

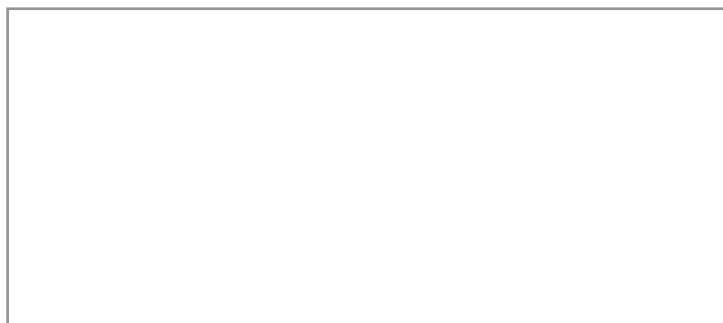


Winter/Spring 2016

Creating a Lifetime of Abilities For People with Disabilities

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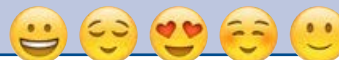


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Technology has made it possible for friends and family to see all of the wonderful things that are happening at ARC of Rockland in real time.

For that reason, we will no longer publish Highlights & Happenings in *ARCLIGHT* Magazine. Instead, we urge you to *like* us on our various Facebook pages: ARC of Rockland, Prime Time Schools of Rockland, A Taste of Rockland, Strawtown Jewelry and ARC HealthResources. Please visit our websites at www.arcofrockland.org, www.primetimeschools.org and www.strawtownjewelry.com. Whether you are at work, at home, or out jogging. Whether you find us on your phone, your ipad or your laptop—wherever you are—we're right there with you.



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From the President

Richard S. Sirota

With the current serious reduction in government funding, NYSARC chapters throughout the state are seeking innovative ways of bringing in dollars to maintain programs. Simultaneously, the impending closure of sheltered workshops has created the need to explore new employment opportunities for the people we support.

When a well-known local jewelry store went on the market several months ago, ARC of Rockland saw the potential purchase as a profit-making endeavor and the chance to provide meaningful job training for people with intellectual and other developmental disabilities. The story on page 4 is a testament to creativity, both literally and figuratively, as ARC of Rockland joins the ranks of entrepreneurs.

From our perspective, Strawtown Jewelry is far more than a charming shop with a lovely display of unique bracelets, rings, earrings and necklaces. We see Strawtown Jewelry as a metaphor for inclusion. The

term inclusion has long been used to describe the ways in which people with disabilities ought to be viewed in the realms of education, housing and employment. As the owners of a retail store, inclusion takes on even broader meaning.

Situated as it is, in the heart of New City, Strawtown Jewelry is clearly an integral part of the business community. People of all abilities will work there. Equally important, the people who work at Strawtown Jewelry will, in all likelihood, purchase coffee from the place across the street, order lunch from the restaurant around the corner, frequent the store down the block. People of all abilities who work at Strawtown Jewelry will come to know the proprietors and customers of other businesses. And those proprietors and customers will come to know us. As the proud owners of Strawtown Jewelry, ARC of Rockland is a visible, viable part of the community. And isn't that the essence of inclusion?



From the Chief Executive Officer

Carmine G. Marchionda

Those of you who have been loyal *ARCLIGHT* readers for many years will notice a change in the contents of this magazine. Beginning with this issue, *ARCLIGHT* will feature a series of in-depth articles of local and national concern to people with intellectual and other developmental disabilities. We introduce this concept with a look at the ways in which education, research and health care are approaching the topic of autism spectrum disorders (ASD), particularly in connection to high school graduates.

Also new to *ARCLIGHT* is the Annual Report which you will find in the center of this publication. We hope you will take a few minutes to read about our 2015 accomplishments. A listing of the year's many generous donors may be found on pages 12-13 of the Annual Report.

The advent of Facebook has eliminated the

need for a Highlights & Happenings section in *ARCLIGHT Magazine*. To learn about the daily goings-on at ARC, please visit any of our several Facebook pages at *ARC of Rockland*, *Prime Time Schools of Rockland*, *ARC HealthResources*, *A Taste of Rockland* and *Strawtown Jewelry*.

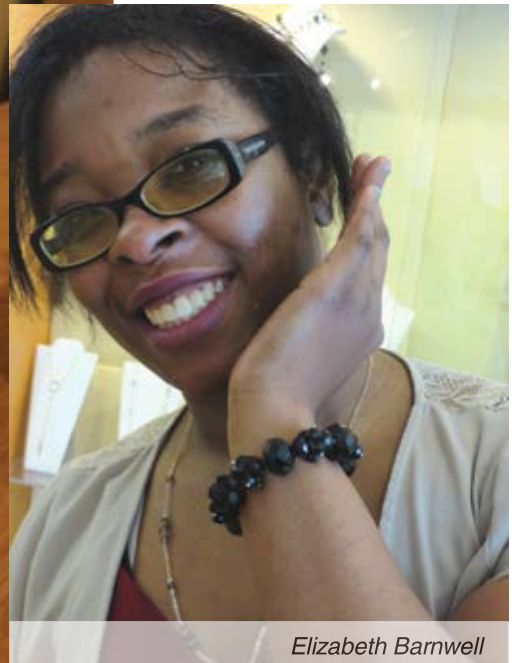
As has been the case for a number of years, *ARCLIGHT Magazine* is available in electronic form on our website at www.arcofrockland.org. However, we continue to believe in the value of the printed page—hence, our twice yearly publication of a tangible version of *ARCLIGHT Magazine*.

Some of the programs and services described in the following stories might serve as blueprints for future projects to be established locally. We invite you to contribute your creative ideas, your comments and concerns as together, we shape the future of ARC of Rockland.

STRAW TOWN Jewelry

Under New Ownership

"For many years, ARC of Rockland has been successful in encouraging members of Rockland's business community to hire people with disabilities to work in shops, stores and other venues throughout the county," says ARC Chief Executive Officer Carmine Marchionda. "Now it is time for ARC to lead by example."



Elizabeth Barnwell



Rochelle Braunstein

As the new owner of Strawtown Jewelry, ARC pledges to maintain the high quality of merchandise and the spirit of warmth for which this New City shop is known. “We are hiring qualified people with and without disabilities to work in the shop,” notes Mr. Marchionda. “This is the first of a number of business ventures we intend to pursue.”

Rochelle Braunstein is enjoying her first experience as an employee in the jewelry business. “I like jewelry, and I like wearing it,” she says with a smile. Ms. Braunstein is eager to take on her new responsibilities. “When a customer comes in, I say ‘Good morning or good afternoon. Can you tell me what you would like to see?’ And then, I show them something and see if it is to their liking. And when they leave, I say, ‘Have a nice day.’”

