

# What Happens Next?

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## The Transition to Adulthood for Individuals with Fetal Alcohol Spectrum Disorders and other Developmental Disabilities

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# What is transition and why is it important?

## Various aspects of transition

- Change in environment
- Pediatric to adult health care
- Independent/supported living skills
- School, home, community changes

## When does transition occur?

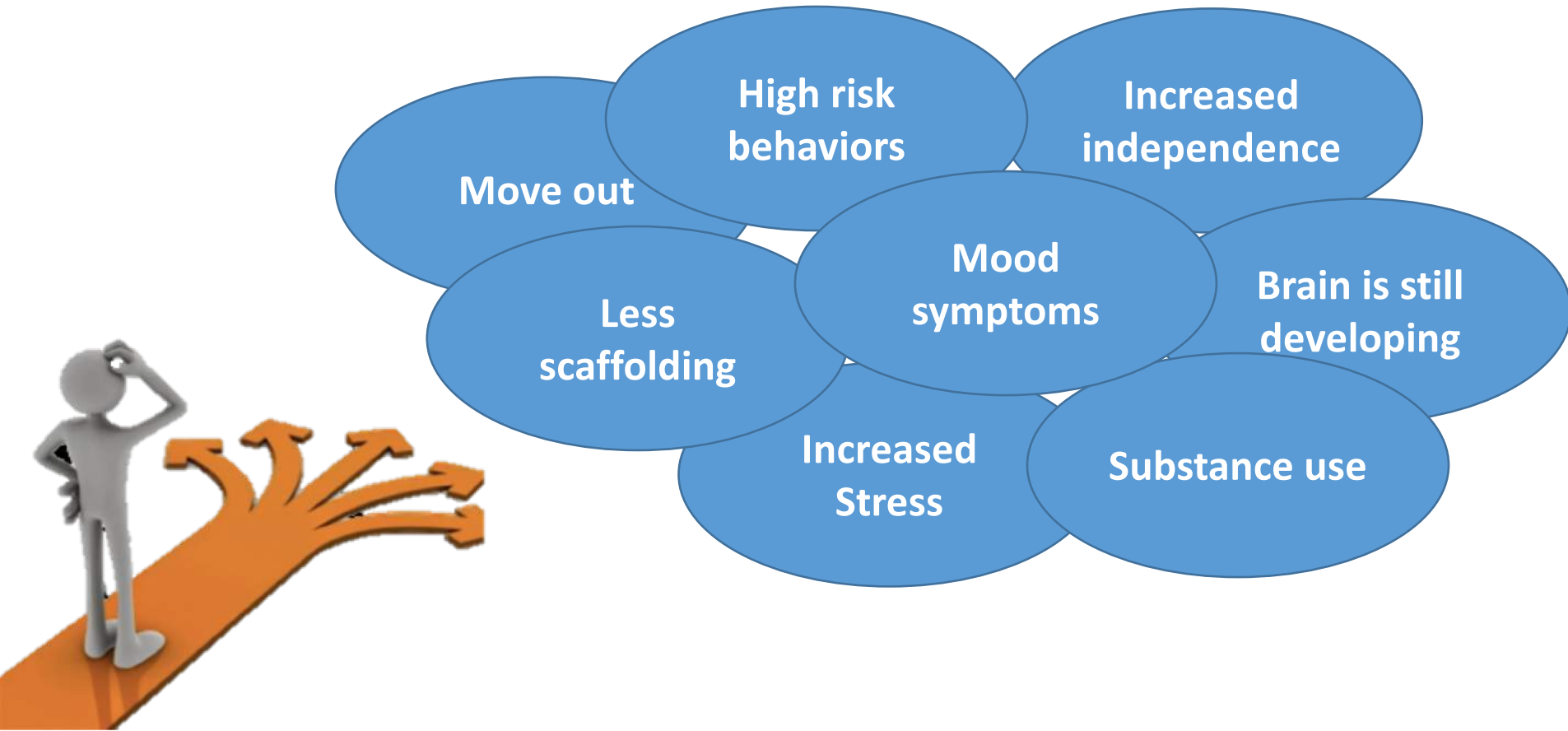
- Typically age 16-22

## Why is this important?

- Many adjustments
- Services cliff
- Many changes at once

Transition to adulthood can be hard

**FOR EVERYONE!**



# Here's the Plan

- Review developmental trajectory
- Holistic conceptualization
- Discuss how symptoms manifest in the real world
- Intervention and considerations for transition

***Lens of Fetal Alcohol Spectrum Disorders***

# Fetal Alcohol Spectrum Disorders

Alcohol causes more damage to the developing baby's brain than any other substance, including marijuana, cocaine, methamphetamine, and heroin

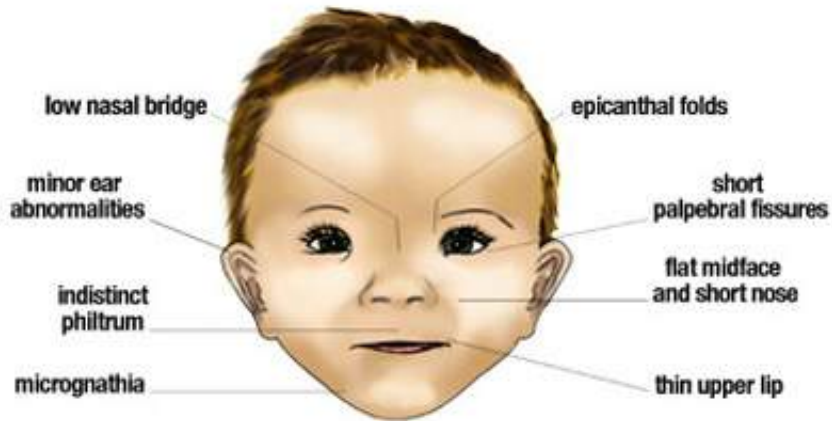
*- Institute of Medicine Report to Congress, 1996*

**Estimated 2-5% of all school children have FASD**



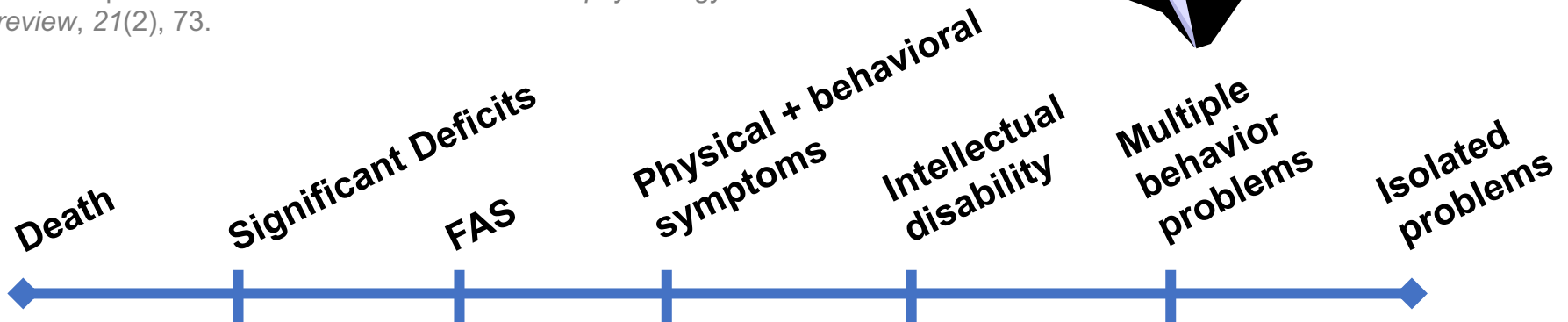
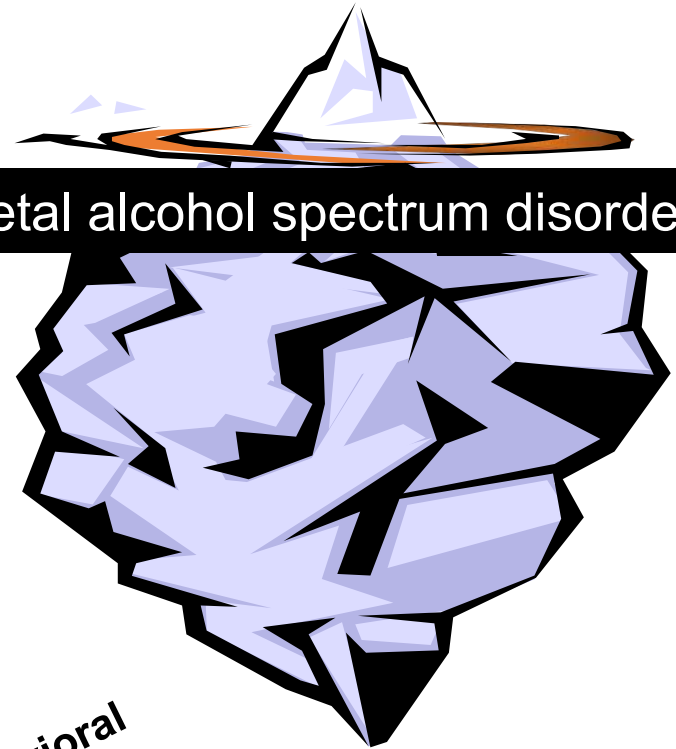
# FAS is only the tip of the iceberg

## FETAL ALCOHOL SYNDROME



Riley, E. P., Infante, M. A., & Warren, K. R. (2011). Fetal alcohol spectrum disorders: an overview. *Neuropsychology review*, 21(2), 73.

