Florida Bioethics Network FBN

Florida Bioethics

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Guardianship

Legislature Enacts Major New Provisions

Florida's Legislature has enacted two measures likely to have far-reaching effects on the way decisions are made for incapacitated patients. Both changes to state law, approved in the 2003 legislative session, address the role of guardians and other surrogates in end-of-life and other kinds of cases.

One measure provides for social workers to be deputized as guardians in cases in which no surrogate or family member is available. The other moves the Office of the Statewide Public Guardian into the Division of Elder Affairs and calls for new education and licensure standards for guardians.

Apparently motivated by difficulty in many jurisdictions in finding guardians to make medical decisions, the Legislature approved adding social workers to the list of those authorized to make decisions for patients when no surrogate has been identified. That list – one of the best-known features of Florida Statute 765 –

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In this issue

Schiavo Feeding Tube Removed, Replaced as Gov. Bush Intervenes

The 13-year saga of Terri Schiavo has leapt to the front pages of the nation's newspapers as her feeding tube was removed under court order, the Legislature approved a special bill against the withdrawal and Gov. Bush ordered the tube replaced, which it was.

The case has emerged as one of the most complex and bitterly contested end-of-life cases ever. At its core, the dispute pits Ms. Schiavo's parents, who want life support continued, against her husband, who does not. The parents say they represent her wishes; the husband says he does.

Ms. Schiavo, 39, has been diagnosed as being in a persistent vegetative state since 1990. Her artificial hydration and nutrition was discontinued at a Pinellas County hospice, but then replaced under the governor's order and with the Legislature's authorization

The Legislature approved a measure forbidding the removal of hydration and nutrition in the case because there is no written advance directive and because there is a family dispute.

A complete report on the case will appear in the next issue of *Florida Bioethics.*

FBN

Florida Bioethics Network

The Florida Bioethics Network is a program of

- **Program in Bioethics, Law, and Medical Professionalism, University of Florida College of Medicine**
- **Bioethics Program, University of Miami**
- **Division of Medical Ethics and Humanities, University of South Florida School of Medicine**
- **Nova Southeastern University**
- **Florida State University College of Medicine**

Florida Bioethics

The newsletter of the Florida Bioethics Network is edited by the University of Miami Ethics Programs: ethics@miami.edu

The Web site is hosted by the University of Florida Program in Bioethics, Law, and Medical Professionalism: fbn@chfm.health.ufl.edu

Please e-mail submissions to ethics@miami.edu

November 6-7, 2003, Kissimmee — The AARP and Stetson University's College of Law are sponsoring the International Conference on Aging Law and Policy. Issues in elder law, guardianship and health care quality are among those to be addressed. Information: 727-562-7830 or cle@law.stetson.edu.

November 7, 2003, Miami Lakes — The Florida Bar's Elder Law Section is sponsoring a CLE course titled "Conscious Aging in the Elder Law Practice: Cultural, Religious & Ethnic Diversity." Program features a number of sessions that address ethical issues. Information: 850-561-5831.

December 16-18, 2003, Miami — The Fifth Miami International Conference on Torah & Science will feature some of the leading thinkers in Jewish bioethics for a program titled "Absolute Standards in an Age of Relativity." The program, to be held at Florida International University, includes as sponsors FIU's Department of Religious Studies, The Shul of Bal Harbour, The Aleph Institute and *B'Or Ha'Torah Journal of Science, Art & Modern Life in the Light of the Torah.* Information: http://www.borhatorah.org

January 9-10, 2004, Davie — Public policymakers, health care professionals and members of the public will debate health care access and policy at a third annual conference, "A Glimpse of the Future of Health Care in America" at Nova Southeastern University (NSU). Keynote speakers include Dr. Lisa Simpson, former deputy director for the U.S. Department of Health and Human Services' Agency for Healthcare Quality Research (AHRQ). The annual conference, held at NSU's Health Professions Division, will offer continuing education credits. Information: 954-262-1597 or 800-356-0026 (extension 1597); or http://www.nova.edu/cwis/centers/hpd/allied-health/futurehealth/.

April 16-17, 2004, Miami Beach — The **FBN's annual spring meeting** will feature an unprecedented collaboration with the American Society for Bioethics and the Humanities and the American Medical Informatics Association on a conference emphasizing the theme of ethics and health information technology. Information: http://www.miami.edu/ethics.

