

Transition to Adulthood: The Pile of Paperwork & Navigating the Process

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Learning Objectives

1.	Identify key services and supports for adolescents transitioning to adulthood
2.	Be equipped with knowledge and strategies to guide families in navigating the paperwork and processes required for a successful transition to adulthood
3.	Understand clinician involvement in transition planning in order to support adolescents in self-advocating for key services – saving clinical time down the road

Disclosures: nothing to disclose



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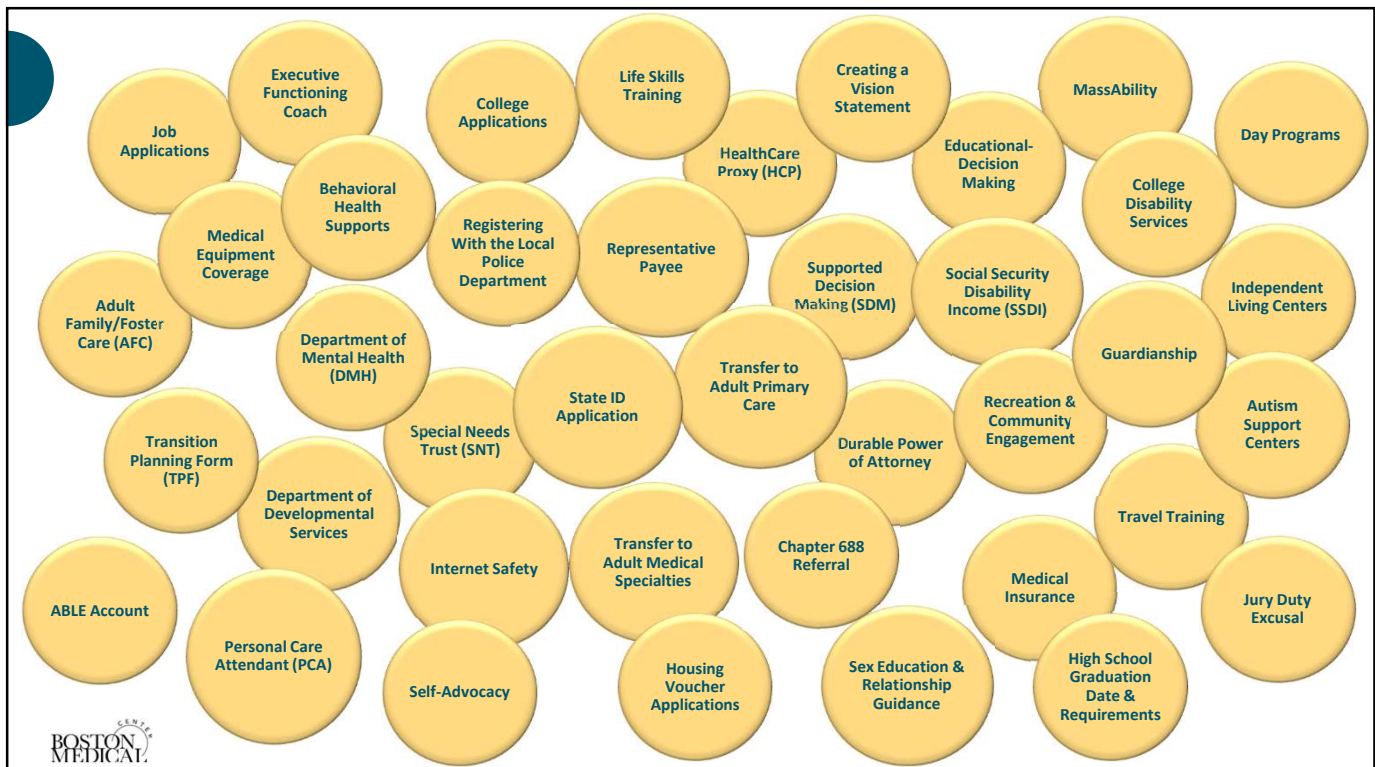
What is Transition to Adulthood?

