

# DEVELOPMENTAL DISABILITIES

## Watch

GAINING ACCESS: NEW EFFORTS ON HOUSING  
AND AUTISM SERVICES

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New York State has set the highest Medicaid fraud recovery targets of any state in the nation—and if it doesn't meet them, the state will lose critical federal aid intended to smooth the road to a more efficient health care system. But there's another problem: to even attempt to meet its objectives, the state must cast a net of fraud audits so large it will enmesh most Medicaid providers and require a massive investment of resources. In the end, there's no guarantee the state will uncover the billions of dollars in misspent funds it hopes to find.

Worse, the intensified audit strategy may have the side effect of undermining creative efforts to improve services provided to thousands of New Yorkers with developmental disabilities by nonprofit organizations. Already, some agencies say they are spending enormous amounts of time simply documenting that community-based services, such as swim lessons at a local municipal pool, are being provided.

State leaders have said they expect to look for fraud in most large agencies, simply because they devour so much government money (see "Guilt by Association," page 9).



Susan Brown, courtesy of Pure Vision Arts

"There is a frequently repeated estimate that 10 to 40 percent of Medicaid payments are fraudulent," said then-Deputy Attorney General Peter Pope at legislative hearings two years ago. "If that estimate is correct, then huge additional recoveries must be obtained from these institutions." Today, Pope is policy director to Governor Eliot Spitzer.

Identifying the misuse of government funds must always be a high priority for any administration entrusted with taxpayers' dollars. But when the effort to find fraud emerges out of a political

imperative—a deal to win federal dollars for health care system reform—it’s all too likely that investigators will press forward with an exclusively green-eyeshades, accounting-police approach. In fact, there’s a more important reason for close scrutiny of public spending in the developmental disabilities field. Oversight should be consumer-focused, assuring quality and seeking excellent outcomes for people with disabilities who

- The number of New York City schoolchildren diagnosed with autism has increased 72 percent since 2001 to 5,627 students last year. Nearly a quarter of children under age 12 receiving services from the state Office of Developmental Disabilities and Mental Retardation (OMRDD) now have an autism diagnosis. And of the 135,000 people with disabilities OMRDD assists statewide each year, 13 percent have been diagnosed with autism—up from only 4 percent in 1990. (See “Reaching Critical Mass,” page 15.)
- Under Mayor Michael Bloomberg’s ambitious housing agenda, the city is in the midst of building or financing 165,000 new units of affordable housing, 9,000 of which are supportive units linked to social services. While the city does not keep statistics on how many people with developmental disabilities are living in these apartments, anecdotal evidence indicates few are moving in. (See “Bridging the Divide,” page 5.)
- Low salaries have long been identified as a leading cause of the high rates of turnover among frontline caregivers in the developmental disabilities field. The state Department of Labor reports that the median annual wage for personal and home care aides hovers at \$21,230, or about what people earn in fast food jobs. More than one-third of the expected openings in the field over the next decade will be due to turnover of existing staff. (See “The Staffing Crunch,” page 18.)
- Leaders of the state services system for people with developmental disabilities succeeded in deflecting a legislative push earlier this year for a separate system for people with autism, but some parents are still pressing for autism-only services for their children. (See “Reaching Critical Mass,” page 15.)
- Under a 5-year pact with the federal government signed by the Pataki administration, New York has set the highest Medicaid fraud recovery targets in the nation—and some worry about the effects on services for people with developmental disabilities. (See “Guilt by Association”, page 9.)

depend on flexible, inclusive supports to live lives distinguished by their own choices and aspirations.

Dealing with the changed climate surrounding Medicaid is one of the key tests faced by Diana Jones Ritter, who was appointed earlier this year as commissioner of the state Office of Mental Retardation and Developmental Disabilities (OMRDD).

At the same time, she will have to deal with pressure from a growing movement of families whose children are part of the huge wave of people diagnosed in recent years with autism spectrum disorder. Some parents are pushing for specialized, autism-only programs that can better meet the needs of their children, largely because they have found it difficult to get the individualized help they require in the OMRDD framework (see “Reaching Critical Mass,” page 15).

These two powerful trends—intensified Medicaid scrutiny and the demands for improved supports for people diagnosed with autism—threaten to pull the services system in opposite directions. How far will OMRDD and its contract agencies go in committing themselves to services that are responsive to individual needs, including the complex and little understood needs of people diagnosed with autism, if the system is under tremendous pressure to hold back Medicaid spending?

To her credit, Ritter has acknowledged the existence of this dilemma and says she is confident the state’s new scrutiny of Medicaid spending will not sidetrack efforts to create more flexible supports that offer individuals with all types of developmental disabilities greater choice and control. To accomplish this, Ritter says OMRDD must establish more effective working relationships with other state agencies, notably the city and state departments of education and the state Office of Mental Health. Her aim is a more seamless services system that uses existing resources more efficiently.

But if the lessons of the past several decades of reform in the developmental disabilities field reveal anything, it’s that lasting change doesn’t rest on bureaucratic reorganization alone. The same trends posing problems for OMRDD also hold out opportunities for the system to make dramatic improvements in the way services are designed and used.

Nonprofit leaders say more parents of children with autism need earlier access to Medicaid-funded services such as respite care and after-school programs. Accomplishing this would also help families of children with other developmental disabilities who could benefit from such early support. Similarly, designing services that are less uniform and more individualized will help reach more people across the wide and varied autism spectrum—as well as those with other disabilities who feel poorly served by existing, more standardized group programs.

Amid all the pressure to slow the pace of Medicaid spending, we must not forget that these public dollars are intended to improve the lives of people with developmental disabilities—to respect and promote their autonomy and ensure their ability to contribute to their communities. ♦ —BARBARA SOLOW

## Recommendations proposed by *Developmental Disabilities Watch*

**T**he culture of New York State's services system for people with developmental disabilities has made a pointed shift in recent years towards some of the ideals of community inclusion. In the past decade, the state Office of Mental Retardation and Developmental Disabilities (OMRDD) has moved many New Yorkers with developmental disabilities out of large institutions and into group homes and, for some, individual apartments with accompanying support services. Skills training and recreation programs provided by nonprofit agencies are increasingly geared to the needs of individuals, as opposed to the large-group "sheltered workshops" of the past.

But despite these efforts, real progress on ending segregation and creating individualized services for people with developmental disabilities—particularly in New York City—is still lacking. On two key statistical indicators of such progress, supported employment and Self Determination—a program that allows participants and their families to design their own supports and control their own Medicaid resources—movement has stalled. The number of New York City residents receiving long-term job supports through OMRDD's supported employment program actually fell in the last fiscal year from 1,747 to 1,712. And while OMRDD leaders had expected the number of city residents enrolled in Self Determination to triple in 2007, the program remains miniscule: only eight people were signed up in 2006, and just 11 in 2007 (see "Watching the Numbers," page 23).

For the system to effectively support the autonomy of people with developmental disabilities, bolder, more creative measures are required. Below are recommendations from the Developmental Disabilities Watch advisory board that focus on how the services system can make real gains on such key fronts as individualized housing, transition programs for vulnerable young adults and a more stable frontline caregiver workforce.

### OMRDD SHOULD MAKE FAR GREATER USE OF THE CITY'S EXTENSIVE NETWORK OF AFFORDABLE AND SUPPORTIVE HOUSING INITIATIVES TO PLACE MORE PEOPLE WITH DISABILITIES IN THEIR OWN APARTMENTS.

The current waiting list for New York City residents with developmental disabilities who are seeking housing with support services is now 1,800 people long. There are dozens of community-based housing developers with decades-long track records of building affordable residential units—many of them linked to social services. But OMRDD has been notably absent when such projects are planned, built and publicized. (For example, the state agency was not part of the process that led to the New York/New York III agreement between the city and state which provides 9,000 units of supportive housing for nine different populations of people with special needs, from people with mental illness to youth aging out of foster care.) Nor has the agency done enough to expand options for the hundreds of people with developmental disabilities now living in group homes who

could be viable tenants for new affordable housing developments. While some community-based housing developers have discovered that residents who receive Medicaid-funded services and Social Security Disability Insurance can be a stable source of support for their projects, many others are unaware that people with developmental disabilities are in dire need of affordable housing.

### OMRDD SHOULD ASSIGN A SENIOR LEVEL STAFF PERSON WITH EXPERIENCE IN THE AFFORDABLE HOUSING FIELD TO OVERSEE ITS HOUSING EFFORTS.

In order to move more city residents with developmental disabilities off the waiting list for residential services with supports, OMRDD needs to ensure that the people in charge of its housing programs have direct experience in affordable housing and strong relationships with the city's network of nonprofit community-based housing developers.

### OMRDD SHOULD BUILD RELATIONSHIPS ACROSS SECTORS BY CONVENING FREQUENT, SMALL-GROUP MEETINGS OF LEADERS FROM THE AFFORDABLE HOUSING AND DEVELOP-

### MENTAL DISABILITIES FIELDS.

More needs to be done to break down prevailing attitudes that result in barriers between affordable housing experts and people with disabilities and their advocates. Many service providers and advocates are skeptical that existing affordable housing programs can accommodate people with developmental disabilities. Worse, some have inaccurate views of such housing, believing that the units are home to mainly unstable tenants in bad neighborhoods. On the other hand, many community-based housing practitioners doubt that people with disabilities actually need affordable housing or can live on their own with supports. OMRDD can play an important education and organizing role in bringing these two communities together for mutual benefit.

### OMRDD SHOULD EXPAND ITS SUPPORT FOR MODEL PROGRAMS FOR PEOPLE ON THE AUTISM SPECTRUM THAT ACCOMMODATE THEIR DISTINCT NEEDS, WHILE STRESSING INCLUSION IN THE BROADER COMMUNITY.

Programs such as the NEST public school program and Job Path's Life Coaching initiative are designed to respond to the particular behaviors, abilities and challenges that characterize people with autism, while retaining the larger goal of integrating them into their school or workplace. The Life Coaching project, for example, offers long-term job supports that emphasize the social aspects of employment that many people with autism find hard to handle. OMRDD and other government agencies should find ways to replicate these and other model programs so that the mistakes of the past—setting up group-oriented services for people with particular disabilities—are not repeated with the city's growing autism population. Frustration with the dearth of programs that can accommodate the wide range of needs of people on the autism spectrum has led many parents to seek segregated, autism-only services. This could ultimately narrow the choices available to people with autism and close them off from the broader community.

**THE STATE DEPARTMENT OF EDUCATION NEEDS TO DO MORE EFFECTIVE OUTREACH TO YOUNG ADULTS MAKING THE TRANSITION FROM SCHOOL TO ADULT LIFE SO THAT MORE WHO QUALIFY FOR LONG-TERM OMRDD SERVICES ARE ABLE TO RECEIVE THEM.**

Expanding services such as job coaching, life skills training and assistance with independent living would be especially helpful to young people on the autism spectrum, who often fail to find adequate supports when they leave school-age services for jobs or higher education. Such efforts would also help people with other developmental disabilities who face similar difficulties in those vulnerable transition years in their late teens and early 20s. The state Department of Education's Office of Vocational and Educational Services for Individuals with Disabilities (VESID) must do more effective outreach to young people so that more of them who qualify for the department's short-term employment services can take part—and so that more can be in a position to receive longer-term supports through OMRDD if they need them. At the same time, OMRDD must expand its employment assistance program and extend new pilot programs that help young people with autism attend college.