## Fetal alcohol spectrum disorders



# Effects of Prenatal Alcohol Exposure

- FASD are associated with permanent, life-long, and clinically significant negative outcomes
  - Neurological Issues
  - Medical Issues
  - Cognitive Deficits
  - Academic Difficulties
  - Behavioral Problems
  - Psychological Comorbidities
  - Adaptive Function Deficits
  - Involvement with the Justice System
  - Long Term Care Needs



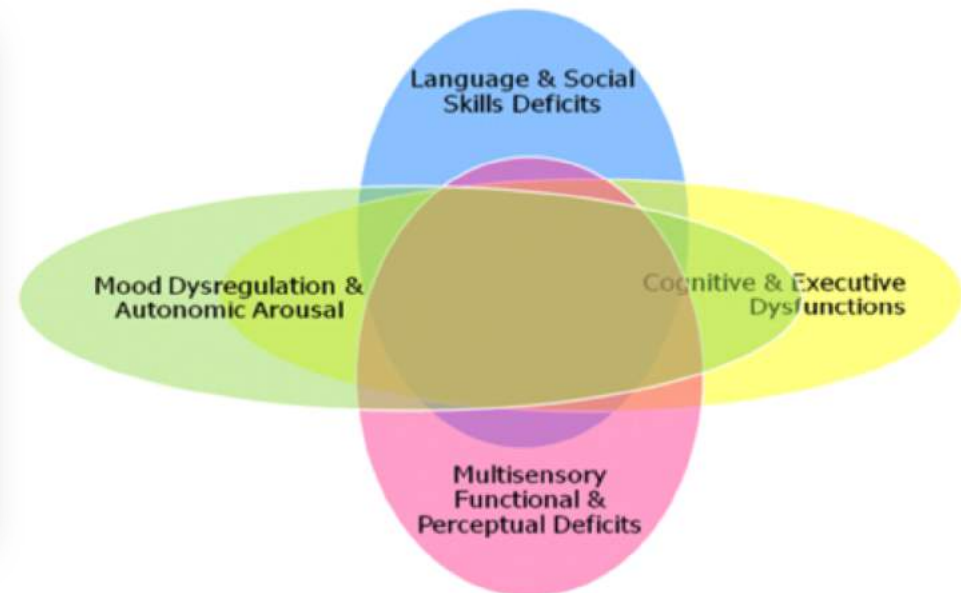
# Core Symptoms of ND-PAE

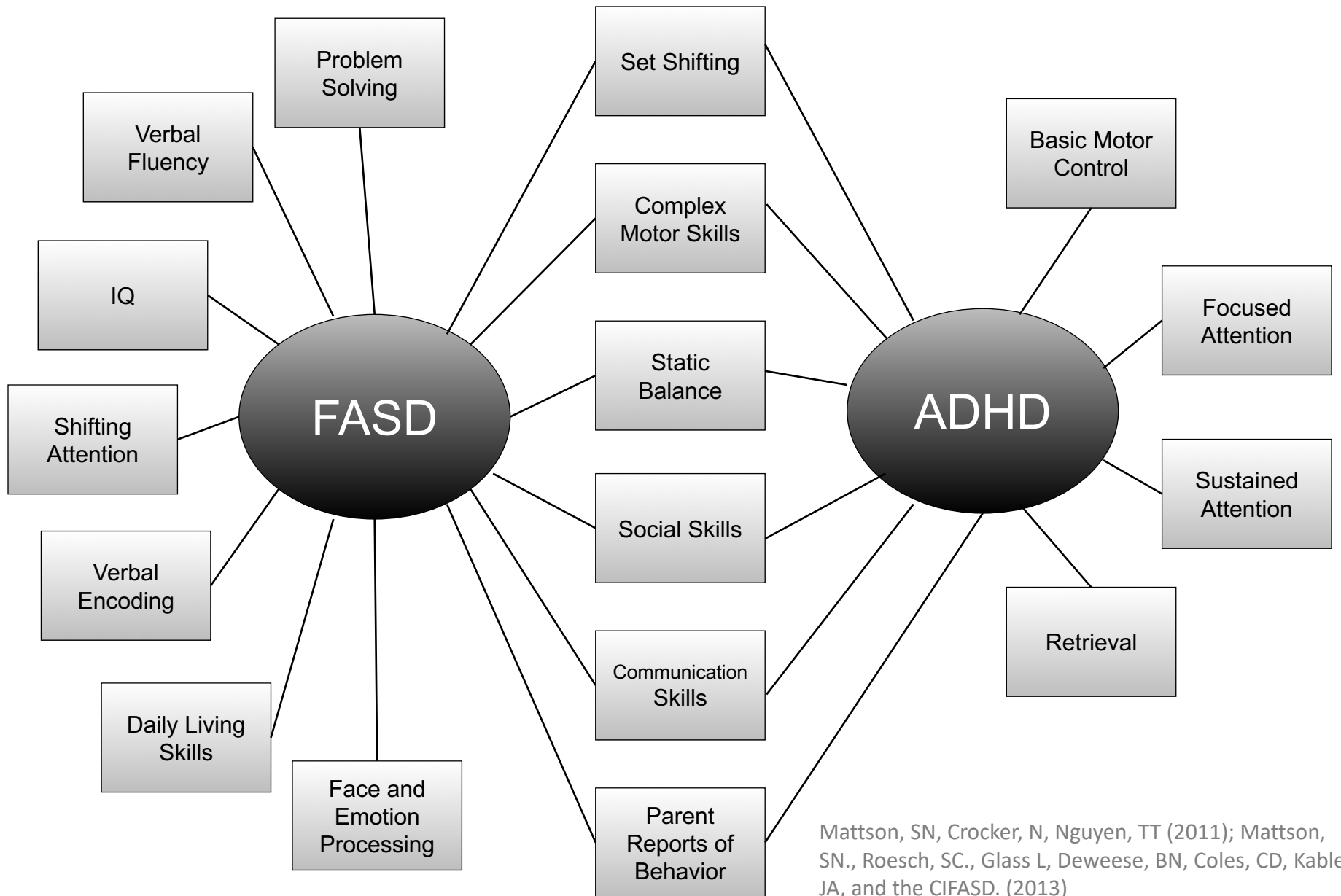
- **More than Minimal Prenatal Alcohol Exposure**
- **Neurocognitive Impairment (one or more):**
  1. Impairment in Global Intellectual Functioning
  2. Impairment in Executive Functioning
  3. Impairment in Learning
  4. Impairment in Memory
  5. Impairment in Visual-Spatial Reasoning
- **Self-Regulation Impairment (one or more):**
  1. Impairment in Mood or Behavioral Regulation
  2. Impaired Attention
  3. Impairment in Impulse Control
- **Adaptive Functioning Impairment (two or more):**
  1. Impairment in Communication
  2. Impairment in Social Interactions and Communication
  3. Impairment in Daily Living Skills
  4. Impairment in Motor Skills
- **Onset of Symptoms in Childhood**



# Overlapping Behavioral Characteristics & Related Mental Health Diagnoses in Children

Overlapping Characteristics & Mental Health Diagnoses	FASD	ADD/ADHD	Sensory Int. Dys.	Autism	Bi-Polar	RAD	Depression	ODD	Trauma	Poverty
	Organic	Organic	Organic	Organic	Mood	Mood	Mood	Mood	Environ	Environ
Easily distracted by extraneous stimuli	X	X								
Developmental Dysmaturity	X			X						
Feel Different from other people	X				X					
Often does not follow through on instructions	X	X					X	X	X	X
Often interrupts/intrudes	X	X	X	X	X		X			X
Often engages in activities without considering possible consequences	X	X	X	X	X					X
Often has difficulty organizing tasks & activities	X	X		X	X		X			X
Difficulty with transitions	X		X	X	X					





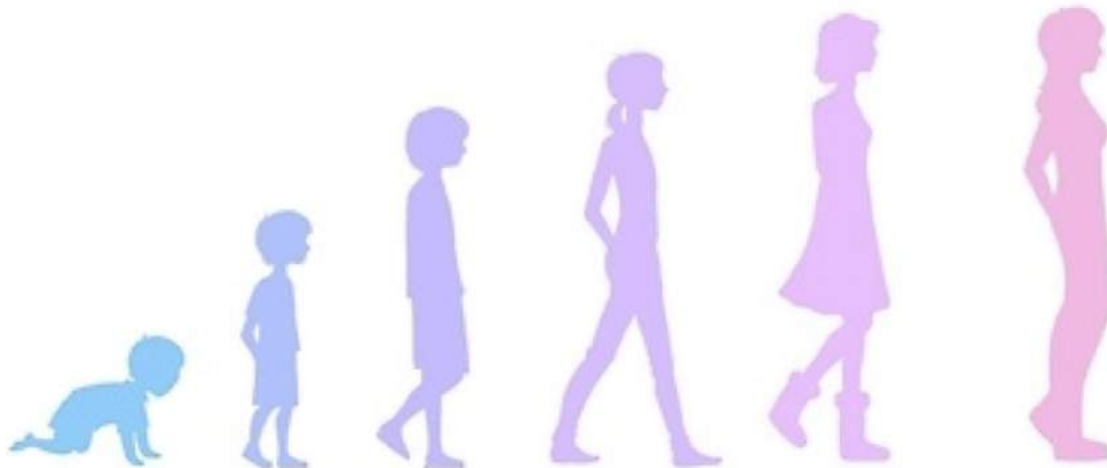
Mattson, SN, Crocker, N, Nguyen, TT (2011); Mattson, SN., Roesch, SC., Glass L, Deweese, BN, Coles, CD, Kable, JA, and the CIFASD. (2013)

# Here's the Plan

- Review developmental trajectory
- Holistic conceptualization
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# Fetal Alcohol Spectrum Disorders

Skill/Characteristic	Developmental Age Equivalent
Chronological Age	18
Physical Maturity	18
Developmental Level of Functioning	9
Daily Living Skills	11
Expressive Language	18
Receptive Language	7
Artistic Ability (or other strength)	23
Reading: Decoding	16
Reading Comprehension	6
Money and Time Concepts	8



