

July 1, 2011

Julie Hamos Director Illinois Department of Healthcare and Family Services 201 South Grand Avenue East Springfield, Illinois 62763-0002 hfs.webmaster@illinois.gov

Re: Key Policy Issues in the Coordinated Care Program

Dear Director Hamos:

Established in 1980 and nationally recognized as a leading force in the disability advocacy community, Access Living challenges stereotypes, protects civil rights, and champions social reform. Access Living is committed to fostering an inclusive society that enables Chicagoans with disabilities to live fully-engaged and self-directed lives. Perhaps no area is more important to assuring self-direction than health care that enables people with disabilities to maintain wellness and to participate vigorously in their communities and individual lifestyles.

We are writing on behalf of the disability community in response to the questions posed by your office on key policy issues in the Illinois Coordinated Care program that will affect 50% of all Illinois Medicaid recipients and an even higher percentage of those individuals in the densely-populated area of Chicago. Many of the comments we are proffering were gleaned from interviews with our consumers. We encourage your Department to consider carefully what our consumers have to say, as they are the experts in what kind of health care works for them. We are also privileged to have been provided comments by Dr. Dianne Collins, an internist who has served people in low-income neighborhoods, including people with disabilities, and a person with disabilities of her own. We integrate her observations and comments in the text below as indicated, together with our own policy research.

## 1. How comprehensive must coordinated care be?

#### a. A full panoply of providers

People with disabilities often have complex health care needs that require a full network of providers. Just eight of our consumers identified for us the following specialty physicians that they are required to see to maintain even basic health and wellness:

Physical medicine and rehabilitation

**Psychiatry** 

Cardiology

Ophthalmology

Orthopedics.

Urology

Nephrology

Neurology with a specialty in multiple sclerosis.

Ophthalmology with a specialty in multiple sclerosis.

The provider directories for both Centene's IlliniCare and Aetna's Better Health reveal striking deficits in such specialties. For example, Aetna provides only a single orthopedist who does not practice in an accessible facility. Centene and Aetna provide only two physical medicine and rehabilitation specialists each. Neither of Centene's rehabilitation specialists is board-certified; neither of Aetna's rehabilitation specialists practices in an accessible facility.

These deficits in needed specialists will have a profound impact. Our consumers emphasized that they work hard over long periods of time to set up complex provider networks and are very apprehensive and upset when they contemplate losing these providers.

- ➤ One consumer with a severe mobility disability related to multiple sclerosis states that it has taken her years to put together a viable network of providers. For example, she found a pharmacy that delivers and is very concerned that contracting pharmacies will not do that. She stated that all of her providers are affiliated with Rush University Medical Center, a provider not available through the Medicaid coordinated care contractors.
- Another consumer who requires dialysis, is awaiting a kidney transplant, and is in a wheelchair also emphasized that it may take years for someone like her to find a health care team who knows her, can talk to and communicate with her, and can treat her with respect. She expressed the view that Medicaid coordinated care may work for nondisabled people, but people with complicated health care situations need to have whole networks of providers.
- A consumer with mental illness stated that she loves her current physician who has really helped her feel better. He is understanding and compassionate. She's afraid to lose this kind of doctor.
- A consumer with a mobility disability stated that allowing some degree of meaningful choice in providers can help to offset other negatives in the Medicaid coordinated care system.

Our consumers suggested that these access problems can be remedied by allowing them to go out-of-network when appropriate care cannot be otherwise located in-network, and, given the deficiencies in the Aetna and Centene networks, Access Living requests that out-of-network accommodations be mandated.

#### b. ADA-compliant accessibility

The mere provision of needed specialty care is insufficient if people with disabilities cannot access that care. Our consumers emphasized their need for accessibility in location and transportation, medical equipment, and health care personnel who are trained in working with people with disabilities. A consumer who requires a motorized scooter stated that she has trouble even in a fee-for-service system receiving proper care given inaccessible medical equipment. She is concerned about having even less choice in the Medicaid coordinated care system. Other consumers emphasized their need for providers who are accustomed to working with people with disabilities, sensitive to their needs, and able to provide needed accommodations such as interpreters.

