



Youth Advocate Programs, Inc.

10 BEST PRACTICES for Serving People with Autism and their Families

ASSET Center for **ASD/DD**

Autism Spectrum Disorders and Developmental Disabilities

Services, Supports, Education and Training



INTRODUCTION

► *What are the Youth Advocate Program's "Best Practices" for serving people with autism and their families?*

YAP families, staff, and self-advocates have identified 10 key practices that should guide the provision of direct services, supports, accommodations, therapies, and trainings. As you review that list below, you will notice that there is a common thread uniting all 10 practices into what is known as a "relationship-based approach": respect for the uniqueness and integrity of each person, and a willingness to learn and engage *with* people rather than work *on* them. In such an approach, the quality of relationships is seen as fundamental.

BEST PRACTICES for YAP's Relationship-Based Approach:

1. Focus on the person, not the label
2. Support development through reciprocal relationships
3. Presume capacity
4. Honor and unconditionally support preferred interests
5. Respond to behavior as communication
6. Learn from the experts: people with autism and their families
7. Adopt strategies that are proactive, not reactive
8. Respect and accommodate emotional and sensory needs
9. Interact age-appropriately
10. Be open to lifetime opportunities for growth and development

► *Why does Youth Advocates promote and require these "Best Practices" in its autism services? Why are they important?*

The autism field is filled with an ever-growing number of treatments, therapies, theories, and claims. No one can be expected to understand or evaluate them all, but we *are* all capable of building the kind of supportive relationships that will allow us to ask the right questions and make positive, appropriate, individualized choices in partnership with people on the autism spectrum and their families.

YAP *requires* that all staff learn and act according to these 10 practices because **they are our best assurance of maintaining program quality; our best assurance of staying true to the evidence base about how people learn, develop, and sustain mental health and resilience; and our best assurance of keeping faith with the promises we make to respect the "wholeness" and strengths of our clients.**

As a support person, therapist, or trainer, you will also find that following these "Best Practices" clarifies your daily efforts, enhances your relationship with -- and therefore the motivation of -- the person you support, and leads you to important insights and useful discoveries in your daily work.

This publication will take a look at each of these 10 important practices, what they mean, and how to incorporate them into your daily activities.

1. Focus on the person, not the label

None of us wants to be seen as just a label. When we are on the receiving end of negative comments such as "That's just like a woman (or just like a man)!" we bristle and defend ourselves: we are unique individuals, and our interests, talents, and challenges cannot be predicted or explained away on the basis of a chromosome.

People on the autism spectrum feel the same way. In fact, autism involves such a wide spectrum and so many yet-to-be-understood factors that no one should even be tempted to make predictions based on a child's genetics. Autism experts often note that there is as much diversity among people on the spectrum as between people on and off the spectrum. This means **there can be no "typical" person with autism.** Rather than a precise "thing" a person "has," autism might best be thought of as a tendency to encounter certain types of challenges and differences during development. *How* they are experienced and responded to will be as unique as each person and each set of circumstances.

For these reasons, **we should not assume that people diagnosed with autism need programs or treatments "for autism."** **What they *do* need are approaches, activities, options, and real choices** for Nick, Sue, Matt, Kim, and each individual who happens to receive this diagnosis. If we focus on addressing the real, live person rather than on the odd task of trying to address the label, we greatly increase our chances of success.

Seeing a person through the narrow lens of "autism" can distort our vision of what is really happening, and prevent us from recognizing obvious, common-sense solutions to problems. For example, parents of young children diagnosed with autism may start seeing every unwanted activity as "autistic behavior." A small child who tantrums during a long trip to the mall does not necessarily need to be viewed as exhibiting self-injurious autistic behavior or subjected to a behavior analysis and new treatment plan. The more appropriate solution might be to see this outburst as a typical communication of fatigue that any small child is likely to make under those circumstances, and to shorten or avoid mall outings in the future.

