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**DIVORCE AND AUTISM:
ISSUES INVOLVING CHILDREN
WITH SPECIAL NEEDS**

April 9, 2021



SEPARATION, DIVORCE AND AUTISM SPECTRUM DISORDER

Presented by Lawrence Jones and Joni Jones

** This program is presented for general educational purposes only, and is not intended or designed to establish or provide any specific legal, psychological or other professional relationship or advice for any specific case.*

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ABOUT THE PRESENTERS

Lawrence R. Jones retired in 2017 from service as a New Jersey Superior Court Judge (family court). While on the bench, he served as the President of the New Jersey Council of Juvenile and Family Court Judges (NJCFJC), and authored over 60 opinions on novel issues of law, including a significant unpublished opinion regarding custody and parenting issues for children with autism (Rooney v. Wall, 2015). Following his departure from the Judiciary, he was honored by the New Jersey Law Journal in June 2017 as a Distinguished Leader of the N.J. Bar. In November 2017, he was appointed by Governor-elect Phil Murphy to serve on the gubernatorial transition team relative to legal issues and social justice. He previously served on both the New Jersey Council of Developmental Disabilities (2007-2009) and the Governor's Adults with Autism Task Force (2008- 2009), both times as an appointee of Governor Corzine. On the latter committee, Jones served as Chair of the Subcommittee on Legal Issues, and helped develop the "Plan for Action" which ultimately resulted in the creation of New Jersey's Office of Autism Services. Thereafter, following Jones' appointment to the Judiciary and consistent with the aforementioned Plan for Action relative to educating Superior Court Judges on autism, Judge Jones founded, developed and co-presented the first program in New Jersey for sitting family court judges on autism and divorce, which was presented at the New Jersey Judiciary's Judicial College in 2010. Jones also coauthored the 2010 Judicial Bench Guide on the subject, and is the co-author of the "Jones-Holmes criteria" of special considerations for judges deciding custody issues regarding children with autism, which was presented at the N.J. Judicial College in 2010, and at the Autism Society of America's national convention in Pittsburgh in 2013. In 2021 he co-hosted the Academy of Profession Mediators (AFPM) national seminar on Mediation and Autism Spectrum Disorder.

Joni Jones is a registered nurse, board certified in psychiatric and mental health nursing, former certified developmental disabilities nurse, and a retired member of the NJ State Board of Nursing. She served on New Jersey Governor Murphy's transition team for health-related issues and also served on Governor Corzine's transition team for social service issues. In 2013, Joni was the recipient of the Elizabeth Kellogg Award for excellence in nursing. Joni is one of the original founders and former vice president of Parents of Autistic Children (POAC). From 2002-2009, Joni worked with multiple major league baseball teams to create the first-ever "Autism Awareness Day" games hosted by the New York Yankees, the Florida Marlins, the Pittsburgh Pirates, and the (then) Montreal Expos. In 2002, the National baseball Hall of Fame in Cooperstown New York honored the Lakewood BlueClaws, minor league affiliate of the Philadelphia Phillies, for hosting pro baseball's first-ever Autism Awareness Day, in which Joni served as chairperson of the event. CN-8 won a 2003 Emmy award for its coverage of the event. Joni has presented at multiple health-related conferences on state and national levels. Some of these venues have included The Developmental Disabilities Nurses Association, Autism Society of America, COSAC (now Autism NJ), AFCC National conference, FACES, Association of Schools and Agencies for the Handicapped (ASAH) State Parent Advocacy Network (SPAN), Monmouth Inns of Court, and Rutgers University. She has appeared on NBC News and other media outlets on the subject of autism spectrum disorder. In 2021 she he co-hosted the Academy of Profession Mediators (AFPM) national seminar on Mediation and Autism Spectrum Disorder.

A) To Submit Comments to Presenters on the Program :

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B) Links to Additional Resources

Association for Science in Autism Treatment <https://asatonline.org/>

Hume, K., Waters, V., Sam, A., Steinbrenner, J., Perkins, Y., Dees, B., Tomaszewski, B., Rentschler, L., Szendrey, S., McIntyre, N., White, M., Nowell, S., & Odom, S. (2020). *Supporting individuals with autism through uncertain times*. Chapel Hill, NC: School of Education and Frank Porter Graham Child Development Institute, University of North Carolina at Chapel Hill. Retrieved from:

<https://afirm.fpg.unc.edu/supporting-individuals-autism-throughuncertain-times>

National Child Traumatic Child Stress Network. (2020). Parent/caregiver guide to helping families cope with the Coronavirus disease 2019 (COVID-19) At

https://www.nctsn.org/sites/default/files/resources/factsheet/outbreak_factsheet_1.pdf

Wong, C., Odom, S. L., Hume, K. Cox, A. W., Fettig, A., Kucharczyk, S., M. E., Plavnick, J. B., Fleury, V. P., & Schultz, T. R. (2014). Evidence-based practices for children, youth, and young adults with Autism Spectrum Disorder. Chapel Hill: The University of North Carolina, Frank Porter Graham Child Development Institute, Autism Evidence-Based Practice Review Group.

<https://cidd.unc.edu/Registry/Research/Docs/31.pdf>

EXHIBIT A*Rooney v. Wall*

Superior Court of New Jersey, Chancery Division, Ocean County, Family Part

September 19, 2014, Decided

DOCKET NO. FM-15-1229-09 CIVIL ACTION

Reporter

2014 N.J. Super. Unpub. LEXIS 3067 *

C. ROONEY¹, Plaintiff, v. T. WALL, Defendant.**Opinion**

Notice: NOT FOR PUBLICATION WITHOUT THE APPROVAL OF THE COMMITTEE ON OPINIONS.PLEASE CONSULT NEW JERSEY RULE 1:36-3 FOR CITATION OF UNPUBLISHED OPINIONS.**Core Terms**

autism, autistic child, therapy, parties, custody, divorce, progress, ongoing, cooperate, reinforcement, therapists, diagnosis, best interests of the child, recommendations, consistency, intense, communicate, autistic, joint legal custody, schedules, divorced parents, legal custodian, jointly, legal custody, challenges, training, attend, sake, family court, residential

Counsel: [*1] Plaintiff, Pro se.

Plaintiff, Pro se.

Judges: L. R. Jones, J.S.C.**Opinion by:** L. R. Jones

L. R. Jones, J.S.C.

When divorcing or divorced parents have a child with autism, there are often very specific concerns regarding custody, parenting time, and a child's need for specific therapies and special education services. This case presents such a scenario, involving post-judgment litigation between divorced parents of a five year old autistic boy. There is little precedential case law on the subject of autism and divorce in New Jersey. This litigation, however, raises important issues on what separated or divorced parents may need to do in order to jointly help, rather than hurt, their child's progress and well-being after the marriage has ended.

FACTUAL BACKGROUND

Plaintiff and defendant married in 2006. In 2009, plaintiff filed for divorce. At the time, she was pregnant, with H.W., the parties' son and only child. Plaintiff gave birth during the litigation. When the child was nine months old, the parties finally settled the case in April, 2010. Due to the infant's tender age, neither party was aware at the time that their son was autistic. Under their settlement agreement, the parties agreed to share joint legal [*2] custody of H.W., with plaintiff serving as primary residential custodian and defendant having reasonable and frequent parenting time two to three times per week.

In February, 2012, nearly two years after the parties' divorce, H.W. was formally diagnosed with Autism Spectrum Disorder (ASD). The clinical diagnosis

¹ The court utilizes pseudonyms and initials in place of the actual names of the parties and child.

followed the child's ongoing manifestation of several classic behavioral symptoms and early warning signs of autism, including but not limited to poor eye contact, delayed speech, and impaired social interaction. Following receipt of the official diagnosis, plaintiff arranged for H.W. to begin receiving multiple professional interventions and therapies for young children with autism, including behavioral therapy ("Applied Behavioral Analysis", or "ABA" therapy), speech therapy, and occupational therapy, all through New Jersey's Early Intervention program.

Upon H.W. reaching his third birthday, and pursuant to applicable special education law, the child's home school district began providing academic services and developed an Individual Education Plan (IEP)² for the child, including the child's enrollment in a pre-school disabled program providing behavioral therapy for children [*3] with autism. Additionally, plaintiff arranged for the child to receive additional hours of private and supplemental behavioral, speech and occupational therapy to the extent available under her health insurance policy. Plaintiff's position, however, was that defendant was not working with her as a co-parent, but in fact was refusing or otherwise failing to accept the reality of the child's autistic diagnosis by responding to respond to his special needs.

Notwithstanding multiple ongoing therapies and interventions, the teachers and professionals overseeing the child's behavioral development began to notice emerging inconsistencies between the child's social and emotional functioning in the school setting, as compared to other settings in the home and community. Specifically, while the child was apparently making some positive progress at school, his development was comparatively stagnant or regressive outside of the school environment.

Believing a cause to be an apparent lack [*4] of joint cooperation between the parties in jointly working together on reinforcing the child's educational program, and in meeting his needs in a consistent fashion, the therapists and professionals recommended, among other suggestions, that the child's divorced parents work on

improving their personal dealings with each other on child-related issues. The professionals also recommended the parents maintain an ongoing autism "communication log" between them, so as to enhance consistency of approach between their respective homes. Still further, the therapists recommended that, for the child's sake, the parents needed to better synchronize and coordinate their efforts in taking what the child was learning in therapy and then reinforcing same by working with the child during "down time," thereby consistently helping generalize the child's progress into their respective homes and other environments outside of a educational formal setting.

Notwithstanding these recommendations, the parties have continued to have an ongoing problematic relationship. As regarding the communication log, plaintiff contends that defendant has not only refused or otherwise failed to appropriately utilize the [*5] notebook, but in fact has misused same by writing inappropriate communications in the log for her to read. Plaintiff also asserts or implies that defendant does not cooperate with her relative to following the child's special education program and therapeutic needs, and that he insists on parenting time schedules which obstruct or conflict with the child's therapy schedule. She further contends that the child's educational progress has been impeded in substantial part because of a lack of consistency by defendant in his approach to, and reinforcement of, the child's educational program. Plaintiff alleges that because defendant disagrees with, and does not accept, the child's diagnosis of autism, he does not support or follow through with the child's therapy program as is necessary for the child to achieve progress. She asserts that defendant's actions and inactions are ultimately obstructive to the child's chances for meaningful improvement, and are therefore contrary to the child's health, well-being and best interests. Under the circumstances, plaintiff requests that the court modify the joint legal custodial arrangement at this time and grant her sole legal custody of the child [*6] until further order of the court, so that she can make decisions regarding the child's autism program and oversee his progress in order to make sure he stays on course without derailment. She further asks the court to reduce defendant's parenting time so as to decrease the risk of the child's behavioral regression while in defendant's care, while simultaneously providing more time for consistent therapy.

²The Individuals with Disabilities Education Act (IDEA), requires school districts to supply a free and appropriate education to developmentally disabled children as young as three years of age. See 20 U.S.C. 1401; 20 U.S.C. 1412.

Defendant strongly opposes plaintiff's motion. He denies that he is refusing to accept the child's diagnosis of autism, and further asserts that he has been doing his own online research into the disability. He further objects to any change in his status as joint legal custodian, or diminishment of his existing parenting time with the child.³ He denies that he is responsible for impeding the child's development and progress. Additionally, while admitting that there is presently a sub-par relationship between the parties, he professes that he would like to improve the situation and move forward in the future for the sake of the child.

In 2007, the State Legislature created the New Jersey Adults with Autism Task [*8] Force, (A4057/S2559), which was signed into existence on September 12, 2007 by Governor Jon Corzine (P.L. 2007, c. 173). This legislation charged the task force with studying, evaluating and making recommendations intended to meet the needs of adults associated with the significant challenges presented by autism. In October, 2009, the Autism Task Force released its report of findings to the Governor and Legislature entitled, "Addressing the Needs of Adults with Autism: Recommendations for a Plan of Action for the State of New Jersey," which contained multiple recommendations for addressing the needs of New Jersey's vastly growing population of individuals with autism. While the Task Force technically dealt with the needs of adults" with autism, several recommendations and goals expressly also related to the needs of children with autism, especially those in the family court system. The Task Force recommendations included a focus on the state judiciary and need to educate Superior Court judges on autism.⁷ The report to the Governor and Legislature contained multiple recommendations, including a finding that, as a matter of public policy, members of the Judiciary's Family Court will benefit [*9] from having ongoing judicial education about autism spectrum disorder . The Task Force report expressly noted the following:

LEGAL ANALYSIS:

Autism Spectrum Disorder: [*7] Overview

The United States Center for Disease Control (CDC) reports that nationally, 1 in 68 children have autism spectrum disorder (ASD).⁴ Further, the CDC reports that New Jersey has the highest incidence of autism in the country, with 1 in 45 children having ASD.⁵ Given the high rates of both autism and divorce, there is a substantial likelihood that every divorce judge in New Jersey will confront at least one case involving a child with autism over the next several years. Historically, however, there has been relatively little formal education of New Jersey's family court judiciary on special issues which may arise when divorcing or divorced parents have a child with autism. For this reason, over the past several years there has been an increased effort and focus on the need for judicial education in autism spectrum disorder, in order to support a greater general awareness of, and familiarity with, the disorder and the special needs which may follow a child's diagnosis.⁶

- a) A high percentage of marriages end in divorce when the parties have a child with ASD. Thus, children with ASD are often the subject of court proceedings relating to custody, visitation schedules, support and funding of special needs.
- b) The court and counsel must advocate for the best interests of the child with ASD under *parens patriae* jurisdiction, so that the child may hopefully grow to be an adult who can be a functioning member of society.
- c) Accordingly, public policy supports the establishment of autism education for family court, in conjunction with the Judicial College through the Administrative Office of the Courts.

