

The Arc of Massachusetts Transition Conference 2021-2022

**Holistic Transition Planning:
Looking across the Life Domains**

Advocacy and Engagement

Deborah Flaschen

Ed Underwood

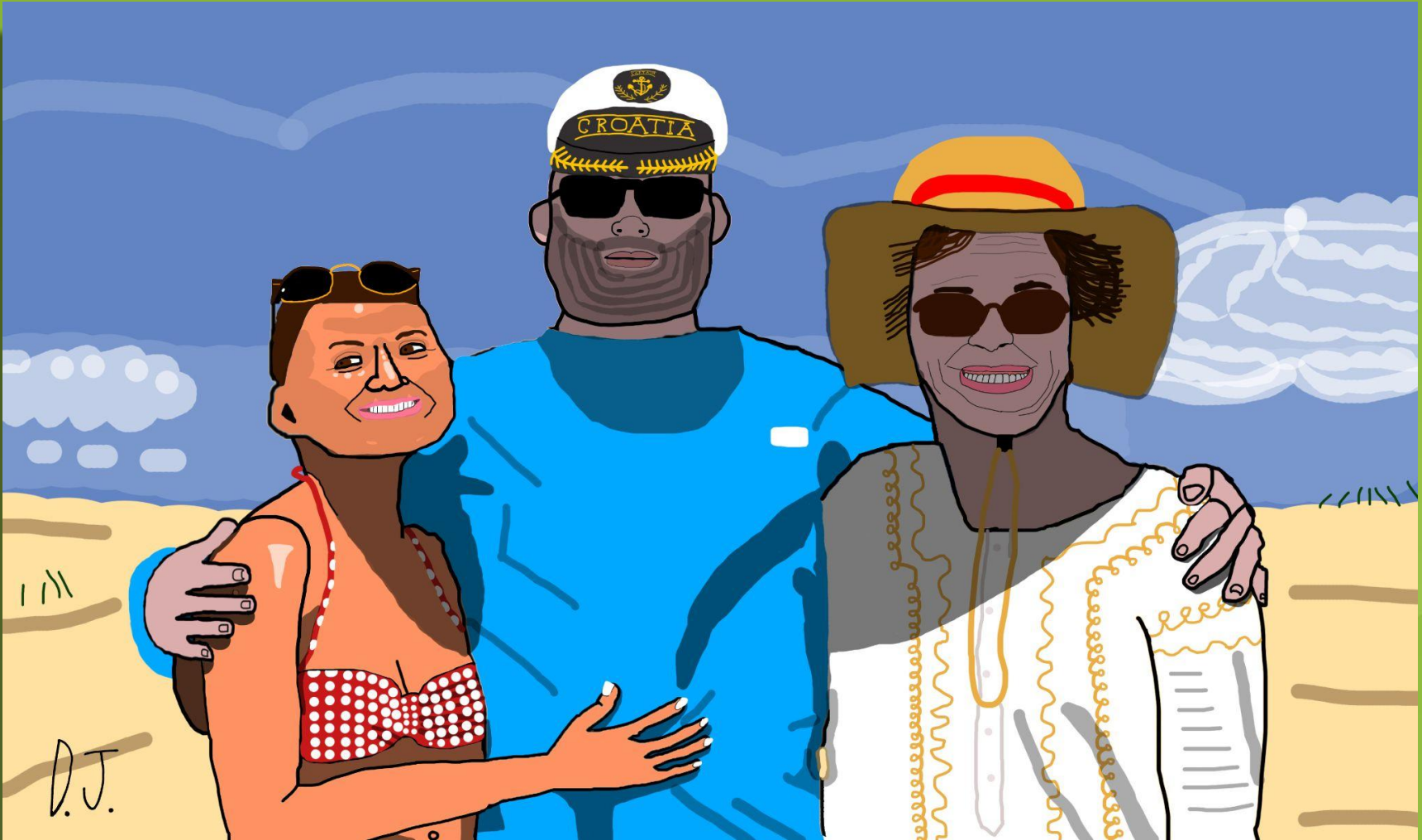
June Peoples Mallon

November 10, 2021

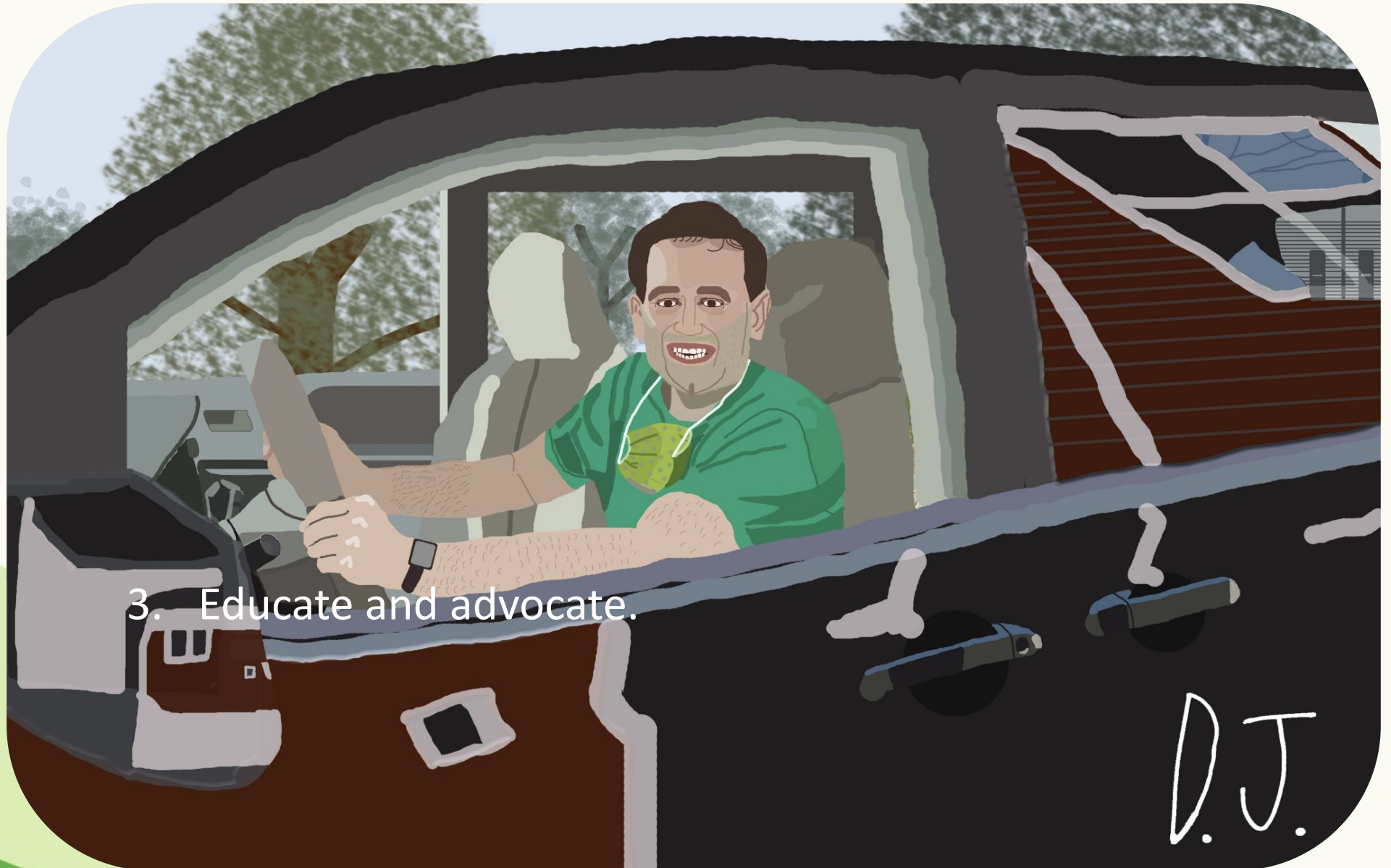
Advocacy and Engagement Transition Tools

Deborah Flaschen
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Parent & Advocate
November 10, 2021

Hello, my name is Deborah Flaschen



Supporting your transitioning adult




3. Educate and advocate.

D.J.

3LPLACE

Celebrate neurodiversity. Grow your abilities.
Choose your path with us.

ABOUT US | ADMISSIONS | LEARNING | LIVING | LINKING | CONTACT US



Learning | Living Linking

News & Events | Our modules | Support 3LPlace

Welcome to 3LPlace!

We're building exciting opportunities and a warm, diverse community that embraces neurological differences and encourages self-determination.

