Educational Interventions and Support for Children Affected by Prenatal Alcohol Exposure (PAE)

Formed Families Forward
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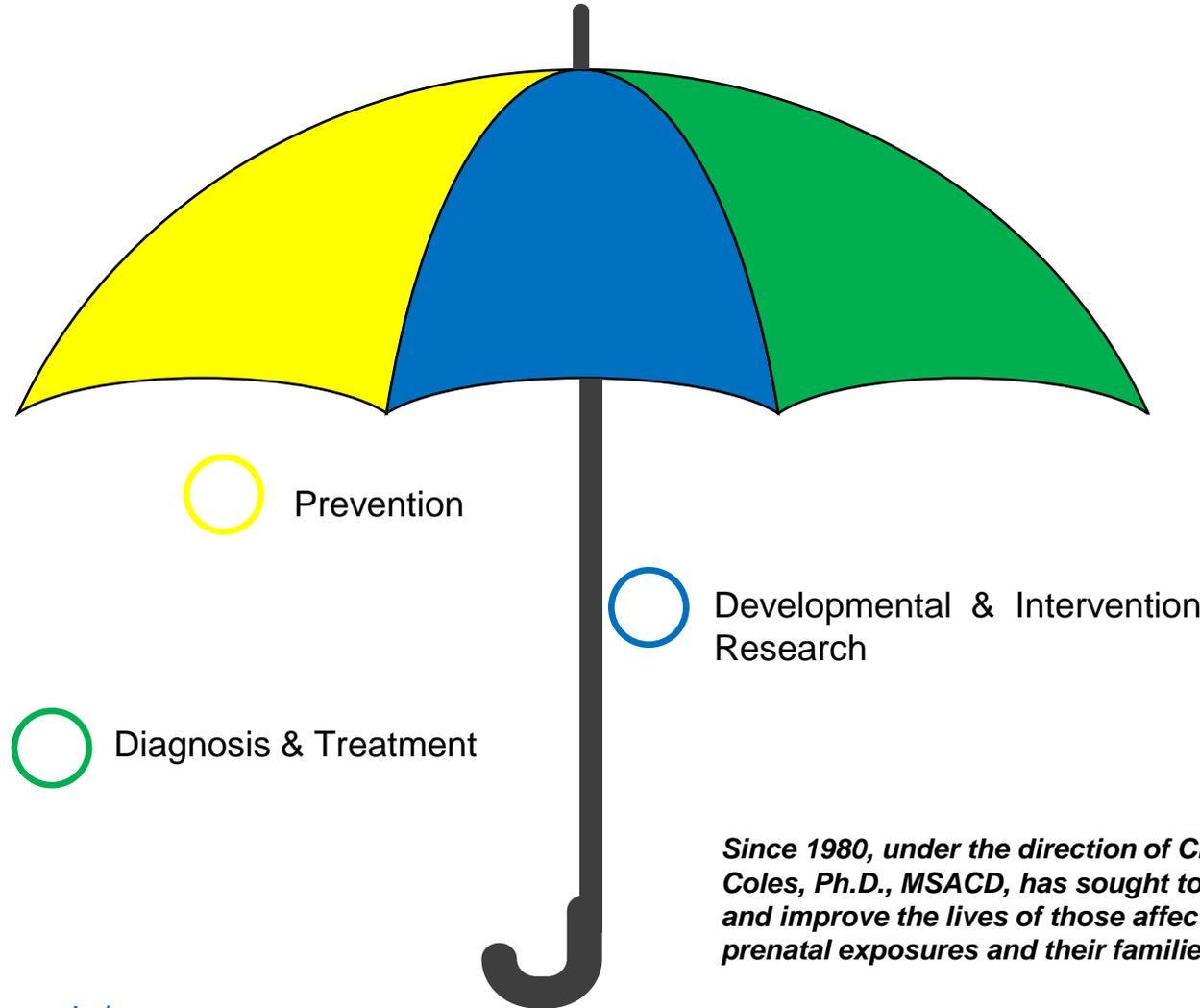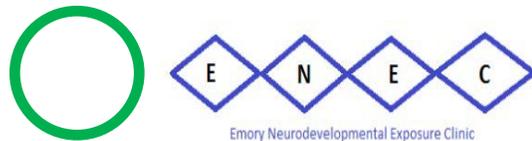Department of Psychiatry and Behavioral Sciences
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Statement of Conflict of Interest

The presenter has no conflict of interest to disclose.

