



NATIONAL ASSOCIATION OF
Community Health Centers®

Disability in the Medical Record: Standards and Opportunities

Julia Skapik, MD, MPH, FAMIA
CMIO

National Association of Community
Health Centers



NACHC's STRATEGIC PILLARS

1



Equity and Social Justice

Center everything we do in a renewed commitment to equity and social justice

2



Empowered Infrastructure

Strengthen and reinforce the infrastructure for leading and coordinating the Community Health Center Movement, notably consumer boards and NACHC itself

3



Skilled and Mission-driven Workforce

Develop a highly skilled, adaptive, and mission-driven workforce reflecting the communities served

4



Reliable and Sustainable Funding

Secure reliable and sustainable funding to meet increasing demands for Community Health Center services

5



Improved Care Models

Update and improve care models to meet the evolving needs of the communities served

6



Supportive Partnerships

Cultivate new and strengthen existing mutually beneficial partnerships to advance the shared mission of improving community health

To learn more about NACHC's Strategic Pillars visit <https://www.nachc.org/about/about-nachc/>

THE NACHC MISSION

America's Voice for Community Health Care

The National Association of Community Health Centers (NACHC) was founded in 1971 to promote efficient, high quality, comprehensive health care that is accessible, culturally and linguistically competent, community directed, and patient centered for all.



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* Disclosure: Julia is also the volunteer Board Chair of HealthLevel7 International, an international health IT standards development organization (SDO).



Agenda

- Understanding the scope of disability in the health data ecosystem
- The challenge of disability documentation in EHRs
- Structured data around disability and functional status
- Health equity and SDOH: PRAPARE, Gravity, and more
- Workflow for disability determination– data extraction and capture

THE COMMUNITY HEALTH CENTERS: AN OUTGROWTH OF THE CIVIL RIGHTS MOVEMENT



Dr. Robert Smith formed the Southern branch of the Medical Committee for Civil Rights (MCCR) in 1963 to protest the American Medical Association (AMA), which allowed southern medical societies to remain segregated and often kept Black physicians from being employed at hospitals.

Health centers were created to provide culturally competent healthcare in healthcare access deserts, a practice which continues today.

Originally intending to pursue a cardiology practice, Dr. James Hotz somehow found himself practicing family medicine in southwest Georgia instead. Below: one of the first sites of a clinic he helped establish.



@NACHC    

HEALTH CENTERS

FIVE ESSENTIAL ELEMENTS

1. Located in **high-need areas**.
2. Provide **comprehensive** health and wraparound services (including enabling services).
3. **Open to all** residents, regardless of insurance or ability to pay, with sliding scale fee based on income.
4. Nonprofits, governed by **community boards**, to assure responsiveness to local needs.
5. **Follow performance and accountability requirements** regarding their administrative, clinical, and financial operations.



TODAY

Community Health Centers are the most comprehensive, wide-spread and effective primary care providers. **No patient is turned away.**

 **14K** Delivery Sites
 **1,487** Health Centers



31.5+M people served (1 in 11)

400K Veterans

1.3M Homeless People

8.6M Children

3.3M Elderly Patients

1 in 5 uninsured 

1 in 5 rural residents 

1 in 3 people living in poverty 

How I see disability in my work with individual patients

- Disability means different things to different individuals
- My primary goal for patients is helping them achieve and maintain needed or desired functionality and goals
- Traditional model of care has limited focus on assessing and improving functional status
- Different lenses of ability include behaviors, mental health, physical and cognitive ability
- Much of what a PCP sees on “disability” is paperwork (sometimes unpaid)



What about the EHR?

- Theoretically, the EHR contains all the information about a patient needed to understand their functional and disability status
- In reality, EHRs do not adequately support functional status and disability workflows. A concerted effort is required to gain a data-driven picture of the patient and their status.
- The patient's story is often lost in translation and fragmented pieces exist across the ecosystem. This gap then comes back to hit the care team as they seek to support the patient.



The time for FHIR is NOW: Fast Healthcare Interoperability Resources

Designed for and excels at:

- Ease of data extraction
- Exchange through API
- Use of services
- Easy for programmers to use,
 - even without health IT (HIT) expertise
- Open source (free to use)
- **Required FHIR API available to certified products Dec 31, 2022**




The Office of the National Coordinator for
Health Information Technology



What Is HL7® FHIR®?

HL7® FHIR®¹ – Fast Healthcare Interoperability Resources

is a next-generation interoperability standard created by the standards development organization Health Level 7 (HL7®). FHIR is designed to enable health data, including clinical and administrative data, to be quickly and efficiently exchanged.

USCDI Draft v5 Summary of Data Classes and Data Elements

Allergies and Intolerances

- Substance (Medication)
- Substance (Drug Class)
- Substance (Non-Medication)
- Reaction

Care Team Members

- Care Team Member Name
- Care Team Member Identifier
- Care Team Member Role
- Care Team Member Location
- Care Team Member Telecom

Clinical Notes

- Consultation Note
- Discharge Summary Note
- Emergency Department Note
- History & Physical
- Operative Note
- Procedure Note
- Progress Note

Clinical Tests

- Clinical Test
- Clinical Test Result/Report

Diagnostic Imaging

- Diagnostic Imaging Test
- Diagnostic Imaging Report

Encounter Information

- Encounter Type
- Encounter Identifier
- Encounter Diagnosis
- Encounter Time
- Encounter Location
- Encounter Disposition

Facility Information

- Facility Identifier
- Facility Type
- Facility Name

Goals and Preferences

- Patient Goals
- SDOH Goals
- Treatment Intervention Preference
- Care Experience Preference

