ACPI Exclusive

Relationship and Regulation for Coaching the Special Needs Family

Introduction to ACPI's Coaching Certification for Special Needs & the Open Heart Model

Resource List of Behaviors

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Overview

Relationship and Regulation for Coaching the Special Needs Family

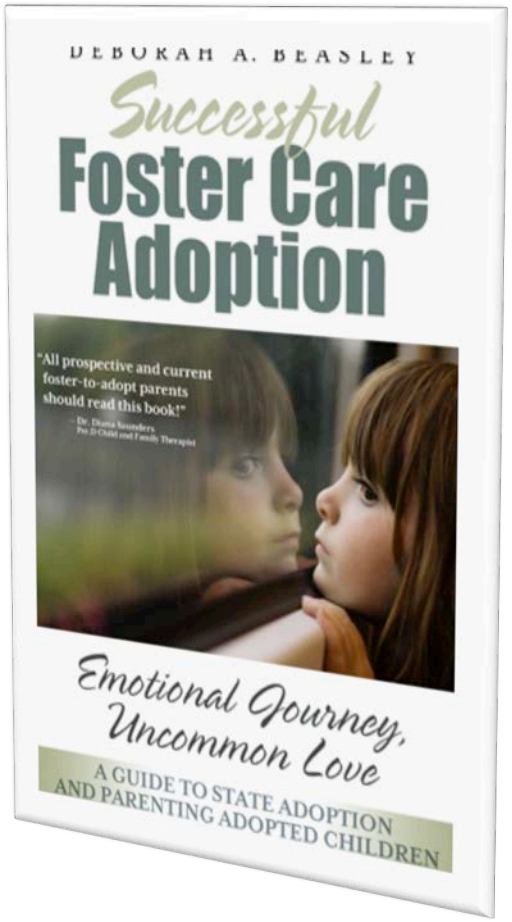
Introduction to Open Hearts

Welcome to ACPI course for special needs certification. This training and certification is called Relationship and Regulation for Coaching Special Needs Families. This promotes understanding in how to coach and work with parenting children with special needs. Additionally, I cover working with agencies and coaching families with unique needs.

My name is Deborah Beasley, and I am privileged to present this course to you. A few years ago, I received my coaching certification from ACPI, with my specialty niche in Special Needs. My experience with ACPI has been very positive. In fact, from the first time I met Dr. Caron Goode, my professional and personal life have improved in ways I could not have imagined, and I wish a similar wonderful experience for each of you this year in your training and certification process with ACPI.

I began my educational journey toward coaching and parenting education in 2007, by acquiring intensive training and certification in trauma, stress, and regulation.

Between 2009 and 2010 I went on to receive certifications in Advanced Mindfulness, Somatic Body Mapping, a Level II Reiki Certification, and of course, my coaching certification with ACPI.



In 2012, I published my first book: *Successful Foster Care Adoption, Emotional Journey, Uncommon Love*, a guide to state adoption and parenting adopted children. As a new author, I am pleasantly surprised that this book has sold with great regularity in over 47 states in the past year and a half. This year, 2014, I will release a therapeutic children's book. *Sweet Pickles, The Girl Who Would Not Speak,* the heartwarming and humorously told story of a little girls struggle with anxiety and selective mutism, and how a mother's creative love helps her overcome her fears.

Since 2008, I have worked with adoptive and biological families with children whose challenges include almost every aspect of atypical and difficult behavior, and present with a mindboggling array of particular and unique needs. The parents who desire to raise these children often do not know how to begin to meet the demands required for their high needs and disabilities.

My mission in presenting this training on behavior regulation is to help you develop new insights into the culture and lifestyle of working with, living with, and raising a child with profound special needs and behavioral difficulties. This training is your

introduction to the joys, concerns, fears, and barriers families face with their disorganized and dysregulated children, and how you facilitate transformational change in the family dynamic through the power of secure relationships. You will understand the heart of the disorganized/dysregulated child, the root and cause of difficult behavior, and the science and practical solutions to help parents provide healing regulation for themselves and their children. Coaches leave this training with tested and valuable tools, and user-friendly resources that blend seamlessly into the work they do with families. Moreover, the tools assist coaches and excite clients to explore and discover their potential as the primary healing agents in their family.

