Tips and Strategies

for Successful Healthcare:

A Family Perspective

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AUTISM SOCIETY
Improving the Lives of All Affected by Autism
Central Ohio

www.autismcentralohio.org

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TRANSITIONING TO ADULT MEDICAL CARE

The transition to adulthood, including medical care, should be a process that extends over several years. The next two pages include a sample transition readiness assessment. The goal is to determine which skills the individual already has, which can be learned by the time of transition and what supports need to be in place for those areas in which the individual will not be fully independent at the time of transition. Recommendations for the start of this process range from 12 to 16 years.

Additional examples of transition readiness assessments may be found at:

www.gottransition.org/providers/staying-3.cfm

www.waisman.wisc.edu/wrc/pdf/pubs/THCL.pdf

www.family.cedwvu.org/workbook-for-youth.pdf

https://www.rheumatology.org/Practice-Quality/Pediatric-to-Adult-Rheumatology-Care-Transition

www.cdlsusa.org/what-is-cdls-cdls-publications.htm

https://www.ohiogps.org

https://www.pacer.org/transition/learning-center/health/transition-to-adult-health-care.asp

A curriculum designed to teach individuals with disabilities to make healthcare decisions and manage health care, My Health-My Decision can be found at:

http://myhealthconsent.org/myhealthmydecision.html

NOTES:

Medical Transition Readiness Assessment for Parents/Caregivers
of Youth With IDD

This document should be completed by caregivers of youth with intellectual or developmental disabilities (or the individual, if able) to assess the individual's readiness to transition to an adult health care provider.

Patient Name: Date of Birth:

Name of Person Completing Assessment:

Relationship to Patient:

Patient Age at Anticipated Transition to Adult Care:

Skill	Mastered	Learning	Can Learn	Will Require Assistance
Understands his/her health needs				
Can communicate medical needs				
Understands difference between emergency (go to hospital) and illness (call doctor)				
Knows what to do in medical emergency				
Knows what medications he/she takes				
Knows what quantity of medication he/she needs to take				
Knows when he/she needs to take medications				
Can take medication independently				
Can take medication if placed in pill minder by a caregiver				
Knows his/her allergies, including medications				
Can independently fill and refill prescriptions				
Knows or can access doctor's phone number at all times				
Can make own doctor's appointments				
Can prepare a list of questions/concerns to take to an appointment				
Keeps a calendar of appointments Can communicate questions/concerns to medical practitioner				
Can independently access transportation to medical appointments				
Knows where to obtain medical care if physician's office is closed				

Has summary of medical information and plan of care				
Knows what to take to physician appointment (ID, insurance card, medical information, etc.)				
Can fill out medical forms				
Carries ID, insurance card and emergency contact information with him/her at all times				
Can follow spoken medical instructions				
Can follow written medical instructions				
Has access to health insurance after age 18				
Has a plan to obtain health insurance after age 18				
Can name 2 or 3 people who can help him/her with health care needs				
Can understand and make health care decisions independently				
Can manage payments to health care providers				
Knows how to ask for help to pay providers				

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Adapted from American College of Physicians Pediatric to Adult Care Transitions Toolkit and Wisconsin Community of Practice on Transition Practice Group on Health Transition Health Care Checklist: Preparing for Life as an Adult

FINDING A MEDICAL PROVIDER

Finding a health care professional can be challenging. A summary of this process, including practical tips, may be found at https://autismandhealth.org/. Possible sources include:

Networking – ask your friends and co-workers.

Autism Society or other local disability groups
Insert AS contact information

Hospitals may have local physician referral services

Your health insurance company may have a list of approved providers. Check their website or call their customer service line.

Medicaid Lists
https://portal.ohmits.com/Public/Public%20Information/search%20provider%20directory/tabId/61/Default.aspx

Ohio Association of Community Helath Care Centers
www.ohiochc.org

Managed Care Lists
https://memberportal.caresource.com/App/OH/FindaDoctor/Medicaid

https://providersearch.molinahealthcare.com/

https://www.buckeyehealthplan.com

UCEDD/LEND program (OSU Nisonger Center; University of Cincinnati)

https://aucd.org/directory/state.cfm?state=oh&program=LEND

MAKING A MEDICAL SUMMARY

A medical summary assists a new health care practitioner to understand the patient's medical history and needs. Review of a complete chart can be difficult and time consuming. A “snapshot” of the chart can help the new practitioner to provide care. Attached is a sample portable medical summary to assist in transition from pediatric to adult care. Ideally, it should be completed by the pediatric care provider in collaboration with the patient and parents/caregivers.

