



Shifting Paradigms: Working Together to Help Parents with Disabilities Succeed

Montana Child Abuse and Neglect
Conference
April 2024

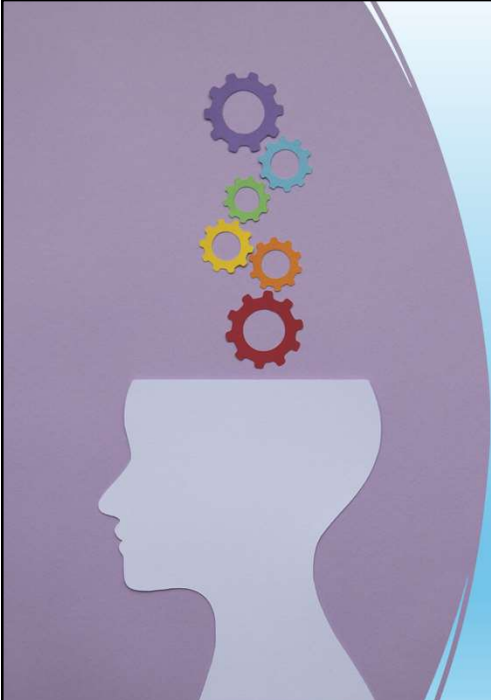
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What We'll Be Talking About...

- How to identify parents with IDD
- Adapting and improving our communication with parents with IDD
- Building rapport and increasing engagement
- Understanding parents' rights and ADA protections
- Attitudinal and other barriers to reunification
- Best practices for Family Time Coaching, parent education, support, and services

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What are Intellectual & Developmental Disabilities (IDD)?

Below average cognitive ability with 3 characteristics:

- IQ between 70-75 or below
- Significant limitations in adaptive behaviors (conceptual, social, practical)
- Onset before age 22


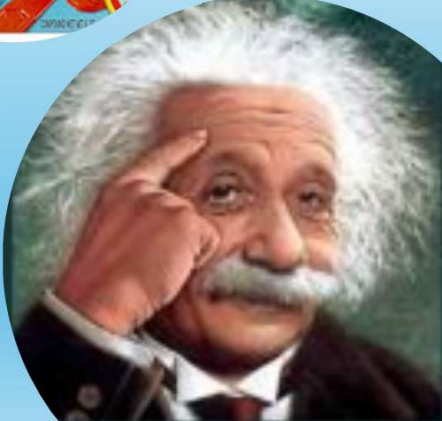
Developmental Disability (DD) is umbrella term that includes autism spectrum disorder (ASD), epilepsy, cerebral palsy, fetal alcohol syndrome (FASD), and others.

Developmental disability does not always indicate low IQ.

“People with IDD may be some of the smartest people you’ll meet”

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Intelligence Quotient (IQ)

- There is no correlation to parenting ability unless IQ is extremely low.
- IQ doesn't measure love, compassion, creativity, and empathy.
- IQ testing can be useful to evaluate memory, language, processing speed, and for eligibility for services.
- IQ testing is not always needed.

- Is there historical information documenting a disability?
- Self-report: Did the parent have an IEP?
- Information from family member
- Information from other agencies or doctors

- Conative abilities are more important!

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Social Model of Disability

- Barriers are socially constructed
 - Attitudinal
 - Environmental
 - Institutional
- Anyone can create change

"People are only as disabled as the inadequacy of their support"

