



**Kristi Kirschner, MD**, Director  
Donnelley Family Disability Ethics Program

### **From The Director's Desk**

The Donnelley Family Disability Ethics Program is pleased to dedicate this new issue of *Ethics Matters* to the theme of "Children with Disabilities." We are honored to profile Dr. Deb Gaebler-Spira, a RIC pediatric physiatrist who has played a pioneering role in the rehabilitation care of children with Cerebral Palsy. She recently joined a very select group of physiatrists in this country as she was promoted to full professor in the Department of PM+R at the NU Feinberg School of Medicine.

The "Ashley Treatment" has garnered a lot of media attention this year, sparking passionate debate about whether medical technologies should be used to alter the bodies of children with disabilities. We are pleased to reprint an editorial by Teresa Savage PhD, RN of the DFDEP staff that was recently published in *Pediatric Nursing*. For those who are interested in reading more about the Ashley case, the DFDEP staff also published a commentary "Ashley X: A Commentary" in the *American Journal of Physical Medicine and Rehabilitation* (2007;86:1023-1029).

## **Pediatric Physiatry: An Interview with Dr. Deb Gaebler-Spira Director of the Cerebral Palsy Program at RIC**



Dr. Gaebler-Spira in clinic with Lilly, courtesy of Katie Lorenz, RIC Marketing

### **(Director's desk, cont)**

A former disability ethics scholar, Sheila Hickey, and her colleague Justine McBride – also now a social worker at Children's Memorial Hospital – write about child abuse and children with disabilities. We often talk about the "ripple effect" of the ethics scholar's program, and Sheila reflects on how her experiences as a scholar have shaped her perspectives and current work. This article is followed by brief profiles of our ten wonderful current ethics scholars. We are also in the process of accepting applications for the next group of scholars through April 1. We hope you enjoy this issue and would love to hear your reflections or thoughts for future issues!

*Teresa A. Savage, Ph.D., RN, consultant to the Donnelley Family Disability Ethics Program, conducted an interview with Dr. Gaebler-Spira who was recently promoted to Professor of Pediatrics and Physical Medicine and Rehabilitation. We took this opportunity to ask her to reflect on her chosen specialty.*

**TS:** Tell me how you got interested in Pediatric Physiatry?

**DG:** I completed a pediatric residency at the University of Chicago and wanted to develop skills in chronic care or disability management after working at LaRabida. I was lucky to find RIC

(cont. on p. 2)



Dr. Gaebler-Spira with Lilly entertaining us in front of the camera, courtesy of Katie Lorenz, RIC Marketing

(Gaebler-Spira, cont.)

and the Physical Medicine and Rehabilitation residency. In 1985 there were no formal fellowships in pediatric rehabilitation medicine, so I ended up just starting the job at RIC. I combined pediatrics and rehabilitation to contribute to the care of children with disabilities. Since 2003 a new subspecialty has been recognized from the ABMS—Pediatric Rehabilitation Medicine. A subspecialty board exam is given and there are now 140 certified Pediatric Rehabilitation Specialists, although many more physiatrists provide care to children. Prior to fellowship training and board exams a person would gravitate towards pediatric rehab because of an interest in children. Many of the earlier pediatric rehabilitation medicine physicians were people who were pediatricians in another country and trained in PM&R in the United States. In fact, one of the founders, Gabrielle Molnar, was a pediatrician from Hungary. Angella Badel-Rivera, who was in residency with Dr. Betts, was a pediatrician from Spain and is a founder of the small but active pediatric special interest group of the American Academy of PM&R.

A major advance in the field of pediatric rehabilitation is the defined training and definition of the body of knowledge necessary to take care of children with disability. It is not just assumed that children are little adults. The core knowledge is based on development. We take into account disability in the context of the child's and family's development. There is a large distinction between acquired disabilities vs. the congenital developmental disabilities.. In the 1990's it was very common to find as many children with congenital problems as inpatients as acquired

disabilities from neurotrauma. Now the majority of children with congenital problems like, cerebral palsy or spina bifida, are treated in outpatient centers. Inpatients are almost all children who have had acquired injuries. For physicians who are more specialized in cerebral palsy, our work is more focused on outpatient vs. inpatient work. Once you have the diagnosis of cerebral palsy, for many neurologists they have little to contribute. There are some pediatric neurologists who are interested in function but mainly they are involved in the early stages of diagnosis. Developmental pediatricians are an overlap with pediatric physiatry though frequently the developmental pediatrician concentrates on cognitive and speech and language impairments. The main focus for pediatric rehabilitation is function and prevention of complications. We recommend management strategies and treatment through the lifespan.

**TS:** How have you seen pediatric physiatry change over your career?

**DG:** The biggest change is the pediatric rehabilitation training programs and the recognition of the unique nature of the field. One of the most positive changes in treatment for children and families was the initiation of early intervention for children 0-3 years of age.

