

The Autism Support Center

The Spectrum

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Coping with a Child's Diagnosis of Autism: Part 2

Contributed by Nicholas Golden, Psy.D, M.Ed, BCBA-D, LABA
Northeast Arc's Autism ABA Services

In the previous article, I discussed the importance of allowing for the natural grieving process when getting an initial Autism Spectrum Disorder (ASD) diagnosis for your child. In addition to the grieving process, I will now include tips for parents and family to better help cope with a new diagnosis. This is not an all-inclusive list, nor is it in order of importance or what to do in order. It is designed to help navigate and pace all the aspects that are suddenly new and potentially overwhelming. It is extremely important to use available resources, coping strategies, and self-care when navigating this influx of new information and challenges.

1. **Research-** There is a vast amount of information out there regarding ASD. You will want to educate yourself, but be mindful of what is available for information. Although the internet has an extremely large source of information, try and focus most of your reading on respected published books and peer reviewed articles. Major autism support networks/websites will have suggested reading/research sections to check out. If you do research on the internet, try and focus on acclaimed organizations and medical sites. It can be very helpful to read blogs and forums, but don't replace medical and scientific research on anecdotal information when gathering information on autism. There will be different treatments that might work for some, but not others, so look for treatments with validated scientific evidence to support it. There is no such thing as a miracle treatment or cure for autism, so don't be fooled by any claim that says that.
2. **Identify skills your child has and needs help on-** It is important to make an honest inventory of those skills your child already has and those they will need help with. This can be done by using the assessments that have been completed across the different areas of need, requesting further assessments from the various specialties, and simply by knowing your child. Knowing the areas that need to be addressed will help you formulate a game plan to move forward.
3. **Develop a plan-** Work with your loved ones and professional TEAM to develop a plan for your child. Where do you see your child in a year? In five years? In ten years? In twenty years? What are realistic expectations for your child and how would you go about attaining them? What areas of need do you want to focus on? What areas of strength do you still want to focus on and strengthen even more? What resources will you need to attain these goals and better support your child? Never sell your child short, but make sure goals are realistic and attainable. Having a game plan will be instrumental in your child's development and future progress.
4. **Accept mistakes-** Along the way you are going to make plenty of mistakes. You will never be perfect as a parent or as a parent with a special needs child. As much research and insight you put into your child's development, there will be times that it won't work or that you should have tried something different. It will be ok, especially if you learn to accept mistakes and learn how to move forward. Making mistakes is a natural human experience and that is how we learn and grow.

(Continued on the next page)

Coping *(continued from page 1)*

5. **Just do-** By being able to accept mistakes, this will allow you to 'just do'. Whatever your decisions will be, do them from the heart. Do what you feel is right, even if in the end it may be wrong or not the best decision. In the long run, if you make decisions from your heart, no decision will end up being a bad one.
6. **Love from others-** There will be times you feel alone or overwhelmed, I have yet to meet a parent that hasn't felt those emotions at one time or another. When I ask them what has helped them through that difficult time, they always mention the love and support of those around them is what gets them through. Accept help when it is offered, sometimes it might not always be the best way or exactly how you envisioned it, but be open to those that are willing to help out to get the best outcomes. Those with the most support are the ones that have the best outcomes. Cherish in that love from family and loved ones. Take time to strengthen your love from a partner or child. That love will help pull you through the darkest of times.
7. **Support from other families with ASD experience-** To best help you through this new world and keep you sane, reach out to other families that have gone or are currently going through having their child diagnosed on the spectrum. They have gone through what you are about to and know the best ways to navigate the system and what to expect. Although every child with autism is different, there are many common experiences along the way. Other parents will be an excellent resource and necessary support for you. You will find parents in your community, in community/agency support groups and in online support groups. They will prove to be a valuable resource and area of support. Respect those that have gone through this, they will be your greatest supporters and ones that fully understand what you are going through.
8. **Educate loved ones-** As you continue to research and better understand autism and how the diagnosis relates to your child, help other loved ones better understand your child. Whether it be other siblings, grandparents, aunts/uncles, family friends, babysitters etc., it is extremely valuable to educate others on autism and your child. Have them sit in during trainings with other professionals and share research with them.
9. **Learn from your child-** Your son/daughter will show you amazing things and teach you more about being human than anyone in the world. They will teach you to see the world and humanity through a different lens. Things you didn't know your child could do, they will show you and leave you breathless. You will live in awe of what your child is capable of and what they show to the world as they grow.
10. **Learn what's most important-** a long day of work and taking care of your child, you will learn how to pick your battles or what to focus your energy on. Is it more important that they try their new food on the plate or set up the environment so the risk of a meltdown is low? Know when to push and when to let it be. At the end of the day, you will want your child to have the best day possible with the least difficulty.
11. **Research and explore the service system-** Navigating the system, be it insurance, the educational system, the legal system, or the different medical professions can be daunting to say the least. Make sure you know what your insurance carrier covers and what it does not. Know your rights and your child's rights when it comes to IEPs and services. Know that you can get second opinions and how to advocate strongly. Learn how to push through the system when it slams a door in your face. Others that have gone through it can help you, so please utilize them.
12. **Get financial help-** Autism is an expensive endeavor, it can be very expensive depending on your insurance, what services you seek, the needs of your child, and the area that you live. I advise sitting down with a financial advisor to better help out your finances and how to make it all work. The more you know about your options, the better you can make decisions that will be beneficial and cost efficient. Look for free resources such as play groups, continuing education, webinars, social support, technology, toys, and sensory items. Thankfully there is support out there to help, you will just need to know where to look and who to ask.
13. **Be an advocate-** The strongest advocate for your child is you (and your partner). You know them best and through time, you will know what works and what doesn't work. Unfortunately the system isn't set up so resources and what is needed is readily available, so you will have to speak up for your child. Paired with your child's fellow professionals, you can achieve so much for your child by speaking up and never giving up.
14. **Get an advocate-** Sometimes the system may seem too daunting and overwhelming and that is a cue to try and get an advocate. An advocate is an individual who knows the system very well, all the ins and outs and they work with you to achieve what is needed for your child. They can help be a loud voice for your child and family. Some advocates you must pay for but there are also options to retain a free advocate. They can help get you support and services that may be difficult to attain without further support.
15. **Therapy/ Family Therapy/ Couples Therapy-** As a Psychologist, my view might be slightly biased on this. Personally I feel everyone should utilize some form of therapy and even more so when they have a son/daughter on the spectrum or with special needs. There are so many emotions and feelings that come up daily that need a good filter to come out in ways that will benefit a person and better allow them to get through the day. There is nothing wrong with seeing a therapist and if nothing else it gives you a hour to just vent and let it out. You will find that a therapist can help you process those feelings, help give family members and yourself a louder voice, or help to open up communication between a spouse/partner for better parenting. An autism diagnosis is a huge impact on you, your child, and the entire family. It can be extremely beneficial to get additional support to get through it.
16. **Grieve, cry, have a pity party-** let those emotions out, whatever they are. Parenting is the most difficult job in the world (where is your salary?) and knowing that things aren't going to be exactly as you thought or hoped, is going to take some time to accept. Whatever the emotion is you need to let out, do it. Crying is an excellent way to let out those emotions (that means you, as well, my fellow males). If you feel the need to have a pity party, throw one. The worst thing you can do is keep those feelings locked up. Just remember to pick yourself back up as your child needs you. Know when to fall off the horse and when to get back on it. Allow yourself that time to vent and know when to be fully available to your child and family.

