

# Fetal Alcohol Spectrum Disorder

A Common and Often Misunderstood  
Developmental Disability and its Major  
Impact on California

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## A Common and Often Misunderstood Developmental Disability and its Major Impact on California<sup>1</sup>

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Alcohol is the strongest known teratogen to the developing brain in utero, far stronger than heroin, cocaine, and marijuana combined (Institute of Medicine). A great deal of public interest is currently focused on the Opioid Crisis, but there is another epidemic. One that goes mostly unnoticed, with far ranging effects. It is called Fetal Alcohol Spectrum Disorder or FASD.

Alcohol kills brain cells, alters cell migration, and damages every neurotransmitter system during pregnancy. The result is diffuse brain damage. Alcohol can damage not only the brain, but also every developing organ system in the body, depending upon the time of exposure. The effects of prenatal alcohol exposure are complex, yet awareness about these effects is limited in California.

### Fast Facts About FASD

- FASD is an umbrella term describing the range of disorder that can occur from prenatal alcohol poisoning to the developing brain and body
- It occurs on a spectrum; only 10% of affected people have the syndrome (FAS), with its defining physical characteristics
- 90% of individuals with the disability have no outward, physical sign of difficulties, yet have the same brain damage
- FASD is more common than Autism, Spina Bifida, and Down Syndrome combined (SAMHSA, 2014)
- 75% of affected people have typical range IQ; Having a typical IQ predicts poorer outcome
- A child with FASD will grow into an adult with FASD



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<sup>1</sup>All photos in this position paper show real people with FASD.

- Early diagnosis and intervention are critical to achieve positive outcome in adulthood
- Fetal Alcohol Spectrum Disorder is a lifelong disability that is 100% preventable



## **Brain Damage in FASD**

Alcohol is a strong toxin to the developing brain in utero and exposure can cause a cascade of adverse effects.

### **No two people with FASD are the same, but common challenges are:**

- Brain size, structure and chemistry are affected
- Even with typical IQ, adaptive functioning (daily living skills and the ability to live in a community) is impaired and gets worse with age
- Cognitive problems are present even with typical IQ
- Deficits in memory, information processing, abstract thinking, spatial reasoning and language
- Poor understanding of cause and effect and limited ability to learn from consequences
- Executive functioning deficits, especially poor judgment and impulse control
- Reduced ability to recognize risk or danger
- Behavior problems including mood instability and rage reactions
- Social deficits, as found in Autism
- Developmental age is typically much lower than chronological age

## Development is Uneven in FASD: A Profile at 18 Years of Age

Physical Maturity _____	18
Emotional Maturity _____	9
Daily Living Skills _____	11
Expressive Language _____	23
Language Comprehension _____	9
Reading Decoding _____	16
Reading Comprehension _____	8
Money & Time Concepts _____	8
Social Skills _____	9
Understanding Danger _____	5

### Diagnosis and Fetal Alcohol Spectrum Disorder

- Northern and Central California do not have the capacity to diagnose FASD
- Southern California has several sites for diagnosis
- Diagnosis by 6 years of age strongly predicts better outcome in adulthood
- Treatment is diagnostic specific;<sup>2</sup> Without diagnosis, appropriate treatment may not be delivered
- Lack of diagnostic capacity for FASD in California is directly related to the lack of training of professionals
- FASD is not part of the curriculum in medical school or graduate programs in social work, mental health and education
- Failure to diagnose FASD has medical consequences; affected people are medically high risk

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<sup>2</sup> SAMHSA, Treatment Improvement Protocol 58: Fetal Alcohol Spectrum Disorders: Modifications to Treatment for Mental Health and Substance Use Providers (2014)

## Cost of Fetal Alcohol Spectrum Disorder

FASD can be a very costly disability, especially when not addressed early on. Affected children and adults incur high costs due to the complexity of the disorder and involvement of multiple systems of care. One major factor driving the high cost of care is the difficulty in obtaining a diagnosis in California. Most people with FASD are not diagnosed or are misdiagnosed.



As a result, appropriate treatment is not delivered and multiple secondary disabilities develop, each one also requiring care. Common secondary disabilities include mental illness, addiction, school dropout, homelessness, victimization, and incarceration. Without early diagnosis and treatment, 80% of adults with FASD will not live independently as adults.

