


WHEN WORDS HURT

Part One

A photograph of a woman with long brown hair hugging a young boy with dark curly hair. They are sitting on a wooden deck. The woman is smiling and has her arms around the boy. The boy is looking directly at the camera. In the background, there is a grassy field, trees, and a small white building under a cloudy sky.

It is natural to get defensive or upset when someone says something unkind. But by staying open to the conversation, you have the opportunity to teach others about how to be more supportive to you and your child.

By Marisa L. Petruccelli, Psy.D., and Susan G. Lauermann, May Institute

People can be cruel even when they don't mean to be. The looks of disapproval, litany of unsolicited advice, and careless references directed at a person with autism or special needs – or their family – can be as emotionally painful as any physical injury sustained.

For Tracy Pennington of Camp Lejeune, North Carolina, mother of four-year-old Jaxson and wife of Rollie Brandon Pennington, USMC E6, interactions that suggest she is not doing enough as a parent are particularly hard-hitting. “People are always asking me if I've tried such and such...that if I did whatever they suggest, my child would be ‘more normal,’” she says.

“Autism, like most disorders, is very complex. Insensitive remarks typically come from people who have a limited understanding of what the disorder is and what it isn't,” says Hanna C. Rue, Ph.D., BCBA-D, Vice President of Autism Services at May Institute and Director of Evidence-based Practice at the National Autism Center. “People in general are slow to accept what they don't understand, but have the capacity to be more supportive when they learn more – in this case, more about autism spectrum disorders.”

Even so, chalking up hurtful language or attitudes to ignorance offers little comfort to parents who find themselves in social settings with people who are quick to judge a behavior that is unfamiliar or uncomfortable. Keep in mind that there are strategies to help you successfully turn these encounters into opportunities to inform and educate, while advocating for your child and family.

What's pushing your buttons?

As part of a broader public awareness campaign about autism, May Institute asked military and civilian families served by Institute centers and schools to identify insensitive or hurtful comments they have experienced.

There were a number of recurring “offenders” that will likely sound familiar to parents of children with autism:

1. “What's wrong with her?”
2. “If you just disciplined him more he would know that isn't acceptable behavior.”
3. “Does your kid have issues?”
4. “Have you tried? If you did, she would be more normal.”
5. “Your child doesn't look autistic or retarded.”
6. “Oh, so he's like Rain Man? Neat!”
7. “Why don't you just leave your kid at home? It would be so much easier for everyone.”
8. “My child doesn't know how to play with your autistic child.”
9. “Funding would be better spent on normal children.”
10. “Don't worry – he'll grow out of it.”

These comments hurt, regardless of their intent. Responding to the comments and to those who share them is not an easy task.

A parent may be better equipped to handle challenging situations on some days rather than others. “It is hard not to lash out at times,” acknowledges Laura Blair, who serves in the military and is mother to 14-year-old Austin, who has a diagnosis of high-functioning autism. “But you have to think of it as a way to teach compassion and tolerance. Any time my son hears something hurtful, I use it to teach him how to handle his own emotions. After all, we will never change everyone's views, but we can change how we respond to and view



Laura and sons Nathan and Austin enjoy a sunny afternoon outdoors. *Opposite:* Tracy and Jaxson have fun on a tractor ride at a farm.

everyone else.”

For Laura and other military families, this impressive combination of skill and patience can be difficult to muster and maintain, due in large part to the frequent relocations that are typical of military life. Disruptions to routines and structure create significant challenges for the parent trying to introduce a child with autism to a new environment, while at the same time adapting to new doctors, therapists, peers, and a whole new community – one that may or may not be familiar with the complexities of the disorder. •

About the Authors:

Marisa L. Petrucci, Psy.D., is the Director of the Autism Spectrum Disorders Clinic, a joint program of the National Autism Center and May Institute. Dr. Petrucci has served as Director of Home-based Services for the Institute, and was responsible for an early intervention program for children with ASD under age 3 as well as community-based intensive behavioral services for youth under age 21 with behavioral health challenges.

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Next month: Part Two

WHEN WORDS HURT

Part Two of Two

It is natural to get defensive or upset when someone says something unkind. But by staying open to the conversation, you have the opportunity to teach others about how to be more supportive to you and your child.

