Managing Transitions to Adulthood for Youth with Fetal Alcohol Spectrum Disorders (FASD)

MOFAS Mission

Our mission is to eliminate disability caused by alcohol consumption during pregnancy and to improve the quality of life for those living with Fetal Alcohol Spectrum Disorders throughout Minnesota.

Our vision is a world in which women do not drink alcohol during pregnancy and people living with Fetal Alcohol Spectrum Disorders are identified, supported, and valued.

Learning Objectives

• Brief overview of the FASD transition dilemma
• A strategies (not solutions) focused discussion as a framework for addressing transition issues
• Navigating education related transition issues as a foundation to addressing overall transition issues to improve outcomes for the population
• Review some practical strategies for supporting transition to adulthood

The FASD Transition Dilemma

61% of adolescents on the fetal alcohol spectrum have a disrupted school experience.

60% of adolescents and adults on the spectrum will come into contact with the criminal justice system.

80% of individuals with an FASD are unable to live independently regardless of IQ.
The FASD Transition Dilemma

50% of adults with an FASD have trouble finding a job and 60% have trouble maintaining employment.

Streissguth, et al 1996

FASD by the Numbers

Sample of adults age 21+ were unable to accomplish the following daily living activities:

- 82% Manage money
- 78% Make daily living decisions
- 70% Obtain social services
- 68% Get medical care
- 57% Handle interpersonal relationships
- 52% Grocery shop
- 49% Cook meals
- 48% Structure leisure activities
- 48% Stay out of trouble
- 37% Handle hygiene
- 24% Use public transportation

Streissguth, et al 1996

Strategies Framework

- Behaviors that result from the effects of FASD can be challenging and try the patience of the most dedicated and experienced providers.
- Go to the source for information.
- Strategies and solutions are not always transferable from one person to another.

Strategies Framework

The most important strategy to remember when working with individuals with an FASD is to be patient and understanding. Apply the maxim seek first to understand and then to be understood.

Strategies Framework

The external brain concept coined by International FASD expert Sterling Clarren, MD

“The individual with disability caused by prenatal alcohol exposure will always need an external brain”.

Strategies Framework

The goal of most interventions focus on helping students act their chronological age.

- Ask yourself the following question: What is the developmental age of this person’s behavior?
- If they reflect an earlier stage: think younger and meet the individual where they are developmentally.
Strategies Framework

- **Friendly, likable:** May be outgoing and sociable and have little anxiety about strangers.
- **Verbal, chatty:** May be very socially interested (but not necessarily socially-skilled).
- **Helpful, hard-working:** If you ask, they will do it. They can be very good workers with the right job and training.
- **Determined, resilient:** They don’t hold grudges and will come back if rejected. Every day is a new day!
- **Want to be liked:** They will do whatever they can to have friends.
- **However,** these strengths also may get them into difficulty.

Dispel the Myth:

Individuals with and without disabilities are more successful when the goal is **interdependence** rather than independence.

Navigating Rough Waters: Education

- **2004 Congressional Findings: Individuals with Disabilities Act (IDEA)**

Almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by:

(A) having high expectations for such children and ensuring their access to the general education curriculum in the regular classroom, to the maximum extent possible, in order to:

(i) meet developmental goals and, to the extent possible, the challenging expectations that have been established for all children; and

(ii) be prepared to lead productive and independent lives to the maximum extent possible (20 U.S.C. Sec. 1401 (c)(5))

What is the goal of the Individuals with Disabilities Act (IDEA)

- The goal of IDEA is to promote maximum independence in adulthood
- The goal of transition planning is to promote a maximum transition plan to adulthood
- Transition plans must address child’s interests, aptitudes, plans regarding education, career, housing and community involvement
### Navigating Rough Waters: Education

**Accommodations and Modifications**
- Develop and awareness of FASD and how to fully work with students
- Focus on changing the environment
- Avoid the insanity cycle
- Understand that punishment and consequences will not change brain damage
- Expect inconsistency. Celebrate consistency!

**Proactive Planning is Key!**
- Identify student’s interests and preferences: person centered planning
- Identify a course of study that reflects student’s post-school goals
- Develop self-advocacy and self-determination skills

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**Self-Determination and Self-Advocacy Skills**

> “We’re encouraging people to become involved in their own rescue.”

**Transition to adult life is a major life cycle change for youth with and without Fetal Alcohol Spectrum Disorders:**
- Families and schools need to start early
- Gather information and be informed
- Develop the network of external brains and typical support

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- Peer support can provide comfort and help families throughout the process
- Evaluate the expectations related post-secondary education, employment, and housing
- Get clarification on plans and responsibilities
- What is the life plan for your child
Navigating Rough Waters: Education

What to teach students with an FASD
• Depends on the desired post-school outcome
• Depends on the degree to which curriculum can be adapted to meet the needs of the student
• Basic life skills and social skills

Strategies for Navigating Failure to Launch

FASD requires appropriate support across the life time! The absence of housing = Inability to Function. Period.

Think about living arrangements:
• Ask the individual about their goals and dreams related to housing.
• It can be very complicated!
• Bottom line: what supports do they require to be successful

Jenny Hatch at 29, who has Down Syndrome, sought the right to live independently with Friends, at odds with her parents’ wishes.
### Strategies for Navigating Failure to Launch

**If the goal is supervised independent living you need the right supports in place**
- Awake Staff 24/7
- Integrated individualized case management
- Meals provided
- Programs (Education, Employment, Leisure)
- Comprehensive Supported Activities of Daily Living
- Peer Support
- Family Support
- Chemical Health and Recovery Services
- Health Care
- Mental Health
- Transportation
- Legal Resources

### Strategies for Navigating Failure to Launch

**If the goal is supervised independent living you need the right supports in place**
- If you are co-signing a lease, take out the maximum in apartment insurance
- Explore conservatorship and guardianship
- Representative payees
- Special Needs Trusts
- Use auto pay

### Strategies for Navigating Failure to Launch

**If the goal is supervised independent living you need the right supports in place**
- Support finding employment
- Find a job that suits their body clock
- Assist with setting up schedule for preparing for work
- Have a plan for seeking reasonable employment accommodations

### Strategies for Navigating Failure to Launch

**If the goal is supervised independent living you need the right supports in place**
- Model daily living tasks (cooking, cleaning, laundry, etc.)
- Shadow daily living tasks
- Provide visual cues of daily living tasks
- Program alerts and notifications to cue tasks
- Structure! Supervision! Support!

### Strategies for Navigating Failure to Launch

**If the goal is supervised independent living you need the right supports in place**
- If driving is not an option, teach the individual how to use public transportation or schedule special transportation
- Develop a risk management plan
- Help with finding positive peers and social groups
- If it is working, don’t take the support away!!!
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