



# *Wish Fulfilling Justice*

*Creating Individualized Residential  
Supports with HomeBuilders*



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## *Creating Individualized Residential Supports with HomeBuilders*

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Stories of people with disabilities who are living in their own homes through  
AHRC's HomeBuilders Program

By Beth Mount, Carole Gothelf, and Jennifer Teich

With contributions by Janice Bartley, JoAnn Dolan, Diana McCourt and Jerry Petroff

A Publication of AHRC New York City  
Department of Individualized Supports

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## *Creating Individualized Residential Supports with HomeBuilders*

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## • about the ARTWORK

The artwork tells the story of Janice Bartley who lives happily in her own apartment in the Bronx. Janice's life reminds us that her capacity to live independently is directly related to her interdependence with others who are dedicated to her well-being.

Janice is featured in the center in her new accessible ground floor apartment in the Bronx. It is a vast improvement over her last apartment on the sixth floor of a building with a chronically broken elevator. Janice's new apartment is a short ride from her parents. Her siblings live near by. One bus ride away is her church, where she has been a member for 11 years. And her support worker through the last twelve years lives just down the street.

The 25 figures surrounding Janice each have a part in sustaining her vision. They solve problems together, negotiate hard times and have fun, secure needed resources, provide day-to-day support, and build a stronger community in which Janice's gifts can unfold. These 25 people represent careful attention to the development and deepening of the Five Commitments, which are fully explored on page 9. Each person carries emblems that represent gifts of friendship and support (see page 18). Janice is a remarkable, generous woman who inspires everyone in her circle---so her qualities of courage, wisdom, and determination radiate from her joyful presence.

The central golden pentagon takes shape as Janice's life becomes increasingly filled by commitments in the five surrounding segments. The pentagon represents the space of "Wish-fulfilling Justice," where quality of life grows. Not only does Janice's life unfold in unexpected ways, but she also sets a standard for others to emulate, and teaches them the courage to change.

The star represents the Five Accomplishments that guide Janice's contributions to the world beyond her family and neighborhood. Janice has left a traditional day program behind and is now working in several highly valued paid jobs. She is also a speaker and leader in the self-advocacy movement and a participant in "The Moth," a poetry reading group.

“The more we take the welfare of others to heart and work for their benefit, the more benefit we derive for ourselves. This is a fact we can see. And the more selfish we remain and self-centered, the more selfish our way of life is, the lonelier we feel and the more miserable. This is also a fact we can see.”

***His Holiness, the Dalai Lama***





## ● **BACKGROUND** ●

The goal of HomeBuilders-NYC is to increase the capacity of AHRC New York City to provide self-directed housing and individualized supports. The HomeBuilders project is one of several innovations in individualized supports supported by AHRC New York City. AHRC New York City's commitment to person-centered planning and individualized supports is reflected in the vision of the senior executive team and in emerging practice throughout the agency. They believe that OMRDD funding, regulations, and administrative practices make it possible for strong service organizations, like AHRC New York City, to adapt their practices and deliver individualized supports. AHRC New York City is restructuring its resources to align with the individualized services environment. The agency supports people having maximum personal freedom and many opportunities to take part in community life.

AHRC New York City was founded in 1948 to "Build a Better World" for people with disabilities and their families. In 2006, AHRC New York City created its Department of Individualized Supports as a "development space" where new ideas can be explored outside the traditional service practice. This department is responsible for developing new programs of individualized supports and for forging a new community of person-centered practice by changing existing programs.

Under the direction of Carole Gothelf, the Department of Individualized Supports has fostered numerous inter-departmental collaborations generating new options that increase inclusion, self-direction, and individualized supports for people with disabilities. HomeBuilders is one such initiative. Launched in July 2007, the AHRC HomeBuilders initiative is one of four projects sponsored by OMRDD and the DDPC to become the New York City Resource Consortium. With the leadership and support of Kathy Broderick and Denise Pensky, each project in the Consortium has committed to support ten people to live in their own homes, and to learn together how to leverage government funds with other resources to help yet more people to live in quality situations.

The Consortium projects started with a clean slate. They dropped the assumption that individuals should fit into existing boxes. Although each project approaches the journey from a different vantage point, all begin by asking many questions of individuals and their families. They listen intently to what individuals say about where they want to live and what supports or other accommodations they need to live the most fulfilling and independent life possible. For more information about the Housing Consortium, see "The New York City Resource Consortium: A Handbook for Success" ([http://www.omr.state.ny.us/wt/.../wt\\_publications\\_nycresourcehandbook.pdf](http://www.omr.state.ny.us/wt/.../wt_publications_nycresourcehandbook.pdf))

The AHRC HomeBuilders initiative exemplifies the vision for individualized supports. It blends the use of Individual Support Services (ISS) with an emphasis on relationship and community building, where Medicaid Service Coordinators (MSCs) have input. The AHRC "development space," underwritten with additional funding from the Housing Consortium, is the exploratory container that enables people such as Carole Gothelf and Jennifer Teich to devote the time and energy essential for creative individual design.

This monograph explores questions posed and lessons learned from this two year process of incubating change. Part One identifies four qualities of effective residential design which provide the framework for development.

Part Two provides five stories that illustrate application of these design principles. In many ways these examples seem quite simply the result of common sense and quick thinking. However they are extraordinary because they are so uncommonly encountered. For example, the 2007 Multi-year statistical survey of services for New York City residents with developmental disabilities reports that only 279---less than 3%---of the 8,697 people served in residential settings by OMRDD in NYC are supported with ISS dollars. The vast majority of people, 8,418, receive more-restrictive and more-costly residential supports. Clearly, our capacity to provide straightforward individualized supports is overshadowed by traditional development. It is time for a change.

Part Three summarizes three steps for future development. While the funding (ISS) associated with the Homebuilders project is clearly not adequate for all people served by OMRDD system, the values and related design principles can inform the design of all residential supports. The implications of this little program can be extensive if we attend to the lessons learned.

## ● OVERVIEW: Wish-fulfilling Justice ●

### *Creating Individualized Residential Supports with HomeBuilders*

“If you have come to help me, you are wasting your time. But if you have come because your liberation is bound up with mine, let us work together.”

*Queensland Aboriginal activist slogan*

Wish-fulfilling Justice puts forth the vision that people with severe disabilities can live in their own homes with the devotion and support of others who create richness of life together. The stories in this paper provide examples of residential design that maximize people's relationships to others---their families, paid support workers, natural supports and community members, civic life, and political and advocacy associations. We believe that the success of individual supports relies on the quality of relationships that sustain people over time. While we also value independent living skills, self-direction, rights, and autonomy, our experience demonstrates that people in individualized situations thrive through the virtuous cycle of compassion and responsiveness. Therefore, above all, we should make design decisions that maximize the growing network of supports for people.

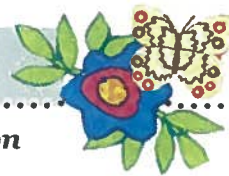
Wish-fulfilling Justice takes inspiration from the Buddhist concept of a Wish-fulfilling Jewel. This jewel is a symbol of the space between people who commit not only to one another's development, but also to the development of their community and of humankind. In this jewel-like shared space, the highest intention of each person can be realized. The development of the highest potential of every person depends on the capacity of a community to treasure the gifts of all and sustain conditions in which potentials can emerge. A person's development depends on her concern for and commitment to the whole.

