

# Goings on in the Gardens





Volume 1 | Issue 3 | NGOH | October, 2019|

#### Who we are

Nicky's Gardens of Hope is building permanent homes for autistic and intellectually developmentally disabled (IDD) adults. We provide progressive services for an inclusive community, such as employment training, on-site business opportunities & family support & lodging. We are dedicated to providing a revolutionary level of care for America's rapidly growing and aging Autistic and IDD population.

## Join the Revolution!

"The harvest is plenty, the workers are few."

This month's Feature Article: Fall Festival Fun

First Holistic Autistic Residency & Jobs Village



\$50 raised of \$500,000 goal		
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<u>JUST LAUNCHED!</u>
Nicky's Gardens of Hope

<u>GoFundMe crowdfunder:</u> http://bit.ly/2M0Ryjl



#### Fall Fun Events with some IDD & Autism Friendly Options!

Here's a list of some fun events coming up in New England over the next month with an IDD and/or autism-friendly component. A few pro tips: Plan ahead, map out your day, locate the restrooms and food vendors ahead of time, and if you are in need of more information, we've included the contact information for each event. Keep expectations low and have a blast!

#### NY

## Staten Island ZOO goes blue for Autism Oct 14 from 9 am to 12 pm

The Staten Island Zoo is once again proud to be going blue in partnership with Autism Speaks, providing a friendly, judgment-free environment for families affected by autism spectrum disorders. The day will allow families to enjoy our Zoo exhibits along with sensory-friendly activities. A quiet area will be available for those who need a rest. Gates will open one hour early at 9:00 am so families can enjoy the exhibits in a more private setting.

Limited tickets available at \$6 for online purchase only. Tickets must be purchased in advance and will not be sold at the door.

If you have any questions or would like visual support materials, please visit our website or e-mail <a href="mailto:jhartmann@statenislandzoo.org">jhartmann@statenislandzoo.org</a>

#### Connecticut

#### American Farm Barnyard Boogie Oct 12 from 2 to 5 pm

Horses Healing Humans

340 New London Turnpike, Stonington

Fun activities for military kids with special needs in a sensory-friendly environment

## ARCADE Game for autism & SPARK for autism Oct 12 from 11 am to 7 pm

Westfarms Mall, 1500 New Britain Av. West Hartford, CT 06110 FREE event, however sign up is required.

#### Maine

#### Adaptive Climbing at MaineBound Adventure Center!

October 26 @ 1:00 pm - 4:00 pm | Free Join MAIER's Family Partnership (MFP) at the Maine Bound Adventure Center for a fun afternoon testing your skill on their climbing wall with all the necessary adaptations and support for those with physical and/or developmental challenges!

This FREE event is intended for families impacted by autism spectrum disorders and is appropriate for children over the age of 4, teens, and adults. Specially-trained volunteers and the staff of the Adaptive Outdoor Education Center (AOEC) and MaineBound will be on hand to guide those new to this activity or those returning for more fun. MAIER Staff and UM student volunteers will also be on hand with additional activities between climbs.

Registration is required to help us plan, so register online here, or contact Donna at MAIER: donna.doherty@maine.edu or 207-581-2468.

No experience is required to participate and siblings, parents, and caregivers are invited to test their climbing skills with us, too!

#### Massachusetts

**Northeast Arc**, Danvers, October 18th, 2019. For youth with special needs ages 13+. The Arcs' annual Halloween Costume Dance welcomes attendees to wear their favorite super hero, spooky character and more.

\* First time attendees to any Arc events are asked to complete a quick intake so participants can be assessed to ensure that the program (s) will be a fit.

