#IncludeRespect

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We all want a respectful and inclusive community.

How do we get there?
Many times throughout my life, I have felt like I was the mitzvah project of the week, like the community didn’t really want me there, but knew including me was what they were supposed to do. I always felt like we were one step away from my face being on the community bulletin with a story reading something like “We did it! We included somebody with special needs! Be proud everyone. Be real proud.” OK, maybe that’s a bit of an exaggeration. But feeling like my presence was another’s mitzvah made me feel even more like an outsider.

Pamela Rae Schuller, “I’m not your mitzvah project”
https://www.jta.org/2016/02/11/opinion/op-ed-im-not-your-mitzvah-project
Inclusion isn’t charity. It is ingathering of exiles.

- Jews with disabilities have always been part of the Jewish people.
- We have always belonged in our schools.
- We have always belonged in our communities.
- We have often been excluded.
- This needs to change.
This is also a problem in the secular world

Speechless, Season 1, Episode 1
Meaning well is not the same as being respectful
How did we get here?

- Segregation and exclusion of disabled people used to be the norm.

- Professional-led efforts towards greater integration and inclusion have inadvertently created new barriers.
The first problem: Institutionalization and exclusion

• People with disabilities have been thoroughly excluded from nearly every aspect of society.

• Seen as unworthy of going to the same schools as everyone else.

• Treated as unemployable.

• Forced sterilization and forced abstinence.

• Institutionalization and not even being allowed to be present.
Wolf Wolfensberger’s attempt to fix it: Normalization

• Key principle: People with disabilities should be integrated into normal community settings.

• Key principle: Institutionalization is inappropriate because institutions are abnormal and stigmatizing.

• The core idea: With appropriate support, people with disabilities can become normal, and integrate into normal society.
Framing disability as correctable deviance

- Wolfensberger believed that disabled people are socialized to be deviant, and can be re-socialized to be normal by:
  - Teaching disabled people to take on the characteristics of normal people.
  - I.e: Behaving in ways considered ‘the way normal people act’.
  - I.e: Having the emotional responses and affect considered ‘normal’.
Why does this theory matter for our purposes?

- Normalization has shaped our professional culture.

- Inclusion work led by professionals almost always makes assumptions rooted in the normalization approach.

- (Even in contexts where words like “normal” and “abnormal” make people uncomfortable.)

- Awareness of those assumptions allows us to think critically about them.
Normalization of settings

• The goal is to make the lives of disabled people more normal than is possible in an institution.

• Sometimes this involves putting disabled people into the same places as everyone else (e.g., their neighborhood school, an apartment building, a company).

• It can also mean placing people in ‘practice’ settings designed to be somewhat similar to normal society in order to teach them how to be normal.
Normalization of behavior and emotional response

• The goal is to teach disabled people how to be like everyone else and to do the things that society generally expects of people.

• Disability professionals teach and enforce behaviors seen as normative.

• Disability professionals teach and enforce emotional responses seen as normative.
This makes a certain amount of sense

• Disabled people have been treated as inherently outside of society.

• Disabled people are often taught to behave in ways that separate them from the community.

• Disabled people are often taught to feel and think in ways that are contrary to social norms.

• None of this is inherent to disability. It is a problem we can fix.
And sometimes this model for integration works!

- We don’t have to exclude students with disabilities from schools. We can decide not to do that.

- We don’t have to see disabled people as unemployable. We can facilitate work.

- Disabled people don’t have to live in institutions. They can live in homes and apartments like everyone else.

- Everywhere is for everyone, and disabled people need normal access to normal spaces.
Some problems really can be solved by teaching and enforcing norms, eg:

- Teaching emotional self-regulation to people who scream and hit people every time something upsets them.

- Teaching people who are enraged that someone won’t go out with them about consent and respecting other people’s boundaries.

- Teaching people how to ask questions and make small talk.