By Marisa L. Petruccelli, Psy.D., and Susan G. Lauermann, May Institute

What tools are most effective in diffusing or managing potentially hurtful experiences? With input from military and civilian parents from across the country, we offer the following suggestions. The goal? More successful interpersonal communications, greater understanding, and increased support.

- **Practice patience**

It is natural to get defensive or upset when someone says something unkind. It is human nature to feel protective or want to fight back in response – particularly if it involves your child. Remind yourself that the other person's knowledge of autism may be limited or non-existent. By staying open to the conversation, you have the opportunity to teach others about how to be more supportive to you and your child.

- **Be communicative**

You may be surprised by how accepting others can be when your child's behavior is attracting unwanted attention in a public place (such as in a grocery store or at the mall). A little information can go a long way. Take a moment to say, "My child has autism. He's nonverbal, so this is one of the ways he communicates." When there are typical children involved in the interaction, it can be especially effective to explain to both the parent and their child what your child is doing and why he is doing it. This will help ease their own anxiety and make it easier for both the parent and the child to relate to the emotions your child is experiencing.

People generally want to be helpful. If they ask you how they can be helpful, tell them what you need. If it means helping get the groceries out of the cart or helping you with the popcorn at

the movie theater, let them. Everyone benefits.

- **Take advice in stride**

Everyone has an opinion. Your job is to decide which opinions matter. A smile and "thank you" often works best for the know-it-alls. But, if there is an opening for longer dialogue, use it. Consider sharing some of the facts you have learned on your journey to correct a misperception about autism.

- **Keep an open mind**

You are the expert when it comes to your child and your family. But every one of us takes in new information, perspectives, and experiences every day. We process, file away what is useful, and discard what is not. Even when you feel your choices may be challenged, try to remain open-minded. You never know when a new piece of information will emerge that will be helpful with future decisions.

- **Disarm them with charm**

There may be instances where you feel compelled to apologize for your child's behavior when in fact, an apology is not justified. For example, this may occur if you sense that your child's behavior is making someone else anxious. Instead of apologizing, try to find a way to calm the person down by getting their attention and explaining the behavior. For instance, another person in line is visibly anxious about your child's behavior. You smile and say, "You know that is a lovely sweater. The colors are beautiful." Then you continue, "This is my son Tommy. He is 8 and very excited about this poster. Tommy has autism, and this is how he lets me know that he's excited."

A remark to redirect their attention opens the door to then

“Everyone has opinions. Your job is to decide which opinions matter.”

introduce your child, and possibly more. It may seem unfair that you should have to spend the time and energy, but in doing so you will have helped raise awareness about autism to one more person – one individual who will likely share a portion of that information with 10 other people who will use it to benefit others in the community.

- ***Find strength in perspective***

You are not weak to acknowledge that caring for a child with special needs is not easy. You are being realistic and honest. There isn't a person on the planet who does not face challenges. Consider the possibility that a person asking whether caring for a child with special needs is “difficult” may sense a connection to you and want to find a way to be supportive. Do not be afraid to let them in.

- ***Consider alternatives***

“I don't know how you do it” pushes buttons for many parents. Many interpret this as an expression of pity, or commentary that life with a child with special needs must be overwhelming. Others might hear it as an implication that their child's disability somehow affects the amount of love they as a parent are able to give that child. While any of these interpretations might be correct, there is another scenario to consider.

Think about the other parents in your circle who you envy at

times for their apparent ability to leap tall buildings in a single bound. We all observe people doing incredible things under challenging conditions; they impress us because we believe we would be less equipped to do the same ourselves. Before assuming the worst, entertain the notion that the comment was intended as a compliment, or even a person trying to reach out and learn from you.

- ***Positive attracts positive***

Being the parent of a child with special needs can sometimes feel isolating. It takes courage to go out into the world when you know there are people who will be critical and judgmental. You are not alone. There is a large community of parents who understand your struggles. Find ways to surround yourself with those who share your values, support your needs, and subscribe to a positive outlook.

- ***Practice self-care***

In a 24-hour day in which 34 hours are needed, it is almost unfathomable to contemplate building in time to take care of your personal needs. But it is imperative that you do. You cannot center your life exclusively on the child with special needs and still be the person that child and your family needs you to be. Apply the same creative resourcefulness you apply to other facets of your life to find time to stay healthy at every level.

