

DEVELOPMENTAL DISABILITIES

Watch

*MORE VOICES, MORE CHOICES: NEW DIRECTIONS
IN SUPPORTS AND SERVICES IN NYC*

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Medicaid reform has become a mantra of politicians in New York, not least the leading candidate for Governor, Eliot Spitzer. And yet the vast \$3.3 billion budget of the state's Office of Mental Retardation and Developmental Disabilities (OMRDD), comprised mostly of Medicaid funds, has stayed below the radar of the political leadership and the media.

By many measures, this stream of federal support represents one of the great successes of state government, as it fuels the services and supports that make life livable for people with developmental disabilities and their families. More than 30 years after the Willowbrook exposés, state officials point with pride to the dramatic decline in the numbers of men, women and children with disabilities who live in large, state-run institutions. The trend today is toward smaller residences and training and work programs that link people with disabilities to their neighborhoods and communities. The state OMRDD prides itself on "governing principles" that emphasize the essential rights of the people it serves, such as: "A person with developmental disabilities



*Art by Leon McCutcheon, courtesy of
The Shield Institute Pure Vision Art Studio*

shall be as independent as possible and determine the direction of his or her life."

The rhetoric is strong. But despite good intentions, the reality for too many New Yorkers with disabilities still comes up short. As our reporting in this issue of *Developmental Disabilities Watch* reveals, the money and leadership directed toward creating a truly "person-centered" system—one that accounts for individual abilities and desires, and grants people with disabilities a substantive role in shaping their own assistance programs—has so far been modest.

Take OMRDD's newest initiative, New York Options for People Through Services, which we explore in this issue of the *Watch* (see "Options and Opportunities," page 10). Described by officials as a "systems transforming" prototype for more consumer-directed services, the pilot program represents a tiny fraction of OMRDD's current spending—particularly in New York City—and has not been well promoted. (One agency leader described the program's rollout as going over "like a lead balloon" with nonprofit agencies in New York City)

And as another of our stories shows, despite official backing for the concept of individualized "supported living," only a handful of New York City residents with disabilities hold the lease to their own apartments or have the option to choose their roommates. As for employment, agency leaders concede that existing job-training and support programs are most often reserved for people with the least severe disabilities. Some advocates and service providers are concerned that OMRDD has stepped back from actively encouraging work at a time when unemployment and poverty rates for people with disabilities are climbing in New York and nationwide.

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- 1,934 people with developmental disabilities received supported employment services in New York City as of January, 2005. By comparison, 2,561 city residents were enrolled in sheltered workshops and 10,071 in day programs that did not involve paid work. (See "Employed, For a Change," page 14)
 - The percentage of New Yorkers with all kinds of disabilities who are employed has been dropping in recent years. The employment rate declined from 35.4 percent in 2003 to 34 percent in 2004, according to Census Bureau data.
 - NYS-OPTS has doled out \$137 million so far in five-year pilot contracts for consumer- and family-driven projects. This is just a tiny fraction of the \$2.98 billion that the state Office of Mental Retardation and Developmental Disabilities (OMRDD) spent last year alone to provide services and housing programs for New Yorkers with developmental disabilities. (See "Options and Opportunities," page 10)
 - On the continuum of possible residential scenarios, group homes remain the most typical. Many agencies now emphasize smaller residences and a wider variety of services than in the past, but self-directed supported living remains far from commonplace. (See "Living Their Own Lives," page 5)

State leaders have the power of the purse, yet they have not used that power to take the big steps that would fundamentally change the system to match the rhetoric of individual choice and self-directed living. One reason is that many people with disabilities and their families are understandably comfortable with the often segregated, restrictive but familiar way of life they now have in congregate settings, and are wary of trading this for new and demanding experiments in directing their own supports.

In a similar way, in this time of uncertainty about Medicaid funding, many nonprofit agencies fall back on the tried and true. In most cases this means programs designed around the assumed needs and abilities of groups rather than individuals, with minimal input from the people those services are meant to help.

Yet as our reporting in this issue shows, such experiments can produce very positive results not only in the lives of individuals with disabilities but in changing the limited mindset society has about their potential. This is one reason why a nationwide movement of people with developmental disabilities and their families has sought to create more person-centered systems, rooted in the civil right of every person to control their own life.

In public pronouncements, state leaders acknowledge that supports designed around specific people are ultimately more accountable—and potentially more efficient—than those designed around the hazy outlines of a population. That's the idea behind a program like NYS-OPTS. Yet many in government and the nonprofit agencies seem stuck in an earlier era of reform, content to cite trends toward smaller residences while failing to quantify how often these homes are merely addresses created by large organizations rather than homes defined by the people who live in them.

So, how best to close the gap between rhetoric and reality? It will take more than simply laying out new programs or relying on decent safety track records. State leaders must ensure that people with disabilities and their families have the information and supports they need to recognize opportunities for more individualized services and take advantage of them.

Other states, and even some innovative nonprofits working closely with OMRDD in upstate New York communities, have learned to use federal Medicaid funds and other resources in bold, accountable and effective ways. Of course innovation is easier in smaller jurisdictions. But there is no reason New York City practitioners can't begin moving more forcefully in the same direction.

OMRDD should take the lead through better incentives, enforcement and a bully-pulpit approach that encourages autonomy and individuality in every aspect of the system. Otherwise, for too many New Yorkers with developmental disabilities, the state's lofty governing principles will remain words, not deeds. ♦

Recommendations proposed by *Developmental Disabilities Watch*

Most businesses lose customers if they fail to satisfy individual patron's unique tastes and demands. The same would be true of publicly funded social services—except that the agencies and programs that provide those services were historically structured in a manner that allows little in the way of individualized choice or flexibility.

Government agencies that fund services for people with developmental disabilities (and many nonprofit organizations that provide those services) often prefer the efficiency that comes with greater conformity and less choice. Yet there is today a growing trend toward—and increasing pressure from the grassroots for—more individualized, supportive services.

The inspiration for change comes in part out of people's demand for an end to years of discrimination and segregation of people with disabilities. But it also reflects a growing body of evidence that shows that many people with developmental disabilities thrive when they have opportunities to make choices and live in a supportive but not overly controlled environment (see "Living Their Own Lives," on page 5). Almost by definition, such a lifestyle requires individualized services and supports and tremendous flexibility in the way programs are designed, managed and funded.

In New York State, people with developmental disabilities and their families often find individualized services very difficult to achieve. Meaningful, lasting change is needed that will open up opportunities for thousands more men and women who have the right to make personal choices about their lives.

Below are recommendations from the DD Watch Advisory Board, which aims to strengthen infrastructure that allows for greater flexibility and individuality and challenge the pressures for conformity and cookie-cutter services.

THE STATE OMRDD SHOULD INSTITUTE OUTCOME-BASED MANAGEMENT PROTOCOLS THAT ENCOURAGE PROVIDER AGENCIES TO INNOVATE AND IMPLEMENT MORE INDIVIDUALIZED, FLEXIBLE AND SELF-DIRECTED SERVICES.

Government officials control many of the key levers of power in the developmental disabilities system, even though nonprofit agencies provide most of the direct services to consumers. Officials can use their power to enforce policy changes through the contracting process, and to encourage providers to innovate.

In the current, intensified climate of scrutiny of Medicaid spending, politicians and government accountants demand perfection in nonprofit organizations' corporate compliance on a host of indicators and process measures. But they are not as focused on results for consumers. More important than process are the answers to questions such as: Are people with developmental disabilities participating in community activities they have chosen and that correspond with their interests? Are they receiving individualized supports

that help them find and keep jobs and live in homes they have selected? Are they in situations where they are meeting and interacting with people without disabilities? Are they making friends? How effective are their support services at helping them to achieve their personal goals? Are individuals, families and providers forging mutual agreements about shared decision making, defining roles and relationships and clearly assigning responsibility for essential tasks?

In collaboration with stakeholders, OMRDD officials should pare down and revise current performance-based management protocols so they are clearly linked to the goals of individualized and flexible services. They should hold the state's own direct-care services to the same standards. And federal Medicaid officials should ensure that their procedures support this approach, which matches their own policy statements.

OMRDD SHOULD ESTABLISH INDEPENDENT BROKERS IN NEW YORK CITY WHO CAN FACILITATE PLANNING FOR INDIVIDUALS

WHO CHOOSE TO SHAPE THEIR OWN SUPPORT SERVICES AND THEIR HOUSING AND LIFE SITUATIONS.

Currently, a few overstretched government employees are expected to help individuals and their families plan and organize their budgets and services so that they can live as they choose. Instead, independent brokers should be available to people and families seeking to control their housing and services under the state's self-determination program. For those who prefer to partner with an established agency to help them find their own home, plan budgets and manage services, there should be a handful of state-funded nonprofit organizations with a special capacity to provide these essential supports.

LEADERS IN GOVERNMENT, ADVOCACY AND SERVICES MUST BETTER DEFINE AND MORE ASSERTIVELY PROMOTE MODELS OF INDIVIDUALIZED, SELF-DIRECTED SUPPORTED LIVING.

Many people with disabilities and their families fear the potential social isolation of life outside a group home, and worry about the complicated planning required to organize support services outside a traditional agency-run setting. With more systematic awareness and public education efforts rooted in examples drawn from real life, there will be deeper understanding of what constitutes self-directed supported living—not only among consumers but providers and government employees as well.

