

**Medicaid Reform in Florida:
Recommendations for Promoting Access and
Quality in Medicaid Managed Care for
Persons with Developmental Disabilities**

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Medicaid Reform in Florida: Recommendations for Promoting Access and Quality in Medicaid Managed Care for Persons with Developmental Disabilities

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Table of Contents

Executive Summary	4
Introduction	8
Methods	9
Review of the Literature: Medicaid, Managed Care and Developmental Disability	10
• Medicaid and Managed Care	10
• Medicaid and Managed Care in Florida	10
• People with Developmental Disabilities in Florida	11
• Characteristics, Costs and Service Used	12
• Health Care Challenges for People with Disabilities	12
• State Implementation of Medicaid Managed Care	13
• The Benefits and Risks of Managed Care	14
• Financing Managed Care	15
• Experiences and Outcomes of Managed Care for People with Disabilities	18
Survey of State Agencies	21
• Survey Objectives	21
• Survey Methodology and Analysis	22
• How do States Structure their Managed Care Programs?	22
• Identifying Persons with Developmental Disabilities	25
• Determining Medical Necessity	25
• Managed Care Enrollment and Choice Counseling	26
• State Methods of Financing Managed Care	26
• Disability-Specific Requirements and Features	28
Successful Managed Care Models for Persons with Developmental Disabilities	29
• Community Medical Alliance, Massachusetts	30
• Developmental Disabilities Health Alliance, New Jersey	33
• Independent Care, Wisconsin	35
• Minnesota Disability Health Options	39
• The Oregon Health Plan Special Needs Program	41
• Texas STAR+PLUS	44
• The Health Care Partnerships, Kentucky	45
Analysis and Recommendations	49
Citations	55

EXECUTIVE SUMMARY

Florida, like most states, is in a dynamic process of changing its health care delivery system. The State of Florida's Legislature has adopted major Medicaid Reform legislation that will shift the delivery of Medicaid services to a managed care system. The legislation includes a one-year, two-county pilot program, followed by adding additional counties. Over a five-year period, most Medicaid recipients will be enrolled in mandatory capitated managed care. The chronic nature and unique medical conditions of many individuals with developmental disabilities could make it difficult for a managed care system to adequately meet the needs of these individuals, unless the necessary structures are in place.

The Agency for Health Care Administration (AHCA) has indicated that persons with developmental disabilities cannot be enrolled in managed care until mechanisms for managed care organizations to meet their special needs have been developed. The current Medicaid HMO Contract does include provisions regarding persons with developmental disabilities that include ongoing care coordination and monitoring and engagement with the individual's support coordinator. However, the new plans for Medicaid reform have created concern among the disability community about the impact of managed care on persons with developmental disabilities. At the same time, the plans for Medicaid reform have also created an opportunity for examining how managed care can best work to meet the needs of this population. The Florida Developmental Disabilities Council (FDDC) was aware that some states had developed effective managed care programs for persons with developmental disabilities. They contracted for this project in an effort to obtain information about successful programs and recommendations for Florida.

To complete the project, meetings and conference calls were held with FDDC staff, representatives from AHCA, the Florida Department of Children and Families, the Agency for Persons with Disabilities, staff from the Florida legislature, and family members of persons with developmental disabilities, and an Advisory Committee consisting of representatives of these groups was formed. A full review of the literature, program descriptions, and evaluations of managed care initiatives for persons with disabilities was undertaken; a national survey of state Medicaid and Developmental Disability agencies was conducted; and managed care programs that were designed to serve persons with disabilities in other states were examined. Findings from these sources were incorporated into the final recommendations for managed care for persons with developmental disabilities in Florida.

Florida has invested a great deal of time and energy into Medicaid reform and the move toward managed care, and all parties should be commended for their efforts to ensure that persons with disabilities are enrolled in managed care programs that, while being cost effective, will also meet their health care needs. States that have successfully implemented managed care for persons with developmental disabilities and other disabilities have taken different paths. We have identified and described seven different models of managed care, ranging from very small specialty plans developed specifically to serve the population to provider networks to relatively minor modifications of standard HMOs developed to meet the needs of the TANF population. Despite the differences among these models, each offers a range of different ideas and innovations that are useful for Florida to consider in its move toward Medicaid reform.

Key recommendations to successfully integrate persons with disabilities into Medicaid managed care are discussed in detail in this document. The recommendations include:

1. Given the diverse spectrum of Medicaid beneficiaries, and particularly those receiving SSI benefits, it is important to clearly identifying the target population for whom the managed care program is being developed in order to build appropriate models. Because Florida plans to serve the entire Medicaid population in managed care, the decision to include multiple models of managed care and allow different types of entities to serve as managed care organizations is very sound.
2. The method of financing is critical to the success of Medicaid managed care, especially for persons with disabilities. While capitation allows for flexibility and ability to use funds creatively, this only works if the capitation rate is sufficient to encourage health plans to meet members' needs. Risk adjusted capitation should provide managed care plans with sufficient funding to serve their members and will limit problems with adverse selection, which is especially important for managed care plans that serve persons with the most severe disabilities. Because HMO encounter data are not available, AHCA plans begin with pharmacy-based risk adjustment using Medicaid Rx and then move to diagnosis-based risk adjustment using the Chronic Illness and Disability Payment System when HMO encounter data are available. It is important to recognize that risk adjustment can be especially challenging for persons with developmental disabilities, as developmental disability encompasses a range of different diagnoses, and there can be extensive variation in costs, depending on both diagnoses and the severity of those diagnoses. It is important to understand how Medicaid Rx will be able to account for the multiple issues of persons with developmental disabilities if they do not take medications for these conditions. Because of the challenges of risk adjustment for persons with developmental disabilities and using pharmacy-based risk adjustment such as Medicaid Rx is relatively new, it is recommended that the state continue to examine new financing models over time, in case a new model is developed that will be even more effective.
3. Although managed care implementation will begin with pilot programs in two counties, it is expected that persons with developmental disabilities will be required to enroll in managed care after one year, and that there will then be county-by-county implementation, with statewide mandatory managed care enrollment that will include persons with developmental disabilities over five years. It is extremely challenging to implement statewide, or even countywide, managed care for persons with disabilities, and this schedule may be too rapid. It may also take longer than five years to successfully implement Medicaid managed care on a statewide basis, and it is recommended that persons with developmental disabilities not be required to participate in mandatory enrollment until an evaluation of their experience in the pilot program is complete.
4. Although people with developmental disabilities are excluded from mandatory managed care enrollment during the pilot phase, and the state has developed a mechanism to identify persons with developmental disabilities who are receiving services from the Agency for Persons with Disabilities (APD) and ensure that they are not required to enroll in managed

care, there still is no method for identifying individuals with developmental disabilities who are not receiving APD services. As a result, these individuals may be forced to enroll. A mechanism, such as a screening tool, that will allow all persons with developmental disabilities to be excluded from mandatory enrollment during the pilot phases should be established before mandatory enrollment begins.

5. Managed care organizations contracting with AHCA will be expected to meet a minimum set of requirements in order to serve persons with disabilities. Depending on the composition of the managed care applicants, AHCA may elect to identify particular plans as having special expertise or being specially “certified” to provide services to individuals with one or more types of disabilities. This is especially important for individuals who have very severe disabilities or those with multiple types of disabilities. Beyond this, specific contract language to determine if a plan is able to meet the needs of persons with disabilities is recommended. Areas to address might include choice among providers, identification of providers with disability expertise in the provider manual, role of a disability advocate or ombudsman, requirements for case management and care coordination, disability training, accessibility requirements, requirements for new member assessments, quality improvement initiatives, and the specific benefit enhancements available.
6. To make managed care viable for persons with disabilities, consumers and family members must be actively involved in its design and implementation. A task force of stakeholders can serve in an advisory capacity and given an active role to partner with AHCA in managed care program development. It is particularly important that advocacy groups, professionals serving persons with developmental disabilities, and adults and children with disabilities participate in review of the standards that will be required for managed care plans serving persons with developmental disabilities. The FDDC Health Care Task Force has long been committed to these issues and would represent an excellent group to research and review standards of care and provide recommendations to AHCA.
7. Although it is indicated in the Medicaid contract that each managed care organization must have policies related to transition planning upon enrollment and out-of-network care, it is important that these policies include parameters, such as time frames, to ensure continuity of care when persons with disabilities move from fee-for-service to managed care or change managed care plans. In addition, out-of-network care should remain an ongoing option if there are not providers within the managed care network who have expertise and experience serving persons with developmental disabilities, including those with severe disabilities and multiple disabilities.
8. The enrollment broker selected by AHCA to conduct managed care enrollment can develop strategies for smooth enrollment of persons with disabilities into managed care, such as training enrollment staff on working with persons with disabilities or subcontracting with an organization serving persons with disabilities. Persons with disabilities may be most successfully enrolled if there are options for in-person meetings at their homes or other convenient locations. Family members and developmental disabilities program also need an understanding of managed care and how it works to assist consumers to navigate managed care systems.

9. To retain persons with disabilities in managed care, specialty plans and provider networks will need to accommodate individuals dually eligible for Medicaid and Medicare, and bill Medicare on a fee-for-service basis. For Medicare risk plans, AHCA will have to develop separate Medicaid capitation rates for Medicaid-only beneficiaries and for dual eligibles. It can be challenging to manage both one's Medicaid and Medicare benefits. Although individuals who are dual eligibles can voluntarily enroll in managed care plans, it will be important that health plans be required to build in billing and other management mechanisms that will smooth any administrative burdens on persons with disabilities.
10. Managed care plans can obtain the most positive results and buy-in among persons with disabilities if they are flexible, are willing to meet individual needs, and allow consumers as much choice as possible. One important aspect of choice is to allow persons with disabilities to select a primary care provider (PCP) who can best meet his or her needs, and allowing specialists to serve as PCPs, if this is the best option to meet that individual's specific needs.
11. Managed care plans may need to be educated about the complexity of persons with developmental disabilities. Each person is different, and many individuals with developmental disabilities do not have a single disability: they might have a developmental disability, behavioral issues, and a physical disability. These factors will interact and be important to understanding the particular needs of each individual. The PCP should serve as the "medical home" for persons with disabilities, and, in addition to coordinating medical care, should have a strong connection to the services that support persons with disabilities in their homes and communities.

INTRODUCTION

In 2005, the State of Florida's Legislature adopted major Medicaid Reform legislation that begins the process of shifting the delivery of Medicaid services to a managed care delivery system. This legislation (SB 838) provides for the piloting of a Medicaid managed care system of service delivery in two counties for one year, with a move toward overall mandatory managed care statewide for most Medicaid recipients over a five-year period. Florida, like most states, is in a dynamic process of changing its health care delivery system. The chronic nature and unique medical conditions of many individuals with developmental disabilities could make it difficult for a managed care system to adequately meet the needs of these individuals, unless the necessary structures are in place.

While the initial managed care pilots will not require that individuals with developmental disabilities participate in the managed care system, after the pilot phase is completed, managed care enrollment for persons with developmental disabilities will be mandatory in the two pilot counties. Within the next several years, mandatory Medicaid managed care beneficiaries will be implemented statewide. With the new initiative, persons with developmental disabilities will come to depend on a managed care system for their health care services. This will be impossible unless the necessary structures are in place.

SB 838 requires Florida's Medicaid agency, the Agency for Health Care Administration (AHCA), to develop and recommend service delivery mechanisms within managed care in order that managed care organizations can sufficiently meet the medical, developmental, and behavioral health needs of their enrollees with developmental disabilities, and indicates that mandatory enrollment of persons with developmental disabilities cannot be implemented until these systems are developed. Currently, it is unclear what the special mechanisms for persons with developmental disabilities within managed care will be, but AHCA wants to ensure that persons with developmental disabilities be enrolled in a managed care system that will meet their special and unique needs. While the current Medicaid HMO Contract includes provisions regarding persons with developmental disabilities that include ongoing care coordination and monitoring and engagement with the individual's support coordinator, the plans for Medicaid reform provide an opportunity to add new models of managed care as alternatives for providing health care to persons with developmental disabilities. The goal of this white paper is to review key issues in managed care for persons with disabilities, examine how other states have developed managed care systems that meet the needs of persons with developmental disabilities, and offer recommendations to the State for how managed care can best work to meet the needs of this population.

Medicaid is the nation's most important program for meeting the health care needs of people with disabilities. Medicaid reform will impact the majority of the over 2.2 million Medicaid beneficiaries [1] across the state of Florida, over 500,000 of whom have disabilities [2], including over 52,000 persons known to have developmental disabilities [3], and even more persons with developmental disabilities who are currently unknown to the state. Given the health challenges and special health care needs of many persons with developmental disabilities, it is crucial that this population not lose the health services and support that enable their maximum health and functioning.

The Florida Developmental Disabilities Council (FDDC) is paying a great deal of attention to the impact of Medicaid reform on persons with developmental disabilities, and is aware that managed care has effectively served persons with developmental disabilities in some states. The FDDC believes that Florida's managed care system can best serve persons with developmental disabilities if those involved in its development and implementation are aware of how Medicaid managed care for persons with disabilities has been implemented nationally, and what important lessons have been learned. To obtain this information, the FDDC funded researchers from the Bedford VA Research Corporation, Inc. to collect and provide information from the health care literature and from existing managed care systems with the goal of making recommendations for a managed care delivery system in Florida that will adequately meet the needs of individuals with developmental disabilities.

METHODS

The data and recommendations in this white paper come from several activities conducted to obtain the most up-to-date information on the status and successes of managed care for persons with disabilities and persons with developmental disabilities. To provide the FDDC with information about how managed care can be optimally used to meet the needs of persons with developmental disabilities and examine how other states have successfully handled these issues, we completed the following activities:

1. Conducted meetings and conference calls with FDDC representatives, representatives from AHCA, the Florida Department of Children and Families, the Agency for Persons with Disabilities, and staff from the Florida legislature, and family members of persons with developmental disabilities; and formed an Advisory Committee consisting of representatives of these groups to determine their concerns and identify the important issues to be addressed;
2. Completed an extensive review of the literature on managed care for persons with developmental disabilities. This review was extended to also include managed care programs for persons with a broad range of disabilities, as well as program descriptions and evaluations of managed care initiatives that serve the population. The review of the literature was comprehensive and included the academic literature; materials available through the Internet, foundations, and government sources;
3. Conducted a national survey of state Medicaid and Developmental Disability agencies to learn about their managed care activities for persons with developmental disabilities and other disabilities, how they dealt with the issue of medical necessity and expanded benefits for the population, and successful managed care models they had implemented; and
4. Obtained information about successful managed care programs and plans in other states serving persons with developmental disabilities or other disabilities to examine what made them successful and to identify ideas and approaches that would be useful or adapted for Florida.

The information obtained from these sources, as well as the experience of the lead author providing technical assistance to states and managed care plans developed to serve persons with disabilities, guided the results and recommendations presented here, and will hopefully offer helpful information to lead the development and implementation of managed care for persons with developmental disabilities in Florida.

REVIEW OF THE LITERATURE: MEDICAID, MANAGED CARE AND DEVELOPMENTAL DISABILITY

Medicaid and Managed Care

Medicaid programs face a challenging future. As states struggle with escalating health care costs and likely reductions in federal funding for Medicaid, they may also have more flexibility to experiment with purchasing options. As these developments unfold, many states are exploring managed care as an alternative to the existing fee-for-service delivery system for some of their more expensive populations, including people with disabilities. As of 2004, there were over 44 million beneficiaries in the US [1]. People with disabilities comprise approximately 15% of the total Medicaid population, but they account for about 40% of total Medicaid expenditures nationally [2]; these percentages have been relatively consistent for many years. Any state effort to restrain the growth of Medicaid expenditures includes a close examination of the costs associated with health care services for persons with disabilities. However, although the managed care industry has for many years provided services to substantial numbers of women and children, including increasing numbers of Medicaid recipients in their Transitional Assistance to Needy Families (TANF) populations, health plans are not traditionally as familiar with Medicaid's recipients with disabilities- either adults or children. Until the 1990s, most of the Medicaid policy focus on people with disabilities was not been directed toward managed care program development. Instead, Medicaid programs expanded optional services, targeted case management, and Home and Community Based Services waivers for people at risk of institutional care.

