

We Are Family!



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About The Riot...

The Riot! is produced by HSRI in Tualatin, OR.

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**Teresa's Spotlight**

What I appreciate most about my brother and sister is that they don't treat me differently than anyone else. As kids, we played with each other, but we also loved and supported each other. Our relationships are similar today.

In this issue, you will see many articles that talk about the incredible relationships people have with their brothers and sisters. Throughout the pages, we use the word "siblings" a lot. Siblings is another word for brothers and sisters.

Siblings play different roles. In some families or cultures it is expected that siblings will take over the guardianship role when parents are no longer able to do so. This

is a topic I encourage you to make decisions about while everyone is healthy. When I talk to people about this, many prefer their sibling be a friend and supporter rather than a guardian. We talk about alternatives to guardianship on page 4.

Just like your self-advocacy groups, siblings have their own groups too. You will learn about some of these groups on page 5. With the younger crowd, if siblings are close in age, it is common for self-advocates and siblings to go to self-advocacy meetings together.

As you read this issue, you will see that siblings are important in everyone's lives. My siblings are very important to me. I hope you find the ideas, advice and information helpful to nurturing the sibling relationships in your lives.

We Are Family

By Sheli Reynolds

Growing up as a sibling to a brother with a disability isn't unique; it is just the way it is and all I have ever known. Eric is part of our family. He may have certain quirks and challenges but all siblings and family members do - each is strange, talented and cool in their own way.

Eric is just like every other member of our family. As we have grown older, our needs for support have changed. Some of Eric's needs are different from my brothers and mine. Eric requires additional supports to achieve the life that makes sense for him. For example, he requires 24-hour companion supports while I need support with cooking.

Sheli Reynolds, Jeff Kleba (middle back), Eric Kleba (middle front), and Joe Kleba (right)



As members of Eric's family, sometimes we provide direct support ourselves and other times we advocate for and find the perfect support to help him be self-determined and have a good quality of life. As Eric's sister, I advocate for the best and most innovative supports available. Not all siblings are able to do this and that is okay. The most important role for all siblings is to be a family member - loving, laughing and celebrating life.



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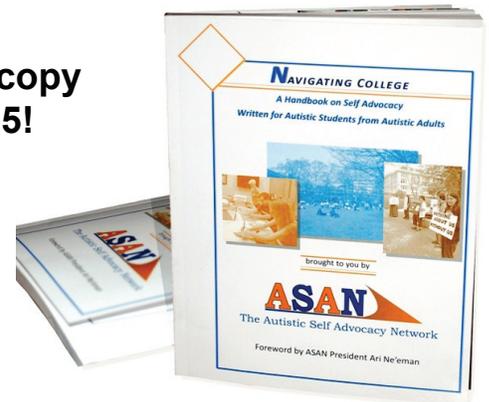
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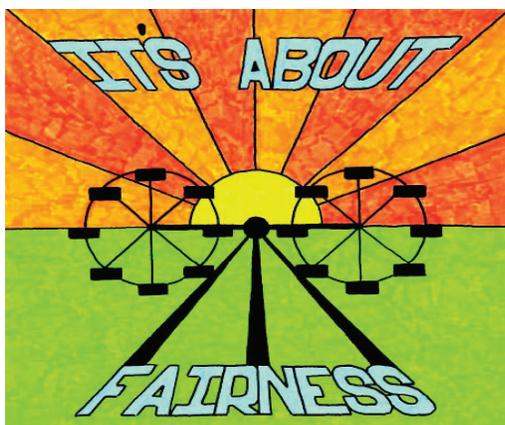
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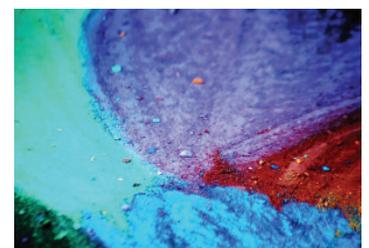
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Alternatives to Guardianship Contributions by Bill Krebs

Most of us ask for advice to make important life decisions. Many of us ask our siblings for this kind of help. Siblings are often asked to be the guardian of a brother or sister with disabilities. **Guardianship is a legal process that removes a person's rights to make important life decisions and gives decision-making authority to another person.** We interviewed attorney Robert Fleischner from the Center for Public Representation (www.centerforpublicrep.org) to find out how people with intellectual and other developmental disabilities (IDD) can get legal support to make important decisions *and* keep their rights.

