



Welcome to FASD Across the Lifespan

A training series for Alaska families

Class Guidelines



- Sign in by entering your name and location in the chat box (if you are not a foster parent, but need credit for this class, please email acrf@nwresource.org).
- Find the handouts and slides at www.acrf.org
- Our session will last about 1 hour, followed by Q&A.
- This session is being recorded and will be made available online.
- The same Zoom link will work for upcoming sessions.

Netiquette

- Use the chat box to ask questions, or message one of the hosts for support.
- We will allow opportunity for phone questions at the end of the session.
- Be sure to maintain confidentiality when asking a question.





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Land acknowledgment

“We are gathered today on the land of the Dena peoples. I ask you to join me in acknowledging the Dena community, their elders both past and present, as well as future generations. We also acknowledge that our organizations were founded in the aftermath of influences that led to exclusions and erasures of many Indigenous peoples, including those on whose land we are currently located. This acknowledgement demonstrates a commitment to continuing the process of working to dismantle the ongoing legacies of settler colonialism including racial, cultural, and political accusations and judgments about risk and blame associated with alcohol use and the role it plays in shaping and reinforcing stigma in our communities.”

In this series



Introduction and Diagnosis

Infant Learning and Early Intervention

Preschool and Social Development

School Age and Learning

Middle School and Challenging Behaviors

High School and Transition to Adulthood

➔ Adulthood and Interdependence

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Labels and Stigma

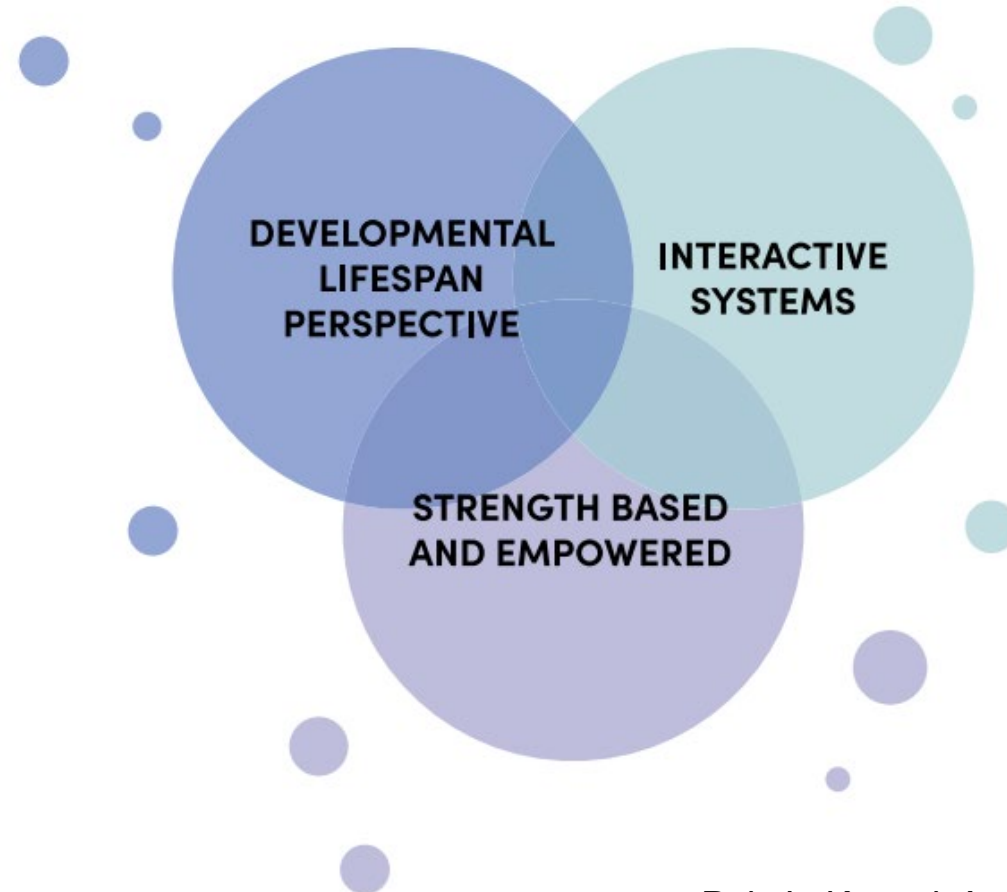


Remember the Individual

- We all have a right to our own stories, and we have the right to decide who to share that story with.
- We all have gifts and challenges.
- We all need autonomy, and we all need relationships.
- We all have a right to make our own choices about our lives, and to feel supported in our own decisions.
- We all need to be safe.