More recently, states have begun enrolling persons with disabilities receiving Supplemental Security Income (SSI) into managed care plans. For people with disabilities, including persons with developmental disabilities, managed care holds a promise that health care services can be delivered more cost-effectively without sacrificing quality of care, restricting eligibility or reducing benefits. At the same time, managed care organizations have not typically had experience serving people with disabilities, who are a complex mix with complicated and heterogeneous health care needs. Therefore, states need to tread carefully and take important steps to safeguard the needs of people with disabilities when enrolling them in managed care. While there are many concerns about managed care for this population, there are programs that have effectively served people with disabilities, while other programs have failed. Those programs that have been successful have been developed with particular attention to adequately serving people with disabilities.

Medicaid and Managed Care in Florida

Florida implemented its Medicaid program in 1970, to provide medical services to the indigent population. The Medicaid program in Florida is administered by the Agency for Health Care

Administration (AHCA). Individuals become eligible for Medicaid benefits in one of two ways: by applying directly for Medicaid through the state's Department of Children and Families; or by becoming automatically eligible for Medicaid once deemed eligible for Supplemental Security Income (SSI) benefits by the Social Security Administration. The majority of individuals with developmental disabilities who receive Medicaid in Florida fall into this SSI category. Florida Medicaid covers over 2.2 million individuals in total, and both its enrollment and expenses are rapidly increasing: expenditure growth has averaged 13% per year for the past six years, and it is expected that in 2005 Medicaid expenditures will represent approximately 24% of the entire state budget, costing the state over \$14 billion. One of the goals of Medicaid reform is to curb these sharp increases, as without disruption in these trends, by 2015 Medicaid expenditures would represent 59% of the overall state budget at a cost of over \$50 billion [4].

Currently, there are several Medicaid managed care options in Florida, through which Medicaid beneficiaries, including persons with developmental disabilities, can receive their health care services: fully capitated HMOs in many areas of the state, a statewide primary care case management (PCCM) program (MediPass), and in some areas of the state, Provider Service Networks (PSNs), the Minority Physicians Network and the Emergency Room Diversion Program. Enrollment in one of these options is mandatory in Florida for most categories of Medicaid recipients, and if an individual does not choose either MediPass or an HMO, he or she is assigned [5]. As of December 31, 2004, over 1.5 million, or more than 67% of Florida's Medicaid recipients, were enrolled in a managed care program [1], placing Florida about in the middle among all states in terms of managed care penetration rates for Medicaid recipients nationally [2]. Similar to many states with fee-for-service and capitated managed care options, the majority of persons with disabilities are enrolled in the fee-for-service PCCM program [6, 7]. Despite a history of mandatory managed care enrollment, consumers remain concerned about mandatory enrollment into capitated managed care programs

People with Developmental Disabilities in Florida

In Florida, about 17%, or over 500,000 Medicaid beneficiaries are people with disabilities. However, this group accounts for 41% of total Medicaid expenditures[2]. While a study of health care costs of non-institutionalized adults (including Medicaid and SSI beneficiaries) defined high-cost individuals as being in the top 20th percentile for health care spending with average annual total medical expenditures over \$4,052 [8], average cost of health care services per Medicaid beneficiary with a disability in Florida in Fiscal Year 2001 was more than twice that, at \$8,547. It is also more than 5.5 times that of Florida's adults (\$1,493) and children (\$1,040) in the TANF population, and somewhat higher than the elderly (\$7,783) [2].

As in almost all states, the total number of persons with developmental disabilities in Florida is unknown. In 2005-2006, the Agency for Persons with Disabilities (APD) is expected to serve approximately 40,000 persons with developmental disabilities, an increase of 18% from 2004-2005. The APD also indicates that there are also over 12,000 additional persons with developmental disabilities on the waiting list for APD services [3]. However, 52,000 is likely an underestimate of the number of persons with developmental disabilities in the state. There are potentially many more persons with developmental disabilities who receive Medicaid benefits, but are not being served by APD or on the waiting list for APD services. Any person falling into this category will be immediately affected by Medicaid reform because they are unknown to

APD and will therefore not be exempt from mandatory enrollment during the pilot phase of managed care.

Characteristics, Costs, and Services Used

A developmental disability is a condition that arises prior to age 18, persists into adulthood and can create problems with language, learning, mobility, and the capacity for self-sufficiency [9]. Approximately 4.5 four million Americans have a developmental disability[10], and persons with developmental disabilities account for about 28% of the SSI population nationally[11]. In Florida, as in many states, developmental disabilities are defined as spina bifida, autism, cerebral palsy, Prader-Willi syndrome and mental retardation[3]. There are some important characteristics and facts about persons with developmental disabilities that are important to understand when considering their health care needs:

- About 25% of the developmental disabilities population will require an intensive array of services for most of their lives, often paid for with Medicaid benefits[9].
- People with disabilities receive services from other payers besides Medicaid. About 30 percent of the Medicaid population also receive Medicare benefits and thus receive their acute care through the Medicare system[12]
- Among people with disabilities, as among those without disabilities, health care costs are skewed toward a small number of high cost individuals. Among Medicaid beneficiaries with disabilities, almost half have health care costs of less than \$1,000 each year. On the other hand, about 4 percent incur costs of over \$20,000 per year. [12]. This high cost group is likely to have multiple and severe disabilities that include more than just a developmental disability. They are likely to have some sort of physical disability, and may also have behavioral health issues. This is the group that most needs a medical home and coordinated care, and that is most at risk.
- There is wide variation in the per capita costs of people with different diagnoses. Among persons with developmental disabilities, the ratio of average costs for persons with mental retardation is 1.3, just above the average costs for all non-institutionalized Medicaid recipients with disabilities (1.0), while the ratio of average costs for persons with cerebral palsy is 2., significantly above the average [13]. Similar data are unavailable for spina bifida, Prader Willi and autism.

Health Care Challenges for People with Disabilities

Studies show that people with disabilities face serious economic and health-related challenges. A 2003 national survey of people with disabilities found that, compared to the non-disabled population, they have lower incomes, are more likely to be female, unemployed and in poorer health. They also are more limited in their daily activities and more likely to use the health care system intensively. Unlike the developmental disabilities population, however, most people with disabilities (80%) became disabled as adults[14]. Persons with developmental disabilities will face these needs for intensive use of the health care system for most, if not all, of their entire lives.

Health insurance is crucial to facilitating access to health care[15]. Many people with disabilities have health insurance, often through Medicaid, Medicare or both. Persons with developmental disabilities, because of the long-term nature of their disability and lack of work history, are most likely to be covered by Medicaid, although a substantial proportion will also receive Medicare benefits (dual eligibles). A major challenge for dual eligibles with disabilities is often coordination between Medicare and Medicaid, which is particularly challenging if the beneficiary is enrolled in different health plans for Medicare and Medicaid.

Family members and friends, rather than professionals, are the primary source of support for people with disabilities. In the national study, less than 10% used home health aides or personal care assistants. But they used the health care system frequently, with 90% seeing a physician within the past six months and a third having an emergency room visit during that time, and 90% using at least one prescription medication. However, they still received health care services less frequently than generally recommended[14].

As mentioned earlier, another serious challenge is that many people do not have a single disability. A study of 16,403 of people on Medicaid with and without disabilities living in the community who responded to the 1996 Medicare Current Beneficiary Survey found that 64% reported at least one disabling condition and 30% reported more than one disabling condition. In this study, 90% of people over age 65 reported a usual source of care, except the deaf or very hard of hearing at 88%. In general, people under age 65 were less satisfied with their health care than those over 65. Among those under age 65, 85% had a usual source of care, except blind persons at 65%. People with disabling conditions reported higher rates of dissatisfaction with care, though it varied by dimension of care and age range. People with disabling conditions were less satisfied with their access to care, and with the costs of care. In this study, managed care enrollment did not significantly affect satisfaction with most aspects of care. For those in managed care, older members, disabled or not, were less satisfied with access to specialists, but all members were significantly more satisfied with the costs of care. Among those with disabilities, despite their age, they were least satisfied in general with the information received about their condition, costs of care, availability and ease of getting to the doctor[16].

State Implementation of Medicaid Managed Care

States use waiver mechanisms to obtain federal approval to change the way they provide Medicaid coverage or deliver Medicaid services. In recent years states have used either 1915b waivers that allow states to test a variety of new mechanisms or broader 1115 Waivers that allow states to make changes in eligibility, benefits, or cost sharing within Medicaid. As of January 2005, 27 states and the District of Columbia had approved 1115 Waivers[17]. One of the most common uses of 1115 Waivers is to require mandatory enrollment in Medicaid managed care. As of 1998, almost 75% of states were using waivers to enroll at least some of their SSI disabled Medicaid recipients into Medicaid managed care[18].

The growth of Medicaid managed care for people with disabilities has been swift. From less than 10% in 1991, by 2000, close to 60% of Medicaid beneficiaries were enrolled in managed care. It has been slower for people with disabilities, but nationally, about 25% of people with disabilities on Medicaid were enrolled in managed care in 1998, with at least six states enrolling over 75% of their Medicaid disabled beneficiaries in managed care. By 1998, nearly 75% of states were

using waiver authority to enroll at least some people with disabilities in managed care[19]. However, Medicaid managed care programs were not initially created to serve people with disabilities, but were developed to meet the needs of low-income families and children. Because plans are not targeted to serve people with disabilities, enrollment in managed care among the population creates challenges in terms of ensuring access and quality of care. Therefore, while some states have made very active moves toward enrolling people with disabilities in managed care, others have elected not to include this population, sometimes after previous experiences that were unsuccessful. However, although most SSI recipients elect not to enroll in managed care if they have the option, the majority of those enrolled in managed care are enrolled in mandatory, capitated plans[19].

The Benefits and Risks of Managed Care

Managed care for persons with developmental disabilities is attractive to states for its potential to decrease costs. Managed care can also provide high quality services for persons with developmental disabilities if it meets its potential to offer flexible care, non-traditional benefits, and better coordinate care. However, if not carefully monitored, it can also be used to under serve persons with developmental disabilities. Studies have shown that while there may be room for efficiencies in the care of persons with disabilities, they are particularly vulnerable in managed care programs that restrict access to services as a way to control costs[20].

The benefits and risks of managed care for people with disabilities, including persons with developmental disabilities, are frequently discussed. Persons with disabilities have the potential to greatly benefit from managed care, including having a medical home and care management done by a primary care provider (PCP) who is compensated for this function, as any mechanism to coordinate care and appropriately target services could improve care for people with disabilities. Capitation also has the potential, through a less restrictive payment mechanism, to create incentives to encourage health care plans to invest in services that encourage use of lower cost, but also effective, services to meet the needs of people with disabilities if plans use those funds creatively and flexibly. This arrangement can encourage better disability management strategies to maintain health and functional status[20].

However, managed care also has the potential to harm people with disabilities and limit their access to necessary services if not handled correctly. It can lead to incentives to limit services or inappropriately treat people with disabilities. While establishing preferred provider networks is a crucial mechanism for managing care and costs, some people with disabilities have longstanding relationships with specialists who are not part of certain networks. Access to these specialists may be placed in the hands of PCPs who are unfamiliar with the enrollees and who may have incentives not to refer to these, or any specialists. In addition, some people with disabilities see many specialists and ancillary service providers. At times, persons with developmental disabilities need very specialized services, not merely access to a specialist, but a specialist with expertise in a rare and complex condition. Important and necessary health care relationships may be lost without a policy allowing for some level of out-of-network care.

One concern among persons with developmental disabilities, their families and advocates when moving toward managed care is the concept of medical necessity and the philosophy of managed care. Persons with developmental disabilities often use a range of habilitative services to

maintain, rather than improve, their functioning. There is apprehension because HMOs often have a narrow view of medical necessity based on cure and restoration, rather than on maintenance. As a result, HMOs have traditionally placed strict limits on home care, supportive services and speech, physical and occupational therapies, as well as assistive devices. These limits and a rigid definition of medical necessity have the potential to shift care towards a medical model that may be inappropriate for persons with developmental disabilities[20].

Financing Managed Care

The organization and financing of managed care is critical. Managed care financing has the potential to work for or against high-quality care for persons with developmental disabilities. In general, Medicaid provider rates are substantially lower than market rates, contributing to access problems[21]. The goal of many states has been to move toward capitation, both to save money and to encourage the provision of alternatives to inpatient and emergency care. Several different financing mechanisms have been explored for managed care, and specifically for managed care for high cost populations, including persons with disabilities. As states shift from fee-for-service Medicaid to Medicaid managed care, they shift the financial risk from the state to managed care plans. At the same time, managed care plans want to minimize their risk, not increase it. In their perspective, this can be accomplished through adequate capitation rates. For states, the goal of a risk adjustment arrangement is to encourage managed care plans to compete on the basis of quality and efficiency rather than risk selection.

Risk adjustment within managed care is important because of the imbalance in health care costs across individuals, based on their health status. Nationally 30% of all health care dollars are spent on 1% of the US population, while 50% of the US population only spends 3% of total health care dollars[22]. Because of this imbalance, managed care plans have an incentive to enroll the healthy population and avoid the sicker population. While there are regulations prohibiting these practices, a successful risk adjustment model will counter the effects of negative selection, and plans that do a good job serving an expensive population will not be penalized. Risk adjustment helps to ensure that health plans do not have incentives to pursue the healthiest enrollees and discourage those who are less healthy from enrolling.

When Medicaid managed care was first implemented, capitation rates were not risk adjusted on any health measures. Rather, there was typically an SSI rate and a TANF rate, in which states establish capitation rates for the TANF population and the SSI population for each region of the state based on age and gender. However, it is clear that for persons with disabilities, demographically adjusted rates are not specific enough. There is huge variation in costs among persons with disabilities receiving SSI benefits, both across different disability categories and even within a certain general disability category. For instance, among persons with developmental disabilities, there are variations based on whether a person has mental retardation with little or no physical health conditions or disabilities versus a person who has mental retardation and cerebral palsy, for example, that may create many more health problems. There is more, but clearly not absolute, consistency in costs within specific diagnoses. There is also more consistency based on level of severity of a particular diagnosis. This leads to support for capitation rates that are adjusted based on diagnostic data.

There are several advantages to diagnostic risk adjustment. Some diagnostic data is easily available. ICD codes are required for all health encounters. In addition, ICD coding is relatively accurate. Finally, some diagnoses have a strong relationship to future expenditures, particularly chronic conditions. Risk adjustment is not an answer by itself; however. Risk adjustment requires significant investment of time and resources and must be useful enough to provide benefits to offset the cost of its implementation. In order to calculate appropriate risk adjusted rates, a significant amount of accurate data is needed and state Medicaid departments have found that the lack of data is the biggest problem to doing diagnosis-based risk adjustment[23].

Several different risk adjusted methods for calculating capitation rates have been developed. Risk adjustment is a highly sophisticated, technical procedure that cannot be addressed in full here. However, several of the more common methods of risk adjustment for enrolling persons with disabilities within Medicaid managed care are discussed below. Generally, risk adjustment can be based on diagnostic data, pharmacy data, or service utilization. Some of the most common risk adjustment methods that use diagnostic data are Adjusted Clinical Groups, Diagnostic Cost Groups, and Chronic Illness and Disability Payment System. These three risk adjustment methods use diagnostic data from Medicaid claims records.

