*Issue Brief*

# The Case for Including Functional Limitation Measures in Electronic Health Records

*The Disability Rights Education and Defense Fund (DREDF) strongly supports including either the American Community Survey (ACS) set of six disability questions or other equivalent functional limitation measures in electronic health records.*

## Health Disparities and Barriers to Care

In 2014, an estimated 53 million people with disabilities over age 18 lived in the United States, or 23 percent (23%) of the population. An estimated 14 percent (14%) of people within the adult U.S. population have a complex activity limitation that affects their ability to participate in society, including maintaining a household, working, and pursuing hobbies. People with disabilities or complex activity limitations are likely to be at greater risk for health and health care disparities than the general population.[1]

Research has shown that people with disabilities are more likely than the general population to experience difficulties or delays in getting the health care they need, not have had an annual dental visit, have high blood pressure, use tobacco, or be overweight. Women with disabilities are more likely not to have had a mammogram in the past two years or to have been screened for cervical cancer in the past three years.[2] They also have higher death rates from breast cancer than women without disabilities. Studies show that people with disabilities also die from lung cancer at higher rates than the general population.[3] Health and health care disparities among people with disabilities can be attributed in part to complex barriers to care that contribute to difficulties or delays in getting needed health care and increase the likelihood of poor health outcomes. Identified barriers include lack of provider awareness and training, lack of accessible medical offices and facilities, and a dearth of accommodations such as accessible medical and diagnostic equipment, lifting assistance, or Sign Language interpreters. Certain inflexible policies also create barriers to care such as the inability of a provider to extend a patient visit to ensure time for lifting assistance on to an exam table or effective communication for someone with a speech or cognitive limitation.[4]

A 2015 study has shed additional light on these problems by analyzing in some detail the underlying causes of health disparities among people with disabilities. Authors found that, "Population-level differences in health outcomes...are related to a history of wide-ranging disadvantages, which are avoidable and not primarily caused by the underlying disability."[5] Another recent study illustrates certain of these avoidable disadvantages. In 2014, 256 specialty providers were asked if they would accept a referral of a large patient who used a wheelchair and required transfer assistance. The study revealed that 22 percent (22%) of the specialty provider offices could not accommodate this patient, 4 percent (4%) were architecturally inaccessible and 18 percent (18%) couldn't assist the patient to transfer onto an exam table. Gynecology was the subspecialty with the highest rate of inaccessible practices (44%).[6] Such lack of accessibility and impairment-related accommodation is commonplace not only among specialty providers, but also among primary care practices, diagnostic centers and facilities, clinics, and hospitals. These barriers frequently prevent patients from obtaining needed care and treatment.[7]

## Three-Step Process to Improve Access

The disability community has long advocated for a three-step process that would assess physical accessibility in health care settings and establish processes whereby providers consistently identify and accommodate patients' functional limitations. The overarching, long-term goal of this process is to improve accessibility among providers over time so identifying accommodation needs and meeting those needs becomes routine, efficient, and expected.

Facilitating programmatic access is a central goal of the process. Programmatic access means that the policies and practices that are part of the delivery of health care do not hinder the ability of patients with disabilities to receive the same quality of care as other people. Where usual health care practice may impose barriers, modifications in policy or procedure may be necessary to assure access. Policies and procedures that comprise programmatic access involve: methods of communicating with patients for the provision of individual medical information and general health information; appointment scheduling procedures and time slots; patient treatment by the medical staff; awareness of and methods for selecting and purchasing accessible equipment; staff training and knowledge (e.g., for operation of accessible equipment, assistance with transfer and dressing, conduct of the exam); standards for referral for tests or other treatment; system-wide coordination and flexibility to enable access; and disability literacy.[8] Including functional limitation questions in the EHR can trigger the process whereby providers identify, plan for, and meet these individual patient needs.

