

National Autism Association - New York Metro Chapter
Comments on the Draft Statewide Comprehensive Plan: 2010-2014
of the State of New York Office for People with Developmental Disabilities

August 23, 2010

NAA-NY Metro Chapter appreciates the opportunity to submit to OPWDD comments on OPWDD's Draft Plan. As an initial matter, we commend OPWDD for its "people first" plan and its intention to allow more self-direction and patient-centered treatment and services. We wish to specifically address why we believe that the needs of those with autism deserve special attention. We hope that the flexibility and individual-driven services that OPWDD intends to provide will serve to address the needs of the growing population of individuals with autism and we would be happy to meet with OPWDD representatives to discuss further our submitted comments.

People Diagnosed With Autism Are A Unique Population

Historically, OPWDD has met the needs primarily of those with mental retardation, and New Yorkers with that diagnosis still make up approximately 83% of those served by OPWDD, according to the draft plan. However, as is becoming more evident with the advent of better testing and a better understanding of autism, old paradigms concerning the overlap between autism and MR are being revisited and many now accept that the majority of people with autism may not be what is traditionally considered "cognitively disabled" and often have IQs in the average, and even the superior, range. Often those with autism show uneven skills development, unlike those diagnosed with MR, who frequently show more even global delays. Moreover, those diagnosed with autism can show significant jumps in IQ scores following appropriate treatments and appropriate testing. The challenge in working with those who are diagnosed with autism spectrum disorders ("ASD") is figuring out how to reach and teach the individual to access their true potential. When the key is found - and it can be highly individualized - those with autism can flourish. Because those diagnosed with autism often have strong cognitive abilities but are impaired in language, socialization and other areas, their needs - medically, educationally, vocationally and socially - are, in many respects, different from the majority of New Yorkers served by OPWDD. Thus, those who work for and with OPWDD on behalf of people with autism need intensive and regular training about all aspects of ASD, including alternative treatments that many families find helpful. General training on developmental disabilities is, frankly, insufficient to address the unique needs of the growing population of individuals diagnosed with ASD and a focus on comprehensive training and flexible needs assessment is required.

Autism Is A Systemic Disorder With Underlying Medical Conditions

Autism is more complex than the disorders traditionally served by OPWDD and as the population of New Yorkers with autism grows, and ages, OPWDD will need to focus increasingly on this unique population. Methods applicable for addressing the needs of MR, CP and other disorders often will not work for those with autism. In particular, those with autism often have underlying physical conditions that, if treated, can improve significantly the symptoms of autism. For example, many with autism have one or more of the following: seizure disorder, severe gastrointestinal disease, food allergies/sensitivities, immune system dysfunction, metabolic/mitochondrial disorder, sleep disorders, sensory processing disorder, central auditory processing disorder, and inflammatory conditions. It is necessary to recognize those underlying conditions and to provide appropriate supports and treatments, as well as to address the social, language and other deficits of those with autism diagnoses - it is not a "one or the other" option - people with autism need global support in many areas in order to reach their greatest potential.

"Behavior" In Autism Is Not Necessarily A Psychiatric Disorder

Because of the underlying medical conditions and the language and social deficits frequently seen in people with autism, "behaviors" in those with autism cannot be treated in the same way as behaviors with respect to other disorders. Frequently, in those with autism, behaviors are a sign of underlying physical pain (from, for example, GI distress) or frustration from an inability to effectively communicate. These and similar medical or social reasons must be ruled out before resorting to psychopharmaceutical treatments. In people with autism, psychopharmaceuticals should not be the treatment of first resort because the cause of behaviors frequently is not psychiatric and use of these drugs could be both unnecessary and harmful. For those reasons as well, prior to using the antecedent-behavior-consequence model to address a behavior, the behavior needs to be assessed to determine if it is related to underlying physical or similar causes before assuming that the behavior simply can be "unlearned."

How OPWDD Can Meet The Needs Of Those Diagnosed With ASD

With respect to educating and communicating with those with ASD, OPWDD needs to explore the many methodologies that are successful in meeting the educational and social needs of those diagnosed with ASD, including, but not limited to, Applied Behavior Analysis, Floortime/DIR, RDI, Son-Rise, Soma/Halo, augmentative communicative devices, and TEACCH. Because "autism" is so variable, different individuals respond to different methodologies and OPWDD needs to be well versed in all available methodologies to meet its clients' needs and to provide for the best individual outcomes. People diagnosed with autism also benefit from a variety of therapies, including, depending on individual needs, speech therapy, occupational therapy, physical therapy, auditory therapy, and others. Need for these services should be assessed on an individual, case-by-case basis, regardless of age.

Those diagnosed with autism often have specialized diets to address food allergies and sensitivities. In particular, for many, removal of gluten, dairy and other common allergens can improve outcomes, in some cases dramatically. Therefore, family and individual wishes with respect to diet need to be respected in whatever living/working environment (with the family, group home, supported independent living, residential treatment, dayhab etc.) a person with autism is placed. People with autism often can be sensitive to environmental toxins as well and the family and individual wishes with respect to personal care and household products also needs to be respected. People diagnosed with autism often respond positively to supplements and medications prescribed by doctors and nutritionists well-versed in treating ASD. A family's and individual's wishes in this regard also must be respected. Failure to respect family wishes with respect to diet, environmental exposures, medications and supplements could, for some diagnosed with autism, have significant detrimental effects.

Moreover, many people with ASD have sensory integration issues and may be hypersensitive or hyposensitive (or a combination) to many things, such as noise, clothing (tags, materials, fit etc.), tastes/smells, and touch. Therapy can help regulate the sensory system, but those who work with people

with ASD need to understand that these issues are real and that the person with ASD is not being "difficult" when they encounter things their sensory systems cannot appropriately process.

Family support services also are critical in helping individuals with autism achieve their greatest potential. People diagnosed with autism do present challenges to the family dynamic in many instances and caring for a loved one diagnosed with autism can be stressful. Respite services are helpful and some families may require significant services in order to keep their loved one with ASD in his or her home. Those respite workers need specific training regarding ASD. Family counseling and similar services also can be beneficial for parents, siblings and other family members who may be struggling in helping to care for a family member diagnosed with autism.

Finally, it is critical that issues surrounding wandering and ASD be addressed. Many people diagnosed with ASD have a proclivity to wander or "run" and can be severely hurt, or, in too many instances, die, as a result. NAA-NY Metro's national parent organization has launched a campaign to bring education on this issue to the forefront and we urge you to visit <http://www.awaare.org/> for more information.

Thank you for the opportunity to submit these comments and we look forward to reviewing more detailed plans from OPWDD to address the needs of the growing population of people diagnosed with ASD.

We are available to meet with OPWDD and would welcome the opportunity to discuss these issues in greater detail.

Sabeeha Rehman, President
srehman@naanyc.org

Kim Mack Rosenberg, Vice-President/Treasurer
kim.mackrosenberg@naanyc.org

Peggy Becker, Secretary
peggybecker@naanyc.org