Health Insurance Information

- Coverage Status
- Coverage Type
- Relationship to Subscriber
- Member Identifier
- Subscriber Identifier
- Group Identifier
- Payer Identifier

Health Status Assessments

- Health Concerns
- Functional Status
- Disability Status
- Mental/Cognitive Status
- Pregnancy Status
- Alcohol Use
- Substance Use
- Physical Activity
- SDOH Assessment
- Smoking Status

Immunizations

- Immunizations
- Lot Number

Laboratory

- Tests
- Values/Results
- Specimen Type
- Result Status
- Result Unit of Measure
- Result Reference Range
- Test Kit Unique Device Identifier
- Result Interpretation
- Specimen Source Site
- Specimen Identifier
- Specimen Condition Acceptability

Medical Devices

- Unique Device Identifier - Implantable

Medications

- Medications
- Dose
- Dose Unit of Measure
- Route
- Indication
- Fill Status
- Medication Instructions
- Medication Adherence

Observations

- Advance Directive Observation
- Sex Parameter for Clinical Use

Orders

- Orders

Patient Demographics/ Information

- First Name
- Last Name
- Middle Name
- (Including middle initial)
- Name Suffix
- Previous Name
- Name to Use
- Pronoun
- Date of Birth
- Date of Death

Patient Demographics /Information

(cont)

- Race
- Ethnicity
- Tribal Affiliation
- Sex
- Sexual Orientation
- Gender Identity
- Preferred Language
- Interpreter Needed

- Current Address
- Previous Address
- Phone Number
- Phone Number Type
- Email Address
- Related Person's Name

- Relationship Type
- Occupation
- Occupation Industry

Patient Summary and Plan

- Assessment and Plan of Treatment

Problems

- Problems
- SDOH Problems/Health Concerns
- Date of Diagnosis
- Date of Resolution

Procedures

- Procedures
- Performance Time
- SDOH Interventions
- Reason for Referral

Provenance

- Author
- Author Role
- Author Time Stamp
- Author Organization

Vital Signs

- Systolic Blood Pressure
- Diastolic Blood Pressure
- Average Blood Pressure
- Heart Rate
- Respiratory Rate
- Body Temperature
- Body Height
- Body Weight
- Pulse Oximetry
- Inhaled Oxygen Concentration
- BMI Percentile (2 - 20 years)
- Weight-for-length Percentile (Birth - 24 Months)
- Head Occipital-frontal Circumference Percentile (Birth- 36 Months)

United States Core Data for Interoperability

Draft Version 5 | January 2024

US Core Data for Interoperability (USCDI)

Disability Status

- Disability Status exists in USCDI and as part of eCR reporting
- The USCDI binding is limited to LOINC codes
- Needed metadata is likely missing by using only LOINC
- Alignment or standardization of tools will impact interoperability

Disability Status

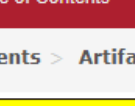
Assessment of a patient's physical, cognitive, or psychiatric disabilities.

Examples include but are not limited to American Community Survey, Veterans RAND Health Survey, and Patient-Reported Outcomes Measurement Information System (PROMIS).

Applicable Vocabulary Standard(s)

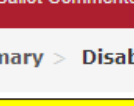
- Logical Observation Identifiers Names and Codes (LOINC®) version 2.76

Disability Status: eCR Implementation Guide



HL7 FHIR® Implementation Guide: Electronic Case Reporting (eCR) - US Realm

1.1.0 - STU 2 Ballot

IG Home

Table of Contents

Notice to Ballot Commenters

Transaction Profiles ▾

Implementation Guidance ▾

Downloads

Artifact Index

Table of Contents > Artifacts Summary > Disability Status

This page is part of the electronic Case Reporting (eCR) (v1.1.0: [STU 2](#) on FHIR R4 Ballot 1) based on [FHIR R4](#). The current version which supercedes this version is [2.1.0](#). For a full list of available versions, see the [Directory of published versions](#).

Content

Detailed Descriptions

Mappings

Examples

XML

JSON

TTL

8.27.1 Resource Profile: Disability Status

Defining URL:	http://hl7.org/fhir/us/ecr/StructureDefinition/disability-status
Version:	1.1.0
Name:	DisabilityStatus
Status:	Active as of 2020-12-16T19:27:50+00:00
Definition:	This profile represents the Disability Element defined here: https://aspe.hhs.gov/basic-report/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-and-disability-status
Publisher:	HL7 Public Health Work Group (http://www.hl7.org/Special/committees/phew/index.cfm)

Status

g?

g, even when wearing glasses?

on, do you have serious difficulty concentrating, remembering, or making decisions? (5 years old or older)

airs? (5 years old or older)

old or older)

on, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)

Standard and the questions and answer categories cannot be changed. Additional questions on disability may be added to any

e ACS changes the disability questions in the future, HHS will revisit the standard and modify as necessary.

1. Do you have serious difficulty walking or climbing stairs? (5 years old or older)

5. Do you have difficulty dressing or bathing? (5 years old or older)

6. Because of a physical, mental, or emotional condition, do you have difficulty doing errands alone such as visiting a doctor's office or shopping? (15 years old or older)

The six-item disability standard represents a minimum standard and the questions and answer categories cannot be changed. Additional questions on disability may be added to any survey as long as the minimum standard is included. If the ACS changes the disability questions in the future, HHS will revisit the standard and modify as necessary.

