

TRANSITION TO ADULT LIFE: ADVOCATING FOR ADOLESCENTS WITH ASD

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LEGAL AUTHORITY - WHAT DO THESE TERMS MEAN?

Free appropriate public education is defined as special education and related services that are provided at public expense, under public supervision and direction, and without charge; meet the standards of the state educational agency (SEA), include appropriate preschool, elementary school, or secondary school education in the State involved; and are provided in conformity with an individualized education program (IEP) that meets the requirements (34 C.F.R. Sec. 300.320-300.324) related to IEP development. 34 C.F.R. Sec. 300.17. The United States Supreme Court, in its 1982 decision in *Rowley v. Board of Education*, 458 U.S. 176, 200 (1982) determined districts - in order to provide each child with a disability a free appropriate public education –must offer one that is reasonably calculated to yield meaningful educational benefit. *Rowley* determined that districts did not need to offer programs that maximize a student’s potential. *Id.*

Special education is defined as specially designed instruction to meet the unique needs of a child with a disability. 34 C.F.R Sec 300.39.

Specially designed instruction means adapting, as appropriate to the needs of an eligible child under this part, the content, methodology or delivery of instruction to address the unique needs of the child that result from the child’s disability and to ensure access of the child to the general curriculum, so that the child can meet the educational standards within the jurisdiction of the public agency that apply to all children. 34 C.F.R. Sec. 300.39(b)(3).

Child with a disability is defined as a child evaluated in accordance with §§ 300.304 through 300.311 as having mental retardation, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), a serious emotional disturbance (referred to in this part as “emotional disturbance”), an orthopedic impairment, autism, traumatic brain injury, an other health impairment, a specific learning disability, deaf-blindness, or multiple disabilities, and who, by reason thereof, needs special education and related services. 34 C.F.R. Sec. 300.8

Student with a disability—A child of school age who meets the criteria in 34 CFR 300.8 (relating to child with a disability). 22 PA Code Section 14.101 (definitions)

Related services are defined as supportive services as are required to assist a child with a disability to benefit from special education. 34 C.F.R. Sec. 300.34; essentially can be anything other than the care and treatment of a physician and a surgically implanted medical device, *Garret F. v. Cedar Rapids School District*, 526 U.S. 66 (1999). The IEP team must meet at least annually to review the student’s IEP.

TRANSITION PLANNING AND IEP DEVELOPMENT

In Pennsylvania, both districts and charters must start transition planning at the IEP meeting during the year in which the student will turn 14 or younger if the IEP team deems appropriate 22 PA Code Sec. 14.131(a)(5); 22 PA Code 711.41(b); 34 C.F.R 300.320(b) (provides for the younger age if determined appropriate by the IEP team).

a. Definition of Transition Planning

Transition Planning

The Individuals with Disabilities Education Act provides that transition planning is a “Coordinated set of activities for a child with a disability that-

(A) is designed to be within a results-orientated process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

(B) is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and

(C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and when appropriate, acquisition of daily living skills and functional vocational evaluation. See 20 U.S.C. Sec. 1401(34) (A)-(C)

The IDEA implementing regulations provide at 300.320(b) provide that the transition services must include appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and where appropriate, independent living skills; and the transition services - including courses of study) needed to assist the child in reaching those goals.

Pennsylvania 22 PA Code Sec 711.3(b)(8) incorporates by reference the IDEA requirements related to transition to adult life see 34 CFR 300.43, and 711.41 reiterates this obligation. At this point, the only difference between obligations between charters and districts is that 711 does not require charters to have transition coordinators (as district are required, compare 22 PA Code 14.131(b)).

TRANSITION PROVISIONS IN THE IDEA

20 U.S.C. § 1401(34)

(34) Transition services

The term “transition services” means a coordinated set of activities for a child with a disability that--

(A) is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

(B) is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and

(C) includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation.

