

# **DIRECT SUPPORT PROFESSIONALS**

## **The Frontline of Change**



**NEW YORK STATE ASSOCIATION OF  
COMMUNITY AND RESIDENTIAL AGENCIES**



**SEAN DELANEY**

*Composer & Performer*

**Direct Support Professional**

**OPEN YOUR EYES**

With these rhymes I can give sight to the blind.  
It's time to take flight with me while I speak with my mind  
about another side of life people tend to ignore.  
I guarantee that this will open up their eyes for sure.  
Sometimes children are born with disabilities  
torn from their families and this was killin' me.  
That's why I willingly lended my hand out to help  
the less fortunate. I wouldn't want to be by myself  
if I was lost in my head on this giant planet.  
Are you with me? Are you startin' to understand it?  
Then these young kids become grown men.  
There's a select few that wanna see them grow till the end.  
All they really need is a friend, someone to guide 'em.  
They came a long way from the times we used to hide 'em  
in institutions that failed to provide 'em  
their rights in the constitution. That's why I'm beside 'em.

**Chorus**

Open your eyes.  
It's time to see the big picture.  
These are people's brothers and sisters.  
I couldn't resist the opportunity to show my love  
to all the ones who sometimes catch a shoulder shrug.  
Open your minds. Open your hearts.  
This goes out to staff members who cared from the start,  
played the part in another individual's life.  
You wouldn't know unless you seen it with your own two eyes.

To order a DVD of Sean Delaney's video, *Open Your Eyes*,  
please visit [www.hudcitygear.com/official-open-your-eyes-dvd.html](http://www.hudcitygear.com/official-open-your-eyes-dvd.html).

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## Foreword

Today's system of services and supports for individuals with developmental disabilities in New York State stands in stark contrast to that which existed a mere 40 years ago. Thanks to parents, visionaries, advocates, public officials, and individuals with developmental disabilities who spoke of their needs and desires, the days of one-size fits-all institutional care are long gone. In its place is a myriad of service options and supports tailored to meet the needs of individuals in their home communities. At the vanguard of this transformation, and upon whom its success rests, are direct support professionals who assist individuals with developmental disabilities in mastering and enjoying everyday life.

*Direct Support Professionals: The Frontline of Change* was inspired by the men and women of this workforce, some of whose profiles and insights are presented herein. It discusses the history of the system's transformation and the challenges confronting direct support professionals. These challenges, if not met head on, will place a system of care in crisis by threatening the quality of life of thousands of individuals with intellectual and other developmental disabilities and their families.

More importantly, *Direct Support Professionals: The Frontline of Change* reflects NYSACRA's commitment to individuals with developmental disabilities by presenting the association's plan of action to assist the men and women who directly support them. NYSACRA has long served as an advocate for direct support professionals.



**Tom McAlvanah**  
*President*  
Board of Directors  
NYSACRA



**Ann M. Hardiman**  
*Executive Director*  
NYSACRA

## Foreword, *continued*

Our efforts in this regard have recently been bolstered by the Office of Mental Retardation and Developmental Disabilities (OMRDD) which, in response to NYSACRA's 2008 proposal, *Meeting the Workforce Challenge: A Comprehensive Approach*, awarded the association a three-year Quality Improvement Demonstration Grant.

*Direct Support Professionals: The Frontline of Change* also presents a call to others for action to ensure the viability of our system of supports and services for individuals with developmental disabilities and their families.



**Tom McAlvanah**

*President, Board of Directors*

NYSACRA



**Ann M. Hardiman**

*Executive Director*

NYSACRA



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## CHAPTER ONE

# A System Transformed



**f**orty years ago in New York State and across the nation, most individuals with developmental disabilities who could not live independently or with family members faced one option: confinement to a public institution. Arising in the mid- to late-19th Century as alternatives to alms houses, these public facilities were intended to provide short-term education, training, and other services to enable persons with developmental disabilities to return to their homes with the skills necessary for community living.



## The Early Years

A variety of factors, including societal attitudes towards persons with disabilities and the absence of social services, family supports, and jobs in the community, soon reshaped the mission of public institutions. “Training Schools,” as many were called, became asylums geared to providing life-long protective and custodial care for the people they housed.

***We have a situation  
that borders on a  
snake pit . . .”***

Senator Robert Kennedy  
on visiting Willowbrook  
State School in 1965.

Within a century, the schools were grossly overcrowded. In the late 1960s, New York’s 14 State Schools housed over 27,000 individuals. Upon touring the Willowbrook State School on Staten Island, Senator Robert Kennedy remarked, “We have a situation that borders on a snake pit...children live in filth...our fellow citizens are suffering tremendously because of a lack of attention, lack of imagination, lack of adequate manpower.” Several additional schools were constructed to relieve overcrowding, but to no avail.

Residents rarely left the confines of the schools which were designed to provide cradle-to-grave services, including medical and nursing care. Their autonomy and individual choice, even in matters as simple as when to wake up or what to eat, were sacrificed to the rigors and regimentation of running facilities housing hundreds, if not thousands,

of individuals. They spent their days on filthy units that were usually locked, interacting only with fellow ward-mates or attendants. The attendants were so few in number that their attention was focused primarily on keeping order on the overcrowded wards. At night, residents slept dormitory-style on the same wards, sometimes inches apart from ward-mates with whom they spent their mind-numbing idle days.



Direct support professionals are relied upon by families of people with developmental disabilities as being closest to their loved ones and the people who know them best.

## Community-Based Service Development

The landscape of New York's service system for individuals with developmental disabilities began to shift with the advent of community residences. This shift would take on seismic proportions as a result of the Willowbrook Consent Decree and other initiatives.

The first community residences (or *hostels* as they were then called) were developed in the early 1970s by not-for-profit organizations that were created by family members who sought alternatives to institutional care for their loved ones. By 1972, twelve such facilities were in operation, serving 160 individuals. The typical residence provided housing and supports for 7-12 individuals in their home communities. However, several hostels in operation at that time served up to 20 or more men and women.

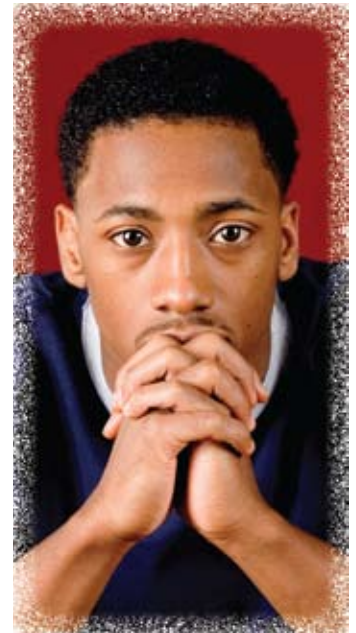
That same year, families of individuals living in the Willowbrook State School sued New York State in federal court over inhumane conditions at the facility. Shortly after his 1974 election, Governor Hugh Carey signed the Willowbrook Consent Decree. The decree committed the state not only to improving conditions at the facility, but to establishing community residential placements for the nearly 5,000 individuals living at Willowbrook at the time the class action suit was initiated. The decree also pledged that Willowbrook would be downsized to a 250-bed facility and that community residences for Willowbrook class members would serve no more than 15 individuals with mild mental retardation and no more than 10 individuals with more disabling conditions.

This commitment accelerated community residence development by not-for-profit service provider agencies. It also ignited advocacy efforts on behalf of individuals who lived in other overcrowded, substandard state schools and those who lived at home with aging parents who had refused to institutionalize their family members. During his tenure, Governor Carey extended the commitments made on behalf of the Willowbrook class members to all residents of state schools, which were renamed *developmental centers*. Furthermore, it became public policy that 50% of all community residential development would be dedicated to individuals who had not been institutionalized, thereby achieving two objectives: downsizing developmental centers and creating alternatives to institutionalization.

In the late 1970s, legislation sponsored by State Senator Frank Padavan (Mental Hygiene Law §41.34, also known as the Padavan Law) created a procedural framework for the site selection and establishment of community residences. By the early 1980s, more individuals were living in community residential facilities (12,100) than were living in developmental centers (11,728).

