

# The Riot!



Advising  
Self-Advocacy  
Groups Issue!

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

## What's Inside

Julie's Jive.....2  
 Know Your Role.....2  
 Role of an Advisor.....3  
 What Do You Think?.....3  
 Good, Bad & the Advisor.....3  
 Friends of the Movement.....4  
 Self-Advocate as Advisor.....4  
 Roland Johnson Quote.....4  
 Riot! International Page.....5  
 Horoscopes.....6  
 Jack and Jill.....6  
 Summer Recipes.....7  
 Puzzle.....7  
 Joe's Sports Zone.....8  
 Riot! Fun Page.....8  
 Craig Says, Cartoon.....9  
 Riot! Action Page.....10

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## Self-Advocates say - Ask... Don't tell Us!



The self-advocacy movement has grown stronger over the years and is here to stay. Self-advocates have come together to say, "We are people first and we deserve the life we choose."

All over, self-advocates want to run their own movement. They don't like being controlled or pushed around. Self-advocates say "Ask... Don't tell us!"



Still, the self-advocacy movement relies on allies or friends to support and believe in the movement.

Success of grassroots organizations often depends on self-advocates getting the support they need. Betty from Indiana says, "We can use some good friends to help us get the work done."

People who help or support us are

called "advisors." Sometimes we call them other names, but mostly "advisors."

An advisor supports self-advocates and the self-advocacy group by providing information and other help in order for goals to be reached.

Advising a self-advocacy group is not easy. Advisors can give too much help or too little. Maybe they don't give the right kind of help at all.

Anyone who advises a self-advocacy group understands how rewarding it can be... and how hard!

An advisor, Kurt from Michigan, says, "It's easy to give bad help."

There are many fine lines when advising a self-advocacy group. In this issue we showcase the advisor. The good, the bad and the Advisor!



## Fun Vacation Ideas to Try!

By Nancy Ward



It's summer and time for a vacation! Vacations are a good way to explore the world, learn something new, or hang out with family and friends.

Fun places to go are theme parks, national parks, cruises, camping, and visiting other countries. Remember that when you travel as a group you may be eligible for discounted admission tickets. Speak up and ask

if a reduced rate applies to your group!

Theme Parks – Disneyland caters to the child in all of us!

National Parks – Visit a national park! They are located all over the country.

Cruises – Cruises are a great way to go somewhere. I went to Alaska and saw glaciers and whales.

Camping – If you are concerned about the price of gas, campgrounds are located all over with showers, swimming pools, and cookouts.



**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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- Eric Matthes – WA
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**At HSRI**

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- Jennifer Negus, Elizabeth Pell,
- Drew Smith, Reena Wagle

**Julie's Jive**

"Summer, summertime, time to sit back and unwind..." as the song goes by Will Smith. I love the summer! It is my favorite season of the year! Summertime is usually when families take vacations together. I plan on taking a vacation with my sons at the beach.

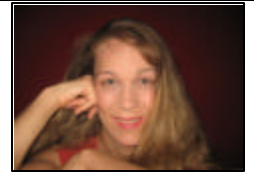
I think everybody should take a break to help "sharpen the saw." When you work hard all the time, you can get tired, worn out and dull like a saw. Taking a vacation can help you rest and get refreshed.

The United States also celebrates Independence Day in the summer. There are many great celebrations on July 4<sup>th</sup> which most

always end with fireworks!

Because of our independence, we have the right to vote. Over 50 organizations are sponsoring the Presidential Forum on Disability Issues featuring the 2008 Presidential Candidates (invited). This is a historic, nonpartisan forum to be held on July 26, 2008, in Columbus, Ohio.

For more information on the forum, visit [www.aapd-dc.org](http://www.aapd-dc.org). For voting information, visit the National Technical Assistance Center for Voting and Cognitive Access at [www.govoter.org](http://www.govoter.org). Enjoy your summer!



Julie Petty

**Summer Days...**



**The National Forum on Disability Issues**

featuring the 2008 Presidential Candidates (invited)

**July 26, 2008 in Columbus, Ohio**

For more information go to: [www.aapd-dc.org](http://www.aapd-dc.org)



**Know Your  
Advisor's Role**

There are two groups: people with disabilities and advisors. Each group has a role and when a good advisor knows what they are doing, their roles can fit.

When advisors do their roles right, they can help people. Not everyone knows the role of an advisor. Sometimes advisors get in and think they know everything.

Sometimes people with disabilities need help writing letters so that they are professional. You can tell them your opinion, tell them what you want to say and they can help you shape your thoughts.

If you use advisors, it does not mean

that you cannot be the chair of SABE or the chair of your Council on Developmental Disabilities.

