

# Family Connections Center

## WHAT DOES IT TAKE to get to the good life?

From a young age, children dream about what they want to be, where they want to live, if they will get married and have a family, and what their life will look like when they are grown. Parents often encourage their children to dream big, even when it might seem like the dream is out of reach. It should be no different for a child with a disability or special health care need. As the child becomes a teenager, it is even more important for the youth and the family to have a vision of what the future might look like. Even as an adult, it is important to keep a vision of the future in mind into adulthood and senior years. The best gift a parent can give a child is optimism and high expectations, offering encouragement, support, and experiences to prepare for the road ahead. Think about shooting an arrow. You need to have a target at which to aim, or the arrow might go off course and not land where you would like. The goal is for the arrow to go towards the bullseye of the target. If the goal is to have inclusive, good lives in the community as adults, then from a young age the child and the family can begin to aim for that goal and set a path to get there. This is called a life trajectory. If individuals and families want to achieve enviable lives in the community, then they must have a vision of where the trajectory is aimed. What does a good life look like –what kind of things would be present? It's also important to think about what they know they DON'T want, so experiences and events don't push the arrow in that direction. By having a vision for the future from a young age, it is more likely the trajectory will lead the person to the good life of which they dream.



### What is the Charting the LifeCourse?

The LifeCourse framework is built on the core belief that all people have the right to live, love, work, play, and pursue their life aspirations. This framework was created BY FAMILIES to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Individuals and families may focus on their current situation and stage of life but may also find it helpful to look ahead to think about life experiences that will help move them toward an inclusive, productive life in the future. Even though it was originally created for people with disabilities, this universally-designed framework may be used by any person or family making a life plan, regardless of life circumstances.

Charting the LifeCourse is a tool to assist you in creating a vision for the future. It is designed to help you think about the questions to ask as well as the choices, options and life experiences to consider as you "plot a course" to a full and meaningful life. It is intended to be a starting point no matter where you are in your life journey.

Go to [www.lifecoursetools.com](http://www.lifecoursetools.com) for more details.

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# Food for *Thought*

## Permission to Fail...and Succeed

Revolutionary Common Sense by Kathie Snow, [www.disabilityisnatural.com](http://www.disabilityisnatural.com)

When my son, Benjamin, was in a general education kindergarten class, the teacher, Mrs. S, was uncomfortable having a child with a disability in her class. Despite lots of support from me, and the special education staff, she seemed content to let Benjamin "be" in her class, so long as she didn't have to exert any effort to help him learn. Which, of course, is exactly what happened: he wasn't learning, even though I know he could.

During an informal meeting with Mrs. S. and the supportive principal, I told her, "I know my son can learn, and I know you can teach him, but you have to be willing to try new things. I trust you enough to put my son in your care every day. You have to trust me enough to know that you can call me and say, "Today was a disaster – nothing worked!" Then you and I can figure it out together. My husband and I need to do this all the time. But if you don't give my son the opportunity to learn – by trying new things to see what works – he won't learn!"

Things got better after that. She was willing to try: she took risks and learned from mistakes, and that enabled her to teach my son. The principal later said to me, "You gave Mrs. S. 'permission to fail,' and everyone needs that. Before, she was unwilling to try things because she was afraid of failing; you let her know you didn't expect her to be perfect, and that enabled her to get out of her comfort zone and feel more confident about trying new things."

Being allowed to make decisions, take risks and try new things, and then learn valuable lessons from our mistakes is regarded as an important element in human growth and development, except in the disability arena. There, children and adults with disabilities are "protected" – and prevented from making their own decisions or taking any risks – so they remain helpless and dependent on others. (Do we ever take

responsibility for the consequences of our actions in creating this situation?)

Similarly, persons with influence (family members and educators, service providers, etc.) may also be unwilling to take risks on behalf of a person with a disability for a variety of reasons.

Like Mrs. S, a teacher may be unwilling to do things that are out of her comfort zone. A mother may be unwilling to allow her child to be in a general ed classroom, participate in community activities, etc., because she's fearful for her child's safety, or she may even feel embarrassed by or ashamed of her child – she's comfortable only when her child is with "others like him" in segregated environments.

