Closing Disability Disparities: 
**EHR Data as First Step**

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<table>
<thead>
<tr>
<th>Data Class</th>
<th>Goal</th>
<th>Use</th>
<th>Who Completes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability Status</td>
<td>1. Identify and address care inequities and improve care outcome</td>
<td>Demographic/ Social</td>
<td>Patient reported</td>
</tr>
<tr>
<td></td>
<td>2. Examine role of SDoH on care</td>
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<td></td>
<td>3. Identify patients who require healthcare accommodations</td>
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</tr>
<tr>
<td>Functional Status</td>
<td>1. Care planning</td>
<td>Medical</td>
<td>Patient reported or clinical assessment</td>
</tr>
<tr>
<td></td>
<td>2. Clinical assessments</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3. Connecting to medical, social or educational services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Status</td>
<td>1. Care planning</td>
<td>Medical</td>
<td>Patient reported or clinical assessment</td>
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<td></td>
<td>2. Clinical assessments</td>
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</tr>
</tbody>
</table>
1 in 4 Have a Disability
Significant Health and Healthcare Disparities

- 2.7x
- 3x
- 6x
- 54% v. 83%
- 1 in 3
- 3x
Disability Data Gaps Limit the COVID-19 Response

EHR data is needed to track COVID-19 infection, vaccination, outcomes, and care/equipment allocation
We can’t improve what we don’t measure

Data needs:

Quality of health and healthcare

Effects of equity interventions

Provision of disability accommodations
### Documenting Disability Status in EHR

<table>
<thead>
<tr>
<th>Patients are supportive</th>
<th>Legal requirement</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identified as top research and policy priority</td>
<td>Health systems struggling to implement</td>
</tr>
</tbody>
</table>
ACS and Washington Group Questions

1. Are you deaf or do you have serious difficulty hearing?

2. Are you blind or do you have difficulty seeing, even when wearing glasses?

3. Do you have serious difficulty walking or climbing stairs?

4. Do you have difficulty concentrating, remembering, or making decisions?

5. Do you have difficulty dressing or bathing?

6. Do you have difficulty doing errands alone such as visiting a doctor’s office or shopping?

7. Using your usual language, do you have difficulty communicating (for example, understanding or being understood)?
Recommended Future Question Categories

1. Learning Disability
   a) Do you have serious difficulty learning how to do things most people your age can learn?

2. Mental Health Disability
   a) Do you have serious difficulty with the following: mood, intense feelings, controlling your behavior, or experiencing delusions or hallucinations?

3. Autism/Social Disability

4. Health Care Accommodations

5. Caregiver
   1. Caregiver’s disability
   2. Caregiver regularly attend appointment with patient
Disability is a socially constructed concept

Not everyone will an impairment will identify as having a disability

Language changes over time

Despite challenges, people with disability cannot wait any longer
Reasons for Urgency

- COVID-19 & Public Health Emergencies: lack of disability information negatively impacted access to PPE, vaccination prioritization, critical support persons, and the ability to recover health.

- Lack of disability demographic ID means less funding, less understanding, less inclusion, and greater stereotypes.

- Health Equity and SDoH discussions happening now.

- Lawmakers, policymakers and lawyers need facts and evidence of disparities.

- Non-white racial/ethnic and other populations need to know how their disabled members experience discrimination and health/healthcare disparities.

