

Impact

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Sarah Brengman (center), with her parents Sylvia and Warren. She is one of the young people with complex medical needs receiving care coordination through the U Special Kids program. See story below and on page 22.

Caring for Sarah: A Mother's Story

By Sylvia Brengman

Sarah was born on October 19, 1986. When she was eight weeks old she was diagnosed with a rare metabolic disorder and given two weeks to live. The error in her metabolism is in the energy-producing part of the cell that makes energy for proper muscle function. All of her muscles have been affected. She is significantly developmentally delayed, profoundly deaf, and has cerebral palsy, to mention a few of the many issues she is dealing with.

Sarah has no safety skills, needs help with all basic acts of daily living, and needs 24-hour supervision. I typically sleep less than five hours a night and have chronic shoulder and back pain from helping her. My husband and I work opposite shifts so that someone is always available for Sarah. Very few people can understand the depth of responsibility that comes with caring for her; it is a huge emotional, physical, and financial stressor for our family.

Because of our combined income, we make too much money to qualify for financial assistance. To qualify for most services, we would have to live near poverty level. This makes stress levels very high and finances very tight. I have to work, so I work 10 minutes from Sarah's school so that I'm close in case of a problem, and my employer is very understanding of the situation. But, the bills do not go away when we can't work because Sarah is sick and needs us at home. We have never had a family vacation because our financial situation prevents it.

Because Sarah has multiple problems and physicians, making appointments, understanding tests, and finding answers to questions is difficult. Eight years ago we
[Brengman, continued on page 32]

From the Editors

For individuals with disabilities and/or chronic illnesses who have complex health care and other support needs, it is too often the case that they must navigate complex service systems largely on their own, trying to identify and put together all the pieces of the services and supports they require. The outcome is often fragmented, with the individual or family exhausted, frustrated, and experiencing significant and even life-threatening unmet needs.

Throughout the country, growing numbers of individuals with complex medical and support needs are receiving health care and other human services with the assistance of care coordination programs. Though care coordination is in its infancy as a practice, the experience of these individuals and their care providers suggests that it's promising in not only improving effectiveness of care and quality of life, but it may also prove more cost-effective through its ability to help individuals access appropriate and preventive care before conditions escalate. This issue of *Impact* highlights several of these programs, and individuals whose lives have been changed, even saved, by them. It also describes system-level issues and options for further exploration by those shaping service policies and systems in our country.

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Costs, Options, and Inclusion: Issues in Health Care for People with Disabilities

by John Tschida

Health care costs are rising at a ridiculous pace, and the impact of this growth is hitting most American families hard. Increased monthly premiums are taking a bigger bite out of worker paychecks. Higher prescription drug co-payments and \$10-20 surcharges for a trip to the doctor are not uncommon. Worker strikes and protracted contract negotiations bogged down by health care costs are popping like popcorn all across the country. And policymakers at every level of government are looking for the magic bullet that will cure what ails the nation's health care system.

People with disabilities and those who advocate on their behalf are nervous about the current situation, and rightly so. Why? Because both the public and private health care insurance systems are struggling with how to control costs. A growing number of government-controlled health care dollars are spent on individuals with disabilities, and the greatest potential for cost savings comes from exploring how services are delivered and paid for when it comes to this often vulnerable population. Rising private market or employer-based health insurance costs have many small businesses on the ropes. People with disabilities in the competitive workforce have seen premiums go up, while benefits to cover more expensive items like wheelchairs and orthopedic devices have declined in recent years. The future remains very uncertain for this group of Americans.

Cost and Quality Issues

Just how bad is the growth rate of health care spending? A report released in November by the Minnesota Department of Health says total spending on health care rose 10.1% in 2002, surpassing the national growth rate of 9.2%. Twenty-three billion dollars was spent in

Minnesota alone, with just over half of those dollars paying for hospital and physician services (Minnesota Department of Health, 2004). The fastest growing part of state budgets nationwide is the health care budget. As lawmakers and policy analysts parse where the dollars are spent, it is clear that persons with disabilities consume a disproportionate amount of the spending. Most are enrolled in Medicaid, the health care program jointly funded by state and federal government that serves the nation's poorest citizens and those with disabilities. Nationwide, people with disabilities comprise 17% of the Medicaid population, but account for 40% of program expenditures (Kaiser Commission on Medicaid and the Underinsured, 2003). In Minnesota alone, 92,000 individuals with disabilities rely on Medicaid for their health insurance (Minnesota Department of Human Services, 2004).

Policymakers nationwide have three fundamental choices in recognizing Medicaid cost savings:

- **Eligibility:** Who qualifies for publicly funded services and what are the rules governing access to health care programs? Each state sets the bar a little differently. Some allow for better access than others.
- **Benefits:** What services is government willing to pay for (and how)? The federal government has a required minimum benefits package, but many states offer additional services above and beyond these.
- **Provider payments:** How much are medical professionals and those who assist people with disabilities in navigating the health care system paid? States decide how much doctors, home health aides, and nursing homes get paid under the Medicaid program. And while the cost of providing services continues to increase

with inflation, reimbursement rates rarely keep pace.

Across the nation, lawmakers have tinkered with each of these three options to help keep costs down. In many cases, victory has been declared if the rate of growth in health care budgets has been held to single digits. Again, Minnesota is no different. Most providers saw their rates dip during the last budget process, and some individuals who previously qualified for services found themselves without health insurance. Those who remained eligible saw new cost-sharing co-payments enacted for prescription drugs and doctor visits.

But, addressing only the cost side of the ledger with the options outlined above doesn't create better health outcomes for persons with disabilities enrolled in Medicaid. Instead, they often limit access to services rather than provide creative options for achieving better results. While the cost trends have been easy to identify, components of a better, more efficient health care delivery system have been tougher to formulate and implement.

Former U.S. Senator Dave Durenberger, tapped by Minnesota's Governor Tim Pawlenty to lead a blue ribbon panel on the state of Minnesota's health care system, has said that we reward volume of service rather than value. Instead of paying for services based on what works and what makes a positive difference in the lives of health care customers, we're paying for procedures based on cost, not necessarily on effectiveness. While this may be true today, there are exciting options being created and model programs now in existence at the state and federal levels that address both cost and quality of health care services for those with disabilities. Among the options being explored are consumer control, care coordination, and managed care.

Consumer Control

Some believe that by removing the disconnect between what consumers pay for health care in insurance premiums and the true cost of those services, individuals will make more prudent choices about when and where to seek health care. The phrase *consumer-driven health care* – as defined primarily by proponents of medical or health savings accounts – is getting a lot of attention these days, and is an attempt to link consumer health care purchasing decisions with a limited pool of dollars to pay for them. These personal savings accounts, which often provide catastrophic coverage after a significant cost-sharing contribution by the individual once the account has been exhausted, are being used by a number of private employers as a way to give employees more control over how they get their health care services, on the theory that they will be wise and frugal purchasers and make an informed decision based on price and quality. The challenge in the health care market is that shopping for a neurosurgeon or psychiatrist is not like a trip to the grocery store. There are no clearly marked packages displaying the price and no list of ingredients to be found. There exists no consumer guide or equivalent to give us the information we need to determine where the best buy for the dollar is or where the “high end” providers are if we’re willing to spend a little extra. While some research has been done on these programs, this emerging option needs further analysis, especially to understand the effects on the people with chronic illness and disabilities.

Within the Medicaid program, individuals with disabilities and their advocates have long desired greater freedom from regulations governing how and from whom they can purchase needed health services. A growing number of states, with approval from the federal government, have secured waivers in recent years that allow consumers to do just that. Programs like Cash and Counseling and Independence Plus are now operating in at least 15 states and give

people the freedom to purchase their long-term care services within an allocated budget. These differ from private market medical savings accounts in that personal budgets are often based on the need for services, and rely on a “risk-adjusted” system based on previous health expenditures. With these programs, people with disabilities can, for example, decide how many hours of home health care they need or raise the wage rates for their aides, if needed, and rely on fewer hours of service or purchase services not traditionally covered by Medicaid. Minnesota has just implemented a consumer-directed community supports program for all individuals with disabilities, which trades this greater freedom in purchasing decisions for a discounted personal budget determined by the state.

Care Coordination and Managed Care

The traditional fee-for-service Medicaid program provides no assistance to a person with a disability to navigate the Byzantine system of doctors, specialists, and ancillary providers of medical supplies and equipment. Those Medicaid recipients who are eligible for waiver programs do get a care coordinator or case manager, but these people often only assist with the long-term care services that individuals need to remain in the community. They don’t manage acute care services or the complex array of providers. As budgets have been tightened, access to this benefit is increasingly being limited.

A few programs nationally – in Minnesota, Wisconsin, Massachusetts – have successfully integrated both care coordination strategies and the financing of care across the continuum, from hospital to the home, in a way that addresses the person’s complete health and social support needs (for reports on these programs see www.chcs.org). There is hope in these examples that care coordination can work if planned and implemented effectively for a high needs, high cost population.

[Tschida, continued on page 32]

Resources of Interest

- **Center for Health Care Strategies, Inc.** (www.chcs.org, 609/895-8101). Offers extensive materials on topics related to improving the quality of health care services for beneficiaries of Medicaid and the State Children’s Health Insurance Program. Among its online publications is “Care Coordination in Medicaid Managed Care: A Primer for States, Managed Care Organizations, Providers, and Advocates” (July 2000), by M. L. Rosenbach & C. G. Young, Mathematica Policy Research, Inc.

- **Strengthening the Community System of Care for Children and Youth with Special Health Care Needs and Their Families: Collaboration Between Health Care and Community Service Systems.** (2004). By S. Bronheim & T. Tonniges. Published by Georgetown University Center for Child and Human Development. This workbook contains suggested approaches for health care professionals who want to connect better with other community services, and approaches for broader community service providers and agencies to engage health care professionals. Available online at http://gucchd.georgetown.edu/files/products_publications/BSOFwkbkfinal.pdf or by phone at 202/687-5000.

- **Best Practices in Coordinated Care.** (2000). By Chen, A., Brown, R., Archibald, N., Aliotta, S., & Fox, P., Mathematica Policy Research Inc. A report describing lessons learned from current best practices in coordinated care for persons with chronic illness. Available online at <http://www.mathematica-mpr.com/publications/PDFs/bestpractices.pdf>.

- **Children’s Health: Building a Caring Community.** (2001). By M.F. Mastal. *Healthplan*, 42(5), 58-62. A journal article describing resources needed to coordinate health and life care for children with special needs, and positive outcomes.

Self-Direction and Accountability in Health Systems for People with Disabilities

by William D. Clark

The health care delivery environment with which we interact as consumers is continuously changing. The Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (MMA) represents a significant health reform milestone that defines important changes in the Medicare program, including the addition of outpatient prescription

reform even within large nationwide reforms that are to be implemented. These first-of-their-kind health plans are available for people eligible for Medicaid and Medicare, and they integrate all the benefits covered by Medicaid and Medicare while employing a variety of strategies to promote self-directed services for their members.

Questions of Accountability and Control

In order to deliver effective health care and support services, human needs must first be identified. Then, systems of care and support must be flexible enough to meet those needs to the greatest extent possible with the resources that are available. In other words, an important characteristic of optimally-designed health care systems is for consumers to be able to seek the care they need, when they need it, with confidence that, whatever their need, a way will be found to work within the system and with care partners to make the best arrangement to fulfill their needs.

Step by step, our health care system is responding to consumers' desires to control and direct either a part, or all, of their health care and support services (Mahoney et al., 2003). This differs from the paradigm in which consumers are expected to be "patients." While consumer involvement is especially evident in the principles for independent living among people with disabilities and others, consumer choice is now further embodied and promoted by the President's New Freedom Initiative and the congressionally mandated system change grant activities for states. Health Savings Accounts, also mandated by the MMA, are touted as yet another form of health care financing in which participants are provided maximum flexibility to direct and arrange for their individual health

care needs. The independent living principles and these other examples might all be considered as potential answers to a question asked by consumers: "How can I do the best I can to be in charge of the services that I need?"

However popular concepts of self-direction may become, many people do not desire to pursue this option. Not everyone wants to assume responsibility for making these choices or is necessarily equipped to assume the responsibility for directing their own health care and/or support services. Just as the provision of health care can foster consumer dependency and absence of control, imposing self-direction upon consumers who don't want to or can't assume responsibility would seem equally unbeneficial. Therefore, in an era of increasing interest in self-directed care, providers of care must continue to be responsive to meeting the needs of those who do not participate in these arrangements. Under these conditions, care providers attempt to both arrange and provide services while doing their best to inform and educate consumers and their caregivers.

Financing for most fee-for-service insurance and out-of-pocket arrangements is unlikely to include payment for the time and involvement of providers seeking to educate and inform consumers. Furthermore, providers are often not well organized to work across medical and human service disciplines to assure that care is both coordinated and effective. Simply put, people working in all the various venues involved with health care and support services often appear to have difficulty understanding the role of others involved in meeting a particular consumer's care needs and communicating with each other.

Providers must be knowledgeable about and accountable to individual program requirements according to

"How can I provide the best care for people requiring complex medical and support services when I am only accountable for limited, specialized, and clearly defined services and responsibilities?"

coverage through pharmacy plans, new coverage expansion in prevention screening services, and significant changes in the way that Medicare Advantage health plans operate. These changes and many others in the law will, over the years ahead, have an impact on almost all Americans in one way or another. These changes in Medicare will also affect how Medicaid and other State programs will operate and the impact they will have. In addition, Medicaid has been targeted for reform in the near future.

This article poses questions about accountability and control that might be asked by consumers, providers of care, and governments responsible for the administration of Medicare and Medicaid. It then describes how two demonstration initiatives serving people with disabilities in two Midwestern states offer alternative models of health care delivery that serve as small-scale templates of

various payment streams. They often face frustrating limitations because individual program coverage and eligibility parameters may not quite fit a particular consumer's needs or because a particular service or piece of equipment may not be determined to be a medical necessity by one third party payer or another. Given the responsibilities that

“How can I do the best I can to be in charge of the services that I need?”

fall to providers of care as they seek to provide the best quality of service, providers may ask: “How can I provide the best care for people requiring complex medical and support services when I am only accountable for limited, specialized, and clearly defined services and responsibilities?”

Payers operate under the authority of Federal, State and private insurance laws and regulations. They must implement programs under requirements that may change depending on the direction of legislative initiatives. Medicare and Medicaid have been constantly changing ever since they were enacted in 1965. It takes time to change the way these programs are implemented. Meanwhile, the core functions of program administration and making provider payments must always proceed uninterrupted. A payer may ask: “How can I make sure that consumers get the care they need from my program, assure that the services provided are of good quality, and work effectively with provider partners while making timely and appropriate payment for the work that they do?”

Health care reform through legislation, such as the MMA, is perhaps the most important way to implement big changes in health care delivery. Demonstration initiatives sponsored by the Centers for Medicare and Medicaid Services and States also provide opportuni-

ties for changing the way consumers obtain needed care through these Federal and State programs, albeit on a smaller scale. Two such initiatives – the Minnesota Disability Health Options and the Wisconsin Partnership Program – are pilot coordinated care plans designed to provide people with disabilities all the covered benefits of both Medicare and Medicaid under one integrated model of care with minimal out-of-pocket costs for members. Consumers enrolled in these unified health plans participate in health care delivery models that offer accountability for the quality of care being delivered. Yet, they are designed so that members have the option to self-direct their care, especially personal care attendant (PCA) services. Three innovative plans under these initiatives are profiled in detail below: UCare Complete/AXIS, the Community Living Alliance, and the Community Health Partnership.

