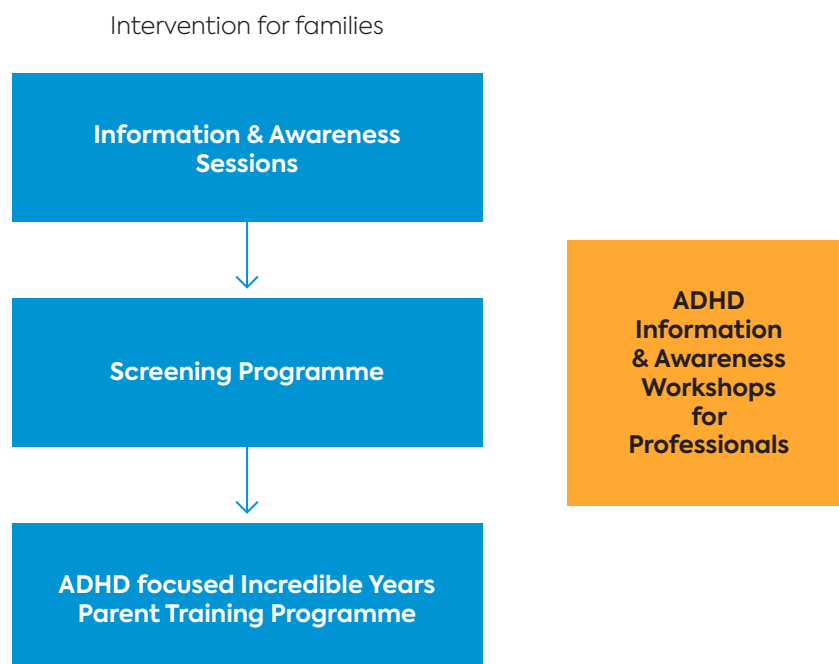
Aileen O'Donoghue

Chairperson, The Changing Lives Initiative Steering Group

The Changing Lives Initiative

Recognising a lack of availability of early and psycho-social interventions for ADHD in the Republic of Ireland, Northern Ireland and in Scotland, a number of organisations came together in 2016 and developed a project plan for a cross-border project, The Changing Lives Initiative. Funding was secured through the EU's Interreg VA programme, with match funding from the Departments of Health in Northern Ireland and the Republic of Ireland, as well as the Project Partners, for a three-year project to commence in late 2017.

The Changing Lives Initiative is a community-based project, which sets out to create a better understanding of ADHD and to provide an intervention programme for families with children (aged 3-7) experiencing behaviours consistent with ADHD. The project offers a tiered intervention for families starting with Information and Awareness Sessions, through to a Screening Programme and finally an intensive intervention in the form of an evidence based ADHD-focused Incredible Years Parent Training Programme. The intervention is primarily delivered to a prediagnosis population; with potential families being identified via a range of agencies including schools, preschools, GPs, family support hubs and paediatric health services.



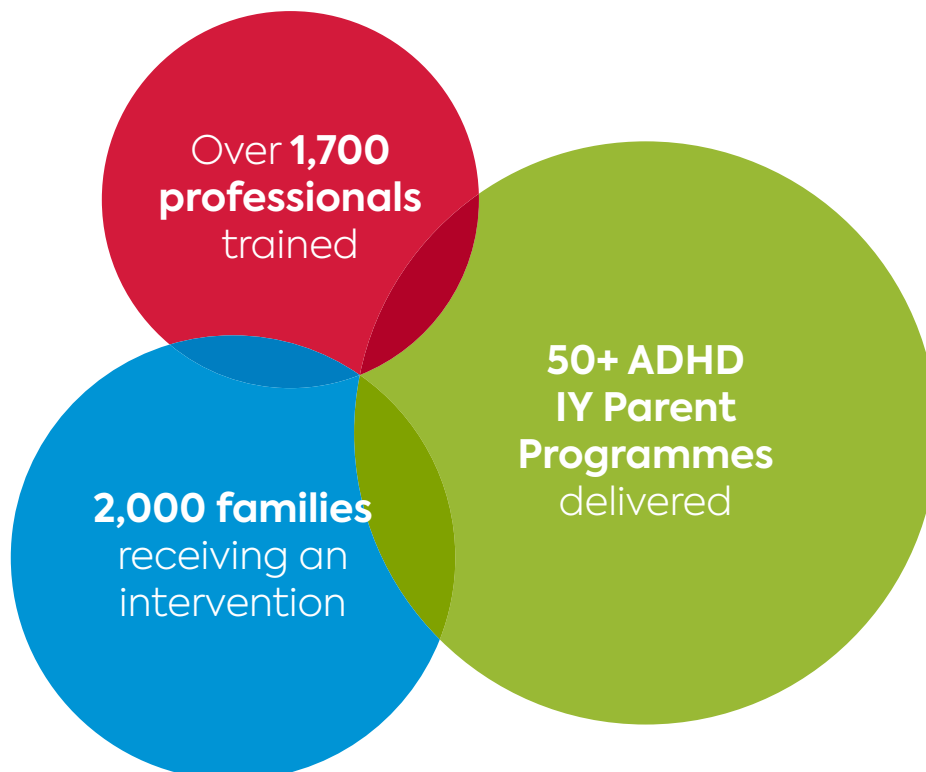
The Incredible Years Basic Parent Training Programme (IYBP; Webster-Stratton, 1989) is a group-based intervention underpinned by the principles of behavioural and social learning theory. The programme has been extensively evaluated as an intervention for children (aged 3-7 years) with conduct problems and its effectiveness is now well-established. The Changing Lives Initiative offers a lengthened (18-20 sessions versus 14 sessions basic programme) and ADHD-focused programme.

