

Family Connections Center

To Save Disability Community Programs, GOP Disability Allies Must Speak Out!

THIS IS THE FIGHT OF OUR LIVES to protect health and human services!!!

from Gary Blumenthal, ADDP

The 52 year old Medicaid program will end if the Trump/Ryan American Health Care Act (AHCA) passes the Senate, intact with a mostly unknown and not understood provision that seeks to end Medicaid eligibility standards, instead making Medicaid into a block grant program and reducing it by over \$880 Billion over the next 10 years. Medicaid, known as MassHealth in Massachusetts, is the source of funding for nearly all community developmental disability and brain injury services across the nation, funding anywhere from 50% to 90% of these programs dependent upon the state formula match.

Gutting Medicaid has long been the goal of U.S. Speaker Paul Ryan, who included an identical provision in many prior year failed budgets. In the 2016 presidential campaign, candidate Donald Trump promised to protect Medicaid, but his House passed healthcare plan fully endorses Ryan's draconian cuts to the program.

If Medicaid is converted to a Paul Ryan envisioned Block Grant, here's what will happen:

- \$838 Billion will be eliminated in Medicaid spending over the next decade
- Massachusetts will lose \$1.3 billion to \$1.5 Billion in the first year, and then substantially more in additional years
- Governors will be forced to choose between cutting budgets or dramatically raising taxes to make up for budget reductions
- Disability programs will be forced to compete against elder services, children's services, mental health, maternal health care programs, education and all other human service and poor folks health services for limited appropriations, including the 14 million who will lose health care across the nation with an AHCA repeal.
- Disability service waiting lists will dramatically expand with little chance for new individuals being served with less dollars being available
- Governor Baker's ACO program, expecting \$5 Billion in discretionary Medicaid Waiver dollars will be in great jeopardy.

The key to defeating Trump/Ryan Care, and the destruction of Medicaid, will be decided by the Members of the U.S. Senate, controlled 52 to 48 by the Republican Party. To defeat the AHCA, 3 members of the Republican Party will need to join with the 48 Democrats to protect Medicaid and prevent an \$880 Billion cut to Medicaid.

Disability advocates will need to encourage their friends, family and allies who live in states with Republican Senators to understand the damage to key programs and people's lives if Medicaid is made into a Block Grant and then gutted. Cutting Medicaid will have negative economic consequences for the economy. Millions of jobs will be lost with programs discontinued; families will struggle for help; health care costs will skyrocket with uncompensated health care costs being unpaid and costs transferred to others; waiting lists will grow and parents will lose jobs having to opt to stay home to care for their loved ones dismissed from community programs. **We urge you to reach out to your friends and family in other states and urge them to call upon their Republican Senators to save Medicaid.**



DDS COMMISSIONER ELIN HOWE TO RETIRE JULY 14TH

It is with deep regret that we have learned that Department of Developmental Services Commissioner Elin Howe will be stepping down from her position on July 14, 2017, coinciding with her ten year anniversary as the leader of DDS. Commissioner Howe was first appointed to the helm of the then Department on Mental Retardation (DMR) by former Governor Deval Patrick, and then reappointed by Governor Charlie Baker in 2015.

Commissioner Howe has been viewed by members of the advocacy, self-advocacy, family, provider and legislative community as **an extraordinarily talented manager** bringing together diverse elements of the community in the pursuit of best outcomes, supports and lives for the people impacted by the department's services and programs. Howe's reputation for leadership, innovation and determination made her a respected national leader in the disability field. **She was often cited as the best DDS Commissioner in the nation.**

Legislators, advocates, family members and providers respected her for her devotion to people with disabilities, transparency and excellent leadership. Her door was always open to those who agreed with her policies and priorities and those who had differing opinions.

During her term in office, historic achievements occurred, including

- the closure of four state institutions
- the expansion of the community system
- the dramatic movement of people with I/DD from nursing homes into more inclusive community based systems
- the expansion of Family Support programs
- the changing of the name of the Department from DMR to DDS
- the recognition of self determination
- the closure of sheltered workshops
- the expansion of Community Based Day Supports
- the development of the Blueprint for Employment of People with I/DD
- the endorsement of Positive Behavioral Supports
- expanding efforts to promote greater Social Inclusion
- expansion of DDS Services to people with Autism
- Implementation of the National Background Check Law
- Enactment of the Autism Omnibus Bill
- Tremendous increase of FFP Medicaid Revenue to help balance the state budget during time of significant budget crisis
- Expansion of Home and Community Based Waivers
- Expansion of Residential Services to People with Brain Injuries
- Increased respect for the provider and advocacy communities.
- Protection of DDS Programs from deep budget cuts during the Great Recession.

