

Supporting Adults with Fetal Alcohol Spectrum Disorders and Sexual Concerns

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Fetal alcohol spectrum disorder (FASD) is an umbrella term that covers several conditions. These are each related to exposure to alcohol or drugs due to the mother's drinking of alcohol or using harmful drugs during pregnancy. There is no known safe amount of alcohol during pregnancy or when trying to get pregnant. There is also no safe time to drink during pregnancy. The FASD conditions have lifelong effects. Children with FASD become adults with FASD due to lasting damage. We support many adults with FASD in residential care settings and through the PRS program.

FASD conditions are one of the most commonly identified underlying causes of intellectual disabilities (ID) and other learning disorders. People with FASD can have problems with learning and memory, attention span, communication, vision, and hearing. They frequently do poorly in school or work and have difficulties with math, judgment, impulse control, and a range of emotional and behavioral challenges.

Secondary Conditions

There are many areas in a person's adult life that can be affected by FASD. Some of these are called "secondary conditions" -meaning secondary to the effects on the brain itself. These include:

- Inappropriate sexual behavior: unwanted comments, advances, or touches; promiscuity, sexual touching, exposure, compulsions, voyeurism, masturbation in public, incest, sex with animals, and making obscene phone calls.
- Mental health conditions: ADHD, ID, conduct disorder, depression, anxiety.
- Histories of disrupted school experiences: special education placement, suspensions, expulsions, dropping out.
- Trouble with the law: contacts with the police, problems controlling anger and frustration, verbal and physical aggression episodes, explosive episodes. Many have been involved with the criminal justice system, jail, or prison.
- Alcohol or drug dependence: more than a third of people with FASD have troubles with AOD. More than half of those people require inpatient treatment.
- Being dependent adults: living with family members or supported living arrangements, and group home placements.
- Problems with employment: poor motivation to seek employment, difficulties with acquiring and keeping a job.

Communicating with adults with FASD can at times be very challenging. Adults with FASD related brain impairments often have difficulty with:

- Hearing words and meanings.
- Processing information and interpreting social cues.
- Expressing themselves.
- Remembering points made during conversations.

FASD Related Social and Sexuality Issues

People with FASD conditions have the same physical development processes as people who don't have FASD. Those with FASD tend to have significant psychological and social challenges. They are often less socially mature than their same aged peers. They often have childish social behaviors that would not be expected for a person at their age. As an example, people with FASD often blurt out comments without any thought as to how other people will take it. Not filtering what he says aloud, a man might say "you have nice boobs" to a woman with whom he has no relationship. Or he might say that to one of his staff persons or to his doctor. Another example is that people with FASD often misinterpret social gestures. A man with FASD might get a smile from someone and take it as an invitation to touch the person, although it was not meant that way. Friendliness might be mistaken as sexual interest. Some men with FASD touch others on the arm or shoulder, while others may touch on the chest or buttocks without permission.

The most frequent inappropriate sexual behaviors done by adolescents and adults with FASD conditions involve poor sexual boundaries, e.g., inappropriate sexual advances and promiscuity. Females with FASD have been found to engage in promiscuous behavior twice as much as males. Males with FASD have been found to more often engage in inappropriate sexual advances. Males with FASD are also twice as likely as females to have trouble with the law.

Many people with FASD have trouble forming friendships. Making friends and knowing when that friend is interested in a more romantic relationship is full of challenges. Men with FASD are often clueless about how much work it takes to make a relationship last. While many people with FASD long for an emotionally intimate relationship, having one that lasts is elusive. Because of the impulsivity related to FASD, some men are more inclined to just take whatever they want -or to just touch what they want. Some assume that because they want it, the other person must want it too. For some men with FASD they are not comfortable trying to relate to someone their own age and turn to teens or even children to be friends with. Expressing their sexual interest with a person who is more of a match with them in terms of lower social maturity, rather than age, can of course lead to trouble with the law. Or alternatively, may lead to a referral to the PRS program.

How can direct care staff members support adults who have an FASD condition?

It can be difficult to support individuals with FASD who exhibit these kinds of cognitive, emotional, and behavioral challenges. Attachments are more difficult to form with individuals who have FASD. Our communications are often interpreted differently than we intended them. Here are some ideas that may help to improve communication and cooperation when supporting individuals who have FASD.

- **Be constant:** The best approach in supporting adults who have FASD in residential care is to give almost constant supervision and model how to organize

one's thinking. We need to be an external hard drive to make up for the person's underlying cognitive challenges caused by the FASD.

- **Be accepting:** Remember that for the adult with FASD to take on responsibilities, it is first dependent on having functional support by staff to allow him or her to feel accepted, treated fairly, and to focus on the positive things in their lives. We need to convey that we accept the client where they are but also expect them to want to grow and learn to meet adult expectations in healthy ways.
- **Be uncomplicated:** people with FASD, like people with ID, require us to use simple and plain language, and give concrete examples when teaching. We need to use plain language and be very specific in our instructions and interactions.
- **Be firm:** describe your physical and emotional boundaries with your words and your role model. Stick to the healthy boundary expectations in the PBSP. We need to demonstrate acceptable boundaries every day.
- **Be sensory aware:** people with FASD, like people with Autism, have difficulty with sensory input. They can be bothered by florescent lights, distractions in the environment, and other people crowding in their space. We need to make adjustments to the home environment to avoid unnecessary sensory challenges.
- **Be the structure maker:** staff are the external scaffolding that can help individuals with FASD and ID to learn. We need to:
 - Be consistent and stick to the individual's routines.
 - Offer structure and repetition.
 - Use hands-on approaches to learning and teaching.
 - Use behavior rehearsal, repetition, then more behavior rehearsal, and all this with ongoing supportive feedback.
- **Be an organizer:** adults with FASD are almost always dependent on others to help organize their lives even though they often claim to have the ability to live independently. We need to use notes written in plain language, schedules, and fun charts to help individuals with FASD learn to be organized.
- **Be a non-threatening explainer:** help the person with FASD understand why they keep getting into trouble over the same behaviors, and to think before they act. We need to gently and nonjudgmentally help the person see any patterns in their lives that are not helpful for them.
- **Be an undercover teacher:** Help the individual set up methods of sticking to their routines. We need to help the individual by:
 - Setting cell phone alarms.

- Sending reminder texts.
 - Creating visual cues.
 - Color-coding charts and calendars.
 - Writing out schedules or using.
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- **Be alert:** we can be deceived by the person “looking capable” from the outside and often being a fast talker. Adults with FASD often say they can do things, but this actually means that they would like to do things. We need to be patient and ask the individual to use actions not words to demonstrate their skills.

 - **Be aware:** many people with FASD who have exhibited sexual problems or offending behaviors do not pay attention to their surroundings or may not respond appropriately in some situations. We need to pay attention to the person’s specific risk factors, i.e., children in the environment or intruding on other people’s space. We need to learn the individual person’s risk factors -and the needed interventions- as this can help us be more effective in reducing opportunities for sexual misconduct to happen.

 - **Bring your best tools:** creativity, flexibility, humor, compassion, and patience. We need to:
 - Be thoughtful of the different ways of seeing things the person with FASD might have.
 - Be easy going and adjustment on the fly to accommodate the person’s needs.
 - Be empathetic and recognize the person did not ask to have these FASD-related challenges.
 - Be non-demanding and tolerate the time the person needs for remembering, learning, and making positive changes.