











Autism

featuring material from

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About the autism spectrum

Brief descriptions
from autism to autism spectrum disorder



Autism is a developmental disability that typically appears during the first 3 years of life. Classified as a neurological disorder that affects the functioning of the brain, autism impacts the normal development of the brain in the areas of social interaction and communication skills. Children and adults with autism have difficulties in forms of communication, social interactions, and leisure or play activities.

Why Autism as a Spectrum Disorder?

Major advances have been made since the 1980s in understanding the social and communication difficulties of children with autism. Because individuals exhibit varying levels of impairments, the disorder is classified along a spectrum. The autism spectrum consists of three core features: impairments in social interaction, impairments in verbal and nonverbal communication, and restricted and repetitive patterns of behavior. However, not every person with autism will show signs of all three impairments, and even individuals who do exhibit all three of these features vary drastically in the severity of their impairments.

Here's a closer look at the three core features of autism:

Impairment in social interaction. For children with autism, this is brought on by impaired nonverbal behavior, lack of spontaneous sharing, socioemotional response, and/or failure to develop peer relationships.

Impairment in communication. This is represented by a delay in or lack of development of spoken language and gestures, the ability to initiate or maintain conversation, repetitive and spontaneous use of language, and/or lack of pretend play.

Restricted repertoire of activities and interests. Children with autism are often preoccupied with patterns, inflexible to routines, show repetitive movements, and/or have preoccupation with parts of objects.

The symptoms and characteristics of autism vary by person as well as disorder, from mild to severe, and fall under the umbrella term Pervasive Developmental Disorders (PDD). The following five PDDs make up the autism spectrum.

- **Autistic Disorder:** This is the most common PDD. The word *autism* was first used to describe a social aloofness and "preservation of sameness" noticed in a number of young children in the 1940s. Many of the features observed then are still observed today.
- **Asperger Syndrome:** Children with Asperger syndrome exhibit the same signs as those with autistic disorder but do not show severe impairments in language development. Children with Asperger syndrome have significantly stronger abilities with rote learning, spelling, and vocabulary.
- **Childhood Disintegrative Disorder (CDD):** With this rare condition, children develop typically until between the ages of 3 and 5. Then, they show a decline in language, social skills, play, motor skills, and even bowel and bladder control. The decline eventually stabilizes, and the child will then display symptoms of autistic disorder.
- **Rett Syndrome:** This primarily affects girls and is caused by mutations of a gene that is essential to early brain development. This is a neurological disorder characterized by loss of purposeful hand use, spasms in the legs, seizures, small head size, and mental retardation.
- **Pervasive Development Disorders-Not Otherwise Specified (PDD-NOS):** This term is used to describe a child whose behavior resembles autistic disorder or Asperger syndrome but may be too mild to truly diagnose. When there are clear problems with social learning, however, this diagnosis is often made.



The symptoms in each of these areas can overlap, although the disorders do not. Children and adults can exhibit any combination of behaviors from any area, making it possible for two children with the same diagnosis to exhibit different behaviors, reinforcing why there are no clear distinctions among these five disorders.

Why early diagnosis?

Early diagnosis can be the key to a brighter future for a child with autism. The earlier a child is diagnosed, the sooner he or she can benefit from the intervention programs available. Diagnosing a child's learning process at an early age not only helps the child develop, but also can be a comfort for the parents. Early diagnosis gives parents the opportunity to grow with their child and lets them realize that they are not alone; there are many other families in similar situations. Remember, help is available.

Parenting a child with autism

Excerpt from Robert A. Naseef's
Special Children, Challenged Parents
A Father's thoughts, Chap. 9, pp. 196–199



When I look back over my own experiences of searching for help and support in the early days of worrying about Tariq, I see that much of what I went through was fairly typical. At first, I believed that if he could just start talking again then everything would work out from there. When something is wrong with your child, you often feel like a little child yourself, and you want your mom and dad to help you—to rescue you and protect you from the hurt that you are feeling.

My mother and father would counsel me to be patient and tell me that things would work out. My mother would tell me that she was praying. They would ask me how Tariq was doing, as if he had the flu and was expected to get better each day. I would describe any little changes that I had noticed. Our conversations lessened the tension I felt, helped me to get through another day, and kept me working with Tariq to help him develop. They couldn't, however, wipe away the tears or bandage the wounds; that has been hard for them as well as for me.

My grandparents, who were still alive when Tariq was younger, would reassure me, too. I have a cousin my own age who has mild mental retardation and whose speech came late, and my grandparents helped my aunt and uncle a lot when Gregory was a little boy. They reassured me, based on how my cousin had developed. Even though he still stutters, he learned to read and write a little bit. He has a driver's license and holds a civil service job as a janitor. All in all, he has done very well for someone with his ability. My grandparents seemed confident that Tariq would be like Gregory. Because of their direct experience and their love for me, I trusted their wisdom and hoped desperately that they were right.

I remember how my grandfather would put Tariq on his lap and recite Italian nursery rhymes, the same ones that he had recited to me when I was a small boy. He would take Tariq's hands within his strong palms, as he had taken mine, and rub them on his coarse beard until it tickled. Tariq would smile and then squirm to get away because he didn't like to be held for long. My grandmother, too, would try to hold him, and she would sing the lullabies that she had sung to me, my siblings, and my cousins when we were little.

So many people never tried to hold my son, perhaps shying away from what they could not understand and what was uncomfortable. They would just make small talk, and I would withdraw in the embarrassment of the moment, always remaining outwardly calm. That's why I get such a warm feeling recalling those moments that my grandparents tried to hold Tariq, despite his squirming and wriggling. Of course, I wished that he would sit still and cuddle with them, but nonetheless, I felt myself held by them because they never stopped trying with him.

No parent wants his or her child to be noticed as different from the norm. You want a healthy, happy child who fits in and makes you proud. But what do you do when your

From Robert Naseef:

"Because autism affects communication and behavior, it strikes at the core of your relationship with your child. It is vital to get intensive and individualized services as soon as possible. Other parents of children with autism may be your best sources of information and support, so I always urge people to take advantage of support groups.

"I also stress the importance of accepting where your child is on the developmental ladder. Don't push all the time, follow your child's lead, and find mutually enjoyable activities. Your relationship with your child along with appropriate interventions and therapies will help your child grow. Spending some time each day just enjoying your child is also great chicken soup for the parent's soul."



child is different? Speaking for myself, I had a hard time when my son was diagnosed with autism. I walked around looking out of the corner of my eye ready to pounce on people for their reactions. Actually, it was more my perceptions of their reactions, not to mention the perpetual knot in the pit of my stomach. Like many parents whose children are different, it felt to me that I was battling the whole world.

I wish we had *Everybody's Different: Understanding and Changing Our Reactions to Disabilities* by Nancy Miller and Catherine Sammons much sooner. These authors give us an enlightening look at the many differences that exist among people in every walk of life and explain that these differences need not divide us socially. Life is definitely easier when you understand your own reactions, as well as those of others, while realizing that you are not alone—not by a long stretch. The authors help us understand our internal emotional reactions to disabilities and the differences that result from those conditions. They teach us strategies to build our lives, our families, and our communities in a way that is inclusive and respectful of our differences.

When Tariq starts “stimming” (i.e., repetitive behavior patterns that are a prominent characteristic of children and adults with an autistic spectrum disorder) or flapping, especially now that he is full grown, I automatically want him to stop and act “normal.” Internally, my reaction can be rather desperate because I don’t want him *and* me to be noticed as different. I also still find myself trying to avoid taking photographs when he is not behaving “normally.” There is a certain image that I prefer of him in my head, as much as I hate to admit that. But his behaviors are, after all, a part of him.

Even though I would consider myself a veteran parent, I have struggled to understand and own up to these reactions. It has taken me some time, but eventually I am learning to love my son not despite his differences—but rather because of them. The knot in my gut is long gone. Now, for the most part, I can look comfortably around me. I can notice what must have been there before—the friendly faces and kind eyes of compassionate folks.

I know I am not alone. Many parents have told me how isolated and abandoned they have felt in their hour of greatest need. There is a longing for someone to reach out and take a special interest in your child and therefore in you. When you finally do find that kind of support—a gentle hand to touch you and your child and a kind heart to ask how things are—that’s when you know for sure that you are not alone.

