

All About Human and Civil Rights!

Written by, and for, people with
Intellectual Disabilities and/or Autism

This is a SAPNA event!



The Self Advocacy Power Network for All (SAPNA) is a project of the PA Office of Developmental Programs (ODP).

SAPNA is managed by Self Advocates United as 1.

Self Advocates United as 1 (SAU1) has followed its mission since 2007:

To support the self advocacy of
people with disabilities
for positive impact
in our communities
and in people's lives.

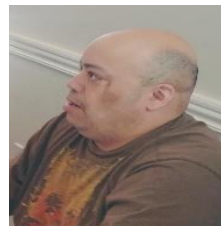
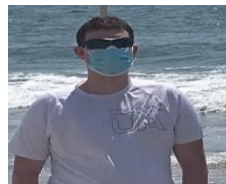


Board meeting 2022

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Who writes SAPNA stuff?

- ▶ SAPNA staff meet with experts to learn about things important to people with intellectual disabilities and/or autism.
- ▶ All materials are written in words that make sense to most people by SAPNA Power Coaches - professional self advocates.
- ▶ ODP approves the materials.
- ▶ SAPNA staff create and lead events.



SAPNA shares SELF ADVOCATE POWER!

- ▶ Our events are
 - ▶ **BY** people with disabilities
 - ▶ **FOR** people with disabilities.



SAU1
Founder, Past
President,
and Lead
Ambassador
Oscar
Drummond.

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Today, let's talk about

- ▶ Human and Civil rights,
- ▶ History of the rights of people with disabilities,
- ▶ The Office of Developmental Programs and services,
- ▶ Complaints about your services,
- ▶ How to speak up for your rights, and
- ▶ What to do if your rights aren't respected.

Let's Get Started!

How do people learn or speak up if they do not:

- ▶ see?
- ▶ hear?
- ▶ use words?



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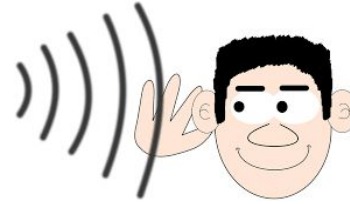
Did you think of:

- ▶ body language?
- ▶ picture boards?
- ▶ pointing?
- ▶ with pictures?
- ▶ sign language?



Did you think of:

- ▶ listening?
- ▶ screen readers?
- ▶ interpreters?
- ▶ braille?
- ▶ other assistive technology?
- ▶ silence?