Coping *(continued from page 2)*

17. **Know your limits-** Parenting is extremely difficult. Parenting with a child on the Spectrum adds another layer to it. Remember, it is ok to take a break. It is ok when you reach that absolute limit and you feel like your head is going to explode. It happens to all parents and will happen a lot to parents with children on the spectrum. It is ok to tag in a partner to take over for a bit so you can get a breather. There will be times you feel like you will break and you just can't do it. It is perfectly ok to feel like that, just know when to take a break and get that rest. If you feel like you are going to snap then chances are you will, so take some space. Be kind to yourself, but remember that as much as you try and do that, there will be times when you do snap. Just know how to rebound from it and get support the moment you need it. You aren't going to be Wonder Woman or Superman, probably more like the guy from the Greatest American Hero (if you have to look that up, then I am way too old), and that's ok. Know how to apologize when you've said or done something that wasn't the best. Show that humility when it needs to come out.
18. **Ask for help-** This is a no brainer! By knowing your limits and having humility, asking for help will be easy. Asking for help does not make you weak or a bad parent, rather it strengthens you and is better for your overall health and well being. Utilize the resources available to you, you will be happy you did.
19. **Self-care-** So I lied to you, and I apologize. I said that the list wasn't in any order, but honestly this is probably the most important, right up there with 'educate yourself' and 'ask for help'. You have to take care of yourself. Nothing will get done if you fall apart or you are just too miserable to parent. There is a reason why when you fly the flight instructors tell you to put the breathing apparatus around you first before your child. You have to make sure you are stable first, before your child will be. Finding time for yourself (and relationships) will be difficult, but is HAS to be done. Whatever it looks like for you (date night, reading, spending some time with friends, going for a walk, playing an instrument, yoga, meditation, going to concerts, art, working out, etc) find time to do it. Whether it's for 15-30 minutes every day or a large chunk of time every week, you must find that time for yourself and/or relationship. Looking into different relaxation strategies, such as meditation, mindfulness/body scans, yoga, reiki, tai chi, acupuncture, etc. is a great way to help your mind, body, and soul take a breather and relax. Make a list of things you like to do and work down the list throughout the month to make sure you are making it a priority. If you are in a relationship or marriage, take extra special care of it. You will both need to communicate, trust, love, spend time with each other, and work as a team. It won't be easy, but as long as you work on the relationship and you find time for it then it will survive. Remember, if you feel good, your child will soak that in. They are going to need you as they grow, so make sure you are taking care of yourself.
20. **Take a deep breath, smile, and have fun with your child-** As a fellow parent, I can tell you that the saying "they grow up so fast" is absolutely true. Yes, you will have to spend a lot of time and resources as your child grows, but make sure you spend plenty of time enjoying your child and the unbelievable experience of being a parent. Bask in all the beautiful things they do and honor all the things they will teach you. Rejoice in the small things. Little accomplishments are actually big accomplishments and celebrate those moments. Live in the moment and simply love your child with all your heart.