20 U.S.C. § 1414(d)

(d) Individualized education programs

(1) Definitions

In this chapter:

(A) Individualized education program

(i) In general

The term “individualized education program” or “IEP” means a written statement for each child with a disability that is developed, reviewed, and revised in accordance with this section and that includes--

(VIII) beginning not later than the first IEP to be in effect when the child is 16, and updated annually thereafter--

(aa) appropriate measurable postsecondary goals based upon age appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills;

(bb) the transition services (including courses of study) needed to assist the child in reaching those goals; and

(cc) beginning not later than 1 year before the child reaches the age of majority under State law, a statement that the child has been informed of the child's rights under this chapter, if any, that will transfer to the child on reaching the age of majority under section 1415(m) of this title.

(6) Failure to meet transition objectives

If a participating agency, other than the local educational agency, fails to provide the transition services described in the IEP in accordance with paragraph (1)(A)(i)(VIII), the local educational agency shall reconvene the IEP Team to identify alternative strategies to meet the transition objectives for the child set out in the IEP.

TRANSITION PROVISIONS IN THE FEDERAL REGULATIONS

34 C.F.R. § 300.43

(a) Transition services means a coordinated set of activities for a child with a disability that--

(1) Is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child's movement from school to post-school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;

(2) Is based on the individual child's needs, taking into account the child's strengths, preferences, and interests; and includes--

(i) Instruction;

(ii) Related services;

(iii) Community experiences;

(iv) The development of employment and other post-school adult living objectives; and

(v) If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation.

(b) Transition services for children with disabilities may be special education, if provided as specially designed instruction, or a related service, if required to assist a child with a disability to benefit from special education.

34 C.F.R. § 300.321(b)

(b) Transition services participants.

(1) In accordance with paragraph (a)(7) of this section, the public agency must invite a child with a disability to attend the child's IEP Team meeting if a purpose of the meeting will be the consideration of the postsecondary goals for the child and the transition services needed to assist the child in reaching those goals under § 300.320(b).

(2) If the child does not attend the IEP Team meeting, the public agency must take other steps to ensure that the child's preferences and interests are considered.

(3) To the extent appropriate, with the consent of the parents or a child who has reached the age of majority, in implementing the requirements of paragraph (b)(1) of this section, the public agency must invite a representative of any participating agency that is likely to be responsible for providing or paying for transition services.

34 C.F.R. § 300.322(b)(2)

(b) Information provided to parents.

(2) For a child with a disability beginning not later than the first IEP to be in effect when the child turns 16, or younger if determined appropriate by the IEP Team, the notice also must--

(i) Indicate--

(A) That a purpose of the meeting will be the consideration of the postsecondary goals and transition services for the child, in accordance with § 300.320(b); and

(B) That the agency will invite the student; and

(ii) Identify any other agency that will be invited to send a representative.

PENNSYLVANIA INDIVIDUALIZED EDUCATION PROGRAM (IEP) FORM – TRANSITION SERVICES SECTION

II. PRESENT LEVELS OF ACADEMIC ACHIEVEMENT AND FUNCTIONAL PERFORMANCE

Include the following information related to the student:

- Present levels of academic achievement (e.g., most recent evaluation of the student, results of formative assessments, curriculum-based assessments, transition assessments, progress toward current goals)
- Present levels of functional performance (e.g., results from a functional behavioral assessment, results of ecological assessments, progress toward current goals)
- Present levels related to current postsecondary transition goals if the student's age is 14 or younger if determined appropriate by the IEP team (e.g., results of formative assessments, curriculum-based assessments, progress toward current goals)
- Parental concerns for enhancing the education of the student
- How the student's disability affects involvement and progress in the general education curriculum
- Strengths
- Academic, developmental, and functional needs related to student's disability

III. TRANSITION SERVICES - This is required for students age 14 or younger if determined appropriate by the IEP team. If the student does not attend the IEP meeting, the school must take other steps to ensure that the student's preferences and interests are considered. Transition services are a coordinated set of activities for a student with a disability that is designed to be within a results oriented process, that is focused on improving the academic and functional achievement of the student with a disability to facilitate the student's movement from school to post school activities, including postsecondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation that is based on the individual student's needs taking into account the student's strengths, preferences, and interests.

