

# Case Study 1

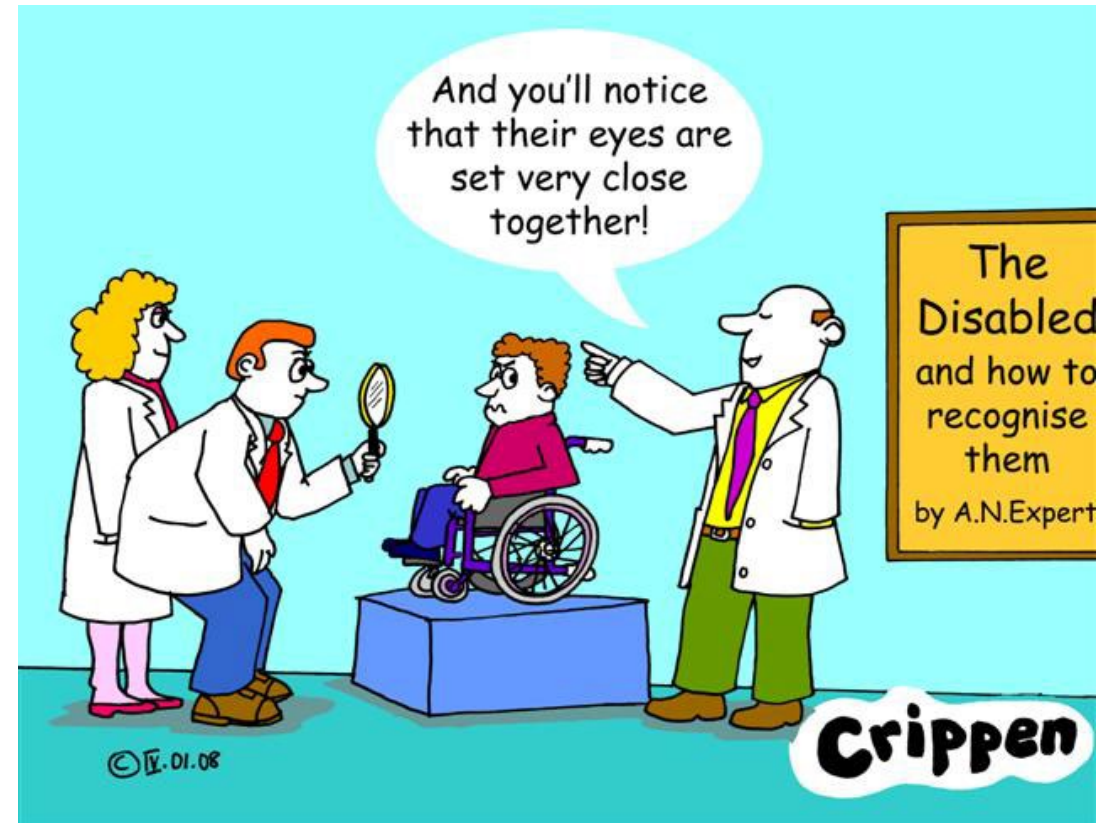
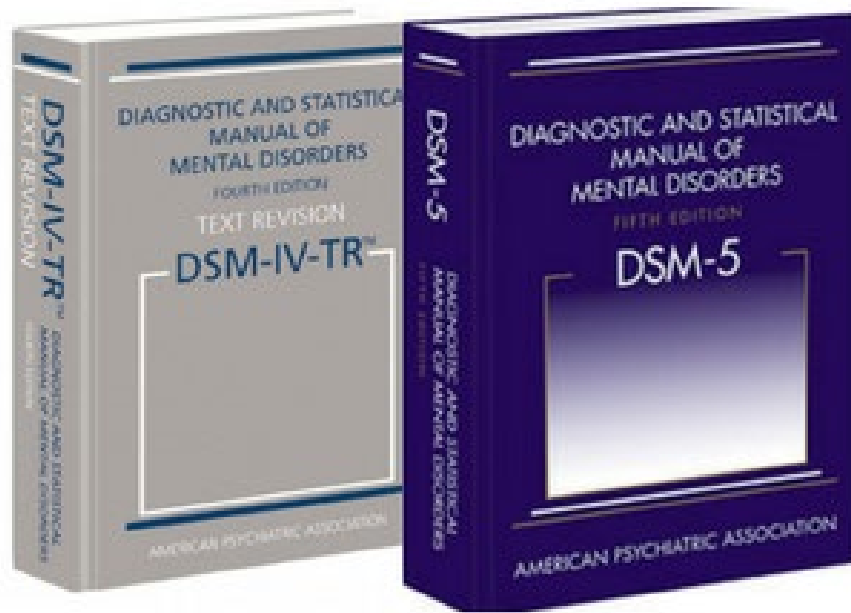
A patient who uses a wheelchair presents to clinic, is forced to sit in the hallway because there isn't space for their chair in the waiting room, cannot position him/herself in the exam table because there isn't appropriate slide equipment