I speak confidently about children with special needs and behavioral disorders, because I have three children with special needs, each one uniquely different in how they interact with and are affected by the world around them. I have been married for 31 years. I have a large blended family with 2 stepchildren, 3 biological children, and 2 adopted children. I am Caucasian and my adopted daughters are African American. The five older kids are married and we have 9 grandchildren.

Part of what I bring to this course, is equal to a generational life span of experience with a child diagnosed with ADD, and learning disabilities, who is now an adult. Our youngest daughter endures her own story of trauma and medical complications, and suffers the side effects of growing up with an older sister with complex emotional issues from early trauma. Yet, the fuel that fires my passion to support you and the parents you work with comes particularly from the intense and life-altering experiences with my older adopted daughter.

Groundwork in Early Behavioral Theories

The groundwork that laid the early theories for our current understanding of treating, and parenting children with emotional, psychological, and developmental disorders is

about 60 years old. In the last thirty years, research in the areas of trauma, stress, PTSD, and the child's developing brain has intensified through the dedication of the superstars of the world of trauma, children, and affect-regulation. Noteworthy names include

- John Bowlby and Mary Ainsworth, for their work in early parent child attachment
- Allen Shore for his extensive contemporary work in affect-regulation
- Peter Levine, Bruce Perry, and Bessel van der Kolk for their unstoppable research and discovery in the effects of trauma on the neurobiological and social-emotional development of children.

Their collective, groundbreaking, work is the sound philosophy of this training, backed by the science of neurobiology and neuropsychology. We now know that the healing path for children and families with emotional and behavioral difficulties rests on the firm foundation of these principles:

1. Affect-regulation
2. Healthy Attachment
3. Loving and Healing Relationship with the primary caregiver

A Comprehensive Model

One comprehensive approach, a behavioral model, for children with special needs has emerged as the most beneficial to families and children. The model emphasizes training in

1. Healthy relationship and attachment between the parent and child as its pivotal point, and
2. Understanding affect-regulation and brain development as the fulcrum of healing in the family.

Our relationship-focused model combines the best strategies and methods of all other approaches. The results we seek in this coaching/parenting model are

- To support and maintain a healthy relationship between the parent and child and unity in the family.
- To respect the unique cultural differences in family composition, and
- To identify and build upon the individual strengths and qualities of parent and child.

This model uses the best practices of current behavioral, cognitive, sensorimotor and interpersonal approaches, as well as traditional wisdom and related modern science, to create a path to healing which best fits the circumstances and behavioral needs of individual families. We use what is usable within the context of a healing relationship and discard the rest.

The Model of Systemic Developmental Regulation
The Open Heart Model

This model uses the social and emotional components of human attachment and interpersonal relationship in a systemic (broad) approach to enhance developmental regulation. The results when applied effectively help adults and caregivers develop skills, which can be successfully applied to parenting children across developmental ages with and without behavioral disorders.

The model is equally effective when applied to typically developing children and the parent/couple/marriage, strengthening relationships between all family members, enabling personal healing, higher achievement, and safe parenting skills.

The Case for Using a Relationship-Based Framework With Children with Behavioral Disorders

In 2008, Dr. Joshua Feder, M.D., made a clear case for using a relationship-based framework with children with behavioral disorders. His work was visionary and well ahead of its time. I increased my knowledge and experience working within a relationship framework with my daughter, and recognized its efficacy in our lives. The multiple diagnoses applied to my seven-year-old daughter included, Pervasive Developmental Disorder NOS, and Reactive Attachment Disorder, and I did all I could to find solutions to her difficulties.

In his published work *Beyond Medication and Behavioral Therapy: The Case for Using a Relationship Based Framework for the Treatment of Persons with Autism Spectrum Disorders"* Dr. Feder uses the term engagement interchangeably with relationship. He states that engagement goes beyond compliance.

