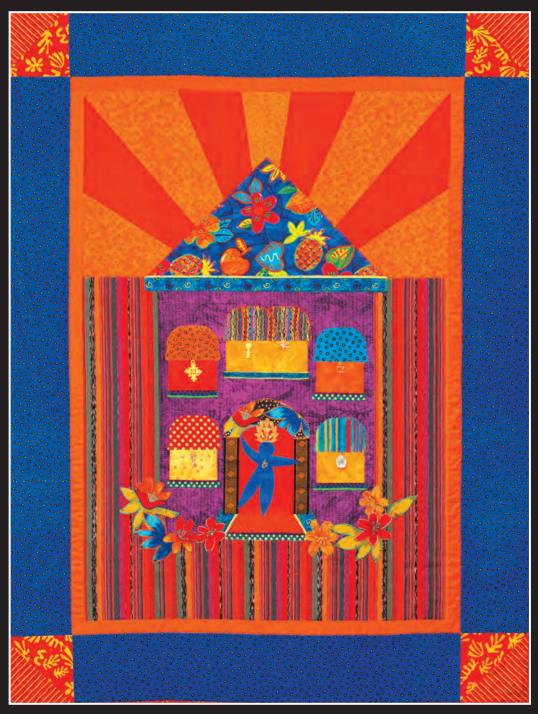
LIFE BUILDING OPENING WINDOWS TO CHANGE



Using Personal Futures Planning Personal Workbook

BY DR. BETH MOUNT

Life Building

OPENING WINDOWS TO CHANGE USING PERSONAL FUTURES PLANNING

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Inside, Everything's Changed Open these windows, open these doors Darkness can't hide in this house anymore Pull back the curtains, let in the light Let the world see who is living inside, Pick up these pieces of pain and regret Scattered out on the floor Cause inside these walls, a new heart is beating, and you're not alone anymore. **Edward Grant DEDICATION** This book is dedicated to my brother, James Steward Mount, Jr. who inspired us all with his determination to live a valued life far beyond the predictions given to him. My family life was deepened through our mutual struggle to find hope and meaning during hard times, and it was brightened by Jim's awesome sense of humor and his compassion for others. Life Building: Opening Windows for Change Using Personal Futures Planning © Graphic Futures, Inc., 25 West 81st Street, 16-B, New York, NY 10024. 1995, 2000 All rights reserved. Copyright: Materials in this manual to do with Personal Futures Planning have already been copyrighted and cannot be reproduced without the written permission of Beth Mount, Graphic Futures, Inc. Published by: Capacity Works - PO Box 271, Amenia, NY 12501-0271 888-840-8578. In New York State: 845-373-4218 Additional copies of this and other publications related to Person-Centered Planning are available from Capacity Works. Design and Production by: Rooney Design Group, Ltd. - PO Box 26. Amenia, NY 12501 Cover Artwork by: Beth Mount © Graphic Futures

A Message to People with Disabilities and Their Families

This workbook is written for families and people with disabilities who are open to changing their lives. While I have been professionally involved with people with disabilities and their families for more than 25 years, this book is written by the sister part of me who grew up with a brother who had multiple medical and learning challenges. My family grappled over the years to support my brother to live a meaningful and valued life in spite of his complex issues, the frustration of dealing with agencies that hurt more than they helped, and a lack of direction related to how to make things better.

Often our hopes for a better life for my brother seemed to lie dashed among unfulfilled promises and agreements, the latest life and death medical crisis, and other related breakdowns. The windows and doors in our life often seemed shut. These were the dark days, weeks, months, and sometimes even years in our lives.

I have listened to families and people with disabilities for many years, and I see how often people feel trapped in difficult situations. When life seems that dark, people are reluctant to hope without support, opportunities, or reasons to think that life could be better.

I am reminded of all the people with disabilities I have met, who stand by windows and doors waiting, watching, looking, and pointing. They are people who are tired of being alone, engaged in meaningless tasks, bored with isolated activities, and waiting for a life that does not seem to come their way. Of course there are many people in the world who have no hope for other reasons; poverty, imprisonment, abuse, war, hunger, illness, and other limiting conditions. We must believe that people want out of these situations, and that every one of us can change the pattern.

The struggle toward a dream is hard work, but no worse than the despair of living without hope. Hope is worth opening when there is at least one person to walk with us toward something different. It takes a lot of courage to hope, to open doors, to confront discrimination, to face the challenge of change, and to connect.

This book is about building a life; opening doors and windows to hope, building connections to support, making contributions to community, and challenging organizations to be more responsive. It is written for people with disabilities, their families, and others who support them. The seven exercises have evolved from thousands of discussions with and relationships to people with disabilities and their families who are seeking to build a better life, in spite of the challenges and conditions that limit them.

"We" is All of Us

This workbook is written for people with disabilities, their families, and the people who wish to walk with them toward a more hopeful future. The personal profiles provided in every chapter are about people with disabilities I have known for an average of ten years (except for Temple, who I hope to meet someday!). In different ways, we have been part of each other's journeys — exploring possibilities, deepening friendships, celebrating accomplishments, and sharing struggles, upsets, health problems, and disappointments. While I am the primary author of this workbook, I use the inclusive reference of "we or us" because the ideas represented come from a wide network of people with and without disabilities who are learning about this work together.

I avoid the use of any language that labels people as staff or clients because it seems to me that we are all in this journey together. I find that the most effective helpers are often people who are themselves wounded, and through their own struggles, mistakes, and pain they approach someone else's struggle as equal. I believe that healing that empowers and liberates emerges from a sense of mutual struggle with the forces that hurt us all. Therefore, the text is directed to "you," whether you are a person with a disability, a family member, someone who wants to help, or someone without a disability who wants to change one's life.

Beth Mount



BACKGROUND

In the early 1980s I began my doctoral work related to Personal Futures Planning, a different way to plan with people with disabilities and their families in Georgia. Personal Futures Planning was designed to emphasize a capacity view of people with disabilities in contrast to a deficiency view-a hallmark of the medical treatment model. I was involved with John O'Brien, Connie Lyle, and a wide network of people engaged in changing our thinking about people with disabilities and imagining their futures. Changing the way we thought about people had a profound impact on the course of people's lives.

In 1985, the Connecticut Developmental Disabilities Council funded a five year project to encourage the development of support circles and Personal Futures Planning in Connecticut. As a result of this project, I worked with Pat Beeman, George Ducharme and a number of people and families in Connecticut to further integrate the concepts of Personal Futures Planning, circles of support, and community building.

With the support of this project, we had the freedom from human service settings and thinking to build futures plans and support circles for people. We learned about the power of bringing together people who love and believe in the focus person. We learned about the journey of walking with people over time in mutual friendship, in contrast to ruling over people because of the mandate of a job description.

We were clearly engaged in a process of liberation with people. People became more powerful when they were reminded of their gifts and they had a vision of how to change their lives. They gained the energy for change when other people offered to help and to share the struggle. They became community leaders when the work toward their personal future increased the opportunities available to others.

An earlier version of this book was published in 1995 by Communitas in Connecticut under the name of Capacity Works; Finding Windows for Change Using Personal Futures Planning. This publication described many of the ideas that clarified a path toward freedom in our journey with people.

In 1989, I moved to New York City, and began working with people with disabilities and their families in the inner city schools and diverse neighborhoods of an urban environment. Many of these students and families live in overwhelmingly limiting situations, and I find that the key to change is hope combined with incredibly hard work that sustains people over time. Working with people in New York City further clarifies the value of person-centered planning as a process with and a relationship to people and families that evolves over time. We must be prepared to build lives with people, not just plan them, the only honorable way to encourage people to dream.

Life Building; Opening Windows to Change Using Personal Futures Planning, provides the reader with seven tools for reflection. I hope that each reader will use this book to clarify a way to contribute their own gifts in the process of building a more meaningful life, strengthening relationships, and creating stronger communities.

How to Use This Workbook

You are presented a glass that is filled halfway with your favorite drink. Do you look at the glass and complain that it is half empty, or do you see the glass and celebrate that it is half full?

For too long, people with disabilities have been seen as people who are half, if not fully, empty. Known only as people with needs, deficiencies, and labels, people are seen as less than equal, often mistreated, and deprived of opportunities to contribute in community life.

This workbook is designed to help us see people with disabilities as full citizens by reclaiming people's hopes and capacities, restoring people's friendships and communities, and remembering people's personal vision for a life fully lived.

