

# If not a cure, then what? Parenting autistic children

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## **Introduction: a different course of development requires different upbringing**

Most everyone at some time in their life has experienced what it feels like to lose the use of a single part of their body (e.g. broken arm; sprained toe; numbed mouth after visiting the dentist) for a short, or what can seem like a long, time. Think back on how suddenly even the simplest of tasks became difficult if not impossible, and how glad you were when this temporary disability no longer 'afflicted' you. You did not look at this 'temporary change' as any big deal because you knew it would end and you would return to being the capable person you perceived yourself to be.

What about those individuals who lose effective or efficient use of multiple parts of their body (spinal cord injury, multiple sclerosis)? The sudden change from 'able' to 'disabled' is often very devastating; in great part because being 'able' is the way they viewed themselves. It became a part of their identity. What they were 'able' to do gave them a sense of mastery, control and accomplishment. Some individuals continue to mourn for their loss and never move on. Others look to their remaining strengths, capitalize on them, and gain a new sense of mastery, control and accomplishment, along with a newly empowered identity. They remain, medically, 'disabled', but, through hard work and determination, they have become 'able' again, in their own way (different from that of others).

Now consider the individuals who are born with differing abilities, or acquire a medically diagnosed disability very early in life (e.g. asthma, cerebral palsy, learning disability, autism)? These individuals have no memory of a self that is any more able or less able than the person they are right now. This is true for typically developing children as well. Their self image, satisfaction with self, and drive to grow and acquire new skills is as much linked to their awareness of self as it is to others' expressed and non-expressed perceptions of the person they are (or that others want them to be). The motivation to strive to be someone you have no awareness of ever having been doesn't exist. That puts one's image of self in conflict with the perception of others (based on their own self-images) of who this child could be/should be. If you think that this conflict doesn't exist, think again, or better yet, if your child has expressive language, ask him/her.

### A different course of development

Since this article's focus is on autistic children, consider the child who is born with neurological and biochemical differences that dramatically alter the way in which his/her senses perceive, and therefore respond to, the world around them. Making connections and regulating responses to the sensory input coming in from the environment, or, more

importantly, from one's own body, is under developed and/or highly inconsistent in most autistic individuals.

The world is often perceived as a confusing, frustrating and even threatening place. Left alone, the autistic child will, like the typically-developing child, use what strengths they have to make sense of the information they receive and respond in ways that allow them to develop some sense of control and mastery of this information. Many autistic children lack sensory awareness of their body. They are observed to engage in repetitive motor movements, typically of their arms, hands, and trunk muscles (which do not receive the same sensory feedback that their legs do through walking) in order to experience these parts of their body. This "stimming" behavior is perceived by others as taking their attention away from that which others determine they should be attending. How can one attend to, and respond to, the world around them when they can't "feel" their own body in order to coordinate and direct its movements? Consider your actions and focus of attention when you lose feeling in your arm or leg when it "falls asleep." Autistic and Asperger Syndrome children who experience anxiety will also "stim" because repetitive contraction of muscles is calming to the nervous system. Neurotypical adults engage in "stimming" when they click a pen repeatedly or swing their leg, for the same reason, to relieve anxiety. Rather than understanding the legitimate reasons for autistic behaviors, parents are advised by the "experts" to stop or even punish this form of coping behavior, simply because *it looks different*. These types of conflicts, between one's perception of self (based on what makes sense to the nervous system autistic children are born with) and the perception of others who don't understand them is an ongoing problem for most autistic individuals even through adulthood.

Typically developing children are provided the time and materials to engage in self-instructive play. The patterns of natural learning through play are well documented. Autistic children do not follow these same patterns; therefore, the thinking is that they must be taught to play like other children do. Being taught the mechanics of what others do does not guarantee that the autistic child will learn the concepts underlying this form of play. Without understanding why they are doing what they are doing, there is little drive to continue to do it (except to please others to whom it seems so important). Autistic play, as different in its patterns as it is, does help autistic children to learn what they need to learn to cope with the challenges of everyday life, as they perceive it, just as typically-developing children do, only without the same skills and resources.

The books all say that autistics are not capable of meaningful relationships. That is a fallacy, like many other false conclusions made about autism based on observation of behaviors that are not well understood. Think about those that you consider your closest friends. They share many of your interests and experiences, do they not? This enables them to understand you and provide the support you each need from each other. Being put in a 'peer' group of children who do not experience life the way you do, nor understand you, is NOT the way to teach a child about *meaningful* relationships. Think back on the many stories of individuals, or maybe your own experiences or experiences of those you know, who were pushed by others, or circumstances, into a career or relationship that they had no motivation to seek for themselves. Achievement of self-driven goals is what leads to happiness, productivity

and self-worth. Sharing experiences that are meaningful to both individuals is what builds *meaningful relationships*. Autistic individuals DO form very strong, meaningful and long lasting relationships... when they come into contact with someone who understands and accepts them for who they are (not who they want them to become). Don't we all? Finding service providers who meet your child's criteria for someone they *want* to work with will do far more to foster the internal drive toward personal growth and development than putting your child through an intensive array of services simply because some "expert" recommends it.

Parents, as well as the professionals who support (and even pressure) them, in their pursuit of a "cure" for their autistic child, rarely see any harm in what they are doing. After all, scientific research reassures them that they are maximizing their child's development by taking advantage of the brain's plasticity at this young age. Even parents of typically-developing children are made to feel guilty if they are not bombarding their infant with flash cards in order to stimulate their future intellectual abilities. Most children are quick pick up the non-verbal messages parents send about the hopes and expectations they have for and of them. Children instinctively strive to meet these parental expectations. Their self-esteem generally reflects how well they have been able to accomplish this challenge set out for them by their parents. Typical development has been well documented. Parents have guidelines to help them establish realistic expectations that their children can reasonably achieve. The harm is in not being realistic and setting the expectations too high or too low. There are no guidelines for parents of children with autism. Research has made no attempt to determine the pace or pattern of skill acquisition in autistic children (something that laudably has been attempted with also-differently-developing children with Down's Syndrome). The expectations, *by default*, are set at "normal" and "as early as possible", which means tons of therapy and a stressful pace of life for everyone.