Functional Status

- Functional status is a key data element supporting understanding ability; however, it is not routinely documented in health records
- Standardization and coding of existing instruments is feasible; however, individual organizations may need to take action locally to support with variable interoperability and extraction success

Functional Status

Assessment of a person's ability to perform activities of daily living and activities across other situations and settings.

Examples include but are not limited to Functional Assessment Standardized Items (FASI) and Timed Up and Go (TUG).

Applicable Vocabulary Standard(s)

- Logical Observation Identifiers Names and Codes (LOINC®) version 2.76

[View Submission +](#)

Cognitive Status

- Cognitive status in USCDI does not point to any specific instruments
- Even when there is EHR documentation, there may not be an easy way to identify changes in the status over time— additional build may be needed to alert care teams or trigger actions

Mental/Cognitive Status

Assessment or screening for the presence of a mental or behavioral problem.

Examples include but are not limited to alertness, orientation, comprehension, concentration, and immediate memory for simple commands.

Applicable Vocabulary Standard(s)

- Logical Observation Identifiers Names and Codes (LOINC®) version 2.74



• **Observation:** "Eating: The ability to use suitable utensils to bring food and/or liquid to the mouth and swallow food and/or liquid once the meal is placed before the {patient/resident}" (CMS GG0130A1, LOINC 95019-6)

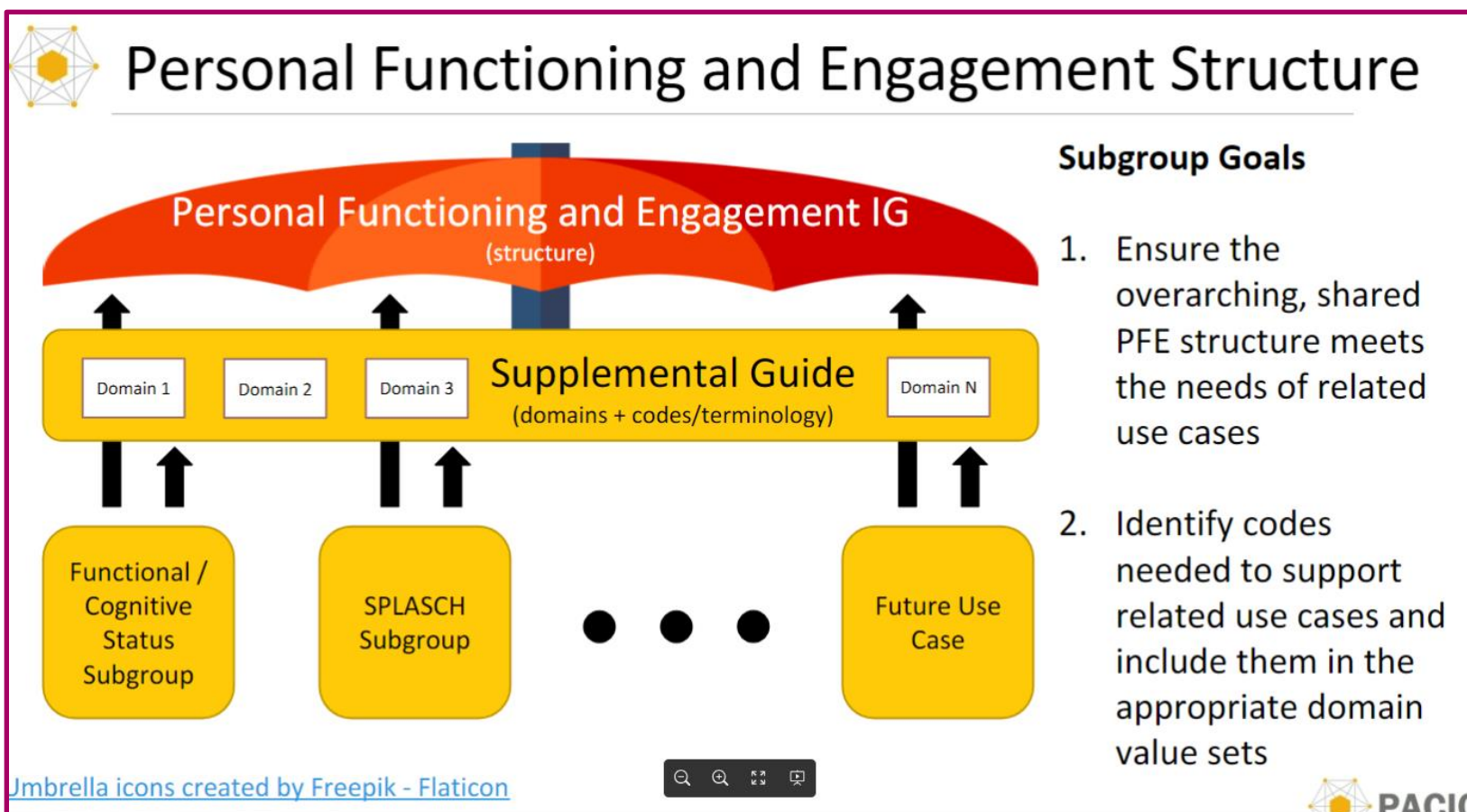
• **Hierarchy:** "Activities and participation", because the focus is on the task of eating, including many constituent parts

• **Chapter:** "Self-care" (d5), because the "Eating" activity appears underneath it