**TS:** What do you see as the distinct differences between pediatric neurologist, developmental pediatrician, and pediatric physiatrist?

**One of the most positive changes in treatment for children and families was the initiation of early intervention for children 0-3 years of age.**

**DG:** The major focus of neurology is definition of etiology and providing correctable treatment, e.g. seizure disorder. Prior to a specific diagnosis, treatment can begin that provides therapy in home to babies that are delayed in development. This provides a very family (cont. on p. 3)

(Gaebler-Spira, cont.)

friendly, child-centered management since care comes into their home. Many children used to have delay in treatment and now have the opportunity to improve from the intervention.

**TS:** What do you see as the successes/major achievements over your career and also the challenges that remain?

**DG:** I think the challenges will be how do you deliver enough services with the resources you have, and how do you evaluate for what are the most appropriate services, given they ultimately may not change outcome. You need to deliver services even if you're not going to make someone 100% independent, and how do you justify that and how do you work with that?

**TS:** Would you like to see more evidence-based data for prescribing treatment?

**DG:** I think that it's certainly going to assist with large populations, like cerebral palsy, definitely pediatric brain injury, but there are going to be some (diagnoses) where you'll never have large population bases to support evidence-based. Evidence-based (practice) sounds like it's the be-all-and-end-all, but it has limitations, because each patient you see is an individual and it's not like every individual fits into a large population-based study.

**It (Pediatric Physiatry)  
doesn't save lives,  
but it adds life to the living**

**TS:** And there is such a wide spectrum of presentation with developmental delay. It's hard to nail down what the greatest needs are and how much and what kind of therapy a child needs.

**DG:** Right, right.

**TS:** What about the major accomplishments or achievements of pediatric physiatry?

**DG:** You are making an impact at many levels, not just the patient's life. Every life that you touch, you have that opportunity to assist with the adaptation of the family and child which is major. It's the most sophisticated care



Golfing at the Diversity Driving Range, part of RIC's adaptive recreational and fitness program.

that people can get. It doesn't save lives, but it *adds life to the living*. If you make a positive effect on a child, they have, hopefully, 60-70 years to live it versus your impact on a similar process with an adult. So you've got a long-lasting impact, you're touching lives of kids as well as families, and it really contributes to the whole understanding of the dynamics of disability.

**TS:** So even if you may not see improvements in function, you get an adaptation and accommodation within the family and that improves the quality of life of the child?

**DG:** Yes, and it also frames the child. You may not be able to relieve the burden of disability, but you can act positively to lift that child in terms of the impact on the family. You get to experience and understand what that child represents and how that child is represented in the family which is

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is a little known specialty,  
but it's a great gig**

equally important. These kids have tremendous meaning within a family and in the community that has reached out. It's really a network effect. I have had the opportunity and privilege to work with all kinds of families and each one has touched me and I have learned from all. From my perspective, pediatric physiatry is a little known specialty but it's a great gig.

## In Opposition of the Ashley Treatment

by Teresa A. Savage, PhD, RN

Reprinted from *Pediatric Nursing*, 2007, Volume 33, Number 2, pp. 175-178. Reprinted with permission of the publisher, Jannetti Publications, Inc., East Holly Avenue, Box 56, Pitman, NJ 08071-0056; (856) 256-2300; FAX (856) 589-7463; Web site: [www.pediatricnursing.net](http://www.pediatricnursing.net); For a sample copy of the journal, please contact the publisher. Also in this article: "In Support of the Ashley Treatment," by Sarah Shannon, PhD, RN.



Ashley from parents' Blog: <http://ashleytreatment.spaces.live.com/blog>

Ashley, at age 6 years, had surgery to remove her uterus and breast buds and after recovering from surgery, was placed on high doses of estrogen for 3 years to permanently stunt her linear growth; her parents refer to the surgeries and hormonal medication as the "Ashley Treatment." Her parents believed the surgery and medication would improve their daughter's quality of life by keeping her from reaching adult growth in height and weight. Ashley is permanently disabled from a static en-

cephalopathy. She is reported to have the cognitive abilities arrested at a 3-month level. She is unable to move out of the position in which she is placed and prefers not to be in a sitting position but in a lying position. Her parents are devoted to their daughter and say that they made the decision for the "Ashley treatment" in order to keep her at home. They fear that if she grew an anticipated adult height of 5'6" and adult weight, they would be unable to move and carry her and include her in family gatherings.

Her parents described their reasoning in choosing the "Ashley treatment" in their blog (<http://ashleytreatment.spaces.live.com/>). Within their blog, there are certain assumptions that underlie their reasoning. I challenge these assumptions.

