

A Quarterly Newsletter of the National  
Alliance for Direct Support Professionals

# Frontline Initiative

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## John F. Kennedy, Jr. Lighting the Way for DSPs



John F. Kennedy, Jr. with a group of direct support professionals.

Photograph by Andre Beckles, University Relations, CUNY, New York

John F. Kennedy, Jr. Tribute  
Frontline Initiative Newsletter

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Writing this brief tribute to John F. Kennedy, Jr. was more than a bit daunting. Although I had met John and served on the President's Committee on Mental Retardation (PCMR) with him, I did not really know him. In fact, I cannot even begin to imagine what it was like to be John F. Kennedy, Jr., except to believe his joyful self-assessment that its benefits greatly exceeded its annoyances. John's sense of being blessed fostered greatly his ability to give so much, because he felt and expressed a personal sense of obligation to try to repay some measure of what he felt he had received. It was fortu-

nate, but not surprising, that among his involvements was that of contributing to the social movement that championed the rights and opportunities of persons with intellectual disabilities to enjoy full and respected membership in the communities of their birth.

It is not surprising that John made a commitment to this movement because so much of it is a direct legacy of his own family. His father, President John F. Kennedy, established the first meaningful federal government commitment to the well-being of people with intellectual disabilities. His uncle, Senator Robert Kennedy, became the

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# Frontline Notes

## Editorial Information

Editor · **Nicole Lei**  
Assistant Editor · **John Jendro**  
Supervising Editor · **Susan O'Neill**  
Managing Editor · **Amy Hewitt**  
Graphic Design · **Connie Burkhart**  
Web · [ici2.umn.edu/rtc/dsp](http://ici2.umn.edu/rtc/dsp)

## Board Members

**Pamela C. Baker**  
Long Beach, MS — FAAMR

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New York, NY — Reaching Up

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Developmental Supports

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Rockville, MD — DSP,  
The Arc of Montgomery County

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**Rick Rader**  
Chattanooga, TN — Orange  
Grove Center

**Marianne Taylor**  
Cambridge, MA — HSRI

**Ralph W. Vunderink**  
Wyoming, MI — DSP, Spectrum  
Community Services

**Marci Whiteman**  
O'Fallon, MO — Self-Advocacy  
Coordinator

If you are interested in commenting on or contributing to Frontline Initiative, or in becoming a member of the editorial board, please contact —

Nicole Lei  
P.O. Box 13315  
Minneapolis MN 55414  
Tel. 612.624.0060

It never hurts to have friends in high places. For the hundreds of thousands of Direct Support Professionals (DSPs) across the nation and indeed across the world, John F. Kennedy, Jr. was one of those friends. His death is a tragedy for his family and friends and a great loss to all those whose lives he touched directly and indirectly through his civic work. This edition of *Frontline Initiative* is devoted to the memory of John and his contribution to the profession of direct support.

While much of the impact John had in improving the status and opportunities for DSPs happened through the Kennedy Fellows program in New York, there were other activities of his Reaching Up Foundation, Inc. His influence was felt more broadly through support to publications related to DSP issues (such as this newsletter), through sponsorship of public policy forums, and by bringing his name, his status, and his familiar face to these important issues.

For those of you who knew John, we hope that these articles reflect at least a little of what you knew to be his many contributions to this field. For those of you who weren't familiar with his work in this area, we hope you take some time to read these articles and get a better sense of how much he cared about forwarding the cause of the DSP.

When you lose a friend, sometimes you have to become a better friend to yourself. It's time for DSPs to look beyond their own walls, as Kennedy Fellow Cindy Mowris did (see *The Big Picture*, page 4), and to take the opportunity to let the world know that the skills, knowledge and attitudes it takes to excel at direct support work are the same attributes that make for better parents, neighbors, and citizens. This is your forum. Let us hear from you.

Our next edition will feature articles about diversity in our typical features and columns format but in an expanded 16 pages. We welcome two new editors, Nicole Lei and John Jendro, with this edition and say good-bye to editor Tom Beers. We wish Tom good luck with his future ventures. We greatly appreciated his efforts and commitment to *Frontline Initiative*.

The Editors

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P.O. Box 13315  
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# NADSP Member Organizations and State Contacts

**Frontline Initiative** is a product of the National Alliance for Direct Support Professionals. The NADSP is a collaboration of organizations who are committed to promoting the development of a highly competent human services workforce that supports individuals in achieving their life goals. The following are some of those organizations—

- Administration on Developmental Disabilities
- American Association on Mental Retardation
- American Association of University Affiliated Programs
- American Network of Community Options and Resources
- The Arc of the United States
- Association of Public Developmental Disabilities Administrators
- Association for Persons in Supported Employment
- CARF...The Rehabilitation Accreditation Commission
- Consortium for Citizens with Disabilities
- CUNY Consortium for the Study of Disabilities
- Council for Standards in Human Service Education
- Human Services Research Institute
- Institute on Community Integration (UAP), University of Minnesota
- International Association of Psychosocial Rehabilitation Services
- Irwin Siegel Agency Inc.
- National Association of State Directors on Developmental Disabilities
- National Association of State Directors of Vocational Technical Education
- National Center for Educational Restructuring and Inclusion
- National Center for Paraprofessionals in Education
- National Organization of Child Care Workers Association
- National Organization for Human Service Educators
- National Resource Center for Paraprofessionals
- New Jersey Association of Community Providers
- President's Committee on Mental Retardation
- Program in Child Development and Child Care, University of Pittsburgh, School of Social Work
- Reaching Up
- Self-Advocates Becoming Empowered
- TASH
- United Cerebral Palsy of America

## NADSP Co-chairs

### James Meadours

Self-Advocates Becoming Empowered  
8326 Kelwood Ave., Baton Rouge, LA 70806  
504.927.0855

### Mark Olson

Owobopte Inc.  
3195 Neil Armstrong Blvd., Eagan, MN 55121  
651.686.0405 ext. 148