“We expect to hire eight to ten people to work in the shop on a rotating basis,” explains Kathy Canter, ARC Senior Director of Job Placement Services. “As with any other job prospect, we meet with applicants who have expressed an interest in a position with Strawtown. If we feel the person is qualified, we arrange for an interview with the Strawtown management team.”

Selling jewelry is just one aspect of the business. While some workers will learn to make beaded jewelry to be sold in the shop, others will help customers select items. Still others will be positioned at the register. There are labels to be affixed to boxes and bags, inventory to be polished and items to be

arranged in cases and on counters. ARC’s job coaches will help to ensure that the employees become proficient at their assigned positions.

“The fact that Strawtown Jewelry is located in the heart of the business district is a plus,” says Mr. Marchionda. “We look forward to getting to know our neighbors and meeting with new customers and customers who have been Strawtown Jewelry patrons for years.”

In 2015, Ellen Arkin, owner of Strawtown Jewelry for more than a quarter of a century, announced her imminent retirement to Florida. However, she stayed on in an advisory capacity for several months to shepherd ARC through the initial stages of ownership. Ms. Arkin says she will miss Strawtown Jewelry, but is pleased to have sold to ARC of Rockland. “They will do a great job at running the business, and I like knowing that they will employ some people with developmental disabilities.”

Strawtown Jewelry is located at 40 South Main Street in New City. www.strawtownjewelry.com. 845.358.4911. ■



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On the Spectrum *Higher Education for People with Autism*

Throughout the country, an increasing number of colleges and universities are offering an array of supports for people with autism spectrum disorders. In some instances the schools are partnering with other segments of society, including private donors, to create pathways for people to earn degrees towards the goal of gainful employment. The following stories provide a brief overview of some post-high school opportunities.



First Place

Arizona-based First Place® is receiving national attention for its innovative approach to issues of housing, employment, lifelong education and research through its first mixed-use property, First Place-Phoenix.

Denise D. Resnik is co-founder of the Southwest Autism Research & Resource Center (SARRC), the parent of an adult son with ASD and founder of First Place-Phoenix. “There is no ‘one size fits all’ solution for young adults transitioning from high school,” says Ms. Resnik. “First Place is not for individuals who require a medical home or who do not need support to live independently. First Place is designed for about 80 percent of people with ASD who fall between these two groups—those individuals who have some communication abilities and who can enjoy the benefits of living within the greater community. In the case of First Place-Phoenix, that also means a more urban setting.” Ms. Resnik and her team have spent 15 years



researching viable residential solutions. “I believe the autism community today is where the country was 40 years ago with senior housing,” she says. “We need more models for people in different settings, with varying features and at a range of price points.”

Upon completion, First Place-Phoenix will comprise three interrelated uses: 50 studio, one and two-bedroom apartments for residents; a Transition Academy for 32 students; and a 10,000-square-foot

Leadership Institute. Situated in the heart of Phoenix within walking distance to public transit, and slated for completion in late 2017, First Place-Phoenix is being funded by a \$25 million capital campaign that includes public, private and charitable sources.



The Transition Academy

Tuition for the two-year First Place Transition Academy is \$42,000 per year and includes the cost of rent, 40 courses focused on independent living, interpersonal skills and career readiness and the experience of living independently. The fee is private pay, however, Ms. Resnik says discussions are underway with government sources regarding possible help in reducing costs.

Says Ms. Resnik, “The apartments serve as independent living classrooms. The community-at-large represents a model learning lab equipped with natural supports.” The Transition Academy currently offers courses at GateWay Community College in Phoenix with plans for expansion to other college campuses.

In advance of the completion of First Place-Phoenix, an affordable living apartment complex launched in partnership with the Foundation for Senior Living in 2015, is a beta site for the First Place Transition Academy. Seniors and adults with ASD are next-door neighbors. Courses are developed and taught by First Place’s operating partner, SARRC, together with First Place Executive Director Jeff

“The apartments serve as independent living classrooms. The community-at-large represents a model learning lab equipped with natural supports.” —Denise D. Resnik

Ross and Leadership Institute Curriculum Specialist Valerie Paradiz, PhD. All students are engaged in paid internships or volunteer employment.

Dr. Paradiz has a diagnosis of ASD and is the parent of two young adults with ASD. In addition to her consulting practice, she serves as part-time director of the Autistic Global Initiative, a division

Continued on page 10

Continued from page 9

of the Autism Research Institute, and she is a national board member of Autism Speaks.

Upon completion in 2017, the First Place mixed-use property will house the Transition Academy.

First Place Apartments

The apartments reflect the research conducted by Ms. Resnik's team, including design goals and guidelines set forth in the "Opening Doors" report, co-published in 2009 by SARRC, the Urban Land Institute and Arizona State University. The apartments will feature an on-site wellness center equipped with a private telemedicine kiosk with computer access. "We are partnering with hospitals and clinicians in providing comprehensive training to support individuals with autism in managing their health and wellness," says Ms. Resnik. "By doing so, we are also training the medical community to better serve individuals with autism."



graduate and doctoral students from Arizona State University and Teach for America (TFA) alumni to conduct research or fulfill graduate practicum requirements. "They will provide direct support to residents and demonstrate what it means to be a good neighbor in a neuro-diverse community,"

"Our goal is to make more options available to more people. It is stultifying to try to do only one thing for everybody with ASD." —Valerie Paradiz, PhD

says Ms. Resnik. Fellowships are paid positions, and include rent in the apartments.

"The intent is to put forward information, based on new models, to support policy and decision-making at Federal and State levels," states Dr. Paradiz. "Annual symposia will bring together researchers and leaders who will share information and collaborate on policies and projects devoted to adult life on the spectrum." Additionally, Dr. Paradiz notes, "We are developing curricula and real-estate models to spur adaptation and replication across the country."

Ms. Resnik echoes this sentiment. "We need everyone participating," she says. "We need all parties at the table to increase capacity and options." ■

National Leadership Institute

The third component of the First Place Project is the Leadership Institute, intended, in large measure, to train direct support professionals and health care providers, advance research on best practices and public policy and assist other communities in opening doors to more options for people with ASD. "Our goal is to make more options available to more people. It is stultifying to try to do only one thing for everybody with ASD," says Dr. Paradiz. "We need many choices and locations, and we need to demonstrate results rather than limit ourselves by prescriptive policy."

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RUTGERS University Launches Autism Initiative for Adults

Employment and Housing on Campus

If all goes as planned, 2018 will see the establishment of the Rutgers Center for Adult Autism Services (RCAAS) on the grounds of the University's Douglass Campus in New Brunswick, NJ.

