

From the book *The First Year: Autism Spectrum Disorders* by Nancy D. Wiseman. Excerpted by arrangement with Da Capo Lifelong, a member of the Perseus Books Group. Copyright © 2009.

DAY 4

learning

Is Recovery Possible?

EVERY PARENT INEVITABLY agonizes over the answer to this question: “Will my child ever recover and lead a normal life?” I can remember wanting to ask this question when my daughter was diagnosed ten years ago, but I was too afraid to say it out loud—for fear of what the answer might be.

In a very large number of cases today, recovery is unquestionably possible. But just as the word “normal” has been burdened with many meanings, “recovery” also has been given many interpretations. So let’s find out exactly what this question is really asking.

The most common English-language meaning of the word is “to bring back to a normal position or condition; to return to an original state; the act of regaining or saving something lost (or in danger of becoming lost).” Recalling that the current diagnostic criteria for an autism spectrum disorder are:

- impairment in social interaction
- impairment in communication
- repetitive behaviors and restricted areas of interests

we could consider an individual is *recovering* as he or she experiences less frequent and lower intensity manifestations of these

characteristics. Just as there is a spectrum of autism disorders, we could say there is a spectrum or continuum of recovery from autism.

Thus, based on today's definition of the diagnostic criteria for ASD, we might say a child has recovered when he or she manifests no clinically significant amount of impairments or restrictions in these characteristic areas. In other words, *the individual no longer meets the diagnostic criteria for the disorder*; he or she is judged to no longer be on the autism spectrum. This is how many professionals currently define "recovery."

Other perspectives on recovery:

1. "You cannot recover from autism, but you can improve."

Some professionals believe that once a child is diagnosed as being on the spectrum, he or she will always be on the spectrum—that there is no way to fully recover from the disorder. They are not saying that a person cannot improve, just that ASD is a lifelong diagnosis.

2. "Autism is neurological diversity, not a disorder from which you can recover or be cured."

There is a growing movement within the autism community of individuals with ASD who view themselves as having neurological differences and not a disease or disorder. "We believe that the autism spectrum and those on it are important and necessary parts of the wide diversity present in human genetics," says the website of the Autistic Self Advocacy Network (ASAN). "ASAN supports Autism Acceptance through measures to promote success for each person on the spectrum. By abandoning old and inaccurate models of pathology and adopting a new approach focusing on both the unique challenges and strengths of autistics, we believe that we can improve outcomes and promote a new paradigm of inclusion and respect."¹

This movement is new and just now gaining a voice in the autism world. While many professionals and parents strongly disagree with their view (or parts of it), it is important that we fully understand what they are saying and give them every chance to express their beliefs even if it runs contrary to what most believe about autism. By doing so, at the very least we may learn something new about the true meaning of the word "acceptance."

In my view, however, this is not the end of the story, and while there is no doubt that the diagnostic criteria for ASD must be reclassified and redefined, until this happens (the fifth edition of the DSM is expected to be published in 2012), the definition for recovery is open to interpretation.

Many children are technically no longer on the spectrum (as defined by today's definition of the diagnostic criteria) but need to continue special education services or treatments in order to remain off the spectrum or to eliminate any remaining difficulties. However, if they lose their official autism diagnosis, they could potentially become ineligible for services in their school district and become vulnerable to a serious setback. So parents are, in essence, being forced to represent their children as being in a worse condition than they actually are, in order to remain eligible for assistance.

These children may no longer meet the current diagnostic criteria for ASD but might very well have "residual issues"—subclinical symptoms. With special supports and services in place—classroom modifications and/or accommodations, therapies, medication, and/or restricted diet and supplements—they appear very typical. But this is not full recovery. Many of these children are extremely vulnerable. Without these supports, they could be right back on the spectrum to a greater or lesser degree.

This continuing need for services is not an absolute either. Perhaps over time, with further treatment or services, the individual may require fewer and less frequent special supports. Should we not be able to claim that this person is continuing to recover?

Then suppose one day the individual no longer needs any special services, supports, modifications, accommodations, or treatments at all (not even medication); he can live a stable life acceptable to himself and places no special burden on others *as judged in the light of the diagnostic criteria for ASD*. I suggest that this would be a reasonable definition for full recovery as far as autism spectrum disorders are concerned.

"Necessary and Sufficient Conditions" for Recovery

In order for recovery to be possible someday, there are many necessary steps to take. And even though we may take all the necessary steps, the conditions around us still may not be sufficient for recovery. For example, let's say you want to go shopping at the mall many miles away. There are some conditions that have to be satisfied in order for this to occur.

