

Advocating for the Student with FASD

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This is a general outline to follow, step by step, to advocate in the U.S. education system for the child who has or may have Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), or Alcohol Related Neurodevelopmental Disorder (ARND), collectively referred to as Fetal Alcohol Spectrum Disorders (FASD). Before an actual IEP is written up, there are several steps to take first.

I. Gather Information. When asking for services for children with FASD, some school personnel may view the problems as ordinary behavior problems due to poor parenting, and may perceive the child as "lazy" and the parents as either "too lenient" or "overprotective." In cases where the school might be reluctant to evaluate the child for special ed, it is helpful to have some record of problems in the recent past that you have seen with your child that would have an adverse affect on the child's ability to learn. Collect all information from past testing or appointments and keep them in one place, and start an advocacy file.

A. Journal. Keep a journal and record all incidents and situations you observe. Write the date and time of each incident or behavior. Use the "[ABC](#)" method, listing the antecedent (a trigger to behavior, or what happened before the incident, or what might have contributed to it), the behavior, and the consequence, whether natural or imposed. Here is a pdf form you can use to chart behavior: <http://www.dbpeds.org/pdf/abcform.pdf>

B. Documentation. Keep a log of every conversation you have with school personnel regarding your child.

C. Identify your concerns. Make a list of all your concerns. Pick out the most important ones that you want to deal with first. Here is a planner that will help you organize and identify your concerns: http://www.tourettesyndrome.net/Advocacy/SpecEd/worksheet_sample.htm. Besides areas of need that will be revealed by evaluations (below), areas of concern regarding a child's needs in a school setting include the following issues, which should be written into the IEP:

- **Training** of all staff on FASD issues
- **Communication** log for sharing information between home and school
- **Supervision** at all times, including on the bus, before school, on the playground, in the cafeteria, in the locker room, and all other times in and out of the classroom.

II. Educate yourself. Know your rights. Check up on current law regarding special education. Sometimes parents know more about IDEA law than the school, and this can work in your favor because no one will try to get away with sidestepping the law with regard to your child's IEP, and they will be least likely to intimidate you at IEP meetings.

A. IDEA law. [IDEA stands for Individuals with Disabilities Education Act Amendments](#). Here are some links that can be helpful:

- <http://www.reedmartin.com/index.html> - Reed Martin is a lawyer with practical suggestions, articles, and a newsletter.

- <http://www.wrightslaw.com/> - Wrightslaw has a Game Plan for New Parents and an article on Getting Started.
- <http://www.kerrlaw.com/toc.html> - Kerr Law Offices offers a special ed glossary, a parents resolution chart, and articles on discipline and other relevant issues.

B. Protection and Advocacy. Every state has a Protection and Advocacy agency, paid for by your tax dollars, that can provide you with answers to questions, quotations of the law, training workshops, handouts and booklets, legal advice, and even legal representation in certain cases they may choose to take and fight on your child's behalf. It is good to be familiar with your local P&A. Sign up for a class, or talk to a lawyer or volunteer, just to have a contact.

Here is where to find your local P&A office:

<http://www.acf.hhs.gov/programs/add/states/pas.htm>. At the very least, ask them for a copy of your rights as a parent of a child with special needs.

C. FASD Information. Educate yourself well about FASD and be ready to offer information on FASD to the school personnel. Rather than hand them a stack of papers that you have downloaded off the Internet, which is too overwhelming to read and might end up in the waste basket, give them each a copy of the brochures on FASD that are available here: <http://come-over.to/FAS/brochures/> Find someone locally who knows what FASD is and who understands how it can impact a child's ability to learn, and ask that person to advocate with you. Although you as the parent are THE expert on your child, and probably know more about FASD than anyone else on the team, your credibility might be questioned, and they are more likely to listen to an outside party that you bring in as an expert, even though you know just as much as they do.

D. Disability Groups. If your child is developmentally disabled (IQ under 70), join [The Arc](#). If your child has normal IQ but has an attention deficit like ADD or ADHD, join [CHADD](#). If your child has co-occurring mental health issues, join [NAMI](#). You will learn more about how to access local services from other parents than from any other source.

III. Assessments and Evaluations. Sometimes parents or others only suspect that the child may have FASD. In most cases, the effects of prenatal alcohol exposure are not recognized early and often a diagnosis has not been made before the child enters the school system.