Similarly, parents and teachers may view the oppositional behavior of a teenager with autism as evidence of worsening "autistic symptoms," forgetting that self-assertion through opposition is a natural part of teenage development. It is ironic that sometimes the very people who label those with autism as "perseverative" and lacking in perspective fall into the trap of perseverating on the diagnosis and losing perspective on the bigger developmental picture. To avoid this common mistake, we must do our best to get to know the child, or teenager, or adult as a unique individual.

Evidence shows vast differences in outcomes for people on the autism spectrum. Interestingly, and contrary to some experts' predictions, those differences don't necessarily correlate with the observable extent of a person's diagnostic symptoms. Many people with the most complex sensory, motor, and communication challenges grow up enthusiastic, sociable, productive, and happy. Others

whose autism diagnoses are described as "mild" nevertheless become lonely, depressed, and unhappy. If the ability to enjoy a good life is not dependent on the diagnosis itself, then how can we explain it?

Differences in outcomes seem to be, in large part, a reflection of differences in attitudes and approaches toward a person: does he or she have friends, secure and caring relationships, support to pursue personal hopes and dreams, high expectations for achievement, the respect of others, and interesting things to do each day? Those are the areas where we can make a significant difference. That is why we "focus on the person, not the label."

2. Support development through reciprocal relationships

From the moment of birth, all of us are wired to develop through relationships. Our most basic needs for safety and belonging are fulfilled through our first relationships with caregivers. Once assured, that sense of security and self-worth becomes the basis for the rewarding relationships we will establish with friends, teachers, teammates, "significant others," co-workers, colleagues, and the various people who will enter our lives.

A lack of reliable, trusting relationships has been shown to have dire effects on development, including increased rates of anxiety, obsessive/compulsive activities, and depression. Over the long term, lack of relationships deprives people of the foundation they need to learn new things, be open and flexible, and become mature and well-adjusted adults.

The formation of trusting personal relationships is also vital to successful planning and problem-solving. Many of the things we need to know in order to support a person on the autism spectrum may not be immediately apparent. Difficulties with communication and with sensory and motor regulation may challenge support staff and caregivers to understand how a person is feeling and what they intend. Yet there is no rule book, chart, or "behavioral dictionary" that can translate a person's activities and experiences for us. Rocking or flapping hands, for example, may sometimes mean "I'm overexcited and need to calm down" and at other times "I'm bored and need to rev up." **The only path to understanding is to forge a relationship that allows us to see the world through another person's eyes.**

"Reciprocity" takes the concept of relationships to the next level. Some relationships are "one way": one person holds the power and reaches out to tell, direct, prompt, demonstrate, tutor, or simply "do for" another. Reciprocal relationships are two-way. They involve sharing and mutual involvement as equals in an activity. **In a reciprocal relationship, we don't try to take charge and initiate all the interactions; instead, we look for openings in which we can respectfully support what our partner wishes to do.** If a child is not yet ready to interact purposefully but likes to line up blocks on the floor, we begin by joining them in lining up blocks. This sends a strong message that they are safe with us, that we are interested in their world, and that forging a relationship with us might be fun.

Reciprocity entices children to initiate social responses. For example, research has shown that when a stranger imitates the play behavior of a child with autism by exploring a duplicate object in the same way, the child makes much longer and more frequent eye contact with that person. The stranger's demonstration of reciprocal behavior, based on following the child's lead, attracts and reassures the child. When you consider the extent to which most people with autism spend their days on the

receiving end of direction and redirection, it is not hard to imagine how refreshing reciprocity must feel.

Reciprocity sets the stage for richer interactions in which both partners begin to invest in each other, rather than one partner investing in getting compliance and control while the other invests in getting artificial rewards. We engage in it because reciprocal relationships support development, and we pay special attention to reciprocity because its vital importance is often underappreciated.

3. Presume capacity

To "presume capacity" brings together two powerful ideas in just two words. **"Capacity" refers to a person's intellect and awareness, innate motivation, and ability to learn and contribute to the world.** But why "presume" capacity rather than wait and see, administer a few tests, or insist that people with autism "prove themselves" first?

