

Frontlines

THE RHODE ISLAND DEVELOPMENTAL DISABILITIES NETWORK

Paul V. Sherlock Center on Disabilities • Rhode Island Disability Law Center • Rhode Island Developmental Disabilities Council

Guardianship strips people of their freedom

Advocates say there are many alternatives

The Developmental Disabilities Network will host a conference on April 30 on guardianship and its alternatives, which our research has shown is an important issue for thousands of Rhode Island families.

Guardianship uses concepts such as “competency” and “capacity” to invoke probate court rulings that deny people with any kind of cognitive impairment their rights to make decisions about their own lives, including where and with whom they live, how much of their own money they can spend, how far they can travel and with whom.

Perhaps there are thousands, but no one really knows how many people in Rhode Island have been deemed to be incompetent by a court.

The American Bar Association, in a 2006 survey, found that state court administrators in Rhode Island and 10 other states are not prepared to gather statistical data from probate courts because there are no resources to pay for data collection and information is “unavailable or uneven locally.”

This lack of local data has been the subject of Congressional hearings lately. Following a string of chilling reports detailing abuse of the elderly, the U.S. Senate Special Committee on Aging, in December, called for nationwide data collection on guardianship cases, mandatory quality standards for guardians and an infusion of federal funds to boost local court supervision programs.

The age of majority

Special education, transition and vocational education programs want to help teens with disabilities build community living skills, like counting money, finding a job, getting to and from work, buying food and budgeting money. These are vi-



Alternatives to Guardianship

An all day conference for people with disabilities, teachers, parents, lawyers, guardians and caregivers. April 30, at the Crowne Plaza Hotel in Warwick, RI. Details on page 4.

tal skills to community inclusion, but they are decision-making skills as well. Yet, schools routinely advocate guardianship for students with cognitive disabilities as they approach their 18th birthday, assuring parents that it is the best way for them to continue to provide guidance for their children when they become adults under the law.

Unlike some states, Rhode Island has yet to provide schools and parents formal guidance on alternatives to guardianship. According to data published by Kids Count, there may be as many as 500 families in Rhode Island facing the guardianship issue at any given time.

One Rhode Island mother says that both the school and her family’s lawyer have urged her to obtain full guardianship for her son, even though she thinks he has a right to make his own decisions in most matters. “He knows right from wrong, knows how to do the family grocery shopping and use a debit card at the check out lane. And, who am I to say he can’t date someone?”

Instead she is determined to seek a limited power of attorney so that she can have a say over how he spends his money and whether or not he should undergo certain medical procedures.

While Rhode Island’s law has been revised in recent years to emphasize the use of alternatives to guardianship, the degree to which the state’s 39 probate judges pursue these alternatives before imposing full guardianship is unknown.

John Hoyle, Executive Director of the ARC of Michigan and keynote speaker at the Network’s upcoming conference, wrote in 2005 that, “Despite good statutes and language, rights are ignored when it comes to practice in many courts. Due process apparently would take too much time and to what end. The person would still have a disability. Sadly, necessity is seldom viewed in light of available, viable alternatives.

“Representation for those who are the subjects of guardianship petitions,” he wrote “is weak, if present at all. If the court appoints an attorney, he or she typi-

cally has no background in disability, and does not wish to upset the court or take up much of the court’s time. This is especially true if they would like subsequent appointments by the court. Judges and attorneys blur the role of guardian ad-litem and act in a very paternalistic manner. The brevity of hearings, usually only a few minutes, speaks volumes about the lack of due process and care with which guardians are appointed. Lady Justice, blindfolded and evenhandedly weighing evidence and individual rights, is clearly absent from most courtrooms during guardianship proceedings.”

“School professionals,” Hoyle says, “typically have little understanding of life for people with disabilities, and even less contact with them as they live some thirty to thirty-five years beyond their parents’ lifetimes. Yet, professionals blithely make the recommendation to seek guardianship without such understanding and without knowledge of the myriad of alternatives to guardianship which don’t remove a person’s rights. Making a recommendation for guardianship without either is inexcusable.