How can we overcome our resistance to risk-taking and give ourselves Permission to Fail? One way is to ask, "What's the worst thing that can happen if [fill in the blank]?" Examining the potential worst-case scenarios can shore up our courage when we realize those scenarios are usually *not really* that risky after all. We can also ask, "What the *best* thing that can happen if [fill in the blank]?" Ahhh, envisioning positive outcomes can be highly motivating and (self-fulfilling)!

What will it take to give children and adults Permission to Fail? Let's remember *who* this is really about: do we dare allow our own fear or discomfort to impose limitations on another? And don't persons with influence have a *responsibility* to ensure that children and adults with disabilities have opportunities to be self-directed: to experience the dignity of risk, own their triumphs and tribulations, and benefit from the lessons learned? If we deny a person Permission to Fail, aren't we also denying Permission to Succeed?

Winston Churchill said, "Success is going from failure to failure without a loss of enthusiasm." Give yourself *and* people with disabilities Permission to Fail and you'll also be sowing seeds for success!

**I've missed more than 9000 shots in my career. I've lost almost 300 games. 26 times, I've been trusted to take the game-winning shot and missed. I've failed over and over and over again in my life. And that is why I succeed.**

**Michael Jordan**

# Did You Know

## Introducing Ivone Rego, Family Support Advisor and H.U.G.S. Support Group Facilitator

**Ivone Rego** has been working with the Family Connections Center at The Nemasket Group since 2016 as a Family Support Advisor. "I am a mother of two rambunctious kiddos who keep me on my toes. My son's ASD diagnosis was the catalyst that pushed me to become a better informed and participating parent. My thirst for knowledge led me to seek opportunities that would better prepare me to navigate the systems of special education. Through these pursuits, I was encouraged to work with other parents who were going through similar experiences and to use this information as a platform for parents with children on the Autism Spectrum." Ivone is also the facilitator for the Autism Spectrum Support Group organized through the Family Connections Center.



### **H.U.G.S is an Autism Spectrum Support Group open to parents, family members, guardians of people on the spectrum.**

This is an inclusive group and we encourage ALL families to join us and share their experiences and expertise. We recognize that it takes more than a village to raise a family, so LET'S BUILD A TRIBE.

This group meets every 2nd Tuesday of every month 10.30 a.m. at The Nemasket Group 109 Fairhaven Rd Mattapoisett. We guarantee you will Be HEARD, you will Feel UPLIFTED, we will help Promote GROWTH and Encourage SUPPORT.

For more information contact Ivone at 508 999-4436 ext 118

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## IMPORTANT DATES

**OCTOBER 17, 2018** - last day to register and be able to vote in the state election

**NOVEMBER 6, 2018** – State Election



# ABLE Accounts: 9 Things You Should Know

## What is an ABLE account?

ABLE Accounts, which are tax-advantaged savings accounts for individuals with disabilities and their families, were created as a result of the passage of the Stephen Beck Jr., Achieving a Better Life Experience Act of 2014 or better known as the ABLE Act. The beneficiary of the account is the account owner, and income earned by the accounts will not be taxed. Contributions to the account, which can be made by any person (the account beneficiary, family and friends), must be made using post-taxed dollars and will not be tax deductible for purposes of federal taxes, however some states may allow for state income tax deductions for contribution made to an ABLE account.

## Why the need for ABLE accounts?

Millions of individuals with disabilities and their families depend on a wide variety of public benefits for income, health care and food and housing assistance. Eligibility for these public benefits (SSI, SNAP, Medicaid) require meeting a means or resource test that limits eligibility to individuals to report more than \$2,000 in cash savings, retirement funds and other items of significant value. To remain eligible for these public benefits, an individual must remain poor. For the first time in public policy, the ABLE Act recognizes the extra and significant costs of living with a disability. These include costs, related to raising a child with significant disabilities or a working age adult with disabilities, for accessible housing and transportation, personal assistance services, assistive technology and health care not covered by insurance, Medicaid or Medicare.

For the first time, eligible individuals and their families will be allowed to establish ABLE savings accounts that will largely not affect their eligibility for SSI, Medicaid and other public benefits. The legislation explains further that an ABLE account will, with private savings, "secure funding for disability-related expenses on behalf of designated beneficiaries with disabilities that will supplement, but not supplant, benefits provided through private insurance, Medicaid, SSI, the beneficiary's employment and other sources."

