



Applied  
Self-Direction

# Disabling Ableism: Tips for Partnering With Disabled People

# Who Am I?

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- Works for Applied Self-Direction as a Senior Consultant
- Owns [Empowering U](#), a business that helps people get the most out of their services, so they can get the most out of their lives
- Has Spinal Muscular Atrophy and manages her own care since 1995
- Helped people self-direct their lives as an IRIS Consultant for 8 years
- Holds degrees in Communication, Marketing and Human Resources



# About this Webinar

- This presentation is geared toward support brokers but applicable to anyone
- Many different kinds of disabilities and experiences, it's not possible to fully represent everyone's perspective
- This training is a compilation of my own experiences as well as numerous discussions with others who have different disabilities
- As an organization, ASD focuses on self-direction, so we are talking about these topics in the context of support brokers interacting with clients, but the basic principles will translate even if you aren't directly involved in self-direction



# Agenda

- The Basics
- Importance of Language
- Common Mistakes
- Tips for Successful Communication
- Additional Resources
- Time for Q&A



# For Starters



[\(15\) Questions To Stop Asking People In Wheelchairs | Disability Awareness Month | Freeform - YouTube](#)



# The Basics



# Basics of Ableism

- Discrimination and social prejudice against people with physical or mental disabilities [Ableism - Wikipedia](#)
- Characterizes people as they are defined by their disabilities and it also classifies disabled people as people who are inferior to non-disabled people [Ableism - Wikipedia](#)
- On this basis, people are assigned or denied certain perceived abilities or skills [Ableism - Wikipedia](#)
- For example:
  - ❑ Disabled people are helpless and need non-disabled people to help them
  - ❑ Disabled people need protecting
  - ❑ If a person doesn't use words to communicate, they are less intelligent or have nothing to say



# Self-Direction in LTSS

## Long-Term Services and Supports (LTSS)





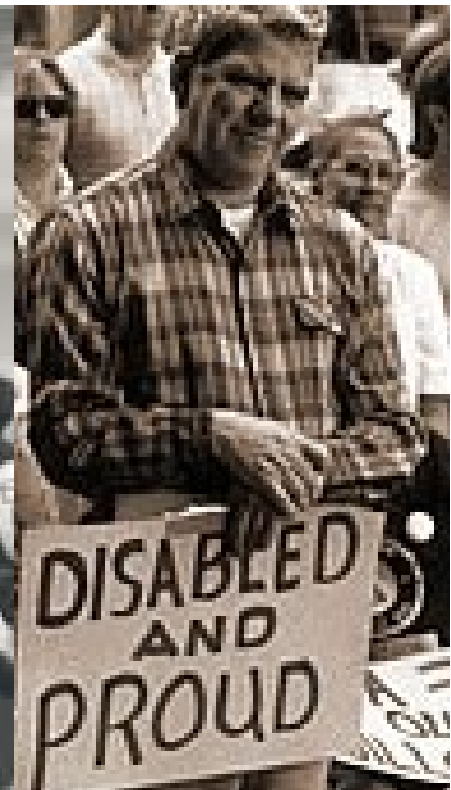
# Prior to the ADA and Self-Direction

- Disabled people treated as less than human
- If family couldn't take care of a person, put in institutions
- Families encouraged to put people in institutions
- Locked away, chained to beds, left naked, soiling themselves
- Seen as scary or “possessed by the devil”
- Segregated classrooms
- Ok to say: “I am not hiring you, because you are disabled”
- Ok to not allow people in wheelchairs or with service dogs into an establishment
- No transportation
- No curb cuts



# Independent Living Movement

- Late 1970s
  - All human life has value
  - Every human being should have meaningful options and make choices pertaining to issues that affect their lives



# Benefits of Self-Direction

- Self-directing participants are up to 90% more likely to be very satisfied with how they lead their lives
- Self-direction significantly reduced unmet personal care needs
- Primary caregivers were significantly more satisfied with their lives in general
- Self-direction did not result in the increased misuse of Medicaid funds or abuse of participants
  - ❑ Fraud does not occur at greater rates than in traditional home and community-based services (HCBS); 0.02% from self-direction [untitled \(nih.gov\)](#)
  - ❑ Financial Management Services (FMS) entities play a crucial role in preventing and detecting fraud in self-direction programs [Participant Direction Handbook.pdf \(appliedselfdirection.com\)](#)