Likewise, HomeBuilders is inspired by a justice-driven vision. Without a justice- and relationship-building commitment, residential design work does not necessarily create conditions in which human potential can emerge. HomeBuilders seeks to break the chains of segregation through thoughtful attention to residential design that maximizes positive relationships. This shows up as supporting people to live near their families, holding onto the family home when parents die, helping mothers and children stay together in quality settings when they face eviction and homelessness, and supporting people to acquire their own homes and self-direct their supports when desired. Response speed matters because tenuous relationships and connections can quickly unravel, landing people in institutions, costly certified settings, or homeless shelters.

The wish-fulfilling quest includes a passion for justice, a commitment to develop relationships, the desire to act quickly, an effort to help people reach for their highest potential as valued community members, and access to resources. This matters because the funding related to HomeBuilders, Individualized Supports Services (ISS) often only alleviates a financial crisis (Housing! fast!), and fails to build a stronger community and a future for the person. Leadership committed to “breaking the cycle of poverty, disability and exclusion,” (in Carole Gothelf's words), can direct the financial resources to reverse the impact of misfortune.

## • MISFORTUNE OR INJUSTICE

*Breaking the Cycle of Poverty, Disability and Exclusion*  
by Carole Gothelf, HomeBuilders Project Director



***Justice, and only justice, shall you pursue.***

Deuteronomy 16:20

Misfortune is unnecessary and unforeseen trouble. Injustice is undeserved trouble caused by acts or conditions for which humans are responsible. As we continue to enhance our knowledge, technology, and capacity for agency, we can better limit the consequences of misfortune. Once such a change for the better becomes possible, it is injustice to refuse it. To deny people the means of liberation from misfortune, not to free them from pain or social conditions through available knowledge or technology, is to promulgate injustice in the world.

The sociopolitical conditions under which people with disabilities frequently live are often thought of as “natural outcomes” of the misfortune of being born with or acquiring a disability. But many of the limitations experienced by people with disabilities stem from institutional intolerance, inaccessible public spaces, unusable transportation systems, segregated education, congregate living models, underemployment, isolation from popular culture, and social marginalization. We—the society—can alter all these conditions. Since we can, reducing the pain and trouble of misfortune is a justice issue.

Einstein said: “We cannot solve problems by using the same kind of thinking we used when we created them.” In order to shape a future for people with disabilities that is not characterized by the injustices of poverty, marginalization, loneliness and a “one size fits all” mentality, we need to work together differently than we have in the past. How institutions, government, business, schools, etc., operate reflects how we think about things and how we operate as people. To stop misfortune from becoming injustice we need to see the deeper patterns that connect many different social problems. Injustice has the power to numb us and render us incapable of fighting it. How can we prevent this from happening? We need to nourish our capacity for “imaginative empathy” – which is our ability to stand in others’ shoes, think outside of the box, and act collectively to change the pattern.



“Deep democracy is based upon the realization that everyone is needed to represent reality. A sense of justice arises only in connection with community, with inner peace of mind, sustainable ongoing relationships, and world work that processes the tension between groups.”

***Arnold Mindell***



# **PART ONE: Framework for Development**

## ***Four Qualities of Effective Residential Design***

“If I consider my life honestly, I see that it is governed by a certain very small number of patterns of events which I take part in over and over again. There are surprisingly few of these patterns of events in any one person’s way of life, perhaps no more than a dozen. If these few patterns are good for me, I can live well. If they are bad for me I can’t.”

***Christopher Alexander, The Timeless Way of Being***

### ***1. Desire for Justice; Creative Development and Design Space***

The Desire for Justice represents a response to people that moves them beyond marginalization, exclusion, and poverty toward building together valued, inclusive lives. This desire for justice, often an invisible assumption, becomes visible in the ways that we obtain, design, and deliver supports.

### ***2. The Five Commitments; Framework for Relationship Development***

The Five Commitments provide a framework for relationship development. It is a long journey from the social isolation and loneliness experienced by most people with disabilities and their families, to the experience of belonging and membership that comes with development of the five commitments. We believe this is the relationship path toward justice, and the Five Commitments provide a map for where to build.

### ***3. The Five Accomplishments: The Vision of Person-Centered Work***

The Five Accomplishments of person-centered work help us move beyond subsistence toward seeing and holding people in light of their potential. We move beyond “room and board” thinking towards the “star” that represents a life of distinction in which people live lives that are valued in their communities.

### ***4. The Resources of HomeBuilders: Building Supplies***

The Resources of HomeBuilders include the invisible art of person-centered design, and the visible aspects of ISS funding and other resources that are combined to pay for rent, start up costs, furniture, emergencies, support staff, and more. ISS is the lowest cost residential option available through OMRDD services. Ironically, the simplicity and flexibility of ISS helps to leverage and harvest what we might call “natural resources”—family life, owned family homes, familiar neighborhood places and connections, and effective response networks that avert the crises and breakdowns that cause life to unravel.



## • QUALITY ONE: Desire for Justice •

*Elements of Creative Development and Design Space*

*“Just because you can’t see it does not mean it isn’t there”*

**Basic Assumption:** *Create the conditions in which justice trumps misfortune*

**Commit to the relief of suffering:** a deep desire for social justice that shifts the conditions of people’s poverty and limitation.

**Listen to people:** be curious! Value long conversations and encounters. See the world through the eyes of the other.

**Care enough about people to act:** become relentless in the face of low expectations and bleak situations and emergencies.

**Generate a vision for this person’s quality of life:** stretch beyond stereotypes.

**Respond:** the capacity to put supports in place within two to three months of learning about a situation, and keep the transaction costs at a minimum.

**Adapt over time:** continually track life changes and revise supports, using person-centered planning and adapting personal budgets.

**Take initiative to solve problems:** find administrative allies who can intervene. Kathy Broderick is a great example of an administrative ally.

**Develop relationships with reliable MSCs and others who can provide support:** MSCs are the link between the person and the system.

**Build community on behalf of the person:** connect people, families, and networks where people can benefit from mutual support.

**Obtain back up resources from the organization which can cover the two to three month waiting period for OMRDD funding:** a big agency has advantages in responding to people and filling in the gap.

**Pound the pavement to find affordable, quality housing for people:** develop relationships with others who also do this well.

**Maintain access to development space needed to respond creatively to each situation.**

“Treat people as if they were what they ought to be and you help them to become what they are capable of being.”

*Johann Wolfgang Von Goethe*

## • QUALITY TWO: The Five Commitments



### *Framework for Relationship Development*

“ Hope cannot be achieved alone. It must be an act of community, whether the community be a church or a nation or just two people struggling together to create liberation in each other. People develop hope in each other that they will receive help from each other ”

*William Lynch, Images of Hope*

### ***Support and Develop Anchors***

Are there examples of supporting the lifelong commitments of family, friends, and others who know the person deeply and stand with the person in difficult times? Have new relationships developed into anchors; people committed to grow in knowledge of the person, include the person in life decisions, and advocate for their basic rights and creative potentials?

### ***Recruit and Deepen Allies***

Is there an increase in people who share time and activities with the person, appreciate the person's gifts and challenges, share practical help, negotiate conflicts, and enjoy one another? Have direct support professionals become more engaged as allies and advocates?

### ***Access Assistance***

Is there an increase in organized services and/or cash transfers which make money available to increase personal control, personal assistants, links to job and learning opportunities, devices, adaptations, teaching, advice, and representation?