UCare Complete/AXIS

Operating in the Minneapolis/St. Paul metropolitan area, UCare Complete/AXIS is a coordinated care plan offered under the Minnesota Disability Health Options program. It combines the health plan expertise of UCare, with the care management expertise of AXIS in serving people with physical disabilities. Members are Medicaid recipients with physical disabilities ages 18-64. All hospital, physician, pharmacy, long-term institutional care, and community-based services are covered by the plan. Each member participates as part of a care coordination team in developing their own plan of care. Approximately 50% of all members use PCA services. AXIS works with each member to assess their health care needs in determining and authorizing the amount of PCA service to be provided. UCare contracts with home care agencies or a PCA Choice agency for provision of PCA services.

Less than 10% of PCA service users in the plan choose the self-management/direction of care. Working with People Enhancing People (PEP), a PCA Choice agency founded by AXIS members,

UCare Complete/AXIS members are able to hire, schedule, and replace their own PCA workers (including some family members and friends). PEP itself is responsible for hiring the PCA workers, doing background checks, and assisting with training them. It also handles the administrative paperwork involved with hiring and paying the worker. It is able to offer educational scholarships as an added incentive for workers, and members may decide whether to use that option. The consumer-controlled PEP organization works with members to encourage self-direction of their PCA care and bill UCare for the care provided.

Most UCare Complete/AXIS members with PCA needs do not select to

“How can I make sure that consumers get the care they need from my program, assure that the services provided are of good quality, and work effectively with provider partners while making timely and appropriate payment for the work that they do?”

self-direct PCA services. These members continue to benefit from the accountability of the UCare Complete/AXIS coordination of care and authorization for PCA services. PCA workers are provided through a liaison with home care agencies. Because it is a specialized coordinated care plan, AXIS is able to authorize higher wages for PCA workers, and more efficiently redirect Medicaid and Medicare funds that would have paid administrative overhead or hospital expenses, instead applying them across the spectrum of services.

[Clark, continued on page 33]

Disability, Culture, and Health Disparities

by Jean Johnson, Martha Guinan, Steven E. Brown, and Valerie Shearer

The federal Healthy People 2010 initiative calls for the elimination of long-standing disparities in health status that exist among segments of the population, including disparities that occur by race or ethnicity (U.S. Department of Health and Human Services, 2000). Health disparities in relation to persons with disabilities have been amply documented, as have disparities by gender, race or ethnicity, education or income, geographic location, or sexual orientation. However, only limited research has examined the cumulative effect of multiple risk factors for disparities. What happens, for example, when disability intersects with culture? Some studies, while providing qualitative research on quality of life concerns for persons with disabilities, fail to address the effect of cultural differences within the research design. Even a landmark forum by three large federal agencies, seeking to bring visibility to the issues of health and well-being for people with disabilities, failed to address the importance of culture in contributing to health and well-being (Centers for Disease Control and Prevention, 2003).

In order to provide persons with disabilities from diverse cultural groups with health care that is effective and coordinated, we first need to understand the relative roles of disability and culture in health disparities that exist. Hawai'i, a state long recognized for its diversity and without an ethnic majority, provides an ideal laboratory to examine how these multiple factors may influence health disparities among persons with disabilities.

Questions From Hawai'i

We know that in measures of preventive health care, people with developmental disabilities living in Hawai'i rank poorly. Since 2001, the state has participated in the Core Indicators Project conducted by the National Association of State

Directors of Developmental Disability Services and the Human Services Research Institute. Data have been collected by interviews with clients or caregivers for each of the health indicators as shown in Table 1 (Fray, 2004). In the first year, Hawai'i ranked lowest of all states. This result continued in the second year of participation, with the ranking of Hawai'i actually being lower than for the previous year of participation. Clearly, there is a problem in the area of health care and health status for persons with disabilities.

In Hawai'i, significant differences have been found in health status across cultural or ethnic groups. For example, persons of Hawaiian ancestry have the highest percentage of low birth weight babies and adolescent pregnancies (Hawai'i State Department of Health, 2002). An examination of cancer screening by subgroups of Asian American and Pacific Islander (AAPI) women has found evidence of disparities in the receipt of cancer-screening services; AAPI women are less likely to receive cervical and breast cancer screening (Chen et al., 2004; Tan, 1999). Furthermore, Southeast Asian, Korean, and Chinese women have been found to have the lowest Pap smear rates of all AAPI women, a finding consistent with observed higher cervical cancer rates among Southeast Asian women (National Center for Health Statistics, 2002). Clearly, there is a need to understand why disparities such as these exist; there is a need to examine the interaction between practices and expectations in the health care delivery systems, and the cultural backgrounds and values of those delivering and receiving health care.

What is not known is the degree to which there are overlapping influences in these examples and in the core indicators data. Did cultural factors influence the core indicators health data for persons with developmental disabilities? Does the data reflect primarily disabil-

Table 1. Core Indicators Health Data for Persons with Developmental Disabilities: Hawai'i and the Nation

Indicator	2001		2002	
	Nation	Hawai'i	Nation	Hawai'i
Physical Exam	87%	53%	88%	49%
OB/GYN Exam	46%	27%	55%	18%
Dental Visit	46%	20%	52%	26%

ity-related issues, culturally-related issues, or both? What are the relative contributing factors for each? And what is the impact of culture and ethnicity on the development of chronic diseases among persons with disabilities? Such questions have yet to be adequately answered in Hawai'i and elsewhere.

In addition, Hawai'i, as elsewhere, has moved from a paradigm that viewed disability as a medical problem requiring medical management with the goal of "fixing" the problem (medical model), to a paradigm that views disability as a product of interactions between multiple individual characteristics (social model). It is not known how this paradigm shift from a medical model to a social model differs across cultural groups.

All of the questions identified above must be addressed if effective strategies for health care delivery for persons with disabilities, including care coordination, are to be designed and implemented.

Millie's Story

It was difficult to understand Millie. Her speech was laborious because of cerebral palsy and even worse because calcium deposits on her vertebra affected her neck muscles. The staff at Rehab was kind, but in a hurry. Many had been trained in another country and spoke English as a second language. However, the language difference was less important than the attitudes the caregivers brought with them from their culture.

Their previous experiences and expectations led them to think that anyone with difficulty communicating had significant cognitive limitations. Millie tried to ask them to warn her before they lifted her stiff hands so she could prepare herself. They smiled and nodded but didn't understand. So they picked up her hands without warning. Millie yelled loudly. Millie's mom would visit and the nurses would ask her how Millie felt. Mom reassured the nurses they were doing a good job, but she didn't tell them to listen to Millie. Even Millie's mother was a part of the cultural divide; as a Pacific Islander she was not able to be critical of caregivers and sought to avoid confrontation. So Millie yelled.

Finally Millie complained to a friend, "They only see the physical, not inside you." They decided to provide a little education. They wrote down all the words Millie had to say and posted them on the walls of Millie's room. They wrote ideas like, "When you don't understand, ask me to repeat. Two or more times if necessary." They wrote, "No pureed food!" They wrote, "Millie is not deaf or dumb. She respects your intelligence, please respect hers." Over time, her room was covered in words. The staff was amazed. They began to respect her, and working together Millie finally left the hospital. She never reached her goal of walking again, but she did regain her self-respect and dignity.

Finding Answers

If the nation is to achieve the Healthy People 2010 goals of reducing health disparities, and if individuals such as Millie are to receive the quality health care they need, a great deal of work must be done during the last half of the decade. Some questions that demand to be addressed are as follows:

- What barriers to health and wellness for persons with disabilities exist by cultural group? How do they differ by specific disability?
- How do cultural beliefs and attitudes of health care providers and consum-

ers contribute to health disparities for persons with disabilities?

- What is the impact of income and education on the health status of persons with disabilities across cultural and ethnic groups?
- What is the extent of chronic illnesses among persons with disabilities and how does this differ by culture or ethnicity?
- What are the differences in anticipatory guidance and preventive services provided to persons with disabilities across different cultural groups?
- How do people with disabilities from different cultural groups approach issues of physical energy, pain management, and personal control?

In Hawai'i, we are aware of the health disparity issue and are actively seeking resources to begin to answer the questions posed above. One of the areas we're addressing is ensuring that the data gathered through the Healthy Hawai'i 2010 project includes data on persons with disabilities across cultural groups. The questions and issues raised in this article are not relevant just to Hawai'i. There are individuals like Millie everywhere. There is a need to find ways

everywhere to gather the data that will illuminate the relative roles of disability and culture, separately and in interaction, in health disparities that exist in this country, and then to shift health care practices accordingly.

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Applying Cultural Competence to Disability

Many individuals with disabilities contend that they represent a distinctive cultural group based on the shared experience of disability. Just as strategies can be developed by health care providers to ensure competence in addressing ethnic and linguistic differences, so strategies can be developed to enhance cultural competence in relation to disability. The following is an example of ways to start applying cultural competence to disability culture:

<u>Strategy</u>	<u>Ethnic/Linguistic</u>	<u>Disability</u>
Hire interpreters	Hire bilingual interpreters knowledgeable about health care terminology	Hire staff trained in American Sign Language, familiar with technology-based communication, knowledgeable about health care terminology
Create a culturally-friendly atmosphere	Have signs in multiple languages, hire culturally-diverse staff, have cross-cultural and multi-lingual reading material in waiting areas	Configure service counters for wheelchair approach at eye level; hire staff with disabilities; have disability publications, and large format and Braille reading material, in waiting areas

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Health Care Coordination for Persons with Disabilities: Its Meaning and Importance

by Brian Abery, Rhonda Cady, and Erin Simunds

Pam is a 36-year old woman who lives in a large urban area in the Midwest. Until recently she was employed as a computer programmer; she was let go because of layoffs at the business and because of some of the complications she experiences due to cerebral palsy (spastic type) that affected her work performance. Over the past several years, her ability to efficiently operate an adapted computer keyboard and use her wheelchair have declined due to the loss of muscle flexibility. She also has an increasingly difficult time independently completing many activities of daily living including dressing, making meals for herself and eating, and getting safely from place to place in the community. The muscle tightness has also made it difficult for Pam to sleep well and it causes her a great deal of pain. She has become susceptible to upper respiratory tract infections, which at times have resulted in pneumonia.

For many years, Pam attempted to navigate the health care and social service systems on her own with limited success. She had several different primary care physicians, none of whom appeared to take very seriously her pain and increasing mobility limitations. The professionals who provided “support” would neither prescribe the medications needed for pain relief nor seriously consider alternative methods of treating her decreased flexibility in a manner that improved her functional abilities and lessened discomfort. In addition, with her increasingly limited mobility and independence she has had to seek assistance with a number of daily tasks. She tried to find assistance on her own, but did not know where to look. Her research led to organizations that promised to address one or two of her multiple concerns, but she could not find one resource to address all of her medical and other support issues.

Two years ago, Pam finally found someone who could help her navigate these complex systems. She joined an agency that provides care coordination for all of her health care and social service needs. Through her care coordinator, Pam found a primary care physician who not only understands her disability, but is a resource for assisting her to effectively deal with her other medical needs. Her care coordinator has assisted Pam in obtaining an appropriate wheelchair that meets her unique needs, wrist braces, adaptive equipment for her computer, a personal care attendant (PCA), and a variety of other supports. Pam was also introduced to a support group that specializes in her disability, providing a means for emotional support and information sharing. In addition, her care coordinator makes sure that she has transportation for clinic visits and provides telephone triage of health concerns before they become major issues that might result in hospitalization or the need for long-term treatment. If she does not get the answers she needs from health care and other service providers, Pam’s care coordinator is available to serve as her advocate with the goal of assisting Pam to more effectively advocate for herself. Today, Pam is receiving the health care and other supports she needs to reduce her pain and increase her functional abilities and independence. She has just begun exploring additional assistive technology that will enable her to be employed again.

Pam is a composite of a number of individuals we have met, and her story is typical of their need to navigate the health care system along with other supports and systems in a way that addresses complex, ongoing medical needs in the context of a whole life. One strategy that is holding out promise for making the navigation process easier and more effective is care coordination.

From Case Management to Care Coordination

What is care coordination and where has the idea come from? Case management has been used in the disciplines of nursing, social work, and public health since the early 1900s. The evolution of managed care organizations in the 1990s, however, precipitated the widespread use of this approach throughout health care, insurance, and social service settings. Across the years, case management has been characterized by supervision or oversight of care or supports, monitoring of the utilization of high-cost / high-use consumers of services, and employment of a medical model for coordinating authorized services within a single organization that delivers care. Although case management appears to meet the needs of many individuals with acute, episodic conditions, this approach is not necessarily promising as a strategy for persons with multiple and chronic conditions.

New paradigms are needed that more effectively address the needs of persons with disabilities and/or chronic illness and the effects of multiple health-related conditions on their lives. In addition, the necessity of close coordination between primary care physicians, medical specialists, and other human service supports (e.g., housing, transportation, childcare, vocational supports) needed by this segment of the population must be considered. The Chronic Care Model developed by Dr. Ed Wagner (ICIC, 2004) supports the need for care coordination, rather than case management, for individuals with multiple and chronic conditions. Proponents of the model believe that persons with complex, chronic conditions are best served when support systems consider all essential elements critical to persons leading a high quality of life. But what exactly does care coordination involve?

Description of Care Coordination

The specifics of this approach to coordinating supports for persons with complex health care and other needs must differ depending upon the unique needs of each individual. Generally, however, it is the responsibility of the care coordinator to ensure effective communication and information exchange within and between organizations including health care providers, social service providers, and state and county government agencies, resulting in high quality care and support for the individual with complex health care and other needs. Care coordinators must therefore have knowledge of and be able to work within a variety of different systems, bringing them together to create a seamless set of supports. Individuals serving in this role, for example, may assist persons with disabilities and/or chronic illness to find appropriate housing, gain access to reliable transportation, and locate primary care physicians who understand their unique health care needs. The role of a care coordinator also extends to ensuring that the individuals they serve are attentive to their own health care and other support needs, and use available supports in a cost-effective manner. For example, a care coordination agency may offer 24-hour phone contact for use by those it supports when they need immediate evaluation of health concerns to ensure that illnesses and other conditions are attended to promptly and appropriately, reducing the need for emergency room care or hospitalization.

Care coordinators may work within an organization specifically established to provide care coordination, or they may be employed within a health care, disability service, or social service agency. They are often social workers or nurses by training. That professional training, however, often does not adequately prepare them for their roles as coordinators. Most learn how to effectively serve in the care coordinator role through “on-the-job” training.

One of the inherent challenges of the care coordination role is that, in order to be most effective, coordinators must

view themselves not as advocates for the system within which they may work, but rather, for the persons with disabilities and/or chronic illnesses whom they support. A care coordinator for example, may need to assist a person with a disability to document the need for durable medical equipment and then help ensure that the person receives the funding to purchase the equipment. Serving in such a role, of course, has the potential to create conflict between the care coordinator, the organization that employs him or her, and the agencies that provide direct supports to the person. Such situations can present care coordinators with significant challenges that can be best resolved only if those serving in this position keep first and foremost in mind their primary responsibility to serve and support the persons with disabilities for whom they work.

Another aspect of the coordinator role that may be challenging is to advocate only when necessary. Coordinators are to support persons with disabilities to develop and refine their own personal advocacy skills so that they experience greater self-determination and independence and, over time, require less support from their care coordinator.

Care Coordination Outcomes

The critical outcomes of care coordination include the following:

- Facilitation of access to a variety of medical and non-medical services that will assist individuals in meeting their health care needs and living the lives they choose in the community.
- Productive interactions between informed, activated patients and the multiple staff persons who provide them with services and supports.
- Prepared, proactive support teams that create environments in which consumers make progress toward positive functional and clinical outcomes.
- Monitoring of the quality of services and supports received by individuals.

- A level of flexibility that allows consumer direction of health care to the degree desired by the individual.
- A service model emphasizing development of new resources, linkages between existing service agencies, coordination of care, advocacy, and education of the consumers, providers, and funders of health care and social services.