As well as working with families, the project offers a specialist training programme for those working with young children, in particular teachers and early years professionals.



The Changing Lives Initiative has involved project partners from both the Community and Statutory Health Sectors with Archways as Lead Partner; Dundalk Institute of Technology as Research Partner; Colin Neighbourhood Partnership delivering the programme in Belfast and Lisburn; The Genesis Programme (Louth Leader Partnership) delivering the programme in Louth and surrounding border areas; and NHS Highland (Argyll & Bute Health and Social Care Partnership) delivering the programme in Scotland. The project has successfully engaged both urban and remote communities in the different jurisdictions and is working with some of the most disadvantaged communities in these areas.

This new early intervention model of treatment has been successfully delivered across the three project sites and when the project is complete more than 2,000 families will have received an intervention, including the delivery of more than 50 ADHD-focused Incredible Years Parent Training Programmes and the training of over 1,700 professionals.



In addition to delivery of the Information and Awareness sessions and Parent Programme, The Changing Lives Initiative has developed a Project App to help disseminate information while also increasing the reach and sustainability of the project. The App was launched in March 2020 and has been utilised by more than 600 parents and professionals from both within and outside the project areas. The App helps families understand what ADHD is and provides practical strategies and tools for parents to use with their children. The App is also extremely useful for those working with children, helping them to understand ADHD and how they might support children who have issues with inattention, hyperactivity or impulsivity. The App continues to be available to parents/guardians and professionals post project and can be downloaded at www.changinglivesinitiative.com

In March 2020 the COVID -19 pandemic brought changes to how The Changing Lives Initiative continued to support families. Along with other projects throughout the world, The Changing Lives Initiative had to adapt to the changing circumstances and restrictions arising from the pandemic. The added strain on families, who had lost support structures and routines due to the restrictions, made it even more important that the project continue its work. The Changing Lives Initiative adapted quickly and completed some of the programmes underway in spring 2020 through remote delivery methods. Over the summer months, the project went on to pilot the first ever fully remotely delivered ADHD IY Parent Programme. From August 2020, Information and Awareness workshops for both practitioners and parents/caregivers were moved online and extended, with more emphasis on effective strategies to support children's behaviour. The Screening Programme was also then successfully adapted to remote delivery via telephone. A full cohort of remotely delivered ADHD IY Parent Programmes were then delivered from September 2020 through to late January 2021.

Although the project evaluations were mostly complete at this stage, it was felt important to gather feedback from parents in relation to the remotely delivered programmes and so a piece of qualitative research was added to the evaluations in order to explore the acceptability of the remotely delivered ADHD IY Parent Programme, a summary of the findings are included in this report.

Launch of The Changing Lives Initiative

Mairead McGuinness MEP and Gina McIntyre, CEO of SEUPB with members of the Steering Group and Project Staff at the launch of The Changing Lives Initiative at the Carrickdale Hotel, Dundalk on the 6th November 2017



The Mid Project Conference Belfast, May 2019



Stakeholder Event and Launch of Project App Dundalk, March 2020



Executive Summary

The Changing Lives Initiative is a community-based initiative aimed to create a better understanding about ADHD and provide an early intervention programme for families with children (3yrs-7yrs) experiencing behaviours consistent with ADHD. Launched in November 2017, the 3-year initiative offered a programme for families consisting of Information and Awareness Sessions, a Screening Programme, and an intervention in the form of an ADHD focused Incredible Years Parent Training Programme. The Initiative was delivered in project areas within the Republic of Ireland, Northern Ireland, and Western Scotland. As part of the Initiative, three evaluations were conducted: An Outcomes Evaluation, a Process Evaluation and Economic Evaluation. This report presents the findings of these evaluations.

ADHD is a neuro-developmental disorder characterised by inattention, hyperactivity and impulsivity which causes significant difficulties throughout many aspects of a child's life, including their family, school and social life.

