

**The Challenges that Confront Teens with High Functioning Autism & Asperger's as They Transition to Young Adulthood: What Every Parent, Educator & Clinician Should Know**

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What we have learned along the way



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Areas of concern for young people with Asperger's & HFA

Personal, college & workplace relationships

Skills for Safety & Independence

Earning a Living  
College/Work  
Job Routes

Fun & Contribution

Living  
Arrangements

Health and  
Mental Health

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## Easter Seals' Living with Autism Study

[www.actforautism.org](http://www.actforautism.org)

**Population Studied**  
Parents of a child age 30 or less who either has ASD OR does not have any special needs

**Survey conducted online**  
June 16 - July 17, 2008.  
Email invitations sent by Harris Poll Online, Easter Seals, or the Autism Society of America

**Sample Size:**  
2969 surveys were collected  
927 parents with children age 30 or younger without any special needs  
1653 parents with children age 30 or younger with ASD

**Weighting:** Data was weighted to be representative of the U.S. population on the basis of age by gender, education, region, household income, and race/ethnicity, and propensity to join an online panel.

**Significance testing at 95% level of confidence:**  
Circles indicate numbers significantly higher in the parents with children with ASD than the general population.

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## Objectives of the Study

Identify financial needs for families with special needs and uncover ways for Easter Seals & Mass Mutual to address these needs

Support the need for additional funding/resources in:  
School to work transitions  
Employer support  
Residential and community support  
Financial planning

Call attention to the ongoing and critical lifetime challenges of people living with autism

Assist service providers in their roles of providing assistance

Understand how parents and care givers prefer to access information

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## Living with Autism Study: Worried about the Future

Percentage Extremely concerned or Very concerned

	Parents of Typical Children	Parents of Children w ASD
Independence	28 %	79 %
Financial well-being	42 %	78 %
Quality of life	38 %	78 %
Employment	35 %	76 %
Housing needs	30 %	71 %
Education	36 %	70 %
Health	34 %	50 %
Longevity of life	29 %	41 %

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**% of Parents Who Agree with Statements –**  
**“My child will...” (Very strongly agree/Strongly agree)**

	Parents of Typical Children	Parents of Children w ASD
Have the ability to make his/her own life decisions	65%	14%
Have friends in the community who shares interests	57%	17%
Have a spouse or life-partner	51%	9%
Be valued by his/her community	50%	18%
Regularly participate in recreational activities	50%	20%
Have a strong religious affiliation	36%	19%
Have developed age-appropriate recreation and leisure skills –		16%

*Living with Autism Study:*  
Worried about their children  
fitting into society

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**Education**

*“What happens after high school? We have fallen into a black hole. Everything stopped and now we are on our own.”*

*“What resources are available after our child ages out of the educational system? How will we best fill our child’s life after he is finished with school? Are there adult support services when he no longer qualifies for school related educational services at age 21?”*

\*Samples of verbatim comments shared by survey participants ***Living with Autism Study***

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**College?**

- Not even half (46%) of parents with children with some type of Autism Spectrum Disorder expect their children to receive education beyond a high school diploma.
- However, among children with Asperger’s, 70% are thought of as college-bound by their parents.

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## Information needed

Parents living with ASD would like to receive life skills training for their children, emotional and stress training for their families and financial training for themselves.

Among parents of children with Asperger's, many expressed that **information resources for high-functioning children with Autism Spectrum Disorder just does not exist.**

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## Asperger's & HFA: Caught in the middle

*"Everyone seems to think that since my daughter is high functional, that I don't need the help."*

*"I cannot find help for an adult (18 yrs old) w/ PDD-NOS for things like Life Skills or job skills training. There's help for people with severe disabilities, but not for people with High Functioning Autism."*

*"How to navigate through the educational and government systems, receive services with a high-functioning autistic child, and be able to maintain our standard of living without draining every financial resource we have."*

*"If a child is high functioning how can you get them the help they need if they do not qualify for benefits?"*

\*Samples of verbatim comments shared by survey participants

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## A meaningful Transition Plan: The key to the Future



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### The purpose of the Individuals with Disabilities Education Act (IDEA)

To “ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living.”

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### Why are transition services required?

