

Advocacy Kit for Adults with Disabilities

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With thanks to the following editors and reviewers:

Bev Harp, Morgan Turner, Ryan Riley, Erin Tiemeier, and the
Commonwealth Council on Developmental Disabilities' Partners in
Policymaking®.



[alt text: image of person with megaphone]

Advocacy Kit for Adults with Disabilities

You took an important step in learning to represent yourself. You opened this kit! Advocacy (say: *add-voh-ka-cee*) means supporting a cause (Webster, 2019), which in this case is YOU! Your needs are important. This kit can help you learn skills to meet your needs, whether you are new to advocacy or want to practice meeting your needs. The kit includes 5 sections with resources and practical activities. You can also go to a library or ask a friend for more ideas.

The purposes of this kit are:

- to help you, as an adult with an intellectual or other disability, learn ways to meet your physical, emotional, and medical needs.
- to set goals and find resources to help you meet your goals.

Having the information that you need will help you take action. Then, you can make great things happen! The kit is not meant to be done in one day. **Take your time; learn from it; work at your own pace.**

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[alt text: Picture of and quote from Helen Keller: “I long to accomplish a great and noble task, but it is my chief duty to accomplish small tasks as if they were great and noble.”]

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[alt text: image of road leading to mountains and open sky]

Section 1: What is advocacy for adults with disabilities?

Let's talk about how advocacy and discrimination are described and related to each other. Advocacy is about stating your needs, especially when you are being treated unfairly or discriminated against. More on discrimination soon!

What is Advocacy?

Advocacy is learning to stand up or speak out for our needs.

The Alliance for Advocacy (2019) says that advocacy includes:

- Telling your story
- Organizing your support
- Educating leaders
- Educating the public
- Voting for issues that affect you
- Attending meetings with persons like you
- Reaching out to others when you need help and friendship



[alt text: image of person with megaphone]

There are many different ways to advocate.

1. You can **speak up** when you have a need. You might say one of the following:

- ✓ “I don’t agree with this report.”
- ✓ “This isn’t fair to me.”
- ✓ “There should be a ramp so everyone can get in this building.”
- ✓ “Please don’t lean on my wheelchair.”
- ✓ “Please don’t pet my service animal. It will distract them.”

2. You can **make videos**, podcasts, or blogs for social media that tell your needs. For example, see the video below.



[Research & Training Center on Independent Living: Stoplights Don't Stop Us!](https://www.youtube.com/watch?v=BQEf-y08-To&feature=youtu.be)

<https://www.youtube.com/watch?v=BQEf-y08-To&feature=youtu.be>

3. You can **share facts** and numbers. Some people tell about their needs with facts. One example is during a job interview. You might share these facts. People with disabilities:

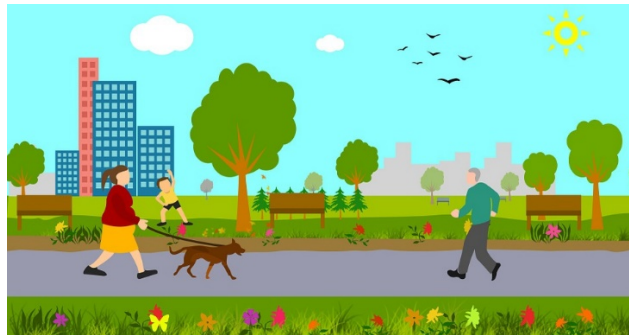
- have equal or better job performance ratings,
- stay at their jobs longer, and
- do not miss work often (Assistive Technology Center, 2019).



[alt text: image of person with newspaper leaning against the word facts]

