



**ÉNDpae**

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1

## ENDpae

In Ireland, our cross-border support group was formed in 2017, when a number of families came together to discuss their common needs and concerns as families impacted by Prenatal Alcohol Exposure. We now have:

- A membership of 60
- We are in alliance with European support groups
- We are an active and vibrant online support group
- We meet regularly face to face and are joined by members from Cork to Omagh, using web based platforms (Zoom)
- Completed a members survey
- Published a promotional leaflet
- 2019 launch of Not for Profit Association



2

# Why NDpae?

Neurodevelopmental Disorder (ND) is a term that describes a number of brain-based conditions arising from a range of diverse causes. If the impact is from alcohol, it is referred to as NDpae which stands for prenatal alcohol exposure (pae). This is also known as Foetal Alcohol Spectrum Disorder (FASD). We use the term “ND” because it allows individuals to choose whether or not to share how their brain-based condition was acquired.



3

## NDpae (FASD) Statistics - Ireland

- Irish population in 2019 4.89 million
- Birth Rate approximately 61,000 p.a.
- 1% prenatal exposure to alcohol: 610 babies p.a., 1.8 per day or 5 every 3 days
- 4.75% exposure: 8 babies per day or 1 every 3.3 hours
- It is estimated that \*Ireland, at 47.5 per 1000 population has the third highest prevalence of NDpae in the world  
\*JAMA Pediatr 2017 Oct 1;171(10): pages 948-956



4

# Health Issues

- A large study in 2016 (Lancet) found 428 conditions to be concurrent with NDpae including:
  - Infant cardiological conditions
  - Seizure disorders
  - Eustachian tube malformations
- Higher risk of serious secondary disabilities
- Parents live with the knowledge that without adequate support life expectancy for their children is only 34 years

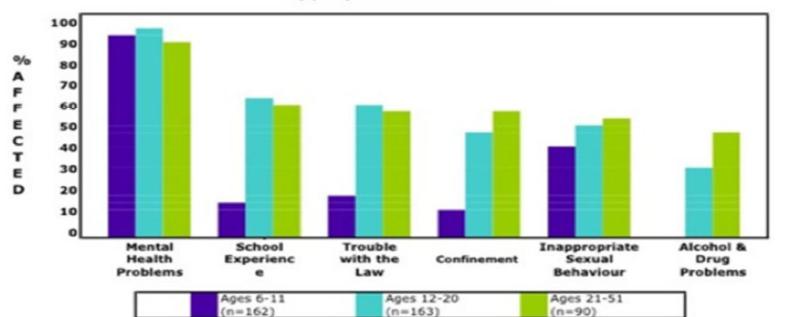


5

# Health Issues

## Secondary Disabilities

Individuals with FAS/FAE have a range of secondary disabilities - disabilities that the individual is not born with, and which could be ameliorated with appropriate interventions.



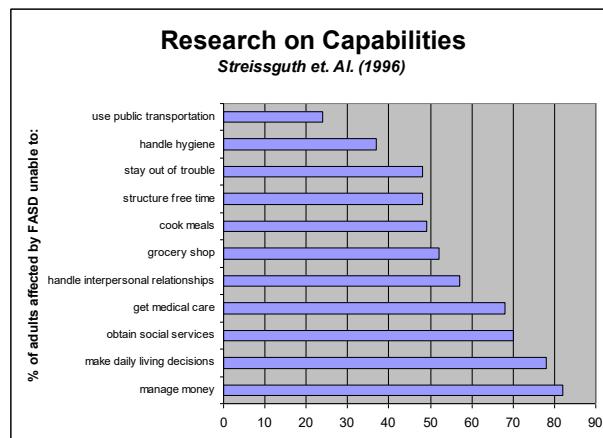
(Streissguth, et al., 1996)



6

# Living with NDpae / FASD

- 80% of individuals affected with the condition are **unable to live independently**



7

# Living with NDpae / FASD

## Education:

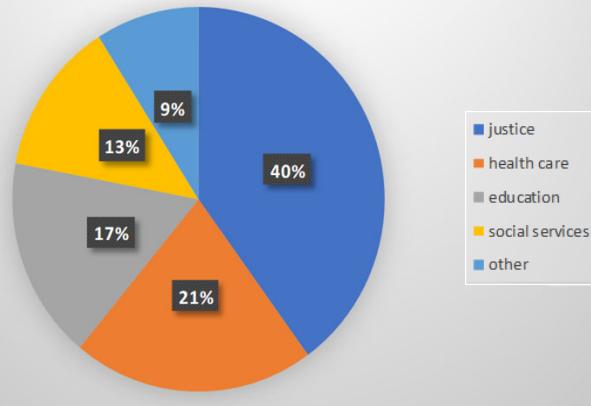
- In Ireland 2016-17, 900,000 students in primary and secondary schools
- at 1% prenatally exposed: 9,000 students
- at 4.75% prenatally exposed: 42,750 students



8

## Cost of NDpae to Irish taxpayers

**Break down of 1 M Euros extra cost to Irish tax payers for everyone with FASD**



### 10 Year Plan:

- We need a 10 year plan to make diagnosis available and to put in place appropriate supports
- Examples can be drawn from Alberta and where programmes have been put in place
- In Canada, it has been shown that for every \$1 invested the estimated social return is between \$1.5 and \$2.9