**Assumption 1:** Keeping Ashley small will improve her quality of life. Her parents listed "bedsores," "pneumonia," and "bladder infection" as reasons for keeping her small and therefore less likely to be "bedridden" and susceptible to those three complications of immobility.

In my experience in caring for premature infants, who are the smallest human beings *ex utero*, if you do not re-

position them, they will get skin breakdown. If you do not use appropriate bedding, they will get skin breakdown. If you do not reposition them and perform pulmonary hygiene, they will get pneumonia. If you do not keep them adequately hydrated with appropriate nourishment, they are at risk for bladder infections. Size is less important as attention to positioning, bedding materials, pulmonary hygiene, nutrition, and elimination.

**The stigma towards people with disabilities  
has persisted  
despite community integration,  
mainstream education, independent living,  
and the Americans with Disabilities Act**

Ashley will still require total care and keeping her smaller will make it easier to provide her care. Keeping her small makes it physically easier to care for her, which will positively impact the quality of her life. If she was not kept small, she could still have a "good" quality of life, but her care may require more effort. Caregiver effort is no minor factor in Ashley's quality of life; it is perhaps the most critical factor in her quality of life, so I don't think her parents should deny that it was a motivating factor in the decision to use high dose estrogen to stunt her growth.

**Assumption 2:** Ashley will never bear children so she doesn't need her uterus. It is anticipated that menstrual hygiene will pose a caregiver problem and she may have menstrual cramps.

Do the risks of a hysterectomy outweigh the potential for monthly cramps and bleeding? One might argue that she will be wearing diapers all her life, so what difference does it make if there is urine, stool, or blood in the diaper? She may have discomfort with her periods or she may not. Do the known and real risks of a hysterectomy outweigh the potential risks of her monthly periods? (cont. on p. 5)

(Ashley, cont.)

If she does have skin problems associated with her menses, or she has discomfort that cannot be relieved with medication, she can be treated as any woman is treated--with hormonal therapy to relieve symptoms or to reduce or eliminate menstrual flow. If conservative therapy fails, she could have endometrial ablation or a hysterectomy. Why is it necessary to make this decision at age 6?

Some parents believe that a hysterectomy will protect their child from sexual abuse. A hysterectomy will protect against pregnancy but not molestation, rape, or sexually transmitted diseases.

***Assumption 3:** Ashley will have large breasts because there is a family history of large breasts, fibrocystic disease, and breast cancer. [It is unclear if she tested positive for the BRCA1/2 gene. If she has the gene, she's at a greater than average risk for ovarian cancer, so why weren't her ovaries removed too?] Therefore, she is better off having her breast buds removed.*

Large breasts can be uncomfortable, although there are many women with large breasts who do not choose to have them removed or even reduced. Her parents worry that her breasts will create difficulties in strapping her into her adaptive seating. A penis and scrotum may present difficulties when positioning boys with the same type and degree of disability as Ashley's, but it has not been suggested that the penis and scrotum be removed because of ease in positioning. A boy with the same disability will not reproduce and can void through a shortened urethra, much like a girl's urethra, and surgery may require minimal cutting. So the same argument about justifying removal of the uterus and breasts could be made to remove a disabled boy's penis and scrotum, but that sounds more like mutilation.

Her parents' blog also maintained that large breasts could "invite" abuse. Parents of children with this level of disability worry about vulnerability to sexual molestation. No surgery or hormonal medicating can prevent molestation, and large breasts do not "invite" abuse. Opportunity and lack of supervision invite abuse. Only close supervision of anyone coming in contact with the vulnerable person can protect against abuse.

***Assumption 4:** High dose estrogen will cause the growth plates to close, thereby stopping linear growth and concomitant weight gain.*

Are the long-term risks of high dose estrogen in a 6-year old girl known? Is it known whether or not the high dose

**Disability Groups have responded to the "Ashley Treatment" with a fervor. They criticize the medical establishment for offering drastic interventions with unknown long-term risks instead of advocating for social changes that would support Ashley and her family**



Ashley from parents' Blog: <http://ashleytreatment.spaces.love.com/blog>

estrogen will reduce growth to the degree that is desired? (Were the breast buds removed because of the possibility for breast cancer with high dose estrogens?) Again, it is disturbing to have healthy tissue removed in anticipation of a problem.

***Assumption 5:** Adults with a mental age of an infant are undignified.*

Adults with profound intellectual disability often do not look like the rest of the population. Their features may be coarse; they may have open mouths, protruding tongues, and drooling. They are often the subject of ridicule by unkind, cruel people. Do the attitudes and behavior of uncouth people warrant surgery and hormonal (cont. on p. 6)

(Ashley, cont.)

medicating of the recipient of the bad behavior? The stigma toward people with disabilities has persisted despite community integration, mainstream education, independent living, and the Americans with Disabilities Act. The parents' view of dignity, keeping Ashley's appearance more consistent with her intellectual level, differs from the view of dignity from people in the disability communities. The parents quote a passage in their blog that says "The estrogen treatment is not what is grotesque. Rather, it is the prospect of having a full-grown and fertile woman endowed with a mind of a baby." It is regrettable if her parents capitulate to the stigma and believe growth attenuation is necessary to preserve their daughter's dignity.

