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**EVALUATING CONSUMER  
SATISFACTION WITH  
MANAGED HEALTH CARE AND  
LONG-TERM SUPPORTS**

Report to the Illinois Planning Council on  
Developmental Disabilities

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# 1. INTRODUCTION

## 1.1 Overview

In July 1998, the Illinois Planning Council on Developmental Disabilities (IPCDD) awarded a two-year grant to Human Services Research Institute (HSRI), to explore how well health care plans in Illinois meet the needs of people with developmental disabilities. HSRI teamed with Medicaid Working Group, People First of Illinois (PFI), and the Illinois Family Support Network. Initially designed to assess the impact of a new managed health care initiative, called Medi-Plan Plus, the study soon broadened in scope to look at Medicaid overall, because the Illinois Department of Public Aid (DPA) decided to exclude people with developmental disabilities from Medi-Plan Plus. Although the evaluation activities of the study focused largely on people served through Medicaid, the study team, in consultation with the Council, decided to examine health care with an eye to the *potential* of managed care, thus highlighting strengths and challenges in the current health care system that should be carefully addressed when and if Illinois considers a managed care approach to meet the health care needs of people with developmental disabilities. In this way, the Council is equipped to address whatever scenario emerges – modification to the current fee-for-service system, or a significant shift to a managed care approach.

As policy makers in Illinois begin to contemplate reforms to the health care system for people with developmental disabilities, managed care is one of several options to be debated. In the acute health care sector, managed care has been “acclaimed as better, more accessible medicine at a more affordable price... (but) evidence remains mixed on whether this claim is true.”<sup>1</sup> It has been successful in containing costs, but sometimes at the expense of consumer safeguards and the long-term soundness of the health care delivery system. More important for the discussion at hand, however, is that, regardless of its track record, the managed care industry has historically served a commercially insured, employed population, in a medical model of health care service delivery – traditional medical services to populations who do not have disabilities. Over the past decade Health Maintenance Organizations (HMOs) have slowly expanded their services to low income women and children covered by Medicaid under the Aid to Families with Dependent Children program (now known as TANF—Temporary Aid to Needy Families); and, in recent years, some public sector managed care plans have begun to serve the elderly, individuals with disabilities, and foster care children.<sup>2</sup> Nonetheless, as a whole, the managed care industry has not evolved to serve special needs populations. It is thus critical for policy makers to examine the ways in which people with disabilities require *different* health care delivery system features than the general population or, even, than the general Medicaid population.

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<sup>1</sup> Gary Smith and John Ashbaugh, Managed Care and People with Developmental Disabilities: A Guidebook, Alexandria, VA: NASDDDS, 1995, page 30.

<sup>2</sup> P. Fox & T. Fama, eds. Managed Care and Chronic Illness: Challenges and Opportunitie, Gaithersburg, MD: Aspen Publishers, 1996.

## 1.2 Methodology

The study had three primary goals:

1. To inform consumers about what managed health care is currently available in Illinois, in both managed care and fee-for-service options, and what key questions they should ask as they choose their health care;
2. To provide consumers with sufficient knowledge to influence state and local policy in health care and long-term supports for people with developmental disabilities; and,
3. To inform government, providers and health care organizations of key issues in serving people with developmental disabilities, so they can adapt their approach to better serve the population.

To achieve these goals, the study team pursued four broad activities:

1. Work closely with an Advisory Committee of key stakeholders, including people with disabilities and family members, to clarify the focus of the study and to obtain their input to all study products;
2. Learn about what health care plans exist for people with developmental disabilities by gathering background materials and interviewing key stakeholders;
3. Identify the key health care issues facing people with developmental disabilities by holding community forums for people with developmental disabilities and their families throughout the state;
4. Explore the satisfaction of people with developmental disabilities and their families with current health care plans by interviewing selected consumers.

The step-by-step process followed by the study team over the course of the project has been detailed in Quarterly Progress Reports to the IPCDD, hence it will not be reiterated here. However, it is important to highlight the following aspects of this evaluation. First, the Project Advisory Committee has played a significant role throughout the project, reviewing proposed questions for the community forums and consumer interviews and by critiquing policy and research reports. The 16 member committee was comprised of people with disabilities, family members, and representatives of advocacy or service provider organizations (see Appendix 1). Second, PFI has played a crucial role in assuring the connection between the disability community and the project, in arranging the community forums and in conducting consumer interviews. Participation in this study provided members of PFI a unique opportunity to increase their knowledge and experience in program evaluation. Specifically, members gained valuable skills in critiquing interview tools and sharpened their interviewing techniques through interactive training and the conduct of face-to-face interviews. Building on this experience, PFI is better equipped to pursue additional evaluation projects in the future.

## 1.3 Organization of the Report

This report integrates and summarizes the various products of the two-year study, including two policy papers on Illinois health care<sup>3</sup>, the input from consumer and family focus groups throughout the state, and findings from the face-to-face interviews with consumers of health care. Sections Two through Four describe the policy context of Medicaid and managed health care in Illinois, profiling key considerations for health care policy reforms. Section Five offers primary data on selected people with developmental disabilities in Illinois. The sections of the report are organized as follows:

- ⌘ **Section 2** describes the current Illinois Medicaid program, highlighting facts about service availability, eligibility, participation and costs.
- ⌘ **Section 3** highlights some unique aspects of health care needs of people with disabilities. This is important to understand when systems are contemplating changes to health care programs.
- ⌘ **Section 4** discusses the structure of managed care in Illinois Planning Council on developmental Disabilities.
- ⌘ **Section 5** presents the finding from the community forums and consumer interviews, detailing key concerns regarding health care and revealing strengths and challenges of current health care coverage.
- ⌘ **Section 6** summarizes the report and offers recommendations when considering changes in the health care arena.

## 2. MEDICAID IN ILLINOIS

### 2.1 Overview

Medicaid is a federal program created under Title XIX of the Social Security Act, that pays for medical care for low income individuals. Medicaid is funded jointly by the federal and state governments. The manner in which this is done varies from state to state. In Illinois, the state government funds 50%, while the other half is funded by the federal government. The federal government and the states also share administrative responsibility for Medicaid. For example, the federal government establishes minimum benefit levels and broad eligibility rules, while the states have flexibility to increase coverage or expand eligibility. In Illinois, the state agency responsible for the administration of the Medicaid program is the Illinois DPA.

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<sup>3</sup>The two policy papers prepared as part of the evaluation study include: (a) Mari-Lynn Drainoni and Carol Tobias of the Medicaid Working Group, and Madeleine Kimmich of Human Services Research Institute, (December 1998), Policy Brief: Reforming Health Care for People with Developmental Disabilities in Illinois, Salem, OR: HSRI; and b) Mari-Lynn Drainoni, Carol Tobias, Jena Chambers, Jessica Sotelo, and Karin Haberlin, (March 2000), A Profile of Illinois: The Medicaid Program, Managed Care, and People with Disabilities, Boston, MA: Medicaid Working Group, at Boston University School of Public Health.

In 1997 the total Illinois' population was 11,923,000 individuals. Of these, 13%, or 1,550,000 persons, qualified as low-income, based on federal guidelines.<sup>4</sup> Fifteen percent (15%) of the total population, or 1,775,061 persons, were enrolled in the Medicaid program at some point during the year. Total Medicaid spending in Illinois during state fiscal year 1999 was \$6,154,000,000.<sup>5</sup>

**2.1.1 Medicaid Benefits**

The federal government requires all Medicaid programs to cover a mandatory package of health services, such as physician visits, hospital services, long term care, and laboratory and X-ray services. Table 1 lists some of the mandatory Medicaid benefits for all states.

**Table 1: Mandatory Medicaid Coverage for All States<sup>6</sup>**

|  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• Inpatient hospital</li> <li>• Rural health clinic</li> <li>• Federally qualified health centers</li> <li>• Physician visits</li> <li>• Early and periodic screening, diagnosis, and treatment for individuals under age 21</li> </ul> | <ul style="list-style-type: none"> <li>• Outpatient hospital</li> <li>• Laboratory and X-ray</li> <li>• Nursing homes</li> <li>• Home health care</li> <li>• Family planning</li> <li>• Nurse Practitioner</li> <li>• Nurse-Midwife</li> </ul> |
|--|--|

States may provide additional services, known as optional benefits, at their own discretion. In Illinois, these optional benefits include such services as physical, occupational, and speech therapies, prescription drugs, and hospice care. Table 2 on the following page highlights some of the additional services covered by Medicaid in Illinois.

Although Illinois recently expanded its optional Medicaid services, a few critical services not covered by Illinois Medicaid are particularly important to people with disabilities. These include services such as personal care, medical social work and respiratory care.<sup>7</sup>

<sup>4</sup> Henry J. Kaiser Family Foundation, "Medicaid and Uninsured Facts", The Kaiser Commission on Medicaid and the Uninsured, 1999

<sup>5</sup> Nelly Ryan, Chief of Bureau of Managed Care, Illinois Department of Public Aid, written communication, February 17, 2000

<sup>6</sup> "Medicaid Services State by State." HCFA Publication No. 02155-97.

<sup>7</sup> *ibid.*

**Table 2: Optional Medicaid Services Covered in Illinois<sup>8</sup>**

|   |  |
|---|--|
| <ul style="list-style-type: none"><li>• Private duty nursing</li><li>• Physical therapy</li><li>• Speech therapy</li><li>• Diagnostic services</li><li>• Prescribed drugs</li><li>• Inpatient psychiatric services for individuals over 65</li><li>• Emergency hospital services</li><li>• Intermediate care facilities for the mentally retarded</li><li>• Medical equipment</li><li>• Podiatry</li><li>• Routine dental care</li><li>• Optometry</li><li>• Dentures</li></ul> | <ul style="list-style-type: none"><li>• Occupational therapy</li><li>• Prosthetic devices</li><li>• Rehabilitative services</li><li>• Case Management</li><li>• Hospice Care</li><li>• Inpatient psychiatric services for those under 21</li><li>• Screening services</li><li>• Nursing home services for those under 21</li><li>• Transportation</li><li>• Chiropractor</li><li>• Eyeglasses</li><li>• Psychology</li></ul> |
|---|--|

### **2.1.2 Medicaid Eligibility**

In Illinois, Medicaid is available to anyone who can demonstrate need, as established through income and asset standards, and either has dependent children, or is pregnant, blind, disabled, or over 65. DPA estimates that 1 in 8 Illinois residents were covered by Medicaid during any given month in 1998.<sup>9</sup> People with disabilities can become eligible for Medicaid in several ways. We describe below some of the different Medicaid eligibility categories. Two of these categories are linked to a cash grant, while the others are not.

#### *Medicaid Assistance with a Grant (often called MAG)*

Two programs in Illinois provide medical assistance automatically as a result of qualifying for a cash grant program:

- ◆ *Temporary Assistance for Needy Families (TANF)* provides income assistance to people who meet low income standards and who are pregnant or have dependent children under age 19. A person who qualifies for TANF also qualifies for Medicaid. The TANF program is administered by the state's new Department of Human Services, while the Medicaid benefits are administered by DPA. Some low-income children with developmental disabilities receive Medicaid benefits through this option, because their parent has not applied for SSI or

<sup>8</sup>Nelly Ryan, Chief of Bureau of Managed Care, Illinois Department of Public Aid, written communication, February 17, 2000.

