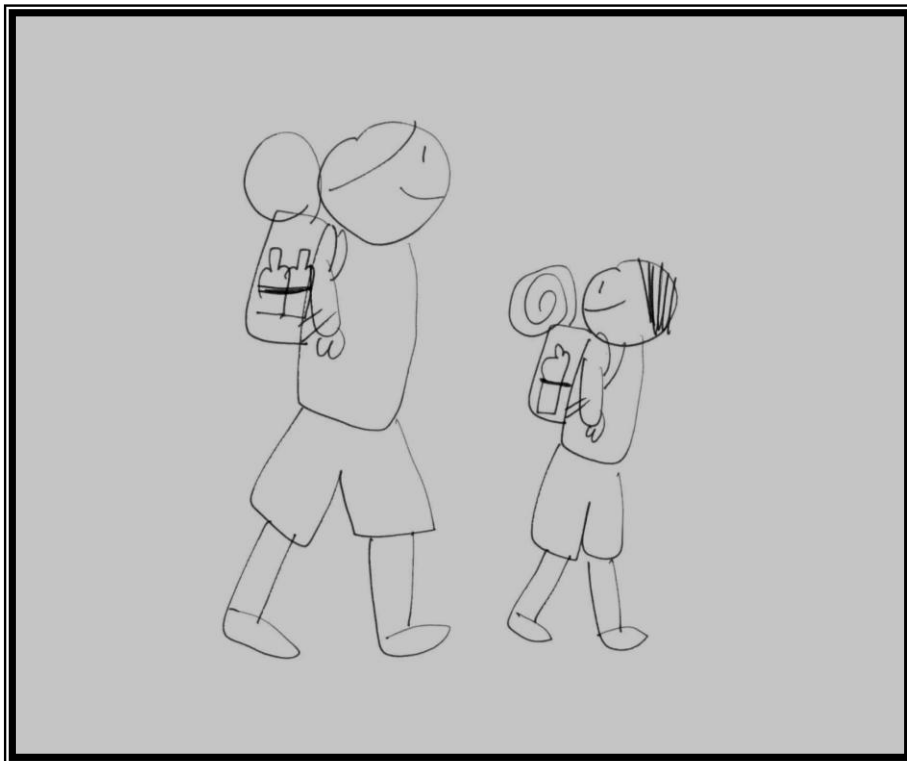


It's About Relationships

For you, for your child



Uniting Journey and Goal on the Autism Spectrum

Youth **Advocate**
PROGRAMS, INC.

ASSET Center for ASD/DD

Autism Spectrum Disorders and Developmental Disabilities

Services, Supports, Education and Training

INTRODUCTION: Why Focus on Relationships?

Our lives are made of relationships. They are our stories, which we read and write each day. Each of us is alert to the ebb and flow of the relationships around us, and is drawn to those people who can partner with us in bringing forth our best selves. As our life stories develop, we find that more and more elements of our everyday worlds speak to us in the language of relationships: cherished photos in a wallet, songs on the radio that bring back memories, a ring that's always on the finger, a recipe we learned to love because someone we love invented it, special dates circled on the calendar, an author we struggle to read to please a favorite teacher, a funny expression we over-use because Mom always used it. Relationships give our lives richness, meaning, and connection at every turn. Even when we are physically alone, we continue to think and act within an invisible web of relationships. Images of others and their expectations come to mind to guide our actions, and we earnestly converse with these absent others "in our heads" or even address them out loud. Whether we consider ourselves extroverts or introverts, very sociable or very shy, we are fundamentally social beings whose identities develop through relationships.

Through relationships we explore the world and become aware of the possibilities of our lives. We learn to attach shared meanings to our emotions and experiences, figure out what is and is not considered important, and test our emerging ideas by seeing how others respond. Bit by bit, we develop motivation and direction as our daily experiments receive positive and gratifying responses. Relationships shape us - not in a coercive way, but as mutually engaged participants exploring the world together. We learn to trust, to give and take, and ultimately to empathize and "feel with" others.

These things cannot be taught in a lecture or a lesson; they can only be experienced over time, in the company of caring guides. They do not flourish in artificial and isolated settings, and their development cannot be forced or imitated. Instead they involve a mutual journey. Our cultural wisdom stresses the importance of the travel itself over the destination, urging us that "life should be a journey, not a race" or lightheartedly reminding us that "getting there is half the fun." For children on the autism spectrum and their families, it is especially important to think of the journey and the destination as a seamless whole, and start out as we wish to end up:

- *If our vision for the future is one of friendships and inclusion in a caring community, then fostering desirable and inclusive experiences is also the way to get there.*
- *If a lifetime of nurturing and joyous relationships is our goal, then relationships must pave and power our journey toward that goal.*

This parent guide is dedicated to those propositions. It does not attempt to tell you "what autism is" for your child and family, but to explore the possibilities of living creative and fulfilling lives as we and our children develop through relationships.

PART I: YOUR CHILD'S DEVELOPMENT

The Dance of Relationships

A child is born and placed in the arms of eager parents. From these first moments, parents seek to make contact, to talk and sing, catch the baby's eye, wave a toy or make a face. They engage that child right away in the social world and his or her first experience of communication. The baby starts to make those first connections between the parent's sounds, movements, and emotional "feel" and its own, and in a tentative way to both regulate and be regulated by these connections. Child development researchers have a lovely name for this universal activity between parents and babies - they call it "the dance of relationships." Of course, the dance should not end with infancy or childhood. The ultimate goal of the dance of relationships is to keep learning and changing throughout life, to invent new steps and improvise new routines, but always within the meaningful and intelligible framework of a shared activity. We are safe with our dance partners. They invite us to explore, give us confidence, and share with us the amazing gift of shaping the jumble and chaos of daily experience into a real story - our story.