The project is a partnership between private donors and the Graduate School of Applied and Professional Psychology (GSAPP) at Rutgers University. The RCAAS will take advantage of the many resources already available on campus for individuals with Autism Spectrum Disorders. One such resource is Project: Natural Setting Therapeutic Management (NSTM), which is affiliated with GSAPP and provides consultation services in a variety of community settings. "The Center for Autism will be cutting edge because it will be built right on the campus," says NSTM Assistant Project Director Andrea Quinn, PsyD.

"We can take advantage of the expertise available at Rutgers to enhance the lives and daily experiences of the men and women who will populate the program."

Mel Karmazin, former CEO of Viacom, CBS and Sirius XM Radio and his daughter Dina, Executive Director of the Mel Karmazin Foundation, are spearheading the private fundraising aspect of the project—the cost of which is projected at \$35 million.

Ms. Karmazin's son Hunter was diagnosed with autism at age two. Says Mr. Karmazin, "The Rutgers Center will offer adults with autism a one-of-a-kind support program that makes independent living and a fulfilling life possible. It will rise to the challenge of giving program participants the tools they need to achieve their potential—from earning a living to navigating social interactions to building meaningful relationships."

Architects are beginning to work on plans for the Center this year. According to Dr. Quinn, the Workday Program and Building will support up to 60 adults and the Residential Building and Program will house 20 adults—all of whom will participate in the Workday Program alongside 20 Rutgers

graduate students in an integrated community setting.

"Our mission is to train future psychologists and social workers," says Dr. Quinn. "For graduate students interested in gaining experience in working with people who have autism spectrum disorders (ASD), both

the Workday Program and the Residential Program will serve as field placements." The graduate students will help adult participants learn to navigate the campus, provide job coaching and facilitate social skills groups. Job coaches will be paid as part of their coursework through internships and externships and will include undergraduate and graduate students studying psychology, education and social work,

"The Center for Autism will be cutting edge because it will be built right on the campus."

—Andrea Quinn, PsyD

among other disciplines.

“The Center is an attempt to build a community on campus,” explains Dr. Quinn. “The transportation system at Rutgers provides access to meaningful employment opportunities in the University’s dining halls, libraries, recreation centers and on the University’s working farm.” A pilot vocational program with five or six participants is set to launch in late 2016. Based upon individual eligibility, participants in the Workday Program will be funded through the New Jersey Division of Developmental Disabilities.

Mary T. Chow is Assistant Dean of Advancement, Graduate School of Applied and Professional Psychology. According to Ms. Chow, “A primary purpose of RCAAS is to build a robust vocational

training program within the Workday Program, providing highly customized and individualized supports. We hope to train approximately 50 Rutgers undergraduate and graduate students annually to develop a pipeline of future professionals who can go on to provide high-quality services.”

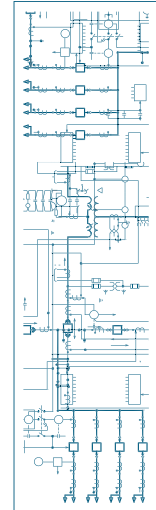
The Residential Building and concurrent Program are expected to commence three to four years after implementation of the Workday Program. The residence will be designed for life span living—with the length of stay based upon individual preference.

Says Dr. Quinn, “The overall goal of the Rutgers Center for Adult Autism Services is to provide a quality experience for the participants and to train the new generation of professionals who will serve adults with ASD going forward.” ■

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Choosing a College *The Quest for Affordability*


“The short answer is that there is nothing quite like First Place or what Rutgers University is doing for young adults with autism spectrum disorders,” says David Kearon, Director of Adult Services for Autism Speaks, one of the country’s most well-known advocacy organizations. “We are hoping that as these all-encompassing projects get off the ground they will be replicated elsewhere.”

One of the chief drawbacks to college attendance is the financial burden. “When you have to pay full tuition of \$40,000 or more and, when additional supports might cost another \$12,000, the fees can be prohibitive.” Mr. Kearon points out that some scholarships are available for people with ASD through Autism Speaks. He recommends that students consider applying to colleges offering federal student aid through a Comprehensive Transition and Postsecondary Degree Program (CTP) approved by the U.S. Department of Education. Among other stipulations, the Department of Education website states that CTP programs must be “designed to support students with intellectual disabilities who want to

continue academic, career, and independent living instruction to prepare for gainful employment.”

To ensure the best possible chance at a successful college experience, Mr. Kearon says, “It is absolutely essential that the students receive effective transition services.” Some outside programs are available on and off campus to provide additional assistance for a fee. Once such initiative is New Frontiers in Learning (www.nfil.net), the mission of which is “to provide the highest quality education and social support services to young adults who learn differently... Personalized programming is designed to meet the needs of students who benefit from individualized supports in the areas of academic learning, executive functioning and social interaction at the secondary and postsecondary levels.”

“Our supports allow students to prepare in advance for the rigors of college,” says Samantha Feinman, Director of New Frontiers in Learning. “Because we work with a secondary and postsecondary population, students can apply for and attend colleges based on their plan of study or personal



“People should lobby for colleges to offer more programs that enable young men and women with ASD to qualify for financial aid.”

—David Kearon

campus preferences. We work collaboratively with the schools and families to assist students in learning how to access the supports available on their respective campuses, while providing the supplementary supports students need in order to be successful.”

High costs are clearly an impediment to the

possibility of higher education. Mr. Kearon offers several suggestions to improve prospects for prospective students. "People should lobby for colleges to offer more programs that enable young men and women with ASD to qualify for financial aid," he says. He contends that the likelihood of matriculation is increased when the student receives the necessary supports in either academic and/or independent living skills. "But the majority of colleges or outside companies offering meaningful programs are out of the financial reach of most families." Mr. Kearon advises families and agencies supporting people with ASD to communicate with the powers that be at local colleges and universities—particularly community colleges. "Educate the decision makers about the types of supports that students with ASD may require. Colleges are seeing more and more applicants on the autism spectrum. They are coming to realize that given some soft supports and independent living instructions, students with ASD can be successful." ■

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Setting the Pace

Support for People with ASD on Campus

Through a program aptly named OASIS (Ongoing Academic and Social Instructional Support), students with Autism Spectrum Disorders (ASD), learning disabilities, nonverbal learning differences and related challenges receive assistance with coursework, college life and career opportunities at Pace University.

OASIS is located at the University's School of Education building on the New York City campus. Janet Mulvey, PhD, is Director of the program. "The goal is to help students adapt to academic and social aspects of college life," she explains. "We look at how we can best help students transition from dependence to independence."