# The Importance of Language



# The Power of Language

**Largest  
minority  
group**

**Self-image  
tied to words**

**Inaccurate  
descriptors**

**Medical  
diagnoses &  
person's value**



# Person-First vs Identity-First Language

- Person-First Language
  - ❑ Example: Person with a Disability
  - ❑ Way to keep the emphasis on the person as a *person*, and the disability as only one part of the whole person
  - ❑ Focus on the person and not implying the person is *only* their disability
- Identity-First Language
  - ❑ Example: Disabled Person
  - ❑ Disability is a central part of the person's identity
  - ❑ Means of empowerment and of claiming disability as a cultural component of the person





# Body Language Says So Much: Do's

- ✓ Smile
- ✓ Sit where the participant is comfortable and can see you
  - ❑ Be aware of personal space boundaries and preferences
  - ❑ Be aware of physical boundaries, the person can't turn their head
- ✓ Give head nods, lean in and other cues that you are listening
- ✓ Have arms at side or in lap
- ✓ Face the person you are talking to
- ✓ Look at the person who is talking
- ✓ Keep hands away from your mouth when talking





# Body Language Says So Much: Don'ts

- × Sit behind a computer/desk
- × Slouch in your chair
- × Make faces
- × Keep arms crossed
- × Keep hands on hips
- × Scowl
- × Roll eyes



# Word Choice is Important

Don't	Do
Caseload	Participant count
Case manager	Partner, support coordinator, service coordinator
Gave a service	Added services to the plan
Patient	PERSON, participant, consumer
Wheelchair bound	Uses a wheelchair, wheelchair user, person who has a mobility disability
“Watching” a participant	Providing care, providing companionship, supporting someone

For more, check out: [Watch Your Language \(webflow.com\)](http://webflow.com)



# Things That Should Not Be Said

- I wish I could sit down all day
- I wish I had someone else to do everything for me
- If the house isn't clean, I will have to report you
- Do you have a license to drive that thing? Did you pass your driving test?
- Slow down speedy!
- Wanna race?
- Can I get a ride on that thing?
- You're too pretty to be disabled



# Things That Should Not Be Said

- I give you credit, because I couldn't live like that
- I could never ask for help with \*fill in the blank\* (going to the bathroom, getting dressed, etc.)
- I give you credit, because I couldn't do that (when talking to a Direct Service Professional)
- Don't need nice things, because of incontinence issues
- Must be nice to live off the government and go on vacation
- Off-handedly using the word fraud
- So glad you are getting out
- You look healthy to me. Why do you need this program/a wheelchair?



# Common Mistakes



# Not Respecting the Participant as a Person

- Deciding the program isn't right, because of a disability
- Mentioning self-direction might not be for the participant if one mistake is made or going through a rough patch
  - ❑ Can't find a worker, because of the nationwide crisis, so forcing a homecare agency
- Presuming incompetence
  - ❑ Disabled = Incompetent
  - ❑ Forcing a representative



# Not Respecting the Participant as a Person

- Being a boss, not a partner
  - Telling participants what is going to happen
  - Telling participants how things are going to happen
  - Giving opinions when not asked
  - Giving advice and expecting it to always be followed
- Dehumanizing people
  - Focusing on paperwork
  - Not telling people about services that will require more work
- Talking louder
- Talking slower
- Finishing sentences for the participant



