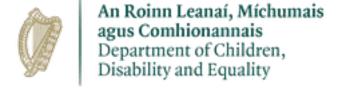


### Submission to the Public Consultation on

## Statement of Strategy 2025 - 2027 Dept. of Children, Disability, and Equality







## "When I talk about this tug of responsibility [for FASD policy], I genuinely see it as a disability piece."

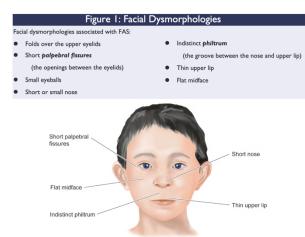
- Then Minister of State for Disability, Anne Rabbitte TD (17 Apr 2024)<sup>1</sup>

#### Introduction

Foetal Alcohol Spectrum Disorder (FASD) results when prenatal alcohol exposure affects the developing brain and body. FASD is a spectrum, and each person living with FASD is affected differently. While any of 428 recognised conditions can co-occur (co-morbidities), FASD is at its core a lifelong neurodevelopmental condition<sup>2</sup>.

All people living with FASD have many strengths. Early diagnosis and appropriate support are essential, especially for executive functioning.

FASD is an umbrella term used to describe several conditions which can result from consuming alcohol during pregnancy. Namely, Foetal Alcohol Syndrome (FAS); Alcohol Related Neurodevelopmental Disorder (ARND); Partial Foetal Alcohol Syndrome (PFAS); and Neurobehavioral Disorder-Prenatal Alcohol Exposure (ND-PAE).



<sup>3</sup> FASD is a broader term than foetal alcohol syndrome (FAS) which makes up around 10% of cases it includes those affected by antenatal exposure to alcohol, but who do not fulfil the full criteria for FAS. Those being:

- Antenatal growth retardation
- Facial dysmorphology (see graphic 1)
- CNS dysfunction
- Neuro-behavioural disabilities<sup>4</sup>

Presently, the Republic of Ireland does not recognise FASD as a disability. The Minister of State for Disability, Deputy Naughton told Deputy Aidan Farrelly in response to a parliamentary question; "FASD is not deemed to be a disability at this time" in March of this year<sup>5</sup>.

<sup>&</sup>lt;sup>1</sup> Houses of the Oireachtas (2024). *Topical Issue Debate on Foetal Alcohol Spectrum Disorders* 

<sup>&</sup>lt;sup>2</sup> Popova, S., Lange, S., Shield, K., Mihic, A., Chudley, A. E., Mukherjee, R. A. S., Bekmuradov, D., & Rehm,

J. (2016). Comorbidity of fetal alcohol spectrum disorder: a systematic review and meta-analysis

<sup>&</sup>lt;sup>3</sup> Chandra, Z., & Schwartz-Bloom, R. (2008) <u>Understanding Fetal Alcohol Spectrum Disorders: A Comprehensive Guide for Pre-K – 8 Educators</u>

<sup>&</sup>lt;sup>4</sup> HSE (2024). PQ 45065/24 - Deputy Mark Ward

<sup>&</sup>lt;sup>5</sup> Houses of the Oireachtas (2025). PQ 12516/25 – Deputy Aidan Farrelly



#### **About FASD Ireland**

FASD is the national organisation supporting people living with FASD in Ireland, their families/caregivers, and professionals in Education, Health & Social Care and the Justice sector. FASD Ireland is part-funded by the HSE Mid-West Disability Services. We work to create awareness of the risks around alcohol and pregnancy at all levels and in turn, working to lower prevalence going forward. We also work with professionals to provide training about working to support people living with FASD – particularly in Education, Health & Social Care and the Justice sector.

In March 2023, we established our national telephone helpline, FASD Hub Ireland™ which provide expert advice, guidance, support and advocacy for anyone living with FASD, their families or carers, or professionals working to support someone living with the condition in Ireland. We also operate FASD Hub Northern Ireland™ which offers the same service to the FASD community in Northern Ireland. An online enquiry platform is also available if people prefer to submit their questions in writing.

