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## **Disability-Competent Health Systems**

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### **Abstract**

In July 2005, the United States Surgeon General issued a national *Call for Action to Improve the Health and Wellness of Persons with Disabilities*. This article offers one response. Drawing on the best practices of consumer-driven health programs for people with disabilities, we offer a Disability-Competent Health System model. The model integrates health and social services to maximize opportunities for independent living and person-centered care. This approach is an opportunity for the independent living movement to address health-related issues without subscribing to the medical model.

### **Introduction**

In July 2005, the United States Surgeon General issued a national *Call for Action to Improve the Health and Wellness of Persons with Disabilities*. Sara Watson was one of the first disability researchers to argue that disability advocates should acknowledge the distinctive health needs of many people who have disabilities (Watson, 1993). Sutton and DeJong (1998) suggested that the comprehensive benefits and organizational structure of group-

model health maintenance organizations (HMOs) hold high potential to improve the health of people with disabilities. It was not until 2000, however, that some disability advocates, state Medicaid agencies, and HMOs combined forces. These new partnerships adapt the best features of organized comprehensive care offered by HMOs to the social and medical needs of working age adults with physical or mental impairments (Palsbo & Kroll, 2005).

This paper proposes that disability advocates, state Medicaid agencies, and HMOs should encourage the development of "Disability-Competent Health Systems," our adaptation of the Chronic Care Model (CCM) (Wagner, 1998; Wagner, Austin, & Von Korff, 1996a, 1996b). Over 100 HMOs and clinics have applied the CCM to population-based care for asthma, diabetes, depression, or cardiovascular disease (Bodenheimer, 2003; Lin et al., 2005; Wagner et al., 2001). Randomized trials suggest that reorganizing HMO resources into a CCM can significantly improve clinical outcomes (Pearson et al., 2005; Schaefer & Davis, 2004; Tsai, Morton, Mangione, & Keeler, 2005). We believe the interdisciplinary team approach espoused by the CCM is a promising framework for reorganizing social and medical resources and improving outcomes and independence of people with disabilities who also have significant medical needs.

## **Methods**

This study used an inductive approach to collating data from prior qualitative studies as well as consulting experience that the authors had gathered over several years. The idea of using the CCM as a descriptive framework occurred to the first author (Palsbo) while conducting a program evaluation study site visit to AXIS Healthcare in 2003. Having identified that framework, Palsbo drew upon the contents of a file of "interesting approaches" to providing health care for people with disabilities, that she had collected since 1999. Discussion with the second author (Kailes) about how to describe disability-competent health plans led to identification of additional best practice examples. After more refinements to the CCM, we proposed to try applying the construct of the Disability-Competent Health System to the variety of empirical examples already collected.

We demonstrated face validity of the construct through a descriptive analysis of a qualitative observational study that had been conducted for a different purpose in 2004. In that study, Palsbo had visited six programs that had applied for financial support from the Center for Health Care Strategies. Palsbo and Kailes had also, independently of each other, worked with Kaiser Permanente of Northern California and Inland Empire Health Plan. Thus, this study used a convenience sample that had the merit of representing approximately half of known disability-specific programs at the time. Having conducted this exploratory study, we suggest that the model should now be subjected to hypothesis-driven, deductive scientific inquiry.

## **Findings**

Figure 1 presents the Disability-Competent Health System. We illustrate each competency component with examples drawn from site visits to Medicaid demonstration projects and our first-hand experience with progressive HMOs.

## Community Resources and Policies

*Rethinking "medical necessity."* Every health system — and every patient — operates within a complex context of federal, state, and local policies. Most of these policies are derived from a medical model of health care focused on acute care needs, rather than from a social model that considers long-term environmental needs. The private and public insurance sectors have not kept pace with advances in rehabilitation therapies and assistive devices that can improve function, quality of life, health, and independence.

