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Board of Legislators

Department of Community Mental Health

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Commissioner

**Westchester County Autism Advisory Committee
Year-End Recommendations
April 1, 2009**

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I. Mission Statement

Autism is a complex, neurobiological developmental disability that is characterized by poorly developed verbal and nonverbal communication skills, unusual speech patterns, limited interest in social interactions often leading to social withdrawal. Individuals with autism often struggle to be flexible or tolerate even small changes in routines, experience sensory sensitivities, exhibit repetitive or ritualistic behavior and often focus on objects rather than on people. It occurs in all racial, ethnic, and social groups and is four times more likely to impact boys than girls. Symptoms can range from very mild to quite severe.

It is the fastest growing developmental disability in the country. In 2007, the CDC reported that 1 in 150 children born were being diagnosed with autism spectrum disorders (ASD).¹ This compared with 1 in 500 in 1996. People with autism need to be treated with a variety of interventions including but not limited to medical, educational, social and vocational services. Because autism and autism spectrum disorders last a lifetime and encompass a broad range of symptoms, services must meet the needs of children, adolescents, young adults and adults as well as address various levels of needs and supports. Often families must spend a burdensome level of energy and time in identifying services and resources for their family members with autism.

Today In *Westchester County, there are currently approximately 4,000 individuals living with ASD.*² Therefore, at the direction of County Executive Andrew Spano, the Westchester County Department of Community Mental Health convened an Autism Advisory Committee. It was comprised of parents, advocates and professionals knowledgeable in the field of autism. They met with the Westchester County Department of Community Mental Health on a monthly basis for the term of one year. Their mandate was to:

- assist the Department in identifying research, services, resources and funding mechanisms that would expand and enhance the opportunities for children and adults in Westchester County on the Autism Spectrum and their parents
- assess the existing services available to individuals and families in Westchester County and determine, based upon current trends, research and resources, where gaps exist in the current service delivery system and the types of services that will help to fill those gaps
- consider and propose a plan for a “clearinghouse” for services for use by individuals, families, and service providers seeking services for individuals on the Autism Spectrum.

This report reflects the work of the committee and includes the following recommendations:

- Declare Westchester County as an “Autism Friendly” County
- Establish a Westchester County Autism Family Resource Center
- Establish an Adult Advocacy Department
- Establish a Special Liaison for Adult Autism Services
- Develop a “How to” manual for Westchester businesses to successfully employ adults who have ASD
- Develop a post-secondary educational program for adults with ASD
- Broker the establishment of a specialized medical/psychiatric treatment facility
- Establish a Family and Service Provider Training Institute
- Establish an Autism Sensitivity Awareness Training Program for first-responders
- Maintain the work of the Autism Advisory Committee
- Provide the public an opportunity to review and comment on the recommendations of this report.

Recommendations and Rationale
Section A: Declare Westchester County, "Autism Friendly"

Recommendation: Declare Westchester County as an "Autism Friendly" County; a place to live, work, shop, to go to school and participate in community events, where all residents, "Think Autism."

Valued Outcomes:

- A public campaign will be launched to promote "Autism Friendly" businesses, organizations and services that are sensitive to the needs of individuals with autism and their families.
- Westchester County will provide incentives and motivation to local employers in shops, businesses and corporations who employ adults with ASD.
- Westchester County will encourage the employment of adults who are diagnosed with ASD, by providing a "How to" manual for Westchester businesses to guide/train them in making necessary adaptations to successfully employ adults with ASD.
- All county employees will receive basic awareness and sensitivity training in autism spectrum disorders starting with first responders, followed by all other county workers; court employees, transit workers, DMV, DSS, Section 8, all other department and agency heads and their office staff, legislators, and other elected public officials.
- Provide training opportunities where possible to the non civil service work force of Westchester County to equip all workers with basic knowledge of autism, enabling adults with ASD to make their individual contribution to the mission of being employed in an Autism Friendly County.

Why Westchester County Needs This:

Westchester County is impacted, as are all locales, by the current rate of diagnosis of autism. Residents of Westchester find family members, neighbors, fellow students and citizens struggling to overcome the daily challenges presented by this life long disability. Our schools, agencies, health care providers, organizations, civil service work force, places of work and worship, our parks, our neighborhoods and communities have witnessed the increase in autism and have been directly impacted by it. As a County we need to promote a collective awareness, sensitivity, acceptance and tolerance of people with autism in its many manifestations within our midst. We must make a commitment to improve the lives of individuals with autism and thus their families and care takers.

