

External Brain

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Where did this term originate?

The idea of the alcohol affected person's need for an external forebrain was first voiced by Dr. Sterling Clarren, one of the pioneers in the field of FASD research in Seattle, Washington. The term "external brain" has been paraphrased and used by many presenters. The first time I heard it was during a conference on FAS in 2000 by Susan Doctor (now Dr. Doctor, from Reno, Nevada). Susan Doctor shared the wisdom she had gleaned from having Dr. Clarren as a mentor while pursuing her doctorate. Notes from her presentation on Modifying the Environment can be found [here](#) and notes on her presentation on Intervention can be found [here](#). The Susan Doctor/Sterling Clarren quote I use often is "The person with FAS will always need an external brain - key words are 'always' and 'external'."

What is the rationale behind the claim that the person with FAS or FAE will always need an external brain?

The person who has impaired vision is given a seeing eye dog. The person with impaired hearing is given an interpreter or a hearing aid. The person who has cerebral palsy or muscular dystrophy is given braces or a wheelchair. These external devices are necessary for the person with physical impairments to be able to function to maximum potential in life. The person with FAS or FAE - collectively called FASD or Fetal Alcohol Spectrum Disorders - has a physical impairment in the area of the brain, especially the forebrain or frontal lobes, which regulate the executive functions. Read about the forebrain [here](#). See the article about FASD and the Brain [here](#).

We would never blame a person who is sight impaired if he were to bump into a table and knock over a vase. We would never blame a person who is hearing impaired if she didn't follow instructions she could not hear. We would never judge a person who could not walk for choosing not to participate in a foot race. Instead we would advocate for these persons to receive the assistive devices needed for them to participate in life in as normal a capacity as reasonably possible.

FAS and FAE are physical disabilities, brain damage from prenatal alcohol exposure.

The person with FAS or FAE has a physical disability ([static encephalopathy](#)) that precludes normal function of an important part of their body, the brain. As the above linked article explains, there are several parts of the brain that are affected, but the crucial area that causes the most significant impairment is the front of the cerebral cortex, the frontal lobes. Sometimes the lesions in the brain are large enough to be detected by a brain scan, as is the case in about 20% of individuals with full FAS. But in 95% of cases of FAE, the damage to the brain is tiny and scattered and does not show up on brain scans performed at this time. Perhaps in the future, technology will be refined enough to detect the more subtle yet serious damage done by prenatal exposure to alcohol. Regardless of the inefficiency of brain scans, there are ways to assess the degree of brain damage. According to Dr. Ed Riley, leading researcher on FASD and the brain,

the best way to determine which areas of the brain are affected and to what degree is by having a good psychological evaluation done on the person.

Assessing the degree of disability is not difficult.

A good Psych eval would include an IQ test and an assessment of functional ability and adaptive behaviors by an instrument like the Vineland Adaptive Behavior Scales. Read one parent's rationale for requesting the school perform a Vineland for her son [here](#). Read Dr. Robin LaDue's recommendations for assessments for adults with FASD [here](#). For affected infants from age of birth to 4, the recommended assessment is the [Bayley Scales of Infant Development](#). The IQ test that seems to give the most detailed results in different areas of information processing is the [Woodcock-Johnson](#). Because children and adults with FASD typically have an IQ in the "normal" range, the brain dysfunction and developmental deficits may not be apparent to professionals. But a detailed assessment (Woodcock-Johnson and Vineland for example) will show specific areas where the child succeeds and where the child has difficulties. The results can be charted to look like this [Array of Abilities](#) of a typical young man with FAS.

Interpreting test results may require professional guidance.

When the assessments have been done, the testing professional will share a written report and will explain the results. It is most helpful to have the scores interpreted as age levels. We will often see an individual with a "normal" IQ who has good expressive language skills and adequate information, but who does not have the ability to communicate effectively, to use the information appropriately, or to interpret his or her world in a manner that promotes safety and well being.

External brains come in many models.

Because the individual may appear to be bright and normal, the disability that is brain damage may only be apparent in the test results, and of course in actions that place the person at serious risk. It is the risk of danger to the person and to others that justifies the need for the "external brain." If you have not figured it out yet, that external brain refers to the presence of another responsible person (parent, teacher, job coach, sibling) who can mentor, assist, guide, supervise, and/or support the affected person to maximize success (which may need to be redefined as the avoidance of addiction, arrest, unwanted pregnancy, homelessness, or accidental death).

The risk to pursue independence without an external brain is not always apparent, but is always present.

There are many neurological effects caused by the alcohol induced brain damage: learning disabilities, attention deficits, memory deficits, behavior problems, hyperactivity, lack of impulse control, and poor judgment. It is my opinion, based on consultation with hundreds of families, that the most serious difficulties in adulthood are based on these three effects:

- Memory deficits
- Lack of impulse control

- Poor judgment

It is my further opinion that of these three, it is the poor judgment that gets the person in the most serious trouble. For example, my son John may forget the rules and the consequences of breaking the rules when he is interacting with others in a social situation. He just is plain not thinking. If he breaks a social rule, such as hugging to close and too long, he will be able to remember the rule and explain the consequences later, but will not always think of it at the moment. If he remembers the rule to not hug women he doesn't know very well, he may just do it anyway, without much thought, as an act of impulse, without really considering the seriousness of the possible consequences. Or he may remember the rule, and stop and think about the consequences, and then do it anyway. I have seen this happen several times. Usually when I was present and observing but he was not aware that I was observing, or when I was not present as his external brain. Sometimes his memory works and sometimes it doesn't. Sometimes he can control his impulses and sometimes he can't. His judgment is sometimes good and sometimes not. Neither he nor I can predict when his memory, his impulse control, or his judgment will be working adequately.