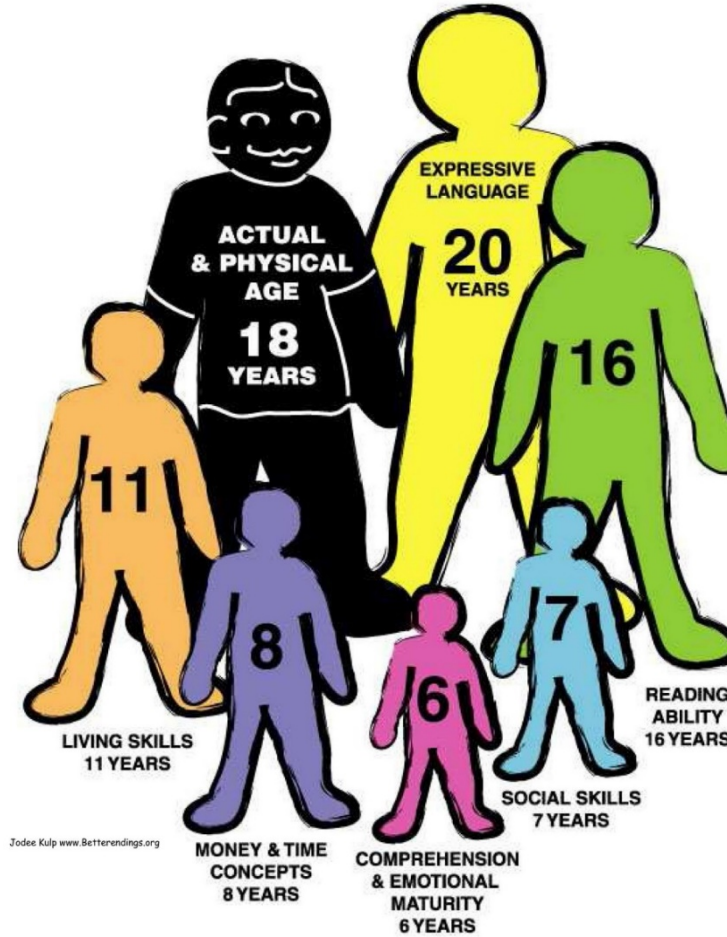
Philosophical Model



- Pei, J., Kapasi, A., Kennedy, K.E., & Joly, V. (2019). Towards Healthy Outcomes for Individuals with Fetal Alcohol Spectrum Disorder. Canada FASD Research Network in collaboration with the University of Alberta.

Developmental Level of Functioning

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Developmental Lifespan

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- A person is a combination of where they are developmentally, their goals, and their own history. Each of these things plays an important role in who we are as a human.
- Individuals grow and develop across their lifespans, and services and needs will change as an individual grows.
- Services and support for individuals who experience FASD need to take into account that individual's unique developmental strengths and needs.

