What’s in a name?

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Disability-related language can be really loaded

- People often have very intense opinions about disability-related language.
- There are very few words that everyone agrees about.
- Conflicts over words are often really conflicts over other things.
Some common points of conflict

• Person-first language vs identity-first language, e.g.: “disabled” vs “people with disabilities”

• Is the word “disability” stigmatizing, positive, or neutral?

• Should the concept of disability be replaced by a more universal concept like difference or uniqueness?

• Preferences of clinicians vs parents vs teachers vs disability communities
Almost everyone agrees that the r-word is offensive

- Most disability-related words are controversial.
- The r-word is almost universally regarded as offensive by service providers, parents, teachers, and people who are called it.
- Don’t use or tolerate the words ‘retarded’, ‘retard’, ‘mentally retarded’, or ‘-tard’.
- These words are offensive whether they’re used as insults or as clinical terms.
A central source of conflict: Who gets to decide what your name is?
EACH OF US HAS A NAME – Zelda

Each of us has a name
given by God
and given by our parents

Each of us has a name
given by our stature and our smile
and given by what we wear

Each of us has a name
given by the mountains
and given by our walls

Each of us has a name
given by the stars
and given by our neighbors

Each of us has a name
given by our sins
and given by our longing

Each of us has a name
given by our enemies
and given by our love

Each of us has a name
given by our celebrations
and given by our work

Each of us has a name
given by the seasons
and given by our blindness

Each of us has a name
given by the sea
and given by our death.
Names given individually

- The name your parents give you.
- Nicknames.
- “Friend”, “classmate”, “neighbor”
- These names matter. And we also need to be able to talk about disability.
The problem with “can’t you just call him Bob?”

- It’s important to call people by their names.
- It’s also important to remember to build ramps.
As Dumbledore said, fear of the name increases fear of the thing itself.

- As Dumbledore said, fear of the name increases fear of the thing itself.
- If we want to normalize disability, we need to be able to talk about it.
Names given by evasion

- Disability is stigmatized.

- Some people try to fight stigma by using euphemisms.

- The name given by evasion can implicitly be “unspeakable” or “unacceptable”.

“Focus on the ability, not the disability!”

- If you can’t talk about disability, you can’t talk about accessibility and adaptation.
- Without accessibility, people are much less able to do things.
- Discussing disability supports ability!
“differently abled”, “handicapable”, and other euphemisms

• Most people with disabilities find these euphemisms offensive.

• Euphemisms imply discomfort with disability and disabled people.
The problem with “it’s not a disability, it’s a difference!”

- Everyone is different.
- Not everyone has a disability.
- People with disabilities face discrimination.
- Eliding disability into something universal interferes with efforts to fix this.
In some sense, don’t we all have a disability?
The problem with “labels are for shirts!”

- People need ways to refer to important things.
- Disability is important.
- If you can’t talk about disability, you can’t talk about accessibility.
The problem with “normal is just a setting on a washing machine”
If you try to “look past the disability and see the person”, you miss the person.
“Person first language”

- “Person first language” describes people as “people with disabilities” “person with autism”, “person with a visual impairment”, etc.

- Most people don’t care about this much, but people who do tend to have extremely intense preferences.

- Some people find it offensive.

- Others find all other ways of referring to disability offensive.
Person first language is linguistically awkward

- English does not usually work that way.

- English often uses nouns: We say “woman”, not “person with femaleness”.

- English often uses adjectives: We say “Jewish person”, not “person who is Jewish”.

- Most people just use typical English grammar when they refer to disability.
Why do some people prefer person first language?

- Historically, many people have been defined solely by their disabilities.
- Some people believe that saying “person” before you mention disability fights dehumanization by emphasizing personhood.
- Some people believe that mentioning disability interferes with normalization and integration.
Who prefers person first language?

• Special educators usually strongly prefer PFL.

• Self advocates in the intellectual and developmental disability self advocacy movement usually strongly prefer PFL.

• Preference for PFL is also common (but significantly less intensely so) in the Independent Living Movement and other cross-disability advocacy.
Why do some people object to person-first language?

- People who see disability as part of their identity don’t like having their identity downplayed.

- People who identity with a disability community don’t want their community erased.

- Disability and humanity aren’t opposites.

- Downplaying disability can also downplay accessibility.
Who objects to person first language?

- People who see their disability as part of who they are generally see PFL as a form of offensive erasure.

- Their preference is sometimes called “identity first language.”

- The Autistic community.

- The Deaf community considers language like “people with hearing loss” to be an offensive attack on them as a linguistic minority culture.
Why is there so much conflict about this?

• There’s more at stake here than whether adjectives or nouns are more respectful.