**OMRDD SHOULD DO MORE OUTREACH TO FAMILIES WITH CHILDREN IN CITY SCHOOLS WHO COULD BE ELIGIBLE FOR MEDICAID WAIVER SERVICES SUCH AS DAY PROGRAMS, RESPITE CARE AND SKILLS TRAINING PROGRAMS FOR YOUNG ADULTS.**

Provider agencies report that many parents of children with autism are unaware that their families are even eligible for assistance from OMRDD. Others see the state system for people with developmental disabilities as geared solely toward those with mental retardation. Still others are frequently referred to programs for people with psychiatric disorders or other services that don't match their children's needs. There are OMRDD services—including respite care, after-school activities and skills training—that, if offered early on, could help young people with all types of disabilities lead more fulfilling lives. Finding and engaging families who need services

is difficult work, but it is worth the investment to ensure that more families that qualify for help can receive it while their children are still in school.

**GOVERNOR ELIOT SPITZER SHOULD SUPPORT FEDERAL LEGISLATION TO COVER THE COST OF HIGHER WAGES FOR FRONT-LINE CAREGIVERS.**

The Direct Support Professionals Fairness and Securities Act (HR 1279) would increase federal Medicaid reimbursements to cover the cost of higher wages for frontline caregivers and close the estimated \$10,000-a-year pay gap between those who work for nonprofits and those who work for government agencies. The bill has been introduced in Congress for the past three years, but lobbying efforts have not been powerful enough to move it out of committee. A broader and more organized coalition encompassing people with developmental disabilities and their advocates, unions, nonprofit leaders and state officials could provide the political muscle needed to pass this legislation and address a root cause of staff turnover in the caregiving field. After the initial five-year period of enhanced Medicaid reimbursements, states are responsible for maintaining the higher wage levels for frontline caregivers employed by nonprofits. While the bill will cost the state money down the road, without progress on the wage issue, turnover in the field cannot be adequately addressed, and efforts to improve services for people with disabilities will fall flat.

**THE GOVERNOR AND HIS COMMISSIONERS MUST ENSURE THAT THE NEW RAPID PACE OF AUDITS OF NONPROFIT AGENCIES RECEIVING MEDICAID FUNDING DOESN'T SLOW INNOVATION AND UNDERMINE CREATIVITY IN PROVIDING SERVICES.**

Although no one knows the extent of Medicaid fraud in the developmental disabilities services field, government agencies are ramping up their scrutiny of the sector in order to meet ambitious fraud recovery targets tied to federal Medicaid funding. The state's new Office of Medicaid Inspector General (OMIG) has, in the past year, completed more than twice as many audits of

healthcare and homecare agencies as its predecessor agency did in 2002. The goal of reducing Medicaid fraud is a worthy one. But the type of open-ended scrutiny the Spitzer administration appears to be pursuing could lead to less willingness on the part of nonprofit agencies to offer more accessible, individualized services to people with disabilities. Billing mistakes in a complex Medicaid system should not lead to the presumption of fraud. Medicaid funds must be used creatively to help people with disabilities lead more fulfilling lives—and the governor must make sure his Medicaid auditors understand and respect this imperative.

**AGENCY LEADERS AND SELF ADVOCATES SHOULD STRIVE TO SHIFT THE PUBLIC DEBATE FROM MEDICAID FRAUD TO WHETHER MEDICAID SPENDING PROMOTES INDIVIDUALIZED, FLEXIBLE LIFESTYLES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES.**

Lost in the swirl of recent headlines about Medicaid fraud is any discussion of the impact of Medicaid spending on consumers. United Cerebral Palsy (UCP) recently published a report called "The Case for Inclusion 2007" that ranked all 50 states and the District of Columbia on how well they provide community-based supports to people with developmental disabilities. While New York ranked in the top 10 overall, on some measures it did less well. The state was 39th in the percentage of day program participants served in competitive employment, for example. OMRDD leaders—like leaders of similar agencies in other states—have quibbled with UCP's methodology and results. Still, the underlying point of the study is an important one: Medicaid spending should be evaluated based on the quality and effectiveness of the services it funds. Self advocates and agency leaders in New York should launch efforts to make the results of Medicaid spending for consumers as important a public issue as Medicaid fraud. How wide a range of services and choices does such spending make possible? How effective are Medicaid services in helping people with developmental disabilities achieve their goals and participate fully in their communities? These are indicators that should be considered. ♦



# BRIDGING THE DIVIDE

New York City has a vast network of community-based affordable housing developers. But few people with developmental disabilities benefit.

**A**nthony Paul, 51, keeps his Bronx studio apartment tidy, cleaning up after fixing himself breakfast and making his bed before turning on the TV. Paul, who has mental retardation and a seizure disorder, sometimes needs help remembering to brush his teeth or open the window blinds. But he sets his own schedule, deciding when he wants to sit in the apartment complex's manicured backyard and when to go to his volunteer job or do grocery shopping.

"I like it here. It's OK. I'll be downstairs, I talk to people, I'll sit outside," Paul says.

He is one of about 1,800 New Yorkers with developmental disabilities who live in apartments on their own or with roommates, with the rent paid for mostly out of their monthly Social Security Disability Insurance (SSI) checks. They are assisted by visiting caseworkers and caregivers who help with domestic chores and other daily needs.

The Center for Family Support, a social service agency, manages 10 studio apartments in 1212 MLK Apartments in Highbridge where Paul lives. The remaining 44 units are for working-class and formerly homeless families without disabilities. The center leased the apartments from Beulah Housing Corporation, a nonprofit organization that built the complex in partnership with Dunn Development in 2005. Center staff identified interested tenants among the men and women it served in group homes or in their families' homes, and today they maintain 24-hour staff at the building.

Paul lives in a manner that has defined the disabilities rights movement for years: as an engaged and self-directed member of the community. Hundreds of others who currently live in group homes or with their parents would like to do the same. But there aren't enough affordable apartments in New York City with the type of supports they need to live on their own.

Executives at half a dozen agencies interviewed for this article said they have many more clients interested in individualized housing with supports than the number of apartments they manage. As a result, most clients live in group homes where their lives are more regimented.

The current waiting list to arrange residential services with supports is 1,800 people long, according to Kathy Broderick, associate commissioner of the state Department of Mental Retardation and Developmental Disabilities (OMRDD). Not all of these men and women are necessarily interested in having their own apartments, but there is no central list that makes that

distinction, say service providers who work with people with developmental disabilities.

"We just have tremendous waiting lists," says Tom Hopkins, chief operating officer of the Center for Family Support, which assists the 10 residents at MLK Apartments, as well as 10 clients in other apartments and more than 100 residents of group homes in the city.

There are currently no targeted financial incentives for building individualized housing for people with developmental disabilities with social services on-site or nearby. But there are dozens of community-based nonprofit developers in New York that have for decades been building a vast array of affordable housing—a few of which have discovered that tenants who receive Medicaid-funded services and are eligible for SSI can

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**"ONE OF THE ADVANTAGES OF WORKING WITH THE STATE OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES IS THAT THEY HAVE VERY STABLE FUNDING. YOU ARE GUARANTEED THE RENT."**

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be a reliable source of long-term funds for such projects.

"One of the advantages of working with OMRDD is that they have very stable funding," says Martin Dunn, president of Dunn Development. Once construction of new housing units is financed, he says, residents with developmental disabilities or the agencies that oversee their care can pay rent from monthly benefits checks, supporting the building's operating costs. "You are guaranteed the rent," Dunn says. "The nonprofit stands behind it."

Nonetheless, people with developmental disabilities make up only a fraction of those living in the hundreds of thousands of affordable housing units developed in New York City since the

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## "THE SUPPORTIVE HOUSING COMMUNITY FEELS THAT THE OMRDD POPULATION IS WELL-SERVED AND WELL-FUNDED AND NOT IN NEED."

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1980s as part of the succession of multi-billion-dollar, government-backed housing plans that contributed to the wholesale reconstruction of many city neighborhoods after years of urban disinvestment. One large segment of this community-based development boom has been the large and varied network of so-called "supportive housing," individual apartments with support services on-site or nearby.

The Supportive Housing Network of New York says there are 22,000 units of supportive housing in the five boroughs. These developments vary widely. Some are targeted specifically for formerly homeless, mentally ill men and women; others are for very low-income parents with children who need more modest supports. Some have a wide mix of people, from students to working class families to recovering drug addicts. All have the space to house some variety of supports, ranging from case managers to child care, which are tailored to fit the needs of residents in the building.

Under Mayor Michael Bloomberg's ambitious housing agenda, the city is in the midst of building or financing 165,000 units of affordable housing, 9,000 of which are supportive units linked to social services. While the city does not keep statistics on how many people with developmental disabilities are living in these apartments (it tracks income and disability in general, which also includes mental illness and physical disabilities) anecdotal evidence indicates that few are moving in.

The dearth of individualized housing options for people with developmental disabilities has a number of causes, say service providers, housing advocates and OMRDD leaders. Chief among them are a limited supply of affordable housing, the lack of historical connections between housing organizers and disabilities rights advocates, and misconceptions about people with developmental disabilities.

"A common belief by developers, realtors, housing groups and even some within the disability community is that people with developmental disabilities cannot live in residential settings other than institutions and group homes," says Lucinda Grant-Griffin, OMRDD's director of housing initiatives. "That is something we are really trying to educate them about."

Part of the challenge is that for so long, people with developmental disabilities and their support systems were segregated from other publicly funded programs, says Barbara Carole Gothelf, director of individualized supports for the Association for the Help of Retarded Children NYC (AHRC). "We want our voice to be heard," she adds. "We can do things differently now."

**IN THE PAST 30 YEARS, THE LIVING** situations of people with developmental disabilities have shifted from state hospitals and institutions to group homes and increasingly, individual apartments in the midst of the general community. A patchwork of nonprofit social service providers, among them the Cerebral Palsy Associations of New York State and Sinergia Inc., lease apartments from landlords, then rent them to and coordinate assistance for their clients.

But the system is expensive and scattered, providers say. Agencies pay full market rate in an archipelago of buildings across the city to landlords who may have no particular sympathy with the mission of supporting people with disabilities.

"When we've been in private buildings and then the buildings are sold, the new landlords want to get rid of the apartments with people with developmental disabilities," says Myrta Cuadra-Lash, of Sinergia Inc. "It's just a different mindset."

Now, advocates and OMRDD are seeking ways to avoid the hazards and hurdles of the private real estate market and overcome the shortage of housing for people with developmental disabilities. The newest thinking has service providers partnering with affordable housing developers to build housing with on-site assistance for their clients. Such buildings, like the MLK Apartments, would also welcome members of the general population who need affordable housing (see "A One-Stop Resource on Housing," page 7). Indeed, the developers see having a mix of tenants as a fundamental element of promoting a truly inclusive way of life.

New York City has a sophisticated and experienced network of nonprofit community-based housing developers. But by and large, neither the supportive housing community nor the larger community-based housing movement has historically thought about people with developmental disabilities.

