

Context – my lens

My goal for this class is to just give some ideas about how to start advocating for yourselves in the public space. I'll just say up front that I'm not going to give any answers, my goal is to give you ideas.

My perspective is **intersectional**, by that I mean I believe that no one aspect of your identity defines you, that the power you have in society is dependent on all the facts of your identity" (in no particular order: perceived gender, race/ethnicity, sexuality, education, language, income, religion, etc.)

What I think, about disability and how people with disabilities fit into and are treated by society, shapes the things that I'll talk about and the lens that I view these issues through. So I'm just going to front load these things :

- Disability is a social construct
- You are not defined by your disability
- You do not personify your diagnosis: you are not a "car accident" or "a stroke" (*linguistics and mental short-cuts)
- You get to decide what is offensive or demeaning to you. But note: the more that you challenge social norms, the more pushback you'll get. So be prepared for a proportional response. For example: if you prefer "Disability" vs "Handicap" and a preference to someone be prepared to explain why
- Your injury/illness is something that happened to you. It is *your* choice how much (if at all) it is part of *your* identity.
- You define your narrative: your story as you tell it from your perspective includes only elements you decide because it is **yours**.

Ingroup/outgroup

A note on "otherness" and in-group/out-group dynamics:

IN/OUT group: psychologically people favor helping other people who they believe are in "their group" however that may be defined (red/blue study). If you're not in the "ingroup", you're in the "outgroup".

Otherness is the state of being in the out group, typically in relation to power.

I think of Disability as a sort of **Universal Otherness**, meaning that even if you are with people who are in your same socio-economic in-group, if you are a person with a disability, you are always different.

People will claim to be part of the group they imagine you in, they will do this because they think that they can tell what you're experiencing just by looking at you. They'll usually have good intentions but it doesn't mean that you have to tell them what they're asking.

RIDICULOUS COMMENTS TO BE READY FOR IN ANY SITUATION:

- **Claiming medical authority** "It's ok, I'm a doctor" (or "used to be an EMT", "...do massage"
- **Claiming ingroup status** - "It's ok, I'm a caregiver" or "my daughter has/is _____" or "my cousin sprained their ankle as a child"
- **Offering faith or healing** – "can I pray for you?" "my uncle/friend/neighbor/ is a healer. Can I introduce you to them?"
- **Projecting their faith on to you** - "I'll pray for you." "god has a plan (for you)" "if you let Jesus into your heart..."
 - o This is a cognitive path that correlates with the belief in a preordained destiny or "good things happen to good people" and implicit in that is that if you are experiencing a hardship it is either

punishment for something or a challenge that you need to endure for some natural order to be in harmony (or “bad things happen to bad people”) Also that their prayers are more powerful

- **Diagnosing you** – “how long have you had CP?” “T6?” “does your MS mean _____?”

The four groups of people

An important point to remember here is that, *most* people when they say anything (Are you going to get better? What happened? Etc.) are trying to connect with you. Obviously it’s a miscalculation, but they imagine that it will lead to a long conversation with you where they learn and you connect. (That’s the motivation at whatever level conscious or unconscious.) Being on the receiving end it can seem completely ill-conceived because you may be on a bus and not have time to talk about it even if you wanted to, but inside their head (or heart) that’s what they want.

The four groups of people that you could interact with	
<p>STRANGERS/RANDOS [These are people you won’t likely see or interact with again.]</p> <ul style="list-style-type: none"> - Many offensive comments/implications can come from this group. This can be unexpected and occupy much of our headspace. IT IS NOT WORTH IT, don’t waste your time or thoughts. - Redirect, or Ignore (or <i>ridicule</i>... not advisable when you’re starting out advocating for yourself. Aside from self-satisfaction, nobody gains anything anyway.) - “I don’t want to talk about it” - “I’m sorry but I don’t have time to talk to you.” <p>On language: say, “please don’t do that.” Instead of, “you don’t need to do that”</p> <ul style="list-style-type: none"> - Being clear about what you want, the first example cuts out the ambiguity that lets people respond with comments like, “I don’t mind” or “I want to help”. - Ambiguous declines leave room for more awkward conversations with people who don’t understand <p>Decline to answer: “It’s actually a pretty personal question and I don’t know you”</p> <p>Random strangers accosting you with offers of unsolicited help: you can dismiss them</p>	<p>2ND DEGREE ACQUAINTANCES/RETAIL [These are people you may see on a somewhat regular basis: Partners of friends, family of your friends, etc.]</p> <ul style="list-style-type: none"> - Redirect, ignore, or Educate - Equally capable of ignorant comments, but the time it takes to educate them can often be worth it. <ul style="list-style-type: none"> o inappropriate or ill-conceived small talk about disability o presumptions about needs or limitations (that you don’t drive or have cognitive limitations) o speaking to the people you’re with rather than to you directly (more common in retail) o violations of personal space or autonomy
<p>GATEKEEPERS [These are people who influence or regulate your access to things. You may or may not interact with multiple times]</p> <ul style="list-style-type: none"> - Their judgements (assumptions) can have actual tangible effects on your outcomes: what providers you are scheduled with, for how long, what your concerns are described as, etc. 	<p>PROVIDERS/FAMILY/FRIENDS [these are the people who it is worth educating, your outcomes]</p> <p>EDUCATING – this is calling out assumptions for big things it can be confrontational and takes time.</p>