Disability groups have responded to the "Ashley treatment" with a fervor. They view the choices these parents made as a failure of society to provide the support to people with disabilities and their families (American Association on Intellectual and Developmental Disabilities, 2007; Disability Rights Education & Defense Fund, 2007; Not Dead Yet, 2007; Dick Sobsey [parent of a child with a disability and Director of the John Dossetor Health Ethics Centre, University of Alberta], 2007; Feminists Response in Disability Activism, 2007; ADAPT Youth, 2007r; TASH, 2007). They criticize the medical establishment for offering drastic interventions with unknown long-term risks instead of advocating for social changes that would support Ashley and her family.

I have a colleague who talks about "holding families hostage to the revolution." It's unfair to malign this family who acted with medical endorsement in choosing interventions that many people in the disability community find repugnant. They were doing what they thought was best for Ashley and their family and were extremely brave in publicly sharing their experience. However, before the revolution is over, and to afford children like Ashley all the protections that a human being should have, due process should occur when interventions like the "Ashley treatment" is recommended. The child should have an independent advocate to weigh the risks and benefits of the proposed intervention. Preferably, the advocate should be a person with a disability who is better able to envision from a disability perspective what able-bodied parents can never know---what it is like to live with a disability. Albrecht and Devlieger (1999) describe the disability paradox where people with moderate to severe disabilities report a good or excellent quality of life. The parents' projection of Ashley's quality of life may be conflated with the projection of their own or their family's quality of life. They fear the effects of the "unending work" (to borrow from Corbin and Strauss, 1988) on their lives and, in turn, believe it will adversely affect Ashley's quality of life. It seems the vast majority of disability activists strongly

oppose the "Ashley treatment." I wonder if her parents viewed it as the lesser of two evils.

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(Ashley, cont.)

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Dr. Savage is the former Associate Director of and now a consultant to the Donnelley Family Disability Ethics Program, Rehabilitation Institute of Chicago, and Assistant Professor--Research, Maternal Child Nursing, University of Illinois at Chicago, College of Nursing, Chicago, IL.

## Improving the Diagnosis and Treatment of Child Abuse in Children with Disabilities

By Sheila Hickey, LCSW, MJ ED/PST Social Worker and Justine McBride, LCSW Stem Cell Social Worker, Children's Memorial Hospital

Children's Memorial Hospital trains licensed social workers and social work graduate students to understand that the experiences of disabled children may cause them to be at an increased risk for child abuse.

Children with disabilities may learn at an early age that their "voice" and knowledge of their body is unimportant to adults and medical professionals. This risk factor has a high correlation for child abuse. The curriculum explores in depth many of the risk factors that make children vulnerable to abusers.

**The most important lessons I learned  
during my  
disability ethics fellowship  
at the Rehabilitation Institute of Chicago  
were to  
include children in their own treatment  
and to  
respectfully listen to  
what they have to say.**

The two most important lessons in our curriculum are children are to be listened to, and children are to be believed. The most important lessons I (S.H.) learned during my disability ethics fellowship at the Rehabilitation Institute of Chicago ("RIC") were to include children in their own treatment planning and to respectfully listen to what they have to say. These are two seemingly commonsense lessons that are not so common amongst even the most well intentioned medical professionals.

As a senior disability ethics scholar (S. H.), I collaborated with faculty and other senior scholars to make a documentary film in which we interviewed five adults who had disabilities since childhood. Reflecting back to the filming of the "Insights: Adults with Disabilities Reflect on their Pediatric Health Care," I remember being mesmerized by the remarkable stories of these adults. I remember feeling challenged by what I heard and to reflect on my own clinical practice with disabled children as a pediatric social worker at RIC. At the time I had to acknowledge that my "get the job done" approach often did not take into account what the children and their caregivers defined as "the job".

Several years after working on the documentary I began my current position as a social worker in the Emergency Department at Children's Memorial Hospital, where my primary responsibility is to work with the medical team in assessing for child abuse. The lessons learned while working on the filming of this DVD began to take on a fuller, more generalized meaning.

### *Relationships with Medical Providers.*

When medical professionals do not acknowledge (cont. on p. 8)

**(Diagnosis and treatment, cont.)**

a child's' expertise or allow him or her to participate in their diagnosis or medical treatment, as is developmentally appropriate, it may have negative effects on a patient's experience of the medical system and make them more at risk for abuse. The increase in risk is the result of the medical team "teaching" the child that his or her "voice" and knowledge of their body is unimportant.