ADHD is one of the most common disorders of childhood, estimated to affect 5.29% of children. It is the most common reason for referral to mental health services in childhood in Ireland (35.7% of all cases) (CAMHS Fourth Annual Report, 2011-2012). ADHD has a pervasive and significant effect on many aspects of a child's life, including family, school and social environments. The majority of people diagnosed with ADHD in childhood continue to meet criteria for the disorder as adults. Adults with ADHD have higher levels of unemployment (Hechtman, 2016) and also experience greater levels of workplace impairment, reduced productivity and absenteeism. Those with ADHD also experience increased rates of substance abuse and misuse, traffic citations, offending behaviours and incarceration (Breslau et al., 2011; Küpper et al; 2012). Many children have difficulty concentrating, sitting still or may act before they think and some children may experience behaviours that are consistent with ADHD. However, this does not always mean that they will go on to be diagnosed with ADHD. It is the frequency, pattern and intensity of these symptoms which denote the presence of ADHD.

Group-based parent programmes are recommended as the first course of intervention for young children with behaviour consistent with ADHD by leading international bodies such as the National Institute for Health and Care Excellence (NICE UK) and the Global ADHD Working Group. Group-based parent programmes may be supplemented with additional child-focused programmes to assist in the development of regulatory behaviours in social, emotional and behavioural domains. While there are dozens of evidence-informed parenting programmes available, NICE guidelines currently recommend that the parenting programme of choice should be the Incredible Years



Programme developed by Carolyn Webster Stratton in the University of Washington, Seattle, USA. The Webster-Stratton Incredible Years (IY) Parent, Teacher and Child Training Series was designed for the early treatment and prevention of conduct disorders in childhood (Webster-Stratton and Hancock, 1998): the IY series comprises a suite of comprehensive, specially designed programmes, which target children aged 0-12 years, their parents and teachers. The programmes are designed to improve social and emotional functioning and reduce or prevent emotional and behavioural problems.

Group-based early intervention programmes offer a potentially effective means of improving the lives of families and children with behaviour consistent with ADHD. Such interventions teach behavioural strategies to parents, guardians and teachers, increasing resilience for children in their early years. Developmentally sensitive preventive interventions offer the potential not only to alter the chronically impaired course of ADHD, but to prevent the onset of many of the social, emotional and academic difficulties that impede successful treatment when the child is older (Halperin, Bédard & Curchack-Lichtin, 2012). Lack of evidence about how early intervention and prevention programmes work in real-world settings is restricting local learning to inform service delivery and future planning to meet the needs of children aged 3 to 7 years with behavioural difficulties.

The **Outcomes Evaluation** aimed to explore the effectiveness of the ADHD-focused Incredible Years Parent Training Programme on participating parents, their child's behaviour and parent/child relationship. The research design was a non-randomized, pre-post evaluation. Five measures were used to measure child's behaviour and to elicit the parent/guardian experience in relation to discipline and stress. These questionnaires were:

- The Strengths and Difficulty Questionnaire (SDQ) (Goodman, 1999), which looks at social and emotional issues.
- The Conners Parent Rating Scale (3rd Edition) Short Form (CPRS; Conners, 2008), a widely used and well validated instrument that allows for the identification of comorbidities and ADHD behaviours.
- The Vanderbilt (Wolraich et al., 1998), used to assess ADHD symptoms and their effects on behaviour and academic performance.
- The Parenting Scale (Arnold et al., 1993), which explores disciplinary practices.
- The Parent Stress Index (Abidin, 1995), which measures the parent/guardians stress levels.

Quantitative data were collected at four time points – at baseline (T1), post programme (T2), 6 months post programme (T3) and 1 year post programme (T4). Data were gathered from all locations where the Initiative was delivered.

The Outcomes Evaluation examined the following questions:

- Does the ADHD-focused Incredible Years Parent Training Programme lead to an improvement of parenting skills and competencies?
- Does the ADHD-focused Incredible Years Parent Training Programme lead to improvements in parent /child functioning?
- Does access and exposure to the ADHD-focused Incredible Years Parent Training Programme improve the behaviour of young children (aged 3–7 years) who have behaviours consistent with ADHD?

The **Process Evaluation** aimed to explore the mechanisms and challenges involved in developing and delivering the intervention in different locations. Semi-structured interviews were carried out with programme participants, staff and Project Partners. In addition, fidelity and participant satisfaction measures were examined for a number of programmes. The key research questions which guided the Process Evaluation were:

- Has the intervention been delivered with fidelity?
- What factors facilitate or inhibit effective implementation?
- What are the experiences of parents and project stakeholders?

The **Economic Evaluation** adopted a cost consequence analysis. As there was no control group, it compared costs six months prior to the intervention and six months post completion of the intervention. Data were collected for the cost of the intervention through facilitator cost diaries. Data for the frequency of health and social care service use for relevant children of parents attending the intervention were collected using the Client Service Receipt Inventory (CSRI) (Beecham & Knapp, 2001). These were completed by parents at baseline (before intervention), on completion, and six months post intervention. The CSRI provided a structured record of the type and frequency of service use, such as visits to emergency departments and outpatient clinics etc. The perspective of the analysis for the UK jurisdictions was that of the NHS and for Ireland it was the HSE. As costs and outcomes in relation to ADHD are not borne exclusively by the health service, a broader perspective (societal) was also explored. Costs falling on the education and social care sectors and the economy more generally (e.g. reduced productivity/wages of family members of children with ADHD) were also explored.