### The illusion of a 'cure'

Autism is a pervasive developmental disability. Pushing for performance before an individual is physically, emotionally or mentally ready to take on that task is to teach splinter skills that are only performed on demand. They are not generalized because their relevance and purpose are not understood. The key to independence is not in performing a task, but in learning who to seek out to advocate for what one needs (until or if one decides they can do it for them self). Parents can give their autistic child, regardless of the severity of their limitations, the gift of a meaningful life by modeling advocacy skills, which will get the child what they need, in socially-acceptable ways, which helps the child to understand the relevance and purpose of social skills.

The scientific community claims that an individual with autism is "cured" or "recovered" when they no longer qualify for a diagnosis under the DSM-IV. Certain therapies can help to ease the stress associated with being autistic in a world of non-autistics, but using your intellect to learn what you need to learn to "pass" does not make you "normal."

Psychiatrists are increasingly recognizing the symptoms of post traumatic stress in individuals with autism. The source is not one single trauma but chronic trauma. Not having

the 'person you are' accepted because you are not yet cured is pretty traumatic. Consider how the hyped-up focus on 'curing' and 'ridding the world' of autism has on their emotional/social desire to become a part of a world that doesn't want them? Even the occasional televised program or article that shows what autistic individuals are capable of achieving when allowed to use their strengths isn't enough to counter the glaring fact that a high percentage of those who are in or are looking to move into the work force fail. They lose their job, and often end up on social security due to depression, not because of a lack of skill in performing the job, but because they don't recognize, much less know how to engage in, the social interactions and games people play without conscious thought or effort. Where is the public attention and research money for educating, guiding and accepting autistic individuals that can make a difference today?

#### Treat a different child as different

The hard-to-understand fallacies in this "cure" approach are the assumptions by parents that every child wants to be normal and that this vast array of therapies will make them normal. Many individuals with autism have exceptional abilities that are a direct result of their autism. They may really like the person they "are." Many adult individuals with autism have been convinced that they wanted to be normal, until they realized that, in their efforts to do so, they have lost any sense of how to "be themselves".

Parents and teachers, in their best-of-intentions, try hard to NOT treat this differently-developing child as "different." To a child who perceives the words and actions of others literally and concretely, the message they get is that they are expected to grow up to be 'like everyone else'... there is no other choice. Is anyone aware of how heavy of a psychological burden this places on a child already struggling to survive in an alien world where no one seems to understand them?

The harm in this approach is not because it tries to provide the autistic child with biochemical and therapeutic interventions that can make their lives a little easier or less stressful. It is in the unspoken message that these interventions are being provided so that the autistic child can become the person his/her parents so desperately want (which from the autistic child's perspective is easily interpreted as 'not the person you are'). Autistic children are often emotionally hypersensitive. Their parent's disappointment and/or desperation with the person they "are" is often perceived far in advance of their awareness of being "different." In the black-and-white world of autism, if a child is told they are 'like everyone else' then logically, everyone else must be like them. If the autistic child assumes that everyone else perceives the world as they do, then the only conclusion they can come to when others turn on vacuums that hurt their ears or all talk at once, which overwhelms them, is that others are rude and insensitive. The child is left with feelings of confusion or anger, or both. On the other hand, if the autistic child is observant enough to realize that others are different from them, yet their parents and teachers insist with their words and actions that they are not different, then the conclusion must be either 1) adults can't be trusted to tell the truth, or 2) being different is very bad and something that needs to be hid because clearly *adults don't want to see their differences*. The child is left with no one to

whom they can turn to talk about these conflicting feelings about themselves and those to whom they should be able to turn for support.

The argument for not pointing out a child's differences is 1) to spare their feelings from being hurt, and 2) to protect them from being picked on by their peers because of their differences. It is true that to simply point out a child's differences can hurt, but to not ever talk to a child about differences and how to deal with them hurts even more. Interestingly, there is a very obvious flaw in the assumption that being different attracts bullies. What about the 'way out' teens that set fashion trends (that drive adults crazy and their peers can't wait to copy)? Individuals who are confident in their differences and flaunt them get noticed (which depending on your opinion may be good or bad) but they don't get bullied. It is the individual who appear ashamed of their differentness (a sign of emotional weakness and vulnerability) that becomes the victims of bullying.

### The position of the autistic community

The purpose of this article is to open the eyes and minds of parents (as well as teachers, therapists, and doctors) to the possibility that seeking a 'cure' is NOT the only choice when raising a child with autism. There is a way that is far less stressful and painful for the child as well as the family. It requires effort, but in the minds of those who have chosen this path, it is much more rewarding. This approach calls for patience, understanding, and acceptance of differences. The guiding principle is that *autistic children need to be allowed to develop in their own way and pace*. Like typically-developing children, autistic children need guidance, boundaries, attention to medical needs, education, and meaningful relationships to grow and develop the internal drive they need to be the best person they are capable of being.

The autistic community maintains that autistic people have worth. They can achieve and they can experience happiness, (regardless of the quantity or level of abilities they possess) if accepted for the persons they are now, and allowed to use their strengths in their own way and at their own pace to become the best person they were born to be.

