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The Arc NEWS



Sunday, Oct 6, 2013
9 am — 2 pm
Camp Harkness

REGISTER ONLINE!

TheArcNLC.org



The Arc
New London County



A Message from The President of The Board of Directors

"It's very nice to meet you!"
New Board President brings
education, leadership
experience



Enrico DeMatto

After nearly a decade on the Board, it's wonderful to serve The Arc New London County as its new Board President. **Some 40 years as a special education teacher and a special education administrator put this agency's mission close to my heart.**

sively addresses the needs of the people we serve in new and exciting ways.

The process began with a listening session in which we

We know the funding landscape

We are strongly committed to reinventing current models to fully serve people and families.

presents significant challenges in the next five to ten years for all who commit to serving people with intellectual and developmental disabilities. **The Arc New London County has been preparing for what lies ahead for several years now.** In September, The Board and Leadership Team embarked on a period of discernment to build a strategic plan that comprehen-

sively addresses the needs of the people we serve in new and exciting ways. The process began with a listening session in which we heard from parents and from leaders in the Department of Developmental Disabilities. **What are the needs of families in New London County?** We are confident in the creativity of our group, and we are strongly committed to reinventing current models to fully serve people and families while allowing for the efficiencies that government rightfully requires.

These are exciting times!

A Message from The Chief Executive Officer of The Arc

We're learning all we can in some states are alarming. *Funding challenges demand inventive solutions*

At The Arc's national convention this year, we discovered that states grappling with budget woes are rethinking services. We

too must assess how we serve people. *Is this the best we can do?*

Connecticut thus far has wisely avoided Managed Care. But fighting cuts here continues to be a challenge equal to reinventing strong supports for the people we serve: *See the person!*

Largely negative reviews regarding Managed Care along with 35% budget cuts in some states are alarming.

Some solutions only lead to bigger problems. Managed Care – where administrators and insurance companies make decisions for you – threatens 26

states. **One problem with Managed Care? It's a medical model. The Arc New London County doesn't serve people who are sick.** We support people with intellectual and developmental disabilities intent on finding independence. Largely negative reviews regarding Managed Care along with 35% budget cuts



Kathleen Stauffer

Thanks for being a part of our family. We couldn't do it without you. Our Annual Appeal mails shortly. *Please be generous!*

P.S. – Don't miss our 36th Annual Jack O'Keefe Memorial Strides Road Race Sunday, October 6, at Camp Harkness. Register at TheArcNLC.org. **Family Fun Run, Walk and Roll ... Food provided by Outback Steakhouse.**

Meeting the Needs of Connecticut's Families

Can The Arc New London County Solve The Respite Care Crisis in Southeastern Connecticut?

The Arc Network gives families a much needed break

Board member **Denise Walstra** has a 17 year old daughter, Nicole. Nicole is diagnosed with Angelman Syndrome, characterized by intellectual and developmental delays, seizures and a happy demeanor. For the first seven years of Nicole's life, Denise and her family had no outside support.

The Arc: What prompted the need for respite care?

Denise Walstra: As Nicole got older, I needed help. Respite care seemed to be the answer. I tried local agencies, referrals from friends, even placing personal ads in the newspaper to find the right support. Nothing worked. I wanted the security of a Social Service agency at an affordable price, but with very little financial support from the state, my options were limited.

The Arc: When did respite care become critical?

Walstra: The stress of caring for Nicole without respite services began to take its toll on my marriage. When we talked, it was always about money or Nicole. I wanted another child, but knew I could not provide 24-hour support for Nicole and care for a baby at the same time. At my breaking point, I contemplated residential placement for Nicole. The Arc was my savior back then and I will never forget that.

Denise's story is not unique. Families caring for loved ones with intellectual disabilities in Southeastern Connecticut are struggling. Finding supports, programs and resources is a daunting task that often leads to a dead end. Families are pushed to their emotional and financial brink. Critical Respite supports are either not available or not affordable.