It is recognised that undiagnosed and/or poorly managed ADHD has the potential to have an economic impact over the lifetime of an individual (and family) with ADHD. The time horizon of this study was limited to data collected six months prior to and six months following completion of the intervention programme under consideration. Modelling long-term costs and benefits as a result of this intervention is possible but beyond the scope of this evaluation.

The key questions which guided the Economic Evaluation were:

- What is the cost of delivering the ADHD-focused Incredible Years Parent Training Programme in Ireland, Northern Ireland and Scotland?
- Are there differences in resource utilisation (relating to health, social care and education) before and after engagement with the programme?

The **Qualitative Research on Remote Delivery**, in the wake of COVID-19 lockdowns, sought to understand remote delivery from the participant's perspective. All participants who had taken part in the remotely delivered ADHD IY Parent Programmes in Louth and Belfast were invited to either a Zoom focus group or to give feedback during routine follow up calls with the project psychologist. Feedback was collated and thematically analysed using questions asked as an initial framework.



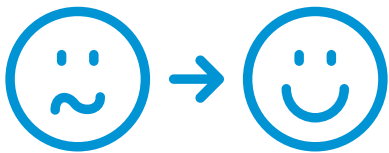


Key Findings

Children and Families

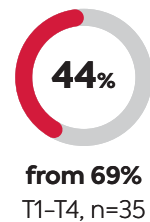
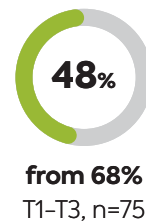
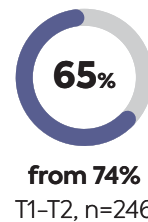


Parents/guardians with children with behaviours consistent with ADHD reported **improved disciplinary practices** across all time points of the research. Specifically, they reported that since completing the ADHD-focused IY Parent Programme, they were more likely to employ positive parental strategies when their child misbehaved, less likely to overact and overall their disciplinary practices had improved after taking part in the parent programme.



Parent/guardians reported that they experienced **parenting as less stressful** after taking part in the parent programme and found their child less difficult to parent. Other findings were improved parent-child interactions and a reduction in the distress they experienced in relation to their role as parent/guardian.

Parental reports also indicated a consistent improvement with regard to children's **concentration, attention levels and distractibility**. Reductions in these behavioural features were observable across all time points. The percentage of children with the Predominantly ADHD Inattentive subtype reduced to:



Parents/guardians saw reduced **hyperactive and impulsive** behaviours in their child after they had taken part in the parent programme. This improvement was sustained and significant across all time points.



Social and emotional presentations, such as externalising emotional problems, difficulties with peers, hyperactivity and conduct problems experienced by the programme child, were all seen to have reduced across all time points by the parent/guardian.

The results showed a **strong correlation** between changes in the parent/guardians' disciplinary practices and changes in the child's behaviours. Specifically, children of parents/guardians whose disciplinary practices improved showed fewer of the problems and behavioural patterns that are typical for ADHD. The relationship between improved parenting practices and ADHD-consistent behaviour was particularly strong immediately post programme but remained evident for the later follow ups.

Implementation

15.36
of 16
level of
satisfaction

Participants in the ADHD IY Parent Programme reported **high levels of satisfaction** (with mean scores of 15.36 out of a possible 16 achieved on the IY Parent Weekly Evaluations). Key factors for parents were the lengthened programme to allow additional time to practise skills and work on problem behaviours as well as the ongoing support they received from the Programme Facilitators and their fellow parent participants.



Training, support and fidelity

measures were used to ensure the quality of The Changing Lives Initiative, while some flexibility

was still provided to allow programme facilitators to tailor the programme in response to specific presenting needs of families.



The core components for the **successful partnership** in

implementing The Changing Lives Initiative were shared values,

shared protocols for delivery, and a shared vision based on a preventative approach. Much time and effort was also put into engaging with local communities and services, and building capacity with local stakeholders.



Cross border success:

Partners used the same programme, practices and protocols across the three jurisdictions.

Additionally, the implementation of the Initiative benefited from cross-border training, knowledge sharing and the sharing of expertise and resources.



Factors that could **potentially inhibit implementation** included

practical operational issues, as differing IT systems, staff working in a statutory partner organisation being called for higher priority work; and the high level of reporting requirements and slow turnaround of payments from the project funder.

Economic

€1,155.09 – €1,555.42

The **cost per family** completing The Changing Lives Initiative programme across the jurisdictions ranged from €1,155.09 to €1,555.42. For all three jurisdictions costs were commensurate (or lower) than reported elsewhere in the literature.



No immediate direct cost savings were demonstrated in relation to health and social care costs;

an evaluation over a longer period would be required to determine long-term cost saving potential. There is extensive wider evidence, however, of the **long-term cost effectiveness** of this type of early intervention.

Remote Delivery



Remote delivery of the ADHD IY Parent Programme had **wide acceptability** from both parents and facilitators. The IY programme structure and strategies translated well to remote delivery and provided an otherwise unavailable support network during a stressful and pressured time for families (COVID-19, Lockdown).