Some infants and children dance differently. A baby may be difficult to engage and appear inattentive, perhaps due to a health problem or a nervous system that does not respond readily to sights and sounds in the usual range. Such babies may be described as "good babies" because they seem to demand so little. However, their parents soon become concerned that they are missing out on experiences they should be enjoying. On the other hand, a baby's nervous system may be too sensitive. These babies seem to go back and forth between two extremes: fretful and tearful from overstimulation, or shut down and sleeping as much as possible to avoid the sights and sounds that are so overwhelming. Of course, we can't say that these infants don't want to interact, aren't interested in people, or would rather be left alone. We know they are much too young to form such intentions. And usually we don't accuse them of being unintelligent. Instead, parents wisely assume that their baby is eager to learn and to socialize, and set to work looking for the best ways of adapting to their child's unique style of relating. If parents are fortunate enough to have the right help and support for a baby who dances differently, they will be able to seek and find successful ways to adapt to that baby's rhythm. It can be intensely rewarding and enjoyable to play dance coach with these little partners as they take their first steps in the social world.

Many awkward dancers come to be diagnosed, often between the ages of 18 months and three years, on the autism spectrum. Some are called autistic, others labeled with Pervasive Developmental Disorder (PDD) or Asperger's Syndrome, while still others are simply described as developmentally delayed. Sometimes a child's different way of dancing is not obvious in infancy, and doesn't lead to concern, frustration, or a search for diagnosis until later in childhood, when the "dance of relationships" becomes faster and more complicated. Sometimes even an adult, after decades of "stepping on toes" and feeling out of sync, will find comfort and support in a diagnosis like Asperger's. These adults tell us that they are relieved by the diagnosis because it opens the door to a community of like-minded people who perceive the world as they do. They feel reassured to know that their differences are not due to some failure on their part.



Unfortunately, as a child on the autism spectrum gets older parents may have to struggle to hold onto their belief in their child's capacity to develop through relationships. An adult's determination to "assume the best" may be challenged by other people's snap judgments or deep-seated misunderstandings about the meaning of a child's behavior. Children diagnosed on the autism spectrum too often come to be described as not wanting to do sociable things, as deliberately behaving badly, and even as lacking intelligence. A sensational story gets invented about a mysterious disability that consists of "odd behaviors" and self-centered "aloneness," and sometimes the media

accept and spread this negative image without further question. If they come to believe this depressing story, well-meaning people may forget about the dance of relationships and its importance. They may decide to focus on getting rid of isolated behaviors by training children in compliance and how to respond on cue. These decisions flow from the understanding of autism that people have received. They reflect the hope of parents, teachers, or therapists that a child with autism who receives such training will at least grow up socially appropriate, predictable, and safe.

New Goals for a New Day

Fortunately, the goals for children on the autism spectrum have expanded positively and dramatically in recent years. One of the foremost experts in the field, a developmental pediatrician, has set the new goals as helping children on the spectrum become warm, spontaneous, and joyful.¹ This does not mean that safety, appropriateness, and predictability in certain activities are not useful goals, but that we can achieve them best by aiming even higher.

To aim higher, it is often recommended that we set our priorities to fit what a child needs to experience and know at the current point in his or her unique development. It makes sense that a child might not be willing to sit quietly at a desk and sort shapes if that set of demands offers the child no help in understanding the baffling world of school, if he has no ongoing means to communicate and influence what is asked of and done to him, if her body is so badly in need of movement and stimulation that she can barely respond to the teacher, or if he climbs on the school bus each morning feeling like a lonely stranger in a strange land. Before traditional academic tasks can be learned, children must be supported to engage in pleasurable relationships with others.

Relationship triggers and sustains development. It draws the child into the larger world while helping him or her to organize and make sense of everyday experiences. Without a firm grounding in human relationship, children with autism spectrum disorders may find everyday experiences to be unintelligible or may withdraw in distress and fear. More than a quarter-century ago, a very influential occupational therapist observed about such children, "When the flow of sensation is disorganized, life can be like a rush-hour traffic jam."² People caught in the jam don't need a back-seat driver criticizing them as their panic grows; they need a trusted companion beside them to calmly guide and show them the way.

How often do we hear a parent or teacher say, "I think this child is an underachiever - there's just not enough motivation!" A child's intellect and potential for achievement cannot be explored accurately until the groundwork is laid for sustained, emotionally



satisfying interactive experiences. Emotionally meaningful interactions are the necessary foundation for a lifetime of flexible, self-motivated development. Children who become able to take cues from social relationships will not need to rely heavily on specific prompts or memorized routines. They will be more likely to move to greater independence and better personal decision-making. The things that motivate them will be more likely to have a natural connection to the task at hand and come from within.

For example, one young child diagnosed on the autism spectrum was placed on a "funny money" reward system by his teachers. They had read that children with this diagnosis need pieces of candy and other artificial motivators to shape their behavior in the classroom. The child's mother was concerned that this "money" and the rewards for

which it was exchanged would distract her son from developing a genuine interest in his schoolwork, and would send negative messages about him to his classmates. In the meantime, one of the child's teachers had been quietly giving him a little note of appreciation at the end of each school day. The child's mother realized with delight that he was carefully pinning up each of these notes on the wall of his room, proving that his caring relationship with his teacher was an effective natural motivator for his school success. Since he treasured her notes, why invest in treasury notes?

The Power of Relationships

What makes us who we are? Some people talk about genetics, DNA, and all the things we inherit, such as Mom's brown eyes or the potential to grow as tall as Dad. Others talk about identity being in the brain, where we recognize an "I" who is different from a "you." People who study human development have learned to focus on another factor that makes us who we are: the ongoing, vital relationships that support and shape us. From this point of view, relationships are not merely a reward to be earned by good behavior, or an optional feature to be added to a child's academic or therapy program if time permits. Instead, relationships become the foundation of how we approach, work with, and support a child who is developing differently.

Children with sensorimotor differences have trouble perceiving and moving effectively and comfortably in the world. This means they are at risk for missing the beat in the "dance of relationships." For example, a playmate may call a child's name to join in a game. If there is a delay before that child is able to process and respond to that invitation, the playmate may feel ignored and move off in search of other friends. A



parent may tap the child on the shoulder to get his or her attention, but that light touch may be perceived as so threatening that the child instinctively lashes out - and another chance for purposeful interaction is lost. Children with sensorimotor differences also may become deeply immersed in solitary activities that interest and make sense to them. Seeing this, others can be tempted to leave them too much to themselves, or to fill their time with highly structured academic activities (such as memorizing numbers, coloring pictures, or doing puzzles) that are not interactive. Over time, these activities can become increasingly rigid. Through the

power of relationships, these activities can be continually and gently expanded into more flexible and people-oriented occupations.