The Adjusted Clinical Groups (ACGs) mechanism, formerly called Ambulatory Care Groups, classified individuals into 1 of 93 mutually exclusive categories based on the diagnoses on claims data that a person was assigned during a specified time period. Diagnoses are then clustered into the 32 categories based on several criteria, including clinical similarity, likelihood condition will recur or is chronic, and the likelihood that the patient will return to their physician for treatment or need a referral to a specialist. The final categories are not clinical, but are based on the duration of the condition, its severity, and the types of services that will be used. Examples of some of the categories of ACGs are "time limited: minor" for a rash, or "chronic medical: unstable" for cystic fibrosis. The combination of groups is then used along with information on age and sex to assign the patient to one of 93 mutually exclusive adjusted clinical groups, and capitation rates are set for the clinical groups.

A second risk adjustment system using diagnostic claims data is Diagnostic Cost Groups (DCGs), which were developed for the Medicare program for inpatient care only, and used only inpatient data. Now, DCGs are also used for Medicaid and commercial populations, and also can be developed for overall costs. Depending on what they are being developed for, DCGs can be developed using different types of data (inpatient data only or all encounter data). If DCGs are developed using all encounter data, all possible medical condition categories are categorized into 136 groups (called hierarchical condition categories) based on diagnosis codes, and each individual is assigned to one or more diagnostic clinical group based on their diagnosis codes. Each member is also assigned to one of 32 age/gender categories. Capitation rates are then based on the categories to which the person is assigned.

A third risk adjustment mechanism using diagnostic data that is becoming more widely used for the SSI population is the Chronic Illness and Disability Payment System (CDPS), formerly called the Disability Payment System (DPS). The CDPS defines 67 major categories by body system or condition and 16 age/gender categories. Rates are based on these categories, with an additional adjustment based on level of severity ranging from extra low to extra high. CDPS can

take into account multiple diagnoses as well as severity levels, adjusting for low, medium or high severity of each diagnosis.

Rather than risk adjusting based on diagnostic data, capitation payments to predict total costs for each member of a managed care plan can be adjusted based on pharmacy data. Using pharmacy data to set capitation rates is newer than using diagnoses from claims. Three of the more common pharmacy data based risk adjustment methods are Medicaid Rx, RxRisk and Rx Groups. Medicaid Rx was developed and intended for the Medicaid program, and assigns individuals to one or more of 45 medical condition categories based on prescription drugs used and also to one of 11 age/gender categories. Medicaid Rx has separate weights for setting rates for adults and for children.

RxRisk assigns children and adults to different medical categories. Adults are assigned to one or more of 27 medical condition categories based on prescription drugs used, and children are assigned to one or more of 42 medical condition categories based on prescription drugs used. Each member is also assigned to one of 22 age/gender categories.

RxGroups is somewhat different than the other risk adjustment mechanisms that use pharmacy data, as it assigns individuals based on pharmacy categories rather than diagnostic categories. Each individual is assigned to one or more of 127 drug therapy categories and one of 32 age/gender categories to predict costs and set capitation rates.

Episodic Risk Groups (ERGs) combines diagnosis-based risk adjustment and pharmacy-based risk adjustment. The ERGs group individuals to one or more of 119 medical condition categories called episode risk groups. The episode risk groups are based on both diagnosis and pharmacy claims data. Each individual is also assigned to one of 22 age/gender categories.

Another different for setting rates is to risk adjust based on prior service utilization. Rather than categorize individuals based on their diagnoses or their prescription medications taken, states may risk adjust based on a person's past experience or service utilization. Rates are based on the concept of using prior utilization to predict future utilization. Many states have their own systems to examine past experience.

In addition to all of the risk adjustment methods discussed above, several new systems and modifications of the current systems are also under development. Software is available for each system. Despite the many types of risk adjustment systems, there is no consensus on a single system that is most effective in all situations. One study involved a comparison of DPS and the Ohio Prior Expenditure System, which is based on past experience, that used a retrospective review of data on 157,142 persons with disabilities eligible for an Ohio Medicaid managed care demonstration project. Neither DPS nor the Ohio Prior Expenditure System was especially effective in predicting expenses for new eligibles. OPES severely underpaid for those who were the highest cost. While, DPS predicted expenditures somewhat better, it was also not extremely accurate. Better methods are needed, especially for those with little Medicaid fee-for-service claims experience or high predicted expenditures[24]. In one study, Medicaid officials in six states were interviewed to examine how they selected their financing methods, and what their recommendations would be for other states. Their suggestions were to allow ample time for

discussions with advocacy groups and health plans, allow two years for financial modeling and start-up, and to select a method that is politically acceptable, financially feasible and actuarially sound[23].

It can be extraordinarily challenging to develop risk adjustment methods specific to each enrollee and very specific diagnostic categories. As a result, some states do not use full risk adjustment, but use a modified risk adjustment mechanism that includes the traditional demographic adjusters and overall Medicaid rating category, with some broad diagnostic risk groups. However, this type of risk adjustment can be detrimental to specialty plans that tend to enroll the highest cost individuals with multiple disabilities or dually diagnosed persons. Mainstream HMOs that include both commercial and Medicare enrollees, as well as Medicaid enrollees have stopped enrolling the Medicaid population in a number of states due to low payment rates[25]. It is important that the risk adjustment provide an incentive to provide sufficient high quality care for people with disabilities, rather than encourage managed care plans to deny services to those with the potentially greatest needs.

Risk adjustment is especially important for smaller managed care organizations and specialty plans that may focus on one or more groups of persons with disabilities. They can suffer in a system that relies on marketplace competition, as these plans tend to be smaller and cannot compete with the larger plans in the health care marketplace. As these plans are more likely to be developed to meet the needs of people with disabilities, people with disabilities are more at risk through this market-driven mechanism. Consequently, it is most important is that capitation rates be set that adequately reimburse for the costs of caring for people with specific types of disabilities. The potential of managed care to slow or decrease spending makes it particularly important because, unlike in the fee-for-service system where providers are compensated more for more services, plans are not compensated for providing more or more costly services. For persons with disabilities, if managed care plans are not adequately capitated, services may be limited. It is recommended that good risk adjustment models pay more to managed care plans that serve those with the highest needs, be relatively easy to administer, resist gaming, have ongoing incentives for efficiency, and protect privacy and confidentiality[22]. While no one risk adjustment system is perfect, and each has strengths and weaknesses, it is clear that within capitated managed care, risk adjustment is more likely to be fair to managed care plans that enroll persons with disabilities. If a risk adjustment mechanism that accounts for type, number and severity of disabilities is used, managed care plans are then more likely to be able to meet needs of their members with disabilities.

Experiences and Outcomes of Managed Care for Persons with Disabilities

There have been few specific studies specifically examining the experience of persons with developmental disabilities in Medicaid managed care. However, the experience of people with disabilities in managed care in general, including Medicaid managed care, commercial managed care, or Medicare managed care, can provide us with a proxy estimate of the experience of persons with developmental disabilities in Medicaid managed care. Results of some key studies show that the experience of people with disabilities in managed care has been mixed.

A study of SSI disabled enrollees under age 65 enrolled in four managed care plans in Tennessee, found that the managed care plan with the largest provider network received the

highest ratings from members with disabilities about their provider's knowledge of disability, how the disability affects their day-to-day life, and the information staff gave about managing their disability. Two plans, one a network of university-affiliated physicians and the other a network of traditional safety-net providers was not ranked as highly. Almost all of the enrollees in the all four of the plans had a usual source of care and could schedule appointments within one week. Three of the managed care plans paid their providers on a capitated basis, while the fourth paid them on a fee-for-service basis; enrollees in the plan that paid providers on a fee-for-service basis indicated that they received more preventive care and reported more visits to manage their chronic conditions. None of the managed care organizations provided much care coordination, even though three had care management programs. More often, a family member or friend coordinated care. Overall, differences found in access to specialists and delays in approving care appeared to be unrelated to the managed care organization characteristics, but rather to the level of utilization management[26].

A examination of SSI Medicaid enrollees' experiences with managed care in four counties in New Jersey, that included individuals ranging from children to the elderly, administered both in English and Spanish, it was found that the most important factors in choosing a plan were the participation of the consumer's doctor and the reputation of the doctors in the plan. When choosing their managed care plan, 69% said they had sufficient information to select an HMO that best fit their needs and 56% got information regarding HMO choices. After joining a plan, one-third of respondents had to change doctors, and a third of this group said that was a problem. Most (82%) said the PCP was close to where they live, but 23% cancelled a medical appointment in the past year due to transportation problems. Most (81%) could get an appointment for a routine check-up within a week or less, 64% could get a same day appointment for minor illness or injury, and 90% could get same-day urgent care. Over a third said that they had to wait more than 45 minutes in the provider office when they had an appointment and 17% said they typically wait more than 4 hours for a provider to return a telephone call. Enrollees said that the things they were most satisfied with about their managed care plan were that their doctors treated them with respect and courtesy, the ease of filling prescriptions, not feeling rushed by their providers, good office hours of their providers, and the medical care they receive. They were only relatively satisfied with their ability to get medical care in an emergency, reach their doctor with questions, the ease of getting to care, and their waiting time at doctors' office. Almost three-quarter (73%) said that they would recommend their plan to a friend or family member. When asked what they disliked about their managed care plans, most common were the process of getting referrals for specialty or urgent care and the limitations placed on which doctor they could see. Respondents said that they preferred their health plan to fee-for-service on the following dimensions: choice of doctor, ability to get advice by phone, and ability to get specialty care. They preferred fee-for-service in terms of waiting time for routine care appointments, waiting time in a doctor's office, convenience of clinic or office hours, and ability to get dental care. Respondents with excellent or good health status were more likely to prefer their HMO compared to respondents whose health was fair on poor[27].

Another study documented the experience of two groups of Medicare beneficiaries in HMOs: elders, persons with disabilities, some of whom were dual eligibles. The group consisted of 3,080 individuals who had been enrolled for two or more months in managed care plans, of whom some were still enrolled and others had disenrolled. The enrollees with disabilities were more

likely than the enrollees who were elderly to disenroll from managed care, and were more likely to report fair or poor health. The major reasons for enrolling in managed care were costs and benefits; these were more important for persons with disabilities than elders. However, almost half (47%) of the enrollees with disabilities said there were specific things about their managed care plan that appealed to them because of their disability, such as having a doctor with special knowledge of their condition, better prices on medications, or location of the doctor. Virtually all enrollees said that, upon enrollment, they received a booklet explaining how the plan worked, a list of participating doctors, and enough information to be comfortable using the plan. However, only 34% said they were encouraged to have physical examination or health assessment. Although most enrollees with disabilities did not report problems with access to care, the proportion reporting access issues was higher among the enrollees with disabilities than among the elderly enrollees (12% of enrollees with disabilities had problems making appointments and 40% who received home health care felt they needed more care than they were able to get. The enrollees with disabilities also said they experienced more access barriers than the elderly enrollees within the fee-for-service system, but the differences between the groups as well as the level of barriers were more pronounced under managed care [28].

Comment [s1]: Language

The same study also documented the experiences of those who had disenrolled from managed care and were now in the fee-for-service system and compared it to those who remained in managed care. Enrollees in managed care indicated better preventive care than fee-for-service enrollees: 51% of persons with disabilities enrolled in managed care received a flu shot versus 36% in fee-for-service. Females with disabilities enrolled in managed care were more likely to have had a mammogram than those in fee-for-service Medicare. In general, beneficiaries with disabilities in managed care were satisfied with the care they received; 89% of disabled enrollees said they would recommend their plan to a family member or friend[28].

A study of satisfaction of dual eligibles over age 65 enrolled in a voluntary managed care plan designed specifically for dual eligibles that provided transportation for all types of medical visits, access to care via onsite nurse practitioners who functioned as PCPs, and high levels of preventative services, compared this group to dual eligibles of the same age locally and nationally. The managed care plan was a for-profit organization that served an almost exclusively black population, a group that has been shown to be less satisfied with care in other fee-for-service settings. Those enrolled in the managed care organization were significantly more satisfied with their care in general, their access to care, and the technical skills of their PCP. They were very highly satisfied with interpersonal manner of their PCP. In terms of health care utilization, fewer managed care enrollees reported emergency department visits and hospitalizations. More also reported receiving preventative care, including mammograms, pap smears and vaccinations[29].

Finally, a study in 2000 was conducted in New England to test the hypothesis that chronic illness would predict greater enrollee dissatisfaction under capitated managed care than in fee-for-service. This was a study of employed people, and compared the experience of respondents with and without chronic illness. The analyses compared those in two types of managed care—prepaid group practices and independent practice associations—to those in traditional fee-for-service programs. The results showed that chronic illness was associated with increased odds of dissatisfaction in both independent practice association plans and prepaid group practices, but

not under FFS coverage. Chronic illness also appeared to exacerbate difficulties and to attenuate the benefits experienced by healthy persons under managed care. Compared with enrollees in fee-for-service, those under managed care were proportionately younger, male, non-Whites, had a lower family income, had shorter tenure with their employer and with the health plan, reported higher functioning on a standardized instrument, and were likely to have any medical illness and/or a chronic illness. The authors concluded that persons with chronic illness may be at particular risk under managed care and that their experiences may warrant particular attention when health plan performance is being monitored. They also believed that at least two features of managed care may create particular difficulties for persons with chronic illnesses: first, compared to fee-for-service, managed care relies less on incentives for patients and more on provider incentives and clinical practice constraints to contain costs, and these mechanisms are less visible to healthy than to sicker enrollees who are more impacted if a provider does not provide them with referrals or other services. Second, capitated plans are prepaid on the basis of the average health care costs of an insured population and have a strong incentive to attract relatively healthy, low-cost enrollees.[30].

In summary, the study results are mixed. While most people with disabilities, whether on Medicaid, Medicare, or commercial insurance, are satisfied within their managed care plans, there is wide variation regarding what makes people with disabilities more or less satisfied with managed care or between managed care and fee-for-service alternatives. In general, people with disabilities appear to be satisfied with managed care, although they become dissatisfied when their access to care is restricted. It is also important to note that when people with disabilities are dissatisfied with managed care, those who tend to be dissatisfied are those who are the sickest or most disabled. Rather than an indictment of managed care, however, this points to the importance of close monitoring of managed care and the need for diagnostic risk adjustment in order to ensure that people with disabilities receive access to the care they need, as well as having multiple managed care options so that individuals can have reasonable choice. In addition, it appears that care coordination is not as important to health care consumers with disabilities as the quality, breadth, knowledge and attitudes of the network providers, as well as good access to care. Finally, people with disabilities are consistently more likely to obtain preventive care when they are enrolled in managed care.

SURVEY OF STATE AGENCIES

Survey Objectives

From November 2005-February 2006, we conducted a survey of state Medicaid and Developmental Disability agencies. The primary objective was to identify managed care initiatives in other states that had successfully served persons with developmental disabilities. We also wanted to understand if any states had established mechanisms to distinguish this population from the general SSI population for managed care enrollment. However, because we suspected that most states would be unable to differentiate their developmental disability population, we also surveyed state developmental disabilities agencies, hoping that they could provide us with more information about the developmental disability population in their state, how they received their health care, and their experiences with Medicaid managed care. Below we provide the results of our surveys.

Survey Methodology and Analysis

The survey was developed by the project team and then reviewed by the project Advisory Committee and FDDC. The Advisory Committee recommended some minor modifications; these were made and the survey was sent back to the Advisory Committee and the FDDC. After final approval, the surveys were sent via email to the state Medicaid Director and the state Developmental Disabilities agency director in 49 states (Florida was excluded) and the District of Columbia, using lists from the State Developmental Disabilities Association and the State Medicaid Directors Association. The agency directors were asked to complete the survey themselves or to give it to the person in their office who could best provide the answers to the survey questions. Approximately 10 days after the initial email, a second survey and request for responses was sent to non-respondents. After another week, these requests were followed by telephone calls to the non-respondents, with at least three telephone follow-up requests to each state agency.