For more information contact the Northeast Arc's Recreation Department <a href="https://nearcrec.recdesk.com">https://nearcrec.recdesk.com</a> or Katie Sweet, Director of Recreation and Leisure at Northeast Arc, 978-624-2308

#### **New England**

#### Sensory & Family Friendly Showings

Sensory & Family friendly movies are for individuals living with autism and families with small children, to enjoy their movie going experience in a safe and accepting environment. In order to provide a more comfortable setting for individuals on the autism spectrum and those with young children, we keep the auditorium lights turned slightly up and the sound turned slightly up and the sound turned slightly down. The movie (typically G- or PG-rated) will start promptly at 10:00 a.m. Because some have strict, special dietary needs, families are permitted to bring their own gluten-free, caseinfree snacks from home.

Additionally, audience members are welcome to get up and dance, walk, shout or sing - in other words, our no talking policy will not be enforced unless the audience safety is in question. This is especially nice for those with young children new to the movie-going experience. Being able to relax and enjoy your movie-going without worrying if someone will complain or be disturbed by noise or movement is wonderful. Sensory & Family Friendly movies are a great opportunity to enjoy a movie in a climate of acceptance and understanding. Movies, dates, times and locations may change due to movie availability.

Some shows are not available at the Salisbury Cinemagic. Shows will be specified below if they are only showing in Salisbury.

https://www.cinemagicmovies.com/page/3588/Sensory-Friendly-And-Family-Friendly

#### **Rhode Island**

**Jack-O-Lantern Spectacular** (Sensory-Friendly) 1000 Elmwood Avenue, Providence, RI 02907

Providence

October 31, 2019 - November 3, 2019

Join us for a special sensory-friendly Jack-O-Lantern Spectacular an hour before the trail opens to the public: designed those with Autism Spectrum Disorders (ASD) and sensory processing differences and their families from  $5:00-6:00~\rm pm$ .

For maximum enjoyment, the over 5000 pumpkins will light up the Zoo's Wetlands Trail, but there will be no music or special effects. This year's highlights include intricately carved pumpkins with scenes from New England's beautiful four seasons - winter, spring, summer and autumn.

Please note: Tickets are available for purchase in person ONLY at the Zoo's admissions booth. Jack-O-Lantern Spectacular is open rain or shine. In the case of light to moderate rain, the show will be open. NO REFUNDS OR RESCHEDULING. For event details, parking information, and to purchase tickets please visit: rwpzoo.org/jols.

#### **New Hampshire**

#### **Sensory Sensitive Weekends**

2020 Dates To Be Determined.

Join us for a customized Story Land experience!

You can expect park music to be turned down, ride music will be off/turned down, ride announcements will be turned down to a lower decibel, certain geysers/water features turned off and MAP (Medical Access Pass) passes will be available for any guests who cannot wait in line. In 2018 we held the Grand Opening of our new Calming Room, a sensory sensitive environment for those who need a break. New in 2018 as well, we designated a Quiet Dining area next to Poblano Cantina. During Sensory Sensitive Weekend only, a VIP line at two lunch locations will be set up. This will allow guests with a MAP pass to order food quickly. As always, guests are more than welcome to pack lunches/snacks if food lines are of concern. During this weekend only, a special exit by Bamboo Chutes will be open from 4 pm – 6:15 pm to offer families an easier way back to their cars.

#### Vermont

#### **Sensory Friendly Drumming**

Co-presented with Inclusive Arts Vermont Chase Studio, 1st floor of FlynnSpace Map It Sunday, October 13, 2019, 1:00 PM Sunday, December 8, 2019, 1:00 PM

Fun and inclusive drumming workshop for families with a child or adult on the autism spectrum (or for anyone who would enjoy a sensory friendly experience). Classes use sensory-friendly drums and percussion instruments and relaxed expectations. No experience necessary.

## Did you know...?

A naturally occurring substance derived from bacteria in the soil of Easter Island has led to development of promising treatments for some aspects of TSC. #TSCFACTS

Read more at https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2884086/

# Family Perspective

By Thomas VanAntwerp



Adults with Autism & IDD, is the phrase FOX News New York, Mike Paul, used to describe Nicky's Gardens of Hope resident population. I think this is as concise and descriptive as it can be while having solid footing on political and medical ground. The concept of the first holistic and sustainable resident village for Adults with Autism & IDD has pushed us to envision how to best represent this voice and so that we stay in tune with the evolving wants and needs within it.