ADA-compliant access is a core requirement to assure full inclusion for people with disabilities in the services and benefits available to others. Over twelve years ago, the U.S. Department of Health and Human Services published recommendations for ADA compliance in the area of health care, including accessible materials in alternative formats and providers trained in caring for people with disabilities. Currently, the Affordable Care Act mandates that medical diagnostic equipment be made accessible. These federal guidelines and standards are meaningless, however, if the State of Illinois cannot assure that its Medicaid providers are ADA-compliant.

Access Living recommends that Illinois follow the model of New York's 1997 guidelines that mandate health care organizations' compliance with the ADA – and submission of a compliance plan – simply to qualify as approved providers in New York's Medicaid managed care program. The New York "Health Plus" compliance plan is exemplary. Filed in 2005, the plan includes environmental accessibility, ADA and disability awareness trainings for staff, ASL interpreters, alternative-format written materials, training in assisting people with cognitive disabilities, assistance with transportation arrangements, recourse and appeal processes, and availability of out-of-network providers when medically necessary care cannot be obtained innetwork. Implementation of these reforms netted Health Plus a quality rating so high that the plan was awarded an extra 1.5% in Medicaid premiums in 2008, translating to an additional \$6 million in annual funding. Access Living recommends that the State of Illinois implement the New York compliance system and appoint a statewide ADA coordinator to oversee its implementation.

#### c. The qualities of care coordination

We asked our consumers what they would expect and need from a care coordinator. They stated that a care coordinator for people with disabilities should be:

- ➤ Ideally, a person with a disability or, at a minimum, a provider trained in disability rights and awareness who is disability-friendly;
- A person who listens and does not have an agenda of her or his own;
- An advocate who is there to work proactively for the patient and not for the system;
- > Someone who is familiar with the consumer's medical record, needs, and information, and has ready access to that information when necessary.

With respect to the operationalizing of medical homes, our consumers requested:

- ➤ An emphasis on preventive care;
- ➤ Incentives to pull in a wider network of providers, perhaps by creating a sign-on bonus for providers who are willing to take in Medicaid patients and assurances that Medicaid will reimburse providers promptly;
- Good communication with patients. This communication need is particularly urgent during the initial transition process. One of our consumers with cognitive issues stated that she is nervous and apprehensive about the change. She knows how her Medicaid card works but is fearful about navigating this new system.
- Consumer choice and recourse. One consumer pointed out that, if a care coordinator proves to be a "dud," the consumer should be provided some recourse. Another consumer who uses a wheelchair, is on dialysis, and is awaiting a kidney transplant stated that she wants to have the ability to move from one hospital to another for care if necessary. She had a big problem receiving proper care in one hospital and did not get back on track until she switched hospitals.

Dr. Dianne Collins makes the following points about the qualities and comprehensiveness of coordinated medical care:

- A mandatory element of effective coordinated care is the patient-centered medical home (PCMH), which links patients to a primary care physician who leads a multidisciplinary team. An excellent and comprehensive description of the operations of the PCMH has been made available by the American College of Physicians at <a href="http://www.acponline.org/running\_practice/pcmh/">http://www.acponline.org/running\_practice/pcmh/</a>.
- ➤ Coordinated care requires a written treatment plan with monitors for patients' progress that documents changes in condition and fosters communication between health care providers and patients about outcomes.
- ➤ Coordinated care prevents fragmented care through facilitation of communication between care coordinators and providers and integration of health care services, including supportive community services.
- Coordinated care is not managed care, and those terms should not be used synonymously. Unlike managed care, coordinated care should improve patient outcomes, reduce hospital visits, and reduce morbidity and mortality.
- ➤ Coordinated care should be personal care from a primary care practitioner, with multidisciplinary team assessment and input, to integrate more effective medical care with preventive intervention and patient education. This quality is particularly important in providing health care to people with disabilities.