Our organisation works across three pillars; awareness, education, and support

We work to highlight a greater **awareness** of FASD in society, which is the only preventable neurodevelopmental disorder. The HSE estimates that up to 7.4% of the population live with some form of FASD and as it stands there is no standard criteria for diagnosis, and no State support for people living with FASD.

We provide **education** about FASD to educators, students, private companies, and the public sector to equip them with knowledge and skills so that they can support people living with FASD. We provide guidance about how we can all work together to create a society where people with FASD are able to live a more inclusive life. Around 125,000 members of the Irish workforce live with FASD, whether they know it or not. So, it is vitally important that people living with FASD are supported at work as needed.

We **support** the FASD community by bridging the gap between the voices of living experience and key stakeholders and policymakers to improve support and services for people living with FASD, and their families and carers. We also support State Agencies like TUSLA, the HSE, and An Garda Síochána to better support people living with FASD who are accessing their services.

FASD Ireland is a proud member of the following:

- The Disability Federation of Ireland
- Children's Rights Alliance
- EUFASD the European Alliance for FASD
- The HSE Experts by Experience Group on Alcohol and Pregnancy

FASD Hub Ireland ™ | Mon to Fri, 10am to 4pm | 065 670 3098



# The Need to Recognise Foetal Alcohol Spectrum Disorder (FASD) as a Disability in Line with International Best Practice

As outlined on the previous page, Foetal Alcohol Spectrum Disorder (FASD) is a lifelong neurodevelopmental disability resulting from prenatal alcohol exposure. It encompasses a range of physical, cognitive and behavioural challenges that have a significant impact on the lives of people living with the condition, and their families. Recognising FASD as a disability is crucial for ensuring appropriate support and services, aligning with international best practices and Human Rights standards.

#### International Best Practices:

#### United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)

The Convention emphasises the need for inclusive policies that protect the rights of people who are living with disabilities, including people living with FASD. The Convention advocates for equal opportunities in education, healthcare and social participation<sup>6</sup>.

The second paragraph of Art 1 of the Convention identifies that "persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others". According to Harding & Whittingham, Given the known impairments associated with FASD across the lifespan, it would fall well within the definition of disability provided by the Convention. That being said, the inability to secure a diagnosis because of the limited diagnostic resources has meant that people who are living with FASD may not be able to access the necessary supports and services and may continue to experience ongoing mental health effects of discrimination and stigma<sup>8</sup>. <sup>9</sup>

Furthermore, even when there is recognition of FASD as a Disability, people who are living with FASD are often required to meet the diagnostic criteria for an intellectual disability (i.e., an IQ below 70) to receive support and services despite evidence of the scope and severity of needs<sup>10</sup>. <sup>11</sup>

<sup>&</sup>lt;sup>6</sup> Harding, K., & Whittingham, L. (2021). <u>Framing Fetal Alcohol Spectrum Disorder Policy, Practice, and Research Using the United Nations Convention on the Rights of Persons with Disabilities</u>

<sup>&</sup>lt;sup>7</sup> United Nations. (2006). <u>Convention on the Rights of Persons with Disabilities and Optional Protocol</u>

<sup>&</sup>lt;sup>8</sup> Green, C.R., Cook, J., and Salmon, A. (2015). Why is FASD Diagnosis important?

<sup>&</sup>lt;sup>9</sup> Ibid, ref. 6

<sup>&</sup>lt;sup>10</sup> Ferreira, V.D.L., & Cruz, M.S. (2017). <u>Intelligence and Fetal Alcohol Spectrum Disorders: A Review</u>

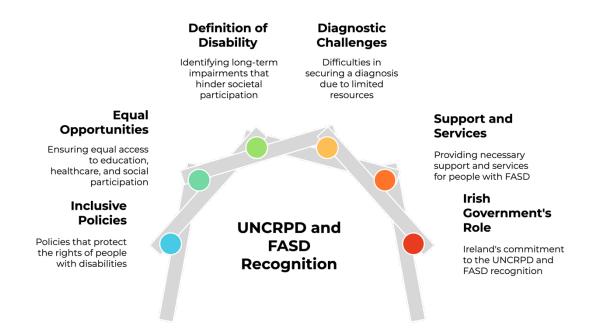
<sup>&</sup>lt;sup>11</sup> Ibid, ref. 6



The Irish Government signed the Convention in 2007 and it was ratified in 2018. Ireland is the only country within the EU and the wider OECD not to recognise FASD as a disability.