## Am I eligible for an ABLE account?

The ABLE Act limits eligibility to individuals with significant disabilities with an age of onset of disability before turning 26 years of age. If you meet this age criteria and are also receiving benefits already under SSI and/or SSDI, you are automatically eligible to establish an ABLE account. If you are not a recipient of SSI and/or SSDI, but still meet the age of onset disability requirement, you could still be eligible to open an ABLE account if you meet Social Security's definition and criteria regarding significant functional limitations and receive a letter of certification from a licensed physician. You need not be under the age of 26 to be eligible for an ABLE account. You could be over the age of 26, but must have had an age of onset before the individual's 26 birthday.

## Are there limits to how much money can be put in an ABLE account?

The total annual contributions by all participating individuals, including family and friends, for a single tax year is \$15,000. The amount may be adjusted periodically to account for inflation. Under current tax law, \$15,000 is the maximum amount that individuals can make as a gift to someone else and not report the gift to the IRS (gift tax exclusion). The total limit over time that could be made to an ABLE account will be subject to the individual state and their limit for education-related 529 savings accounts. Many states have set this limit at more than \$300,000 per plan. However, for individuals with disabilities who are recipients of SSI, the ABLE Act sets some further limitations. The first \$100,000 in ABLE accounts would be exempted from the SSI \$2,000 individual resource limit. If and when an ABLE account exceeds \$100,000, the beneficiary's SSI cash benefit would be suspended until such

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time as the account falls back below \$100,000. It is important to note that while the beneficiary's eligibility for the SSI cash benefit is suspended, this has no effect on their ability to receive or be eligible to receive medical assistance through Medicaid.

Additionally, upon the death of the beneficiary the state in which the beneficiary lived may file a claim to all or a portion of the funds in the account equal to the amount in which the state spent on the beneficiary through their state Medicaid program. This is commonly known as the "Medicaid Pay-Back" provision and the claim could recoup Medicaid related expenses from the time the account was open.

### **Which expenses are allowed by ABLE accounts?**

A "qualified disability expense" means any expense related to the designated beneficiary as a result of living a life with disabilities. These may include education, housing, transportation, employment training and support, assistive technology, personal support services, health care expenses, financial management and administrative services and other expenses which help improve health, independence, and/or quality of life.

### **Can I have more than one ABLE account?**

No. The ABLE Act limits the opportunity to one ABLE account per eligible individual.

### **Do I have to wait for my state to establish a program before opening an account?**

No. While the original law passed in 2014 did stipulate that an individual had to open an account in their state of residency, this provision was eliminated by Congress in 2015. This means that regardless of where you might live and whether or not your state has decided to establish an ABLE program, you are free to enroll in any state's program provided that the program is accepting out of state residents.

To determine which state ABLE programs are accepting out of state programs, please refer to the individual state pages. Examples of state ABLE programs accepting enrollment nationwide include: Ohio, Nebraska, and Tennessee. An example of a state ABLE program only accepting in-state residents would include the Florida ABL United program.

### **Will states offer options to invest the savings contributed to an ABLE account?**

Like state 529 college savings plans, states do offer qualified individuals and families multiple options to establish ABLE accounts with varied investment strategies. Each individual and family will need to project possible future needs and costs over time, and to assess their risk tolerance for possible future investment strategies to grow their savings. Account contributors or designated beneficiaries are limited, by the ABLE Act, to change the way their money is invested in the account up to two times per year.

### **How is an ABLE account different than a special needs or pooled trust?**

An ABL Account will provide more choice and control for the beneficiary and family. Cost of establishing an account will likely be considerably less than either a Special Needs Trust (SNT) or Pooled Income Trust. With an ABL account, account owners will have the ability to control their funds and, if circumstances change, still have other options available to them. Determining which option is the most appropriate will depend upon individual circumstances. For many families, the ABL account will be a significant and viable option in addition to, rather than instead of, a Trust program. For more information, the webinar on ABL Accounts, Trusts, Financial and Benefits Planning is archived on our website along with its slides and transcript.