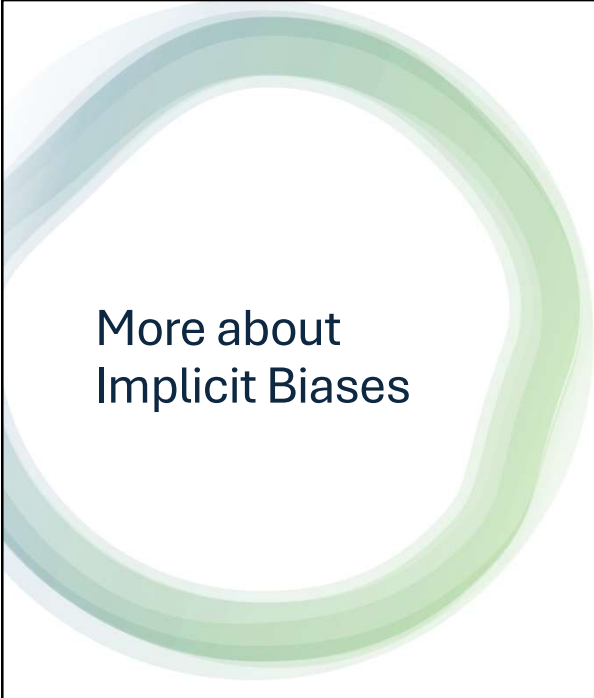


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Explicit & Implicit Bias



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More about Implicit Biases

- Operate at the subconscious level
- Run contrary to conscious belief
- Triggered by rapid & automatic mental associations
 - Which are correlated with attitudes and behaviors

We all have them but what can we do about them?

with thanks to Durshaw Hockett

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Implicit Bias

When asked, "How does having Down Syndrome affect you?" the father answered,

"It doesn't affect me. I don't let it get to me. I just live my life to the fullest. I always try to challenge myself to be better than I am...My philosophy is once you become a parent, there is no turning back. Be the best you can; that's all you can be. I was always told I couldn't have children. Finding out I could was a miracle to me. I was happier than ever. I love our kids. I would do anything for them. If I could give them the world, I would."

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Biases Create Roadblocks to Reunification

- Parent is said to have not made progress, or their “condition” will not improve (Presumption of unfitness bias)
- Lack definite goals (shifting)
- Found not to have “improved”
- Subjective conclusions (“may,” “apt,” “likely”)
- Services are proforma (Failure is projected and expected. Services are one-size-fits-all)
- When parents “fail,” the failure is presumed to reside in the parents rather than in the service



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How biases played a role in the Sara Gordon case

“DCF acted on assumptions about Ms. Gordon’s disability and did not individually analyze what supports would be appropriate.”



- Focused on obtaining a diagnosis rather than using information they had.
- Could not “Recognize, comprehend and react to the demands of an infant.”
- View based on “intuition” – “When you meet with someone, you get a vibe whether they are going to be able to do it or not.”
- Inability to learn.
- Needs to be a perfect mother and parent totally on her own.

See Resource slide for DOJ Technical Assistance

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Presumptions about parent's decompensation as the case progresses

Mothers whose children are in foster care have significantly higher rates of depression, substance use, physician visits for mental illness, and psychotropic medications compared to mothers surviving the death of a child.

(Kenny, 2018)



Threatened Mother Syndrome (TMS)

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Self-Reflection

- Have I been able to support parents with IDD to parent successfully?
- If so, how?
- If not, what got in the way? How might my own biases, implicit or explicit, have interfered?

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FROM REFLECTION TO ACTION: WHAT CAN WE DO?

