Behavioral Tips for Parents and Professionals Dr. Cathy Pratt and Eustacia Cutler

A webinar presentation June 19, 2015 by The Temple Grandin and Eustacia Cutler Autism Fund go to <u>www.templegrandineustaciacutlerautismfund.com</u> for additional information.

This document is provided merely as an overview of the webinar conversation with Dr. Cathy Pratt and Eustacia Cutler. Please join the conversation or listen to the recording to fully understand this information.

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1. TIP ONE

Cathy Pratt: Accept the fact that there is no single recipe/approach for handling problem behavior. Each individual and situation is different.

Eustacia Cutler: That also applies to us. It's not just that they don't get where we're going. We don't get where they're going.

Autism is two way traffic on a one way street where there's no cop, no traffic light--- and it's dark. What do we do?

Some helpful words from bio-neurologist V.S. Ramachandran:

"Autism reminds us that the uniquely human sense of self is not an airy nothing without habitation and a name... the self actually emerges from a reciprocity of interacts with others."

Ramachandran sees ASD young as lacking the basic neural ability to see themselves in reciprocal interaction with others.

In 1786 the Scotch poet Robert Burns summed the problem up:

O wad some Pow'r the giftie gie us To see oursels as ithers see us! It would frae mony a blunder free us, An' foolish notion

To A Louse (on seeing one on a Lady's Bonnet, at church)

No answers, only choices. But choices can be changed. And you will change them. And you will be changed by them.

2 TIP TWO

Cathy Pratt: Recognize that "punishment" is only a short-term solution to problem behavior. It does not necessarily equate long term behavior change. Typical disciplinary approaches are often ineffective with those on the spectrum.

Eustacia Cutler: What worked for Temple was consistency and expectation. The school days were consistent. Home life was consistent. Temple's teacher and I talked frequently to establish this. As a result Temple knew what to expect from each day.

And in return what behavior was expected from her.

When she deliberately stepped outside the expected behavior, she soon learned there would be no "Howdy Doody" that evening.

However, when the school day was too much for her (and there were those days) the teacher would call me; I'd come and take her home. You and the teacher have to know the difference.

3. TIP THREE

Cathy Pratt:

- Consequence Follows a Behavior or Response
- Reinforcement
- Punishment
- What is the payoff?
- What maintains behavior?

Eustacia Cutler: Social behavior is communication—both your child's and yours. How do you help your child—any child-- to grow into the social pattern we all need to make life work?

Temple is a social being. She was happy to learn how to dress up and behave at a formal Sunday dinner table. Also how to shake hands with guests. Guests will carry out their role in the hand shake. They've taught the same lesson to their children.

What's the payoff?

My son told me years later that he'd hated the hand shaking routine until-- after college—when he was looking for a job. He found then that interviews with an older man

came easily because of early hand shake training. He also noted that friends who'd never been taught it, had trouble getting work because they couldn't get past the first interview.

4. TIP FOUR

Cathy Pratt:

- Our escalation (yelling) can escalate the child's behavior.
- Stay as calm as possible, and know when you need to take a time out, if possible.

Eustacia Cutler: For your child: first re-read TIP TWO.

Another situation where you may have to step in is in games with other children. Because Temple was used to being praised for accomplishment, it was hard for her to understand when she did not win the game. Nor did she understand when she complained and other children yelled: "bad sport." Though aware of her own emotions, she could not see herself in relation to other children- and their emotions.

Because this social gap is fundamental to autism, you have to recognize when you, too, need time out— enough escape time to reestablish your own identity in relation to others.

My escape time was acting. The group I worked with knew that I had children, but didn't know that one of them had autism. When I was with them, my social identity was solely my own.

5. TIP FIVE

Cathy Pratt: Keep words to an absolute minimum. Use visuals, signs or other non-verbal strategies to avoid arguments.

Eustacia Cutler: In our house arguments were not part of the scheme. I had two verbal Strategies:

- 1. "This is what we're going to do. Do you want it nice or cross? I'm happy to do it either way." That meant no arguments.
- 2. "We'll see." This meant "I'm thinking about it, but if you nag at me I'm liable to get my back up and say no."

All four of my children understood both of these—and that included Temple. The other three also saw I was a sucker for a laugh, and soon learned how to joke about what they wanted. Temple picked up on this. It wasn't about words, it was about having a good time negotiating. Today when Temple talks at conferences people are surprised at her ability to joke. She learned it early from her siblings.