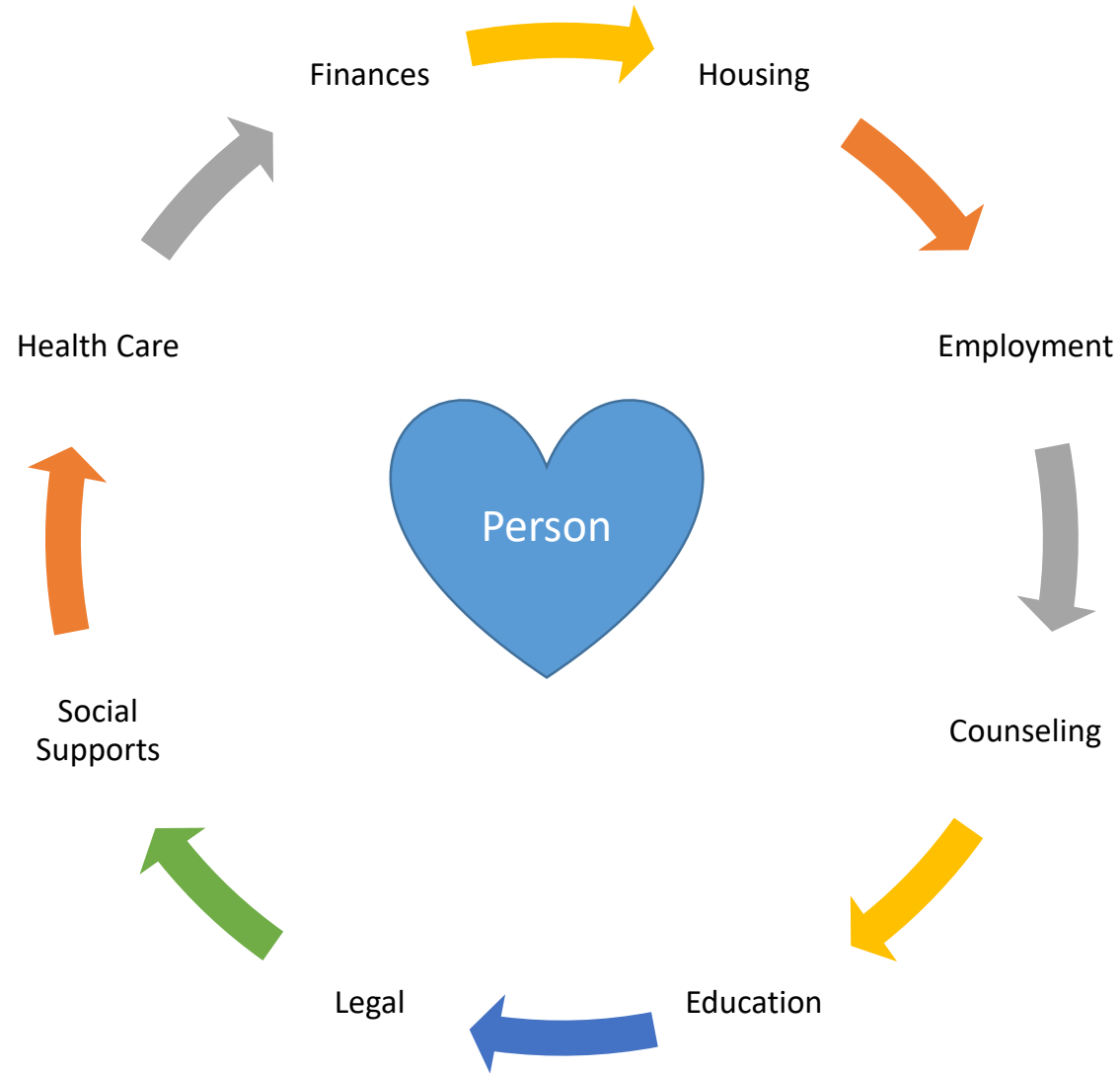
Interactive Systems

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- How do families integrate services and systems when often these are silos?
- What systems in Alaska are better poised to appropriately interact with each other?
- How do systems and services interact with the adult we are supporting? What influences do those services have on the individual and the individual's self-worth?

Interactive systems



Strength-Based and Empowered

- We must ensure individuals receive person-centered services... how do we maintain that while ensuring individuals are safe?



Structure versus control



Structure versus control





Executive function

Adaptive Living

Communication

Sensory integration

Attention/Hyperactivity

Fine or gross motor

Visual perception/motor integration

Learning & Memory

Common Domains of Brain Impairment

Healthy Outcomes

- Employment
- Parenting Skills
- Adaptive Skills
- Housing
- Identity Development
- Community Engagement
- Education
- Mental Health and Regulation



- Pei, J., Kapasi, A., Kennedy, K.E., & Joly, V. (2019). Towards Healthy Outcomes for Individuals with Fetal Alcohol Spectrum Disorder. Canada FASD Research Network in collaboration with the University of Alberta.