- The time period between the ages 14-22
- Term used for adolescents with disabilities
- Period of knowledge building and skill development to prepare for greater independence
- Planning to move from school-based services to life after school
- Planning to become a legal adult

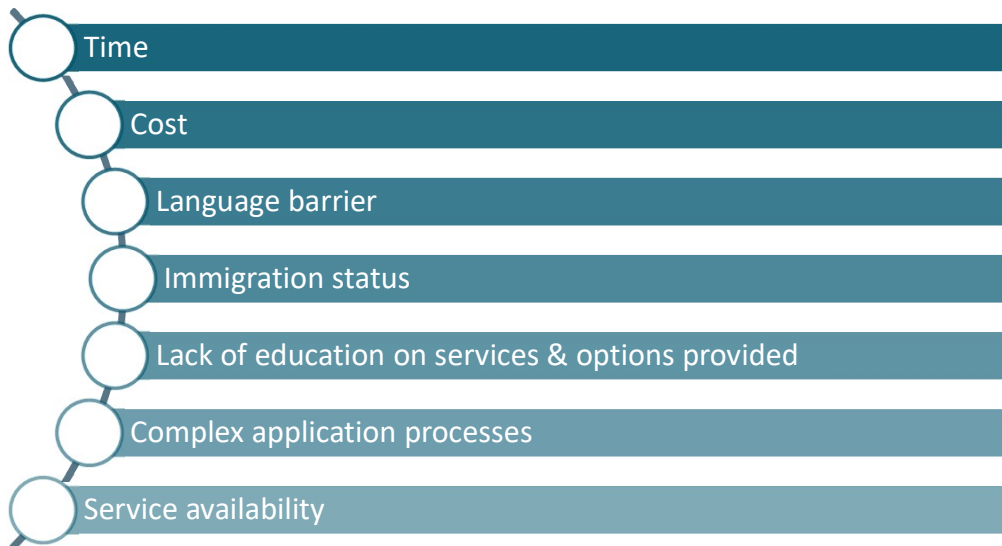


"Population outcomes among autistic young adults are poor across indicators of physical health, mental health, employment, postsecondary education, community participation, independence, financial security, and access to needed community services."

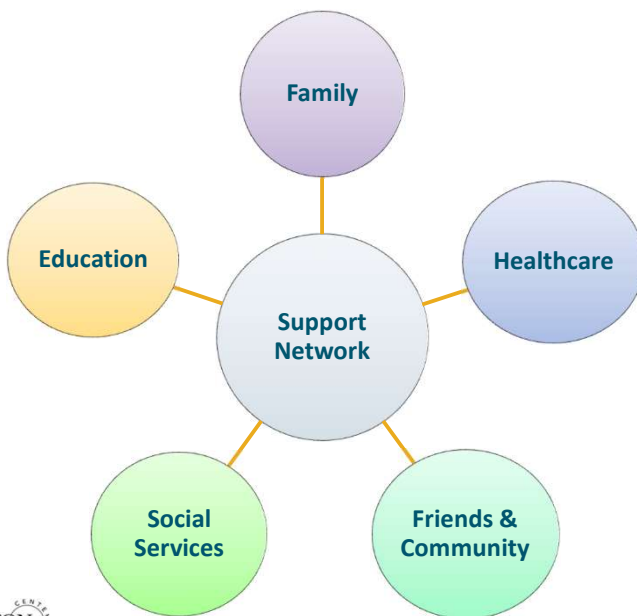
(Shattuck & Shea, 2022, p. 1).



Transition to Adulthood: *The Barriers*



Transition to Adulthood: *The Support Network*



*"...difficulties typically manifest pervasively across domains of physical and behavioral health, motor and speech development, and social and emotional development. Thus, **delivery of physical health care and health care transition in this population are almost always inextricably intertwined with other developmental domains** and a need for communication and coordination with the patient, his or her family, and a myriad of other health and community service providers."*

(Shattuck & Shea, 2022, p. 1).

Transition to Adulthood: *Where to Start*

1. What transitions are time sensitive?
2. What are the adolescent's **current** needs & priorities?
3. Establish a support network early
4. Create opportunities for skill development



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Case Studies: *Introduction*

Patient 1: *Jeremy*

- 21 yo autistic male with IDD
- Lives with mom and older brother
- Attends life skills program at school. IEP with ST, OT and ABA
- Minimally verbal and receives support from mom and older brother with ADL's. In-home ABA recently ended
- Interests: playing basketball with his older brother, listening to music and walking his dog



Patient 2: *Sabrina*

- 17 yo Hispanic female with ASD & ADHD
- Lives with parents and three younger siblings, in a bilingual household
- Graduating senior in an integrated classroom. IEP with ST and counselling
- Challenges with executive functioning skills and maintaining friendships. Deciding between college and employment with a goal to work with kids
- Interests: painting, helping others and playing with siblings



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What Transitions Are Time Sensitive?