Id. at 35-37.

The report further stated the following:

³Each party asks for further additional post judgment relief as well, which is outside the scope of this opinion.

⁴See <http://www.cdc.gov/hcbddd/autism/states/ADDM-New-Jersey-fact-sheet.pdf> (last visited November 1, 2014).

⁵*Id.*

⁶The court notes that this opinion is posted on April 2, 1015, which is National Autism Awareness Day.

⁷The report's content may be read at <http://www.state.nj.us/humanservices/ddd/boards:AATF rpt.pdf>.

... In New Jersey's judicial system, Superior Court Judges often must address legal issues concerning persons who have ASD. Judges are often personally unfamiliar with ASD. In view of the growing number of persons diagnosed with ASD, it is in the public's interest for judges and attorneys to learn as much as possible about ASD as such education may significantly [*10] impact how cases are viewed by judges in matters involving persons with ASD. Education should be developed through such educational outlets as the Judicial College and other court-sponsored or supported programs.⁸

Id. at 43-45:

Children with Autism: Importance of Early Diagnosis, Intense Intervention, and Consistency of Approach

In considering the needs and best interests of a child with autism, it is logical, as a starting point, for family court judges to have a basic understanding of autism, as well as a general grasp of the importance of early diagnosis, intense behavioral intervention, and consistency of parental approach, even when the parents are divorced and are living in separate homes.⁹

Autism is a pervasive developmental disorder of the brain, which can significantly impair a child's ability to learn, communicate, and socially interact with other people. Infants and young children who are diagnosed with autism are said have "infantile autism". The exact cause is unknown, and the State of New Jersey's Department of Health acknowledges that there is no known universal cure.¹⁰

While no two autistic children are exactly alike, the

⁸ Thereafter, the 2010 Judicial College included in its curriculum a first-time ever course entitled: *Family Court: Issues Involving Developmentally Disabled Children*, which included, as a participating panelist, a representative from the State of New Jersey's Department of Human Services and newly created Office of Autism Services.

⁹ Many of the following general points and principles regarding childhood autism are summarized in the article: *"Autism and Divorce: Guidelines for Family Court Practice"*, *New Jersey* [*11] *Lawyer*, No. 256 (February 2009), pages 7-17, by Lawrence Jones and Dr. David Holmes.

¹⁰ <http://www.nj.gov/health/shs/documents/autismguidelines.pdf>

behavioral and social deficits of children with ASD sometimes manifest themselves in common fashion. For example, young autistic children often have little or no speech, and those who do speak might only initially parrot what they hear others say (a behavior known as "echolalia"), and/or speak in monotone with a blunt affect. Additionally, autistic children often have great difficulty making eye contact, and frequently engage in obsessive-compulsive, perseverative, repetitive and self-stimulatory behaviors such as spinning in circles, flapping their arms, rocking their bodies back and forth, persistently lining up objects in a row, or endlessly spinning the wheels [*12] on a toy car or other toy and staring at the motion in fixated fashion.

Autistic children frequently are unable to read and understand people's facial expressions, or respond to social cues and gestures. Additionally, autistic children often have little or no interest in socializing with other people, and prefer isolation to interaction with same-age peers. Other autistic children may interact with people, but only adults. Some autistic children engage in explosive temper tantrums and self-injurious behaviors, such as head-banging on walls and floors. Additionally, many autistic children do not readily appreciate or understand the concept of danger, or easily learn from past experience. For example, a child with autism might put his or her hand on a hot stove even if he or she burned his or her hand on the same exact stove the previous day.

As noted, there is no known "cure" for autism. It is well-documented and critical to note, however, that young children who receive an early diagnosis, followed by intense behavioral intervention often make very significant improvement to the point that they can effectively mainstream with non-autistic children., both in school and otherwise. Perhaps [*13] the most recognized form of behavioral intervention for young autistic children known as Applied Behavioral Analysis (ABA), with a sub-category known as discrete trial techniques (DTT). This therapy is based on a 1987 study conducted at UCLA known as the "Lovaas"¹¹ study,

¹¹ The study was conducted by Dr. Ivar Lovass of UCLA., who is considered one of the major pioneers is the treatment and education of children with autism. See *Right from the Start: Behavioral Intervention for for Young Children with Autism*. 2d edition (2007), page 32.

which supports intense behavioral intervention for a young autistic child of 25-40 hours a week or more. Thus, such a therapy program generally involves an extensive and consistent commitment of time, energy, and effort by the parents of the autistic child, usually in conjunction with trained professionals such as behavioral therapists, speech therapists, and other appropriately educated professionals. As stated by Dr. Sandra Harris in the autism text, *Right from the Start: Behavioral Intervention for Young Children with Autism*. 2d edition (2007):

There are several features that make applied behavioral analysis (ABA) special in the treatment of young children with autism. One is the intensity of the treatment. . . . It should be done for at least 25 to 40 hours a week with most of the teaching being done in a one to one student to teacher ratio. Second ABA is a highly structured approach to teaching. . . .(which) is [*14] carefully designed and follows very predictable patterns of instruction. Third, there is very little downtime during which the child is not actively learning. Brief breaks are followed by brief lessons at a rapid pace. . . . In addition, applied behavior analysis is based on well-studied principles of human learning and is designed to capitalize on the capacity of children to benefit from proven methods of instruction. *Id.*, at 5-6.

Generally, the earlier the diagnosis and start of intense therapeutic intervention, the greater the chance for possible success in improving the autistic child's functional abilities. *Id.* at 33-34. Some professionals refer to the age bracket of two to five as the greatest "window of opportunity to improve an autistic child's functionality, since the brain is still forming (i.e., the age of "plasticity of the brain"). *Id.* at 13. Failure to provide a young autistic child with intense behavioral intervention during his or her early [*15] years of life may have significant negative consequences on the child's progress and future.

While professionals may develop, oversee, and administer the child's therapy, it is critical for parents and other family members of the autistic child to not only understand how autism therapy works, but also to learn how to reinforce such therapy at home when the professional therapists and special education teachers are no longer present. Since most parents may not be

able to afford to hire professionals for up to 40 hours a week, there is a clear importance for parents to learn how to reinforce the therapists' and teachers' lesson plans themselves so the child receives the maximum benefit reasonably possible under the circumstances. This way, the autistic child constantly receives opportunities to practice generalizing his or her progressive steps and skills in different environments and situations, spearheaded by properly instructed and motivated parents.

Since autistic children frequently have difficulty generalizing what they learn in one environment into other environments, it is generally in a child's best interest for *both* parents to constantly reinforce the child's learning steps in [*16] a uniform fashion with specifically coordinated intensity and consistency. This point becomes extremely important and challenging in cases of divorce, where parents not only live in separate homes, but may have an impaired and compromised ability to effectively communicate and cooperate with each other on any issue at all.

Autistic children often do poorly with "down time" and unstructured routine. Additionally, without constant reinforcement, some autistic children regress, i.e., go backwards, by losing skills they have previously learned and mastered. Still further, autistic children often do not transition well into different environments, and often resist changes to their set routines. For this reason, constant changes in the child's schedule, including fluctuating parenting schedules between separated or divorced parents, may in some cases ultimately be detrimental to an autistic child's need for consistency and predictability. Accordingly, for purposes of establishing an autistic child's behavioral therapy schedule, it is generally in the child's best interest for separated or divorced parents to jointly coordinate their schedules in a way that the child can constantly learn in [*17] a uniform and predictable manner, without unnecessary disruptions to the routine or point of focus.

Further, it is logical for both parents to coordinate their parental education and training efforts, in conjunction with the child's therapists and teachers, so that there is as much consistency as possible in approach between the two homes, and so the child optimally continues to receive the benefits of consistent education, skill reinforcement and generalization, irrespective of whether the child is in one parent's care or the other

parent's care at any particular point in time.

Even in an intact family where two parents live under the same roof, the challenges of raising a newly diagnosed, young child with autism can for some parents be stressful. This is particularly true when one parent is unable or unwilling to accept and handle the additional parental responsibilities which are necessary to advance the child's progress and best interests. Some parents unfortunately choose a road of inaction and inattention, or sit back contently while the other parent carries the entire load of responsibility.

In addition to the emotional challenges of raising a developmentally disabled child, there [*18] can be serious economic challenges as well. For example, a parent might have to leave or alter his or her career path and goals in order to care for an autistic child on a full-time basis, including transporting the child to and from necessary behavioral therapy sessions. In such instance, the other parent might have to work overtime or two jobs in order to help pay for the cost of private therapy. Both parents may need to forego "leisure time" and other activities to focus on their child's needs, and to learn behavioral therapy reinforcement techniques and how to effectively apply them on a regular basis in their ongoing interactions with the child.

Further, parents of autistic children are often faced with costs and expenses of therapy and special education services which may not be fully covered by insurance, and which are sometimes not voluntarily provided by the child's school district. In such circumstance, there is often the need for additional income to either privately pay for therapy services, or alternatively to pay for legal fees in court actions against health insurance carriers or school districts to compel appropriate services for the child.

There are, however, numerous [*19] invaluable rewards in raising a child with autism, including the joy and satisfaction of seeing a young child progress, improve, and hopefully grow to meet his or her greatest potential, hopefully at all times with the full support and effort of both parents. For such success to have the greatest chance to occur, however, it is logical that parents, whether married, separated, or divorced, strive to develop a united front in (a) obtaining, and accepting the diagnosis ; (b) educating themselves as parents in the intricacies of the disability; (c) formulating a joint plan

for therapeutic intervention with the help of trained professionals, and (d) most importantly, approaching and working the plan as a unified parental team with as much intensity, consistency and focus as possible, free from unnecessary drama and marital or post-marital battles having little or nothing to do with the child's needs and best interests.

Unfortunately, when one layers a contentious divorce on top of the inherent challenges and responsibilities of raising a child with autism, a complex family dynamic often emerges. Specifically, two participants in an unsuccessful marriage must now nonetheless step up to the [*20] plate as joint parents, and work together to accept, understand, and meet the special needs of their autistic child, while living in two separate houses. Inherent in this joint obligation is the further need of each parent to fully and fundamentally appreciate how a *failure* of joint cooperation between them can wholly and irreparably threaten the child's progress and permanently damage the child's chance to fully reach his or her potential regarding behavioral improvement, mainstreaming and future independent functioning. While parents may divorce each other, there is no divorce between parent and child. Even in the most strained marriages and contentious divorces, there remains an ongoing, critical obligation of each parent to rise above the ashes of their failed union and work together to meet the special needs of their autistic son or daughter.¹²

The court recognizes that, as a general proposition, parents who divorce often have difficulties in effectively cooperating with each other thereafter as joint legal custodians. See *Madison v. Davis*, 438 N.J. Super 20, 44-45, 101 A.3d 1132 (Ch. Div. 2014). As a result, many children [*21] of divorce grow up in two homes, raised by "joint legal custodians" who in theory are *supposed* to cooperate with each other, but who in actuality have no real-life practical ability to do so. Yet, the most basic and fundamental element of a joint custodian's job description is a willingness and ability to leave the hurt feelings and dirty laundry from an unsuccessful marriage behind, and move forward by constructively and effectively working with the other parent to the extent reasonably possible on important child-related

¹² If there is a domestic violence restraining order in place between the parties, however, then the restraints must be honored at all times.

issues. When one or both parents are unable to do so or unwilling to even try, a child of divorced, "joint legal custodians" may be raised in two separate homes where he or she must endure a complete lack of parental consistency while struggling from being buried alive in an avalanche of back and forth fighting between the adults.

Unfortunately, divorcing or divorced parents sometimes subordinate a child's interests to their own, including an often paramount interest in demonstrating that their ex-spouse cannot "tell them what to do." In the case of a child with autism, such a breakdown in parental cooperation can have a catastrophic consequence upon the child's development. [*22] The reason is that, as previously noted, an autistic child may have a heightened need for consistency, which can easily be derailed by two parents who spend more time trying to show each other who is in charge than presenting a joint front in meeting the child's needs and challenges.

In family court, there is a "real responsibility in matrimonial actions to remain above the fray and try to preserve the best interests of the child." *Quinn v. Johnson*, 247 N.J. Super. 572, 580, 589 A.2d 1077 (Ch. Div., 1991). This point is overwhelmingly true in a case involving divorced parents of a young child with autism. For this reason, in divorce litigation, if the evidence reflects that a parent either cannot or will not accept and meet this basic responsibility, there may be legal consequences relating to both custody and parenting time in the child's best interest.