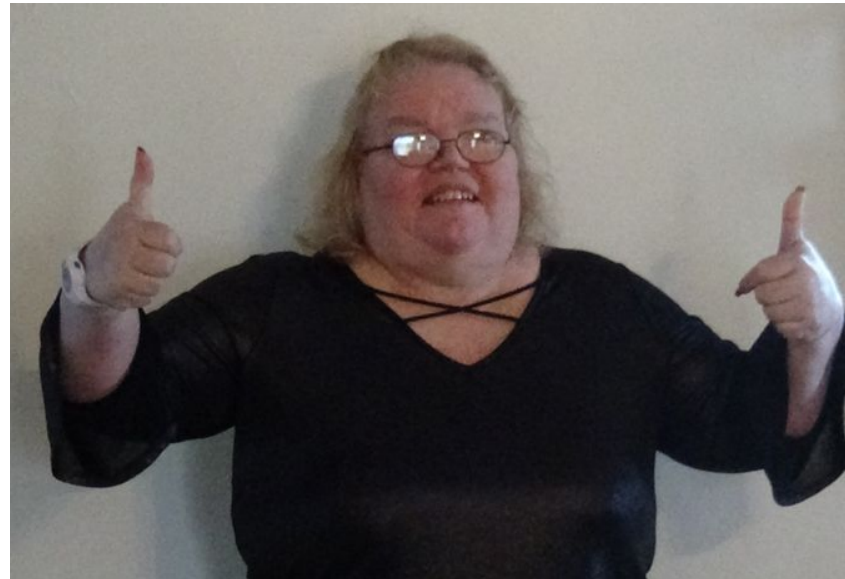


www.explainthatstuff.com



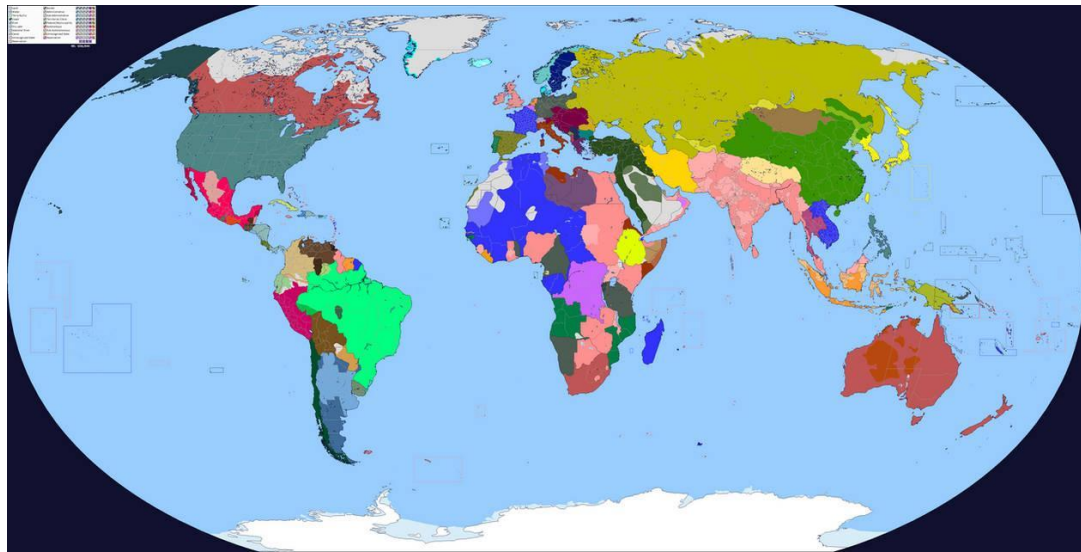
Why should we talk and learn about these things?

Because
**Knowledge
is Power!**



SAU1 staff Peggy gives 2
thumbs up for
Knowledge and Power!

We believe everyone all over the world has rights, called Human Rights.



- ▶ This is a map of the whole world.
- ▶ Tell us some Human Rights.

Here are some human rights we thought of.

- ▶ To communicate and be understood,
- ▶ To be respected,
- ▶ To love who we want,
- ▶ To have enough food.
- ▶ To have shelter, and



Citizens of the United States have Civil Rights.

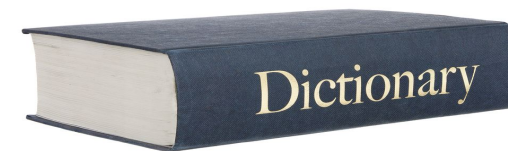


The parts of this map
circled in yellow
show the United
States of America.

- ▶ Let's talk about these words.

What do we mean by citizen?

- ▶ A Citizen is a person born, or naturalized, in the United States.
 - ▶ Naturalized is a way to become a citizen, if a person was born somewhere else.
- ▶ Civil rights are the rights each citizen has, protected by laws.
- ▶ Tell us some civil rights you know.



This is a picture of a dictionary, a book used to learn about words. We will show this picture when we are explaining what something means.

We thought of these rights that all citizens have:

- ▶ Speak up – called Freedom of Speech.
- ▶ Make decisions about your own body and health.
- ▶ Vote.
- ▶ Gather as a group – called Assemble.
- ▶ Complain to our government without fear.
- ▶ A free public education, and
- ▶ Choose to practice any religion, or no religion.



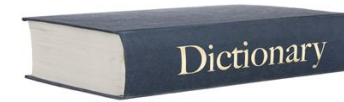
Have the rights of citizens with disabilities always been respected?

NO!

Let's learn a little bit of history.

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Many towns in the US used to have what were called “Ugly Laws”.



- ▶ “Ugly Laws” said it was against the law for “any person, who is diseased, maimed, mutilated or deformed in any way, so as to be an unsightly or disgusting object, to expose himself to public view”.
- ▶ PA’s “ugly” laws said people with disabilities could not go out in public.
- ▶ If people with disabilities went to school at all, they went to special schools only with other people with disabilities.
- ▶ Places were built for people with disabilities to live, apart from other people. These places were called institutions.