Disability-incompetent reimbursement policies take a very narrow view of medical necessity. A well-known example is the Medicare restriction on payment for a motorized wheelchair if the person can move around inside the home without one. This in-the-home policy restricts coverage of mobility devices to devices that are reasonable and necessary for use inside a person's home — a medical model. The social model recognizes that the in-the-home requirement denies a basic mobility tool to people who would otherwise be able to participate in the community. For example, one author's cousin with cerebral palsy did not qualify for a motorized chair because he could get around his apartment via crutches, wall-walking, and furniture-surfing. He chose a college campus that was on level terrain. Now that he is looking for a job in a more hilly community, he has found he is not strong enough to wheel two blocks from the accessible apartment up a hill to the subway stop, nor fast enough to cross a busy 4-lane road in the time allotted by the traffic signal. A motorized wheelchair would allow him to commute more independently and safely to job interviews, to attend religious services, to visit museums, to shop at malls, and go out for dinner or a movie.

In stark contrast is the recent Cash and Counseling Demonstration Program in New Jersey and Arkansas. In this project, Medicaid beneficiaries received a monthly cash stipend to spend any way they wanted on health-related goods and services. Beneficiaries met with counselors to help them assess the tradeoffs around care-related decisions. While Medicaid expenditures increased in the first year, many recipients had not been receiving all the services to which they were entitled before enrolling in the demonstration. In the second year, participants in the Cash and Counseling program had fewer nursing home placements and hospital expenditures than the control group. This disability-competent policy enabled participants to buy convenience items such as microwave ovens or taxi transportation that improved their instrumental activities of daily living (shopping, transportation, money management, etc.) scores. It also enabled them to avoid institutionalization (Dale, Brown, Phillips, Schore, & Carlson, 2003; Mahoney, Simon-Rusinowitz, Loughlin, Desmond, & Squillace, 2004; Simon-Rusinowitz et al., 2003).

*Accessing community resources.* Local human service and health-focused organizations offer many resources to people with disabilities including Meals-on-Wheels, support groups, and health education programs. However, these programs do not always anticipate that members of their audience may have a disability. A disability-competent health system will work with community-based organizations such as Alcoholics Anonymous and mall walking clubs to ensure that programs are held in physically accessible facilities. A disability-competent health system helps the organizations develop content that can be used by people with learning disabilities or sensory (vision, hearing, speech) impairments. A best practice

example is the initiative by The Special Olympics Health Athletes®. This initiative developed easily understood pamphlets on healthy behavioral choices about nutrition and sun exposure for youth with intellectual disabilities. These are excellent models for health systems to use in partnering with community resources to redesign educational newsletters.

### **Health System Resources**

The Chronic Care Model addresses four elements of healthcare organizations: delivery system design, decision support, self-management support and clinical information systems.

### **Delivery System Design**

*Gate-openers.* The typical health maintenance organization or primary care case management practice is designed to address acute care needs. Standard operating practices to manage the demand for services use the primary care physician as a gatekeeper to specialty care, prescriptions, and durable medical equipment. Unfortunately, these gatekeeping duties can be a double-edged sword, reducing unnecessary medical expenditures but prohibiting timely access to care for people with disabilities.

Disability-competent systems convert the "gatekeepers" into "gate openers." These systems establish guidelines to expedite referrals and prescriptions under certain scenarios, without requiring a face-to-face physician encounter. For example, a person with a spinal cord injury above the thoracic vertebrae #7 level who has an irritation, pain, or stimulus to the nervous system below the level of injury, such as a urinary tract infection, should start treatment immediately rather than waiting a day or two to see a physician for a prescription. Even a short delay can lead to autonomic dysreflexia, a physiological reflex action that tightens the blood vessels and causes the blood pressure to rise. If the high blood pressure is not controlled, it may cause a stroke, seizure, or death (Hickey, Vogel, Willis, & Anderson, 2004; Pan et al., 2005).

