

MCARE Policy Brief

The National Clearinghouse on
Managed Long Term Services and Supports
for People with Developmental Disabilities and Their Families

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Developmental Disability Services At The Century's End: Facing The Challenges Ahead

The developmental disabilities field stands before this next century filled with pride over the accomplishments of the past three decades. During this time, the living hell that people with disabilities were made to suffer in public institutions was ended. Institutions have not been eliminated – about 60,000 people reside in such facilities nationwide -- but residential conditions have improved dramatically. Meanwhile, a community services system was established that now serves about 250,000 people through Medicaid Home and Community Based waiver programs, and thousands more in state and locally funded programs (e.g., family support, day time services).

As this century draws to a close, there is enormous hope and concern for the future. There is hope for continued action to improve the quality of life of people with disabilities, and to do so in ways that place individuals in charge of their lives. But there is concern, too, for a service system that feels the pressures of its recent growth and changes. There is debate on a range of issues involving: (a) the persistent tension between past and emerging service practices (e.g., the future of ICFs-MRs, group homes vs. supported living, facility based day

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services vs. supported employment), and (b) the overall well-being of the community services system (e.g., concern for the community direct supports work force, and in particular the low pay that is offered and high turnover rates).

These discussions are important because their resolution creates the context within which thousands of individuals with developmental disabilities live their lives. Such discussion, however, is generally internal to the field, reflecting an ongoing evolution of thought and practice. Yet there are also other factors that must be taken into account that have little to do with the developmental disabilities field.

Over the next few years, five elemental trends -- internal and external to the field -- will come together to prompt significant reform within developmental disabilities service systems. The purpose of this policy brief is to illustrate five of the most significant of these trends. These include:

- The push for continued changes in the service system to promote self determination.
- The continued pressure to contain the growth of Medicaid expenditures.
- The growing demand for developmental disabilities services.
- The increasing used of managed care strategies to administer Medicaid health and behavioral health care systems.
- The emerging re-structuring of the developmental disabilities provider industry.

These pressures are felt to some extent in all states, although there is variance

across the states. The pressure for reform that these trends -- alone or in combination -- will place on developmental disabilities systems cannot be underestimated. Failure here may well place at risk the gains made over the past three decades, resulting in expanded waiting lists at the least or a roll back to past practices at the worst.

★ The Push for Self Determination

As important as *what* services or supports are delivered, is *how* such assistance is offered. Until recently, professional judgment was more heavily weighted than the choices and preferences of service recipients. In addition, the choices available to people with disabilities were restricted to the residential and vocational slots available. Emerging practice, however, dictates that people with developmental disabilities should play leading roles in determining the substance of their lives, and that services should be developed as needed to support their preferences. Moving past traditional professional or supply dominated approaches, the field is struggling to become more responsive to the demands of service recipients -- to promote and honor *self determined lifestyles*.

The push for self determination will promote changes in the substance of services and in related system administrative structures. In essence, the notion of self determination implies that individuals are free to “act as the principal causal instrument in one’s life and to make choices and decisions regarding one’s chosen lifestyle independent of undue influence or interference from

others (Wehmeyer, Kelchner & Richards, 1996). At the core of the concept is the belief that individuals have the authority, power and resources to control their own destinies. Inevitably, this must also include the authority to plan their own futures, and directly negotiate for funds (Barrs et al., 1995; Nerney & Shumway, 1996; Agosta & Kimmich, 1997).

This latter point -- the ability to negotiate directly for funds and ultimately the authority to control the funds available to pay for one's services or supports -- presents a dramatic challenge to the field.

As policy and practices have evolved over the past decades, the ongoing discussion within the field primarily concerned the substance of services. Early on there was argument over the size of community residences, the merit of community ICFs-MR, the appropriate response to challenging behavior, and the day time activities afforded people with developmental disabilities. Later, the debate shifted and centered on newer alternative approaches such as supported living, including home ownership by people with disabilities, supported employment, family support, and the utility of natural supports.