OMRDD SHOULD TAKE A LEAD ROLE IN PROMOTING EMPLOYMENT AS A VALUED OUTCOME FOR PEOPLE WITH DISABILITIES, AND IN COORDINATING THE AGENCIES RESPONSIBLE FOR SUPPORTING WORK.

Only a few thousand residents of New York City with developmental disabilities have a job that provides a paycheck, of the more than 44,000 taking part in various OMRDD-funded services. In New York as in the rest of the nation, labor force participation rates have declined substantially since 1990 among people with developmental disabilities. This trend can be countered, and the numbers increased substantially—but today there are insufficient employment supports, few incentives and little encouragement for people with

developmental disabilities to enter the workforce. And there are often bureaucratic hurdles or misconceptions that make paid work more complicated than it should be. (See “Employed, for a Change,” page 14).

OMRDD and its funded agencies should develop a strong advocacy effort promoting the option of supported work to participants in its programs, and underlining the benefits of job coaches and employment. They should also help consumers and their families understand they can maintain SSI and Medicaid benefits even when they have substantial earnings, and encourage them to receive high quality benefits counseling.

In addition, OMRDD should take responsibility for marshalling the resources of the many state and local agencies that fund or provide supports for people already employed or hoping to join the workforce.

STATE AND LOCAL DEPARTMENTS OF EDUCATION, LABOR, EMPLOYMENT AND YOUTH SERVICES SHOULD MAKE MORE SUBSTANTIAL EFFORTS TO PROVIDE JOB OPPORTUNITIES FOR YOUNG PEOPLE WITH DEVELOPMENTAL DISABILITIES.

The routines and ethics of work are learned at an early age. If a person with disabilities has a job as a teenager, he or she is far more likely to be employed as an adult. The state and city can make more focused use of vocational funding for young people in special education as well as the Summer Youth Employment Program and other existing resources.

THE STATE SHOULD PROVIDE GREATER REIMBURSEMENT FOR EMPLOYMENT AND VOCATIONAL SUPPORTS UNDER THE MEDICAID WAIVER, THE VESID PROGRAM AND OTHER WORKFORCE INITIATIVES.

Currently, a few nonprofit organizations are exceptionally skilled at reaching out to employers and encouraging them to hire people with developmental disabilities. Others have helped men and women with disabilities manage their own small ventures. These cutting-edge organizations need funding for job development and recruitment, individual job coaches, counseling and job preparation services, marketing outreach and placement, among other things. In New York City, employment-related support services for people in OMRDD’s supported employment

program are reimbursed at less than one-third the level of day habilitation. Organizations working with men and women in VESID programs receive even less. They should be more fully covered for the wide-ranging costs of their services.

NEW YORK STATE’S LEGISLATURE AND THE GOVERNOR SHOULD DEVISE A PROPOSAL FOR AN EARNED INCOME TAX CREDIT (EITC) FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES WHO EARN A WAGE.

Modeled on the widely recognized federal and state EITC, a tax credit would significantly increase the incomes of working people with developmental disabilities and make work more attractive. As we note above, agencies supporting work should receive higher reimbursements for their services—but the individuals themselves should also derive significant economic benefits from their jobs.

THE OPTS PROGRAM SHOULD BE CHAMPIONED, FUNDED AND IMPLEMENTED AS A WAY TO BROADLY EXPAND ACCESS TO SELF-DIRECTED AND INDIVIDUALIZED SUPPORTS AND SERVICES.

The Options for People Through Services (OPTS) program begun two years ago by OMRDD establishes a valuable precedent for involving people with disabilities and their families in the design and planning of the services they need. OPTS has already provided funding to organizations trying to break through unwieldy barriers erected by complicated requirements of traditional funding streams. For example, men and women in one supported, self-directed, part-time employment program in Brooklyn are now also able to participate in other organized day programs when they are not working. Another new project is filling a troubling gap in services by assisting young people as they make the transition from school-based programs to supported work.

However, there is a very long way to go in building the program. As of the end of 2005, annual statewide spending commitments for OPTS amounted to \$48 million, of which just \$5 million has gone to organizations in New York City, despite the fact that 31 percent of the state’s residents with developmental disabilities live in the city. These numbers pale in comparison to the state OMRDD’s total

budget of \$2.98 billion devoted to services and housing for New Yorkers with developmental disabilities.

Nonetheless, state officials say they consider OPTS a model for the future planning and funding of services through OMRDD, and the program’s budget is growing quickly (it is \$100 million statewide for the 2006-2007 fiscal year).

Some observers say that OPTS is, in some cases, simply supporting fringe add-ons to people’s regular services, and in others is funding services that could just as well have been funded through more traditional routes. Yet the OPTS program has the potential to support a wealth of person-centered, flexible and creative services. If it is to truly be a model for transforming the system, then officials should be more aggressive in promoting OPTS’ stated mission of creative and individualized services for all those who are eligible and desire them. Innovation itself needs strong champions within OMRDD and the wider advocacy and provider community. And OMRDD needs to provide agencies with hands-on assistance to solve problems and make sure these programs succeed.

THE GOVERNOR MUST ESTABLISH, IMPLEMENT AND ENFORCE POLICIES TO BETTER COORDINATE SERVICES FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES ACROSS MULTIPLE AGENCIES AND SYSTEMS.

Education, employment, family supports and housing often involve multiple state, city and federal agencies and funding sources in the provision of programs and services—and they rarely function smoothly with one another. In housing, for example, New York’s vast, multi-billion dollar community development sector has extraordinarily little involvement with the many agencies that provide community-based housing to men and women with developmental disabilities. Meanwhile, overlapping systems for young people, including special education, youth services and employment supports rarely coordinate and communicate with one another or with the agencies that serve young adults. Leadership from the top of state government could begin to address these flaws, improve services and open up new opportunities for choice. ♦

LIVING THEIR OWN LIVES

Self-directed and individualized supported living is working for people with even severe disabilities, but hurdles are high.

When Diana McCourt gave birth to her daughter, Nina, in 1961, she knew next to nothing about the struggles she would face finding humane and dignified care for her child, who had mental retardation and autism.

As Nina grew up, she moved from private home-care in the New York City suburbs to Willowbrook—the infamous state institution in Staten Island whose closure marked New York’s sweeping shift to community-based care—and then through a series of group homes. Most recently, she has been living in her own Manhattan apartment.

This latest arrangement, McCourt says, has been the most beneficial for her daughter by far. “All the previous situations were so frustrating for her that she acted out, hurt herself or went into her own world,” McCourt says. “Now that she gets to build her life according to her—not what works for the group or what the group can do—she is much healthier and less harm has come to her.”

Nina, whose last name is Galin, is one of just a handful of New York residents with developmental disabilities who live in their own homes, on their own terms, with carefully designed, 24-hour intensive and individualized support services. Several hundred more men and women in the city have some variation of this but with fewer hours of support or less comprehensive services.

The rise of individualized supported living, while still a small part of the total services system for people with developmental disabilities, represents an important shift in mainstream attitudes toward people with disabilities. “It has grown out of the changing perceptions of who people with disabilities are and what is possible for them,” says author and activist John O’Brien, whose Georgia-based consulting firm, Responsive Systems Associates, advises governments and nonprofits about putting supported living into practice. “It’s the difference between living within an arrangement that is tailor-made for you and being placed in a facility of any size where you are just one of a group. It’s the difference between life and treatment.”

Advocates and service providers estimate that between 1,000 and 1,500 New York City residents with disabilities live in two- or three-person residences that comply with the certification rules required for Medicaid-backed supports. Of these, they say that just a small fraction have complex home-care and other full-time services similar to Galin’s. There is no way to tell how many of them have some measure of self-directed care, or hold an apartment lease in their own name. And there

is no data available that differentiates the extent of services people receive in these small, supportive homes.

The large majority of men and women with developmental disabilities who have round-the-clock support staff in New York City live in group homes or larger facilities. According to the state Office of Mental Retardation and Developmental Disabilities (OMRDD), 4,777 men and women live in community-based group residences with day and night staff support in 2005. Another 497 lived with families who receive monthly stipends from the state for providing services.

By contrast, creating more individualized and self-directed home lives is widely considered to be a progressive approach to help people with even severe developmental disabilities devise respectful and more personally fulfilling lives. In setting up such an environment, practitioners begin by surveying a person’s unique characteristics, then build a support system tailored to those traits and to specific goals expressed by the person and their family. Services run the gamut from home-care, cooking and other one-on-one supports to recreation and job placement. Some agencies also focus on community building so that people with disabilities can rely on a circle of family, friends, co-workers and neighbors to provide assistance.

JobPath—a Manhattan-based agency that helps people with developmental disabilities find work and affordable housing—worked with Galin to find an apartment and a roommate, and even to set up weekly swim lessons to fulfill her desire to learn new skills. In her new living situation, Galin’s behavior and outlook have improved tremendously, her mother says. Gone are the self-destructive incidents, such as biting the backs of her hands. Gone are the feelings of confinement she had at her group home because she was often considered too agitated to participate in outings with other residents. Gone is her fear of going outside.

SUPPORTED LIVING IS ONE ELEMENT of the broader independent living movement that emerged in the United States in the late 1960s and early 1970s. Inspired by the civil rights and consumer rights organizing of that era, people with disabilities and their families began to push for services that allowed them greater autonomy and more control over making decisions.