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Time Sensitive Transitions



High School Transition
Planning



Age of Majority



Healthcare Transfer



The Department of
Developmental Services

** Not applicable to all
but important to
consider the differences
when applying early*

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High School: Transition Planning Process Definition

Individuals with Disabilities Education Act (IDEA):

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.

(Individuals with Disabilities Education Act, 2017).



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High School: Transition Planning Form

Longitudinal population-based surveillance cohort from the Autism and Developmental Disabilities Monitoring (ADDM) Network during 2002–2018

POSTSECONDARY TRANSITION PLANNING*
Complete for eligible students aged 14–22 and update annually. Complete indicate the pages of this IEP that are dedicated to secondary transition plan.

Postsecondary Transition	Strengths, in
Education/training	
Employment	
Community experiences/postschool independent living, if applicable	

The identified areas of postsecondary transition will be addressed in the following:
☐ Accommodations/Modifications
☐ Goals/Objectives
☐ Services/Details
☐ Additional Information

Projected date of graduation/program completion: _____
 Projected type of completion document (diploma, certificate, attainment, or other locally defined completion document): _____
 Planned Course of Study
 What requirements does the student need to meet to receive: _____
 What is the student's current status regarding meeting those requirements: _____

The defined line indicates that this page of this IEP is dedicated to secondary transition planning.

COMMUNITY AND INTERAGENCY CONNECTIONS

Agency	Description of Support Provided	Role and contact information of school staff who will be the liaison to the agency

TRANSFER OF RIGHTS TO STUDENT
 (The student and parent(s) must be notified at least 1 year before the student's 18th birthday that decision-making rights will transfer from parent(s) to the student when the student turns 18. Is the student 17 or will they turn 17 during the timeframe of this IEP?)
☐ Yes ☐ No
 On what date was the student provided with the notice of transfer of rights and a copy of procedural safeguards concerning special education rights? _____
 On what date was the parent(s) provided with notice of transfer of rights and a copy of procedural safeguards concerning special education rights? _____

DECISION-MAKING OPTIONS FOR STUDENT*
 Complete for student who has turned 18. Please indicate the decision-making option that the student or court-appointed legal guardian has selected:
☐ The student will make their own educational decisions.
☐ The student will share decision-making with their parent, caregiver, or other adult.
☐ Individual with whom the student will share decision-making: _____
☐ The student has delegated decision-making to their parent, caregiver, or other adult.
☐ Individual to whom the student has delegated decision-making: _____
☐ A court has appointed a legal guardian for the student who will make educational decisions.
 Name of court-appointed legal guardian: _____
 Date of determination: _____

TRANSITION TO ADULT SERVICE AGENCY OR AGENCIES—688 REFERRAL
 Is the student within 2 years of exiting special education (senior)? ☐ Yes ☐ No
 If yes, has the team discussed whether the student meets the criteria for a 688 referral? ☐ Yes ☐ No
 Has a 688 referral been submitted for the student? ☐ Yes (If so, date the 688 referral was submitted: _____) ☐ No (If so, date the 688 referral will be submitted: _____)
 If yes, please identify the agency to which referral was made: _____
 If the team has determined that the student does not meet the criteria for a 688 referral, _____

* The defined line indicates that this page of this IEP is dedicated to secondary transition planning.



(Massachusetts Department of Elementary and Secondary Education, n.d.-a).

What is the content and quality of the transition planning goals?

(Hughes, Shaw, et al., 2023)

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High School: Transition Planning Process Key Features

The Transition Planning Form

Vision Statement

Anticipated Graduation Date

Extended School Programming (*ages 18-22*)

Chapter 688 Referral (*date & agency*)

Decision-Making Support Options

Transition Goals (*based on Transition Assessments*)

IEP Meetings

COMMONWEALTH OF MASSACHUSETTS CHAPTER 688 REFERRAL FORM
 Directories
 All referrals should be submitted using the electronic T22/Chapter 688 Referral Application which is accessed through the E2020S Visual Gateway.
 For more information please see the STP website at <https://www.transitionplanning.org>

STUDENT INFORMATION (SAD/CP)
 Name: _____ Date Completed: ____/____/____ DOB: ____/____/____ Sex: CM CM DP
 SSN: ____-____-____ Receives SSD/SDO? ☐ Yes ☐ No ☐ Interview
 Disability Category: Primary _____ Secondary _____ Level of Need: Chgh Chmoderate Chlow
 Parent/Guardian Name: _____ Legal Guardian? ☐ Yes ☐ No Language Spoken: _____
 Address: _____ Phone: ____-____-____