Tools and screening

Taken from past newsletters and videos



Importance of Early Screening

In the 1980s, many children with autism did not have their first contact with a professional until they were school age. By definition, the characteristics of autism spectrum disorder appear before the child is 3 years old. Diagnosis at an early age will allow the design of personalized interventions that help maximize the child's abilities. Early diagnosis also facilitates better communication between parents and child, better defines a child's development, and the appropriate help parents would need to seek.

Early interventionists know the importance of developmental screening to identify disabilities or delays early in a child's life. Nancy Wiseman is working hard to make widespread developmental screening a reality. Since 1998, she has served as founder and president of First Signs, an advocacy group committed to promoting developmental screening for all children.

At 23 months, Nancy's daughter was finally referred for a speech and hearing assessment, and it was discovered that her receptive and expressive language skills and social-emotional development lagged far behind the norms for her age. She was eventually diagnosed with pervasive developmental disorder-not otherwise specified (PDD-NOS).

Ms. Wiseman happily reports that her daughter responded very well to intervention and now attends school with typically developing children. Although she still has some language delays and auditory processing difficulties, her cognitive and receptive skills are actually above the norms for her age. But, Ms. Wiseman adds, "we lost about a year [of potential intervention]."

In April of 2001, First Signs launched a pilot project in New Jersey. Working in collaboration with the Robert Wood Johnson Medical School, First Signs sent a mailing to every pediatrician in the state, offering them the opportunity to earn continuing education credits by participating in the First Signs program. The program consists of viewing the First Signs video on screening and developmental delays; filling out an evaluation questionnaire; and ordering the First Signs kit of screening tool samples, which also includes directions for their use, a milestones wall chart, and an early intervention referral guide.

First Signs continues to receive requests from pediatricians, parents, and other clinicians for information on early detection. It has also launched a mini-pilot program in Tallahassee, Florida, and is starting a statewide program, similar to the first started in New Jersey, in Minnesota. After finalizing a program model, First Signs would like to take the program nationwide rolling it out on a state-by-state basis.

The Assessment

Once a screening indicates signs of autism, the next step is to determine what type of assessment to conduct. A proper assessment will help to design an intervention program relevant to the child's unique learning style and will provide parents with answers without misleading them.

The book *LINKing Assessment and Early Intervention* is designed to help intervention programs select an appropriate tool for assessing possible developmental delays. Dr. Stephen J. Bagnato, one of the co-authors of this book, gave us a brief overview of eight standards that program staff can use to evaluate assessment tools:



1. **Authenticity**—A good assessment/intervention system should encourage staff to observe the child’s behavior in natural settings. “Table-top testing” is not developmentally appropriate. Examples include a child’s ability to recognize a favorite toy or a McDonald’s sign.
2. **Collaboration**—The assessment method should ensure that parents and professionals are partners in decision making.
3. **Equity**—An assessment tool should allow staff to make accommodations for children with special sensory, motor, cultural, or other needs. The tool should measure a child’s accomplishments rather than require the child to have specific sensory or motor skills.
4. **Sensitivity**—There should be a sufficient number of items for assessing behaviors of the lowest-functioning children as well as the most capable. Each child’s individual strengths and needs should be identified.
5. **Congruence**—The method should be designed for use with children with disabilities; in other words, children with disabilities should be included in the normed group.
6. **Convergence**—The assessment approach should allow you to collect information from multiple people in multiple settings, including the home, and should incorporate both observation and interview data so that a professional is able to see the full range of a child’s abilities.
7. **Acceptability**—The assessment approach should be acceptable to both parents and professionals. The tool should allow for a socially acceptable approach, such as play-based assessment, instead of an IQ test. The process should tap “real” skills, such as a child’s ability to communicate with others, as opposed to a child’s ability to identify pictures.
8. **Utility**—The method has to be useful for a specific purpose, such as intervention planning. For example, an IQ test would be useless for linking assessment and intervention because it has nothing to do with a child’s development.

From Dr. Bagnato:

“An assessment’s purpose is to create individualized plans,” notes Dr. Bagnato. “Goals then become benchmarks for measuring the progress a child is making.” It is essential, says Dr. Bagnato, that assessment, intervention, and progress evaluation be linked together. “It’s a check-and-balance system.”

From diagnosis to intervention

Talking with Emily Rubin and Amy Laurent



Emily Rubin, MS, CCC-SLP, and Amy Laurent, OTR/L, are contributing authors to Dr. Barry Prizant's The SCERTS Model, Enhancing Communication and Socioemotional Abilities of Children with Autism Spectrum Disorder. With Dr. Prizant, they have developed a new approach to teaching children with ASD. The result of their hard labors is a model that addresses the three core challenges in teaching children on the autism spectrum: social communication, emotional regulation, and transactional supports. To further discuss their work and findings, Rubin and Laurent collaborated in answering the following questions:

1. What gaps do you see in other educational practices developed for children with ASD that the SCERTS Model is able to successfully address?

In the SCERTS model, it is recognized that most learning in childhood occurs in the social context of daily activities. Therefore, efforts to support a child's development occur with caregivers and familiar partners in everyday routines in a variety of social situations in the home, school, and community settings. Because a number of current educational approaches focus on working with a child in isolation of these settings and social partners, a gap in the provision of support for that child's partners (e.g., family training, peer training, and support to service providers) is often created.

In the SCERTS Model, developmental objectives for the child in Social Communication (SC) and Emotional Regulation (ER) are addressed not only by focusing on the child, but also by measuring the progress of that child's partners in their ability to implement Transactional Supports (TS) (e.g., interpersonal supports, learning supports, and environmental modifications) to achieve more successful social exchanges.

In the forthcoming SCERTS Manual, a curriculum-based assessment will be accessible for families and educators to gauge both a child's development in social communication and emotional regulation as well as the success of that child's partners in implementing transactional supports.

2. In what settings is the SCERTS Model designed to be followed?

As alluded to in the response to the first question, the SCERTS Model is designed to be a comprehensive framework that supports a child's development of Social Communicative (SC) and Emotional Regulatory (ER) abilities. Within the SCERTS Model, the facilitation of these core capacities through the implementation of Transactional Supports (TS) is viewed as essential for supporting a child's active learning. Since the SCERTS Model is based upon typical child development and social learning theories, it is critical that developmental objectives for SC and ER be addressed across a child's educational, home, and community settings in order to successfully promote the child's generalization of learning within natural activities and functional routines.

The overarching goal of the SCERTS Model is to enable children to participate more successfully in developmentally appropriate activities with family members, adult partners, and peers in a variety of settings. Therefore, to ensure social success from the onset of intervention, transactional supports must be implemented not just across settings, but also across all partners within a child's life. The model works best as a team approach, as the expertise of professionals from different disciplines in partnership with families is viewed within the SCERTS model as the most effective and efficient way to best support a child's development across a range of settings and partners.



3. How can the SCERTS Model be implemented in an inclusive classroom without detracting from the needs of typical children while providing individualized attention to students with ASD?

Within the SCERTS model, a child's individualized education plan and educational placement are based upon many factors. First and foremost, a child's individual strengths and needs are considered with respect to his or her social-communicative abilities and emotional regulatory capacities. In addition, the child's family's priorities, as well as the demands and resources of the available educational programming options are considered.

Regardless of the child's educational placement, individualized Transactional Supports (TS) aimed at facilitating the child's attainment and maintenance of a well regulated state, a state which supports a child's ability to learn, attend and "fit in," are essential components of the child's educational plan. Within an inclusive classroom, these supports may consist of both Interpersonal Supports (e.g., communicative style adjustments) and Learning Supports (e.g., environmental and curricular modifications). The implementation of these types of individualized supports within the natural routines and activities of a classroom fosters the child's attainment of developmental objectives in the areas of Mutual Regulation and Self- Regulation. The child's resultant expanding repertoire of regulatory abilities enables the child to be a more active and engaged member in the inclusive classroom setting. As an active participant in the classroom activities and routines, the child is an integral part of the classroom community, enhancing rather than detracting from the learning environment.

Likewise, many of the Transactional Supports (TS) implemented by partners, such as environmental accommodations (e.g., reducing extraneous stimuli) and other Learning Supports (e.g., schedules and visual organizers) may be of benefit to many of the child's peers within the inclusive classroom.

4. Do you feel it is most beneficial for children with more severe cases of ASD to be taught in an inclusive classroom or special education classes? Why?