We found a best practice at AXIS Healthcare in Minneapolis, Minnesota. AXIS collaborated with its primary care provider panel on standing orders for nurses to order tests that determine when an antibiotic should be prescribed. AXIS also prepared educational brochures that underscore the necessity of patients contacting their health coordinator immediately if a urinary tract infection is suspected.

*Accessible provider panel.* Disability-competent health systems can identify physically accessible facilities, including facilities with accessible bathrooms, weight scales, adjustable-height exam tables, and exam chairs. Accessible facilities are designed with an examination room that has space to maneuver a wheelchair or scooter. It also has a mechanical lift or staff trained in wheelchair transfer techniques. Disability-competent systems can also direct their patients to diagnostic facilities that are not only physically accessible but have diagnostic equipment such as mammography machines that can accommodate people with disabilities.

We found a best practice example at Inland Empire Health Plan (IEHP) in San Bernardino, California. IEHP publishes a provider directory that rates each clinic's parking, entrances,

offices and examination tables for accessibility. The directory lists pharmacies that deliver medications to a person's home. IEHP also worked with a local disability organization to list wheelchair accessible bus routes to each doctor.

*Extended appointment times.* Disability-competent systems budget extra time for appointments when a patient uses an augmentative communication device, American Sign Language, or needs assistance with transferring or positioning onto medical equipment for diagnostic procedures. This is similar to the practice in health plans that automatically allow extra time when a language translator is required. Ideally, competent systems would also reimburse clinicians for this extra time. We have not been able to identify any plans that do this. Physicians in Minneapolis told us that the opportunity cost of lost revenue from seeing fewer numbers of patients during the day places financial restrictions on the number of people with disabilities they can accept in their practice.

*Addressing the whole patient.* Disability-competent systems proactively address the psychosocial needs of their members, acting on the realization that these are inseparable from their members' physical health. Independence Care System (ICS) in New York City is one of several disability-competent plans that work holistically with their members. ICS enrolls nearly 600 Medicaid beneficiaries with physical disabilities, 90% between ages 30-50. At enrollment, each beneficiary meets with a nurse-social worker team at the member's residence. The nurse-social worker team conducts a thorough inventory of the beneficiary's psycho-medical health and social environment and identifies gaps that ICS can fill, such as providing personal assistance services and home modifications (ramps, grab bars, lowering countertops). ICS may arrange for mental health services, dental care, wheelchair repairs, and social outings, such as group visits to Central Park or Weight Watchers meetings. The team will contact the members to remind them of clinical appointments and refilling prescriptions. The nurse-social worker team helps the member set goals and priorities, and re-evaluates each member's goals every three months.

*Benefit management.* Incompetent systems manage the benefit; competent systems manage the need. Most health plans and the Center for Medicare and Medicaid Services (CMS) place visit or dollar limits on therapy, such as the 20-visit limitation for occupational or mental health therapy institutionalized in the HMO Act of 1973. Many people with physical disabilities require periodic therapy to *maintain* their functional ability, even though no improvement is expected. Benefit limitations lead to the person losing more and more function until he or she finally meets the payer's definition of medical necessity. Thus, the individual cycles between functional levels, gaining and losing benefit coverage and probably costing the insurer more, in the long run.

Disability-competent systems implement the adage "An ounce of prevention is worth a pound of cure." A best practice example is at Community Living Alliance (CLA) in Madison, Wisconsin. CLA is working with the state to address the needs of CLA participants who benefit so much from additional therapy that they lose eligibility for Medicaid skilled nursing services. The proposal is for Wisconsin Medicaid to continue to reimburse CLA for care coordination services, so the beneficiary does not lose function and slip back into a

nursing home level of need.

## **Clinician Support**

The second component of the Chronic Care Model is "decision support," but we broaden this to "general clinician support."

*Disability competency skills.* Personnel in disability-incompetent health systems have trouble grasping the complexity of living with a disability, particularly when the individual has significant functional limitations. In our focus groups participants recount numerous experiences of ignorance and insensitivity on the part of policy-makers, clinicians, and health plan staff (Palsbo & Kroll, 2005).