Research documenting the achievement of these outcomes through care coordination practices is in its early stages. Preliminary studies conducted by the National Rehabilitation Hospital, however, show promising results (Palsbo et al., 2004). For the past two years, data has been collected from adults with physical disabilities who are Medicaid eligible and receiving services through a managed care organization that provides care coordination. Preliminary analysis of the data reveals that hospitalizations have been reduced by 50%, reducing health care costs and disruption to individuals' lives. In addition, 89% of members reported higher levels of satisfaction with their health care services in the year after enrollment compared to the year prior to enrollment, and 94% reported they were involved as much as they wanted to be in their own health care decision-making.

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Comprehensive Service Coordination Organizations: A New Health Care Model

by Susan E. Palsbo and Margaret Fisk Mastal

One of the greatest challenges in health services research and policy is devising an appropriate delivery system for the most expensive health care users. In any given year, about 20% of the insured population in the U.S. incurs 80% of the health care costs. This 20% is comprised of two groups of people: those with *non-systematic* risk, who have one-time acute care needs (e.g., pneumonia, broken bones), and those with *systematic* risk.

Comprehensive service coordination appears to be a promising approach for people with disabilities and other complex medical needs.

Those classified with systematic risk are people with long-term chronic needs, for example people with diabetes, heart/lung abnormalities, cerebral palsy, epilepsy, Fetal Alcohol Syndrome, and other complex medical conditions or disabilities. Managed care organizations (MCOs) are successful at controlling costs and providing preventive and acute care for the people with non-systematic risk. They are so successful that “unmanaged care” for the general population is a thing of the past in private sector insurance. In contrast, the results of the managed care experience for people with systematic risk is mixed. Some MCOs have tackled two subgroups of people with systematic risk: frail and nursing home eligible elderly, and, more recently, people with prevalent chronic conditions such as diabetes, asthma, or chronic obstructive pulmonary disease (COPD). Studies suggest that at least some MCOs are successfully providing quality, cost-effective care for

these populations. This is not the case for the subgroup of people with disabilities and other complex medical needs.

Most states do not include children and adults with disabilities in Medicaid managed care programs. Historically, state legislators and disability activists have feared that the financial incentives inherent in MCOs designed for people with nonsystematic risk will lead to undertreatment, restricted access to services and providers, and poor care quality. These fears appear to be realized when one looks at managed care utilization data on people with disabilities, as well as the results of focus groups and interviews (Kroll & Neri, 2003; Palsbo et al., 2004; Scheer et al., 2003). Yet, in theory, organized delivery systems should be well-suited to arranging care for people with disabilities and other complex medical needs. When people with disabilities are asked to design the ideal health care system, they describe something that sounds very much like an MCO (Kroll & Neri, 2003; Palsbo et al., 2004; Scheer et al., 2003). Six desired attributes consistently rise to the surface:

- Comprehensive and flexible benefits tailored to people with disabilities and other complex medical needs.
- Timely access to knowledgeable, high quality physicians.
- Integrated care management teams in constant communication with each other and the person with a disability or other complex medical needs.
- Financial incentives aligned with providing high quality care.
- Live at home when medically appropriate.
- A single person who assembles resources and advocates for the participant.

Thus, our challenge: How can we design a health care delivery system that takes the best attributes of MCOs and successfully adapts them to provide high-quality, cost-effective care for people with disabilities and other complex medical needs? Several disability organizations and state Medicaid programs are answering this question through pilot programs offering comprehensive service coordination.

Comprehensive Service Coordination Pilot Programs

At least 10 states are piloting comprehensive service coordination programs for Medicaid adults with disabilities, including Florida, Massachusetts, Minnesota, New Mexico, New York, North Carolina, Oregon, Vermont, Wisconsin, and Washington, as well as the District of Columbia (Palsbo & Mastal, 2004; Rosenbach & Young, 2000). These pilot programs are a new breed of social services delivery system. We suggest calling them Comprehensive Service Coordination Organizations (CSCOs) to describe the medical and social services domains they encompass, as well as the various sources of funding.

In 2004, we visited seven pilot programs for adults of working age with physical or behavioral disabilities. Each is unique, with different target populations, financial incentives, missions, and staffing. Despite these differences, they have many similarities. These include:

- Using advance practice nurses, general and specialized registered nurses, and social workers collaborating as teams.
- Coordinating medical and behavioral health services.
- Coordinating social and life services (housing, transportation, personal care assistance, etc.).

- Emphasizing patient-centered, planned health and life care.
- Developing a carefully selected provider network.
- Creating a culture of deep commitment to partnering with the individual so that each moves beyond day-to-day management of the consequences of disability and participates in higher-order life activities such as personal relationships, parenting, community involvement, and employment.
- Being dedicated to improving the quality of care and services.

At all sites, about 60% of the participants have behavioral issues as a primary or secondary disability. Each site has had to grapple with integrating physical, behavioral, housing, and support services. Most sites team an advance practice nurse with registered nurses and a social worker. The advanced practice nurse facilitates

At least 10 states are piloting comprehensive service coordination programs for Medicaid adults with disabilities.

communication across diverse providers, assembles and manages meetings among interdisciplinary teams of practitioners, and develops a comprehensive health management plan. The advance practice nurse, depending on state law and organizational policy, also has considerable authority to prescribe medications and treatment. Generally, the teams meet regularly, discuss each beneficiary's needs, and authorize the appropriate services such as medical supplies or equipment. At least one person on the team makes routine home visits.

Another common feature is that nurses often accompany participants on

physician visits. Participants report that their physician encounters are much more productive when a care coordinator nurse attends. The nurse serves as an objective intermediary and coach who knows what questions to ask and how to interpret the responses in ways the participant can understand. The nurse also helps the participant to follow through on the physician's instructions, such as filling prescriptions or making appointments with specialists.

Most sites help their participants gain control over their lives by shouldering the burden of scheduling appointments and providing reliable transportation services. The programs also corral all of the physician orders and diagnostic testing values, often electronically. Some programs help the participants organize hard copies of appointment schedules, contact information, and physician orders in a binder or journal.

Written health management plans are the cornerstone of comprehensive service coordination. These are updated at least annually, and more often when needed. Each participant has substantial input into his or her plan. Interestingly, most programs have had to scale back their expectations of solving all problems at once to a pace that is comfortable for the participant. The participant has to be willing and ready to change their health choices. Several venues employ "harm reduction" as a long-term goal, rather than harm elimination (e.g., reduce the number of cigarettes rather than quitting smoking altogether). In addition, the programs have learned that some participants are not interested in having an active role in designing individualized coordination plans, while others are highly engaged in the process.

In all these programs, care coordinators have to bridge multiple social service agencies as they assemble the arc of services. A single participant may be working with a housing agency, child protection services, WIC, a community asthma intervention program, school personnel, and substance abuse treatment. This means the program has to coordinate with the other case workers

to prioritize the issues to be tackled. Health-related issues may have to wait several months until more immediate concerns are resolved.

With so much going on in participants' lives, most programs maintain an extensive medical-social electronic record for each participant. Some have invested heavily in flexible information system reporting tools. The databases allow the programs to stratify their participants into high, medium, or low resource users. In turn, this helps senior managers to allocate the case load equitably across the coordination teams. Many programs also use their database to identify formal quality improvement projects and monitor progress toward meeting quality improvement goals.

All sites proactively communicate with participants on a regular schedule, often through home visits. This function plays a key role in detecting social or medical problems before they prompt a crisis. Care coordinators provide a single point of contact available 24 hours a day every day. Most programs assign one team member as the primary contact person for the participant. This team member carries a cell phone and can be reached at any time. The assigned team member is a gate-opener to all the benefits and services described in the management plan.

Service Coordination Financing

One of the most striking differences across the seven pilot programs we visited is in financing service coordination. The programs have two different approaches. Some are paid a fixed fee per person per month, with slightly more money for more complex beneficiaries. The program funds coordination of services through savings achieved in shorter hospital stays, deinstitutionalization, and medical stabilization/early interventions. Several sites enroll dual eligibles under Medicare waivers, and are paid almost three times as much for their enrollees as other Medicaid managed care plans receive for non-frail beneficiaries. In this financing model,

[Palsbo, continued on page 34]

Strategies for Meeting the Needs of Persons Moving Out of Nursing Homes

by Lee Bezanson

It has been five years since Lois C. and Elaine W. successfully sued for the right to live in their communities in Georgia; in the landmark *Olmstead* decision the Supreme Court interpreted Title II of the Americans with Disabilities Act (ADA) to require states to administer programs “in the most integrated setting appropriate to the needs of qualified individuals with disabilities” (*Olmstead v L.C.* 527 U.S. 581). The Court noted, “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement and cultural achievement.” In the intervening years, Congress has appropriated funds for “systems change” grants and President Bush announced his New Freedom Initiative to “tear down barriers to equality” for individuals with disabilities or chronic illnesses. States and consumer advocates have responded to the *Olmstead* challenge with multiple strategies to strengthen programs that support individuals with disabilities to live successfully in their communities. One important component of these efforts is directed at nursing home transition.

Nursing home transition programs work to identify institutionalized individuals who want to move back to the community and to assist them to make the transition successfully. Transition works when an individual is highly motivated to succeed and invests himself or herself in the transition process. Beyond this motivation, transition is all about planning and more planning. This planning, while detailed, is not rocket science. It requires methodically thinking through all of the supports that will be necessary to support the individual in community living. Most of us have done this planning in our own lives without thinking much about it. Where will I live? What kind of home do I want?

With whom do I want to live? How will I get around? How will I support myself? How will I manage my health? It is no different for individuals with complex support needs except that these complexities present more logistical challenges in planning and implementation.

In this article, we will look at the transition process from a systemic approach that focuses on the components of successful transition programs. The first step in creating a transition program is to think through all of the requirements for success. Without careful planning in the beginning, every transition program risks failure. To the extent it is politically feasible these programs also include diverse stakeholders in every stage of planning and evaluation. All successful programs consider in great detail at least the seven questions described below before embarking on any transitions.

How Will We Identify Appropriate Individuals?

If individuals don't know they have a choice, they don't know to speak up. Many individuals who live in institutions have been told that is their only option. Without education that community options exist, even for those with severe disabilities, these individuals are unlikely to ever consider whether they would prefer to live elsewhere. As one person asked, “What am I allowed to want?” (Assistive Technology Partners, 2004). Good programs educate broadly about available options, and put in place processes that allow the individual a strong and valued voice in expressing preferences for particular options.

Once a program knows who is interested, the next step is to assess with (not for) the individual what supports will be needed for a successful transition. Every institutionalized individual has a story

to tell and this story is a good starting point for assessing the supports needed. A person's story reveals what supports failed that led him or her into the institution in the first place. Good programs presume an individual can transition regardless of the complexities of support needs, and focus available resources to craft a customized plan.

How Will We Educate on Transition as a Viable Option?

Until nursing home transitions become more commonplace we can expect resistance from families and professionals who hold strong, if erroneous, beliefs that individuals with severe disabilities cannot live safely in community settings. Good programs work to educate families, professionals, providers and the public that community options not only provide safe living arrangements, but also lead to healthier outcomes and increased consumer satisfaction (Foster et al., 2003).

Are Community Supports Available?

Communities vary greatly in the amount of infrastructure they offer to support individuals with disabilities. Each transition plan must assess whether the local community structure is adequate to provide the supports that the individual will require. If not, creative problem-solving can be used to create new approaches of support that fill in the gaps in the community structure with less formal supports. Informal community supports can arise naturally through relationships with family and friends or can be arranged by seeking out volunteers from faith communities or other groups.

What Will be the Transition Process?

Individuals with complex support needs have to understand from the outset that making the transition may involve a lengthy process. The process will include all the following:

- Consumer interviews
- Person-centered planning
- Development of the transition team (consumer, family, friends, supports broker, other)
- Assessment of medical needs
- Assessment of support needs
- Assessment of gaps in community infrastructure
- Solutions to fill community gaps
- Concrete plan
- Consumer contract
- Timelines and checklists
- Quality assurance/improvement
- Transition day planning
- Follow-up

The individual has to consider how all the supports he or she has relied on the institution to provide will be obtained in the community. Institutions generally provide housing, utilities, meals, medical and dental care, transportation, social events, religious services, and personal care by professional staff.

Many individuals develop a dependency in the institutional environment and need help to think through how to manage for themselves in the community. Key areas to explore include:

- Housing
- Transportation
- Recreation/social interactions
- Spiritual/religion
- Utilities
- Work
- Income sources
- Assistive technology/home modifications
- Personal assistants
- Funding of supports and expenses
- Dental needs

- Medical needs including insurance and finding a primary care physician
- Mental health/substance abuse issues, if applicable
- Case management, if appropriate

Do We Have Assessment Tools and Train Staff in Their Use?

Successful transitions involve evaluation of an individual's needs across all aspects of community living. Good programs develop practices that standardize the assessment processes that will be used throughout the transition. Much of this standardization is accomplished through the development or acquisition of tools that can assess an individual's support needs, assess community capacity, and assist the individual to create a community living plan within the resources available. Once the tools are available, extensive staff training in their use assures the integrity and consistency of the transition program. Michigan characterizes staff needs to include "people who are knowledgeable about resources, familiar with how nursing homes function, skilled at building rapport and trust, experienced in assessing care needs, and alert to medical issues. Additional traits are resourcefulness, creative problem-solving, strong organizational skills, reliability and attentiveness to detail" (MACIL, n.d., p. 9).

What is the Follow-Up Plan?

No matter how careful the planning, the individual and those assisting him or her must expect the unexpected. The dynamics of community living will produce challenges that no one anticipated in the transition process. Follow-up strategies assure that the individual has support to confront and meet these unexpected challenges, including strategies for back-up for personal care workers and strategies to manage acute health events that may result in short-term hospitalization. Good programs have follow-up procedures for the day of the transition, the week after transition, the month after

transition, and ongoing as needed by the individual. These programs also recognize that re-learning to live in the community is itself a dynamic process and that many individuals want to work into full independence over time; these individuals may require long-term follow up.

Do We Have a Quality Management and Improvement Strategy?

A quality assurance and improvement strategy for a transition program accomplishes multiple goals. It measures outcomes with meaningful metrics, provides a mechanism for continuous feedback from the individuals in the program, and generates the data to justify continuation of the program. Good programs routinely measure outcomes and consumer satisfaction and use the data collected to evolve new strategies to improve both.

Conclusion

Experience shows that individuals of all ages who have complex support needs can successfully transition from institutional settings to community living. Success requires a motivated individual together with careful and comprehensive planning that views the individual holistically. And, in the long run, individuals who sustain success surround themselves with family, friends, and others who can help create an environment in the community that supports them to live the life they choose.

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Children with Special Needs: Integrating Health Care and Family Support

by Margaret Fisk Mastal

All children are vulnerable – their lives, health and welfare dependent on others. However, children with special needs, particularly in the Medicaid system, are at critical risk, their defenselessness at times reaching toxic levels. This high risk stems from absent or minimal coordination of care resulting from a confluence of factors that may include inexperienced and/or ill-prepared provider systems, state programs and funding streams that do not support holistic health and life care, and complicated family and home environments. For children with special needs, quality health care is particularly critical, but their welfare also requires integrated supports for their families as well.

Inadequately Prepared Provider Systems

The adequacy of provider systems is frequently dependent on geographic location, the availability of appropriate specialist care and community services, and providers' insights into the multiple health, family, and life needs of children with special needs. Rural areas often lack the diverse types of specialist care needed, with those that are available often at great distances; transportation to receive even basic care frequently poses a distinct challenge.