The departure of Commissioner Howe is coming at a particularly difficult time when programs, such as DDS are threatened by the efforts of the Trump Administration to cut over \$880 Billion from Medicaid (the source of 50% of DDS funding); and during a time when authority in EOHHS appears to shifting away from program specific departments and towards centralized and less program specific control at Mass Health and its contracted third party agents. Commissioner Howe was widely respected for standing up for her department's goals, during both the Patrick and Baker Administrations. **It is hoped that Governor Baker will take an active role** in the selection of her successor to ensure that a wide array of voices are heard within his Administration.

Food for Thought

BEYOND HIGH SCHOOL: COLLEGE AND MORE!

by Kathie Snow, www.disabilityisnatural.com

What do we dream for students with disabilities? That after high school, they enter the adult service system, move into a group home, join a waiting list for vocational services, enter a sheltered workshop, and/or take an entry-level position at a fast-food restaurant, attached at the hip to a job coach (a job that – some believe – will be the highest position the student will ever attain)?

Low expectations are the bane of teenagers and young adults with disabilities. Too many of us – parents, family members, educators, and others – don't believe in their *unlimited potential*. On the other hand, we may feel the student is capable of successfully entering the real adult world of post-secondary education and work, but we don't believe other people (college instructors, employers, etc.) will "accept" the young person with a disability. Simultaneously, unwritten – and erroneous – rules such as, "People with Down syndrome [or other conditions] can't go to college," dictate our actions.

In any case, life after high school is often the *beginning of the end* for many students with disabilities. Hopes and dreams are quashed when the "reality" of the adult world is faced. But it doesn't have to be that way! Students with disabilities can and should pursue their dreams of college, vocational schools, employment, and anything else!

The first step to a successful life is, of course, to dream big dreams! Parents must dream with and for their children. That doesn't mean we should dream specific dreams: "Ryan will be a lawyer." It does mean, however, that we talk to children, throughout their lives, like this: "When you grow up and [go to college, get a job, drive a car, get married, or whatever]." *And*, we need to really listen when children say, "When I grow up, I want to be a -----" and then we need to support those dreams every way we can. A child can make such a statement, however, only if he's heard his parents or other significant adults say, "You

can be whatever you want to be!" If this isn't a regular part of your conversations, start saying it now and say it often!

I hope you're not shaking your head, thinking, "She doesn't know *my* child! My son can't be anything he wants! I don't want to give him false hope." If this is *your* frame of mind, then you're probably right – *your child won't achieve much*. Your child's lack of success won't occur because he has a disability, but as a result of your not believing in him! Children see themselves through our eyes, at least until they're old enough to escape our influence and can carve their own identities. If we believe in them, *they can believe in themselves*. And nothing great has ever been achieved without high expectations!

It's also important to remember that children and young adults may change their minds many times! Most of us did – I've never done any of the jobs I talked about as a child! So it's important that we not get hung up on any particular hope a child may have. Things change!

My 19-year-old son, Benjamin, has had many dreams. When he was younger, he wanted to be a newspaper reporter, a TV weatherman, the host of *Jeopardy!*, and more. One day he announced, "I'm going to be a professional basketball player like Michael Jordan." I didn't reply, "Honey, you have cerebral palsy and use a wheelchair. That's not a realistic dream." I knew *Benj* would figure out what was right for him as time passed. As a young teenager, he wanted to be an actor, so we enrolled him in drama lessons and he performed in several plays. Today, he wants to be a film critic (the next Roger Ebert), and have a newspaper column, TV show, and more! He may change his mind again and again about his career path, and that's okay! We'll move on to the next dream with him. *Supporting a young person's dreams is the most important step in helping him become a successful adult.*

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The next step is to figure out what needs to happen to make the dream a reality. Some young people know exactly what they want to do and may not need formal post-secondary education to achieve their career goals. In another article (“On Becoming a Business Owner”), employment guru Cary Griffin details strategies that can enable people with disabilities to become successfully self-employed. A young adult’s dreams may, however require college or post-secondary training. Simultaneously, *exposure* to the career – a job in the field or even volunteer work – may be helpful.