“IDEA ‘04 (IDEA),” Hoyle continues “mandates that a student learn of his/her rights and responsibilities one year before reaching the age of majority. One can expect that this will provide an opportunity for the relevant school personnel to recommend petitioning the courts for guardianship. Parents will be told and frightened into believing they will lose the ability to control their child’s educational program and even to receive information regarding their child unless they become their son or daughter’s guardian. This time could, and I believe should, be spent instead with the school and parents working collaboratively with the student towards such outcomes as self-determination, employment options, transitioning to post-secondary education alternatives, and the like. And, if necessary, preparing the alternatives to guardianship for the student for when he/she does reach the age of majority.”

The Developmental Disabilities Network Partners

The Paul V. Sherlock Center on Disabilities

The Sherlock Center, located at RI College, is a University Center for Excellence in Developmental Disabilities (UCEDD). The mission of the Sherlock Center is to promote membership of individuals with disabilities in school, work and the community. Initiatives provide training, technical assistance, service, research, and information sharing. The Center partners with state and national agencies, schools, institutions of higher education, and community providers to create opportunities for people with disabilities and their families.

Paul V. Sherlock Center on Disabilities

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The Rhode Island Disability Law Center

Advocates for people of all ages who have a physical disability, developmental disability or mental illness to help them overcome a wide range of barriers that prevent them from leading productive and independent lives. Services include: investigating cases of abuse or neglect; legal representation to protect rights or to secure benefits and services; self-help information; educational programs; and administrative and legislative advocacy.

The Rhode Island Disability Law Center

275 Westminster St., Suite 401
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Voice (401) 831-3150 • TTY (401) 831-5335 •
FAX (401) 274-5568 • Clients (800) 733-5332
www.ridlc.org
e-mail: info@ridlc.org

The Rhode Island Developmental Disabilities Council

People with developmental disabilities and family members, along with representatives of agencies and groups that work on behalf of people with disabilities, make up this 24 member council dedicated to promoting ways that families, service agencies and federal, state and local governments can help people with disabilities to live more independent, fulfilling lives.

The Rhode Island Developmental Disabilities Council

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AGE OF MAJORITY

TRANSFER OF RIGHTS FOR STUDENTS WITH DISABILITIES

Parents want their children to have the skills they need to succeed as adults. While this is important for every young person, youth with disabilities often face extra challenges. That's why they need to be actively involved in setting their high school goals and planning for their transition to adulthood well before they reach the age of majority.

Students' transition plans should reflect their interests and preferences, current accomplishments and skills, what they still need to learn, as well as what they want to do in life. This can include a range of goals—everything from the type of career the student would like to pursue to the kind of living situation he or she hopes to have.

Transfer of Rights

When an individual with a developmental disability reaches the age of 18, he or she is considered an adult with all the rights and responsibilities of any adult—the right to vote, to sign contracts, to make decisions on health care, to stay in school or not, to decide where to live, how to spend money.

Students, not their parents, become the primary participants in developing their individual education programs and they become responsible for making other decisions, such as consenting to any changes in placement, or requesting mediation or due process hearings to resolve disputes about their education or transition plans.

Reaching the age of majority can be an exciting time for most students. Transferring rights to young adults who are unable to make informed decisions or take responsibility for their choices, however, carries many risks. Will students decide to drop out of high school or accept a quick diploma and become ineligible for much-needed transition services? Many

of the decisions young adults make affect their quality of life after high school.

Parents, whose roles include providing for and protecting their children, may find themselves at odds with the teen who wants to experience life, develop individual values, and achieve independence. When a child is vulnerable, families may view control as a responsibility to ensure safety. Families may have extensive fear of how the world will treat their child, or they may hesitate to give up their primary role as protector and advocate. In spite of this, teens with disabilities want and need to experience and obtain the same things that all adolescents want and need no matter how significant their disability.

Decision-making Capacity

One reason a statement of transfer of rights is given at least one year before a student with a disability turns 18 is to alert parents to consider whether or not their child has the capacity to make informed decisions at the age of majority. Some students may not be able to recognize when a decision needs to be made, consider possible options, or recognize the consequences of their decisions without additional support. For these students, schools often recommend that guardianship or another form of substitute decision-making may be appropriate.

