

# Prenatal Alcohol Exposure and Fetal Alcohol Spectrum Disorder.

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## What is it?

Fetal Alcohol Spectrum Disorder (FASD) is an overarching phrase that encompasses a range of diagnoses related to alcohol consumption during pregnancy. The individual diagnosis includes:

- fetal alcohol syndrome (FAS)
- partial fetal alcohol syndrome (pFAS)
- alcohol related birth defects (ARBD)
- alcohol related neurodevelopmental disorder (ARND)
- neurobehavioural disorder associated with prenatal alcohol exposure (ND-PAE).

FAS is the clinical diagnosis resulting from prenatal alcohol exposure (PAE)<sup>1</sup> and was the first term to be used to describe a group of children born who had been exposed to alcohol during pregnancy. These children had characteristic facial anomalies and poor prenatal and/or postnatal growth and, during early development, exhibited problems with learning and cognition.

The term FASD was later used when it was recognised that alcohol exposure during pregnancy may result in neurodevelopmental problems without physical or facial anomalies.

FASD describes a range of physical, cognitive and developmental impairments, and people born with FASD may experience over 400 comorbid conditions across nearly all systems of the body including mental and behavioural disorders, poor

growth, birth defects, heart, bone and kidney problems.<sup>2</sup> Sensory impairments are common including vision and hearing loss.

Alcohol use prenatally not only increases the risks of FASD, but also the risk of miscarriage and stillbirth.<sup>3,4</sup>

In Australia, clinical guidelines: ‘[Australian Guide to diagnosis of FASD](#)’, developed in 2016 (used in Australia, Canada and New Zealand) refer to FASD as: “a diagnostic term with two subcategories: FASD with three sentinel facial features and FASD with less than three sentinel facial features (this includes ARND, ND-PAE, ARBD and pFAS).”<sup>5</sup>

Early diagnosis in cases without the three indicated changes to facial features remains difficult, with many children not diagnosed until they start schooling.

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The range and severity of FASD differs from case to case and the signs and symptoms become apparent to varying degrees from birth to adulthood.

Diagnosis is based on symptoms, especially if it is known that alcohol was consumed during pregnancy.

A person who has FASD may have difficulties including, but not limited to, memory; information processing; the comprehension of social rules and expectations; the ability to connect cause and effect relationships; and, the ability to learn from past experience.<sup>6</sup>

People who have FASD are more likely to have difficulties with regulating their emotions and, as a result, are more often diagnosed with conduct disorder, attachment disorder, and have a history of suicidality.<sup>7</sup>

Physical symptoms that are commonly reported by people who have FASD include increased likelihood of infection and poor sleep.<sup>8</sup>

The consequences of impairment from FASD may increase over a person's lifespan, in particular in relation to their cognitive or behavioural symptoms, as there tends to be less social tolerance for some behaviours in adults than there is in childhood.<sup>9</sup>

People who have FASD may display characteristics such as hyperactivity, impulsivity, aggressiveness and poor judgement. If appropriate diagnosis and interventions are not put into place early in life, many people with FASD are at increased risk of becoming involved with the legal system, as offenders or victims.<sup>10</sup>

Additional 'secondary' disabilities commonly experienced by people with FASD include poor education outcomes, inappropriate sexual behaviours and increased risk of alcohol and other drug use.<sup>10</sup>

FASD places significant financial burden on individuals, families and society.

FASD is the most common preventable cause of neurodevelopmental disability but accurate data on the economic impact in Australia is limited. New Zealand studies have reported a cost of 0.03 – 0.09% of GDP for lost productivity alone (\$NZ49 million to \$NZ200 million).<sup>11</sup> These figures are conservative estimates as under-diagnosis of FASD is very likely.

Incorrect or misdiagnosis of FASD may result in the person not receiving the most adequate care and assistance that may help them manage better.

FASD is a public health issue, not just a medical condition.



## Why?

Alcohol is known as a teratogen (something that can cause malformation of a developing embryo) and can alter the normal development of a fetus, including impacts on the brain and major organs.

Alcohol readily crosses the placenta from mother to fetus. The developing fetus has very limited ability to process alcohol as the liver is not fully formed resulting in a blood alcohol content (BAC) the same, or higher, than the mother, which remains high for a longer period of time.<sup>12</sup>

Alcohol can cause variable physical and behavioural effects on the developing fetus.