"I don't think our members work with that population," says Cynthia Stuart, a spokeswoman for the 150-member Supportive Housing Network of New York. "I don't think they are excluded per se, but I don't think that is where our members' concentration is."

Jim Buckley is the longtime executive director of University Neighborhood Housing Program (UNHP) in the Bronx, where he helps finance affordable housing through a loan fund and offers technical assistance to nonprofit housing developers. His response, when asked about housing for people with develop-

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## A ONE-STOP RESOURCE FOR HOUSING

A coalition of service providers and governmental agencies took shape this past summer to streamline individualized housing options for people with developmental disabilities who need supports. Founded in July with grants from the state Office of Mental Retardation and Developmental Disabilities (OMRDD), the New York Resources Consortium has three main goals: to advise people with developmental disabilities and their families on housing choices; to centralize information about apartments that provide support services; and to place 40 individuals in such units in New York City in the next two years.

Four nonprofit service providers that currently support people in independent apartments each received \$50,000 from OMRDD to form the nucleus of the consortium: Cerebral Palsy Associations of New York State, Sinergia Inc., HeartShare Human Services and AHRC NYC. They are collaborating with OMRDD's New York City office, the Disabilities Planning Council and the city's Department of Health and Mental Hygiene.

"We want to develop a one-stop resource center where parents can call for assistance with housing information," says Myrta Cuadra-Lash, executive director of Sinergia Inc., a 30-year-old Manhattan agency that, among other services, provides day programs and transitional housing for homeless people with developmental disabilities and their families—among other services. "I'm hoping the consortium will help people navigate the options and at the same time develop more units."

Through the consortium, Sinergia will offer workshops on supportive housing for other service providers and families, and will help educate private and nonprofit housing developers on how to build housing that responds to the needs of people with developmental disabilities.

The organization—whose name means synergy in Spanish—is not new to the world of independent housing. It currently supports 50 people with developmental disabilities in 25 sites across the city, including units for mothers and their children, and an apartment

in Brooklyn for three people with traumatic brain injuries.

When the Ecumenical Community Development Organization of New York was building its housing development at 125th Street in Manhattan in 2000, Sinergia helped secure five apartments for people with developmental disabilities. It is currently in talks with a private developer in Brooklyn to build housing that would support some of its clients as well as house the Sinergia offices.

"It would be great if we could do this with other developers," Cuadra-Lash says. "We want developers to know that what extra services our customers need, we are going to provide. And just because they have developmental disabilities doesn't mean they are completely incapable and need 24-hour support."

With most of its supportive housing clients, Sinergia pays the rent out of the client's disability benefits, interacts with the landlord and sends a caseworker or personal assistant to help with grocery shopping, appointments and other aspects of daily life. But the residents themselves decide how they want to structure their days—a big difference from life in a large group home.

Other service providers manage a handful of supportive apartments in the city, helping people with developmental disabilities live more independently in buildings alongside those without disabilities. But until the consortium was formed, none of the groups communicated or even knew the others existed, says Jackie Romolo, director of community affairs at Cerebral Palsy Associations of New York State.

Cerebral Palsy Associations manages 23 apartments in New York City, each with two residents. Almost all of these are in buildings with for-profit landlords. Romolo says fostering more relationships with nonprofit developers makes sense because they may be more receptive to the goal of creating housing that supports independent living.

"This is about looking outward, seeing what is out there, what is happening. It's really about allowing choice," she says.

◆ —EILEEN MARKEY

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mental disabilities, is typical: "Huh, I don't know anything about that," he says.

For one thing, the demand for affordable housing is so overwhelming, UNHP doesn't need to advertise for tenants and doesn't have time to set aside available slots for those with developmental disabilities. Buckley notes, "We see units filled up before they are even built."

Other nonprofit housing developers say it's not that they are resistant to renting to people with developmental disabilities or their advocates. But while supportive housing and nonprofit housing both grew out of anti-poverty and anti-homelessness work, there just aren't the same connections with the developmental disabilities community.

**MARTIN DUNN PREVIOUSLY WORKED** as executive director of the East New York Urban Youth Corps in Brooklyn, which built affordable housing for low-income and working-class residents. He says housing advocates too often assume people with developmental disabilities are already taken care of. "The supportive housing community feels that the OMRDD population is well-served and well-funded and not in need," he says.

There are structural barriers, as well, says Dunn, who is currently building three more housing complexes that include supportive units for people with developmental disabilities. He says OMRDD can be difficult and intimidating for developers unfamiliar with the agency and the needs of the population it serves.

For example, the state agency does not maintain a census of people who are interested in living in independent units like those at MLK Apartments. Instead, each of the many provider agencies that contract with OMRDD has its own list. So if a housing developer contacts OMRDD to say they have 20 units available for people with developmental disabilities, there may be only five or six clients who are known to be ready for independent living at that moment, Dunn says. “OMRDD could definitely be more user-friendly,” he adds.

In addition, information isn’t routinely shared among service providers. So, if the Center for Family Support is partnering with a housing developer but has only five clients who are ready to live in their own apartments, staff members won’t know that Sinergia has clients who could fill the other slots. And in order to include those residents the housing developer would have to initiate a separate contract with Sinergia.

“It’s not necessarily a bad model, but it doesn’t always match up well,” Dunn says.

Another key barrier cited by housing developers is the fragmented structure of government funding for low-income units.

“You’re always thinking about what program your project fits into,” says Patrick Logan, deputy executive director of the non-profit Fordham Bedford Housing Corporation in the Bronx. He says there is no tax incentive or subsidized loan program he is aware of for building supportive housing specifically for people with developmental disabilities.

There are however, federal and state programs aimed at fighting homelessness, so the nonprofit housing developers draw from that well, receiving tax credits based on the number of units provided to low-income people.

In fact, building housing for people with developmental disabilities—the majority of whom are indeed low-income—qualifies developers for a variety of government incentives, says Grant-Griffin, OMRDD’s housing director. “People with developmental disabilities are a special needs group that, as long as their income is low enough—and it usually is—qualify developers for all of the same development incentives as for other low-income disability populations,” she says. “This includes tax credits, Housing Trust Fund dollars, Federal Home Loan Bank grants.”

For developers, Dunn says, the real challenge is navigating the maze of regulations and practices set up to serve the needs of clients with disabilities, while still making the housing affordable to build. For example, service providers who rent private apartments for their clients usually have two or three people with developmental disabilities sharing an apartment. But if a housing developer builds housing with three-bedroom apartments, the tenants’ combined Social Security income may be too high for the developer to qualify for low-income tax credits. Studio apartments are easier to finance, but are problematic for people who may prefer roommates, or service providers who want to coordinate services for several clients in one unit.

“I think for a lot of developers, it’s more trouble than it’s worth,” Dunn says. “You already deal in affordable housing with all sorts of issues. Now you bring in a new funding source, OMRDD, and oversight and certification. It just adds a layer of complexity to projects that are already complicated.”

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## FOR DEVELOPERS, THE REAL CHALLENGE IS NAVIGATING THE MAZE OF REGULATIONS AND PRACTICES SET UP TO SERVE THE NEEDS OF CLIENTS WITH DISABILITIES, WHILE STILL MAKING THE HOUSING AFFORDABLE TO BUILD.

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**DESPITE THE DIFFICULTIES**, more creative efforts are underway to bridge the divide between the city’s supportive housing community and advocates for people with developmental disabilities.

The Center for Family Support is already working on another collaboration with Dunn Development, this time a building that will include apartments for women with developmental disabilities and their children. Agency Chief Hopkins says word of the program’s success in the Bronx is bound to spread.

OMRDD is also committed to fostering more partnerships like the one that created MLK Apartments, says Grant-Griffin. “I really like the idea of breaking down these silos. We can begin to say, ‘If you are doing this, maybe we can work together.’”

But for this to happen, some believe the developmental disabilities community must make more noise about the need for affordable housing.

Erica Robinson, assistant director of residential services at MLK Apartments, who has worked in developmental disabilities for more than 15 years, says the field is still isolated, focusing on reforming itself at the expense of linking with potential partners in other arenas.

“It needs to be more publicized. Builders need to be informed. It needs to be advertised,” she says. “There needs to be town hall meetings to let people know what’s out there. I think developers don’t know about us.”

◆ —EILEEN MARKEY



# GUILT BY ASSOCIATION

## Will the state's high-stakes Medicaid fraud targets put a brake on improved services for people with developmental disabilities?

Attorney James Lytle remembers a moment during state legislative hearings on Medicaid fraud two years ago when an official from the attorney general's office pulled out a list of New York's "Top 200 Medicaid Providers."

On it were a number of agencies of the type that Lytle's firm represents: nonprofits that provide services to people with developmental disabilities, including the Brooklyn Developmental Center, NYSARC and Cerebral Palsy Associations of New York State.

None of the agencies were on the roster because they had committed fraud or were suspected of misusing Medicaid funds. They were there because they receive significant amounts of the state's burgeoning \$46 billion Medicaid and health care budget, which accounts for more than one-quarter of all state government spending.

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**"THE EMPHASIS ON FRAUD IS A BLUNT INSTRUMENT AND DOESN'T CREATE ANY CHANGE OTHER THAN DRIVING PROVIDERS OUT OF BUSINESS."**

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At the hearing, the deputy attorney general made clear that such "top providers" would be the focus of stepped-up efforts to recover Medicaid dollars lost to fraud: "There is a frequently repeated estimate that 10 to 40 percent of Medicaid payments are fraudulent," he said. "If that estimate is correct, then huge additional recoveries must be obtained from these institutions."

Since those hearings, reducing Medicaid fraud has risen to the top of the state's agenda. Governor Eliot Spitzer has upped the number of fraud inspectors by 30 percent and created the state's first Office of Medicaid Inspector General (OMIG)—making Texas and New York the only states with an investigative arm dedicated to Medicaid. In 2006, the OMIG completed 401 audits of healthcare and homecare providers—more than twice

as many as were closed by its predecessor office in the state Department of Health five years ago.

Under an agreement with the federal government, New York has set the highest Medicaid fraud recovery targets in the nation. Already, Attorney General Andrew Cuomo has launched a two-year investigation of the home healthcare industry that his office anticipates will recover \$100 million in deceptive Medicaid spending.

Lytle, a partner in Manatt Phelps and Phillips, says he supports the idea of going after agencies that scam the system. But he worries the state's aggressive new push is based on "wildly overstated" estimates of fraud.

"Based on our experience in representing agencies, outright fraud accounts for a very small percentage" of Medicaid spending, says Lytle, who works in the law firm's Albany office. "A much larger amount of money that properly should be recovered relates to errors in billing and system deficiencies in an enormously complex Medicaid system."

Lytle is concerned that state investigators lack a thorough understanding of community-based care, where most people with developmental disabilities now seek services. For example, one of his firm's clients is an agency that provides personal care aides to people with disabilities under the state's new and still very small "self-directed" program that allows individuals and their families to handle hiring and assign tasks to support workers. Even before the new audit push, the agency came to the state's attention because a computerized check of Medicaid billing records showed that an aide had been paid for services on the same day that his client was hospitalized.

But as Lytle points out, "In many cases, the personal care aide is there helping the patient deal with hospitalization. They are welcomed by the hospital. So here, out of a lack of understanding of what the program is about, the auditor scores points."