Northeast Arc's Autism ABA Services are available in Greater Boston, North Shore, Metro North, Central Middlesex, Merrimack Valley and the eastern Lowell area. For more information contact Stacey Villani, director, at 978-624-2340 or svillani@ne-arc.org



El Northeast Arc Autism Support Center Presenta
Su Séptima
CONFERENCIA ANUAL EN ESPAÑOL



Viernes 7 de Octubre, 2016
8:30 am to 1:30 pm
Lawrence Heritage Museum
One Jackson Street
Lawrence, MA 01840
FREE

Desayuno:
Café, bagels, muffins, jugo & fruta

ENFOCADOS EN LA TRANSICION

Tere Ramos-Dunne, Abogada de Acceso Lingüístico, Massachusetts Law Reform Institute

Los estudiantes en Massachusetts que reciben servicios de educación especial comienzan a recibir servicios de transición a los 14 años. La transición es un proceso en el que se determinan las necesidades, preferencias, e intereses del estudiante y como se relacionan a las necesidades de su colocación actual y post-secundaria, como el trabajo, la casa, escuela y ambientes sociales. Este taller le explicará las leyes que las escuelas tienen que cumplir para asegurarse que el estudiante tenga una transición exitosa que satisfice las necesidades del adulto en las áreas de educación, empleo, y participación en la comunidad.

INTRODUCCION AL CUIDADO FAMILIAR DE ADULTOS

Iluminada De La Cruz, Northeast Arc Adult Family Care

Cuidado Familiar de Adulto (siglas en Inglés AFC) (también conocido como Cuidado Temporal de Adultos) es un programa de MassHealth que puede apoyar a las personas de 16 años y más para que vivan en la comunidad con sus familias o personas relacionadas o no. Los participantes y los cuidadores son evaluados por MassHealth. Atienda esta presentación la cual le ayudará a descubrir si su hijo o hija califica para este programa.

VAMOS A ORGANIZARNOS!

Sara Diaz, Family TIES of Massachusetts

Participe de nuestro taller y empiece a armar una carpeta para su niño. Les mostramos a los padres cómo organizar la información y manejar el papeleo, ideas generales para mantener la calma, y consejos de actividades en la comunidad para su hijos o hijas con necesidades especiales.

PARA MAYOR INFORMACION Y PARA REGISTRARSE LLAMAR A:
GLORIA RICARDI CASTILLO AL 978-624-2301 O GCASTILLO@NE-ARC.ORG
O THE AUTISM SUPPORT CENTER 978-777-9135 ASC@NE-ARC.ORG



NortheastArc

Lifelong support for people with disabilities



The Northeast Arc Autism Support Center Presents
The 7th Annual
SPANISH LANGUAGE CONFERENCE



October, 07 2016
8:30 am to 1:30 pm
Lawrence Heritage Museum
One Jackson Street
Lawrence, MA 01840
FREE

Breakfast will be provided :
Coffee, bagels, muffins, juice & fruit

FOCUS ON TRANSITION

Tere Ramos-Dunne, Language Access Attorney at the Massachusetts Law Reform Institute

Children in Massachusetts receiving special education services begin transition services at age 14. Transition is an ongoing process of determining a student's needs, preferences, and interests as they relate to the demands of current and post-secondary settings, such as work, home, school, and social environments. This workshop will explain the legal requirements districts have to ensure a student has a successful transition that meets the adult needs for further education, employment, and full participation in the community.

INTRODUCTION TO ADULT FAMILY CARE

Illuminada De La Cruz, Northeast Arc Adult Family Care

Adult Family Care (also known as Adult Foster Care) is a MassHealth program which can support individuals age 16 and older living in the community with related or non-related families. Participants and caregivers are assessed for eligibility according to MassHealth. Learn about the Adult Family Care program and the benefits of accessing these services for your son or daughter.

LET'S GET ORGANIZED!

Sara Diaz, Family TIES of Massachusetts

Do you wish you had a way to keep track of your child's IEPs, evaluations, progress reports, doctor reports, test results, and more? We will offer effective ways for parents to organize and manage paperwork, building a customized binder for your child - plus general ideas on "keeping it together" and tips for developing community connections for your child.

**FOR MORE INFORMATION AND REGISTRATION CONTACT
GLORIA RICARDI CASTILLO AT 978-624-2301 OR GCASTILLO@NE-ARC.ORG
OR THE AUTISM SUPPORT CENTER 978-777-9135 ASC@NE-ARC.ORG**



NortheastArc

Lifelong support for people with disabilities



Back to School



Is your IEP appropriate?
Does it meet your child's
unique needs?

Take advantage of a 1 hour Individual IEP Consult
with an Educational Advocate for \$25

Thanks to the Support from Department of Developmental Services and the United Way of the North Shore these Consultations may be FREE to families who are eligible to receive family support services through the North Shore Area office.

Restrictions: 1 per year at the \$25 rate per person (Regularly \$50)

September 7th & 21st

Northeast Arc Center for Excellence

6 Southside Road, Danvers, MA

9:30am, 10:45am & 12:00 noon

September 12th & 26th

Centerboard

16 City Hall Square, Lynn, MA

9:30am, 10:45am & 12:00 noon



For more information or to schedule an appointment, please contact:

alucifora@ne-arc.org / 1-978-624-2381
or
fodonald@ne-arc.org / 1-978-624-2380



FREE WORKSHOP FOR PARENTS

Wednesday, September 14th 12-2pm

Presented by the Northeast Arc Advocacy Department

Bullying Prevention

Special Education Students and the IEP



Is your child being bullied at school?

What is the school's responsibility and policy?