A judge presiding over a family court action has broad discretion in determining custody and other provisions regarding the child's welfare, which is the controlling consideration. See *Sobel v. Sobel*, 46 N.J. Super. 284, 286, 134 A.2d 598 (Ch. Div., 1957). The New Jersey Legislature has set forth many statutory factors for a judge to consider in resolving a *bona fide* custody dispute. These criteria are embodied in *N.J.S.A 9:2-4*. In the context of a custody battle over an autistic [*23] child, some of the most relevant factors listed in *N.J.S.A 9:2-4* include the fitness of the parents, the needs of the child, the safety of the child, and the quality and continuity of the child's education. In addition to the stated statutory factors, however, the family court also has equitable discretion to consider supplemental factors it deems relevant and appropriate on a case-by-case

basis. Specifically, a court presiding over a custody or parenting dispute involving an autistic child may consider the relevancy of additional significant factors, including but not limited to the following¹³:

- 1) Each parent's role in obtaining the initial diagnosis of autism, and any delay caused by a parent in obtaining the diagnosis;
- 2) Each parent's acknowledgement and acceptance of the child's autistic disorder, as opposed to a denial of the condition;
- 3) Each parent's role in obtaining early intervention and therapy for the child, and the reasons for any delay in attempting to obtain services for the child;
- 4) Each parent's ability to reinforce and follow-through on daily recommended behavioral interventions for the autistic child, and the level of participation the parent has in working with the autistic [*24] child;
- 5) Each parent's history of increasing his or her education on the needs of an autistic child, by attending seminars, joining autism support groups, seeking private professional assistance and engaging in other reasonable self-education techniques;
- 6) Each parent's history of willingness to be a tireless and effective advocate for the autistic child, and ability to do so;
- 7) Each parent's ability to handle the emotional and psychological challenges which may involved with raising a child with special needs;
- 8) Each parent's understanding and appreciation of the window of opportunity concept and the importance of early intense intervention and potential consequences to the child and family if intervention does not take place;
- 9) The quality of the special education (either in public school or private school) the child will receive while in the parent's care.

In a given case, any or all of the above factors may be very relevant in considering whether a parent is ready and able to assist his or her autistic child on an ongoing basis, and to assist in a positive, intense, [*25] consistent and significant manner in the child's progress and development.

¹³ See *Autism and Divorce: Guidelines for Family Court Practice*. *New Jersey Lawyer*, No. 256 (February 2009), pages 7-17.

In the present case, plaintiff seeks an order of sole legal custody over the parties' child. Defendant objects and wishes to remain a joint legal custodian. In New Jersey, there are generally two kinds of custody: legal custody and physical (residential) custody. See *N.J.S.A. 9:2-4*. While the residential custodian is one with whom the child primarily resides (in this case plaintiff, by prior agreement of the parties), the legal custodian is the parent who makes the major decisions on the child's behalf.

Generally, even if one parent has primary physical custody, both parents may still have joint legal custody. In the present case, the parties previously agreed to such an arrangement at the time of divorce, when their son was an infant, but when neither party knew of his autism and special needs.

In some cases, a parent may seek joint residential custody of the child, and a schedule under which each parent has the child approximately fifty percent of the time (either splitting the week at 3.5 days each or rotating weeks back and forth). While flexible 50/50 timesharing may sound fair on paper, such an arrangement [*26] may in some cases not be in the best interest of a particular child, especially an autistic child whose parents either cannot or will not coordinate either the therapy schedules or their follow-up reinforcement of behavioral therapy in a compatible and consistent manner. Specifically, the back-and-forth nature of shared 50/50 residential custody may in some cases work against the need of an autistic child to have a predictable and consistent schedule, especially when the parents cannot effectively communicate and cooperate in synchronizing the implementation of the child's behavioral intervention program in each home. Autistic children often do not do well handling inconsistency or significant deviations in their schedules. The need for a relatively regimented schedule of behavioral therapy may be compromised if the child has to be passed back and forth between two households with two completely different and unpredictable parental methods of overseeing, or *not* overseeing, the autistic child's need for consistent and intense and reinforcement of those skills taught to the child by therapists and other professionals.

An autistic child may have enough hurdles to overcome without parental [*27] dysfunction further complicating matters by requiring the child to bounce between two

totally inconsistent educational and therapeutic programs and expectancies. A parent who cannot or will not engage in a consistent program with their ex-spouse, for the child's sake, and who replaces consistency with defiance and refusal to recognize an autistic child's needs while under his or her care, may be compromising the child's best interests. Hence, unless there is reason to believe the divorcing parents can effectively and cooperatively work together to consistently coordinate their schedules and seamlessly reinforce the child's therapy and progress from one household to another, shared custody might in some cases not be appropriate or in the child's best interests.

In the present case, there appears to be no issue that plaintiff is, and continues to be, the child's primary residential custodian. The issue in serious dispute is not residential custody, but legal custody of the child. Under a joint legal custodial arrangement, parents are supposed to confer in a mutually dignified and respectful manner and attempt in good faith to reasonably agree on significant issues affecting the child's [*28] health, education and welfare. If there is a disagreement on a significant issue after such reasonable efforts have been mutually attempted, then either party may seek judicial intervention and the family court may have to resolve the disputed issue in dispute.

N.J.S.A. 9:2-4(a) states that the court is to establish the residential arrangements (residential/physical custody) as well as arrangements for consultations between the parents in making major decisions regarding the child's health, education and welfare (legal custody). In any proceeding involving custody of a minor child, the case starts with the premise that the rights of both parents shall be equal. *N.J.S.A. 9:2-4*. In some cases, however, the evidence reflects that joint legal custody between two specific parties is simply unworkable, as a result of the conduct and attitude of one or both parties.

Pursuant to *N.J.S.A. 9:2-4*, a court has the discretion to award joint legal custody to both parents or sole legal custody to one parent. If sole legal custody is granted, the sole legal custodian makes the decisions for the child. The noncustodial parent still may have the right to parenting time with the child, but generally does not participate in [*29] making the major decisions in the child's life unless the custodial parent consents. The concept of joint legal custody was advanced by the New

Jersey Supreme Court in the landmark case of *Beck v. Beck*, 86 N.J. 480, 432 A.2d 63 (1981). As a matter of public policy, New Jersey generally favors joint legal custody. *Grover v. Terlaje*, 379 N.J. Super. 400, 879 A.2d 138 (App. Div., 2005). Theoretically, joint legal custody enables both parents to share an equal right to participate in the decision-making process regarding significant issues in a child's life. However, in many divorces a husband and wife have virtually no ability to communicate with each other rationally and reach agreements on anything at all — including issues concerning their autistic child. In fact, the inability to communicate may be a major reason why the parties' marriage failed in the first place. See *N.J.S.A. 2A:34-2(i)* (establishing "irreconcilable differences" as a legal ground for divorce). See also *Madison v. Davis, supra*.

In New Jersey's custody statute *N.J.S.A. 9:2-4*, the first listed element for the court to consider is the parents' ability to agree, communicate and cooperate in matters relating to the child. In matters involving a child with autism, it is imperative that there be an unobstructed decision-making process on critical issues [*30] such as therapies, interventions, comparative school programs, adaptations of programs, and modification of programs, as applicable. These issues may need to be considered and addressed by parents swiftly and with reasoned decisiveness. There is no room for fighting, posturing or promoting of hidden agendas by parents who still have unfinished business with each other long after the divorce is over. The autistic child's best interests and development can be seriously compromised by parents who constantly argue and battle with each other to the point where the decision-making process is stalemated and damaged to the child's clear detriment.

Some parents are in fact able and willing to prioritize their autistic child, put aside their differences and learn to communicate, and cooperate, and even agree on important issues as joint legal custodians. Other parents, however simply do not have the ability or selflessness to do so. Accordingly, in cases where parents have a demonstrated and historical inability to deal with each other and reach agreements for the sake of the child, a court may conclude that joint legal custody is *not* in the child's best interests. Rather, for the child's sake, [*31] there may be a necessity under such conditions to grant one parent sole legal custody and authority to make decisions relative to the child, particularly regarding

treatment and therapy for autism spectrum disorder.

In *Nufrio v. Nufrio*, 341 N.J. Super. 548, 550, 775 A.2d 637 (App. Div., 2001), the Appellate Division ruled that the prime criteria for establishing a joint legal custodial relationship between divorced or separated parents centers on the respective abilities of the parents to agree, communicate and cooperate in matters relating to the health, safety and welfare of the child. Without such abilities, joint legal custody may be inappropriate. The facts in *Nufrio* did not involve an autistic child. Nonetheless, the principles of *Nufrio* may be logically applied by a family court judge presiding over a case involving custody of a child with autism. In controversies between parents for the custody of children, there can be no restraint upon the mind of the court, and all legitimate force must be accorded to those considerations that touch the well-being of the child. *Quinn v. Johnson*, 247 N.J. Super. 572, 574, 589 A.2d 1077 (Ch. Div., 1991). Custody is not an absolute right of either parent, but rather is a trust reposed in a parent by the state for the welfare of the child. Thus, the state—through the court—must determine [*32] the custody arrangement that best furthers the child's best interests.

As regarding parenting time, the state generally supports the right of the noncustodial parent to have such time with the parties' child. *Wilke v. Culp*, 196 N.J. Super. 487, 483 A.2d 420 (App. Div., 1984). In fact, the right of a parent to companionship with his or her child is a fundamental right protected by the U.S. Constitution. *Wilke v. Culp*, 196 N.J. Super. 487, 496, 483 A.2d 420 (App. Div., 1984). See *In re J.S. & C.*, 129 N.J. Super. 486, 490, 324 A.2d 90 (Ch. Div., 1974). See also *DYFS v. J.Y. and E.M.*, 352 N.J. Super. 245, 800 A.2d 132 (App. Div., 2002). When weighed, balanced and tested against competing constitutional principles, however, the welfare of the child must have paramount importance. See *Fiore v. Fiore*, 49 N.J. Super. 219, 225, 139 A.2d 414 (App. Div., 1958); *Hoefers v. Jones*, 288 N.J. Super. 590, 608, 672 A.2d 1299 (Ch. Div., 1994). The child's best interests is always the controlling consideration in deciding issues of parenting time, including schedules and conditions relating to same.

There are many different types of parenting schedules which vary from case to case depending on various factors. In the case of an autistic child who is actively

involved with an ABA therapy schedule, it is important that any proposed parenting schedule include due consideration to the child's need for a continued and consistent schedule of therapeutic intervention. For example, an autistic child might be enrolled in a year-round extended school year (ESY) special education program provided by the school district, for the purpose [*33] of helping prevent regression and loss of previously learned skills over the summer when there is no ongoing school or other professional structure and support. In such case, removal of the child from the program for several weeks to accommodate either parent's extended summer vacation plans must be looked at with due caution, as such an arrangement may unwittingly have a detrimental effect on the child's behavioral progress. While relatively short absences to accommodate vacations of brief length might possibly be reasonable, periods of longer length may be inappropriate and in fact unreasonable under the circumstances.

Similarly, if a child is involved in an intense behavioral intervention program which has been successful in overcoming past significant behavioral challenges, such a program may require daily behavioral reinforcements from the caretaking parent in order to be truly effective. In such a case, it is critical that both divorced parents receive appropriate parental education and training in behavioral intervention and reinforcement. Taking this concept one positive step further other members of the parents' respective households (second spouses, teenage siblings, etc.) [*34] should logically and optimally receive similar training as well. Even during short stays such as weekday dinners or alternating weekend parenting time, a non-custodial parent's lack of understanding of autism can lead to serious problems if the child has a behavioral meltdown, temper tantrum, or engages in other challenging behaviors. For this reason, a court exercising *parens patriae* jurisdiction over a child with autism may in some appropriate circumstances order that parenting time be conditioned upon the parent demonstrating ongoing participation with ongoing parental training and education in autism.

Parenting schedules need to be formulated in such a manner that they do not unduly interfere with the intensity and consistency of the autistic child's therapy and training. Further, regardless of the specific parenting schedule, it is very important for both parents

to be educated in autism and in the child's therapies, so their efforts at reinforcing the child's learning is consistent. In such fashion, the child can better generalize what he or she learns in different environments such as, each party's home.

The Present Case: Logical Goals and Interim Arrangements

Against this general [*35] backdrop, the court considers the parties' present positions and the child's best interests. A best interest analysis logically extends beyond what is best for a child only on the motion return day, but rather what is more likely than not best in terms of a reasonable long range plan.

First, notwithstanding plaintiff's assertion that defendant has historically refused to accept their son's diagnosis, defendant does presently assert and acknowledge under oath that the child has autism, and that he accepts the reality of the diagnosis. This stipulation is the first important step in the parties moving forward in jointly addressing their child's present and very important needs.

As regarding the viability of continued joint legal custody, the court is not presently inclined to grant plaintiff's application for sole legal custody, and will maintain the parties' joint legal custodial status at this time. While theoretically the court may enter an order in the future modifying joint legal custody to sole legal custody if necessary to protect the child's best interests, this court presently finds that a different approach is more appropriate and more potentially beneficial to the child in the [*36] long run. Similarly, the court denies any modification in either party's parenting time at this juncture.

The court schedules this matter for a status conference and further proceedings which will take place in approximately eight weeks, on November 17, 2014 at 1:30 pm, at which time both parties will be in attendance. In the interim, between this present court date and November 17, 2014, the court will afford both parties the opportunity to demonstrate, both to the court and to themselves through a series of specific interim steps, whether they can or cannot work together as parents for their child's sake, and whether their child does or does not come first in their lives, even above

whatever animosities they may feel towards each other at the present time.

First, the court orders that between the date of this order and the next court date, both parties will jointly attend parental training classes, together, in raising a child with autism. Parents in intact families often attend such classes together when their child is diagnosed with autism, and therefore there is logically no reason why the two divorced parents in this case, as "joint legal custodians" with no restraining order [*37] between them cannot attend as well. In its role as *parens patriae*, the family court may require two divorced parties to attend professional interventions, together, as an ongoing condition of joint legal custody. See *Madison v. Davis, supra*, 438 N.J. Super at 45-46 (Ch. Div. 2014) (authorizing mandatory, court-ordered joint attendance by both parties together at co-parenting counseling sessions, for the child's sake).