A common argument against this standpoint is that those who believe in it are against any treatment of autistic children. Parents of autistic children who receive an autism-spectrum diagnosis, even if they have a gut feeling that trying to make their children more normal would not be good for the child, usually don't have anything else to go by. At this stage they need real help and advice as to what to do, but concrete treatment plans usually come in the form of intensive "therapies" which try to make the child as normal as possible, as fast as possible.

In this article we illustrate some practical approaches for raising an autistic child to become the best autistic adult they can be. We obviously can not give all parents of all autistic children all answers to all challenging situations. Nor will we dwell here on theoretical guidelines for the upbringing of autistic children, although such guidelines are an essential basis for delineating the solutions to such situations. (Theoretical analysis is found in the reference list.) We address some common issues that parents of young autistic children struggle with, and give some practical guidelines for parents on where to start and how to

seek for further help, and how to be informed consumers of resources such as educational programs, therapists and literature.

## **Where to start**

The main feeling parents experience when their child receives an autism-spectrum diagnosis is that of disempowerment. Parents of normally developing children are usually considered to be competent to care for their child without any particular help, based on the standard services for normally-developing children (e.g. education, health care) and on "parental instincts". When the child is identified as having special needs, all of a sudden the parents need to learn both about these needs and about the special services available to them. Although the emotional implications of finding out that "there is something wrong with my child" (see reading list) is an important aspect that needs to be addressed, it is outside the scope of this article. Some parents choose to depend on professionals to guide them through this situation. There are so many treatment methods, though (some of them appearing quite contradictory to each other), that the search for professional guidance can be not only confusing but expensive. Others interpret the statement that "parents are experts on their child" as a recommendation to rely mainly on their "parental instincts". This approach is problematic too, because most parents are NT and so their instincts, if they apply them, are generally only suitable for raising normally-developing children. These parents need to come to the realization that they must abandon everything familiar to them and enter an alien territory. If receiving a diagnosis is going to improve the situation in any way, they need to start learning about autism. This learning process, however, takes time; meanwhile there are situations they need to deal with. Parents need concrete advice they can use **now**.

Another emotion at the time of diagnosis is a deep concern about the child's future: will they continue to depend on the help of others, what will happen to them when the parents can no longer care for them? The ability to reach out and connect with other people is viewed by most neurotypicals as essential to having any quality of life. The autistic individual's openness and honesty is viewed as naiveté which requires protection from those who would take advantage of them. Many autistics, regardless of intellectual ability, have difficulties with activities of daily living (bathing, keeping their environment clean) that others perform easily. Parents struggle to see how there can be any quality of life in living this way, so the temptation is very strong to adopt one of the therapies which promise "recovery." This approach gives the parent both something concrete to do with their child right here and now, and the feeling that they are in control of the situation. The more intensive the treatment, the better the parents may feel about their decision. This approach also gives them hope for the future so that they don't have to worry that the child will remain dependent on services (thus they can forget about the need for advocacy and adult services).

Although a vision of the child's future is a key factor in determining how to raise them, it can't be dealt with in the first stages. We recommend parents bear in mind that autistic children do develop, and can be helped to use their unique strengths in a way that would maximize their autonomy and would enable them live a meaningful life. We recommend, first, that parents focus on dealing with the most pressing needs, so that when the situation

is more stable and less hectic, they have the peace of mind to learn more and prepare themselves for future challenges, something all parents face.

Nowadays, many autistic children receive a DX at the age of 2 or even younger. Even normally-developing children are hard to deal with at this developmental stage. Autistic children are not simply developmentally-delayed, which means that the child may experience the same developmental processes that cause normal young children to tantrum and exhibit other "problematic behaviors", they have less skills to deal with them. It is important that parents have the tools to respond to "problematic behaviors", even before parents face the issue of determining which treatments would be most suitable.

### Understanding the why's

Let's explore some of the more "problematic behaviors" that autistic children exhibit that may exceed those problematic behaviors that typical children experience, from an autistic perspective. They include stimming, not responding, over reacting, resistance to change and transitions, perseveration on a single focus, limited interests/obsessions, aggression, self-abuse and unemotional passivity. I have no doubt that parents could add plenty to this list.

Let's now look at a few of the many reasons why autistic children exhibit these behaviors. Many autistic individuals have difficulties in digesting foods that create the neurotransmitters the brain needs to trigger connections or initiate or stop a response (resulting in inertia or impulsiveness). Most experience either under- or over-sensitivity to body senses (touch, movement in space) resulting in walking into things, lack of awareness of pain, extreme responses to sounds, touch or being moved. Almost all experience difficulties in picking up information that others acquire on a non-conscious "knowing" level, causing them to feel bewildered or upset when expectations are made and they have no clue what people are talking about. This also contributes to literal, inflexible, "black-and-white" thinking and a lack of awareness of even the 'existence' of options or choices.

Many autistic individuals have decreased input from the muscles and joints that help them to plan, direct and control their movements. Without feedback from their body the individual is likely to not try, give up easily, over-try to the point of frustration, or try to make others do things for them. Underdeveloped connections between various parts of the brain are characteristic of autism. Thus extra, extra (and maybe more) processing time is required before input is understood and a response can be initiated (making adapting to new situations very difficult). Since the connecting areas of the brain are underdeveloped, autistic individuals often resort to thinking their way through tasks that others do easily and automatically. Such over-use of the intellectual area of the brain is fatiguing. When pushed by others, or self, beyond what the brain can do, blowups and meltdowns are not unexpected. Due to poor connections, autistic individuals need and will seek lots of repetition of experiences they want to remember in order to be able to recall them.