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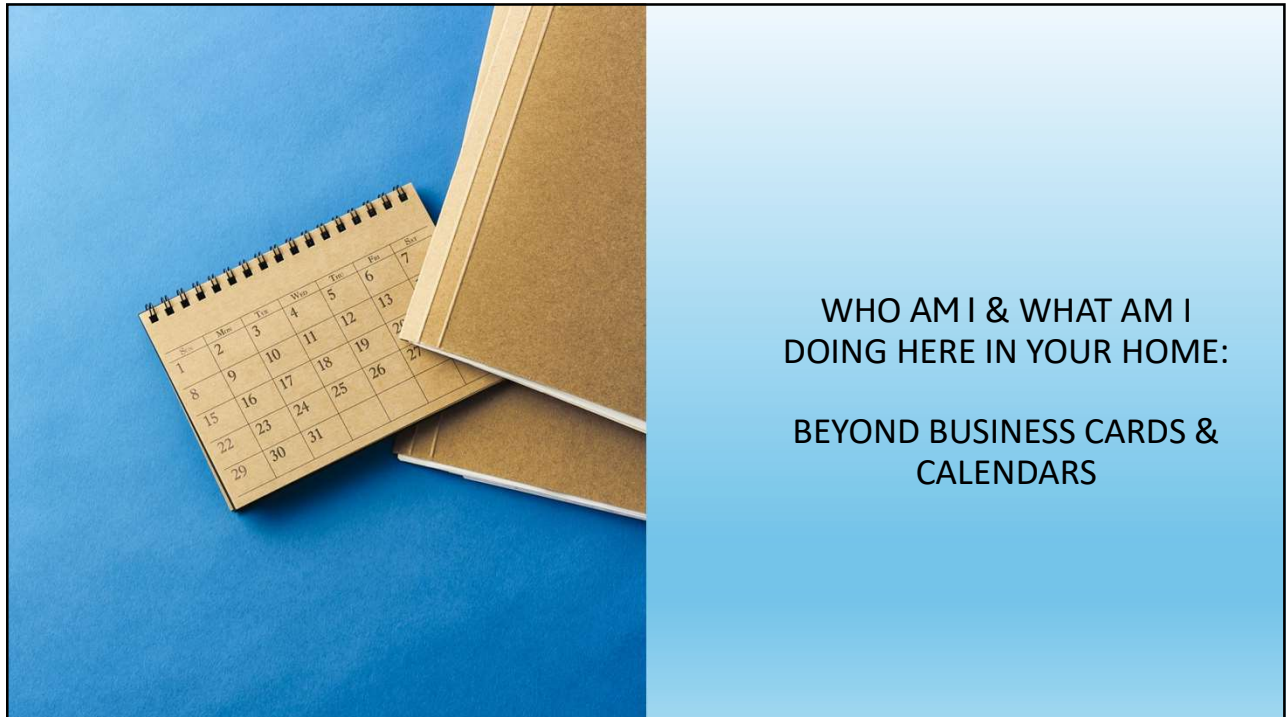
Become a Trusted Ally

Be	Be Approachable
Stay	Stay Reliable
Respect	Respect Parents as equal and expert on their experience & unique culture
Clarify	Clarify Your Role and Use Clear Language
Listen	Listen and Ask - Be Genuinely Curious
Discover	Discover Multiple Ways to Communicate
Find	Find Common Ground

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Come with a smile, not a badge.

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WHO AM I & WHAT AM I
DOING HERE IN YOUR HOME:

BEYOND BUSINESS CARDS &
CALENDARS

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Joining with Parents



Presume competence



Find common ground



Create shared experiences



Build self-efficacy perception



Be a team

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Checking for Understanding

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Build Rapport

Use initial meetings to get to know the person rather than relying on reports/diagnoses

Ask questions such as:

- How do you best learn new things?
- Tell me about something you learned to do recently...How did you learn to do that?

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Still Building Rapport



- Ask parent to use their own words to explain DCF involvement with their family
 - Be willing to explore the risks from the parent's perspective
- Ask parent what they want from the relationship
- "Tell me about your daily life with your child when things were going well."

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CREATE OPPORTUNITIES FOR SUCCESS

For Learning New Skills:

- Turn a task or an expectation into achievable steps
- Find or create materials that work
- Learn how to check for/agree to understanding
- Design a way to track success

For Parents with Children in State's Custody

- Create Opportunities to Parent!
- Participate in Family Time
- Promote Shared Parenting

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CELEBRATE!!