Employment

- Many adults who experience FASD state that it is significantly challenging to keep employment, even when training is offered.
- Structure, schedules and help with personal advocacy are essential.
- Have realistic expectations.
- Find a mentor.
- Expect impulsivity.



Parenting



Parenting skills

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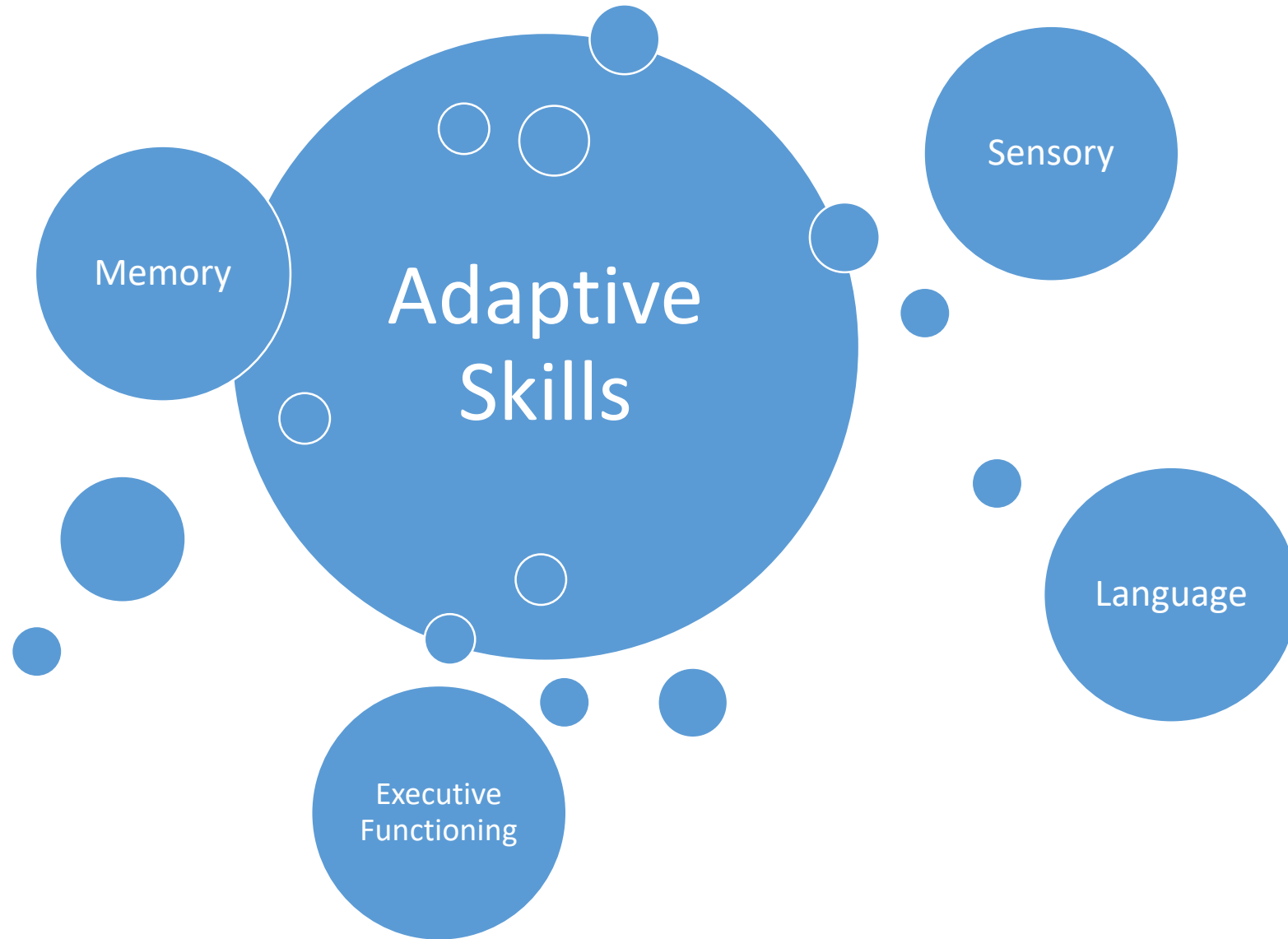


- Stigma and secondary/tertiary effects of FASD often result in disruption.
- Parenting may look different, but maintaining relationships where appropriate is essential for healing and preventing further intergenerational trauma.
- Individuals with executive functioning, mental health and other challenges need supportive, non-judgmental help with family planning.

