

# KEYS TO LIFE



## Creating Customized Homes for People with Disabilities Using Individualized Supports

Stories of support options created by The Arc of Rensselaer County that enable people with disabilities to live in their own homes

Beth Mount, Ph.D. | Sandy VanEck, M.S.





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## Dedication

Our Guiding Inspiration and Genius:  
**Henrietta Messier**

*People are what matter, and it is the relationship  
with others at home, at play, and at work that  
creates a meaningful life!*

— Henrietta Messier

A *muse* is an *inspiration* or a *guiding genius*. For 40 years, Henrietta Messier has been our muse in the quest to individualize the supports we provide to people at Rensselaer ARC. Henrietta's life journey has informed our mission, vision, priorities and everyday actions. Her calling as one of the premier national advocates for people with disabilities came with the birth of Cherie, her first child of six. Born with Down Syndrome in 1948, Cherie profoundly influenced Henrietta's journey. Contradicting the expert medical opinion of the day, Henrietta refused to institutionalize her daughter. Cherie would live, learn, play and work in her family's neighborhood — and Henrietta was going to make it happen on many levels, and not only for her daughter. Ultimately, she would forge pathways for all who were once rejected as citizens and members of our communities.

Henrietta's vision has always been about quality of life for all. She has engaged individuals, neighborhoods, organizations, and whole service systems in transformative change. She worked closely with parents to provide a typical and individually unique life experience for their children. Unsatisfied with the supports provided to people with disabilities, she moved to the public policy frontlines, advocating for resources, calling for legislative action, working with local schools and communities, and creating wholly new provider organizations.

Henrietta's vision affirms a philosophical framework which includes humanism, Judeo-Christian values, social change theories, enlightened management practices, and — most important to the leadership of RARC — the concept that small is beautiful. Henrietta was prophetic in her belief that the demands of large organizational systems undermine person-centeredness and are not sustainable. She reminds us that "people are what matter, and it is the relationship with others at home, at work, and at play that creates a meaningful life." Rensselaer ARC seeks this "gold standard" in striving to create individualized supports.

Our ability to listen and respond to the individuals described through the stories in this book is made possible with the vision, advocacy, and presence of Henrietta Messier.

Hanns Meissner, 2010  
Executive Director

## About the Keys to Life Quilt

The Keys to Life Quilt expresses the spirit of innovation described in this book. Henrietta's conscience, symbolized by an angel, serves as a guardian of the space in which person-centered development can emerge. Look closely and you will find a "golden ruler" or measure in several places. This measure stands for the spirit of the golden rule, inviting us to imagine a standard of quality founded on a desire to serve others as we ourselves would hope to be served.

The centerpiece house symbolizes the Template for Residential Design that is elaborated for each of the ten people described in the book. Two figures stand in the doorway to represent the focus person and the champion who is listening to and holding the concerns of the focus person. When a champion listens carefully and deepens his or her relationships with the person, family, and support circle then the champion is more able to see with the eyes of the heart and have the courage and determination to create something new.

Deep listening to the person and the family leads to the discovery of patterns that define quality of life for each person. These patterns are the Keys to Life. We find that the keys to each unique support configuration are found through person-centered conversations and planning by those who are deeply invested in the quality of life for each person. When we are true to these patterns, the potential in people blooms. The organization is continually called to align and nurture the relationships and supports that strengthen the Keys to Life pattern for each person.

Level One of the house symbolizes the physical aspects of a situation which include the home and the surrounding neighborhood. Level Two of the house symbolizes significant relationships, both natural and paid support, and the pattern of decision making between them. Level Three captures aspects of the space that represent the vision, values, and leadership commitment that defines the standard for quality support.

The ten story squares pictured on the side panels convey the essence of something unique about each person and his or her situation. These images were drawn from story collages made by all ten people and their support circles. Each of the ten story scrapbook pages express the meaning of each symbol, the keys to quality, the details of each support arrangement, photos of the person, their home, template collage, and summaries of steps taken by RARC to strengthen organizational keys to success.

As a whole, the quilt seeks to express the colorful, complex, creative vibrancy of the implementation of individualized supports. The book describes leadership commitments to the creative container in which these ten situations flower and blossom.

Beth Mount, 2010  
Author and Artist





## Background and Acknowledgements

*Presencing is a blending of the words “presence” and “sensing.” It means to sense, tune in, and act from one’s highest future potential—the future that depends on us to bring it into being. The question that underlies the journey is “How can we act from the future that is seeking to emerge, and how can we access, activate, and enact the deeper layers of the social field?”*

Theory U: Leading from the Future as it Emerges  
— Otto Scharmer, 2009

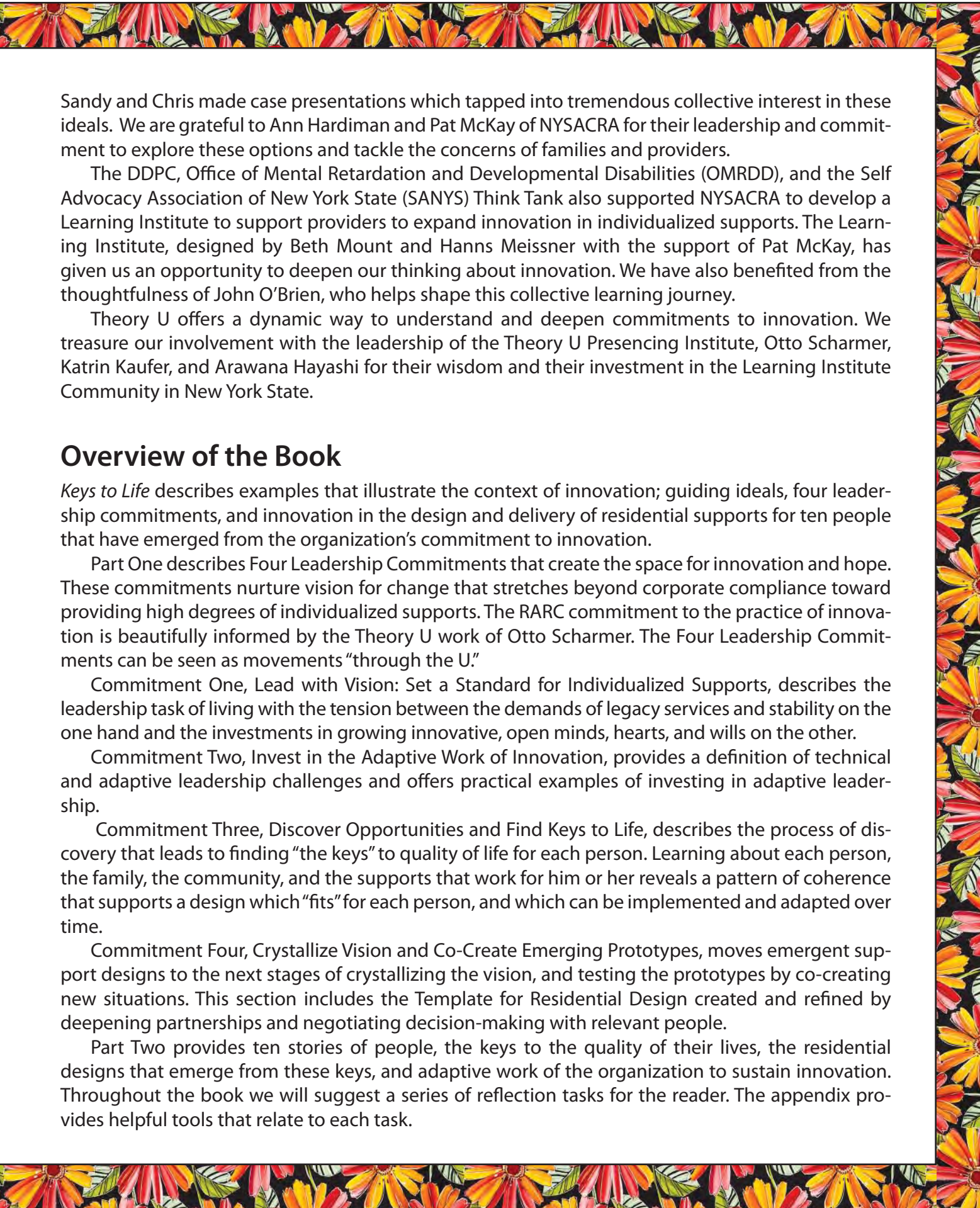
This story of innovation at Rensselaer ARC begins with Henrietta Messier, Ellie Pattison (citizen advocate) and other parents who are the guardians of ideals that bring forth the highest future potential in the lives of people with disabilities. Their striving for the inclusion of their children, and their insistence that all people with disabilities be valued as citizens rather than clients, sets the standard for personal integrity and organizational innovation required to actualize these assumptions.

The history of development at RARC is a study in minimizing organizational demands that distract from this higher purpose, while strengthening learning and practices that encourage the highest potential of every person involved with the agency—the people with disabilities, their families, the staff who support them, and the community members who interface with people at all levels. Bringing his passion for organizational change into every detail of leadership, Executive Director Hanns Meissner holds the vision of RARC as a “learning organization” which prioritizes efforts to innovate and reach for new ideals. *Keys to Life* describes one aspect of the agency’s innovation of ways to enable people with severe disabilities to live in their own homes. The ten customized situations described below emerged between 2000 and 2010. Each offers a prototype of innovation. Together they illustrate how an agency can innovate by listening to people and then changing itself to bring out the best in and from all.

We decided to write this book in 2006 when Beth Mount was invited into RARC to work with Sandy VanEck to help communicate Sandy’s unique style of person-centered planning that leads to creative individualized options. The secret to Sandy’s success is her immersion in the lives of the people she plans with, learning about and connecting to the people, their families, and their support staff. Compassion, intuition, and sound analysis are always in play. In her role as Director of Design and Innovation (see page 20), Sandy makes the “space” to improvise and create new possibilities that honor real person-centered planning. Sandy partners closely with Chris Liuzzo, the Associate Executive Director of Family and Community Supports, to blend creative design with the nitty-gritty detail and operational expertise essential to effective implementation. Together, they are a learning laboratory where new ideas incubate and hatch into reality.

Sandy and Beth organized several retreats where people have come to tell their own stories about living in their own homes with individualized supports. We are grateful for their time and their willingness to describe their lives and share their stories.

As we were developing descriptions of these residential innovations, good things were happening. OMRDD increased its commitment to self-directed, individualized supports. The New York State Association of Community and Residential Agencies (NYSACRA) received a grant from the Developmental Disabilities Planning Council (DDPC) to explore concepts and issues related to Life Sharing and subsequently sponsored several information-gathering events throughout the state.



Sandy and Chris made case presentations which tapped into tremendous collective interest in these ideals. We are grateful to Ann Hardiman and Pat McKay of NYSACRA for their leadership and commitment to explore these options and tackle the concerns of families and providers.

The DDPC, Office of Mental Retardation and Developmental Disabilities (OMRDD), and the Self Advocacy Association of New York State (SANYS) Think Tank also supported NYSACRA to develop a Learning Institute to support providers to expand innovation in individualized supports. The Learning Institute, designed by Beth Mount and Hanns Meissner with the support of Pat McKay, has given us an opportunity to deepen our thinking about innovation. We have also benefited from the thoughtfulness of John O'Brien, who helps shape this collective learning journey.

Theory U offers a dynamic way to understand and deepen commitments to innovation. We treasure our involvement with the leadership of the Theory U Presencing Institute, Otto Scharmer, Katrin Kaufer, and Arawana Hayashi for their wisdom and their investment in the Learning Institute Community in New York State.

## Overview of the Book

*Keys to Life* describes examples that illustrate the context of innovation; guiding ideals, four leadership commitments, and innovation in the design and delivery of residential supports for ten people that have emerged from the organization's commitment to innovation.

Part One describes Four Leadership Commitments that create the space for innovation and hope. These commitments nurture vision for change that stretches beyond corporate compliance toward providing high degrees of individualized supports. The RARC commitment to the practice of innovation is beautifully informed by the Theory U work of Otto Scharmer. The Four Leadership Commitments can be seen as movements "through the U."

Commitment One, Lead with Vision: Set a Standard for Individualized Supports, describes the leadership task of living with the tension between the demands of legacy services and stability on the one hand and the investments in growing innovative, open minds, hearts, and wills on the other.

Commitment Two, Invest in the Adaptive Work of Innovation, provides a definition of technical and adaptive leadership challenges and offers practical examples of investing in adaptive leadership.

Commitment Three, Discover Opportunities and Find Keys to Life, describes the process of discovery that leads to finding "the keys" to quality of life for each person. Learning about each person, the family, the community, and the supports that work for him or her reveals a pattern of coherence that supports a design which "fits" for each person, and which can be implemented and adapted over time.

Commitment Four, Crystallize Vision and Co-Create Emerging Prototypes, moves emergent support designs to the next stages of crystallizing the vision, and testing the prototypes by co-creating new situations. This section includes the Template for Residential Design created and refined by deepening partnerships and negotiating decision-making with relevant people.