Probably you'd have to:

- get into your car
- make sure your car had enough gas to make the round trip
- drive to the mall
- have some kind of way to pay for what you want at the mall

Each of these conditions is necessary for you to shop at the mall, but by themselves or even collectively, they are not *sufficient* for the trip to be a success. The mall would have to be open; the stores would have to have the things you want to buy, etc.

In the world of treating autism, we do know some of the conditions necessary for successful treatment, but unfortunately we do not know them all. We do not know what would be *sufficient* conditions to guarantee success.

The following are some of the conditions found to be *necessary* for significant improvement and even recovery:

- getting a team of experts in place who
 - conduct the proper in-depth evaluations
 - can identify the underlying problems
 - know the best possible treatments for your child's particular condition
- committing the time and resources necessary to work toward recovery
- dedicating yourself to achieving it
- ensuring your child receives a full range of carefully integrated therapies, supports, and programming—each of which addresses the causal factors underlying each aspect of the child's particular set of characteristics

The children who have improved the most have at least these elements in common.

However, as pointed out earlier, autism is a *spectrum* of related disorders. The spectrum is very wide, and the disorders are often very different from one another. The exact causes of the disorders are still not known with certainty.

Some children have very complex medical situations, and these can be exceedingly difficult to treat. The so-called "comorbid disorders" are currently considered separately classed disorders that are not technically part of ASD according to the DSM but demonstrably influence the severity of the ASD condition.

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Additionally, many children regress after making initial progress. This can happen because unknown causes make the treatment imprecise or because comorbid disorders make treatment more complex. Thus, while the list above gives some of the conditions known to be necessary for reaching recovery, at this point no one knows all the conditions that must be satisfied to make a full recovery possible. For this reason, it's not possible to say with certainty that any particular child can recover.

Treatments: "Evidence-Based" and Otherwise

For well-understood diseases or pathologies, treatments are often very clear-cut: an antibiotic for a throat infection, an antifungal agent for a skin rash, antivenom for snakebite. But when the actual causes of a disease or unwanted condition are unknown, the practitioner, to some degree, is forced to treat symptoms. Unfortunately, this is the current state of affairs with regard to autism and some of the comorbid disorders often associated with ASD: the causes and cures are not obvious.

For this reason, professionals often compare notes with their colleagues, polling one another for what seems to work well for which particular cases. Lacking a fully workable, comprehensive treatment plan, parents often try methods that have no rigorous proof of efficacy but for which there may be **anecdotal evidence** of workability.

Anecdotal evidence is informal evidence that tends to support some particular theory. Often anecdotal evidence is obtained under noncontrolled conditions or without rigorous application of the scientific method.

Parents will often hear professionals insisting on only administering "**evidence-based treatments.**"

The trouble arises when some professionals do not realize that the "evidence-based" approach in itself is a *spectrum of certainties*, with every treatment being somewhere along this scale, from an educated guess to completely proven.

When they are speaking of "evidence-based treatments" (EBT), professionals are generally referring to practices that represent the highest level of certainty of results attained—as applied to both the treatment and its method of implementation.

The concept of evidence-based treatments refers to what clinicians must do to come up with approaches to treatment when there simply isn't any clear-cut cure available. Often in these cases:

1. The treatment starts with an educated guess and some evidence of workability from an individual case report.
2. Perhaps a small, informal study will follow.
3. As more controlled experimentation is done, the evidence grows stronger.
4. More random trials are done to further prove or disprove the usefulness of the approach or to better define the limitations of the approach or in which cases it will work.
5. Ultimately, the aim is to validate the approach using large, well-designed, randomized testing by multiple researchers with systematic reviews.

Unfortunately, the term “EBT” gets misused in two directions.

Some practitioners and treatment organizations operating in the field of ASD claim their methods are evidence-based when in fact they may be economically successful because of good marketing; other researchers using the same methods may be unable to replicate the claimed results.

The EBT label also gets misused when professionals object to a treatment proposed by parents, claiming it is not evidence-based when in fact they won't even look at the evidence. The professional's judgment is based upon a personal bias or ignorance of methodologies outside their zones of immediate familiarity.

The fact is that in the world of ASD treatments, there are *no* treatment methods that are proven to work consistently and in the same way for all children. In fact there are no treatment methods that have been proven to work (per number 5 above) *at all!*

The ASD Recovery Process: The Missing Framework for Treatments

You are going to be talking with a lot of parents, some of whom have been on this journey for a long time. You will hear; “Oh, we tried X, and it worked beautifully.” Another parent will tell you something else. While gathering the experiences of others is very valuable—and is often the basis

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for important discoveries—just jumping in and experimenting on your child with what *appeared* to work for someone else is unwise.