Conclusions

Outcomes Evaluation

The results of the Outcomes Evaluation suggest that the availability of a specific ADHD parenting programme can prove beneficial in terms of reducing the symptoms of ADHD experienced by children and in improving the parent-child relationship. The study demonstrated that there were significant differences post intervention in terms of child behaviours and ADHD symptom presentation as well as parent stress and disciplinary practices (harsh /punitive parenting styles). The parents also reported improvements in relation to their child's pro-social skills. Taken collectively these results are striking.

The programme brought about qualitative improvements to children's behaviour by reducing the frequency, intensity, duration and severity of problem behaviours, the impact of which extends to the day-to-day functioning of the child and their family. The central element of the intervention programme made available to participants was a series of shared strategies such as enhanced communication skills, praise, contingent reward systems and positive discipline. The purpose of these strategies is not simply to reduce challenging behaviours but to teach the child important social and emotional regulatory skills. Parents' confidence and knowledge of effective strategies increased as did their knowledge and understanding of ADHD. The long term impact on families of this upskilling and behaviour change in parents represents an investment that has the potential to continue to reap benefits for the child, parent and wider social systems, e.g. school, extended family. By training parents in therapeutically-based interventions, the child has wrap around support and a resource lasting into adolescence and adulthood.

ADHD is a continuum and is further complicated with comorbidities, but despite this, the study suggests that even parents whose children experienced limited change in ADHD symptomology, still viewed the participation and process as successful.



The evaluation outcomes suggest that post programme parents experienced a significant reduction in their level of stress. Parenting a child with ADHD has been demonstrated to be a stressful process, with a feature of the lived experience of those who parent a child with ADHD being the levels of stress and anxiety they experience (Brubaum 2016). This anxiety relates to parents' ability to deal with their children's behaviour as they develop and grow, and they fear for their children's future. The presence of stress, fluctuating mood and fractious relationships within the parent-child/dyad were noted in the majority of those tested. However, exposure to the programme, as seen across all time points, significantly changed and almost extinguished entirely the coercive nature of relationships between parents and children. It should also be noted that this change was accompanied by significant and lasting reductions in overall levels of stress and anxiety for participating parents.

ADHD is a disorder characterised by persistent and impactful behavioural patterns that affect a child's experience of the world as well as affecting how the child is viewed by their world. The project at its core offered tangible skill development to parents which gave them the opportunity to be active participants in their child's treatment.

As stated throughout this report, ADHD is a pervasive disorder which can affect all aspects of a child's life. Current pharmacological treatment focuses on the short term relief of symptoms and is often applied with a specific purpose to constrain behaviours to allow the child to engage with academic institutions. This means that outside of this domain the majority of the child's and family's lived experience is unaffected by the treatment. It is also the case that children often experience a bounce back effect from these medications, resulting in elevated levels of symptom intensity and frequency. This negatively impacts on the child and family functioning, and consequently results in the embedding and normalization of family dysregulation and reductions in collective family efficacy. The evidence of potentially severe difficulties for the child and family resulting from current medical intervention suggests that alternative treatment pathways are a requirement. In addition, ADHD and specifically the labelling of children with this condition remains problematic for families who view the diagnostic identifier as negative and stigmatizing. This study demonstrates that the use of an evidence-informed ADHD-specific parenting protocol delivered within communities and accompanied by coordinated multi agency ADHD Information and Awareness workshops can significantly reduce the impact of ADHD on the lives and functioning of children and families. This community-led approach provides substantive evidence that community-led parenting interventions are a viable alternative to current treatment regimens and, by virtue of information dispersal, can go some way to dispelling the negative connotations associated with ADHD. Moreover, it confirms that community-based health care professionals have a vital role in the provision of balanced and supportive information regarding ADHD and in addressing the needs of affected children and their families.

It is hoped that the findings from this research will go towards reframing dialogue in relation to ADHD and parent programmes. Further, that it will contribute to understanding ADHD and the importance of early intervention and the pertinence of parenting programmes in relation to improving outcomes for both the parent/guardian and children with behaviours consistent with ADHD.

Process Evaluation

ADHD is a serious public health issue affecting a large number of children. It impacts on many aspects of the child's life, including academic difficulties, social skills problems, and strained parent-child relationships. Usually first diagnosed in childhood, it often lasts into adulthood and is associated with substantial long-term depressive outcomes. Thus early interventions that target children at risk for ADHD is believed to offer the best chance of improving both educational attainment and social functioning (Feil, Small and Seeley et al 2016).

The effectiveness of IY programmes has long been demonstrated in RCTs and meta-analyses confirming positive outcomes for both parents and children. What is much less known is how programmes work, the planning and delivery of interventions, and the contextual factors that can help the interpretation of outcome results. This report presents much-needed information on the processes behind the IY intervention delivered by The Changing Lives Initiative in Ireland, Northern Ireland and Scotland. Drawing on data gathered from parents participating in programmes and those involved in managing and delivering them, the findings from this report provide a timely insight into programme planning and the steps taken to strengthen and broaden fidelity, as well as the role of cross-sector partnerships in meeting the needs of local communities.

