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Navigating the Service System for Children 0-5 with Developmental Delays/Disabilities & Mental Health Needs

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Objectives

Identify	Identify the mental health needs of young children with developmental delays and disabilities.
Explore	Explore a trauma-informed approach to systems navigation.
Examine	Examine barriers encountered by families who have young children with complex needs.

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Vignette

Fernando was born preterm and had complications leading to a 2-month NICU stay.

He's now 26 months old. He lives with his parents, Juana and Rick, and 4-year-old brother. His mother speaks Spanish and his father is bilingual in Spanish and English.

Fernando has language delays and is receiving early intervention services. In our observation, Fernando is playing with his mother, Juana. He is trying to initiate talking with her. She responds with smiles and gestures but no words. Fernando seems frustrated and withdraws to play by himself.

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Intersection of developmental delay/disability and mental health

- Many children who have developmental delays have also experienced . . .
  - Early medical adversities (e.g. NICU stay)
  - Disrupted attachment during hospitalization
  - Social-emotional and behavioral challenges
- Infant and early childhood mental health is the developing capacity of the young child to form close relationships, manage and express emotions, and explore the environment and learn (ZERO TO THREE).

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Psychological Tasks of Early Childhood

- Handle sensory input
- Get attached to an adult
- Learn to handle big feelings
- Communicate and get needs met
- Adapt to a changing world

Stroud, B. (2012). *How to measure a relationship: A practical approach to dyadic interventions.*

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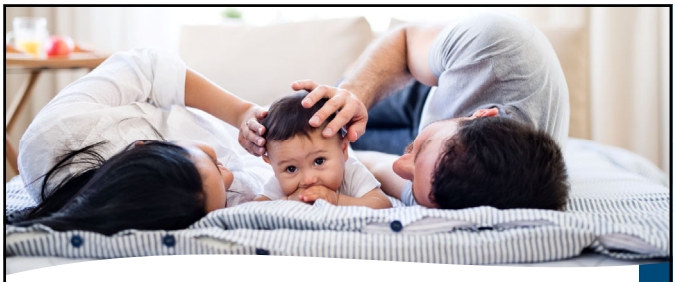

How do infants and young children achieve these tasks and develop?

It all happens in the context of relationships…

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How common are mental health disorders in children with developmental delay?

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Research on Autism Spectrum Disorder and Mental Health Symptoms

Toddlers aged 17 – 36 months with ASD

Higher rates of:

- tantrums
- inattention/impulsivity
- anxiety
- eating problems
- sleep problems

Matson et al (2010)

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Prevalence of Trauma in Children with DD

- 18 - 20%: child abuse
- 14 - 17%: sexual abuse
- 18%: emotional abuse
- 10%: neglect
- 30%: bullied
- Many have a history of pediatric medical traumatic stress

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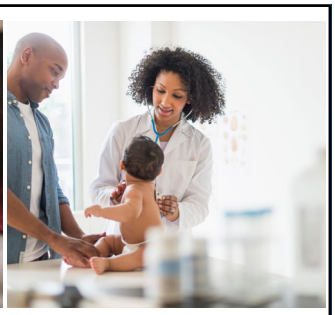

Supporting Social-Emotional Development: Recognizing Impact of Trauma

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Understanding Behaviors: Trauma Triggers

- Trauma related to medical or therapeutic interventions
- Even in young or nonverbal child, the body remembers
- Examples of trauma triggers related to medical trauma
  - Type of room or building
  - Smells, sounds
  - Person in white coat or with stethoscope around neck
  - Sensing parent's anxiety
  - Seeing or hearing other distressed children
  - Feeling pain or discomfort
- Can lead to dysregulated behavior without a clear behavioral trigger or function

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How does stress alter the course of development?

- Infants' brains react to stress, even during sleep. There is no such thing as "too young" to be affected
- Exposure to trauma in the first 2 years affects brain development. Young children are uniquely vulnerable.
- Level of development changes the impact of stress
- Developmental disabilities change the impact of stress
- Supportive relationships buffer the impact of toxic stress

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Developmental Capacity Changes Impact of Stress

- Developmental level of child
  - Chronological age
  - Social emotional history
  - Biological vulnerability to stress
  - Ability to create a verbal narrative

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Developmental Capacity Changes Impact of Stress

- 4-year-old child's parents separate and his father moves out of state. The child talks about his father, draws pictures about him, and looks at a book they used to read together.

versus

- 12-month-old child's parents separate and his father moves out of state. The child searches for his father, cries more, has less pleasure in activities, pushes his mother away.

