

Bright Futures: Creating College Opportunities/Programs for Students with Fetal Alcohol Spectrum Disorder

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Higher education institutions that strive to serve the needs of diverse post-high school groups and those seeking to boost enrollment by serving new populations should consider developing programs specifically tailored to the considerable number of young people in our nation with fetal alcohol spectrum disorder (FASD). Though often bright and highly verbal, these young people may have impairments in working memory, impulse control, processing speed, executive/adaptive functioning, and receptive language skills—things which would make attending college a challenge. Parents worry about their kids' ability to navigate the campus, stay on task, navigate the social milieu, and even though many parents feel their kids may be able to do college coursework, most feel they would still need accommodations in the areas of executive and adaptive functioning.

FASD is an often-overlooked disability, yet it is 2.5 times more common than autism (Flannigan, Unsworth, & Harding, 2018). It is more common than spina bifida, Down syndrome, and muscular dystrophy combined (National Organization on Fetal Alcohol Syndrome, 2014). According to some research, as many as 1 in 20 babies are born each year with FASD (May et al., 2018). FASD has been called a “silent epidemic”—epidemic in number, and silent in that it has been underdiagnosed and unrecognized, and those with FASD have been under-supported. However, there is currently bipartisan-sponsored legislation working its way through the House and Senate called the “Advancing FASD Research, Prevention and Services Act”, which, if passed, will allocate more than \$40 million for services and programs for those with FASD (Advancing FASD Research, Prevention, and Services Act, 2019–20).

Although FASD affects people across the globe as well as people of all socio-economic levels, some populations seem to experience a disproportionately high prevalence. For example, in 2012, the late Chicago psychiatrist Dr. Carl Bell

was stunned to discover that 39% of more than 600 patients he studied in the south side of Chicago where he practiced had FASD. He called this a “hidden epidemic of fetal brain damage,” responsible for perpetuating a cycle of violence, poverty, crime, and poor outcomes, and concluded that FASD is the “biggest public health problem for African Americans since slavery” (Washington, 2015). This was an important revelation because those with FASD require unique interventions in order to thrive, and typical behavior modification strategies and reward/consequence systems used for other behavioral disorders do not typically work for FASD (Zieff, Schwartz-Bloom, & Williams, 2016). However, he had much reason for hope, as proper diagnosis leads to proper support and improved outcomes.

Other populations with disproportionately high prevalence of FASD include U.S. children in foster care, 70% of whom are estimated to be affected by prenatal alcohol exposure (National Organization on Fetal Alcohol Syndrome, 2012), those in prison—who, according to a Canadian study, are believed to be 19 times more likely to have FASD—and indigenous populations (Humphreys, 2019).

Research suggests that women do not intentionally seek to harm their unborn children. Though some women are problem drinkers who can't succeed in stopping drinking during pregnancy, many women simply may drink before they know they are pregnant. In fact, almost half of all pregnancies are unplanned (Rich, 2016). Thus, in the window between conception and awareness of pregnancy, prenatal brain damage of a fetus can occur with surprisingly small amounts of alcohol consumption. The Centers for Disease Control (CDC) now recommends that no amount of alcohol is safe during pregnancy.

People with FASD have many positive traits; they are commonly: “Highly verbal, bright in some areas, artistic, musical, mechanical, athletic, friendly, outgoing, affectionate,

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determined, willing, helpful, generous and good with younger students” (Specialist Schools and Academies Trust, 2018). Many parents would also state that their kids are socially driven, eager to fit in, and eager to please. Most want to be seen as “typical” and generally are not accepting of being in programs with those with more obvious intellectual or physical impairments.