Failure to diagnose FASD in children from birth to 5 years of age means early intervention is not provided at the exact time that treatment would be most effective. Without access to diagnosis, the impairment in FASD increases, as does the resulting lifetime cost of the disability. A review of the literature on costs of care was recently published in the *Journal of Addiction Medicine*. Note that the cost of care in FASD is higher than the cost for Autism per individual.<sup>3</sup>

### Annual Cost for Children and Adults with FASD vs Autism

Child with Autism	\$17,000
Child with FASD	\$21,000
Adult with FASD	\$23,000

<sup>3</sup> Greenmeyer, RJ. A multi-country assessment of the economic impact of fetal alcohol spectrum disorder. *J of Addiction Med*. 2018; 12 (6), 466-473

## Criteria for Diagnosis

There is no biomarker for Fetal Alcohol Syndrome. Diagnosis of FASD can be done by a trained physician or psychologist. Diagnosis of non-syndrome FASD requires neuropsychological testing with knowledge of the criteria for diagnosis.<sup>4</sup>

- FAS, f 88, ICD 10
- ND-PAE, 318.5, DSM 5
- Both physicians and psychologists can diagnose

## Fetal Alcohol Spectrum Disorder and Public Health



FASD has a major impact on public health in California. Without early diagnosis, secondary disabilities develop, including school drop-out, unemployment, incarceration, mental illness, addiction, and homelessness. The cost to the state across systems of care is considerable.

- Children with FAS have 9 times the cost to Medicaid vs children without FAS<sup>5</sup>
- FASD is the largest known cause of birth defects in the Western world (World Health Organization)

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<sup>4</sup> Kable, J. and Mukherjee, RA. Neurodevelopmental disorder associated with prenatal alcohol exposure (ND-PAE): a proposed model for capturing the neurocognitive phenotype of FASD. *Eur J Med Gen*, 2017; 60 (1), 49-54

<sup>5</sup> Amendah, DD, Grosse, SD, and Betrand, J. Medical expenditures of children in the United States with fetal alcohol syndrome. *Neurotoxicol and Teratol*, 2011, Mar-Apr; 33(2), 322-324

- Medicaid spends on average, \$16,800 annually per child with FAS; with approximately 9.12 million children in California in 2016, up to 5% will have FASD; the conservative number of California children with FASD is 364,800<sup>6</sup>
- Over 400 medical conditions are co-morbid in adults with FASD<sup>7</sup>
- Infants are at a much higher risk for premature birth and SIDS
- Average life span for a person with Fetal Alcohol Spectrum Disorder is 34 years<sup>8</sup>

Prenatal alcohol exposure can damage the development of every organ system in the body, depending upon the timing of exposure and when a specific organ develops. In addition to direct damage, prenatal alcohol exposure causes epigenetic changes, altering the function of genes in the body. This leads to a process that is well known in cancer research. Epigenetic changes can lead to the developmental origin of disease in adulthood.<sup>9</sup>

People with FASD are at higher risk for many adverse health outcomes, including epilepsy, cancer, metabolic disorders, auto-immune diseases, liver, heart and kidney damage, hearing loss, vision loss, bone disease and skeletal abnormalities, as well as diseases of aging that instead occur in young adulthood. Individuals with FASD should be viewed as medically high-risk patients. However, first they need to be identified as having the disorder so the risks can be recognized.

There is no specialty medical program or clinic for FASD in California. Several other states have developed specialty medical care, such as Minnesota and Alaska. Identification of health problems early on can lead to lower medical expenditure for conditions that become advanced or when complications occur.

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<sup>6</sup> Bailey, BA and Sokol, RJ., Prenatal alcohol exposure and miscarriage, still birth, preterm delivery, and sudden death syndrome. *Alcohol Res Health*.2011; 34(1), 86-91

<sup>7</sup> Thanh, NX and Jonssone, Life expectancy of people with fetal alcohol syndrome. *J Popul Ther Clin Pharmacol*. 2016;23(1) e: 53-9

<sup>8</sup> Thanh, NX and Jonssone, Life expectancy of people with fetal alcohol syndrome. *J Popul Ther Clin Pharmacol*. 2016;23(1) e: 53-9

<sup>9</sup> Lunde, ER. Alcohol induced developmental origins of adult onset disease. *Alcohol Clin Exp Res*. 2016; 40(7), 1403-1414