But this evolution of thought seldom touched on the underlying flow of money, and so power, in the services system. From the beginning, the community services system was based on the establishment of thousands of local service providers, and on a service contracting arrangement between the payer (i.e., state or county authorities) and the community agency. The result is

multi-billion dollar national industry where service providers expect routine renewals of their contracts, and where the pace and substance of systems change unfolds within this context.

The notion of self determination -- played out in policy and practice -- challenges all that. Beyond change in the substance of services, the concept implies a change in the structure of service systems. Breaking from the pre-set contractual arrangements between payers and providers, people with developmental disabilities and their families are demanding direct control over the dollars, freeing them to choose between providers or other support givers. For the first time, service recipients may act as real "consumers" or "customers", with providers having to compete for their business.

Already methodologies for system redesign that are consistent with these themes are taking shape. "Participant driven managed supports", for example, refers to a variety of strategies for administering systems to increase their effectiveness and efficiency, while maintaining a commitment to community integration and self determination for people with developmental disabilities (Agosta & Kimmich, 1997). The approach builds on the idea that individuals will in some way exert control over the dollars allocated for their support. This may be achieved through vouchers, direct cash grants or third party payments. To help assure success, individuals may use: (a) a "broker" or personal agent to develop a plan for purchasing or otherwise acquiring support, and (b) a fiscal or administrative

intermediary to handle the resulting paperwork (e.g., IRS tax reporting requirements, Department of Labor requirements, fiscal accounting).

Such methodologies are being applied to varying degrees in several states, including Colorado, Michigan, Vermont and Rhode Island. In these states the re-design plans to some degree call for program practices to become significantly more “consumer directed.”

Complementing such activity, in 1997 the Robert Wood Johnson Foundation made grants to 18 states to push ahead with their own “self-determination projects” (New Hampshire previously had such a grant). These projects promote new configurations of support, in combination with existing services, to empower individuals with developmental disabilities

The 19 RWJ Self Determination Project Sites	
Arizona	New Hampshire
Connecticut	Ohio
Florida	Oregon
Hawaii	Pennsylvania
Iowa	Texas
Kansas	Utah
Maryland	Vermont
Massachusetts	Washington
Michigan	Wisconsin
Minnesota	

to gain control over their selection of needed services or supports. More recently, a smaller group of states, was selected by the Foundation to receive a technical assistance grant to help resolve

issues related to “customer driven” systems.¹



Continued Pressure To Curb Medicaid Spending

Medicaid was created in 1965 to help states pay the medical bills of low income individuals. Today, Medicaid has three service domains: a health insurance program for low income individuals, a long-term care program for seniors and people with disabilities, and a specialized service program for people with developmental disabilities or mental illness (Congressional Research Services, 1993).

The costs of Medicaid services nationally are split between the federal government and the states. The percentage of costs borne by the federal government varies from state to state depending on state-specific socio-economic indicators, but the national average is 57% federal and 43% state. In 1970, Medicaid spending totaled \$5 billion. Expenditures have skyrocketed since then. From 1985-1995, spending grew by 15% annually. In 1995, program outlays on behalf of 34.8 million individuals had climbed to \$157.3 billion. Of this total, the federal portion amounted to about \$90 billion.

Such growth in spending and the concern it brings should interest people with disabilities. Many people with disabilities

¹ For more information about these planning grants, contact the Robert Wood Johnson Foundation Office on Self Determination for People with Developmental Disabilities; 10 Ferry Street (#14); Concord NH 03301 -- phone: 603-228-0602.

of all ages rely on Medicaid for health care and long-term services and supports. As illustrated by data from 1995, people with disabilities account for about 16% of program beneficiaries, but utilize about 38% of all expenditures. As policy makers search for ways to control Medicaid spending, the expenditures tied to people with disabilities, including health services and long-term supports, may well be one of the first targets (King & Christian, 1996).

