Transition from Pediatric to Adult Health Care – Challenges for Youth with Autism

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Connecticut Children’s Medical Center
Associate Professor of Pediatrics
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Objectives:

1. Distinguish developmental aspects of adolescence and young adulthood, as they influence health care.
   - Understand how ASD affects developmental accomplishments and health care transition.

2. Name barriers to successful health care transition.
   - Recognize disparities in HCT planning specific to youth with ASD.
   - Identify provider considerations specific for youth with ASD.

3. Describe self-care skills essential to health care transition.
Scope of the Problem:

- Over 30% of adolescents have at least 1 chronic illness or disability, and one-third of these conditions are moderate to severe.
  - Half have intellectual/developmental disabilities or significant mental health issues.
  - The other half have diseases such as asthma, cystic fibrosis, diabetes, or sickle cell disease.

90% of children with disabilities survive beyond 20 years of age; 500,000 transition from pediatric to adult health care each year.
Scope of the Problem:

Youth with autism spectrum disorders (ASD) are an important subgroup of YSHCN because of their increasing numbers, high level of service needs, cost, and societal impact.

Nearly 50% of individuals with ASD have a major coexisting condition that requires regular medical attention.
Terminology:

**Transfer**: an *event* characterized by the movement to a new health care setting, provider, or both.
**Terminology:**

**Transition:** a purposeful, planned *process* that provides comprehensive, developmentally appropriate health care in a coordinated and uninterrupted manner.

**Transfer:** an *event* characterized by the movement to a new health care setting, provider, or both.
A Consensus Statement on Health Care Transitions for Young Adults with Special Health Care Needs

- American Academy of Pediatrics
- American Academy of Family Physicians
- American College of Physicians
- American Society of Internal Medicine

- Pediatrics 110:1304-06; December 2002.
Consensus Statement Goal:

To ensure that by the year 2010 all physicians who provide primary or subspecialty care to young people with special health care needs

1) understand the rationale for transition from child-oriented to adult-oriented health care;

2) have the knowledge and skills to facilitate the process; and

3) know if, how, and when transfer of care is indicated.
Rationale:

A well-timed transition from child-oriented to adult-oriented health care allows young people to optimize their ability to assume adult roles and functions.

- Children receive optimal primary care in a medical practice experienced in the care of children.
- Adults benefit from receiving care from physicians who are trained and experienced in adult medicine.

- Pediatrics 110:1304-06; December 2002.
Maturation:

As teens mature to adulthood, they move to independent living, enter post-secondary education or an adult vocation, and develop adult relationships.

Individuals with ASD have difficulties with motor and sensory processing, use of social language, and maladaptive cognitive styles – all of which impact independent functioning.
Tasks of Young Adulthood:

- **All:** Leave home and learn to live with peers or a partner, start an occupation, manage a home, find a congenial social group, and assume civic responsibility.

- **ASD:** Face challenges with social engagement, friendships, and processing emotions in themselves and others.

- **YSHCN:** Can develop an irresponsible attitude to their health, a lack of understanding of their condition and of the effects of treatment, and failure to accept adult responsibilities.
Challenges for Youth with ASD:

• Deficits in social language (e.g., difficulty understanding metaphors) can interfere with ability to understand instructions

• Tendency to engage in “all or nothing” thinking patterns and difficulty generalizing information

• Limitations in planning and organization

Challenges for Youth with ASD:

• More likely to experience mental health conditions:
  • loneliness
  • anxiety
  • depression
  • symptoms of attention deficit-hyperactivity disorder
  • psychosis
  • symptoms of obsessive compulsive disorder

Challenges for Youth with ASD:

- Poorer general physical health than their typically developing peers
- Higher prevalence of:
  - gastrointestinal disorders
  - sleep problems
  - diabetes
  - obesity
  - seizures
  - autonomic nervous system differences
  - respiratory, skin, and food allergies
- Less likely to receive preventive care and more likely to end up in the emergency department.