Do all adults with IDD need guardianship?

No, the majority of people with IDD do not need guardians.

Why do so many adults have guardians?

Families and state agency staff often underestimate what people can do and their ability to make decisions. Most families and staff are not familiar with alternative options to guardianship.

What alternative options exist?

Many alternatives exist that help people keep their rights.

- **Circles of support.** Some states allow people to get help making decisions from a "circle of support." This is a group of people trusted by the person that volunteer to help him or her make decisions.
- **Representative payees** help people make decisions about money. If a person receives SSI or SSDI, a representative payee can help him or her manage money.
- **Trustee.** Sometimes families set up a "trust," or bank account to be used for a person's wellbeing. A trustee over that money helps people make decisions about how to use it.
- **Power of attorney** is a person legally appointed to make certain decisions, usually related to health care.



- **Limited guardianship** appoints a decision-maker for certain decisions but not every decision.

Why don't family members use these alternatives more?

Many families choose guardianship because they do not know about alternatives and because guardianship is very protective. But, from the person's point of view, it is the most restrictive.

Are guardians ever removed?

Yes, but it is much harder to remove a guardian than to get one. Guardianship should be used only if necessary, and should be reviewed every year to be sure it is still necessary.

People with IDD have a voice in the guardianship process. They can say what decisions they need help with and can ask for the type of guardianship or alternative they need.

Guardians should help people practice making decisions. In some states, guardians are required to show the court that a person is learning decision-making skills and practices making decisions so that a guardian would not be needed any more. People with guardians may need to ask the court for an attorney to help them tell the judge whether they still need a guardian.

Each state has different guardianship laws, but in every state it is wrong for guardians to steal money, abuse or hurt people. If a guardian mistreats you or someone you know, report it.

The Arc's National Sibling Council

Interview with Laurie Ertz, Shira Jacobson and Sarah Bal, The Arc National Sibling Council

Contributions by Erica Rachel Fiel

The Arc's National Sibling Council is a new group led by siblings of people with disabilities. The Council is working in partnership with other national organizations such as the Sibling Leadership Network. The Council is also working on providing ways for siblings across the country to connect through Facebook, Google Plus, and video chat. On the local level, Arc chapters offer more opportunities for siblings to meet, gain leadership skills and become better advocates.

They have found that many siblings are choosing jobs in the field; either providing direct support or working for advocacy organizations like the Arc.

There are differences in the ways that parents and siblings can advocate for their family member with a disability. Sometimes a sibling can be a more effective advocate in peer situations.

Shira Jacobsen, a sibling and a Council member shared her story about the unique bond between siblings. Shira feels that the connection with others who have siblings with disabilities is really important. When she was growing up, her



different relationships with their siblings. When she did meet a peer who had a sibling with a disability, she felt that she had found someone who understood.



The Sibling Support Project

Contributions by Ricky Broussard

The Sibling Support Project is a national program dedicated to supporting brothers and sisters of people with disabilities. The program provides opportunities for siblings to meet their peers and get information.

The project offers many ways for siblings to connect including workshops, Facebook and Yahoo groups, and a peer support program called SibShops for school-age kids who have brothers or sisters with disabilities.



There are over 360 SibShops worldwide where kids come together to have fun, talk about their experiences, learn about available services, and how to handle sticky situations.



Sometimes they include siblings with disabilities in activities. Other times siblings meet by themselves like self-advocacy or parent groups.

Don Meyer, Sibling Support Project director and creator of SibShops, believes "it is important for siblings to connect with their peers." Siblings have unique concerns and opportunities. For many, sibling relationships are the longest lasting relationships in their lives.