In the SCERTS Model, an appropriate educational setting is not a "prescription" based upon the level of "severity" of the child with ASD. Determination of social learning contexts must be a flexible process that is dependent on a child's learning strengths and needs, the family's priorities, and the demands of the child's natural routines and ongoing educational programming.

The SCERTS Model provides a framework for determining natural social activities that are the most conducive to addressing educational priorities such supporting the most functional abilities in social communication and emotional regulation, goals that directly address family priorities, and goals that are developmentally appropriate. Since participation in one learning context, either entirely inclusive or entirely self-contained, may not fully address these priorities, it is more common that a child will be participating in a range of social learning settings throughout his or her day.

Having said this, interactions with children without special needs and children who could provide good social and language models in more natural activities and routines are viewed as an essential part of supporting communication and emotional regulation for children participating in a SCERTS Model program. In these more "natural" learning contexts, there are numerous opportunities for developing functional communication and social problem solving skills. These opportunities may also help "typical" children to become more sensitive and supportive partners by developing a greater understanding of how to



adapt to and develop relationships with children with developmental differences, thus promoting growth in both the child with ASD as well as the “typical children.”

5. One of the three main areas the SCERTS Model addresses, and that children with ASD typically have the most difficulty with, is social communication. What do you see as the key components for forming a relationship with a child with ASD?

In the SCERTS model, the social communication dimension has been designed to address the overriding goals objectives that help a child to become an increasingly competent, confident and active participant in social activities. These developmental objectives fall under two primary domains, the capacity for joint attention and the capacity for symbol use, recognizing that in addition to symbolic language and play, a child needs to develop strategies for establishing shared attention with his or her partners to ensure successful and mutually satisfying social exchanges and the development of relationships. Since becoming a competent communicator, however, relies on the support of a responsive social partner, the SCERTS model recognizes that direct instruction focused on the child in socially isolated “teaching programs” does not necessarily ensure positive social communicative exchanges and development of relationships across a number of different partners.

Therefore, to ensure social success, supports must be fostered across all partners and settings within a child’s life, including family members at home, same-aged peers and teachers at school, and those within the larger community. In the SCERTS Model, partner objectives are written to address Interpersonal Support modifications (e.g., communicative style adjustments) and Learning Support modifications (e.g., the use of visual modalities and environmental modifications). Relationships develop when both the child and the partner bear some responsibility for change and mutually enjoyable and successful exchanges are achieved.

6. Do you view stimming as a problematic behavior that educators and parents should try to eliminate from a child’s behaviors or do you see it as a positive behavior that falls under self-regulation, one of the goals of the SCERTS Model?

Behaviors that may be viewed by some as “self-stimulatory,” are often regarded as Behavioral Strategies for Self-Regulation within the SCERTS Model. Behavioral Strategies develop initially during infancy and are simple motor actions or sensory motor strategies that a child engages in to regulate his or her arousal level, remain alert, and/or self soothe. The use of Behavioral Strategies for the purpose of regulation persists throughout the course of a child’s development and may either be biologically driven (e.g., sucking one’s thumb to self soothe) or modeled by responsive partners (e.g., stomping one’s feet when mad).

Often times, children with ASD have difficulty responding to conventional Behavioral Strategies modeled by partners (e.g., squeezing hands together, tapping feet, chewing gum, etc.); and, therefore, frequently employ unconventional patterns of behavior (e.g., jumping, walking on toes, flapping hands, and fleeing from the social setting) regardless of their age. This is particularly true for children with ASD when they are experiencing periods of extreme dysregulation. In the SCERTS Model, these idiosyncratic behaviors are viewed as either “starting points” for attempts at regulation or as signs of dysregulation, not necessarily as “problem behaviors.” As a result, these Behavioral Strategies as well as the environmental and social factors associated with their display are considered carefully when designing Transactional Supports (TS) and targeting developmental objectives in the domain of Emotional Regulation.

From diagnosis to intervention

Interview with Paula Kluth



Paula Kluth, author of “You’re Going to Love this Kid!”: Teaching Students with Autism in the Inclusive Classroom, has been working with students with autism for many years. Here she talks about her book and how to support children with autism in inclusive classrooms.

You seem to recognize great things, not only in children with autism spectrum disorder, but all students. How important do you think it is to get students in the classroom directly involved with students with ASD?

It is so important! Any teacher who wants a classroom that makes all learners feel safe, comfortable, and capable should think seriously about how to create a space and a curriculum that gives learners opportunities to share with and support each other.

For most students, the best part about coming to school is seeing and spending time with friends. For students who struggle to make social connections, however, going to school can be a lonely and frustrating experience. Many students with autism who are being educated alongside their peers without identified disabilities are indicating that they need more than an inclusive classroom to feel successful; students with autism are increasingly asking teachers to facilitate the development of friendships and of access to social opportunities.

While no teacher can *create* friendships between students, every educator can create conditions in the classroom that will give students opportunities to strengthen social relationships, learn about/from each other, and get/give support—the hope being, of course, that these opportunities eventually lead to the development of friendships.

How do you think inclusion affects the learning capabilities of students with ASD?

An inclusive education gives students opportunities to access academic content, study social interactions, and learn new skills and information from a variety of sources (teachers, peers with a range of abilities and talents, classroom materials).

Students with autism often profit from watching and interacting with others their own age. Since many of these learners are master imitators, watching 20 other students learn to read or use science lab equipment can be more powerful than watching the teacher or following written directions. Students in these classrooms typically serve as natural supports for one another; they serve as models for speaking, listening, reading, writing, and using new materials. They also teach new skills to each other as they play, socialize, and work together.

You have said in the past sometimes the challenge is more the classroom than the kid. What would be the first steps for teachers in setting up their classroom for inclusion for the first time?

Yes, in some instances, the teacher is doing everything right—effective teaching strategies are in place, instruction is motivating and responsive, and the curricular adaptations are all appropriate, but the environment is in some way problematic.

For instance, some students with autism struggle with certain sounds. Some of the sounds that disturb students might be obvious. Many learners with autism, for example, will scream when the fire alarm sounds. Some students with autism report, however, that they are equally bothered by some “everyday” sounds like buzzing electric pencil sharpeners and whirring air conditioners. To help students deal with classroom sounds a teacher might try earplugs or headphones for some activities or for use in some parts of the school building (e.g., gymnasium); reduce classroom noise when possible (e.g., have students push chairs in quietly or put carpet samples under chairs); or allow students to listen to soft music using



headsets in noisy or chaotic environments.

Some individuals with autism also have incredible sensitivity to light. Children and adults with autism have reported problems in particular with florescent lights. The teacher may want to turn off the overhead lights for a few days to see if change seems to have an impact on the student.

Finally, appropriate seating may not be the first thing a teacher considers when planning for a student with autism, but for some students comfortable classroom furniture is pivotal to their success. One of my former students couldn't sit in a desk for more than a few minutes but he could sit in a beanbag chair for 40 minutes at a time. We soon purchased several beanbag chairs for the school (a few for the library, two for the music room, a handful for hallways, and one for the office) so that this student could be at ease throughout the school and so that all students could enjoy a change in seating now and then.

Your upcoming book focuses on students with ASD, but would you suggest any teacher be able to use the many activities and insight in any classroom?

Of course. Since teaching is a dynamic process, the strategies that may work for one student may or may not work for another. Having expressed that, it is also true that there are certain strategies that are often successful with some students with autism as well as many students without identified disabilities. Many of these strategies, in fact, are simply suggestions for good teaching that can support students with a range of needs, strengths, and abilities in inclusive classrooms.

Students with the most significant needs often cause teachers to get creative and to stretch their idea of what it means to reach all learners. While a teacher can meet the needs of all students without ever having a student with disabilities in her classroom, these students are often a catalyst for change and creativity. Specifically, including students with autism may help teachers think more carefully about the choices students have, the design of the lesson, the ways in which students participate in teaching and learning, and the comfort, engagement, and opportunities for ALL.

From Paula Kluth:

"This book provides concrete examples of how to plan lessons, engineer a safe and comfortable classroom, provide communication opportunities, and understand and support challenging behaviors. Drawing on classroom and school observations, as well as my own experience as an elementary and high school teacher, I explore pragmatic ways of making schools safe, challenging, and accessible for students with autism spectrum disorders."

