

EXPLAINING AUTISM TO YOUR CHILD WITH AUTISM

Explaining the diagnosis of autism to your child is extremely important. This knowledge sets up your child for a lifetime of self-awareness and independence.

Possible Parent Concerns:

Telling your child may lower his self-esteem.

Even having a basic understanding of autism can reduce your child's fears and self-blame, and can help him better understand and accept himself. It opens the door for your child to learn successful coping strategies.

Your child will use autism as an excuse for negative behavior or not doing tasks that are difficult.

Autism is not an excuse for bad behavior. Children with autism make bad choices, just like their typical peers.

Seek Professional Advice

Your team can give you advice on your approach, and give you some talking points. Your doctor knows your child personally, and you can even set up an appointment specifically to address autism with your child.

Timing is Everything

A young child with autism may not see herself as different, which makes it the best time to lay the groundwork. When she starts becoming aware, she will already have an explanation that emphasizes the positive and encourages self-acceptance. When presented proactively, you can share the positive aspects, focus on talents and strengths, and empower your child with knowledge and helpful strategies.

Prepare for the Conversation

Make a list of questions your child may ask and answer them in advance. A loose outline of your conversation will help you stay focused and on point. Having some facts and information will help move the conversation forward and keep you feeling calm.

Expect the Unexpected

It's normal for your child to feel unsure about what this means for their life. Your child could act like they don't care, which may be a sign that they not quite ready to have this conversation - and that's okay. Let it go and wait for another time when you think your child may be ready. You don't have to have all the answers-figure it out together. Let your child guide your conversations. Answer their questions simply and honestly.

The Conversation

Explaining autism is not a one-time event where you sit down, explain things and never talk about it again. In deciding where to begin, think in terms of what your child needs and wants to know right now and in the foreseeable future. Whatever the age of the child, there are critical truths your child needs to understand:

- You love your child and autism doesn't change that.
- Your child is a unique and valued person, who also has autism.
- Your child is not alone. Everyone has strengths and challenges. Many people have autism.
- People are born with autism. You can't catch autism. It is not a disease, and can't be cured with medicine.
- Some things are different for a person with autism because their brain works differently.
- People with autism feel their senses very strongly and can get overwhelmed.
- Communicating with others is challenging for a person with autism.
- People with autism might learn things in different ways, but they are still capable and intelligent.
- Remind them of their support system, including family, teachers, therapists and friends.
- People with autism can learn strategies that can help in challenging situations.
- Keep the focus on autism as your child experiences it, not a standard list of common characteristics.

FIVE TIPS FOR A HAPPY FUTURE FOR KIDS WITH AUTISM BY DR. KRYSTI DEZONIA

Parents' greatest worry is what will happen to their children when they are no longer able to watch over and advocate for them. Here are some tips about what you should focus on to assure your children with special needs have the best chance for a happy life after you are gone.

1. Be sure there are people in their life who are not paid to be there. You may be lucky enough to have one or more people who will take up where you leave off. Many people are not as lucky. Start now by developing a formal or informal circle of support for your child. There are specific steps you can take to do this. If you want to know what they are, read my blog entry titled "Who Will Take Over."

2. Social skills are the most important thing to work on with your child. Many may argue that eliminating problem behaviors or developing effective communication are the most important skills a child can acquire, and I agree that they are critical. Believe it or not, when your child is 40 years old, there are plenty of people (usually staff who work in the field) who will want to spend time with him even if he doesn't talk and even if he hits them. This is because they have found a way to connect. People fall in love with a personality or a smile or because of the hug they get at the end of the day. Focus your energy on helping your child learn to do things that will connect him to other people. Until they can do this on their own, be sure you have plenty of videos, stories, and "All About Me" books that show others the lovable, quirky, and unique person behind the autism. Lonely people rarely lead happy lives.

3. The more interests they have and things they like to do, the happier they will be. The great thing about a lot of kids and adults with special needs is that they often have passionate interests. Celebrate this—it could become a future career. The fact is that the more things they can do to occupy their own time, the easier it is to be around them. If they are easy to spend time with, more people will want to do this. We are all happiest when we are engaged in something we enjoy. Offer your child hundreds of big and little things to do and hope that a few of these will stick. Make sure EVERYONE knows about their favorite activities.

4. Unless your child can do it on their own, YOU need to make a plan to assure their happy future. Special needs trusts, letters of intent, and futures planning are all great and necessary, but they don't take the place of a life quality plan. You need to think about each category of life (residential, friendships, recreation, etc.) and write out what you believe they need in these areas in order to be happy. If they are able, your child should help you. If this is too big a job to tackle, you can have someone do it for you. To learn more, go to www.teriinc.org/ialq and click on Life Quality Planning.

5. Help them do things that society values. Unfortunately, despite the fact that we have made some progress, people with significant special needs are still viewed by much of society as folks who aren't able to make much of a contribution. Prove them wrong. Think beyond recycling and cleaning tables when you are helping your child get ready for adult life. Instead, think, "What does society value?" We value friends (can your child become a "friend" to someone in a nursing home?); community volunteers (can your child be part of the group that volunteers once a month to paint houses for the poor?); members (of a church, synagogue, club, team, or class); home and business owners. Start now and keep expanding. Even people with very severe autism can contribute, you just need to get them connected.