Westchester County needs to advance the image and practice of our residents' employees and business owners need to increase their knowledge base and understanding of autism and by so doing contribute to a county where people with autism are understood, recognized and permitted opportunities to become, wherever possible, contributing members of Westchester County society. Including people with disabilities in our community is beneficial for all county residents.

Section B: Establish an Autism Family Resource Center³⁴⁵⁶

Recommendation: Establish a Westchester County, comprehensive, physical (bricks and mortar) and virtual Autism Family Resource Center in which the County partners with other agencies focusing on ASD and serves as a hub of information and direction to constituents on diagnosis, treatment and services.

Valued Outcomes:

The Autism Family Resource Center will employ staff to be available full time by phone, in person or email to:

- Serve as the central service/first point of contact to help guide one through the maze of external agencies/service providers and service systems available across an individual's lifespan.
- Provide up-to-date and reliable information about service systems, services available, including but not limited to eligibility requirements, locations, fees, ages served, times of operation, insurance accepted and qualifications of providers.
- Empower constituents; strengthen families' advocacy skills, provide information and services in a style that supports and validates parents and caregivers, sensitive to the cultural and socio-economic differences amongst families in Westchester County.
- In partnership with other agencies, NGO's and service providers, serve as a clearinghouse for community education (conferences, training, workshops, lectures and newsletters).
- Develop an Education Resource Center within the Family Resource Center, including a point person for educators.
- Guide families in obtaining early identification of ASD.

Why Westchester County Needs This: The diagnosis of autism or an autism spectrum disorder catapults families into a state of dismay, often fear and almost always confusion. There are no clear roadmaps for individuals with autism and their families. From initial diagnosis, during the school years and throughout adulthood there exists an array of questions and concerns these families face, often compounded by pressures related to maintaining employment, managing the demands of other children in the household, social ties and extended family. Developing a plan for treatment and implementing it requires that caregivers not only have excellent "project management" skills but also have the ability to research, network, evaluate, negotiate and plan with multiple service systems; understand educational law and disability-rights; and have a command of medical and psychological terms and treatments.

To protect as well as insure civil rights to individuals with autism and their families, Westchester County need a "one-stop" resource to provide answers to families' questions, to guide them through the service delivery systems, to support them in managing the intense challenges of raising a child with autism.

Section C: Adult and Transition Services

Recommendation: Establish an Adult Advocacy Department within the Westchester County Autism Resource Center to advocate for adults with ASD and their family members, and to serve as a liaison with community resources and services focusing on adult-related issues.

Valued Outcomes:

- The Adult Advocacy Department will act as a clearinghouse for the dissemination of “best practices” to families and adult service providers. This will enhance the quality of services delivered to the autism community.
- The Adult Advocacy Department will synthesize information for the DCMH website about adult services and programs.
- Provide a roadmap of supports and services for individuals with ASD, across the lifespan.

Why Westchester County Needs This:

The growing population of children diagnosed on the autism spectrum will soon be adults, and for those who are already there, a crisis has erupted. While families with young children with autism face enormous challenges, the IDEA law requires that school systems provide a basis for supports and services to the child from 3-21 years of age. Once a child with ASD leaves the school system, in New York State he is considered an adult. Most do not attend college and most cannot live and work completely independently. At age 21, young people with ASD and their families are faced with trying to navigate a confusing array of Federal, state, county and private provider agencies in order to access essential services. The rising numbers of adults with autism, the expanding diversity of their needs, and the growing cost of adult services have made it imperative that Westchester ensures that the adult autism service delivery system reflects “best practices.”

Recommendation: Establish a Special Liaison for Adult Autism Services. This individual would assist families in understanding the transition planning process, the resources and programs serving adults with autism, and partner with adult providers ensuring that program environments, program activities and staff training is appropriate and specific to the needs of the program participants.