In your book, you state that students often recognize each other's needs and gifts in ways not seen by teachers. This is a great observation. How would you go about teaching teachers to illicit some of the great qualities that students see in each other?

I think students will always possess a special knowledge and vision of one another that adults do not have, so the best way to tap into this knowledge and vision is to work with students as you would any other group of colleagues. Teachers who approach students for guidance and inspiration often gain new information about their learners and therefore become better educators, able to individualize instruction more effectively and make a curriculum more relevant to students' lives.

Teachers who are good listeners often find that students are able to provide them an exceptional education about teaching, learning, and dozens of other topics. One way to lis-



ten is by tuning into students as they work and socialize. Teachers who participate in casual conversations at lunch time or “hang out” in hallways can learn about students in more holistic ways. What are students excited about? Worried about? Knowledgeable about? Interested in? Afraid of?

Teachers may find keys to teaching and learning and discover ways to better support students by listening carefully and respectfully during informal, but important moments. One teacher found ways to listen to her students by forming an “anyone-is-welcome” poetry club. She benefited as a teacher not only by participating in a social activity with students, but by eliciting their voices through the poems they wrote.

Educators must also be constantly scouting for students’ talents and seeking situations that highlight their abilities and support the needs of diverse learners. Teachers of students with autism must believe that students *are* competent and then they must “set the stage” for students to perform competently. Teachers looking for competence and complexity in learners should constantly consider questions such as Under what circumstances does this student thrive?; What gifts/skills/abilities does this student have?; How can I help this student find success?; and How and what can I learn from this student?

Activities

Taken from
Kathleen Ann Quill's
DO-WATCH-LISTEN-SAY



The following activities were taken from Kathleen Ann Quill's book DO-WATCH-LISTEN-SAY: Social and Communication Intervention for Children with Autism. The activities here provide guidelines for intervention when addressing social and communication skills.

Activity 1

Core Skills Curriculum

These skills are fundamental for an understanding of all social and communication skills.

Activity

C. Organization

Possessions 1. Recognizes personal belongings (mine)

Strategies

Make distinct the separation between the child's possessions and others' by

- Marking the child's space and materials
- Clearly defining community space and materials
- Identifying shared space and materials

Designate spaces for personal belongings (e.g., coat hook, chair, cubby, shoe rack, table area, work materials) using the child's photograph and name.

Create personal tags with the child's name and photograph to label items the child owns or is using.

Define possession by color-coding objects in the environment. For example, all of the items with red circles belong to the child. Items with purple circles belong to peer A. Items with blue circles belong to the teacher. The child does not have free access to items not marked by red circles. Mark common materials with multicolored dots.

Give the child a box. Prior to free play time, have the child fill it with his toys of choice. All items in the box belong to the child. Any items not in the box belong to others.

Set up a joint tabletop activity (e.g., playdough, art project, puzzle, simple building task) with shared materials. Give each child a small bin. Divide the materials between the child and his play partner by filling their bins. Define for the child that the items in his bin are his and the items in the play partner's bin belong to the play partner. If the child wants an item that is not his, prompt the child to identify who has it and direct his request to that person.

Give each child a place mat colored or labeled (with the child's photograph and name) to indicate his personal play space. Present play materials in one centrally placed box. The items placed on the child's mat are his, the items on the play partner's mat belong to the play partner. Materials in the box are shared.

Use woven place mats with two colors to represent a shared play space.

Engage the child in show-and-tell activities. Have the child bring in a personal item to show and describe to his peers. When other children bring in items, have the child identify which items belong to whom.

DO-WATCH-LISTEN-SAY: Social and Communication Intervention for Children with Autism
by Kathleen Ann Quill © 2000 Paul H. Brookes Publishing Co.



Activity 2

Social Skills Curriculum

Social skills should help children with autism understand what to DO, who to WATCH, how to LISTEN, and what to SAY.

Activity

B. Group Skills

Following Group Directions I. Nonverbal directions

Selecting Activities

When preparing the child for a group activity, consider the following:

- Does the child attend to the adult in the group?
- Does the child follow the nonverbal directions in a one-to-one situation?
- Does the child understand the nonverbal directions used in the group?
- Does the child follow the lead of peers when confused?

Sample Activity: Group instruction

Design a social story about following group directions. The story should describe one or more types of nonverbal directions and explain what to do. For example, it is time to stop and look at the teacher when the lights flick on and off. Read the story to the class several times a day. Silently flick the lights whenever it is time to give group directions. Wait for all of the children to stop what they are doing and look at you before giving any verbal directions. If the children have not stopped, have another adult silently stop them and point them in your direction. Fade the silent, physical prompting as soon as possible.

Strategies

Organizational Supports

- Turn the lights on and off.
- Ring a timer.
- Ring a bell.
- Snap to a beat.
- Have everyone raise their hands and put a finger to their lips.
- Clap to a rhythm.

Social Supports

- Use similar nonverbal group directions across the day.
- Use exaggerated gestures.
- Target a peer coach for the child to watch in order to remember what to do.
- Assign a peer partner to assist the child.

Visual Supports

- Make a visual list of the group rules: watch, wait, and listen. Cue the children as needed.
- Provide individual cue cards that specify the group rules.
- Preview and review a social story about group rules.

DO-WATCH-LISTEN-SAY: Social and Communication Intervention for Children with Autism
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Activity 3

Communication Skills Curriculum

The activities here enhance three areas of communication: basic communicative functions, socioemotional skills, and basic conversational skills.

Activity

B. Socioemotional Skills

Express Feelings 1. Requests a break when upset

Sample Means

Communicative gestures: Moving person's hand, reaching, pulling person's hand

Emergent: Vocalizations or speech, signs, photographs, pictographs, a voice output system, or written language to say *Break* or other appropriate word

Verbal: Speech, signs, photographs, pictographs, a voice output system, or written language to convey a multiword message, such as *I need a break, please*

Learn a Target Message to Replace Behavior(s)

Context: All settings in which the child demonstrates a high level of discomfort or frustration

Materials: A tangible symbol (e.g., object, photograph, pictograph, written message) that means *break* to the child—children with autism often lack the ability to verbalize any communication that is a replacement for problem behavior, so a tangible symbol is essential even for verbal children

Procedure: Work with the child in a setting that is challenging. Wait for the child to demonstrate some level of agitation. Present the *break* symbol to the child and silently guide him to a clearly defined break area. A break should be calming for the individual child but not reinforcing. Maintain a neutral affect and do not engage the child in any discussion. Examples might include sitting on a beanbag chair or walking in the hall. The break must have a definitive end point and the child must come back to the activity. A request for a break must never equal a request for *All done*. Continue to anticipate the child's frustration and move from picking up the symbol yourself to gesturing toward the symbol and, finally, to the child initiating that process. The final goal is for the child to request a break spontaneously, without any cuing. Repeat the sequence many times in the same manner. Initially, all of the child's communication attempts should be acknowledged, even though he may overuse this new privilege. Gradually limit the number of breaks that are available. Once the child is requesting breaks from various adults, he can also be encouraged to tell a peer.

Strategies

- Teach meaningful social and communication replacement behaviors at the moment the child is engaged in inappropriate behavior.
- Offer the child maximum support to ensure success.
- Do not prompt in exactly the same way every time.
- Limit the use of verbal prompts in the form of questions.
- Simplify language complexity.
- Use AAC supports that are consistent across various settings.
- Keep the length of breaks consistent and clearly define the end point with a timer or clock.
- Observe what situations frustrate the child.
- Ignore any of the child's attempts to engage in conversation; remain neutral.
- Clarify expectations.
- Use nonverbal reinforcement that mirrors the child's emotional state.

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Autism encyclopedia

Excerpt from John T. Neisworth & Pamela S. Wolfe's,
The Autism Encyclopedia, pp. 12, 202, & 230



Do you know what magnesium therapy is? Learn about this therapy and more in the entries below excerpted from The Autism Encyclopedia, by John T. Neisworth & Pamela S. Wolfe.

