

TRENDS IN CARE FOR THE DEVELOPMENTALLY DISABLED

by James Legner

During the past 30 years, significant changes have occurred in how health-care providers serve the developmentally disabled population. Non-state agencies are more involved in care provision, replacing the state-run institutional model that prevailed for many decades. Increases in the quality and effectiveness of health care for the developmentally disabled has accompanied this shift in provision of care. As a result, a population with chronically low life expectancies is now producing its first comprehensive population of elderly persons. They present unique challenges to health-care providers, as they couple the needs of the elderly with the specialized care required by the developmentally disabled. Care providers are faced with daunting challenges, especially in today's fiscal environment, as they strive to meet the needs of this emerging population.

I. INTRODUCTION

During the past 30 years significant changes have occurred in how health-care providers serve people with developmental disabilities. For years, institutionalization was the dominant service model, reflecting society's "out of sight, out of mind" mentality. Government-run facilities were the mainstays of the care system. However, the current emphasis on community integration and residential treatment has reduced the prevalence of government institutions and private organizations are now the dominant care providers. Increases in the quality and effectiveness of health care for persons with developmental disabilities have accompanied this shift in provision of care. As a result, a population with chronically low life expectancies is now producing its first comprehensive population of elderly persons.

Elderly persons with developmental disabilities are an emerging group, unprecedented in the American health-care system. They present unique challenges to care providers, as they couple the needs of the elderly with the specialized care required by people with developmental disabilities. This paper

focuses on the provision of care to persons with developmental disabilities in four areas: (1) organization of care providers, (2) financing provision of care, (3) cost containment and (4) quality assurance. Each of these issues presents continuing challenges to care providers.

II. KEY INFORMANT BACKGROUNDS

I interviewed two key informants for this paper. The first is the president and CEO of a private, non-profit agency serving the developmental, residential and vocational needs of people with developmental disabilities. The agency, called Rainbow for purposes of this paper, located in the western suburbs of Chicago, is a large organization with a budget exceeding \$15 million. The organization operates residential centers, therapy centers, vocation-training facilities, an intermediate care facility (ICF) and a dementia unit. The ICF is an 82-bed facility providing 24-hour nursing care, occupational therapy and physical therapy for adults with multiple developmental disabilities. The dementia unit provides 24-hour health care to developmentally disabled adults suffering from Alzheimer's disease and other dementias. The therapy centers provide specialized therapy and nursing care to persons of all ages with severe developmental disabilities. Another part of the agency serves children from birth to age 3 who have disabilities, developmental delays and at-risk conditions. That part provides developmental, physical, speech and occupational therapies, nursing care, vision and hearing clinics, and parental support services.

The other person is a close relative of mine (Phyllis for this paper) and the mother of an adult daughter (Elizabeth for this paper) who has moderate developmental disabilities. Although Phyllis is not a health-care provider in the technical sense, her experiences in obtaining care for her daughter provide insight into the state of health care for the developmentally disabled population.

Elizabeth is 27 years old and resides at home with Phyllis and her husband. Elizabeth also has one younger and one older sister. She does not have a specific diagnosis such as Down's syndrome or cerebral palsy, but due to complications during gestation and birth suffered brain damage, resulting in moderate cognitive disabilities. For instance, she can perform some basic life skills like brushing her teeth and using the bathroom, but she is completely unable to live on her own. Elizabeth does not have significant physical limitations, although some of her physical traits, like her gait and speech, are affected by her disabilities. She completed public schooling at the age of 21 and has worked several jobs since graduating from high school. She currently works at a local restaurant several days a week with the assistance of a job coach.

III. CARE PROVIDERS SERVING PERSONS WITH DEVELOPMENTAL DISABILITIES

Change in the types of organizations providing care to persons with developmental disabilities is an ongoing issue in this sector. Traditionally, state government dominated care provision, using large institutions that essentially warehoused the developmentally disabled (American Health Care Association, 1996). However, during the past 20 years, the population of large, state-run facilities has drastically decreased. Between 1980 and 2001, the average daily population of large state-run institutions decreased 65 percent, with three-quarters of the states experiencing decreases of 50 percent or more and 17 states seeing decreases in excess of 80 percent (Bruininks et al., 2002).