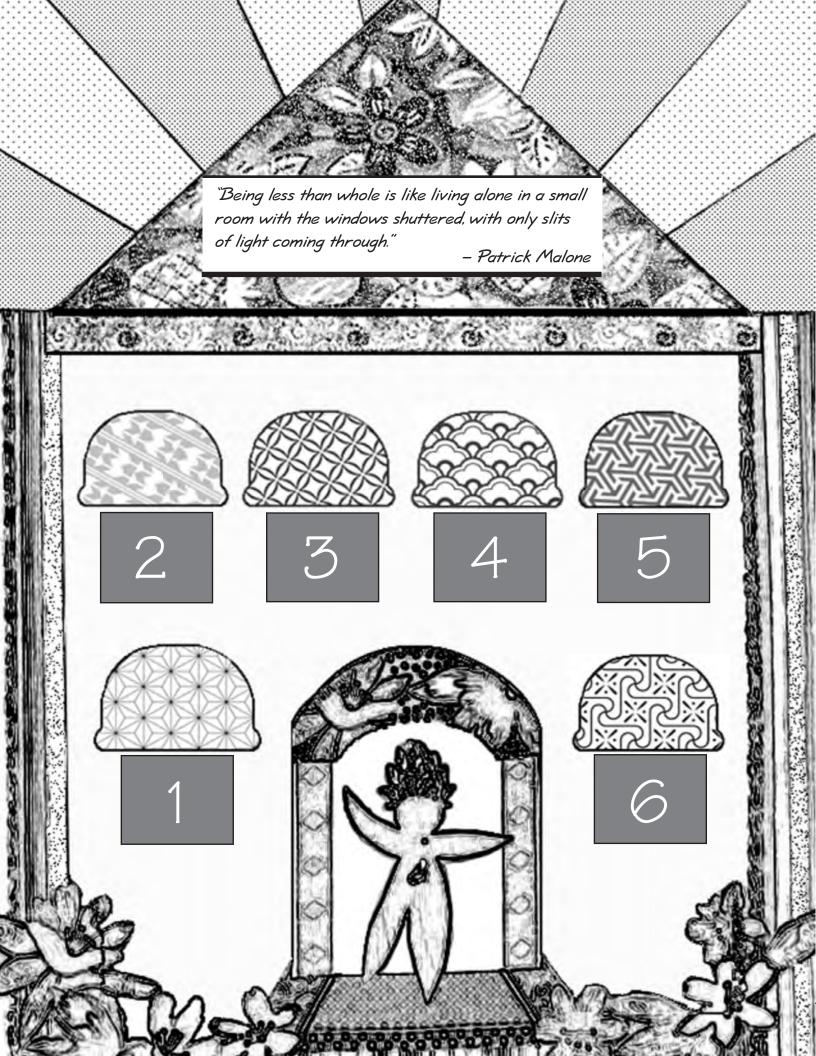
If you are working to reclaim a capacity view of yourself, then you are likely to need help. Ask a friend, or several people who believe in you, to help you complete some or all of the reflection tasks provided in this workbook. Do not invite the people who seem invested in seeing you as half empty. Do invite the people who fill you up with a strengthened sense of self, and who have the energy and courage to challenge the conditions that may oppress you.

The workbook provides *one door and six windows of change* and a variety of reflection tasks that offer you and others a chance to see your life differently and find new directions for change.

When the people around you help you to recognize and strengthen your capacities, they will help you – feel your power, participate as equals, give and receive in relationships, and contribute in community life.

When you break the chain of limitation in your own life, with help from others, you change the pattern of oppression for all people. By changing your own life, you change the world.

"People became more powerful when they were reminded of their gifts and they had a vision of how to change their lives."



LIFE BUILDING: Opening Windows to Change

The Confinement of Segregation and Stereotypes

For too long, the experiences, needs, desires, and contributions of people with disabilities and their families have been defined by segregated settings and limiting stereotypes. Segregated classrooms, sheltered workshops, group homes, institutional units, and mini-vans can be like small boxes in which we have hidden people with disabilities, their gifts and contributions. People are often trapped by human service settings that tolerate and reinforce the separation of people with disabilities from people and places in community life in which they can contribute.

People often languish in these confining places. Without access to opportunities in community life, people give up hope that life can be different and make the best of impossible situations. Families and people with disabilities may live with unbearable stress, with only the energy to make it through the day, much less think about the future. Segregated options may appear to be their only choice, and a welcome option over no support at all.

Life Building: Creating Possibilities with Personal Futures Planning

Life Building challenges us to walk with people on a path toward a life as a citizen in the community. As a result of this journey, we seek to break the cycle of isolation and oppression that people with disabilities and their families often live with. We join with people to discover a way out of the conditions in which they feel trapped.

Personal Futures Planning is a tool to help clarify a path out of the stereotypes and programs that define and limit people. We enter each unique journey with people by weaving together the threads of a person's personal history and character, the contributions of the people who care for them, the opportunities and challenges in their local communities, and the resources in human service programs. Personal Futures Planning is a process that helps design a road map for bringing these contributions into relationships and community life.

Personal Futures Planning offers us a completely different way to think about our lives and move in a new direction which can be a powerful force for change. This workbook describes one door and six "windows" that help clarify our thinking and focus our advocacy efforts through a variety of reflection tasks. The following seven exercises will guide us through the process of developing a vision and a strategy for action.

The Windows of Change: Finding Opportunities for Development



We begin with **hope and a question.** Hope encourages us to question our current lives and wonder if we can really change things. We begin the process of change when we give voice to our deepest longings and share our hope with at least one other person. Opening this door helps us examine our relationship to hope, clarify our questions, and identify an ally who will help explore this question with us.



Having hope leads to the heart of person-centered work which is an emphasis on **expanding relationships.** Expanding and deepening personal relationships for people with disabilities and their families is essential to person-centered work. Window One helps us clarify our support system and find new ways to strengthen and build our friendships.



Capacity work encourages us to **recognize the gifts** of each person and find opportunities for the expression of these gifts in community life. We find and clarify these gifts by deepening our relationships and learning to listen to people and their families. Window Two provides some thinking tools for exploring and clarifying individual gifts.



Finding personal gifts can be an empty exercise unless we also work hard to **discover**, **build**, **and strengthen community life**. Personcentered work requires that we focus our attention on the patterns, routines, rituals, and fabric of local community life. Exploring community reveals many ways that people with disabilities can be valued citizens in their local communities. Window Three provides a variety of exercises for clarifying opportunities in local community life.

As we strengthen our understanding of personal gifts and community opportunities, we begin to **clarify a personal vision** for the person. This task requires that we take a flying leap away from previous stereotypes and assumptions about people and their futures. This leap of faith in the person, and our capacity to support them can compel us to work toward a dramatically different life-style. Window Four outlines some suggestions for clarifying our ideas about the future.



Once we have new ideas for a different future, we have to take the first step toward the vision by starting somewhere, often starting small, to **find** the time, energy, and resources to get new ideas into a weekly schedule. This challenge usually brings us into conflict with the realities of our existing lives and the limitations of existing supports and services. Window Five challenges us to put our ideas into action by starting somewhere.



Finally, each journey toward hope actually escalates the struggle we face in the process of working for change. We seek to transform our struggle into an on-going problem solving process which we share with other people. We clarify what we are up against, and **what we need to learn** to overcome these obstacles. Window Six helps to clarify our obstacles and find a learning path around them.





"The facilitator
may need to defend
the focus person
from being called
unrealistic, or from
having
his or her vision
rewritten by wellmeaning people
who don't want to
see him/her
disappointed."

OPENING THE DOOR: This is My Question

Personal futures planning is designed to strengthen people's sense of hope so that the opportunities available in life outweigh the challenges that leave people feeling paralyzed. When we initiate a personal futures planning process, we begin a journey of building hope that sustains people through life's challenges. This is no small or simple task.

To be hopeful is not some blissful or visionary experience, but rather a deep internal state that leads us to work toward better conditions for ourselves and others. To have hope for ourselves is to see how we can change our lives and the world we live in. To have hope for another is to feel their pain, appreciate their predicament, and light the way toward some action that changes things.

Building hope does not imply avoiding depression or despair. Many of us involved in this work live with depressing times in which we are frozen by our inadequacies, or we feel overwhelmed by the patterns of injustice and the conditions that oppress people. In our despair we may languish in the pain of our helplessness, but we may also come to feel all the more committed to changing these conditions. In our hopefulness, we join with others to support our efforts to change the patterns that bind us. We depend on our hope to lift us out of despair toward constructive action and change.

We notice that the path toward hope is not a direct, steady, upward and outward spiral toward better conditions. We get discouraged, become isolated and filled with self or other blame, and lose our sense of hope all the time. Just when we think we've finally gotten somewhere, then we are confronted with a new set of problems and issues that seem to set us back. We strive to be in this struggle along with other people, and to build a community in which it is increasingly safe to live with and realize a dream.

Through this door, people are encouraged to give a voice to their despair and their hopes, and to identify at least one person who understands the despair and believes in the hope. Use the following Reflection Tasks to clarify your concerns, hopes, and the person(s) you trust who helps to amplify and strengthen your voice.

When we gather in Connecticut with people involved in Personal Futures Planning and support circles, people talk about "hope" time and time again. They say:

"This process gives people hope and a belief in their abilities and gifts."

"The first gathering is incredible—to have so much encouragement while at the same time you are sharing the incredible complexity of your life."

"Hope is the food for a circle, we are remembering hope for ourselves, family, and friends."

"Being hopeful doesn't have a time frame and it is not romantic. Real dreams take a really long time to realize."

"People need real support once we've unleashed hope. This process requires walking with people over time, not just sitting there thinking stuff up, or running fast to the next agenda. Hope requires slow, steady walking with people."

"It is essential not to bash people's hope or judge or evaluate hope. People will come to the places they need to for themselves."

"The most powerful hopes are not just personal—these hopes require a change in the world that makes the community a better place for many people."

Breaking the Silence with the Sound of Our Questions

Having hope helps us to ask the questions we would rather avoid. When we are oppressed by stereotypes, discrimination, and a lack of opportunity, then we often silence the voices within us that want to scream for something better.

Pablo Friere reminds us that oppressed people live in "a culture of silence." This is a condition common to all oppressed groups of people, perhaps even more so when people with disabilities literally cannot speak. These reflection tasks help us strengthen the voices of our discontent as well as value the voices of hope.



