1

Description

- Intended audience: case managers, therapists working with children and families with Reactive Attachment Disorder Reactive Attachment Disorder
- RAD impacts the entire family unit and requires treatment through a family lens in order to be effective. Abby's recent study gave a voice to caregivers of children with RAD who shared their lived experiences. Learn about the results of that study and the change that can be made right now to improve the care and treatment to increase positive outcomes.

2

Objectives

1. Learn about the experiences and needs of caregivers/families of children with RAD and what they are asking for.
2. Explore treatments and interventions you can use now to improve positive outcomes within families with RAD.
3. Learn resources and supports families with RAD are asking for that are currently unmet needs.

3

Reactive Attachment Disorder

DSM-5 Code: 313.89	ICD-10 Code: F94.1
A. A consistent pattern of inhibited, emotionally withdrawn behavior toward adult caregivers, manifested by both of the following: The child rarely or minimally seeks comfort when distressed. The child rarely or minimally responds to comfort when distressed. B. A persistent social and emotional disturbance characterized by at least two of the following: Minimal social and emotional responsiveness to others. Limited positive affect. Episodes of unexplained irritability, sadness, or fearfulness that are evident even during nonthreatening interaction with adult caregivers. C. The child has experienced a pattern of extremes of insufficient care as evidenced by at least one of the following: Social neglect or deprivation in the form of persistent lack of having basic emotional needs for comfort, stimulation, and affection met by caregiving adults. Repeated changes of primary caregivers that limit opportunities to form stable attachments (e.g., frequent changes in foster care.) Rearing in unusual settings that severely limit opportunities to form selective attachments (e.g. institutions with child-to-caregiver-ratios.) D. The disturbances in Criterion A began following the lack of adequate care in Criterion C. E. The criteria are not met for autism spectrum disorder. F. The disturbance is evident before age 5 years. G. The child has a developmental age of at least 9 months.	Starts in the first five years of life and is characterized by persistent abnormalities in the child's pattern of social relationships that are associated with emotional disturbance and are reactive to changes in environmental circumstances (e.g. fearfulness and hypervigilance, poor social interaction with peers, aggression towards self and others, misery, and growth failure in some cases). The syndrome probably occurs as a direct result of severe parental neglect, abuse, or serious mishandling. [1] It may occur alongside an associated failure to thrive, or growth retardation. Exclusion: Asperger syndrome, disinhibited attachment disorder of childhood, maltreatment syndromes, normal variation in pattern of selective attachment, sexual or physical abuse in childhood (which results in psychosocial problems)

4

What RAD looks like:

- Destructive to self and others
- Absence of guilt or remorse
- Refusal to answer simple questions
- Denial of accountability—always blaming others
- Poor eye contact
- Extreme defiance and control issues
- Stealing
- Lack of cause and effect thinking
- Mood swings
- False abuse allegations
- Sexual acting out
- Inappropriately demanding or clingy
- Poor peer relationships
  Abnormal eating patterns
- Preoccupied with gore, fire
- Toileting issues
- No impulse control
- Chronic nonsensical lying
- Unusual speech patterns or problems
- Bossy—needs to be in control
- Manipulative—superficially charming and engaging

5

According to the current US census the number of children under 18 years old in the US is 75.5 million. Total US population is 317 million.

So, if the *lowest* research numbers are used (24% of abused children) that makes the number of US children with RAD 186,000. If the *highest, most current scores* are used from Princeton, (40 % of all US children) that makes the number just over 30 million with RAD. If we divide that by 50 states that makes just over 600,000 per state!!!!!

*attachment.org

6

What we hear from caregivers of children with RAD are important.

We talk about putting on our oxygen masks before helping others with theirs.

What have you heard?

7

The positive experiences about parenting with RAD??

"…that's an interesting question because most people don't think of any positives."

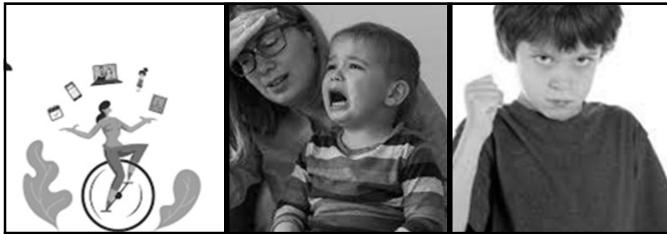
"you know being a RAD parent, it's kinda hard to pick out anything positive."

8

Growth is rewarding!