Legislature OKs Major Guardianship Changes

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identifies and ranks those whom health professionals should turn to in seeking a proxy decision maker.

Under the new law, an institution may turn to a social worker at another institution to serve as a temporary guardian. The social workers would be selected by institutional ethics committees. Any decision to limit life-prolonging measures would need to be reviewed by an ethics committee. This requirement marks the second time the Legislature has required ethics committee review. The first is also laid out in FS765, the advance directive statute; it requires guardians of certain patients in persistent vegetative states to seek ethics committee review before a request to terminate treatment can be honored.

(It is this paragraph that also assigns a formal role to the Florida Bioethics Network – if the ward's hospital or other health institution does not have an ethics committee the guardian must seek the services of a community ethics committee "approved by" the FBN.)

The legislation was not formally reviewed or approved by the state's social worker, guardian or bioethics communities. The new law raises a number of questions:

1. How willing and able will social work departments be to releasing staffers for guardianship duty at another institution?
2. Precisely what criteria should ethics committees use in selecting a social worker to serve as guardian?
3. How many social workers can realistically be expected to obtain the necessary education (especially in light of other changes to guardianship curricula and licensure)?

The second measure approved by the Legislature and signed into law by Gov. Bush moves the Statewide Public Guardian Office to the Florida Department of Elder Affairs and creates a Guardianship Task Force within the Department. The Task Force is charged with reviewing the state's guardianship practices and determining best practices.

"The Guardianship Task Force will be instrumental in addressing issues critical to guardians and the people they serve. It is also important that those Floridians who don't need full guardianship have access to other forms of assistance," said Gov. Jeb Bush, according to the Department of Elder Affairs. "I look forward to their recommendations on how we can best help to ensure that our most vulnerable citizens have access to guardians."

The governor used the same phrase – "most vulnerable citizens" – in arguing unsuccessfully for a court-appointed guardian for a fetus in the case of a mentally disabled rape victim in Orlando. The woman gave birth to ``Baby Girl S,'' by C-section on Aug. 30 and was placed in the temporary custody of Florida's Department of Children & Families. It is not clear if the new Guardianship Task Force will take up the question of fetal guardians.

The Task Force has 10 members, each to represent and be appointed by one of the 10 entities named in the new law:

- Prof. Gordon T. Butler of Miami, St. Thomas University School of Law; law professor appointed by Secretary of the Department of Elder Affairs
- Judy Thames of Orlando, State President, Florida AARP; appointed by the Executive Director of the Florida AARP
- Ed Boyer, Esq., of Sarasota, Boyer & Jackson, P.A.; appointed by the Florida Guardianship Foundation
- David Brennan of Orlando; appointed by the Real Property Probate Section of the Florida Bar
- Judge Mel Grossman of Fort Lauderdale, Administrative Judge Probate Division of the 17th Circuit Court; appointed by the Florida Conference of Circuit Judges
- Dr. Karl Jones of St. Petersburg, psychiatrist; professional as stated by section 744.331(3) of Florida Statutes
- Kate Mingle of Port Orange, professional guardian; appointed by Florida State Guardianship Association
- Jed Pittman of New Port Richey, Pasco County Clerk of Court; appointed by the Association of Clerks of Court and Chairman of the Guardianship Task Force
- Randy Pople of Tallahassee, president and CEO of Capital City Trust Co.; appointed by the Florida Banker's Association
- Enrique Zamora, Esq., of Miami, Zamora & Hillman Law Firm; appointed by Elder Law Section of the Florida Bar

"The diversity of the members of the Guardianship Task Force will provide us insight into a myriad of issues relevant to public guardians," said Elder Affairs Secretary Terry White in a statement released by his office. "The Department looks forward to working with the Task Force as they work together to review current practices and suggest ways to recruit more guardians."

The Task Force is required to submit a preliminary report to Secretary White by January 1, 2004, and submit its final report to the Secretary by no later than January 1, 2005.

More information about the Statewide Public Guardian Office and the Guardianship Task Force is available by calling the Department of Elder Affairs at (850) 414-2000 or visiting http://elderaffairs.state.fl.us.