## **FASD and Child Welfare**

FASD occurs with children in care at a much higher rate than in the general population; These children often require specialized placement

- An estimated 55,983 children in California live apart from their families in out-of-home care ([www.kidsdata.org](http://www.kidsdata.org))
- 28% of children who are in foster care or who are adopted have an FASD<sup>10</sup>
- FASD in foster care occurs at 10 to 15 times the rate seen in the general population

### **Estimated Costs of FASD in the Child Welfare System in California**

- The 2018-2019 California budget: \$512.9 million dollars for child welfare spending
- Based on the prevalence of FASD in the foster care system, \$150 million spent in child welfare is for children with FASD

In addition, children with FASD will likely require special needs foster care, due to a high percentage of birth defects, premature birth, as well as behavioral, medical and psychiatric concerns. These children will incur greater costs in placement.

Being a foster parent of a child with FASD can require support and special training. Recognition of brain damage and therapeutic parenting are vital for raising these children. Infants and toddlers with FASD have sleep disorders, feeding problems and are at high-risk for additional birth defects. Preschool and school age children show additional behavior and cognitive deficits, requiring modification of most discipline techniques.

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<sup>10</sup> Chasnoff, IJ, Wells, AM, and King, L. Misdiagnosis and missed diagnoses in foster care and adopted children. *Pediatrics*. 2015; 32 (2), 264-270

Many of these kids also have a specific deficit in understanding danger, requiring much greater supervision to maintain safety. In Minnesota, the effect of Fetal Alcohol Spectrum Disorder on the foster care system and children in care has been recognized legally. State law now requires foster care parents to receive training in FASD. No such requirement exists in California.



## Education and FASD

Approximately 6 million children are enrolled in public education in California. Based on a 2% to 5% prevalence rate, 240,000 to 300,000 of those children will have FASD.

The above statistics are based on recent research. May, et al., found an overall prevalence of 2% to 5% of children in the

United States have FASD.<sup>11</sup> The prevalence was close to 5% of every 1<sup>st</sup> grade child in San Diego, one of the four communities in which the study was conducted. The cost of educating children with FASD, given their cognitive, learning, behavioral, social, and motor deficits, is considerable.

FASD is not a recognized category for special education under IDEA. It is also not named as a disorder under the Other Health Impaired category by the California Department of Education, as is true in some other states. Children with FASD, even with typical intelligence, show a profile of neuropsychological deficits that affect learning and behavior in the classroom. These problems include deficits in memory, abstract thinking, processing speed, attention and language comprehension. Research shows that math is typically the lowest academic skill. Behavioral deficits, sensory processing problems and marked social deficits are also part of the disability and all affect learning.

For youth, 61% will experience repeat suspensions, expulsion or will drop out of high school.<sup>12</sup> Failure to identify the disability and to find special education eligibility can have devastating results for children with FASD. Several states have education programs for assessment of FASD, training programs for teachers, and specialty services for children who have this

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<sup>11</sup> May, PA. et al. Prevalence of fetal alcohol spectrum disorders in 4 U.S. communities. *JAMA*, 2018; 319(5), 474-482

<sup>12</sup> National Association Fetal Alcohol Syndrome (NOFAS). [www.nofas.org](http://www.nofas.org)

disability. California does not. Minnesota and Alaska name FASD as a condition under the Other Health Impaired category for special education, thus aiding recognition of the disorder amongst educators and eligibility for special education. This needs to happen in California.

- New Jersey, Maryland, North Dakota, Minnesota and Alaska provide FASD training to teachers
- The school district of Winnipeg (Canada) has specialized classrooms for students with FASD
- Minnesota has a consortium between the university, the public schools and Proof Alliance to serve children with FASD
- Minnesota has special level classrooms for students who have behavioral and sensory issues in severe FASD
- In Alaska, a behavior specialist in FASD is available in every school district

No such program to train teachers or serve students with FASD exists in California.

## Homelessness and Fetal Alcohol Spectrum Disorder

Adaptive function deficits, (difficulty paying bills, living independently, keeping a job), are a key part of FASD.

With typical IQ, it can be difficult to qualify for SSI; the same is true for Regional Centers, despite deficits in the ability to live independently and maintain work.



