

ISSUE 35 Spring 2015

The Riot!

Now We Can!





About the Riot...

The Riot is produced at Human Services Research Institute (HSRI). We would like to thank everyone who contributed to this issue. Without you, The Riot would not have a voice.

Richard Chapman is a mental health counselor, living in Tampa Florida. He is actively involved in the disability rights movement and most of his advocacy efforts promote inclusive environments for all individuals with disabilities.

Cathy Enfield is Vice President of SABE. She is an active advocate in the state of Missouri, holds leadership positions on many committees, and is a Partners in Policymaking graduate.

John Fenley is President of People First of New Hampshire. He serves on the New Hampshire Council on Developmental Disabilities and is a professional speaker on disability rights.

Bill Krebs is the Executive Director of T.R.A.P.S., which stands for Training, Resources, Advocacy, Personnel & Specialists, because people feel like they are trapped in the system and don't know how to get out.

Cindy L. is a self-advocate who lives in Portland, Oregon. Cindy loves listening to music and attending concerts. She also loves spending time with her favorite cat, Moki.

Eric Matthes is an Outreach and Advocacy Coordinator with the Arc of King County and a longtime Riot Editor.

Jon McGovern is the Board Chair of Speaking Up for Us, a statewide self-advocacy organization in Maine.

Teresa Moore started People First of Arizona and now supports the Self-Advocacy Coalition of Arizona. She owns Moore Advocacy, a consulting business and travels all over the country advocating for people with disabilities.

Ari Ne'eman is the president and co-founder of the Autistic Self Advocacy Network (ASAN), an advocacy organization run by and for Autistic adults seeking to increase the representation of Autistic people in society.

Julie Petty works at Partners for Inclusive Communities, University of Arkansas and is the Chair of the President's Committee on Intellectual Disabilities.

Ross Ryan is a member of the Oregon Self Advocacy Coalition and represents OSAC on a number of statewide committees. He speaks to legislative committees to inform disability policy.

Julie Sanchez is a member of the Oregon Self Advocacy Coalition and an active member of SPARC, a local self advocacy group.

Chaqueta Stuckey is co-director of Our Community Standing Strong.

Trena Wade is a Coordinator for PADSA. A long time member of San Diego People First, Trena is a frequent speaker and trainer at local events & conferences.

Erick Yeary lives in Idaho and keeps busy as a member of the University of Idaho Center on Disability and Human Development, the Self Advocate Leadership Network, and the State Independent Living Council.

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~Cover art by Alisa Rojas~

Now We Can

In January of 2014, the Centers for Medicare and Medicaid (also called CMS) made new rules for Home and Community Based Services. These services help many people with disabilities live in their community.



The new rules make sure that:

- Where people live or get supports, like group homes and day or job centers, really are in the community.
- People get quality supports based on their needs and choices, and that their rights are protected.

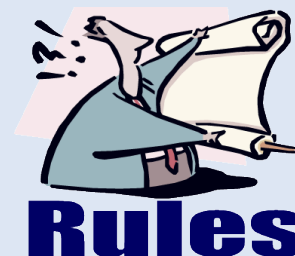
States must follow the new CMS rules by 2019. Each state has created a Transition Plan that spells out what they plan to do to meet the rules.

You are probably thinking that rules are SO boring. Well, not in this case. These rules are based on many of the things that self-advocates have been saying for years. Policy makers finally listened and self-advocates are saying **NOW WE CAN...**

- ☆ Have some privacy!
- ☆ Be in charge of our lives!
- ☆ Be included in our community!

Now are you hooked?

This Riot issue will explain the rules in plain language. Leaders from across the nation shared their thoughts on the rules, and tips on how to track what's going on in your state. Now let's do this *Riot Style* and really shake things up!



Try Asking, "Why?"

By Teresa Moore

People with disabilities have rights like any other citizen. The new rules will help protect these rights, but sometimes silly rules might still get in the way. Here are some things you can do.



1. **Ask why.** Rules can be made up for no good reason. Like, "No eating in the living room." If you ask, "Why not?" The person will need to think about their answer. And it better be a good one!
2. **Tell someone.** If you feel your rights are being taken away, find someone you trust and tell them. Ask for help if you need it.

