

## Supportive Housing For Adults with Autism

### A Place of Their Own: Residential Services for Soon-to-Be Adults with Autism

By Marina Sarris  
Interactive Autism Network  
Kennedy Krieger Institute

An unprecedented number of families will soon watch their children with autism leave school and flood the adult disability system. Up to a half million children with autism will reach adulthood in the next decade, according to estimates.<sup>1,2</sup>

These children, the first wave of the so-called “autism epidemic,” will enter a disability support system already under strain, according to a journal paper co-authored by Peter F. Gerhardt, EdD, chair of the Organization for Autism Research’s Scientific Council. The influx of newly-minted adults represents a “looming crisis of unprecedented magnitude for adults with autism, their families, and the ill-prepared and underfunded adult service system charged with meeting their needs,” the paper said.<sup>3</sup>

Across the nation, adults with autism spectrum disorder (ASD) encounter diffi-



culties finding housing and other services tailored to their needs. They face “long waiting lists for subsidized communi-

ty-based services,” according to the U.S. Interagency Autism Coordinating Committee (IACC).<sup>4</sup>

A 2009 study reported that about 88,000 people with developmental disabilities were on state waiting lists for housing services.<sup>1</sup> And numbers continue to climb. “There are states that have waiting lists of eight years or more before they can provide services,” said Steve Muller, president of the National Association of Residential Providers for Adults with Autism.

#### Less Research on Adults with Autism

Research on adults with autism has taken a back seat to children’s issues. As the number of children diagnosed with ASD grew rapidly in the 1990s, researchers focused attention on early diagnoses and interventions. They have devoted “less attention to issues concerning adults with ASD,” according to the Institute on Community Integration at University of Minnesota.<sup>5</sup>

“We would like to see increased research on adults with autism, particularly on quality of life issues,” said lead author Jennifer Hall-Lande, PhD.

*see Residential on [page 24](#)*

## Autism Speaks Addresses Significant Home and Community-Based Support Needs

By Leslie Long  
Director, Adult Services  
Autism Speaks

What does the number 221,898 mean to you? To individuals with autism and other developmental disabilities, it is the number of people waiting to access supports that would enable them to live in the community through a Medicaid Waiver. Some estimates go even higher. (Source: Kaiser Family Foundation)

How about the number 710? To people on Supplemental Security Income (SSI), it is the maximum amount they are eligible to receive per month as a federal disability benefit. Which is less than 758, the average monthly rent for a one-bedroom apartment in the United States.

These numbers sum up the current housing crisis for adults with autism and oth-

er developmental disabilities. Even if you reach the top of the waiting list for Medicaid Waiver support, would you be able to afford renting or buying a home? If not, do you know what financial help you can get to rent or own?

At Autism Speaks, our goal is to help improve outcomes for all individuals with autism and their families – this includes the choice to live where they want and to reach their best potential. We do this through awareness, education and action. Many are aware of the growing prevalence of autism, but have we done enough to educate our families on how to find and maintain adult housing? This requires understanding the rules that govern assistance in capital costs (“bricks and mortar”), the operating costs (rent and maintenance) and the support services (staff) that many adults with autism will need to live as independently as possible in the community.

Purchasing a home can be an over-

whelming process for any individual, but particularly for a person with needs that go beyond the traditional homebuyer. For a person with autism and their family, each step in the process requires careful consideration of the different options that may be available, particularly based on their support needs. One piece of the puzzle is the type of housing: a single-family home, a townhouse, an apartment, or another type of physical structure. What about roommates, distance to local stores and other places of interest, or access to help with activities of daily living, and access to public transportation? The list of questions can be extensive to ensure success and maximum independence for the person with autism. One’s home is defined not only by a physical structure, but by how we live in the home, and the surrounding community. Each person will have his/her own definition of home and it most likely will be unique.

There is little consensus as to how best to address the overwhelming demand for affordable housing and community supports and overcome the severe lack of services to meet the needs of all individuals with developmental disabilities. This lack of consensus has created a significant barrier to developing a comprehensive and sustainable plan on the federal, state and local levels that will provide hope to the hundreds of thousands of people with developmental disabilities and their caregivers, a growing group that currently has very little chance to plan for their future with any certainty of supports.

When looking at the housing issue, the term “overwhelming” becomes an understatement. For most individuals with autism, some type of support is required. As a result, receiving services through a Medicaid Waiver may make the difference

*see Support Needs on [page 20](#)*

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## ASN 2013 Editorial Calendar

**Fall 2013 Issue:**  
 "Managing the Financial Needs of Autism"  
**Deadline: September 5, 2013**

**Winter 2014 Issue:**  
 "Using Technology to Enhance the Lives  
 of Individuals on the Spectrum"  
**Deadline: December 5, 2013**

**Spring 2014 Issue:**  
 "Autism in the Workplace"  
**Deadline: March 5, 2014**

**Summer 2014 Issue:**  
 "Autism and Mental Health Services"  
**Deadline: June 5, 2014**

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# AUTISM SPECTRUM NEWS DESK

## Founder of Special Needs School Named NY State Woman of Distinction

From the Office of  
NY Senator Greg Ball

On May 8, 2013, New York State Senator Greg Ball (R, C, I - Patterson) nominated Theresa Pirraglia of Katonah as his 2013 New York State Senate Woman of Distinction.

"I can't think of a more deserving person for this honor. From helping other parents with special needs children navigate the education system, to fighting the closure of the Devereux Day Habilitation Program, Terry is truly doing God's work," said Senator Greg Ball. "What a fitting tribute to honor Terry into the 2013 New York State Women of Distinction alongside other women of distinction from throughout this great state."

"I would like to sincerely thank Senator Greg Ball for selecting me as the 40th NYS Senatorial district's Woman of Distinction. It is a great honor and I am truly humbled by it," said Theresa Pirraglia. "It has been my privilege to work with persons with developmental disabilities and their families, who struggle every day to have a quality of life that all New Yorkers take for granted."



**Theresa Pirraglia receives the New York State Woman of Distinction award from Senator Greg Ball**

Theresa Pirraglia is a leader in the developmental disability community in New York State. Mrs. Pirraglia possesses a wealth of knowledge and experience in the

field of developmental disabilities, especially autism.

As the parent of 25 year old son with autism she has both developed and pioneered

cutting edge programs for person with autism through New York State's Special Education and OPWDD systems.

In 1996 along with her husband, Joe and seven other families she founded the Devereux Millwood Learning Center in Westchester County New York. The center was the first school for children with autism based on the principles of applied behavioral analysis in the lower Hudson Valley.

Mrs. Pirraglia has co-chaired twelve educational and medical conferences on autism with such partners as the Mount Sinai School of Medicine and the Westchester Institute for Human Development.

In 2009 to help meet the demographic tsunami of adults with autism in New York she designed and co-founded with the Devereux Foundation the first Enhanced Supported Employment and Day Habilitation Without Walls program. This program has enabled young adults with autism to obtain and maintain paid employment in their communities in the lower Hudson valley. In addition, this program provides ongoing voluntary opportunities for all its participants. This has enabled these young adults with autism to

see *Distinction* on [page 19](#)

## Autism Science Foundation Announces 2013 Grant Recipients

Staff Writer  
Autism Spectrum News

On April 15th, 2013, the Autism Science Foundation, a not-for-profit organization dedicated to funding autism research, announced the recipients of its annual pre- and postdoctoral fellowships, as well as the first recipient of a new 3-year early career award, and the recipient of its first treatment grant. Three postdoctoral and four predoctoral grants will be awarded to student/mentor teams conducting research in autism interventions, etiology, treatment targets, early diagnosis, biomarkers and animal models. Dr. Jill Locke of the University of Pennsylvania was named the recipient of ASF's first multi-year grant, and Dr. Alex Kolevzon of the Icahn School of Medicine at Mount Sinai will receive ASF's first treatment award.

"The autism community has demanded more research to understand what is causing autism and to develop better treatments," said ASF President Alison Singer. "We are proud to be able to increase our research funding in response to this national health crisis and we are especially grateful to all our donors and volunteers who have come together to support autism research and make these grants possible."

This year, the Autism Science Foundation will fund just over \$350,000 in grants. In its four years of operation, ASF has funded over \$1.1 million in grants.

"ASF attracts outstanding applicants across the board, representing a broad range of perspectives on autism science," said Dr. Matthew State, Chair of the ASF Scientific Advisory Board and Chairman of the Psychiatry Department at the University of California, San Francisco. "These projects show great potential to move the field forward."

The following projects were selected for 2013 funding:

### 3-Year Early Career Award

Dr. Jill Locke:  
University of Pennsylvania

*Multi-Site, Randomized, Controlled Implementation Trial of an Evidence-Based, Adult and Peer-Mediated Social Skills Intervention for Elementary School Children with Autism Spectrum Disorder Co-funded with the FAR Fund*

### Treatment Grant

Dr. Alexander Kolevzon:  
Icahn School of Medicine  
at Mount Sinai

*Human Clinical Trial of IGF-1 in Children with Idiopathic ASD*

### Postdoctoral Fellowships

Dr. Aimee Badeaux & Dr. Yang Shi:  
Boston Children's Hospital

*Molecular Characterization of Autism Gene CHD8 in Shaping the Brain Epigenome*

Dr. Sara Schaafsma & Dr. Donald Pfaff:  
Rockefeller University

*Sex-Specific Gene-Environment Interactions Underlying ASD*

Dr. Teresa Tavassoli & Dr. Joseph Buxbaum:  
Icahn School of Medicine at Mount Sinai

*Developing a Sensory Reactivity Composite Score for the New DSM-5*

### Predocctoral Fellowships

Alexandra Bey & Dr. Yong-hui Jiang:  
Duke University

*The Role of Shank3 in Neocortex Versus Striatum and the Pathophysiology of Autism*

Ezzat Hashemi & Dr. Veronica  
Martinez-Cerdeno:

University of California, Davis  
*Alteration of Dendrite and Spine Number and Morphology in the Human Prefrontal Cortex in Autism*

Jessie Northrup & Dr. Jana Iverson:  
University of Pittsburgh

*Development of Vocal Coordination between Caregivers and Infants at Risk for ASD*

Russell Port & Dr. Timothy Roberts:  
University of Pennsylvania

*GABA and Gamma-Band Activity: Biomarker for ASD?*

Learn more about the projects selected for funding at <http://www.autismsciencefoundation.org/current-grantees-2013>.

The Autism Science Foundation is a 501(c)(3) public charity. Its mission is to support autism research by providing funding to scientists and organizations conducting autism research. ASF also provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism. To learn more about the Autism Science Foundation or to make a donation visit [www.autismsciencefoundation.org](http://www.autismsciencefoundation.org).

# AUTISM SPECTRUM NEWS DESK

## New Brain Bank Set to Collect Samples for Autism Research

By Apoorva Mandavilli  
SFARI.org

A new initiative aims to collect brain tissue for autism research, adding welcome resources to the struggling Autism Tissue Program (ATP) ([www.autismtissueprogram.org](http://www.autismtissueprogram.org)), according to an announcement on May 2nd at the 2013 International Meeting for Autism Research in San Sebastián, Spain.

The project, called Autism BrainNet, has \$7.5 million in funds for the first five years, and aims to collect, process, store and distribute postmortem brain samples for autism research. It begins with three sites — Mount Sinai School of Medicine in New York, the University of Texas Southwestern Medical School in Dallas and the University of California, Davis MIND Institute.

The network will also integrate the ATP, a collection funded by the research and advocacy organization Autism Speaks ([www.autismspeaks.org](http://www.autismspeaks.org)). Last year, a freezer malfunction destroyed one-third of the ATP's frozen autism samples, housed at the Harvard Brain Tissue Resource Center ([www.brainbank.mclean.org](http://www.brainbank.mclean.org)).



But there are still a significant number of frozen and fixed tissues left in the collection, notes Robert Ring, vice president and head of translational research at Autism Speaks. "One-third of the collection was impacted, but not wiped out," he says.

Autism researchers have long bemoaned

the dearth of postmortem brain samples — and the poor quality of the few that are available. The logistics of getting tissues to a collection site rapidly — not to mention the ethical and emotional considerations involved — all work to limit their availability.

In recent years, the ATP has struggled to

increase the number of donations. It's estimated that fewer than six brains are donated to autism research each year. The new brain bank's mission will be aided in part by a large outreach effort, led by Alison Singer of the Autism Science Foundation.

The goal is to collect brains not just from those with autism but from people with related disorders, from their unaffected siblings and parents, and also from typically developing individuals.

Autism Speaks is donating \$2.5 million to the new network, which will be led by David Amaral, director of research at the MIND Institute. The Simons Foundation, SFARI.org's parent organization, is providing the rest. The project is expected to be operational by the end of the year.

The brain bank has been in the works for years. The two organizations submitted a proposal to the National Institutes of Health (NIH) in 2010, and are still hopeful of its support.

The ultimate goal is to have collection sites across the U.S. and abroad, says Ring. "We are going to need additional resources to do that," he says. "One seat we'd like to see [filled] is by the NIH."

see *Brain Bank* on [page 19](#)

## Autism Spectrum News Welcomes New Editorial Board Member

Staff Writer  
Autism Spectrum News

Autism Spectrum News is pleased to announce the appointment of Susan Cortilet-Jones, MS, LMHC, to its esteemed Editorial Board. According to David Minot, Publisher of *Autism Spectrum News*, "I am so pleased to have Susan join the Editorial Review Board. She is truly one of a handful of professionals who not only understands the complexity and needs of individuals with autism, but combines that with passionate dedication as well. She meshes her clinical astuteness with a practical, hands-on approach to working with young adults. Susan has taken an advocacy and leadership role in Rockland County, NY, where she resides and practices. As this is an area with a growing autism population where many people and families touched by autism are uninformed and underserved, we look forward to working with Susan to broaden the distribution of *Autism Spectrum News* into the Rockland County community."

Susan Cortilet-Jones is a New York State Licensed Mental Health Counselor, College and Life Coaching Expert and Consultant who works with adults and those in transition on the high functioning end of



Susan Cortilet-Jones, MS, LMHC

the autism spectrum. She describes herself as fortunate to have had a variety of professional experiences for the past 25 years. Her eclectic and diverse work experiences have centered on working with populations of people who are considered most at risk in our society. She has worked in high-

er education, rehabilitation, counseling, healthcare and secondary education.

Susan received her counseling degree at Syracuse University in 1989, originally intending to work with professional athletes who retired from sports. After graduating from Syracuse, Susan was offered a position at the University of Maryland's premiere Sports Counseling Center, but turned it down, instead choosing a position at Syracuse University working with first generation students mostly from inner-city and rural areas. A former athlete herself, Susan bases the foundation of her practice on many of her experiences as an athlete, her parallel training in counseling, and her belief in cognitive behavioral therapy techniques.

Due to the timing of her early ambitions, Susan shifted gears and spent the next 25 years working with the most at-risk populations, including as previously mentioned the HEOP (Higher Education Opportunity Program). She then went on to accept a position working in three rural school-based health centers as a clinician and later as a supervisor. She was selected by Family Health Network to participate in a National Disease Collaborative, which focused on improving healthcare for the poorest and most in need of healthcare in our society. While in Cortland, NY she also worked as a Rehab Specialist with adults

who had experienced lasting effects from Traumatic Brain Injuries helping them to "re-enter" their communities and improve the quality of their lives. At the time there was limited understanding of the plasticity of the brain, so much of her work was focused on "thinking out of the box" and trying new things.

In 2003, Susan met and married her husband Bill and moved to the Hudson Valley region of New York to work for Jawonio, a vocational rehabilitation organization in Rockland County which serves adults who have both psychiatric and developmental disabilities. While at Jawonio, she worked both as an employment counselor and an education coach for several years. An interesting phenomena began to occur in her role as an education coach: Parents began calling in desperation because their adult children who had high functioning autism, who were intellectually gifted and able and were attempting college, were struggling with their academic experience and/or dropping out of college as they had difficulty navigating the higher educational systems including services for students with disabilities. The parents and young adults did not know where to turn for help, as services were non-existent or limited. She began focusing on this population in

see *Board Member* on [page 31](#)

# Selecting Quality Residential Services for Adults with ASD

By Kay Brown, LISWS,  
Jan Cline, MS, CCC-SLP,  
Christine Keran, BA,  
Donna Owens, MA,  
Andie Ryley, Med,  
and Ellen Williams, PhD  
State of Ohio Adult Service  
Quality Indicators Work Group

There has been much discussion about bridging the gap between school services to adult services for students with Autism Spectrum Disorders (ASD). Families might experience this transition as a leap into the unknown. The daunting task of finding quality services for individuals with ASD is a cradle to grave process. Families are faced with the responsibility of locating, evaluating and choosing services often without experience, knowledge or guidance. What assistance is needed to support families in their decision making process?

A group of concerned professionals gathered to discuss the quality of adult services specific to individuals with ASD and how to help families make informed choices for their family member. Based on their work with families, the professionals recognized that caregivers could be looking at a variety of quality indicators when they shopped for services. A family's values and preferences are the overall guide to services being assessed. Depending on



their family member's specific needs and the intensity of those needs, families might be considering the quality of medical care, educational and vocational programs, recreational opportunities, etc. Two quality indicators that were often cited by families as being keys to their choice-making were related to happiness and safety. Happiness is an abstraction and defined differently for most every individual, but it seemed important to find some measure that addressed this priority need.

The outcome of this work is the *Quality Residential and Other Services for Adults*

*with Autism Guide*. The services being evaluated might include residential, vocational or other supports. The guide is a starting point for individuals/families/guardians to use in evaluating programs when seeking services for adults with ASD. It could also be used by service providers to evaluate how their existing services meet the needs of adults with autism. The guide addresses the following six categorical areas related to service provision: Health and Safety; Happiness/Well Being; Community/Recreation/Leisure; Staff; Administration; and Program.