Additional samples can be found at:

https://www.acponline.org/system/files/documents/clinical_information/high_value_care/clinician_resources/pediatric_adult_care_transitions/gim_dd/idd_transitions_tools.pdf

www.gottransition.org

http://www.gottransition.org/resourceGet.cfm?id=227

https://www.ohiogps.org

https://redcap.partners.org/redcap/surveys/?s=e2wykW

The Ohio Department of Health has created a secure, accessible, on-line resource, called Guiding People Through Systems, for the creation and storage of healthcare records and summaries, as well as many other helpful information. Go to https://www.ohiogps.org to create an account. This will allow patients and providers to access this information from any location via smartphone.

Medical Summary for Youth with IDD
Transitioning to Adult Caregivers

This document should be completed through a collaboration of pediatric medical practitioner, parent/caregiver and patient. A copy of the completed document should be shared with and carried by the patient and caregivers to assure information transfer to new healthcare providers.

Patient Name: Date of Birth:

Patient Address:

Telephone Numbers: Home _____; Cell _____

E-mail:

Preferred Mode of Contact (Circle): Telephone Text Message E-mail

Patient is Verbal Patient is Non-Verbal Patient Uses Assistive Communication Device

Name of Person Completing Assessment:

Relationship to Patient:

Emergency Contact:

Address:

Telephone Numbers: Home _____; Cell _____

E-Mail:

Preferred Emergency Care Location:

Health Insurance/Plan:

Group Number: ID Number:

Please provide any special information, including patient's strengths and talents, that the new health care team should know:

VACCINATION RECORD ATTACHED (Circle One): YES NO NOT VACCINATED

DEVELOPMENTAL DISABILITY DIAGNOSIS:

DIAGNOSIS	YES	NO		SENSORY	Avoidant	Seeking	Impaired
Autism Spectrum Disorder				Visual (Seeing)			
Cerebral Palsy				Auditory (Hearing)			
Down Syndrome				Gustatory (Taste)			
Fetal Alcohol Syndrome				Olfactory (Smell)			
Fragile X				Tactile (Touch)			
Intellectual Disability				Proprioceptive			
Rett Syndrome				Vestibular			
Spina Bifida				Other (Specify)			
Tourette Syndrome							
Other (Specify)							

ETIOLOGY (Circle):

Genetic/Chromosomal Preterm Birth Prenatal Substance Exposure Prenatal Viral Exposure

Birth Complication Acquired or Traumatic Brain Injury Other (Specify) Unknown

OTHER DIAGNOSES/CONCERNS

System	**Date of Diagnosis**	**Describe**
Heart		
Respiratory		
Urinary/Genital		
Gastrointestinal		
Nutritional		
Weight Loss/Gain		
Bruising/Bleeding/Anemia		
Diabetes		
Thyroid/Growth		
Skeletal/Bone/Muscle		
Environmental Allergies		
Skin Problems		
Neurological/Seizures		
Sleep Problems		
Recent Changes in Mood/ Behavior		

Dental		
Visual		
Physical Anomalies		
Stamina/Fatigue		
Sensory		
Other		

ALLERGIES

Allergies	Reactions

CURRENT MEDICATIONS

Medication	Dose	Frequency

PROCEDURES/MEDICATIONS TO BE AVOIDED OR PLANNED

Procedure/Medication to Be Avoided	Why?

PRIOR PROCEDURES, SURGERIES AND HOSPITALIZATIONS

Date	Procedure/Surgery/Hospitalization

ADAPTIVE FUNCTIONING

Communication	
Social	
Behavioral	
Community Activities	
Employment	
Functional Academics/IQ	
Sleep Issues	
Nutritional Issues	
Safety Issues	
Other	

FREQUENT MEDICAL ISSUES (Please include any suggestions/considerations for testing and treatment)

MOST RECENT EXAM/LABS/RADIOLOGY

	Date	Results
Blood Pressure		
Baseline Neurological Status		
CBC		

EEG		
EKG		
X-Ray		
C-Spine		
MRI/CT		
Other (Specify)		

OTHER PROVIDERS

	Name/Address	Telephone	Fax
Primary Care			
Specialty Provider			
Specialty Provider			
Dentist			
Eye Care			
Physical Therapist			
Speech Therapist			
Occupational Therapist			
Mental Health			
Other			

Adapted from American College of Physicians Pediatric to Adult Care Transitions Tools

Health Care Transition and the IEP

Healthcare and preparation for independent healthcare management can be a part of the IEP.