People with disabilities can work on their own but sometimes they need help. Learn to use your advisor support properly and you will be successful. But, if your advisor oversteps his or her boundaries, don't be afraid to tell him or her to back down.

Self-advocates and advisors working together can help the disability community go to the next level.

*Bryon Murray*  
"Big Mouth for Self-Advocates"  
He currently lives in  
Roosevelt, Utah.



Bryon Murray

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## The Role of an Advisor

By Erick Yeary

Advisor Michelle Aman from South Dakota, was asked about her role as an advisor.

**The Riot:** What is the role of an advisor?

**Michelle:** To support people when they ask for your help and to offer assistance when needed. The self-advocate should always be in the lead.

**The Riot:** How do you make sure everyone in the group is involved in meetings?

**Michelle:** Talk before the meeting, set-up a game plan and discuss it afterwards. If someone didn't speak during the meeting, figure out why so they will want to talk next time.



**The Riot:** How do you share your opinions with the group without influencing their decisions?

**Michelle:** We go around the room and ask for everyone's opinions - including the advisor - that way everyone is heard.



## What Do You Think About Your Advisor?

By Marian West

Self-advocate Dennis Greenwood from New Hampshire, was recently asked how he felt about his advisor.

**The Riot:** What do you think about your advisor?

**Dennis:** My advisor is very good and she helps me with different things.

**The Riot:** How does your advisor help you take part in meetings?

**Dennis:** She gives everyone a chance to talk. She listens and talks with you about the program. I think a lot about my three advisors.

**The Riot:** Do you respect your advisor's opinion? If so, why?



**Dennis:** She is a good person and she listens to me and everyone in the group. She talks to me when I am wrong and get out of hand at meetings.

## The Good... The Bad... and The Advisor



Self-advocates across the country were asked what they thought of their advisors. Here are their words...

I fell in my hotel room and I didn't know who to call so I called my advisor. She stayed on the phone until help came.

She stands back while we run our meetings but is always there when we need help.

I wanted to work for a magazine writing articles but when I asked my advisor to help me she said she wouldn't unless I paid her. She said it was beyond her job description. Due to lack of support, I almost lost the job but someone from the magazine helped me instead.

During a grant meeting, an advisor did not use the self-advocate's words. When the grant reviewers talked to the group, they could not answer their questions because different words had been used. They did not get the grant.



She gives us advice on the pros and cons on stuff but we make the decisions. She cares about us and is what an advisor should be.

An advisor used members of a group for a project of theirs. When the project was over, they stopped talking to them and stopped being nice. This really hurt the members.

## Friends of the Movement

Advisors help self-advocacy groups in many ways. Sometimes they are chauffeurs, coaches, event planners and consultants. Mostly, advisors must be friends of the movement. An advisor's role is complicated - and it is really important!

Good advisors give self-advocacy groups the help that they ask for - not the help they think the group needs. Advisors can make suggestions, as friends often do, but finally self-advocates decide the direction of their movement.



The Riot! recognizes that advising self-advocacy groups well is critical to their success. So, we hosted a three part teleconference series to start a conversation about this important issue.

Each call had three presenters. We invited a mix of self-advocates and advisors from different parts of America and Canada to talk with us. Self-advocates Chester Finn, Gordon Fletcher and Patricia Jones presented on the first call.

National, state and local advisors, Janet Hunt, Aimee Morry, Michelle Reynolds, Vicki Turnage, Carol Utterback and Bill Worrell talked about their experiences and the supports necessary to do a good job. Julie Petty, interviewed the presenters

on the phone during the calls.

There were major themes that emerged during the three calls. First, presenters agreed that self-advocates are the leaders of the movement. Advisors are important to its success, but must support it while staying in the background.

Second, it was important that advisors provide help without influencing decisions made by self-advocate leaders.

Finally, presenters suggested that training, peer support and evaluation were important to help advisors do a good job.



There were many other topics discussed during the three calls. But one thing was clear: The movement has come a long way and self-advocates are now ready to make serious change. As these leaders become experienced, the help they need is becoming more complex. With this, advisors' roles are changing and they need to learn new skills to keep up with changing times.

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### The Self-Advocate as an Advisor... Trend for the Future

By Teresa Moore

Self-advocates are the most experienced members of groups and organizations. In the advisor role, they listen and assist group members to share their ideas. They can talk about the history or by-laws of the group to assist them in decisions.

The self-advocate as advisor may need a support person to drive, help set-up meetings or use a flipchart. Others may need assistance to attend a meeting.