• This is often a conflict over who has the power to decide what disability means and what it doesn’t.

• Do disability professionals have the right to tell disabled people that they’re describing themselves the wrong way?

• Do communities led by disabled people have the right to decide what language they want to use?
Sometimes there is no neutral language

• When disability-related words are controversial, there’s usually a reason they’re controversial.

• Sometimes language is a way of taking sides.

• You can’t always avoid that.

• Consider context, and err on the side of using language people use for themselves.
People with the same condition may have a different identity or worldview

- Identity is about how you see yourself.
- And how you see yourself in relation to others.
- It’s not directly caused by your body or brain or condition.
- Sometimes people change their mind over time.
An example: Autism language

- David, Sarah, Mordechai, and Rachel are all neurologically similar.

- David identifies as autistic because he objects to attempts to edit out or erase part of who he is.

- Sarah identifies as a person with autism because she objects to being seen solely as a diagnosis.

- Mordechai identifies as aspie and insists he is nothing like David and Sarah.

- Rachel believes that autism isn’t real.
Another example: Hearing and Deafness

• David’s first language was ASL, he identifies as Deaf, and is offended by “person with hearing loss.”

• Sarah has a cochlear implant. She also knows ASL and identifies as Deaf.

• Mordechai identifies as a “person with hearing loss”, and objects to being called deaf because he doesn’t want to be defined by his hearing.

• Rachel grew up without ASL, found the Deaf community as an adult, and now identifies as Deaf.
Names given by diagnosis
“Special needs”/“Exceptional”
“Attention-seeking behaviors”
The ever-shifting diagnostic labels in the DSM and other diagnostic manuals

- “ADHD”
- “Autism spectrum disorder”
- “Rett Syndrome”
- “Cerebral palsy”
- “Down’s syndrome”
Colloquial use of associated words

• Every well-known clinical word has popular associations that may or may not be closely related.

• E.g.: “ADHD”, “OCD”, and “autistic” have colloquial meanings distinct from the clinical meanings.

• Sometimes people retain words for themselves that clinicians no longer use. (E.g.: “Asperger’s syndrome” is no longer a separate diagnosis from “Autism” but a lot of people still identify as “Aspie”)

Names given by violence
Being exiled to the ‘place better equipped to meet his needs’
"As a last resort"
Functioning labels

- “High functioning” and “low functioning” are not defined clinical terms.

- Whether someone is called high or low functioning is determined by context and assumptions someone else is making.

- “High functioning” means impairment is being overlooked; “Low functioning” means ability is being overlooked; both are dangerous.

- Better language “high support needs”.
Beware of hierarchies and false comparisons

• "He’s not disabled, look at all the things he can do!"

• "I’m not disabled, I can do anything but [see/hear/walk/etc.]!"

• Everyone can do things.

• Disability is not inability.
“inspirational”
Disability language is not just a matter of individual preference

- Community identity.
- Beliefs about disability.
- Political identity.
Names given by politics and power

- “special needs kids”
- “disability rights”
- “disabled rights”
- “consumers”
Names given by communities
Self Advocates Becoming Empowered (sabeusa.org)
‘It is sunlight  
Wen you practice seeing  
Strength and beauty in everyone,  
Including yourself.
It is dance  
when you practice knowing  
That what you do  
And the way you do it  
Is the right way for you  
And cannot be called wrong.  
All these hold  
More power than weapons or money  
Or lies.  
All these practices bring power, and  
power  
Makes you proud.  
You get proud  
By practicing.”

From “You Get Proud by Practicing” by Laura Hershey
Names given by respect
Watch how you’re using “we”, “I”, and “they”

- When you say “we”, does it mean everyone in the room?
- Does it mean “people without disabilities”?
- Does it mean everyone in the community?
Watch what you mean by “inclusion”

- If the phrase “inclusion students” makes sense, something has gone wrong.
- When things go right, everyone is there on equal terms.
- Jews with disabilities are Jews, not outsiders!
You are going to say the wrong thing sometimes

- Don’t let fear of saying the wrong thing become a barrier.
- Accept that you will sometimes say the wrong thing, and plan to deal with it constructively.
It’s not always really about the words
Words do matter
Context matters
Honesty and respect go a long way

• You don’t have to solve all the language conflicts in order to talk to people!

• It’s ok that it’s complicated.
Matan Jewish Disability Acceptance and Inclusion Pledge

• I acknowledge that ability, disability and humanity coexist, and I pledge to see my students as they are.

• I will not look past their disabilities; I will seek to understand. I will not overlook their abilities; I will seek to support them effectively.

• I will not ignore the humanity of my students; I will remember that they have individual interests and a perspective of their own and that they were each created in the image of God.