The Present Level of Academic and Functional Performance provides a description of how the individual is performing, strengths and disability-related areas of educational need. Any health issue or limitation can be included in the PLP if it describes how the the disability affects participation in school, transition or recreational activities and may include the need for supports, adaptations, accommodations, equipment, etc.

Examples:

Mary recognizes when her asthma requires use of her inhaler. She does not always remember to take her inhaler lunch, recess and specials. She needs reminders to carry her inhaler at all times.

Sara does not consistently communicate with school staff or medical providers when she feels unwell. When Sara feels unwell, she is unable to meaningfully participate in the classroom or employment based activities.

Goals can be aimed at skills in any of the areas typically considered in an IEP: communication, self-advocacy, self-awareness, independent living (like refilling a prescription), safety, nutrition & fitness, recreation and community participation, social skills (like telephoning to make an appointment), locating health providers, establishing a medical home, and managing medications, monitoring and equipment.

The IEP or Postsecondary Transition Plan would then include a measurable annual healthcare goal. This goal could be characterized as a postsecondary education, employment or independent living goal.

Examples:

Goal: Mary will carry her asthma inhaler with her at all times.

Objective: Mary will take her inhaler with her when she leaves the classroom with no more than 2 verbal prompts 100% of the time by the end of the first grading period.

Objective: Mary will take her inhaler with her when she leaves the classroom with no more than 1 verbal prompts 100% of the time by the end of the second grading period.

Objective: Mary will take her inhaler with her when she leaves the classroom with no prompts 50% of the time by the end of the third grading period.

Objective: Mary will take her inhaler with her when she leaves the classroom with no prompts 50% of the time by the end of the third grading period.

Goal: Sara will learn and utilize strategies to inform school staff or medical providers

when she feels unwell with 75% accuracy and decreasing prompts.

Objective: When provided with a 5-point visual scale every morning, Sara will point to the icon correlating to how she feels with no more than 3 verbal or physical prompts 60% of the time by December 15.

Objective: When provided with a 5-point visual scale every morning, Sara will point to the icon correlating to how she feels with no more than 2 verbal or physical prompts 75% of the time by May 15.

Goal: Josh will independently make a doctor's appointment.

Objective: With his speech therapist, Josh will develop a list of the information he will need in his possession to make an appointment (calendar, insurance card, transportation, etc.)

Objective: With his speech therapist, Josh will develop a script to use when making an appointment.

Objective: Josh will practice dialing the telephone, waiting on hold and utilizing his script prior to independently making an appointment.

Resources:

www.autismconsortium.org/families/transitioning-to-adulthood/

www.autismspeaks.org/family-services/tool-kits/transition-tool-kit

www.ocali.org/project/transition_to_adulthood_guidelines

NOTES:

PARTNERS IN CARE

Medical care should be regarded as a partnership between caregivers, family and patient. There should be a free flow of information and everyone's voice must be heard. Family and patients have a responsibility to educate medical providers and vice versa.

The medical home model involves the creation of patient-centered primary care that is team-based, comprehensive and of high quality. The philosophy is to encourage providers and caregivers to provide individualized care aimed at the individual's needs and talents while building strong, trusting relationships within the team. The model envisions care provision at the right place, in the right time and in the manner best suited to the individual. Coordination of all aspects of the individual's life – school, medical, therapy, transition, employment, and community and leisure is envisioned. This includes personalized care, ongoing medication monitoring, coaching and advice and community and natural supports. Studies show that the model results in better support and communication, time saving and stronger relationships with providers than the less integrated traditional approach.