Recently, however, growth in Medicaid expenditures has slowed, increasing 3.2% from 1995 to 1996. In April 1996, the Congressional Budget Office (CBO) forecast that spending would increase at 9.7% annually from 1996-2002, with federal expenditures growing by \$898.4 billion during this five year period. CBO's most recent estimate projects a reduced growth rate of 7.9% between 1997-2002. Others speculate, however, that Medicaid costs will grow at an even lower 7.4% annual rate (Holahan & Liska, 1996). The lower rates imply lower annual costs and reduced pressure for Medicaid reform, at least at the federal level.

Medicaid Recipients & Expenditures, 1995

	Recipients	Expenditures
Families	72.4%	32.7%
Disabilities/Blind	16.4%	37.6%
<u>Elderly</u>	<u>11.2%</u>	<u>29.7%</u>
Total	34.8 million	\$132.8 billion*

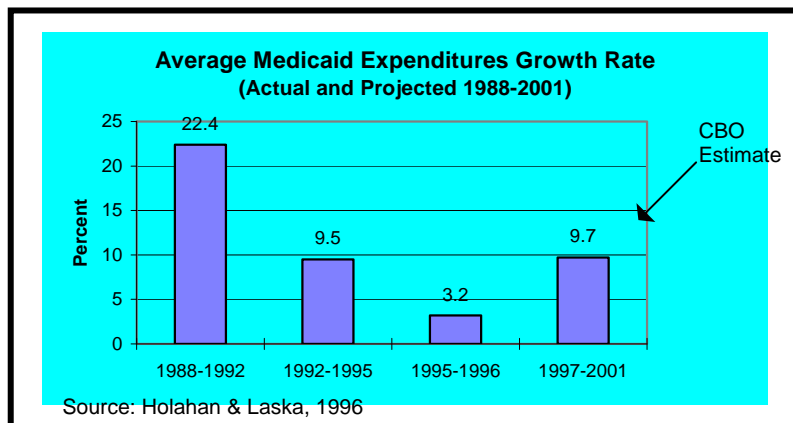
* Another \$5.5 billion was spent on administration, and \$19 billion more on Disproportionate Share Hospital Payments, so that total costs amounted to \$157.3 billion.

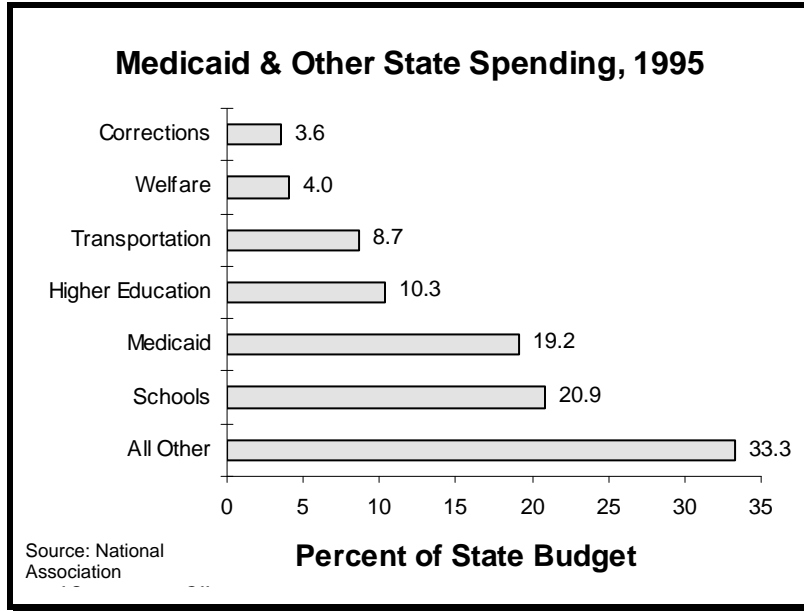
Source: Holahan & Liska, 1996

Smith (1997) notes that in 1995–1996 there was great momentum for terminating the Medicaid program and substituting a “block grant” program (i.e., “Medigrant”). But the momentum stalled and the proposal failed to gain Congressional approval. More recently, the budget reconciliation process between the Congress and the President left the Medicaid program largely in tact, although the bipartisan budget agreement reached in May, 1997 called for spending cuts of \$13.6 billion over five years. However, there appears to be little residual attraction to re-opening discussions about significant reform of the Medicaid

program. Yet, trends in Medicaid spending are not easily predicted and continued growth in the program is a concern to policy makers at all levels of government.

