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NYS Office of Mental Retardation & Developmental Disabilities

Putting People First

The New York City Resource Consortium
A Handbook for Success



*Helping people get a new "lease" on life
...one person at a time*

Funded by:
NYS Office of Mental Retardation and Developmental Disabilities
&
NYS Developmental Disabilities Planning Council

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OMRDD is pleased to have partnered with the Developmental Disabilities Planning Council (DDPC) in the implementation of the New York City Resource Consortium. The Consortium supports a transformation of the service environment from the present system to one in which the people it serves are able to readily gain access to person-centered supports, and that those supports will allow for a broad range of individualization and choice.

Four voluntary agencies, AHRC New York City, Cerebral Palsy Associations of New York State, HeartShare Human Services of New York, and Sinergia, Inc., were selected via the Request for Proposals process. Together with OMRDD and DDPC, these Consortium agencies have worked in New York City since July 1, 2007 to promote access to small, individualized living environments for people with a wide range of ability and support needs. Over the past two years, the Consortium agencies have worked with local Developmental Disabilities Service Offices (DDSOs), OMRDD’s Service Delivery and Integrated Solutions (SDIS) Region 2 and other OMRDD units, NYC Department of Health and Mental Hygiene (NYCDHMH), and NYC housing organizations, including the NYS Division of Housing & Community Renewal (DHCR).

Each Consortium agency identified and convened its own agency resource workgroup, including staff, families/advocates and one or more persons with developmental disabilities who were also employed as interns and mentored by the agency as part of OMRDD’s Employment Training Program (ETP). The interns have been invaluable to the Consortium effort as they offer insights to the planning process and have proved themselves to be responsible and productive employees with the agency in the future.

As a result of this initiative, the most appropriate funding sources and resources have been utilized to support individuals to move into small individualized living environments of choice or to continue in their living arrangement. In both instances, flexible supports and methods of assistance have been identified that most closely match the personal goals and needs of the individual.

This handbook compiles the stories of people impacted by the Consortium with lessons learned. It is hoped that this information will lead the way for others in implementing innovations and best practices that facilitate the availability of small individualized living arrangements and work experiences via the internship program to meet the growing demand from the people we serve.

Helping people in
New York City ...

to live in the home of their choice and contribute in the workplace
with meaningful relationships
with friends, family and others in their lives,
and as members of their communities



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About the Consortium Agencies

HomeBuilders—NYC

AHRC-New York City, founded in 1949, is a family governed, person-centered organization dedicated to serving people with developmental and intellectual disabilities. Steered by a board primarily comprised of parents and siblings, the concerns and values of families are a guiding force in everything AHRC does. In 1970, AHRC opened the first group home in Manhattan as an alternative to institutionalized care. Today the agency operates more than 112 homes and apartments for approximately 500 individuals throughout New York City. Through **HomeBuilders-NYC**, AHRC has increased its capacity to provide self-directed housing and individualized supports.

MORE

Metro Options for Residential Environments

Cerebral Palsy Associations of New York State (CP of NYS), with over 60 years of history, has a collective mission to promote lifelong opportunities for enhanced quality of life for people with cerebral palsy and other significant disabilities and their families throughout New York State. As a partner in the NYC Resource Consortium, **MORE** has collaborated to establish the resources necessary to support individualized living alternatives, and help break down attitudinal and systemic barriers to these options. The goal of **MORE** is to utilize a personalized approach to create self-directed housing with individualized supports for people with developmental disabilities.

Project CHOICE

Creating Housing Options for Individuals in Challenging Environments

HeartShare Human Services of New York is a 95-year old human services organization in NYC; its Developmental Disabilities Division was created in 1977 and provides a continuum of community-based services for individuals of all ages with intellectual and developmental disabilities. **Project CHOICE** has assisted individuals, primarily from the boroughs of Brooklyn, Queens and Staten Island, who needed creative and individualized housing alternatives and supports to enhance their lives. As part of the program's services, Project CHOICE worked with each person to develop a Housing Supports Life Plan that meets his or her unique needs.

Project SHORE

Sinergia’s Housing Opportunities & Resources Enhancement

Sinergia, Inc. is a multi-service agency serving children, adults with disabilities, and their families since 1977. The agency specializes in providing multi-cultural services, especially to Spanish speaking individuals, families and other underserved populations. **Project SHORE** has provided a one-stop housing and resource center for persons with developmental disabilities; offered training workshops on housing; established a database of housing resources and helped persons seeking housing assistance; and developed new housing opportunities and enhanced Sinergia’s existing Housing and Residential Services.



GETTING STARTED:

A PERSONALIZED APPROACH TO HOUSING AND SUPPORTS

New York City was once described in a 1948 classic film as the city with eight million different stories. More than sixty years later, it is *still* a city of eight million people living in five boroughs composed of hundreds of diverse neighborhoods and teeming with individuals from all different backgrounds, cultures and experiences. It is *still* a city of eight million different stories, and we are pleased to share some of these stories, circa 2009, with you. Our stories offer a unique perspective. We have explored how to make small, individualized living arrangements happen for more than 40 people with developmental disabilities, either by adding supports within their existing residential situation or by creating new and customized housing and support services.

Four agencies joined forces with OMRDD and DDPC to become the New York City Resource Consortium. They started with a clean slate, bringing no preconceived notions about fitting individuals into existing boxes. While the agencies may have approached the journey from a different vantage point, each began by asking numerous questions of individuals and their families and by listening intently to what they had to say about where they wanted to live, what supports they would need, and other accommodations that would help them have the most fulfilling and independent life possible.

For some people, this meant staying right where they were, in the home they had grown up in, with the financial and human supports that would make their desired way of life possible. For others, it meant facilitating moves from existing living arrangements that were undesirable or unsafe into apartments of their own, with the array of supports that they needed. For yet others it meant helping them along in their personal journey of moving from a more restrictive residential environment, such as a supervised group home, into their own apartment. In some instances, these individualized living arrangements helped families to stay together, others were finally able to start a home with their special life partners, and others chose to live on their own. Relocations required special strategies to overcome the challenges of finding and creating accessible housing in New York City. In all instances, it was imperative to consider natural supports, community connections and interagency collaborations.

In the stories that follow you will hear about the partners and collaborators that helped make each story happen, the resources uncovered, and the many happy endings that unfolded. Please reference the Glossary of Terms and associated web links at the end of this handbook to learn more. We hope you enjoy the journey and stories as much as we have!





A FAMILY PERSEVERES

In December 2007, Sinergia received a call from the Capital District DDSO, referring Jasmine, a Latino woman with an Individualized Supports and Services (ISS) contract interested in moving to New York City to be closer to extended family members, who could serve as natural supports, in an effort to keep her family intact. Jasmine needed not just immediate housing but a myriad of other supports!

Regrettably, no immediate and appropriate housing was identified for a mother with a disability and two children, so Jasmine took temporary refuge with family members in the Bronx. In the meantime, Sinergia assigned a Medicaid Service Coordinator (MSC) to provide assistance and help enroll the children in school. This situation was far from appropriate, living in a small apartment with no bed to sleep on and no room to call their own. Jasmine became increasingly uncomfortable, so she and her family moved out and lived in several shelters in three different boroughs over the next eight months.

It was clear that no single agency would be able to develop a unilateral plan to address the family’s needs. To get Jasmine and her children settled, Sinergia worked with landlords, realtors, the NYC Administration for Children’s Services (ACS), the NYC Department of Homeless Services, the NYS Division of Human Resources Administration, the NYC Department of Education, and OMRDD. Resources for Jasmine’s residence, furniture and food were acquired through SSI and OMRDD. DSS and ACS helped with the resources and food allowances for the children. DSS paid the broker’s fee. The NYC Department of Education provided the educational and related services of counseling for the children.

Some glitches and setbacks notwithstanding, Jasmine and her children have now lived almost one year in a lovely two-bedroom apartment on the upper West Side of Manhattan. The children attend their neighborhood school. Jasmine receives residential habilitation services, has assumed many responsibilities and has plans for her future. She can now live and dream for a future of increasing independence and a quality of life.



NAVIGATING THE MAZE OF SERVICE PROVIDERS MAY BE DIFFICULT, BUT THE RESOLUTION IS MORE LIKELY TO BE SUSTAINED IF THE PROPER AGENCIES ARE INVOLVED FROM THE ONSET. LINKAGES TO SUPPORT CHILDREN ARE ESPECIALLY IMPORTANT.

Lessons Learned

In most instances there is no protocol for the interagency collaboration that is required between various agencies when planning for individuals with developmental disabilities with children.

Listen to the person and develop a comprehensive plan that addresses the individual’s strengths, needs, desires and wishes. Remember cultural and interrelated needs for the person served and their family. Parents who have developmental disabilities need to learn how to become effective parents and require adequate housing with support services, including training for themselves and their children.