In this case, the parties, as joint custodians, must communicate with each other and within fourteen days either meet jointly with the child's autism therapist, or alternatively jointly select a program from an appropriate agency or recognized autism organization designed to coordinate their education, training and commence parental training in assisting their son's needs. The parties will jointly attend a minimum of three sessions prior to the next court date, and will jointly supply proof of attendance. Further, the parties will at all times treat each other courteously and respectfully in such sessions, with a common goal of obtaining a consistency in approach to educating their child in their respective homes and generalizing the education which the child receives from his therapists, teachers and other professionals. If a parent [*38] refuses to attend with the other party, the court may issue sanctions or other relief including, if necessary, suspension of the violating party's status as a legal custodian of the child.

Second, the court further orders that the parties may reasonably communicate with each other on child-related issues in person, or by text, email, phone, or as otherwise agreed. All such communications, however, shall at all times be mutually respectful. While the parties are not obligated to agree with each other on all issues, they are obligated for their child's sake to treat each other at all times in a mutually courteous and

dignified manner. They will further jointly recommence use of the communication log book, and maintain same either by hard copy or by email, with the purpose of providing each other with ongoing updated information as to the child's progress, and observable deficiencies as applicable.

Third, the parties will communicate as joint legal custodians with the child's teachers and therapists and commence the establishment of a group email listing for ongoing communication on the child's gains and deficiencies between the date of this Order and the November 17, 2014 conference, to [*39] further discuss the child's progress so that parents and professionals alike are all active participants in the information loop, with an opportunity to share relevant observations and discuss issues relevant to the child's ongoing progress. The parties will cooperate with, and follow, the advice and recommendations of the child's ABA therapist on how to improve the consistency of approach and scheduling of the child's educational development in each home, so that the approaches are consistent rather than inconsistent with each other.

Fourth, the Court directs that the parties jointly obtain from both the child's teacher as well as home ABA therapist, private speech therapist, and occupational therapist, updated reports dated no later than November 10, 2014 indicating what if any progress the child has made following the date of this Order and what deficiencies if any have developed or remain intact without improvement, along with any ongoing recommendations and suggestions for how the parties may together best address such deficiencies as well as the child's ongoing educational needs.

Fifth, between the date of this decision and the November 20 status conference, the parties will fully [*40] cooperate with each other with maximum flexibility in attempting to reach a mutually agreeable parenting schedule which accommodates not only both parties' schedule, but most importantly, the child's ongoing therapy schedule as well. If they are unable or unwilling to do so, then pursuant to *Rule 5:8A*, a court may appoint a *guardian ad litem*, at both parties' costs, to investigate and report to the court with recommendations on parenting time as well as any other autism-related issues. In a case involving (a) an autistic child with special needs, and (b) parents who, for

whatever reason, have fundamental issues in dealing and cooperating with each other, such appointment may be particularly helpful and consistent with the court's role in exercising *parens patriae* jurisdiction, which is to protect and watch over the interests of children who are incapable of protecting themselves. *In re Baby M*, 217 N.J. Super 313, 324, 525 A.2d 1128 (Ch. Div., 1987), *rv'd on other grounds, sub.nom., Matter of Baby M*, 109 N.J. 396, 537 A.2d 1227 (1988).

In dealing with the custody and control of infants, the touchstone of the court's jurisprudence is the safeguarding of the children's welfare and happiness. A court may make such order touching the care, custody, education and maintenance of the children as the circumstances [*41] of the parties and the nature of the case renders fit. See *Henderson v. Henderson*, 10 N.J. 390, 395, 91 A.2d 747 (1952). In this case, the court will presently refrain appointing a *guardian ad litem*, opting instead to provide the parties with one more opportunity to demonstrate to the court, and to themselves, that they can co-function in a cooperative manner for the sake of their disabled son. If, however, the parties return to the court with a record of ongoing continuous disharmony relative to their son's needs, and choose contentiousness and litigiousness over mutually mature and respectful cooperation, the Court may exercise its discretion to appoint a *guardian ad litem* at both parties' expense for the child's sake.

The court enters this order with the hope and expectation that these two parties have within themselves the ability, and desire, to help their son. The question which remains to be answered is whether that desire outweighs all of the personal negative feelings which the parties may have against each other. If their true top priority is to help their child, they now each have a fresh opportunity to prove this point to the court, through actions rather than words.

As noted, the court orders both parties to return to court on November [*42] 17, in person, to advise of any and all progress over this upcoming two month period in meeting the specific steps set forth in this opinion.¹⁴

¹⁴ On November 17, 2014, the parties returned to court and jointly reported that since the last court proceeding, they did in fact jointly attend parental training for autism together, and have further begun to deal with each other in a positive and mutually respectful fashion. More significantly, the child's home therapist confirms this

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development, writing a report to the court indicating that since the prior court date, ". . . we have seen continued progress with (H.W) in areas of academics and communication." Further, "(A)s everyone has started to focus and working on improving his communication, his expressive communication has started to improve" The therapist adds that the most important point is for the child's parents to continue this course and "present a united front, keep their lines of communication open, and be consistent and positive." Finally, both parties, as parents, stipulate that based upon the noticeable improvement in the situation, there is no further need for ongoing court proceedings, and by joint stipulation the [*43] court concludes and closes the litigation and court proceedings at this time, without prejudice, and with all prior orders remaining in effect.

AUTISM AND THE LAW

Part 1: How 'Endrew' Can Improve Future Educational Prospects

By Lawrence R. Jones

This article is the first of a four-part special series on autism, in honor and recognition of National Autism Awareness Month.

In March, 2017, the U.S. Supreme Court issued its opinion in *Endrew F. v. Douglas County School District*, 580 U.S. ___, 137 S.Ct 988, 197 L. Ed. 2d 335 (2017). In *Endrew*, the court overturned a 10th Circuit Court of Appeals decision holding that a child with autism in a non-mainstreamed, special education program, under an Individualized Education Plan (IEP) was entitled only to an educational program that was calculated by the child's school district to provide "merely more than a de minimus" benefit. In a unanimous opinion authored by Chief Justice Roberts, the Supreme Court held that to meet its legal obligation under the Individuals with Disabilities Education Act



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(IDEA), "a school district must offer the special needs student an Individualized Education Plan (IEP) that is reasonably calculated to enable a child to make progress appropriate in light of the child's circumstances." *Id.* at 14-15, 16.

The court emphasized that, in dealing with a special-needs child who is not mainstreamed, "the goals may differ" from those for a child in a regular education curriculum. *Id.* at 14. Nonetheless, "every child should have a chance to meet challenging objectives." *Id.* Moreover, the court held that while a primary standard for a fully included student may involve the child "progressing

smoothly through the regular curriculum," a different circumstance exists when a child is not fully included. *Id.* In such instance, school officials must look to the disabled child's unique needs to develop an IEP that is "pursuing academic and functional advancement." *Id.* at 11. Further, in a statement of interpretation dated Dec. 7, 2017, the U.S. Department of Education announced that, "The *Endrew F.* decision is important because it informs our efforts to improve academic outcomes for children with disabilities." Accordingly, *Endrew* essentially raises the legal bar for school districts in meeting their responsibilities

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for overseeing the preparation of IEP plans for students with Autism Spectrum Disorder.

Under the spirit of *Endrew*, IEP plans must logically be approached and prepared with a constructive, creative and reasonably expansive mindset in order to meet a student's needs, with more than "de minimus" progress in mind. In this respect, a post-*Endrew* IEP plan for a special-needs student will reasonably involve: (a) developing meaningful objectives which (b) are challenging to an individual student, in terms of (c) addressing both academic and functional needs of the student as underscored by the court itself.

For certain, functional advancement means something beyond mere academic advancement. Otherwise, there would have been no need for the court to include the qualifying words "and functional" after the word "academic." These terms are expansive enough to include countless different potential components of meaningful IEP plans, which are designed to educationally and functionally assist a special-needs child on the path to adulthood.

Because of the inherently broad scope of the term "functional," as set forth in the context of a remedial Supreme Court decision, parents, school personnel, lawyers and judges may be analyzing and debating the meaning of this term under *Endrew* for years or decades to come. As *Endrew* is a relatively new case, there has been little opportunity for the development of a body of subsequent case law interpreting the scope of its language. Applying logic and

common sense, however, a reasonable person may reasonably conclude that, as a matter of law and social policy, *Endrew* expands the lens of focus in a pro-child manner upon not only the child's academic progress, but also the child's non-academic, functional progress and the need, when applicable, to improve a child's social skills to help meet a long-term "challenging objective" of achieving future independence and employability following graduation.

Since an IEP is an individualized education plan, each plan must be uniquely designed and tailored to appropriately fit each child's needs. While sometimes overlooked in the IEP process, it is clear that an underlying goal and purpose of any IEP, when possible, is "to prepare students for further education, employment and independent living." 300 C.F.R. 300.1. Hence, in preparing a child with special needs for the possibility of future employment and independent living, the focus must often logically be as much on a child's social deficits and challenges as on purely academic ones.

As expressly noted by the Supreme Court in *Endrew*, autism is a neurodevelopmental disorder generally marked by various behavioral components, including *impaired social and communicative skills*. *Id.* at 6. Further, under the DSM-5 for neurodevelopmental disorders, autism spectrum disorder includes deficits in *social communication and interaction*, and restrictive repetitive behaviors, interests and activities. Social communication deficits are particularly prevalent with

children who have Asperger Syndrome or "Asperger's"—which is often referred to as a high functioning form of ASD. Some students with Asperger's may perform exceptionally well in mainstream scholastic settings and even achieve test scores and grades which far exceed their non-disabled peers. Notwithstanding such academic success, the social deficits that often accompany Asperger's can, in certain instances, seriously obstruct a child's ability to successfully obtain or maintain a job later in life.

While academics are certainly important in the realm of special education, social skills are often at least as important—if not even more important—for long-term goals such as the child's future employability and independence. If a student has academic challenges but strong social skills, he or she may actually have a greater chance of obtaining and maintaining long-term meaningful employment than a student with strong academic skills but very poor social skills. Yet, time and time again, child study teams and other applicable school personnel often move a child with Asperger Syndrome and severe social challenges through the scholastic system without adequate supports to meet his or her needs, simply because the student has achieved good grades and performed well on standardized tests designed to measure progress. In essence, the child may fly under the radar for years, while receiving little or none of the educational help that could be most relevant and

beneficial to helping meet his or her special needs on the road to potential independence.

While an advancement from grade to grade may be appropriately ambitious for “most” children in a regular classroom setting, the *Andrew* court explicitly cautioned that this concept “should not be interpreted as an inflexible rule.” *Id.* at 14, note 2. Rather, the court expressly declined to hold that every special-needs child who is advancing from grade to grade is automatically receiving a free and appropriate education. As *Andrew* noted, an IEP is not a form document, but is “constructed only after careful consideration of the child’s present levels of achievement, disability, and potential for growth.” *Id.* at 12. Such consideration should then be utilized to create an educational program that is “appropriately ambitious” in light of the circumstances, and which allows the special-needs student to strive for challenging objectives and goals. *Id.* at 14. The adequacy of an IEP turns on the unique circumstances of the child for whom it was created. *Id.* at 16.

Accordingly, while *Andrew* factually focused upon an autistic student who was placed outside of a mainstreamed, regular education setting, the ambitious spirit of the opinion arguably and logically applies, on an educational basis, to addressing the challenging social needs of students with high-functioning autism and/or Asperger Syndrome who may have in fact been placed

in mainstreamed classrooms, but who nonetheless still critically suffer from major social deficits and challenges which need to be appropriately addressed as part of a functional IEP plan. The overlooking or glossing over of such components of the disorders in educational planning may severely undermine the express purpose of the IDEA in helping further prepare such students for future education, employment and independent living.

Programs with an intense focus on the enhancement of social skills may be highly appropriate under *Andrew* as part of the “challenging objectives” for legal consideration by parents and school districts in the formulation of appropriate IEP plans. In the context of developing post-*Andrew* IEP plans for children with autism, Asperger’s and other ASD-related disabilities, there is often a very legitimate need to place social skills on as important a level as academic skills. Historically, there has been an overwhelming focus in the plan on academics, but comparatively little focus on specific plans, exercises and goals relating to the child’s need for developing and/or improving social skills. Further, some IEPs address the issue of social skills in an over-generalized manner, without any specific, detailed plan, such as how such improvement is designed to take place, or how success will be incrementally measured over time, or who will be doing the measuring and analysis of progress, or the

need for periodic adjustments of an ongoing program in order to reach certain milestones and goals.

Some academic traditionalists or purists take the position that education in school is supposed to be primarily about academics, and that ancillary concerns such as “socialization” are of secondary importance. Given the purpose of our special education laws and policies, however, such a viewpoint is arguably out of step with the expansive spirit of *Andrew* itself. In fact, there is an often overlooked, or unknown, federal regulation found at 34 C.F.R. 300.320(a)(4), which states that, when possible, an IEP is to be designed with a goal to enable the child to not only advance appropriately toward attaining annual goals, and to be involved in and make progress in the general education curriculum, but also to participate in extracurricular and other nonacademic activities, and participate with other children with disabilities and non-disabled children. Accordingly, in creating an appropriate IEP plan, the federal regulations to IDEA require consideration and focus not only on the student’s academic needs, but on non-academic needs as well.