Here's a final, bonus tip. Your kids won't be happy now, or in the future, if YOU are exhausted, broke, and overwhelmed. Step back, get reasonable, and focus on what you need to do (or stop doing) so that you are able to be a parent who has the time and energy to simply enjoy their child, as they are, right now. You are more important to your child's present and future life quality than any therapy, plan, or treatment.

TRANSITION CHECKLIST FOR PARENTS

Throughout the Transition Process

- Explore employment interests, aptitudes, and abilities, options and supports required
- Explore Employment options and supports
- Pursue leisure and community activities, social opportunities and friendships (including needed supports)
- Identify options for future living arrangements, including needed supports
- Develop self-help and independent living skills (including personal care, finances, shopping, household management, etc)
- Learn and practice interpersonal, communication, and social skills for different settings (employment, school, recreation, with peers, etc.)

Age 12 (Middle School)

- Consider Self-Directed Services through OPWDD (if eligible)
- Begin Person-Centered Planning Process

Age 14 (High School)

- Begin community based employment training opportunities
- School conducts Level 1 Transition Assessment
- School Implements first IEP with Transition sections included

Age 15

- The Transition section of the IEP is legally required to be in effect
- Transition section of the IEP updated at least annually

Age 16

- Annual CSE meeting should include any community service agencies serving the student
- IEP should include a coordinated set of transition activities such as career exploration, job sampling, volunteer experiences, etc.
- Examine criteria and requirements for graduation or exit from High School
- Obtain NYS-issued photo identification
- Gather information about guardianship, power of attorney, and other legal options relating to your child reaching the age of majority
- Gather information on needed financial supports (Social Security, Medicaid etc.)

Age 17

Explore and apply to ACCES-VR and other adult service agencies

Explore independent transportation options and mobility training

Explore options for post-secondary education and training programs, including admission criteria

Gather information on needed financial supports (Social Security, Medicaid etc.)

Pursue legal issues about guardianship, power of attorney, and other options relating to your child reaching the age of majority

Age 18

Register to vote

Males register for Selective Service

Apply for Social Security Benefits (to insure Medicaid eligibility)

Apply for Adult Services

Guardianship or other alternatives in place

Ages 18-21

Match career interests and skills with academic course work and community work experiences

Transition to adult health care providers

Adult Services coordinated and in place

Succinctly identify accommodations needed for success in education, workplace, and home

Create a resume and/or portfolio and update as needed

Take responsibility for coordinating transportation and schedules for arriving on time to work, appointments, social activities, etc.

Skills for Independence

Household Skills

Food Preparation and Management	Plan to Start	Needs Practice	Accomplished
Operate kitchen appliances safely			
Use common kitchen tools safely			
Plan & prepare meals			
Follow a recipe			
Set the table			
Put away leftovers			
Wash the dishes			
Wash hands before preparing or eating food			
Recognizes signs of spoilage in food			
Follow the instructions on cans or boxes			
Laundry	Plan to Start	Needs Practice	Accomplished
Put dirty clothes in hamper			
Sort clothes by color and washing instructions			
Use washer and dryer			
Hand wash and dry			
Fold clothes			
Put clothes away			
Housekeeping	Plan to Start	Needs Practice	Accomplished
Clean room			
Make bed			
Change bed linens			
Use vacuum cleaner and changes bags			
Sweep floors			
Mop floors			
Clean toilet			
Clean tub and sink			
Dust furniture			
Uses appropriate products for each cleaning job			
Maintenance	Plan to Start	Needs Practice	Accomplished
Change a light bulb			
Unclog a toilet			
Dispose of garbage and recyclables			
Knows how to lock and unlock windows			
Check smoke alarm and replace battery			
Emergencies	Plan to Start	Needs Practice	Accomplished
Plan fire exits and emergency procedures			
Use candles and flashlights			
Use a fire extinguisher			
Know how to turn water off			
Know how to call 911 + when			
Understands basic fire prevention			
Knows what to do if they smell gas			
How to put out a small fire (and what NOT to do)			