# 2. What should be the appropriate measures for health care outcomes and evidence-based practices?

Our consumers stated that they would base quality on factors that include

- ➤ Good preventive care;
- Reduced hospitalizations;
- > Prescription coverage;
- ➤ User-friendliness;
- ➤ Opportunities for patient feedback that is regular, standardized, and reported to the State (consisting of such mechanisms as consumer surveys or consumer focus groups);
- > Time to spend with the doctor that is sufficient to allow them to ask questions and understand medical information;
- > Good communication with explanations of complex medical information;
- ➤ Disclosure of information about possible side effects and risks of treatments;
- ➤ Disclosure of information to help them make decisions, such as whether they should elect to be immunized for the H1N1 virus;
- ➤ Respectful treatment;
- Mechanisms to eliminate disparate treatment of Medicaid recipients. Citing the tendency of providers to avoid accepting Medicaid patients, one consumer suggested that the medical card be coded to avoid revealing that it is a Medicaid card. This consumer pointed out that similar precautions are taken in mixed housing situations. Another consumer stated that tracking should be done and measurements taken on disparities in treatment for Medicaid recipients, such as length of time required to see providers.

# 3. To what extent should electronic information capabilities be required?

#### Electronic health records

Our consumers were eager to have access to their electronic health records. However, they cautioned that access to technology is reduced among people with disabilities, both because of poverty and because of technological accessibility issues. By the same token, one consumer stated that she found that the cost of a hard copy of her medical record was prohibitive. Given these difficulties, our consumers urged that a free paper copy of one's medical record should be made available upon request to people with disabilities in Medicaid coordinated care.

Dr. Dianne Collins agrees that electronic medical records are an absolute necessity for reducing costs in coordinated care and making information available to patients, thereby improving patient adherence, self-management, and continuing education about their health conditions. While Dr. Collins agrees that many companies produce expensive and limited software products for physician use, she strongly encourages the State of Illinois to make use of the federal electronic medical record system that has been in use throughout Veterans' Medical Affairs hospitals and clinics (military and civilian) for more than fifteen years. The federal government software (FGS) facilities electronic coding and billing, which further reduces operational costs in health care facilities and results in fewer billing errors to third party payers. Dr. Collins states that the system's software should be obtained by Medicaid/Medicare and

offered to providers as an excellent, low-cost incentive to embrace the electronic medical record system as well as to improve effective communication between care coordinators and providers (with providers independently purchasing any necessary hardware).

Access Living urges that advancements in health care technology contemplate universal design principles. A research study conducted in 2003 demonstrated that over half of workingage computer users in the United States, or more than 74 million Americans, could benefit from accessible technology based on even mild vision, hearing, dexterity, speech, and cognitive impairments. In the case of health information technology, the advantages of universal design have even greater impact.

- Users include not only consumers of health care services but health care providers who have disabilities.
- A policy of inclusiveness is consistent with and promotes the principles and philosophy underlying the Americans with Disabilities Act of 1990.
- People without disabilities may have temporary or situational constraints that require accommodation, such as noisy work environments that limit the usefulness of audio features and necessitate accommodations designed for hearing-impaired people.
- People with limited English language capability will benefit from the use of clear and simple language designed for individuals with visual and learning disabilities.
- Products that are designed to be used by the largest audience possible will ultimately be the most cost effective products to design and produce. Stated simply, "Addressing the divergent needs of special populations increases usability for everyone."

To assure that people with disabilities may access their health care records and more fully participate in their health care monitoring and decisions, Access Living recommends that the following disability-related accommodations be provided:

#### Visual impairments:

- o Text-to-speech software, screenreaders
- o Alternative forms of media, such as audiotapes
- Alternative formats, such as screen enlargements and accompanying printed materials in large print and Braille
- o Auditory descriptions, videodescription
- O User-adjusted formats (e.g., text that can be enlarged by the user)

#### **Hearing impairments:**

- Text captioning
- o Telecommunications Relay Service (TRS) with ASL interpreter and/or text input
- o User-adjusted formats (e.g., sounds that can be amplified by the user)

### **Speech impairments:**

o Availability of email communication

#### **Mobility impairments:**

- o Alternative keyboard and mouse system
- Speech input system
- Wheelchair accessibility

#### Impairments in manual dexterity:

o Avoid real-time chat communication requiring keyboard input

#### Learning disabilities affecting reading ability:

- o Simple and clear language
- o Screen enlargements
- Auditory descriptions

#### Photosensitive seizure disorders:

o Compliance with Section 508 of the Rehabilitation Act, which requires flickering confined to 2-55 Hertz per second cycles to avoid seizure-inducing flickering effects.

