



Booster Session 1: IMH-HV with Parents and Children with Disabilities

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Today's Agenda

- Welcome and Introductions
- Group Activity
- Disability, ableism, intersectionality, and supporting parents with ID/DD
- Supporting families with children with developmental delays and special needs
- Reflection on IMH-HV treatment—the “Davis” family
 - Watch family assessment and treatment videos/interviews
 - Small group and large group discussion activity
- Resources for working with families
- Wrap up/Q&A/Evaluation



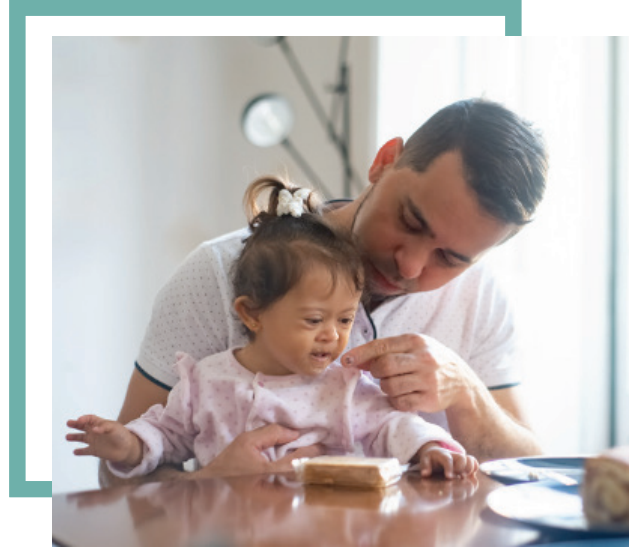
Wet Paint Story



Group Activity

Introduce yourself

- Name, agency
- When you participated in IMH-HV training
- Since training, share any job changes or 1 thing you are excited about in your work
- One thing you hope to learn or get out of today's booster