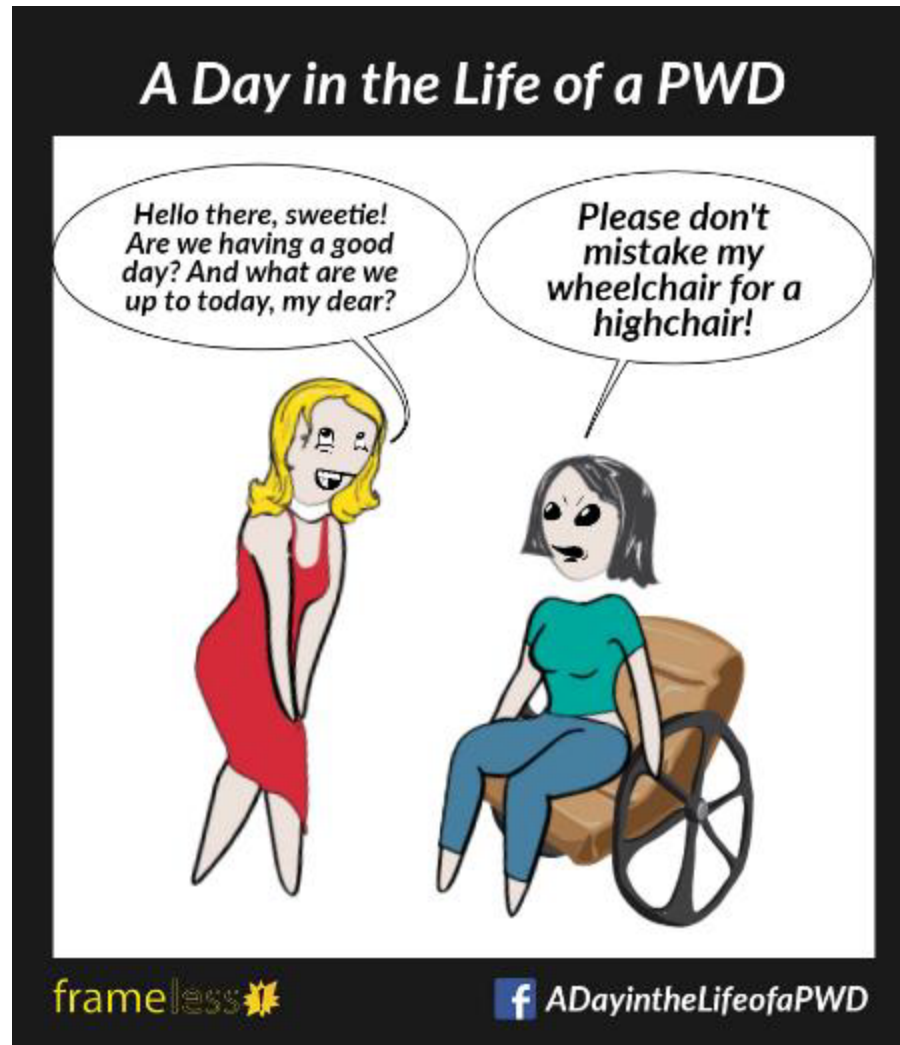
# Not Respecting the Participant as a Person

- Assuming the participant knows/understands what is being said, because you know you explained it well
- Putting words in participant's mouth
- Assuming if a person can't verbally talk:
  - They have nothing to say
  - They don't communicate
  - They are less intelligent
  - They are less of a person





# Not Respecting the Participant as an Adult



# Not Respecting the Participant as an Adult

- Talking about the participant as if they are not there
- Referring to the participant in the same room as “she/he” or “participant”
- Talking to family members, instead of the participant
- Talking/treating the participant like a child
- Patting the person on the head
- Assuming a participant can't go out on their own
- Assuming everyone with the person is a relative
- Deciding you have to be the participant's protector:
  - Parents will take advantage of them
  - Direct Service Professionals will take advantage of them



# Not Respecting the Participant as an Individual

- Comparing people and services needed
  - Assuming all people with the same disability are the same and need the same thing
- Thinking you know a person's needs more than they do and that they don't need certain things
- Deciding people could do things that they have said they can't
- Assuming you know everything about a disability, because you have worked with 1 person with that disability
- Not giving the full information about what is available in the program, because don't think services are needed/appropriate
- Forgetting that success looks different for everyone



# Not Respecting the Participant's Time

- Calling last minute to make required contacts or schedule appointments
- Being upset when the participant doesn't answer the phone
- Rescheduling or cancelling appointments
- Showing up late or early or not at all for meetings
- Having phone on or taking other phone calls during meetings
- Rushing meeting
- Dragging out meetings