Professionals who provide medical and clinical services for children can improve on that service delivery by recognizing and respecting the expertise children have in knowing their own bodies. In an acute care setting, it is important to listen to the story of the child during the abuse assessment. It is important that we recognize and respect these children. We need to assess the children for:

- increased dependence on caregivers;
- low self esteem;
- disempowerment;
- learned dependence on caregivers,
- and feelings of being unwanted

***Child abuse literature.*** Child abuse literature typically refers to risk factors that relate to the *caregivers' characteristics*. These are:

- unrealistic expectations for child development;
- incorrectly high expectations for child development;
- personality of caregiver -- low self-esteem, external locus of control, poor impulse control, depression, anxiety, antisocial behavior;
- personal history of abuse;
- addiction — 1/3 to 2/3 of cases report parental substance abuse;
- age — young or inexperienced parents
- punitive child rearing style

The literature also refers to risk factors that relate to the *caregivers' social situation*. These are:

- social isolation;
- single parent household;
- domestic violence;
- marital conflict;
- poverty;
- unemployment/financial problems;
- non-biologically related male in the home

***Assessment for Abuse/Empowering Children.*** The most important information to obtain from the caregivers and children who come to an acute care setting with injuries suspicious of abuse are: the history of injury, the developmental level of the child, and how the child is perceived by the parent(s) or caregiver.

Do the caregivers and children provide consistent histories of how the injury was obtained? Who was present at the time of injury? How did the children react to the injury? How did the caregivers react to the injury? Was there a delay in seeking medical treatment? What is the child doing developmentally? Does the history match the developmental skills of the child? Does the history match the pattern and location of injury?

How does the caregiver describe the personality of the child? Is the child perceived in a positive or negative view by the care giver? What is the child's self esteem?

The presence of drug or alcohol abuse, domestic violence, and criminal activity are important risk factors to screen for in an assessment, however they have little relationship to a diagnosis of child abuse. It is important to primarily focus on the history of injury, the child's developmental status, and how the caregiver perceives the child.

***Conclusion.*** It is very important to respect the expertise and knowledge children bring to the assessment. This not only enhances the validity of the assessment, but it also teaches children that we value their knowledge of themselves and trust their words. (cont. on p. 9)

(Diagnosis and treatment, cont.)

## Children with disabilities as compared to non-disabled children

are:

- ◆ 1.8 times more likely to be neglected
- ◆ 1.6 times more likely to be physically abused
- ◆ 2.2 times more likely to be sexually abused

– University of Maine,  
*Interdisciplinary Disability Studies, 2008*

Medical and rehabilitative professionals can use each contact with children as a point of teaching strong personal boundaries by acknowledging children have expertise and ownership over their own bodies, as is developmentally appropriate. We teach children personal boundaries: by listening and acknowledging children when they voice fear or pain; by working with them in seeking positions of comfort; by discussing with them their medical or rehabilitative diagnosis and recommended treatment; by allowing them to question the need for a certain treatment, and allowing them to direct their care, as developmentally appropriate. Medical and rehabilitative professionals prevent child abuse by listening to children.

**Children are to be seen and heard.**

## The Disability Ethics Scholars Program

Edited by Carmen A. Cicchetti, M.Ed, MA

Each year, the Donnelley Family Disability Ethics Program offers a year-long scholars program in Disability Ethics. The scholars program provides education and professional development for persons with an interest in clinical or institutional ethics, opportunities for creative studies, research, and projects which will enhance the understanding of the ethical issues that surround disability, and fosters heightened awareness and critical thinking about the models of care used in rehabilitation and the meaning of disability in our society.

Currently, we are accepting applications for the 2008–2009 Scholars Program which will begin on August 1, 2008. Information on the program as well as an application for it can be found on our website. The Scholars Program is open to anyone working within the RIC system of care. Persons not employed by RIC may apply as an external scholar. If interested, you can find both at: <http://www.ric.org/conditions/community/ethics/Education.aspx>

For this current year, we have 10 Ethics Scholars. We take this opportunity to introduce them and their focus projects. (cont. on p. 10)



Scholars Weekly Seminar

**A person without ethics  
is a wild beast  
loosed upon this world**

– *Albert Camus*  
*Philosopher and Nobel Laureate*

(Disability Ethics Scholars, cont.)



**Karin Baker, MD**, is a second year fellow in Pediatric Rehabilitation Medicine at RIC. Prior to coming to RIC, she completed her Physical Medicine and Rehabilitation residency at the University of Pittsburgh Medical Center.

