

Ethics and Intellectual Disability

The Ethical Components of a Capacity Hearing: The Joe M. Case

Peggy Dervitz, MSW
Daniel Jurkovic, Esq.
Joan Kakascik, Ed.D.

Where, after all, do universal human rights begin? In small places, close to home – so close and so small they cannot be seen on any maps of the world.....Eleanor Roosevelt

Nothing is more sacred to Americans than our constitutional right of self-determination. Yet people all over the country who have a developmental disability lose that right every day in courtrooms all across the nation.

Eleanor Roosevelt's profound observation was brought close to home in the case of Joe M., a 50-year old gentleman with developmental disabilities. The case illustrates the ethics of care – how staff from a large government organization and its contract agencies joined together for the good of someone else, put that person first, and advocated for his right to self-determination. The case also demonstrates the ethical components of a capacity hearing – a good assessment, a good lawyer, and a good judge. This is a case where everything that could go wrong did, and then was righted.

Mr. M. is a 50-year old man with mild mental retardation and cerebral palsy who

lives in a group home licensed by the State of New Jersey. Mr. M.'s cerebral palsy manifests itself with hand tremors, an unsteady gait, and severely affected speech. He understands what is said to him and is able to express his wants and needs through simple sentences of nouns and verbs, gestures, and a picture communication book that he helped develop. He cannot verbalize more complex sentences as it is physically too difficult for him to formulate too many words in a row.

The case came to the attention of the State when Mr. M.'s case manager learned that Mr. M.'s sister, Ms. M., had retained an attorney to petition the Court for guardianship of Mr. M. Ms. M. had plans to sell her house in New Jersey and move to Virginia. As guardian, she intended to remove Mr. M. from the group home and employment program where he had resided and worked for the past seven years and move him to a group home near her in Virginia. Mr. M. did not want to go.

Ms. M.'s attorney filed for guardianship using a statute that required the submission of a certification by either a licensed physician

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or a licensed psychologist, and a certification from the Regional Administrator of the state agency responsible for Mr. M.'s care. The attorney used Mr. M.'s treating physician as his expert. The treating physician stated by way of a certification that he had examined Mr. M. and gave the following diagnosis: "cerebral palsy, obstructive sleep apnea and abdominal distention." The doctor indicated that he had also reviewed Mr. M.'s medical records and concluded that Mr. M. "is unfit and unable to govern himself and to manage his affairs because of cerebral palsy." He attached a report of a physical examination he had performed at a local hospital listing the chief complaint as abdominal pain with a recommendation for a surgical consult.

The Court appointed an attorney from a local law firm to represent Mr. M. The attorney had no specialty in guardianship matters and had little knowledge of developmental disabilities.

Prior to the hearing date, the case manager expressed concern to psychologist, Joan Kakascik, Ed.D., that Mr. M.'s hearing was coming up soon and that Mr. M. did not want to move with his sister to Virginia. At the request of the case manager, Dr. Kakascik evaluated Mr. M., reviewed his record, talked with the court-appointed attorney, and mailed him a copy of her report in which she described Mr. M.'s

many strengths and recommended a limited guardianship for legal matters and medical decisions that require informed consent.

The Court appointed an attorney from a local law firm to represent Mr. M. The attorney had no specialty in guardianship matters and had little knowledge of developmental disabilities.

According to the group home staff, the court-appointed attorney never met with Mr. M. or any of his caregivers. Mr. M. did not sit with his attorney during the hearing and did not testify. He sat in the spectator section of the courtroom with his case manager and staff from the provider agency. Testimony consisted mostly of a review of Ms. M.'s responsibilities as a guardian of person and property, and of her reporting responsibilities to the Court.

During the hearing, the Judge asked the court-appointed attorney if he saw any need to contravene the conclusions of the physician or the psychologist. The court-appointed attorney said no. The Judge also asked the court-appointed attorney if he saw any need to have Mr. M. testify. The court-appointed attorney responded that he did not think it would be helpful to the Court.

The attorney made little to no attempt to consult his client and ask him what he wanted and, therefore, he did not apply the standards in the 1994 New Jersey Supreme Court Decision: In the Matter of M.R. In the M.R. Decision, the Court ruled that even though an individual may be generally incapacitated, the individual may be able to make particular decisions. In the case of M.R., she clearly expressed a preference for where she wanted to live. The Court also clarified the role of the court-appointed attorney as one of advocacy for the wishes of M.R. In the case of Mr. M., the court-appointed attorney did not seek the wishes of his client, he used a medical diagnosis alone as evidence of incapacity, and he ignored the functional analysis and recommendation of an expert in the field. In the end, he made his recommendation based on what he thought was in the best interest of his client. That is not his job according to the M.R. Decision.