We found a best practice at Kaiser Foundation Rehabilitation Center in Vallejo, California. This Center developed and distributed laminated pocket cards to help clinicians interact effectively with people with disabilities. The cards include prompts for clinicians to ask about functional abilities and mental health status, tips on physician-patient interaction, and reminders on best-practice clinical diagnosis and management pathways. The Center also published a booklet on disability as part of Kaiser-Permanente's clinical education series on Cultural Competency (Kaiser-Permanente, 2004).

*Clinical competency skills.* Most general practice physicians probably do not see enough patients each year with a particular type of disabling condition, such as cerebral palsy or depression, to maintain a level of clinical expertise in that specific area. It can also be challenging to keep abreast of new findings in evidence-based medicine and expert consensus panels. Disability-competent systems arrange to employ or contract with subject-matter experts to serve as consultants to primary care providers. For example, if a woman with cerebral palsy presented for a pelvic examination, the subject-matter expert would consult with the gynecologist on positioning methods and possible spasticity medication to allow for a good examination (Turk, Scandale, Rosenbaum, & Weber, 2001).

Disability-competent health systems may also provide disability-specific inservice education. A best practice example is CLA's seminar on the risk of comorbidity of poor mental health with physical disability. CLA's nurses detected that 60% of their members with physical disabilities had anxiety or depression, yet many of the CLA contracting primary care physicians were unaware of the risk.

*Technology assistance.* It is especially difficult for busy clinicians to keep abreast of the continuing advances in assistive technology and supportive equipment for people with disabilities. Disability-incompetent health systems do not always understand or appreciate the significance of the fact that some vendors or clinicians are much more knowledgeable than others about fitting and repairing equipment (Hoenig et al., 2005). As an example, proper wheelchair seating can significantly alleviate pain and reduce the risk of pressure ulcers or other postural musculoskeletal problems.

Disability-competent systems also work with the patients to distinguish between what is

wanted and what is really needed. Sometimes an air conditioner is wanted, when a fan is all that is needed. On the other hand, occupational therapists in disability-competent systems know about simple modifications that can reduce disability and improve instrumental activities of daily living, such as sliding boards for transfers from a wheelchair, or a small microwave to cook meals.

### **Self-Management Support**

*Health education and behavioral modification.* People with disabilities are significantly less likely to access basic preventive measures and patient education about healthy life-style choices than people without disabilities. Primary data analyses and secondary data analyses of the National Health Interview Survey, Medicare Current Beneficiary Survey, and Behavioral Risk Factor Surveillance System show that people with disabilities report less access to specialists, follow-up care, and ease of getting to doctors; a greater likelihood of being obese and heavy smokers; and a lesser likelihood of being counseled to engage in an exercise program (Gold et al., 1997; Iezzoni, Davis, Soukup, & O'Day, 2002; Jones & Bell, 2004; Kennedy & Erb, 2002; Sutton & DeJong, 1998; Turk et al., 2001; Weil, Wachterman, McCarthy, & al., 2002). Women with major lower extremity motor impairments have much smaller odds of receiving Pap smears, mammograms, or smoking queries (Iezzoni, McCarthy, Davis, Harris-David, & O'Day, 2001). People with schizophrenia who are on some of the newer atypical anti-psychotic medications are at higher risk for obesity and type 2 diabetes—but many of these people distrust medical physicians and are less likely to seek care (Clark & Burge, 2003; Tardieu, Micallef, Gentile, & Blin, 2003).