Part Two provides ten stories of people, the keys to the quality of their lives, the residential designs that emerge from these keys, and adaptive work of the organization to sustain innovation. Throughout the book we will suggest a series of reflection tasks for the reader. The appendix provides helpful tools that relate to each task.





## Part One : Leadership Commitments: Making Space for Innovation and Hope

*With the beginning of this millennium we have entered a phase of increased tension between two principal sets of conflicting forces. The difference between them is that the first one—the forces of fundamentalism, manipulation, and destruction—works by decreasing the degrees of freedom for the people involved. By contrast, the other set of resources at work increases freedom by shifting the inner place of operating and*

*showing people additional ways to attend and respond to situations at hand. The difference, simply put, is that the first looks at a human being as an object that is determined by its environment and conditioned by its past. As a consequence, it can be influenced, manipulated, and controlled through exterior mechanisms. The second view sees human beings as subjects — carriers of a dormant capacity to connect with a deeper source of creativity and knowing. Through this capacity, people can link with and realize a future that depends on each of us in order to come into being. As a consequence the essence of this view of the human being is to create through connecting to one's highest future possibility, one's authentic Self.*

The Battle of Our Time from Theory U

— Otto Scharmer, 2008

### A Learning Organization

Organizational life at RARC is shaped by “the second view” of human beings as subjects — carriers of a capacity to connect with a deeper source of creativity and knowing that leads to creative action. RARC commits to learning and innovation as the pathway toward community inclusion on behalf of people with disabilities. Forging this path requires conscious commitments and intentional investments in learning, reflection, and team building to create a responsive learning organization.

*Keys to Life* describes the customized homes and lifestyles of ten people. These innovative prototypes emerged from people at all levels of the organization who were invited to become instruments of change and champions of innovation by listening to the people served.

These ten prototypes are some of the many ways that RARC builds on its founding core principles that include: small is better; social justice and inclusion for all; build community through collaboration; find the uniqueness in each person, and discover the creative way.

The next section outlines significant commitments by RARC during the past thirty years that steadily strengthened the container for members to create new kinds of supports. The more that RARC finds its innovation groove, the deeper commitment grows toward person-centered development, and the more staff aspire to become instruments of change, creating positive futures.

## BACKGROUND OF DEVELOPMENT DECISIONS

### 1980s and 1990s:

- Will not open Intermediate Care Facilities (ICFs)
- Everyone will have a single bedroom
- Will not open any residence for more than three people
- Will move people out of low-income neighborhoods
- Explore home ownership and life sharing
- Support people to stay in their own homes as they age through the last stage of life
- Mentored by Nancy Howes, coach to Hanns, which led to the Learning Organization Orientation.

### 1990s:

- Downsized sheltered workshop design of the Community Inclusion Project (CIP)
- Obtained DDPC grant to support downsizing
- Recognized that even 3-person residences are not necessarily individualized
- Created individualized arrangements for Albert, Phyllis, Regina, and Phillip
- Recognized that people wanted to get married and live together
- Created home ownership option for the Judges, then for several other married couples
- Increased investment in person-centered planning and SRV mentoring relationships: Guy Caruso, John O'Brien, Beth Mount, Michael Kendrick, Michael Smull
- Started first self-advocacy group

### 2010 and beyond (goals):

- Increase commitment to Self-Determination and Self-Directed supports
- Implement Agency With Choice
- Increase investment in leadership development at all levels: Corporate University, Everyday Heroes, Peer Mentoring, College of Direct Support, and Accelerated Leadership.
- Strengthen sustainable service practice and community building.
- Expand retirement options for people at Riverside Enterprises.
- Expand Lives of Distinction Initiative and implementation.

### 2000s:

- Committed to more live-in and life-sharing options; including shared living arrangements and paid support from a neighbor
- Created three mother-daughter options
- Committed to individualized supports; group-development model discontinued
- Created Department of Design and Innovation
- Downsized several large situations such as Prout and the Affiliate
- Created life-sharing with many variations, not just one style or type
- Worked with NYSACRA to challenge legal issues related to Life Sharing
- Increased involvement with Theory U and innovation/prototyping models
- Increased commitment to health at all stages of life: end of life, aging, and health-and-wellness concerns
- Implemented first effort in self-determination and brokerage
- Expanded commitment to three levels of Individualized supports





## Going Green

*Throughout the book we will highlight qualities of a learning organization in green to symbolize generative aspects of this work. Practices that merely download traditional options are coded in red.*

## The Power of Theory U

Much of the development of services for people with disabilities in New York State follows the path of expanding traditional service options, which segregate and congregate large groups of “clients” to provide care and treatment apart from the wider community. In Theory U, doing and teaching things already known is called “downloading.” Theory U offers a map for negotiating a different path, one leading into the territory of new, effective practices. At RARC, the map of the “U” is in use.

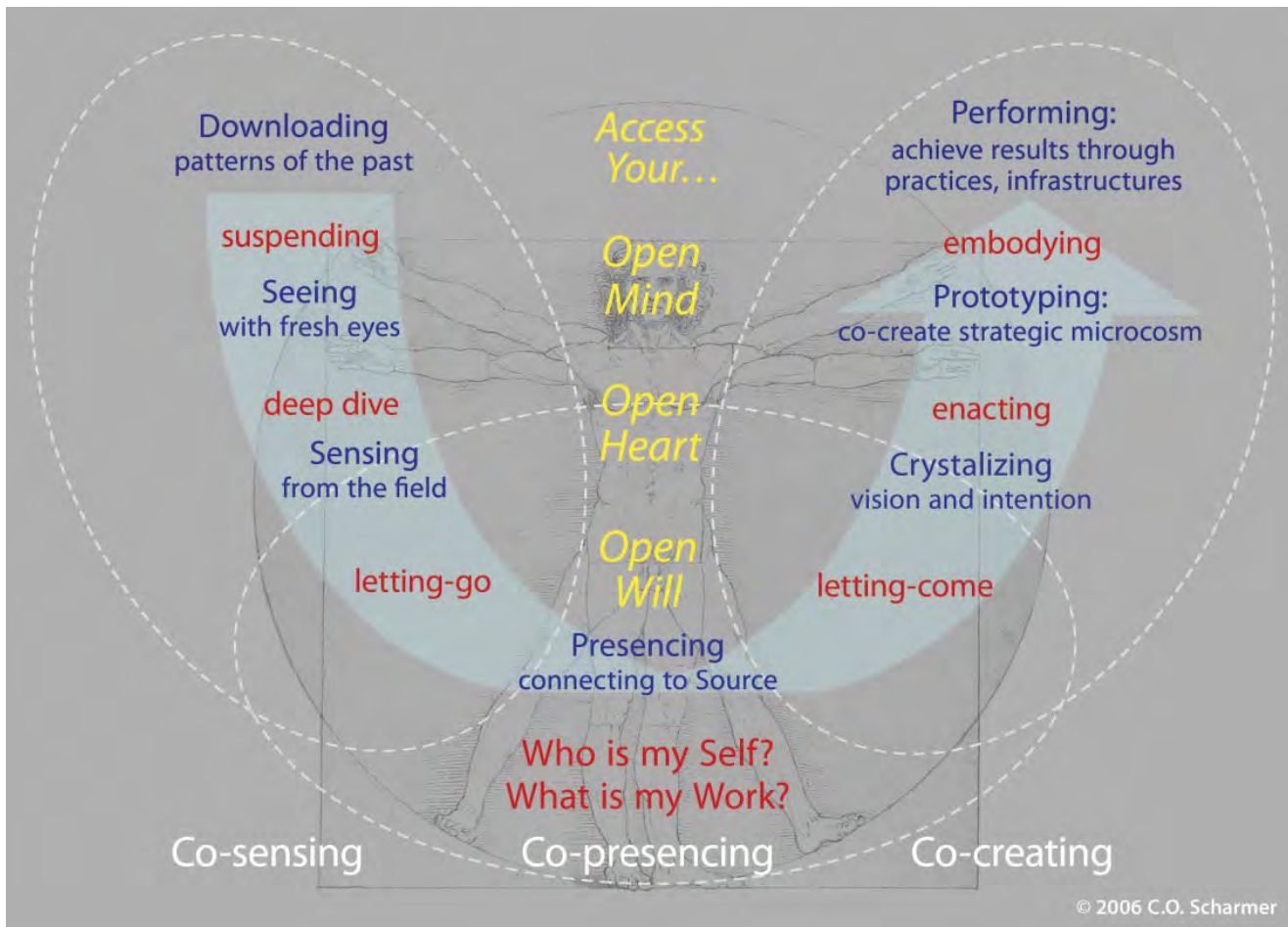
Person-centered individualized options are an emerging alternative that seek to amplify the gifts of people and find ways to sustain them in valued social roles and supportive communities. John O’Brien soberly observes that where creative attention lapses, even person-centered planning may end by being “downloaded” into the same old services. Theory U practices focus our attention first by stopping downloading habits and second, by helping us move beneath the surfaces of our ordinary understanding of the person. Possible futures emerge as we engage in deeper levels of discovery that lead to something genuinely new. The pattern of innovation at RARC reflects this deep-dive process.

For example, Alice is an older woman who spent many years in state institutions and large group residences. She was finally able to live in her own home with a roommate and support, but when her beloved roommate died, Alice faced added challenges of aging and dependency. A traditional “downloaded” response would place Alice back into a group home or a nursing facility. By going deeper in the “U”, the people who care for Alice created a wonderful apartment situation in an apartment complex where she has access to 24/7 support and, when the time comes, to hospice.

Making space for innovation and hope depends on reaching higher for purpose and meaning in our work, while going deeper into the journey of creating individualized supports. The Four Leadership Commitments describe important aspects of reaching higher and going deeper into the U journey. Commitment One describes how that vision is sharpened through open minds, hearts, and wills. Commitment Two describes ways that RARC values adaptive work by creating a Department of Design and Innovation. Commitment Three briefly describes the person-centered discovery process. Commitment Four illustrates a process for shared decision-making and a Template for Residential Design.

# Theory U: Leading from the Future as It Emerges

## The Social Technology of Presencing



*The U-Process raises an important question. Will we find what we desire by proceeding in a straight line from where we are, taking our direction from our past and doing more of what we are already doing, or do we need to invest time and energy in moving beneath the surface of our current understanding of the person and the possibilities for action? Experience shows that people can spend a great deal of time and money on person-centered plans that proceed forward in a linear way without producing what we desire — a substantially greater number of people succeeding in valued social roles and enjoying a widening social network. What we desire embodies a purpose above what we can reach by moving straight ahead. To reach higher, we will have to move deeper.*

Moving Past the Limits in Person-Centered Planning  
— John O'Brien, 2006





## Commitment One: Lead with Vision

### Set a standard for innovation in individualized supports

*The spirit of democracy cannot be imposed from without.  
It has to come from within*

— Mohandas K. Gandhi

The stories in this document reflect ten different ways that staff, families, and people with disabilities have moved away from traditional service designs toward individualized supports. While each of the ten prototypes is unique, even within each scenario, the development, preferences, and challenges of the individual often lead to changes in the design. Each profile becomes a prototype that might prove relevant to others, and each application of the prototype is further adapted to fit specific persons, families, and communities.

For example, Story Six about Theresa and her mother describes an arrangement that enabled them to live in the family home throughout mom's aging, illness, and death. When mom died, Theresa was already settled and was able to stay in her own home. Obviously the supports changed after mom died, and they continue to be adapted as Theresa develops and grows into a world without mom. This prototype, one that supports an aging parent to live with her child with a disability and receive supports for both the daughter and parent in the company of various support workers, has now been replicated two times at Rensselaer ARC, with appropriate adaptations for each situation.