Forty students are currently enrolled in OASIS. More than half have autism spectrum disorders. Graduate and Master's level students in the liberal arts, technology and business colleges, meet one-on-one with OASIS students for an hour or more each day to assist with time management and organizational skills and help the young men and women gain the attributes necessary to communicate effectively with professors. Coaches are paid on an hourly basis and on average work with four students for a total of twenty hours per week.

In the realm of socialization, OASIS gives the young men and women in the program an opportunity to get to know one another within the OASIS program and assists them in finding their places within the broader University community. "Fridays at OASIS are pizza lunches," says Dr. Mulvey. The group then engages in social

activities on campus and/or the city.

As is the case with most colleges and universities, Pace operates an Office of Disability Services. While the OASIS program works hand-in-hand with that office, it is a stand-alone program.

Eligibility for OASIS begins with a student's acceptance to the University. If a student chooses to join OASIS, he or she is asked to sign a Family Educational Rights and Privacy Act (FERPA) allowing the OASIS professionals to communicate with professors, parents and others outside of the University when the need arises. Says Dr. Mulvey, "We feel very strongly that parents are our partners in this program."

For many young people, college is the first time away from home. People with ASD may find the experience especially daunting. "Our OASIS Housing Coordinator works closely with the University Housing Director to make sure that the students are comfortable within the residential setting and they understand the roles and obligations of having a roommate," says Dr. Mulvey. OASIS gives freshman the choice of rooming with other students enrolled in the program. Dr. Mulvey notes that by their junior year, most students are comfortable rooming with peers from within the larger student body.

"While most of the participants communicate verbally, some have difficulty understanding social cues, nuances and cynicism," states Dr. Mulvey. Small class sizes within most disciplines at the University are a plus for young men and women with ASD. "And we work to educate the professors about autism. We communicate to let them know which students with ASD are in their classes."

When there are issues involving academics, the



“We work to educate the professors about autism. We communicate to let them know which students with ASD are in their classes.”

—Janet Mulvey, PhD

OASIS staff speaks to professors on behalf of or in conjunction with the students. “The expectation is that by junior year, the students will communicate with the professors on their own,” explains Dr. Mulvey.

To help acclimate new students, an OASIS Social Coordinator gives incoming freshman an overview of the more than 100 clubs and organizations on campus. Dr. Mulvey notes that involvement in organizations serves as a stepping stone for future involvement in the broader community.

Now in its sixth year of operation, OASIS boasts a retention rate of 77.7 percent. “That is a little higher than that of the University,” says Dr. Mulvey. Most OASIS enrollees graduate within five years rather than the traditional four years.

At the beginning of sophomore year, students meet with an OASIS Internship Coordinator to find volunteer internships within the community. During junior and senior years, OASIS tries to secure paid

internships. “The intent,” says Dr. Mulvey, “is to make sure that the students have employment when they leave Pace.”

Even before freshman year, OASIS gives incoming freshman an opportunity to ease into college life by attending a six-week summer Social Literacy course taught by the OASIS Educational Coordinator. Topics include an overview of appropriate social skills, a look at what to expect in college and which campus resources might prove helpful. The cost for the summer session is \$780.00.

The cost for OASIS is \$12,000 per year above the annual tuition rate of \$41,600. Some tuition assistance is available for eligible students through an Autism Speaks grant and other sources.

According to Dr. Mulvey, one future OASIS initiative will be geared towards potential employers. “Research has confirmed that students with ASD and other disabilities may have some difficulty with time management, but they will do the job, are talented and productive,” says Dr. Mulvey. “We want employers to understand what they will be missing if these young men and women are not accepted into the workforce. Employers should look at the individuals' strengths and talents and recognize them for what they are... they are assets.” ■

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SUNY Purchase

Putting Autism on the College Map

Fifty students are enrolled in the Autism Spectrum Disorders Program at Purchase College. Now in its ninth year of operation, the program is free to participants. Lauren Greiner, PhD, is Program Coordinator. Her office is housed in the College's Career Development Office—a location which aligns with the goal of helping students become employment-ready prior to graduation.

Intellectual pursuits are important to college life. However, Dr. Greiner says, "Fifty percent of what we do in this program is focused on socialization. College is more than just getting a 4.0 GPA." She meets weekly with many of the students enrolled in the program to discuss issues of concern. "I meet more frequently with freshmen and transfer students to help them with the transition, although I see many students regularly for four years."

When first joining the program, an individualized plan is established based upon the student's needs and goals. A graduate student intern helps participants resolve issues related to socialization and independent living. Graduate interns are required to finish 600 hours

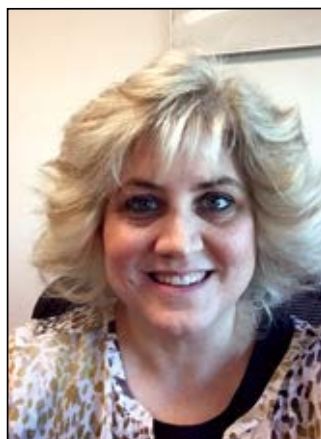
of direct and indirect services to complete Master's Degrees and be licensed in New York State. Dr. Greiner verifies completion of the interns' hours.

A Peer Mentorship program component pairs sociology and psychology majors with students who have autism spectrum disorders (ASD). "The mentors work one-on-one introducing people to clubs, facilitating social events, occasionally tutoring, helping students gain organizational skills and connecting them with resources on campus," explains Dr. Greiner. "We use a big-sister, big-brother model. The mentors develop relationships with the students, introduce them to their friends and act as a bridge between the students in the program and other students at Purchase." A peer mentor may recommend clubs and accompany the student to several meetings until he or she feels comfortable attending on his or her own. "The ASD program is a community, and the peer mentors and

graduate interns are essential members," says Dr. Greiner. Depending upon the number of hours they work each week, peer mentors receive between one and four credits.

A Social Skills Support Group meets weekly

during which time students with ASD offer support and feedback to one another. Participants who require additional help with academics may request tutoring or coaching through the Learning Center on campus.



"Honestly, I think a piece of what makes a person with ASD succesful in college and career is feeling comfortable with the diagnosis of autism spectrum disorder."

—Lauren Greiner, PhD

When the situation merits her intervention, and with permission from the specific individual, Dr. Greiner touches base with professors. “Often professors misperceive a person with ASD as having a behavior problem or a mental health issue,” she explains. “Some of the students have difficulty advocating for themselves. I do a lot of one-on-one consultation with the professors. And frequently, the professors come to us for advice.”