In October 2024, the Irish Government ratified the Optional Protocol of the UN CRPD. As the Minister works to implement the Optional Protocol with the support of the Department, IHREC and her Government colleagues, we strongly recommend that she makes the recognition of FASD as a Disability a key piece of the remedying work to ensure that all people with disabilities are equal not just to every other person in society, but also that all people with disabilities have equal rights of access to diagnosis and support.

Art. 25 of the UN CRPD holds that people with disabilities are provided with the provisional right of "enjoyment of the highest attainable standard of health without discrimination on the basis of disability" this is not consistent with Ireland's treatment of people living with FASD who are not on equal footing with other people with disabilities as they have no formal recognition of their disability or access to diagnosis and support. We would advise the Minister to remedy this as a matter of priority for her and for the Department as a key part of this Statement of Strategy.



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<sup>12</sup> Ibid, ref. 7



#### **Early Diagnosis and Intervention:**

International studies have highlighted the importance of early diagnosis and intervention for people living with FASD. Early support can significantly improve outcomes and reduce the risk of secondary disabilities, which will be discussed in greater detail below.

At their White Paper symposium last year, FASD United, the National Organisation for FASD in the United States identified 6 reasons to screen before of the age of 6 which are as follows, underpinned by research that shows early identification and diagnosis of FASD, especially before 6 years of age, helps to reduce challenges later on by:

- Empowering parents with a sense of understanding
- Reducing the risk of maltreatment toward the child if behaviours are misunderstood
- Increasing opportunities for timely interventions
- Identifying appropriate specialty care
- Making it easier to discuss accommodations or considerations in education
- Finding peer and community-based programmes<sup>13</sup>

#### **Importance of Early Diagnosis**

- 1. Understanding Strengths & Challenges
  - Early diagnosis allows for a comprehensive understanding of an individual's strengths and challenges, facilitating entry into appropriate intervention and support services. This understanding is crucial for provided tailored interventions and wraparound support to meet the unique and specific needs of the individual<sup>14</sup>.
- 2. Mitigating Secondary Disabilities
  - Early identification and intervention can prevent or reduce the severity of secondary disabilities that would be associated with FASD, such as mental health issues, substance use issues, and difficulties with daily living. Studies indicate that approximately 90% of people who live with FASD experience mental health challenges, and 48% face substance use issues<sup>15</sup>.
  - o In a Canadian study, 26% of individuals aged 6 to 59 years who were assessed for FASD experienced suicidality. This includes suicidal ideation, suicide-related communications and suicide attempts. Some individuals living with FASD experience suicidality at a significantly younger age compared to those without the condition. This early onset

<sup>&</sup>lt;sup>13</sup> FASD United. (2024). <u>FASD Symposium White Papers: Co-Creating Recommendations for Progress in the FASD Field and Community</u>

<sup>&</sup>lt;sup>14</sup> Cook, J., McFarlane, A., Flannigan, K., Hanlon-Dearman, A., & Unsworth, K. (2023). <u>Why FASD Diagnostic Assessment is Important</u>

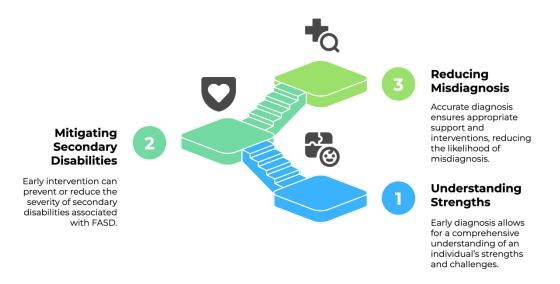


highlights a greater need for early intervention and tailored specific supports<sup>16</sup>. Other research in the United States highlighted that adults living with FASD are five times more likely to attempt suicide than those within the general U.S. population<sup>17</sup>.

