

**LEADERSHIP, SELF-
DETERMINATION, AND
INTELLECTUAL AND
DEVELOPMENTAL
DISABILITY**

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ABOUT ME



- Bachelor's in Foundation of Special Education from University of Minnesota
- Accessibility and autism consultant, public speaker and writer
- Autistic full time AAC user

WHAT IS DISABILITY?

- Many different definitions
- **ADA:** a physical or mental impairment that substantially limits one or more major life activities
- **Convention of Rights of People with Disabilities:** long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder [a person's] full and effective participation in society on an equal basis with others

MODELS OF DISABILITY

MEDICAL MODEL

- Disability comes from a deficit within a person, a medical problem
- The goal is to make disability less impactful by treating or curing the condition, “fixing” the person

SOCIAL MODEL

- All people have different abilities, this is a natural form of diversity
- People are disabled by their environment when it doesn't accommodate their abilities
- The goal is to reduce barriers by making society more accessible, “fixing” the environment

INTELLECTUAL + DEVELOPMENTAL DISABILITY

- **Intellectual disability:** Differences in ability to learn and reason, and differences in adaptive skills (the ability to respond to the environment). The mismatch between the person's skills and environmental demands means that they require support in daily life
- **Developmental disability:** Lifelong differences in ability to perform independent living skills in the way expected by the environment, which results in need for support
 - Autism, Cerebral Palsy, Fetal Alcohol Spectrum Disorder, etc.

LANGUAGE

Identity first language versus
person first language

Differences between
communities

Autism: "Autistic person"

Intellectual disability: "Person
with an intellectual disability"

HISTORY OF EMPLOYMENT AND I/DD

Prior to 1840s, most people with I/DD did not work, lived in poorhouses or asylums

Starting in 1880s, institutions started becoming more common instead

1840s-1880s

1840s

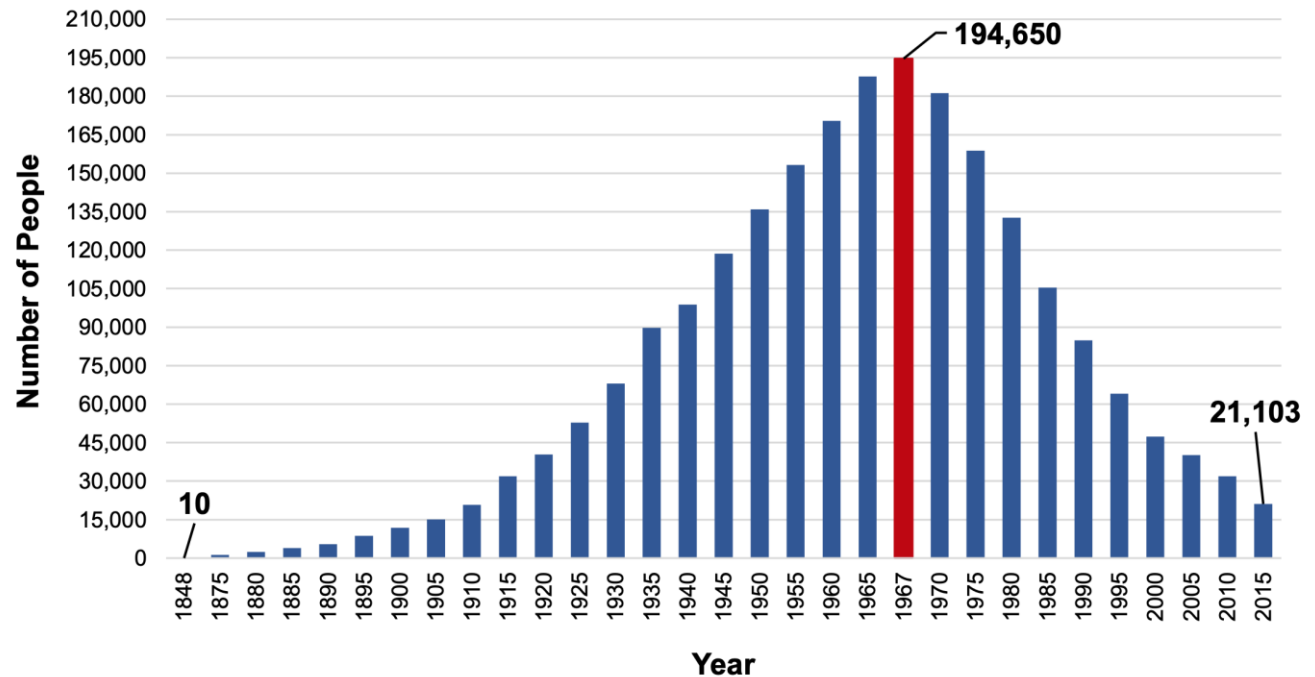
1880s

Training schools for people with I/DD began, with goals of training for menial labor