4. You can advocate through **positive or negative stories**. Here's an example.

The Park and Parking Lot Puzzle



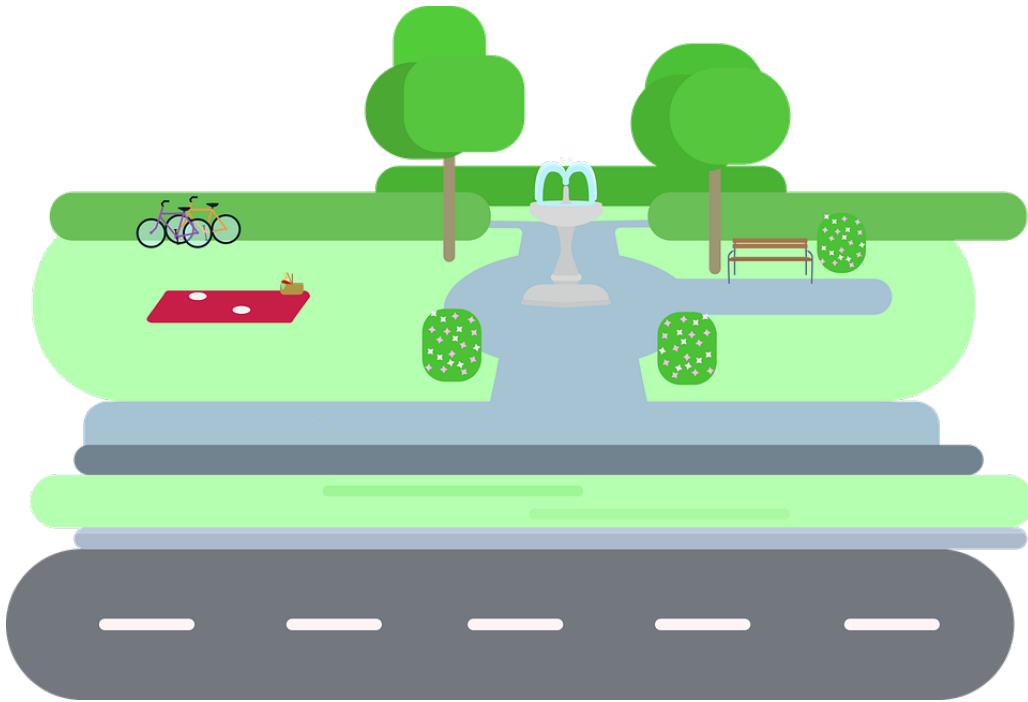
[alt text: image with persons walking on a sidewalk next to a park]

Example 1:

Picture a park that you love in your town. There is no parking lot nearby. You can't get in to the park with your wheelchair as there are no curb cuts. You must park up the street and cross busy roads to get to the park. You want a parking lot near the park with curb cuts and sidewalks. You call your local mayor and tell why it is needed:

- 1) You can't get safely from your car to the park.
- 2) You can't get to the park in your wheelchair without help.
- 3) You can't get from the parking lot to the park without help.

You want a new parking lot. The current lot is not safe to use.



[alt text: image of road next to a park]

Example 2:

Picture yourself using a park that you love that does have a parking lot nearby. Your town wants to replace the parking lot with a store. You use this parking lot and want to keep it. You call your case manager and ask them to contact the mayor. You ask your coordinator to explain that the parking lot is needed:

- 1) So that you can go from your car to the park without crossing streets.
- 2) So that you get to the park using sidewalks from the parking lot.
- 3) So that you can get to sidewalks through curb cuts from the lot.

You want to keep the current parking lot. It allows you get to the park safely.



[alt text: image of 6 persons holding hands, including child and person in wheelchair]

What is Discrimination?

Now let's talk about discrimination. It is "the practice of unfairly treating a person or group of people differently from other people or groups of people (Webster, 2019)." When you tell your mayor that your busses need wheelchair lifts, you are **advocating** for people with disabilities. If the mayor won't help people with disabilities but does help people who do not have a disability, then the mayor is **discriminating**.

There are fun resources that can help you address discrimination. Disability Don't Mean Can't (Project CHEER, 2019) is a comic book that can be ordered at <https://www.wellness4ky.org/ddmc-comic/>.

What does advocacy mean to you?

Think about what you just read and what you know. There are no wrong answers! What does advocacy mean to you? Is it:

- ~About change?
- ~About a better life?
- ~About finding people who have needs like yours?

List your ideas here.



[alt text: image of office building]

Did You Know?

In 2008, some families and a young lady named Michelle P. worked with the Office of Protection & Advocacy to advocate for more services. They wanted more access to Medicaid for people with disabilities. People were waiting for years for Medicaid services. Thanks to this advocacy, the Michelle P. Medicaid Waiver was created. People with disabilities can now receive personal care, community supports, respite, and day training through Medicaid. The Waiver program has been so popular that people are again waiting for services 😊 You could advocate for another Waiver to increase Medicaid services!

Section 2: Identify Your Strengths and Needs

Why is it important to know your strengths and needs? So that YOU can decide how to be a better advocate.



