

***General guidelines for supporting adults with
Fetal Alcohol Spectrum Disorder***

*(and other similarly handicapping
brain dysfunctions)*

in

Mental Health or Forensic settings

By

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Some adults with FASD (and other similarly handicapping brain dysfunctions) are likely to always be unsafe when they are expected to function independently in the community:

Adults with FASD tend to not be internally organized. They tend to “take on” the role of influential persons in their environment that are accepting and friendly. They have limited judgment about the consequences of their own actions. They have little ability to be affected by their own limited knowledge of those consequences.

Some adults with FASD are likely to continue to do whatever it is that “seems like a good idea at the time.” They are not likely to learn from their own negative experiences. To live a safe and partially effective life, many affected individuals will be functionally dependent on having the assistance of an “external brain” to remind them what needs to be done, and when things need to be done. The correct approach when working with a person who is functionally dependent is to provide them with almost constant external organization.

The psychosocial goal versus functional dependence:

What is wrong with a psychosocial rehabilitation model?

Adults with FASD who express a desire for more independence often find philosophical support from the professional mental health community.

Psychosocial rehabilitation is: “The process of facilitating an individual’s restoration to an optimal level of independent functioning in the community... psychosocial rehabilitation encourages people to participate actively with others in the attainment of mental health and social competence goals. (Cnaan, et.al, 1988. Psychosocial rehabilitation: towards a definition. Psychosocial Rehabilitation Journal, Vol 11, #4, April 1988, page 61.)

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To apply psychosocial rehabilitation to all persons with FASD assumes “restoration” of all brain dysfunctions is physically possible. This also assumes that all individuals with brain dysfunctions are capable of “participating actively with others” to attain social competence.

The assumption of Cnaan, et.al., that “people are motivated by a need for mastery and competence” applies equally to those with brain dysfunctions such as FASD.

In some individuals with handicapping brain dysfunctions it is not always correct that, “New behavior can be learned and people are capable of adapting their behavior to meet their basic needs” (VICSERV.org.au - What is Psychosocial Rehabilitation. <http://www.vicserv.org.au/library/papers/whatispsr.htm>.)

The issue of becoming independent and acting responsible versus functional dependence:

What is wrong with a behavioral model tying “privileges to responsibility?”

In a mental health, forensic or other behavioral **rehabilitation** settings, increasing privileges are often contingent on increasing evidence of self-control and self-management of one’s behavior. For individuals who are not independently capable of adapting their behavior to meet their own basic needs this contingent structure often leads to endless failure. There is a failure of the support system to rehabilitate the individual with certain types of brain damage. There is a failure of the person with FASD to feel fairly treated or to establish trust. The result, in both care providers and persons being supported, is mutual animosity and feelings of helplessness and futility.

Instead of “eventual independence,” the more appropriate goal is to protect adults with FASD and other similarly handicapping brain dysfunctions from being in situations where they cannot independently sustain themselves in a responsible manner. Instead, provide the individual the level of support he/she requires to be able to do well, within the dependent structure provided by others.

People living in a model of psychosocial rehabilitation (or behavior management) are often provided with behavioral support programs tailored to address the needs of someone who is expected to eventually learn from his/her experiences. Adults with FASD who live in a model of psychosocial rehabilitation are also expected to eventually become responsible for their own actions. They are expected to learn from their experiences and to act in their own best interest.

The part that is often “missing” in such programs is the acknowledgement that the ability of an adult with FASD to take on responsibility may first be dependent on functional support to allow him/her to feel accepted, fairly treated, and positively focused.

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Under such highly supported circumstances, the adult with FASD is often able to take on responsibility and follow programs. The outside observer may come to the conclusion that his/her ability to do so is “inside” of the individual. **The sad fact is that, in a “support vacuum,” the individual with FASD may be unable to sustain responsible behavior.**

Some adults with FASD and mental health issues are often only able to be responsible when their essential dependence on the external structure provided by those in their support environment is recognized and continually provided.

Adults with FASD often do not learn from their experiences and do not self-regulate their own actions. They often are dependent on others to assist them to be relatively organized.

The issue of establishing trust:

The adult who has both FASD and mental health issues is expected to earn the trust of those around him/her by acting in a responsible manner. This is a good psychosocial rehabilitation goal, but this goal is not so relevant to (and often not achievable by) a person who is dependent on others to be able to sustain his/her own ability to act in a trustworthy manner. Many adults with FASD are only able to behave in a “trustworthy manner” while living within a highly structured environment.

The issue of disruptive behavior:

The adult with a handicapping brain dysfunction often requires positive external structure to keep him/her organized, focused and busy. For some, if external structure is not provided the individual is not able to internally organize his/her own actions. The individual may react impulsively in response to whatever is uppermost in his/her mind at the time; may fall into repetitive or perseverative actions where he/she becomes over-focused on random external stimuli; or may become over-focused on his/her own internal fears and shift into an altered or psychiatric state.

The issue of “how can I treat this person differently from everyone else who lives here? What message am I sending to the other residents?”

What is wrong with a “you have to learn just like everyone else” model?

