## Contents

<table>
<thead>
<tr>
<th>Page</th>
<th>Section</th>
</tr>
</thead>
<tbody>
<tr>
<td>02</td>
<td>How to Use this Handbook</td>
</tr>
<tr>
<td>03</td>
<td>About People First</td>
</tr>
<tr>
<td>04</td>
<td>Leadership</td>
</tr>
<tr>
<td>05</td>
<td>Defining Qualities</td>
</tr>
<tr>
<td>09</td>
<td>Better Together</td>
</tr>
<tr>
<td>11</td>
<td>How to Start a People First Chapter</td>
</tr>
<tr>
<td>17</td>
<td>Professionalism</td>
</tr>
<tr>
<td>18</td>
<td>How we look</td>
</tr>
<tr>
<td>25</td>
<td>How we act</td>
</tr>
<tr>
<td>37</td>
<td>Self-Advocacy</td>
</tr>
<tr>
<td>38</td>
<td>Becoming a Self-Advocate</td>
</tr>
<tr>
<td>44</td>
<td>Assertiveness</td>
</tr>
<tr>
<td>46</td>
<td>Self-Determination</td>
</tr>
<tr>
<td>49</td>
<td>Know Your Rights</td>
</tr>
<tr>
<td>50</td>
<td>History of Disabilities Rights</td>
</tr>
<tr>
<td>53</td>
<td>Disability Law</td>
</tr>
<tr>
<td>58</td>
<td>Human Rights</td>
</tr>
<tr>
<td>61</td>
<td>Bill of Rights for People with Disabilities</td>
</tr>
<tr>
<td>63</td>
<td>Centers for Medicare and Medicaid Services</td>
</tr>
<tr>
<td>65</td>
<td>Guardianship</td>
</tr>
<tr>
<td>66</td>
<td>Supported Decision-Making</td>
</tr>
<tr>
<td>67</td>
<td>Citizenship</td>
</tr>
<tr>
<td>71</td>
<td>Employment</td>
</tr>
<tr>
<td>74</td>
<td>Voting</td>
</tr>
<tr>
<td>80</td>
<td>How Change Happens</td>
</tr>
<tr>
<td>82</td>
<td>Cultural Change</td>
</tr>
<tr>
<td>83</td>
<td>Official Change</td>
</tr>
<tr>
<td>84</td>
<td>Examples of Change</td>
</tr>
<tr>
<td>85</td>
<td>How a Bill Becomes a Law</td>
</tr>
<tr>
<td>87</td>
<td>Glossary of Terms</td>
</tr>
<tr>
<td>89</td>
<td>Resources</td>
</tr>
</tbody>
</table>
How to use this handbook

This publication seeks to educate, empower, and inspire people with intellectual and developmental disabilities to understand the heritage of disability rights and how leaders organized advocates to achieve equal human and civil rights.

This handbook is appropriate for use by public schools, service providers, vocational rehabilitation programs, self-advocacy support groups, disability advocacy organizations, post-secondary private and public programs. It may also be used by individuals as a self-directed learning tool, organized programs for youth with disabilities, and more.

Most youth will benefit from the opportunity to learn from the handbook with a family member, tutor, teacher, or a group of other self-advocates. Having one-on-one supports will ensure that all learning abilities will benefit. We have included a glossary of terms and additional resources for both the instructors and youth to supplement the content.

People First believes that advocates are the best instructors of this material for other advocates. Please contact the People First State Office if you would like a advocate trainer to present to a group or additional materials including Powerpoints and supplemental activities. These resources will provide participants with many opportunities to practice new skills and demonstrate their understanding of important concepts included in this resource. This free handbook and other resources are available at, www.njcdd.org/peoplefirstnj.
People First of New Jersey is a statewide organization comprised of youth and adults with intellectual and developmental disabilities that promotes choice and control for its members. There are chapters around the state. Contact us to learn more about a chapter near you.

Dedication
This handbook is dedicated to the youth of New Jersey of all abilities who, with character and strength of heart, will lead us to a future where all lives are considered equally valuable.

People First Office
609-984-4513 | jaymes.brill@njcdd.org njcdd.org/peoplefirstnj
Leadership

Defining Qualities

Better Together

How to Start a People First Chapter
Defining Qualities

Introduction

DEFINITION:

A leader is a person who guides or inspires others.
Examples of **Leadership**

“The time is always right to do what is right.”

Martin Luther King Jr.  
Civil Rights Advocate

YOU ARE A LEADER IF YOU...
- Volunteer in your community.
- Set a good example for others to follow.
- Help others reach their goals.

YOU SHOULD BE A LEADER IF YOU WANT TO...
- Make a difference.
- Experience personal growth
- Be a valued member of the community.

Legacy Project

United State Congress  
Capital Building, Washington D.C., US

Dalai Lama  
Religious Leader
OFFICERS: How to Get Started

+ Ask yourself, “If I could change one thing about the world, what would it be?”

+ Identify a leader whom you admire, and follow his or her example.

+ Find existing groups or organizations that are working toward the same goal that you are and join them.

+ Start small. Short-term goals are more manageable. Remember, changing the world takes time.

+ Start local. It is easier to accomplish goals close to home.

+ Work with your strengths. If you are good at public speaking, focus on that. If your strength is networking, focus on that.

“If your actions inspire others to dream more, learn more, do more and become more, you are a leader”

John Quincy Adams
What Makes A Good Leader?

**A GOOD LEADER**

- Is a team player.
- Makes decisions well.
- Is willing to help.
- Treats other kindly.
- Listens well.
- Works hard.
- Sets a good example.
- Shows empathy (understands how others feel).
- Compromises (meets others in the middle).

What Makes A Bad Leader?

**A BAD LEADER**

- Bullies other people.
- Behaves unprofessionally.
- Does not listen to others ideas (a know-it-all).
- Judges others.
- Does everything themselves and does not ask others to help.
- Takes credit that belongs to others.
BETTER TOGETHER: Benefits of Working within a Group

+ Everyone has different skills, so each person can do what they are good at to make a successful team.
+ People can encourage each other when things get tough.
+ You alone do not have to know all of the answers.
+ It is more fun than working by yourself.
+ You can learn from other people.
+ It can be faster than working alone.
+ A team of individuals has more resources and has a bigger network.
+ Your personal and organizational goals are more likely to be achieved.
Organization
Tips
Recruitment is often the hardest part of starting a chapter. Be creative about ways to recruit. Go to disability events with information about your chapter. Have members contact people with whom they graduated.

Next Steps
Invite more people. Use the group members’ personal networks, and network within the state disability agencies and public schools.

Establish details for the organization:

WHEN AND WHERE TO MEET:
make sure space is accessible.

PUBLICITY:
let people know when, where, and why you meet.

TRANSPORTATION:
assist people in coordinating rides.
How To Start A People First Chapter: ADVISOR

+ To recruit advisers, identify teachers or university professor’s familiar with disabilities, people who have worked for disability agencies, and parents or family members of PF members.

+ It helps if the advisor has some experience helping people organize into groups and knows and respects people with developmental disabilities.

+ It is best when members vote to approve the advisor and that the advisor is well-informed.