Disability, Ableism, & Intersectionality

Checking bias

Framework

Curb Cuts

**Does anyone know what the
“Curb Cut” effect is?**

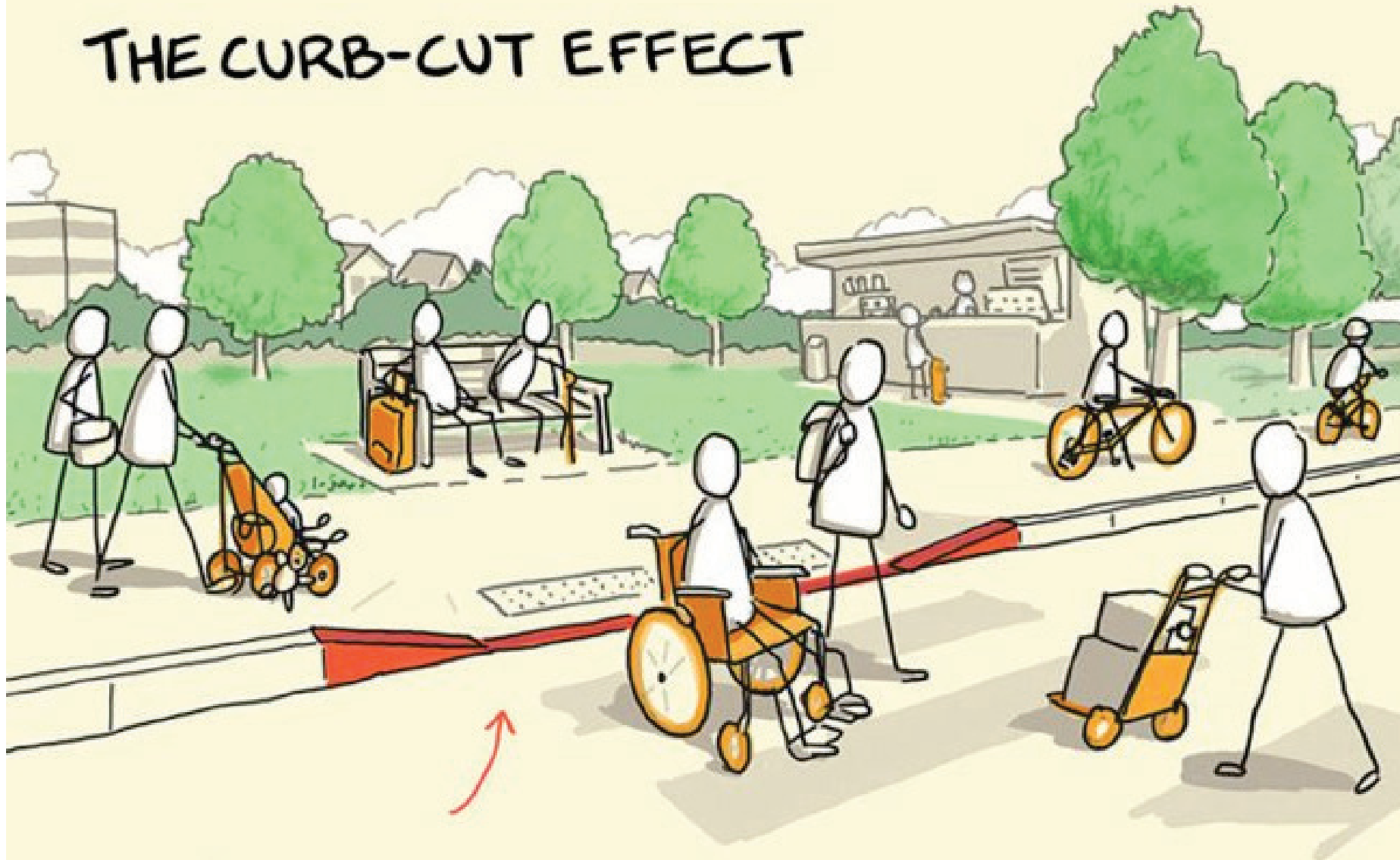
The “Curb Cut” effect

- How sidewalk ramps (“curb cuts”) were installed to make communities more accessible for wheelchair users (Angela Glover Blackwell)
 - Tremendous activism
 - ADA compliance
- became universal because of the tremendous value (including safety and ease) for all people



Photo from San Francisco Chronicle

THE CURB-CUT EFFECT



What are
some other
examples
of this?