Barriers to transitioning:

1. Pediatric provider(s)
2. Adult provider(s)
3. Patient and family
4. Timing
Barrier: Pediatric providers

• Have long-standing relationships with patients and families

• May believe that their knowledge and/or skills are preferable for the care of the chronic condition regardless of the patient’s age

• May be unfamiliar with community resources or lack the time/knowledge to effectively coordinate the transition process

• Patients and families may have more contact with subspecialists than PCPs
Barriers Affecting the Provision of Transition Support Services in Pediatric Practices

- Lack of primary adult providers
- Lack of adult specialists
- Lack of knowledge/links to adult community services
- Lack of insurance reimbursement for HCT services
- Lack of sufficient time to provide transition services
- Lack of pediatric staff skills in transition planning
- Difficulty in breaking bond with patient/family
- Lack of adolescent knowledge/skills to self advocate

For most
For some

% Responders

Barrier: Adult providers

- Few may be willing to care for young adults with chronic diseases
- Many have little training in management of traditionally childhood diseases
- Capitated reimbursement systems serve as a disincentive
- May lack support from the adult hospital or other subspecialists
Barrier: Patients and families

- Different practice styles
- May perceive transition as abandonment, especially if it occurs haphazardly or during a crisis
Health Care Transition Skill Sets

Age 12-14: New Responsibilities

- Transition Checklist
  - I can describe how my disability or health condition affects my daily life.
  - I can name my medications (using their proper names), and the amount and times I take them.
  - I answer at least one question during a health care visit.
  - I have talked with my doctors or nurses about going to different doctors when I am an adult.
  - I manage my regular medical tasks at school.
  - I can call my primary care doctor’s or specialist’s office to make or change an appointment.

Age 15-17: Practicing Independence

- Transition Checklist
  - I keep a personal health notebook or medical journal.
  - I reorder my medications when my supply is low and call my doctor when I need a new prescription.
  - I answer many of the questions during a health care visit.
  - I spend most of the time alone with the doctor(s) during health care visits.
  - I tell my doctors I understand and agree with the medicines and treatments they suggest.
  - I know if my doctors do not take care of patients who are older than a certain age (for example, 21).
  - I regularly do chores at home.
  - I can tell someone the difference between a primary care doctor and a specialist.

Age 18+: Taking Charge

- Transition Checklist
  - I can tell someone the effects that getting older may have on my disability or health condition.
  - I can tell someone about medications that I should not take because they might interact with the medications I take.
  - I am alone with the doctor(s) or choose who is with me during health care visits.
  - I answer all the questions during a health care visit.
  - I have identified adult doctors and facilities that I will go to when I leave my current doctors and facilities.
  - I manage all of my regular medical tasks outside the home (school, work).
  - I can tell someone what new legal rights and responsibilities I gained when I turned 18 years old (sign medical consent forms, make medical decisions by myself).
  - I can tell someone how long I can be covered under my parent’s health insurance plan and what I need to do to maintain coverage (such as being a full-time student).

Health Care Transition Skill Sets

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### Health Care Transition Skill Sets

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<th>Age 18+: Taking Charge</th>
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<td><em>(Check the items that are true for you.)</em></td>
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<td></td>
</tr>
<tr>
<td>- I can call my primary care doctor’s or specialist’s office to make or change an appointment.</td>
<td>- I can handle consent forms, make medical decisions by myself.</td>
<td></td>
</tr>
</tbody>
</table>

**Can be done independently**

- Can be done with support (identify specific support)

**Will need assistance for a while (identify time period)**

- Will need assistance permanently (identify responsibility)

## Table 2. Provider transition checklist and timeline

<table>
<thead>
<tr>
<th>Transition step</th>
<th>Ages 11–13</th>
<th>Ages 14–16</th>
<th>Ages 17–19</th>
<th>Ages 20–22</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Transition preparation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Encourage the adolescent to assume increasing responsibility for his/her healthcare management</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Meet privately with the adolescent for part of the visit</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Assure the adolescent understands his/her health condition and medications</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Assess the adolescent’s and the family’s readiness for transfer to an adult care provider</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Address gaps in preparation, knowledge and skills</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td><strong>Transition planning</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Address healthcare transition needs</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Assess the need for guardianship/conservatorship; assess the adolescent’s ability to make independent decisions</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Create Healthcare Transition Action Plans, Portable Medical Summary</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Identify possible adult care providers</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Initiate communication with the adult provider</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td><strong>Transition and transfer of care:</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Send ‘Transition Package’ and transfer letter</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Discuss nuances of care with the adult provider via direct communication</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
<tr>
<td>Follow-up after the transfer</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
</tr>
</tbody>
</table>
Transition Support Services Offered in Pediatric Practices to Adolescents with Special Needs