[alt text: image of person lifting dumbbell]

What are your strengths?

Think about what you do well. Are you:

- ~Good at making new friends?
- ~Good at writing?
- ~Good at using social media like Facebook or Twitter?
- ~Good at public speaking?
- ~Good at using the internet?

Watch this video on finding your strengths.

https://www.youtube.com/watch?v=s_30jf4Zmlc

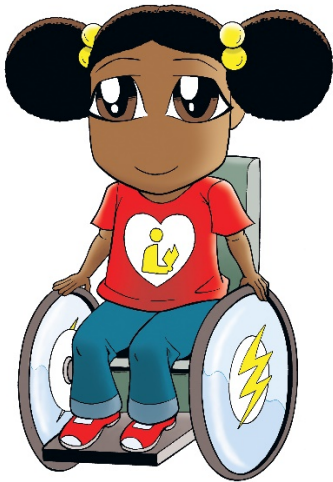
List your strengths here. It's okay to have many. We're all unique!

Did you know?

Gallaudet University was the first college for students who are hearing impaired. Its students held a week-long protest. As a result, the college hired a President who was deaf (USA Today, 2018). To learn more about Gallaudet, visit:

<http://www.gallaudet.edu/about/history-and-traditions>

Let's practice finding your strengths. Meet Tera.



[alt text: image of girl with pig tails in wheelchair with lightning bolts on wheels]

Like all of us, Tera does some things well. And, she needs help with others. She needs a bus with wheelchair lifts so that she can go see friends. Let's see what she does well. Where does she need help?

- Does well
 - ✓ Moving in her wheelchair herself
 - ✓ Making friends
 - ✓ Making speeches
- Needs help
 - ✓ Writing letters
 - ✓ Driving a car
 - ✓ Using Facebook



[alt text: image of 3 heads, with 2 gears in each head]

Pop Quiz!

To ask her town to have sidewalks and curb cuts, which should Tera do:

- a) Write a letter?
- b) Make a Facebook post?
- c) Give a speech?

Tera could write a letter. But she's not good at it.

Tera could write a Facebook post. But she doesn't know how.

The Answer? C. Give a speech! Correct! Tera is good at saying what she needs. She can give a speech that a friend helps her write.



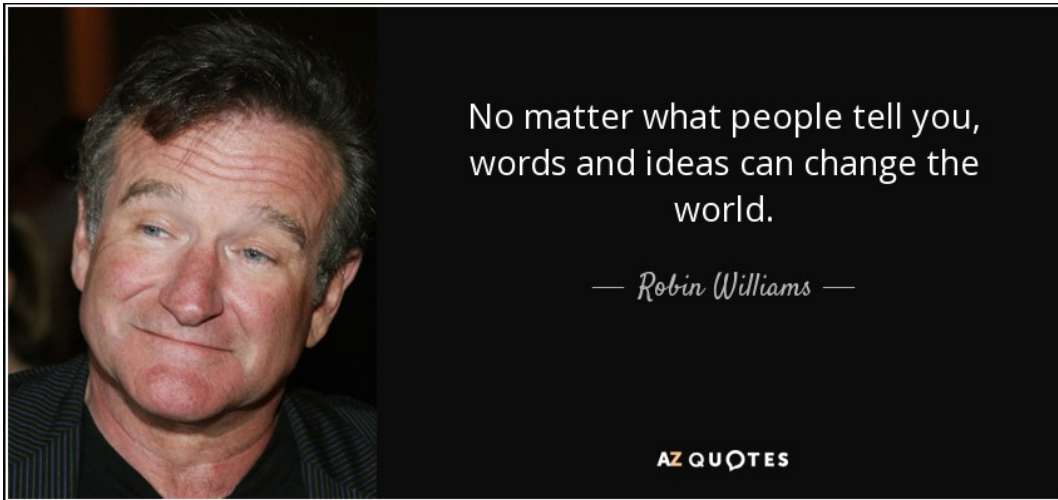
What If My Goal Is to Be Better at Something?

[alt text: image of open book]

You may want to get better at something to reach a goal. You can set one goal to help reach a different one!

- Do you want to give a speech but you're afraid to talk in public?
- Do you want to learn about computers so you can talk online?
- Do you want to get better at writing letters?
- Do you want to read more?

Think about something you want to do better. List it here. It's okay to have more than one!



