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**DIRECTOR’S MESSAGE**

CAROLINE I. MAGYAR, PH.D., Associate Professor of Pediatrics, University of Rochester

Welcome spring!!! It has been a long, cold winter, but here at the Rochester Regional Center for Autism Spectrum Disorder (RRCASD) we used the time indoors to develop some new informational resources, assist a wide variety of parents with information and referral, and offered 6 webinars on various topics. We also continued to follow the status of licensure for Board Certified Behavior Analysts (BCBA), professionals trained in Applied Behavior Analysis (ABA) and the treatment of children and adults with ASD. I am pleased to inform you that Governor Cuomo signed into law the licensing credential for BCBA, which should improve access to services provided by BCBA.

As many of you may know, April is Autism Awareness Month and there are a lot of community events occurring around the region in honor of those affected by ASD. Be sure to check our website www.golisano.urmc.edu/rrcasd-nyautism for a listing of, or links to, various events. Also, check out the recent NYS initiative called the Olmstead Implementation Plan. The Plan provides guidance to multiple state agencies to increase opportunities for individuals with disabilities including those with ASD to live more integrated lives within their communities. The Plan requires agencies and their regional offices to work collaboratively to address integrated housing, employment, transportation, community services and other important issues related to disability rights. With Plan implementation we can expect that increasing numbers of individuals with ASD will work, shop, and recreate in our community. As a result of this Plan, multiple state, regional, and local programs are engaging in new activities that can affect individuals with ASD as it relates to community living. To learn more about this state initiative visit the website http://www.governor.ny.gov/olmstead/home.

Finally, this edition of the Newsletter includes information on a range of ASD topics and issues relevant to our community and region. Here are some highlights. In the RRCASD Activities & Resources section you can learn about the 2013/2014 Webinar Series, which was a huge success with 464 individuals from around the state registering. In the For Your Information (FYI) section I review Applied Behavior Analysis (ABA) and its role in ASD treatment. I provide a link to the Autism Speaks website where you can learn more and download a Tool Kit on ABA treatment. In the Regional Program and Agency Highlights section two regional activities are highlighted. One describes advocacy efforts by Family Advocates United, a grassroots organization addressing various gaps in services for individuals with ASD and other developmental disabilities. The other describes a new regional program called the START Program that will be providing a wide range of supports and services with a focus on crisis support to assist in maintaining the individual’s level of community integration. The Research & Practice Update section provides information about the new report out on evidence-based interventions in ASD. Finally, in the Question and Answer section I respond to a parent asking about supports to help her with care coordination. I hope you find the information in these sections useful.

**RRCASD ACTIVITIES & RESOURCES: UPDATES ON OUR 2013/2014 ACTIVITIES**

We were busier than ever this year! Our community education activities included the 2013/2014 Webinar Series. This is the second year we offered this free webinar series and it has been a huge success! This year we offered 6 webinars covering topics from understanding adolescence in ASD, to employment supports, and updates on evidence-based practices in the school setting. To download a copy of any of the handouts from these webinars, please visit our website at www.golisano.urmc.edu/rrcasd-nyautism, call us at 1-855-508-8485, or e-mail us at rrcasd@urmc.rochester.edu. We plan to offer free webinars again next year and will be sending out the ‘Save the Date’ for the 2014/2015 Webinar Series in late August.

Continued on Page 2...
**RRCASD Activities & Resources: Updates Continued...**

The RRCASD website continues to be a point of contact for our region with over 1000 unique visits since July 2013. If you haven’t visited the website recently, please check it out at [www.golisano.urmc.edu/rrcasd-nyautism](http://www.golisano.urmc.edu/rrcasd-nyautism). There you will find a wide variety of community education resources including copies of our Newsletters and Information Sheets from previous years. In addition, be sure to check out our 2 self-guided training DVDs, one on Daily Visual Schedules, and the other on Teaching Social Skills Using Direct Instruction. These DVDs can be for personal use and/or for staff training. Each contains a short, narrated power point presentation, and a Study Guide with reproducible forms for use in your work or the care of someone affected by ASD. This spring we will be working at improving our website so that visitors can better identify and access the various resources we have posted. Check out our new format later this spring and send us an e-mail with your feedback.

**Features: For Your Information (FYI): Applied Behavior Analysis (ABA) in ASD Treatment** by Caroline I. Magyar, Ph.D., Associate Professor & Director, RRCASD

With the passing of the NYS Autism Insurance Reform legislation last year and the licensing of Board Certified Behavior Analysts (BCBA), I thought it would be important to provide a brief overview of Applied Behavior Analysis (ABA) and its role in ASD treatment.