### ***Develop Associational Life***

Do people have growing connections to associational relationships within both formal and informal groups? Are there examples of people connecting to civic life via membership? Are people growing in skills and passion about their common interests, and are they developing friendships and mutual engagements in community life?

### ***Organize Agendas***

Are people increasingly involved in political action to insure just and effective public policies? Are people developing leadership skills as a result of involvement in action agendas? Are people involved in ever widening opportunities for learning and development with others?



**CHANGE the Lives of People Related  
to the *Five Commitments***

**Support & Develop  
ANCHORS**

**Organize  
AGENDAS**

**Recruit  
& Deepen  
ALLIES**

**Develop  
ASSOCIATIONAL  
LIFE**

**Access  
ASSISTANCE**



## • **QUALITY THREE: The Five Accomplishments**

### *The Vision of Person-Centered Work*

#### ***Contribute through Work and Cultural Connections***

What are the specific changes in the way people spend their days?  
Have people moved into inclusive job and volunteer experience?  
Are people earning an income and making a contribution to community?  
How many hours a week do people benefit from individualized supports?

#### ***Share Places through Community Involvement***

Where and how are people involved in their communities?  
Are people engaged in the same places regularly and have they developed relationships with other community members?  
Is there evidence of true community membership and belonging?  
How many hours a week are people involved in community using individualized supports?

#### ***Belong through Building Relationships***

Have people developed relationships with community members besides staff?  
How have people sustained and strengthened relationships with their families?  
What about romantic relationships and friendships with people with disabilities?  
Are there examples of co-housing and life-sharing?

#### ***Increase Choice and Control through Self-Determination***

How do people's weekly schedules reflect their interests and dreams?  
Are people making more day-to-day decisions in every aspect of life?  
Are people making more life-defining decisions about where they live and with whom?  
Are people supported in individualized living situations?  
Are people managing their own budgets, holding their own leases, and involved in hiring and supervising their own staff?

#### ***Be Somebody through Making a Difference***

Are people seen for their capacities and contributions in the community?  
Can we cite examples of their distinctive contributions to cultural life?  
Have they developed skills and expertise to better enable their contributions?  
Do people have more access to individualized supports that increase involvement?

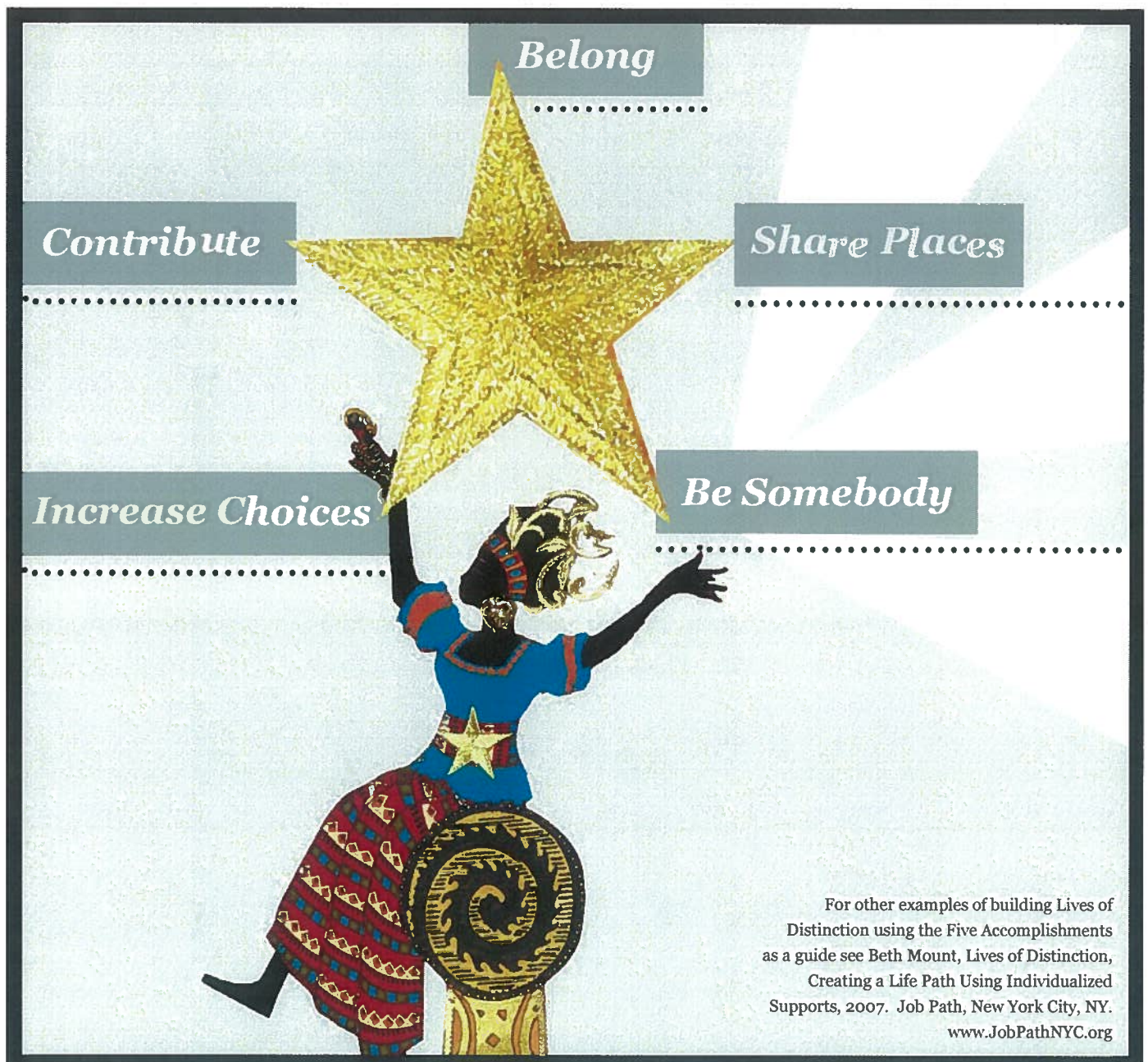
See John O'Brien (1989): What's Worth Working For:  
Leadership for Better Quality Human Services  
<http://thechp.syr.edu/whatsw.pdf>



## CHANGE the Lives of People Related to the *Five Accomplishments*

“Attentional violence is to not be seen and recognized in terms of who you really are—in terms of your highest future possibility. Instead you are only seen in terms of your journey of the past. Not being seen is a form of violence because it violates fundamental human needs. Attentional violence hits the hardest those of us who happen to live in marginalized groups in which people are habitually not recognized and not referred to in terms of their true future potential.”

**Otto Scharmer**





## • QUALITY FOUR: The Resources of HomeBuilders •

“Development is not a collection of things, but rather a process that yields things. The Thing Theory supposes that development is the result of possessing things such as factories, etc.--things subsumed under the category of infrastructure. To suppose that things, per se, are sufficient to produce development creates false expectations and futilities. Worse, it evades measures that might actually foster development. The requirements for development are initiative and resourcefulness--qualities abundant in the human race when they aren't discouraged or suppressed.”