However, there were times when Temple simply wouldn't do what the others had been asked to do. (generally chores) I knew it wasn't fair, particularly when I'd said to the others: "You don't have to like it, you just have to do it." But in the interests of keeping the family peace, I'd let Temple off the hook.. It seemed wiser than arguing; also more comfortable for the siblings who had to live with the stress of autism which they already understood was beyond the reach of fairness. Or of words.

6. TIP SIX

Cathy Pratt: "The best time to address problematic behavior is when behavior is not happening. Proactive approaches more effective then reactive.

Eustacia Cutler: Agreed. However, it's equally important to help neighbors understand problematic behavior before it happens.

In all situations, major and minor, in order for life to function smoothly, neighbors need to understand how ASD's think i.e. though they know their own mind-set intimately, they rarely understand how others think. It's not surprising, therefore, that they can't see themselves in relation to the neighborhood.

When Temple was little, the community accepted her—foibles and all. Now she was 17 (still only 10 socially) and we were moving to Westchester, a New York suburb. And that meant change. She was very uneasy.

Before she arrived I introduced myself to each of our new neighbors, I then explained that soon there'd be a knock on their door, and when they opened it, there'd be a girl standing there who'd announce:

"I'm Temple Grandin."

I then explained autism—still an unknown subject. It prepared them for what I knew Temple would do.

And she did. And they were ready to handle it.

Neighbors are willing to help, but they need to learn how to help before the problem arises..

7. TIP SEVEN

Cathy Pratt:

- Understand that behavior may be an indicator of: no useful communication system, health issues, boredom, confusion, anxiety, unexpected changes, not feeling well, or a multitude of other things.
- Behavior is symptom of underlying conditions.
- Often an indicator of a skill deficit.

Eustacia Cutler: Behavior is social communication, particularly if the child can't talk. The more extreme the behavior (and distasteful to us), the more desperate the child. It's the only way he can get us to pay attention.

8. TIP EIGHT

Cathy Pratt: Saying "no" or punishing the child will not teach them a replacement behavior. Distract, refocus, and teach.

Eustacia Cutler: We have to get over the old adage "spare the rod and spoil the child." It's left over from Victorian thinking when prisons were called "penitentiaries:" forbidding places where felons were sent till they repented of their wicked ways. In the Victorian years those in authority, convinced of their righteousness, imposed the court rulings—an era when the term "stubborn child" entered the legal books. In effect, the ruling told the judge "this child is incorrigible. Put him away." "Stubborn child" was still on the books in 1961.

We've come a long way from that today. However we still have the problem of what eccentric behavior the family, the school and the community can absorb, what is beyond handling. And where does understanding play in?

This story of James was told to me by Chris Curry. James raised his hand in a school class. The teacher recognized him. James pointed to the clock and said: "You have two minutes left in this period. You better hurry." Understandably the teacher was outraged by what she saw as deliberate impudence. She didn't understand that James, who's literal, thought raising his hand meant he could speak. He didn't understand that he could speak only on the lesson subject. To this day the meaning of the word "unsuitable" escapes him.

How do you draw the line? Lines depend upon the child—and that leads into the next tip.

9. TIP NINE

Cathy Pratt:

- Focus on control can be detrimental to process.
- Provide choice.
- Be careful not to overly accommodate behaviors.

Eustacia Cutler: In other words, don't confuse unconditional love with unconditional acceptance. That you love your child goes without question. But the only way any child learns to live in the world with the rest of us is by learning what behavior is acceptable and what is not..

If control isn't the answer, where do you draw the line? And how?

First of all: Choice depends on what's happening, and whether your child is capable of understanding it..

Next, is your child capable of understanding the choice you're offering?

Third: can your child act on the choice?

In essence this is executive function,

i.e. the ability to access what's going on, make a decision and act on it..

When Temple (age 14) was abruptly dismissed from the school she was attending, immediate action had to happen. Fortunately I'd been researching schools for ASD teenagers in preparation for a WGBH documentary on the subject. I picked out 3 schools I'd seen and thought were tops. I told Temple we'd go visit them..