Given the state's growing emphasis on Medicaid fraud, he's concerned that community-based programs will be especially vulnerable to audits and penalties.

"In the last 20 years, many programs that did not depend on Medicaid funding now depend on it to a very dramatic degree," Lytle says. "These agencies are not as well-trained or sophisticated in their billing services and often don't have the systems in place that other providers do. So they have real reasons to fear."

Critics say the Medicaid system may be far too generous. A

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## "YOU WANT TO SEE IF THERE IS FRAUD AND ABUSE. THAT'S SEPARATE FROM USING THE RESOURCES WE HAVE MORE EFFICIENTLY TO PROVIDE SERVICES THAT ARE MORE INDIVIDUALIZED."

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recent report by the Citizens Budget Commission pointed out that the \$3.5 billion New York State spends on personal care services "is nearly 19 percent of the national total" and is much more substantial than other states. This category includes funding for people with developmental disabilities.

Nonetheless, state officials say they are not out to disrupt services or target agencies just for the sake of recovering more money.

"Our model is to be firm but fair," says Bob Hussar, acting general counsel for the state Office of Medicaid Inspector General. "We believe in getting patients and clients the services they are entitled to. Whenever we take administrative action, we are required to look at the impact on the recipients."

**MEDICAID FRAUD IS NOT A NEW ISSUE** in New York. But experts say that in recent years, fiscal and political pressures have raised the stakes on enforcement.

In 2006, the state reached an agreement with the federal government that tied Medicaid fraud recoveries to healthcare funding. Under the pact signed by the Pataki administration, the feds will pay New York \$1.5 billion over five years to help reorganize the state's hospital industry in exchange for Medicaid spending cuts and a substantial rise in funds recovered from audits and prosecutions—up to \$644 million in the final year. If the benchmarks are not met, New York must forfeit the aid money from Washington.

On the political side, Spitzer was criticized during his gubernatorial campaign for not doing enough to curtail Medicaid fraud during his tenure as attorney general. After he took office, Spitzer not only created the new inspector general's office, he successfully pushed for passage of a state False Claims Act that allows those who blow the whistle on fraud to receive a share of the recovered funds.

Many provider agencies are reluctant to respond publicly to the state's new crackdown on Medicaid fraud because they don't want to appear in any way opposed to its aims. Instead, they talk about efforts to ensure that their organizations are following Medicaid rules.

When asked about his agency's presence on the "Top 200" list at the legislative hearings, Al Shibley, vice president for communications at Cerebral Palsy Associations of New York State said, "With the increased scrutiny by the Office of the Medicaid Inspector General and others, we have continued our compliance efforts and have been working with affiliates to ensure that all our record-keeping practices meet the increased level of scrutiny."

But some provider associations and disabilities rights advocates have voiced anxieties about whether the state's new focus on fraud will inhibit moves to offer more accessible, individualized Medicaid-funded services to people with disabilities.

"I raised the concern early on with people in the Spitzer Administration about the need for training for investigators so they would be more familiar with community-based settings for care and the idea of individualized, person-centered planning," says Susan Dooha, executive director of the Center for Independence of the Disabled, New York. "I haven't heard a single thing about it."

In a tighter enforcement climate, she worries that fewer agencies will be willing to try out new ways of using Medicaid funds to promote greater independence for people with developmental disabilities.

"The emphasis on fraud is a blunt instrument and doesn't create any change other than driving providers out of business," Dooha says. "I want a strong, community-based system with a lot of integrity. But if all you do is prosecute people, that doesn't give them the resources they need to change the way they do business."

Others believe the growing attention to fraud distracts from the issue of whether Medicaid funds are being spent effectively on services for people with disabilities.

"Fraud isn't where we ought to look," says Tom Nerney, executive director of the Michigan-based Center for Self Determination. "Wasteful spending with no decent outcomes is where we should look. What we ought to be doing is developing program audits and financial audits that measure whether individuals with developmental disabilities have made advances."

**HISTORICALLY, PROSECUTIONS** for Medicaid fraud in New York have been modest relative to the enormous size of the state's program, says Howard Berliner, professor of Health Services Management Policy at Milano The New School for Management and Urban Policy. (An investigation by *The New York Times* in 2005 found that of the 400 million claims Medicaid had paid out the previous year, regulators identified only 37 cases of suspected fraud—evidence, the reporters

inferred, of inadequate enforcement.)

The problem with the state's current enforcement efforts, Berliner says, is that nobody really knows the extent of fraud in the Medicaid services sector.

The definition of fraud is also unclear, he says: "Technically, it's whatever the Medicaid auditors say it is. But the rules are so complex that even people with the best intentions can make mistakes. And then the headline comes out, 'Medicaid fraud!'"

Hussar, of the OMIG, says fraud occurs when there is a clear intent to deceive the system. "It's the kind of thing where you know it when you see it," he adds.

The OMIG has not yet developed a work plan or identified a profile of agencies to audit. Hussar says investigations will be triggered by numerous factors, including agencies' past audit records, calls to the state Medicaid fraud hotline and "data mining" of Medicaid billing and service records.

When asked if this year's \$400 million Medicaid fraud target is realistic, Hussar notes that the figure also includes "non-fraud" recoveries, such as overpayments to agencies and

monies recovered from third-party insurers.

"I think it's a fair target," he says. "It's something that we can obtain."

**EVEN BEFORE NEW YORK'S NEW** crackdown on Medicaid fraud, leaders of the state's developmental disabilities services system had taken steps to raise accountability standards for agencies receiving Medicaid funds.

For example, beginning in 2005, the state Office of Mental Retardation and Developmental Disabilities (OMRDD) tightened its regular cycle of agency audits from once every five to seven years to once every three to four years. By March of 2008, OMRDD expects to have completed field work on more than 300 such audits.

The agency also has an Early Alert Committee that identifies providers with serious billing or program delivery problems.

While they know that developmental disabilities services agencies are being looked at more closely, OMRDD officials are confident that most can withstand the scrutiny.

"OMRDD has done a really good job upfront with agencies about how to document services," says Commissioner Diana Jones Ritter. "I think because of that, the risk of fraud has been minimized."

As to fears that the state's high-stakes targets on fraud will prevent providers from experimenting with new types of services or expanding access, Ritter says, "I see them as totally different things. You want to see if there is fraud and abuse. That's separate from using the resources we have more efficiently to provide services that are more individualized. I think you can be creative and accountable at the same time."

Attorney Lytle is not so sure. He points out that even if they are not charged with outright fraud, service agencies may still feel some sting from the state's ramped-up efforts to recover funds.

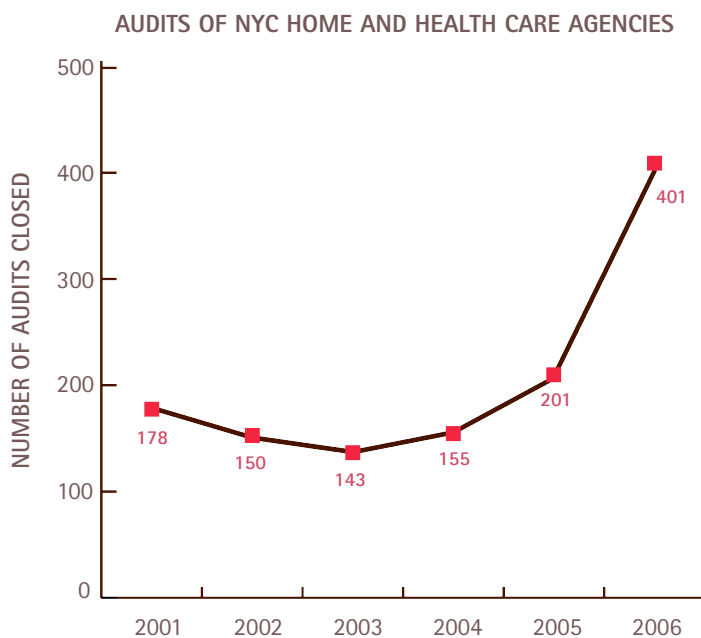
"I don't believe that, at least to date, there are efforts to impose criminal penalties on healthcare providers in cases where there are innocent billing mistakes," Lytle says. "But from a healthcare provider's point of view, if you lose reimbursements for services that were rendered to eligible people because someone feels you did not bill properly, that can still be an enormous penalty."

Bob Gundersen, compliance officer for the Association for the Help of Retarded Children NYC (AHRC), says that even though his agency is not a target in the attorney general's ongoing probe of home health care, managers there still had to respond to subpoenas—a task that took weeks of staff time.

"It's more a matter of energy," he says, when asked about the effect of the state's heightened attention to Medicaid fraud. "So much has to go into compliance these days that it's just not there to deal with creativity." ♦ —**BARBARA SOLOW**

## MORE OVERSIGHT ON MEDICAID SPENDING

*The total number of completed audits of hospitals, health care and home care agencies in New York City has nearly doubled in the year since the state's new Office of Medicaid Inspector General was established. Prior to 2006, such audits were done by the state Department of Health's Office of Medicaid Management. This chart does not include audits performed by the state Department of Mental Retardation and Developmental Disabilities (OMRDD).*



Source: NY State Office of Medicaid Inspector General

# "SOMETIMES, STRUGGLING IS GOOD"

Former residents of the infamous Willowbrook institution share stories of their lives since the school's historic closing.

*This year marks the 20th anniversary of the closing of Willowbrook, the notorious residential state school for people with developmental disabilities. At its height, the Staten Island-based institution housed more than 5,000 children and adults in overcrowded, understaffed and filthy conditions. Physical and sexual abuse of residents was common.*

*Journalist Geraldo Rivera and a camera crew gained access to the school in 1972 and captured the horror that was Willowbrook on film. The widespread attention paid to Rivera's expose led to a federal class action lawsuit on behalf of Willowbrook residents. When New York settled the case in 1975 with a consent decree, the state firmly committed itself to the burgeoning movement to transfer people with developmental disabilities out of large institutions and into smaller group homes.*

*Today, there are 541 New Yorkers with developmental disabilities still living in large developmental centers, according to the state Office of Mental Retardation and Developmental Disabilities (OMRDD). This year, the state has budgeted funds to move 100 residents of such institutions into community settings.*

*Reporter Helaine Olen spoke with four former Willowbrook residents about their memories of the institution and their lives today. They now live in small group homes or apartments and spend their time in day programs or paid jobs. Their desire for home, family, work and other trappings of community life is palpable. Many, having been installed at Willowbrook as children, now have little or no contact with parents and relatives. Instead, social workers and advocates are their de facto family. "We do what the family would do," says Tawnie Ferguson, executive director of the Consumer Advisory Board (CAB), the organization set up by the 1975 consent decree to represent the interests of former Willowbrook residents. "We make sure they get what they are entitled to and are living a good life."*

*To protect their privacy, we use only the first names of people Olen interviewed.*



*Courtesy of Archives & Special Collections, Department of the Library, College of Staten Island, CUNY, Staten Island, New York*

*Erwin, 41, tall and fair-skinned, was sent to Willowbrook as a young child. He has mental retardation and issues with anxiety. After Willowbrook, he lived in a variety of institutional and group home settings. He now shares an apartment on Long Island with a roommate. Erwin works between 20 and 30 hours a week at a local Kmart. He took the train from his home to meet with me. He fervently wishes to see his family again.*

*"My family had so many of us. I remember my sisters and my brother named John, and there was me, and there was the birds. I loved playing with the birds and having fun with them. I miss my whole family. I have not seen them since I was a child, after I was five, six years old and I moved into Willowbrook.*

*There were 50 to 60 in the ward—a ward where you cannot get out unless you have attended to the school and attended to the meals. And after that, you go back on the wards. About four attendants each ward. Some of them was mean, which I didn't like, and they'd fight over you. 'You cannot have this. You cannot eat this!'*



All of a sudden, the advocates started coming on. Like I had Viena who first came, saw me, and she had me for many years. I moved from there to Kings Park [Psychiatric Center, also now closed], then Maryhaven [a group residence and school]. Speaking about Maryhaven, I got the letter from the school last week. I'm going to the school party in October, and I'm going to see all my friends.