Dr. Greiner notes that Purchase is committed to diversity and inclusion. “Sometimes I hear from the Admissions Department saying that a family wants to speak to me to help the student decide if this is the right place for him or her. I am happy to talk to prospective students and parents. Diversity is one of Purchase’s core values,” says Dr. Greiner. “The College is dedicated to incorporating this message into every aspect of college life. Disability is one type of diversity.”

The Autism Spectrum Disorders Program sponsors annual seminars with the focus on networking, resume building and interviewing. Recently, Dr. Greiner’s staff has begun tracking graduates. “We would like to know what, within the college experience of people with ASD, leads to employment.

“Over the years, I have seen that the students who are most successful are the ones who accept that they are on the spectrum. These students tend to avail themselves of services, identify and seek accommodations when necessary, engage in more extra-curricular activities and incorporate the other students they meet through the program into their social network. A subset of students with ASD come to the College with the idea that this will be a fresh start, and they will no longer have any of the difficulties they had in the past. They insist that they are not on the spectrum and want nothing to do

with other students with the diagnosis. Sometimes it works. In many cases, though, they do poorly academically and socially because they are unable to connect.” Says Dr. Greiner, “Honestly, I think a piece of what makes a person with ASD successful in college and career is feeling comfortable with the diagnosis of autism spectrum disorder.”

The Autism Spectrum Disorders Program is funded in part by the College and by a private grant from the FAR Fund which, according to its website at www.farfund.org, “awards grants to non-profit organizations working toward far-reaching goals in their efforts to support the social and emotional well-being of the people they serve... The Fund has a particular, but not exclusive, interest in developmental disabilities as an area of funding.” ■

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Transition Boot Camp *at Westchester Community College*

With the goal of increasing the retention of students with Autism Spectrum Disorders (ASD) and helping to ensure the success of incoming students, Westchester Community College (WCC), created Transition Boot Camp.

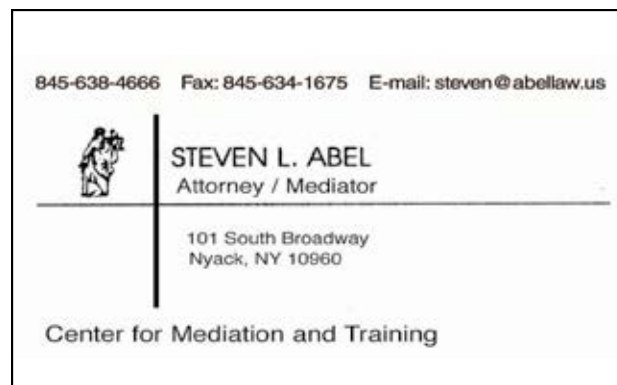
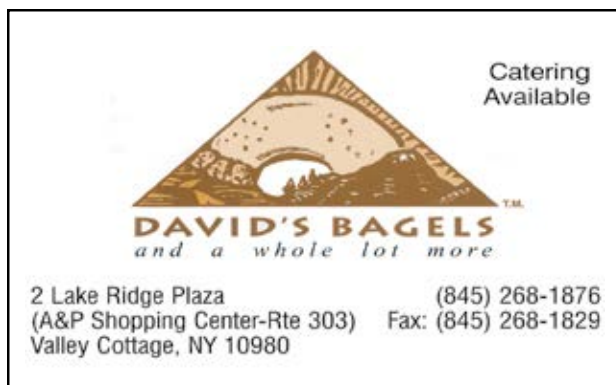
Now in its fourth year, the free program takes place during the last two weeks of August just prior to the beginning of the school year.

According to Theresa Revans-McMenimon, Counselor for students with ASD, Transition Boot Camp focuses on writing skills, social skills and appropriate college behaviors. "The goal of the Boot Camp is to increase student access, involvement and success. It is a means of bridging the gap between high school and college, so students can hit the ground running on their first day at WCC," says Ms. Revans-McMenimon. "Boot Camp enrollment takes place on a first-come, first-served basis and generally caps off at about 12 students."

Beginning in the fall of 2016, Westchester Community College will partner with College Steps, a non-profit organization providing support

for students living with social, communication, or learning challenges. "This is a win-win program for all involved," says Ms. Revans-McMenimon. An on-site College Steps Program Coordinator will train students within the broader WCC student body to become peer mentors. "The mentors will be paid an hourly rate by College Steps for the time spent helping students learn to weave their social network into the fabric of the community college setting." Mentors must have completed one year at WCC and have a GPA of 3.0 or higher. College Steps is currently affiliated with seven colleges in New England and Virginia. According to Ms. Revans-McMenimon, Westchester Community College will be the first college in New York to offer this program. Students with ASD who participate in the College Steps program may also enroll in Transition Boot Camp.

Two additional Transition Boot Camp sections for students with disabilities other than ASD were made available during 2015. Says Ms. Revans-McMenimon, "It is the goal and hope of the Disabilities Services Office of Westchester Community College to continue offering the additional Transition Boot Camps for summer 2016." ■



ARC of Rockland and RCC

to Create College Path for People with ASD

"In upcoming months, we hope to collaborate with leaders at Rockland Community College regarding the creation of a campus-based program geared towards high school graduates with autism spectrum disorders (ASD)," says ARC Chief Executive Officer Carmine Marchionda.

"Our intention is to bring together representatives from other agencies serving people with autism, members of the Rockland County community, families and high school graduates with ASD. ARC of Rockland has many years of experience in working with children from pre-school through age 21 with ASD. We know that there are many high school graduates with



"We look forward to mapping out a program that gives students with autism a chance at college and career."

—Cliff L. Wood, EdD

autism who deserve to pursue their dreams of a college education."

Dr. Cliff L. Wood, President of RCC says, "We are aware of successful programs currently available on other college campuses, including one at Westchester Community College (see story page 20). While we have not yet begun to formulate a concept for

this endeavor, it is clear that peer-to-peer mentorships are a viable model. Students with ASD may need assistance in acclimating to campus life. Some may require tutoring. We will speak with representatives from colleges across the

country to understand

best practices, and we will count on input from our Accessibility Services Department. We look forward to mapping out a program that gives students with autism a chance at college and career." ■

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Rockland District Attorney's Office Leads the Way

Programs for People with Developmental Disabilities

It might be extreme frustration, the feeling of being sidelined in every aspect of life, or the overwhelming desire to be accepted by peers that lead a person with a developmental disability to commit an act that is against the law.

“Right now, we are seeing more and more people with developmental disabilities coming into the criminal justice system,” says District Attorney Hon. Thomas P. Zugibe. “Until recently, the options have been to dismiss the charges, or prosecute a person who may not have understood the crime—let alone the consequences.”