<sup>9</sup> Illinois Department of Public Aid, July 1999

because the application for SSI was denied. A smaller number of high-functioning parents with developmental disabilities receive Medicaid through this category for the same reasons

- ◆ *Aid to the Aged, Blind, and Disabled (AABD)* is a program for low income people who are blind, disabled, or over 65 years of age. Generally, this population is also covered under the federal Supplemental Security Income (SSI) program, although in Illinois, receipt of SSI benefits does not lead to automatic Medicaid eligibility, as it does in most states. Most of the people in the AABD category are adults, although children who are blind or have disabilities are also eligible. The majority of individuals with developmental disabilities who receive Medicaid benefits receive them by qualifying under this category.

*Medicaid Assistance without a Grant (often called MANG)*

Certain groups of people who live in Illinois are eligible to receive Medicaid benefits even though they do not receive a cash benefit:

- ◆ The *Medicaid Spend-Down* option is for people who can show that they have paid and unpaid medical bills that exceed their monthly income. The program allows individuals who do not qualify for Medicaid under regular income/asset guidelines to receive coverage through “spending down” their excess income and/or assets on medical expenses. DPA determines a monthly “spend-down” amount, which works like an insurance deductible; each month that a person exceeds this amount, s/he receives a month of Medicaid coverage to use during the month of her/his choice. This eligibility category is important in Illinois because of the state’s restrictions in providing Medicaid benefits to people on SSI (described below). For example, an individual with developmental disabilities who has a part-time job may not qualify for Medicaid due to excess income. If this individual has a lot of medical expenses, s/he could obtain Medicaid benefits through the spend-down option. However, the documentation and paperwork required for spend-down may put this option out of reach for some individuals, and the coverage is very sporadic.
- ◆ The *Qualified Medicare Beneficiary (QMB)*, *Specified Low-Income Medicare Beneficiary (SLIMB)*, and *Qualified Individual (QI)* programs are designed to assist low-income individuals with Medicare coverage. The QMB program helps them pay Medicaid Part B premiums, deductibles, and coinsurance. The SLIB program pays Medicare Part B premiums only. The QI-1 program pays Medicare Part B premiums for individuals not eligible for Medicaid. The QI-2 program pays a small portion of Part B premiums.
- ◆ Other eligibility categories include children whose care is subsidized by the Department of Children and Family Services; refugees who are part of the *Refugee Resettlement Program*; individuals who are considered “not employable;” and low income children or families who do not qualify for TANF.

## 2.2 People with Disabilities and Medicaid

As stated earlier, receipt of SSI benefits does not automatically guarantee receipt of Medicaid benefits in Illinois. Although the AABD program largely coincides with the SSI program, Illinois is one of nine states which use somewhat different criteria than the federal SSI program to determine Medicaid eligibility. Because of this difference, the total number of people with disabilities who receive Medicaid does not accurately reflect the statewide population of people with disabilities; not all people with disabilities receive Medicaid. The data presented below only addresses the group of people with disabilities who receive Medicaid benefits.

According to data received from the Illinois DPA, approximately 250,000 people with disabilities in Illinois currently receive Medicaid. The percentage of the Illinois population on Medicaid with a disability, 1.9%, is comparable to other states. The majority of this population (87%) receive Medicaid and a cash grant through the AABD program, while the remainder (13%) receive Medicaid only through other programs.

More detailed data regarding people with disabilities in Illinois is incomplete, such as the number of people with disabilities by type of disability. Illinois classifies people with disabilities into two groups, developmentally disabled and other disabled. Neither category specifies the nature of the developmental disability or other disability. However, national data suggest that people with developmental disabilities typically represent 27-28% of the Medicaid Disabled population, thus 70,000 people with developmental disabilities are estimated to be in the Illinois Medicaid population.

### 2.2.1 Costs of Care

In Illinois, Medicaid costs for people with disabilities are higher than the national average. Illinois Medicaid spends an average of \$9540 per person per year, compared to the national average of \$8784 per person per year. Table 3 compares Medicaid expenditures for people with disabilities in United States as a whole with Illinois, by service area and managed care payments.

**Table 3: Average Per Capita Medicaid Costs for People with Disabilities<sup>10</sup>**

|                                     | Illinois     | United States |
|-------------------------------------|--------------|---------------|
| <b>Total cost per beneficiary</b>   | \$9540       | \$8784        |
| <b>Spending by service category</b> |              |               |
| • <b>Acute care</b>                 | \$5533 (58%) | \$4042 (46%)  |
| • <b>Long-term care</b>             | \$3053 (32%) | \$3074 (35%)  |
| • <b>Managed care payments</b>      | \$ 287 (3%)  | \$ 615 (7%)   |
| • <b>Other</b>                      | \$ 667 (7%)  | \$1053 (12%)  |

<sup>10</sup> Henry J. Kaiser Family Foundation, "Medicaid and Uninsured Facts", The Kaiser Commission on Medicaid and the Uninsured, 1999.



Although average per capita Medicaid costs differ between the United States as a whole and Illinois, in both cases the highest proportion of costs are for acute care. Long-term care accounts for about a third of costs for both the United States and Illinois. The proportion of dollars that go to managed care is fairly small in both cases, but these costs are even lower in Illinois, as people with disabilities are currently excluded from Illinois' Medicaid managed care program.

Several potential explanations exist for the higher costs in Illinois, including:

- ◆ The cost of living and cost of medical services may be higher than the national average;
- ◆ A lack of access to good primary and preventive care for people with disabilities may drive up costs of acute care for secondary complications of disability;
- ◆ Sporadic or intermittent coverage through the spend-down program often means that people do not get care until they are already sick; and
- ◆ Coverage for some of the home and community-based optional Medicaid benefits increased in July 1999, and the research cited above does not reflect those changes. Decreased access to home and community-based services may cause people to rely on more expensive hospital-based care, so it is possible that the more comprehensive benefit package will help to decrease costs. However, Illinois' package still lacks coverage for personal care assistance, an important service for people with disabilities, which may help to explain the higher than average costs per person.

### **3. UNIQUE HEALTH CARE NEEDS OF PEOPLE WITH DISABILITIES**

Medicaid services can be conceptualized as falling into three broad categories: health care, behavioral health care, and long term care and supports. In contrast to other population groups, people with disabilities are likely to use services in all three categories. However, the state of the art in the purchase and delivery of services under a managed care model is very different in each of these categories. For example, while many states have implemented managed health care programs, few have implemented managed long term support systems. Furthermore, there is very little experience nationally in providing disability-specific behavioral health care services in either the fee-for-service or managed care arenas. Understanding the differences in and interface between the three benefit categories is essential in any health care reform initiative.

Further, any discussion of Medicaid managed care for people with disabilities needs to include two key considerations: the range of services to be included in managed care; and the unique needs and characteristics of people with disabilities that may require modifications to conventional managed care delivery systems. People with disabilities differ from the broader Medicaid population in several crucial ways:

1. *People with disabilities have a different scope, intensity, and duration of service needs.*

Many of these differences are related to the life-long aspects of disability (in contrast to the acute care needs of other populations) and the goals of care, which are often to maintain or

slow the deterioration of a condition rather than to cure it. Services with a different scope of use include medications, durable medical equipment, assistive technology, mental health, and long term supports. Services with a different intensity include dental care, personal assistance, and transportation. Services with a different duration include home health, rehabilitation therapies, and long term support services.

2. *People with disabilities have different issues regarding access to care.* First, some people with disabilities have special requirements regarding physical access to care. This includes transportation, equipment, accessible offices and accessible examining tools. Secondly, some people with disabilities have access issues related to communication, expression of symptoms, understanding instructions, or communication through a relative or caregiver. Thirdly, there may be heightened access issues in rural areas because people with disabilities are more likely to need services from a broad range of specialized providers. These providers are often located only in urban areas, increasing the need for telecommunication or long distance transportation. Finally, people with disabilities often have difficulty accessing primary care because few primary care providers are knowledgeable about disability.
3. *Importance of maintaining relationships that work well.* Given the access issues described above, especially the difficulty involved in finding providers that understand and can communicate with people with disabilities, it is especially important to maintain and support relationships with primary care physicians and specialists that work well. People with disabilities and their families are likely to spend enormous time and energy developing relationships with appropriate providers. These relationships may be severed or compromised in conventional managed care plans due to their restricted provider networks.
4. *People with developmental disabilities are particularly vulnerable.* Many people have limited self-advocacy skills, and are often not aware of their rights or how to exercise them. Additional oversight of services is necessary to assure that rights are protected. This is particularly important if providers are not trained to explain procedures or protocols, or are hesitant to include family members and guardians in decision-making.
5. *People with disabilities often need care coordination services.* Because people with disabilities use services in different delivery systems, coordination of services is often much more complex than the coordination of care provided in conventional managed care plans. Depending on the state system, there may be multiple case managers in different service systems. The design of this system under managed care requires particular attention.

#### **4. MANAGED HEALTH CARE IN ILLINOIS**

The Illinois Medicaid Managed Care program is a voluntary program, operating in Cook and St. Clair counties. Cook County covers Chicago and some of its suburbs, while St. Clair County covers East St. Louis and its suburbs. The Illinois DPA contracts with Health Maintenance Organizations (HMOs) and Managed Care Community Networks (MCCNs) to provide services to managed care enrollees. MCCNs serve only persons receiving Medicaid. HMOs are full risk

models of care; they serve Medicaid recipients and may also serve privately insured individuals and Medicare beneficiaries. MCCNs are provider-sponsored organizations certified by the Department as meeting certain standards. Contractual requirements are the same as those for the HMOs, although financial, solvency and licensing standards are less stringent<sup>11</sup>.

Only those individuals who receive Medicaid benefits through the TANF or MANG programs (and individuals in KidCare, a state-funded program for children) are currently eligible to join managed care plans. This means that most people with disabilities, who receive Medicaid benefits through the AABD program, are excluded from joining managed care plans.

Currently six HMOs and two MCCNs operate under the state managed care system. Illinois has no fee-for-service Primary Care Case Management (PCCM) program, although this is being considered as a possibility. The HMOs and MCCNs are listed below:

- | <b>HMOs</b>                              | <b>MCCNs</b>            |
|--|-------------------------|
| ◆ Americaid Community Care               |                         |
| ◆ American Health Care Providers, Inc.   | ◆ Family Health Network |
| ◆ United HealthCare                      | ◆ Neighborly Care Plan  |
| ◆ Harmony Health Plan of Illinois        |                         |
| ◆ Humana Health Plan                     |                         |
| ◆ Illinois Masonic Community Health Plan |                         |

Table 4 shows managed care enrollment comparisons of Illinois with the other states in Region 5 (of the federal Health Care Financing Administration (HCFA)).