“Effective advising for self-advocacy organizations provides support in such a manner that people with intellectual and developmental disabilities with diverse needs, including significant communication and behavioral challenges, can exercise self-determination at many levels to pursue both individual and organizational goals. Finding ways to empower both individual people and the collective group, while staying in the background in a support role, is a difficult art demonstrated by the very best advisors.”

Sharon Lewis
U.S. Department of Health and Human Services
Leadership
Defining Qualities, Better Together, How to Start a People First Chapter

PLANNING A MEETING

FIND AN ACCESSIBLE PLACE TO MEET

MAKE SURE THE DAY AND TIME YOU MEET WORKS FOR MOST PEOPLE
Some groups decide on a set day of the month, such as the first Saturday, and other groups schedule the meetings on different days each month.

CHOOSE MEETING TOPICS AND ACTIVITIES THAT ARE EXCITING AND INTERESTING FOR THE WHOLE GROUP
To do this, ask members for recommendations or give them a survey.

PLAN TO HAVE REFRESHMENTS.
Some chapters have members donate snacks; some have members bring money and order a simple meal.
Inviting People to a Meeting

- Use different methods to contact people (mail, phone call, email, social media).
- Ask members what is the best way to reach them.
- Include the date, time, location, and contact information in case someone gets lost on their way.
- Some groups have a closed Facebook group for their chapter.
- The committee should call two days before the meeting to remind everyone.
- Make a personal connection with members and potential members, and their support systems.

Before the Meeting Checklist

- Create a meeting agenda.
- Give the organizing committee, officers assignments. Don’t forget to assign someone to clean up afterwards.
- Ask speakers if they will need materials such as handouts and agendas.
- Make sure technology such as a computer or TV is working before the meeting.
- Designate someone to bring refreshments.
- Review rules for space. It is important to be respectful of the rules.
Leadership
Defining Qualities, Better Together, How to Start a People First Chapter

Tips for **During The Meeting**

- Strive to make everyone feel like an important and equal member.
- Involve and engage everyone in the group.
- Make sure that everyone gets a chance to speak and participate during the meeting.
- Make sure everyone understands what is going on during the meetings. Use easy-to-understand words and pictures, if presenting. Make sure everyone understands what is being voted on before a vote.

  Keep members interested and engaged. Make the discussions about things that are important to the members.

- Be a good host.

  Be friendly to everyone, especially people who are new or don’t know many people.
  Keep an eye out for anyone who needs help.
  Offer to get people more refreshments.
How To Start A People First Chapter:

**Tips for During the Meeting**

+ Keep the mood as welcoming and informal as possible.
+ Server refreshments.
+ End the meeting well:
  - Thank the speaker.
  - Thank the members for coming.
  - Hand out calendars so everyone will know when the next meeting will be.
  - Know who is responsible for cleaning up afterwards.

**Tips for Electing Officers**

+ Do not elect officers until two or three meeting have passed. This gives everyone a chance to speak and get to know the other members before voting.
+ When you do elect officers, have the people running for office give a speech on why they would make great officers.
+ Put pictures of the people who are running for office on the ballot box. This makes it easier for people to identify the person for whom they want to vote.
Leadership
Defining Qualities, Better Together, How to Start a People First Chapter

Group Decisions

- As a group, make rules for how the group will work.
- Each group has to decide what is really important to them.

Types of Decisions to Make

Meeting rules

- Examples: only one person speaks at a time, how to vote to decide on things, etc.
- Robert Rules of Order has helpful rules for groups.

Chapter rules

- People First has by-laws, which are rules that chapters follow.

Other decisions

- Are there membership fees?
- Can anyone join?
- When and how will the chapter elect its officers?
- How will the meeting topics be determined?

Chapter TIPS

Community members and allies who do not have disabilities are encouraged to participate in meetings, but they can not be voting members or officers.
Professionalism

How we look

How we act
Professionalism

HOW WE LOOK AND ACT

Introduction

Definition:
Professionalism means that you are seen as a respected adult citizen in your community.

Why Professionalism is Important

+ People take you seriously when you show that you care about the way you look.
+ People will listen to you when you listen to them.
+ People will give you adult responsibilities when you show others you are capable of handling them.

Perks of Being Professional

+ Get and keep paid jobs.
+ Make friends more easily.
+ Get more recognition for achievements.
+ Have more opportunities to be successful.
Professionalism

HOW WE LOOK

Clothing

+ You don’t have to own expensive clothing to look professional.
+ Clothing should be clean, odor free, and free of stains and tears.
+ Wear clothes that are appropriate for that season. (Example: Wear sandals or open toed shoes in the warm weather seasons.)

Dressing for the Occasion

It is important to dress for the occasion. Do not over or under dress. What is appropriate and professional in one situation might not be for another. The event and who you are meeting determines what is appropriate. There are three general categories of clothes: casual, business casual, and business professional. It is not always clear what clothing a certain event calls for. You can always ask someone for help. The general rules on the next page apply to most situations.
### Professionalism

**How We Look, How We Act**

<table>
<thead>
<tr>
<th>WEAR THIS</th>
<th>NOT THIS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wear dark socks with dark shoes.</td>
<td></td>
</tr>
<tr>
<td>NEVER wear socks with open toed shoes or sandals.</td>
<td></td>
</tr>
<tr>
<td>AVOID excessive makeup and jewelry</td>
<td></td>
</tr>
<tr>
<td>AVOID tops of dresses that are low cut in the front or back, and skirts and dresses that are shorter than a hands width above the knee.</td>
<td></td>
</tr>
</tbody>
</table>
Casual Clothing

For an informational community activity such as shopping or attending the movies or a friend’s home, wear casual clothes. You might think it doesn’t matter how you look while in the community, but you never know who you will see. Also, people who dress well usually get treated better by other people.

Style TIP

Wear clothes that are in mainstream style for your age group. If you have a nontraditional/usual style, know how that style might affect the way people think of you. Know the places where it is important to dress traditionally and the places where it is ok to dress nontraditionally. If you wear t-shirts with writing or images, make sure they aren’t offensive.
Professionalism
How We Look, How We Act

Business Casual Clothing
WHAT TO WEAR

MEN  khakis, dress pants, polo’s or other collared shirts, dress shirts, or nice sweater

WOMEN  collared, knit shirts or sweaters; dresspants, conservative dresses; dress shoes or boots

Style TIP
Avoid mixing bright colors with patterns. Women should avoid low cut tops and short, skirts, dresses. Avoid showing any undergarments.

When to Wear Business Casual Clothing
Business Professional Clothing

WHAT TO WEAR

MEN Suit or sports coat, jacket; dress pants with a button down shirt, tie, dress shoes

Style TIP Make sure that clothes are free of wrinkles and are in good condition. Men should always keep their shirts tucked in.

When to Wear Business Professional Clothes

When you are a speaker at a formal event and for certain jobs that require business professional attire. If you are not sure what the dress code is, you should ask your employer before starting a job.
**Professionalism**

**How We Look, How We Act**

**Professionalism**

**How We Look**

**Grooming**

**Body Spray, Cologne, or Perfume**

Use only a small amount. Once you put it on, you might not realize how strong it is. Ask someone else if you have on too much.