Valued Outcomes:

- Provide guidance to individuals with ASD and their families about the transition process and moving into a quagmire of services for adults with disabilities.
- Work with families to obtain the services individuals with ASD are entitled to through the school districts, adult providers, OMRDD, government entities and VESID to ensure meaningful, adult services are in place.
- Disseminate the most current information on transition services to families, service coordinators, school personnel and adult service providers.⁷
- Partner with the county's Transition Services Coordinator, the Aging-out Network, VESID, OMRDD, the new enhanced supportive employment programs, supportive employment agencies and local businesses to promote employment opportunities and supports for adults with ASD.⁸
- Promote the utilization of "best practice" techniques with all adult day providers.⁹

Why Westchester County Needs This:

All interested stakeholders should be able to access necessary and legitimate information in a timely fashion. Like all young adults, those with ASD need to be able to live as independent a life as possible. Yet most people with this disability will require moderate to extensive support throughout their lives. Pockets of services do exist for adults with disabilities, yet often the transition from the school system to the "adult" system is fractured. When families are knowledgeable about taking the appropriate steps at the correct time there is a greater chance for maximizing the child's potential while minimizing the time and expense required to support the transition process.

Because adult day and residential providers in Westchester County do not possess the necessary knowledge of the specific needs of adults with autism, this results in poor transitions plans, inadequate and outdated adult services, and missed opportunities for a fulfilling life for our citizens.

Recommendation: Westchester County should develop a county-based “How to” manual for Westchester businesses to include and make necessary adaptations to successfully employ adults with ASD.

Valued Outcomes:

- Provide a web-based “How To” manual ¹⁰for Westchester businesses that includes guidance on making necessary workplace adaptations to successfully employ adults with ASD.
- Partner with agencies to provide on-going workshops to potential employers, job coaches, adult provider agency staff and families that include concrete strategies and techniques that will assist adults with ASD in becoming employed. ¹¹

Why Westchester County Needs This:

While people with autism do have challenges, many are capable and interested in meaningful employment. While the number of adults with autism is rising, the number of successfully employed individuals with autism is very low. Research has shown that with the right supports individuals with autism can work in a variety of jobs, leading to more productive lives, less financial dependency on government and family supports, more natural social opportunities and better overall mental health. Potential employers and agency staff are lacking education and support in how to plan, train, find and maintain employment opportunities for individuals with autism.

These initiatives can lead to an increase in the number of individuals with ASD that are employed, which is beneficial to the individual as well as to our community.

Recommendation: Partner with local Westchester colleges and other educational institutions to develop a program for adults with ASD for appropriate post-secondary education to include academic, vocational and life skills instruction.

Valued Outcomes:

- Provide opportunities for adults with ASD to continue to pursue academic interests and/or to develop vocational and life skills necessary to be as independent as possible.^{12 13}
- Provide appropriate learning alternatives to current and often, unstimulating adult programs.

Why Westchester County Needs This:

Most students leaving high school are ill-prepared for independent, adult life and continue their education through post-secondary options (2 or 4 year colleges/vocational training programs, internships etc). Many individuals with ASD are also interested in continuing their education, yet they have few, if any formal opportunities to continue to learn and develop skills. They may have a particular educational interest or need on-going training in developing independent living skills, in managing their finances, living independently and in finding and maintaining employment. By definition of the autism diagnosis, they are often socially isolated and need supports in developing the social skills to connect with others, “to have a friend”.

Some are in unstimulating programs or are underemployed with little opportunity to make learning choices for themselves.

Recommendation: Broker the establishment of a specialized medical/psychiatric treatment facility for individuals with autism spectrum disorders.

Valued Outcomes:

- Bring stakeholders together, including staff from Yale, WIHD, YAI, NY Cornell/Columbia to establish a specialized medical/psychiatric facility to treat adults with ASD.
- Support the availability of trained behaviorists/ABA specialists who can provide to families, training and guidance in helping families develop realistic behavioral intervention strategies.
- A crisis support person will provide telephone support in emergency situations, reducing the need to involve the police.

Why Westchester County Needs This:

People with ASD have sensory and emotional regulatory challenges. As a result many can behave in ways that seem unusual and often not socially appropriate. Since there is no cure for autism, the current approach is to turn to neurological, psychological and psychiatric experts for help in dealing with challenging behaviors. At times there is a need for professional intervention to help the individual as well as the family address these behaviors. Currently there are no facilities in Westchester County that specialize in providing medical/psychiatric services to adults with ASD. Families report great difficulty accessing medical providers who are willing to work with their adult child with ASD.

When an adult with ASD exhibits challenging behaviors, it is far more difficult for a family to control their child's behaviors due to the physical size of the autistic person and their complicated emotional life. Often there is a co-morbid psychiatric as well as developmental delay complicating the individual's presentation.