For more information about the Medical Home Model, go to:

www.hrsa.gov/healthit/toolbox/Childrenstoolbox/BuildingMedicalHome/whyimportant.html

https://www.pcpcc.org/about/medical-home

https://www.acponline.org/practice-resources/business-resources/payment/models/pcmh

https://pcmh.ahrq.gov

NOTES:

EDUCATING YOURSELF

Some resources which may be helpful in preparing family and caregivers for medical visits are attached:

List of common medical terms

Pediatric and Adult Vaccination Schedules (Center for Disease Control)

Table of Standard Medication Choices and Potential Side Effects (Autism Treatment Network)

Questions to ask

NOTES:

PREPARING FOR A MEDICAL VISIT

Think about what you want to do during the appointment (Talk about a health concern? Get or change medication? Talk about treatment options?). Write any questions down. If you forget to ask a question, call the office rather than waiting for the next appointment. Attached is a form from www.ohiogps.org which might help.

Take a list of medications with you.

Prepare a "symptom story"

1. How is your body feeling (Ex. "My back hurts")
2. Your thoughts on cause (Ex. "I fell down the stairs" or "I got a new mattress")
3. How your symptoms affect your life (Ex. "When I'm in pain, I can't get any work done.")

Think about the history of your symptoms

1. When did it start?
2. How long have you had them? Do they come and go?
3. What does it feel like?
4. Is the pain in one spot, or does it change?
5. What makes it worse? Better?

Tell the doctor or nurse that you want to talk about the problem at the beginning of the appointment. After the exam, make sure you understand what is causing your problem, what will make you feel better, when you should feel better and when you should come back.

Other questions you might wish to ask:

- What is the diagnosis?
- What are the treatment options? What are the benefits and side effects of each option? How can the treatment be modified to accommodate patient's individual needs?
- What is test for? How is test done? What arrangements must be made? How can test be modified to accommodate individual needs? What will the test results tell us? Is there a less invasive (expensive?) way of getting that information? How will I get the test results? Who will explain the results to me?
- What will the medicine you are prescribing do? How is it taken? Is there any other way of delivering it? What side effects should I look for and what should I do if we see them? Are there any things I should not eat or drink (or over-the-counter medications I should not take) while I am using the prescription?
- Why do I need surgery? Are there other ways to treat? How can the surgical prep, etc. be modified to accommodate individual needs? What pre-teaching is available?
- What changes should be made in patient's daily routine and life style? How do I help him/her make those changes?
- May I have written instructions, brochures, videos, visual supports, etc. to help prepare patient for treatment?

What should we work on before the next visit?
What can we do to prevent this from happening again?
How many patients like us have you treated?
When should we come see you again?

NOTES:

HEALTH TERMS

"Wait", "What"? – Commonly used terms or abbreviations used in an appointment

BID	twice daily or every 12 hours
TID	three times daily
QID	four times daily
HS	at bedtime
QH	every hour
QD	every day
NPO	nothing by mouth
ASAP	as soon as possible or STAT
BP	blood pressure
NKA	no known allergies
PRN	when necessary or on request
QNS	quantity not sufficient
R/O	rule out
ROM	range of motion
Rx	prescription, treatment or therapy
Void	urinate
WNL	within normal limits

COMMON LAB TESTS

BMP	basic metabolic panel (blood test measuring glucose, electrolytes, fluid balance and kidney function)
CBC	complete blood count (number of red blood cells, white blood cells, and platelets in a sample of blood)
HgA1C	diabetes blood test –three month average of blood glucose (sugar)
LFT	liver function test (measures enzymes and proteins in liver to assess damage or disease)
RBC	red blood cells (carry oxygen from the lungs to the tissues via circulatory system)
UA	urinalysis (screens for or helps dx conditions such as urinary tract infections, kidney disorders, diabetes, to name a few
WBC	white blood count (measures the number – these help fight infections)

OTHER TESTS

EEG	electroencephalogram – electrical activity of brain
EKG	electrocardiogram – electrical activity of the heart
MRI	magnetic resonance imaging – computerized images based on nuclear magnetic resonance within the body induced by radio waves. Provides 3-D images of body's interior, delineating muscle, bone, blood vessels, nerves, organs and tumor tissue.

