# SURROGATE'S COURT OF THE STATE OF NEW YORK COUNTY OF KINGS

Proceeding for the Appointment of a Guardian for

### MICHELLE M.

**DECISION and ORDER** File No. 2014-XXXX

Pursuant to SCPA Article 17-A

## LÓPEZ TORRES, S.

Nicole M. and Daniel M. (together, the petitioners) bring the instant petition seeking guardianship of their daughter, Michelle M. (Michelle), pursuant to Article 17-A of the Surrogate's Court Procedure Act.

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Michelle is a vibrant and engaging thirty-four year old who enjoys an independent life. Since 2008, Michelle lives in Brooklyn with two roommates in a supported apartment. Taking pride in her culinary skills, Michelle enjoys grocery shopping and cooking for herself and her roommates, and especially likes to use her mother's recipes. For the past six years, until 2015, Michelle worked part-time at a cellular phone supply store. She travels independently, using public transportation to go to work, run errands, and meet friends. Michelle engages in vocational and recreational activities at a day habilitation program run by Ohel Bais Ezra, a social services agency that provides programs and services for individuals with developmental disabilities. Michelle sees her doctors on a regular basis, making and keeping her appointments with her physicians. She takes medicine daily for her thyroid and stores her medicine in her room. Michelle does banking at her local bank, where she deposits her checks and uses both online banking and the ATM machine to keep track of and access her money. In her spare time, Michelle likes to go shopping for clothes, get her nails done, spend time with her boyfriend, and invite friends over to her apartment. On the weekends, she may visit her parents in New Jersey. In the regular course of her everyday life, Michelle makes decisions about her employment, finances, health, interpersonal relationships, personal safety, and place of residence. Michelle is also an individual living with Down's Syndrome and diagnosed with an intellectual disability.

While acknowledging that Michelle is independent in her activities of daily living, the

petitioners contend that Michelle is unable to make medical and other decisions relating to her welfare. A hearing was held on September 30, 2015, at which oral testimony was presented by Michelle, who was represented by Mental Hygiene Legal Services (MHLS),<sup>1</sup> and the petitioners, who were represented by counsel. In addition to testimony, certifications by Anna L., M.D., and Myriah R., Ph.D. (together, the certifications), as well as a psychological evaluation dated September 3, 2014, and Individualized Service Plans (ISP) from Ohel Bais Ezra for 2012, 2013, and 2014, were considered.<sup>2</sup> The certifications opine, in a conclusory manner, that "the respondent is mentally retarded<sup>3</sup> and in my opinion incapable of managing himself/herself and/or his/her affairs by reason of mental retardation . . . the respondent is not capable of understanding and appreciating the nature and consequences of health care decisions, including the benefits and risks of and alternatives to any proposed health care, and of reaching an informed decision in order to promote his/her own well being." Michelle scored a full scale IQ of 46 on the Stanford-Binet Intelligence Scales-5th Edition, placing her cognitive ability within the Moderate Intellectual Disability range, and a Vineland Adaptive Behavior Composite Standard Score of 33.

An affirmation from MHLS by Rebecca Kittrell, Esq., dated June 24, 2015, has been submitted. MHLS observed that the petitioners are actively involved in Michelle's life, that Michelle trusts the petitioners and often consults with them in her decision-making process, and,

<sup>&</sup>lt;sup>1</sup> Pursuant to Article 47 of the Mental Hygiene Law, Mental Hygiene Legal Services provides legal assistance to individuals who live in residences supervised by certain social service agencies including Ohel Bais Ezra.

<sup>&</sup>lt;sup>2</sup> These certifications are often boilerplate forms that include sections where the affirmant physician or psychologist checks off pre-printed conclusions relating to the decision-making capabilities of an intellectually or developmentally disabled individual. The court has found the certifications wanting in useful information and requires, at a minimum, psychological and psychosocial evaluations of the respondent as well as the respondent's IEP or ISP.

