

STRAIGHT TALK

About *Autism*

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On Recovery

About 18 months ago, I attended a national conference on autism in Providence, Rhode Island. One of the keynote speakers was a well-known researcher who gave an eloquent presentation about the dangerous effects of toxins on child health and development. She made a clear and convincing argument about the importance of funding research to examine the relationships between toxins and chemicals in our environment and foods, and the increase in neurodevelopmental disorders such as autism. Sprinkled throughout her presentation were comments that implied that we are at the precipice of being able to “reverse the course of autism”; “resolve the toxic influences that cause autism”; and yes, “recover children from autism”. Knowing that approximately one-half of the audience of 800 was comprised of parents, I immediately began to reflect on what they were likely taking away from this presentation, and my discomfort increased. There was a strong implication that nutritional and biomedical interventions were the only hope for the future.

Immediately after the presentation, a few parents of older children who I had known for many years came up to me and said, “Here we go again; lots of promises with no accountability. We’ve been down this road too many times”. No one thought that the talk

was unimportant. The concern of these “veteran” parents was the message that would be taken away by parents new to autism.

Spurred on by the concern of these parents, I approached the speaker and respectfully asked her to expand on how she defined and would measure “recovery”, and “reversing the course of autism”. After quizzing me on my credentials, she brusquely stated, “Yes, I guess we need to consider this issue. My colleagues and I intend to have further discussions about this”. Quite frankly, I was dumbfounded. Although she felt free to use the term, this renowned researcher had not yet operationally defined *recovery*, a concept that most parents and practitioners would agree not only requires, but actually begs for clarity, since the idea of recovery is arguably one of the greatest areas of debate and divisiveness in the field of autism today. Specifically, should we continue to consider autism to be a lifelong developmental disability for the majority of affected individuals, as it is currently defined, or should we consider recovery a realistic goal to strive for? My true concern about this presentation was its lack of balance, given that the speaker clearly implied that all hope lies within biomedical approaches; whereas educational approaches (by clear omission during the presentation) offered little hope.

The Controversy Surrounding the Term *Recovery*

Now why should the issue of recovery even be controversial? Certainly, the great majority of professionals and parents, and many individuals with autism, would welcome and even celebrate breakthroughs that reduce or eliminate the great challenges and stressors associated with autism. However, the language we use does make a difference, and there is growing evidence, albeit mostly anecdotal, that setting unrealistic expectations (and in the worst case, making unsubstantiated promises to parents), can have a profound, detrimental impact on families and children.

Let’s start with the issue of the language that is used. Many phrases have been tossed around loosely over the past few decades regarding progress that we hope to see in children and older individuals with autism. The word *cure* has been used infrequently over the years, but as many neurologists have noted, to cure a neurologically-based condition: 1) the specific nature and site of impairment must be identified; and, 2) it must be demonstrated that the impairment or damage is no longer present following treatment. Neither of these criteria has been met regarding individuals with autism. Furthermore, most research indicates that autism is not likely caused by neurological “damage”. Rather, the problem appears to be that of *brain function*; that is, in how the wiring “works” (“connects up”), not in *damage*

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to the wiring itself. As a replacement for the word *cure*, the term *recovery* has become increasingly popular (although given how it is currently used, one would be hard-pressed to define the difference between the two!) Indeed, *recovery* is the preferred term today, and has been used in various versions such as, *making progress towards recovery; recovery from autism; and on the road to recovery*. Coming from an educational and therapeutic perspective, I've come to wonder how these terms are different from descriptors I have used, and that have been used commonly by colleagues and parents in reference to so many children over the past 30 years, such as, *she is making excellent progress; is doing really well; appears to be overcoming many of his challenges*; and so forth. The answer is obvious: The descriptors that are becoming increasingly popular today focus on the destination (i.e., *recovery*), while the terms that educators and therapists continue to use focus on the journey (i.e., *progress*). A similar issue arises with the phrase that has come to be used as a motto by some organizations: *Autism is treatable*. In my three decades of practice, the overwhelming majority of practitioners I have known have never assumed anything different, despite the fact that a few professionals—typically those who have never followed children over time—have erroneously declared children with ASD as “hopeless”.

