



Shifting Paradigms:

Working Together to Help Parents with Disabilities Succeed

Montana Child Abuse and Neglect
Conference

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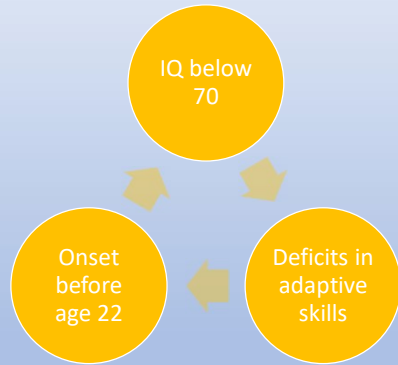
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Welcome!



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Parents with Intellectual & Developmental Disabilities (IDD)



Conceptual skills: language and literacy; concepts of numbers, money, and time

Social skills: interpersonal skills, avoiding being victimized

Practical skills: activities of daily living (personal care), occupational skills, travel/transportation, schedules/routines

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.

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Outcomes of being raised by a parent with a disability

- Better-than-average development and function
- Enhanced coping and problem-solving skills
- Greater acceptance of difference
- More positive attitudes towards disability
- Little parentification
- Resilience, compassion, interest in social justice
- Sense of belonging

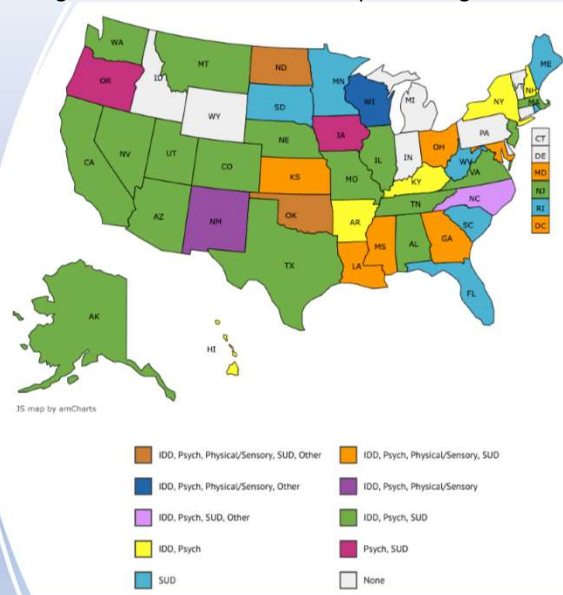


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Scope of the problem

- **9%** of the youth have disabled parents but make up **19%** of the children in foster care.
- Removal rates are up to **80%** in some areas (NCD, 2015).
- **240 days** longer in foster care than that of a child without a disabled parent (University of MN, 2017).
- “Backdoor Eugenics”
- **31 states** have legislations that permits permanent involuntary sterilization (Lutterman, 2022).

This map shows states that include disability as grounds for the termination of parental rights.



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DOJ/HHS Enforcement



“Sara Gordon”
letter of
findings
Jan. 2015

HHS voluntary
resolution
agreement
with Oregon
Dec. 2019

DOJ
settlement
with
Washington
Apr. 2021

DOJ/HHS
settlement
agreement
with Rhode
Island
Mar. 2022



Aug. 2015
DOJ/HHS
technical
assistance

Nov. 2020
DOJ/HHS
settlement
agreement
with
Massachusetts

January 2022
DOJ settlement
agreement with
Florida (Broward
County)

Aug. 2023
HHS voluntary
resolution
agreement
with
Pennsylvania

DOJ Technical Assistance
<https://www.hhs.gov/sites/default/files/disability.pdf>

DOJ Letter to MA DCF
https://www.hhs.gov/sites/default/files/mass_lof.pdf

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How do you know if a parent has IDD...

- Did you receive extra help with learning in school?
- Did you have an IEP?
- Can you usually read and fill out forms by yourself? What about reading children's books?
- How would you describe yourself as a learner? (*Do you learn quickly, or does it take longer for you to learn than other people?*)
- How do you learn best?
- Is there anything that made it hard for you to learn in school?

