

Changing Lives Initiative

Opening Statement to the Oireachtas Sub-Committee on Mental Health

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An Early Intervention Approach to ADHD

Delegation

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INTRODUCTION

Cathaoirleach, we welcome this opportunity to make a submission to the Sub Committee on Mental Health and thank you, and the members for this opportunity.

Attention Deficit Hyperactivity Disorder (ADHD) is a pervasive and impactful condition that can have a profound effect on many aspects of a child's life. These issues often persevere into adulthood resulting in ongoing mental health problems, higher levels of unemployment and higher risk of offending and incarceration. Young people with ADHD are twice as likely to come from socio-economically disadvantaged areas.

New diagnoses of ADHD have risen in recent years across all age groups.

ADHD accounts for over one-third of referrals to Child and Adolescent Mental Health Services (CAMHS) in the Republic of Ireland.

National and international guidelines - World Health Organisation (WHO) and National Institute of Health and Care Excellence (NICE) - recommend high quality group-based parent programmes as a first course of treatment for young children with ADHD.

Unfortunately, this treatment is currently not available to many families. For children with ADHD/queried ADHD there are often lengthy waiting lists for assessment and limited treatment options offered.

The focus in many instances is on pharmaceutical treatment.

THE CHANGING LIVES INITIATIVE

The Changing Lives Initiative is an innovative community led early intervention programme for ADHD.

The programme was delivered and evaluated through a 3.5year EU funded project involving partners in the Republic, Northern Ireland and Scotland. The EU funded project worked with over 2,000 families in Louth, Belfast and Western Scotland from late 2017 to early 2021.

The programme targets families with children aged 3-7 who demonstrate behaviours consistent with ADHD but are oftentimes too young or have not had access yet to formal assessment and diagnosis. Potential families are identified through health, educational and community services, or can self-refer to the programme.

EVIDENCE

Three large-scale evaluations were conducted as part of the EU funded project, results demonstrating:

- A significant and sustained reduction in ADHD related behaviours.
- Significant and sustained reduction in other emotional and conduct problems.
- Parenting skills and functioning improved.
- Parental stress reduced.
- High levels of parental satisfaction with the intervention.

On foot on these evaluations, the Changing Lives Initiative has just successfully completed detailed assessment to be one of the first five interventions included in the new **What Works Ireland Evidence Hub** launched last month by the Department of Children, Equality, Disability, Integration and Youth.

The Evidence Hub includes programmes which demonstrate improved outcomes for children and young people across the five national outcomes for children under Better Outcomes, Brighter Futures.

ROLL OUT OF THE PROGRAMME

Throughout the EU funded project, the Changing Lives Initiative partners engaged with the statutory health services North and South around sustainability and roll out of the intervention.

At the end of last year funding was secured from HSE Mental Health Operations for an initial pilot rollout of the Changing Lives Initiative programme in Counties Louth and Meath. The service began rolling out in January this year.

There has been an overwhelming response from statutory, community services and families to the programme.

SUBMISSION TO OIREACHTAS SUB-COMMITTEE ON MENTAL HEALTH

We believe the Changing Lives Initiative, the results of its evaluations, and the potential benefits of further roll out of the programme, has great relevance to the work of the Sub-Committee.

This highly successful community led initiative has a proven ability to improve outcomes for families and has the potential to provide a positive solution to current gaps and shortages in services for children with mental health/neurodevelopmental issues.

The initiative is heavily aligned with achievement of the National Mental Health Policy, with potential to contribute to 11 recommendations in the Sharing the Vision Strategy 2020 – 2030.

Value of this Intervention:

- Provides treatment in line with international best practice (WHO recommendations, NICE guidelines)
- Responsive and effective.
- Early identification and intervention.
- No diagnosis required.
- No waiting lists.
- High levels of satisfaction.
- Potential to reduce waiting lists, improve outcomes and reduce the need for further treatment.

Discussions with HSE Mental Health Operations around further expansion of the programme have been very positive, but large scale roll out and ongoing funding will require wide ranging support from all stakeholders, including Government.

A PARENT'S PERSPECTIVE

Before we conclude, we wanted to ensure we captured the perspective of families in our opening statement. A parent who availed of the programme during the EU funded project, has kindly offered to share her story:

I am a parent to two incredible, wonderful boys with ADHD.

And I can tell you wholeheartedly that parenting ADHD is a privilege.

It's not the type of parenting that I imagined I would do, and coming to terms with it in the beginning was difficult.

But to step into my boys' shoes and view the world the way they do has changed my perception of many things.

As we all do as parents, I have worked tirelessly behind the scenes to find a different way of teaching so that my children can be on par with their peers, academically, socially and emotionally.

I needed to find a way to encourage their independence and their abilities.

Like the ability to listen and follow instruction, or the ability to stay focused and finish the task at hand, the ability to ride a bike or the ability to understand his role within a team sport and not take over!

I learned early on to stop trying to fit them into society's expectations.

And instead, I changed my way of life to flow with theirs.

So now, my boys are thriving.

They are able.

They are intelligent, funny, empathetic and popular amongst their peers.

People stop me in the street to tell me how polite, friendly and helpful they both are.

And like every other child, they both have dreams of conquering the world.

I tell you all this today because it was the Changing Lives Initiative that brought me to where I am.

We went from crèche to crèche as we struggled with behavioural issues.

We had half-day school days for months as I worked with the school to ease them into a settled routine.

We had movement breaks and sensory rooms.

We had meltdowns and classroom evacuations.

We had the endless birthday parties to which they were never invited.

Then I was blessed with a space as a parent on the Changing Lives Initiative programme.

The strategies that we were given within the programme had such a massive and positive impact on our lives at home that it gave me hope again as a mam.

I finally felt empowered as a parent.

Because of the tools I was given from the Changing Lives Initiative, my boys advanced from fulltime special unit access to 90% mainstream, the Primary School saw such a turnaround in my eldest within 4 years that they awarded him a never-before-given plaque for courage for embracing his uniqueness and unapologetically being his wonderful self every day.

It was the Changing Lives Initiative that gave me the strategies to encourage that confidence and self-belief in my son.

He is now in full-time mainstream in Secondary School, academically ahead and voted most popular kid.

I now feel that no matter what comes my way as a mum, I can tackle it.

Because of the programme, I feel equipped and confident, and the relationship I now have with my 2 boys is unbreakable.

And nothing matters more to me than that.

Completing the Changing Lives Initiative programme gave me the confidence to go forth and re-educate myself in the world of special needs, so I could become a supporter in my local area for other parents who are struggling.

We need more programmes like this made available in every community, so that we all can reap the benefits of early intervention.

FURTHER INFORMATION

The full report on the Changing Lives Initiative evaluations is available here:
<https://changinglivesinitiative.com/project-report/>

ADDITIONAL NOTES

The EU funded project was led and delivered in ROI and NI by community and voluntary organisations (Archways as lead Partner, The Genesis Programme in County Louth, Colin Neighbourhood Partnership in West Belfast – along with NHS Highland in Scotland and Dundalk IT as evaluation partner).

Funding was provided by the Interreg VA programme, as managed by the Special EU Programmes Body.

The HSE funded pilot is being delivered by the lead partner Archways.