Northeast Arc Center for Excellence, 6 Southside Road, Danvers, MA

To sign up for the workshop please contact:
alucifora@ne-arc.org / 978-624-2381 or fodonald@ne-arc.org / 978-624-2380
(registration required)



HELPING FAMILIES NAVIGATE THE SPECIAL EDUCATION SYSTEM



4TH ANNUAL
FAMILY HARVEST FESTIVAL

A celebration for Northeast Arc
staff and families served

Saturday, September 24th • Noon to 3:00 PM
Endicott Park • 57 Forest Street, Danvers
RAIN OR SHINE

LUNCH (FIRST COME, FIRST SERVED)

LIVE MUSIC - BOUNCY HOUSE
CRAFTS - SNACKS - BUBBLES
CURIOUS CREATURES
PUMPKIN DECORATING
FACE PAINTING - LAWN GAMES
BALLOON ART - MAGICIAN

\$10 donation per family suggested
but not required.

RESERVATIONS REQUIRED.
RSVP by September 13th to our Autism Support Center
at asc@ne-arc.org or 978-777-9135.

1. Parking: do not go into parking lot if you are charged a fee, only the spaces designated for the event are open. Arrive before 11:00am. 2. The festival is a family event. No alcohol, no smoking, no drugs, no pets. 3. If you are bringing a picnic, please bring it to the picnic area. 4. A parking lot is located at the end of the parking lot. 5. Please note that you have to be 18 or older to be a volunteer. 6. Please note that you have to be 18 or older to be a volunteer. 7. Please note that you have to be 18 or older to be a volunteer. 8. Please note that you have to be 18 or older to be a volunteer. 9. Please note that you have to be 18 or older to be a volunteer. 10. Please note that you have to be 18 or older to be a volunteer.

Transition
Support
Group



Tuesday, September 20th, 2016
6:30-8:00 pm

Guest Speaker - Ruth Price
"Healthy Relationships"

Northeast Arc Center for Developmental Excellence
6 Southside Road, Danvers

Facilitated by: Kathy Kelly

\$10 suggested donation kindly requested to help defray costs

- Are you the parent or guardian of a teen or young adult between 14 and 22 years old?
- Would you like some support as you work to prepare your loved one for a fulfilling life beyond school? (Of course you would!)

Join us! But first, please RSVP via e-mail to Nancy Lucier, nalucier@ne-arc.org

Upcoming Speaker
October 18th - Adam Quinn, "Northeast Arc Recreation"



IT'S A FACT:

ASC serves 68 communities in northeastern Massachusetts.

A Wall of Miracles

Contributed by ross pergament



One of the most life-changing experiences I had was my trip to Israel. Israel was full of history, and it was the history of the old city of Jerusalem that fascinated me the most. As I made my way to the Kotel (Western Wall) what I saw changed my views of the Jewish people, and my life in a way that it so difficult for me to put into words. There were thousands of Jews standing by the wall praying together. It didn't matter if they were Orthodox, Reformed, or Conservative.

Their religious diversities were all united by the holiest site of worship in Judaism. As I got closer to the Western Wall, I could feel an immediate connection to my religion and it's past. I chose not to place a prayer into the wall but with my hand I held onto it and spoke my prayer directly to God. The prayer that meant the most to me was to have a sign that my grandfather was at peace after this death, and that he didn't have Alzheimer's in heaven. As Shabbat approached the vibe at the Kotel changed. The number of people went from what felt like hundreds to thousands. I couldn't believe how connected everyone appeared as they were hugging and dancing together. I was not surprised to see the overwhelming numbers of Jews happy that they were in their homeland and at the holiest site in Jewish history.

My most powerful walk in life will definitely be the one I took to the Kotel on that memorable day. I feel so blessed to have had this experience because I knew traveling to Israel with autism could be challenging for me. Israel was full of history, experiences and joy, and I felt like I was home. I met the most fascinating people on my journey through Israel and made some lifelong friends who I plan to visit again someday. I will always be thankful to The Lappin Foundation for giving kids like me the gift of traveling to Israel.

Ross Pergament is the son of Stuart Pergament, MD, and Jody Kipnis, ASC Board Co-Chair.

ArcWorks invites you to view its newest exhibit

SPECTRUM

September 8—October 15, 2016

Opening Reception: September 8, 2016

5—7 pm

22 Foster Street, Peabody

This exhibit features works from artists of the Asperger/Autism Network in Watertown. The Asperger/Autism Network (AANE) works with individuals, families, and professionals to help people with Asperger syndrome and similar autism spectrum profiles build meaningful, connected lives. They do this by providing information, education, community, support, and advocacy, all in an atmosphere of validation and respect.

For information, contact ArcWorks at 978-548-5855
www.arcworksart.org

IT'S A FACT:

Autism is the fastest growing serious developmental disability in the United States.

Transition Talk



Transportation Access Pass (TAP)

Did you know that you or your loved one may be eligible for the Commonwealth of Massachusetts reduced fare program?

This pass entitles you to reduced fares on all MBTA services including buses, trains, rapid transit, trackless trolleys, commuter rail and commuter boats. Automatically eligible applicants include: Medicare card holders(A and B), Customers of The Ride, Clients of DMH and DDS, Veterans with a disability rating of 70%, Seniors(65+), and out of state reduced fare card holders. If you do not meet one of these criteria, you can still complete the application and obtain a letter from a licensed health care professional.

http://www.mbta.com/uploadedFiles/documents/ACCESS_PASS.pdf

If you have questions about Turning 22 and adult services, contact Phyllis Kizner, Adult Specialist, at 978-624-3747.

PARENTS OF ADULTS JOIN US SEPTEMBER 12TH!