BECOMING INDEPENDENT AND MAKING IT ON HER OWN

Jenny is a 20 year-old woman who had been living in the apartment she grew up in with her mother, father and brother. She had a very rich life characterized by relationships with neighbors, friends from the dog run and her synagogue. For many years, Jenny had expressed the desire to live on her own. However, initially, it appeared that Jenny would require too much support to live independently. In addition to her developmental disabilities, Jenny has many physical and health concerns; she uses a power chair for mobility and has home attendant services through Community Alternative Systems Agency (CASA) after school and on weekends. Years ago, Jenny’s mother elected to be part of the Consumer Directed Personal Assistance Program (CDPAP). This enabled Jenny and her family to hire, train, supervise and, if need be, dismiss their personal assistant. Jenny also uses a service dog to assist her with daily activities such as laundry, homework and answering the phone. Jenny’s dog is named “Indy” short for Independence. He was born on the 4th of July. A very fitting beginning for a dog that is one of the keys to Jenny’s freedom. Supporting Jenny in her own apartment would take a lot of creativity, cooperation and “out of the box” thinking.

An apartment became available in the building that Jenny and her family lived in. The family purchased the apartment for Jenny with the equity from their home. Currently, Jenny uses ISS funds to rent the apartment from her parents. Start-up funding through ISS was secured to assist her in purchasing furniture and house wares for her apartment. To support Jenny in living independently she receives Residential Habilitation Services through Special Citizens Futures Unlimited, Inc. The family is also working with OMRDD to acquire funds for environmental modifications through the HCBS Waiver (E-MOD) to make the apartment more accessible for Jenny.

Finally, Jenny and her family have started on her long-term plan to self-direct all her services and they have begun the CSS (Consolidated Services and Supports) process.



"PEOPLE COMMENT THAT INDIVIDUALIZED HOUSING IS SO HARD TO DO - BUT IN MY OPINION ANYTHING WORTH DOING IS HARD, AS WE ALL KNOW. THE AMOUNT OF ANXIETY REDUCED FROM KNOWING YOU HAVE YOUR OWN PLACE - IN A WORLD WHERE PEOPLE WHO ARE VULNERABLE HAVE SO LITTLE CONTROL IS IMMEASURABLE."

Jenny's mother

Lessons Learned

Use natural supports as often as possible. Encourage family and friends to take a positive ongoing role in the now more independent life of their loved one.

Encourage a person to follow their dream, despite any challenges they may have.

Allow people to take chances, respect their right to make informed choices.

Support interest from the person served and their family to self-direct their funds: CSS is the means to do this.

Think outside the box! Creative solutions helped facilitate Jenny’s move to her own apartment.



EDWARD'S JOURNEY REPRESENTS THE EPITOME OF OMRDD AND HEARTSHARE'S COLLECTIVE MISSION - TO SUPPORT INDIVIDUALS BY EXPANDING OPPORTUNITIES AND ENHANCING LIVES.

A “MAN ON A MISSION”

Edward’s journey to independence and his own apartment was 30 years in the making. Edward first moved into a HeartShare group home as a teenager. Coming from a family of 21 siblings, he needed many staff and clinical supports early on. Edward had many stops along the way ~ transferring to another large HeartShare group home; moving to a smaller Supervised Individual Residential Alternative (IRA); and moving from a Group Day Habilitation setting to a Blended Day Services program in 2008 where he is learning vocational skills and participating in volunteer experiences in diverse settings, in preparation for supported employment. Each move provided him increasing independence. All along the way, Edward has been his own strongest advocate, always reminding people of his ultimate dream ~ to have his own apartment.

Four years ago, as HeartShare began developing life plans for people, Edward had the opportunity to have his dream formalized. When Project CHOICE launched on July 1, 2007, Edward was one of the first individuals considered with the blessing of his planning team. A life plan was developed and planning proceeded accordingly.

Edward was excited about the opportunity to move back to his home borough of Brooklyn and to be nearer to his downtown Brooklyn day program. He is thrilled to have a spacious one-bedroom apartment that is just blocks away from Eastern Parkway and the route of the West Indian parade that he regularly attends. Edward has selected paint colors for his rooms, gone shopping for furniture and household items, and has already begun to plan the open house he will host. He is recommending individuals to be considered for his residential habilitation staff and worked with staff to develop the goals he needs to work on, including more complex cooking skills. Edward moved into his new apartment on Valentine’s Day 2009.

Lessons Learned

Taking Risks & Letting Go. For years, the staff supporting Edward was not sure that he was ready for this next big step due to difficulties with interpersonal skills. At the end of the day, staff has prepared him as best they can, and everyone is now ready to support him in taking the risks inherent in a non-24 hour living environment.

Fulfilling Dreams. HeartShare’s requirement that every person it serves has an individual life plan. This practice has focused staff more clearly on the dreams and wishes of the individuals they support. Edward’s life plan provided the impetus to make his dream a reality. At the end of the day, program and administrative staff worked together to bring his apartment to fruition.



“IF I CAN MAKE IT THERE, I’LL MAKE IT ANYWHERE”

Kevin is a 22 year-old man who lives at home with his mother. Kevin and his mother had been subletting an apartment in Queens, where Kevin is known as “The Mayor.” Everybody knows him, the neighborhood is supportive and a safe haven for Kevin and his mom.

The woman they were subletting their apartment from was not paying rent to the landlord with the money from Kevin and his mother. Eviction proceedings had begun. The landlord agreed to rent the apartment directly to Kevin and his mother at a greatly increased rate. Even though his mother has a good job, they could not possibly afford that rent increase. She worried that if they could not meet their expenses, she and Kevin would have to go into a shelter. Kevin’s mother called OMRDD in Albany to inquire about the NYS Home of Your Own Program. When Dr. Lucinda Grant-Griffin heard her story she referred the family to SDIS Region 2, who referred her to the New York City Resource Consortium and finally, to AHRC NYC’s HomeBuilders-NYC .

Another apartment was located in their neighborhood. While it was still more than they were paying at their current sublet, it was something they could afford if Kevin was able to help out with his living expenses. OMRDD worked determinedly to approve ISS funds so that they could move into their new apartment before the eviction date.

Kevin and his mother were moving from a furnished apartment to an unfurnished one so furniture would be needed along with a security deposit and the first and last month’s rent. They would also have moving expenses. HomeBuilders-NYC sought monies from AHRC NYC’s Francesca Nicosia Family Reimbursement Program, to secure funds for the family to purchase furniture for Kevin. Additionally, staff from the HomeBuilders program reached out to the “Families First” Reimbursement Program with the Queens Center for Progress to secure funds for additional household items and furniture.

Kevin and his mother are living happily in their new apartment. Mom has just signed up for the NYS Home of Your Own training and is on her way to purchasing a home for herself and Kevin.



THE THING ABOUT NETWORKING IS THAT YOU MEET SO MANY PEOPLE ALONG THE WAY. EVEN IF THEY CANNOT HELP IMMEDIATELY, THERE MAY COME A TIME WHEN THEY CAN BE HELPFUL.

Lessons Learned

Networking is essential. The ability to network is the key to this family’s story. Kevin’s mother reached out in many directions to find the assistance they needed. She was and continues to be a persistent advocate.

Listen to what is important to a person and their family. Kevin and his mother wanted to stay in their local community where they had many connections and supports.



JI “GROWS” IN BROOKLYN

If you happen to be dining at Magnolia’s Restaurant in Brooklyn, you are very likely to be in the company of Ji-Eun, a.k.a.”Ji”. Since fulfilling her dream of living in Park Slope in August, 2008, Ji is leading the life that she never thought would be possible. When she was born in Korea with cerebral palsy, Ji’s family moved to the United States to reunite with other family members and seek enhanced medical treatment for their daughter. After completion of high school in Staten Island, Ji furthered her education and received her Bachelor’s Degree after attending New York University.

Most people who know Ji personally would definitely describe her as an activist. Her outgoing personality combined with her brutal honesty makes her a force to be reckoned with. Ji has channeled this energy into such projects as getting “curb cuts” placed outside of her local Starbucks so that she could easily get her power wheelchair into the store for a quick latte. Her career goals mirror her personal life. She aspires to be the accessibility ‘guru’ and bring about changes desperately needed in our city. As an intern at CP of NYS Project MORE, Ji has used her unique perspective to assess properties and surrounding neighborhoods targeted as potential development opportunities. Her insight has already contributed in a positive way.

Ironically, while searching for real estate, Ji found a perfect place for herself in the area where she had hoped to live. Her Church community, her social life and her circle of friends were centered in one Brooklyn neighborhood in particular. Although Park Slope embodied all that was important to Ji, it is a neighborhood comprised of brownstones and older architecture which presented many obstacles due to her physical challenges. Ji truly found a “needle in the haystack” when she came upon a small, but newly constructed , apartment building possessing all the characteristics of a desirable home.

On August 15, 2008, Ji began the next chapter of her life as she signed the lease to her new apartment. In typical fashion, Ji threw a roof-top party to celebrate!



JI TRULY FOUND A
“NEEDLE IN A
HAYSTACK”

WHEN SHE CAME UPON
HER NEW APARTMENT
IN PARK SLOPE,
BROOKLYN.

Lessons Learned

Utilize our expertise to create accessible environments. It is important that our work helps increase public awareness and promotes universal design.

Gaining independence brings on a new set of challenges. There needs to be an integration of supports for people during the transition to independent living that address emotional, physical and financial aspects.