It was expected that individuals living in community-based settings would spend a good portion of their days, as most people do, outside their homes at work or engaged in educational, training, or other meaningful opportunities. Thus, community residential development gave rise to the proliferation of community-based day programs offering activities tailored to the interests and needs of individuals with developmental disabilities. By 1983, 30,000 people who lived at home, in community residences, or even in state-operated institutions, were attending such programs.

Direct support professionals often work 60-80 hours per week to make ends meet.



Direct support professionals have the primary responsibility for the health, welfare and safety of people living in community group homes and apartments.



The 1980s and 1990s ushered in other initiatives that reshaped the landscape of service delivery to New Yorkers with developmental disabilities, including:

- The creation of family support services to assist individuals living at home with their natural families.
- The establishment of the Self-Advocacy Association of New York, an organization comprised of individuals with developmental disabilities and dedicated to assisting voluntary provider organizations, public officials and individuals with developmental disabilities on matters relating to individualized services, self-determination and personal choice.
- The emergence of self-directed services in which individuals with developmental disabilities, along with their families and/or friends, identify the supports they need to live full lives and hire the direct support professionals they need to reach that goal.
- Modifications to the community residence model to allow smaller settings, which blended with other neighborhood homes, and supervised apartment living. (Between 1990 and 2000 the number of people living in residences serving six or less individuals increased eight-fold.)



- Augmentations to day program models to bolster opportunities for supported or other types of employment.
- The development of community residences operated by OMRDD which was downsizing its developmental centers. (The vast majority of community-based programs, however, continue to be operated by not-for-profit provider agencies licensed or funded by OMRDD.)
- The closure of 11 developmental centers which, in the late 1970s, collectively housed over 9,500 individuals.
- The implementation of OMRDD's multi-year initiative, New York State—Creating Alternatives in Residential Environments and Services (NYS-CARES), to address the needs of individuals still living at home and those who were on waiting lists for services. (By 2009, approximately 16,500 individuals will have received out-of-home residential supports and services through NYS-CARES.)

Direct support professionals are continuously being told that they are the most important people in the field, yet their salaries do not reflect this.

*Today over 140,000 New Yorkers with intellectual and other developmental disabilities reside in community residences or receive day services or other supports while living independently or with family members. Only approximately 1,600 people continue to live in state operated developmental centers with plans to continue to decrease this number each year.*

# MILESTONES IN SUPPORT

## 1960s

**IN 1968, OVER 27,000 INDIVIDUALS LIVED IN NEW YORK STATE SCHOOLS, LATER RENAMED DEVELOPMENTAL CENTERS.**

## 1970s

**DURING 1971-72, THE FIRST 12 HOSTELS OR COMMUNITY RESIDENTIAL FACILITIES OPEN, SERVING 160 INDIVIDUALS.**

- **1972** Parents of 5,000 persons living at Willowbrook State School sue in federal court over inhumane conditions at the facility.
- **1975** Willowbrook Consent Decree is signed committing New York State to a program of community placements for residents of Willowbrook. Governor Carey subsequently extends this commitment statewide.



- **1977** Starting with a handful of member agencies, NYSACRA is created and begins to share information during the early development of community-based residential settings.

## 1980s

**FOUR STATE OPERATED DEVELOPMENTAL CENTERS CLOSE, BEGINNING WITH THE FORMER WILLOWBROOK STATE SCHOOL.**

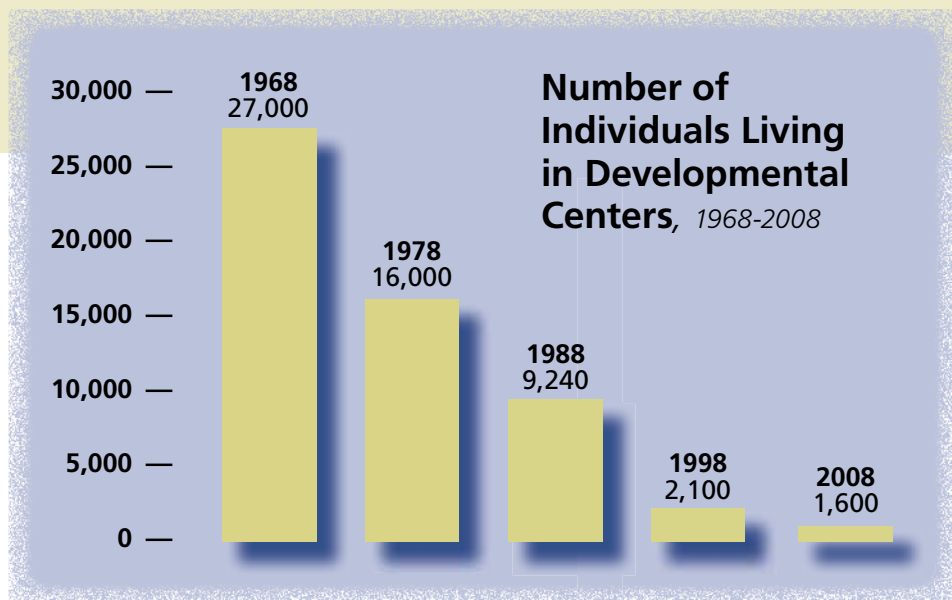
- **1982** NYSACRA sponsors its first direct support professional conference at Keuka College in Penn Yan, NY. Four other DSP conferences are subsequently convened in other regions of the state.

SERVICE TYPE	NUMBER OF INDIVIDUALS SERVED						
	1968	1978	1983	1988	1992	1998	2008
State-Operated Developmental Centers	> 27,000	> 16,000	> 11,700	< 9,200	< 5,000	< 2,100	1,600
Community Residential Programs	*	7,000	12,100	16,000	27,000	32,000	40,000
Community-Based Day Programs	*	23,000	30,000	38,000	46,000	58,600	64,000
Family Support Services	*	*	*	15,000	34,500	51,000	> 60,000

\* Data not available.



- **1984** Family Support Services initiative launched.
- **1985** Supported Work Programs created, augmenting day programs.
- **1986** Self-Advocacy Association of New York established.




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**DURING THE 1990S, SEVEN ADDITIONAL STATE-OPERATED DEVELOPMENTAL CENTERS CLOSE.**

**1990s**

- **1991** Home and Community Based Services Waiver approved by the federal government, followed by the Care-at-Home Waiver, allowing the use of Medicaid funds for certain community-based services at the core of person centered planning.
- **1998** NYS-CARES program initiated.

---

**IN 2001, NYSACRA, ALONG WITH 1,000 PARTICIPANTS FROM SISTER ASSOCIATIONS, RALLY AT THE STATE CAPITOL DEMANDING WAGE INCREASES FOR DIRECT SUPPORT PROFESSIONALS.**

**2000s**

- **2004** NYSACRA begins to offer the Disability Studies Certificate Program. NYSACRA and CUNY publish Keeping Workers Covered: Employer-Provided Health Insurance Benefits in the Developmental Disabilities Field, resulting in funding for the NYS OMRDD Healthcare Enhancement Program.
- **2005** OMRDD announces Healthcare Enhancement for Direct Support Professionals in New York.
- **2008** NYSACRA represents nearly 200 provider agencies that employ approximately 65,000 staff serving more than 55,000 persons with developmental disabilities.

***The most rewarding part of this job is assisting people achieve their goals—be it living independently or getting a job, etc.—seeing their pride in what they’ve accomplished.”***

Day Services  
Direct Support Professional

## Putting a Human Face on System Change

Today, Larry is a self-advocate who lives in Amherst, New York. With the support of staff who assist him with personal care and certain physical and other activities of daily living, he works part-time with AmeriCorps, teaches others self-advocacy skills, and enjoys independence and life in his own apartment, in his own community. But it was a long time coming.

Larry was born 42 years ago with cerebral palsy and spastic quadriplegia. Unable to care for his complex needs, Larry’s family placed him in a state school in Western New York. The year was 1968 and he was two years old. Larry was one of over 1,300 children

and adults living at the facility. A total of more than 27,300 individuals lived in 14 such schools across the state.

The year Larry was placed, there were no such things as community-based group homes for people with developmental disabilities. Funding for the first “hostels”, as group homes were called in those days, was proposed in the Governor’s Executive Budget of that year. However, by 1972, there were only 12 hostels in operation, serving a mere 160 individuals,



*Larry in the 1970s*

offering little hope for the thousands of individuals who, like Larry, were confined to overcrowded public institutions.