APPLIED BEHAVIOR ANALYSIS (ABA)

An applied science that develops methods of changing behavior and a profession that provides services to meet diverse behavioral needs. ABA is based on the scientific study of principles of operant and respondent conditioning and has a well-respected research literature that has accumulated over decades. ABA is applied (the outcome has practical significance), behavioral (behavior itself is of interest), analytical (functional relationships can be established), technological (procedures are described, so replication of an intervention is possible), conceptually systematic (procedures are derived from basic theoretical principles), effective (interventions are socially valid), and generalized (behavior changes are evident over time and in different settings) (Baer, Wolf, & Risley, 1968). Interventions using ABA that have been found to be effective for individuals with autism (New York State Department of Health, Early Intervention Program, 1999a) include analysis of verbal behavior (AVB) and Discrete Trial Training (DTT). ABA is the only therapeutic/educational approach for children with autism that is deemed effective by the Surgeon General of the United States. *See also* analysis of verbal behavior (AVB), behavior modification, behavior principles, behaviorism, discrete trial training, operant conditioning, respondent conditioning, social validity, verbal behavior (VB). *Gerald L. Shook*

SPLINTER SKILLS

Areas of ability that far exceed what the child can do in other skill areas. Children with such abilities are sometimes referred to as *savants*. Although most children have ability profiles that are uneven, the term *splinter skills* is usually reserved for skills that are markedly above the child's other abilities or above average. Most splinter skills in autism are in the areas of mathematical calculation (e.g., identifying prime numbers, multiplying large numbers); calendrical calculation (i.e., knowing the day of the week for random dates); art; music; balance and other motor skills; and memory for locations, facts, or events. There are no definitive explanations for these abilities; the simplest is that obsessive interests lead to continual practice and skill development (see Hermelin, 2001). *See also* restricted interest, savant syndrome. *Deborah Fein*

VITAMIN B₆ AND MAGNESIUM THERAPY

Vitamin B₆ and magnesium therapy was one of the earliest nutrient supplement therapies ever used for autism spectrum disorder (ASD). This combination treatment has both theoretical and experimental support. Vitamin B₆ (pyridoxine) and magnesium are pivotal nutrients involved in neuronal cellular energy production. Deficiencies of either can lead to disordered central nervous system (CNS) integration of all body processes (Grimaldi, 2002). Magnesium deficiency inhibits the production and tissue uptake of pyridoxal phosphate, the active form of vitamin B₆. A vitamin B₆ deficiency causes increased magnesium excretion. In animals and humans, experimental or accidental deficiencies of magnesium and B₆ cause many abnormalities associated with autism (e.g., neuromuscular hyperexcitability, muscle spasm, heightened sensitivity to touch and sound, inattention, abnormal movements). Since 1965 several dozen studies have demonstrated some improvement, occasionally dramatic, in approximately half of study participants using various regimens of vitamin B₆ and magnesium supplementation in individuals with autism (Pfeiffer, Norton, Nelson, & Shott, 1995; Rimland & Edelson, 2003). It is unlikely that vitamin B₆ and magnesium defi-



ciencies are primary causes of autism. Many behavioral and physiologic abnormalities of autism can cause negative vitamin B₆ and magnesium balance (e.g., decreased intake due to restrictive self-selected diets and malabsorption, increased excretion secondary to chronic gastrointestinal abnormalities). Whether independent of or caused by the underlying pathophysiology of autism, vitamin B₆ and magnesium deficiencies may add adverse physiologic consequences to the autism spectrum, expanding its heterogeneous presentation. Because of low cost, relative safety, and some literature support, a therapeutic trial of these nutrients at appropriate dosages may be attempted to ameliorate symptoms of autism, although this treatment currently is not recommended (New York State Department of Health, Early Intervention Program, 1999a). *Robert A. Da Prato*



Case study 1

Excerpt from V. Mark Durand's,
Sleep Better! A Guide to Improving Sleep for Children with Special Needs,
Help with bedtime snooze, Chap. 5, pp. 80–82



Nick was a 12-year-old boy who had received a diagnosis of autism. He lived at home with his parents and a sister and attended a general sixth-grade class at his neighborhood school. Of most concern to his parents and school were his frequent self-injurious behaviors, which mostly involved his poking himself in the eyes. He also frequently would get upset at home and at school, throwing objects and sometimes even breaking windows.

We first had contact with Nick because of his very disruptive and disturbing behaviors. As we talked with his family, we found that he also had difficulty at bedtime and throughout the night, and we suspected that his sleep problems may be contributing to the daytime behavior problems observed at home and at school. One of the major problems surrounding Nick's sleep was his unwillingness to go to bed at night. Often, he would remain awake for up to 4 or 5 hours after he was put to bed for the night. During this time, he frequently would scream, yell, throw things around his room, and bang on the walls with his fists. Unfortunately, this was almost an every-night event.

As happens very often in children with bedtime problems, Nick also sometimes had trouble remaining asleep at night. Several nights each month after he fell asleep, he would awaken, be unable to fall back asleep, and then become disruptive in the middle of the night. Two or three times each month, he would not sleep at all and would have tantrums on and off throughout the night.

Before we had contact with Nick and his family, a physician had prescribed several different medications to try to help him sleep. As is often the case, they tried giving him some Benadryl at bedtime to make him drowsy. Unfortunately, Benadryl seemed to have just the opposite effect on Nick, making him more agitated, and he stayed awake later than ever. For a short time they tried a drug called Inderal—which is used to control high blood pressure and migraine headaches and is also used sometimes to reduce anxiety—but this drug seemed to have no effect on his sleep. A third drug, Mellaril, was prescribed to be given right before bedtime, and this seemed to help Nick fall asleep more easily. The positive effects of using this drug were not without cost, however. During the first 4 months that Nick was taking Mellaril, he gained 40 pounds. One night he somehow got access to the bottle and drank a large amount of the drug and needed emergency treatment. Because of these concerns, Nick's parents were anxious to try a different approach that did not involve the use of medication.

Nick's parents had already established a fairly stable bedtime routine. When we looked at his sleep diaries, we found that, even with the Mellaril, it would take him an average of almost 2 hours each night for him to fall asleep. His parents had selected an 8:00 p.m. bedtime, in part because they wanted him to get more sleep and also because they relished time alone at night for themselves. Our suggestion for a later bedtime (10:00 p.m.), which was probably more appropriate for a child his age, was met with obvious resistance. The compromise that we all agreed to involved continuing to put Nick in his bedroom at 8:00 p.m., but instead of turning out the lights and trying to get him to sleep, he would be allowed to stay up and play in his room until 10:00 p.m.

From Mark Durand:

“A parent’s proper response to bedtime is essential. A 30-minute bedtime routine that is designed to prepare a child for sleep. Activities during this period can include reading to the child, washing, and getting undressed. Activities to avoid include any sort of aerobic activity (which increases body temperature and makes it harder to fall asleep) and any intake of caffeine. In fact, Dr. Durand recommended that children avoid exercise (including rough housing) and caffeine for a few hours before their bedtime.”



Each evening, Nick's parents would begin the bedtime routine, which would end with his being in his room at 8:00 p.m. He could keep his light on and play until 10:00 p.m. If he were very disruptive, then the parents could go into his room, but other than these times they were to leave him alone. An alarm clock was set to go off at 10:00 p.m. to signal both Nick and his parents that it was time to sleep. At this time they would enter his room and sit by his side for a few minutes of quiet activity (backrubs, quiet talking). After no more than 15 minutes, his parents were instructed to say goodnight, turn off the light, and leave the room.

The compromise at bedtime dramatically reduced the disruption at night. During most evenings, Nick did not fight bedtime and generally cooperated with going to sleep. There were still one or two nights each week when Nick was disruptive, however, so we designed a graduated extinction plan for these times. On nights when Nick refused to stay in his bed at 10:00 p.m. and go to sleep, his parents were instructed to wait 5 minutes before going into his room. We suggested that they stand by his closed bedroom door so that they could hear him and so that they could respond when he tried to leave his room. If he opened the door and tried to come out, then his parents would lead him back to his bed without saying anything other than, "Go back to bed." On a few nights, they could hear him banging his head, so they calmly entered the room, placed him back into bed, and then left the room. Over the course of several weeks, the problems continued to decline, and Nick's parents were delighted with the changes.

The solution of having Nick stay in his room from 8:00 p.m. until 10:00 p.m. obviously was a compromise that was not without some risk. By letting him spend so much time playing in bed at night, we were concerned that he might associate the bed with play rather than with sleep, and this might interfere with his sleep. Fortunately, this was not the case, and on most nights he fell asleep soon after the alarm went off. Ideally, his parents should have kept him up until 10:00 p.m., but the needs of the family—some "mental health" time together—were important to consider when we designed the plan. Its success was welcomed by the whole family.