- In FASD, brain damage is always the primary disability, not mental health; Problems occur when a Regional Center only recognizes the mental health issue and finds the person ineligible
- FASD is not a named developmental disability under the Lanterman Act

- Difficulty in finding employment; 61% of affected youth experience disrupted schooling<sup>13</sup>
- 35% have substance use problems starting at 12 years of age (see footnote 12)
- A high percentage of people with FASD have been in the foster care system

## **Prevalence of FASD in People Experiencing Homelessness**

In a recent study of homelessness in Calgary, (Canada has the same prevalence for FASD as in the US), the following information was found:<sup>14</sup>

- 35% of people in Calgary experiencing homelessness had an FASD
- 70% of people with FASD experiencing homelessness were considered chronic --greater than 1 year
- 62% of people who had FASD and were homeless also had a history of foster care
- 67% of individuals with FASD who were experiencing homelessness had been in the legal system
- 92% of people who were homeless and had FASD also had a substance use problem

Fetal Alcohol Spectrum Disorder contributes significantly to the problem of homelessness. The cost to lives, communities, and budget is enormous. In Calgary, 33% of the homeless population were found to have FASD. In California, the state and communities do not have a program to identify FASD amongst Californians who are experiencing homelessness. However, one-third of the \$500,000,000 California budget allotted to homelessness in 2018 is significant.

Currently in California the burden of helping adults with FASD maintain housing falls on families due to the lack of Regional Center services for many affected people. These individuals have brain damage, which is typically not recognized, nor is the resulting need for lifelong support. The problem is most acute when IQ is within the typical range and the person is expected to

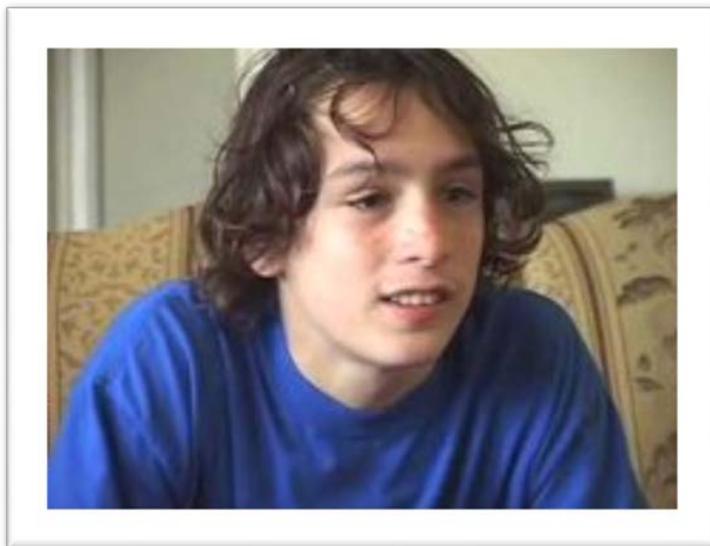
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<sup>13</sup> Astley, SJ. Profile of the first 1400 patients receiving diagnostic evaluations for fetal alcohol spectrum disorders at the Washington state fetal alcohol syndrome diagnostic and prevention network. *Can J. Clin Pharmacol.*2010; 17(1),132-164

<sup>14</sup> Badry, D. The fetal alcohol spectrum disorder and homelessness project: Making connections and promising practice. *J Sub Abuse and Alcoholism.* 2015; 3(1), 1027

function independently and cannot do so. Factors contributing to the high risk of homelessness in FASD include:

- Difficulty understanding and managing money even with typical IQ, i.e., failure to pay rent and utilities
- Difficulty organizing and keeping a house clean without support
- Vulnerability in being taken advantage of and used by others
- Average schooling for adults with FASD is the 9<sup>th</sup> grade
- Repeat incarceration followed by release without needed structure and support
- Inability to access needed services without assistance
- Inability to find and maintain employment



## **Criminal Justice and FASD**

Individuals with FASD have a high risk of incarceration from adolescence through adulthood

FASD is widely over-represented in the criminal justice system. Research shows prevalence data indicating 17% to 33% of youths incarcerated as having this disability.

The prevalence data is also very high for adults. Difficulty in the legal system occurs at all levels. An attorney may face a client with significant memory deficits for the event in which he/she has been charged. False confession is high due to the suggestibility of this population, as related to brain damage. In addition, language problems, confabulation, difficulty understanding consequences of actions, and rage reactions raise questions of criminal intent and the ability to contribute to a defense. When incarcerated, inmates with FASD are highly vulnerable to victimization.