Why? Well, first of all, inasmuch as parents try to do everything possible for their children, often they may try numerous treatments at once. If they did not use a controlled, methodical process, they did not know what really worked—it could have been something else they were doing at the same time that caused (or added to) the improvements seen.

Second, since each child can have a wholly different configuration of contributing disorders, what works for one child may not necessarily work for another.

Parents must have a thorough understanding of their child's unique profile so they don't end up chasing treatments based on hearsay, not knowing if it is truly appropriate for their child.

Additionally, when you do find a treatment that works, it may work for a few weeks or months and then cease working altogether. Treatments that work at one point must be modified or changed as they cease to show results, and new treatments may be added as they are developed and recommended by practitioners or discovered by the parents.

A lot of this confusion may be due to the fact that, at the present time, there is no standardized, globally accepted process for the creation and operation of comprehensive treatment plans that also treat the immunological, gastrointestinal, and metabolic problems that so many children with ASD experience. Such a process would provide a kind of framework or context for the selection, operation, monitoring, evaluation, and refinement for all ASD treatment methods.

Perhaps such a process will be forthcoming in the near future, once there is a better definition of ASD and we have a better understanding of the root causes. Until then, we must depend upon the initiative and genius of researchers, practitioners, and each parent, as the team leader who assumes the many roles outlined in this book.

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At this time, recovery is a long and uncertain road; however, there are many children who no longer meet the current diagnostic criteria for ASD and many more who have made vast improvements.

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Understanding, Accepting, and Embracing the Diagnosis

COMING TO TERMS with your child's developmental disability or disorder, particularly autism, can be a lengthy process. While every parent responds differently, most parents instinctively educate themselves on what to do to take immediate action. Understanding in great detail what autism is about is what makes acceptance possible. This book and the materials referenced in these pages will help you considerably in that regard.

You don't need a degree in psychology or medicine to help your child. But you will come out of this process feeling as if you have earned that degree! And certainly, you will become the top expert on your child.

Acceptance is the second step. This is an emotional leap from a detached, rational understanding of the information to internalizing it into your life and your future. This can be very difficult for some parents.

Acceptance means fully internalizing the reality of the diagnosis and that it is what it is. Having reached this point, you will be able to move onto the third and final step.

I highly recommend that you read *Voices from the Spectrum: Parents, Grandparents, Siblings, People with Autism, and Professionals Share Their Wisdom*, edited by Cindy N. Ariel and Robert A. Naseef (Philadelphia: Jessica Kingsley Publishers, 2006). It is a must-read for any parent struggling to accept the diagnosis.

Embracing the Diagnosis

Understanding and acceptance are necessary steps, but they won't take you to your final destination. The point you really want to reach is embracing the diagnosis.

This is where you will experience a sense of inner strength. Embracing it means: *"I'm not going to live in denial. I am going to climb that mountain."* It is that unbending determination; it is diving into the situation headfirst. You bring yourself to the point where you can say, *"This is my world; this is what I live in; I'm not going to fight it. I'm going to welcome whatever help I can get, whatever understanding, whatever support."*

Your mission becomes your primary focus. You accept the fact that the dreams you once had for your child may be different—they won't be over. She may not go on to college; she may not have the same kinds of experiences you once thought she would. Your family life is going to be different; your daily life will be different; your future will be different. That doesn't make it better or worse; it's just going to be different.

In fact, in many respects my life has changed for the better. I've learned to prioritize things in my life, the good things are more meaningful to me, and I have learned to let go of the bad things more quickly. I've learned to roll with the punches better. I've learned to figure out what really matters in life and go after what I know and want. It becomes a new way of life.

I do *not* accept the claim that ASD is not treatable. I accept that my daughter may have limitations and that her life will be different, but I don't accept that my daughter won't reach her goals.

It is educating yourself, accepting the diagnosis, and ultimately embracing the diagnosis that will make you a stronger person, a better advocate, a better parent for your child.

The only magic formula is:

- Be a very active, involved parent.
- Get educated—more educated than your doctors if necessary.
- Look at your child's various difficulties from new perspectives; look for possibilities that have never been tried; challenge even the well-meaning preconceptions of others.
- Use the child's strengths as opportunities to circumvent challenges.

IN A SENTENCE

Understanding and accepting your child's diagnosis are necessary; however, embracing it is what will see you through the difficulties of the journey.