**Table 4: Medicaid Managed Care Enrollment for HCFA Region 5\***

| State     | Medicaid Enrollment | Managed Care Enrollment | % in Managed Care |
|-----------|---------------------|-------------------------|-------------------|
| Illinois  | 1,308,582           | 175,649                 | 13%               |
| Ohio      | 1,032,405           | 292,819                 | 28%               |
| Wisconsin | 397,295             | 194,874                 | 49%               |
| Minnesota | 428,842             | 255,498                 | 53%               |
| Indiana   | 404,000             | 233,065                 | 58%               |
| Michigan  | 1,106,466           | 752,568                 | 68%               |

(\*see [www.hcfa.gov/medicaid/mcsten98.htm](http://www.hcfa.gov/medicaid/mcsten98.htm))

<sup>11</sup> Illinois Department of Public Aid, September 1999.

Of the states in HCFA Region 5, Illinois has the lowest managed care enrollment at 13%. The highest enrollment rate is Michigan with 68%, while four of the remaining states have approximately 50% Medicaid managed care penetration. Ohio is the only state in addition to Illinois whose Medicaid managed care enrollment is less than the national average of 36%. In addition, between 1998 and 1999, managed care enrollment in Illinois declined by over 10,000 individuals<sup>12</sup>.

Illinois' low Medicaid managed care enrollment rate has several causes:

- ◆ The program is voluntary rather than mandatory;
- ◆ The program exists in only a few geographic locations;
- ◆ The program is restricted to the TANF, MANG, and KidCare populations; and
- ◆ Cook County has seen a decline in the number of persons receiving Medicaid with a grant.

The majority of states in HCFA Region 5 mandate that the TANF population join managed care plans. Like Illinois, most states in Region 5 exempt the disabled population from managed care enrollment. Only Michigan, the state with the highest managed care penetration, mandates enrollment of people with disabilities in managed care. Minnesota, like Illinois, currently excludes people with disabilities from managed care, although they are currently in the process of developing some specialized managed care programs for people with disabilities in some counties. Ohio and Wisconsin also exclude people with disabilities from managed care except in special programs where enrollment is voluntary. Indiana allows people with disabilities in certain counties to enroll voluntarily.

These data suggest that (1) managed health care is only beginning to take hold in the Illinois Medicaid population, so there is time to carefully plan its expansion; and (2) people with disabilities are a significant portion of the Medicaid population, pointing to the importance of carefully considering the needs of this population in any plans to expand the Medicaid managed health care program.

## **5. CONSUMER AND FAMILY PERSPECTIVE ON HEALTH CARE**

Consumers and family members offer a unique and critically important perspective on the quality of a service system and the need for system reform. In the course of this study, the evaluation team conducted two separate but related data collection efforts, to learn directly from individuals and families about how well the current system operates.

- ◆ HSRI and MWG conducted community forums with people with disabilities and their families, at numerous locations throughout Illinois, in the fall of 1998.
- ◆ Members of People First of Illinois conducted face-to-face interviews with individuals with disabilities, in various locales around the state, during 1999.

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<sup>12</sup> Illinois Department of Public Aid, September 1999.

This following section describes the nature of the two activities, including comparison of the populations involved. We then integrate the findings from the two activities, highlighting the similarities and the contrasts.

## **5.1 Primary Data Collection Activities: Forums and Interviews**

### ***5.1.1 Conducting the Community Forums***

To learn first-hand about the concerns of people with developmental disabilities regarding their health care services, the evaluation team conducted eleven community forums throughout the state of Illinois. During the months of November and December of 1998, staff from HSRI and Medicaid Working Group (MWG) visited communities from Chicago to Mt. Vernon, and from East St. Louis to Champaign, holding afternoon and evening meetings that were open to individuals with developmental disabilities and their family members or guardians. One of the forums, in the Chicago area, was conducted in Spanish. Out of a total of 136 people who attended the community forums in their area, 100 of them were people with developmental disabilities or family members of people with developmental disabilities. Others in attendance included staff from provider agencies or state agencies. Appendix 2 shows the number of attendees from each part of the state.

At the community forums, participants were invited to participate in subsequent face-to-face interviews. Most attendees completed a brief form expressing their interest. From these forum volunteers, HSRI and MWG initially selected a small interview sample, to enable us to expand on the information gathered at the community forums and to learn in more detail about the strengths and weaknesses of the health care system for people with disabilities in Illinois. Some of the sampled people could not be contacted when the time came for interviews, or were no longer interested in participating in the study. As a result, PFI invited other people with developmental disabilities, who attended any of several regional PFI conferences, to participate. This strategy yielded additional interviewees, so that the interview sample totaled 26 individuals.

### ***5.1.2 Conducting the Consumer Interviews***

HSRI subcontracted with PFI to do the face-to-face consumer interviews. In turn, PFI selected four of its members, each living in a different region in the state, to schedule and conduct the consumer interviews. HSRI developed an interview guide, with significant input from the Advisory Council, PFI and the IPCDD. In July of 1999, HSRI held a day-long training for the interviewers, which included an orientation to the study effort, description of the main and ancillary interview guides, and discussion of how to conduct the interview. Throughout the training, role-playing was used to familiarize interviewers with situations that might arise.

Over the course of a four-month period, PFI completed the interviews. This process included scheduling the interview and arranging for any needed accommodations, obtaining consent forms, conducting the interviews, and reviewing the interview guides for completeness. Each interview lasted an average of two hours. Overall, interviewers rated the interviewees as being

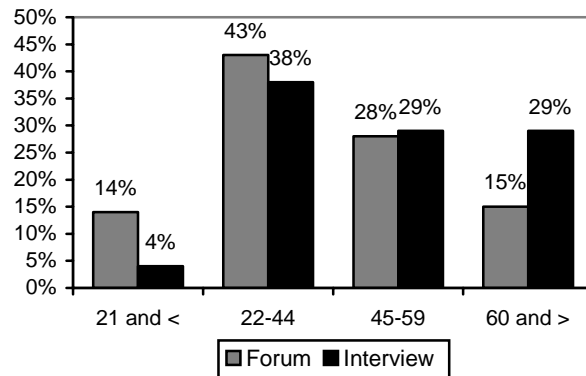
generally relaxed throughout the interview. Approximately half of the interviews (54%) were conducted solely with the consumer, while the remainder were conducted with either a parent, other relative or caregiver present. The majority of consumers (88%) answered the interview questions with no or little help. Interviewers judged that the presence of other people during the interviews was helpful, assisting the consumer in understanding and answering the interview questions.

### 5.1.3 Population Comparisons

As we examine data from the forums and the interviews and begin to draw conclusions from the combined findings, it is important to recognize the comparability of the two populations. To the extent they are similar people, we can have more confidence that the interviews provide a more detailed understanding of the health care experiences of the larger group of forum participants.

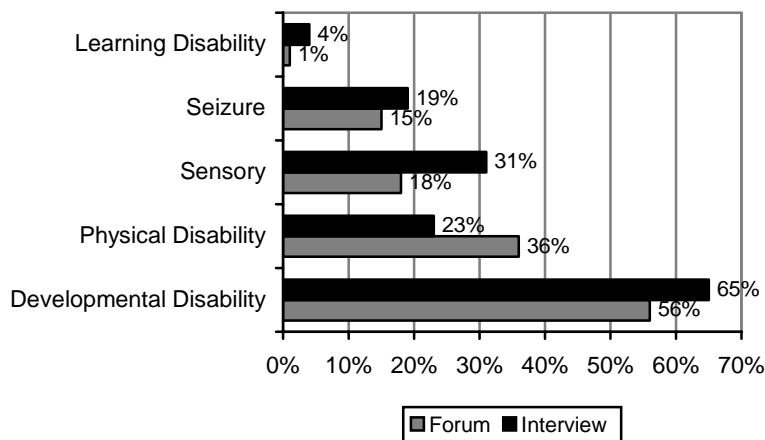
These 26 individuals fairly closely resemble the community forum participants. Comparable proportions were male and female – 51% female in the forums, 50% in the interviews. As Chart 1 illustrates, the two populations were also similar in age; roughly 40% were aged 22-44, and nearly another third were 45-59 years of age. Differences are apparent in the lowest and highest age categories, reflecting the presence of more parents of minor children at the community forums.

**Chart 1: Age Comparison of Forum and Interview Participants**



Population comparisons are a little more difficult to make regarding types of disabilities. An individual may appear in more than one of the bars in Chart 2, so the percentages add to more

**Chart 2: Type of Disability**

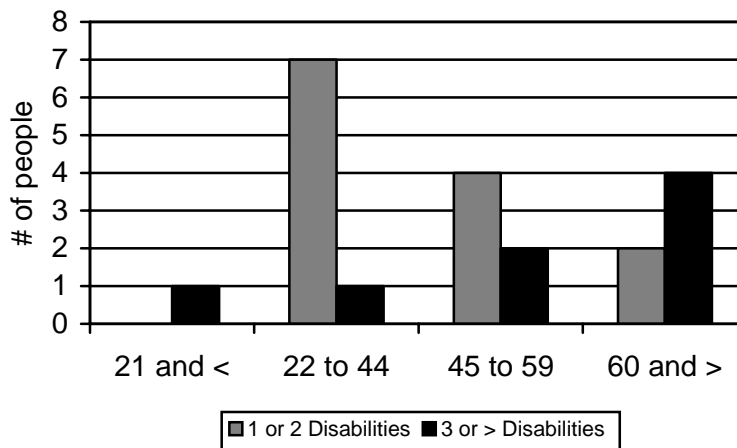


than 100%. In addition, the original categories differed, and some translations have been made for the sake of comparison<sup>13</sup>. What is not shown on the chart is the fact, among the interviewees, 19% had a neurological/ brain injury and 31% had a mental health disability while among the forum participants, 14% reported having a behavioral disorder and 8% said they were medically fragile.

Despite these limitations in the data, it is interesting to note the large degree of comparability across the two populations. As designed, both populations are predominantly people with developmental disabilities; the forum percentage is somewhat lower because the meetings were advertised to the general public. The categories of physical disability and sensory disability likely differ because of differences in the original question posed to the individuals. What is most relevant in Chart 2 is that the relative frequency of the particular disabilities is highly consistent across the two groups: very few people had a learning disability, 15-20% had a seizure disorder, approximately a quarter had some type of sensory disability, somewhat more people had a physical disability, and the largest portion had a developmental disability. This analysis suggests that the interview information can be regarded as representative of the somewhat larger population of people who attended the forums.

Another key point of comparison is the proportion of respondents who have multiple disabilities. Approximately 60% of forum participants and 62% of interviewees had more than one disability. And, not surprisingly, there appears to be a relationship between the number of disabilities and age among the interviewees. The largest category of individuals with one or two disabilities was found in the 22 to 44 year old age group, while the largest category of individuals experiencing three or more disabilities occurred in 60 and older age group (Chart 3).

**Chart 3: Number of Disabilities by Age Group**



<sup>13</sup> Forum category “uses a wheelchair” has been compared to interview category “physical disability; forum category “developmental disability” has been equated to interview categories of mental retardation, spina bifida,

#### 5.1.4 Health Insurance Status

Despite advertising the community forums as discussions for people receiving Medicaid, the meetings drew a variety of individuals with disabilities and family members. This was fortunate, because it soon became clear that Medicaid eligibility is a valuable commodity for people with disabilities, and the ability to retain their eligibility looms large in their life decisions. Several families spoke graphically about tough decisions they had to make to remain on Medicaid, such as refusing temporary work, and about their struggles when Medicaid came and went in their life. These stories influenced the design of the interview guide; a section dealt specifically with insurance coverage, including how it was obtained and whether people had coverage from more than one insurance plan.