Applied Behavior Analysis (ABA) is the clinical application of principals of learning. It developed out of decades of theory and research about how people and other organisms behave and learn. The result of all this research (past and current) has provided us with a scientifically-based set of methods for developing and modifying behavior. Behavior Analysts and Behavioral Psychologists are professionals trained to apply these methods of behavior change to meet the treatment and organizational needs of individuals and groups in diverse settings. For example, behavioral psychology has a long history of work in:

- The education of children, with and without disabilities;
- The treatment of children and adults with mental health, behavioral, and developmental disorders;
- Business/Organizations to provide leadership skills training; establish effective employee recruitment, training, retention procedures; improve productivity; improve employee satisfaction; and consult to marketing strategies.
- Medicine to prevent life-style related health conditions (e.g., heart disease, diabetes, obesity) and to improve compliance with medical treatment recommendations;
- Law enforcement to assist in describing and predicting criminal behavior;
- Military to develop behavioral profiles of terrorists and other enemy combatants.

Behavioral treatment methods continue to be researched and found to be effective for a wide variety of clinical needs. Because the practice of ABA continues to be informed by rigorous research this knowledge contributes to the establishment of standards for evidence-based practice for behaviorally-trained professionals. ABA has been applied in the treatment of ASD since around the 1960’s-1970’s (at that time ABA was called Behavior Modification). ABA has been applied to address improvements in the areas of cognition, language, speech and communication, social skills, and emotional and behavioral self-regulation. Methods have consistently been shown to be effective in ASD treatment. If you are thinking about obtaining ABA services for your child or an individual you care for/work with, it is important to be knowledgeable about the education and training that professionals need to practice behavior analysis.

If you would like to learn more about ABA treatment in ASD, and what credentials you should be looking for in a professional, visit the Autism Speaks website for a summary and additional relevant links: [http://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-ab](http://www.autismspeaks.org/what-autism/treatment/applied-behavior-analysis-ab)

**Regional Program/Agency Highlights:**

Family Advocates United  
*by Pat Muir, Parent Advocate*

Family Advocates United is a group comprised of family advocates from numerous community organizations around the Finger Lakes region. The group engages in a range of grass-roots advocacy activities. Their goal is to inform the enactment of legislation mandating supports and services critical to the needs of individuals with developmental disabilities, including ASD, and the families who care for them. For example, on Tuesday, May 20, 2014, the group will hold its first statewide flag demonstration at the NYS Capital in Albany. The purpose of this event is to increase awareness of the growing shortage of residential and day program service options in NYS as a result of continued budget cuts to state social service programs. If you are interested in attending or in assisting with planning other events in Albany, Rochester or Buffalo, please contact Pat Muir at [familyadvocatesunited@aol.com](mailto:familyadvocatesunited@aol.com)

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Regional Program/Agency Highlights: Continued...

Systemic, Therapeutic, Assessment, Resources (Respite) and Treatment (START) Program
by Pamela Overdorf, LMSW

The START Program of the Finger Lakes Region of NYS, coordinated by Chemung ARC, is a collaborative network of agencies that provide supports and services for individuals with developmental disabilities, including ASD, with and without behavioral health needs, with the goal of maintaining the individual’s current level of community integration. The START Program will provide timely and effective supports in the community for individuals’ eligibility for services through the Office for Persons with Developmental Disabilities (OPWDD). The Program is modeled after the University of New Hampshire’s Center for START Services (http://iod.unh.edu/Projects/start/description_history.aspx). The core functions of the NY Finger Lakes START Program include:

- Establishment of formal linkage agreements with various agencies and organizations that provide services to individuals with developmental disabilities including developmental organizations, behavioral health organizations, law enforcement groups, school districts, hospitals, psychiatric centers, and large medical groups.
- Provision of a mobile crisis management service, which will make available within 24 hours a clinical team to address behavioral emergencies/crises.
- Establishment of a Cross Systems Crisis plan for individuals, families and providers based on individualized assessment and the development of a plan for intervention strategies, a process for the prevention of additional crises, and guidance on simplified access to supports and services across various systems of care needed by the individual.
- Provision of emergency short-term respite, both in and out of the individual’s home, for purposes of stabilizing behavioral difficulties and preventing a crisis.

The START Program will begin receiving referrals mid-summer 2014. To obtain additional information about the Program, please contact Ms. Pamela Overdorf; LMSW, DHS Clinic Director, Chemung ARC, Elmira, NY 14901 OR Phone: (607)734-6151, extension 155.