At age 14, my daughter wanted to be a pediatrician. Emily loved being with babies and young children, and she was a busy babysitter. I recommended she volunteer in a hospital to see if she enjoyed the “medical environment.” As a junior volunteer for more than a year, she gained experience in different parts of the hospital, and enjoyed meeting new people and learning new things. She also decided a medical career was *not* for her!

Several months later, Emily thought she wanted to be an interior designer. We talked about it, did a little research, talked some more, and she enrolled in an interior design correspondence course. She tackled the first half of the lessons with enthusiasm. But over the next several months, her interest waned. She didn’t think this was the career was for her. Nevertheless, she completed the course and enjoyed redecorating her bedroom, using her new-found knowledge. Knowing what we *don’t* want to be as valuable as knowing what we *do* want!

If a young person isn’t sure which career path to take, it’s time to explore, beginning with the person’s interests. What does she enjoy doing? We’re all happiest when we do what we love!

Although Emily decided she didn’t want to be a pediatrician, she still liked the idea of having a career that involved being with young children, so we discussed jobs where that could happen: working in (or owning her own) private preschool or daycare center; being a professional nanny; and so forth. Because Emily has taken ballet for several years, I suggested she might consider teaching ballet to the youngest ballerinas.

Again, we don’t need to get hung up on a specific dream job. Let’s explore all the jobs that could fulfill a person’s hopes, interests, and needs.

If “Ryan” thinks he wants to be a lawyer, we can help him explore that career, along with other jobs associated with trials and courts: paralegal, court reporter, court clerk, and so forth. It’s important to learn what a person thinks or knows about the actual job they envision.

For example, when Emily pictured herself being a pediatrician, she saw herself being with children. She didn’t envision blood, needles, urine exams, and more. If I had said, “You can’t be a pediatrician – you can’t stand the sight of blood!” I would have crushed her hopes and/or she could have decided to pursue that career to prove me wrong and herself right! Her first-hand experience (volunteering) helped her decide.

It’s important to help young people learn as much as they can, and let them make the decision. *Whose life is it anyway?* We can help a young person research a career path, visit places where those careers take place, introduce them to people in those careers,

and more. Be wary, however, of “official” vocational/career aptitude tests. These may reveal a student’s *abilities* for a particular job, but these may not represent the career the student actually *wants*. Parents, educators, and others may push a student in the wrong direction based on the results of a test!

When helping a young person explore careers of interest, don’t let the “way things are” get in the way of “what can be.” Remember: *the possibilities are endless!*

In some states, students who receive special ed services do *not* receive a high school diploma; instead they receive a “certificate of attendance.” This might be seen as a barrier to the student moving on to post-secondary education, but it doesn’t have to be! Many children who are homeschooled do not receive a high school diploma; instead, they take the GED (General Educational Development) test and go on to college. Students with disabilities can do the same thing. A wide variety of GED study guides are available at public libraries and bookstores, and free practice tests are available on the Internet. (And see my article, “Diploma or Certificate” for more helpful info about this issue.) In addition, with the advent of homeschooling via the Internet, students can take classes online and earn a diploma that way.

It’s important to help a young person learn as much as she can, and let her make the decision. *Whose life is it anyway?*

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At many community colleges, a diploma, GED, and/or SAT tests are not required! Instead, students simply take the college's placement tests. Today, my son is in his second semester of college while he is *simultaneously* studying for his GED. In essence, a GED or high school diploma is the "ticket" to financial aid. Since Benjamin doesn't have his GED yet, we're paying for his tuition. And, in many states, *four-year schools* waive the Act or SAT test for students transferring from community college!

Students can earn a two-year degree at community college, or use the two years to earn credits before transferring to a four-year college! Many community colleges also offer vocational/trade programs in auto mechanics, electrical, and more.

Sadly, many students who receive special ed services are *not* receiving the education they need to easily move into post-secondary education. Even this barrier can be overcome, as evidenced by the experience of a woman who shared her story with me.

In high school, "Robin" enthusiastically announced that she wanted to be a preschool teacher. Her parents and special ed teachers assured Robin she could do "anything she wanted," but *they did nothing* to actually support her dream of going to college for a two-year degree. When she finished high school, Robin took the community college entrance exam, and was shocked and saddened by the results: "They said I tested at an elementary school level."

Throughout her public school years, Robin had *not* received the education she needed to fulfill her dream. And she didn't know this at the time – how could she? Robin was a child, segregated in special classrooms, with no access to the general curriculum. But surely her parents and teachers knew it, and she was hurt and angry that they deceived her.