3. **Reach out to each other.** It is important for self-advocates to have a safe place to talk outside of the service system. No one should feel like they are alone.
4. **Be responsible.** With rights comes responsibility. This means taking care of yourself, and not hurting other people or their things.
5. **Learn and grow.** Everyone learns and changes over their lifetime. Rules for youth are different than adults. This is also true for people with disabilities.



Now We Can!

The federal government made new rules for Home and Community Based Services. To learn what this means for you, check out our website for more tools you can use!

- ☆ Now We Can toolkit
- ☆ Presentation at the next AAIDD conference
- ☆ National Conversation Series



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Space Race!

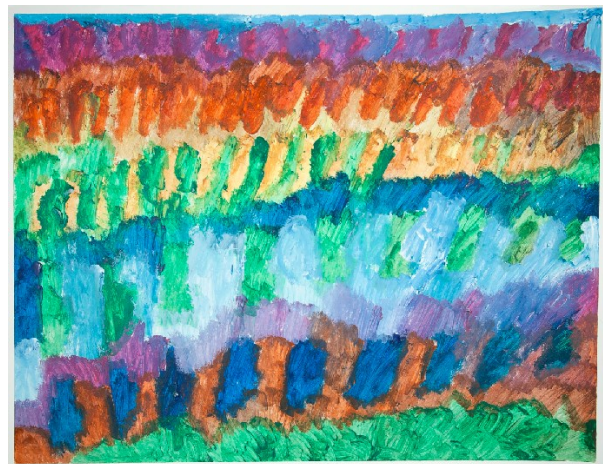
A game to teach self-determination



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SPOTLIGHT STUDIOS



Artist ~ Judy Billiard

Celebrating artists with intellectual
and developmental disabilities!

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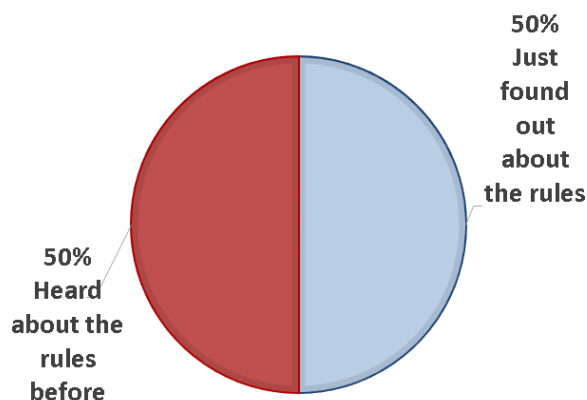
Survey Says!

The Riot is all about the voice of people with disabilities. In April of 2015, The Riot sent out an online survey to find out what people knew about the CMS rules and how they felt about them. Here is what self-advocates had to say.



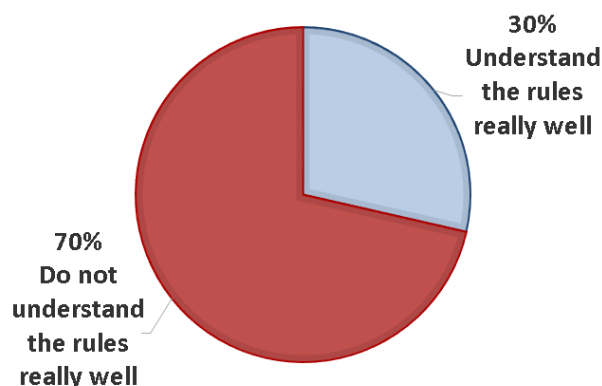
1) When did you first hear about the rules?

About **5** out of **10** said they **had already heard about the new rules**.



2) How well do you understand the rules?

About **3** out of **10** said they **understood the rule changes really well**. About **7** out of **10** said that they **understood a little** and would like to know more or **didn't know much about the rules**.



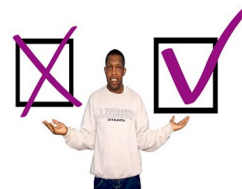
3) What do you think of the rules?

About **2** in **10** said the changes were **awesome and that services will be a lot better**.



About **3** in **10** said they **didn't like** the changes or felt they **wouldn't change much**.

About **5** in **10** people said they **didn't know enough about the changes right now**.