An analogy may be useful. Diabetics are often served a different diet. At times when they are having an insulin reaction they may be given ice cream or fruit that is not available to others who also live in the same residence. The explanation to others is that the individual with diabetes has different biological and metabolic requirements.

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Similarly, many individuals with handicapping brain dysfunction require a different level of external organization and support to be able to do what is within his/her potential to do. Some individuals with FASD may require the availability of 24/7 supports to intervene to protect him/her from his/her own impulsive actions. Some individuals may require the availability of 24/7 supports to keep occupied as a means of protecting him/her from becoming over-involved in his/her own overwhelming sensory states, or emotional arousal.

Long-term goals:

Eventually the adult with both a handicapping brain dysfunction (such as FASD) and mental health issues may be able to learn life-long routines for self-management. Even so, he/she likely will always need to be living in some form of highly supportive environment to protect him/her from becoming overwhelmed and also to keep him/her focused.

The general goal when working with an adult with FASD who is supported in a residential mental health, forensic or other behavioral rehabilitation setting is to focus not so much on developing more “independence,” but rather on more small, achievable, “in-the-moment” goals.

Try to look much more at increasing the positive aspects of the adult with FASD. Provide much more structure to the day in the form of positive guidance through modeling, the use of visual schedules and verbal reminders to create as many opportunities as possible for the person’s positive attributes to be displayed.

Rather than reacting to the disruptive behaviors of the adult with FASD, arrange environments to evoke positive interactions with the adult with FASD.

For the adult with FASD, his/her difficulties stem from his/her dependence on his/her external environment to keep him/her focused and positively organized. This difficulty is associated with brain dysfunction that has been, and will be, life-long.

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Attachment: Other important, specific issues to consider when supporting adults with FASD and similar brain dysfunction in residential settings.

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Other important, specific issues to consider when supporting adults with FASD and similar brain dysfunction in residential settings.

The issue of night staffing (Provided by David Gerry.):

Due to his or her underlying brain dysfunction, it can be very hard for someone with FASD to get to sleep. It can also be very hard for him/her to wake up. You cannot assume that a fire alarm that would jar most people out of bed will necessarily arouse someone with FASD. In specialized residential settings this may present a safety issue, as in the case of an emergency, someone will have to physically check to see that every room is evacuated. For individuals who are extremely unresponsive when asleep, this will affect the requirement for the on-site presence of a night staff.

The issue of reducing sensory overload (Provided by David Gerry.)

Due to their underlying brain dysfunction, too much visual clutter over stimulates many individuals with FASD. Reducing the amount of visual stimuli works well in specialized classrooms, and is often effective as well with adults with FASD. In general, every environment needs to be assessed to reduce extraneous stimuli that can both be distracting as well as triggers to impulsive reactivity.

Cleaning agents, perfume and other personal products can overwhelm some individuals with FASD. In some specially adapted classrooms the fluorescent lights have been removed to eliminate the sound and the flicker that can be overwhelming to someone with FASD. If he/she seems over stimulated, try meeting in a different room or outside.

The best guide to making an environment FASD friendly is to ask the affected person, "What can be done to fix this room?" (Note: If you ask, "What is wrong?" that is too open-ended and abstract.)

The issue of diminished taste sensation (Provided by David Gerry.):

Not so well known is the impact of underlying brain dysfunction on taste sensation for many individuals with FASD. For many, their sense of taste is so attenuated that they will only eat food that is very spicy or very sour. Sometimes individuals with FASD may not eat apples or oranges but will eat lemons because they are able to taste them. This may need to be explained to people in a support environment who are unfamiliar with this phenomenon.

The issue of the need for ritual to be able to cope (Provided by David Gerry.):

Two parents with FASD prepare the exact same breakfast, lunch and dinner, day after day. This allows them to budget and shop for themselves, and prepare foods that are always familiar. The dietician working with this family recognized that trying to

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expand the family diet would be beyond this family's capacity. The creative solution was to add a multivitamin to round out their diet. This is a good example of working with the existing functional competencies of the adults with FASD.

Immediate behavior management suggestions (Provided by Eric Bontogon.):

There are many, repeated situations when the person with FASD gets stuck in the here and now, demands immediate gratification, and can't move on with "regular" explanations. How can support persons take a different approach when behavior modification isn't working?

Example: The supported person is working towards something that will take place on Friday and says on Wednesday, "I want it now." How to respond when he/she keeps escalating and can't process "wait" or "it is coming soon?"

Find a way to avoid "wait." Do not set up plans with delayed gratification. Set up plans so that any reinforcement that is planned will be delivered before the end of each day!

Do not have any negative carry over from one day to the next. If it is earned today, great. Anything not earned today should have no impact on what will take place tomorrow. Do not assume that there is any connection in the supported person's mind between today and tomorrow's experiences.

Example: The person is stuck on an argument and can't let it go.

Find a way to "back off" and divert and distract the person. Best is for the targeted support person to disappear, and for there to be a "new face" to deal with, in the moment! Usually this is enough to change the person's reality, and they can take a different tack.

Or, for the moment, the support person could "give up" their side of the "argument." Ask for a break to go have a cup of tea, or to go for a walk. Then when the stuck moment is past, sometimes it is possible to approach the situation again and the previous emotion is diffused.

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