

"Charting Life's Journey to 22 and Beyond"

Saturday, April 4, 2020 MMArc: 35 Forest Ridge Road, Concord, MA 01742

Minute Man Arc welcomes parents and guardians who have a loved one with an

intellectual/developmental disability and are seeking the essential information needed for future planning. These workshops will not only address the "nuts and bolts" in preparing for the next phases that your family will encounter, but will also consider the *whole person* i.e. how to help prevent loneliness and assist others in enriching and supporting this individual's life.

Please join us as we strive to educate, inform and assist you and your family as you plan the best life for your loved one.

Professionals are welcome to attend as well.

## Schedule:

8:15 Registration, coffee, light refreshments

8:45 Opening remarks

9:00-10:15 Choose <u>either</u> 1A or 1B:

1A: **Planning for Two Generations** John Nadworny,  $CFP^{\mathbb{R}}$  and Alexandria Nadworny,  $CFP^{\mathbb{R}}$ , Special Needs Financial Planning, a specialty practice of Affinia Financial Group

1B: Guardianship: Exploring the Options Meredith Greene, Attorney, Fletcher Tilton

10:20-11:35 Loneliness: The Great Unspoken Crisis – and the Strategies You Need to Fight It -Cheryl Ryan Chan, Person-Centered Planning Practitioner and legislative activist, and Jeffrey Keilson, Senior Vice-President for Advocates, Inc. and Co-founder of Rewarding Work

11:40-12:10 Lunch (provided)

12:15-1:45 **Ask the Agency:** Representatives from the Department of Developmental Services Northeast Regional Office will provide information and answer questions regarding: Transitioning to Adulthood • DDS Eligibility • Adult Autism Services

Amy Nazaire, Regional Family Support Director Cindy O'Donnell, Regional Eligibility Manager/Regional Clinical Director Lea Hill, Regional Autism Program Coordinator Ken Underwood – Assistant Area Director from the Central Middlesex DDS office will be present as well.

1:50-3:15 Thinking About Housing - Catherine Boyle, President of Autism Housing Pathways

Full Workshop Descriptions and Bios: (below)



**Planning for Two Generations** John Nadworny, CFP<sup>®</sup> and Alexandria Nadworny, CFP<sup>®</sup>, Special Needs Financial Planning, a specialty practice of Affinia Financial Group

Special Needs Financial Planning is planning for *two generations*. Many children with a disability must be supported their entire lives, even long after their parents have died. Our approach reaches beyond the limited boundaries of wills and trusts to provide you with a road map to address your own family's Special Needs.

**Planning for Two Generations** centers upon our Special Needs Planning Timeline<sup>™</sup>. The timeline highlights the various planning pressure points where parents should be aware of changes relating to their child's benefits, legal and financial issues. The primary focus in this session will be planning for transition and will include a discussion of housing and creating a team to carry on when you can no longer do all you do to care for your child.

## John Nadworny, CFP®, CTFA

Partner, Wealth Advisor

Special Needs Financial Planning, a specialty practice of Affinia Financial Group

John began his practice as a Certified Financial Planner and Investment Manager focused upon helping individuals plan for their life goals: financial security, education, home ownership, retirement and other traditional financial milestones. He continues to have a thriving practice advising clients with traditional goals but began to explore planning on a different level after the birth of his son, James, now 29(!), who has Down Syndrome.

He teamed with the like-minded Cynthia Haddad to establish Special Needs Financial Planning and to coauthor the ground-breaking book, *The Special Needs Planning Guide: How to Prepare for Every Stage of Your Child's Life* (Brookes Publishing, 2007). As a thought leader/subject matter expert on the topic of planning for people with disabilities, John has been quoted extensively in the media. Investment News devoted their September 2017 issue to planning for individuals with special needs and chose to feature John and James as their cover story. They produced the video, *A Father First*, telling the story of John's interwoven personal and professional lives.

Key to the mission of Special Needs Financial Planning is educational outreach. Having served on boards of many advocacy organizations for decades, John currently serves on the Board of Directors of the Arc of Massachusetts and the Massachusetts Real Lives Law Advisory Committee.

# Alexandria Nadworny, CFP®, CTFA

### Wealth advisor

Special Needs Financial Planning, a specialty practice of Affinia Financial Group

Alex brings her experience as a Certified Financial Planner<sup>®</sup> Professional, and her empathy and knowledge as a sibling and future guardian of her brother James, to advising families of individuals with special needs. She has become a sought-after speaker on the topic of building a Team to Carry On<sup>™</sup>, encouraging and guiding families to plan for when they are no longer



able to do all they do for their loved one.