**Things To Avoid**

- **Excessive piercings** (piercings anywhere other than on your ears)
- **Tattoos visible while dressed professionally.**
- **Unnatural hair color.**
- **Unkempt facial hair.** (if any is allowed)

**Style Tip**

Employers have rules about facial hair, tattoos, and piercings. Ask what their policy is before starting a job.

- **Shave Regularly**
- **Shower Daily**
- **Wear Deodorant**
- **Basic Hygiene**
- **Hair clean, brushed, and off face**
Professionalism

HOW WE ACT

Time Management

Before you schedule appointments

+ Make sure you can get transportation.
+ Make sure you have time to get there.
+ Make sure you don’t already have an appointment during that time.
+ You can always tell the person you will check and let them know later if you can make an appointment.

Keep Track of your Appointments

+ Use a calendar (paper/phone/computer)
+ Set reminders on your phone to notify you before the appointment begins.
+ Be on time! If you can’t make an appointment or are going to be late, let whomever you are meeting know immediately.

Meeting Tips

It is ok to have more than one event or meeting on the same day. Just make sure that the events, including the time it takes to get there and back, are not at the same time. For example, if you have an appointment in the morning you can schedule a second appointment for the afternoon.
Professionalism
How We Look, How We Act

Respect Others’ Time

+ Be prepared for and stay on topic during a conversation.
+ If someone has only a short amount of time to talk, keep the conversation brief.
+ Watch for the clues below that the other person wants to end the conversation.

Conversation TIPS
Ask yourself these questions before talking:

+ Is the person interested?
+ Do we both have time to talk?
+ How many details do I need to include?

Things people DO when they want to end the conversation:

+ Look at their phone or watch.
+ Start to turn away.
+ Stand up after sitting or move toward the door.
+ Pick up a purse or personal items.

Things people SAY when they want to end the conversation:

+ “I’d better get going.”
+ “It was nice meeting you.”
+ “It’s good to see you.”
Meal Manners
When having a meal or a snack in a group during a meeting or social event, you never want anyone to think that you are more interested in the food than the reason for the meeting or get together.

**DON'T's**
- Don’t talk with food in your mouth.
- Never pile food on your plate.
- Don’t take food home with you unless someone offers for you to do so.

**DO's**
- Let others be first in line.
- If small plates are provided, then it is a light meal, and you should serve yourself a small portion.
- If you need to cough repeatedly or sneeze or if you feel ill, leave the table and visit the restroom.

**SERVING SIZE**
Only take one serving of whatever is offered until everyone has eaten. Afterwards, it is alright to get seconds but not thirds. When in doubt, stick to these serving sizes:

- 2 slices of pizza
- 1 brownie
- 1 sandwich
- 1-2 cookies
Meeting Manners
Listen to the speakers and show interest and respect.

Contribute to Conversation
+ Wait until there is a pause before speaking to avoid interrupting.
+ Be brief in your comments.
+ Even if you disagree, be respectful of others’ ideas.
+ Do not dominate the discussion.

Minimize distractions during meetings
+ Avoid getting up and moving around.
+ Before the meeting starts, use the restroom and get a snack, if one is provided.
+ Place cell phones on silent, and leave them out of sight.

Meeting Tip:
Most formal meetings will have an agenda (a list of things that will be talked about during the meeting). It is necessary to stay on topic so the important topics are discussed, and the meeting does not last longer than planned.

Never Fall Asleep!
Professionalism

HOW WE ACT

Attitude

+ Be helpful – be willing to do things for other people.
+ Be respectful – treat others how you want to be treated.
+ Be cooperative – work together towards a common goal.

Know your limits.

+ If you can’t do something or don’t have time, don’t say you can do it.
+ If you say you are going to do something, do it. If you need help, ask for it.

Take responsibility for your actions.

+ Everyone makes mistakes.
+ It is important to let the right person know you made a mistake and to apologize.

There is a time and place for everything.

+ Handle personal business outside of work.
+ Don’t text or play games on your phone during a meeting.
Communication

Communication with others is the primary way to make decisions. Did you know that most communication is nonverbal? We communicate with people through facial expressions, actions, and other body language.

Avoid

+ Profanity
+ Sharing too much or inappropriate personal information
+ Gossip, such as talking negatively about a coworker

Make a Positive First Impression

+ Offer a firm handshake for 2-3 seconds.
+ If you are asked a question, answer and then ask a question in return.
+ Be prepared with a few “small talk” topics.

Examples:

+ “Where are you from?”
+ “Where do you work?”
+ “Where did you go to school?”
Professionalism

HOW WE ACT: Communication

Body Language

Body language communicates more than you think. Many times people are unaware of their own movements. It is important to know what our facial expressions, arms, and body positions are telling people. You might be paying attention, but if your body language is telling someone you aren’t then you need to change your position. Try practicing respectful body language in front of a mirror.

<table>
<thead>
<tr>
<th>Respectful Body Language</th>
<th>Disrespectful Body Language</th>
</tr>
</thead>
<tbody>
<tr>
<td>Still Hands</td>
<td>Doing something else (doodling or on the phone)</td>
</tr>
<tr>
<td>Looking at the speaker</td>
<td>Looking down or away</td>
</tr>
<tr>
<td>Open arms</td>
<td>Repetitive movement (tapping toes, swinging feet or drumming fingers)</td>
</tr>
<tr>
<td>Sitting up or slightly forward</td>
<td>Slouching and leaning on hand</td>
</tr>
</tbody>
</table>
Who to Tell What

**TMI:** avoid sharing **Too Much Information.** The topics that you discuss with your close friends and family are not always appropriate to discuss with other people. Sharing information with the wrong person can be dangerous, hurt your reputation, give the wrong impression, or show poor judgment. The chart below is a guide for what information to share within different relationships.

**Close Friends and Family**
Share most secrets as well as things that are both happy and sad such as getting a raise at work or having a fight with a friend.

**Acquaintances and coworkers**
Share major life events like getting a new pet or what your weekend plans are.

**Strangers**
In general, strangers don’t need to know any personal information about you.
Professionalism

HOW WE ACT:

What is Social Media?
Social media includes Facebook, Twitter, Snap Chat, or Instagram and other ways people access virtual (Internet) relationships, including video gaming with others through technology.

Things to know
- Social media is best when its used to enhance your real life relationships, not to replace them.
- Don’t believe everything you see online. There is lots of information on social media that is simply not true.
- If you end up mostly looking at sad things on social media, it can be depressing.
- Limit how much time you spend on social media. Many people will take a short break from social media each year as a way to evaluate their lives without it.
- It is a good idea to ask those you respect for help before you make new “friends” or purchase anything on the internet.
Things to Know

Know who you can see what you post on social media
Different social media outlets have different privacy settings.
Your reputation is on the line.
People form opinions about others based on what they share online.

Once something is posted on the internet people can always see it, even if you “erase” it. Potential employers can access your social media accounts and can use the information you post to decide if they want to hire you or even fire you.

Want to Share

+ Use good judgment.
+ Although someone might agree with what you share, they might feel like it is too personal for social media.
+ Only post pictures and information that you would share with people in person.
+ Share positive information. Don’t share sad things; that is what your friends and family are there to hear.
Professionalism
HOW WE ACT: Social Media

Be Safe
+ Be careful if someone you don’t know contacts you on social media.
+ Most people do not contact others online that they don’t know.
+ If someone you don’t know contacts you, they might have bad intentions.