Under guardianship, a person is considered to be legally incompetent. The individual loses the authority to make some or all the decisions granted to adults. A guardian is assigned by the court to make these decisions. The guardian is frequently a parent. The person under guardianship is legally referred to as the ward.

Establishing a guardianship has significant implications for people with disabilities. On one hand,

it can put protections into place so the person can live life more safely, with as much self-determination as possible. On the other hand, it limits civil rights. Many rights can be lost through guardianship; it should not be undertaken lightly. The rights that can be lost include:

- The right to marry or divorce
- The right to make a contract
- The right to make a will
- The right to get a drivers' license
- The right to own or sell property
- The right to rent property
- The right to decide about medical treatment
- The right to make decisions about one's own social life
- The right to decide where to live
- The right to decide how to spend one's own money

Balancing the values of independence and protection can be a challenge. Consider the person's needs and wishes. Less restrictive options to guardianship are often available. In fact, Rhode Island law requires that less restrictive alternatives to guardianship be considered **before** any guardianship may be ordered. The law also requires that, absent a finding that the person lacks all decision-making capacity, guardianships be limited.

Alternatives to Guardianship

There are many alternatives to guardianship that may meet the needs of a person who has impaired decision-making capacity. Potential alternatives include the following:

Education: Releases; Durable Power of Attorney for Education

Health Care: Releases; Durable Power of Attorney for Health Care

Finances: Representative Payment through the Social Security Administration; special needs trusts; Powers of Attorney

Helping Your Child Prepare for the Age of Majority

Ideally, the student, parents, and other family members will all continue to be actively involved in planning the services and programs for the student's transition into adulthood. As parents of children with disabilities, our challenge is to seek opportunities for our children to make choices for themselves, beginning at a very early age and continuing throughout their school years. As parents, we can begin to help our children prepare for adulthood by looking at the role we play in their lives. Do we try too hard to sway our children's decisions? Do we tend to speak for our children instead of letting them speak for themselves? Can we separate our own desires from our children's wishes? It can be hard to let

go of our parental role when we love our children and worry about their future. But we may need to step back and look at our own actions. Our role is to help our children to become comfortable making their own decisions and capable of making good choices. Children develop decision-making skills over time. Young children can practice these skills within the family. Older children can take increasing responsibility for the decisions that affect their lives.

Teaching Young Children How to Make Decisions

- Include your child in purchasing decisions. Does your child help select his or her own clothing and help with grocery shopping and meal planning?

- Discuss important decisions, such as vacation plans and major purchases, as a family. Routinely state your thoughts out loud so your children have a model for good decision making: "We are not ready to decide on that yet, let's talk about it tomorrow after dinner;" or "Let's gather more information before we buy this."
- Practice with your child what he or she should do if lost.
- Encourage your child to participate in planning his or her IEP and even leading the IEP meeting.
- Role-play IEP meetings with your child ahead of time to help him or her clarify what he or she wants from the meeting. Practice how to step out of the meeting to discuss a decision in private. Ask your child if he or she wants to invite anyone to the meeting for support.

- Help your child develop good working relationships with school personnel and other IEP team members so there is little disruption when he or she reaches the age of majority.

- Do not allow educators to pressure your child into making decisions he or she is not able to handle.

- Avoid being overprotective. Do not interfere with your child's desires when it is not truly necessary.

Stay involved even after you are no longer the primary participant in the development of your child's IEP. Parents must still receive notice of IEP meetings once a student reaches the age of majority. The school or student could, however, invite a parent to attend the meeting as an individual who is knowledgeable about the student's educational needs and abilities.

MANAGING HEALTH CARE

LET THE PATIENT DO THE TALKING

For families of young people with disabilities, the transition to adult life can be intimidating. In the area of health care, it can be scary. Parents who have made difficult medical and treatment decisions for their children for years are suddenly no longer legally in charge of health care decisions.

However, when families actively share medical information and decision-making with their son or daughter early on, and assist them in becoming their own healthcare advocates, it can reduce the anxiety associated with turning 18.

Jennifer Irish, mother of 24-year old Rhode Island College graduate Dana Wright, says she taught her daughter to be assertive at an early age. When doctors would ask how Dana was feeling, “I’d say, she’s right here! She can tell you.”