<p>- Advocating with this group of people can be tricky, they may use jargon which mask some of their judgements, they may ask questions about you that are couched in standardized interviews, or they may modify the questions or your answers based on their judgements</p> <p>How to advocate with this group? Be attentive! Notice if things are different with different gate keepers in the same situation, for example if one CNA asks you to rate your pain on a 1-10 scale and another asks you if it's <i>Mild Moderate or Severe</i> ask why the question is different?</p> <p><i>If someone moves your chair without your permission tell them loudly that you didn't give them permission to touch you. (being assertive tells people that you are strong, but be ready for pushback: "but, I'm helping!")</i></p> <p>In some ways it might be better to go through formal channels if you feel you've been objectified or otherwise demeaned.</p>	<p>Some topics are easy to point out and people are receptive. But other things are harder to hear and people may be defensive.</p> <p>It's also very important to listen to the other persons side, because (especially with caregivers) people are not typically trying to offend you or whatever... so also listen and Learn. Give and take.</p> <p><i>I'll just put this here (you do whatever you want with this information):</i></p> <p>The three important factors in an effective confrontation:</p> <ol style="list-style-type: none"> 1 – tell the person exactly how they made you feel. 2 – tell the person the specific thing that they did that made you feel that way. 3 – tell the person the impact of their action. <p>(Simon Sinek)</p>
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The four ways you can interact

How?	
The four ways to respond to invasive questions or implications (simplified)	
<p>Ignore – Just pretend that the person isn't there, you can also just leave, or if you see someone with who is clearly really excited to say <i>something</i>, you can also Avoid. This is good for a majority of people. It's <i>usually</i> not worth the energy of engaging people.</p>	<p>Redirect – this is just <i>changing the subject</i>. There are a number of ways to do this, the least confrontational way is with a positive complement: Them: What Happened? You: I really like your glasses, where did you get them?</p>
<p>Educate – We are correcting assumptions here. This is rarely easy. People aren't automatically open to having ideas that they hold, often unknowingly, challenged.</p> <p>So it means taking the time to explain your experience. Or academically unpacking the concepts that your experiences represent. Ideally they grow to understand through the process of learning. It can be mutually beneficial but can also be one sided and draining, depending on how open they are to questioning their assumptions.</p> <p>THERE ISN'T TIME FOR THIS WITH EVERYONE.</p>	<p>Humiliate – It can feel gratifying to have a zinger of a one liner that really catches someone off guard. I think that's because so often people ask invasive questions and it catches us off guard. It feels good to give it back to them sometimes.</p> <p>BUT... IT IS SELDOM WORTH IT OR PRODUCTIVE.</p> <p>BE CAREFUL BECAUSE PEOPLE CAN RESPOND POORLY TO EMBARRASMENT</p>

Advocating with Service providers – in many situations if you feel that need to advocate for yourself with a provider the best solution could be to just see a **different provider**.

The biggest risk with a provider is that you are not heard, the provider could make assumptions about you and base their care recommendations or treatment on a misunderstanding of your condition. There are a few things that you can do make sure that you are understood and that you and your provider are on the same page

- Audio **record your appointment** on your phone
- **Bring someone** with you to take notes and help ask questions
- **Repeat** what the provider has told you to confirm that you understand correctly, if you don't keep asking questions for clarification until you and your provider are in agreement.
 - o Ask, "**can you say it again in a different way?**"
- Make sure that any medications that you're new to are discussed
 - o Ask about **side effects** that you should be aware of, how to take it
- Ask them to go over the **visit summary** with you at the end of your appointment
 - o Ask them to **clarify** anything you don't understand
 - o Ask when you should have a **follow up**
 - o Ask **how to reach someone in the clinic** if you have questions in the future
- Sign up for whatever **online service** your provider uses, this will typically be an easy way to reach them or people who work in their clinic

Tips for phone calls

- Write down your main points before you pick up the phone
- Have note paper, and note the person's name
- Repeat back what they've said (appointment time, provider, diagnosis, etc.)
- If there is conflict, or discussion of conflict make the person on the phone your ally
- If you hit a dead end ask if there is anyone else who can help you
- If you talk to someone who is especially helpful, ask if there is a way to reach them again
- If you're making several calls about an issue, make notes about who you talked to and what they said, note times and numbers of extensions also.