Compared to their peers without disabilities, people with disabilities experience:

- Half the graduation rate
- Higher drop out rates (21% v. 10%)
- Lower college entrance/completion
- Lower employment (35% v. 78%)
- Higher dependency on public assistance
- Higher poverty rate (26% v. 9%)
- Lower life satisfaction rate (34% v. 61%)

(pages iv–v, *Transition to Adult Living*)

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### Definition of transition services in IDEA:

... a coordinated set of activities ... 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...**

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**Postsecondary goals** are what the student plans to do upon school exit.  
IDEA '04 requires...  
*“appropriate, measurable post-secondary goals based on age-appropriate assessments related to training, education, employment, and, where appropriate, independent living skills.”*

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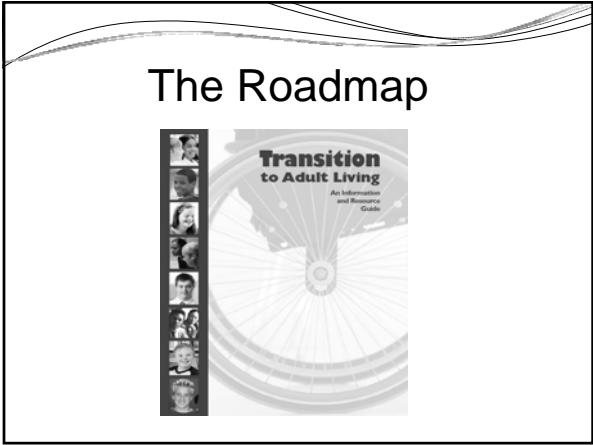
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**Transition to Adult Living:  
An Information and Resource Guide**  
2007, California Department of Education

- Developed by California Services for Technical Assistance and Training (CalSTAT) through a contract with the California Department of Education, Special Education Division
- Supports schools, districts, and special education local plan areas in the implementation of the secondary transition requirements of the IDEA '04
- A resource to improve post-school outcomes for students with disabilities

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**The Transition IEP:  
A Foundation for Secondary Transition**

**Four Step IEP Process**

1. Identify student's post-school goals
2. Determine present levels of performance
3. Develop annual goals to support post-school goals
4. Identify needed transition services

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**National Standards & Quality Indicators for  
Secondary Education and Transition**

- *Schooling*  
School- and work-based instruction
- *Career preparatory experiences*  
Career awareness, assessment, and preparation
- *Youth development and leadership*  
Self awareness and self advocacy
- *Family involvement*  
Meaningful family participation
- *Connecting activities*  
Connection to post-school options and resources

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**Preparatory Experiences & Student Development**

**Self Awareness**

- Decision about high school
- Interest inventories
- Self esteem
- Interpersonal skills

**Career Awareness**

- Connecting school to careers
- Online career exploration
- Job shadowing
- Guest speakers

**Career Preparation**

- Applications/résumés
- Interview skills
- Punctuality and appearance
- Working in teams

**Work Experience**

- ROP
- WorkAbility
- Work experience
- Internships

**Independent Living**

- Community access
- Travel training
- Health, housing, recreation

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## Transition to Adult Living: An Information and Resource Guide: Appendices

- A. Transition-Related Legal References OSEP
- B. Comparison of IDEA '97 and '04
- C. National Standards for Secondary Education and Transition
- D. System Assessment and Action Plan Tool
- E. Transition-Related Assessments
- F. Sample Transition Goals
- G. Agencies that Support Transition
- H. Students Not Passing Exit Exam
- I. CDE Letter about Graduation Ceremony Participation for Certificate students
- J. Transition-Related Web sites
- K. Transition-Related Curricula
- L. Guide to Acronyms Used

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## Transition to Adult Living: An Information and Resource Guide

Hard copies are available free of charge:

Mail:

NCOE-WEST/CalSTAT

Attn: Transition Guide Request

5789 State Farm Drive

Rohnert Park, CA 94928

Email: [publications@calstat.org](mailto:publications@calstat.org)

The guide is also available in an interactive PDF at:

[www.calstat.org/transitionGuide.html](http://www.calstat.org/transitionGuide.html)

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Ready or not, here they come!  
Insider tips to improve outcomes



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## Tip/Warning #1



### A Diploma is an EXIT DOCUMENT

- “A student’s eligibility for a free and appropriate public education (F.A.P.E.) ceases upon graduation from high school with a regular diploma”
- “When a student graduates and receives a regular high school diploma, she/he is no longer eligible for special education services.”