### Marianne Taylor

HSRI  
2336 Mass. Ave., Cambridge, MA 02140  
617.876.0426 ext. 330

## State Contacts

### Louisiana

David H. Belton, TRI\*ADD Human Development Center  
Louisiana State University Medical Center  
New Orleans, LA 70119  
504.942.8207  
*DBelton@HDC.lsumc.edu*

### Massachusetts

Marianne Taylor, HSRI  
2336 Mass. Ave., Cambridge, MA 02140  
617.876.0426 ext. 330  
*mtaylor2@concentric.net*

### Michigan

Karen Wolf-Branigan, Wayne State University  
Leonard Simons Bldg., Detroit, MI 48202  
313.577.7981  
*K.Wolf-Branigan@wayne.edu*

### Minnesota

Mark Olson, Owobopte Inc.  
3195 Neil Armstrong Blvd., Eagan, MN 55121  
651.686.0405 ext.148

### Missouri

Marci Whiteman  
104-3 Old Hwy 40 #274, O'Fallon, MO 63366

### New York

Bill Ebenstein, CUNY  
535 East 80th Street - 4th floor  
New York, NY 10021  
212.794.5486  
*wiebh@cunyvm.cuny.edu*

### Ohio

Amy Gerowitz, Outlooks/ANCOR  
3883 Blackwood Ct., Cincinnati, OH 45236  
513.793.1946  
*gerowitz@ix.netcom.com*

## NADSP Regional Representatives

### Regis Obijiski

Mid-Hudson Coalition  
P.O. Box 367, Staatsburg, NY 12580  
914.473.3000 x304

### Mark Olson

Owobopte, Inc.  
3195 Neil Armstrong Blvd, Eagan, MN 55121  
651.686.0405, fax: 651.686.0312  
State Coordinator

### Marci Whiteman

MO Division of MR/DD  
104 - 3 Old Hwy 40 #274, O'Fallon, MO 63366  
State Coordinator

### William Ebenstein

CUNY Consortium for the Study of Disabilities  
535 East 80th St., New York, NY 10021  
212.794.5486, fax: 212.794.5706  
*wiebh@cunyvm.cuny.edu*  
State Coordinator

### Karen Wolf-Branigan

Wayne State University, DD Institute  
Leonard Simons Bldg, 4809 Woodward  
Detroit, MI 48202  
313.577.7981, fax: 313.577.3770  
*k.wolf-branigan@wayne.edu*  
State Coordinator

### Carole Thibodeau

### George Smith

Region 10, Community Support Services.  
8 Commerce Drive, Atkinson, NH 03811  
603.893.1299, fax: 603.893.5401  
*region10@tiac.net*

### Tom Gannon

University Affiliated Cincinnati Center  
for Development Disorders  
3333 Burnet Ave., Pavilion Bldg., Rm 4-79  
Cincinnati, OH 45229  
*gannt0@chmcc.org*

# The Big Picture

## A DSP First-Person Story

It is with great sadness and distress that I write this article to memorialize a man whose passion to improve humanity has touched so many lives. Fortunately for me, mine happens to be one of those lives touched and changed forever. Through my connection with John F. Kennedy, Jr. and the Kennedy Fellows, I have changed from a direct support worker who barely saw beyond the walls of my everyday environment to a Direct Support Professional (DSP) whose resources span the globe. Those connected with the fellowship have been there to guide and support me in my endeavors, provide me with new opportunities and challenges, and above all else helped me to break down the walls that hid the “big picture” from my everyday life as a DSP. It’s amazing how much confidence some recognition, support, and a simple handshake can create.

When a friend gave me the application for the Kennedy Fellowship, I stuffed it in the desk because my crazy, hectic days didn’t allow much personal time. While tidying up weeks later I found the application and completed it with the attitude, “What’s to lose?” As I pursued the application, I learned that the Kennedy Fellows Program supports the education and career advancement of DSPs in the disabilities field through a scholarship/mentoring program. I thought to myself, “Wow! Someone to support us? I’m in.” You know how it seems there is often very little support, especially when you really need it. Needless to say, I was ecstatic when I received the letter of acceptance. It was the greatest honor I have ever known.

That confidence boost helped me strive harder and reach for things I previously thought unattainable both academically and professionally. I became involved with the Fellowship, attending conferences as a representative. Then I began sitting on panels and presenting infor-

mation and perspectives on direct support work. Eventually I worked to organize and attend international conferences. I have continually been challenged when given these opportunities to represent the direct support perspective but those challenges became easier as time went on. I had

changed from a shy young girl who hid in the corner to a professional woman.

When I learned that my agency put together a team to attend an international conference on childcare to be held in Glasgow, Scotland, I teased a colleague on the team saying that I wanted in. Initially I thought of it as a joke, because what agency would sponsor a direct support worker to go to an international conference across the “Great Pond”? But I filled out the brochure anyway and a couple of weeks later got a reply from my Executive Director stating that there was not enough money in the budget to allow me to attend. At that point I was determined to go even if I had to pay for it myself. I soon came to my senses and realized that on my salary it would never happen. Determined, I wrote a letter to the Fellowship outlining my expenses and explaining my situation. A couple of weeks later I received a check for three-quarters of the expense and a letter wishing me well with a request that I act as a representative of the Kennedy Fellows! My agency decided to sponsor the balance of the trip. Not in a million years would I have pictured myself as an International Delegate.

While I was in Glasgow, I made many international friends and business contacts. The title of the conference I attended was *Realities & Dreams*. Can you imagine? During that week and half, I felt the weight of the world. It was an overwhelming sense of responsibility and obligation. Nations of the world looked to us for guidance, they

The best thing about being a fellow is the opportunities to meet other people in the field, [such as] direct care workers who have spent a lot of years in the field. We had the opportunities to go to different conferences and were able to network with people not only here but abroad.