Emotional hypersensitivity can also be a significant factor in autism. Autistic individuals have a heightened sensitivity to the emotions of others and just a change in volume or tone of voice in others can trigger the autistic individual's own strong emotions. On the other hand, autistic individuals may experience real difficulty connecting with their own emotions,

especially when processing input in some other area of the brain. Autistic individuals often have difficulties with multitasking (processing input from more than one sense at a time). Thus, maintaining eye contact and being asked to listen are conflicting expectations. If they look, they can't listen. Filtering out input that is familiar or unimportant so one can focus one's attention on important input is another difficulty autistic individuals experience, resulting in either constantly shifting attention or shutting down and hyperfocusing on only one thing. This certainly doesn't cover all the challenges autistic children face, but the length of this list alone should give you some perspective on why autistic children find the world (mostly people because of their inconsistencies and ever changing ways of responding to the world) so frightening, frustrating, confusing and overwhelming (and respond accordingly).

Meltdowns are perhaps the most confusing of the 'problematic behaviors' parents face. Meltdowns can have recognizable triggers (similar to what happens when others "push your buttons") or can occur "totally out of the blue" (which generally means the child is exhausted from trying so hard to hold it together, and can't do it one second longer). At this point the adrenaline (the fight, flight, fright, or freeze hormone) starts flooding the system. The thinking mind shuts down and the body reacts. The reactions are likely to be physical or verbal aggression (toward others or self), escape (mentally or physically), a shift to passive or robotic compliance (total disconnect from self and one's own emotions), or shut down (mentally frozen and unable to think or act). The sad part is that others mistake these reactions as unprovoked acts of aggression, personal rejection of their attempts to interact with or help them, deliberate manipulative behavior to get out of something, or adoption of an attitude of not caring (emotions or conclusions which trigger reactions that are the opposite of what is needed in this situation).

The really hurtful part of this misunderstanding is when attempts are made to extinguish this problematic-behavior through punishment (or the absence of rewards for what others consider 'positive behaviors', which is the same thing to the autistic child who has no clue what those positive behaviors are, can't retrieve them, or is too exhausted to perform them). If stimming behaviors are also being extinguished as "inappropriate" behaviors, the child is left with no understandable-to-them ways of coping with the stresses we all face, but they experience far more intensely and more often. If the child were able to self-monitor, they might realize that this stress was building up and let others know what is happening. But, because the brain doesn't shift easily and has difficulty multitasking, the autistic child (or adult) can only be aware of self OR the input coming from others. Autistic's can learn to self-monitor and self-advocate. They can also learn alternative ways of coping with stress. But, until parents, educators and therapists accept understanding, rather than elimination, of differences, people don't think to teach them.

The failure to comprehend what is being communicated and/or being misunderstood when one is trying to communicate one's own needs and feelings are the biggest causes of meltdowns. Others are:

- Sensory overload (too much too fast)
- Not knowing options in the presence of expectations

- Unexpected expectations/being interrupted (unprepared)
- Anticipation of unrealistic expectations or sensory overload
- Inadequate/inconsistent sleep patterns
- Cognitive exhaustion
- Biochemical flooding
- Fatigue from trying to do/be what one can't/isn't

The big push today is to get autistic children diagnosed as early as possible, to alter the neurological and biochemical influences that stress the child (and family) before these problematic behaviors start. Relief of stress is always a good choice! Relieving stress will certainly result in a decrease in irritability, mood changes, and mental/physical exhaustion (problematic behaviors) in anyone. A reduction in stress frees the person (autistic or not) to approach, rather than hide from, the world and to grow as a person, rather than restrict their activities and interests to only those that don't cause them stress. This begs the question of whether the autistic behaviors that contribute to one getting a diagnosis of autism or not are a direct result of the neurological and biochemical differences, or the stresses of trying to live in a world with others who don't share or accept those differences. Those in the autistic community who have experienced sharing a world with others like themselves, such as Autreat provides (see reading list), have spoken of how relaxed and comfortable they are when allowed to be the persons they are in an atmosphere of acceptance. A not- too-surprising outcome of this environmental opportunity is the development of lasting personal friendships and individual growth in those who continue to participate. An accepting environment may not be a 'quick fix', but it would make an interesting study to compare the growth and development, and ability to adapt to life in the world, of children who come regularly to Autreat with those who are given medications and training in order to 'cure' them.

#### What do we **do** now?

Does the above analysis mean that parents have to become experts in sensory integration or augmentative communication before they can treat their children effectively? Not at all! This is what professionals are for. One of the first steps, after getting a diagnosis (better yet, when difficulties become apparent even before the diagnostic process results with an autism spectrum label) is finding professionals who can work with both the child and the parents (ideally with anyone involved with the child, e.g. teachers). However, remember that the purpose of turning to a professional is not to seek their opinion on what the goal of the treatment should be, but to evaluate the child's personal profile of strengths and needs, and find ways to help him or her cope better as described above, *not* to make the child more normal. Make sure to establish working relationships with the therapist, which include frequent consultations on problems that arise throughout the whole activity span of the child, so that the help the child receives is not limited to the therapy room. It may be hard to find professionals who are willing to work with you on accommodating your child's needs as

an autistic person rather than trying to make them more normal, but this defines a clear criterion in the confusing task of looking for an choosing a professional.

Go with your system of values and beliefs, but be careful about your "natural instincts". Remember that the external expression of your child (e.g. body language and even usage of spoken language) is markedly different from anything you know. Keep asking yourself if what you think about the reasons for your child's behavior is true. Start observing your child and listen very carefully to what they are trying to convey.