Damage to the fetus may occur at any time prenatally and the level of harm may be dependent on the amount and frequency and timing of alcohol exposure.<sup>13</sup>

It may also be moderated by other factors such as genetics,<sup>14</sup> intergenerational alcohol use, parent age, alcohol consumption of the father, health of the woman, nutritional status,<sup>15</sup> tobacco use and environmental factors including stress, exposure to violence, poverty and family structure.<sup>5</sup>

### Prevalence of Prenatal Alcohol Exposure and FASD

In 2016, 56% of women in an Australian survey reported abstinence from alcohol during pregnancy, a slight increase from 53% in 2013.<sup>16</sup>

However, research shows that up to 50% of Australian pregnancies are unplanned and Prenatal Alcohol Exposure (PAE) occurs in the period before the discovery of pregnancy – i.e. exposure is inadvertent and unintended.<sup>17, 18</sup>

Australian data reports that 75% of pregnant women are most likely to drink in their own home with their partner;<sup>19</sup> with the partner initiating the drinking occasion 40% of the time. A recent systematic review found that paternal alcohol consumption during preconception or pregnancy has an impact on maternal health and alcohol consumption during pregnancy, fetal outcomes and infant health outcomes.<sup>20</sup>

FASD occurs in all parts of society where alcohol is consumed.

A global meta-analysis reported that 1 of every 13 pregnant women who consumed alcohol during pregnancy delivered a child with FASD.<sup>21</sup>

Global prevalence of FASD is estimated to be 7.7 of 1000 births.<sup>21</sup> The prevalence of FASD among special populations can be higher: 15.6 to 24.6 times higher among populations subjected to historical trauma, dispossession and systematised discrimination; 5.2 to 67.7 times higher among children in care; 30.3 times higher in the correctional population; 23.7 times higher in the low socioeconomic status population; and, 18.5 times higher among a population in psychiatric care.<sup>5, 21</sup>

Children in contact with youth justice services are thought to include an over-representation of individuals living with undiagnosed FASD.<sup>22, 23</sup>

A prevalence study of young people assessed in a youth detention facility in Western Australia found that 36% were diagnosed with FASD.<sup>24</sup> Canadian research indicates that young people with FASD are 19 times more likely to be arrested than their peers.<sup>6</sup>

### Reducing the burden of harm from FASD

The outcomes of an Australian formal inquiry into FASD, published in 2012, outlined 19 key recommendations to begin to address the harms associated with prenatal alcohol exposure, the consequences of FASD and the economic and social impact of the condition.<sup>25</sup>

The development of a national approach made particular reference to education, diagnostic tools and improved access to support services in setting out three key areas:

1. Prevention – including education campaigns, considerations of product warnings and other mechanisms to raise awareness of the harmful nature of alcohol consumption during pregnancy.
2. Intervention – including diagnostic tools and early intervention strategies aimed at minimising the impact of FASD on affected individuals.

3. Management – including access to appropriate community care and support services.

Additionally, the National Fetal Alcohol Spectrum Disorder Strategic Action Plan from 2018-2028 has identified prevention of FASD as a key goal.<sup>12</sup>

This paper focusses on the evidence and strategies around prevention of prenatal alcohol exposure and FASD.

## Evidence

### 1. Correlation between PAE and FASD risk

Comprehensive evidence exists about the risks of high alcohol consumption during pregnancy.<sup>26, 27</sup>

A 2014 meta-analysis reviewed the association between mild, moderate<sup>1</sup> and ‘binge’ prenatal alcohol exposure and child neurodevelopment.<sup>27</sup> The results of this supported previous findings that show a detrimental effect of binge drinking on child cognition and that prenatal alcohol exposure at levels ‘less than daily’ might be detrimentally associated with child behaviour.<sup>12</sup>

Evidence about alcohol intake at low levels is less clear, although an association was found with being small for gestational age. Given this evidence, the authors advised abstention during pregnancy as a precautionary principle, acknowledging the paucity of evidence.<sup>28</sup>

In Australia it has been shown that even low levels of prenatal alcohol exposure are associated with differences in craniofacial shape in children.<sup>29</sup>

A 2019 systematic review of alcohol use during pregnancy and miscarriage found that exposure to alcohol is associated with a dose-dependent increase in risk with alcohol exposed pregnancies 19% more likely to end in miscarriage.<sup>3</sup>

The timing of alcohol exposure is thought to play a critical role in determining risk of miscarriage but currently there is limited information on how to measure this risk.<sup>3</sup> Heavy alcohol consumption during pregnancy may also result in an increased risk of stillbirth.<sup>4</sup>

There are a number of major challenges facing research into the effects of low to moderate level alcohol consumption during pregnancy on neurodevelopmental or executive functioning.

