Disability Status in the Electronic Health Record

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David with his parents at his high school graduation

Disability Documentation in the EHR

Diagnosis Codes

- Medical model

- Used to inform billing and medical treatment

- Documented by a clinician

- Located throughout a patient's chart

Disability Status

- Social model

- Used to inform: (1) provision of accessible healthcare and (2) identify/address disparities

- Self-reported

- Appears in prominent location in chart

Disability Status Questions

Disability Category	Patient-Centered Disability Questionnaire
Hearing	Are you deaf, or do you have serious difficulty hearing?
Vision	Are you blind, or do you have serious difficulty seeing, even when when wearing glasses?
Cognition	Do you have difficulty remembering or concentrating?
Mobility	Do you have serious difficulty walking or climbing stairs?
Activities of Daily Living (ADL)/Fine Motor	Do you have difficulty dressing or bathing?
Communication	Using your usual language, do you have difficulty communicating communicating (for example, understanding or being understood)? understood)?
General screener	Due to a disability, do you need any additional assistance or or accommodations during your visit?

Diagnosis codes are insufficient to identify and address disparities

- Diagnosis codes are inconsistently used across encounters

- Diagnosis code often do not provide information on disability status
  - Functional status/disability status can change over time
  - A diagnosis often does not reveal a patients' disability status

- To identify accommodations and potential solutions to address disparities, we need to know patients' disability status

Disability Bias in Clinical Notes

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Disability Stigmatizing Language	Language that suggests biases and stereotypes
- Wheelchair or bed-bound - Confined to a… - Suffers from… - Stricken with… - Retarded - Handicap - Special needs - Challenged	Language that suggests patients are: - Lazy - "faking" a disability - Non-reliable historian - Incompetent - Childlike - Non-compliant

Biased language in the EHR can:
- Perpetuate bias and stereotypes
- Medical care and decisions

Documenting Disability Status in Electronic Health Record

Top research and policy priority	Patients are supportive
Tie to legal requirement for accommodations	Health systems struggling to implement

Recent Policy and Research Advances

- 2022 – ONC United States Core Data for Interoperability (USCDI) Version 3 includes Disability Status Data Elements

- 2023 – Joint Commission Health Equity Certificate requires disability status documentation

- 2024 – CMS Enhancing Oncology Model requires disability status documentation

- NIH grant to develop and evaluate workflows for:
  - Consistently document disability status in the EHR
  - Use the data to inform provision of accommodations

THANK YOU

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disabilityequitycollaborative.org

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