- Referral to specific adult provider
- Referral to specific adult specialists
- Discussion of consent/confidentiality issues by 18
- Assistance with medical documentation for SSI
- Assistance in creating portable medical summary
- Assistance with identifying insurance options
- Assistance in creating an individualized HCT plan
- Provision of educational packet to families

% Responders

For most For some

Disparities in Transition Planning

- Encouraged responsibility
- Received transition planning services
- Adult physician discussion
- Adult health needs discussion
- Adult health insurance discussion

% Receiving Service

- OCSHNC (n=17,392)
- ASD (n=806)
ASD Severity and HCT Planning

- Condition affects ability compared with peers:
  - Never (n=5)
  - Sometimes (n=30)
  - Usually (n=37)
  - Always (n=29)

ASD Youth Age and HCT Planning

- Received any transition service
- Adult health needs discussion
- Help teaching youth self management
- Discussed how to manage HCT
- Guardianship information

Age of youth:
- 13-15 y (n=102)
- 16-18 y (n=60)
- 19+ y (n=21)
ASD Youth Age and HCT Planning

Age of youth:
- 13-15 y (n=102)
- 16-18 y (n=60)
- 19+ y (n=21)

% Receiving Service

- Info materials about HCT process
- Written transition plan
- Written medical summary
- Help finding an adult PCP
- Info on adult medical specialists
Obstacles in HCT for ASD Youth

Difficulties related to insurance
Lack of coordination
Difficulty finding adult specialist
Difficulty finding adult PCP
Lack of information on HCT process

Difficulties related to guardianship
Information on HCT process
Assistance in finding adult PCP
Assistance in finding adult specialist
Coordinated HCT
Assistance with insurance problems
Advice related to guardianship

Transition Survey 2010:

33 question survey mailed to ~2100 physicians in Connecticut

- 600 pediatricians
- 1500 internists and family practitioners

313 responses

- 134 providing care to children only
- 116 providing care to adults only
- 63 providing care to both children and adults
Transition Survey 2010:

Do you have a standard transition process?

- **Child**: Yes (50%) / No (50%)
- **Adult**: Yes (50%) / No (50%)

Below is a breakdown of respondents by transition process:

<table>
<thead>
<tr>
<th>Process</th>
<th>Percent of Responders</th>
</tr>
</thead>
<tbody>
<tr>
<td>Written</td>
<td>16%</td>
</tr>
<tr>
<td>Alt visits</td>
<td>2%</td>
</tr>
<tr>
<td>Self-mastery</td>
<td>4%</td>
</tr>
<tr>
<td>Trans coord</td>
<td>6%</td>
</tr>
<tr>
<td>Eval process</td>
<td>2%</td>
</tr>
</tbody>
</table>
Transition Survey 2010:

Where did you learn about patient transition?

Percent of Responders

- Med School
- Residency
- Post-Res
- Indep
- None
Autism Treatment Network Survey:

Seven interventions that are needed:

- **Pediatric provider focused**
  - Binder of materials for families
  - More advanced education for families
    - How to utilize available resources
    - Care management techniques, skill building
    - Increasing capacity of youth/families to direct their own transition
  - Resource links of adult providers and community resources
2017 Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care

New in 2017:
- Code 99420 has been replaced with codes 96160 and 96161, which can be used for reporting administration and scoring of a patient/caregiver transition readiness or self-care assessment using a standardized, scorable tool.
- New clinical vignettes have been added with recommended coding suggestions.

Improving transition from pediatric to adult health care is a national priority, a medical home standard, and a meaningful use requirement for electronic health records. Health care transition involves increasing youth’s ability to manage their own health and effectively use health services. It also involves ensuring an organized clinical process to prepare youth and families for adult-centered care, transfer to a new adult provider, and integration into adult health care.