For her disability ethics scholars project, she is examining the ethical dilemmas faced by parents of children with disability. Some of these ethical dilemmas have been well documented. Areas such as the role of parent vs. caregiver, chronic sorrow and guilt, balancing the needs of several children and the fair use of resources, transition to adulthood, social roles and isolation, and the establishment of guardianship and determining care needs once no longer able to actively parent have all been explored. One area that is not well documented is the treatment decision making process for parents who are subject to a wide array of advice. Decisions regarding therapies, equipment, surgeries, pain management/sedation are all influenced by the recommendations of many members of the medical team. The availability of resources for treatment is influenced by payors, including school systems and government and insurance companies. Dr. Baker would like to try to examine the influence of competing factors on how decisions are made by parents.

**Ethics is a code of values  
which guide our choices and actions  
and determine the purpose  
and course of our lives.**

**— Ayn Rand  
Philosopher and Novelist**

**The first step in the evolution of ethics  
is a sense of solidarity**

**with other human beings**

**— Dr. Albert Schweitzer  
Physician and Nobel Laureate**

**Amy Bowers, MSW, LCSW**, external scholar, is the Director of Quality Improvement and Strategic Direction at the Anixter Center.



For her scholars project, Amy seeks to examine frameworks for decision making surrounding risk and ethics. She is interested in studying how the RIC ethics team investigates ethics concerns and would like to research, develop and apply a model for the Anixter Center. She currently chairs a Risk Committee at Anixter Center. Cases involving various stakeholders are brought to the committee regarding participant safety, employee safety, decision making capacity of participants, and liability for the organization. Anixter Center strives to enhance the ability of people living with or at risk of disability – physical, intellectual, developmental, sensory, psychiatric, or HIV/AIDS-related – many individuals supported by Anixter Center have more than one disability. Most cases brought to the Risk Committee involve individuals with intellectual and developmental disability. As part of her project, Amy is researching and applying models of ethics (such as care ethics, utilitarianism and casuistry) to cases reviewed at Anixter Center. (cont. on p. 11)

(Disability Ethics Scholars, cont.)

**To care for anyone else enough  
to make their problems one's own,  
is ever the beginning  
of one's real ethical development.**

**— Felix Adler  
Founder, Society for Ethical Culture**



**Caren Jeskey, MA, LSW**, is a Care Manager in the Arthritis Program at RIC.

Caren's focus project is entitled *On the Ground Dilemmas: Honoring the True Meaning of Social Work in Real-Life Situations*. According to the Social Work Code of Ethics, the ethical principles to which all social workers should aspire pertain to the values of service, social justice, dignity and worth of the person, the importance of human relationships, integrity and competence.

Social workers are called to help people in need, address social problems, pursue social change, treat everyone in a caring and respectful fashion, strengthen relationships, promote ethical practices within organizations, and contribute to the knowledge base of social work. With these principles in mind, how does a social worker comport herself in a brain injury unit consistent with the ethics of her profession? Caren will use a case example to explore ethical dilemmas involving the best interests of the patient and/or family, team disagreement, and cultural factors in health-care. (cont. on p. 12)



**Joanne Garces, LCSW**, is a Flex Care Manager at RIC.

Joanne, for her focus project, will observe a town hall meeting, tentatively titling her project *Making Disability Visible in the Asian Pacific American (APA) Community*. She will seek the input of APA's with disabilities, service providers, and government officials on how to bring disability issues to the forefront in the APA community. Her project involves collaboration with both the Leadership Center for Asian Pacific Americans ([www.Icapachicago.org](http://www.Icapachicago.org)) and with Access Living of Metropolitan Chicago. ([www.accessliving.org](http://www.accessliving.org)). Her project has four goals. First, she seeks to work towards changing the perception of disability in the APA community. Second, she wants to document the need for more access to existent services among APA's with disabilities. Third, she wants to show that greater advocacy is needed for more culturally competent services. Finally, she plans to facilitate an exchange of resources, information and expertise between APA service providers and disability-related organizations.

**Action indeed  
is the sole medium of expression  
for ethics**

**— Jane Addams  
Founder, Chicago's Hull House**

(Disability Ethics Scholars, cont.)



**Jaime Lee, MS, CCC-SLP**, is a Research Speech Pathologist in the Center for Aphasia Research at RIC.

Jaime is studying the concept of telerehabilitation from a disability ethics perspective. She plans to frame her project around a current study underway at the *Center for Aphasia Research*

which is evaluating a computerized oral reading treatment for aphasia that is delivered over the internet.

The American Speech Language Hearing Association (ASHA) code of ethics states that clinical services should not be provided solely through correspondence, although telecommunication is acceptable where it is not prohibited by law. Telerehabilitation, the concept of performing rehabilitation away from a clinical setting or the home by using high speed internet, first appeared in the literature in 1996. Jaime plans to discuss the pros and cons of telerehabilitation in terms of ethics principles, such as beneficence, egalitarianism and privacy.