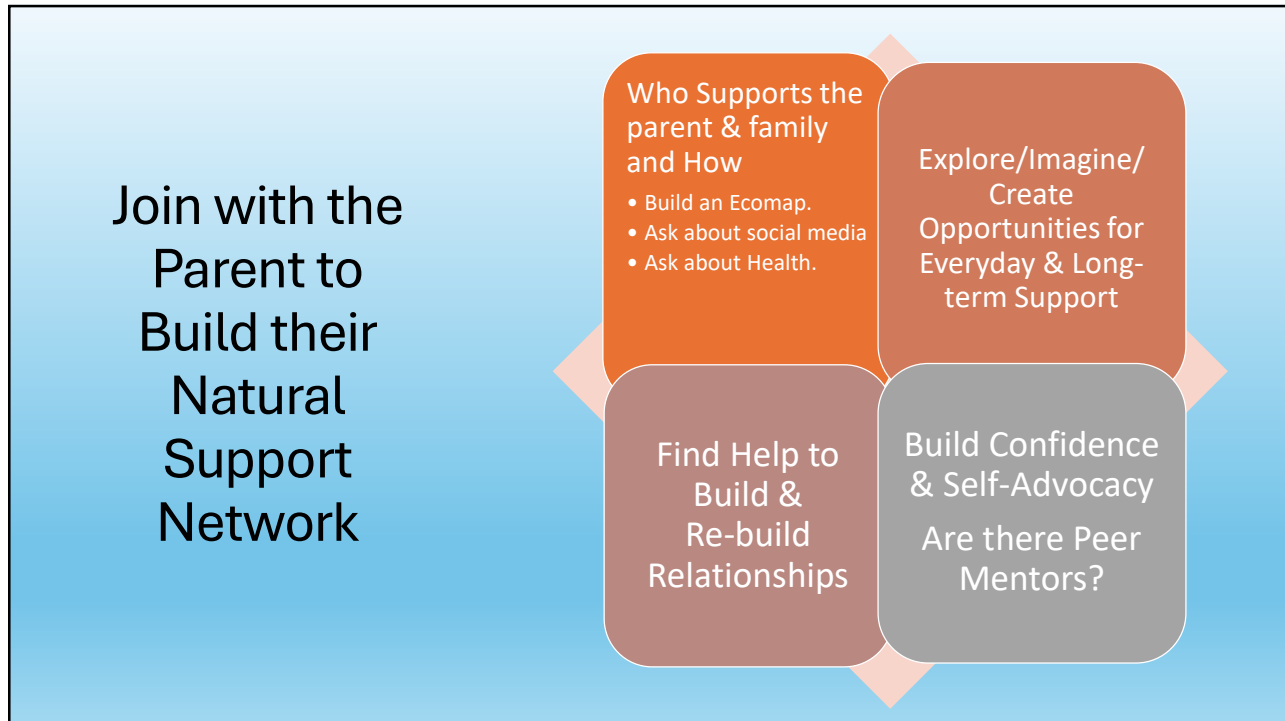
All successes no matter how small they seem

All attempts to learn or master a new skill

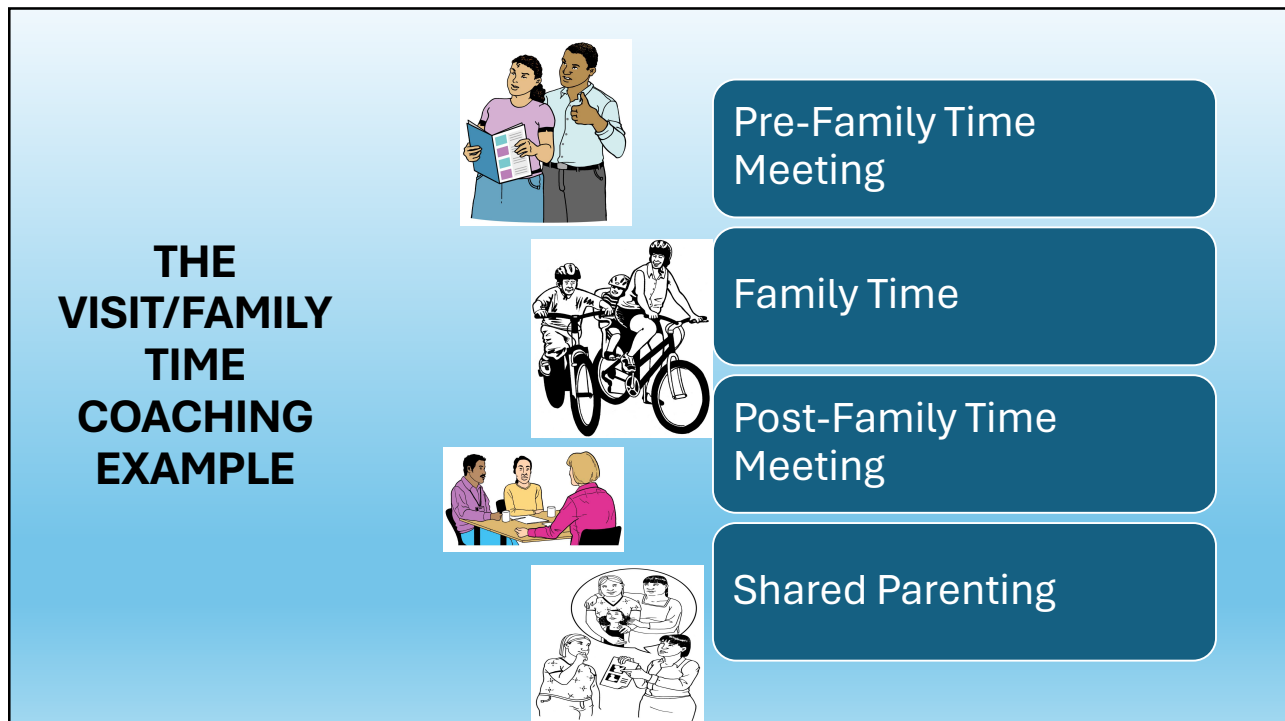
Always BEFORE feedback on what needs to be changed