3LPlace supports individuals with intellectual and developmental challenges who are on a journey of life-long learning. Together, we are:

- Exploring community and what it means to be part of one
- Expressing creativity
- Thinking more critically
- Exploring careers
- Supporting job choices and placement
- Becoming more aware of body/mind connections and fitness
- Practicing the life skills we need to live successfully in our choice of housing, and in the community.



Our members include people living with autism, Down syndrome, and various other challenges. Diagnosis isn't important; what our members have in common is their readiness to grow their abilities and choose a path to a meaningful, gratifying, healthy and connected adult life.

Our modules

- Community
- Work and Career
- Daring to Dream
- Life Skills
- Social/Recreation

3LPlace offers a ground-breaking and highly individualized **modular programming structure**. Our members decide what they want to explore based on their own interests, goals, timing, and budget.

We begin by building a thorough understanding of each individual, particularly about their interests and passions in life. **We believe** that those personal interests can be harnessed to accelerate self-determination, independence skills, friendships, and social behavior.

Our menu of **day, evening and weekend programming** is based on our unique 3LPlace Curriculum. **The Curriculum**, a comprehensive and ground-breaking blueprint for change, was developed by a collaborative writing team guided by experts from Tufts, Lesley and Harvard universities as well as educators, clinicians and agency staff, and people living with disabilities.

News

This just in ...

Members of the 3LPlace Community, Deborah Flaschen, June Peoples Mallon, and Ed Underwood will be speaking at Boston Children's Hospital Transition to Adult Care Series, Tuesday, October 12, 2021 from 12-1pm. They will share their experience and advice for pediatricians looking to help adults with developmental disabilities move into adulthood and self advocacy in their healthcare.

Also featured in this speaking opportunity is a curated piece, "Transition Tools and Tips" written and edited by June and Deborah. It features links and resources as well as a guide by age to help support young adults and their families as they move into the next chapter of their lives. You can download and share the document by clicking here:



Transition process begins in the school system at age 14.

1. For all students with an IEP.
2. Begins at age 14. Students exit the school based transition process upon graduation from high school or age 22 at the latest.
3. There are many steps along the way.
4. Turn the page. We have a resource we think may be helpful.

3LPLACE



TRANSITION TOOLS & TIPS

3LPLACE.ORG

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AGE 14 TO DO:

- ☑ **IEP Transition Planning** begins at age 14 with a school team transition meeting and the addition of a [transition planning form](#) to your child's IEP. This form, required by law, must be updated annually and is included with all IEPs between 14 and 22. In conjunction with this, the school will assess your young adult's likely future needs and supports, including training, further education, employment, and independent living skills. Here's [a slide show](#) that explains this in more detail. Here's a [discussion](#) of what should be in the plan.

This important transition process should:

- Provide the opportunity to learn self-determination skills.
- Conduct person-centered planning with family and friends (see LifeCourse Nexus, below)
- Develop post-secondary vision based on needs, preferences, and interests.
- Identify disability related needs around each individual's goals and preferences.
- Develop an action plan based on desired outcomes for adult living, postsecondary education, and employment.
- Integrate transition needs and activities into the IEP goals, objectives/benchmarks, and services if appropriate for the student.

- ☑ **Review [this fact sheet](#)** from The Autism Program at Boston Medical Center for more guidance about what schools are required to do during the transition years, which begin now and continue until graduation or age 22.
- ☑ **Apply for a [non-driver's identification card](#).** This is a permanent, official government-issued ID card, useful for many purposes. You must be at least 14 to apply.
- ☑ **Review the [LifeCourse Nexus](#),** a strategy for whole life planning for people with developmental challenges. This is a comprehensive framework that can be accessed free of charge, and it will grow with your family member through various stages of life.



AGE 14 THINGS TO THINK ABOUT:

- Am I going to need help with this?** If the terminology is unfamiliar and the paperwork and deadlines feel overwhelming, [consider a special education advocate](#).

- Who else should be on our transition team?** Identify respected and trusted family members, friends, helpers, clinicians and others who can contribute to planning and/or provide continuity after transition.

- How are we going to pay for services after age 18? Age 22?** Consider this [interactive benefits calculator](#). You might also want to consult [an attorney or a special needs financial planner](#), who can advise you on savings and investment plans, estate planning, and also about benefits that might be available to your family.