The Office of Vermont Health Access (OVHA) is an excellent best practice example of how a public program can offer disability-competent, life-changing support to a vulnerable population. Under OVHA's pilot program for Medicaid beneficiaries with severe and persistent mental illness (SPMI), it is collaborating with the Vermont Center for Independent Living and the Vermont Psychiatric Survivors to help people with SPMI and secondary diabetes to learn self-management skills as part of their recovery process. Diabetes nurse educators split their time between a community mental health center and a federally qualified health center. The nurses work one-on-one with beneficiaries to help their clients learn self-management skills such as goal setting, progress monitoring, and strategizing how to overcome obstacles. The nurses meet with their patients as often as needed — even weekly — to assist them in adhering to their plan. The nurses provide the intervention at the person's home, take them grocery shopping, and teach them how to cook meals using fresh foods instead of high-carbohydrate packaged foods. They also ensure that their patients make and keep primary care appointments for their physiological health.

*Web-sites.* Many health plans use an Internet site to communicate with their members. The sites allow members to schedule an appointment, select or change a primary care physician, learn lab results, take an on-line wellness class, and refill prescriptions. Published papers and our own review of many health insurance sites show that, unfortunately, they use visually appealing animations, constantly changing backgrounds and "click here" doorways that are inaccessible to people with a variety of vision or manipulation disabilities, especially when

they use adaptive software (Chiang & Starren, 2004).

Disability-competent sites are accessible to people with limitations in cognition, manipulation, vision, hearing, learning, and/or reading ability. Guidelines for web site accessibility are available at the World Wide Web Consortium ([www.w3.org/WAI/quid-tech.html](http://www.w3.org/WAI/quid-tech.html)). Design guidelines for people with dyslexia proposed by the Centre for Educational Technology Interoperability Standards are available at the University of Leeds in the United Kingdom ([www.cetis.ac.uk](http://www.cetis.ac.uk)). Other web accessibility features include drop down menus instead of radio buttons for people who cannot manipulate a mouse or keyboard but use voice-activated software; plain-language question-answer style information and simple layouts for people with impaired cognition.

### **Clinical Information Systems**

The final CCM component addresses clinical information systems (IS). The typical managed care or medical practice system is built for setting appointments and collecting fees. Few medical practices have an IS that can look at population-based measures of care. Even fewer have electronic information on physiological measures (Elder & Hickner, 2005; Smith et al., 2005).

Disability-competent systems collect and manage comprehensive psycho-socio-medical information, including detailed information on functional status, caregiver supports, and the individual service plan goals. Care coordinators rely heavily on these clinical systems to successfully integrate services across multiple providers and to keep abreast of their client's status. The systems track utilization, costs, specific care coordination services, vital signs, upcoming appointments, and prescription refills. Quality managers use the IS to select quality improvement goals and monitor progress.

Effective disability-competent ISs range from very basic to far-reaching. One simple best-practice system is located at a neighborhood health center in central Massachusetts. Eight care coordinators at the Brightwood Community Health Center in Springfield input their data for 400 clients with HIV/AIDS, substance abuse, or disabling physical and/or mental health condition into a shared database. The data include an assessment tool, plan of care instrument, disease-specific worksheets, and chart review checklists. Each night, the on-call care coordinator runs a program to dump the equivalent of a problem sheet into a lap-top computer. Thus, when a client calls with a problem, the care coordinator can instantly view all relevant information.

A very sophisticated best practice example is the Care Management Information System developed by The North Carolina Foundation for Advanced Health Programs. The system offers safety-net providers immediate access to key information through a secure web portal. It includes alerts, reminders and prompts for best clinical practice, especially in pediatric well-child care and asthma, and performance reports for quality improvement. Each month, this relational database links together medical claims data from Medicaid claims with data from case managers in social services departments such as child welfare agencies, and specialized hospital programs such as pediatric leukemia. Health care coordinators embedded

in pediatric group practices can query the database using a secure Internet portal and instantly see what is going on in the child's entire family. The Foundation also prepares quarterly performance reports for the group practices to benchmark the quality of care cross-sectionally against other groups in the state, as well as longitudinally against their prior quarterly performance.