*Jane Jacobs, The Nature of Economies*

### *A process that yields things*



### *Person-Centered Design: Eight areas of quality residential design:*

- Knowledge of the person.
- Issues related to the house.
- Neighborhood life, belonging, membership, connections.
- Personal relationships, intimacy and family involvement.
- Paid personal supports and organizational support.
- Collaborative decision-making/circle of support.
- Signs and symbols of quality space.
- Leadership commitment and support.

Sandy VanEck, Beth Mount and Hanns Meissner,  
Keys to Life, Unlocking the potential of individualized residential supports (2009)  
Rensselaer ARC, Troy, New York



## • **RESOURCES: The “Things” of Quality Residential Design**

### ***1. An analysis of a household budget***

Monthly expenses -

Wages, SSD and SSI allotments, food stamps and other income =

The difference needed from ISS funding.

### ***2. ISS funding***

**A monthly payment that covers the difference between expenses and SSI/other income.**

Sometimes higher for extraordinary situations. May range from \$300 to \$1,000 monthly

**Start up funds to cover usually one time costs such as:**

Moving expenses,

Furniture

First month rent, broker fees, and other deposits.

**ISS budgets can be amended to cover unexpected costs and other emergencies.**

### ***3. Connections to and advocacy for other funding***

Family Support Funds up to \$500.00 a year from one agency or DDSO.

Can sometimes find another family support allotment from another agency.

Covers expenses not covered by any other funding source.

### ***4. Public assistance and other low income resources***

Rent subsidies, public housing units, housing developments.

Food stamps and 1/2 fare MTA (transportation) cards.

Eviction subsidies and services.

HRA Rental Assistance and Homelessness Diversion Programs.

Safelink- Free cellphones.

Lifeline- Reduced rate landline phones.

HEAP- ConEdison.

### ***5. Personal Support***

Goal directed residential habilitation services and personal care assistance from home health care agencies (CASA).

### ***6. Medicaid Service Coordination***

# PART TWO: Learning from Experience

## *HomeBuilders Stories in Process*

This paper summarizes a two year conversation between the evaluator Beth Mount and HomeBuilders staff Carole Gothelf, Jennifer Teich, and Janice Bartley. We met on a regular basis to review the situations of ten people supported by HomeBuilders. We used a template for discussion that creates a picture of each individual in the context of the Five Commitments. Data collection was organized by building a description of:

- A) the individual's situation before the HomeBuilders intervention;**
- B) the nature of the HomeBuilders intervention—both the “things” and the energies involved;**
- C) the changes in people's lives that resulted from the intervention;**
- D) conditions that can improve the situation even more.**

As templates developed, we sorted the ten situations by high and low change outcomes, and looked for patterns across situations using the “Eight areas of quality residential design” as a guide. Each conversation led to reflections on lessons learned and implications bearing on future development for the people, the project, and the organization.

The five profiles that follow represent a sample of ten diverse situations and arrangements that we followed over time. Careful attention to the lessons learned from HomeBuilders should support new individualized development that leads to lives of distinction and inclusion. Analysis of the HomeBuilders stories leads to three Next Steps described in the conclusion.

### *Evaluation Design*

- Step One: Map the Five Commitments
- Step Two: Map the Intervention
- Step Three: Sort Stories by High and Low Success: Pattern Analysis
- Step Four: Listen for Themes in Person-Centered Design
- Step Five: Reflect on Experience and Change over Time



*The following template illustrates the data collection process for Janice.*

		<b>A. The individual's situation before Home Builders</b>	
		working	not working
<b>B. The nature of the Home Builder's Intervention</b>		<b>C. The changes in people's lives that resulted</b>	
<b>INTERVENTION</b> Things	Energy	D. Could be better under these conditions:	
14			



## • JANICE: A Woman of Valor and Independence •

“It is sad to say, people with developmental disabilities are often considered outcasts and are not always seen to have a place in society. However, my life is proof that just because our brains work differently, it doesn’t mean we are not capable of leading productive lives. People with disabilities have desires, hopes, and dreams just like any other person.

There are many people with disabilities who think they have to settle for any- 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 with them, the people who support them and with people who work in human services.

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. My MSC told me about the Self-Advocacy Association. I joined the AmeriCorps program where I had the opportunity to travel throughout the five boroughs giving presentations on disability-related issues. I finally felt part of the community. After two years with the AmeriCorps program I was introduced to the New York State Employment and Training Internship Program (ETP).

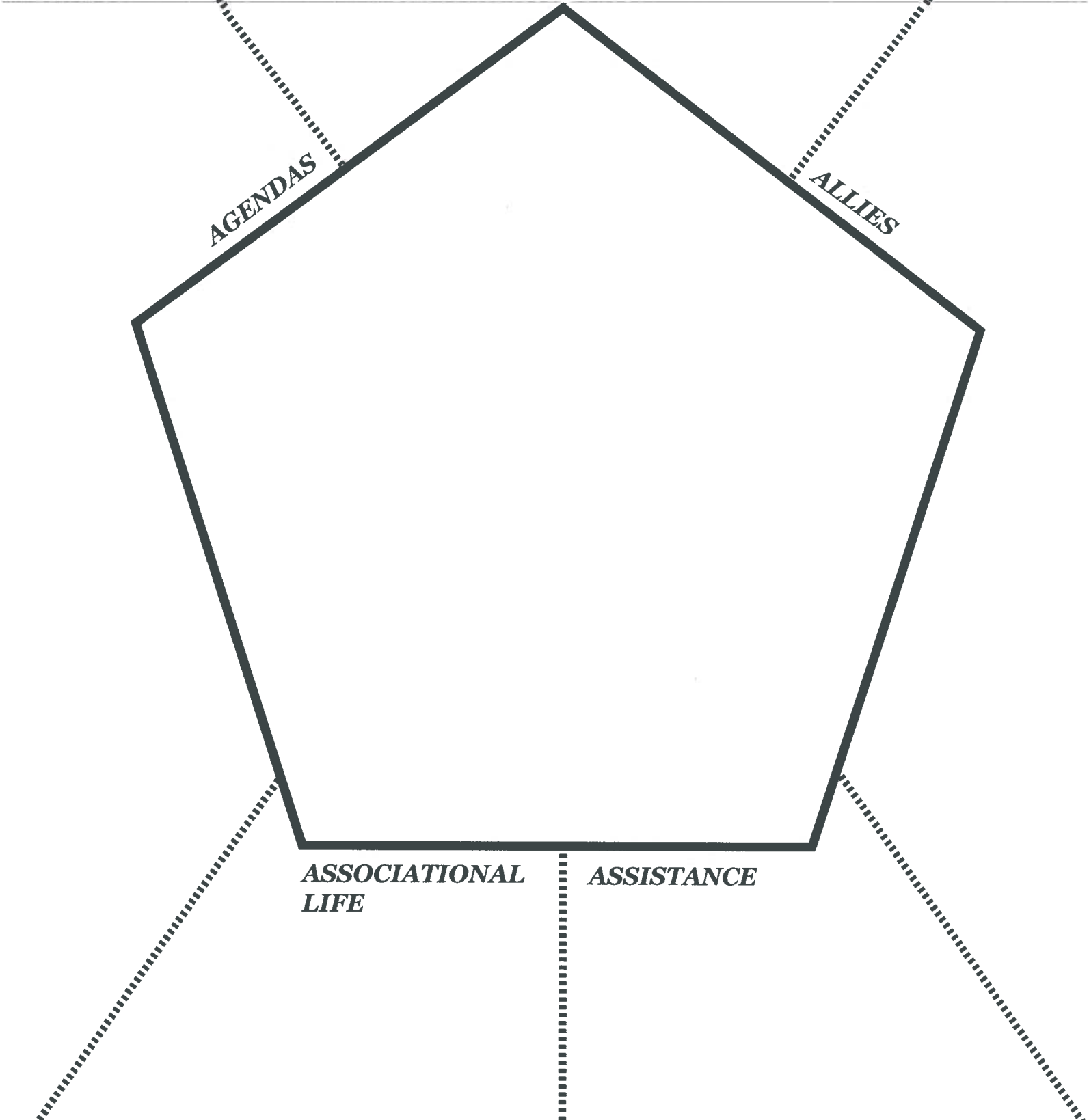
I started my internship with AHRC New York City in September of 2007. I was placed with HomeBuilders in Manhattan where I work with Carole Gothelf and Jennifer Teich on the Home Builders project one day a week. My job with HomeBuilders consists of meeting with people interested in having an individualized living situation and doing research on topics like Social Security and housing in New York City. I am responsible for coordinating the quarterly intern Reflection and Training meetings, I create forms, I do faxing and copying, and I am even using my graphic arts skills! Besides helping people with disabilities find the right apartment, I also participate in all meetings related to the project.