Ask for parent feedback first

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Pre Family Time Meeting

Ask about	What needs to be left out of Family Time today
Review	Roles: How do you want to be coached?
Review	Goals and coaching approaches <ul style="list-style-type: none"> • One goal per Family Time • Plan a schedule or visual

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Family Time

- Model skills to be learned
- Redirection to tool or schedule
- Wondering as a cue to next steps



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Build on competencies

**Talk gets a lot of smiling and nodding.
With pictures, everyone in the room
can react as an equal.**



**“My Baby and Me” pictures mean
more and double as reminders &
Baby Books**



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Making a bottle- how many steps?

- Measure 6 ounces of water
- Warm the water
- Measure three scoops of formula
- Place in baby bottle with warm water
- Shake until mixed
- Test on wrist to ensure not too hot
- Feed baby 2 ounces
- Burp baby...(this could be broken down into 3 steps)...



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Breakout scenarios

You are working with a mom who needs support with changing her newborn baby's diaper.

You are working with a dad to understand how to prepare a bottle and feed his 3-month-old baby.

You are working with a mom to create a safe family time space for her crawling 8-month-old baby.

You are working with a dad with a three-year-old who repeatedly goes to the door wanting to leave the Family Time room.

You are working with a mom who is planning to go for a bike ride with her 10-year-old in the community.

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Parents and Coaches being creative