Table 5 compares the insurance coverage of the two populations. While there are differences between the two groups, it is clear that some general themes exist. Most people in the study had either Medicaid only (44% and 38%), or both Medicare and Medicaid only (12% and 50%). While there were forum participants who received Medicare only (22%), and Medicare and private insurance (6%), the interviewee group did not show similar numbers because we attempted to screen out Medicare recipients who were not also on Medicaid.

**Table 5: Variations in Insurance Coverage**

| <b>Insurance Type</b>        | <b>% of Forum Participants</b> | <b>% Interviewees</b> |
|------------------------------|--------------------------------|-----------------------|
| Medicaid Only                | 44%                            | 38%                   |
| Medicare and Medicaid        | 12%                            | 50%                   |
| Medicare Only                | 22%                            | 0                     |
| Medicaid & Private Insurance | 3%                             | 4%                    |
| Medicare & Private Insurance | 6%                             | 0                     |
| Private Insurance Only       | 13%                            | 8%                    |

Health insurance coverage is the most critical factor in access to health care. In the analysis below, we analyze the experiences of Medicaid-only recipients with other groups.

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autism, and cerebral palsy; and chart category “sensory disability” combines hearing and visual impairments of interviewees with communication/speech disability of forum participants.



## 5.2 Focus of the Data Collection Activities

By nature, group discussions have a very different tone and focus than individual interviews. Community forums are dynamic interactions among the participants, with general guidance from a facilitator. An initial broad question leads to a comment from one person, which in turn may trigger a series of related comments from others. The same major topics are covered in each forum, but the road that is traveled in the process may differ significantly. In each of the Illinois forums, HSRI posed a discrete set of questions:

- ◆ What three things do you like most about the health care you get?
- ◆ What three things do you like least about the health care you get?
- ◆ If you were in charge of the health care system for people with developmental disabilities in Illinois, what three things would you change?
- ◆ What are desirable qualities in doctors?
- ◆ Overall, how satisfied have you been with your specialists?

By contrast, the individual interviews primarily used closed-ended questions to elicit specific responses from each person, to produce a coherent profile of that person's experiences in the health care system. The key topics are shown in the accompanying box, and the interview guide is included in Appendix 3.

The key difference between these two data sources is the unit of analysis. The forum information reflects views expressed by one or more people; it does not represent the experience of a single individual, nor a consensus of the group as a whole. The interview data, on the other hand, is the response of one individual, and thus the aggregation of the individual interview responses can be considered a more accurate representation of the larger population of people with disabilities receiving health care services in Illinois.

### **Interview Guide Topic Areas**

- Introduction
- Health Insurance Status
- Access & Service Satisfaction (followed by specific questions regarding each identified service)
- Complaints
- Emergency Service
- Out-of-Pocket Expenses
- Care Coordination

The forum responses were aggregated by hand, and used to guide the design of the interview questionnaire. The interview data have been entered into a database and analyzed using SPSS.

The following sections of this report highlight what we learned in the forums and through the interviews. We first present the forum findings, to establish the context for the findings from the interviews.

### 5.3 Findings from the Community Forums

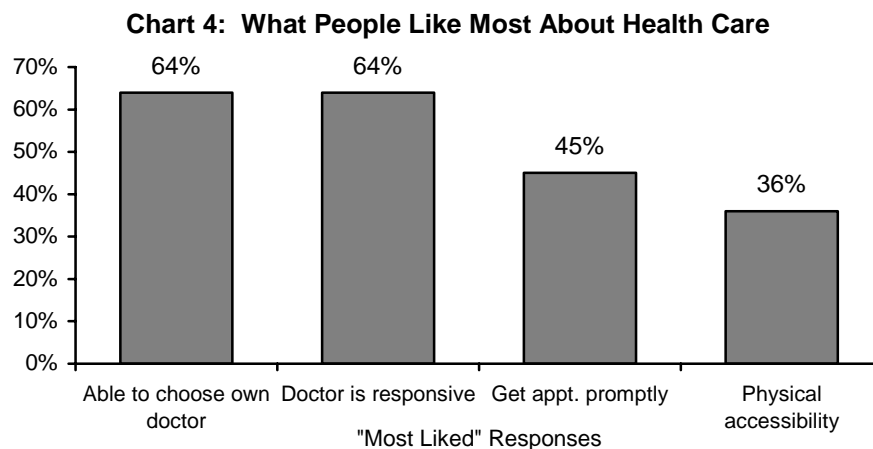
The forums opened with two basic questions: what do you like most and least about your health care? Responses to both questions clustered in five broad categories:

- ❖ Choice of providers
- ❖ Availability of services
- ❖ Access to services
- ❖ Quality of care
- ❖ Financial concerns

The category of **choice of providers** includes such considerations as the range of available physicians and specialists, and information provided to the respondents about other specialists so they could make informed choices. **Availability of services** covers acute, long-term, and specialty services, as well as availability of insurance and what a specific insurance plan would cover. **Access to services** includes issues concerning transportation, physical access to buildings, equipment and examination rooms, hours of operation, communication and cultural appropriateness, and eligibility limitations. The responses in **quality of care** revolve around provider sensitivity and training, provider-client relationships and whether a patient gets what he/she wants or feels is needed from the health care provider. The last category, **financial concerns**, encompasses the payment process and financial coverage. Comments in this area include promptness of payments to the provider or patient, amount and frequency of coverage, treatment of pre-existing conditions, and amount of out-of-pocket expenses.

#### 5.3.1 What People Like Most

Statewide, people who attended the forums were pleased with a variety of things relating to their health care. In over half of the forums, participants indicated that they most value being able to choose their own doctor (Chart 4). A similar proportion applauded a key aspect of quality of care, that doctors are responsive and that they care about the individual's care. In the category of



access to services, two issues received quite positive responses. People attending five of the 11 forums noted that they can get an appointment promptly, and participants in four of the forums identified physical accessibility as one of the things they like most about health care. It is relevant to note that 40% of the forum participants use a wheelchair, and 9% are medically fragile.

The most varied responses to things people like most about their health care emerged in the category of financial concerns. In three of the forums, discussion reflected the benefits of having more than one type of insurance, such that, in the end, most medical expenses are covered.

Forum participants included people with varying combinations of insurance coverage, although most are covered by only one type of insurance (see **Table 6** above). Comments included:

- ◆ Medicaid picks up the Medicare co-pay after spend-down.
- ◆ Private insurance picks up Medicare deductible.
- ◆ Medicaid covers what private insurance does not cover.

## COMMENTS

*From East St. Louis:*

Doctors accept Medicare and Medicaid;  
While on Medicaid, patient does not  
have to file insurance claims.

*From Rockford:*

Doctor gets paid promptly;  
Health insurance is portable.

In more than a third of the forums (4 of 11), good coverage was a highly valued quality of health care (although this same issue came up even more frequently in the discussion of “least liked” aspects of health care). For these participants, dental coverage, prescription costs, first-time equipment needs, medical transportation, and having a small co-pay were noted. Various other comments heard surrounding financial issues include those found in the accompanying box.

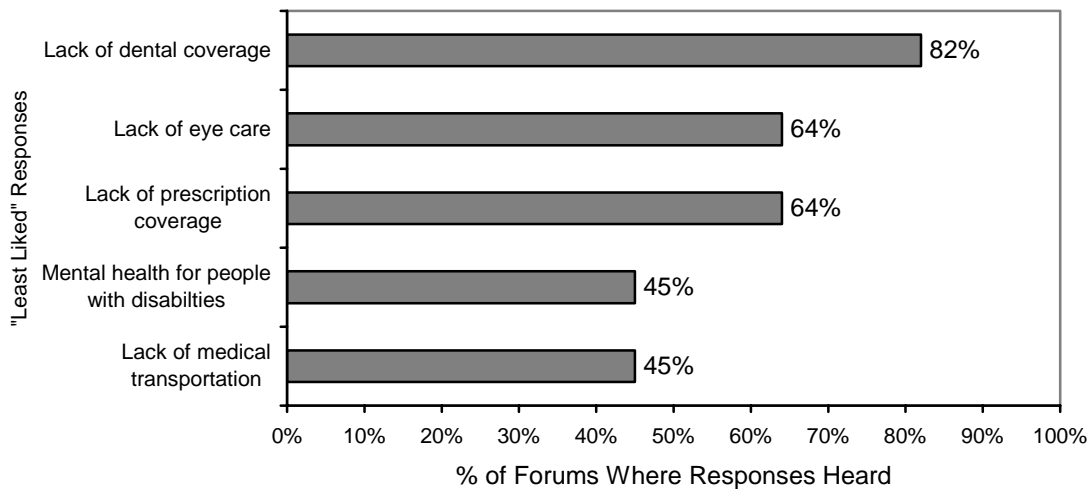
Additional factors which surfaced as among those most appreciated by forum participants included:

- ◆ In the Springfield forum, there was discussion about good advocacy organizations, as well as good caseworkers to help coordinate medical care.
- ◆ In a few forums, availability of services was highlighted. In Peoria, East St. Louis, and Mount Vernon, participants like that the pharmacy delivers prescriptions to their homes; Springfield respondents noted that they can get care out of state, and Champaign and Chicago respondents commented on good emergency services through local hospitals.
- ◆ People at three forums in different parts of the state value their access to Medicaid-funded transportation to medical appointments.
- ◆ Suburban Chicago participants (in two forums) appreciate that doctors give free samples of expensive medicines, and that specialists take time to explain procedures and discuss options.

### 5.3.2 What People Like Least

When forum participants were asked what they like least about their current health care, coverage was the biggest issue (Chart 5). In nine out of 11 forums, people commented on the lack of dental coverage. In seven of the forums, comments were heard regarding lack of eye care (including glasses) coverage, as well as limited prescription coverage. Other topics receiving the most attention as problem areas were access to medical transportation ( five forums) and the poor quality of mental health services for people with other disabilities (five forums).

**Chart 5: What People Like Least About Health Care**



Quality of care figured prominently in discussion about the things forum participants liked least about their health care. In five of the 11 forums, there was concern with psychiatrists and other mental health professionals misdiagnosing, prescribing segregated care, and having a poor understanding of people with developmental disabilities. Participants in several forums found themselves frustrated when they found a practitioner who they liked and was good with people with developmental disabilities, but their practice was full, and/or the doctor was not on their insurance plan. Participants in Springfield and Chicago noted the lack of time physicians spend with people. Respondents in four locations lamented that doctors don't talk with the individual with disabilities but with whomever accompanies them instead.

Access to services was problematic in numerous ways, beyond the issue with medical transportation noted above. People at three forums complained of having to wait several hours for a scheduled appointment – Medicaid recipients especially voiced this comment, saying dozens of people were given the same appointment time. In three forums, respondents emphasized that examination tables and other equipment were not accessible to them; and participants in two forums felt that they are sent too far away for specialist care.

In addition to the coverage problems noted above, respondents also remarked on the poor availability of foot care, mammograms, and X-rays (two forums each); and chiropractic services and hearing care (one forum each). Edwardsville respondents especially noted the lack of preventive care. People at three forums particularly emphasized that they cannot get insurance for pre-existing conditions such as autism, or only by paying a very high premium.