Tips for leaving messages

- Don't wait for a call back, if it's been more than 3 business days it's probably not coming
- Be the politely "squeaky wheel"
 - o Don't be mad, irritated or unpleasant
 - o Be the person who they want to call back
 - o Smile while you're leaving a message
- Develop a narrative in your messages, if you're leaving multiple message reference other messages you've left, even for other people in the organization
- Call everyone who could possibly be the person to help
 - o Press 0 if you get voice mail, this *could* get you to an operator
 - o I'm not sure who I need to talk to can you help me figure out?
- When you reach a person, make them your ally, tell them your needs and be as sweet as pie, make them like you and want to help you

Being a good ally

For Caregivers: Being a caregiver is hard, you become deeply emotionally involved in the health of another person. Caregiving is essential for many people to maintain their quality of life, and it is work that can be

rewarding. You are committed to helping them, it is reasonable to feel outrage or disgust, both out of empathy and personally, at the treatment of the person you are caring for. It is important that you respect their humanity and dignity if in a position to advocate for them. I would suggest a discussion to find a way that you both feel is appropriate to communicating the message you agree on.

It might be helpful to write a list of situations or interactions that you both remember and note the emotions you recall feeling, the best possible outcome, and then plan for something that you could say in the future that might get you closer to that best-case scenario.

Example: at a kayaking event a volunteer asked my partner if I wanted to kayak? She told this person to ask me.

Advocating as a bystander (UN-involved ally) – you may see something that offends you on an ethical or emotional level, but the most important thing is that you don't make the situation worse or put the person you hope to advocate for. in danger, further objectifying them, etc

Example: someone is being very pushy with a person who is using a wheelchair asking about their disability etc. Take the lead from the person in the wheelchair, if they are remaining composed but are not enjoying the interaction, you inserting yourself into it will just make things worse.

Coming into an interaction like that and trying to explain to the person who is being pushy just reduces the person who is being violated to an object that you are explaining how to interact with.

If a situation escalates to the point where you feel that there is danger or the someone experiencing disability is unable to advocate for themselves (and your involvement is not just to make you feel important or helpful (use your judgement)) you can ask the person how you're hoping to advocate for if there is anything that you can do to help. Do not add to the conflict by being confrontational to a stranger in the name of advocating for another stranger you could put other's in danger by making them a thing that you're fighting about. (ex: on a bus wheelchairs are attached to the floor and mobility is restricted)

use your judgement, do not fight with the person who is being objectionable, the bar is high for intervention: there is a high risk of further objectifying the person who you're attempting to defend, it is rarely your place. Sometimes I'll see people I'm not connected to in public fielding inappropriate questions or comments about their "otherness" I have the urge to intervene but usually my inserting myself into the situation would be inappropriate.

For the Ally

Tips for talking to people with disability about disability:

- 1- Let the person with the disability bring up the topic of their disability
- 2- Even if the person with the disability refers to their disability, don't talk about it unless they open up a discussion.
- 3- Don't ask a bunch of questions.
- 4- Follow the person with the disability's lead (If they're trying to change the subject, let them)
- 5- Don't dwell on it.
- 6- Don't try to change the subject if they're comfortable talking about their disability, or disability in general. (p.306 Beatrice Wright)
- 7- *use person first language,

How to start

Choose what to say/how to respond:

- identify goals for outcomes, use the tools above to help frame your thinking about paths to achieve your goals
- I can't over stress the importance of journaling, when you're learning a new task from beginner to expert, tracking your progress is a great way to learn what works and what doesn't.
- My best suggestion for developing a habit of journaling is to record something that you do every day,
 - o What you ate, exercise, what you watched, or read
 - This gets you in the practice of writing in your journal every day and then if something happens you will already have a place that you're recording it,
 - Leave space at the end of each week to summarize and write conclusions, this can help you learn from your past successes and things that didn't go how you had hoped.
 - I like to make a note of just one line that represents of summarizes each day. It can be a good way of making you think about things from a different perspective.
 - o Find more resources and strategies for journaling here: <https://bulletjournal.com/>
 - o Youtube.com search for "bullet journal" or "journaling techniques" or "best ways to journal" etc.
 - I think it's a great strategy to just start journaling and then adjust

choose one type of interaction and focus on it, either in the retail or gatekeeper spaces. These types of interactions are good places to practice because they are regulated with social **and** institutional codes of conduct, many formal. They are safer and that code of conduct allows for a more structured response that can help you practice different strategies for managing more common situations.

- Making a plan
 - o Choose one or two types of situations, ideally in the middle zones: retail/gatekeepers
 - What are some things that happened that you remember bothering you?
 - Write these down, add the emotions that you felt
 - Below that write what you would have liked to have happened
 - Try to think about how to use the one of the types of interactions listed above to get there next time
 - o Or even just start by deciding what type of communication you'd need to use: *would you need to educate them? Or redirect them?*
 - o Then write a few ideas about how you could have done that (tip: even write down things that might seem like bad ideas because they might make you think of better ideas or ways to adapt them)
 - It could help you become more comfortable using the strategies that you decide on by roleplaying with someone you trust