One autism researcher, Anne Donnellan, addressed this question with a rule of thumb she named "The Criterion of the Least Dangerous Assumption." By this she meant that **decisions about a person's life and how we approach them should be based on assumptions which maximize opportunities, education, and experience, and minimize the danger of poor outcomes.** To assume that someone lacks capacity and intellect creates a self-fulfilling prophecy, because it leads to inferior instruction, segregation, and fewer choices as an adult. On the other hand, there is no such downside to presuming capacity; the respectful climate fostered is unlikely to have a dangerous effect on how a person is supported and treated throughout life.

Children with autism are not always fortunate enough to be in the company of people who presume capacity. For example, rather than respectfully addressing their presence others may talk over them and about them as if they were not there. When communication challenges are unaddressed, a person with autism often cannot protest this treatment and assert his or her point of view. **The child who is presumed "unable to understand" and "not really there" is in great danger of being deprived of literacy experiences, of interesting activities and opportunities to explore the world, of inclusion and friendships, and of self-esteem and a sense of self-worth.**

People do not presume lack of capacity because they are unkind, but because they have been taught a flawed and outdated message about the nature of autism and the nature of intelligence. This old message said that most people with autism were of low intelligence, as measured by I.Q. (Intelligence Quotient). It also presumed that I.Q. tests, and related forms of "intelligence testing," were a valid and helpful measure of the capacity of people with autism - and, in fact, of people in general.

That message has since been rocked by many revelations. **We now recognize that typical testing methods cannot be applied accurately to most people with autism.** A person who does not speak cannot take an oral test, and one with delayed response time will not perform well on timed tests. People with sensory and movement differences experience many challenges to traditional testing. Among the factors interfering with their performance may be noise, lights, stress, pace, processing time, and difficulty initiating responses or switching formats.

That is why we can only say that typical "intelligence testing" shows us the floor - that is, the very least a person can do - but it can never show us the ceiling. The more that testing and evaluation have been

adapted to the needs of people with autism, the more experts continue to revise their statements that all, or most, or even many, people with autism are "of low intelligence."

I.Q. itself has turned out to be a deeply flawed and changing concept - and not just for people with autism. **Experts used to think intelligence was one unified "thing" with which people were born, but now they recognize that it is made up of many different elements and life experiences. People who are very adept in some ways may be far less able in others.** Educator Howard Gardner developed the "Theory of Multiple Intelligences" to describe the many different capacities found among different learners: Bodily-kinesthetic, Interpersonal, Verbal-linguistic, Logico-mathematical, Intrapersonal, Visual-spatial, Musical, Naturalistic, and Emotional. People on the autism spectrum are helping educators and researchers to appreciate that **many types of intelligence exist in a neurodiverse world.**

By presuming capacity, we can build relationships that support people on the autism spectrum to be all they can be. By respecting each person's intellect through all our interactions, we pave the way for the best possible outcomes.

4. Honor and unconditionally support preferred interests

Children and adults on the autism spectrum have strong natural interests, just as we all do. **Research shows that acknowledging, sharing, and working with passionate interests brings great dividends: the person becomes more self-motivated and socially connected, and less dependent on prompts and artificial rewards.**

Because of the communication challenges of autism, passionate natural interests may be overlooked. Because of the sensorimotor differences of autism, those interests may be judged "odd" or "perseverative" and actively discouraged. Sometimes a support person or caregiver needs to be a detective to discover deep personal interests that are not obvious to others, and sometimes he or she needs to be an advocate for the right of the person with autism to pursue their preferred interests.

Passionate interests come in many different varieties. We can identify the child or adult's passionate natural interests by observing such areas of expertise as: informational (topics on which the person has amassed great amounts of knowledge), educational (preferred school subjects, books, etc.), musical, technological, hobbies, sports, games and preferred play, favorite stories, and favorite types of community places and activities.