The power of relationships can change the course of a child's development in the direction of greater adaptability. When a child has a partner who is not simply dictating and cueing his actions, but actually slowing down, relating to, and working with him, the activities they undertake together will become more and more flexible and spontaneous. The child cannot achieve this state alone or in a controlling, rote interaction. Only in a relationship with an astute partner can new and more spontaneous activities be fostered and supported. Experts in the autism field have pointed out that some of the most natural and useful strategies for dealing with sensorimotor differences develop within relationships: "They are the natural outgrowth of listening to each other." ³

A lack of social capacity is not really "in" the nature of the child's disability, since children on the spectrum do become warm, spontaneous, and joyful. Yet these new abilities and possibilities are not really "in" the child, since the child cannot achieve them alone. And they are not located "in" the helpful partner, because that person cannot make them happen by willpower or demand. Researchers in child development say that the new, more flexible abilities and possibilities that emerge through relationships are "co-regulated" or "co-created."⁴ Co-creators respect each other's differences. Co-creators also value improvisation. Instead of one person pulling or dragging the other toward a pre-set finish line, they are able to adopt and adapt their destinations as well as their means of getting there. This observation gives credit to both partners in the dance of relationships.

Since human development is co-created, the answer to "who we are" is not in our genes, in our brains, or in any diagnosis or label that we might be given. It is not possible to know the chapters in our story before they are written, because we keep creating who we are through our relationships with others. Through



relationships, our children are always works in progress and never completed. They can reach for the stars because they first reached for other human beings.

Following the Child's Lead

Children's worlds can look so simple when we view them from the distance of adult height and adult interests. But as soon as get down on the floor and open our minds to the games, explorations, and experiments that engross them, we start to see differently. We remember how amazing the world looked to us when it was all new, how passionately we struggled to learn how things worked, and how exhausting the job of being a child could be. We rediscover the truth in the old saying, "A child's work is to play."

Children have good reasons for the interests and passions they develop, and for the activities that become dear to them. Sometimes, however, parents may worry that those

passions are becoming too unusual and leading them away from activities in which other children will want to participate. Taking a relationship-based approach to this concern, parents or teachers may remember to "follow the child's lead." By learning from the child they can determine what is important to him or her, why that is so, and how that activity might be broadened in scope to include others and to open even more desirable possibilities.

"Following the child's lead" does not mean abdicating adult responsibility or letting the child "run wild" - far from it! It means deliberately and thoughtfully entering the child's



world, communicating respect for the child's intelligence, and learning to be a good observer and listener. It is a labor-intensive and delicate process for both child and adult, but the partnerships that result can be very effective. In time, they can broaden a child's dance skills from the simple "box step" to far more complex routines.

One family embraced this process when their young son developed an intense interest in industrial storage tanks. His favorite family

outing involved driving to the site of a local chemical plant and stopping by the side of the road to admire the industrial storage tanks that covered acres of ground. Following his lead, his family took many trips to allow him this outlet for his enthusiasms. When they considered that other young children were equally fascinated with containers, and that it was considered normal for children to spend hours putting beads or water into cans and dumping them out again, their son's interest in storage containers seemed less unusual in concept, if more heroic in scale.

Eventually this youngster began to read, and they took him to get his first library card. He immediately demanded to be taken to where the books on storage tanks were shelved; when no such books could be found, he was devastated. More investigation on the part of his parents led to the realization that storage tanks - which after all are just containers for chemicals - might be reintroduced into his experience in the form of beakers and test tubes from the catalog of a scientific supply warehouse. During the next few years he saved his dollars and intensively collected these miniature storage tanks, arranging them on shelves and admiring them daily.

But shouldn't something be inside a storage tank? His parents started to bring home science experiment kits, and introduced their son to interesting activities he could do by filling his "tanks." This soon became a passion in its own right, and he worked through so many science kits that by middle school this student - once diagnosed with autism and significant cognitive disabilities - joined his school's Science Olympics team, a

breakthrough which increased his social status and social skills enormously. In high school he enrolled in the science courses designed for students who were college-bound, and later attended and graduated from college. Would he have come so far with such confidence and enthusiasm if his parents had not followed his lead and taken a relationship-based approach to embracing and expanding his own natural interests?

Fostering Language Through Relationships

Watching a group of people in constant conversation with companions or on cell phones, we are reminded of how deep-rooted is our need to check in with friends and family. Anxiety sets in when we cannot monitor how they're feeling and what they're doing. As adults, we use language to build relationships. Little children need to use relationships to build language, because relationships structure their experiences in meaningful ways that prepare them for language. By working through relationships, a child can be supported to have the experiences and the successful preverbal interactions that will motivate and develop language acquisition. Teachers and therapists have found that working with children in real-life settings and through desired activities helps to make language flow more naturally, and reduces the wandering attention and wandering feet that signal boredom. It also turns out that natural rewards, such as being able to participate in a real interactive game that involves language, ultimately brings far better results for most children than doling out raisins or stickers to reward compliance with language tasks in an artificial setting.

Our first uses of language are to tell little stories that are important to us: "Want juice" or "See doggie" or "Hug Mommy." These stories have actors, actions, emotions, resolutions - entire little plot lines. As children get a feel for these stories, experience them again and again, and come to envision how they should play out, they are actually building the structure of experience that will eventually emerge in language. This structure is being built long before a child starts to use language. Children act out their first stories as they explore their worlds. They learn how actions fit together in predictable sequences, how causes lead to effects, and the impact of their own efforts. As they partner with people who can help them explore, they begin to develop what is called "preverbal communication" such as pointing, gesturing, mirroring, touching, or even moving and pulling their partners in order to create an activity together.



The child who is developing differently may miss out on some of these early communication experiences that help set the stage for language. The child's different ways of perceiving and moving in the world may make preverbal gestures difficult to

carry out. For example, some children have difficulty orienting accurately to sounds or cannot separate and extend an index finger in order to point. Some children have difficulty coordinating their bodies and synchronizing them with others in a way that readily conveys their intentions. Their movements may be misperceived as random, clumsy, or even aggressive. In that case what the child means to do, and what actually happens, may not unfold as a meaningful and predictable sequence. The child with motor control problems who cheerfully runs to "help brother," slams into him instead, and watches as tears begin, is left confused. From his or her point of view, the story was jumbled and the "surprise ending" didn't make sense. Confronted with such challenges to communication, children with sensorimotor differences need a supportive relationship with a caring person who can be their guide and interpreter. Such a partner can establish a well-paced, individualized rhythm of interaction, and can offer them the structure they need to respond meaningfully and be understood successfully.