"Although the dream may be ambitious and failure is a possibility, most people would rather try and fail than not have the opportunity to try at all. And often the journey results in many positive developments, even if the dream is not realized in exactly the way it was envisioned."

- Cathy Ludlum



"Hope is an orientation of the spirit, an orientation of the heart. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out."

- Vaclay Havel

Listening to Hope

Jeanne Archerberg has extensively researched the role of the imagination and hope throughout the history of healing in all cultural traditions. She concludes that the most prevalent theme that healers share, particularly folk healers, is their ability to engender hope, to renew people's sense of self, and to reconnect people to their communities. When the entire community becomes a healing network, when time is devoted to focusing acutely on one's problem, and when a person's support system becomes active and obvious, then people experience far greater health and fulfillment in life.

Personal Futures Planning often begins when people have a vague sense of hope that life can be positively different.. Through the process of building a healing support network and focusing on capacities, a faint hope can become a powerful, detailed personal vision and community vision.

Who Will Value Our Questions and Hopes?

Breaking the silence requires giving a voice to the longings, dreams, and hopes we have for ourselves, as well as the despair, frustration, and disappointment we face. These voices are strengthened when we have interested, empathic, and understanding listeners in our midst. The voices of hope wither away in the presence of practised cynics and people whose hearing is limited. We must find at least one good listener who can help us value our hopes, name our question, and use our anger for constructive action.





OPENING THE DOOR: THIS IS MY QUESTION

Reflection Task 0.1: What do I want to Change?

In the following reflection task people with disabilities and their families are encouraged to give voice to the often intolerable conditions and experiences that they would most like to change. The following examples help illustrate conditions that people hope to change:

Why do I have to:

Ride a bus two hours a day?
Live with a bunch of people I don't like?
Sit for hours with nothing to do?
Spend so much time alone?
Do these stupid programs?
Rely on so many assistants who I don't like?
Have so many people around who don't understand me?
Live this way?

Reflection Task 0.2: This is my Hope:

This reflection task encourages us to give a voice to our hopes and dreams. These longings include not only the hopes we have for ourselves, but also the hopes we have for our communities and friends. The following examples help illustrate people's hopes:

I would like to:

Live in a place of my own.

Be married.

Have someone to do things with on the weekend.

Have a best friend.

Live near my brother if anything ever
happens to my parents.

Have a family to visit and be part of.

Have a van.

Find my friends from the past.

Make some more money.

Win the lottery.

Make it possible for all people with
disabilities to have the personal support
they need to live in the community.

Reflection Task 0.3: This is my Keeper of the Question:

Who do you most trust to help you clarify your questions and express your hopes? Who is the person who will listen to you and believe in your dreams? Who can you count on to value these yearnings and explore these questions? List the names of everyone you can think of, and identify the person you would most like to ask to be the "Keeper of the Question." This person might be your mother, father, friend, a staff person you like, a neighbor, a teacher, a person from your past, or a person you would like to include in your future.

This is my Keeper of the Question: My mother



OPENING THE DOOR: THIS IS MY QUESTION:

Reflection Task 0.1: This is what I would like to change:

3 · 3 · 4 · 4 · 4 · 4 · 4

Reflection Task 0.2: This is my Hope:

Reflection Task 0.3: Who is my Keeper of the Question? Who will be the Guardian of my Hopes?



THE FIRST WINDOW:

These Are my Friends and Supporters: Expanding and Deepening Relationships

Expanding and deepening personal relationships is the heart of person-centered planning. The wider the network of people who care about us, the more likely we are to be seen as sacred beings with a contribution in community life. The quality of our personal relationships affects the richness of our vision and hope for the future, and the sense that we can actually make it happen.

Relationship building is essential to this process because people with disabilities are so at risk of being unseen, segregated, and alone. The more people are isolated, the more likely they will be treated like objects of the system; hurt, neglected and ignored. We have to act vigorously to work against the prevailing cultural reality that devalues and isolates people from one another.

Our vision for the future also includes finding good jobs for people, creating good homes, and finding many ways for people to contribute in community life. The specifics of our ideas about work, home and community life are often determined by the potential to build and enhance personal relationships.

"We cannot control relationships or force love and concern between people. We can only increase the probabilities that people will meet, get to know each other, and begin the mutual exchange that strengthens the fabric of relationships. Therefore, this is mysterious work, rather than a science. We have to give up control of the outcomes while also working really hard to increase the probabilities that people will be known in community life. We try to find many ways to deepen a wide variety of relationships."

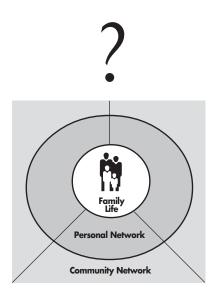
Finding Friends for the Journey

We begin the task of expanding and deepening relationships by naming existing important relationships. Who are the people in our lives now, both unpaid and paid? How connected are we to each person? What are the tokens and gestures of our exchange?



In describing our relationship life now, we identify our allies in the journey of building a community life. We find that there may be more people in our lives than we thought, and we are challenged to find a variety of ways to deepen and encourage these relationships.

We can hopefully identify a few people who can help us claim our strengths, envision a dream of a different personal and community life, and share the on-going struggle of working toward an ideal. We need not have a cast of thousands, we just need a few committed people to find new hope. These people are the beginning of our support circle.





Reflection Task 1.1: Describing Personal Relationships

Use this relationship circle to provide a guide for mapping your relationships. Begin by naming the people you most love and rely on in the center circle, the place of *family life*. These people need not be biologically related, but they are the people who you trust the most, who know you better than others, and who care for you because of the mystery we call love. There may be just one or two people in this inner circle, while some people may feel that this circle is empty.

The middle circle represents your *personal network* and includes family, friends, neighbors, coworkers and students, and helpful paid support people. These are people you rely on, with whom you exchange the tokens of friendship and concern; special occasions, triumphs and struggles, acts of kindness and consideration, direct support and assistance, mutual interest and affiliation. There may be just a small number of people in this group as well.



The outer circle represents your *community network* and includes acquaintances, friends from the past, helpful staff, people from the neighborhood, and other people with whom you do business, greet on the street, and generally acknowledge in some way as part of the fabric of your community life.

In this reflection process, the gaps and areas of development in our relationship life can be painfully revealed. This is particularly true when

people with disabilities have been separated from both their family of origin as well as segregated in human service programs.

We can begin the exit from isolation in many ways. It doesn't matter where we start, it does matter that we decide that we are not going to tolerate isolation anymore. One of the most powerful acts is to invite and include others in the process of working toward change. Forming a support circle can happen formally, by convening a group of people who meet together to help us think about our lives, or it can be developed informally by strengthening our ties to supportive others in a variety of ways.

Task 12: Finding ways to Strengthen our Circle of Support:

For many people with disabilities, new relationships are emerging as a result of new patterns of inclusion and integration. This exercise encourages you to strengthen and deepen your existing relationships. The following examples illustrate strategies for expanding and strengthening a circle of support.

I can: Call Uncle Walter and see if he wants to go fishing.

Call up Peter and invite him to go to a movie.

Bake some cookies and take them to my neighbor.

Find out the birthdays of people at work and send them cards.

Invite several people over to talk about starting a support circle.

Send a letter to all my extended family members and let them know about all the positive changes in my life.

Find ways I can be a member of a family even though I don't really have one of my own.

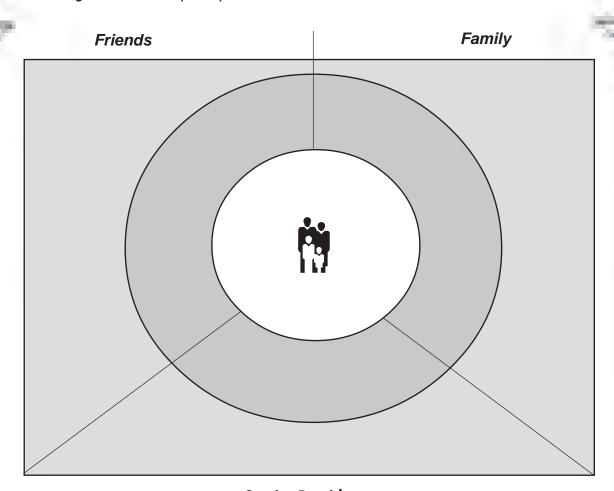
Call Phil and ask him for a date.



THE FIRST WINDOW:

These are the People I Can Count On:

Reflection Task 1.1. Building a Relationship Map



Service Providers

Reflection Task 12: I Can Strengthen my Relationships by



Notes on the Healing Power of Relationships

"You will experience, through the many walks with people, the incredible importance and value of relationships for others (not to mention what they do for each of us personally) and that this work is really bigger and more global than getting a relationship built, that you are building a better and healthier world and community for the sake of humankind; that you are helping to take away the isolation that exists in people's lives; that you are bringing equities and things that any citizen has a right to; that you are bringing care and compassion to people's lives; that you are building up the value in people that gives them the self-confidence and self-esteem to give to others rather than always take; that you are bringing hope and light to people and their communities; and that without you that difference would have never been felt."

Pat Beeman







THE SECOND WINDOW:

These are My Gifts: Recognizing and Developing Personal Preferences

Personal Futures Planning encourages us to support people in a wide variety of citizenship roles. By developing creative community roles, we are freeing people from the stereotypes that confine them to traditional segregated settings so that they have growing opportunities to participate in community life.