Is there information from family members or other agencies and doctors confirming IDD?

Parents with IDD may have:



"People with IDD may be some of the smartest people you'll meet"

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Let's talk
about
Margaret



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BEGINNING
WITH
SELF-REFLECTION

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APPROACHING
THE
INTERSECTION



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A Look at the Intersectional Experience: Health Care

- Henan Li et. al. (2021) looked at racial and ethnic disparities in the perceptions of adults with IDD, regarding their access to health care
 - Cost was the largest barrier for all
 - For Black and Latinx participants ,after cost, the biggest barrier was about trust “don’t like/don’t trust doctors.”
 - White participants talked about, after cost, location and insurance related barriers.



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Poverty



- Affects “cognitive bandwidth”
- Exposed to higher levels of violence
- Difficult to trust others
- Having children at an earlier age
- Communication – Casual register
- Fatalistic vs. can change the future with good choices
- “Hidden talents”

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The Intersection of Trauma, Parenting, & IDD

People with IDD have often never been asked, believed, or helped with regard to their traumatic experiences

People who have IDD and traumatic experience may develop post-traumatic stress disorder

Trauma informed doesn't always mean IDD aware

Various trauma therapies can be useful and adaptable for people with IDD if therapists are IDD informed

In-home parenting, prevention, early intervention services should be individualized to accommodate parents with IDD or other severe learning challenges.

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Intersections: The example of Interpersonal Violence



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People with Disabilities and Interpersonal Violence

People with disabilities are targeted for violence at rates 2.5x (adults) 4 x (children higher than people without disabilities. (Davis, 2011; Harrell, 2017)

Women with disabilities are uniquely vulnerable to all forms of violence, including intimate partner violence. They are more likely to experience physical, sexual, and psychological abuses and stalking and intimate partner control of reproductive and sexual health than peers without disabilities.

80% of women and 30% of men diagnosed with DD have experienced sexual violence. At least 50% of people with intellectual disabilities have been victimized sexually. (The Arc, 2011, Disability Justice, 2019)

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Parents with Intellectual Disability and Interpersonal Trauma

In a review of 20 studies, over 50% of participants reported interpersonal trauma, whether childhood or lifetime prevalence

Exceptionally high proportion of parents with ID was found to have experienced prolonged childhood separation from their caregivers

The most consistent link between Interpersonal Trauma and adverse caregiving-relevant outcomes was regarding the participating parent's own mental health.

Hammarlund et al (2023)

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Unique Interpersonal Violence Concerns for People of Color with Disabilities

Double oppression

Lack of culturally appropriate accessible services

Isolation and shame

Lack of knowledge about services

Lack of trust in the human service system

Multiple cultural identities

Double communication barriers

Cultural differences towards disabilities

Lightfoot & Williams, 2009

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Cultural Respect

'Disability' is a culture!



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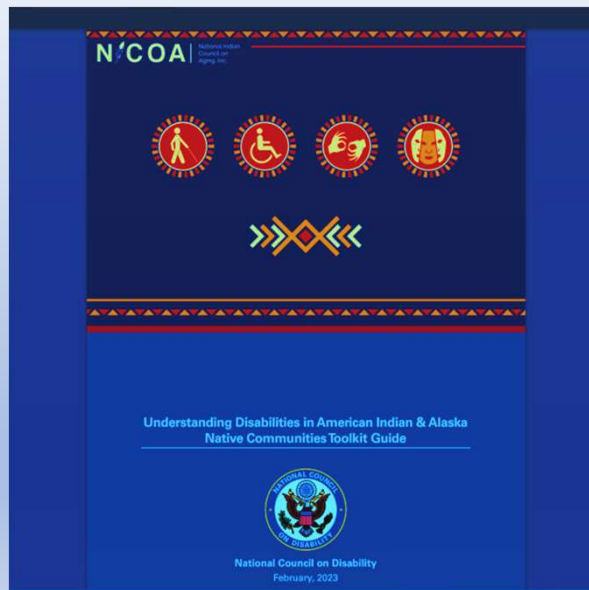
- ❖ All humans and non-humans are unique, necessary, and adaptable
- ❖ There is no “ideal” as all things are in flux (Cajete, 2000)
- ❖ One could think of differences as talents
- ❖ Differences require Community Assistance
- ❖ Interdependent living
- ❖ Engage with Respect, Reciprocity and Perspective
- ❖ Should one live long enough, disability will be everyone’s lived experience (Wendell, 2008)