Only in Florida? Alien Cloning Announcement Produces Controversy, Anger — But No Baby

CHANTAL ABITBOL
Special to Florida Bioethics

HOLLYWOOD — The probe into the welfare of the world's first human cloning may have been dismissed, but the controversy and mystery surrounding cloned baby Eve – if she exists at all – is far from over.

Months after Clonaid first sparked a media frenzy over its claim of Eve's birth, the company still hasn't offered any proof that the baby is a clone, or even exists.

The company originally promised to conduct DNA tests. But the child's parents quickly reneged, Clonaid officials claimed, when opponents speculated over the child's well-being and pursued a court case to determine whether to appoint a legal guardian.

For all the hype, however, the inquiry proved to be anticlimactic.

Brigitte Boisselier, president of Clonaid, testified that the baby is living in Israel, prompting the judge to cite lack of jurisdiction and throw out the case.

Boisselier is a member of the Raelians, a religious group that believes beings from outer space created life on Earth. Its founder, a former French journalist who calls himself "Rael," established Clonaid in 1997.

Since Eve, the company announced the birth of four other cloned babies, and claims a second generation of up to 20 babies is on its way.

"All five babies are doing very well," Thomas Kaenzig, vice president of Clonaid, told *Florida Bioethics Network.* "They're all obviously monitored closely, and Clonaid has proven that human cloning is safe. The skeptics will be even more surprised when the DNA tests are published."

The company still hasn't set a date for such a disclosure.

Bernard Siegel, a Coral Gables attorney who filed a motion asking the Raelians to producethe baby, is trying to track down Eve through child advocates in Israel. He accuses the media of not investigating the matter vigorously enough.

"It's as if the media inoculated Clonaid from further scrutiny. That's a big mistake," said Siegel, who spoke about the case at the Florida Bioethics Network's spring conference in March.

The company "is now going to have every chance in the world to conduct these experiments with impunity. Even if Eve is a hoax, why shouldn't they be subjected to scrutiny?"

Siegel, a personal injury attorney and former pro-wrestling promoter, believes reproductive cloning is comparable to child abuse because it unduly exposes a child to problems encountered in the cloning of other mammals. He also fears the child will struggle with identity issues. He argued that Broward courts had jurisdiction because the company conducts business over the Internet in Florida and elsewhere.

"They had created a child without a medical safety net," said Siegel. "Just because you have the scientific ability to create a child doesn't give you the right to maim a child. Every medical organization has concluded that human cloning at this time has the risk of producing a child with severe genetic handicaps. At this time, [cloning] is an untested medical experiment and is immoral."

Jonathan Schwartz, Kaenzig's attorney, says it isn't so.

"Other than speculation and fear, there was nothing to justify child abuse," said Schwartz, who also argued that cloning is just an "offshoot" of *in vitro* fertilization – a procedure also once called "terrible" and "playing God," he

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Cloning Announcement Produces Controversy — But No Baby

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noted.

"All of these same fears and questions were made of the first artificially inseminated child created in 1981. Now she's 20-years-old and doing fine," he said. "The cloning procedure is fairly indistinguishable from IVF."

Siegel also excuses the company of exploiting the child for financial gain.

Schwartz denies this. "No one has ever paid for a child yet. Everything has been financed by investors," he said.

On its website, the company advertises "a new cell fusion device specializing in embryonic cell fusion," which it says Clonaid developed. Some of the equipment sells for as much as $9000.

As the debate wages on, some opponents – both at home and abroad – are pushing for an outright ban of the procedure.

The European Union's commissioner for research has called for an international drive to outlaw cloning, while some U.S. representatives and Florida legislators are seeking prohibitions.

Professor Bill Allen, director of the University of Florida's Program in Bioethics, Law and Medical Professionalism, said he agrees with a temporary moratorium on reproductive cloning.

"The probabilities of harmful outcomes and the inconsistency of results at this stage of development in the technology make it morally irresponsible to attempt," said Allen, also co-director of the Florida Bioethics Network.

But at the same time, he said, he couldn't argue such a procedure constituted child abuse because "until a child is born, there is not a child to abuse or neglect." Some might also argue, he added, there's little to distinguish between taking risks with reproductive cloning and choosing not to terminate a pregnancy after pre-natal testing shows a high probability of congenital disability. Though a woman is aware of the risk from the outset, he said, it doesn't disqualify her from being a good parent.