TO DO SUMMARY:

AGE 14

- Begin IEP Transition Planning & [Transition Planning Form](#)
- Review this [fact sheet](#)
- Apply for a [non-driver's identification card](#)
- Review the [Life Course Nexus](#)

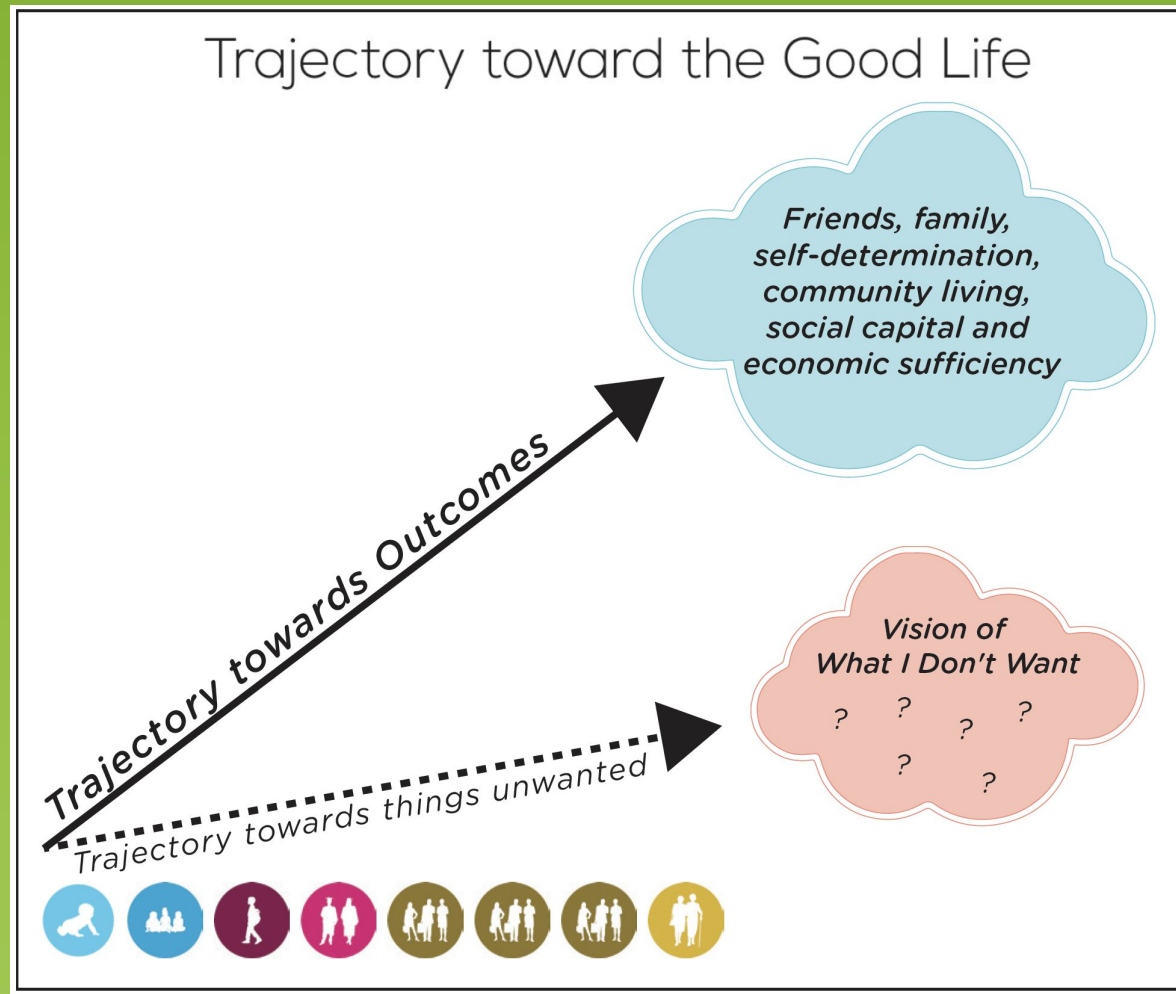
AGE 15 to 16

- Reread & review prior section
- Update your shared document file
- Update the Transition Planning form
- Confirm your school has submitted a "Chapter 688 referral" if they have not submit on your adults behalf.