POST SCHOOL GOALS - Based on age appropriate assessment, define and project the appropriate measurable postsecondary goals that address education and training, employment, and as needed, independent living. Under each area, list the services/activities and courses of study that support that goal. Include for each service/activity the location, frequency, projected beginning date, anticipated duration, and person/agency responsible.

For students in Career and Technology Centers, CIP Code:

Postsecondary Education and Training Goal:					Measurable Annual Goal Yes/No (Document in Section V)
Courses of Study:					
Service/Activity	Location	Frequency	Projected Beginning Date	Anticipated Duration	Person(s)/Agency Responsible
Employment Goal:					Measurable Annual Goal Yes/No (Document in Section V)
Courses of Study:					
Service/Activity	Location	Frequency	Projected Beginning Date	Anticipated Duration	Person(s)/Agency Responsible
Independent Living Goal, if appropriate:					Measurable Annual Goal Yes/No (Document in Section V)
Courses of Study:					
Service/Activity	Location	Frequency	Projected Beginning Date	Anticipated Duration	Person(s)/Agency Responsible

Transition 7

WHAT IS SELF-ADVOCACY?

Self-advocacy refers to:

an individual's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights. It involves making informed decisions and taking responsibility for those decisions. (VanReusen et al., 1994)

Self-knowledge is the first step toward advocating for your rights. You need to know your strengths, needs, and interests before you can begin to advocate.

TIPS FOR SELF-ADVOCACY

- Know and understand your rights and responsibilities
- Learn all you can about your disability, needs, strengths, and weaknesses
- Know what accommodations you need as well as why you need them
- Know how to effectively/assertively communicate your needs and preferences
- Find out who the key people are and how to contact them if necessary
- Be willing to ask questions when something is unclear or you need clarification

Kent State University's College of Education, Health, & Human Services
www.ehhs.kent.edu/cite/CASAP/docs/SADef+tips.doc

RESOURCES, LINKS AND PUBLICATIONS

Resources – College Bound Students

<http://autisticadvocacy.org/wp-content/uploads/2012/02/NavigatingCollegeHandbook-1.pdf>

College-Based Inclusion Programming for Transition-Aged Students with Autism

<http://foa.sagepub.com/content/25/3/151.abstract>

Video Self-Advocacy

http://www.youtube.com/watch?v=Y_dPZDcX_ck

Parent Guide to Special Education

<http://parent.pattan.net/files/parent/SchAgeParentGuide.pdf>

Parents' Rights

<http://www.pattan.net/files/Parent/ParentRights.pdf>

Is Your Child Having Difficulty in School?

<http://www.pattan.net/files/Parent/EffectCommBroch.pdf>

Pennsylvania Training and Technical Assistance Network (PaTTAN) www.pattan.net

You can access statutes and regulations as well as topical publications and training materials – look under —Secondary Transition.☐

Pennsylvania Autism Transition Handbook

http://www.autismhandbook.org/index.php/Main_Page

This website, published by Devereux through a grant from the PA Department of Education, contains extensive information regarding transitioning autistic students, including employment, health care, support services, financial planning, living in the community, and more.

Accommodations and Supports for Independent Living

<http://pattan.net-website.s3.amazonaws.com/files/materials/handouts/docs/Transit051210a.pdf>

Accommodations and Supports for Post-Secondary Education and Training

<http://pattan.net-website.s3.amazonaws.com/files/materials/handouts/docs/Transit041410.pdf>

Secondary Transition Directory

<http://pattan.net-website.s3.amazonaws.com/images/2011/05/14/ST-Directory.pdf>

Post Secondary Education and Training: Strategies for Success

[http://pattan.net-
website.s3.amazonaws.com/files/materials/handouts/docs/Trans033011.pdf](http://pattan.net-website.s3.amazonaws.com/files/materials/handouts/docs/Trans033011.pdf)

Parent Guide to Special Education

<http://parent.pattan.net/files/parent/SchAgeParentGuide.pdf>

Parents' Rights

<http://www.pattan.net/files/Parent/ParentRights.pdf>

Is Your Child Having Difficulty in School?

