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AUTISM ISOLATION SYNDROME

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Families with autistic children face many challenges. Emotional, physical, financial, and social difficulties arise in a variety of different contexts. The stress of dealing with these challenges can be overwhelming. One way families cope with this stress is to isolate themselves from people and situations. I call this pattern of coping "Autism Isolation Syndrome". The three main components of the syndrome are:

- emotional isolation from the self
- physical isolation from others
- social isolation

The patterns' goal is to create a sense of control for parents who often feel overwhelmed. Couples often go for long periods of time without seeing their friends and avoid multi-family gatherings. A complex set of emotions explain why the isolation occurs. Conflicts like, "How will I deal with my feelings in public?", "How much should we share?", "How will I deal with people if they are judgmental or insensitive", "Will I be able to relax and have fun?" are common. Because autism, autistic behavior and how it effects each child in an individual way, is so hard to explain to people, many families opt for isolation as a way to feel more in control of the disorder and its challenges.

Fatigue also becomes a problem. Intensive schedules of treatment and schooling consume many hours on a weekly basis. Sleep patterns are often erratic in an autistic child and the entire family is affected. So fatigue is often used as an "excuse" not to socialize.

Many people lose sight of the importance of staying socially connected. This is partly because many of their personal feelings and needs are being over-shadowed by their love and concern for their autistic child and other children in the family. They forget their own needs to laugh, be nurtured, intellectually stimulated and self actualized. This pattern of deprivation often leads to depression and other emotional and physical problems. Addressing the issue of fatigue with a doctor may become necessary in order to regain the energy to resume a more socially active life, both as a family and as an individual.

EMOTIONS THAT CONTRIBUTE TO ISOLATION

Many parents experience overwhelming feelings of grief, anger, sadness, guilt, and even shame in the early stages of the isolation syndrome. Emotional isolation usually starts within the home itself, and between family members themselves. Concerns about having "wrong" feelings or burdening other family members with feelings arise. Individuals can decide to deal with many of their feelings by themselves. This suppression is normal on an occasional basis but becomes unhealthy as a pattern. It keeps family members from getting the support and nurturing they need from each other and can lead to depression and depletion. The suppression of emotions can also facilitate denial. Denial can be a coping mechanism which helps people function during difficult times. It can keep feelings contained to a manageable level, which allows for success in seeking and securing proper medical and education intervention for their autistic child. At the same time it can block powerful feelings and the awareness of the need to talk and to get support. The focus becomes about doing what has to be done to deal with the demands of daily situations in the family, and it becomes too threatening to feel. Lost in the frenzy of trying to follow professional advice to help the child, one can lose a sense of their own feelings and needs. In the breakdown of emotional communication, exhaustion can occur ("isolation syndrome" stage 1), judgment can be lost, and the likelihood of inappropriate decisions regarding treatment strategies for the child can increase.

BREAKING THROUGH STAGE 1 - ISOLATION WITHIN YOUR FAMILY

Talking about sadness is essential in helping families break the pattern of emotional isolation from each other. Feeling sad about your child's autism is normal. There are things you imagine that he/she will never experience such as a career, a relationship, security or happiness in their lives. Before treatment and education begins to yield progress for your child, it is understandable to feel more loss than gain, more despair than comfort. Families who fail to vent this emotion become less intimate in general and more isolated from each other. It is as if each person in the family represents a trigger for raw emotion, and it is scary to go into the feelings. To avoid the discomfort of emoting, excessive time is spent talking about autism schools and programs instead of broader issues pertaining to the lives and feelings of the entire family.

One method for breaking through this emotional isolation is to schedule a family meeting and have what I call "an open book session". This involves everyone in the family revealing feelings and being open to each other. Asking questions like "Why do you feel sad about Johnny having autism?" "Did you cry this week about anything that we have been dealing with?" "What do you think we are missing out on? Are you angry, and if so what are you angry about?" Questions specifically about sadness and anger can open up communication and put feelings back into the vocabulary of the family. If the family gets used to "venting" in a structured way about issues pertaining to their autistic family member, they can feel a release that allows them to access their individual desires to focus on themselves and the parts of their life that are not consumed with dealing with issues related to autism.

Discussing guilt within the family is crucial. Many people feel guilty about their feelings. They feel guilty about their sadness as they perceive it to imply pity and the diminishment of the value of their autistic child. They feel guilty about their anger, in the realization that their child's problems are a result of a disability that is not their fault.

Parents struggle with questions about their responsibility in the appearance of the disorder. "Is there something I did or did not do to cause this?" is a common conflict. If guilt is not resolved, compassion for oneself will continue to be blocked. The result of this can be lead to "isolation state II syndrome", the physical and social isolation from others. If a person does not feel compassion and acceptance of themselves and their feelings, it lowers self esteem and raises shame and anxiety around other people. It is only through the venting of sadness, fear and anger that guilt can be resolved. It is through the experience of these difficult feelings that positive and constructive feelings about oneself and life in general can emerge.

STYLES OF PHYSICAL AND SOCIAL ISOLATION (Stage 2 and 3 of the "Autism Isolation Syndrome")

One style of physical isolation is to cease physical contact. This helps to keep emotions buried. Less hugging and touching is a common result of emotional suppression. This physical shut down discourages socialization where the possibility of physical contact is high. Allowing people to comfort you in a physical way can re-open the door to your normal pattern of socializing. Having a child with autism exposes one to the extremes of social and interpersonal disconnectedness, and it can take effort to fight the temptation of "joining" the child's world in order to feel connected to them. The family's ability to stay connected to themselves, each other, and social connections can greatly increase the child's potential for socialization.