Center for Maternal Substance Abuse and Child Development

MotherToBaby
GEORGIA
Medications & More During Pregnancy & Breastfeeding
Ask The Experts

MILE Go FAR

E N E C
Emory Neurodevelopmental Exposure Clinic

Prevention

Developmental & Intervention Research

Diagnosis & Treatment

Since 1980, under the direction of Claire D. Coles, Ph.D., MSACD, has sought to understand and improve the lives of those affected by prenatal exposures and their families

EMORY UNIVERSITY SCHOOL OF MEDICINE
Center for Maternal Substance Abuse and Child Development
Department of Psychiatry and Behavioral Sciences

http://msacd.emory.edu/

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Objectives

- Discuss selecting interventions based upon the needs of the individual rather than the diagnosis

- Discuss the purpose of interventions to improve an individual's participation, engagement, and quality of life

- Review evidenced-based interventions for individuals affected by prenatal exposures and from other disabilities

Perspectives from the Field of Developmental Disabilities

- Shifting the focus from deficits to a focus of building skills, strengths, self-advocacy, and improving quality of life.

- Service delivery targets functioning and participation rather than diagnostic labels.

Carmichael Olsen & Sparrow, 2020; Benson & Oakland, 2011

Impact of PAE on Learning, Academics, and School Functioning

Emory Neurodevelopment Exposure Clinic's Criteria

Exposure	ICD-10-CM Codes	Diagnosis	Impact
Prenatal Alcohol Exposure	P04.3 Prenatal Exposure to Alcohol Only Q86.0 Fetal Alcohol Syndrome or Partial Fetal Alcohol Syndrome F88 Neurodevelopmental Deficit Associated with Prenatal Alcohol Exposure (ND-PAE)	• Documented evidence of exposure during pregnancy (not hearsay) • Growth delays at birth or currently <10th percentile (rule out from other causes) • Dysmorphia (changes to the physical features, checklist with cut score of 10) • Range of delays in cognitive abilities, adaptive functioning, learning, attention, behavioral regulation (developmental/cognitive testing) • ***FAS or PFAS Must be diagnosed by a trained physician, geneticist or developmental pediatrician (MD)*** • **ND-PAE may be diagnosed by a licensed clinical psychologist or medical provider**	• Life-long • Medical issues (e.g., congenital heart defects; vision problems) • Decreased intellectual abilities • Problems with learning • Poor adaptive skills

Neurobehavioral Traits Associated with Prenatal Alcohol Exposure (PAE)

Neurobehavioral Traits

Neurocognition

- Global cognitive impairments (IQ scores <70) <u>or</u>
- Specific cognitive deficits in executive functioning, working memory, visuospatial abilities, memory, and processing speed

Self-Regulation

- Emotional/behavioral regulation
- Attention deficits
- Poor impulse control

Adaptive Functioning

- Language or communication deficits
- Social interactions/social communication
- Daily living skills
- Motor skills
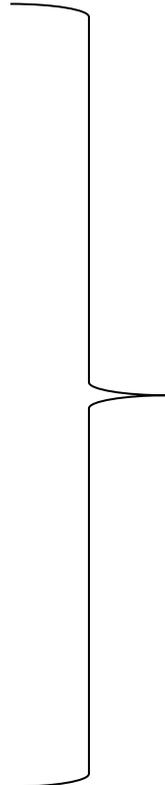
Deficits in one or more areas

Adapted from Kable et. al., 2016

PAE and Academics

- Academic Underachievement (Howell et al., 2006; Glass et al., 2017)
- Challenges learning preacademic skills (Coles, et al., 1991)
- Lower scores on academic achievement measures of reading, including word reading and comprehension (Streissguth et al., 1994)
- Poorer performance in spelling when compared to children without effects from PAE (Glass et al., 2015)
- Poor oral and written language skills (Doyle et al., 2018; Kippen et al., 2021; Millians, Kable, Coles, & Mattson, in review)
- Poor functional handwriting (Duval-White, Jirikowic, Rios, Dietz, Carmichael Olsen, 2013)
- Deficits in Mathematics (Streissguth et al., 1994; Kable, Coles, & Taddeo, 2007; Woods et al.,2018)