Do Not Give Out Personal Information
+ Your location or home address.
+ Your schedule – when you are about to go out of town or details about your daily routine.
+ Your purchases such as a TV or computer.
+ Your finances or identity information like your social security number, state ID number, or bank account number.

There are harassment laws that protect people from being bullied online. If you make a remark about someone else, they may report you to the authorities. Keep comments truthful and respectful.
Professionalism
How We Look, How We Act

Positive Communications

+ When starting a conversation, don’t just say, “Hey.” Also ask a question such as, “Hey, how have you been?”
+ Have a reason for the conversation.
+ Be respectful if someone does not want to communicate with you as much as you would like to communicate with them.
+ Don’t use social media to talk negatively to or about other people.
+ Use social media to congratulate friends about successes.
+ Use social media to find out about activities and to let others know about activities they might want to attend.
+ Get advice from those you respect if you are uncertain about the appropriateness of sharing your interests on social media.
+ Use social media to let others know about your advocacy issues and work.
Self-Advocacy

- Becoming a Self-Advocate
- Assertiveness
- Self-Determination
Self-Advocate

Introduction

Definition:
Self-Advocacy is speaking up for yourself to get your needs and wants met.

Examples of Self-Advocacy
+ Asking for more hours at work
+ Speaking up for yourself when someone treats you unfairly.
+ Asking for help when you need it.
+ Looking for solutions to common problems that people with disabilities faces.

Self-advocacy empowers people to make their own decisions for their lives. It allows people to achieve their dreams and goals by giving them freedom over what they do.

“Nothing about us without us.”
Know Yourself
+ It is important to know yourself.
+ Pay attention and know your strengths and needs.
+ It is hard to advocate for yourself if you can’t explain your disability.
+ Know about your disability and be able to talk about it.
+ Friends, family, teachers, and other professionals can help you understand how your disability affects you.
+ Remember, you are wonderful and unique.

Identify Who Know You Best
+ The best expert on you is YOU. No one knows you better than you know yourself.
+ When other people make decisions for you, those decisions often don’t fit your needs.
+ There are experts who help people with disabilities succeed.
+ Having the support of experts is helpful, but regardless of their help, all PWD should be self-advocates.
Self-Advocate
Becoming a Self-Advocate

Know About Your Disability

+ Embrace your disability.
+ Appreciate your uniqueness.
+ Know what your disability is.
+ Know how it affects you.
+ Be able to talk about it.
+ Know what things you need to help with and the things you don’t.

Having a disability often creates positive opportunities for your life that you might not have otherwise. The friends you have, community recognition you have received, and many positive qualities that you possess are a result of your disability.
Personal Goals
+ Set short-term goals such as washing your own clothes.
+ Set long-term goals such as living independently.

Make a Plan
+ Decide who you should talk to about accomplishing your goal.
+ Prepare what to say.
+ Pick the best timing for your conversation.

Example: Wait until your boss is in a good mood before asking for more work hours

Get to Work
Do something small every day to reach your goal.

Stick to It
Don’t give up. Reaching your goals can takes time. If one way doesn’t work, try another.

Reach your Goals
Once you have reached your goal, you will have a sense of accomplishment because you did it!

Goal Tip: Ask yourself if what you are doing today is getting you closer to where you want to be tomorrow.
**Self-Advocate Stories**

**Ryan Roy**

Ryan is a peer mentor who describes himself as an "Autism Advocate". He lives in Saddle Brook Township, NJ with his wife and son. According to Ryan, "Developing empathy has helped me be the voice for myself and other friends who are on the Autism Spectrum, as well as how to understand how having an ASD affects their life."

**Myrta Rosa**

Myrta is a seasoned and dedicated self-advocate. She is the second Vice President for Helping Hands Self Advocacy Group, Myrta serves as Vice Chair for New Jersey Council on Developmental Disabilities (NJCDD) board. She is also a member of the New American Movement for People with Disabilities at Community Access Unlimited (CAU).
Becoming a Self-Advocate

Self-Advocate Stories

**Andrew McGeady**
Andrew is a New Jersey Council on Developmental Disabilities board member. He is a high school and college graduate. He is a longtime advocate who has fought for issues related to developmental disabilities. “I want all people with disabilities to have the opportunity to live in the community and enjoy the quality of life that I have,” says Andrew.

*Self-Advocate*

**Barbara Coppens**
Barbara is an experienced self-advocacy leader. Barbara has been advocating for herself and other people with I/DD for more than 30 years. She served as President of the Advisory Board for The NJ Statewide Self Advocacy Network and as co-convener of the National Council on Self Advocacy (NCSA).

*Self-Advocate*
Self-Advocate

Assertiveness

What Does “Assertive” Mean

+ Being assertive means that you communicate courage and stand up for yourself to show that you want to be treated fairly while remaining respectful to others.

  **Example:** if someone tries to take a book from you, you say, “I’m reading it right now. You may have it when I’m finished.”

An assertive person understands that his or her beliefs, ideas, needs, and feelings are just as important as someone else’s.

“Not All Superheroes Wear Capes”

Quentin Kenihan

Opposite of Assertive: Passive

+ Being passive means that you do not stand up for yourself and let others take advantage of you.

+ A passive person is shy, fearful, submissive, or weak.

  **Example:** Saying, “You can have the book; I don’t need it”, when you do need it.

+ Being passive doesn’t sound too bad, but passive people don’t get what they need and want, and they often regret their passivity.

+ To be less passive, avoid saying, “It doesn’t matter,” or, “I don’t care.”

+ Practice voicing your opinion on small matters like where you’d like to go eat and what time you want to meet.
Self-Advocacy
Becoming a Self-Advocate, Assertiveness, Self-Determination

Opposite of Assertive: Aggressive

- Being aggressive means that you get what you want through force or confrontation.
- An aggressive person is often rude, argumentative, pushy, or angry.
- **Example:** “You have to give me that right now or I will take it.”
- Being aggressive might get you what you want, but in the long run people won’t respect you because they see you as rude or hurtful.

To be less aggressive:

- Always be kind while telling people what you want or need.
- Let other people speak first, and don’t interrupt.
- Be respectful of others’ rights.

Ways to Become More Assertive

- Be firm, direct, and honest.
- Be confident about who you are.
- Speak clearly and to the point.
- Have a good role model to follow.
- Realize you have the ability to make choices about your life.
- Pay attention to how you think and feel and what you want and need.
Self-Advocate
Self-Determination

What is Self-Determination?
Self-determination is the concept that all individuals have the right to direct their own lives. Self-determination skills are the abilities that help people successfully make their own decisions.

Why Self-Determination is Important?
Self-determination helps youth with disabilities achieve positive adult outcomes. Its result will include a measurable increase in self-sufficiency and, perhaps even more importantly, a greater sense of purpose and satisfaction during adulthood. People who have self-determination skills have a stronger chance of being successful in making the transition to adulthood, including employment and independence preferences.