Family
Time
Books

Felt
Activity
Boards

Reminder
Flip Books

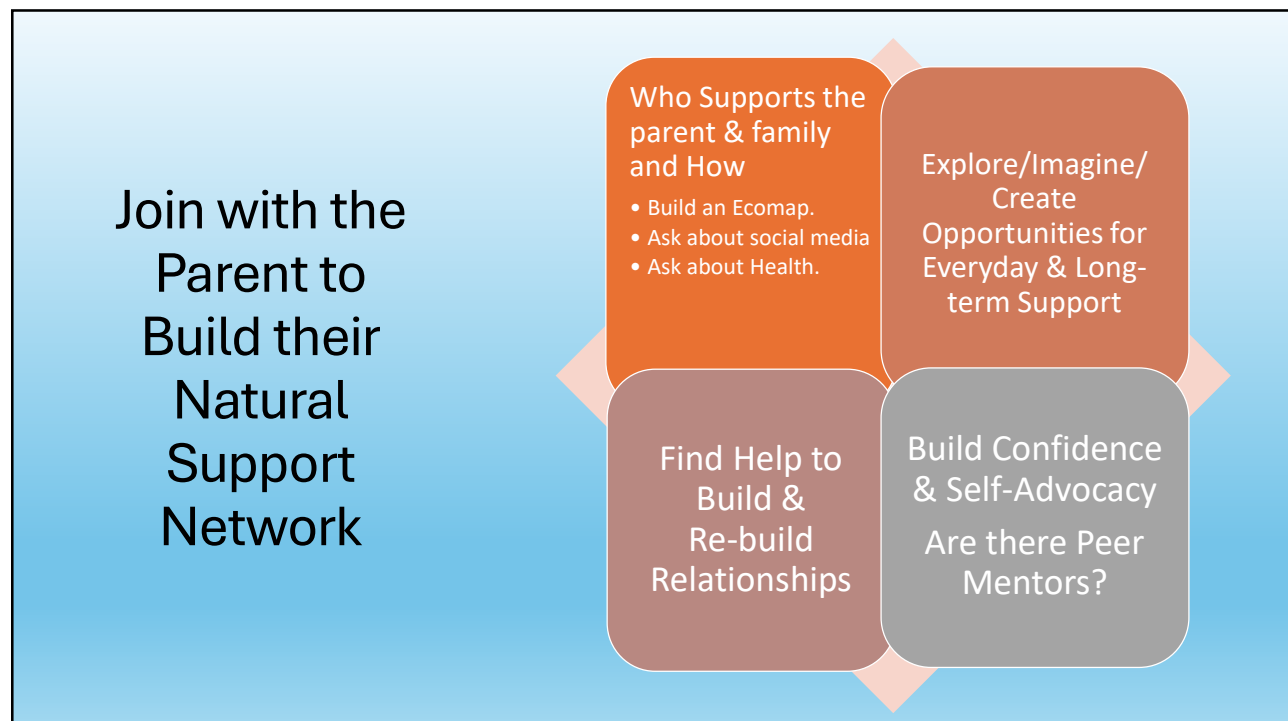
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The key to learning is doing!

- Performance-based
- Modeling, practice, feedback, and praise
- Multisensory
- Immediate and sincere feedback
- Do activities (fly kites, picnic, library)
- Use tangible reinforcers
- Your relationship IS the curriculum!

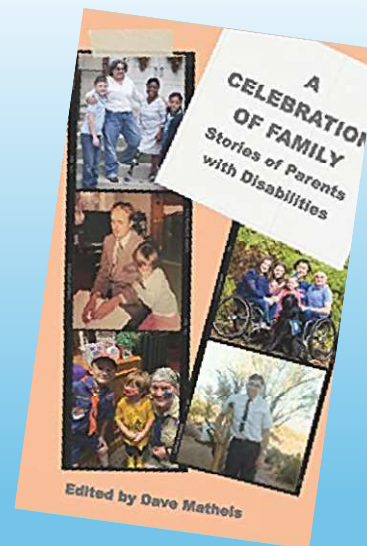


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Becoming a Self-Advocate



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Supporting parents in partnering

Shared Parenting Meetings

Team meetings

Advocating for themselves with
community supports



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What information does the parent want people to have?

About my child

About our family

About me

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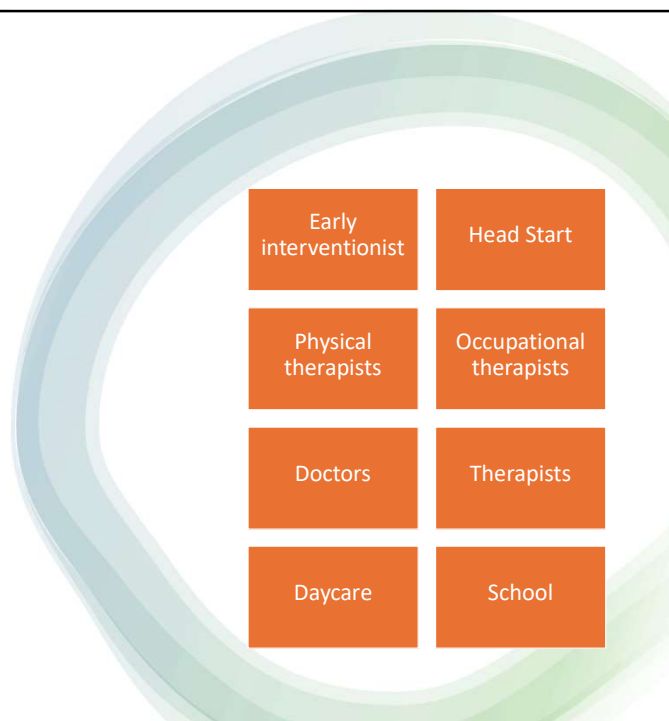


Look over here!

