Invisible Disability: “Mr. Cellophane shoulda’ been my name.”

The social and employment hurdles of invisible disabilities.

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My first teacher about invisible disability
What is invisible?

This is my port where I receive nine infusions a month.
Invisible Disability

• Definition of disability?

• Disability
  – 22% of the US population has a disability (CDC, 2015).
    • 13% mobility
    • 11% cognition

• Invisible possibilities
  – Mental illness
  – Learning disability
  – Head injury
  – Muscle/bone disease
  – ASD
  – Chronic pain
  – Neuromuscular
  – Heart/lung disease
  – Hearing/sight
  – Autoimmune
  – Endocrine
  – Gastrointestinal
  – Cancer

  – 40% of individuals with disabilities have invisible disabilities (Lingsom, 2008)

• Difference between visible and invisible
  – Able to “pass” for nondisabled in social, family, or work situations
  – Lack of research on invisible disabilities
  – Legal definition problems
  – Social stigma
    • Lack of belief – can’t see it, it doesn’t exist
    • Performance reduction without visible understanding by others/ Improper attribution of performance because of lack of understanding (Santuzzi, Waltz, Finkelstein, & Rupp, 2014).
  – Caught between disability stigma and failure due to overextension brought on by concealment efforts
Disability Stigma

• Body Perfection (Schur, Kruse, & Blanck, 2005; Stone, 1995).
  – Ideal = young, fit, healthy, in control
  – Normal = accepted, responsible, working to maintain self
  – Imperfection = laziness, low self-esteem, moral failure
  – Illness = negative, helpless, weak
  – Disability = dependent, a personal tragedy, minority, saint, embittered

• Social Stigma
  – College educated persons with invisible impairments were 14 times more likely to be employed than those with visible impairments (Martz 2003).
  – 80% of respondents with an invisible disability knew their rights and how to request accommodations, but 75% hadn’t (Atkinson, 2016)
  – Investigating corporate culture about accommodations: employees were less likely to see an accommodation as warranted if the disability was invisible (Schur et al., 2005)
Visible vs Invisible

• Passing (Clair, Beatty, & MacLean, 2005)
  – Cultural performance by a person with an invisible disability pretending to be non-disabled to enjoy the privileges afford members of that dominant group
  – Allows the person to be perceived, incorrectly, by others as someone without a devalued social identity
  – Methods:
    • Fabrication – deliberately provide false information
    • Concealment – actively prevent others from obtaining information
    • Discretion – ‘dodge’ issues which might reveal disability
Visible vs Invisible

• Revealing (Clair et al., 2005)
  – Disclosing an identity that would otherwise remain hidden
  – Methods
    • Signaling – Ambiguous cues, subtle comments, or nonverbal cues
    • Normalizing – Acknowledge the disability, but minimize it and find ways to make it normal
    • Differentiating – Revealing and claiming identity
Cost/Benefit of Passing/Revealing

• Passing - Cost
  – Live a “double life”, adopt different personas, dishonest (Clair et al., 2005)
  – Isolation from work relationships which limits effectiveness. Fewer networks, interpersonal connections, mentors, help in advancement (Clair et al., 2005).
  – Physically, emotionally, and psychologically exhausting (Spiegel, De Bel, & Steverink, 2016).

• Passing – Benefits
  – Avoid risk of stigmatization, prejudice, and discrimination (Clair et al., 2005)
  – Normalizing for personal psychological reasons and allow privacy (Spiegel et al. 2016)
  – Break from protecting self and others from disability (Lingsom, 2008)
Cost/Benefit of Passing/Revealing

- Revealing: Cost (Clair et al., 2005; Lingsom, 2008; Spiegel et al., 2016).
  - Risks stigmatization, prejudice, and discrimination
  - Mistrust from disbelief
  - Increased expectations for performance to prove better than disability
  - Decreased employment opportunities
- Revealing: Benefits (Clair et al., 2005; Lingsom, 2008; Spiegel et al., 2016)
  - Desire for experiences - Opportunity for experiences without over-extending self and disclosing unintentionally
  - Reducing demands and altering evaluation standards—Opportunity to be seen in light of reality and evaluated according to accurate standards
  - Personal integrity and cohesion – Not having to hide, live a double life, and spend energy concealing identity
  - Value transformation and political activism – Sharing with others, teaching others, and joining a community
- There will be a risk/benefit assessment needed for every new relationship that will cost the person energy (Clair et al., 2005).
Experiences of Individuals

• Read the vignettes provided
• What passing or revealing strategy is the person using?
• Is there a cost or a benefit from the strategy used?
• Would you share other advice with the person if they were your customer?
What is Needed - Employers

“Whether the conspiracy of silence emanates from social forces, personal psychodynamics, or both, there is no doubt that it exists in organizations: Individuals with invisible disabilities are unlikely to speak; employers do not want to listen” (Vickers, 1997, p.247).

• Women with MS and maintaining employment (Dyck & Jongbloed 2000)
  – ability to take sick time when needed (74%)
  – understanding employer or supervisor (66%)
  – understanding colleagues (63%)
  – flexible work hours or reduced work hours (48%)

• Interviewing (Dalgin & Bellini, 2008)
  – Best prepared candidates have the edge regardless of disclosure
  – Bias toward type of disability (psychiatric vs minor physical)
  – More information is not always better, but job focused may be
Disclosure Issues

A Conceptual Model of the Decision to Pass or Reveal

Individual differences
- Propensity toward risk taking
- Self-monitoring
- Developmental stage
- Motives

Choice to pass or to reveal

Individual and interpersonal costs and benefits of revealing or passing

Interpersonal and environmental context
- Organizational diversity climate
- Professional and industry norms
- Legal protections
- Target relationships and characteristics

Clair et al., 2005
Social Change

• Invisible Disability Association
  – https://invisibledisabilities.org/

• London
  – Public transportation badge

• Be an advocate
  • https://youtu.be/hiXS5rsceEw
Best Teacher – Invisible Disability

Isaac Syndrome
References


References