Two main areas need attention right from the start: communication and structuring. If your child does not have speech or any other means of expressing his or her needs, start working on establishing an effective communication system. Remember that the goal is to let your child express their needs, *not* to teach them the mechanics of speaking. There is a wealth of alternative communication methods out there. Learn about them and find a speech-language pathologist or an expert on augmentative communication to work with you. Some strategies can be adopted even before finding the most suitable system, e.g. making simple choices between too concrete objects. It is hard to imagine the huge difference that a simple change in the child's communication, e.g. the ability to signal "yes" or "no", can make. A lot of the stress is relieved when the child knows that they have choices and that they can have a role in determining what is going to happen to them.

Parenting is not only about providing the means for the child to grow and explore for themselves (although this is highly important); parents actively contribute to the learning process by mediating between the child and his or her environment. Therefore, in addition to enabling the child to express concrete needs, parents should become fluent in whatever communication system makes sense to their child, so that they can start conveying messages back to the child that the child can understand.

Structuring is a way to set clear boundaries in terms of time and space. Again, there is a wealth of information out there on how to set clear and consistent daily routines that the child can follow and understand, and how to design an environment that will help the child to navigate both physically and mentally. Teachers working in programs serving autistic kids are (or should be) trained in structuring techniques. Some occupational therapists are familiar with this approach too. If materials available to you do not provide the solutions your child needs, find an informed professional who will help you in this area. As with communication, it is hard to imagine the major change in the child's well-being once the world becomes less chaotic for them.

Does that mean that from now on, the needs of your child will always come first, before yours and the needs of everyone else in the family? Not at all! What the child needs, in addition to clear boundaries in time and space, are clear boundaries between needs of self and others. Parents need to balance between the needs of the child and the rest of the family, and to teach the child that things do not always go their way.

That said, it is important to remember that an autistic child needs an environment and routines which may not be consistent with the family's former lifestyle. Therefore, some important decisions about changes in the family life must be taken carefully so that the child

is not pushed beyond their limits on one hand, but the family life does not revolve only around the exceptional child on the other hand. For example, if the family has a habit of going out for Pizza in a mall where the autistic child can't tolerate the noise and commotion, then the child can be left with a trustworthy adult. An effort should be made to keep routines as stable as possible. Often times, careful planning can allow the family some non-routine activities, while at the same time, the autistic child can find comfort in a familiar environment. On the other hand, breaking of routine can be practiced where the surrounding and activity are something that the child will like, e.g. a field tour or a museum displaying the child's favorite interest.

## **Where do we go from here: Some guidelines**

The list below is an attempt to summarize some important guidelines on raising an autistic child to be the best autistic person they can be. The first three items were already mentioned above, as being the first steps. The rest of the list relates more to the parent's mindset, in how to approach longer-term planning, and how to translate the main idea of "help the child to grow as an autistic" into parental decisions.

- 1) **Communication:** Teach your child how to not only communicate basic needs but also acceptable ways to let others know what they don't want or can't handle. Use the form of communication that makes the most sense to them. If they gesture, use gestures. If they understand pictures, use pictures. Don't expect them to understand you and how you communicate.
- 2) **Boundaries:** Teach your child the concept and practice of boundaries between parental and child's needs, and the importance of both! Be very clear and consistent about them. If you believe that being autistic does not imply being selfish and obnoxious, you as a parent are responsible to set boundaries and to teach them in a way that the child will understand. Forbid behaviors that compromise other people's rights, and tolerate behaviors that are merely "strange" but harmless. Show that you respect your child's right to be who they are, and expect them to respect your right to be who you are.
- 3) **Make life simpler:** Accommodate your child's needs for predictability, structure, and a general sense of control of their environment, within the boundaries established. Use schedules, timers and other environmental triggers to help them recall tasks and options for greater independence.
- 4) **Be a parent, not a therapist.** Parenting is about helping the child, day-in-day-out, to become the best person they can be. "The best person" includes both talents/functioning, as well as virtues and values. Bear in mind that your child's needs are *different* than the majority of their age peers, and create an environment that will enable them to use their natural strengths *their way*, not the way other kids are "supposed to" develop. As mentioned above, establish communication, teach boundaries and set simple daily routines. Learn about your child's sensory needs and accommodate them, within established boundaries. If your child has food sensitivities, provide a suitable diet, just like it should be for anyone with a similar condition, autistic

or not. Play with your child in a way that would be enjoyable to both of you, rather than do "play therapy". Turn to professionals to provide therapy as needed in specific areas (e.g. sensory integration) that will help the child cope better as an autistic person, not therapy aimed at "fixing the child" to become more NT.

- 5) **Don't assume, ask.** Listen to your child and learn from them what bothers or what hurts them, even if it is outside of your ability to understand it based on your own experiences. Check and re-check to make sure that you really understand your child's replies.
- 6) **Your child is not a project.** Do not become a project manager, hiring or supervising a variety of professionals to work with your child around the clock, while forgetting that you are a family where everyone has their place. Remember that your child is developing all the time. Over-pressure to develop at a certain pace or course may be harmful to the child and family. Provide frequent breaks and plenty of time to process information to avoid overwhelming your child. Provide only as much support as requested or needed to avoid learned dependency. Learned dependency exists when the individual is unable or unwilling to initiate anything and becomes anxious if prompts and/or assistance are not given to direct every step of every thing they do that is not already memorized or routine.
- 7) **Be your child's ally.** Make sure to justify your child's trust in you as someone they can count on to defend them and advocate for them, not hurt them. Don't minimize how difficult tasks are for them that you find easy. Let them know that you can see how hard they are working to meet the expectations we all share, without equal abilities or resources. Be honest with your child about their differences, and according to their degree of maturity, work *together* with them on ways to deal with challenges.
- 8) **Awareness:** Be aware of your own motives when making decisions on behalf of your child. Ask yourself what the real life values are that underlie the educational goals you set for your child, and avoid making conformity your goal for your child. As your child matures, include them in the process of goal setting (even if sometimes their goals may differ from what you might have wanted for yourself if you were in their place). Only *then*, with clear goals, turn to educators and other professionals to seek help in implementing those goals.
- 9) **Find allies in professionals** who share your vision, goals and values. Don't expect professionals to set your child's goals; choose professionals *according to* these goals
- 10) **Learn, learn and learn.** Educate yourself about various methods. Get involved with the autistic community. Avoid generalizing from the writings of one or two AC celebrities (not everyone experiences autism, and therefore life, in the same way).