<sup>&</sup>lt;sup>3</sup> This court adopts the diagnostic term "intellectual disability," in lieu of "mental retardation," a diagnosis which has been replaced in the current edition of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). The revision has been adopted by the Supreme Court of the United States (see *Hall v Florida*, 572 US \_\_\_, 134 S Ct 1986 [2014]), by the U.S. Department of Education and other federal agencies (see Rosa's Law, Pub. L. 111-256, 124 Stat. 2643 [references in federal law to "mental retardation" are to be substituted with the term "intellectual disability"]) and by the New York State Office for Persons with Developmental Disabilities (OPWDD), previously known as the "Office of Mental Retardation and Developmental Disabilities" (OMRDD). The terminology contained in SCPA 17-A has not been amended and continues to refer to a diagnosis that no longer exists. The term "mental retardation" in the SCPA is antiquated and offensive, and will not be used by this court to describe individuals with disabilities.

if the court were to determine that Michelle is in need of an Article 17-A guardian, the petitioners would be appropriate. However, MHLS concludes that "there may be less restrictive means available to protect both Michelle and her family's interests, while maximizing Michelle's independence and autonomy." This court agrees.

### Statutory Framework of Article 17-A

Article 17-A of the Surrogate's Court Procedure Act (Article 17-A) governs guardianship of persons who are intellectually<sup>4</sup> or developmentally disabled. An intellectually disabled person is defined by SCPA 1750 as a person who is permanently or indefinitely incapable of managing herself and/or her own affairs because of an intellectual disability. The condition must be certified by a licensed physician and a licensed psychologist, or by two licensed physicians, one of whom has familiarity with or knowledge of the care and treatment of persons with intellectual disabilities. It must appear to the satisfaction of the court that the best interests of such person will be promoted by the appointment of a guardian. SCPA 1754 (5).

A developmentally disabled person is defined by SCPA 1750-a as a person who has an impaired ability to understand and appreciate the nature and consequences of decisions which result in an incapacity to manage himself and/or his own affairs. The developmental disability must be permanent or indefinite and attributable to cerebral palsy, epilepsy, neurological impairment, autism, traumatic brain injury, or any condition found to be closely related to intellectual disability. The condition must have originated before the age of twenty-two, except for traumatic brain injury which has no age limit. As with SCPA 1750, the condition must be properly certified by the appropriate healthcare professionals, and the court must determine that appointment of a guardian is in such person's best interest. SCPA 1754 (5). Regardless of whether an individual's disability is categorized under SCPA 1750 or SCPA 1750-a, the determination of the need for guardianship is functionally the same and relies upon the same body of law.

Unlike guardianships granted under Article 81 of the Mental Hygiene Law, in which the relief granted is "closely tailored to grant the guardian no more power than is absolutely

<sup>&</sup>lt;sup>4</sup> See footnote 3.

necessary under the circumstances of the case" (*Matter of Chaim A.K.*, 26 Misc 3d 837, 844 [Sur Ct, New York County 2009]), the appointment of a guardian under Article 17-A is an entirely plenary guardianship. The plain language of Article 17-A does not grant a court authority or discretion to limit or tailor the scope of guardianship of the person to address the individual's specific areas of need.<sup>5</sup> Article 17-A guardianship completely removes that individual's legal right to make decisions over her own affairs and vests in the guardian "virtually complete power over such individual," *Matter of Mark C.H.*, 28 Misc 3d 765, 776 (Sur Ct, New York County 2010). Many decisions that define the essence of an individual, such as where and with whom she lives, whether she can travel, work, marry, engage in certain social activities, whether and how she manages her income and resources, and what medical treatment she undergoes or refuses, are removed from that individual, who will have lost the legal right and ability to govern her own affairs and participate in society without the approval of another. For this reason, Article 17-A guardianship is perhaps the most restrictive type of guardianship available under New York law.

In order to support the significant loss of individual liberty to the person with disability, the petitioners bear the burden of proving, to the satisfaction of the court, that the appointment of a guardian is necessary and in the "best interest" of the person whose legal rights are being removed. SCPA 1750; SCPA 1750-a; *Matter of Maselli*, NYLJ, March 29, 2000 at 28, col 4 (Sur Ct Nassau County). The term "best interest" has been aptly described as "amorphous" *(see Matter of Chaim A.K., supra* at 845) and the criteria necessary to support a finding that appointment of a guardian is appropriate in a particular case are rarely articulated but frequently assumed. *Matter of Akiva*, NYLJ, June 11, 2013 at 31 (Sur Ct, Kings County). One such assumption is that upon a diagnosis of intellectual disability, an individual is presumed to lack capacity to make independent decisions in every area of his life. The perfunctory appointment of a plenary guardian based upon medical certifications or diagnostic tests alone, without careful and meaningful inquiry into the individual's functional capacity, relies upon the incorrect