After conducting this extensive follow-up, we received at least some response from 42 of the 50 states, or 84%¹. As agreed to by the Advisory Committee, and because it was important to the FDDC that we obtain as much information as possible from all states, we supplemented the survey data with information available in the literature and from state agency materials for states that were non-respondents and for questions that the state agency staff had been unable to answer. Below, we provide a summary of the survey results.

How do States Structure their Managed Care Programs?

All but three states (Alaska, New Hampshire and Wyoming) have managed care for at least some of their Medicaid populations. However, while the remaining states all enroll the Transitional Assistance to Needy Families (TANF) population in managed care, not all include persons with disabilities (identified by the receipt of SSI benefits) in managed care. Some states enroll only specific populations, such as children with special health care needs (District of Columbia), or children on SSI who are part of families on Medicaid managed care through the TANF program (Connecticut). Five states (Tennessee, South Dakota, Georgia, Arizona, Maryland) enroll over 75% of their disabled population in managed care. Among states that do enroll their SSI population in managed care, most do not distinguish among the population, and typically enroll the entire population, including persons with developmental disabilities in managed care. Only two states specifically exclude persons with developmental disabilities in managed care. Connecticut, which has a mandatory Medicaid managed care for children on SSI, excludes all individuals who are clients of the state Developmental Disabilities agency. Ohio, which has a specialized managed care program for people with disabilities, excludes individuals who have developmental disabilities diagnoses from this program, based on an assessment at the time of enrollment. However, several other states essentially exclude persons with developmental disabilities from enrolling in managed care since they do not allow those being served through Home and Community-Based Services Waivers or any other type of developmental disability waiver to enroll in a managed care plan.

States enrolling people with disabilities into Medicaid managed care use different managed care arrangements, with 32 states offering at least one capitated plan that includes people with

¹ Those states not responding include Iowa, Maryland, Mississippi, Montana, New Mexico, North Carolina, South Carolina, and Vermont.

disabilities and 22 offering a primary care case management (PCCM) program for this population. While there are a small number of states that have developed specialized or targeted programs for persons with disabilities, standard capitated HMO models are most common, although they may add special features for persons with disabilities. Some states prefer to use fee-for-service PCCM programs, or have both capitated and fee-for-service managed care. Managed care models may also vary geographically within a state. If there is geographic variation, most common is capitated programs in urban areas and fee-for-service programs in rural areas, due to limited numbers of providers in rural areas.

Variation by geographic region within a state may also occur related to whether enrollment in managed care is mandatory or voluntary, and this may differ between the TANF and SSI populations. For example, in Montana, the TANF population must enroll in a capitated managed care organization, but enrollment in capitated programs is voluntary for persons with disabilities. Another variation on this theme is different program structures for SSI beneficiaries and TANF beneficiaries. For example, Arkansas and Georgia require enrollment in fully capitated HMOs for TANF beneficiaries, but in a fee-for-service PCCM program for their SSI populations.

Table 1 below provides information about the care across the 47 states that have any type of Medicaid managed care program. The first column indicates the state, followed by whether they include the SSI population in Medicaid managed care. The third column indicates whether there is a capitated managed care program that includes the SSI population, followed by columns indicating whether the capitated program is mandatory or voluntary and whether behavioral health is carved in or out of the capitated program. The sixth column indicates whether there is a fee-for-service PCCM program that includes the SSI population, followed by a column indicating whether the PCCM program is mandatory or voluntary. The final column indicates any special notes that are important regarding exclusions or other key issues for the SSI population.

Table 1: Information about States with Medicaid Managed Care Programs

State	Enroll SSI	Capitated	M / V	BH	PCCM	M / V	notes
AL	yes	yes	mand	in	yes	mand	HCBS or group homes excluded
AZ	yes	yes	mand	in	no	NA	
AR	yes	no	NA	NA	yes	mand	
CA	yes	yes	both	out	yes	vol	
CO	yes	yes	mand	out	yes	mand	
CT	yes	yes	mand	in	no	NA	DD excluded
DE	yes	yes	mand	out	no	NA	
DC	yes	yes	vol	in	no	NA	for CSHCN only
GA	yes	no	NA	NA	yes	mand	HCBS excluded
HI	no	NA	NA	NA	NA	NA	
ID	yes	no	NA	NA	yes	mand	
IL	no	NA	NA	NA	NA	NA	
IN	yes	yes	vol	in	no	NA	
IA	no	NA	NA	NA	no	NA	
KS	yes	no	NA	NA	yes	mand	
KY	yes	yes	mand	out	no	NA	

LA	yes	no	NA	NA	yes	mand	
ME	no	no	NA	NA	NA	NA	
MD	yes	yes	mand	in	no	NA	
MA	yes	yes	mand	in	yes	mand	
MI	yes	yes	both	out	no	NA	CSHCN program voluntary
MN	yes	yes	vol	in	no	NA	
MS	yes	yes	vol	out	no	NA	
MO	no	NA	NA	NA	NA	NA	
MT	yes	yes	vol	out	yes	mand	
NE	yes	yes	mand	out	yes	mand	all on waivers excluded
NV	no	NA	NA	NA	NA	NA	
NJ	yes	yes	mand	in	no	NA	
NM	yes	yes	mand	in	no	NA	
NY	yes	yes	mand	in	yes	vol	all on DD waivers voluntary
NC	yes	yes	mand	out	yes	mand	
ND	no	NA	NA	NA	NA	NA	
OH	yes	yes	vol	in	no	NA	DD diagnoses excluded
OK	yes	yes	mand	out	no	NA	HCBS excluded
OR	yes	yes	mand	in	yes	mand	
PA	yes	yes	mand	out	yes	mand	
RI	yes	yes	vol	in	yes	vol	only for children on SSI
SC	yes	yes	vol	out	yes	vol	
SD	yes	no	NA	NA	yes	mand	
TN	yes	yes	mand	out	no	NA	
TX	yes	yes	vol	in	yes	vol	
UT	yes	yes	mand	out	yes	vol	
VT	yes	yes	mand	in	no	NA	
VA	yes	yes	mand	in	yes	mand	
WA	no	NA	NA	NA	NA	NA	
WV	yes	no	NA	NA	yes	vol	
WI	yes	yes	vol	in	no	NA	excludes HCBS

Behavioral health services are an area of concern for managed care plans, and obtaining appropriate mental health and substance abuse services can be particularly challenging for people with disabilities, as many providers have no experience with the population. States use very different structures for providing behavioral health care to their managed care enrollees, and different managed care plans also use different behavioral health mechanisms. With PCCM programs, behavioral health can be fee-for-service or the state can contract with a behavioral health managed care organization to provide all behavioral health services for Medicaid beneficiaries on a capitated basis. However, with the PCCM model behavioral health is typically not integrated with physical health, although the PCP may be “expected” to coordinate care as part of his or her PCCM program case management fee.

With capitated programs, there are different mechanisms for dealing with behavioral health, both at the state level and at the managed care organization level. At the state level, the Medicaid agency may include the behavioral health portion of the capitation in the overall HMO capitation payment and hold the HMO responsible for the risk. In this case, the Medicaid agency may require that the HMO provide behavioral health care directly. They may also allow the HMO to

subcontract behavioral health to a behavioral health managed care organization. On the other hand, the state Medicaid agency may directly contract with a behavioral health managed care organization for the entire state and not hold the HMO responsible for behavioral health, but require that the HMO provide evidence of care coordination between physical and behavioral health. As shown in Table 1 above, of the 32 states with capitated managed care programs for persons with disabilities, 18 of those states “carve in” behavioral health and include behavioral health in their capitation payments to HMOs. In 14 states, behavioral health is “carved out” of the HMO capitation rate and is provided directly to a behavioral health managed care organization that is at risk for behavioral health services. In the 18 states that include behavioral health in the HMO capitation, some or all of the HMOs in each state may elect to subcontract the services out to a behavioral health organization rather than provide them directly if the state Medicaid agency allows this. However, no matter what organization provides the behavioral health care, the organization receiving the behavioral health portion of the capitation from the Medicaid agency is at risk for and responsible for the provision of the behavioral health services.

Comment [s2]: Sentence needs something

In terms of coordination between physical health and behavioral health, it is likely that the services will be most coordinated if there is a model that includes services provided by the same organization, but this has become less common with the advent of behavioral health managed care organizations. In addition, HMOs are traditionally not considered to have expertise in delivering behavioral health services. Although states can develop mechanisms to require evidence of coordination of care, it is disappointing that although behavioral health is a major challenge for persons with developmental disabilities, there is little evidence of integration between behavioral health and physical health in most states.

Identifying Persons with Developmental Disabilities

States appear to find it impossible to identify persons with developmental disabilities unless they are being served by the state developmental disabilities system. While Medicaid programs can identify people receiving Medicaid benefits by Medicaid eligibility categories, the inability of state Medicaid programs to provide accurate information to health plans about new members is well-documented[31]. No state Medicaid agency has developed a mechanism to identify persons with developmental disabilities, although they can identify the overall SSI population. No state developmental disabilities agency has developed a mechanism to identify persons with developmental disabilities unless they are receiving state developmental disabilities services or on the waiting list. While states often obtain Medicaid encounter data, these data have not been used to identify populations by diagnosis or disability type. It appears that unless the Social Security Administration begins to document the reason for SSI benefits, state Medicaid departments will be unable to obtain these data.

Determining Medical Necessity

We asked how the Medicaid agency defined medical necessity in the managed care contract, as we hoped to find how states take into account the habilitative and maintenance services used by persons with disabilities that are not focused on recovery or rehabilitation. What is considered medically necessary for a person with a developmental disability does not always fit within the medical model or a strict definition of medical necessity. Many services used by persons with developmental disabilities such as ongoing physical and occupational therapy, are not restorative, but will help to maintain functioning. Most states indicated that medical necessity

was defined in the contract between the state and the managed care organization. If a definition was provided, it was relatively general, such as services are medically necessary if they “create optimal level of functioning” (Connecticut) or “appropriate and necessary health care services which are rendered for any condition which, according to generally accepted principles of good medical practice, requires the diagnosis or direct care and treatment of an illness, injury, or pregnancy-related condition, and are not provided only as a convenience. Services must be sufficient in amount, duration and scope to reasonably achieve their purpose (Virginia).” Importantly, most states indicated that medical necessity criteria are driven by clinician determination and vary by service type.

However, even if a service is considered reasonable and necessary, coverage may be limited if the service is provided more frequently than allowed under the managed care policy or a clinically accepted standard of practice. Concern among persons with developmental disabilities and their advocates are that habilitative services will be limited within Medicaid managed care under the guise of strict medical necessity criteria. The goal is to have very broad medical necessity criteria that incorporates maintenance of functioning as well as recovery and rehabilitation and is determined by the PCP or other clinician who knows the patient and his/her situation.

Managed Care Enrollment and Choice Counseling

When enrolling people with disabilities into managed care, using an enrollment broker to counsel beneficiaries and answer their questions about enrollment was common. Of the 32 states that enroll persons with disabilities in managed care, 21, or about two-thirds, used an enrollment broker. In most cases, the enrollment broker is a firm that specializes in this activity for the entire Medicaid population, and does not have a particular focus on disability. A few states do add some unusual or special features to their managed care enrollment programs (beyond having a TDD or TTY line or making sure the enrollment broker has some basic disability training) to better support persons with disabilities. The special enrollment features we were able to uncover included home visits by enrollment staff for persons with disabilities (Maryland), contracting with disability agency providers to conduct managed care enrollment (New Mexico), special disability training for enrollment staff (Vermont), giving people with disabilities additional time to choose a managed care plan (Utah), and having special telephone “help lines” or ombudsmen to answer questions for people with disabilities, as well as continuity of care forms to assist in enrollment (Oregon). Typically, if people with disabilities do not select a managed care option, they are enrolled in a managed care plan that includes a PCP in their geographic area or one who has previously served them. A common practice within states that use PCCM programs is to allow people with disabilities to select a specialist to serve as their PCP when they enroll in managed care. Of the states that have a PCCM program, all but seven (Virginia, Rhode Island, South Carolina, South Dakota, Kansas, Arkansas, and California) allow this option. New Jersey, due to a specialized primary care option within its capitated managed care plans (to be discussed below) is the only state we were able to find in which specialists can serve as PCPs for persons with developmental disabilities.

State Methods of Financing Managed Care

The methods states use to determine capitation rates were discussed earlier in this document. Our survey indicated that most states have not yet moved to full risk adjustment. Among the 32 states

with capitated managed care programs, more than half (17) have a single payment rate for the SSI population, which is typically adjusted based only on age, gender and geographic location. The remaining 15 states did use some type of risk-adjusted payment rates for people with disabilities. Table 2 below identifies these states, the type risk adjustment used, and, if risk adjustment is based on diagnoses, what diagnoses are included.

Table 2: States Using Risk Adjustment

State	Type of Risk Adjustment	Diagnoses Adjusted for
CA	diagnoses	AIDS
CO	utilization	
DC	diagnoses	CSHCN
IN	diagnoses	Multiple diagnoses
MD	diagnoses	Multiple diagnoses
MA	Diagnoses, utilization	AIDS, severe physical disabilities, medically fragile foster children
MI	diagnoses	Multiple diagnoses; CSHCN
MN	diagnoses	severe physical disabilities
NE	utilization	
NY	diagnoses	Multiple diagnoses
OH	diagnoses, utilization	Severe physical disabilities
TN	utilization	
UT	diagnoses	AIDS
VA	diagnoses	Multiple diagnoses
WI	diagnoses	Multiple diagnoses

Among the 15 states using risk adjusted capitation payments, diagnostic risk adjustment was used in 12 states and risk adjustment based on service utilization was used in four states (Ohio uses both methods, depending on the managed care plan). As indicated above, six states use full diagnosis-based risk adjustment (Indiana, Michigan, Maryland, New York, Virginia, Wisconsin), and pay different capitation rates for individuals based on their diagnoses. Most of these states using overall diagnostic-based risk adjustment used the CDPS, although Maryland uses ACGs. Rather than base capitation rates on diagnosis-based risk adjustment, four states use prior service utilization to build their rates.

Six states have special rates for high-cost diagnoses or specialized managed care programs. Three states have special capitation rates for severe physical disabilities (Ohio, Massachusetts, Minnesota) and three have special rates for AIDS (Massachusetts, California, Utah). Two states have specialized managed care plans for children with severe disabilities and special health care needs (Michigan, District of Columbia) and have capitation rates developed for this population. Risk adjustment can be especially challenging for persons with developmental disabilities, as developmental disability encompasses a range of different diagnoses, and there can be extensive variation in costs, depending on both diagnoses and the severity of those diagnoses. However, risk adjustment mechanisms such as the CDPS allow for adjustment based on different types of diagnoses, the number of diagnoses, and the severity of the diagnoses, ensuring that the capitation rates for persons with developmental disabilities are adequate.

Among the states with fee-for-service PCCM programs that include people with disabilities, most do not pay an additional fee to PCPs for managing care. However, if a case management fee is paid, most common is a small per member per month payment (such as \$3.00 paid to the PCP each month for each member with a disability). A less common option was a higher payment rate to the PCP for each visit made by a person with a disability. Only one state, Massachusetts, indicated using enhanced payments for PCP visits within its fee-for-service PCCM program.

Disability-Specific Requirements and Features

Several Medicaid agencies have implemented disability-specific requirements for managed care organizations. The three most common were required case management for people with disabilities, that persons with disabilities have a full screening and needs assessment prior to enrollment, and that each persons with disabilities been seen for a complete physical examination within a specified period after their enrollment in managed care (typically 60 or 90 days). Table 3 below identifies the states that have these disability-specific requirements, as well as any other state-specific requirements for persons with disabilities.