IT'S NEVER TOO LATE TO HAVE A HOME OF YOUR OWN

At 64 years of age, Billy is a survivor. Having spent many years of his earlier life in Willowbrook, he has experienced a variety of living situations over the years, including a developmental center, family care and (most recently) sharing a small room in an adult home in Far Rockaway, Queens.

But it has been Billy's goal for many years to move into his own apartment. In the fall of 2007, he was referred to HeartShare's Project CHOICE by his two longtime advocates—his MSC from Bernard Fineson DDSO and his representative from the Consumer Advisory Board (CAB). After being screened and accepted into the program, the next step was to find a one-bedroom apartment that would meet Billy's requirements, including plenty of physical space for his vast movie collection, lots of shops and stores in the surrounding neighborhood, and ready access to public transportation. Billy was agreeable to relocating to a new borough, and HeartShare's Project CHOICE found a spacious one-bedroom apartment near the Botanic Gardens and Prospect Park in Brooklyn. He promptly fell in love with both the apartment and its surrounding Crown Heights neighborhood.

Due to Billy's age, health issues, and greater need for staff support related to learning to cook, clean, budget and manage his money, Billy and his team agreed that he needed a Supportive IRA, which is a non-24 hour, certified setting. Billy moved into his apartment on October 21, 2008. While it will undoubtedly take him awhile to learn all the skills he needs to master, including his personal objective to be a "gourmet cook," he is accomplishing new things every day and living a full and independent life in the community.



BILLY SHOPPED
FOR HIS OWN
FURNITURE AND
HOUSEHOLD ITEMS
FOR THE FIRST
TIME IN HIS LIFE!

Lessons Learned

Advocacy. In addition to being his own strongest advocate, Billy had the support and commitment of two exceptional long-time advocates who always had his best interest at heart and helped to make his goal a reality.

The Importance of Choice. Billy has definite ideas on what he wants, and he has learned that his voice counts. With the support of HeartShare staff, Billy shopped for his own furniture and household items for the first time in his life.

As One Journey Ends Another Begins. There have been new responsibilities and challenges for Billy in his new apartment, including keeping it clean, managing his money well, selecting appropriate foods and being both responsive and responsible to the staff who support him.



CREATING AN ACCESSIBLE & INDEPENDENT LIFE FOR RICKY



APPRECIATE
LANDLORDS AND
DEVELOPERS WHO ARE
GOOD AND PATIENT
PERSONS.

NURTURE AND
CULTIVATE THESE
RELATIONSHIPS!

Transitioning to independence and life on one’s own is a big step for every young adult. Even more so for Ricky due to his need for a fully accessible apartment. When Ricky found out about HeartShare’s Project CHOICE, he quickly put his name forward as a candidate. At 28 years of age he was ready to move out of his adoptive mother’s home and into a place of his own. The challenge would be finding an accessible and affordable apartment in Brooklyn that would accommodate Ricky and his wheelchair—something that is always a daunting undertaking given the age and types of structures in the borough of Brooklyn and in New York City as a whole.

Fortunately, HeartShare’s Project CHOICE was able to collaborate with a developer who had a track record of successfully rehabilitating older apartment buildings for lower and middle income individuals. His most recent project was a 52-unit, century old structure in a vibrant community in Crown Heights. The developer was willing to work with HeartShare to make both the building and the apartment accessible for Ricky. This included ramping the front entrance and gutting both the bathroom and kitchen in Ricky’s apartment to create a roll-in shower and accessible kitchen. The developer also widened doorways in Ricky’s apartment to meet ADA standards and installed a new elevator in the building as part of the overall renovation.

Many resources were pulled together to make an independent life possible for Ricky. Environmental modification (E-Mod) funds were made available through OMRDD to contribute towards the overall accessibility costs. In addition, Ricky will be supported on a daily basis through three separate resources:

- an Individual Supports and Services (ISS) contract to cover his rent and basic living needs;
- At Home Residential Habilitation (AHRH) evenings and weekends to provide staff support to Ricky for working on his cooking, shopping, laundry, and budgeting goals; and
- a home health aide provided through CASA to assist him in the mornings with self-care needs.

Lessons Learned

Creative Partnerships. Sometimes it takes a village to make things work, and in this case Ricky has benefited from a truly diverse group of individuals and resources—especially an accommodating landlord who was willing to absorb some of the added costs of making Ricky’s apartment fully accessible.



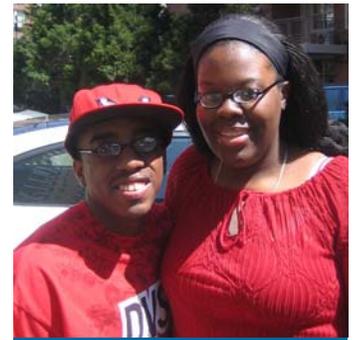
A "KING" IN QUEENS

For most 19 year-old men, life is carefree and the biggest worry might be getting a date for the weekend; but not so for Travis. His early years were marred by the violent death of his mother which left him and his siblings with their elderly grandmother who was unable to care for them. He was thrust into the Foster Care System and spent many years seeking stability but instead was shifted from one foster home to another. If these challenges weren't enough to bear, Travis has "diplegic" Cerebral Palsy involving both lower extremities. Despite these obstacles, Travis refused to abandon his dream of getting his High School Diploma.

Once connected with CP of NYS, a Medicaid Service Coordinator (MSC) was assigned to support Travis, who took on the arduous task of helping him obtain his discharge from ACS. At the same time, the MORE Project was launched and immediately began to help Travis build a better and more independent life. Funds were creatively blended from ACS with start-up funds from OMRDD through an ISS contract to establish his own home. Necessary supports were identified and provided to enable him to live on his own and complete his education. By combining services such as Residential Habilitation and counseling with natural supports, MORE has prevented Travis from being limited by another service system. Additionally, CP of NYS provides life skills training related to budgeting, food preparation and household management to sustain his progress. Planning is already underway for work upon graduation.

Travis now has a "bachelor pad" in a barrier-free apartment building in a bustling neighborhood in Flushing, Queens. He proudly chose the furnishings along with the helpful eye of his girlfriend, Tracy, who supports Travis in many aspects of his life.

Travis now has a place where he can develop friendships and entertain his friends on weekends with his talent in karaoke. He has maintained his commitment to completing his high school education and will be graduating in June 2009. Travis is truly the king of his new domain.



TRAVIS IS TRULY
KING
OF HIS NEW DOMAIN.

Lessons Learned

Coordination is the key. It was difficult to develop a primary contact for Travis, which caused confusion as MORE navigated through ACS and the Foster Care System in order to cut through the "red tape." Capitalize on natural supports that can come from a person, school, neighborhood, etc., whenever possible.



MAKING A BAD DAY GO RIGHT: KEEPING YOUR APARTMENT IN NEW YORK CITY

Peter came to HomeBuilders through his AHRC New York City Medicaid Service Coordinator (MSC). Peter’s story is remarkable on many levels. The perseverance and advocacy of his MSC helped to identify a network of supportive organizations that joined forces to keep this family together and in their own home.

Peter is a 20 year-old man who lives in his apartment with his mother. When Peter turned 19, he aged out of the Jiggetts Rent Supplement Program. This program is available to families on public assistance with children living at home. Losing this subsidy put the family at great risk for eviction. Legal action had been taken against them to begin the eviction process. Peter’s mother worried that if they were evicted the family would be broken up by the system. She feared that Peter might have to go into a group home and that she would go into a shelter.

HomeBuilders, Peter’s MSC and his mother worked with a large number of New York City agencies and non-profit organizations to ensure that their rent arrears could be alleviated while at the same time developing an ISS contract to support Peter’s share of the living expenses. Catholic Charities and Palladia (Homebased Homeless Prevention) came to the aid of the family by providing funds to assist them with their rent arrears. OMRDD approved an ISS contract and currently helps to cover Peter’s share of the living expenses.

The rent arrears were paid down, the family met their rent obligations for four consecutive months and demonstrated their ability to meet future rent obligations. This was all made possible through ISS funds and an MSC’s unyielding work on behalf of a family.

Lessons Learned

Learn about resources. Being informed of the many services and supports available in New York City is vital when developing successful individualized living situations.

When faced with a crisis situation, having a passionate and informed advocate is an essential tool. Peter’s MSC relentlessly pursued agencies and charities as well as tackled the legal system to help the family stay in their apartment.

Don’t judge a book by its cover. A family’s financial crisis is not an indication of a parent’s ability to care for their child.



TWO TOWARDS INDEPENDENCE

Martin and Karen, 58 and 47 years old, respectively, have received residential and other services from Sinergia since 1994. They have been a couple for 15+ years and lived together more than 10 years.

While living in a Sinergia IRA, they had received Residential Habilitation (Res Hab) that covered a variety of life skills, including bill paying, attending medical appointments and following through with medical recommendations, shopping efficiently and economically and preparing healthy foods. Martin’s various medical issues called for him to follow a certain diet and Karen adopted much of his diet to support him. At the IRA they took increasing control of their daily routine and gained more independence with these activities. The two had also settled into a rhythm of life with defined roles and responsibilities.