<sup>&</sup>lt;sup>5</sup> While Article 17-A allows for the limited guardianship of property, as provided in SCPA 1756, there is no equivalent statutory provision permitting limited guardianship of the person.

assumption that the mere status of intellectual disability provides sufficient basis to wholly remove an individual's legal right to make decisions for himself. This approach is contrary to established conventions of international human rights (see Convention on the Rights of Persons with Disabilities, G.A. Res. 61/611, U.N. Doc. A/RES/61/611, art. 12 [Dec. 6, 2006]) (CRPD), the implementation of the United States Supreme Court decision in Olmstead v L.C., 527 US 581 (1999) (Olmstead), and the findings and underlying purpose of the Americans with Disability Act of 1990 (ADA). Instead, article 12 (1) and (2) of the CRPD provide persuasive authority for the foundational premise that "persons with disabilities have a right to recognition everywhere as persons before the law" and "persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life." Consistent with the ADA's mandate "to assure equality of opportunity, full participation, independent living and economic self-sufficiency" (42 U.S. Code § 12101 [a] [7]) for individuals with disabilities, any evaluation of "best interests" requires assisting those individuals in an integrative manner that least restricts their autonomy. Interpreting the ADA, the Supreme Court in *Olmstead* held that a state's services, programs, and activities for people with disabilities must be administered in the most integrated setting appropriate to each person's unique needs. Charged with developing a plan consistent with the state's obligations under *Olmstead*, New York State Governor Cuomo created the Olmstead Plan Development and Implementation Cabinet (Olmstead Cabinet) in 2012. The Olmstead Cabinet issued a report of its recommendations, finding that

Community integration includes the ability of people with disabilities to make their own choices to the maximum extent possible. Guardianship removes the legal decision-making authority of an individual with a disability and should, consistent with *Olmstead*, only be imposed if necessary and in the least restrictive manner.

*(see,* Report and Recommendations of the Olmstead Cabinet: *A Comprehensive Plan for Serving New Yorkers with Disabilities in the Most Integrated Setting* at 27, October 2013).<sup>6</sup> With the

<sup>&</sup>lt;sup>6</sup> The Olmstead Cabinet also identified the need to reform the guardianship laws for people with intellectual and developmental disabilities in New York. Criticizing Article 17-A as "diagnosis driven" rather than based upon functional capacity of the person with disability, and recognizing the inability of Article 17-A to limit guardianship rights to the individual's specific incapacities as inconsistent with the least-restrictive philosophy of *Olmstead*, the Olmstead Cabinet "recommends that Article 17A be modernized in light of the Olmstead mandate to mirror the more recent Article 81 with respect to appointment, hearings, functional capacity, and consideration of choice and

increasing recognition that a wide range of functional capacity is present among persons with diagnoses of intellectual disability, autism, and other developmental disabilities (*see Matter of Chaim, supra*), the New York State Legislature, in evaluating Article 17-A in 1990, observed

[S]ince this statute was enacted in 1969, momentous changes have occurred in the care, treatment and understanding of these individuals. Deinstitutionalization and community-based care have increased the capacity of persons with mental retardation and developmental disabilities to function independently and make many of their own decisions. These rights and activities which society has increasingly come to recognize should be exercised by such persons to the fullest extent possible  $\dots$ <sup>7</sup>

Consequently, this court finds that understanding the functional capacity of an individual with disability, that is, what an individual can or cannot do in managing her daily affairs, and assessing what is the least restrictive tool available to address that individual's specific area of need, is a necessary inquiry in determining what is in her "best interest." *Proceeding for Hytham M.G.*, NYLJ 1202756960466 (Sur Ct, Kings County 2016).