A. Medical Assessments. Concerns and suspicions should be taken to the child's primary care physician, who can either make a diagnosis or make a referral to a geneticist or neurologist who is trained in making a diagnosis of FASD. Sometimes a geneticist will suggest DNA tests to rule out genetic disorders. If there is any documentation of alcohol exposure during pregnancy, that will be helpful to provide. This can be an admission by the birth mother or it can be a report from a family member or physician or other reliable witness. Having anything in writing that suggests there was alcohol consumption during pregnancy, such as a social worker's report, might be valuable. The IEP must consider all outside reports from private sources that you submit.

B. Psychological Evaluation. A psych eval can and should be done by the school system. A parent can request that an evaluation be performed. Call the principal and tell him/her of your concerns. Follow up with a written request for an evaluation of your child. If the school refuses, they must provide a written explanation. Although most children with alcohol related disorders test in the normal range, they may have areas of high ability and areas of difficulty, and these problem areas are not reflected in an IQ score. There are areas of concern that should be

assessed, including fine motor skills, social skills, visual-spatial skills, adaptive behaviors, and functional ability. Be sure to include this information in your written request.

a. IQ test. Schools often use the Wechsler test, known as the WISC-R. Another test is sometimes used, the Woodcock-Johnson complete battery (WJ-III). The Woodcock-Johnson is the preferred IQ test because it shows more detailed results in areas of mental processing, where we might see high and low scores in different areas. In some states, a child's eligibility for DD services (services for individuals with developmental disabilities) could depend on getting a score under 70. These services are separate from educational services, but the tests administered at school now could assist in getting other services later, such as respite care and medical services.

b. Visual-spatial test. The Bender Visual Motor Gestalt (BVMGT) can determine visual processing ability, and the Human Figure Drawing (HFD) can be administered to assess ability to conceptualize visually.

c. Social skills test. Functional abilities, communication skills, and social skills can be measured best using the Vineland Adaptive Behavior Scales (VABS). There is a test being developed called the FAS Adaptive Behavior Scales (FABS), but until it is released, we can rely on the Vineland to show problems in functional abilities. This is a questionnaire with several hundred questions about the child's ability to perform tasks, communicate, and participate in typical daily living activities. There is a version for parents and a version for teachers. It is recommended that the version for parents be administered to get a more thorough idea of how the child performs over-all. The score of the Vineland for a child with FAS or FAE is expected to be much lower than the child's IQ, sometimes by 20 or 30 points. Parents should answer the questions honestly, in a way that truly reflects the child's ability. If the question asks if the child can brush his own teeth, a parent might want to answer "yes" but if the child forgets to use toothpaste unless reminded, and needs to be watched to be sure he brushes adequately or can't really do a thorough job without help, then the correct answer should be "no, not by himself, he needs assistance." This is not the time to "brag" about the child's one-time or infrequent accomplishments. How the question is answered could determine how the psychologist scores the points on the test. Here is a sample letter requesting a school to administer the Vineland: <http://www.come-over.to/FAS/VinelandRationale.htm>

C. Reports. Every test or evaluation should have a report written by the professional who administered the test and should be given to the parent, with an opportunity to explain the results. Sometimes parents can request "raw data" from the testing, which will show subtests such as those on the Woodcock-Johnson or the Vineland that will be helpful to understand and use for planning to meet the child's needs when writing the IEP. Be sure to request copies of these reports and any data to which you might legally be entitled. Here is a site that will show you how to interpret the scores:

http://www.wrightslaw.com/advoc/articles/tests_measurements.html

IV. M.E.T. The M.E.T. stands for Multidisciplinary Evaluation Team. This team is formed before an IEP is written to determine if the child qualifies for special ed and what evaluations will be performed. Typically, the team includes the school psychologist, the child's teacher, and a special education teacher. If the child has a suspected or confirmed disability, then an expert in the field of the disability should be on the team. Often the parent is more of an expert than anyone else, but to find someone in

your area that can act as the FASD expert, look in the USA FAS Resource Directory: <http://www.mofas.org/fasdirect> It is important to have an FASD expert give input to the team to ensure that all the proper assessments are done. If the team decides that your child is not eligible for an IEP, refer to the following article on how to resolve an eligibility dispute: http://www.wrightslaw.com/advoc/ltrs/eric_eligibility_disputes.htm.