#### For all disabilities:

- Use of the 21<sup>st</sup> Century Communications & Video Accessibility Act of 2010, P.L. 111-260, as a model, including hearing-aid compatibility of all telephones
- Compliance with the Web Accessibility Initiative guidelines, http://www.w3.org/WAI/
- Compliance with the United States Access Board's Electronic and Information Technology Accessibility Standards, <a href="http://www.access-board.gov/sec508/standards.htm">http://www.access-board.gov/sec508/standards.htm</a>
- Compliance with the United States Access Board's Telecommunications Act Accessibility Guidelines, <a href="http://www.access-board.gov/telecomm/rule.htm">http://www.access-board.gov/telecomm/rule.htm</a>
- Use as a resource of the AccessIT database on electronic and information technology, http://www.washington.edu/accessit/

#### Remote monitoring capabilities

We also discussed with our consumers the issue of "telehealth" or remote in-home monitoring capabilities. Such telemonitoring of chronic diseases is a promising management approach that empowers patients, provides for relatively easy compliance, produces reliable and accurate data, and potentially improves medical conditions. With the caveat that such remote monitoring should not increase social isolation of persons with disabilities, Access Living recommends that it be made available to assure adequate coordinated care, particularly in rural areas of Illinois. Our consumers generally agreed, however, that any such monitoring should be optional. One consumer suggested that an effective substitute for electronic monitoring would be nurse house calls on a monthly or other periodic basis to record blood pressure, blood sugar, and other essential health information.

# 4. What are the risk-based payment arrangements that should be included in care coordination? What is the minimum Medical Loss Ratio for a provider?

Our consumers recommended that measures be taken to keep the Medical Loss Ratio as favorable to them as possible, given the absence of not-for-profit alternatives to the State's for-profit Medicaid coordinated care system. Their proposals for ways to accomplish this end included:

➤ Prohibiting the use of Medicaid funds for either advertising or lobbying. Advertising is, of course, unnecessary in a State-sponsored system, and the use of Medicaid dollars for lobbying is unconscionable.

- Prescribing budgeted amounts for administrative costs as a means of controlling those costs.
- ➤ The State's pursuit of nonprofit delivery systems.

One of our consumers thought the medical loss ratio could be kept to 92% with such measures in place. This suggestion is not unrealistic. In 1993, leading health care insurers were spending a full 95% of the premiums they collected on medical care. Recently, the medical loss ratio has dropped, dipping to an average of 81% of premiums by 2007. But the increased "bonus" to insurers correlated not with increased medical costs but with skyrocketing profits. Between 2008 and 2009, the five largest health insurers in the nation saw profits increase 56%, from \$7.7 billion to \$12.1 billion. Despite the health insurance industry's gloomy predictions about profits after enactment of the Affordable Care Act, the five largest health-benefit carriers saw a double-digit increase in profits during 2010, realizing a 17% gain in profits in 2010 after a 28% gain in profits in 2009 – yet amounts spent on health care during the same period actually declined. Shares in the two largest health insurance companies were *upgraded* in 2011 from "hold" to "buy." <sup>15</sup>

A claim that an increase in profit margin is necessitated by increasing costs of medical care is belied by several factors.

- Medical costs are actually reasonably stable. 16
- Insurers are paying vast sums of premiums in the form of CEO compensation. In 2009, the CEOs of the ten largest for-profit health insurance companies took in total pay of \$228.1 million dollars, up from \$85.5 million in 2008. From 2000 to 2009, their total compensation amounted to nearly \$1 billion.<sup>17</sup> CEO pay nearly tripled in 2009.<sup>18</sup> Wellpoint, which earned a \$4.7 billion profit in 2009, paid its CEO \$13.1 million in total compensation that year, a 51% percent increase.<sup>19</sup>
- Large amounts of premiums are spent on measures that do nothing more than protect insurers' ability to continue making profits. An example is the expenditure by Anthem Blue Cross of \$2 million lobbying the California legislature and another \$1.6 million on campaign contributions between 2009 and 2010.<sup>20</sup>

Implementing the minimum medical loss ratios required in the Affordable Care Act – 80% for the individual and small group market, 85% for the large group market – is an important first step in beginning to control the hemorrhaging of premium payments for costs unrelated to health care. Access Living proposes, however, that those minimum ratios of 80% for the individual and small group market and 85% for the large group market are a floor, not a ceiling, and that they can reasonably be raised to 85% and 90%. These medical loss ratios are achievable.