Families' experiences indicate that when their adult child with ASD needs mental health services, there exists a shortage of treatment providers who have an expertise in adults with ASD. For those who have been hospitalized, there are few in-patient providers who understand the complexity of autism. These circumstances result in poor treatment outcomes which lead families to attempt to manage the behavioral demands of their autistic children alone. Physical altercations and emotional exhaustion are common and a growing concern as the parents of adult children with ASD age.

Additionally, families report hesitantly using the police as back-up when their child's behavioral outbursts threaten the safety of the child and/or those around him/her. They fear that the police may not have a basic understanding of ASD and have experienced police actions as exacerbating an urgent situation.

Adults with ASD have unjustly been placed into the criminal justice system, where legal services professionals have no understanding of and misperceive the unique behaviors and challenges of people with autism.

Section D: Service Provider Needs

Recommendation: Partner with other providers and/or local Westchester colleges to establish a Family and Service Provider Training Institute

Valued Outcomes:

- Sponsor no-to-low cost workshops for families and providers on autism awareness and sensitivity training.
- Sponsor no-to-low cost workshops for families and providers in best-practices, research based interventions.
- Advocate with NYS Department of Health to mandate that Early Intervention Service providers be appropriately trained and educated in evidence based practices such as ABA, TEACCH, and Positive Behavioral Supports.
- Advocate for school districts to encourage their special education staff to receive the same appropriate training and education in autism spectrum disorders;
- Encourage the development of an Autism Specialty Tract at local colleges¹⁴ with emphasis on evidence based and best practice interventions, so that educators and direct care providers can receive appropriate training and certification as an autism specialist.

Why Westchester County Needs This:

As the population of individuals with autism grows, an increasing number of families, staff, educators and service providers will face the challenges of effectively interacting with their children or the people they serve. Workshops that sensitize and provide education about the characteristics of autism/ASD and basic intervention strategies are critical.

Early and intensive behaviorally-based treatment, in particular the use of Applied Behavior Analysis (ABA), is effective in systematically teaching skills and reducing problematic behaviors. Since so many direct service providers are lacking training in behavioral intervention strategies, individuals with ASD often fail to receive quality services that could optimize their development and potential.

Recommendation: Establish an Autism Sensitivity Awareness Training Program for first-responders.

Valued Outcomes:

- Provide training for EMS, Fire Department and hospital staff.
- Use Role Call Briefing Video from Chicago PD to refresh awareness in police departments on a regular basis.
- Provide a panel of family members to speak with first-responders to sensitize providers to the unique characteristics of persons with ASD.
- Create an alternative to calling police as a first line of defense in pressing situations by establishing a point person in various agencies that is knowledgeable in ASD to help educate county employees.

Why Westchester County Needs This:

While the Committee acknowledges and appreciates the work of the Commissioner of Public Safety, Thomas E. Belfiore, for implementing the Autism Awareness Training for recruits at the Police Academy, this training needs to continue and expand. Contact with the police is often frightening for persons with ASD who might be unable to comply with verbal commands and react with agitated behavior to loud noises, yelling, or a change in routine. Frequently first-responders misinterpret the behavior of a person with ASD. Families' experiences indicate that the police are not sufficiently trained to understand and handle the needs of a person with ASD, often resulting in expensive and sometimes unnecessary hospitalizations¹⁵ or incarceration.

Section E: Other Recommendations:

Recommendation: Maintain the work of the Autism Advisory Committee as a task-oriented and problem-solving work group.

Goals:

- Provide assistance to County employees working towards recommendations of this report, by connecting staff with formal and grass-root autism organizations
- Explore additional funding opportunities to continue the development of supports and services offered through the County and its partners

Why Westchester County Needs This:

The members of the Westchester County Autism Advisory Group are advocates for individuals with ASD and bring a wealth of up-to-date information about autism. Some members are the parents of children with ASD and all represent a vast number of individuals and organizations that offer treatment, education, training advocacy and funding opportunities to the autism community.

Recommendation: Enable the public to view the recommendations of the Autism Advisory Group for comment and suggestions.