For each of the previously mentioned categories of quality indicators, there are subcategories to consider. For example under the category of Health and Safety, families are directed to look at multiple levels of information gathering, including Health Care, Environmental Issues and Safety. To assist in their information gathering families are provided questions; such as "Where are the visual supports for safety posted?" "How do you incorporate special interest and talents into activities?" and "What specific autism training is given to staff?" Families are encouraged to add some of their own questions to the list. There is also a section on the guide for note keeping.

Below is a listing of topics and suggested questions/observations that may be explored in the evaluation of services for those with ASD.

## Quality Residential and Other Services for Adults with Autism

*A Guide for Individuals, Families and Service Providers*

### 1. Health and Safety – Health Care

*Medical care:*

How do you provide medical care?  
Who is the medical provider?

see *Quality Services* on [page 26](#)

## Spectrum Services

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**Rahimeh Andalibian, PsyD**, Psychologist  
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**Beth Yurman, PsyD**, Psychologist

**The Asperger Syndrome Training & Employment Partnership (ASTEP)** focuses on employer education and training, and advises employers on how to recruit and manage employees with Asperger Syndrome. [www.asperger-employment.org](http://www.asperger-employment.org)

**Asperger Syndrome and High Functioning Autism Association (AHA)** provides support programs, conferences, activities, a hotline and reliable, up-to-date information for individuals and families. [www.ahany.org](http://www.ahany.org)

**Career and Employment Options, Inc. (CEO)** provides transition supports for students in special education and job placement services for students and adults with Asperger Syndrome and other disabilities. [www.ceoincworks.com](http://www.ceoincworks.com)

**The Elija Foundation** provides advocacy support, educational outreach and comprehensive workshops in Applied Behavior Analysis for educators and family members. [www.theelijahfoundation.org](http://www.theelijahfoundation.org)

Contact us through [www.spectrumservicesnyc.com](http://www.spectrumservicesnyc.com) for clinical services.

Please visit [www.aspergercenter.com](http://www.aspergercenter.com) for articles of interest for families and adults with Asperger Syndrome.



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## Searching for an Appropriate and Safe Residential Community

By Carolann Garafola, MA  
Executive Director  
Mt. Bethel Village

As the adult population with ASD grows and their parents age, the primary concerns of the parents or guardians are: Where will my son or daughter live when I am not here? Where can my adult/child live even in a semi-independent community setting? Who will be responsible for managing the over-sight and financial aspects in this placement? Will the community foster friendships? Will my adult/child be safe and happy? One of the more significant issues that our families deal with is the issue of guilt in even making a decision to seek residential housing outside of the family home, a guilt that follows our families like static electricity; it clings and never really gets shaken off. The push and pull of encouraging our adult/children to seek independence from parents exists for all parents with all adult/children and for the family with a son or daughter with ASD, the stress of making this happen is magnified. How can we help parents change their role to support the independence of their adult child after they transition into residential housing?

Siblings, who may eventually become responsible for the brother or sister with ASD, may not have a clue as to what is in-



Carolann Garafola, MA

involved. They are good brothers and sisters who pledge to their parents that they "will take care of" their brother or sister, forever and after. Although they have grown up in the same household, may have shared a bedroom or struggled for attention from their parents, their knowledge of what is involved in taking responsibility of a sibling with ASD is not reality-based. They may or may not even know what the parents want

for the adult/child with ASD, the siblings may not know what financial planning has taken place and are truly in the dark about the emotional undertaking and the 24/7 responsibilities in becoming the guardians of a brother or sister with ASD, no matter how high functioning the sibling may be. If the siblings are older, they also worry about what will happen when they are gone and who will care for the sibling-in-need. For siblings who are married with their own children or with grown children, the responsibilities increase exponentially, especially depending on the extent of the needs of the sibling with ASD; and will the time needed to fulfill their roles as surrogate parents take from their own children or grandchildren? As the sibling with ASD ages in place and as we all worry about living arrangements for the older person, especially someone with medical needs such as seizures or intestinal problems and psycho-social issues, guardians trying to make their way through the system learning through trial and error.

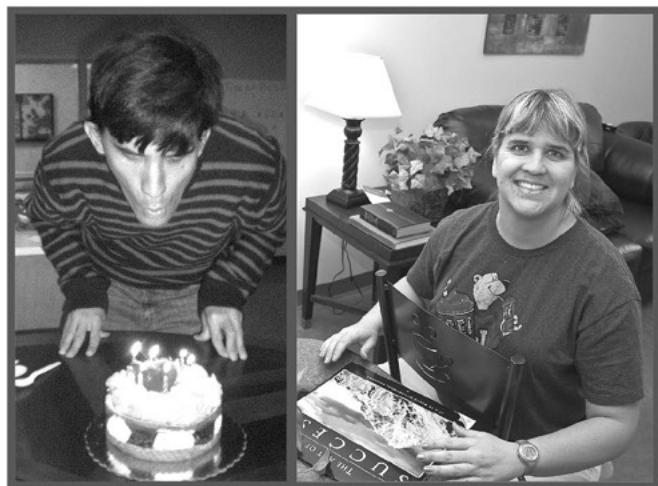
The point of detailing the issues is that no one wants to ask the questions: Doesn't an adult with ASD have the same rights as the rest of us to live well, to live in a routine, to live safe, to live happy, to have friends, to live in their community of choice and to have a purpose in life? Based on the acknowledged issues, there then is the need to critically look at the parameters for residential living outside the family's home.

### Issues of Safety

The issues of safety, comfort and happiness are consistently the most important aspects of what families will look for in choosing a residential community. When we talk about safety, we are talking about a swipe key entry system, window stops that open to a limited width, digital ceiling camera systems in all common areas, the option to set up cameras in each apartment, fire ratings that promises to protect residents, hall refuge areas with a phone system, alarms on exit doors to make staff aware of a resident leaving the building, shut-off valves that are easily accessible, smoke and alarm systems that minimize stress response, and an intercom system that provides a visual presentation of whomever needs to enter the building, all of which exist at Mt. Bethel Village. The presence of administration for two shifts, 24-hour staffing, maintenance of a Shift Log for important notes on residents, weekly, if not daily e-mails between administration and staff to keep everyone in the loop on various resident issues, non-violent video games and movies on premises, safe vehicles and drivers without points as well as finger printing and background checks every two years all reassure families that their adult/child will be safe and protected. Even when adults are picked up,

see *Searching on page 22*

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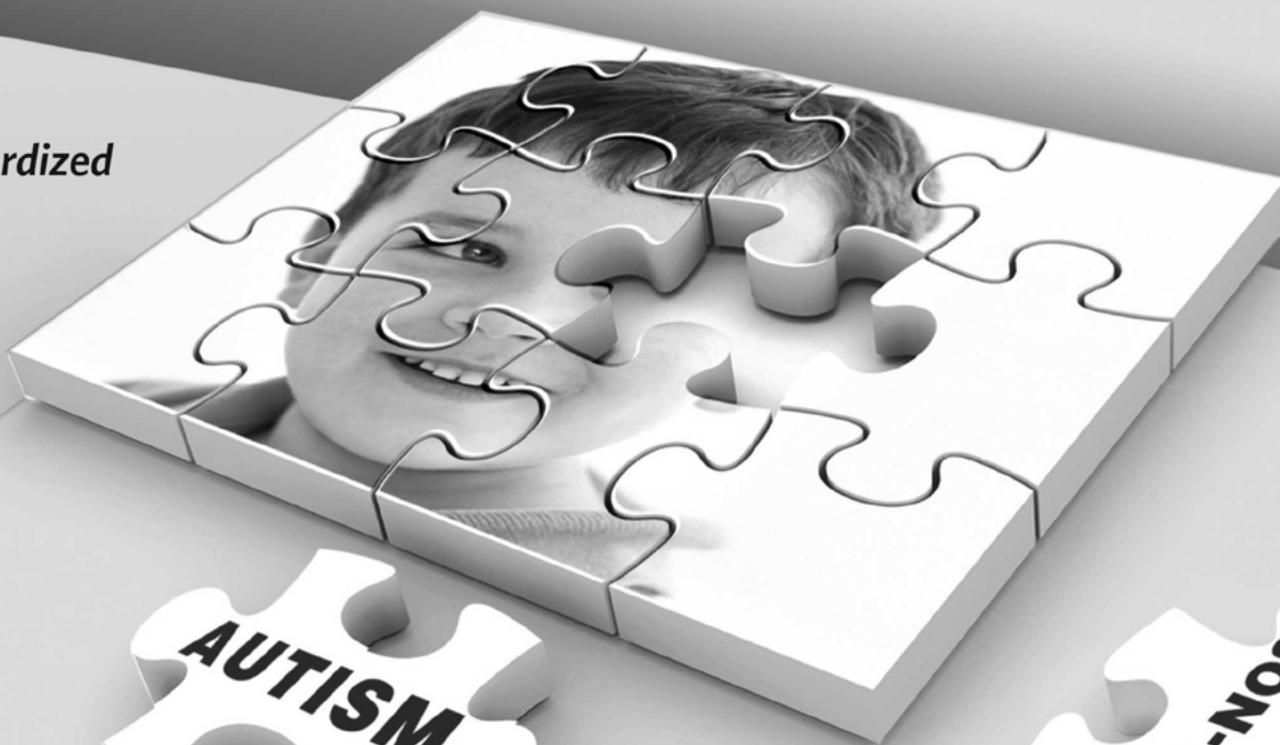
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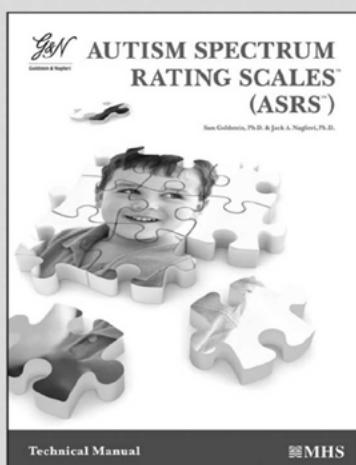
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## The Creation of a Model Independent Living Program: The POINT Program of White Plains, NY

By Ellen Forrest  
Mother and Advocate

One of the most perilous times in the lives of young adults on the spectrum is the transition from the stability and structure of school to lives away from their parents' homes - lives with as much independence as possible. I know this road well because I am the mother of a young man with an autism spectrum disorder. I have often thought that if I knew I would outlive my son, none of this would be necessary and I would be more overly protective and have him remain at home with his family. I'm sure many of you reading this feel the same way. The statistics show that most young adults on the spectrum live at home. However, we must all come to terms with the realities of life and the imperative to help our children mature.

With this in mind, I was excited when my son started a post-secondary vocational independence college program around ten years ago. Upon graduation, this education would provide a steppingstone to a housing program where young adults lived independently with supports in the metro NYC region. I, as well as many other families, had high hopes for this housing program to be a successful and long-lasting



residential support for our children, but it didn't work out.

The lessons learned from this experience lead to the hard-earned success and growth of the POINT (Pursuing Our Independence Together) Program of White Plains, NY.

What were some of the lessons learned? First, it is crucial to determine what the most appropriate entity is to be in charge of an independent living program. Should it be a school or some type of parent-run group or not-for-profit or a social service agency (with a willingness and commit-

ment to create a new model for independent living) or something else? Secondly, because many adults on the spectrum do not drive, it is important to place an independent living program in a geographic area with as much easily accessible public transportation as possible. This keeps program costs down and leads to greater independence and greater integration into the community. It is beneficial to have some shopping and recreation within walking distance. The costs of apartment rentals in the area must be considered. The pro-

gram needs to be of high quality, creative and affordable, with an emphasis on using government funds as much as possible and the knowledge that private funds may be needed to supplement this.

With the aforementioned considerations in mind, our hardy and determined group of a dozen or so families banded together in 2007 to answer these questions. Deciding on locating our proposed program in the urban-suburban city of White Plains, NY seemed an answer to some of our concerns. Deciding on what entity would run this program was a more lengthy process for us. We needed an outlet for our creative ideas on how a program should be run. We knew we needed a program which was not a group home but was more supportive and more of a creation of community than renting an apartment somewhere with a Community Habilitation (Comm Hab) paying a weekly visit. For a while, we considered that a parent-controlled entity have responsibility for the program. Then, we decided to meet with various social services agencies in the New York metropolitan area to explain our plight, our concerns, our vision and our time constraints to create a program by the summer of 2008. We had to determine if it would be feasible to partner with an existing social

see *POINT Program* on [page 27](#)

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# Affordable Housing Advocacy: An Approach to Success

By Mary K. Meyer, BA  
ASPEN Coordinator  
Adult Issues North Chapter

The question that keeps ASD parents awake at night: "Where will he/she live when I am no longer able to provide a home?" Questions and emotions swirl around whenever housing is the topic of any discussion: "It's scary." "It's complicated." "There are so many factors to consider." "Maybe someone else will figure this out for me." "What's the cost?" "What is appropriate for your son may not work for my daughter." "How do I assess the supports offered by the organizations/support systems intended to provide services?"

The Objective: Find the Best Possible Housing for Your Adult with ASD

But how? The approach of one small group of determined, every-day people, provides one possible answer. This is not a one-size-fits-all story, but the account of finding appropriate housing for a segment of the ASD population. The type of housing that will be discussed is for those who can live independently, with less restrictive supports.

## Background

The Adult Issues North chapter of ASPEN (Asperger's Syndrome Education Network),



located in Bergen County, New Jersey has been in existence for 14 years. When we began, we identified three over-arching concerns: social skills, jobs and housing. Initially, we focused on social skills and jobs, with housing taking a back seat. We judged that the housing issue was just too big for us; too complex for a small group.

In 2000, we enlisted West Bergen Mental Healthcare to facilitate a therapeutic social skills program for our Asperger's adults. In 2004, we came back to them with our jobs program proposal. They declined, saying employment was not their

expertise. Instead, they offered to help us with housing. This marked our first foray into housing advocacy: demonstrating the need. We sponsored a meeting, where West Bergen described their tentative plan. The room was packed with potential tenants and their relatives. Our early contribution to this effort was to recommend a HUD consultant, who we found through research and networking. After a lengthy, arduous effort, the final result was a ten-unit apartment complex that opened this spring for those with Asperger's Syndrome.

## Getting More Involved

The catalyst for becoming more involved in housing advocacy occurred in March 2009, with a half-day Affordable Housing Forum. Our panel of experts included:

1. A county official who described government programs
2. A developer who spoke of her company's involvement in meeting the affordable housing need
3. A mental health CEO who talked about a new group home, and
4. The mayor of Allendale, NJ who showed us pictures of the newly opened complex for 10 developmentally disabled adults

The Housing Forum achieved three results:

1. A better educated and informed membership
2. An inspired individual who committed to approach her municipality
3. The genesis of a chapter housing committee

see *Affordable* on [page 27](#)

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## Residential Farms Provide Housing and Employment for Adults

By Rachel Silverman  
Writer, Speaker, and Advocate for  
Adults with Autism

The U.S. autism community is facing a “perfect storm.” More adults need services amid economic crisis and budget cuts. Today, about 300,000 adults are living with autism (Advancing Futures for Adults with Autism, n.d.). The total annual cost per adult with autism is roughly \$71,000 in 2009 dollars (SAGE Crossing Foundation, 2009, p. 3). Thus, the total cost of caring for adults with autism today is \$21.3 billion.

Between 2014 and 2028, an additional 395,000 children with autism will enter adulthood (SAGE Crossing Foundation, 2013, p. 1). By 2030, the population of adults with autism will reach 747,000 to 794,000 (Rogers, 2011, p. 15). Depending upon the projected population of adults with autism, the total cost of caring for adults with autism will increase to \$53 billion to \$56.37 billion in 2030. Thus, the search for solutions to the financial crisis facing the autism community is urgent.

Adults with autism particularly need supportive housing programs. Such programs allow adults with autism to live and work in the community and to achieve their maximum level of independence. Residential farm programs represent an emerging but promising strategy for pro-



Rachel Silverman

viding supportive housing to severely impacted adults with autism. Such programs began with Somerset Court in the UK in 1974 and spread to the United States in the 1980's (Safe Haven Farms (b), n.d.).

Several European studies have demonstrated the benefits of residential farm programs for adults with Autism Spectrum Disorder (ASD). A four year study of ten adult residents with ASD and cognitive disabilities at the Italian farm community of Cascina Rossago tested the participants for improvements in adaptive behavior

(Orsi, Caputi, Pace, Di Nemi, & Barale, 2008, pp. S390-S391). The participants showed statistically significant progress in overall adaptive behavior and the communication and socialization sub-scales (Orsi, Caputi, Pace, Di Nemi, & Barale, 2008, pp. S390-S391). Thus, the program helped adults with ASD to improve the most critical weaknesses associated with autism.

Six German experts explained why agricultural work is suitable for many adults with autism. First, severely impacted adults with autism can participate in agricultural labor. “Development prospects for agricultural farms in the area of social work with people with autism are particularly evident in the fact that even hard handicapped people with autism can be qualified to perform meaningful work [and]...live in a “free” environment” (Nail & Von Elsen, 2011, p. 371). Second, agriculture offers a wide range of possible employment choices for autistic adults, including horticulture, work with animals, and general farm chores.

Third, working with animals can provide a feeling of emotional stability and meaning for adults with autism. The German experts said, “The animal area offers many useful work processes. In addition, animals create a clear and repetitive rhythm that is particularly suitable for people with autism, who are dependent on structure of meaning.” (Nail & Von Elsen, 2011, p. 369).