By 2007, Residential Habilitation staff noted that Martin and Karen’s division of labor had become increasingly successful ~ the apartment was clean and neat, the refrigerator stocked with healthy foods, nutritious meals were being prepared, medications taken, their calendar of appointments correctly and thoroughly filled out, their bills paid and their social calendar set for the night or the weekend. Their Res Hab hours were scaled back accordingly. Aware of their success, Martin and Karen advocated for even less Res Hab support and as part of the Resource Consortium, their IRA certification was changed to an ISS.

Thinking further ahead than their support team, in 2004, Martin and Karen went on their own to a New York City Housing Authority (NYCHA) office and applied for subsidized housing. Working with their MSC, they regularly checked the status of their application. Finally, in March 2008, the approval from NYCHA was given and they moved into NYCHA’s East River Housing complex.

Martin and Karen are doing well and they are happy. Their health is stable, they successfully manage their medical appointments and they take care of the everyday details in life. They continue to volunteer and are happy to consider themselves members of their community.



DON'T
UNDERESTIMATE
THE ABILITIES OF
INDIVIDUALS WHO
YOU ARE
SUPPORTING.

Lessons Learned

Patience. Sometimes the best, long-term solution may be a long time in coming and everyone has to be willing to accept that. It is worth the wait.

There will be instances when another agency, either within or outside the OMRDD system of services, may be better suited to provide necessary services or interventions.



DARREN AND LOUISE,
FINALLY A NEW
FAMILY UNIT,
HAPPY AND ABLE TO
LIVE LIFE
ON THEIR OWN TERMS.

STAYING TOGETHER

Darren and Louise have been soul mates from the time they first met at their day program in Queens. Their desire to be together had led them to many temporary and unsatisfactory living arrangements, from a sublet apartment from which they were evicted when they got behind in their rent to living in a variety of crowded households with different relatives. At the end of the day, they wanted a calm and permanent living environment that would be theirs alone. They were very excited when they first heard about HeartShare’s Project CHOICE through Darren’s MSC and the possibility it held for making their dream a reality.

There were many challenges to overcome along the way. Project CHOICE staff, their MSCs and Darren’s CAB representative convened many meetings with them to ensure that their commitment to each other was reality-based and that they understood their mutual responsibilities in contributing towards rent and other living expenses. Time and again, they proved to everyone that they truly wanted to be together and that they would do everything possible to make a shared household work. Finally, it was agreed that Project CHOICE would help them locate a one-bedroom apartment in a community with plenty of shopping, good public transportation and many local amenities.

On February 6, 2009 Darren and Louise moved into their own apartment, which is being operated as a Supportive IRA due to Darren’s need for extensive training and support in several life skill areas. A final hurdle has been securing the proper Medicaid so that they will receive the right benefits for contributing to their living expenses.

Their happiness at being together while receiving the critical supports that they need to manage on their own cannot be described. They are a couple – a new family unit – who now have the opportunity to live life on their own terms.

Lessons Learned

Patience. Doing things the right way takes time. The many individuals who supported Darren and Louise in setting up their own household needed to be assured that this could be a successful living arrangement and that there were clearly identified options if their relationship did not work out in the long term.



IN JANICE'S OWN WORDS: THE UPS AND DOWNS OF ELEVATOR BUILDINGS

There are many people with disabilities that think they have to settle for anything and everything. This drives me crazy! I want to share my experience of living in my own apartment, working and building the kind of life I want, and the people who support me. I think this will be helpful to other people with disabilities, their families and those who work in human services.

For 12 years I lived on the 6th floor of a building whose elevator kept breaking down. In some cases it was breaking down daily. Whenever it broke down, my family had to carry me and my motorized wheelchair up six flights of stairs. At times I called the fire department, police department, or 311 and they all tell me, they can't help me because it is not an emergency.

I am a success story in finding an accessible apartment. I never thought it would be possible. In December 2007 my elevator was going to be out of service for eight weeks for repairs. I needed to find an apartment by February. In the end, I could not find an apartment in time for the repairs and I had to move home with my parents. I didn't want to go to my parent's house because I felt my independence would be taken away. My parent's house is not accessible and I would need help with everything. However, after following up with possible leads on temporary housing, I decided the best place to be was my parent's house. In the first week of March I was able to go back to my own apartment. I was so happy to get back to my normal routine. Some people don't realize how lucky they are to have all use of their limbs.

I am proud to report that as of April 1, 2008, I am living in an accessible house, where I can roll in and out without worrying about an elevator. I am able to live in this house with the assistance of ISS funds, a great resource for people with disabilities. It provides funding to maintain my household. Also, I am getting assistance with fixing my bathroom to be more accessible through Access to Home.

I feel so blessed to have the opportunity to be living in a house where I thought it would never be possible.

"I HAVE 12 YEARS
OF EXPERIENCE
LIVING
INDEPENDENTLY.
EVEN THOUGH IT
HASN'T BEEN EASY,
I LOVE EVERY
MINUTE OF IT."

Lessons Learned

Finding accessible housing in New York City is not easy! Don't give up! I am proud of achieving my goal of finding an accessible apartment.

The Self-Advocacy Association (SANYS) is a place where people can learn to speak for themselves, share their dreams and network. Encourage people to participate in SANYS.



ADVANCING OMRDD'S EMPLOYMENT FIRST GOAL

The Employment Training Program (ETP) internships provide an *opportunity* for participating individuals to enhance and learn skills through an on-the-job work experience and job readiness training sessions. Internships last about 18 months and during this time, the employer is able to assess the intern's performance. Similarly, the intern is able to demonstrate that he or she is a valued and productive member of the workforce.

During the internship, the intern's wages are paid by OMRDD Special Employment Programs. This unique approach allows an intern to work at a job that might otherwise be unobtainable as it is difficult for businesses to pay wages while someone is learning a job skill.

It is evident that OMRDD is committed to assisting the individuals we serve to seek, acquire and maintain employment. However, this program goes a step further and assists individuals in *creating the job that they want in an organization that has a need for those skills*. The program acts as a liaison between the individual and employer to continually align their respective needs. This is accomplished in coordination with service providers and through the program's design which includes creation of a specific job description, specific duties, specific goals, and a formal progress review each quarter with the employer and intern to assure open communication.

Customizing and carving out positions are integral to successfully matching an intern and a business. This means that *before a job is developed* for an intern, his or her interests, skills and preferences are discussed in detail. Once this occurs, a job developer assists with identifying potential jobs. One of the primary goals of the program is to assure that the job identified matches the intern's stated goals to the greatest extent possible and that it will lead to competitive employment.

An additional component of the intern program is to facilitate the identification of job supports needed by the individual based on the job description developed. Initially, interns are provided with significant job supports while they are becoming acclimated to a new work environment, learning new skills, and adapting already-learned skills. Through these supports, interns are able to master skills, establish working relationships with other employees, and learn to navigate through the complexities of an organization. After a period of time, *natural supports* may take the place of some of the more formal job supports.

The Employment Training Program can be summarized as being a **TRAINING FOR EMPLOYMENT** program. It is designed to provide all of the ingredients for an intern to maintain successful employment over the long term. As a result, OMRDD is helping people live richer lives by providing an opportunity to create meaningful relationships at work, grow and develop as an employee and a person, and become an active participant in a business in their community.

TEDDY ROOSEVELT
ONCE SAID,
"FAR AND AWAY
THE BEST PRIZE THAT
LIFE OFFERS
IS THE CHANCE
TO WORK HARD AT
WORK WORTH DOING."



GETTING STARTED: HOW TO MAKE THE JOB WORK!

- Make a list of your interests, hobbies, skills, and favorite activities.
- Think about what kinds of jobs there are for each of these and make a list.
- Compare the jobs under each area and see if a job is listed under one or more of the topics.
- Select two or three possible jobs, and make a list of employers in your area with these jobs; organizations that need volunteers to do this type of work; and people you know that need this type of work done.
- Make a list of friends and family that work at one of these organizations. Call, write, contact or ask friends to contact the people they know at these places; get information about the organization and who to contact to discuss job possibilities. Identify the employer's needs through research.
- Seek assistance from your employer to evaluate your wages and benefits.
- Don't rule out volunteering as a way to open doors.
- When you start to talk to an employer, be flexible and listen.
- Write out a weekly schedule incorporating current activities, and commitments (doctors, etc.). Realistically evaluate the number of hours you can work.
- Talk to an employer about carving part of an existing job that you can do well. Start out working a few hours and then see if you can add duties as you go along.
- Have a written job description with job duties and performance standards BEFORE you begin working. You and your employer should work together.
- Continually work with the employer to identify areas for improvement, or where support is needed. Obtain the job supports you need to be successful.
- Be on time and keep your schedule. Employers depend on employees to be at work, and if you are not there the work will have to be assigned to someone else.
- **MAKE YOURSELF INDISPENSABLE!** Do tasks that might not seem important but when not done, have an impact on the business.
- Be cooperative, have a positive ATTITUDE, and always try to meet or exceed expectations.
- *Communicate, Communicate, Communicate!*

WHILE FINDING
THE JOB YOU WANT
CAN SEEM LIKE A
CHALLENGE,
USE THE ETP
STEP-BY-STEP
APPROACH.
YOU WILL SEE THAT
WITH COMMITMENT
AND
DETERMINATION,
YOU CAN FIND THE
RIGHT
OPPORTUNITY.