"We are on the cusp of having a cloned person on this planet [whether] there are prohibitions or not. It will be worse if that child is shot from a cannon into a world unprepared to receive her."

— Attorney Bernie Siegel

"The decision to take the risk should not automatically mean that the mother would be unfit, abusive or a negligent parent from that point forward," he said. "If we want to discourage reproductive cloning, other disincentive measures than child abuse or neglect paradigms would be better suited to that end."

Allen also quashed the notion that a cloned child would be irreparably harmed as a result of sharing the parent's DNA, saying such an assumption is "not grounded in careful reasoning."

"Identical twins have identical DNA, but do not have horrible identity crises that make it unconscionable to have twins, even though they usually share more in the way of environment than a parent and her cloned infant could share being a generation apart," he said.

Beyond the uncertainty of reproductive cloning, however, Siegel argues there's something else at stake – the rights and protection of a cloned human being.

"There are hardly any laws addressing the rights of cloned persons," he said. "What about laws of inheritance, or potential legal arguments of wrongful life or birth?"

To address those issues, Siegel has established a non-profit organization, the Human Cloning Policy Institute.

"We are on the cusp of having a cloned person on this planet [whether] there are prohibitions or not," he said. "It will be worse if that child is shot from a cannon into a world unprepared to receive her."

Access to Health Care for the Hearing-Impaired: Part III

MELINDA J. BROWN, J.D.

This is the final article in a three-part series on access to medical care for the hearing-impaired. This article discusses doctors' and hospitals' responsibilities to their hearing-impaired patients.

Part I provided an overview of the importance of the issue and discussed the legal rights of the hearing impaired. Part II addressed the hearing-impaired individual's responsibility for ensuring that he or she obtains quality medical care for him or herself and his or her family.

Hospitals and doctors' offices are places of public accommodations under the ADA. As such, they have a legal duty to provide their hearing-impaired patients with an atmosphere fostering effective communications between the medical staff and the hearing-impaired individual.

Health care providers, including hospitals, thus are to render services to deaf persons that are "equal to" and as "effective" as those it renders to hearing persons. [1] Health care providers are not to provide deaf persons with "different or separate" services, or provide services in a way that limits their participation in a particular program.[2] Deaf persons are entitled to proper notice of the benefits and services that providers offer, as well as information on waivers and consents to treatment.[3] Most significantly, health care providers must establish a procedure for effective communication with hearing-impaired persons for the purpose of providing health care, including emergency care.[4]

When health care providers are in the process of obtaining valid informed consent[5] from a hearing-impaired individual, they can use any means possible to achieve effective communication. Absent the use of interpreters, however, it is unlikely that the informed consent of many deaf patients can be obtained.[6] A health care practitioner may be found liable for malpractice if, due to the lack of effective communication between the practitioner and patient, a deaf patient suffers medical injury.[7]

Hospitals especially should take seriously the duty to communicate effectively because communication affects the hearing-impaired patient's access to quality health care and individualized participation in the decision-making process there even more than in an office setting. Without effective communication, the patient cannot explain his or her symptoms to the medical staff, who in all likelihood (unlike a primary care physician's staff) has no previous familiarity with that patient's mode of communication. Neither can the hearing-impaired patient comprehend what is being done or why it is being done. Hospitals are scary places for hearing patients. But they are terrifying to deaf individuals because of the silence and confusion characterizing everything going on around them.

Thus, hospitals should have easy-to-read notices posted in the emergency room, outpatient clinic, and all admitting areas to inform deaf people how they can obtain interpreter services or other assistance.[8] Hospitals also especially should have procedures in place before the hearing-impaired patient comes into the hospital environment. Finally, they should conduct regular in-service training sessions on how to best accommodate the hearing-impaired so that the hearing-impaired individual can have equal access to their services.

The National Association of the Deaf has developed a set of guidelines to aid health care providers in meeting the communication needs of deaf individuals and in complying with federal regulations.[9] Copies of this book may be obtained by writing or calling Self Help for Hard of Hearing.[10]

In sum, health care providers' use of common sense and basic information about deafness will help their deaf patients obtain better service and better-quality care. Simple things like answering the deaf patient's questions and explaining

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Deaf and Hard-of-Hearing Consumer Action Network

The Deaf and Hard of Hearing Consumer Action Network (DHHCAN) is the premier coalition of national consumer organizations representing a wide continuum of deaf and hard of hearing people, including those who are deaf-blind and late-deafened. There are over 28 million deaf and hard of hearing people in the United States.