At the close of the hearing, the Judge awarded full guardianship of person and property to Ms. M. Mr. M. was depressed for several days following the hearing.

Prior to the hearing, the case manager and the psychologist sought help from their administrators and a referral was made to the Attorney General's Office. However, Ms. M. was about to sell her home and there was not enough time for the Attorney General to respond. Dr. Kakascik

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talked with the Executive Director of the Guardianship Association of New Jersey, Inc. (GANJI). The Executive Director asked a GANJI attorney, Lawyer Dan, as Mr. M. called him, if he would accept the case. Daniel Jurkovic, Esq., an elder law and disability attorney, agreed to accept the case without fee. Upon Mr. Jurkovic's request, the Court issued a restraining order barring Ms. M. from removing Mr. M. from his group home pending a review by the Court.

This time the hearing went very differently. Mr. Jurkovic narrowed the issue before the Court to the question of whether Mr. M. had the capacity to decide where he wants to live. He also vigorously advocated for Mr. M.'s position that he wanted to remain at the group home. Both of these issues very clearly mirrored the M.R. Decision.

Mr. Jurkovic met with Mr. M. on numerous occasions, learned his communication style and was able to understand him. Mr. M. understood Mr. Jurkovic's questions and responded verbally, with gestures and signs, and with his picture book. Dr. Kakascik interviewed Mr. M. again and made a thorough report of her conversations with Mr. M. Opposing counsel requested her own expert, submitted a report to the Judge but did not request the expert's testimony.

Dr. Kakascik testified at length and went through a grueling cross-examination in which Plaintiff's counsel attempted to discredit Dr. Kakascik by focusing on Mr. M.'s inability to communicate. The

Group Home manager testified, as did a speech therapist who worked with Mr. M. and helped him develop his picture book. Mr. M., dressed in his best suit, sat with his attorney and, from time to time, they consulted with each other. Mr. M. took the witness stand, was sworn in and questioned by Mr. Jurkovic, Plaintiff's attorney and the Judge.

This case was clearly a victory for Mr. M. and for all people with developmental disabilities.

Mr. M. confirmed everything that Dr. Kakascik had said in her testimony. When asked if he wanted to live in Virginia, he said no. When asked why, he pointed to his house in the picture book indicating that this was his home. When asked again, he said no. When asked why, he said, "I'm a man, not a baby."

In his summation, Mr. Jurkovic asked the Court to honor Mr. M.'s decision to remain in his group home based upon the M.R. Decision – that Mr. M.'s right to his decision should be respected, unless that decision was proved to be, by clear and convincing evidence, inappropriate.

The Judge stated that "... the evidence seems to be fairly clear that Mr. M., albeit generally incapacitated and in need of some type of guardianship, does have the specific capacity to determine where he wants to live. He has made his wishes very clear. Although not required to give a reason, he said I

like where I am. I like my friends. I like my job. I don't want to leave. I love my family and I miss them, but this is where I want to stay." Therefore, the Judge modified the earlier order and allowed Mr. M. to remain in his group home.

Mr. M. was so happy. Everyone there supported him and cried. The case manager remarked that now she understood what guardianship and rights were really all about.

Dr. Kakascik went to see the Judge the following day to thank him for his ruling. The Judge apologized for the first ruling explaining that his job is to rule based upon what the attorneys present. He was happy to have had the opportunity to make things right for Mr. M.

This case was clearly a victory for Mr. M. and for all people with developmental disabilities. It shows how important the assessment is and how important it is to be represented by an attorney who is familiar with disability law and who advocates for what the client wants.

It also makes clear the meaning of choice. Removing choice removes dignity. Having choice makes us adults.

Ethics and standards in guardianship are rooted in the principles and goals of freedom, fairness and justice. These goals are unachievable without a foundation based on good assessments, good lawyers and good judges.

Eleanor Roosevelt believed in human rights for everyone. Margaret

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Mead believed that when people work together they can change the world.

Never doubt that a group of thoughtful committed people can change the world. Indeed it is the only thing that ever has.