Identifying, developing and expanding personal qualities and gifts is another key to opening windows to community life. By naming and claiming the positive aspects of a person's identity, we help strengthen a growing sense of self that can be developed in community life.

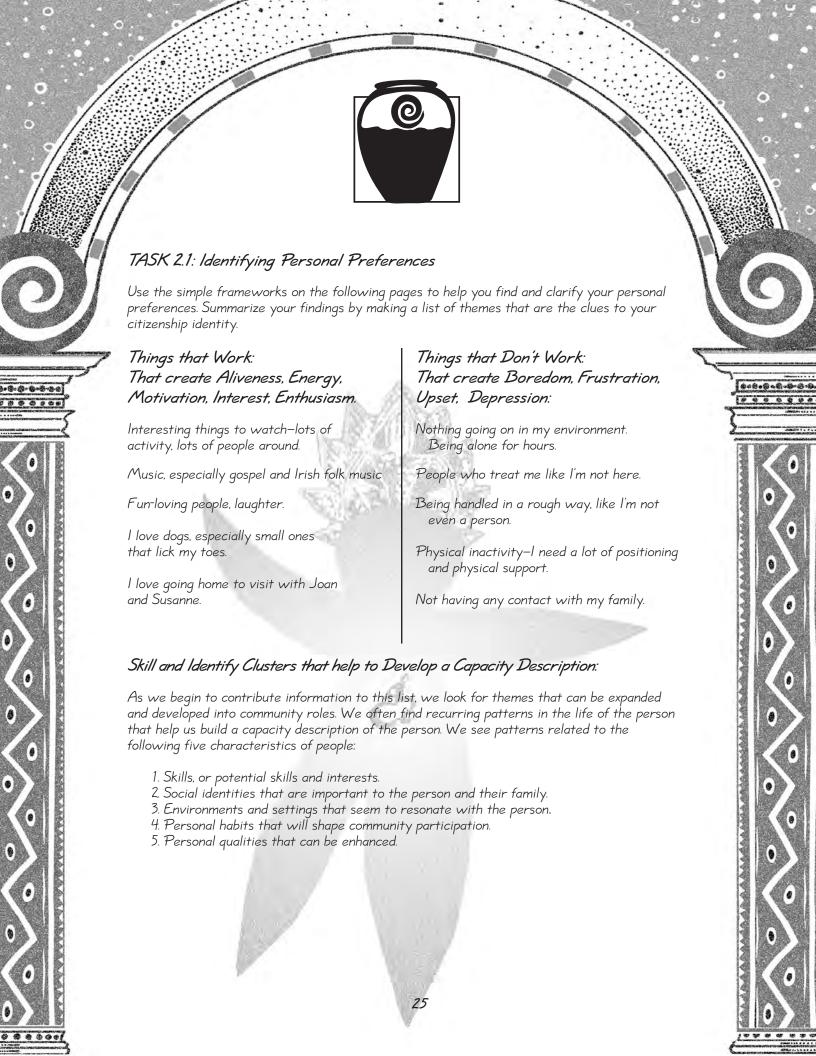
The positive identities of many people with disabilities are often deeply mired in deficiency descriptions and negative predictions. People with disabilities and their families are often unaware of their gifts, capacities, and preferences. Their potentials and preferences are often misinterpreted, misunderstood, and unseen by others particularly when people do not have the words to express themselves.

In this planning process, we seek to bring forth the positive identities in people in a variety of ways. We believe that people are empowered from within as the positive aspects of themselves emerge. This power from within is strengthened when others see and nurture these aspects of the self.

This reflection task begins the search process of finding capacities. We look for any clues about personal preferences that help to build a capacity description. We look for patterns and themes in the skills that people have, the ethnic and family traditions, identities, and interests people and their families express, the environments and settings people prefer, the personal habits that shape their participation, and the often subtle personal qualities that are appreciated by others. The themes that best describe personal preferences are clues to the citizenship identities we seek to strengthen in the process of community building.

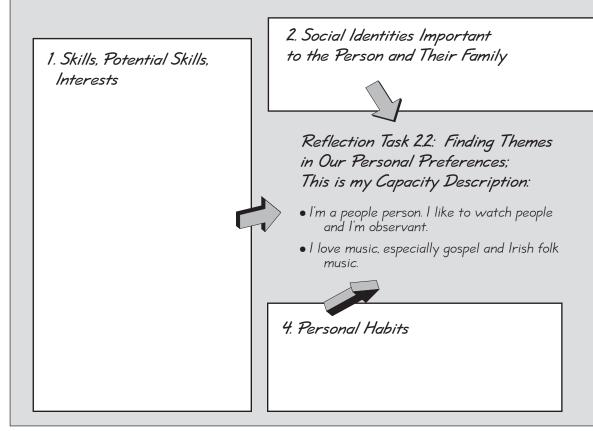
Starhawk

[&]quot;The root of power means to be able. Power from within is linked to the mysteries that awaken our deepest abilities and potential. So if our work is to evoke power-from-within, we must clearly envision the conditions that would allow that power to come forth, we must identify what blocks it, and create the conditions that foster empowerment. Given a world based on power-over, we must remake the world."





Reflection Task 22: Use these five lists to help you identify themes related to your personal preferences list.



1. Skills, or Potential Skills and Interests. Patterns to look for include:

Using hands: assembling, using tools, fixing, repairing, building. Using one's body: being physically active, outdoor activity.

Using helpfulness: being of service, showing sensitivity to others, drawing out people.
Using artistic abilities: singing, fashioning, shaping things, dealing with colors, conveying feelings through body, face, or voice.

Using analytical thinking: organizing, classifying, putting things in order, comparing, evaluating, reviewing.

Using leadership: selling, promoting, persuading, leading, directing, beginning new tasks. Using follow-through: using what others have developed, attending to details, recording, filing, classifying.

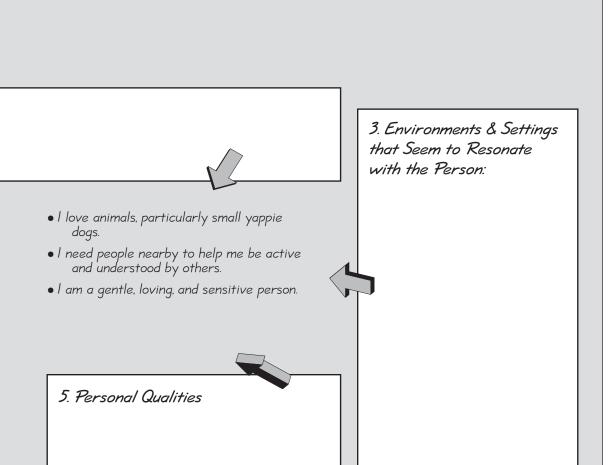
2. Social identities that are important to the person and their family. Themes to look for include:

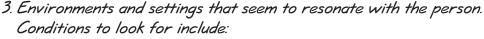
Trade or work identities: being a teacher, a lawyer, a repair person, a restaurant worker, a nurse, a construction worker, a beautician.

Ethnic and religious identities: African American, Asian, Hispanic, Irish, Jewish, Native American.

Interest identities: sports, music, sewing, singing, politics, birdwatching, collecting, motorcycles, animals, beauty.

Appearance Identities: types of uniforms, badges, name tags, formality or informality of dress, grooming standards.





Noise and commotion levels: quiet places, busy places,

Ethnic places: places where people speak the same language, share similar beliefs, celebrate similar rituals.

Familiar places: places with in walking distance, places where people know you.

Standards of efficiency and perfection: uptight, real loose, busy, laid back, repetition or variety of tasks.

4. Personal habits that will shape community participation. Characteristics to consider include:

Activity levels: morning people, night people, high energy, sedentary.

Health issues: medications, stamina, side effects.

Disability issues: sensory and physical impairments and adaptations.

Structure preferences: high or low structure, fixed or flexible routines.

5. Personal qualities to appreciate and enhance. Qualities to recognize include:

Essence: observant, calm, funny, loving, caring, energizing, kind, "brings out the best in others," gentling, provocative, smart, sensitive, effusive, tolerant.

Ancient self: wise, spiritual, challenging, activist, seeker, rebel, warrior, peacemaker, protector, teacher, preacher.



"The overall character of our lives is given by those events and patterns which keep on happening. If these patterns are good for me, I can live well. if they are bad for me. I can't."

> - Christopher Alexander

Learning About People Over Time

We can discover powerful personal preferences from talking to people for an hour, or we may need months or even years to get to know people in a variety of community roles and settings to see what works. Learning about personal preferences involves at least three investments; being with the person over time, talking to the people who know the focus person well, and spending time with the person in a variety of settings and circumstances.

The first investment is simply spending time with people in an informal way, asking the person about their interests, dreams, and sense of personal identity. We might discover that people want to be office workers, writers, firemen, computer programmers, church goers, family members, and so on.

The second investment is to talk to the people who know the focus person well to collect their insights about the preferences of the person. If the focus person cannot describe their own preferences, then it is essential to talk to the people who care for and admire the focus person, and have an interest in supporting a vision for the person.

The third investment is to spend time with the focus person in a variety of settings and circumstances in order to discover and imagine how the person can be present in community life. This task is essential when the person has very limited community experience and also lacks people in their life who can dream with them about community futures.