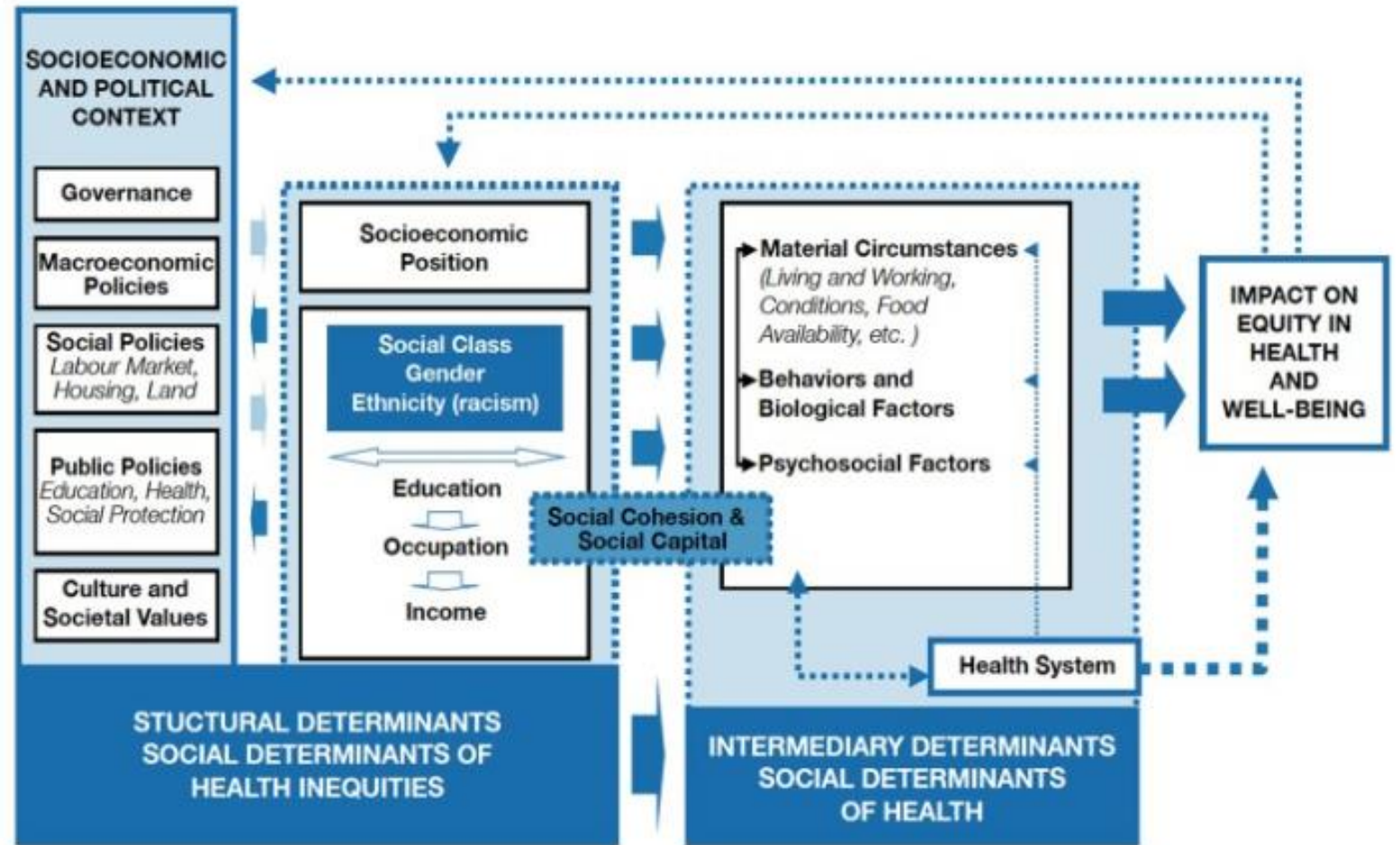
1. ICF Category
 - Body functions
 - **Activities and participation**
 - Body structures
2. Activities and participation
 - Learning and applying knowledge
 - General tasks and demands
 - Communication
 - Mobility
 - **Self-care**
 - d510 Washing oneself
 - d520 Caring for body parts
 - d530 Toileting
 - d540 Dressing
 - **d550 Eating**

Domain = "Self-care" (d5)

Partnership in HL7 that seeks to create formal standards for post-acute, home and functional status improvement