<http://www.pattan.net/files/Parent/EffectCommBroch.pdf>

Pennsylvania Training and Technical Assistance Network (PaTTAN)

www.pattan.net

In addition to obtaining the text of the Individuals with Disabilities Education Act (IDEA) and the Pennsylvania special education forms, you can access topical publications and training materials – look under “Secondary Transition.”

Pennsylvania Autism Transition Handbook

http://www.autismhandbook.org/index.php/Main_Page

This website, published by Devereaux through a grant from the the PA Department of Education, contains extensive information regarding transitioning autistic students, including employment, health care, support services, financial planning, living in the community, and more.

Education ABC's

<http://www.pattan.net/files/Bookmarks/EducationABCs.pdf>

This link will translate all of the special education acronyms.

Accommodations and Supports for Employment

[http://pattan.net-
website.s3.amazonaws.com/files/materials/handouts/docs/Transit042810.pdf](http://pattan.net-website.s3.amazonaws.com/files/materials/handouts/docs/Transit042810.pdf)

Accommodations and Supports for Independent Living

[http://pattan.net-
website.s3.amazonaws.com/files/materials/handouts/docs/Transit051210a.pdf](http://pattan.net-website.s3.amazonaws.com/files/materials/handouts/docs/Transit051210a.pdf)

Accommodations and Supports for Post-Secondary Education and Training

[http://pattan.net-
website.s3.amazonaws.com/files/materials/handouts/docs/Transit041410.pdf](http://pattan.net-website.s3.amazonaws.com/files/materials/handouts/docs/Transit041410.pdf)

Secondary Transition Directory

<http://pattan.net-website.s3.amazonaws.com/images/2011/05/14/ST-Directory.pdf>

Post Secondary Education and Training: Strategies for Success

[http://pattan.net-](http://pattan.net-website.s3.amazonaws.com/files/materials/handouts/docs/Trans033011.pdf)

[website.s3.amazonaws.com/files/materials/handouts/docs/Trans033011.pdf](http://pattan.net-website.s3.amazonaws.com/files/materials/handouts/docs/Trans033011.pdf)

Independent Living and Community Participation: Strategies for Success

[http://pattan.net-](http://pattan.net-website.s3.amazonaws.com/files/materials/handouts/docs/Transtn022411a.pdf)

[website.s3.amazonaws.com/files/materials/handouts/docs/Transtn022411a.pdf](http://pattan.net-website.s3.amazonaws.com/files/materials/handouts/docs/Transtn022411a.pdf)

PowerPoint from recent presentation – extremely informative section by PA Health Law Project – especially good description of different criteria for individuals with disabilities to access adult services in Pennsylvania – not limited to individuals with autism. Numerous links to housing, community living and work place sites.

Works for Me – Employment Solutions for People with Disabilities

www.worksforme-pa.org

One stop shopping for all employment resources In Pennsylvania– click on “Going from School to Work” tab.

Ansell Casey Life Skills Assessment

<http://www.caseylifeskills.org/> The student completes this assessment on-line and receives a profile. At this website there is also a list of resources that are free or not that expensive that may assist your client and the IEP team in planning for transition.

Independent Living Skills Assessment Tool

http://www.dshs.wa.gov/pdf/ms/forms/10_267.pdf This assessment is available on line and can form the basis of the assessment of independent living goal or it will rule out the need to address in an IEP it because the student has mastered all of the skills, OR will provide a framework for providing skills to be taught as part of the transition goal.