# Brain-Behavior Relationship

## Neuroanatomical and Functional Changes

- Global brain
- Cerebral cortex
- Corpus callosum
- Cerebellum
- Hippocampus
- Basal ganglia
- White / gray matter
- Functional

## Cognition & Behavior

- Intelligence
- Executive dysfunction
- Learning & memory problems
- Poor spatial abilities
- Poor language development
- Reduced motor function
- Attention deficits & hyperactivity
- Poor emotional regulation
- Social difficulties

# Profile of FASD

PERCENTILE RANK	COGNITIVE	ADAPTIVE	LANGUAGE	MOTOR	MEMORY	EXECUTIVE FUNCTION	PERCENTILE RANK
100							100
95							95
90							90
85							85
80							80
75							75
70							70
65							65
60							60
55							55
50	X						50
45				X			45
40							40
35							35
30			X				30
25							25
20					X		20
15							15
10						X	10
5		X					5
PERCENTILE RANK	COGNITIVE	ADAPTIVE	LANGUAGE	MOTOR	MEMORY	EXECUTIVE FUNCTION	PERCENTILE RANK

# With development....

Symptoms change

Behaviors change

Needs change

What works changes

What is appropriate changes

What is acceptable changes

What is expected changes



# Developmental Trajectory: FASD

**0-2 years**

**3-8 years**

**8-16 years**

**16+ years**

Facial features - - - - - diminished

<3<sup>rd</sup> %ile height, weight - - - - - generally caught up

Behavioral problems - - - - - generally persisted

Cognitive difficulties - - - - - generally persisted

Social difficulties - - - - - generally persisted

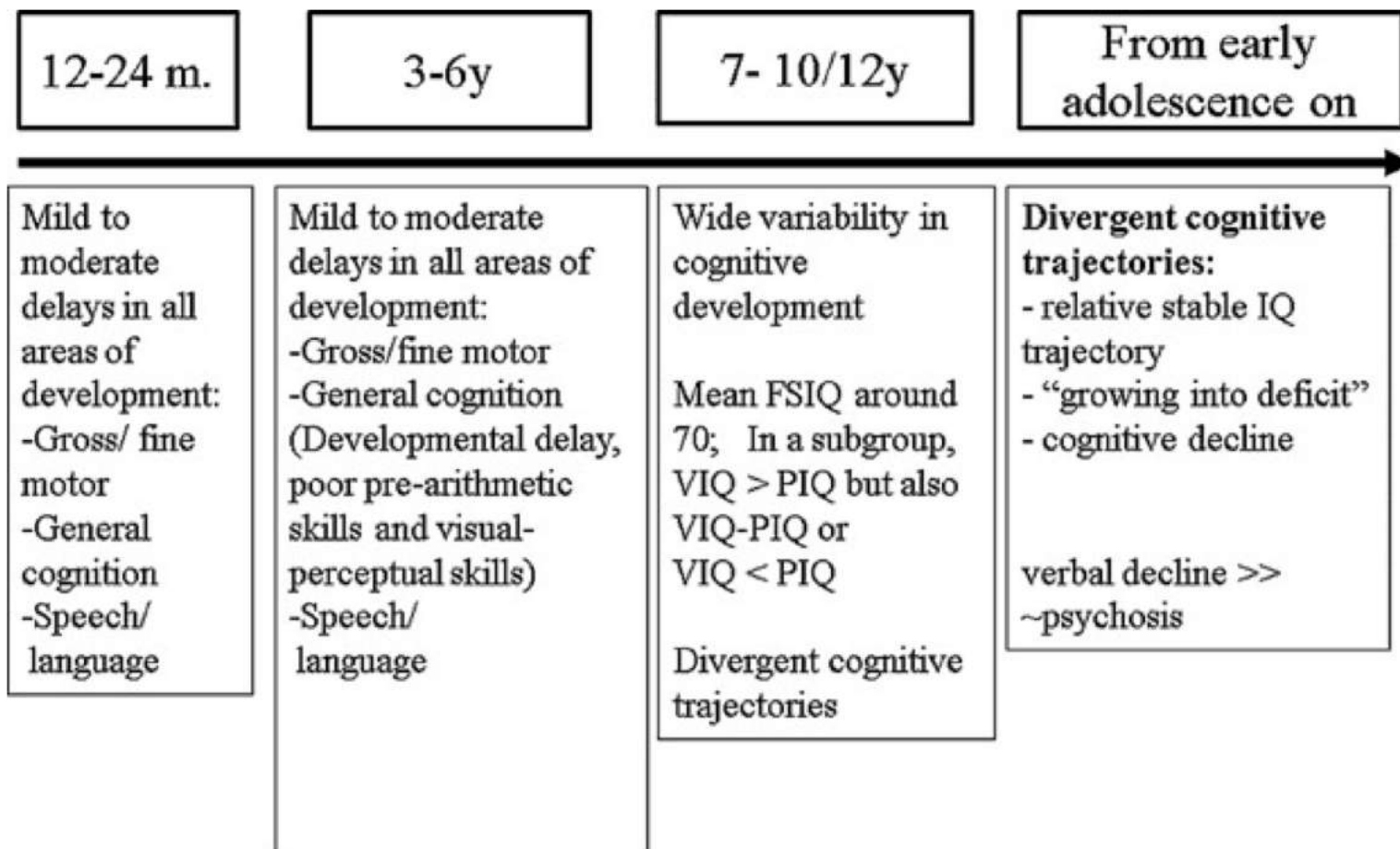
Mood concerns - - - - - worsened

Substance use - - - - - worsened

Justice system involvement - - - - - worsened



# Developmental Trajectory: Williams Syndrome



# ADHD Symptom Manifestation by Age

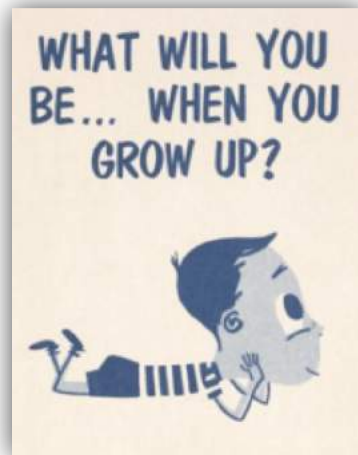
CHILDHOOD	ADOLESCENCE	ADULTHOOD
Hyperactivity	Easily distracted, inattentive	Inattentiveness
Low frustration tolerance	Easily bored	Poor organization of time/money
Aggression	Impatient	Missing deadlines or appointments
Easily distracted	Emotionally immature compared to peers	Poor bill tracking
Difficulty developing routines	Shifts activities	Restlessness
Impulsiveness	Poor driving	Emotional reactivity

Wasserstein. JCLP 2005. Wilens et al. Ann Rev Psychiatry 1999.  
Millstein et al. J Atten Disord 1997.

# Can we predict the future?

For children diagnosed with ASD at age 2, when assessed at 19

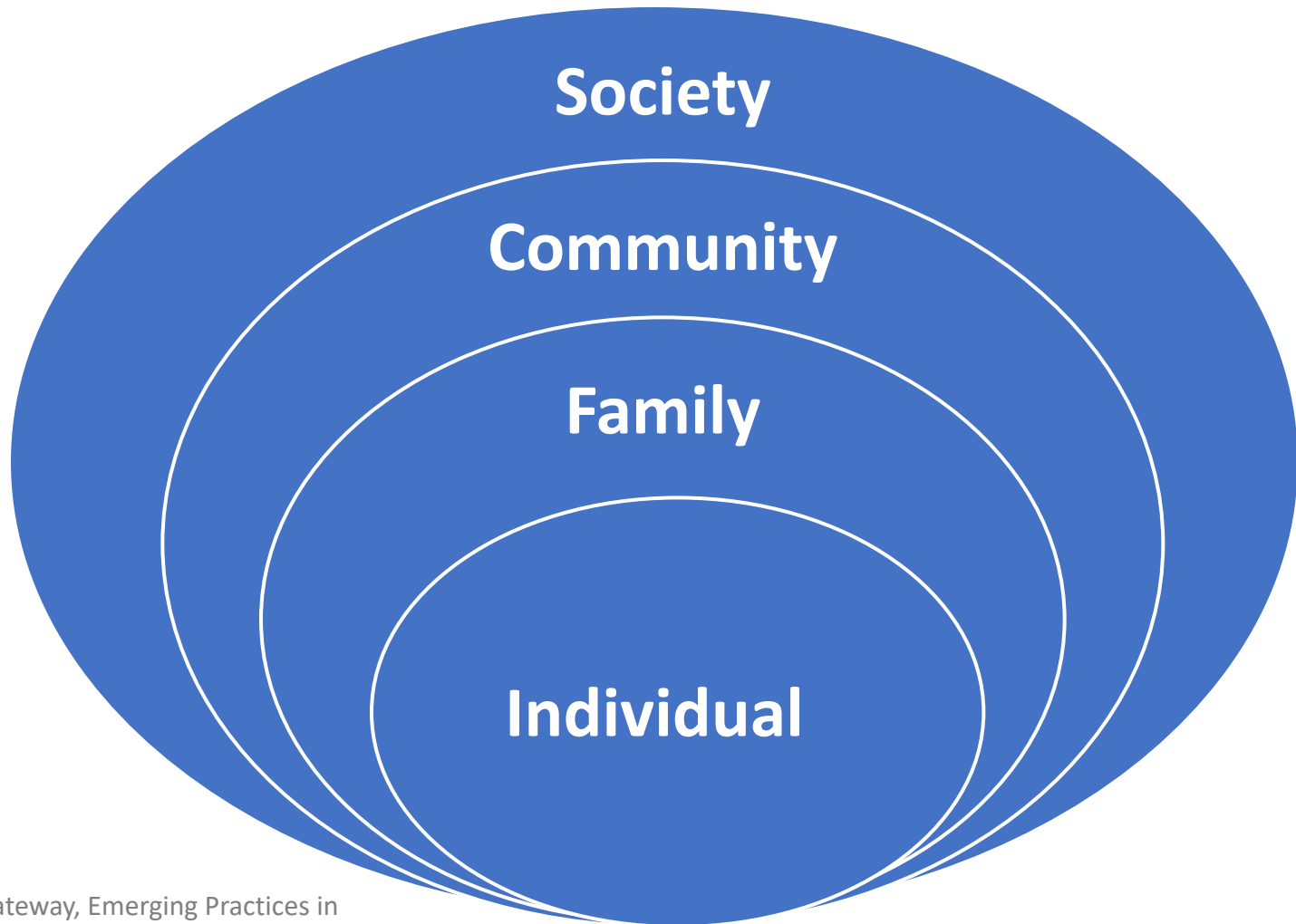
- Poorer outcome was accurately predicted about 85% of the time from **IQ scores alone**.
- Almost **10%** no longer had a clinical diagnosis
- **25%** had symptoms of ASD, though were not impaired



# Here's the Plan

- Review developmental trajectory
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# Overall Framework



Two young adults are facing this transitional time with very different concerns...