This is in large part due to the many independent factors that are associated with a child’s developmental outcomes. The mechanisms by which prenatal alcohol exposure affects infants are multifaceted and may depend on:

- the trimester of pregnancy when consumption occurred – early exposure may lead to birth defects; last trimester exposure to neuro-behavioural difficulties<sup>25</sup>
- dosage level – the amount consumed has been shown to be a critical determinant of the effects of alcohol on the fetus, particularly in combination with timing of exposure<sup>25</sup>
- other factors – genetics, diet and maternal smoking, maternal age and use of other substances all influence outcomes<sup>25</sup>
- ‘binge drinking’ - drinking more than five standard drinks in one sitting, coupled with timing of exposure may contribute to neurological damage.<sup>25</sup>

Another major challenge facing research is the impact that social determinants of health have on outcomes.

Older age, higher educational attainment, higher parity, being employed and higher income are all consistent predictors of increased likelihood to use alcohol during pregnancy.<sup>26</sup>

Lower educational attainment, being single during pregnancy, unemployment, residing in a remote area and lower income are associated with an increased risk of having a child with FASD.<sup>27</sup>

1. Mild-to-moderate was defined as >0 to 6 drinks per week; “binge” defined as ≥4 or ≥5 drinks per occasion

Maternal age, substance use, smoking and experience of trauma or violence are also common risk factors for FASD and prenatal alcohol exposure.<sup>26</sup>

Whilst there is yet to be conclusive evidence that low level alcohol consumption in pregnancy is associated with adverse outcomes, it is also important to note that no level of alcohol has been determined as completely safe either.

Most policy makers and researchers recommend abstinence during pregnancy to reduce the risk of potential alcohol-related harms to zero.

### **Prevention Strategies**

The risks associated with not addressing the wider social and cultural determinants of health present a significant societal challenge when addressing the issue of preventing FASD.

Actions to raise awareness, consistent messaging, culturally relevant and appropriate health promotion that is aimed at women and their partners/family are all important factors in helping to reduce FASD.

International clinical guidelines recommend that pregnant women should abstain from alcohol use.<sup>30</sup>

The draft Australian National Health and Medical Research Council (NHMRC) guidelines state that: “To reduce the risk of harm to their unborn child, women who are pregnant or planning a pregnancy should not drink alcohol. For women who are breastfeeding, not drinking alcohol is safest for their baby”<sup>31</sup> These guidelines are in place because we are yet to determine at what point the risk commences. Whilst it may currently appear that the risk of one standard drink is low, risk increases the more alcohol is consumed and is dose dependent.

Prevention research in Canada has identified a four-part framework for FASD prevention:

- **Level 1:** Broad public awareness and health promotion
- **Level 2:** Conversations about alcohol with women of childbearing age and their partners
- **Level 3:** Specialised support for pregnant women
- **Level 4:** Postpartum support for new mothers.<sup>32, 33</sup>

### **Level 1: Broad public awareness and health promotion**

It is important to consider in all public awareness and health promotion campaigns the significance of a ‘drinking culture’ and the impact that this has on rates of alcohol consumption during pregnancy. The highest rates of FASD occur in the highest consumption communities leading to a need to address consumption at a community level in the first instance.

There appears to be growing awareness in the community that abstinence is the safest option during pregnancy.<sup>34</sup>

Broad public awareness and health promotion programs such as Pregnant Pause, and local community campaigns to raise awareness of the risks of alcohol in pregnancy are an essential first step to improve knowledge and awareness of the risks.<sup>35</sup>

The perception that the consumption of alcohol during pregnancy is only a women’s issue is a barrier to effective prevention.<sup>36</sup>

The responsibility to reduce alcohol consumption during pregnancy is the responsibility of men and women and community. There is emerging evidence of links between paternal age, environment and alcohol consumption on birth defects.<sup>37</sup> The consumption of alcohol occurs as a social ritual, women must be supported by their partners, family, health care providers and social service providers to not consume alcohol during pregnancy.