- As noted above, leading health care insurers were able to maintain a 95% medical loss ratio in 1993.<sup>21</sup>
- Medicare, despite arguably inefficient administrative costs, has since 1993 consistently had a medical loss ratio *greater than 97%*. Indeed, Medicare's medical loss ratio *increased* from 97.7% in 1993 to 97.9% in 2007.<sup>22</sup>
- In Minnesota, the total loss ratio in 2009 for individual health plan companies was 96%. Small employer health plan loss ratios were 87% in 2009. In 2009.

- An amendment introduced in Congress in 2009 would have imposed the medical loss ratios that Access Living recommends, those of 85% and 90%. <sup>25</sup>
- The Main Street Alliance, a nationwide network of small businesses, recommends a minimum medical loss ratio of 90% as a means of restoring tens of billions of dollars to individuals and businesses.<sup>26</sup>

# 5. What structural characteristics should be required for new models of coordinated care?

Medicaid should lead rather than "follow the market." Health care is not a commodity. In addition, experimentation and innovation should be encouraged in pilots and demonstration projects only. Evidence-based and proven models of health care delivery should be used in generalized health care systems. We agree that Department of Insurance certification should be required. We also applaud the passage of House Resolution 286, creating the Medicaid Managed Care Oversight Task Force to monitor the performance and effectiveness of the coordinated care model that is now mandated for people with disabilities who receive Medicaid and thus to ensure that those individuals are receiving quality health care through the State's selected providers.

#### Coordinated care for particularly expensive patients

Access Living agrees that the provision of care to people who have chronic conditions that tend to be expensive to treat should be accommodated by the State. Based on the lack of specialty providers in the current coordinated care program, we encourage the State to seek available federal funds to promote pilot or demonstration projects that are designed to address the needs of this population of Medicaid recipients.

An outstanding and compelling example of such a service delivery model is that established by Dr. Robert Master in Boston. Dr. Master heads the Commonwealth Care Alliance, a not-for-profit health care system that offers a full spectrum of medical and social services for older adults and for people with physical and mental disabilities. By providing intensive and individualized primary care with 24/7 access to electronic health records, care coordination, behavioral health, and supportive services in the home and community through multidisciplinary teams, Commonwealth Care has reduced hospitalizations and nursing home placements, resulting in drastically lower costs far below fee-for-service rates and resulting in quality gains that achieved a 2009 score above the 90<sup>th</sup> percentile on Healthcare Effectiveness Data and Information Set measures for diabetes care, medication monitoring, and access to preventive services.<sup>27</sup> By reinvesting these savings into Commonwealth's primary care network, Commonwealth was able to make \$3.24 million of improvements in primary care above what Medicare would have paid and managed to reduce hospital care by half and nursing care placement by 70%. 28 The Commonwealth Care Disability Care Program is expanding to two more states through a demonstration collaboration with New York's Independence Care System and Wisconsin's Community Health Partnership and establishing an Institute for Disability Care Practice to monitor the model's development, use of information technology, and quality measures. <sup>29</sup> Access Living strongly encourages the State of Illinois to explore expansion of Dr.

Master's model and seriously consider its use as the optimal service delivery system for high-cost patients who need and deserve high-quality care.

#### Physician shortages

Dr. Dianne Collins notes that, according to statistical reviews, there are about 200 physicians per 1000 persons in the United States. Both current shortages as reported in the media and future shortages predicted based on the aging population and decrease in absolute numbers of physicians over the next fifteen years or so complicate the creation and maintenance of patient-centered medical homes, particularly in rural areas. Health care organizations like Aetna and Centene are encumbered by these provider shortages (as revealed in their provider directories, discussed above), a factor that has significant impact on the Illinois population of people with disabilities.