Go confidently in the direction of your dreams!
Live the life you’ve imagined.
Thoreau
Examples of Self-Determination

- I can sleep late on the weekends when I don’t have anywhere to be.
- I can get my hair cut and shave when I want.
- I can hire and fire my staff.
- I can control my transportation.
- I can go places with my friends and not be rushed or hurried.

Promoting Self-Determination

Families of PWD as well as professional supports are often the facilitators of self-determination and should actively encourage PWD to make their own choices. Although some decisions involve risks and potential failure, PWD have a right to fail like everyone else. Supports should be provided to educate the person about potential risks, but the final decision should be the self-advocate’s. There should be a clear understanding of everyone’s support roles.

Consider what the barriers are to your own self-determination and how to eliminate them. Remember that often family and professionals contribute to these barriers.
Self-Advocate: Self-Determination

Ways to Improve Your Self-Determination Skills

+ Know what you are good at and where you need help.
+ Start by making small choices like what you wear and eat.
+ Know what things you like or don’t like; have an opinion.
+ Speak for yourself as much as possible instead of relying on a family member or caregiver.
+ Don’t be afraid of making mistakes.
+ Think about your future and what you want it to look like.
+ Know who to ask if you need help, and be willing to ask only when you need it.
+ Know what will happen as a consequence of your decisions.
+ Identify the things that you want to make your own decisions about, and aim to make choices about them.

A self-determined person is one who sets goals, makes decisions, sees options, solves problems, speaks up for himself or herself, understands what supports are needed for success, and knows how to evaluate outcomes.
Know your Rights

- History of Disability Rights
- Disability Laws
- Human Rights
- Bill of Rights for People with Disabilities
- Center for Medicare and Medicaid Services Rules
Know your Rights: History of Disability Rights

Introduction

There are different kinds of rights that people have. Human rights are those that all people have simply because they are human beings. Civil rights create equality of legal treatment based on our country’s constitution. Throughout history, people have had to fight to achieve their rights. African Americans are a good example of a group of people who have to fight to have equal rights. Their actions have inspired people with disabilities to fight for their rights. It is important that rules and policies in our society ensure that people’s rights are respected.

Importance of Knowing Your Rights

People need to know what their rights are so that they can be good self-advocates. In order to get needed services, they need to know what rules, policies, and practices service providers have in place.
Know your Rights: History of Disability Rights

Imagine if you could not go to school or places with your family. Imagine if your family kept you a secret. It would be pretty awful! It was common for families to hide their children with disabilities or cover up their disabilities.

Fortunately, thoughts about PWD have changed over the past 100 years. PWD are now, more often seen as equals and individuals, but there is still progress to be made.

### Burden on Society
Babies born with disabilities were often left to die after birth, and if they lived they were seen as a burden on society.

### Public Institutions
During the 20th Century, medicine and science progressed. This led to the development of public institutions and hospitals for children and adults with disabilities. Often, well-intended, these places isolated PWD from the greater community. Many families would send their children to an institution and never visit, disregarding them as part of their family.

### Rehabilitation
After World War II, thousands of young men came home with devastating war injuries. They were in need of rehabilitation services to help them to become contributing citizens again. Services provided for these men lead to higher expectations for all people with disabilities.
Know your Rights
History of Disability Rights, Disability Laws, Human Rights, Bill of Rights for People with Disabilities, Center for Medicare and Medicaid Services Rules

Receive Treatment
As people with disabilities became more visible, they started to receive treatment, the goals for treatment related mostly to personal care, not reintegration to society.

Public Education
By the 1950’s, families organized to receive public education for their children with disabilities. This was a result of the growing opinion that PWD were “educable,” meaning that they were capable of learning.

Civil Rights Movement
In the 1960’s and 1970’s, adults with disabilities were inspired by the civil rights movement lead by Black Americans. PWD began advocating and demonstrating for their rights, too.

Most Integrated Setting
PWD and their allies worked to make legal and policy changes to ensure services were provided in the “most integrated setting.” This meant that people could live in their own communities instead of institutions and that students with disabilities could go to regular schools and be in regular classes instead of schools just for youth with disabilities.
Know your Rights: Disability Laws

Developmental Disabilities Assistance (DD Act)

+ Became law in 1963 and was reauthorized in 2000.
+ Gives people with developmental disabilities and their families access to community supports. They also get a say in the design of services including individualized supports that promote independence.
+ This means that people get to pick what supports they need order to live in the community instead of living in institutions.

The Person Behind the Law

Dr. Robert Cooke was one of two children with intellectual disabilities. He worked as a professor of pediatrics at Johns Hopkins Hospital. He also worked with President Kennedy and others to develop the DD Act. Furthermore, Dr. Cooke was also involved in the development of Head Start and served on the board of the Special Olympics.
Know your Rights:
Disability Laws

Rehabilitation Act (Work Innovation Opportunities Act, 2014)

+ **Prohibits federal employers from discriminating** against qualified individuals with disabilities. It also requires them to hire people with disabilities.
+ This means that if someone with a disability applies for a job they cannot be turned down just because they have a disability. Employers also must proactively hire people with disabilities.
+ The act created community independent living centers in each state.
+ In 2014, the Rehabilitation Act was re-authorized and renamed the Work Innovation Opportunity Act. It now focuses on youth with disabilities.

The Person Behind the Law

The Person Behind the Law Ed Roberts was known as the “Father of Independent living.” At the age of 14, Ed acquired polio and had a physical disability for the rest of his life. He fought for his rights to attend high school and college and to live independently. Ed faced many challenges to achieve his dream. He did not let the fact that he used a wheelchair prevent him from going to class and advocating for himself. He was a tireless organizer and leader of others with disabilities. Once denied vocational rehabilitation services in his state, eventually Ed was appointed and served as head of the state vocational rehabilitation agency for California which celebrates Ed Roberts Day each year. Self-advocates like Ed Roberts are responsible for the Rehabilitation Act.
Know your Rights: Disability Laws

**Individuals with Disabilities Education Act (IDEA)**

+ Passed in 1975
+ Requires that children with disabilities have the opportunity to receive a free appropriate public education
+ This means that children with disabilities can go to the same schools as other children and they get the supports they need.

**The Person Behind the Law**

Gunner Dybwad was a professor who fought for people with disabilities to have a public education. He believed that it was their civil right to receive a real education; not just medical treatment. At that time, children with disabilities were not taught things like reading and math. Dybwad worked with families to go to court. In 1972 they won the court case which impacted educational rights. The fact that children with disabilities are allowed to go to public school today is largely due to his fierce conviction to supporting the families that stood up for their children’s rights. This led to the passage of a federal law guaranteeing education for all. Today this is now known as the Individuals with Disabilities Education Act.
Know your Rights: Disability Laws

Americans with Disabilities Act (ADA)

- Became law in 1990
- Ensures that people with disabilities have the same rights and opportunities as everyone else.
- This means that no employer can turn someone down for a job because they have a disability and that employer’s must provide reasonable accommodations for workers with disabilities. Public buildings must have ramps, elevators, restrooms, and work spaces so people with physical disabilities can use them. Public transportation; buses, trains, and airplanes must also be accessible.