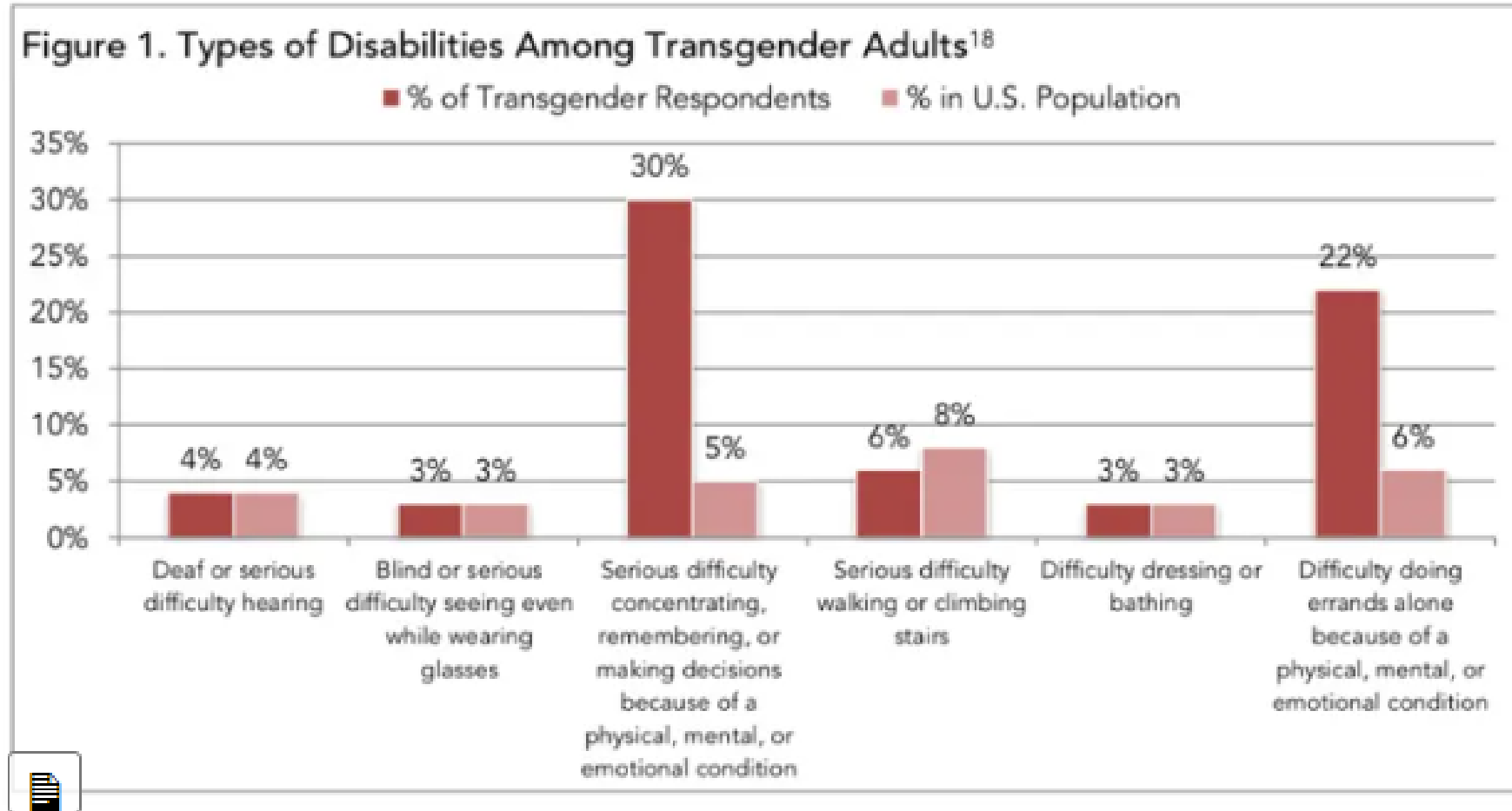


Intersectionality of SDOH/HSRNs and Disability



<https://sites.rowan.edu/diversity-equity-inclusion/blog/2023/10/race-disability-social-determinants-of-health.html>

Intersectionality of SDOH and Disability



https://dredf.org/health-disparities-at-the-intersection-of-disability-and-gender-identity/#_ftn1

ACCELERATING ADOPTION

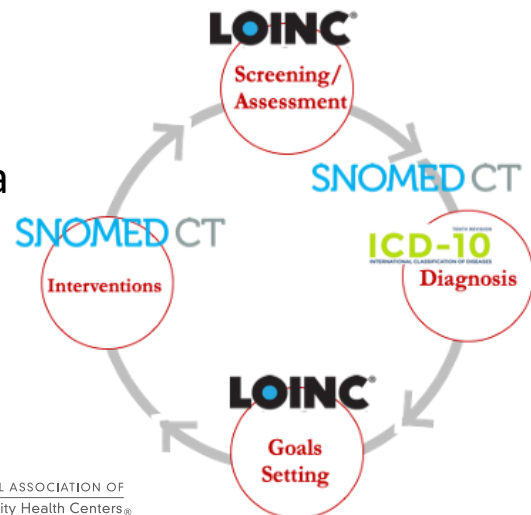
Using nationally recognized standards to advance SDOH