Thousands of people with disabilities were put into institutions, away from their families and communities.



New PA Hospital for the Insane being built in 1859

Use your Power to take care of **YOURSELF!**

- ▶ The next few slides talk about life in large institutions.
- ▶ They show and describe abuse and neglect.
- ▶ Many people think it is important to hear and know the history.
- ▶ It can be upsetting to hear and see.
- ▶ You can close your eyes or step away if you want.

People were abused and neglected in many of these places.

- ▶ People were tied or chained to their beds, walls, or benches.
- ▶ Bathing was done by hoses, if at all.
- ▶ Many were not dressed.
- ▶ Medical treatment was rarely provided.
- ▶ People's teeth were pulled to make life easier for staff.
- ▶ Operations that kept people from making children were done without their knowledge or agreement.
- ▶ People were used for medical experiments.

The pictures we will show now may be disturbing.
Please feel free to close your eyes or turn your head.



These pictures are from a report called Bedlam. They show many people who are not wearing clothes, with body waste on the floor, and who are mostly sitting with nothing to do.

Many people with disabilities were not thought of as people at all.

- ▶ Many things we think of as human rights weren't respected.
- ▶ None of their civil rights were respected.

Let's find out how this started to change.

People with disabilities, families, and allies spoke up.

- ▶ They gathered, held rallies, and visited their legislators.
- ▶ They demanded that their civil rights be respected.
- ▶ After many years, laws started to change.



Thousands of people with disabilities and allies fill the Capital building in Harrisburg to fight for their rights to be respected.

We must keep speaking up!

- ▶ There are still many people whose rights aren't respected.
- ▶ We are here today to talk about people's rights if they get services.
- ▶ You will know how to speak up if your rights are not respected!



Oscar Drummond, SAU1
Founder, Past President,
and current Lead
Ambassador.

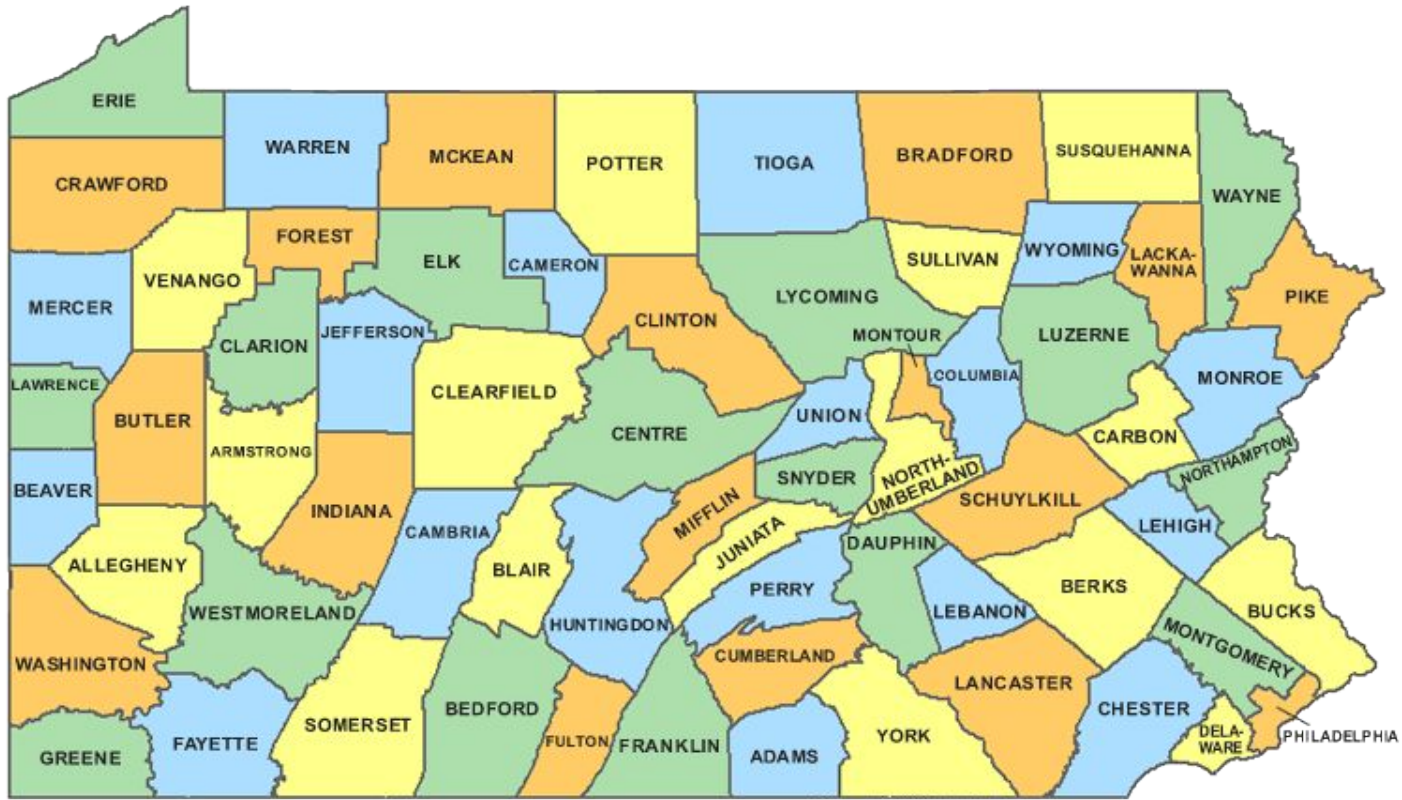
Citizens who get government funded services have the same rights as any other citizen!