Private agencies like Rainbow have filled the gap and are now the primary care providers. These organizations moved away from the institutional model, instead emphasizing smaller-sized residential services, with rehabilitation and integration into the community as the primary treatment goals (Dougherty and Eggers, 1996; AHCA, 1996). According to research at the University of Minnesota's Institute of Community Integration, more than 80 percent of the total residential settings in the United States had 15 or fewer residents and 66 percent of those had six or fewer residents (Bruininks et al., 2002). Illinois (5 persons) was one of 18 states that exceeded the national average (3 persons) of persons per residential setting (Bruininks et al., 2002). The shift to private care providers in both smaller and larger residential settings has been equally dramatic. For example, as of June 2001, non-state agencies operated nearly all (98 percent) of residential care facilities with 15 or fewer residents and 83 percent of residential care facilities with 16 or more residents (Bruininks et al., 2002).

Within the network of care providers, a new niche is emerging. As the elderly developmentally disabled population continues to grow, more providers are desperately needed to serve this group. For example, Rainbow is the only private agency in Illinois with a facility specifically designed, equipped and staffed to provide care to developmentally disabled persons with Alzheimer's disease or other dementias. However, the agency's facility has a limited number of beds, not nearly enough to serve this expanding population. As a result, clients are forced to seek care at state institutions.

That option presents significant challenges in Illinois, as the state is currently downsizing and consolidating its institutions for persons with developmental disabilities. For instance, the state is currently closing parts of the Lincoln Developmental Center, a large state-funded center for developmentally disabled persons located in Lincoln, Illinois. Especially affected by the

closing were 28 residents who required intensive medical care (*Chicago Tribune*, 2002).

Another need is traditional health-care providers trained to work with and willing to provide care to patients with developmental disabilities. For example, when Elizabeth needed orthodontics, Phyllis was fortunate to have a care provider who adapted to Elizabeth's special needs as a patient. Although it took much searching, Phyllis has also established a network of other care providers who are comfortable working with Elizabeth. As policy-makers stress community integration, persons with developmental disabilities are increasing their demand for health care from private providers as opposed to institutions. In addition, persons with developmental disabilities expect providers to offer them a wider array of health care services than was provided in the past. Care providers need to satisfy these demands.

IV. CARE PROVIDERS' FINANCIAL CHALLENGES

Care providers face myriad challenges in receiving compensation for their services. Medicaid is a significant financial entity in this sector, funding intermediate care facilities and home- and community-based services, although levels of financing vary, with each state administering its Medicaid programs differently (Bruininks et al., 2002; Iglehart, 1999). Medicaid funding priorities have shifted in line with the new emphasis on community and residential care for persons with developmental disabilities.

Expenditures for home- and community-based services are growing significantly, with increases of more than 50 percent between 1990 and 2001 (Bruininks et al., 2002). This does not mean there was an increase in Medicaid funding, rather a redistribution of how that funding is spent. Medicaid is also shifting financing to residential services provided in the community, funding substantially more home- and community-based clients than institutional residents (Bruininks et al., 2002).

As a result, non-state care providers are receiving larger percentages of their revenues from Medicaid. Medicaid's complex reimbursement procedures create uncertainty among agencies about how to bill for services. For example, the 2002 Illinois regulations governing payment to providers of community living arrangements for persons with developmental disabilities (like Rainbow) are more than 400 pages long and contain numerous forms and payment worksheets. As a result, Rainbow employs staff with specific responsibility for Medicaid billing and reimbursement.

Heavy dependence on government funding puts private agencies in precarious financial positions. Illinois' current budget deficit is putting enormous

pressure on Rainbow and other care providers. Rainbow currently faces a significant gap per client between what Illinois pays and what costs Rainbow incurs in providing care. Illinois also changed its reimbursement schedule for day programs and intermediate care facilities, to where it now pays care providers at the end of each month with longer delays in receipt of payment. Illinois is considering a similar payment system for community programs, and that would complicate cash flow operations for Rainbow, which operates several community programs. The budgetary environment for care providers is not likely to improve (and probably will worsen) in the near future as Illinois legislators work to reduce the state's significant budget deficit.