I live in an apartment through FREE [Family Residences and Essential Enterprises]. FREE has you doing a number of things: going to work, doing your medical appointment, doing your own food shopping, doing your own laundry, doing your recreation, and travel by bus and trains by yourself where you need to go to.

The anniversary of the day I started at Kmart is February 28. Every year on that day they give me a raise. I had jobs in the past, before Kmart. I had JCPenney. I worked at Lord and Taylor. I worked at Waldbaum's. I started Kmart in 2001. We have different types of things we are basically supposed to work on. I'm supposed to work on the bathrooms, the break room, the sidewalk, carts. If something happens at work, I call up my coach. All of a sudden, they wanted me to do overnight, and I don't mind doing overnight. I have done it in Kmart before. But, see, they feel uncomfortable with me working on overnight. I said, 'Why? What's wrong with me doing overnight? Other people do it.'

My mom was slight and not that heavy. She was like, kind of slim. My father was heavier, and he almost has the same face as me, but different. And my sister looks almost the same as me and same with my brother. I'd like to see them or hear from them, and I'd like to send them a postcard. I don't know if they're still alive or anything. My mom may be wondering, 'Where's my son, Erwin? I haven't seen him lately.'"

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*Kathleen, 54, has lived in a group home on the Upper West Side since 1978. She is blind and has mental retardation. She spent her teenage years and young adulthood at Willowbrook, as well as in a series of group and foster homes. Her parents would occasionally bring her home to celebrate holidays with her siblings, but refused her requests to stay on. Kathleen says she can't talk about Willowbrook with the other residents of her group home who spent time there because they get upset when the subject is brought up. She rocks back and forth rhythmically as we speak.*

"My birthday is in October. I was taken from the hospital to another woman's house. Then my mother got me back again in the 1960s. She took me for good, and then she couldn't—it was too much for her to take care of me. So, the court had me and

I was put in Willowbrook. I was 14 when I went to Willowbrook. I didn't want to because I wanted to stay with her.

They [the aides] wouldn't let you wash yourself. I didn't like it. When a woman gets that time of the month, they would shout it out. I was kind of embarrassed. But you can't say nothing to them. They get offended. I was always afraid. Some of them get very frustrated with you. If somebody does something to you and you try to stick up for yourself, they would punish you.

I wanted to come here. It was an emergency. The foster mother was hitting me. I told my caseworker I didn't want to put up with this anymore. I wanted to move here. This is the only residence I like. It's my home.

I'm in a class with 11 other people in my day program. I'm learning to be a secretary. I answer phones in my classroom. I make jewelry. I used to go and teach staff [at group homes] how to work with blind people. I had to give it up. The Guild didn't want to do it anymore. That was paid. I was showing staff how to work with blind people, because some of them don't know how. They would hold their arm. You're not supposed to do that. They're supposed to hold your arm. You're not supposed to hold theirs. And it's supposed to be by the elbow.

I work at Red Cross too. I call senior citizens that are shut-ins. It's volunteer. I just ask the seniors how their day is and if they have any concerns."

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*Kenneth, 49, was given up shortly after birth by a teenage mother. Cerebral palsy has left him with a pronounced limp, but his mental impairments are slight and might well be the result of spending his childhood in Willowbrook. Kenneth and his teenage daughter live in a small apartment in Brooklyn's Sunset Park neighborhood. His daughter's mother—with whom he is no longer romantically involved—lives across the hall. Kenneth has no contact with his birth family and limited contact with his foster family.*

"I was in Building 10. We were put into these dormitories that had beds on one side, and I think what they would call a big playroom at the other end. And there was nothing to play with in there, only—you know, you sit there and look around. These big prison windows. You're sitting there and you're sitting in urine. You're sitting in people's defecation. It was a lonely, sad feeling.

You get up in the morning and you've got to stand on line waiting to eat. You get out of the line, you get beat up. After you get your bath, you got to go onto a table, where they—they sit there and they dry you off. There be some sexual misconduct going on in—while they drying you off. The [attendants] would like, try to feel your private parts . . . I had to sort of separate

myself, and, you know, learn to say, ‘Okay, you’ve got this happening.’ You couldn’t say much, because nobody’s going to believe you. You are supposedly mentally retarded, so who going to believe somebody that’s mentally retarded over somebody that’s a staff?

When I found out that we was leaving and going to the foster home, I was basically in tears. When I started being able to go on to the outside and looking like other people, I still didn’t know how to act, you know, as far as trusting people. The mentality of that institution somewhat stays with one person. When I got into a foster home, I used to eat fast. You couldn’t beat me at eating. I’d be finished before everybody else. And the lady—she used to be mad at me. And I told her, ‘This is all I know. If you want me to stop this, you got to teach me, because this is all I know.’ And I started telling her bits and pieces about Willowbrook. She started crying. I said, ‘Don’t cry. I went through that. You didn’t go through that. Why are you crying?’

Me and my daughter’s mom, we met, she liked me. I didn’t like her. She just kept pursuing me. Somehow life predicted that we were going to have a kid. This place had a holy fit. Ooh, did they have a fit. ‘What are we going to do with a baby!? We’re not taking in a baby. And we’re going to take that baby from you.’ I said, ‘You must be out your damn mind! You ain’t taking my kid. I’m keeping my kid. I’ve got a trick for you. I ain’t stupid as you think I am.’ I went to Family Court and explained I had a baby coming. ‘Can I get some help?’ And they gave me the help.

I took care of my daughter all her life. I went to parenting classes. I had to show them, or else they’d snatch my kid. And I’ve been left alone ever since. I told them I had nobody to love me. Nobody. Period. And now I got her. I was a little boy, struggling like hell, and now I’m a grown ass man with a daughter. Oh my God! This is amazing.

I took my daughter damn near all over the world. We’ve been to Disney World. I saved up money, rented a hotel, close to everything. My daughter knows I have a disability. But she doesn’t know about my life fully. I want to tell her when she can understand it. She’s a teenager now, and it’s going in one ear and out the other ear. I teach my daughter that she has to strive for the best and be good in life and respect those who are older than you. I teach her about struggling. I tell her that sometimes, struggling is good, because when you struggle, your journey can continue. Then you know where you’re going in life.

I want my daughter to have the best life possible. I’m going to see that she goes to college, if that’s what she wants. And when she gets older, she wants to move out of New York. I said, ‘me too.’ I’m almost 50 years old. New York is changing. And I’m scared to death of having to be here old. I want to go somewhere new. My daughter will be married, have two or three kids. I can look back and say, ‘Damn. I’ve done it.’”

*Jewel, a slim 44-year-old, enjoys an almost sister-like banter with CAB Executive Director Tawnie Ferguson. They’ve known one another since 1991, when Ferguson was new to CAB and Jewel was one of her assigned clients. Jewel wanted Ferguson present during our interview, which took place at Jewel’s new apartment in Brooklyn. It was the first time Ferguson had visited and she took care to comment on details, such as the choice of paint color and placement of a mirror. Jewel, who has mental retardation, entered the foster care system as a toddler and spent several years in Willowbrook before being placed in a foster home. As an adult, she’s lived in group homes and apartments. She would not talk about Willowbrook, only about her life afterward.*

“I do volunteer work—soup kitchen, church, food pantry. It’s all the way uptown, on 103rd or 110th Street. They want me to go three times a week. When we don’t get work, they take us out. I went to the Museum today—the Metropolitan. The Egyptian museum. We saw the tomb, the mummy. I’ve been there three or four times.

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## “THE MENTALITY OF THAT INSTITUTION SOMEWHAT STAYS WITH ONE PERSON.”

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I was raised in Brooklyn, in a foster home. I don’t remember Willowbrook. I remember my grandmother would come there and take me out on weekends. She lived in Manhattan at the time. That’s how I know my brother. I was in foster care till I was 21. I wanted to be on my own, my own person. I missed my caregiver and I would go and visit on the weekends. Then I said to myself, I need to find my family, I need to connect with them. It was a miracle. My grandmother got us all together. I met all my sisters and nieces. We met in the hallway of a senior citizens home. It was magic. I went to my sister’s house. She lives in the Bronx. I have two sisters and one brother. I have to call them and tell them I moved. I know my brother will want to come and check it out. That’s how brothers are.

I have a roommate. If I need assistance, I ask [support services]. I can do mostly everything myself. I need assistance with cooking. Since I’ve been living here, I’ve been eating out. I’m not used to cooking with gas. For breakfast, I’ve had cereal, milk, some days French toast or waffles.

I like it here. It’s comfortable. I have my own space. I had a lot of conflicts [at her last apartment]. I lived with an older woman, and she wanted things her own way. I was tired there, I was crazy there. It was too much. It’s much better here.” ♦

# REACHING CRITICAL MASS

The rapidly rising number of New Yorkers diagnosed with autism is testing the limits of the services system for people with developmental disabilities.

**B**rooklyn resident Winston Searon sometimes stays awake at night, worrying about his 12-year-old son's future. Such anxieties aren't unusual for a parent, but in Searon's case they take on added dimensions.

Winston Jr., who was diagnosed with autism before age 2, communicates mostly by parroting the speech of others. Searon, a recent widower who is also raising a 14-year-old daughter, isn't sure whether his son understands the words he echoes. But he knows that beneath the inexpressive surface is a bright child.

"I will hear him laugh," Searon says, "and I realize that in order for him to find this particular thing funny, he must be thinking about the other aspects of the situation."

Winston Jr. has impeccable rhythm on the hand drum, his dad says, and can finish a jigsaw puzzle that might take someone else the better part of a rainy weekend in less than half an hour. He is currently enrolled in a six-person class for children with developmental disabilities staffed by a trained teacher and two assistants at P.S. 380 in Williamsburg. Searon has tried to find some additional speech therapy classes for Winston, but says the one agency he approached told him they couldn't duplicate services the boy was receiving at school.

When he thinks about his son's future, Searon feels a weight of worry descending. He is happy with Winston's school pro-

gram, but unsure about what kinds of supports his boy will need as he grows older and wants to participate in community life.

"I'm hoping he is able to function as somebody who will be able to go out and work for a living," Searon says. "I don't know. What do I do? I don't know what to do."

**AS THE INCIDENCE OF AUTISM** spectrum disorder (ASD) has risen, more parents are facing the same uncertainties. Since 2001, the number of New York City schoolchildren diagnosed with ASD has soared by 72 percent, to more than 5,600 students, according to the city Department of Education.