— Kennedy Fellow  
Karen Dennis

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# Reaching Up

## John F. Kennedy, Jr. and the Soul of the Service Delivery System

Reaching Up is a non-profit organization that was founded in 1989 by John F. Kennedy, Jr. Its purpose is to support higher education and career advancement of frontline workers in health, education, and social service occupations. In association with The City University of New York, the largest urban university system in the country, Reaching Up developed new college level courses and specialized training programs for direct support workers. Over the last ten years, 10,000 individuals employed as group residence workers, classroom aides, job coaches, mental health workers, home care workers, personal care attendants, nurse aides, child care workers, and youth counselors have enrolled in certificate programs that have been created at 15 public colleges throughout New York. These credited courses can be integrated into associates and baccalaureate-degree programs in related fields.

Higher education is the cornerstone of Reaching Up's attempt to address the chronic problems of high turnover, low wages and minimal training of frontline workers. John was an especially strong advocate of public higher education and felt that the most reliable and efficient way to upgrade knowledge and skills, and support the career advancement of low wage earners, was to increase their access to college. He was aware that in our society the socioeconomic fault line that separates those who are "making it" from those who are being left behind runs through higher education.

John also started the Kennedy Fellows program which has provided scholarships and career mentoring to

over 400 exemplary workers. He contrasted "instrumental" mentoring aimed at achieving specific outcomes and "classical" mentoring that addresses the development and empowerment of the individual. On the one hand, he stressed the importance of Fellows achieving concrete objectives, such as maintaining college enrollment, making progress toward a degree, continuing to be employed and advancing in their careers at a human services agency. By any of these measures they have been very successful. On the other hand, he spoke of the goddess Athena, who appears in guise of Mentor in Homer's *Odyssey*, as the patron of classical mentoring. He challenged the mentors to embody Athena's "wise counsel" but warned that, like the warrior goddess, mentors must sometimes fight for and protect the rights of both workers and people with disabilities. In other manifestations the mentor is a "divine sister," friend and companion to those who are engaged in the difficult task of balancing work, school and family life.

One pleasant surprise of the mentoring program that John created is that a great deal of informal mentoring and professional support take place. Fellows often identify individuals who are helping them quietly behind the scenes, providing timely advice at moments of decision, and encouraging them to become their best selves. John imagined exemplary direct care workers as modern-day heroes assisted by Athena-like mentors.

John's involvement with the Kennedy Fellows reflected some of

### Senate Version of the *DD Act Extends Reaching Up Scholarship Program to the Nation*

On November 8, the United States Senate passed its version of the Developmental Disabilities Assistance and Bill of Rights Act of 1999 and sent it to the House of Representatives for their consideration. The Senate language made some refinements and additions to existing portions of the Act (Titles I and II—those portions authorizing State Councils on Developmental Disabilities, State Protection and Advocacy Services, University Affiliated Programs—renamed "University Centers for Excellence in Developmental Disabilities Education, Research and Service"— and a new state grant program for family support).

But of special interest to DSPs is a new section (Title III) called, "Program for Direct Support Workers who Assist Individuals with Developmental Disabilities," which includes a provision for a "Reaching Up Scholarship Program." The legislation will allow the Secretary of Health and Human Services to award grants to institutions of higher education, state agencies or partnerships of the two, to carry out scholarship programs which can provide vouchers for up to \$2,000 per year in scholarship assistance toward postsecondary education to direct support workers. Specific conditions of participation will be defined as the applicant organizations develop their individual programs. The Senate has authorized \$800,000 for the program's

# Hands Across the Water

*It is from numberless diverse acts of courage and belief that human history is shaped. Each time someone stands up for an ideal, or acts to improve the lot of others, or strikes out against injustice, he sends forth a tiny ripple of hope, and crossing each other from a million different centers of energy and daring, those ripples build a current that can sweep down the mightiest wall of oppression and resistance.*

—Robert Kennedy, *South Africa*, 1966

Perhaps Mr. John Kennedy, Jr. developed his spirit of service and idealism that has lifted up so many direct support professionals by embracing the message that continues to live in the words of his uncle, or it may have grown from the example of his family's longstanding service to people with disabilities. Whatever the reason for his commitment and quiet action on behalf of the direct support workforce, one of Mr. Kennedy's legacies is the creation of an international movement to advance the recognition and education of this workforce.

In August, I was privileged to attend an institute with the theme of *International Perspectives on the Training of Personnel in the Disability Field*. This gathering of people in New York City was organized by Bill Ebenstein, Jason Chapin and Lyda Clifton of the City University of New York (CUNY), who have been the skillful and energetic leaders assisting Mr. Kennedy in fulfilling his vision of providing direct support professionals. It was made up of many people whose lives were touched by the generosity and spirit of Mr. Kennedy, who was a co-spon-

sor of the institute along with the American-Ireland Fund and other groups. Lyda, Bill and Jason were close to Mr. Kennedy and deeply saddened by the recent tragedy, but

The way he [John F. Kennedy, Jr.] impressed me had nothing to do with his status as a well-known celebrity. It was the way he made people not to feel intimidated by his status. It was the way he went around the room and made himself such a people person. He ate with us, laughed with us, talked with us, and he listened. He was like an old friend.

— Kennedy Fellow  
Patricia Robinson

chosed to honor his memory by carrying forward with the conference.

The meeting opened with Bill's reflections on the remarkable work of Mr. Kennedy in strengthening the workforce and to the bittersweet strains of an Irish ballad. Bill described Mr. Kennedy's deep understanding of the challenges of low wages and status that confront today's human service workforce and how he brought these issues to the

national forefront in his speeches at the American Association on Mental Retardation (AAMR) conference in 1996 and through his service to the President's Committee on Mental Retardation (PCMR). He described the Kennedy Fellows program and, through out the two-day institute, many of the Kennedy Fellows in attendance spoke about how Mr. Kennedy knew each of them personally and about their deep sense of loss with his death.

In recent years, without diminishing his attention to national issues in direct support work, Mr. Kennedy took up the additional challenge of reaching out to people throughout the world to exchange information on workforce development and to explore models of supporting people with disabilities with particular emphasis on developing countries. The summer institute continued this work by convening delegates from the North and South of Ireland, the Caribbean nations of Haiti and Jamaica, Vietnam, and the United States to discuss each culture's approach to training and educating personnel supporting people with disabilities.