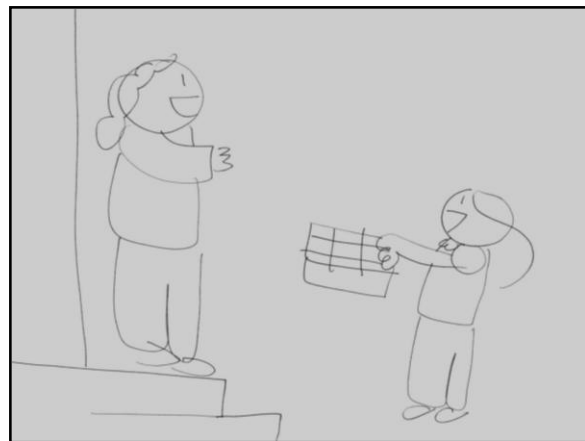
It's important to remember that children can be supported to develop language whether or not they develop speech. The child who has problems with motor control and coordination, who struggles with dysfluency or cannot produce spoken language, has many other options available. These come in many forms from signing to keyboards. Sometimes the use of alternative systems supports the development of speech by supplying the child with the necessary structure, experience, and motivation, which then carries over into verbal expression. The alternative system may also become a person's primary, and perfectly valid, means of language expression. Some individuals with autism who communicate by means of computer keyboards have taken to wearing t-shirts that declare "Just because I don't speak doesn't mean I don't have anything to say." Through typing, they participate in their communities and make their voices heard.

Give and Take

"It's better to give than to receive" is a saying we all know. Most adults feel very unhappy when they are always on the receiving end of a relationship, and actively try to find ways to give back to others. We even argue and resist help when we are sick in bed, hate being dependent on others to bring our chicken soup, and can't wait to get up and start taking care of our families again.

People with disabilities share these feelings. One adult, looking back on a childhood filled with therapy at a residential treatment center, says she wishes that - even once - staff

members had stopped trying to "help" her and instead had shared their own problems with her. She recalls her dream that one day a staffperson would cry on her shoulder,



that she could comfort them, and that she would be allowed into the kitchen to bake them a batch of brownies and cheer them up. "Why am I always in the box marked 'take'," she asked at one point, "and never in the box marked 'give'?" Sadly, a narrow view of autism kept her in the "take" box throughout her youth. Now, as an adult, she has finally achieved the distinction of becoming an active autism advocate and is thrilled to know she finally is helping others.

Often children who are developing differently are placed in settings that operate like "take" boxes. They are expected to receive learning or therapy, and they come to feel that they are surrounded by adults who know everything, control everything, and exist to correct them. They may miss out on some of the most memorable experiences of childhood, such as knowing something important that others don't, showing others "how to," and simply being proven right (especially when others have to admit they were wrong)! People diagnosed with autism are often described as not having a clear sense of who they are, and of not realizing that other people have separate identities and see the world differently. Yet many people on the autism spectrum have not had much opportunity to develop this understanding. As one mother advised, "Let our children be givers, not just takers. Allow them to help you, thank them for their ideas and criticisms, apologize when you are wrong and let them offer their forgiveness." Isn't that how we all develop "social thinking" and the motivation to communicate with others? By building relationships for children on the autism spectrum, we establish safe contexts in which they can learn to give and forgive. As they do, self-awareness and empathy can grow.

Goodbye to the "Readiness Model"

A new world of possibilities is opening for children on the autism spectrum. To keep up that momentum, it's useful for parents to know where we've been and what attitudes once held our children back. The old view of children with autism was based on negative assumptions about their abilities and low expectations for their futures. It belonged to a less enlightened way of thinking about human differences and their value, and a failure to appreciate the place of diversity in our lives. This negative way of thinking was the basis of a segregated design of special education and adult services that failed spectacularly. This design, known as the readiness or medical model, assumed that people with disabilities are served best when they are removed from the community settings into which they were born to more specialized places designed only for people with disabilities. Once removed, they were supposed to work on whatever skills or behavior had been targeted for improvement until they looked and acted more like "everybody else."

It was felt that by somehow becoming (or appearing) less different, people with disabilities would demonstrate "readiness." By working toward readiness they would earn their way back into the typical settings enjoyed by the rest of the world. Not surprisingly, this unrealistic and abstract goal was not very motivating to the children and adults who spent their days with few desirable choices on the horizon. So the

readiness model had to rely for its results on artificial motivation through rewards and punishments. While some special education programs prided themselves on using only positive motivators, many parents and teachers started to question reward-based systems on the grounds that "rewards rupture relationships" and "the task being rewarded comes to seem less appealing in its own right."⁵ It appeared that the more children became locked in a system of bribes or threats to get them to act in a certain way, the less prepared they seemed to become to act independently, handle responsibility, or learn the kinds of skills that are needed in the "real world."

Sometimes a child's different ways of learning or behaving were viewed as medical problems that must be fixed before he or she could be returned to more typical settings. The medical model is described as "deficit-based" and "remedial" because it pays attention almost exclusively to the things a child cannot do or cannot do well. It tries to target and get rid of these "deficits"

by placing the child in a special setting devoted to treatment, much as a medical specialist would do if you were taken to a hospital with an illness. However, hospital stays are usually brief and highly focused, while most programs that took a medical treatment approach to behavioral and learning differences were neither. Many children who started school in segregated, readiness-based or



treatment-based settings spent their entire school careers "getting ready" for an entry into integrated settings that never occurred. Over time it became clear that such children tended to have more difficulty being included in their communities when they became adults. They were at a disadvantage in finding jobs, making friends, and participating in desirable adult activities. Many grew old still "getting ready to get ready" for a transition to community participation that never came.