Transition Health Care Checklist: Transition to Adult Living in Pennsylvania

http://www.portal.state.pa.us/portal/server.pt/community/special_kids_network/14205/transition_health_care_checklist/558090

This transition checklist is contained within a really expansive publication by the Department of Health - the link to which you may want to provide to all parents of kids with IEPs whether they have ASD or some other disability.

The Learning Clinic's Transition & Independent Living Skill Assessment

<http://www.thelearningclinic.org/PDF/TILSAInstructionsandForm.pdf>

Another assessment that once completed is sent to the Learning Clinic for Scoring

Home and Community Based Services Transition to Community Living Self-Assessment

[http://www.hcbs.org/files/112/5587/Transition Guide to Community Living.pdf](http://www.hcbs.org/files/112/5587/Transition%20Guide%20to%20Community%20Living.pdf)

This is a document published in Louisiana (and thus has resources that may not be available in PA) but has good self-assessment tools related to community living.

Autism Speaks Family Services Transition Tool Kit

http://www.autismspeaks.org/docs/family_services_docs/transition.pdf

It appears that everyone who is anyone in the field of autism has contributed to this brand new publication. It has a family friendly format.

Life Journey Through Autism: Guide for Transition to Adulthood

<http://www.researchautism.org/resources/reading/documents/transitionguide.pdf>

The Organization of Autism Research (“OAR”) published its first guidebook titled *Life Journey Through Autism: A Parent’s Guide to Research* which served as an introduction to the world of autism research for parents of children newly diagnosed with an autism spectrum disorder. OAR published two additional volumes in the *Life Journey Through Autism* series, *An Educator’s Guide to Autism* and *An Educator’s Guide to Asperger Syndrome*. This publication is described as “the next logical progression in this series, *A Guide for Transition to Adulthood*.”

Transition to Community Living Self-Assessment,

[http://www.hcbs.org/files/112/5587/Transition Guide to Community Living.pdf](http://www.hcbs.org/files/112/5587/Transition%20Guide%20to%20Community%20Living.pdf)

Functional Behavioral Assessment,

<http://cecp.air.org/fba/>

North Central Regional Resource Center’s List of Assessments

<http://www.transitionassessment.northcentralrrc.org/methodsTools.aspx>

Quickbook of Transition Assessments

<http://doe.sd.gov/oess/specialed/forms/tacklebox/docs/tb07/QuickbookIEP%20Checklist%20Final.pdf>

Autism Handbook

<http://www.autismhandbook.org/index.php/Recreation>

Self Determination Housing Project of PA

www.sdhp.org

877-550-7347

Pennsylvania Housing Finance Agency

www.phfa.org

Resources for apartment locator and homeownership

PA Health Law Project

www.phlp.org

800-274-3258

Residential Living Options (rental toolkit)

www.residentiallivingoption.org

610-701-9301

Pennsylvania Assistive Technology Foundation:

Low-interest loans and information about other funding resources.

www.patf.us

888-744-1938.

Renovate and Repair (a program of PHFA):

Marisa Shull, 717-780-4034 (limited state dollars)

PA Accessible Housing Program

Department of Community and Economic Development) contact: SDHP, www.sdhp.org

877-550-7347

www.autisonline.org

Good resource for young adults with ASD. Site addresses sexuality issue – caveat when using for transition planning for school aged students because as of print date Pennsylvania has not approved a sex education curriculum.

Adult Autism and Employment.

<http://www.dps.missouri.edu/Autism/Adult%20Autism%20&%20Employment.pdf>

A guide for vocational rehabilitative professionals – but an excellent resource for planning for employment for a transitioning young adult. Excellent section on experiential descriptions that will provide framework for developing workplace accommodations for individuals with ASD.