#### 3. Reducing Misdiagnosis

- Due to the complex and multifaceted nature of FASD symptoms, people are often misdiagnosed with other conditions. Early and accurate diagnosis helps to ensure that people living with FASD, their families/caregivers and EHSC professionals working with them receive the correct support and appropriate interventions, reducing the likelihood of misdiagnosis and inappropriate treatment<sup>18</sup>.
- o In Ireland, the prevalence of FASD is estimated to be up to 7.4% of the population which equates to roughly 381,000 people<sup>19</sup>. However, this figure from the HSE is an estimate, the source of which is not cited, and it has such a wide margin of error that it would be simply not possible to effectively plan service provision and support for the people living with FASD in Ireland into the future. It is essential that to effectively service plan, we must understand the true face of the rate of prevalence in this country. This work to capture an accurate prevalence and epidemiology of the condition across the State should take place immediately to inform future policy and financial decisions that are taken by the Minister and Government colleagues with respect to FASD.

#### **Steps to Improve FASD Outcomes**



<sup>&</sup>lt;sup>16</sup> Morrison, K., Harding, K., McMorris, C., & Badry, D. (2022). *FASD and Suicidality: Rates and Associated Factors* 

<sup>&</sup>lt;sup>17</sup> Centers for Disease Control and Prevention (CDC). (2024). <u>Data and Statistics on FASDs</u>

<sup>&</sup>lt;sup>18</sup> Ibid, ref **14** 

<sup>&</sup>lt;sup>19</sup> HSE. (2022). <u>HSE Position Paper on Prevention of Fetal Alcohol Spectrum Disorders (FASD)</u>



#### **Benefits of Early Intervention:**

#### 1. Improving Developmental Outcomes

 Early intervention services, such as therapies to support speech, motor skills, and social interactions, can significantly improve developmental outcomes for children living with FASD. These services are most effective when they address specific impairments and build upon the child's strengths<sup>20</sup>.

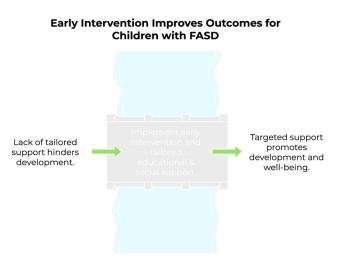
#### 2. Educational Support

Currently in Ireland, 25% of children/young people living with FASD will exit education before the age of 15<sup>21</sup>. Early diagnosis enables children to be placed in appropriate educational streams that are tailored to their unique learning needs. Additional educational support can help children and young people living with FASD to reach their full potential by addressing their specific challenges and promoting positive learning experiences<sup>22</sup>.

#### 3. Health & Social Care Involvement

Early diagnosis also facilitates access to social work and family support that can provide vital assistance to families and school staff. However, it is essential that anyone who is supporting the child/young person and their family in a social work capacity demonstrate a clear understanding of FASD, which is not currently the case in this country. In a recent survey by the HSE, 48% of social care professionals surveyed said that they were not confident in their knowledge of the presentation of FASD<sup>23</sup>. This is deeply concerning given the high prevalence and incidence of that cohort interacting with social work. It is essential therefore, that every

social care
professional in
Ireland should take
be required to take
FASD training in
order to be CORU
registered and
compliant.



<sup>&</sup>lt;sup>20</sup> Centers for Disease Control and Prevention (CDC). (2023). <u>Treatment of FASDs | Fetal Alcohol Spectrum Disorders</u>

<sup>&</sup>lt;sup>21</sup> Tobin, K., McCarthy, E., and Paavonen, A. M. (2023). <u>FASDcare: Understanding the experiences and needs of family caregivers of people with Fetal Alcohol Spectrum Disorder (FASD) in Ireland</u>
<sup>22</sup> ibid

<sup>&</sup>lt;sup>23</sup> Source available upon request



#### **Challenges and Future Directions:**

#### 1. Diagnostic Challenges

Despite the benefits of early diagnosis, identifying FASDs in infancy where possible and early childhood remains challenging with no standard criteria for diagnosis and support existing currently in Ireland. Children/young people living with FASD often phenotypically resemble those with other neurodevelopmental and neurobehavioural conditions, making accurate diagnosis difficult. Continued research and development of a single agreed standard diagnostic tool is essential to improve early identification and therefore support for children/young people living with FASD<sup>24</sup>.