WHEN WE DESIGN
FOR DISABILITIES

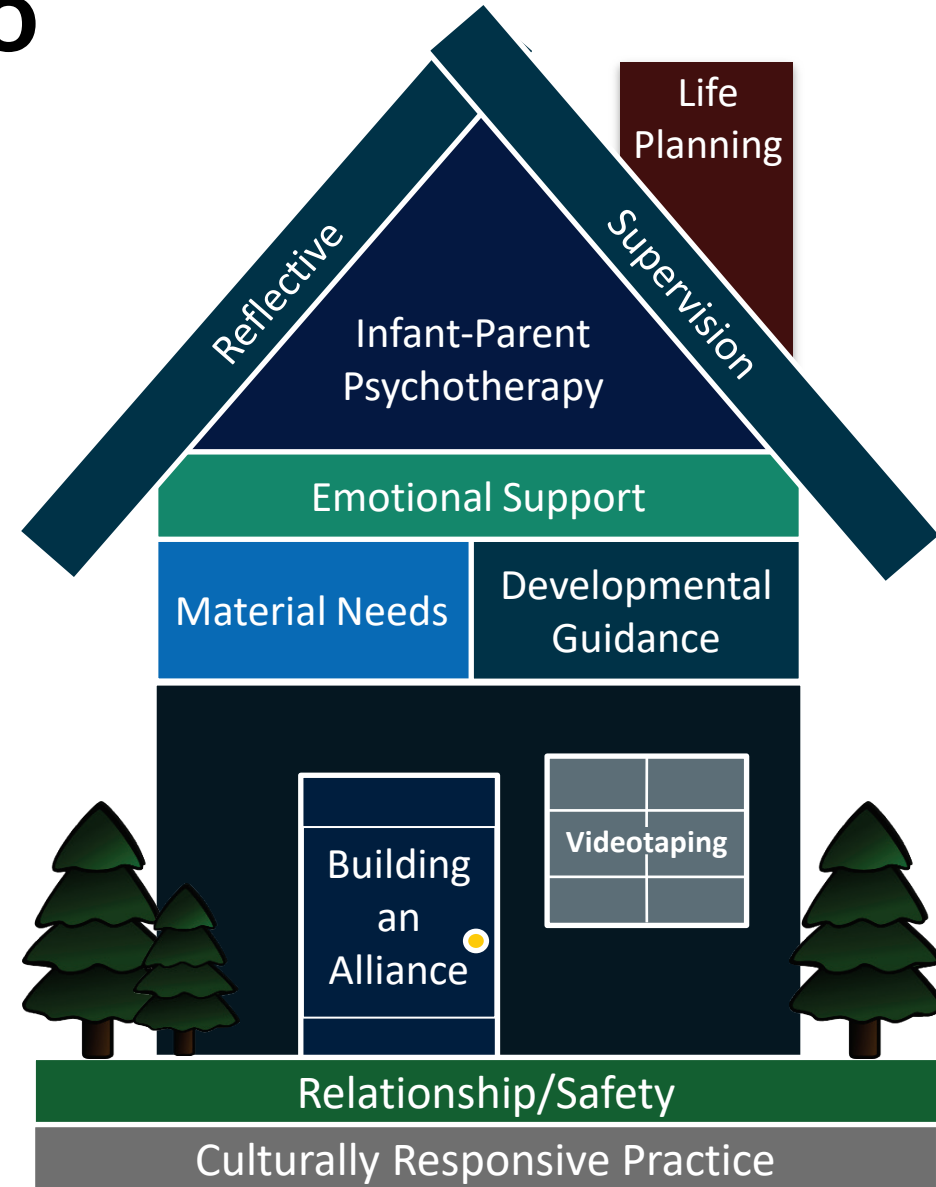
... WE MAKE THINGS
BETTER FOR EVERYONE

Disability and Intersectionality

- Intersectionality is often primarily focused on race and gender, and disability as a category of identity is frequently overlooked
- Yet disability is also socially constructed and is often kept “separate” from these discussions
- People with disabilities have noted that their other identities may not be recognized by others
- Attention to structural and systemic racism and bias is critical, as these have important implications of health equity (e.g., whether a child is seen as “oppositional” vs having a developmental delay is related to child race and gender)

How is this relevant to IMH-HV?

- Culturally Responsive Practice
- Building an Alliance
- Material Needs
- Developmental Guidance
- Emotional Support
- Infant-Parent Psychotherapy
- Life Course Planning
- Reflective Supervision
- Videotaping



Two Perspectives Relevant to IMH-HV

1. Work with parents/caregivers who experience ID/DD
 2. Work with infants and young children who experience ID/DD
- Potential for both/and,
 - though note that just because a parent has an intellectual disability or other disability does not mean that their child necessarily will

How is this relevant to IMH-HV?

- Who do we serve in IMH-HV?
- How do we serve families with varying identities, abilities, needs?
- Accessibility for one group can increase accessibility for all

Working with Parents with ID/DD

Who are parents with Intellectual Disabilities/Developmental Disabilities

An intellectual disability (ID):

- Occurs before 18 years of age
- Characterized by significant limitations in intellectual functioning and adaptive behavior in cognitive/conceptual, social, and adaptive (practical) skills

Mild cognitive limitation describes individuals who:

- May have been diagnosed at some time in their lives.
- Lower than average learning, communication, judgment and understanding abilities
- Eligibility for service varies from state to state

Challenges Faced

- Parents with ID/DD are more likely to experience scrutiny and monitoring by CPS or other mandated reporters, elevating the likelihood that their children may be removed
- Indeed, parental rights more likely to be terminated simply because of ID
- Of note-- this may happen without a meaningful assessment of parenting capacity, ability, or possibility of success in parenting with appropriate supports
- Parents with ID/DD may have lower level of social support and reduced access to opportunities for community connection

Challenges Faced Cont'd

- Despite challenges faced (including ableism, discrimination, and structural/environmental challenges) -- people with ID/DD can be good parents
- Adequate capacity to provide nurturing, responsive relationships and safe care *cannot be determined on basis of intelligence alone*
- Factors that predict adequate care in context of ID/DD include modifiable factors such as:
 - support from service providers,
 - good physical and/or mental health,
 - low financial strain,
 - low stress,
 - Education





Association with Child Outcomes

Protective factors: ***RELATIONSHIPS***

- Parent personality (eg outgoing, responsive)
- Family warmth, mutuality and stability
- External supports (eg supportive relationships outside home, involvement in wider community)

Continued: Association with Child Outcomes

- Study of 30 adults brought up in a family headed by a parent or parents with ID (Booth & Booth, 1997)
 - Half had ID as well (meaning half did not)
 - Results indicated that children's destinies are not determined by parent ID
 - Experiences they reported were similar to others in their communities.
 - Little support for concern that they may bear responsibility for parenting their parents

What are Strategies for Effective Support?