"Relationship based intervention is the use of ongoing affective connected interaction to promote developmental progress, focusing on co-regulation, engagement, and social reciprocity." Joshua Feder, M.D.

He states, "This is done is a context of a well-rounded bio psychosocial (body, brain, inter-relational) understanding of the person, and carried out throughout the day by caregivers who are guided and supported as they develop growth producing relationships." Dr. Feder further makes a comparison between a relationship and a behavioral approach. He says,

- "The main goals of a behavioral program are to help a person to engage in more appropriate behaviors, leaving aside inappropriate ones, and learning about the world and what to do in the world to live, work, play, and survive.
- This is a top down approach.

- The main goals of a relationship-based intervention are to help the person connect with others in a way that promotes social and cognitive development and problem solving with flexible adaptation to a changing world.
- This is a bottom up approach." (Joshua Feder, M.D.)

We engage through the heart, connecting the child with their family and world through the power of a loving healing relationship. This is the Open Heart approach. Over time, as organization and regulation increase, the brain reformats and gets it. Much research concludes…

1. The role of the primary caregiver to assist the child in developing self-regulation far outweighs the influence of genetics or temperament.
2. However, it is the interaction of attachment and temperament that forms the working model of relationship between child and parent and parent and child.

In this course, you'll be learning how the energy-dampening effect to behaviorally challenged children is a relationship-based approach. Either parent, grandparent, aunt, or uncle, or others closely involved with the child can have the same positive impact on the child's development, internal self-regulation, and the regulation of (emotion) affect.

Indeed, it does take a village to raise a child well. Through a relationship-based model, the caregiver facilitates what the child cannot, until the child is capable of accomplishing it by herself. The caregiver returns to the basics of an early parenting model when and where necessary to better meet their child's needs through modeling, influencing, guiding, supporting, instructing, and monitoring the boundaries and expectations. I simply call this good parenting.

Return to Basics – Parenting 101

Good parenting happened automatically and intuitively when our children were babies. New parents are attentive and responsive to their babies' needs and difficulties. New parents anticipate circumstances and dangers, and watch for those teaching moments. They are fully engaged in a loving, caring prevention and intervention approach. Very early in parenting experiences, a parent tenderly addresses a babies needs whether or not they respond in positive ways.

To put it differently, loving care of the newborn child is not dependent on what parents want or need, but upon what the child needs. If responses to newborns were based on what parents needed, many new parents would not tolerate repeated nightly interruptions of sleep by wailing hungry babies, or endure smelling like baby vomit for the first few months, and would not go happily to the changing table and diaper pail!

The point is we parents take a lot, do a lot, and put up with a lot from and for our babies. I am saying that we must do it all over again with our special needs children, and we must do it with the same uncommon love and tenderness.

Adapting childhood parenting practices to the older child is a revolutionary, psychologically-sound approach. It is a natural, whole child parenting style. It is instinctive, purposeful, mindful, in the moment, and adapts to the needs of the child.

Dr. Feder cites several limitations and challenges of implementing a relationship model.

1. *Dr. Feder suggests: "It is not a didactic model." I say: We* must give up our old notions of the hierarchy of control – The parent's will no longer dominates the child's will
2. We allow for respectful application in cross-cultural contexts.

3. There is no clear book of directions, and you are creative in the moment, being flexible in choosing responses.
4. The training required is in how to relate…developing an interpersonal and coaching component. First, the parent, and ultimately the child, must accept guidance. That is where you, as the coach, step in to shape responsive interactions.
5. Dr. Feder says: "Boundaries must be tended." I say: The parent must tend lovingly to the boundaries. This approach is called Creative Scaffolding because it provides the supportive framework for strengthening relationships of the child and family.
6. Dr. Feder says: "We're not 'holding the baby". I say: Parents are not using physical tactics to punish or restrain, rather they teach coping skills that enable the child to stand on their own. We are coaching caregivers to coach their children to wholeness within the framework of their recognized abilities.
7. Dr Feder says: "There is a need for reflective process."
    - This is the Open Heart practice of mindfulness, self-awareness, and breathing.
8. Dr. Feder says: "There is a need for more practitioners." I
    - This must be YOU

To rephrase Dr. Feder's question:

Why Should We Use Relationship Based Interventions?