The three-step process involves:

1. Surveying physical accessibility of provider facilities
2. Identifying physical, mental and/or cognitive functional limitations and required accommodations in electronic health records
3. Creating policies and procedures that providers follow when patients with identified functional limitations require accommodations

## *1. Surveying physical accessibility of provider facilities*

People with various impairments require architectural accessibility in order to get to and into the medical offices and facilities of health care practitioners and diagnostic centers. While disability rights laws such as the federal Americans with Disabilities Act (ADA) require health care facilities to be accessible, not all are fully accessible or even meet minimum requirements. Even as 84 percent (84%) of visits to primary care delivery sites occur in physician offices,[9] in most locales around the country accessibility information is very limited and people with disabilities have no reliable way to determine accurately whether or not the facility of a primary health care provider, including parking, main entrances, offices, exam rooms and restrooms will be accessible to them until they arrive for a medical visit. Moreover, as health care is increasingly provided through managed care, patients enrolled in such health plans only have access to providers participating in the plans' networks and therefore do not have the option of switching to an accessible provider who does not participate in the plan. Consequently, managed care plans must take accessibility into consideration when they determine provider network adequacy and inform patients about which participating providers are and are not located in accessible facilities, yet few do so. They also should be proactively recruiting providers that meet minimum accessibility requirements and helping current providers meet accessibility obligations in order to avoid discrimination by ensuring that members with disabilities have the same choice of providers that is available to members who do not have disabilities.

In recent years, California Medicaid Managed Care Organizations (MMCOs) have made some progress assessing the accessibility of their primary care provider networks. A few MMCOs in the state began testing an accessibility survey in the mid-2000's and in 2011 the California Department of Health Care Services (DHCS) began requiring all MMCOs to use an updated on-site survey with their primary care physician (PCP) network and post certain outcomes on their websites.[10] In addition to architectural accessibility the survey also measures the availability of accessible weight scales and height adjustable exam tables. A published study of

findings from an earlier iteration of the survey carried out by the Disability Rights Education and Defense Fund (DREDF) and researchers with Syracuse University revealed two important facts in addition to the extent to which MMCO PCP networks are physically accessible. Among over 2300 provider offices, the study found that only 8.4 percent (8.4%) had height adjustable exam tables and 3.6 percent (3.6) had accessible weight scales.[11] Lack of such equipment means that people with certain mobility disabilities cannot be weighed or be properly examined if they cannot independently climb onto a high exam table. These barriers contribute to certain health and health care disparities previously described. Even as most states have done little to assess health care provider accessibility, new proposed federal regulations and initiatives suggest a growing understanding of why this information is critical to patient care and health outcomes. For example, draft managed care regulations issued by the Centers for Medicare and Medicaid Services (CMS) in June 2015 require that each Medicaid managed care organization ensure that practitioners provide physical access, accommodations, and accessible equipment for individuals with physical or mental disabilities. The draft regulations also indicate that in developing network adequacy standards, the State must consider the ability of providers to ensure physical access, reasonable accommodations, culturally competent communications, and accessible equipment for individuals with physical or mental disabilities. Moreover, the commentary to the draft regulations emphasizes the importance of electronic health records for the coordination of care, thus opening the door to collecting patient functional limitation information in order to arrange needed accommodations.[12] If these proposed regulations are implemented, states will need to find adequate ways to assess the extent to which health care provider networks meet the requirements. It is therefore likely they will turn to models already in place that have proven effective.