- Teaching norms about nudity and bathroom privacy.
And it really is important to apply social norms to disabled people, eg:

- Doing b’nai mitzvah ritual for kids with disabilities who reach b’nai mitzvah age.

- Expecting everyone to learn appropriate physical boundaries.

- Age-appropriate sex education for people who go through puberty.

- Opening Hebrew schools, day schools, and youth programs to kids with disabilities.
Rabbi Yosef [who was blind] said: At first, I said that if someone said that the halakha agrees with Rabbi Yehuda who says that a blind person is not obligated in mitzvot, I would throw a party for the rabbis! Because I am not obligated and yet I observe.

Now that I have heard the opinion of Rabbi Haninah that one who is obligated and performs is greater than one who is not obligated and performs — on the contrary, if someone tells me that the halakha is not like Rabbi Yehuda I will throw a party for the rabbis!
But normalization is also based on a lie

- Socialization is not the only difference between people with and without disabilities.
- Some of the differences are innate.
- Bodies and brains are important.
- No amount of integration or normalcy lessons will actually make disabled people just like everybody else.
The problem with “focus on the ability, not the disability!”

- Lev. 19:36 “You shall have an honest balance, honest weights, an honest ephah, and an honest hin.”

- The Talmud (Bava Metzia 49a) teaches that this verse also requires us to have an honest “yes” and an honest “no”.

- Having an honest “yes” *depends* on having an honest “no”.

- In order to meaningfully speak about ability, we need to be able to acknowledge disability.
Not all disability-related problems can be solved by making a disabled person more normal

- Disability-related difference is not always the problem.
- Sometimes becoming more normal is harmful.
- Sometimes it’s not even possible.
- (And it is always harmful to force people to repeatedly attempt the impossible.)
Sometimes we have a different problem

- When people are bigoted or hateful towards disabled people, the solution is to change the bigoted response, not the disabled person.

- When becoming normal is impossible or harmful, the solution is accessibility.

- When a social norm is constructed in a way that makes it impossible for disabled people to follow it, the norm needs to change.
Is “normal” just a setting on the washer?

- Not exactly.
- Social norms exist whether or not we acknowledge them.
- The problem isn’t that we have social and emotional norms.
- The problem is that our current “normal” doesn’t have room for disability and people with disabilities.
- We need to fix the norms.
Understanding a norm does not create the ability to follow it

- No amount of broomstick socialization can make it possible for muggles to fly one.

- Knowing that speech is socially expected does not create the ability to speak.

- Understanding that echolalia is socially inappropriate does not create the ability to communicate without using it.

- Understanding that eye contact is socially normative does not make it possible to understand language while looking at someone’s face.

- Understanding that reading is important does not replace the need for braille.
Even when following a norm is possible, it can be harmful, eg:

• Being required to have the same emotional response as everyone else around you, even when your reality is different.

• Not being allowed to be angry about inaccessibility when everyone else is happy about the fun experience they’re having.

• Being expected to like everything others like and dislike what they dislike.

• Not being allowed to be unusually interested in anything.
This is a reason that Oscar the Grouch is my hero
Some examples of harmful normalization efforts

• Telling a 40 year old that her dolls aren’t “age appropriate” and taking them away.

• Forcing autistic people to make eye contact at all costs, even when it damages their ability to communicate.

• Making someone who would be better off using a wheelchair spend their whole childhood trying to learn to walk normally.

• Preventing people with disabilities from interacting with each other.
When someone is considered abnormal, there are three possibilities:

• 1) They need to learn to do normal things or have normal feelings.

• 2) The norms need to change.

• 3) Sometimes there are ways in which the disabled person needs to change AND that the norm needs to change.

• It is not always easy to tell which is which. We need to make our best guess and be prepared to course-correct.
The critical importance of disability acceptance and pride

• It’s ok to be disabled.

• It’s ok that this makes us different from other people in ways that matter.

• We need to be able to accept ourselves as we are.