Government programs for adults with developmental disabilities represent a

major funding source for many U.S. residential farm programs serving adults with autism. Ms. D. DeScenza, founder of Farmsteads of New England (FNE), said that Medicaid provides 85% of the funding for her program (personal communication, May 2, 2013). The Homestead program in Iowa receives 100% of its funding through Medicaid (D. Berry, personal communication, May 6, 2013). The GHA Autism Supports program in North Carolina receives over 90% of its funding from Medicaid (J. Banks, personal communication, May 14, 2013). Similarly, Mandy's Special Farm in New Mexico receives 50% of its funding through the state's Developmental Disability Waiver (Mandy's Special Farm, n.d.). Many programs including Mandy's Special Farm, Homestead, Bittersweet Farms, and GHA Autism Supports fall under the Medicaid designation of ICF/ID, or Intermediate Care Facility for Intellectual Disabilities.

In addition, residential farm programs for adults with autism also build relationships with the local community. Homestead sells its horticultural products to area businesses, who in turn provide grants for needed machinery and buildings to store large equipment. Homestead Campus Youth / Home Director Deb Berry stated, “Revenue from sales of produce/plants helps support the Farm operation. We sell CSA (Community Supported Agriculture)

see Farms on [page 30](#)

### This is what success looks like...



### This is what an adult living with autism looks like!

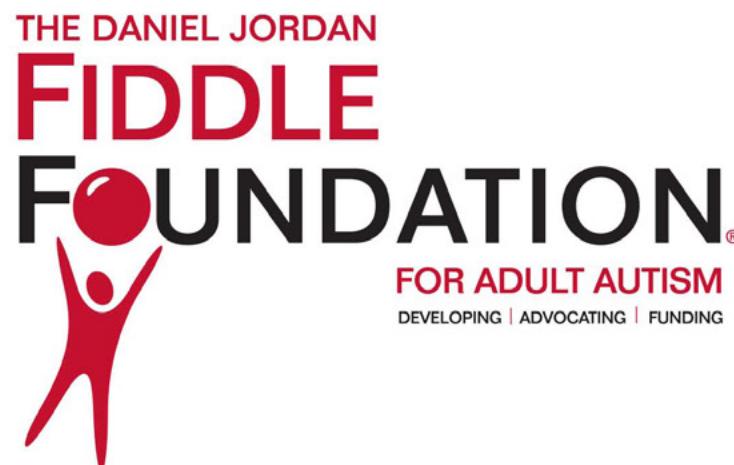
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# Robots as Co-Therapists in Behavior Therapy for Individuals with ASD

By Joshua John Diehl, PhD,  
Charles R. Crowell, PhD,  
Michael Villano, PhD,  
Kristin Wier, MA, LLP, BCBA,  
and Karen Tang, MA  
University of Notre Dame

Recent technological advances have opened the possibility of using robots in therapy for individuals with Autism Spectrum Disorder (ASD). This approach has received a lot of press, but to date most research has focused on developing the robots rather than clinical issues related to the use of robots. These clinical issues include both potential benefits and drawbacks to the approach. For this study, we decided to examine the integration of a robot as a co-therapist in a commonly used behavior therapy approach known as Applied Behavior Analysis (ABA). The goal of this study was to examine whether or not children with ASD responded to the robot co-therapist, in comparison to the same type of treatment with only a human therapist. It is important to note that we are not developing a robot or any type of technology for sale. We purchased an existing robot (NAO, Aldebaran Robotics) to test our clinical questions. It should also be noted that we operated independent of this company and received no benefits from them.



Joshua John Diehl, PhD, with Kelly the Robot

Participants were 19 individuals with ASD between the ages of 6-13 years with varying levels of communication and cognitive abilities. Participants completed 12 therapy sessions, half of which included both a human therapist and a robot co-therapist, and half of which included only a human therapist. We also collected data on how they were doing before the therapy,

immediately after the therapy, and three months after the therapy was completed. In the therapy sessions, we taught basic social skills, such as responding to questions, making social comments, and asking appropriate questions. The child would practice the target skills with the human therapist, and then they would practice them with the robot while being coached

by the human therapist. The NAO robot was controlled remotely by an unseen person, who observed the session and selected appropriate responses for the robot. This unseen person controlled the robot by initiating pre-programmed responses (“What did you do today?”) in the robot, but also typed in responses for the robot to say in other circumstances. Interestingly, when children were not interacting with the robot, we used the person who had been controlling the robot as a practice partner in the “no-robot” sessions. Essentially, in both of the types of therapy sessions that we were comparing, the child was interacting with the same person, except half of the time that person was communicating through an interactive robot.

Overall, we found that the inclusion of a robot co-therapist lead to increased social skills gains, compared to sessions that did not include the robot (but in many cases included the practice partner). Importantly, we found that children who learned skills while interacting with the robot would then use these skills with their human therapist, and at home as well. It is important to note that there was considerable individual variation in how children responded to the robot; a significant majority of children learned skills more quickly when the robot was present, but a minority of children responded better to the human therapist, and a few

see *Robots on page 24*

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## A New Way of Thinking About Autism

By Eric London, MD  
Director of Autism Treatment Research  
NYS Institute for Basic Research

On April 29, 2013 Dr. Thomas Insel, the Director of the National Institute of Mental Health (NIMH), wrote on the NIMH Director's Blog that the Institute will be re-orienting its research away from currently used diagnostic categories (the Diagnostic and Statistical Manual or "DSM") and recommending the use of new criteria, the "Research Domain Criteria." Hopefully, this will yield research outcomes more consistent with the actual biology of the brain. While this change is primarily aimed at researchers, it may prove to be the first in a series of steps that will radically alter the way we conceptualize psychiatric disorders. Given that research informs our clinical understanding, researchers and clinicians will need to eventually speak the same language. Autism will likely be one of the diagnoses that need to be reconceptualized.

In the current era of unlimited information, medical terminology has become a part of our general information. We all hear about medical research findings on a daily basis. Despite our familiarity with medical diagnostic terminology, few realize that many medical diagnoses are recent constructs - and often controversial - even among those who study those diseases.



Eric London, MD

This is most certainly the case for psychiatric diagnoses and its catalogue, the DSM.

First, let's review a little history. Many of the modern psychiatric diagnoses were first described in the late 1800s. Most prominently, Emil Kraepelin compiled the symptoms he observed into syndromes and they were named as diagnoses modeling this after the methods used in other branches of medicine. Originally, this was considered a radical innovation as it was at odds with the then prevalent psychoan-

alytic approach emphasizing the person's lifetime narrative and premised on the understanding that mental illness is a reaction to difficult life events. The change from description of symptoms into diagnoses was harmonious with those who advocated a more biologic approach. Through the 1970s, a psychiatric diagnosis was still, for the most part, a matter of the physician's judgment. This state of affairs changed dramatically with the advent of the third revision of the DSM in 1980. The DSM-3 brought some huge advantages to the field of psychiatry. For the first time, diagnoses were standardized such that any competent psychiatrist would arrive at the same diagnosis for a given patient. Research could be performed with standard diagnoses thus facilitating the psychopharmacologic revolution that was already taking place. Psychiatry took a huge leap forward to become a recognized medical specialty with similar vocabularies and methods as their medical peers.

Despite the benefits, there were some significant drawbacks to the DSM-3 that have largely been forgotten, including by many in the health professions. In order to obtain reliability, only observable symptoms were used as part of the diagnosis. The DSM-3 was "agnostic" as far as the etiology (i.e. cause) of the disorder. An etiologically based diagnosis (for example, strep throat) has predictable symptoms but there are various reasons why a person would get a

sore throat. In order to make the diagnosis of strep throat, therefore, it is not enough to describe symptoms. A physician must get a throat culture and grow out the strep bacteria to prove it is indeed "strep." With infectious diseases we can grow out the bacteria in a dish and then test the medicine in that dish for its efficacy. In contrast, without knowing the *cause* of a psychiatric illness, devising a rational, definitive treatment strategy is difficult. The creators of DSM knew this. Alan Frances, the leader of the DSM-4 effort, stated that the DSM diagnoses were meant to be a "way station" en route to more valid approaches and he cautioned investigators and clinicians not to "reify" (that is, to make real something that is not) the diagnoses. Despite that, the DSM diagnoses have been nearly universally reified. The evidence is now clear that most of the diagnoses are not good mirrors of nature, do not have zones of rarity (that is, natural boundaries between disease and normalcy), are not good predictors of prognosis, and are not generally predictive of treatment outcome. Little progress has been made in our understanding of schizophrenia, depression or, for that matter, autism over the past half century. This is a huge disappointment given that almost all of the prototypes of our current psychiatric medications were discovered prior to 1980. In this era of modern genetics and

see *Thinking on page 23*

### Eric London, MD

Psychiatry Practice Specializing in Autism Spectrum Disorders

Director, Autism Treatment Research Lab, Institute for Basic Research

Scientific Advisory Board, Autism Science Foundation

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# Taking Learning Out of the Clinic and Into the Community

By Samara P. Tetenbaum, PhD and Monica Arevalo, BS  
ASPIRE Center for Learning and Development

When working with youth and young adults on the autism spectrum, professionals and parents are often faced with the daunting task of teaching life skills. These skills can include grocery shopping, stranger awareness, everyday cleaning, and self-care. Youth and young adults often need to be taught to make small purchases, order off a menu, and navigate social situations with community members. Surprisingly, although frequently cited as important, there is currently no life skills program which is considered to be effective for teaching youth with high functioning autism spectrum disorders (Drahotka, Wood, Sze, & Van Dyke, 2011). Parents and professionals instead must teach life skills without much guidance as to what works. In part due to the lack of knowledge as to what works and because it is often difficult, very frequently parents and professionals tend to do many life skills tasks themselves or they teach using the same strategies they use to teach academic subjects - worksheets and readings. While many skills can initially be taught using these methods at home and in the clinic, these skills need to be practiced where they are going to be used - in the community.



Samara P. Tetenbaum, PhD and Monica Arevalo, BS

### Why Teach Life Skills?

Life skills deficits are common in individuals with autism spectrum disorders due to both executive functioning deficits and social/communication skills deficits. Life skills for youth with autism spectrum disorders are extremely important as it is a strong contributor to overall prognosis (Gillham, Carter, Volkmar, & Sparrow, 2000). Independence in life skills is one of several factors

that will help determine if the individual will be able to live on their own or need a more supportive living environment as they mature into adulthood. Young adults who rely on their parents often express a desire for independence and may be embarrassed about their own inability to complete various tasks. Even in childhood, there may be negative emotional effects to deficits in independent living skills. Children may become anxious because of their overreliance

on their caregivers (Wood, 2006). Many independent living skills are inherently social. For example, a task as simple as buying a soda at a convenience store may involve a multitude of social interactions. First, one has to enter the store which may or may not have other customers inside. Upon entering, one may be greeted by the store clerk or someone may be leaving or entering at the same time. If this occurs, does the young person on the autism spectrum know to hold the door open? What is an appropriate greeting for a store clerk? Are they considered a stranger? One then has to navigate around the other customers to find the soda they want to purchase. What if someone bumps into you? Are they intentionally causing harm? All of these social interactions have occurred and the soda has yet to be purchased.

Executive functioning deficits can also be a major obstacle to independent living. Executive functioning can be described as the CEO of your brain and controls tasks such as goal setting, planning, organization, flexibility, working memory and self-monitoring (Meltzer, 2007). Executive functioning skills in youth with autism spectrum disorders have been shown to be significantly linked to adaptive skills (Gilloty, Kenworthy, Sirian, Black & Wagner, 2002). If we return to our example of the individual purchasing a soda, we can see how executive

see Learning on page 26

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## The Benefits and Challenges of Housing for People with ASD in a Post-Facility World

By John Maltby, MS  
Director, Community Support Network  
Westchester Institute for  
Human Development

Group Homes, a housing model that began in the 1960s and '70s, were a tremendous improvement on the dismal institutional settings that they largely superseded. Created by a partnership between the state and "voluntary" agencies, the goal of the group home model was that people with autism and other intellectual and developmental disabilities (ASD & I/DD) would live in homes that looked like others in the community and would attend Day Programs, rather than sleeping in dormitories and spending their waking hours in "Day Rooms." Forty years later, those of us who seek housing for our adult sons and daughters with ASD & I/DD have a lot to thank the pioneers of group homes for; with over 26,000 people in NY State living in housing funded through the Office for People With Developmental Disabilities (OPWDD), the Group Home system is the primary form of state funded housing for people with special needs. However, today the system is at a crossroads. Many would call it a broken unsustainable system, and we are on the cusp of significant change.



John Maltby, MS

Why is the system unsustainable? Through a combination of high staffing ratios and turnover, real estate costs, administration and other historical factors, group homes have become very expensive. A supervised setting in our region costs approximately \$120,000 per person per annum. The labor force of Direct Support Professionals (DSPs) is inelastic and there is a growing demand for their service as the general population ages.

People with ASD & I/DD are living longer, and the number of people diagnosed with ASD & I/DD is increasing so there are more people in need of support. Lastly, the people seeking support are less likely to want to live in a congregate setting. Young people leaving school today have spent a large portion of their school career in typical settings, they have no interest in being segregated, or living with people they have nothing in common with in places that are regimented and heavily supervised. Congregate care for a person with sensory issues, a person who is averse to excessive social contact will lead to deterioration in their quality of life and perhaps to medication or seclusion. When well-meaning providers go to the opposite extreme – creating an "Autism" house for example – the deleterious effects of social isolation are just as pronounced.

The good news is that in part due to a combination of compromised budgets and scandals related to overbilling and unaddressed abuse, our state is undergoing a fundamental systems reform, comparable to the change in direction that we took post-Willobrook. We are embarking on the biggest change in how residential services are provided since the deinstitutionalization movement began over fifty years ago. For these changes to work for people with ASD & I/DD three elements have to succeed.

Group Homes were fashioned and funded along institutional principles. "Voluntaries" - nonprofit provider corporations - are contracted by the state to provide residential services that combine shelter, habilitation and living supports in one facility. However, as long as the provision of a place to live has to be combined with the provision of support services, people with a disability are potentially held hostage. If they don't like their accommodation and want to change, they can only move within the group home system, and with that move will be compelled to change the people who are delivering their support services. Alternatively if they like where they live but don't like the service delivery, they have no choice but to leave their home in order to find better services. They are stuck in the "Company Store" trap. Separating the provision of shelter from the provision of support is vital if we are to move on from the group home model.

Institutional settings are by their nature homogeneous rather than individual. This bias is compounded by the institutional evaluation system used in NY State, the Developmental Disabilities Profile (DDP) which was first introduced in the 1980s. The DDP is a medical model, deficit-based assessment biased to highlight weaknesses.

see *Post-Facility* on [page 30](#)

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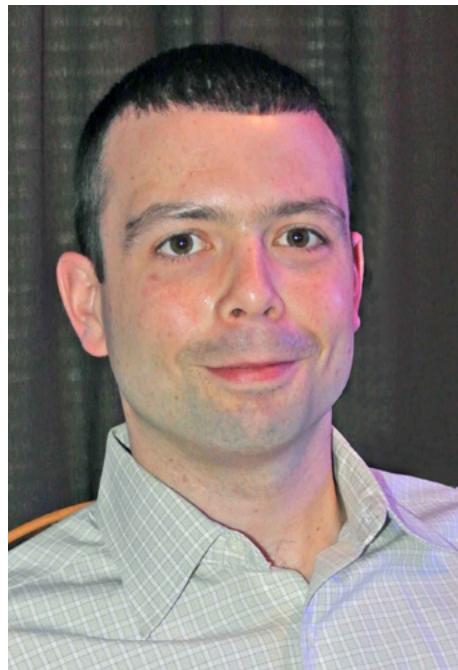
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# How to Improve the Public Special Education System

## *Empowering Parents, Educators and Treatment Providers*

By John Ferrera, PhD  
Child Psychologist and  
Learning Specialist

The Special Education system in New York City is an ever evolving work in progress, and any shortcomings of the current system might be excused by the difficulty of the task at hand and/or the relatively short time-frame the system has had to evolve. Other challenges include changes in the prevalence and nature of developmental disorders, as well as changes in the preferred methods and approaches used for treatment. Thomas Insel, the Director of the National Institute of Mental Health recently wrote, "Part of the polarization and confusion around autism is that it now applies to a 5-year-old who has no language, a 20-year-old computer science student at MIT who is socially awkward, and a 40-year-old parent who has no interest in social interaction" ([www.nimh.nih.gov/about/director/2013/the-four-kingdoms-of-autism.shtml](http://www.nimh.nih.gov/about/director/2013/the-four-kingdoms-of-autism.shtml)). Dr. Insel goes on to say that "Autisms" is a better term to describe the broad spectrum of traits that comprise autism. This sentiment was echoed by Dr. Eric London in his article *An Interdisciplinary Treatment Program in the School: A New Model*, which appeared in the Win-



John Ferrera, PhD

ter 2013 Issue of *Autism Spectrum News*. In his article, Dr. London outlines the core components of the "Medical Home" model, an interdisciplinary approach that says the "complete treatment" of individuals with autism spectrum disorders and other brain-based developmental disorders is

difficult for any one provider since most disorders comprise a host of medical, neurological, psychiatric, and behavioral problems, all of which combine to impact learning and development in different ways across individuals. Dr. London and other proponents of the medical home model also recognize that children spend most of their time at school and in order to have the most accurate picture of their functioning at any one time-point, input from professionals who work with the child on a consistent basis is valuable information that they do not typically receive in the present system. Accordingly, the medical home model dictates that "best practices" for the educational and clinical treatment of this population involves teachers and school personnel working closely with physicians and other members of each child's clinical team.

### The Medical Home Model and the Inclusion Model: Shared Philosophies

I was pleased to read Dr. London's article because it is a sign that medical doctors are beginning to advocate for more involvement in the school system. In today's day and age, psychiatrists and other medical doctors often prescribe medication to regulate behavior and functioning at school. Unfortunately, the information that most doctors receive about the learning and be-

havior of their patients is usually limited to what they hear from parents and the patients themselves. Contact with teachers and related service providers continues to be the exception and not the rule, although when there is contact with a medical doctor or specialist, school officials and IEP team members are usually open to collaboration. This makes sense because the inclusion model of special education that guides IEP development calls for a team approach involving specialists from different disciplines collaborating to optimize the learning and development of a specific student. The medical home model also calls for a team approach. In fact, the only difference between both approaches seems to be that the medical home model includes a physician as part of the interdisciplinary treatment team, whereas the inclusion model is limited to providers who are mandated by student IEPs to deliver services.