AGE 17

- Reread & review prior section
- Update your shared document file
- Update the Transition Planning form
- Decide about guardianship ([use this guide](#))
- If your adult is male, [register for Selective Service](#) before their 18th birthday

The next tool I highly recommend is called the LifeCourse framework.



Core Beliefs: All people have the right to live, love, work, play and pursue their aspirations just as others do in the community.



Charting the LifeCourse

Introduction to the LifeCourse Framework

LifeCourse framework tools

- Comprehensive
- Systematic
- User friendly
- Free resource

www.lifecoursetools.com

The image displays three interconnected planning tools from the LifeCourse framework. The top-left tool, 'INTEGRATED SUPPORTS STAR', is a star-shaped diagram with 'Personal Strengths & Assets' at the top and 'Community Based' at the bottom. The vertical axis is labeled 'Technology' on the left and 'Relationships' on the right. The top-right tool, 'LIFECOURSE PORTFOLIO | PLANNING', includes fields for 'NAME' and 'DATE', a large text area for 'WHAT PEOPLE LIKE AND ADMIRE ABOUT ME', and a smaller area for 'WHAT'S IMPORTANT TO ME'. The bottom tool, 'LIFE TRAJECTORY | PLANNING', is a flowchart with four main boxes: 'Past Life Experiences' (top-left), 'Moving Forward' (top-right), 'Vision for What I Want' (right), and 'What I Don't Want' (bottom-right). Below 'Past Life Experiences' and 'Moving Forward' are two smaller boxes: 'List past life experiences that pushed your trajectory toward things you don't want' and 'List things to avoid that could keep you from your good life vision or lead to what you don't want'. The 'Vision for What I Want' box contains the letter 'I'. The 'What I Don't Want' box contains the text 'List the things you don't want or what is NOT a "good life"'. Social media icons and a footer with the text 'Developed by the Charting the LifeCourse Needs - LifeCourseTools.com © 2020 Curators of the University of Missouri | URMIC, INC. • March 2020' are located at the bottom of the page.

Recap

1. Start the transition process early and continue over time to address the key elements.
2. Presume competence of the rising adult and engage them consistently in the process. It is their life.
3. Continue to educate and advocate. The tools we've shared can be enormously helpful.

Q & A

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Advocacy and Engagement

John's Story

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November 10, 2021

This is John

1. Typical development until age 3
2. Unexplained daily seizures since
3. Developmental regression
4. Many interventions for seizures
5. Still has seizures every night
6. Cognitively about 6, but not really
7. Needs help with most ADL's
8. Limited comprehension
9. Struggles with daily transitions
10. Strong willed. Not always compliant
11. Limited safety awareness
12. Needs 24/7 support & supervision

This is also John

1. He's now a 23-year-old man
2. Very focused in the moment
3. Can stick with some tasks forever
4. Knows what he wants
5. Knows what he doesn't want
6. Will be a Boy Scout forever
7. Yes to bowling. No to soccer.
8. Enjoys live music and dancing
9. Sometimes wears an Elvis costume
10. Loves to sell things
11. Has his own sense of humor
12. Likes to make people smile

And this is also John



- <https://appliedselfdirection.com/news/stories-home-johns-story>
- <https://mansfield.wickedlocal.com/news/20190904/mansfield-man-finds-cool-career-with-ice-cream-pushcart>
- <https://www.instagram.com/johnsdreamicecream/>
- <https://www.facebook.com/JohnsDreamIceCream/>

John's Dream Ice Cream



- John loves doing it!
- Many learning opportunities
- Engagement in the community
- Fundraiser for Epilepsy Foundation New England



John's Week (Pre-Pandemic)

Mansfield Connections (Mon & Wed, 8:30-2:30)

- <https://www.attleboroenterprises.org/day-services/day-habilitation#Mansfield>
- Small, relatively new (younger population), close to home
- DayHab (or Day Habilitation) = MassHealth/Medicaid funded

Mansfield Redemption (Fri, 8:30 - 2:30)

- Group supported employment sorting bottles & cans
- Generally works 1 hour/day plus other supports and training
- Commonwealth Enterprises funded by DDS run by AEI

3LPlace (Tues & Thur, 10:00 - 4:00)

- www.3LPlace.org
- Long drive to Somerville, but worth it!
- 4 days/week via Zoom for over a year... due to pandemic
- Funded through DDS Self-Direction budget

John's Dream Ice Cream

- Many evenings & weekends
- 50+ events in 2019... and again in 2021

It's not all about money, but...