Members of DHHCAN include American Association of the Deaf-Blind (AADB), Association of Late-Deafened Adults (ALDA), American Society for Deaf Children (ASDC), Conference of Educational Administrators of Schools and Programs for the Deaf (CEASD), CSD (formerly known as Communication Service of the Deaf), Deaf Seniors of America (DSA), Gallaudet University, Gallaudet University Alumni Association (GUAA), Jewish Deaf Congress (JDC), National Association of the Deaf (NAD), National Black Deaf Advocates (NBDA), National Catholic Office of the Deaf (NCOD), Registry of Interpreters for the Deaf (RID), TDI, Inc. (formerly known as Telecommunications for the Deaf Inc.), USA Deaf Sports Federation (USADSF), and WGBH.

For more information about DHHCAN, contact Jerald Jordan at Jerald.Jordan@verizon.net.

Access to health care for the hearing-impaired

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what is happening will help lower the deaf patient's anxiety about being in any health care environment -- a doctor's office or a hospital.

Access to quality medical care begins with effective communication. There is no doubt that effective communication has a great impact on the type of service that the deaf individual receives, whether it be from the doctor, the doctor's office staff, or the hospital's staff. Each one plays an interlinked relationship in the access and quality of medical care the deaf individual receives and in that individual's recovery process.

Notes

1. See 45 C.F.R. §§84.52(a)(2)-(3) (2001).
2. See 45 C.F.R. §§84.52(4)-(5) (2001).
3. Elizabeth Ellen Chilton, *Ensuring Effective Communication: The Duty of Health Care Providers to Supply Sign Language Interpreters for Deaf Patients*, 47 HASTINGS L.J. 871, 882 (1996). See e.g. 45 C.F.R. §84.52(b) (2001).
4. Id at 882. See e.g. 45 §C.F.R. §84.52 (c) (2001).
5. A person's agreement to allow something to happen such as surgery that is based on a full disclosure of facts needed to make the decision intelligently; *i.e.*, knowledge of risk involved, alternatives, etc. BLACK'S LAW DICTIONARY 779 (6th ed. 1990).
6. Bonnie Tucker, *Health Care And The Americans With Disabilities Act: Article Access To Health Care For Individuals With Hearing Impairments*, 37 HOUS. L. REV. 1101, 1112 (2000).
7. Id. at 1112.
8. NATIONAL ASSOCIATION OF THE DEAF, LEGAL RIGHTS: THE GUIDE FOR DEAF AND HARD OF HEARING PEOPLE, AT 105 (5TH ED. 2000).
9. NATIONAL ASSOCIATION OF THE DEAF, LEGAL RIGHTS: THE GUIDE FOR DEAF AND HARD OF HEARING PEOPLE, 107-110 (5th ed. 2000).
10. Self Help for Hard of Hearing Publications, 7910 Woodmont Avenue, Suite 1200, Bethesda, MD 20814, 301/657-2248 Voice, Fax:301/913-9413.

Disabled Rape Victim Gives Birth to Girl in Orlando

BY ANTHONY COLAROSSI
Orlando Sentinel Staff Writer

ORLANDO – Her name, for now, is "Baby Girl S."

Born Aug. 30, she is the daughter of J.D.S., the severely retarded woman who was raped and became pregnant while living in a southwest Orlando group home.

J.D.S. and her unborn child spent the summer at the center of a statewide scandal over treatment of the developmentally disabled and a national debate on fetal rights. Gov. Jeb Bush outraged abortion-rights advocates when he asked the courts to appoint a guardian for the fetus.

Now, the pregnancy that generated so much controversy is over. J.D.S.' daughter was born during a scheduled Caesarean section at an Orlando-area hospital.

"She's pretty. She's got lots of hair. It's curly," said Patti Riley Jarrell, J.D.S.' guardian, who was at the hospital during the birth and saw pictures of the newborn but did not see the child.

The baby, Jarrell said, weighed 6 pounds, 7 ounces and was 21.5 inches long.

Baby Girl S looks normal and healthy, but it may take months before it is known whether the child shares her mother's serious developmental disabilities, the guardian said.