I have 12 years of experience living independently. Even though it hasn’t been easy, I love every minute of it. 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. 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 told me they couldn’t help me because it was 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 parents’ house because I felt my independence would be taken away. My parents’ house is not accessible and I would need help with everything. 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. During my ordeal, I never gave up hope and I was determined to find an accessible apartment so that I would not have to put up with this bad situation anymore.

I am proud to report as of April 1, 2008, I am living in an accessible house, where I can roll in and out without worrying about using 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. I feel so blessed to have the opportunity to be living in a house where I thought it would never be possible. By being part of the Housing Consortium project, 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.”

***The Five Commitments***





## A. The individual's situation before Home Builders

+ working	- not working
Had two jobs Family, friends, circle of support SANYS Speakers Bureau MOTH poetry group	Sixth floor apartment with frequently broken down elevator Irregular work, unreliable income  My DynaVox Needed back surgery

## B. The nature of the Home Builder's intervention

INTERVENTION	
Things	Energy
ISS funding Bathroom renovations A new augmentative communication system	Jen finding new apartment Jen and Carole arranging for AHRC New York City internship job MSC and Jen getting bids for bathroom renovations MSC follow through through Marisol, my job coach



## C. The changes in people's lives that resulted

My apartment that I can roll in and roll out of My new internship in the finance department at AHRC New York City My health The extension given to my internship because of my hospitalization	The bathroom is not really accessible
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## D. Could be better under these conditions:

Bathroom renovation Personal care support on the job Res Hab services so that I can learn how to cook independently
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## • Richard and Catherine hold onto their home

### *Invisible Lines of Connection*

Richard and Catherine are brother and sister. They have always lived with their father in Far Rockaway, Queens. In February of 2009, their father died with no will, leaving the two to live on their own. His social security benefits ceased with his death, withdrawing essential financial support for the costs of the home. But their circle includes some resources even more critical than money. They are a kindred family. Their Aunt Catherine feels very close to them and lives close by, too. And their brother Stephen is their strong advocate, determined to keep his siblings in the home they grew up in.

Some time before their father died, he had put the deed to the family home in Stephen's name. However, Stephen has his own home and family in Staten Island. This leaves him without the financial means to maintain the house for Cathy and Richard. And although the house is clean, it and its furnishings are old and worn and in need of maintenance. An ISS budget was developed to assist Cathy and Richard in paying rent to Stephen to cover the home's recurring costs, including heating and lighting, phone service, and upkeep. Without this financial support, Stephen would have to sell the house. Then Cathy and Richard would have to move into a group home, risking their separation from one another.

Both Richard and Cathy attend an AHRC New York City Day Hab program in Far Rockaway. Cathy has been going since 1984, but Richard only since 2004, before which he had no program. Among Richard's many skills, he is a gifted artist. He also can travel---he shops and does his banking. To ensure his safety and well being, however, Richard does require some oversight. Cathy needs round-the-clock support.

Prior to their father's death, they received personal care assistance through CASA X after program and on weekends. Since his death, they now receive homemaker services through CASA on weekdays from 3PM to 7AM and 24-hour services on the weekend. If one of them is sick during the week, however, or if the program is closed, they are at risk. The M11Q was being amended so that they will have the support they need. It will state that they need 24-hour care --- but not when they attend day program.

Cathy's and Richard's lives remain stable. They are closely linked to a community of people whom they have known for over 35 years. Their story exemplifies what is possible when families are clear about what they want for their loved ones and when agencies are willing to be creative and flexible.

## Lessons Learned



It is essential to listen to families. Everyone wanted Cathy and Richard to be able to continue living in their home together---especially Cathy and Richard!

When people experience loss, they often need a lot of hands to hold. AHRC New York City, OMRDD, CASA, and family and friends all came together to hold the vision of Cathy and Richard remaining in their home.

When creating or maintaining individualized living situations, each person requires unique supports. We must reach out beyond the individuals directly in our care to determine whether family or other natural supports are available and what they will need to fulfill this role for a person they care about. Stephen wanted his siblings to live in the family home, but his own responsibilities made it unrealistic to provide the additional finances.



## • Peter: Keep your family and apartment together in New York City



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. (See [www.citylimits.org](http://www.citylimits.org) for more about the Jiggetts program.) 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 feared that if they were evicted, Peter might have to go into a group home and that she would go into a shelter.

HomeBuilders and Peter's Mom and his MSC Gus worked with many New York City agencies and non-profit organizations. Catholic Charities and Palladia (Homebased Homeless Prevention) assisted the family with rent payments in arrears. An ISS budget was approved and is currently helping to cover Peter's share of the living expenses. Now the family has paid current rent and demonstrated their ability to keep current in the future. This was all made possible through ISS.

### Lessons Learned

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

When a person with a disability faces a crisis, having a passionate advocate is essential. 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 that the parents are unable to care for their child.



## • Kevin: At home with the neighborhood Mayor •

Kevin is a 22 year old man with Down syndrome. He lives at home with his mother in Rockaway Beach, Queens, and attends an AHRC New York City day program there. Kevin is known as “The Mayor.” Everybody knows him. This neighborhood is a supportive safe haven for Kevin and his mom.

The family was subletting their apartment from a woman who, incredibly, was not using the money to pay the landlord. Finally, the landlord agreed to rent the apartment directly to Kevin and his mother, but at a rate they could not possibly afford—even though his mother has a good job. She worried that if they could not meet their expenses, they would have to go into a shelter. Kevin’s mother called OMRDD in Albany to inquire about New York States Home of Your Own mortgage program. When Dr. Lucinda Grant-Griffin heard this story and the urgency of their need for a new apartment, she referred the family to Pat Sarli at NYCRO. Mr. Sarli connected her with the New York City Resource Consortium. We began the process of developing an ISS budget with the family.

Another apartment was located in the neighborhood. Although it cost more than the current sublet, they could still afford it if Kevin could contribute toward his living expenses. The very supportive new landlord was willing to hold the apartment until Kevin’s ISS funds were secured.