While the sense of urgency for Medicaid reform may for the moment lie dormant at the federal level, the





same is not true for state policymakers. From a state perspective, in 1970 Medicaid spending amounted to about 4% of state budgets, but by 1995 the proportion had nearly quintupled to 19% (NASBO, 1996). And this trend is predicted to continue on through the year 2002 (Wharton Economic Forecasting Associates, 1995). This poses enormous problems for state policy makers who must juggle competing demands (see box), such as education, corrections and transportation. When Medicaid takes up more of the budget, then less is left for other important functions. As a result, with or without federal action, governors and legislatures have made holding down Medicaid spending a top priority.

Within this context, Medicaid spending for people with developmental disabilities must be brought into focus. The growth in the overall Medicaid program and the resulting pressures have also been reflected in increased spending on **long-term services and supports** within state

and local developmental disabilities systems. Today, about 72% of what states spend on *long-term* services and supports (excluding acute health care) for people with developmental disabilities is paid by state and federal Medicaid dollars, at a cost of about \$15 billion annually (Braddock & Hemp, 1996). During 1977-1988, total federal-state Medicaid spending for individuals with developmental disabilities

grew by 15% annually in real economic terms, declining to about 9% annually from 1988-1992 and holding steady at an estimated growth rate of 9.5% for 1996 (Braddock and Hemp 1996).

These increases in Medicaid spending cannot be sustained indefinitely. While at the federal level the move for Medicaid reform has lost some of its recent steam, state policy makers remain quite interested in curbing Medicaid spending. Such interest will likely affect how services are funded for people with developmental disabilities and their families.

★ **Demand For Developmental Disabilities Services**

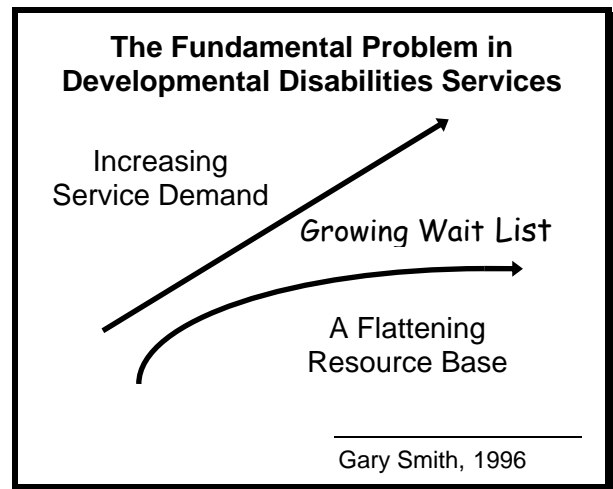
America is graying. At the turn of the century, life expectancy was 47 years and by 1991 it was 76 years (Economics and Statistical Administration, US Department of Commerce, 1995). People are living longer and that

includes people with disabilities. Due to advances in medical care coupled with the demographics of an aging population, the demand for developmental disabilities services will continue to increase.

The parents of many adults with disabilities are growing too old to continue to provide care at home. Middle aged baby boomers who had children with disabilities are finding that their children are now aging into the adult system. Consequently, the pressures placed on the long-term supports system for adults with disabilities can only grow over the next several years. Prouty and Lakin (1997) estimate that in June, 1996 there were 87,187 individuals who were on wait lists for residential services. This count does not address the thousands others who may be waiting for day time vocational services. Further, the *Community Services Reporter* (November, 1996) notes that:

Despite a steady increase in the total number of individuals receiving publicly-funded residential services over the past two decades, waiting lists have grown larger in many states. According to studies conducted by the University of Minnesota Research and Training Center on Community Integration, states, collectively, would have to increase their overall residential capacity by 18% simply in order to meet current demand. The prospects of achieving this goal are all the more daunting as access to additional public dollars becomes

more and more constrained and agency budgets flatten out.