Dr. Collins points out that this situation may be dramatically improved by identifying and employing disabled physicians, nurses, and other health care workers in coordinated care settings. These workers, who currently are unemployed or underemployed, <sup>30</sup> may serve as highly qualified staff in patient-centered medical homes for people with disabilities. Staffing coordinated care settings with providers and workers who need jobs and who would meet our consumers' ideal of a person with a disability or, at a minimum, a person trained in disability rights and awareness can only be a "win-win-win" situation for patients, health care providers and workers, and the State of Illinois.

#### Access to specialty care

Access Living addressed the need for access to specialty care for people with disabilities in its response to Question #1.

# 6. What should be the requirements for client assignment?

#### Assignments based on medical condition and population group

Access Living does not support segregation of people with disabilities in a separate health care system. We decry the intractable disparities in health and health care that have historically affected people with disabilities, and we commend the provisions in the federal Affordable Care Act that seek to root out and eliminate such disparities.

Nevertheless, until those disparities truly cease to exist, we support the type of service delivery model established by Dr. Robert Master and discussed above under Question #5. By focusing on the particularized needs of a limited population characterized by disability and chronic health conditions, this model has achieved an efficiency and affordability that provides a high quality of care that our consumers want, need, and deserve.

#### Assignments by geography

For all low-income people, transportation difficulties are a basic structural impediment to quality health care.<sup>31</sup> For people with disabilities, however, and particularly those with mobility disabilities, inadequate transportation can prove prohibitive. Assigning those individuals to health care providers that are located far from their own neighborhoods will have a definite chilling effect on their ability to access quality health care. On the other hand, assigning people with disabilities to geographic areas with a scarcity of needed specialists provides no solution. This set of issues creates another compelling reason for out-of-network specialist access in the State's coordinated care program.

## Assignments by population

Access Living addressed coordinated care for people with disabilities and chronic conditions in the context of Question #5, "particularly expensive patients." While we do not endorse segregation of people with disabilities in health care any more than in any other area of life, we are mindful of the inability of a for-profit health care system to provide a cost-efficient, quality spectrum of medical and social services for people with disabilities. For that reason, we emphasize that consumers with disabilities who have not self-assigned must be assigned to the entity with the most extensive network and the most numerous and accessible locations of facilities. In this context, we reiterate that the State of Illinois should explore not-for-profit delivery models, such as Dr. Robert Master's Commonwealth Care Alliance in Boston, that are capable of addressing the complex needs of this group of people.

## 7. How should consumer rights and continuity of care be protected?

With respect to continuity of care, Dr. Dianne Collins emphasizes that use of the patient-centered medical home model for coordinated care would go far by providing choices of providers and out-of-network referrals, and by acquiring quality community support.

Our consumers unanimously agreed that their rights would be best protected through a choice of providers. See "A full panoply of providers" within response to Question #1, above. Another important form of consumer protection that was mentioned was assurance of ADA compliance. See "ADA-compliant accessibility" within response to Question #1, above. Our consumers also highly valued

- > The right to get a second opinion;
- ➤ Patient mediation and appeals procedures, with involvement of people with disabilities in the mediation process;
- The right to have a copy of their medical records; and
- ➤ A role for a Consumer Advisory Board.

Access Living strongly recommends involvement of consumers with disabilities in policymaking, program evaluation, and oversight generally. Our consumers, who have lived years with disabilities, are the experts when it comes to their needs. Their expertise can provide unique insights into ways to make a coordinated care delivery system fit their needs rather than

shoehorn them into a predesigned and inflexible system designed for people who do not have disabilities. It is they who are also more likely to notice and flag environmental, communication, and other access barriers and thus to trigger responses that will increase ADA compliance. In light of the upcoming new regulatory standards on accessible medical diagnostic equipment from the U.S. Access Board and possible expansion of those standards into Titles II and III of the ADA by the Department of Justice, a strong voice from the disability community on accessibility will be to the advantage of all coordinated care providers and entities. We endorse the recommendation of the National Council on Disability that

[c]onsumers representing a wide range of disability perspectives should be included in decision making at every step in the process that ultimately shapes programs: from development and implementation of a research agenda through policymaking to program design, oversight, and evaluation. Consumers provide a truly unique source of information about the human services and health care delivery system.<sup>32</sup>