“People started looking at individuals and what made sense for those individuals,” says Steven Taylor, a professor and coordinator of Disability Studies at Syracuse University’s School of

Education. “The agencies I visited in the early 1980s that were doing this solved people’s housing needs and then figured out what other supports they needed. The lease would be in the individual’s name or the name of a family member.”

In New York, people with developmental disabilities who entered the state’s services system before the 1970s “deinstitutionalization” movement were most often confined to large, hospital-like settings that activists and historians describe as little more than warehouses. The Willowbrook State School for the Mentally Retarded on Staten Island, where Galin lived in 1971, became the target of a class-action lawsuit after media investigations uncovered overcrowding, poor sanitary conditions and physical abuse of residents by school employees. Diana McCourt and her husband were lead plaintiffs in the lawsuit.

A settlement reached with the state in 1975 led to improvements at the school, which then housed more than 5,000 men, women and young people. The lawsuit also built support for the shift away from large institutions to community-based care for New Yorkers with disabilities. Willowbrook, then renamed the Staten Island Development Center, closed in 1987 and six other large, developmental centers followed suit by 1992.

Deinstitutionalization sowed the seeds for the broader reforms embodied in supported living. Advocates had long argued that people with disabilities would do better if they were living in community settings among friends, family and people without disabilities. Shouldn’t they benefit even more from living arrangements that put them in closer touch with that community?

But establishing programs and service strategies that truly acknowledge the personal needs and interests of unique individuals requires yet another giant leap. Other states and nations, ranging from Washington to England, have gone further than New York in developing policies and structural supports that enable people with disabilities and their families to live lives they have designed for themselves.

Despite the fact that nearly two decades have passed since innovators in the field began to develop and put in place “person-centered” strategies for services and supports, there is only a small body of research documenting outcomes and nothing in the way of an extensive, control-group research study to compare the experiences of people with substantial disabilities receiving individualized services with those taking part in more traditional, system-based programs.

Yet a number of small studies published in recent years indicate that individualized planning has produced significant improvements in people’s feelings about their own lives, their ability to make choices and achieve their goals, and their willingness and ability to participate in community life and relationships. For example, one highly personalized planning method tested in England found that, after one year in the project, the six participants evaluated were more than twice as likely to achieve the goals they set and to be happier with their quality of

life than they had been at the outset. There is also evidence that outcomes improve simply by taking part in the closer engagement, preferred activities and active encouragement that come with establishing a more individualized lifestyle (see “Resources and Research,” page 17).

Qualitative research has also found that many people with both mild and severe disabilities have experienced positive improvements in their lives after taking part in individualized planning and services, ranging from more pleasant housing situations to feeling more respected and allowed to make choices.

AT ITS CORE, SUPPORTED LIVING is not just about offering services, advocates say, but creating a different relationship between the person with disabilities and the agencies and individuals that assist them. As O’Brien writes in a recent paper on the topic, “Instead of controlling people with disabilities in order to fix (train, habilitate, rehabilitate, treat) them, supported living workers seek to cooperate with people with disabilities in order to develop the assistance they need to get on with their own lives.”

JobPath, for example, follows a person-centered ethos, says Executive Director Fredda Rosen, that emphasizes small living situations of one to two people per residence and involves people with disabilities and their families in decisions about hiring and programs.

While many agencies have incorporated the vocabulary of supported living into their residence programs by emphasizing smaller residences and a wider variety of services, the approach is still far from commonplace in New York. On the continuum of possible residential scenarios, group homes remain the most typical. Despite experiments with state funding of apartment-style living, advocates say it is rare to find situations where people with disabilities have the opportunity or the resources to make choices about their living situations and daily activities.

When it comes to supported living, Taylor says that while people in the developmental disabilities field “agree about a lot of things on a philosophical level,” the practice is a long way from becoming the standard. There are numerous obstacles, he adds, including longstanding agency preferences for putting professionals in charge of decision-making, rather than people with disabilities, and funding mechanisms that favor larger group residences over highly individualized residential programs.

The latter is certainly true in New York, agency leaders say. For one thing, properties owned or leased by nonprofit groups that provide housing must remain occupied—otherwise, revenue from the federal and state governments will not be available to pay the mortgage or rent. If an apartment is held in the name of the person living there—as in Nina Galin’s case—then the funding for her care goes in part to cover her rent to a landlord and has little beneficial impact on an agency’s bottom line.

JobPath receives reimbursement of about \$9,000 per month from OMRDD for clients who live in supervised group residences with round-the-clock support staff, and \$6,500 per month for those in apartments that have less than 24-hour staffing. While the extra funding compensates for the extra staff needed to have three 8-hour shifts, some other agencies have been more inclined to retain the apartment lease themselves and place three or more people together in one apartment, thus achieving economies of scale.

"EVEN THOUGH WE'VE MOVED PEOPLE OUT OF INSTITUTIONS, THERE'S STILL A LOT OF INSTITUTIONAL THINKING GOING AROUND."

Such practices are a source of frustration for O'Brien, who has written about what he calls the "crippling assumptions" that "inmates of facilities deserve much higher levels of per-person expenditures than people who live in their own homes" and "that people who rely on public funds for necessary assistance must be passive and grateful recipients of professional control."

It's also a disappointment for parents like McCourt. "Even though we've moved people out of institutions, there's still a lot of institutional thinking going around," she says. "There's a belief that it's more efficient to deal with people in groups and arrange people's lives for them; a non-belief that people have a right to benefit from having their own lives."

IN RECENT YEARS, OMRDD OFFICIALS have made commitments to expand individualized services through initiatives such as NYS-OPTS (Options for People Through Services) and the state's Self Determination pilot program, which gives people with developmental disabilities direct control over their Medicaid and other public funds designated for services.

And for many years, people with less severe disabilities have been able to live on their own, often in two- or three-person apartments that are visited a few times each week by support staff from a nonprofit provider. In fact, this is the preferred approach to supported living at many of the city's large service organizations.

"Generally, consumers who are high-functioning will be in a supported apartment model," says Margery Ames, executive director of the Inter-Agency Council, a trade group of city-

based providers of services to people with developmental disabilities. "We're holding the lease and making payments to make sure it stays stable, and a direct-care worker usually visits a couple hours each day, when people are home from work or their programs, to check up on them: 'Is everyone home? Has everyone showered? Did someone get the groceries?'"

"A lot of consumers prefer to live in congregate settings," Ames adds. "We tend not to push them out into independent living unless they are asking for it."

But advocates such as JobPath's Rosen believe supported living should be available to everyone, including people like Galin who need round-the-clock care. "Often the people who need it most are the people least likely to be thought of as 'ready,'" she says.

It's not only agencies that are sometimes reluctant to change. McCourt points out that some parents are cautious about placing their children in smaller or individualized living situations. "Parents are worried about their adult kids being alone too much," she says. "With [such] individualized services there's a risk that the person doesn't have friends or anywhere to recreate." But that, she says, is a challenge of education and advocacy, and of designing supports so that men and women with developmental disabilities have opportunities to be with other people on a regular basis.

IN NEW YORK CITY IN 2005, of the 8,934 men and women with developmental disabilities in out-of-home residential settings, 3,453 lived in intermediate-care facilities or institutions, and most of the rest lived in community-based housing. But this includes a wide range that includes group homes for a dozen or more people.

Statewide, the median size of group homes has dropped from about nine residents in 1980 to about five in 2002. Yet the trend toward smaller group homes doesn't always translate to more personal control. In less individualized situations, men and women often spend their lives in very structured routines and with fewer choices about where and with whom they will live.

"The temptation in New York has been to create a big silo and fill it with billions of dollars and say, 'We will take care of you your whole life in one package,'" O'Brien says. "That can be appealing to some family members. What we have discovered is there are quite a number of family members who find alternatives appealing if they don't have to jump through burning hoops to use them."

For many parents, navigating the system and pressing for a new approach is daunting, McCourt says. "People are treated as if they're all the same because they have a developmental disability. That's just looking at the disability and not at the person."

Still, she is confident that supported living will eventually become the norm, just as group homes and other reforms did in the past. "I don't see the leadership really carrying us in that direction," McCourt says. "But it's going that way because people are really fighting for it." ♦

ON THE HOME FRONT

What does supported living look like for one man in Harlem?

En route to the train and a doctor's appointment, Stephen Hernandez and his counselor debate whether they should go to a movie that evening after cooking Hernandez' favorite meal of rice and beans, or watch comedies on television in the Harlem apartment he shares with another man.

Then again, counselor Norma Bernardez suggests, they could put off the theater until the following day after a trip to his favorite restaurant, BBQ. "It depends on what you want to do," she says.

It wasn't always that way.

A decade ago, Hernandez' days were prescribed by a day treatment facility. Back then, agency counselors worried that his tendency to speak with strangers on the street could be perceived as aggression. So they limited his daily activities to the care center before sending him home each night to his father and five siblings. (Hernandez' mother passed away when he was nine.)

Staff at his previous facility wanted Hernandez, who has mental retardation, to conquer his sometimes difficult behaviors completely before venturing into the world outside the center. But at JobPath, which subscribes to the philosophy of supported living, staff members viewed those behaviors as a reaction to an overly circumscribed life. And sure enough, when they began offering him other opportunities based on his interests, such as volunteering and job training, Hernandez began acting out less often.

His family has also noticed a difference. "I see that he has calmed down," says Hernandez' father, Francisco. "He used to give me a crisis when he would go into one of his tantrums. He doesn't do that anymore."