- Seeing a whole person, not defined by disability
- Responding to the individual's specific and unique, needs
- Attending to entire family –attention to child, parent, and family
- Seeing support from a “long term” perspective– as children grow and mature, new developmental challenges unfold and needs also change
- Focusing on helping parents establish meaningful connections with others, including other parent with disabilities
- Considering how the experience of, or the disability itself, may also be a source of strength and resilience

Supports

- Developmental guidance
- Adaptations to training curricula to make it accessible
- Help with life course planning– money management, school/training
- Coordination of services
- Childcare
- Physical and Mental Health care and support for substance abuse and additions
- Transportation
- Playgroups
- Crisis intervention/support
- Advocacy/self-advocacy

How does IMH deliver these supports?

- In home– opportunities for modeling, observation of home environment and family interactions, and skills building
 - More targeted support for specific needs, eg nutrition, cleanliness, safety issues, parent-child interaction
- Case management
- Parenting groups/Cafés
- Center based programs
- Shared parenting (eg parent and child live in foster care)

Disability experiences have meaning

- These can show up as important aspects of infant-parent psychotherapy
- Can you imagine (or have you witnessed) how this might show up in your IMH-HV work with a family?

Example from a handout: Advice for Expecting Parents

"Some mothers have intellectual disabilities. Having an ID means it is harder to learn and understand things. But everyone can still learn new things. Sometimes it just takes longer. Having an ID can also mean it is hard to do some things by yourself, so you may need extra help. Mothers with ID can still be good parents and raise their children."

Facts about parents with ID:

- Just because you have ID does not mean your child will
- Having ID does not mean you are a bad parent. You can be a good parent.
- Parents with ID sometimes have a hard time getting healthy food. They may also deal with stress and worry.
- Raising children without help can be hard. So it is important to look for help at the beginning, even before your baby is born.
- People with ID may need help understanding pregnancy and childbirth.

What stands out to you in that text?

- Anything you saw as a strength?
- Anything a concern?
- Anything you would add?



Advice Regarding Pregnancy and Childbirth

It is important to ask for help. Everyone needs help when they are getting ready to have children. There are some kinds of help you can ask for while you are pregnant:

- Extra time when you are visiting the doctor. This will help the doctor explain things to you about your pregnancy. Ask your doctor lots of questions, and ask them again until you understand the answers!
- Advice in clear, plain language to help you understand what it is like to give birth or to raise a child
- Tools to make parenting and childbirth easier. An example might be an app for your phone to track your pregnancy. You can share information from the app with your doctor
- Community support. Reach out to other parents with ID to see what they did when they were pregnant or raising children.

Advice for Raising Children

- If you are having a hard time helping with homework, ask your child's school for tutors. You could also ask your partner or friends for help.
- You can talk to other people about how to make rules for your children. Lots of parents- with and without disabilities- have a hard time making rules for their kids.
- Talk to other parents with and without disabilities to see what they have done well to raise their kids. You can find parenting groups in person or connect online.

Legal advocacy

- IT IS IMPORTANT TO KNOW YOUR RIGHTS.
- Sometimes child welfare will try to take your child away from you just because you have an ID.
- Connect to people who can help your know your rights



Reflections

Working with Infant/Child DD

Working with Infants with Developmental Disabilities

How do kids with DD show up in IMH-HV?

Share your experiences-put in chat or share out



What are Developmental and Intellectual Disabilities

- Intellectual and developmental disabilities is an umbrella term that refers to intellectual disabilities and also other disabilities that are apparent during childhood.
- Developmental disabilities appear before early adulthood and are likely to impact an individual across the life span. Some developmental disabilities are largely physical conditions, such as cerebral palsy or epilepsy.
- Some children may have co-occurring physical and intellectual disabilities, for example, Down syndrome or fetal alcohol syndrome.
- An intellectual disability is one type of developmental disability that impacts intellectual functioning, often thought of as “intelligence,” and adaptive behavior, or how a person functions in everyday life.
- Intellectual functioning generally refers to mental abilities such as learning, reasoning, and problem solving. Adaptive behavior relates to the social and life skills that we use in our everyday lives, such as language, time, money management, self-direction, the ability to follow rules, personal care, schedules and routines, safety, occupational skills, and much more.

Infants and toddlers with DD

- Often, changes in behavior that may be symptoms of trauma can be mistakenly attributed to a child's disability.
- Children with DD are more often exposed to repeated medical procedures and hospitalizations. These may entail pain, stress, and fear.
- Children with DD often have multiple caregivers (home-care workers, residential staff, family members, and school staff, among others), some of whom may exploit them and cause repeated trauma with long-term consequences.
- Simply being viewed as different may increase the risk for trauma
- <https://www.nctsn.org/resources/children-with-intellectual-and-developmental-disabilities-can-experience-traumatic-stress-for-parents-and-caregivers>



Children with Medical Issues

May experience DD as a result of medical events: Charlie's Story

May experience DD in addition to serious medical issues: Brad's story

How Families Come to Us

Who is concerned? Parents?
Grandparents? CPS? Pediatricians?