# Ableism & Defining Worth

# Definitions

**Ableism** refers to practices or policies that treat people with disabilities as if they were invisible, disposable and less than human, while taking for granted able-bodiedness as humanity's default state

# Clinicians' Power to Name Disabilities



# Underestimating quality of life

**Table 2.** Mean responses to functioning domains on the EORTC QLQ-C30 for patients with metastatic breast cancer, their partners, and the treating physician

| QLQ-C30 item          | Patient response <sup>1</sup><br>(Mean ± SD) | Physician response <sup>1</sup><br>(Mean ± SD) | Close relative <sup>1</sup><br>(Mean ± SD) | <i>p</i> -Value <sup>2</sup><br>(Patient vs. physician) | <i>p</i> -Value <sup>2</sup><br>(Patient vs. family) |
|-----------------------|--|--|--|---|--|
| Overall health        | 52.3 ± 25.9                                  | 41.5 ± 24.9                                    | 48.1 ± 24.0                                | 0.0004  | 0.16   |
| Role functioning      | 54.0 ± 30.3                                  | 40.0 ± 32.2                                    | 54.0 ± 32.7                                | 0.0001  | 0.99   |
| Global QoL            | 59.9 ± 25.1                                  | 43.0 ± 25.1                                    | 53.5 ± 24.1                                | 0.0001  | 0.03   |
| Social functioning    | 59.9 ± 30.5                                  | 42.7 ± 32.2                                    | 53.3 ± 29.1                                | 0.0001  | 0.08   |
| Physical functioning  | 62.0 ± 22.7                                  | 54.1 ± 28.7                                    | 58.5 ± 23.2                                | 0.004   | 0.17   |
| Emotional functioning | 64.3 ± 26.8                                  | 60.4 ± 25.4                                    | 56.1 ± 23.9                                | 0.15  | 0.002  |
| Cognitive functioning | 75.4 ± 25.3                                  | 76.5 ± 22.3                                    | 76.5 ± 23.7                                | 0.70  | 0.70   |

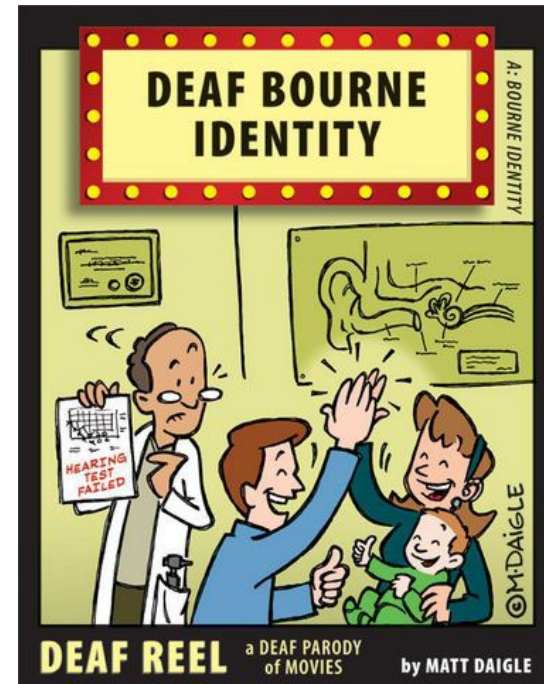
<sup>1</sup> A higher score indicates a higher level of functioning (less impairment).