By intensifying focus upon not only a child’s academic needs but social needs in creating a functional IEP, educators and parents can jointly improve the quality of services provided to many children with autism in a more expansive manner, consistent with the ambitious spirit of *Andrew* itself. ■

AUTISM AND THE LAW

Part 2: Discrimination Against Persons with Autism

By Lawrence R. Jones

This article is the second installment of a four-part special series in honor and recognition of National Autism Awareness Month.

New Jersey's Law against Discrimination (LAD) protects against discrimination based upon age, race, gender, marital status, disability and other categories as well. See N.J.S.A 10:5-5, 10:5-12. Accordingly, as a matter of public policy, our case law is evolving so as to help eradicate the cancer of discrimination. See *L.W. v. Toms River Regional Schools Board of Education*, 189 N.J. 381, 399 (2007). Freedom from this cancer is in fact one of the fundamental principles of our society. *Lehmann v. Toys R Us*, 132 N.J. 587, 600 (1993).

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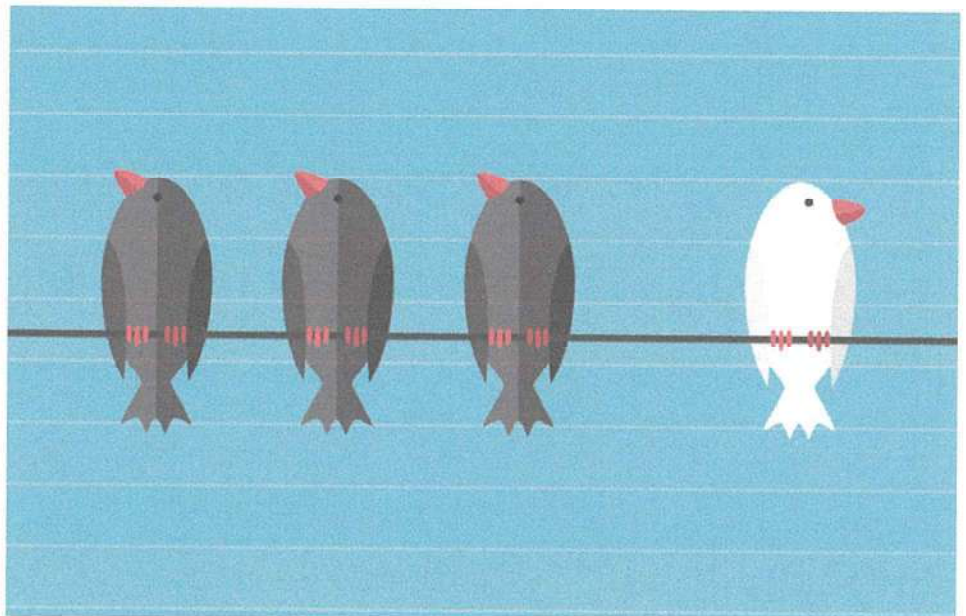


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The recent case of 'Oasis Therapeutic Life Centers v. Wade' serves as a significant breakthrough in this underdeveloped area of the law.

While there is a growing body of precedential case law that focuses on issues of discrimination based upon race, religion, gender, age, familial status, and various physical disabilities, there has been comparatively little focus of the law of discrimination relating to persons with developmental disabilities such as Autism Spectrum Disorder. The recent case of *Oasis Therapeutic Life Centers v. Wade*, ___ N.J. Super. ___ (App. Div. 2018), however, serves as a significant

breakthrough in this underdeveloped area of the law. *Oasis* is relevant in not only in addressing discrimination against people with autism, but in serving as a decision which has been approved for publication by the Committee on Judicial Opinions, thereby giving the ruling a significant degree of precedential value. In *Oasis*, plaintiff alleged that defendants interfered with efforts to purchase property for use as a group home for persons with

autism, in violation of the New Jersey Law Against Discrimination. The trial court dismissed plaintiff's action. On appeal, however, the appellate court reversed and remanded the matter for further trial-level proceedings, concluding that plaintiffs set forth a case that defendants "targeted and tormented Oasis because Oasis was providing a residence for autistic individuals." The court concluded that plaintiffs established a potential cause of action because: (a) it is unlawful to discriminate against a buyer of real estate because of the disabilities of the persons with autism intending to live on the premises, N.J.S.A 10:5-4.1; and (b) it is improper, with discriminatory intent, to interfere with another's transaction under N.J.S.A. 10:5-12, by attempting to obstruct plaintiff's attempt to secure a monetary grant from a nonprofit foundation to assist with the proposed purchase of the subject estate to establish the group home.

From a legal standpoint, the alleged facts of *Oasis* are particularly noteworthy. Apparently, there were some homeowners and residents who opposed the creation of a group home for persons with autism in the neighborhood where they resided, based upon unfounded, purported "fears" that people with autism were somehow dangerous to the community and/or created a risk to public

safety. Certain neighbors began a door-to-door campaign, compiling signatures on a petition objecting to the proposed group home, and taking steps to derail or otherwise interfere with the property owner's plan to sell his land to the organization intending to establish the group home on the property.

When such efforts failed, and the land sale was proceeding, the defendant-neighbors attempted to interfere with the group home's access to a shared driveway (erecting a fence across the easement), and further defaced and vandalized the area around the property with "enormous, garish and frightening graffiti" that included depictions of snakes and fire covering approximately 600-700 square feet on and around the property driveway. Thereafter, defendants participated in having animals trespass onto the Oasis property, including an aggressive goat and a horse that grazed and left piles of manure on the land.

For the autism community, the legal and social relevance of *Oasis* potentially extends far beyond the specific facts of the case. In a larger sense, *Oasis* shines a light upon the reality that as members of the autistic community become further integrated into the mainstream of society, there may potentially be additional cases and circumstances where the cancer of discrimination rears its head in the form of unfounded stereotypes and

misinformation, resulting in additional social hardships to persons with autism. For this reason, it is critical that members of the autistic community, as well as family members and professional service providers, become as educated as possible not only on the nature of ASD itself, but on the legal rights designed to protect persons against prejudice and discrimination as well.

What is particularly interesting about the *Oasis* opinion is that while the content focuses upon the New Jersey Law against Discrimination and its liberal construction and application under N.J.S 10:5-1, the decision makes no specific reference to a 2009 statutory amendment to N.J.S.A 10:5-12(q) which provides that the anti-discrimination statute applies to persons with a disability "which shall include, but not be limited to ... any ... developmental disability, including autism spectrum disorders" While the Legislature amended the law nearly a decade ago in order to better protect members of the autistic community from discrimination in housing, employment and other important aspects of daily living, many people are simply unaware that this statutory provision exists. Yet, it does exist and will likely be relevant on an ongoing basis to the autistic community and the public as a whole.

As a participant to the drafting and enactment of this statutory

amendment, the author can detail the history of this legislative development. In 2007, the New Jersey Legislature enacted legislation enabling the governor to (a) create an "Adults with Autism Task Force" and (b) appoint its members. The main function of the Task Force was to study the needs of adults in the autistic community, and to write a report of concise recommendations for consideration of implementation by the governor and legislature. In 2009, following over a year of intensive study and debate, the Task Force rendered a report of 44 specific recommendations to the governor on ways to assist adults with autism, including, but not limited to, issues relating to the development of day programs, life skills, health care, employment, housing, and private sector engagement.

This author chaired the Legal Issues Subcommittee of the Governor's Task Force. A copy of the 2009 report is available here: <http://state.nj.us/humanservices/ddd/boards/AATFrpt.pdf>

As part of this report to the governor, the Task Force recommended an amendment of N.J.S.A.

10:5-1(q), to expressly reflect an intent of the governor and legislature to prohibit discrimination against persons with autism and other developmental disabilities. This clarification was of specific importance to the Committee on various issues including but not limited to housing, so as to cover the exact type of circumstances that ultimately arose in the *Oasis* case. In the end, the legislature voted overwhelmingly to approve the proposed amendment accordingly.

While nearly 10 years have passed since enactment of this statutory amendment, the issue of discrimination against persons with autism has rarely presented itself in such a publicly magnified manner as in *Oasis*. The concept of neighbors acting out in such a socially inappropriate manner against developmentally disabled members of our society reflects not only a genuine present risk of discrimination, but also exemplifies why there is a need for (1) heightened social education on autism in general, and (2) greater social tolerance, acceptance and inclusion of persons with autism and other developmental disabilities.

For these reasons, and consistent with the spirit of April as National Autism Awareness month, it is urged that our public officials and the legal community spend a reasonable allotment of time and energies in educating the public in a constructive manner on Autism Spectrum Disorder. Arguably, the more educated the general population becomes about autism, the less common will be occurrences of discrimination based upon ignorance, and fear-induced prejudices which have no legitimate place in our society.

Moreover, as nearly 10 years have passed since the issuance of the 2009 Report to the Governor, the time is arguably ripe for the present New Jersey Legislature and governor to convene a new task force to review the status and progress made in assisting the autistic community over the past decade, and to thereafter update, develop and frame fresh new strategies to meet specific, still-outstanding goals and objectives. Such new strategies would logically include but not be limited to the goal of effectively countering and eradicating the cancer of discrimination against persons with Autism Spectrum Disorder. ■

AUTISM AND THE LAW SERIES

Part 3: Why NJ Must Increase Social Awareness of the Need for Early Diagnosis

By Lawrence R. Jones

This article is the third installment of a four-part special series in honor and recognition of National Autism Awareness Month.

On April 26, 2018, the United States Center for Disease Control (CDC) issued a periodic report of updated findings by the Autism and Developmental Disabilities Monitoring (ADDM) Network. The results were noteworthy and must be viewed as relevant by lawmakers throughout the state and nation.

The data contained in the report reflected that the estimated percentage of children identified with Autism Spectrum Disorder (ASD) was higher than in previous reports. Approximately one in 59 children were identified with ASD, based on tracking within 11 communities in the United States. (2018 Report, page 2.) Moreover, the percentage of children identified with ASD was significantly higher in areas of New Jersey than in other specified parts of the country. In New Jersey, the incidence was one in every 34 children—the highest rate of any state included in the study.

The reasons for regional differences in statistics are unknown, and may have been partly attributable to the diagnosis

Lawrence R. Jones is a former New Jersey Superior Court Judge, who retired from the Bench in 2017. Prior to his appointment to the Judiciary, he served as a gubernatorial appointee to both the New Jersey Council on Developmental Disabilities and the Adults with Autism Task Force.



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The study reflects that most children (85%) identified with ASD actually had concerns about their development noted in their records by three years of age.

process. Both on a state and national level, however, it is clear that the rate of autism is prevalent and recurring enough to warrant increasing public concern and focus. For this reason, the ADDM report itself expressly urges policymakers and community leaders to use the information in its report of findings to: (a) promote social awareness of autism spectrum disorder and bring the community together to address the growing needs of families living with ASD; (b) develop policies and promote early identification and equity in access to services and supports so that all children get the help they need; and (c) serve as the basis for the creation of a task force or commission, focused on

the coordination of ASD activities in local communities.

The ADDM report further notes that service providers, such as healthcare organizations and school systems, can use the findings in the report to: (a) promote early identification efforts in order to lower the age when children are first evaluated for developmental concerns, diagnosed with ASD, and enrolled in community based support systems; (b) plan for resource and service needs; and (c) target outreach to under-identified groups of children.

Moreover, the study reflects that most children (85%) identified with ASD actually had concerns about their development noted in their records by three

years of age. Specifically, parents or caregivers may have noticed concerns through ongoing tracking of a child's development (developmental monitoring) and/or developmental screening. Parental concern regarding development is a reason to have a comprehensive developmental evaluation. In turn, such evaluation is often a key step in getting access to services, including through an applicable school system.

Yet, while the majority of children with ASD had concerns about their development documented in their records by three years of age, there was frequently a lag between first concern and first developmental evaluation. Accordingly, despite the fact that developmental concerns were noted in many of children's records by three years of age, fewer than half of children with ASD received a comprehensive developmental evaluation by this same age. Further, while ASD can be diagnosed as early as two years of age, about half of children were not diagnosed with ASD by a community provider until after four years of age. Such a lag can negatively impact when children with autism may begin to actually obtain the services they need. It is well-established that obtaining services as early as possible can make a very positive and meaningful difference in the development of a child with autism. Unfortunately, however, the CDC study found that fewer than half (42%) of children with ASD received a developmental evaluation by three years of age. Yet, the percentage of children with ASD increased in New Jersey, from about 2.5% in 2012 to about 3%, in 2014.

Future efforts may therefore need to emphasize the importance of screening young children with standard tools and connecting families to needed services before three years of age. The importance of early diagnosis and intervention cannot be overstated. As noted in the undersigned's judicial opinion in unreported New Jersey case of *Rooney v. Wall* (2015):

There is no known "cure" for autism. It is well-documented

and critical to note, however, that young children who receive an early diagnosis, followed by intense behavioral intervention often make very significant improvement to the point that they can effectively mainstream with non-autistic children, both in school and otherwise. In the realm of intervention and behavioral therapy for autistic children, perhaps the most recognized form of behavioral intervention is known as Applied Behavioral Analysis (ABA), with a sub-category known as discrete trial techniques (DTT). This type of therapy is based on a 1987 study conducted at UCLA known as the "Lovaas" study, which supports intense behavioral interventions of 25-40 hours a week or more.