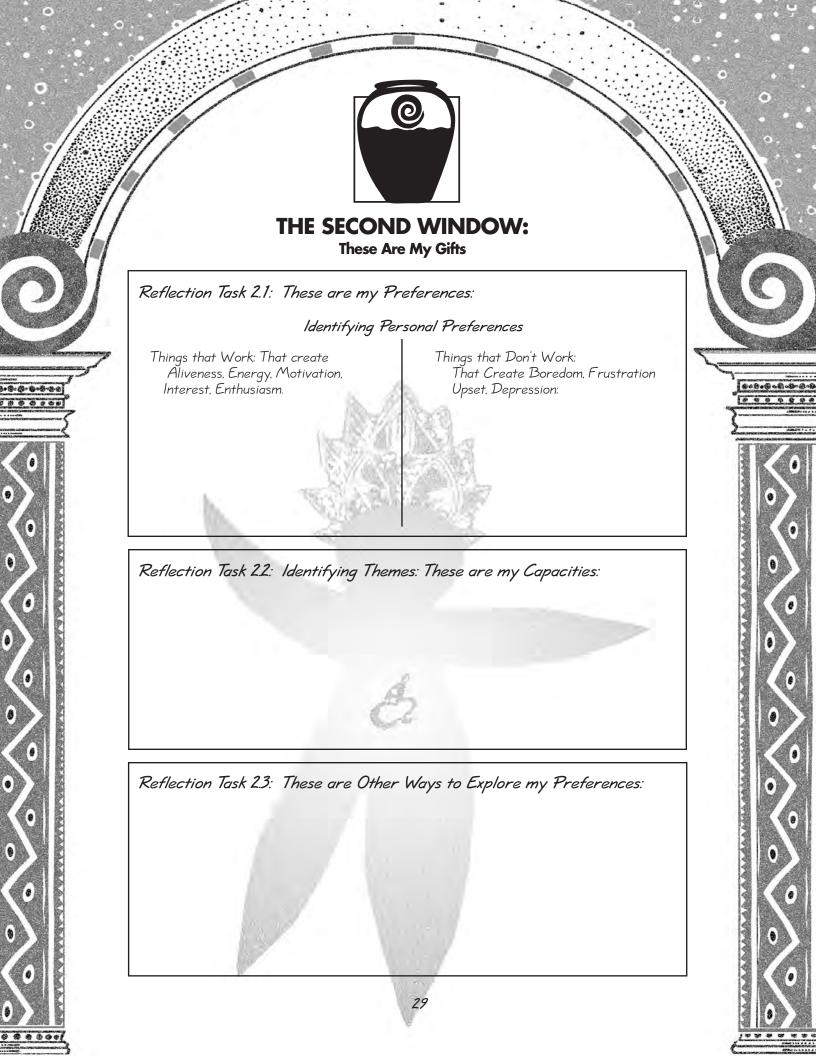
Task 2.3. Finding Ways to Learn More about a Person's Capacities:

Use this reflection task to brainstorm ways to explore and discover possible personal preferences:

Learn more about the person's past, especially when things went well. Learn more about the person's family, their work and personal interests. Spend time in a variety of places with the person. Talk to many people who spend a lot of time with the person.

Try out a variety of volunteer roles and skills.

Imagine that you are this person-how would you most like to spend your day if you were this person? What would be your ideal day, job, or community activity. What would you love to do?





THE THIRD WINDOW: Building Community

Now that we have identified potential allies and potential gifts, we are more prepared to find a wide variety of opportunities in community life in which these gifts can be expressed. To open the third window to community experience, we need to conduct an extensive search in our local communities to find many potential sites, settings and roles in which people can contribute.

We explored a variety of ways to increase the likelihood that people will experience love, mutual concern, and security in their personal lives through the first window related to expanding and deepening relationships. In this section, we consider four additional investments that relate to the public and civic life of people that provide opportunities for belonging, affiliation, contribution, and other valued community roles.

We begin this community search by brainstorming every conceivable opportunity available in community settings, networks, associations, public spaces, and relationship & family life, in which a person can have a role and contribute in the fabric of community life. Any one connection in this fabric increases the probability for additional connections, ties, and experiences of belonging.

When we <u>encourage friendships</u>, we are seeking to introduce people with disabilities to others to strengthen and deepen those relationships. This work requires us to consider a variety of ways to explore common interests between people with disabilities and others.

Community building includes a growing investment in helping people with disabilities be part of the <u>associational life</u> of their communities—the many formal and informal networks in community that form around a specific interest, cause, event, or desire for affiliation. Belonging to associations provides additional ways for people with disabilities to assume citizenship, leadership, and friendship roles within the life of their communities.

Neighborhood connections include many rituals of community life such as: being a regular in stores and restaurants, tipping the bag boy at the grocer, saying hello and waving to each other, exchanging favors and common courtesies, and just having a sense that people are looking out for one another. A full description of community building not only includes, but also celebrates the many small ways that people are seen and known in the daily routine of community life.

The definition of <u>building school</u>, <u>work</u>, <u>and homemaking roles</u> changes over time as people move through the phases of their life from early childhood through adult life into retirement. The "mainstream" represents a set of activities and citizenship roles that might be assumed by the majority of people in a given community during each life phase. Personal Futures Planning helps define "the mainstream" for each person and then design the supports that strengthen the person's participation.

FINDING OPPORTUNITIES IN COMMUNITY LIFE

The reflection task for community building encourages people to find a variety of ways to explore, expand, and strengthen the roles they can assume in four areas of local community life.

1. Encourage Friendships:

- a. What activities bring people with similar interests together?
- b. What are the patterns of reciprocity?
- c. How do people deepen their relationships over time?
- d. What are the informal networks that draw people together?

2. Strengthen Associational Life:

- a. What are the associations in the community? For example:
 - Clubs: service, collectors, men's, women's groups,
 - Service organizations,
 - Civic events,
 - Ethnic associations
 - Sports, health, and fitness groups,
 - Community and personal support groups.
- b. What religious communities have a rich associational life?
- c. What artistic communities have a rich associational life?
- d. What are the places that are the center of voluntary networks?

3. Make Neighborhood Connections:

- a. What are the places of commerce in which people can become a valued consumer or a regular?
- b. What are the commercial or civic settings that are also the center of a voluntary, informal network of people?
- c. What are the opportunities in local neighborhoods for daily interactions, greetings, and acts of neighborliness?

4. Build School, Work, and Homemaking roles:

- a. What are the opportunities to be included in the life of schools; public schools, extracurricular activities, community colleges, universities, night and trade schools, study and interest groups?
- b. What are the job opportunities that relate to specific interests?
- c. What are the opportunities for home ownership, homemaking, and building a home of one's own?



THE THIRD WINDOW:

Building Community

Reflection Task 3.1: These are the Opportunities in my Community

Brainstorming Places that Enhance Citizenship Contributions

Summarize the interests, gifts, qualities, and identities we hope to develop:

List community opportunities: settings, associations, networks, and places where people come together who have similar interests, qualities and values:

Imagine a variety of citizenship roles the person could assume, learn, and contribute in such a network:

I'm a people person: I like to watch people, I'm observant, I like fun-loving people. Places where there are regulars: Irish Pub Coffee shop Barber shop Being a regular: a customer a participant

I love music, especially gospel and Irish Folk music. Music groups: Church choir College choir Irish folk music group Irish group at parade Choir member Group member Carry banner

l love animals, particularly small dogs.

Pet store Dog training school Breeder, groomer Dog trainer, walker groomer

I use a wheelchair and I need people nearby to help me be active and understood. Small accessible settings where the same people are there day after day. Places where people have the time to get to

Being seen as an active citizen

know me.

Friend

Reflection Task 32: Five Action Steps for Getting Started:

ldentify several ideas that seem most appealing and then outline five specific strategies for getting started.

1. Visit the Irish Pub in the town nearby.

2 Talk to Kate at church who sings in the choir about how I could join.

3. Talk to John who had a dog at the dog training school. Find out more about what goes on there.

4. Talk to lady in the neighborhood who breeds dogs.

5. Find out about Irish group participation in local parades and events.



THE THIRD WINDOW: Building Community

Reflection Task 3.1: These are the Opportunities in my Community

Brainstorming Places that Enhance Citizenship Contributions

Summarize the interests, gifts, qualities, and identities we hope to develop:

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List community opportunities: settings, associations, networks, and places where people come together who have similar interests, qualities and values:

Imagine a variety of citizenship roles the person could assume, learn, and contribute in such a network:

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Reflection Task 32: Five Action Steps for Getting Started:

Identify several ideas that seem most appealing and then outline five specific strategies for getting started.

Joseph Moses: A Community Building Legend

Joseph Moses is a legend of his time, in a way that quiet, unassuming people gain notoriety through the strength of their character, the quality of their determination, and the impact they have on others. The legend began in 1990 when Joseph was one of the last people to move out of Laconia State School in New Hampshire, one of the first states to close all institutions thereby ending institutional life for its citizens with disabilities.

When Joseph moved to the community at age 33, he weighed 31 pounds. Having spent most of his life laying on a mat, he challenged creative people to imagine with him a real life in the community. Joseph was fortunate that he depended on a service system that valued relationships as a key to community life. Thus he benefited from the opportunity to make a home with two women, Sue Ann Merrill (Sam) and Mary Drivers, who had worked with him at the institution. As of the year 2000, these three exceptional people are still intimately connected; sharing a home, a lifestyle, a rich network of friends and family, surprising developments, and the joys and challenges of a full life.

