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Toward a conceptual model for national policy and practice considerations

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Abstract

Chronic diseases and conditions are serious threats to the population's health. Chronic diseases represent seven of the top ten causes of mortality in the U.S. and are major economic drivers underlying burgeoning national health costs. People with disabilities experience dramatically higher rates of some chronic conditions, but only recently has this problem been recognized. We propose a set of contributing factors and a model to help better understand the relationship of disability with chronic disease. The paper summarizes current CDC initiatives to include disability status and considerations in public health surveys and programs, exemplifying a strategy to promote inclusion of people with disabilities in mainstream programs wherever possible; use cross-disability strategies for conditions unique to people with disabilities where necessary; and implement condition-specific approaches where essential. This initial model is intended to invite dialog on a conceptual framework for preventing chronic conditions and additional functional limitations among people with disabilities.

Keywords

Chronic conditions; Chronic disease; Disability; National

Dramatic escalation in rates of chronic diseases and conditions make them a major public health problem in the U.S.¹ and globally.² We are beginning to recognize the major contribution that chronic diseases make to the poor health of people with disabilities. Among the most significant chronic diseases are heart disease, diabetes, cancer and respiratory problems.² The major modifiable risks for these chronic diseases relate to lifestyle behaviors such as smoking, physical inactivity and poor nutrition, and excessive use of alcohol. This paper describes the magnitude of chronic conditions in the U.S. and several initiatives to address them; briefly reviews historical approaches to disability and health; describes potential factors that contribute to poorer health of people with disabilities; proposes a model for understanding chronic diseases in relation to disability; and describes

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the approach of the Centers for Disease Control and Prevention's (CDC) to improve health of people with disabilities. The paper demonstrates an opportunity to strengthen the connection of public health with clinical practice to improve the health of an important population.

Basic terms

In the broader public health arena outside of disability researchers, writers refer to “multiple chronic conditions” in highly variable ways. They vary widely in the number of conditions included and, importantly for disability researchers, often implicitly or explicitly include functional limitations and developmental disabilities within their categorization of chronic conditions. This inclusion of disability as a chronic condition does not allow examination of the health risks posed by chronic diseases to people with pre-existing functional limitations. Because public health approaches to disability and to chronic conditions have been hampered by this variability in definitions,³ we offer the following nomenclature for this paper:

“Chronic diseases” and “non-communicable diseases” refer to health conditions that are of long duration, slow progression, and not transmittable person to person.⁴

“Chronic conditions” refer to a broader group of health-related conditions that include chronic diseases, substance abuse and addiction disorders, chronic communicable diseases (e.g., tuberculosis, human immunodeficiency virus infection), mental health conditions, and developmental disabilities.¹

“Multiple chronic conditions” refers to the co-occurrence of two or more chronic conditions in the same individual.¹

“Secondary conditions” are health conditions that are generally preventable, experienced at higher rates among people with disabilities, and are causally linked to the disabling condition.⁵

“Disability” is used in two ways. In our main discussion, we rely on the WHO⁶ conceptualization of disability as defined by impairments, activity limitations, or participation restrictions related to a health condition and as experienced in interaction with the environment in which the person lives (see also Drum, this issue, p. 2). When referring to studies cited within this paper, the definition of “disability” is determined by each study and can vary by data source.

“Functional limitation” refers to restriction or lack of ability to perform an activity or action within a range considered normal⁷ regarding vision, hearing, mobility, cognition, and/or need for assistance in activities of daily living (e.g., bathing, eating) or instrumental activities (e.g., shopping, going to the doctor's office). This aligns with recent data collection standards for disability identification.⁸

Discussion: context and initial considerations

Although the roots of public health grew out of the need to control infectious diseases, chronic diseases have surpassed infectious diseases as the major threat to health in the U.S. since the middle of the 20th century.⁹ In the U.S., chronic diseases currently represent seven of the top ten most common causes of death¹⁰ and are a contributor to functional limitations among all segments of society. Chronic diseases significantly impact quality of life of those affected and their families, and may increase vulnerability to social determinants of health such as poverty, unemployment, and unmet health care needs.