There is also a trend toward "unbundling" services, meaning that the services provided within a community program such as day programs and individual therapy are no longer compensated in a single payment (Illinois Department of Human Services, 2002). Although unbundling was aimed to increase client choice in providers and type of services received, it has created funding problems for the service providers, as they now must navigate multiple payment processes.

Private-sector care providers also are subject to continual fiscal cutbacks and insufficient budget increases. For example, Illinois' funding for private community programs has run significantly under the cost of living index since 1992, and the gap is projected to widen again in 2003 (Arc of Illinois, 2002). However, despite the national trend toward privatization of care in smaller facilities, Illinois' funding of large state-run institutions has exceeded cost of living over that same time period (Arc of Illinois, 2002). Thus, in Illinois, there is a mismatch between funding priorities and the trends in care provision.

Because of the uncertainty and complexity associated with government funding, private agencies must diversify their funding base to survive. For example, the majority of Rainbow's funding comes from state government, with the remainder coming from the United Way, private foundations, local and county government grants and individual donations. However, these funding streams are also subject to cyclical volatility, especially in the uncertain economic climate the nation is currently experiencing.

With the increasing number of persons with developmental disabilities integrated into local communities and in the workplace, other forms of payment to care providers are becoming more prevalent. For instance, private medical insurance has increased its role in reimbursement, but still primarily covers more medically focused care for infants and children. Moreover, private insurance coverage is almost exclusively limited to families who have working members who, in turn, have insurance coverage.

In addition, with the advancements in care, persons with developmental disabilities are more routinely outliving their parents and inheriting assets such as trust funds that are then used to finance their health-care needs. This is an interesting development, but it also raises questions about how the funds are managed and who is responsible for management of the funds once the person's parents are deceased. Another dilemma raised by trust funds or inheritances is whether they are sufficient enough to cover care for the person's remaining life. This is particularly tricky if the amount of the funds moves the person above the maximum asset threshold for qualifying for government funding. In that case, the person might lose government funding and have to completely rely on the alternative funds. Then, someone must ensure that an application for renewal of government funding is completed, but that still leaves the potential for a significant gap in coverage once the private funds are expended.

V. COST CONTAINMENT STRUGGLES

As with other health-care sectors, providers of services to persons with developmental disabilities also face constant cost pressures. This concern is intensified when an agency, like Rainbow, relies primarily upon government funding and the funding provided leaves a deficit between revenues and expenses. However, the cost control battle is not unique to private-care providers. Large, government-run facilities face increasing costs, especially regarding personnel (e.g., salaries and benefits). In 2000, for example, those costs comprised 81 percent of large state-run facilities' total costs, increasing to 86 percent for Illinois facilities (Bruininks et al., 2001). High turnover rates at large state-run facilities contribute to increasing personnel expenses, as institutions are continually seeking new workers and incurring the startup costs associated with training new employees. In 2000, almost one-third of a large state-run facility's staff turned over annually (Bruininks et al., 2001). Illinois had a lower rate, but facilities still experienced an 18 percent turnover rate (Bruininks et al., 2001). More troubling is that Illinois' turnover rate increased 59 percent and the national rate 33 percent between 1998 and 2000 (Bruininks et al., 2001). In the current fiscal environment, that rate will likely continue to increase.

Although care has shifted from large institutions to smaller settings, costs have continued to rise for the care of persons remaining in the institutional setting (Bruininks et al., 2001). In 2000, the average expenditure for care in a large state-run facility was \$113,864 per individual, a 6 percent increase from 1999 (Bruininks et al., 2001). A primary reason for this trend is that the large institutions generally serve those persons with the most severe developmental

disabilities (Bruininks et al., 2001). For example, in 1977, 46 percent of residents in large state facilities had severe disabilities; by 2000 the number was 62 percent (Bruininks et al., 2001). Consistent with this concentration, Medicaid per-resident expenditures for large institutions continue to rise, even though the number of residents and facilities steadily decreases (Bruininks, 2001).