SUPPORTING PROVIDERS TO PARTNER with PARENTS

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Is the parent receiving the same information as other members of the team?



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Adapt and improve communication

- No distractions
- Avoid abstract language
- Ask one question at a time
- Avoid leading questions
- Pause frequently and allow time for them to process
- Talk about one subject at a time and signal when changing topics.
- Use either or questions. “Does that make sense, or not really?”
- Check understanding (e.g., by having them explain in their own words or teach it back. Avoid only asking, “Do you understand?”)



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Adapt and improve written communication



If giving written information, follow the Federal standards for plain language. See <https://www.plainlanguage.gov/resources/checklists/checklist/>.



To simplify text, use an online tool like [Quillbot.com](https://quillbot.com).

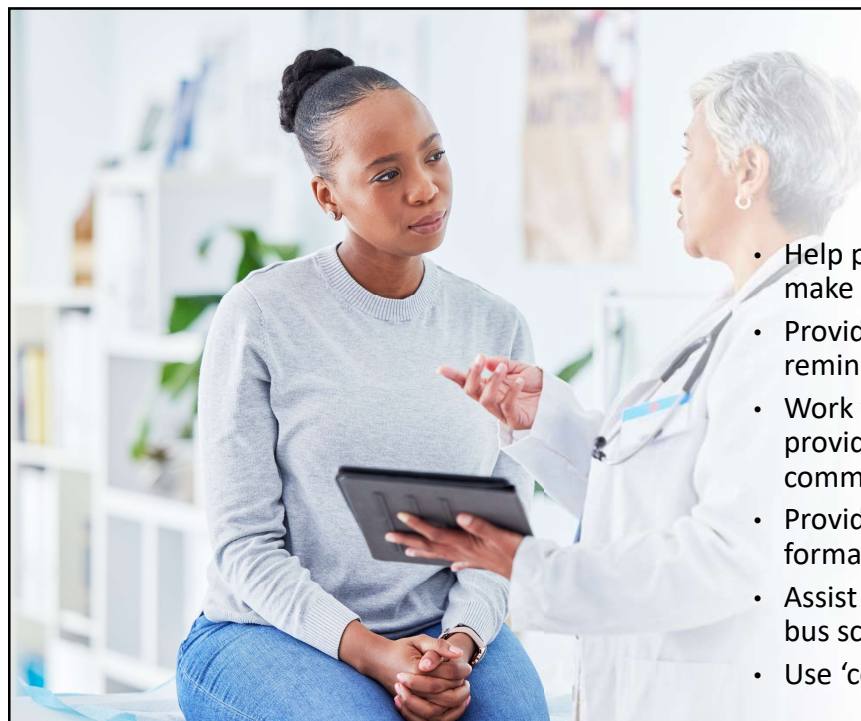


Check readability of Word documents. Click on the **Home** tab and then on **Editor** (the blue pencil icon). At the bottom of the list, click on **Insight/Document Stats**.

Flesch Reading Ease Scale

Score	Notes
90-100	very easy to read, easily understood by an average 11-year-old student
80-90	easy to read
70-80	fairly easy to read
60-70	easily understood by 13- to 15-year-old students
50-60	fairly difficult to read
30-50	difficult to read, best understood by college graduates
0-30	very difficult to read, best understood by university graduates