#### 2. Comprehensive Assessment

- A comprehensive multidisciplinary assessment process is vital for individuals with prenatal alcohol exposure (PAE). This process provides important information about learning, behaviour, and physical and mental health, guiding appropriate care and support<sup>25</sup>.
- o The core variables for the diagnosis of FASD have remained somewhat consistent, and typically include documentation of prenatal alcohol exposure, evidence of growth impairment, presence or otherwise of sentinel facial features [in around 10% of cases], a wide range of structural brain abnormalities and neurobehavioural impairments, and birth defects<sup>26</sup>. However, the definitions and diagnostic cutoffs for each of these criteria vary depending on the diagnostic criteria used<sup>27 28 29</sup>.

#### 3. Tailored Interventions and Support

- Evidence-based programmes that are tailored to FASD are being studied, targeting areas such as arithmetic, social behaviours, attention, self-regulation, language development, and literacy. These interventions hold promise but require further research and investment to optimise their effectiveness<sup>30</sup>.
- o Some possible interventions that can be undertaken are outlined in appendix 1 below. It is essential that any interventions taken by families should be taken under the supervision of, and in partnership with

<sup>&</sup>lt;sup>24</sup> Carter, R.C., Jacobson, J. L., & Jacobson, S. W. (2019). *Early Detection of Fetal Alcohol Spectrum Disorders: An Elusive but Critical Goal* 

<sup>&</sup>lt;sup>25</sup> Ibid, ref. 14

<sup>&</sup>lt;sup>26</sup> Popova, S., Charness, M. E., Burd, L., Crawford, A., Hoyme, H. E., Mukherjee, R. A., Riley, E., & Elliot, E.J. (2023). *Fetal Alcohol Spectrum Disorders* 

<sup>&</sup>lt;sup>27</sup> Brown, J. M., Bland, R., Jonsson, E., & Grenshaw, A. J. (2019). <u>The standardization of diagnostic criteria for fetal alcohol spectrum disorder (FASD): implications for research, clinical practice and population health</u>

<sup>&</sup>lt;sup>28</sup> Burd, L., Burd, M., Klug, M. G., Kerbishian, J., & Popova, S. (2019). *Comorbidity and intellectual disability* 

<sup>&</sup>lt;sup>29</sup> Ibid, ref. 25

<sup>&</sup>lt;sup>30</sup> Ibid, ref. 23



Education, Health and Social Care. It is therefore essential to ensure that EHSC professionals working to support families with FASD are fully trained and capable in carrying out/supporting these interventions.

## Better Outcomes: The impact of early and targeted interventions for Children and Young People living with FASD

Early and targeted interventions – guided by a comprehensive, multidisciplinary assessment – can significantly improve long-term outcomes for children/young people living with FASD across several critical domains:

#### 1. Educational Outcomes:

Children/young people living with FASD often face challenges in attention, memory, executive functioning, and adaptive behaviour, which can hinder academic success without the right supports and accommodations in place. When these challenges are identified early:

- o Individual Education Plans (IEPs) An IEP is a written document prepared for a named student that specifies the learning goals that are to be achieved by the student over a set period of time and the teaching strategies, resources and supports necessary to achieve those goals<sup>31</sup>.
- Specialised teaching strategies there many ways in which children with varying levels of identifiable need can be supported in the classroom to achieve their full potential. Visual supports, repetition, structured routines, reduced timetables and team teaching are just some of the possibilities that can be explored in the classroom.
- Early literacy and numeracy interventions can prevent any academic delays from compounding over time.
- o Result: Children/young people are more likely to stay engaged in school, experience academic success within their ability, and avoid school exclusion or avoidance<sup>32</sup>. The rate of young people living with FASD exiting education before the age of 15 will decrease through young people feeling supported by the school community in their holistic development.