Upon release, without accommodations and recognition of the brain disorder, affected people often have difficulty following the terms of probation or parole. Deficits in language comprehension, abstract thinking, and memory can mean that instructions need to be broken down into smaller steps, repeated, and made concrete, with specific examples. Increased structure and supervision may be required, due to difficulty in executive functioning involving judgment, impulse control and being easily misled by others. Remand can occur due to lack of understanding and failure to build in supports. Recidivism is high in FASD.

### **The American Bar Association Resolution on FASD (2012)**

FASD presents law enforcement, the courts, correctional facilities and probation/parole with serious issues related to the ability of the affected person to form criminal intent, contribute to their defense, vulnerability to victimization and parole violation, all related to brain damage. The ABA urges attorneys and judges to receive training in this disorder. No such program exists in California.

### **FASD and Justice: Issues Raised by the Disability in the Legal System**

- Major language processing problems with failure to understand questions from police, attorneys and judges
- Difficulty forming criminal intent
- Poor memory and inability to recall events that led to arrest along with confabulation (making up what happened due to poor recall)
- Ability to contribute to his/her defense is questionable
- High rate of false confessions (suggestibility) and easily misled by leading questions
- Punishment may not act as a deterrent because of poor ability to learn from consequences

### **Common problems seen for criminal justice in real life scenarios**

- Not understanding that an action is against the law: A man drove a car that was stolen; When stopped the affected person said, “but I didn’t do anything wrong, I didn’t steal the car”
- Immaturity: Robbing a bank with a bicycle as the get-away vehicle
- Poor impulse control: A woman sees a necklace at her friend’s house and takes it
- Poor Judgment: She wears the necklace to a party at the same friend’s house

- Repeatedly making the same mistake: Being arrested 4 times for not paying traffic tickets; the only solution being the loss of driving privileges
- Being used by others: The “friend” of a young woman with FASD tells her to take a scarf for her; the person with FASD is convicted of shoplifting and the other person is not

## Mental Health and Substance Use in FASD



Photo Courtesy of Proof Alliance

40% of people in an outpatient psychiatric clinic are identified as having an FASD.<sup>15</sup>

90% to 95% have mental health problems (See footnote 10).

- Having an FASD predisposes children to psychiatric disorders
- 87% of children with FASD will have at least 2 mental health diagnoses<sup>16</sup>
- 30% of children in in-patient psychiatric programs have a documented history of prenatal alcohol exposure
- 35% will have a substance use disorder, starting at 12 years of age<sup>17</sup>
- Schizophrenia occurs with FASD at 3 times the rate seen in the general population
- 23% will attempt suicide<sup>18</sup>

<sup>15</sup> Bell, C. This doctor discovered an epidemic. *PBS News Hour*: May 31, 2016

<sup>16</sup> Connor, MJ and Paley, B. Psychiatric conditions associated with prenatal alcohol exposure. *Dev Disabilities Res Review*. 2009; 15, 225-23

<sup>17</sup> Connor, MJ et al. Under recognition of prenatal alcohol exposure in a child inpatient psychiatric setting. *Mental Health Aspects of Developmental Disabilities*. 2006; 9(4): 105– 109

<sup>18</sup> Huggins, JE. Suicide attempts among adults with FASD: clinical considerations. *Mental Health Aspects of Developmental Disabilities*. April 1, 2008

- The body stress system, the HPA axis, is damaged, leading to a high rate of stress disorders, such as anxiety and depression
- As in Autism, sensory integration problems increase difficulties with behavior regulation
- Trauma is endemic in FASD



According to SAMSA, the most commonly used evidenced-based treatment in mental health and substance use are contraindicated in FASD. Group treatment is also not recommended. Modification to standard treatment is needed because of the cognitive deficits resulting from brain damage.

With most children and adults going undiagnosed or misdiagnosed these same people will receive treatment unlikely to work in a population in which mental health problems are almost universal. The same is true for substance use treatment. In addition, the use of psychotropic medications in this population comes with additional medical risk due to 1) possible kidney and heart damage with complications and 2) atypical and severe reactions to such medication.

The picture between FASD and mental illness is complex. Almost all individuals with FASD also have a mental health diagnosis. There can be considerable symptom overlap, leading mental health professionals untrained in FASD to misdiagnose mental illness rather than recognizing the acquired brain damage.