The Person Behind the Law

Justin Dart was called the “Godfather of the ADA.” Justin acquired polio before going to college. Despite his disability due to polio, he completed his degree in education. However, the school refused to give him a teaching certificate because of his disability. Justin became a business man. Later, he focused on legislative advocacy. Justin worked with members of congress to write the ADA.
Know your Rights: Disability Laws

Olmstead Decision

+ A Supreme Court decision made on June 22, 1999.
+ PWD must receive services in the most integrated setting.
+ This means people can choose where they live and work and receive supports in their own communities.

The People Behind the Decision

Lois Curtis and Elaine Wilson are women with disabilities who stood up for their rights and helped thousands more access their rights and meet their full potential. Lois and Elaine were admitted to a mental institution in Georgia. After receiving treatment, the doctors said they were doing better and could move to a community-based program closer to home and be more involved in their communities. Yet, the state of Georgia denied them their right to leave the hospital for several years because there weren’t any community-based programs. In 1999, Lois and Elaine went to court to fight for their rights and won. Not only did they get to move into a community-based program, so did many more people like them. This case is known as the Olmstead decision. The decision requires states to have policies that comply with the Americans with Disabilities Act. Today, every state must have an “Olmstead Plan” to ensure that supports meet the standard of the 1999 Supreme Court ruling.
Know your Rights

Human rights are rights you are entitled to merely because you are human.

The United Nations Declaration of Human Rights was written in 1948.

Not all human rights have laws that enforce them, but that doesn’t make those human rights less important.

We have a duty to defend other people and to protect their rights.

You cannot be put in prison without good reason.

Others cannot make copies of your work without permission.

The right to your own things.

The right to make up your own mind (self-determination).

The right to life and safety and to seek a safe place to be.

The right to adequate medical care.
Know your Rights:
Human Rights

The right to education
We are all born free and equal
The right to believe what you want to believe
No discrimination
No slavery
The right to work
Freedom to move. Your have rights no matter where your go
No torture no harm
Know your Rights

History of Disability Rights, Disability Laws, Human Rights, Bill of Rights for People with Disabilities, Center for Medicare and Medicaid Services Rules

The right to marry and have children

The right to privacy

The right to belong to a country

The right to rest and relax

The right to be considered innocent until proven guilty

The right to trial by laws that are the same for everyone

The right to food and shelter

No right to public assembly

Right to vote
Know your Rights: Human Rights

Bill of Rights for People with Disabilities

Rights of people with disabilities include, but are not limited to, the right to:

+ Be treated like everyone else.
+ Be the leader in making plans or decisions about your life.
+ Have a clean, safe, affordable place to live and a place to be alone.
+ Choose food for themselves and have access to healthy food.
+ Have transportation to go to places in the community they choose; including places for recreation and entertainment.
+ Choose a quality doctor when sick and to only take the medicine needed.
Know your Rights

History of Disability Rights, Disability Laws, Human Rights, Bill of Rights for People with Disabilities, Center for Medicare and Medicaid Services Rules

- Have assistance with walking, communicating, completing physical activities, or expressing feelings, when needed.
- Choose their own friends and spend time with them.
- Work, make money, and spend it as desired.
- Not be held down if not hurting yourself or others.
- Vote and learn about laws and your community.
- Have a family.
- Legal representation and protection of all legal rights.
- Be treated respectfully at all times as a competent citizen.
Know your Rights: Centers for Medicare and Medicaid Services

The Centers for Medicare & Medicaid Services (CMS) is the federal agency that oversees these two public health insurance programs. Medicare is the federal insurance program for people 65 years old and over and for people who have worked a good deal and acquired a disability that interferes with their employment. Medicaid is a state health insurance program for citizens who have not had substantial employment and for people living in poverty. In each state, Medicaid also provides community supports for individuals in jeopardy of institutionalization. Medicaid eligibility for health insurance and for community supports vary from state to state.

CMS must approve each state’s Medicaid program. In 2011, CMS introduced new standards that every state must meet in order to provide Home and Community Based Services (HCBS). States have until 2019 to fully implement these new standards (rules). The rules meant that HCBS support recipients have greater support to spend their day in the way they choose.

Tyshon Woods

Tyshon Woods served on one of the first Youth Leadership Project groups. Ty’s goal was to become a better advocate. He also wanted to develop skills that would help him transition from high school to adulthood. Tyshon has been recognized as advocate of the year by the ARC of New Jersey. He also received a leadership award from the ARC of Monmouth.

Tyshon says it’s good to be recognized, but he just wants to continue to grow as a leader and a person. With his busy schedule working, attending classes at Brookedale Community College and working toward his Black Belt in Karate. He still believes his best advocacy is yet to come.
Know your Rights
History of Disability Rights, Disability Laws, Human Rights, Bill of Rights for People with Disabilities, Center for Medicare and Medicaid Services Rules

Rules for people who receive supports through a Home and Community-Based Medicaid Waiver include the following:

Rules about my home:
I choose where and with whom I live. I come and go when I choose and have visitors when I want. I decide what and when I eat. I decorate my house, how I prefer. I have a rental agreement that gives me rights. I get around in my own home and staff asks before they come into my room. My staff talks to me in a respectful way and respects my privacy.

Rules about my person-centered plan:
I can lead and participate in my person-centered plan and invite the people I want to come. People at the meeting say positive things about me. If I don’t understand something, it is explained to me. People tell me about resources that can help me. I choose the services I want and staff that support me. I can make changes to my plan whenever I want.

Rules about where I live, work, and play:
I go to activities in my community and do things I enjoy during the day. I can choose a paid job working with people who do not have disabilities. I have my own bank account that I use when and how I want. I choose what I wear and how want to look. I can learn how to be more independent. I have private conversations with people when I desire.
Know your Rights: Guardianship

Definition: A guardian is a person charged with making decisions about the care for a person with an intellectual disability.

A guardian must be appointed by a court. The person with the disability does not have to agree to the ruling (although the court listens to the person's wishes).

Historically, people with intellectual disabilities have been placed under legal guardianship, losing the right to make their own choices about life issues such as where to live and whether to work, marry, or receive health care. PWD must protect their right to self-determination and should be assured it is not restricted or harmed by guardianships.

Voting

People have the right to vote, even if under guardianship. Only a judge can decide that someone is not competent to vote. No one else can bar people from voting. People with disabilities have the right to get help with voting and to decide who will help them vote. Help can be provided by a friend, family member, caregiver, or service provider.
Know your Rights: Supported Decision-Making

The current generation of people with disabilities is the first to grow up having their rights and opportunities protected and promoted by the Americans with Disabilities Act (ADA). There is growing recognition that using guardianships for decision-making can hinder or prevent inclusion, self-determination, and community integration in violation of the ADA and other federal law. Self-advocates can get assistance to prevent guardianships and conservatorships, and can get help to terminate or limit existing guardianships and conservatorships.

Supported Decision-Making (SDM), in contrast to guardianship, offers an opportunity for many adults with disabilities to make their own decisions, an effort that’s consistent with fundamental human and legal rights. SDM is a process in which adults who need assistance with decision-making receive the help they need and want in order to understand the situations and choices they face. This allows them to make life decisions for themselves without the necessity of full guardianship.
Citizenship

Citizen
Volunteering
Employment
Being Informed
Dignity of Risk
Voting
Citizenship

Introduction
Definition: a member of a community who has rights, privileges, and duties

A citizen is a person who participates in his or her community. Legal citizenship is determined by the government. Citizens have rights and are responsible for following community rules and laws. Citizens with disabilities have very important gifts to offer our communities. Our communities are better places because people with disabilities are part of them.
People with disabilities should have all the normal experiences that all citizens have. This means that people with disabilities should experience both the opportunities and responsibilities that the rest of society does.