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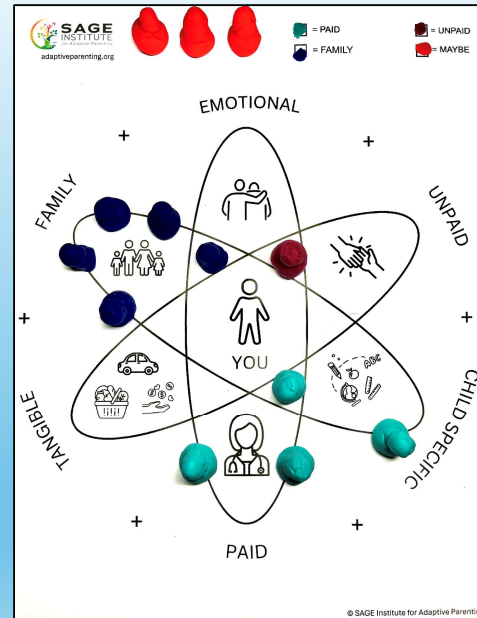


Other Communication Accommodations

- Help parents fill out paperwork and make referrals with them
- Provide frequent visual and auditory reminders for appointments
- Work with schools, service providers, and doctors to adapt communication
- Provide a calendar (multiple formats)
- Assist with transportation (reading bus schedule)
- Use 'cognitive interpreters' (peers)

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Building Community



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Parents who identify as having IDD teach us to:

- Examine our own biases
- Ask about learning and understanding
- Use language that is clearer and easier for anyone to understand: prioritize what idea I want to share
- To break down, **with parents**, risks, expectations, interventions, tasks into manageable and creative sentences, pictures, and activities
- To measure and celebrate progress in ways that are understandable and enjoyable!



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Where to go from here...

- Build inclusive communities
- Shared Family Care
- Education & collaboration
- Peer mentors
- Supported Decision Making/Parent Centered Planning
- Advocacy!

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Resources - Websites



<https://achancetoparent.net/>



<https://heller.brandeis.edu/parents-with-disabilities/>



<https://lookingglass.org/>



adaptiveparenting.org

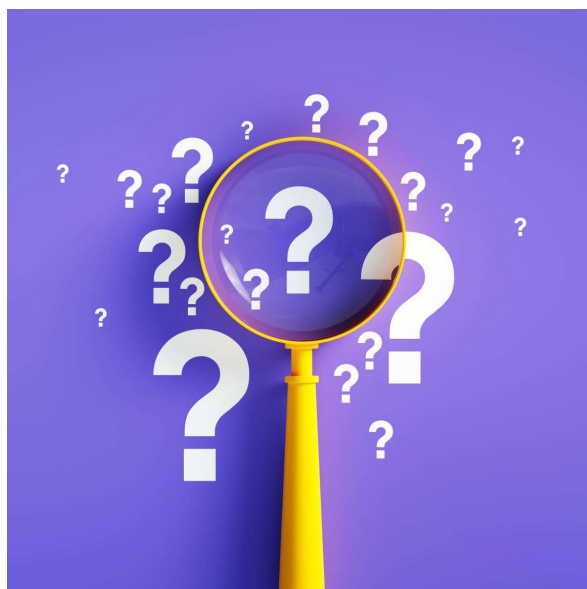
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Resources

- **Investigation of the Massachusetts Department of Children and Families** by the United States Departments of Justice and Health and Human Services Pursuant to the Americans with Disabilities Act and the Rehabilitation Act (DJ No. 204-36-216 and HHS No. 14-182176). https://www.hhs.gov/sites/default/files/mass_lof.pdf
- U.S. Department of Health and Human Services & U.S. Department of Justice (2015). Protecting the Rights of Parents and Prospective Parents with Disabilities: **Technical Assistance for State and Local Child Welfare Agencies and Courts** under Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act. <https://www.hhs.gov/sites/default/files/disability.pdf>
- National Council on Disability. (2012). **Rocking the Cradle: Ensuring the Rights of Parents with Disabilities and their Children**, Washington, DC. <https://www.ncd.gov/publications/2012/Sep272012/>
- **Supported Decision-Making: User's Guide for People with Disabilities and Their Supporters.** <https://supportmydecision.org/assets/tools/DRM-SDM-Handbook-Rev.-7.19.19.pdf>
- **Easterseals Family Time Coach Training Workbook.** Contact tlongley@eastersealsvt.org

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Time for
questions &
take-aways



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