## Jack

- Diagnosed with ASD at age 3
- Significant intervention
- Has an IEP, though generally did well in school
- Received HS Diploma
- Difficulty making friends
- Finished college through a specialized program
- Now spends his time at home playing videogames
- Very socially isolated

## Jill

- Diagnosed with an FASD at age 7
- Several foster-care placements
- Has an IEP in special ed. classes
- Difficulty making friends
- History of being taken advantage
- Lives with her adoptive parents
- Works in supported employment
- Safety concerns related to relationships
- Significant mood issues

# Framework: Individual

## RISK

Lower cognitive ability  
Increased behavioral issues  
Lower adaptive functioning  
Reduced access to services  
Comorbid psychopathology  
Physical and medical concerns  
Developmental disabilities  
History of abuse, trauma  
Mismatch of temperament  
Lower social skills  
Interactions with juvenile justice

## RESILIENCE

Good health  
Intact intellectual functioning  
Access and engagement in intervention  
Internal locus of control  
Interests and hobbies  
Emotional regulation  
Easy temperament  
Coping strategies  
Positive self-esteem  
Social skills

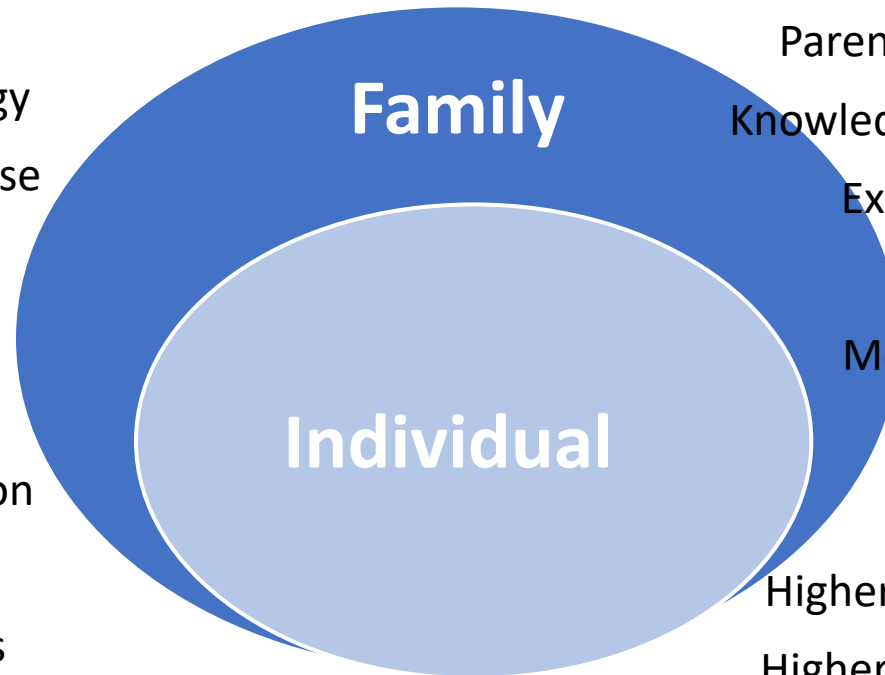


**Individual**

# Framework: Family

## RISK

Lack of trust  
Lack of stability  
Attachment issues  
Mood / psychopathology  
History of trauma / abuse  
Lack of support  
High stress level  
Intellectual functioning  
Level of psychoeducation  
Parent-child interaction  
Substance use, Partners



## RESILIENCE

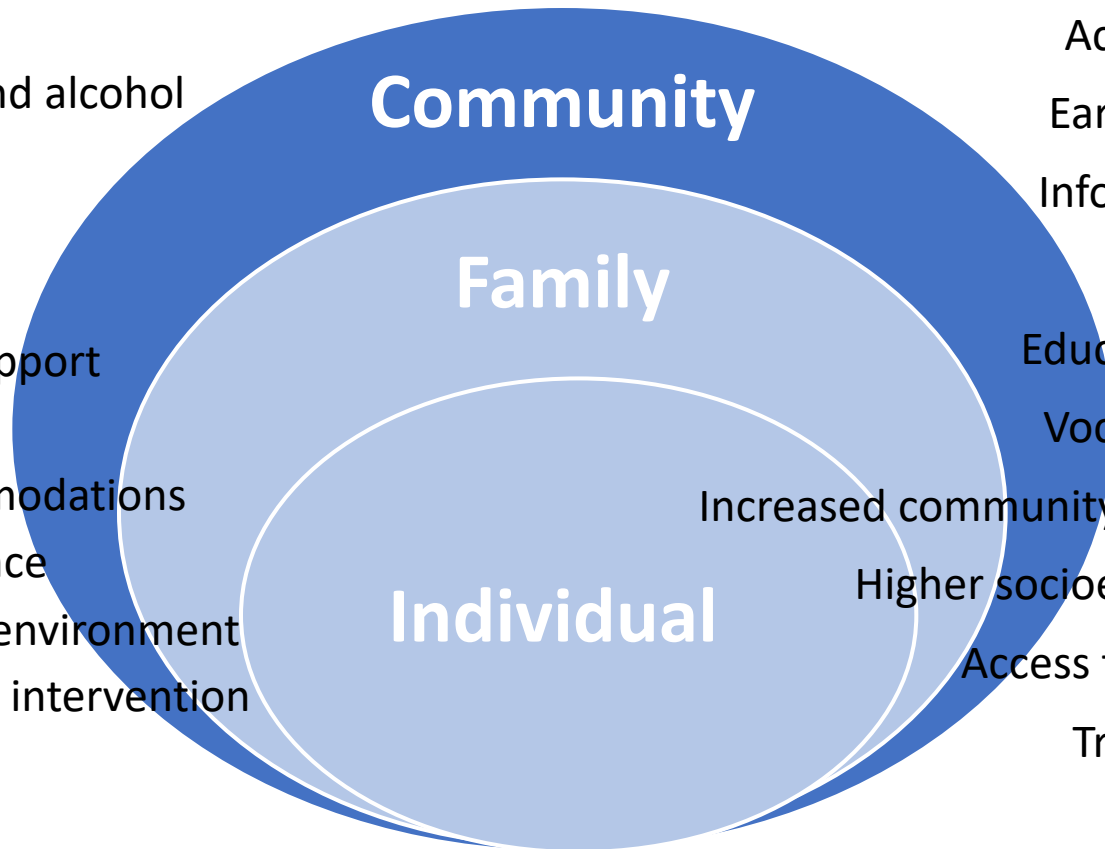
Positive parent child relationship  
Supportive, stable family structure  
Parental monitoring of child  
Knowledge and understanding  
Expectations of behavior  
Parental education  
Modeling of coping skills  
Access to services  
Early intervention  
Higher socioeconomic status  
Higher education attainment



# Framework: Community

## RISK

Safety  
Access to drugs and alcohol  
Homelessness  
Lack of awareness  
Lack of screening  
Reduced social support  
Instability  
No school accommodations  
Community violence  
Poor educational environment  
Lack of behavioral intervention



## RESILIENCE

Access to services  
Early identification  
Informed providers  
Support groups  
Educational systems  
Vocational systems  
Increased community understanding  
Higher socioeconomic status  
Access to targeted care  
Transitional plans