J.D.S., who did not understand her pregnancy, was sleeping and recovering after the delivery.

"She looks beautiful," Jarrell said. "No more stomach. She's all curled up, feeling safe and warm."

Due to J.D.S.' inability to care for her newborn, the state Department of Children & Families moved swiftly to request emergency temporary custody of the child.

Circuit Judge Jose Rodriguez granted the agency's wish and also ordered a DNA sample to be taken from the child in hopes that Orlando police investigators can determine who raped the 23-year-old mother. Florida law allows the state to take custody of a child it considers to be at risk of abuse, neglect or abandonment.

With the mental capacity of a young child, J.D.S. cannot identify the individual who raped her, much less answer simple questions from investigators.

Infant now ward of state

Now a ward of the state, Baby Girl S has entered the system in which J.D.S. has lived for most of her life – the same system that failed to protect the young woman from a sexual attack.

During a hearing less than two hours after the birth, DCF attorney Kelly McKibben said the infant would be in "imminent risk" if she were allowed to remain with her biological mother.

McKibben asked Jarrell, who speaks for J.D.S.' interests, whether she thought the same.

Should fetuses have guardians? Does appointment of a fetal guardian establish fetal rights that bear on abortion debates? What would happen if a fetal guardian disagreed with the guardian of the mother-to-be?

"Are you in agreement with the child being sheltered and placed in the department's custody?" McKibben asked Jarrell during the brief proceeding. "Yes, I am," Jarrell said, who testified via telephone.

Jarrell asked that J.D.S. have some supervised contact with the baby while in the hospital. The guardian also suggested that she and a caregiver be allowed to see the baby and that pictures be taken.

Rodriguez agreed, but said the child's health and safety must be priorities.

"Any visitation should not tax the child," Rodriguez said. "This child is the top tier. I don't want the child to be a rope in a tug of war. We cannot put everyone's desires and needs before the child."

But, he added, "I don't think there's too much love that can be provided this child."

Jarrell said she waited several hours but did not see the baby. "I'm still a little upset I didn't get to see the baby," said Jarrell, adding that she especially wants a picture of J. D.S. and her baby.

"I want it for her [J.D.S.]," Jarrell said. "I think she deserves that dignity. It's her baby. She is the victim here."

Guardian appointed for baby

At the hearing on Aug. 30, Rodriguez appointed attorney Lisa J. Augspurger to serve as the newborn's guardian ad litem because the girl has no other relatives or family members available to look out for her best interests. McKibben noted that J.D.S. does have a sibling, but that sibling is a minor and cannot care for the child.

McKibben would not comment after the hearing. Augspurger said her role will be making sure the baby's medical needs are met. "Her safety and health are of paramount importance," Augspurger said.

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Disabled Rape Victim Gives Birth to Girl in Orlando

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In addition to severe retardation, J.D.S. suffers from cerebral palsy and autism. For most of her life, she lived in a small, southwest Orlando group home operated by a woman named Hester Strong and licensed by the state.

In April, Strong learned J.D.S. was pregnant. The pregnancy was reported to DCF, and Orlando police were told.

Because J.D.S. could not have consented to sex, the case was investigated as a sexual assault and battery.

Lacking a positive identification from J.D.S., police hoped they might use amniocentesis to get a fetal DNA sample before birth to match with DNA samples they have of suspects.

Controversy ignites

But authorities soon learned that J.D.S., though under the state's supervision, lacked a legal guardian to help her make life decisions. By mid-May, the state was asking to have guardians appointed for both J.D.S. and her fetus.

That decision set off the controversy because it could have created a conflict between the interests of the mother and the unborn.

Circuit Judge Lawrence Kirkwood appointed Jarrell as guardian for J.D.S., but he refused to appoint one for her fetus, finding no basis in state law.

Jennifer Wixtrom, an Orlando woman who asked to be the fetal guardian, appealed Kirkwood's decision. The 5th District Court of Appeal is considering whether fetal guardians should be appointed in cases in which a mother is incapable of making any decisions about her pregnancy.

But it has been known for some time that the court's decision would have no bearing on this case.

The J.D.S. case also prompted Bush to appoint a panel to investigate problems with the state's guardianship system, particularly among the developmentally disabled. The group came up with a series of proposals designed to help anyone in state care who needs a guardian but lacks one. Some of those recommendations require new law and may cost millions.