The IDD name comes from the name change of its publisher, the American Association on Intellectual and Developmental Disabilities, formerly AAMR, the world's oldest organization representing professionals in developmental disabilities. For Nicky's Gardens of Hope, IDD means both Intellectually Developmentally Diverse and Intellectually Developmentally Disabled. The phrase Autism or Autism Spectrum Disorder (ASD) adequately covers the same ground as the phrase Intellectually Developmentally Diverse, and it can then also be assumed to include neuro-diverse and intellectually developmentally diverse.

For the umbrella community representing Adults with Autism and IDD, whose voice we will serve as a pulpit for, using the acronym AAIDD would be confused as a reference to the American Association on Intellectual and Developmental Disabilities. By including an ampersand in the acronym to make it AA&IDD we can mitigate this potential for confusion. This also makes AA&IDD focused on Adults because it's part of the title. This is a differentiator because we are one of the first to focus on the issues that pertain to AA&IDD (as our research has shown this far). I think we also need to voice that we want the umbrella organization for AA&IDD to embrace the primary caretakers as a part of the AA&IDD+family equation. Once again, envisioning the concept of the first holistic and sustainable resident village for Adults with Autism & IDD pushes us to envision how to best represent this voice.

Within the AA&IDD community labels are needed to obtain services and early on for diagnosis and definition of what the medical situation is and how to treat it. In part, because of lobbying for them, medical definitions related to services are improving and are less offensive and archaic than in the past. Nicky's Gardens of Hope will be a medical facility so we respect what professional terminology there is in place. At the same time this is where we can use our voice representing the AA&IDD community to help create better suited definitions /labels, put discussions on the public agenda for needed services, and problems not addressed. For example, there are many available services managed by different disability hubs with no integration of services (especially medical services). Is there a web-based shareable database of available services? Can Nicky's Gardens of Hope facilitate creation of one if it is not out there yet? or be a resource to point our community toward it if it is? Can we help our community to get to reasonable levels of stability or security without risking accumulating assets and becoming ineligible for the needed services? It's a diverse community and there is much work for us to do. Creating Nicky's Gardens of Hope is just the beginning.

As a young dad I was a big proponent of early intervention and treatment because if you can make a difference as a parent you do it ASAP. In order to receive treatment a doctor needs to give a diagnosis to provide for the treatment of the diagnosis. This is the label that services are tied to. Having this label is often not wanted by higher functioning people with ASD or their parents. When you consider that 13% of the Autistic population originally diagnosed as having ASD as children, now are no longer diagnosed with ASD because of misdiagnosis or maturing out of it1, it is easy to understand some reluctance to labeling. In addition, a part of the ASD population were diagnosed with Asperger's Syndrome, given OT, PT, IEP's, 504's and

then had the diagnosis removed from the DSM-5 and rolled in as Autistic (often Asperger's Syndrome or PDD-NOS which means "were not sure what it is but you're on the spectrum"). Our understanding of the granularity of how the brain works and matures is imprecise because the process is imprecise. ASD has a myriad of symptoms, nuances and eccentricities that bleed into shadow traits (Can you be 1/4 Aspergers or nearly neuro-typical?) so we have a patchwork of symptoms that equals being on the spectrum.

I like the terms neuro-typical and neuro-diverse and I think they have some medical acceptance as general references though they should not be confused as a diagnosis.

As I was explaining what the acronym IDD stands for to my son it struck me that especially if they are high functioning, and especially if they are teens or young adults they are not going to want to be referred to or considered "intellectually (developmentally) disabled".