Parents of adults (18+) living with Asperger syndrome or high cognitive autism have unique needs for information and support. To meet those needs we have formed a support group that will meet at the Autism Support Center, 6 Southside Road, Danvers on **2nd Mondays from 6:00 to 8:00 p.m.** Why join a support group? Many parents find it very useful to attend a group with other parents who have similar needs.

This is a great way to network and share information about services and supports in local communities. It's also a way to give and receive emotional support, to share the joys and challenges of living with a person on the autism spectrum.

Participants will also learn what programs and services are available at Northeast Arc as well as other agencies. Information shared at a support group is confidential and will be respected. Participants may shape the group to specific needs, for instance requesting speakers on topics of interest. **For more information please contact Phyllis Kizner at 978-624-3747 or pkizner@ne-arc.org**



IT'S A FACT:

Autism is the fastest growing serious developmental disability in the United States.

P.R.E.P. for Students 16-22

CONTRIBUTED BY
Brian Lane, program coordinator

Recently across the nation there has been a focus on the transition needs of students with disabilities between the ages of 16 to 22. This group needs access to program and curriculum that will empower them to succeed after their traditional education comes to an end. With this emphasis put on transition programs the Northeast Arc for the last several months has been running a new community based Pre-Employment Transition Services program called P.R.E.P. (Preparation Readiness and Employment Program). This program is designed to prepare students ages 16 to 22 with developmental, intellectual or learning disabilities for employment in the workforce through the cultivation of employment tools and experience that can be utilized to access meaningful internships and future competitive employment. The Northeast Arc was awarded this grant by MRC (Massachusetts Rehabilitation Commission) in January 2016 and began its first cohort of ten students in April from school districts on the North Shore.

P.R.E.P. offers students:

- Employment Readiness Trainings
- Group activities (team building, job tours, etc.)
- Travel Training
- Resume Development

- Career Portfolio Development (Includes copy of resume, interest inventory, vocational assessment, I-9 Information, letters of reference and a certification of completion),
- Enrollment at a local Career Center
- Paid Internship (with support of a job coach)

Students take part in these trainings one day a week and finish the program off with a two month paid internship. The internships allow each of the students to constructively put to practice all of the skills that they have learned during duration of the program and have ownership of their career path. This fall the Northeast Arc has the opportunity to expand P.R.E.P. and offer the program to a larger number of students on the Northshore. We firmly believe that this program is and will continue to be a great resource for individual and families that are transition aged (16-22) and are looking for a career readiness program. If you are interested in having your student or know of a student that might be interested in applying for P.R.E.P. this coming fall of 2016 please feel free to get into contact with the Program Coordinator, Brian Lane at blane@ne-arc.org to learn more about the application process.

BARN PROGRAM

The Holland Project:

Barn Program for Teens/Young Adults (14-30) with Autism and Other Developmental Delays

An integrated farming and agricultural Saturday program for teens diagnosed with autism and other developmental delays. The program is designed for the teens to have a typically developing volunteer from the community to assist them. Each program participant will experience the many educational, therapeutic, vocational and social benefits of working on a farm with a peer and caring for the animals on a farm setting. \$150 per session.

Location: 81 Church Street, Merrimac, MA

Program Structure: 6 Week Saturday program, 9:30:am - 11:00 am, begins September 17.

- 1:1 ratio participant to volunteer
- 8 participants
- Additional volunteer staff include a LICSW.

We start off each session by pairing up with a volunteer buddy. Participants are encouraged to work as a team to help with barn chores, caring and grooming the animals, and other unmounted activities. We typically take short group hikes with our dogs on our trail. All activities are unmounted.

Participant Requirements:

- Ability to handle the physical aspects of the program and interact with animals
- Behavioral assessment/intake questionnaire completed by parent, caregiver, or educator prior to start of program.
- Screening for medical conditions or allergies that might interfere with the participation of the program

Contact Eileen Mitchell at thehollandproject@comcast.net or 978-764-8611 for more information.

Arab American Caregivers of Children with Autism and other Developmental Disabilities

A Study of Stress, Coping, Stigma and Acculturation

This study involves:

- Completing questionnaires online about yourself and your child (30-40 minutes)
- Completing an optional follow-up phone interview (20-30 minutes)

Eligible participants must be:

- first- or second-generation Arab (from an Arabic-speaking country of southwestern Asia or North Africa) living in the United States
- raising a child with a developmental disability between 2 and 17 years-old
- proficient in English

Use this link to access the survey:

<https://bit.ly/ArabCaregiverExperience>

Participants who complete the phone interview can enter a lottery to receive a \$50 gift card.



This study is in partial fulfillment of requirements for a Ph.D. in Clinical Psychology at the Catholic University of America.

For questions please contact

cobiab.cua@gmail.com

404.907.3591



DDS Ask the Agency Information Session

Representatives from DDS Northeast Regional Office will be available to answer your questions about:

DDS Eligibility	Adult Autism Services
Children's Services	Family Supports
Self-Directed Services	Transitioning to Adulthood
And more...	

All Ask the Agency events will take place on Wednesdays from 6:00 PM – 8:00 PM.

Choose from any of the dates below and RSVP with the Family Support Center. The session will begin with a brief introductory talk and then we will open it up for your questions.