SOCIAL AWKWARDNESS

The feeling of being different from other families occurs for people with children on the autistic spectrum. In other words, the differences in their child translate to the family being different. This line of thinking can result in families thinking about where they "should" or "can" go, as opposed as where they "want" to go. Families often stop doing the things they used to do. They become unsure about how to participate now that their child's autism has resulted in difficult behaviors and emotions. Isolation provides its own form of comfort, but not without profound loss.

Fear and shame are also major emotional challenges to overcome in stage 2 isolation. "Will I look like a bad parent if my child acts out or sounds off in public?" "Will my child be ridiculed or cause fear in others?" "How will I handle it if it happens?" "Isn't it better to stay home or socialize only with families who have autistic children?" These questions can bring up fear and conflict and cause many families to decide to isolate. Developing communication skills for dealing with the public helps decrease fear and social avoidance. Learn how to:

- Explain the situation to others in ways that respect your privacy
- Request that people not get involved
- Express your feelings of anger
- Apologize as the situation calls for
- Have a plan and a script ready to deal with your most feared situation

For example, if you are in a mall and a nice old lady tries to prompt your non-verbal child to talk you can say, "He doesn't talk to strangers". If your child is having a tantrum because he wants something that you are not going to buy him and a stranger says, "What a brat. He is spoiled", you can say, "This is not your business, please stay out of it." When emotions are running high, do not always hold yourself to politically correct standards of communication. There are rude and uninformed people out there who will hurt, embarrass or anger you. They are not worth isolating over. As a matter of fact it can be quite cathartic sometimes to let them know what is really going on with your child and watch THEM feel the discomfort of having been inappropriate and uncompassionate with you, your child and family. Also remember, there are nice, caring people out there who will understand and feel compassion and show tolerance.

ISOLATION VS COMMON SENSE AND JUDGMENT

It is understandable that situations should be evaluated for their appropriateness for the autistic child and the family. Concerns about safety and emotional and physical appropriateness are necessary. But the challenge remains for families to learn how to reduce fear and discomfort and adapt to environments in order to encourage a broader repertoire of social experiences. It is important to have plans that include specific coping techniques for public and semi-public situations. It is also important to know when things are not working out and to go home and try again another time. The commitment to try again and to learn how to better deal with the child's special needs while out in public is essential for breaking the isolation pattern.

SOCIAL SETTINGS OF PARTICULAR CHALLENGE

Many families avoid restaurants, airports and travel, sporting events, amusement parks and social celebrations. The more crowded and "rule driven" the environment, the more challenging is the management of the situation. To assist in developing a successful plan, it is essential to understand:

- Your child's sensory and motor challenges
- Your physical and emotional state
- The goal of the social outing and it's importance and value to you
- Rules and boundaries of the social setting

THE ROLE OF SENSORY ISSUES AND SOCIAL SUCCESS

A lack of knowledge in this area can result in chaotic experiences that make you long for the safety of the insulated environment of home. Knowing how to deal with your child's sensory overload can create more social mobility. For example, taking the right equipment with you or extra people to help you cope with your child's emotions and behaviors encourages going out into the social realm. Every child has an individual sensory profile, and an experienced occupational therapist should be consulted on an ongoing basis for support in this area. Having tactile and auditory props can provide "treatment" for your child's dysregulation in a situation.

After obtaining a "sensory diet" and "sensory profile" from the therapist you are better equipped to branch out into the world and return to activities that make you feel a part of a normal life, (whatever that may mean to you and your family).

TIPS TO CONSIDER FOR THOSE CHALLENGING PLACES

Airports:

- If your child must travel and has anxiety in airports, consult your physician for possible medications in anxiety reduction or sleep
- Play with airplane toys or read books about traveling by air in advance of your trip
- Drive by the airport without stopping and gauge their responses (Desensitization process can reduce anxieties and phobias)
- Check with the airline ahead of time for early boarding privileges
- Try sitting in the back of the plane. This allows for easy access to restrooms and more controlled contact with the general public
- Bring earplugs or headphones with favorite music
- Bring comforting toys from home
- Have food and water ready at all times
- Bring pictures of where you are going as well as photos of home

To help orient the child to the experience.

Restaurants:

- Bring food for your child so he won't be ravenous and impatient
- Bring new or favorite toys to keep them busy
- Start out with short stays to build familiarity and tolerance
- Try to seat your child against a wall for behavioral containment
- See the environment as an opportunity to ready your child for the world outside of controlled environments like school and therapy
- Use the new food environment to introduce new foods, new language and socialization
- Make sure the restaurant has "kid friendly" food that works for your child

Remember: It is the being out in public, and the breaking of isolation that is the main goal here. Your favorite restaurant may need to be reserved for outings with friends.

Many of these tips can be applied to movie theaters, sporting events and other settings. The idea is to know your child's needs and be as prepared as you can be. The reality is when out in the public all tricks can fail. What you are faced with then is a decision to leave if you can, or accept that the discomfort you feel now is worth the knowledge that you can be out in the world trying to live as full a life as possible.

Access to support groups and other families dealing with autism is another way for people to keep connected. What is most important is that you find a balance between professional support, group and organizational support, and a way to resume a satisfying pattern of social connections. What better environment is there for an autistic child than one that is focused on contact with people and exposure to life's adventures.