IN PAT'S OWN WORDS: WORKING "9-5" ~ AN EMPLOYMENT DIARY

Working as an intern on the MORE Project with CP of NYS has been a wonderful experience for me. Some of my tasks at work include locating accessible and affordable housing for people with disabilities, finding low cost computers for their use as well as general office work. This job is different than others I have had in the past because I am encouraged to work independently and to voice my opinions on various topics.

I feel that I have an impact on the policies and procedures of the agency and how they affect people. I enjoy feeling like I am working as part of a team and hope to see myself working full time for the organization in the next year. I also hope to expand my skills related to my position such as learning new software programs, working more closely with the people and advocating for them to find the necessary supports and services they need. I can even see myself taking some college courses as well.

I have had to make many changes in my life because of my internship but they have all been positive:

- I had to learn to come out of my shell and to once again be a part of the community that I live in.
- I had to learn what it is like to be an everyday "working girl." That meant getting up in the morning, arranging my own transportation, getting to work on time and doing the job tasks that were placed before me.

Although these changes were very difficult in the beginning, I have slowly begun to get the hang of the new life routine.

I love every minute of my work and would not change a thing!

Lessons Learned

Some individuals with developmental disabilities discount their competence based on their lack of confidence. When Pat first started working in our agency, she needed frequent reassurance when performing her assignments; however, she has developed the self-assurance to work independently on any given task.

Interns grow both professionally and emotionally as a result of their work experience. With the proper guidance and support, they learn how to set realistic goals and the techniques necessary to accomplish them. Success in the work place has a positive impact on self-esteem.

Interns bring their creative spirit to the office with their ingenuity and distinct personalities.



" I HAD TO LEARN
WHAT IT IS LIKE TO
BE AN EVERYDAY
WORKING GIRL."



IN JANICE'S OWN WORDS:

MY EXPERIENCE AS AN ETP INTERN

When I was a teenager I saw my brothers and sisters get jobs and move out on their own. I thought, "If they can do it, why can't I?" After years of attending a Day Program I felt that my good mind was going to waste. I knew life had something better to offer. I was introduced to the OMRDD'S ETP. They told me about an internship with the NYC Resource Consortium through AHRC New York City's HomeBuilders project.

I started my internship in September of 2007. I was placed at two job site locations, one with HomeBuilders in Manhattan and one with AHRC's Employment and Business Services in the Bronx. I wasn't completely satisfied with my placement in the Bronx and I used my advocacy skills to make the situation better. I have now been transferred to AHRC's main office where I am going to be working in the finance department doing data entry.

My job with HomeBuilders requires me to do many different things. I meet with people interested in having an individualized living situation and see if they are right for the project. I created a form to use to get useful information from people who would like to participate. I do research on topics like Social Security and accessible housing in New York City using the internet. I also get to use and learn new office skills: I create forms, do faxing, copying, and I am even using my graphic art skills!

I am responsible for coordinating attendance for the quarterly Intern Reflection and Training meetings which are developed and hosted by AHRC New York City. I send out emails inviting interns, Consortium Partners and OMRDD staff to attend meetings. I then create a list of who is attending.

As part of the Resource Consortium, my goal is to gain more experience and knowledge. Learning all about disability-related issues means so much to me. I knew this would be my ideal job. Advocating is what I live for. Making change and helping people with disabilities realize that they don't have to settle for less, always settle for the best.



AHRC NEW YORK CITY
HOSTED QUARTERLY
MEETINGS OF ALL THE
INTERNS FOR THE
PURPOSE OF TRAINING
AND REFLECTION.
IT IS CALLED
PROJECT SAGE
(SUPPORT, ASSISTANCE,
GUIDANCE,
ENCOURAGEMENT.)"

Lessons Learned

People with developmental disabilities are often considered outcasts and are not always seen to have a place in society. My life is proof that just because our brains work differently, it does not mean we are not capable of leading productive lives. People with disabilities have desires, hopes and dreams, just like any other person.



AN EYE ON TOMORROW



MICHAEL HAS VISIONS OF USING HIS INCOME TO MOVE OUT FROM HIS FAMILY'S HOME INTO A PLACE HE CAN CALL HIS OWN.

Michael is a very outspoken and active individual who enjoys being busy. He is enrolled in Sinergia’s Day Habitation program and while he enthusiastically partakes in the social-based community activities, Michael is not afraid to engage in a good day’s work. Even before he was involved in ETP through the Consortium, Michael was quick to volunteer to assist with various jobs around the agency. As part of his vocational training Michael was already helping with various clerical tasks and when the internship program became available, we knew we had the perfect candidate.

Michael has learned to accurately fax, copy, collate, assemble and distribute various documents, type up forms such as attendance sheets and assist at workshops by helping people with handouts, setting up the room, collecting workshop evaluations and the like. Michael also regularly works at the front desk as the receptionist at both the main office and the housing office at 902 Amsterdam Avenue. He can cheerfully and seamlessly take calls on the busiest of days and route them to the right person or into that person’s voicemail. He has a great desire to either become a full-time employee with Sinergia or to continue to hone his working skills so that he can become a valuable team member for any employer.

In addition to the clerical work that he has learned to do, Michael states that he also enjoys attending the housing workshops and learning about things such as tenant/landlord dispute resolution, assistance with rental arrears and other related topics. Michael is a tremendous advocate and can always be counted on to speak up at the full Consortium meetings and at reflection meetings that are held with the interns. Michael speaks up not only for his own interests but advocates for those he meets as part of his work in the Housing Intake process. Michael listens intently to the needs of these individuals and is eager to help them find answers to their concerns. He states that you never know when someone else’s problems or concerns might become your own.

Michael also states that working has taught him that he needs to be flexible. In order to fill out his weekly schedule and to be paid for the maximum amount of hours possible, Michael has found that it benefits him to be able to work mornings or afternoons, to work at the main office or to head uptown to pitch in at our office at 902 Amsterdam Avenue.

Lessons Learned

Michael likes to receive a paycheck for his work with Sinergia, as it provides him with additional income, which he uses primarily to participate in his community and travel about New York City.



THE "GO TO" GUY

David joined HeartShare's Project CHOICE as an ETP intern in May 2008, almost half-way through the project. He slipped easily into the team and was an eager and willing learner. As a Project CHOICE Associate working 15-20 hours weekly, he was expected to use the computer to find information and send communications, answer the phone and document calls appropriately, respond to callers in an informed way, relay detailed information to his supervisor, and create good record keeping systems for filing documents accurately. He also participates actively in Project CHOICE meetings at HeartShare, attends full Resource Consortium meetings in Manhattan, and participates in the intern "Reflections" sessions. In addition to working with Project CHOICE, David supports administrative staff at HeartShare's Executive and Administrative Offices by assisting with mailings, making follow-up phone calls, doing internet research, performing copying jobs, and shredding documents on a regular basis. In fact, David is one of only three people trained to use a large shredder that handles the biggest shredding jobs at HeartShare. While David already knew basic computer functions and how to surf the web, his job coach and HeartShare staff helped him learn to write and send memos and honed his phone skills and assertiveness through role playing.

Ten months into his job, David has become an integral member of the HeartShare team. His friendly personality, constant helpfulness, and willingness to take on any challenge has made him the "go to" guy when someone needs anything done, even on short notice. Most recently, he is being trained as a relief staff for HeartShare's main receptionist. He will fill in for her during lunch hour, greet and assist visitors, answer calls that come into the central agency number and route them via a computer console, and receive and sign for packages delivered to the site—all complex and multi-faceted skills.

No matter what the challenge, David takes everything in stride. He is willing to learn anything and is receptive to feedback and suggestions. His interpersonal and communication skills are expanding as he comfortably seeks out work from others. When asked what is the one change he has had to make because of his job, David responds that he has learned to better budget his money and to be more assertive and independent. HeartShare eagerly anticipates hiring him into a permanent part-time position at its central offices.



NO MATTER WHAT
THE CHALLENGE,
DAVID TAKES
EVERYTHING IN
STRIDE.

Lessons Learned

Besides doing a good job, a positive attitude and constant willingness to help go a long way toward making an individual a valued and indispensable employee.

Learning is a constant, lifelong journey that will continue to "add value" to the individual in his work environment.



LEARNING JOURNEY: AHRC NEW YORK CITY

The goal of HomeBuilders-NYC is to increase AHRC New York City’s capacity to provide self-directed housing and individualized supports. AHRC New York City is working to restructure its own resources to align itself with the individualized services environment. The agency committed itself to supporting people to have as much personal freedom as possible, integrated into their own communities. Best stated by a sibling and staff within the agency, “There would be no more selling ourselves into a community by promising invisibility.”

AHRC New York City’s commitment to person-centered planning and individualized supports is reflected in the vision of the senior executive team and emerging practice throughout the agency. What we realized is that advancing a culture of person-centered service and individualized support at AHRC New York City is different from replicating a service model or implementing a new program. Culture building is not simply training, it is facilitating a new way of thinking. Person-centered supports and shared values are being built into all aspects of AHRC New York City to stimulate cultural change. In addition, innovation must be balanced with stability.