Chronic diseases are a major driver of health care costs, with attention now focused on people with multiple chronic conditions. The Centers for Medicare and Medicaid (CMS) series of Chartbooks summarize data for Medicare beneficiaries on prevalence and cost of multiple chronic conditions.^{11,12} Among the Medicare population (over age 64 and persons with disabilities) in 2008, beneficiaries with multiple chronic conditions represented about two-thirds of beneficiaries and accounted for \$260 billion of the total \$280 billion spent.¹¹ The group of people with poorest health, greatest health care utilization, and most complicated care management are those with the most multiple chronic conditions.¹² To improve the nation's health and contain health care costs, national efforts must find ways to reduce and better manage chronic conditions.¹³

Federal actions to address chronic diseases

Responding to this public health threat, CDC established the National Center for Chronic Disease Prevention and Health Promotion at CDC in 1988.⁹ Its priorities focus on well-being, health equity, research translation, policy promotion and workforce development. In FY2012, this Center received an appropriation of about \$1.2 billion between general appropriations and the Prevention and Public Health Fund, with some of these funds awarded to communities to develop innovative partnerships at the local level to promote select health behaviors and prevent chronic conditions.

Recognizing the escalating challenge of controlling the increase of chronic conditions, the Department of Health and Human Services (HHS) launched a cross-department work group in 2008 to identify options to improve the health of people with multiple chronic conditions. The resulting HHS Strategic Framework on Multiple Chronic Conditions outlines four goals, each with a set of objectives and strategies to: 1) foster health care and public health systems changes to improve the health of individuals with MCC; 2) maximize the use of proven self-care management and other services by individuals with MCC; 3) provide better tools and information to health care, public health, and social services workers who deliver care to individuals with MCC; and 4) facilitate research to fill knowledge gaps about, and interventions and systems to benefit, individuals with MCC.¹

Improving health of people with disabilities

During the past decade, there has been a juxtaposition of two positions. On the one hand, there has been growing awareness that disability need not be equated with poor health¹⁴; and on the other, improved data document that people with disabilities are four times more likely

to self-rate their health as fair or poor relative to the general population.¹⁵ Research is needed to disentangle chronic disease from pre-existing functional limitation to begin to understand the contributors to this dramatically poorer health and to identify prevention opportunities. Within the field of disability and health, we have seen an expansion in the scope of health from a more exclusive focus on the primary disabling condition, to consider secondary conditions as contributing to poor health, to a more comprehensive view of co-morbid health conditions that include chronic diseases and conditions.^{5,16} When the focus is on the primary disabling condition, rehabilitation efforts focus on improving the individual's function through specialty medical services, durable medical equipment and assistive devices. This perspective is still critically important, particularly during acute post-injury phases or for maintenance of function. Beginning in the early 1990's, we witnessed a growing focus on preventable secondary conditions of people with pre-existing disabilities that went beyond rehabilitation.¹⁷ Examples of secondary conditions are decubitus ulcers, pain, and depression secondary to paralysis. This perspective was exemplified in the name of Healthy People 2010's Chapter – "Disability and Secondary Conditions"¹⁸ – and in *The Future of Disability in America*.⁷ More recently and reflected in the Healthy People 2020 Chapter "Disability and Health",¹⁹ the emerging perspective has broadened to include those problems that are major threats to everyone's health—chronic conditions—and the need for healthier lifestyles, as well as education, employment and social integration. This expansion of focus on the health of people with disabilities has moved from considering problems unique to people with disabilities to recognizing the critical role of chronic conditions and social determinants on people with pre-existing disability. There is still an ongoing need to consider those issues unique to disabilities.