Again, Nick's case illustrates the need to tailor these programs for each family. When children present multiple problems surrounding sleep, as Nick did, it is important that you be patient and continue to monitor your child's progress. Parents should complete the sleep diaries throughout the time of the program so that they can see whatever changes are occurring, even if progress is slow. Nick's parents initially were skeptical about the program until we showed them his improvements each week. Seeing that Nick's tantrums were becoming shorter and shorter gave them motivation to keep going. Remember to keep monitoring your child's progress, and, if you need it, use this information to help you persist.

Case study 2



Excerpt from Virginia Walker Sperry's, *Fragile Success: Ten Autistic Children, Childhood to Adulthood, Second Edition* Elizabeth Stanley: "I had to identify her emotions for her...", Chap. 9, pp. 140–150

In early 1966, after several months of careful examination and study, the Yale Child Study Center told me that my 3-year-old child was different—"atypical" was the word they used. They went on to say that her atypicalness fell within the broad syndrome known as "autism." I had never heard the term. They told me that she was born with built-in deficits, with no cause yet known. It was simply the way she was constitutionally constructed. This basic personality, along with its limitations, would be hers always. We had to accept and live with that.

I was terrified—at first by the cloud of mystery, and then by my gradual awakening to what it really meant, which was worse. Karen was this lovely baby we had so wanted, who was adored by all of us, including our four other children and relatives, who would never be normal. Since then there has been no significant disagreement among the different specialists we have consulted on Karen's diagnosis and prognosis. All observed that Karen was not capable of imaginative play; she was withdrawn and unable to relate normally to other children. She was obsessive and perseverative. She was autistic.

By the time Karen was diagnosed, I had already known for some time that there was something wrong with her. When she was 2, our family lived for a year in a large city in the Orient. Before we left the United States, when getting the necessary immunizations at the pediatrician's office, I hesitantly raised my hidden fears about Karen. Although none of her development was out of step with what I knew to be normal, she seemed slow: She wasn't speaking; she felt limp; she lacked ordinary aggression (my other children at her age would have been all over the doctor's office, climbing on chairs, or pulling papers from his desk). I said she seemed docile, too quiet. Was something wrong? The pediatrician mulled that over a bit, gazed thoughtfully at Karen, then reassured me: All children develop at different rates and over different spans of time; she was within normal bounds.

Our voyage abroad by freighter was a lively experience: 2 months at sea, visiting many ports in the Mediterranean, the Red Sea, the Middle East, and India. But I grew more troubled about Karen. Although I took two trunks full of toys, games, and books for the children, she touched none of them. She would not play with any of us, although she enjoyed it when we tossed her about and tickled her. The only amusement she found was splashing in the sink or bathtub in our room, and being carried about by the crewmen, who adored children.

After our arrival in the East, following the custom there, I employed an aide to take care of Karen. I also enrolled her in a small nursery group. But while all the others joined in play or listened to stories or sang songs, Karen sat on the fringe poking at the sand at her feet. She stood all alone, isolated.

After a while, we started to refer to Karen as "the quiet one." We began to feel increasingly cut off, even rejected by her. At her age, after all, children look at you, hear you, laugh at and with you, and annoy you. Not Karen. I suspected that she needed medical help, and, so far from home, I became increasingly worried and at times nearly frantic.

When we returned in the fall of 1965 I immediately took Karen to the Yale Child Study Center to undergo professional scrutiny. While we awaited the outcome, friends and family tried to reassure us. But in those assurances I dimly sensed their need to protect me from some horrible truth they themselves had begun to fear. "After all," they reasoned, "what do you expect? All of you dote on her and baby her to death. She doesn't have to talk or do anything. Before long, she'll get tired of that, and then you will see a big change. Einstein, you know, didn't talk until he was 3." We needed to believe that, so we did.

Meanwhile, we enrolled her in a nursery school, and our experience there prepared us for the reality the extensive testing would soon reveal. The teacher was completely baffled by Karen, so much so that she began to question her own competence. Finally, she insisted





Karen must be deaf. Worse, she worried that Karen didn't like her and therefore would not respond to her as the others did. She felt hurt, a failure. I felt the same.

After 3 months of careful examination, observation, and consultation by the staff of the Child Development Clinic at the Yale Child Study Center, our doctor there told us the tragic truth. Karen was not deaf; she could hear a pin drop. This developmental specialist, her eyes full of dread her professionalism could not hide, said Karen suffered from autism, an affliction for which there was no known cure. Education was the only possible therapy.

The problem was that deficits in the formation of Karen's personality were interfering with its normal development. Karen had no sense of her own identify, and she could not locate and use her own emotions. "You must get through to her, press yourself upon her, barrage her, make her hear you and respond. We are certain she can. You must reach her." I could not miss the desperate insistence in the doctor's voice.

The doctor went on. She said there was one other thing I had to do: I had to identify Karen's emotions for her, and then interpret them for her and teach her what they were and the appropriate responses to them. I had no idea what this meant. For a long time Karen had seemed incapable of feeling or expressing any emotion. Now, the doctor was telling me that she really had emotions but could not understand what they were for or how to express them. Likewise, the doctor said that Karen had intelligence but could not use it. She could not relate normally to people or even to her physical surroundings.

As I listened, my mind whirled and my throat went dry. It all seemed unreal. I realized

Karen's responses and behavior were distressingly impersonal and sometimes bizarre. Now I was told I had to develop some way to force her to do what she apparently could not to do on her own—hear me, respond to me, deal with me, act like a human being. My God, what was she? Even dogs lick your hands, jump on you, invite you to play. Was she a sub-being of some sort? Could she even learn, respond naturally? What if she couldn't? Would she become a "vegetable" and have to be "put away"? There are no words to describe those moments, the pain and terror I felt as I walked out of that office.

On arriving home, I opened the door. Full of apprehension, I went to the kitchen and put my purse on the table. Karen stood in the hallway. She acted as if I was not there. I looked at her. She did not look at me; I wasn't "there." "Karen," I called softly, "come here." She didn't move. "Karen," I said louder. She looked at the door. "Karen!" I shouted. She did not move. Tears of desperation filled my eyes. With both hands, I picked up a fat cookbook, lifted it over my head, and slammed it with all my might on the table, sending the salt and pepper shakers flying. "Karen!" I screamed. She turned and looked at me. She heard! I had reached her! She could respond! I was stunned. I knelt before her, gathered her in my arms, and sobbed. This was where I had to begin. What to do? Who would help? What would happen to her, to all of us, to me? Karen said, did nothing. So began the long trek to today.

Virginia Walker Sperry was director of the Elizabeth Ives School for Special Children from 1966 to 1972. From her years at the school, and through many to follow, she takes the reader into the lives of 10 of her students. From the beginning, where they experienced early diagnosis, medical and educational intervention, on into adulthood, Fragile Success shows us the determination not only of the students, but also the parents, teachers, and doctors giving their time and support. Her dedication, not only to the students education, but also their lives, shows the true spirit of Virginia Walker Sperry.



Karen and Our Family

At the very time in the life of a child when one expects the beginning of social interaction, Karen withdrew from us. She was rigid in body, fragile in bearing, vulnerable, and very frightened. All stimuli confused her unbearably and caused her either to recede or to engage in what we thought of as bizarre behavior. She seemed to be deaf. She found refuge in the bathroom, where she flushed the toilet endlessly; or she sat on the floor and rubbed the feet of a bronze statue we had brought with us from the East.

She immersed herself in things, in objects, in meaningless behavior. She was withdrawn, out of touch. Her gaze fixated at times on certain objects, such as the reflector pan of the stove or a crack in the table top. She screamed in terror when we blew up a balloon. She poked things repeatedly that caught her glance: a piece of jewelry on another person's dress or a mole on the neck of a friend.

And the greatest problem of all for her future was her very poor reasoning ability and severe thought disorder. She had little to no ability for abstract thinking: She learned by rote, retaining what she held in her unusual memory. Pain, sorrow, anger—all these were beyond her. Such concepts as under, over, near, and far were like a foreign language to her, to be learned and routinely applied.

Her speaking as it emerged was often unrelated to anything and made little sense to others. She repeated a word or phrase over and over. As she learned speech, it was echolalic—automatically repeating what another person has just said.