The following example illustrates how the guidelines above are implemented in daily life. While waiting for the school bus, an autistic boy is pacing back and forth, talking to himself. What should his mother do about it? If she tries to protect the child from the harshness of life, assuming the he will always be sheltered in segregated programs, she would do

nothing: he is unaware of his difference, and she is there to intervene if passers-by have a problem with his behavior. If she aims at normalization, she should tell him to stop, because self-talking is weird and he should (and can) adapt to normal standards. If she respects him as an autonomous, self-aware person, she should leave him the choice whether to behave normally or not, as long as he does not harm anyone. Therefore, she approaches him and asks: "are you talking to me?" When he replies "no," she explains: "most people do not talk to themselves. They talk when they want to say something to someone else. Therefore, when you talk to yourself in the presence of others, they may think that you are talking to them. They are likely to respond to whatever you are saying." On other occasions, when the boy is in his mother's presence and she is not sure whether he is talking to her, she asks him. Sometimes he would say "yes," sometimes he would say "no, I was just talking to myself."

By talking to the child in this way, his mother alerts him to what he is doing and how it may be perceived by others. She raises his awareness of his differences but does not label his difference as bad. It is up to him to choose whether to monitor his natural processing or to remain his own self and be prepared to deal with responses from other people.

## **How to be a wise consumer of treatments and programs**

Nowadays, many treatments and therapies are available for autistic children. However, most of them either strive for normalcy, or underestimate the capability of autistic children, and in a condescending way, try to "protect them from life". However, it is still possible to make use of parts of these methods, if one is aware of the possible discrepancy between the goal the method was attempting to achieve and the goal of raising an autistic child as autistic.

### Treatment- paradigms

If eliminating autism is not a goal, one can wonder why the child needs a treatment plan. The answer is that every child needs love, attention, and thoughtful guidance. Parents are supposed to know how to treat normal children (though this is not always a justified assumption) from their experience with their own parents and from observing other parents. When the child is autistic, both the parents and the educational system cannot use their usual tools. Treatment paradigms offer general ways of relating to the child. These methods aim to teach skills by changing the child's environment. Examination of each method includes the following questions:

- What is the perception of autism that is the foundation for this method?
- What is the main long-term goal?
- Which elements of this method can be employed to work towards our goals?
- Which elements of this method are inherently incompatible with our goals?

**Behavioral methods**, like Behavior Modification or Applied Behavior Analysis (ABA), are based on Skinner's ideas of the organism's response to stimuli. Teaching skills is done by encouraging desired behaviors (by positive responses) and discouraging undesired behaviors

(by negative responses). There is no specific assumption about the nature of autism, because this method is concerned mainly with behaviors and not with internal mechanisms. Caregivers who employ this method usually opt to normalize the child, but parents who accept their child as autistic have used elements of this method to help their child gain more autonomy.

Some positive elements of this method are:

- It is highly structured.
- Discrete- Trial Teaching, which breaks up tasks into small stages and teaches them systematically, increases the chances for success.
- Behavior analysis examines the environmental causes for undesired behaviors, thus helps to design an environment to maximize the child's learning.

If taken to an extreme, or if not supplemented by other treatments, this method might be harmful:

- Negative responses might be too painful for the child, sometimes bordering on abuse. For an auditory sensitive child, even a loud "no" can be painful.
- Some users of this method advocate an intensive treatment schedule, sometimes as many as ten hours a day, disregarding the child's need for downtimes.
- The learning method is automatic, and does not depend on conscious processing by the learner. This way, the child learns some behaviors but not why these behaviors are desired or when to use them.
- Instead of developing self-awareness and self-monitoring, this method induces autopilot functioning.
- If used without a combination of other methods or therapies, important needs such as sensory ones may be neglected.

**Relationship-based methods**, like play therapy (Greenspan) and Relationship Development Intervention (RDI), highlight the importance of interactions between child and caregivers. Comparing social and communication development of autistic children with that of normal peers, the essence of autism is defined as developmental deficits in these areas. Treatment aims to minimize these deficits by allowing the child to experience positive interpersonal exchanges and encouraging interactive responses by the child.

Some positive elements of these methods are:

- They consider internal states of the child, including sensory and motor-planning issues.
- Caregivers are guided to identify the child's preferences and follow them, aiming at mutual enjoyment.

- The essence of communication is highlighted, rather than the technicalities of communication.

Drawbacks of these methods, as currently employed, are:

- They opt to normalize the child's internal world, as well as behaviors.
- They ignore autistic ways of relating and assume that the only way of making connections is the NT one.
- They do not respect the child's need for downtime, including solitary play.
- Typical Autistic behaviors, like perseveration and stimming are perceived as anti-social, and thus short-term goals include elimination of these behaviors.

### Therapies

Therapies use specific techniques or theories to address a specific delay or area of dysfunction in the child. Many special education programs employ therapists from a variety of disciplines, like occupational therapy/sensory integration, speech-language, or Music / art / movement / physical therapy etc. All of these methods may be helpful to address the child's developmental needs (e.g., sensory-motor needs), help the child understand the essence of communication and interaction, or teach useful skills. Since autism is not a disease, therapies should not be expected to "cure" the child or get rid of autistic characteristics.