A new solution to the Respite care crisis is The Arc Network. Thanks to a generous grant from the Community Foundation of Eastern Connecticut and the Gildersleeve White Fund, The Arc is developing a Windows platform for The Arc Network, an online respite care database invented and managed by The Arc New London County. For the price of a \$25 membership fee, the database offers New London County residents an online listing of highly trained professionals who are off-duty employees of The Arc New London County, able to provide in-home respite care to the families and caregivers of people with intellectual and developmental disabilities of all ages. The windows platform allows employees of The Arc New London County to administer the Network, making updates and customer service readily available.

With The Arc Network, New London County's parents and caregivers no longer have to search out an available provider, sit on a waitlist for a respite bed or wonder who will be caring for their loved one. The Arc Network allows family members to locate direct care professionals who meet their specific qualifications via the database and make contact to determine the best fit for the family and support recipient.

For more information about The Arc Network and to learn how to join, please contact Lara Chiaverini at 860-889-4435 ext. 103 or join online at The Arc's website, TheArcNLC.org and click:



The Top 3 Respite Facts You Must Know

- ✖ There are approximately 2.9 million family caregivers of persons with I/DD and most have significant unmet needs for respite care
- ✖ 83% of family caregivers report their biggest concern is not having enough respite care
- ✖ Nearly 80% of family caregivers for persons with I/DD report being dissatisfied with the availability of respite care



Denise and Nicole Walstra at the Strides Road Race at Camp Harkness

"The Arc was my savior back then and I will never forget that."

From Our Kitchen to Yours

Janet's Story: "We Are Family"

CONTINUED FROM PAGE 4

By 3pm, Janet is anxious to get home and spend time doing what she loves most - painting, singing and being with her friends. She is excited for summertime cookouts and picnics. She also volunteers with the Niantic Lion's Club, shucking corn and helping to prepare for the annual Lobsterfest every July.

Would she prefer to live by herself? Janet doesn't hesitate. "I want to live here! We are very close, and we love that."

To learn more about The Arc's Residential program, visit TheArcNLC.org/residential.php.

Try Janet's Special Strawberry Shortcake Recipe



Janet's favorite thing about summer is the abundance of fresh fruit. From strawberries to blueberries to watermelon, fruit is Janet's go-to treat on a hot day. And for dessert, nothing beats a bowl of strawberry shortcake. Try this recipe for yourself!

Ingredients:

- ♦ 1 quart fresh strawberries (or more if you like)
- ♦ 1/2 cup sugar
- ♦ 8 ounces cream cheese, softened
- ♦ 1 cup powdered sugar
- ♦ 1 (8 ounce) container frozen whipped topping
- ♦ 1 (14 ounce) angel food cake, cut into cubes

Directions:

Wash, stem, and cut strawberries in half. Add sugar; toss to mix well. Chill.
Next, beat cream cheese and powdered sugar well. Fold in whipped topping and cake cubes.
Spread cake into an ungreased 13x9 dish.
Cover and chill for at least 2 hours.
Cut cake into squares; top with strawberries.



Ahoy Mateys!

6th Annual Pirate Party brings scallywags from across the state



The highly popular Pirate Party offered a night of fun, fine food and a quality silent auction in April. Along with special honorees **State Representative Betsy Ritter of the 38th District, Department of Developmental Services Commissioner Terrence W. Macy, Ph.D., Chief Lynn Malerba of the Mohegan Tribe and Jim Reed from Hall Communications**, guests were treated to a visit from Mystic's sailing ship, *The Argia*, while a band of select swashbucklers (The Free Men of the Sea) duelled in true pirate fashion along the Mystic River.

Save The Date! Did you miss this year's Pirate Party? Check out The Arc website, TheArcNLC.org, to attend and/or become a sponsor next year on April 26, 2014!



Top right: (l-r) Rep. Betsy Ritter, The Arc CEO Kathleen Stauffer and Sen. Andrea Stillman
Lower Right: Immediate Past President John Fournier (left) with DDS Commissioner Terrence Macy
Far left: John Fournier with award recipient Aaron Newman
Left: Kathleen Stauffer (right) with Kara Lawson of the Connecticut Sun

The Arc From My Eyes by Julia Brust

A Chat with Chef Tom Meet Chef Tom Murphy of The Arc General Store & Bakery

Julia Brust, the newest member of The Arc's news team, is 24 years old and a graduate of Griswold High School. In this edition, Julia interviews Tom Murphy, Head Chef at the Employment Transition Center in Groton.