She had no idea of spatial relationships or similarities, differences, or opposites. She had little sense of her own body or of her body's relationship to the space around it. She seemed not to know that she had arms and legs, ears and eyes, or what they were for.

She insisted on objectifying anything (including living things) so she could touch it, handle it, mouth the words for it endlessly. She treated animate things as inanimate and inanimate things as animate. She turned people into things to be poked. She would pat and stroke a desk, or put a barn door hook-and-eye-latch in the baby buggy and push it about. Records were for spinning, not for listening. Dolls were for pulling apart. She even tried repeatedly to pull off her own head and stick it in the toilet.

She was tense and fearful. When frustrated, she would hit herself, pull up her skirt, or recede in a corner, thumb in her mouth. She dug at her fingers until they bled.

In all, this one fact stood out: She could not relate to people as people. Locked inside this vacant isolation, Karen was virtually unreachable by anyone, beginning with her family, and of course I feared she could eventually back out of human contact entirely and into a world none of us would be able to enter. The prospects were horrifying.

Worst of all, she did not know us, who we were, or that she was our baby girl and our other children's sister. She had no idea who she was, that she was a girl, a daughter, a sister, a playmate, a person. She did not play with her siblings or delight them, as babies always do. This was, I felt, a loss for my other children beyond speaking. Likewise, she did not know me as her mother: I had no special meaning for her. She could easily walk off with the next stranger on the street, and sometimes did. She didn't know the difference. It was years before she knew who her parents and siblings were, and where and what home and family were. All of us felt rejected.

I was nearly crushed. If you can penetrate the heart of a mother and perceive what really feeds her inner being and makes her enjoy being a mother, it surely includes the wonder and excitement and ineffable satisfaction of the response of her child to her. But



this could not be; it was impossible to mother Karen. I was screened out. I had no cue from her to go on; I was at a dead end. I could only do things for her or to her and see that she was fed and clothed. The distance between such care and mothering is vast.

In those early days, I could think that I, in some way unknown to me, had caused her problem. I am sure every mother of an autistic person suffers this torture. But in time I came to understand that the cause stemmed from Karen's own constitutional makeup and her consequent development. Slowly, I began to realize that these symptoms of autism were not rejection of me or of us but rather her escape from impossible-to-endure confusion and inner turmoil over which she had no other control. The symptoms were, in fact, her very means of survival. We would have to find out how to get around or through them to help her take control and release the real person within.

Parents and Family At Risk

The difficulties an autistic person brings to a family are enormous, especially for the mother. You go on being a wife, a mother to the others, a neighbor, a friend, a relative—taking up those relationships while you try not to allow the autistic person to absorb you to the detriment of your life. You try to avoid feeling guilty, for if the mother feels guilty the problem is only compounded. And no matter how much you give, the autistic person still needs more.

Siblings often feel abandoned by a mother given over to the care of an autistic child. They feel neglected, or worse, they feel guilty that their demands might increase their mother's already too-great burden. It is easy for them to fear that adding to their mother's worries might push her over the brink. They do not feel free to express what might be ordinary discontent about their situation.

In such circumstances, how can a normal adolescent work through the ambivalence and complexities of growing up? This was especially true in the 1960s and 1970s when Karen was young, which was a time of great social upheaval and disenchantment of the young with the establishment of which we, the parents, were of course a part. So, Karen's siblings became mute and tended to go their own ways, missing sorely what they needed from their parents.

Their apparent alienation made things difficult for me, too. Because they were normal, I expected them to do a lot better for themselves and to help with Karen. It was very easy for me to feel everyone left me with the burden, isolated and alone. Such feelings on my part only increased their worries and drove them further away. And the problem worsened.

My husband was usually not directly involved in the day-to-day care of Karen. Some men, my husband included, find the pain of having and caring for an autistic child simply too great to live with intimately, and still carry on their work. I now see that it might have destroyed him, as he feared it would me. He had to protect himself, and this meant distancing himself as he could from the everpresent trouble.

My husband did help where he could—with the transportation of the children to their social and school obligations and of Karen to her numerous appointments and programs. He did keep steadily at his job and its demands and supported the family. He sometimes made it possible for us to get away alone where we could restore ourselves and be refreshed. He involved himself in every decision. Although relating to Karen baffled him, he cared about her and in one way or another built a strong relationship with her that today serves her well. Now, he delights in her accomplishments, growth, and presence and participates in the new challenges we face with her. He often picks her up at her residence to take her shopping and to dinner at a restaurant, a treat she always accepts with much pleasure.



Once, when speaking to a parent group, my husband said he often felt as though we were in a lifeboat. Karen had fallen overboard and I was about to jump in after her, even though I didn't know how to swim. His job, he said, was to steady the boat and keep me from jumping. (It is the mother, after all, who jumps. How could I possibly sit there and watch my child drown?) He once told me flatly, "If it is a choice between you and Karen, I choose you." Well, in a way I was reassured and in a way threatened. What did choose mean? Giving up Karen? I had to keep Karen and myself stable so that such a choice would not be necessary. So I kept quiet.

And in that is the essence of the deepest isolation of all the mother of an autistic child feels. I couldn't imagine giving up on Karen, yet, I couldn't express to my husband or children what I was feeling, for I knew it would hurt them and drive them away from me. So, I felt increasingly alone, trapped. I have since learned that most mothers of autistic children do.

Karen's Education

At the time Karen was diagnosed, there was only one small school in our area that was trying to deal with autistic children: the Elizabeth Ives School for Special Children. The doctors at the Yale Child Study Center suggested we enroll her there, which we did.

In all, Karen has gone to five schools, some of them new and experimental. From her earliest years, schooling for Karen followed a consistent pattern. She had a succession of wonderful teachers who were committed deeply to her, and who believed she could be made to hear them and to learn. Many of them believed firmly that she had a concealed intelligence and emotional sensitivity, which they sought desperately to reach and to activate. These forceful and persistent people provided Karen with the necessary structure and support for her to begin to participate in life, to respond, to speak, to know herself and to let herself be known.

Fundamental to the method used was the drive to get a reaction from her. They, the teachers and we, the parents, demanded a relationship with Karen, and in demanding it from her, we began to get it. She had to look into her eyes, hear us and respond to us. We insisted. It was a gut job, not a paper exercise. It made us sweat. Teaching her reading, writing, and arithmetic at that stage seemed less relevant than nurturing a relationship in which we helped her to identify pain, anger, affection, humor, hurt, and grief and express them appropriately.

Karen's education and training went on at school and at home. Her disabilities forced us to teach her survival skills—what she had to know and to adapt to a world she could not understand. We demanded, so far as we could, acceptable behavior. She gradually learned to look after her personal care, to take her own shower, to tidy her room, to understand and manage menstruation, to dress nicely, to greet people. Each acquired skill prepared her to learn the next and to grow in the art of being human.

There was an additional, extremely potent, force at work for Karen. It lay within her. She wanted to relate to us. She wanted to learn and be independent. All the while she was growing up, she had not been really so out of touch as her withdrawal had made it seem. As time and schooling went on, the layers of resistance and withdrawal peeled away, and we learned that she wanted to laugh, to sing, to dance, to be with us, to draw, to pile up blocks and knock them down, to swim, to walk, to listen to records, to watch the birds, to learn the names of flowers and trees, to go places and do things.

Speech came awkwardly. At first it was hollow and regimented, then slowly her own speech emerged, clear and crisp. She learned to assert herself and defend her possessions and her privacy. She wanted friends. As she learned to express her pleasure in people she



began to elicit the affection of those with whom she came in contact. Her smile took over and the pleasant person she is emerged. For all her stilted speech, she won interest and affection, and more and more people made their adjustments to her difficulties and peculiarities and related to her. They not only made her happy, they helped her learn to live her life. It all came with glacial slowness. It was only after long spans of time had passed between what she had been and what she was becoming that we knew progress was being made.

As Karen learned to relate to people, her ability to learn the fundamentals of the simplest survival skills and elementary academics improved, and her inner disturbance began to give way bit by bit to inner calm. She began to take control of herself and emerge as a person. She learned more and more of the social skills that are essential to normal living. In time, we found that she could not progress very much academically. We had to learn when to stop our pressure.