<sup>2</sup> *p*-Values obtained by an ANOVA.





# Pathologizing



- Toombs, S. Kay. "The lived experience of disability." *Human studies* 18.1 (1995): 9-23.
- Tucker, S. J. (1980). The psychology of spinal cord injury: Patient–staff interaction. *Rehabilitation Literature*, 41 (5-6), 114–121, 160.
- Harris CA, Muller JM, Shauver MJ, Chung KC. Leveraging the Medical Context to Increase Upper Extremity Reconstruction Among Patients with Tetraplegia: A Qualitative Analysis. *Arch Phys Med Rehabil*. 2018 Mar;99(3):459-467.e1.

## Feelings and Perspectives about Self.

| Statements                    | <i>N</i> | <i>M</i> <sup>*</sup> | <i>SD</i> | % Agree <sup>†</sup> |
|-------------------------------|----------|-----------------------|-----------|----------------------|
| Are you happy with your life? | 276      | 1.2                   | 0.5       | 99                   |
| Do you like who you are?      | 277      | 1.2                   | 0.5       | 97                   |
| Do you like how you look?     | 278      | 1.2                   | 0.6       | 96                   |
| Are you sad about your life?  | 277      | 3.7                   | 0.6       | 4                    |

## Feelings and Perspectives about Others.

| Statements   | <i>N</i> | <i>M</i> <sup>*</sup> | <i>SD</i> | % Agree <sup>†</sup> |
|--|----------|-----------------------|-----------|----------------------|
| Is it easy to make friends?  | 276      | 1.5                   | 0.9       | 86                   |
| Do you feel that you help other people?  | 275      | 1.5                   | 0.8       | 85                   |
| Do you love your family?   | 277      | 1.1                   | 0.3       | 99                   |
| Do you like your brother(s) or sisters(s)?   | 258      | 1.2                   | 0.5       | 97                   |
| Do you feel your brother(s) or sisters(s) is a good friend?  | 255      | 1.4                   | 0.8       | 89                   |
| Do you feel your parents pay more attention to your brother(s) or sister(s) and not enough to you? | 256      | 3.4                   | 1.0       | 15                   |

\* People with DS were asked to rate their level of agreement with the statements on a Likert scale with "1" being "yes"; "2" being "most of the time"; "3" being "once in a while"; and "4" being "no."

† Percentage of people with DS who circled "yes" or "most of the time" for that statement.

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**EXHIBIT 2****Quality Measures For Which People With Disabilities Report Worse Experiences Than People Without Disabilities**

| <b>Topic</b>           | <b>Description of quality measure</b>   |
|------------------------|---|
| Access                 | People without a usual source of care who indicated a financial or insurance reason for not having a source of care<br>People who were unable to get or delayed getting needed medical care in the past 12 months:<br>Dental care<br>Prescription medicines<br>People with a usual source of care, excluding hospital emergency departments, that had office hours nights or weekends<br>People with difficulty contacting their usual source of care over the telephone<br>Adults who did not have problems seeing a specialist they needed to see in the past 12 months |
| Lifestyle modification | Adults with obesity who spent half an hour or more in moderate or vigorous physical activity at least three times a week  |
| Patient safety         | Adults age 65 or older who received potentially inappropriate prescription medications in the calendar year   |
| Patient-centeredness   | Adults who had a doctor's office or clinic visit in the past 12 months whose:<br>Providers listened carefully to them<br>Providers explained things in a way they could understand<br>Providers showed respect for what they had to say<br>Providers spent enough time with them<br>Rating of health care by adults who had a doctor's office or clinic visit in the past 12 months<br>People with a usual source of care for whom health care providers explained and provided all treatment options   |