Echoing such research, a recent National Arc study concludes that the nationwide shortfall of community support services has reached crisis proportions for people with mental retardation and their families. The Arc's report examines state-by-state data regarding the status of requests for critical residential, day/vocational and other community support services. According to the report, more than 218,000 requests for support remain unanswered for people with mental retardation and their families (Arc, 1997).

Admittedly, wait lists are difficult to track. There is no standardized way to collect the information, nor is it often verified. Also, there is no easy way to estimate the "urgency of need" of those on the wait list. As a result, some argue that the numbers are overstated, while others counter that the uncertainty in data collection means that the real waiting list is under reported. While there are problems with wait list data, the numbers cannot be discounted.

The numbers – and accompanying personal stories -- reflect a growing problem for policy makers.

Mixing together the concern for funding and an increased demand for services, the developmental disabilities field is faced with an enormous problem. If present circumstances unfold without modification, the outcome can only be an increase in the wait list. Despite encouraging isolated events where “new money” is allocated to state developmental disability authorities to accommodate portions of the wait list (e.g., as in LA and NJ), the field must face up to the sobering challenge it faces. No further dramatic increases in funding will be forthcoming, the demand for services is increasing, and means must be implemented to make service systems more efficient; That is, to do more with the resources already available.



The Emergence of Managed Care Strategies

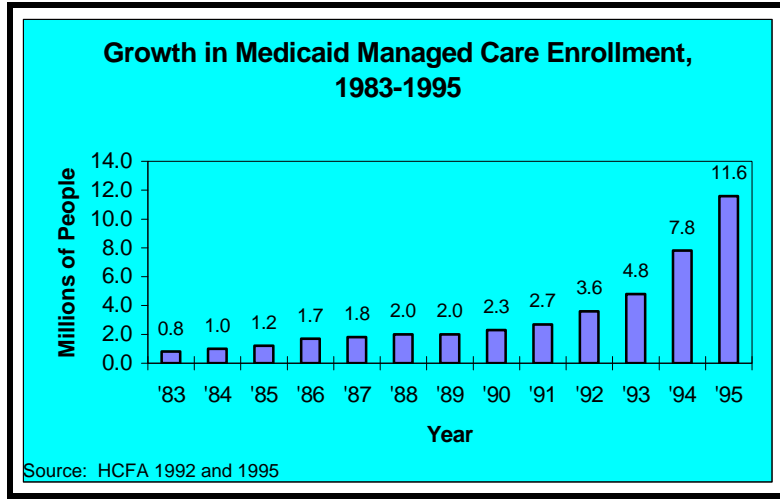
Managed care strategies increasingly are being used to administer Medicaid health and behavioral health care systems, and long term support systems, including developmental disability services, may be next in sight. In the health sphere, managed care “includes a broad array of health and financing delivery arrangements designed to reduce costs by eliminating inappropriate and unnecessary services and by relying more on primary care and care coordination” (The Kaiser Commission on the Future of Medicaid, 1996). Typically, managed care arrangements involve the enrollment of individuals in a managed care organization (MCO), where the MCO has

contractual agreements with a payer and providers to assure delivery of services to the enrollees. In essence, the MCO is a risk-bearing entity which receives a fixed payment to assure that a set of people get the services they need as specified in the managed care plan.

To contain service costs, efforts may be made to: (a) alter the price paid for services; (b) insert economic incentives for providers to hold down their costs; (c) influence service utilization patterns, in terms of both choice of provider and amount of services used; and (d) better coordinate the services needed, both within the developmental disabilities system and across other human service systems (Smith & Ashbaugh, 1995).

Increasingly, states are applying managed care strategies as a central means for taming rising Medicaid expenditures. In 1983, 750,000 individuals -- or 3% of the Medicaid population -- were enrolled in managed care plans. By 1994, this number had grown to 7.8 million (23% of the Medicaid population), and by 1995 it stood at 11.6 million (33%).