PAE and School Functioning

- Observations of longer periods of passive or disengaged behaviors in a classroom when compared to nonexposed peers (Olswang, Svensson, & Astley, 2010)

- Show many prosocial skills and engaged in the classroom for shorter durations that nonexposed peers (Olswang, Svensson, & Astley, 2010)

- Teachers reported more impulsive, unpredictable and possibly aggressive behaviors in children with PAE (Streissguth, 1997)

- Poor quality of play (Pearton, Ramugondo, Cloete, & Cordier, 2014; Molteno, Jacobson, Carter, & Jacobson, 2010)

- Studies show skills to initiate friendships but challenges to maintain them (Laugeson, Paley, Schonfeld, Carpenter, Frankel, O'Connor (2007)

- Poor adaptive functioning that cannot be explained by cognitive ability (Ware et al., 2012; Doyle et al., 2018)

Other Factors Influencing Learning, Behavior, and School

Adverse Childhood Experiences (ACEs)*	Other Challenges
Emotional, physical, and/or sexual abuse	Chaotic homelife
Witnessing domestic violence	Harsh, over-authoritarian parenting
Caregivers' continued substance abuse	Social/economic disadvantage
Household member with mental illness	Mental Health Conditions
Neglect, deprivation	Medical Conditions
Multiple foster home placements	
Racism/Discrimination	

*Individuals affected with PAE experience high rates of early adversity

Mukherjee et al., 2019; Flannigan et al., 2021

Possible Barriers to Educational Interventions

Flannigan et al., 2017; Roozen et al., 2020; Skorka et al., 2020

Stigma (social, caregiver, and self-stigma)

Lack of understanding of range of impact of PAE on learning

Lack of accessibility to resources

Challenges explaining the educational needs

Unaware of available interventions

Considering Intervention Needs

ICF-CY and FACT Tool

World Health Organization
International Classification of Functioning, Disability and Health-Children and Youth (ICF-CY)

- Uses a common language to talk about "ability" and "disability"

- "Ability" refers to engagement and participation in an activity

- "Disability" refers to impairments that restrict participation

- Emphasizes building skills in relation to "participation"

- "Functioning" refers to body functions, activities, and participation

- Environmental factors can refer to barriers or supports that influence functioning

- Target to improve quality of life

https://www.whofic.nl/en/family-of-international-classifications/derived-classifications/icf-cy

The Functional Abilities Classification Tool (FACT)

Developed by Klein & de Camargo, 2018

Based on the ICF-CY

FACT gives a way to talk about what individual can do and how to increase their participation

- *Classifies what an individual can do*

- *Analyzes interactions between abilities and environments*

- *Behaviors are a symptom rather than an outcome*

- *Examines barriers*

- *Includes the individual and their preferences*

- *Guides the development of goals and supports to increase individual's involvement in their environment*

- *Can be completed by a therapist, psychologist, special education teacher, clinician*

Limitations and Reservations

- Needs to be put through validation

- Subjective

- Relies on accuracy of records

- Needs to adjust and define some categories

FACT Tool for Intervention Planning

FUNCTIONAL ABILITIES CLASSIFICATION TOOL (FACT)

LEVELS OF CLASSIFICATION OF PARTICIPATION
Level 1 - Participates adequately for age (within typical range)
Level 2 - Participates with lower frequency or less involvement than expected
Level 3 - Participates with lower frequency and lower involvement than expected
Level 4 - Does not participate significantly (very low or none)

DISTINCTIONS BETWEEN PARTICIPATION LEVELS
- **Level 2** is distinguished from **Level 1** by decreased frequency *or* quality of involvement of participation.
- **Level 3** is distinguished from **Level 2** by decreased frequency *and* quality of involvement of participation.
- **Level 4** is distinguished from **Level 3** in that participation is vastly different in involvement compared to typical peers, as well as very infrequent or non-existent.