- We CAN change outcomes despite genetics which only provide a blueprint for potential or possibility.
- Affect or emotional regulation IS the key to growth and development, and this model is based on affect and attachment.
- We need to go beyond behavioral treatments. We will no longer rest on the commonplace and expected practices, but skillfully blend the most effective into our work with families.

- Medication can support treatment, but cannot address relational deficits nor make up for an environment that fails to adapt to a child's core needs
- We currently have plenty of clinical research to support the efficacious use of a relational model.

Raising a child with special needs and behavioral difficulties is a tale of love, fear, struggle, and courage. No amount of magic counting, no accumulation of time outs or forced sitting, and no step-by-step sticker rewarded behavior system will suddenly transform an emotionally, behaviorally challenged child into the vision of a child once imagined.

The way to influence lasting change in children is through the development of a healthy relationship…a secure attachment that promotes and supports internal organization and self-regulation.

Special Needs or Just Plain Special

Attitudes and Perspectives – This is the Child I Have

I am not a therapist, but I play one in real life.

Like most parents of a child with disabilities, I did not plan ahead. No one trained me or adequately prepared me for what life would be like, should I have to raise a child with special needs, behavior, and mental health disorders. Nevertheless, here I am, learning as I go.

Candidly, I admit, this is not the situation I dreamt of when I imagined having or adopting a child. No. Reality and the dream seem like a chasm with a bottomless pit. There are days I cannot see the bottom, and moments of light when I do see it. In these moments, I find the courage to continue, and hope for the future.

I loved my child before I ever saw her. I love my child still. I have a child with emotional and mental health problems. This is the child I love. This is the child I have.

My daughter has the dubious distinction of being THE most discussed case history among therapists, behavioral assistants, and clinicians. One agency director informed me that she regularly uses my daughter's case for training of her new case managers and therapists. It does not give a parent the warm fuzzies to hear repeatedly from mental health professionals, whom you look to for help, that your child's case is the most difficult one they have ever seen.

This is the child I have. This is the child I love.

These sentiments are my personal reflections. They also match the experiences of some of the parents you will coach…parents, who struggle to move forward after facing the reality of one or more diagnoses like ADHD, Autism, Conduct disorder, Bipolar disorder. The effects on the family are the same. It triggers a parent's worst nightmares. Concerns, fears, sleepless nights, and the search for answers begin.

This is how a parent enters the world of mental health and special needs…a world where terminology is confusing and diagnoses sound like the unending combinations of an alphabet soup.

If care is not taken, a parent or teacher might begin to refer to the child by the labels of their diagnosis, and see in the child's behaviors, both positive and negative, only symptoms of the same. As months or years of struggle pass, parents don't differentiate which part of the behavior belongs to their child's temperament, and which part is a symptom of the diagnosed condition. Amid the onslaught of doctors, neurologists, medical tests, and therapists elucidating the deficits in their child's development, parents easily lose sight of the child and concentrate on what they see most, the disorganized and dysregulated behavior. The question that brings this home is simple:

Which child do you see…one with special needs or one who is just plain special?

This Is the Child I Have

I always dreaded having to fill out treatment questionnaires, and even worse, interviews by therapists and case workers about the strengths, likes, and dislikes of my child. I did not know her favorite color, or if she enjoyed a certain cartoon show. She did not have a favorite rattle or play like other babies and children.

Most activities upset my daughter intensely. People she did not know upset her by their presence or close proximity, and this reaction extended to family members. Each time she saw them, she acted as she were meeting them for the first time. She reacted with aversion and clung to me.

She did not like being held or touched. While still an infant in a baby sling, she squirmed and wriggled around in order to face away from me. I saw the back of my child's head more than I saw her face. Imagine raising a child who would not allow herself to be hugged, snuggled, and kissed. Imagine a young child desperately needing love, connection, and affection, yet vehemently rejecting it at every turn.