2017 Coding and Reimbursement Tip Sheet for Transition from Pediatric to Adult Health Care

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<th>Health Risk Assessment⁶</th>
<th>Medicare</th>
</tr>
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<tbody>
<tr>
<td>96160</td>
<td>Administration of patient-focused health risk assessment instrument (e.g., transition readiness assessment) with scoring and documentation, per standardized instrument</td>
</tr>
<tr>
<td>96161</td>
<td>Administration of caregiver-focused health risk assessment instrument (e.g., transition readiness assessment) for the benefit of the patient, with scoring and documentation, per standardized instrument</td>
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</tbody>
</table>
Vignette #4

Preventive medicine visit with established 18-year-old female for her final pediatric visit before she goes off to college. She wants to see a new physician who treats adults, and she asks the physician for suggestions. She has been treated for major depressive disorder (mild) since she was 14. During the visit, the patient describes high levels of stress associated with all the changes that are happening in her life and persistent sadness. The physician takes an extra 15 minutes to re-assesses her depression and determines that a different medication is required. The physician reviews the last transition readiness assessment conducted when the youth was 17, updates the medical summary, and recommends an adult physician who can accept her as a new patient. He also recommends that she schedule a visit with her child/adolescent psychiatrist to discuss her depression and transfer plans to an adult psychiatrist. Following the visit, the physician takes an extra 30 minutes of non-face-to-face time to prepare a transfer letter for her to take to college and to her new adult provider that includes an updated medical summary, plan of care, and transition readiness assessment.
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Coding:

1. CPT 99395 (Preventive medicine visit, established visit, ages 18-39)
2. CPT 99213-25 (Office visit, established patient, low to moderate severity, 15 minutes, with significant, separately identifiable E/M service above and beyond the service performed by the same MD)
3. CPT 99358 (Prolonged E/M services before and/or after direct patient contact; first hour)

ICD-10-CM:

1. Z00.121 (Encounter for routine child health examination with abnormal findings)
2. F41.8 (Other specified anxiety disorders)
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Coding:

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<th>Description</th>
<th>Prolonged Services[^3]</th>
<th>Medicare</th>
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<tr>
<td>99354†</td>
<td>Prolonged evaluation and management (E/M) or psychotherapy beyond the typical service time, in office or other outpatient setting, with direct contact beyond the usual service; first hour</td>
<td>$131.35</td>
<td></td>
</tr>
<tr>
<td>99355†</td>
<td>Each additional 30 minutes</td>
<td>$99.06</td>
<td></td>
</tr>
<tr>
<td><strong>99358</strong></td>
<td>Prolonged E/M services before and/or after direct patient contact; first hour</td>
<td><strong>$113.41</strong></td>
<td></td>
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<tr>
<td>99359</td>
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<td>$54.55</td>
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Autism Treatment Network Survey:

Seven interventions that are needed:

• **Pediatric provider focused**

I think what’s really hard is that there are no providers within our community that are autism adult providers. There is one good psychiatrist in town who is probably ridiculously inundated at this point because I think everyone sends these young adults and adults to.

• **Resource links of adult providers and community resources**

- Autism. published online 4 Feb 2014, DOI: 10.1177/1362361313518125
Autism Treatment Network Survey:

Seven interventions that are needed:

- **External to pediatric practices**
  - Adult provider training
  - Training for medical students and residents

- Autism. published online 4 Feb 2014, DOI: 10.1177/1362361313518125
Autism Treatment Network Survey:

Seven interventions that are needed:

- External to pediatric practices

I think there’s a long way to go with the adult providers understanding the perspective that a child with autism – in terms of sensory sensitivities, anxiety, need for sameness, or need for advance preparation. I think that adult providers often assume that if a child comes in with autism and has good intellectual abilities that maybe he or she won’t really require anything extra or anything different – which is often not the case.

I think the pediatric primary care doctors and the adult providers probably don’t have enough time to really sit and make up their list of questions and call and connect with each other to get their questions answered. I think it’s exactly what the adult provider probably needs and what the patient needs.
Arranging to visit the adult service prior to transition and facilitating the first appointment increase satisfaction with transition for both parents and adolescents with chronic illness.

You think it’s hard now … It gets much, much harder for our children [after they turn 18] … They won’t even give you an idea who this next doctor is because they don’t know until your child is 18 … Our child had no chance to meet this person, no chance in a safe environment with their old doctor to get comfortable with the [new] doctor. Unfortunately [healthcare] kind of really sucks for our children.

Provider Considerations for Youth with ASD:

Sensory sensitivities lead to being overwhelmed by a crowded, noisy waiting room.

Offer patient an alternative, less stimulating waiting area.