Go to [www.ablenrc.org](http://www.ablenrc.org) for more information

## DID YOU KNOW THAT OCTOBER IS



## NATIONAL DISABILITY EMPLOYMENT AWARENESS MONTH

The United State Department of Labor recognizes National Disability Employment Awareness Month as a time to "educate about disability employment issues and celebrate the many and varied contributions of America's workers with disabilities."

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### Autism Insurance Resource Center DDS Autism Waiver Open Interest Period

The opportunity to apply for this waiver through an open request application period will be held from October 17 - 31, 2018

The Autism Division of the Department of Developmental Services (DDS) runs a Autism Waiver Program that provides one-to-one interventions to help children with autism who exhibit severe behavior, social and communication problems through a service called Expanded Habilitation, Education (intensive in-home services and supports for an average of 6-8 hours per week). This service occurs in the child's home or other natural settings under the supervision of trained clinical staff and is available for a total of three years. The waiver also provides related support services such as community integration activities and respite. At the conclusion of the three years of intensive services, a child may access supplemental services that meet the child's needs and help with the transition out of the intensive Autism Waiver Program until the child's 9th birthday.

**If you wish to have your child/children considered for the Autism Waiver Program then you must complete the one-page Application Request Form that is attached to this letter. All prior application forms from the last open request period are no longer valid.**

For more information on the waiver program, please contact us at 774-455-4056.

# Upcoming *Events*

## Commissioner's Turning 22 Town Hall Meeting

With: Commissioner Jane Ryder

Date: Wednesday, October 24, 2018

Time: 6:00 p.m. to 8:00 p.m.

Why: To solicit information and feedback from families and individuals to improve the transition process for young adults eligible for DDS services.

Where: The Southeast Regional Office  
151 Campanelli Drive, Suite B, Middleboro, MA 02346

R.S.V.P. By October 19, 2018  
To Jennifer Jensen at 508-866-8872 or [Jennifer.jensen@state.ma.us](mailto:Jennifer.jensen@state.ma.us)

**Light refreshments will be served.**

The Dartmouth SEPAC invites you to:

6<sup>th</sup> annual Southeastern MA  
COMMUNITY RESOURCE  
& CRAFT FAIR

**SUNDAY  
28<sup>th</sup>  
OCTOBER**

Date: Sunday October 28<sup>th</sup> 2018  
Time: 10am until 3pm  
Location: Dartmouth High  
555 Baskerville Road  
Email: [DartmouthSEPAC@gmail.com](mailto:DartmouthSEPAC@gmail.com)

**\*\*FREE and OPEN to the PUBLIC\*\***

# DREAM EXPLORE PLAN

Transition planning begins when a student on an IEP turns 14 and continues throughout their high school and young adult years. It is important that families, students, and professionals use this time to collaboratively plan a post-secondary vision in preparation for life after high school. The process can be overwhelming, so connecting students and families to resources, information, and services is a central goal of Planning a Life.

Offered three times each year at locations across the state, **Planning a Life (PAL)** is a two-day Transition planning conference with information and resources for families, educators, and professionals.

**Our next Planning a Life conference will be held on October 25 and 26** at the Brockton Area Arc. Each day's session will run from 8:30am – 4:00pm. The registration price is \$125 per individual or \$175 per family/professional. Scholarships are available – please contact us for more information.

Federation for Children with Special Needs  
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Email: [fcsninfo@fcsn.org](mailto:fcsninfo@fcsn.org)

## Joining Voices 2018

***Using the Power of Your Story for Positive Change***

**November 13, 2018** (8:30am – 3:00pm)

Edwards House Meeting and Retreat Center | Framingham, MA

Joining Voices is an annual event sponsored by the Federation for Children with Special Needs for families of children and youth with special health needs (CYSHN) and their professional partners. The conference promotes effective advocacy for children, informed decision-making around healthcare services and supports, and collaborative partnerships between parents and providers.

This year Elaine Gabovitch, Director, Division for Children and Youth with Special Health Needs, MA Department of Public Health will be the keynote speaker. Elaine's presentation, *Your Story Matters-- How to tell It and Be Heard*, discuss's how to effectively share your story with organizations like DPH for positive change in your family's life.

Please visit the conference website for a full list of presentations, speakers and registration information. [fcsn.org/mfv/joining-voices](http://fcsn.org/mfv/joining-voices)