Table 3: States with Disability Specific Requirements in Managed Care

State	Case Mgmt.	Needs Assessment	Physical Exam within specified time
AZ	Yes	No	No
CA	No	Yes	Yes
DC	Yes	Yes	Yes
IN	Yes	Yes	Yes
CO	No	Yes	Yes
DE	Yes	Yes	No
NE	No	Yes	Yes
NJ	Yes	Yes	Yes
KY	Yes	Yes	Yes
MD	Yes	Yes	Yes
MI	Yes	No	Yes
MA	Yes	Yes	Yes
MN	Yes	Yes	Yes
NY	No	No	Yes
OH	Yes	Yes	Yes
OR	Yes	Yes	No
PA	Yes	Yes	Yes
RI	Yes	Yes	No
TN	Yes	No	No
TX	Yes	No	No
UT	No	Yes	Yes
VT	Yes	No	No
WI	yes	Yes	Yes

Beyond the features listed above, and the model programs discussed in the next section of this document, we were unable to find many specialized features for persons with disabilities in

general, and even fewer targeted to persons with developmental disabilities. Three states (Colorado, Oregon, Massachusetts) require that HMOs conduct an annual quality improvement activity focused on the SSI population. Colorado and Massachusetts also expect managed care organizations to develop and monitor clinical protocols for certain chronic conditions (such as asthma or diabetes). In Delaware, HMOs are not allowed to change the care plans of persons with disabilities without a home visit. Pennsylvania tries to enroll physicians who have traditionally treated persons with disabilities into their networks; Pennsylvania also requires each managed care organization to have a special needs unit focused on persons with disabilities. Nebraska uses their enrollment broker to monitor access to specialty care for persons with disabilities. Rhode Island and Wisconsin require that their managed care plans have an ombudsman devoted to persons with disabilities.

Almost all states require that managed care plans conduct a satisfaction survey of their members, typically annually or at least every two years. People with disabilities and persons with developmental disabilities are typically included in the survey population, but except for in the case of specialized managed care programs for persons with disabilities, there was no indication that members report whether they have a disability, and therefore managed care plans are unable to analyze the surveys separately for people with disabilities.

MANAGED CARE MODELS FOR PERSONS WITH DISABILITIES

Our research allowed us to identify some unique managed care programs serving persons with disabilities. While models designed specifically for persons with developmental disabilities are limited, often persons with developmental disabilities are included in a models designed for a broader population of persons with disabilities.

Seven of these models are discussed below. Some were developed specifically for persons with developmental disabilities, while most serve a broader population and include persons with developmental disabilities. The programs selected range from small, targeted managed care programs that provide all services directly to specialized case management programs that contract with traditional HMOs. We also include two states that have implemented special features for persons with disabilities within statewide Medicaid managed care. The models below show that creative models of managed care and use of capitation can support early intervention, care coordination, and the development of specialized services targeted to meet the needs of specific populations. We begin with a brief overview of each program, followed by a more detailed description.

1. Community Medical Alliance, Massachusetts

Program Overview

Program Type: Specialized clinical program within Medicaid HMO (formerly a separate managed care organization only serving persons with disabilities)

Population focus: individuals age 18 – 64 with HIV/AIDS, severe physical disability, developmental disability; individuals under age 18 who are medically fragile foster children or have serious emotional disorders

Origination: 1992 as full-service managed care organization, capitated contract with state Medicaid agency to serve persons with late-stage AIDS and severe physical disability; developmental disabilities program began in 1996; in 1999 became a specialized clinical program within Medicaid HMO

Model: primary care physician/nurse practitioner team; home visits and primary care at home by nurse practitioner

Mandatory/Voluntary: mandatory managed care enrollment; CMA program is voluntary and available only if enrolled in one HMO

Region: available only in parts of state

Enrollment: 400 - 500

Financing mechanism: HMO receives the capitation payment from Medicaid; subcontracts with CMA on capitated basis; capitation rate is risk adjusted for AIDS, severe physical disability, medically fragile foster children; standard SSI rate for other persons with disabilities, including persons with developmental disabilities

Includes dual eligibles: no (except for those with severe physical disabilities enrolled before 1996)

Behavioral health: carved-in to managed care contract for CMA members but not for other HMO members; specialized network

Inpatient care: included

Long-term care: not included

24-hour availability: yes

Case management system: nurse practitioner as care manager

Special features: home-based primary care; disability-specific crisis intervention services; flexible use of capitation; disability-specific language in provider contracts; behavioral health specialists share care management; integrated physical health and behavioral health

Description

Community Medical Alliance (CMA) was the first fully capitated managed care plan in the nation developed specifically to serve people with disabilities. CMA has its origins in the 1970s in the Urban Medical Group, a non-profit physician and nurse practitioner group practice in Boston that specialized in providing care to frail elders and adults with severe physical disabilities[32]. This group of clinicians pioneered the use of nurse practitioner/physician primary care teams, with nurse practitioners providing much of the primary care to frail elders in their homes or in nursing homes[33]. In 1982, the clinical model began being used with people with severe physical disabilities who were moving from institutional care to independent living. In this model a private practice group of nurse practitioners and physicians provide primary care and care management to these individuals in their homes, and coordinated and authorized all care. A clinician was available for routine care and consultation on a 24-hour per day basis. Massachusetts Medicaid paid for the primary care on a fee-for-service basis, with enhanced fees

Comment [s3]: Language / sentence structure

for home care and case management. The program continued on a fee-for-service basis until 1992, when CMA entered into a capitated contract with Medicaid. At the same time, a separate group of nurse practitioners and physicians began providing the equivalent services to persons living with late-stage AIDS, also using capitation under a special contract with Medicaid[32]. In the mid-1990s, the program was expanded to include other persons living with HIV/AIDS. As a full-service HMO, CMA had all of its own services, including claims payment, utilization management facilitated by nurse practitioners, provider network and contracts, member services, and all other aspects of a full-risk HMO.

In 1996, CMA collaborated with the Massachusetts Department of Mental Retardation to begin a similar model for persons with developmental disabilities. Any person age 18 or older is eligible for the program as long as they have a developmental disability and are receiving Medicaid benefits and have no other health insurance. Clinical management is provided by a nurse practitioner who monitors medical problems, conducts home visits, primary care in the home, staff training in developmental disabilities residential programs, 24-hour on-call services, provides assistance with making appointments, transportation and referrals, evaluates service plans, and facilitates service authorization, taking that out of the hands of non-clinician who is unfamiliar with the population. A specialized provider network for persons with developmental disabilities, including mental health providers who specialized in developmental disabilities, was under development. In addition, a specialized behavioral health crisis team was developed through the CMA program to manage mental health and substance abuse emergencies. This program included emergency mental health professionals trained to deal with persons with developmental disabilities, severe physical disabilities, and HIV/AIDS. Creation of the crisis team led to a \$5.00 per member per month decrease in costs during its first six months of operation[34].

A challenge for CMA was the capitation rate: for those with developmental disabilities not eligible for the severe physical disabilities program, the capitation rate was the standard SSI rate. While this rate was sufficient for some enrollees with developmental disabilities, it was not sufficient for all, particularly those with other co-morbidities or severe mental health or behavioral disorders. In addition to a lower than needed capitation rate for the developmental disabilities program, the enhanced rates for severe physical disability and advanced AIDS were declining: as CMA was doing a good job managing care and coming in under or at the capitation, Massachusetts Medicaid would decrease capitation rates to a point where it became very difficult to manage. A second challenge was the size of CMA: because of the clinical criteria and because of the need to have nurse practitioners go to people's homes to provide care, the program was not available statewide. At its peak prior to 1999, CMA was never larger than about 400 – 500 members; however, it included all of the functions and positions of an HMO, leading to high administrative costs.

In 1999, in part due to financial pressures, the CMA HMO was purchased and was integrated into Neighborhood Health Plan (NHP), a Medicaid HMO founded in 1987 by a group of community health centers across Massachusetts. NHP had a membership of almost 100,000 Medicaid enrollees in 1999, including over 8,000 SSI disabled enrollees, for whom they received the standard SSI capitation rate. In the merger, while CMA maintained its clinical programs, there was not a need for two sets of infrastructure and administrative support. Currently, the

specialized clinical programs within CMA retain their structure, including the developmental disabilities program, but CMA is no longer a freestanding HMO. The CMA programs are integrated into NHP, which provides all administrative functions as the HMO of record. Massachusetts requires that all SSI disabled Medicaid recipients who are not dual eligibles enroll in managed care. Individuals can choose the state's primary care case management program or an HMO. For individual's who select an HMO, one option is NHP. If an individual meets the clinical criteria, he or she will be enrolled in one of the CMA programs within NHP. Capitation rates vary based on the enrollees' diagnosis and health status. To obtain the higher rates for the severe physical disabilities program, a member must require personal care services and have functional quadriplegia, or have paraplegia and other complex medical conditions or mental health or substance abuse disorders. The HIV/AIDS program also has a higher capitation rates based on clinical criteria. All capitation rates are determined through a comprehensive clinical assessment prior to enrollment. For those who do not meet the criteria for a higher capitation rate, including most persons with developmental disabilities, there is a single SSI capitation payment.

The keys to the CMA program, in addition to clinically-based capitation rates for some populations, include the following: flexible use of capitation to provide services based in the home and community and discourage inpatient and emergency care and, the role of the nurse practitioner who provides comprehensive initial assessment upon joining the plan, first response to new medical problems, frequent home visits, and overall case management and care coordination. A special network of providers, with expertise in HIV/AIDS or severe physical disability, serves each program. The two programs have some differences, but were both based on this concept.

In the CMA developmental disabilities program within NHP clinical management remains the purview of a nurse practitioner acting as a physician extender. Many basic health services are provided to enrollees with developmental disabilities in their homes, and the nurse practitioner authorizes and facilitates coordination of all services. Enrollees have access to the entire NHP provider network, which includes the specialized mental health providers recruited for their developmental disabilities expertise.

Despite many initial challenges, CMA and NHP have been able to integrate the functions of a clinically based managed care program into a larger, standard HMO model of care. However, because of the many disability-specific features of CMA, as the CMA/NHP integration moved forward, NHP needed to create new infrastructure to support the clinical programs, including developing a health risk assessment process, revising their referral and authorization system, and creating a new structure for provider network management[35]. Within NHP, there are now different systems of care and a continuum of care management models from the CMA highly intensive model with the nurse practitioner at the hub to a more traditional case management and utilization review model of managed care. In addition to the HIV/AIDS, severe physical disabilities, and developmental disabilities programs, there are also "CMA-like" programs for medically fragile foster children and youth with serious emotional disturbances. Although NHP holds all provider contracts, specified "CMA provider" contracts include much of the disability-specific language that was originally in the CMA provider contracts, as well as specifications about participation in multi-disciplinary team meetings, on-call and coverage responsibilities,

and working with nurse practitioners, primary care providers and care coordinators[35]. In addition, although NHP uses a behavioral health carve-out, for individuals enrolled in the CMA programs, behavioral health is carved in and fully integrated with physical health, with special mental health and substance abuse provider contracts.

2. Developmental Disabilities Health Alliance, New Jersey

Program Overview

Program Type: specialized care provision and case management system for persons with developmental disabilities

Population focus: persons of all ages with developmental disabilities

Origination: first services in 2000

Model: private health care company that contracts with HMOs and other entities to provide primary care, mental health services, and care management

Mandatory/Voluntary: mandatory managed care enrollment; DDHA program is voluntary and available only if enrolled in an HMO that contracts with DDHA

Region: six sites statewide; three HMO contracts

Enrollment: 750 individuals through Medicaid HMO contracts

Financing mechanism: subcontract from HMOs, have both capitated and fee-for-service subcontracts

Includes dual eligibles: yes

Behavioral health: carved-in to HMO contract; provided by DDHA

Inpatient care: not included

Long-term care: not included

24-hour availability: yes

Case management system: nurse practitioners

Special features: physicians with specialization in developmental disabilities serve as PCPs; close working relationship with state Division of Developmental Disabilities; integrated physical health and behavioral health

Description

Developmental Disabilities Health Alliance (DDHA) is a privately owned, statewide health care company with six sites that provides primary care, mental health services, and care management to persons with developmental disabilities. DDHA was created in 1997 and began serving persons with developmental disabilities in 2000, with the goal of having specialty physicians in developmental disabilities address the unmet health and mental health needs of people with developmental disabilities in New Jersey. DDHA comprehensive primary care sites each serve a distinct region of the Division of Developmental Disabilities, with at least one office in each region. DDHA staff work closely with state developmental disabilities community services. DDHA takes a teamwork approach to care and includes physicians, nurse practitioners, psychologists, social workers, and administrative support staff.

Managed care enrollment is mandatory for approximately 95,000 of the state's SSI recipients with disabilities. Recipients can select one of five HMOs. If recipients with developmental disabilities select an HMO that contracts with DDHA, they will receive their primary care and

case management services through DDHA. Three HMOs in New Jersey, AmeriChoice, Horizon New Jersey Health, and University Health Plan, currently contract with the DDHA to provide these care management services to their enrollees with developmental disabilities. Current enrollment in DDHA through Medicaid managed care HMOs is about 750 individuals. In addition to the HMOs, state agencies and health systems contract with DDHA to provide health and case management services, and DDHA serves another 2,300 –2,500 persons with developmental disabilities through different financial arrangements[36]. For their Medicaid managed care enrollees, the state of New Jersey contracts with the HMOs, who then sub-contract with DDHA to provide a set of services to their enrollees on either a capitated or fee-for-service basis. For dual eligibles, DDHA bills Medicare on a fee-for-service basis, and they also have a large fee-for-service population for whom they provide care management.

DDHA's focus is primary medical care and care coordination. Care coordination is provided on-site at the DDHA office locations. DDHA physicians rotate among the DDHA sites. All care is office-based, and no DDHA services are provided to individuals in their homes. Care management is embedded within primary care, and DDHA provides a "medical home" for persons with developmental disabilities, offering primary care, care management, mental health treatment, immunizations, nutritional counseling and planning, routine gynecological care, patient and family education, health maintenance and promotion, and referrals to specialty care. The care coordination component includes problem identification and clarification, initial assessment, resource identification and assistance accessing resources, scheduling and appointment monitoring, assistance interacting with other professionals, interagency communication and planning, assistance with treatment compliance, case communication, documentation assistance, crisis stabilization, behavioral consultation and assistance with implementing behavioral programs, individual and family counseling, and parent and family training and consultation. Depending on whether the enrollee receives primary care through DDHA, there are two different models of care coordination. For those enrolled through the Medicaid managed care HMO program who receive their primary care through DDHA, nurse practitioners serve as care coordinators. For those receiving DDHA case management services, but not primary care, care is coordinated by social workers. DDHA is planning to move toward a more flexible care coordination system that determines type of care coordinator based on client needs[36].

DDHA conducts satisfaction surveys focusing on access to care, quality of care, overall satisfaction with DDHA, and consumer health status. Results have been positive in all areas, although there are some opportunities for improvement. Over 90% of consumers surveyed indicated excellent access to care. However, despite an average reported waiting room period of only six minutes, only 79% of respondents rated access to waiting or exam rooms as excellent, which may reflect some other type of access problems, such as problems with physical accessibility or overcrowding. Almost all respondents were able to schedule appointments within two weeks. In terms of how DDHA handles situations, 95% and 93% of respondents agreed that phone calls and emergencies, respectively, were handled efficiently. In terms of quality of care, 82% said quality of their medical care was excellent, 90% felt their questions were answered, and 90% felt the office staff was courteous and professional. Over 95% of consumers indicated overall satisfaction with the services and the facility in which they received care [36].