**Opportunities and Responsibilities of Citizens with Disabilities**

- Have families of their own
- Pay taxes
- Go to restaurants and movies of their choosing
- Develop friendships and close relationships
- Tell their lawmakers the needs of their communities
- Participate in local recreational programs
- Practice in their local recreational programs
- Practice their religion in places which they choose to worship
- Take classes and enjoy hobbies
- Choose where and with whom they live
- Have careers in the field of their choosing and receive company benefits
- Vote for officials and laws
- Attend schools and universities
- Volunteer to make their communities better
Citizenship: **Volunteering**

Volunteering

All communities rely on their citizens to help each other and the community. These citizens are called volunteers. Volunteers choose which activities in the community they would like to support, and they choose when and how they help. People with disabilities are great volunteers. It is important to get paid for work so we can pay our bills, but volunteering is also very important.

**Reasons to Volunteer**

+ You will get satisfaction from helping others.
+ You will meet new people.
+ You will learn about needs in the community.
+ You will be informed about issues.
+ You will gain skills that help with employment.
+ You will be less focused on your own problems.
+ You will set a good example for others.

**Citizens with disabilities can relate to situations and issues that those without disabilities have no knowledge of.**

**Examples of Volunteering**

+ Helping in the nursery at church
+ Serving meals to the homeless
+ Tutoring children in after school programs
+ Being a companion for an elderly person
+ Collecting for a food drive
Employment

Paid employment is an important way for all citizens to contribute in their community. When people have employment they are able to pay taxes and are less reliant on government benefits. In addition, people who have paid jobs can afford nicer places to live and can buy more things. Almost every person who wants to work is capable of paid work.

A national movement called Employment First is centered on the idea that all citizens, including individuals with significant disabilities, are capable of full participation in integrated employment and community life.

Employment Supports

Paid employment for people with disabilities should be the first option. Supports like job coaching are in place to assist with employment. Today, many people with significant disabilities who want to work need greater supports, such as customized employment, to be successful.
Citizenship: Being Informed

Everyone has a right and a need to be aware of civic events and issues in order to be safe and happy in our homes and communities. This common information allows us to make decisions that help us be successful. Citizens with disabilities should be included in the communication about issues that affect them.

Reasons to stay informed

+ You will be able to talk to people about news.
+ You will make better voting decisions.
+ You will show others that you are a competent adult.
+ You will know how to solve problems.
+ You will know where you stand on issues.
+ You will stay connected to your community.
+ You will learn about needs in your community.
+ You will discover places to go and things to do.

Ways to Stay Informed

+ Watch or read the news
+ Use social media such as Facebook or Twitter.
+ Talk to family and friends about what they know.

Citizens with disabilities may find it harder to get information than those without disabilities and may need to ask for personal assistance or utilize technology.

Warning!!

Most of the news reports sad things that happen around the world. Everyone needs to find a balance of being informed without focusing too much on negative situations.
Dignity of Risk

**Definition:** People have the right to take risks, to have normal life experiences, and the right to fail while taking these risks.

**Tips:** Develop a personal support system that allows you to have full life experiences. Ask people in your support system to help you make the best decisions.

Just like citizens without disabilities, people with disabilities have the right to take reasonable risks. If people with disabilities are prevented from reaching their full potential because of fear, they are left to lives of regret instead of full, happy lives. Everyone must use good judgment to decide what a reasonable risk is.

**Examples of Reasonable Risk:**

- Crossing the street.
- Independently going to the mall.
- Trying out for a sporting team.
- Learning to drive.
- Cooking your own meals.
- Staying home alone.
Citizenship
Citizen, Volunteering, Employment, Being Informed, Dignity of Risk, Voting

Citizenship: Voting

What is Voting?

**Definition:** Voting is a way for everyone to participate in decision making by expressing their opinion or choice (either for or against).

Examples of Things People Vote for:

- Families might vote on where to eat or what movie to watch.
- People vote in contests for cutest dog or best singer on American Idol.
- Groups like churches and clubs vote to make decisions.
- Citizens vote for political candidates such as the president, governor or mayor.
- Citizens vote for laws, policies, and taxes.
Citizenship
Citizen, Volunteering, Employment, Being Informed, Dignity of Risk, Voting

Voter Requirements in the USA
+ Must be 18 years of age or older.
+ Must complete a voter registration form.
+ Must be a citizen of the USA.
+ Must have a photo ID.
+ You do not have to be able to read or write.
+ You can have an intellectual or a physical disability or a vision or hearing loss and still be a voter.

How to Register to Vote
Complete a New Jersey Mail-In Registration Form. You can find the registration forms a few different ways: Online at https://www.state.nj.us/state/elections/voting-information.html Mail your completed voter registration form to the address listed on the back of the form.
Citizenship: Voting
Help America Vote Act (HAVA)

+ A federal law that makes voting accessible.
+ Ensuring that everyone can vote privately and independently.
+ Ensures that states give people provisional ballots if there is a question about whether or not they can vote.
+ Creates statewide computerized voter lists.
+ Ensures that polling places are physically accessible.
+ Requires that states have accessible, working voting machines that are available along with poll workers who can help voters use them.

Voting Rights at Election Sites

+ You can bring someone you trust to help you vote.
+ You can ask a poll worker to help with the voting process.
+ They cannot tell you who to vote for or explain the issue to you.
+ You can get a new ballot if you make a mistake.
+ You can receive a provisional ballot if you are told that you can’t vote for some reason.
+ Anyone can use the accessible voting machines.
Voter Responsibilities

- Make sure you are registered to vote.
- Get a ride to your election site.
- Know the candidates and issues.
- Bring your photo ID or voter ID.
- Ask question if you need help voting.
- Be a role model and exercise your right to Vote.
- Help someone else learn how to vote.
- Inform poll workers if the site is not accessible or if the voting machine is not available so they can fix the issues.

Notify the New Jersey Disabilities Advocacy Program (NJDAP) and your local election officials about any issues at the polling site.
Citizenship: Voting

Ways to Learn About the Candidates and Issues

+ Talk with family and friends
+ Make a list of what is important to you, and check to see if the candidates share your ideas.
+ Find information in the news and on candidates' websites.
+ Attend public meetings like candidates' events, and watch TV debates and community forums on candidates and issues.
+ Keep up with information about elections and disability issues that is provided by your area's disability advocates or self-advocacy organizations.
My Vote

“They say I can’t vote. They say the decision is not mine. They say I don’t understand. I guess they think they are being kind. I wonder what they would say or think if they only knew.

That is when they call the President Our President, I want to call him mine too.

If I never get the chance to vote - pulling the lever, punching the card or writing his name down, I stay the same – dumb, misinformed, unchanged, un-empowered.

That is what this world expects me to be. But I want so much more.

I want to be the most educated, the most informed, the most totally changed, the most totally empowered person that I can be when I vote.

