

# The Riot!

Guardianship Issue!

A National E-Newsletter from the Self-Advocate Leadership Network @ HSRI

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# Who's In Charge?

## Self-Advocates Wonder About Guardianship

The word “guardianship” describes a relationship between people. It is a legal arrangement that is decided by a court. It gives a legal guardian the power to care for another person. This can include control over what that person does and over his or her property.

The court gives this power to a “guardian” when it thinks that the person, called a “ward,” cannot care for him or herself.



Parents seek guardianship of their adult sons and daughters. They worry that their family member will not be able to stay safe, manage their money, or make big life decisions on their own.

This is not always bad. For instance, in a hospital it can be good to have a guardian to make sure that a self-advocate gets the best care.

Yet, self-advocates say guardians are used when not needed. Or, they use their power to overrule the opinion of a self-advocate. Guardianship can put a big limit on a person's want to be in charge of their own life.

There are also alternatives to guardianship. Person-centered planning and services are a good start. Power in decision making can also be shared. Guardianship can also be limited to specific types of life situations.

Self-advocates think it's time to rethink guardianship.

## Man Wins Millions!

### Wins big and plays big too



Did you see the big news story? Rob Johnson of Idaho won the 2.5 million dollar lottery!

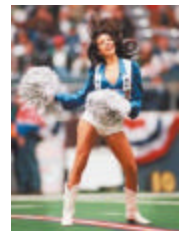
Rob lives with his parents and has cerebral palsy. When asked what he will do with his new fortune he said that he was moving to Hollywood and hiring the Dallas Cowboy Cheerleaders for his

support people.

After that, he said he will “buy out an amusement park for the day so I can ride all the rides.”

Rob wasn't done yet! Next, he said he will “buy a fancy new lift van with a tub in the back to fill up with candy! Then I'll eat the biggest ice cream ever made!”

Rob was last seen with an ice cream cone in an amusement park with a Cowboy cheerleader. Good luck Rob!



**April Fools!!**

## About The Riot!...

The Riot! is produced by the Self-Advocate Leadership Network at the Human Services Research Institute.

We work together with self-advocates to develop and write each issue.

Here's who "we" are:

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## RIOT FUN PAGE

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- Funny jokes
- Plus, much more!



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[www.theriotrocks.org](http://www.theriotrocks.org)

## Julie's Jive

Happy spring to everyone from The Riot! I love this time of year! It's a great time to go outside with your friends, go to the park, catch a local softball game, go out on a date or just hang out and soak up the sun.

Can you be free to do these things if you have a guardian? I guess so, but I'm not sure.

Guardianship is the topic for this issue of the Riot! This is a hard topic to write about because so many people have mixed feelings about guardianship.

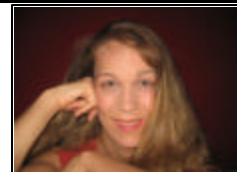
I looked up "guardian" on the computer, and I found these

words: protector, keeper, guard and warden.

Do people with disabilities need to be protected? I think sometimes we do, but others need protection too.

Let's face it, in the past people with disabilities have been seen as weak and unable to care for themselves. I think over the last decade, through self-advocacy, we have changed others perspectives and have been able to be in charge of our lives.

I hope this issue will let you think and then decide how you feel about guardianship.



Julie Petty



## National Conversation on Advising Self-Advocacy Groups

April 7, May 5 and June 2, 2008

You Can Still Register for the May and June Teleconferences!

Don't be left out! Register Now!

Go to the Riot Website for more details

## Guardianship Is About Trust

Guardianship is a relationship between people. Basically, another person gets power over a self-advocate. There are different kinds of guardianship. But it's all about trust.

Guardians need to get to know us as individuals so they can really understand what is important to us. This builds trust and helps us make good decisions together.

There is a trust that the person getting the power will only take what is needed to keep the self-advocate safe and well. There is also the trust that he or she will not take advantage of the self-advocate.

*Eric Matthes*  
Riot Editor in Seattle, WA  
Former President of People First of Utah



Eric Matthes

There are examples of people acting as good guardians. However, there are also stories of guardians taking too much power or taking advantage of the self-advocate. When this happens, this is not right because the trust is broken.

We self-advocates know that we can use some help. In guardianship, we have to trust that the person taking the power will help us live the quality of life we want. We really do want to be in charge of our own lives as much as we can.



