Slide 2

A Model to Support Individuals with Fetal Alcohol Syndrome in the Real World

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Slide 3

Child Profile

Alejandro –

"My Story"

Fetal Alcohol Spectrum Disorders

Child with Prenatal Alcohol Exposure

Slide 5

Diagnostic Continuum

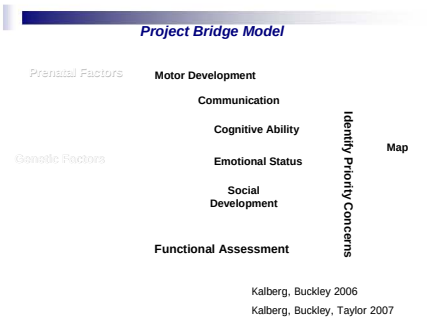
- **FAS - (Fetal Alcohol Syndrome)**
  - Confirmed history of maternal alcohol abuse during pregnancy
  - Prenatal onset growth retardation (including length and/or weight), persistent postnatally
  - A specific pattern of minor anomalies of the face
  - Neurocognitive deficits
- **PFAS – Partial FAS**
  - Confirmed maternal alcohol exposure
  - Some typical facial anomalies and
  - Either
    - Growth retardation
    - CNS anomalies
    - Behavioral and /or cognitive abnormalities
- **ARBD – Alcohol-related birth defects**
  - Heterogeneous list of malformation which have been described in concert with FASD, e.g. ASD, VSD, Klippel-Feil, renal dysplasia, strabismus
- **ARND - Alcohol related neurodevelopmental disorder**
  - CNS neuro-developmental anomalies [e.g., microcephaly, agenesis of corpus callosum, soft or hard neurologic signs] and/or behavioral and cognitive abnormalities).

Slide 6

Alejandro

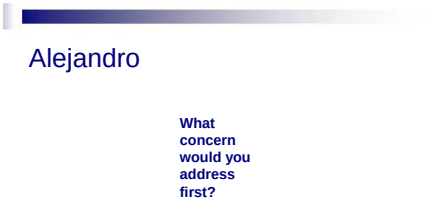
Where does Alejandro fall on the continuum?

Slide 7



Slide 8

Slide 9



Slide 10

You Know it is a Priority When:

- It is a concern of the family
- It is getting in the way of the child's educational development
- It is getting in the way of everyday life
- It is getting in the way across multiple environments and domains of learning
- It persists – it is outside the typical expected developmental course

Slide 11

Research Base of Model

Deficit Area		Strategy
Executive Functioning	=	***Routine***
*memory	=	***Visual Structure***
*planning	=	***Organization***
*sequencing		
Auditory Memory	=	***Repetition***

(Vaurio, et al, 2008; Kodituwakku, et. al, 2006; Kodituwakku et al., 2002; Mattson, et. al, 1996; Mattson et al, 1998; Mattson, et. al, 1999; Mattson, et al, 2002; Kodituwakku, 1995; Kodituwakku et al., 2001;)

Slide 12

Research Base of Model

Deficit Area		Strategy
Attention/Hyperactivity	=	***Opportunities to move***

(Mattson et al, 2006; Coles et. al, 2002; Coles, et al., 1997; Streissguth, et al, 1995)

Behavioral		
Sensory Regulation	=	***Sensory support***
Social Pragmatics	=	***Social skills training***
Social-emotional	=	***Clinical support - counseling***

(Fryer, et al, 2007; Roebuck et al, 1999; Mattson and Riley, 2000; Roebuck et al; 1999; Schonfeld et al, 2005; Steinhausen et al, 1998; Thomas et al, 1998)

Slide 13

Research Base of Model

Deficit Area		Strategy
Brain and Motor Connections		
Messages transmitted across the corpus collosum	=	***Bi-manual activities***
Fine motor deficits in early years	=	***OT/PT services***

(Roebuck et al., 2002; Roebuck-Spencer, et. al, 2004; Kalberg et al, 2006)

Slide 14

Alejandro

Individualized Intervention Map

Specific Concerns	What you See	Strategy	Deficit Area
Alejandro is anxious	■ Licks lips ■Repetitive motor patterns ■Seems to be more anxious when there is pressure or he is anticipating something ■Shuts down or tries to avoid work	1. Visual guide to tell him what is happening 2. Uses weekly schedule at home 3. Lunch schedule with Azu 4. Oral option (neck-laces, gum provided by family) 5. Listening program at home 6. Weekly play therapy with counselor	■ Executive functioning ■Theory is the anxiousness is related to his inability to sequence activities without external supports.

Slide 15

Specific Concerns	What you See	Strategy	Deficit Area
Self-esteem *** His awareness that he isn't reading as well as the others in class bothers him the most.**	■ Does not see himself as a reader ■ Notices that kids his age are reading harder books ■Will choose books that are too hard for him to read ■Seeks a lot of adult approval to keep going academically	1. Previewing his reading book for school at home (Mr. Moss will send book home the night before and parents will go over it with him.) 2. Peer tutors in class will be used to help him read. 3. Counseling 4. Positive behavior support	■ Is this a reading disability ■ Some children with FAS also have specific learning disabilities.

Slide 16

Specific Concerns	What you See	Strategy	Deficit Area
Activity level and focused attention	■Fiddles with stuff I hands and is off task ■Has a hard time staying with a task through completion ■Attention may be getting in the way of sequencing sounds for reading ■Gets distracted fro task	1. Developed clipboard that Alejandro charts behavior. Parent developed-Parent and teacher decide if it is needed. 2. Second step program at school 3. Option to use structured outdoor, large motor activities during the day. 4. Pool therapy to address sensory needs and direction following. 5. Parent will research medication for attention 6. Oral motor 7. Possible functional behavior assessment	■Social/emotional ■Pragmatics ■Sensory regulation (including emotional regulation)

Slide 17

Specific Concerns	What you See	Strategy	Deficit Area
Inconsistency in showing his ability to use his knowledge. Generalization to the real world	■ Inconsistent performance in reading, math (time, coins, cooking measurements), spelling, and written language.	1. Repetition 2. Give lots of positive support when he does functionally generalize 3. Continue to research alternative learning programs 4. Continue books on tape 5. Parents will research "Fast Forward"	■ This seems to be a hallmark feature of affected children and is still a mystery, being researched.