Health care provider systems are not always expert in treating children with disabilities, nor are they sensitive to the impact of the tangled complexity of these children's health, developmental, psychosocial, educational, and functional life needs. Provider systems for children with special needs would also benefit from supports – care coordination professionals to support and enhance their ability to provide quality health and life care.

State Programs

While many states have some type of program for children with special needs, most of these programs are constrained by tight Medicaid budgets and by the inexperience of the industry in designing programs that coordinate health and life care services to holistically meet the needs of the child/family unit. Coordinated care for this population is often haphazardly achieved due to ineffective systems. For example, some of a child's problems such as mental health needs are carved out of the coordination process or, in some cases, are addressed by multiple agencies with their own agendas and funding streams, staffed by a variety of professionals who have little communication with each other. The result is fragmentation and/or duplication of benefits with critical elements of care often overlooked, poorer child health and functional states than need be, and providers, caregivers and payers who are frustrated.

Family Needs

The families of children with special needs who receive health care supports funded through Medicaid have not only the child's disability with which to contend, but often have other family needs, as well. Parents are often unschooled about navigating the complexity of health and social agencies necessary for the child to reach optimal health, and need assistance with that process. In some families, children may reside with a grandparent, other family member, or a guardian, or reside in a foster home as the parent is absent, incarcerated, ill, or has a mental health and/or substance abuse problem. These caregivers often require support in securing the benefits that serve their child best, as well as supports for the caregivers and the family as a whole.

What's the Answer?

There's no magic prescription that will solve every state's, provider's, family's or child's problems. But there are programs that are making a difference. Care coordination programs focusing on improving the health and life of children with special needs have developed strategies that improve the status quo. Hallmarks of these programs include:

- Providers, care coordinators, and state agencies who are intensely committed to maintaining the child in the community, including the family in all decisions and options, and supplying benefits unique to the individual child's needs.
- A central care coordination agency with a child/family centered approach that have integrated, expert teams that formally plan health and life care.
- Consistent communication among the provider community, the family, and care coordination organization.
- Integrated funding streams.
- Databases that provide useful information.
- Planned health care quality assurance and improvement strategies.

Barriers to optimal health, function and life are formidable for children with special needs. Yet, coordinating and providing the best care to each individual child is within our grasp – not easily or quickly achieved, but well within the realm of possibility. It will take planning, commitment and the judicious use of available dollars to make it happen.

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Care Coordination in the Transition Years: Gillette's Lifetime Speciality Healthcare

by Ronna Linroth

The passage from adolescence to adulthood is often a time of internal and external upheaval. It can be especially complex and anxiety-provoking for young adults with special health care needs, their families, and those who work on their behalf. Unfortunately, during the period of transition, there is likely to be a hiatus in the provision and utilization of appropriate health care (Carroll, 1983). For some youth who have been through multiple procedures and have long histories of spending school vacations recovering from surgery, there is a health care fatigue that prevents them from seeking out appropriate adult care. For others who have enjoyed pediatric models of coordinated care and welcoming specialists, the adult world is too fragmented, and the roles of self-advocacy and medical decision-making are too new. Navigating the adult world of insurance and learning about coverage changes is daunting.

In 1999, Scal et al. reported that in their study of trends in transition, the lack of adult medical providers interested in transition health issues appeared to be the primary obstacle in the development of transition health service programs. They suggest this may be a reflection of a lack of training in transition health issues. Thus they conclude that it appears that the most significant barriers to transition are not the resistance of adolescents or their parents, but limitations in health care systems. The attention to addressing this important health care concern is growing in children's hospitals across the country. Issues in health care transition that must be addressed include the provision of services, financing of care, training of staff, and research.

Gillette Children's Specialty Healthcare in St. Paul, Minnesota has undertaken a multi-year plan to ensure continuity of quality care for transition-

age young people with special health care needs. In 2001, it developed the Lifetime Specialty Healthcare clinic for adults with childhood-onset conditions; in 2004 it adopted a transition philosophy and policy; and in 2005 it will open an adult inpatient unit.

At the start of Gillette's shaping of its plan for adolescent and adult care, it convened focus groups of adults with disabilities and asked why transition to community-based adult care was not meeting their needs. They reported that they needed a medical and rehabilitation staff that was skilled, understood the context of disability, and would be responsive to their needs. They wanted to be treated with respect, which meant to be listened to, have their preferences acknowledged, and have their privacy considered. They wanted appointments that would allow them the time to be able to communicate their most important concerns and questions to care providers. In response to this input, the Lifetime Specialty Healthcare clinic was established to provide coordinated, integrated visits where the physician and other rehabilitation staff communicate with each other and the patient. The patient is expected to be as participatory in the prioritization of goals and in decision making as they are capable of being. Appointments are lengthy for new patients to allow for discussion with a social worker; screening by occupational and physical therapists, speech language pathologists, seating specialists, and orthotists; a health assessment by the nurse; and 40-60 minutes with the physician. Specialty clinics were assembled within the Lifetime clinic; these are days set aside each month to bring together the teams needed to best address a specific patient population. For example, a physical medicine and rehabilitation specialist and an internal medicine physician for the cerebral

palsy clinic, and a neurosurgeon, urologist, and physical medicine and rehabilitation specialist for the spina bifida clinic. This encourages a comprehensive look at an individual's health status and promotes interdisciplinary communication and the engagement of the patient and their caregivers.

In September 2004, Gillette adopted a policy whereby all patients age 16 and older would be assessed for their readiness for transition to adult care providers. Gillette's goal is that patients will be introduced to transition at age 14, have a written transition plan at age 16, and be prepared to go to adult care by age 17. Patients will receive a transition binder that educates them on the activities that occur in transition, provides checklist type tools that will help to assess self-advocacy skills and self-awareness, and supports the organization of paperwork such as dictations from visits and insurance information.

The success of Gillette's Lifetime Specialty Healthcare clinic is due in part to providers who recognize the needs and preferences of young adults with childhood-onset conditions. In Gillette's previous attempts to transition young adults to other adult specialty providers in the community, they kept coming back because they preferred caregivers who understood disability even through they were oriented toward pediatric care. Now, they can transition to adult health care at Gillette.

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Meeting Social Service and Health Care Needs in NYC: Independence Care System

by Rick Surpin

Independence Care System (ICS) is a nonprofit, Medicaid managed long-term care plan serving adults with physical disabilities in New York City. Through coordinating and providing a wide range of health and social services, ICS allows many New Yorkers with disabilities to live independently in their own homes.

In New York City, as in many places, adults with physical disabilities have limited access to appropriate and effective health care and social services. Viewed as “problem consumers” who take up too much time and have unusual problems that are not easily addressed, many of their basic needs are virtually ignored by the system. ICS’ mission is to turn the prevailing approach on its head and build a system designed to meet the social service and health care needs of adults with disabilities, a system based on their determination of their own needs and active participation in managing their own care.

ICS is jointly sponsored by the Paraprofessional Healthcare Institute (PHI) and Cooperative Home Care Associates (CHCA). PHI is a national nonprofit organization that conducts policy research and advocacy related to creating high quality jobs for paraprofessionals in long-term care. CHCA is a worker-owned home care agency that is widely recognized as a model for providing both high quality home care paraprofessional jobs and high quality services to persons with disabilities and seniors.

ICS began operation in 2000, and today has approximately 650 members. Members must be at least 21 years old, eligible for Medicaid and for placement in a nursing home. Most are Latino or African-American (90%), women (60%), and under 65 years of age (90%), and 50% are dually eligible for Medicare and Medicaid. Their disabilities are primarily due to severe injury or degenerative neurological and muscular diseases.

The ICS Program Model

ICS is paid by Medicaid for the following set of services:

- Care coordination. Coordination and management of all member health and social service needs, including physician and hospital services.
- Home care aide services, including home health aides, personal care aides, home attendants, and personal assistants.
- Home health nursing: physical, occupational, and speech therapies.
- Nutrition services.
- Home delivery of meals.
- Medical equipment and supplies, including prosthetics and orthotics.
- Transportation (non-emergency).
- Prescription and non-prescription drugs, if ordered by a physician.
- Respiratory therapy.
- Dental care.
- Optometry, including eye exams, glasses, and other vision services.
- Audiology and hearing aid services and equipment.
- Adult day health care.
- Social day care.
- Social and environmental supports, including respite, chore/housekeeping services, and home modifications.
- Personal emergency response system.
- Site-based rehabilitation services, including physical, speech, and occupational therapies.
- Nursing home care.

The services are covered through fixed, or “capitated,” monthly payments for each member. This payment system allows us to provide some services that are not available in fee-for-service, such as care coordination, and make more flexible service arrangements than is

possible in fee-for-service. Inpatient and outpatient hospital services are billed to Medicaid fee-for-service. All Medicare services for the dually eligible are billed directly.

Our program model is based on three fundamental premises:

- People with disabilities need medical services episodically while their daily living needs are primarily social. They need a service system which blends the social and medical models of care.
- Each individual with disabilities has unique needs and preferences, which must be recognized and addressed. What is most valuable to one person will probably not be the same for another. We need to enable each individual to get what they consider valuable as much as possible.
- People with disabilities typically know a great deal about their bodies and their needs. They often can take the lead role in planning and managing their own health care and social supports. They need knowledgeable people to collaborate with them in making the system work for them.

The core of our approach is an interdisciplinary care management process with either a nurse or social worker serving as the primary care manager. The care manager is responsible for working with the members to coordinate their overall care and identify gaps in needed services. An individualized plan of care is developed with each member soon after enrollment based on their priorities and their choices about their providers. The plan is reviewed every four months and re-done annually. ICS also has an advocacy department, led by a disability rights activist, that forms a special bridge to members and advocates both within and outside the organization for their needs.

[Surpin, continued on page 35]



“Without Independence Care System, I’d be Dead.”

To understand what Independence Care System (ICS) means to Wilfred Graulau, you have to know where he came from. “You have to know the pieces they picked up,” he says. Wilfred grew up in the South Bronx. When he was 12 years old, he fell in love with art. In any class, he could be found furiously pencil sketching. His teachers collected his drawings, which he assumed they were throwing out. Instead, they made a portfolio and sent it to Manhattan’s High School of Art and Design. Wilfred got in, and his talent blossomed. But one night in 1969, while he was walking down a South Bronx street, a bullet pierced his 17-year old neck and lodged in his spine. Wilfred left the hospital in a wheelchair, paraplegic.

Wilfred’s fierce spirit helped him face adversity and become not only an artist with a job at the Fashion Institute of Technology, but an activist who helped force New York City to install the first wheelchair ramps in city-owned buildings. He drove a Nissan Maxima, flew to Puerto Rico for vacations, and maintained a 32 -inch waist. “Those were the best days of my life,” he says. “I had a job I was secure in, and I loved doing it.”

Then, calamity struck again. A wound, a decubitus ulcer, on his lower back would not

heal. He went back and forth to doctors’ offices and emergency rooms, receiving questionable care. At home, it fell to Wilfred and his sister to cleanse, pack, and repack the wound several times a day, which requires specialized clinical management. Without that clinical oversight, Wilfred’s infection raged and his health deteriorated. In October 2000, he was hospitalized, barely conscious. Even when the infection was under control, hospital staff said he needed rehabilitation at a nursing home. He was admitted for a stay of two weeks. Two years later, Wilfred was still there. In the meantime, he had lost his job, car, and independence. “It was as if my life before the nursing home had never happened,” says Wilfred. “I wasn’t a person anymore, I was this 105-pound thing, hanging on the edge. I didn’t know if I was going to live or die, and it didn’t seem to matter. I thought I’d never get out.”

Hope arrived in the form of a young man named Yuri Martinez, ICS’s assistant director of community outreach. Martinez had come to talk to the nursing home’s admissions counselor about ICS. The counselor casually mentioned Wilfred. Martinez paid Wilfred a visit. “Yuri was saying, ‘Whenever you’re ready to leave this place, let us know,’” reports Wilfred. But Wilfred was full of distrust. Still, he kept Martinez’s business card. Over the next few months, Martinez called Wilfred four or five times, “just checking in.” Then at a discharge meeting, the home told him their plan: Wilfred was to get himself into a homeless shelter to qualify for emergency services. Wilfred was enraged. He had no intention of “volunteering myself to the streets.” Wilfred called Martinez. He was ready to join ICS.

Suddenly, Wilfred says, “ICS was in there. First the intake nurse came and evaluated me. Then came the next nurse,” Mona Leon, his nursing care manager. “Then came my social worker,” Bonnie Prest-Thal. In three weeks, ICS care managers put together a real discharge plan. ICS staff worked with nursing

home staff to get doctor’s orders for all the services Wilfred would need on his first day home. They arranged for a personal care aide to help Wilfred shop, make meals, keep house, do laundry, and get to medical appointments. They determined that his wheelchair and hospital bed were satisfactory, but he needed minor items of durable equipment, such as a padded tub transfer bench and an array of medical supplies. ICS staff reviewed the list with its rehabilitation coordinator and passed it on to a contracted equipment provider. ICS contacted a participating pharmacy, ensuring that on the day of discharge he would either have enough medications with him to go home or they would be delivered. In the spirit of collaboration in which ICS staff and its members work, Wilfred agreed to schedule an appointment with his primary care doctor, and make the call to resume his Supplemental Security Income benefits. ICS guided nursing home staff in submitting the paperwork to transfer Wilfred’s Medicaid from institutional to community status.

Persistence was key to putting everything in place, and Prest-Thal had it. “I was totally determined,” she says. “Will was coming out of that home, come hell or high water.” She was confident that with the help of ICS, he could manage an independent life. “I know the services we provide. A lot of our members are a lot worse off than Wilfred and live at home. I have utter confidence in ICS that we can do what needs to be done.”

Today, with the help of a host of home and community services arranged by ICS, Wilfred is reclaiming his life. He moves about his Bronx community freely and works at computer programming. “Bonnie has no idea how she saved my life,” he says “You can save my life physically, but that means nothing. It’s what’s in my head that’s important. She gave me a chance to think about the future, a sense that there is a future.” And finally, he is in a place where he can act on that future.

Contributed by Angela Bonavoglia.

Coordinated Care for Children in D.C.: Health Services for Children with Special Needs, Inc.

by Bruce Goldman and Margaret Fisk Mastal

In the early 1990s, the District of Columbia government, in considering ways to better manage the cost and quality of services for its Medicaid enrollees, decided to implement Medicaid managed care programs. This decision was controversial, with particular concern raised regarding the pediatric population with special health care needs. There were two schools of thought about this population: One was that they could not be part of a managed care program because they could fall through the cracks of the delivery system, and the other held that they would benefit from a specially designed program of managed care.

During that time, the HSC Pediatric Center in Washington, D.C. hosted a conference sponsored by the National Association of Children's Hospitals and Related Institutions in which these issues were explored. The conference focused on the future of managed care and the role of pediatric specialty care facilities in the continuum of care for children and youth with disabilities. All involved in caring for this population expressed their frustration with the lack of care coordination when children were discharged from inpatient care. Out of this conference a decision was made by the HSC Pediatric Center leadership to submit a letter of intent to the District of Columbia government expressing interest in developing a Medicaid managed care program for children with disabilities. The District's public agency responsible for administering the city's Medicaid program, the Commission on Health Care Finance, was receptive to the submitted proposal. After much discussion and debate, the Center for Medicare and Medicaid Services (formerly the Health Care Finance Administration), the District government, and the HSC Pediatric Center contracted to launch a pilot program, naming it

Health Services for Children with Special Needs (SN). In February 1996, SN enrolled its first member.