It was a privilege to be part of a group of thoughtful, caring and committed individuals who changed the world for Mr. M.

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Peggy Dervitz, MSW is the Regional Director of the New Jersey Bureau of Guardianship Services, Northern Regional Office. Daniel Jurkovic, Esq. is a certified elder law attorney in New Jersey. Joan Kakascik, Ed.D. is a licensed psychologist with the New Jersey Division of Developmental Disabilities, Upper Central Regional Office. The authors are members of the Guardianship Association of New Jersey, Inc. Ms. Dervitz and Dr. Kakascik are also members of the National Guardianship Association and the International Guardianship Network.

Report from the Courts: Recent American Legal Decisions

Susan Poland

In a decision dated October 25, 2007, Judge Kristin Booth Glen of the Surrogate's Court of New York, New York County appointed the biological mother of a 34-year old woman as guardian with end-of-life decision making authority. Judge Glen appointed the stepfather as standby guardian, without prejudice to the right of the biological father to apply for gua-serve. Natalie Stevens, who is nonverbal and has autistic features, has an IQ of less than 20 and a mental age of two. Her mother, a Jehovah's Witness, acknowledged that although she could not consent to blood transfusion for Natalie, a court could order such. Being a Jehovah's Witness was not otherwise problematic for end-of-life decision making. The case raises the question of whether the mental health status of an intellectually disabled patient is relevant to determining who is the more appropriate guardian, the stepfather, with whom the patient lives and who may be emotionally closer to the patient, or the biological father. Proceeding for the Appointment of a Guardian for Natalie Stevens Pursuant to SCPA Article 17-A, 238 N.Y.L.J. 81.

On June 12, 2007, the United States Court of Appeals for the District of Columbia Circuit determined that the District's 2003 policy authorizing surgeries for intellectually disabled persons who have never had the mental

capacity to make medical decisions for themselves and who are in the District's care is not inconsistent with D.C. law and the Due Process clause of the Fifteenth Amendment of the U.S. Constitution. The court reasoned that the "best interests" standard, not the "known wishes" standard, applies to those persons who have never had capacity for medical decision making, because the wishes of these persons are unknown and cannot be ascertained. The court distinguished incompetent patients between those who were once competent to make health care decisions for themselves and those who have never been competent. D.C. law requires that health care decisions be made after assessing the patient's best interests, in particular medical needs as determined by medical doctors. As the court explains, "accepting the wishes of patients who lack (and have always lacked) the mental capacity to make medical decisions does not make logical sense and would cause erroneous medical decisions – with harmful or even deadly consequences to intellectually disabled persons." *Jane Doe v. District of Columbia*, 489 F.3d 376 (D.C. Cir.)

Susan Poland, JD, is the Legal Research Associate, The National Reference Center for Bioethics Literature, Kennedy Institute of Ethics, Georgetown University.

End-of-Life Healthcare for those with Developmental Disabilities: A New York Training Program

Lawrence R. Faulkner

As discussed in the last issue of the *Newsletter of the Network on Ethics and Intellectual Disabilities*, the ability of a surrogate decision maker to make an end-of-life healthcare decision for an individual with developmental disabilities is severely limited by statute and case law in New York State. Thus, it is unlikely that the hospice provider will enter a situation in which individuals can, on behalf of themselves, have the capacity to make decisions to enroll in hospice services and decline end-of-life aggressive care or in which the hospice worker will be assisted by a healthcare proxy authorizing a family member to enroll the individual in hospice services and decline life-sustaining treatment.

More likely, the hospice provider will be entering into a situation in which the ability of surrogate decision makers to decline artificial food and hydration or other end-of-life aggressive treatments will be severely limited. An understanding of the legal and ethical restrictions on providers is therefore essential. The hospice provider may, and hopefully will, come upon a situation in which the surrogate decision maker is an Article 17A guardian who, pursuant

to the Healthcare Decisions Act for Persons with Mental Retardation, can exercise the appropriate legal and ethical considerations, enroll an individual in hospice care, and decline aggressive intervention.