## Overlapping Behavioral Characteristics & Related Mental Health Diagnoses in Children

Overlapping Characteristics & Mental Health Diagnoses	FASD	ADD/ADHD	Sensory Int. Dys.	Autism	Bi-Polar	RAD	Depression	ODD	Trauma	Poverty
	Organic	Organic	Organic	Organic	Mood	Mood	Mood	Mood	Environ	Environ
Easily distracted by extraneous stimuli	X	X								
Developmental Dysmaturity	X			X						
Feel Different from other people	X				X					
Often does not follow through on instructions	X	X					X	X	X	X
Often interrupts/intrudes	X	X	X	X	X		X			X
Often engages in activities without considering possible consequences	X	X	X	X	X					X
Often has difficulty organizing tasks & activities	X	X		X	X		X			X
Difficulty with transitions	X		X	X	X					
No impulse controls, acts hyperactive	X	X	X		X	X				
Sleep Disturbance	X				X		X		X	
Indiscriminately affectionate with strangers	X		X		X	X				
Lack of eye contact	X		X	X		X	X			
Not cuddly	X			X		X	X			
Lying about the obvious	X				X	X				
Learning lags: "Won't learn, some can't learn"	X		X			X			X	X
Incessant chatter, <b>or</b> abnormal speech patterns	X		X	X	X	X				
Increased startle response	X		X						X	
Emotionally volatile, often exhibit wide mood swings	X	X	X	X	X	X	X	X	X	
Depression develops, often in teen years	X	X				X			X	
Problems with social interactions	X			X	X		X			
Defect in speech and language, delays	X			X						
Over/under-responsive to stimuli	X	X	X	X						
Perseveration, inflexibility	X			X	X					
Escalation in response to stress	X		X	X	X		X		X	
Poor problem solving	X			X	X		X			
Difficulty seeing cause & effect	X			X						
Exceptional abilities in one area	X			X						
Guess at what "normal" is	X			X						
Lie when it would be easy to tell the truth	X				X	X				
Difficulty initiating, following through	X	X			X		X			
Difficulty with relationships	X		X	X	X	X	X			
Manage time poorly/lack of comprehension of time	X	X			X		X			X
Information processing difficulties speech/language: receptive vs. expressive	X			X						
Often loses temper	X		X		X		X	X	X	
Often argues with adults	X				X			X		
Often actively defies or refuses to comply	X				X			X		
Often blames others for his or her mistakes	X	X			X		X	X		
Is often touchy or easily annoyed by others	X				X		X	X		
Is often angry and resentful	X						X	X		

Cathy Bruer-Thompson, retired, Minnesota Organization on Fetal Alcohol Syndrome Board Vice-President, Special Needs Adoption Trainer cathybt@gmail.com 4/29/2016

With deep appreciation to the many who edited and contributed  
www.mofas.org

## Recommendations for Mental Health and Substance Use Treatment

- Establish training for mental health and substance use professionals on the recognition of FASD, diagnosis, and its treatment<sup>19</sup>
- Establish FASD specialists trained in the disorder as consultants for mental health professionals
- Develop model programs, as has been done in Michigan, through an action plan developed by the state legislature<sup>20</sup>

## Developmental Disability Services

Fetal Alcohol Spectrum Disorder is an ID-Equivalent disability.<sup>21</sup> By definition, it is acquired before 18 years of age, caused by insult to the developing brain in utero from prenatal alcohol poisoning. FASD is a developmental disability with significant impact for most affected people.

One does not outgrow FASD. A child with FASD will grow into an adult with FASD. In fact, FASD gets worse over time. Adaptive function deficits increase with age in this disorder. Most affected adults, especially those with typical IQ, simply fall through the cracks or land in jail because they do not have the supports, supervision and structure they need to be safe and act safely.



The problem is acute because 1) most affected people have typical IQ and their deficits are not recognized 2) high expressive language gives a false impression of higher functioning and 3) professionals do not know about the disorder or how it presents.