- Prepares the way for documenting accommodations and providing higher quality care.
# Recommended Action Steps

## #1
Include Washington Group and ACS disability questions in EHR (demographic)

## #2
Ensure a patient-reported data collection approach is used

## #3
Recognize this is first step. Future efforts should focus on accommodations

## #4
Support use of disability data to improve clinical care and address healthcare inequities
References

- Iezzoni L. Eliminating health and healthcare disparities among the growing population of people with disabilities. *Health Affairs*. 2011 30(10)
- [https://ncd.gov/progressreport/2021/2021-progress-report#:~:text=KEY%20FINDINGS%3A%20NCD%20found%20that,report's%20seven%20areas%20of%20focus.](https://ncd.gov/progressreport/2021/2021-progress-report#:~:text=KEY%20FINDINGS%3A%20NCD%20found%20that,report's%20seven%20areas%20of%20focus.)
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Appendix
Benefits of the Washington Group and ACS Questions

Standard across other public health surveys (e.g., CDC surveys)

Culturally and linguistically tested

Pilot tested in large health system with no patient complaints

Coded in LOINC
<table>
<thead>
<tr>
<th>Disability</th>
<th>American Community Survey (ACS) Disability Questions</th>
<th>Washington Group (WG) Disability Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hearing</td>
<td>Are you deaf or do you have serious difficulty hearing?</td>
<td>Do you have difficulty hearing even if using a hearing aid?</td>
</tr>
<tr>
<td>Seeing</td>
<td>Are you blind or do you have difficulty seeing, even when wearing glasses?</td>
<td>Do you have difficulty seeing, even if wearing glasses?</td>
</tr>
<tr>
<td>Mobility</td>
<td>Do you have serious difficulty walking or climbing stairs?</td>
<td>Do you have difficulty walking or climbing stairs?</td>
</tr>
<tr>
<td>Cognitive</td>
<td>Do you have difficulty concentrating, remembering, or making decisions?</td>
<td>Do you have difficulty remembering, or concentrating?</td>
</tr>
<tr>
<td>Self-Care</td>
<td>Do you have difficulty dressing or bathing?</td>
<td>Do you have difficulty with self-care such as washing or dressing?</td>
</tr>
<tr>
<td>Independent Living</td>
<td>Do you have difficulty doing errands alone such as visiting a doctor’s office or shopping?</td>
<td>N/A</td>
</tr>
<tr>
<td>Communication</td>
<td>N/A</td>
<td>Using your usual language, do you have difficulty communicating, for example, understanding or being understood?</td>
</tr>
<tr>
<td>Disability</td>
<td>Survey Source</td>
<td>Hybrid Approach - Oregon System</td>
</tr>
<tr>
<td>--------------------------</td>
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<td>Hearing</td>
<td>ACS</td>
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<td>Cognitive</td>
<td>ACS</td>
<td>Because of a physical, mental, or emotional condition, do you have serious <strong>difficulty concentrating, remembering, or making decisions</strong>?</td>
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<td>Self-Care</td>
<td>ACS</td>
<td>Do you have <strong>difficulty dressing or bathing</strong>?</td>
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<tr>
<td>Independent Living</td>
<td>ACS</td>
<td>Because of a physical, mental, or emotional condition, do you have difficulty doing <strong>errands alone</strong> such as visiting a doctor's office or shopping?</td>
</tr>
<tr>
<td>Communication</td>
<td>WG</td>
<td>Using your usual language, do you have serious <strong>difficulty communicating</strong>, (for example understanding or being understood by others)?</td>
</tr>
<tr>
<td>Learning</td>
<td>Additional domain</td>
<td>Do you have serious <strong>difficulty learning</strong> how to do things most people your age can learn?</td>
</tr>
<tr>
<td>Psychological</td>
<td>Additional domain</td>
<td>Do you have serious difficulty with the following: <strong>mood</strong>, intense feelings, controlling your behavior, or experiencing <strong>delusions or hallucinations</strong>?</td>
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</table>
88% of ALL patients believe collection of disability status is important

1,894 patients asked disability questions during registration

ZERO complaints
Disability status is rarely collected or documented

- **EHR**
  - Patients’ disability status rarely collected

- **Patient experience surveys**
  - Seldom captures disability

- **Big Data (e.g., Claims data)**
  - ~70% miss disability diagnosis

- **ICD-10**
  - XXX.XX
Opportunities

We know which questions to ask

Patients are okay disclosing disability status

We can integrate collection with other demographic characteristics