Other issues— clinical, administrative and ethical – faced by the hospice and developmental disabilities provider

provided for by the New York State Developmental Disabilities Planning Council in collaboration with the Hospice and Palliative Care Association of New York State, NYSARC Inc., the Center for Excellence in Aging Services at the State University of New York at Albany, and the Office of Mental Retardation and Developmental Disabilities of New York State (OMRDD), a curriculum

was developed and a training program provided during the period running from September 1, 2005, through February 28, 2007, for hospice and developmental disability workers throughout New York State. Providers of services from both fields spent a day together sharing experiences, organizational structures, and legal

DEVELOPMENTAL DISABILITY SERVICES		HOSPICE AND PALLIATIVE CARE SERVICES
Person	↔	Patient
Natural Team	↔	Interdisciplinary Team
Direct Support Staff not medically trained	↔	Direct Support Staff medically trained
"I know the Person best"	↔	New on the scene
Used to finding answers within the "system"	↔	Provider from outside the "system"

include supervisory issues, the provision of nursing and other care, billing issues, etc. In addition, the "family" within which the hospice provider is working will be quite different from that usually encountered. Family may well consist of five or six other long-time residents of the facility with developmental disabilities and staff members, as well as external biologically-related family members.

As introduced in the last edition of the Newsletter, pursuant to a grant

and ethical considerations in decision making and attempted to further develop programs for the delivery of hospice care to individuals with developmental disabilities.

A total of 109 hospice workers and 165 developmental disability workers attended the nine programs. Attendees at the program were broken up into small groups consisting of workers from both fields. The first part of

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the curriculum, entitled "Making the Connection," is intended to familiarize each set of service workers with the other's responsibilities, legal constraints, program types, and terminology. An overview of developmental disabilities is provided along with a review of program types most likely to be encountered and the nature of residential facilities. An overview of hospice and palliative care programs is also provided along with its legal foundations, history, and culture. Individuals are then encouraged, within the structure of their small groups, to share experiences, issues, and antidotes from their own practices. The group, thereafter, reconvenes in general discussion which, importantly, includes a review of the terminologies used by the different sets of workers. The previous chart is an example of some terminology reviewed.

The second component of the program is a review of the legal background and issues providing the structure of both hospice and OMRDD programs, as well as healthcare decision making and end-of-life care, entitled, Healthcare Decision-Making and End-of-Life-Care. This component reviews, with the participants, the background of law, including delineating the right of an individual to make his or her own healthcare decision, definitions of capacity, how capacity is determined, who makes decisions when an individual lacks capacity and what types of decisions can be made for an individual under a variety of circumstances when facing "end-of-life" care. As discussed elsewhere in this article, the importance of the Healthcare Decisions Act for Persons with Developmental Disabilities and the otherwise limited authority of guardians is carefully reviewed.

The next component of the program is entitled the Dynamics of Mutual Caring. This component helps the participants identify the role of hospice

A training manual along with an accompanying CD and Powerpoint presentation was developed . . . and an interactive website is under development at: <http://www.ddhospicepalliativecare.org>.

and palliative care for individuals with life-long disabilities. Items in the program include a review of appropriate interventions and caring tools.

A final component of the program is entitled "Dealing with Illness, Loss and Grief". This component assists the participants in understanding their own, as well as "family members" connected with the individual, feelings and concerns during the dying process. Importantly, it attempts to address an understanding of the complexity of feelings associated with the end-of-life experience. In this case, the context of the "family" is of particular importance.

A training manual along with an accompanying CD and Powerpoint presentation was developed for the program and an interactive website is under development at: <http://www.ddhospicepalliativecare.org>.

The process of developing a relationship between hospice and palliative care associations and programs providing residential services

to individuals with developmental disabilities, and the employees of both, is in its infancy. However, it is clear that a working relationship between these two parts of the service provider system is essential if we are to provide services to an increasingly elderly and medically frail population of individuals with developmental disabilities.

Lawrence R. Faulkner is the General Counsel and Director of Quality Assurance at Westchester ARC. Prior to this position, he was the Deputy General Counsel for the New York State Office of Mental Retardation and Developmental Disabilities. He has authored articles on medical care decision making and the patient who is developmentally disabled, the New York State Do Not Resuscitate and Health Care Proxy statutes, abuse of older adults, guardianship and surrogate decision-making for persons incapable of giving informed consent for medical care and research on behavior modification plans. Recently, Mr. Faulkner was instrumental in the drafting and passage of the Healthcare Decisions Act for Persons with Mental Retardation.

Mr. Faulkner has been Co-Chairperson of the Committee on Issues Affecting Persons with Disabilities, and is currently a member of that Committee as well as the Health Law and Elder Law Sections of the New York State Bar Association.