How do we support caregivers
during the process of assessment?



Some Advice and Guidelines from Parents

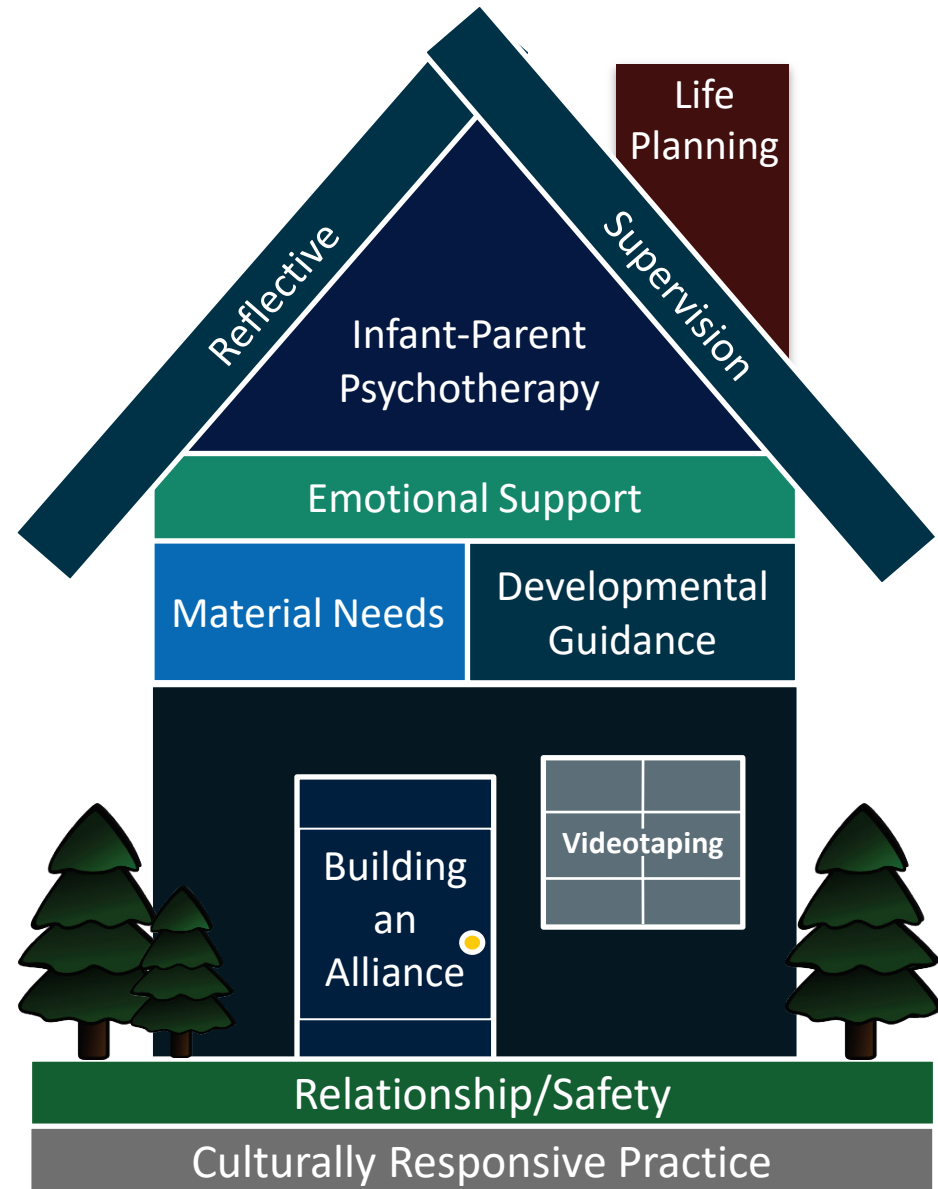
- Most parents did not choose to know you under these circumstances, ie., having a child with DD
- Parents may find it difficult to welcome you: accepting your help and support demands that parents acknowledge that something with a baby isn't going well.
- Parents may appear to be in "denial"
- OR Grieving, angry, with reminders all around them that their infant may not "look" like other children

Advice on how to partner with parents

- Explore hopes and dreams
- Fears
- Include the parents' story along with supporting their baby's story
- Patience

How is this relevant to IMH-HV?