Factors contributing to chronic disease and health

Although chronic diseases have long been recognized to lead to functional limitations, the converse is only recently recognized and is less well understood – that people with pre-existing functional limitations are more prone to risk factors that can lead to higher rates and earlier onset of chronic diseases.^{20,21} Analyses of Medical Expenditure Panel Survey data showed adults with cognitive limitations up to five times more likely to experience diabetes for all age categories over 30, with commensurate increases in risk for asthma, arthritis, cardiovascular disease, hypercholesterolemia, hypertension and stroke.²⁰ These chronic diseases may have little obvious physiological etiology in cognitive impairment, and more likely result from social and environmental influences on health behaviors and health. To illustrate for one segment of the cognitive limitation group, poor nutritional practices and sedentary lifestyles of people with intellectual disabilities are likely contributors to higher rates of obesity that, in turn, lead to increases in diabetes.²²

The onset of chronic diseases involves a myriad of factors including personal factors, social circumstances, environmental conditions, behavioral choices, medical care and complex interactions among factors. Table 1 presents a framework adapted from McGinnis and colleagues²³ with factors that potentially contribute to chronic disease, and additional factors contributing to chronic disease related to pre-existing disability. These are not comprehensive; instead they are offered to stimulate dialog to develop a conceptual framework on chronic conditions and disability. Factors that escalate chronic diseases in

people with pre-existing functional limitations include the continuous stressors of living with a functional limitation,²⁴ social isolation and restricted social participation, barriers to community transportation, inaccessible gyms and parks, restricted food choices, and medical inattention to risk factors for secondary and chronic conditions.

Potential causal pathways to chronic disease and disability

How much does the co-occurrence of functional limitation with chronic disease relate to having a pre-existing disability, and how much does having chronic diseases result in functional limitations? These questions are central to assessing chronic disease risk in disability populations and to assessing disability risk in chronic disease populations. Yet analyses of these relationships have been limited primarily to cross-sectional data because of the dearth of longitudinal data. Cross-sectional data preclude directly examining causal relationships over time. Initial efforts to disentangle causality have suggested the situation is a “complex web” of interacting relationships among disability, chronic conditions, and health services utilization.²⁵ To help understand causality, we propose a basic model with two possible pathways that result in a person having both a disability and chronic disease (see Fig. 1). The nature of these pathways may differ depending on the functional limitation and the specific chronic disease. The first pathway depicts a person with congenital or acquired functional limitation who is subsequently diagnosed with a chronic disease. We use “diagnosis” when referring to chronic diseases because these diseases develop slowly and are often not recognized until diagnosed. The top of Fig. 1 illustrates this pathway. This reflects the life course of a person with intellectual disability or spinal cord injury, for example, who is subsequently diagnosed with diabetes. The second pathway, illustrated in the lower part of Fig. 1, depicts a person first diagnosed with a chronic disease that over time leads to disability. This is the experience of someone whose diabetes led to vascular complications and need for lower limb amputation resulting in disability. Over time, pathways 1 and 2 both lead to people experiencing both disabilities and chronic diseases, with considerable interaction between disease and disability. At that point, it may be difficult to determine causation, and knowing the pathway may be less relevant for treatment.

The causal pathway is very relevant, however, for preventing chronic disease in a person with disability (pathway 1) and in preventing disability or further limitation in a person with chronic disease (pathway 2). From a public health prevention perspective, the target audiences differ in pathway 1 versus pathway 2. “X” designates prevention opportunities along the pathways. X_1 designates opportunities for preventing chronic disease in persons with functional limitations through activities like a) increasing awareness in the disability community about the risk of chronic disease; b) including people with disabilities in mainstream health promotion activities to prevent chronic conditions; and c) eliminating physical and attitudinal barriers to participation X_2 indicates activities such as adopting healthier lifestyle behaviors, increasing self-management of the chronic disease, and ensuring access to health care. X_3 includes the activities of X_1 and X_2 and adds coordinating care of multiple chronic conditions to avoid additional disease and functional limitations. To date, much attention has been devoted to pathway 2—preventing and managing chronic diseases and conditions in the general population—but less attention has been dedicated to

pathway 1—recognizing and addressing the prevalent threat of chronic diseases and conditions to the health of people with pre-existing functional limitations.

Identifying and preventing chronic conditions in people with disabilities

The CDC's current public health efforts for people with disabilities focus on documenting disparities and improving health behaviors to prevent chronic diseases (pathway 1) for people with disabilities. To that end, CDC's Division of Human Development and Disability is collaborating with others in targeted ways described below.