On this fall day there are no confrontations on the trip between JobPath's Midtown offices and Penn Station. And in general, whether he is visiting former co-workers at Riverbank State Park where he used to put away basketballs, or walking dogs as an ASPCA volunteer, Hernandez, now 39, helps his round-the-clock caretakers structure his life more as a partner than a patient.

His experience is still a relatively rare one in New York. It's hard to track the number of people who receive supported living services, since the state does not use that category in statistics it collects about programs for people with developmental disabilities (see "Living Their Own Lives," page 5).

Part individualized service provision and part personal empowerment program, supported living is at the cutting edge of practice in the field of developmental disabilities. Although state officials say it is the direction in which they want all care to go, supported living has yet to replace more traditional models in which agencies decide on daily activities and living

arrangements without much input from clients with disabilities.

Under supported living, by contrast, people with developmental disabilities take part in designing services tailored to their own needs and desires, and have more opportunities to shape their living situations and the simple day-to-day choices that most people take for granted: Where will I live? Will I have a roommate or not? Is it time to move closer to family? Further away? These are the type of questions that give rise to services fitted to each person, rather than trying to fit the person into an institution's routines.

For Hernandez, having a role in directing his activities is a marked contrast to the narrowness of life at his former day treatment program. He now has his own room in a Harlem apartment which he shares with Darryl Crenshaw, who also has developmental disabilities. Their two families met to determine if the roommates would get along, and now each has a wider support system that encompasses one another's parents and relatives.

Hernandez is especially fond of his roommate's mother. On a tour of their fourth floor walk-up, he kisses a picture of her hanging on his bedroom wall. "That's Mama," Hernandez notes with pride.

SUPPORTED LIVING ARRANGEMENTS often pair a person with severe disabilities with someone who is more independent or who does not have disabilities, which further widens their network of supporters and sharpens social skills. Caregivers say Hernandez and Crenshaw are evenly matched and compliment one another. While his roommate is more able to take on household tasks like cooking and washing dishes, Hernandez has better recall of names and faces. Recently, when the two answered the front door of the neat brownstone they call home, Hernandez recognized a visitor immediately and offered a warm greeting, while Crenshaw remembered to close and lock the door.

There are only a few institutional touches in the two-bedroom apartment the two men lease with JobPath as the guarantor. Printed signs list a rotating schedule of caretakers and reminders not to let Hernandez open the door alone or re-hang the mirror since moving it could be dangerous. The household's phone number is writ large above Hernandez' bed on 10 sheets of paper to help him remember it. In the living room, a locked file cabinet with each man's name on a drawer contains records of their care, medicines and money for each roommate and for the household.

Despite a little friendly competition for the attention of a visitor or the support staff, the two men get along well.

“He’s all right and it’s a nice place to live,” says Crenshaw.

“They have their little arguments,” adds Hernandez’ father. “But they do love each other in one way or another and they do get along.”

Hernandez’ rent money comes from his Supplemental Security Income (SSI) payments. Medicaid pays for his support staff and skills training. Once funds are apportioned to rent and staff, any remaining money goes to household expenses—including grocery money, laundry and petty cash for takeout meals and movies. Each man gets a personal allowance of about \$100 per month. Any additional funds that come in, such as Hernandez’ \$11-per-week stipend from work he does at a skills training program he attends during the day, serves as pocket money.

Hernandez has held a range of part-time jobs in recent years, from hanging clothes at K-Mart to bagging groceries at PathMark. He’s currently trying to turn a recent interest in house cleaning into another paid position.

“He’s very capable,” says Bernardez, one of the support staff that provides round-the-clock care and companionship. “He’s able to communicate and has his own will. He told the lady [at JobPath] directly that he wanted to do cleaning work.”

In fact, Hernandez has progressed so far that soon he will be shifting gears again, mixing paid work and group activities

instead of having a personal companion accompany him at all times. “He seemed tired of one-on-one” supervision, Bernardez explains. “We were worried that he’d become socially isolated.”

ON THE HOME FRONT, HERNANDEZ is sticking with the apartment living that lets him enjoy his favorite salsa music, explore the foods he likes and enjoy recreation at the library and local parks. Each morning, he will join a group that travels together to skills training programs and work sites. Then, he will be dropped off at home.

Without a personal companion, Hernandez will have to be responsible for fulfilling all of his commitments. Bernardez is confident he is up to the job. “This way, he’ll learn money management and take the skills he’s been practicing around the house—he likes to clean windows—and put them to use in the work world,” she says.

His family was nervous at first about Hernandez moving into his own place and taking more responsibility for his life. Now, although they miss living with him, they view the changes positively.

“We were looking for a program that would keep him more active,” says his father, Francisco. “In this one, he has dancing classes and gym, so that helps him. He has definitely been progressing.” ♦

INDIVIDUALIZED SERVICES AND SUPPORTS: WHAT THEY ARE AND WHAT THEY ARE NOT

Prepared by the OMRDD Commissioner’s Task Force on Willowbrook, Subcommittee on Person Centered Planning and Positive Behavioral Support, 2006.

Services and supports are individualized if:

1. A person is empowered through advocacy, that is, being his/her own advocate and having his/her own circle of family and friends to determine and promote his/her own personal goals.
2. A person chooses his/her own unique relationships with others. The person selects those who provide direct services and supports.
3. A person lives where and with the people he or she wants to live with (without consideration to others with similar disabilities). In general, the person has significant control over his or her home and living situation.
4. A person works and receives needed services and supports (without limitations related to other individuals with similar disabilities).
5. A person has regular and ongoing community connections and personal relationships.

Services are not individualized if:

1. A person’s personal goals are compromised because the goals, planning, supports, and services must take into account other people with disabilities, thus limiting choices and opportunities.
2. A person’s relationships and opportunities for relationships are limited to those who provide services to a group of which the person is a part or is associated with because of his/her disability.
3. A person’s choices of where and with whom to live are limited to settings established to house groups of people with similar disabilities and depend upon the “acceptability” of the person to the facility or group home. If the factors related to the person’s “acceptability” change, the person may have to move.
4. A person’s choices for work and for services and supports are limited to settings and types of services for people with similar disabilities. These settings may be physically separated from the community at large or may segregate people with DD from those without disabilities.
5. A person’s access to the community at large is limited by the lack of available resources (personal assistance, transportation, etc.), the lack of physical accessibility, and the misguided perceptions of direct support people; or a person’s opportunity for access to the community is limited to “group” trips which stigmatize all involved and constrain any interaction with people in the community.

OPTIONS AND OPPORTUNITIES

A still-modest funding stream could change the direction of services and housing in New York State. How far will the reform efforts go?

Katrina DeBruce was having a hard time finding part-time work she enjoyed. The 51-year-old Brooklyn resident, who has mental retardation, had been working at a local Goodwill Industries store hanging clothes. But when she was nervous or under stress, she had trouble communicating with her supervisor. And her supported work service—a state-funded program that provides job coaches and job placement assistance—kept cutting back her hours.

Still, she wanted a job. “I needed to do something to keep me busy,” says DeBruce, a tall woman with large, dark eyes and a shy smile.

One day, an administrator at CAY Community Services Organization in Downtown Brooklyn, where she takes computer classes, asked her what job she felt most skilled to perform.

“I’m a good cleaner,” DeBruce replied. “I’m a really good cleaner.”

For the first time in her working life, it seems, someone listened. In April, DeBruce began a new schedule at CAY, training for a job as a maintenance worker. She is one of four people with developmental disabilities enrolled in a pilot program that will give participants the personal coaching and equipment they need to find and keep their dream jobs.

Claudia Morgan, CAY’s founder and executive director, says individuals were chosen based on conversations much like the one she had with DeBruce. “We asked people to choose their own job titles,” Morgan says, “And we selected ones we felt were capable of being trained for success.” Other jobs for which people are being coached are receptionist, mail clerk and assistant teacher.

Participants have also helped hire job coaches for the new program, Morgan says, and their families and caseworkers meet regularly with CAY administrators to hammer out details and discuss progress.

This and other projects like it are at the leading edge of a new strategy, launched two years ago by the state Office of Mental Retardation and Developmental Disabilities (OMRDD), which aims to involve people with developmental disabilities and their families in designing their own services. The Brooklyn jobs program is one of dozens of pilot efforts at nonprofit agencies statewide that are funded under the New York State Options for People Through Services initiative (NYS-OPTS).

The state- and federally funded initiative has so far doled out \$137 million in five-year pilot contracts, just a tiny fraction of

the \$2.98 billion OMRDD spent last year alone to provide services and housing programs for New Yorkers with developmental disabilities. That translates to \$48 million worth of annual OPTS funding awarded to date—of which just \$5 million has gone to organizations in New York City, despite the fact that 31 percent of the state’s residents with developmental disabilities live in the city. The statewide annual budget for OPTS is growing quickly, however, and is \$100 million for the 2006-2007 fiscal year.

OPTS is closely watched by advocates for people with disabilities who want more consumer voices and person-centered planning instilled in the state’s vast system of programs and services—exactly the principles OPTS was set up to support, and which state officials describe as central to their vision of the future. OMRDD leaders hope this pilot project will eventually become the standard mode of operation.

“The intention is for this to be systems transforming,” says Gary Lind, the agency’s director of policy, planning and individualized initiatives, who helped design OPTS. “It is not meant as a sidelight. OPTS is the mechanism to get us systemically to the next level.”