Julia: What do you do at The Arc?

Chef Tom: I am the chef of the culinary program. We train people how to cook, bake and work in the culinary profession

Julia: What do you like to bake?

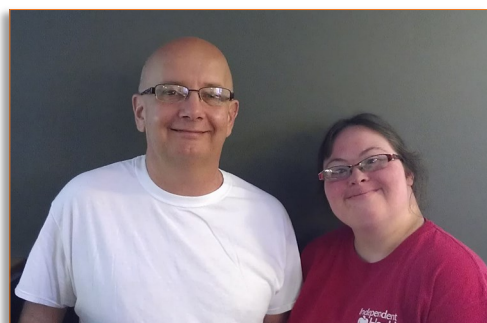
Chef Tom: I like to bake bread, cookies, gluten-free magic bars and try new recipes.

Julia: What is your favorite kind of pie?

Chef Tom: Pumpkin pie! When I was a kid, I would have a pumpkin pie on my birthday instead of a cake.

Julia: What do you like to do outside of work?

Chef Tom: I like to spend time with my family. I have six children – four boys and two girls – ages 10 to 22. I teach them how to cook and go to their school and sporting events. I also like photography, particularly taking wildlife pictures.



Chef Tom Murphy and Julia at the Employment Transition Center

Our Wish List

2013 Strides Road Race Needs Your Support Sponsorships needed, registration open!

This year, The Arc is holding the 36th Annual Jack O'Keefe Memorial Strides Road Race on Sunday October 6, 2013 at Camp Harkness in Waterford.

Sponsorship levels:

- ♦ **Platinum Sponsor** \$1,000
- ♦ **Gold Sponsor** \$ 500
- ♦ **Silver Sponsor** \$ 250
- ♦ **Bronze Sponsor** \$ 100

With the above sponsorship, company names and logos (gold & platinum) will be featured on commemorative t-shirts, in a thank-you display advertisement published in *The Day* newspaper, *The Resident* and *The Norwich Bulletin*, in the agency newsletter mailed to over 2,500 businesses and families and on The Arc's Web page, Facebook and Twitter account.

Contact Meghan Horan at (860) 889-4435 ext. 116 or at mhoran@thearcncl.org for more information. To register go to TheArcNLC.org.



Technology For Communication iPads give a voice to participants

Have you recently upgraded your technology? Are you looking for a place to donate your old iPad? The Arc will take it off your hands! The Arc is rolling out iPad technology agency-wide. If you have an iPad you would like to donate, please contact Lara Chiaverini at 860-889-4435 ext. 103.



DDS Focuses on Autism

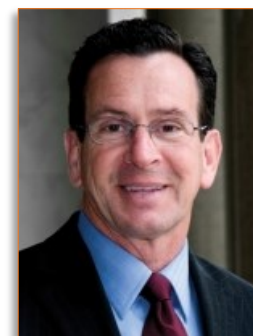
New website, committee unveiled in conjunction with Autism Day 2013

The Connecticut Department of Developmental Services (DDS) published a new section on its website focusing on Autism Spectrum Services. The new section serves as a resource for families, individuals and professional providers.

The new feature is a direct result of the 2011 Autism Feasibility Study commissioned by Governor Dannel P. Malloy. Results from the study indicated that families wanted a more user-friendly system, more collaboration between state agencies and service providers, consistent reimbursement rates among public and private carriers. The new Web section aims to address these and other gaps in the current service system.



In addition, as part of the recently passed Public Act 13-20, an Autism Spectrum Disorder Advisory Council (ASDAC) was established. The newly appointed council will coordinate a multi-year plan to expand and improve the existing service issues identified in the study.