To deepen this commitment, staff has been supported to explore new ideas outside of traditional service practice. In 2006 AHRC New York City created a Department of Individualized Supports to create new programs based on a vision, work with others to change existing programs, and forge the development of a person-centered practice. This focus has seeded systemic change and is a shared responsibility among departments.

Since this time, AHRC New York City has:

- Convened a “change team” to steer and advise implementation.
- Focused staff from throughout the agency who want to establish individualized ways to support individuals, which has led to continuous interaction across departments.
- Fostered the continuous creation of innovative projects between departments. In addition to HomeBuilders-NYC, projects include Building Futures with support from the FAR Fund, to support the development of our Middle/High School curriculum for person-centered transitions to adult life for students with ASD; higher education programs at The College of Staten Island and Kingsborough Community College for students graduating high school with an IEP who want to go to college; Adult Day Services and Employment/Business Services collaborating to support people in enhanced supported employment; and an after-school program and weekend cultural exploration, for students from Brooklyn with ASD “City Teens.”
- Taken learning journeys along with interested families to agencies known for innovation and excellence in delivering individualized supports. We are focused on supporting people in self-advocacy activities and continuing to support the growth of family leadership.
- Developed and supported mentoring of staff at all levels as a mechanism for change, particularly Direct Support Professionals, the largest segment of the workforce.



LEARNING JOURNEY: CEREBRAL PALSY ASSOCIATIONS OF NEW YORK STATE



Cerebral Palsy Associations
of New York State

Cerebral Palsy Associations of New York State is a proud partner in the New York City Resource Consortium whose commitment has brought about positive change in the lives of people with developmental disabilities. Through our work on the MORE Project, we have helped individuals with unique needs meet their challenges and supported them in their efforts to live independently in communities. We created an internal workgroup dedicated to helping develop these individual living environments, and doing so has proved to be both a challenging and rewarding experience.

Our primary focus was to create individualized living arrangements for ten individuals with developmental disabilities, including several with physical challenges that made accessibility a main concern. Our agency has historically worked with people who have physical challenges by helping to arrange residential services. Through this unique collaborative effort, the initiative shifted toward creating “independent” housing options. CP of NYS recognized that it needed to do more than just identify appropriate housing for people; it would also need to provide emotional support to help sustain their success. With the development of a counseling program specifically designed for the MORE Project, we have helped to provide reassurance during the transition phase to help alleviate concerns that may arise.

As a result of CP of NYS’s work as a Consortium agency:

- We can help people learn to live independently and responsibly with structured finances and resources by developing an ISS contract created on an individual basis. By interviewing each person using a survey and assessment tool designed by our agency, a person-centered plan was outlined that made sense.
- We have facilitated the formation of new personal “partnerships” enhancing the lives of two people who balance each other out perfectly; one woman is the nurturing, quiet type and the other is much more outgoing. Their relationship brings out the best traits in each of them.
- We realized that it is still possible to re-enter the work force after 20 years; one of our intern’s self-esteem has increased exponentially resulting in a much more positive outlook on life.
- We provided assistance and guidance to one young man to help navigate the judicial process to “liberate” him from the foster care system.
- Our agency has permanently altered our perspective on strategies and planning for people embarking on a more independent life. By partnering with a low-income housing developer, CP of NYS has addressed the issue of accommodating individuals with developmental disabilities to help create several units of housing in the Bronx. Additionally, plans to utilize several other properties owned by the agency for the development of affordable, accessible housing are under way.



LEARNING JOURNEY: HEARTSHARE HUMAN SERVICES, INC.

Working on the Housing Resources Consortium and our own Project CHOICE has been an incredible experience for those involved at HeartShare. It has been a journey of collaboration and enlightenment that has strengthened our creativity in developing services for individuals seeking highly customized and person-centered housing and housing supports.

Early on, Project CHOICE workgroup members—which included our two ETP interns, three parents and a diverse group of employees from both the Developmental Disabilities Division and the agency’s Quality Improvement Department—defined our collective vision as follows:

To provide housing and housing supports for individuals that meet their unique needs, wants and lifestyle choices, utilizing innovative service models that result in a high degree of personal satisfaction.

Fifteen months into Project CHOICE, we reviewed our vision again and agreed that it still appropriately defined our project. We then discussed lessons learned about ourselves and what the project has meant to HeartShare as a whole. Through this process we discovered that:

- Individuals now have the opportunity to make choices about their housing and their lives that were never available to them before.
- The project has created an opportunity to remove individuals from volatile situations and place them in a safe environment.
- One individual in particular has a dramatically different living situation as a result of Project CHOICE, moving from an adult home to his own one-bedroom apartment.
- Our two ETP interns have learned a great deal about themselves, as well as the world of work, through their involvement in the project.
- The project indirectly helped not only the son of a parent in the workgroup, but also numerous other individuals that were part of a group developing a new community residential model in White Plains. For HeartShare staff, the individuals’ responses to the project have been exceptionally motivating and encouraging.
- Project members have been encouraged to think “outside of the box” and to be as creative as possible. Our approach of developing a Housing Life Plan for each person helped everyone to focus on creating opportunities for success and enabling people to achieve their dreams.
- For everyone involved, the project has provided an opportunity to share information and transfer knowledge on best practices. It has permanently altered how we approach the development of housing supports at HeartShare, both in terms of our philosophy (even more individually focused than before) and practice (a diverse and collaborative work group that supports the total effort).



LEARNING JOURNEY:
SINERGIA, INC.



Sinergia, Inc. is a non-profit, community-based, multi-service organization that has historically provided advocacy and services to people with disabilities and their families in low-income communities of New York City since 1977, particularly those residing in upper Manhattan.

In 1988 Sinergia opened its first Tier II shelter for families who have children and family members with disabilities. With continued funding from the Department of Homeless Services these apartments continue to serve families who are homeless. While in these transitional apartments, hundreds of families have availed themselves of the opportunity to receive housing and support services, which helped them to stabilize and move on to permanent housing opportunities. In 1989, Sinergia opened its first supportive residence for individuals with developmental disabilities, for two individuals who shared an apartment in a multiple dwelling in the Manhattan Valley community. Today the agency provides community housing with supports to more than 55 people in Manhattan, the Bronx and Brooklyn; Family Support Services through its Community Residential and Supports Program; and operates a Neighborhood Preservation Program funded by DHCR. With its participation in the Consortium, Sinergia has assisted individuals to secure small housing opportunities or the resources and supports to retain their existing housing, allowing each the highest level of independence possible and the chance to become productive members of inclusive communities.

Gentrification and the scarcity of affordable and accessible housing in New York City makes it ever more important for Sinergia staff to assist families with members with disabilities to secure housing assistance and support services. We continue our long-term commitment to the development of accessible, affordable housing with supports for low-income New Yorkers and individuals with disabilities.

As a Consortium agency, Sinergia has learned that there is much concern and true awareness amongst service providers and within OMRDD to find and implement timely and individualized living arrangements that address the needs of people with developmental disabilities and their families, who are faced not only with the challenges of a disability, but who may also be indigent and feel ostracized due to language, culture and citizenship status.

The positive relationships developed from the Consortium, its members and sponsors, have helped to instill a heartening feeling that Sinergia’s experience with the provision of person-specific housing assistance to individuals with disabilities is not only familiar to other service providers but is being embraced as a goal and philosophy throughout New York City.



EPILOGUE: AN END OR A NEW BEGINNING?

In July, 2007 four agencies with long and different histories were funded by OMRDD and the DDPC to come together to explore options for individualized and self-directed housing for people with developmental disabilities in New York City. The creation of the New York City Resource Consortium focused on housing issues specific to the city, launching a learning journey that will continue long after the project ends. As a result, each agency committed itself to:

- listen to at least 10 individuals and work with them to make their desired living situation a reality;
- initiate a sustainable evolution in how they support people as individuals; and
- increase its workforce of people with developmental disabilities through OMRDD’s Employment and Training Program.

This handbook tells the stories of what can be accomplished when agencies and government work together to “Put People First.”

We are hopeful that this handbook has translated our experiences into useful information and challenged you to reflect on your assumptions about housing, employment and what is possible. The world has changed. People with developmental disabilities are reclaiming their right to live and work in their communities and not just be “a group” of marginal observers of community life. The Resource Consortium has learned that there are many more creative housing models to be discovered. The Consortium agencies are proud to have worked over these two years to provide guidance in New York City to help actualize OMRDD’s commitment to people with developmental disabilities, for both individualized housing and employment. We have learned that we are only limited by our imaginations.

Dr. Carole Gothelf and Jennifer Teich; AHRC-NYC Homebuilders-NYC

Jacqueline Rumolo and Christine Price; CP of NYS, MORE

*Linda Tempel, Joyce Levin and Melissa Pierre; HeartShare Human Services of NY,
Project CHOICE*

Myrta Cuadra-Lash and Michael Mitchell; Sinergia Inc., Project SHORE

*“Imagination is more important than knowledge.
For while knowledge defines all we currently know and understand,
imagination points to all we might
yet discover and create.”*

Albert Einstein



GLOSSARY OF TERMS

ACCESS TO HOME PROGRAM

Provides financial assistance to property owners to make dwelling units accessible for low- and moderate-income persons with disabilities. For more information, go to <http://nysdhcr.gov/programs/accesstohome/index.htm>

ADAPTIVE DEVICES

HCBS Waiver funded aids, controls, appliances or supplies that enable a person to increase his or her ability to function in a home or community-based setting with independence and safety, i.e., communication devices, adaptive switches and guide or service dogs.