Some of the more common IEP-mandated services include speech therapy, occupational therapy, physical therapy and counseling, although the number and type of services that each student receives varies depending on the needs of the student, the age of the student, and the type of school the student attends. Interestingly, the number and type of services any given

see *Improve on page 29*

# YAI Central Park Challenge Provides Opportunity to Promote Vision for the Future

By The YAI Network

"Join the movement" doesn't sound like your typical slogan for a fundraiser, but this year, YAI recognizes that it's time to change the way society views people with disabilities. And, as YAI CEO Stephen Freeman says, "the prevailing custodial care-taking model has reached its sell date."

"The challenge is to create a better system," Freeman said. "Our Central Park Challenge provided an opportunity to raise awareness about true inclusion of people with disabilities. We, as professionals, need to stop looking at their deficits and start seeing their strengths. Raising our expectations will yield better outcomes. All of us need to change our thinking and see beyond disability."

Thousands of people gathered on June 1 for the Central Park Challenge, which featured a competitive 5K run, a 3K walk, and children's activities. The event raised more than \$1.2 million and contributions are still coming in. Contributions will be accepted through June 30, 2013 at [yai.org/cpc](http://yai.org/cpc).

"Every step we're taking today is a step toward leveling the playing field," said Bill Ritter, WABC-TV's Eyewitness News Anchor, in remarks before the start



Thousands gathered to support YAI's Central Park Challenge on June 1

of the walk. "Everyone deserves an equal opportunity for happiness, fulfillment and a great life."

Ritter and YAI Spokesperson Sherri Shepherd of ABC-TV's "The View" and author of "Plan D: How to Lose Weight and Beat Diabetes Even If You Don't Have It," shared a personal connection to the field. Ritter had a brother with Down syndrome who died years ago. Shepherd has a son with developmental delays, who

attended a YAI preschool and kindergarten program.

"YAI is so my family," Shepherd told thousands of people gathered for the walk. "When I first moved to New York with my son, I didn't know where to take him. A mother told me about YAI. We walked into the preschool, and the staff immediately loved him. It's because of YAI that my son has the confidence to go out in the world and smile and talk

to people. I will be forever grateful to YAI."

Broadview Networks, the Premier Sponsor of the Central Park Challenge, brought nearly 450 employees to the event. "All you need to do is look at your T-shirts to see what the day is about," said Broadview Networks' CEO Michael Robinson. "Seeing beyond disability and changing the world is a walk in the park. That's why we're here and proud to be involved with YAI and the Central Park Challenge."

The field of developmental disabilities is changing rapidly across the country. Two words – "managed care" – are prompting tremendous fears for parents of adult children with autism, Down syndrome and other intellectual and developmental disabilities. Couple that with New York State's \$90 million budget cut to nonprofit providers and you have great uncertainty about the future.

"The only sustainable future is one of care that is efficient and outcome-based," Freeman said. "We see this as an opportunity – one that's long overdue."

A day where people with disabilities, who were once warehoused and marginalized by society, can gather in Central Park for a community-wide celebration

see *Vision on page 19*

# Creating Innovative Housing Models Using Medicaid State Plan Services

By Catherine Boyle, MA, CGS  
President  
Autism Housing Pathways

Approximately 90% of adults with autism are not employed full-time or are underemployed, and more than 80% of young adults with autism live in the family home (1). Nationally, the cost of a studio apartment is 90% of the federal SSI payment rate (2). Finding workable housing solutions for individuals with autism is a daunting challenge that will get worse as increasing numbers of young people enter adulthood. While Medicaid waiver programs, such as that in Pennsylvania, have been used to create innovative housing solutions, the difficulty with waiver programs is that there are numeric caps on the number of individuals who can participate.

State Medicaid services are not limited to waivers, however. States also offer a menu of services referred to as "state plan services." Unlike waivers, state plan services are not capped. In some states, these services are sufficient, when cobbled together with other benefit programs and family resources, to form the basis of individualized housing solutions. In Massachusetts, examples of state plan services include Adult Foster Care, Adult Family Care, Group Adult Foster Care, and Personal Care Attendant services. Importantly, individuals



Catherine Boyle, MA, CGS

do not need to meet an institutional level of care to qualify for state plan services (3).

It is up to each state to determine what services it will offer through the state plan, subject to approval by the Centers for Medicare and Medicaid Services (CMS). Historically, states have been conservative in choosing what services to offer, as state plan services must be provided to anyone who qualifies. Some of the services available under the state plan in Massachusetts are only available as waiver services in

other states. However, the Affordable Care Act made changes to Section 1915(i) of the Social Security Act (4). These changes provide a new incentive for states to offer certain services through the state plan: states can now choose to define certain populations to receive services. For example, a state might decide to offer Adult Foster Care to adults on the autism spectrum. This would mean fewer individuals would qualify than if the state were required to offer Adult Foster Care to all adults needing assistance with activities of daily living, regardless of diagnosis. Further, a state can have multiple targeted 1915(i) benefits: a state could choose to have a benefit that provides life coaching to individuals with Asperger's, as well as a benefit that provides Adult Foster Care to those with more intensive support needs. An opportunity exists for advocates on the state level to encourage their state to apply to CMS for a 1915(i) amendment to their state plan (5).

State plan benefits under 1915(i) have one major limitation: they can only be used to pay for services, not for room and board. That is why they need to be supplemented with other available benefits, and with family resources. SSI limits what resources can be used to pay for room and board outside of the SSI check; if earned income exceeds \$65 per month, or unearned income exceeds \$20 per month, the amount of the SSI check will be reduced. However, SSI does permit the use of certain additional

benefits to pay for room and board. Section 8 housing vouchers allow an individual to pay 30% of his or her income for rent, while the balance of the rent is paid to the landlord by the Dept. of Housing and Urban Development. Another program allows individuals who are working even part-time, and are from low-income households which do not own their home, to save money for housing through Individual Development Accounts (IDA); the amount saved is matched by as much as 3:1 (6). The Supplemental Nutrition Assistance Program, or SNAP, benefits (more commonly known as food stamps) may be used to pay for groceries.

Unfortunately, the waiting list for Sec. 8 vouchers exceeds a decade in some parts of the country, and federal sequestration promises to make the wait longer still (7). However, it is still possible to make productive use of the wait. One scenario available to Massachusetts families is as follows: upon turning 18, an individual signs up for as many Sec. 8 waiting lists as possible (likely options are the Centralized Waiting List, a regional non-profit waiting list, and any lists maintained by local housing authorities not participating in the Centralized Waiting List). He or she also applies for SSI. Once SSI is received, the individual should start to receive MassHealth (Medicaid). If the individual needs

see Medicaid on [page 28](#)

## Distinction from [page 4](#)

be full contributing members to their state and local communities.

Presently, Mrs. Pirraglia is a Board member of the Foundation for Educating Children with Autism, Mental Health News Education Inc. and a member Westchester County's Autism Advisory committee. In addition she

sits on the Editorial Board of *Autism Spectrum News*.

Theresa will also be honored at Senator Greg Ball's 40<sup>th</sup> Senate District Women of Distinction Hall of Fame on Saturday, September 8, 2013 at the Putnam County Emergency Services Building starting at 2pm.

For more information, please contact Joe Bachmeier at (845) 200 9716.

## Brain Bank from [page 5](#)

For more reports from the 2013 International Meeting for Autism Research, please visit <http://sfari.org/news-and-opinion/conference-news/2013/international-meeting-for-autism-research-2013>.

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original article, written by Apoorva Mandavilli and published 2 May, 2013, online at <http://sfari.org/news-and-opinion/conference-news/2013/international-meeting-for-autism-research-2013/new-brain-bank-set-to-collect-samples-for-autism-research>. This material is reproduced with the permission of sfari.org.

## Vision from [page 18](#)

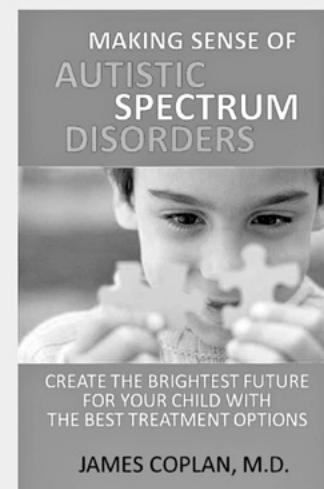
was unimaginable 40 years ago. With deinstitutionalization came the development of community-based services.

"That system worked well for a long time, but now it's too restrictive," Freeman added. "People with disabilities want and deserve more. They want the same things anyone else does – a nice place to live, strong friendships

and relationships and a good job."

YAI is an organization of dedicated people of diverse skills and talents, all focused on a single goal: helping people attain the fullest and most independent life possible. You can find out more about the agencies in the YAI network and the range of programs and services they offer at [yai.org](http://yai.org) or by calling 1-866-2-YAI-LINK.

## James Coplan, MD Clinician, Author, Public Speaker



*I'm so deeply grateful for this book. . .  
I just finished reading 'Making Sense of Autistic Spectrum Disorders' and had to take a moment to thank you. The information in the book was easy to understand, comprehensive, and helped me calm down and focus on the steps I need to take to help my son.*



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James Coplan MD - Developmental Pediatrician

## Summer Offers Opportunity for Skill Development for Children and Young Adults with ASD

By Mike Kunin, MA,  
Jennifer Buri da Cunha, MA,  
and Johanna Kinsley, MPA  
Ramapo for Children

Summer can be a perfect time for children and young adults to leave their everyday environments and discover new opportunities for skill development. Yet parents of children and young adults with Autism Spectrum Disorders (ASD) often struggle with the idea of immersing their child in a new setting—especially if it is a residential program. Families worry that a new place with new people and new rules may be too challenging for their child. They worry their child's behavior may be too difficult or that he or she will disturb others' experience.

Ramapo for Children sees these new experiences differently. Ramapo is based on the belief that all children and young adults seek the same things: to learn, feel valued, have friends and experience success. The Ramapo Approach centers on personal relationships, positive role models, thoughtful rituals and routines, collective celebration of individual accomplishments, open communication, and proactive reflection. By bringing these factors to bear in the context of emotion-



Jeffrey tackles new challenges and grows more independent at camp

ally safe, nurturing environments, Ramapo helps young people learn to align their behaviors with their aspirations.

Children and young adults with ASD are no exception. Children and young adults with ASD who benefit from the Ramapo Approach develop communication and relationship skills, independence and self-con-

fidence. They have successful summers and take home skills that move them forward in the classroom, at home and in life.

Summer Camp for Children with ASD

Children learn many skills during the school year - adapting to a time schedule,

how to follow rules, what is appropriate interaction with peers and adults - but often times these skills are diminished or lost during the summer months. Children with ASD typically experience delayed skill development, making it even more critical to maintain and build on skills learned in school. The right summer camp can play a critical role in accelerating skill development.

Camp Ramapo offers one example. Camp Ramapo is a traditional residential summer camp in Rhinebeck, NY for children aged 6 to 16 with social, emotional or learning challenges, including children with ASD. The summer counselors and year-round staff are expertly trained to help children learn to live within a group, form healthy relationships, make good choices, develop self-control and experience success.

*Living within a group helps children with ASD form healthy relationships* - Jeffrey came to Ramapo with delayed communications skills and hyperactive behavior. In addition, he was hypersensitive to sound, so it was difficult for Jeffrey to be around large groups. On the first day of camp, Jeffrey's counselor brought him to the all-camp opening ceremony before the crowd arrived. This tactic helped Jeffrey feel comfortable with his surroundings not just that first night,

see Summer on [page 28](#)

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[www.mhnews-autism.org](http://www.mhnews-autism.org)

#### Support Needs from [page 1](#)

between moving out of the family home or not. The latest waiting list numbers show a 10-year wait to get on a Home- and Community-based Medicaid Waiver in most states. Due to the pervasive lack of understanding of the importance of Waiver Services, eligibility requirements and how to actually get on a Waiver, the chances of someone receiving the supports they need on a timely basis is increasingly unlikely. Unless there is a crisis of "imminent peril" - a fancy term for a desperate cry for help - planning for the actual event is anyone's best guess. That is clearly not good enough for our loved ones. We need a plan of action.

#### Surveying the Need

In order to substantiate the actual needs of adults with autism, Autism Speaks is supporting a National Market Survey to quantify and characterize the housing needs across the country. Once aggregated, this information will be presented to individuals and their families, policy leaders, housing developers, social service providers and the community at large. The goal of the survey is simple: we need to understand the demand for housing and residential supports, the current supply, and specifically how adults with autism

are impacted. Existing data considers some variables that are common to all people with developmental disabilities and tiers of funding based on a hierarchy of needs. But the specific needs of adults with autism has not been systematically collected and analyzed to determine future housing development and the need for training caregivers.

#### Supporting Caregivers

Many caregivers for adults with autism feel that they are provided no help or training to understand how to support their loved one in the family home. In fact, statistics show one of the significant factors influencing housing needs is the age of the caregiver and the demands they face as their developmentally disabled son or daughter ages as an adult. Nearly three-quarters (72%) of the 4.9 million Americans with developmental disabilities still live with their families. (Source: *Brad-dock et al. 2013 based on Fujiura, 2012*).

Therefore, in addition to the survey, Autism Speaks is supporting an online training program for caregivers of adults with autism who live at home. The online training was developed by the Autistic Global Initiative (AGI) within the Autism Research Institute (ARI) [www.autism.com/index.php/tests](http://www.autism.com/index.php/tests). The online training is in addition to a more comprehensive curriculum for

staff supporting adults in a residential setting outside of the home. We hope that both of these critical training components will lead to a better understanding of supporting adults with autism and standards on how best practices should be implemented.

#### Reviewing Model Homes

Thankfully, there is model housing across the country that is smoothing the road for adults with autism to move into their own homes. Organizations such as the National Association of Residential Providers of Adults with Autism (NARPAA) [www.narpaa.org](http://www.narpaa.org) and Advancing Futures of Adults with Autism (AFAA) [www.afa-us.org](http://www.afa-us.org) have highlighted specific models of support that have been successful in meeting the unique needs of the autism community. Previous efforts by these two national groups have advanced our understanding of the specific desires of individuals with autism, their families, and providers through National Town Hall meetings, published literature and congressional briefings. Yet, more is needed to keep pace with the increasing demand for housing and support services. Autism Speaks is using a housing portal page [www.autismspeaks.org/family-services/housing-and-residential-supports](http://www.autismspeaks.org/family-services/housing-and-residential-supports) to feature homes across the country and to highlight articles that discuss where

homes are being built. A Tool Kit was created for families to get a better understanding of the housing and support needs they will face at [www.autismspeaks.org/sites/default/files/housing\\_tool\\_kit\\_web2.pdf](http://www.autismspeaks.org/sites/default/files/housing_tool_kit_web2.pdf)

#### Advocating for Best Practices

We know that health and safety are a top priority for adults with autism living in the community. In addition, we need to advocate for their choice of lifestyle, wherever that choice takes them. Competent staff who understand not only autism spectrum disorders, but the value of social inclusion and how that needs to be maintained must also be a priority. Autism Speaks will host a housing conference next spring to bring together all the best-practice models to help educate our stakeholders on what is possible now and in the future.

#### In Summary

The developmental disabilities community needs to have a collective voice with a national strategy that focuses efforts on meaningful and sustainable change to the current housing situation. This national strategy should include a plan that is our guide toward a more inclusive life for all people with autism and developmental disabilities to live in the community of their choosing.



# The Lighter Side of the Spectrum ~ A Mom's View

By Carrie Cariello

## What's Normal?

Nearly every day someone asks me something like, "When did you know that Jack wasn't normal?" And then they stop themselves, stammer a bit, and apologize for saying normal. Their faces turn all red and they look away and stare at their feet. "I mean, you know, what's normal, there is no normal, sorry for saying normal."

I can never understand what all the fuss is about. Personally, I love the word normal. Normal is good. Normal is, you know, normal. If we didn't have normal, we wouldn't have other things like extraordinary or mediocre or stupendous. Normal sets the bar.

I mean, for the most part, I'm normal. I'm extraordinary at some things (making chocolate-chip banana bread) and mediocre at others (doing pull-ups). I'm not particularly stupendous at anything, so I feel like this balances me out to right around normal. It's a pretty good place to be.

And the rest of my family? Pretty normal. They're a quirky bunch for sure, but the quirky things like Henry's rigidity and Joey's fascination with Minecraft and Charlie's anxiety about thunderstorms are balanced out by all of the other things they're amazing at, like dancing to Thrift Shop and



Joe and Jack looking at the dogs

throwing a baseball and coloring in the lines. And making their brother Jack laugh.

Because Jack is not so normal. Jack does not laugh every day or even every other day. He does not like baseball or team sports in general, he does not play with other kids, he doesn't look people in the

eye. He won't eat wet food and he's terrified of dogs, blue water in the toilet bowl, and fire drills.

Reading this, some of you may be gasping or cringing or feeling as though this post is incredibly inappropriate. Just let me say that's okay, *that's a very normal reaction.*

But it needs to be said, and as his mother, I have to be the one to say it. I have to own this about him and his autism. He is not normal. It is not normal to ask the same question about black widow spiders a hundred times a day or to shriek if a dog comes on Funny Home Videos or to panic if the right radio station isn't playing in the car.

But you know what else is not normal about Jack? The uncanny way he remembers dates, his love of music, his ability to operate appliances. The way he defies his spectrum disorder to write letters and secretly admire ([www.carriecariello.com/2013/03/25/letters-from-a-secret-admirer](http://www.carriecariello.com/2013/03/25/letters-from-a-secret-admirer)).