### **Prepared Practice Teams, Informed Patients**

The previous sections describe how a health system can implement new structures and processes to reframe its relationship with community resources and redesign its four internal components of system delivery, clinician support, self-management support, and clinical IS. In the original chronic care model, these revised structures and processes lead to prepared practice teams having productive interactions with informed patients, culminating in improved outcomes.

In practice, disability-competent Medicaid plans have discovered that it can be very difficult to move beneficiaries away from "learned helplessness" (Miller, Seligman, & Kurlander, 1975; Lunt, 2004; Hommel, Chaney, Wagner, & Jarvis, 2006). The beneficiaries need constant ongoing support and motivation for behavioral change. One approach is one-on-one mentoring between a nurse or social worker and the patient, with frequent contact over long periods of time. A broader, population-based approach is the custom newsletter developed by Inland Empire Health Plan (IEHP). IEHP mails its "AccessAbilities" newsletter to over 30,000 members with disabilities and activity limitations. The newsletter contains tips on navigating the HMO, such as calling beforehand to schedule longer appointment times for routine checkups and to notify the provider of accommodations that are needed, such as patient education materials in alternative format.

### **Discussion and Conclusions**

This paper offers a strategic response to the Surgeon General's *Call for Action to Improve the Health and Wellness of Persons with Disabilities*. We adapt and extend a model originally devised to improve the health of people with chronic conditions such as diabetes. While people with disabilities are not chronically ill, many of them need sustained support to enable them to live independently and make their own decisions. And, the CCM takes a population-based approach to health improvement, while we highlight the importance of individualized, self-directed approaches to health and wellness improvement. Regardless, the CCM is a very useful framework to define components of a disability-competent health system, and we need to acknowledge its influence.

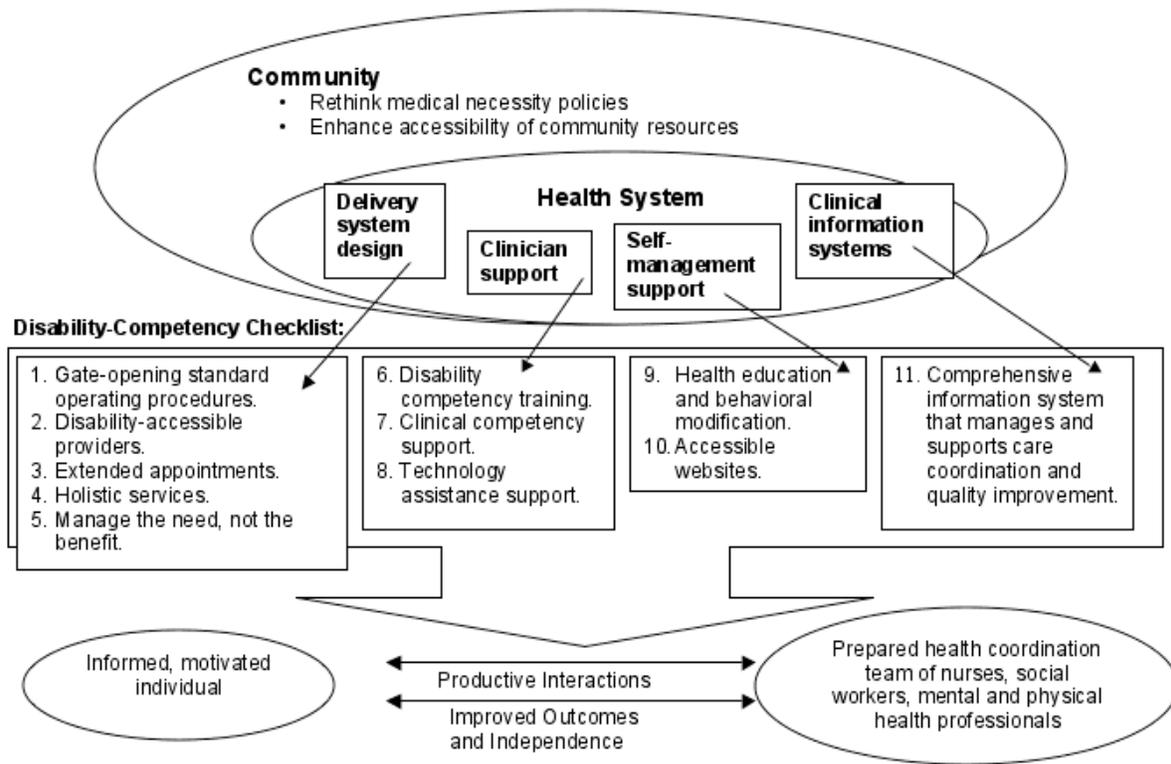
Another advantage of adapting/extending the CCM to people with disabilities is the currency it enjoys in the medical arena. There is an impressive body of research documenting improved clinical outcomes when even only one component is implemented. It is very reasonable to propose that these process improvements can similarly improve the health and wellness of people with disabilities and medical needs. We think the medical profession will see our disability-competent health system as a very do-able next step from the CCM.

