

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 these tasks can be a scary reality for adults with fetal alcohol spectrum disorders (FASD).

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 an FASD. Hundreds of thousands of adults have these disorders.

Most adults with an 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 an 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 may be associated with substance abuse, unemployment, and jail time. With appropriate support, such negative outcomes can be avoided.¹

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.

CAN PEOPLE WITH AN FASD LIVE INDEPENDENTLY?

A supportive community is important for everyone, but it is essential for people with an 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 an FASD should start planning early for the transition to adulthood, when eligibility for many services will end.

Most adults with an FASD will need more help than others to meet the more routine demands of work and home. 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.

In a 1996 study of adults with an FASD conducted by the University of Washington:

- 50 percent had trouble finding a job.
- 60 percent had trouble keeping a job.
- 18 percent achieved independent living, but most had employment problems.
- About 80 percent had trouble managing money and making decisions.¹

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

The box shows the percentages who require help with other daily tasks.

- 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 AN FASD SUPPORT THEMSELVES?

Appropriate training and assistance can help many people with an FASD find and hold jobs. Job training for persons with an 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 Rehabilitation Services Administration 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 an FASD is an employer who understands FASD, has reasonable expectations, and can provide a supportive environment. Helpful strategies include:

1. Using concrete 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 an FASD often find it difficult to access financial benefits. Many States base eligibility for developmental disabilities benefits on IQ. Many people with an 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 an 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 an FASD may be 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 an 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 an 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

- Rehabilitation Services Administration, www.ed.gov/about/offices/list/osers/rsa/index.html?src=mr
- 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.