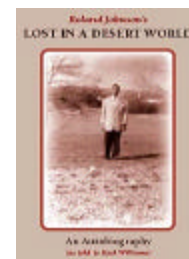


Being a great advisor can be hard. You have to give up control and follow the group while at the same time be able to ask the group if they know critical pieces of information that would help the members make their own decisions; use just the facts - not lead them in the direction you want.

### Roland Johnson Speaking about Advisors

Excerpt from the book "Lost in a Desert World"

Roland Johnson spent half of his childhood in Pennhurst State Hospital. He emerged as a great speaker and leader in the self-advocacy movement. Roland spoke these words during a March 1993 workshop presentation...



"Sometimes staff are in control of your groups and that takes away what you're trying to do. I think it's a good idea that staff is not a advisor. Advisors are there for to help you to make things happen.. when you get stuck.. or things that you can't not do.

That's what an advisor role is. If you get too many staff person try to run the group they try to take over. And that's one thing you can't let do - let staff persons take over."

## Speaking Up in Canada about Advisors

Interview of Gordon Fletcher from Trail, B.C.

The Riot! recently interviewed Gordon Fletcher who has worked as a janitor for the past 16 years and was the President of People First of Canada from 2001 to 2003.

We asked about his experience with advisors. He told us, "The advisors that I have worked with have always been supportive and usually didn't try to make me see their view, respected me and my ideas."



Taking part in meetings is very important. We wanted to know how they helped him. "If I needed help they were there, but if I didn't then they would step back and let me do my thing."

"The main issue is that advisors need to get to know us and who we are as a person. We are all individuals."

Mutual respect is vital. "I respected them because they were people too. They respected my opinion, even if it was different than theirs."

Gordon went on to say that sometimes friendships develop between self-advocates and advisors but not always. "If it does, that's fine but the movement comes first."

## The Advisor's Turn - What Do They Think?

Interview with Bill Worrell of Toronto, Ontario

The advisor should believe in equality for people with disabilities and that self-advocates can speak for themselves. They can help self-advocates make good decisions and become better leaders of their groups plus create relationships between their group and the community. An advisor takes on many roles but they should always be supporting self-advocates in the background.

Make sure everyone has transportation. Maybe talk with the group about how self-advocacy is for everyone, especially those who don't have a voice. Sometimes sit with members who need more support, or suggest a member support another member to speak. Spend extra time to really understand how a member communicates.



When I give my opinion, I encourage everyone to think of what works best for the group. It's important to be supportive of group decisions. Many times, my opinion just isn't important. If I have serious concerns about something like safety or unfairness in the group, I try to share my opinions and show how they relate to the goals of self-advocacy.



## Fun Trivia about Canada! Did you know?...

- ✓ The first *People First* group was started in British Columbia by a few people living in institutions in 1974.
- ✓ Computerized Braille was invented by Roland Galarneau in 1972.
- ✓ Ottawa, located in Ontario, is the capitol of Canada.
- ✓ Over 100 languages are spoken across Canada. But English and French are the official languages.
- ✓ Ice hockey and Lacrosse are Canada's national sports.

Local Canadian treat!



## THE FREEDOM TOUR

In August 2007, Canadian self-advocates travelled in an RV across the Prairies to raise awareness about people living in institutions. The trip left from Winnipeg and ended in Calgary Alberta with stops in Portage la Prairie, Dauphin, Moose Jaw, Regina, Saskatoon, Edmonton and Red Deer.

With the help of a media crew, they filmed stories that they collected during this tour! By telling these stories they hope to share the experiences of people living in institutions so that others don't have to live through what they have survived. This documentary film will be released in Fall 2008.

<http://www.freeourpeople.ca/>



For more information about self-advocacy activities in Canada go to

[http://www.peoplefirstofcanada.ca/index\\_en.php](http://www.peoplefirstofcanada.ca/index_en.php)

# Horoscopes

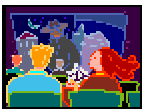
By The Alliance in Illinois



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 what's in store for you!

**Capricorn** (Dec. 22-Jan. 19): This summer you will have trouble communicating with friends. Spend time alone and treat yourself to a day at the spa!

**Aquarius** (Jan. 20-Feb. 18): Cheer up a friend who is feeling blue. Take them out to dinner and a movie.



**Pisces** (Feb. 19-March 20): This summer go with the flow. Sit back and enjoy whatever comes your way!

**Aries** (March 21-April 19): You are fire hot like summertime and you love the heat! Summer is a good time to have fun and let your hair down!

**Taurus** (April 20-May 20): You might feel your right hand doesn't do what your left hand is doing.



Defend your emotional territory. Overall, you will have a good summer.

