

FASD: Relationship Based Interventions for Caregivers and Professionals

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Learning Objectives

Caregivers often feel guilty or judged when the person they are supporting does not experience outcomes that they had been expecting. This can be compounded by approaches that do not appreciate the unique needs of the individual with FASD. We will explore supportive interventions which include insulation, interdependence and relationship building as ways to prevent the onset of secondary disabilities. The idea of insulation will be introduced as an effective strategy to get ahead of high risk behavior. We will discuss the need to help individuals transitioning to adulthood to live interdependently so that they can rely on their families and support systems when they need an external brain. We will explore the need for people with FASD to have strong relationships with their caregivers, families and support people for a lifetime, and how nurturing and developing these pre-existing relationships should be at the forefront of any intervention.

Introduction

In 2007 five women came together to participate in the photovoice project called “Picture” This: Life as a parent of children with FASD (Lauer 2007). As part of a thesis project this author worked with these women in 2009 to expand on their ideas specifically regarding secondary disabilities. The group has been working together since this time and have developed strategies to combat secondary disabilities for their children. They hope that their ideas and strategies can help other families.

Fetal Alcohol Spectrum Disorder (FASD) may be associated with a variety of challenges including developmental disabilities, hyperactivity, attention and impulse control problems, language delays, and social skills deficits. These problems can lead to “secondary disabilities” such as mental health issues, academic and vocational failure, substance abuse, and interactions with the justice system (Doris, 1989; Buxton 2004; Malbin, 2007; Michaud, M & Michaud, S, 2003, Streissguth, 1996). Parents can find themselves struggling with the overwhelming demands of supporting children and not really knowing the cause of their child’s behavior (Doris, 1989; Buxton 2004; Malbin, 2007). Their burden can be compounded as they try to navigate systems that misunderstand the disability and increase the stress (Brown, Signvaldason and Bednar, 2004; Green, 2007). We sometimes view “bad parenting” as the cause of behavior and approaches with this philosophy can work to undermine commitment, effective parenting and compound stress for caregiver (Buxton 2004).

Caregivers need support, not criticism (Buxton 2004; Graefe, 2004; Michaud, 2009). Supportive interventions which include appreciating and supporting the need for insulation, interdependence and strong relationships can help caregivers continue to support their loved one with FASD even when things become difficult (Michaud, 2009). A strengths based approach with the underlying view that families know what is best for their children is the most effective response (Buxton 2004; Malbin, 2007).

Insulation

Insulation in terms of caring for children with FASD can be defined as putting into place relationships, activities, structures and routines that prevent the people with FASD from engaging in behavior that might increase risks of secondary disabilities. These techniques seem to be more affective when they are done in the context of a caring relationship and when the younger person is involved in the decision making. **Some** insulation techniques could include:

- Constant supervision
- Limited screen and internet time (supervised)
- Attendance at private or smaller schools with more supervision (homeschooling)
- Engagement in youth groups or church activities
- Enrollment in sports or other structured activities
- Planned and supervised social activities in the home on a regular basis
- Reinforcing relationships and planning activities with pro social peers
- Residing in the county to prevent access to unstructured time at malls or downtown areas
- Developing close relationships with other families trying to create insulated environments
- Reducing access to money outside of a supervised environment and encouraging planned spending
- Preparing others to support and understand the young person's insulation needs
- Avoid introducing concepts that might plant ideas (drugs, sex, suicide, cutting)
- Distracting from activities that will pose risks

We tend to think of caregivers as overbearing, meddling and intrusive when they use “insulation” techniques as a way to get ahead of potentially dangerous situations. Sometimes young people with FASD need to be guided away from toxic or even dangerous relationships and social opportunities need to be choreographed by the caregivers or the community to ensure pro social connections. These techniques even for young adults can be very helpful in steering young people in the right directions should be supported, respected and reinforced.

Interdependence

The concept of interdependence is one in which the caregivers and the person with FASD grow to rely on one another and value each other's roles in the family. Some young adults with FASD may need to live “interdependently” so that they can count on their families and support systems when they need an “external brain”. We need to make sure that we are not planning ideas about independence that may make them feel like failures when they are unable to live autonomously. The concept that young people should go off on their own and make all their own decisions at a certain age is embedded in the western culture as well as child welfare, education, mental health and justice systems. Some ways to create interdependence:

- Normalize the need for young people to rely on family and caregivers for their day to day decisions
- Preparing young people to live at home longer, forever if need be (prolong moving)
- Prepare for young adults to live close to home
- Encouraging young people to share bank accounts with caregivers or have a trustee
- Reinforcing the need for caregivers to work with teacher and employers on decisions that affect their child

- Holding off on full drivers licence until later in adulthood – but drive together
- Arranging for the young person to live with family if they need to go away for college or going with them
- Go with or hiring other adults to accompany young people on trips or vacations
- Make sure young people have strong roles in their family
- Having caregivers rely on young people to take care of household chores or other things that need to get done (shopping, errands, cooking)
- Encouraging young people to contribute financially to the household

It is important that people with FASD are supported and have help to make decisions and navigate life in a safe way with people they trust. By creating interdependent relationships young people can feel like a valued member of their family and community and will welcome and accept help when it is presented as a way of life and built into the fabric of family and community.

Strong Relationships

Strong, supportive and safe relationships will go a long way in helping young people avoid difficulties as they navigate in the world. Family and caregivers are really important because paid staff allotments can change throughout the lifecycle. Care and concern for the young person could be viewed as judgmental or controlling so all strategies to build interdependence and create insulation need to be used with care. We do not want to force young people out of safe relationships with caregivers into relationships that might cause risks (Michaud, D and Temple, V, 2009). Ways to nurture ongoing relationships:

Caregivers

- Approach issues with the young person in a nonjudgmental and supportive way
- Do not yell or threaten the young person in anyway
- Avoid power struggles
- Do not approach things punitively – this is very important as they get older
- Know what a young persons “shame” trigger is and avoid that
- Allow for decisions and freedom as much as possible and in safe ways
- Allow for young people to make mistakes and be supportive when they do
- Don’t constantly remind them of their failures or what they cannot do
- Allow them to make mistakes and keep taking them back
- Forgive them
- Focus on what they are great at and build their confidence within the home
- Ensure the home environment is organized and structured with little stress
- Remember there is always hope
- Believe in the young person
- Utilize supports
- Have fun
- Smile at them, hug them, make them feel valued
- Take care of yourself

Professionals

- Talk positively about the young person and their relationship with their caregivers
- Help the young person talk about and remember the good things in their relationship
- Encourage the young person to seek support from their caregiver
- Include caregivers in all decision making
- Value the opinions of caregivers (they know the young person best)

Young people need to feel they belong and that they are respected. When they feel safe and are welcome home unconditionally they will return home. Home is where they are safest.

Young people living with FASD will need strong relationships with their caregivers, families and support people for a lifetime. Nurturing and developing these pre-existing relationships should be at the forefront of any intervention.

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