As well as building her own general wealth management practice, Alex is a key member of the Special Needs Financial Planning team, working with client families to educate and advise the next generation of family members. She is a co-author of *SibTips*, an e-book outlining tips and vocabulary for brothers and sisters of individuals with special needs. Alex is an active participant in several organizations and fundraisers designed to benefit individuals with disabilities. She is the former President and current Vice President of the Massachusetts Guardianship Association (MGA), on the board of the local Department of Developmental Services (DDS) Citizens Advisory Board, and the area liaison to the Massachusetts statewide Advisory Council.

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## Guardianship: Exploring the Options - Meredith Greene, Attorney, Fletcher Tilton

As caregivers for children with special challenges, obtaining timely information is crucial. Toward that end, Attorney Meredith Greene will focus on the variety of legal options that are available when your child turns 18 and the pros and cons as you make that decision. Additionally, she will speak about the importance of the Special Needs Trust and the process of creating one. Time will be allotted for questions.

**Meredith Greene** is the chair of the Special Needs Practice Group at Fletcher Tilton and an Officer with the firm's Trust & Estate Department. As both an attorney and a mother to a child with Williams Syndrome, Meredith brings both competence and passion to her work. Her practice focuses on special needs planning, estate planning, guardianship & conservatorship, elder law, adult services advocacy, and government benefits advocacy. She was trained as a parent advocate through the Federation for Children with Special Needs and is a member of numerous professional organizations including Council of Parent Attorney and Advocates, Inc., Special Needs Advocacy Network, Inc. and National Academy of Elder Law Attorneys. Meredith is on the Board of Directors at Minute Man Arc, is a parent-mentor through MMA's Early Intervention Program, and participates in Operation House Call through the Arc of Massachusetts.

Attorney Greene received her law degree, cum laude, from Suffolk University Law School and her BA in political science from the College of the Holy Cross, where she captained the women's soccer team.

## **Loneliness: The Great Unspoken Crisis – and the Strategies You Need to Fight It** *Cheryl Ryan Chan* and *Jeffrey Keilson*

Loneliness is among the key factors in contributing to poor physical and mental health, early mortality rates, and a diminished quality of life across the board. Myths and misunderstanding of people with disabilities, systems limitations, and other factors have contributed to this crisis. Families, educators, providers, and medical professionals can all contribute to combating loneliness through the lifespan with an approach that starts early and is built intentionally.



We will present an overview of current statistics on loneliness, contributing factors and consequences to citizens, followed by strategies for preparing, identifying, and building sustainable relationships through the lifespan.

**Workshop Learning Objective:** Participants will learn person-centered strategies for building Circles of Support, and how to shift the conversations with caregivers from "I am the friend" to "I need to find the friends" and with educators and providers from "we need to protect" to "we need to foster relationships."

**Cheryl Ryan Chan** is, first and foremost, Mom to Nicky – a 27 year-old man severely impacted by autism and intellectual disabilities. Cheryl has spent over 20 years in Massachusetts, integrating her son and family into the disability community and becoming a well-known leader in community organization, legislative activism, mentoring and public speaking. She has served on Boards for a number of nonprofit human service providers, mental health providers, and Support Centers. Her work as a Person-Centered Planning Practitioner began in 2010 and has become her greatest passion. Cheryl has traveled to present, train and provide planning services in California, Wisconsin, Maryland, and across New England.

**Jeff Keilson**, Senior Vice-President at Advocates, has more than 45 years of experience working with elders, people with autism, intellectual and other developmental disabilities, and persons with mental health needs and their families. He is a passionate advocate for the rights of individuals with disabilities to gain self-determination and greater control over decisions impacting their lives.

At Advocates, which provides supports for more than 30,000 people with disabilities and their families, Jeff works on the implementation of a more person and family centered system of services. He provides leadership in supporting Advocates' strategic growth, building partnerships, and directing marketing and fundraising efforts. He is particularly focused on working with families in implementing comprehensive services and supports for family caregivers, including partnering with businesses, educational institutions, and other community agencies.

Jeff was previously the director of the Lindemann Mental Health Center and served as Assistant Commissioner for Community Programs and Regional Director for the Metro Region for the Massachusetts Department of Developmental Services.

He spearheaded an initiative from the Robert Wood Johnson Foundation to support self-determination in communities of color; and co-founded Rewarding Work Resources, a national non-profit organization that provides a means for individuals with disabilities and families to find direct support workers.