Identify disparities—The *Disability and Health Data System* (DHDS) is an online interactive system²⁶ that translates state-level, disability-specific data into usable public health disparities information. Using Behavioral Risk Factor Surveillance System (BRFSS) data, it demonstrates differences based on cross-sectional data between people with and without disabilities on 79 health indicators, including risk behaviors and chronic disease variables. A second initiative is promoting the inclusion of HHS disability data standards⁸ in public health surveillance systems and evaluation strategies to improve public health disability data.

Identify and reduce disparities in obesity—Located on the causal pathway to numerous chronic diseases, obesity is a primary target for prevention and intervention. Obesity rates for children and adults with disabilities are 38% and 57% higher, respectively, than their peers without disabilities.²⁷ Contributors to obesity among people with disabilities include factors such as inadequate access to information, poor food choices, and reduced physical activity. Barriers relate to transportation, management of medication side effects, limitations in food choices, accessible weight scales, accommodation to disability in interventions, and supports for clear communication. Poverty, social isolation, lower educational attainment and other social determinants are underlying contributors to poor health generally. CDC's initial focus on healthy weight among people with disabilities is to increase awareness among people with mobility limitations.

Inclusion of people with disabilities in mainstream health promotion programs—CDC is working to include people with disabilities in mainstream programs and policies that address chronic conditions. The *Guide to Community Preventive Services* (the Community Guide)²⁸ is a resource for evidence-based recommendations to improve the public's health on topic areas that include chronic diseases such as obesity, cancer, diabetes, heart disease and stroke. To date, these recommendations have not specifically addressed people with disabilities. Through collaboration with researchers and people with diverse disabilities,²⁹ efforts are underway to provide web-based information to support the inclusion of people with disabilities in these community-based interventions.

Conclusion and invitation to dialogue

Emerging evidence indicates that chronic conditions are serious threats to the health of people with disabilities. With 16% of the population reporting serious limitations and the majority of these people being under the age of 65,³⁰ this is an important public health population. The risk factors leading to chronic conditions for people with pre-existing

disabilities must be better understood to improve the health and longevity of this population. Otherwise, we risk the unintended consequence that chronic condition disparities between those with and without disabilities may actually increase,⁹ because social determinants such as poverty, lower education levels, and inaccessible services make this population especially vulnerable to chronic conditions. Without understanding these factors, efforts effective in the general population may not be effective with the disability population. To maximize public health impact, the Division of Human Development and Disability at CDC is implementing the following approach: promoting inclusion of people with disabilities in mainstream programs wherever possible; using cross-disability strategies for issues unique to people with disabilities where necessary; and implementing condition-specific approaches where essential. This means engaged collaboration between disability programs and chronic disease programs as exemplified by Seekins in this issue,³¹ and improved disability-relevant epidemiologic research as Reichard discusses in this issue.³² We present these considerations and initial conceptual model as an invitation to continued dialog among chronic disease and disability stakeholders to develop a conceptual framework and approach for preventing and managing chronic diseases and conditions that includes people with pre-existing disabilities.