To enact a Medicaid managed care program, states typically obtain from HCFA one of two types of waivers of the Social Security Act: (a) Section 1915(b) waiver (a “freedom of choice” waiver); or (b) a Section 1115 research and demonstration waiver. A 1915(b) waiver allows states to implement plans that require mandatory managed care enrollment, or for only parts of a state or for certain populations. As of September, 1995, 42 states and the District of Columbia had 1915(b) managed care



waivers (Kaiser Commission on the Future of Medicaid, 1996).

States interested in systematically exploring new ways of managing Medicaid may also apply for waivers of Section 1115 of the Social Security Act. Here, the Secretary of the US Department of Health and Human Services authorizes states to establish statewide managed care demonstration projects that do not meet federal statutory requirements. These plans can shift traditional Medicaid populations into mandatory managed care arrangements, or explore expansions of coverage to certain populations or modifications in the service array offered. By 1996, 1115 demonstration waivers were already underway in ten states, with four others approved and another 11 under review (HCFA, 1996).

It is too early to tell if the move to managed care will result in the Medicaid cost containment objectives that policy makers hope for. However, there is a growing feeling that big overall savings cannot be achieved without extending managed care to the elderly and disability

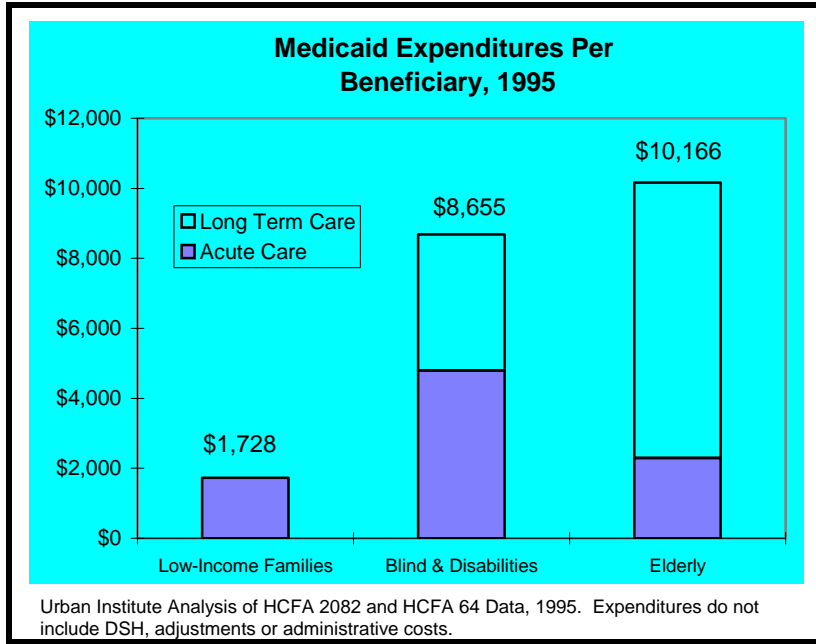
populations. After all, as illustrated earlier, Medicaid spending for children and families, the target for most managed care initiatives, accounts for about a third of the spending. The balance of the spending (67.3% in 1995) is for elderly and disability populations.

Aside from spending patterns related to categories of Medicaid beneficiaries, a further distinction can be

made regarding the type of spending. Medicaid spending is divided between acute health care or long term supports, with about 62% dedicated to health care. However, long term supports comprises a more significant proportion of Medicaid spending for elders and people with disabilities. For people with disabilities, spending per person is just about split evenly between acute health and long term support services.

Given these circumstances, it is not hard to see why managed care proponents are attracted to Medicaid spending related to disabilities and aging, and especially to long term supports spending. The path is first to establish managed care programs related to: (a) health care for low income families and children, (b) health care for elderly/disability recipients, and finally (c) long term services and supports.