- ▶ Some services may be things like
 - ▶ SNAP (sometimes still called food stamps) – Supplemental Nutrition Assistance Program
 - ▶ EBT (Electronic Benefits Transfer) card for SNAP or cash benefits, and
 - ▶ Medical Assistance



People who get services funded by the PA ODP have rights!

- ▶ Tell us what ODP means!



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This is a map of Pennsylvania, with the names of each county.

Every government funded service has rules called Regulations, called Regs.

- ▶ Some Regs protect the rights of people who get and use government funded services.

Here are just a few services that are funded by ODP:

- ▶ In Home and Community Supports, used to be called Habilitation
- ▶ Transportation
- ▶ Residential, like Life Share or Group Home
- ▶ Supported Employment
- ▶ Assistive Technology
- ▶ Nursing.
- ▶ Do you know any other services



ODP funds these services through providers.



- ▶ A provider is any person, or agency, or organization, paid for their services.
- ▶ There are many kinds of providers.
- ▶ Some people have family who provide services funded by ODP.
- ▶ Anyone, or any organization, paid to provide ODP funded services must follow these Regs!

Here are some of the jobs people may have providing ODP funded services.

- ▶ Direct Support Professional (DSP), Support Service Worker, or staff
- ▶ Supports coordinator
- ▶ Job coach
- ▶ Companion
- ▶ Respite worker, or
- ▶ Nurse



SAU1 staff Josh Harper gives a thumbs up in front of his staff, Quon.

It is every provider's job to make sure people understand their rights.

- ▶ Providers have to
 - ▶ Find out, and use, the best way to communicate with each person, using things like
 - ▶ sign language or braille
 - ▶ pictures or photos to explain the rights
 - ▶ words and language that make sense to the person, or
 - ▶ whatever communication device may be needed.
 - ▶ **Your provider must communicate as often as needed until you understand!**

About guardians:

- ▶ Parents or other family members are not automatically guardians.
 - ▶ That means, if you are an adult, providers cannot allow family members to make choices or decisions for you without your permission.
- ▶ Only a court can name a guardian.
- ▶ Next, let's talk more about guardians and what they can, and cannot, do.

“X?”

Guardianship – Facts

- ▶ A legal guardian has these duties:
 - ▶ Assert the rights and the interests of the person
 - ▶ Respect the wishes and preferences of the person
 - ▶ Participate in the planning of services to meet the person's needs, and
 - ▶ A guardian must encourage the person to
 - ▶ take part in all decisions that affect them,
 - ▶ act on their own behalf when they are able to do so, and
 - ▶ manage their everyday lives as best they can.

“X?”