It is increasingly recognised that addressing pressing social issues requires the capacity to work collaboratively across sectors and borders. The partners in The Changing Lives Initiative were drawn from the public and community sectors, with each having distinct strengths that they drew on to work with local communities and with Project Partners. For the community sector partners this included flexibility of working and structures, which meant that parents benefited from programmes delivered outside of standard working hours in the evenings and, in some cases, over weekends. For the statutory sector partner, facilitators often knew the families through previous child health programmes. This prior knowledge of the families meant that facilitators had a strong starting point for engaging with families and delivering programmes locally. Beyond this, the diverse project team also served to promote the exchange and transfer of knowledge, in turn strengthening fidelity of the implementation in diverse settings, with key staff working across the jurisdictions. The growing confidence of partners in working across borders also extended to programme delivery in the latter stages of the project, with programmes offered to parents on a cross-border basis to improve parents' access in Ireland/Northern Ireland.

Our findings suggest that the core components for this successful partnership were shared values, shared protocols and a shared vision.

For the partners in The Changing Lives Initiative, the vision was based on a prevention approach, starting with support for the most important building block in a child's life – the family – but also including schools to further strengthen the structures needed for intellectual and social-emotional development. Across the three jurisdictions staff engaged with local communities and services, building capacity and relationships with local stakeholders. This type of cross-sector partnership has, at a broader societal level,

been seen to have the potential for welfare-enhancing systemic change in sectoral relationships and societal values and priorities (Austin and Seitanidi, 2012).

Some difficulties were however noted, including differences in software requirements for using video web platforms when moving to remote delivery during Covid-19 restrictions and slow systems for reimbursement of programme costs to facilitators. While these did not represent a barrier to implementation, it was a source of stress for some facilitators. In addition, while there are many benefits in using existing staff to carry out facilitator roles, such as cost savings linked to recruitment, improved productivity, and career development opportunities, there does need to be a backup for when staff are moved again at short notice. Project partners also found the reporting requirement from SEUPB particularly onerous, with long turnaround periods between the submission of claims and payment, causing serious financial stress.

The findings from this research also point to very high levels of participant acceptability of the ADHD-focused Incredible Years Parent Training Programme. Incredible Years parent programmes tend to be provided over 14 weeks. In offering 18-20 sessions, the project aimed to give parents time to practise the skills they were learning. Previous research has highlighted the tension in families stemming from hyperactive behaviours of children with ADHD. A longer programme thus gives parents time to learn how to be with their child in a positive way. Likewise, it gives facilitators time to focus on areas where parents need support the most. Parents felt supported by facilitators and their fellow parent participants, including between sessions if they needed additional assistance. The combined effect on parents included increased feelings of wellbeing, better relationships, and thinking positively about the future. On completion of programmes and six months' post programme, parents felt confident and positive about their ability to manage their child's behaviour and the everyday situations that had challenged them and that had been a source of stress for the family.



Economic Evaluation

The cost per family completing The Changing Lives Initiative programme are comparable to other evaluations which have sought to determine the cost of delivering parent programmes in a community setting. Indeed, given that this is a 20-session programme, the costs may be considerably less than similar interventions, which are typically 14 weeks.

The findings from our cost analysis do not show differences in health and social care related costs. However, early childhood investments unfold over time, often taking years for the cumulative benefits to exceed the up-front costs, and would therefore require an evaluation over a longer period. From an economic perspective, the benefits of early childhood investments often take years for the cumulative benefits to exceed the up-front costs (Cannon, Kilburn and Karoly et al. 2018). This is because the major source of benefit only begins to accumulate after the child reaches adulthood and enter employment. Thus, it is not surprising that the findings from our cost analysis did not show differences in health and social care related costs.

Remote Delivery

In March 2020 the COVID -19 pandemic brought changes to how The Changing Lives Initiative continued to support families with children displaying behaviours consistent with ADHD. All elements of The Changing Lives Initiative intervention, including Information and Awareness sessions for both practitioner and parents/caregivers, the Screening programme and the ADHD IY Parent Programme, were moved online and remotely delivered via Zoom and other platforms.

Key changes to delivery of the ADHD IY Parent Programme were made for the remote delivery mode: session duration was 90 minutes long instead of 2.5 hours; programme materials were posted and emailed to participants, and weekly telephone calls by Programme Facilitators to participants were extended when needed to allow for any additional support required.

23 participants who had completed a remotely delivered programme (n=7 Louth, n=16 Belfast) gave feedback on their experience of it. Key themes emerged from this feedback around the acceptability of IY delivered remotely via Zoom. Most participants reported the ADHD IY Parent Programme was well facilitated and planned, with key elements of IY such as vignettes and small group work (break out rooms) translating well to online mode. Some, however, felt that role plays were difficult to take part in remotely. Almost all participants reported feeling nervous about using Zoom for the first time to take part in the programme, but reported that these reservations and nerves faded after attending a few sessions. Participants felt they bonded well with their facilitators and the other participants in their group. Most participants found Zoom to be a convenient and easy way of participating because it required less effort than face-to-face group activities, such as finding childcare, and transport to and from a venue. Participants who did not have their own transport

emphasised that they would likely have struggled to maintain participation because of this. Some participants also mentioned that the remote delivery mode meant co-parents, grandparents and older teen siblings could join in when available.