Quality of Life Framework for Special Education Outcomes

Turnbull, Turnbull, Wehmeyer and Park, *Remedial and Special Education*, Volume 24, Number 3, March/April 2003, 67-74

Description of linking IDEA goals to quality of life outcomes.

http://kuscholarworks.ku.edu/dspace/bitstream/1808/5928/1/DP10_A%20quality%20of%20life%20framework.pdf

The Commonwealth of Pennsylvania's Approaches to Financing Autism Services: Medical Assistance and Mandated Benefits

Pennsylvania Medicaid Policy Center University of Pittsburgh (Costlow and Love 2008)

http://www.house.state.pa.us/SpkrJournal/documents/8/v8_a6.pdf

Creating a Successful College Experience

Powerpoint Presentation at 2010 PSU Autism Conference by Janet E. Graetz, Ph.D., Associate Profession of Oakland University provides data related to experience of college students with ASD

http://www.outreach.psu.edu/programs/autism/files/session_58-67.pdf

Transition From School to Adult Life: Procedure Manual

Addresses transition needs of individuals with all disabilities but of particular benefit to addressing the needs of all individuals across the spectrum of needs from minimal to severe disabilities in the transition process.

http://www.outreach.psu.edu/programs/autism/files/session21and30_mcdowell.pdf

Pennsylvania Transition Directory

This publication provides a list of transition contacts by Intermediate Unit, school district and charter school.

<http://pattan.net-website.s3.amazonaws.com/images/2011/05/14/ST-Directory.pdf>

National Longitudinal Transition Study-2 (NLTS2)

http://www.nlts2.org/data_tables/datatable_training.html

NLTS2 began updating and expanding data on youth with disabilities in 2001, including information on employment. The following are publications based upon this data collection:

The Post-High School Outcome of Young Adults with Disabilities up to 8 Years After High School (September 2011)

http://www.nlts2.org/reports/2011_09_02/index.html

Secondary School Programs and Performance of Students With Disabilities (November 2011)

http://www.nlts2.org/reports/2011_11/index.html

Youth Employment Study

<http://www.ncset.org/publications/viewdesc.asp?id=1310>

Secondary School Experiences of Students with Autism (NLTS-2 2007)

<http://ies.ed.gov/ncser/pdf/20073005.pdf>

Life Journey Through Autism: A Guide to Transition to Adulthood

<http://www.researchautism.org/resources/reading/documents/transitionguide.pdf>

Travel Training for Youth with Disabilities

<http://nichcy.org/wp-content/uploads/docs/ts9.pdf>

College Success Skills – Palomar College Library

Go to <http://www.palomar.edu/library/subjects/collegesuccess.htm#time>

Click links for:

Distance Learning

- [Distance Learning at Palomar College](#)
- [Center for Independent Learning](#)

Goal Setting

- [Goal Setting](#) (Brookhaven College)
- [Motivation and Goal Setting](#) (Cuesta College)

Learning Styles

- [Concepts of Learning](#) (Bucks County Community College)
- [Index of Learning Styles](#) (North Carolina State U.)
- [Life Colors](#)
- [Master Teacher Program: On Learning Styles](#) (Georgia State U.)
- [VARK - A Guide to Learning Styles](#)

Listening Skills

- [Listening Skills](#) (U. of Minnesota Duluth, Student Handbook)
- [How to Develop Effective Listening Skills](#) (Capital Community College)
- [Listening Skills](#) (Texas A&M U., Student Counseling Service)

Memory

- [Remembering](#) (Virginia Tech., Cook Counseling Center)
- [Exploratorium: Playing Games with Memory](#)
- [Memorize Anything Using a Study Stack](#)

Note-Taking Skills

- [Cornell Note Taking](#)
- [Note-Taking Skills](#) (Sweet Briar College, Academic Resource Center)

Test-Taking Skills

- [Making the A: How to Study for Tests](#) (ERIC Digests)
- [Preparation for a Successful Exam Day](#) (Southwestern U.)
- [Test Preparation and Test-Taking Skills](#) (Purdue U., Center for Academic Success)