Not only did the children who grew up in segregated settings have a hard time chasing that elusive goal of "readiness," but across the nation communities were making disappointingly slow progress toward the goal of welcoming and supporting people with disabilities. Families and other advocates came to realize that this lack of progress had its roots in the center-based service delivery systems created by the readiness and medical models. For example, if local pediatricians believe that children with autism can only be diagnosed at a distant medical center specializing in their care, they will never develop the local capacity to understand and serve these patients and their families. If neighborhood schools and recreation facilities believe that the needs of children on the autism spectrum can only be met at special centers, they will never learn how to teach, include, and appreciate those children in typical, everyday activities.

Dependence on “special places” once drained much-needed knowledge and capacity out of many communities. It left them unable to respond thoughtfully and confidently to people with developmental differences. Now we have learned that knowledge and capacity must be shared widely if our children are going to enjoy the promise of “liberty and justice for all.”

The Road Ahead

Faced with our new awareness of the power of relationships, the readiness model is finally crumbling. Schools are beginning to understand that optimal learning takes place when children enjoy relationships that support and guide them to grow into new abilities. A new appreciation of the developmental importance of collaboration has led to an increased emphasis on classroom teamwork and group problem solving. These insights support the movement for inclusive education. There are an increasing number of teacher training programs that require each graduate to be educated in both special and regular education. Parents of children without disabilities are beginning to realize that having different means of instruction available in the classroom is good for all students, and that inclusive schools model and teach desirable values and skills that students will need in adult life.

Across the country, states are experimenting with new kinds of supports and funding for families. These new supports are aimed at helping families to build relationships and



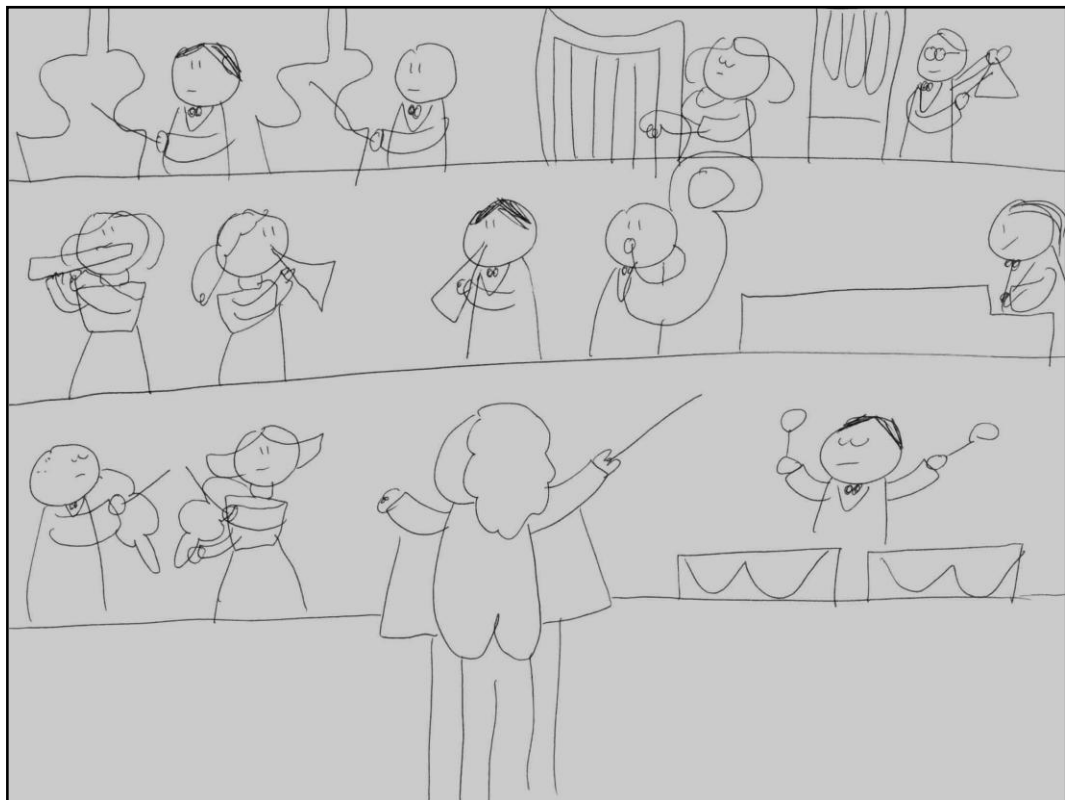
connections, and access needed services, within their local communities. Rather than building more “special centers,” the new emphasis is on capacity building and the prevention of placements that unnecessarily pull children away from their communities. Each year, more students with autism diagnoses are being included in their local schools, riding the bus with their siblings and neighborhood friends, and even going on for post-secondary education and college. They are employed in an ever-widening variety of jobs, with a variety of supports in place to assist them.

They are living in their own homes, condos, and apartments, and are enjoying social lives, recreation, and vacations. Exciting new concepts such as the formation of “support brokers” and “microboards” are allowing adults on the autism spectrum to select their services and manage their funding without yielding control to an agency or being required to live in a facility.

It is often said that advocacy work in any movement for social change comes of age when the people it addresses begin to organize and advocate for themselves. That is now happening among many people on the autism spectrum, who have reached out and found each other in recent years. They are running their own advocacy and support groups,

presenting at conferences, approaching legislators, writing books, producing web sites, and standing up for themselves and for each other. They are making sure that our understanding and treatment of people with autism has to answer to a higher authority - people with autism themselves. This is a powerful force for ending negativity and discrimination, and for assuring that decisions made about their lives are made with them rather than for them.

More and more, we are coming to appreciate the ways in which a world that values diversity is good for all of us. You and your child can be on the forefront of this positive activity. Your son or daughter can benefit from all we now know about the abilities and capabilities of people on the autism spectrum. When we foster relationships, presume intelligence, and work with rather than on our children, the autism spectrum reveals itself as a rainbow of unique individuals whose futures can be very bright.