SCHOOL PARTICIPATION ACTIVITY DOMAINS
• individual work (reading, writing, math)
• project (or multistep task)
• student directed group work
• teacher directed group instruction (e.g. circle time, question and answer)
• group unstructured (e.g. lunch)
• group unstructured physical (e.g. recess)
• group structured physical (e.g. physical education)

LEVELS OF FUNCTIONAL ABILITIES CLASSIFICATION
Level 1 - allows participation in a typical environment for age without special supports
Level 2 - allows participation with partial involvement or intermittently in typical activities without special supports; intermittent support would be expected to facilitate participation within typical limits
Level 3 - allows child to participate with partial involvement for a minority of time; child would require intensive or frequent support to facilitate participation in typical activities
Level 4 - even with continuous, intensive support does not allow meaningful participation in intended activities in a typical environment (i.e. significant modification of activity or environment expected)

Benjamin Klein & Olaf Kraus de Camargo, 2018

Case Review using the FACT Tool

Clinical Information for EG

Background Information
- 14-year-old female
- Prenatally exposed to alcohol, opiates, and tobacco
- One prior placement before adoption at age 5
- Repeated kindergarten
- Private occupational therapy and speech and language therapy through middle school, released from services

Testing Summary
- Scores on measures of cognition, verbal, spatial, nonverbal reasoning, language, and memory fell in the Very Low to Low Average Range.
- Overall abilities in the Very Low range.
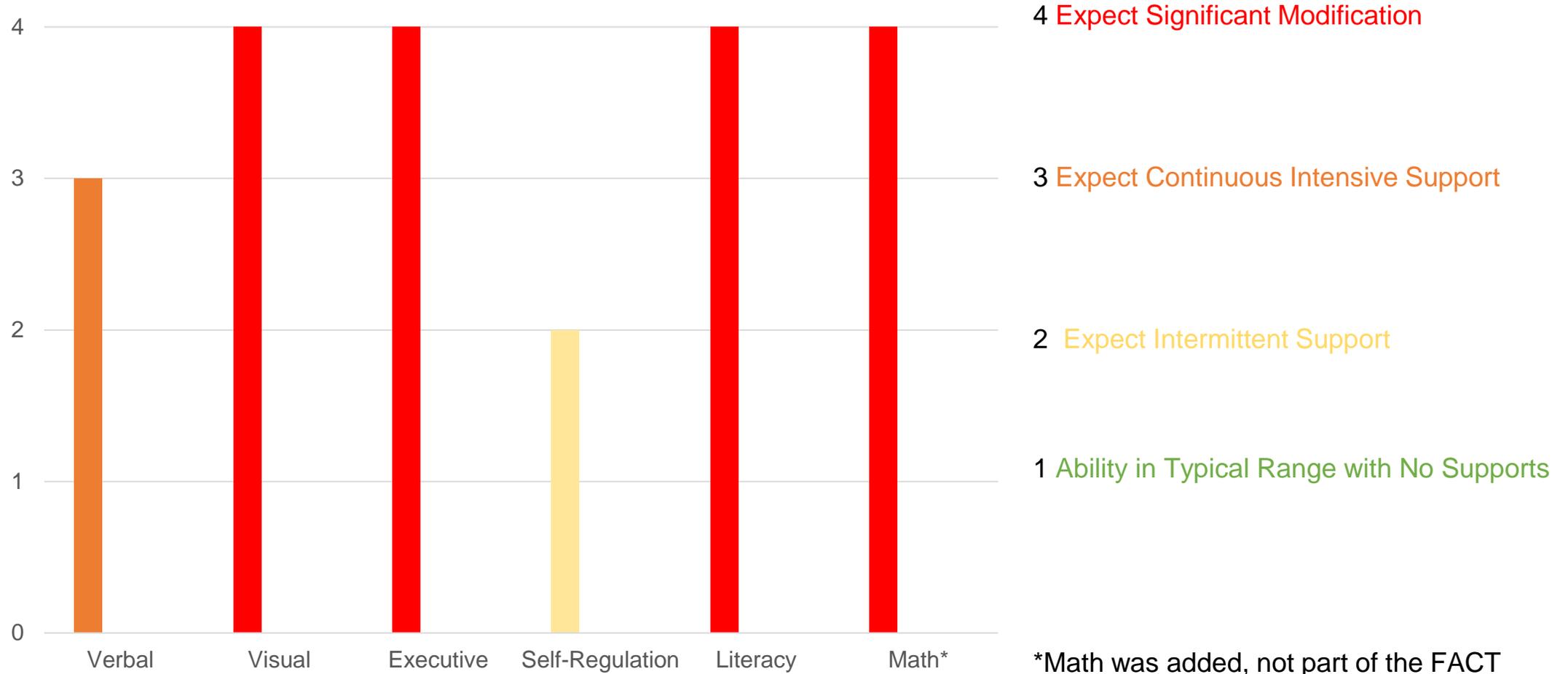
Clinical Diagnoses (ICD-10 Codes)
- Q86.0 Fetal Alcohol Syndrome
- F88 Neurodevelopmental Disorder associated with Prenatal Alcohol Exposure