V. Individualized Education Planning Team The IEP team includes the regular teacher, a special ed representative, and a member of the MET. By law, parents must be invited to be active participants in the meeting. An explanation of the IEP team can be read here: <http://www.resa.net/sped/parent/iept.htm>

A. Labels. There are many labels for classification of special ed, including but not limited to: MR (mental retardation), LD (learning disabled), EH (emotional handicap), MH (multiple handicaps), and OHI (other health impaired). If your child has an IQ low enough to qualify for the MR label, that is an appropriate classification. If your child's disabilities are mild, then the LD label could be helpful. If your child has mental retardation and physical disabilities, then MH would be appropriate. The least favorable label for the child with FASD is EH because placement in the EH classroom is not the best environment for a child with FASD to learn, and the approach to behaviors is based more on psychological basis than on a neurological basis. The best classification for the child with FASD is **OHI, Other Health Impaired**. This is appropriate because FASD is a neurological impairment of a physiological nature.

B. Objectives. Goals and objectives for your child should be based on the results of the assessments made earlier. Goals and objectives for a child with FASD should include social skills, and expectations should be reasonable and based on the child's level of development as noted in the Vineland test results. Here is a game plan for writing goals and objectives: http://www.wrightslaw.com/advoc/articles/plan_iep_goals.html

C. Placement. Become familiar with the legal meaning of the term "[least restrictive environment](#)." Sometimes, for children with FASD, restrictions offer needed structure and reduce factors that contribute to some of the problems. In most cases the "least restrictive environment" for a child with FASD is one with many environmental controls. Just because your child has an IEP does not necessarily mean your child will be placed in a special ed classroom. The classroom and classification that is right for your child depends on your child's unique needs, on the environment of the classroom, and on the education and attitude of the teacher.

1. Regular Classroom. Inclusion in the regular classroom might work, if the teachers and aides are educated about the nature of alcohol related disorders and if adequate one-on-one is provided. However, the regular classroom is usually too chaotic and the child with FASD is likely to become frequently overwhelmed from sensory overload due to the level of noise. Regular teachers are seldom trained to work with children with FASD, and conventional behavior management might not only be less effective but could make the problems even worse.

2. EH Classroom. Many children with FASD are placed in a classroom with children who have serious behavior problems. This may or may not be the best placement for the child with FASD. If the other children's inappropriate behavior is a model for your child to imitate, or if the teachers approach your child's behavior problems solely from a psychological perspective, then the EH classroom will probably not work well. But if the

teacher is knowledgeable about the nature of FASD and knows and practices the techniques that are known to work well with children with alcohol related disorders, then this placement could work.

3. Special Ed Classroom. Other classrooms, such as those for children with MR (mental retardation) or MH (multiple handicaps) classifications, can be an option for the child with FASD, as a full time placement or as a "pull out" for special assistance. Some experts believe that the ideal classroom for the child with FASD is the one designed for students with autism, because that provides for a quiet environment with adequate structure and favorable staff ratio.

4. Homeschool. Some parents do not wish to go through the struggles of changing the school system to meet their child's needs, and choose to homeschool. After having suffered from chronic frustration of unrealistic expectations and feelings of failure in the school system, children with FASD seem to do very well when homeschooled. Some parents would like to homeschool but fear they will not have the information or stamina to do so, but most who try it wish they had not waited so long to pull their child out of regular school. Here is how to get an idea if homeschooling is for you:

<http://www.come-over.to/homeschool/>

D. Conflict Resolution. Here is a simple plan to help you resolve IEP conflicts easily: <http://www.come-over.to/FAS/IEP123Plan.htm> Print it out and take it with you to every IEP meeting. Even if you don't have a conflict, this will help prevent any conflicts from occurring.

VI. Teresa's Tips

- **Know where to go for help.** Bookmark this page so you can find it when you need it. Ask a friend to go with you to the IEP meeting. Talk to someone at one of the organizations mentioned above.
- **Do your homework.** Think of this as a class you are taking. Give yourself time to study the information on the links provided, and take notes to put in your folder or notebook.
- **Avoid becoming an adversary.** When it's you against them, they usually win. Think "team work" and remind everyone that we all have the same goal, to set up a program that will help your child succeed in school. Everyone wants your child to succeed. It's okay to get angry, but vent your emotions with a trusted friend or family member, and go into the IEP meeting with a cool head, armed with facts. It is much easier to work WITH the team than to work against the team.
- **Think positive.** When making a complaint, be ready to propose some possible solutions. When you go in to discuss a problem, begin the conversation with a few issues you are pleased with to balance your attitude and defuse the need for defensiveness. Visualize how the situation will look when your child's needs are being met in school.
- **Give yourself a pat on the back.** You deserve credit for having read this article all the way through. You also deserve credit for seeking ways to make your child's life easier. FASD issues are difficult enough to cope with on a daily basis, but struggling with educators and professionals who don't understand FASD is even more difficult. Know that you are not alone, and that you can do it. Now go take a break and do something nice for yourself.