Because of the seriousness of the consequences of acting with poor judgment on sexual impulses, some individuals with FASD will require close supervision at all times. Even "innocent" hugs can be interpreted as sexual assault - I have letters from many parents of teens who have been incarcerated for such impulsive acts. Some teens and adults will only require guidance and monitoring on a daily basis. But experience tells us that the greater the freedom, the greater the risk of serious consequences. The risk of arrest for inappropriate sexual behavior is so great, that to most parents it is not worth the risk of giving "normal" freedom to teens and adults who cannot handle independence as society urges us to give our growing children.

Other factors increase the risk of failure.

If we have a bright individual who appears to others to be normal, the risk of failure in an independent setting is intensified because of unreasonable expectations of others that this normal, bright person should be able to control his or her behavior and society wants to hold them accountable for their actions, even if they cannot - CANNOT - control their social behaviors. If we have teens who have adult hormones surging through their bodies and these adult-looking persons have the social skills of a child and the impulse control of a first grader and the judgment of a toddler, then we can see more clearly the risk and vulnerability. Even those who have learned to act like an adult may revert to a child when making decisions that could affect their future, their safety, their life.

Choice of friends, sexual activity, use of alcohol and other drugs, potentially criminal behavior - these are all risks inherent in the lives of individuals with FASD. With close guidance, they can be assisted in thinking through a situation and might arrive at a wise decision. Without close guidance, they are likely to end up in jail, an institution, on the streets, or in the morgue. No freedom there! Being realistic in assessing their ability to handle pressures from peers, from society, from their own impulses, and being realistic about the risks of erratic problem solving skills and poor judgment helps us accept their need for that external brain. Our challenge is now to help THEM accept the need for an external brain.

Not all teens and adults with FASD need an external brain all the time for all decisions. And not all FASD experts are comfortable with the term "external brain." One expert with extensive experience in the clinical setting said that this term sounds like a reference to a brain on the outside of the head. Ewwwww! But that is just what a person with FASD might need. My son John's brain does not always function properly, so he needs my brain to be working for him. And he needs more than one external brain. We have several on hand: myself, his brother, a mentor volunteer, his job coach, his music group leader, his respite provider. There has to be one available at all times for John to succeed (not get arrested, in trouble, or killed), because his brain may function at any given time at any age level from 4 to 24.

Building a Circle of Support can ensure success.

Bonnie Buxton, co-founder of FASworld, has stated the need for a Circle of Support for the adult with FASD, to be developed and stabilized during the early adult years so that it is functioning well enough to be sustained later when the parents are no longer able to function as primary external brains. The Circle of Support is a crucial component of success for even mildly affected individuals. The affected person needs to be within that Circle of Support at all times.

Assess the level of need by making an inventory.

Some teens only need an external time-keeper or external change-maker. Others might need an external friend-chooser. Some adults will need an external alarm clock or external budget manager. Many will need a hygiene monitor. Most will need an external decision-maker. Whatever kind of external brain is needed, it should be one that is working properly, that can be vigilant to foresee potential problems to prevent difficult situations in the first place. The external brain definitely needs to be trained in the area of FASD issues, and should have a good understanding of the individual's specific talents and deficits.

The level of support or supervision will depend on the individual's specific abilities and disabilities. A family can determine the level needed for their child by assessing the risk factors in the child's teen years and recent history of events in the person's life. Making a list of situations that have resulted in serious problems or presented high risk to the individual or others can help to demonstrate the level of guidance that is needed. It would be helpful to note in this inventory the instances when guidance or supervision was provided and whether it was adequate. For instance, problems can occur when the individual is with a family group, if there is not consistent vigilance by a family member who understands the risks and vulnerabilities and the areas of neurological dysfunction in the individual. Again, that external brain needs to be in good working order.

Acceptance is the key to successful support.

This idea may take some getting used to, especially if the person has had significant levels of freedom in the past. Acceptance by the affected individual is as important as acceptance by the responsible external decision-maker (parent or care provider). It is important to be frank and honest with the individuals about their impairments. Discussions should be based on fact, on the reality of the individual's situation and the results of their behavior in the past. Set some realistic

goals (maintaining a healthy relationship with significant other, keeping a stable job, pursuing a fun and healthy life style) and outline some steps to achieve these goals (avoiding addiction, staying healthy, avoiding pregnancy, pleasing the employer, keeping a budget). The objectives should be reasonable and should take into account the neurological dysfunction and risk inherent in FASD.

The reason we pursue getting assistive devices for person with physical impairments is because we care about them and want to maximize their ability to function. The reason we want to provide an external brain for the teen or adult with FASD is not because we want to restrict their freedom, but because we want to maximize their ability to be as independent as possible.