**Gemini** (May 21-June 20): Friends need your help this summer. You are always ready to lend a helping hand.



**Cancer** (June 21-July 22): You get the cleaning bug this summer! You will organize your whole house and enjoy it!

**Leo** (July 23-Aug. 22): You are an advocate. Speak up for your equal rights. Don't be left out in the cold; enjoy summer activities with friends.

**Virgo** (Aug. 23-Sept. 22): Be careful not to push yourself too hard this summer. Too much fun will leave a dull Virgo.

**Libra** (Sept. 23-Oct. 22): You are a good listener, but make sure you are being heard. Let friends know what you want too!

**Scorpio** (Oct. 23-Nov. 21): Can you keep a big secret? This summer you will be asked to! Shhhh....



**Sagittarius** (Nov. 22-Dec. 21): You will be easily distracted this summer, try to stay focused.

## Need Romance Advice?...Ask Jack & Jill

Dear Jack,

My parents are going out of town so they told me not to have anyone over, but I'm 25 and want some alone time with my sweetie. What can I do?

Dear Reader,

We all want alone time with someone special. It's sad parents sometimes don't fully understand we have the same desires to have a personal relationship with someone as they did growing up.

My advice to you is to be careful whatever you do. Talk and find out what you both want in this relationship. If you decide to have sex, make sure to use protection. If you want one person to come over, don't invite 20. Don't wreck the house and clean up afterwards. Have fun! Everyone should have some time alone with their sweetie. ~ Jack



Dear Jill,

My boyfriend wants to dance with other girls at an upcoming self-advocacy conference. I don't want him to. How do I tell him?

Dear Reader,

Think about what it is that makes you feel uncomfortable. Do you think if he danced with someone else that he won't be committed to you? Talk to him privately and tell him how you feel. Let him know that it isn't something he's done but that it makes you feel uncomfortable. Listen to him as well. He might not see things the same way. If he really cares about you, he would want you to tell him if you were uncomfortable because your feelings will be important to him too! ~ Jill



Email your romance questions to Jack & Jill at:  
**theriotrocks@hsri.org**



**A Fun New Recipe to Try!**

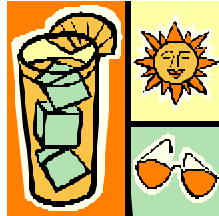
**Sparkling Strawberry Ice**

By Betty Williams

I was sitting on my porch on a bright sunny afternoon sipping a Sparkling Strawberry Ice and thought I'd share it with you. It only takes 20 minutes to make plus breathing time of 3 hours.

**You'll need:**

- \* 1 cup water
- \* 1 packet Jell-o brand strawberry daiquiri mix
- \* 1 cup cold lemon-lime soda
- \* 1/2 teaspoon grated lemon peel
- \* 1 tablespoon fresh lemon juice



Boil water. In a medium bowl, add water to the strawberry daiquiri mix and stir together for 2 minutes or until completely dissolved.

Add lemon-lime soda, lemon peel and lemon juice. Stir until well blended. Pour into a 9-inch square pan and cover. Freeze for 3 hours or until firm. Remove from freezer and let stand for 10 minutes at room temperature. Beat with electric mixer on high speed in a medium bowl until smooth. Spoon into 6 dessert cups and serve immediately or store in freezer.

**A cool, no-bake treat!**

**Pink Lemonade Pie**

Looking for a cool treat that's a snap to put together? Without turning on that oven on a hot summer's day? Look no further! Try our summer dessert.



**Prep:** 10 minutes. **Freezer time:** 4 hours

**Ingredients**

- \* 1 (14-oz.) can sweetened condensed milk
- \* 1 (6-oz.) can frozen pink lemonade concentrate, partially thawed
- \* 1 (8-oz.) container frozen whipped topping, thawed
- \* 1 (6-oz.) ready-made prepared graham cracker crust

**Preparation**

1. Whisk together first 2 ingredients in a large bowl until smooth. Fold in whipped topping.
2. Pour into crust; freeze 4 hours or until firm.

Makes 8 servings

Each of these summer-related words and phrases are hidden in this puzzle. Can you find them? We did one for you so you can get the idea. Look from top to bottom, bottom to top, left to right, and right to left. See if you can find them all.

- |            |             |
|------------|-------------|
| swimming   | music       |
| barbecue   | dancing     |
| beach      | camera      |
| vacation   | hiking      |
| summer     | sandcastles |
| parks      | suntan      |
| fireworks  | lotion      |
| picnic     | shopping    |
| basketball | baseball    |

**SUMMER FUN  
WORD FIND PUZZLE**

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

**Beach Fun!**





# Joe's Sports Zone

Written by Joe Meadours



Welcome to **Joe's Sports Zone!** In the new Sports Page you will find info on what is going on in the world of sports. I'll tell you my opinion about who is playing and what is happening, so keep checking in to see who's winning and who's going home crying!