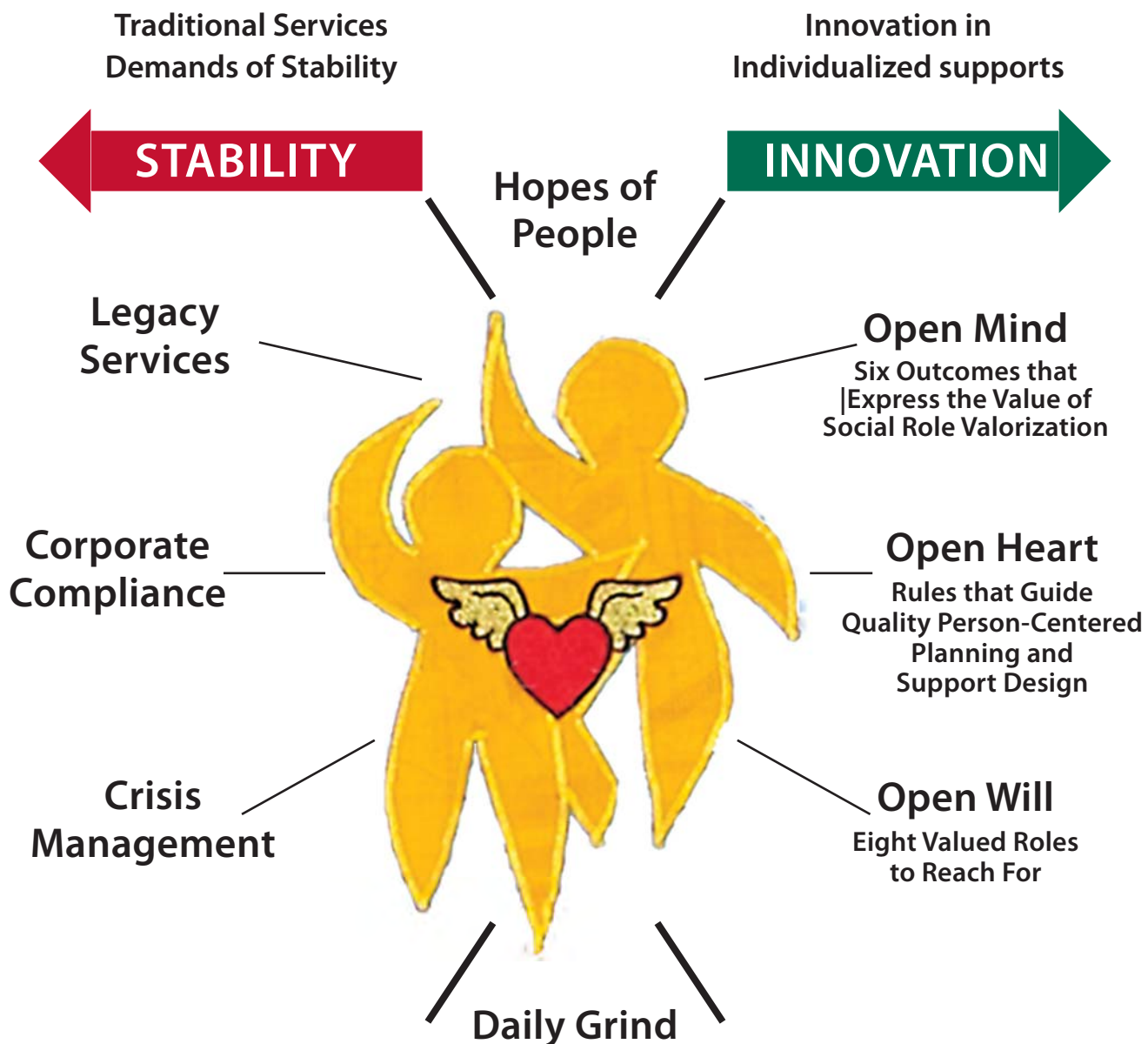
This style of adaptive work differs profoundly from the tasks of creating and managing traditional supports. Rensselaer ARC's unique perspective over the whole field comes from its long history of both providing traditional services and seeking innovation. Traditional supports (which RARC calls "legacy services") require managers to balance crisis management with the daily grind of details arising from the lives of the many, many people they support while attending to demands of the OMRDD system and corporate compliance.

RARC has learned how to manage these relentlessly competing interests and has thereby made space to become a leader in innovation. RARC's executive function supports staff at all levels to see themselves as instruments of change in the challenge to make a difference in the lives of people with disabilities. The following graphic captures the essence of the tension between the pursuit of innovation and the daily constraints that arise in any large agency.

## Leading and Living with the Tensions of Creating Innovation in Individualized Supports

Leading with vision requires continuous, conscious investment. RARC develops this vision throughout the organization by creating learning spaces where people feel safe to open their minds, hearts, and wills to discover insight and try out new plans of action. Here is a brief description of three types of vision making.

### Graphic of Tensions







## Open Mind: The Power of Socially Valued Roles

*If we want people to be, or become, valued in the eyes of others, then we must do things which strongly prompt others to perceive them in positively valued ways – and this largely means that they must be perceived by others as holding valued social roles. Further, the more a person holds “big” roles that are highly valued, the more are other people likely to put up with the person’s characteristics, behaviors, or minor negative roles, or even reinterpret these as not being so bad. Thus the impairments or afflictions of persons in valued roles are likely to be overlooked. Thus, regardless of the importance of valuing humans for their intrinsic worth, it is still crucial to attend to the social roles of devalued people so as to increase the likelihood that others will want good things for them, and will do good things on their behalf which it is in their power to do so.*

Social Role Valorization  
— Wolf Wolfensberger

All development at Rensselaer ARC is directed by the broad principles related to Social Role Valorization (SRV) as defined by Wolf Wolfensburger. The passions of board member Henrietta Messier, Chris Liuzzo, and other managers have imbued SRV values throughout the organization. They have felt the power of SRV to open people’s minds to discover the many ways that human services hinder or help people with disabilities in acquiring valued roles in community life. SRV thinking and language now permeates the agency and provides both a vision for desirable outcomes in the lives of people with disabilities, and a guide for right action in moving toward the vision.

The commitment to Social Role Valorization is reflected by the Six Desired Outcomes outlined on page 10 that clarify the vision and provide a framework for development in the lives of all people supported by RARC. Staff strive to “Level 5” accomplishments in each of the six areas of development, and all decision making is made in the light of these ideals. The Six Desired Outcomes and the Rating Levels are examples of reflection tools used throughout the agency in conversations that reinforce the power of these principles to guide critical thinking.

## **Six Outcomes that express the values of Social Role Valorization**

### **Outcome One: Promoting and Sustaining Life-Affirming Relationships**

Rating Level 5 – The number of unpaid relationships with persons who play valued roles exceeds the number of relationships with paid personnel. Time spent with unpaid persons is significant and can sometimes last days or even weeks. Contact can occur spontaneously and is likely to be initiated by either person. The relationships are affectionate and can be expected to be of long (even life-long) duration.

### **Outcome Two: Promoting and Sustaining Valued Social Roles**

Rating Level 5 – The person plays multiple valued social roles on a regular and consistent basis. Negative roles are either non-existent or have only nominal negative impact on the person. Support personnel and people with unpaid relationships with this person are highly conscious of the issue and routinely evaluate progress toward promoting and sustaining valued roles for the person.

### **Outcome Three: Promoting and Sustaining Community Presence and Participation**

Rating Level 5 – The person spends the majority of his or her time in non-program settings. S/he has numerous and routine presence and participation in typical community settings. Support personnel have internalized the importance of the issue and have instituted safeguards to insure the person's community presence and participation are sustained.

### **Outcome Four: Promoting Life-Enhancing Competencies**

Rating Level 5 – The person is engaged in several activities that promote life-enhancing competencies. The activities occur in fully integrated settings. It is clear these activities are of the person's choosing. Life-wasting is not a concern. Support personnel are engaged in evaluating and safe-guarding continuation of these activities.

### **Outcome Five: Expressions of Individuality**

Rating Level 5 – There is significant evidence that the person has multiple forms of expression of individuality. His or her living environment is highly individualized. Support personnel clearly recognize the living environment as the person's home. His or her daily routines are unique and are not driven by the needs of others. The support structure is unique to the person. The person is able to engage in desired activities spontaneously. Support personnel have put in place safeguards to protect the person's individuality.

### **Outcome Six: Promoting and Preserving Health and Wellness**

Rating Level 5 – The person's basic health needs are being addressed. Basic medical and dental health is addressed routinely. Acute illness is addressed appropriately. Absent accident, the person's physical well being is likely to be preserved. There is planning for the person's health and significant activity to promote health and wellness (e.g. exercise is in place). Support personnel are keenly aware of a holistic view of health and promote the person's participation in relationship-building, spiritual activities, etc. Those around him or her consider the person to be content and likely to live a full, healthy life-span.





## Open Heart: The Rule that Guides Quality Person-Centered Exploration and Support Design

The Golden Rule, intrinsic to all spiritual traditions, describes the heart of a person-centered process. When done well, person-centered work brings us deep into the reality of the person we are learning with and about. From that immersion in the experience of the other, we have insight, make discoveries, and feel the passion to activate change.

**Buddhism:** *Hurt not others with that which pains yourself.*

**Christianity:** *Do unto others as you would have them do unto you.*

**Hinduism:** *Treat others as you would yourself be treated.*

**Islam:** *Do unto all people as you would wish to have done unto you.*

**Judaism:** *What you yourself hate, do to no person.*

**Native American:** *Live in harmony, for we are all related.*

**Sacred Earth:** *Do as you will, as long as you harm no one.*

Adapted from Marilyn McFarlane  
*Sacred Myths: Stories of World Religions*

## Powerful Points of Reference

*Transformation gives us the audacity to advance along a road of unknowing. At the same time we can't be totally unknowing. There must be points of reference. One point of reference is the vision that we human beings can get together by aspiring to a vision of unity, peace and acceptance. It is a promise that the walls between people and between groups can fall, but this will not be accomplished by force. It will come about through a change of heart — through transformation. It will begin at the bottom of the ladder of our societies.*

Living Gently in a Violent World; The Prophetic Witness of Weakness  
— Stanley Hauerwas and Jean Vanier, 2008

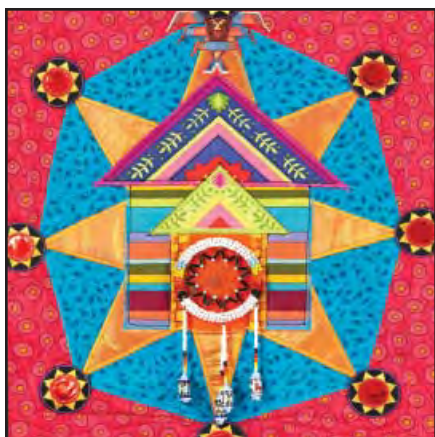
Social Role Valorization provides a point of reference for vision and critical thinking at RARC, while the Golden Rule guides right action. Leadership throughout the organization aspires to create a culture of caring and compassion in which right action is inspired by connections and accountability to each other that nurtures development. Therefore, those at the bottom of the ladder of our societies and organizations, who have the most to teach us about the transformation of the heart, must be foremost at the conversation table.

At RARC, person-centered planning is a practice of relationship building and discovery which expresses the Golden Rule. The heart of person-centered practice is the heart — a commitment to engage in learning and caring about the other that brings wisdom into design and passion into activism.

The concerns of families are also at the heart of this person-centered work. Each of the ten stories is as much about building partnerships and understanding with families as it is with the person with disabilities. Person-centered planners aspire to walk in the shoes of the families, parents, siblings, extended families---and even pets! The careful effort to learn about the interests and concerns of families is critical to building trust and to the hard work of getting support right. Stories of building family partnerships are filled with celebration as well as heartache. Person-centered planners seek to “hold it all” together during the messy birthing of new possibilities and support options. Creating a container of partnership is far more important than paperwork, and richness of relationships is the fine outcome of this effort.

Finally, person-centered planners strive to walk the walk of direct support staff. New design arrangements are intended to support the development and quality of life of support staff. Attention to the details of life-sharing, compensation and benefits, family concerns, mentoring, and development add up additional golden measures of quality of life for all.





## Open Will: Eight Valued Roles and Desired Outcomes of Individualized Supports Development

*Growing demand for deep change offers the stakeholders in local services to people with disabilities a choice between two paths: compliance or commitment. Pursuing the path of commitment calls on people to do three difficult but rewarding things. It asks people to set high expectations and then to*

*engage in honest and thoughtful self-evaluation and then to implement new kinds of services. Higher expectations, thoughtful assessment of practice, and development of better supports can't be imposed from the outside. People need to embrace them as the right thing to do.*

Reflecting on Valued Social Roles;  
Identifying Opportunities to Support  
Personal Freedom and Social Integration  
— John O'Brien, 2006

Leading with vision at RARC involves

- Open Mind, using the principles of Social Role Valorization to guide critical thinking,
- Open Heart, engaging the Golden Rule as a measure for right relationships and action
- Open Will, taking direction for innovation by reaching for the highest potential of every person.

Conversations to explore the highest potential for every person are guided by development toward a variety of social roles described by the Eight Valued Roles by John O'Brien. Self Advocates in New York State have incorporated these Eight Valued Roles into a symbol they call "Wheel Power" which people use to describe meaningful elements of their personal future.