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Prior Traumatic Experience Changes Impact of Stress

- Neonatal intensive care unit or other inpatient stay
- Painful medical procedures
- Separation from parent when in pain
- Intrusive procedures in mouth

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Prior Traumatic Experience Changes Impact of Stress

- 18-month-old child with history of hospitalizations and tubes down her throat has routine medical exam; physician puts tongue depressor in her mouth. The child cries loudly, clings to mother, hits doctor.

versus

- 18-month-old child with no history of medical trauma has routine medical exam. The child allows physician to examine her, laughs with nurse, accepts comfort from mother after vaccination.

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Developmental Disability Changes Impact of Stress

- Mobility challenges
- Communication difficulties
- History of procedures/therapies
- History of being "done to" rather than feeling in control

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Developmental Disability Changes Impact of Stress

- 2-year-old child with cerebral palsy and intellectual disability starts in new childcare setting. Child has difficulty maneuvering around room and communicating with peers; he sits alone, missing his mother.

versus

- 2-year-old typically developing child starts in new childcare setting. He has difficulty separating from mother at first, but gets distracted by running and playing in new space and approaching peers.

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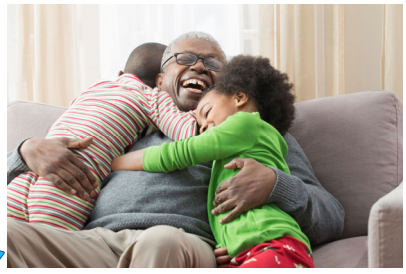
Caregivers can Provide a Protective Buffer

- Help child understand/make meaning
- Help child cope with the stressor



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Caregivers can Buffer

- 12-mo-old child bitten by dog while walking with his father. His father comforts him, takes him to the doctor, and stays with him while he gets medical care. Later he talks to him about different kinds of dogs, shows him books about dogs, helps him visit a friend's small dog where he stays with him while they pet and play with the dog.

versus

- 12-mo-old child bitten by dog while walking with his father. His father begins screaming at and threatening the owner. He takes his son to the doctor and stays in the waiting room while the nurse takes the boy into the examining room. Later, his father makes fun of him when he shows fear of a dog in the street.

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What is "trauma-informed care"?

According to SAMHSA's concept of a trauma-informed approach, "A program, organization, or system that is trauma-informed

- *Realizes* the widespread impact of trauma and understands potential paths for recovery;
- *Recognizes* the signs and symptoms of trauma in clients, families, staff, and others involved with the system;
- *Responds* by fully integrating knowledge about trauma into policies, procedures, and practices; and
- Seeks to actively resist *re-traumatization*."

- http://gucchdtacenter.georgetown.edu/TraumaInformedCare/

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Principles of Trauma Informed Care

1. Safety
   Clients and staff alike feel physically and psychologically safe
2. Trustworthiness and transparency
   Decisions are made with transparency to build and maintain trust among clients, families and staff
3. Peer support
   Mutual self-help is a key to building safety, trust, and hope

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Principles of Trauma Informed Care (cont'd)

4. Collaboration and mutuality
   The leveling of power differentials between clients, professionals, support staff and the recognition that everyone has a role in healing
5. Empowerment, voice and choice
   Reflects a belief in the resiliency and ability to recover for clients and families exposed to trauma.
6. Cultural, historic and gender issues
   Moves past stereotypes and recognizes ways clients have historically been denied a voice. Respects individual cultural values of clients and families

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Applying Trauma-Informed Care

- Encounters with:
  - children and families in healthcare settings
  - children and families in early intervention and education
  - parents involved with the child welfare system
  - providers in community-based organizations
  - policy makers
- Instead of asking, "What is **wrong** with this child and family" ask "What **has happened** to this child and family?"