- "I have learned a lot about attachment…I have learned a lot about parenting."
- "It has forced me to have to think about how I am going to take care of myself so I don't become overwhelmed with her. So, I have had to do a lot of self-care. At some points it has pushed me closer to my religion because I felt like I didn't have a whole lot of people there to support me."
- "it has caused me to become a more patient person… and a better parent to my other children."
- Watching their child make progress and heal is rewarding and positive

9



Challenges

10

Primary Parent-Child Relationships

Healthy	Unhealthy
Hugs, Kisses, high fives, snuggles	"when he was little, he was affectionate toward me…Um and even now he's a little bit warmer with me. But not like say my nephew would be to his mother."
Emotional expression between child and parent	"it is like bonding with a brick wall."
Talks and spends time with parent without needing something	"vessel for meeting needs"
Expresses frustration about others and seeks assistance and nurturing from parent	"even if it (child's anger) is about someone else it's directed towards me."
Child respects parent as a caregiver and provider	"You know that parent-child love, that respect, everything is there, just moments, it's just moments that they have."
Parent and child can spend healthy space apart from each other for reasonable amounts of time	"if I go out of town and I leave her with a relative, when I come back it's a nightmare or she will do something stupid like overdose, so I have to come back."

11

Sibling bonds

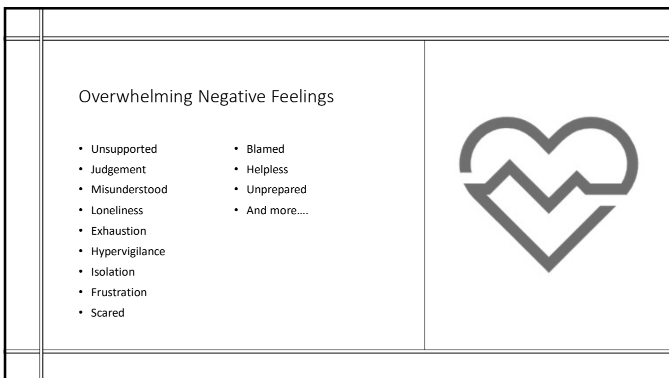
Healthy	Unhealthy
Picking on and bickering in a mostly harmless way	"being mean and just hateful" towards her sibling
Siblings support each other, work through issues together, and provide space as needed to each other	"Having a kid with RAD is not just the kid with RAD is affected and the parents are affected, the whole family is affected. Living in a very dysfunctional and chaotic state and it effects my other children. So, I really really really need family therapy and I have requested this many times over a couple years and they still have not provided me with that. And more recently they have acted like they are going to and then they don't."
Siblings feel safe in the home environment and support each other	other children have felt a need to protect the parent from the child with RAD's aggression and violence.

12

Bonding with Other Family Members

Healthy	Unhealthy
Child will share stories of successes and things they need to work better on with family members	tell exaggerated stories like, "I hit 50 home runs in my game, and he may have not have hit any you know but 'I hit 50 home runs' " to impress grandpa.
Non-primary parent or caregiver is an extension of the primary parent	The spouses or significant others of the primary caregiver are described to have good connections when it is on the child's terms.
Child goes to parents appropriately to meet needs	daughter does "choose him over me most times."

13



14

- UNSUPPORTED:
  - "I felt like I didn't have the support that I needed to navigate the challenges that I've had with her."
  - "It's not like your kid has diabetes or something where there are a lot of doctors that understand it and classes where they can train parents on, and even though you might be stressed out and concerned because it is your child's health, at least you have support where I think with RAD you are desperately trying to find support for your kid."
- JUDGEMENT
  - "this lady though, the looks that she gave me, she literally pulled her children away from me like I had leprosy"
  - "So when I would go to school to see about extra precautions to make sure she didn't run away or cut herself or make sure she doesn't do this or doesn't do that, I actually had a school try to report me that I was trying to make (daughter) look sick, like I was trying to make it like something was wrong with her. Because they could just not imagine that there was anything wrong with this child so young."

15

- MISUNDERSTOOD
  - If I ever shared stories about my son, they would normalize, and they would downplay it. There was one time he went into a rage over not wanting to brush his teeth. And it was like a 45-minute rage. And I just said to my co-workers, colleagues, oh it was such a rough night last night. He got into such a snit over brushing his teeth. 'Oh yea, all kids do that, don't worry about it, you're a new parent.' And I wasn't a new parent at that point, but you know. But basically 'you don't have the parenting experience to understand it' was the message I got. And I just snapped at her and said, 'oh going into a 45 min rage, taking out the TV and needing to be restrained, that's what normal kids do when they don't want to brush their teeth?'
  - "not just like raising a difficult child, it is raising the most difficult children" and "a lot of these people don't understand, and you would think that they would."