While the state Departments of Health and Education have expanded early childhood and classroom offerings in response to this burgeoning population, parents say there are still gaps. And the expansion of early intervention programs has underscored a new challenge: More older children with heightened abilities and higher expectations are graduating from school-age autism services into an adult-services system that doesn't always fit their needs.

Frustrated parents have formed their own service organizations—groups such as New York Families of Autistic Children (NYFAC) and Quality Services for Autistic Children (QSAC). The latter has been around since the 1970s, but has grown rapidly in recent years. Its original name, Queens Services for Autistic Children, was changed to reflect the fact that it also now serves residents of Manhattan, the Bronx and Staten Island, says Janice Silber, the organization's vice president. QSAC's budget grew from \$18 million in 2003 to \$24 million in 2005.

Meanwhile, the state Office of Mental Retardation and Developmental Disabilities (OMRDD) is trying to tailor more of its Medicaid-funded services to people with autism. Currently, 13 percent of the 135,000 people with disabilities the agency assists statewide each year have been diagnosed with ASD—up from only 4 percent in 1990. For children, the proportion is even higher: nearly a quarter of children under age 12 who are receiving OMRDD services have autism.

OMRDD leaders have resisted calls from some quarters for a separate services system for people with autism. Instead, they are trying to improve existing programs and supports offered by nonprofit contract agencies. Last year, the state agency dedicated 75 percent of its family support grants—which pay for

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"IF YOU'VE GOT ALBERT EINSTEIN ON ONE END OF THE SPECTRUM AND YOU HAVE SOMEBODY ON THE OTHER END OF THE SPECTRUM THAT IS SITTING AT HOME, WEARING A HEAD-RESTRAINING DEVICE ... THAT THROWS PEOPLE FOR A LOOP."

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services such as respite care and after-school training—to autism-specific programs.

Gary Lind, OMRDD's director of policy, planning and individualized initiatives, says the growing emphasis on personalized services for people with all types of developmental disabilities will help the system accommodate the surge of people with autism.

"Because we are so focused on being individualized, that allows us the flexibility to respond to people—including people with autism—with a variety of different approaches," he says. "We need to get better at that and make sure we learn more and know more. We are trying for a very careful balance here between not setting up another silo but, instead improving services for all."

Still, pressures are building for more services targeted to people with autism. A bill that would have created a separate autism department within OMRDD was defeated in the state legislature earlier this year.

But some advocates say the distinctive nature of autism means many existing services aren't well suited to the needs of people with ASD. Conversely, many parents of children diagnosed with autism are reluctant to seek services from a developmental disabilities system they see as designed mainly for those with mental retardation.

"Autism is different," says NYFAC founder Andrew Baumann, whose 14-year-old son has ASD. "It presents with different symptomologies and problems. Do we need a separate services system? No. Do we need a separate budget and separate monies? Yes."

The issue goes beyond OMRDD, adds Baumann, who is trying to build a new "one-stop-shop" autism services center in Queens. Currently, he says, parents of children with autism must stitch together a patchwork of services run by different government agencies with different eligibility rules. The state Department of Health runs early intervention services, for example, while the Department of Education handles school-age services and OMRDD coordinates long-term supports for adults (though it also provides after-school and some other services for children).

"Let me tell you that DOH does not talk to DOE, which does not talk to OMRDD," Baumann says. "They don't even use similar eligibility tests. It's great to say we're going to expand the system, but nobody says how we're going to do it and make it work."

Dealing with a fragmented services system is not a new problem for parents of children with developmental disabilities. What's different about autism, experts say, is the degree of public attention it has garnered and the resulting urgency behind the demand for distinct programs for those with ASD.

"There is an autism bandwagon," says Lisa Fleisher, an associate professor of educational psychology and director of programs in special education at New York University. The positive aspect, she says, is that it has enlightened people that there are

certain characteristics associated with ASD—such as high cognitive abilities and difficulties with interpersonal communication—that are different from other developmental disabilities. "Therefore, when you are creating individualized behavioral programs and school, job and living opportunities, you need to take those into account," Fleisher says.

If there is a negative side, she adds, "It's when you think about the amount of attention and resources going to autism, perhaps at the expense of the huge numbers of people with other significant disabilities who need the same kind of focus on their characteristics, their needs and what their rights and opportunities should be."

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**"THE REAL ISSUE IS THAT FAMILIES OF CHILDREN WITH ASD DO NOT WANT TO BE IDENTIFIED WITH PEOPLE WITH INTELLECTUAL DISABILITIES. THEY HAVE A HUGE GRASSROOTS MOVEMENT ARGUING THAT THIS IS A COMPLETELY DIFFERENT DISABILITY, WHICH IT IS."**

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**NO ONE KNOWS PRECISELY HOW** many New Yorkers have autism. Kara Smith, OMRDD's director of public information, says population figures "literally don't exist." The federal Centers for Disease Control's reports that the ratio of 8-year-olds diagnosed with ASD in the U.S. is now 1 in 150, compared to the centers' 1 in 2,500 estimate just three years ago. If the disorder is genetic—and there is still no consensus that it is—then presumably the adult population would contain an equal share of autism cases. Based on current population estimates, that would mean that more than 54,000 New York City residents are on the spectrum.

The one widely agreed-upon measure is that more people have the diagnosis than ever before. Last year, 5,627 students in New York City public schools had an autism diagnosis, compared to 3,278 in 2001.

But even those figures may not fully capture the reality of the city's autism population. As Maggy Ames, executive director of



the Inter-Agency Council of Mental Retardation and Developmental Disabilities points out, the spectrum has “broadened at both ends in recent years.” Children who might have been classified as having mental retardation two decades ago are now being identified as having autism, she says, while those who might not have received a diagnosis at all are now being placed on the high-functioning end of the autism spectrum.

When it comes to designing effective support services, advocates say the fact that autism is a spectrum disorder characterized by a range of behaviors and abilities poses serious challenges.

Michael John Carley, founder of Global and Regional Asperger’s Support Program (GRASP), a city-based support group for people with ASD, sums it up this way: “If you’ve got Albert Einstein on one end of the spectrum and you have somebody on the other end of the spectrum that is sitting at home, wearing a head restraining device, will never say a word, have an intimate relationship or hold down a job—that throws people for a loop.”

There has been a proliferation of schools, training programs and even group homes designed for people with autism in the past few years. But some worry that such ASD-specific services are too uniform in their approach, and risk segregating people with autism from their communities.

“What makes us believe that everyone with autism needs the same learning or behavioral intervention?” says Fleisher of NYU, who has a 29-year-old son on the spectrum. “Or that everyone would benefit from living, working or going to school only with people on the autism spectrum?”

On the other hand, advocates and nonprofit leaders say services offered by the current system for people with disabilities aren’t always geared to the complex cognitive, social and behavioral needs of people with ASD.

“The services that are generally available for people with other developmental disabilities were not designed to take into account people with autism who have some kind of cognitive strength and particular difficulties around communication and socialization,” says Fredda Rosen, executive director of Job Path, a Manhattan-based agency that offers housing assistance and job training to people with developmental disabilities.

One place where that gap is especially wide is during the “transition” years, when many young adults with autism are leaving school and trying to launch more independent lives. Job Path recently completed a study that found that city teenagers with milder forms of autism are having a hard time finding ongoing supports that will allow them to succeed in the workplace.

Although the majority of such teenagers qualify for short-term job supports offered by the state Education Department’s Office of Vocational and Educational Services for Individuals with Disabilities (VESID), “many are not receiving the type of services they need or want,” the report found. For example, some teens were referred to programs for people with psychi-

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## “A SEPARATE AGENCY WITHIN OMRDD STARTS TURF WARS, DEFINITION WARS, BUDGET WARS.”

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atric disorders or group training programs for jobs that didn’t match their intellectual capabilities.

At the same time, teenagers with less severe autism often had difficulty qualifying for the long-term job supports offered by OMRDD because their day-to-day functioning levels were too high. Those who did get help from OMRDD reported that their programs rarely emphasized the social aspects of the workplace, which they needed more than basic skills training.

Job Path’s report laid the groundwork for the organization’s Life Coaching Project for People with Autism Spectrum Disorders, which provides individualized supports to 10 young adults. Services offered by the foundation-funded program range from mock job interviews to ongoing one-on-one skills coaching in the workplace and college classrooms.

Harriet Gozali says the program has been a huge boost for her 35-year-old son, Evan, who has Asperger’s Syndrome. Evan, who is mathematically and artistically gifted, has problems in social situations and with general organization. He spent several years in large group programs run by agencies serving people with mental retardation. Last year, Evan was accepted into the Life Coaching program and this fall he is taking graphic arts classes at City Tech College.

The Life Coaching project “offers very personalized services to address the full spectrum of participants’ needs,” Gozali says. “They focus on all aspects of participants lives and figure out how the pieces fit together.”

**PROGRAMS THAT COMBINE** autism-specific approaches with the goal of inclusion in the community are still rare in New York City. But there is tremendous interest. Job Path had to stop outreach efforts for its Life Coaching program after just three weeks, when it had received requests for three times the available slots.

With such high demand and so few appropriate services, some nonprofit leaders worry that parents will begin to push for a separate services system that will end up competing for resources.

“The real issue is that families of children with ASD do not want to be identified with people with intellectual disabilities,” says Harriet Golden, the associate director for adult day service-

*continued on page 22*

# THE STAFFING CRUNCH

A growing scarcity of frontline caregivers threatens the expansion of services for people with developmental disabilities.

**A**fter Mandy Levy finishes her shift at the group home in Manhattan where she assists four men with developmental disabilities, she rushes off to her second job at a day care center. For almost two years now, Levy has been working a second job to support herself on the salary she receives as a frontline caregiver at the group home.

Before being hired by Cerebral Palsy Associations of New York State as a direct care counselor, Levy worked as a special education teacher for the city's Department of Education. "I came here over one summer just wanting to see how it was," she says of her decision to change careers. "I started liking it and so I stayed."

Levy, who has a bachelor's degree in education, is in many ways the ideal candidate for a caregiver's job. She is committed and educated, and more importantly, she enjoys working with people with developmental disabilities.

But agencies like the one where Levy works are finding it increasingly difficult to recruit and retain employees like her to support people with developmental disabilities. Studies show annual turnover rates in the field average 50 percent nationwide, a symptom of persistent low wages—but also, workers

Secretary for Planning and Evaluation (ASPE), found that by 2020, the need for direct support workers will outstrip the supply by almost double. The report anticipates that demand for direct support workers in the developmental disabilities field will increase nationwide by about 323,000 jobs, or about 37 percent, in the next decade. But the number of adults aged 18 to 39 who have traditionally filled those positions is expected to grow by only 7 percent in the same period.

"We don't have enough direct support professionals now to meet the need and it's going to get even worse," says Sheryl Larson, research director and a principal investigator at the Research and Training Center on Community Living (RTC) at the University of Minnesota and a contributor to the ASPE report.

In New York City, experts say the shortage will be compounded by a disproportionately elderly population whose need for caregivers will draw from the same pool as people with developmental disabilities. Of the 5,980 expected average annual job openings in the city over the next decade for personal and home-care aides—the categories that cover workers who assist people with developmental disabilities—64 percent will constitute new openings, and 36 percent will be replacements, according to the state Department of Labor (see chart, page 19).