In moving toward Medicaid managed care for persons with developmental disabilities, the state planning process included a task force consisting of stakeholders whose only focus was persons with developmental disabilities who would be required to enroll in managed care. This task force provided input to the state when they drafted the RFP to which HMOs could respond to be a contractor. As a result, there were important accommodations for persons with developmental disabilities in the request that HMOs knew that they would have to respond to. Some of these included a carve-in for behavioral health services for persons with developmental disabilities, a role for specialty networks to serve as providers, exemptions from managed care if networks did not include necessary providers, use of specialists as primary care providers for persons with developmental disabilities, required care coordination and case management, an individualized health treatment plan annually, disability-specific quality improvement measures, a set of requirements related to the Americans with Disabilities Act accessibility, communications accommodations, disability-specific education programs, linkages with developmental disabilities state agencies and community organizations, risk adjusted capitation rates, and incentives to enroll dual eligibles in managed care[37].

3. Independent Care, Wisconsin

Program Overview

Program Type: Specialized Medicaid HMO for persons with disabilities who are SSI recipients

Population focus: all SSI recipients with disabilities ages 15 – 64

Origination: 1994

Model: fully capitated HMO with all acute care services

Mandatory/Voluntary: mandatory managed care enrollment for 60 days; can disenroll after 60 days and return to fee-for-service.

Region: Milwaukee county

Enrollment: 6,000 – 7,000

Financing mechanism: full capitation from state; single rate; arrangement with state Medicaid agency that includes risk corridors

Includes dual eligibles: no

Behavioral health: carved-in to I-Care by state; I-Care subcontracts to behavioral health managed care organization which is paid fee-for-service

Inpatient care: included

Long-term care: not included

24-hour availability: yes

Case management system: three levels of care coordination done by social workers or nurses, with discipline or care coordinator and level based on intensity of disability and health and social service needs

Special Features: active consumer advisory board, recruit providers previously serving members; meetings with providers; extremely detailed electronic care plan with outcome targets; weekly meetings between HMO and behavioral health carve-out

Description

Independent Care Health Plan (I-Care) is a specialized HMO that provides the full range of acute care through Medicaid for persons with disabilities who are SSI recipients. The state of Wisconsin has a unique managed care enrollment structure in Milwaukee, the county where I-

Care operates. Although managed care enrollment is mandatory in this county, it takes an all in/opt out enrollment model. This model includes a mandatory 60-day initial enrollment in an HMO. During the 60-day mandatory enrollment period, people have time to try out the HMO and determine if they would like to continue their enrollment. After the initial 60-day enrollment period, enrollees have an opportunity to disenroll and return to fee-for-service from days 61 to 120 after initial enrollment. If they choose not to return to fee-for-service during those 120 days, they must remain in the HMO until the end of 12 months, at which point they can again disenroll from the HMO. This includes all SSI disabled enrollees in that county, excluding those living in an institution or nursing home, or those in a HCBS waiver program, who are excluded from managed care enrollment. The all in/opt out option is viewed a compromise between universal/mandatory enrollment, which offers a choice of HMOs but not an opportunity to choose or remain in fee-for-service, and voluntary enrollment, which does not provide the initial level of participation required to attract managed care organizations. All in/opt out allows consumers multiple opportunities to choose different plans or to return to fee-for-service. It also allows consumers with disabilities the opportunity to try a specialized HMO for people with disabilities, such as I-Care, as well as other managed care options, and to disenroll if the program does not work for them.

I-Care began in 1994 with a three-year federal grant. The purpose of the grant was to conduct a research and demonstration to determine whether managed care could work for persons with disabilities. I-Care is a joint venture arrangement of Humana Health Care Plan of Wisconsin and the Milwaukee Center for Independence, an independent living center that serves primarily persons with developmental disabilities. I-Care began with some knowledge about the population, but has learned a great deal over the years about the spectrum of disability and chronic illness. I-Care provides access to medical, dental, behavioral health, vision, prescription drug coverage and social services through a unique care management model. Their behavioral health services are managed through a carve-out model. As a plan developed and devoted only to people with disabilities, the mission of I-Care is to improve the quality of life for individuals with unique and complex medical, behavioral and human service needs while providing value to customers and stakeholders, and respecting the dignity of people with disabilities. In addition, they use capitation to reallocate resources and to improve coordination between and within health and social service delivery systems.

Eligibility for I-Care includes being age 15 or older, residing in Milwaukee County, and receiving SSI and Medicaid benefits. Only people with disabilities are eligible to enroll, including persons with developmental disabilities. Although I-care began as a joint partnership between an independent living center the primarily serves people with developmental disabilities, a challenge is that many persons with developmental disabilities cannot enroll because the state excludes persons with developmental disabilities in HCBS waiver programs from managed care. For several years, both developmental disabilities administrators and I-Care administrators have been trying to develop a mechanism to allow these individuals to enroll in program.

I-Care provides a complete and coordinated health care program for individuals who meet their criterion. A care coordinator will work with individuals to choose a doctor and a hospital, find appropriate medical help, find services after a hospital stay, sign up for social services, and

identify community resources. I-Care began very slowly, with a small number of enrollees and has grown to over 6,000 members. I-Care began with small partnerships, targeting providers serving people with disabilities, developing contracts with them, and adding and including new providers as people with disabilities or providers expressed an interest. As a result, for several years, as new members joined, I-Care would consider adding their providers to the network, provided they could meet their criteria and were willing to work with I-Care and follow their rules, including participating in disability training and quality improvement activities. This allowed people with disabilities to enroll in I-Care without losing their provider relationships. However, if providers are unwilling to conform to I-Care's standards, they cannot be part of the network. Today, I-Care includes most physicians and clinics in Milwaukee County who understand I-Care, its mission and its expectations. The plan has made a concerted effort to establish responsive systems of care, including provider contracting decisions, risk arrangements and management decisions that promote flexibility and individual decision-making, and care coordination systems that can address the varied and complex needs of individuals with multiple disabilities.

I-Care uses an unusual model of care coordination. Case managers are either social workers or nurses, and level of care coordination is based on members needs. There are three different levels of care coordination, which are based on intensity of disability and health and social service needs. After initial referral, each member receives a full health assessment by a case manager within sixty days of enrollment that includes both a full physical and social service assessment and includes a battery of standardized tools, such as the London Handicap Scale. Based on the results of this assessment, members are placed into one of the three care coordination or case management levels. The first level consists of staff with bachelors' degrees and a social service background that answer telephone calls and provide non-intensive services. The second level consists of Master's level social workers and RN case managers who coordinate services for enrollees with more complex needs. The third level includes an intervention specialist who provides care coordination for all enrollees with exceptional needs and severe medical problems. Examples of the medical problems of the caseload of the intervention specialists include renal failure, uncontrolled diabetes, amputations, arthritis, degenerative joint disease, cancer, sickle cell, chronic pain and depression, developmental disabilities and severe behavioral health problems, and joint replacements. After each member is assigned to the appropriate case management level, the case manager works with a primary care physician to build a full care plan and implement the care plan. If level of needs changes, there is the ability for a member to move between the different levels of case management.

I-Care receives a capitation payment from Wisconsin Medicaid. The capitation rate has been a major challenge for I-Care, but they have been able to work with their capitation rate to become successful, and have doubled in size from 1997 to 2004, today enrolling over 6,000 members. There have been several different payment mechanisms used to determine the capitation rate. I-Care has used the capitation flexibly, and even without risk adjustment, was able to achieve financial stability despite a capitation payment of less than \$600 per member per month, with approximately \$30 - \$40 of this going to care coordination services. Because there is no risk adjustment by disability type or level of severity of disability, I-Care does have an arrangement with the state that includes risk corridors[37], with a certain level beyond which they cannot be held financially responsible, and a level beyond which they cannot profit.

Although I-Care is a full-service HMO and has its own systems for utilization management, claims payment, provider credentialing, etc., some services are not provided in-house. Because they wanted to ensure full integration between physical health and behavioral health, I-Care initially planned to provide its own behavioral health services. However, because they were already taking on a great deal in developing a full-service HMO and did not have behavioral health expertise, I-Care elected to carve-out its behavioral health services to Aurora Behavioral Health in Milwaukee, a behavioral health carve-out plan that worked with several HMOs, was willing to contract with disability-specific providers, and was willing to work with I-Care to make the service work for both sides. Aurora has worked with I-Care to credential disability-specific behavioral health providers, allowing I-Care members access to these providers as well as the full range of behavioral health providers available through the larger Aurora network. Each I-Care case manager has a close relationship with Aurora, and weekly case management meetings are held between the I-Care case managers and Aurora to discuss cases and care plans, review progress, address any concerns, etc. Aurora reports every new episode to ICARE care coordinators and works with them to establish network relationships, make utilization management decisions, and identify the appropriate providers for specific individuals. Aurora also maintains a log of individuals who are frequent users of emergency services. The log includes guidelines for care and special considerations for each frequent user, and is used by the after-hours on-call staff to assist in making referrals for members who need services on nights and weekends. Aurora maintains a list of providers with special expertise in different disabilities, and has educated their providers regarding behavioral health needs for people with disabilities and has developed guidelines for them to follow. In turn, I-Care has also conducted in-service training for the Aurora staff.

Although the management of the behavioral health services is carved out, I-Care retains all risk for behavioral health services and pays Aurora on a fee-for-service basis. The carve-out organization makes the initial utilization management decisions, but ICARE has the ability to over-ride these decisions, because the carve-out is still learning how enrollees with disabilities access and need services. I-Care has had excellent experience with Aurora and has considered sub-capitating the behavioral health carve-out. However, this would give Aurora, rather than I-Care the risk for behavioral health services. For now, one reason that I-Care has elected to retain financial decision-making authority is that, due to their intensive case management system, ICARE has the full picture of what is going on with the member in terms of their need for food, shelter, and support services, and this may alter the utilization decisions.

The state has been very supportive of the I-Care model. The state conducts regular quality monitoring including examining service utilization data and performing random medical chart reviews to look at medical necessity and avoidable hospitalizations. They have developed quality indicators that monitor service utilization for people receiving SSI benefits; they audit inpatient admissions, and managed care plans have to demonstrate adequate access and capacity to serve people with disabilities before a contract is signed with the state.

There was strong involvement in the planning of I-Care by the disability community, particularly the Independent Living Center in Milwaukee. There remains a lot of consumer input, and the state has public meetings and forums for consumers. The state also has a consumer advisory

committee. I-Care also has an ombudsman who helps members navigate the managed care system. I-Care is voluntary program and people can disenroll if they are unsatisfied. Although, some individuals have disenrolled when I-Care has tried to work with them not to use the emergency room, overall, the state and I-Care both report high levels of satisfaction and low rates of disenrollment.

4. Minnesota Disability Health Options

Program Overview

Program Type: Specialized managed acute and long-term program; partnership between HMO and disability services provider

Population focus: adults age 18 and older who would be eligible for nursing home placement due to severe physical disability (includes persons with developmental disabilities if meet the severe physical disability criteria)

Origination: 2001

Model: fully capitated HMO for acute and long-term care

Mandatory/Voluntary: voluntary

Region: four urban counties in the Minneapolis-St. Paul area

Enrollment: 350+

Financing mechanism: HMO receives the capitation payment from Medicaid and/or Medicare; subcontracts with care management organization; Medicaid capitation rates not diagnostically risk adjusted, but paid based on historical fee-for-service experience of population

Includes dual eligibles: yes

Behavioral health: carved-in

Inpatient care: included

Long-term care: included

24-hour availability: yes

Case management system: all members assigned health coordinator (nurse) responsible for overall care coordination and resource coordinator (social worker) to coordinate all non-medical supports; member service coordinator manages administrative details of care coordination and often serves as the central point of contact for member

Special features: active consumer involvement; development of structures by disability-specific organization

Description

The Minnesota Disability Health Options (MNDHO) program, as part of its provision of a broad range of services for people with disabilities, contracts with an HMO (UCare) to provide comprehensive acute and long-term care to people with disabilities. UCare then contracts with a care management organization with extensive experience serving people with disabilities (Axis Healthcare) to perform many of their services. The program serves a population that has primarily severe physical disabilities, but also serves persons with developmental disabilities if they meet the severe physical disability criteria (primarily cerebral palsy and spina bifida). The MNDHO program functions in four urban counties in the Minneapolis-St. Paul area.

Minnesota Medicaid program attempted several times to develop managed care programs for people with disabilities. Their first attempt was mandatory managed care for people with

disabilities as part of their overall Medicaid managed care program for low-income families. This program was unsuccessful due to the complex needs of people with disabilities and inadequate capitation rates. However, Minnesota was successful in the 1990s with the Minnesota Senior Health Options (MSHO) program, which integrates Medicaid and Medicare funding for dually eligible elders. MSHO expands Minnesota's existing mandatory Medicaid capitated managed care program to cover more Medicaid services (specifically a portion of nursing home costs) and merges it with prepaid Medicaid managed care. Capitated Medicare and Medicaid payments are pooled to create a single fund which must be used to cover at least the usual benefits covered by each program but which can be used to obtain services that are outside the range of defined benefits to meet the specific needs of the enrollee, with mandatory care coordination.

Based on the successes of MSHO, the state made a second attempt to enroll people with disabilities into managed care. In this model, counties would receive capitation and take risk, and contract with the providers of their choice. This program was never implemented because the counties could not take the financial risk within the payment parameters offered, it was very difficult to set up the managed care programs within the county government structure, and advocates did not want to include children with disabilities in mandatory managed care. The next step was collaboration between an inpatient rehabilitation hospital and a community-based rehabilitation center to establish Axis Healthcare, a care management program, after several years and significant infrastructure investment, in 1997[36]. Ucare was already serving the TANF and MSHO populations, and agreed to partner with Axis to enroll persons with disabilities. Axis and Ucare then approached the state Medicaid agency to conduct a demonstration to provide a specialized managed care program for people with disabilities, specifically people with severe physical disabilities. Axis then also began a small, pilot care management program in order to further develop their model and to engage consumers and providers.

In 2001, MNDHO began enrollment. After about three years, almost 350 individuals with physical disabilities were enrolled in the voluntary program. Ucare receives the capitation payment from Medicaid and then contracts with Axis to provide care coordination, provider relations, member services, and utilization management to adults with physical disabilities. Persons with developmental disabilities who also have physical disabilities and are not in certain waiver programs can enroll in MNDHO. MNDHO can enroll both Medicaid recipient and dual eligibles; for dual eligibles they receive separate capitation rates from Medicaid and Medicare. However, Medicaid capitation rates are not diagnostically risk adjusted; rather the HMO is paid based on average historical fee-for-service experience of people with physical disabilities and then grouped into multiple rate categories, but not based on disability type. The capitation rate has been used flexibly to provide alternative benefits and home-based services.

The program is completely voluntary. All services are provided through the HMO provider network. Axis provides the care coordination and service authorization for MNDHO members. Through Axis, all members are assigned a health coordinator, a resource coordinator and a member services coordinator. The health coordinator is a nurse who is responsible for overall care coordination; health coordinators have a caseload of about 35 members. Resource coordinators have caseloads of about 70 – 75 members. Resource coordinators are social workers

whose role is to coordinate all non-medical supports, including housing, financial assistance, and health education activities. Member service coordinators have about 70 – 90 members, and assist with the administrative details of service coordination and also often serve as the central point of contact for members. The health coordinator is responsible for meeting with and conducting a comprehensive assessment of each member upon enrollment in MNDHO, and then developing a comprehensive treatment plan in collaboration with the member, that includes regular contact between the health coordinator and member. The treatment plan includes health-related goals and other life goals that would be possible once better health is achieved. All information is maintained in an electronic medical record.

The MNDHO program incorporates six service delivery principles: a holistic focus on the person being served within the context of his or her living system, support system, and health status; maximum enrollee choice and self-direction; integrated service coordination; providers are disability literate and competent to meet the needs of the population; providers continuously strive to improve access of site, equipment, and staff; and support for community-based independent living[38].