The last question was open-ended and left a space to type in an answer. Here are just a few things that self-advocates wrote:

4) Would you like to tell us more?

"I need to know them."

"I think things will get a little easier."

"Simplify the explanations of the rule changes."

"Based on what I just learned, I think it'll give me freedom to be more independent."

"Please tell me more about the rule changes so I can stay *in the know*."

"I don't know what is meant by the 75% of day programs."

"I'm sad to be losing my friend and provider. I don't want strange people."

Let's Break it Down

Based on the results of the Riot survey, people said they wanted more information about the CMS rules in a way that is easy to understand. So, let's break it down. The final CMS rule for Home and Community Based Services has a few parts. The rules spell out what really is a community setting, and your rights in your home or at places like day programs or job centers. There are also guidelines to make sure people are in charge of planning and directing their own services as much as possible. Here are answers to questions that people might have.

What IS a community setting?

A place that...

- People with and without disabilities can go.
- People can get out easily to places they like to go.
- Supports people in getting real jobs.
- Helps people do things on their own as much as possible.
- Respects a person's right to privacy, dignity and freedom.

What is NOT a community setting?

- Institution (or Developmental Center)
- Hospital
- Nursing home
- Places that are on the same grounds as institutions, hospitals, or nursing homes.



What rights do I have where I live?

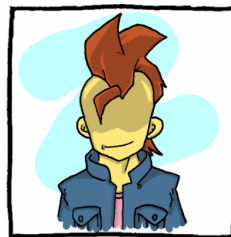
If you live in a place where you get home and community based services you should have the following things.

Rental agreement. Have a rental agreement that spells out your rights as a renter in writing. This includes people who live in places that are owned by a provider, like a group home.

Privacy. Have keys to locks on the doors to your room or house. Make phone calls, or send texts or emails in private. Support staff must knock on your door and ask if it's okay to come in.



Choice. Choose who you live with, and what you do during the day.

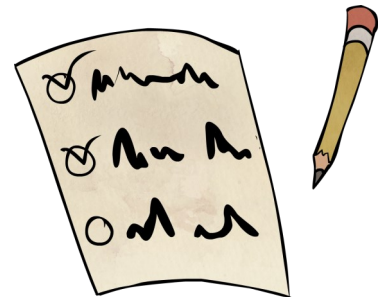


Freedom. Get to food whenever you want and have visitors at any time. Have your own personal style with how you dress, wear your hair, and decorate.

Accessibility. Get around your house and to what you need easily.

Are there any situations when the rules don't apply?

In most cases the answer is no. But some people with disabilities may need supports that help them stay healthy and safe, and the rules might be different for them. If someone needs a certain type of support that goes against the rules then it will be talked about during their planning meeting and written in their plan. This is sometimes called a Behavior Support Plan.



What do the rules say about Person-Centered Planning?

- You will be in the lead when planning your supports as much as possible.
- You will choose where, when, and who will go to your planning meeting.
- You will get information in a way that is easy to understand.
- You will make choices about how you want to be supported and who supports you.
- You will get a copy of your support plan.
- You will talk about things like friendships and relationships, going out in the community, getting a job, staying healthy, and learning new things.



What if I get a service that doesn't meet the rules right now?

Things won't change overnight. States have until 2019 to make sure that home and community based services meet the rules. Those who provide services will work to make any changes that are needed. We know that any changes to services can make people feel nervous. Hang in there, and speak up for yourself and what you need!



For more information about your state's Transition Plan, go to www.hcbsadvocacy.org

Riot Cartoon by John Fenley



When Mandy found out about the new federal regulations, she showed her home providers that she had a few changes of her own to make!

What Do YOU Have to Say?

The Riot asked self-advocates from around the county what they thought of the rules for Home and Community Based Services. Here is what they said.

Cathy Enfield

Cathy feels that the rules need to be in people first language. "People need to be able to understand them so they know what their rights are." She said, "I think that this is the right way to live in the community." If you feel the rules aren't being followed, she said you should speak up and find someone who will listen to you.



Ari Ne'eman

"The new CMS Settings rule is a great opportunity for people with disabilities to push for real community inclusion in their states. For too long, group homes, sheltered workshops and segregated day centers

have been able to call themselves community-based. Self-advocates and our allies should use this rule to raise the standard of what gets funded using HCBS money in our states."