Four years later, and hundreds of miles away, the fires of serious state-wide institutional reform, and community-based service development, were sparked by the signing of the Willowbrook Consent Decree. Although it would take time for the wave of reform to reach Larry, it did come. In 1984, when he was 18 years old, Larry moved to a group home.

Living in a regular neighborhood for the first time since he was a toddler, Larry shared a home with 12 other individuals with developmental disabilities and attended a locally-based day program where he learned skills necessary for everyday life in the community. In a few years, he moved to an even smaller group home where he, his five house-mates, and staff, became “like family.” Of the direct support professionals who supported him in those years and prepared him for living today in his apartment, Larry says: “The staff listened to me and treated me like an adult...they took direction from me when assisting in my personal care...they helped me to speak for myself...they respected me and allowed me to be who I am—Larry.”

After decades, Larry lives in a home, not a system, thanks to direct support professionals.



*Larry today*



## CHAPTER TWO

# The Frontline of Change



**D**einstitutionalization, or the shift to a community-based care system, entailed more than just a change in where services are delivered. It represented a fundamental change in how services and supports are provided and the roles of those on the front-lines who provide the supports.



Direct support professionals create bonds and friendships with people with developmental disabilities, many of whom do not have active family members.

## At the Fulcrum of the System's Shift

As self-contained service environments, institutions offered all services on site: doctors visited wards to tend to the ill and nurses dispensed routine medications; large food service departments prepared and delivered thousands of meals daily to living units; and if individuals left their wards, the institution's campus was the limited world they had to navigate. The role of institutional aides—the staff spending the most time each day with individuals—was largely one of maintaining order and ward-life routines.

With neighborhoods and communities now the boundless service environments for thousands of New Yorkers with developmental disabilities, staff who provide them with day-to-day supports have taken on new and more complex roles. They assist individuals to schedule and keep medical appointments with community-based physicians; accompany them on appointments, often acting as their medical advocates; and guide individuals with complying with medical recommendations. They administer medications and/or offer medication training to individuals. They assist in healthy meal planning, grocery shopping and food preparation. They teach basic living skills in residential, day program and natural-family settings, and serve as coaches for individuals in supported work environments. And, as the “real” world can be a more risky one to navigate than the campus of an institution, they offer protective and advocacy services, sometimes as simple as travel training, sometimes as complex as avoiding or resolving abusive or exploitive situations. In incalculable and often intangible ways, they support individuals in being at home in their communities as good neighbors and citizens.

By job description, these employees have many titles — direct care aide, residential or day habilitation counselor, program specialist, job coach, etc. Collectively, however, and with the proper training, they are known as direct support professionals. Working in literally thousands of small, sometimes one-on-one, care settings across New York, they are required to exercise independent thinking and keen judgment. Trained in medication practices, CPR, first aid, state regulations, issues relating to developmental disabilities generally, and the individual developmental, medical, and behavioral needs of the persons they support, the men and women of this 60,000 member-strong workforce are the backbone upon which today's system of supports and services was built and hinges.

Direct support professionals often leave the jobs that they love because of poor salaries.

## Profiles in Service

Economic and other factors threaten the viability of this workforce. Meet several of its members and read about the work they do, the values they promote, and the challenges they face. Each profile showcases the key concepts that direct support professionals employ: relationship building, promoting physical and emotional well-being, advocacy and crisis intervention, person centered supports, responsibility and integrity, self-determination, respect, and perseverance.



## Relationship Building

***Turnover is hard on staff. It means overtime, extra work to pick up the slack. But it's harder on the individuals. They develop relationships with staff. Suddenly, the relationships are gone and they truly grieve."***

Residential Services  
Direct Support Professional

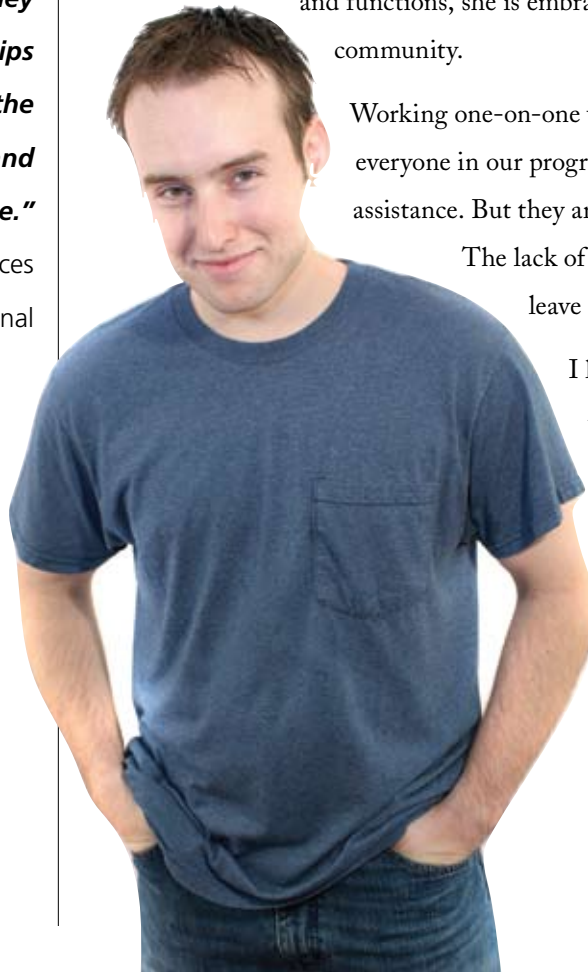
### TIMOTHY

I was privileged to advocate for and assist Alma to become an active member of a faith community whose members have now rallied around her, providing her with emotional and physical supports. Not only does she attend church services and functions, she is embraced as a valued member of her new community.

Working one-on-one with Alma, I quickly realized that everyone in our program could benefit from that same level of assistance. But they aren't because of the revolving door of staff.

The lack of a living salary almost demands that staff leave for jobs that pay better.

I love my work, but when my day ends at 4 pm, I go to a second job to support my family, and wonder: how many of us are there who are not flourishing because direct support professionals are not paid a decent wage?





## *Promoting Physical and Emotional Well-Being*

### THE WASHINGTON TRIP

In September 2001, Diane, Rhonda, and Donna were on vacation in Washington, DC with eight people they support.

Just after touring the White House and looking forward to their last full day of sightseeing, sirens began sounding all around and emergency vehicles sped past them in a frenzy. The three staff knew something was wrong—very wrong—as armed soldiers patrolled the streets and all tourist attractions and transportation services were immediately closed down. The group began the long walk back to their hotel, purchasing flashlights and snacks along the way. Despite the health and mobility impairments of some of the individuals, they arrived safely at their hotel only to find it too roped off as a possible target of a terrorist attack.

Once allowed back into the hotel, under unprecedented circumstances, the staff provided reassurance to the individuals and made contact with their families and agency back in upstate New York. With airports closed, the weary group made their way home to waiting families several days later on a bus which their agency sent to pick them up.

*These direct support professionals remained calm and kept the people they support active and feeling safe. There was little training that could have prepared them for 9/11, yet they worked together and checked their own fears and concerns until they had assured the safety and well being of those for whom they worked.*

As parents of people with developmental disabilities age, they want to know that their children are safe, secure and well-cared for by people they know.

## MELISSA

As a domestic violence specialist, Melissa chooses daily to enter the disturbing world of family violence. She works in a program that provides emergency housing, counseling, and advocacy to over 30 developmentally disabled women and men seeking refuge from domestic violence. A typical day for Melissa could include court appointments, crisis counseling, and/or group sessions. Some days there are trips to the emergency room.

It is difficult for many to understand what would attract Melissa to work in such a difficult field. She cites the statistics: 83% of women with developmental disabilities will be sexually assaulted in their lifetime, which represents a 50% higher rate than the rest of the population.



Like many direct support professionals, Melissa struggles with her desire to serve others and the need to earn a living. “The salary issue is frustrating, because I worked hard to earn a Master’s degree,” explains Melissa. “But I actually made more money when I was in school, bartending twice a week.”

However, the success stories are what keep her going.