Consensus
Approved
SDOH Data
Elements



Coded
SDOH Data
Elements



FHIR

Fast Healthcare Interoperability Resources

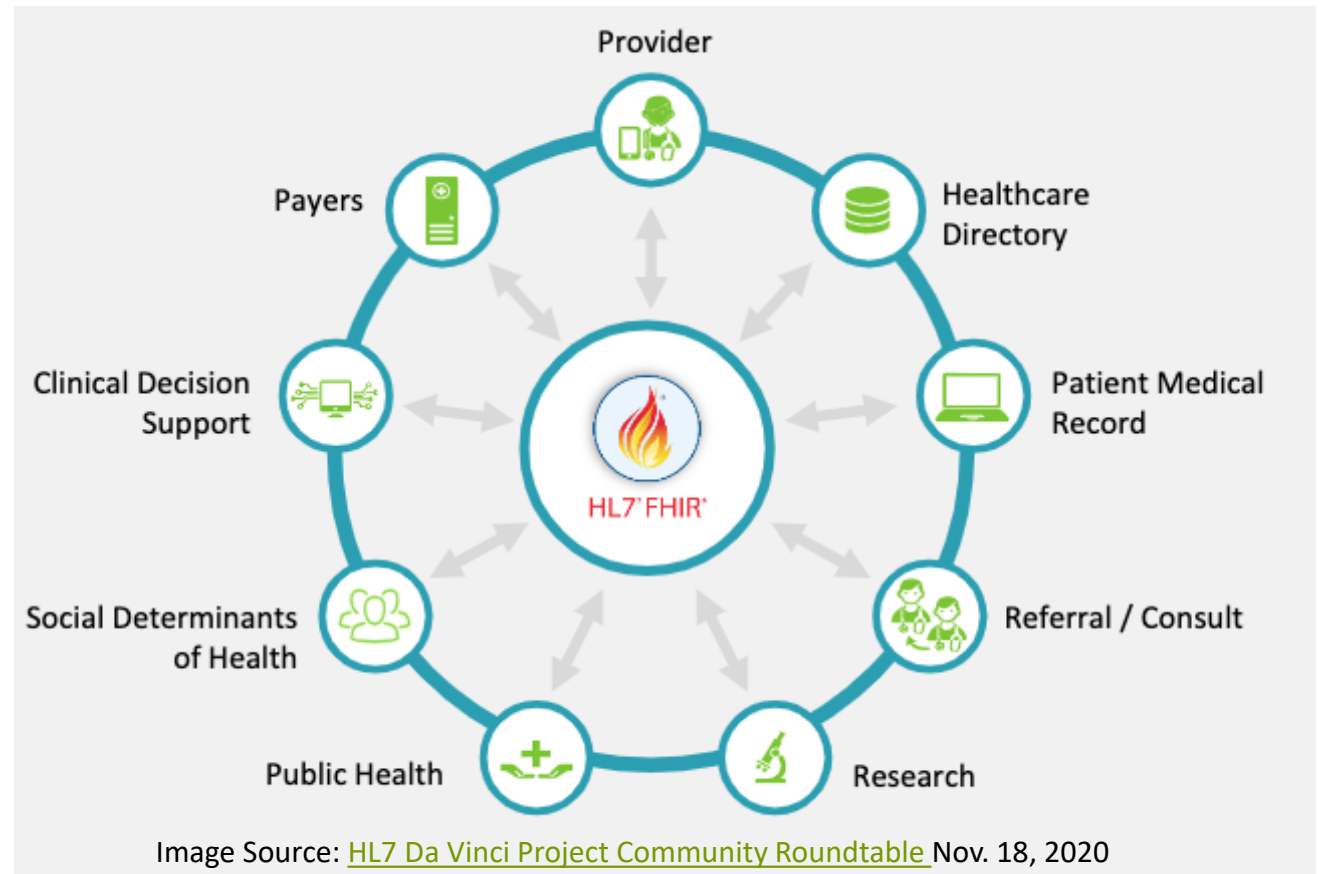


Image Source: [HL7 Da Vinci Project Community Roundtable](#) Nov. 18, 2020

Gravity Terminology Domains



FOOD INSECURITY

Definition: Uncertain, limited, or unstable access to food that is: adequate in quantity and in nutritional quality; culturally acceptable; safe and acquired in socially acceptable ways.

HOUSING INSTABILITY

Definition: Currently consistently housed but experiencing any of the following circumstances in the last 12 months: behind on rent or mortgage, 3 or more relocations, housing cost burden, homelessness, or risk of eviction.

HOMELESSNESS

Definition of Sheltered Homelessness: Because of economic difficulties, currently living in a shelter, motel, temporary or transitional living situation, scattered-site housing, or not having a consistent place to sleep at night.

Definition of Unsheltered Homelessness: Residing in a place not meant for human habitation, such as cars, parks, sidewalks, abandoned buildings, on the street.

INADEQUATE HOUSING

Definition: Housing does not meet habitability standards.

TRANSPORTATION INSECURITY

Definition: Uncertain, limited, or no access to safe, reliable, accessible, affordable, and socially acceptable transportation infrastructure and modalities necessary for maintaining one's health, well-being, or livelihood.

FINANCIAL INSECURITY

Definition: A state of being wherein a person has difficulty fully meeting current and/or ongoing financial obligations and/or does not feel secure in their financial future.

MATERIAL HARDSHIP

Definition: The lack of specific socially perceived basic physical necessities.

EDUCATIONAL ATTAINMENT

Definition of Less Than High School Education: Failing to meet academic criteria for high school diploma or equivalent.

EMPLOYMENT STATUS

Definition of Unemployment: Jobless, looking for a job, and available for work.

VETERAN STATUS

Definition of Veteran: Having served as active military and honorably released or discharged.

STRESS

Definition: Occurs when a person perceives the demands of environmental stimuli to be greater than their ability to meet, mitigate, or alter those demands

SOCIAL CONNECTION

Definition of Social Connection: An umbrella term that encompasses the structural, functional, and quality aspects of how individuals connect to each other.

Definition of Social Isolation: Is objectively being alone, having few relationships, or infrequent social contact.

Definition of Loneliness: Is subjectively feeling alone. The discrepancy between one's desired level of connection and one's actual level.

Definition of Social Support: The actual or perceived availability of resources (e.g., informational, tangible, emotional) from others. Four types of social supportive

Gravity Terminology Domains



Health Literacy

Healthy People 2030 Health Literacy Definitions

Definition of Personal Health Literacy: The degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Definition of Organizational Health Literacy: The degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.

Health Insurance Coverage Status

Definition: Documentation of presence and type of insurance.

INTIMATE PARTNER VIOLENCE (IPV)

Definition: Describes physical violence, sexual violence, or psychological harm by a current or former partner or spouse. Often including a pattern of methods and tactics to gain and maintain power and control over the other person.

ELDER ABUSE

Definition: An intentional act or failure to act by a caregiver or another person in a relationship involving an expectation of trust that causes or creates a risk of harm to an older adult and can be in the form of physical abuse, psychological abuse, sexual abuse, financial abuse, and neglect by someone in a caregiving role.