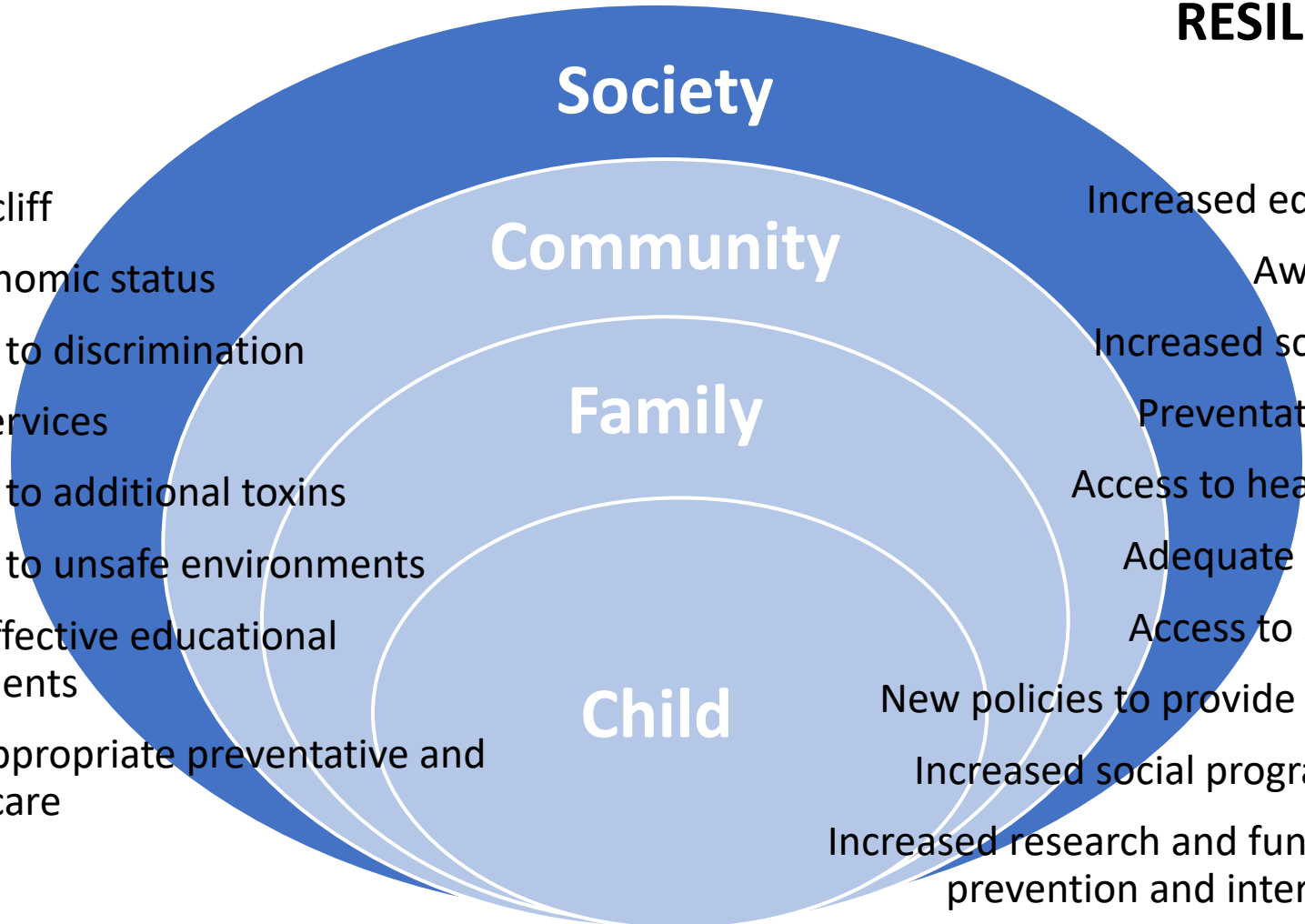
# Framework: Society

## RISK

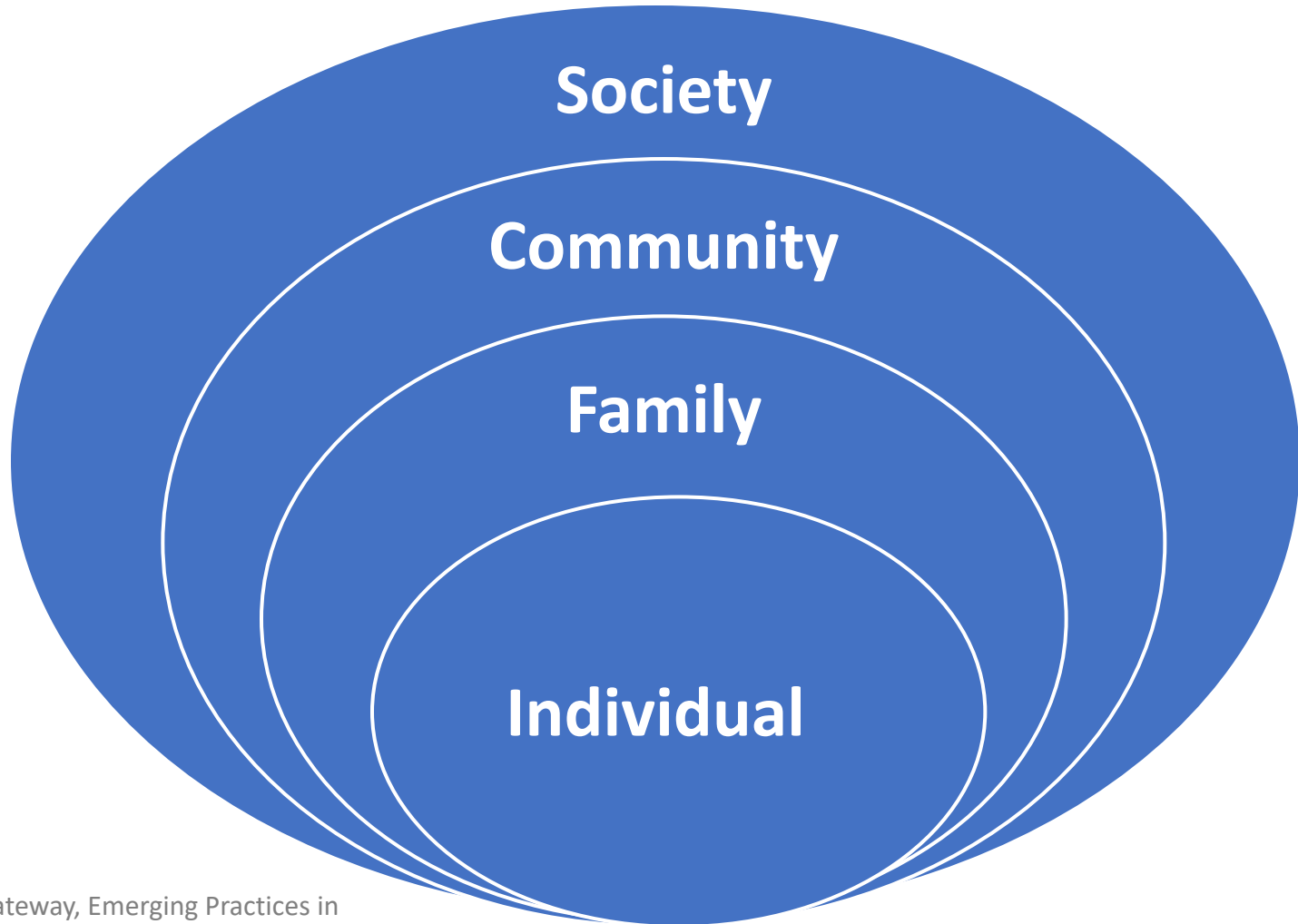
Services cliff  
Socioeconomic status  
Exposure to discrimination  
Lack of services  
Exposure to additional toxins  
Exposure to unsafe environments  
Lack of effective educational environments  
Lack of appropriate preventative and ongoing care

## RESILIENCE

Increased education  
Awareness  
Increased screening  
Preventative care  
Access to health care  
Adequate housing  
Access to services  
New policies to provide support  
Increased social programming  
Increased research and funding for prevention and intervention



# Overall Framework



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## Fetal Alcohol Spectrum Disorders

# FASD



### PRIMARY DISABILITIES

Typical brain-based, primary disabilities of FASD include:



Inconsistent **MEMORY**  
and **RECALL**



Decreased **MENTAL STAMINA**



Difficulty interpreting, and  
applying **ABSTRACT CONCEPTS**



**IMPULSIVITY** and  
poor **JUDGMENT**



**RESISTANT** to change



Inability to **PREDICT OUTCOMES**



Inability to see **ANOTHER PERSON'S**  
perspective



Inability to recognize indirect  
**SOCIAL CLUES**



### SECONDARY DISABILITIES

Secondary disabilities are those not present at birth, but occur later in life as a result of the primary disabilities associated with FASD.

They include:

**MENTAL HEALTH** problems



Poor **ACADEMIC** achievement



Inability to live **INDEPENDENTLY**



**ALCOHOL** and/or  
**DRUG** problems



Problems with **EMPLOYMENT**



**INCARCERATION** or  
**CONFINEMENT**



Trouble with the **LAW**



Disrupted **SCHOOL** experience



Source: CAMH

# Secondary Disabilities

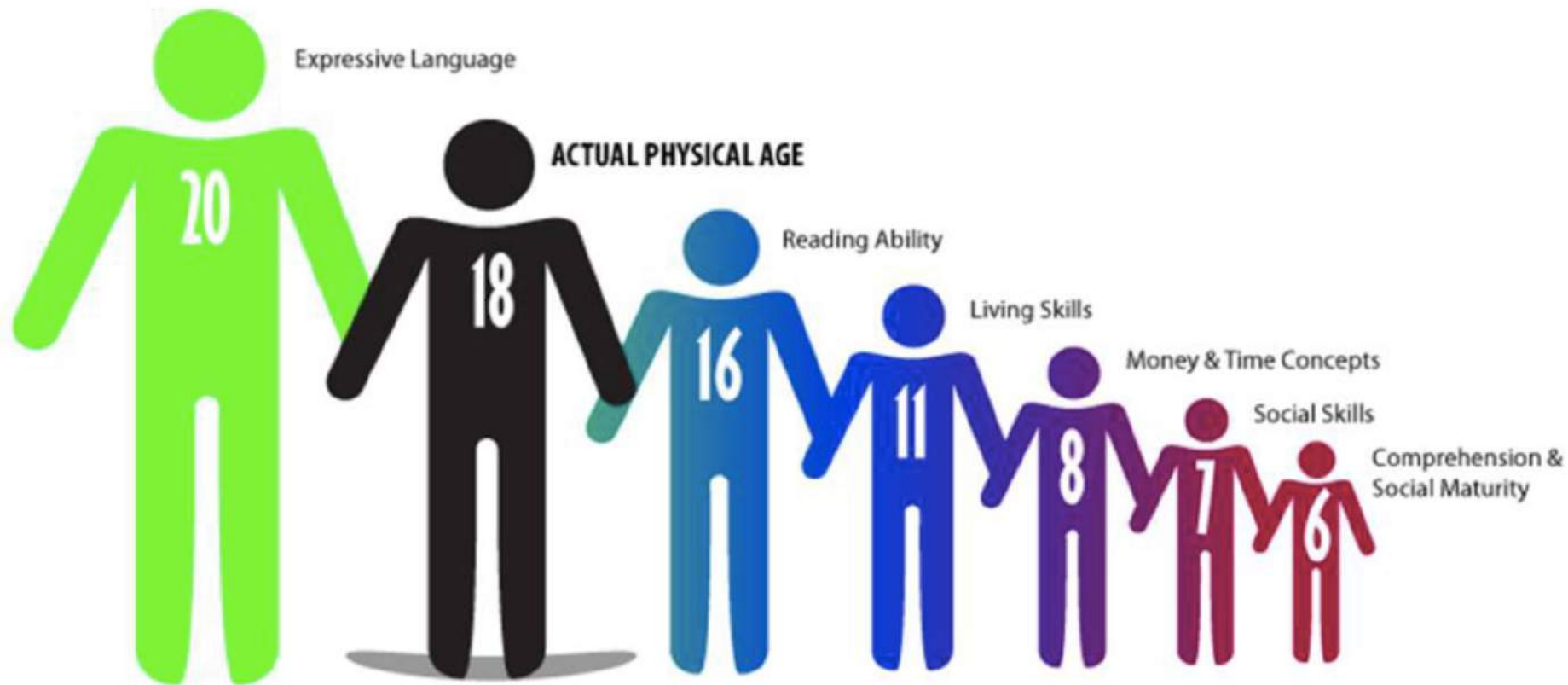
- **94%** - Mental health issues
- **80%** - Trouble with independent living
- **80%** - Trouble with employment
- **70%** - Trouble in school
- **60%** - Trouble with the law
- **60%** - Confinement in prison or institution
- **50%** - Adults abuse alcohol/drugs
- **45%** - Legal problems with sexual behaviors

Streissguth, 1996



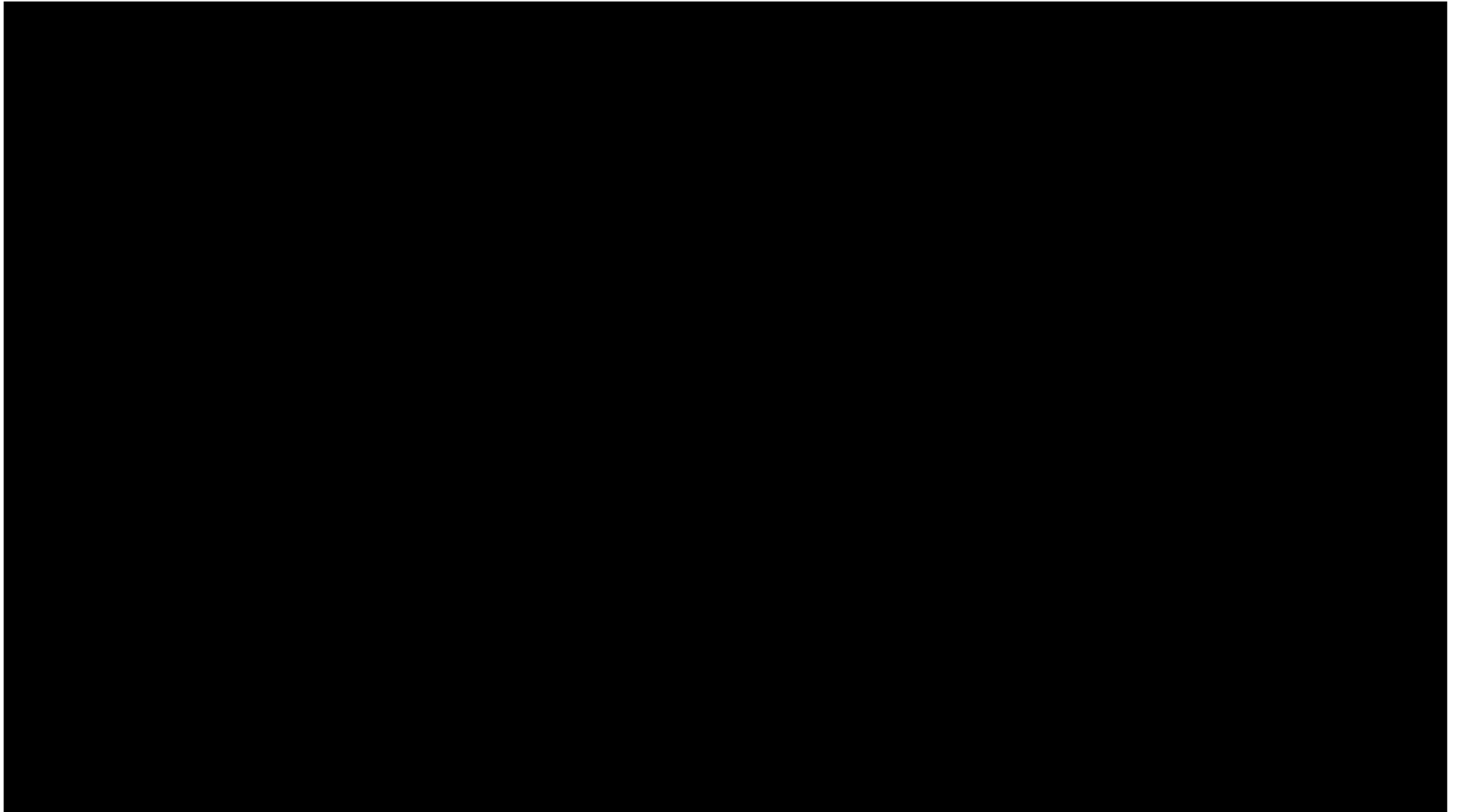
# What you see is NOT what you get...

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# Moment to Moment: Growing up with FASD





# From Young Adults

“I lived with my family for a while. Then I lived with some friends but I got in trouble. I went to jail for a bit. . . . Then I lived in assisted housing. That is when caregivers help out adults in their homes. Sometimes I need that extra help. I like living on my own because I can do what I want, but if I need help, it is there. I can have my own life. That is very important to me. I like to decide where I am going and what I will be doing, but sometimes my schedule can get mixed up and I might not eat or sleep. I also have a hard time doing my laundry and I have lots of problems managing my money. These are things I deal with daily.”

– Joanne, age 25



*Details have been changed to protect privacy*

[http://www.asantecentre.org/Stories\\_Of\\_Adults\\_With\\_FASD.html](http://www.asantecentre.org/Stories_Of_Adults_With_FASD.html)

# From Young Adults

“I did ok in high school and I was excited to go to college. I really thought I could do it. The first few weeks were fine. But then I got in trouble with some people on my hall. I got upset and we got in a fight. I didn’t know what to do, so I just stayed in my room and played videogames. There was too much stuff going on and I got really depressed. Eventually, I failed all my classes and ended up in a hospital. I don’t know think I want to go back.”

– Robert, age 18



*Details have been changed to protect privacy*

# From Parents

“There's no saying you're 18 now they can go, or they can be home and you don't have to worry about them. You always have to worry about them and it's hard because you never know what they're going to do. They could end up with a gang, they could get hurt easily drinking and being in a crowd. They're so easily led astray...Yeah, it's a lifetime of worrying about them”

– Mother of a 21 year old with FASD



# Here's the Plan

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# Federally mandated transition plan

**For those with an IEP, transition planning should:**

- Start before age 16
- Be based on their strengths, preferences, interests
- Include opportunities to develop functional skills

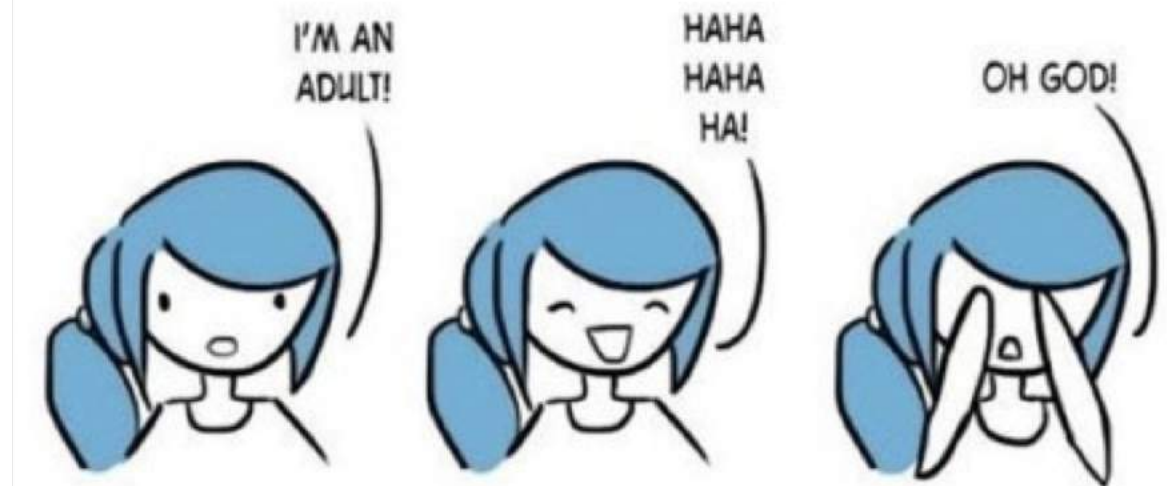
A banner for the California Transition Alliance. The background is dark blue with a lighter blue banner across the middle. The banner has the text 'FUTURE III' in large, white, serif capital letters. Below this, the words 'CALIFORNIA TRANSITION ALLIANCE' are written in large, bold, yellow, sans-serif capital letters. At the bottom of the banner, in smaller white text, it says 'Supports youth-serving professionals who assist youth and families as they transition from secondary education to adult life.'