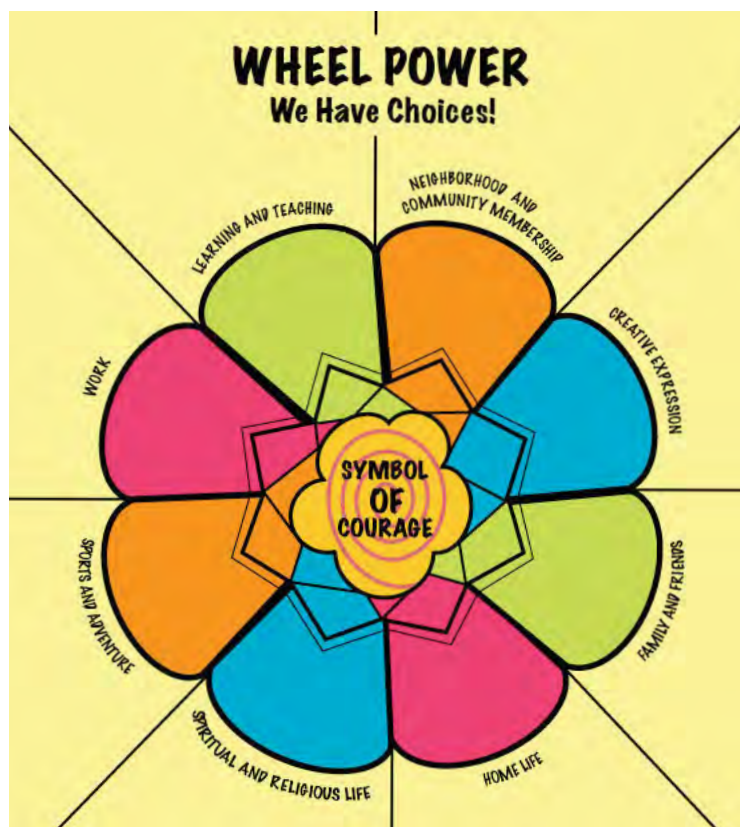
Person-centered planners at RARC have incorporated *Wheel Power: Steering Your Way Toward a Life of Distinction* into planning with people throughout the agency. Development in all eight directions requires attention to sustainable person-centered discovery and planning, local solutions, and learning circles. Implementation of the ideals discussed in these conversations usually calls for a significant increase in the individualization of supports. The organization finds direction for innovation from listening to the people and families, and finding new support designs that will further the development of each person towards these life experiences.

While every Wheel Power conversation differs, they generally follow the eight-step sequence described on the following page. The energy that flows from these eight steps opens individual and collective will toward unexpected new possibilities. Commitment to action follows, inspired by a desire to have "power with" people served rather than "power over" them—the compliance-driven command- and-control behavior typical of traditional support systems. The seeds for all innovation and change emerge from these quiet, colorful conversations with people and their support circles.

# Imagine

## Wheel Power: Steering Your Way Toward a Life of Distinction

1. Employment.
2. College life and self advocacy leadership roles
3. Volunteerism and community service
4. Creative arts and careers
5. Self-directed supports: individualized budgets, direct hiring, brokerage and support  
Family support: current approaches with self-direction and greater intensity
6. Individualized homes: life sharing, choices of roommates, parent associations
7. Spirituality
8. Adventure, health and sports



- Step One** Discovery: Take time to learn about the person and family – their capacities and vision – in their home community.
- Step Two** Your Current Life: Using the wheel, describe your current life pattern by naming the people, activities, places, and ways you spend your life. Be very specific regarding time and frequency. What are the activities that you really love? Where do you see gaps and find longing?
- Step Three** Brainstorm Potential Valued Roles: After listening to the person's past and present ways they spend their life, develop a list of potential valued roles. .
- Step Four** Imagine the Possible: Dream of what could be and what needs to happen to develop the valued roles. Use the wheel to organize your ideas. Identify ideas for development in each area of life. Be as specific as you can regarding time and frequency, location, and people involved.
- Step Five** Identify Gaps: Make a record of the gaps between what is and what could be. Break the gaps into three areas: Personal, Community, and Organizational. Develop potential solutions to each of the identified gaps.
- Step Six** Action Steps: Describe the commitments the circle members are willing to make, and what actions they are willing to take.
- Step Seven** Accountability: Who is going to be the champion for the person, who is going to hold the circle accountable? When are we going to meet again? Set a date
- Step Eight** Symbol of Courage: Find a symbol to give you strength when things are hard and uncertain. Make something out of this symbol: a song, a poem, a picture, gesture or dance. Invite others to carry it with and for you.





## Commitment Two: Invest in the Adaptive Work of Innovation

*The single most common source of leadership failure we've been able to identify is that people in authority treat adaptive challenges like technical problems. In the face of adaptive pressures, people don't want questions; they want answers. The table "Distinguishing Technical from Adaptive Challenges," captures the difference between the technical work of routine management and the adaptive work of leadership.*

Leadership on the Line: Staying Alive through the Dangers of Leading, Heifetz and Linsky, 2006

The distinction between technical and adaptive work as described by Heifetz and Linsky helps describe the culture of innovation and consequent organizational interventions at RARC. "Technical" challenges are defined as those issues that usually have clearly defined solutions, or at least a process for solution, such as maintaining Medicaid billing and regulatory compliance. Authorities are often in a position to provide complete answers to technical challenges, which further strengthens their command and control of the implementation of the solution. Sometimes technical challenges require a re-engineering of separate elements of a system to bring about more-effective outcomes. RARC has a long history of re-engineering better outcomes for people.

"Adaptive" work, by contrast, is not accomplished through authoritative problem solving. In adaptive work, the people who live and work with a complex problem are engaged in a process of discovery to find new ways to respond. Command and control just does not work in a situation that depends on collaboration, discovery, and creativity. However, adaptive work can create anxiety and stress for people and organizations, especially when they feel an urgent need to respond. Heifetz and Linsky help us understand that technical solutions often relieve our stress with quick fixes, but they don't get to the heart of the systemic problem, and therefore don't actually *solve* anything. Innovation requires adaptive, not technical, change. Executive staff and board members at RARC are savvy sorters and solvers of problems and make significant investments in adaptive change.

### DISTINGUISHING TECHNICAL FROM ADAPTIVE CHALLENGES CHART

	WHAT'S THE WORK?	WHO DOES THE WORK?
Technical	Apply current know-how	Authorities
Adaptive	Learn new ways	The people with the problem

## Commitment to Adaptive Work: The Department of Innovation and Design

RARC seeks to excel at both the technical side of routine management, and the adaptive work of leadership. Supporting all staff to be “instruments of change” is one way of inviting people at all levels of the organization to develop the confidence and trust necessary to create adaptive solutions in complex situations. RARC manages the tension between technical and adaptive challenges by creating jobs and entire departments that focus on one or the other. For example, the agency created a Department of Innovation and Design led by Sandy Van Eck and her team. This unit is a fine example of investing in adaptive work by making a space for those who excel at it. The purpose of the Department of Innovation and Design is to create capacity for staff and people supported to innovate and find new ways to reach toward Lives of Distinction (see appendix for a job description).

All staff time in the Department of Innovation and Design is allocated to adaptive work, which is the engine of innovation. Any organization invested in innovation must create and protect a “free space” where discovery and invention can emerge. As New York State’s compliance requirements invade every crevice of our organizations, free space is increasingly hard to find. Nevertheless, RARC consciously embraces and safeguards its space for adaptive work. In this learning laboratory, new prototypes emerge as described in the ten stories.

## Director of Design and Innovation Job Functions

Organizations that learn to develop adaptive and innovative responses invest in at least one full-time staff position person devoted to person-centered planning and innovation. These innovators explore the frontiers of possibility, trying things, and inventing new solutions. The resources of the people, their families, and their community become part of the discovery and design of responsive innovations, and so these directors spend a lot of time with people with disabilities and their support circles. The directors develop “change teams” and create learning opportunities which nurture development in all members. They also challenge their organizations to abandon dated practices and reinvest funds into new supports.

While the job descriptions of various Directors for Design and Innovation\* differ, they share the following functions:

- ❖ Take the agency in a new direction: engage in research and bring new ideas in.
- ❖ Create containers for learning: create and support communities of practice.
- ❖ Foster trusting relationships: encourage openness and trust.
- ❖ Advocate for new investments: examine risks and create sustainable budgets.
- ❖ Communicate: describe and grow best practices.

\* Thanks to Carole Gothelf, Sandy VanEck, Josh Skolnick, Cara Levy, and Tina Miller, who also have similar jobs, for their contributions. See the appendix for more detail about each of these functions.





## Commitment Three: Discover Opportunities and Find Keys to Life through Person-Centered Exploration

*The exact meaning of educate is to bring forth what is within, to bring out potential. If you can hand someone the key to their own power, if you can help someone open the door at the critical moment, then you are educating them in the best sense. You are teaching them to open doors for themselves.*

— Aimee Mullins

Person-centered planners at RARC engage wisdom when they get out and get into the details of people's lives in such a way that intuition comes in for "what makes sense." The capacity to intuit what makes sense comes from good detective work to imagine what is best for those served. This wisdom leads to hunches and rough sketches about a support design that will work, trusting that implementation will provide testing and guidance for adjustments.

## Find Capacities

You build a life path by finding capacities in these four aspects of your life:

### Learn about...



- skills
- identity
- environments
- challenges
- qualities

... in the person

### Explore...



- neighborhood
- economic opportunities
- recreation options
- what is on the block
- transportation options

... in the community

### Contribution

A Valued  
Identity Support

### Listen for...



- values & identity
- connections
- resources
- neighborhood
- extended family

... of the family

### Design Supports...



- individualized support
- natural supports
- service coordination
- creative res & day hab
- creative employment

... using services

*Wisdom is being shed every single second. Intuition means being aware of your environment in every moment, as wisdom comes in from human beings, the natural world, from all around us.*

— Judith Orloff, M.D.

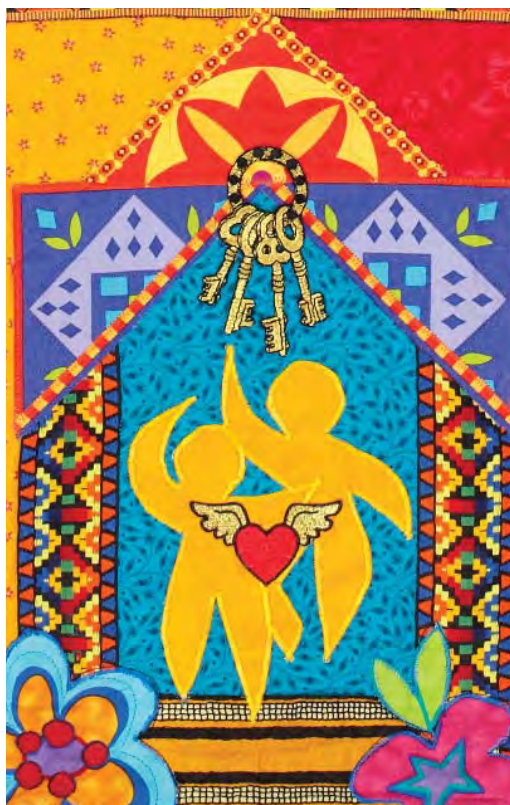
## Find and strengthen a Pattern of Coherence and Quality

*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.*

The Timeless Way of Being

— Christopher Alexander

A person-centered support design will build on the capacities brought by a person, her family, and her communities. These distinctive patterns are the KEYS that lead to an effective design. An effective design maximizes the capacities of the person who is reaching for a better life, while also making sensitive accommodations to his vulnerabilities. Effective person-centered planners spend a lot of time with people to understand these capacities and vulnerabilities, adjusting the initial support design in response to how it is going for the person and the family.







## Commitment Four: Crystallize Vision and Co-Create Emerging Prototypes

*The essential activity of a change lab is a collective rhythmic repetition of the movements from power to love and back again. In the first movement, from power to love, we convene diverse actors who together are able to see and influence the system as a whole. We enable them to co-sense; to see and*

*connect to more of the whole. The second movement, from love to power, involves supporting actors to undertake individual and collective actions—arising out of and remaining in connection with their co-sensing of the whole of the system—to shift the system. It involves shifting from “someone should” to “I will.”*

Power and Love; A Theory and Practice of Social Change  
— Adam Kahane

Person-centered planning brings people together to “co-sense” the possibilities in each situation, to describe the patterns that are good for people, and to generate support designs that amplify the patterns that predict quality. As a support design begins to crystallize, it must be tested through collective action and then revised based on observation, honest dialogue, and careful analysis. The RARC Department of Innovation and Design fits Kahane’s description of the “collective rhythmic repetition” of the activity of a change lab. Co-sensing leads to rough drafts that lead to action and revision.

In the design of an individualized residential option, the design process requires an alignment of both the “things” of a living situation (see The Template for Residential Design) and the “quality space” which is directly related to quality relationships and shared decision making. Staff at RARC use the “The Level of Family Involvement” tool to clarify decision making preferences and responsibilities related to 29 issues identified on the following page, and described in detail in the appendix.



## Negotiating partnerships: Level of Family Involvement Planning Tool





# Template for Residential Design

## Creating Customized Homes for People with Disabilities Using Individualized Supports

### Build a Prototype of a New Situation based on Discovery

#### Part One: Put the basics together:

1. **The person:** Who is the person? What are his dreams, relationships, community, preferences, images of the future?  
How do we get to know the strengths and vulnerabilities of the person and her family well enough to tailor supports that fit?  
How can we predict which assumptions about the person will change over time? How can we adapt supports?
2. **The home:** How do we think about and create the house?  
What are the aspects of the environment that will work, that will create quality and personalization. Will environmental modifications help?  
How will the real estate be financed? Who will provide maintenance?
3. **The community:** How is the person connected to the community?  
Describe vignettes that express ties to community and natural supports.  
How can you keep this person connected to her community?  
What will keep people safe in this community?