Mission and Goals

Health Services for Children with Special Needs, Inc. is a health plan that coordinates health and life care for children and youth with special health care needs. It's a voluntary program available to pediatric Supplemental Security Income (SSI) enrollees in the District of Columbia. The mission of SN is to ensure that children and youth with special needs, their families, and their communities have appropriate, timely, and cost-effective access to and use of quality, medically necessary health benefits and services. Specific goals include:

- Ensuring access to health care and services through developing, supporting and partnering with a committed network of community-based providers and services.
- Facilitating members' appropriate, timely usage of services that focus on disease prevention, restoration to optimal health, adaptation to chronic illness/disease, health promotion, and palliation at the end of life.
- Collaborating with public and private organizations, agencies, caregivers, and members to jointly identify and creatively remedy situations and circumstances that threaten the optimal health of children and youth with special needs, their families, and communities.
- Maximizing the effectiveness of monies allocated for health care and services needed by the member population.

Program Components

In carrying out its work, SN addresses eight key areas: provider network, benefit structure, member eligibility, care coordination, member services, outreach, financing, and quality management. The following are the primary characteristics of each area:

- **Provider Network.** The provider network is based on an "open panel" design that allows any provider (physicians, hospitals, etc.) that meets SN's credentialing and practice requirements to execute a contract with the plan. Emphasis is placed upon obtaining contractors with experience and interest in caring for children and youth with disabilities, and guaranteeing access to the wide array of services that members require.
- **Benefit Structure.** The benefit structure for members includes traditional Medicaid benefits that meet the criteria for medical necessity, as well as the option to design special benefits that meet an individual child's health needs. Special benefits address multiple needs and emphasize keeping the child in the community setting; they include respite care for families and caregivers of home-bound children and youth, home reconstruction to accommodate wheelchairs, and assistive devices.
- **Member Eligibility.** Eligibility is through SSI designation for children and youth, birth through age 21. The most unique feature of program eligibility is that children and youth with both physical and psychosocial primary diagnoses are members. SN uses an integrated biopsychosocial model with each member receiving holistic care coordination addressing medical, mental health, behavioral, and developmental needs in home, school, and work environments.

- **Care Coordination.** Care coordination staff include care managers, member service personnel, and outreach staff, interacting to enhance care coordination activities and outcomes. Care management staff, of which there are two levels, handle the actual care coordination services. Care managers are licensed registered nurses (RNs) and licensed social workers who coordinate care for medically and psychosocially complex members. At the other level, care manager associates have baccalaureate degrees but are not licensed; they are assigned the members with less complex needs. The education and backgrounds of the associates includes nursing, social work, education, and health care management. The staff function in teams of care managers and care manager associates, working with the providers, members, and caregivers (parents or legal guardians) to develop and implement an individualized plan of treatment for each SN member. The plan of treatment identifies the member's needs and appropriate benefits and services, documents advice on the member's health situation, and serves as the rationale for members to access and receive timely, quality care. The care manager or care manager associate coordinates all benefits and services for each member assigned to their caseload, from medical appointments, to appropriate home modifications, durable medical equipment and supplies, and special benefits.

Within the care coordination department are five teams, each with a team leader. Because over 60% of the members have a mental/behavioral health diagnosis, one team is responsible for the care coordination of members with severe mental health diagnoses. A pediatric psychiatrist supervises this team of social workers who are experts in behavioral health services. A second group of members who have their care coordinated by a distinct team is infants

and children from to five years of age. These children pose a unique challenge due to the intensive intervention and teamwork with the caregivers that are necessary. In 2005, a third specialized team will be organized to work with the adolescent population in recognition of the particular issues facing these youth, including needs in relation to transitioning out of SN's program; the transition period begins at 19, in preparation for when the member "ages out" at 22. The remaining teams are general, working with a cross-mix of the membership whose needs are not as intense or complex.

Care coordination staff report to the medical director to ensure total collaboration between medical treatment and care coordination.

- **Member Services.** The Member Services Department is the first contact for members and providers to access care coordination services. They are available 24/7 to transfer callers to the appropriate department or staff member, receive complaints, and make all transportation arrangements for health appointments.
- **Outreach.** Outreach staff work in the community, contributing significantly to care coordination efforts by locating potentially eligible members as well as unreachable members and families. Families enrolled in Medicaid are often transient and frequently change contact telephone numbers, resulting in difficulty locating them for needed health care. Outreach workers are known and trusted in the community, connecting with individuals who can help locate missing members and their families.
- **Financing.** SN receives a fixed rate of payment per member per month regardless of the complexity of a member's needs. Eighty-six percent of these funds are used for medical and health care services. If the costs for a particular member exceed 86%, Medicaid pays for the overage, which must be justified by SN. The admin-

istrative and care coordination cost components of the per-member-per-month expenses are covered by SN from its resources.

- **Quality Management.** Managing quality of care coordination and of the health care that members receive has been an evolving process, starting with ethical considerations and expanding to include both quality assurance and quality improvement dimensions. An Ethics Advisory Panel provides a multidisciplinary advisory group for counsel about specific ethical issues. In addition, SN has a Director of Quality and quality management department, which monitor outcomes in terms of member health and satisfaction.

Conclusion

Health Services for Children with Special Needs, Inc. has grown from an idea and a pilot program into a respected and valued source of care coordination for over 3,200 children and youth with special needs who receive SSI. In September 2003, an external evaluation of SN utilizing the *Consumer Assessment Of Health Plans Survey* showed SN receiving strong approval levels from its members, with 88% of members "highly satisfied" with their overall plan. And, in December 2003, SN received accreditation from the Joint Commission on Health Care Organizations. Today, it continues to improve and increase its capacity to provide timely and cost-effective access to quality health care for some of the District of Columbia's most vulnerable children and youth.

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Improving Care Coordination Through Medical Summaries: Utah's CFS Project

By Jeff Sheen and Jessica Carpenter

Families who have children with special health care needs often face multiple challenges when trying to coordinate the primary medical care of their children with the additional care they receive, or need to receive, from numerous medical and non-medical specialists. In an effort to address these and other challenges, the Center for Persons with Disabilities at Utah State University and the Budge Clinic Pediatric Unit, an Intermountain Health Care Center, initiated the Coordinated Family Support project (CFS) to establish a *medical home* for children with special health care needs. A medical home is defined by the American Academy of Pediatrics, National Center for Medical Home Initiatives for Children with Special Health Care Needs (2004), as follows:

A medical home is not a building, house, or hospital, but rather an approach to providing health care services in a high-quality and cost-effective manner. Children and their families who have a medical home receive the care they need from a pediatrician or other health care professional. Pediatricians, families, and allied health care professionals act as partners in a *medical home* to identify and access all the medical and non-medical services needed to help children and their families achieve their maximum potential. (p. 2)

The overall purpose of establishing a medical home for children in the Budge Clinic is to provide an improved level of care that is more coordinated, comprehensive, family-centered, compassionate, culturally competent, continuous, and accessible. A critical component of this improved care is use of a strategy that will be described in the remainder of this article: the *medical summary*.

Medical Summaries

The CFS project team first encountered the idea of using medical summaries in 2003 while participating in the National Medical Home Learning Collaborative conducted by the National Initiative for Children's Healthcare Quality. When the CFS team heard about the benefits of medical summaries from several other pediatric practices in the Collaborative, they decided to focus their efforts on adapting this tool for use at the Budge Clinic for each child involved with the CFS project.

The basic idea behind a medical summary is to take all of the critical medical information for a child that is usually scattered throughout the medical chart (often multiple charts) and place it into an easy to read one-page (front and back) document. This summary can then be used by families and primary care physicians to communicate more effectively with other medical and non-medical providers who may not be aware of the many unique needs of a particular child, and who do not have access to the full medical chart and/or time to comb through hundreds of pages of records looking for the most recent lab results or lists of medications.

The medical summary can be particularly helpful to the family when a child is seen by a doctor covering for their primary care physician, by a specialist for the first time, or during a visit to the emergency room. With a medical summary in hand, a family does not have to repeatedly recite an often lengthy medical history to each new medical provider with the hope of not leaving out anything vital. Conversely, the medical summary can be very helpful to physicians seeing a child for the first time. The medical summary can save physicians from having to spend significant amounts of time trying to pull vital information from charts (if the

charts are even available for review) or from replicating costly and time-consuming tests before providing treatment. All of this leads to medical care that is more coordinated, comprehensive, and family-centered, and subsequently less frustrating, time-consuming, and expensive.

The medical summary form that is currently used at the Budge Clinic has undergone multiple revisions during the past year and a half, based on feedback from both the medical staff at the clinic and families participating in the CFS project. Currently, the medical summary contains the following main sections:

- Patient/family contact information.
- Principle diagnosis.
- Unique clinical facts/special considerations.
- Baseline data for vital signs/neurological status.
- Routine lab/x-rays etc.
- Immunizations.
- Dates of past hospital admits/reason.
- Consultants/specialists with contact information and date of last visit.
- Home care agency and equipment.
- Rehabilitation providers.
- School services received with contacts.
- Community resources being accessed.
- Team/family goals.
- Common emergency conditions with treatment considerations.
- Allergies list.
- Typical problems list.
- Medications list.

The process of completing a medical summary for each new child in the CFS project begins with the medical home

care coordinator and/or other medical assistants in the practice pulling information needed for the form from the medical chart(s). A draft of the medical summary is then sent to the family for their review and input, which is used to complete the form. After the changes and updates received from the family are made, the draft summary is sent to the primary care physician for their review and input. A copy of the completed medical summary is then sent to the family for them to use as they see fit. Some families provide copies of the medical summary to the specialists they see, the school, and/or other community resource providers with whom they interact. Other families maintain one copy and take it with them to the emergency room or other medical appointments. The original copy is kept in the child's medical chart.

In order for the medical summary to be a viable document that is useful to both medical providers and families, it must be kept current. In the CFS project, the medical home care coordinator has the primary responsibility for ensuring that each child's medical summary is updated as often as needed. To accomplish this task, the care coordinator works closely with the family, the primary care provider, and any other medical providers to maintain the most accurate summary possible. At the Budge Clinic this task is made easier by a computer system known as Clinical Workstation.

Clinical Workstation allows any medical provider in or approved by the Intermountain Health Care system to access a child's medical summary on demand so that primary and specialty care can be better coordinated from the beginning. Specialists can post notes, lab results, x-rays, or any number of other test results in real-time for the primary care physician to review and vice versa. This can be particularly helpful to families who have often been left to coordinate the exchange of information between multiple specialists and their child's primary care physician on their own. These timely exchanges of information allow the primary care

physicians and specialists to more effectively coordinate the treatment of the often complex cases involving children with special health care needs. Additionally, Clinical Workstation allows the care coordinator to keep the medical summaries updated more accurately and frequently, which allows families to have the information they need to make important decisions about the care.

Even with the use of Clinical Workstation, completing medical summaries for children with very complex cases and multiple charts, although extremely beneficial in the long-run, can be very time consuming. The part-time care coordinator, assisted by other clinic staff a few hours a week, completes 2-5 new medical summaries and updates 5-10 each week.

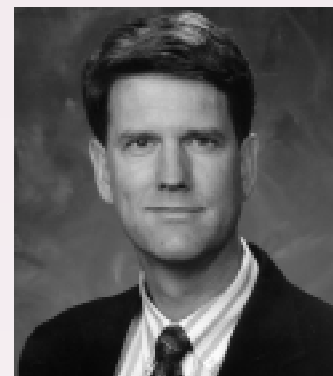
Conclusion

Medical summaries have been completed for over 80 of the children with special health care needs seen at the Budge Clinic Pediatric Unit. The feedback received from families and physicians who use the medical summaries on a regular basis has been overwhelmingly positive. One pediatrician stated that he wished all of his patients had a medical summary because it makes reviewing and preparing for each appointment so much more efficient. Feedback from families suggests that the use of medical summaries has eliminated much of the time they previously spent on the phone and in doctors' offices attempting to coordinate all the details of their children's medical care. It has also helped them feel more comfortable talking to their pediatrician and care coordinator about non-medical aspects of their children's lives.

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Medical Summaries From a Physician's Perspective

The medical home concept has been a great advance for the provision of care to our patients with chronic medical conditions. We have worked on developing this program for two years in our pediatric clinic that is staffed by eight pediatric health care providers. Our clinic is 70 miles from the main tertiary care center and the medical care summaries that we produce help immensely with improving the communication process among providers. The summaries are especially helpful with emergency room visits or when the primary care physician is unavailable and care is provided by colleagues. Every enrolled child has a specific medical regimen and medical summary readily accessible to anyone who will be making medical decisions. Additionally, there is now a computer network that links many of the private practices in the state as well as hospitals and specialty care providers. Records of medical care provided anywhere in the system can now be accessed at any site.

Although the program may increase our workload in the short run, as we are able to provide more efficient and better quality care everyone benefits, and we are excited about the progress that has been made.

Contributed by J. Dennis Odell, M.D., Medical Home Project Director, Center for Persons with Disabilities, Utah State University, Logan.

Care Coordination for Children with Complex Medical Needs: U Special Kids

by Anne Kelly

Medical advances and new technologies are allowing children with complex medical problems to survive and grow-up living at home with their families. The challenge in meeting their ongoing medical needs is to provide care in both urban and rural communities, and to coordinate the complex array of service systems utilized by these children. Unfortunately, families report services

typically fill the role of central information source. While providers are often dependent on the information they hear from parents, they may be distrustful of its accuracy, placing parents in an awkward position. For families, tracking all of this information is a monumental task with obvious limitations.

Traditional approaches to care are not effective for children with complex, chronic illnesses. Routine, encounter-driven care results in poorer outcomes for children with chronic illnesses because of delays in early detection of health status changes, a failure to adequately train parents in illness self-management skills, inadequate monitoring of treatment effectiveness, and failure to treat child and family psychosocial distress. Common elements of successful interventions include use of explicit treatment plans, attention to the information needs of children and their families, ready access to expert advice, inclusion of psychosocial and behavioral needs, and organized, accessible patient health-related information.

The U Special Kids (USK) Program, a model demonstration project in the Department of Pediatrics at the University of Minnesota, was established in 1996 to provide comprehensive care coordination to children who have complex, multi-system medical problems, are technology dependent, and have frequent hospitalizations. Approximately 200 children throughout Minnesota have been served by the program, which is supported through a combination of program clinical revenues, and funding from the State and from Fairview University Medical Center. Although over 500 children in Minnesota meet the criteria for admission to the program, current funding can only support care coordination for approximately 40 children.

The USK program does not replace primary care, but collaborates with the

child's primary care provider to improve access to and coordination of needed health care services. The core program team includes a pediatrician, pediatric nurse practitioner, nurse coordinator, and clinic coordinator. When a child is initially referred to USK, the nurse coordinator conducts a pre-intake phone call with the family to obtain details regarding the child's medications, allergies, medical problems, multiple services, providers, and detailed contact information. The nurse practitioner obtains the child's past medical summaries, which may be from multiple sites, and reviews them for pertinent problems, treatment recommendations, and results of key laboratory and radiologic investigations. From this information a condensed summary of critical information is generated for review by the pediatrician. A team meeting with the child and family is conducted to review the medical summary information, conduct a baseline physical examination, and discuss a plan of care and care coordination needs. The clinic coordinator is responsible for ongoing coordination of care by ensuring that the multiple appointments each child has are scheduled at convenient times for the family, properly sequenced with recommended testing, and coordinated with other visits when possible. The clinic coordinator also acts as a central hub for information flow.