There is a strong focus on program improvement. For example, there are ongoing team meetings across UCare and Axis to monitor inpatient care, emergency care, alternative benefits and other clinical issues. In the first year of the program, it was determined that about 40% of inpatient admissions were for three conditions, many of which were potentially preventable. As a result, an urgent intervention model for these conditions was developed and implemented[38]. All aspects of the MNDHO program included extensive consumer involvement, including a pilot project, focus groups and consumer advisory committees. Early evaluations of MNDHO show an increasing level of enrollment over time and low levels of disenrollment. They also indicate good satisfaction, with higher overall satisfaction in almost all areas during the year after enrolling in the MNDHO program than they had during the prior year[38].

Comment [s4]: Sentence needs something

5. The Oregon Health Plan Special Needs Program

Program Overview

Program Type: special features for persons with disabilities in HMOs contracting with Medicaid statewide

Population focus: all SSI recipients with disabilities

Origination: 1995

Model: fully capitated HMOs for all acute care services

Mandatory/Voluntary: mandatory enrollment in managed care

Region: statewide

Enrollment: 50,000+

Financing mechanism: risk adjusted using DPS

Includes dual eligibles: no

Behavioral health: mental health carved out by state to managed behavioral health organization; substance abuse carved in

Inpatient care: included

Long-term care: not included

24-hour availability: yes

Case management system: Exceptional Needs Care Coordination

Special features: individualized choice counseling, continuity of care form; prior authorization for out-of-plan referrals during the transition process

Description

Oregon has taken a broad approach to providing specialized services within managed care for persons with developmental disabilities within their overall Medicaid managed care structure, which may make the program the easiest to implement and to replicate. Oregon requires all people with disabilities to enroll in managed care, unless they are exempted due to being in an institution, are covered by private insurance, or have special needs that cannot be met by the existing managed care delivery system. Oregon Medicaid beneficiaries, include those with disabilities, are expected to choose a managed health care plan, a managed dental plan and a managed mental health provider. While mental health services are carved out of managed health care in Oregon, substance abuse treatment services are carved in to the managed health care plan.

In the early years of the Oregon managed care program, there was no risk adjustment, although the state offered stop-loss insurance to address plan concerns about adverse selection, and there was some evidence that high cost cases were not equally distributed across managed care plans[39]. However, in 1998, Oregon began to use risk adjustment for several populations, including people with disabilities. For people with disabilities, risk adjustment is based upon the Disability Payment System, which used data from Medicaid beneficiaries in five states to develop rates based on the presence of diagnoses that are predictive of future service utilization[12]. The Disability Payment System was modified for Oregon to reflect services not covered, in particularly mental health services to due the carve-out model[39].

Oregon has long used a priority process for determining service needs. This process had to be considered and slightly modified when enrolling people with disabilities into mandatory managed care. The state had to extend coverage to some conditions and benefits appropriate for people with disabilities in order that this population would not lose some of its needed health care services. They also had to begin individualized choice counseling, and the developed a continuity of care form that is used by the choice counselor to ensure that people do not lose important services in the transition to managed care.

The continuity of care form is important, in collaboration with one-to-one choice counseling. Beneficiaries meet, typically for 90 minutes to two hours, with a choice counselor who is trained by the state's disabled services agency in all aspects of managed care enrollment, including the criteria for exemptions from enrollment, information about each health plan, and how the overall program works. Each choice counselor helps the potential managed care enrollee complete a continuity of care referral form and takes the necessary steps to obtain prior authorization for out-of-plan referrals during the transition process. This form and process allows potential members to select a managed care plan that would be a good fit. This is very important since beneficiaries are actually selecting three managed care plans: one for health care, one for mental health care, and one for dental care. The choice counseling and continuity of care form and process eases the transition into managed care and prevents any disruptions in care. The form is sent to the Exceptional Needs Care Coordinator at the plans of the beneficiary's choice, and includes complete information about the immediate and transitional needs of the member.

When Oregon began to require mandatory enrollment of people with disabilities in managed care, medical case management, later termed Exceptional Needs Care Coordination (ENCC), was mandated by the legislature to provide safeguards. Each HMO that contracts with Medicaid is required to develop an ENCC program and hire at least one ENCC. The ENCC's job is to safeguard vulnerable populations by identifying their needs and resolving them through the use of community and social supports. ENCC was a significant change for HMOs. ENCC is allocated a specific portion of the capitation rate within each managed care organization[40].

Comment [s5]: Language

All managed care enrollees receive standard HMO case management. Some enrollees with disabilities also receive ENCC, although ENCC is not mandatory for all people with disabilities. A subgroup of people with disabilities and special health care needs are required to receive ENCC, including people with physical disabilities complicated by emotional or behavioral needs, mental health disorders, or lifestyles that require special attention and linkages to various services[37]. Although persons with developmental disabilities are not a mandatory ENCC population, the ENCC program serves many persons with developmental disabilities, who are also served by developmental disabilities case managers or service coordinators not familiar with managed care. Similarly, many of the HMO case managers are not familiar with the developmental disabilities system and services. Therefore, ENCC serves as a bridge between the managed care system and the state developmental disabilities system.

Managed care in Oregon has been cost effective, with a savings of about 20% annually[41]. Although there has been no specific evaluation of the ENCC program, Oregon Medicaid requires a biannual client satisfaction survey of all managed care programs, which includes people with disabilities and persons with developmental disabilities. Based on survey results, the ENCC program is considered successful, and both the state and the managed care plans believe that the ENCC program is meeting its goal of acting as the advocate, navigator and coordinator of managed care and community services for vulnerable populations[42].

There are some concerns regarding the ENCC program. The roles and responsibilities of the ENCC are not well-defined, and therefore, may vary across different managed care organizations. The ENCC may also face a conflict of interest, with a role in some managed care plans is as both high-cost case manager and patient advocate. Because the level of awareness of the ENCC role varies, ENCCs are not used as fully as they might be in some cases, and coordination among ENCCs, state agencies, and state ombudsmen is considered less than optimal[42]. Other concerns are that HMOs are not required to hire a ENCC per a certain number of members with disabilities and that requirements for an enrollee to receive ENCC appear vaguely defined. As each HMO is responsible for hiring and training the ENCC rather than the state, this allows for the continued vagueness and lack of clear directives in the ENCC position. The state does hold periodic ENCC meetings to discuss general issues.

6. Texas STAR+PLUS

Program Overview

Program Type: managed acute and long-term care for persons with disabilities through HMO contracts

Population focus: all SSI recipients with disabilities

Origination: 1998

Model: fully capitated HMOs for acute and long-term care services for Medicaid-only; long-term managed care only for dual eligibles

Mandatory/Voluntary: mandatory for some (including most adults with developmental disabilities); voluntary for some (including under age 21 with developmental disabilities)

Region: Harris county

Enrollment: 60,000+

Financing mechanism: fully capitated based on prior utilization

Includes dual eligibles: yes

Behavioral health: carved in

Inpatient care: included

Long-term care: included

24-hour availability: yes

Case management system: nurses and social workers manage and authorize all care

Special features: much consumer input into model; home-based enrollment if needed

Description

Texas STAR+PLUS is a state program in a Harris county (Houston). STAR+PLUS is derived from the Texas Department of Human Services contracting with two for-profit HMOs, Amerigroup and Evercare, to provide acute and long-term care services using a managed care model. Although the eligibility criteria are somewhat complex, enrollment in STAR+PLUS is mandatory for some categories of SSI recipients with disabilities including most SSI disabled adults with developmental disabilities. Enrollment is voluntary for other categories, including children under age 21 with developmental disabilities. STAR+PLUS began when the Texas Senate required the pilot test of a model of integrated acute and long-term care services for people with disabilities. An advisory committee that included HMOs, health care providers, consumers, advocates, and state agency staff met for about a year to discuss program implementation and provide input on models. This allowed for considerable consumer input and ability to educate and allay consumer fears about gate keeping and loss of services. The advisory group decided that, although the program should be mandatory, some groups should be excluded, such as people residing in institutions and those with chronic mental illness. These populations were excluded to ensure that the program was targeted to the appropriate populations and was not a one-size fits all model[43]. STAR+PLUS was implemented voluntarily in 1998. By 2004, over 60,000 were enrolled in STAR+PLUS, just under half of whom were Medicaid-only and receive both acute and long-term managed care through the program, with the remainder being dual eligibles who receive only long-term managed care through STAR+PLUS [36].

STAR+PLUS enrolls individuals through an enrollment broker that sub-contracts with community organizations and consumer groups to conduct the outreach and enrollment activities. Enrollment can be done either by telephone or in-person, and enrollment counselors will conduct home visits if needed. Using consumer advocacy groups provides an important link to the

disability community. The enrollment process is somewhat different between Medicaid-only beneficiaries and dual eligibles, as dual eligibles do not have their acute care managed through STAR+PLUS. Medicaid-only beneficiaries who have both their acute and long-term care managed through STAR+PLUS work with the enrollment broker to select an HMO and a PCP to manage their acute care. Enrollees are allowed to change HMOs at any time. Most Medicaid services are obtained through the HMO's provider network, which includes long-term and acute care providers. Behavioral health services are carved-in, as well, although there are limited behavioral health benefits for adults in the Medicaid benefit package. STAR+PLUS providers are encouraged to add additional benefits beyond the state Medicaid benefit package as value-added services to encourage participation. There are some services excluded from the HMO capitation, but the HMO is responsible for providing referrals for them. Services in this category that particularly relevant to persons with developmental disabilities are MR targeted case management and MR diagnostic assessment. Some additional services, such as personal assistance, are not included in the benefit package, but are expected to be provided to STAR+PLUS members when necessary within the overall capitation[36]. The HMOs in the STAR+PLUS program are capitated by Texas Medicaid. Initially capitation rates were based on historical fee-for-service expenditures, but in 2003, they began being based on the actual HMO experience and discounted 5%. The HMOs also have a rebate process by which they share cost savings with the state. The two HMOs participating in STAR+PLUS, Amerigroup and Evercare, were selected through a competitive process.

STAR+PLUS includes specialized care coordination designed to ensure that members receive all necessary services and that care is coordinated and integrated. Care coordinators must be either registered nurses or licensed social workers, and are expected to be available to consumers when needed. Their responsibilities are outlined in the state's contract with the HMO. The state defines care coordination to include identifying physical and mental health and long-term support needs; developing a care plan to address each member's needs; ensuring timely access to providers and services; and coordinating all plan services with services delivered outside the plan[36]. However, the actual model of care coordination is not defined by the state and the HMO can develop its own model as well as set its own ratio of care coordinators to members. The two HMOs use different types of care coordination: one uses telephonic care coordination, while the other conducts home visits.

7. The Health Care Partnerships, Kentucky

Program Overview

Program Type: state Medicaid managed care system of regional partnerships

Population focus: all SSI recipients with disabilities

Origination: 1994

Model: regional Partnership among providers that historically serve Medicaid population; each region functions as a local Partnership that includes hospitals, physicians and managed care plans; single partnership for each region of the state

Mandatory/Voluntary: mandatory

Region: statewide; eventually eight regions; currently two are operational

Enrollment: 35,000+

Financing mechanism: fully capitated based on prior utilization, single SSI rate

Includes dual eligibles: yes

Behavioral health: carved out

Inpatient care: included

Long-term care: included

24-hour availability: yes

Case management system: Medically fragile case management for those with certain health conditions; specialized case management often for persons with developmental disabilities

Special features: extensive consumer input, provider collaboration and limited competition; health information surveys upon enrollment; can self-refer for case management, flexible case management, SSI beneficiaries can select specialist, or team of specialists, as PCP

Description

In 1994, the state of Kentucky wanted to increase Medicaid managed care and incorporate persons with disabilities into their managed care program that was already serving the TANF population, using a primary care case management model. This decision was made without the input of consumer and advocacy groups, leading to considerable opposition. There was concern about the potential limiting of services and being locked in to a single provider. Physicians also opposed the move, particularly specialists who did not want to serve as primary care providers for persons with disabilities. This opposition led the state to consider other options for serving persons with disabilities within managed care.

Eventually, the state asked providers to develop their own managed care organizations on a regional basis to serve the entire Medicaid population within their area, which is the Partnership model in place today. Eight regions for Partnership development were established by the state. Providers are expected to determine the structure of their managed care models, within the overall concept of a regional Partnership among providers that had historically served the Medicaid population. Each region functions as a local Partnership that includes hospitals, physicians and managed care plans, and includes providers that traditionally have served Medicaid beneficiaries. Each region must select a single Partnership to serve the entire Medicaid population. If more than one group applies to be the Partnership, they are encouraged to collaborate and form a single Partnership. However, if they are unable to form a single Partnership, the state will choose one Partnership to serve as the regional Medicaid provider. If no regional Partnership is established among providers, the state will select an HMO to serve as the provider for that region. Traditional Medicaid providers have been eager to establish Partnerships in order to keep commercial HMOs from becoming the regional provider. Partnerships are paid on a capitated basis, based on a percentage of historical Medicaid fee-for-service costs. There is a single SSI rate, although the state is considering an adjusted rate for HIV/AIDS[7].

Because not engaging with consumers and advocates for persons with disabilities was a major stumbling block in their first attempt to move toward mandatory managed care for persons with disabilities, prior to setting up the Partnerships, the state was very inclusive of persons with disabilities and other stakeholders. Many of the program's design features and regulations were constructed in view of consumers, advocates and providers, with the hope that once the program was implemented it would be acceptable to all parties. State Medicaid staff encouraged debate and building of consensus. The initial request for proposals was also issued as a draft and public

comment was encouraged. Public hearings were also held on the regulations once they were developed, and groups concerned about how they would fare under managed care were encouraged to suggest modifications to ensure that their needs would be met, rather than suggest an exemption process. Each Partnership was allowed a great deal of choice in developing its structure, as long as it included traditional Medicaid providers and a broad range of other providers working together and met the state's other requirements, which included being embedded in an HMO, being provider-driven, and being able to take risk.

The first two Partnerships, Passport and Kentucky Health Select operate in the most urban areas of the state. Partnerships are expected to develop in the remainder of the state over time, including rural areas in which there are fewer providers. The two Partnerships have mandatory enrollment for all Medicaid recipients, including SSI beneficiaries with disabilities, although some populations that are excluded from mandatory enrollment. Among those with developmental disabilities who do not have to enroll in managed care are individuals living in institutions and those on HCBS waivers. Behavioral health services are carved out of the Partnerships, and it is expected that, over time, each Partnership region will establish a separate behavioral health managed care organization to provide mental health and substance abuse services, with each Partnership will be linked to a regional behavioral health managed care organization. Until that time, most behavioral health services are provided on a fee-for-service basis.

Of the approximately 175,000 Medicaid beneficiaries enrolled in the two Partnerships in 1999, about 20% of the enrollment, or an estimated 35,000 enrollees, were SSI disabled Medicaid beneficiaries[7]. The Partnerships include some special features for persons with disabilities. Each managed care plan sends out health information surveys upon enrollment; the member's responses to the survey can trigger case management services. Providers may also refer patients for case management and enrollees can self-refer if they believe they are in need of services. They have two types of case management: medically fragile case management and specialized case management. Because the state also requires that individuals considered "medically fragile" enroll in the managed care program, they have developed a definition of this category that includes many people on SSI. Criteria for medically fragile individuals were developed by clinicians and through examination of service utilization data including inpatient care, specialty care, emergency care and durable medical equipment. Individuals considered "medically fragile" include those who are likely to require specialized, chronic or costly services, as well as anyone having one of 29 different diagnoses. These diagnoses do not include the typical diagnoses that make up the developmental disability population, however[44]. Before the Partnerships can enroll the medically fragile, they must develop specialized care plans and have contracts with a certain number of providers that have traditionally served this population. Beyond the medically fragile populations, specialized case management for those with certain other conditions and disabilities is strongly encouraged, but not mandated, by the state. For children, some conditions for which specialized case management is recommended include cerebral palsy, autism, mental retardation with related physical disabilities, neurological impairments, seizures, genetic conditions or congenital abnormalities that include complex treatment regimes, and severe health defects. For adults, developmental disabilities, mental retardation, and cerebral palsy are all conditions for which specialized case management is recommended. Case management is not

required on an ongoing basis and Partnerships can move people out of the program if they believe it is appropriate.