#### Part Two: Describe decision making and personal support:

4. **Natural supports:** How are family and friends involved? How much time will people want to spend with family?  
How much do families want to be involved in decision making, both major and minor?  
What helps families to be involved?
5. **Paid supports:** What is the best pattern of paid/reimbursed supports?  
How will you find these supports? How will the person be involved in this?  
What will contribute to the commitment and longevity of staff?  
How will staff find meaning in the work? How will families support staff?  
What are the small and big things that improve quality of life for staff?
6. **Decision Making:** What are the aspects and rituals of shared decision making?  
Can you clarify levels of family involvement?

#### Part Three: How do people create quality space for personal development?

7. **Quality Space:** What are the signs and symbols of quality in people's lives?  
How do we know people are learning, loving, and expanding?  
How will we know that people are not doing well or need more support?
8. **Leadership:** How can leadership create and protect quality space?  
Describe the behavior and characteristics of leadership that contribute to this situation.

With this context in mind, we will now turn to the ten people who helped us understand this pattern of innovation, and who are leading the organization forward into increased commitments to individualized supports.







# *Mothers, Wait for Miracles*

## **Family and agency working together benefits all parties**

The Hall family is well known at Rensselaer County ARC (RARC). We started planning with the Halls almost 15 years ago when Mom (Edie) and Dad (Gary) began to make long term plans for their sons, Doug and Brian. If Doug and Brian were assessed traditionally, their eventual placement would most likely have been a service environment that would have included nursing, physical therapy, occupational therapy, behavior support and high level of direct support staffing. When Mom visited a traditional Intermediate Care Facility and then a Community Residence (also known as a Group Home), she knew that was not what her sons wanted, needed, or were willing to accept. At the time the RARC was just beginning to use person-centered planning and after several meetings it was decided to create an individualized arrangement for the Hall brothers.



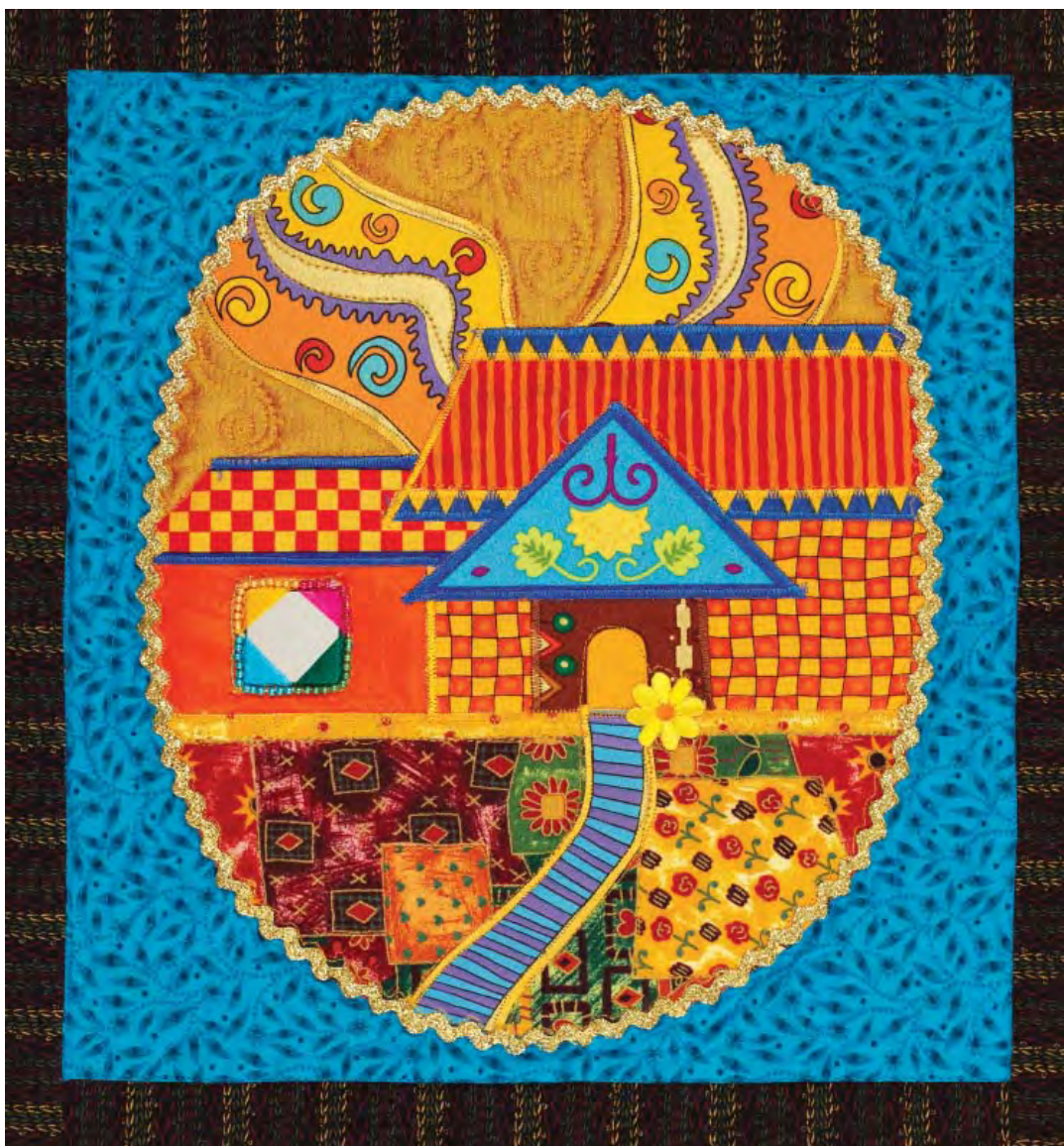
At the time, Edie and Gary were also exploring an in-law apartment for Edie's mother. Edie thought, "Why not consider this type of arrangement for the guys?" Gary thought she was crazy and he was unsure about having people in and around their house 24 hours 7 days a week. This kind of arrangement had not been attempted in New York State, so with the hard work of several people at RARC and the State and Regional offices that oversee the development and funding a novel arrangement came together 5 years later. The family turned the first floor of their existing home over to the boys and it was defined as a certified Individual Residential Alternative (IRA) with Rensselaer ARC providing 24 hours support. After permission to move forward was granted, the hard work began.

Questions the family and agency struggled with:

- Do we keep the floor plan open so Doug and Brian can pace around the home or do you put a door on the back section so the staff has a private office?
- Who would pay for what?
- How would the clinical supports be implemented in the home?
- Who made the decisions regarding staffing issues, Doug and Brian's care, etc?

Staff members were fearful of both coping with each brother's challenging behaviors and of providing supports with parents living upstairs in the same house. Initially there was quite a bit of accommodation by all involved. There were many questions, few answers. Mom sums up how the process works with the statement: "Work together; push each other... with a smile." Decision-making was and still relies on team partnership. Parents go to staff members first to solve problems when they feel they need to intervene, and they respect opinions of staff, too. The parents are positively affected when there are positive interactions between Doug and Brian and the support staff. It is also important to the parents when their sons' needs are recognized and met, when there is respect, when questions are asked before assumptions are made, when there is a sense of humor, and when there is true affection.

The residence has been operating for over ten years, and Brian and Doug are fully integrated into the community in which they grew up. Over time, the team came to realize that neither brother liked to go to the Day Treatment Program, so the team designed individualized day supports that enabled staff to work from Doug and Brian's home and in their community. The day and residential team became one group supporting the brothers while the parents are nearby to provide encouragement, feedback and a presence that created a high quality life for both Doug and Brian.



The Hall home is portrayed as a golden circle to represent the whole, which maintains the delicate ties to family and connections to community that define quality in the lives of these two young men. The round egg also captures the circular “walking path” within the home that enables Doug to walk in circles, which is key to his personal freedom.

#### Identifying Keys to Life:

- Maintain lifelong connections to home and community.
- Shared decision making in all matters.
- Create the space for all to move around freely.
- Support constructive conflict and work it out.
- Interests, dreams and concerns were always based on the family knowledge,
- Staff know the parents well in order to best support the men.



## SIGNS AND SYMBOLS OF QUALITY SPACE

- Big parties to celebrate anniversary marks
- Neighborhood parties with more non-paid community friends than paid staff.
- A family relative made a beautiful videotape of the story.
- Staff has a deep awareness of the life, history and concerns of the family.

### NATURAL SUPPORTS

- Parents live upstairs.
- Family and friends visit regularly
- Parents create a sense of family time and share a deck and hot tub.
- The parents and their sons are in each other space everyday.

### DECISION MAKING

- "Success comes with pushing each other with a smile", Mom
- Flexibility instead of Rigidity
- All parties having genuine concern for each other and recognize mutual needs
- Ample communication and maintaining reasonable expectations of each other.

### PAID SUPPORT

- The two young men have 24/7 staff support.
- Doug has cycles when he is awake all night, so overnight staff is provided at these times.
- They receive daytime supports that allow them to volunteer and explore the community.
- An RN consults with parents & staff regularly.

### THE HOME

- They live in the home they grew up in.
- They live close to their parents.
- There is a "pacing circle" in the home and in the yard for Doug.
- Each brother has his own room.
- Home feels like an Adirondack bachelor pad.
- Phones and personal items fill the home.

### KEYS TO SUCCESS

- Perseverance: We fought for this situation for five years; every time authority figures said no, we scheduled another meeting.
- Partnership: In addition to the family, we had several internal State and Regional agency allies and champions; we found the heart in the State Agency and built alliances.
- Honesty and Integrity: We found a reputable and viable way in invest state money into the renovation of the family home, and it has paid off a million times over.

### THE COMMUNITY

- Retained connections from childhood.
- People know them at the local restaurants and sandwich shops.
- People want to know where they are if not seen regularly.
- They volunteer at a local community preschool and developed long term relationships.

**Doug and Brian  
and  
Their Circle of Support**



# Poster created by Doug and Brian Hall





## *Emily and John Judge*

**"We are all on a journey to respect and we should love one another and help each other when help is needed. We need to help staff understand how we feel."**

**— Emily Judge**

John and Emily Judge are married and live in their own home with their dog, Blackie. They both work and struggle to pay the bills that come with owning your own home. The two worked hard to get to where they are now.

Emily lived grew up with her parents and John lived in family care situation in the area. They met after they both moved into a supervised apartment program which was operated by the RARC After getting to know each other they found that they had a lot in common and soon fell in love. After dating for awhile they won the support of their family, friends and staff, who helped them get married in the late 80's and move to an apartment. They received staff assistance four to five times per week. That was okay for a while but they did not like the landlord or staff telling them what they could and could not do. Since the apartment was rented by the RARC they did not feel like they had choice of neighborhood. But what bothered them the most was the frequent complaints about their dogs.

Emily remembers that several people said they would not be able to handle owning their own home but they proved everyone wrong and have been in their home for several years. Emily and John feel that the RARC helped them achieve success by helping them manage their expenses and money and handling some of the more difficult maintenance tasks. The house is a small cottage with room for storage and a fenced in yard for the dog. Both Emily and John have various champions who made this possible, including the RARC financial office, the service coordinator and Emily's parents.

Both Emily and John receive staff support several times a week to address nutrition, keep medical appointments and most importantly, assistance with decision making. For example, if Emily needs advice concerning her marriage she will ask a trusted staff member to help her. The staff are careful to listen and provide her with several options in order not to take sides.

John understands the importance of making money to pay the mortgage. Until Emily's recent medical concerns, she did as well. They continue to be involved in the church in which they were married many years ago. They enjoy having meals with Emily's parents each month.





Emily and John Judge are so very proud of the sweet house that they own, their long term marriage, their devotion to each other and to their beloved dog, Blackie, who led them on their search for this place that they call home.



## SIGNS AND SYMBOLS OF QUALITY SPACE

- Their marriage has hung together for 20 years!!!
- A home that they call their own.

### NATURAL SUPPORTS

- Emily's parents meet them once a month at the Pizza Hut; John and Emily have regular barbeque dinners at their home for who the parents as well.
- Two neighbors watch the dog when there is need .

### DECISION MAKING

- Most of the time Emily brings up issues, and if she and John can't sort it out, they will talk with their manager to work out details.

### PAID SUPPORT

- Non-certified setting.
- Individual supports adjust as needed.
- A visiting nurse comes weekly for routine assistance and guidance.
- A cleaning person comes in once a month.
- Staff assist Emily & John in getting to and from medical care & communications with doctors.

### THE HOME

- Emily and John own their own 2 bedroom cottage style home.
- Even the dog, Blackie, has his own little house!
- They choose all their own furniture and décor, and there is a lot of it.
- They are collectors; now they have room to collect.
- RARC helps with maintenance such as repairs and yard work when necessary.