All was not lost, however. In her mid-20s, Robin took the bull by the horns, studied on her own, asked for and received study help from others, passed her GED, entered the community college, and received her degree. It wasn't easy and it took a long time, but Robin made it happen. *Why, though, did it have to happen the way it did?*

The lessons from Robin's experience are profound. We must really listen to a student's dreams: we must take them seriously, even while knowing they

may change – many times! Then we must do whatever is necessary to support those dreams. Parents, educators, and other adults in the student's life all have a role to play in this life-altering endeavor.

Before deciding something "isn't possible," do the research! Help the student learn how to call or write the schools (university, community college, trade school, etc.) that she may be interested in attending to learn about admission requirements and procedures. Take a tour of the school and get a taste of the environment. Help the student find out what it would take to visit some of the classes. Talk to teachers and students. And do all this with a "can-do" attitude – *your* attitude will rub off on others!

Even if a student doesn't have the academic strengths (or the desire) to master college-level curriculum, the "college experience" can be a valuable addition to the young person's life! A student with a disability (just like other students) can "audit" classes – attending classes without receiving grades or college credit. Learning whatever she can in those classes, making friends, and having new and different experiences can enrich the life of a young person and ensure her success. Furthermore, *adults* with disabilities of all ages can and should explore post-secondary education as way of broadening their horizons and meeting their career goals.

Politicians, business leaders, educators, and others routinely say, "Children are our future." It seems, however, that students with disabilities have *not* been included in this credo, and this must change! Whether a young person with a disability wants to be a butcher, a baker, a candlestick maker – or a hairdresser, actor, lawyer, teacher, doctor, auto mechanic, or President of the U.S.A. – we can help turn a student's career dream into a reality. The time is right to make sure "*All* children – including those with disabilities – are our future."

UPDATE; Since the time this article was originally published, a variety of "special" college programs for students with disabilities have been created at many universities across the country. These seem like a "good idea," but most simply replicate public school "life-skills" classes on a college campus. Proponents say they're "inclusive," but most are not, in reality. Furthermore, they're open only to a select few, and many require students to be SSI recipients (for tuition, plus more moola from parents). Why are we creating more segregation? We can do better!

Available Resources

Disney Guide Aims to Help Guests With Special Needs

by Eric Schwartzberg, Journal-News/TNS | March 7, 2017

WEST CHESTER TOWNSHIP, Ohio — When Amy Schinner realized there wasn't a comprehensive guide for guests with special needs to travel to Disney World, she decided she needed to write one. The mother of two said her epiphany arrived at a bookstore following her family's fifth trip to the theme park, the "happy place" for her 19-year-old son Ben, who has autism.

"I was looking at the different guides to Walt Disney World and I realized there were books for many reasons, including the single person's guide," she said. "I was surprised nobody had written one for people with disabilities. I feel like this information is vital for a lot of families to have a successful vacation at Disney."

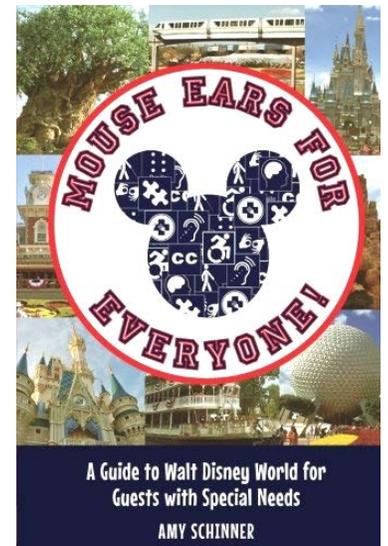
"Mouse Ears for Everyone: A Guide to Walt Disney World for Guests with Special Needs" is packed with information and tips for traveling to Disney World with a focus on needs for people with disabilities, including accessibility, sensory issues, dietary needs, emotional health, medical concerns, visual and hearing impairments as well as developmental disabilities. "Originally the book was just going to focus on autism, but so many people with autism spectrum disorder need wheelchairs, gluten free foods, have seizure disorders and service animals, that it didn't require too much more to make it a more encompassing book," Schinner said.

Schinner indicated that she started working on the project around four years ago, and there have been a few stops and starts along the way, especially when Disney Parks changed most of their policies concerning access in the parks. The book is organized in a similar fashion to many Disney guides. There are chapters for choosing a hotel, preparing for the trip, traveling and a chapter for each park. Through all of them, Schinner weaves the needs of people with disabilities. "For example, I review each hotel but I use a lens for accessibility, sensory needs, etc.," she said. "The same is true for all of the attractions and most of the restaurants. Then I also have a very detailed special needs chapter."