“I learned to be as knowledgeable as I could, and I make sure I’m organized and prepared,” said Dana. “I do my own research, but I ask a lot of questions. And I know my own body.”

Before medical appointments, they make a list of questions--separately. “It’s a strategy so we don’t forget anything,” Jennifer said.

Dana, who has had several surgeries, including three heart operations and a spinal fusion, says doc-

tors treat both of them as partners in her health care. “Medical guardianship is not an issue. Communication is the key. I’ve never been excluded,” said Jennifer.

That wasn’t always the case for Lina Dupont, who called her daughter’s doctor to reschedule and appointment shortly after Allyson’s 18th birthday. “I couldn’t even change the appointment,” Lina said. “They told me Allyson had to do it.”

Lina later contacted the Hasbro Children’s Hospital Family Help Desk, and was connected with a law student, who provided planning assistance to the family.

Allyson used an extensive worksheet to prepare an advanced directive. Allyson was adamant that she did not want to be intubated, although she is reshaping that position after a close friend was permanently ventilated. Lina says it was difficult to talk about end of life issues at such a young age, although “Allyson is very matter of fact about it.”



At the same time, Allyson created a Durable Power of Attorney granting her mother power to make health care decisions for her if she is no longer able.

Allyson has been involved in health care decisions for most of her life. When she needed back-fusion surgery at age 10, she chose to schedule it late in the summer, so she wouldn’t miss camp. Although she learned all about the surgery, “It was worse than I expected. From that point on I became lot more involved.”

When she left the care of her pediatrician for an adult care provider, she brought a list of questions to help him understand her needs. “A lot of doctors don’t understand

because they haven’t seen young adults--typically, they didn’t survive,” Lina said.

Today, Allyson, about to turn 21, is a junior at the Rhode Island School of Design. She manages all of her health care, and “deals with the bills,” Lina said, although she has signed releases so her mother has access to information from the doctor and health insurer.

It’s difficult for parents to let their children take over decision-making, Lina said. “The key is to direct less and provide information more. You can’t start preparing kids when they’re 17. You have to start in tiny little pieces.”



Take Charge of Your Health Care

A Guide for Youth with Disabilities

Be Your Own Health Care Advocate

- Learn about your condition or disability.
- Know who to call in an emergency. Carry that information with you.
- Learn how to make your own appointment.
- Write down your questions before you go to see a doctor.
- If you have a lot to discuss with the doctor, ask for an extended appointment so you won’t feel rushed.
- If you don’t understand an answer, ask the doctor to explain it again.
- Ask your parents to wait outside if you want to talk about difficult topics, such as relationships, sexuality, drugs, or family issues.
- Ask your doctor to explain all medical tests and their results. Ask for copies of reports for your own files.
- Write down what the doctor says to help you remember after your visit.

- Be persistent. You’re entitled to know all about your condition, your treatment and the available options.
- Call back if you have questions after the appointment.

Take Charge of Your Health Care Information

- Medication – Be sure you know the names, dosages, and why and when you take them.
- Know how to call your pharmacy and how to fill and refill prescriptions.
- Keep a list of addresses and telephone numbers of all your medical providers.
- Carry your insurance card and other important health care information with you.
- Learn all you can about your health plan.
- Know how to order and care for any special equipment you use.

Plan Your Transition to an Adult Care Doctor

- Talk to your pediatrician about a plan to transfer your care. Begin by age 14, but plan over a period of time to address your specific health care needs.
- Work with your primary care provider to find appropriate specialists.
- Schedule interviews with adult care doctors before you transfer to their care. Make sure you are comfortable with their expertise and with them personally.
- Make sure your records are transferred as soon as you select a new provider.

Adapted from: Transition Planning for Adolescents with Special Health Care Needs and Disabilities, Institute for Community Inclusion/UCEDD at Children’s Hospital, Boston, MA.

RI Developmental Disabilities Network presents:

Alternatives to Guardianship

April 30, 2008

8:30 AM to 3:30 PM

Crowne Plaza Hotel, Warwick

Register
by April 11

This full-day conference, sponsored by the RI Developmental Disabilities Network, will address the art of decision-making and alternatives to guardianship in relation to health care, finances, and education. Ample opportunity will be available for questions and answers.