[alt text: image of Robin Williams and quote: “No matter what people tell you, words and ideas can change the world.”]

Now you know what you do well. Let’s talk about what you need. Think about your life today.

- Do you need help living on your own?
- Do you need to learn about a Medicaid Waiver?
- Do you need a way to talk with people at the park?

You may have a few needs. It’s okay to have many! List them here.



[alt text: 4 images, including children listening to a book being read, a stack of 3 books, a person guiding another person in a wheelchair, and a sign for guide dogs]

Section 3: Set Goals

Now you know what you do well and what you need. Let's set a goal.

Setting Goals

What are goals? Why do they matter? Goals are something you are trying to do (Webster, 2019).

- They help you decide what you want.
- They help you change.
- They help you improve.
- They help you do your best.



[alt text: image of arrow in center of target]

What Makes a Good Goal?

Remember the word **SMART** when you choose a goal. What does **SMART** stand for with goals? Let's look at the first letter in each word. Goals need to be **S**pecific, **M**easurable, **A**ttainable, **R**elevant, and **T**imely.

- First, select a goal that has a **S**pecific and clear purpose.
- Be sure your goal can be **M**easured, so that you can know it is met.
- Your goal needs to be **R**elevant to you. It needs to matter to you!

- And, set a goal that you can do fairly soon- that is **Timely**. In that way, you won't get discouraged.



[alt text: image of SMART goals, each with a letter and a banner below it, including S for specific; M for measurable; A for attainable; R for relevant, and T for time based.]

Let's write a SMART goal for practice.



[alt text: image of girl with dark hair]

This is Kim. She is an adult with an intellectual and motor disability. She loves to swim! She wants to go to the pool in the summer. She cannot get to the pool because there are no public busses with lifts in her area. Kim wants to ask her town for busses with wheelchair lifts to come to her road.

Let's help Kim pick a goal. Which one is SMART?

Goal 1: I will call my case manager for help.

Goal 2: I will ask my case manager to call the head of transportation in my town. I will ask her to call next week. She will request busses with lifts to stop on my road within a month.

Which of these goals is a SMART goal for Kim?

If you chose Goal 2... you're correct! It is a SMART Goal.

- ❖ Specific – Ask case manager to call head of transportation
- ❖ Measurable – Call next week
- ❖ Attainable – Ask for busses to come to my road
- ❖ Relevant – Ask for busses with lifts
- ❖ Time-based – Within a month



[alt text: image of staircase with letter above and word below each step, including S for specific, M for measurable, A for achievable, R for realistic, and T for timely]

Want to Dig Deeper?

Watch these videos about goals.

<https://www.youtube.com/watch?v=8cCiqbSJ9fg>

<https://www.youtube.com/watch?v=XrsERz952qM&t=4s>

Did You Know?

Aaron “Wheelz” Fotheringham was the first person to do a backflip in a wheelchair. He set small goals for himself and worked hard. To learn more about him, visit his website: <https://www.aaronfotheringham.com/>

How Do I Set Advocacy Goals?

Just do it☺ Advocacy goals are no different than other goals you set.

It’s time to set an advocacy goal. You know what advocacy is. You know what you do well and what you need.

Set one goal for now. Make it SMART.

My Goal:

I want to:

_____ by _____ (specific date).



[alt text: image of hand with thumb up]

What If I Have Trouble with My Goal?

That's okay! We all struggle with goals at times. Below are some ideas to help. The key is: Don't give up!

People to Help You:

The easiest part about goals may be setting them. Making them happen can be harder! Don't worry. Let's think about *who* can help you. They may be friends, family, case workers, or aides. This can be a chance to make a new friend!

List people to help reach your goals. List as many as you can!

_____	_____
_____	_____
_____	_____

What May Get in the Way?

You may have a great goal. Sometimes, things get in the way of meeting a goal. For example:

- ✓ Do you have a computer if your goal is to speak up online?
- ✓ Can you get to the library to find resources?
- ✓ Do you have the computer program to make a video to tell your story?

Part of advocacy is saying your need. Another part is finding some answers! Fill in the table below. Write your goal at the top. Write some things that might get in the way. Then, list some possible answers. One example is shown here. Ask for help filling it in if needed.