A consumer advisory committee is a plausible means of providing that oversight and feedback. Consumers with disabilities should be included on such a committee in order to have an opportunity to evaluate program effectiveness, identify relevant quality measures, help to design consumer education and outreach materials, and engage other consumers in the coordinated care model of health care delivery. A consumer advisory committee can serve as a true partner of health care entities, encouraging transparency and accountability in policy and decisions that will enhance the legitimacy of those entities' policies and will boost the overall credibility of the organizations among all consumers. The advisory committee should be a meaningful one. Mere tokenism will defeat the many benefits to be gained by involving consumers and their advocates.

# 8. What is your organization's preliminary anticipation of how it might participate in coordinated care?

We discussed with our consumers what kind of role Access Living and other Centers for Independent Living should play in coordinated health care for people with disabilities. Our consumers suggested the following activities:

- Assisting with enrollment and explanations of provider options.
- > Serving as an advocate for people with disabilities within the coordinated care system.
- Assisting as a mediator or ombudsman.
- > Serving as a site for consumer feedback, including focus groups and evaluations.

Bill Henning, Executive Director of the Boston Center for Independent Living (BCIL), corresponded with Access Living's health team on June 21, explaining the relationship of that Center with the creation of Dr. Robert Master's coordinated care organization for people with disabilities in Boston. Mr. Henning explained that relationship as follows:

BCIL has a longstanding relationship with Bob Masters—as he'll tell you, it was BCIL members, in the late 1970s, who met with him and his partners to create

what became Boston Community Medical Group, which still exists 30 years later. It provides coverage to 300+ highly medically-involved people with physical disabilities, integrating all elements of care, including provision of DME and behavioral health, with a person-centered, holistic approach. Our members swear by it. 33

BCIL continues its relationship with the medical group by communicating with Centers for Independent Living in Massachusetts and elsewhere about potential expansion of that health care system. The Center also works directly with Dr. Master to promote innovative health care programs for people dually eligible for Medicaid and Medicare.

We appreciate this opportunity to comment on some of the key policy issues in the Illinois coordinated care program. We look forward to working with the State of Illinois as it continues to implement these important provisions of the Medicaid reform law.

Very truly yours,

Marilyn J. Martin Tom Wilson Judy Panko Reis, The Access Living Health Care Team,

Amber Smock, Director of Advocacy

<sup>&</sup>lt;sup>1</sup> <u>http://www.illinicare.com/files/2011/06/rpt-illini-Directory-06-20-2011.pdf;</u> http://www.aetnabetterhealth.com/Illinois/FindProvider.aspx?menu=.

<sup>&</sup>lt;sup>2</sup> "Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs," <a href="http://library.findlaw.com/1998/Oct/8/130735.html">http://library.findlaw.com/1998/Oct/8/130735.html</a>.

<sup>&</sup>lt;sup>3</sup> Section 4203, "Removing barriers and improving access to wellness for individuals with disabilities," <a href="http://www.ncsl.org/documents/health/ppaca-consolidated.pdf">http://www.ncsl.org/documents/health/ppaca-consolidated.pdf</a>

<sup>&</sup>lt;sup>4</sup> "Guidelines for Medicaid MCO Compliance with the ADA," http://www.health.state.ny.us/health\_care/managed\_care/pdf/appendixj.pdf,

<sup>&</sup>lt;sup>5</sup> http://www.healthplus-ny.org/data/HP ADA Plan 2005-revisions.pdf

<sup>&</sup>lt;sup>6</sup> http://www.healthplus-ny.org/en/79\_ENG\_HTML.html

<sup>&</sup>lt;sup>7</sup> See, for example, Bisgaier, J., Rhodes, K., "Auditing Access to Specialty Care for Children with Public Insurance," N. Engl. J. Med. 2011; 364:2324-33, finding striking disparities in acceptance of Chicago-area Medicaid-CHIP pediatric patients for appointments and in length of wait times, http://healthpolicyandreform.nejm.org/?p=14707