Time Management

- [Time Management](#) (U. of Chicago)
- [Time Management Strategies](#) (CalPoly, Academic Skills Center)

Writing

- [Improving Your Writing Style](#) (U. of North Carolina Chapel Hill, Writing Center)
- [Writing About History](#) (UToronto)
- [Spanish Writing Guide](#) (Sweet Briar College)

Search also [English & Writing](#)

- [Study Guides and Strategies](#)
- [Study Skills](#) (U. of Chicago, Virtual Pamphlet Collection)

DSM-V: PROPOSED REVISION AUTISM SPECTRUM DISORDER

*Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association)
Revised January 26, 2011 anticipated release date MAY 2013)*

Must meet criteria A, B, C, and D:

- A. Persistent deficits in social communication and social interaction across contexts, not accounted for by general developmental delays, and manifest by all 3 of the following:
 - 1. Deficits in social-emotional reciprocity; ranging from abnormal social approach and failure of normal back and forth conversation through reduced sharing of interests, emotions, and affect and response to total lack of initiation of social interaction,
 - 2. Deficits in nonverbal communicative behaviors used for social interaction; ranging from poorly integrated- verbal and nonverbal communication, through abnormalities in eye contact and body-language, or deficits in understanding and use of nonverbal communication, to total lack of facial expression or gestures.
 - 3. Deficits in developing and maintaining relationships, appropriate to developmental level (beyond those with caregivers); ranging from difficulties adjusting behavior to suit different social contexts through difficulties in sharing imaginative play and in making friends to an apparent absence of interest in people
- B. Restricted, repetitive patterns of behavior, interests, or activities as manifested by at least two of the following:
 - 1. Stereotyped or repetitive speech, motor movements, or use of objects; (such as simple motor stereotypies, echolalia, repetitive use of objects, or idiosyncratic phrases).
 - 2. Excessive adherence to routines, ritualized patterns of verbal or nonverbal behavior, or excessive resistance to change; (such as motoric rituals, insistence on same route or food, repetitive questioning or extreme distress at small changes).
 - 3. Highly restricted, fixated interests that are abnormal in intensity or focus; (such as strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
 - 4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of environment; (such as apparent indifference to pain/heat/cold, adverse response to specific sounds or textures, excessive smelling or touching of objects, fascination with lights or spinning objects).
- C. Symptoms must be present in early childhood (but may not become fully manifest until social demands exceed limited capacities)
- D. Symptoms together limit and impair everyday functioning.

Person Centered Transition Planning
Quality of Life Framework – Schalock, R.L. & Verdugo, M.A. (2002)

Factor	Domain	Exemplary Indicators
Independence	1. Personal Development The things that individuals are interested in learning about, and things that they enjoy and are important to them.	Personal Skill Adaptive Behaviors
	2. Self-Determination The choices and decisions individuals make about areas that matter to them in their life.	Choices Decisions Autonomy Control
Social Participation	3. Interpersonal Relationships Type of support and help individuals get, relationships with family and friends, and the types of activities that individuals do with people in their life.	Social Networks Friendships Social Activities
	4. Social Inclusion The activities and things individuals do and would like to do in the community, the people individuals do things with and places they go in their community.	Involvement in Community Community Roles
	5. Rights Individuals' right to privacy, how individuals are treated by people, how much individuals are listened to.	Equal Opportunities Respectful Treatment Legal Access and Due Process
Well-Being	6. Emotional Well-Being Happiness and safety, and how individuals feel about their life.	Safety and Security Positive Experiences Success
	7. Physical Well-Being Energy levels, being able to get medical help, health and lifestyle.	Health and Nutritional Status Recreation Physical Exertion
	8. Material Well-Being Personal possessions that are important to individuals, how much individuals can use money for things they want or need.	Income Possessions

Program Gaps for Transitioning Students and Adults with ASD

The following are significant program gaps in the current system as identified in the *Pennsylvania Autism Census* (Pennsylvania Autism Census Project, October 2009. Lawer and Mandell).¹

- The need for high level planning for the thousands of children with ASD who will transition into adulthood in the near future;
- The need for planning for the housing requirements for the growing population of adults with ASD;
- The need for cross systems coordination;
- The need for consistent data collection methods;
- The continued need to increase the capacity of professionals to evaluate, diagnose, educate and provide services.