Many of the regular health care needs of the children we serve are efficiently handled through the child's primary care clinic. Families have more difficulty finding assistance with specialty care or chronic problems that have not responded to the recommended treatments. Addressing these issues in the primary care clinic may be daunting. The USK program provides telephone management for each child's multiple problems, particularly for illness symptoms. A primary function of the USK

The U Special Kids Program was established in 1996 to provide comprehensive care coordination to children who have complex, multi-system medical problems, are technology dependent, and have frequent hospitalizations.

are often uncoordinated, episodic, fragmented, or do not exist in some communities (Kelly et al., 2002). Physicians have reported that they feel uncomfortable caring for children with complex problems, do not have knowledge of resources to meet the children's unique needs, and lack enough time to deliver and coordinate appropriate care (HRSA, 1997). Adding to the problem of disconnected services is the cumbersome and generally antiquated method of recording medical and health-related information. For children with complex conditions and multiple providers, over time a plethora of fragmented bits of information is generated that is of limited value to decision-makers such as physicians, school staff, and therapists. Parents

program is telephone triage. When possible, illnesses are addressed over the telephone by a member of the USK team. Addressing illnesses promptly over the phone avoids delays in implementing treatments, potentially avoiding a more severe illness, which can ultimately reduce the number of emergency room visits and hospitalizations. In a review of telephone triage logs for 21 patients, there was an average of 184 calls per month. A significant number of the calls are related to minor acute illnesses and adjustment of treatments and are resolved over the telephone. Reorganization of services so that symptoms can be managed by telephone has

Another function of the program is to support families and build their confidence as they learn to manage their child's care at home. The children served by USK have serious, low-incidence, chronic diseases for which protocols seldom exist.

obvious benefits for families, in particular for those with transportation difficulties or from rural areas.

The capacity of families to coordinate care is a balance between resources and responsibilities. One of the responsibilities shifted to the USK program is information management. A key function of the program is to condense, organize, and make accessible critical information that is related to care and necessary to effective medical management decisions. The Summary of Critical Information is a tool developed to organize the voluminous information, some of which families are repeatedly

queried for (e.g. did you smoke or drink alcohol during your pregnancy, how did your child's injury occur, and has your child ever been in the hospital?). The summary is stored electronically and hard copies are given to the family; their hospital's children's ward, emergency room, and medical records department; the primary care physician; and specialists prior to appointments. Consequently, families do not have to repeat this information for every provider or clinic visit, saving everyone time. It also lifts from the family some of the burden of remembering important events and information.

Another function of the program is to support families and build their confidence as they learn to manage their child's care at home. The children served by USK have serious, low-incidence, chronic diseases for which protocols seldom exist. Key to this program function is the development of customized, recurrent-illness plans. These plans have the benefit of earlier identification of problems by the family and health care providers, earlier implementation of effective treatments, reduction in the length of illnesses, and reduction in unplanned hospitalizations.

A preliminary evaluation of the U Special Kids program has demonstrated that its services are associated with lower hospital admissions for acute illnesses, high parent satisfaction with the quality of services and the impact on their child's health, and provider satisfaction with the time saved because care and information are coordinated. Research is needed to better understand which aspects of care coordination work best for different categories of children and families. For example, in theory, adding a social worker to the USK staff should be beneficial by shifting responsibility for psychosocial issues away from clinical team members, freeing them to spend more time on clinical issues. But enlarging the team may potentially dilute its effectiveness. Many similar issues related to effectiveness need to be researched.

There also needs to be additional

attention to who should pay for the care coordination services. To ensure the continuation and replication of programs for children with complex chronic health problems, strategies for funding, particularly integrated funding from private and public insurers, must be developed. There is currently no financial

To ensure the continuation and replication of programs for children with complex chronic health problems, strategies for funding must be developed.

incentive to serve children with complex conditions and high health care costs. However, with targeted care coordination, cost savings may be substantial through reduced utilization of hospital services. State and private health plans save money, but hospitals also benefit when children with complex conditions have shorter lengths of stay. Strategies that integrate health plan and hospital funding streams are needed to overcome the cost-shifting and barriers to efficient and effective care that currently exist. Ultimately, children will be optimally healthy, and care the most cost-effective, if services are appropriate, timely, and of high quality.

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A New Approach to Health Care Delivery in Minnesota: The AXIS Model

by Chris Duff and John Tschida

No matter where you live, the health care system in the United States can be complex and difficult to navigate. For individuals with disabilities, one of the greatest challenges lies in being able to access health care providers when needed, obtain approval for services or medical equipment in a timely manner, and make sure the lines of communication among providers are open so that multiple individual needs are met. In Minnesota, a new program has been designed to meet these needs of people

AXIS empowers people with disabilities to make choices about their health care and helps cut through the red tape to coordinate the unique needs of each consumer.

with physical disabilities who receive Medicaid. It's called AXIS Healthcare.

AXIS doesn't provide health care services. It empowers people with disabilities to make choices about their health care and helps cut through the red tape to coordinate the unique needs of each consumer with a disability. While many managed care organizations have care coordinators or case managers charged with linking consumers with the services they need, what they often lack is expertise in disability issues. AXIS Healthcare, an organization specializing in disability and founded by two rehabilitation service providers – Courage Center and Sister Kenny Institute – was designed for and with people with disabilities.

Development of AXIS Healthcare

With grant support from the Robert Wood Johnson Foundation, AXIS worked with consumers in a pilot project in 2000 and 2001 to build the program model. The goal was to build a quality organization people *wanted* to join, not a mandatory managed care plan people *had* to join. The starting point – and the best health care consultant – was the customer. During the pilot project, AXIS provided health coordination services on a voluntary basis for over 40 individuals who voiced their expectations, designed their own care plans, and identified their preferred health care providers. More importantly, they expressed their frustration with the existing delivery system and recommended changes and opportunities for improvement or efficiency. The goal was to have doctors view their patients not as intermittent problems or symptoms caused by their disabilities or chronic conditions, but as whole people needing a range of health care services. Together, AXIS staff and the pilot participants built interest in this new model, engaging key providers and demonstrating that obtaining the right care or service at the right time is primarily the result of coordination rather than increased dollars. In fact, we strongly believe there is plenty of money in the system now serving people with disabilities. The problem is that rules haven't allowed for the flexibility to spend it in the right places at the right times.

AXIS Healthcare and the pilot participants worked with UCare Minnesota, a health plan created to serve persons receiving Medicaid or dual eligible for Medicaid and Medicare, with UCare Minnesota's extensive health care provider network, and with the Minnesota Department of Human Services to build a better system. With almost 100,000 members, UCare Minnesota brought to

the process extensive experience in managed care and a commitment to flexibility in meeting the needs of persons with physical disabilities. The Department of Human Services, serving as the state Medicaid office, understood that the existing fee-for-service system had created "islands of care," with minimal integration of services and supports.

What AXIS Offers Members

AXIS started accepting enrollment in July, 2001. No longer a pilot program, today it serves over 400 persons in a manner that promotes holistic, self-directed health management. It is available for adults with physical disabilities on Medicaid, with or without Medicare, residing in the Minneapolis/St. Paul metropolitan area. It is a voluntary program, and people can leave the program at any time, making consumer satisfaction a top priority for AXIS.

AXIS is staffed by health coordinators and resource coordinators who have extensive experience working with persons with physical disabilities and their providers. Health coordinators are registered nurses who manage health issues, medications, rehabilitation equipment, and clinic visits. Resource coordinators generally have a background in social service and assist the members in the housing, financial, and social support areas.

Upon a member's enrollment in the program, a health coordinator conducts a comprehensive assessment to identify the enrollee's health care needs. Together they design an individualized plan that promotes independent living and builds in the right level of support. The level of specialization of each plan encourages enrollees to play a more active, informed role in their health care. The member, their primary care physician, and the AXIS health coordinator function as the core team in managing the full range of

services and supports needed for members to experience quality in their lives. The focus of staff is on risk prevention strategies including routine clinic exams and purchase of needed medical equipment to avoid future problems. If an acute illness or medical concern arises, AXIS staff assist the member in receiving early intervention. Staff are also available around the clock to triage emergency concerns.

There is plenty of money in the system now serving people with disabilities. The problem is that rules haven't allowed for the flexibility to spend it in the right places at the right times.

But history and program operation only tell part of the story. The best way to describe AXIS is through the people who live and breathe it – people like Ron Franke.

Ron's Story

For more than 20 years, Ron Franke has lived with multiple sclerosis. For the first 18 of those years, he navigated the health care system on his own and stayed fairly healthy. Then four years ago, he developed a skin ulcer the size of a fist that landed him in the hospital and then a nursing home for more than a year. As he recalls, "In the winter of 2000, I started to have skin breakdown. I had a nurse visit me once a week on Tuesdays. She noticed the breakdown and prescribed a treatment that was painful and caused more breakdown. The next week when she checked my skin, the breakdown was so bad that she had me call the wound clinic. I was told I needed a skin debridement. The doctor encouraged me

to go to a nursing home for treatment. The nursing home did a pretty good job, but I developed bone, urinary, and two intestinal infections. I was in bed for nine months." "After all that time," says Ron, "I still had my condominium, but didn't know how to put the pieces together to move back home." For Ron, the health care system had become a big dark room. "You're fairly certain everything that you need is in there, but you either don't know what it is or can't find it when you need it."

Ron began a search to find alternative care so that he could move back to his condominium. During this search he learned about AXIS. "I was told I was a good candidate for this new program called AXIS," says Ron. "I enrolled in AXIS Healthcare in January 1, 2002. Patty, my health coordinator from AXIS, sprung me from the nursing home on February 3, 2002."

Through joining AXIS, Ron believes he has finally discovered a light switch to that room. Though he had another skin breakdown shortly after joining, this time he made a six-week recovery at home. "Whenever there is a problem now, I just call Patty," he says. "It is a night and day difference. The health coordinators have lots of good ideas. Recently, I received a remote control device that I operate with my cheek. It controls the TV, lights, and stereo, everything I need. I also received an automatic door opener that I control by moving my head. Now I can keep my door closed and feel safe. Yes, life is good!" he says.

Like Ron, many people with disabilities who are on Medicaid experience barriers to coordinated care and integrated services. Without good care coordination, they receive fragmented specialty care and too little primary care, and often incur costs that may have been reduced or prevented. Ron Franke describes the difference in his health care as "graphic" because of AXIS. "I figure my first skin breakdown cost the state between \$50,000 and \$100,000. In the 36 months that I have been a member of AXIS Healthcare, I've been hospitalized twice for a total of two



days. Compared to before, that's a huge difference. It's cheaper and better – a win/win situation."

Ron is back working part-time. He's got flowers planted outside of the window, and his daughter can take the bus from school to stop by for a visit. "Plus," he says, "I have peace of mind. I never feel like I can't get help."

Conclusion

While a comprehensive evaluation of outcomes for AXIS members is in the process of being completed, findings from preliminary data indicate higher consumer satisfaction with providers and health care services since enrollment in AXIS, and increased member participation in making health care decisions. Results for cost-effectiveness and clinical outcomes have not yet been analyzed.

Ultimately, the AXIS Healthcare program is about improved community living for people with disabilities. Better health care outcomes allow people with disabilities such as Ron to continue living as active, engaged members of their communities.

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Integrated Health and Long-Term Care Services: The Wisconsin Partnership Program

by Steve Landkamer and Ruthanne Landsness

The Wisconsin Partnership Program (Partnership) is an integrated health and long-term managed care program. Partnership provides services for both people with disabilities and older adults, and has been operational in six counties in Wisconsin since 1999. Partnership combines all health and long-term care services offered under Medicare, Medicaid, and the Medicaid Home and Community-Based Waiver programs. As such, it provides a very comprehensive benefit package. Two capitation payments, Medicare and Medicaid, are paid to one of four community-based organizations that coordinate and manage all aspects of care for program enrollees.

Partnership Operation

The term “partnership” is indicative of the numerous collaborative relationships that it took to develop the program and that it takes to administer and achieve optimal outcomes for consumers. Partnerships exist between:

- The Center for Medicare and Medicaid Services (CMS) and the Wisconsin Department of Health and Family Services (DHFS).
- DHFS and the four Partnership organizations – Community Health Partnership, Eldercare Health Plan, Community Living Alliance, and Community Care Organization.
- CMS and the Partnership organizations.
- The Partnership organizations and their members.
- Various segments of state and county government.
- Partnership organizations, members, and subcontracted providers.

The successful operation of Partnership is dependent on maintaining collegial and sometimes contentious relationships

in the face of competing regulations and priorities. The program would not operate or deliver successful outcomes for members without these collaborative partnerships.

Partnership operates under 1115 Medicaid demonstration authority and 402/222 Medicare payment waiver. To be eligible for Partnership, a potential enrollee must be Medicaid eligible and meet nursing home level of care criteria. Partnership members enter the program with an average of 17 diagnoses and take more than an average of 13 prescription medications. As of October 1, 2004, there were 1,723 people enrolled in Partnership – 1,330 older adults and 393 people with physical disabilities. Eighty-three percent of those enrolled live in their own homes with various levels of support, about 10% live in assisted-living situations, and approximately 7% live in nursing facilities. Roughly 95% of the older adults and 60% of people with disabilities are dual eligible for Medicare and Medicaid.

Care coordination is the heart of the Partnership program. Partnership care coordination is based on a team approach. The team is comprised of the enrollee, the enrollee’s primary care physician, a nurse practitioner, a registered nurse, and a social worker or social service coordinator. Additional staff join the team as called for in the enrollee’s care plan. This team approach has been central to eliminating system and service fragmentation, increasing comprehensive primary care, and providing support for the person in his or her home. It has also been a major factor in minimizing the need for expensive hospital and nursing home care. The outcome has been the provision of comprehensive primary care, prevention services, and community-based long-term care services for Partnership enrollees.

The team conducts assessments,

develops plans of care including the provision of health and psychosocial services to meet identified needs, and arranges for the delivery of the services whether they are staff-provided or purchased from subcontractors. Examples of services include primary health care, hospital care, transportation, supportive home care, personal care, and home modifications.

Partnership Medicaid capitation payments are a blend of institutional and home and community-based care costs. Rates are risk-adjusted by age cohort, level of care, and Medicare eligibility (dually eligible/Medicaid eligible only). The risk-adjusted, blended cost is then subject to a managed care efficiency adjustment of 5%. After the end of the year, DHFS staff review the actual enrollment experience of each Partnership organization against the assumptions made in rate development and adjust the capitation payment retroactively.

Within the next three years, rate setting for Partnership will change to a risk-based system. It is likely that this new system will have two components – one to predict health care costs based on diagnostic information, and a second to predict long-term care costs based on limitations in activities of daily living and instrumental activities of daily living. The development of this new method is a collaborative effort between representatives from each of the four Partnership organizations and DHFS.

An Area of Particular Challenge

Partnership has faced a significant challenge in providing services to people with disabilities with a high incidence of mental health and/or alcohol and other drug abuse (AODA) issues in addition to a primary disabling condition. Approximately 53% of all Partnership members have diagnosed or suspected mental

health and/or AODA issues. The rate is higher among people with physical disabilities than the elderly; we have not studied why this is the case. Community Living Alliance, one of the Partnership organizations that provides care specifically to people with physical disabilities, estimates that 70% of its membership has issues related to one or both of these conditions. DHFS investigated the impact of mental health and AODA issues on utilization of other services at the Community Living Alliance (Crawford, 2004). The research found that people with an AODA diagnosis spend 65% more days in a hospital than people with no known or suspected AODA diagnosis. This group also experienced nursing home stays at a rate that was 359% greater than those with no AODA diagnosis. Also, the rate of no-shows for scheduled appointments was four times higher than for people without an AODA diagnosis. In a related study, people with both mental health and AODA diagnoses received twice as much inpatient care as those with no mental health or AODA diagnosis (Crawford, 2004). Thus, it is clear that the presence of AODA issues drives much of the cost of serving this subgroup of people with disabilities. Early developers of related long-term care programs, including Partnership, did not anticipate the extent to which AODA problems among enrollees would affect the programs.