Bill Gates isn't normal. Mother Theresa isn't normal, and neither is Hugh Jackman. They all have special qualities like brilliance and kindness and extremely good looks. (I'm referring to Hugh Jackman with this last one, in case there was any confusion).

Over the weekend we were at my sister's house for her son's First Communion, and in the middle of the party Jack was deregulated and distressed and excited. He was bouncing from room to room, making his way around the guests as he stimmed and zoomed ([www.carriecariello.com/2013/01/07/getting-the-hang-of-it](http://www.carriecariello.com/2013/01/07/getting-the-hang-of-it)).

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## ROBIN'S VOICE ~ A Resilient Mom's Commentary on Autism

By Robin H. Morris, Freelance Writer

### Supported Housing for Adults with Autism

The concept of a "group home" for individuals living with autism is an obsolete avenue. We, as a society need to be more creative, productive and pro-active. It takes a village.

There is a catch-all phrase that has been assigned to the public conception of autism: "If you have met one person with autism, you have met one person with autism." Although this may sound cliché, it is simply true.

How can one human being acquire all of the knowledge base of the encyclopedia, but it is on one single subject? That's autism. How can a human being know the entire map of the transportation system, but be afraid to step on a bus? That's autism. How can a human being write voraciously on a computer, but cannot speak a word? That's autism.

Adult individuals with autism want to live just like you and me. The walls may be different and safety net parameters altered, but supported housing is an essential ingredient for the future of adults with autism.

"I'm an adult, I can make my own decisions," said my 24 year old adult child

who has learned the lingo of the grown up world. So is his mantra when he is trying to establish his ground, as he agonizes over choices about a simple schedule change. We, as adults have learned to navigate adjustments, some better than others, but what happens when inflexibility is so paralyzing that it can be a game changer. No question mark here, just a reflection.

One day we sat around a boardroom table, assessing our son's Individualized Service Plan for the upcoming year. I could read his body language, as he tried not to explode over a suggestion that he try to revisit a possible job opportunity. "Deep breaths," I could hear his internal whisper. It was then that I pulled a prize out of my infinite bag of tricks: "So, I was watching the news this week," I said. "I was shocked to learn that Citizen Kane never won an Oscar." He stopped his agony on a dime. "Mom, it was 1941, How Green was My Valley won that year." Everyone at the table simply paused in awe. How can a 24-year-old know such precise information, without skipping a beat and share it, when he cannot drop the pervasive occupation of rigidity.

What is even more suffocating for me, as a mother, is the constant nagging that I must be always available with my bag of

tricks. That is my problem. Our son has certainly risen above many challenges and learned to assimilate and acquiesce. However, he is still autistic, and while he has tried with Herculean efforts to comply, there must be a balance.

Society must comply as well. Help them live.

We, as parents, recognize that there are significant and complex changes as our children grow into adults. Autism Speaks has authored "The Transition Tool Kit." It is a valuable resource that you can make your own, as it provides questions and food for thought, as you shepherd your child into the next phase of his/her life. Advancing Futures for Adults with Autism has made it a mission to investigate ways for our young adults to become active members of society. There is a light, now it will take a village.

Four years ago, I was preparing dinner while listening to the news. When I heard NBC's Brian Williams I stopped, and noted that history might actually be taking place. It was a story of pride and hope. Randy Lewis, Vice President of Walgreens had implemented a work force that hopefully would change the face of employment for those with disabilities. Mr. Lewis, prompted by concerns for his son Austin, diagnosed with autism, recognized the vacuum in the

arena of jobs for adults with disabilities. He devoted a Walgreens Distribution Center in Anderson, South Carolina to hiring workers with developmental disabilities. Mr. Lewis said that "Austin's gift to me was to look past the disability and see the person."

The irony here is that this particular distribution center is 20% more efficient than all others in the Walgreens Company, and it is staffed by more than 40% disabled individuals. The building is designed with touch screens and flexible work stations. Randy Lewis' model of "same pay, same job, same performance" would hopefully have been a prototype for future companies.

The most compelling emotion that Mr. Lewis shared was the burning question that we as parents can identify with: "What would happen after I'm gone...could I live that one day longer than my child?" It was answered by a mother in the interview: "I don't have to have that worry anymore...as long as he does his job; he'll have a home at Walgreen."

The reality is that autism does not fit into a neat package. I don't know that a person with autism will always "do his or her job." However, it is the commitment and understanding that Randy Lewis has pioneered

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### Searching from [page 8](#)

there is a need to require that the guardian has provided a list of approved visitors, that visitors and residents sign in and out and that non-family members show identification when taking a resident out of the building. For greater detail and ideas on safety, see the report *Opening Doors: A Discussion of Residential Options for Adults Living with Autism and Related Disorders* at <http://www.autismcenter.org/openingdoors.aspx>.

#### Design and Environment

Families may often look at how new, pretty, big, modern and structurally appealing the building looks in terms of its curbside look. However, if the family members really want to do their research, they need to begin their review of the study *Opening Doors*. This Collaborative Report by the Urban Land Institute Arizona, Southwest Autism Research & Resource Center and Arizona State University's Report of 2009 reports on what the environment should have in terms of the physical aspects of the building, sensory reduction through lighting and HVAC, color schemes, artwork hanging on the walls, style of furniture and durability in the common areas, availability of common and social areas, and physical accessibility. This report goes into much detail and in working with the Mt. Bethel Village decorator, Pat Thatcher of Clinton, NJ and Dr. Elizabeth Roberts of the NYU Child Study Center to design the interior colors and furnishings of Mt. Bethel Village, this team effort resulted

in a setting that meets many of the design issues that support the programming for adults with ASD. Common areas that support adult activities such as working out in a gym, using a computer lab, cooking in the Family Activities Room, creating in the Art/Vocational area, gathering for social events in either the dining room or TV/Social room, seeking a quiet time in the Family Conference room or the Library all support the opportunity to make choices, to develop friendships and to continue to learn on a daily basis.

#### Staffing and Operations

In looking at staffing, there is a need to ask such questions as: What is the experience of those in leadership positions; How accessible are the administrators and staff; Are support staff experienced in working directly with adults or children with ASD; Are line staff paid a minimum hourly rate or is the pay rate appealing to a higher level of staff capabilities; Do they get benefits; What kind of staff training occurs prior to starting a position; What kind of staff training is available on-going; and What is the turnover of staff within the structure of the organization? Do the individual hires have a personal investment in working with adults with ASD? Do staff members have a family member or sibling on the spectrum? Are they qualified ASD adults who can be employed in this environment?

Families usually ask, "What is the makeup of the adults who are admitted to the residential community? Can they provide cognitive and language challenges that would stimulate the adult/child? What kind

of transitions can be implemented to ease the adult/child from living at home to living in a semi-independent setting?" It is interesting to note that the adults themselves who come to live in Mt. Bethel Village or attend the Day Program always ask about the number of men and women and what is the level of functioning that can provide challenges for them. Family members are always concerned that their adult/child or sibling is NOT the lowest functioning adult in the living environment and that they will have friends who are verbal and are similar in nature to the capability level of the incoming resident.

#### Dietary and Nutrition Issues

Families know the importance of nutritional intake and also struggle with limited choices of foods by many of our adults with ASD. Therefore, families again need to ask about food preparation and should have the opportunity to sit at the dining room table to sample the foods. Thus, Chef Teresa at Mt. Bethel Village, who has a degree in culinary arts as well as a degree in nutrition, takes into consideration the varying dietary needs and interests of adults with ASD. Every day there is a need to offer gluten-free foods at all three meals, lactose-free food offerings and limited sugar/carbohydrate foods to support those with diabetes. In addition, there is a critical need to get the residents to at least try various foods in terms of textures and tastes. The issue of dietary needs consistently comes up in discussion with families during the intake process and should be part of any intake

for consideration in planning of meals and should become part of the investigation of the community.

Other questions that should be part of any checklist in considering where the adult/child resides outside of the home must include: What is the residential emergency disaster plan? Will electricity be available from a generator? Who will support the medical needs? How often will community outings take place? Where, with whom and what is the reputation in the industry? Have there been complaints and/or any incidents reported to the licensing agency? How active will the adults be on a seven-day a week basis? Is there an independent review that parents and adults on the spectrum can access to evaluate the appropriateness of a placement at this facility?

In conclusion, researching for a residential setting for the adult/child with ASD and/or developmental disabilities can sometimes be as difficult as finding a needle in a haystack. However, the hard questions need to be asked so that parents have the right information for making the decision about semi-independent living outside of the family's home for their adult/child.

*Carolann Garafola is the Executive Director of Mt. Bethel Village, the only apartment complex of its kind in the country with 24/7 supportive services for adults with Autism, Developmental Disabilities or Traumatic Brain Injury. She can be contacted at: [cgarafola@mtbethelvillage.com](mailto:cgarafola@mtbethelvillage.com) or 908-757-7000 x201 or cell-908-922-1973. Mt. Bethel Village is located at 130 Mt. Bethel Road, Warren, NJ. For more information, please visit [www.mtbethelvillage.com](http://www.mtbethelvillage.com).*

## Doctoral Study Shows Parents are Concerned for their Adult Child's Future

By Veera Mookerjee, PhD  
Director of Preventive Services  
SACSS

The process of transitioning to adulthood is always difficult for parents; more so when their children have special needs. For parents of young adults with ASD the challenges are manifold, including but not limited to financial problems, social difficulties and long term care and planning. Long term planning is often referred to independent living and/or housing.

To explore the experiences of parents, the author had conducted a qualitative study as a doctoral research student in Yeshiva University's Wurzeiler School of Social Work, New York. The study's uniqueness lies in its focus primarily on the parents of young adults with ASD and their strengths and concerns. The idea of the study was to understand how parents and caregivers plan long term care strategies for their young adults with ASD. In the available literature, this aspect of autism research is not readily available mostly due to the unavailability of parents of young adults with ASD and their unspoken needs.



Veera Mookerjee, PhD

### Details of the Study

This was a qualitative study of a select group of parents of young adults with ASD who have faced or are facing significant challenges in the transitioning process. The three primary research questions were: 1)

What barriers are faced by parents during the transition out of mandated educational services to services addressing community inclusion? 2) What kind of necessary supports encourage caregivers to pursue continuing services? 3) Has a greater awareness of ASD increased the access to appropriate services?

During the study the interviews were audio recorded. The qualitative data was initially analyzed manually by audio recording transcription, triangulation and constant comparison. Following this, the data was technically analyzed by the Atlas-ti software (<http://www.atlasti.com/>) and open coding through which the primary themes were identified. The data was divided into quantitative and qualitative codes to understand the parents' psycho-social support system.

The *quantitative codes* included age, gender and kinds of medical support available for the individual with ASD. The codes also included religious identity of parents, their marital status, and number of children they have to understand sibling support. Parents were also asked if they were the primary decision makers for their child. The *qualitative codes* focused on the ambiguous loss for parents after they received their child's diagnosis, their awareness about autism, and their concerns and coping strategies. Qualitative codes also

included information about parents' social interactions to understand friend and family support and perception of their feelings of hope and hopelessness. Parents qualitatively shared information about their experience with accessing available services, their sense of confusion in decision making and the barriers they faced in seeking services, especially when seeking long term support. These frequently occurring qualitative codes were selected to generate hypotheses and prepare recommendations for future research.

### Results of the Study

One of the themes that repeatedly occurred was concerns about independent living and housing. Parents expressed their concerns affecting everyday life. About 63% of the participants were working full time and 47% of the parents interviewed were associated to special education services either as volunteers or as professionals. All participants had insurance for their children and had medical services as their only continuing resource. However, 77% of them had limited insurance coverage. Only 55% of the parents who participated in the study had their children enrolled in post-high school services with varying

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## Give Someone in Need the Gift of Hope and Education:

### A Gift Subscription to Autism Spectrum News - See Page 3 for Details

#### Thinking from [page 15](#)

molecular biology, there have very few triumphs in the realm of the psychiatric disorders. One emerging understanding is that the symptoms that we are using (which are complex behaviors) are far removed from the basic molecules, genes and cells that can be studied. Too many factors go into influencing complex behaviors. Dr. Insel and many others are calling for the study of symptoms more directly related to neural circuitry.

Autism research also suffers from the dilemmas described above. Dr. Leo Kanner first described autism in 1943. Since then, Kanner's descriptions have been tweaked by the various versions of the DSM but, essentially, we are working from the same model. Despite the belief that autism is highly heritable, researchers have found no genes responsible for more than a few cases of autism while over 100 genes have been described as having some association with autism. In terms of being a brain disorder, we have found many brain areas affected. As things go awry in development, it leads to abnormalities in other regions of the brain not initially affected, analogous to a house having a poorly poured foundation resulting in all sorts of structural problems. De-

spite the nearly universal understanding that autism is, in reality, a collection of many different disorders, the reified use of the diagnosis has hampered quality research. Much research on "autism" utilizes a large group of diverse disorders in the study. As an analogy, if we were to look for the treatment for "cough" we might not find one as cough is a symptom of not a single but many diseases.

Autism does not have natural boundaries. This is evidenced by the fact that even small changes in diagnostic criteria cause very large changes in prevalence numbers (an observation noted since the 1950s) and by research which shows that autism traits are found in a smooth distribution in the population. Therefore, the borders of autism must be arbitrary. The diagnosis is not good at predicting outcome (prognosis). Children diagnosed with autism might become very severely impaired or have a good outcome, and have cognitive functioning from the severely retarded to genius level. Research has demonstrated that the most powerful predictors of outcome are the child's I.Q., the mother's educational level, and having a non-minority mother. In two year olds diagnosed with autism, the most powerful outcome predictor was the quality of their motor (i.e. neurologic) functioning. All of these

predictive factors are not part of the diagnosis. Treatment is also not necessarily guided by diagnosis. Behaviorists, starting from Ivar Lovaas, have said that the diagnosis is not necessary as behavioral treatment focuses on behaviors rather than the diagnosis. Medications are also generally targeted to specific symptoms so that the medications currently used by psychiatrists are given to patients based on their symptomology and across diagnostic boundaries.

The diagnosis only describes a small part of what seems to be present in individuals with autism. Close to 100% of individuals with autism have neurologic symptoms other than those described in the diagnosis. There is reason to believe that these symptoms might be central to the development of the diagnostic symptoms. Nonetheless, not being a part of the current diagnostic criteria, they are frequently ignored. Other psychiatric problems, such as anxiety and emotional dysregulation, are ubiquitous in the autism population and are often the target of treatment, yet play no part in diagnosis. So many medical problems have been associated with autism that one study, found that **all** diseases were found more frequently in autism with the exception of blood diseases, neoplasms and genitourinary disorders.

Again, none of the physical disorders are involved in the diagnosis.

Could we do better with a different concept of autism? The answer is not clear; however, I believe we should try. One concept would be to reconsider all of the developmental brain disorders together. It is likely that there is tremendous overlap in the biological and developmental pathways that lead to the outcome. Our understanding of what *produces* the symptoms might emerge from the study of the symptoms that transcend the individual developmental diagnoses. For example, motor stereotypies are likely the same in a child with autism and in a child without autism but with an intellectual deficit. This is the goal that Dr. Insel is calling for in the research realm. A good question is, would this approach also benefit us in the clinical realm? I believe it would. By demystifying the diagnoses, it would lead to more confidence on the part of primary care physicians to treat the cases. Educators and other treatment professionals need to become more sophisticated at assessment of the child's needs. Relying on a diagnostic name might make us feel like we are being scientific - even if we are not.

Stay tuned for developments as these changes may help lead to those much sought after research breakthroughs.

### Residential from page 1

In a policy paper, the Autism Society of America predicted that many parents will experience a shock when their children leave school and enter the adult system. Every child with a disability is entitled by law to a free, appropriate education from birth to 21. Public schools must provide educational and therapy services based on a student's needs.<sup>6</sup>

Once someone reaches adulthood, however, the service system changes dramatically. Adults don't automatically get services just because they need them. They get them when their state has enough funds to pay for them. They also may find themselves dealing with multiple agencies for vocational, day, residential and health care services, rather than just one organization.

#### Most Young Adults Live with Parents

Due to a "lack of focused, coordinated, well-funded services," many youth and young adults with ASD must depend on relatives and programs such as welfare and Medicaid.<sup>7</sup>

One study reports that adults with ASD are more likely to "live at home with family" and "less likely to live independently" than adults with other developmental disabilities. Another study found that almost 80 percent of people with ASD ages 19 to 30 live with parents or guardians.<sup>8,9</sup>

As parents grow older, these living situations may become more difficult for families, experts say. "It takes a toll," Dr. Gerhardt said in an interview with IAN.

#### Housing Options

Residential services may vary by area, but they generally include options such as:

- Staff support provided in the client's home, which could be the family home or a home the client rents or owns.
- Living with a few other adults in a home provided and staffed by a disability agency.
- A farmstead, a working farm for adults with disabilities found in some rural areas.

- Larger Residential-Care Facilities.

Many families rely on government Medicaid waiver programs to pay for adult services, including residential support staff. The federal government adopted the waiver in 1981 so states could pay for residential and other services in communities, rather than institutions. With federal oversight, states create their own waiver rules.

States generally require adults to have a certain disability, demonstrate a need for support services, and have financial need.<sup>5</sup> Many services are available only to people who need the high level of care typically found in institutions.<sup>4</sup>

Most states require people to have an IQ score below 70 to receive waiver services,<sup>5</sup> which could disqualify many children with ASD when they reach adulthood. Experts considered intellectual disability to be common among older generations with autism, but it is less so among the younger generation. The Centers for Disease Control now reports that a majority (62 percent) of children with ASD do not have intellectual disability.<sup>10</sup>

Nonetheless, research shows many people with autism still need help with communication, community living and social skills,<sup>5</sup> which may affect their ability to live independently.