Dr. Roy McConkey of Ulster University spoke about the Community Based Rehabilitation (CBR) approach promoted by the World Health Organization. This approach focuses on building the capacity of indigenous community members and community organizations to support people with disabilities rather than temporarily infusing specialists and specialized services which are not typically sustainable over the long run in poor countries.

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# Part of the PCMR

John F. Kennedy, Jr. was appointed to the President's Committee on Mental Retardation (PCMR) in 1995 by President Clinton. As a PCMR member, he brought to the table his deep commitment and devotion to people with disabilities and the people who make up the workforce of individuals who assist people with disabilities. John was deeply concerned about the quality of supports and services for people with developmental disabilities. He demonstrated keen insight into an often neglected aspect of the disabilities movement by focusing on the relationship between quality of care for people with mental retardation and the manner in which we treat the people who provide direct support for people with mental retardation.

This modest man, who could have had or done anything he wanted, chose to work on behalf of those who support people with disabilities. In his group photo with fellow members of the PCMR, John stands smiling in the second row, wearing his name tag. One of the group, he worked very quietly, but his accomplishments were many. Through his private foundation, Reaching Up, Inc., John initiated an innovative program that allowed direct support workers who wished to stay in the field an opportunity to complete their college education. Here, in his own words, he describes the work of the Reaching Up Foundation as part of the commencement address at Washington College, Maryland in May of 1999 —

*Today is your day and I hope it is just one of the many that will define who you are and what you make with your*

*life. As Thomas Paine said, 'Youth is the seed time of good habits, in individuals and in nations.' You have played a vital part in your community and I know that your good work will not end with graduation.*

*Now, I should tell you something about the organization you have so kindly and generously acknowledged here today. Ten years ago, Jeffrey Sachs (who's somewhere in the audience) and I founded Reaching Up in order to improve educational and career opportunities for the workers in health, education and social service, the front-line workers, those who teach and care for people with disabilities and children with special needs, disadvantaged youth, the chronically ill, the frail and elderly.*

*Typically, entry level caregivers receive virtually no training and earn just above the minimum wage. They have few prospects for advancement and are more likely to leave their jobs than to stay, more often than not to flipping burgers in McDonald's or Burger King because that pays them a lot more money than being a direct care worker. Reaching Up and City University of New York joined together into a partnership to create opportunities for thousands of direct care workers to enroll in job-related courses that can lead to undergraduate degrees.*

*Through our Fellows Program, we have also provided college scholarships and career mentoring to 400 exemplary workers. Since 1990, half of them have graduated with baccalaureate or master degrees. One quarter have completed certificates or associate degrees and, more importantly, 95% of them are still employed in those jobs. Many of those who've completed their degrees have become social workers, teachers and psychologists, and*

*some are even running the human service agencies [that they served in as entry-level workers — editors revision]*

*What this means is that our most vulnerable people in our society receive better care and support and their families feel more secure. Employers experience less turnover and caregivers are better trained, better compensated and better appreciated. The colleges where they attend benefit from their real world experience and are enlivened. The families of direct care workers are not struggling as hard to make ends meet. Their children have also benefited, many of them attending the best colleges in the country.*

*No doubt many of you know what it means when I say "service is its own reward" and I hope you continue to serve. For me, working with Reaching Up has been a tremendously rewarding experience and I've learned a great deal from it.*

*You have learned a great deal at this college but your learning must continue to be a lifelong experience that is informed by your direct involvement in the lives of your fellow citizens. As George Washington wrote dozens of times, over and over to practice his penmanship when he was a young man: 'Labor to keep alive in your breast that little spark of celestial fire called conscience.'*

*Thank you very much for this honor. Good luck.*

Over the years, John touched the lives of countless direct support workers and people with disabilities through Reaching Up and the PCMR. John brought direct care professionals together on a national scale to further the principles he

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# Alliance Update

Most people knew John F. Kennedy, Jr. as the son of a famous president, a member of a famous family or the founding editor of the national magazine, *George*. Fewer knew him as the impetus behind the development of a national coalition to address direct support worker issues or a supporter of a grassroots newsletter for direct support professionals: *Frontline Initiative*. In the inaugural issue of *Frontline Initiative*, John F. Kennedy, Jr. challenged national organizations to unite and form an alliance that would strive to bring direct support workers a much deserved professional identity, to increase attention and resolution to the problems faced by direct support workers across the United States and to focus on the important partnerships needed between direct support professionals and people with disabilities. We are reprinting his initial article (page 9) to remind readers about the important role he played in forming the National Alliance for Direct Support Professionals and supporting the publication of this newsletter.

John F. Kennedy, Jr. believed in the importance of direct support workers, support participants and other stakeholders in our human service community joining hands across the nation and, indeed, around the world to strengthen the workforce and to empower consumers.

In launching the *Frontline Initiative* and celebrating the beginnings of the National Alliance for Direct Support Professionals, John F. Kennedy, Jr. expressed hopes and images that many of us share. These images include a future where direct support professionals and people

receiving support walk together, talk together and create a future that has more to do with partnership and common goals than with the differences and formal service structures that keep us apart. A future where token presence of DSPs and consumers at conferences and policy meetings is eclipsed by the full presence and participation of these constituencies who share so much common ground.

The NADSP and its publication, *Frontline Initiative*, are working hard to cultivate the changes that John Kennedy envisioned when he planted the fiscal and strategic seeds for our work in the Alliance and facilitated our outreach to DSPs by supporting the newsletter. The NADSP embraces and elevates the voice of direct support professionals and consumers by ensuring that its steering committee is led by a direct support professional, a self-advocate, and a workforce development professional. Our primary goals this year are to support and broaden the network of local coalitions aligned with NADSP goals. Coalitions are gathering in New York, Missouri, Ohio, Kentucky, New Hampshire, and Washington and affiliating with the NADSP mission.