### **Level 2: Conversations about alcohol with women of childbearing age and their partners**

It is important that all health workers have conversations with women during pregnancy about alcohol use.

One potential approach is the use of Screening, Brief Intervention and Referral to Treatment (SBIRT), which involves the use of a validated screening tool for alcohol use (e.g. the AUDIT-C) on each occasion.

If a woman is at low risk, they can be provided with a brief intervention around alcohol use, such as education about the effects of alcohol use on the developing fetus and child. If screened at high risk they can be referred to treatment with an appropriate service and assisted to access that service.

It is recommended that SBIRT be applied by all health professionals during pregnancy for all women at all occasions, and be recorded.<sup>38</sup> This approach may reinforce reductions in alcohol use and make professionals aware of women who resume use during pregnancy.

Being offered as part of routine practice, received by all pregnant women, can help normalise the procedure, reduce stigma, and reduce bias in administration.<sup>39</sup>

### **Level 3: Specialised support for pregnant women**

Other strategies, such as accessible contraception, alcohol use disorder support, family supports, and cultural family planning are essential as wrap around service areas in prevention.

An example of a well evaluated and effective program (which operates over both Level 3 and 4) is the Parent Child Assistance Program, which provides three years of case-managed outreach, based on the principles of motivation interviewing and harm-reductions, for women at high risk of alcohol or other drug exposure during pregnancy.

Other holistic services offering ‘wrap-around’ support for women are valued for using non-judgmental approaches, offering peer support in a communal environment and having multiple services at one location.<sup>40</sup>

### **Level 4: Postpartum support for new mothers**

Along with programs such as the above Parent Child Assistance Program, support for breastfeeding women and education around alcohol consumption during breastfeeding can help to reduce risk of harm to a baby. 41 Australian guidelines state that: “For women who are breastfeeding, not drinking in the safest option.”<sup>31</sup>

### **Prevention programs**

Currently there is a lack of published evaluation of campaigns or strategies that have successfully addressed alcohol use during pregnancy.

However, FASD researchers have identified key areas to be addressed in any prevention campaign. These include:

- information to be culturally sensitive to the community in which it is being delivered
- be respectful

- be informed by community knowledge, attitudes, and practices
- focus on the damage that alcohol can do and not focus blame on the woman
- engage all of the community, including men
- be consistent with Australian guidelines to reduce health risks from alcohol.<sup>12</sup>

Whilst there has been little evaluated research to support prevention programs, learning from other health promotion campaigns can help as a guide to effective outcomes.

### **Diagnosis**

Diagnosis of people with FASD has been difficult.

Prior to 2016 there was no formally accepted diagnostic criteria for FASD in Australia, making it difficult to determine prevalence, and to initiate management plans.

The 2016 Australian FASD Diagnostic Instrument was developed to facilitate and standardise the diagnosis of FASD in Australia. The recommended criteria are similar to those recently published in Canada and use clinical aids developed at the University of Washington.

“A diagnosis of FASD requires evidence of alcohol exposure and severe impairment in three or more of the ten specified domains of central nervous system structure or function.” (see appendix 1)<sup>42</sup>

Three essential criteria must be considered when assessing an individual for FASD:

1. maternal alcohol use and other exposures
2. neurodevelopmental impairment
3. facial and other physical features.

Other diagnoses that might account for neurodevelopmental impairment must be excluded. FASD may also co-exist with other conditions.<sup>42</sup>

Diagnosis of FASD is complex, time consuming and costly and ideally requires a multidisciplinary team of clinicians to evaluate an individual’s level of exposure, neurological impairment and general physical or developmental delay.<sup>42</sup> Multidisciplinary teams, however, tend to be only in major centres and innovative methods must be found to allow regional and rural populations to access appropriate assessment and management options.

In some cases, there may be no physical impairments and FASD may go undetected or misdiagnosed until much later in life. As with other areas of health care, diagnosis needs to be coupled with a package of care.