A guardian does NOT have the right to:

- ▶ Make decisions that they know the person would not want
- ▶ Ignore the wishes and preferences of the person, or
- ▶ Keep the person from
 - ▶ taking part in all decisions that affect them,
 - ▶ acting on their own behalf when they are able to do so, and
 - ▶ managing their everyday lives as best they can.

“X?”

For example, let's pretend Oscar has a guardian.

- ▶ Oscar wants to vote.
- ▶ His guardian says that Oscar can't vote.

Does Oscar's guardian have the right to keep Oscar from voting?

NO!



It is your right to not be discriminated against.

An individual may not be discriminated against because of race, color, creed, disability, religious affiliation, ancestry, gender, gender identity, sexual orientation, national origin or age.

- ▶ Discrimination means to be treated unfairly or differently because of any of the things listed above.



Let's show how discrimination works.

- ▶ Everybody with a purple pen gets a stim toy!
- ▶ No one else gets a stim toy.
- ▶ Is this fair, or equal, for people who don't have a purple pen?
- ▶ That is discrimination.
- ▶ We don't discriminate.
- ▶ So here's a stim toy for everyone who wants one!



It is your right to be treated with dignity and respect.

Dignity and respect are words for the ways people show that other people are important and equal.



Let's talk about some ways people have been treated. Tell us if you think dignity and respect were shown by the provider.

Did these staff show dignity and respect?

Oscar's staff talked to someone else's staff about personal things they do to support Oscar.

NO

A person uses adult diapers. Their staff leave the diapers on a table at a meeting, where anyone can see them.

NO

Oscar is at a restaurant. His staff order for him without asking him or getting his permission.

NO

Staff make jokes about how a person speaks.

NO

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It is your right to

- ▶ to make decisions for yourself.
 - ▶ you have the right to choose and do things that may not be best for you
 - ▶ You have the right to make mistakes, just like anyone else!

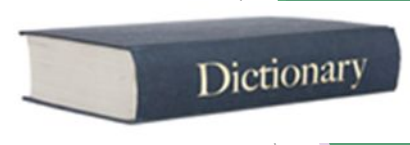
This is also known as Dignity of Risk.

- ▶ As a human being, you have the right to choose things.
- ▶ What are some things a person may choose that may not be best for them?
- ▶ Providers must respect your right to choose.
- ▶ You can ask your provider or staff to help you think about your choices, and what may happen with each choice.
- ▶ You are responsible for the risk - what may happen with your choice.



What if you have a complaint about the way you get, or do not get, services?

- ▶ A complaint may be something like
 - ▶ You cannot go to church because there are not enough staff
 - ▶ Your supports coordinator does not listen to what you want
 - ▶ You are given a roommate who you did not choose or want
 - ▶ Your transportation is late and you are late for work, or
 - ▶ Someone else sees your staff not doing their job.



Remember some of the jobs people may have providing ODP funded services?

- ▶ Direct Support Professional (DSP), Support Service Worker, or staff
- ▶ Supports coordinator
- ▶ Job coach
- ▶ Companion
- ▶ Respite worker
- ▶ Nurse



If you have a complaint tell the provider, as best you can,

- ▶ Your contact information, if you want.
- ▶ If you are making the complaint for yourself or someone else.
- ▶ What happened that you are making a complaint about.
- ▶ Who did what, if you know.
- ▶ The date, or dates, that the thing happened.
- ▶ Tell as much as you can.

What questions do you have about your rights?



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SAU1 thanks the thousands of self advocates and families in the past who shared the power of self advocacy.

Thanks to ODP for supporting this event,

and Thank You!



SAU1 Past President
Laura Bale

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Contact Us:

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**KNOWLEDGE
IS
POWER!**

Use it!

Share the Power of your Knowledge
on your form!



Self Advocacy Power Network for All

Use your POWER to tell us what YOU think!

Please circle your best answer.

1. Do you think today's talk is important?



2. What's one thing you learned today?

I learned: _____

3. Will this help you in your own life?



4. Did the people do a good job helping you learn today?



5. Did they listen to what you had to say?



6. Did the pictures and the screen help you learn?



Are you a: _____ self advocate – person with disability
 _____ family member _____ staff
 _____ other – please describe _____



Thank you for telling us what you think!