Despite overall rising costs, there is evidence that the cost-control philosophy so prevalent in the health-care field also has influenced care providers to persons with developmental disabilities. For example, the average annual per-person Medicaid expenditure for care in large state facilities increased 5 percent during the 1990s, whereas the same expenditures increased 15 percent from 1970 to 1989 (Bruininks et al., 2001). One reason for the cost controls is the growth of managed care for persons with developmental disabilities. This change especially affects the private agencies, which are subject to managed care in private insurance relationships as well as the cost controls imposed by state agencies responsible for Medicaid administration. Illinois' payment guidelines are extremely detailed, specifying reimbursement amounts for items such as telephone usage by clients and the different rates of pay for workers who are working during prime time, non-prime time, at night and during the day (Illinois Department of Human Services, 2002). This attention to cost control is likely to continue and even intensify, especially with the emergence of the elderly developmentally disabled population, a group that is likely to need increasing amounts of health care services.

VI. PROMOTING, ASSESSING AND MEASURING QUALITY CARE

Despite the financial challenges providers continually face, overall quality of care for persons with developmental disabilities has significantly improved over the past 30 years. This increase in quality is a major reason why the developmentally disabled population is producing its first comprehensive generation of elderly clients. However, promoting, assessing and measuring quality of care in the developmental disabilities sector presents similar challenges to quality evaluation in other health-care sectors.

As with physicians and hospitals, care providers for persons with developmental disabilities face layers of regulation from federal and state authorities. State government is the dominant regulatory force, although federal agencies also have authority. The Illinois Department of Public Health and the Illinois Department of Human Services' Office of Developmental Disabilities have licensing and sanctioning authority over providers, with extensive regulations that govern all aspects of care. For example, the portion of the Illinois

Administrative Code governing providers of community living arrangements for persons with developmental disabilities requires that providers have written quality assurance plans and a mechanism for conducting quality review (Ill. Adm. Code, 2002). Failure to meet state quality standards can result in withdrawal of state certification (Ill. Adm. Code, 2002).

Quality assurance is an emerging national trend in this sector. States are implementing review programs rooted in business concepts like Total Quality Management and Continuous Quality Improvement (Polister et al., 1998). Other programs are specifically designed for care providers to persons with developmental disabilities. For instance, Oklahoma is conducting an ambitious longitudinal study of service quality involving approximately 3,700 persons with developmental disabilities in a variety of care settings (Polister et al., 1998). That program focuses on outcomes in levels of independent living, community integration and patient satisfaction (Polister et al., 1998). Likewise, Illinois recently began a comprehensive quality evaluation project to assess care for its developmentally disabled population, and the Illinois Council on Developmental Disabilities has a five-year goal of improving the quality of care provided to residents with developmental disabilities (Illinois Department of Human Services, 2002).

An interesting development in this sector is the power vested in independent accrediting organizations. The Rehabilitation Accreditation Commission (CARF) is the primary accrediting organization. Although private agencies pay for CARF audits, Illinois requires certification by an accrediting agency like CARF before a care provider receives government funding. This is a promising development, as CARF certification is extensive, and with the state power behind it, it can serve as a powerful tool for quality assurance and improvement. For example, Rainbow uses its CARF accreditation review and CARF's quality guidelines as integral parts of the organization's quality assurance program.

Unfortunately, governmental budget cuts, particularly in Illinois, could have a powerful negative effect on quality care. The scarce funding means that public and private agencies generally offer low wages in proportion to the demands of the jobs, often resulting in a substandard employment pool and the high turnover documented earlier. The national average starting wage for large, state-run facilities in 2000 was \$9.19 per hour, with an average wage of \$11.57 per hour (Bruininks et al., 2001). For similar facilities in Illinois in 2000, starting wages were \$8.87 per hour and average wages were \$12.43 per hour (Bruininks et al., 2001). However, between 1998 and 2000, Illinois average wages increased less than 1 percent (Bruininks et al., 2001).

Moreover, those wages are for workers at Illinois state-run facilities, which consistently receive more total dollars in funding than private community programs. The ever-present budget crises in this sector pose a serious threat not only to care providers' financial status but ultimately to the quality of care they provide to their clients.

VII. CONCLUSION

With the extensive involvement of government in both funding and regulation, providers face an environment where they are continually asked to do more with less. As the developmentally disabled population continues to live longer, issues will arise that providers never considered before, such as caring for persons with developmental disabilities who also have Alzheimer's disease. Unfortunately, the complex environment in which care providers exist is slow to adapt to changes, a trait that ensures continual challenges. ■

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