### **Stigma**

Whilst the many dedicated FASD teams work tirelessly and actively to practice a no judgement culture, stigma and judgement remain significant barriers to both diagnosis, reporting and information provision during pregnancy – mostly in the absence of specialist supports.

The notion of blame can shape attitudes towards, and reactions to, women who drink during their pregnancy.

‘Blame and shame’ can negatively impact on the self- perception of pregnant women with many women fearing they will be negatively judged by the general public and health care workers if they disclose the full extent of their alcohol consumption.<sup>43</sup>

This potential negative judgement may further prevent early monitoring and support for the woman and delay diagnosis and effective early interventions for the child.<sup>43</sup>

Women may also be reluctant to report alcohol use during pregnancy if they are concerned that this could result in their child being removed from their care by child protection services.

These reasons, amongst others, form the basis of recommendations that prevention policy development requires well-designed planning that targets community, not just women.<sup>44</sup>

## **Current situation**

### **The Marulu Strategy**

The Marulu Strategy is an example of a community initiative to overcome Fetal Alcohol Spectrum Disorders and Early Life Traumas in the Fitzroy Valley, Western Australia.

In 2007, leaders became aware that many children in their communities displayed learning and behavioural difficulties as well as unusual facial features and poor growth.

Due to the growing awareness of FASD and the impact alcohol was having on the community, the women of Fitzroy Valley spearheaded a community campaign, under the leadership of Marninwarntikura and Nindilingarri Cultural Health Services.

The campaign achieved what had been fought for years: legal restrictions on the sale of full-strength alcohol in the Fitzroy Valley.<sup>45</sup>

In addition to reducing alcohol availability, a broad community strategy – the Marulu Strategy – was developed, with targets to prevent FASD, improve diagnosis, help support affected individuals and families. The strategy is an interagency collaboration with strong local leadership and meaningful community engagement in planning and implementation.

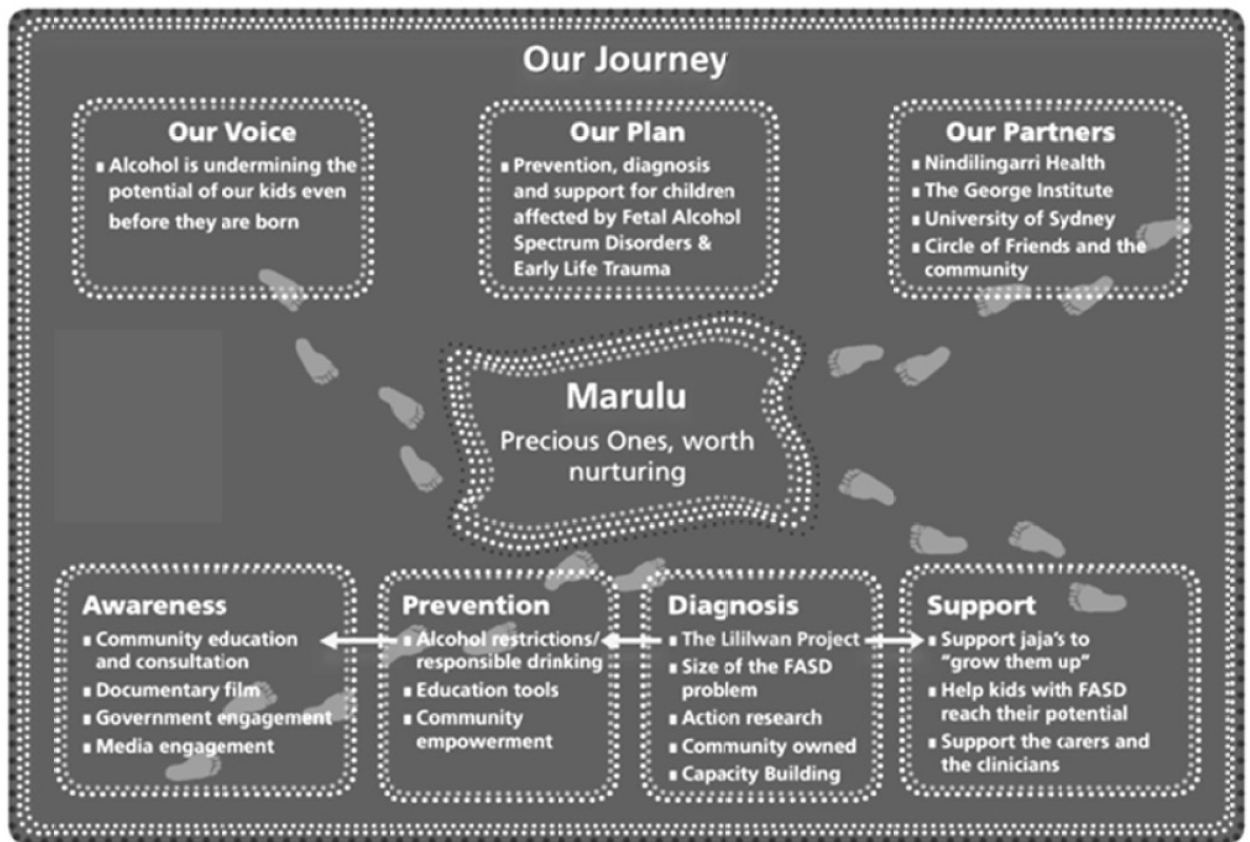
The Lililwan Project (developed out of the Marulu Strategy) was Australia’s first prevalence study to document FASD and partial FASD in a community.<sup>46</sup>