Gov. Dannel P. Malloy

"This is a very exciting time for the State of Connecticut," said DDS Commissioner Terrence W. Macy, Ph.D. "We now have a road map to helping thousands of families. It is the first time in the state that so many different parties have come together with the same goal: to expand and improve services for individuals on the Autism Spectrum."

To view the new autism section and to read the Autism Feasibility Study, visit the DDS website at www.ct.gov/dds

SSA Chooses Respect

Social Security Administration ends use of the "R-word."

The Social Security Administration announced a resolution to use the term "intellectual disability" on all official listings of impairments and regulations. While the amended terminology will not change who is eligible for benefits, SSA has opted to voluntarily use the modern, respectful terminology moving from initial public notice of proposed rulemaking to the final ruling in only eight months. To view the changes on the SSA website, please visit www.ssa.gov.



The Success Stories of The Arc NLC New video by NFA senior debuts at Annual Meeting

Norwich Free Academy senior Patrick Kudej produced a short film, "Spread The Word," highlighting the abilities of people with intellectual and developmental disabilities in The Arc NLC family at the 61st Annual Meeting in June. "Spread The Word" is a sequel to a short film by Kudej that went viral on YouTube garnering nearly 60,000 views. Kudej, along with Norwich Free Academy teacher, Katie Beit and Stamford School Psychologist Alyssa Beit, interviewed 18 people with intellectual and developmental disabilities. The message from participants was loud and clear, "Don't *dis* our abilities. We are very proud of exactly who we are." Patrick was recognized at the Annual Meeting for his talents and ability to capture exactly what The Arc represents - full inclusion for all in south-eastern CT. The "Spread the Word" video can be seen at TheArcNLC.org.



Stars of the video "Spread the Word" gathered to preview the film before it went live

The Arc Helps Employees and Participants Breathe A Little Easier

Smoking banned on The Arc properties

On January 1, 2013, The Arc became a smoke-free campus. In keeping with promoting healthy lifestyles for everyone, smoking is no longer permitted on the premises of any property owned or operated by The Arc. Employees are encouraged to seek smoking cessation options offered through the Human Resources department. For more information, contact Christine Pemberton at 860-889-4435 ext.111

Janet's Story: "We Are Family"

How one woman's search for family led her home

Janet carries an oversized scrap book with the few precious pictures she has left of her parents and brother to her kitchen table. Janet cradles the book close to her heart as she begins to speak.

"When I was young, my father drove a bread delivery truck. He would ask if I wanted to ride with him, and I had the most important job of guarding the food in the truck when he made deliveries. At night, mom, dad and I would each sit at our looms and weave. They would make floor rugs to sell in town, and they taught me how to make small purses that I gave to my family as gifts."



Janet with her mother and brother in 1941

Janet's childhood is filled with loving memories of her mother, father and brother. She loves to talk about her Penobscot Native American heritage, being born in a house instead of a hospital and growing up in New London. She talks about her father's loom and how he would let her help as he weaved. Her face lights up as she remembers her brother, who was twelve years older and took care of her while her parents were at work.

"This is the family I chose. My friends here are my family now."

Sadly, Janet also knows what it is like to lose a family. Janet's mother, father and brother have all passed away. "My mother sat me down and said she wouldn't always be here for me and I would have to find a new family. This is the family I chose. My friends here are my family now."

Janet moved twice after her parents died, finally settling in to her current home in East Lyme, operated by The Arc New London County. In 1991, she met Kitty, a direct care professional employed at the house. The two formed an instant bond. They laugh about how Janet had to show

Kitty where the silverware was when she first started working in Janet's home. When it was time for Janet to move into her current home, Kitty knew she had to make the transition with her.

Janet's new family functions much like any other. "I do some cooking and I do laundry on Saturdays." Janet and Doug, her housemate and best friend, sit in matching rockers to watch television and look forward to going out together on the weekend. "We just saw *Superman!*" Janet and all her housemates attend recreation events, dances and birthday socials, but wherever they go, Janet always sits with Doug. "He always saves a place for me."

Still, something was missing for Janet. She wanted to see her parents and brother one last time.