Generally, the earlier the diagnosis and start of intense therapeutic intervention, the greater the chance for possible success in improving the autistic child's functional abilities. Some professionals refer to the age bracket of two-to-five as the greatest "window of opportunity to improve an autistic child's functionality, since the brain is still forming (i.e., the age of "plasticity of the brain") Thus, failure to provide a young autistic child with intense behavioral intervention during his or her early years of life may have significant negative consequences on the child's progress and future (Citing Dr. Sandra Harris in *"Right from the Start: Behavioral Intervention for Young Children with Autism 2d edition* (2007)).

This benefit of early diagnosis and intense early intervention, was documented in a 1987 study by Dr. Ivar Lovaas of UCLA, who was considered one of the major pioneers in the treatment and education of children with autism.

According to the CDC, there are possible "red flags" that a child might

possibly have autism. For example, a child with ASD might:

- Not respond to their name by 12 months of age
- Not point at objects to show interest (point at an airplane flying over) by 14 months
- Not play "pretend" games (pretend to "feed" a doll) by 18 months
- Avoid eye contact and want to be alone
- Have trouble understanding other people's feelings or talking about their own feelings
- Have delayed speech and language skills
- Repeat words or phrases over and over (echolalia)
- Give unrelated answers to questions
- Get upset by minor changes
- Have obsessive interests
- Flap hands, rock his/her body, or spin in circles
- Have unusual reactions to the way things sound, smell, taste, look, or feel

A child may possibly have autism even without demonstrating any or all of these traits. If a parent or guardian believes that his or her child might possibly have autism, it is logical for such parent or guardian to schedule an appointment with the child's physician as soon as possible. If the child does in fact have autism, an early diagnosis and the start of intense early intervention may potentially make a world of difference in the child's future progress.

Based upon the findings of the report from the ADDM and CDC, there is arguably a clear and compelling social need to focus upon increasing public education and awareness of the need for early diagnosis of childhood autism. Accordingly, in view of these statistics, the New Jersey governor and legislature may consider reviewing the status of the state's prior public awareness efforts and strategies, and thereafter launching an increased public awareness campaign through the Department of Health and/or Human Services of the critical importance of early diagnosis and intervention of children with autism. ■

AUTISM AND THE LAW SERIES

Part 4: Separation, Divorce and a Child With Autism

By Lawrence R. Jones

This article is the fourth and final installment of a special series in honor and recognition of National Autism Awareness Month.

The United States Center for Disease Control (CDC) has recently reported that one in 59 children have Autism Spectrum Disorder (ASD). Given the nearly 50% divorce rate in the United States, it is mathematically likely that a reasonably active matrimonial attorney will, over the course of a career, professionally participate in one or more cases involving parents of a child with autism.

Unfortunately, when one mixes a contentious divorce with the unique challenges and responsibilities of raising a child with autism, a complex dynamic often emerges. Specifically, two participants ending an unsuccessful marriage with "irreconcilable differences" must nonetheless attempt to work functionally together as joint parents in accepting, understanding and



PHOTO BY BIGSTOCK

meeting their child's special and intricate needs. Inherent in this joint obligation is the further need of each parent to fully and fundamentally appreciate how a failure of mutual cooperation can potentially threaten the child's progress and ability to fully reach his or her potential regarding behavioral improvement, mainstreaming and independent functioning.

Studies repeatedly show that children with autism have an increased chance of improvement when they receive: (a) an early diagnosis and (b) intense early intervention via behavioral therapy and other related therapies. What most, if not all, therapies appear to have in common

is the requirement of application of intensity and consistency in reinforcement on a regular (daily) basis. Additionally, studies show that the earlier the child is diagnosed and professional intervention begins, the greater chance there may be of success. This concept is based upon the idea of *plasticity* of the brain, meaning that the brain is more flexible and susceptible to changing its thinking patterns when a child is very young. Conversely, the older a child grows with little or no behavioral intervention, the smaller the window of opportunity may shrink for the child to ultimately achieve results in accordance with his or her inherent potential.

Lawrence R. Jones is a former New Jersey Superior Court Judge, who retired from the Bench in 2017. Prior to his appointment to the Judiciary, he served as a gubernatorial appointee to both the New Jersey Council on Developmental Disabilities and the Adults with Autism Task Force.

For this reason, it is beneficial for both parents to be fully on the same page in supporting sustained consistency of the therapeutic approach, delivery and reinforcement in the generalized settings of the child's everyday life. In the case of a contentious separation or divorce, however, former partners often have "irreconcilable differences" over absolutely everything, and either cannot or *will not* attempt to respectfully and effectively communicate or cooperate with each other on anything at all. Instead, power struggles often supersede logic and reason, leading otherwise reasonable and responsible parents to spend exorbitant time, money and negative energies on contentious litigation, while emotionally destabilizing their own child in the process.

In the case of a child with autism, parents who engage in a never-ending war with each other may not only stress their child, but can impair the intensity and consistency of the child's ongoing therapeutic program. While some divorced parents of a child with autism are in fact able to put their past marital issues aside and work together to maintain a consistent approach between two homes during each party's respective parenting time, other ex-couples are not so successful. Instead of peacefully, flexibly and constructively synchronizing their efforts for their child's sake, they perpetually fight and create their own impediment to a consistent approach and therapy schedule. This unfortunate circumstance sometimes leads to stagnation or even regression in the child's improvement, which may have long-term consequences on the child's road to mainstreaming, functioning, and his or her possible

chance of achieving independence as an adult.

So long as there is no restraining order prohibiting contact between the parties, separated or divorced parents of an autistic child generally have a clear ongoing obligation to attempt to cooperate and consistently address the needs of the child, rather than dooming the child's chances for improvement as the result of ongoing parental hostility and dysfunction. Often, following educational mediation sessions, counseling sessions or settlement conferences, the parties agree to forge a working relationship as divorced co-parents for the child's sake. When parties are unable or unwilling to do so, however, custody litigation often arises.

In custody litigation, a court's function is to protect the child's best interests. *Hoefers v. Jones*, 288 N.J. Super. 590, 608 (Ch. Div. 1994). The controlling consideration is the child's welfare. *See Sobel v. Sobel*, 46 N.J. Super. 284, 286 (Ch. Div. 1957). For certain, a court in any case must consider the statutory factors in the New Jersey custody statute, N.J.S.A. 9:2-4. Among the relevant statutory factors for consideration are: the needs of the child, the safety of the child, the quality and continuity of the child's education, and the fitness of the parents. Notably, however, the statutory factors for custody under N.J.S.A. 9:2-4 are not exclusive or exhaustive. To the contrary, the statute expressly states that in making an award of custody, "the court shall consider but not be limited to the (statutory) factors."

Accordingly, several years ago, the author of this article joined with noted autism expert Dr. David

Holmes (formerly of Princeton University) to develop proposed additional criteria for family courts to consider when adjudicating custody litigation concerning a child with autism. Labeled as the "Jones-Holmes criteria," these considerations were published in a 2009 article in *New Jersey Lawyer* magazine entitled: "Autism and Divorce: Guidelines for Family Court Practice," and were further presented at the Autism Society of America's annual convention in Pittsburgh in 2013, and the American College of Forensic Psychology symposium in San Francisco in 2008. The author included the criteria in the unreported opinion of *Rooney v. Wall* (Ocean County, 2015), which involved custody of a child with autism.

The Jones-Holmes criteria include the following additional factors, which a court may appropriately wish to consider on issues concerning custody and the child's best interests:

1. Each parent's role in obtaining the initial diagnosis of autism, and any delay caused by a parent in obtaining the diagnosis;
2. Each parent's acknowledgment and acceptance of the child's autistic disorder, as opposed to a denial of the condition;
3. Each parent's role in obtaining early intervention and therapy for the child, and the reasons for any delay in attempting to obtain services for the child;
4. Each parent's ability to reinforce and follow through on daily recommended behavioral interventions for the autistic child, and the level of participation the parent has in working with the autistic child;

5. Each parent's history of increasing his or her education on the needs of an autistic child, by attending seminars, joining autism support groups, seeking private professional assistance and engaging in other reasonable self-education techniques;
6. Each parent's history of willingness to be a tireless and effective advocate for the autistic child, and ability to do so;
7. Each parent's ability to handle the emotional and psychological stress which may be involved with raising a particular child;
8. Each parent's understanding and appreciation of the importance of early intense and consistent intervention, and potential consequences to the child and family if intervention does not take place;
9. The quality of the special education (either in public school or private school) the child will receive while in the parent's care.

Pursuant to N.J.S.A. 9:2-4(a) a court has discretion to establish different types of custody, including joint or sole residential or legal custody. Public policy generally favors joint legal custody. *Beck v. Beck*, 86 N.J. 480 (1981). However, joint legal custody requires an ability of parties to agree, communicate and cooperate in matters involving the health, safety and welfare of the child. If there is no ability to cooperate, then sole custody may be appropriate in some circumstances. See *Nufrio v. Nufrio*, 341 N.J. Super. 548, 552 (App. Div., 2001).

Before granting sole custody to one parent, however, a court has discretion to provide an opportunity for a previously non-cooperative parent of an autistic child to demonstrate the ability to act in a manner consistent with the child's special needs. With regard to parenting time with an autistic child following separation or divorce, it is generally recognized that absent compelling circumstances, each party will be entitled to reasonable parenting time in his/her home. Indeed, public policy favors the right of the parents and child to have parenting time. See *Wilke v. Culp*, 196 N.J. Super. 487, 496 (App. Div., 1984). Yet, in determining the parenting specifics of a custodial arrangement, a primary and controlling consideration is the welfare of the child. See *Fiore v. Fiore*, 49 N.J. Super. 219, 225 (App. Div. 1958). When weighed, balanced against the constitutional principles, *parens patriae* jurisdiction must be of paramount importance. See *Hoefers v. Jones*, 288 N.J. Super. 590, 608 (Ch. Div. 1994).

Accordingly, while it is understood that the accommodation of a reasonable parenting schedule between homes may logically require consideration of some reasonable flexibility or adjustment to a therapeutic schedule that has been in place for the child, a parenting schedule should not unduly or unreasonably interfere with the general ability of the child to attend a regular schedule of behavioral therapy with intensity and consistency. Further, when possible, the parents should attempt to implement similar approaches to

therapy and reinforcement in their homes, so as not to go against the child's need for consistency by presenting inconsistent or conflicting expectations. Additionally, when possible, both parents should be simultaneously receiving the same information, advice, input and feedback from any of the child's treating professionals (therapists, teachers, etc.), so that the parents are on the same page in providing a consistent program to enhance the child's potential progress.

It is advisable for both parents to engage in consistent and ongoing parental training on autism. Additionally, when permissible and not prohibited by a restraining order, parents should strive to engage in positive, constructive, coordinated communication with each other on the child's progress. There should be no parental arguments in the child's presence which may cause the child unnecessary stress.

If the evidence reflects that a parent is acting in a manner which unreasonably interferes with or undermines the autistic child's therapeutic and educational program, or need for parental cooperation and support of a consistent program, a court may take any and all action to protect the child's interests, including short or long term modifications of custody and parenting time schedules, and/or a requirement of further mandatory education for the interfering parent on the nature and intricacies of autism. Hopefully, with responsible and cooperative conduct by both sides, such steps will rarely be necessary to protect a child's best interests. ■

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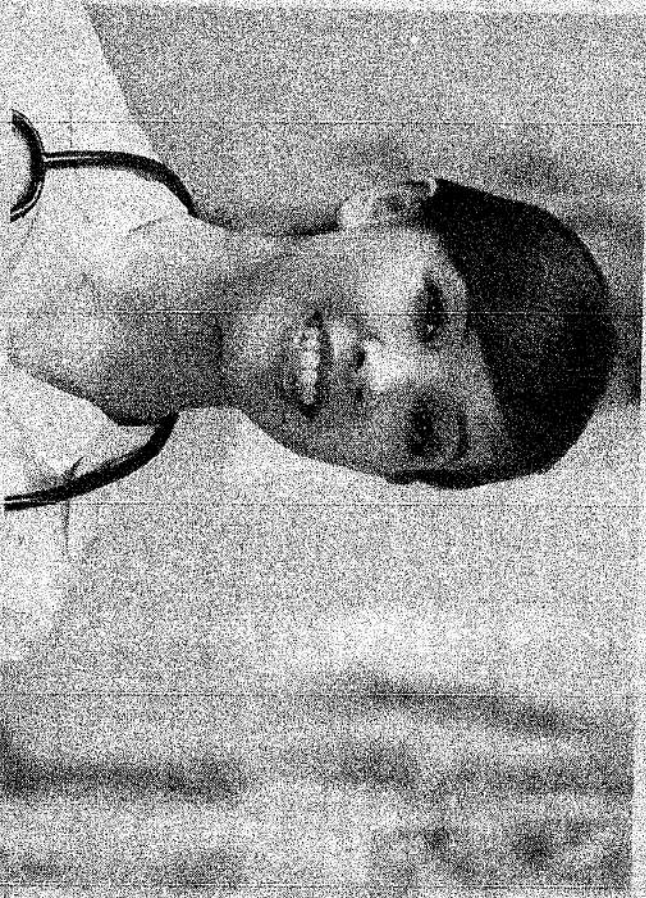
Developmental Disabilities Nurses: Consultants in Mental Health Settings

By Joni Jones RNBC-CDDN
Certified Developmental Disabilities Nurse

There has been recent discussion about health reform and its potential impact in the community setting. With the implementation of a new or changed concept there comes a period of transition. Discussions that include exchanges of ideas to ease the transitional process may become very relevant if the outcome is projected as a positive one. The intent of this article is to foster an idea, promoting a new concept during this period of revision as it relates to the merging of two very important services. This includes services to the population affected by developmental disabilities and those that seek or require services in the mental health setting.