Local affiliates are communicating primarily by telephone, email and our recently organized list-serve. Groups are sharing legislative and policy initiatives that strengthen the workforce and are helping NADSP develop a code of ethical practice for direct support professionals and a framework for a national credential. Along with their role as local change agents, the NADSP envisions these coalitions as the key nodes in a network of locally driven, nationally

connected credentialing bodies participating in the credentialing criteria they have developed and endorsed.

*Frontline Initiative* brings the voice of direct support professionals and self-advocates to thousands of readers on a quarterly basis. This publication is written by and for direct support professionals, bringing them timely information to help them provide better support. This publication is playing a vital role in enhancing the image and leadership of the direct support workforce.

In these efforts we are committed to carrying on the vision and challenge that John F. Kennedy, Jr. left with us — “to transform chronic work problems into creative possibilities.”

Amy Hewitt, Institute on Community Integration, University of Minnesota.  
Marianne Taylor, Human Services Research Institute.



# A Forum for Change

## John F. Kennedy, Jr. Looks at the Alliance

In 1989, several colleagues and I founded Reaching Up, Inc., a non-profit organization devoted to improving educational and career opportunities for direct care workers. Since 1994, we have been meeting with leaders of national organizations who share a concern about the low wages, high turnover, minimal training, and lack of career opportunities for dedicated, hard working staff. Recently, a number of national organizations including Reaching Up have joined together in convening a National Alliance for Direct Support Workers. The Alliance creates a national network for professional and provider organizations, consumer and advocacy groups, academic and research institutions, government agencies, and private foundations to develop effective strategies to strengthen the role of direct support workers within an evolving service delivery system.

Frontline Initiative is an Alliance-sponsored newsletter of the American Association on Mental Retardation Special Interest Group for Direct Support Professionals, Reaching Up, and the University of Minnesota-Institute on Community Integration Direct Service Training Initiative. An Alliance goal is to increase access to competency-based training, higher education, and career mentoring for all direct support staff. Improving services to people with disabilities

by acknowledging and rewarding qualified staff is also an Alliance priority. To support these activities additional work force research is needed that focuses on the relationship between the quality of services and opportunities for career advancement for exemplary employees. The expectation is that this newsletter will promote an ongoing dialogue and an exchange of ideas in these related areas.

In recent years, all sectors of the disability field have increased their outreach to both workers and self-advocates. One result is that members of these constituencies attend more regional and national conferences. We need more forums like these, outside of the service environment, where workers and people with disabilities can talk directly to each other to discuss their common interests as well as their differences. As allies with a shared agenda, they can help each other achieve their goals. My hope is that this publication will also help to foster communication and networking among the millions of self-advocates and direct support workers from all around the country.

The powerful economic, social, and political forces that are reshaping our systems of health care, special education, and social welfare will require concerted action by all members of the developmental disabilities community. It ap-

pears certain that in the future the role of direct support workers will be expanded. This publication is timely because it will anticipate future trends and present ideas and innovations that can transform chronic work force problems into creative possibilities that will improve the quality of life of both consumers and staff.

Getting to know him [John Kennedy, Jr.] was a big deal for me. He was a prestigious person with a lot of simplicity. It was amazing to see someone with that magnitude had genuine interest in helping people.

He was a people's person.

— Kennedy Fellow  
Wilson David

# One Parent's Perspective

At 2:30 a.m., in Boulevard Hospital, Woodside, New York, the obstetric doctor showed me Michael, an hour old in his small crib in the nursery and said, "Your son will be mentally retarded. Notice his features and his hands. I'm sorry."

Mike had Down syndrome. With that, our family would be changed forever. The year was 1960 and at the time our culture favored institutionalization of children like Mike.

Over the next weeks, Margie, Mike's mother, and I were confronted with a bevy of questions, doubts, and fears about his future and that of our family — we had a 3-year-old daughter and a year-and-a-half-old son (over the next several years two more boys and a girl would be born). Fortunately, things began to fall into place. After conflicting advice, including from our parents and the obstetric staff, Mike came home three weeks after his birth. Unlike some of the doctors we had contact with, his pediatrician strongly believed that he would be as easy to care for as his siblings, which turned out to be true.

Today there are a number of options for support for parents of children with disabilities that we didn't have. Fortunately, Flower Fifth Avenue Hospital included Margie, Mike and me in a year long pilot support program for infants with mental retardation and their parents. We became acquainted with the Association for the Help of Retarded Children (AHRC), founded in New York City in 1949, which proved to be very helpful as a parent resource for information and inspiration. I joined AHRC's board in 1966, was its president from 1974

to 1977, and am still an involved board member.

Mike grew and prospered, principally due to a large extended family and friends and the excellent special education programs of the city's public schools.

In the mid 1970's there was a radical change in New York in the care of persons with mental retardation and developmental disabilities (MR/DD). Geraldo Rivera's expose on local ABC TV of the deplorable conditions in the state run Willowbrook Residential Facility led to a court action. The resulting Willowbrook Consent Decree required New York State to establish comprehensive community based programs for persons with MR/DD. A whole new industry gradually began to grow.

By the mid 1980's, community programs (residential, day treatment, workshop, recreation, and health) had reached a critical mass. Even then the workforce was plagued with high turnover, low pay, and under-preparedness. These needs were first identified by the top staff at AHRC. A big issue was how to create meaningful career paths for those who wanted to stay in the field.

In 1989, Mike Goldfarb, AHRC's Executive Director, and his colleague Dr. Jack Gorelick asked me, in my capacity as chairman of the City University of New York's (CUNY) Board of Trustees, if CUNY and its network of 20 colleges might undertake an effort to educate and train Direct Support Professionals (DSP) in the MR/DD field. Through Jeff Sachs, a former Health Policy Administrator and

guru for New York Governors Carey and Cuomo, and a good friend, we approached John F. Kennedy, Jr. with the problem. Out of numerous discussions and independent analysis by John, the Kennedy Fellows program and Consortium for the Study of Disabilities was established at CUNY, and simultaneously, Reaching Up Inc. was founded.

John F. Kennedy, Jr.'s intervention and creativity substantially increased the quality of care for persons with MR/DD and other disabilities. By making available low cost quality higher education, he empowered thousands of DSPs to pursue career paths that are well paying, challenging and rewarding.