Although there is much more to a visit to Disney World than just the lines, it's an important issue for many and the book explains how park policies work to help families of those with special needs. "I think people would be surprised at how welcome service dogs and emotional support animals are in the parks," she said. "They can even ride many of the rides, although they have to skip Space Mountain. You just need to have the certified paperwork."

Schinner said "Mouse Ears for Everyone" was an important book for her to write. "I am asked all the time how we manage to travel and especially, how do we do Disney?" she said. "It does require planning, probably more than most vacations, but if you know what accommodations are available, and how to navigate it all, it can not only be done, but you can have a wonderful time." She's been touched by all the comments received since the book's February release. "Families have been waiting for this information for quite a while," she said. "I was thrilled to have likes and shares from all over the country."

Mouse Ears for Everyone is available for purchase online at sellers like [amazon.com](https://www.amazon.com)



85 MUSEUMS & CULTURAL EVENTS 10 FRIDAYS. 100% FREE FREE FUN FRIDAYS!



JUNE 23

Lyric Stage Company of Boston
Mary Baker Eddy Library
The Sports Museum
Clark Art Institute
The Mount: Edith Wharton's Home
Worcester Art Museum
Peabody Essex Museum
The Discovery Museums

JUNE 30

Boston Children's Museum
MIT Museum
Norman Rockwell Museum
Springfield Museums
EcoTarium
Maritime Gloucester
New Bedford Whaling Museum
The Gardens at Elm Bank (Mass Hort)

JULY 7

Isabella Stewart Gardner Museum
New England Historic Genealogical Society
Ventfort Hall Mansion and Gilded Age Museum
Mahaiwe Performing Arts Center
Amelia Park Children's Museum
Falmouth Museums on the Green
Pilgrim Hall Museum
Children's Museum in Easton
The Hall at Patriot Place

JULY 14

Edward M. Kennedy Institute
The Metropolitan Waterworks Museum
Harvard Museums of Science & Culture
Larz Anderson Auto Museum
Provincetown Art Association and Museum
Edward Gorey House
Museum of Russian Icons
Cape Ann Museum

JULY 21

Museum of Fine Arts, Boston
Tanglewood
Boston Athenæum
The Museum of the NCAA
Fruitlands Museum, The Trustees
Spellman Museum of Stamps & Postal History
Lynn Museum
Hancock Shaker Village
Sandwich Glass Museum

JULY 28

JFK Presidential Library and Museum
Commonwealth Museum
Arnold Arboretum
The Eric Carle Museum
Berkshire Theatre Group
Historic Deerfield
Cape Cod Museum of Art
Wenham Museum
Tower Hill Botanic Garden

AUGUST 4

Commonwealth Shakespeare Company
Old State House
The Greenway Carousel
Fort Devens Museum
Children's Museum at Holyoke
International Volleyball Hall of Fame
The Old Manse, The Trustees
JFK Hyannis Museum

AUGUST 11

Franklin Park Zoo
Fuller Craft Museum
Cape Cod Maritime Museum
Worcester Historical Museum
Griffin Museum of Photography
Fitchburg Art Museum
Jacob's Pillow Dance
Smith College Museum of Art
Naumkeag, The Trustees

AUGUST 18

The Institute of Contemporary Art/Boston
Old Sturbridge Village
Freedom Trail® Foundation
Buttonwood Park Zoo
Cape Cod Children's Museum
Concord Museum
Berkshire Museum
Emily Dickinson Museum

AUGUST 25

Boston Harbor Islands National and State Park
USS Constitution Museum
Plimoth Plantation
MASS MoCA
Nantucket Whaling Museum
The Children's Museum of Greater Fall River
Museum of African American History
Cape Cod Museum of Natural History
Heritage Museums & Gardens

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ABLE ACCOUNT OVERVIEW

What is an ABLE account?

In late 2014, the Stephen Beck Jr., Achieving a Better Life Experience Act, better known as the ABLE Act was passed into law. ABLE accounts are tax-advantaged savings accounts for individuals with disabilities. The designated beneficiary of the account is the account owner and any earnings on distributions used for qualified disability expenses will not be subject to federal income tax*.

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 with very limited assets. ABLE account assets will not be counted towards means tests unless the ABLE account balance exceeds \$100,000. If an ABLE Account exceeds the \$100,000 limit, certain SSI benefits may be suspended. For more information on SSI eligibility and benefits, please visit www.ssa.gov.