Indigenous Concepts of Difference

Lovern (2001)

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You have to have a resource to get a resource



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Current Parenting Capacity Assessment Practices

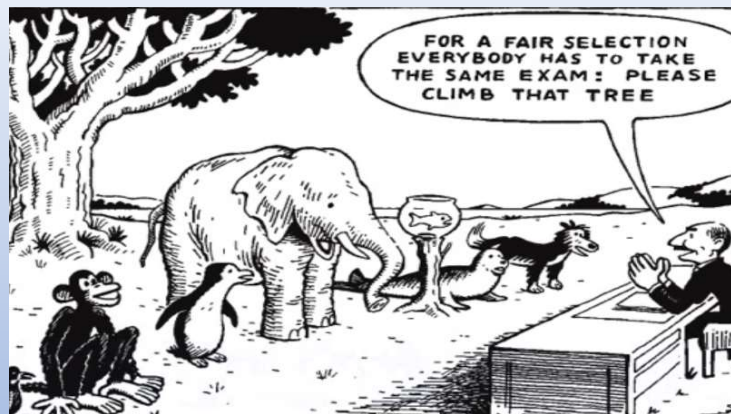


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Current Practices

“The hallmark of testing is standardization; the essence of disability is individualization.”

- Rhonda Olkin



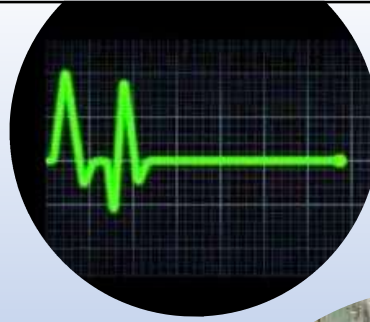
Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid.

- Albert Einstein

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Psychological/ Neuropsychological Tests

Psychological tests can offer a hypothesis to prove or disprove using clinical judgment and other methods.



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Mental Health

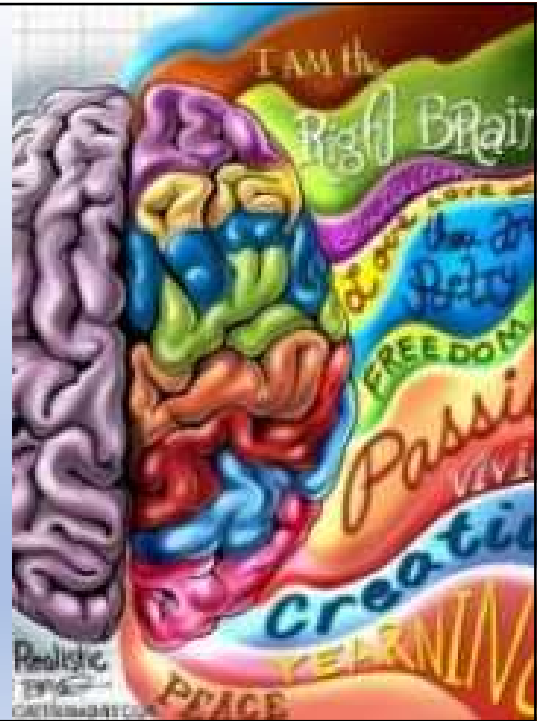
- People with ID 4 to 5 times more likely to have a mental health diagnosis.
- Misdiagnosis is common
- Mother's whose children are in foster care have higher rates of mental health problems and prescriptions of psychotropic medications compared to mothers surviving the death of a child (Kenny, 2018).