### ARCADIA HOUSE


Extensive home renovations can be inconvenient and nerve racking. When the contractor called with the start date for renovations to Arcadia House, the direct support professionals working there were wise to not underestimate how stressful “camping-out” at home could be. So the staff elected to move with the residents to the agency-owned vacation home in Lake George, almost three hours north of their own homes and families. The Lake George house was familiar to the individuals from their previous vacation visits. The staff were more than willing to do whatever was necessary to rearrange their own lives and personal obligations to ensure the comfort of the people they support. Being true professionals, staff vowed to keep this work schedule, no matter how long it took contractors to finish renovating the house.

Being at the Lake George home in July proved to be fantastic! They enjoyed berry picking, tourist attractions, and backyard barbeques at the end of the day with all the creature comforts of home.

*Dedicated direct support professionals willing to go the distance, people with developmental disabilities whose comfort level allowed them to be flexible, and a good contractor who met his completion date, made for a home renovation adventure.*

Direct support professionals watch consumer and family satisfaction decrease with constant staff changes.

## *Responsibility and Integrity*



***The hardest part of the work is staff turnover. I've seen at least 20-30 people come and go in my six years. It is most difficult for the individuals, not having the same people to support them for any length of time."***

Residential Services

Direct Support Professional

### **JANICE**

Since beginning her job seven years ago, Janice has supported and been a part of Tammy's life. She still is. Janice works with Tammy as a direct support professional. She has seen Tammy's six-year-old son turn 13, and has assisted Tammy when her three year old needed to be registered for day care.

"I love Janice," Tammy says, "she is really good with me and my children, and she always makes sure that I understand what is going on...she helps me make good decisions." Janice offers Tammy information and assistance on a variety of everyday critical decision making issues, ranging from parenting skills to daily nutritional planning for the family.

In her seven years, Janice has seen her fair share of staff turn over. "Staff leave for different reasons, but it is usually to make more money." Instead of following suit, Janice works two jobs. "I like to see people meet their goals. The longer I work with them, they begin to trust me, and let me into their world," says Janice. Commenting on her direct support role Janice says, "I can barely make ends meet, but I would not do anything different. It's not always easy, but I love it."

## *Self-Determination*

### **SABINE**

Sabine has been a direct support professional for fifteen years. Over that period, she worked full time while also pursuing a degree in physical therapy. She juggled two other part-time jobs to cover household and tuition expenses and is now a medical counselor at one of the agency's residences.

But that is not her claim to fame. For the past two years, Sabine has been a hero to Olivia, one of the residents. Olivia is a middle aged woman with multiple disabilities. She loves to laugh, interact with people and takes great pride in her appearance. She requires the use of a wheelchair that at times has been a roadblock to participating in things she likes to do. But that didn't stop Sabine, who explored Olivia's dreams and spent countless hours helping her make them happen.

For the past two years, thanks to Sabine's "can do" attitude, Olivia has attended the Fashion Rocks shows at Radio City Music Hall, delighting in experiencing firsthand the latest fashion trends while dressed in all her finery. Olivia is living a life of distinction, thanks to a direct support professional.



Direct support professionals assist people with developmental disabilities to become good neighbors and valued members of society.

## LARUE

“I love my house. I love my family (here) and I love my family that lives in the city. I love LaRue and all my staff.” Melissa celebrates everything with exuberance. She lives in a group home where she enjoys life to its fullest.

One of the people who make life so grand for Melissa stands nearby and stirs a wonderful mix of sausage, vegetables, and rice that will be dinner for Melissa and the other individuals who live in the home. LaRue is a full time direct support professional. She pauses in the meal preparation to answer a question: “I do this work because of the people that I support.” As LaRue continues to stir, she praises one individual for his helpfulness and comforts another who was cold at his program that day.

This is an enormously diverse and responsible position that pays well below what the labor is worth. Why does she do it? “I love the people.” It is as simple as that.

***My son is 16 and has autism. I am very scared about his future. He has a wonderful direct support worker who supplements what I can do by providing in-home rehabilitation services. But she works two other jobs to make ends meet; she can't keep that schedule forever. In 20–30 years, when Michael is grown and I'm gone, who'll be willing and able to provide the type of supports he's now getting given the salaries direct support professionals are paid?”***

A Parent

### KIMBERLY

For the past five years, Kimberly has worked for an agency's At-Home Program. "I enjoy my job very much...love serving the people I support," she says, "but it just keeps getting harder and harder to make ends meet when the money we're making isn't catching up to the way prices are increasing."

A single mother of two youngsters, Kimberly works as many hours as she can, usually about 50 a week, to earn as much as she can while still being able to spend quality time with her children, as any responsible parent would do.

The nature of her job requires that she work in the homes of the people she supports. This means Kimberly drives from one home to the next throughout each day, logging on many miles in a single week. "My mileage reimbursement doesn't come close to the amount of money I put into the car in terms of gas, oil, and repairs." She needs her car for the job, and her 1996 vehicle will soon need to be replaced. "But I can't buy a new car, or even a newer model, on the salary I make."

Kimberly's knowledge of economics comes from the school of hard knocks: she's seen the prices of gas, groceries, daycare, rent, and utilities go up, while she struggles on a salary that has not kept pace.

She loves the job; she just wants a decent wage that keeps up with the cost of living.

Direct support  
professionals  
sacrifice their own  
free time to work  
extra hours due to  
high turnover and  
difficulty recruiting  
new employees.







# NYSACRA's Commitment



A

s an association dedicated to advocating for persons with intellectual and other developmental disabilities and the organizations that support them, NYSACRA is keenly aware of the issues assailing the vitality of the direct support workforce. Quite simply they are: inadequate salaries; increasing health insurance premiums which present a conundrum for agencies that struggle to provide both a living wage and decent benefit packages; high turnover; and an ever increasing demand for willing and capable workers in the face of a shrinking labor pool.



***My husband and I hired Ken, our direct support worker, several years ago after months of looking and many, many interviews. Ken visits our home each week and helps us with money management, menu planning, grocery shopping and cooking meals. Most of all, Ken is dependable. We don't know what we'd do without him."***

Self-directed

Individual

## Understanding the Challenge

The quality of disability services lies in the hands of this workforce. Knowledgeable, experienced and compassionate direct support professionals act not only as caregivers, but also as teachers, advocates and friends. Frequently, close family-type relationships develop between direct support professionals and the individuals they support, especially when those receiving services have no contact with their family. Despite the fact their jobs demand complex skills, independent thinking, ethical judgment and the ability to create long-term relationships of trust and mutual respect, the work of direct support professionals has not been recognized as a profession in this country. They are neither viewed as the key lynchpin of a system of community services, nor compensated and otherwise supported on par with the importance of the work that they do. This is a matter that must be forthrightly addressed if we are to avert an impending crisis as more and more Americans become reliant on community supports due to aging or other disabling conditions.

Toward that end, and in partnership with its member agencies, New York State and other partners, NYSACRA is committed to ensuring that direct support work is recognized and valued as a profession by:

- providing easy access to high quality, competency-based training and career development opportunities for direct support professionals;



# Direct Support Workforce Facts and Challenges

- The direct support workforce ranks among the top 20 fastest growing occupational categories in the country. The U.S. Bureau of Labor Statistics projects the demand for this workforce will increase more than 40% between 2002 and 2012 due to changing demographics including increasing numbers of persons with disabilities and the aging of baby boomers.
- The demand for workers to support individuals with developmental disabilities specifically will increase by approximately 37% by the year 2020, according to the U.S. Department of Health and Human Services. However, the number of workers who typically perform direct support, adults aged 18-39 years, will increase by only 7% in that time frame.
- Wage increases for private-sector direct support workers are far below trends for comparable job categories. During a recent nine year period, their hourly wage increased only \$1.20 versus \$2.79 and \$1.75 for public-sector direct support workers and Fast Food employees respectively.
- In New York State there is a critical shortage of candidates for direct support work, and some agencies experience a 40% turnover rate. The financial cost of continual recruitment is high. More critical is the cost to individuals with disabilities who experience a revolving door of staff, resulting in the loss of relationships and continuity in the delivery of supports and services.

Direct support professionals provide support and services in the communities in which people with developmental disabilities and their families **choose** to live.

- promoting a national code of ethics and nationally validated skill standards to guide the training efforts and the work of direct support professionals; and
- developing promotional materials to educate the public and prospective employees about the significance of direct support work and careers in the profession.