Over the years, Karen has been examined, evaluated, and treated by competent psychologists, psychiatrists, social workers, and educators. We have employed helpers and teachers privately. Connecticut during these years was in the forefront in taking governmental responsibility for the education of all children, even those with impairments as serious as Karen's. So, happily for us, the state bore part of the horrendous cost of educating and treating her.

Adulthood and Supported Independence

After many years living at home and in group homes, Karen now lives with two other women with developmental disabilities in a semi-supervised apartment in a nearby city. The state DMR provides 20 hours a week of staff supervision for this semi-independent living program. In Karen's case, the staff person is a capable adult who helps Karen and her apartment mates organize their home, provide food and necessary supplies, schedule medical visits and plan and take part in social and recreational activities. A vocational counselor helps locate jobs in the community. Thus, Karen is more and more thrown on her own resources, and often she is able to develop her own skills to meet her emerging needs. However, she still needs much help—the most difficult sort to provide—in taking responsibility for herself, and in planning and executing the means of satisfying her needs.

Given her basic impairments and the long-term care by staff members, her progress toward increasing independence is slow. She still has no concept of numbers or money, and quite confidently empties her wallet in front of store clerks, who are then expected to take only what is needed. So far, her trust has not been betrayed. But this illustrates how much we who parent such autistic people, must trust the fragile and often dangerous society into which we launch our children, hoping not only that they can manage, but that others will give them a hand and not harm them. With Karen, our trust has been rewarded, but I can never give up fearing for her. Even crossing the street is a major hazard because with cars coming, she will start across the street, all the while assuring me she has "looked" and, having looked, is free to go. Looking, assessing what she sees, and transferring that into appropriate action is still a very complicated process. For Karen learns not so much by instruction as by immersion. I was never one to throw a child into a swimming pool and say "swim," but now I do it all the time with Karen. There is no alternative if she is to be able to live in the world as it is. For that goal I am willing to risk her life, to take the chance that she will make it. This is not a testimony to rashness but to my desperation and her need.

Any program in semi-independent living for an autistic person is full of risk and uncertainty. Karen is frequently on her own, busying herself at her home, traveling over the one



bus route she knows to a mall, which, I have learned, is like a village green, opening to take her to the world of shops and the possibility of meeting a friend. She takes up formerly impossible tasks such as getting herself bathed, dressed, and outside ready to meet a van that takes her to work each morning. Even managing not to lose her house key and actually being able to put it in the lock, turn it, and open the door without a helper in sight is a major step ahead, and a building block upon which she develops more confidence and other skills. The two people who share her apartment are good friends, and they all help each other in many ways. Their apartment has become a kind of informal gathering place for others in nearby semi-independent programs. They celebrate birthdays, go out together to special events, send out for pizza, and watch TV and videos. They hang out.

Efforts are made to help Karen and her friends explore and use resources in the community, such as churches, YMCAs, health centers, libraries, movies, concerts, and eating places. Like most adults, they move about in a circle they come to know and can handle on their own. Up until 2 years ago, Karen lived in group homes under 24-hour supervision and had never been left alone 1 day in her life, even at home. Until she was 30, her entire life was programmed, supervised, and carried out under close staff supervision. She could not use a telephone or take a bus or taxi. She could not prepare her own meals, organize her daily life, plan and carry out wanted to do, or pay her own bills.

Now she can use the telephone and most of the time, dial it correctly. She helps clean the house and does her own laundry. She can open canned food and microwave TV dinners. She is often alone in her apartment, even for an entire weekend, sometimes preferring that to coming home to her parents. She can take the bus on a limited basis; she can call a taxi when needed. She can walk alone down her street a couple of blocks to a variety store to buy milk and bread. On Sunday she takes a taxi to church (having telephoned the previous day to arrange to be picked up). She goes to work each morning, still in a semi-supervised job, but increasingly on her own.

Karen still has major deficiencies that would confound any normal person. She cannot handle the telephone reliably: She will frequently pick up the receiver and not say anything, expecting it to talk to her. She does not get messages straight. She cannot read or write beyond primitive levels. She gets lost if a well-defined route is interrupted. She does not approach others to ask for help or directions. Her recreational outlets are few, her friends limited to those at least as limited and impaired as she is. When frustrated, she may "act out" by screaming and breaking things, not yet knowing how to express her feelings appropriately and work out her frustrations in a more useful way.

As inadequate as it sometimes seems, I know Karen's life depends on the resources the state can give her in living independently and learning to manage her own life. Although I cannot see very far down the road, I am sure she can grow more and more into a life she can manage on her own. Increasingly, she will become independent, a goal once so far beyond the realm of possibility. Never in my wildest dreams did I imagine it could happen. Well, it hasn't yet, and every week is fraught with problems. But, we muddle through, and in the end, I am sure Karen will survive as her own person in her own life.

Jonathan Lerman

Breaking the Mold



The mind is mysterious, especially when it comes to autism. A person with autism might lack the ability to put together a complete sentence, but at the same time exhibit gifts that outreach the grasp of most people. Such autistic savants commonly excel in art, music, and math. Often, their skills are not cultivated through instruction but are self-taught.

Meet 16-year-old Jonathan Lerman from Vestal, New York. Despite his limited communication skills, Jonathan is able to convey through art a world that stretches far beyond the confines of language. Although autistic savants have gained a lot of attention through films like *Rain Man*, only an estimated 10% of people with autism display savant abilities. Nevertheless, according to Stephen M. Edelson, Ph.D. at the Center for the Study of Autism, people with autism tend to be 10 times more likely to possess special skills than people with other developmental disabilities.

The Artist Within

At the age of 10, Jonathan suddenly began drawing. He had just lost his grandfather with whom he shared a special bond. Upset over his grandfather's death, Jonathan would often ask Caren when he could visit him in heaven. Equally fond of Jonathan, his grandfather used to tell Caren that Jonathan had promise and that one day he would surprise her. Apparently, he was right.

In 1997, Caren received a call from Jonathan's helper at the local Jewish Community Center. "You've got to come over to see what he's doing," she said. With trepidation, Caren

replied, "What, holding the other kids hostage?" "No, he's drawing," came the answer. Jonathan was not only drawing, he was doing so with the ease, swiftness, and confidence of a master, turning out 5 and 10 drawings in one sitting. Even more remarkable, he was drawing faces complete with sorrow, happiness, and the vast array of emotions that make up the human psyche. It is something that no other recognized artist with autism has ever done before. "He totally broke the mold," explains Caren.

Jonathan's work has met more than his mother's standards. Art critics and professors have also proclaimed its excellence. In a *New York Times* article, John Thomson, chairman of the art department at New York State University at Binghamton said Jonathan's drawings "would not be out of place in my classroom." Thomson added that it was "really exceptional, characterized by an amazing lack of stereotypes common to drawings of all age levels."

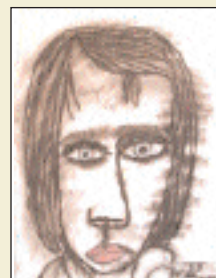
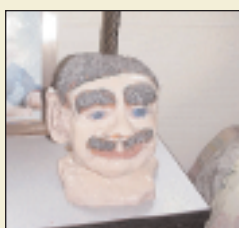
Living with Success and Autism

Jonathan wasn't always tuned into people and faces. In an unpublished memoir, "The Solitary Heart," Caren described Jonathan's anti-social behavior as a child. "When our friends would come to our house, he would find a wall, lie along its side and stare at it for hours." Similarly, at the beach, Jonathan would step on sunbathers with the same gusto that he would step on sand.

Now, Jonathan isn't just noticing people, people are noticing him. K.S. art gallery in New York City has featured

From Caren Lerman:

"[His art has] given us a window into his soul, to help show us how he sees people and the world."





his work in several solo shows. Ranging in price from \$500 to \$1800, about 70 of his drawings have sold so far. Charcoal is Jonathan's preferred medium but he occasionally uses pastels. Over the last couple of years, Jonathan has ventured into working with clay. Caren confesses, "We've kept all the sculptures so far. They're just so amazing, but we plan to share them and market them in the future."

Caren is thrilled about her son's talent and success but she admits that raising Jonathan wasn't easy. Still, she says, "[Raising a child with autism] has taught me compassion, patience, and the value of unconditional love." To view samples of Jonathan's artwork or to purchase *Jonathan Lerman: The Drawings of a Boy with Autism*, visit www.ksartonline.com.



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