I can make a difference and then I can say with pride, Not yours, not theirs, but my President because I put him there.”

Jeff Ridgeway, Advocate
How Change Happens

- Cultural Change
- Official Change
- Examples of Change
- How a Bill Becomes a Law
How Change Happens: Introduction

History demonstrates the progress made over the centuries with people with disabilities (PWD) becoming valued citizens.

How has this progress been achieved?

+ Improvements in science and medicine allowed PWD to live longer and more productive lives.
+ Religious and cultural views evolved through the ages to dispel myths that fueled prejudice against PWD.
+ Societies became more organized and inclusive of all human “imperfections.”
+ Civilizations have developed rules/laws that require people to change, such as desegregation rules requiring public schools to enroll students by geographic regions, not their ethnicity. When new rules are made and enforced, change takes place. It often takes generations for the rules to be implemented universally.
How Change Happens
Cultural Change, Official Change, Examples of Change, How a Bill Becomes a Law

Cultural Change

One most powerful ways that public opinion (what most people think) changes is through personal interactions and experiences. For example, many people don’t think that people with disabilities are capable of working, but when they see a PWD working at a grocery store, they change their minds. Anytime that someone with a disability is seen by the public as an active citizen (learning, working, and living), they are changing people’s opinion of what a person with a disability can do. When most people believe that PWD should be treated like everyone else, then PWD will have real jobs, live independently, get married, and do all the things that other people do.

Ways to Change the Culture

+ Standing up for your rights
+ Being a good role model
+ Having a job in the community
+ Having friends with and without disabilities
+ Going to community events like movies, meetings, and celebrations
+ Voting in public elections
+ Being the best you can be
How Change Happens: Official Change

Official change is a response to cultural change and advocacy. Public opinion may vary from one region to another. Once popular opinion in favor of change is widespread, then advocacy is required for new laws to be introduced and passed. Once a law is changed it can take years for the law to be enforced. It often takes a lawsuit before the law is actually enforced.

Ways to advocate for official change

+ Writing letters to legislators or policy makers
+ Speaking to legislator’s policy makers in person
+ Getting petition signatures
+ Voting for legislators who support you
+ Planning and going to public rallies and meetings
+ Implement a media campaign advertisement
+ Civil disobedience (creating public awareness) generations for the rules to be implemented universally

Policy Change

Some changes occur without laws. They only require a group or organization to change their policies. State agency regulations and policies in education, mental health, and rehabilitation can be changed without changes in to the law.
**Examples of Change**

**Because of Katie, Children with Severe Disabilities Can Live at Home**

At 5 months of age, a disease called encephalitis left Katie Beckett spending most of her early years in the hospital. When she was 3, doctors cleared her to go home with proper supports – she still needed to be on a respirator for twelve hours a day. Her insurance had been exhausted. Medicaid refused to pay for her care unless it was done in the hospital – even though treatment could be administered at home at one-sixth of the cost.

Katie Beckett’s mother tirelessly advocated. In 1981 she succeeded in bringing Katie’s plight to the attention of President Ronald Reagan. Reagan acknowledged the illogic of “hidebound regulations” and waived the rule so Katie could go home. The following year, Reagan signed what became known as the “Katie Beckett Waiver” so all disabled children could receive Medicaid supports.

Because of the legislation that bears her name, hundreds of thousands of children are able to be at home with their families instead of being institutionalized.
How Change Happens: HOW A BILL BECOMES A LAW

The U.S. Congress, America’s lawmaking body, is made up of two houses: The Senate and the House of Representatives. In a typical year, U.S. Senators and Representatives introduce about 5,000 bills, or proposed laws. But only about 150 become laws. Read the diagram to see how laws are made. A bill must be passed by one house of Congress before it can go to the other for action. This is the same process for New Jersey lawmaking.
How Change Happens
Cultural Change, Official Change, Examples of Change, How a Bill Becomes a Law

Congress

Bill is introduced in the Senate

Bill is introduced in the House of Representatives

Bill is passed on to a Senate Committee and subcommittee for hearings, debate, and changes.

Bill is passed on to a House committee for hearings, debate, and changes.

House and Senate vote on final passage; if compromise bill passes both houses, it goes to the President.

If House passes bill, it goes to the Senate. (If both Senate and House pass bill, it goes to a House Senate joint committee.)

If committee passes bill, it goes to the House. (If both House and Senate pass bill, it goes to a joint committee.)

President can sign bill into law or veto (reject) it. Congress can override veto by a two thirds majority vote of both houses. Bill then becomes a law.

Congress Senate joining committee settles any difference in the bills; it sends this compromise bill back to both houses.

House and Senate vote on final passage; if compromise bill passes both houses, it goes to the President.

If House passes bill, it goes to the Senate. (If both Senate and House pass bill, it goes to a House Senate joint committee.)
Glossary of Terms

**Accessible** – Easy to approach, reach, enter, speak with, or use for someone with a disability

**Accountability** – To accept responsibility or to account for one’s actions

**Advocate** – A person who publicly supports or recommends a particular cause or policy

**Aggressive** – Getting what you want through force or confrontation

**Assertiveness** – Communicate courage and standing up for yourself to show that you want to be treated fairly at the same time, remaining respectful of others

**Body language** – Communication through physical behaviors, such as facial expressions, body posture, gestures, eye movement, touch and the use of space

**Citizenship** – A member of a community who has rights, privileges, and duties

**Civil Rights** – Legal rights determined by a country’s constitution

**Dignity of Risk** – People have the right to take risks, to have normal life experiences, and the right to fail in taking these risks

**Grooming** – To tend carefully to one’s person and dress
Glossary

Guardianship – When another person has the legal authority to make decisions on behalf of a person with a disability

Human Rights – Rights that all people have simply because they are human

Leadership – A person who guides or inspires others

Networking – Building connections with other individuals or groups

Passive – Not standing up for yourself and letting others take advantage of you

Professionalism – Having qualities which communicate that you are worthy of respect

Segregation – the separation of groups of people based on the differences between them (i.e. race, beliefs, or ability)

Self-Advocacy – Speaking up for yourself to get your needs and wants met

Self-Determination – The concept that all individuals have the right to direct their own lives

Time Management – The ability to use one’s time effectively or productively

Voting – A way for everyone to participate in decision making by expressing their opinion or choice (either for or against)
Resources

Information on Supported Decision Making
www.jennyhatchjusticeproject.org
www.supporteddecisionmaking.org

National Association for the Dually Diagnosed
www.thenadd.org

New Jersey Council on Developmental Disabilities
www.njcdd.org

New Jersey Self-Advocacy Project
www.njselfadvocacyproject.org

People with Disabilities: Living Healthy from the Centers for Disease Control and Prevention
www.cdc.gov/ncbddd/disbailityandhealthy

Rooted in Rights (updates on disability rights)
www.rootedinrights.org

Self-Advocacy Online
www.selfadvocacyonline.org

Self-Advocates Becoming Empowered (SABE)
www.youtube.com/channel/UCBxZhch5AWPUNA3ufQy5JzpQ

The Disability Scoop
www.disabiltysoop.com

The Riot Newsletter
www.theriotrocks.org
PEOPLE FIRST NJ
Educate · Empower · Inspire