SCHOOL DISTRICT/PROGRAM INFORMATION Is this student expected to graduate before age 22?
☐ Yes, expected date ____/____/____ ☐ No, expected date of SpEd termination ____/____/____
 School District (LEA): _____ LEA Address: _____
 LEA Contact Person: _____ Phone: ____-____-____ Name of High School: _____
 Type of Placement: _____ List All Funding Agencies: _____
 School/Educational Placement: _____ Address: _____
 Signature of Special Education Director/Designee: _____ Date: ____/____/____ Phone: ____-____-____

REFERRAL SUBMISSION: Send to ONLY ONE of the following:
☐ Department of Children & Families (DCF) ☐ Department of Developmental Services (DDS)
☐ Department of Mental Health (DMH) ☐ MHA Commission for the Deaf & Hard of Hearing (MCDHH)
☐ MA Rehabilitation Commission (MARC) ☐ MHA Commission for the Blind (MBCB)
 If you are unsure of agency, or more than one agency seems appropriate, please send to:
☐ The Bureau of Transitional Planning (BTP)

I hereby authorize the release of all personal information contained in this student's records, including medical and educational evaluation, to the Bureau of Transitional Planning at E2020S and to any member agencies for the purpose of eligibility determination and transition planning. I also authorize the release of any other personal information concerning this student that is required during the transitional planning process by any state agency to any other state agency.
 Signature of Student (18 or over) or Parent/Guardian: _____ Date: ____/____/____

Massachusetts Department of Elementary and Secondary Education | Chapter 688 Referral Form
 Revised 02/2022

AGE: 14-22



(Massachusetts Department of Elementary and Secondary Education, n.d.-b).

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High School: Transition Planning Goals



FIGURE 1
 (A) IEP postsecondary transition planning and (B) IEP postsecondary transition planning by ID status.

Figure 1. IEP postsecondary transition planning by ID status (Hughes, Kirby, et al., 2023, p. 4).



EXAMPLES OF TRANSITION SERVICES

Transition services must consider the student's strengths, preferences, and interests, and may include (but are not limited to):

Instruction in:

- Financial planning and management;
- Self-care (e.g., hygiene, health & wellness);
- Independent living (e.g., cooking, housekeeping, home maintenance);
- Time/organizational management;
- Self-determination (e.g., self-advocacy, problem-solving, self-monitoring);
- Social/communication skills (e.g., peer relationships);
- Leisure skills; and
- Job-specific and soft skills for employment.

Community Experiences:

- Travel training to settings similar to those of their age peers (college campuses, work settings, community settings);
- Enrollment in postsecondary education programs* (e.g., vocational-technical programs, adult basic education, college programs, apprenticeships, dual enrollment);
- Career and technical education (CTE) programs;
- Community access (e.g., accessing community services, social roles/ citizenship); and
- Peer mentoring and career mentoring.

The development of employment and other post-school adult living objectives:

- Referrals and interviews with adult-serving agencies or State VR agencies;
- Participation in any or all five required pre-ETS;
- Arrangement of work-based learning experiences, work study, and paid work;
- Embedding self-care/independent living skills instruction into academic coursework and class/program procedures; and
- Supports to access other services or post-school/adult environments (e.g., completing a housing application, navigating access to adult healthcare providers (including Medicaid), opening an Achieving a Better Life Experience (ABLE) account, applying for college, scheduling an appointment with disability support services in college, obtaining Social Security Disability benefits).

* IDEA Part B funds may be used to pay for transition services in postsecondary education settings only if certain conditions are met. See Questions and Answers B-4, B-7, C-1, and C-2 for details.

Figure 2. Examples of Transition Services for students with disabilities to help them reach their postsecondary goals in school (U.S. Department of Education, 2025, p. 8).

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Age of Majority



Legal Change of Rights

MALE: Register for the draft

AGE: 18

Healthcare Transfer



Pediatric Primary Care

Pediatric Specialties

Medical Insurance

AGE: 18-26



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The Department of Developmental Services (DDS)

Apply for adult services before leaving high school (DDS recommends applying between the ages 17-18) to allow for:

- DDS attending IEP meetings
- Sufficient time for transition planning

CHILD
ELIGIBILITY
ENDS AT AGE: 22
(or when school
services end)

(Commonwealth of Massachusetts, n.d.-a).