The Lililwan Project has been instrumental in quantifying an evidence base from which to advocate for resources to prevent and manage FASD.

Work is now underway to build on the success of the Marulu Strategy in developing a national approach to tackling FASD.

A multipronged FASD prevention strategy 'Make FASD History' has commenced in other areas in Australia, supported by community, researchers and local health agencies.

An overview of the Marulu Strategy 2017- 2022 can be found [here](#).



## Risks to the ADF

There could be a risk of increasing anxiety of mothers who have consumed low levels of alcohol during pregnancy and delivered apparently otherwise healthy babies.

Just because there is no evidence does not make something safe. The safest option is to avoid prenatal alcohol exposure.

## ADF position

1. More information about the prevalence and impact of FASD is required to allow for improved interventions, early detection and service planning and implementation.
2. Prioritising prevention in the general community and designing targeted interventions for known at risk communities is required.
3. Providing adequate screening and diagnostic tools to ensure early intervention for those children with pre-existing FASD is required.
4. FASD can be prevented. Currently, a clear causal link can be made between consumption of alcohol and FASD and mounting evidence of harms associated with prenatal alcohol exposure. The safest option is not to drink during pregnancy.
5. All family members and partners of pregnant women should be supported to reduce or abstain from drinking alcohol during their partner's/family members' pregnancy.



**Appendix 1**

Taken from the Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD).{Bower, 2016, Report to the Australian Government Department of Health: Australian Guide to the diagnosis of Fetal Alcohol Spectrum Disorder (FASD)}

<b>Fetal Alcohol Spectrum Disorder</b>		
<b>Diagnostic criteria</b>	<b>Diagnostic categories</b>	
	FASD with 3 Sentinel Facial Features	FASD with <3 Sentinel Facial Features
Prenatal alcohol exposure	Confirmed or unknown	Confirmed
Neurodevelopmental domains <ul style="list-style-type: none"> <li>• Brain structure/Neurology</li> <li>• Motor skills</li> <li>• Cognition</li> <li>• Language</li> <li>• Academic Achievement</li> <li>• Memory</li> <li>• Attention</li> <li>• Executive Function, including impulse control and hyperactivity</li> <li>• Affect Regulation</li> <li>• Adaptive Behaviour, Social Skills or Social Communication</li> </ul>	Severe impairment in at least 3 neurodevelopmental domains	Severe impairment in at least 3 neurodevelopmental domains
Sentinel facial features <ul style="list-style-type: none"> <li>• Short palpebral fissure</li> <li>• Smooth philtrum</li> <li>• Thin upper lip</li> </ul>	Presence of 3 sentinel facial features	Presence of 0, 1 or 2 sentinel facial features

Key components of the FASD diagnostic assessment include documentation of:

- History - presenting concerns, obstetric, developmental, medical, mental health, behavioural, social;
- Birth defects - dysmorphic facial features, other major and minor birth defects;
- Adverse prenatal and postnatal exposures, including alcohol;
- Known medical conditions - including genetic syndromes and other disorders;
- Growth

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