OTHER

Edema	swelling
Emesis	vomiting
Infusion	slow intravenous delivery of fluids and/or drugs
Palliative	relieving symptoms and/or pain of disease/disorder without effecting cure
URI	Upper Respiratory Infection – viral/ contagious – affecting nose, throat, lungs, etc.
UTI	Urinary Tract Infection – infection in any part of the urinary system, any part of the kidneys, ureters, bladder or urethra
SOB	shortness of breath
F/U	follow up

For an extended list of health terms, go to:

http://familydoctor.org/familydoctor/en/diseases-conditions/by_name.html

www.eskaton.org/glossary.html

http://www.asha.org/uploadedFiles/slp/healthcare/Medicalabbreviations.pdf

Sample Social Stories, Visual Supports & "First-Then" Supports

The following pages contain samples of supports to help individuals, families and caregivers to communicate with health care professionals, prepare for medical care and to self-advocate.

Materials are copied with the express permission of the Academic Autistic Spectrum Partnership in Research and Education (http://aaspire.org), The Wisconsin Community of Practice on Transition ( ), and the Center for Autism Services and Transition.

Included Resources:

Center for Autism Services and Transition Visual Supports (Check in, Bring, Pay for Visit, Weight, Height, Visual Screen, etc.)

The Wisconsin Community of Practice on Transition
- "How to Make an Appointment"
- "How to Arrange Transportation for your Appointments
- "How to Get Prescription Medications and Refills"
- "Getting Ready for your Medical Appointments"
- "Questions to Ask at your Regular Appointment"
- "Questions to Ask at an Appointment When you are Sick"
- "Questions to Ask about Hospitalization or Surgery"

Academic Autistic Spectrum Partnership in Research and Education
- "Making an Appointment"
- "What to Bring"
- "Symptoms"
- "After the Visit"

NOTES:

CHARTING THE LIFECOURSE

The LifeCourse Frameworks is based on the premise that all people and their families have the right to live, love, work, play and pursue their life aspirations in their community. LifeCourse was created by families to help individuals and families of all abilities and all ages to create a vision for a good life and to identify and develop strategies and supports to live that life. A number of tools have been develop to assist families in thinking about what they need to do. These can be found at www.supportstofamilies.org/resources/lifecourse-toolkit/. The Ohio Department of Developmental Disabilities has launched a statewide Community of Practice for Supporting Families to help teach and develop this model within Ohio systems. For more information, contact OSU's Nisonger Center.

Attached is basic information about LifeCourse and a copy of the LifeCourse Trajectory and Integrated Supports Star which provide visual models for the discussion.

NOTES:

RESOURCES ON HEALTHCARE TRANSITION

Ohio Coalition for Autism and Low Incidence – www.ocali.org

AASPIRE – www.autismandhealth.org

ASAN – Transition to Adulthood: A Health Care Guide for Youth and Families – www.autisticadvocacy.org/2014/07/asan-unveils-toolkit-for-advocates-on-health-care-and-the-transition-to-adulthood

Autism Society Living with Autism Resources – www.autismsociety.org/about-the-autism-society/publications/resource-materials

Autism Speaks Tool Kits – https://www.autismspeaks.org/family-services/tool-kits

The North Carolina Office on Disability & Health: Child & Adolescent Healthcarehttp://projects.fpg.unc.edu/~ncodh/ChildandAdolescentHealth/

Missouri Developmental Disability Resource Center: Medical Transition – A New Way to Support Families – http://www.moddrc.org/user_storage/File/ihd/Medical%20Transition%2020-23-10.pdf

Rhode Island Department of Health: Adolescent Transition for People With Special Health Care Needs – http://www.health.ri.gov/specialhealthcareneeds/about/adolescenttransition/index.php

Institute for Child Health Policy FL – http://hctransitions.ichp.ufl.edu/hct-promo & http://hctransitions.ichp.ufl.edu/gladd/

Florida Developmental Disabiities Council: Welcome to Health Care Transition – http://hctransitions.ichp.ufl.edu/ddcouncil/index.php

“Leaving the Pediatrician: Charting the Medical Transition of Youth with Autism” Interactive Autism Network – http://iancommunity.org/ssc/medical-transition-youth-autism

Preventative Women's Health Care for Women with Disabilities – https://www.csp.nsw.gov.au/information-and-resources-for-health-professionals/publications/preventative-womens-health-care

Guiding People Through Systems – https://www.ohiogps.org

Autism Transition Handbook: An Online Resource for Families in Pennsylvania www.autismhandbook.org

www.gottransition.org

www.autismandhealth.org

https://www.jointcommission.org/assets/1/18/hot_topics_transitions_of_Care.pdf

http://pediatrics.aappublications.org/content/content/128/1/182

http://www.transitioncoalition.org/wp-content/originalSiteAssets/files/docs/healthcarechecklist_final_july20081259892127.pdf