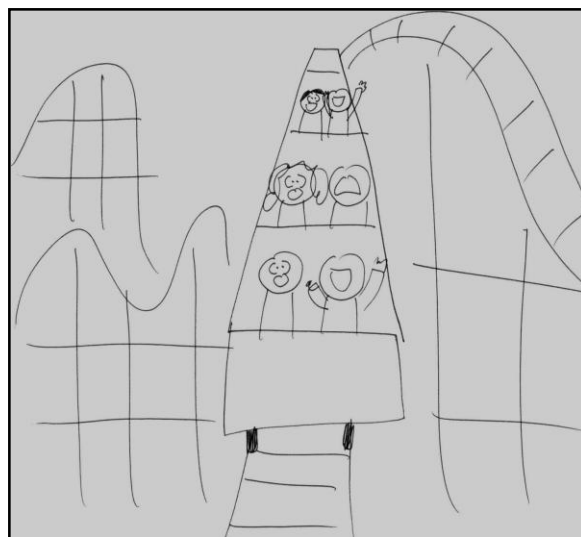


Part II. PARENTING AND RELATIONSHIPS

Enjoying the Ride... Together

Parenthood is a roller coaster of exhilarating highs and heart-stopping lows. Some people wait in line a long time just for the opportunity to experience it, others have their doubts about whether they'll make it through to the end, but almost everyone agrees afterward that it was over too fast and wishes they could do it again.

When parents realize that their child is developing differently, the parenting roller coaster often becomes more intense. They grip the safety bar harder out of fear that this ride was not as well-designed as they believed. They wonder whether it will come to a happy ending, or just loop endlessly around the track. They look around to see whether the other passengers feel the same concern.



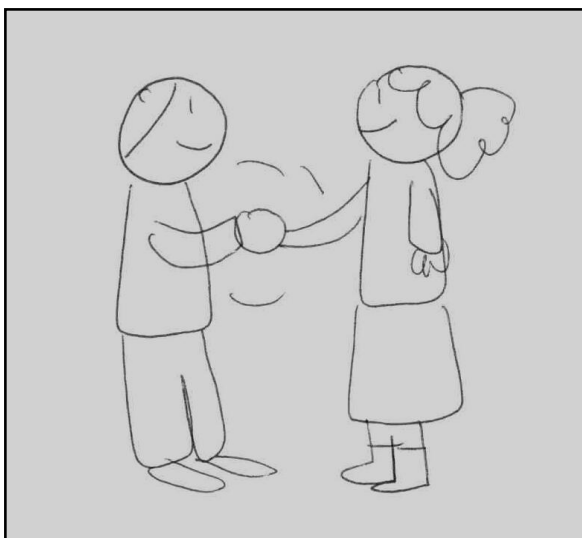
Reassurance is frequently found in the faces, the attitudes, and the examples set by others. Parents of children who have been diagnosed with disabilities often identify the most important influences in their lives not as doctors, therapists, or teachers - however vital and helpful these professionals may be -- but as other parents. They speak of the understanding, approval, and inspiration that they receive from other parents of children who are developing differently. They feel mentored by the parents of older children, and eagerly observe how these families cope with the transitions ahead. They share a special brand of everyday humor that is heartfelt and healing.

Parents need relationships in their lives just as much as their children do. Through relationships they develop their parenting abilities and connect with resources that will help their children move out into the wider world beyond the family. It's also a little-known fact that parents remain the same people after the birth of their child as they were before. They appreciate opportunities to reconnect with friends and to cultivate their own interests and talents. Of course, they may require support and helping hands so that their favorite activities can again find a place in the daily life of the family. Since parents always want to put their children first, they may also need reassurance that attending to their personal goals is not selfish. In fact, when parents are able to take time for themselves it creates a win-win family situation. Happiness and enthusiasm for life are contagious, and can help set the stage for raising a similarly enthusiastic and motivated child.

Building Parent to Parent Relationships

All of us instinctively build networks of relationships as we raise our children. These networks are such a part of daily life that they may seem unremarkable. When we try to describe them and explain how they are made, however, we realize that our networks are amazing creations with remarkable properties. Like a spider's web, they are almost invisible until you come in contact with them. They seem fragile but are amazingly strong and durable. When damaged, they can be rebuilt with relative ease. They match form with function through intricate designs, yet are created without any complex technology and can be used without instruction manuals.

For one mother, the first strand of her web was simply the telephone cord used to connect with a local parent support group. She reached out for help -- to parents she had never met -- because her son was "slipping through the cracks" in an elementary



school that lacked knowledge about teaching students with autism. The parents she met stuck with her as she fought a long campaign for her son's inclusion in regular school settings and for respectful approaches to his behavior. Through the power of parent to parent relationships, her son was pulled back inch by inch from the brink of a segregated residential placement and into the life of his community. He eventually graduated - with honors and awards - from the local high school and went on to enjoy the life of a college student. Strands

continue to be added to this family's closely-woven web of relationships as this mom reaches out to support others, counseling with parents and sharing her knowledge and experience through teacher trainings.

Another family reached out to their neighbors and faith community when their son and daughter, both of whom experience significant movement and sensory differences, were young children. They formed a "support circle" of friends who were interested in their children's lives, meeting regularly as an informal group to brainstorm decisions and navigate life's transitions. When their children became adults, this family drew on their well-developed web of relationships to help found a small non-profit organization that could organize services for a number of adults with autism. Today their son and daughter live nearby in homes of their own choosing. They are supported by respectful staff and recognized as full members of their communities.

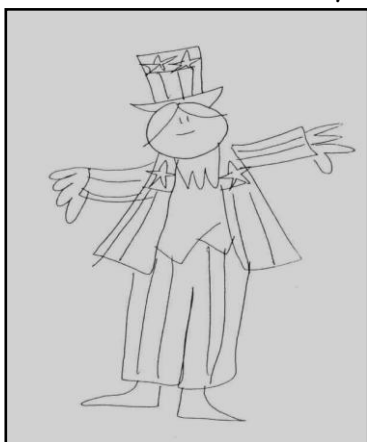
From small beginnings and personal connections, so much can develop. From parent to parent relationships, communities can come together and learn new ways to welcome and support people with disabilities.

Building Supportive Communities

Watch any mom or dad of a young child preparing for a trip to the park - with juice, snacks, blankets, wipes, balls, toys, extra clothes, and more - and you will witness a masterpiece of organization. When a child is diagnosed with a disability, one of the first things many parents do is seek out an advocacy group and start applying those organizing skills to ever wider targets. They may begin to organize other parents in their communities to improve the local schools, or to build a statewide movement for better services, or to take their message about ensuring homes and jobs for adults with disabilities all the way to Washington, D.C.