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IQ Tests

- IQ does not measure love, compassion, creativity, or empathy
- IQ tests can help identify parents' strengths and if they qualify for services.
- Over five decades of research states IQ is an unreliable predictor of parenting. With training and support, parents with IDD can redress parenting skill deficits (Aunos, Feldman, & Goupil, 2008).
- DSM-V warns that IQ test scores are only approximations and may be insufficient to assess reasoning in real-life situations



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Personality Tests

- I like mechanics magazines
- I wake up fresh and rested most mornings
- I think I would like the work of a librarian
- My hands and feet are usually warm enough
- I'm about as able to work as I ever was
- I have diarrhea once a month or more
- I am sure I get a raw deal from life



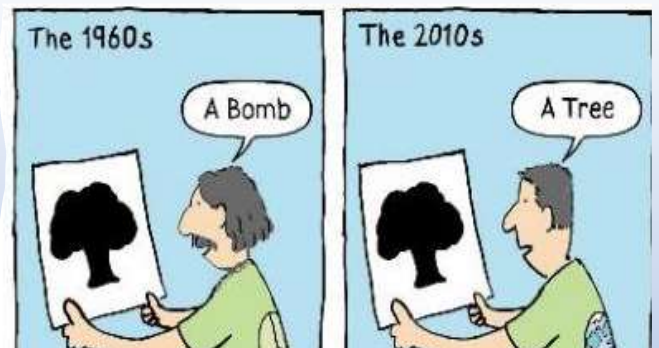
"Mother portrayed herself in a more positive light"

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Projective Tests

Watch for the 'appeal to authority fallacy' and confirmation bias.

"He appears to be struggling with a serious degree of mediational distortion indicating a severe problem with reality testing associated with psychotic process..."



Arms and hands:

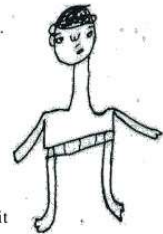
Omitted: represents a complete withdrawal from the environment. If a male omits a female's arms, then is unacceptable by females or lack of confidence in social contexts.

Fingers:

Too long may mean the person is overly aggressive. Too short means they are reserved.

Toes:

often not included in drawings because of shoes, but if they are, it is a sign of aggression. If a female shows painted toenails, they may have heightened female aggression.



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Risk Assessments

- Risk assessments do not measure response to treatment, how they manage risk, or consider protective factors.
- Results are presented as absolute.
- Systemic bias can be inherent in the tool.
- There is lack of transparency how algorithms are constructed & how factors are weighted.



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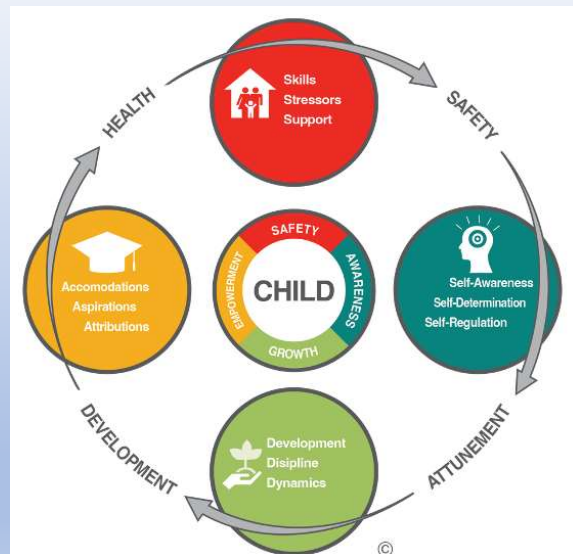
Adaptive Parenting Assessments

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Adaptive Parenting Assessments

It's not about CAN THEY?

It's about HOW CAN THEY?