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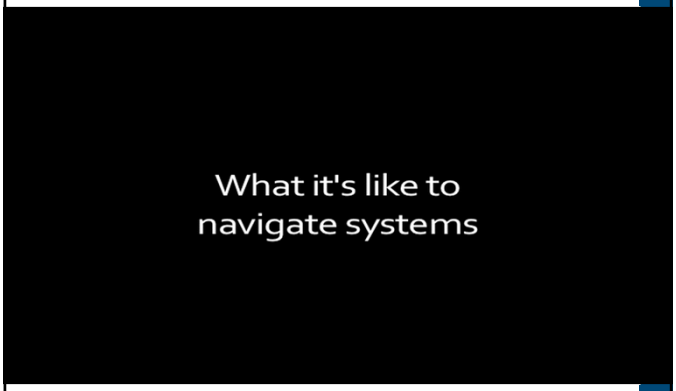

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Trauma-Informed Healthcare Encounters

- Assess and help with **Distress**
  - Assess pain; fears and worries; grief or loss
  - Provide child and parents with as much control as possible
  - Actively assess and treat pain
  - Listen to how the parent understands what is happening
  - Clarify any misconceptions
  - Provide reassurance and realistic hope
  - Pay attention to grief and loss

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Trauma-Informed Healthcare Encounters (cont'd)

- Assess and help with **Emotional Support**
  - Assess what the child needs to help cope; who is available to help; how can existing supports be mobilized?
  - Encourage parent presence
  - Empower parents to comfort and help their child
  - Encourage social support and involvement in "normal" activities

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Trauma-Informed Healthcare Encounters (cont'd)

- Assess and help with **Family**
  - Assess parents' or siblings' distress; gauge family stressors and resources; address other needs, beyond medical
  - Encourage parents' basic self-care
  - Remember family members' emotional needs
  - Be sensitive to resource needs of family

National Child Traumatic Stress Network: Pediatric Medical Traumatic Stress Toolkit

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Every Encounter Can Be Therapeutic

- Examples, 12-month-old with dog bite:
  - He is greeted by name by everyone from the front desk to the medical provider. The PCP introduces herself to the family and examines his injuries while he is sitting in his father's lap. She checks in about both physical injuries and emotional distress. Before cleaning his wound, she explains what she is going to do, and asks his father what will help him feel calm. She tells father and child her impressions and what to expect in simple, child-friendly language.

    versus
  - Nobody looks at or talks to him at the clinic, they just get basic information from his father. The PCP greets them by telling his father to place the child on the exam table. She responds to his resistance firmly and calls an assistant into the room to hold him still so she can examine and clean his wound. She snaps off her gloves and says "check in at the window on your way out" before leaving the room to see her next patient.

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Trauma-informed Early Care and Education

- Center for Early Childhood Mental Health Consultation Tutorial 7: *Recognizing and Addressing Trauma in Infants, Young*
  - Interactive, free on-line tutorial designed for Head Start and Early Head Start (takes about 30 – 40 minutes)

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Child Care and Education Provider Encounters

- Examples, 3-year-old boy with history of frequent hospitalizations; in first week of preschool
  - When it's time for his mother to say goodbye, his teacher helps his mother to tell him she is leaving and will be back to pick him up after school. When he looks scared, she encourages his mother to give him a hug and say goodbye, and helps another child to invite him to join in her building activity. When his mother picks him up at the end of the day, the preschool teacher shares several positive behaviors she observed during the day.

    versus
  - When it's time for his mother to say goodbye, his teacher encourages her to "sneak out" so that he will not be upset by her leaving. When he realizes she is gone and cries, his teacher encourages him to be a "big boy."

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How does your agency support trauma-informed care?

Talk to the person in your breakout room about:

1. A positive example of trauma-informed care within your organization, or in an encounter you had with another service system

AND/OR

2. An idea for a change in your own agency that could improve trauma-informed approach

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Collaborating with Systems and Teams to Promote Trauma-Informed and Culturally-Sensitive Care for Families

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Promoting Trauma-informed Medical Care

- Fernando has never had a dental exam . . .
- Challenges contributing . . .
  - No dental insurance
  - Parents not aware that dental care is recommended for young children
  - No medical home, so did not come up in doctor's visits
  - History of painful medical procedures in the mouth; now he resists toothbrushing

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Promoting Trauma-informed Medical Care