**CALIFORNIA TRANSITION ALLIANCE**

Supports youth-serving professionals who assist youth and families as they transition from secondary education to adult life.

# Transition to Adulthood

- Continuing Education
- Work + Money Management
- Independent + Supported Living
- Health + Safety
- Mood
- Relationships





# Continuing Education

- Consider the educational environment
  - Are there special services in place?
  - Is a junior or community college more appropriate?
  - What other factors may influence success?
- Ensure that the IEP follows the young adult to any post high school education



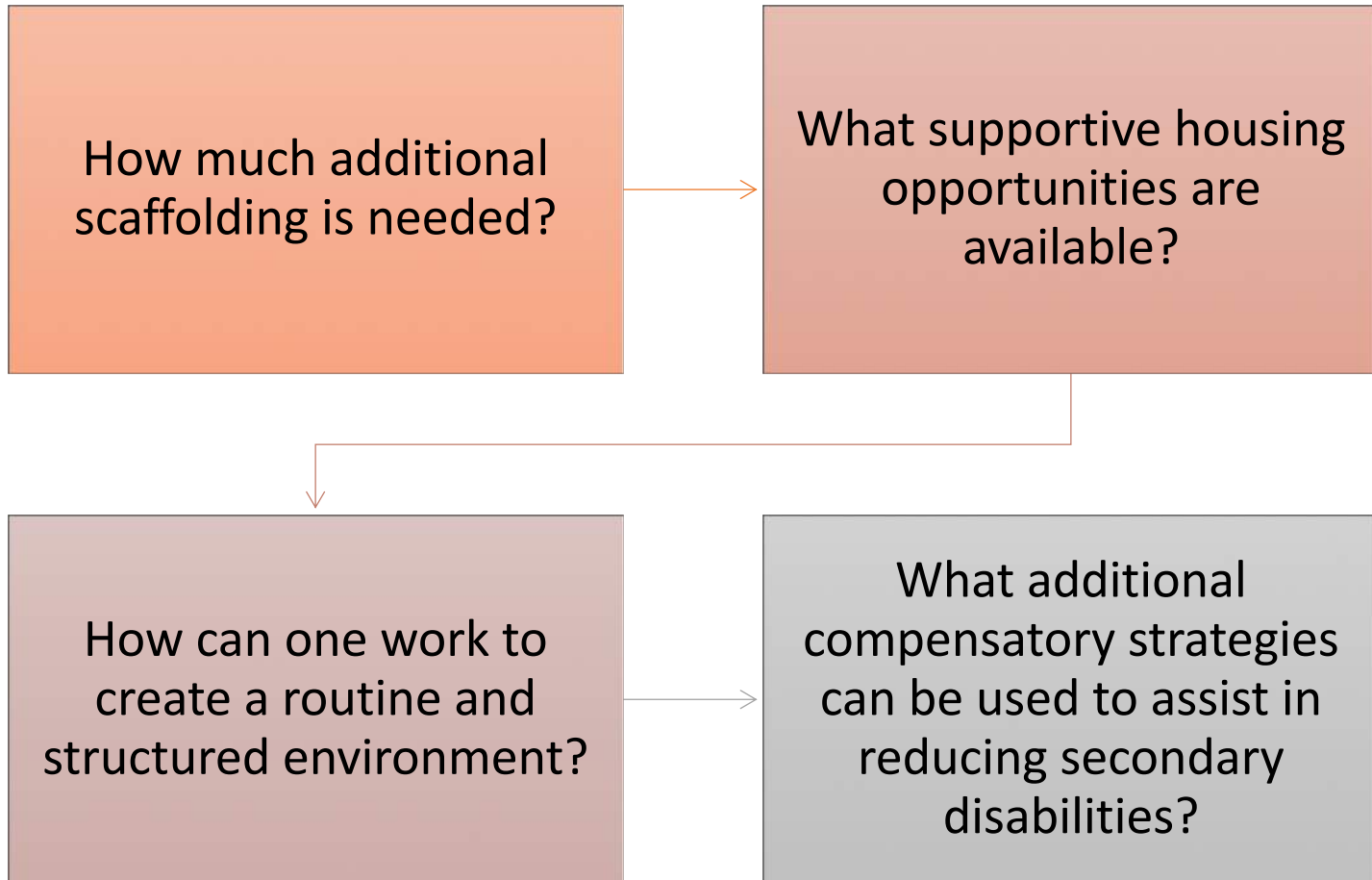
# Work + Money

- Is there a need for supported employment?
- Are there specific strengths or interests that can be involved in planning?
- Is there oversight for financial management?
- Find positive, supportive environments
- Consider SSI



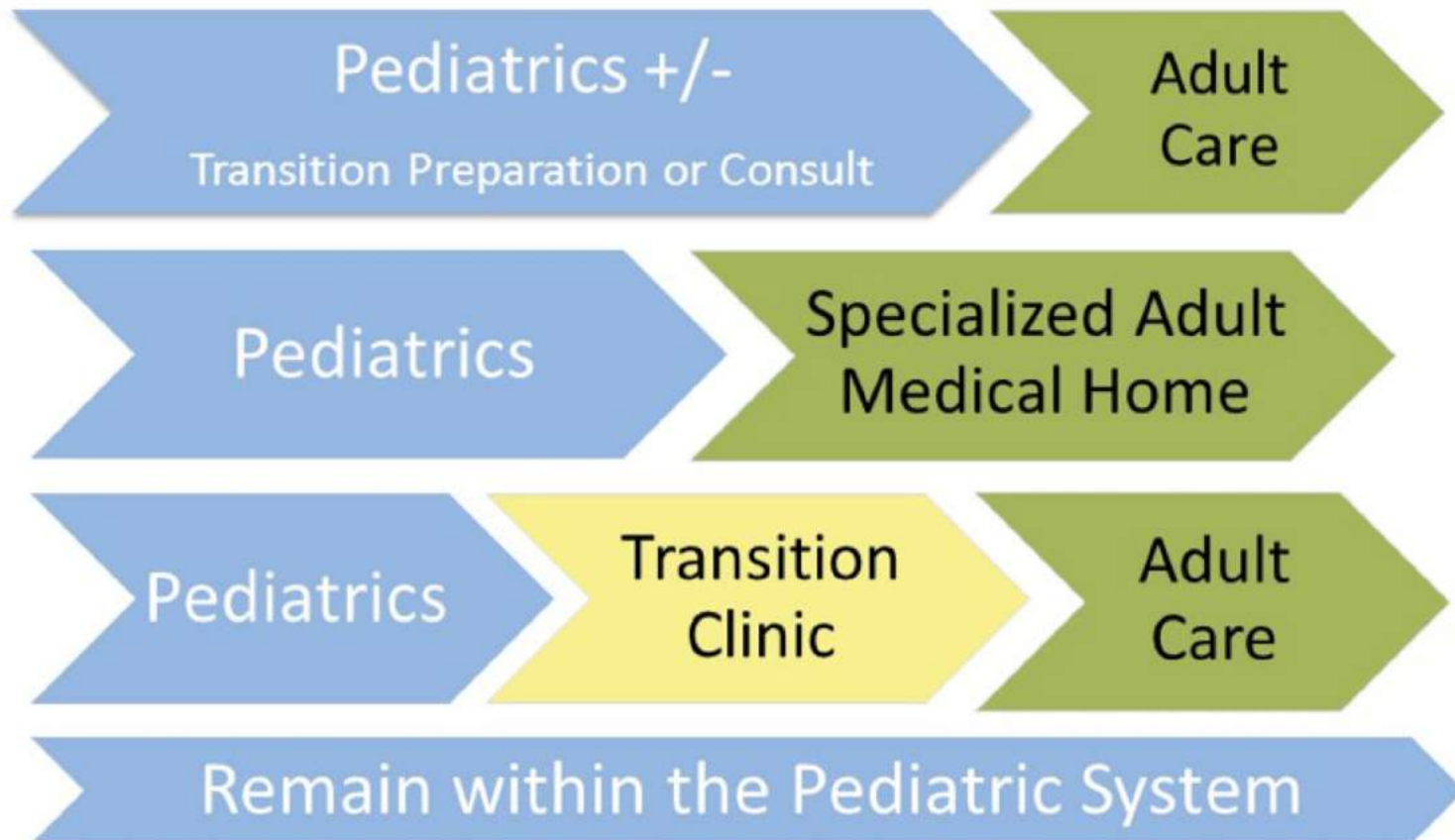
**Most individuals with developmental disabilities are underemployed**

# Independent + Supported Living



# Health

- Prior to 18, consider the transition from pediatric care to adult care and what that entails



# Safety + Legal Issues

- Assess needs and concerns
- Consider formal safeguards
  - Conservatorship, money management
- Consider additional training and support
- As well as support within the legal system
- Young adults are also often taken advantage of

# Mood

- Increased risk for mood symptoms including suicidal ideation.
- Continued care with a psychologist/psychiatrist familiar with your young adult's level of functioning.
- Consider mood and psychological well being in other decisions regarding independence.