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<sup>19</sup> Improving awareness and treatment of children with fetal alcohol spectrum disorders and co-occurring psychiatric disorders. *Disability Service Center JBS International, Inc.*

<sup>20</sup> Fitzgerald, K. Building a FASD system of care within Michigan's Community mental Health System. *8<sup>th</sup> International Conference on Fetal Alcohol Spectrum Disorder. 2019*

<sup>21</sup> Greenspan, S, Novick Brown, N, and Edwards, W. FASD and the concept of intellectual disability equivalence. M. Nelson and M. Trussler (eds.), *Fetal Alcohol Spectrum Disorders in Adults: Ethical and Legal Perspectives, 2015.* International Library of Ethics, Law and the New Medicine

An adult with FASD, who is a high school graduate, can still be expected to have difficulty understanding money, time, and even the concept of ownership, due to concrete thinking. In addition, social skills are typically poor. As in Autism, an affected adult may not understand the intent of other people or how they affect others.

This leaves people with FASD who are not supervised or in a supportive structure, vulnerable to victimization. Another deficit in social cognition that creates even more risk for this population is the lack of understanding who, what and where is dangerous. Problems in eligibility with FASD as a developmental disability in California include:

- 75% will have typical IQ, yet 80% of those with typical IQ and FASD will not be able to live independently as adults
- 90% to 95% have mental health problems, but with FASD, it is the brain damage that is the primary disorder, not mental health
- With a disability that is not well understood or even recognized, affected people are found ineligible for DD services as having a “solely psychiatric disorder”

Regional Centers often misinterpret the 5<sup>th</sup> Category as needing to have a condition closely related to Intellectual Disability AND requiring services similar to someone with ID. Disability Rights has recognized the above problem. The law states, however, that a person can qualify under the 5<sup>th</sup> Category if they have a condition similar to ID, OR they require services similar to a person with ID.

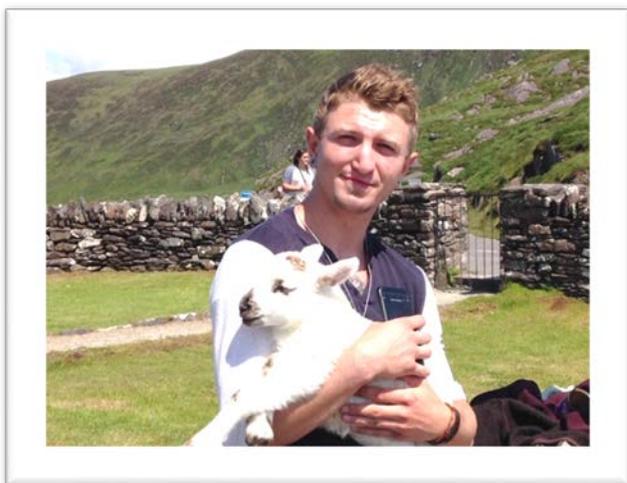
In FASD, many adults should qualify for Regional Center services by the second half of the 5<sup>th</sup> Category; needing services similar to a person with ID. In fact, FASD has been characterized as an ID equivalent disability due to 1) the disconnect between IQ and low adaptive functioning and 2) the severity of executive function deficits that reduce the ability of the person to live in community without support. The above is true across the range of IQ.

## **FASD and Developmental Disability Services: The Response Across States**

Alaska and Minnesota list FASD by name as a developmental disability. Oregon also names fetal alcohol and other drug effects as meeting the requirement for a developmental disability. Similarly, the state of Washington in 2015 recognized FASD as a “neurological condition similar to intellectual disability,” thus a qualifying condition. Colorado regulations now state that a

person qualifies for services when there is a neurological condition with either “generalized impairment in IQ or adaptive functioning.” With lowered adaptive functioning in FASD versus IQ, the change in 2014 to Colorado criteria opened needed services for many people with FASD. In addition, the Colorado change emphasized the neurological basis of an intellectual disability; the latter is an impairment in brain functioning.

The DSM 5 recognizes the inadequacy of using IQ alone to determine who does and does not have an intellectual disability. The DSM now emphasizes executive and adaptive functioning, both of which are typically low in FASD, in fact, far lower than IQ. The ability of a person to survive in the world counts, not a score that does not really predict real world functioning.<sup>22</sup> Currently, Regional Center practice still relies heavily on IQ as the determining factor in eligibility for developmentally disability services.



## Work Programs and FASD

Most people with Fetal Alcohol Spectrum Disorder will be eligible for the Department of Rehabilitation, given the presence of learning disabilities, intellectual deficit, and mental health.