<sup>&</sup>lt;sup>8</sup> Universal Design: A Commitment to Accessible Software from SAS Institute, p. 3 (SAS Institute 2005), <a href="http://www.sas.com/govedu/accessibility-white-paper-091305.pdf">http://www.sas.com/govedu/accessibility-white-paper-091305.pdf</a>

<sup>&</sup>lt;sup>9</sup> M. Burks, "Raising Awareness of the Economic Advantages of Universal Design," Keynote Speech to ACM Conference on Universal Usability, November 2000, http://www.icdri.org/BurksMISC/raising\_awareness\_of\_the\_economi.htm

<sup>&</sup>lt;sup>10</sup> D. Rose & A. Meyer, *Teaching Every Student in the Digital Age: Universal Design for Learning*, Chapter 4: What is Universal Design for Learning?, <a href="http://www.cast.org/teachingeverystudent/ideas/tes/chapter4">http://www.cast.org/teachingeverystudent/ideas/tes/chapter4</a> 2.cfm

<sup>&</sup>lt;sup>11</sup> Pare, G., Jaana, M., Sicotte, C., "Systematic review of home telemonitoring for chronic diseases: the evidence base," J. Am. Med. Inform. Assoc. 2007 May-Jun: 14(3):269-77, <a href="http://www.ncbi.nlm.nih.gov/pubmed/17329725">http://www.ncbi.nlm.nih.gov/pubmed/17329725</a>

<sup>&</sup>lt;sup>12</sup> PricewaterhouseCoopers, "Beyond the sound bite: Review of presidential candidates' proposals for health reform," 2008, http://www.pwc.com/us/en/healthcare/publications/popups/medical-loss-ratio.jhtml.

<sup>&</sup>lt;sup>13</sup> Senator Dianne Feinstein, Testimony on Health Insurance Rate Authority Act of 2010, April 20, 2010, <a href="http://www.achp.org/themes/ACPH\_Main/files/FeinsteinTestimony04.20-10-RateReview.pdf">http://www.achp.org/themes/ACPH\_Main/files/FeinsteinTestimony04.20-10-RateReview.pdf</a>

<sup>&</sup>lt;sup>14</sup> Market Watch, "Study points out large health-insurer gains," March 3, 2011, http://www.marketwatch.com/story/study-points-out-big-health-insurer-gains-2011-03-03

<sup>&</sup>lt;sup>15</sup> Bloomberg Businessweek (Associated Press), "Analyst raises insurer stocks to 'buy' from 'hold," March 3, 2011, <a href="http://www.businessweek.com/ap/financialnews/D9LNVSH80.htm">http://www.businessweek.com/ap/financialnews/D9LNVSH80.htm</a>

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<sup>&</sup>lt;sup>29</sup> <u>Harris Meyer1</u>, A New Care Paradigm Slashes Hospital Use And Nursing Home Stays For The Elderly And The Physically And Mentally Disabled, *Health Affairs*, March 2011 30(3):412–15., http://content.healthaffairs.org/content/30/3/412.extract [Abstract only]

<sup>&</sup>lt;sup>30</sup> The U.S. Department of Labor has released new statistics showing that fewer than one in five people with disabilities held jobs in 2010, and those who did were more frequently underemployed. Even those with advanced degrees lagged significantly behind other educated individuals without disabilities in employment. "New Stats Confirm Disability Employment Woes," Disability Scoop, June 28, 2011, <a href="http://www.disabilityscoop.com/2011/06/28/new-stats-employment-woes/13427/?utm\_medium=email&utm\_campaign=June+28%2C+2011%3A+News+from+Disability+Scoop&utm\_source=YMLP&utm\_term</a>

<sup>&</sup>lt;sup>31</sup> Robert Wood Johnson Foundation, Program Results Special Report, "Causes of Disparities" (2007), <a href="http://www.rwjf.org/pr/product.jsp?id=49717">http://www.rwjf.org/pr/product.jsp?id=49717</a>

<sup>&</sup>lt;sup>32</sup> National Council on Disability, "Consumer-Directed Health Care: How Well Does It Work?" (2004), http://www.ncd.gov/publications/2004/Oct262004

<sup>&</sup>lt;sup>33</sup> Email from Bill Henning, Executive Director of BCIL, June 21, 2011.