Participants who received regular weekly calls from their Programme Facilitator reported how important these calls were for one-to-one support, trouble-shooting issues related to parenting or practising strategies, or just having someone listen to them. Most parents reported that lockdown restrictions had been incredibly stressful on them and their family.

Participants reported successful implementation of programme strategies such as 'ignoring unwanted behaviour' and 'praising wanted behaviour'. Other strategies used successfully included 'child-directed play' and 'persistence coaching'. Most participants saw great improvements in their child's behaviour despite the added stress of lockdown. Some participants felt that the programme had a positive impact on them personally with some saying it brought them greater awareness of their own behaviour and its impact on their child. Several also mentioned improved communication between partners in parenting together.



Strengths and Limitations

The Strengths and Limitations of the Project Evaluations included:

- The use of valid and reliable measures of child behaviour and the collection of outcome data from participants at regular intervals throughout the study including 6 months and 1 year post programme.
- A comprehensive and detailed implementation and process evaluation to explore the mechanisms of change and implementation processes (including identification of potential barriers to implementation and ways to address them).
- A cost consequence analysis to better understand the associated costs and resource utilisation associated with engagement in the programme, with the potential to inform service planning and provision as well as long term sustainability.
- Participating families in this project came from a range of backgrounds reflecting a cross sector of local communities. Families participating included those with socio economic risk factors e.g. low income, poor educational attainment, lone parents and minority ethnic status, as well as families who were employed, had good incomes and stable family background. The mix of families worked well and presented few problems indicating the applicability of the programme across communities.
- Without a control group, we cannot report whether it was the intervention or some other variable that caused the outcomes of the intervention. This was however never our intention. The IY programme has been used extensively and studied internationally both as a treatment and as a preventative strategy for behavioural problems in children, providing ample evidence of its outcomes. Our intention was rather, to pilot The Changing Lives Initiative programme under real-world conditions and with samples reflecting local communities, something which is increasingly recognised as important and novel.
- Attrition rates from baseline to follow up was high, but this is not uncommon in such interventions. Previous research has found that attrition rates have been as high as 60% in some cases (Michael, 2018). The richness of data gathered from participants in this study provide valuable insights into how The Changing Lives Initiative programme was experienced by families and the aspects of their lives that benefited most from support. This not only included relationships with children and service providers but positively impacted everyday situations that had previously been a source of stress for the families, providing valuable opportunities for learning for policymakers and practitioners.

Concluding Thoughts

The Changing Lives Initiative evaluations have provided much evidence and learning in terms of the effectiveness, cost effectiveness and implementation of a community-based early intervention programme to address the growing prevalence and impact of ADHD in Northern Ireland, the Republic of Ireland and Scotland. The findings in this report provide compelling evidence for the potential of a specifically designed ADHD parenting programme with tailored ADHD Information & Awareness Sessions for parents and professionals to achieve lasting change for families whose children experience behaviour consistent with ADHD.

The Changing Lives Initiative programme brought about qualitative improvements to children's behaviour by reducing the frequency, intensity, duration and severity of problem behaviours, the impact of which extends to the day-to-day functioning of the child and their family. The programme not only reduced challenging behaviours but built important social and emotional regulatory skills. Even parents whose children experienced limited change in ADHD symptomology, still viewed the participation and process as successful. Parents reported the importance of the support they received from other parents in similar situations, and increased coping skills and awareness to explain this feeling of success.

Improvements in parent-child relationship were widely reported as well as improved functioning in family relationships, including parent-to-parent and child-to-siblings. There was a significant reduction in levels of stress experienced by parents as well as negative patterns of interaction between parent and child. ADHD is a disorder characterised by persistent and impactful behavioural patterns that affect a child's experience of the world as well as affecting how the child is viewed by their world. The project at its core offered tangible skill development to parents, which gave them the opportunity to be active participants in their child's treatment.

It is evident from the evaluations that the project would not have been possible without a strong foundation of cross-sector partnerships, relationship building and cooperation. Partnerships brought strength and added value across all aspects of the project – including within families, as well as parent-to-parent, facilitator-to-parent, and among Project Partners, schools and those involved in children's lives including agencies and services best placed to identify families in need of the intervention.

Training, support and fidelity measures were used extensively throughout the project to ensure the quality of The Changing Lives Initiative programme. It was, however, also key to the success of the project to provide appropriate flexibility and autonomy in the delivery of the programme to adapt elements to suit the target population and differing situations. The project worked with a target population with specific and often complex needs and relied on the skills and expertise of facilitators to engage

parents considered 'hard to reach'. A key function of the project was ensuring that Programme Facilitators had appropriate experience, skills and support to make informed adaptations to match the needs of the group and the barriers they may encounter, without affecting programme fidelity.