## Training and Career Development Opportunities

### Disability Studies Certificate Program

Since 2004, with funding provided by the New York State Departments of Health and Labor, NYSACRA has administered a Disabilities Studies Certificate Program in upstate New York. Similar programs are being funded and administered in New York City by the City University of New York (CUNY) and the John F. Kennedy Jr. Institute for Worker Education and on Long Island by the Long Island Alliance of Agencies.

The requirements for this program consist of three major components: an assessment and a 12-week, non-credit college preparatory class (Bridge to College); four special topic courses bearing a total of 12-16 college credits (Disability Studies Certificate Program); and completion of the on-line College of Direct Support curriculum. The certificate program's objectives are to train



direct support professionals to meet the requirements of a changing service system and to provide a foundation for longer-term employment and career mobility in the field.

NYSACRA and the participating member agencies work closely with State University of New York (SUNY) colleges to identify, assess, select and enroll qualified direct support professionals. All potential participants enroll in a Bridge to College class that assesses readiness and prepares them for college-level work. A contextualized disability studies curriculum has been designed for the Bridge to College course and it has proven effective in identifying students who are likely to complete four credited, job-related courses.

The heart of Disability Studies Certificate Program consists of four courses totalling 12-16 credits. The costs of tuition for these courses are paid by NYSACRA. Coursework includes foundational and specialized courses and field-based learning experiences that will assure a better trained and prepared direct support professional. To fulfill certificate requirements, workers and the member agency choose from a menu of credited, job-related courses at participating SUNY schools. Access to the on-line College of Direct Support is also provided to students to augment the theoretical knowledge they receive in college classes.

Lastly, it is hoped that the Disability Studies Certificate serves as a conduit to a college degree by providing the student with academic confidence and the relief of financial burden as they start, or re-start, their college careers.

Direct support professionals are members of a workforce that is in crisis, as demand for their service grows faster than their numbers. Although in high demand, low wages thwart recruitment efforts.

Direct support professionals are the heart and soul of the work we do.

### **College of Direct Support**

The College of Direct Support is a learning gateway for contemporary best practices for direct support professionals. By incorporating web-based learning, backed by a nationally recognized curriculum, it is designed to promote a profession of direct support. Since 2006, NYSACRA has used the College of Direct Support for 200 staff

and frontline supervisors enrolled in its Disability Studies Certificate program.

### **Courses Offered by the College of Direct Support**

- Community Inclusion
- Cultural Competence
- Direct Support Professionalism
- Documentation
- Employment Supports: Exploring Individual Preferences and Opportunities for Job Attainment
- Individual Rights and Choice
- Introduction to Developmental Disabilities
- Introduction to Medication Support
- Maltreatment of Vulnerable Adults and Children
- Person-Centered Planning and Supports
- Positive Behavior Support
- Safety at Home and in the Community
- Supporting Healthy Lives
- Teaching People with Developmental Disabilities
- You've got a Friend: Supporting Family Connections, Friends, Love and the Pursuit of Happiness

With the award of OMRDD's three-year demonstration grant for Quality Improvement in 2008, NYSACRA will become a Master Administrator for the oversight, marketing and dissemination of the College of Direct Support's on-line training program, thereby offering member and non-member service agencies in New York low cost access to the program.

The College of Direct Support curriculum is based on extensive analysis of the job content of the direct support role and the specific areas of competent performance demanded

in providing high-quality community supports to people with developmental disabilities. It focuses on the core introductory knowledge and skill sets needed by direct support professionals throughout the United States, and also provides opportunities for custom tailoring to address specific conditions, needs, and desires of individual states and agencies. The multimedia interactive training curriculum has two critically important features:

- By offering a training program that is computer-based and easily accessed from any location with a computer, the project responds more flexibly to the needs of employees who face demanding schedules and difficulty in traveling off-site.
- The program establishes a national standard for adequate and appropriate training for the direct support professionals on whom persons with intellectual and other developmental disabilities depend for their health, safety, liberty, and quality of life.

Direct support professionals need to be well trained and duly compensated in order to give quality care and supports.

## Courses in Development by the College of Direct Support

- Accommodation of Physical Disability
- Aging and Disability
- Civil Rights and Advocacy
- Communication Supports
- First Aid
- Functional Assessment
- Household and Domestic Skills
- Personal Care and Self-Care
- Teams and Team Building
- Working with Families and Support Networks



***I've seen people fresh out of college who love this work, and would want to do it for the rest of their lives, but can't afford to. The cost of everything is going up. They move on to better paying fields."***

Day Services  
Direct Support  
Professional

### **National Alliance of Direct Support Professionals**

The National Alliance for Direct Support Professionals (NADSP) is a coalition of organizations and individuals committed to strengthening the quality of human service support by strengthening the direct support workforce. NADSP has developed a national code of ethics for direct support professionals. It was also instrumental in promoting the Community Support Skill Standards for training support professionals. The Community Support Skill Standards adopted by NADSP, were developed by the Human Services Research Institute (HSRI) with funding from the United States Department of Labor in 1996 and adopted by NADSP. NADSP has also developed a national credentialing program for direct support professionals working in community programs. (See *Appendix One: Workforce Values and Practice Standards.*)

In 2008, with the assistance of the OMRDD grant, NYSACRA will embark on incubating a New York Chapter of the NADSP to advance its Code of Ethics,

national credential in direct support, and overall goal of professionalizing the career of direct support. NYSACRA will provide the initial registration fees for NADSP membership, create and maintain a website for the chapter, and work with NADSP leadership to organize five regional direct support professional conferences each year. Beginning with NYSACRA's support, the New York Chapter of NADSP will then become an autonomous entity.





# NADSP Guiding Principles

The NADSP mission is to promote the development of a highly competent human services workforce which supports individuals in achieving their life goals. It has organized its members into committees to develop strategies to address each of the following goals:

1. Enhance the status of direct support professionals.
2. Provide better access for all direct support professionals to high quality educational experiences (e.g., in-service training, continuing and higher education) and lifelong learning which enhances competency.
3. Strengthen the working relationships and partnerships between direct support professionals, self-advocates, and other consumer groups and families.
4. Promote systemic reform which provides incentives for educational experiences, increased compensation, and access to career pathways for direct support professionals through the promotion of policy initiatives (e.g., legislation, funding, practices).
5. Support the development and implementation of a national volunteer credential process for direct support professionals.

See *Appendix One, Workforce Values and Practice Standards* for the NADSP Code of Ethics and the Community Support Skill Standards developed by HSRI.

Direct support professionals often share their days off and holidays with the people with developmental disabilities they work with so they can experience a full life.

**National Training Institute for Frontline Supervisors**

NYSACRA also endorses the University of Minnesota’s National Training Institute for Frontline Supervisors (NTIFFS). This three-year grant project is designed to improve recruitment and retention of direct support professionals, who are competent and confident in the skills needed to provide quality supports and services to individuals with developmental and other disabilities.

This project refines, tests, and delivers a national train-the-trainer and technical assistance model to assist community organizations that provide supports and services to recruit, retain, and train direct support and frontline supervisor staff members.

**NTIFFS Technical Assistance Model Components**

- |   |  |
|---|--|
| 1. Assisting organizations to assess their recruitment and retention challenges.                  | and training to organizational representatives.  |
| 2. Providing web-based training on recruitment and retention strategies.                          | 6. Supporting technical assistance efforts by organizational representatives for frontline supervisors.  |
| 3. Conducting two intensive train the trainer institutes for 10-15 organization representatives.  | 7. Supporting ongoing follow-up measurement to assess the effectiveness of interventions to guide future work.                                     |
| 4. Supporting organizational representatives to provide training to 70-100 frontline supervisors. | 8. Developing project products and reports to share the project outcomes with policy makers, provider organizations, and other interested persons. |
| 5. Providing on-site as well as remote technical assistance, support,                             |  |

## Public Education

Recruiting and retaining a knowledgeable and committed direct support workforce also requires education designed to inform the public-at-large about the value of the profession and prospective employees about career paths and the reality of the work.

With the assistance of OMRDD's Quality Improvement Demonstration grant, NYSACRA is:

- developing public service announcements for various media outlets to increase the public's awareness of the roles of direct support professionals;
- designing printed materials for distribution at One-Stop Career Centers, Educational Opportunity Centers, and community colleges to provide clear and consistent information about various employment opportunities within the profession; and
- filming and distributing realistic job previews—one from the perspective of an individual with a developmental disability, and the second from the view point of a service provider agency—for use by service providers to give potential employees detailed and balanced information about job expectations so they can make informed decisions about working in the field.