# Potential Critiques



Interventions do exist for disability that may improve QoL for some



I can't know the words for everything



It's hard to make everything accessible

# Operationalizing



# Operationalizing

**YOU** ARE AT THE CENTER OF YOUR CARE



# Case Study

A patient who uses a wheelchair presents to clinic, is forced to sit in the hallway because there isn't space for their chair in the waiting room, cannot position him/herself in the exam table because there isn't appropriate slide equipment

## Discussion Points

- What does this environment communicate to the patient?
- How can you prevent these occurrences? What should you do if you notice this scenario unfolding?
- Do certain environments have a responsibility to be more accessible than others?

# Case Study

The trauma team, while rounding on an awake and alert 27 y/o who sustained a traumatic brain injury in a motor vehicle crash only addresses the patient's parents

## Discussion Points

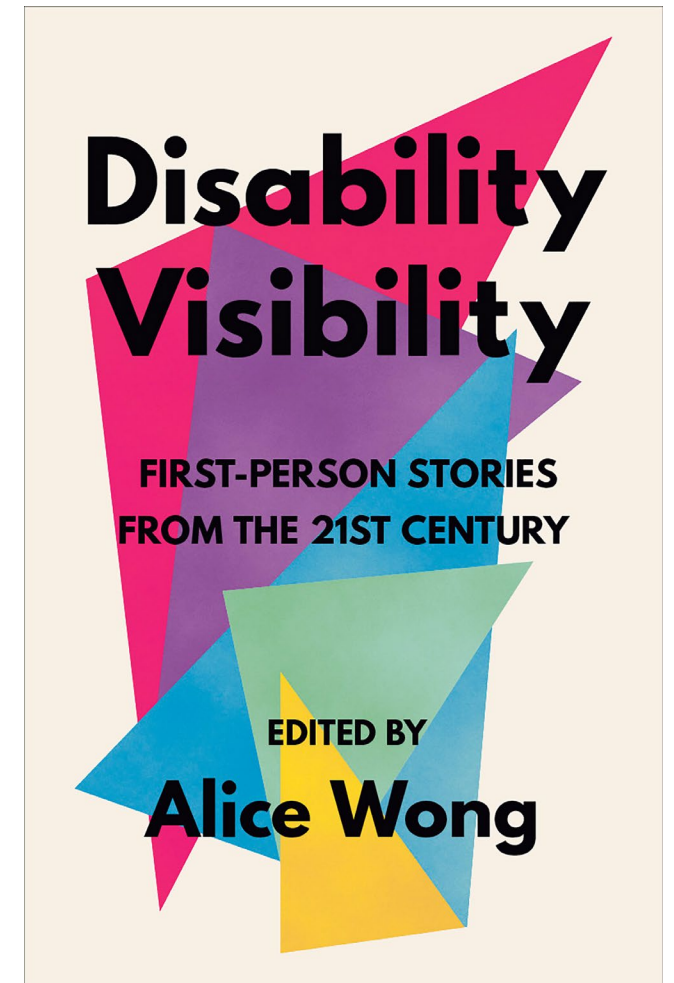
- What does this behavior communicate to the patient?
- How can you adapt rounds to be more inclusive of patients with different needs?
- What should a team member who observes this behavior do?



# Blue Ocean Brain Links of Interest

[Video: Hero or Victim? How About Neither  
Ableism](#)

[What You Can Do About It](#)



# Survey

Please complete the following brief survey to assess your learning from today's session and provide feedback on your experience.

1. Open camera app on your phone
2. Point your phone at the QR code to scan it
3. Tap the pop-up banner/link and fill the brief survey

Thank you!!