However, failure to identify the disability and difficulty in obtaining special ed services in childhood can complicate eligibility for

vocational rehabilitation. In addition, eligibility is just one factor. It is critical for the DOR to recognize the presence of an acquired brain injury and to modify its services accordingly.

Currently, DOR in California has a program for adults who have a Traumatic Brain Injury. Individuals with a FASD are not eligible for the TBI program, despite having an acquired brain injury with significant impact on functioning. As mentioned earlier, FASD has a major impact on employment; 75% of affected people with a typical IQ will be unable to obtain or maintain a job

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<sup>22</sup> Greenspan, S, Novick Brown, N, and Edwards, W. FASD and the concept of intellectual disability equivalence. M. Nelson and M. Trussler (eds.), *Fetal Alcohol Spectrum Disorders in Adults: Ethical and Legal Perspectives*, 2015. International Library of Ethics, Law and the New Medicine

(see footnote 12). Difficulty in employment is also a major factor leading to homelessness. Factors that impact employability include:

- Poor understanding of time and being late for work
- Poor social skills and difficulty interacting with co-workers, customers and supervisors
- Poor memory and receptive language interfering with the employee's ability to follow oral directions or recall of what he/she is to do
- Needing repetition to learn new skills
- Being promoted to a more complex job (with the employer not realizing the employee will not be able to perform at a higher level)
- Repeat involvement with the law leading to loss of employment
- Inconsistent performance is common with brain damage, which is true for FASD which can lead to loss of employment
- Overwhelm with full-time employment
- Requiring a job coach, with the above need not recognized or a job coach removed even when such support is still required

As with mental health and substance use treatment, modification of services and supports with DOR are needed. The process of becoming a client of DOR starts with attendance at a mandatory group meeting during which the steps a new applicant must follow are outlined. Requiring a person with FASD to obtain information in a group setting is likely to be ineffective due to poor language comprehension, slow processing speed and memory deficits.

Another common practice used by the DOR is sending clients to job fairs, which is not likely to be successful without support in this population. The DOR counselor must also adapt how he/she works with most clients who have an FASD. Providing written instructions, role play and modeling are critical for success, rather than relying on what is said to the client. Finally, full time employment may be neurologically overwhelming to some people with FASD and the above needs to be recognized and planned for when helping a client look for work.



## **Recommendations For California**

Fetal Alcohol Spectrum Disorder is a complex, neurodevelopmental disorder that affects every system of care in California. It is the most common, known cause of developmental disability in the United States, one that is serious and lifelong. Approximately 2 million Californians have an FASD. Most will be undiagnosed or misdiagnosed due to the lack of training of professionals to recognize the disability and the absence of diagnostic capacity in large areas of the state. As a result, children go without early diagnosis and intervention which are critical to a better outcome in adulthood.

FASD affects not only the person with the disability. Its effects are felt by the family, community, and society. Yet, training of professionals in FASD is not part of any system of care. Today in California, people with FASD are often “treated” via incarceration, being homeless, or in mental health programs with intervention that is specifically contraindicated for the disability. It is critical to note that treatment in FASD is diagnostic specific.

Finally, state developmental disability services do not recognize FASD. Most affected people have a typical IQ. Despite significant deficits in adaptive functioning, Regional Centers often deny eligibility. Whereas FASD means there is brain damage, the mental health and substance use problems that are endemic to this disorder also lead to denial by the Regional Centers, as only the mental health issues are recognized.

The result is youth and adults with FASD are incarcerated and receive treatment that is contraindicated for the disorder or become homeless because they do not receive the support and services needed. The cost to society is considerable. The cost to affected people and families is incalculable.



California can do better. It is time for the state to address Fetal Alcohol Spectrum Disorder, not just for prevention, but to meet the needs of those who have the disability, their families, and communities. We can look to what other states have done to develop an action plan addressing FASD. One such state is Michigan, where specialist teams have been trained and model programs established. From these model programs services can be developed system wide. California can follow a similar path and key issues to address are:

- Prevention, based on research in public health
- Training of professionals
- Diagnostic capacity
- Model programs for intervention

The legislature can establish a task force on Fetal Alcohol Spectrum Disorders with a mandate to develop an action plan for FASD. It is time for FASD to come out of the shadows in California and for the state to respond to the largest known cause of developmental disability in the United States.