However, it is important not to mistake soothing or calming activities (e.g. rocking, spinning, flapping, shredding paper) for preferred interests. People with autism have preferred ways of regulating their nervous systems, as we all do. Sensorimotor regulation is a personal health need that must be understood and supported, but is not generally an intellectual interest that lends itself to shared exploration, socialization, and deeper connection with other aspects of the world.

Once a person's interests have been identified, we can engage with the person on the autism spectrum to enjoy, explore, and broaden those interests. Incorporating deep interests (e.g. maps, trains, dinosaurs, Harry Potter) into such everyday activities as math problems, book reports, vocabulary enrichment, art and music, conversations, hobbies and collecting, clothing and décor, recreation, travel, etc. helps the person with autism to make sense of their world and become self-

motivating rather than reward-dependent or prompt-dependent. The more a person "learns how to learn" in response to a passionate interest, the more he or she will learn to think independently and problem-solve flexibly.

It is important not to take away access to passionate interests in order to use them as rewards or punishments. To be effective, a support relationship must be proactive and positive (based on two-way sharing) rather than reactive and negative (based on one-way responses of "no" and "don't"). Deep personal interests are for mutual exploration and growth, not for use in gaining power over others. **A person who finds that their personal enthusiasms are being used to manipulate or control them tends to feel betrayed, lose trust, and shut down communication** to avoid exposing any more personal information. Such a person may turn against a subject or activity he or she previously loved, resulting in less engagement with the world and with others.

If natural interests are being incorporated appropriately into a person's day, they will be so deeply woven into the fabric of all activities that taking them away as punishment will not even be possible. In fact, **taking preferred interests away would deprive a staff person or caregiver of one of their most useful means of supporting a person with autism to communicate what went wrong and resolve the problem.** For example, a Social Story incorporating a person's interests can help them process how and why a bad situation occurred, and what to do differently next time. Through art or music, a deep personal interest can become the basis for exploring the feelings and perceptions that resulted in a loss of control.

Helping the child or adult into the familiar territory of a shared interest can be calming and help them regain a sense of safety. When people are stressed, upset, or having a bad day, depriving them of the things that give meaning to their life is especially destabilizing, and deprives both the person and their supporters of the very tools they need to figure out a solution. These are practical and effective reasons to unconditionally support preferred interests.

5. Respond to behavior as communication

The next time you jump for joy over good news, or slam your door because you are upset, imagine how it would feel to have people rush to your side with one narrow purpose in mind: stop that behavior! You would "use your words" to explain what your behavior meant: that jumping in the air was a sign of happiness, and not inappropriate or dangerous; and that you realize slamming the door was annoying, but you were too stressed to think of a better means of self-expression. **Dealing with the meaning of your behavior is the approach you would automatically expect,** and your intentions and needs would soon be clarified. Yet if you had autism, the people around you might not look beyond the surface. They might not respond to your behavior as communication. And in responding simply by implementing a new training program to get you to stand quietly or shut the door carefully, they would be shutting down important messages and missing crucial information.

Communication is always happening all around us, yet may be overlooked when it does not happen through typical forms of spoken language. Nowadays we are becoming much more aware that people can speak out and speak for themselves without actually creating sound waves in the air. We recognize that people on the spectrum should be encouraged as communicators in their own right and their own ways, sometimes with the assistance of technology, keyboards, letter or picture boards, sign language, or other forms of support.

While these forms of communication are language-based, and therefore easier to recognize, behavior itself is a powerful and basic conveyor of meaning. **Sometimes a person's actions are deliberately intended to send us a message. However, due to the sensorimotor differences of people with autism, we need to be careful about observing and interpreting body language.** For example, a person with autism may not be able to create a convincing smile to show us they are happy, and may develop some other, very personal signal to use instead.

