



15 Tips for Facilitating Liftoff For Youth Diagnosed with FASD

by Jodee Kulp and Cathy Bruer-Thompson

An 18-year-old diagnosed with FASD typically has difficulty transitioning into adulthood. Experts suggest that parents start planning for the adult years, perhaps as soon as the child joins the family. In order to substantiate and qualify for services that may be needed in independent living, parents will need to do the following:

1. Create two three-ring notebooks, one for medical information and one for educational information.
 - The education notebook contains assessments, progress and IEP reports, grades, and information from teachers. Ask and include end of the school year paragraphs from teachers that consist of strategies used with your child and difficulties encountered. Such reports are invaluable for future documentation.
 - The medical notebook includes emergency information, doctors with contact information, the primary clinic, the child's verbal abilities with examples such as not understanding idioms, respite care providers, background medical history and other reports. Include all file and case numbers and telephone numbers. Create computer files of contact names, addresses, medical information and make a backup copy. Saved data will ease completing future online filing.
2. Don't wait until the child is an adult to apply for waived services, PCA services, Developmental Disability or Social Security benefits. Apply even if you do not need the assistance during your child's early years. One parent said, "I did not apply to the county because I didn't want to use taxpayers dollars I didn't need, but then as my child got older and was approaching adulthood, I found that I couldn't get the services for her as an adult because I didn't get the services for her as a child."
3. If the adult child requires transitional services after graduation, at the fall IEP meeting of the senior year discuss all dates and paperwork for the future. In order to qualify for summer services such as a job coach immediately after graduation, paperwork must be completed by March of the senior year.
4. Expect to be rejected for Social Security benefits several times before getting accepted. Log onto www.ssa.gov and make an appointment to start the process. Have your medical notebook, educational notebook, copies of all reports and assessment and your computer data list on hand. Also expect to invest a couple of hours, not the twenty minutes stated on the website to complete the process. **DO NOT QUIT** if you are denied. Appeal immediately and repeatedly in writing and be prepared to wait for a determination.
5. Make a transition notebook by the time the child is 12 or 13 that includes his or her goals, dreams and accomplishments to build on for the future. Establish relationships early with medical personnel, support staff and future trainers that the child will use as an adult. To ease transitions, consider beginning adult support services during the senior year with one class or program. The information will help you make informed choices regarding your child's future. (For an online example, www.obs.org/napa.goal9.htm)
6. If your adult child will not be able to drive, teach him/her how to use the public transportation system or to schedule special transportation. Apply for a Metro Mobility card if you live in the Twin Cities area (www.metrotransit.com). Get a cell phone that includes free text messaging such as "Need Help" and "Come Get Me." As long as the phone is charged, and even if cell phone minutes have expired, text messaging and 911 can still be used.

7. If independence or supervised independent living is the goal, get supports in place. A 20-year-old with 12- year-old abilities will not be able to manage an apartment alone. If you need to co-sign a lease, take out the maximum in apartment insurance.
8. For further substantiation of the need for services, write a one page parent observation that is factual and includes name, age, diagnosis, limitations and abilities.
9. According to the Individuals with Disabilities Education Act (IDEA), youth with disabilities who have continuing transition needs may be eligible to get free educational services through a technical college or other post secondary facility until they are 21 if a hold is put on their diploma. Ask your local high school for details and the necessary OMB -0960-0105 form.
10. At 18, the child will receive a letter stating that medical assistance is being terminated within 10 days. Have a letter of appeal already written to send upon receipt of the letter. (See a sample Appeal Letter on last page of this fact sheet.) The Department of Human Services will send a letter that adoption assistance may be extended until the adult child turns 22 if he/she is still dependent upon you, remains in high school and continues to live in your residence.
11. Develop a Risk Management Plan to identify predictable future risks, to develop a strategy to deal with riskier areas of independence, and to construct a safety net for the adult years. Include protections for sensory limitations and at-risk behaviors as well as a plan for birth control. Also create a Medical Information for Police card for the young adult to carry with them. (See <http://depts.washington.edu/fadu/legalissues/faslaw.html>)
12. Ask for a cognitive assessment from the University of Minnesota or another diagnostic center when the youth is 17 to accurately show developmental discrepancies. Recommended tests include The Vineland (to measure adaptive skills functioning), the Global Assessment of Functioning test (to assess the gap between cognitive ability and functioning) and the Scales of Independent Behavior – Revised (SIB-R).
13. With an attorney, explore establishing a conservatorship, a limited conservatorship, or guardianship for your adult child. Each offers different options that protect both you and your adult child. Consider setting up a special needs trust fund that the youth will not be able to access until 21. Work with a tax attorney to protect your assets for your child after your death. If your child lacks the ability to understand money, buy funds such as treasury or savings bonds that come due intermittently to provide for your child’s future as an adult.
14. Regarding money matters, consider establishing several accounts that might include a parent savings account, a representative payee account where Social Security check or any government service check is deposited, and/or an account in the youth’s name with limited funds available. Use auto pay for bills. Some parents put aside the adoption assistance attained throughout the child’s younger years as a nest egg, but due to management issues, it might be advisable not to put this in the youth’s name.
15. For household maintenance, simplify and instill safety. Change recipes to be simple and safe. An electric frying pan, crock pot, microwave or griddle is preferable to a gas or electric stove. An onion chopper in a glass jar is safer than knives. Parents can set up a time to cook meals for the entire week or for several days in advance.

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APPEAL LETTER WHEN MEDICAL ASSISTANCE IS DENIED

Date

Parent Names
Re: **Child Name – SSI #**
Address
City, State, ZIP

Addressee
Agency
Address
City, State ZIP

Re: **Letter dated** _____ -- Claim number _____



THIS IS A LETTER OF APPEAL

Dear _____

This letter is to appeal your decision to terminate survivor medical assistance benefits for name of child on insert date, the reasons we are appealing are:

1. Insert Name will be attending insert program/school as a full time student until insert date and she/he will hold her high school diploma until she is 21, as she/he gains skills in independent living.

2. Insert Name is disabled and was born with Fetal Alcohol Spectrum Disorder (Other Health Impaired) and has an IQ of insert number, GAF insert number and lower adaptive skills. Insert Name has a diagnosis from the insert program. The last psychological and medical examinations and testing were completed insert date, previous dates of testing and examinations occurred between insert dates. All documentation is available for your examination.

Her medical diagnosis is insert diagnosis with Azis Codes I-V

3. Insert Name is currently living insert information.

I am writing this letter on her behalf as her insert your relationship legal to child. Please advise if I need to do anything further. You may reach me at my office at insert number.

Sincerely,

Client Name Your Name
Case #Insert number Relationship to Client