In one example, a woman who worked as an entry level worker in my son's residence, and would not have had the opportunity to go to college otherwise, has completed over 95 credits of the 120 needed for a bachelor's degree in six years as a Kennedy Fellow. She is now a manager in another AHRC residence making a middle-class salary and with further opportunities ahead.

John Kennedy and CUNY wisely invested in the DSPs. As a parent, I know there is no one more important in helping my son and others like him on a day-to-day basis than the DSPs.

James P. Murphy is the past chairman of the board for CUNY and past president of AHRC where he remains an active board member. He can be reached at 212.780.2661.

# Agency Believes in Kennedy Fellowship Program

YAI National Institute for People with Disabilities (YAI/NIPD) is a health and human organization that provides comprehensive community-based services to individuals with mental retardation, developmental disabilities and learning disabilities, and their families. We currently serve the New York City metropolitan area inclusive of New Jersey, Connecticut and Pennsylvania in over 250 community-based programs. Founded in 1957 and formerly known as the Young Adult Institute, the organization has expanded its scope of services over the years and works with individuals of all ages. We serve about 15,000 people daily through about 3,000 staff. Additionally, YAI is a training institute providing management training as well as training for direct support staff in over 30 states. Currently YAI is honored to have almost 40 Kennedy Fellows employed.

YAI National Institute for People with Disabilities has always recognized that the quality of services that we provide is contingent on the quality of our staff, which is our greatest resource. We have always believed in providing a career path for our staff. When we first met John F. Kennedy, Jr. and Dr. William Ebenstein, we realized that Reaching Up shared the same vision and values which include tremendous respect for direct care staff providing an environment where staff can develop into competent professionals. At YAI we believe that the better educated direct care staff are, the better able they are to perform a multi-faceted job. To that end we encourage staff development through higher education.

One of John's greatest legacies is his advocacy to ensure that at the City University of New York there is a curriculum in the field of developmental disabilities. While there was no curriculum at all before, now students are getting exposure in coursework. That has significant

Being a Kennedy Fellow is a really great feeling. I was not studious as a younger person and, when I really gave it everything I had like I should have given it many years ago, I achieved it — it felt very rewarding.

— Kennedy Fellow  
Seth Krakauer

impact on people interested in the field as well as the general public. John has helped to reframe the perception of even those students who might not work in the field towards individuals with disabilities as a result of this coursework. That is a very powerful thing.

President Kennedy once said that "individuals with disabilities are victims of fate, let them not be the victims of neglect." John clearly understood this and acted on it. Many people know he had an aunt who had a developmental disability.

He experienced first-hand the impact of having an individual with disabilities in the family. Therefore, John clearly understood the importance of having a qualified, competent direct care workforce.

John was committed to the professionalism of direct care workers. A profession is defined as a circumscribed body of knowledge that is recognized by the public. John was concerned not only to recognize those core areas of expertise and standardize them, but to also ensure that the public recognized and valued this expertise thus truly meeting the definition of a "profession." John was very active on the national level helping to broker agreements on what those competencies are and the best way to credential direct care staff. YAI, in our training throughout the country, recognizes that core competencies need to be developed and standards set. In that respect there is tremendous synergy between the Reaching Up Foundation and YAI.

Our Kennedy Fellows come from all aspects of our programming, such as group homes, schools for adults and children, as well as community and family support programs. The Kennedy Fellows serve as role models and inspire their coworkers to move on to obtain their degrees, apply to the Kennedy Fellowship Program, and to see the intrinsic values of professionalism in this field. The Fellows have exhibited caring, sensibility, professionalism, and an ability to see the larger picture leading to a career in the field of developmental disabilities. The Kennedy Fellowship Program

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# Frontline Resources

The following resources are available to people who care about DSPs and the people they support, thanks to the generous support and vision from the late John F. Kennedy, Jr.

## PCMR Resources

The following publications are available from the President's Committee on Mental Retardation (PCMR). To receive a free copy, call Terry Lion at 202.619.0634 or fax requests to 202.205.9519, email [tlion@acf.dhhs.gov](mailto:tlion@acf.dhhs.gov).

***With a Little Help From My Friends... A Series on Contemporary Supports to People with Mental Retardation***  
Services and supports to people with mental retardation have undergone significant change in the last 50 years. Today people with disabilities are living longer. They and their families are asking for and expecting meaningful support to live their lives as full citizens in their own communities. This series of five booklets provides information in a comprehensive but basic manner designed for individuals who do not know much about how supports are currently provided, but who would like to know more about the history of services and supports as well as current issues and future trends.

*Book 1: Speaking up—Speaking Out:* definitions and prevalence, current issues, self-advocacy and self-determination.

*Book 2: Growing Strong:* issues in early intervention, family supports and the educational system.

*Book 3: Real Lives:* services and supports in supported living, vocational opportunities and supported recreation.

*Book 4: I Am Who I Am:* person-centered planning, challenging behaviors, aging, culturally competent services.

*Book 5: Changing Systems:* quality assurance and funding of supports and services.

## ***Opportunities For Excellence: Supporting the Frontline Worker***

This publication reviews critical information regarding direct support workforce issues across the United States. Direct service workers, consumers, families, researchers, and provider agency personnel all provide insight to critical factors regarding direct support workforce problems and creative strategies for solutions.

## **Reaching Up Resources**

The following publications are available from the *Reaching Up*. To order, contact: Jason Chapin, Reaching Up/CUNY, 535 E. 80th St., New York, NY, 10021, email [jccbh@cunyum.cuny.edu](mailto:jccbh@cunyum.cuny.edu).

## ***The Mentor Guide for the Kennedy Fellows Program***

*Cost: \$2.50*

## ***1993 Report on Cultural Diversity and the Developmental Disabilities Workforce in New York City***

*Cost: \$2.50*

## ***Workforce Issues in the Developmental Disabilities Field (video)***

The main topics are enhancing status of Direct Support Professionals (DSP), providing better access to higher education and lifelong learning, strengthening working relationships and partnerships between DSPs, self-advocates, families, and professionals, and creating incentives for higher education and career pathways for exemplary staff.