• We have better things to do than devote our lives to futile efforts to become normal.
Positive thinking is not an alternative to disability acceptance

No amount of smiling at a flight of stairs has ever made it turn into a ramp.

— Stella Young —
And editing out someone’s disability isn’t actually positive

Keep flapping your arms and trying to fly! You can do it! I believe in you!
We can do more when we accept reality

• When you give up false hope, you can have the real kind.

• When you stop wasting time attempting the impossible, you have a lot more time and energy available for things you *can* do.

• Accepting disability makes it possible to think about doing things differently without shame.
Disability rights activists are better at disability acceptance than disability professionals are

- Normalization is central to professional inclusion work.
- Disability acceptance is central to disabled disability rights activism.
- Learning disability acceptance from disability rights culture can make us stronger inclusion professionals.
Normalization also sets inclusion professionals up for failure

• We can’t erase disability.
• We can’t make disability irrelevant.
• When we constantly attempt the impossible, it leads to misery and burnout.
• We need room for honesty.
The relationship between burnout and normalization has been studied directly

- Sociologist Martha Copp embedded at a work training (sheltered workshop) facility for adults with intellectual disabilities.

- Trying to normalize disabled adults didn’t work.

- Trying to do impossible things made staff burn out.

Moving towards respectful inclusion work

• There are no easy answers.

• There are some questions worth asking in an ongoing way.
When there is a conflict: Is it possible that the disabled person is right?

- Be careful not to jump to the conclusion that a disabled person needs a lesson in socially appropriate behavior.

- Consider the possibility that they are right.

- If you disagree, know *why* you disagree.
Have I listened?

- What does the disabled person think is going on?
- Why do they think that?
- How do you know?
- What do you think?
- Why?
Do they know something I don’t?

• If you live with a disability every day, you learn something about it.

• Chances are high that they know something you don’t (even if you have a disability too.)

• Take their expertise seriously.
Do the people I’m trying to support feel respected? How do I know?

- Our attempts to be respectful don’t always work.
- It’s important to know whether the people we’re trying to respect actually feel respected.
- The answer to this is not always obvious.
Am I respecting their right to have feelings?

- Are students with disabilities allowed to like things and to be enthusiastic?

- To be angry when people treat them disrespectfully?

- To be upset when they’re left out of something fun and others would rather not think about the fact that they’re excluded?

- To be upset when things are inaccessible?
When people hurt them, do they apologize?
Is their age respected?

- Am I treating a teenager like a toddler?
- Are others?
Are they allowed to mention things that aren’t universal?

- Disability is part of who someone is.

- Are they allowed to talk about things that aren’t universal, or are they expected to pretend to be just like everyone else?
Am I respecting their privacy?

- Are they being asked to disclose things that are private?
- Are they expected to answer personal questions about their disability?
- Are they allowed to have the same boundaries others do?
- Am I telling their parents more than I would normally share about a kid their age?
Are their contributions to class discussions taken seriously?

- When they speak up, are they ignored, or do they get a response?

- Is the response just praise like “good job!”, or does it engage with the substance of what they are saying?
Are their questions being answered?

• When they ask a question, do you make sure you know what they are asking?

• Do you answer the question?

• Do they feel like they’ve been answered?

• How do you know?
When they are being serious, are they taken seriously?

• People with disabilities are often presumed to be joking when they’re not.

• Do you notice people with disabilities being laughed at?

• Do you know whether they are being serious?
What could be made more accessible?

• Accessibility isn’t just a practical issue, it’s a respect issue.

• Respect people by remembering their access needs.

• Don’t wait for a problem to arise — be considerate and plan for accessibility.
Will this lesson plan work for all of my students?

- When a student is left out due to our failure to plan appropriately, they lose more than just that day’s learning.

- They also lose the sense that we respect them.

- Don’t leave anyone behind. Plan for access, every time.
It is not upon us to complete the work, but neither are we free to desist from it.

-The Mishnah
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.