Jarrell said she was simply happy both the mother and her child were safe. Jarrell agreed with her attorneys not to name the hospital where the birth occurred to protect the privacy of the mother and the child.

"All we hoped for was for [J.D.S.] to be healthy, for the baby to be born healthy and for [J.D.S.] to have a quality of life," Jarrell said.

"She's young," Jarrell said of J.D.S. "She's got a lot of life in her."

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ETHICS BRIEFS:

State Disbands Innovative Corrections Ethics Committee

The state prison system's ethics committee — the first in the nation and a source of education, policy review and consultations for a decade — has been disbanded by the Department of Corrections.

The reason for the move was not entirely clear, though Department officials apparently came to believe that there was no statutory authority for the committee and, in the absence of enabling legislation, the unit had to be terminated.

"I believe the Bioethics Committee has provided very useful guidance to the Department in some difficult ethics issues," said Dr. Charles Matthews, who chaired the committee. He said he hoped the committee might one day be re-established.

Created in 1993, the group held its first meeting the next year. In the course of a decade, the committee addressed issues such as human-subjects research, the role of health professionals in executions and end-of-life care for prisoners.

The committee was featured in the Autumn 2001-Winter 2002 issue of *Florida Bioethics*. Four FBN board members served on the unit.

FBN LINKS WITH PANAMA CITY GROUP

For nearly a decade, health professionals and institutions in Panama City have sponsored a thriving bioethics program. This year, the FBN linked with the Eighth Annual Community Bioethics Consortium for the Sept. 5 workshop on "technology and ethics." Topics included health information technology, nanotechnology and religious issues. As part of the joint sponsorship, FBN members were able to attend the daylong program free of charge. Other sponsors: Bay Medical Center, Gulf Coast Community College, Gulf Coast Medical Center and Health South Emerald Coast Rehabilitation.

WEB SITE PROVIDES HIPAA EDUCATION

Health care organizations seeking HIPAA education resources may find help in a Web site developed by the University of Miami Ethics Programs. The site — http://privacy.med.miami.edu — provides tutorials, a glossary, links to key resources and other tips and tools. HIPAA compliance requires education in individual policies, so the site needs local augmentation. Faculty are available for developing institution-specific training efforts. More information: 305-243-5723.

Who Can Consent for a Minor? Notes on Florida Law

KARON COLEMAN, J.D.
Assistant County Attorney,
Miami-Dade County Public Health Trust

End-of-life and other ethically fraught decisions for minors are among the most interesting and challenging in health care. In some cases, the law provides guidance or, if not guidance, at least an attempt by society to come to terms with decisions that must be made no matter the difficulty. This is the first in a series of annotated notes on Florida law and how it applies to these decisions.

I. Who is a minor? (§ 744.102(11), F.S.)
"Person under 18 years of age whose disabilities have not been removed by marriage or otherwise."

II. Parents. (§ 744.301)

A. A. Parents are known as "natural guardians." §744.301.
B. Married Parents. Both parents are decision-makers for child
C. Divorced Parents
1. Custody/parental responsibility is established by a court order.
2. If *shared parental responsibility* (commonly known as "joint custody" or "shared custody"), both parents are decision-makers not just the parent with whom the child lives (known as the "primary residential parent" or the "custodial parent") **Note**: It is important to distinguish between having custody ("parental responsibility") and being the custodial parent ("primary residential parent"). You don't have to be the custodial parent ("primary residential parent") to have custody ("parental responsibility")‡
3. If only one parent has been awarded sole parental responsibility ("sole custody"), then only that parent is the decision-maker. **Note**: This parent will have custody ("parental responsibility") and be the custodial parent ("residential parent")

D. Single Parent, Never Been Married
1. Single mother is the natural guardian unless and until a court orders otherwise. §744.301, F.S.
2. Single father needs to establish paternity under Ch 742, F.S, and seek custody through the courts.
3. Single father who is unable to establish paternity make seek temporary custody under Ch. 751, F.S. *See* III below.

III. Temporary Custody by Extended Family or Putative Father (Ch. 751)

A. Chapter 751 allows a family member or putative father (a/k/a father who is unable to establish paternity) who has physical custody of a minor child to establish temporary custody.
B. Must get court order
C. Allows the family member or putative father to consent to all necessary and reasonable medical and dental care, including nonemergency surgery and psychiatric care; secure copies of medical, dental, psychiatric records.

