Autism and Transition to Adulthood

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Autism and the Law
Cases, Statutes, and Materials
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What is Transition?
What is Transition?

- Childhood to Adulthood
- School to Out-of-School
- Diagnosed with Autism
- Into School
- Medicaid Recipient
- Working Environment
- Life with Parents
- Control Affairs
What Laws Govern Transition?

• Student - IDEA
• Housing – Fair Housing Act, State Law
• Legal Status – State Law
• Medicaid – Medicaid Act/Katie Beckett/TEFRA/EPSDT/State Law
• Employment – ADA
• Insurance – State Law, Mental Health Parity Act
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--

   a. Instruction;
   b. Related services;
   c. Community experiences;
   d. The development of employment and other post-school adult living objectives; and
   e. If appropriate, acquisition of daily living skills and provision of a functional vocational evaluation.

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.
States with Autism Insurance Reform

2001 - Indiana
2007 - South Carolina
2007 - Texas
2008 - Arizona
2008 - Florida
2008 - Louisiana
2008 - Pennsylvania
2008 - Illinois

2009 - Colorado
2009 - Nevada
2009 - Connecticut
2009 - Wisconsin
2009 - Montana
2009 - New Jersey
2009 - New Mexico

2010 - Maine
2010 - Kentucky
2010 - Kansas
2010 - Iowa
2010 - Vermont
2010 - Missouri
2010 - New Hampshire
2010 - Massachusetts

2011 - Arkansas
2011 - West Virginia
2011 - Virginia
2011 - Rhode Island
2011 - California
2011 - New York

2012 - Michigan
2012 - Alaska
2012 - Delaware
2013 - Minnesota
2013 - Oregon
2014 - Utah
2014 - Nebraska
2014 - Maryland
Housing Needs for Adults with Autism

http://vimeo.com/album/2176968/video/98068531
Educational Entitlements

The Individuals with Disabilities Education Act (IDEA) mandates a public education for all children and makes schools responsible for providing the supports and services to make this happen.
Transition

One of the goals of IDEA is for students to be prepared for employment and independent living.
Adult Services

Where you live and work. There is no entitlement system. Some services are provided through Medicaid Home and Community-based Services (HCBS)
What we know about housing – Survey results

SIS International Research

100 Phone surveys
- People with ASD
- Service Providers
- Families/Caregivers

10,000 online surveys responses
- 8700 from families/caregivers
- 400 response from people with ASD

AUTISM SPEAKS®
It’s time to listen.
Housing and Residential Supports Survey

The physical space
Six out of ten families believe a single family home would be most appropriate

Preferred Home Location
64% thought a suburban environment would be most appropriate

Eight in ten caregivers would like to live within an hour of the person with ASD
Survey results from Families and Caregivers

**Ideal Level of Support Needed**

- No support: 1%
- Less than a few hours per week: 12%
- A few hours per week: 13%
- Support throughout the day: 24%
- 24-hour support: 31%

*It's time to listen.*
Survey results from Families and Caregivers

Top Concerns about Securing Housing

- Treated with care and respect: 60%
- Paying for his/her home: 50%
- Paying for the support services he/she needs: 40%
- Not having continued support from caregivers: 30%
- Safety issues: 20%
Survey results from people with ASD

The physical space
Seven out of ten people – believe a single family home would be most appropriate

Preferred Home Location
55% thought a suburban environment would be most appropriate

Five in ten people with ASD would like to live within an hour of their families
Survey results from people with ASD

Current Level of Support Needed

- No support: 14%
- Less than a few hours per week: 38%
- A few hours per day: 18%
- Support throughout the day: 8%
- 24 hour support: 8%
Survey results for people with ASD

Top Concerns Related to Securing Housing

- Paying for my home: 90%
- Fear of social isolation: 30%
- Setting up/maintaining supports: 30%
- Not having continued care from family/caregivers: 30%
- Being treated with care and respect: 20%
- Paying for support services: 10%
Survey results – what have we learned?

- Demand for housing and support services far exceed the current supply. This will continue for the foreseeable future.

- More information and education is needed about funding streams.

- More options and choices for service provision must be available to meet the demand.

- Families are primarily concerned that their loved one’s practical and emotional needs are met. This concern outweighs their preference for the style and location of housing.
What are we doing?

Angela Lello, Director of Housing and Residential Supports

Leslie Long, Director Adult Services

Dave Kearon, Assistant Director Adult Services

Sarah Andrews, Coordinator Adults Services
Housing and Community Living: Understanding the Needs

- A System not Purposefully Built
  - Action is needed
  - Complexity creates barriers
  - Leadership is critical
  - It’s time to listen

AUTISM SPEAKS®
It’s time to listen.
Specific strategy for Housing and Community Living

- Federal
- State
- Family Focus

Housing and Community Living
Federal Objectives

- Further Relationships with CMS
- Establish Autism Speaks as a key congressional resource on Medicaid for individuals with ASD
- Work with Federal partners who have shared concerns
State Objectives

- Develop state-specific strategies
- Supplement and enhance existing advocacy
- Utilize key relationships with key policy makers to influence systems design
Family Focused Objectives

- Housing and Residential Tool Kit
- Housing Database
- LinkedIn Group
- Online course for direct support providers
Autism Votes

Medicaid Waiver outreach

- Idaho
- Indiana
- Iowa
- Georgia
- Louisiana
- South Carolina
- Massachusetts
Family Focused Objectives

Housing and Community Living Town Halls
Working Together
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Autism Speaks
Government Relations

- Headquartered in New York

Autism Speaks Government Relations
- Headquartered in D.C. at 1990 K Street
Thank You!
One person can make a difference, and everyone should try.
~John F. Kennedy

Never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it’s the only thing that ever has.
~ Margaret Mead