- Children's Hospital Los Angeles partnered with occupational therapy researchers at USC to develop a **sensory-adapted dental environment**.
  - Lighting directed to mouth and avoiding eyes
  - Soothing music and a light pattern on ceiling
  - Butterfly weighted vest made of X-ray vest material
- Education about impact of prior pediatric medical traumatic stress on current sensitivity in the mouth
  - Gradual exposure at home with Fernando having control and choices

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Promoting Trauma-Informed and Culturally-Sensitive Early Intervention

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Equity Issues in Access to Care

- Families must go to the regional center in their geographic area
- There are disparities in amount of services provided at different regional centers and to consumers from different racial and ethnic groups
- Each regional center is now required to post "POS" (point of service) data for the public on their website

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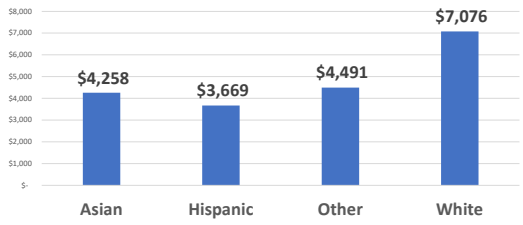
San Diego Reg Ctr Per Capita Authorized Expenses 2019-2020 (age 0-2)



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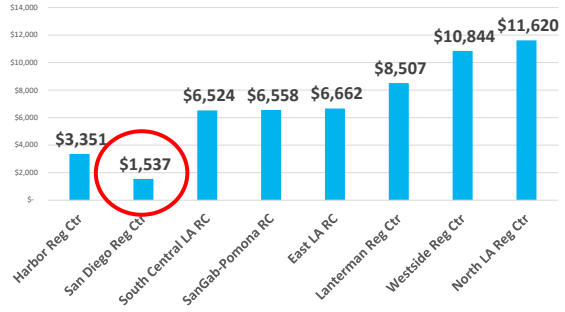
Autism Expenditures Per Capita 2019-2020 (Ages 3-21)



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Advocating to Reduce Disparities in Access to Services

- Each Regional Center must hold a public meeting annually to discuss disparities
- Encourage parents to testify
- Share your own experiences

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Addressing Challenges re Different Regional Centers

- Encourage parents to ask for information about what services are available
- Parents should focus more on what child *needs* in the community and at home and ask how regional center can help with those needs
- Same service has different names
- Encourage parents to talk to other parents or advocates about what services are available

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Promoting Trauma-Informed Care in Early Intervention

- Refer for mental health consultation
- Consider in treatment planning
  - Impact of prior trauma on child's functioning
  - How can the family be incorporated into service delivery
- Consider socio-cultural influences on development and relationships

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More about Fernando . . .

- Recall that in the observation, Juana was interacting with Fernando nonverbally and not using words.
- Juana explains that she has been counselled by a professional to speak only English to her child, because his speech is delayed. Juana speaks fluently in Spanish but has limited English skills. So she has stopped talking to Fernando, worried that she will interfere with his language development. Rick gets upset with Juana if he hears her speaking in Spanish to Fernando. He wants his son to have the best opportunities and he reminds her what the professional said.

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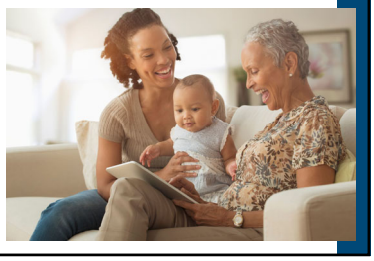
The live human presence is critical to language learning

- Attention and arousal = **motivation**
- Live humans combine speech with eye gaze
- Joint attention
- Reciprocal interactions



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Adults are Language Models

- Parents and caregivers provide a more rich language model when speaking their home language
- People using their home language speak with more heightened affect/emotion which stimulates children's learning

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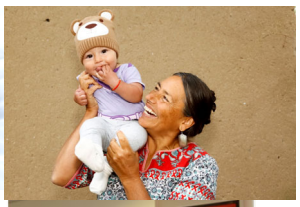
Home Language Contains Culture

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Home Language Contains Culture

- Language is the medium for children to learn about the values, beliefs, and norms of their family culture
- Parent-child attachment is linked to language and communication
- Language connects children to extended family members
- Loss of home language especially likely when the home language is a minority language in the culture

