Transition

Planning a Life & Setting the Stage – Future Growth for Your Adult on the Spectrum

Sue Loring RN

Director

HMEA’s Autism Resource Central
Transition to Adult Services
Adult Services is a Black Hole
It’s like being lost in the woods
Your child falls off a cliff........
You enter the abyss
Is it any wonder that parents are scared?
It’s time we changed the way we talk about transition. This is a natural part of growth for our children. Our job is to be ready to help them make a smooth transition to adult life.
Transition is not a black hole. It is more like leaving the tree line as you scale a mountain.
You’ve got this.
Over the past 10-12 years, you’ve developed mad hiking skills and there are Sherpa's to help you as you move towards the summit.
Your Child’s Vision

As you leave the tree line you can actually see better, the road ahead is clear, the darkness is behind you and, you’ve learned to carry a flashlight at all times just in case. While the road may seem daunting at times, you now can plot out a route for your child’s future. This vision will guide you through the next few years.
At times you may find yourself struggling to breathe as the air gets thin, but if you PACE yourself you’ll reach the summit.

Positive Attitudes Change Everything
BREATHE
It’s time to get your head out of the sand.
Getting Ready - Age 14

By age fourteen you should have a good idea of your child’s capabilities, and trajectory. It’s time to begin to plan for your child to become an adult. Your child will join you at IEP team meetings, it is his or her future. A Transition Planning Form becomes part of the IEP now.

Do the thing you fear most and the death of fear is certain.

Mark Twain
Everything you want is on the other side of FEAR.

- Jack Canfield
You need to be brutally honest and read the handwriting on the wall.

“Man is a strange animal. He generally cannot read the handwriting on the wall until his back is up against it”

~ Adlai E. Stevenson

If you wait to start planning until your child is eighteen to twenty, your back will be against the wall.
Failure to Plan is Planning to Fail
The transition process begins in the early teens for a reason. You’ve four to eight more years to prepare your child for the maximum independence he is capable of achieving. Reading Writing and Arithmetic need to share the time left in school with teaching Activities of Daily Living, Self Advocacy and Vocational Exploration in order for them to succeed as an adult.
Your transition plan in the IEP is an evolving document. It should be updated yearly, inviting agencies or people working with your child to the IEP. At age 18 begin inviting your DDS transition coordinator. When your child is in his last years of public education his learning should be work based.
Your plan should include a full array of supports for your child. None of us will live forever, and our children will live beyond us. For the rest of your life you can be the back up and the constant in your son’s or daughter’s life. You will be there to help them over the bumps along the way, but be sure to include others so a circle of support is in place when you are gone.
Friends, Siblings, Extended Family, Neighbors, Employers may all have insights and ideas outside your vision. Listen and consider all input but especially listen to and work with your young adult to craft a support plan that gives them the life they want. Consider Person Centered Planning if this is hard for you to facilitate.
Sometimes we are our own worst enemy
Equipment for Your Journey
Having an independent educational consultant evaluate your child’s programmatic needs could be of great value as you plan for the future. Their assessment can be a blueprint to help you advocate for the best program and services for your child. This is one of the Sherpas you can use on this climb.
Assess Your Child’s ADL Skills

Complete checklist can be found at www.autismresourcecentral/resources/living-skills

<table>
<thead>
<tr>
<th>Skills to learn</th>
<th>Can Do Already</th>
<th>Needs Practice</th>
<th>Plan to Start</th>
<th>Accomplished</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kitchen:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Operate appliances (cook top, oven, microwave, toaster, dishwasher)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use common kitchen tools (can opener, bottle opener, knife, measuring cups and spoons, grater, timer, egg beater, ice cream scoop)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help plan and prepare meals</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Follow a recipe</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Put away the leftovers</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Set the table</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do the dishes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Familiarity with contents of packaged foods</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laundry</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Put dirty clothes in hamper</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sort clothes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Use washer and dryer</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Iron</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hand wash</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fold clothes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Put clothes away</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
It is extremely important that you include a plan to work towards competency in several realms of daily living. Cooking, housekeeping, safety, hygiene, health care, use of public transportation, money management, housing options, how to apply for financial assistance should all be included in the plan.
Be sure that instruction for areas where there are skill deficits is provided in the IEP. Set realistic, measurable and achievable goals. Recognize that progress may not be perfection. Now with ARICA, you have insurance that covers autism, use it to augment training in social, self advocacy, daily living & community skills.
Explore alternative programs that will help prepare your child for becoming an adult.