"A few years ago, I made a goal to finding where my parents were buried. My Life Skills Instructor and I went to the library and researched Native American burial grounds. I found my mother, father and brother. We were together again."

Together, Janet and her Instructor were not only able to locate Janet's parents' and brother's gravesites, but they also took a trip to see them. "We were together again." Janet is now determined to find the gravesites of her grandparents and learn more about her Native American heritage.



Janet at the 2012 Strides Road race.

At 73, Janet remains active. She works at Easter Seals and Goodwill and takes great pride in her work. "My job coach and I work together. She tags the clothes and I put them on the hanger. We talk about how much the clothes cost and how many we hung that day. I am lucky because I am doing the job I want."

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*What is Janet's favorite desert?
Check out page 7 for the recipe!*

Community Partners Make Dreams Come True

The Arc Network Expansion

The Arc received a \$7,000 grant in April from the Community Foundation of Eastern Connecticut to expand The Arc Network. The Arc Network provides parents and caregivers who are members of The Arc New London County an online list of qualified direct care professionals who are off-duty employees of The Arc NLC to provide Respite supports in the family home as needed. *For more information on The Arc Network, please see page 2.*

Leave a Legacy for The Arc

The Arc is honored to be recognized in the Snyderman Family Trust. Families and individuals are encouraged to call Kathleen Stauffer, Chief Executive Officer, at 860-889-4435 ext. 102 if they would like to remember The Arc New London County in this way.

Chelsea Groton Bank Dives Into Employment Venture

Thanks to a \$2,500 grant from Chelsea Groton Foundation, The Arc is embarking on plans to expand its Aquaponics project to Groton from its current location at The Employment Transition Center.

The Rotary Club of Mystic Supports The Arc's Special Olympics Program

The Rotary Club of Mystic donated \$1,000 to The Arc to support Special Olympics. Funds will be used to purchase much-needed uniforms and safety gear for athletes.

Self-Advocates Receive Eastern Savings Bank Donation

Eastern Savings Bank Foundation has awarded \$1,000 to The Arc to support the Community Life & Advocacy program, which is 100% funded by The Arc's generous community donors and by annual fundraisers - Strides Road Race, The Arc Night and The Pirate Party - along with The Arc's Annual Appeal, Self Advocate fundraisers and United Way.

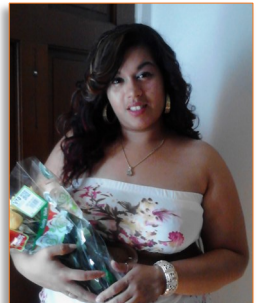
Knights of Columbus Contribute With Tootsie Roll Drive

Thanks also to the Knights of Columbus Council #34 in Taftville for their generous donation of \$484. These proceeds were raised from the Tootsie Roll drive and will also support the Community Life & Advocacy program as it offers empowerment and self-advocacy groups, community involvement and volunteer opportunities to participants.

Congratulations to The Arc New London County's Newest Stars

Team members earn recognition

Congratulations to **IHS employee Jeannette Martinez** who graduated from Eastern Connecticut State University in Spring 2013 and was accepted into the University's Social Work program starting in the Fall.



Congratulations to The Arc's **Special Olympics athletes** who brought home 22 gold, 14 silver and 12 bronze medals in swimming and track and field events during the Summer 2013 games at Southern Connecticut State University in June.

Nobody Donation Grows Gallery

Artwork Donated In Memory Of Janine Theve

The Janine Theve art gallery, located in the Sachem Street lobby, received two new additions this summer including a painting donated by Brian Grabell, cartoonist for *The Day*, titled "The Passion of Nobody."

The second work is a collaborative piece created by participants from The Arc and students in Norwich Free Academy's integrated Art program. Don't miss these new additions, along with other amazing artwork by employees and participants in our lobby gallery.

The Gallery is dedicated to the memory of Janine Theve, who passed away in 2011. Janine, a Three Rivers Community College student, was highly committed to helping people with intellectual disabilities succeed and express themselves through art. The gallery remembers a spirit who enriched the lives of all who knew her.



"The Passion of Nobody" by Brian Grabell