When Joseph left the institution, he seemed to enjoy the company of small dogs, music, and being with interesting people, a relatively small list of interests on which to build a life. To know him now is to know a vibrant man who belongs to a local choir and has an extensive collection of CDs and musical instruments. Joseph has participated in a dog training academy and he has owned his own beautiful Collie. To everyone's surprise, he has become an honorary member of the local Harley Davidson Club. He prefers to be driven around in his own 1972 Volkswagen Beetle. He is active and present in local community life in a wide variety of ways.

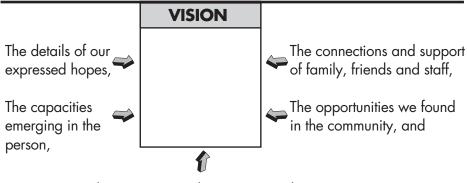
He is equally engaged with friends and family. Joseph, Mary, and Sam are true collectors and therefore appreciate the zeal and commitment that collectors have for each other, one's collections and the ties that deepen over time from sharing such passions. For example, Joseph takes great satisfaction in visiting antique stores and flea markets searching to find one of the many treasures that are appreciated by his many collector friends, such as: music boxes, pencil boxes, owls, snow men, magnets, key chains, nesting dolls, Pez dispensers, Harley Davidson memorabilia, piggy banks, Collie figurines, car models made in the year 1957 (happens to be the year Joseph was born), only to name a few!!!!

This brief profile of Joseph does not convey the depth to which he and Sam and Mary are committed to one another and their wide network of friends and family. Their local postman captures the impact that they have on others as a result of their devotion to each other. After many years of bringing mail to their home, the postman shared the story of a time when he was troubled by many things and was trying to find meaning in his own life. The postman came upon an interaction between Joseph, Mary, and Sam, that was so filled with tenderness and respect that it moved him to change his life. These are the observed and unobserved moments that add up to a lifetime of belonging and contribution, the many moments that add to the legend of Joseph Moses.

THE FOURTH WINDOW: THIS IS MY VISION FOR A POSITIVE FUTURE

A personal vision helps to bring people together and clarify a focus. When we share our personal vision we give voice to the inner desires that may have been silenced while trying to cope with impossible situations. We make it clear to ourselves and others that we want to change things, and we give specific detail to our hopes for the future. Often we have to search and learn about new possibilities and visit others in order to inform and strengthen our vision.

A personal vision is simply a detailed summary of the experiences in life we want to increase, making the most of the opportunities and capacities we found to work with as a result of the reflection tasks we have completed. Therefore, our ideas include:



The resources and opportunities that we can create in service supports.

We use our imaginations to develop ideas for a positive future. We begin the journey of change with our highest ideals knowing that they will inevitably be shaped by the barriers, obstacles, and challenges of everyday life.

The vision generated by this exercise provides a menu of possibilities to pursue in three areas of life. Most people then choose a "main course" priority which is an idea that may take years to realize. It also helps to select some "appetizer" action steps which can be accomplished in the immediate future and can keep us going in the struggle to work toward long-term change.

In this section we provide hints for shaping the content of a personal vision. We suggest characteristics of a positive future worth working for, some suggested categories for thinking about the future, and some ideas about getting started.



"Chances are that the vision will not be reached in a one-year grant cycle, and the funder may or may not appreciate the value of enhanced relationships, increased selfesteem, having fun, making mistakes, and growing together in a struggle to make life better."

- Cathy Ludlum



CONTRASTING IMAGES OF THE FUTURE

Characteristics of Traditional Program Plans:

Goals focus on specific negative behaviors of the focus person to decrease.

The plan identifies program categories and service options that are often <u>segregated</u>.

Many goals and objectives reflect potentially *minor accomplishments* that can be attained within existing programs without making any changes.

These plans will <u>look similar</u> to the plans and ideas written for other people.

These plans will probably <u>not even</u> <u>mention personal relationships</u> or community life.

Characteristics of A Positive Future Worth Working For:

Images of the future contain specific, concrete examples of positive activities, experiences, and life situations to increase.

Ideas and possibilities reflect specific *community* sites and settings and citizenship contributions within those settings.

Some ideas will seem far out, unrealistic, and impractical, and will require <u>major changes</u> in existing patterns such as: funding categories, service options, how staff spend their time, where people live and work, and the reinterpretation of rules and regulations.

These plans will reflect the unique interests, gifts, and qualities of the person, and the <u>unique</u> characteristics, settings, networks, and life of the local community.

These ideas will emphasize creative ways to focus on the development and <u>deepening of personal</u> <u>relationships</u> and community life.

The Next Dream... And the Next! by Cathy Ludlum

Do people with disabilities have the right to dream? My whole life resonates with the answer: YES!

When I was little, my parents had big wonderful dreams about my future, even though they knew I had a significant disability. I used a wheelchair, participated in special education, and attended an adapted camp in the summer. But none of that seemed to matter to my parents. They wanted me to reach as far as I could.

In high school I began to dream of living on my own. With my extensive support needs, which included breathing problems, this was an ambitious goal. After eight years of researching options, I was about to give up. Then on a March evening in 1987, my friends (old and new) committed themselves to making my dream come true. The housing cooperative I live in, as well as the organization that developed it, grew out of my vision and the commitment of these people; but not without a long and sometimes painful birth process.

To say that the work of creating Common Thread Co-op was monumental would be an understatement. It took five years of meetings, visits to potential sites, and all of the delays, pitfalls, and headaches of building a 16-unit complex.

I had to change jobs, which led me to write and speak about my experiences, provide technical assistance to groups involved in housing and personal assistance issues, and work with people one-on-one as they pursued their dreams of independence.

I had to learn how to hire and train assistants, helping me dress, transfer, and when necessary, cough! It has now been ten years since I began hiring personal assistants, and on the whole it has been a good experience.

Over the last seven years, I have lived out my dream of being on my own. My co-op unit is beautiful, accessible, and close to shopping and the highway. Between my ever changing support system and the dynamics of the co-op, things rarely run smoothly. But for the most part I am safe and happy with my life.

I had dreamed the impossible dream and seen it come true, so when I first realized that the center of my life had shifted away from Manchester, and was waiting for me in West Hartford, I was horrified. For ten years, during the five years it took to develop the co-op and for five years after I moved in, I believed that I would live here for the rest of my life.

So it seems almost disloyal to say I now want to live somewhere else. Why do I feel that way? People without disabilities take for granted that they will pursue dreams, accomplish them, and then move on to new heights. Should not the same standard apply to those of us with disabilities? My head says, of course it should. But my gut, which is very much into not inconveniencing others, and being grateful for everything I get, is having a hard time with the next step.

When I timidly mentioned to a few people that I was thinking about buying a house, I was afraid they would feel that their self-sacrifice for the co-op was in vain. Instead they said, in different ways, that we all grow out of things and dream new dreams. They are eager to walk with me as I reach for the stars yet again.