# Not Respecting the Participant's Privacy and Space

- Going throughout the house without the participant or permission from the participant
- Coming in while a participant is changing, bathing, etc.
- Asking invasive questions that have nothing to do with the job
- Freely giving out information about a participant, especially when interviewing workers
- Leaning on the participant's chair
- Helping without being asked
- Getting really close when talking to the participant
- Kneeling to talk to the participant, without being asked



# Other Common Mistakes

- Maintain Professionalism
  - ❑ Telling all your drama to participants during meetings that should be to discuss the participant's needs and plan
  - ❑ Giving opinions on everything
  - ❑ Not modeling appropriate behavior for people that learn by examples
  - ❑ Forcing beliefs on others- religious and otherwise
  - ❑ Deciding your way is the only way to do things
- Maintain Objectivity
  - ❑ Avoid coming in with a decision in mind
  - ❑ Address the issue by asking questions to get more information
  - ❑ Avoid assuming the worst



# Other Common Mistakes

- Trying too hard to make a connection:
  - ❑ Saying “I have a cousin with MS, so I get it”
  - ❑ Saying “I had to use a scooter once, so I get it”
- Holding meetings in a place that portrays authority or represents an imbalance of power
  - ❑ You sitting behind a desk or computer
  - ❑ Participant in a smaller chair or on the other side of the desk
- Deciding that lack of follow through = lack of motivation
  - ❑ No idea what the day/week was like
- Behaviors are due to lack of follow through or poor parenting
- Assuming a disability is the worst thing ever
  - ❑ Practice compassion and empathy, not pity
  - ❑ Don’t be inspired by the normal life of a disabled person
  - ❑ Don’t call people brave for living



# Tips for Successful Communication





# Tips For Success

- Remember that the participant is the boss, the #1 priority and in the driver's seat
- Remember that all people are equal and deserve equal respect
- Instead of assuming, ask
- Teaching is imperative in self-direction
- All of us have the right to be able to learn new things
- Ask tough questions to ensure you are being the best support for the participant
  - Is there a reason I am doing this, instead of teaching?
  - Is this a conflict of interest?
  - Am I providing the full picture?
  - Am I providing an accurate picture?



# Tips For Success

- Be aware of biases, educate yourself on the roots of them and where they come from, then actively work to engage these feelings, even though it is uncomfortable
- Be comfortable with uncomfortable
- Approach feedback with curiosity instead of defensiveness
- Learn about the culture and values of the people you are supporting
- Think outside the box
- Approach situations from every angle



# Tips For Success

- Something not working the first time, doesn't mean it won't ever work
  - Unsuccessful attempts don't reflect poorly on you
- If the participant doesn't do what you would do, it doesn't mean it isn't right
- Participants don't always have to do the “right” thing
- It is not your responsibility to protect participants
  - You must ensure safety, but that is relative to the situation
- Don't fix, support
- Don't try to fix the person to fit into society
  - Help society to fit the person



# Final Note

**There is  
no greater  
disability  
in society,  
than the  
inability  
to see a  
person as  
more.**

Robert Hensel

 SleepingAngel.com  
Quotes of Hope



# Additional Resources

## ■ Articles:

- [Here's what to say and not to say when discussing disability: NPR](#)
- [Disability Inclusion Resource Guide - Kresge Foundation](#)

## ■ Books:

- [Disability Visibility: First-Person Stories from the Twenty-first Century by Alice Wong | Goodreads](#)
- [Demystifying Disability: What to Know, What to Say, and How to Be an Ally by Emily Ladau | Goodreads](#)

## ■ TV/Movies:

- [Crip Camp | A Disability Revolution](#)
- [The Peanut Butter Falcon \(2019\) - IMDb](#)
- [The Fundamentals of Caring \(2016\) – IMDb](#)
- [Still Alice \(2014\) – IMDb](#)
- [The Intouchables \(2011\) – IMDb](#)
- [Atypical \(TV Series 2017–2021\) - IMDb](#)





# Questions?



[www.appliedselfdirection.com](http://www.appliedselfdirection.com)