That means more than one-third of the openings will be the result of people leaving their jobs. If providers could reduce staff turnover by just 2 percent each year for the next 20 years, says Larson, they could significantly ease the scarcity of direct support workers. "If we can address turnover, we can reduce the problem of increased demand," she says.

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**"WE DON'T HAVE ENOUGH DIRECT SUPPORT PROFESSIONALS NOW TO MEET THE NEED AND IT'S GOING TO GET EVEN WORSE."**

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and employers agree, of sometimes unrealistic job expectations, poor supervision and lack of career advancement.

As the services system has begun to provide more people with developmental disabilities one-on-one supports in community settings or their own homes—as opposed to large institutions or group homes—the need for direct caregivers has increased. Yet the task of filling those positions is growing harder.

A report submitted to Congress last year by the Department of Health and Human Services' Office of the Assistant

**FOR MANAGERS AT THE SCORES OF** nonprofit agencies that provide services for people with disabilities, frontline worker "churn" makes a challenging job that much harder for those who stay.

"Staff turnover is one of the biggest job pressures I face," says Jennifer Freeman, a senior assistant psychologist at YAI/National Institute for People with Disabilities Network, one of the city's largest service providers. "When a staff person leaves here, it can trigger a whole range of emotional and behavioral issues for people with disabilities who have gotten used to that person."

Margaret Puddington, a parent and founder of the New York

City-based advocacy group, the Coalition of Families for Direct Support Staff in Services for People with Developmental Disabilities, knows about that firsthand. Her son, Mark, who has mental retardation, recently moved into a group home for the first time. “Mark just lost the best teacher he’s ever had in the day program,” Puddington says. “The agency wanted to keep him because he was so wonderful. But he left for the public schools, where he’s doubling his salary.”

Low salaries have long been identified as a leading cause of support worker turnover. Though the demands of their jobs and the level of responsibility have increased, wages have not kept pace. The state Department of Labor reports that the median annual wage for personal and home care aides hovers at \$21,230, or about what people earn in fast food jobs. In New York City, studies show, one in seven low-income workers is a frontline home or community-based caregiver.

Group homes and day programs must compete with one another—and with government agencies, which invariably pay workers higher wages than nonprofits can afford—for the best employees.

Agencies providing services to people with disabilities are pushing for national legislation that would address this inequity. The Direct Support Fairness and Security Act, introduced for

the third year in a row by House members Lee Terry (R-NE) and Louis Capps (D-CA), would increase the wages of “direct support professionals” who assist people with disabilities. The bill, now in committee, would provide states with planning grants to develop five-year plans to close the gap between salaries of direct support workers in nonprofit agencies and those employed by state or local governments. The difference between salaries in the two sectors is as much as \$10,000 a year, according to the legislators. An enhanced federal match on Medicaid would cover some of the costs.

But many nonprofit leaders wonder whether the measure will succeed. Amy Bittinger, director of family support services at United Cerebral Palsy of New York City, attended a rally in Washington this fall of workers, families and agency leaders in support of the bill. “For those workers who have been in the field for a long time, there was a sense of euphoria and excitement,” she says. “But when will they really see increased wages? We were left with a sense of, ‘Wish we could do more.’”

On the state level, the Office of Mental Retardation and Developmental Disabilities (OMRDD) has successfully lobbied state budget leaders in recent years for modest salary increases for direct care workers at its nonprofit contract agencies. In addition, OMRDD has set aside funds to make grants to agencies that present plans to improve healthcare benefits for frontline workers—a strategy shown to decrease turnover.

But given the pressures on Medicaid spending, nonprofit agencies and OMRDD are also pursuing other, non-wage strategies to reduce worker turnover. These include efforts to promote career advancement through mentoring, apprenticeships and skills training.

The New York State Association of Community and Residential Agencies (NYSACRA), for example, is promoting the College of Direct Support, an online training program that certifies frontline workers who complete courses that follow standards set by the National Alliance for Direct Support Professionals.

The idea behind such voluntary “credentialing” programs is to raise the competency levels and respect for frontline caregivers, says Joseph Macbeth, director of member services for NYSACRA. “You get well-trained workers who are familiar with jobs, who understand the value that is placed on them and who will stay longer,” he says.

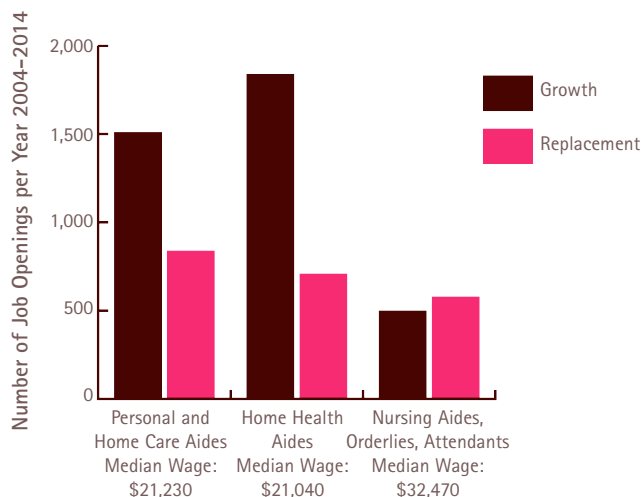
With the field’s growing emphasis on individualized supports, agencies are looking for skilled workers who can support people with developmental disabilities over the long term. “The better educated you are, the better able you are to do a multifaceted job,” says Jules Feiman, director of Human Resources at YAI.

His agency has made it a priority to hire frontline workers with advanced training. Of YAI’s nearly 2,000-person direct support workforce, more than half have associate’s degrees, 42 percent have bachelor’s degrees and 4 percent have master’s

*continued on page 22*

## HELP WANTED

*More than a third of the openings for frontline caregiver positions in the developmental disabilities field in New York City are the result of people leaving their jobs. This chart shows the difference in annual job openings anticipated over the next decade that are due to new openings (growth) and how many are replacements. The chart also shows that median wages are higher for frontline jobs with the smallest anticipated new growth.*



Source: NY State Department of Labor

# A GOVERNMENT VETERAN AT THE TOP

Diana Jones Ritter talks about her role as head of the state agency for people with developmental disabilities.

**D**iana Jones Ritter first started working for the State of New York in the early 1980s. As a budget examiner, she was in charge of designing a prototype for a new 12-person group home, which at the time was the gold standard of community residences for people with developmental disabilities. Ritter went on to serve as an associate commissioner in the Office of Mental Retardation and Developmental Disabilities (OMRDD), and after two decades in government she became the state's executive deputy comptroller. Earlier this year, newly elected Governor Eliot Spitzer tapped Ritter to become commissioner of OMRDD, which now serves 140,000 New Yorkers with developmental disabilities. Barbara Solow spoke with Ritter about her plans for the agency.

## WHAT ARE YOUR PRIORITIES FOR OMRDD IN THE IMMEDIATE FUTURE?

My top three priorities would be: working collaboratively with our sister state agencies to provide seamless cross-agency services; working in partnership with people with developmental disabilities and their families to provide our consumers with services designed to meet their individual needs; and promoting models of excellence statewide. Cross-agency collaboration is important because many of our consumers have co-occurring conditions which require services across a swath of agencies, not just OMRDD. Working with our sister agencies is critical if we want to help them achieve real progress.

## YOU'VE TALKED ABOUT WANTING TO MOVE MORE PEOPLE OUT OF LARGE INSTITUTIONS AND INTO THE COMMUNITY. HOW ARE YOU GOING ABOUT DOING THAT?

First, just recognizing the significant progress we've made. Fifteen thousand people in 1980 were still in developmental centers and now it's down to about 600. That was one of my surprises—I was surprised to find people still in those developmental center beds. We know who these people are; we've done the analysis on how long they've been there.

We are now conducting a statewide community placement process. I've directed all my districts to look very closely at who these people are and start to assess what their abilities are and what their needs are so that we can continue to plan for community placement for them. The budget this year already includes resources to move 100 people into the community. And I want to be very aggressive about doing that. I want to do that working with the families and the guardians—and the unions are very important to me in this process. And of course, the nonprofit providers.

## THE BURGEONING NUMBER OF PEOPLE DIAGNOSED WITH AUTISM REPRESENTS A NEW CHALLENGE FOR THE SERVICES

## SYSTEM. WHAT DO YOU SEE AS THE MAIN IMPACT OF THIS GROWING POPULATION?

Well, it's not new because currently, 13 percent of the people we are supporting and serving have an autism diagnosis. But if you look down the road at the number of kids being identified in the school system, the bubble is getting larger and larger. So we have to be prepared to offer the supports and services that will be needed for people to lead quality lives as they age out of the education system.

I've been very vocal on this. Setting up a separate system of supports is not something I think that would be helpful or meaningful because we're supposed to be serving all individuals with developmental disabilities and already we're serving people on the spectrum. I think the discussion should change to how prepared are we to provide the supports and services that are required or will be required? How do we educate parents on the best strategies for dealing with individuals that are in the spectrum? What does the research say and how are we applying it? Do we have the right mix of supports and services that individuals need? I'm not about cookie-cutter [approaches] for any segment of our developmental disability groups.

## THE SPITZER ADMINISTRATION HAS COMMITTED ITSELF TO FINDING SUBSTANTIAL SAVINGS IN MEDICAID SPENDING AND UNEARTHING FRAUD INVOLVING MEDICAID DOLLARS. WILL THIS HAVE A SIGNIFICANT IMPACT ON THE DEVELOPMENTAL DISABILITIES SERVICES SYSTEM?

I think the governor's goal to have greater accountability in Medicaid resources is exactly the right goal to have. [Former OMRDD] Commissioner [Tom] Maul has a legacy and did a fabulous job bringing in the Medicaid funds to help deliver and create the supports and services we have today. And he was also good about creating the internal capacity to actually look for—to provide technical assis-



tance to minimize the risk of fraud and abuse. He created within his quality assurance unit a very aggressive approach to overseeing quality, both on a financial side and the program side. So the bottom line is, we've been doing it all along. We've been looking for fraud and waste and working with providers to actually avoid it.

**DO YOU THINK, THOUGH, THAT AGENCIES WILL BE LESS LIKELY TO PURSUE INNOVATIVE PROGRAMS BECAUSE THEY ARE WORRIED ABOUT CROSSING THEIR T'S AND DOTTING THEIR I'S ON MEDICAID SPENDING?**

I hope not. I really do see them as different goals. We want to—and we will—raise the bar and hold it high for accountability. At the same time, we want to support and incubate, if you will, different ways of doing business and being innovative.

**YOU'VE TALKED ABOUT OVERSEEING AN "EXTREME MAKEOVER" OF THE NYS-OPTS PROGRAM [FOR PERSON-CENTERED SERVICES]. WHAT CHANGES WOULD YOU LIKE TO SEE?**

There was a lot of confusion about what OTPS was and wasn't—a lot of complaints from families that it was taking too long. The providers thought that they were kind of in the middle. They'd come forward with a proposal and the central office would say, 'We can't fund that. It's too much.'

One thing I can tell you right off the bat is that the principles behind OPTS are good ones that we are going to keep: that is, that the families and the individuals need to be involved in planning for their individual and person-centered supports. That's what it's about.