#### Planning Ahead

Parents can take steps now to help plan for their children's future needs. "Where possible, they should apply to their state developmental disability agency before their children reach adulthood," said Diane Dressler, program director at the Maryland Center for Developmental Disabilities. "Parents also should collect paperwork that will be needed for their children to apply for federal Supplemental Security Income benefits at age 18," she said.

Some parents want to bridge the gap caused by long waiting lists. "We're seeing more families trying to band together to buy a property where their soon-to-be adult kids would reside," said Ian Paregol, executive director of Community Services for Autistic Adults and Children in Maryland. Those families plan to purchase residential support services themselves or through waiver programs, he said.

Legislation that would help parents save for adult disability services tax-free has been pending in Congress since 2011. The Achieving a Better Life Experience (ABLE) Act would allow parents of children with disabilities to save for their future expenses, just as people save for other expenses through college savings or individual retirement accounts. "That's a step in the right direction," Mr. Paregol said.

Dr. Gerhardt said the school and adult systems should work closely together to improve the transition into adulthood. If students left school with jobs and better community living skills, they would require less expensive support services as adults, he said.

Another challenge is the lower levels of training and pay typically given to workers who provide support services to adults, Dr. Gerhardt said. "We need to professionalize the adult service system. It is harder to become a licensed manicurist than to become someone who works with an adult with autism. We bring in people with the least education and smallest knowledge base and pay them the least amount of money," he said.

One possibility is to put residential programs at universities; graduate students in disability-related fields could provide support services to adults with disabilities, he said.

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### Robots from page 14

children showed no difference between therapists. This is an important point because it should not be assumed that this approach will work for all children with ASD.

There are a number of important implications of this study. First, there seems to be a benefit to practicing simple social skills rules, such as asking questions or responding appropriately to questions, with a robot. It is possible that the robot simplifies the social situation (no facial expressions, limited gestures), and allows the child to focus on the skill that is being taught. It is also possible that the presence of a talking, interactive robot is so novel and socially motivating that it provides an intrinsically interesting situation in which the child can practice skills. We did not specifically test what led to this improvement in our participants, so this is an area for future research.

A second important implication is that

this approach will not be appropriate for all children. It will be important to determine what factors lead some children to respond to the approach, and others not to respond. This will allow parents and clinicians to be appropriately informed when deciding whether or not to use this approach.

Should robots be used in therapy right now? We think that there is considerable work that needs to be done before this becomes a widespread approach for teaching skills to individuals with ASD. Minimally, robots (as with any technology) should not replace human interaction. In essence, a robot therapist will not replace a human therapist. We believe that this approach will be beneficial in cases where it is used to target specific skills that can then be transferred to other people in the child's life. Robots can be quite expensive (the robot in this study cost over \$10,000, for example), and it will be important to work on ways to minimize the cost of the approach, without

losing its effectiveness, before robots will be recommended for widespread use. Additionally, our robot did not act on its own; it was controlled by someone, which is a setup that requires additional resources. Still, we consider this work a first step toward understanding the potential benefits of this approach.

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*If you have any questions, feel free to con-*

*tact us at [fun.lab@nd.edu](mailto:fun.lab@nd.edu), 574-631-5729, or visit our website at: [www.nd.edu/~jdieh1/Home.htm](http://www.nd.edu/~jdieh1/Home.htm). You can also follow us on Twitter at @ND\_FUN\_Lab or #funlab.*

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# Mom, What Will Happen to Me When You're Gone?

By Jackie Mayer  
Mother and Advocate

“What will happen to me when you're gone?” is a concern that weighs heavy on my heart after receiving a phone call eleven years ago. When my son Dillon was 1 year and 6 months old (currently age twelve), he was diagnosed with Fragile X Syndrome, which forever changed our lives. The Physicians told me that my son will have a small window of learning and that he will most likely reach a cognitive level of a first grader and then stop. My heart sank and every part of my being was triggered into a hurried search mode. I searched and searched for resources, professionals, organizations, and therapy providers that could help me help my son learn and grow. A couple years after receiving the diagnosis of Fragile X Syndrome, when he was five years old, Dillon was also diagnosed with Autism.

I'll never forget a conversation that I had with one of Dillon's therapy providers that struck a cord and it put a lot of things into perspective. I shared with him my plans on having Dillon always live with us for as long as we are able to take care of him. My husband and I had dreams to purchase land to build two small homes; one for us and



Jackie Mayer with her son Dillon

one for Dillon. I thought that was a pretty good idea until he said to me, “That is the worst thing you can do for your son.” I was completely taken aback. He explained to me in a kind and compassionate tone that Dillon needs his own world to live in. He said,

“You need to help him become as independent as possible. Help him learn how to take care of himself, help him find a job, give him purpose. Do you think you are going to live forever? When you pass away, his world should not be changed or uprooted.”

His perspective became very clear to me. And he was right! It's so important that we teach our kids daily living and community-based skills to prepare them for independent living. However, I quickly found out that this is not an easy task and we need a lot of help in this effort. In order to practice community living skills such as grocery shopping, getting a haircut, going to the bank, the movies, we need safe and non-judgmental environments. We need businesses to open their doors to individuals with disabilities and their families giving us opportunities to practice these skills and hopefully to eventually gain employment. Business owners that currently employ individuals with disabilities need to advocate and share with other businesses the advantages of hiring these individuals. I know this will take time and collaborative thinking, but if we all come together in a frame of mind that is open to creativity and innovation, our kids with special needs will have a chance to live independently. I assure you everyone will reap the rewards.

It is my dream that one day my son will have the skills and the help that he needs to live on his own and that this question will no longer be heavy on my heart.

*If you wish to reach me please follow me on my personal blog at [www.askjackie.org](http://www.askjackie.org). You may also call or email me anytime at [jnmayer@tlha.org](mailto:jnmayer@tlha.org) and (920) 860-0639.*

## Concerned from [page 23](#)

levels of satisfaction. It was evident that parents were not enthusiastic about the services available after high school as they are not age-appropriate and cease to help parents in identifying meaningful services for their young adult children with ASD.

Leaving home is a major transition for any young adult. Parents from certain ethnic groups believe that group homes disconnect the individual from the family. The study supported that those parents who consider the choice of sending their young adults with special needs to live in the community face higher levels of anxiety. They feel that their young adults will not be able to adapt to the new environment or will have a tough transition with new services, program schedules and/or unfamiliar professionals. As parents confront the various stages of transition, they also get a hands-on experience with the changes in service facilities and institutional options. During the transition process, professionals in service-providing agencies refer individuals with developmental disabilities to other agencies for vocational training or they provide options like group homes and/or day habilitation programs to parents. However, the new arrangement may not be acceptable to the individual or his/her family. Due to previous experience with services, inadequate facilities, and/or inappropriate age levels of other program participants, many parents decide to forego continuing adult services.

Young adults with ASD face “significant obstacles” in their “way to college, work, community participation and independent living” (Hendricks & Wehman, 2009). Helpful guidance for choosing services and effective case planning along

with proper housing can create a positive impact on individuals with ASD and their families, yet many autistic young adults stay confined to home while aging parents struggle to address the basic needs for their child's independent living.

Developing housing facilities is not easy either, given the current lack of funding especially in the non-profit world. Service providing agencies have usually voiced their concerns about trickling down of financial resources for much needed programs. They also complain that certain neighborhoods often try to stop group homes from functioning in their locations due to their resistance towards people with special needs. However, it is a fact that many group homes tend to be inappropriate, especially for high functioning individuals with ASD. Additionally, news related to abuse and neglect by the staff within agencies' premises demoralize parents to allow their children to stay there. Parents express concerns about safety factors and various levels of potential risks.

Concerns about daily life and general inclusion in the community are major stressors for the parents. Answering the questions on these issues was the most difficult process for them. They demonstrated stress, fear and hopelessness. One of the parents stated, “I find it very discouraging because I know that she does not have the basic skills to lead a life alone. She cannot live by herself. Generally she is a very happy child, but if she cannot live alone, then she needs to stay at home, and I am not sure if my husband or I are ready to quit either of our jobs to take care of her at home. We don't want to put her into an institutionalized setting because we fear that she will be taken advantage of...” Another parent who is in the midst of preparation said, “I don't think

that he has any future and he should live with his family. I try to structure his time like...we are getting old and if we are gone then at least we should leave after building a structure for him...If I am not alive and my husband is not alive, I can't force my children to take him as their own child, no! They have their own lives, everybody has their own lives. I don't want to separate him from his family either, so we think that if my other son and daughter are living elsewhere, then we would set up a basement up for him and keep him in the home environment. If somebody can take care of him, then they can keep an eye on him. But I can't tell them to keep him. We are planning to buy a house and set the basement for him. So when we are not there, he can live there, he has a place to live.” This parent seeks to create an environment according to their child's needs and hopes to get help from their other children but cannot blindly rely on them because they have their own families for which to care. Also, for many parents, buying a house and planning to set it for their child with ASD is financially not possible.

## Summary

The study highlighted parents concerned about their child's future. 68% of the aging parents shared that they are looking for private caregivers for their children while 63% hope that their other children can take care of the sibling with ASD. In each response to the research questions, participants demonstrated fear of the unknown, and worries associated with their children's future. Each parent believes that their child will be vulnerable and isolated once the parents are no longer there for support.

The responses reflect that parents of

young adults with ASD are stuck in time, since they are confronting a dead end in their lives and in the lives of their children. Through their answers, parents have demonstrated hopelessness due to lack of adequate support for successful social inclusion, vocational support and housing. Services that individuals with ASD could access through the county, city, or the federal government usually become private and expensive services after they graduate from the mandated school services. Many parents are unable to afford these services. As a result, parents realize that their financial resources are inadequate or nonexistent, especially if they are ineligible for loans or charities. The services that are available are not necessarily age appropriate or adequate and, in the case of housing, many parents find the option risky considering their child's vulnerability. Awareness and knowledge that facilitated access to services became impractical. Many parents struggled to fit their knowledge with available resources, especially with the housing facilities, while thousands of young adults with ASD wait for a home away from home.

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**Quality Services from [page 6](#)****Dispensing medicine:**

How do individuals get medications?  
Who is responsible for administration of medications?

**Diet:**

How do you provide for individuals preferences/dietary needs?

**Physical activity & exercise:**

What opportunities are there to exercise/have physical activity?

**Personal hygiene:**

How do you assist/support routine daily hygiene?

**Health and Safety – Environmental****Cleanliness:**

How do you keep the environment clean?

**Technology:**

How do individuals access technology?

**Sensory needs:**

How do you modify the environment to meet sensory needs?

**Visual supports:**

What visual supports for daily living are posted?

**Physical accessibility:**

What accommodations are available for accessibility?

**Health and Safety – Safety****Emergency safety plans:**

What are your emergency safety plans?

**Safety drills:**

What safety drills are practiced with individuals and how often?

**Visual supports for safety:**

Where are visual supports for safety posted?

**Staff trained in safety measures:**

How are staff trained in safety?

**2. Happiness/Well Being – Choice****Opportunity for choice:**

How do you provide for individual choice?

**Opportunity for free time:**

How do you provide for free time?

**Happiness/Well Being – Interactions/Well Being****Develop friendships:**

What opportunities are there to develop friendships/dating/sexual relationships?

**Interactions:**

How does staff engage in activities with individuals?

**Smiles/laughter:**

What are the indicators of contentment and happiness in the environment?

**Feeling of being valued in personal celebrations (e.g. birthday):**

How does the staff make the individual feel cared for, accepted and respected?  
How are special events celebrated?

**3. Community/Recreation and Leisure – Community Activities****Community activities available (e.g. religion, shopping, dining, volunteering):**

How often so you provide for diverse activities for individuals in the community?  
How often and what type of diverse community activities do you provide?

**Individual preferences:**

How do you integrate special interests/talents into activities?

**Opportunities for learning:**

How do you use community to support new learning and experiences?

**Community/Recreation and Leisure – Support/Transportation****Transportation services provided:**

What is used for transportation for community activities?

**Supervision:**

What supervision is provided for community activities?

**4. Staff – Hiring****Background checks:**

How do you handle background checks of employees; current and new?

**Staff qualities/skills:**

What qualities and skills do you value in employees?

**Staff evaluations:**

How are staff evaluated? How do families

give input?

**Staff – Supervision****General staff training:**

What is included in your staff orientation?  
What is included in ongoing training?

**Autism-specific training:**

What autism-specific training is given to staff?

**Supervised on the job:**

What type and length of training does staff get before working alone?

**Ongoing supervision:**

How are staff supervised?

**Staff retention:**

What is your staff turnover rate?  
How do we evaluate equitable pay?

**5. Administration – Policies/Procedures/Manuals****Licensure/Accreditation:**

What is the agency's licensure/accreditation/certification?

**Agency policy/procedure:**

How do you assess your policies/procedures?

**Policy on Major Unusual Incidence:**

Has your agency had any death, case of abuse/neglect, serious accident, and/or theft in the last five years?

**Administration – Fiscal/Resource Management****Annual financial records:**

How are financial records made public?

**Personal property:**

How do you oversee an individual's personal money/possessions?

**6. Program – Self Determination****Individual preferences:**

How do you determine and support what individual interests are?

**Program – Program Components****Behavior support:**

How do you provide support for challenging behavior?

**Social skills:**

How does your program address/foster social skills?

**Communication:**

How does your program address/foster communication?

**Transitions:**

How does your program address/support individuals in transitions or change?

**Coordination of community services:**

How does your program coordinate with other service providers?

**Individual progress/evaluation:**

How does your program measure the progress of the individual?

**Employment:**

How do you support work adjustment and opportunities for employment?

**Family input:**

How are families included in program planning?

“Quality Residential and Other Services for Adults with Autism” can be used by parents, guardians and service providers as a framework to assess potential services for individuals on the Autism Spectrum. More specifically, this guide can be used to determine if an agency, vocational and/or residential program provides services that are consistent with values of the family and are designed to meet the needs of a particular adult with autism.

*Kay Brown, LISWS, is the Director of Southwest Ohio Regional Autism Advisory Council. Jan Cline, MS, CCC-SLP, is the Training and Consultation Director at Bittersweet Farms. Christine Keran, BA, is Director of Admission and Outreach at Sunshine Residential and Support Services. Donna Owens, MA, is the Director at the Family Center of Ohio Autism and Low Incidence. Andie Ryley, MEd, is Chair of the Northwest Ohio Advisory Council and is an Autism Consultant. Ellen Williams, PhD, is Professor Emerita at Bowling Green State University.*

*Choosing the Right Services for Your Adult with ASD is made available by the Ohio Center for Autism and Low Incidence (OCALI) at: [http://www.ocali.org/project/donnas\\_favorites](http://www.ocali.org/project/donnas_favorites). This guide is intended to be shared freely.*

**Learning from [page 16](#)**

functioning deficits may also impair the purchase. First, one must find the store and navigate the community to get there. They must also make sure they have enough money for the purchase and that they receive the correct change. These steps require planning, initiation, and organization. By practicing in the community, one is able to practice these skills in real time and in the real situation. Skills deficits may become more noticeable in the community; however this provides a great opportunity to assess and create new goals.

**Why is Community-Based Learning Important?**

Many pivotal social and life skills are

learned in groups. However, it is important for youth and young adults with autism spectrum disorders to practice these skills outside the group setting. This assists in generalization of skills. It is also important for individuals on the autism spectrum to have supervised interaction and engagement with people they are not familiar with, as a facilitator or parent may not always be there to assist in interactions. When a parent or professional observes an individual in the community setting they are better able to identify where the individual on the spectrum is having difficulties. This allows for the creation of new goals and identifies areas of need. Most importantly, by allowing these opportunities for practice, the individual with an autism spectrum disorder is put on the path to becoming more self-sufficient.

**Out and About with ASPIRE**

The ASPIRE Center for Learning and Development's “Out and About” community-based program is for children and young adults with ASD between the ages of 10-25. This program helps facilitate generalization of life skills as well as social skills by taking youth and young adults with autism spectrum disorders into the community. Trained facilitators provide small group support allowing for incidental teaching. Participants are able to learn while having fun and meeting new friends. Outings have been scheduled based on age ranges, including pre-teen, teen, and young adult. This summer we are scheduled have a variety of outings and events that will start off with

our Annual Summer Kick-Off Barbeque for young adults and a cake-decorating contest for pre-teens and teens. Other outings will include movie night, bowling with friends, mini golf, and a mall outing for pre-teens and teens. These outings provide great opportunities for learning life skills while having fun!

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**POINT Program from page 10**

service agency. After an exhaustive search, we felt comfortable that two agencies shared our vision, were flexible, were willing to create a new type of independent living community with supports, and were collaborative enough to allow the parents to have a voice in program concerns. These two think-outside-the-box agencies were even willing to collaborate with each other in the creation and running of the program. With each agency's special expertise and track record for quality management of programs, our parent group concluded that the Jewish Child Care Association (JCCA) and Westchester Jewish Community Services (WJCS) would manage our proposed community. We certainly were and continue to be grateful to WJCS and JCCA for their willingness to take on this challenge.

And so, in 2007, our parent group started to meet regularly with WJCS and JCCA to help in the creation and planning of a program of excellence. It was serendipitous that our random group of parents had diverse skill sets that proved quite valuable in areas of finance, government benefits, fundraising, real estate, writing, knowl-

edge of resources in the White Plains area, etc. I believe the positive collaboration of agencies and an active parent group helped us all challenge ourselves to move forward. After much planning by the agencies, a POINT Program director was hired as was other personnel. Initial contacts were made with Vocational and Educational Services for Individuals with Disabilities (VESID), which is now Adult Career and Continuing Education Services-Vocational Rehabilitation (ACCES-VR), regarding employment for POINT members. The first monthly social calendar was created. By the summer of 2008, our pioneer group of a dozen or so young adults had rented apartments in a lovely White Plains apartment building near shopping, transportation etc.