**Transitioning to Adult Program (TAP)**
The TAP, funded by Massachusetts Rehabilitation Commission (MRC) is offered through six independent living centers and provides peer mentoring, independent living skills and self-advocacy services to special education students (ages 14 - 22) regardless of type of disability. If a student is interested in receiving independent living skills training through the TAP while in school, contact Maryellen MacRae, T22 Services Coordinator at 617-204-3618 (voice) or 617-204-3815 (TTY) who will make the referral to the appropriate Independent Living Center.

Center for Living & Working – Worcester
HMEA’s TRACS
(Transitional and Community Services)
The TRACS Program provides evaluation, training, and consultation services to ensure students with special needs aged 16 to 22 years can comfortably and successfully transition into the community after they leave high school. The TRACS program also provides assessment, job placement, and job coaching services for adults with disabilities who are trying to re-enter the work force.
http://hmea.org/services/childrens-services/#tracs
Easter Seals of Massachusetts Transition Services

High school students with disabilities, their families and educators are given tools to help achieve their vision. Assistive technology, rehabilitation therapy, vocational evaluation, career skills development, job placement, on-the-job training, Independent living-skills, social and recreational opportunities are just a few of offerings.

For more information, contact transition@eastersealsma.org, call 800-244-2756
ROUGH ROAD AHEAD
Ages 17-18
Overload
The year leading up to age 18 is emotionally charged as you begin preparations to insure your child’s future well being. While others are filling out FAFSA’s and visiting colleges, you are looking at guardianship, conservatorship and power of attorney. You are applying for adult services for your child.
Wrapping Your Head Around Reality

It is easy to become overwhelmed and sad at this point, this is not the life you envisioned for your child. If you think logically about the natural maturation of a child to an adult and apply this to your thinking about your child with a disability, the tasks become easier. The path is simply different and there have always been supports for him through childhood and so this continues. But he is becoming an ADULT.
Applying for Adult Services

You should begin to explore adults services at around age 17, your will need to apply for Adult Services from DDS, your children’s coordinator from DDS can assist you through this piece of transition, call them at age 17 they are one of your Sherpas.

A 688 referral form should be filed by the school with DDS or another appropriate agency (DMH, MRC) at this time.
Applying for Adults Services

Before your child is 18 you need to prepare to apply for Social Security Income (SSI) and MassHealth for your child. Call your Social Security office to make an appointment and begin gathering the needed documents to bring to that appointment. The Social Security office will send you a list of what you need to bring. The people at Social Security are your Sherpa on this part of your journey.
Medicaid & Medicare

It is important to have your child be Medicaid eligible to fund services that Medicare does not, like residential services. Try to get your child Medicaid before you retire.
ARC Support Brokers

SUPPORTbrokers mission is to assist persons with disabilities to achieve their vision. Consumers or families hire a support broker to help them find appropriate services and supports to thrive in their community. Brokers can help consumers find transportation, a place to live, someone to help them with daily living skills, a job counselor, and other linkages within the community. Brokers can also facilitate and create a person-centered plan and help consumers apply for Social Security or health insurance, among other benefits.
Guardianship, Conservatorship and Power of Attorney.

If your child is not capable of being his or her own guardian around their 17\textsuperscript{th} birthday you need to begin exploring professionals, a clinical team consisting of a psychologist, LICSW, and physician who will make a determination of competency. It can take months to get appointments so don’t wait. Documentation should be within 2 months of the person’s 18\textsuperscript{th} birthday.
Roger’s Guardianship
This is needed if your child is on an antipsychotic medication.