Additional Key Timelines

Supplemental Security Income (SSI)

CHILD
ELIGIBILITY
ENDS AT
AGE: 18

Children's Behavioral Health Initiative (CBHI)

SERVICES
END AT
AGE: 21



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Case Studies: *Time Sensitive Transitions*

Patient 1: *Jeremy*

- Graduating at age 22
- Chapter 688 to DDS
- Plan to attend day program but lengthy wait lists
- Delegated decision-making & guardianship in process
- Looking for new PCP & specialty care
- ABA recently ended
- **IEP transition goals**

Patient 2: *Sabrina*

- Deciding upon graduation date
- Chapter 688 to MassAbility
- Receiving Pre-ETS at school
- Age of Majority has been discussed & shared decision-making
- Re-applying for DDS adult services & SSI
- **IEP transition goals**

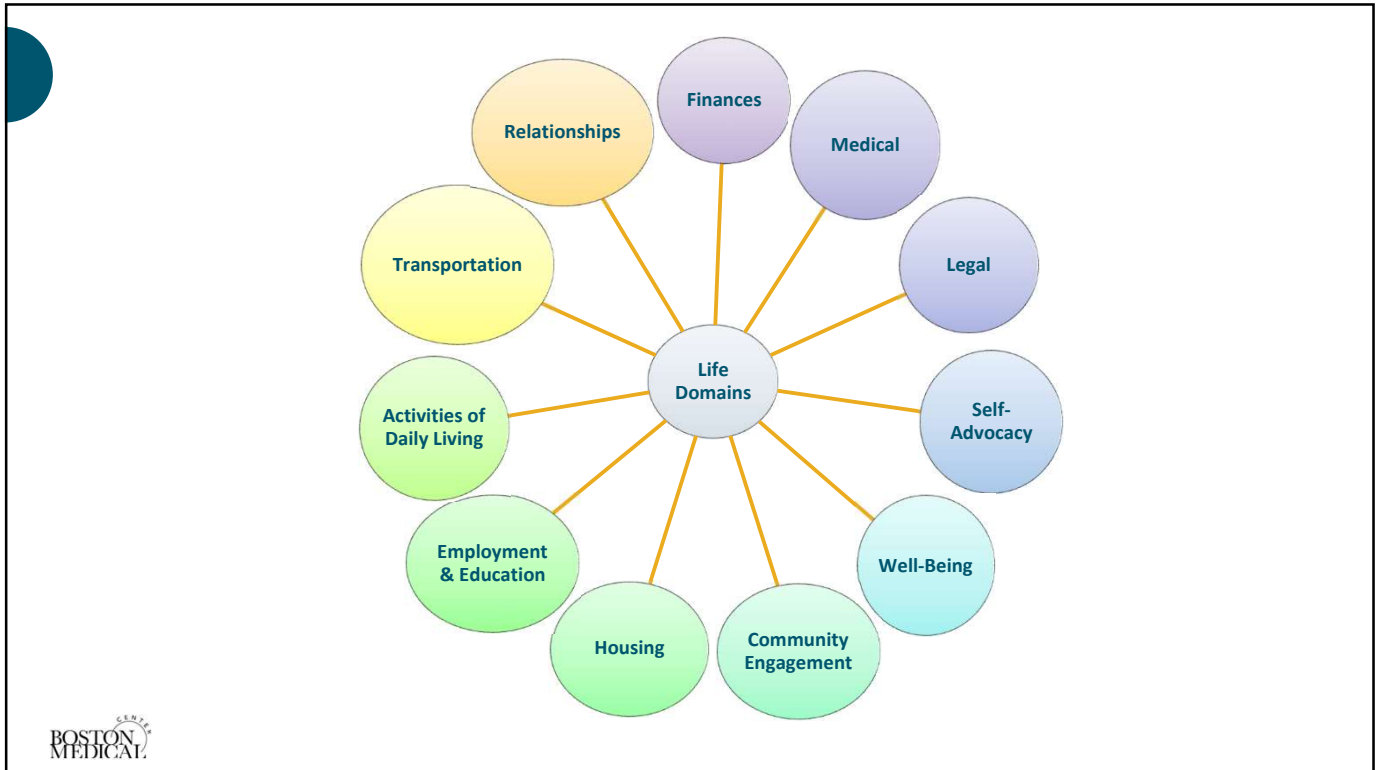


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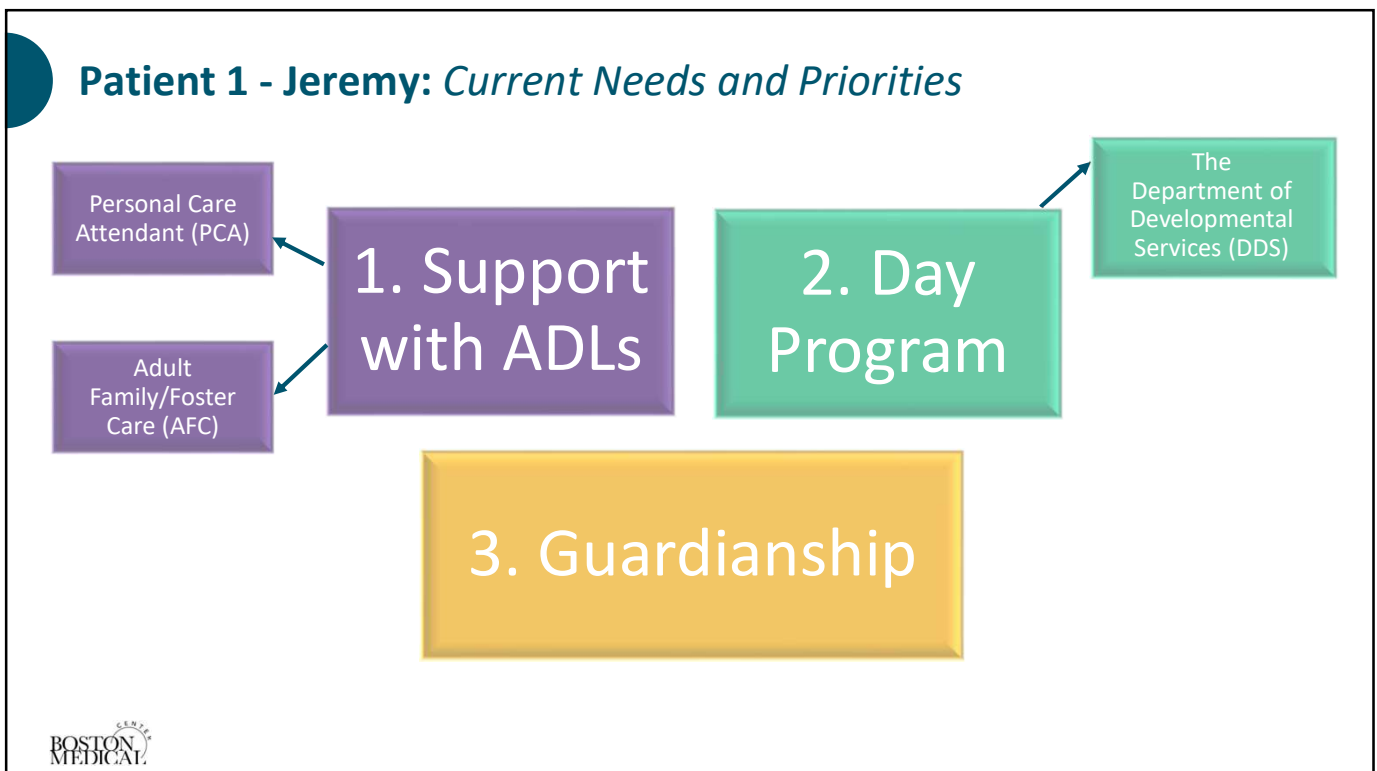
What are the adolescent's **current** needs and priorities?



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Patient 2 - Sabrina: Current Needs and Priorities



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Establish a Support Network



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Support Network: *Supported Decision-Making (SDM)*

- Who?
- What?
- When?
- How?



Supported Decision-Making Agreement developed by Center for Public Representation

This is the Supported Decision-Making Agreement of

Name: _____ Date of birth: _____

Address: _____

Telephone: _____ Email: _____

A. I need supporter(s) to help me make decisions about:

- ☐ Taking care of my financial affairs, like banking
- ☐ Hiring a lawyer if I need one and working with the lawyer
- ☐ My health care, including large and small health care decisions
- ☐ Personal care (like where I live, the support services I need, managing the people who work with me, my diet, exercise, education, safety and activities)
- ☐ Other matters: _____

B. I expect my supporter(s) to help me in the following ways:

- ☐ Giving me information in a way I can understand
- ☐ Discussing the good things and bad things (pros and cons) that could happen if I make one decision or another
- ☐ Telling other people my wishes
- ☐ _____

C. I express myself and show what I want in the following ways:

- ☐ Telling people my likes and dislikes.
- ☐ Telling people what I do and do not want to do.
- ☐ _____
- ☐ _____

D. I designate the following individual(s) to be part of my Supported Decision-Making Network to assist me in making decisions.