**You're born with intelligence,  
but not with ethics**

— *Massad Ayoob*  
*Author*

**Reason and compassion  
guide our efforts  
to apply knowledge ethically,  
to understand other people,  
and have ethical relationships**

— *Molleen Matsumura*  
*Author*

**Christina Papadimitriou, PhD**, is a Research Associate in the Center for Rehabilitation Outcomes Research at RIC.

Dr. Papadimitriou plans to explore the ways that Physical Therapists and Occupational Therapists (POTs) reason about moral issues in their day-to-day clinical encounters in the rehabilitation setting. She hopes to discern the interrelations among personal, structural, and institutional factors that effect moral reasoning in order to better inform development efforts directed at POTs.

She is designing an observational/ethnographic study of clinical encounters among staff and inpatients. After securing IRB approval, she will observe a small number of POTs while they interact with their inpatients. This approach would allow her to be part of the actual clinical reasoning practices of staff, rather than retrospectively reporting on them through interviews. (cont. on p. 13)



(Disability Ethics Scholars, cont.)



**Aditi Sansanwal, MS, OTR/L**, is an Occupational Therapist, Float Staff, at RIC.

According to Atwal & Caldwell (2003), research suggests that the four bio-ethical principles of autonomy, beneficence, non-maleficence and justice are unintentionally violated during clinical practice. This results in a failure to abide by the occupational therapy code of ethics and professional conduct. Therefore, it is critical that further research be conducted to delineate a course of action for ethical clinical practice.

Aditi is interested in exploring disconnects between the four fundamental bio-ethical principles of autonomy, beneficence, non-maleficence and justice with regards to inpatient occupational therapy care at RIC. She plans to do so by designing a single case study of a patient with traumatic brain injury. She chose traumatic brain injury because of the challenges it presents surrounding decision making capacity, discharge planning and quality of life issues for the patient and family members.

In her study Aditi will attempt to focus on the following:

- Identify the ethical concerns surrounding occupational therapy care for a patient with traumatic brain injury
- Identify solutions for the ethical concerns using the four fundamental bio-ethical principles
- Identify the challenges or the lack of the same while applying the bioethical principles during inpatient occupational therapy practice
- Identify the changes that an occupational therapist can make in clinical practice at an inpatient rehabilitation hospital to bridge the gap between what the Code of Ethics proposes in theory and what is actually done in practice

#### Reference

Atwal, A. & Caldwell, K. (2003). Ethics, occupational therapy and discharge planning: Four broken principles. *Australian Journal of Occupational Therapy*, 50 (4), 244-251.

**Ours is a world of nuclear giants  
and ethical infants.**

**We know more about war than peace,  
more about killing than living**

**— Gen. Omar Bradley**

**First Chairman, Joint Chiefs of Staff**

**J u d i t h Schiffman, MSW, LCSW**, external scholar, is the Assistant Director of the Graduate Program in Genetic Counseling and an Instructor in the Department of Psychiatry at Northwestern University. She is also the Co-Director of the Child and Adolescent Psychoanalytic Psychotherapy Program at the Chicago Institute of Psychoanalysis.



Judy's interest is about the way parents talk to children about either the child's disability or their own disability. Judy plans to do qualitative interviews with 5 adults who have the same type of syndrome or illness that started in childhood. Her focus would be on learning from the interviewees what was communicated to them as children and what they thought was helpful and what was not helpful. This will be a retrospective study and the interviews will be based on memory. While there will be some distortion, the information should enable a beginning understanding of how illness or disability is communicated to children. From an ethics framework, she will explore such questions as what should children be told about their illness or disability, when they should be told, and whose responsibility it is to tell. (cont. on p. 14)

(Disability Ethics Scholars, cont.)



**Matthew Sorenson, PhD, RN**, is an assistant professor at DePaul University, an instructor at the Northwestern University Feinberg School of Medicine, Department of Physical Medicine and Rehabilitation, and is also a member of RIC's Flex Nursing Staff on the Spinal Cord Unit.

Dr. Sorenson's focus project is on the concept "Quality of Life." Quality of life has been conceptualized as a subjective sense of well-being. Healthcare provider perceptions of patient outcomes and future quality of life could influence the care and education provided to patients. Discrepancies have been found between healthcare providers expectations and patient self-reported quality of life. This finding has been replicated across practice settings, being noted on the part of emergency room personnel, mental health providers, professional caregivers of those with spinal cord injury and in those working with tuberculosis patients. Experience within long term care or rehabilitative settings may reduce the reported discrepancies, by providing healthcare providers with role models who may report higher than anticipated quality of life.

Dr. Sorenson will investigate quality of life perceptions among individuals familiar with providing rehabilitative care to individuals with long-standing spinal cord or neurologic injuries, using the Wisconsin Quality of Life Index. This would determine if rehabilitative experience with these populations mediates quality of life perceptions.