If those with FASD are not supported, or if expectations for their performance are consistently too high, they are at high risk of developing secondary manifestations, called “secondary disabilities,” such as: fatigue; tantrums; irritability; frustration; anger; aggression; fear; anxiety; avoidance; withdrawal; shut down; lying; running away; trouble at home, school and community; legal trouble; drug/alcohol abuse; and mental health problems (depression, self-injury, suicidal tendencies)” (Specialist Schools and Academies Trust, 2018). These secondary disabilities may further lead to the poor life outcomes experienced by the FASD population, and include a much higher than average prevalence of addictions, homelessness, institutionalization, incarceration, disrupted school experience, trouble with the law, suicidal ideation, problems with employment, and inability to live independently. Further, individuals with FASD whose IQs are higher than 70 actually have worse outcomes than those with a lower IQ (Rasmussen, Andrew, Zwaigenbaum, & Tough, 2008). Indeed, in order to understand FASD, professionals and parents must be able to come to grips with the fact that someone can be bright and articulate and still be profoundly impaired. Duke University’s “Understanding Fetal Alcohol Spectrum Disorders: A Comprehensive Guide for K-8 Educators,” shares this quote: “Almost without exception, children with FAS[D] fall in the mentally handicapped range in terms of adaptive behavior, no matter how bright they are intellectually” (Zieff et al., 2016). Because they are articulate and bright in some ways, individuals with FASD risk being misunderstood, and risk having expectations that are too high placed on them, setting them up for failure.

When programs and supports are specifically geared towards adolescents and adults with FASD, their challenges and adverse outcomes can be mitigated. But few interventions exist for adolescents with FASD. Even though FASD is, at this time, a lifelong disability, nearly all FASD interventions are geared towards school-aged children, even though adolescents and adults face greater challenges than children (Pei, Flannigan, Walls, & Rasmussen, 2016), and are at risk for the adverse life outcomes mentioned above. One helpful intervention particularly geared towards adolescents and young adults, and an intervention that many parents desire, is post-secondary programming.

Though there are no 2-year or 4-year colleges in the U.S. with programs specifically designed to support individuals with FASD, some 148 colleges have developed either autism support programs or describe themselves as being autism friendly (Endlich, n.d.). Students with FASD are sometimes advised to enroll in autism support programs at colleges—but the disabilities and the accommodations required by students with FASD are not the same as those provided to individuals with autism. However, colleges that have autism programs in place, as well as colleges that run summer bridge programs or specialty summer camps for high school students, would likely not find it difficult to develop another specialty program—such as one for FASD.

Post-secondary institutions are in the unique position of being able to offer adolescents an intervention, a rite of passage, and a time to mature, which at this time do not exist. Some individuals with FASD would be able to work towards a degree, while others would benefit from socialization and an independent living experience on a college campus, practicing employment and life skills needed in adulthood.

Adoptive and biological parents of children with FASD have begun to network formally and informally through websites, Facebook pages, support groups, and organizations. They help spread awareness about FASD, share experiences, and seek support and services for their children—not just for childhood, but throughout the lifespan. Some of these parents have come up with a wish list of components they would like to see in a post-secondary program for FASD. This is shared below. Input from adults with FASD who had college experience was also included.

Features of an FASD college program would include:

1. Presence of FASD-informed staff. FASD-informed staff is crucial for a successful FASD college program. FASD is a poorly understood disability, and strategies that work with other disabilities do not necessarily work with FASD.
2. FASD students being more sheltered and supervised than a typical college experience, perhaps with a cohort group in which kids live, eat, and learn together, with a low-student-to-staff ratio.
3. Smaller-sized campus (5,000 or fewer students). Small, well-supervised environments often work best for those with FASD.
4. Alcohol- and drug-free environment, as studies have shown that without support, greater than 1 in 3 adolescents and adults with FASD have developed substance abuse problems due to impaired impulse control. (In the world of FASD, it is thought easier to prevent a habit than to break one).

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5. Fun counselor-led group activities and communications/social skills support, since many with FASD struggle with isolation and difficulty forming positive or lasting friendships.
6. Life skills/“adulting” type classes, including education on topics specific to building FASD success.
7. Academic support and possibly the option to take classes online in a learning lab environment with peers and coach versus attending regular classes with peer mentoring, note-taking help, and coaching to keep pace with assignments and turn in assignments.
8. Training about employment as it pertains to someone with FASD—and how to maximize their chances for employment success.
9. A variety of programs of varying length and purpose: For example, programs for those who are degree-seeking versus certificate programs versus independent living skills programs versus a gap year program. Some students may want to work towards a degree, while others may benefit from a rite-of-passage, supportive college-type experience with peers which provides training on topics as listed above.
10. Wellness and stress reduction training. Those with FASD are often easily overwhelmed and at risk for developing secondary mental health issues such as depression.
11. For those completing a degree program: The option to take a reduced work load. In conversations with FASD-affected adults, those who graduated typically took longer to complete their programs.
12. For those completing a degree program, executive functioning accommodations and academic tutoring/coaching.
13. FASD college programs could perhaps be run as a summer camp, or run concurrently with the academic year.
14. Offering internships to master’s level students of psychology and social work could provide specialized staffing for college programs as well as train FASD-informed professionals.