Network Supporter #1

Name: _____ Date of birth: _____

Address: _____

Telephone: _____ Email: _____

Relationship: _____

Areas of Assistance for Supporter #1: Check all that apply:

- ☐ Finances ☐ Healthcare ☐ Living Arrangements
- ☐ Relationships/Social ☐ Employment ☐ Legal Matters
- ☐ Other (please specify): _____

Areas I don't want Supporter #1 to assist me with:

Network Supporter #2

Name: _____ Date of birth: _____

Address: _____

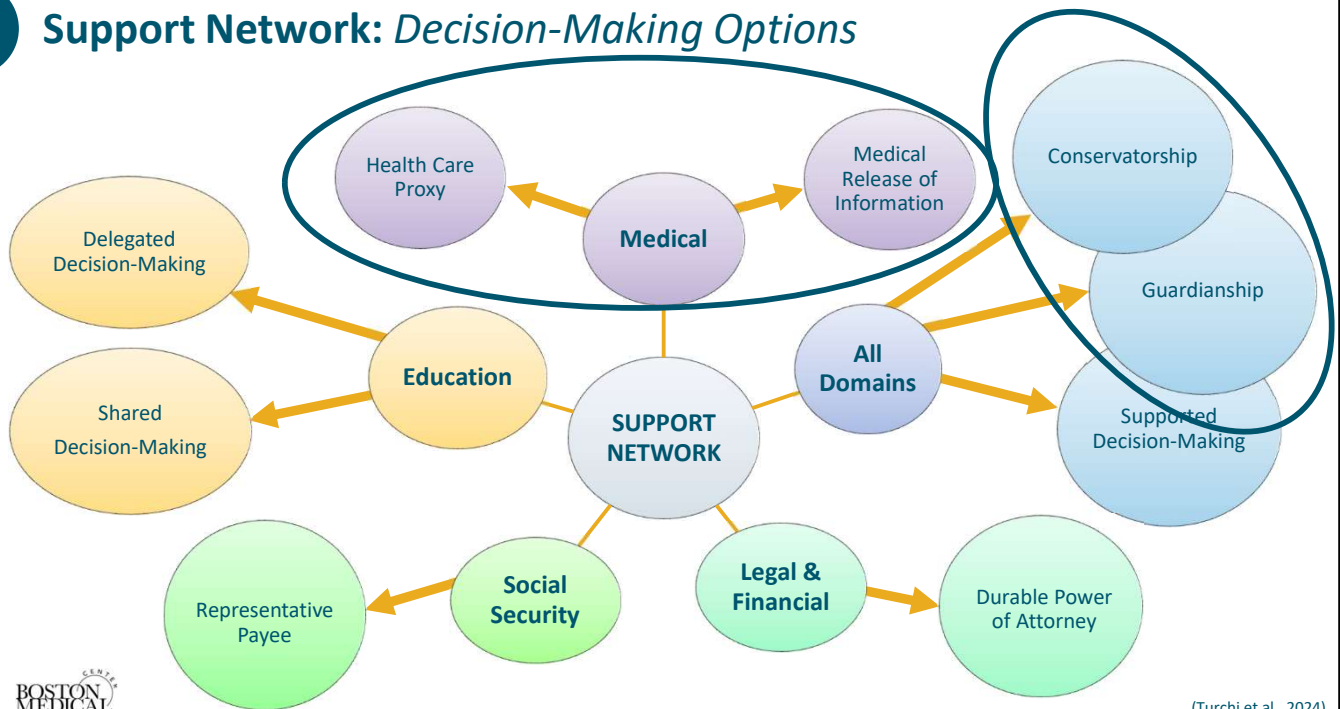
Telephone: _____ Email: _____

Relationship: _____

(Center for Public Representation, 2025)

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Support Network: *Decision-Making Options*



(Turchi et al., 2024)

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Case Studies: *Support Network*

Patient 1: *Jeremy*

PLAN:

- Guardianship
- Representative Payee

APPLICATION SUPPORT:

- Pro-bono legal service
- Autism Support Center

SUPPORT NETWORK:

- Mom and brother
- Mom's PCP
- Neighbor
- School peer
- Support Center

Patient 2: *Sabrina*

PLAN:

- Supported Decision-Making
- Health Care Proxy and ROI
- Durable Power of Attorney