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IMH Components

- Which components are most relevant and why?
- Supports to parents within Early On systems
- Supports to parents within medical system
- Infant-parent psychotherapy: exploring what disability means to parent: ghosts and angels, grief, joys
- Connecting parents to peer support

Advice to Professionals Who Must "Conference Cases"

by Janice Fialka

- Before the case conference, I looked at my almost five-year-old son and saw a golden-haired boy who giggled at his baby sister's attempt to clap her hands, who charmed adults by his spontaneous hugs, who played "peace marches"
- and who, at the age of four, went to the Detroit Public Library requesting a book on Martin Luther King.
- After the case conference, I looked at my almost five-year-old son. He seemed to have lost his golden hair.
- I saw only words plastered on his face Words that drowned me in fear
- primary expressive speech and language disorder, severe visual motor delay sensory integration dysfunction fine and gross motor delay developmental dyspraxia and RITALIN now.
- I want my son back. That's all. I want him back now. Then I'll get on with my life.
- If you could see my worry, feel my ache then you would return my almost five-year-old son who sparkles in sunlight, despite his faulty neurons.

Continued

- I want my son back. That's all. I want him back now. Then I'll get on with my life.
- If you could see my worry, feel my ache then you would return my almost five-year-old son who sparkles in sunlight, despite his faulty neurons.
- Please give me back my son undamaged untouched by your labels, test results, descriptions and categories.
- If you can't, if you truly cannot give me back my son. Then just be with us quietly, gently, softly.
- Sit with us and create a stillness known only in small, empty chapels at sundown.
- Be there with us as our witness and friend. Please do not give me advice, suggestions, comparisons or another appointment. (That's for later.)
- I want only a quiet shoulder upon which to rest my head. If you cannot give me back my sweet dream then comfort me through this evening.
- Hold us. Rock us until morning light creeps in. Then we will rise and begin the work of a new day

Time for a Break!





The Davis Family

Introduction

Review Video

Reflect/Discuss

Reflecting on an IMH-HV Family Experience Together

Parent, Child, & Clinician Perspectives



Check Out

We welcome your feedback!

If you would like social work CEUs, the evaluation is required

The evaluation will be open until 5pm
Tuesday 3/26



Thank You!

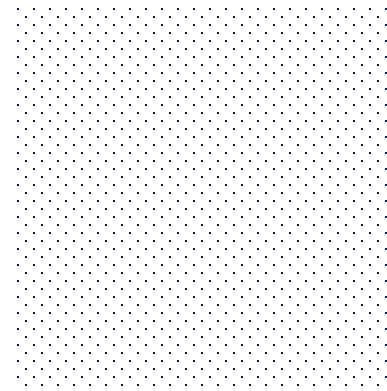
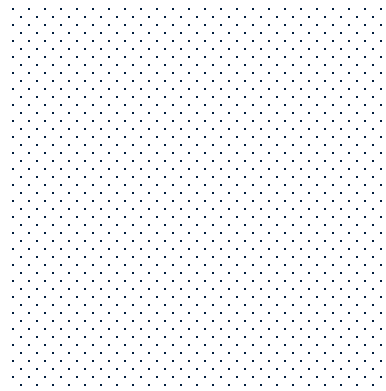
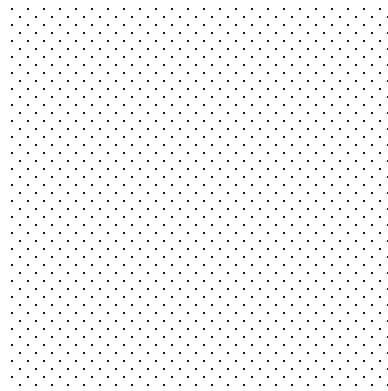
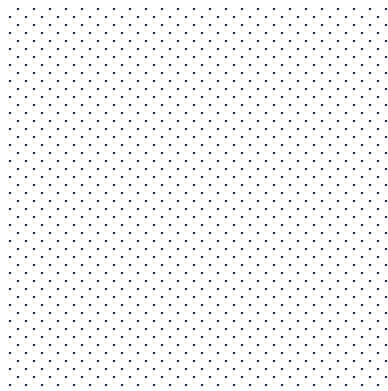
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www.zerotothrive.org





zero  TO    Thrive



“

Dddd quote.

Author of quote