Getting into their new apartment, the family was going to incur significant one-time expenses. They were moving from a furnished apartment to an unfurnished one. In addition to moving expenses, they would have to pay a security deposit and first and last months rent all at once. We worked with the AHRC New York City Francesca Nicosia Family Reimbursement Program to reimburse the family for Kevin’s bedroom furniture. We also reached out to the Queens Center for Progress “Families First” program for funds to reimburse the family for additional household necessities for Kevin.

OMRDD worked determinedly to approve their ISS funds so that they could move into their new apartment on December 1st (the date they would face eviction from their old apartment). Kevin and his mother are living happily in their new apartment. Mom has attended the New York State Home of Your Own training and is on her way to purchasing a home for her family.

### Lessons Learned



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.

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

Finding affordable housing in New York City remains a challenge. People can be working very hard, earning a decent wage, and still be unable to afford housing.



“For as long as there is residential segregation, there will be de facto segregation in every area of life. So the challenge is here to develop an action program.”

*Dr. Martin Luther King, Jr. 1963*



# PART THREE: Findings and Implications

## Next Steps 1: The Design Challenge



The HomeBuilders experience offers portraits of quality individual design that maximize “natural resources” using minimal system dollars. Primarily, however, these portraits interest us not because they are cheaper than traditional services but because they create new patterns for individualized residential design. Both inside and outside the system, these new patterns function like new language for developing and expanding what we all care about. The future of residential design that seeks justice for people with disabilities and their families through relationship-building and inclusion will find fuller expression in this pattern language.

The small HomeBuilders grant from the DDPC and OMRDD to AHRC provided resources to hire Jennifer Teich. Jen works two days a week on the project, with close support from Carole Gothelf and Janice Bartley. Kathy Broderick also nurtures this project through her commitment to move an ISS budget quickly into place. Although unseen, the value of fast response cannot be overestimated. People who have benefited from HomeBuilders have held onto their family homes when a parent died. They have found very nice, accessible apartments, even in the face of eviction, largely because they had the support and resources to compete in the housing market and sign a lease in a timely manner. AHRC also helps in these urgent situations. As a large agency with a good record of reimbursements from OMRDD, AHRC has the flexibility to provide cash on hand in quick response to thoughtful design.

This brings us back to the role of Jen Teich. Since Jen’s job is not defined by billable Medicaid service units, she is free to spend time with people to explore options, develop budgets, find real estate, schmooze landlords, shop for furniture, build relationships between all sorts of people, programs and providers, hustle resources, and generally do whatever it takes to get to “Home.” “Home” is where people stay in apartments and neighborhoods of their choice, fragile ties become strong, and support systems stand firm, sustaining people over time. Jen functions as detective, match maker, real estate diva, architect, designer, social worker, advocate, and wise mother. She has the “open space” to respond to people—space not constrained by the need to fit people into boxes or beds, or process situations based on billable Medicaid service units. AHRC New York City’s commitment to developing and supporting individualized residential supports and its understanding of what it takes to do this has been codified by securing an alternative funding source for Jen’s position after the two year grant period ends.

In the pattern of Jen’s work, we see the variety of ways by which she brings care and attention to each situation. A meaningful design emerges that clarifies the “things” and energies needed to build a life in a community. While every person and situation supported by HomeBuilders is unique, the HomeBuilders pattern language is expressed in all Jen’s design processes. These twelve patterns are summarized on the following page.

For all of us in the field of developmental disabilities, the capacity to design individualized residential options is the critical-change factor for our mission in this new century. Design is the often invisible function which only exists where leadership intends it and supports it with staff, time, and money. If we fail to develop this function, the system reverts to unintended, thoughtless “placements” in which people become isolated, marginalized, and vulnerable and often slip into despair. To move towards an individualized supports environment, we must strengthen and expand the design function.



## • THE HOME BUILDERS PATTERN LANGUAGE •••••

### *Twelve Essential Investments*

**Listen** to the person and family to discover what matters to them.

Attend to sustaining and growing **family relationships**.

Strengthen the quality of life of **support workers**, especially by sustaining quality relationships that last. (Fern has been with Janice for 12 years.)

**Nurture partnerships** between people, particularly between family members, support people from different agencies, service coordinators, friends, and community members.

Always consider the **power of place in the family home** or in other quality affordable housing. There is simply “no place like home.” In three out of ten situations, the person is living in the family home and/or a home owned by the parents.

Pay attention to **neighborhood life**. The vital network that is within walking distance enhances the potential for autonomy.

Give attention to **unlived potentials** and ways to bring those forth, particularly in relation to people’s days, their work opportunities, and their increased capacity to be wage earners.

Explore **cutting-edge technologies**, environmental modifications and **other adaptive strategies** that support personal independence and safety. These supports may be as simple as cell phones, intercoms, and doormen, as complex as kitchen and bathroom renovations, or as high-maintenance as a service dog.

Take initiative to **respond quickly**. Finding resources and implementing services is always good as gold. Whether overnight or in one week, inside two months, depending on the case.

**Keep it simple** for the people with a disability, their families, landlords, support workers, and other important allies. ISS funding procedures are amazingly simple and user-friendly. In the NYC urban environment, this fact matters very much.

Build an **associational community and commitment** of families who can support and assist each other, particularly in areas related to quality safeguards and mutual concern for development. We develop this idea by describing the Big Tent in Next Steps 2.

Help people with disabilities and their families be members of networks and organizations that **take collective action** to build capacity related to all the key investments of this pattern language. (In collaboration with Kathy Broderick, we are exploring more ways to do this.)

“It is not essential that each person design or shape the place where she is going to live or work. However, the love and care and patience needed to bring every part into adjustment with the forces acting on it can only exist when each detailed part is cared for and shaped by someone who has the time and patience and knowledge to understand the forces acting on it.”

*Christopher Alexander, The Timeless Way of Building*

## Next Steps 2: The Relationship Challenge

### *The Potential Power of Family Associations*



“How we address issues of isolation, quality of life, and stability of relationships is completely interwoven with our success in creating good individualized housing solutions. Even when people with developmental disabilities have lived many years in communities and outside of institutions, most are still suffering from segregation and isolation. This will only change when we learn how to nurture relationships with neighbors and offer a more holistic approach to support services.”

*Diana McCourt and JoAnn Dolan*

Growing natural supports in the lives of people with disabilities rarely happens naturally. Rather, such growth is intended; it is designed. We are acutely aware that the common experience of people with disabilities and their families is social isolation, rejection, discrimination, and exclusion. It is true that the “next generation” of young people with disabilities who have benefited from inclusion in schools and family neighborhood life report a somewhat different experience. Nevertheless, successful relationship building is a relentless, intentional task that we are only beginning to understand. If a life full of relationships is key to richness of experience, personal development, and reliable safeguards, then we need to invest strongly in ideas for development that accomplish this end.

The Big Tent provides a compelling vision for a holistic, intentional approach that strengthens all twelve essentials-of-HomeBuilders’ pattern language. The Big Tent is a parent association founded by Diana McCourt and JoAnn Dolan. They have been developing this vision over the past five years, and in the last two years, through HomeBuilders, AHRC New York City has become the agency partner working with Diana and JoAnn toward implementation of the vision. Aspects of the Big Tent are described in the following section.