Numerous payment-related difficulties were voiced by forum participants. These included low or no reimbursement for certain services; poor coverage of needed services; and high out-of-pocket expenses (Table 6). In addition, in two forums, respondents noted that doctors and even the emergency room will not serve you until you show proof of insurance or make a payment. Several more comments concerned the difficulties of coordinating varied insurance plans: respondents in East St. Louis talked of the problem of parents becoming eligible for social security and Medicare, leaving their adult child with developmental disability not eligible for health coverage for two years; Mt. Vernon participants noted that when you have both Medicaid and Medicare, Medicare takes precedence, and Medicaid will not cover any service that Medicare doesn't; Mt. Vernon participants further spoke of being on SSI without Medicaid, and not being able to afford medical care. In three forums, respondents complained of the bureaucratic nature of DPA, denying needed medications and use of specialists in favor of lower cost options, and being very slow to process requests for durable medical equipment.

**Table 6: Least Liked Aspects of Financing/Payment of Health Care**

| <b>Reimbursement for services:</b>                                  | <b># of Forums</b> |
|---|--------------------|
| Low reimbursement for therapies and nursing care                    | 2                  |
| Physicians won't see people with disabilities because rates are low | 3                  |
| Doctors have to wait a long time for reimbursement                  | 2                  |
| <b>Coverage by insurance:</b>                                       |                    |
| Assistive technology is not covered                                 | 2                  |
| Loss of coverage when a young adult moves out of the parent's home  | 1<br>2             |
| Medicaid and Medicare won't pay for replacement equipment.          | 1                  |
| Medicaid will only pay for a 10-day supply of medication at a time. |                    |
| <b>Out-of-Pocket expenses:</b>                                      |                    |
| High spend-down for prescriptions                                   | 3                  |
| In general, spend-down is too much                                  | 5                  |
| Co-pay is too high.   | 2                  |

In four of the forums, advocacy and care coordination emerged as things people like least about their health care. People in several locations said that it is very hard to get information about

what services are available and from where. In East St. Louis and Mt. Vernon, participants liked least that specialists they received services from did not help them to make connections with other health professionals, nor help coordinate care. In Chicago Heights and Rockford, participants voiced frustration due to lack of advocates or advocacy organizations. One person commented, “Providers don’t tell you what you could get covered,” and “case managers give you the run-around too.”

Additional factors which emerged among those least liked by forum participants:

- ◆ In one of the Chicago forums, people noted that there are delays in getting pre-approval for services and equipment.
- ◆ In Chicago Heights, one family spoke of losing a rented wheelchair before the purchased one had been obtained.
- ◆ Rockford and Chicago respondents complained of lack of choice of doctors, especially at teaching hospitals and especially in choice of gynecologists.
- ◆ Chicago respondents complained of doctors not giving enough information, especially about medications, such as why you have to take them and what the side effects could be.

### 5.3.3 *Desirable Qualities of Doctors and Specialists*

Much of the discussions about desirable qualities of doctors and specialists built on the responses concerning quality of care. It is relevant to note that 92% of all forum participants have a regular doctor, and nearly ¾ of those are general practitioners or internists (72%). People at several forums commented that a most desirable quality in a doctor is having knowledge and understanding of people with developmental disabilities (Table 7). A doctor who is sensitive to people with developmental disabilities and is willing to take the time to explain things to them is quite important. One individual even offered that if a doctor “can’t work with people with developmental disabilities, then refer them to someone who can.” People at three forums emphasized the importance of having a doctor who will make accommodations for your disability, such as getting accessible equipment and having staff who will help with wheelchair transfers.

**Table 7: Most Desirable Qualities of Doctors**

| Desirable Qualities   | # of Forums |
|---|-------------|
| Trained and sensitive to people with developmental disabilities             | 5           |
| Doctor cares about the individual: listens, takes you seriously, takes time | 4           |
| Promptly refers to capable specialists, and follows up                      | 2           |
| Patient accommodation (e.g., personal care, transfer, accessibility)        | 3           |

Other particularly poignant comments included having a doctor who:

- ⊖ “Is willing to admit when he/she makes a mistake.”
- ⊖ “Makes sure I get the services I need.”
- ⊖ “Is a team player”, listens to staff and family who are closest to the individual.

- ⊖ Is willing to serve you, regardless of type of insurance.
- ⊖ Is able “to work outside the medical model”, such as helping people get needed equipment.
- ⊖ Has evening and weekend hours.

Comments about specialists were far less positive. People who had specialists were generally pleased with their care, but at the majority of forums people spoke of problems of insufficient specialty services, especially close to where people live. Cardiology and neurology received good reviews in some areas of the state, but behavioral services and psychiatric services were more uniformly seen as inadequate. It is important to note that 60% of the forum participants need their doctor’s permission before seeing a specialist. Desirable qualities, although not often present, include high-level skills in working with people with particular disabilities, and having ongoing communication with the primary doctor of the individual.

## **5.4 Findings from the Consumer Interviews**

### **5.4.1 Health Insurance**

The primary distinguishing characteristic among interviewees is their type of health insurance. Health insurance often determines what services a person can receive, whom he/she can receive the service from, where the service can be provided, and how often it can be provided. In the following pages, where differences appear between Medicaid-only recipients and people who are covered by both Medicaid and Medicare – the two largest insurance groups in our study (see **Table 6** above) – we highlight these contrasts.

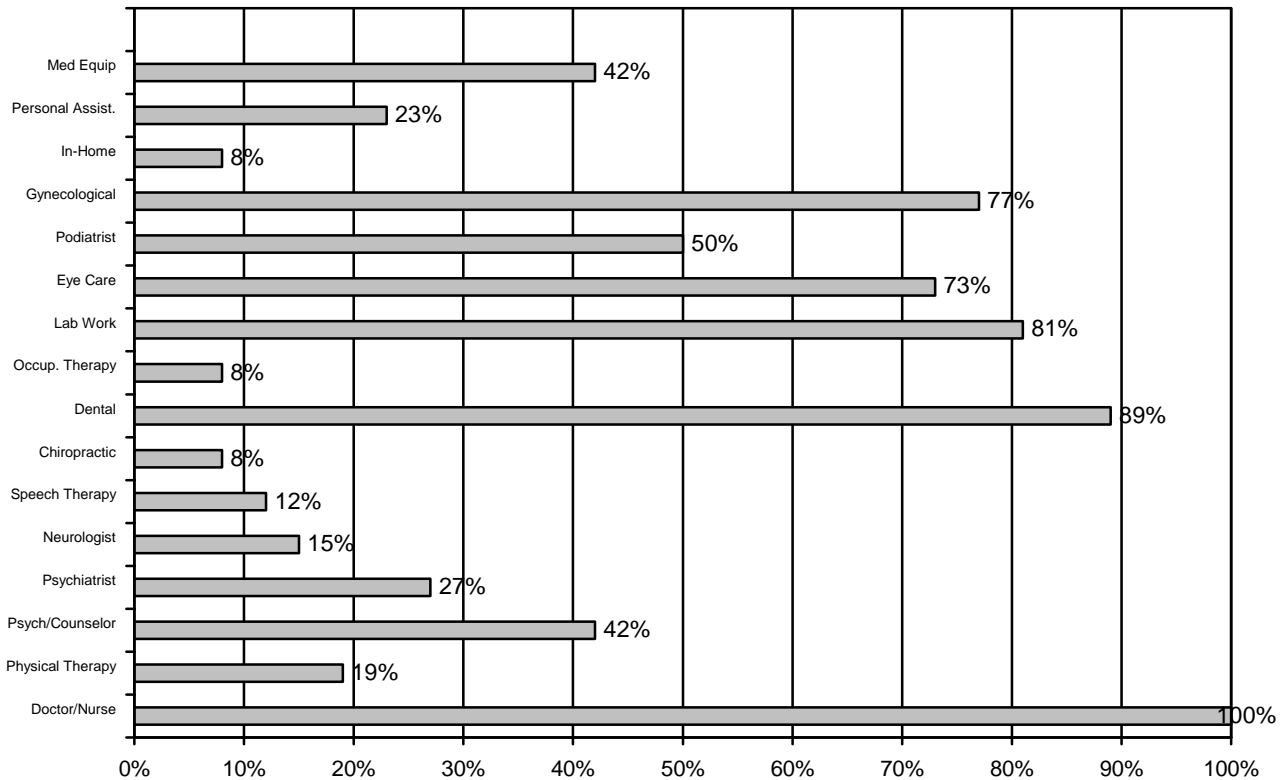
Responses to questions regarding the ease of access to Medicaid and Medicare coverage were similar for people covered by each of the public insurance plans. Of the individuals receiving Medicaid (including people in *both* of the major insurance groups), 67% felt it was easy to access and 29% felt access was hard. Similarly, of the individuals receiving Medicare (alone or in conjunction with other insurance plans), 69% felt it was easy to access while 23% felt access was hard.

Individuals enrolled in either Medicaid or Medicare were fairly knowledgeable about the coverage of services through the plans. Eighty-eight percent (88%) of Medicaid enrollees and 77% of Medicare enrollees were knowledgeable about plan coverage.

### 5.4.2 Service Utilization

During the interview, individuals were asked to indicate, from a list of 16 different health care services, which types they received. Three individuals indicated they received 0-4 services; eight individuals indicated they received 5-6 services; fourteen individuals indicated they received 7-9 services; and one individual received 10 or more. As Chart 6 illustrates, the majority of services received were in the categories of 1) doctor/nurse, 2) dental, 3) lab work,

**Chart 6: Percent of Respondents who Receive Services from Each Type of Medical Provider**



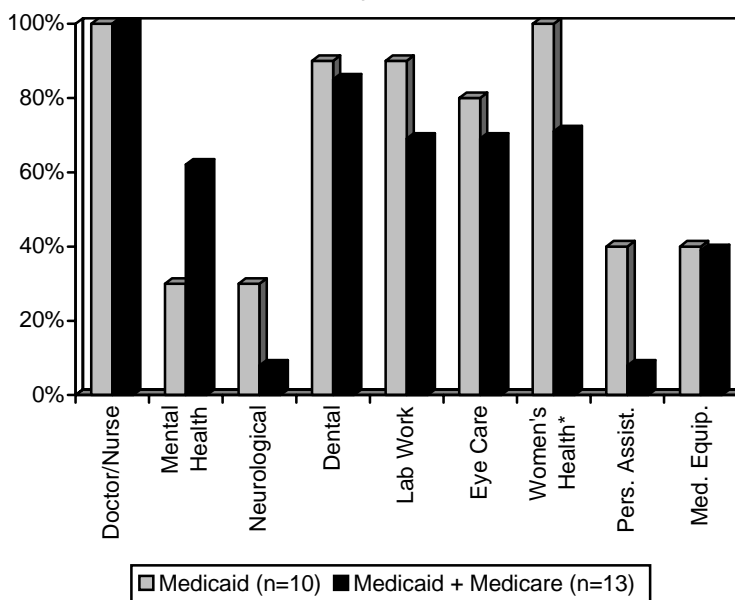
and 4) eye care.