By profession I am a Registered Nurse. Although I am certified in psychiatric and mental health nursing and as a developmental disabilities nurse, nothing has prepared me more in the provision of services as being a parent to children affected by both. With that combined experience I found an enhanced ability to relate to others that are in fact impacted by similar challenges. The result is the engagement in *functional* solutions to help others reach their individual optimal potential in life.

Experience becomes our best teacher if we are aware of the presented opportunity.



This submission will provide two real life situations that occurred in a mental health setting for the purpose of providing the education that captures the vision of the benefit that can be obtained by the creation of such a position. The details of these examples have been slightly modified for the purpose of confidentiality.

It's a gloomy day. The rain is pounding on the roof top accompanied by loud cracks of thunder, bolts of lightning and inside lights flickering. Word has been received that an 18 year old woman has

found herself in a crisis situation with thoughts of taking her own life. Shortly she found herself in a mental health setting, very much confused with an overwhelming feeling of helplessness and hopelessness.

When I first set eyes on Mary, I did not encounter the stereotypical presentation one might expect from a depressed individual with suicidal ideation. I met a very well groomed individual with sophisticated language enhanced with an air of such mannerism and politeness. We engage in conversation that revealed her life

had turned so upside down that she could not "take" not knowing what was "wrong" with her any longer. She sought such relief because the tortured thought in her mind progressed to those focused, ending her life altogether. This was truly tragic situation.

With the process of gathering information I was able to inquire and obtain information about Mary's history that was listed on the standardized computer generated questionnaire. My added experience this particular specialty made this encounter a positive one. As we talked further at further Mary felt the weight lift right off her shoulders. She felt like a changed woman simply from someone *understanding* who she was going through.

Conversation revealed she had many signs of Asperger's Syndrome. She learned to read at a very young age and used sophisticated language. She did not "hang out" with people her own age and to this day described herself as having social phobia. She always had focus in challenges but was always exceptionally bright in her area of interests. She possessed literal translation and felt it was difficult to maintain eye contact while conversing. She became confused about emotions especially when two different emotions co-existed. She laughed about her peculiar traits as it related to obsessions and compulsions. It was terrific to

see Nurses on page 3

Nurses from page 24

see this modification in her mood as we continued to talk.

I inquired if she ever heard of the term Asperger's Syndrome. She became very excited and said yes. In fact an acquaintance several years ago, who actually had the Syndrome, felt she too possessed similar characteristics. She said that her dad was actually going to look into this, but she has gone to Psychiatrists that have prescribed antipsychotic medications that were making her feel worse instead of better. She stated she was tired of all the medication changes. When asked if she ever was evaluated by a neurologist her response was "no." As a child she was never examined by a developmental pediatrician.

We connected. It was very simple and uncomplicated. I reinforced that I was not a Physician and had no authority to diagnose but could provide information that she can discuss with the Psychiatrist about the consideration of such a diagnosis. We discussed reading materials, support groups and organizations should she be interested.

In that moment I watched a beautiful young lady exclaim excitedly her interest and reverse those feelings of helplessness and hopelessness as the weight lifted so effortlessly off her shoulders. We were both happy we met.

Then there was David. David was a teenager diagnosed with a developmental disability with a coexisting cognitive impairment who suffered from feelings of depression, triggered from the rejection of a desired first sexual relationship. He

heard voices that reminded him of the event; replaying in his head over and over throughout the day. Those voices emerged into command hallucinations. As one can imagine, life became tortuous for David.

David's mother was very supportive and quite educated about his disorder. Her love for her son was evident. She was quick to educate staff, covering feelings of her own helplessness. She came to us once before and was not pleased with the outcome so she dreaded his return. She felt like there was no choice though, for her son's life too, had spiraled out of control.

Staff complained of her overbearingness. Personally, I saw it quite differently. I saw a part part of me in her so relating came quite easily. I picked up the phone with a plan to anticipate her needs. Not only was she quite surprised, but her defensiveness became thin as the security rose in her voice. The conversation of helplessness and hopelessness to hopefulness came swiftly and naturally. The air seemed simply magical.

David was quite popular on the unit. His developmental challenges were evident in his looks and presentation. Although he had an auditory processing delay he answered questions and expressed himself quite appropriately.

Quite often I find that individuals fall prey to IQ testing that was performed many years ago. Unfortunately results sometimes attach to them like metal does to a magnet. His expressions certainly did not match those IQ conclusions.

As in any mental health setting there are rules and regulations based on existing pro-

cedures. However, modification within interpretation can be sometimes necessary to individualize effective plans of care. Being certified or educated with the specialty of working with the developmental disability population gave me the credentials needed for persuasion related to such modification.

Orders were received that allowed this gentleman to have his security bedding. It also allowed him to listen to his music in an isolative room under camera surveillance. To my surprise was the response; inflexibility of surrounding staff and support from all the patients that didn't receive such privileges.

This was such a simple and reasonable accommodation for his disability. There were no explosive outbursts as disclosed in his history and he felt safe. With the mood stabilization, calm environment, and sense of security, therapeutic intervention soon followed.

A conference with both David and his mother became life altering. We discussed the use of classical music with headphones to manage the voices. We agreed that the lyrics in songs could trigger the reminder of the failed relationship. David was very excited. He shared that he really enjoyed classical music. We discussed referral to supported employment for David.

We discussed job coaching and opportunities for him to meet others in the community to aid in the development of healthy relationships and to help resolve the isolation, disturbing thoughts and depression that followed. We discussed IQ testing, cognitive behavioral therapy, self-talk and affirmations. David was equally

excited and so was his mother. She could not believe the difference in her experience this time around. With permission we all hugged.

David now had a sense of purpose and direction. If non experienced, nurse cross paths I am confident such direction would not have been provided, an the circle for this family would have continued. It is very important for professionals to *listen* and be *alert* to all presented disclosures that can provide the clues necessary to develop an *effective* plan of care.

Going through motions should not be in any repertoire when it comes to the preservation of life itself. Because of my experience and certification in developmental disabilities, the visit to our facility became life altering. I believe it is time for legislators and organizations to become more aware of the many specialized skills that Developmental Disabilities Nurses possess.

Yes, this is the time for health reform. Many people are now finding themselves with mental health challenges and many of those individuals have an existing developmental disability. The health management specialty of the Developmental Disability Nurse can help preserve life and should be viewed as a valuable asset to the healthcare system.

Joni Jones RNBC-CDDN, is a Registered Nurse, Board Certified in Psychiatric and Mental Health Nursing, is a Certified Developmental Disabilities Nurse, and is a member of the Developmental Disabilities Nurses Association (DDNA).

Celebrating 90 Years

NEW JERSEY

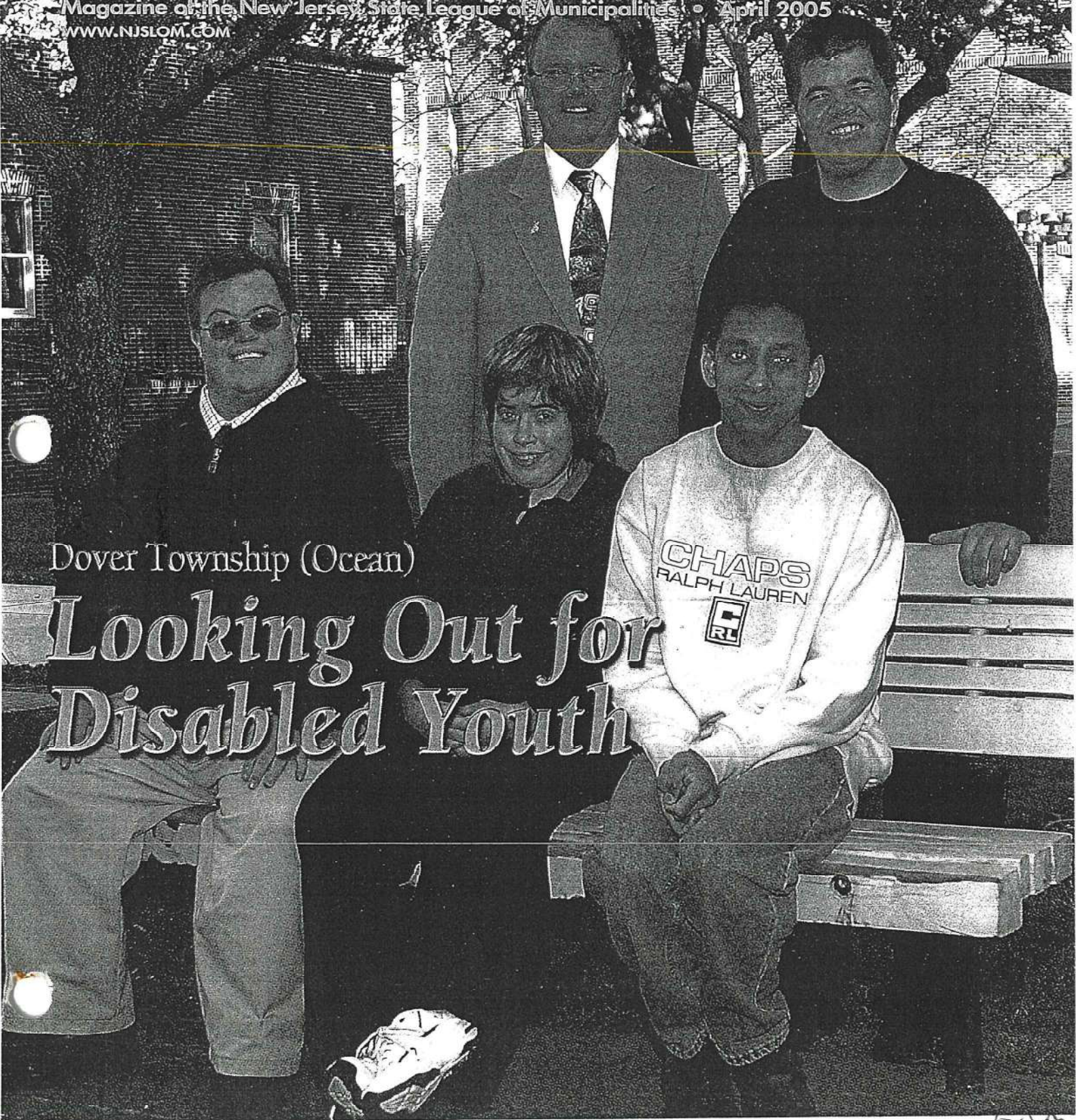
MUNICIPALITIES

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Dover Township (Ocean)

Looking Out for Disabled Youth



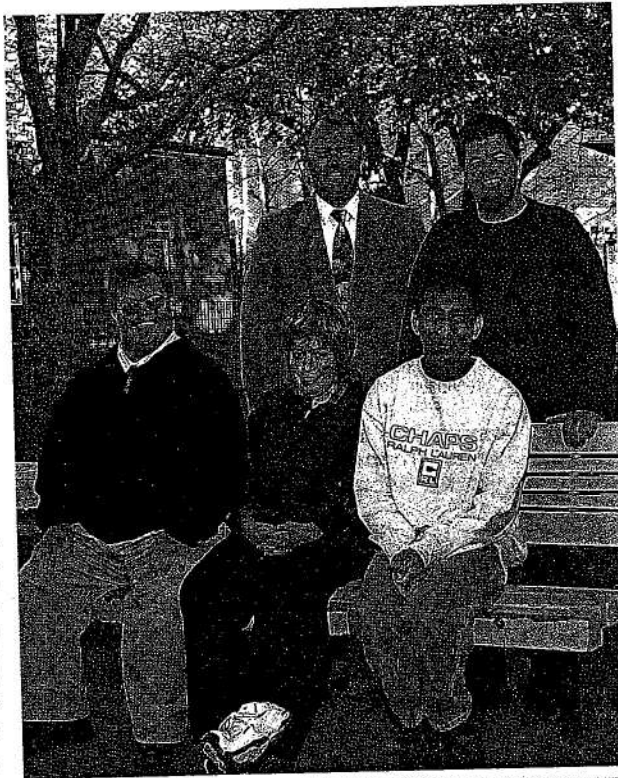
Dover's Council on Developmental Disabilities Helping Parents Raise Our Most Vulnerable Citizens

Joni Jones
and
Lawrence R. Jones

As the parents of two developmentally disabled boys, we have spent years dealing with government agencies and private professionals/service providers on issues relative to our children's health, education and well-being. We have also spent years talking with similarly situated mothers and fathers throughout New Jersey.

As a result of these experiences, we gradually learned a simple truth: notwithstanding everyone's best intentions, governmental agencies and private service providers do not always see eye-to-eye with parents. Rather, there are often huge communication gaps and mutual negative perceptions which impair the ability of both sides to work together effectively. Parents often perceive agencies and providers as insensitive, incompetent or both. Agencies and service providers sometimes unofficially label certain parents as "difficult." Consequently, those who suffer most in this dynamic are the disabled children, whose best interests are supposed to be the paramount concern of all involved.