IV. Other Family Members (743.0645(2), F.S.)

A. Applies only when, after a reasonable attempt, the appropriate decision-maker (parent or guardian) for the child cannot be contacted and no actual notice to contrary has been provided by the decision-maker. Attempts must be documented. Must notify decision-maker as soon as possible.
B. Allows the following people, in order of priority, to consent to medical care or treatment for a minor:
1. power of attorney to consent to medical care
2. step-parent
3. grandparent
4. adult sibling
5. adult aunt or uncle

C. Allow consent for ordinary and necessary medical and dental examination and treatment, including blood testing (except HIV testing and drug testing), preventive care including immunizations, tuberculin testing and well-child care. Excludes: surgery, general anesthesia, psychotropic medication, or other extraordinary measures/procedures.

V. Guardian (744.3021)

A A court-appointed guardian can make medical decisions on behalf of a child (the "ward").
B However, the guardian must seek a court order in

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Who Can Consent for a Minor? Notes on Florida Law

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order for any of the following:

1. Sterilization
2. Abortion
3. Admission to a mental health facility or drug rehabilitation facility
4. Engage in any experimental biomedical or behavioral procedure or participate in any biomedical or behavioral experiment.

VI. Department of Children and Families

A. Investigating Abuse, Neglect, Abandonment (§39.304)

1. DCF can have child examined/diagnosed by a physician or ER without consent of parent if examination for injuries/illnesses related to abuse, neglect, abandonment.
2. If child needs medical treatment:
   a. Must get consent from parent/guardian or a court order
   b. If parent not available and court is closed, DCF can consent to "necessary medical treatment" (care which is necessary within a reasonable degree of medical certainty to prevent the deterioration of a child's condition or to alleviate immediate pain of a child --§39.01(44), F.S.) until such time as DCF can obtain a court order
   c. If parent refuses consent to necessary treatment, then DCF must seek a court order
   d. If parent refuses consent and there is an emergency or the treatment is related to suspected abuse or neglect, DCF can provide consent until such time as a court order can be obtained

B. Removed from Home/Out-of-Home Placement. (§39.407)

1. Medical screening examination for injury, illness, communicable diseases and to determine necessity for immunizations.
2. If child needs medical treatment *See* VI(A)(2) above.

C. Child in Legal Custody of DCF

1. DCF has duty to provide ordinary medical, dental, psychiatric and psychological care — §39.01(33)
2. Must seek court order for extraordinary care. *See* Section V above.

VII. Foster Care & Permanent Placement with Family (§ 39.621)

A. Long Term Custody Arrangement. (§39.622).

1. With a family member or other adult; DCF supervision ended
2. Vested with rights of a guardian (*see* Section V above).
3. Charged with duty to provide with "ordinary medical, dental, psychiatric and psychological care unless the rights and duties are otherwise enlarged or limited by the court order establishing long term custodial relationships."

B. Long Term Licensed Custody (Foster Care)

1. Jurisdiction and supervision retained by DCF
2. Normally vested with rights of a guardian. (*see* Section V above).

VIII. Emergency Treatment (§743.064)

A. Physician may render emergency medical care to a minor without parental/guardian consent if:

1. Cannot determine who parent/guardian is, or parent/guardian cannot be immediately located by telephone at home or business
2. Minor has been injured in an accident or is suffering from an acute illness, disease or condition and within a reasonable degree of medical certainty, delay in the initiation of or provision of medical care or treatment would endanger the health or physical well-being of the minor; and
3. The emergency medical care or treatment is administered in a hospital.

B. Applies to paramedics, EMS technicians or other EMS personnel

C. Notification to be provided as soon as is practicable to parent/guardian; record/document efforts to reach parent/guardian as well as the identified medical emergency.

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‡"Access to records and information pertaining to a minor child, including, but not limited to, medical, dental and school records, may not be denied to a parent because the parent is not the child's *primary residential parent*.... A parent ... has the same rights upon request as to form, substance, and manner of access as are available to the other parent of a child, including without limitation, the right to in-person communication with medical, dental and education providers." §61.13(2)(3), F.S.