Supported with a very small three-year grant from the FAR Fund for Social Change, Diana and JoAnn developed the Big Tent vision by going on learning journeys to other organizations such as Rennselear ARC and an urban demonstration of Camp Hill in Barrie, Ontario. They have held numerous conversations with The Disability Opportunity Fund and other Community Development Financial Institutions (CDFI), Center for Urban Community Services (CUCS) and housing developers. They meet regularly with families who have organized themselves and who are also looking for something different. They have visited vibrant community centers and intentional living communities in New York City. All in all, they have been struggling mightily to put forth their vision and therefore create more options for NYC families. AHRC New York City is also devoting leadership time and energy toward this development.

The Big Tent matters not only because of the integrity of the vision, but also because similarly motivated parent groups are springing up throughout New York State. At least eight such associations have formed in New York City alone. These parents are a treasure-trove of devotion, energy, resources, and long-term commitment to the development of quality individualized supports for their loved ones. However, they do not want to be working alone on these commitments---and frankly, they can’t. Their resources and energy can be multiplied by working with others and forming partnerships with organizations who can help develop this model.

We must support the development of these parent groups. For their part, invested parents need stipends to devote the time and energy to develop their ideas. For our part, we must demonstrate organizational capacity to create these new options with them. The next stage of residential development must include and address the concerns of these parents.



## • At Home in the Heights

### *An Inclusive Neighborhood Development Project*

*by JoAnn Dolan and Diana McCourt*



At Home in the Heights is a proposal for a new way of living in New York City for people with disabilities and their supporters. The intention of this neighborhood project is to offer a person-centered life plan that 1) offers new choices and quality standards for those who wish to share life with supportive persons in a caring household and, 2) taps into the neighborhood community assets for housing, paid or volunteer work, recreation, a neighborly social life, and a rich cultural experience.

Our project, At Home in the Heights, is so named because we have targeted a Manhattan neighborhood in north Washington Heights on the border of Inwood. By externalizing a life of support and relationships within a given neighborhood, with housing units scattered within walking distance of each other, building community will be a natural outcome. At Home in the Heights is a community model that can be replicated in neighborhoods throughout Manhattan and the Boroughs or elsewhere.

This inclusive neighborhood development concept has taken shape over the past three years and is formulated through partnership support. Our model currently proposes three major partners to begin: AHRC (as provider agency), The Big Tent (an association of self-advocates, parents, advocates and service providers), and Camphill (as source of training, home making, planning, evaluation, etc.)

## *What makes our houses real homes with friends and meaning?*

At Home in the Heights will start small, developing one home at a time. There will be a variety of living arrangements in housing units. An important part of the community living experience will be to regularly visit each other, share meals, become “regulars” in neighborhood stores and restaurants, or go on excursions together.

At Home in the Heights neighborhood project proposes support of 8-12 people in a life-sharing network through home ownership, lease, or rent. Individualized living arrangements within the neighborhood will be within walking distance of one another. Participants with disabilities will achieve a life of their choosing and have the opportunity to interact with people throughout their day who are not paid providers and who are not developmentally disabled.

Participants who have a disability can live where and with whom they want, for as long as they want, with whatever support is necessary to make that choice possible. Individuals will own their own homes or have lifetime leases on housing purchased for them, keeping services separated from housing through contracts that define that understanding.

We will start with a cornerstone home that will include a central gathering space for participants, and will provide a place to invite family, friends, and neighbors for meals, song, celebrations, meetings and other activities.

Our project approaches individualized housing solutions that will reinforce and transform its support systems. The neighborhood project engages all stakeholders: (1) self-advocates, (2) shared living members, roommates, caregivers, etc. (3) existing parent associations, (4) community asset-based resources, (5) local provider agencies (6) OMRDD and (7) supporters and sponsors of social change.

# ***Through a neighborhood and economic development perspective, our community model will:***

## ***Commit to the economic life of the neighborhood while living and working there by:***

engaging in local commerce with its purchasing power in the community  
offering employee skills and volunteer services

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## ***Employ local people for resources and as support staff***

## ***Create micro businesses through partnerships with existing local businesses or develop new ones***

## ***Foster community inclusion by:***

utilizing facilities and resources that are available to all community members  
developing opportunities to interact with neighbors  
participating in cultural activities and share in the artistic life of the neighborhood

## ***Enhance the experience of caregivers by offering a nurturing, supportive and meaningful environment that recognizes their dignity and importance, eliminates on-the-job isolation, and heightens enjoyment of work and quality of life.***

## ***Empower responsible families to move from consumer advocates to full citizen participants in a giving role***

## ***Instigate change through social invention and by teaching and sharing***

## ***Transform the roles of direct support staff:***

We are facing a crisis in recruiting and maintaining a stable, qualified and integrated workforce in services for people with developmental disabilities. Support workers are underpaid and many are poorly trained. These positions have as high as a 75 percent turnover rate each year because of poor wages, worker isolation and high job demands, putting the quality of life for people with disabilities at risk. Demand for these workers was forecast to grow 62% between 2000 and 2010 as disabled Americans grow older.

Direct care workers do the crucial work of assisting people with disabilities with daily medications, dressing, preparing and eating meals, getting to work, gaining life skills and handling daily affairs. By transforming the relationship of caregiver to community member, with rich opportunities for training, support, and participation, we can create a life of mutual interest with a strong degree of personal fulfillment.

Because of the overwhelming needs, not only in New York City but also on a national level, we are anticipating a seismic shift in the way we think about providing opportunities for self-determination and person-centered planning for people who are vulnerable. Inclusive neighborhood development offers a creative and progressive way of life that is an alternative choice for urban areas across the country.

## ***Life Sharing***

Life sharing is an alternative to traditional residential service models in New York City. It is not a program but a way of life. People with and without disabilities cook meals together, take responsibility for household chores, finances, and food shopping, as well as for creating a flexible and integrated work life, social life, and cultural life. Although life sharing is at the core of the community, a variety of arrangements for support will be in place according to need and choice. All caregivers will be supported as valued community members.



### **Neighborhood**

We have targeted a Manhattan neighborhood in north Washington Heights on the border of Inwood. This is an established community surrounded by significant institutional assets and easily accessible public transportation. It is a vibrant section of the City with an ethnically diverse community and some of the most reasonable real estate values. Several of our interested families live in Washington Heights.

### **Life Activities**

In life sharing communities connections are built among different life sharing households, which are within walking distance from one another. The neighborhood living experience fosters regularly visiting each other, sharing meals, going on excursions together, and nurturing and supporting each other in a family-style interdependent fashion. Life sharing community members may plan what they can do together to participate in the wider community and to help make it a better place.

Guided by the strategies of asset-based community development experts Mike Green and John McKnight, we intend to tap into what exists in the local neighborhood. We will explore partnerships and entrepreneurs with local businesses, non-profit organizations, service-based religious institutions, recreation centers, and the art community.

Rather than staff who ride with people with disabilities on a bus for three hours a day to transport a companion to a Day Hab center and supplemental activities, we envision something more recognizable: a morning routine followed by a walk to work (paid or volunteer) and to recreational activities in the neighborhood, with a blend of Res Hab and Day Hab activities woven into a natural daily rhythm.

Music and art are an integral part of life. Expression and self-awareness are major components for joyful living and are integrated into life activities.