We asked self-advocates around the nation  
 “How do YOU feel about guardianship?”  
 Here is what they said...



**Chad** - “There are pros and cons having a guardian. I wouldn’t want the guardian to stop me from making my own decisions and choices if I were capable of doing so.”



**Gayle** - “I feel in my case that it wasn’t right for me. My aunt was my guardian and I really wanted my freedom.”

**Elouise** - “Guardians take control of people lives, stand in our way and keep us from doing the things we want to do like living on our own.”

**Local People First Chapter** - “Guardianship should be a thing of the past....my life is my choice!

“We believe that each person and situation is different. So with that in mind, if a person is able to safely live independently, they should be allowed to do that. If not that person should be able to live with supports in the community with the least restrictions needed.”

**George** - “People with disabilities strive to live life to the fullest, having jobs, living independently in the community and making our own decisions. Guardianship is something that we don’t want.”

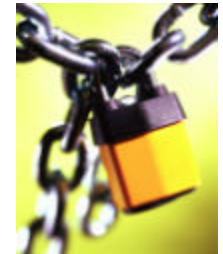
**Jeff** - “I think the person with the disability should have some part in it. Maybe they do not want a full guardianship or maybe they want to be their own guardian. I’m all for that. I think many people should be their own guardian.”

**Tim** - “It all depends on how you look at it. A good guardian understands you and your access needs. Guardians that don’t listen to what you want in life or disregard your thoughts about things that you think are interesting aren’t very helpful to you.”



**Bernard** – “I think it’s terrible that so many people have guardianship and that people don’t think we’re capable of having it. I have my own guardianship but I had a hard time getting it. I think the laws should change so it isn’t so hard to get it.”

**Jen** - “People overuse guardianship. When someone has full guardianship over them, that person has all of their rights taken from them and it is hard to get them back.”



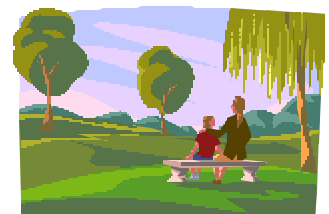
**David** - “My parents have full guardianship over me and I feel like I have no say over my life.”



**Orrie** - “Even though there is a legal procedure for guardianship, it really takes away the person’s right to autonomy. Just like people without disabilities have the privilege to make decisions, even if they regret it later on, we wish the same right when it comes to finances, career moves, sexuality/intimate relationships, living arrangements, accepting or refusing medical treatment, and how we choose to live our life. ”

**Burke** - “Being in charge of me is so very important to me.”

**Shawna** - “My guardian lets me do what I want and we have a good relationship.”



**Deanne** - “I am my own guardian and I absolutely love it.”

**George** - “I have no limitations. I purchase anything I want. We have a friendship.”

**James** - “I wish I did not have one because I don’t need one. I know how to get help if needed.”

## Has Guardianship Kept Up with The Times?

By Marian West and Teresa Moore

Dohn Hoyle and Kathleen Harris have written many articles on guardianship. They explain how people with disabilities were thought of through time and how it affects people's lives now.



In the 1950's, it was believed that people with disabilities could not do anything for themselves. Many lived in institutions. There were no community services. Beginning in the 1970's, community services were developed. Still, then and now, there is an ongoing belief that people with disabilities cannot decide things for themselves.

This belief often resulted in parents, and even service agencies, having guardianship power over people. Mr. Hoyle says, "Even with changes in the law, individuals with disabilities still may struggle with loss of rights and lack of control."

Over time, individuals involved in self-advocacy are getting stronger. They ask to be in charge of their lives. Many who have guardians are asking for their rights to be restored.

For more information on the views of Mr. Hoyle and Ms. Harris, go to:  
<http://www.self-determination.com>

## Guardianship in North Carolina

From Holly Riddle, Director, NCCDD

The North Carolina Council on Developmental Disabilities believes that with the right support, self-advocates can make their own decisions. The Council believes that most people, with disabilities or not, sometimes need guidance in making decisions.

People should always consider help from friends and family first before guardianship. Taking someone's rights away should be the last resort.

In North Carolina, the courts must consider limited guardianship first. During the legal process, a lawyer must talk to the person whose status they are talking about and respect that person's decision.