Currently in New York, most men and women with developmental disabilities are not yet covered by programs funded by OPTS. Instead, they take part in a more traditional set of services offered by nonprofit agencies. Families must shop around for what’s available in their area and request services either directly from OMRDD or through a local government or nonprofit agency. The state’s Medicaid waiver, which allows eligible individuals to use federal Medicaid money for services in community settings, has introduced a larger degree of flexibility and choice in recent years. But people with disabilities and their families still have very little voice in what services look like or how they are provided.

By contrast, OPTS aims to encourage nonprofit agencies to work directly with consumers and their families to create services that meet specific, individual needs rather than the broad-brush requirements of the population with disabilities. To qualify, service providers must show that consumers are involved in all stages of program planning and evaluation.

“It’s the vision itself that’s important,” says Mary Ellen Tegmeier, a parent representative on the statewide OPTS Steering Committee created by OMRDD to help monitor the program. “It’s the fact that this is possible.”

BY THE END OF 2005, OMRDD had approved 68 OPTS proposals serving more than 5,000 men and women with developmental disabilities statewide. The scope of the projects ranges

"THE INTENTION IS FOR THIS TO BE SYSTEMS TRANSFORMING. IT IS NOT MEANT AS A SIDELIGHT. OPTS IS THE MECHANISM TO GET US SYSTEMICALLY TO THE NEXT LEVEL."

from serving one individual to more than 300, and they include a wide array of services, from housing to higher education to help with transitioning from school to work.

Many of the approved proposals are designed to test new ideas. In upstate New York, for example, a nonprofit agency teamed up with Syracuse University to offer six young people with autism and other complex disabilities the opportunity to take part in campus life. Participants receive tuition discounts, transportation and one-on-one coaching while they take college classes for the first time. Another project, in the Finger Lakes district, will help people with developmental disabilities set up "future care plans" to be used in the event of a family crisis. And in the Taconic district, a young man with behavioral difficulties who is graduating from school will have support to find daily activities connecting him to his community.

Peter Smergut, executive director of Life's WORC (Working Organization for Retarded Children and Adults) on Long Island, has received funding to offer 24 children with developmental disabilities an after-school music and art program. He says OPTS pushes agencies to be more creative. "The biggest difference is, in the traditional marketplace, you apply for things that the state funds and vie with your colleagues for a piece of the pie," he says. "With OPTS, you come up with an idea for an appropriate activity," and it is funded or not based on its merits.

While the OPTS vision of consumer and family involvement is ambitious, many of the newly funded programs represent only modest changes from more traditional services. More than one-quarter of the proposals approved by the end of 2005, for example, were for downsizing existing group homes to smaller-scale living arrangements—a shift that may offer people with disabilities more options but is not all that forward thinking.

"Some of the proposals, you sit back and wonder, 'Why didn't we do that with the funding we already had?'" says Ann Hardiman, executive director of the New York State Association of Community and Residential Agencies (NYSACRA), and a member of the OPTS Steering Committee.

In some cases the changes are at the margins, representing an increase in consumer involvement in some decisions. On Staten Island, a parent who wanted more life-skills training for her teenage son inspired a local agency, Lifestyles for the Disabled, to seek funding for a once-a-week activities program for 24 students from the nearby Hungerford School. The program, which has been up and running for nine months, aims to ease the students' transition from school-based programs to adult day activities after they graduate. In the past, school staff designed the activities, but now that's largely up to the students, says Kevin Joyce, Lifestyle's OPTS director.

"Consumer input has become a big part of the program," Joyce says. "It's a priority. We want to know what the students want to do and where they want to go."

If OPTS is to become a blueprint for the future, traditional agencies will need to be encouraged to think more creatively, says Pat Fratangelo, executive director of Onondaga Community Living, which is in the final stages of securing approval for the project at Syracuse University. "OPTS has the possibility for some unique things to happen but there is also the great possibility for the same old things to happen," she says. "It depends on the mindset of the agencies."

Part of the problem is inherent in the larger Medicaid funding structure, says Janice Fitzgerald, executive director of Parent to Parent of New York State, an advocacy and support group for parents of children with special needs.

"What is the agencies' motivation for changing the way they are operating now?" Fitzgerald asks. "The present funding system is unlimited in duration and if a person with a disability no longer wants services, then the funds stay with the agency to serve another individual of the agency's choosing."

The OPTS program is structured very differently. Funding is provided to agencies under five-year contracts. On the other hand, OPTS offers agencies more flexibility, providing funding for services they can't always support within existing budgets and allowing for the mixing of services in ways that are often difficult under the current system.

The new jobs program at CAY Community Services, for example, blends so-called "day habilitation" and supported work services for a more seamless package of assistance. Such blending is possible but very difficult, state officials and agency leaders say, under Medicaid-waiver rules that segregate funds for services such as skills training and job placement.

For Katrina DeBruce, the program means she'll be trained to do the same job her father did before he died. "My dad used to do cleaning," she says. "I'm going to follow him." Her previous

work experience was limited to babysitting and her job at the Goodwill store. In April, DeBruce began working with a new job coach at CAY to learn the tasks required of professional maintenance workers and hone her interview skills. When she is ready, CAY will help DeBruce apply for maintenance worker positions and also provide some of the supports she might need to stay on the job once she is hired.

Another woman in the program has always dreamed of finding a job as a receptionist, says Executive Director Morgan. But the only work experience she has received through her existing supported work service is as a volunteer at an agency for people with disabilities. Another young man, who is in a wheelchair, wants to work as a telephone operator and will require special equipment to do so.

The \$180,000 OPTS project will provide participants with whatever assistance they need to find jobs in the community, Morgan says, without her agency having to face programmatic or funding barriers. The size of the OPTS grant is comparable to other programs CAY offers, but it will be the nonprofit's first "one-on-one" program designed around individual needs.

ALTHOUGH MOST OPTS PROGRAMS are just getting off the ground, there are some hints at how the initiative might help spur broader changes in the system. One groundbreaking effort cited by OPTS backers is a residential program that began

in December at the Rensselaer County chapter of NYSARC (formerly the state Association for Retarded Citizens) near Troy.

Two years ago, families of people receiving services at the agency began to talk about how to fulfill their loved ones' wishes to live in smaller group homes or on their own.

Taking up where that initial planning left off, ARC's \$1.5 million OPTS grant will pay for a new support network of live-in managers and "paid neighbors" who will help a dozen residents with disabilities live more independently. One person might want a live-in manager to help with daily chores and activities, while another might prefer a "paid neighbor" who does not share their residence but who lives nearby and can be called on for help. Eventually, ARC hopes to expand the service to 20 people.

Hanns Meissner, chief operating officer of the Rensselaer ARC, says what's really different about the pilot is the degree of control it gives participants over such things as staff hiring, residence design and performance review. Parents now sit on a mini-governing board for the residential program. "The OPTS proposal really heightened the partnership between family and provider," he says.

Meissner points out that his agency was primed for OPTS because it had already been moving in a consumer-friendly direction. The program made possible a vision he and his colleagues had been pursuing for years—and brought in some added administrative funds for his agency, which he says had long been "thinly administered."

NEW YORK CITY SLOW TO ADOPT OPTS

While the number of OPTS applications has been steadily increasing—the total hit 295 in March—even supporters say the initiative has gotten off to a slow start and needs to be more widely publicized.

Participation remains uneven. The number of applications from New York City, for example, has been strikingly low. Minutes from a November 2005 OPTS Steering Committee meeting showed OMRDD's Metro New York district had submitted only 11 OPTS proposals by that time (with only one approved), compared to 27 from the Hudson Valley. The amount of OPTS money so far allocated to the city—\$5 million this year—has been minimal compared to funding in other parts of the state.

Agency leaders and OMRDD officials cite the size and complexity of New York City's services system as the major obstacle, and point out that more OPTS applications from the five boroughs are now in the pipeline.

Part of the hesitancy about submitting proposals, says Lisa Persante, OPTS liaison for OMRDD's Metro District in New York City, is a lack of familiarity—especially among more traditional service providers—with the principles of person-centered planning. "A lot of agencies are just not aware of how to do that," she says.

Pat Fratangelo, executive director of Onondaga Community Living in upstate New York, also sees resistance in some quarters to the way OPTS requires agencies to work with consumers and families. "Providers are not used to the kinds of checks and balances they have with this," she says. "If the agencies have only done the same old type of four-wall business and that's all they know..." She lets her trailed off sentence sum up her point.

Kathleen Broderick, associate commissioner of OMRDD, warns that, on its own, the number of OPTS applications submitted doesn't tell the whole story. "Some agencies saw OPTS as a new way of doing business and put forth proposals *en masse*," she says. "What became apparent was that they had not really reached out to individuals and families. It took us a while to clear those [applications] out."

When asked specifically why the response to the program in New York City has been slow compared to other areas, Broderick says, "The sheer volume [of people served] and the very tight environment in New York City make it difficult. We have over 300 agencies in the city. Trying to make sure each and every one is up to speed is a challenge."

"SOME OF THE PROPOSALS, YOU SIT BACK AND WONDER, 'WHY DIDN'T WE DO THAT WITH THE FUNDING WE ALREADY HAD?'"

Asked what advice he would give to others who want to submit OPTS proposals, Meissner says, "People have to start with themselves. What is your relationship with families? What is your motivation for doing this? I've seen OPTS proposals that aren't that different from what exists now. I think people should be looking at this as an opportunity to experiment in a safe way."