9

## Hopeful Precedents

- Alaska, population 720,000, has 6 NDpae/FASD clinics, funded by small surtax on sales of all alcohol
- Alaska has some of the most innovative and successful education programmes
- Alberta, population 4.4 million, had 3 clinics in 2008; now has 27 capable of 900 diagnoses p.a.
- Equivalent provision for Ireland would be about 40 clinics



10

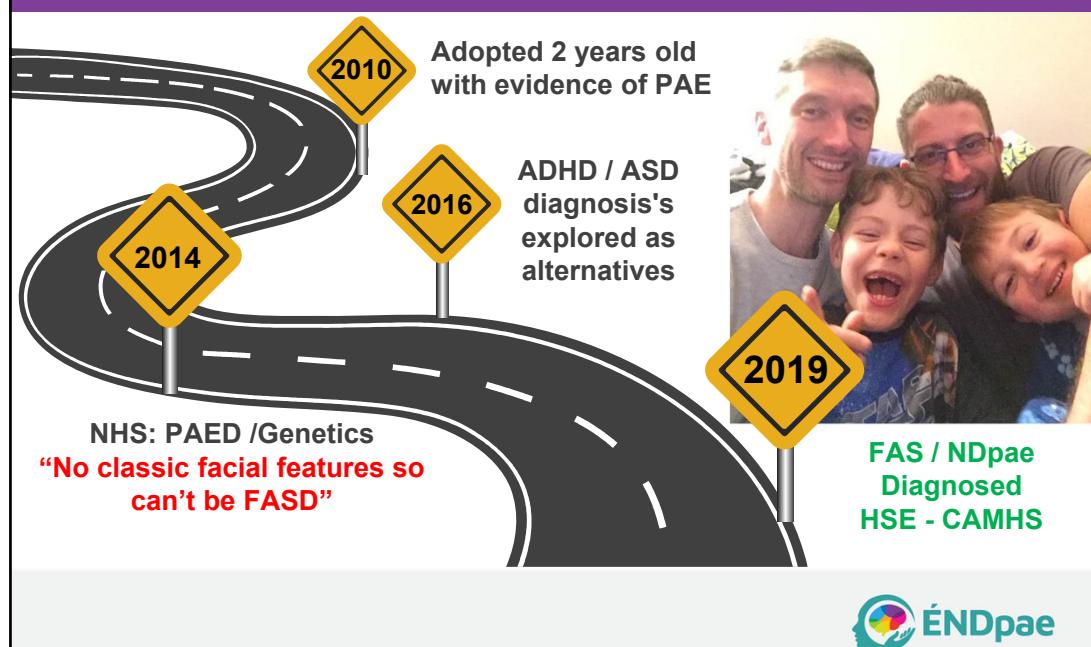
## In a Perfect World

- A main concern for parents of children with the condition is “What will happen when I’m gone? How well will she/he be able to cope with life?”
- Our wish for the future of our children is that
  - comprehensive diagnosis enables them to deal with their needs, building a good quality of life
  - they learn skills of self advocacy as a guarantee for after the parent’s time.



11

## NDpae / FASD – Kevin’s Journey



12

# Guy's Journey

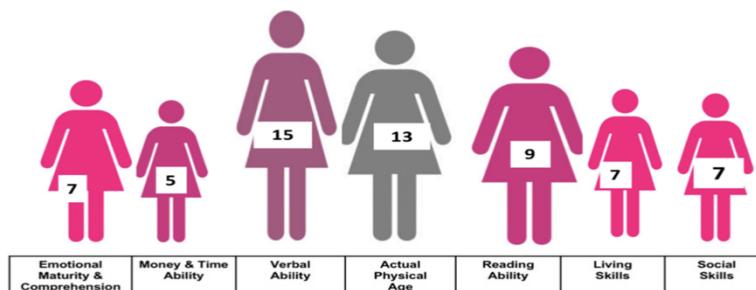
## Adaptive Functioning – What's that?

- It describes the kinds of intelligence we use to navigate everyday life – our ability to consistently remember and apply the lessons learned yesterday – to improve outcomes and life tomorrow.
- It describes aspects of human intelligence ignored by IQ tests.
- A strong mis-match (15 points in some cases) between AF and IQ is one of the key diagnostic criteria for NDpae.



13

## What it Looks Like



- The disparities can be remarkable : a seemingly mature, chatty 14 year old may well have a very immature grasp of money, for instance, of time or of social responsibility.
- A pictogram such as this, developed by Maria Catterick in the UK, conveys well the complexity of this **Hidden Disorder** and makes clearer its **confusing manifestations**.



14

# What Happens

**"Please empty  
the dishwasher,  
Anna."**



- That is exactly what she did. I forgot to complete the instruction.: “ and put things away.”
- She wasn’t being ‘smart’. Concrete thinking is common. You can imagine how it might get someone into trouble.
- Some people refer to the kinds of support needed, especially as a person enters adulthood, as being an **External Brain**, supplied by an appropriate third party/parties.
- It’s hard work, sometimes, even when you love them. We parents can’t do it all



15

**Q&A  
Thank You**



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16

## Helping Families affected by NDpae

Parents and Carers can be Healers – when they have appropriate support.

**Positive** networks create **strength**... be part of your clients' network.

Parents and Carers are experts through experience. Be open to new working partnerships.

Plan to share your NDpae knowledge within your Teams.  
Momentum, momentum, momentum

Play an active part in our collective journey supporting families affected by NDpae. Support our Children in safely reaching their potential.