### KEYS TO SUCCESS

- Determined champion: The service coordinator became determined to make this happen.
- Determined financial champion: The RARC Chief Financial Officer researched grants and various funding mechanisms.
- Unlikely allies: The bookkeeper in the agency became an ally, helping out with day to day details of financing.
- Flexibility: when Emily's health issues significantly limited her ability to participate, the team would come together around her to think through how to best maintain the life that John and Emily built for themselves.

### THE COMMUNITY

- They are active members of the First Baptist Church.
- They attend wrestling matches at the city arena.
- They both work in the community about 20 hours a week.

**Emily and John  
and  
Their Circle of Support**



[illegible]



## *I'm a man with means by no means, King of my road*

We believe that supports should adjust to meet people's needs versus adjusting people to meet supports.

If you drive through town you are likely to see Rich walking down the street in a bright orange vest or jacket. He spends much of his time visiting various store owners, churches and other community venues. He is known for being helpful and concerned for others. This is in stark contrast to the beginning of his life when Rich was institutionalized, and then later when he lived in a developmental center and then a group home. At that time he earned the title "Enforcer". He made the other people living there behave and do what staff wanted.

While Rich adjusted to each of these settings he never stopped fighting for his desires and freedom. Rich's team is in a continuing struggle to figure out how to balance Rich's supports between what is important **for** him and what is important **to** him. He pushes his team to assist him in balancing health and wellness with independence and choice. Since Rich is a diabetic and enjoys visiting others for various meals and snacks, at times he finds it difficult to make "good" choices.

Rich pushes his team to balance his independence with safety concerns. Approximately ten years ago he had an altercation with some kids who were picking on him, he reacted badly and after the police intervened, he had to move from that neighborhood in order to ensure it did not happen again. He stayed in an empty two-family home that RARC had recently taken ownership over. The move was intended to be temporary because of the reputation of the neighborhood, but Richard wanted it to be permanent. Since that time Rich has lived there and enjoyed his home. He is a collector and has ample space to store his stuff. He enjoys outdoor work and has a yard and a community garden within a block. He is in walking distance to most of his needs including the office where he gets his supports.

When Rich moved to his home he received traditional supports that consisted of staff stopping by several times a week to help him with finances, grocery shopping and household tasks. These supports have increased overtime. For a while the support staff stopped by every day for large blocks of time. The supports increased from grocery shopping to cooking meals, from helping with finances to actually taking him shopping. Rich's medical concerns continued to increase as well. The support team was unsure if he would be able to continue to live independently. Rich was very clear by his statements and his actions that he did not want to move and was unwilling to do so.

Due to his kind heart, there had been occasions when people took advantage of him by using his stuff and even moving in to his home. It was decided to have a staff member move upstairs and be available to Rich if he needed it. This made a big difference for Rich and his support team. The paid neighbor confirmed the support Rich actually received from his community. He was amazed how supportive the neighborhood people were in accepting Rich and accepting him as Rich's neighbor.





Rich is the King of his road!!! He exudes a commanding desire to be a free man in spite of his need for extensive supports. These supports are ever-adjusting in response to his health changes, and they are brilliantly designed to support his life lines with people from every walk of his life in the community.

#### Identifying Keys to Life:

- Rich is well-known by many people throughout his community. He is known as being helpful and concerned about others. He likes to mow lawns, fix things around his house, and do chores for others. He loves to help others who are in need.
- Helping Rich to stay in his own neighborhood where he knows everyone. Balancing health and safety with privacy and independence and dignity of risk (danger).
- Rich is persistent: he will do almost anything to meet his needs for friendship, belonging, and food and he will not cooperate when he does not agree with others.
- Assisting Rich in distinguishing between legal and illegal activity.
- Monitoring and modifying terrible eating habits in the face of severe diabetes.



## SIGNS AND SYMBOLS OF QUALITY SPACE

- Space for storage for his belongings and collections.
- Walking down the streets and people knowing him by name.
- Interchange of needs being met between Rich and his neighbors.

### NATURAL SUPPORTS

- Rich has many partnerships in the community that RARC staff do not even know about. Staff respect the privacy of these relationships.
- Rich mows lawns, shovels walks, brings in mail and newspapers for people & helps out in exchange for friendship, food and/or money. He barter for and collects many things.

### DECISION MAKING

- Staff educate Rich about his choices and options, but after a lifetime of institutionalization Rich basically makes the final decisions.
- He needs to be in charge and his support team respects that.

### PAID SUPPORT

- Rich lives in his own apartment with a "paid neighbor" upstairs.
- The paid neighbor ensures Rich is home at night and no one takes advantage of him.
- Staff visit every day.
- An RN monitors Rich's health closely.
- Rich goes to RARC office regularly for assistance.

### THE HOME

- Rich's home is more than his home: it is his Castle
- He lives in a 2-family home with lots of storage space.
- He has a yard and shed to store his tools, garden wagon and shopping cart.
- He painted his steps pink.
- He has environmental modifications such as a shower bar, a telephone with large numbers and an answering machine.
- The home is an IRA.

### KEYS TO SUCCESS

- Understanding: The leadership has a deep understanding of Rich and what matters to him. Personal involvement of many at RARC help the group stay sensitive to his interests, and engage in conversations about balancing personal risks and desires.
- Champion: The Director of Health and Wellness has been a champion for Rich.
- Creative tradeoffs: Rich's choices led him to stay in a "sketchy" neighborhood, but RARC invested in renovation of the home and Rich had a hand in every detail of the renovation.
- Constant contact: People at RARC see Rich almost daily; this provides info to calibrate and monitor his supports.

### THE COMMUNITY

- Rich has lived in Troy for 30 years, and in his current neighborhood for 10 years.
- For better or worse, he is well known and cared for and about by hundreds of community members.
- He is very involved with the nearby community garden.

**Richard  
and  
His Circle of Support**



# Poster created by Rich





## *Always Moving Forward*

**People want to be supported by staff members who have passion: Yes, it does matter!**

Alice has had a long life journey through the service system. She has collected much wisdom and is willing to share it with those who take time to listen and get to know her. She has incredible insight about what good support looks like and when it is not. Alice was actually born in Rome State School and spent her childhood there with her mother. Later they both moved to rural Rensselaer County in a family care arrangement. Once in the community, Alice always pushed to move towards more and more independence. She has experienced all the typical living arrangements the system has to offer, from group home to supportive living.

If you ask her, Alice will say that her favorite place was with her best friend, Beth and a paid neighbor, Tracy, with whom she still has a close relationship. Unfortunately her friend passed away and the apartment building where they lived was being sold. Alice had a very difficult time adjusting. The loss of her best friend and her own concerns that came with aging challenged her team because of great concerns for Alice's health and safety. Alice is a very good advocate for herself and made it known that a group home was not an option. So the team needed to provide an arrangement to keep her healthy and safe but not in a congregate setting.

Several years prior, the RARC developed a living situation that attempted to answer this concern for others. Those familiar with RARC know of "Diamond Rock," a large senior complex where the RARC rented four apartments. Each apartment has an accessible bathroom, sprinkler system, and two large bedrooms. The apartments are located on two different floors. Each floor has 24 hour support available with extra staff during key hours. This situation affords the people who live there the privacy and the benefit of having their own place, plus the supports that a supervised group home provides. The team thought this would be great for Alice.

They knew that it would be a success when they had her visit and she sat at the window and watched the deer grazing. She also enjoys the birds and has many friends in the building. Alice likes to participate in several events held for the residents of the building in the community room.

Even though she lives in senior housing, Alice has not slowed down. She volunteers in the community, she often makes crafts and sells them, donating the proceeds to various non-profit organizations. She attends the self-advocacy group and is proud of her accomplishments as a Toastmasters member.





Birds, flowers, dolphins express the spirit of Alice's life in her home at Diamond Rock. With thoughtful attention to how care and support are designed and delivered, Alice and others who grew up in state institutions now live colorful, independent lives, in their own homes, even as they age. This capacity to respectfully hold people at the time of their greatest vulnerability is truly a hallmark of person-centered care.

### Identifying Keys to Life:

- Balancing health needs with the individual's desire to be independent.
- Being present and participating in the community.
- Appreciation for nature.
- Self-advocacy making a difference.



## SIGNS AND SYMBOLS OF QUALITY SPACE

- Sitting in her living room watching the deer outside.
- Surrounded by her favorite things (dolphins and deer figures).
- Planning trips with her favorite people.

### NATURAL SUPPORTS

- Alice has many natural connections to people in the complex.
- She has a long-standing friendship with a former service coordinator she spends time with, especially during holidays.
- She continues to have phone contact with her former roommate's mother.

### DECISION MAKING

- The expression "Nothing about us without us" from the Self Advocacy group truly expresses the decision making process for Alice.

### PAID SUPPORT

- Alice and her roommate share 24 hour support with two people in the apt. across the hall.
- During the day staff members help her volunteer & maintain community involvement.
- Alice loves to take vacations & short day trips. Past and present staff ensure it happens often.

### THE HOME

- Alice's home is shared with a friend.
- Her home has accessible components that make it easier for her to continue to be independent.
- Her home is filled with birdhouses, flowers and dolphins.
- Each apt. is considered an Individual Residential Alternative and is certified by the state agency.

### KEYS TO SUCCESS

- **Respect:** The leadership gained un-derstanding of Alice's past and respected her need for control and independence.
- **Community:** The environment in which Alice lives provides her opportunity to interact with community members both with and without disabilities.
- **Accessibility:** The apartment has all the elements that Alice needs now and also what she will need in the future as she ages.

### THE COMMUNITY

- Diamond Rock is a senior housing complex with a community room.
- There is a sitting area by the door for social gatherings.
- Alice volunteers in her community.

Alice  
and  
Her Circle of Support



Celebrate Friends  
 good times  
 good friends  
 Time of your life!  
 Life, Love and Laughter

HOLIDAYS

love, it's a gift  
 Cape Cod

Play  
 work  
 BLOOM where you are planted  
 Respect the Past



## *Learning from our Ancestors: Keepers of the Circle*

**Support designs often evolve before they finally work!**

Philip grew up with his parents and sister in a rural community. He moved into a supervised apartment program that was operated by RARC. Philip moved from his parents' home expecting independence and privacy. He moved into an apartment building on Prout Avenue, where all the apartments were occupied by someone supported by RARC. It seemed like a group home to him and he struggled with the arrangement. Actually no one living at Prout liked it very much so soon after Philip moved in we developed a more person-centered arrangement for all ten people.

Since that time, Philip's journey has twisted and turned. After Prout, he moved to another apartment downtown with a non-disabled roommate but after two unsuccessful roommate situations, Philip decided to move to yet another large apartment complex. The support situation was getting better, but soon after he moved in the apartment complex was purchased by another management company and the rent was raised too high.

Finally he moved to another nice complex, Vanderburgh, with just the right support arrangement. The complex has approximately 200 apartments and Philip's support staff occupies one apartment. There are other 8 people living in various apartments that are located both within a few miles so the team is able to provide assistance to a number of individuals supported by RARC. Staff members assist Philip with going to the doctors, medication administration, budgeting and grocery shopping. What works best for Philip is adjusting the support to how he is feeling and coping. Philip struggles with mental health concerns and at times needs staff available to reassure him. Philip enjoys his own space and his life continues to unfold creatively.

Philip is involved in many aspects of the community, mostly within 4 to 5 miles of his home. He volunteers at a local food co-op, he takes classes at a local art center and attends church. Philip is a member of a Native American circle and attends pow-wows and other events, and he is involved in gay rights groups. It's a rich and diverse life.





The Native American dream catcher captures the multifaceted ways that Philip brings his sensitive spirit to life through self expression and engagement in community life. The eight golden points represent principles that guide the work of the many reflective practitioners who have assembled the supports for Philip to live his dream.

#### Identifying Keys to Life:

- Listen and gain understanding of this feeling
- Respective his sensitive and artistic capacities



## SIGNS AND SYMBOLS OF QUALITY SPACE

- Staff members are available by telephone for problem-solving but not immediately in his space.
- He has a support circle of individuals who know him well.
- His space is decorated to reflect his interest in Native American culture.

### NATURAL SUPPORTS

- Philip's parents are very involved and available to him.
- His parents talk to him weekly and help him sort out a lot of decisions.
- Both parents keep him grounded, and are a consistent presence in his life.
- A friend drives Phillip to church each week.

### DECISION MAKING

- Philip is the decision maker, with input from staff and family.

### PAID SUPPORT

- Philip has his own apartment in a complex with 200 other units.
- Staff members support Phillip in his apartment, and assist eight other people within an 2 mile radius, so he has 24/7 access to staff support.
- Day support staff assist him in connecting to the community.

### THE HOME

- Philip's home is a very masculine space that includes his home office.
- His modern apartment complex suits him.
- His home incorporates Native American décor with photos of family and friends throughout.
- His home is considered an Individualized Residential Alternative which is certified by the state governing agency.

### KEYS TO SUCCESS

- Parent Partners: Philip has very involved and committed parents who are taken seriously and who provide a voice for his issues and concerns, and recognize the needs to make changes in his situation.
- Proximity: Location matters for Philip—he is close to his supports, including his parents.
- Diversity: People planning with Philip have been highly sensitive to his gay lifestyle preferences.
- DDSO Champions: The state agency liaison has been a champion for adjusting arrangements that work for Philip.