Fortunately, Partnership has been in a unique position to provide the care required to address the AODA problems of this population. Because it is a fully integrated health and social services program, Partnership pays for and provides social services, including those needed due to AODA issues. Most other health care insurance programs or providers cover health care, but not social services, or vice versa. To our knowledge, for example, few health care providers and payers have well-developed programs devoted to AODA prevention and intervention. Therefore, as a health care entity, Partnership has been in relatively uncharted territory. It should also be noted that Partnership is unlike

typical AODA treatment and/or behavioral health managed care programs. Behavioral health programs do not pay for health or social services needed after clients complete or drop out of AODA treatment. Partnership does.

In addition to implications for costs and general program infrastructure, Partnership also found that the strong presence of AODA issues among enrollees had important implications for staff training. This was true from both a clinical and psychological perspective. Partnership staff reported difficulty in identifying and approaching members with these issues. They questioned the “fairness” of giving more time and resources to those who abused when it was theoretically the individual’s choice to abuse, and experienced frustration when enrollees failed in their attempts at abstinence. Some expressed concern that they may be “enablers” if they tried to rescue abusers from negative consequences.

Because of Partnership’s unique opportunity and challenge in addressing AODA, DHFS applied for and received a grant from the Robert Wood Johnson Foundation to develop training and a training manual for Partnership staff specific to dealing with AODA issues. DHFS contracted with the Center for Excellence in Long-Term Care in the University of Wisconsin-Madison School of Nursing to research AODA literature for best practices and work with Partnership staff to address their concerns. When enough post-training data are available, a follow-up study will be conducted to determine the effectiveness of the training and determine if additional resources are needed. (The training manual is available at <http://dhfs.wisconsin.gov/WIpartnership/pdf-wpp/WPP%20AODA%20Manual.pdf>).

Partnership’s Impact

In its service provision to people with physical disabilities, Partnership has had its greatest effect on the number of hospital admissions for ambulatory sensitive conditions. The rate of hospital

admissions for diabetes, congestive heart failure (CHF), bacterial pneumonia, and chronic obstructive pulmonary disease has diminished by 43.9%, 61.3%, 37.2%, and 10.7% respectively in the year after enrollment as compared to the year prior to enrollment. Likewise, the length of stay for these conditions has also been significantly impacted, down 18.6% for diabetes and 71.6% for CHF.

DHFS also measures the achievement of desirable social outcomes that significantly impact a member’s quality of life. Members are interviewed to determine if their desired outcomes are met in the areas of self-determination and choice, community integration, and health and safety. Partnership has consistently compared favorably to other DHFS programs as well as to results of a national indicator. (The complete report is available at <http://dhfs.wisconsin.gov/WIpartnership/pdf-wpp/Member%20Outcomes%20Partnership070901FINAL.pdf>). As architects of the Wisconsin Partnership Program, we are very proud of the program, and eager to share the accomplishments of the Partnership organizations and their members.

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A New Approach to Evaluating Support Effectiveness: Florida's Delmarva Foundation

by Robert Foley

In 2001, Delmarva Foundation was awarded a four-year contract to help the State of Florida develop a quality assurance system for evaluating services provided to people with developmental disabilities. Two independent processes were developed and implemented by Delmarva over the next few months. One focused on interviews with people receiving services to determine the desired outcomes and supports present in their lives. The other focused on evaluation of service and support processes utilized by support coordinators and direct service providers. Over the next two years, thousands of interviews and provider reviews were conducted, resulting in an extensive quantity of data. The findings showed that the providers of support coordination and other services adapted their systems of operation and documentation such that their processes were rated highly in relation to Medicaid handbook requirements. Conversely, the people receiving services reported either a stagnant or even a decreased presence of desired outcomes and supports in their lives. How does one account for this disconnect? Why were provider scores not predicting quality of life for the people they were so passionately serving?

Though policies and procedures, hiring practices, staffing ratios, documentation modalities, and a myriad of other "process" oriented aspects of running a business may certainly lay the foundation for efficient operations and help meet funding requirements, they do not guarantee results for those receiving services. In fact, the infrastructure produced by the above mentioned items might not emphasize the need for results. Providers entering the field for all the right reasons have in many instances become buried and even lost in process, with no system to evaluate the true effectiveness of their service delivery.

The magnitude of these realizations was felt immediately as Delmarva Foundation, its contract partners, and a group of stakeholders (including people receiving services and representatives of the Agency for Persons with Disabilities) began to revamp the provider review process. Development of this new review process began with an agreed upon emphasis being placed on outcomes, with outcomes being defined as *results that reflect communicated choices and preferences that matter most to the person*. Not only does this definition demand accountability in that services need to generate results, it specifically speaks to the need for those results to be something of importance, value, and priority as defined by the person receiving the services. Thus began the six-month experience of converting an evaluation approach from one that was process based, to one that is results based, and implementing it for a system serving over 24,000 Floridians with developmental disabilities.

The remainder of this article will focus primarily on the development of a results-oriented evaluation of support coordinators, titled the Waiver Support Coordination Consultation (WiSCC). However, it is critical to note that concurrent with this activity, the measurement of success for providers of residential, vocational, and other direct support services was also being shifted to emphasize results. With similar accountability at all levels within the service delivery system, each stakeholder has had to realize the importance of teamwork and collaboration in generating success. This is at the very heart of the service culture changes in Florida.

The New Evaluation: WiSCC

The WiSCC begins with interviews of people receiving services to determine

whether or not they are receiving the support necessary to achieve that which is important to them. Using the *Personal Outcome Measures* developed by The Council on Quality and Leadership, information is gathered not only to determine the presence of desired outcomes and supports, but also to generate discussions with support coordinators regarding their organizational practices and systems for generating results for the people they serve. The intent of the WiSCC process is to provide recommendations to support coordinators about the sample of individuals interviewed, and to identify strengths that can be capitalized upon and challenges that can be addressed so that the support coordinators can generate desired results for all the people they serve.

Developing a new tool to capture and report upon the performance of support coordinators required a fresh way of thinking when incorporating a results orientation. Delmarva had been scoring support coordinators on roughly 180 elements with the original provider review tool that focused primarily on process. The new WiSCC tool has only 11 elements. Five elements continue to focus on process-oriented topics such as background screening, training, and billing. The remaining six speak to the very essence of what Florida is trying to accomplish, as each element builds upon the previous elements, ultimately focusing upon the generation of results:

- Expectation 1: The support coordinator has an effective method for learning about the people they serve.
- Expectation 2: The support coordinator is aware of the health, safety, and well-being of the people they serve.
- Expectation 3: The support plan is developed with the person and reflects what the person wants.

- Expectation 4: The support coordinator has evaluated the effectiveness of all supports.
- Expectation 5: The support coordinator uses education, exposure, and experience to support informed choices.
- Expectation 6: The support coordinator has assisted the individuals they serve to accomplish positive results.

The “simplistic relevance” incorporated into the WiSCC approach enables both the support coordinator and the Delmarva consultant to easily see the big picture goal of results generation and avoid what historically has been a mundane focus – the “monitoring” of details that have little to no impact on what is important to the people being served. The possibility of a more creative and less scripted approach fosters an environment more likely to generate a meaningful end.

Several activities have been included in the WiSCC that are consistent with its consultative intent. Support coordinators are invited to observe interviews conducted by Delmarva consultants, with the consent of the person being interviewed. The goal is that out of this modeling activity the support coordinator will develop additional skills that can be applied when communicating with the people they serve. Additionally, Delmarva consultants are responsible for collecting detailed health and safety information during the individual interviews, utilizing this information to generate recommendations and insights directed towards the support coordinator or general support network. Delmarva has a developmental disabilities registered nurse (DDRN) on staff who not only validates the recommendation process, but who can also be incorporated into discussions with the support coordinator during the WiSCC process via conference-call technology. Real-time health, safety, and behavioral discussions provide concise feedback to support coordinators striving to provide the best possible services. Delmarva’s DDRN additionally has the ability to

compare WiSCC results to Medicaid claims data, and to request additional information from individuals, service providers, and physicians if inconsistencies are identified.

Support coordinators are no longer required to complete Quality Improvement Plans to address areas of “non-compliance.” The Delmarva consultant instead works with the support coordinator to develop a three-month plan. This plan focuses on ways to address challenges to the support coordinator and barriers preventing the generation of results. At the completion of the WiSCC, the consultant provides both a report of WiSCC findings and a manageable strategy to address the challenges that were identified. With these tools in hand, the Support Coordinator can quickly and effectively implement changes which will enhance the likelihood of results being generated for the people they serve.

One Provider’s Reaction

Leigh Meadows is the Director of District 3 Operations for People Systems, a support coordination agency serving people with developmental disabilities in north central Florida. She was a member of the stakeholder workgroup challenged with the task of shifting the statewide support coordination evaluation process from a process to a results orientation. People Systems recently experienced a WiSCC, and of the new evaluation approach she had the following to say:

First and foremost, I was very pleased to observe that the focus of this process was as it was conceived to be, in that support coordinators (SC’s) learned from the experience how to better do their jobs. Observing the process of interviewing consumers was the most educational, as the interview methods demonstrated by consultants through this process showed new methods for interviewing consumers not learned through previous training. In being interviewed by consultants on how SC’s

perform their jobs, we have also learned that while being consumed with solving crisis situations and handling state-imposed deadlines for consumers, we have missed opportunities and lacked time to develop much needed natural and community supports. We have learned that consumers can express choices in many areas that were previously unexplored.

As I watched the process unfold, I must admit that it worked better than I had imagined. I expected much more of an authoritative hand from Delmarva. However, we were respected as professionals, with no “gotcha” mentality. We were guided and instructed on ways to better handle information gathering and address provider issues. Barriers were acknowledged and addressed. The benefits from this process and how it will affect future training and quality improvement are invaluable.

I am sure if you asked each SC from our company who went through this process, they would agree that the experience was a good one for them and that they learned how to more effectively do their jobs, which from my perspective, having a hand in the development, was the whole purpose behind it all. I have great faith in the WiSCC process and the potential for positive change and growth within our overall system.

Conclusion

It is anticipated that this fundamental shift to a results-oriented, consultative evaluation system in Florida will not only serve to evaluate existing services, but will also become the impetus for culture change and quality of life improvements for people with developmental disabilities.

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Promoting Healthy Lives: The National Center on Physical Activity and Disability

by Jennifer Gray and William J. Schiller

Research shows that persons who engage in regular physical activity have a lower risk of many chronic conditions including type 2 diabetes, stroke, and coronary heart disease, and retain greater physical independence throughout life. Unfortunately, people with disabilities who might benefit most from the effects of physical activity are often sedentary, and have poorer health status compared to the population at large (Heath & Fentem, 1997; Rimmer, 1999, 2002; U.S. Department of Health and Human Services, 2000). Prolonged physical inactivity can cause a downward health and functioning spiral, and sedentary behavior over time can make it more difficult to engage in physical activities that could promote health. It can also have a negative effect on performing self-care activities and other activities of daily living. At a societal level, this contributes to higher health care costs and a greater strain on the national health care budget (Rice & Trupin, 1996).

The National Center on Physical Activity and Disability (NCPAD) was created in 1999 as a national health promotion initiative to gather, synthesize, organize, disseminate, and produce information and resources on physical activity and disability. NCPAD's information resources – including its Web site at www.ncpad.org – are geared to consumers, caregivers, practitioners, policymakers, and researchers, and it serves to network these constituencies to produce new information and increase linkages supporting physical activity for persons with disabilities.

What NCPAD Offers

NCPAD makes available the following resources to its constituencies:

- Consumers. Persons with disabilities are empowered to pursue the health benefits of daily physical activity by

utilizing NCPAD information on how to exercise and engage in recreation and sports. For example, consumers can call or e-mail NCPAD information specialists with questions on how to exercise with a specific disability, available adaptive equipment, the location of accessible fitness programs in their areas, as well as a range of other questions. Information specialists respond with a packet of materials geared to the consumer. In addition, consumers often write pieces for the “Your Writes” area of the NCPAD Web site on the experiences of people with disabilities becoming more physically active and can also participate in the NCPAD online discussion groups.

- Practitioners. NCPAD supplies information to practitioners who work with people with disabilities to enhance the effectiveness of their health and activity programs by disseminating fact sheets and research-based articles written by practitioners on exercising with a variety of disabilities. A personal trainers' database is currently being developed that will provide information about U.S.-based personal fitness professionals who have experience working with people with disabilities and other health conditions.

Care coordinators can utilize NCPAD's information specialists and resources to include a wellness component to services they are coordinating for their clients with disabilities. For example, care coordinators might use NCPAD's programs database to locate a wheelchair-accessible fitness center in their area, they may consult an information specialist about adapted equipment for a specific disability, or they could request information on how someone with a

chronic condition such as diabetes can exercise safely.

NCPAD maintains an extensive bibliography of resources on specific topics such as adapted physical education for children, fitness programming for people with specific types of disabilities, and guidelines for ADA compliance for health clubs and fitness facilities. It also conducts outreach to specific professional groups whose members can impact their affiliated programs and populations with information on physical activity and disability.

One of NCPAD's related projects, AIMFREE (Accessibility Instruments Measuring Fitness and Recreation Environments), is the product of a three-year study funded by the Centers for Disease Control and Prevention. The AIMFREE instruments are used to measure accessibility of fitness centers, swimming pools, parks and trails. It can be used by both people with mobility limitations and by professionals, such as fitness and recreation center owners and staff.

- Policymakers. NCPAD provides information for policymakers, governmental agencies, and industry leaders developing policies, guidelines, and programs promoting physical activity for persons with disabilities. Its monthly e-mail newsletter serves as a forum to provide current information in the physical activity-disability arena, and topics include research and policy updates.
- Researchers and evaluators. NCPAD and its related projects supply assessment instruments and resources on evaluating the physical activity level of persons with disabilities and accessibility for people with disabilities to fitness and recreation programs and facilities. The *PADS (Physical*

Activity Disability Survey) instrument, for example, is used to assess low-level physical activity among persons with physical disabilities and chronic health conditions. A complementary instrument is the *Barriers to Physical Activity and Disability Survey (B-PADS)*, which is used to measure barriers to physical activity encountered by persons with disabilities.

NCPAD's Web site serves as the key repository for its information, with mailed materials and a toll-free phone line also available. NCPAD plans to develop a section of its Web site that allows individuals to use the *PADS* to determine their current level of physical activity, develop realistic activity goals with an appropriate timeframe for achieving those goals, and monitor their progress. NCPAD is also developing a portion of its Web site for children with disabilities with information on recreation and exercise for use by parents, therapists, teachers, and recreation staff, and fun games and activities for children.

Candace's Experience with NCPAD

Candace Bennett of Chicago is one individual with a disability who has benefited from NCPAD resources. She relates her experience as follows:

For the past six and a half years, I have worked as a writer and editor, focusing on assistive technology devices for people with disabilities. It's been gratifying helping others access life's activities, but I also benefit because I have a disability. I've had multiple sclerosis for more than half my life. As my ability to ambulate has receded, I've needed to devise creative ways to accomplish tasks. I mostly use a motorized scooter, and for short trips around my house I use a walker. That means that I accomplish as much as possible while seated (i.e., shopping, cooking, and bathing). I even got married sitting down!

For me, finding appropriate exercises is very difficult. Since I must stand to ease the continuous strain on

my back, working out in a swimming pool is an excellent activity. I use the water's buoyancy, plus a flotation device or two, and I can stand up easily. If I don't make time to swim, I experience much more back pain.

Recently I moved from a house to a condominium for greater access to the city. From my new location, I called an NCPAD information specialist to learn about the location of accessible pools. Then I searched NCPAD's Web site. It provides information on adaptive equipment, programs, and how-to videos, as well as demonstration video clips. This is very reassuring as it demonstrates that I have many more options from which to choose than repetitive movements or low-impact water aerobics. NCPAD fact sheets and other materials help me to learn water yoga, martial arts, water Pilates, Yogalates, and adapted land sports. I now can be fit and have a lot of fun!