Parenting



- Provide concrete modeling.
- Provide structure and support.
- Remember an individual's sensory needs and recognize when those needs are disrupting their ability to provide care.
- Provide breaks in the form of babysitting, child care enrollment, or just companionship (here's a great time to model!).
- Many individuals with prenatal exposure are exceptional parents.



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Mutual Supports

- Support for adaptive skills needs to be mutual.
- Consider taking notes or logging frustrations to find areas where assistance is needed.
- Ask the individual to help identify ways what work for them.



Managing Finances

- Consider whether conservatorship is necessary.
- Help set limits and goals.
- Consider smaller increments of money to protect against impulsivity and social vulnerability.
- Practice concrete budgeting.

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Housing

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- In a recent survey of adults with FASD, housing was reported as a major issue.
- Eligibility for housing support, and maintaining housing create barriers.

Housing

- Living at home
- Living with supportive roommates
- Living in an apartment close to caregivers
- Public housing works, but rules and eligibility can be challenging



Housing

- Organized spaces
- Help maintaining organization
- Daily or weekly check-ins from a safe person
- Establish multiple check-in strategies (parent, case manager, grandparent or friend stop by regularly)
- Create lists and schedules
- Visual reminders



Identity Development



Community Engagement

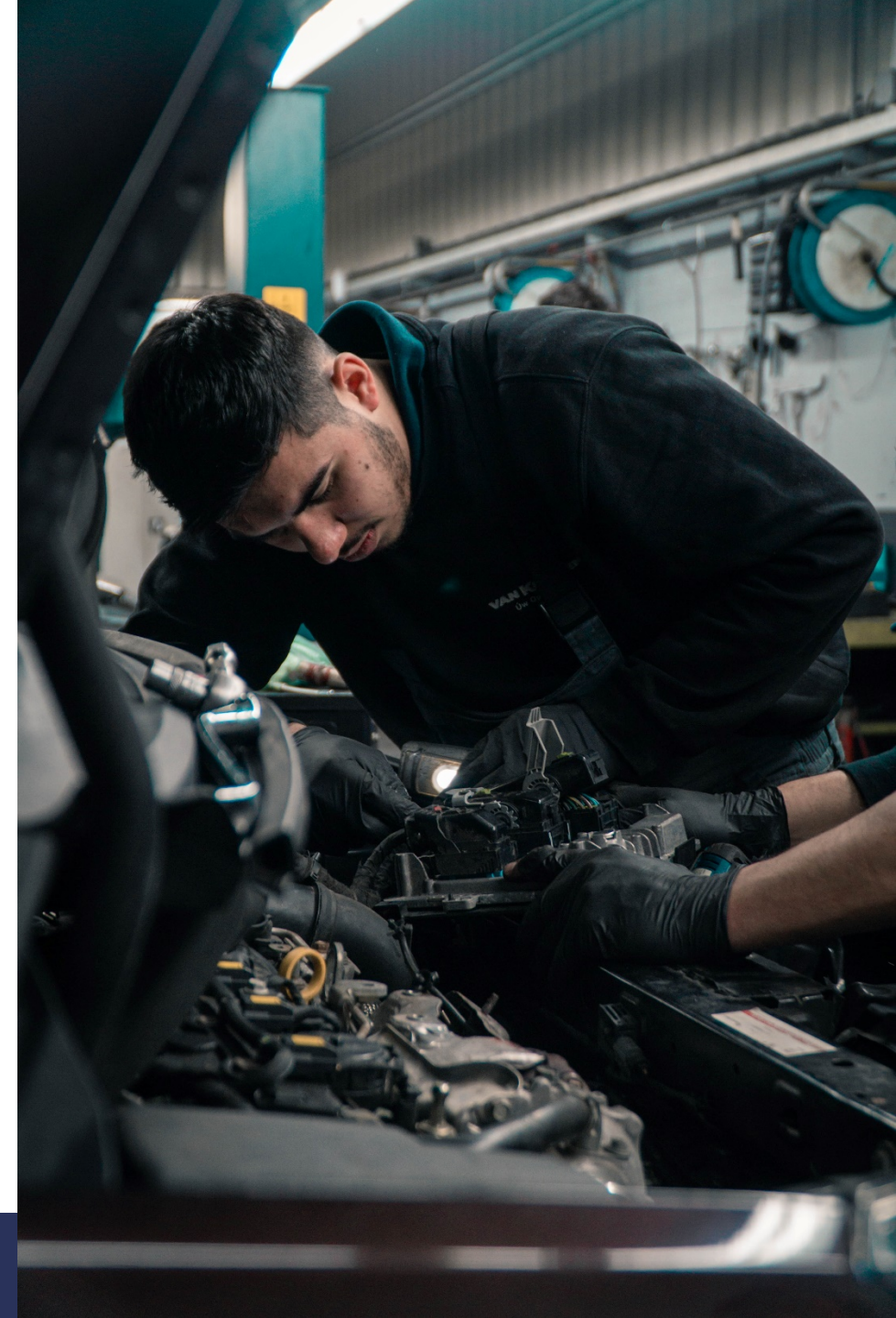
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- Think strengths.
- Look for natural connections with interests.
- Make sure there are supportive people.