16

- LONELINESS
  - "You know I think I dated like once or twice in the past 2 years and I can't do it because my daughter won't let it happen. She threatens people she makes it so I cannot do that. So that affects my relationships with people as well."
  - alienating herself from others to avoid having to answer questions about her daughter.
- EXHAUSTION
  - "I have to watch her every second or if she doesn't get the attention she needs from me, there is no limit to what she will do to get the attention that she needs from me and she will continue to escalate until I step in. That is challenging because number one that means that I don't get a break and number two it means that if I need to do something (outside of the house and her) that there is going to be a price to pay for me doing that."
  - "the rigorous schedule of services and the amount of travel required to access those resources and supports with the amount of planning, taking time off of work, balancing FMLA and paid time off, educating herself and performing therapeutic parenting as getting 'so exhausting.' "

17

- HYPERVIGILANCE
  - "you are on guard 24/7…because you don't know what is going to happen next."
  - One example was one of her children with RAD telling the service provider that they did not have any socks, which then the provider took the child to the store and bought them socks instead of working on the goals and tasks outlined for the service time. <u>In reality, the child had socks and did not need socks, but quickly led to service providers questioning the parenting of the participant.</u>
  - waking up and smearing paint all over the carpets of two rooms, smeared body powder all over the bathroom and her husband's keyboard.
  - eating dog treats, raw meat, tainting food and putting it back in the refrigerator or freezer, and attempting to poison the pets and her.

18

19

- ISOLATION
  - people avoid them like they have the plague, because mental health still has such a stigma compared to medical conditions.
  - "Some of the other people around me. Like they don't want their kids to come over because of the way she acts, and they are worried that she will hurt them, which is not going to happen, I would never let that happen, but they have those thoughts in their head. So, they don't want their kids to come over and play with my kids. So, it does effect relationships and make things really hard."
- FRUSTRATION
  - "most services and facilities excluding RAD from their treatment array. "
  - child not wanting to be picked up and not meeting her milestones and a pediatrician accounting it to a difference in temperament, as well as, not getting the supports or help that has been offered, available, or professionals who understand also causing feelings of frustration.

20

- SCARED
  - "he would make me public enemy number one and he would have told them what a horrible worthless mother I am and (the police and Child Protection Services) didn't understand RAD enough and they would have taken him."
  - "I record every single bruise because I was terrified. I am still terrified of losing my other kids."
  - "most people don't have to deal with children that try to start their house on fire or jump out of the car numerous times."
- BLAME
  - a social worker not calling her back for 2 days while her son, as a minor, was hospitalized due to the belief that the "parent is at fault for everything."
  - professionals telling her not to ask her child with RAD questions because that is a known trigger and "you are setting them up to lie to you."

21

- HELPLESS
  - "*it feels like no matter what I do I can't meet her needs*."
  - "Doesn't treat you really nice and nobody else does either and nobody knows how to help you. I would call CPS, the social workers that placed her in my home every day and tell them something's wrong. And they would be like 'ok you are getting the extra money because she has issues.' But what am I supposed to do with it? That doesn't help me. It was, it was really frustrating to not get the help where I needed it and from the people that were supposed to be helping me. And then when I finally did figure out, she was adopted later, and then I thought great now I will be able to figure this stuff out on my own and get some actual help. And I was so wrong."

22

23

- UNPREPARED
  - told that one of her children with RAD "only needed therapy, a [service worker], and love," however, she feels the issues were downplayed at the beginning by the county placing the child in order for her to take the child.
  - I did not understand a lot of the issues that she had when she was younger, like I said, there are a lot of things I would go back and do completely different… And you know they just put her in my home and didn't offer me any support from the beginning. They didn't even offer me any information or anything.
  - not knowing what was available for supports and information, the processes for getting supports, or that having a private adoption hindered the process in getting support when needed.

24

Where is the support?

"If I told somebody today that my child had leukemia, there would be people knocking down our door demanding to help. If I said my child has a malignant brain tumor. People would be begging us to help us. Those things might kill my child. My child has a very serious, chronic illness that can not only kill her but others around her, and no one can help us."

25

Recognized Positive and Helpful Supports

- Online support groups
- Funding and financial support from state foster or adoptions
- Attachment and trauma trained and experienced therapists
- ATTACH conferences
- Parent Retreats
- Books:
  - Dan Hughes, PhD
  - The Connected Child

26

Reported Barriers to Supports:

- No knowledge of what resources and supports are available
- Lack of updated registries and information
- Money/insurance coverage
- Long waits
- Restrictions and disqualifying behaviors/diagnoses

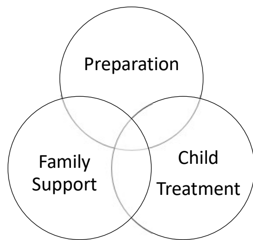
27

Unmet Needs:

- Trauma and attachment trained therapists and providers
  - Psychiatrists
  - Pediatricians
  - Nurses
  - Specialists: Speech, OT, PT
- local support groups (in-person and online)
- Respite
- School systems and staff that understand trauma and attachment
- Parent and Family-Specific Support
- Community education
- Social and self-care opportunities
- Local resources
- Timely services
- Financial support for the added costs
- Legislative change
- Prevention/early-intervention

28

So how do we put those unmet needs into action?