Direct support professionals are unable to stay in a job that means so much to people with developmental disabilities — because it doesn't pay a living wage.



# Call to Action



**T**he future success of today's system of services for individuals with intellectual and other developmental disabilities is inextricably linked with the degree to which the men and women who support them each day are nurtured and valued as professionals. In its commitment to action, NYSACRA—in collaboration with its members, several New York State agencies and other partners—is providing tools to promote the noble work of direct support as a profession. Attaining that goal, however, requires a commitment to action by many, many others.

Direct support professionals provide support and services to people with developmental disabilities 24 hours a day, 7 days a week.

## Service Organizations

Boards of directors, executives and managers of service provider agencies should reflect on what actions their organizations can take toward that goal.

- Are the service provider agency's internal training programs competency based and modeled on proven, national practice standards, such as the Community Support Skill Standards?
- Does the service provider agency encourage the continuing education of direct support workers by offering, among other things, tuition assistance; flexible hours for attending classes or access to computers for on-line instruction; salary differentials for completed course work; and opportunities to attend conferences, network with other direct support professionals, and share best practices?
- Does the service provider agency promote the concept of direct support work as a career?
  - Are prospective employees exposed—through in-depth interviews, realistic job previews, job-site visits, or shadowing current employees—to the genuine expectations of the positions for which they are applying? Are the individuals and families served by the service provider agency involved in the interview process?



## THE CHALLENGE

- Are prospective employees also informed about the career opportunities the agency offers and the expectations for such?
- Has the service provider agency created career ladders for direct support professionals—ladders of increasing responsibility based on training and competency—and commensurate compensation?
- Does the service provider agency's board of directors and senior management regularly review its financial position with an eye toward maximizing resources dedicated to salaries and benefits for direct support professionals?
- Most importantly, does the culture of the service provider agency truly embrace the work of direct support professionals as the most critical activity of the agency?
  - Being central to the mission of the service provider agency, are direct support professionals actively involved in discussions, reviews, and changes in the organization's operations?
  - Are direct support professionals given opportunities to assume leadership roles within the service provider agency by participating in standing or ad hoc committees—such as committees on staff recruitment, retention and training—or by working on special projects?

Direct support professionals are working just as hard as their public-sector peers and making 1/3 less money.





Direct support professionals assist people who have visual & hearing impairments, mental retardation, cerebral palsy, autism and other neurological impairments to reach their highest potential and lead enriching lives filled with choices.

## Direct Support Professionals

Prospective and current direct support professionals can also act.

- Individuals seeking a future in direct support work should query prospective employers about educational and career advancement opportunities and consider this information, as well as salary and benefit data, in their final decision making by asking themselves: “Is this a service provider agency with which I can prosper, grow and have a career?”
- Current direct support professionals should ask their employers about educational and career advancement opportunities and seize every chance to grow with the service provider agency – be it through tuition assistance, participation on committees or in leadership roles and other opportunities.
- Current direct support professionals can also pave the way for new generations of support professionals by welcoming them into the service provider agency, acting as role models and mentors, and by embracing them in the shared goal of providing quality supports and service through professional growth and development.

## Individuals & Families

Individuals with developmental disabilities and their families, as “customers” of services, can act to ensure that the supports they receive are delivered professionally by qualified staff in several ways:

- In searching for prospective service provider agencies, individuals and families should inquire about each organization’s efforts to maintain a well qualified and trained direct support workforce, as well as the agency’s turnover rates. They should ask to meet with direct support professionals to hear directly from them their experiences in this regard. Finally, they should choose the service provider agency with which they are most satisfied based on these inquiries and other factors.
- Individuals and families already affiliated with a service provider agency can make similar inquiries. They may also wish to share their unique experiences with the service provider agency’s leadership and offer to participate on any committees the agency has established to address workforce issues, as their views and experiences are at the heart of the matter.
- Individuals and families should share their praise of a direct support professional with the person providing the care and the agency as well. Job satisfaction increases when people receive positive reinforcement for a job well done.

Direct support professionals are in short supply across the nation, and by 2020 demand for their services will grow by 37%.

At more than 60,000 strong, the direct support professional workforce makes a significant contribution to the local economy.

## Public Policy Makers

Finally, public policy makers—well aware of the disconnect between the high demand for direct support professionals and the low salaries they are paid—can act, but with a surgeon’s precision. It is understood that until such time society as a whole recognizes the intrinsic dignity of individuals with disabilities, public funding for the people who support them will be insufficient – sizeable influxes of public funds are not in the offing, nor are they desirable as a quick fix. Rather, in partnership with service provider agencies and individuals with disabilities and their families, public policy makers should closely examine the degree to which existing reimbursement methodologies, regulations and public policies support accountability and a well-qualified and professional direct support workforce.



- In view of the impending workforce crisis, do state and federal government human service and labor agencies have adequate mechanisms in place to monitor issues relating to the supply and demand, salaries and benefits, and turnover rates of direct support professionals providing supports and services across various service industries (e.g., Health, Mental Health, Developmental Disabilities, etc.)?
- Are the roles played by public and private sector direct support professionals sufficiently different to justify wide salary differentials and, if not, what legislative action can be taken to create parity?

- Do regulatory requirements promote the professional growth and development of those individuals upon whom care systems most directly rely?
- Are reimbursement methodologies structured to support career ladders in human services, particularly in the area of direct support?
- Are policies in place to ensure cost of living salary adjustments for direct support professionals across all programs serving individuals with developmental disabilities, regardless of whether the program is state or federally funded?

New York State has been a national leader in the reform of services for individuals with developmental disabilities. Through the untiring work of self-advocates, families, direct support professionals, service provider agencies, and public policy makers, in four decades it has turned a largely institutional care system on its head by developing a myriad of community-based supports and service options. Now, as the nation faces a shortage of direct support professionals that will reach crisis proportions in the near future, New York can take a leadership role in preserving and advancing the success of the last 40 years by embracing the work of direct support as a profession and attracting new generations of men and women who seek it as a career. But we all must act together.

The recurring costs of recruitment and training associated with direct support turnover create fiscal constraints for community programs.





# Appendixes



## APPENDIX ONE **Workforce Values & Practice Standards**

## APPENDIX TWO **Resources**

## APPENDIX THREE **About NYSACRA**





# Workforce Values & Practice Standards

## National Code of Ethics for Direct Support Professionals

Developed by the National Alliance of Direct Support Professionals (NADSP), the Code of Ethics is intended to serve as a straightforward and relevant guide for direct support professionals as they resolve the ethical dilemmas they face every day on their jobs, and encourages them to achieve the highest ideals of the profession. For more detailed descriptions of the Code of Ethics, visit [www.nadsp.org](http://www.nadsp.org).

### 1. Person-Centered Supports

As a direct support professional, my first allegiance is to the person I support; all other activities and functions I perform flow from this allegiance.

### 2. Promoting Physical and Emotional Well-Being

As a direct support professional, I am responsible for supporting the emotional, physical, and personal well-being of the individuals receiving support. I will encourage growth and recognize the autonomy of the individuals receiving support while being attentive and energetic in reducing their risk of harm.

### 3. Integrity and Responsibility

As a direct support professional, I will support the mission and vitality of my profession to assist people in leading self-determined lives and to foster a spirit of partnership with the people I support, other professionals, and the community.

### 4. Confidentiality

As a direct support professional, I will safeguard and respect the confidentiality and privacy of the people I support.

### 5. Justice, Fairness and Equity

As a direct support professional, I will promote and practice justice, fairness, and equity for the people I support and the community as a whole. I will affirm the human rights, civil rights and responsibilities of the people I support.

### 6. Respect

As a direct support professional, I will respect the human dignity and uniqueness of the people I support. I will recognize each person I support as valuable and help others understand their value.

### 7. Relationships

As a direct support professional, I will assist the people I support to develop and maintain relationships.

### 8. Self-Determination

As a direct support professional, I will assist the people I support to direct the course of their own lives.

### 9. Advocacy

As a direct support professional, I will advocate with the people I support for justice, inclusion and full community participation.