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Myths and Facts About Bilingualism

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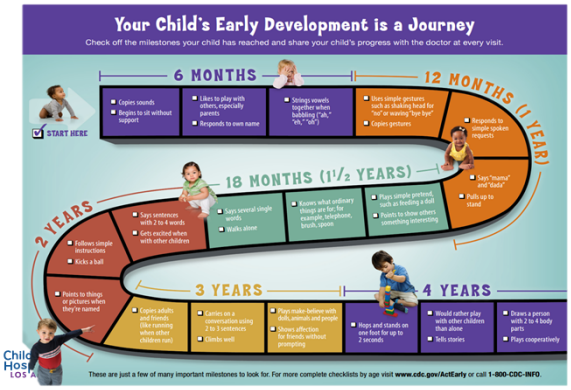
Myth 1: Bilingual Children's Language Will be Delayed



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Fact

- Classic study showed that language milestones are the same for bilingual and monolingual children
  - 25 Spanish-English bilinguals and 35 from monolingual homes
  - Language milestones were tracked from ages age 8 to 30 months
  - Combining vocabulary in both languages, bilinguals had same vocabulary as monolinguals

- Pearson, Fernandez, & Oller (1993). Lexical development in bilingual infants and toddlers: Comparison to monolingual norms. *Language Learning, 43,* 93-120.

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Fact: Bilingual Children Develop Language at the Same Rate as Monolingual

- Many studies have now shown bilingual children reach milestones at the same rate:
  - Babbling
  - First words by 12 – 13 months
  - Range of nouns, verbs, prepositions, etc
  - Two-word combinations between 18 and 24 months
- If a bilingual child is not reaching typical milestones—seek help! It's not because he or she is being exposed to 2 languages.

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Fact: The second language may take time to become as strong as the first

- Sequential bilinguals will initially have stronger skills in their first language
- If assessed in their second language they may seem "delayed"
- To determine if delayed, need to assess in first language and combine words from both languages

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Myth 2: Children are Confused by Exposure to Two Languages

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Facts

- Some children may show cross-linguistic influence: rules from the more dominant language may get applied incorrectly in the less dominant language
  - This is a typical part of bilingual language development
- Children don't have difficulty distinguishing between the two languages
- Children are good at figuring out when/with whom they should use which language

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Facts

- Children feel confused when their parents change their language use
  - Parent stops speaking in the home language to the child after concern about language delay is raised
  - Family members stop conversation when child comes in the room to avoid exposing him to the "wrong" language

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Myth 3: Reducing to English will Increase Children's Chances for Success in School and Life

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Reducing to English: Facts

- Learning one language well helps children learn other languages
- Learning to read in the home language helps children learn to read in English
- Children need the best language models: rich vocabulary, grammatical structure

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Reducing to English: Facts

- Parents should speak to their children in the language most comfortable for the parent
  - They will speak with correct grammar
  - use a wider range of vocabulary
  - enable their children to be part of family conversations
  - help children learn from overheard conversations as well as when spoken to directly

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Myth 4: Children with Developmental Delays Will Have More Delays if Exposed to Two Languages

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Facts: Bilingual Language Development in Children with DD/ASD

- Studies have compared children with disabilities from monolingual and bilingual homes to determine if there is a difference in language acquisition
- Important to test children in their dominant language or in both languages if bilingual

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Children with Down Syndrome

- Study of children with Down Syndrome being raised in bilingual (English-French) vs monolingual homes in Canada
- Ages 2 ½ to 8 years
- No difference in language abilities for the two groups—bilingual children had equally developed skills as monolingual children

- Kay-Raining Bird et al. (2005). The language abilities of bilingual children with Down syndrome. *American Journal of Speech-Language Pathology, 14,* 187-199.

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Children with Autism Spectrum Disorders

- Study of children with ASD from bilingual (n = 45) and monolingual (n = 30) environments
- Ages 3 to 6 ½ years
- No differences in language skills between the two groups

Hambly, C. & Fombonne, E. (2012). The impact of bilingual environments on language development in children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders, 42,* 1342-1352.