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Social Model of Disability

Attitudinal

Environmental

Institutional

People are only as disabled as the inadequacy of their support





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Closing the Doors of the Institution

Opening the Hearts of Our Communities

*Brandon Training School
1915 - 1993*



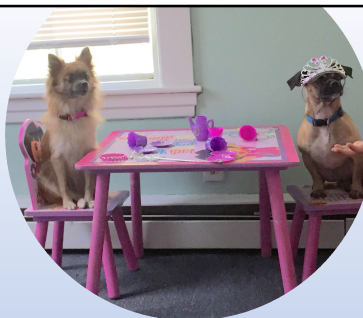
Vermont Agency of Human Services
Department of Mental Health and Mental Retardation
Division of Mental Retardation
103 South Main Street
Waterbury, VT

Principles of Deinstitutionalization

- Normalization
- Social role valorization
- Self-determination
- Dignity of risk
- Community integration

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Adaptive parenting assessments rely heavily on observation



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"Good parenting does not mean giving a child a perfect life. It means teaching them how to lead a good and happy life in our imperfect world." – Author Unknown

"Good Enough" Parenting Standard

- Minimum amount of care needed to not cause harm to a child (Dr. Donald Winnicott)
- Using this benchmark to evaluate parenting is consistent with child protective services' primary concern of keeping children safe.
- It guards against parents with disabilities being judged against stricter criteria or harsher standards than parents without disabilities.
- Ask yourself, "If a parent without a disability did this would it be an issue?"

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Adaptive Parenting Assessments consider the parent's perspective

"What I couldn't figure out but didn't want to ask is why would anyone sing a song about a baby falling out of a tree. Maybe this has another meaning? In her report it said I wasn't bonding with the baby because I refused to sing."

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Adaptive Parenting Assessments consider the family's support network!



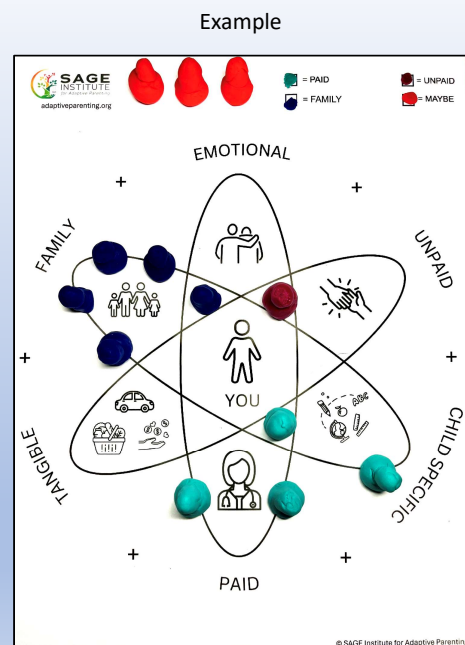
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Natural Supports

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Ecomap Activity

1. Choose 4 colors of playdough and place a piece in each square of the key.
2. Put 3 pieces of one color on top of page.
3. Create a family and place on the FAMILY ellipse (Write the initials)
4. Place PAID and UNPAID support on the map.
5. Move the primary supporters in each overlapping category to the triangles.
6. Fill in the gaps with the people on the board or think of where you can find people and use the MAYBE people. Be Creative!



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Where to go from here...

- Shared Family Care
- Parent Centered Planning
- Education & collaboration
- Building inclusive communities
- Peer mentors
- Advocacy!



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Recap and overview of this afternoon



Dr. Marjorie Aunos

https://www.youtube.com/watch?v=XeYYVz_PH30

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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
https://www.hhs.gov/sites/default/files/mass_lof.pdf
- U.S. Department of Health and Human Services & U.S. Department of Justice (2015). **Technical Assistance for State and Local Child Welfare Agencies and Courts**
<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>
- Working with Parents with Intellectual and Developmental Disabilities: Easterseals Vermont Guide to Coaching Parents with Learning Challenges/Intellectual-Developmental Disability (2022). Contact tlongley@eastersealsvt.org
- Change People Easy to Read Resources; Images to create your own <https://www.changepeople.org/>

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Time for questions & take-aways



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