Parent Perspectives

“Yes it is hard, yes it is frustrating, and yes for the most part I am exhausted beyond belief. But yes my child is amazing, yes my child is smart, and yes my child has something to give to this world that no normal child could contribute.”

– Navy parent, Georgia

“I exhaust myself day in and day out with research, therapies, approaching strangers for ideas and answers. It is not fair nor right for someone who has no idea about the challenges of raising a child with autism to assume what amount of energy I invest in my child. Trust me, it is a 24/7 job!”

– Army parent, Fort Benning, Georgia

As part of a broader campaign to raise awareness about autism, May Institute polled military and civilian families about what they believe most people don't “get” about raising a child with autism. Examples from those responses are included here. We encourage you to share these with friends, family, colleagues, neighbors, and others who might benefit from these perspectives and glimpses into the lives of other families.

“More than anything, I want people to understand the cycle of absolute joy, fear, sadness, pain, pride, love, uncertainty, etc., that it takes to raise a child with autism.”

– Army parent, Fort Hood, Texas

“Just because a child with autism is non-verbal or does not make eye contact, it does not mean he or she doesn't notice the looks or feel pain from being ignored, bullied, or disregarded.”

– Civilian parent, Massachusetts

“It is not that he doesn't want to be a good student, a good communicator, behave or do right.... it's that he finds it more difficult than I to do the 'normal' things, like be organized or hold a conversation.”

– Navy parent, Yorktown Naval Weapons Station, Virginia

“Be kinder than you need to be, because just about everyone is battling something you know nothing about.”

– Civilian parent, Massachusetts

United States Military Section

- **Build the foundation early on**

The younger you are, the easier it is to learn a new language. One of the best strategies for cultivating a community of acceptance is to seek out opportunities while your child and his or her peers are young to engage both the children and their parents in shared activities. Don't be discouraged by parents who resist those opportunities. Focus on those families who are receptive. Spend time teaching your child and his or her typical playmate about each other's preferences and ways of communicating. Praise the parent for their child's ability to relate to yours. Before you know it, the barriers come down and the opportunity for a new friendship emerges.

- **Acceptance begins with you**

Not every social situation can be controlled or orchestrated to strike the perfect chord every time. But each encounter has the potential to inform, educate, build connections, and extend the critical circle of support for families of children with special needs. In the end, each of us is looking for the opportunity to do our best, free from criticism, judgment, or



Shawna and Tyler share a sweet moment

unrealistic expectations.

"I am not a superwoman. I do not always have it all together," shares Shawna Rowan from Georgia, mother to 11-year-old Tyler and wife of Christopher Rowan, OSC E7. "Do not bless my heart or tell me how big my crown in heaven is going to be. Just let me be myself sometimes – not the person who can handle everything and has a child with autism."

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Susan G. Laueremann is a Director in the Office of Communications at May Institute. She has been a senior-level communications professional for more than 20 years.

Parent Perspectives

"There are days that in my mind he's just a little boy who needs extra help, and others where his autism rips my heart out because I know what a struggle it can be for him to communicate, and that never goes away."

– Army parent, Fort Hood, Texas

"Although autism doesn't run our life, we do plan and do almost everything differently or in ways to help our child to have the best day he can, every day."

– Army parent, Fort Hood, Texas

"Parenting a child with autism is difficult and rewarding, just like it is for parents of typical children. It just takes a little more patience and understanding."

– Civilian parent, Massachusetts

Try spending a day in my shoes and tell me your advice then!"

– Marine Corps parent, Camp Lejeune, North Carolina

"Parents of autistic children need support. They need their friends and family to ask about their children, how things are going, and if there's anything they can do to help."

– Army parent, Fort Hood, Texas

"Not all children with autism are exactly alike. Yes some are not interactive with others but others do want so badly to be social and have friends – they just do not know how."

– Navy parent, Georgia

"IT IS HARD! Especially when you have more than one child. It is a difficult balance between helping my autistic son, being a good mother, a good wife, and a good employee. It takes a lot of strength!"

– Navy parent, Yorktown Naval Weapons Station, Virginia

"There can be a light at the end of the tunnel... never feel defeat."

– Army parent, Fort Hood, Texas

"I don't think others understand how time-consuming therapy, safety, and taking care of the child is. I don't think they understand the anxiety on the child's end."

– Air Force parent, Fort Hood, Texas