DIGITAL ACCESS

Definition of Inadequate Digital Access: Lacks: Adequate internet (reliable and of sufficient speed) to participate in day-to-day and work life OR A digital device to access the internet (the device must be appropriate for the user's functional abilities).

UTILITY INSECURITY

Definition: TBD.

Medical Cost Burden

Definition: A measure of financial pressure resulting from health spending stemming from inadequate resources to meet medical cost needs.

DIGITAL LITERACY

Definition of Inadequate Digital Literacy Skills: The inability to access, manage, understand, integrate, communicate, evaluate, and create information safely and appropriately through digital devices and networked technologies for participation in economic, social, and political life (USAID).

What is PRAPARE?

A national **standardized** patient risk assessment **protocol** **built into the EHR** designed to **engage patients** in assessing and addressing social determinants of health.

Customizable Implementation and Action Approach

Assess Needs



Respond to Needs

At the Patient and Population Level

www.nachc.org/prapare

PRAPARE DOMAINS

Core

UDS SDH Domains	Non-UDS SDH Domains (MU-3)
1. Race	10. Education
2. Ethnicity	11. Employment
3. Veteran Status	12. Material Security
4. Farmworker Status	13. Social Isolation
5. English Proficiency	14. Stress
6. Income	15. Transportation
7. Insurance	
8. Neighborhood	
9. Housing Status and Stability	

Optional

1. Incarceration History	3. Domestic Violence
2. Safety	4. Refugee Status

USING Z CODES:

The **Social Determinants of Health (SDOH)** Data Journey to Better Outcomes

What are
Z
codes

SDOH-related Z codes ranging from Z55-Z65 are the ICD-10-CM encounter reason codes used to document SDOH data (e.g., housing, food insecurity, transportation, etc.).

SDOH are the conditions in the environments where people are born, live, learn, work, play, and age.



Step 1 Collect SDOH Data

Any member of a person's care team can collect SDOH data during any encounter.

- Includes providers, social workers, community health workers, case managers, patient navigators, and nurses.
- Can be collected at intake through health risk assessments, screening tools, person-provider interaction, and individual self-reporting.

Step 2 Document SDOH Data

Data are recorded in a person's paper or electronic health record (EHR).

- SDOH data may be documented in the problem or diagnosis list, patient or client history, or provider notes.
- Care teams may collect more detailed SDOH data than current Z codes allow. These data should be retained.
- Efforts are ongoing to close Z code gaps and standardize SDOH data.

Step 3 Map SDOH Data to Z Codes

Assistance is available from the ICD-10-CM Official Guidelines for Coding and Reporting.¹

- Coding, billing, and EHR systems help coders assign standardized codes (e.g., Z codes).
- Coders can assign SDOH Z codes based on self-reported data and/or information documented in an individual's health care record by any member of the care team.²

Step 4 Use SDOH Z Code Data

Data analysis can help improve quality, care coordination, and experience of care.

- Identify individuals' social risk factors and unmet needs.
- Inform health care and services, follow-up, and discharge planning.
- Trigger referrals to social services that meet individuals' needs.
- Track referrals between providers and social service organizations.