IDEALISM IS ONE ELEMENT OF the OPTS equation. Another is fiscal pragmatism. For state officials, the program is part of a larger strategy to maximize the flow of federal Medicaid funding to community-based services.

With OPTS, the state's OMRDD assumes the central management role now played by nonprofit providers. "The provider bills us and we decide what gets billed to Medicaid," says James Moran, OMRDD's deputy commissioner for administration. "It relieves the provider of that responsibility so they can focus more on the programmatic side." What's more, in some instances, depending on the services involved, the state receives a higher federal reimbursement rate than nonprofit agencies.

OPTS is not limited only to people who are eligible for Medicaid, but "obviously it's an advantage for us because it stretches the dollars further since we can draw in federal partnership," Moran explains.

The OPTS model can help shift Medicaid dollars to services consumers truly want, OMRDD officials say, while giving agencies more flexibility in providing them. But while they welcome more flexibility with Medicaid funding, some nonprofits are wary of the way OPTS centralizes control in Albany, says Hardiman of NYSACRA, which has been surveying provider opinions about OPTS for the state.

"There's some concern about the fact that this is a contract approach. OMRDD gets the money and gives it to the agencies," says Hardiman. "In tight times, providers might not get what we expect now from Medicaid. So there's some insecurity" about taking a chance on a new program whose finances are controlled by the state.

Nonetheless, more agencies are trying. By the end of March 2006, the number of approved OPTS proposals had climbed to 79, including two more in New York City. But while OPTS sup-

porters are confident that interest in the program is growing, some challenges remain. The application process, though streamlined, is still complex, agency leaders say. Program evaluations, which are built into the OPTS proposals, have not been in place long enough to produce results.

And on the federal level, continuing threats of Medicaid cuts have families and nonprofit agencies nervous about taking risks. The Bush administration's 2006 budget proposal to cut \$37 billion from Medicare and Medicaid did not survive in Congress, though the final budget resolution enacted earlier this year included \$26.5 billion worth of Medicaid cuts over 10 years, according to the Washington, DC-based Center on Budget and Policy Priorities. Regulatory changes proposed in President Bush's 2006 budget—including limiting Medicaid payments for prescription drugs, community-based services and other services vital to people with disabilities—are still being considered by Congress. In addition, the new Deficit Reduction Act, signed into law in February, tightens some eligibility rules for Medicaid. Finally, a federal Medicaid Commission is due to make recommendations at the end of this year that may result in legislative action in 2007.

Despite these uncertainties, OMRDD officials believe OPTS may actually help strengthen the state's position as far as Medicaid spending is concerned.

"The issue of what's going to happen with Medicaid is always a concern, whether it's OPTS or not," Moran says. "But once you get families involved on the ground floor, no one is more powerful than that. It's going to be hard to say we shouldn't have those services."

OMRDD officials liken the rollout of OPTS to the start of the state's Home and Community-Based Services waiver in 1996. When it began, many people were skeptical that providing services in the community could become the standard, given the entrenched practice of providing them in institutions. By funding more programs in the community, the waiver made that shift possible.

"It takes time for the comfort level to increase," says OMRDD's Associate Commissioner Kathleen Broderick. "Now that we have stuff up and running under OPTS, it becomes more concrete. That's how it becomes systematized."

Ro Vargo, whose 25-year-old daughter, Rosalind, was the inspiration for the OPTS campus program in Syracuse, agrees. "It would be nice if we could translate this so that others could do it too," she says. "Right now, it's a few people taking the first steps."

What keeps her hopeful about OPTS is the conviction that it is moving the system in the direction it needs to go.

"Our proposal reflects a broad range of limitations and desires. It isn't a cookie cutter document," Vargo says. "Right now, there are so many rules and regulations and you can't go outside the boundaries. But things are changing. People are dreaming more. And that's what OPTS is about." ♦

EMPLOYED, FOR A CHANGE

Working for a wage can be uplifting, but there are systematic barriers to supported employment.

Christopher Degoski is a burly young man with dark hair and dark brows that knit together when he is concentrating. The 24-year-old Queens resident is fascinated by languages and can speak a smattering of Spanish, Russian and Chinese. When he is frustrated or tense, Degoski, who has autism, tends to curse. He also dislikes sitting still for long periods.

His family worried that finding a job would be difficult. Yet for the past year, Degoski has been working for FreshDirect on a loading dock in Long Island City. Two mornings a week, he hauls boxes at the food company's warehouse, where he is surrounded by other men who can handle heavy lifting, speak different languages—and do their share of swearing.

"He fits right in," says Joshua Skolnick, coordinator of community-based initiatives for The Shield Institute, the agency that placed Degoski at FreshDirect and provides him with a job coach who helped with on-site training and now accompanies Degoski to work each week. Job coaches are a standard feature of what is formally known as "supported employment" services.

The Flushing-based Shield Institute runs a school for young people with developmental disabilities and, as part of their training, helps set up part-time jobs for students at companies such as Old Navy, Strawberries and Xerox. In addition, a three-year grant from the FAR Fund has allowed the Shield to hire job coaches, pay stipends and provide other assistance to young adults such as Degoski, who need ongoing support in the workplace.

Last year, the organization placed 37 men and women in jobs alongside people without developmental disabilities. Skolnick says the success of such programs relies on finding openings that correspond to individual temperaments and abilities. "In a lot of places, a group goes out to one job site that may not match everyone's interests," he says. "I've worked at places where they say everyone has to go to McDonald's and flip burgers. But who says I have to go there to know that's not what I want to do? We do person-centered planning that asks, 'What do you like? What are you good at? What do you need around you?'"

Degoski's job coach, Wayne Bramble, helps break down tasks into manageable parts and describe the young man's likes and dislikes to new co-workers. "I explained he wouldn't be working at the same pace," Bramble says. "And I talked about the nature of Chris and some of the things he doesn't appreciate, like being tapped on the back of the shoulder."

The Shield doesn't shy away from placing even young people with complex disabilities in job settings in the community. "We

don't have a readiness model. Nobody is ever 'ready' to go out," Skolnick says. "You either support someone so they can be successful out there or you don't."

SUCH PROGRAMS FOR MEN AND women with developmental disabilities are rare in New York City. Despite advocates' and policymakers' growing emphasis on supported work, individual job placements have not yet caught up with the traditional model of sheltered workshops, where people with disabilities work in groups on piecework contracts, or with the popular non-work day programs offered by many nonprofit agencies in the developmental disabilities field.

Planning documents at the New York State Office of Mental Retardation and Developmental Disabilities (OMRDD) show there were 1,934 people with developmental disabilities enrolled in supported employment programs in the five boroughs as of January 2005, down from 2,306 four years earlier.

By comparison, 2,561 city residents were enrolled in sheltered workshops and 10,071 were enrolled in day treatment, day training and "day habilitation" programs that do not involve paid work.

OMRDD officials say statewide trends show a continued decline in participation in sheltered workshops and a steady rise in supported employment—an evolution that many families and advocates for people with disabilities have encouraged. The agency's most recent five-year plan notes that workshop enrollments statewide dropped from a peak of 17,991 in 1990 to 12,267 in 2004, while supported employment rolls grew from around 4,000 to 8,268 during the same period.

Officials attribute the recent decline in supported employment participation in New York City to an administrative transfer of several hundred participants to a program run by the state's Department of Education. (When these people are taken out of the tally, enrollment shows a slight increase.) The Vocational and Educational Services for Individuals with Disabilities (VESID) program is essentially the gatekeeper for government-funded supported employment in New York, and is funded almost entirely with state tax dollars. The Supported Employment Program administered by OMRDD serves men and women with developmental disabilities who qualify for federal support under a 10-year-old agreement with Washington, the Home and Community-Based Services Medicaid waiver (see "A Fragmented Work Support System," page 16).

No one says that finding and keeping a job is easy for people with developmental disabilities, or for the organizations that support them in their workplaces. Nonetheless, some in the field say they are disturbed by the recent stagnation of OMRDD's supported employment program. "In the last couple of years, the folks who want to be outside the workshops are finding they need more supports," says Tom Hughes, associate executive director of Westchester ARC, who is active in the New York state chapter of the Association for Persons in Supported Employment, an education and advocacy group. "The challenge is to recognize that placements have dropped and providers are hitting the wall. Right now, VESID is more active on supported work than OMRDD. OMRDD is dropping the ball on this."

ONE BIG PART OF THE PROBLEM, supported employment advocates say, is that there are not enough financial incentives for nonprofit agencies to encourage people with disabilities to take part in work programs. Under New York's Medicaid waiver, OMRDD pays lower rates to agencies for coordinating supported work than for providing other day programs, such as recreation and skills training programs in community centers.

OMRDD's planning documents show that the reimbursed annual cost per person for these "day habilitation" programs in New York County, for example, was \$21,836 last year, while the cost for supported employment was \$6,112. (VESID, which is where supported employment starts, pays even less. William Deschenes, VESID's director of operations support, says the agency pays only about \$2,500 per person per year at the highest level of need).

Deborah Sturm Rausch, a spokesperson for OMRDD, says rates for different services are based on how intensive they are and on how great the demand is from consumers. "Under day-hab, the rates have to be higher because you're dealing with more intensive needs," she says. "Activities, for example, can include socializing, communications skills, personal hygiene and one-on-one intensive care."

But not everyone believes the current funding methods make sense—particularly if the goal is to get more people employed in community settings that require concentrated supports.

"There's a feeling that job support shouldn't be as expensive because it doesn't require an actual building," says Skolnick of the Shield. "But it really should be reversed. Work should be supported at the highest level."