Defining Recovery

A related issue is how we define *recovery*. Here are some possibilities:

He no longer “looks autistic”, but now looks “normal”; her behavior “no longer meets DSM-IV criteria for ASD”; he is “indistinguishable from his peers”; she is “no longer in a world of her own”; he is “quite independent and no longer needs 1:1 support”; and so forth. When this term is used in regards to neurological conditions with a later onset, such as “recovery from a stroke”, the phrase “degree of recovery” is often used. This refers to the progress a person makes following a stroke resulting in improvement that approximates the pre-stroke functioning of that individual in language, motor skills and so forth. However, this seems to be less appropriate for children with a developmental disability such as autism. With more time, we could give much attention to how the definition of recovery can be quite elusive. We have had a number of examples in recent years of parents who have written books or have gone public, sometimes on television, about “recovering” their children from autism, who in subsequent interviews, or in less public forums, have backed off to say, “Oh, he is a child with autism who is high-functioning”, or, “I didn’t mean to say he has recovered, rather he is on the road to recovery”. I have known children who meet many, if not all of the “criteria for recovery” noted above, but still have clear vulnerabilities that require attention and support. In some of these cases, parents do not wish to abandon the label of autism,

as they are aware of their child’s vulnerabilities and the importance of keeping supports in place, and educating others. Nevertheless, it is reasonable to ask those who continue to use the term *recovery*, to be clear about what they mean by it, so that this information may be used in evaluating treatments and in setting appropriate expectations for families.

The Downside of “Recovery”

At this point, we must consider the potential detrimental effects of overly focusing on the destination of recovery, as opposed to focusing on the journey of progress. To be honest, I feel a bit uneasy about raising this issue, since questioning the concept of recovery as anything but hopeful and positive feels akin to criticizing apple pie, motherhood, and the Stars and Stripes! However, my experience—and the experience of many valued colleagues and parents—indicate that the picture is not as clear as it may seem, and that there is a clear downside to an extreme focus on recovery.

Before considering this other side of recovery further, it is important to recognize that this issue is far more than an objective exercise in semantics. We are talking about one of the most sensitive issues for any parent—the

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primal and deeply personal desire that one's child have a happy and healthy life, as well as all of the opportunities in life afforded to any child. Above all else, this is what parents live for, and our individual self-assessments of our parenting skills are largely based on how successful we are with our kids. Indeed, it may very well be that an extreme focus on recovery exploits these primal desires, and may also interfere with the processes of adaptation and coping through which all parents of children with special needs must navigate. With this in mind, let's reflect on this darker side of "recovery".

An excessive preoccupation with recovery may be problematic for the following reasons:

1. Current research does not support the likelihood of recovery for the majority of individuals with autism. In fact, many of the most successful people with autism still experience residual challenges and do not refer to themselves as "recovered". Additionally, some see autism as such an inseparable part of who they are that they do not wish to be "recovered from" autism. Dena Gassner, a woman with autism who is a social worker, told me at a recent conference that, "People don't recover from autism; they recover into autism". In other words, those individuals that she knows who have the best outcomes and quality of life are those who have a greater understanding of their autism and how it impacts them, so that they may be able to anticipate and learn to cope with their challenges, and grow and evolve as individuals.

2. Speculation about, or promises of "recovery" most often come from professionals who have a vested interest in disseminating and promoting their particular treatment, whether behavioral, educational, or biomedical. Their intentions may be honorable; however, emotional or fiscal investment always muddies the waters of intention. When the term *recovery* is used in association with, and/or as a justification for selling services or treatments, there are serious ethical considerations. In fact, some claims about recovery may actually be in violation of the code of ethics of some professional organizations, since many of these typically require a minimal level of research prior to making claims about anticipated treatment outcomes.

3. When parents overly invest (fiscally and/or emotionally) in the destination of recovery, it may result in an inordinate focus on the child "who could be", as opposed to the child "who is". Following a talk I gave at a recent conference, four mothers approached me and introduced themselves as "Moms Who Are Recovering from Trying to Recover Their Children". One went on to say:

I was taught to be so focused on training skills, extinguishing and controlling behavior, and 'curing' autism that I lost sight of who my child was. We are still working hard to support his development, but I now celebrate the child that he is rather than wait for the child he could be.