Information and Awareness sessions for professionals, such as early years providers, teachers and allied health professionals, were well attended and requested throughout the project. The Changing Lives Initiative trained in excess of 1,700 professionals against an anticipated target of 500. This highlights the need for increased knowledge of ADHD and effective strategies, among a wide range of practitioners. These Information and Awareness sessions continued to grow in popularity when moved online, when there were no geographical barriers to attending.

In response to the COVID-19 pandemic, the well-structured IY programme content and training techniques translated effectively to remote delivery via Zoom. Parents completing the programme through Zoom reported high levels of acceptability, demonstrating a very viable alternative to face-to-face delivery during Lockdown restrictions.

Recommendations and Areas for Further Study

There is much that needs to be done to improve the lives of families with children at risk of ADHD. The findings from this study suggest the following recommendations:

- Early interventions that target children at risk of ADHD in preschool/primary school offer a potential avenue for improving educational and social functioning of vulnerable children. Long-term support is needed for intersectoral and interagency collaborative planning and service delivery targeting early intervention for children at risk of ADHD and their families.
- There is a demand for focused information, awareness and training in effective strategies to target the behaviours associated with ADHD in childhood but also for adolescents. This demand extends beyond the geographical areas of the three delivery partners. There is also demand across a diverse range of professions, including education, allied health, early years, medical and psychological services. It is recommended that a needs analysis be conducted assessing gaps in knowledge and requirements per profession to support children, young people and their families.
- There is a need for longitudinal research to better understand the costs and benefits of early interventions programmes and to ascertain whether such approaches can improve long term outcomes in ADHD. The learning from this partnership and legacy of the cross-border framework created is therefore an important area for further research.

The case for scaling up The Changing Lives Initiative

The Changing Lives Initiative approach is heavily aligned with current health and broader government policy in all three project jurisdictions. It fits well with current policies in terms of early intervention; empowering and supporting parents and communities; ensuring best outcomes for children; and complementing and optimising current resources and infrastructure.

The Changing Lives Initiative project and its evaluations have added to the body of evidence supporting the effectiveness of early and psycho-social based interventions in treating / preventing ADHD, and has demonstrated the feasibility and benefits of delivering this type of intervention as a community based, multifaceted initiative.

It is well documented that families with children with behaviours consistent with ADHD lack support in the early years when behaviours are emerging that make parenting and teaching difficult. The assessment and diagnostic process across jurisdictions in this Initiative start well after the first signs of behaviours emerge. The lack of support available until this process is activated leaves parents feeling unsupported and labelled as 'bad parents', and their children unsupported and developing maladaptive coping strategies and behaviours, failing in school, developing poor self-esteem and feeling like the 'naughty child'.

What The Changing Lives Initiative programme offers when targeted to support families with children whose behaviour is consistent with ADHD is the opportunity for parents to increase their skill base, meet the needs of their child, and feel supported by others coping with similar behaviours. It offers effective tools, tailored training and an intervention that does not need a diagnosis to bring about positive change.

The Changing Lives Initiative model has much to offer in terms of a review of ADHD service provision. Not only should The Changing Lives Initiative programme be continued in the current project locations but efforts must be made to scale up service provision to make the intervention available to all families that require it across the Republic of Ireland, Northern Ireland and Scotland. The results of project evaluations provide much information to inform scaling up of the intervention.

With the current COVID-19 pandemic and the additional pressure on Child and Adolescent Mental Health services, there has never been more need to look at new models of intervention, which could not only provide better outcomes for children with behaviour consistent with ADHD, but free up scarce mental health resources towards addressing the needs of other children and young people who require support and treatment.

What families had to say about The Changing Lives Initiative

Pre-intervention

Every day would be a challenge, chaotic. A battle of wills. Just constant.

He didn't feel loved by myself and his daddy. Different treatment for him than his sister.

A lot of emotional outbursts. And afterwards, so distraught and very ashamed of himself for his behaviour. Peers picking up on this. Wasn't really being accepted ... difficulty making friends. A lot of extreme emotions.

Going out for a family occasion, you would have had that fear about what he was going to do.

I resented my child. Dreading in the morning to see what that day was going to bring.

I resented my child. Dreading in the morning to see what that day was going to bring.



Post-intervention

You have changed our lives and helped us achieve a happy home for our child.

This group has made a massive difference to my confidence. It has made me happy to talk about my kids with other parents and teachers. It has made a big difference to my kid's behaviour. I would recommend this course to anyone.

Even going to school in the morning. Days out are far more relaxed, we can take him anywhere now. Putting the things the programme taught you in place, just makes vit in general so much easier.

I got my son back, I got my family back. I got more support from this group than anything else.

My son got his childhood back

We gained a son through the project. He is a totally different child; the child I knew he could be. We got our family back.

He is happier too. Not as much telling off. Knows when I say something now that I mean it.

Nobody teaches you how to be a parent, I think everybody should do the programme.





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