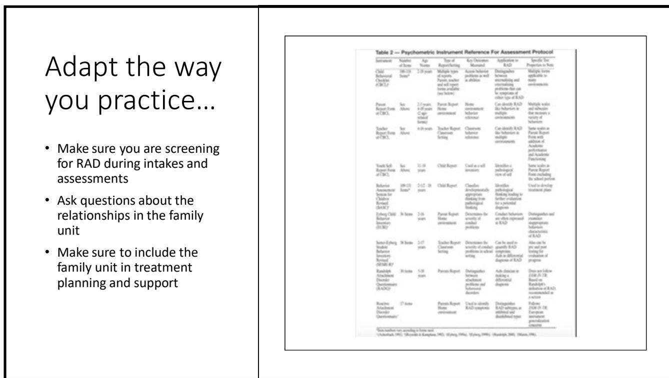


29

Prepare… Educate Yourself…

- Materials into handouts and easily accessible resources for parents and families
  - Facebook groups:
    - Reactive Attachment Disorder
    - Surviving Reactive Attachment Disorder
  - Radsibs.org
  - www.radkids.org
  - www.attachment.org
  - www.attach.org
  - Institute for Attachment and Child Development
  - Local RAD and trauma experts
  - Local and state grants or organizations that specialize in RAD
- Purchase, rent, borrow books on Attachment and Attachment theories for yourself, co-workers, parents, and guardians
  - Dan Hughes
  - *Parenting the Hurt Child: Helping Adoptive Families Heal and Grow*, by Gregory Keck and Regina M. Kupecky, Pinon Press, 2002.

30



31

Improve the professional community…

- Trained professionals:
  - Require training on attachment, positive parenting, etc.
  - Supervise and staff cases from a trauma and attachment lens
  - Train on how to identify attachment and trauma in children and families
    - Foster care
    - Adoption
    - ACES
  - If child is coming from Fostercare or Adoption:
    - Be up front about the information and diagnoses
    - Assist in getting the RAD diagnosis or a screening
    - ALL parents have stated "I wish I knew from the beginning, so I was more prepared. I wasted so much time trying to figure it out."

32

Treatment has 2 parts

Both parts are needed to be successful as a family unit and produce positive outcomes

1 or the other is good, but both together is where the magic happens

33

Part 1: Individual

- Therapy for the child with RAD
  - Attachment
  - TF-CBT
- Individualized Education Plan & Behavior Intervention Plan at school that follows attachment and trauma-focused treatment
- Skill development support to learn, practice, and repeat coping skills, emotional regulation, communication, relationship development and maintenance
  - How to communicate your needs
  - When to ask for help
  - What is a friend
  - Who is a safe adult and who is a stranger or aquaintance

34

Part 2: Family

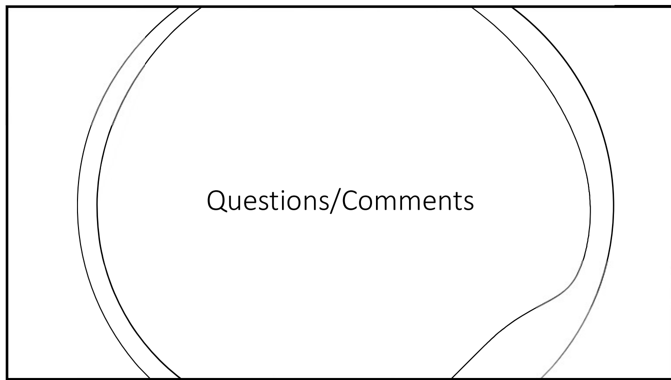
- Education-Be real and upfront about the challenges and expected behaviors!
- Parent and sibling support groups
  - Facebook
  - Local chapters
  - Radsibs.org
  - Vlogs: Life of a RAD Mom;
- Information on organizations and programs to promote or support in doing family fun activities
  - Six Flags special needs passes
  - Special times at movie theaters
  - Sponsored games or community events
- Family therapy
  - Family Systems allows for flexibility in doing therapy always as the family unit as the client, but with flexibility in attendance.
    - Just parents
    - Just siblings
    - Everyone together
    - **A mix of talk therapy and experiences, observations, and activities**
- Respite or planned breaks
  - Don't wait until things get bad or worse; make sure that family time and interactions do not end on a negative or break on a negative---"I did something bad so I was removed"="I am bad and they don't want me."

35

Therapy Interventions & Activities

- Office-, Community-, & Home-based Therapy
- If adopted or foster child
  - Encourage healthy bio sibling relationships as appropriate
  - Support sharing about family of origin
  - Encourage practicing perceived or actual family traditions
- Action interventions to promote positive experiences
  - Cooking dinner as a family
  - Playing a board game
  - Playing cards
  - Group art project or painting time

36



37