Jeff gets his deepest rewards when working directly with consumers and families, supporting them to become more empowered and assisting them to create visions for independence—and then implementing them— in states as diverse as Arkansas, Kentucky, Indiana, Georgia, Colorado, and Massachusetts. His commitment and experience in supporting people's right to direct their services was the foundation for his work with Bay Path Elder Services to develop a self-direction initiative for elders that received a 2010 Local Innovation Award from the federal Administration on Aging.



In 2017 Jeff was honored to receive the Marie Feltin Award from the Boston Center for Independent Living and in 2008 Jeff was the recipient of the prestigious Gunnar Dybwad Leadership Award from the Commonwealth of Massachusetts. He also received the President's Award from Northeast Arc in 2015 and serves on the Massachusetts Attorney General's Disability Rights Advisory Committee. He also serves on the Boards of NADD and HIPPY, USA.

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### Ask the Agency

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#### Amy Nazaire, Regional Family Support Director

**Cindy O'Donnell**, Regional Eligibility Manager/Regional Clinical Director **Lea Hill**, Regional Autism Program Coordinator **Ken Underwood**, Assistant Area Director, Central Middlesex DDS office

**Amy Nazaire** is the Director of Family Support & Children's Services at the Department of Developmental of Services, Northeast Region. She has been working in the field of Intellectual and Developmental Disabilities for over 25 years, and has served in a wide variety of roles ranging from direct support to administration. In her current role she oversees Family Support services for both children and adults in the Northeast Region, and also works with the Regional Turning 22 Coordinators. She has done graduate work in Sociology, Social Policy and Nonprofit Management. She is also the founder of the Massachusetts Lifespan Respite Coalition and was Project Director of the Massachusetts Lifespan Respite Grant from 2010-2017.

**Cindy O'Donnell, MSW** is the DDS Regional Eligibility Manager/ Regional Clinical Director. She joined DDS in the Fall of 2018. Prior to joining DDS she was at North Shore Community College as the Assistant Dean of the Health and Human Services Division. In this role she oversaw the Developmental Disabilities Direct Support certificate and Human Services Practitioner programs that provide education to staff working in the field as well as serving as a member of the Students at Risk Committee. In addition, she oversaw the development and implementation of education and training programs for people with intellectual and developmental disabilities at the college. Cindy has a social work degree and a certificate in nonprofit management from Boston University. She has worked for over twenty-five years with people with disabilities, young people, families and communities.

Lea Hill is the Autism Program Coordinator for the DDS Northeast Region. The position was created in response to the 2014 Autism Omnibus Law which expanded DDS eligibility to include adults with autism regardless of intellectual disability. The role was created to provide support, training, and guidance for ASD Service Coordinators, Supervisors, and Area Directors for the newly eligible population. Lea also works closely with providers and direct support staff on their training needs, issues and challenges they're facing while serving adults with autism, and celebrating successes along the way. Lea is a



member of four of the Autism Commission's Sub-Committees, the Youth At Risk Planning Committee, and the North Shore Community Health Network.

**Ken Underwood** is the Assistant Area Director of the Central Middlesex Area Office for the Department of Developmental Services. With a degree in psychology from the University of Lowell, Ken has been working with the Department in different capacities for 22 years, including 18 years as a Service Coordinator as well as 2 years as a Program Monitor prior to assuming his current position in Acton. In his current role, he works closely with the Area Director, the Central Middlesex management team and the regional Contracts office to oversee the provision of all contracted services, manage the Area Office budget and work closely with provider agencies to ensure that supports provided are meeting the needs of the individuals. Ken also is an active member of the Northeast region's Alternatives to Housing workgroup and facilitates the region's committee on Service Coordinator Workload Efficiency.

This presentation is "Housing 101" for parents but is also helpful to those who have already done some exploration. "Thinking About Housing" introduces families to the range of public funds available to pay for housing and supportive services (including for those without DDS supports). Some examples are given of how these can be combined with private funds to create housing.

**Catherine Boyle** is the president of Autism Housing Pathways, a Massachusetts non-profit that builds the capacity of families to find or create housing for their adult family members with disabilities. She is a commissioner of the Winchester Housing Authority and has completed 60 hours of housing counseling training through HUD intermediaries. A former Foreign Service Officer, Catherine is a graduate of Dartmouth College and holds a certificate of graduate studies from UMASS Boston in adapting curriculum.