There is even talk now of integrating health and long term supports under a single managed care entity (e.g., Kastner, Walsh & Criscione, 1997). While managed care proponents understand the



➤ While organizations within the health care industry have developed the management and financial capacity needed to manage the provision of health care on a capitated basis, they have not yet achieved such capability for long term supports. In fact, organizations already within the long term care industry are in the process of developing the equivalent for the

challenges these arrangements impose, they have not recoiled from the prospect. Riley (1997), in testimony before the US Senate Special Committee on Aging, suggested that if a managed care organization is to incur the risk and liability associated with delivering health care to people with disabilities, then it should also have command over long term supports, given the interrelation between health and long term supports.

Ashbaugh and Smith (1997) refute this suggestion (See *MCARE Policy Brief #1*). Considering the major arguments in favor of systems integration, they conclude that:

➤ Systems integration does not necessarily bring improved care coordination and system efficiencies, with the evidence to date suggesting instead that integration brings with it higher rather than lower overhead costs.

provision of managed long term services and supports.

➤ While some states (e.g., MD, WI, DE) are pursuing integrated care models for specific sub-populations, such as those with disabilities, any such approach must not be forced prematurely, i.e. that managed care entities not be asked to cover the costs of the health care / long term care for the different subpopulations until the magnitude of these costs are understood and unless the prospective payment (cap) is sufficient to cover them. This is because when the risk is unknown or unmanageable, outcomes detrimental to disabilities subpopulations and systems are likely.

Un-accommodated service demand and a troubled financing base create a favorable environment for pursuing managed care strategies to contain costs and increase systems productivity. In the first part of

1997 alone, the Health Policy Tracking Services (1997) reported that over 500 long term care legislative bills were introduced in 47 states. Legislative activities included: (a) creating study commissions, (b) creating or considering a managed care system for aging and disability services, and (c) exploring alternatives to nursing home care.

States -- with federal encouragement -- are aggressively expanding their use of managed care across Medicaid population groups. While the emphasis for the moment is on health care, interest is growing for applying managed care strategies of some type long term support systems, including developmental disabilities services. There is the feeling that it is not a matter of whether managed care comes to developmental disabilities services, but rather when and how it will come.

Already, several states (e.g., CO, MI, VT) have taken concrete measures to establish a managed supports structure that is uniquely tailored to existing developmental disabilities systems. Clearly, the present momentum for managed care will likely carry significant implications for developmental disabilities service systems that have come to rely so heavily on Medicaid dollars to sustain their growth.



Restructuring of the Provider Industry

The establishment of managed care plans for health services surely has resulted in a restructuring of that industry. Managed care companies have gained prominence,

complete with Standard & Poor rankings of their financial security. But times are not stable and the future of these organizations holds both promise and risk. Witness how health services providers have had to scramble to keep pace with events, seeking to offer consumers the services that are wanted and to play by the rules set by the overseeing managed care companies.

In responding to the changing environment, managed care companies and providers alike have followed a course involving: (a) coordination, (b) consolidation, and (c) merger and buy-outs. During this time, companies or cooperating networks have grown larger while others failed.

In the developmental disabilities field, circumstances are not nearly the same as in health services. There is not the same type of money at stake, and the markets at work -- health vs. social services -- are not easily compared (Smith & Ashbaugh, 1995). Yet plainly, the developmental disabilities field has caught the eye of managed care companies looking to diversify into long term services, and of other for-profit entities seeking a variety of business opportunities.

While there is no ground swell for provider restructuring yet apparent in the developmental disabilities field, there are clear signs of change:

- With increasing frequency, multi-state service providers (typically for-profit) are accelerating their entry into developmental disabilities service markets. These types of organizations

have existed for many years and have contributed to the development of the present service system. Over the past few years, however, some have gained the capital (e.g., through association with much larger health oriented organizations) to aggressively expand their base, either through outright purchase of provider businesses or by contract with a state or local payer.

Is this good or bad for the developmental disabilities field? Some argue that if the services offered by these large companies are satisfactory, then there is no harm done. In fact, some welcome the stability a large organization may bring to a network of affiliates sprinkled across the states. And these organizations have sometimes stepped in to deliver services in states where the existing service providers have balked (e.g., for “difficult to serve” individuals).