Health Care Skills

Personal Appearance and Hygiene	Plan to Start	Needs Practice	Accomplished
Can dress self completely			
Can bathe self			
Knows how to use soap, shampoo, deodorant, shaving cream, other common personal products			
Brushes teeth regularly.			
Keeps hair clean and neat.			
Dresses appropriately for the season and weather conditions			
Shaving			
Uses deodorant			
I understand how poor hygiene affects relationships with others and increases the risk of getting sick or spreading germs.			
Medications	Plan to Start	Needs Practice	Accomplished
Know medications by name and appearance			
Knows what each medication is for			
Can refill a prescription			
Can take medication independently			
Can open childproof container			
Knows not to take someone else's medication			
Can read a prescription label and follow the instructions			
Knows side effects of and what to do if they occur			
Can fill a daily/weekly pillbox			
Sexual Health	Plan to Start	Needs Practice	Accomplished
Understands public vs. private activities			
Knows parts of the body and sexual functioning			
Knowledge and use of birth control methods			
Knowledge of sexually transmitted disease			
Knows how pregnancy occurs			
Doctor Appointments	Plan to Start	Needs Practice	Accomplished
I know the names of doctors and their specialties			
Prepare and ask questions during appointments			
Answer questions from doctors, nurses, therapists			
Schedule medical appointments			
Self Care	Plan to Start	Needs Practice	Accomplished
I can describe my medical condition to others			
Knows how and where to get emergency health care			
Knows what to do for minor injuries (cuts, burns, etc.)			
Correct use of over the counter drugs for pain, stomach upset, diarrhea, fever, cold, etc.			
Knows the difference between an emergency (go to hospital) or illness (call my doctor)			
Can follow the plan of care recommended by my doctor			
I carry my health insurance card everyday			

Community Skills

Legal	Plan to Start	Needs Practice	Accomplished
Knows how and where to register to vote.			
I know who to complain to if I am discriminated against.			
I know what my rights are if I'm arrested and who to call			
Has the phone number of someone to call if arrested or victimized.			
Understands generally what actions are against the law and what the consequences are.			
Knows legal rights as an employee			
Housing	Plan to Start	Needs Practice	Accomplished
Know about utilities: electricity, phone, water			
Understands the concept of renting			
Can identify type of housing that is within budget and meets current needs.			
Knows the role of the landlord			
Shows concern for neighbors (noise levels, etc.)			
Interpersonal	Plan to Start	Needs Practice	Accomplished
Telephone etiquette			
Email and text messaging etiquette			
Can make introductions, including approaching others to introduce self.			
Make arrangements with peers for social activities			
Accepts no for an answer			
Can tell others no			
Gets people's attention appropriately			
Gives negative feedback appropriately			
I understand that there are social boundaries that differ depending on the type of relationship			
Problem Solving	Plan to Start	Needs Practice	Accomplished
I recognize when I have a problem.			
I ask for help with a problem when I need it.			
I consider several solutions to a problem			
I understand the possible consequences of my choices.			
I know how to manage conflict and keep calm			
Self Advocacy			
Can describe my disability to others.			
Can describe the accommodations needed to others.			
I ask for accommodations when needed			
Knows name, address, telephone number			
Knows height, weight and birth date			
Carries personal I.D. when leaving home			
Knows when and how to protect my identity and private information			

Financial Skills

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Employment Skills

Job Seeking	Plan to Start	Needs Practice	Accomplished
Knows what the minimum wage is			
Knows appropriate dress for an interview			
Can complete a standard job application			
Knows how to prepare for a job interview			
Can complete a job interview			
Has a resume			
Can follow up an interview with a letter			
Understands legal discrimination and where to seek help if discriminated against illegally			
Job Maintenance	Plan to Start	Needs Practice	Accomplished
Dresses appropriately for work			
Reports to work on time			
Knows job responsibilities and how to complete tasks.			
Knows who to contact if I can't go to work			
Knows how to ask for help on the job			
Understands benefits like sick time, vacation time, or personal time			
Can handle criticism (understands the difference between bullying and being corrected)			
Knows where and when to talk with co-workers			
Has a plan for handling anger when angry at supervisor, co-workers, or customers			
Know that my behavior and attitude at work can affect whether I keep my job or get promotions			
Knows what to do if I have a grievance			
Can explain disability and how it impacts learning/job performance			
Can advocate for needed accommodations or modifications at work			
Can correct unacceptable work behaviors when identified			
Understands the importance of having a good work history			



Learning•Information•Sharing•Training•Education•Navigation

Parent Workshops

Workshops provide hands-on, strategies for parents. Techniques and materials that can be implemented immediately at home.

Online Support

AutismUp members can join our active online support groups. Private groups are available on Facebook and a Yahoo Message Board.

Family Navigator

The Navigator is on site at the Kirch Center at Strong to connect families with resources and support. For more information email: navigator@autismup.org

Parent Connections

Coffee and conversation with facilitated support. Connect with other parents and expand your support system.

Autism 101

An introduction to Autism for parents and family of newly diagnosed children. A road map to begin your family's journey.

Parent Mentors

Newly diagnosed families are matched with a trained, experienced parent to help you navigate the world of autism.

PEP Program

Dr. Laurence Sugarman developed the Parent Effectiveness Program. Parents learn to apply research-based clinical techniques at home.

Speaker Series

Community professionals speak about topics relevant to raising and educating a child with autism.

Adult Connections

Monthly meetings for adults with ASD and their parents. Each month features a speaker, followed by group sharing and support, with the parents separated from the individuals.

Ask An Advocate

Address your concerns and problem-solve with an educational advocate.

Family Swim

Swimming with your kids in a quiet, supportive environment, reserved just for AutismUp families.

Family Gatherings

Join with other AutismUp families for activities and fun in our community.

Specific information on each program can be found at www.autismup.org. Support services and programs are offered free or at a reduced rate thanks to the generosity of our many donors and supporters in the community.