A number of states are also participating in demonstrations that are testing the benefits of integrating care for people who are dually eligible for both Medicare and Medicaid. Some three-way contracts between CMS, participating states and MMCOs have included specific provisions requiring that MMCOs assure physical and programmatic access and the provision of accommodations for people with disabilities. For example, the Massachusetts OneCare Three-Way Contract calls for developing and implementing a strategy to,

> "Manage the Provider Network with a focus on access to services for Enrollees, quality, consistent practice patterns, the principles of rehabilitation and recovery for Behavioral Health Services, the Independent Living Philosophy, Cultural Competence, integration and cost effectiveness. The management strategy shall address all providers. Such strategy shall include at a minimum, conducting on-site visits to Network Providers for quality management and quality improvement purposes, and for assessing meaningful compliance with ADA requirements…[and] the Contractor must…reasonably accommodate persons and ensure that the programs and services are as accessible

(including physical and geographic access) to an individual with disabilities as they are to an individual without disabilities."[13]

Similarly, the Michigan MI Health Link contract states that, "The ICO [Integrated Care Organization] must reasonably accommodate persons and shall ensure that the programs and services are as accessible (including physical and geographic access) to an individual with disabilities as they are to an individual without disabilities." It goes on to call for, "…written policies and procedures to assure compliance [with the Americans with Disabilities Act], including ensuring that physical, communication, and programmatic barriers do not inhibit individuals with disabilities from obtaining all Covered Services…"[14]

In addition to such mechanisms as these, in 2015 CMS issued an Equity Plan for Improving Quality in Medicare that includes a priority of increasing physical accessibility of health care facilities.[15]

## *2. Identifying physical, mental and/or cognitive functional limitations in electronic health records*

In light of the changing regulatory landscape and a growing understanding of the underlying causes of health and health care disparities among people with disabilities, it is increasingly important to consistently identify and record physical, mental and/or cognitive functional limitations in electronic health records (EHR). This data is required in order to understand and plan for the prevalence of functional limitations among the patient population and to be able to cross reference it for research and policy purposes with population health and other demographic information such as race/ethnicity, gender, age, and LGBT status. Including functional limitation queries in the EHR would significantly benefit research into the health care disparities experienced by people who have intersectional bases for discrimination and unequal treatment such as disability and another demographic characteristic because such cross-analysis cannot currently be carried out without reliable information about the prevalence of functional limitation.

Moreover, the medical diagnostic codes that are presently included in medical records do not offer a solution because a single diagnostic code can be associated with wide variance in functional capacity and does not correspond to or represent the level or degree of a given individual's functional limitation. Information on functional need is critical to trigger provider administrative processes that result in needed accommodations before and during a patient's health care visit such as lifting assistance, assignment to an exam room with an adjustable height exam table, an ASL interpreter, or extended exam time.

# An Early Innovator: LifeLong Medical Care Tests Functional Impairment Questions

Several years ago, LifeLong Medical Care, a Federally Qualified Health Center located near San Francisco, in Alameda County, California, decided to embed functional impairment questions in the health center's registration form in order to alert primary care staff that some patients required accommodations so they could receive maximum benefit from health care. These questions are included in the clinic's electronic health record and can be flagged in individual patient records.

## TABLE 1. LifeLong Medical Care Disability and Language Assistance Data – 2015

| Jan. – Dec. 2015 | Unduplicated Patient Count |
|---|---|
| Language Interpreter Needed | 633* |
| Long Appointment Only | 26 |
| Sign Language Interpreter | NA |
| Mobility Assistance | 2281 |
| None | 30555 |
| Support for Low Vision or Blindness | 39 |
| (blank) | 62 |
| **Grand Total** | **33596**[16] |

*(LifeLong includes a query about language interpretation needs along with disability accommodation questions in the EHR.)

Table 1 sets forth some categories of information that LifeLong collects and data showing the number of patients requesting certain spoken language or disability assistance or accommodations who visited either one of LifeLong's ten primary care clinics, health care practitioners located at several supportive housing sites, a dental practice or two school-based sites in Alameda County during 2015.