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, assisting a working age adult with disabilities, providing accessible housing and transportation, personal assistance services, assistive technology and health care not covered by insurance, Medicaid or Medicare. The ABLE legislation explains 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."*

Starting in the Spring of 2017 eligible individuals and their families will be allowed to establish an ABLE account with the Massachusetts Educational Financing Authority (MEFA). Visit mefa.org for more information on the program launch.

Who is eligible for an ABLE account?

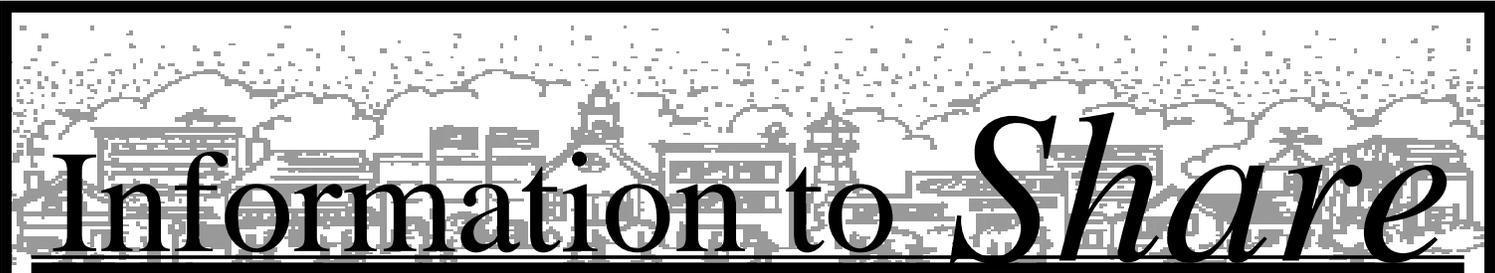
In accordance with the ABLE Act, individuals are eligible to open an ABLE account if they certify that they are receiving benefits under Title II or Title XVI of the Social Security Act (SSA) or that they have a physician's letter that certifies the individual meets certain disability requirements as defined by the SSA. Also, under both circumstances, the disability must be onset before age 26. For more information on ABLE account eligibility requirements, please visit www.ssa.gov.

Annual Contribution Limit for 2017 is \$14,000 – contributions can be made by anyone.

Only one ABLE account per eligible individual is permitted.

***Qualified disability expenses 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.**

Fidelity does not provide legal or tax advice. The information herein is general in nature and should not be considered legal or tax advice. Consult an attorney or tax professional regarding your specific situation.



Information to Share

SELF-DIRECTION & CONNECTIONS

June 8, 2017

6:00PM – 8:00PM

Central Congregational Church
2 Webster Street, Middleboro, MA 02364

An opportunity to learn about Self-Directed Services and other innovative services which are helping individuals with disabilities connect with people in their community.

Opening Remarks

Rick O' Meara, Regional Director, Southeast Region
Department of Developmental Services

You're With Us!

Michael Plansky

You're With Us! seeks to create better communities by harnessing the benefits of inclusion for the disabled. We believe that not only do people with disabilities need inclusion opportunities in order to thrive, but also that these opportunities allow them to contribute to their community in ways that have gone unrecognized in the past. *You're With Us!* does this by identifying and training college clubs, groups, and teams to be welcoming and supportive peers to the disabled. The college group then creates and supports a Positive Experience Design (PED) customized for the young adult to help him or her transition from school to an adult life in the community. <http://www.yourewithus.org>

Self – Directed Services: Taking Control of Your Future

Ed Wilson, Southeast Regional Manager, Self-Directed Services

Individuals and their family can determine their vision and strive to achieve it by creating their own individualized supports. This presentation will provide an overview of Self-Direction as well as traditional service options. The presentation will be given by Ed Wilson the Regional Manager for Self-Directed Services in the Southeast Region. In addition, parents whose children are receiving Self-Directed Services will also share their stories.

To register please contact Raquel Pereira at Raquel.pereira@state.ma.us

Registration Deadline is June 5, 2017



Save the Date!

Summer Sizzler



Date: August 17, 2017

(rain or shine)

Time: 5:00 – 8:00 p.m.

Location: Mattapoisett YMCA
38 Reservation Road
Mattapoisett, MA



Bay Club

Save the Date

Monday, August 28, 2017

The Louis Nisenbaum Memorial Golf Tournament
to benefit The Nemaasket Group