## Missouri to Study Guardianship Issues

By Betty Williams and Dayna Davis

The Missouri Planning Council for Developmental Disabilities is studying guardianship issues. To learn more, we interviewed Susan Pritchard-Green, Director of the Council, about their project.



**The Riot:** Why did the Council put out this Call For Investment (CFI)?

**Susan:** The Council is concerned about guardianship. Families are encouraged to seek guardianship for loved ones right from high school and are pushed towards full guardianship. People don't always know that there are options such as limited guardianship or a conservator.

**The Riot:** What is the purpose of the project?

**Susan:** The Council wants to study what issues and practices are currently in place in Missouri. We want to train families, service coordinators and people in the public service system on all the guardianship options available to them. We also want to change guardianship decisions around from people with full guardianship to lesser or no guardianship at all. The Council strongly supports lesser or no forms of guardianship because they feel full guardianship can limit an individual's participation in the community.



**The Riot:** Will self-advocates be in control of decisions during the guardianship process?

**Susan:** The Council would like there to be more discussion with self-advocates before the decision is made. They also believe that the decision should not be made by someone who doesn't know the person or family involved.

**The Riot:** What do self-advocates in Missouri think about the project? Did they help develop it?

**Susan:** The Council has quite a few self-advocates as members who helped develop this project. They are very excited about it.

# Horoscope

By Dale Froese and Aimee Morry in Canada



A horoscope predicts the future based on the position of the planets and your birthday. Find the sign that fits with your birthday. Then read about what's in store for you!

**Aries** (March 21-April 19): Be assertive. Stand up and talk about the things you want and need.

**Taurus** (April 20-May 20): You are a good speaker. You need this to help others understand you better.

**Gemini** (May 21-June 20): A friend needs your help. Help them speak out about a problem they're having.



**Cancer** (June 21-July 22):

You are a kind person but right now you need to think about you! What is holding you back?

**Leo** (July 23-Aug. 22): You need to take the lead. People need you right now and you have so much to offer!

**Virgo** (Aug. 23-Sept. 22): Time to change and go after that goal you've been putting off!

**Libra** (Sept. 23-Oct. 22): Harmony is important for you right now. Create a peaceful environment for yourself.

**Scorpio** (Oct. 23-Nov. 21): You have passion for an important cause. This is a great time to talk about the things you believe in!



**Sagittarius** (Nov. 22-Dec. 21): Time to explore and learn new ideas. Don't be afraid to ask for help from people you trust.

**Capricorn** (Dec. 22-Jan. 19): Your determination and persistency will pay off. Be assertive and talk about what is important for you.

**Aquarius** (Jan. 20-Feb. 18): Networking and learning new and creative ideas are important to you right now. Learn new ways to achieve your goals. You are on the right track. Keep going!



**Pisces** (Feb. 19-March 20): You will teach someone this month. Your expertise and knowledge will be very powerful!



## Need Romance Advice? ...Ask Cubby

**Dear Cubby:** The Chicago Cubs haven't won baseball's World Series in 99 years. Will they this year? How will they do?

— Cubbie Fan in Chicago



Chicago Cubs  
Ryan Theriot

**Dear Cubbie Fan:** Yes. Of course they will win. It's springtime. They will win. Trust Cubby. All that Cub fans want is that St. Louis does not win. We just want one championship to shut down those people that call us names and tell us to just stay home and drink our beer. One thing for sure is that we will have fun whatever happens this year. And next year too. Play ball!

**Dear Cubby:** My boyfriend and I want to get married. But he has a guardian, his dad, who says that he can't get married. What can we do?

— Wedding Bells Wanted in Chicago

**Dear Wedding Bells:** Tell dad that he needs to grow up. Your boyfriend should tell him that he loves his lady and should have the option to get married. Then he should ask why he can't. If dad still won't budge, it's time to get some help. Try a pastor or family friend.

**Dear Cubby:** I forgot my girl's birthday. She's really mad at me even though I get her presents all year long. How do I get out of the doghouse?

— In the Doghouse in Chico



**Dear Dog Boy:** My friend, you could end up in the doghouse a long time or maybe forever. If she really loves you, she will forgive you and move on. Then you can get out of the doghouse.

Email your romance questions to Cubby at:  
[www.theriotrocks.org](http://www.theriotrocks.org)



## Fun Movies To Watch On Developmental Disabilities



By Dayna Davis & Nancy Ward

Spring is here! That means April showers to help bring May flowers! So when it's raining outside and you have to stay in, you may want to check out a cool movie.