September 14

Bridgewell

www.bridgewell.org

162 Boston Street

Lynn, MA

RSVP: Call (339) 883-1761 or

(339) 883-1760

Or email: rlolay@bridgewell.org

or blanco@bridgewell.org

October 19

LifeLinks

www.lifelinksinc.net

285 Mill Road

Chelmsford, MA

RSVP: Call (978) 349-3043 or email:

golanco@lifelinksinc.net

September 28

Northeast Arc

www.ne-arc.org

6 Southside Road

Danvers, MA

RSVP: Call (978) 777-9135

Or email: arc@ne-arc.org

October 26

EMARC

www.themarc.org

26 Princess Street, 3rd Floor

Wakefield, MA

RSVP: Call (781) 587-2316 or email:

ghompson@themarc.org

October 5

Fidelity House

www.fidelityhhs.org

439 S. Union Street, Suite 401

Lawrence, MA

RSVP: Call (978) 685-9471 or

(781) 686-7276 or email:

alynn@fidelityhhs.org or

mberoli@fidelityhhs.org

November 2

Riverside Community Care

www.riversidecc.org

300 West Cummings Park, Suite 354

Woburn, MA

RSVP Online: www.RiversideFamilySupport.org/events.php

or Call (781) 686-7276 or email:

ahed@riversidecc.org

Ask about bilingual/translation services at your Family Support Center



BENSON-HENRY INSTITUTE
FOR MIND BODY MEDICINE
at MASSACHUSETTS GENERAL HOSPITAL



SEEKING INPUT FOR A NEW STUDY: How Parents of Children with Autism Spectrum Disorder Cope

Researchers at the Benson-Henry Institute for Mind Body Medicine are conducting a research study to learn about stress and coping among parents of children with autism spectrum disorders (ASD). If you have experience working with families of children with ASD, or children with ASD we want to talk to you. Your input will help inform the design of a new Resiliency Program for Parents of Children with ASD.

Purpose and Benefits

We want to talk to you about stress and coping. Your input will help shape a Resiliency Program for Parents of Children with Autism Spectrum Disorders.

If you join this study, you will be asked to:

- Fill out a short survey about your background
- Take part in a 60-90 minute focus group, in-person or virtually
- Complete an anonymous, online survey after the focus group

Who Can Participate

We are looking for clinicians and leaders in organizations that work with parents and families of children with autism spectrum disorder

How to join

If you are interested in participating, or if you would like to learn more about this study, please contact Emma Chad-Friedman at echadfriedman@partners.org or (617) 643-6036.

Thank you for considering our research study!

You will be helping us gather important information about a training that may help parents like you in the future.

www.bensonhenryinstitute.org

Northeast Regional Diversity Committee



Northeast Arc
Helping people with disabilities

REV UP!
Register! Educate! Vote!

Election Day is coming soon! So MASS and the Northeast DDS Diversity Committee are teaming up to educate everyone about voting.



Be an informed voter and learn about:

- ✓ Your voting rights
- ✓ Where to vote
- ✓ How to overcome barriers at the polls
- ✓ How to find information on candidates

Date: Thursday, September 22nd

Where: Northeast Arc, 6 Southside Rd, Danvers

Time: 6:30-8:30PM

This event is free, and all are welcome, but please RSVP:

Email or call Bridget at bridget.mass.northeast@gmail.com or

781-789-4274, or with Rick Camara at

rick.camara@state.ma.us or call him at 978 206-2034

IT'S A FACT:

The Autism Support Center was founded in 1991.

Team VERGE

Try a practice with Team VERGE at our
OPEN PRACTICE

Saturday, September 24
(Rain date October 1)

Locations:

9:30 at Lexington Center Track
90 Worthen Rd, Lexington

And

10 am at Peabody HS Track
485 Lowell St., Peabody

Questions?

arussell@teamverge.org
www.teamverge.org



BOOTCAMP

**Mass Families Organizing for Change's Advocacy
Bootcamp**

Mass Families Organizing for Change's Advocacy Bootcamp focuses on building foundational advocacy skills to empower our children to lead rich, meaningful, and exciting lives. Applications from primary caregivers of young children from birth to 10 years who have developmental disabilities, chronic illnesses, and/or complex medical needs are welcome.

Advocacy Bootcamp is comprised of two parts:

Part 1 – Six in-person sessions where participants will

- get to know one another
- identify their strengths
- discuss how to apply these strengths when advocating for their children.

This will include discussing how to navigate medical and therapeutic services, as well as the school system and local communities.

- Participants will each identify a goal to achieve in the following six months.

Part 2 – Through one-hour phone calls each month for six months, participants will be provided with the support needed to

reach this goal.

** All application materials must be submitted by August 17th, 2016.

LOCATION:

Cooperative for Human Services, 420 Bedford Street Suite #100, Lexington, MA 02024

WHEN:

September 17, 2016 – November 19, 2016

[Event website](http://www.mfofc.org/advocacy-bootcamp/abc-application.html)

<http://www.mfofc.org/advocacy-bootcamp/abc-application.html>

For questions and further information, please contact:
Sophia Johansson, Northeast Regional Coordinator
Ph: 617-935-2264

Email: o.sophia.johansson@gmail.com

IT'S A FACT:

Autism is the fastest growing serious developmental disability in the United States.

SUPPORT GROUPS

Acton

ASC Sponsored; Target Group: Mandarin-speaking parents.

Acton Memorial Library, 486 Main St (Rt. 27) Acton; bi-monthly meetings TBA; Parent facilitator: Wen Li
Contact ASC 978-777-9135 or asc@ne-arc.org for info.