My daughter did not like leaving the house for any reason, even for the promise of ice cream or going to play in the park. Certainly pre-school and later grade school years were big problems. The mere prospect of these outings terrified her, and her strong aggressive reactions threw us into dismay. Her situation was worsened in that her first two with us, a streaming variety of strangers transported her to weekly-supervised visitation at a state office, with her mother the first year and with her father the second year. Should a parent not arrive for the scheduled visitation, my daughter was passed around the office up to 3 hours or longer until they could procure her return transportation.

Each week, I watched helplessly as the vehicle grew smaller in the distance, while the baby and then a toddler, restrained in a car seat, arched her back and craned her neck to see me still standing on the sidewalk in front of the house. As long as I could make out her features through the rear window of the vehicle, her wide eyes never blinked or left mine. She never cried, but internalized every fear.

Caseworkers described her desperate attempts for them to remain in the visitation room with them, even to crawling after them and wrapping her tiny body around their

legs. She experienced trauma upon trauma. Once home she clung to me to the point of clawing at my clothing. Visitation ended after her first birthday, and we had a period of three months where she began to make good developmental progress. She was babbling and saying simple words. Due to legalities, visitation began again and within a few short weeks she stopped speaking altogether. Her trauma became our trauma.

I described her to her neurologist as having only two emotional states, screaming rage or silent withdrawal. Other than these states, we could not read her. She always appeared uninvolved, as if she observed life happening around her. She slept little and screamed a lot. Her neediness was unending and seemed insatiable. I was most often unable to put her down. She had no self-soothing skills. No internal regulation. No identifiable calm state. What I once believed was a state of calm was, in realty, a state of withdrawal and fear.

No amount of attention appeased her. Speech and motor skills were delayed. This only made it more difficult for her to communicate, which she did loudly through screaming, hitting, spitting, pinching, and other negative behaviors. Doctors and specialists repeatedly stated, "She is consistently inconsistent." She lacked a middle ground, a balance to her emotions. At times, she smiled or laughed, but we had to work overtime to elicit any positive response.

No part of caring for my daughter was easy. I felt at a loss to identify anything specific about her likes or preferences. This was my daughter, my little baby, and I did not know who she was. I only knew how she acted.

As she grew older, her inability to adapt to changing environments grew worse. By the age of three-and-a-half, her rages and meltdowns typically lasted three hours per episode. I could set a clock by it. I often ran from her with baby in tow to hide and

cry in the bathroom, while the sounds of chaos demolished the kitchen. She attacked me for the most insignificant requests like "It's time to pick up your toys."

Therapists and psychiatrists taught us to restrain her, and as good parents, we diligently followed every directive. She head butted us, bit, kicked, and scratched us to bleeding. She only stopped screaming when she became too hoarse and too exhausted to fight or scream any longer. She fell into an exhausted sleep in my arms, but if disturbed, she wakened into the same rage in which she fell asleep.

As her aggression worsened against members of the family, on the advice of her psychiatrist, we fell into calling 911 for help. Policemen flexed their authoritative muscles in questioning why we couldn't handle such a small child. When they witnessed her rage, we received only sympathetic looks, as they motioned for EMT's to take her to the local hospital. We went so often that they knew us by name at the crisis center. I begged them to keep her for evaluation when she grabbed a butcher knife from the counter to cut off her arm, and especially one night when she threatened to stab me with a long skewer used for the grill. The crisis center sent us home. Eventually the ambulance refused to come. "They are not in the business of helping or curing; they are in the business of maintenance," I thought. "*Stabilize the child and send them home.*"

I did not know about affect-regulation before 2007. I knew nothing about the effects of trauma on a child's developing neurological system. I knew absolutely nothing about the brain. I knew only that our family was falling apart before my eyes, and I felt powerless as a parent to know what to do.

Over the course of my daughters first seven years of life, our home was a revolving door for more than thirty helping professionals, and my daughter was the recipient of the ever-adjusting adult-sized cocktails of psychotropic drugs. Some therapists were

worth their weight in gold. Some…well…I suggested they find a new day job, especially when their only solution was complete residential housing for my child, without hope of her returning home.