It is now widely recognized that autism is not an emotional disturbance, so psychoanalysis is not recommended for autistics. However, psychologists still treat autistic children and adults (going beyond simply performing evaluations to determine a diagnosis). Autistic children and adults may need psychotherapy in crisis situations, as any other person might. Again, the psychologist should respect autistic communication and internal mechanisms and not try to impose normal ways of relating on the autistic client. This is important also in the case of therapies like art and music, which are sometimes used as means to approach the client for psychodynamic purposes. Many autistic clients are not likely to benefit from being pressured to use their imagination or discuss their feelings. Cognitive therapy has the best potential for helping autistic people.

Generally speaking, autistic children need acceptance and guidance rather than emotional support and protection. Therapy is helpful inasmuch as it is viewed as an effective teaching method.

### Biochemical interventions

Various diets and dietary supplements have been tested by parents seeking a cure for their autistic child. This cannot be an argument against using these methods. Many autistic children do have medical issues (gastric reflux, digestive problems, swallowing difficulties, food sensitivities, allergies, etc.), but then so do non-autistic children. Digestive and immune system problems can be associated with biochemical imbalances, which in turn may cause

the child to have more difficulties attending or leave them in a more sensitive or irritable state. The result is a noticeable change in their behavior. It is not the behavior that needs treating. It is the underlying biochemical imbalance that needs to be addressed. Before starting a special diet or even checking whether the child needs one, there should be some symptomatic indication (the existence of autism is not one!) that the child has a medical problem. Parents should thus ask themselves: "Would we pursue this direction if the child were not autistic?"

The same reasoning applies to psychiatric medicines. If there is an indication of a psychiatric problem (e.g., anxiety or obsessive thoughts) causing the child stress, then medication might be considered, along with a careful examination of the child's environment, to relieve this problem. Keep in mind that many autistic individuals, because of the medical/biochemical issues mentioned above, have a low tolerance for, or are slow to metabolize standard doses of medications. The use of medication might be particularly dangerous if the child does not have enough communication skills to report reliably on the effect of the medicine, because external observations (e.g. body language) can be misleading. Alternatives to medications, or very low doses, might need to be considered. Whatever the parents and their doctor works out, the goal should be to relieve the medical condition that is causing their child stress, not to rid their child of their autism, or control them so that others can better manage them.

#### Choosing educational settings

The following paragraphs discuss some parameters to consider when choosing a program for the autistic child, in addition to the treatment methods and the available therapists employed in the program. It is important to collect information about the program, but also to bear in mind that the names of treatment methods may not describe accurately their actual implementation. A sensitive, open-minded kindergarten teacher in a "behavioral program" may be found more helpful for the child than a rigidly doctrinarian therapist declaring she fully accepts every child for who he is.

#### Educational vs. therapeutic

Since autism is not a disease and autistic kids need education and learning skills rather than healing, an educational program (a school or a kindergarten) seems more appropriate than a therapeutic one (e.g., a psychiatric day-care). As mentioned above, one should check whether a special school actually focuses on teaching rather than filling the day with various therapies. On the other hand, some programs for toddlers and young children calling themselves therapeutic kindergartens are in fact similar to regular ones but with smaller classes, autism-trained staff, and supplementing therapists. These may be very helpful for young children who need a lot of one-on-one instruction.

#### Inclusion vs. segregation

As mentioned above, contact with other autistics of all ages is important for the child to develop identity and meaningful relationships. Physical proximity of other autistics is almost automatic in segregated programs for autistic children only, but that does not ensure meaningful connections between them. To make segregated programs advantageous, the

staff has to be not only well informed about treatments, but also respectful of the children's autism and not intent on forcing them to behave normally. On the other hand, the purpose of inclusion should be not normalization, but teaching how to navigate the normal society.

Some points to consider are:

**Message conveyed:** Preferring integration might convey the message that only normal peers are worth connecting with; segregation might mean that the child must be protected from the general society.

**Environment:** In segregated programs, it is easier to design the environment to meet educational and sensory needs of the autistic children. Normal peers in integrated schools must be given guidance and support; otherwise they might reject the autistic children or even bully them.

**Educational opportunities:** Segregated programs are usually smaller and serve students with highly diverse abilities; therefore the variety of academic experiences available to a student with specific learning style and interests is limited much more than what is offered in regular education.

**Staff expertise:** A program for autistic children gives staff more opportunities for developing expertise and learning from colleagues; Teachers in integrated settings are more informed about the regular curriculum and activities.

**Staff expectations:** Teachers in special education tend to have lower expectations from students, partly because they lose contact with normal standards. Teachers in integrated settings might push autistic students to try to perform in normal ways that are inconsistent with how they learn best.

**Exposure to normative environment:** The environment in segregated programs might be too accommodating of autistic needs (quiet, structured, predictable) so that students do not learn to cope, and their possibilities later in life are limited. The environment in integrated programs might be so challenging for autistic students that they may not have a chance for effective learning.

When learning about programs, one has to find out whether the potential strengths of each program are really developed and what is done to counteract potential weaknesses. Integration is a continuum; therefore there are ways to combine strengths from both types. For example, a small special education class in a regular school may give the autistic students both contact with autistic peers as well as access to regular academic curriculum and some experience of navigating the general society.

#### Academic vs. vocational

It is true, that academic skills alone are not enough in preparing an autistic child for adult life. Some autism experts underestimate the importance of formal or academic education. Unless the child is bright enough to be expected to graduate college, these experts recommend discontinuing academic studies and focusing on life and workplace skills when

the child reaches adolescence. However, academic or "formal" education may be particularly useful for an autistic person:

**Vocational:** Many autistic people who have motor or sensory problems would do better in "white-collar" jobs (e.g., clerical work, computer programming) than in "blue collar" jobs.