"Transition to Adulthood for Individuals with Autism Spectrum Disorder: Current Issues and Future Perspectives"
http://lurie.brandeis.edu/pdfs/Friedman%20parish%20Ericson%202013%20Transition%20to%20adulthood%20for%20individuals%20with%20autism.pdf

Curriculum for Teaching Individuals with IDD to Make Healthcare Decisions
http://myhealthconsent.org/myhealthmydecision.html

Resources on Specific Procedures and Issues

Going to the Doctor

http://positively-autism.blogspot.com/2014/02/social-story-for-preparing-for-doctor.html
http://www.helpautismnow.com/going_to_the_doctor.html

Blood Draw

http://www.autismspeaks.org/sites/default/files/documents/atn/blood-draw-parent.pdf
http://www.kidshealth.org/en/kids/video-bldtest.html
https://www.autism.com/phlebotomy

Blood Pressure

https://www.urmc.rochester.edu/childrens-hospital/developmental-disabilities/services/visual-supports/having-my-blood-pressure-taken.aspx

X-Ray

http://fledglingkids.com/preparing-your-child-for-an-x-ray/

Overall Kids Health Site (for ideas on what to put in social stories)

http://kidshealth.org/en/kids/stay-healthy/

EEG Social Story

http://www.oneplaceforspecialneeds.com/main/library_eeg_test.html

Surgery

Check to see if your hospital has information or coloring books available to help prepare for surgery.

http://my.clevelandclinic.org/childrens-hospital/specialties-services/programs-services/child-life-services/surgery-tours

Shots

http://www.bayclinicpediatrics.net/Forms.aspx

MRI

http://www.pitt.edu/~nminshew/MRIact_12.html
http://www.stanfordchildrens.org/en/topic/default?id=magnetic-resonance-imaging-mri-and-children-90-P01805

Going to the Dentist

https://www.youtube.com/watch?v=s_n1aZy1NV8
http://www.autismspeaks.org/family-services/tool-kits/dental-tool-kit
http://www.iidc.indiana.edu/?pageId=3384
https://www.dentistry.uiowa.edu/pediatric-autism

Puberty

http://kc.vanderbilt.edu/healthybodies/ (Guides for both boys and girls with disabilities)
http://www.coultervideo.com/puberty-video-for-boys-with-aspergers
http://raisingchildren.net.au/articles/autism_spectrum_disorder_periods.html

Gynecological Exams

"Table Manners and Beyond: The Gynecological Exam for Women with Developmental Disabilities and Other Functional Limitations" – copy available for download at www.nisonger.edu/odhp/resources/accesstocare

AUTISM SOCIETY
Improving the Lives of All Affected by Autism
Central Ohio

Autism Society Central Ohio does not endorse any specific treatments, programs, therapies or professionals providing those therapies. All information is provided FOR INFORMATIONAL PURPOSES ONLY. Parents and advocates are responsible for the choice of any treatment, therapy or service provider. Inclusion of any information or organization in this newsletter does not imply endorsement, and omission does not imply disapproval.

Autism Society Options Policy

The Autism Society promotes the active and informed involvement of family members and the individual with autism in the planning of individualized, appropriate services and supports. The Board of the Autism Society believes that each person with autism is a unique individual. Each family and individual with autism should have the right to learn about and then select the options that they feel are most appropriate for the individual with autism. To the maximum extent possible, we believe that the decisions should be made by the individual with autism in collaboration with family, guardians and caregivers.

Services should enhance and strengthen natural family and community supports for the individual with autism and the family whenever possible. The service option designed for an individual with autism should result in improved quality of life. Abusive treatment of any kind is not an option.

We firmly believe that no single type of program or service will fill the needs of every individual with autism and that each person should have access to support services. Selection of a program, service or method of treatment should be on the basis of a full assessment of each person's abilities, needs and interests. We believe that services should be outcome based to insure that they meet the individualized needs of a person with autism.

With appropriate education, vocational training and community living options and support systems, individuals with autism can lead dignified, productive lives in their communities and strive to reach their fullest potential.

The Autism Society believes that all individuals with autism have the right to access appropriate services and supports based on their needs and desires.