\*For gynecological services n=13

Information gathered through the consumer interviews shows that in some cases, individuals on Medicaid only were receiving more services than individuals who had both Medicaid and Medicare coverage (Chart 7). For Medicaid-only recipients, mental health, neurological, personal assistance and medical equipment were the least cited services. Similar patterns were found with recipients of both Medicaid and Medicare.



**Chart 7: Percentage Receiving Each Service by Insurance Type**



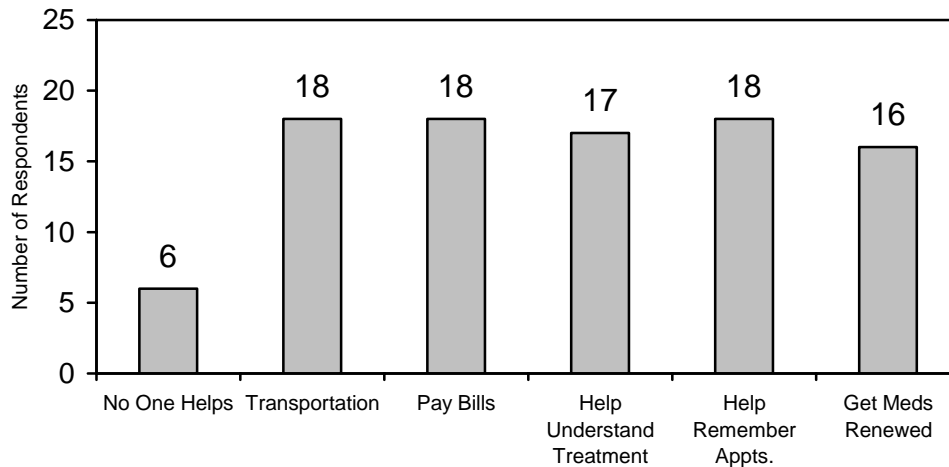
The majority of respondents (76%) indicated they either saw or talked to a health care provider of some kind at least monthly over the course of six months. A small percentage (10%) saw their health care provider less than monthly. No significant differences were apparent between the two major insurance groups. Further, no relationship was observed between the number of disabilities a person experienced and the frequency of contact with a medical care provider.

In addition to the medical services listed on the previous page, eight individuals (31%) indicated they needed emergency services, such as an ambulance or hospital emergency room, in the past six months. Further, twenty-three individuals (89%) indicated they take medication(s) on a regular basis. Again, no differences were evident between the two insurance groups.

### 5.4.3 Managing Individual Health Care

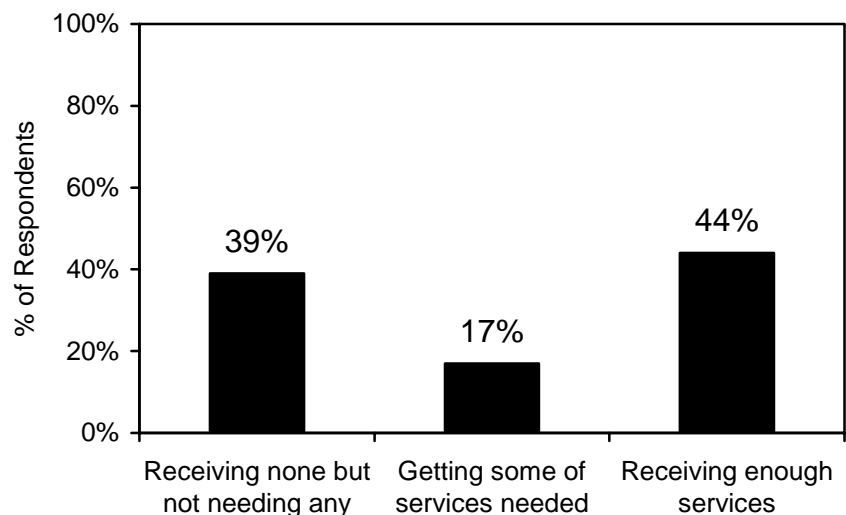
Managing and tracking health care needs requires careful coordination and planning. Twenty of the respondents (77%) indicated they received some type of support from either a parent, case manager or other staff in tracking their health care needs. Chart 8 shows the variety of supports individuals receive in tracking their health care needs. The most common types of supports included transportation (noted in the forums as a significant problem), paying bills, and keeping appointments. Also important was helping the individual to understand the treatment he or she was receiving; this is consistent with views expressed in the community forums, where people noted the desirability of a physician who was willing to take the time to explain things to them.

**Chart 8: Assistance with Tracking Health Care Needs**



Less than half of the 23 individuals responding to this question (9) reported that they could take care of themselves at home without outside assistance. The fourteen other respondents stated that they needed help using medical equipment and taking care of themselves at home. Half of these individuals were receiving support through either personal assistance

**Chart 9: Percentage Receiving Enough Help at Home**



or in-home nursing services. Ten individuals (seven of them those receiving in-home supports) felt they were receiving all of the help they needed, while the remaining people received only some of the help they needed (Chart 9).

#### 5.4.4 Satisfaction

Overall, the individuals interviewed were generally happy with the medical services they received in the past six months. Of those individuals who were unhappy with any medical service (23%), over half talked to someone about their concern and were satisfied with the result. Some of the reasons cited for dissatisfaction with services included:

- Medical supplies take too long and are not of good quality;
- Services are too slow.

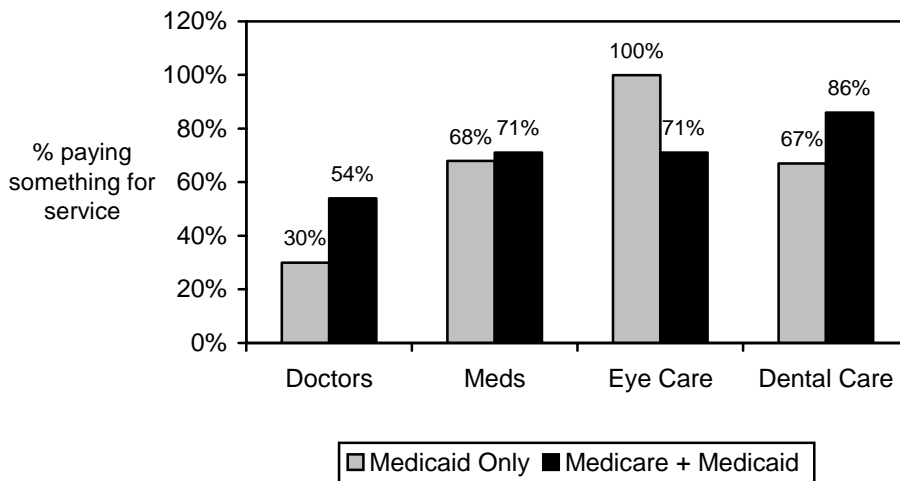
Others barriers to health care that were cited included:

- services are too expensive;
- Staff shortages;
- transportation.

Not surprisingly, because of the complexity of disabilities, five out of the six individuals who were unhappy with any medical service experienced three or more disabilities.

Closely tied to the level of satisfaction with medical services is the amount people have to pay out-of-pocket expenses for those services. Throughout the community forums people talked about problems with health care costs (see section 5.3.2 and **Table 7 above**). Of particular note, forum participants stressed the problems of low or no reimbursement for certain services; poor coverage of needed services; and high spend-down and out-of-pocket expenses. The cost of services forum participants were most concerned about and most wanted to change was coverage

**Chart 10: Out-of-Pocket Medical Expenses**



for medications, eye and dental care. In follow-up to the concerns voiced, interviewees were asked a series of questions about their health care costs. Chart 10 summarizes their responses. Interestingly, in three of the four categories, the proportion of recipients having to make out-of-pocket payments was greater for those in the Medicaid + Medicare group than for people only receiving Medicaid.

### 5.4 5 Specific Findings about Major Health Services

As part of the interview process, respondents indicated specific services they had received within the past six months (shown in above **Chart 8**). In this section we explore more detailed information gathered about interviewees’ use of the five most common services – services from a doctor or nurse (called “medical care”), dental care, eye care, laboratory services, and medical equipment. Among the specific topics examined:

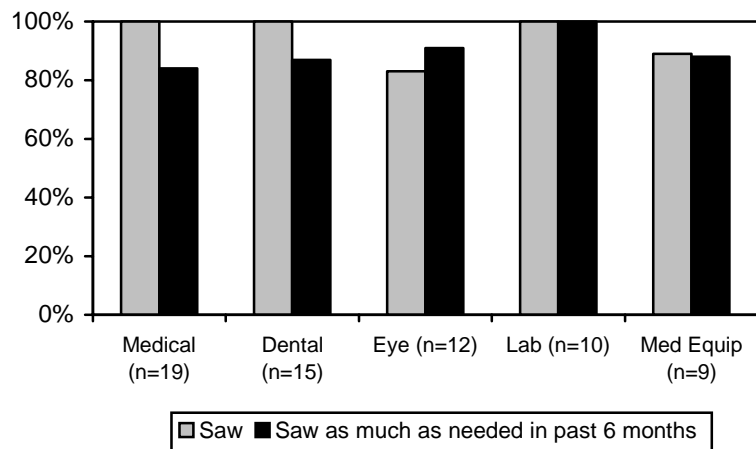
- / Frequency of use
- / Choice of provider,
- / Ease of access (scheduling and physical access),
- / Overall attitude about the provider,
- / Use of transportation to get to the service site.

#### *Frequency of Service Use*

In assessing overall use of health care providers/services, individuals were asked whether or not they needed to see or use a provider/services in the past six months, if they actually saw or used that provider/service, and if they were able to see or use that provider/service as often as they needed. For example, in regards to medical care, 19 individuals felt they needed to see a doctor or nurse in the past six months.

All of these individuals were able to see their medical provider; and 84% felt they were able to see their medical provider as often as they needed. Findings were similar in the use of dental and lab services. Chart 11 summarizes the use of the five major health care categories over the past six months. For those individuals who did not see or use the medical provider/service as often as they needed, transportation was frequently cited as the reason.

**Chart 11: Frequency of Use of Major Health Care Providers**

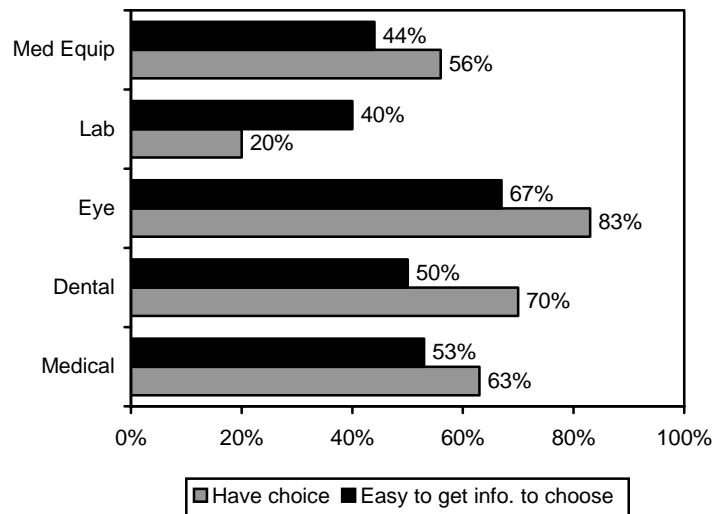


### Choice of Provider

Choice among health care providers and services is an important element that leads to overall satisfaction. In the community forums, approximately 64% of participants cited “ability to choose own doctor” as one aspect they liked most about their health care. In the individual interviews, however, choice varied dramatically across the major types of services (Chart 12).