Conclusion

Though NCPAD was initially developed to be purely an information clearing-

house, it has grown into an expansive network of consumers, professionals, and researchers promoting physical activity for persons with disabilities. Its network and resources are positioned to support coordination and collaboration between professionals and organizations, as well as empowerment of persons with disabilities, encouraging healthy lifestyles and participation in community fitness, recreation, and wellness options for persons with disabilities.

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Resources of Interest

- **Community Living Exchange Collaborative Clearinghouse (www.hcbs.org)**. A Web site offering a broad array of articles, reports, and resources for infrastructure development to support individuals with disabilities within the community. Includes resources related to long-term care, aging, mental health, and disabilities, among other topics.
- **The Consortium for Children and Youth with Disabilities and Special Health Care Needs (http://gucchd.georgetown.edu/programs/consortium_for_children;202/687-5000)**. The mission of the Consortium is to improve rehabilitation outcomes for children and youth with disabilities and special health care needs by increasing the effectiveness of service systems. It distributes an extensive array of print and online reports, briefs, and fact sheets.
- **Health Care Transitions (<http://hctransitions.ichp.edu>)**. Operated by the Promising Practices in Health Care Transition Project, Institute for Child Health Policy, University of Florida. The site offers an array of training materials, listservs, publications, and events related to the transition from pediatric to adult care.
- **The Provider's Guide to Quality and Culture (<http://erc.msh.org>)**. A Web site designed to assist health care organizations in providing high quality, culturally competent services to multi-ethnic populations.

[Bregman, continued from page 1]

started working with the U Special Kids Program at the University of Minnesota. It now does care coordination for Sarah. Barb and Nancy, the U Special Kids nurses, know everything about Sarah and they make her appointments, keep her medical profile, and also answer questions from physicians, nurses, her school, anyone. I also needed someone that I could ask any question to, and Barb and Nancy are there for me, not just for information about medical care, but also about what resources are out there for our family, from medical supplies and durable medical equipment and home modifications to developing a “recipe” for diaper ointment that works. There is so much that parents do not know and until U Special Kids no one resource was available that did for us what U Special Kids does.

Sometimes it is hard just caring about the “normal everyday stuff” like food, housing, and my other kids. Add the 24-hour care of Sarah and I’ve been on an emotional roller coaster. Barb, Nancy, and Dr. Kelly at U Special Kids are advocates who have helped me off it. As busy as Dr. Kelly is, she always manages to make time for you when you need her. Like when she drove in early to hold my hand and cried with me when Sarah’s brother Marcus died (he died of the same disease in 1999).

When I think about what our family and others like us need from the health care and social services systems in this country, first, I would say that we need them to stop making parents justify care when a child is severely disabled. To qualify for most services, we would have to live near poverty; this makes stress levels very high and finances very tight. As I said earlier, before we enrolled Sarah in USK, we did not know where to find or apply for resources. The county case managers should have the resource information and know who should apply and how, but they often don’t. Parents should not have to search for resources. And second, we need U Special Kids and other programs like it to be funded and made available to us 24 hours a day.

Sylvia Bregman and her family live in Andover, Minnesota. For more information about the U Special Kids program at the University of Minnesota see pages 22-23 of this Impact issue, or contact the program at 612/626-3081, 800/276-8642 (toll-free) or usplkid@umn.edu.

[Tschida, continued from page 3]

While an increasing number of states are including individuals with disabilities in Medicaid managed care plans, the success of these efforts is mixed at best. Very few states have programs specifically designed to meet the needs of this often medically complex population. Most include those with disabilities in programs designed for the general Medicaid population. In addition, Indiana and Ohio have crafted programs to better address the multiple needs of the Medicaid population with disabilities. The centerpiece of these programs is care coordination, or assistance in navigating the array of specialists, medical equipment providers, and pharmacy needs of these consumers (for further information see www.indianamedicaid.com and <http://jfs.ohio.gov>).

Short of managed care, states also are looking increasingly at incorporating persons with disabilities into altered disease management programs or at least focusing on a *medical home* or designated primary care doctor for each Medicaid recipient. The challenge is often in securing the effective provider relationships with insurers who view Medicaid as a poor payment source and its enrollees as challenging and time-consuming to serve.

Olmstead v. The Budget

In 1999, the U.S. Supreme Court, in its landmark *Olmstead* decision, established a standard that individuals with disabilities should receive their government-funded services in the most integrated setting. Hailed universally as a strong statement in favor of community integration and against the institutionalization of people with disabilities, policy

and legal advocates across the country have used this to influence the decisions of those allocating scarce budget resources. In many states it has led to a more comprehensive approach to disability services planning and implementation, recognizing that in order for those with complex health needs to succeed, there need to be supportive, integrated policies that link housing, transportation, employment, and health care services. Forty-eight states have filed plans with the federal government describing how they are addressing the *Olmstead* standard. In some cases, additional resources have been dedicated to this effort. In others, Minnesota included, new problems have been addressed, including an effort to move the state’s 3,000 non-elderly persons with disabilities from nursing homes to more integrated community living settings.

Conclusion

There is hope in these examples and reason to believe that there will continue to be emerging options for individuals with disabilities and the providers who serve them. In the near-term, cost will continue to be a primary driver of decision making. And policymakers and those in the health and rehabilitation industry will continue to struggle with how to measure successful outcomes to help drive change that will both control costs and produce better health and quality of life results for those seeking to preserve – or improve – their level of independence and participation in community life. People with disabilities deserve nothing less.

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[Clark, continued from page 5]

Community Living Alliance and Community Health Partnership

The Community Living Alliance (CLA) and Community Health Partnership (CHP) are part of the Wisconsin Partnership Program, and use a similar approach to PCA services as the Minnesota pilot project, providing the full range of Medicaid and Medicare benefits and services under their coordinated care plans. While CLA serves members 18-64 years of age with disabilities, approximately 30% of CHP members have disabilities and 70% are seniors who are medically fragile.

In a way, these plans see 100% of members as having a level of self-direction, just not total self-direction. For example, members of CLA do not self-direct in the sense that out-of-pocket costs for personal care are authorized for them to recruit their own PCAs. Instead, PCAs get a list of members seeking attendants and call them. This is considered most efficient. The members meet with the plan's personal care coordinator, a RN, to determine the type and hours of care needed and preferred time of day for care to be delivered. The CLA and CHP plans have the responsibility for recruiting, training, and supervising PCAs, and the plans perform the payment duties. Members have full authority to help recruit, make initial selection

of PCA workers, and change the PCAs assigned to them.

Approximately 10-20% of members seeking to self-direct their PCA care have plan approval to use Paid Family Caregiver services. Both CLA and CHP work with their members to encourage self-directed care, and oversee how those services are provided. Nevertheless, most members with PCA needs prefer not to take on the additional responsibility that accompanies self-directed family caregiver services.

Conclusion

The Minnesota Disability Health Options and Wisconsin Partnership Program initiatives are unique coordinated care systems that offer the fullest extent of unified Medicare and Medicaid coverage under one umbrella as can be found anywhere in the United States. These plans encourage and prepare members to be involved with self-directed care, are sufficiently flexible to offer a range of options in relation to self-directed care, and have developed well-defined programs for those members who seek to self-direct. Because their funding is based on capitation payments and not tied to specific fees for discreet services, they also have far greater flexibility to offer services and benefits not covered by either Medicare

or Medicaid, such as an air conditioner or other items that the plan determines are medically necessary to support member health and optimally independent functioning in their homes.

These demonstration initiatives do appear to provide answers to the questions posed by consumers, providers, and payers as mentioned above. Participants in these special coordinated care plans have the flexibility to take charge of, and assume responsibility for, self-directed care. Yet, these unified and integrated health plans are also providing and arranging services for the majority of their members requiring PCA services. Providers have the ability to meet individual needs without having benefit coverage decisions fall between the cracks of various program definitions. Payers, such as the States of Minnesota and Wisconsin and the Centers for Medicare and Medicaid Services, may be able to more effectively monitor these coordinated care plans as they are the single accountable health care provider for all the care received by beneficiaries. Through routine monitoring and oversight, payers can better understand and assure that the overall system of care is best suited to meeting the needs of program beneficiaries.

As our Medicare and Medicaid programs change in future years as part of large-scale national health care reforms, it is important to consider the unique models of health care delivery offered through these initiatives, and what they may have to offer individuals with disabilities, health care and support services providers, and payers in all areas of our country.

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Resources of Interest

• **Healthy People 2010 – People with Disabilities** (www.cdc.gov/ncbddd/dh/hp2010.htm). This Web site includes data, discussion proceedings, fact sheets, a listserv, and leading health indicators related to people with disabilities and the federal Healthy People 2010 initiative.

• **National Survey of Children with Special Health Care Needs: Chartbook 2001**. By the Maternal and Child Health Bureau, U.S. Department of Health and Human Services. A report presenting major findings of the National Survey of Children with Special Health Care Needs; provides data on the prevalence of special health care needs among children nationally and within each state, and on access to and satisfaction with care among the children and their families. Available online at <http://mchb.hrsa.gov/chscn> or in print from 888/ASK-HRSA.

• **National Center of Medical Home Initiatives for Children with Special Needs, American Academy of Pediatrics** (www.medicalhomeinfo.org, 847/434-4000). Offers medical home tools, resources, training materials, state contacts, and funding opportunities.

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[Palsbo, continued from page 11]

the financial incentives are clearly aligned with keeping the participant as healthy as possible.

In the other financing model, program sites are housed in community health centers or primary care coordination model programs. The financial incentives are comparatively cloudy since savings are realized at the county or state level rather than the organizational level. Most of these sites fund their coordinators out of grants.

Is Service Coordination “The Answer?”

Participants in the pilot programs are uniformly enthusiastic about service coordination. In our interviews, they have told us, “This plan saved my life”; “I’m in charge of my health instead of my health being in charge of me”; “I’m much happier”; “I know what’s going on when I go to the doctor”; and “I get the services and supplies I need, when I need them.” These statements align with published studies reporting high satisfaction with care coordination pro-

Participants in the pilot programs are uniformly enthusiastic about service coordination. They have told us, “This plan saved my life” and “I’m in charge of my health instead of my health being in charge of me.”

grams geared to children with special needs (Toce & Collins, 2003), people with severe mental disorders (Balsera et al., 2002), neurologically impaired patients (Bennett et al., 1997), and people with spinal cord injury or AIDS (Master et al., 1996), among others. Inversely, we and others have found that lack of

care coordination is associated with dissatisfaction with their health care (Gehl, 1993; Hill & Woodridge, 2003; Palsbo et al., 2004).

Physicians participating in the pilot programs are also enthusiastic. They support the programs because they see improvement in their patients and because they know the coordinators will help the patients follow through on referrals, prescriptions, and other necessities. As they’ve told us, “We found that the ability to get equipment, supplies and specialized beds to people really made a big difference”; and “It makes my life and their lives much easier. My patients with complex medication regimens are much healthier because they have help staying on track.” Physicians also appreciate having a single person (the coordinator) who knows everything going on with that patient and community resources that might be available.

Currently, there is no definitive published study that service coordination is cost-effective. Several analyses are underway and Medicare will start a study in 2005. In the research that does exist, several studies suggest coordination of services leads to a short-term increase in total expenditures from social programs as the coordinator steers the beneficiary to services he or she previously did not use. For example, secondary analysis of National Health Interview Survey Disability Supplements found that school-aged children with disabilities and poor psychosocial adjustment were more likely to access mental health services if they had a health professional involved in care coordination, increasing total costs to public programs (Witt et al., 2003). There are other hints that service coordination could culminate in monetary savings. Master et al. (1996) analyzed a capitated care coordination program for adults with spinal cord injury or late-stage AIDS; they found that the covered costs (that is, not including the care coordination costs) for Medicaid beneficiaries were 91% of the fee-for-service population, illustrating the savings that can be achieved by preventing long hospitalizations.

Conclusion

Based on our experience with the pilot programs, comprehensive service coordination appears to be a promising approach for people with disabilities and other complex medical needs. It holds the promise of maximizing the quality of health and life for individuals receiving services. For providers it offers a way to enhance their delivery systems. And for payers it may have the potential to use fiscal resources more effectively.

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Evolution of the Program Model

We have been developing an expanded framework, beyond the care management process, for managing all of the health care and support services that we provide/coordinate. There are five program areas that our members consider valuable and in which we have developed distinctive skills and knowledge. Each of these areas combines care management functions and direct services. Together, they represent a significant portion of our medical expenses and foundation building blocks for ICS' approach for addressing the long-term care and support needs of adults with physical disabilities. They are as follows:

- Pressure Ulcer Prevention and Intervention Program. Approximately 40% of our members have been determined to be at moderate to high risk for developing pressure ulcers. The Braden Scale for Predicting Ulcer Risk is a regular component of the nursing assessment completed upon enrollment in ICS and every 120 days. Nurse care managers, in consultation with the program director, develop appropriate interventions for each individual at moderate-high risk.
- ICS Wheelchair Purchase and Repair Service Program. Approximately 70% of ICS' members rely on some type of wheeled mobility device – manual wheelchair, powerchair or scooter – for their primary means of mobility. A physical therapist who is specialized in seating and mobility services is available to members who are in need of new equipment. The therapist assesses joint flexibility, sitting balance, skin conditions, and functional mobility skills; the member articulates previous experiences with mobility products, and their intended use for the new equipment. A wheelchair repair technician visits members in their homes to repair chairs as needed, and members also have access to maintenance training and a workshop to perform preventive maintenance.
- Home Care Aide Services Program. Approximately 80% of our members use home care aide services (not including Consumer-Directed Personal Assistance Services) as the primary support. They are also the link between members/family caregivers and professional service providers. The program consists of a general orientation for all aides that provides information about the member's condition and goals to enable them to be active participants in supporting the member's needs and interests. We also provide problem-solving assistance when members are unable to obtain stable home care aide services.
- Consumer-Directed Personal Assistance Services. Approximately 20% of our members use consumer-directed personal assistance services in which they hire and supervise their own personal assistants through a contracted agency. We are currently planning a program that will provide additional support services as of mid-2005. It will include consumer training on the role and responsibilities of consumers in terms of recruiting, hiring and supervising their personal assistants; personal assistant training on the role and responsibilities of the assistant; and a central registry of personal assistants to aid consumers and assistants in connecting with each other.
- Social Activities Program. Adults with physical disabilities have very limited opportunities for social participation and recreation. We are now planning a social activities program for implementation in mid-2005 with the following components: a cafe setting at our office providing an informal meeting space; organized activities including support groups (men, women, weight management) and affinity groups (writers, movie lovers); classes in ESL/GED, computer skills, painting, and woodwork; and social events.

The ICS Organizational Model

The care management process and the programs described above are meant to offer services that create unique value for our members and contain costs over time, especially by reducing the frequency and duration of hospitalizations. Part of the unique value is also connection to a community of people – other members, our staff, our key providers. We are committed to developing processes and systems that support collaborative relationships among members and with ICS staff and providers. This requires giving members a real “voice” in operations through satisfaction surveys, group meetings, and a

Discussions about choices and trade-offs are more frequent and honest when people feel “known” by each other and respected.

member council. It requires taking responsibility for all of the services we coordinate as if we provided them all ourselves. And it requires creating social opportunities for members and staff to get to know one another.

What is the connection between community and care coordination? Connectedness and hope are healthy antidotes to isolation and depression. Discussions about choices and trade-offs are more frequent and honest when people feel “known” by each other and respected. When people feel they not only have a good experience with the organization but are treated as major stakeholders, they will be prepared to balance cost and service issues as if they are spending their own money and not someone else's.

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