National Sibling Support Groups

The Sibling Support Project

www.siblingsupport.org

The Arc's National Sibling Council

www.thearc.org/page.aspx?pid=2661

The National Sibling Leadership Network

www.siblingleadership.org

Celebrating Siblings Contributions by Joe Meadours

Brothers, sisters, sisters and brothers - they make life wonderful and challenging. For many, siblings play a major role in our lives. They are our friends, supporters, advisors, challengers, and sometimes act as mother or father figures. Either way, they have a profound impact on our lives. We celebrate siblings here with quotes about their relationships.



Jessica Milbern, NC & Stacey Milbern, CA

“We are so close. We have a very strong bond - like twins. We rely on each other for different kinds of support.”



Julie Petty, AR & Jamie Hamilton, MO

“We are friends - that’s how we support each other. We don’t hold back. We tell each other what we think.”



Diane Karpinski, OR & Kaaren Londahl, OR

“Kaaren reminds me how important inclusiveness, acceptance and diversity are and has taught this to my children.”



George Neal, AL & Greg Neal, AL

“When we were kids we used to walk a couple miles to Grandma’s house. If I went, I was walking the whole way. If George went, he would get picked up along the way - every single time!”



Adrian Forsythe-Korzeniewicz, MD & Gabriel Forsythe-Korzeniewicz, OR

“Adrian helps me think through social situations. Sometimes people don’t know how to deal with differences and you have to confront this with potential friends. This is a natural way to select who you might want to be friends with.”



Ask Bill Krebs

Bill "Trouble" Krebs is an advocate from Philadelphia who fights for the rights of people with disabilities

Dear Bill,

How is a 504 Plan different from an IEP?

Dear Reader,

Both 504 plans and Individualized Education Plans (IEP) help students with disabilities to be successful in school.

There are big differences in what each of these plans do.

504 Plans come from Section 504 of the Rehabilitation Act - a civil rights law that protects the rights of people with disabilities.



- 504 Plans remove barriers and provide equal access to education.
- A student with a 504 Plan may receive accommodations (like materials in large print) or modifications (like a wheelchair ramp).

IEPs come from the Individuals with Disabilities Education Act (IDEA) to ensure that children with disabilities receive free and appropriate education.

- IEPs describe how teachers and other professionals should provide educational and other services so a student can learn.
- Students with IEPs receive individualized special education and related services designed to meet their unique needs.

In short, the 504 gets you in the door with equal access to the same education as everyone else. The IEP provides individualized education so you can participate.

Movie Review

By Dayna Davis



The Other Sister

Directed by Garry Marshall

Starring Juliette Lewis, Diane Keaton and Giovanni Ribisi



The Story: A girl with an intellectual disability, played by Juliette Lewis, proves herself to be every bit as capable as her sister when she moves into an apartment and begins going to college.

Riot Rave: This movie shows how people with disabilities can live independently, go to college, and have romantic relationships. It also shows the conflict that can happen within families when self-advocates branch out to live the lives they want. Through the ups and downs, this movie did have some LOL (laugh-out-loud) moments.

Riot Rumble: The director should have done a little more research. Carla acts out on a few occasions, which is not realistic. The "R-word" is mentioned one time in the film (thumbs down!). Carla's boyfriend, Daniel, played by Giovanni Ribisi, also has a disability. This sends the message that people with disabilities only date other people with disabilities. Although it is not exactly true to real life, overall it is fairly well portrayed.

Other movies to check out:

- Door to Door
- Riding the Bus with My Sister
- I Am Sam
- Simon Birch
- Best Boy / Best Man



Spring Horoscopes

by Sienna Otero (age 10, 4th grade,
DC Bilingual Public Charter School)

A horoscope predicts the future based on the position of the planets and your birthday. Find the sign that fits with your birthday.

Capricorn (Dec 22 - Jan 19): You're successful and passionate, but moody and sarcastic. Look on the bright side more.

Aquarius (Jan 20 - Feb 18): You're truthful and original, but can be opinionated. Express your feelings in a journal.

Pisces (Feb 19 - Mar 20): You're nurturing and receptive, but gullible too. Use caution before believing everything you're told.