References

1. Parekh AK, Goodman RA, Gordon C, Koh HK. Managing multiple chronic conditions: a strategic framework for improving health outcomes and quality of life. *Public Health Rep.* 2011; 126:460–471. [PubMed: 21800741]
2. World Health Organization. *Global Status Report on Noncommunicable Diseases 2010*. Geneva: WHO Press; 2011. Available online at: http://www.who.int/nmh/publications/ncd_report2010/en/ [Download Feb 5, 2013]
3. Goodman RA, Posner SF, Huang ES, Parekh AK, Koh HK. Defining and measuring chronic conditions: imperatives for research, policy, program, and practice. *Prev Chronic Dis.* 2013; 10:120239.
4. World Health Organization. *Noncommunicable Diseases Fact Sheet*. Sep. 2011 Available at: <http://www.who.int/mediacentre/factsheets/fs355/en/index.html> [Download Feb 5, 2012]
5. Turk, MA. *Institute of Medicine Workshop on Disability in America: A New Look*. Washington: National Academies Press; 2006. Secondary conditions and disability; p. 185-193.
6. World Health Organization. *International Classification of Functioning, Disability and Health*. Geneva, Switzerland: World Health Organization; 2001.
7. Institute of Medicine. *The Future of Disability in America*. Washington: National Academies Press; 2007.
8. DHHSOMH. *Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status*. 2011. Available at: <http://minorityhealth.hhs.gov/templates/content.aspx?ID59227>
9. Remington PL, Brownson RC. Fifty years of progress in chronic disease epidemiology and control. *MMWR Surveill Summ.* 2011; 60(04):70–77. [PubMed: 21976169]
10. Hoyert DL, Xu J. Deaths: preliminary data for 2011. *Natl Vital Stat Rep.* 2012; 61(6)
11. DHHS CMS. *Chronic Conditions Among Medicare Beneficiaries: 2011 Edition*. 2011. Available at: <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/Downloads/2011Chartbook.pdf> [Download Feb 5, 2013]
12. DHHS CMS. *Chronic Conditions Among Medicare Beneficiaries: 2012 Edition*. 2012. Available at: <http://www.cms.gov/Research-Statistics-Data-and-Systems/Statistics-Trends-and-Reports/Chronic-Conditions/2012ChartBook.html> [Download Feb 5, 2013]
13. Goodman RA, Parekh AK, Koh HK. Toward a more cogent approach to the challenges of multimorbidity. *Ann Fam Med.* 2012; 10(2):100–101. [PubMed: 22412000]

14. US DHHS Surgeon General. The Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities. 2005. Available at: <http://www.surgeongeneral.gov>[Download Feb 5, 2013]
15. Wolfe LA, Armour BS, Campbell VA. Racial/ethnic disparities in self-rated health status among adults with and without disabilities—United States, 2004—2006. *MMWR Morb Mortal Wkly Rep.* 2008; 57(39):1069–1073. [PubMed: 18830209]
16. Krahn GL, Hammond L, Turner A. A cascade of disparities: health and health care access for people with intellectual disabilities. *Ment Retard Dev Disabil Res Rev.* 2006; 12(2):70–82. [PubMed: 16435327]
17. Seekins T, Clay J, Ravesloot C. A descriptive study of secondary conditions reported by a population of adults with physical disabilities served by three independent living centers in a rural state. *J Rehabil.* 1994; 60:47–51.
18. DHHS. Healthy People 2010 Disability and Secondary Conditions Focus Area 6 Reports and Proceedings. Atlanta, GA: 2003. National Center on Birth Defects and Developmental Disabilities.
19. DHHS Healthy People. Healthy People 2020. 2010. [Internet]. Available at: <http://www.healthypeople.gov/2020/default.aspx>[Download Feb 5, 2013]
20. Reichard A, Stolzle H. Diabetes among adults with cognitive limitations compared to individuals with no cognitive disabilities. *Intellect Dev Disabil.* 2010; 49(3):141–154. [PubMed: 21639741]
21. Reichard A, Stolzle H, Fox M. Health disparities among adults with physical disabilities or cognitive limitations compared to individuals with no disabilities in the United States. *Disabil Health J.* 2011; 4(2):59–67. [PubMed: 21419369]
22. Rimmer JH, Yamaki K. Obesity and intellectual disability. *Ment Retard Dev Disabil Res Rev.* 2006; 12(1):22–27. [PubMed: 16435329]
23. McGinnis JM, Williams-Russo P, Knickman JR. The case for more active policy attention to health promotion. *Health Aff.* 2002; 21(2):78–93.
24. Jackson JS, Knight KM, Rafferty JA. Race and unhealthy behaviors: chronic stress, the HPA axis, and physical and mental health disparities over the life course. *Am J Public Health.* 2010; 100(5): 933–939. [PubMed: 19846689]
25. Gulley S, Rasch EK, Chan L. The complex web of health: relationships among chronic conditions, disability, and health services. *Public Health Rep.* 2011; 126:495–507. [PubMed: 21800744]
26. DHHS CDC. Disability and Health Data System (DHDS). 2012. www.dhds.cdc.gov
27. CDC. Disability and Obesity. 2012. Available at: <http://www.cdc.gov/ncbddd/disabilityandhealth/obesity.html>[Download Feb 14, 2013]
28. DHHS CDC. The Guide to Community Preventive Services: The Community Guide. 2012. Available at: www.thecommunityguide.org
29. Kraus, LE.; Campbell, VA. Presentation at the National Network of Public Health Institutes, , May 23, 2012. New Orleans: Louisiana; Including people with disabilities in the CDC's community guide. Available at: http://nnphi.org/CMSuploads/Kraus&Campbell_NNPHI_2012_Community_Guide.pdf. [Download Feb 14, 2013]
30. Krahn GL, Fox MR, Hootman J, et al. Where in health is disability? Public health practices to include people with disabilities MMWR. in press.
31. Traci M, Seekins T. Integration of chronic disease and disability and health state programs in Montana. *Disabil Health J.* 2014; 7(1):19–25. [PubMed: 24411503]
32. Reichard A, Nary D, Simpson J. Chronic conditions and disability: Research contributions and implications. *Disabil Health J.* 2014; 7(1):6–12. [PubMed: 24411501]