## Community Support Skill Standards

The Community Support Skill Standards - developed by the Human Services Research Institute with funding from the United States Department of Labor, and adopted by the National Alliance of Direct Support Professionals - are a set of nationally validated practice standards describing the philosophical underpinnings, knowledge, and work expectations in the field of direct support services. The twelve core areas are summarized below. For more detailed information about the standards, visit [www.hsri.org](http://www.hsri.org) or [www.nadsp.org](http://www.nadsp.org).

- 1. Empowerment:** The direct support professional enhances the ability of individuals requiring supports and services to lead self-determining lives by providing support and information necessary to build self-esteem, and assertiveness; and to make decisions.
- 2. Communication:** The direct support professional should be knowledgeable about the range of effective communication strategies and skills necessary to establish a collaborative relationship with individuals requiring supports and services.
- 3. Assessment:** The direct support professional should be knowledgeable about formal and informal assessment practices in order to respond to the needs, desires and interests of individuals requiring supports and services.
- 4. Community and Service Networking:**  
The direct support professional should be knowledgeable about the formal and informal supports available in his or her community and skilled in assisting individuals requiring supports and services to identify and gain access to such supports.
- 5. Facilitation of Services:** The direct support professional is knowledgeable about a range of participatory planning techniques and is skilled in implementing plans in a collaborative and expeditious manner.
- 6. Community Living Skills & Supports:** The direct support professional has the ability to match specific supports and interventions to the unique needs of individuals requiring such and recognizes the importance of friends, family and community relationships.
- 7. Education, Training and Self-Development:**  
The direct support professional should be able to identify areas for self improvement, pursue necessary educational/training resources, and share knowledge with others.
- 8. Advocacy:** The direct support professional should be knowledgeable about the diverse challenges facing individuals requiring supports and services and should be able to identify and use effective advocacy strategies to overcome such challenges.
- 9. Vocational, Educational and Career Support:**  
The direct support professional should be knowledgeable about the career and education related concerns of individuals requiring supports and services and should be able to mobilize the resources and support necessary to assist individuals to reach their goals.
- 10. Crisis Intervention:** The direct support professional should be knowledgeable about crisis prevention, intervention and resolution techniques and should match such techniques to particular circumstances and individuals.
- 11. Organization Participation:** The direct support professional is familiar with the mission and practices of the support organization and participates in the life of the organization.
- 12. Documentation:** The direct support professional is aware of the requirements for documentation in his or her organization and is able to manage these requirements efficiently.

# Resources

## Organizations

### **American Network of Community Options and Resources (ANCOR)**

1101 King Street, Suite 380  
Alexandria, VA 22314  
(703) 535-7850  
[www.ancor.org](http://www.ancor.org)

### **Coalition of Families for Direct Support Workers**

562 West End Avenue, 2A,  
New York, N.Y. 10024  
(212) 799- 2042

### **College of Direct Support**

111 Center Park Drive, Suite 175  
Knoxville, TN 37922  
(877) 353-2767 *toll free*  
[www.collegeofdirectsupport.com](http://www.collegeofdirectsupport.com)

### **John F. Kennedy Jr. Institute for Worker Education**

101 West 31st Street, 14th floor  
New York, NY 10001  
(646) 344-7315  
[www.jfkjrinstitute.cuny.edu](http://www.jfkjrinstitute.cuny.edu)

### **The Long Island Alliance of Agencies**

400 Garden City Plaza  
Suite 202  
Garden City, NY 11530  
(516) 542-0088

### **Mid-Hudson Coalition**

36 Violet Avenue  
Poughkeepsie, NY 12601  
(845) 452-5772  
[www.midhudsoncoalition.org](http://www.midhudsoncoalition.org)

### **National Alliance for Direct Support Professionals**

PO Box 13447  
Minneapolis, MN 55414  
[www.nadsp.org](http://www.nadsp.org)

### **National Clearinghouse on the Direct Care Workforce**

349 East 149th Street, 10th Floor  
Bronx, NY 10451  
(718) 402-4138  
(866) 402-4138 *toll free*  
[www.directcareclearinghouse.org](http://www.directcareclearinghouse.org)

### **New York State Association of Community and Residential Agencies**

99 Pine Street, Suite C110  
Albany, NY 12207-2776  
(518) 449-7551  
[www.nysacra.org](http://www.nysacra.org)

## Appendix Two, *continued*

### President's Committee for People with Intellectual Disabilities

Administration for Children and Families  
370 L'Enfant Promenade, S.W.  
Washington, D.C. 20447  
(202) 619-0634  
[www.acf.hhs.gov/programs/pcpid](http://www.acf.hhs.gov/programs/pcpid)

### Quality Mall

150 Pillsbury Drive SE, Room 204  
Minneapolis, MN 55455  
(612) 624-6328  
[www.qualitymall.org](http://www.qualitymall.org)

### Self-Advocacy Association of New York State

Capital District DSO  
500 Balltown Road  
Schenectady, NY 12304  
(518) 382-1454  
[www.sanys.org](http://www.sanys.org)

### University of Minnesota

Research and Training Center on Community Living  
204 Pattee Hall  
150 Pillsbury Drive S.E.  
Minneapolis, MN 55455  
(612) 624-6328  
[www.rtc.umn.edu](http://www.rtc.umn.edu)

## Video

### Everyday Heroes

[www.omr.state.ny.us/hp\\_everyday\\_about.jsp](http://www.omr.state.ny.us/hp_everyday_about.jsp)

## Publications

*NYSACRA Toolkit: Public Relations* presents strategies and vehicles for promoting greater understanding and acceptance of people with disabilities.

*NYSACRA Toolkit: Site Selection* describes the site selection process for community residential development in NYS, offers suggestions on best practices, and answers frequently asked questions.

*NYSACRA Legislative Action: Guide to Advocacy* explains the legislative process and presents effective advocacy strategies.

*NYSACRA Legislative Action: Key Contacts* offers contact information for key state and federal government officials/agencies as of January, 2008.

*NYSACRA Policy Action Paper: Medicaid in New York State – It Works and It Puts People First* provides an overview of the Medicaid program in New York and person-centered accounts of how it enables people with disabilities.

These publications are available by contacting:

NYSACRA  
99 Pine Street, Suite C110  
Albany, NY 12207-2776  
(518) 449-7551

# About NYSACRA

## Background

Founded in 1977, NYSACRA originally provided not-for-profit service provider agencies with the opportunity to meet and share ideas and information in what were the early stages of the development of community residences for people with intellectual and other developmental disabilities. NYSACRA also provided an important public voice representing the needs of its members at the federal, state, and local levels.

### VISION

NYSACRA is a catalyst and leading advocate for people who have developmental disabilities and the organizations that support them.

Since 1977, however, the service delivery system for people with intellectual and other developmental disabilities has changed dramatically. From virtually no choices (other than home or institutional care) to an array of opportunities for those with a variety of disabilities, NYSACRA now represents nearly 200 not-for-profit service provider agencies with a combined workforce of approximately 65,000 employees. The supports provided by these agencies and their staff are wide-ranging and include: supportive and supervised residential living alternatives, prevocational and vocational training, family care and respite services, clinical, and educational and preventive education services.

The 1990s, in fact, saw an unprecedented change in the intellectual and other developmental disabilities service delivery

system, i.e. services that were once peripheral, such as case management and family supports, emerged as central to the service delivery system. Accordingly, in 1994, in order to meet the challenge of providing appropriate support to its members in this rapidly changing field, NYSACRA implemented a strategic planning process. That process has helped NYSACRA prepare for the future needs of its members over the longer term.

### MISSION

NYSACRA represents the collective voice of its members in promoting the full participation of persons with developmental disabilities in the communities of New York State. NYSACRA executes this mission by:

- *influencing public policy, public understanding and community action dedicated to quality services designed to realize inclusion and meet individual need.*
- *acting as a resource to provide services, advocacy, information, technical assistance, education, collaboration and networking experiences to our members.*
- *promoting choice, quality supports and services in the community, working in partnership with people with developmental disabilities, their families, those who provide their supports and others involved in their lives.*

## Strategic Plan

As a professional trade association, NYSACRA's obligation and commitment to its members is as wide-ranging as their ever-changing needs. Thus, the strategic planning process provides the organization with the mechanism to identify member needs through its committee structure (*see page 53*), and to take action to address those needs. That Strategic Plan is firmly grounded in the vision, mission, and overall goals of the association.