- I'm retired from a 35-year career in agricultural finance, business consultation, tax planning, appraisal, project management, relationship management and systems implementation.
- So I can't help but gravitate toward the numbers and understanding how the various funding sources work together.
- The rest of this presentation is NOT a complete primer on these topics, but instead focuses on just a few key points that are often missed.

John's Funding

SSI (Age 18)

- Helps fund basic living expenses
- Document individual's payment of rent & food from their own funds to justify change of Living Arrangement and higher SSI
- <https://www.ssa.gov/ssi/text-living-ussi.htm>
- <https://www.mass.gov/doc/federal-and-state-payment-levels-for-calendar-year-cy-2021>

MassHealth(Medicaid Age 18)

- Automatic with SSI
- Funds AFC, PCA & DayHab programs
- We switched from AFC to PCA at age 22
 - Change driven by John's high level of help needed with ADLs
- Secondary to any other family health insurance
- Also apply for Premium Assistance which may reimburse you for the premiums you pay for your employer provided family plan.
 - <https://www.mass.gov/info-details/masshealth-premium-assistance-pa>

John's Funding (continued)

DDS (Typically age 22)

- Get to know your Area Director 2-years before transition
 - ... and make sure they understand the needs
- Understand what DDS funds and what MassHealth funds
 - Community Based Day Supports (CBDS) = DDS funding
 - Day Habilitation (DayHab) = MassHealth/Medicaid funding
- Participant Directed Program (PDP) Self-Directed option
 - Funds participation at 3LPlace... and some other services
- (John is not a priority for DDS residential funding)

SNAP (“Food Stamps” - Age 22)

- Can help with cost of food
- Also includes a “Card to Culture” benefit
 - <https://www.mass.gov/ebt-card-to-culture>
- May need to pay higher rent to qualify
- Medical expenses can increase SNAP
- This online calculator can help you understand the numbers
 - <https://www.masslegalservices.org/online-snap-calculator>

John's Funding (continued)

Section 8 Housing Choice Voucher (HCV)

- Get on MA Centralized Waiting List at age 18
 - www.affordablehousing.com
- Visit your local Housing Authority regarding local options
- Mainstream Funding Program for non-elderly disabled
- Reasonable Accommodations open doors
 - 2nd bedroom for live-in aide
 - Renting from relatives
 - Special Housing Types
- Checkout <https://autismhousingpathways.org>

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John's Funding (continued)

ABLE Account

- Allows tax-free savings above \$2,000 SSI/Medicaid limit
- Some similarities to 529 College Savings Plans
- Only allowed one ABLE account per beneficiary
- Can use any state's plan that allows out-of-state participants
- Must be used for "disability-related expenses" broadly defined
- Can help facilitate higher rent payments while preserving Living Arrangement for higher SSI benefit (and maybe SNAP)
- 529 College Savings can be rolled over into ABLE
- Warning: ABLE accounts are currently subject to Medicaid payback

Supplemental Needs Trust and other legal/financial stuff

- Do it! And periodically review it.
- Make sure the rest of your legal and financial planning integrates
- Recent tax law changes may impact what types of assets are best to leave to an SNT vs. other siblings... and may even require changes to the language in your documents
- www.maxifi.com is a useful financial planning tool

Final Thoughts



My background and past career still steer me toward the numbers and financial side of things.

It's not all about the numbers. It's about figuring out how to prepare our adult offspring (with all their diversity) to live their best lives... and the numbers are just one small piece of that.



Sometimes you need to let your hair down and add some color to your life. (Purple just happens to be the epilepsy awareness color.) I'm very lucky to be retired and now just a full-time dad!

If there is anything I can do to help you in your journey, please feel free to reach out.

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A Fish Story

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The image features a white circle on the left side, set against a light green background. The background is decorated with abstract, curved green shapes in various shades, including a darker green in the top right and bottom left corners. The text "What does the future look like?" is centered in the upper half of the image.

What does the future look like?

“I want to be a pro bass fisherman.”

Jake loved flowers ...

What will she need?

The background is a light green color with abstract, darker green curved shapes in the corners. A large white circle is positioned in the lower-left quadrant of the slide.

How do I help without taking over?

Q & A