Goal: Obtain services from Printing House for the Blind	
Possible Problem	Possible Answers
1. Not registered with American Printing House for the Blind	Ask case manager to complete my registration. Call Printing House for information.
2. Can't locate doctor's verification of vision loss.	Contact doctor's office for medical records. Call case manager to ask for records.

My goal:	
Possible Problem	Possible Answers
1.	
2.	
3.	

Did You Know?

Supported decision making is a way to describe how we all make decisions. We go to friends, family members, and other adults to help make decisions. Supported decision making may replace legal guardianship. It can be used in any part of your life. To learn more, see

<http://www.supporteddecisionmaking.org/> and www.mychoiceky.org.

Let's consider another example for setting goals.

Meet Jim



[alt text: image of man in wheelchair]

This is Jim. He wants to move out of his childhood home. Jim’s family wants him to stay. He wants to live by himself! He is excited to live on his own. He is his own guardian and uses a wheelchair. His current family home is accessible. He has the Supports for Community Living Waiver which helps him with his needs. What are some possible problems? What are some possible solutions? List them here:

Goal: Jim wants to live by himself	
Possible Problems	Possible Answers
1.	
2.	
3.	

Did you think of these ideas?


1. Cost: Jim must be able to pay rent each month. Or, he can get a roommate. Or he could live in a group home. He can ask his case worker and friends for help. He can find help with budgeting here:

<https://fliconline.org/documents/patffinancialeducationbooklet-final.pdf>

2. Location: Jim wants to live close to work and a park. He can ask friends and co-workers for ideas on places to live.
3. Physical needs: Jim needs a home with a ramp or elevator if it's not on the first floor. The doorways need to fit his wheelchair. The shower needs rails and a chair. He can ask his case worker for help making his new home fit his needs.
4. Family support: **Jim is his own guardian. He has the right to live on his own.** Sometimes that's hard for families to accept. Jim gets help with his personal needs through his waiver. His family can come to his new place.

Jim can do this! He can make it happen!


He can use the Waiver to help.



“Independent living is not doing things by yourself. It is being in control of how things are done.”

— Judy Heumann
pioneering disability rights movement leader

Women's History Month 



[alt text: image of Judy Heumann with quote: “Independent living is not doing things by yourself. It is being in control of how things are done.”]

Did You Know?

Fight for what's right! Watch this video by University of New South Wales for great stories about advocacy: <https://www.futurelearn.com/courses/working-with-disability/0/steps/19706>

Section 4: Practice with Activities



[alt text: image of open book]

Now you have learned about advocacy. Let's put your new skills to work! Here, you will find activities to put **action** into your advocacy.

You can practice through 7 activities:

- 1: Find a Helpful Quote
- 2: Have a History Lesson!
- 3: Identify Important People
- 4: Who is Judy Heumann?
- 5: Identify SMART Goals
- 6: Consider an Example

Activity 1: Find a Helpful Quote

Use the web, a book, or someone you know for this activity. Find a quote that speaks to YOU about advocacy. Take your time. Write it below. Not sure where to start? Consider your favorite author or a person you admire. Look up quotes by them. It doesn't have to be just one sentence. It could be 3 or 5!

Author of quote: _____

Activity 2: Have a History Lesson!

Step 1: Using the web or a book, look up when the Americans with Disabilities Act (ADA) was *signed into law*. This Act helped Americans get access to things like public bathrooms and buildings. List here: _____.



[alt text: image of building and scroll with writing]

Step 2: Let's go one step further. What types of access are there where you live? Are there curb cut-outs? Is there handicap parking where you need it? Are there accessible bathrooms at the park? List one type of access you have here.



www.shutterstock.com · 1195388785

[alt text: image of child using cane]

Activity 3: Identify Important People

Earlier in this kit, you listed some needs in your life. They may include better access in your town, getting the Waiver, or finding friends. Knowing **who** to contact helps you meet your needs. Based on **your** needs, fill out the names of people who can help you.

Your Government:

Mayor: _____

Governor: _____

Your Local Representative: _____

Your Case Worker:

Case Worker: _____

Agency Name: _____

Don't see a person to meet your needs? Here is a blank. Fill it with your needs!

Agency:

Your State Contact _____

Your Local Contact _____



Want to Dig Deeper?

For more information about advocacy in Kentucky, contact KY Protection and Advocacy. Their website is <http://www.kypa.net/>.



[alt text: image of Judy Heumann]

Activity 4: Who is Judy Heumann?