### Least Restrictive Alternatives and Supported Decision Making

In order to identify less restrictive alternatives to guardianship that meet the state's legitimate goal of protecting a person with intellectual or developmental disabilities from harm connected to those disabilities, an inquiry into the availability of resources to assist the individual, including a support network of family and supportive services, is required. *Matter of Dameris, supra* at 579; *see also*, Leslie Salzman, *Rethinking Guardianship (Again): Substituted Decision Making As A Violation of the Integration Mandate of Title II of the Americans with Disability Act*, 81 Colorado L. Rev. 157 [2010]) (Salzman). As Professor Salzman notes,

 $\dots$  [J]ust as we recognize that the law – and common principles of human decency – generally require that we build a ramp so that an individual with a physical impairment can enter a building without being carried up the steps, we should also recognize a legal obligation to provide decision making support to an individual with limitations in mental capabilities rather than assign a guardian to make decisions for that person.<sup>8</sup>

preference in decision making," Report and Recommendations of the Olmstead Cabinet, supra at 27-28.

<sup>&</sup>lt;sup>7</sup> McKinney's Cons Laws of NY, Book 58A, SCPA 1750, Historical and Statutory Notes, L 1990, c. 516.

<sup>&</sup>lt;sup>8</sup> Salzman at 165-166

Indeed, "proof that a person with an intellectual disability *needs* a guardian must exclude the possibility of that person's ability to live safely in the community supported by family, friends and mental health professionals," *Matter of Dameris*, 38 Misc 3d 570, 578 (Sur Ct, New York County 2012). The extreme remedy of Article 17-A guardianship should be the last resort for addressing an individual's needs because "it deprives the individual of so much power and control over his or her life," *Id.* "SCPA 17-A must be read to require that supported decision making must be explored and exhausted before guardianship can be imposed or, to put it another way, where a person with an intellectual disability has the 'other resource' of decision making support, that resource/network constitutes the least restrictive alternative, precluding the imposition of a legal guardian," *Id.* at 577. If there are less restrictive alternatives that are sufficient and reliable to meet the needs of the person, guardianship is not warranted. *See In re D.D.*, 50 Misc 3d 666 (Sur Ct, Kings County 2015); *Proceeding for Hytham M.G., supra; Matter of Guardian for A.E.*, NYLJ, August 17, 2015 at 22, col 4 (Sur Ct, Kings County).

### **Record Presented**

The record and testimony reveal that, with appropriate supportive services, Michelle already makes decisions and manages herself and her affairs without a guardian. It is undisputed that Michelle is independent in all of her activities of daily living. Since 2008, Michelle has lived in a three-bedroom supportive apartment in Brooklyn with her two apartmentmates, while her parents live in New Jersey. Michelle and her apartmentmates agree on a rotation for cooking and grocery shopping, although Michelle testified that she mostly cooks because "I love to be in the kitchen." Once a week, a counselor from Ohel Bais Ezra's (Ohel) self-directed supportive housing program meets with Michelle and her two apartmentmates in planning for the week. Michelle makes a list of items needed in the house and reviews it with the counselor. According to MHLS, the supportive apartment in which Michelle lives does not have 24 hour-staffing, as Michelle has been determined not to require 24-hour protective oversight. She is fully ambulatory and aware of all fire safety procedures.

The record reflects that Michelle is able to work. From 2009 until May 2015, she was employed part-time at a cell phone supplies store. Her responsibilities included sorting and packaging cell phone parts. She worked four days a week from 10 am to 3 pm when the store was located in Brooklyn. After the store moved to New Jersey, Michelle worked fewer days. Michelle is presently unemployed and attends a day habilitation program where she assists older people by helping to prepare lunch, going shopping for them, and providing manicures. She testified that she would like to be employed.

Michelle is able to manage her money. Michelle testified that her wages get deposited through direct deposit and she uses online banking to check how much money she has in her account. She receives checks from Social Security by the mail, which she testified she deposits in the bank. In the 2014 ISP, it was reported, "In regards to managing her money she at one point needed total support, however she is now able to do a bulk of her money management on her own." Michelle has an ATM card and uses it to withdraw money when needed.

Michelle is able to make decisions about her medical care, in consultation with the nurse at Ohel and her parents. Michelle calls the doctors' offices to make her own appointments, although she may need to be reminded to make the call. She has her primary care physician, gynecologist, and dentist's telephone numbers in her cell phone and she travels to the doctors' offices independently. Michelle keeps track of her doctor's appointments by entering the dates into her calendar, visiting her physician monthly and the dentist twice a month,. The petitioners testified, "We're not even aware of when she goes to the doctor." Michelle testified that her prescriptions are called into the pharmacy, which then delivers the medications to her. Michelle is able to self-administer her medication. She takes her medicine daily without reminders, including thyroid medication, birth control pills, and vitamin D.