I knew why they suggested it. I know what psychotic behavior looks like. After all, I watch *Law and Order Criminal Intent* and *Special Victim's Unit!* But, hold up! This is my little girl, and "giving her up" is not and never will be in my vocabulary.

Nevertheless, twice we prepared to send her to long-term residential on the strong advice of doctors and psychiatric nurses working with our daughter. The first time she was four years old; the second time she was nearly seven. Ultimately, we decided it was not something we could live with, nor did we believe it was in the best interest of our daughter.

It is important for each of you to understand the unbelievable, heart-wrenching choices some parents face as part of everyday life. We believed we had tried everything to help change our daughter's behavior. Nearing the edge of hope, we came to the realization that something had to give. It would either be our child, or us parents and we didn't want it be either.

However, this is not the end of the story…merely the beginning. Information from neuropsychology, trauma, attachment, and relationship, the same information you will learn in the coming weeks, gave us choices and options that allowed us to regain personal and family balance, hope for the future, change and improve our parenting skills, and develop a positive healthy plan to parent our daughter. The information was a revelation that allowed a welcome return to my original parenting philosophy with new knowledge and understanding about raising children with love, compassion, empathy, and relationship.

- Both negative *and* positive reactions, actions, and attitudes of caregivers significantly impact the child, and hinder or support the development of secure attachment.
- Environment, temperament, trauma and stress, is relative to reactive behavior, and internal organization and regulation.
- Parents can learn to manage, diminish, eliminate, and contain even the most severe behavior.

Finally, we had something to DO. We were no longer on the fringe of being powerless to help our daughter. We devoured and assimilated the information, because we had a lot to lose.

WE REFUSED TO CRY UNCLE!

WE RESOLVED TO BE COMMITTED.

WE DID NOT HOLD BACK.

We completely transformed our outlook, honed our philosophy, strategized our plan in every minute detail, and changed our lifestyle. It was not ever easy, but it was easier than what we had been doing and how we had been living for so long.

Let me share who the unruly, dysregulated, and unattached little girl became. She became our mission impossible.

Today she is 13-years-old and attends an out of district school for children with high social anxiety. She is an A-B student, a wonderful artist, and a voracious reader with a big vocabulary and a matching imagination. She looks forward to attending college, but her career choices change frequently. She knows her strengths and areas of difficulty, exhibits all the best coping strategies, and thinks she would like to work with animals as a veterinarian as the one depicted in the Animal Planet series, *The Incredible Dr. Pol*. She hasn't had a meltdown or any significant aggressive behavior

in years. Despite having ten diagnoses, she has not been on any medication since 2008.

Your Mission

Now coaches, your mission, should you choose to accept it, is to help parents in similar situations find clarity, hope, and greater functionality in their family while in this kind of confusion. With your help and guidance, parents will find their center of gravity, push past their feelings of inadequacy and overwhelm, and begin restoring regulation and resilience in their children with behavioral disorders through securing the child-parent relationship.

Are you willing to accept this mission? If your answer is yes, please turn your attention to the handout on ***Terminology and Diagnoses.***

Exercise

A Personal Reflection on Families And Children with Special Needs

Goal of Exercise: Learn to identify hidden personal biases, fears, stigmas, myths, or internal aversion to children or adults with disabilities, behavioral needs, and your feelings toward their parents. Learn to genuinely engage with your clients with an open heart and without prejudice or personal judgment.

Exercise – Create a list of prior experiences or interactions with special needs children and families. Under what circumstances did you interact with them?

- Bullet point types of special needs or disabilities you encountered
- With your personal observations, include initial thoughts, emotions, and first impressions when first meeting someone with special needs and disabilities
- Explore your level of comfort or discomfort with certain disabilities.
- Think about how you really feel; include biases, fears, myths, or stigmas still attached to feelings about people with special needs, including mental health and behavioral problems
- What do you have to overcome in order to work effectively and genuinely in this area?
- Counter every negative you discover with a positive affirmation for change!
- Be prepared to share an Ah! Ha! discovery in the first class.