Mr. Zugibe credits Judy Rosenthal, Director of Fiscal and Program Operations for the Office of the District Attorney, for helping to create the Alternative to Incarceration Program for Defendants with Intellectual and Developmental Disabilities. The program is one of several such innovative programs including the Drug Treatment Alternative to Prison (DTAP), the Mental Health Alternative to Incarceration (MHATI) and a Veterans Alternative to Incarceration (VATI).

“The alternative program for people with developmental disabilities is designed to help defendants better manage their behavior in order to

stay out of the criminal justice system,” says Ms. Rosenthal.

In order to achieve the desired results, the District Attorney's office has partnered with the Rockland Independent Living Center in New City, NY. A case manager headquartered at the Independent Living Center and paid for by the DA's office assesses the defendant's needs in areas such as employment, housing and anger management, among others. The case manager develops an individualized service plan and connects the person with appropriate service providers.

“The whole idea is to have the (criminal) conduct stop so that the public is safe and the defendants can lead productive lives.”

—Hon. Thomas P. Zugibe

The alternative program carries with it a 12-month minimum for a misdemeanor charge and an 18-month minimum for felony charges. Charges are adjourned in contemplation of dismissal for participants on the

misdemeanor track who successfully complete the 12-month program. “This allows people to move forward with no criminal conviction history,” says Mr. Zugibe. Participants on the felony track who successfully complete the 18-month program will have their charges reduced or dismissed.

“The focus of the District Attorney's office has changed over time,” explains Mr. Zugibe. “We emphasize crime prevention and offer diversionary programs. We remain aggressive on the prosecution





“The alternative program for people with developmental disabilities is designed to help defendants better manage their behavior in order to stay out of the criminal justice system.”

—Judy Rosenthal

side—taking a hard approach with violent crime, public corruption and narcotics activities. But in most of the remaining cases, we seek to address the underlying causes—which, in the long run, make the public safer. If the accused comply with the diversionary programs, we let them out from underneath the criminal charges. The whole idea is to have the (criminal) conduct stop so that the public is safe and the defendants can lead productive lives.”

To date, the Alternative to Incarceration Program for Defendants with Intellectual and Developmental Disabilities has a caseload of ten. “The level of engagement and the positive response from the participants has been amazing,” says Ms. Rosenthal. “We are the first in the country to develop a model based on problem solving.”

Mr. Zugibe has held a long-time interest in bettering the lives of people with developmental disabilities. He has been a member of the ARC of Rockland Board of Directors since 1988 and served as president from 1990 to 1993. Prior to his position as District Attorney, Mr. Zugibe worked for two decades in private practice with an emphasis on personal injury and commercial litigation. Between 1981 and 1987, he served as a prosecutor in the Rockland County District Attorney’s Office, where he directed the Narcotics Division and Major Offenses Division before being promoted to Executive Assistant District

Attorney. He also served as West Haverstraw Village Justice from 1989 to 2007.

Ms. Rosenthal holds Master’s Degrees in Counseling and Psychology from Columbia Teachers’ College and an ABD from Fordham University in Counseling Psychology. Prior to her position with the District Attorney’s

office, she oversaw an addiction treatment and prevention program for 17 years.

For more information regarding the Alternative to Incarceration Program for Defendants with Intellectual and Developmental Disabilities (ages 16 and older), please call Ms. Rosenthal at 845.638.5683. ■

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Supporting Research *What the Future Holds*

The Autism Science Foundation (ASF) is a not-for-profit organization dedicated to funding and catalyzing innovative autism research while adhering to rigorous scientific standards and values. The team at ASF serves to increase awareness of autism spectrum disorders and the latest developments in autism science and advocate for the needs of the individuals and families affected by the disorder.

Alison Singer, president and co-founder of ASF, has both a professional and personal interest in furthering autism research. Her daughter Jodie, 18, was diagnosed with autism at age two. She is also the legal guardian of her brother, Steven Tepper, who is diagnosed with autism and is a participant in ARC's Day Habilitation Division. Ms. Singer holds an MBA from Harvard. "I'm a business person," Ms. Singer states. "I have learned the science because I've had to."

"At ASF, we support the work of young and emerging researchers and innovative scientists who might struggle to find support from more traditional funding sources," says Ms. Singer. "We fund research across the board, from gene discovery to treatment models and service delivery models. The common through line is that it will advance our understanding of autism

and lead to the development of better treatments. We want the best and brightest young talent."

The percentage of individuals born with ASD appears to be on the rise, but some of the increase may be attributed to more accurate and timely diagnosis. "We have broadened the diagnostic criteria of autism to include people with ASD who do not have intellectual disabilities," explains Ms. Singer. "Now those who suffer from the deficits at the core of autism include individuals with average, above average and genius IQs. These are the people who used to suffer in silence."

Research has revealed specific risk factors for autism, including premature births. Ms. Singer explains, "More and more babies are being born prematurely because we have the technology to save them. We also know that there is additional risk of giving birth to a child with ASD if you are an older mother or father. And we know that siblings of

brothers or sisters with autism are at greater risk for autism."

A recent initiative by the Autism Science Foundation called the Autism Sisters Project is gaining attention nationwide. The project is based



"A lot of advances in science are the result of not being afraid to look. We can learn from breast cancer research and Parkinson's research. We don't have to reinvent the wheel." —Alison Singer

on the 4-to-1 ratio of males to females diagnosed with ASD and the discovery that some of the genetic deletions or duplications known to cause autism are equally distributed among boys and girls.

"For many years we looked at the 4-1 ratio and thought that there was something about being male

that increased the risk of autism. Now, we are turning that assumption on its head and are wondering if being female confers protection against autism. There are girls who have these genetic deletions or duplications that should cause autism, but the girls do not have any of the clinical symptoms,” says Ms. Singer. “The thinking is that these girls must have something that protects them against it. If we can find this ‘female protective effect,’ we could harness it to protect both boys and girls. The Autism Sisters Project is an effort to build a cohort of unaffected sisters of people with ASD—the idea being that many of them may have no clinical symptoms but still carry the genes that cause autism. A simple saliva test provides the answer to the genetic question being asked in this study.”

Although the causes of autism spectrum disorder remain unknown, recent research has identified several genes associated with ASD. Ms. Singer notes that “By finding these genes, and learning about the proteins that are misregulated because of deletion or duplication of the genes, we can start to identify real targets for treatment that will get at the core symptom of autism. This is done by creating animal models, altering the genetic makeup of mice and rats in the lab, so that they have the genetic deletions and duplications associated with autism.”