EG's Educational Program and Progress

Current School

- 9th grade, public school
- All instruction in co-taught or inclusion classes; No other supports
- Academic curriculum is on grade level
- Grades are D's and lower; except in PE and in Drama
- Retakes about 80% of tests and quizzes to get a minimal passing grade
- Needs frequent adult or peer assistance to complete classwork and homework
- Attempts to engage in class
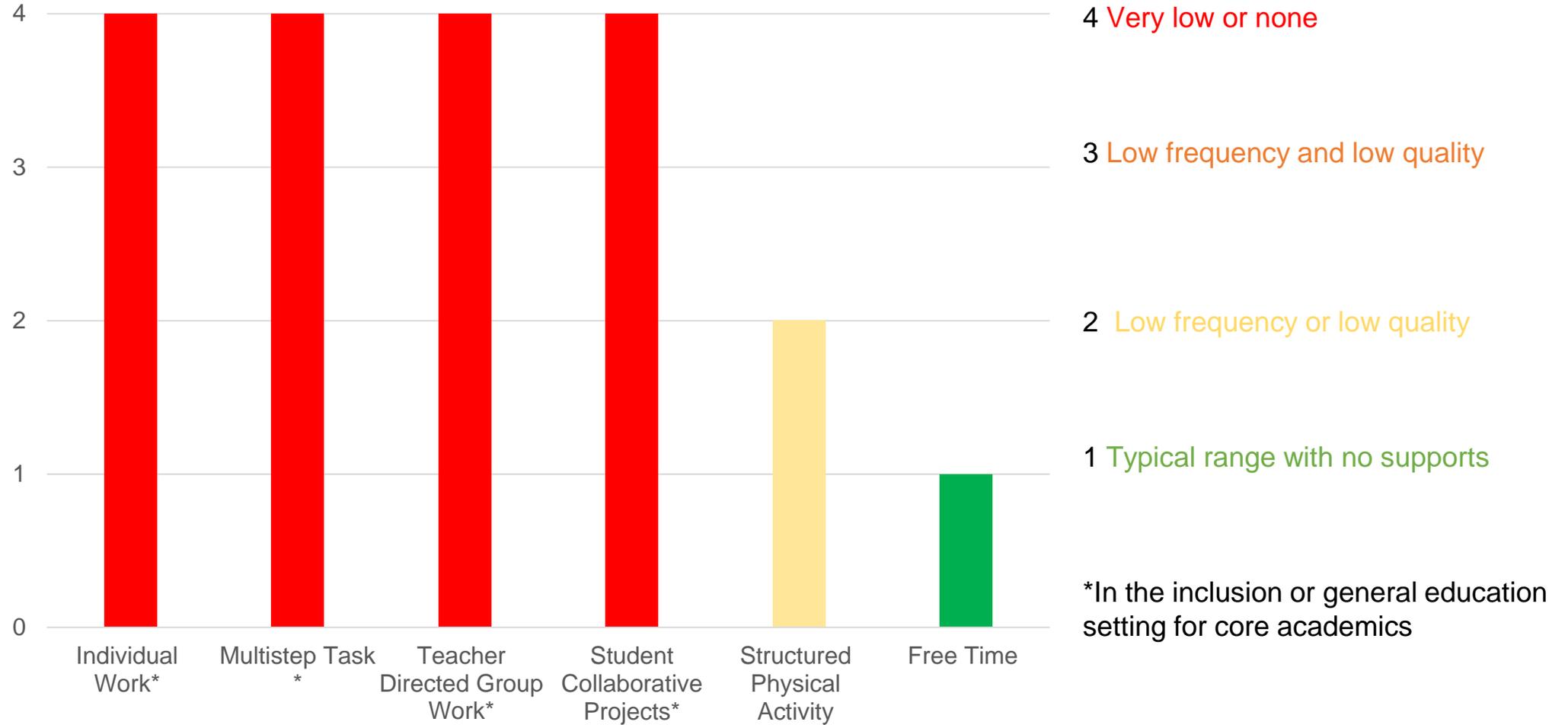- Interacts well with classmates and teachers