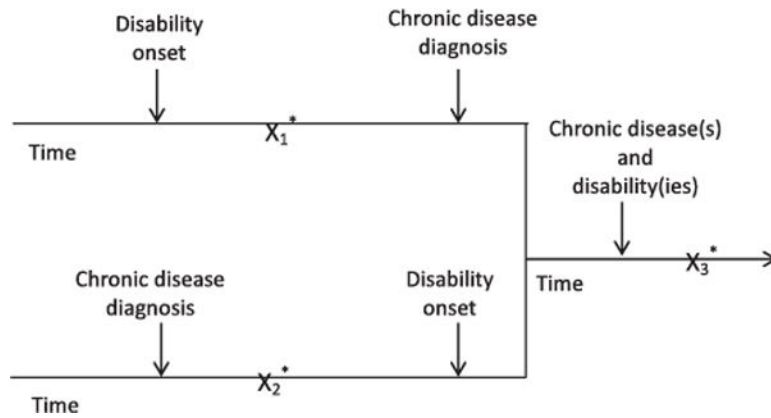


Fig. 1.

Pathways leading to co-occurrence of chronic disease and disability. *X = Prevention opportunity. X_1 = Increase chronic disease risk awareness in disability community; Include people with disabilities in health promotion activities; Eliminate environmental barriers. X_2 = Adopt healthier lifestyle behaviors; Practice good self-management of chronic disease; Ensure access to health care. $X_3 = X_1 + X_2$ plus co-ordinate medical care of multiple conditions.

Table 1

Factors that contribute to pre-existing functional disabilities and chronic disease

Factor	Factors contributing to chronic disease	Factors given pre-existing functional limitation
Personal	Genetics, age, race, sex, ethnicity may lead to higher disease risk.	Genetics, age, race, sex, ethnicity may lead to higher disease risk. Primary disabling condition may predispose to further functional limitations or disease.
Social circumstances	Higher rates of poverty, unemployment, low education may lead to higher risk of disease.	Higher rates of poverty, unemployment, low education may lead to higher risk of disease. Higher risk for social isolation and restricted social participation.
Environmental conditions	Risk of exposure to hazards and infectious diseases, structural hazards contribute to preventable injury.	Risk of exposure to hazards and infectious diseases, structural hazards contribute to preventable injury. Physical barriers to community participation; Transportation barriers; Attitudinal barriers to inclusion; Inaccessible facilities for physical activity; Restricted food choice options in group care settings.
Behavioral choices	Physical inactivity, poor nutrition, smoking, substance abuse lead to higher risk of chronic disease.	Physical inactivity, poor nutrition, smoking, substance abuse lead to higher risk of chronic disease. Coping with disability-related stresses may lead to more smoking; Physical limitations may reduce capacity for healthy food preparation.
Medical care	Health care system inefficiencies lead to increase in mortality and morbidity.	Health care system inefficiencies lead to increase in mortality and morbidity. Inaccessible medical equipment and facilities. Provider inattention to chronic conditions, risk behaviors.