Who should attend?

Individuals with disabilities
Parents, siblings and other family members
Community Service Providers
Educators
Lawyers
Advocates

Keynote presenter Dohn Hoyle

Executive Director, The Arc of Michigan

He says that the principles and practices of person-centered planning and self-determination not only help people with disabilities enjoy the lives they want but also provide the tools needed to make guardianship unnecessary.

He will address why guardianship is seldom, if ever, necessary. He will proffer more contemporary and appropriate alternatives. Guardianship, he maintains, is an outmoded and outdated. He will describe how guardianship is incongruous with what people with disabilities want and how it needlessly impinges upon individual rights, as well as our obligation to honor a person's preferences.

Other conference topics include:

- Self-determination and making choices pertaining to education, career, housing, health and finances
- RI guardianship law and utilizing less restrictive alternatives to guardianship
- Overview of Personal Lifetime Advocacy Networks of RI, Inc. (PLAN RI) and other local resources

The conference registration form is available to download from the Internet at www.sherlockcenter.org.



Registration Information

Register by April 11

\$35 registration fee includes morning refreshments, lunch and all materials.

Pre-registration is required to attend the conference. The deadline to register is April 11; late registrations will be accepted as space permits.

Register through the Sherlock Center by mail or fax. Payment (check, money order or PO) is required at the time of registration. Faxed registrations must include a copy of a purchase order. Purchase orders obligate registrants for payment.

A limited number of scholarships are available for family members and individuals with disabilities to attend the conference. To request a scholarship, call Mary Anne Pallack, (401) 456-8072.

Accommodation Requests

To request a reasonable accommodation, indicate the request on the registration form, or call the Sherlock Center at 401-456-8072. Requests must be made by April 11.

ASL Interpreters have been reserved in advance. Reservations for these services will be released if no requests are made by the registration deadline.

Confirmation

Written confirmation and directions will be provided by April 23.

Refunds

The Sherlock Center will be glad to refund your registration fee in full if you cancel on or before April 11. After April 11, no fees will be refunded; however, the registration is transferable. Call the Sherlock Center to provide the substitute's name.

Professional Development Credit

Conference participants will receive a certificate of attendance.

The conference is approved for RIDE professional development units (PDUs). Documentation of contact hours will be distributed at the close of the conference.

Directions

From 95 North or South, take exit 12A. Bear right before the traffic light onto Greenwich Avenue. Turn right, into the Crowne Plaza driveway.

Contacting the Sherlock Center:

(401) 456-8072 Voice
(401) 456-8773 TDD
(401) 456-8150 Fax
Email: mpallack@ric.edu

Registration Form

Registration Fee: \$35 • Deadline: April 11, 2007
(Please Print Clearly)

Name _____

Organization _____

Address _____

City/State/Zip _____

Phone _____ Fax _____

Email _____

Affiliation:

Individual with a disability Family member Educator Community service provider

Medical provider Legal professional Advocate Other: _____

Reasonable Accommodation Request:

Indicate accommodation request(s) below, or call the Sherlock Center at (401) 456-8072 (v) or (401) 456-8773 (TDD). Requests made after April 11 may not be filled.

Materials in alternate format: large print disk audio tape braille

Assisted Listening Device

Interpreter*: ASL CART

Other request, specify: _____

*Interpreters have been reserved in advance. Reservations for these services will be released if no requests are made by the registration deadline of April 11.

Payment Enclosed:

Check/money order Amount: _____

Cash Amount: _____ (accepted in person only, do not send cash by mail)

Purchase Order (enclose copy) Amount: _____

send invoice to receive payment

do not invoice, check will be sent automatically

Please make checks payable to: Sherlock Center/Rhode Island College

Rhode Island College Federal ID#: 05-6016315

Registration by mail:

Sherlock Center/Rhode Island College
600 Mt. Pleasant Avenue
Providence RI 02908-1991

Registration by Fax:

Fax registration form and Purchase Order to: (401) 456-8150

Registrations sent without payment or purchase order will not be processed until payment or purchase order is received.