EG's Functional Abilities Classification

Cognitive Processes and Academic Skills

4 Expect Significant Modification

3 Expect Continuous Intensive Support

2 Expect Intermittent Support

1 Ability in Typical Range with No Supports

*Math was added, not part of the FACT

EG's Participation Classification

4 Very low or none

3 Low frequency and low quality

2 Low frequency or low quality

1 Typical range with no supports

*In the inclusion or general education setting for core academics

EG's Input

Environmental Supports

Peer Tutoring

Special Education Instructor for support

Environmental Stressors

Classes move too fast

Reading material too difficult

Frequent assignment due date changes

Needs help on most assignments

Virtual learning – cannot follow the lessons

Personal Factors

Prefers small group settings

Check-in person to review schedule, due dates, and assignments

Enjoys acting in Drama class

Discussion with Instructional Team

Summary:

- Academic expectations and current placement in core content classes are beyond her range of learning, limiting her meaningful participation and building of skills

- *Limited meaningful participation in the inclusion classes even with the instructional supports*

- *EG's says she learns better in a small group class*

- *Demonstrates full participation in unstructured and structured non-academic settings with intermittent supports.*

- *Strengths in her skills modulate arousal levels*

- *Interacts well with her classmates and instructors*

- *Motivated*

Adjustments to EG's Educational Program

Setting

- Small group, special education setting for academic classes
- Participation in general education classes for electives with daily special education support
- General education setting for nonacademic and unstructured settings

Program

- Goal is to build her academic skills to use them independently – instruction on her learning level
- Direct intervention/remedial instruction to address deficits in reading and mathematics
- Pre-vocational training
- Continued participation in Drama and other activities where she thrives

Adjustments to EG's Educational Program

Instructional Interventions

- Functional Academics

- Direct instruction to build everyday reading, math, and writing skills

- Training to improve use of problem-solving strategies

Instructional Strategies

- Specific instructional strategies from the University of Kansas Strategic Instruction Model https://sim.ku.edu/learning-strategies

- Errorless Learning http://projectlearnet.org/tutorials/errorless_learning.html

- Edmark Reading – to bypass phonetic decoding, build sight word knowledge and word associations

- Tutoring from a trained learning specialist to remediate reading and mathematical skills

- Assistive technology evaluation

- Multiple accommodations and modifications

Evidenced-Based Interventions

Overview of Some Interventions for Individuals with PAE

Elements of Effective Interventions for Individuals with PAE

Elements of Intervention Planning

- Based upon each child's developmental, cognitive, and/or learning profile

- Target building skills to improve participation, functioning, and quality of living

- Embed specific skill training within a context for application

- Interventions need to be on the individuals' developmental and/or learning level

- Consistent Monitoring

Effective *interventions may be more about the approach, rather than the program.