When asked whether or not an individual was able to choose among providers of health care services, the largest proportion of respondents (83%) felt they had choice in who they saw for eye care, and; 70% reported having choice in their dental care provider; but lesser numbers of people felt they could choose their primary medical practitioner (only 63%), and even fewer had choice among providers of medical equipment (56%) and places to go for lab work (20%). Three reasons were frequently cited in instances where choice was limited:

**Chart 12: Choice About Health Care Provider**



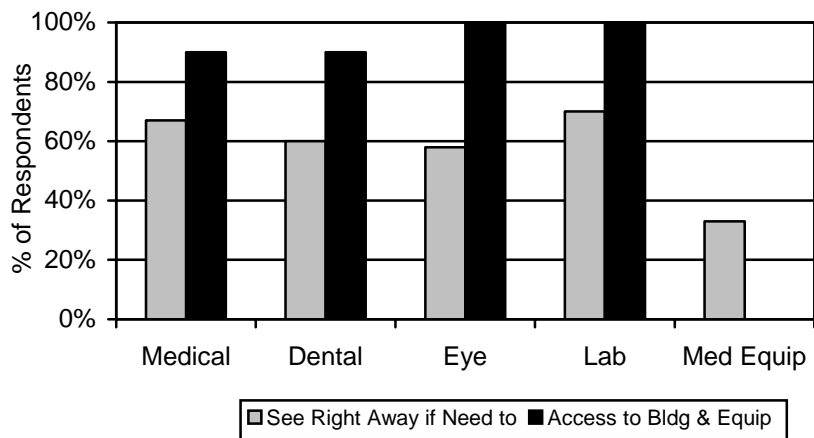
- Provider does not accept the type of insurance the individual has;
- Only one provider exists in the geographic area who is knowledgeable about the individual’s specific disability;
- The primary care physician chose the provider.

It is interesting to note that significant potential exists for individuals to make informed choices. The second set of bars in Chart 12 indicates how easy it was for individuals to get information about available providers, so that they could make an appropriate choice. Half or more of respondents felt it was easy to get information on dental care providers, medical care practitioners, and eye care providers; information on medical equipment providers was nearly as available. The only dearth of information appears to be about laboratories, probably because most health care consumers do not generally think about qualitative differences among labs, nor do they always have to interact with lab staff – often blood and urine samples are drawn by nurses and sent to the lab. These data suggest that choice could be expanded for people with disabilities, without much additional effort being necessary to support those independent choices.

*Ease of Access*

In evaluating access to health care providers/services, individuals were asked whether they could see or use a health care provider/service right away if needed and if they experienced any difficulties accessing buildings and related health care equipment. Analysis shows that building accessibility and use of health care related equipment was much more sufficient than immediate access to a health care provider/service if needed (Chart 13). These results support the findings of the community forums in that two of the four “most liked” aspects of health care were being able to promptly get an appointment and physical accessibility (see section 5.3.1 and **Chart 2**).

**Chart 13: Access to Health Care Provider/Service**



*Attitude About the Provider*

Attitudes toward health care was addressed from four broad perspectives: 1) satisfaction, 2) trust, 3) understanding of disability, and 4) ability of provider to explain things. Table 8 summarizes the interview findings.

**Table 8: Attitude About Health Care Provider**

|                          | <b>Medical<br/>(n=19)</b> | <b>Dental<br/>(n=20)</b> | <b>Eye<br/>(n=12)</b> | <b>Lab<br/>(n=10)</b> |
|--------------------------|---------------------------|--------------------------|-----------------------|-----------------------|
| Very Satisfied with Care | 58%                       | 80%                      | 75%                   | 70%                   |
| Trust                    | 90%                       | 95%                      | 100%                  | 80%                   |
| Understand Disability    | 79%                       | 85%                      | 67%                   | 40%                   |
| Explains Things          | 95%                       | 90%                      | 100%                  | 60%                   |

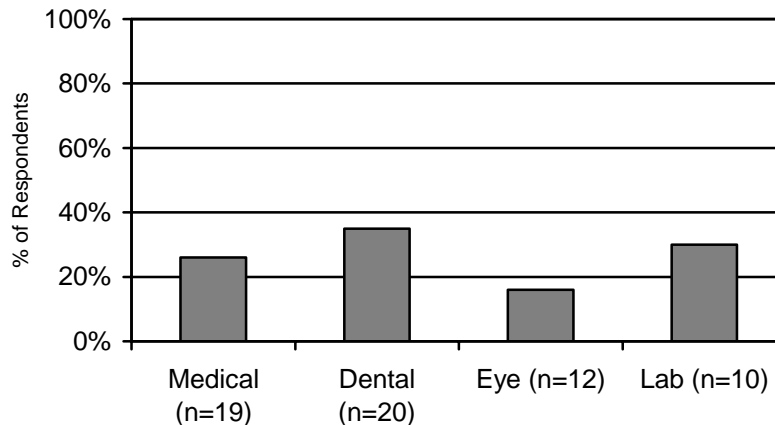
Overall, individuals are very satisfied with the level and type of care they receive from the five major types of health care providers. 90% or more of respondents trust their primary medical provider, their eye care provider and their dentist; and nearly as many (80%) trust the lab that evaluates their medical tests and does special procedures. This finding is of particular interest since trust was one of the “most desirable” characteristics of a health care provider cited during the community forums.

Similarly, having knowledge and understanding of people with developmental disabilities was seen as “most desirable” by forum participants. Information gathered through the consumer interviews indicates that the major categories of health care providers do relatively well in this regard but nonetheless have room for improvement – only 79% of medical care providers are seen as having sufficient understanding of the respondent’s disabilities, and only 67% of eye care providers are judged as understanding relevant disability concerns. Strikingly, only 4 of out ten labs are seen as understanding disability, a shortcoming that could have serious implications for their interpretation of test results.

### *Use of Transportation*

Transportation to medical appointments was an issue that arose during the community forums as an area participants least liked (lack of transportation). Less than half of the interviewees used public transportation (includes Mediacar and paratransit) to and from their appointments with any of the major types of health care providers (Chart 14). A quarter of respondents (26%) relied on public transportation to medical appointments; 35% to dental appointments; 16% to eye care appointments; and 30 % to labs. The majority of respondents relied on “other” sources of transportation, which likely includes family, friends, and staff of day or residential programs where the individuals spend time.

**Chart 14: Use of Public Transportation to Health Care Appointments**



## 6. CONCLUSIONS AND RECOMMENDATIONS

This report has presented findings about the health care experiences of a selected group of people with developmental disabilities in Illinois, nearly all of whom are Medicaid recipients. The population interviewed appears to be representative of the larger group of individuals who participated in community forums held all over all the state. Because of the limited availability of demographic data on the characteristics of the entire Illinois population of Medicaid-eligible people with developmental disabilities, the study team is not able to assess the degree to which the study sample is representative of the underlying Illinois population. However, it is clear that the forum participants, and, by reference, the interviewees, tend to be individuals who are more active in advocacy associations (PFI and IFSN took the lead in advertising and arranging the forums, and in supplementing the list of interviewees). While the most active members of the population may have health care needs and experiences that differ from the larger population, this study of their experiences has particular policy relevance: these are the individuals who are most likely to take a leadership role in any health care reform initiatives in the state. The findings of this study can thus serve to inform all key stakeholders about the most immediately relevant issues in a likely reform agenda.

### Major Concerns in Illinois

- 3 Choice among providers
- 3 Coverage of needed services
- 3 Out-of-pocket expenses
- 3 Providers knowledgeable about disabilities
- 3 Provider participation in Medicaid
- 3 Transportation
- 3 Support in managing care

The findings presented above paint a portrait of a health care system that is currently operating fairly well, despite some marked problem areas. In general, people are satisfied with the quality of the health care they receive, but struggle in some key areas to obtain access to needed care. Both the community forums and the consumer interviews highlighted the *importance of choice* among providers and *service coverage* appropriate to the unique needs of people with developmental disabilities. Some concerns – such as out-of-pocket payments for prescriptions – are shared by a larger population and are being debated on the national stage; other issues are more targeted to a disability population, such as having dentists and other practitioners who are knowledgeable about the impact of specific disabilities on their domain of health care, and who are comfortable serving people with a range of disabilities.

Few of the findings were surprising. Access to certain services and limited choice among providers is often limited due to individuals' Medicaid eligibility – many health care providers either decline to serve people on Medicaid, or limit the number of Medicaid patients they will accept. Since choice and access are such central aspects of quality in health care, policy makers need to address this issue promptly. Respondents at several forums mentioned the need to pay providers better and more quickly, to encourage more doctors to accept Medicaid and thereby give people choice in medical providers and in overall service availability.

Transportation emerges as a core problem in all evaluations of the quality of public social services, and this study was not exception. Lack of transportation affects not only the accessibility of health services, but also choice and quality. If an individual cannot easily get to



a provider's office, he is unlikely to choose to use that provider, even if it is more suitable to his disabilities. Forum participants noted as a priority the value of keeping small rural hospitals open, so that at least emergency and urgent care services could be somewhat more accessible.

Forum participant also felt quality of care could be improved through better communication among various health care providers. Remedying the communication breakdown both between staff and respondents, as well as between different health care providers, was addressed in several forums, and was reflected in interviewees' need for help in managing their health care. Using an interdisciplinary medical team model to serve people with disabilities could improve these interactions and provide some central coordination to the many medical regimens that some people endure. Forum members further suggested that more active advocacy/watchdog groups could help address these types of issues.

Underlying these individual experiences and perceptions is the reality of the Illinois Medicaid program. Compared than the average state in the country, the Illinois Medicaid program has tighter eligibility rules, and it excludes a few benefits that are needed most by people with disabilities, such as personal assistance and respiratory care. The eligibility rules for people with disabilities are among the most restrictive in the country, preventing many individuals from obtaining Medicaid coverage at all. However, use of a spend-down has enabled Medicaid to serve additional individuals.

At the same time, Illinois spends more per person with a disability than the national average. It is likely that the restrictions on benefits and eligibility contribute to these higher costs. High cost services such as hospital and nursing homes are covered by the Medicaid program, but some of the lower cost and preventive services are not. Furthermore, restrictions on eligibility mean that some people with disabilities receive intermittent coverage – mainly when they become sick - and are unable to afford primary and preventive care. While there may be other economic factors contributing to the higher costs, concern about high costs is often what drives state Medicaid programs to consider managed care.

Currently, the Illinois Medicaid program has a small managed care component that typically excludes people with developmental disability. This exclusion has both positive and negative aspects. In some parts of the country, with the appropriate vision on the part of state leaders, sufficient funding, and programmatic attention to the needs of people with disabilities, managed care has expanded access to primary and preventive care. It has also improved service coordination, offered alternative benefits, and improved the quality of services provided. If this kind of a managed care system can be developed in Illinois, it could benefit people with disabilities.