The lights in the office are very bright and that is exacerbated by the white walls. Sometimes the waiting rooms are crowded and I cannot filter out the background of people talking or shuffling magazines. I feel disoriented by being led down long hallways to different rooms.

Provider Considerations for Youth with ASD:

Rigidity, difficulty with change

Ensure sufficient warning of changes in personnel, office environment, and providers.

With my autism it is very difficult for me to understand and follow all the different appointments and procedures I have to schedule and how to do it, and no one will help me since apparently people magically become competent at these things before they turn 21.

Provider Considerations for Youth with ASD:

- Deficits in social language skills
  - Take time to establish rapport with patient.
  - Outline the purpose of the visit and expectations of the patient.
  - Gain information about how the patient prefers to give and receive information.

Provider Considerations for Youth with ASD:

Deficits in social language skills

Take time to establish rapport with patient.

I am not able to bring up my concerns because it is all I can manage to figure out what the doctor is saying so I can respond to his questions.

I prefer and find it easier to communicate in text... But with every doctor I speak to, they wave away the note-card and look at me to ask the same question I have just answered and interpret my confusion as my being non-compliant with the medicine. I wish health care providers would read the notes I make for them.

Autism Treatment Network Survey:

Seven interventions that are needed:

- **External to pediatric practices**
  - Adult provider training
  - Training for medical students and residents
- **Internal and external to the pediatric practice**
  - Care coordination
  - Transition center

- Autism. published online 4 Feb 2014, DOI: 10.1177/1362361313518125
Autism Treatment Network Survey:

Seven interventions that are needed:

- **External to pediatric practices**
  - Adult provider training
  - Training for medical students and residents
- **Internal and external to the pediatric practice**
  - Care coordination
  - Transition center

...some kind of centralized one-stop shop with trained individuals who can answer questions, because there are a million toolkits out there. The process of transition is complicated with many moving parts, where the answer does not lie within one toolkit or intervention strategy, but with a combination of strategies which must be adjusted by need.

- Autism. published online 4 Feb 2014, DOI: 10.1177/1362361313518125
Connecticut Medical Home Initiative for Children & Youth with Special Health Care Needs

Who is eligible?
Children & youth age 0 to 21 who have, or are at increased risk for, a chronic physical, developmental, behavioral or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.

Services available?
All families of eligible children and youth with special health care needs (CYSHCN), regardless of income, will receive a respectful working partnership with you and your child’s medical home; care coordination services and family support referrals.

Uninsured or underinsured families, who fall within income guidelines, can also benefit from payment for limited services (i.e. durable medical equipment, prescriptions, and special nutritional formulas). Contact the Connecticut Medical Home Initiative at FAVOR, Inc. at 1-855-436-6544 (toll free).

SOUTHWEST
Stamford Hospital
Stamford
1-866-239-3907 (toll free)

SOUTH CENTRAL
Family Centered Services of CT, Inc.
New Haven
1-877-624-2601 (toll free)

EASTERN
United Community and Family Services, Inc.
Norwich
1-866-923-8237 (toll free)

NORTH CENTRAL
Connecticut Children’s Medical Center
Hartford
1-877-835-5768 (toll free)

NORTHWEST
St. Mary’s Hospital
Waterbury
1-866-517-4388 (toll free)

United Way of Connecticut’s Child Development Infoline
The central access point for Connecticut’s Medical Home Initiative for CYSHCN. Provides information about medical, educational and recreational resources
1-800-505-7000