Haldol (haloperidol), Haldol Decanoate (haloperidol decanoate), Loxitane (loxapine), Navane (thiothixene), Prolixin (fluphenazine), Prolixin Decanoate (fluphenazine decanoate), Stelazine (trifluoperazine), Thorazine (chlorpromazine), Trilafon (perphenazine).

Abilify (aripiprazole), Clozaril (clozapine), Geodon (ziprasidone), Invega (paliperidone), Risperdal (risperidone), Risperdal Consta (risperidoneconsta LAI), Seroquel (quetiapine fumarate), Zyprexa (olanzapine).

In Massachusetts an incapacitated person can not be medicated without court approval.
You may want to hire an attorney to assist you with guardianship. This is NOT required but will help you make the correct decision for your child and may eliminate the stress factor for you. Be sure that the attorney is one who specializes in specials needs. For resources related to Guardianship check out the link below

http://www.autismresourcecentral.org/resources/guardianship/
Registering for The Draft

Under the law, virtually all male U.S. citizens, and male aliens living in the U.S., who are ages 18 through 25, are required to register with Selective Services.

Penalties for Failure to Register for the Draft
Men who do not register could be prosecuted and, if convicted, fined up to $250,000 and/or serve up to five years in prison. You may also be denied some services.

The easiest and fastest way to register is online https://www.sss.gov/Home/Registration
Housing

While you are still within the tree line you need to think about shelter when you reach the summit. The harsh reality is that not every individual served by DDS can be supported for residential services.
FACT:
Only 13% of Individuals with ASD in Massachusetts who are turning 22 will receive residential services through DDS
HOUSING

You will find out as you approach age 22 what level of funding from DDS they will receive. So it is imperative to have a “Plan B” in place. For this reason I would recommend that you take advantage of Autism Housing Pathways’ workshop “Thinking about Housing”

( This is being presented at HMEA’s Autism Resource Central on Oct 21st )

AHP also offers a full day workshop as well
“Plan B”
If the need for a plan B arises and your child is not given priority for residential services at age 22 you can be prepared for this by developing assets and having your child’s skills optimized which decreases the cost of supports needed. Do not wait until you find out what is allocated – plan ahead.
DDS Adult Waiver Programs: Adult Supports Waiver, Community Living Waiver and Intensive Supports Waiver Program. The Adult Supports and Community Living Waiver programs have similar services which differ by the intensity of need of the individual and individual’s location.
Individuals in the Adult Supports Waiver can live in their own home or apartment or family home due to the combination of a strong natural/informal generic and Medicaid services.
The Community Living Waiver is for individuals who can live in their family home, in the home of someone else, or their own home and do not need supervision 24 hours a day, seven days a week due to the combination of natural, generic and Medicaid services.
Services offered in the Adult Supports and Community Living Waiver:

Intensive Supports Waiver
The Waiver is for individuals who need supervision and support, 24 hours a day, seven days a week due to significant behavioral, medical, and/or physical support needs and the absence of available, natural, generic and Medicaid services. Waiver services offered may differ depending on location of waiver participant.
Services in The Intensive Supports Waiver

DDS Waiver Residential Options

These are typically run by developmental disability providers.

**Group Homes** 4-5 individuals served in a home with rotating staff members

**Shared Living**, an individual lives with a provider family who are compensated for providing a home and care for an individual
Housing
Aside from Waivers and DDS supports there are Medicaid State plans which may serve your child’s needs. These include Group Adult Foster Care, Adult Family Care and PCA services. You may only utilize one of these services. Day Habilitation programs are also Medicaid funded programs but you can have both.
Adult Family Care/Adult Foster Care