Research Update: New Report on Effective ASD Treatment
by Caroline I. Magyar, Ph.D., Associate Professor & Director, RRCASD

Recently a large review of the ASD treatment literature (Wong et al., 2013) was published based on a systematic review of over 1000 treatment studies published between the years 1990 and 2011. Research reviewed focused on children, birth to 22 years of age, with most of the research conducted on children younger than 15 years. The reviewers used specific criteria to determine if a treatment method was considered ‘evidence-based’ and they determined that approximately 27 methods met this criteria with a few methods showing promise, but needing more research. What this means in practical terms is there is a wide variety of methods and strategies that can be used to treat the learning, communication, social, and behavioral difficulties experienced by individuals with ASD. Most of the methods found to be effective were derived from Applied Behavior Analysis (ABA), Behavioral Psychology, and Developmental Psychology. These findings add to what we already knew about effective ASD treatments based on 2 other large reviews published in 2001 and 2009. The information provided in this review (and past reviews) provides much needed information about what methods could and should be considered by early intervention, school, and vocational training personnel working with children and adolescents with ASD in the home and/or school settings; and with young adults who are preparing for employment as part of their ‘life after high school’ transition plan. In practice, the selection of specific treatment methods for a particular individual should always be based on a thorough assessment of the individual’s strengths and needs and treatment goals defined with performance benchmarks for regular monitoring of progress. To learn more about effective ASD treatment visit the website to read/download the full report:


Rochester Regional Center for Autism Spectrum Disorder

Call toll free: 1-855-508-8485
Email us at: RRCASD@URMC.Rochester.edu
Visit us on the web: www.golisano.urmc.edu/rrcasd-nyautism

Our 17 counties cover portions of Western NY, the Finger Lakes, the Southern Tier, and Central NY. We proudly serve: Broome, Cayuga, Chemung, Cortland, Livingston, Monroe, Onondaga, Ontario, Oswego, Schuyler, Seneca, Steuben, Tioga, Tompkins, Wayne, Wyoming, and Yates Counties.
**Question:** My 7-year-old daughter has ASD and some medical and behavioral problems. Each of the professionals she works with have their own intervention plans and I often feel overwhelmed by the amount of coordination I need to do to make sure all professionals know what the others are doing to help my daughter. Do you have any advice to give me to help me feel less overwhelmed?

**Answer:** Individuals with ASD may present with other medical, developmental, emotional, and behavioral conditions in addition to their ASD so they will often require services from multiple providers working in different service agencies. Each service agency may have different procedures and requirements for accessing their services and different procedures for providing services. This means that the parent who is coordinating care needs to be aware of what agencies provide what services, how to access those services, and how to tie each service in with other services their child is receiving. This can be a daunting task! Some basic pointers that hopefully will reduce your feelings of being overwhelmed include:

- Work with your child’s primary care physician to set up a ‘medical home.’ This is a model advocated by the American Academy of Pediatrics and includes developing a collaborative relationship with the doctor who assists with identifying needed services for your child and communicates important care information to other providers.
- Ask your child’s primary care physician to sign you (your child) up for a patient version of the electronic medical record (EMR). EMR is a relatively new technology in health clinics/medical centers that can assist with coordination of care among the various medical providers your child sees and can reduce the amount of follow up you need to do with different medical providers. The patient version allows you to communicate and interact with all providers in that medical center through one electronic system.
- Engage a (Medicaid) Service Coordinator who can assist with identifying and coordinating resources that your child may need. He/she can help you understand the different services and assist with accessing them. The (Medicaid) Service Coordinator can also help you manage the various reports and documents that are often needed for obtaining much needed services.
- Establish a Home-School communication system to improve collaborative planning and problem-solving with your child’s school team. This can be a notebook/email that goes back and forth between you and the team on the specific areas of support/services in the school setting that your child needs. Communication should be frequent and assist with planning and problem-solving any areas of difficulty.
- In addition to asking each professional you work with to provide you with written documentation of the treatment goals, services and progress updates on your child, and to share those documents with other providers (with your permission), you should also keep a copy of all reports and a list of all contacts, by date, and in one location such as a 3-ring binder or electronic file. This will help you retrieve important information as needed for the time period indicated.
- Seek out a support group or individual counseling if you feel you would benefit from the support of others who are also providing care coordination and who may have some good advice based on their own personal experience. Contact the RRCASD and ask to speak to our Information & Referral Specialist. She will try to assist you in problem-solving care coordination challenges by providing information or identifying resources you may need.

*This resource is provided for informational purposes only. Information should not be used as a substitute for professional assessment and judgment. Although the information is believed to be accurate and reliable, all information is provided “as is” without warranties of any kind, either express or implied, including but not limited to merchantability, non-infringement or fitness for a particular purpose. The University of Rochester shall not be liable for any damages, including direct, indirect, special or consequential, which may arise out of the use of the information contained within this resource.*