#### 2. Mental Health Outcomes:

Without support, people living with FASD are at very high risk for secondary mental health issues, such as anxiety, depression, and conduct disorders. 94% of people living with FASD aged 12 and over have a mental health condition<sup>33</sup>. Early intervention can:

 Provide emotional regulation strategies (through DBT informed approaches – see Appendix 1)

<sup>&</sup>lt;sup>31</sup> NCSE. (2006). *Guidelines on the Individual Education Plan Process* 

<sup>&</sup>lt;sup>32</sup> Roozen, S., Stutterheim, S. E., Bos, A. E., Kok, G., and Curfs, L. M. G. (2022). <u>Understanding the Social Stigma of Fetal Alcohol Spectrum Disorders: From theory to interventions</u>

<sup>&</sup>lt;sup>33</sup> Streissguth, A. P., Bookstein, F., Barr, H. M., Sampson, P. D. (2004) <u>Risk Factors for Adverse Life</u> <u>Outcomes in Fetal Alcohol Syndrome and Fetal Alcohol Effects</u>



- Reduce feelings of shame and frustration by helping children/young people to understand their brain based differences
- Offer family-based support to reduce stress and improver caregiverchild relationships (through strategies like NVR – see Appendix 1)
- o Result: Improved emotional wellbeing, reduced risk of psychiatric comorbidities and better long-term mental health<sup>34</sup>.
- 3. Social Integration and Life Skills:

Children/young people living with FASD often struggle with social communication, impulse control, and understanding social norms. Early intervention can:

- o Teach social skills explicitly through structured programmes
- o Support peer relationships in school and community settings
- Build adaptive life skills (e.g. hygiene, time management, money handling) through occupational therapy and CDNT support
- o Result: Greater independence, stronger peer relationships, and reduced risk of social isolation or involvement with the Justice system<sup>35</sup>.
- 4. Family and Community Outcomes

Early intervention also benefits families and communities:

- Caregivers receive training and support from organisations like FASD
   Ireland which in turn reduces burnout and improves family stability
- Schools and public services are better equipped to respond to the child/young person's needs, reducing the need for crisis intervention
- Communities benefit from reduced long-term costs associated with unsupported FASD, including Education, Health & Social Care, and Justice system involvement.

All of the evidence above outlines that when children/young people living with FASD receive early, targeted, and coordinated interventions based on a thorough assessment, they are more likely to:

- o Remain in education and succeed within their academic ability
- o Build and maintain meaningful relationships
- o Live more independently within their means
- Avoid negative outcomes such as homelessness, addiction or incarceration

<sup>&</sup>lt;sup>34</sup> Kodituwakku, P., and Kodituwakku, E. (2014). <u>Cognitive and behavioural profiles of children with Fetal Alcohol Spectrum Disorders</u>

<sup>&</sup>lt;sup>35</sup> Petrenko, C. L. M. (2015) <u>Positive behavioural interventions and family support for fetal alcohol</u> <u>spectrum disorders</u>



Underscoring all of this work, it essential that the Department has a plan for the sustainability of organisations like FASD Ireland who provide advocacy, expert advice and research to support

The Department of Children, Disability and Equality plays a pivotal role in shaping inclusive and responsive services for children and families across Ireland. In this context, it is essential that the Department actively supports the sustainability and growth of specialist organisations such as FASD Ireland who provide critical services, advocacy, and education for people living with FASD and their families/caregivers.

#### Why our work matters:

- Direct support to families: We provide direct support to families and caregivers of people living with FASD, including peer support, expert advice, advocacy, information and navigation of services.
- Training and education: We provide a wide array of training and education for professionals in Education, Health & Social Care, Justice
  - and many other sectors whose services users are people living with FASD and their families.
- Advocacy and policy engagement: To ensure that the voices of people living with FASD are a central part of the conversation, in line with the partnership principles, and are heard at the highest levels of policy level decision-making in this country, such as the Department of Children, Disability, and Equality.
- Community outreach and awareness: to eliminate stigma around FASD which does exist in our society, and also to reduce the incidence of alcohol and pregnancy through our work with the HSE and Government Departments.
- These services are vital in a landscape where FASD remains underrecognised and under-resourced, despite having one of the highest rates of prevalence in the world and significant impact on individuals, families, and public services.