We think that Centers for Independent Living (CILs) should play important roles in the design and implementation of disability-competent health systems. The CILs in Vermont, New York City, Massachusetts, and Wisconsin got involved because they had an opportunity to design a health delivery system that fosters community-based living, self-directed planning, and person-centered services. However, several CILs drifted away from active participation, perhaps because they thought it compromised their role as anti-medical model disability advocates. Other CILs continue their involvement by serving on the Board of Directors, because they want a voice in refining these new models to better meet the needs of people with disabilities.

Figure 1 includes an 11-point checklist for disability advocates, providers, and the Surgeon General to assess disability competency. Federal and state regulators can include this checklist in their Medicare and Medicaid contracts for care coordination organizations and special needs plans. While some features require small changes to usual clinical practice, other changes require a considerable capital investment in employees and information systems. These investments may pay for themselves; preliminary evaluations of the programs in Minnesota and Wisconsin show statistically significant improvements in access to care, quality of services, reductions in acute care expenses, and higher discharges from multi-year nursing home stays to community settings (Landkamer & Landsness, 2005; Palsbo & Ho, 2005).

Finally, this new framework and checklist can guide existing social and health providers, including CILs and HMOs, as they partner to improve the health, wellness, and independence of people with disabilities and medical needs.

**Figure 1. Disability-Competent Health System\***



**Written description of Figure 1, Disability-Competent Health System.**

The top half of this figure is two concentric ovals. The outer oval is the Community. The disability activities of the community are to: (1) rethink medical necessity policies, and (2) enhance the accessibility of community resources.

The inner oval is the Health System, which operates within the community. The four disability activities of the Health System are (1) delivery system design, (2) clinician support, (3) self-management support, and (4) clinical information systems.

Under the ovals is a list of 11 activities in which the Disability-Competent Health System should engage. There are 5 specific activities falling under "health system design": gate-opening standard operating procedures; disability-accessible providers; extended appointments; holistic services; manage the need, not the benefit. There are 3 specific activities falling under "clinician support": disability competency training, clinical competency support, and technology assistance support. There are 2 specific activities falling under "self-management support": health education/behavioral modification, and accessible websites. There is 1 specific activity under "clinical information systems": comprehensive information system that manages and supports care coordination and quality improvement."

This 11 item list is contained within an arrow flowing from the ovals to twin circles containing an "informed, activated individual" on the lower left, and a "prepared health coordination team of nurses, social workers, mental and physical health professionals" on the

lower right. Arrows also flow between the twin circles to illustrate the flow of "productive interactions" and "improved outcomes and independence."

This figure is adapted from Wagner EH. Chronic Disease Management: What Will It Take to Improve Care for Chronic Illness?. *Effective Clinical Practice* 1998; 1:2-4. Used with permission.

### **Authors' note**

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