According to LifeLong, during 2015 about 9 percent (9%) of unduplicated patients who visited the various sites in Alameda County indicated that they needed some type of language

or disability assistance or accommodation. (LifeLong also collects data on patients who need Sign Language Interpreters, but that data was not available at the time this Issue Brief was being written.) About 7.5 percent (7.5%) indicated a solely disability-related accommodation need, excluding Sign Language interpreters. LifeLong records show that 22 individuals had more than one disability or language accommodation need.[17] These data are important because they likely represent the first time that functional limitation questions not only have been embedded in electronic health records, but that also identify some specific areas of disability assistance patients require in the clinical setting. While more study is needed to understand how LifeLong uses the identified functional accommodation information, and indeed whether these are the best questions to ask to collect the needed information, these early data highlight the importance of initiating the inquiry and embedding responses in patient records so clinic staff can plan and prepare adequately for patient visits.

Furthermore, we know from extensive reports from the disability community that unless the need for disability accommodations is proactively recorded in the patient's medical record, provider offices simply cannot or will not provide required accommodations, thus denying access for some people with disabilities to even the most common health measures such as weight measurement and routine prevention procedures such as cervical cancer screening.[18] By recording the presence of a functional limitation, providers can more readily prepare for visits by such patients and take steps to ensure that they receive appropriate diagnostic tests and needed treatment and care.

## *3. Creating provider policies and procedures to be followed when patients with identified functional limitations require accommodations*

The third prong of the three-step process requires that practitioner offices and health care facilities adopt policies and procedures that provide guidance to both front and back office staff about how to arrange needed patient accommodations. Once a patient indicates the presence of a physical, mental or cognitive functional limitation and the requirement for one or more specific accommodations, these policies standardize and guide the process of arranging the accommodations, and help to ensure they are consistently provided over time.[19]

# Selecting Functional Impairment Measures to Include in Electronic Health Records

The American Community Survey (ACS) six disability questions set is particularly appropriate for inclusion in electronic health records because it has been thoroughly tested and validated and has been adopted in many federal data collection systems.[20, 21] The questions concern six disability types:

- **Hearing difficulty**—deaf or having serious difficulty hearing.
- **Vision difficulty—**blind or having serious difficulty seeing, even when wearing glasses.
- **Cognitive difficulty—**Because of a physical, mental, or emotional problem, having difficulty remembering, concentrating, or making decisions.
- **Ambulatory difficulty—**Having serious difficulty walking or climbing stairs.
- **Self-care difficulty—**Having difficulty bathing or dressing.
- **Independent living difficulty**—Because of a physical, mental, or emotional problem, having difficulty doing errands alone such as visiting a doctor's office or shopping.

Moreover, because the ACS six questions set measures functional limitation related to specific impairment categories, the questions are also useful for flagging the need for accommodations that many people with disabilities require in order to receive care, but that are frequently not provided. We recognize, however, that such flagging requires that the ACS 6 disability questions also link to specific accommodation queries in EHRs in order to produce meaningful experiences and results for patients and assist health care practitioners to plan and arrange for appropriate patient care. The accommodation questions in use by LifeLong, specifically long appointment time, mobility assistance, Sign Language interpreter, and support for low vision or blindness, are examples of some follow on questions that could be triggered when a patient answers yes to one or more of the ACS 6 queries.

One fundamental goal of including the ACS six disability questions set in EHRs and flagging the actions required to ensure equitable care is to enable health care providers to understand and anticipate the specific needs of patients with disabilities well in advance of an appointment so appropriate arrangements can be made in preparation for that visit. Without advance planning and preparation, practitioners often simply waive standard procedures such as weight measurement or thorough physical exams or send people away without the scheduled test or procedure having been carried out because it is perceived to be too difficult or even impossible to administer.

## Americans with Disabilities Act (ADA) Litigation

The U.S. Department of Justice and the private bar have brought numerous lawsuits under the ADA against large health care systems and facilities on behalf of patients with disabilities who have been harmed when these organizations have failed to provide accessibility and accommodations.[22] Including information in electronic health records on functional limitations is a key infrastructure change that not only would help patients with disabilities avoid harm and get better care, but would also assist providers to comply with federal disability non-discrimination laws.