The POINT Program of 2008 faced many challenges, especially with respect to obtaining government benefits. Most of our young adults were originally from the New York metropolitan area but a few were from the Hudson Valley and Westchester. So, residency needed to be established. Our parents were paying rent as well as a program fee and other expenses. Even transferring benefits from one county in NYS to another proved chal-

lenging. Expediting the job seeking process was a concern as was providing job readiness, career guidance and volunteer opportunities.

WJCS and JCCA and our parents group continued to work to refine POINT and face the start-up challenges. As a result, the POINT Program of 2013 is a well-established residential program that supports almost 40 young adults with developmental and learning difficulties, including ASDs. POINT members now live in a variety of well-chosen apartment buildings within walking distance of each other. Supports are tailored to the needs of each participant. We have an experienced Director, trained program specialists, Comm Hab workers and a service coordinator. There is a full social calendar available to participants each month that reflect their interests and needs. In addition to having created a genuine community, the vocational rate of POINT young adults is more than 50% in paid employment vs. a national rate of 85% unemployment among persons with developmental disabilities. All POINT participants are expected to be actively engaged in employment, education and

volunteer activities. With the support of UJA, we have the JCCA-Compass Project assisting our members with internships, vocational readiness and jobs. Our crisis intervention and 24-hour emergency coverage has been tested and has proved to be effective.

POINT is a model creative residential solution that provides effective and efficient individual supports. Yet, as OPWDD embarks on its road to reform, we have not been successful thus far in receiving significant OPWDD support. We hope that as OPWDD continues its reform process, it will more fully embrace the POINT model.

It should be noted that the POINT model has inspired other independent living with support models such as the Queens Independent Living Program (QILP) of Queens, NY. We continue to strive to break new ground in creating strong, supportive affordable community networks that enable participants to lead fulfilling lives.

*For anyone interested in finding more about the POINT Program, please contact the director Barbara Greene at [bgreene@wjcs.com](mailto:bgreene@wjcs.com) or by phone at (914) 761 0600 x.175.*

**Affordable from page 12****Housing Committee**

Our housing committee is the lynch pin of our affordable housing advocacy efforts. The primary focus is education (first the committee and then our members) and advocacy. Our six members have a variety of talents and interests, creating a multi-dimensional approach to the problem.

We began by educating ourselves. We discussed topics and researched answers to questions we had. The research took many forms: reading newspaper articles, attending meetings, conducting internet searches, and discussions with local and county officials.

A great deal of time was spent on research and discussion, as we created several versions of ideal settings. Gradually, we developed an approach to advocate for affordable housing at the local level, based on the knowledge we had gained.

Throughout, the talents and interests of our committee members played a vital role. For example, our computer expert found valuable data online, while our marketing person developed a presentation suitable for meetings with planning boards and mayors. Data was important for a number of reasons: we needed to understand how housing worked in New Jersey and the current political environment. We also needed to know which municipalities had available funds designated for affordable housing.

A model presentation was developed. It contained a great deal of information related to affordable housing. This document was designed as a template that could be modified to suit the particular situation in a specific town.

Simultaneously, we invited knowledgeable individuals to speak about housing at several chapter meetings to broaden and deepen our members' knowledge. The information sparked additional questions and areas to pursue for the housing committee.

Our approach crystallized slowly, as committee members tested our model presentation, and learned about potential pitfalls.

**A Summary of Our Successful Approach**

Become as knowledgeable as possible:

1. Make an assessment of what is important for the person in need of housing, and the degree of possible flexibility. This will govern the next step.
2. Research availability of appropriate options in your chosen area.
3. Submit your name to any and all housing lists for that area. Talk to your local municipality for guidance.

If there are no suitable options, determine if your chosen area has funds available to build affordable housing. If the answer is yes:

1. Gather as many community members who are invested in the needs of adults with ASD in the chosen municipality
2. Form alliances with individuals or organizations that have goals similar to yours.\* Educate those who want to participate but don't have the background.
3. Tailor the model presentation to your situation
4. Approach potentially receptive members of your local government. Someone on the council may have a disabled person in their family or have previously shown an inclination to support affordable housing
5. Provide receptive officials with data supporting your objective
6. Request a formal meeting in writing. A written document becomes part of a municipal record; the officials are required to respond.
7. Be persistent and vigilant.
8. Keep track of all written responses from the municipality.

9. Make your presentation, accompanied by as many of your tax paying friends and neighbors as you can muster. Or, coordinate a presentation that includes community members, tax paying friends, neighbors and those invested in diversifying the community.
10. Be persistent. One presentation will not accomplish your objective, but it's a start. Let your audience know that this is a process and it will require a commitment to additional meetings.
11. Follow up. Find out what else the decision makers need from you. Provide it promptly.
12. Be persistent.
13. Communicate throughout the process so that all involved are aware of new developments.

If the above sounds like a grind; keep in mind that it has proven successful. And success is very exciting!

**Challenges**

Before you start, remember your objective: to find the best possible housing for your ASD adult.

The first issue is to overcome inertia. The best way to confront this is to become better informed about affordable housing options in your area. The second step is to form a network with others who have similar goals. With information and allies, much is possible. Is it easy? No. Can it succeed? Yes!

**Considerations**

Securing appropriate housing is a slow process and analyzing potential options can be complex and confusing. Remember that information is your ally. Your network and alliances are key to broadening your knowledge. Persistence and diligence are vital to success.

**Success**

The ultimate success is securing that spot for your ASD adult, but success comes in stages. For our small group of dedicated, determined everyday people, we have achieved the following:

1. One municipality is fully committed to building affordable housing for the disabled, with a developer and building site selected.
2. Another town has the site and is evaluating potential developers.
3. A third is searching for the appropriate building to rehabilitate, given their financial restraints.

The housing committee achieved another success: a recent chapter meeting showcased another panel of experts – our own Housing committee. Committee members described the history, as well as the current status of affordable housing in NJ. The person who committed to housing advocacy at our Housing Forum described the progress being made in her town - they are ready to build, pending permit approvals. And we answered many, many questions. Quite a feat for a small group of dedicated, determined everyday people.

Separate from the above, and due in large part to the education and advocacy provided by our Housing Committee, six of our members' ASD adults have found appropriate housing in the past six months.

\* The BC UW/Madeline Partnership (see their Ad on page 12) is one such organization.

*For more information about the Adult Issues North chapter of ASPEN, please contact Mary Meyer at [AdultAS@aspennj.org](mailto:AdultAS@aspennj.org) or by phone at 201-825-3286. You may also visit <http://aspennj.org/aspennj-chapters/adult-issues-chapters/north-jersey-adult-issues>.*

**Medicaid from page 19**

at least prompting (not simply reminders) with at least one activity of daily living, a family member who is not a legal guardian can apply to become the individual's caregiver through Adult Family Care (AFC), a Medicaid state plan service. (One common arrangement is for one parent to become the guardian, while the other becomes the AFC caregiver.) The AFC caregiver will receive a tax-free stipend of about \$8,000 per year. If the caregiver saves the stipend, by the time the individual receives a Sec. 8 voucher, \$80,000 or more may have accrued. This money can then be used to make a down payment on a home or condo, which is then rented to the individual. The rent payment, including the amount paid via Sec. 8, may then be used to pay the mortgage. Care for the individual in the new home may be paid for via Adult Foster Care, Group Adult Foster Care, or Personal Care Attendant services, depending upon the living situation and needs of the individual. One additional program worth mentioning in this context is the Fannie Mae HomeChoice mortgage, which is open to individuals with disabilities or their family members (8).

Other options may be devised. For instance, three individuals with disabilities

saving \$56 each per month through IDA accounts might be able to walk away with \$24,000 among them for use as a down payment. While not very much for a conventional home loan, that amount could go a long way toward government-owned real estate, if purchased for as little as 3% down via a Fannie Mae HomePath mortgage (9).

Groups currently in existence in Massachusetts are working on a number of models, including: a cluster of 3 group homes on a cul-de-sac with shared services paid for through Group Adult Foster Care; an old Victorian house, serving 7 individuals with two live-in care givers, with services covered by Group Adult Foster Care and housing paid for through project-based Sec. 8 vouchers provided by a local housing authority; and two families splitting the rent on a three-bedroom apartment, with a live-in caregiver receiving a stipend from Adult Foster Care.

While there is room for creative use of existing federal and state programs to innovate a variety of individualized housing options, advocacy will be necessary to make these a reality in many parts of the country. Revisions to Section 1915(i) of the Social Security Act open up new possibilities for families and service providers to fund services through Medicaid state plan services, but only if states can be per-

sued to respond to the incentives created by the Affordable Care Act. Individual Development Accounts will need to be more broadly funded; using tax credits instead of budget line items to fund IDA programs may be a promising avenue for states to pursue. Finally, the threat sequestration poses to the Sec. 8 program will need to be recognized and remedied. The need for new approaches to housing is generally acknowledged, but often little more than lip-service is paid, as the barriers are seen as intimidating. Smart, effective advocacy on the state and federal level can serve to change this.

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8 - [www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&sqi=2&ved=0CEY-QFjAA&url=http%3A%2F%2Fwww.hhs.gov%2Fod%2Fdocuments%2FCommunityHomeChoice.doc&ei=EASmUdXTLeTl0QHP\\_oDgBw&usg=AFQjCNEvNQG-SGRcF3yGsc6SsAy-FgX-JtQ&sig2=71e8ZFcdaf6\\_QNV6t\\_ycd-Q&bv=bv.47008514,d.dmQ](http://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&sqi=2&ved=0CEY-QFjAA&url=http%3A%2F%2Fwww.hhs.gov%2Fod%2Fdocuments%2FCommunityHomeChoice.doc&ei=EASmUdXTLeTl0QHP_oDgBw&usg=AFQjCNEvNQG-SGRcF3yGsc6SsAy-FgX-JtQ&sig2=71e8ZFcdaf6_QNV6t_ycd-Q&bv=bv.47008514,d.dmQ)

9 - [www.homepath.com/financing.html](http://www.homepath.com/financing.html)

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## Advertise Your Organization in Autism Spectrum News!!

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**Summer from page 20**

but had a lasting impact throughout his weeks at camp. He became comfortable enough to manage group settings like the dining hall where he sat and ate with his peers.

*Camp helps children make good choices and develop self-confidence* - Michael came to camp having trouble sitting still and having frequent outbursts. Ramapo believes that difficult behavior like Michael's is the language children use when their needs are not being met or the demands of their environment are misaligned with their social, emotional and learning challenges. Michael was really concerned about safety while at camp, and enjoyed acting as the camp's security guard. Counselors would send him on secret safety "missions" that engaged his interests productively and made him feel valued. By giving Michael opportunities to succeed on his "missions," his self-confidence grew; after eight weeks at camp, Michael improved on what was previously difficult, choosing to participate in activities without his usual outbursts.

The Staff Assistant Experience and Young Adults with ASD

Enhancing skills during the summer months is not only critical for younger

children with ASD, but also young adults on the autism spectrum who may have difficulty transitioning to college or joining the workforce.

Ramapo runs the Staff Assistant Experience (SAE), a residential transition-to-independence program, with a summer session option, for young adults aged 18 to 25 with social, emotional or learning challenges. The participants, known as Staff Assistants, live and work alongside typically developing peers, which allows them to see firsthand the positive behaviors that build the social, independent living and job skills necessary for adulthood.

*Becoming part of a team helps young adults with ASD develop social skills* - Max had trouble connecting to others prior to joining SAE last summer; he frequently would avoid conversation in a crowd of people by staying busy on a hand-held video game. Max shared a cabin with a Ramapo staff member over the summer, which exposed him to regular one-on-one conversation and taught him how to build on a relationship. His experiences have given him a new perspective on his own capabilities, increasing his confidence and interpersonal skills. Max has learned to make friends, is more comfortable starting conversation, and even plans community events like group trips to the movie theater.

*A supportive community helps increase independent living skills* - Andrew began SAE after having trouble at his community college. Andrew lived in an apartment on campus with another staff member who modeled and taught Andrew real-life duties like creating a meal plan, doing laundry and household budgeting. His sense of responsibility and self-discipline increased markedly through this experience. Andrew also successfully completed the college credit summer course that instilled a newfound self-confidence. His parents Andrew's independence after his leaving Rhinebeck, citing that Andrew used to think nothing of arriving an hour or more late, but is now much more consistent in showing up on time to his commitments.

*Gaining job skills during the summer that carry into future work* - Mark found his niche when he discovered his talent for working with children as a Staff Assistant at Camp Ramapo. The work began as a challenge, but soon he looked forward to meeting the next group of campers and helping them gain new abilities. The children looked up to Mark, and his confidence increased as he helped them experience success through the strategies he'd learned as a Staff Assistant. He was no longer only a person who received support, he was a person who supported others, and he truly enjoyed sharing the Ramapo approach with

campers. Thanks to his newfound focus, he became eager to apply himself to a future working with children. With the help of his mentors and peers, Mark studied for a school aide certification test, passed with flying colors, and upon returning home, became a primary school teaching aide.

Skill development is an important part of growth, and no matter what age, summer can be the best time to mature and progress. In particular, residential summer programs have the experts and experiences for children and young adults with ASD to feel comfortable and flourish. Ramapo provides the supportive community and unique approach that enables these children and young adults to develop the skills to align their behaviors with their aspirations. A summer filled with proper support and an inclusive environment often can be exactly what children and young adults with ASD need to enhance their skills and be ready for the fall.

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**Improve from page 18**

student receives is also influenced by geographical location, since some states are known to rely more heavily on related service providers than others. An analysis of publicly available IDEA data reveals that New York State employs more related service staff-members per student than any other state in the country ([www.cbcny.org/cbc-blogs/blogs/needed-mandate-relief-way](http://www.cbcny.org/cbc-blogs/blogs/needed-mandate-relief-way)). Unfortunately, more providers does not automatically translate to better outcomes for our students.

Years of experience with special education in New York City as a classroom teacher, school counselor, classroom consultant and neuropsychologist have taught me that the most effective treatment teams communicate on a regular basis and value the contributions of other team members. The truth is, all of the related service disciplines overlap in many ways and are capable of having different views about the etiology and treatment of developmental and learning disorders. In the same article quoted above, NIMH director Thomas Insel states, "People with autism are likely to be viewed differently by pediatricians, child neurologists, child psychiatrists, developmental psychologists, behavior therapists, special education experts, occupational therapists, speech and language therapists, and any of the other range of providers" ([www.nimh.nih.gov/about/director/2013/the-four-kingdoms-of-autism.shtml](http://www.nimh.nih.gov/about/director/2013/the-four-kingdoms-of-autism.shtml)). This is where the team concept becomes key. The only way to possibly combine such a diverse group of practitioners is to unify them on a common task. The IEP unifies team members with the common goal of optimizing the learning and development of a particular student. According to the IEP process, as students meet their goals, services are modified to meet their changing needs. Moreover, if a goal is not being met after repeated trials, the goal is modified, or a different solution is attempted. Focusing on solutions is an effective way to neutralize any differences in opinion that treating clinicians may have regarding the best way to target a specific goal. Utilizing a solution-focused approach transforms the task of optimizing learning and development from an abstract concept into an objective measure.

Unfortunately, the IEP is a relatively static document in that it is updated annually; a rather unhelpful time-scale when the task at hand involves customizing the educational and related service program for a growing and developing child or adolescent. Individual providers can and do mod-

ify goals throughout the year, however they have no way of communicating these updates with the rest of the treatment team. They submit their written reports for yearly annual review meetings, however they are not required to attend these meetings, where important decisions are made about the student. These and other factors combine to thwart interdisciplinary communication and undermine the team concept. In many cases, different providers end up targeting the same goals using different approaches. What's worse, they are unable to see what other providers are working on and/or what has been successful for a particular student. In addition, providers frequently change during the school year and may be located outside of the school building. If a related service provider is new or located outside of the school building, or if their schedule is so busy that they see kids back to back (as is often the case), and the IEP describes the child's behavior from the *previous* school year, how are they supposed to get an accurate picture of the child's current classroom needs, both academic and social? After all, didn't children begin receiving mandated related services because of their difficulty meeting academic and/or social demands in the classroom, as measured by functional behavioral assessments, performance on academic testing and their ability to follow social norms and conventions?

**Bottom-Up Solution:  
Program Reviews, An Affordable  
Way for Parents to Intervene**

Parents of students who find themselves in one of these terribly frustrating situations, when they know their child needs help but are forced to drop mandated-related services, should know about Program Reviews, an affordable way to effect change in their child's educational plan.

A Program Review is a formal name for an expert consultation on special education matters. During a Program Review, a neuropsychologist and/or educational expert reviews a child's records including past assessments and report cards, visits their school and interviews different related service providers. After considering the treatment plan and related service goals, a summary report is produced that gives specific recommendations for each related service discipline. In addition, part of the program review includes follow up with providers to help explain the findings. Program reviews are privately funded and are not typically covered by insurance, however they are an affordable way to get an expert opinion that would

normally cost \$4,000 to \$5,000 (the average cost of a private neuropsychological assessment). The price of a Program Review ranges between \$500 and \$2,000 depending on the amount of time and work required. Prior to the beginning of the review, parents are informed how much work the review will likely require and both parties agree on the cost.

**Top-Down Solution: Increasing the  
Time-Scale of the IEP as a Way of  
Improving the Efficiency of Our  
Related Service Departments**

In addition, one simple solution with great potential for improving the current system would be to improve the time scale of the IEP by creating an online system for reporting results and communicating with other members of the team. As mentioned above, by the time school starts in September, even the most recent IEPs are nearly 6 months old. In addition, related service providers often provide their services in isolation, or without proper contact with the rest of the team. Why not increase the temporal resolution of the current data stream (i.e. the IEP) by collecting information about student performance from the complete team more frequently throughout the year. One way to do this is to create a dynamic, web-based document that is accessible by the students' family and by all members of the educational and clinical team. All members of the clinical treatment team would benefit from input regarding the cognitive, academic and social progress of the student obtained from other team members. In addition, if there is a successful strategy that would benefit from coordination among team members, such is the case with executive functioning, social skills and the remediation of many academic skills, then common language, strategies and information could be shared. The benefits would be far-reaching. Aside from allowing us to better meet the educational and developmental needs of our children, increasing the efficiency of special education teams would provide needed relief to the strained NYS system.