At other times, a person's actions may be the result of his or her struggles to regulate a fragile nervous system. In that case, the person is engaged in a type of dialogue with their body - from which we can learn - but is not intending to dialogue with *us*. **It is very important to observe both intentional and unintentional communication if we want to understand the feelings of a person with autism, and what they need from us at a particular moment.**

In supporting people on the spectrum, it is vital to recognize that **all of us communicate all the time, in countless ways:** how we act, the actions we repeat, the things we choose, how we move, what we touch and explore, what excites us, what calms us, what we pay attention to, and what we ignore. **There is no such thing as a person who does not communicate, or a time when someone completely stops communicating.**

6. Learn from the experts: people with autism and their families

Who knows us, or our children, best? We do, of course! We -- and they -- are our favorite topics of discussion, observation, and reflection. Why would anyone in our lives want to overlook this treasure trove of information? The people we support feel just the same. **Learning how to listen to people with autism and their families is the path to a deep understanding of each individual's strengths, needs, preferences, and ways of communicating.** Now that we fully recognize the uniqueness of each person on the spectrum, we will want to rely less on generalized information about the label and more on their personal insights and inside knowledge.

Goals and desirable outcomes for people with autism have also evolved enormously in response to the common sense of homegrown experts. Where a diagnostician might still view "autism treatment" narrowly - for example, in terms of traits to reduce or extinguish -- **people with autism and their families have widened our horizons and our definitions of success.** They tend to think of good outcomes in terms that move beyond the label to address quality of life: engagement in rewarding activities and opportunities, the enjoyment of reciprocal relationships, support and respect for varied means of communication, and full participation in the community.

Self-advocates have written autobiographies and created web sites, blogs, videos, conference presentations, and more. **Never before has there been so much information available about the lived experience of autism, from the inside out.** The more we become familiar with these accounts, the more focused and observant we will become. The questions we ask, and the possibilities we explore, with the person we are supporting will become increasingly sensitive and productive.

Parent advocates too have shared their stories extensively, and have challenged old stereotypes. They can help us to understand what support families need to remain confident, resilient, and joyful. **As we do with people on the spectrum, we need to enter the lives of families with an open mind and let them teach us about the nature of their experiences.**

The autism self-advocacy movement has taken as its slogan: "Nothing about us without us!" This means that people on the spectrum need to be engaged in any decisions that have an impact on their lives. From enjoying their preferred interests, to helping create their IEPs, to participating in recreational and volunteer activities in their communities, to choosing the types of adult employment they want, self-advocates are changing support strategies in profound ways. When their vision for the future guides our work, we can proceed with confidence.

7. Adopt strategies that are proactive, not reactive

Few things are more frustrating, or likelier to put us in a bad mood, than making the same mistake over and over. Dialing a wrong number not once but twice, trying to parallel park the car for 20 minutes (while bystanders watch and laugh), or losing our ID card for the third time this week, can really ruin the day!

But also imagine that you are a person with autism, and instead of just getting mad at yourself you have to endure the repeated corrections of a teacher or staff person: "Why don't you pay attention? Not that way; *this* way. Do it again!" You probably would not find this helpful. **What you would want is for someone to analyze the problem and develop a means of preventing it.** You would want to participate in strategies that are proactive, not merely reactive.

Reactive approaches may also have the undesirable effect of making mistakes or bad habits harder to get rid of. Each time we do the unwanted action, we are in effect "practicing" it and making it more likely to happen again. And each time the person with us helpfully corrects us, the two of us are setting up a dysfunctional routine that may become automatic, and on which we may both become dependent.

There are many ways to be proactive and prevent problems from taking root. One, known as "**errorless learning,**" involves taking the anxiety out of learning or social situations by setting the person up for success. For example, if you are encouraging a child to read aloud and a word she has trouble reading is coming up on the page, you could casually mention "I see the word 'yellow' in the next line." By tipping her off with a timely reminder of the pronunciation, you allow her the positive experience of getting it right the first time.

A similar proactive approach is "priming," which means setting the stage for success. For example, imagine that you are standing with a child and the child has a ball. You see a potential playmate approach and eye the ball. Before the interaction can go off track, you can announce "Here comes Jim. He is looking at your ball because he wants to play. If you want to play, you can say, 'Jim, Let's play!'" Through this low-key approach you are supplying the ingredients for success: an interpretation of what's happening, a reminder of the playmate's name, and a useful script.