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“The Transform and Empower approach starts with the mobilizing of changes with and by those for whom those changes are most critical in gaining a life of dignity, respect and opportunity. We focus on solving the situation for the person, and at the same time getting to the underlying structure that grips onto the problem and locks it into place. The repatterning that follows creates profound shifts in perspective, person by person, group by group. This change in thinking innovates new arrangements to support the kind of lives and opportunities that individuals want. We put new tracks in place as we go. These can be used again by others in similar situations. We often call these tracks systems. We review our systems from time to time, to ensure that they are responsive to people’s evolving needs.”

**Julia Wolfson, *Turning Myself Forward*,  
The personal story that led to the Transform and Empower approach**

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## Next Steps 3: Development of Skills in Self-Advocacy through Reflective Practices

### *Commitment to Learning and Development*



**Jerry G. Petroff**

***The College of New Jersey***

“Follow effective action with quiet reflection. From the quiet reflection will come even more effective action.”

***James Levin***

In an effort to enable individuals with disabilities to develop political, economic, and cultural influence, it is important to support skills of self-advocacy and empowerment. In addition, people with advanced skills in self-direction and preservation are less likely to be oppressed and abused. People with disabilities are gaining unprecedented personal growth through the systematic facilitation of life-enhancing personal goals and reflective practices. The notion of “raised consciousness” as an experientially evolved awareness of self (Charlton, 1998) can be developed through periodic opportunities for focusing and reflecting on one’s life. The primary vehicle to life-long learning is the exercise of on-going reflection. In order to achieve continuous learning, an individual must have the capacity and opportunity to reflect in action and on action (Schon, 1983)---that is, both while she is active and afterward too. Individuals with developmental and intellectual disabilities have often been exempted from learning this process, resulting in low expectations and further dependencies.

AHRC New York City’s SAGE Project (Support in negotiating learning needs; Assistance in learning skills in the work environment; Guidance in time management; and Encouragement and feedback to broaden skills) was an integral part of HomeBuilders Resource Consortium project. SAGE supported the growth and development of the ETP interns (Employment and Training Program) that included self-advocates working in the four consortium agencies to promote self-directed housing. The project supported 8-10 self-advocate/interns. As a core component of the SAGE Project, a facilitator would meet with the interns for a full day every quarter to help them reflect on and give voice to their personal goals, progress in the project, and challenges in the work place. Between these meetings, the interns and their supervisors were asked each month to complete a confidential on-line survey designed to encourage processes of review and reflection while working. Survey results assisted the facilitators to plan each quarterly meeting so that important issues and topics got addressed by the interns themselves, whose voices the facilitators could more effectively encourage. At the conclusion of each reflective session, participants were asked to evaluate the day and identify desirable changes in process or content.

This two year project demonstrated that providing guided reflection to the interns improved the quality of their lives. The meetings assisted those involved to establish and monitor short term personal and employment-related objectives that were tied to the overall goal of permanent employment. Over time, the participants seemed to find confidence and increased skills in self-reflection, very often with clear analysis of successes and challenges. Many of the interns were able to delineate clearly which issues they could influence and how to work with those they could not change. The group began to form a small, healthy network of social and political supports.



## What did we learn?

Without a doubt, this project confirmed the hypothesis that people, regardless of their abilities, can and should develop skills in self-reflection. All the participants learned to reflect on their own actions and developed skills in reviewing their work and readjusting their positions. They showed increased confidence as they worked through challenges and identified their strengths as well as opportunities for improvement. With each meeting, they became more able to self reflect and depended less on the facilitator and more on the process and its opportunities. In the end, all participants clearly changed from having narrow or unrealistic views of their futures to holding and communicating more meaningful goals for the future.

Charlton, J.I. (1998). *Nothing About Us Without Us: Disability, Oppression and Empowerment*. University of California Press

Schön D.A.(1983). *The Reflective Practitioner: How Professionals Think In Action*. London: Temple Smith





## Next Steps 4: The Organizational Challenge: *Commitment to Learning and Development*



“What made disabilities service organizations successful since the 1970’s was an environment shaped by compliance with OMRDD’s increasingly sophisticated ways of maximizing Medicaid revenues, along with a pattern of merely incremental changes which constantly added to the range of group service models. Now, a radically changed social, political, and economic environment makes deep change necessary. Experience shows that supporting lives of distinction and self-direction calls for organizational cultures, structures, and practices that are significantly different from those in place through the last forty years. Failure to do developmental work at the organizational level will result in wasteful activities that rename old practices with new labels that sound more appealing but maintain current structures, making only small improvements. This will dilute the possibility of lives of distinction and betray what organizations committed to transformation are working hard to learn. It will be more of the same—until people notice that no progress is being made toward transforming the relationships between people, communities, and services.”

*John O’Brien*

## **NYSACRA Learning Institute on Innovation in Individualized Supports: A Learning History**

*Real organizational innovation is the challenge confronting New York City AHRC. Organizational innovation requires learning and development at every level of organizational life. To meet the challenge, New York City AHRC must increase its capacity to stimulate learning that generates innovation. Here are some steps on the path of the learning journey:*

1. Participate in **learning journeys**: Learning Journeys have sparked creative thinking as we as provided a perspective on how individualized supports can be negotiated, designed and implemented.
2. **Force Field Analysis**: This tool has challenged us to clearly describe our plans for change and identify the forces within the department and the larger agency that will support this idea, as well as identify those forces that will challenge the change. It is a good decision making tool, helping us to survey the organizational environment and identify changes and strategies needed to help improve the plan and optimize the possibility of a positive outcome for change.
3. Create a **PATH**, for the department (e.g. ADS, EBS, Residential, Training, Education, Homecare): What is our image of a possible, possible future for the department and what will it need to look like one year from now for the future to unfold. What the department look likes now, what the department will look like when we are half way there, what will it look like next month. A PATH helps us identify who we need to enroll on the journey, what we need to do and our first step.
4. Develop a **“pilot project”** that is based on an individualized supports model. Convene a small work group of people from the department and those from other departments that have an “affinity” for the project.



5. **A community of practice:** Learn and work in partnership with other agencies. When we change from an isolationist model to a collaborative model it yields remarkable results.

6. Have people with **developmental disabilities** at the table. Listen to them, they have wisdom to share that has been informed and shaped by a lifetime of experience.

7. Engage in **strategic planning:** Look at the pilot project, the Force Field Analysis and the PATH with a context of the next five years of organizational development.

8. Become a “learning organization”. Organize opportunities for learning, engage with consultants, go to meetings, read, etc. Facilitate staff commitment and development through learning.

9. Build the capacity of **Direct Support Professionals:** This is the largest segment of the workforce, they shoulder responsibility for an individual's quality of life from moment to moment and they have the least power. This imbalance often leads to poor morale and diminished enthusiasm for the work.

10. Listen to **families:** They have great ability to think out of the box because they don't know “the rules” and they think with a full heart. These “crazy” ideas are responsible for our most innovative systems change.

## Lessons Learned

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 accomplished through training.

Innovation must be balanced with stability.

Develop and support mentoring. The mentor opens the space for others in their department to learn and begin their own journey. Develop the capacity of Direct Support Professionals; they make up the largest segment of the workforce.

Person-centered thinking and shared values are being built into all aspects of AHRC/New York City to stimulate cultural change, i.e. pre-service and ongoing training, IEP and ISP development based on person centered planning and development, departments working together to help people build a life and not place people in program slots, etc.

## ***The Five Commitments***

***ANCHORS***

***AGENDAS***

***ALLIES***

***ASSOCIATIONAL  
LIFE***

***ASSISTANCE***