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Children with Specific Language Impairment (SLI)

- Studies of bilingual and monolingual children with SLI
- No differences in grammatical morphology (such as use of verb tenses) between the two groups
- Children with SLI were able to become bilingual when a second language was added

Based on research by Paradis and colleagues (French-English bilingual children) and by Gutierrez-Clellen and colleagues (Spanish-English bilingual children)

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Professional Messages to Parents About Bilingualism

- Research literature suggests that many parents are counseled to speak only English to their children, especially if the child has a language delay or autism spectrum disorder.
- In our study, 7% of parents said they had been advised by a physician or teacher not to raise their child to be bilingual
- 12% - 15% of professionals thought that bilingual children would have more delays

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Consequences of Discouraging Bilingualism

- Loss of home language especially likely when the home language is a minority language in the culture
- Parents provide a more rich language model when speaking their home language
- Confusion happens when parents suddenly try to switch to English based on professional advice
- Parents using their home language speak with more heightened affect/emotion which stimulates children's learning

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Consequences of Discouraging Bilingualism

- Culture is embedded in language—language is the medium for children to learn about the values, beliefs, and norms of their family culture
- Parent-child attachment is linked to language and communication
- Children become disconnected from extended family members

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Celebrate Bilingualism

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Supporting the Home Language in Children with Delays & Disabilities

- Encourage parents to speak to their children in the language in which they are most comfortable—even if the child has delays
- Provide bilingual intervention when possible
- If SLP or other professionals do not speak the home language . . .

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Supporting the Home Language for Monolingual Professionals

- Train parents and paraprofessionals as partners in intervention
- Consider peer- or sibling-mediated intervention strategies
- Remember that speech-language therapy provided in the school language will also help with language use at home

Kohnert et al (2005) *Intervention with linguistically diverse preschool children.*

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Recommendations for Parents

- Option 1: Use the language that you are most comfortable in at home. Your child can learn the second language when he or she starts school.
- Option 2: Use two languages from the start. If there are people living in the home who speak different languages, your child can be exposed to more than one language and will learn to distinguish them.

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Recommendations for Parents

- Give your child many opportunities to hear and practice using both languages in everyday situations.
- Tell stories and sing songs; share books
- Talk about your traditions and cultures
- Make sure interactions in home language are varied and fun, and not just giving instructions

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Let's go back to Fernando and his mom and dad . . .

- Fernando, age 2 ½, is playing with his mother, Juana. He is trying to initiate talking with her. She responds with smiles and gestures but no words. Fernando seems frustrated and withdraws to play by himself.
- Juana has been counseled by a professional to speak only English to her child, because his speech is delayed. Juana speaks fluently in Spanish but has very limited English skills. So she has stopped talking to Fernando, worried that she will interfere with his language development. Rick gets upset with Juana if he hears her speaking in Spanish to Fernando. He wants his son to have the best opportunities and he reminds her what the professional said.

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Link to Social-Emotional Development

- How might Fernando's social-emotional development and attachment be influenced by his parents following the advice of the professional?

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Practice Talking to Juana and Rick

- Pair up:
  - One person is Juana (Fernando's mom) or Rick (Fernando's dad)
  - The other person is an early childhood provider (or neighbor)
- Juana or Rick asks for your opinion about speaking Spanish to Fernando.

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Resources on Bilingualism

- American Speech-Language-Hearing Association website: www.asha.org
  - The Advantages of Being Bilingual
  - Teaching Your Child Two Languages
  - Becoming Bilingual/El Nino Bilingue
- Paradis, J., Genesee, F. & Crago, M. B. (2010). *Dual Language Development and Disorders: A Handbook on Bilingualism and Second Language Learning*, 2nd Edition.

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Resources on Bilingualism

- Head Start materials: The Importance of Home Language series
- https://eclkc.ohs.acf.hhs.gov/culture-language/article/importance-home-language-series

Bilingualism: Frequently Asked Questions www.literacytrust.org.uk

- Center for Applied Linguistics
- Wharton, Robert H., Levine, Karen, Miller, E., Breslau, Joshua, & Greenspan, Stanley (2000). Children with special needs in bilingual families: A developmental approach to language recommendations. *ICDL Clinical Practice Guidelines*. The Unicorn Children's Foundation: ICDL Press, Pp 141-151.

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Thank you!

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