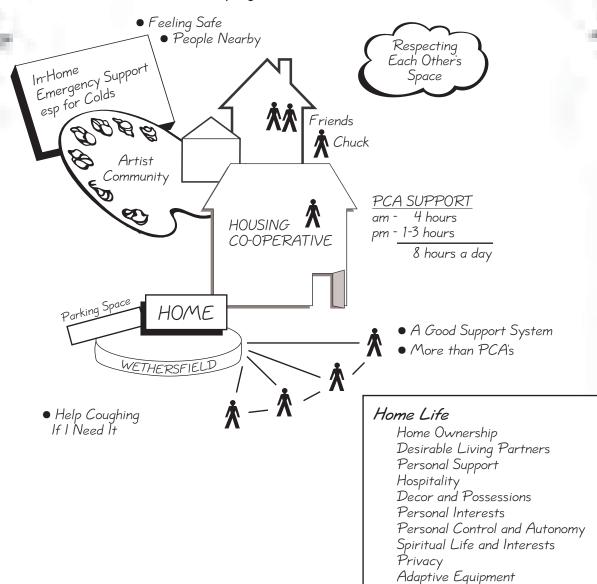
Communitas Communicator, February 1999



THE FOURTH WINDOW: This is My Vision

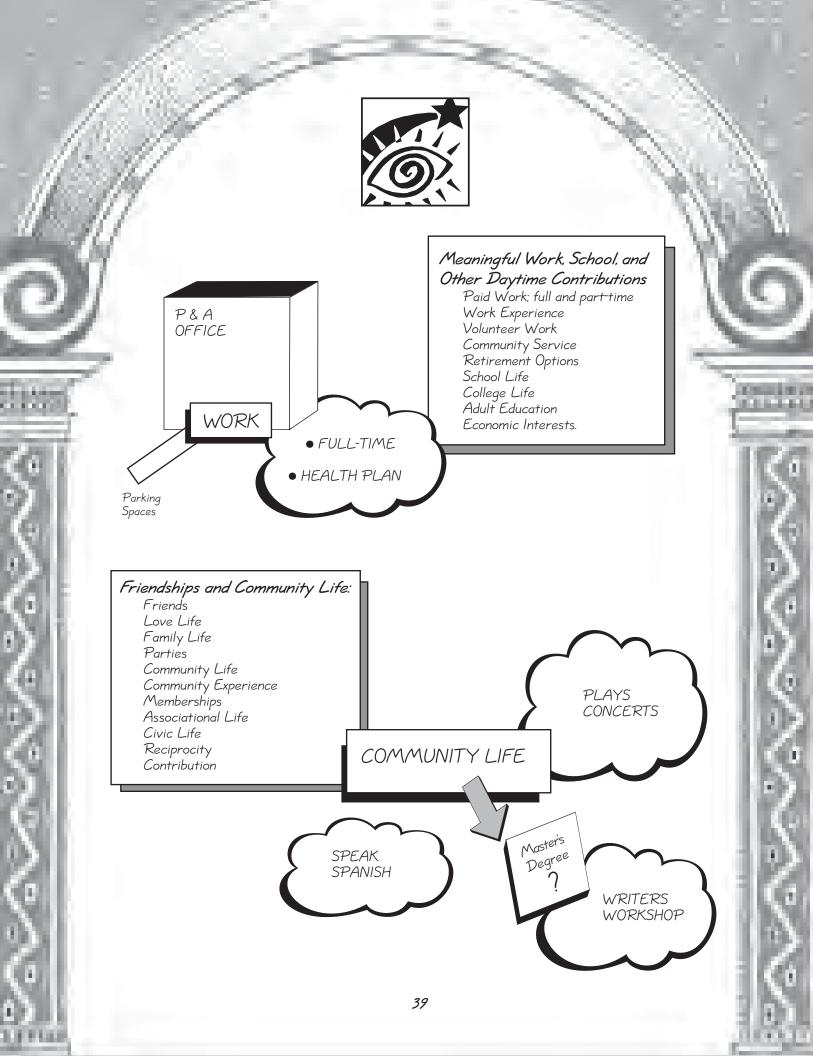
DOMESTIC:

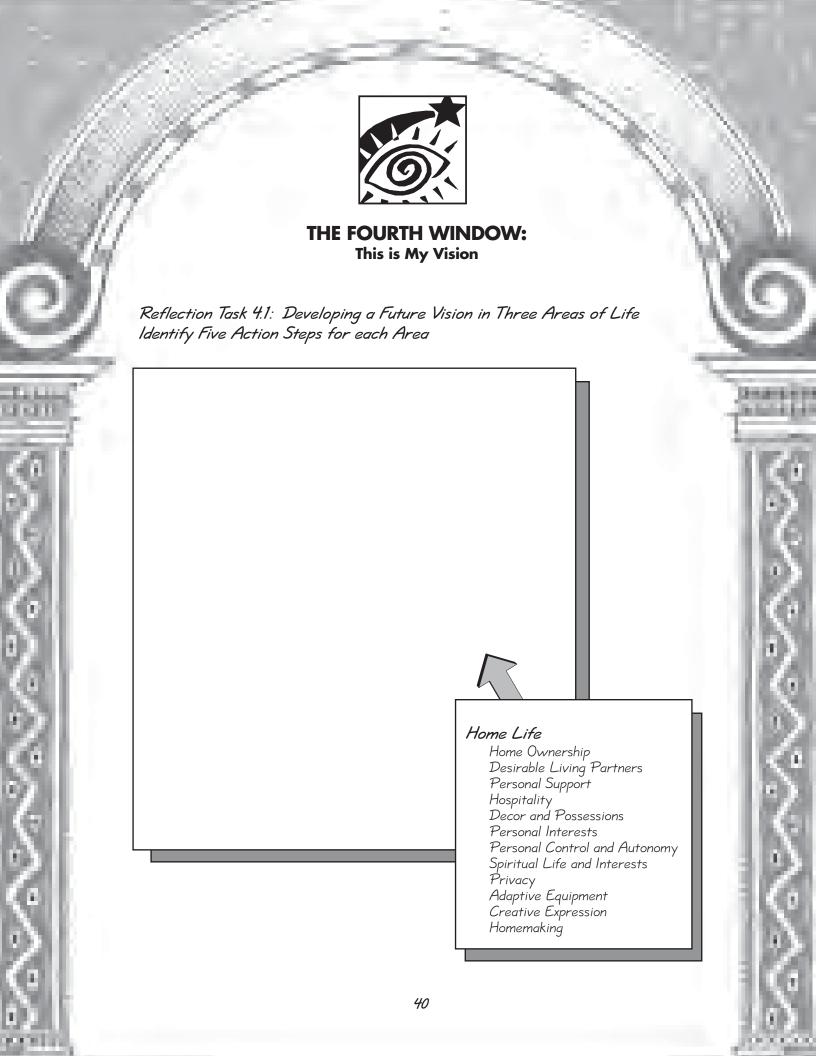
Reflection Task 4.1: Developing a Future Vision in Three Areas of Life

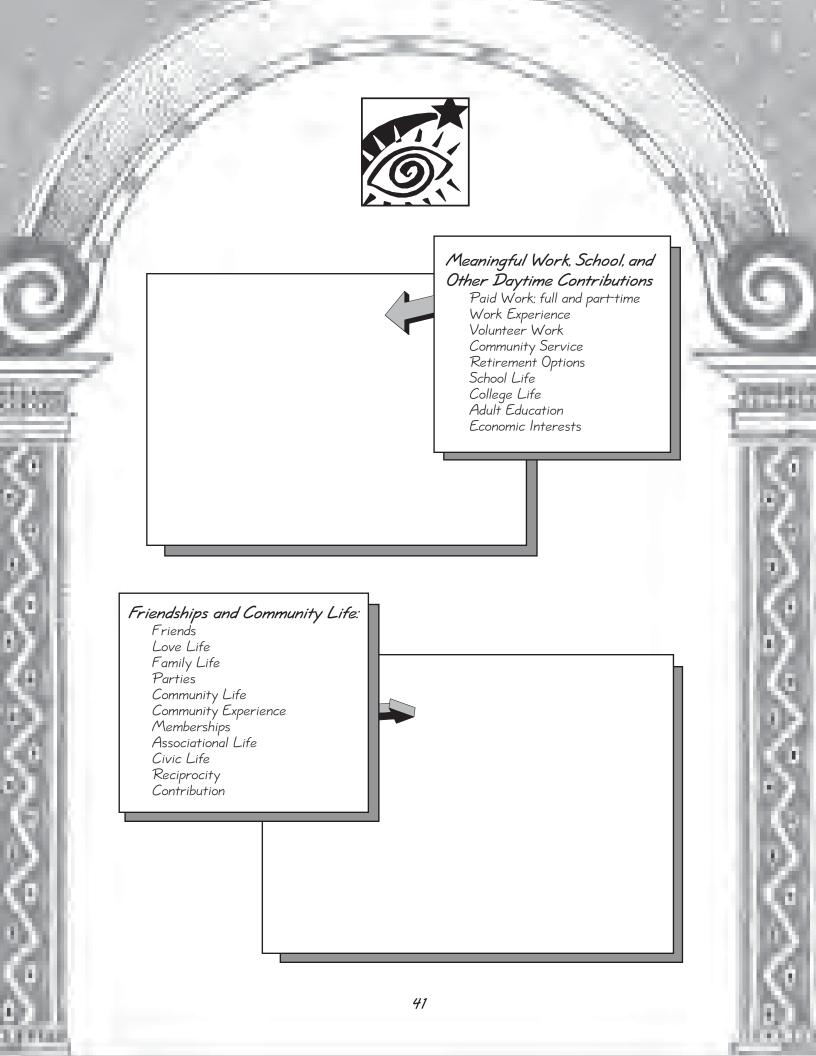


Creative Expression

Homemaking









THE FIFTH WINDOW:

This Is My Weekly Schedule; Finding the time, energy, and resources to turn ideals into reality.

We are what we repeatedly do. Excellence, then , is not an act, but a habit.

-Aristotle

Once we have new ideas for a different future, we take the first step toward the vision by starting somewhere to find the time, energy, and resources to integrate new ideas into our daily lives. The realities of our current lives and the limitations of existing supports and services usually damper if not extinguish our enthusiasm for change. Window Five challenges us to put our ideas into action by scheduling new opportunities into our daily and weekly routine, and by finding the personal and organizational resources we need to support these experiences over time.

In this day and age, anyone seeking life change is challenged to find the time, energy, and resources to do so. People with disabilities and their families in particular are challenged to just get through the day, to maintain consistent personal assistance and support, to acquire the money needed for the most basic expenses, and to overcome the physical and social barriers that limit new community experience.

I am continually sobered by the difficulties people encounter when they try to put their vision for a different life into reality. Heroic efforts are required to accomplish the first steps and then maintain new investments over time. The three exercises in this Chapter support people to translate good ideas into daily practice. You will:

- 1. Choose one or two good ideas that are the seeds of a new future.
- 2. Plant those seeds into a weekly routine, even if only for 15 or 30 minutes a week.
- 3. Obtain the personal, natural, and organizational support required to sustain new activities over time, and to expand these activities into increasing contributions and life-styles.

Where there's no gardener, there's no garden.

Most of us think it would be great if we could just put our gardensor our lives—on automatic and somehow get the quality-of-life
results we desire. But life doesn't work that way. We can't just toss
out a few seeds, go ahead and do whatever we want to do and then
expect to come back to find a beautiful, well-groomed garden ready
to drop a bountiful harvest of beans, corn, potatoes, carrots, and peas
in our basket. We have to water, cultivate, and weed on a regular
basis if we're going to enjoy the harvest. The difference between
our own active involvement as gardeners and neglect is the
difference between a beautiful garden and a weed path.