Ms. Singer explains that these mouse and rat models show many of the symptoms of autism, including learning deficits, inability to vocalize, and

lack of interest in other animals. “The amazing part of this process is that we are finding compounds and medications that restore function in the animal models and many of these medications are now being tested in FDA-approved human clinical trials. Soon we may have medications that target the core deficits in autism. That’s a huge amount of progress compared to when Jodie was diagnosed. I remember asking her doctor about medication and him telling me a little Prozac might make her feel better, but he didn’t really know how or why. That’s not a satisfactory answer.

“A lot of advances in science are the result of not being afraid to look. We can learn from breast cancer research and Parkinson’s research. We don’t have to reinvent the wheel,” says Ms. Singer. “The goal is precise and personalized medicine based on genetic makeup...and that is a long way from ‘a little Prozac’ being the answer. Good science is the answer.” ■



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Autism and Genetic Studies

Science and Technology

“What is going on now in autism research is some of the most exciting clinical and neurobiological science happening anywhere. The findings are coming out of laboratories and consortia where we are finding genes, figuring out what is happening with these genes, identifying what drugs might work to reverse the deficits, and trying the drugs in models and, where appropriate, in patients,” says Joseph D. Buxbaum, PhD.

Dr. Buxbaum is Director of the Seaver Autism Center for Research and Treatment at the Icahn School of Medicine at Mount Sinai and leader of the Autism Sequencing Consortium. Founded in 2010 by Dr. Buxbaum, the Consortium is an international group of scientists who share autism spectrum disorder (ASD) samples and genetic data.

“We know that a large part of autism risk is genetic—but not simple genetics like Mendel’s peas,” says Dr. Buxbaum. “It is complex, and some of it is caused by spontaneous new mutations. Because this is a complicated genetic disorder, we need larger and larger samples to find those genes. The greater the number of samples, the greater the chance of locating mutations. The race to find the causes... and ultimately, the drugs to help mitigate the effects of autism have a great deal to do with the size of studies. It is a numbers game. The more people who participate in studies, the more people who are willing to contribute their time (and perhaps their blood or saliva)...the more quickly we will move forward.

“Basically, the human genome has approximately 22,000 genes—a vast amount of DNA real estate,” explains Dr. Buxbaum. “Those 22,000 genes occupy only about two percent of the DNA landscape. The genes live in deserts of no genes. The rest of the material regulates the genes. Most of the mutations occur in the two percent.” The Autism Sequencing Consortium has amassed 22,000 samples of DNA and intends to expand to 50,000 samples.

Among the current studies on recently discovered genes are those relating to the SHANK3 gene. Simply stated, that gene provides instructions for making a protein found in the brain. The protein plays a role in the functioning of synapses where nerve-cell-to-nerve-cell communication takes place.

“I want to understand how a mutation in the SHANK3 gene affects the function of the brain. The only way to understand what that means is to study the development and functioning of the brain. By creating a lot of mice with that mutation, we can study every aspect of their brain function—when the mice are developing, or older, and we can begin to understand what is going wrong. We started a preclinical treatment trial in mice with SHANK3 mutations and realized that a particular drug was helping them. We are in the middle of a study to see if the drug is also helpful in humans.”

Dr. Buxbaum was trained as a molecular neurobiologist at the Weizmann Institute of Science in Israel. “I really loved the field and wanted to stay with pure science. Then I started to get involved in studying Alzheimer’s Disease. When I moved to Mount Sinai in 1997, science had just begun to suspect that some of the new technology to analyze DNA would help us find answers to many psychiatric disorders, including



The more people who participate in studies, the more people who are willing to contribute their time... the more quickly we will move forward."

—Joseph D. Buxbaum, PhD.

autism. Then-Chair of the Psychiatry Department (now President and Chief Operating Officer of the Mount Sinai Health System), Kenneth L. Davis, MD, has always had an entrepreneurial spirit. He said, "The DNA is there. If you want to apply your methods of neurobiology or molecular genetics to the study of autism, go for it." And so I did. I got involved, and technology kept on moving forward."

In addition to his work based upon SHANK3, Dr. Buxbaum and his team are involved in the Autism Sisters Project (see story page 24). Funded in part by the Autism Science Foundation, the Autism Sisters Project looks at families in which two siblings carry the gene mutation but only one has autism.

"We know for a fact that girls are much more able to tolerate autism mutations," says Dr. Buxbaum. "We would be happy to find that girls have a protective factor. Anything that is protective is good to know about because it can be a means to help others. Maybe we can mimic it—simulate it. But the design of the study is such that no matter what we find, we will get good data by having a large sample."

Of his role in the study of autism, Dr. Buxbaum states, "There is something to be said for having a meaningful and dynamic life." Throughout his career, Dr. Buxbaum says he has "met and interacted with many, many families of people with ASD. At some point, you see them as your extended family.

The feeling that this work of the Seaver Autism Center can be helpful to others gives value to our workday. Every day, when I come to work, I am confronted with different questions and issues. Whatever I know today will be obsolete in a year from now. I can look forward to reading some really exciting paper next week that blows me away. And that is fun."

The Autism Sequencing Consortium receives support from the National Institutes of Health (NIH), including the National Institute of Mental Health (NIMH), the National Human Genome Research Institute (NHGRI), and the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). ■

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Autism From Pediatric to Adult Medical Care *Easing the Transition*

“One of the issues parents have voiced is that there are not many options when their children grow out of pediatric services,” says Dr. Galit Sacajiu. “They describe feeling as though they have fallen off the face of the earth when their son or daughter is considered to be an adult requiring adult medical care.”

Medical Care

Dr. Sacajiu is Medical Director of ARC HealthResources, a practice geared exclusively towards people with intellectual and other developmental disabilities, including young men and women with autism spectrum disorders (ASD).

During her three-plus years at ARC HealthResources, Dr. Sacajiu has come to recognize that the continued

involvement of families in the medical care of their adult children is essential. However, she notes, “Most medical professionals working with adult populations are not trained to deal with families as active players in a patient’s care.”

The extent of parental input varies with the individual. In the majority of instances, Dr. Sacajiu sees the patient first. “But even if a person is capable of handling his or her healthcare needs, I sometimes

ask if it is okay to speak with his or her parent.”

The length of time Dr. Sacajiu devotes to each patient is often longer than the amount most physicians allocate to a visit. “We spend as much time as necessary to make people feel comfortable,” she explains. “I never use the first appointment with a person to conduct a complete physical exam. I would rather have a conversation than spend time doing an EKG and blood tests on someone who doesn’t know me.”

According to Dr. Sacajiu, “Listening to the patient—whether or not the patient can communicate verbally—is essential to good care.” Sometimes it is the subtle cues, a nod of the head, the set of the

shoulders that gives the doctor a sense of what the patient wants to express. “I feel fortunate to work in a place where families do not need to worry about the way in which we treat our patients. At ARC HealthResources,



“Most medical professionals working with adult populations are not trained to deal with families as active players in a patient’s care.”