Against this backdrop, we set out two years ago to initiate and develop a pilot project in our hometown municipality, Dover Township (also



Dover Mayor Paul Brush poses with special citizens (L to R) Josh Ferris, Danielle Abrahamsen, Jay Chawda and Todd Wilson.

known as Toms River). The goal of the project was to create an arm of our local government specifically dedicated to the needs of children and young adults with developmental disabilities such as autism, Down syndrome and cerebral palsy. This arm of government would be composed of parents, family members, service providers and government

agencies all working together to help develop policies and programs of significance to the developmentally disabled community. The end result was the inception of the Dover Township Mayor's Advisory Council on Developmental Disabilities (MACDD).

Governing Body Takes a Personal Interest In 2001, we informally presented the concept of an Advisory Committee on Developmental Disabilities to two Dover Township committeemen, John Russo and John Furey. Both men had family members with developmental disabilities and agreed to support the cause. In 2003, Russo became Mayor and introduced an ordinance that was approved with unanimous bipartisan support, from Mayor Russo and Committeemen Furey, Rich Larsen, Mike Fiore and Carmen Inteso.

The original council members were Tammy Freudenberg from the Toms River School District, Jon Day of the ARC, Sheila Melore of 21 Plus, Judy Potter of Children's Specialized Hospital, Donna Cetrone of Community Medical Center, Eric Joyce of the Epilepsy Foundation, and parents/family members Fay Wilson, Regina Ferris, Joyce Abrahamson, Jean Martowliis, Margaret Murphy, Alice Schovanec, Cynthia Ninivaggi, Karen Russo, Viola Furey, and ourselves.

Upon enactment of the ordinance, it was determined that the council would meet monthly, on the final Wednesday of each month.

Lawrence and Joni Jones of Dover Township are the parents of two developmentally disabled children, who initiated the development of the MACDD, and served as the council's co-chairpersons in its first year (2003). Larry is an attorney and Joni is a registered nurse and professional autism consultant.

Fair, Seminars and Reference Manual Meet a Community Need

The council's initial year included three primary undertakings. First was the development of a public information fair where families of developmentally disabled individuals could speak to professionals and gather information on resources. The event was held at Toms River East High School. Over 65 agencies participated, including professionals from governmental agencies, non-profit corporations and service providers from throughout New Jersey. The fair — which was attended by hundreds of citizens — was sponsored by WOBN-Radio (92.7) which helped promote the event through a series of pro bono public service announcements during the weeks leading up to the event. Various non-profit agencies donated refreshments. A children's center was also created where children could

play and create art projects. Admission was free and open to the public.

The Council's second major undertaking in 2003 was the development



Over 65 agencies, including government and non-profit service providers, participated in a developmental disabilities information fair sponsored by the Mayor's Council.

of a free program of educational seminars on a host of topics relevant to the developmentally disabled community. Dubbed the "Wednesday Workshop Series," the Council

recruited esteemed professional speakers who devoted their time and expertise to lecture on a variety of subjects at Dover Town Hall on 12 consecutive Wednesday evenings from September-December 2003. Series topics included: special education, advocacy, transportation, guardianship/trust law, vocational services, the Catastrophic Illness Fund, housing, social security, psychological issues, nutritional issues, medical/dental issues, and early intervention. All seminars were videotaped for use on cable television and preserved in the Ocean County Library for public use.

The MACDD's third major undertaking was the development and publication of a reference manual for new residents of Dover Township, providing names and addresses of a host of service providers specializing in assisting developmentally disabled individuals.

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The Mayor's Advisory Council on Developmental Disabilities Ordinance

BE IT ORDAINED by the Township Committee of the Township of Dover, County of Ocean, State of New Jersey, as follows....

There is hereby established the Mayor's Advisory Council on behalf of Children and Young Adults with Developmental Disabilities which shall serve for the purpose of advising the Township Committee and making recommendations on ordinances and policies which concern and are of interest to children and young adults with developmental disabilities and their families.

This Advisory Council shall also serve to advise the Township Committee as to prospective and appropriate procedures to provide advocacy on behalf of children and young adults with developmental disabilities in the community. The Council shall

further directly assist the members of our community who are in need of special services and education; specialized governmental services in the areas of physical therapy, occupational therapy, speech therapy and related developmental encouraging techniques; entertainment and educational programs; specialized equipment including but not limited to specialized medical equipment such as walkers, wheelchairs and other similar apparatus; health care, transportation, employment, and housing. The Council shall be comprised of... representatives of the Toms River School District, ARC of Ocean County, 21 Plus, Children's Specialized Hospital/Toms River, Community Medical Center, the Mayor's Advisory Committee on ADA Compliance, and adults with developmental disabilities

and family members who live in our community of those affected by Developmental disabilities. The representative of the first five categories need not be residents of Dover Township provided that their programs shall serve and benefit residents of Dover Township, provided further that, nevertheless, a majority of members shall be residents of the Township of Dover. In addition, the Mayor and one other Township committee member shall serve as liaisons to this Council. The terms for members of the Council shall be for one year. The Township Committee shall select a Chairman of the Council. The Council may also have a representative of the Ocean County Health Department to act as a liaison to that Department and the Ocean County Board of Freeholders.

A Playground for All Children In November of 2003, as the result of a change-of-government referendum, Dover Township voters directly voted for their Mayor for the first time in township history. Independent Paul C. Brush, was elected Mayor. Within days of his inauguration in January 2004, Mayor Brush met with representatives of the MACDD and pledged his continued support of the Council.

Thereafter, the MACDD began developing its second year agenda, beginning with the Dover Township Integrated Playground Project of 2004. The MACDD surveyed the playgrounds in the Toms River area, and concluded there was a need to develop a state-of-the-art integrated municipal playground. An integrated playground is designed to serve both able-bodied and disabled children at the same time. Such a playground can promote social growth, interaction and inclusion between disabled and non-disabled children.

MACDD members researched the issue and appeared before the Dover

Township Recreation Committee to generate support for a \$100,000 allotment in the municipal budget for the development of an integrated playground. During the presentation before the Recreation Committee, a Board of Education representative from the MACDD related her personal observations of how youngsters who use wheelchairs often had to sit on the sidelines of playgrounds, unable to actively participate in many activities. Following the conclusion of the presentation, the Recreation Committee unanimously agreed to support the MACDD's initiative. Shortly thereafter, Mayor Brush included a \$100,000 allotment Dover Township's proposed 2004-2005 budget for development of an integrated municipal playground.

Additional pending projects for 2004-2005 include the development of a continuing education program for municipal and state police on dealing with developmentally disabled individuals, job fairs for the hiring of challenged employees, devel-

opment of additional recreational programs for the disabled (Special Olympic training, after-school programs for socialization, art, drama and dance). The Council also advocated for advancements in housing and work-related transportation as well. More projects are currently in the works.

During 2004, the issue arose as to whether each year's MACDD chairperson should be a parent of a disabled individual, or a representative from a service provider. Following lengthy discussions on the issue, the MACDD determined that the annual chairperson should preferably be a parent, so as to maintain the council's parent-driven nucleus and assistive role of the provider organizations.

A Model for Other Towns Hopefully, Dover Township's MACDD project can be followed in form and substance by municipalities throughout the state, consequently enhancing and improving for the developmentally disabled population on a statewide basis. ▲

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10 Basic Principles of Cultural Competency: A Starting Point for New Mediators

By Hon. Lawrence R. Jones and Joni Jones, RN-BC

As a result of COVID-19 and its impact on courthouse operations, there is an increased focus on mediation as a method of attempting to resolve cases.

With emerging social awareness of the major benefits of understanding and working with people from diverse backgrounds, there is also a heightened interest in the concept of “cultural competency” in an inclusive society. Adding cultural competency and sensitivity to mediation can help mediators in both family and civil proceedings better manage the process.

Those beginning the journey toward cultural competency may at first feel overwhelmed by the absence of any specific roadmap. There is no single, universal, “official” textbook on the subject. Some information is complex, and different resources, studies and articles may at times seem ambiguous or contradictory.

For new mediators who have little or no prior familiarity with the concept of cultural competency, but seek to improve their ability to help people from different backgrounds, there can be a significant benefit to using certain foundational principles as a starting point for further study. To assist in the educational process, we have developed the following:

10 BASIC PRINCIPLES OF CULTURAL COMPETENCY (“BPCC”)

1) *“Culture” is not limited to one’s nation of origin. Rather, culture may include other relevant categories including ethnicity, race, religion, gender, physical or developmental challenges, sexual orientation, and other criteria with which a person may identify.*

This concept addresses recognition of a broad definition of “culture” beyond more traditionally narrow terms.

2) *Cultures may have many sub-cultures and some people may be part of multiple or overlapping sub-cultures, with various levels of self-identification; therefore, cultures are heterogeneous, as individual members have their own thoughts, viewpoints, life experiences and responses which define their uniqueness.*

This point emphasizes that when a person identifies with a culture or sub-culture, the degree of adherence to traditional customs and value systems may vary from person to person. As every person is unique, a mediator cannot presume that any person has particular characteristics, beliefs, or customs merely because one or more other members of that person’s culture have such traits. Such presumptions can lead to overgeneralization and stereotyping. While a culturally competent mediator may research and learn about a culture, one should never pre-suppose a person’s views beforehand, but

rather seek further information, input and clarification.

3) Cultural competency does not require a mediator to be an expert about multiple cultures. Rather, it is more important that a mediator remains constantly open to learning about relevant issues of cultural importance to each person as presented.

A person's self-identification with some cultural norms and traditions may change based upon life experience. One's personal adherence to the customs and rituals of a particular lifestyle may vary over the years for any number of reasons.

4) A culturally competent mediator listens and appreciates that individuals from different cultures may have different viewpoints than a mediator, and no such viewpoints should be disregarded or devalued as a result.

There may be multiple ways of looking at an issue. A culturally competent mediator knows the importance of effective listening and accepts and appreciates that people from varying backgrounds can have differences in viewpoints which are all valuable.

5) A culturally competent mediator remains aware of the potential for implicit and unconscious prejudice and biases, which may negatively impact the mediation process; cultural competency is supported by an ongoing willingness and effort to self-evaluate for open-mindedness to persons and ideas from all backgrounds.

A mediator's willingness to engage in ongoing self-evaluation is key. This helps protect against unconscious bias impairing the mediator's ability to appreciate the merits of other people's ideas and ways of addressing and potentially resolving an issue.

6) A culturally competent mediator is cautious and sensitive about the terms used in addressing or describing members of any particular class.

There can be outdated or conflicting information from different sources as to how to appropriately address people who identify with a particular culture. Different people may prefer different terminology. An example is when parents of a child diagnosed with Autism Spectrum Disorder (ASD) may prefer the term "child with autism" over "autistic child." A mediator can ask people their preferred terminology. Acknowledging and respecting personal preference can help support cultural awareness.

7) If a mediator learns that he/she/they inadvertently offended a person through words, gestures or actions, it is generally helpful and constructive to acknowledge the situation and consciously avoid repetition.

Life teaches us that every person – without exception – may say or do something which personally offends somebody else. The principle is that the mediator accepts responsibility

when learning that his/ her/their words, gestures or actions have unintentionally offended someone. Maintaining trust, rapport and respect is very valuable in the mediation process.

8) *There is no single training program that suddenly transforms a new or experienced mediator into a culturally competent professional.*

While there may be numerous continuing education, professional development workshops and seminars on cultural competency, the topic involves far more than rote memorization of points and principles that might be covered in any particular class or course. Cultural competency is an ever-evolving and ongoing process, which involves a long-term commitment to constant education, open-mindedness and willingness to learn when dealing with people from diverse backgrounds

9) *When mediating a case involving people of different cultures, a primary goal of a culturally competent mediator is not to determine who is "right" or "wrong" but rather to determine ways to respectfully construct a bridge of common interests and agreements between the parties.*

Mediating a case between people of different cultures may present challenges in reaching compromises between minds that view the same issues very differently. A culturally competent mediator appreciates and understands that compassion and reason may help people from different cultures find common ground and reach mutually acceptable resolutions. A successful mediation can occur between people of different cultures when at the conclusion, both sides feel that they have obtained some meaningful benefit.

10) *"Diversity/Inclusion" and "Cultural Competency" are related but different concepts*

The concept of "cultural competency" differs from the concept of "diversity and inclusion." While "diversity and inclusion" supports the concept of persons from multiple and diverse cultures and backgrounds working together, "cultural competency" focuses on the actual ability and willingness of persons from all backgrounds to understand and learn from each other with open minds. For example, a business seeking to practice diversity and inclusion may hire multiple qualified persons from different cultures. Yet, if that same business makes little or no legitimate effort to share ideas and actually understand and learn from the diverse persons hired, then the business may have staff diversity but a deficiency in cultural competency. Reciprocally, if the same business has an open-mindedness to receive and consider different ideas from persons of different cultures, but

little or no actual diversity and inclusion, then the company may never realize the full benefit of diverse teammates working together. By pairing and utilizing both diversity/inclusion and cultural competency together at the same time, the resulting synergy can significantly strengthen a group or organization's efforts in achieving a common goal.

Hon. Lawrence R. Jones retired as a Superior Court judge in 2017. He is a mediator and an adjunct professor at Monmouth University and Montclair State University. Joni Jones, RNBC, is a mental health professional and a member of the New Jersey Association of Professional Mediators' Committee on Diversity and Inclusion. They are the co-authors of "10 Basic Principles of Cultural Competency", which was first presented at the NJAPM'S Inaugural Forum on Cultural Competency for Mediators in February 2021.