Michelle is independent in her socialization. She invites friends over to her apartment and has a boyfriend. She goes clothing shopping on Kings Highway in Brooklyn on her own, or in the mall in New Jersey with her mother, goes to the nail and hair salon, and engages in other recreational activities. She had a gym membership in 2014, where she tried to attend twice a week. Michelle also travels independently. She rides the public bus, takes the subway, or walks, to her job, to her day habilitation program, to the doctors' and dentist's offices, and into Manhattan, on her own.

Petitioners contend that while Michelle can make decisions on her own, she does not make "the best decisions." During the hearing, petitioner Nicole M. was asked by her counsel,

- [Question:] Do you feel that Michelle is able to make decisions with regard to her care plan without your assistance?
- [Answer:] She can make decisions but she doesn't follow through. She needs to be directed on a daily basis. She needs somebody really on top of it. She can make a decision but it's not always the right decision. Then when she decides and she knows and she understands that it has to be a certain way, she doesn't always do it.

Petitioners expressed they "would like her to have regular doctors, somebody that we really follow up and make sure that everything is okay," and are concerned about Michelle's weight. Moreover, other than a brief mention that Michelle had to be taken to the hospital, there were no other medical incidents about which testimony was given. Petitioner was unable to provide specific instances where Michelle made medical decisions contrary to her best interest and the record is utterly devoid of evidence regarding Michelle's inability to make decisions regarding her medical, financial, or daily affairs. Petitioners appear to be motivated by a generalized and speculative fear of unspecified dangers, rather than upon evidence of actual harm arising from Michelle's choices.

It is evident that the petitioners deeply love and care for Michelle, wanting what they believe is best for her. But while parents' desire for peace of mind and natural instinct to protect their loved one may be assuaged by the appointment of a guardian, it is not, however, in the best interest of a person with the capacity to make independent decisions to have her decision making wholly removed through Article 17-A guardianship, no matter how well-intentioned the guardian. The appropriate legal standard is not whether the petitioners can make better decisions than Michelle, it is whether or not Michelle has the capacity to make decisions for herself, albeit with supportive services. *See Matter of Raymond J.R.*, Sur Ct, Kings County, Dec. 9, 2011, López Torres, S., File No. 2011-XXX. Upon the record presented, the credible evidence clearly demonstrates that Michelle is an adult who, despite cognitive limitations, has capacity to make decisions affecting the management of her own affairs with the support of her family and supportive services. Like the rest of us, Michelle makes decisions about her affairs – where to live, where to work, what to buy, whom to date -- with the advice of those whom she chooses to consult. This does not render her in need of guardianship any more than it does an adult of

typical intelligence and functioning who consults with trusted friends and family prior to making important decisions. To the extent that Michelle may require or desire additional support, evidence of which has not been presented, alternatives to guardianship, such as a durable power of attorney, advance directives, health care proxies, representative payee arrangements, and direct bank deposit systems, can provide targeted assistance without wholly supplanting Michelle's right to make decisions in all her affairs.

### Conclusion

Michelle has an inherent right and ability to make her own choices, with dignity, independence, and support. The long-standing view of plenary guardianship as the best and only mechanism available to meet the needs of every person with intellectual and developmental disabilities is challenged by the emerging recognition that persons with disabilities have varying degrees and areas of functional capacity and need, the availability of less restrictive alternatives to guardianship which provide targeted assistance and supported, instead of substituted, decision making, and the growing emphasis on empowering, integrating, and preserving the rights of persons with mental and physical disabilities. To allow Michelle to retain the legal right to make personal decisions about her own affairs, while providing her with any necessary assistance to make or communicate those decisions in a supported decision-making framework which she already has in place, is ultimately in her best interest.

For all the foregoing reasons, the court finds that petitioners have failed to meet their burden of showing that Michelle is in need of an Article 17-A guardianship. Accordingly, the petition is dismissed.

Dated: July 22, 2016 Brooklyn, New York

> HON. MARGARITA LÓPEZ TORRES Surrogate