Peter Smergut, executive director of Life's WORC (Working Organization for Retarded Children and Adults) in Garden City, Long Island, says his agency doesn't do supported work because "at the end of the day, it's a tough model to work out financially. The rate that's used and the [staff] requirements of folks when they first get into new jobs can be demanding."

Yet research by the Institute for Community Inclusion at the

University of Massachusetts Boston, has found that people with disabilities who have been placed in competitive job settings earn more money and have more chances for community interaction than people in sheltered workshops. (The ICI has been conducting national surveys of community rehabilitation providers to track the nature of services offered to people with disabilities. For details, go to www.communityinclusion.org.)

And there are other benefits.

Since he started working at FreshDirect, Degoski's mom, Cynthia, says her son has been more content. "He feels he's accomplished something," she says. "He gets morose when he's not active. On the days he works, he comes home tired, dirty, happier."

"THERE'S A FEELING THAT JOB SUPPORT SHOULDN'T BE AS EXPENSIVE BECAUSE IT DOESN'T REQUIRE AN ACTUAL BUILDING. BUT IT REALLY SHOULD BE REVERSED. WORK SHOULD BE SUPPORTED AT THE HIGHEST LEVEL."

STEPHEN TOWLER HAS BEEN DOING job development for the Association for the Help of Retarded Children (AHRC) for two decades, since about the time the concept of supported employment was introduced.

Before that, job opportunities for people with disabilities were limited to workshop settings, with nonprofit agencies subcontracting with private firms for piecework rates. But under pressure from families and advocates, jobs in the community became an option. A 1986 amendment to the federal Rehabilitation Act defines supported employment as work that takes place in "competitive settings" where people with disabilities work alongside employees who do not have disabilities, supported by job coaches or special equipment.

AHRC most often sends clients with disabilities out to "enclaves" where they work in groups for employers such as Red Lobster. Towler, who is the organization's director of employment and business services, says in recent years he has reduced the size of those groups and does more individual

placements for the approximately 100 adults in the program.

One thing that hasn't gotten any easier in 20 years, however, is finding companies willing to make those hires, says Towler. "Marketing is a big part of the job, getting employers to buy in. Right now, with the increase in the minimum wage and the huge push for welfare-to-work programs, there is a lot more competition" for entry-level jobs.

Similar problems are cited by other provider agencies and experts who say outsourcing, automation and the growth of low-wage service positions—many of which lack health benefits—are making it harder for workers with disabilities to get hired and stay employed.

Some nonprofit leaders worry the economic squeeze means future job opportunities will be limited to people with mild disabilities who are easier to place and easier to support.

Indeed, employment rates for people with disabilities have been dropping nationwide, while poverty rates have climbed. "People with disabilities were the only group whose labor force participation declined in the 1990s," says Andrew Houtenville, senior research associate at Cornell University's Employment and Disability Institute. A report released by the institute last fall shows the drop is continuing, and that New York mirrors national trends. Using data from the Census Bureau, researchers found that the employment rate for New Yorkers with all kinds of disabilities fell from 35.4 percent in 2003 to 34 percent in 2004.

CHANGES IN FEDERAL AND STATE regulations dating to 1999 make it easier for people to earn money while also receiving disability benefits, yet providers say many families still mistakenly fear that part-time work will threaten cash payments or Medicaid eligibility.

In fact, says Dwayne Mayes, benefits advisor for the City University of New York's Youth Transition Demonstration Project, a person who lives alone and is entitled to full Supplemental Security Income (SSI) benefits in New York can earn up to \$1,465 per month before "zeroing out" of cash benefits, assuming there are no additional exclusions being applied to their earnings. In some cases, a person can earn tens of thousands of dollars annually and still be entitled to Medicaid, even if their SSI benefits are stopped under Earned Income rules.

Yet Mayes, whose pilot research project aims to better inform a group of teenage SSI beneficiaries in the Bronx about available benefits, says lingering "myths" about the program and concerns about losing cash payments remain a major obstacle to people seeking work.

Hughes, of Westchester ARC, says non-work programs also have a strong appeal to many families. "If you are a parent and have a choice of this exciting program that doesn't have the stigma of a work center or the risks of a job, you'd choose that," he says. "So one of the struggles going on is upholding the value of work."

A FRAGMENTED WORK SUPPORT SYSTEM

In New York City, the number of people enrolled in the state Office of Mental Retardation and Developmental Disabilities' supported employment services program has grown only slightly from 1,626 in 2001 to 1,667 in 2003 to 1,747 in 2005. Funding and oversight have shifted in the past decade, with responsibilities now divided between OMRDD and the state Education Department's Office of Vocational and Educational Services for Individuals with Disabilities (VESID).

The two agencies, VESID and OMRDD, have different eligibility requirements and funding streams. Ultimately, they also serve different populations. OMRDD's employment program is reserved only for people with developmental disabilities, while VESID's programs are open to people with varied physical, mental and developmental disabilities.

Nonetheless, since 1991, VESID has been the gatekeeper for supported employment programs, providing front-end training and placement services for high school students and adults. Only after it has been determined an individual does not meet VESID's qualifications for having a "reasonable chance of success" on the job can that person apply to OMRDD for support.

Federal education funds for VESID's program, which must be renewed each year, are not nearly enough to cover the program's scope. William Deschenes, VESID's director of Operations Support,

says federal education funds made up only \$1.8 million of the agency's \$41 million supported employment program budget in 2005. The bulk of the remainder came from the state. Last year, VESID served just over 1,000 people in intensive supported employment in New York City out of 3,000 statewide.

In 2002, OMRDD reorganized its supported work program from a contract basis to a fee-for-service model funded under the state's Home and Community-Based Services Medicaid waiver. The waiver allows individuals to use Medicaid dollars to pay for services in community settings—money that previously would have been available only if they were living in an institution. Supported employment services are now part of the menu of items that qualified individuals can choose to fund under the waiver.

OMRDD officials say the change was made in order to extend supported work services to more people. But while they welcome expansion of waiver services, some agency leaders say the new fee structure has also increased red tape. And although OMRDD's efforts are by all accounts geared more than in the past toward work in settings integrated with people who don't have developmental disabilities, some advocates question whether the movement toward individualized jobs has been all that steady.

Skolnick sees that value as greater independence and stronger support networks for people with developmental disabilities. His sentiments are echoed by Barbara Shay, assistant director of Community Employment at the Queens Centers for Progress. “When OMRDD set up dayhab, they talked about it being a stepping stone” to work, says Shay, a longtime advocate for more jobs in integrated settings for people with disabilities. “But to me, it seems more like retirement. If someone doesn’t have a real push to get out there and earn money while they are in their 20s, it’s not going to happen.”

WHAT WILL HAPPEN TO CHRIS DEGOSKI remains a question mark. He had begun working an additional day each week at FreshDirect before some difficulties with his medication

required a hospital stay. But he is now out of the hospital and Skolnick says FreshDirect is holding the warehouse job open for him. With the agency’s grant-funded work program coming to an end, counselors are also helping the young man find permanent job supports through VESID. Another possibility is the state’s Self Determination program, which enables people with developmental disabilities to create individualized budgets for services provided by OMRDD—including employment services.

“One way or the other we’re going to make this happen,” Skolnick says.

Degoski’s mom says he has been saving portions of his \$7-per-hour paychecks to fulfill one of his dreams—travel. She’s happy his first job has worked out, but she’s not surprised.

“If people would just give them a chance,” Cynthia Degoski says, “these children would be capable of so much more.” ♦

RESOURCES AND RESEARCH

on self-directed services, public policy and reform

NONPROFIT POLICY and ADVOCACY ORGANIZATIONS:

Association for Persons in Supported Employment, Richmond, VA, 804-278-9187, www.apse.org. A membership organization that works to expand job opportunities in competitive settings for people with disabilities.

Center for Independent Living, Berkeley, CA, 510-841-4776, www.cilberkeley.org. An organization run by and for people with disabilities that advocates for greater participation in community life.

Disability Policy Collaboration, United Cerebral Palsy, Washington D.C., 800-872-5827, www.ucp.org/ucp_general.cfm/1/8. A political lobbying effort between UCP and the ARC of the United States that seeks better laws and services for people with disabilities.

New York State Association of Community and Residential Agencies, Albany, NY, 518-449-1509, www.nysacra.org. A nonprofit representing agencies that provide community living services and other assistance to people with disabilities.

New York Association on Independent Living, Albany, N.Y., 518-465-4650, www.ilny.org. An education and advocacy group that works to raise awareness and support for the concept of supported living for people with disabilities.

Parent to Parent of New York State, Schenectady, NY, 518-381-4350, www.parentoparentnys.org. An education and support group for parents of children with special needs in New York.

Self Advocacy Association of New York State, Albany, NY, 518-382-1454, www.sanys.org. A grassroots organization run by people with developmental disabilities that advocates for person-centered services and supports.

RESEARCH ORGANIZATIONS:

CUNY Youth Transition Demonstration Project, New York, NY, 646-344-7315. A pilot research project affiliated with the John F. Kennedy Jr. Institute for Worker Education at City University that assists young people and their families with unemployment and benefits issues.

Employment and Disability Institute, Cornell University, Ithaca, NY, 607-255-5702, <http://edi.cornell.edu> and www.disabilitystatistics.org. A research and training institute that focuses on improving the lives of people with disabilities.