### THE COMMUNITY

- He volunteers at a local food coop,
- He takes classes at a local art center
- He attends church.
- He is a member of a Native American circle and attends pow-wows.
- He is involved in a gay rights group.

**Philip  
and  
His Circle of Support**



# Poster created by Philip





## *Partnership: Family, Person and Staff*

**The secret to success is not having secrets from each others, be honest, open, and respect the house rules.**

In the 1950's, Theresa's family like many others were told by the professionals that it would be best for Theresa to have her placed in an institution. Theresa lived at the Rome Developmental Center until her mother retired about 30 years ago. Theresa moved home with

her mother and attended the RARC sheltered workshop where she made many friends. For many years she enjoyed her life at home with her parents it often included watching old television shows and doing puzzles.

About six years ago Theresa's brother, John and sister-in-law, Jane called the RARC to discuss Theresa's future if something happened to her mother. It was clear at that time that both Theresa and her mother needed more support. They were also clear that there mother was not interested in being separated from Theresa. They wanted a back up plan for Theresa if something happened to there mother, and they did not want to wait for a crisis to respond.

After many conversations and several planning meetings it was decided that RARC would provide supports to Theresa in the evening and the family would pay for home health aid supports for the mother in the morning. The home that they lived in became a Certified Individualized Residential Alternative with mom as a border. RARC and family began a wonderful partnership which included working out many important aspects of the mother and daughter supports. For example; mom would go with Theresa and her support staff grocery shopping. Mom needed to ensure that correct food was purchased. Mom continued to go on medical appointments and support staff offered transportation . The supports were designed to keep the relationship between Theresa and her mother strong and healthy.

About a year after this started, Theresa's mother passed away. The support staff from RARC was able to help Theresa and family make the painful transition. The partnership with the family continues to be strong. John and Jane continue to bring dinner twice a week and are only a phone call away and often provide support to Theresa and her staff. Presently, Theresa has chosen to live alone, with increase staffing from RARC. She surprises all of us on how independent she is learning to be.





The colorful patchwork of Theresa's home represents the creative integration of supports that enabled her and her elderly mom to stay together throughout mom's illness and death. The angel and saint that surround this home symbolize the wisdom and spirit of this strong Italian family who value the seen and unseen ties that bind people together over time.



## SIGNS AND SYMBOLS OF QUALITY SPACE

- Personal space that reflects the person's personal tastes.
- Space to do puzzles in the living room on the coffee table.
- Pictures of family past and present.
- The TV land channel is on the television.

### NATURAL SUPPORTS

- Theresa's brother and sister-in-law continue to monitor her situation.
- They were very involved from the beginning, helping Theresa and her mother move in together before Theresa's mother died.
- Her family brings dinner in every Monday and Wednesday night.

### DECISION MAKING

- Her family assists Theresa in managing the decisions.
- Theresa and family have developed a relationship with the staff so they negotiate the supports with them.
- Since the family is present at least two times per week they are constructively involved in many details.

### PAID SUPPORT

- Theresa lives in an IRA certified by the State Governing Agency.
- She has 24/7 access to staff via beeper which she has never needed.
- She has individualized support from 7-9 am & 1-10 pm daily, plus 10 hrs a day on weekends.
- She attends a sheltered workshop she loves.

### THE HOME

- Theresa lives in a two bedroom apartment where she lived with her mother before her mother died.
- Theresa lives in a senior housing complex; people must be buzzed in by her.
- Theresa's home is very colorful and expressive.
- TV land is on the television.
- A puzzle is on the coffee table and is always in process.

### KEYS TO SUCCESS

- Understanding: The leadership had an understanding about the importance of family. This value was the grounding for the design of Theresa's past and present living arrangement.
- Champion: The Direct Support staff that started with Theresa still works with her. Shortly after she started this staff had a child, and Theresa is considered part of her family.
- Partnership: All members involved in Theresa's life engage in open and honest dialogue, which makes the living arrangement successful.

### THE COMMUNITY

- Theresa has lived in the same senior living community for a long time, and so she is well known to neighbors who will help when needed.
- Theresa has many friends who recognize her when she goes to the local stores and restaurants.

## Theresa and Her Circle of Support



Poster created by Theresa





# *A Man in Control of His Own Life*

**Keep adjusting supports until you get it right.**

Mike grew up in a large, loving family. His father was in the military, so Mike had many opportunities to travel. After many years of traveling all over the world, the family settled in a nearby rural setting, Averill Park. Mike enjoyed fishing, snowmobiling, and various other outdoor activities. As his siblings grew up and left home, and Mike's parents realized that he would need to develop a plan for his life.

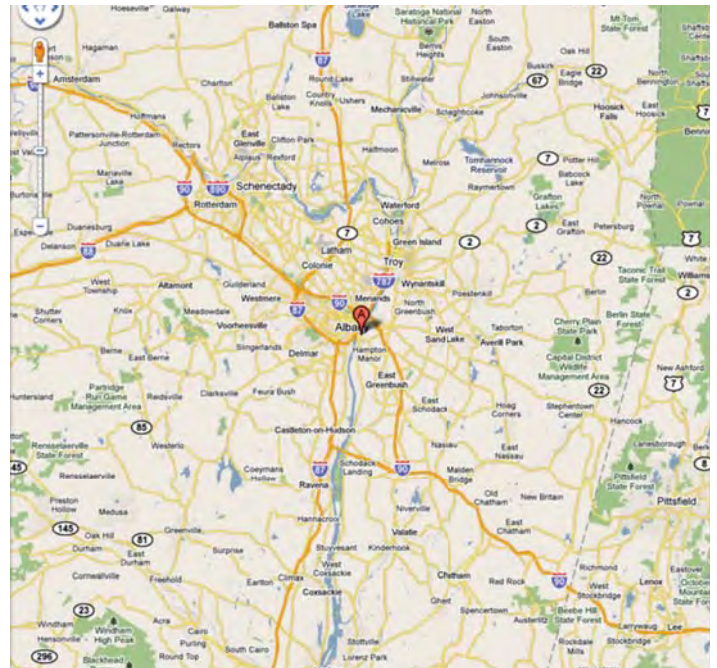
Mike needed support but did not want people to invade his space. He needed to be near transportation but not necessarily in the city. He moved to a supported apartment with staff members coming in at various times to give him support. He did not like the unpredictability of that arrangement because staff kept changing. His needs were met but neither Mike, his family, nor the staff were happy with how it was going.

After a few years, his family decided to plan a way to improve Mike's living arrangement. Some of the themes that arose included:

- It was important that Mike could trust the staff members who worked with him.
- Mike needed to have a sense of control over his life and home.
- He wanted the supports to be provided when he needed them, not when staff members were available.

The planning session led to Mike choosing a staff member to live close by and be available for 40 hours a week, which allowed one person to address all of Mike's needs. The staff negotiated with Mike and his family regarding how and when they would be supporting Mike. The staff member updates the family by email and receives advice from them regarding how to handle sensitive situations. Since Mike has a history of seizures, the paid neighbor living close by is important. Mike is the only person with keys to his apartment and no one enters without his permission. Travel is still one of his passions. Recently he traveled to California to join a group on a tour of Alaska. This was a bit of a stretch for his family, since he refused to have staff accompany him and they were concerned about his safety. But after major negotiation between Mike and his sister, he went on the trip alone and had a great time.

Mike also worked at Home Depot. He enjoyed it for many years but he decided he wanted a career change. He started an apprenticeship with a small engine repair shop and is learning those skills. The journey never ends for Mike, his family or RARC.







Mike's life is framed by the mountain that defined his early childhood freedom in the wild. The light bulb symbolizes the way that Mike serves as his own guiding light and the way in which his family contributes to a support design that illuminates his development. The light bulb and its six rays also represent the clarity of values and outcomes defined by Social Role Valorization.

#### Identifying Keys to Life:

- Holding the only keys to his home.
- Family who support Mike in good times and bad.
- Work that is meaningful to the Mike (working with his hands)



## SIGNS AND SYMBOLS OF QUALITY SPACE

- Mike holds the only key to his home and no one enters without his permission.
- Mike's sister now serves on the ARC's Board of Directors.
- Mike grilling on his deck.

### NATURAL SUPPORTS

- Mike has two brothers and one sister who are involved in his life.
- He also has a large extended family.
- He spends time with his mother, who still lives in Averill Park.

### DECISION MAKING

- The main decisions are made by Mike but are often times negotiated by his sister and brother. Mike often does not accept the routine answers.

### PAID SUPPORT

- A staff member lives in a downstairs apartment.
- He has a job coach.

### THE HOME

- Mike lives in a bachelor pad that has room for his bikes, tools, and his outdoor grill.
- He holds the only keys to his place.
- He takes great pride in his entire apartment.

### KEYS TO SUCCESS

- Family Partnerships: We have been through many conversations, variations, reiterations and revisions with the family regarding Mike's supports; the journey is as important as the outcome.
- Trust is a process and takes time—the family did not agree with us in some situations and we made it work.
- Staff Sensitivity: Staff have gone through much reflection to understand how their contributions are seen through the eyes of the family.
- High Expectations for Self-Determination: We helped Mike to manage his seizures as independently as possible, including learning to self-medicate.

### THE COMMUNITY

- Mike lives outside Troy in an apartment complex.
- He enjoys fixing bikes and donates to kids in need.
- Mike enjoys hanging out at nearby eateries with his family and paid neighbor.

Mike  
and  
His Circle of Support



# Poster created by Mike





## *Girls' Club*

**The power of women working together can create great things.**



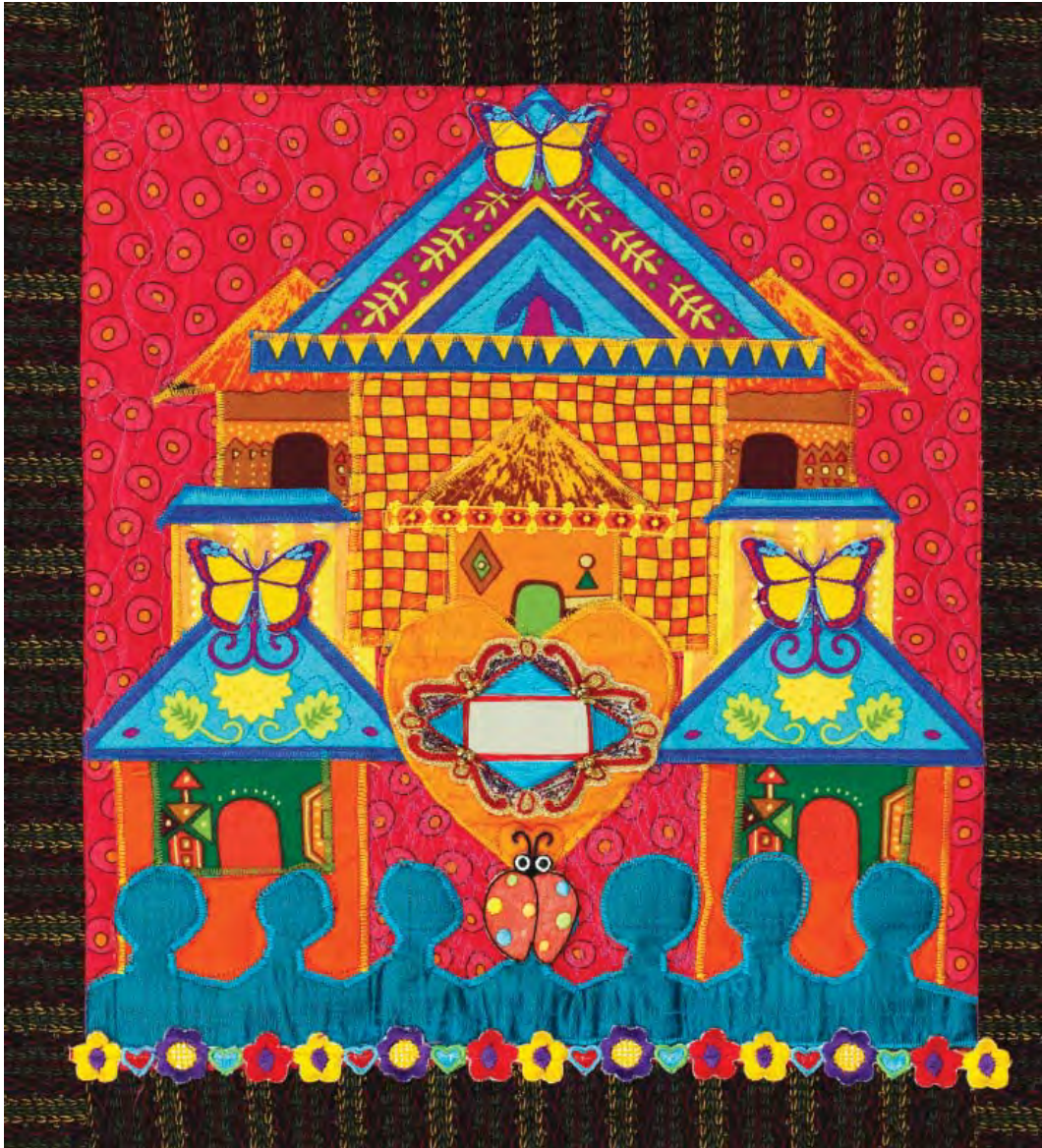
"Regina Octovia Lombardo," Regina states firmly. She is the youngest of a very large family and is proud of her importance as a family member. She grew up in the Troy area and knows many local people. Her mother cared for her nieces and nephews when Regina was growing up so there was considerable of action in the Lombardo household.