NYSACRA's Strategic Plan for 2006-2011 (available in its entirety to members at [www.nysacra.org](http://www.nysacra.org)) is comprised of three strategic areas of activity: shaping the industry, improving member capacity, and improving association capacity. Each area is comprised of goals and includes:

- **Shaping the industry:** exploring a new service paradigm, impacting public policy, shaping industry standards, and professionalizing the workforce.
- **Improving member capacity:** strengthening local membership and providing appropriate technical support for individual members.
- **Improving association capacity:** increasing financial capacity, flexibility and resource development, through the improved use of technology and by increasing membership.

Although NYSACRA will be engaging in a number of new and exciting activities to meet its strategic planning goals, workforce development remains the cornerstone of its commitment to its members. Accordingly, significant effort will be devoted to identifying other industries that have negotiated major shifts in

product development and/or business models by linking success with valued workforces; NYSACRA will then evaluate how those models can improve the delivery of person-centered opportunities in the field of developmental disabilities while retaining the investment in staff.

In addition, NYSACRA is expanding its public information campaign to educate those not familiar with the industry about the continuing crisis in recruitment and retention of direct support professionals. This effort, coupled with proactive political involvement beginning at the local level but supported primarily by NYSACRA's legislative affairs activities, will set the stage for changes in compensation and benefits, and education and training.

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### GOALS

NYSACRA's strategic plan is developed and measured against four basic goals that focus on enhancing the organization's impact on the:

- *policies and practices that affect people with developmental disabilities;*
- *stakeholder relationships within the developmental disabilities service delivery system;*
- *quality of services and supports available to people with developmental disabilities; and*
- *continued expansion of comprehensive services to the organization's membership.*

**BOARD OF DIRECTORS**

Tom McAlvanah, *President*  
Steve Klein, *First Vice President*  
Fredda Rosen, *Treasurer*  
Jim Lawler, *Secretary*

**Regional Vice Presidents**

Desiree Loucks Baer, *Capital*  
Paul Lowry, *Long Island*  
Cathy Varano, *Mid Hudson*  
Louis Cavaliere, *New York City*  
Patrick Waite, *Northern*  
Helen Trowbridge Hanes, *Western*

**At-Large Members**

Evelyn Alvarez  
Jason Chapin  
Lee Rambeau  
Matthew Sturiale  
Jim Wilson

**Immediate Past President**

Robert Budd

**COMMITTEE STRUCTURE**

- Policy Analysis:** analyzes, reviews and influences policies and regulations affecting services to persons with developmental disabilities.
- Education and Training:** promotes agency staff development and training as a service to the NYSACRA membership by identifying training needs and developing educational initiatives.
- Annual Conference:** establishes the direction of the annual conference by developing a theme, identifying topic areas and suggesting presenters.
- Legislative:** identifies, prioritizes and monitors NYSACRA's legislative agenda.
- Workforce:** identifies, develops and implements projects and programs that improve and enhance the quality of the workforce that serves individuals with developmental disabilities.
- Technology:** researches and reports on technology that will enhance the delivery of services to individuals with developmental disabilities.
- Quality:** promotes quality person-centered initiatives and practices that embrace choice, dignity and accountability and also provides guidance on quality assurance, corporate compliance and other regulatory standards.
- Ad Hoc:** ad hoc committees are created at the discretion of the Board of Directors to consider, investigate, take action on, or report on some single issue or subject.



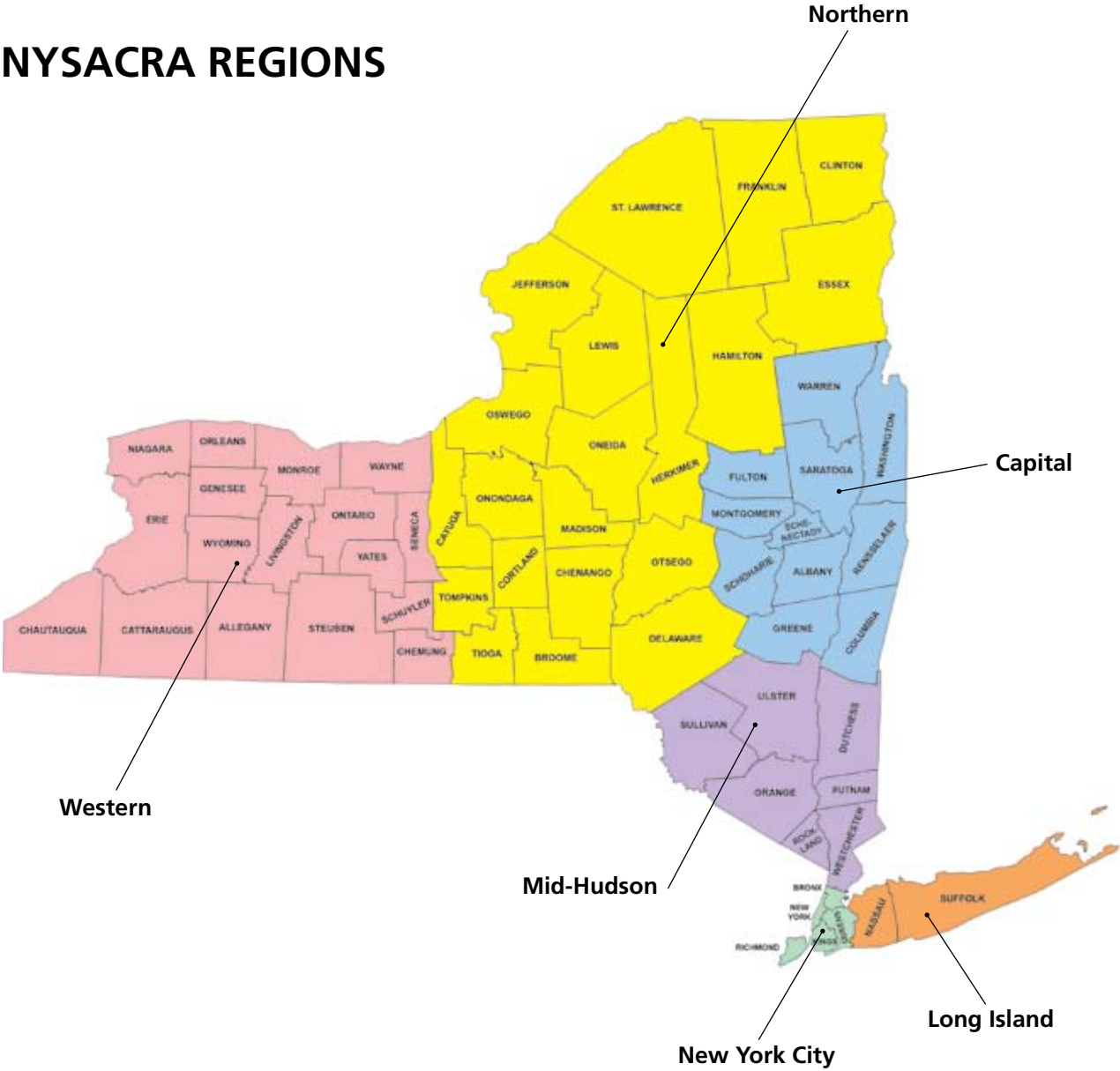
## **STAFF**

Ann M. Hardiman, *Executive Director*  
Jim Kosakoski, *Deputy Executive Director*  
Patricia McKay, *Associate Executive Director*  
Joseph M. Macbeth, *Assistant Executive Director*  
Ann D. Genaro, *Director of Educational Services*  
Forest Cotten, *Director of Legislative Services*  
Diana Denner, *Coordinator of Information*  
Tamelia Fritz, *Office Assistant Intern*  
Philip Kopach, *Financial Coordinator*  
Aileen Rourke, *Office Assistant*

## **CONSULTANTS**

Tom Harmon, *Research/Writing*  
Stephanie Richardson, *Design/Production*

# NYSACRA REGIONS





## **NYSACRA RECOGNIZES AND SUPPORTS THE**

National Alliance for Direct  
Support Professionals (NADSP)

*Code of Ethics*

and the

Human Services  
Research Institute (HSRI)

*Community Support Skills Standards*

***See Appendix One  
Workforce Values***



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