Aries (Mar 21 - April 19): You're positive and make people happy, but you should also get some alone time in.

Taurus (April 20 - May 20): You're gentle and feel for others, but don't take criticism well. Try not taking things too seriously.

Gemini (May 21 - June 20): You have many talents and are very inquisitive. Remember, some things just aren't meant to be known.

Cancer (June 21 - July 22): You're patient but take things too seriously. Look on the bright side more often!



Leo (July 23 - Aug 22): You're creative and strong-willed. Try to enjoy what you have instead of worrying about what you don't have.

Virgo (Aug 23 - Sept 22): You're modest and humble but also worry a lot. Set aside time each day to think about those things, then let them go.

Libra (Sept 23 - Oct 22): You're polite and cooperative, but can be aggressive. Try walking away from tough situations more often.

Scorpio (Oct 23 - Nov 21): You're self-confident and adventurous, but also possessive. Discover how great it is to share with others.

Sagittarius (Nov 22 - Dec 21): You're feeling restless this month. Put your energy into an active sport that you can play with others.

Need Romance Advice?... Ask Jack & Jill

Dear Jack,

Everyone around me seems to have a boy or girlfriend. What can I do to meet someone new?

~ *Lonely in Little Creek*

Dear Lonely,

Wait until you find that special someone. A true friendship is the key to having the guy or gal of your dreams. Try going out and doing new things to meet people. You could also strike up a conversation on Facebook or other social networking websites.

If you meet someone on Facebook, ask your friends about the person. If they know him or her and say good things, it is probably ok to meet. A fun and safe way to meet is on a double date. Do fun things together and have a riot! One day you may get married on a beach in Hawaii! The choice is yours because it is your adventure in life.

~ **Jack**

Dear Lonely,

Sometimes you have to relax and let things happen. One idea is to focus on things you like and go to places that interest you. For example, if you like art, visit galleries, go to art shows or join art walks and talk to people. When you are happy, you attract people!

You can also tell your friends that meeting new people is something you have been thinking about. Ask them to introduce you to fun and interesting people.

When you get introduced, learn about the person and see if you hit it off

~ **Jill**



Health Zone

Contributions by Marian West & Liz Weintraub

Siblings provide lifelong relationships, which is why we should nurture or take care of them. For people with disabilities, siblings can be an important source of friendship and support. This is true for Liz Weintraub, a person with a developmental disability who has three sisters. While she loves each sister equally, she leans on her sister Roni the most for advice and support.



Liz, Adele (top), Roni, and Helen

When asked what makes her relationship with Roni so special, Liz says Roni has always had high expectations for her to act like an adult. "Roni didn't allow me to get away with anything just because I have a disability."

Because Roni and her sisters are so important to her, Liz nurtures these

relationships. Here is Liz's advice to keep your sibling relationships strong and healthy too.

- **Respect each other's personal lives.** Confide in each other but stay out of each other's personal business.
- **Touch base regularly.** Call or email - just like you would with friends.
- **Visit as frequently as possible.** Set aside time to spend with each other in person.
- **Share family responsibilities.** If you are caring for aging parents, do it together and give each other emotional support.
- **Acknowledge** birthdays, weddings, childbirth or holidays with a visit, gifts or a call.
- **Listen to each other** and offer helpful advice.



Sibling relationships are important to all of us. We hope you take care of yours.

SPRING PUZZLE

Find these words. Look up, down, and side to side.

(puzzle answers on page 10)



- | | |
|----------|-------------|
| Break | Kite |
| Flowers | Clouds |
| Birds | Lawnmowing |
| Rain | Outdoors |
| Garden | Seeds |
| Vacation | Park |
| Sunshine | Cleaning |
| Rainbow | Time Change |
| Hiking | Car Wash |

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



Craig Says... "Brothers and Sisters Stink... Sometimes!"

I have two brothers and two sisters. Two are older and two are younger. Brothers and sisters can be a real pain.