Check out ASAN's toolkit for advocates about the rule at www.autisticadvocacy.org/hcbs

Chaqueta Stuckey

"I haven't heard of those rules in particular," Chaqueta says, "but I know people with intellectual disabilities who are living in the community and living more independently. They want to do more on their own, get out into the community, do activities, and meet more people."



Richard Chapman

"This is a long time coming. The CMS regulations provide more opportunities for people with disabilities to live in the community."

While Richard thinks it's definitely a huge step forward, he has some concerns. "I don't want CMS to weaken their intent." When asked what people can do, he said, "People need to know what the state Medicaid and disability agency are doing. Don't assume that your state will do it."

Jon McGovern

"A person from the Department met with us and gave us information about the CMS rules. I think that what they are doing is somewhat good, but I don't agree with everything."



Trena Wade

"The new rules are designed to promote individual choice," says Trena. "I'm all for individual choice!" For example, people can choose to live in smaller groups or their

own apartment. For self-advocates who feel that things aren't working for them, she says to seek help from the Disability Rights organization, Ombudsman office, or a local self-advocacy group or People First group. They could also reach out to their community for support.



Do you have something to say?

Contact us at theriot@hsri.org
or call 503-924-3783 ext. 18

Horoscopes

By the ever-knowing, Cindy L.
from Portland, OR



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): Be happy! Take the bus somewhere new, if you can.

Aquarius (Jan 20 - Feb 18): Be with your friends and ask them silly questions.

Pisces (Feb 19 - Mar 20): Listen to a new song and make up the words as you go.

Aries (Mar 21 - April 19): You deserve a good job. You can spend the extra money on things you like.



Taurus (April 20 - May 20): Enjoy a good meal with your friends and have a laugh.

Gemini (May 21 - June 20): Make some new friends and join a self-advocacy group.

Cancer (June 21 - July 22): Take a second and relax. Maybe lay on the couch and let all of your stress go.

Leo (July 23 - Aug 22): Be nice to someone new when they come to your house.

Virgo (Aug 23 - Sept 22): Get outside! Go for a nice long walk or a roll in your wheelchair.

Libra (Sept 23 - Oct 22): Time to get crafty! Make something beautiful and give to a friend.

Scorpio (Oct 23 - Nov 21): Say hi to someone new who may be having a hard day.

Sagittarius (Nov 22 - Dec 21): Think of your favorite food and eat it all up!



Need Romance Advice?...Ask Jack & Jill

Dear Jack and Jill,
I live in a group home and
I would like to spend the
night with my girlfriend.
What should we do?

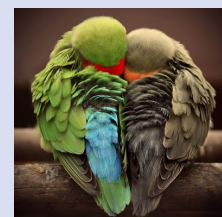


Dear Reader,

I am having a Riot thinking of my girlfriend coming over. My idea would be to call her up and ask if she would like to spend the night. We could snuggle and watch a movie, or just be together and have fun all night. I would talk to my caregiver to make sure they were cool with it first. Then maybe we could have breakfast in the morning, she would kiss me, and then her dad could take her home. ~ Jack

Dear Reader,

Some group homes are for women or men only. If this is the case, you might not be able to have your girlfriend spend the night. However, there might be another way.



If your girlfriend lives on her own, you could go stay at her place. Even if you can't spend the night together, find other ways to be together like going to a coffee shop, movie, or bookstore. Try to make the best of it! ~ Jill

Have a question for Jack and Jill?
Email us at theriot@hsri.org

Log On, Tune In, Speak Up!

Making and posting videos is getting easier all the time with new technology.

Advocates are using videos to share information about

important advocacy topics. Here's the

Riot's Top Three Video Picks of the Year!



1) Tuesdays with Liz: Disability Policy for All



Tune in every Tuesday to hear Liz Weintraub with the Association of University Centers on Disabilities (AUCD) talk about disability policy in ways that everyone can understand. She mixes it up with interviews with

policy leaders and more! Find her latest video on YouTube or go to www.aucd.org

2) Speaking Up for Us (SUFU)

Members of Speaking Up for Us in Maine starred in a video about what to expect at your Person-Centered Planning Meeting. This video explains what the new CMS rules mean when it comes to planning the services and supports you need to live the life you want. Check it out at www.sufumaine.org



SELF-ADVOCACY ONLINE

3) Self Advocacy Online

This website features videos from many leaders from across the nation talking about important topics like supports, jobs, laws, relationships, the R-word, and many more. Take a look around—you might see some familiar faces!