4. It is a well-known and sad fact that the divorce rate in marriages where there is a child with autism is close to 80%. There is a virtual absence of research examining the factors that contribute to this rate; however, differences in attitudes between spouses about treatment and recovery may very well play an important role. At our annual weekend parent retreat, the discussion inevitably comes around to the importance of taking care of the marital relationship, as well as each parent taking care of him- or herself, since doing so ultimately benefits the child. At our most recent retreat, one parent in our closing circle talked about how she finds herself falling back into the "recovery mission" (which entails staying up until two a.m. every morning on-line to explore new treatments), resulting in her being exhausted, neglecting her husband, and being less available emotionally for her child. She stated, "It's all about finding THE answer for my child, but I must remember that I need to take care of myself and my marriage as well".

5. A culture of divisiveness has developed around the issue of recovery, dividing groups of professionals as well as parents into "believers" and "non-believers". For example, in my role as a school consultant, I recently visited a family with two young children with autism in preparation for transition from early intervention to school services. Following the end of a positive and productive meeting, the mother turned to me and said, "Barry, we are looking forward to working with you and the school, but I need to ask you one question. Another mother I spoke to said that you don't believe in recovery. Is that true?" I asked her what she meant by

recovery, to which she responded “Good question, I haven’t given that much thought. I guess I want my children to be happy and to be in the mainstream as much as possible”. When I told her of so many children I’ve known over the years who currently meet that description despite their challenges, and even a few “who have moved off the spectrum”, she seemed to feel better, but remained unsure, since one parent had told her that she should be suspicious of me because I do not use the word *recovery* in my presentations or publications. It was as if my belief or lack of belief in recovery was being used as a “litmus test”. This divisiveness is currently happening among parents, medical professionals, as well as educators and therapists. Given the obvious negative effects on parent-professional relationships, I believe it is fair to ask: Is a belief in recovery and a willingness to use that term (however it may be defined) a prerequisite for professionals to provide the best quality services? (I believe it is not.) Is a belief in recovery a requirement for parents to do the best they can to support their child’s development and quality of life? (My experience says *no*.) Is it possible for parents and professionals to pursue and be involved with educational, nutritional, and biomedical interventions, without holding up *recovery* as the primary standard of success? (I believe it is possible.) Is recovery the only “destination” that provides hope? (I do not think so.)

6. Most importantly, an inordinate focus on recovery may interfere with the process of preparing for the long-term journey, for both the child and the family. When a parent embraces the notion that with X number of sessions, or so many hours a week of a particular type of treatment,

there is a great likelihood that his or her child will “recover”, the hard work and necessary process of grieving and adapting may be deferred, since the expectation is that the child will someday no longer “be autistic”. Recalibrating dreams and expectations, as part of the process of coping and adaptation is a gut-wrenching task, but when the journey starts earlier, the process may not be as paralyzing as when it occurs later, when hope for recovery appears lost, and there is little energy left. In my experience with parents who are overly focused on the destination of recovery, grief appears as a one-two punch over time: First there is the initial trauma of hearing that your child has autism, followed by the loss of the dream of recovery a few years later.

To be sure, all parents respond in unique and individualized ways, and their responses change over time. In my experience, however, for those parents highly focused on recovery, there seems to be an increase in anxiety, depression, and despair as their child approaches the end of the period (typically 5-7 years of age) by which time recovery should have been achieved. In contrast, so many other parents who have not taken on the task of “recovering” their children

seem to derive greater enjoyment from the small gains and daily progress that their children make, precisely because they are more focused on the journey, and the small steps of progress along the way, rather than the destination.

Parting Thoughts

My intention in putting this very tough issue of recovery on the table for discussion is to keep the discussion civil, and to further the dialogue about this critically important topic. We need more “Straight Talk” about this issue, both from a research and professional perspective, as well as from the everyday experiences of families. We all hope and pray for breakthroughs that will result in a better quality of life for children and older persons with autism, but at the same time, we must acknowledge the unintended and unwanted consequences that come from too much of a focus on the destination of recovery, especially considering the current state of knowledge and research. To be clear, it is essential that we keep hope alive, for as Maya Angelou has said, “In order to survive, all human beings must live in a home furnished with hope”. But we also must do so in a responsible manner so that we do no harm. 🏠

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