Connecticut Family Support Network
Contact for family support, information and advocacy at 877- FSN-2DAY
<table>
<thead>
<tr>
<th>SOUTH WEST REGION</th>
<th>SOUTH CENTRAL REGION</th>
<th>EASTERN REGION</th>
<th>NORTH CENTRAL REGION</th>
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<td>Stamford Health Systems</td>
<td>Family Centered Services of CT</td>
<td>United Community and Family Services</td>
<td>Connecticut Children's Medical Center</td>
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BRIDGEPORT ANSONA Ashford ANDOVER BARKHAMSTED
DARIEN BETHANY BOZRAH AVON BEACON FALLS
EASTON BRANFORD BROOKLYN BERLIN BETHEL
FAIRFIELD CHESTER CANTERBURY BLOOMFIELD BETHLEHEM
GREENWICH CLINTON CHAPLIN BOLTON BRIDGWATER
MONROE CROMWELL COLCHESTER BRISTOL BROOKFIELD
NEW CANAAN DEEP RIVER COLUMBIA BURLINGTON CANAAN
NORWALK DERBY COVENTRY CANTON CHESHIRE
STAMFORD DURHAM DANIELSON EAST GRANBY COLEBROOK
STRATFORD EAST HADDAM EAST LYME EAST HARTFORD CORNWALL
TRUMBULL EAST HAMPTON EASTFORD EAST WINDSOR DANBURY
WESTON EAST HAVEN FRANKLIN ELLINGTON GOSHEN
WESTPORT ESSEX GRISWOLD ENFIELD HARTLAND
WILTON GUILFORD GROTON FARMINGTON HARWINTON
WADDAM HADDAM HAMPTON GROTON KENT
HAMDEN KILLINGLY LEBANON GRANBY MIDDLEBURY
KILLINGWORTH LYMES LEDYARD HARTFORD MORRIS
Lyme MADISON LEBANON HEBRON NAUGATUCK
MERIDEN MANSFIELD MARSHALL NEW FAIRFIELD
MIDDLEFIELD MONTVILLE MARLBOROUGH NEW HARTFORD
MIDDLETOWN MOOSUP NEW BRITAIN NEW MILFORD
MILFORD NEW LONDON NEWINGTON NEWTOWN
NEW HAVEN NANTIC PLAINVILLE NORFOLK
NEW BRANFORD NORTH STONINGTON PLYMOUTH NORTH CAANAN
NORTH HAVEN NORTH STONINGTON PLYMOUTH OXFORD
OLD LYMEL PLAINFIELD SMBSURY PROSPECT
OLD SAYBROOK POMFRET SOMERS REDDING
ORANGE PRESTON SOUTH WINDSOR RIDGEFIELD
PORTLAND PUTNAM SOUTHINGTON ROXBURY
SEYMOUR SALEM STAFFORD SALISBURY
SHELTON SCOTLAND SUFFIELD SHARON
WALLINGFORD SPRAGUE TOLLAND SHERMAN
WEST HAVEN STELIER VERNON SOUTHBURY
WESTBROOK STONINGTON WEST HARTFORD THOMASTON
WOODBRIDGE THOMPSON WETHERSFIELD TORRINGTON
WILLIAMSON UNCASVILLE WINDSOR WARREN
WINDHAM UNION WINDSOR Locks WASHINGTON
WOODSTOCK
Keys to Successful HCT:

1) The opportunity to plan and prepare for moving on to adult care;

2) Effective development of self-management skills during the preparation phase (12–16 years);

3) The opportunity for the young person and family to fully discuss adult care options and visit adult services in the active phase (17 to 18 years);

4) Provision of information about the health care system, cost of consultations, cost of medications and how to successfully negotiate the system as a young adult with ongoing health care needs.
### Good 2 Go: Role Transition

<table>
<thead>
<tr>
<th>Age/Time</th>
<th>Provider</th>
<th>Parent/Family</th>
<th>Youth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early</td>
<td>Has major responsibility</td>
<td>Caretaker</td>
<td>Receives care</td>
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<tr>
<td>Increasing age</td>
<td>Provides support to parent/youth</td>
<td>Manager</td>
<td>Participates</td>
</tr>
<tr>
<td>Increasing age</td>
<td>Consultant</td>
<td>Supervisor</td>
<td>Manages</td>
</tr>
<tr>
<td>Adult</td>
<td>Resource</td>
<td>Consultant</td>
<td>Supervisor/CEO</td>
</tr>
</tbody>
</table>
There is no research on how often youth with ASD successfully transition to an adult provider and achieving health-related independence, but looking at other measures of independence suggests most youth with ASD will experience great difficulty.

- Less than 25% of young adults with ASD live independently, work in competitive jobs, and have a social network (Levy & Perry 2011; Seltzer et al 2004).

- Most young adults with ASD live with their parents or are dependent on parental support well into adulthood (Hendricks & Wehman 2009).

Challenges 2017:

- How do we get health care providers to initiate transition services sooner for youth with ASD and other special health care needs and to conduct them in a more organized and comprehensive fashion?
- Can we educate and empower patients and families to direct health care transition?
- How do we provide more coordinated services for adults with special health care needs?
Challenges 2017:

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