Look up **Judy Heumann** using a book or the web. See

https://en.wikipedia.org/wiki/Judith_Heumann. She is a great leader in the field of advocacy. Have fun filling in the blanks!

1. Ms. Heumann gets around in a _____.
2. She is famous for being a disability rights' _____. Hint: It's what you are learning here.
3. Ms. Heumann wanted to be a _____ when she was growing up. She had to work hard because of *discrimination*.

See answers at end of this section.

Want to Dig Deeper?

Watch this Ted Talk video to hear Judy talk about disability rights.

<https://www.youtube.com/watch?v=ABFpTRIJUuc>

Activity 5: Identify SMART Goals



[alt text: image of 3 heads with 2 gears in each]

Circle the SMART Goals. **Cross out** the goals that aren't SMART.

Remember: **S**pecific, **M**easurable, **A**ttainable, **R**elevant, **T**imely.

The first non-SMART goal is crossed out as an example. It's not specific. It can't be measured. The second goal is SMART. It is specific, measurable, attainable, relevant, timely.

a. ~~I will eat a banana for a snack to get healthy.~~

b. I will eat a piece of fruit for a snack instead of a doughnut for two weeks to begin my diet.

Practice with these goals. Which is SMART?

a. I will post a Facebook message.

b. I will post two short Facebook messages. I will ask a friend to help me write the message. I will send the messages once a week for 2 weeks.

Which is the SMART goal?

If you said **b**, you are correct. It is specific and can be measured. It can be reached. It is relevant and timely. Answer **a** is not specific or timely.

Let's try one more. Which is the SMART goal?

a. I will write a letter to the Governor next week. I will ask for his support on a new law for access to buildings. I will ask him to vote on the law next month.

b. I will write to the Governor tonight.

If you said **a**, you are correct. It is specific. It can be measured. It can be reached. It is relevant and timely. Answer **b** is only specific and timely.

Congratulations! You are learning a new skill. You are writing SMART goals!

Activity 6: Consider an Example

Ted was accepted to a local college. He wants to become a car mechanic. He plans to get a 2-year degree. He knows he gets upset when he is stressed. He doesn't know how to register for classes.

- What is one of Ted's needs?

- Who could Ted contact for help with registering?

- Where can Ted find help for his learning needs at college?

- Can you relate to Ted's needs? If yes, tell how.



[alt text: image of the words ready, set, go with exclamation point]

Congratulations! You listed your needs. You set goals and practiced advocating. Use what you've learned. Work towards your goals. Don't give up!

Answers to Activity 4: 1. Wheelchair; 2. Advocate; 3. Teacher.



[alt text: image of raised hand with words
“You’ve got the power!”]

Section 5: Resources and References

BOOKS

- ★ *Advocacy: Championing Ideas and Influencing Others* by John Augustine Daly
- ★ *Disability Don't Mean Can't #2: Busting Down Barriers* by Project CHEER.
<https://www.hdibookstore.org/product/project-cheer-comic-book/>
- ★ *The Dream-Maker's Magic* by Sharon Shinn
- ★ *The Seeing Stick* by Jane Yolen
- ★ *What Do You Do with an Idea?* by Kobi Yamada
- ★ *My Brother Charlie* by H. R. and R. E. Peete
- ★ *Wrightslaw—From Emotions to Advocacy: The Special Education Survival Guide, 2nd Ed.*
- ★ *Wrightslaw—Special Education Law, 2nd Ed.*
- ★ *Self-Advocacy: The Ultimate Teen Guide* by Cheryl Tuttle & JoAnn A. Silva
- ★ *Self-Advocacy Skills for Students with Learning Disabilities: Making it Happen in College and Beyond* by Henry B. Reiff
- ★ *A Handbook for Self-Determined Living* by Scott Michael Robertson, PhD
- ★ *Nothing About Us Without Us: Disability Oppression and Empowerment* by James I. Charlton

WEBSITES: for more in-depth resources

- ✓ Alliance for Justice (2019). What is advocacy? Available from
https://mffh.org/wordpress/wp-content/uploads/2016/04/AFJ_what-is-advocacy.pdf
- ✓ AUCD's Diversity and Inclusion Toolkit implementdiversity.tools/lifecoursetools.com/
- ✓ Kentucky Works: kentuckyworks.org/kentucky-works-youth/i-want-to-know-about-my-rights-as-a-youth-with-a-disability/