No talk of sitting around at home and brooding on injustice, no talk of any other schools. Instead I told her she could choose which of those three schools she'd like to attend. I felt she'd been brutally dismissed from the school she was in, I knew she'd developed enough to know how to assess the three schools and make a choice, and I wanted her to have a hand in her own destiny.

She chose Hampshire Country School, loved the farm and the horses, (I had a feeling she'd go for that) and was happy there for 6 years.

10.TIP TEN

Cathy Pratt:

- Schedules
- Engagement
- Predictability/Routines
- · Activities that Motivate
- Reinforcement System (if, then...)
- Visuals
- Returning to Basics

Eustacia Cutler: Oh boy! No matter how carefully you figure out a plan, don't count on its predictability!

I think of a party we used to give every Christmas night at 8 o'clock. We figured by that hour every household would have opened the family presents, toasted each other in Christmas wine, eaten the Christmas turkey, and collapsed into a happy sodden nap By eight o'clock they'd be wide awake and wondering what to do with themselves till bedtime. The perfect hour for a party.

After we ourselves had completed our Christmas routine, forget about taking any nap. Instead we scurried around, swept up the tissue paper, washed the dishes, set the table and prepared the food.

All except Temple who disdained household chores and I let her off the hook for the sake of peace.

Temple immediately set to work arranging her squeeze machine in a prominent positionready to demonstrate it to the guests. I said: "Temple, please take your squeeze machine upstairs. It doesn't belong in this event and it embarrasses your siblings." Temple did as she was told.

What I hadn't anticipated was that, in the middle of the party, she would escort the guests upstairs, through the bedroom mess we'd left behind—Temple was oblivious to that— then from her own room she'd proceed to demonstrate her squeeze machine by crawling into it herself and suggesting that the guests do likewise.

Like James, Temple only understood that she was not to set up her machine downstairs.

The siblings laughed it off.. And me? I learned you can't predict everything.

If James and Temple—because of their autism-- can only see the social picture from their p.o.v., it's not surprising that they see it as the definitive life view. And that limitation creates an odd combination of self-assurance and anxiety. While they interpret their view, with its lack of shadow and nuance, as correct, they also suffer an anxious loneliness.

"The other boys have a language and I don't understand it." A quote from a presentation by Ami Klin.

11.TIPS ELEVEN and TWELVE

<u>Tip Eleven</u>: Cathy Pratt: Realize that effective change may require that all involved in the individual's life change their behavior, as well.

<u>Tip Twelve</u>: Cathy Pratt: Sometimes changing behavior requires a willingness to change, working hard, and a calm perseverance.

Eustacia Cutler: Dr. Pratt's final tips are essential. Perseverance is probably the hardest. So in those moments when you can't carry it off as you once dreamed you could, don't beat up on yourself. Do what you can, when you can, and as best you can.

For final thoughts, I turn, once more, to the poet Robert Burns.

This time his poem is to a mouse whose nest he has—to his distress-- unwittingly upheaved with his plow:

I'm truly sorry man's dominion
Has broken nature's social union...
The best laid schemes o' mice and men
Gang aft a-gley;
An' lea'e us naught but grief and pain,
For promis'd joy
To a Mouse 1785

For current bio-neurological thinking and human wisdom I quote you the completed paragraph with which V.S. Ramachandran closes his chapter on autism:

Autism reminds us that the uniquely human sense of self is not an "airy nothing" without "habitation and a name." Despite its vehement tendency to assert its privacy and independence, the self actually emerges from a reciprocity of interactions with others and with the body it is embedded in. When it withdraws from society and retreats from its own body it barely exists; at least not in the sense of a mature self that defines our existence as human beings. Indeed, autism could be regarded fundamentally as a disorder of self-consciousness, and if so, research on this disorder may help us understand the nature of consciousness itself.

The Tell-Tale Brain. Norton and Co. 2011, page 132.

The above underlined truth lies at the heart of the autism tangle between us and them. Since we are the ones who can "...see oursels as ithers see us" and those on the spectrum rarely can, we are the ones who must see ourselves in relation to this autism glitch. After all, Robert Burns could see himself even in relation to a mouse.

Who would Temple be if those with vision hadn't stepped forward to guide her? And who would I be if they also hadn't challenged me. Those of us in the know must now guide the mainstream and perhaps turn to the Latin definition of education –"educere" to lead out. Both Cathy and I liked the kindly flavor of this old definition of education.

The ultimate goal is improved quality of life for all involved.