Ylvisaker et al., 2005; Carmichael Olsen & Sparrow, 2020

Parent Training and Coaching

Authors	Program/Skill	Sample	Treatment	Result
Gurwitch et al. 2009	Parent Child Interaction Therapy (PCIT)	46 Children, ages 3-7	Child and parent therapy to improve relationship, increase use of prosocial skills, reduce defiance, and use positive discipline	Improved child behavioral problems. Decreased parent stress. Overall, no group differences between those who received PCIT and those who received other therapy
Carmichael-Olsen et al (in Bertrand, 2009)	Families Moving Forward	52 US Children, ages 5-11	Positive behavioral support and parent training	Parents reported improved parenting skills and reduced problematic behaviors in their children
Petrenko et al., 2017	Families on Track Integrated Preventative Intervention	30 children with FASD or PAE, ages 4-10	Self-regulation, self-esteem, and anxiety	Improved emotional and behavioral regulation in children, decreased disruptive behavior and anxiety

Links for Programs

Families Moving information may be found at the website
http://familiesmovingforwardprogram.com/

Information about PCIT may be found at www.pcit.org

Arousal Regulation, Attention, and Behavior Interventions for Children with PAE

Authors	Program/Skill	Sample	Treatment	Result
Coles, Kable, Taddeo, & Strickland, 2015	GoFar	30 children, ages 5-10	Metacognitive training using a computer game and direct parent training to improve adaptive functioning	Improved self-regulation, sustained attention, and behavior, and adaptive functioning
Kerns et al., 2010	Computerized Attentional Control Training - CPAT	10 Canadian children, ages 8-15	Attentional control training using a computer game with 1:1 coaching	Improved selective and sustained attention, and spatial working memory. Improvements in reading and mathematics fluency
Riley et a;., 2003	Cognitive Control Therapy	Children 8-9 years	Instruction to improve children's skills to recognize their actions, self-monitor, and reflect	Improved behavioral and adaptive skills reported at school.

Arousal Regulation Interventions for Children with PAE

Authors	Program/Skill	Sample	Treatment	Result
Wells et al., 2012	Alert Program	78 US children, ages 6-11	Self-regulation, attention	Improved executive functioning, problem solving, and emotional regulation
Soh et al., 2015	Alert Program	65 Canadian children, ages 8-12	Self-regulation and attention	Improved scores on the BRIEF and NEPSY-II related to executive functioning. Increased gray matter
Wagner et al., 2017	Alert Program	27 Australian children, k-7th grades	Self-regulation	Modified protocol for aboriginal community. Reported positive feedback

Links for Programs

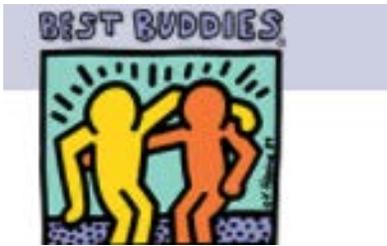GoFAR

Access the computer game and other materials at https://do2learn.com/

Alert Program

Information about the program is https://www.alertprogram.com/

Social and Emotional Skills for Children and Youth with PAE

Authors	Program/Skill	Sample	Treatment	Result
O'Connor et al., 2006; Keli et al., 2010	Social Skills	100 children in US 6-12 years of age	Bruin Buddies (aka. Best Buddies) social skills training (www.bestbuddies.org)	Parent report - improved social skills/reduced problem behaviors; less hostile attributions in social settings
O'Connor et al, 2012	Social Skills	85 children in US 6-12 years of age	Children's Friendship Training	Improved prosocial behavior. Parent report-improved social skills
Keightley et al, 2018 reported in Flannigan et al. 2020	Social and emotional skills	Youth	Intensive theater-based training	Improved self-confidence, peer interactions, social communication
Katz et al., 2020, reported in Flannigan et al, 2020	Emotional and well being	113 School-aged children, 52% identified as having FASD	School-based mental health using the 1. "Brain Unit" mental health literacy program, 2. DBT behavioral skill-building	Intervention group made gains with emotional regulation, interpersonal interactions, tolerating distress and comping

Links for Programs

Best Buddies International https://www.bestbuddies.org/

Children's Friendship Program at UCLA

https://www.semel.ucla.edu/socialskills/research/childrens-friendship-program

Adaptive Functioning and PAE

Authors	Program/Skill	Sample	Treatment	Result
Coles, Strickland, Padgett, & Belmoff, 2011	Fire and street safety	32 children in US 4-10 years of age	Virtual reality game (www.do2learn.com)	Immediate knowledge of street crossing safety and fire safety
Connolly et al., 2016,	Improve adaptive behavior and social communication	1 child, age 3	Applied Behavioral Analysis	Improvements in functional communication skills, adaptive behaviors, parent reported emotional behavioral regulation. Teacher reported increased in rule-breaking
O'Connor et al, 2016	Reduce alcohol consumption in teens with FASD	54 teens in US Mean age 15 years	6-60 minute clinical sessions and caregiving training	Teens in treatment group more likely to refrain from alcohol use