Not only that, but this month is a good month to be aware of how "disability" is shown in the movies. We hope that you enjoy these movies about people with developmental disabilities.

- |                              |                    |
|------------------------------|--------------------|
| Gaby - A True Story          | Inside I'm Dancing |
| My Left Foot                 | The Other Sister   |
| Door to Door                 | Forest Gump        |
| Rain Man                     | Including Samuel   |
| Darius Goes West             | Elephant Man       |
| Edward Scissor Hands         | Radio              |
| What's Eating Gilbert Grape? | I Am Sam           |

## Book Review "Lost in a Desert World"

By Nancy Ward



This is a book about Roland Johnson as told to Karl Williams. Roland spent half his childhood at Pennhurst State School, where he was sexually abused and made to work like a slave - for no money. He won his freedom and became president of *Speaking For Ourselves*, which is Pennsylvania's self-advocacy organization.

Like one of his heroes Martin Luther King, Jr., he traveled across the United States to help teach people that everybody is equal and has the right to speak out for themselves.

In Toronto, in 1993 at the Third International Conference on Self-Advocacy he gave his most famous speech. In that speech he asked self-advocates:

**"Who's in charge?**

**Who's in charge of your life?"**

It's a good question to ask, especially when you think of guardianship. This is a great read! To get a copy go to:

[http://www.karlwilliams.com/lost\\_in.htm](http://www.karlwilliams.com/lost_in.htm)

### WIN a FREE RIOT T-Shirt!

The first 3 people to answer this Movie Trivia question correctly will win a free RIOT T-Shirt!



**Which movie above did Tom Hanks star in?**

Email your answer to: [theriot@hsri.org](mailto:theriot@hsri.org)

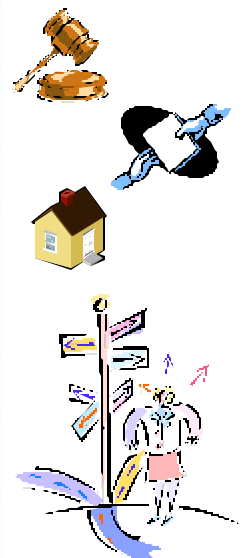
## GUARDIANSHIP PUZZLE

Can you find the hidden words and phrases? Look from top to bottom, bottom to top, left to right, and right to left.

- |           |           |
|-----------|-----------|
| POWER     | LEGAL     |
| GUARDIAN  | PROTECT   |
| FREEDOM   | IN CHARGE |
| CONTROL   | TRUST     |
| DECISIONS | MY LIFE   |
| CHOICE    |           |

P	M	O	D	E	E	R	F	A	C
O	T	C	E	T	O	R	P	N	O
W	I	N	C	H	A	R	G	E	N
E	P	R	I	N	T	S	U	R	T
R	M	K	S	E	I	P	A	D	R
M	Y	L	I	F	E	T	R	W	O
E	C	I	O	H	C	H	D	S	L
R	S	E	N	W	O	U	I	R	O
D	R	O	S	L	E	G	A	L	R
F	E	X	E	C	L	A	N	I	T

## YOUR Life... YOUR Choices





## Craig Says... It's Spring and Life Smells Good!



"Sun is shining, weather is sweet, makes you wanna move your dancing feet!"-Bob Marley sang that.

Hey beautiful people, it's Craig and I'm here to tell you that it's

a lovely spring day! I feel like I'm in a Disney movie, the birds are singing, the trees are swaying in the breeze, and I'm filled with happy juice! If there were little animated deer and bunnies, they'd be dancing next to me as I walk down the sidewalk to work!

That's right kiddos, Señor Craig has a job! I work for the man and I get paid! I am a professional now! Can you believe that?

All is right with the world! I cleaned my apartment today, evicted the dust bunnies that were the size of real bunnies under my couch, then went and sold my TV and bought some books instead. Then, believe it or not, I went and did laundry. All my laundry. Now my socks don't stink anymore!



I may even join a gym and get rid of the spare tires around my waist (you never know when you need a spare!). Maybe I'll get out and make some friends. Maybe I'll meet a special lady... or two, or three! Anything can happen in springtime!

I've started taking piano lessons and I get to perform at a local concert next week. I'm even going to rent a tuxedo with a top hat and tails!