**Life skills:** Unlike their normally developing peers, autistic children and youth do not absorb general knowledge from friends and the media. They may find it easier to learn about society and relationships in the more structured, explicit framework of curriculum.

**Mental patterns:** Formal education uses structured patterns that may help in formulating a problem or a situation. Where normal peers can use emotions and intuition, an autistic can use these more-structured patterns.

**Culture:** An important part of formal education is related to culture and heritage: literature, art, history, and other humanities. Autistic children and youth have the right to access these treasures, like any other child or teen.

**Leisure activities:** Some of the subjects taught at school may develop into hobbies or special interests.

### **Conclusion: There is so much to be done, start now!**

This title sounds like a "cure motto", doesn't it? It may seem so, to those who misunderstand the position of the autistic community or who buy into straw-man arguments of the curebies. The truth is that the disagreement between cure-proponents and anti-cure autistics and supporters is not on *whether or not* to treat autistic children, but on *how* to treat them.

Why is it so important to start *now*? Some parents and even professionals might tend to "wait and see whether the child outgrows his or her difficulties", before giving him or her "this awful label". Meanwhile, the child is treated like a typically developing child, and thus is not receiving the help that may relieve stress from both the child and the family. Some adjustments of daily routines and reorganization in space, e.g. the child's bedroom and some other spaces in the house (e.g. bathroom) can be done fairly easily and inexpensively, if only the parents accept them as the child's basic needs. The same can be said about some very simple communication aids and methods, if the expectation for normal development of speech is abandoned in favor of developing a meaningful way of communicating with the child. What we advocate for starting now is to *respect the special needs* of the autistic child.

Another reason for not waiting is the time and effort involved with the process of the parents undergoing a paradigm shift. Daily life is a series of decisions either planned ahead or ad-hoc reactions to situations. The caregiver's outlook is reflected in every decision and reaction. The message conveyed to the child, and the whole educational process, are the accumulated results of a series of decisions and reactions. It is therefore highly important for caregivers to be aware of their own perceptions. Deciding to not seek a cure (but to raise the autistic child as autistic) means entering an alien territory. Recognition of the essential difference between an autistic child and non-autistic parents is an important first step, and not an easy one to take. Following this step, parents need to learn what course of development would be

"normal" for their child. They can do that by observing their child and listening to him or her. An important resource in this process is the autistic community: autistic writings, discussion forums and conferences. Recognizing and accepting your child as autistic means giving him or her access to the autistic community, culture and even heritage (which is starting to emerge). It is a whole new world for non-autistic parents. Exciting as this journey may be, it takes a long time to happen. The earlier it starts the better for child and parents.

We are not advocating for the whole family to forsake their sensibilities and lifestyle and make their home autistic-friendly at the expense of the needs of the rest of the family. Parenting is involved with many aspects where thoughtful judgment is called for. Parents of all children are expected to accommodate every need of a helpless infant. As the child grows and matures, parents gradually raise the expectation that their offspring respects their and others' needs. This is true in parenting differently-abled children. Balancing accommodation with family life and keeping clear boundaries should be consistent with the developmental stage of the autistic child, and thus should be re-assessed from time to time. Remember that the ultimate goal is to raise a person who will be proud of and respected for who he or she is, and who will also respect you for who you are.

### **Annotated resource list**

A general comment: please remember that the goal of the authors in some of the sites is to make the child more normal; use the material as suggestions for action to promote *your* goals.

#### Parents of newly diagnosed young children

[www.jimsinclair.org/dontmourn.htm](http://www.jimsinclair.org/dontmourn.htm) DON'T MOURN FOR US by Jim Sinclair

<http://www.solashelly.org/goals.pdf> THE MEANING AND PRACTICE OF ACCEPTANCE:  
LONG-TERM AND SHORT-TERM GOALS FOR AUTISTIC CHILDREN by Sola Shelly

#### Sensory-motor issues

[www.ozmofun.com](http://www.ozmofun.com) (autism sensory toys)

<http://specialneedstoys.com/usa/> (autism sensory toys)

[www.iidc.indiana.edu/irca/Sensory/sensoryIntegrate.html](http://www.iidc.indiana.edu/irca/Sensory/sensoryIntegrate.html) (explanation of sensory integration)

<http://www.sensoryint.com/> (to find a sensory integration trained therapist)

#### Structuring

<http://www.teacch.com/education.html> TEACCH website

<http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1065&a=9610> General guidelines from the NAS (National Autism Society, UK)

<http://www.specialed.us/autism/index2.htm> (assistive technology with autistic children)

### Communication

<http://www.nas.org.uk/nas/jsp/polopoly.jsp?d=1070&a=5319> General guidelines from the NAS (National Autism Society, UK)

<http://suedweb.syr.edu/thefci/> The Facilitated Communication Institute, Syracuse

<http://www.teacch.com/communication.html> - TEACCH

<http://thiswayoflife.org/alltospeech.html> Alternatives to Speech, Joel Smith's website

### Autistic community and culture

<http://www.ani.ac>

<http://www.autistics.org> Especially the Library and the list of books written by autistic people.

[www.jimsinclair.org/History\\_of\\_ANI.html](http://www.jimsinclair.org/History_of_ANI.html)

<http://www.inlv.org>

<http://www.users.dircon.co.uk/~cns>

<http://www.wrongplanet.net/>

[http://www.sentex.net/~nexus23/naa\\_02.html](http://www.sentex.net/~nexus23/naa_02.html)

<http://www.autisticadvocacy.org>

<http://grasp.org>