According to the 2009 Pennsylvania Census, in 2005 there were close to 20,000 Pennsylvanians living with autism. Given trends, that number is expected to rise to at least 25,000 by 2010. The report also illustrates that **the number of adults with autism will increase dramatically in the near future, growing by 179% to more than 3,800 in 2010 and to more than 10,000 by 2014.**

Based upon the *Statewide Needs Assessment -- Preliminary Results* (Mandell PA Bureau of Autism 2010)²;

- Caregiver workforce changes – such as leaving job, decreased hours, lost promotion or termination - were reported by 70% of the parent respondents; alarmingly only 50% of the spouse of the respondent reported that they had no workforce change.
- As individuals with ASD age, significant increases in the incidences of emergency room visits and hospitalizations are reported. Over 10% of the post high school individuals with ASD reported emergency room visits and 8% reported hospitalizations as compared to the elementary age population of which 4% reported an emergency room visit and 3% reported hospitalizations.
- A staggering 25% of post high school-aged individuals with ASD report disciplinary police contact.

¹Go to http://bastraining.tiu11.org/file.php/56/PA_Autism_Census_Project.pdf to obtain a copy of this report.

² August 26, 2010 Statewide Needs Assessment – Preliminary Results (Mandell 2010). To obtain a copy of this report, go to the PA Bureau of Autism Website at http://bastraining.tiu11.org/file.php/92/Needs_assessment_webcast_08-26-10_1_.ppt.

- Significant unmet need for mental healthcare exists in the majority of the counties in Pennsylvania.
- Based upon caretaker report, 74% of adults with ASD in Pennsylvania reside at home with their parents; 11% live in group homes; and 7% live on their own with or without support.
- Of the reporting adults with ASD, 9% were employed full-time; 26% were employed part-time; and 21% were actively seeking employment; and 44% of those reporting were not employed and were not seeking employment.

This autism epidemic similarly impacts all parts of the United States. In 2006, the Centers for Disease Control and Prevention (CDC) reported the prevalence of autism in the US among 8 year-olds to be about 1 in 110. See Centers for Disease Control and Prevention (CDC), *Prevalence of Autism Spectrum Disorders—Autism and Developmental Disabilities Monitoring Network, United States, 2006*. MMWR Surveillance Summaries 2009;58(SS-10). The Easter Seals’ “Living with Autism” 2010 study confirms that the finding of the Pennsylvania Autism studies have nationwide applicability and highlights some of the primary issues that families of adult children with ASD face.³ According to the Easter Seals Study, nearly two-thirds (62%) of the adult children with a disability in the US have some form of an Autism Spectrum Disorder (ASD), *Id.* at 10.⁴

³ The study consisted of a 100-question multiple-choice online survey that was completed by 1,652 parents of children with ASD aged 30 or younger. An additional 917 parents of children without any special needs age 30 or younger also completed surveys and were included as a point of reference and comparison. The surveys were completed between June 16 and July 17, 2008, and the data was demographically weighted to achieve a representation of the U.S. population.

⁴ Go to http://www.easterseals.com/site/DocServer/Study_FINAL_Harris_12.4.08_Compressed.pdf?docID=83143 to download a copy of this report.

WHAT POSITIVE OR NEGATIVE IMPACT DOES AUTISM HAVE ON ADULT LIFE ACTIVITIES?

List individual's strengths and challenges related to accessing the following:

COMMUNITY LIVING

POST SECONDARY
EDUCATION/TRAINING

EMPLOYMENT

INDEPENDENT LIVING