## ABOUT DREDF

The Disability Rights Education and Defense Fund (DREDF) is a national law and policy center dedicated to advancing the civil and human rights of people with disabilities through legal advocacy, training, education and public policy and legislative development.

### Our Health Care Work

We advocate for state and federal laws and policies that chip away at the complex barriers people with disabilities experience when they try to access health care. We also conduct research, author journal articles, comment on federal and state health care regulations, train diverse health care stakeholders, develop model policies for accommodating people with disabilities in medical settings, and build alliances with colleagues in the health policy and aging fields.

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## ENDNOTES

[1] Complex activity limitation affects their ability to participate in society, including maintaining a household, working, and pursuing hobbies; see Altman, Barbara & A. Bernstein, Disability and Health in the United States, 2001-2005" (Hyattsville, MD: National Center for Health Statistics, 2008). Complex activity limitation is captured through four measures: any limitations in social or leisure activities, any difficulty or inability to work, self-care limitation (reflected by any ADL or IADL limitation), and an overall combination measure, which reflects any individual or combination of limitations in the first three measures.

[2] Sze Y. Liu, Melissa A. Clark, "Breast and Cervical Cancer Screening Practices among Disabled Women Aged 40–75: Does Quality of the Experience Matter?" *Journal of Women's Health* 17(8) (2008):1321–1329.

[3] Ellen P. McCarthy, Long H. Ngo, Richard G. Roetzheim, Thomas N. Chirikos, Donglin Li, Reed E. Drews, Lisa I. Iezzoni, "Disparities in Breast Cancer Treatment and Survival for Women with Disabilities," *Annals of Internal Medicine* 145.9 (2006):637–45; Lisa I. Iezzoni, Long H. Ngo, Donglin Li, Richard G. Roetzheim, Reed E. Drews, Ellen P. McCarthy, "Treatment Disparities for Disabled Medicare Beneficiaries with Stage I Nonsmall Cell Lung Cancer," *Arch Phys Med Rehabil*, 89.4(2008):595–601.

[4] National Council on Disability, "The Current State of Health Care for People with Disabilities," September 30, 2009.

[5] Gloria L. Krahn, Deborah K. Walker, Rosaly Correa-De-Araujo, "Persons with Disabilities as an Unrecognized Health Disparity Population," *American Journal of Public Health* 105 S2 (2015): S198-S206.

[6] T. Lagu, N.S. Hannon, M.B. Rothberg, A.S. Wells, K.L. Green, M.O. Windom, K.R. Dempsey, P.S. Pekow, J.S. Avrunin, A. Chen, and P.K. Lindenauer, "Access to Subspecialty Care for Patients With Mobility Impairment: A Survey," *Annals of Internal Medicine* 158 (2013):441-446.

[7] National Council on Disability, "The Current State of Health Care for People with Disabilities," September 30, 2009.

[8] Nancy R. Mudrick, Silvia Yee, "Defining Programmatic Access to Healthcare for People with Disabilities," Disability Rights Education and Defense Fund, 2007.

[9] Ester Hing, Sayeedah Uddin, "Visits to Primary Care Delivery Sites: United States, 2008," *NCHS Data Brief 47* (October 2010).

[10] California Department of Health Care Services, "Revised Policy Letter to All Medi-Cal Managed Care Health Plans Regarding Revised Facility Site Review (FSR) Tool," May 23, 2011.

[11] Nancy R. Mudrick, Mary Lou Breslin, M. Liang, Silvia Yee, "Physical Accessibility in Primary Health Care Settings: Results from California On-Site Reviews," *Disability and Health Journal* 5 (2012):159-167.

[12] Medicaid and Children's Health Insurance Program (CHIP) Programs; Medicaid Managed Care, CHIP Delivered in Managed Care, Medicaid and CHIP Comprehensive Quality Strategies, and Revisions Related to Third Party Liability, a proposed rule by the Centers for Medicare & Medicaid Services on 06/01/2015, https://www.federalregister.gov/articles/2015/06/01/2015-12965/medicaid-and-childrens-health-insurance-program-chip-programs-medicaid-managed-care-chip-delivered (February 10, 2016).