AMERICANS WITH DISABILITIES ACT (ADA)

The ADA enacted in 1990 prohibits discrimination, on the basis of disability, in Employment, State and Local Government, Public Accommodations, Housing, Commercial Facilities, Transportation, and Telecommunications. The following are some sites for information:

- ADA HOME PAGE & TECHNICAL ASSISTANCE GUIDE - <http://www.ada.gov/>
- ADA Protection against Discrimination - <http://www.eeoc.gov/types/ada.html>
- ADA Law: Title I and Title II - <http://www.eeoc.gov/policy/ada.html> or <http://public.findlaw.com/civil-rights/disability-discrimination/ada-overview.html>
- Free ADA Guide and Subscription Publication - <http://disabilitiesactguide.com/DisabilityActs-ADA-LV.htm>

AT HOME RESIDENTIAL HABILITATION (AHRH)

Residential habilitation services provided to individuals who do not reside in a residence that is certified or operated by OMRDD. AHRH services may be self-directed, family-directed, or managed solely by an agency; must be delivered at the individual's home, or be initiated or concluded there.

COMMUNITY ALTERNATIVE SYSTEMS AGENCY (CASA)

To apply for Medicaid Personal Care or Home Attendant Program in NYC or to find a list of CASA offices call the Medicaid Helpline at 888-692-6116 or go to http://www.nyc.gov/html/hra/downloads/pdf/list_casa.pdf

CONSOLIDATED SUPPORTS AND SERVICES (CSS)

HCBS Waiver service that offers individuals and their families the opportunity to identify and self-direct supports and services. CSS participants identify the supports they need; select their own staff and community resources; and co-manage (with a fiscal agent) an individualized budget approved by OMRDD. For more information on CSS go to http://www.omr.state.ny.us/hp_communitylink_resourcereceiving.jsp

CONSUMER ADVISORY BOARD (CAB)

A seven-member board established in 1975 on behalf of approximately 5,400 former residents of the Willowbrook Developmental Center. CAB is comprised of parents, siblings and advocates that provide individual active representation for Willowbrook class members who do not have correspondents. The CAB may also provide co-representation for non-correspondent class members.



CONSUMER DIRECTED PERSONAL ASSISTANCE PROGRAM (CDPAP)

Medicaid program that provides services to individuals who are chronically ill or physically disabled and have a medical need for help with activities of daily living (ADLs) or skilled nursing services. Services may include any of the services provided by a personal care aide (home attendant), home health aide, or nurse. The individual or the person acting on the individual's behalf (such as the parent of a disabled or chronically ill child) assumes full responsibility for hiring, training, supervising, and – if need be – terminating the employment of persons providing the services. In NYC, applications for CDPAP services are submitted to the Community Alternative Systems Agency (CASA).

DAY HABILITATION

HCBS Waiver service delivered primarily in a nonresidential setting separate from the person's home that is directed toward acquiring, retaining, and improving those skills necessary for an individual to function successfully in the community. Day habilitation services may be provided in certified sites, or completely in the community (day habilitation without walls). For information go to www.omr.state.ny.us

ENVIRONMENTAL MODIFICATIONS (EMODS)

HCBS Waiver funding for one-time only internal and external adaptations to the home to promote an individual's access and independence, i.e., ramps, widening doors, handrails and grab bars. For information go to www.omr.state.ny.us

FAMILY REIMBURSEMENT PROGRAM

Family Support Service available from voluntary agencies that provides the possibility of purchasing services and goods that are not funded through any other sources as long as prior approval has been obtained and the goods and services have been deemed appropriate to meet the needs of the person being served.

FAR FUND

A grant-making organization that supports innovative approaches to working with individuals with autism. For information go to http://www.omr.state.ny.us/hp_news_autismplatform.jsp

FAMILY EDUCATION AND TRAINING (FET)

HCBS Waiver service providing education and training to care givers of children under the age of 18 who are enrolled in the HCBS Waiver. The purpose is to enhance the family's knowledge, skills, and decision-making capacity to help them care for a child with developmental disabilities. The focus is to provide information, not a direct service. To find out more about this program, please go to http://www.omr.state.ny.us/wt/publications/wt_msc_tb_01.jsp

HOME AND COMMUNITY BASED SERVICES WAIVER (HCBS)

The HCBS Waiver offers individuals and their families a flexible choice of support options. Through the waiver, OMRDD accomplishes its commitment to provide individualized and person-centered services to people. With an increased focus on supporting person-centered options, individuals can choose to live in homes that meet their specific needs. HCBS Waiver services include Residential and Day Habilitation, Consolidated Supports and Services (CSS), Respite, Environmental Modifications, Adaptive Devices, and Family Education and Training (FET).



HOME OF YOUR OWN (HOYO)

OMRDD's HOYO program is a HUD-Certified Housing Counseling Program that assists people with developmental disabilities and their income-eligible parents or legal guardians design individualized living arrangements as an alternative to traditional group-home living. Options include home sharing, independent living, rental subsidy programs and for those who are income-eligible, home-ownership programs. HOYO also assists the workforce with becoming first-time homebuyers. The First Home Club is a 4:1 matched-savings program operated statewide by the Federal Home Loan Bank of NY in partnership with OMRDD. The target population will be people with developmental disabilities, their income-eligible parents or legal guardians, and direct support professionals. For more information call OMRDD at 518.473.1973 or go to http://www.omr.state.ny.us/document/hp_brochures_housingservices.jsp

HOUSING FOR INDEPENDENT LIVING

Resource directory for people with disabilities who live in NYC, which lists rental assistance sources, Adaptive Modification contractors, eviction intervention, legal advice from advocacy firms, listings of assisted living locations and nursing homes, non-profit home care agencies, and other programs and services. Check this web site: <http://www.disablednyc.com/resources/Housing-and-Independent-Living/>

HOUSING WEBSITES:

www.hud.gov US Department of Housing and Urban Development
www.nychdcr.org NYC Housing Development Corporation
www.dhcr.state.ny.us NYS Division of Housing and Community Renewal

INFORMED CHOICE

Right of a person with developmental disabilities and those who support the person to make decisions affecting his or her life, ranging from those that are minor every-day decisions to those that are potentially life altering; and to be provided with sufficient information and experience to decide among various options in keeping with personal goals, interests and needs.

INDIVIDUAL RESIDENTIAL ALTERNATIVE (IRA)

A facility that provides room, board, and individualized protective oversight for people with developmental disabilities. Residential habilitation services provided in the IRA may be “supervised” or “supportive” depending on the support needs of the individuals living in the residence.

INDIVIDUAL SERVICE PLAN (ISP)

Official document that identifies the person-centered plan for developing, implementing and maintaining services for a person with developmental disabilities. To learn more about developing an ISP with your Medicaid Service Coordinator (MSC):

- Check out E-Bility (<http://www.e-bility.com/books>) such as *Individualized Service Plans: Empowering People with Disabilities*. By Spicer, Paul. Publisher: Author House USA 2005; ISBN: 1-4208-2274-8 (sc)pp 173
- PDF Document at www.omr.state.ny.us/wt/images/msc_vm_img/wt_isp.pdf



INDIVIDUAL SUPPORT SERVICES (ISS)

Goods, services, and subsidies that assures the health, environmental and physical needs of the person with developmental disabilities are met in a safe manner; that appropriate modifications are made to housing as necessary, and the person has a support network sufficient to meet his/her needs for independent living. The ISS allows a person with developmental disabilities to access more independent housing. It is for those looking for an alternative to certified community or institutional facilities; living at home with parents and siblings; or being homeless. ISS is provided through individually developed and mutually agreeable contracts that are signed by both the individual receiving the supports and the provider.

INDIVIDUAL SUPPORT SERVICES (ISS) START UP CONTRACT

A contract with OMRDD that may provide initial start-up costs in the first year budget and addresses the person’s ongoing needs in the following areas: rent, utilities/telephone, renter’s insurance (if required for a lease), transportation, food, clothing, leisure/recreation, health, staffing, employment, or any other items included in the plan.

JIGGETS

A rent subsidy available to families on public assistance with children living at home. To find out more about Jiggets and other rent subsidies go to www.citylimits.org

JOB ACCOMMODATION NETWORK

Service provided by the U.S. Department of Labor's Office of Disability Employment Policy (ODEP). JAN is one of several ODEP programs and represents the most comprehensive resource for job accommodations available. JAN's mission is to facilitate the employment and retention of workers with disabilities by providing employers, employment providers, people with disabilities, their family members and other interested parties with information on job accommodations, self-employment and small business opportunities. The ODEP web site is <http://www.dol.gov/odep/programs/program.htm>. You may also check out www.jan.wvu.edu/ for more information.