Burlington

ASC sponsored; Target group: parents of children and teens with ASD

Burlington Public Library, 22 Sears Street, Burlington; 1st Mondays

Parent facilitator: Chris Curtin; Contact ASC for info at 978-777-9135 or asc@ne-arc.org

Danvers

AANE/ASC sponsored; Adults with Asperger's Pizza and Game Night

6 Southside Road, Danvers, 1st Thursday, 6-8 pm
\$12 for pizza, salad, dessert, beverage. *Prior registration required.*

Facilitator: Gail Kastorf 617-393-3824

Danvers

ASC sponsored; Parents of Adults with Asperger's
6 Southside Road, Danvers, 2nd Mondays, 6-8pm

Facilitator: Phyllis Kizner 978-624-3747 or pkizner@ne-arc.org

Danvers

ASC sponsored; Target Group: Parents of young children
6 Southside Road, Danvers; Sept. 15th & Nov 17th at 5:30-7:30pm
Contact: Jackie Murphy at 978-624-

Danvers

ASC/AANE sponsored; Target Group: Adults (18+) with Asperger's syndrome

6 Southside Road, Danvers; 3rd Thursdays, 6:45 to 8:00pm. Contact facilitator Gail Kastorf at 617-393-3824 or gail.kastorf@aane.org

Danvers

NeArc sponsored; Target Group: Parents of Transition-Aged Youth (14-22)

6 Southside Road, Danvers;

3rd Tuesdays, 6:30-8:30 pm.

Facilitated by Kathy Kelly.

Contact Nancy Lucier to RSVP at 978-624-2350



Lawrence

ASC sponsored; Target Group: Spanish-speaking parents of children with disabilities

Families & Youth Initiative, 130 Parker St., Lawrence; 2nd Friday, 9:30-11:30am

Contact facilitator Gloria Castillo 978-624-2301 or gcastillo@ne-arc.org

Newburyport NO SEPTEMBER MEETING

ASC sponsored; Target Group: Parents of children with ASD

Newburyport 5 Cents Savings Bank, State St, Newburyport; 2nd Thurs., 7 p.m. Parent facilitator: Nancy Lucier. Contact: Susan Gilroy at 978-624-2302 or

sgilroy@ne-arc.org



IT'S A FACT:

Autism is the fastest growing serious developmental disability in the United States.

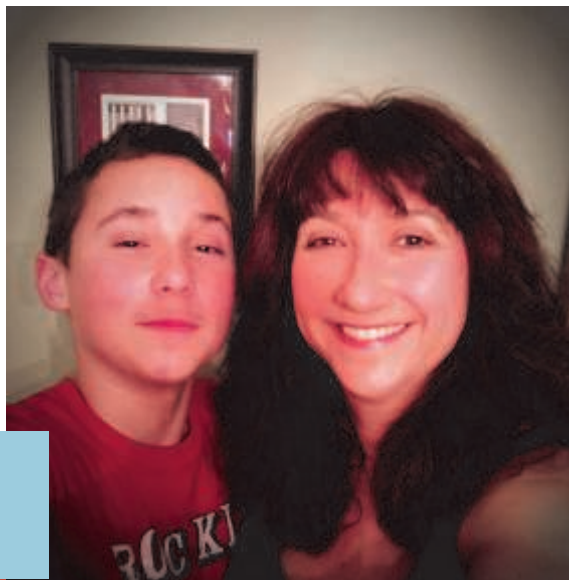
Ask the Advocate

Ask the Advocate!

Question: I've heard the term "Stay Put", what does that mean?

Answer: If the parents and school district disagree with a change regarding a decision of *no special education needs*, the placement, program and services in place through the current signed IEP will remain in effect. A parent can invoke their "Stay Put" rights once the *proposed* IEP is rejected. The student will remain in their current education program, placement or receive those services that the "Stay Put" is placed on, pending the resolution of the dispute.

*If you need an advocate, please call our **Advocacy Intake Coordinator** at: 1-978-762-8352*



REAL LIVES LAW CONFERENCE

Beyond the Real Lives Law!

The best way to predict the future is to create it!

Tuesday, September 13th, 9 am to 3:30 pm

The Ferncroft Country Club, Middleton

Join our leaders in the department, our allies in the state house, our colleagues in the provider community, and the many advocates we support for this unique event.

Let's get together for meaningful conversation, recommendations, and action planning for the future of the *Real Lives Movement*.

Format: Panels and small group discussions on the guiding principles of a Real Life for all recipients of both traditional and self-directed supports. Lunch provided.

\$20/person, register as soon as possible, limited seating. Online registration only as www.thearcofghn.org or call 978-373-0552 for assistance or more info. Registration closes on September 6th.

IT'S A FACT:

Autism is the fastest growing serious developmental disability in the United States.

RECREATION & LEISURE

Tuesday: Zumba Dance Exercise Class!

Ages: 14+ Fee: \$65 Staff Ratio – 8:1

Time: 6:00 PM – 7:00 PM

Location: Northeast Arc Center for Excellence, Danvers MA
Join us as we take the "work" out of workout, by mixing low-intensity and high-intensity ADAPTIVE moves for an interval-style, calorie-burning dance fitness party. Once the Latin and World rhythms take over, you'll see why Zumba Fitness classes are often called exercise in disguise. Super effective and really fun!

Fourth Tuesday: Open Dances — September 27th

Ages: 13 + years Fee: \$5 Staff ratio – 8:1

Time: 6:30 PM—8:30 PM

Location: The Northeast Arc - 6 Southside Rd. Danvers MA
This dance is NOW open to everyone 13 years and older. Bring your dancing shoes and prepare for a night of fun! Drinks and snacks are provided.