**Conclusion**

The Special Education system of NYC has grown and developed a great deal in recent years, and our students now receive more IEP-mandated related services than any other state in the country. Unfortunately, increasing the amount of related services does not equate to a higher quality of education for many students, especially when provider roles are poorly defined and

when providers are unable to communicate or see what fellow team members are working on. The IEP is based on an evidence-based, interdisciplinary approach that focuses on solutions as a way of optimizing the educational program for each child. Using a solution-focused approach is an effective way of neutralizing any differences in opinion or style that exist among members of the treatment team. Unfortunately, several obstacles exist in the current system, namely overlapping responsibilities and the infrequent time-scale of the IEP, that stifle teamwork and communication amongst members of the treatment team. As a result, it is very difficult for all team members to stay informed about how students are performing in the classroom and with other providers. Moreover, medical doctors who prescribe medications are often out of the loop regarding everyday school occurrences. These issues are exacerbated when students go to outside locations for related services, when providers are switched during an academic year, and as students get older and begin to have additional teachers for certain subjects.

Parents should know that they are now powerless to effect change, and also that they do not have to come up with \$5,000 for a private neuropsychological evaluation in order to advocate for their kids. Instead, they can ask the same neuropsychologist for a program review. If the neuropsychologist never heard of a program review, refer them to this article. Last, many or all of these problems would be fixed by improving the frequency and quality of information that is shared by team members. This could be accomplished by adopting a web-based system whereby team members could log on to see up-to-date posts about student progress and other important information, such as medications, effective learning and behavioral strategies. Adopting such a system would greatly improve our ability to educate our children while improving the efficiency of our clinical treatment teams. In doing so, we would also reduce the overall number of mandates and related service providers on each student's clinical treatment team while also doing a better job of meeting the needs of each student.

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**Housing from page 22**

that will be a catalyst for change in the work force.

I was enthused by this stunning concept; an auspicious goal, an exemplar for the future. The future is now; nevertheless it is four years later and given the turbulent nature of the economy our children face further challenges. However, Randy Lew-

is' model is the quintessential village and role model. Advancing Futures for Adults with Autism encourages our children to be productive members of society. They need respect, coupled with patience and understanding.

This includes housing. The concept of a "group home" is an aging avenue. We, as a society need to be more creative, productive and proactive. Funding is an issue.

Let individuals with autism be part of the equation. Whatever the job, or level of contribution, their earnings may contribute to their own supported living. Joint private and public partnerships are an optimal direction for funding supported housing.

Programs with "safety nets" are sprouting all around the country. This is a seductive market, and families are held hostage to high fees with the promise of supported

independence. There must be a marriage between government and private/public funding. It is a winning opportunity.

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### Farms from page 13

shares to members of the community with a goal of selling 100 shares each spring/summer” (D. Berry, personal communication, May 6, 2013). Similarly, Chief Professional Services Officer Janet Banks of the GHA Autism Supports Program said the agency offers a CSA program with 55 members (J. Banks, personal communication, May 14, 2013).

Bittersweet Farms in Ohio was the earliest American residential farm for adults with autism. Founded in 1983, Bittersweet Farms today serves 20 adults with autism (Bittersweet Farms., n.d.). Bittersweet Farms is considered a national model for the residential agriculture movement for adults with autism.

American residential farm programs vary in size, operating history, and gender breakdown. Mandy’s Special Farm (MSF) began receiving government funding in 2008 and today serves four adult women with autism (Mandy’s Safe Haven, n.d.). MSF focuses upon meeting the needs of women with autism. FNE serves 21 residents with an even mix of men and women (D. DeScenza, personal communication, May 2, 2013). FNE began serving two residents in 2003 and built 3 additional group homes between 2008 and 2011 to add 19 new residents. Iowa’s Homestead program began in 1994 and serves 24 adults, including 20 men and 4 women (D. Berry, personal communication, May 6, 2013).

GHA Autism Supports, affiliated with the University of North Carolina-Chapel Hill Medical School, has been serving 15 residents in 3 group homes since 2005, including 10 men and 5 women (J. Banks, personal communication, May 14, 2013). Rusty’s Morningstar Ranch in Arizona, founded in 1985, today serves 8 men. Safe Haven Farms was founded in 2010 and now has 16 residents (Safe Haven Farms, (a), n.d.). Juniper Hill Farms in Pennsylvania has 3 male residents (Juniper Hill Farms, n.d.). Sunridge Ranch in Washing-

ton has 4 male residents since 2010 (Sunridge Ranch, n.d.).

Many farms provide similar types of employment opportunities for adults with autism which typically include horticultural work and animal husbandry. But the specific work options available to adult residents with autism vary somewhat from one program to the next. For example, the Homestead program in Iowa allows residents to engage in gardening, cleaning, and clerical tasks. FNE offers residents the opportunity to participate in gardening, caring for animals, cooking, baking, and producing crafts (Farmsteads of New England, n.d.). Bittersweet Farms in Ohio offers various types of agricultural, gardening, and animal husbandry in addition to woodworking and construction (Bittersweet Farms, n.d.). Female residents of Mandy’s Special Farm (MSF) participate in gardening, animal husbandry, and therapeutic horse riding (Mandy’s Special Farm, n.d.).

Parents of children with autism were the driving force behind many residential farm programs in the US. Rusty’s Morningstar Ranch was formed by his parents Jack and Carlene Armstrong because they wanted to ensure a secure future for their son after their deaths (Rusty’s Morningstar Ranch, n.d.). Ruthie & David Robbins started Mandy’s Farm because they could not find a suitable long-term solution for their daughter Amanda (Mandy’s Special Farm, n.d.). Deborah DeScenza launched FNE because she is a mother of a son with severe special needs (Farmsteads of New England, n.d.).

By 2010, at least 9 residential farms for adults with autism had been operating in 8 states. The existing farms currently house around 115 adults with autism in total. At least 11 additional farms are in various preliminary stages, with some farms having purchased land and others currently in the conceptual stage.

Many residential farm programs for adults with autism are highly successful and popular, as indicated by the fact they typ-

ically have no openings and long waiting lists (Agricultural Communities for Adults with Autism, n.d.). The small number of programs is insufficient to meet the enormous demand for supportive housing for the rapidly increasing population of adults with autism. The creation of additional residential agricultural programs would allow more adults with autism to receive supportive housing services and employment opportunities in the farm industry.

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### Post-Facility from page 17

Families are implicitly (sometimes explicitly!) encouraged to stress how needy their son or daughter is in order to achieve the highest level of services (budget). OPWDD is currently testing a new instrument, the Coordinated Assessment System (CAS), which is more functionally based than the DDP. Functional assessment identifies an individual’s support need rather than their deficit, or their diagnosis. For example, if a person needs help with their Activities of Daily Living (ADLs) - cooking, cleaning, hygiene - a functional assessment is agnostic as to why they have that need; it is simply designed to identify the need and to provide a path to budgeting for that need.

A corollary to a functionally based assessment is the second element, an individualized budget, which sets out the cost of support staff, clothing, food transportation and rent that an individual will need to take their place in society, as well as their resources from benefits and employment. An “individual” budget does not exclude the sharing of services, or the pooling of certain resources (e.g. the need to pay rent for shared accommodation with a live-in caregiver) but it is assigned to the person with a disability rather than as a “slot” or a “bed” to a provider agency.

The third essential element to change is that Money should Follow the Person. (MFP). The principle of MFP is that once an individual’s support needs have been identified through a functionally-based assessment, they will be assigned a budget to pay for the supports they need. In our current system funding is provided to agencies which in turn create a menu of services. People with ASD & I/DD avail themselves of the available services from the available agencies. Agencies creating group housing submit a budget to OPWDD that includes their mortgage cost and maintenance, their staffing cost based on the projected needs of the target group and operating and administration costs. Naturally they seek the highest budget level they can argue for. Housing budgets may be periodically increased when the state provides a Cost of Living Allowance, but generally do not change significantly, regardless of changes in the individuals served. The “rate” is not individualized, but is “rolled up” across an agency’s settings. Given the nature of funding and the length of time some houses have been in operation, there is wide variance in the rates different agencies are paid, a variance that is not explained by the different levels of need of the different people served. Medicaid’s Federal paymaster, the Centers for Medicare and Med-

icaid Services, (CMS) recognizing best practice (and economics) now require that states implement individualized budgets, that the Money should Follow the Person and that the services be as much directed by the person themselves as possible.

These three elements will shape the future of all services, including housing. Consolidated Supports & Services (CSS) is the funding conduit created under the 1915(c) HCBS waiver of 2009 to facilitate self-direction, functionally based assessment and money following the person. Implementation has been slow to catch on around the state, primarily due to the institutional bias embedded in our congregate funding model, but the current reformation underway will eventually require that CSS, or something like it, becomes the norm. OPWDD funding streams for individualized housing will thus become more flexible, but in addition individuals and families need to access the whole range of public and private sources of housing support. These include an individual’s public benefits, like SSI, but also their own earnings as we move to an “Employment First” goal for all. These earnings may be modest and they need to be optimized to ensure benefit continuity but there is nothing that confers self-esteem quite like a paycheck. We need to mobilize family resources. In

the past there were strict limits on how family resources could be utilized for support. This was to avoid inequities arising when a privileged family might offer a resource, - a house for example, in exchange for a lifetime of service provision for their son or daughter in a group home. Once the provision of services and the ownership of real estate are separated however, there will be more flexibility around the use of family assets, assets we need to draw on as state budgets will not be expanding to meet the growing need for services. We need to explore models for housing used by the aging community, the long term homeless, communal living, shared living and ways to provide support that is customized to the person rather than to the provider.

The prospects for housing for people with ASD & I/DD can be daunting but they are also exciting. We are entering a new chapter, moving on from the vestiges of the institutional system to genuine inclusion and independence. There will be a new set of risks and challenges, but individualized housing is here, we are on the path already.

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**Board Member from [page 5](#)**

her office setting and on campuses, which sparked her passion and drive to commit to focusing on adults with autism.

It was through her experience at Jawonio that Susan was inspired to develop a private practice working with adults on the autism spectrum. Combining all of her experiences, her energy, ideas, and her love for this group of individuals, Susan focused her sights on a more independent role intending to go into private practice with the freedom and less restrictive rules of working for an organization. A bit of “luck” came her way as she was invited to work for a summer as the Interim Director for Disability Services at Rockland Community College, which allowed her to transition into her private practice. It should also be noted that a significant influence on her desire to work with adults with autism stemmed from her family experience of having a nephew who was diagnosed at a young age with autism. Sue and her “sister” grew together in the

process of learning about this “mysterious” condition. “Mac” recently graduated from high school and is currently attending college and doing quite well. His father, who is quite successful and was never officially diagnosed with autism, has come to understand his own related issues and the family works constantly to improve social challenges for both father and son.

In her practice, Susan currently serves about 20 clients in a variety of capacities, consults with a variety of professionals and organizations, and co-facilitates a support group for young adults in Westchester, NY. She has also run transition groups for high school students in Rockland County. In addition, Susan has taught various courses in the behavioral health field at Mercy College and has given presentations at numerous organizational and higher education events to both students and faculty. This fall she will present for the second time at a conference for graduate students hosted by Long Island University’s graduate counseling program.

Susan’s unique approach is a combination of current evidence-based practices, networking, community-based immersion, advocacy, teaching, working with families, counseling, consulting with agencies and disability services, goal setting and skills-based training, and social, career, academic and life planning. She constantly updates herself on the latest interventions through literature review, by attending conferences and through collaboration with colleagues and adults with autism, recognizing that the field is evolving at a rapid pace.

Years ago while at Jawonio, Susan became alarmed by the numbers of families coming to her for support for their adult children who were really struggling. She tried to say to her colleagues that it was vital to begin preparing for this group to transition out of high school, indicating that a “tsunami” was forthcoming in the next decade and we were woefully underprepared. Susan’s intuition was correct and today her focus is on meeting the needs of her clients and families to help improve their futures and lives. She feels that we are

in a phase where our understanding of autism is rapidly gaining traction but knows we have a long way to go. In some ways, Susan says, “We must educate individuals with autism, their families, employers, rehabilitation specialists, state vocational agencies, healthcare providers, educators, housing experts and society at large to embrace the many unrecognized talents and gifts that individuals with autism have to share with the community.” Susan’s good friend and colleague who was diagnosed with stage 4B cancer (a missed diagnosis for a year) often says, “I would have loved to have had someone with autism whose job it was to read my radiological slides, because I know without a shadow of a doubt they would have picked up on the cancer earlier.”

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**Normal from [page 21](#)**

Every once in a while he would take his fingers out of his mouth long enough to screech at my sister to make sure her dogs were not going to break loose. Sarah, good aunt that she is, took this all in stride and soothed him by saying the dogs were away, he was safe, not to worry. I, terrible mother that I am, barely noticed, mostly because this is how Jack is every time we visit my sister and I’m used to him. Also because she had the best chocolate cake with sugary white frosting I’ve ever had, so I was distracted.

At one point I stood balancing my second slice of cake and chatting with a guest, who pointed out how *normal* Jack seemed, how high-functioning he is. I looked over at my son, who just then had leaped on top of my brother-in-law’s eighty-year-old-five-foot-tall-a-hundred-pounds-soaking-wet Italian uncle’s back because he thought he heard one of the dogs coming up the stairs. I set my cake down, and walked over to apologize to Uncle Joey and untangle my nine-year old’s legs from the stunned man’s bony hips.

Yep, that’s really normal.

Time and time again I am struck by people’s need to smooth down autism’s prickly feathers, to soften the corners of rigidity and anxiety and language delays by saying *he looks normal*. I think it’s a natural instinct to try and fit Jack into the mold of ordinary, regular, typical. To normalize him. I tried to do it myself in the early days, when I was a terrified new mother and he a wordless toddler. But slowly I’m learning how counter-productive it is to shove a square Jack into our round world, how heartbreaking and painful and wrong it feels.

Last February we were stuck in the house on a snowy Sunday afternoon. When we finished lunch I told the kids they needed to find something productive to do, that the television and Wii were finished for the day. After a lot of groaning and negotiating, they all headed off in different directions: Joey to his Lego table, Charlie and Rose to a game of chess, Henry to his jigsaw puzzle of the United States. Jack pulled out a long-forgotten Christmas gift; a calendar-making kit.

I wandered into the kitchen where he was coloring, and stopped to admire his

work. I was touched to notice he’d included all of our birthdays and drew a picture of the person and their favorite gift for that particular month. And in that moment, I had an odd thought. Sitting at the kitchen counter, watching him painstakingly draw a Lego brick for Joey in March, I thought, *I am so glad he has a diagnosis*.

Because, if Jack didn’t have a diagnosis, if we went along trying to pretend he was fine and normal, I would not be sitting in my warm kitchen praising his project on that wintry day. I would be stressed out, wondering why he doesn’t color in the lines by now, why is he always playing alone, why doesn’t he answer me right away when I ask him what his favorite color is.

I would spend all of my time concentrating on what he is *not*, rather than what he *is*.

This doesn’t mean I’ve lowered the bar or set sub-par standards for him—quite the opposite. Jack’s diagnosis of autism spectrum disorder motivates me to constantly figure out how to help him be the best version of himself possible. But that version may never really be normal, and that’s just fine with me.

Because I don’t want normal. Normal won’t tell me that Thursday is red ([www.carriecariello.com/what-color-is-monday](http://www.carriecariello.com/what-color-is-monday)) and the last time we went to the movies was on February 22<sup>nd</sup>, 2013 and help me understand the meaning behind sexy pancakes ([www.carriecariello.com/2013/02/04/sexy-pancakes](http://www.carriecariello.com/2013/02/04/sexy-pancakes)). Normal won’t inspire me to look for the Wyoming license plate.

Maybe you’re wondering how the rest of the day went at my sister’s house. Eventually Jack settled down, and Joe hoisted him on his back and took him down to the basement to peer into the room where the dogs were staying. While Joe calmly pointed out how gentle the dogs were, Jack alternated between covering his ears and clinging to his shoulders. But he stayed there with his father, quieting down just long enough to say *they look tired today*.

Oh, and before we left I had a third piece of cake. That’s totally normal, right?

*“What Color Is Monday?” is available on Amazon.com and BarnesandNoble.com. You can also follow Carrie on her weekly blog: [www.WhatColorIsMonday.com](http://www.WhatColorIsMonday.com) and [Facebook.com/WhatColorIsMonday](https://www.facebook.com/WhatColorIsMonday).*

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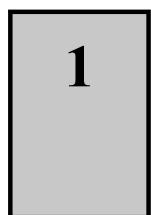
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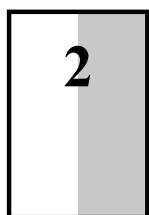
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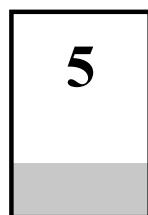
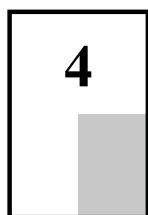
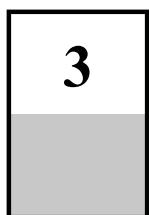
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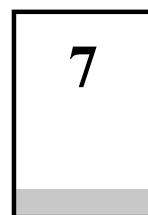
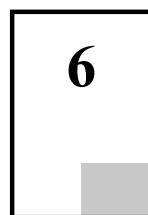
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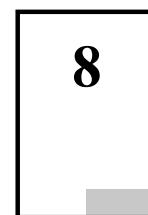
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