Disability organizations and advocacy groups come in many shapes and sizes. Small support groups may meet casually and provide a time simply to talk and share. Local and state groups may meet more formally, elect officers, and vote on a list of goals they want to accomplish - such as organizing teacher trainings or making sure the state legislature votes to fund the supports families want. National organizations may not be able to come to your aid on a personal basis, but they can provide a "do-it-yourself kit" of information with which to help yourself. They can also make sure that your voice joins with others in ways that can be heard by lawmakers and policymakers, and they can link you with important news from around the country.

Some advocacy groups come together around a particular diagnostic category. Joining them can be a useful way to find out more about research and programs that address common concerns for people with that label. Other advocacy groups form to promote issues and values that are common to all children and adults with disabilities, such as inclusive schools, positive approaches to behavior, or community living. They help families look beyond labels to the quality of life they wish their children to enjoy. Many parents also decide that it is important to take part in organizations that are not formed around disability issues. They may throw their efforts into their school's parent-teacher organization, or into local civic groups, business associations, or political parties, and make sure that the interests of people with



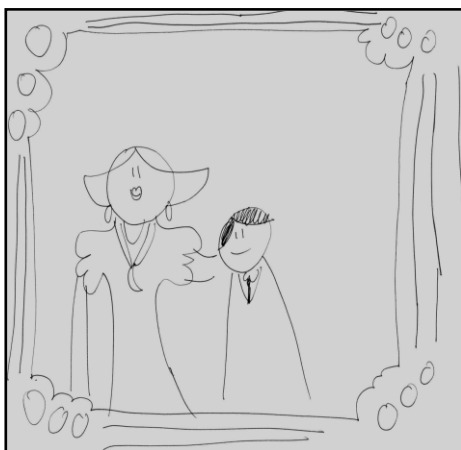
disabilities are well represented in their plans. One young man on the autism spectrum decided to volunteer with two local organizations dedicated to social action - one a project to collect used books for the education of prisoners, and another a labor union with a rich history of standing up for workers in undervalued jobs. As a person with a disability, his worst fears were of being locked away and of being unable to earn enough to support himself. His special insight was that these concerns are shared by many people outside the "disability world" with whom he could forge productive relationships.

Margaret Mead, an anthropologist who spent her life studying what makes societies change, summed up her findings in a quote that became famous: "Never doubt that a small group of thoughtful, committed people can change the world. Indeed, it is the only thing that ever has." She had learned that the most important changes aren't handed down from above because a politician or business executive has a bright idea, and that one citizen acting alone cannot do the job either. It's the little groups, clear in purpose and supporting each member, that really make things happen. By working through relationships, little groups of parents have organized to bring about important changes in the lives of their children, their communities, and even their country.

Sometimes parents are urged to focus all their energies on legislative or research solutions to the challenges of disability. Community building may come to seem slow and unnecessary compared to the prospect of enacting stronger laws or joining a "race for the cure." However, many parents who have followed this path return to their grassroots with a new appreciation that answers to their children's issues must be both global and local. For example, one active statewide advocacy organization was founded by parents who wanted stronger safety laws to protect their children. At first the parents in this group were so busy lobbying legislators and circulating petitions that they barely got to know each other's names. Within a few years, however, they were not only walking the halls of the statehouse together but socializing like lifelong friends, advocating at each other's IEPs, and working on local events to raise awareness of their sons' and daughters' membership in the community. They had realized that building relationships at the local level - and not the passage of laws alone - was vital to the success of their vision of a safer, more welcoming state in which to raise their children.

Building Parent - Professional Relationships

Relationships create our stories and tell us who we are. From the time a child is diagnosed, there is no piece of information about that child's abilities or behavior that



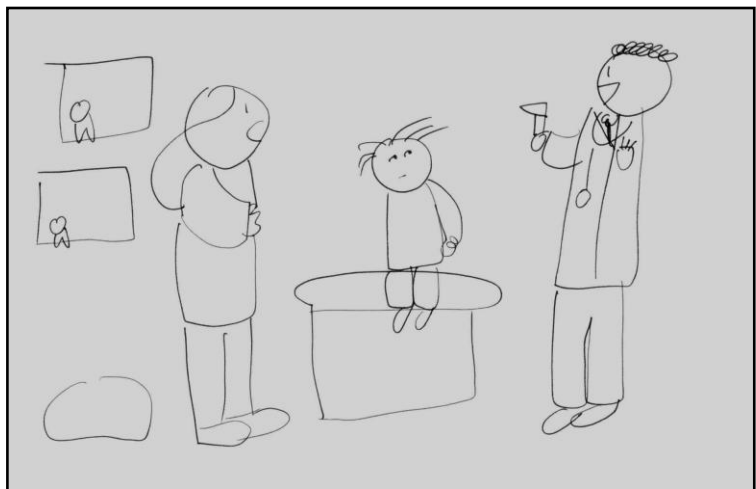
truly stands alone or speaks for itself. Instead, each diagnostic snapshot of a child comes with someone's attitudes and beliefs composing and framing it. Since no one has a crystal ball to see into the future, every doctor, therapist, or teacher is not just giving you a set of "facts" but - intentionally or unintentionally - giving their findings about your child a particular meaning. Parents who have a real relationship with these "significant others" in their lives can work with them to create a shared meaning that is open to new possibilities for their child.

When the creation of meaning is a one-way street, with parents being told what their child's diagnosis should mean to them, the road ahead seems to narrow. The lives of parents of children with disabilities can also become remarkably full of people who are

interacting with them on a daily basis - spending hours with their child, giving them advice, learning all about their family routines - with whom they may have no real relationships. When that happens parents may find themselves at the center of a great deal of activity, yet feel lost and alone. Dealing with diagnoses and labels without the support of shared relationships can lead parents to a dead end from which no solutions or progress seem possible.

One parent tells of how her son was diagnosed with autism at a medical center by a team of doctors who made her feel very incompetent and hopeless. As they painted a grim picture of the "facts" about autism and her son's "low level of functioning" and "low potential," talking in front of him as if he could not understand and recommending immediate placement in a segregated treatment program, she felt all the joy of parenting drain away. When she insisted that her son showed signs of being smart and loving, these doctors recommended psychological counseling to help her "face reality."