Others counter that the existing community provider system was established based on the premise of localized decisionmaking and that larger multi-state agencies would undercut this worthwhile tradition. They also argue against the idea of out-of-state organizations reaping profits from local programs, especially where all local needs (e.g., the wait list) are not fully accommodated. Further, they argue that existing state resources should be spent on strengthening local provider markets rather than bringing in out-of-state competitors.

- Perhaps in anticipation of the need to gain a competitive edge in advance of managed care, providers in several states are pursuing efforts to organize as formal service networks. In some instances (e.g., IL), providers have sought to establish a “managed services organization” (MSO). Like a traditional managed care organization, a MSO is a risk-bearing entity which receives a fixed payment to assure that a set of individuals receive the services they need as specified in the managed care plan; but in this instance the MSO also provides services.

Other providers, while not seeking the management responsibility of an MSO, are exploring networking possibilities that would result in: (a) increased administrative efficiencies, (b) enhanced and consolidated capacity to deliver direct services, and (c) a formal organization for future managed care entities to negotiate and contract with. In addition, because small or niche (e.g., supported employment only) providers may have difficulty competing with larger organizations in a more competitive market, networking may be desirable for such providers because of the added size and safety a coordinated network can bring.

So, again, is the trend toward networking good or bad for the developmental disabilities field? Detractors favor a continued emphasis on autonomous local community organizations. They argue that with providers all participating in a homogenized network, people with

disabilities would have little or no real choice in selecting providers. Others, however, fear that the great number of existing autonomous community providers, some very large and some very small, has resulted in an inefficient services network at odds with emerging cost containment objectives, and vulnerable to outside competition or undesired structural change.

Regardless of the points of view that win out, people with disabilities expect that the community services system must be capable of offering quality supports as needed. To do so, most would agree that the provider market in developmental disability services must stay strong, even as the field meets the challenges ahead.

Concluding Thoughts

In 1848 the first public institution was established for people with mental retardation in the United States. It represented a generally positive period carried by the hope that the mental retardation could be treated, and perhaps reversed. By the year 1900, however, these confident beginnings had been overturned, and an era of neglect and abuse began. You can say that in the United States, people with disabilities had a lousy half century, and then some.

Change overcame over these times beginning in the 1950's with the birth of national parent advocacy organizations, such as the United Cerebral Palsy Association and the Association for Retarded Children (now The Arc). The pace of change quickened thereafter

given successful litigation and federal legislation that was initially pushed along by the concept of "normalization."

In some ways, this trend culminated recently with the passage of the Americans with Disabilities Act of 1990 (PL 100-336). This Act has become the primary lens through which public policy is viewed, suggesting strongly that it is the policy of the United States of America that programs of support for people with disabilities shall be carried out in a manner consistent with the principles of presumed ability, integration and inclusion, full participation, meaningful and informed choice and involvement of families and natural supports (Buttons, 1992). Overall, for individuals with developmental disabilities, the last three decades of the century have resulted in remarkable changes in thinking, funding and services available.

Wolfensberger (1972) asserts that "man's behavior is in good part determined by ... his ideologies... a combination of beliefs, attitudes, and interpretations of reality that are derived from one's experience's, one's knowledge of what are presumed to be facts, and above all, one's values" (p. 7). He notes, too, that ideologies, the force behind policy and behavior, can be good or bad. Today, those involved with developmental disability services -- self-advocates, family members, providers or government officials -- likely believe that the ideologies behind the present service system are more good than bad. Today's ideologies, hopefully the antithesis of abuse and neglect, favor community integration, participation and contribution,

as well as self determination for people with disabilities.

However, these contemporary ideologies, complete with accompanying policy and practice, stand on challenged ground. As this century ends, the developmental disabilities field, aside from its ongoing evolutionary disagreements, must face up to the significant trends that are likely to shape service systems past the year 2000. In this paper five such trends are described. How will the field respond? What history will be made over the next ten years?

Only man is not content to leave things as they are but must always be changing them, and when he has done so, is seldom satisfied with the result.

Elspeth Huxley
The Mottled Lizard, ch. 4 (1962).



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