Sally Mae is the oldest and is everyone's big sister. When we played Monopoly she was the banker and controlled all the money. She always won. When we played the game Candy Land she always won that too. Now we are all older and when we get together she still thinks she is the boss of everyone.

My older brother Billy was a real trouble maker. He liked to pull my underwear up, give me a wedgie, and make me promise to give him my dessert after dinner. Mom thought Billy was such an angel!



Joey is my younger brother and is smart. I liked hanging out with him. He was afraid of me, so he still likes to play tricks on me, and run away. Last week he stole my remote control! Now when he drives by he changes the channel on my TV. That is so annoying!

Then there is Abby, our baby sister. Mom and dad always liked her best. She never got in trouble, even when she let my pet frogs go free in the back yard.

Sally Mae, Billy, Joey, and Abby caused a lot of trouble in my life. So, why do I love them more than anything? I don't know.

What I do know is that it is spring time and Sally Mae is coming over to help me with my garden. Billy and I are going to see a baseball game next week. Joey will eventually give back my remote, maybe when we go to the movies. And Abby always looks after my pets when I am gone and stops by to visit to make sure that I am OK. I love my brothers and sisters. They mean the world to me!



PUZZLE ANSWERS

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



Self-Advocates Speak Up! and Speak Out!



Siblings Supporting Each Other

Contributions by Julie Petty

Everyone needs support sometimes. For many people, this support often comes from siblings. In a way, sibling relationships are just like self-advocacy. Whether you are peers, brothers, or sisters, it takes at least two people to give and receive support from each other to make life better.

People with disabilities give support too. Sometimes siblings without disabilities forget this. Talk about how siblings support each other at your next self-advocacy group meeting. How do members of your group give and receive support from siblings?

Here is a list of ideas to get you started. Have you tried any? If you have, talk about what happened. What other ideas do you have? We understand that many people do not have siblings. These ideas apply to friendships too.

- **Invite your sibling** to a self-advocacy meeting, conference or disability event.
- **Talk about your hopes and dreams** so you can support each other to reach them.
- **Share your problems** and offer ideas or advice.
- **Tell your siblings** how much you care about them.
- **Make time to visit or talk to** your siblings as frequently as possible, especially if you live far apart.
- **Take a trip** or go on vacation together.
- **Just be a friend.** Don't boss each other around.
- **Look out for each other** - always have your brother or sister's back.
- **Have fun.** Go to a movie and dinner together.



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

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Self-Advocacy Man Says...

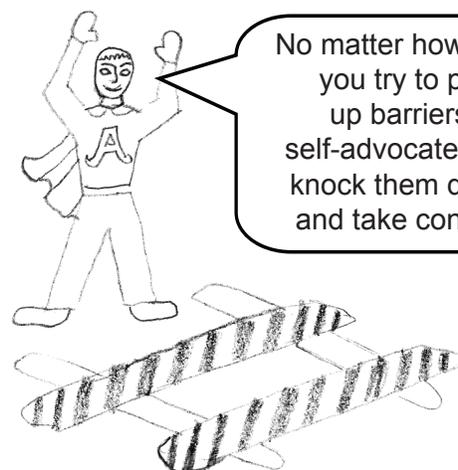
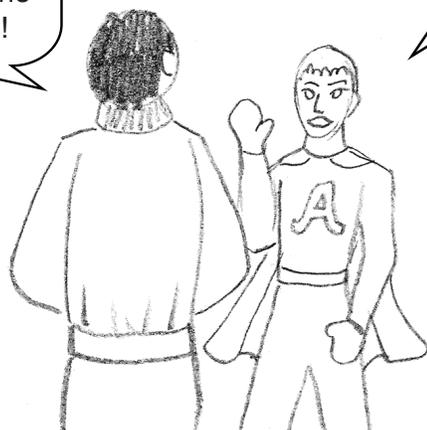


Written and drawn
by Erick Yeary

No, Self-Advocacy Man! I'm going to stop all self-advocates because everyone needs barriers!

No! Move your barrier!

No matter how hard you try to put up barriers, self-advocates will knock them down and take control.



To Be Continued...

SPOTLIGHT STUDIOS



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