Other proactive strategies include environmental modification (to remove sources of distraction and discomfort); previewing of new situations and rehearsal of new routines; the creation and use of methods for self-monitoring, self-calming, and self-awareness; and the use of socially appropriate peers as role models and mentors.

It is vitally important that we **understand and employ the proactive approach of "decoding the hidden curriculum."** This means being aware that, for many people with autism, every day can feel like a trip to a foreign land where everyone is speaking an unknown language. Before mistakes and

misunderstandings occur, we need to use social stories, role-playing, and other strategies to make thoughts, feelings, and expectations explicit. **Being proactive means always thinking a few steps ahead, and never assuming that "Everyone knows..." or "It goes without saying!"**.

Prevention is much more effective than correction, and much more likely to advance and enhance the positive relationships we are working to build.

8. Respect and accommodate emotional and sensory needs

People with autism can experience intense emotional and sensory sensitivities. **Contrary to old myths that depicted people on the spectrum as aloof and self-contained, we now know that they can be extremely attuned to their surroundings, and their feelings can be especially acute.** An effective support person learns to honor these feelings by responding to signals in a person's behavior or language.

The processing of information through the body's sensory channels can be problematic for people on the spectrum. **Sometimes it seems like there is too much information coming in, and sensations cannot be prioritized or filtered.** People may be distracted or pained by sights, sounds, smells, tastes, and skin sensations that others don't mind or don't even notice. **At other times, the sensory system may shut down. When this occurs, most of what is happening in the environment does not register. At still other times, the central challenge is sensory regulation - getting the body to respond efficiently to what the mind wants it to do.**

Many people on the spectrum indicate that they can only process information effectively through one of their senses at a time. For example, if they are required to look someone in the eyes or watch their face, they cannot process what the person is saying. A student who is looking away from the teacher may be doing so in order to attend better to what is being said; unfortunately, this behavior may be misinterpreted as noncompliance or inattention.

None of these challenges is under a person's direct control, or deliberately chosen as a way to act. **Simply urging someone to "just ignore it" or to "pay attention" is reactive and unhelpful. Instead, we need to work with people on the spectrum to design appropriate accommodations** that respond to their sensory needs. Accommodations are strategies and supports that help a person overcome or "work around" sensory differences. They must be personalized and subject to readjustment as needed.

Sometimes the accommodations we need to make are in the environment itself, such as getting rid of uncomfortable lighting and confusing visual clutter, or providing preferred music. **Other accommodations are self-regulatory,** such as having access to "sensory diet" manipulatives and weighted vests or blankets for deep pressure. **Still other accommodations involve the way we interact with people:** for example, we may need to slow down our interactions, talk less when a person is upset, offer more wait time, or avoid gestures and postures that may make the person feel threatened.

Not surprisingly, **most people with autism struggle daily with anxiety and environmentally-induced stress.** Self-advocates have explained that an upsetting incident, even if it happened to someone else, can leave them in a state of high arousal and hypervigilance, with adrenalin pumping, for hours and sometimes even days. When the brain is in that state, it cannot process new information and learning shuts down. Too much of a *good* thing - too much class party, too much attention and fuss over a job well done - often can be just as painful and unnerving as negative attention. For people on the

spectrum, **the emotional safety zone can be fairly narrow.** Those who are forced to live outside it are at risk for developing depression, panic attacks, and post-traumatic stress disorder.

There is much evidence and much information from people with autism indicating that their emotional lives are deep and highly sensitive. With our awareness and support, they can develop a higher degree of emotional resilience and maintain good mental health despite the sensory challenges of autism.