Slide 18

Specific Concerns	What you See	Strategy	Deficit Area
Deciding next steps in supporting Alejandro's learning.	■Some signs of low self-esteem	1. Parents will research categories for "other Health Impaired (can ADHD be used alone?) 2. Research benefits to a 504 vs. an IEP 3. Determine if MDT would accept outside testing 4. Meet with educational team in late April 7th at 1:45 if Mr. Moss OK's this time	■ From formal Speech/Language testing and Psycho educational testing, specific needs will be determined.

Slide 19

Actual Examples of Strategies

- Show videos and slides of actual strategies used
  - Old and new
  - Looking at developmental appropriateness

Slide 20

Teacher and School Feedback

- Miss Debby's comments
- Principal's comments

Slide 21

Factors To Consider

Prenatal Factors

- Maternal health and nutrition
- Alcohol and substance abuse
- Medications taken

Genetic Factors

- Parent history of genetic disorders, learning disabilities, retardation
- Family history of mental stability

(prenatally alcohol-exposed)

Postnatal Factors

- Cultural Context
- Fit of child & caregiver
- Mental health status of primary caregiver
- Nutrition
- Attachment disruption/Exposure to violence
- Richness of Early Stimulation
- Poverty

Kalberg, Buckley, Taylor 2007

Slide 22

Maternal Drinking and Attachment

Mothers' Drinking	Attachment	
	Secure	Insecure
Abstinent-Light	88%	22%
Light-Moderate	52%	48%
Moderate-Heavy	17%	83%

O' Connor, 1987

Slide 23

Stress Hormones When Cortisol Levels are High

- **Abuse** – the memory-making hippocampus is smaller in abused adults than in non-abused adults
- **Vigilance and Arousal** – high cortisol levels 0-3 increase activity in the area of the brain responsible for arousal and vigilance.
- This results in difficulties with inhibitory control (self-regulation and self-control).

(Gunnar, 1998)

Slide 24

Maternal Depression

Interact ional Styles of Depressed Mothers

*** Withdrawn**

*** Intrusive**

Both styles have negative effects on the child because the infant receives both inadequate stimulation and inadequate assistance with arousal modulation. They have disturbed sleep and wake cycles, increased stress hormone levels, low tone, and slower behavioral responses to facial expressions

(Field, 1997)

Slide 25

Alejandro

What did we find out about Alejandro's prenatal, genetic, and postnatal factors?

Slide 26

Developmental Course

Motor Development
- **gross**
- **fine**

- **Sensory/Motor difficulties**
- **Dysgraphia**

Communication
- **Expressive**
- **Receptive**

- **Prosody difficulties**

- **Executive functioning difficulties**
- Planning (cognition based working memory)
- **Attentional Problems**
- shifting attention
- encoding

(prenatally alcohol-exposed)

Cognitive Ability
- **Verbal IQ**
- **Performance IQ**
- **Total IQ**

Emotional Status

- **Extinction of behavior** (emotion based EF)

Social Development
- **moral development**
- **empathy**
- **theory of mind**

- **Pragmatics of social engagement**

Kalberg, Taylor 2007

Slide 27

Alejandro

What do we remember about Alejandro's developmental course and functional assessment?

Slide 28

Making Functional Links to Interventions

Motor Development

Communication

Cognitive Ability

(prenatally alcohol-exposed)

Emotional Status

Social Development
* moral development
* empathy
* theory of mind

Functional Assessment

Provides the Links

Identify Priority Concerns - What gets in the way the most in the child's life?

Intervention Map

Kalberg, Taylor, 2007

Slide 29

HOME

Self Care

Sleep

Play

Relationships

Functional Assessment

Observation – Interviews – Questionnaires

Transitions

SCHOOL

Academics

Friends

Rules

Activities

COMMUNITY

Safety

Rules

Activity Level

Interactions: Adults/Peers

Kalberg, Taylor, 2007

Slide 30

Alejandro

What life (functional skills) were a strength for Alejandro?

What life (functional skills) areas are a concern for Alejandro?

Slide 31

Questions Needed?

- What questions would you ask to gain this information?

Slide 33

Alejandro

Interests?

Strengths?

What Helps?

What gets in the Way?

Slide 34

Project Bridge Model

Prenatal Factors

Genetic Factors

Postnatal Factors

Motor Development

Communication

Cognitive Ability

Emotional Status

Social Development

Functional Assessment

Identify Priority Concerns

Map

Kalberg, Buckley 2006

Kalberg, Buckley, Taylor 2007

Child with Prenatal Alcohol Exposure

Slide 36

Individualized Intervention Map

Specific Concerns	What you See	Strategy	Deficit Area

Priority Concerns

=

Slide 37

How to Know What Strategies to Use

What helps

Interests

What gets in the way

Strengths

Slide 38

Alejandro

What strategies do you think would help Alejandro?

Slide 39

Making Functional Links to Interventions

Motor Development

Communication

(prenatally alcohol-exposed)

Cognitive Ability

Emotional Status

Social Development
* moral development
* empathy
* theory of mind

Functional Assessment

Provides the Links

Kalberg, Taylor, 2007

Slide 40

- **We hope this has been helpful for you and any "Alejandros" you know!**

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