Education

- High school education is not always meeting the needs of individuals with FASD.
- Training needs to be supportive, concrete and hands on.
- Community colleges or other post-secondary programs have disabilities services departments to ensure individuals who are entitled to accommodations in learning receive those accommodations.
- Think strengths and build on those.



Mental Health Regulation

- Medication
- FASD-Informed Counseling
- Case Management
- FASD-Informed Crisis Intervention





Adjusting Expectations

- It can't be about what an individual "should be" doing, it has to be about what that individual CAN do.

Criminal Justice



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Guardianship and Conservatorship

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- Guardianship is a legal arrangement that provides you with some (but not all!) ability to support an individual
- Conservatorship is separate from guardianship and allows you to manage an adult's finances



Supported Decision Making Agreements

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- Involve adults in the decision making process.
- Written legal agreements.
- Provide a guideline for individuals to make choices about where they want to live, what they want to do during the day, how they want to spend their money and when they wish to see a doctor.
- Can be built into a guardianship and/or conservatorship order.



Social Security Income

- To be eligible you must:
 - Be over 65
 - Blind or
 - Disabled
- And have
 - Limited income
 - Limited resources
 - U.S. Citizenship



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Disabled According to SSI

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- If you are over the age of 18 you may be considered “disabled” if you have a medically determinable physical or mental impairment (including an emotional or learning problem) which:
 - Results in the inability to do any substantial gainful activity; and
 - Can be expected to result in death; or
 - Has lasted or can be expected to last for a continuous period of not less than 12 months

Downfalls of SSI



- Receive monthly checks that can make impulsive individuals vulnerable.
- Lengthy application process.
- Lots of reporting requirements, especially if you go to work.
- Limits on how much money you can have on hand (no more than \$2000).
- If an individual lives with another individual (i.e. parents) all of the income in the house is considered.

Alaska ABLÉ Accounts



- Allow individuals to save money outside of income restrictions for SSI
- Money can only be used for particular needs (medical, housing, education) when removed
- Seen as a pathway out of poverty for many
- www.savewithable.com



Development Disability Benefits



- Must show 3 domains of impairment.
- Apply early and start the documentation process.
- IQ is not the only qualifier for Developmental Disability Services.
- Wait lists for supports are long, often years.



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This series is brought to you by...



With funding from the State of Alaska FASD Program and the Alaska Mental Health Trust Authority.

