

Regressive Periods of Functioning: Treatment and Coping Strategies

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When you think about a regression, words like fear, loss, and failure often come to mind. By definition, a regression means going backwards, or in terms of human functioning, the return of previously alleviated negative symptoms or patterns. The autistic brain has difficulty being able to consistently regulate and integrate different sensory processing systems, which creates an unstable pattern of progression and regression in the functioning of ASD children. In other words, it is not uncommon for a child to be tantrum free for a year, and then all of a sudden begin a pattern of tantrums in situations that have been otherwise manageable and stress free for them. My wonderful 12 year-old son Benny suffered a regression last year and this article is an account of his and our experience of it and what we did at the time and are doing now to understand it and use it to help Benny find his way back to where he once was.

For parents, the greatest fear about a period of regression in behavior and other functioning is that the regression will be permanent and or that it is a sign of a poorer prognosis than previously thought. Doubt, guilt and fear can overcome parents and an all-encompassing negative outlook can become more detrimental to the recovery of the child than the regressive episode itself. Being educated about what might be causing the regression is helpful both in treating the presenting problems. Awareness of what might be causing the problem will help the treatment process, and also help parents and professionals deal with the emotional strain of the experience.

My personal story provides the framework for this article and can be used as a template for navigating through regressive episodes and coming to terms with what to do when they happen. Learning how to manage the feelings that emerge through the experience and develop an understanding of what the regression is "communicating" about the child's condition are major goals in the process.

The "Episode": April 2006

I had decided take my son to see a new psychiatrist. He had not had an evaluation by a psychiatrist in years, and my specific goal was to discuss the issues of apathy and the lack of self-initiating behaviors. I felt that these issues were holding Benny back in the in the areas of cognitive, social and language development so I was open to the doctor's suggestion of medication. Celexa, which is an SSRI (serotonin reuptake inhibitor) medication was prescribed in a low dose on a once a day basis. After one dose of the medication, my son had a drastic gastrointestinal reaction (severe diarrhea) which lasted almost 10 days. Ten days after the intestinal symptoms stopped, his regressive patterns of behavior began. The simplest way to describe what he was like is that he just stopped doing what he had been capable of doing before, even down to being able to comply with the simplest requests such as "Benny, come here." We found ourselves using words like "frozen", "stalling", and "sticking" to describe his behavior. He would start to get out of a car, then freeze with one leg hanging out. We would ask him to hand us something he was holding, and he would stare at us as if he did not know what we were saying or what he was supposed to do. Then the behaviors began to vary, from not even trying to move or comply, to starting the action and stopping midway into it. He became unable/unwilling (depending on the perception of the person trying to deal with him) to make simple transitions Sometimes it would take almost an hour to leave a restaurant, store or car. Eating a meal or getting dressed became a drawn out process, most of the time having to result in maximum support to complete the activities.

Benny also lost a significant amount of his already limited verbal communication. Requests for language were met with the same silent, frozen responses as with requests for physical compliance. Life became extremely stressful and painful for us, and seemingly frustrating and scary for Benny. By late April, we began the process of talking to a variety of professionals to get their perceptions and diagnosis of what might be causing the regressive functioning.

The Behavioral Perspective

The behaviorists used words such as non-compliant, oppositional and defiant to describe Benny's behavior. The speculation was that Benny might be testing the limits being place on him and trying to assert his personal control. I was encouraged by this thinking, in that I knew that if this was the reason behind his regressive behavior, it could be an indication of an increase in executive function (cognitive development) or emotional or relational intelligence. The behaviorists were clear with Benny about what