The formation of the "Autism Advisory Committee" was initiated at the request of Mrs. Judy Omidvaran, a parent of a young adult with autism. Here is a synopsis of her request:

III. Historical Framework

I requested the creation of a county committee, because of a culmination of a series of events that myself and my family have experienced over many years because of our very long journey to battle autism and rescue our beloved son, Sina, from the destruction of Sina's life by autism. Sina, who is with me everyday in spirit, is the true catalyst for the development of this committee because of the devastation to his life and his family. This long journey finally led me to cross paths with the County Executive, Andrew Spano on several occasions. The first was in April, 2007 when I attended an "Autism Speaks Kick-Off" luncheon. In December of 2006, Sina was a 28 year old man with High Functioning/Aspergers, who was encountering serious legal difficulties with the criminal justice system. He did not deserve to be treated so harshly for his transgression, yet because of the nature of the act and his severe developmental disability, he was being demonized by the local District Attorney who had no understanding of Asperger's Syndrome, nor cared to have an understanding about this disorder. Sina's lawyer, who was not making any headway with the local District Attorney to reduce the charges, recommended I reach out to people in the community who might assist us in penetrating through the District Attorney's rigid mindset.

I decided to reach out to County Executive Andrew Spano, who I knew would be the keynote speaker at the Autism Speaks luncheon. After his presentation I handed him a letter which explained the serious legal circumstances my son was involved in and pleaded for his assistance. I received a call from him several days afterwards saying he would assist Sina and our family in whatever capacity he was capable of performing. Because of Andrew Spano and many other persons who collaborated with us, the tide turned. Gradually a plan was put in place to have the charges reduced and eventually eliminated. Also, another major person helping in Sina's defense was Rick Swierat, Executive Director for Westchester ARC, who I will always be extremely grateful to.

I also explained to the County Executive in the letter, from the time my Sina had graduated from high school, he had been provided with very limited services from OMRDD and was only receiving Medicaid Service Coordination from the Westchester County Department of Community Mental Health. I finally learned of the "Consolidated Supports and Services Program" (CSS) in 2004 through Sina's service coordinator who, like me was told the application process should take no longer than one year. Nevertheless the application process dragged on indefinitely until my son finally passed away and never qualified for the program. Perhaps, if Sina had become eligible for the CSS program, he would have benefited from a meaningful day program and never would have decompensated behaviorally and emotionally nor become involved with the criminal justice system.

Though Sina was eligible to receive services, none existed for a person with High Functioning Autism/Asperger's Syndrome. Even though I devoted and struggled almost every day of my life, while he was alive, trying to locate services such as job training, employment, socialization programs, social skills training, mental health services, housing and so many other types of services Sina needed, I could not find or obtain these types of services. Agencies would reject him or they would not have a suitable program for him because of his occasional challenging behaviors caused by his high degree of anxiety, rigid thinking, social awkwardness and lack of socially appropriate behaviors.

The second time the County Executive, Andrew Spano and myself crossed paths was because I was one of the recipients of a Mental Health Award presented to me on June 13, 2007, just four days after Sina passed away from an epileptic seizure. After the awards were presented to the recipients, my husband and I recommended to the County Executive that a committee be developed to explore the severe lack of appropriate services for adults with autism, especially for persons like Sina with Asperger's Syndrome and High Functioning autism. He immediately agreed that we should have a meeting to explore this issue and he kept his promise. Within a few months a meeting was arranged with Susan Tolchin, Chief Advisor to the County Executive, Commissioner Grant Mitchell and Deputy Commissioner, Christine Reinhardt, Bonnie Kaplan (Co-Facilitator for the support group "Families with Adult Children with Asperger's Syndrome/High Functioning Autism, my husband (Fred) and myself.

Judith Omidvaran

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V. Citations

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² See Westchester County website, www.westchestergov.com/autism

³ The New Jersey Center for Outreach and Services for the Autism Community (COSAC) www.njcosac.org

⁴ The Cody Center, www.stonybrookmedicalcenter.org/cody_center/

⁵ Autism Spectrum Resource Center, Inc., www.ct-asrc.org/

⁶ Asperger Syndrome and High Functioning Autism Association, www.ahany.org/about.htm

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⁹ TEACH Autism Program, www.teacch.com/SE_Philosophy.html

¹⁰ Walgreensoutreach.com provides information to help potential employees to hire people with disabilities

¹¹ Grandin, Temple & Duffy, Kate, Developing Talents; Careers for Individuals with Asperger Syndrome and High-Functioning Autism, Autism Asperger Publishing Co, 2004

¹² The Lab School of Washington, Washington DC

¹³ Abilities, Inc, Albertson, NY

¹⁴ Bergen Community College, Division of Continuing Education, Corporate & Public Sector Training Certificate Program for Paraprofessional: Autism Specialty Track

¹⁵ Morris, Robin, "He Took a Walk to Get a Soda and Ended Up in a Hospital For a Psych Evaluation", Autism Spectrum News, Winter, 2009