As they mature and become more self-aware they may not want to be considered different in school. Invoking the allotted extra time for tests, being pulled out of high school classrooms for sessions, and multiple school counselor visits add up to being treated "differently" and they understand that this is not lost on their peers. Young adults can be harsh to each other and ignorance isn't limited to people you don't know either. I think the feeling is if you can opt-out of being seen as the retarded kid by your peers, friends and family it's the obvious thing to do. So is there another way to do this gracefully? I suspect

that if you asked any young adult with these issues, "What is the right label?, the answer is

"Just **DON'T** label me!".

The skills we need today are different than those in the past. Consider hyperfocus. Today's millennials have lost the ability to focus. Just texting while driving has added 1.6 million car accidents (and thousands of deaths) every year. Hyperfocus is invaluable in financial analysis, software development, medical research, etc. High functioning autistic hyper-focus. Why aren't they

labeled with their valued qualities? (I'm a hyper, are you one too?) Of course, there are big dangers here. The IDD world could shatter into smaller, less effective groups that don't work together. Still, if we focus on the positive, consider the following list of individuals who urban legend associates with being autistic. While These are all geniuses in different areas, but what is the common name? What do you call it? Maybe Greta Thunberg is correct in labeling it a superpower.

Bill gates Dan Aykroyd Andersen Tim Burton Charles Darwin **Bobby Fischer** Thomas Jefferson James Joyce Michelangelo Wolfgang Amadeus Mozart Sir Isaac Newton Nikola Tesla William Butler Yeats Andy Warhol

Jerry Seinfeld Hans Christian Susan Boyle Lewis Carroll Albert Einstein Bill Gates Steve Jobs Stanley Kubrick

Thomas VanAntwerp is Chief Development Officer for Nicky's Gardens of Hope and Adriana's right-hand man. He is drawing on 20 years of consulting, sales, and project management experience, and can turn common life experience into a teaching moment for his three children, for the teams he coaches, and for his work colleagues. Tom is leveraging his professional sales experience and team building to develop and promote the profitable business ventures that will fund Nicky's Gardens of Hope. Stay tuned for more next month as we dig a bit deeper into a discussion of labels and terminology related to our potential resident population. We want to make sure we get it "right", and give voice to an inclusive, collaborative and supportive environment down to the smallest detail.

## "The trouble with normal is it always gets worse."

## ~ Bruce Cockburn



#### From The Kitchen~with Gitta

Gitta Lakatos is an\_Alternative Healing Therapist at Healing Infocus and is a practitioner of Massage, Magnet, and Reflexology. One of her roles at Nicky's Gardens of Hope is developing a line of food products that use natural, locally sourced ingredients for those with IDD/Autism with the goal of improving overall nutrition and minimizing gastrointestinal issues common to these populations. Food sensitivities often go undiagnosed, particularly in non-verbal individuals and issues such as inflammation, mood instability, sleep difficulties can often be traced to poor diet and gut health. Gitta is building all the food items from the ground right up to the edible product. She's utilizing spices & herbs in different combinations to ensure maximum flavor with minimal post-meal discomfort and directly contributing to improved health and overall quality of life

#### **DARK CHOCOLATE!**

Studying the brain benefits of chocolate—cocoa and dark chocolate, mainly—has become an area of interest in recent years. Numerous studies have suggested that high-potency cacao has significant effects on cognition, mood, cholesterol, insulin sensitivity, and blood vessel function. There are now two new studies from Loma Linda University found that some of chocolate's benefits may also occur at fairly low doses as well. A serving or two of dark chocolate may boost memory, cognition, the immune system, and mood.

For one study, the researchers had healthy participants eat the equivalent of a chocolate bar—48 g of dark chocolate, which was 70% cacao and 30% organic cane sugar. Then

their brains were scanned with EEG, which measures brain wave activity, 30 minutes and 60 minutes after eating the chocolate. The team reports that gamma waves, (related to cognition and memory), increased across multiple areas of the cortex, and the changes were much more robust at the 30-minute mark and largely returned to normal at the 60-minute measurement.

Both studies were presented at the Experimental Biology 2018 annual meeting.