Music Therapy

Ages: 2.5 - 17 Fee: \$120 Staff Ratio – 4:1

Time: Call for details

Location: Northeast Arc Center for Excellence, Danvers MA
2016 Dates:

October 15 – November 19

Creative Movement

Ages: 2.5—17 Fee: \$90 Staff Ratio—4:1

Time: Call for details

Location: Northeast Arc Center for Excellence, Danvers
September 3rd—October 8
The Creative Movement Group is integrated and allows children of all abilities to express themselves through movement in a relaxed and creative atmosphere. A love for music and movement is all that is needed!

Golf

Age—10+ Fee \$80 Ratio: 4:1

Tuesdays, 5 to 6:30

Location: Paradise Family Driving Range, Middleton, & Bill Flynn's Lakeview Golf Course, Wenham; starts Sep-

tember 6. Call for more info.

FRIDAY NIGHT HAPPENINGS

Ages 13+ \$15/week Ratio 8:1 6:30—8:30 pm

Location: 6 Southside Road, Danvers

A different experience each week! First event (September 9) Outdoor movie night (Jungle Book)

SATURDAY OUT-INGS

September 10—
October 29

Ages 13+

Pre-registration fee: \$30, additional fees for ticket prices apply.

Drop-off and pick-up are at 6 Southside Road, Danvers.

Ratio: We keep our programs at a 1:4 staff ratio. Our staffing will determine the number of individuals allowed to attend each outing.

Lunch: Pack a lunch or bring money to purchase one.

In case of inclement weather during outdoor outings, we will have an alternative activity planned.

All events and activities require prior registration. Please contact Adam Quinn at 978-624-2308



DDS Council Members Needed

The Massachusetts Department of Developmental Services is seeking new members for the Statewide Family Support Council.

The DDS Family Support Council currently has 3 openings and we are actively recruiting family members from the Northeast Region who may be interested in participating on the Council. The primary purpose of the Council is to advise the Commissioner and the Department on issues that affect the well-being of families who have family members with intellectual disabilities living at home, including family support policies, services, and supports. Membership on the Council is open to families who have a child or adult family member living at home with them.

The Department strives to have membership on the Council reflect the diversity of families across the state, including ethnic and cultural diversity, a range of ages, types of disabilities and individuals with varying levels of support needs, and geographic distribution.

Only family members who either have a child/adult family member with a disability living at home, or a family member who recently transitioned out of the home and are still actively involved in family support advocacy, are eligible for membership on the Council. Family members who are also providers are eligible to be members of the Council. Family members who have an interest in statewide policy and systems issues related to family support may be most interested in serving on this Council.

The Statewide Family Support Council consists of fifteen family members who are appointed by the Commissioner based on an application process. In addition, a DDS Central Office staff person(s) is designated by the Commissioner to participate on the Council and provide administrative and leadership support. Membership on the Council is designed to include representation that reflects:

- the ethnic, and cultural diversity of families across the state
- a wide range of disabilities
- varying levels of need (complex health care/technology, behavioral, etc.)
- a range of ages (families with preschool and school age children, adults and older caregivers)
- geographic distribution across the state

The Council generally meets on a quarterly basis during the year, though conference calls are also held periodically, and additional meetings may be scheduled based on the work the Council is involved in. Meetings are held at the DDS Central Office in Boston. Meetings are held during the day on a week-day. The Department has funding available to help defray some of the costs necessary for family participation (i.e., respite, transportation, translation, etc.).

Role of Family Support Council Member

- Advise the Department on issues/concerns that families are raising to them in their respective areas, including feedback on the Department's Annual Plan for Family Support.
- Assist the Department in crafting and reviewing policies and procedures affecting individuals with disabilities and their families.
- Offer new ideas/initiatives that would give families more flexibility and choice.
- Actively solicit input from other families in guiding the above activities and work of the Council.
- Disseminate information and resources to other families in their areas/regions, which may also include making presentations on family support to the DDS Regional Advisory Boards.
- Assist the Department in developing its Annual Plan for Family Support by helping get substantial input from family members.

If you have any questions or need more information, please contact: Margaret Van Gelder at (617) 624-7764, or by email at margaret.van.gelder@state.ma.us.

The Spectrum

The Spectrum is a monthly electronic publication of the Autism Support Center. This newsletter is published to inform parents and professionals of resource information, upcoming events, and other autism-related topics. ASC is funded primarily by the Mass. Dept. of Developmental

INFORMED. EMPOWERED. CONNECTED.

Services. The views expressed do not necessarily reflect those of the funding source. ASC does not endorse any product, service or theory referred to in this newsletter. Articles, resources and announcements are included for information only.

Anyone wishing to contribute information for this newsletter should send it to asc@ne-arc.org or to our mailing address. Parent contributions are encouraged. *Announcements are included as space is available.*



Family Harvest
Festival

September 24

12noon to 3 pm

Endicott Park
Danvers

PLEASE CONTACT

ASC AT **978-777-9135**

OR VISIT [HTTP://NE-ARC.ORG/SERVICES/AUTISM-SERVICES/](http://ne-arc.org/services/autism-services/)

FOR MORE INFORMATION.



6 SOUTHSIDE ROAD, DANVERS MA 01923

NortheastArc
Lifelong support for people with disabilities