**NEW YORK'S HOME AND COMMUNITY-BASED SERVICES (HCBS) MEDICAID WAIVER COMES UP FOR REAUTHORIZATION IN 2009. WHAT CHANGES, IF ANY, WOULD YOU LIKE TO SEE IN SERVICES COVERED UNDER THE WAIVER?**

New York operates what is probably the largest HCBS waiver in the country. We have over 60,000 people enrolled in our waiver and more than half of those live in a non-certified residential setting—that is, in their own home or with family. That's a great base upon which we can build as we head toward renewal.

There are two main areas I want to look at. First, we want to make changes to the waiver that will make it easier to provide highly individualized and person-centered services. Our goal in the waiver is to assure that people are able to enjoy meaningful relationships with friends, family and others in their lives; to experience personal growth and development; and to fully engage in relationships in their community. We have to figure out ways to make that happen more easily.

Second, I'm looking to transform what has been a highly successful quality assurance system to one that's more broadly focused on quality management. Our goal is to transform OMRDD into an agency that not only meets, but exceeds qual-

ity expectations and perhaps even sets some standards for quality. This will involve relatively obvious improvements, like collecting more routine information on satisfaction with supports. It's also likely to mean things like benchmarking performance and measuring improvements in the overall waiver program.

**GOVERNOR SPITZER HAS ALSO TALKED ABOUT THE NEED FOR MORE INTER-AGENCY COOPERATION AND THAT WAS THE UNDERLYING MESSAGE OF A "LISTENING TOUR" YOU PARTICIPATED IN OVER THE SUMMER. WHAT WERE THE KEY CONCERNS YOU HEARD AT THOSE SESSIONS? AND HOW WILL YOU ACHIEVE MORE COOPERATION BETWEEN OMRDD AND OTHER STATE AGENCIES?**

The listening tour was a great experience. We had over 2,200 people turn out at the five sites around the state. Among the issues we heard frequently was that locating and accessing

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**"CROSS-AGENCY COLLABORATION IS IMPORTANT BECAUSE MANY OF OUR CONSUMERS HAVE CO-OCCURRING CONDITIONS WHICH REQUIRE SERVICES ACROSS A SWATH OF AGENCIES, NOT JUST OMRDD."**

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services that don't fit neatly into one agency's responsibility was most problematic. When people don't fit easily into our usual ways of doing business, they get bounced around or they don't get access to the right supports.

We also heard about difficulties in accessing critical supports and services that are most important for people whose needs cut across different agency responsibilities. These include such things as critical clinical services like child psychiatry or specialized dentistry. But also access to more basic supports, like housing and transportation. One parent put the issue most poignantly when she said that when a family is in need they shouldn't have to knock on 20 doors to get one service—that family should be able to knock on one door and receive 20 services.

The energy and commitment on the part of my fellow commissioners is exciting. We're talking on a regular basis about initiatives that we can kick off to make things better. The days of finger-pointing and blame are behind us. ♦

degrees, Feiman says.

YAI has also tied skills training for employees who don't have college degrees to concrete benefits. It offers tuition assistance to frontline workers for completion of certificate or college preparatory programs, such as the Disability Studies Certificate Program at CUNY. The one-and-a-half year program is designed for support workers with little or no college experience. When they complete the program, workers receive bonuses or promotional opportunities at YAI. The agency pays for the tuition benefit with private donations and through a scholarship program run by The John F. Kennedy, Jr. Institute for Worker Education at CUNY.

**IN A FIELD CHARACTERIZED BY ITS LACK** of career development opportunities for frontline workers, YAI has managed to create openings for advancement according to a worker's education level and performance. And worker turnover rates show the benefits of this approach. Annual turnover is only 22 percent at YAI, according to agency executives, compared to 50 percent nationally.

But some in the field say broader solutions are needed if more agencies are to offer wages and benefits that will keep

frontline caregivers on the job. Labor leaders, for example, point to the field's uneven unionization as a disadvantage when it comes to pressuring government to raise wages. If the sector were more fully unionized, they say, unions could work hand in hand with nonprofits to demand higher wages from government.

"The nonprofit sector is competing with each other for scarce resources and they are afraid that unions will force them to pay more without additional funding," says Ed Ott, executive director of the New York City Central Labor Council AFL-CIO. "But agencies should work with unions to let the unions rationalize the industry."

For her part, Levy, of the Cerebral Palsy Associations of New York State, intends to begin studying for a master's degree and hopes one day to find work as an administrator at a group home. With direct care experience under her belt, she feels she'll be in a better position to help create programs for people with developmental disabilities.

Still, without more pay, benefits and respect for her work, Levy isn't sure how long she can stay in her frontline post.

"I can't kill myself with two jobs," she says. "Eventually I will have to move on." ♦ —**JULIE CARACINO**

es at the Association for the Help of Retarded Children NYC (AHRC). "They have a huge grassroots movement arguing that this is a completely different disability, which it is."

Such advocacy reflects a genuine need for specialized services, Golden adds. "But the pot is only so big," she says. "Parents of people with other intellectual disabilities start screaming, 'You're taking money away from my child to fund that population.'"

Such concerns were tested last February, when a 13-year-old boy with autism died after being improperly restrained by employees of an OMRDD-funded center near Albany. In the swirl of publicity that followed the incident, state Senator Tom Libous (R-Binghamton) introduced the "Better Focus on Autism Now Act" to create a separate autism services department within OMRDD.

"Everyone opposed it," says Ames of the Inter-Agency Council. "All the agencies, everybody. A separate agency within OMRDD starts turf wars, definition wars, budget wars. It would pretty much defeat any hopes of keeping the various disabilities integrated with each other."

In the end, the bill failed in both houses—not least because the broader disabilities community organized against it. "We received a lot of letters of opposition from parents of children with other developmental disabilities," says Matt Moyse, a spokesman for Libous. "They were worried that the act would strip children with other developmental disabilities of resources."

Instead of a separate department, OMRDD's new commissioner, Diana Jones Ritter, has been focusing on ways to

improve current programs for people with autism. "This is an area where collaboration among state agencies is key," she says. "We have already begun discussions with the state Education Department, the Health Department and the Office of Mental Health to create working partnerships to address ASD."

For his part, Baumann, of NYFAC, is pushing another bill in the legislature that would create a state autism council to formulate cross-agency plans for serving the growing numbers of people on the spectrum. The council would be comprised of representatives of several state agencies, as well as parents of children with autism, educators and medical experts.

"I started warning people in state government years ago that they weren't going to be ready for these kids," Baumann says. "And we're still not ready."

How well the services system responds to the fast-growing population of people with ASD is an issue that affects the entire developmental disabilities community, says Mike Dillon, assistant professor of special education at Dowling College in Long Island. "We have a chance not to repeat the mistakes of the past by creating another congregate-care system for people with autism," he says.

Viewed that way, the current attention to the issue can be seen as positive. "It's reached enough of a critical mass," Dillon says. "You can't ignore it when we're talking about thousands of kids." ♦ —**ROB FISCHER AND BARBARA SOLOW**

## WATCHING THE NUMBERS

### A multi-year statistical survey of services for New York City residents with developmental disabilities

	FY 2001	FY 2003	FY 2005	FY 2007
Population Served				
CHILDREN	17,542*	17,719	18,210	17,752
ADULTS	23,868*	24,288	25,879	26,562
TOTAL	41,410*	42,007	44,089	44,314

(\* These are 2002 figures. 2001 data are not available for these indicators.)

#### MEDICAID HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVER

ENROLLEES	8,751	11,284	12,687	14,616
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The HCBS waiver, which is up for renewal in 2009, allows federal Medicaid money to pay for community-based services for people with developmental disabilities who would otherwise receive services in an Intermediate Care Facility or institution. Its use has grown dramatically in the last decade.

#### HOUSING SERVICES

Reflects the number of people in each type of residential setting. There are no data that specifically break out self-directed housing or small, one- and two-person apartments. These are mostly included in the numbers for IRAs and Individualized Support Services.

• CR TOTAL	558	504	446	274
Community Residences (CRs) are state-licensed group homes and apartments operated either by the state OMRDD or nonprofit agencies.				
• CR SUPERVISED	304	276	240	148
Support staff are on duty 24 hours per day.				
• CR SUPPORTIVE	254	228	206	126
Support staff are on duty less than 24 hours per day.				
• IRA TOTAL	3,361	4,069	4,331	5,240
Individual Residential Alternatives (IRAs) are group homes or apartments with 14 or fewer residents. Most newly developed housing programs fall into this category.				
• IRA SUPERVISED	2,864	3,491	3,716	4,507
Support staff are on duty 24 hours per day.				
• IRA SUPPORTIVE	497	578	615	733
Support staff are on duty less than 24 hours per day.				
• FAMILY CARE	555	528	497	434
Residents live with families who receive monthly stipends from the state for their services.				
• INDIVIDUALIZED SUPPORT	157	176	207	279
Use of this housing assistance, which includes rent subsidies for individuals who live in homes and apartments that are not state-licensed, is modest but increasing.				
• INTERMEDIATE CARE FACILITIES	2,992	2,859	2,817	2,470
ICFs provide round-the-clock supervision and treatment programs, including basic medical care. Their use has declined in recent years.				
• DEVELOPMENTAL CENTERS	318	289	287	256
These are state-operated institutions in campus settings. The state plans to move 100 residents of such centers into community settings in 2008.				
• SPECIAL TREATMENT UNITS	354	339	349	343
These are state-operated clinical, campus-based residences with structured programs and 24-hour supports for people with intensive needs, behavioral problems or multiple disabilities.				
• TOTAL HOUSING	8,295	8,764	8,934	8,697

• RESIDENTIAL HABILITATION	2,490	2,788	3,115	2,831
People receive "res-hab" support services—including skills training and therapeutic and health-related services—in their homes. This number has dropped in the last three years.				

#### DAY SERVICES

• DAY HABILITATION	3,892	6,695	9,464	10,875
"Dayhab" support services are provided outside the home at an agency or in a community setting.				
• DAY TREATMENT	6,408	4,423	3,827	1,665
This category of more traditional day services, typically site-based, is being phased out.				
• SUPPORTED EMPLOYMENT	1,626	1,667	1,747	1,712
Services are provided to facilitate paid employment, including job coaches. Advocates have been concerned about the lack of growth in the program. These data do not include people transferred to the State Department of Education's VESID program in 2003.				

#### SELF-DETERMINATION (CONSOLIDATED SUPPORTS AND SERVICES)

	0	0	8	11
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The program allows participants and their families and advocates to choose their own supports and services and control their Medicaid and other resources.

OMRDD had expected the numbers to triple in 2007 but instead, the increase has been very slight.

#### TOTAL HCBS MEDICAID WAIVER FUNDS (STATEWIDE)

2001: \$2.7 billion

2002: \$3.0 billion

2004: \$3.4 billion

2006: \$3.7 billion

(Federal fiscal year, October 1 to September 30)

Numbers updated from previous issue of Developmental Disabilities Watch to show increases from back billing.

All figures are reported in NYS fiscal years (April 1 to March 31) unless otherwise indicated. Source: NY Office of Mental Retardation and Developmental Disabilities (OMRDD)

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