[http://www.accessmaine.org/Toolkits/GuideforFamilies/guide\\_transplan\\_speced.htm](http://www.accessmaine.org/Toolkits/GuideforFamilies/guide_transplan_speced.htm)

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## Ready to go at 17 or 18?

- A student who is 17 or 18 years old and is not ready for post school learning, a job, or independent living may need additional years of education.
- Beware of the DIPLOMA TRACK!

Special Education Certificate of Attendance - Does it End Special Education Services? By JoAnn Collins  
<http://ezinearticles.com/?Special-Education-Certificate-of-Attendance>

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## Prepared for post-secondary education?

- Students with ASD don’t have to leave school until the age of 22
  - This does NOT mean staying on a high school campus!
- Plan to continue at their own pace, and take the time they need
- There are programs for adults
- Focus on key skills



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### Consider the Skills of the Future Workforce

- Read and do math at the 9<sup>th</sup> grade level or above.
- Work in a group with diverse people
- Be able to communicate orally and in writing



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### Skills of the future workforce



- Use a computer for simple tasks, like word processing
- Resolve semi-structured problems in which a hypothesis is formulated and tested.

From *Teaching the New Basic Skills: Principles for Educating Children to Thrive in a Changing Economy* by Richard J. Murnane (1996)

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### Reading Comprehension:

An active process of synthesis and integration

- Pattern of hyperlexia seen in HFA & Aspergers masks
- Testing well on standardized tests vs. understanding at a post-high school level
- Inference, prediction, perspectives (imagination)
- Main idea and supporting details
- Sequencing and retelling events
- Writing about what was read

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## Comprehension Issues Relate to ASD

- Oral language development
- Vocabulary
- Multiple meanings of words
- Abstract ideas
- Fund of general knowledge- relating what is read to experience and understanding...
- Being able to write at the college level or for work
  
- Coming soon, *Drawing A Blank* from Autism Asperger Publishing Company

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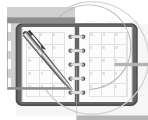
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## Executive Function – how to Organize and plan (things, work, time)

- Organize oneself
- Perceive the order in the world
- Focus on important things
- Shift focus from one thing to another
- Plan use of time
- Get started
- Go step by step to finish



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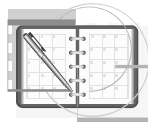
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## Accommodations & Modifications may be needed in higher education or the workplace

- Use visual strategies
- Write it down
- Make schedules
- Give one step or instruction at a time
- Teach how to break down something big into steps
- Know how and when to start and when he or she is finished.



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## Adult Social and Pragmatic Skills

- How to get a date
- Who likes you and who does not want your attention
- How to tell your professor/boss you don't like something
- Looking the part to fit in
- Living with others
- What people expect from you
- Empathy and perspective-taking
- Dealing with rejection, disappointment, "injustices"

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## Vocational skills (work)

- Make the connection with interests and talents for making a living
- See (not imagine) the options
- Find opportunities to visit and practice
- Access supports if they are needed



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## System for motivation

Things that don't make sense are not interesting  
Things that motivate many people may not motivate a person with autism  
Unexpected things may be motivating  
Be consistent and generous because they are working hard to do something that is easy for others



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## System for motivation

It is not that they REFUSE  
Many times they CANNOT  
Sometimes they don't know HOW to do something  
or get started

Help create supports and systems for independence..  
Can he or she do it on their own using a list? Teach  
Read and Do!

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## Life Centered Career Education

Robert J. Loyd & Donn E. Brolin

**Parents often overlook functional and practical skills  
when advocating for their child's education.**

LCCE- Skills inventory



Goals and Curriculum

- Activities of daily living
- Personal and social skills
- Work skills

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Tip # 2 There is only 1 Law  
Promote Safe Behaviors &  
Understanding



[calbar.ca.gov](http://calbar.ca.gov)

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## www.CLEARscv.org

Replace all dangerous behaviors

- Change or replace all behaviors that can be interpreted as dangerous or criminal
- Seek help from specialists
- Use rules

On our website:

- IEP Goals for 10 Essential Skills
- Focus on teen/ young adult issues like safe behaviors, boundaries, weapons, etc.