To qualify for Adult Family Care a person must be unable to live alone due to a medical, physical, cognitive, or mental condition. They must be eligible for MassHealth and 16 years of age or older. The person must need assistance with one or more activities of daily living, such as bathing, dressing, eating, toileting, or ambulation, and require 24 hour care and supervision. The person must be willing to reside with a caregiver. Physician approval is required.
AFC Providers
Caregivers may be family members as long as they are not the guardian of the participant * this is important to consider as you apply for guardianship * Caregivers must be willing to provide care and supervision 24/7 and must comply with all established MassHealth guidelines.
Day Programs

Funded by Medicaid, Day programs can be community based and or employment based. Many individuals have a combination of both. You will want to start looking at programs at around age 20. Your Transition Coordinator can help you with selecting appropriate programs.
Visiting Day Programs

As you explore possibilities you will want to see if the programs you are looking at have the expertise with ASD to serve your child. While there ask about supports that are imperative to your child’s functioning. Do they have behavioral support staff? How is data kept? Are there meaningful activities? Are there visual supports in place? Are there resources for communication? Does staff have familiarity with augmentative communication? How is the day structured? What is the response to sensory overload? How is overload avoided?
Selecting the Right Program

Be aware that the “right” program must have an opening for your loved one when they are ready to transition and be willing to accept them! There are no guarantees that this will happen so always have that plan B, just as students have a “safety school” when applying to college.
Employment

The majority of adults with ASD (85%) are unemployed. It is important to explore vocational aptitudes and begin shaping job skills while still in high school. Today’s obsession may be tomorrow’s job.

The days of sheltered workshops are past, today individuals served by DDS are encouraged to find meaningful employment in their communities.

Employment programs include vocational skills assessment, job identification, job placement and training.
All the world's a stage,
And all the men and women merely players;
They have their exits and their entrances,
And one man in his time plays many parts

- William Shakespeare
Your Role is Changing

You no longer need to be at center stage. You are more than a supporting cast member, if you do this right you become the producer. Essentially you are the team leader supported by production assistants, coordinators and managers. A producer deals with all the practical and political aspects of keeping a project running smoothly, so that the director and the rest of the team can concentrate on the creative aspects.
Growth
Leaving the educational system does not mean the end of growth. Like everyone else, our sons and daughters will be lifelong learners. If we set the stage, provide them with a supporting cast and allow them to create their own dialog we’ve done a good job as a producer and can sit back and enjoy the show.
Transition Happens……..
and Happens Again

“The search for static security is misguided. The fact is security can only be achieved through constant change, adapting old ideas that have outlived their usefulness to current facts”

Wm. Osler MD
RESOURCES

Puberty: A Guide for Teenagers with ASD and their Parents

OAR: Life Journey through Autism – Transition to Adulthood Guide

School Days to Pay Days – An employment planning guide
http://www.communityinclusion.org/pdf/DDS_booklet_F.pdf

Life After IEPs
http://lifeafterieps.com

TACA Preparing for Adulthood
http://www.tacanow.org/family-resources/preparing-for-adulthood
The Road Forward - Transitioning from school to adult services with DDS
http://www.mass.gov/eohhs/searchresults.html?output=xml_no_dtd&client=massgov&proxystylesheet=massgov&getfields=*&ie=UTF-8&oe=UTF-8&sort=date%3AD%3AL%3Ad1&startsite=EOHHSx&q=The+Road+Forward&sit e=EOHHSx&x=0&y=0

Autism Housing Pathways
http://autismhousingpathways.net/

Autism Consortium Transition Guide

Disability Law Center: Planning for a Life after Special Education

Unlocking the Door to Community Living
http://www.jfcsboston.org/Portals/0/PublicDocs/Unlocking_the_Doors_to_Community_Living.pdf
What Happens to my SSI when I turn 18?

Youth on the Move: A Road Map for Transition
http://www.youth-move.org

Job Tips – A program designed to help individuals with autism spectrum disorder explore career interests, seek and obtain employment, and successfully maintain employment.
http://www.do2learn.com/JobTIPS/index.html

Administering a Special Needs Trust , A Guide for Trustees

The Journey to Life After High School

DDS Individual Supports Planning Guide