#### The Need for Sustainable Funding and Partnership of FASD Services:

To ensure long-term impact, organisations like FASD Ireland, a section 39 body working directly with families and CDNTs require:

Core funding to maintain and expand essential services.



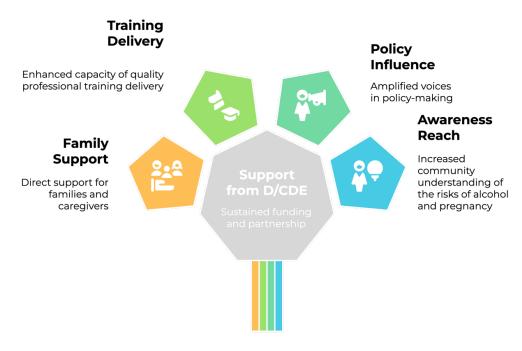
- Strategic partnerships with the Department of Children, Disability and Equality and other Departments to co-develop national strategies and models of service.
- Inclusion in national disability and health frameworks, ensuring that FASD is recognised and resourced alongside other neurodevelopmental conditions, in line with United Nations Convention on the Rights of Persons with Disabilities.

Sustainable support from the Department of Children, Disability, and Equality would not only strengthen the capacity of FASD Ireland but also contribute to broader Government goals of inclusion, early intervention, and improved outcomes for children with disabilities, in line with the commitments in the Programme for Government<sup>36</sup>.

#### A Strategic Investment:

Investing in the sustainability of FASD Ireland is a strategic and cost-effective measure. It enables early identification, reduces the burden on crisis services, and empowers families and professionals to respond effectively to the challenges and strengths of children/young people within their care who are living with FASD. In doing so, it aligns with international best practice, as outlined in the start of this submission, meeting the principles of the UN Convention on the Rights of Persons with Disabilities, which calls for the active involvement of civil society organisations in disability policy and service delivery<sup>37</sup>.

#### **Department Support Enhances FASD Ireland's Impact**



<sup>&</sup>lt;sup>36</sup> Government of Ireland. (2025). Programme for Government 2025 – Securing Ireland's Future

<sup>&</sup>lt;sup>37</sup> Ibid, ref. 7



#### Appendix 1: Key Examples of Targeted Interventions that could be supported by the team around a child/young person living with FASD:

#### PACE:

- o The PACE model, developed by Dr. Dan Hughes, is a relational approach that helps caregivers and professionals build trust and emotional safety with children who have experienced developmental trauma or neurodevelopmental challenges like FASD.
  - 1. P Playfulness Helps reduce shame and defensiveness. Light, non-threatening interactions can build connection and reduce anxiety, which is often heightened in children/young people with FASD due to sensory and cognitive overload.
  - 2. A Acceptance Validates the child's internal experience without judgment. This is crucial for children/young people with FASD, who may struggle with impulse control or emotional dysregulation. Acceptance helps them feel safe even when their behaviour is challenging.
  - 3. C Curiosity Encourages understanding the 'why' behind behaviours rather than reacting to them. For example, instead of saying "Why did you do that?", a caregiver trained in PACE might say, "I wonder what was going on for you then what happened?"
  - 4. E Empathy Builds emotional synergy and trust. Children/young people with FASD often feel misunderstood; empathy helps them feel seen and supported.
- o PACE is especially effective for children who are living with FASD because it focuses on relationship over correction, helping them feel safe enough to learn and grow despite their challenges<sup>38</sup>.