behavior was expected of him and used positive reinforcements when he was able to do the behaviors. Unfortunately the behavioral strategies applied did not work. Benny did not seem to be motivated by positive reinforcements and he continued to physically “freeze up” or physically resist any kind of physical attempt (modeling behavior, hand over hand, etc.) to get him to comply. Other therapists and teachers working with Benny felt the regressive functioning was volitional, that he could control it, but was choosing not to. The presence of certain behaviors, (such as Benny’s ability to reference to a person through good eye contact or indications that he receptively understood what he was being told but refused to do it) encouraged their thinking along these lines. There were times in the beginning of this regressive episode that I felt that this assessment might be correct. But I had my doubts and thought of ways to test the hypothesis of “intentional opposition”. I began to give Benny alternatives to requests being made of him. For example, instead of telling him to come when it was time to eat, I would sit down myself, start to eat and make sounds about how good the food was. I knew he was hungry, and I would put his food far enough away so he would have to come to eat it. I removed the verbal command for him to resist and he would still not come and eat. It was as if he was unable to execute what he needed to do with his body in order to complete a sequence, even if it was about a preferred situation “he” could choose. If I brought the food over to him, (which is a less demanding way to signal him to go into action), he would still just stand there. But when I tapped his hand to move it (sensory input to cue awareness to his hand), or pointed to the food and made the sign to “eat”, he would eat. This told me that with extra communication to his body about what it was supposed to do, he could “unfreeze.” When completely left to his own devices, he could stay stuck indefinitely, as if he was unable to function without us. If his behavior was all about control and defiance, even the milder forms of prompting and instruction would have been resisted by him. Oppositional/defiant kids often do the opposite or choose something other than what is requested in order to assert their independence or to rebel. This did not describe our frozen little boy.

There were times when the sensory input did not work, and we had to come up with other strategies. All the techniques worked for a short period of time, and then they would lose their efficacy. I believe this meant that for some reason, the “novelty” aspect of a strategy would jolt his attention and his awareness and cognition would be heightened, but when any approach became too familiar or predictable by him, he froze up again, almost as if a mind/body separation would occur. Some of the strategies that were effective for a time were:

Putting commands on cue cards that he could read out loud.) When he read them, he would do the action, which reminded me of the powerful influence that language had over the ability to act independently, or spontaneously.)

Reverse Psychology (For a time, if we said “OK, then don’t sit” he would sit.)

Telling him our feelings about what he was doing (We would say, “I am getting upset because you won’t get in the car.”)

Putting a preferred item in the path of where we wanted him to go. The motivation for the object would sometimes “pull” him into motion.

Having different people intervene in facilitating him

Giving him pictures of what we wanted him to do or where we wanted him to go

Giving him a lot of time to process what we were asking of him

Simplified language with the focus on his name and the action

Giving him alternative choices to make

Changing plans and changing some aspect of the requested or the style of communication (changing voice volume or singing the language).

Most of these strategies worked intermittently and we were encouraged. We felt there was hope that we were still able to get into his world. But the “freezing” kept coming back. We knew we had to learn more about the responses he was having and we decided to consult professionals from a variety of different areas of psychological and medical schools of thought. We contacted people who had worked with Benny over the years so we could compare their different mindsets about the regression and hopefully learn more about the cause and treatment.

The Neurological Perspective

I brought my son to see the neurologist within two weeks from the start of the symptoms. At that time, Benny was not responding to requests or commands, was making rigid movements with his arms, and having facial movements that seemed involuntary. The doctor observed Benny and talked to us about

what could have happened to cause this. There were no recent traumas or changes in Benny's life or to anyone in the family. The doctor said Benny did not seem depressed or anxious and the movements, posturing and freezing behaviors seemed to be involuntary. The preliminary diagnosis was a possible allergic reaction to the medication, Celexa, as that was the only recent change to any of Benny's treatment. He told us he would contact the manufacturer of the medication to see if there had been other reports of such a reaction in children Benny's age. In the meantime, he assured us that the symptoms would diminish over time and that there was no medication or procedure to help with this process. He did not believe that Benny was having seizures and did not recommend an EEG or any type of brain scan. He said the symptoms Benny was having was similar to a condition Parkinson's patients have called Tardic Dyskinesia, where the body is unable to complete or initiate movement at certain times.

The Psychiatric Perspective

Several weeks later, Benny was in the same pattern of symptoms and daily life was difficult for him and our family. I took him back to see the psychiatrist who had prescribed the Celexa. I told him what the neurologist's opinion was and he did not agree with it. He said he believed it was possible that the stress of the side effect of almost two weeks of severe diarrhea may have caused Benny extreme anxiety and this could be impairing his ability to move about comfortably and securely. The doctor was unsuccessful in his attempt to get Benny to interact with him or to comply with requests during the consultation. He persisted in his original diagnosis of Anxiety Disorder and made several, non-medication suggestions, such as occupational therapy, physical therapy and acupuncture. He had also mentioned a medication to increase Dopamine levels, as he said the inhibition of physical movement could be a sign of a deficiency in Dopamine. We chose not to pursue medication therapy at this time due to Benny's tendency towards severe side effects.