A few weeks later her son developed an earache, and this mom vowed not to return to the medical practice where he was diagnosed. Instead she took him around the corner to an elderly doctor who had treated three generations of local families in his home office. As he treated the earache, she confided that her son had just been diagnosed with autism. Without any show of alarm or pity, the doctor explained that he had seen a number of such children over his many years of practice, and delivered this advice: "Give him all the love and attention you can. Enjoy him. That's what makes a difference."



More than an earache was cured that day, and this family put aside all thoughts of the segregated treatment program. They supported their son to enjoy an idyllic childhood of ice cream, crayons, games, and fun. They hosted a weekly "unbirthday party" for the neighborhood children to attract playmates. The fact that his good times also involved spinning and shaking beads in front of his eyes seemed okay. This child eventually matured into a well-adjusted, optimistic, highly sociable, and gainfully employed adult on the autism spectrum. The attitude of this family doctor had supported his parents to frame a more wholesome and productive picture of their child and their role in his life - a role that put their joyful parent-child relationship back into the foreground.

When this child was diagnosed, choices were fewer and simpler than they are today. Parents could feel up-to-date by reading an occasional newsletter. Now we are living in an autism information explosion, and no one person can keep up with the changing news on the Internet and in the media. Parents report that the excitement of finding so much information can quickly turn into the confusion of finding so much information. In this climate, it is more important than ever that everyone in a family's life share the same vision for their child. Families can successfully sort through the dizzying array of treatments, therapies, and education methods - and the many claims and promises made - when they stay focused on the goals they and their child find meaningful. These goals become the yardstick by which the products of the autism information explosion can be measured and good choices made. Building and maintaining supportive relationships becomes the key to assuring meaningful goals based on respect for each child's individuality and high expectations for each child's future.

The Future Starts Here

Who is in your life? Whose lives are you in? Do the people with whom you interact energize and recharge you, and do you feel able to do the same for them? It is becoming clear that the relationships parents forge with other parents and with professionals are crucial in supporting their relationships with their children. The way others in our lives respond to us makes all the difference in the world, and can change our world - and with it our children's futures - in profound ways

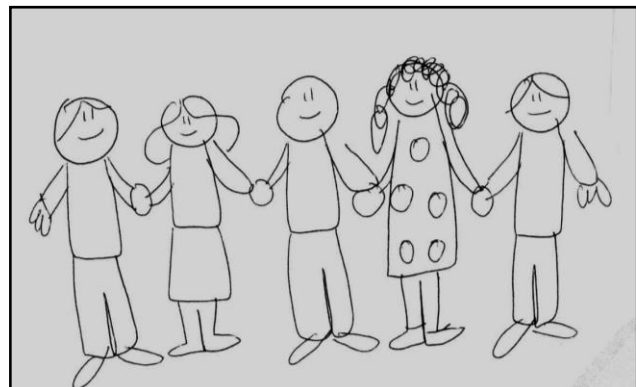
The time and energy you spend building a strong web of relationships is one of the best guarantees that you and your child will be able to live good lives. As that web grows larger, it has the power to transform our communities into increasingly connected, safe, and welcoming places. It also has the power to bring out the best in everyone it touches, and to enlarge our lives and our capacities in ways we may never have imagined.

As the parent of a child who is developing differently, you will meet some extraordinary people. You will get to know people who "don't sweat the small stuff," who have their priorities in order, and who know and appreciate what is really important in life. You will travel along with people who know how to listen, who enjoy thinking outside the box, and who celebrate the richness of human diversity.

And you will be one of those people.

Enjoy the journey!

Written by: Pat Amos
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Ted is a self-advocate living in southeastern Pennsylvania. His artistic specialties include cartoons and puppet shows. Learn more about Ted at: jptedpuppetshows.tripod.com

¹ Stanley Greenspan, "Reconsidering the Diagnosis and Treatment of Very Young Children with Autistic Spectrum or Pervasive Developmental Disorder" *Zero to Three* (Vol. 13, No. 2, 1992), p. 3.

² A. Jean Ayres, *Sensory Integration and the Child* (Western Psychological Services, 1979), p. 5.

³ Anne Donnellan and Martha Leary, *Movement Difference and Diversity in Autism/Mental Retardation* (DRI Press, 1995), p. 86.

⁴ Alan Fogel, *Developing Through Relationships* (University of Chicago Press, 1993), pp. 89-98.

⁵ Alfie Kohn, *Punished by Rewards* (Houghton Mifflin, 1993), p. 175.

ABOUT YOUTH ADVOCATE PROGRAMS

Youth Advocate Programs (YAP) began serving Pennsylvania children with autism spectrum diagnoses in 1997. As a growing initiative within a well-established community service organization, the Autism/Developmental Disabilities Program provides a variety of advocates and aides who tailor support services to the home, school, and community. Supports for children respond to the evolving concerns and desires of the family as a whole and build toward long-term relationship-based goals which typically include:

- enhanced communication skills, social skills, and self-initiated peer interactions;
- increased ability to self-regulate behavior and focus attention;
- better comprehension of, access to, and independence in using the everyday environment and typical community resources; and
- improved functional independence and self-determination.

Reaching these goals requires the cultivation of partnerships with parents, other family members, teachers, and all community members who interact with the child. The success of the program's mission depends on transferring support strategies to the community at large, ensuring continuity and flexibility for a lifetime of inclusion.

YAP's autism services are based on the understanding that people with autism spectrum disorders do best when they can live and learn in appropriate and inclusive environments responsive to their individual choices and needs. YAP staff are trained in the following six research-based "best practices":

1. Focus on the individual, not the label, by tailoring approaches to each person's unique profile, interests, and capacities.
2. Learn from children and adults on the autism spectrum by listening, observing, and respecting.
3. Learn from the families of children on the autism spectrum, who are the real experts about their sons and daughters.
4. Support development through pleasurable human relationships, which provide motivation and organization.
5. Recognize and work with each individual's emotional needs to make interactions meaningful and satisfying.
6. Be open to lifetime opportunities for growth and development by offering people the opportunities and the support to move in new directions and try new things.

YAP continues to expand its Autism/DD Program into other states as well as into Europe.
Contact YAP at: 2007 North Third Street, Harrisburg PA 17102
Tel: 717-232-7580 Fax: 717-232-8727 Web site: www.yapinc.org