INSTITUTIONALIZATION

- Inmates were confined, used as free labor to run the institution, care for others
- Tasks like laundry, farm work, cooking
- More support services and advocacy movements led towards deinstitutionalization

Number of People Living in IDD Institutions in the US by Year (1848 - 2015)



SUBMINIMUM WAGE

- Under section 14(c) of the Fair Labor Standards Act of 1938, employers may be authorized to pay individuals with disabilities wages lower than the federal minimum wage if the individuals' earning or productive capacity is limited as a result of their disability
- Wages based on productivity compared to average nondisabled worker
- Low wages trap workers in workplace

SHELTERED WORKSHOPS

- Segregated employment settings for people with disabilities, usually paying subminimum wages
- Olmstead ruling prohibited states from confining people with disabilities to segregated workplaces, but inadequate effect
- Only 5% of sheltered workshop employees graduate to competitive employment (cite Star Tribune NFB article here)



MY EXPERIENCE WITH SUBMINIMUM WAGE

- Summer farm work program aimed mostly at teenagers with disabilities
- 25-30 hours a week for 6 weeks, heavy manual labor
- \$1.60/hour

SELF ADVOCACY MOVEMENT

- Organizations: Speaking for Ourselves, People First, Self Advocates Becoming Empowered
- Meetings run by people with I/DD, not by supporters
- Fought/fighting for deinstitutionalization, Home and Community Based Services, legal rights to equal employment and healthcare, human rights

AUTONOMY AND SELF-DETERMINATION

- “Support must empower individuals to make their own decisions. Regardless of the degree of disability, we must have support to make our decisions. We must be allowed to take risks. It must be up to us to ask for help from those we trust.” - ILSMH Committee on Self-Advocacy
- **Autonomy:** Treating a person as their own independent person, a full human being
- **Self-determination:** The ability to make decisions concerning your own life

DIGNITY OF RISK

- All human beings deserve the right to take risks, make mistakes, and learn from their failures
- People with I/DD often sheltered from risk
- Dignity of risk means allowing a person their right to take reasonable risks, and providing the support they need to make an informed decision about those risks

CONNECTION TO LEADERSHIP

Ability to make choices and take risks is essential for leadership

These are skills that are developed through practice and experience

Denial of autonomy leads to learned helplessness

Learned helplessness can be unlearned

INCLUSIVE LEADERSHIP



Leading by example, building relationships



Motivation, passion, direction



Seeks out advice and opportunities to learn

ADA RIGHTS

- Title I of ADA: Prohibits discrimination in employment, employees have the right to reasonable accommodation
- Reasonable Accommodation refers to a modification or adjustment to job, environment, or policies to allow qualified employee with a disability to access equal employment opportunity
- Does not include removing essential job functions, and does not apply if accommodation would constitute “undue hardship” on employer

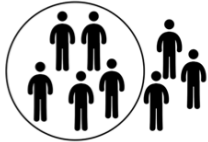
ACCOMMODATIONS + I/DD

- Work with the person, not for them, to determine appropriate accommodations
- Person has insight into what will be helpful for them
- Balancing autonomy vs support
- Mentoring/coaching, splitting up roles

\$7.25



Right now (in September 2018), the minimum wage is \$7.25. The law says that workers have to be paid at least \$7.25 for every hour of work they do.



But the Fair Labor Standards Act leaves out some people.



The part of the law that leaves out disabled people is called **Section 14(c)**.



Section 14(c) lets companies pay disabled people less than the minimum wage.

ACCESSIBLE POLICY - PLAIN LANGUAGE

- Policies are often written in inaccessible, complicated language
- Plain language can support many people, including those with I/DD, to understand their rights
- Easy read materials (simple text and symbol supports) can also be helpful
- Many resources available at <https://autisticadvocacy.org>

UNIVERSAL DESIGN



- Designing an environment to remove barriers and be as accessible as possible to everyone
- Benefits everyone, not just people with disabilities

UNIVERSAL DESIGN FOR I/DD

Mentoring and scaffolding

Building in choice

Providing mastery-oriented feedback

Present information through multiple
ways

Minimize distractions

RESOURCES

- Job Accommodation Network: <https://askjan.org>
- Autistic Self Advocacy Network:
<https://autisticadvocacy.org>
- Universal Design for Learning:
<https://udlguidelines.cast.org>
- Self Advocates Becoming Empowered:
<https://www.sabeusa.org>



You can also contact me at



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QUESTIONS?

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