*Time: 3 hours. Cost: \$25.00.*

## ***Job Coaches for People with Disabilities (video)***

A day in the life of Kennedy Fellow Seth Krakauer, who works for the Association for the Help of Retarded Children and Adults (AHRC), a large agency in NYC. He demonstrates necessary supports for people with disabilities who are in job support programs.

*Time: 15 min. Cost: \$25.00.*

## ***Travel Trainers for Students with Disabilities (video)***

Features Kennedy Fellow Gerard Grillo, who works for the New York City Board of Education Travel Training Program, on how to train students with disabilities to ride New York City buses and subways.

*Time: 15 min. Cost: \$25.00.*

## ***Children and Youth with Emotional Disturbances (video)***

Ten 1-hour shows with panels of experts who discuss assessment, teaching skills, social skills, current research, and other issues related to K-12 students.

*Time: 10 hours (10 tapes). Cost \$250.00*

## Reaching Up

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his deeply felt values. His good manners and personal courtesy were rooted in a profound respect for other people, whether they were rich or poor, powerful or unassuming. John had a personal relationship with hundreds of direct care workers, some of whom he knew for more than ten years. It was second nature of him to bring respect and respectability to direct care workers. It could not be otherwise. For John, recognizing and dignifying direct care work was an extension of his personality. Therefore, it was very easy and enjoyable for him to embody this principle. He loved interacting with the Kennedy Fellows and was awed by their dedication and accomplishments.

John served on the President's Committee on Mental Retardation (PCMR) from 1995 until his death. PCMR, in association with Reaching Up, published *Opportunities for Excellence: Supporting the Frontline Workforce* which he presented to President Clinton in the Oval Office. In 1996, Reaching Up, PCMR, and American Association for Mental Retardation (AAMR) co-founded the National Alliance for Direct Support Professionals (NADSP). Through these efforts, workforce issues continue to receive much needed national attention. In addition, Reaching Up sponsors international exchange programs for frontline workers from Jamaica, Vietnam and Ireland. John was interested in the way that differing cultural, economic, political and social factors influence the emergence of new service delivery models.

Reaching Up was founded on the premise that a quality service delivery system is linked to the creation of quality jobs for direct care work-

ers. Implied in this perspective is that the destinies of people with disabilities and their support staff are intertwined and that an alliance between them is possible. John defined quality in terms of the daily interactions between folks with disabilities and direct support workers and envisioned a service system in which they were both respected and empowered. He also recognized that mothers, fathers, and siblings are also direct care people and share a special kinship with caring staff. Human services organizations, he believed, should be designed to support partnerships among people with disabilities, parents, direct care staff and professional mentors. John discovered the soul of the service system in these sustaining relationships.

John helped workers find their collective voice and listened to what they had to say. Now they will have to speak up more for themselves. The City University of New York has established a John F. Kennedy, Jr. Institute for Worker Education, which will provide a permanent home for Reaching Up. Working together through this new Institute and the National Alliance, we will try to continue what John started, but we will miss him terribly.

William Ebenstein is the executive director of Reaching Up and the CUNY Consortium for the Study of Disabilities. He can be reached at 212.794.5486 or Fax: 212.794.5706.

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## Reaching Up Scholarship

continued from page 5

first year (requiring an additional \$200,000 to be contributed by participating organizations) and included the language "amounts as needed" for future years.

The creation of this program is a legacy of the work of John F. Kennedy, Jr. It recognizes John's vision and commitment through the Reaching Up Foundation and extends that vision and commitment to direct support workers throughout the United States. Hopefully over time, with continued success and advocacy, the program will grow from hundreds to thousands of Reaching Up Scholarship recipients.

The Editors.

John took a very active role in his Kennedy Fellows program. We received many, many applications and I screened them initially, but he would review the final candidates very carefully. He was a lovely, lovely man. He took time out to speak with every Fellow, got to know about them and their families. At the Kennedy Fellows Convocation in April, one of the new recipients worked up the courage to speak to John, saying, 'Oh, this is such a great honor to meet you.' And John took his hand, and said, 'No, I am honored to be able to work with you.'

— Lyda Clifton, Director of the Kennedy Fellows Mentoring Program for the Reaching Up Foundation.

### Agency Believes

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has consistently helped the Fellows to achieve their aspirations. Individuals who never saw themselves capable of obtaining a college degree or struggled to make ends meet have, as Kennedy Fellows, experienced the tremendous exultation of obtaining a college degree. There is a tremendous sense of pride that they feel in themselves, let alone the respect they gain from family members and coworkers. Through the generosity of John F. Kennedy, Jr., the Mentorship, and support provided by the program, Kennedy Fellows have overcome a myriad of obstacles to attain their goals.

The Kennedy Fellows are individuals who clearly have demonstrated the ability to take on more responsibilities. We have found that they benefit from the mentorship experience. I personally have served as a mentor to a Kennedy Fellow and it has been a real gift to see the person that I work with explore his potential and a career in this field.

The Kennedy Fellowship Program is an important part of YAI/NIPD's staff development program. We have a kindred spirit with the goals and aspirations of the Kennedy Fellowship Program. We are so thankful to have had John as a spokesperson and a leader. His passing away is an irreparable loss. This program will be his lasting legacy. The Kennedy Fellowship Program and John's initiatives on behalf of a competent, well trained, and professional direct care workforce must and will continue.

Jules Feiman is the Human Resource Director at YAI. He can be reached at 212.273.6143 or fax: 212.563.4836.

### Part of the PCMR

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cared about. Through his foundation, he co-sponsored many initiatives of the PCMR including the Next Generation of Leadership Symposiums. His collaborative efforts and financial support produced a number of PCMR publications including *Opportunities for Excellence: Supporting the Frontline Workforce*; *Voices of the Next Generation*; and the five-part series on inclusion *With a Little Help From My Friends: A Series on Contemporary Supports to People with Mental Retardation*.