[13] See the Contract for Capitated Model between United States Department of Health and Human Services, Centers for Medicare and Medicaid Services, in Partnership with the Commonwealth of Massachusetts, December 28, 2015 at 2.8 and 2.9

[14] See the Contract Between United States Department of Health and Human Services, Centers for Medicare and Medicaid Services, in Partnership with the State of Michigan, September 25, 2014 at 2.8.1.6 and 2.8.12.

[15] Centers for Medicare & Medicaid Services, Office of Minority Health. "The CMS Equity Plan for Improving Quality in Medicare Equity Plan," September 2015.

[16] LifeLong Medical Care also collects information on patients who require Sign Language interpreters, but that data was not available at the time this Issue Brief was finalized.

[17] Email communication with Kathryn Stambaugh, Geriatrics Service Director, LifeLong Medical Care, Berkeley, California, March 10, 2016, unpublished data:

| Need #1 | Additional Need |
|---|---|
| Mobility Assistance | Sign Language Interpreter Needed |
| Mobility Assistance | Sign Language Interpreter Needed |
| Long Appointment Only | Mobility Assistance |
| Language Interpreter Needed | Long Appointment Only |
| Mobility Assistance | Language Interpreter Needed |
| Support For Low Vision Or Blindness | Mobility Assistance |
| Language Interpreter Needed | Long Appointment Only |
| Support For Low Vision Or Blindness | Mobility Assistance |
| Mobility Assistance | Support For Low Vision Or Blindness |
| Mobility Assistance | Support For Low Vision Or Blindness |
| Language Interpreter Needed | Long Appointment Only |
| Language Interpreter Needed | Long Appointment Only |
| Mobility Assistance | Long Appointment Only |

| | |
|---|---|
| Language Interpreter Needed | Long Appointment Only |
| Long Appointment Only | Mobility Assistance |
| Mobility Assistance | Support For Low Vision Or Blindness |
| Mobility Assistance | Support For Low Vision Or Blindness |
| Support For Low Vision Or Blindness | Mobility Assistance |
| Language Interpreter Needed | Mobility Assistance |
| Support For Low Vision Or Blindness | Mobility Assistance |
| Language Interpreter Needed | Mobility Assistance |
| Language Interpreter Needed | Mobility Assistance |

[18] Intended as an advocacy and educational tool, DREDF produced a video series entitled **Healthcare *STORIES*** that features people with disabilities telling their personal stories about their health care experiences. The narrators describe the barriers to care they experience when health care providers are not adequately prepared for their visit and when necessary accommodations are not provided. The series can be viewed at: http://dredf.org/healthcare-stories/2014/02/05/barriers%e2%80%8e-solutions/

[19] Examples of such policies along with other technical resources are available on the DREDF website at: http://dredf.org/healthcare-access/training-policy-briefs-presentations/

[20] United States Census Bureau, https://www.census.gov/people/disability/methodology/acs.html (February 5, 2016)

[21] The six-item set of questions was developed by a federal interagency committee and reflects the change in how disability is understood consistent with the International Classification of Functioning, Disability, and Health. The question set defines disability from a functional perspective and was developed so that disparities between people with and without disability can be monitored. The federal Office of Management and Budget (OMB) has encouraged the use of this question set by other federal agencies conducting similar population studies due to the extensive testing used in the development of these measures, including the findings that alternative measures did not test as well. U.S Department of Health and Human Services, Office of Minority Health website accessed on February 5, 2016 at http://minorityhealth.hhs.gov/omh/browse.aspx?lvl=3&lvlid=54

[22] US Department of Justice, Civil Rights Division. Barrier-Free Health Care Initiative, http://www.ada.gov/usao-agreements.htm (February 10, 2016).