Regina has been involved with the RARC since her pre-school days. Her journey included many opportunities to grow and learn along the way. She is especially proud of her ability to use and teach sign language.

Regina lived in a group home and decided that she wanted to get her own apartment. She had originally shared an apartment with a friend and a staff member stopped in daily. She later benefited from a live-in staff situation and later she had a live next-to staff arrangement. These situations seemed to work for awhile but for various reasons they eventually fell apart. Each of the living situations enabled Regina to experience life and learn from it.

Presently, Regina's support arrangement is a combination of several of the previous situations. She shares an apartment with her roommate, who also receives support and across the hall live two other women who also receive RARC assistance . Regina enjoys the relationship with all three friends without having to live with each of them. There are also staff members available to the four women at all times. This is provided in two ways. There is a live-in manager who has an apartment in the building. There is also 24 hours of direct support staff that shared between the two apartments with additional staff at peak hours. Regina has been very successful in this living arrangement.

Her family stops by regularly and is very involved, even though the family sometimes finds that Regina is too busy for them. They leave small decisions to the support team, but they are very involved in the larger decisions that have a greater impact on Regina's life.



Flower Power is a key theme in Regina's life! It takes a village to connect the many women who love and are loved by Regina; her seven sisters, her mom of 100 years, her nearby support staff, and her other friends in the apartment complex. These women all hold each other in their creative quest to live a good life.



## SIGNS AND SYMBOLS OF QUALITY SPACE

- Regina's personal space is colorful, warm and a wonderful expression of her comfort, joy, and mastery.
- The life of the family is beautifully embedded in the life of Regina and the other women who live nearby.
- Regina chooses the song "I Believe I Can Fly" to express how she feels living in her apartment.

### NATURAL SUPPORTS

- Regina is the youngest of 8 children in a large Italian family.
- She is very involved in family matters, occasions, celebrations and vacations.

### DECISION MAKING

- Regina is involved in the decision making.
- The family leaves small decisions to the support team.
- They are very involved in the larger decisions that have a greater impact on Regina's life.

### PAID SUPPORT

- Regina has 24 hour staffing which is shared with the other women who live in the other apartment
- There is another staff member during peak hours so there can be individual assistance for community activities.

### THE HOME

- Lives in an apartment with her roommate,
- It's decorated with Olympic medals, snow globes, and other girly things.
- The apartment is in Troy where Regina grew up.
- There is a washer/dryer in the apartment (no more paying for laundry).
- The home is an Individual Residential Alternative certified by State agency.

### KEYS TO SUCCESS

- Continue to create: The leadership has learned that combining existing arrangement in different ways creates success.
- Walking side by side: The RARC has walked beside Regina and her family since she was in pre-school, encouraging her to learn and grow and experience life to the fullest.

### THE COMMUNITY

- Regina lives in the community she grew up in and many people know her.
- Her name is well known in the city of Troy.
- She likes to bowl at the local alley.

**Regina  
and  
Her Circle of Support**



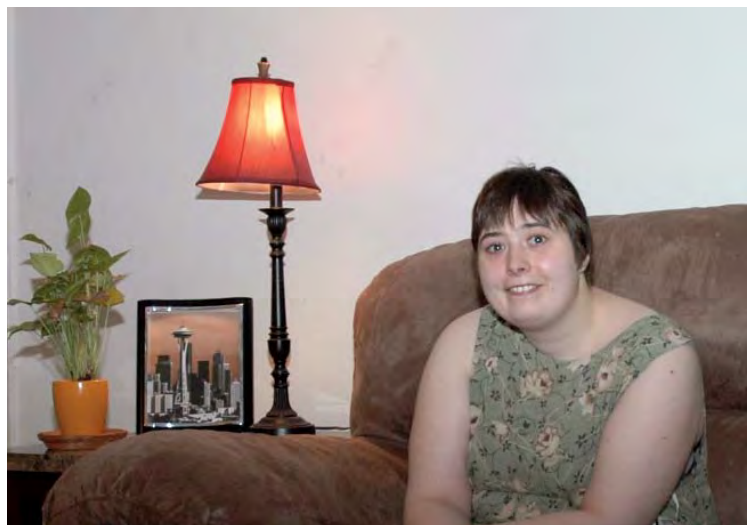
# Poster created by Regina





## *Adult Life Can Be Scary*

More supports are not always  
better supports.



Maria is an amazing young woman with a strong view about how her life should be. She has a vision to go to college and be in law enforcement and legally become part of a family. For her anything is possible.

A former social worker, Catherine made a commitment to Maria when she was younger and has stayed very involved in her life. A few years ago she became Maria's guardian which means everything. Catherine and her family purchased a house in the area where Maria lives and they keep a room for her. Maria spends time at Catherine's house and refers to Catherine's family as her family.

If you told the professionals who previously supported Maria that within a year she would have her own apartment, they would not have believed you. She was removed from her abusive family's home when she was young, which left her anxious and fearful. Maria was placed in a group home with 12 other young people and received years of counseling. When she aged out of that program, the search began for a new program. It was a difficult time for Maria and the thought of the adult life was scary. After several planning sessions, it was decided that Maria would share an apartment with a roommate. Prior to the arrangement, several visits occurred, including two overnights visits at a local hotel.

However, when Maria and her roommate moved in together they did not get along and wanted to separate. They voiced it in many ways and we needed to move them immediately. Maria went to a small group home for a month or so. It was then decided that Maria would get her own apartment. If no one was around than there would be no one to argue with, no one to hit, and in general would create less anxiety for Maria. Staff members checked in frequently and the manager lives close by. She did well and is feeling proud of her accomplishments. Maria is now planning to stay in her apartment and have a single support person living next door instead of the present shift staff. She has chosen the person and is excited about this change.

Maria is active in her community. She did go to a traditional day program and struggled with the demands that were placed on her. She was clear she wanted to go to college and participate in the same activities that other young women enjoy. She now receives support from a community inclusion program which allows for flexibility in her day. She has been going to the library and working hard at learning to read. Watch out world; Maria is on her way.



Life is now an open window for Maria, who spent most of her childhood behind closed doors. With the freedom of her own space, and the concern and guidance of her devoted guardian and allies, the butterfly and flowers symbolize the blossoming of her life from seclusion to a world of possibilities.

### Identifying Keys to Life

- Control over her own apartment and authority over who enters.
- A sense of safety from people and things that scare her.
- A sense of belonging to a family.



## SIGNS AND SYMBOLS OF QUALITY SPACE

- Family connection and a family to call her own.
- A place to decorate herself.
- Maria's space is similar to other college-age young people.

### NATURAL SUPPORTS

- Maria is very involved with her guardian, Catherine.
- Catherine's family is Maria's family.
- She stays with them one weekend a month and visits frequently.

### DECISION MAKING

- Maria has delegated much of the major decision making to her guardian.
- For daily decision making, she relies on staff members she trusts but the final decision is Maria's.

### PAID SUPPORT

- Maria is in her own apt. in a very large complex. Three other apartments in her unit are rented by RARC, one housing the live-next-to manager.
- She has access to 24/7 support & 40 hrs a week individualized support.
- The 'live-near' manager is going to change to a "live-near" staff person that Maria has chosen.

### THE HOME

- Maria's apartment reflects her age: it feels like a college dorm, filled with teenage posters, movies, & family photos.
- She has an outside balcony facing the woods and access to the pool and work-out room.
- The apt is considered an Individualized Residential Alternative and is certified by the state governing agency.

### KEYS TO SUCCESS

- Challenging assumptions continually is important: Maria taught us that adding more staff resources does not necessarily equal satisfaction or success.
- Making dreams happen: It is important to assist people to reach for their dreams; it makes a huge difference with day-to-day outcomes.

### THE COMMUNITY

- Maria lives near a YMCA.
- She attends the library and checks out books and videos
- She uses the pool in the apartment complex.
- Maria lives within a mile of her guardian, an important anchor in her life.
- She has other friends in the complex.

**Maria  
and  
Her Circle of Support**



# Poster created by Maria





## *Transitioning from Childhood to Adulthood*

**You must be intentional to change from being present in the community to becoming part of the community.**

When Madalyn was sixteen her parents, Peter and Darcy, began to think about her future.

Many questions came to mind.

- How would they help Madalyn transition into adulthood?
- How would they ensure she will be happy, successful and safe?
- How does the adult system work?

The RARC staff started to answer these questions by getting a some family and friends together to work with Madalyn and her parents to design a plan. We used a process called "Mapping." We reviewed Madalyn's history and vision for the future. It included information about what family and friends felt were Madalyn's capacities, and what supports would be necessary to increase the likelihood of a completed vision. The planning session ended with an action statement which included exploring the option of self-directed services.

Madalyn has had many typical teenage experiences as her family helps her to experience many things in her community. Her vision was and still is to participate in many young adult experiences in a more complete way. She enjoys sports, (both watching and participating), music, camping, traveling, animals, and 'going out'. She has many positive attributes including; willingness to learn, being friendly, caring, spunky, and very active. While her parents encouraged their daughter to express those attributes and interests they are also concerned about her future safety. Madalyn has at times wandered away to explore her environment and was not easily found.

Madalyn's greatest desire was for friendship. Her parents realized that staff members could provide opportunities for Madalyn to make friends but that they could not "go get them" for her. She needed opportunities to be around other young people who had similar interests. Peter and Darcy hired a staff person who had many friends with the hope that friendship making could be modeled to Madalyn. They also found a staff member who ensured that Madalyn was and is safe when she is out in the community., That staff member provides transportation and help her exercise good judgment. The staff member hired was a student from a nearby college who lives in the same community and who has many of the same interests.

The planning group felt that traditional Respite or Residential Rehabilitation supports would not work for Madalyn because the family wanted to be more involved in choosing and supervising the staff. The self determination plan has been in place for about a year. The people at Madalyn's school report that she is doing so much better. She does not sit home after school hanging out with her mother. She attends baseball games with others from the school. She takes an art class at the local arts center. She is always on the go. Self determination has helped Madalyn and her family as they continue to focus on the goal of building an ever-widening friendship circle.

Madalyn graduates from high school this year, so her self-determination plan will be expanded to assist her in filling her days with meaningful activities, with a balance of paid work and community volunteering. The planning team also hopes to see her explore her interest and talents in music and art.

Beginning self-direction at an early age has given the parents the confidence and knowledge to better assist Madalyn as she is transitioning to adult life.





Madalyn is on a path toward a self-directed life. As a teenager, her immediate focus is on friendship though her love of basketball, and her love of horses. Her parents and allies are guiding her path to adult life as they assemble expanding blocks of support that fit Madalyn's emerging desire for independence.

### Identifying Keys to Life

- Participating as an active member of her community.
- Feeling a sense of belonging with others her age.
- A paycheck for her hard work.
- Her parents providing guidance.



## SIGNS AND SYMBOLS OF QUALITY SPACE

- Access to music — iPod.
- Transportation to sporting events.
- Place in the home that she can go to be alone.

### NATURAL SUPPORTS

- Madalyn has active parents.
- She also has a younger brother, Dylan.
- Her mother manages the majority of the self-determination plan.

### DECISION MAKING

### PAID SUPPORT

- Madalyn receives 18 hrs support staff weekly.
- She attends evening rec events held by RARC.
- She attends high school with assistance from an aide.
- Madalyn's support broker updates the budget and self-determination plan.

### THE HOME

- Madalyn continues to live with her parents and brother.
- They all live on a beautiful farm with a dog and a horse.
- Her parents have the vision of finding a home for Madalyn nearby so she can have her own space.

### KEYS TO SUCCESS

- Ability to Learn Together: Madalyn's self-determination plan was one of the first RARC designed and submitted to the state agency. So Madalyn's family, RARC staff and administrators learned the process together.
- Role Responsibilities Redefined: RARC typically handles all the supervision, paperwork and billing for Medicaid. With Madalyn's arrangement, RARC is the support broker, and a different financial agency bills the Medicaid system and pays the staff. The mother does the paperwork, supervision and monthly notes. RARC staff facilitate and serve as advisors to the process.

### THE COMMUNITY

- Madalyn attends a local high school.
- She takes art class at the community college.
- She works at an area day care center.
- In the summer, she is a junior counselor at the camp she attended as a child.

## Madalyn and Her Circle of Support