**The Summer Olympics:** One of this summer's hottest topics in sports has to do with the 2008 Beijing Olympics. A document was written saying that "persons with mental disorders and or contagious diseases" will be barred from the country and attending the Olympics.



This is a mess! Talk about taking a step backwards for the world! Why should any country be allowed to treat us like this? All countries need to have something like the Americans with Disabilities Act so that we are treated the right way all over the world.

**Surprises of the Season:** What a shock! Fresno State won the 2008 College World Series. I thought North Carolina or Louisiana State would win. They are so good. But it seems like this is the year of the underdogs.

**Teams to Watch:** Chicago's Cubs and White Sox are keeping everyone on their feet. Both could make it to the World Series. Boy, would that destroy Chicago! Other teams to watch are Tampa Bay, Boston and Minnesota.

**Hey sports fans,** The Riot! will be giving you updates on Ryan Theriot, shortstop for the Chicago Cubs. Theriot doesn't only have a great name, but is also a good player!



**Theriot!** Theriot is having a great season! He is batting .310 (that's pretty good)! He wears #2 on his uniform and started playing pro ball for the Cubs in 2005. And get this... his nickname is **The Riot!**

## Welcome to **The Riot Fun Page!**

Want to see more? Go to [www.theriotrocks.org](http://www.theriotrocks.org)

Squiggly by Jeff Ladd



## Introducing...

### **SELF-ADVOCACY MAN!**

Written and drawn by Erick Yeary



I was born in the center of the earth and I fight for the rights of all people. I bring down those who think people with disabilities are not part of the world or think that they can't do much. I am for equal pay, for equal work. I am for all people to be treated as equal.

## Fun Trivia!

What is the largest fish caught on record? It's the Mekong Catfish caught in May of 2005 in China. It was 9 feet long and 646 lbs!



My powers are People First Language, Self-Advocacy 101 and last but not least, the greatest power I have is my **VOICE**.

So, if you are in trouble and not getting freedom and control in your life, call **SELF-ADVOCACY MAN**.

***The superhero for all people!***

**Craig Says... "Advisors that try to control people's lives stink!"**



You know what's wrong with advisors? They give advice! They should be out there living their own lives but instead they're always telling me what to do.

Like, "Craig, you need to take a bath, you smell." Or, "Craig, you really need to clean your apartment, there's nowhere to sit!" If you don't like how I smell, and you don't like how my place looks, maybe you should go home!



Advisors are always trying to help people make up their minds about things. They help you think about how you're going to spend your money and how you're going to spend your time. You know where I spend my money? On me! And Pizza! You know where I spend my time? On my couch! In front of my TV!

Some advisors even let you make mistakes, so that you can learn from them. This is silly to me! If an advisor sees me screwing up, I think they should walk behind me and fix everything so it's perfect. Then people will walk by and say, "That Craig, he's so perfect! He never makes mistakes!" That's how I think it should be.



I had a friend who all of a sudden started meeting with a mentor. The next thing I knew, my buddy who I used to sit on the couch and watch football with, joined a gym, started a new job, and got a cute girlfriend! A gym, a job and a girlfriend?!

Those are three things I don't need! But my friend started doing so well in his life that he didn't have time to hang out with me anymore. He said I brought him down!

So I showed him! I replaced him with one of those remote control robot dogs! He doesn't eat my pizza! He doesn't drink my soda! When he bugs me, I take the batteries out!



Maybe advisors work for some people, but not for me. No advice is good advice!



**Word Find Puzzle Answers**

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

# The Riot! Action Page

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

Would you like to build your own advisor? Wow! An advisor who will do everything exactly as you want. Imagine that! We asked some self-advocates to help us build an advisor. They said a good advisor:

- 1 Listens to what you want
- 2 Is willing to learn from self-advocates
- 3 Helps you figure out the supports you need
- 4 Knows when you need support but stays in the background when you don't
- 5 Doesn't tell you how to do things or make decisions
- 6 Is reliable and trustworthy
- 7 Is one who stays with the group for a while
- 8 Has a good sense of humor, is fun to be around and easy to talk to
- 9 Does not vote when the group makes decisions

What do you want your advisor to do for you? Here are some ideas to help you get started.

Fun to be around



Makes meeting arrangements



Listens



Gives lots of help



Willing to learn



Drives you to meetings



**Talk it up...**

**Have yourselves a regular Riot!!!**

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