Building Academic Skills for Children with PAE

Authors	Program/Skill	Sample	Treatment	Result
Gryiec et al., 2004	Spelling	7yr. old with FAS	Spelling instruction using "cover, copy, and compare"	Increased number of words spelled correctly
Kable, Coles, Taddeo, 2007; Coles, Kable. Taddeo, 2009; Kable, Coles, Taddeo, and Strickland, 2015	Learning readiness and mathematics	55 US children, ages 3-10	One-on-one mathematics instruction that embedded Focus/plan, Act Reflect. Parent education	Increases in math scores that remained more than 6 months after the intervention. Improvements in behavior and self-regulation
Adnams et al., 2007	Language and Literacy	65 children, 9-10 years with PAE (South Africa)	Intervention to improve phonological awareness, letter knowledge, word recognition, decoding, and spelling	Improvement in the skills trained
Millians & Coles, 2014	Saturday Cognitive Habilitation Program	Case Study, 5 children, 4 with FAS, 1 with ADHD, 10-15 yrs.	12-weeks of one-on-one tutoring in either reading or mathematics. All taught mental management techniques	Increases of at least 1 SD on standardize measure of reading or 4 students. 3 out of 5 showed significant increases of at least 1 SD in nonverbal reasoning

Links to Programs

MILE

For information and the materials, please email
molly.n.millians@emory.edu

do2Learn™

For a variety of learning activities and support for children with FASD and other developmental disabilities,
www.do2learn.com

Interventions Found Effective in Other Disciplines

https://intensiveintervention.org/tools-charts/overview

Examples of Interventions Found Effective for Other Disabilities

Domain	Intervention
Academics	
Handwriting	Handwriting without Tears www.hwtears.com
Expressive Writing	Self-regulated Writing Strategies https://www.thinksrsd.com/
Mathematics	Dyscalculia.org www.dyscalculia.org; Skill Boosters https://mathandteaching.org/
Reading	International Dyslexia Association https://dyslexiaida.org/

Examples of Other Interventions Found Effective for Other Disabilities

Domain	Intervention
Attention, Behavior, Learning	
Attention/Executive Functioning	Harvard Center on Developing Child, Executive Functioning https://developingchild.harvard.edu/science/key-concepts/executive-function
Positive Behavior Interventions	Range of ways to support positive behavior at school https://www.pbis.org/
Learning Strategies	The Strategic Instruction Model University of Kansas https://sim.ku.edu/learning-strategies (including how to self-advocate)

Various Assistive Technology Supports

Information:
http://dyslexiahelp.umich.edu/tools/software-assistive-technology

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Electronic Worksheets

Talking calculators (www.independentliving.com/)

Organizational aids

- Applications such as Evernote (apps)
- Vibrating Watching (watch minder www.watchminder.com)
- Notetaking
  - Smartpens (https://www.livescribe.com/site/livescribe-2/echo/)
  - Graphic Organizers (https://popplet.com/)
- Reusable Notebooks such as Rocketbook

Electronic Readers and Speech to Text

- Readers (https://learningtools.donjohnston.com/product/
- Speech to Text/Voice Recognition. Many computers and devices feature built in
- Audiobooks
  - Learning Ally (https://learningally.org/)
  - National Library Services for he Blind and Print Disabled (information available at https://www.loc.gov/nls/about/eligibility-for-nls-services/talking-books-reading-disabilities/)

Spellers

- Phonetic Spelling Software (https://www.ghotit.com/ghotit-for-kids)

Transition to Adulthood

https://transitionta.org/

Conclusion

- Individuals with PAE are at risk for lifelong challenges

- Often risks are compounded by environmental and other factors

- Interventions need to be based upon what a child can do in relation to participation and functioning. Goals are to build skills, self-determination, and independence

- With appropriate interventions individuals with PAE can lead fulfilling lives