In other parts of the country where cost control has been the only driving force behind managed care, managed care has been a terrible experience for people with disabilities. A bad situation can be made much worse:

- ✓ If an already poor choice of providers is restricted further by the health plan network,

- ✓ If access to specialty care and home care is rationed; and
- ✓ If HMO policies and procedures add red tape to a system of care that is already difficult to navigate.

As long as a managed care program remains flexible, people with disabilities should be allowed the option of enrolling in a managed care plan. If the plan does not meet their needs, they can rejoin the fee-for-service system. If the managed care program becomes mandatory, it is essential to ensure that it is adequately funded, includes traditional providers of care for people with developmental disabilities, and that serious attention is paid to accommodating the unique needs of people with disabilities in the benefit package.

The unique needs of people with disabilities and the issues described throughout this report point to some new strategies for adapting traditional managed care to people with disabilities. These include:

1. *Scope of services:* The planning process for Medicaid managed care needs to include a thorough discussion of the scope and duration of services included in the managed care benefit package. Differences between commercial coverage of certain services and Medicaid coverage need to be identified and discussed with consumers and health plans in order to clarify expectations. Of particular concern is coverage of home health and other in-home services, incontinence devices, nutritional supplements, rehabilitation therapies, durable medical equipment, and mental health services. Some states such as Michigan, Minnesota, and Colorado have convened advisory groups consisting of both consumers/family members and health plans to hammer out the coverage issues in advance of implementation. Other states have chosen to exclude these services from the managed care benefit package and maintain them as fee-for-service options. A third option is to include a limited benefit in the managed care contract (e.g. a specified dollar amount of durable medical equipment), and keep additional services as a Medicaid fee-for-service benefit.

The absence of meaningful discussion among consumers and health plans can be costly to all parties. In several states, because coverage of home health services was not made explicit, the health plan denied coverage on the grounds that home health care was “custodial” and therefore not medically necessary. However, these same home health services had been covered by Medicaid in the fee-for-service system and the dollars for these services were included in the managed care capitation rate.

2. *Network Composition:* Differences in health plan network composition also need to be addressed during the planning process for managed care. Particular areas of concern include:
  - ❖ *The full range of specialty care.* Health plans may or may not include all the necessary pediatric subspecialists for serving children with disabilities in their network, or they may not have mental health providers who are experienced in serving individuals with developmental disabilities. Such specialties are important components of a network.

- ❖ *Centers of Excellence.* Health plans need to have contractual or referral relationships with Centers of Excellence that have particular expertise in specific conditions found more frequently among people with disabilities than among other enrollee populations.
- ❖ *Out-of-network providers.* Health plans may not need formal contracts with every single provider experienced in serving people with disabilities, particularly for very rare conditions, but they should have policies and procedures to expedite access to out-of-network providers when in-network services are not sufficient.
- ❖ *Out-of-state providers.* For very rare conditions, it may be necessary for an individual to seek care from an out-of-state provider. It is important to clarify health plan expectations around covering these services.

The state can develop purchasing specifications and a review process to address these issues. For example, the state can identify the full range of specialists necessary and ask health plans to document that these providers are part of the network and to document their availability. Consumer involvement in planning is an important vehicle for identifying providers with disability expertise, designing health plan purchasing specifications, and developing processes to facilitate access. Planning groups that include consumers, advocates, representatives from other state agencies with knowledge and responsibility for the population, health plans, and providers have been convened in several states to develop network specifications:

- ◆ New York’s Office of Mental Retardation and Developmental Disabilities, Medicaid program staff, consumers and advocates developed “Well Qualified Plan” specifications for HMOs enrolling individuals with developmental disabilities.
  - ◆ In Michigan, Colorado, and Minnesota, the Medicaid program and other state agencies convened planning groups of parents, providers, advocates, and health plans to develop network specifications for people with disabilities.
  - ◆ Several states have contracted with specialized managed care plans serving people with HIV/AIDS, including Massachusetts, Maryland, and California. Several of these contracts require plans to contract with Centers of Excellence.
3. *Incentives for Providers in Under-Served Areas.* To promote access to care in rural and under-served areas, the state should consider provider incentives. Such incentives could include requiring some service to Medicaid clients as repayment for state support at medical schools and/or repayment of student loans. State programs could be modeled on the Federal Physician Health Corps, which offers forgiveness of some portion of medical school loans to physicians who practice in under-served areas for a certain number of years.
  4. *Consumer information.* The standard information most people receive prior to selecting a health plan is a list of primary care providers and hospitals. Specialists, mental health providers, durable medical equipment vendors, and home health agencies are rarely part of the marketing and enrollment materials. The state can, through its health plan contracts and enrollment process, ensure that the materials provided to people with disabilities contain additional information.

- ❖ Community Medical Alliance (CMA) of Massachusetts, a specialized HMO for people with disabilities, provides this information to participants. CMA requires physicians to indicate whether they have experience in working with people with cognitive limitations, developmental disabilities, severe physical disability, or HIV/AIDS. CMA also compiles information on which mental health providers have experience working with issues such as cognitive limitations, physical disability, communication problems, trauma, or AIDS.
  - ❖ Vermont is currently conducting a provider survey to identify providers with disability experience within HMOs in order to make this information available to new enrollees.
5. *Direct access to specialty care.* Ease of access to specialty care is essential for many people with disabilities. States and health plans have addressed this issue in a variety of ways:
- ◆ Some states allow, and other states require health plans to develop systems to permit specialists to function as primary care providers for some enrollees with disabilities. For example, psychiatrists or neurologists might serve as primary care providers for people with specific medical conditions.
  - ◆ In Michigan, a managed care program for children with special health care needs includes a provision for specialists to function as coordinating physicians (and the authorizers of care). They are not considered primary care physicians because they are not delivering all the primary care – another pediatrician or family practice physician performs that role. However, the “gatekeeper” and coordination role goes to the physician who knows the enrollee best.
  - ◆ In the Ohio ABC program each enrollee has an Individual Care Plan including anticipated specialty care. The listing of the specialty in the Individual Care Plan serves as prior authorization for the service. Minnesota is currently considering the same option for its Demonstration Project for People with Disabilities. Some health plans now allow enrollees to self-refer for specialty care.
6. *Provider training.* Managed care is often an important vehicle for expanding access to providers, particularly in areas where Medicaid provider participation is low in the fee-for-service system. In many states, people with disabilities often experience great difficulty in accessing primary care. Managed care offers an opportunity to change this; however, there remain few primary care providers, even in managed health care plans, with expertise or experience in disability. Training is needed to meet this goal. Two options include:
- ❖ The state can organize/provide these trainings directly and require some level of participation on the part of health plan providers.
  - ❖ The state can require health plans to offer physicians lacking relevant experience disability-specific medical training and disability-sensitivity training.
7. *Physical Accessibility.* Most Medicaid managed care contracts include provisions about compliance with the ADA. However, these provisions are usually very general and difficult to monitor. Before a state enrolls large numbers of people with disabilities, it is advisable to develop a more comprehensive plan to ensure physical access. For example, some states

require that health plans conduct a disability assessment of their provider network. In addition, some states add more specificity to contracting language around physical access to care (transportation), to facilities (ramps, curb cuts), and to medical services (exam tables, mammography equipment). Disability assessments and specifications have been conducted by CMA in Massachusetts, and by the Wisconsin Partnership.

8. *Care Coordination.* The case management programs established by conventional health plans usually focus on utilization management or the management of catastrophic medical conditions. These medical model programs should be adapted for people with disabilities, who often have a life-long need for chronic care supports, personal assistance, and community-based services. In addition, some individuals also have complex medical conditions or mental health issues. There is no template for the perfect care coordination system; however, several states and health plans have developed care coordination programs that are very different from the conventional managed care model. These include:
  - ◆ Oregon requires health plans to employ Exceptional Needs Care Coordinators (ECCNs). The ECCNs help individuals navigate the plan provider network, and also assist with referral and linkage to community-based supports.
  - ◆ Massachusetts requires plans to provide home-based clinical and support services. One plan, CMA, uses nurse practitioners, a mental health specialist, and a substance abuse specialist to provide 24-hour access to care and home-based services.
  - ◆ Wisconsin ICARE employs nurses and social workers to develop Individual Care Plans for each enrollee and to ensure that individuals access the services noted in the plan.
  - ◆ Michigan requires health plans serving children with special needs to hire family support coordinators, to assist families in coordinating the care for special needs children.
  
9. *Financial Incentives.* Approximately 20% of people with disabilities account for 80% of SSI health care expenditures. This 20% includes individuals with complex medical conditions as well as individuals with multiple chronic conditions. When a health plan receives a single unadjusted capitation payment for each enrollee, there is a clear disincentive to serve this population. Many health plans may be hesitant to provide high quality, accessible services for fear of attracting a disproportionate share of high cost enrollees. One strategy growing in popularity is use of health-based payments, or risk-adjusted reimbursement. Health-based payments compensate plans based on the case-mix or clinical characteristics of their enrollee population, paying more for those with complex conditions and less for those with intermittent or routine health care needs. Examples of risk adjustment systems include:
  - ❖ Massachusetts has a special payment rate for people with severe physical disabilities and people with AIDS.
  - ❖ Colorado uses the Disability Payment System, a risk-adjusted reimbursement system developed by Medicaid Working Group.
  - ❖ Oregon is also planning to use the Disability Payment System in the next round of health plan contracting.

- ❖ Ohio uses a seven-tiered risk-adjusted payment system, based on prior expenditures.
- ❖ Maryland makes risk-adjusted payments to HMOs based on Ambulatory Care Groups (ACGs).

*10. Consumers and Advocacy Involvement.* Consumers play a significant role in program planning and implementation in many states. During the Oregon health reform process, the developmental disability community played a major role in developing managed care policy. In Missouri, the state made extensive use of a consumer advisory panel in designing a managed care program for people with disabilities. The panel met monthly to review the contract and was helpful in clarifying covered benefits. For example, the panel suggested requiring transportation providers to provide door-to-door transportation rather than curb to curb transportation, to better assist individuals who have difficulty entering a building. In Colorado, the state funded a disability working group to advise on program development and contracting. In Michigan, an advisory committee was formed to consult on the design of a program model and contracting specifications for their managed care program for children with special health care needs. In Minnesota, a stakeholder planning group includes a consumer safeguards committee, which drafted standards of care for people with disabilities.

*11. Special Grievance and Protections Mechanisms.* People with cognitive disabilities need supports to help negotiate the health care system. In addition, the grievance and appeals process needs to be accessible and consumer-friendly. Special training may be needed to access the system, and enrollees need support both within the plan and from their external support network to access the grievance and appeals process. In Wisconsin, the state has a special Medicaid advocate to help people through the complaint and grievance process. Oregon has a Choice counseling program and maintains a state-ombudsperson function. In Massachusetts, the plans have designated staff within their member services departments to assist enrollees in accessing care and filing grievances.

Managed care technologies can be employed to improve the efficiency and the quality of the health care delivery systems for people with developmental and other disabilities. However, the conventional managed care approach must be carefully adapted to address the unique health-related needs of people with disabilities, if the emerging systems are to be not only more efficient but also supportive of better health outcomes and improved quality of life for people with disabilities in Illinois.