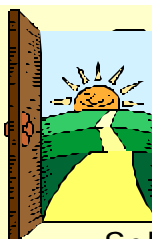
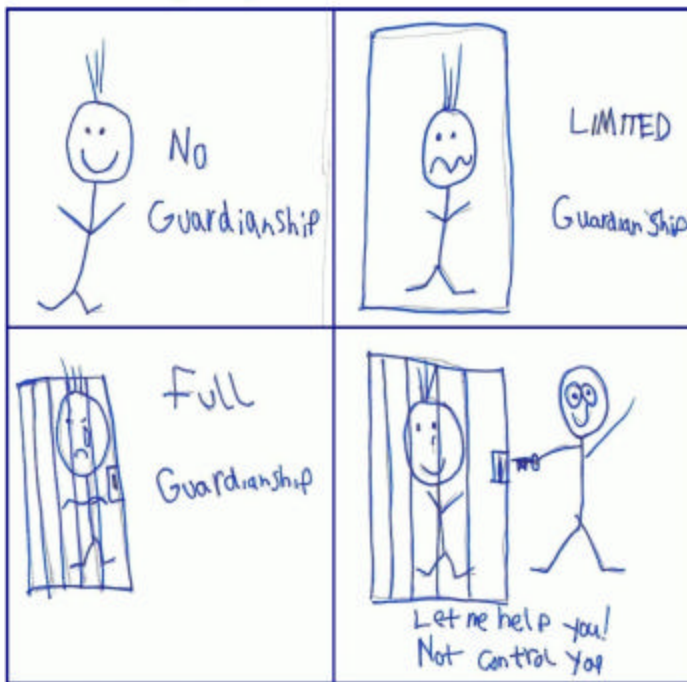
I helped a bunch of little old ladies cross the street today. Then I saw some girl scouts selling cookies and I bought 50 boxes and then donated them to a homeless shelter! I can't decide what I want to do next!

### Ha Ha ... April Fools!

Did I fool you! Believe me... These spring flowers STINK! Don't worry Crotchety-Craig will be back in the next issue.



## Squiggly by Jeff Ladd



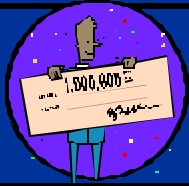
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A Toolkit for Self-Advocates from the Self-Advocate Leadership Network

[www.hsri.org/leaders](http://www.hsri.org/leaders) or (503) 924-3783 x 24

PUZZLE ANSWERS									
P	M	O	D	E	E	R	F	A	C
O	T	C	E	T	O	R	P	N	O
W	I	N	C	H	A	R	G	E	N
E	P	R	I	N	T	S	U	R	T
R	M	K	S	E	I	P	A	D	R
M	Y	L	I	F	E	T	R	W	O
E	C	I	O	H	C	H	D	S	L
R	S	E	N	W	O	U	I	R	O
D	R	O	S	L	E	G	A	L	R
F	E	X	E	C	L	A	N	I	T



# The Riot! Action Page



## Self-Advocates Speak Up! and Speak Out!

How about some FUN?! Imagine that you put down a dollar on the lottery. You picked your numbers and you WON!

Let's say you won \$1 million! One million bucks! What would you do? How would you spend it? Would you save it all?

At your next self-advocacy meeting, ask everyone how they would spend \$1 million, if they won.

Here's what you do:

- 1 Get everyone to sit together in a circle.
- 2 Put jar or a container filled with candy or some other goody at the center of your circle. Ask everyone to pretend that the container is really filled with \$1 million.
- 3 Ask each person to imagine that they won the money in the jar – \$1 million!! YAY!!

- 4 Ask each person what they would do with the money. Would they blow it all on parties? Buy a house? Save it? Go around the world? Quit their job? What would they do? Go around the circle twice, if you have time. Give everyone a chance to tell others what they would do.



- 5 Pass out the treats because everyone is a winner! Remember though...instead of candy you could use healthy treats too!

**Talk it up...  
Have yourselves a regular Riot!!!**

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Get these great Toolkits from the Self Advocate Leadership Network! Each toolkit has information that you need to help self-advocates lead their own lives and help shape the service system.

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and YOU w/CD!**



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**Working Together  
for Change**



**Using Medicaid to Fund  
Trainings for Self-Advocates**



This is  
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Stuff!  
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yourself!