—Dr. Galit Sacajiu

we have created a space where our patients love to come see us, and we love to see them. We strive to know how to ask questions and extract what is clinically meaningful from their answers. Whatever the field of medicine, every doctor—and maybe especially the primary care doctor—has to be an advocate for the patient...to be on the side of the patient and the families whenever they need us.”

Dr. Sacajiu offers two suggestions to improve the



“There is a clear need for pediatricians to pass on relevant medical information to adult care physicians.”

—Karen Kuhlthau, PhD

state of medical care for adults with special needs. “Medical schools would do well to provide training to better equip physicians with the skills necessary to care for people with ASD and other developmental disabilities. No one teaches us to appreciate the great impact people with disabilities have on our society, the incredible achievements they make in their personal lives.” She is concerned by the fact that a significant number of 21 and 22-year-olds with ASD and other disabilities are still being seen by their pediatricians. “It is important for us to treat these patients as adults with special needs because they are adults, they are not children.” Some of Dr. Sacajiu’s sentiments may be found in professional literature, including the work of Dr. Karen Kuhlthau.

Insights Based on Studies

Karen Kuhlthau, PhD, is Associate Professor of Pediatrics at Massachusetts General Hospital and Harvard Medical School and is the principal investigator of a Maternal and Child Health Bureau study. Entitled Transition to Adult Services for Youth with ASD, the study was designed to determine whether teenagers with ASD are prepared to transition to adult medical care and what impediments exist.

The team talked with 55 pediatric and adult medical providers who treat patients with ASD, and they conducted surveys with 194 families in the Northeast and the Midwest. The study found that just 60% of families reported receiving any transition services, with the most common service

being speaking with a doctor about health care needs changing as the youth enters adulthood (33%). The outcome of the study offered several recommendations and addressed barriers to transition from pediatric to adult care. Dr. Kuhlthau discussed some of the findings.

“There is a clear need for pediatricians to pass on relevant medical information to adult care physicians,” she states. “The potential for a seamless transfer of electronic records offers hope.

In addition to pertinent health information, records might include statements such as, ‘I don’t like to be touched.’ Or, ‘I need a quiet space.’”

Data suggest that when a patient with ASD is between 12 and 14 years old, the pediatrician should begin discussing the long-range goal of having the child transition to adult medical care with both the patient and his or her parents. “Yet, it can be difficult finding adult-care physicians who regularly treat people with developmental disabilities,” comments Dr. Kuhlthau. “In defense of doctors—they have very tight schedules, and demands on their time aren’t getting any smaller. There are short time frames in which they can see patients, and reimbursements don’t do a great job of allowing doctors to spend twice as much time with one patient over another.” Because patients with ASD sometimes have difficulty in crowded or noisy situations, Dr. Kuhlthau says, “Physicians might schedule patients with ASD for the first or last visit of the day when the waiting room might be less crowded.”

Although there are medical practices such as ARC HealthResources that focus on people with developmental disabilities, “We still need garden variety doctors to be willing to care for people with all sorts of disabilities,” says Dr. Kuhlthau. “Training is one solution. We need to give doctors a level of comfort and knowledge in treating people with ASD and other disabilities.” Training could

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begin in medical school, but requisite maintenance certifications for physicians might also deal with the topic of ASD.

A simple card to be carried by patients with ASD might help both doctor and patient. Says Dr. Kuhlthau, “The card might include phrases such as: “I have difficulty communicating when I am upset.””

Finally, pediatricians who regularly care for patients with ASD might sponsor training sessions for pre-teens or teenagers informing them of future issues, including the need for adult care. “As much as possible, young adults with ASD should be responsible for their health care,” says Dr. Kuhlthau, “It is the job of parents and schools, pediatricians and providers to prepare teenagers for that opportunity.

“I think a lot of us find our doctors by word of mouth. It is worth talking to other people who might know which practitioners are open to caring for people with ASD and other developmental disabilities. I think the first piece is to start thinking about transition pretty early. Families have a lot on their plates, so that is really hard. My hope is that we can integrate people with ASD into society, but there is no one-size-fits-all answer. It’s a challenge.”

Mental Health

Mental health is an important aspect of overall adult health care. Dr. Russell Tobe is Director of Psychiatry at ARC HealthResources. In addition to this role, he is Director of Outpatient Research at the Nathan S. Kline Institute for Psychiatric Research in Orangeburg, NY, and he is an Instructor of Clinical

Psychiatry at Columbia University.

“People with autism spectrum disorders may have normal intelligence, just as people with intellectual disabilities may not have autism spectrum disorders,” explains Dr. Tobe. While he cautions against generalizations, Dr. Tobe notes that during the time of transition from high school to adulthood, people with ASD are vulnerable. “There will be a higher probability for the development of behavioral and mental health symptoms when young people who have previously had eight hours a day of structured



The idea is to try to create a series of positive supports and structures around the individual and the family. Pragmatically, that is a pretty challenging thing to do.” —Dr. Russell Tobe

intervention in a school setting are abruptly removed into a less structured setting. Young adults might experience anxiety, sadness, anger, agitation and everything that goes along with that.

“Most families are old pros at dealing with their loved ones with ASD, but there can be a sense of helplessness when you pull 40 hours of services. How do you plug that hole?”

Of particular concern to Dr. Tobe and other professionals is the paucity of structured post-high school programs for young adults with ASD—particularly those who do not have intellectual disabilities. “It was once thought that intellectual disability among people with autism spectrum disorders was much more common,” says Dr. Tobe. “The newest epidemiologic data demonstrate that most people with ASD don’t have intellectual disability. Despite this, they may not have the social skills required to navigate independent living, job applications and employment. Many times, their parents are supporting them. Many with ASD need

ongoing, structured vocational training and intensive psychotherapeutic services.” ARC of Rockland is trying to address that need through both its Abilities Initiative (see Annual Report page 6) and ARC in Motion (see Annual Report page 3).

Dr. Tobe is a proponent of teamwork in treating all of his patients. “Generally our approach at ARC HealthResources is collaborative. We involve therapists, residential staff people, other medical personnel and families. If people are not supported by a stimulating environment, they won’t continue to progress at achieving their goals and they may lose ground in gains they made previously. The idea is to try to create a series of positive supports and structures around the individual and the family. Pragmatically, that is a pretty challenging thing to do.”

To learn more about ARC HealthResources, please call 845.267.0110 or visit ARC of Rockland at www.arcofrockland.org. ■

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