

INDEPENDENT LIVING FOR PEOPLE WITH FETAL ALCOHOL SPECTRUM DISORDERS

In the film “Big,” a 13-year-old is stuck in an adult body. He has to get a job, find a home, and pay his own bills. The film is a fantasy, but for adults with fetal alcohol spectrum disorders (FASD), it can be a scary reality.

WHAT ARE FETAL ALCOHOL SPECTRUM DISORDERS?

FASD is an umbrella term describing the range of effects that can occur in an individual whose mother drank alcohol during pregnancy. These effects may include physical, mental, behavioral, and/or learning disabilities with possible lifelong implications.

FASD is not a clinical diagnosis. It refers to conditions such as fetal alcohol syndrome (FAS), alcohol-related neurodevelopmental disorder (ARND), and alcohol-related birth defects (ARBD). Each year, as many as 40,000 babies are born with FASD. Hundreds of thousands of adults have these disorders.

Most adults with FASD look like you or me, but they have cognitive problems that make it hard to live independently. In particular, their social development is stunted and they have poor judgment. Their behavior is unpredictable from one day to the next and can get them into serious trouble.

Many people with FASD do not understand how impaired they are, which puts them at even greater risk. They have a strong desire to be “normal.” Most appear normal to others, raising unreasonable expectations and setting the stage for failure.

FASD often is associated with substance abuse, unemployment, and jail time. With appropriate support, such negative outcomes can be avoided.

WHAT IS INDEPENDENT LIVING?

Independent living refers to the ability to function in a community without support. However, many people hire others to help repair their cars, cut their grass, and fix broken windows. In collaboration

with a spouse, friends, and paid service providers, people can run their households more efficiently. Thus, “interdependent living” is a more accurate term than independent living.

Most adults with FASD will need more help than others to meet the more routine demands of work and home. The kinds of services and the degree of help needed may vary. Areas where assistance may be important include employment, money management, housing, and social skills. Many require close supervision to help them make day-to-day decisions and stay safe.

A supportive community is important for everyone, but it is essential for people with FASD. They need a strong circle of support made up of family members, mentors, social workers, job coaches, and others who understand the realities and limitations of FASD. Parents or guardians of children with FASD should start planning early for the transition to adulthood, when eligibility for many services will end.

CAN PEOPLE WITH FASD LIVE INDEPENDENTLY?

For persons with FASD, daily activities, such as working, managing money, and maintaining a home, present huge challenges. In a 1996 study of adults with FASD conducted by the University of Washington, 50 percent had trouble finding a job, and 60 percent had trouble keeping a job. Eighteen percent achieved independent living, but fewer than 10 percent could do so without employment problems.¹

About 80 percent of people with FASD have trouble managing money and making decisions. The box shows the percentages who require help with other daily tasks.



WHAT YOU NEED TO KNOW



U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Substance Abuse and Mental Health Services Administration
Center for Substance Abuse Prevention
www.samhsa.gov



SAMHSA
Fetal Alcohol Spectrum Disorders
Center for Excellence

- Getting social services, 70%
- Getting medical care, 66%
- Having relationships, 56%
- Shopping, 52%
- Cooking meals, 49%
- Staying out of trouble, 47%
- Structuring leisure time, 47%
- Keeping clean, 36%
- Using public transportation, 24%¹

HOW CAN PEOPLE WITH FASD SUPPORT THEMSELVES?

Appropriate training and assistance can help many people with FASD find and hold jobs. Job training for persons with FASD should begin during high school, with the student’s education team taking the lead in planning the transition from school to work.

The Federal Division of Rehabilitation Services may be able to help with job placement and support services such as job coaches. States and private organizations, such as the Arc, may also offer assistance.

The key to successful employment for individuals with FASD is an employer who understands FASD, has reasonable expectations, and can provide a supportive environment. Helpful strategies include:

1. Using literal language
2. Establishing consistency and routine
3. Providing ongoing training
4. Reviewing job expectations frequently
5. Helping to interpret the wishes and actions of other employees and customers

People with FASD often find it difficult to access financial benefits. Many States base eligibility for developmental disabilities benefits on IQ. Many people with FASD have normal IQs and do not qualify. They may be eligible for Social Security Disability Insurance or Supplemental Security Income from the Federal Government if they can meet the strict definition of disability needed to qualify.

Individuals with FASD typically lack skills managing money. They may receive a paycheck or benefits check and immediately spend it, rather than budgeting for rent

and other expenses. Consulting a lawyer about designating a “representative payee” can help. The payee can be a family member, case manager, or other person who receives an individual’s checks, pays their expenses, and provides spending money on a daily or weekly basis.

WHAT ABOUT HOUSING?

Housing for adults with FASD is hard to find. Those who meet certain criteria may be eligible for Federal housing programs such as public housing, housing vouchers, Section 811 for persons with disabilities, and rural housing programs. States, localities, and nonprofit organizations also may offer housing, but their eligibility criteria and accessibility vary widely.

Supportive housing that offers help with tasks such as cleaning, grocery shopping, and bill paying would be ideal, but few programs are designed for people with FASD. Group homes for individuals with mental retardation or mental illness may be an option. However, they can be a poor fit for people with FASD, who may function at a higher level than their housemates or have different needs. Independent living with services may work for persons who do not need constant supervision.

RESOURCES

- Job Accommodation Network, U.S. Department of Labor, www.jan.wvu.edu/sbses/vocrehab.htm
- National Council on Independent Living, 703-525-3406, ncil@ncil.org, www.ncil.org
- U.S. Department of Housing and Urban Development, www.hud.gov
- “F.A.S.: When the Children Grow Up,” www.knowledgenetwork.ca/know_tool/fas/resources/documentary/index.html

REFERENCE

1. Streissguth, A., and Kanter, J., eds. 1997. *The Challenge of Fetal Alcohol Syndrome: Overcoming Secondary Disabilities*. Seattle: University of Washington Press.

If you’re pregnant, don’t drink. If you drink, don’t get pregnant.

For more information, visit fascenter.samhsa.gov or call 866-STOPFAS.