9. Interact age-appropriately

One of the earliest protests parents hear from a developing child is often this one: "Stop treating me like a baby!" Even though the complaint may come from a child not yet old enough for school, the sentiment behind it - an **insistence on personal dignity and autonomy** - is unmistakable. Parents eventually realize that this protest will be repeated through adolescence or even beyond, and that it is **a vital part of each child's passage to mature adulthood.**

Children with autism feel the same, whether they express it in words or through other forms of communication. **They don't want people to talk down to them, make decisions for them, or treat them like babies.** Unfortunately, this communication is often missed. Many people assume that individuals with autism (or with any disability) are permanent children.

Myths about I.Q. and concepts like "mental age" reinforce the belief that a person with autism can be "a three-year old in an eighteen-year old body" or "a child forever." This is simply not possible! An eighteen-year old, for example, has eighteen years of experience in the world, not merely three. **He or she has a teenager's body, a teenager's hormones and emotions, and (whether caregivers realize it or not) is trying to make a teenager's leap into adulthood.**

Supporting adults age-appropriately brings its own unique challenges. Current service delivery models may encourage staff to behave in "parental" ways with the adults they serve, e.g. talking down to them or chiding them for keeping a messy room. When many of the people providing these services are the client's own age or younger, the problem is readily apparent. **Since no one wants adult life to be an endless replay of teenage conflicts with mom and dad, the breakdown of age-appropriate roles and behavior can become disruptive and counter-productive.**

Age-appropriateness should be a standard by which all activities and interactions are measured, from the time a child is small. Children with autism need inclusive environments, access to literacy and the general education curriculum at grade level, and knowledge and experience of peer culture (music, recreation, sports and games, clothes, etc.). Teens need support and guidance to explore the possibilities of adult life, including romantic relationships, postsecondary education, and career paths.

For many adults with autism, age-appropriate impulses and wishes may have gone unnoticed or even been discouraged in the belief that they might lead to unreasonable expectations. Fortunately, however, it **is never too late to acknowledge and respect a person's actual stage of life and years of experience, and to support people in the roles they would like to play in their families and communities.**

10. Be open to lifetime opportunities for growth and development

Each of us can expect to have many different jobs and careers in our lifetime, to live in different places, explore new hobbies and interests, and seek new friendships. Maybe we'll travel to Italy and learn the language next year, return to university for an advanced degree when we're in our 40's, or take up a musical instrument after we retire. Even if we don't get around to all of these dreams, just knowing that the opportunities exist is important.

Now imagine that the first job you get out of school is expected to be your lifetime job. That instead of a home of your own you are faced with an "adult placement" including obligatory roommates you have not chosen and may not even like. That your success in life will be measured not by the new directions and dreams you seek out and try, but by how well you "adjust" to a "predictable routine." You would probably feel that someone with too much power had failed to make "the least dangerous assumption" about your life! They had failed to assume that **you are an individual who wants choices, and who will continue to grow, change, and wish to explore.**

A label of autism should never be used to limit life choices. People with autism have demonstrated the capacity to continue developing in new areas throughout adulthood. For example, one adult opened his own woodworking business in his 30's, another moved into his own home in his 40's, while another made the change from typed to spoken communication at age 50. People with autism have written books, taken up public presenting, found romance, changed jobs, and moved halfway across the country - all when they were well into adult life.

Too often we concentrate all our care and resources on the school years and the special education system, forgetting about what will happen to people with autism after age 21. We act as if we are afraid to look across the boundary into adulthood, and the people we support pick up on that fear. **Instead, the process of talking about, planning for, and envisioning the future should begin in earliest childhood.** Dreams should be explored, and typical community experiences and expectations should be emphasized. People with autism should learn at a young age to value and anticipate a working lifestyle for themselves.

As a support person for children, you can model and encourage the process of making future plans and choosing present-day activities that will help reach them. If you are working with adults, you can resist the temptation to fall into stifling routines, and be open to growth, change, and the acceptance of reasonable adult risks as one of the ways people continue to learn. **If we give up the old idea of disability as a fixed limitation, we will never think of the people we support as "finished works."** **Instead, we will treat them as the "works in progress" that we all are, throughout our lifetimes.**

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