- ✓ My Choice Kentucky <http://www.mychoiceky.org/>
- ✓ National Resource Center on Supported Decision-Making <http://www.supporteddecisionmaking.org/>
- ✓ Taking Charge of My Health Care Toolkit <https://www.ohsu.edu/oregon-office-on-disability-and-health/taking-charge-my-health-care>
- ✓ The Kidz Club: thekidzclub.com/resources-kentucky-residents/

HANDOUTS, PUBLICATIONS, RESOURCE MANUALS:

- ★ *Cents and Sensibility*. (2013). From PA Assistive Technology Foundation. <https://fliconline.org/documents/patffinancialeducationbooklet-final.pdf>
- ★ *Glossary of Disability Terms and Acronyms* hdi.uky.edu/wp-content/uploads/2018/01/Acronyms-within-the-Disability-Field.pdf
- Human Development Institute's *Kentucky Disability Resource Manual: A Handbook of Program Descriptions, Eligibility Criteria, and Contact Information* <https://resources.hdiuky.org/>
- ★ *Those of Us disLabeled: A Guide to Awareness and Understanding* <http://www2.ca.uky.edu/anr/Agrability/PDF/dislab2000.pdf>

REFERENCES

- ACT Alliance. (2014, November 27). Inclusion of people with disabilities [Video file]. Retrieved from [youtube.com/watch?v=rjluLV1F-U](https://www.youtube.com/watch?v=rjluLV1F-U)
- Assistive Technology Center (2019). Top 10 reasons to hire people with disabilities. Retrieved from <https://www.assistivetechcenter.org/blog/top-10-reasons-hire-people-disabilities>
- Bramanti, A. (2016, April 5). The Disability Rights Movement [Video file]. Retrieved from [youtube.com/watch?v=bE0ta93FuKQ](https://www.youtube.com/watch?v=bE0ta93FuKQ)
- CartoonStudio. (2013, January 14). One-step-at-a-time goal achieving cartoon doodle video [Video file]. Retrieved from [youtube.com/watch?v=8cCiqbSJ9fg](https://www.youtube.com/watch?v=8cCiqbSJ9fg)
- Disability Advocacy Network. (2019). Advocacy. Retrieved from <https://www.pinterest.com/Advocacynetwork/>
- Efficientlyeffective. (2013, April 4). Personal Mastery – Find Your Strengths [Video file]. Retrieved from https://www.youtube.com/watch?v=s_30jf4Zmlc
- FutureLearn. (n.d.). Fighting for what's right - Disability and a Good Life: Working with Disability - UNSW Sydney. Retrieved from futurelearn.com/courses/working-with-disability/0/steps/19706
- Helen Keller Quotes. (n.d.). BrainyQuote.com. Retrieved February 26, 2018, from BrainyQuote Website: brainyquote.com/quotes/helen_keller_114884

- Ellet, K. (2017). SMART Goals- What's the Big Deal? Retrieved from <https://www.hire-profile.com/article/smart-goals-whats-big-deal/>
- U.S. Department of Education. (2000). Judith E. Heumann [Photograph].
- Rooted in Rights. (2015). Disability rights are human rights: Rooted in Rights Explains [Video file]. Retrieved from <https://www.youtube.com/watch?v=lhFu8R8lsxc>
- RTCIL (2017, October 5). Stoplights Don't Stop Us! [Video file]. Retrieved from <youtube.com/watch?v=BQEf-y08-To&feature=youtu.be>
- USA Today. (2018). Gallaudet eyes more progress for deaf community 30 years after "Deaf President Now" protest. Retrieved from <https://www.usatoday.com/story/news/nation/2018/04/03/gallaudet-deaf-president-now-30-anniversary/464611002/>
- Webster Online Dictionary. (2019). Advocacy, Disability, Goal. Retrieved at <http://www.learnersdictionary.com/definition/advocacy;>
<http://www.learnersdictionary.com/definition/discrimination>
<http://learnersdictionary.com/definition/goal>
- Yetter, D. (2016, November 19). Michelle P. lawsuit has helped thousands in KY. *Courier Journal*. Retrieved from <https://www.courier-journal.com/story/news/politics/2016/11/19/michelle-p-lawsuit-has-helped-thousands-ky/93916244/>