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## Teach strategies to resolve problems

- Think, plan and practice in advance
- Take perspective
- Tools for repair
- Narrate and explain our own actions and thought in the moment



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## Additional Transition Goals

- Behavior Plan for problem and dangerous behavior
- Behavior Plan to motivate
- Occupational Therapy for regulation and self control



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**Tip #2**

**Community College During High School:  
Dual Enrollment is Fabulous!**

- It is FREE to high school students
- Earn high school **and** college credits
- Take placement exams
- Enroll in Disabled Student Services (priority registration, accommodations, advocacy, etc.)
- Familiarity aids transition
- Vocational and degree programs available
- Learn about generic community college resources

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**Tip #3**

**Community college after HS**

- Completion of guaranteed transfer programs
  - No SATs,
  - No college entrance exams
  - Admission as a junior (3<sup>rd</sup> year student) to Cal State or UC schools that are not impacted
- Disabled Student Services: use accommodations
- Release form needed for parental involvement

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**Tip # 4**

**Students make decisions about the IEP &  
sign agreement once they turn 18**

- You must ask your student to share their educational rights with you and put it in writing!
- Prepare in advance.
- Help the student understand the IEP before they are responsible for it (start early)

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**Tip # 5**  
**Self-Advocacy and Self-Disclosure**

- Why it matters
- Calendar age vs. Maturity
- Section 504 plans
- Start today

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**Self Disclosure**

- To access the protections and supports provided by the Americans with Disabilities Act (ADA) of 1990 and Section 504 of the Rehabilitation Act of 1973, postsecondary students with disabilities must self-disclose the existence of their specific disability to the institution and provide supporting documentary evidence of a current substantial limitation to learning.
- In the workplace, it is both the right and the responsibility of an employee to self-disclose the existence of a disability to an employer in order to receive workplace accommodations.

Employment self-disclosure of postsecondary graduates with learning disabilities: rates and rationales. (Abstract). Journal of Learning Disabilities, July, 2002 by Foley, Teresa E.; Madaus, Joseph W.; McGuire, Joan M.; Ruban, Lilia M.

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**Build Self-Advocacy Skills**

“Self-Advocacy is learning how to speak up for yourself, making your own decisions about your own life, learning how to get information so that you can understand things that are of interest to you, finding out who will support you in your journey, knowing your rights and responsibilities, problem solving, listening and learning, reaching out to others when you need help and friendship, and learning about self-determination.”

<http://www.wrightslaw.com/info/self.advocacy.htm>

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**Tip #6**

**Adult services are “discretionary”**

- When FAPE ends, there is no entitlement to adult services
- There are no guarantees for admission or eligibility to adult services or programs
- The only exception is Regional Center eligibility, but Regional Center vendors can take you or leave you!

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**Tip # 7 Department of Rehabilitation  
aka “Department of Rehab”**

“The California Department of Rehabilitation works in partnership with consumers and other stakeholders to provide services and advocacy resulting in employment, independent living and equality for individuals with disabilities.”

<http://www.rehab.cahwnet.gov/>

- Assistance with career choices
- Potential to pay for tuition, books,
- May even pay parking if student takes night classes

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**Tip # 8:**

**Health Insurance Eligibility**

- Family coverage usually ends when the person turns 21 or is not a full time student
- Full time students in college must carry 12 credit hours- which can be too much for many students
- Exceptions CAN be made
- Family members can apply for disability status on family insurance- which is permanent (main criteria: receive SSI)
- Regional Center clients can get Medi-Cal insurance through the waiver program BUT

...Must apply and get it before age 18 or become ineligible!

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**Focus on Mental Health & Emotional Well-Being**

- Self-esteem
- Anxiety
- Depression
- Meds?
- AB3632 Mental Health Services
- Support groups

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**To contact me**

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[www.asdatoz.com](http://www.asdatoz.com)

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<p style="text-align: center;"><b>AUTISM SPECTRUM DISORDERS</b> <i>from A to Z</i></p>  <p style="text-align: center;"><b>ASSESSMENT, DIAGNOSIS...&amp; MORE!</b></p> <p style="text-align: center; font-size: small;">Barbara T. Doyle, M.S. Emily Doyle Iland, B.A.</p>	<p style="text-align: center;"><b>LOS TRASTORNOS DEL ESPECTRO DE AUTISMO</b> <i>De la A a la Z</i></p>  <p style="text-align: center;"><b>TODA LA INFORMACIÓN QUE QUIERE</b></p> <p style="text-align: center; font-size: small;">Barbara T. Doyle, M.S. Emily Doyle Iland, B.A.</p>
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