Each enrollee is expected to choose a primary care provider upon enrollment. For the TANF population, if they do not select a primary care provider, one can be assigned. However, SSI beneficiaries cannot be assigned a primary care provider. In addition, SSI beneficiaries can select a specialist, or even a team of specialists, to serve as their primary care provider. Finally, primary care providers are expected to conduct a health assessment on each new member during the first 90 days of enrollment. Prior to enrollment, SSI beneficiaries receive a letter and packet of information about the plan, a provider directory, and the options for selecting a primary care provider. Partnership staff stays in contact until the enrollee makes a choice of a PCP. For those in the medical fragile category, the Partnerships must develop continuity of care plans prior to enrollment, but because the Partnerships attempt to include providers who have served the population, many of the individuals' providers may be included in the Partnership network. Nurse case managers speak with all medically fragile enrollees to explain the program and ensure that they are linked to the necessary care and services, including specialty care. These initial contacts are very important because this level of case management is not required on an ongoing basis. However, the state and the Partnerships appear to be devoted to ensuring that the care of persons with disabilities is appropriate and their needs are met.

The two Partnership programs currently operating have several differences. Kentucky Health Select is the HMO for the Partnership serving the Lexington area. This HMO was in existence prior to the implementation of the Partnership program. Their Advisory Board includes two parents of children with special health care needs and two adults with disabilities. They have contracted with advocacy groups to conduct provider education related to accommodating persons with disabilities. Some of their case management is provided by organizations experienced in serving persons with disabilities. However, this Partnership does not provide ongoing case management to all persons with disabilities; their case management is based on service utilization and is triggered when an individual's health care costs exceed a certain threshold each year or when someone is identified as medically fragile.

Passport, the HMO for the Partnership serving the Louisville area, was a start-up HMO when the Partnership began. Passport is a coalition of providers, including many of the traditional Medicaid providers in the region, such as the academic medical center and community health centers. For SSI enrollment, Passport conducted aggressive outreach using teams of staff from their health services, member services, and utilization management departments. The outreach team conducted extensive outreach and educational activities to the SSI population prior to enrollment. They also offered welcome classes for all new enrollees and conducted educational sessions for staff and providers on issues that affect persons with disabilities. Their case management system is based on the results of a health assessment, which leads to a care plan that is implemented and reviewed periodically. Passport employs case managers for the SSI population and has hired specialty case managers to accommodate the diverse needs of their population.

The Partnerships are required to provide all Medicaid covered services, with the exception of the behavioral health services that are carved out. They can also elect to cover additional services

within their capitation. The state allows the Partnerships to vary the way services are provided and to impose limits on certain services. One example relevant to persons with developmental disabilities is in Passport, which limits the amount of physical therapy provided by physical therapists to children with disabilities. Instead of directly providing extensive physical therapy, they train parents and caregivers to provide the service, with periodic assessments and monitoring by physical therapists. According to staff and providers, this policy has not led to complaints or concerns from parents or advocates[7]. Kentucky Medicaid has a quality improvement program to monitor the Partnerships that includes a consumer satisfaction survey and a set of health outcomes that can lead to financial rewards. By meeting certain benchmarks, Partnerships can receive additional funds of up to one percent of their total capitation payment. The benchmarks with financial incentives do not currently include any developmental disabilities specific measures, but rather are focused in more traditional areas such as pregnancy, cancer, and cardiac disease[44].

Advocates and persons with disabilities feel that the state has done a good job communicating about them regarding the program and, for the most part, about how the program has met the needs of persons with disabilities. Despite the role that consumers with disabilities and advocates, played in the implementation of the Partnerships, as well as their on-going role, there are some concerns about the program's impact on persons with disabilities. For example, managed care has eliminated some of the flexibility consumers experienced obtaining durable medical equipment on a fee-for-service basis, and some are finding that the more expensive durable medical equipment is difficult to obtain. There is also concern that access to some services that are traditionally difficult to obtain within Medicaid fee-for-service can be exacerbated by managed care, such as physical and occupational therapy and specialty care. However, overall, there have been limited complaints and problems with the program for persons with disabilities[7].

ANALYSIS AND RECOMMENDATIONS

States that have been successful in implementing managed care for persons with disabilities have taken very different paths, as the examples above indicate. Multiple models have emerged, based in part on whether managed care is mandatory or voluntary, the types of managed care previously in operation, how quickly enrollment is expected to occur, and for various other reasons. For example, while a small intensive model such as MNDHO can work in Minnesota in part because enrollment is voluntary, the challenges of a required mandatory enrollment of people with disabilities into managed care on a large-scale basis required Oregon to use procedures that could be more easily and quickly implemented on a broader basis. Given the many differences across states, no two states can have identical managed care systems. However, the components and experiences of the successful managed care programs discussed above, as well as other states' experiences and what has been learned from the literature, are important for Florida to consider as it moves toward mandatory managed care. Our specific suggestions and recommendations are discussed below.

There are common components of successful managed care programs for persons. Programs that are effective are clear about the target population for whom the managed care system is being

developed. Medicaid managed care programs serve a broad spectrum of individuals, both within the TANF and SSI populations. Within the SSI population, there is likely to be substantial diversity in diagnoses, demographics, and health care and support service needs. In order to design programs that will be successful in both containing costs and maintaining quality it is necessary to clearly define the population being served. Florida has decided that their goal is to, over time, develop a managed care system that will serve the entire Medicaid population, and to enroll Medicaid beneficiaries into managed care on a county-by-county basis. Given this plan, we support the decision to include more than one model of managed care and allow for provider networks and specialty plans, as well as HMOs. Specialty plans can be developed for specific populations and will be most likely to be able to handle very complex cases. Several of the more successful models of managed care for persons with disabilities have been smaller specialty plans. Similarly, the provider network model also has important strengths for persons with developmental disabilities, and Florida already has some experience with provider networks, such as the current Children's Medical Services model.

The method of financing will be critical to the success of managed care, especially for persons with disabilities. While capitation allows for flexibility and ability to use funds creatively, this only works if the capitation rate is sufficient to encourage health plans to meet members' needs. Risk adjusted capitation should provide managed care plans with sufficient funding to serve their members and will limit problems with adverse selection, which is especially important for managed care plans that serve persons with the most severe disabilities. Because HMO encounter data are not available, AHCA plans begin with pharmacy-based risk adjustment using Medicaid Rx and then move to diagnosis-based risk adjustment using the CDPS when HMO encounter data are available. Risk adjustment can be especially challenging for persons with developmental disabilities, as developmental disability encompasses a range of different diagnoses, and there can be extensive variation in costs, depending on both diagnoses and the severity of those diagnoses. At the present time, it is important to determine how the risk adjustment mechanism will be able to account for the multiple issues of persons with developmental disabilities if they are not taking medications for these conditions. For the future, although moving to CDPS will address these issues, because risk adjustment is so challenging for persons with developmental disabilities, it is recommended that the state continue to examine new financing models over time, in case a new model is developed that will be even more effective.

Although managed care implementation will begin with pilot programs in two counties, currently the plan is that persons with developmental disabilities will be required to enroll in managed care after one year, and that there will then be county-by-county implementation, with statewide mandatory managed care enrollment that will include persons with developmental disabilities over five years. It is very challenging to implement statewide, or even countywide, managed care for persons with disabilities, and this schedule may be too rapid. It may also take longer than five years to successfully implement Medicaid managed care on a statewide basis, and it is recommended that persons with developmental disabilities not be required to participate in mandatory enrollment until an evaluation of their experience in the pilot program is complete. States that have successfully implemented managed care for people with disabilities have developed their systems over extended periods of time. While it is important to move forward, it is more important to move forward with an effective program. Pilot projects and evaluation are important before broad mandatory implementation.

AHCA plans that managed care enrollment will be voluntary for persons with developmental disabilities receiving services from APD during the pilot phase in the initial counties. Although the state has developed a mechanism to identify persons receiving APD services, there is no method for identifying persons with developmental disabilities who are not receiving APD services or not known to APD. As a result, these individuals may be forced to enroll. A mechanism, such as a screening tool, that will allow all persons with developmental disabilities to be excluded from mandatory enrollment during the pilot phases should be established before mandatory enrollment begins. Because no state has a system for identifying all persons with developmental disabilities, initially we recommend that a screening tool that will identify persons with developmental disabilities for the purposes of exceptions to mandatory managed care enrollment be used. CMS has a tool that is currently used to identify children with special health care needs, this could be adapted to identify persons with developmental disabilities. I-Care also has a scale, the London Handicap Scale, a validated instrument, that has worked for them.

To make managed care viable for persons with disabilities, consumers and family members must be actively involved in its design and implementation. A task force of stakeholders can serve in an advisory capacity and given an active role to partner with AHCA in managed care program development. It is particularly important that advocacy groups, professionals serving persons with developmental disabilities, and adults and children with disabilities participate in review of the standards that will be required for managed care plans serving persons with developmental disabilities. The FDDC Health Care Task Force has long been committed to these issues and would represent an excellent group to research and review standards of care and provide recommendations to AHCA. New Jersey and Kentucky both actively included stakeholders in their planning and implementation.

Another way to make managed care plans appeal to persons with developmental disabilities is to establish contract requirements that managed care organizations must meet to be allowed to enroll the population. Some of these requirements might include clearly identifying providers with experience serving persons with developmental disabilities in enrollment materials and member handbooks. Enrollment materials could also specifically note managed care plans that have particular expertise in serving persons with developmental disabilities. Some states, such as New York, have considered actually identifying particular managed care plans as “certified” to serve specific populations of persons with disabilities if they meet certain requirements.

Very specific requirements for serving persons with developmental disabilities need to be included in both the request for proposals and the managed care contract. If managed care plans do not meet these requirements, they should not be allowed to enroll persons with developmental disabilities, although they could enroll other Medicaid populations. This mechanism can be established for any disability population or the entire SSI population. Population-specific requirements can be developed in partnership with the task force of stakeholders discussed above. However, some requirements might include:

- Providers with experience and expertise serving persons with developmental disabilities from each specialty in the managed care network.
- Identifying providers with expertise in the member handbook and plans including these providers in enrollment materials.

- Requiring that each managed care plan hire an advocate for persons with disabilities. Because this person would be an employee of the managed care organization and could be faced with conflicting loyalties, it is important that the person have support through regular meetings with the other managed care plans and also that the person be a seasoned professional with a strong understanding of both health care and other needs of persons with disabilities.
- Mandatory care management for persons with developmental disabilities that includes ensuring integration between members' health care needs and their home and community services, and between physical and behavioral health care that is based on a statewide definition of care management with specific requirements and procedures for its application. These requirements should include ratios of care managers to members that may vary depending upon whether the care management system includes multiple tiers. The I-Care model that includes different types of staff based on member diagnoses and severity of needs is very promising. This model could be required in large HMOs, while specialty plans may have other models that would work for them and their members. A mechanism for care management that includes care coordination needs to be integrated into the PSNs.
- Disability training for providers, such as training about the many challenges faced by persons with developmental disabilities as they age, turning 22 and transition services, the complexity of persons with developmental disabilities, behavioral health issues, community supports, and a wide range of other issues. APD and the FDDC Health Care Task Force can recommend required training topics.
- Identifying providers with physical and communication accessibility beyond that required by ADA regulations, such as providers with staff that speak ASL. This information also belongs in the member handbook.
- An advisory committee within each managed care plan that includes persons with developmental disabilities and/or their family members who are also members of the managed care organization.
- At least one quality improvement initiative focused on persons with disabilities annually.
- Each member with a disability receives a full assessment and physical examination within 60 or 90 days of enrollment.
- Each managed care plan is required to develop a care plan for its members with developmental disabilities, and the member must participate in the development of the care plan. I-Care has an excellent model of a care plan for persons with disabilities within a managed care organization. Coordination between the care coordinator and the PCP.
- Managed care plans must allow persons with disabilities flexibility in their choice of PCP, including allowing specialists to serve as PCPs if this makes the most sense for that member. The provider who will be the PCP should agree to take on this role and be aware of the responsibilities. The PCP should serve as the "medical home" for persons with disabilities, and, in addition to coordinating medical care, should have a strong connection to the services that support persons with disabilities in their homes and communities.
- Some enhanced benefits need to be those that will be attractive for persons with developmental disabilities, such as funds for support services, transportation, respite care, or dental care. They could also include support groups or recreational programs geared toward persons with developmental disabilities.

Enrolling persons with developmental disabilities in managed care will be more acceptable if there are processes for transition plans and out-of-network care. Although it is indicated in the Medicaid contract that each managed care organization must have policies related to transition planning upon enrollment and out-of-network care, it is important that these policies include parameters, such as time frames, to ensure continuity of care when persons with disabilities move from fee-for-service to managed care or change managed care plans. Out-of-network care should remain an ongoing option if there are not providers within the managed care network who have expertise and experience serving persons with developmental disabilities, including those with severe disabilities and multiple disabilities. A continuity-of-care form upon enrollment will allow both the member and the health plan to identify these providers. At this time, the member can meet with a care manager and together, develop a procedure for transitioning to network providers, or determine whether the member should continue to obtain out-of-network care if his/her needs cannot be met within the managed care plan. While each managed care organization will have specific policies for out-of-network care, it is recommended that AHCA have specific requirements for the managed care plans.

AHCA plans to contract with an enrollment broker for choice counseling; the enrollment broker could be given some ideas about how to make enrollment of persons with disabilities as smooth as possible. These ideas might include training all choice counselors in disability sensitivity and on recognizing disability, subcontracting with an advocacy group to conduct enrollment counseling for persons with disabilities, and providing enrollment counseling for persons with disabilities at their homes or at the developmental disabilities agency offices. It is also important to develop some training for family members, support coordinators, and other staff who work with the population about managed care in general so that they can assist individuals who they work with to navigate managed care, as well as select a managed care plan. We have developed simple curriculum and implementation materials that have worked with this population in other states to assist in this process. Providing as many individuals as possible who come into contact with persons with developmental disabilities with information about managed care will enhance the transition and will support enrollment. If persons with disabilities do not make a selection within a specified period of time, rather than automatically assigning them to a plan, the choice counseling staff can make additional contacts to assist them to make a plan choice.

If persons with developmental disabilities are satisfied with their managed care plan, they should be allowed to remain in the plan of their choice and managing their benefits should be made as seamless as possible. To retain persons with disabilities in managed care, specialty plans and provider networks will need to accommodate individuals dually eligible for Medicaid and Medicare, and bill Medicare on a fee-for-service basis. For Medicare risk plans, AHCA will have to develop separate Medicaid capitation rates for Medicaid-only beneficiaries and for dual eligibles. Managed care organizations that are not also Medicare risk plans must be willing and able to bill Medicare on a fee-for-service basis for Medicare services so that this responsibility does not fall on the member. It is recommended that health plans be required to build in billing and other management mechanisms that will smooth any administrative burdens on persons with disabilities. This is an important issue for Florida, as dual eligibles account for a third of Florida's SSI population under age 65, and the dually eligible population is growing.

Florida has invested a great deal of time and energy into Medicaid reform and the move toward managed care, and all parties should be commended for their efforts to ensure that persons with disabilities are enrolled in managed care programs that, while being cost effective, will also meet their health care needs. Managed care plans get the most positive results and buy-in among persons with disabilities if they are flexible, meet individual needs, and allow consumers as much choice as possible. Partnership between AHCA, FDDC, APD and consumers and family members will allow managed care the greatest chance to be successful.

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