Parents and young people with FASD would undoubtedly appreciate being included in any conversation a college might have about developing a program for FASD. In fact, adults with FASD have an often-repeated mantra, “Nothing about us without us.”

Specialized knowledge of FASD interventions would be an important factor in FASD college programming. Professionals should know that both evidence-based and empiric interventions are being developed for FASD. Research

has been increasing over recent years, specifically in the areas of “parent education and training, attention and self-regulation, adaptive functioning, nutrition, medication” (Petrenko & Alto, 2017, para. 5).

Empirical interventions for young adults can include occupational therapy, mentoring, housing initiatives, supported employment, financial literacy counseling/mentoring, supervision, adapting the environment, stress reduction, the concept of an “external brain” or support people to assist individuals with FASD, mental health support, self-regulation training, and cognitive training to improve memory and math skills. Executive functioning and adaptive functioning training specifically for those with FASD will almost certainly be a topic of research in the years to come.

In conclusion, FASD is a poorly understood disability which affects a sizable number of people in the United States. To date, there are zero-to-few post-secondary programs specifically designed to support individuals with this challenging disability.

A large segment of our population is failing to meet their potential. Society is failing individuals with FASD and communities are missing out on their gifts and contributions when they are not offered tailored programs and supports. Colleges and post-secondary institutions have an untapped source of students and an opportunity to take a leadership role in developing programs to serve and support individuals with FASD.

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For Further Study

For further information about FASD and interventions, please consult these resources:

Your Alberta FASD Learning Series: 97 videos (see https://www.youtube.com/playlist?list=PLvrD8tiHIX1JS6FX1OEN9N4_QAt2B1N3t) on aspects of FASD including mentoring, cognitive strategies, the adult learner, building brain boxes, FASD and mental health, addiction and FASD, FASD and the justice system, housing and FASD, Dating and sexuality, Internet safety, and more.

Centers for Disease Control: FASD Treatments: https://www.cdc.gov/ncbddd/fasd/treatments.html?fbclid=IwAR0StOVcrVIQ5d11Lt3mCY-1CiRqvmMdr5rIC8G aB_g-16jL2mB7XR7IhJw

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A Guide on Fetal Alcohol Spectrum Disorders for School Psychologists and Counselors:
https://www.ccf.ny.gov/files/9313/7969/7041/Take20AnotHer20Look_FASD20for20School20Psychologists-WEb.pdf

KNOWFASD: Intelligence Quotient (IQ):
<https://edmontonfetalalcoholnetwork.org/2019/02/05/knowfasd-intelligence-quotient-iq/>

Fetal Alcohol Spectrum Disorders Education Strategies Handbook:
<https://www.usd.edu/-/media/files/medicine/center-for-disabilities/handbooks/fasd-educational-strategies-handbook.ashx?la=en>

Supporting Employment Success in FASD:
<https://canfasd.ca/wp-content/uploads/2018/09/Guide-and-Final-Report-Supporting-Employment-Success-in-FASD.pdf>

Independent Living: https://fasdsocialnetwork.org/independent-living/?fbclid=IwAR3y6fQSBWSZvDcjOupiyLib_5-0WtWcQ7Zm_OQA3Mcl5V2YWSGdr9ndHiA

Value of Occupational Therapy for Individuals with Fetal Alcohol Spectrum Disorders:
<https://www.youtube.com/watch?v=kDPv64Grrfw>

Canada FASD Research Network: CANFASD.ca

National Organization on Fetal Alcohol Syndrome:
NOFAS.org

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