Go to www.selfadvocacyonline.org

This issue is all about MY...

Look forward, up and down to find the words.

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

LIFE
ROOM
FOOD
KEY
FRIENDS
FAMILY
PLAN
SUPPORTS
HOBBIES
JOB
HOME
DAY
CHOICES
VOICE
WAY





Craig Says... Rules Stink!

What's the big deal about rules any way? Rules stink!

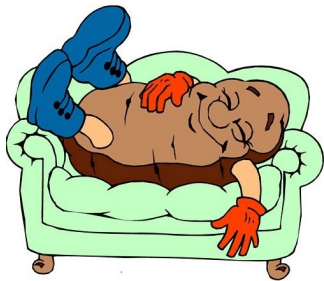
I don't follow any rules.

No way. I do whatever I want. While some people go around breaking hearts, I go around breaking rules. I

don't like people telling me what to do. I know that people with disabilities don't like others telling them what to do all the time either. So



what if I want to eat chips in the living room? So what if I want to have my friends over any time I want to watch the game? So what if I want to be lazy and not clean my room? It's my right!



Oh, I get it now! I just realized that the new CMS rules make sure that I get to do all of those things. Maybe some rules aren't so bad after all. I still won't admit that I like ALL rules though. I'm always on the lookout for silly rules that just don't make any sense and keep people from living the lives they want. I hope you'll be on the lookout, too. If you think something isn't right, speak up about it!



Special Edition Jabbers Now Available! Download all 3 for FREE at www.theriotrocks.org

How To Be a Riot Outlaw

Step #1: Get a cowboy hat, boots, and a bandana.

Step #2: Stick'em up! For your rights that is.

Step #3: Say things like, "You just messed with the wrong bandit" in a deep, surly voice.

Step #4: Learn to catch your drink when they slide it down the bar. (Yes, you might break a few glasses at first.)

Step #5: Lasso but not least, make sure that everybody follows the new rules...or else.



"An outlaw can be defined as somebody who lives outside the law, beyond the law and not necessarily against it."

~ Hunter S. Thompson

Puzzle Answers

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



Ask Bill Krebs

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

contact me at my personal number or email.



As far as rules, I would say:

- 1) People with disabilities should be able to do what they want to do, have jobs, have friends, have meaningful relationships, and have the right to live every day lives.
- 2) Service providers need to inform people with disabilities about any changes that might affect them.
- 3) If providers don't follow the rules, they could get a fine or lose their license. I would have a no tolerance policy. Shape up, or ship out!

Dear Bill,

If you were a top policy maker, what rules would you make?

Ranita J. from Wisconsin

Dear Ranita,

Good question! First of all, if I was a top official, I would meet quarterly with self-advocates to find out what's going on. I would start a toll-free hotline open 24 hours a day. I would work to help self-advocates get what they need. They could

Regional Self Advocacy Projects

The Administration on Intellectual and Developmental Disabilities (AAIDD) funded 6 self-advocacy grants across the nation. The goal is to provide assistance to self-advocacy organizations to help them reach their goals. Check out the map below to find out what's going on in your area.



Riot Action Page

Speak Up and Speak Out!

All Aboard for Boards, Committees and Workgroups

Contributions by Ross Ryan

Many states are forming workgroups or committees to help plan the work to follow the new CMS rules by 2019. These groups may have state staff, service providers, advocacy groups, and self-advocates. Here are a few tips if you are representing your advocacy group.

- ☆ **Tell them what is most important to people with disabilities.** Everyone at the meeting might have different opinions about how services need to change. But the most important thing is that people with disabilities get the supports they need to live the lives they want.

- ☆ **Be consistent.** This means coming up with a message and sticking to it. It helps if people at the meeting hear the same thing from you and other self-advocates.

- ☆ **Talk with your community.** Listen to members of your self-advocacy group to really understand what they want and need. Create position statements on the most important points and share the statements at the meetings.