Institute for Community Inclusion, University of Massachusetts, Boston, 617-287-4300, www.communityinclusion.org. A research and educational organization that advocates for self determination for children and adults with disabilities.

IMPORTANT REPORTS, BOOKS and ARTICLES:

The Five Year Comprehensive Plan for the Period 2006-2010, The New York State Office of Mental Retardation and Developmental Disabilities (OMRDD), March 2006. The document describes OMRDD’s policy and program agenda and provides useful insight into agency leaders’ vision for the future.

The State of the States in Developmental Disabilities, 2005, by David Braddock, Richard Hemp and Mary Rizzolo. Department of Psychiatry and Coleman Institute for Cognitive Disabilities, The University of Colorado. An earlier edition is available online at www.cu.edu/ColemanInstitute/stateofthestates/index.html.

“History of Independent Living,” by Gina McDonald and Mike Oxford, posted on the Web site of the Access Center for Independent Living in Dayton, Ohio, www.acils.com/.

Person-Centered Planning: Research, Practice and Future Directions, edited by Steve Holburn and Peter M. Vietze. Baltimore: Paul H. Brookes, 2002. Excellent collection of articles by scholars, practitioners and advocates exploring the philosophy, implementation and impact of individualized and self-directed services.

“The Willowbrook Futures Project: A Longitudinal Analysis of Person-Centered Planning,” by Steve Holburn, John W. Jacobson, Allen Schwartz, Michael Flory and Peter Vietze. *American Journal on Mental Retardation*, 109:1 pp.63-76, January 2004.

The Impact of Person-Centred Planning. London: Foundation for People with Learning Disabilities, July 2005, available online at: www.learningdisabilities.org.uk/

“Down Stairs That are Never Your Own: Supporting People With Developmental Disabilities in Their Own Homes,” by John O’Brien. *Mental Retardation*, 32:1 pp. 1-6, February 1994.

Celebrating the Ordinary: How Options in Community Living Emerged as a Thoughtful Organization, by John O’Brien, Connie Lyle O’Brien and Gail Jacob. Toronto: Inclusion Press (www.inclusion.com), 1998.

RECENT POLICY STATEMENTS

“Searching for New Solutions: Think Tank Recommendations for the NYCRO Region,” a policy statement available from the Self Advocacy Association of New York State, offers a 10-point summary of key system reforms that would strengthen and expand access to self-directed, individualized supports for people with developmental disabilities in New York City.

“Recommendations for Self-Directed Housing and Supports,” presented to OMRDD Commissioner Thomas Maul by the Commissioner’s Task Force on Willowbrook, January 18 2005. A document asserting the need for more intensive investment in individualized housing and supports and a plan for key reforms, written by the longstanding committee of parent and self-advocates who are veterans of the fight to close Willowbrook. Available from Dixie Blood, Willowbrook consultant, at JDixie@aol.com.

BUILDING A REAL LIFE

Viewpoint: Janice Fitzgerald's son breaks the boundaries of "special" services.

When my son, John, was 6 months old, he became very ill and soon began having seizures and losing developmental milestones he had previously achieved. In the hospital, physicians diagnosed him with infantile spasms, a rare and violent seizure disorder. We brought John home on Christmas Eve of that year, 1985, not knowing what his future would hold. We weren't sure he would survive.

He did, and with medication the seizures stopped. But it was soon clear that he had developmental disabilities and sensory and vision impairments. Early on, we felt fear and dread that our baby's life would not be that of our other two sons. We had seen how individuals with disabilities were treated, first by the medical community, then in school and eventually by the community: isolated in school and isolated in their living arrangements. This was not a world we wanted to be part of.

Sure enough, after John's hospital stay, our family was quickly catapulted into the not-so-special world of "special" services and "special" education. When a family enters this world, it often means an exclusion from everyday life.

Gone are the days of little league, birthday party invitations and neighborhood friendships. Gone also for many parents is the ability to work, because of the overwhelming medical needs of their child and the difficulty finding adequate child care. When a family's income and earning power are diminished, a downward spiral often occurs.

New York succeeded long ago in fashioning lives for most people with developmental disabilities outside of large institutions. Yet our society has barely attempted to get past flawed assumptions about these men, women and children: assumptions that their every minute needs to be provided for, guided and ensconced in a system of social services, special education and housing that is almost entirely beyond their control. Our family has learned over the years of John's life that there is a much more rewarding way, rooted in respect for the passions and skills of people with disabilities, to build a real life for all of us.

When John was a youngster, his behaviors were a challenge to be around. Between the ages of one and five, he had an attention span of less than 10 seconds. He had no concept of danger and required constant and intensive monitoring.

During those years, we were trying to be good parents to John's two older brothers. We didn't want to fall into the trap of isolation and bring them with us, so for several years we were a house divided, with one parent staying home with John, and one parent going to school functions, Scout meetings, parties or picnics with the other children.

We were fortunate to be able to work with nonprofit agencies that supported our family with services like respite care, which sent a trained worker to our home to watch John for part of the day. Since 1996, these and other services have been paid for by the state's Home and Community-Based Medicaid waiver, which enables people with disabilities to receive services even if they don't live in large skilled-nursing institutions.

John started to talk when he was five and, eventually, he learned there were consequences to his behavior and privileges to be earned when he behaved well. He learned to ride a bike and to ski at eight.

But it wasn't always easy for him. I recall a high school transition planning meeting, where a teacher suggested that John go to bingo for recreation and socialization. What made her think he would want to do that? There was a great Celtic music concert that very night and John loves Celtic music. Was it a stereotype about people with disabilities that caused this teacher to overlook his true interests?

John thrived when services and school focused on his interests. He was a Boy Scout for many years and did very well, thanks to one-on-one support provided through the Franklin County ARC. He also learned to run errands, buy a slice of pizza after school, count change and calculate a tip. Being involved in community activities has widened his circle.

Today, at 21, John is a responsible citizen who enjoys working hard and continues to learn and mature. With the help of a job coach, he worked part-time last summer at the Olympic Center in Lake Placid on the maintenance crew.

This month, John will have completed a two-year, post-high school certificate program in culinary arts. The challenges continue. He hopes to find work that moves from menial to meaningful, as well as services provided by people who will support and believe in his abilities.

I want John to be happy, to have friends, to be valued, to have an education, a job, to be free from ridicule and abuse, and to have a life of his own rich with relationships and love. Service systems, while helpful and necessary, do not provide these things. They do not keep people safe—this was proven with the institutions of a generation before us, like Willowbrook—nor do they create relationships. Only other people can do that.

Janice Fitzgerald is executive director of Parent to Parent of New York State, a support and advocacy group for parents of children with special needs. She lives in Lake Clear, New York.

WATCHING THE NUMBERS

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

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

MEDICAID HOME AND COMMUNITY-BASED SERVICES (HCBS) WAIVER

ENROLLEES	8,751	11,284	12,687
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The HCBS waiver 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 five years.

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
Community Residences (CRs) are state-licensed group homes and apartments operated either by the state OMRDD or nonprofit agencies.			
• CR SUPERVISED	304	276	240
Support staff are on duty 24 hours per day.			
• CR SUPPORTIVE	254	228	206
Support staff are on duty less than 24 hours per day.			
• IRA TOTAL	3,361	4,069	4,331
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
Support staff are on duty 24 hours per day.			
• IRA SUPPORTIVE	497	578	615
Support staff are on duty less than 24 hours per day.			
• FAMILY CARE	555	528	497
Residents live with families who receive monthly stipends from the state for their services.			
• INDIVIDUALIZED SUPPORT	157	176	207
Housing assistance, including rent subsidies, for individuals who live in homes and apartments that are not state-licensed. Its use is modest but increasing.			
• INTERMEDIATE CARE FACILITIES	2,992	2,859	2,817
ICFs provide round-the-clock supervision and treatment programs, including basic medical care.			
• DEVELOPMENTAL CENTER	318	289	287
State-operated institutions in campus settings with 24-hour supervision.			
• SPECIAL TREATMENT UNIT	354	339	349
State-operated clinical, campus-based residence 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
• RESIDENTIAL HABILITATION	2,490	2,788	3,115
People receive "res-hab" support services—including skills training and therapeutic and health-related services—in their homes.			

DAY SERVICES

• DAY HABILITATION	3,892	6,695	9,464
"Dayhab" support services are provided outside the home at an agency or in a community setting.			
• DAY TREATMENT	6,408	4,423	3,827
More traditional day services, typically site-based. This category is being phased out.			
• SUPPORTED EMPLOYMENT	1,626	1,667	1,747
Services to facilitate paid employment, including job coaches. 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
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The program allows participants and their families and advocates to choose their supports and services and control their Medicaid and other resources.

The program will grow to about 31 people this year.

TOTAL HCBS MEDICAID WAIVER FUNDS (STATEWIDE)

2001: \$2 billion

2002: \$2.19 billion

2004: \$2.83 billion

(Federal fiscal year, October 1 to September 30)

*OMRDD does not have 2001 figures for these indicators; these are 2002 figures.

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

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72 Fifth Avenue, 6th Floor
New York, NY 10011
(212) 229-5418
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CREDITS

Editor:
Andrew White, Director, *Center for New York City Affairs*

Reporters:
Barbara Solow, Beth Glenn

Copy and Production Editor:
Mia Lipsit

Graphic Designer:
Julia Reich | www.juliareichdesign.com

Cover Illustration:
Leon McCutcheon

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