APPLICATION SUPPORT:

- Pro-bono legal service
- Autism Support Center
- Cultural Center

SUPPORT NETWORK:

- Family
- Pediatrician
- School counselor
- Cultural Center families



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Create Opportunities for Skill Development



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Life Skills: Categories

Categories

Activities of Daily Living Skills

Independent Living Skills

Executive Functioning Skills

Vocational Skills

Social & Communication Skills

Independent Living Skills

Preparing and cooking meals

Traveling i.e., public transportation or driving

Managing finances e.g., managing bank account & buying food

Managing healthcare e.g., booking appointments & taking medications

Managing household e.g., laundry, dishes & taking out the trash

Awareness of safety procedures and plan

Shopping e.g., for groceries, clothes & toiletries



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Life Skills: Resources

Independent
Living Centers

Executive
Functioning
Coaches

Occupational
Therapy

MassAbility
Vocational
Services

Employment
Coaching

Social Skills
Classes

Mentoring
Programs

Academic
Tutoring

Skill Specific
Classes e.g., MBTA
Travel Training



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Case Studies: Opportunities for Skill Development

Patient 1: Jeremy

- **OT** - for ADLs
- **Mentoring program** e.g., Partners for Youth with Disabilities - for community engagement and social skills
- **Adaptive basketball**: e.g., Boys and Girls Club Dorchester Challenger basketball - for community engagement and social skills

Patient 2: Sabrina

- **Independent Living Center life skills workshops** e.g., Boston Center for Independent Living - for vocational training and independent living skills
- **Career coaching** e.g., AANE LifeMap program - for one-on-one coaching about post-college plan
- **Travel training** e.g., MBTA Travel Training program – for safely navigating the community independently



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Getting There and Staying There...

National Longitudinal Transition Study 2 (NLTS2), a 10-year project designed to monitor a national sample of students who in 2000 were in special education, and age 13 to 16 found the following:

66% of youth with autism spectrum disorders had worked at some point after high school. When surveyed a few years later, only 47% of these youth had jobs

(Buckley et al., 2009)

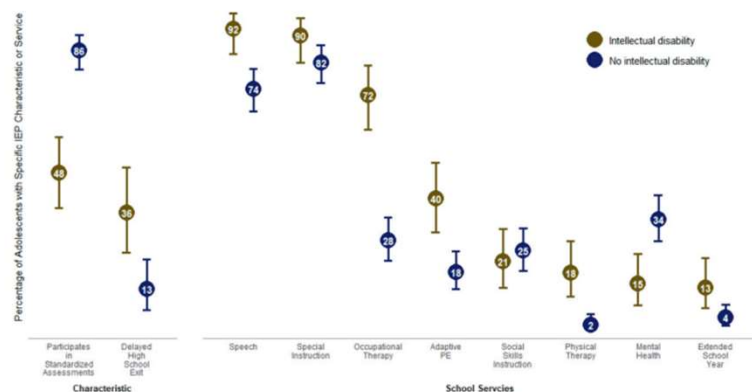


FIGURE 2

Percentage of adolescents with ASD with specific IEP components and services by ID status footnote: bars represent 95% confidence intervals.

Figure 3. Percentage of adolescents with ASD with specific IEP components and services by ID status (Hughes, Kirby, et al., 2023, p. 5).



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Getting There and Staying There...

In 2022 McQuaid et al. looked at perceived stress of autistic adults and surveyed 713 autistic adults.

They found “higher levels of perceived stress compared with non-autistic adults were significantly associated with decreased independence and quality of life, such as struggling to maintain full-time employment, being unable to live independently, and suffering from issues such as anxiety and depression.”

(McQuaid et al., 2022, as cited in Fairbank, n.d.).

“Research has found reduced **self-determination** can lead to diminished quality of life outcomes and reduced community integration and participation.”

(National Council on Disability, 2019, p. 33).

Self-Determination

Self-Advocacy

Self-Acceptance

Independence



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ACTION STEPS: For supporting the transition to adulthood process

- 1 Start the conversation around transition to adulthood at age 14
- 2 Get the IEP and review the Transition Planning Form and transition goals
- 3 Offer options around decision-making support options at age 16
- 4 Promote skill development and building a support network
- 5 Prioritize time sensitive supports and family priorities

A step further:

- 1) Know the services you are sending families to and the common roadblocks
- 2) Bring programs in-house to avoid another barrier in access



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Contact Information

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BMC Autism Program Website



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