- ☆ **Tell your story.** Talk about what works and doesn't work with the supports you get. Remember to keep it short and to the point!

Talk it up...

Have yourselves a regular Riot!!!



Self-Advocacy Man Says...

"It comes to show that all people can have a life of their own no matter who you are. You see all the beautiful things people change by trying to work together to get there! Plus, together we are changing our futures."



Written and drawn
by Erick Yeary



Jabbers

Now We Can
Special Edition!

Jabbers pull-out
featuring

My Day, My Way



A game for
self-advocates!

Look for our other two
games online:

My Life, My Way



My Plan, My Way!



My Day, My Way *Jabbers*

A game for self-advocates!



**The
Riot!**

Produced by *The Riot!* (www.theriotrocks.org) at the
Human Services Research Institute (www.hsri.org)

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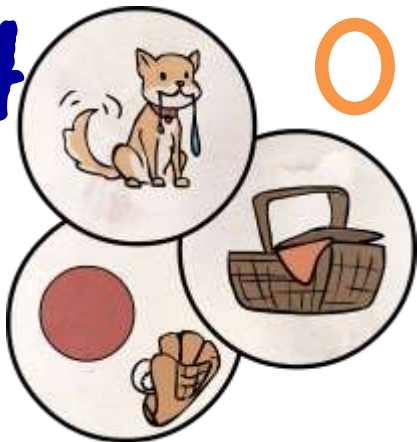
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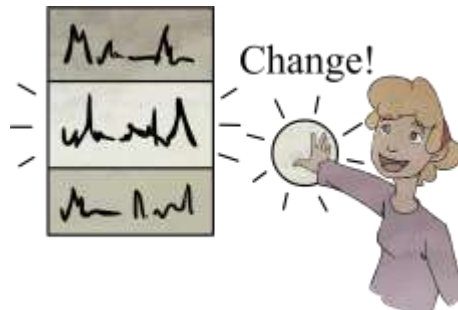
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My Day, My Way Directions

Object

The object of the game is to get people with intellectual and developmental disabilities to think about how the new rules for Home and Community Based Services may affect their lives. The rules are meant to make sure that people can get the support they need and be included in their communities, not separated from others.

You can take charge of your day by:

- Choosing where you go during the day,
- Choosing who you spend your time with, and
- Speaking up about the life you want.

Materials

- One copy of the game card for each player.
- Stickers or a marker, pen, or pencil for each player to mark the picture boxes on their game card.

Get Ready

- The game can be played with a group of three or more people.
- Set aside at least one hour to allow time to *jabber* about each action people can do in their daily lives under the new CMS rules. If more than six people are playing, you may need more time.
- Choose a facilitator, or leader, to lead the game and keep track of time. The facilitator's job is to read each action, ask questions about how the action applies to their lives, and ask for examples from the group. Encourage players to jabber away. Make sure each player gets a chance to talk about his or her thoughts during the game.
- Make sure that players talk about each action within the time available. Have fun, but watch the clock. Time moves fast once the jabbering starts!

How to Play

Each player gets a game card with 12 pictures in numbered boxes that match the 12 written statements. The facilitator, or leader of the group, with help from the players, chooses a number and reads the statement out loud. Players are encouraged to talk about the statement and whether or not it applies to them.

As the jabbering winds down, have players find the number and action picture on the game card. Tell players to mark the orange circle on the action picture if it is something that applies to them. This process goes on until each statement has been read out loud and talked about.

At the end of the game, each player will have identified actions they can take to take charge of their life with the new HCBS rules. Players can choose actions to work on with help from each other and others. This information can also be included in the individual planning process.

My Day, My Way Game Card

12 things about where you live, work, and play.

1. I go to activities and celebrate events and holidays in my community.
2. I have a job with other people who do not have disabilities.
3. I have help with finding a job I want.
4. I do things I enjoy during the day.
5. I have a bank account that I can use when and how I want.
6. I know who to talk to if I am not happy with my services.
7. I choose what I wear and how I want to look.
8. I hear staff talk to me with respectful words and in a respectful way.
9. I see and hear that staff respect my privacy by not talking about my support needs in front of others.
10. I learn new things to help me be more independent.
11. I communicate to people privately when I want (call, email, chat, talk, etc.).
12. I make changes to my services if I am not happy with them.