The Developmental Perspective

I next turned to our developmental psychologist, Dr. Arnold Miller, a renowned autism specialist, director of the Language and Cognitive Development Center in Boston, Massachusetts, and author of two books, From Ritual to Repertoire and the recently published, The Miller Method. Developing Capacities of Children on the Autism Spectrum. Over the past 5 years I have been trained by Dr. Miller, via video conferencing, in his method, the Miller Method, which is a cognitive, developmental systems approach to treating autism. Dr. Miller has also provided direct treatment to Benny through video conference training in our home. His observation of Benny's regressive behaviors yielded a different theory than the other professionals. He believed that Benny was experiencing severe dysfunction in the area of body awareness and body organization. This is an area of expertise for Dr. Miller, whose method for treating autism involves facilitating body awareness, body organization and language through the use of functional systems (i.e. pouring water, stacking dishes) that teach children they can have an effect on their environment by initiating action upon aspects of a system involving objects and people. When we asked him why Benny not pick up his fork to eat on his own anymore or why he would not get out of the car when the door was opened, Dr. Miller said that it seemed that Benny had lost the ability to be automatic and independent in the use of his body and was no longer able to tell his body what to do. Dr. Miller said his dependency on prompting indicated he needed to use other people as an extension of himself.

In other words, he had currently lost a part of himself. This described Benny's functioning when he was 6 and first began treatment with Dr. Miller. This theory explained why Benny now required maximum prompts to physically and verbally react to requests being made of him. He had truly regressed back to where he was 5 years prior.

Dr. Miller helped us devise ways to assist Benny in re-learning what he was supposed to do with his body in different situations. Some of these strategies were:

- Using flash cards to tell him what to do with his legs when we wanted him to walk (i.e. "pick up leg")
- Showing him pictures of himself engaged in resisted activities
- Tapping each individual body part as a signal for him to "feel it" so he would know to use it
- Applying pressure to his joints
- Engaging in big body activity
- Modeling with our body what we wanted his body to do
- Giving an object that is needed to complete a "system" (i.e. a piece of a puzzle, the last block on a block tower, to "urge" his body to move...)
- Counting to 5 or 10 and saying "go"

As the weeks passed, Benny's symptoms lessened. He responded to the strategies and we were able to resume regular activities with more success. But the symptoms did not disappear, and eventually another regression of behavior occurred and the prompts stopped facilitating compliance. Benny became agitated to what had become predictable attempts on our part to get him to comply with requests to talk, transition, and perform simple home and school tasks. It was as if he could not bear the demands of every day functioning and he wanted to be left alone to do very little.

Dr. Miller said that this alienation from his body could be a result of the onset of puberty, with his body beginning to feel differently, he may have lost his ability to relate to it and use it the way had had become accustomed to. He said many kids regress during the years of puberty, experiencing mood changes, body awareness issues, and sensations that confuse and distract them.

Moving into Solution, Acceptance and Cause vs. Cure

After several months of dealing with Benny's regression issues, we became used to having to apply the many rituals necessary to get him "unstuck". We developed curiosity and creativity in helping him to be able to function. Our repertoire had grown into a system of ideas and interventions that took into consideration some of the expert evaluations of Benny's condition and our own intuition and knowledge that grew out of living with him for years. Despite the regression, he was still Benny, a lovable, emotional and complex little boy. He was able to walk, talk in 1-4 word sentences, ride his back, play simple board games, watch his favorite videos, resume his schoolwork, go to stores and movies, and hug and cuddle as he had done before.

We also realized the importance of establishing relationships with professionals that we could trust to listen, (to our emotions and instincts, as well as the details of Benny's behaviors), and be available, curious and persistent in helping us find solutions for the regression and ideas about recovery from it. Part of the solution now included a heavy dose of positive thinking. Our strategies did help at times, and we knew it meant that Benny needed us to be strong, smart and persistent in helping him. We also developed a healthy sense of competition between ourselves, (whose approach would work today?) and often shared some good smiles and laughs about this journey through regression to recovery. The process was difficult, but in hindsight it forced us to pay more attention to the varied ways our son communicated what he was going through by being autistic and experiencing life through a complex and mysterious filter. But the work has yielded much knowledge and effective tools to cope with whatever curve balls autism throws in Benny's path. We hope that through this experience, Benny somehow knows that no matter what those challenges will be, his family is up for the challenge and that regressions are now a part of moving forward.

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