Mr. Faulkner has presented programs to professional and community groups on guardianship, informed consent for medical care, DNR orders, health care proxies and other advanced care directives, consumer choice and informed consent for sexual contact.

He received a Bachelor's Degree from Cornell University and a Master's Degree and Juris Doctor from the State University of New York at Buffalo.

The Sad Case of Richard Lapointe: Update from Robert Perske

In the Summer 1996 issue of the Newsletter of the Network on Ethics and Intellectual Disability, Robert Perske reported on the case of Richard Lapointe, who at the time was a 46-year-old dishwasher diagnosed with Dandy-Walker syndrome that had caused life-long mental and physical disabilities. He had been sentenced to life without parole plus 60 years after signing three conflicting confessions to the 1987 rape and murder of an 88-year-old woman while claiming he could not remember being at the scene of the crime. The contradictions in the accounts led Robert Perske and other advocates to conclude that events could not have occurred in the manner claimed in the trial. Earlier this year Mr. Perske reported the outcome of new legal proceedings before Judge Stanley T. Fuger in the Superior Court in the Tolland Judicial District in Connecticut that was seeking a new trial on grounds of ineffective legal counsel and suppressed evidence.

Like many of you, my mind has experienced a tornado of anguish. Now that it is settling down I want to take my stand regarding the case of Richard Lapointe.

Ever since Judge Fuger recently delivered that scathing ruling against Richard Lapointe, my brain has indeed been caught up in an awful anguish. I am appalled that Judge Fuger admitted, on the opening of the trial, that he had not even read the case. I was also appalled that he threw the case out in the middle of the hearing. And on top of that, he ordered the lawyers to never ever bring this case back into the courts again.

Like you, I have come to know and care about our soft little, concrete thinking friend with Dandy-Walker Syndrome, with hearing aids and thick glasses who as a kid was nicknamed Mr. Magoo, who only walks and never runs, but still proudly tells me "I survived five shunt operations in my brain." He has also told me that when taunts and jeers are thrown at him, "It takes a better man to walk away." Why couldn't Judge Fuger ponder these facts?

Why couldn't Judge Fuger see that Richard could have never committed that raging athletic murder that included brutal blows to the face, boy-scout-knotted ligatures around the neck and hands, raping

He has also told me that when taunts and jeers are thrown at him, "It takes a better man to walk away."

of an old woman with a blunt object, carrying her 160-pound body to another location, burning the handle off a knife, and setting the apartment on fire in three places?

Instead, Judge Fuger eluded that our defense lawyers' case was an offense to the holy writ of Habeas Corpus. But I guess that's the way technical judges think.

So what is left to do now? Thus far, all DNA in Richard's case that

we knew about was used up back in 1990 while the prosecution began to build their case. Even so, our Centurion Ministry lawyer and investigator are continuing to spend time and money and great-hearted energy trying to scrape for something that still may have a small speck of readable DNA on it.

Steve Drizin, the assistant director of The Center on Wrongful Convictions based at Northwestern University School of Law, claims that it is very tough to get an exoneration without DNA. For example, Connecticut recently and quickly exonerated James Tillman as soon as they discovered game-over DNA. That made it a remarkably easy case. So I anguish that Richard's case will be so much harder to solve.

On the other hand, The Centurions never take a case if they do not believe deeply in their heart that their client is innocent. They have told us that they will keep moving forward.

For information about Richard Lapointe's case see:

<http://www.friendsofrichardlapointe.com/>

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These books and articles have been added recently to the collections of the National Reference Center for Bioethics Literature (NRCBL). Similar citations may be found online by searching the ETHXWeb database at the NRCBL. Access and tips for searching at <http://bioethics.georgetown.edu>.

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Harriet Hutson Gray, MSLS, MTS, is the Reference and Digital Services Librarian at the National Reference Center for Bioethics Literature, Kennedy Institute of Ethics, Georgetown University.

MAILING LIST

To add your name to the mailing list for The Network on Ethics and Intellectual Disability write to:

Prof. de Johannes S. Reinders
Institute for Ethics
Free University
Amsterdam, The Netherlands
J.S.Reinders@esau.th.vu.nl
OR
Robert M. Veatch
Joseph P. and Rose F.
Kennedy Institute of Ethics
Georgetown University
Washington, DC 20057 USA
veatchr@georgetown.edu

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