"We suggest that 48 g 70% cacao consumption with a concentration of antioxidant activity is associated with subsequent [gamma wave] increase in the cerebral cortical brain," the authors write. "We suggest that this "superfood" of 70% cacao (organic cocoa beans from Tanzania) enhances neuroplasticity for behavioral and brain health benefits."

In the second study, participants ate the same variety of chocolate as above every day for a week. They were asked to abstain from high-antioxidant foods in the days leading up to the study. Their blood was collected every day after they'd eaten the chocolate so researchers could measure the expression of multiple genes.

It turned out that genes involved in the immune response (e.g. white blood cell activation) were boosted, while those involved in inflammation were reduced. The expression of genes involved in neural signaling and sensory perception also increased.

The results might be encouraging for people looking for more evidence to support their predilection for dark chocolate.

"For years, we have looked at the influence of dark chocolate on neurological functions from the standpoint of sugar content – the more sugar, the happier we are," said study author Lee Berk in a statement. Well, this isn't exactly true, since researchers have been attributing the neurological benefits of cocoa to its polyphenols (antioxidants) for years. Universities have been studying cocoa for a long time, and Mars, Inc. has helped fund studies to quantify the effects of flavanols, and measure their effects on both cognition and the brain. In one Columbia University study, participants who drank a high-potency flavanol drink for three months had improved memory function and changes in a part of the

brain linked to age-related memory decline. Other studies have shown similar results on cognition and memory.

But what may be more noteworthy about the new studies is that they suggest it may not take huge amounts of bitter chocolate or super-condensed cocoa to have measurable effects. "This is the first time that we have looked at the impact of large amounts of cacao in doses as small as a regular-sized chocolate bar in humans over short or long periods of time, and are encouraged by the findings," says Berk. "These studies show us that the higher the concentration of cacao, the more positive the impact on cognition, memory, mood, immunity and other beneficial effects."

The studies were both very small pilot studies, and neither has been published in a peer-review journal, which means that they should be considered preliminary.

But because earlier work has found similar connections, it's not difficult to imagine that the new studies' findings are valid. So if you're a fan of dark chocolate, science again suggests you may carry on.



This is our Chief Inspirational Officer, Nicky 🤢

Thank you for taking the time to read it and contact us if you have questions, would like to volunteer or help!!

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NGOH Leadership:

Founder & CEO~Adriana Piltz
President & COO~Chris Niccolls
Chief of Sales & Business Development
~Thomas VanAntwerp

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Editor in Chief: Adriana Piltz Creative Director: Jill Woodworth Design Director: Amora Correa Copy Editing: John D. Brigham

Submissions this month by:
"In The Kitchen" ~ Gitta Lakatos
"Family Perspective" ~ Thomas VanAntwerp
"Fall Festival Fun" ~Amora Correa

Just In! Adriana Piltz Crowdfunder!

First Holistic Autistic Residency & Jobs Village
(http://bit.ly/2M0Ryjl)

Adriana Piltz on BoldTV:

http://bit.ly/2M8gGER

From NGOH YouTube Channel:

Nicky's Gardens of Hope~Nicky and the Team

A Minute with Nicky~20 with TSC & IDD

IDD & ME: Max, Alex & Nicky There Is No Other Choice From TSC Talks~A podcast hosted by Social Media Director, Jill Woodworth: TSC Talks Podcasts:

When Law Enforcement Meets Autism,
The CBD Cannabinoid Conundrum; On Epilepsy & Autism,
A Discussion on CBD & Cannabinoid Medicine with Mike
Robinson, Founder, Global Cannabinoid Research Center
Nicky's Gardens of Hope or Bust w/Adriana Piltz
I Wish He Could Talk with Max Piltz
Adriana Piltz & Nicky's Gardens of Hope-First Podcast

TSC Talks Crowdfunding Campaign! TSC Talks is launching a new series of talks about cannabis & TSC families, and a crowdfunded project to independently test and review cannabis products. http://bit.ly/2MqzRZq

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