#### **Dialectical Behavioural Therapy (DBT):**

- Dialectical Behavioural Therapy (DBT), adopted for adolescents in increasingly used to support young people who are living with FASD that experience emotional dysregulation, impulsivity and interpersonal difficulties. DBT teaches four core skill areas:
  - 1. Mindfulness Helps children/young people become more aware of their thoughts and feelings.
  - 2. Distress tolerance Provides tools to manage overwhelming emotions without harmful behaviours
  - 3. Emotion regulation Teaches strategies to identify and manage emotions more effectively

<sup>&</sup>lt;sup>38</sup> Hughes, D. (2017). Building the Bonds of Attachment: Awakening Love in Deeply Traumatized Children



- 4. Interpersonal effectiveness Builds skills for navigating social relationships<sup>39</sup>
- DBT is particularly helpful for children/young people living with FASD when adapted to their cognitive profile, using visual supports, repetition, and simplified language<sup>40</sup>.

#### Non-Violent Resistance (NVR):

- Non-Violent Resistance (NVR) is a therapeutic approach designed to support parents/caregivers in managing challenging behaviours without using coercion or punishment. Non-violent resistance parent training (NVR) focuses on helping parents resist the child's negative behaviours without escalating the problem. NVR helps parents to fulfil an anchoring function, supporting the child through presence, selfregulation, structure, and support network<sup>41</sup>. It is especially useful for children with FASD who may exhibit aggression, defiance, or controlling behaviours due to frustration, sensory overload, or executive functioning deficits.
- o In her book, the New Authority for Schools Sarah McGillicuddy, Educational Psychologist with the National Educational Psychological Service (NEPS) proposes an NVR-informed approach that could be rolled out across Irish schools following the model that she has designed<sup>42</sup>. Preliminary results showed that the intervention at a pilot school reduced aggressive and anti-social behaviours at post-primary level. The intervention reduced low level disruptive behaviours to a lesser extent and resulted in increased staff self-efficacy when responding to challenging behaviour<sup>43</sup>.

#### How these approaches work together:

- PACE creates the emotional foundation trust, safety, and connection.
- DBT provides the child/young person with practical tools to manage their emotions and behaviours

<sup>&</sup>lt;sup>39</sup> Flynn, D., Joyce, M., Weihrauch, M., and Corcoran, P. (2018). <u>Innovations in Practice: Dialectical</u> Behaviour Therapy – Skills training for emotional problem for adolescents (DBT-STEPS-A): evaluation of a pilot implementation in Irish post-primary schools

<sup>&</sup>lt;sup>40</sup> Katz, J., Knight, V., Mercer, S. H., and Skinner, S. Y. (2020). <u>Effects of universal school-based mental health programme on the self-concept, coping skills, and perceptions of social support of students with developmental disabilities</u>

<sup>&</sup>lt;sup>41</sup> Schorr-Sapir, I., Gershy, N., Apter, A., and Omer, H. (2021) <u>Parent training in non-violent resistance for children with attention deficit hyperactivity disorder: a controlled outcome study</u>

<sup>&</sup>lt;sup>42</sup> McGillicuddy, S. (2024). *The new authority for schools: Manual for teachers* 

<sup>&</sup>lt;sup>43</sup> McGillicuddy, S. (2023). <u>Responding to challenging behaviour in post-primary schools: Exploring a new authority</u>

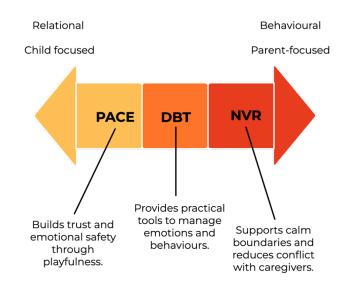


- NVR supports parents and carers in maintaining calm, consistent boundaries and reducing conflict.
- Together, these approaches can form a comprehensive support system that addresses the neurological, emotional, and relational needs of a child or young person living with FASD.

#### **Limitations:**

o Families agreed PACE and NVR helped some families but should not be thought of as a one size fits all approach. For some parents NVR had offered them the resolution they were needed and helped them to feel in control again, for others it did not have the desired impact. For families, having a range of options would provide the support they need<sup>44</sup>.

## FASD intervention strategies range from relational to behavioral





This submission was prepared by Mike Taylor, Director of Policy and Public Affairs, FASD Ireland for the Minister for Children, Disability, and Equality

<sup>&</sup>lt;sup>44</sup> Thorley, D. W., and Coates, A. (2022) <u>CCVAB Book second edition online</u>