# Relationships

- Review Social Skills - PEERS for young adults!
- High risk for social isolations
- Review positive, meaningful friendships
- Be proactive in planning social interactions
- Consider safety in romantic relationships
  - Sexual education
  - Birth control
  - Dating



## Essential Life Skills for All Teens

### Independent Living Skills

#### At Home Skills

Locate Housing options  
Arrange Rent, Utilities, Phone  
Basic Routine Maintenance  
Clean, Vacuum, Dust  
Find a Circuit Breaker/use it  
Locate, use Water Furnace Shut-off  
Fix Basic Plumbing

#### Financial Literacy

Understand Gross/Net pay, Deductions  
Make a Budget -- stick to it  
Use a Bank and/or ATM/ On-Line Banking  
Open, Use, Balance Checking Account  
Apply for Credit Card, use wisely  
Benefits Planning  
Saving Account,  
Keep track of documents file taxes

#### Citizenship

Register to Vote, Vote  
Comply with Laws, Regulations  
Be Environmentally Responsible  
Participate in Community Activities  
Volunteer

#### Use Technology at Work, Home, Socially

Use Social Media Responsibly  
Know Cyber Presence  
Cell Phone Message & Ringtone should Leave a Good Impression  
Validate Sources of Information  
Maintain Safe Identity  
Maintain Current Knowledge of Technology/Applications

#### Food Skills

Plan, shop for Healthy Diet  
Prepare, Store Food  
Cook Balanced Meal  
Use Kitchen Appliances

#### Personal Appearance Skills

Basic Clothing Repair (buttons, hems)  
Iron Garments  
Fold, put away Clothes  
Laundry -- Follow care labels, treat stains  
Maintain Personal Appearance

#### Health and Wellness

Basic First Aid  
Maintain Healthy Diet  
Use Medication Safely  
Routine Exercise  
Make Healthy Lifestyle Choices  
Maintain Hygiene/Grooming  
Be aware of Personal Safety

#### Self Determination & Self Management

Know Yourself -- Your Strengths, Limitations  
Manage Your Time  
Set Priorities  
Monitor Your Performance  
Balance Your Responsibilities and Priorities.  
Adapt and Accept Change  
Advocate for Yourself to Meet Your Needs  
Learn from Mistakes

**Believe in Yourself**

### Transportation Community Access

#### Drive/Maintain Car & Driver's License

Buy Car, Buy Insurance  
Registration  
**Pump gas**  
Maintain Vehicle Oil, Fluids  
Maintain, Change Tires,  
Follow Traffic Laws/Safety

#### Use Public Transportation

Know Schedules  
Know Routes, Pick-up Points  
Know Options (Bus, Taxi, On-demand)

#### Community Access

Know Options  
Read a Map/ Use GPS  
Know Landmarks  
Community Orientation

#### Social / Recreation

Explore Social/Recreational Opportunities  
Pursue Hobbies, Recreational Interests  
Develop, Maintain Healthy Friendships  
Develop, Maintain Healthy Family Relationships

#### Postsecondary Options

Explore Options -- Job Center, Web Postings  
Explore Postsecondary Education Options  
Apply Decision-Making Skills  
Use Labor Market Info. to guide choices  
Develop Resume  
Submit Applications/Resume on-line  
Interview skills

#### Employability Skills

Communication Skills (Listen, Speak, Customer Service)  
Interpersonal Skills (Leadership, Social Skills, Teamwork)  
Personal Qualities / Work Ethic  
Thinking Skills (Analyze, Prioritize, Visualize, Problem Solve)  
Application of Core Academic Skills  
Use of Technology  
Manage Resources, Time  
Understand Value of Lifelong Learning  
Be Adaptable

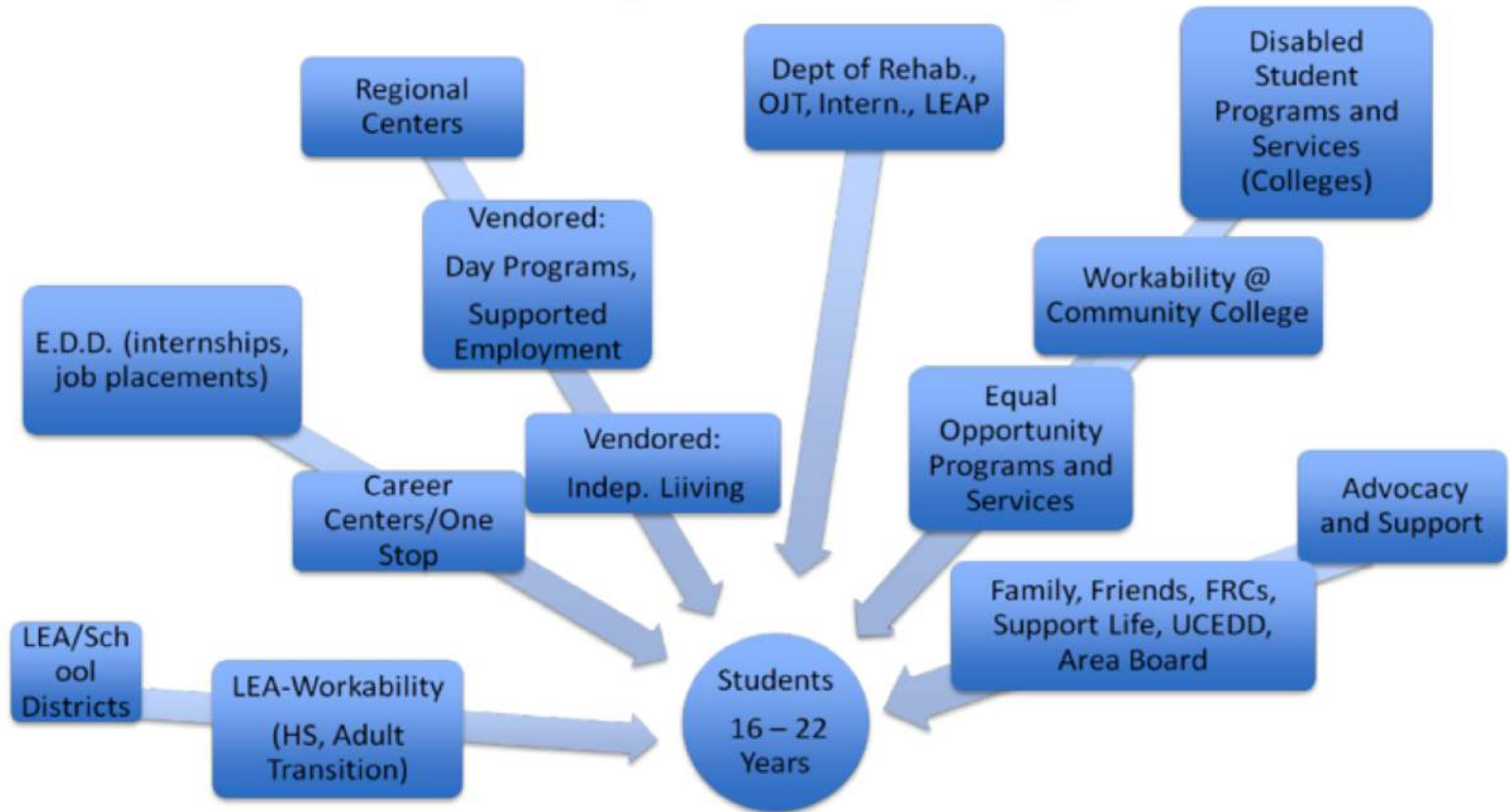
#### Be A Lifelong Learner: Be curious & interested to learn new things or apply old info in new ways

Seek Opportunities to Learn -- in Classroom, with Computers, with Books, with People  
Learn From and With Others -- Share what you Learn -- Recognize You are Not "The Expert"  
Take in Information -- Analyze it, join it with other Information, then apply it





# Supports and Services for Transition-Age Youth (16 – 22 Years)



CENTER FOR EXCELLENCE IN

Developmental Disabilities

**UC DAVIS**  
MIND INSTITUTE

# Knowledge and Training

50% of pediatricians felt prepared to diagnose and 34% felt prepared to manage and coordinate the treatment of children with FASD, 77% cited lack of training

Family Physicians	Pediatricians	Developmental Pediatricians
Geneticists	Dysmorphologists	Psychiatrists
Psychologists	Neuropsychologists	Public Health Nurses
Community Nurses	Occupational Therapists	Physical Therapists
Special Education	Family Advocates	SLPs
Social Services	Youth Justice	Probation Officers
Family Therapists	FASD Courts	Surgeons
Employment Counselors	Guidance Counselors	Teachers
Caregivers/Family	Community Leaders	Community services
Nurse Practitioners	Parents	OB/GYN

Gahagan et al., (2006), Masotti et al (2015)

# Resources + Future Directions

We need additional research on this important transition from youth to young adulthood



# Additional Resources

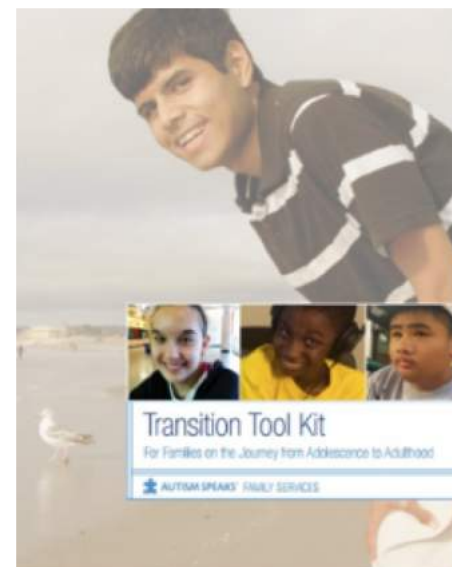
national  
youth  
transitions  
center

Because  
the Future  
Needs Everyone

  
**The Arc.**

*For people with intellectual  
and developmental disabilities*

*Achieve with us.®*



Transitioning to Adulthood:  
Unique Health Care  
Challenges for Youth with  
Intellectual/Developmental  
Disabilities



## OCALI Centers

Informing public policy and developing and deploying best practices - linking research to real life - so that people with disabilities have the opportunity to live their best lives for their whole lives.

# Thank you!

Center for Behavioral Teratology

## Resources and Information



National Institute  
on Alcohol Abuse  
and Alcoholism



U C San Diego



SAN DIEGO STATE  
UNIVERSITY

*Leadership Starts Here*

TARJAN  
CENTER AT UCL



# CIFASD

Collaborative Initiative on  
Fetal Alcohol Spectrum Disorders



# Questions?