MAYOR’S OFFICE OF PEOPLE WITH DISABILITIES (MOPD)

MOPD works hand-in-hand with other City agencies to assure that the voice of the disabled community is represented and that City programs and policies address the needs of people with disabilities. In the area of housing, this agency provides assistance together with the NYC Affordable Housing Resource Center and Rent Guidelines Board.

Visit the web site at <http://www.nyc.gov/html/mopd/html/home/home.shtml>

MEDICAID

A federally funded health-care program administered by each state, which provides health insurance for those who are eligible. Medicaid services include doctor visits, laboratory and x-ray services, in-patient and out-patient hospital care, reproductive health care services and dental services. An additional service is *HOME HEALTH CARE*, which includes the services of a Home Care Attendant. Periodically, the person receiving these benefits must recertify that he or she is still eligible. The OMRDD HCBS Waiver as well as other waivers are available through the Medicaid program. To find out more about eligibility and services, contact the Medicaid Hotline at 1-888-692-6116 or visit the web site at www.health.state.ny.us/health_care/medicaid/



MEDICAID SERVICE COORDINATION (MSC)

Medicaid-funded service provided by OMRDD to assist people with developmental disabilities in gaining access to necessary services and supports appropriate to meet their needs. MSC is provided by qualified service coordinators and uses a person-centered planning process in developing, implementing, and maintaining an Individualized Service Plan (ISP) with and for the person. MSC promotes the concepts of choice, individualized services and supports, and satisfaction of the person being served. For information call OMRDD at 518.474.5647 or go to www.omr.state.ny.us/wt/manuals/mscvm/wt_msc_toc.jsp

MEDICARE

A federally funded health insurance program and prescription drug program for people age 65 and over, under age 65 with certain disabilities, and anyone of any age with end-stage renal failure. Visit the web site at www.medicare.gov

NATURAL SUPPORTS AND COMMUNITY RESOURCES

Routine and familiar supports that facilitate community membership and participation on a day-to-day basis at home, at work, at school, or in other community locations; and that include people, places or organizational affiliations that are a resource to the person by providing supports or services, such as family, friends, neighbors, associations, community centers, spiritual groups, school groups, volunteer services, self-help groups, clubs, etc.

NEW YORK CITY GOVERNMENT BENEFIT PROGRAMS

Manual containing comprehensive information on over 70 government benefit programs including Public Assistance, Medicaid, Medicare, Food Stamps, SSI, Social Security, public housing, Section 8 Housing, eviction prevention, HEAP, child care, Medicaid Buy-In, Family Health Plus, emergency assistance grants, EPIC, HASA, and much more. Additional information can be accessed at <http://pbrcmanual.cssny.org>

NEW YORK CITY HOUSING AUTHORITY (NYCHA)

NYCHA provides housing for low- and moderate-income residents throughout the five boroughs of New York City; also administers a citywide Section 8 Leased Housing Program in rental apartments. Completed applications are mailed to the following address: *NEW YORK CITY HOUSING AUTHORITY* Post Office Box 1342. Church Street Station *New York*, NY 10008. Applications are assigned a priority code based upon the information submitted and placed in NYCHA's preliminary waiting list for an eligibility interview. An acknowledgement letter is sent within 60 days of receipt of an application.

NEW YORK CITY DEPARTMENT OF HEALTH AND MENTAL HYGIENE (NYCDHMH)

City agency with a Housing Services division to provide supported housing implementation guidelines for the development of housing access strategies, support strategies, and the coordination of both access and support services between non-profit agencies and other government agencies. The web site for this agency is <http://home2.nyc.gov/html/doh/html/dmh/dmh-housing.shtml>



NEW YORK STATE ACCESSIBLE HOUSING REGISTRY

A free link, <http://nyhousingsearch.gov>, where it is free to list and search for information on accessible, affordable housing options located throughout New York State.

PALLADIA

Provides assistance with homeless prevention and other housing issues. Additional information can be accessed at <http://www.palladiainc.org>

PREVOCATIONAL SERVICES

HCBS Waiver service that provides activities to prepare an individual for paid employment, but which are not specifically job task oriented. Services may include teaching related concepts such as: following directions, attending to task, task completion, problem solving and safety awareness. Prevocational services are typically provided to individuals in sheltered workshops but may also be provided in community settings.

RESOURCES FOR CHILDREN WITH SPECIAL NEEDS DATABASE

A free resource database, <http://www.resourcesnycdatabase.org/Welcome.aspx>, that provides agencies and services for people who have developmental disabilities, learning disabilities, and physical disabilities.

RESIDENTIAL HABILITATION (RES HAB)

HCBS Waiver service provided by OMRDD through the local DDSO and voluntary agencies. These services are generally provided in the person’s home and are directed towards acquiring, retaining, and improving those skills necessary for an individual to reside in the community. For a summary of regulations, please visit the web site http://www.omr.state.ny.us/regs/hp_regs_ahrh_index.jsp

RESOURCES FOR CHILDREN WITH SPECIAL NEEDS DATABASE

Resource database to provide agencies and services for the developmentally disabled, learning disabled, and physically disabled. This is a free service and the web site address is: <http://www.resourcesnycdatabase.org/Welcome.aspx>

RESPIRE

Provision of short term “substitute services” to a person with developmental disabilities when the people who normally provide care are absent or in need of relief. Respite may be provided on an hourly or overnight basis in the person’s home, in a family care home, in free-standing respite sites, certified group homes with identified capacity for respite, or other OMRDD approved sites.

SECTION 8 (ALSO KNOWN AS HOUSING CHOICE VOUCHER PROGRAM)

A federal government program for assisting families, the elderly, and people with disabilities who are income eligible to afford safe and well maintained housing in the private market. Access additional information at <http://www.closerware.net/cidnyweb/npa.jsp?pg=detail24&tab=Housing%20Programs>



SELF-ADVOCACY ASSOCIATION OF NYS (SANYS)

Statewide not-for-profit grassroots organization run by and for people with developmental disabilities. SANYS supports self-advocates and self-advocacy groups regionally and statewide to speak for themselves individually and collectively. For more information go to www.sanys.org

SUPPORTED EMPLOYMENT (SEMP)

A service that supports individuals with developmental disabilities who require support services to obtain and sustain paid competitive work performed in an integrated setting. Supported employment services may be funded through VESID or the HCBS Waiver. OMRDD promotes individualized and customized employment outcomes, and individuals may also work in group employment settings such as mobile work crews and enclaves.

UNIVERSAL DESIGN

A relatively new paradigm that emerged from “barrier free” or “accessible design” and “assistive technology” to provide broad-spectrum solutions that help everyone, not just people with disabilities, and recognizes the importance of how things look. Examples include utensils with attractive built-up handles for people with gripping limitations manufactured for mass appeal; cabinets with pull-out shelves; and kitchen counters at several heights to accommodate various tasks and postures.

VOCATIONAL & EDUCATIONAL SERVICE FOR INDIVIDUALS WITH DISABILITIES (VESID)

NYS agency offering access to a full range of services that may be needed by a person with disabilities through their lives. For information, go to www.vesidnys.org or these additional websites:

- Transition Services for infants and toddlers with disabilities (ages birth to two years) at <http://www.vesid.nysed.gov/specialed/transition/>
- Special Education and Transition Services for students with disabilities (3-21) at <http://www.vesid.nysed.gov/specialed/>
- Vocational Rehabilitation Services for individuals with disabilities, ages 16 and older at http://www.vesid.nysed.gov/adult_vocational_rehabilitation_services/about.htm . This web site will also direct you to the Employment Training Program (ETP).
- Independent Living Services for adults with disabilities at <http://www.vesid.nysed.gov/lisn/ilc/home.html>

VOLUNTARY AGENCY

Also known as provider agencies, these not-for-profit entities work with OMRDD and local DDSOs to provide services. They are not government agencies.

WILLOWBROOK CLASS MEMBER

Any person who was on the resident rolls of Willowbrook State School on March 17, 1972, or who was added to the Willowbrook resident rolls pursuant to the court ordered stipulation of May 15, 2003.

The Vision Statement for

NYS Office of Mental Retardation & Developmental Disabilities

People with developmental disabilities enjoy meaningful relationships with friends, family and others in their lives, experience personal health and growth and live in the home of their choice and fully participate in their communities.

The Mission Statement for

NYS Office of Mental Retardation & Developmental Disabilities

We help people with developmental disabilities live richer lives.

New York City Resource Consortium Contacts

AHRC—New York City

HomeBuilders NYC

Carole R. Gothelf, Ed.D.

83 Maiden Lane

New York, NY 10038

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www.ahrcnyc.org

HeartShare Human Services of NY

Project CHOICE

Joyce Levin

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www.heartshare.org

Service Delivery and Integrated Solutions Region 2

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NYS OMRDD

CP Associations of New York State

MORE

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www.cpodnys.org

Sinergia, Inc.

Project SHORE

Michael Mitchell

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New York, NY 10001

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mmitchell@sinergiany.org

www.sinergiany.org

Employment Training Program (ETP)

Lynne Thibdeau

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www.omr.state.ny.us



NYS Office of Mental Retardation & Developmental Disabilities

Putting People First

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For further information, please check the
OMRDD Website:

www.omr.state.ny.us