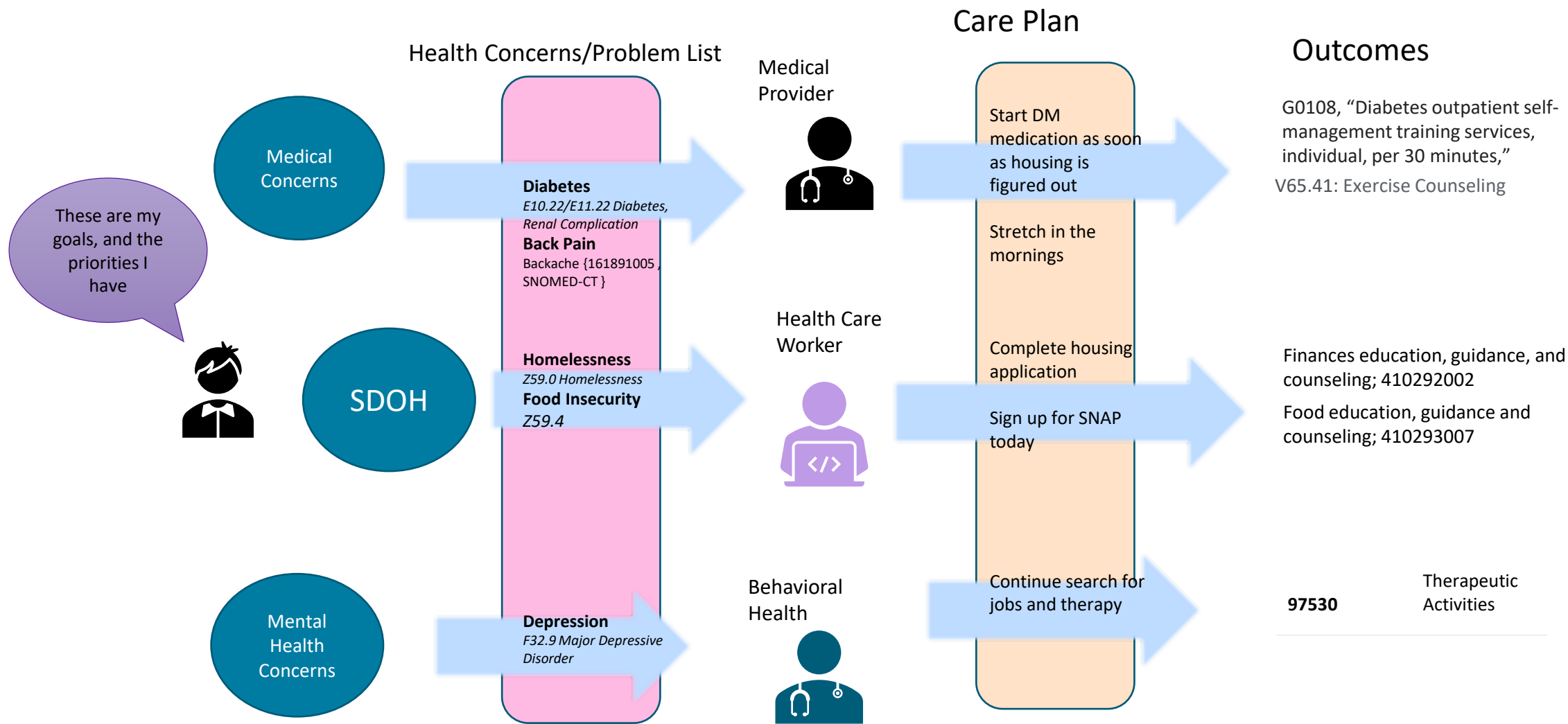
Step 5 Report SDOH Z Code Data Findings

SDOH data can be added to key reports for executive leadership and Boards of Directors to inform value-based care opportunities.

- Findings can be shared with social service organizations, providers, health plans, and consumer/patient advisory boards to identify unmet needs.
- A **Disparities Impact Statement** can be used to identify opportunities for advancing health equity.



Shared Care Plans: A Patient-centered Approach



FHIR Care Plan:

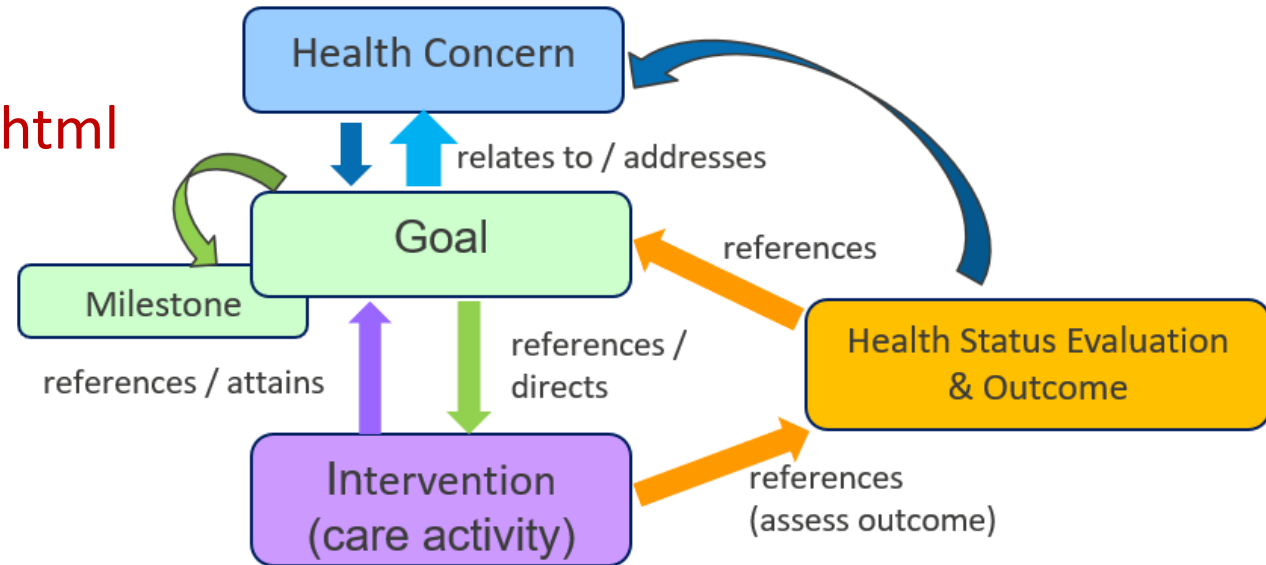
<https://www.hl7.org/fhir/careplan.html>

**Care plan concept –
introduced in 1980s**

Care plans in the 1980s:

- Static structure
 - Problem(s)
 - Interventions
 - Variances
- Care coordination (if done)
 - Completely manual

The 4 cornerstones of a care plan



Content:

- Health concern(s)
- Health goal(s)
- Activity/intervention
- Progress/outcome
- and more ...

Dynamic behavior:

- Machine assisted care coordination

Vision Today

OPPORTUNITIES FOR THE EHR TO SUPPORT DISABILITY

Standardized disability templates and data elements

- Requires partnership from SSA, insurers and care organizations with subject matter experts
- Could be pushed into regulatory frameworks

Electronic submission of forms

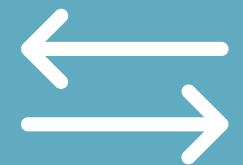
- Would depend on the first opportunity being done first
- Could be done in the model of electronic prior authorization (designed by payers, specified in standards, referenced in regulation)

EHR support for care teams

- Regular evaluation and documentation of functional status, cognitive and behavioral health status, SDOH/HSRNs
- These data could be integrated into templates or decision support for care teams to trigger action

Integration of patient-generated health data

- Patients can utilize apps to track their own status– this data could be integrated back to the EHR using APIs



QUESTIONS?

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THANK YOU!



NATIONAL ASSOCIATION OF
Community Health Centers®

PLEASE VISIT US ONLINE

nachc.org



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