**Always do right  
this will gratify some  
and astonish the rest**

**— Mark Twain  
Author**

**A profession's values  
-- including its ethical values --  
are reflected in the degree to which  
its structures are accessible to people  
with disabilities**

**— Kenneth S. Pope  
Psychologist**

**Annelouise Tookoian, B.S.**, is a Research Regulatory Coordinator at RIC. For her focus project, she is interested in the multi-faceted nature of research and how many offices and individuals interact and coordinate with one another to ensure research compliance, ultimately protecting the safety and well-being of human research subjects. Because a lack of regulatory knowledge and/or an inconsistency in research standards can jeopardize human research ethics as well as degrade academic, scientific and medical integrity, she would like to examine the various methods and tools that could be used to improve researchers' knowledge regarding compliance in human subjects research.



## Ethics Resources for RIC Staff

Currently located on the thirteenth floor in Room 1374, the Donnelley Family Disability Ethics Program houses a library, periodical section, and VHS/DVD collection.

**Library.** The Ethics Library now houses over 700 volumes. The library incorporates a broad spectrum of works on biomedical ethics, disability rights, and narratives of those living with a disability. Staff may check out three items (three books, three videos/DVDs, or a combination of the two) for two weeks, and may renew items for an additional two weeks. We invite you to utilize our library as a quiet place to read and reflect.

**Periodicals.** We currently subscribe to twenty-four periodicals. Among these are *Archives of Physical Medicine and Rehabilitation*, *Journal of Disability Policy Studies*, *The Journal of Clinical Ethics*, *The Hastings Center Report*, *Disability and Society*, and *the American Journal of Physical Medicine and Rehabilitation*.

**Film Library.** Our film library has over 200 videos/DVDs on a variety of ethical issues regarding disability. These may be checked out.

**Film Series.** Once each month, we show a film from our library collection. The film is always shown at noon, but the day varies to enable a variety of staff to attend.

**Educational Seminars.** Ethics Program Staff routinely present educational seminars on ethical issues which are requested by RIC staff.

**Ethics Scholars Program.** Staff teach a one-year program open to all members of the RIC community, providing training and professional development in ethics.

**Ethics Consultations.** Ethics consultations are available upon request by calling 312-238-1119.

### Upcoming Events For RIC Staff

#### Film Series:

Mon., Mar. 24th: **The Key of G**

Tues., Apr. 29th: **The Lobotomist**

Tues., May 20th: **Streetwise**

#### Educational Seminars:

Each month the Donnelley Family Disability Ethics Staff conduct an educational seminar for RIC staff.

For information about times and locations of either our films or our educational seminars please contact Carmen Cicchetti at 8-1119 or [cicchetti@ric.org](mailto:cicchetti@ric.org)

#### Donnelley Family Disability Ethics Staff

**Kristi L. Kirschner, MD**  
Director  
312-238-4744

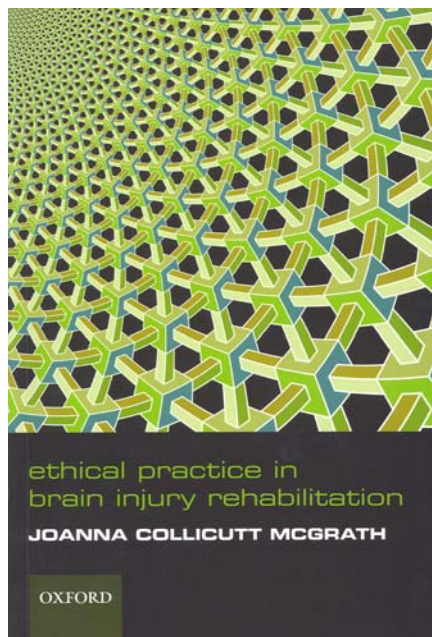
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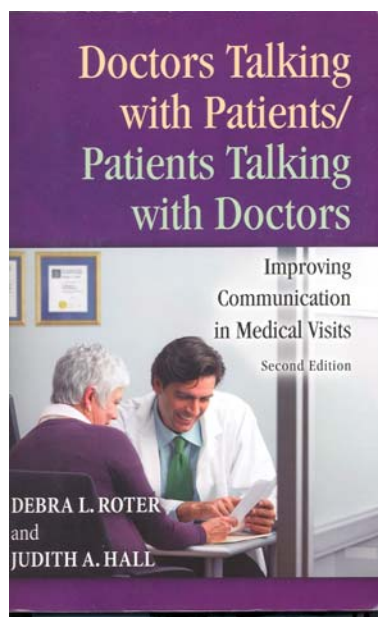
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Two recent additions to our library.



**Rehabilitation Institute of Chicago**

Donnelley Family Disability Ethics Program

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