In accepting his presidential appointment to a second term on the President's Committee on Mental Retardation, John F. Kennedy, Jr. established a mutual agenda for PCMR and Reaching Up in co-sponsoring a national conference on Poverty and Early Onset Disability. As the designated host of this event, John selected the conference dates of February 22 (George Washington's birthday) and February 23, on the Wednesday before his plane disappeared. PCMR and Reaching Up are going forward with the conference, in his memory. As PCMR stated in its press release at the time of his death, "We will miss John and will honor his life and spirit by continuing to work for social justice for people with disabilities with the grace, dignity and respect that he inspired."

This article was co-written by Jane Browning, the current executive director of PCMR, and Gary Blumenthal, the previous executive director. Both Jane and Gary worked with John in his capacity as a committee member. Jane can be reached at 202.619.0634 or fax: 202.205.9519.

### Hands Across the Water

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We learned that Vietnam has adopted the CBR model throughout the country because it is the most practical approach for its largely agricultural economy. Delegates from Haiti described the strong spirit of voluntarism and family-to-family support that is characteristic of their culture. These stories made it clear that it is naïve to presume that wealth is an essential prerequisite to quality support. Indeed, as Phil McCallion of State University of New York (SUNY) — Albany ironically described the "edifice complex" that afflicts many service agencies (the desire to measure service quality through the number of buildings and homes an agency owns), it was clear how the wealth of industrialized countries can create barriers to choice and individualization of support.

Along with former NADSP co-chair, Seth Krakauer, I spoke with meeting delegates about the goals of the NADSP and recognized the critical role that Mr. Kennedy played in launching and sustaining the Alliance. Even as we express our heartfelt sorrow to his friends and family for their loss, let us honor his leadership by committing to combine our ripples of hope into a mighty current of change for direct support professionals and people with disabilities throughout the world.

Marianne Taylor is an NADSP co-chair and works at member organization HSRI in Cambridge MA. She can be reached at 617.876.0426 x 330, or Fax: 617.492.7401.

**The Big Picture**  
continued from page 4

craved our knowledge and experience. During my travels, I discovered a university that sent a chill down my spine as I thought about the possibility of attending. The following year I returned to study at that university. Even today, I still can't believe I did that.

If not for the efforts of John, these opportunities and experiences may have passed me by. What have I learned from my experiences? Always believe in yourself. You may be surprised at what you can accomplish. Networking and partnerships are the key to success. Most importantly, by empowering the direct support professional, the quality of services is bound to excel. I wish for all direct support workers to have a glimpse of the "big picture." Thank you, John, not only for helping me achieve my goals and revise them, but for helping me accomplish things beyond my wildest dreams. I couldn't have done it without your recognition, support, and many handshakes.

Cynthia H. Mowris is a Kennedy Fellow and NADSP editorial board member and works at Anderson School in New York. You can reach her at 914.889.4373 or email [hope@webjogger.net](mailto:hope@webjogger.net). Her mailing address is 875 Route 9, P.O. Box 367, Staatsburg, NY 12581.

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**Lighting the Way for DSPs**

continued from cover  
nation's conscience in bringing public attention to the terrible circumstances of America's institutional treatment of people with intellectual disabilities. His uncle, Senator Edward Kennedy, has played a visible and instrumental role in virtually all major legislation in education, health, long-term care, and employment and rehabilitation affecting persons with intellectual and other disabilities over the past quarter century. His aunt, Patricia Kennedy Smith, has contributed to making visual and performing arts an important part of educational and leisure opportunities for people with

intellectual disabilities through *Very Special Arts*. Another aunt, Eunice Kennedy Shriver, and the whole Shriver family, have contributed immeasurably to enhanced public awareness of the potential of people with intellectual disabilities in founding and building of the enormous and amazing *International Special Olympics* movement. John's cousins, with assistance from the family foundation, have also established new initiatives to improve the developmental, social, and economic lives of people with intellectual disabilities.

No family in America is better or more rightly identified with the cause of opportunity, accomplishment, and inclusion of people with intellectual disabilities than the Kennedys. That was his family legacy, but John also embraced it as his birthright. He gladly accepted his open opportunity to continue and extend the highly valuable commitments of his family, but he chose to do so in a unique and important new way.

Continued back page

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John recognized that the well-being of people with intellectual disabilities is inextricably tied to the well-being of those on whom they depend for love, assistance, and opportunity. Among all who play such roles in the lives of people with intellectual disabilities, John chose to focus on the well-being of direct support personnel because, to use John's own words, of his personal "concern about the low wages, high turnover, minimal training and lack of career opportunities for dedicated, hardworking staff." He committed himself, his resources, and his visibility to the creation and support of opportunities for direct support workers to advance in their skills, their formal education, and in professional careers. In doing so he brought important recognition and meaningful responses to a national

crisis in caregiving for which many more years of his attention and dedication were sorely needed.

We will miss John's leadership and the bright light he was able to shine on the just struggle of direct support professionals for decent pay, due respect, and positive futures. We will miss the visibility of his challenges and the justice of his commitment to do right by those on whom the well-being of hundreds of thousands of people with intellectual disabilities is dependent.

John's legacy was derived from a family legacy, but it found its own direction. That direction will be sustained in part by his bequests to the Reaching Up Foundation which he founded as an organized instrument of his commitment to direct support workers. Other significant initiatives in his memory will no

doubt follow. But no organization or program to carry on John's work will ever be able to rekindle the bright light of John's concern for those who provide direct support to people with intellectual disabilities. It will take thousands of smaller lights to match the intensity of focus that John brought to this issue of great personal concern to him. Each of us must commit ourselves to being one of those lights.

K. Charlie Lakin is the director of the Research and Training Center on Community Living (RTC) at the Institute on Community Integration, University of Minnesota (<http://ici2.umn.edu/rtc>). A current focus of the RTC is recruitment, retention and support of DSPs. Charlie has served on the President's Committee on Mental Retardation since 1995. He can be reached at 612.624.5005 or fax: 612.625.6619.

Visit the DSP Web site at <http://ici2.umn.edu/rtc/dsp/>

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