Stephen Covey First Things First

Family Time versus Organizational Time

Finding time during the week is particularly difficult when family clocks seem to tick much faster than those within organizations. In other words, people with disabilities and their families spend a lot of time waiting for promises of support that take forever for organizations to provide. It is no wonder that people are reluctant to hope, and to believe that organizations will come through for them, and no surprise that people become angry or depressed about the time it takes for others to respond to their most basic needs.

The seeds of change can wither from waiting, and the seedlings of hope will wilt from the absence of care. Hope will not grow in a desert of isolation, neglect, and discrimination. Everyone involved in life building via a futures plan must make an effort to respond to new ideas, and to find the support to nurture these developments over time. People with disabilities and their families must do whatever they can to begin new ideas, and to work with natural supports to take action. People who work within organizations must do whatever they can to respond immediately, and to develop the options to maintain effective support over time. Everyone involved must work together to find even 15 to 30 minutes a week to begin and sustain new possibilities.



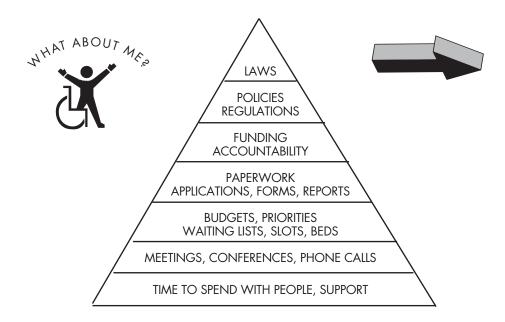
First Things First: Organizational Change

We can succeed only by concert. It is not, "Can any of us imagine better?" but, "Can we all do better?"

Abraham Lincoln

Organizations are like huge reservoirs of resources that can be used to provide the personal supports needed so that people with disabilities have real lives. Organizations are challenged to create channels for the resources to flow to the people who define what they need. Organizations, and the people who work for them, are often so overloaded that there is little time left to listen to people, support them to dream, and most importantly, respond to those dreams. Organizational reality looks like an impenetrable pyramid to people with disabilities and families who depend on the time and energy that is locked inside this storehouse.

ORGANIZATIONAL REALITY

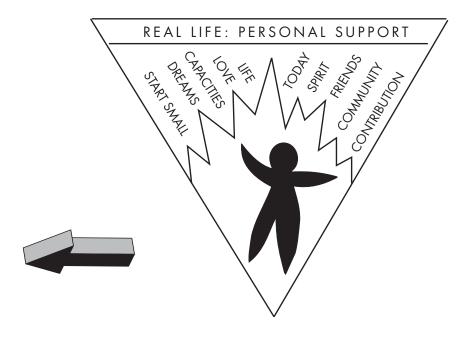


Can We Work Together?

Organizations are challenged to respond to the personal realities of people with disabilities and to therefore channel more time, energy, and attention toward the lives of people. As Abraham Lincoln reminds us, we can't expect to ask people with disabilities to imagine better unless we are all prepared to do better to change organizational life to be more responsive to people. An effective person-centered organization finds multiple ways to put the contributions of people with disabilities first on the agenda, and then redirect resources toward facilitating those contributions. We have to work in concert at many levels so that these potential conflicting realities are complementary.



PERSONAL REALITY





There are many Roses in Spanish Harlem: Dorian's Community and Organizational Garden

Dorian's personal futures plan began in 1994 during his last year of high school. Because of the bleak options for Doran's future after graduation, Doran's teachers, family, and adult service agencies worked hard to get him a job and establish other meaningful community experiences. Six years post graduation, Dorian is still working at the same grocery store even though it has changed management and names three times.

In addition to his job, Dorian is involved in his community in a variety of ways. He takes a community art class at a local art studio. He is a regular at a local billiard club and bowling alley. He checks out books at the library and frequents his favorite pizza shop. His is a valued and beloved member of his church, and from time to time he helps fold and distribute bulletins for the congregation. He is deeply connected to the life of his community, apartment building, family, and extended family network.

Dorian needs continuous personal support to sustain his involvement in all of these activities. He benefits from the support of a number of adult service agencies who work together on his behalf. His life is equally rich in natural supports, as he and his mother are intricately connected to their housing project and neighborhood.

Dorian's mother is a true gardener. She has personally cultivated the community flower and vegetable garden that grows outside of their apartment building. In a similar fashion, she cultivates a fertile network of community support for Dorian that sustains him 24 hours a day, and gives her the freedom to "do her thing."



DORIAN'S LIFE

The Person

- Dorian is a warm & sensitive person who others want to be close to
- While he does not speak & refuses to use his communication board, he expresses preferences clearly
- A stylish & meticulous dresser he loves looking good!

M

HA

JP

HA

work

HA

JP

HA

JP

HA

JP

- Loves music, cars & motorcycles
- Loves being a member of his family
- Needs 24-hour support

The Community

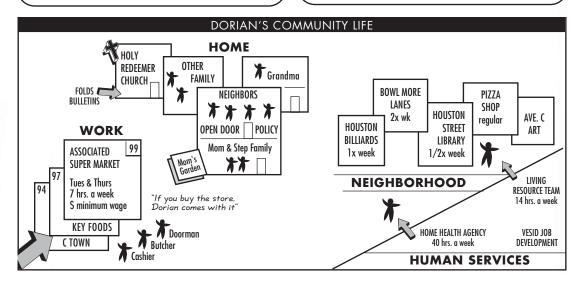
- Dorian has worked in the supermarket for over
 5 years
- The butcher, the cashier & the doorman look out for him
- He is a regular at the billiard hall, bowling alley, Ave. C Arts & Crafts Studio & Houston St. Library
- Member of an auto club & associate of a motorcycle club
 - Has a bus pass MTA
 - A regular church member

The Family

- His mother engages a huge extended family who live nearby along with "open door" neighbors who live in the project
- His mother grows a garden in front of the building.
 Dorian helps her. Everyone knows him.
- Grandmother is in the next building
- Step-kids are supportive
- Everyone in family understands Dorian's communication

The System

- School set up job in grocery store last year
- VESID provided long-term supported employment dollars
- Home health agency provides 40 hrs/week support person (HA)
- Job Path Living Resource Team provides 14 hrs/ week through day & res hab (JP)
- Tom, a former teacher & Ralph, a rehab worker, have been with Dorian for over 5 years. Maria, home attend, has known mother for 30+ years





THE FIFTH WINDOW: This Is My Weekly Schedule

Reflection Task 5.1: Choose Two or Three Ideas that are the Seeds of a New Future

Getting Started

Pick two or three ideas that seem most interesting.

Outline five specific strategies for getting started.

Identify Supports

When and where can these ideas begin?

How will people get there?

Who will support them to be successful?

What are the opportunities to build natural supports?

How can the family help?

How much time is required of a paid staff person?

What are the skills required of these roles?

What are the best ways to teach these skills?

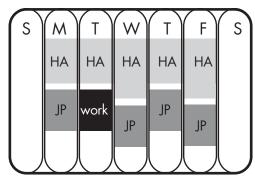
What are the opportunities to build understanding

between people?

What adaptations are required in the environment

to build success?

Reflection Task 52: Plant those seeds into the weekly routine.



Reflection Task 5.3: Obtain the personal, natural, and organizational supports necessary to sustain action over time. Brainstorm five action steps for getting what you need from organizations.

- 1. Reorganize the paraprofessional schedule to support Dorian on the job 10 hours a week.
- 2 Work with the home health care agency to use the in-home worker as a job coach after graduation.
- 3. Work with an adult service agency that provides a "day program without walls" to pick up the supports after graduation.
- 4. Get the paperwork completed to establish a connection to that agency.
- 5. Work with Voc Rehab to pay for supported employment training.



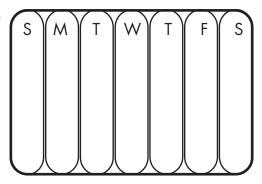
THE FIFTH WINDOW: This Is My Weekly Schedule

Reflection Task 5.1: Choose Two or Three Ideas that are the Seeds of a New Future

Getting Started Identify Supports

Reflection Task 52: Plant those seeds into the weekly routine.

Do a schedule



Reflection Task 5.3: Obtain the personal, natural, and organizational supports necessary to sustain action over time. Brainstorm five action steps for getting what you need from organizations.



THE SIXTH WINDOW: What do I need to learn?

If I already knew what I needed to know,
I'd already be where I am trying to go.

Now that we have a vision we return to the realities of daily life. When we pursue a personal vision of community life, it almost never fits what current systems have to offer. We may also encounter more rejection than acceptance in community life. We may feel that our support network is too weak to make a difference. We may feel that we do not have the strength, the energy, the money, or the courage to rise up to the challenges that our vision presents.

Every person with a disability who lives with a vision must face these struggles. While the specifics of the struggle may vary, people often find that they must learn more about the systems that provide supports, the communities in which they live, the people that they depend on, and themselves. We prefer to think of this struggle as a learning opportunity. We gain power in the face of the obstacles that block us through learning and taking action with others.

The tension between our ideals and reality can be overwhelming and painful. This discomfort seems to push us toward two extremes; we deny reality and live in our fantasy vision, or we feel trapped by our despair about the realities we face. Either extreme leaves us paralyzed. Therefore, we work to find the energy we need for change by balancing these opposites; hope and despair, vision and reality, the future and the present, celebration and disappointment. We seek to use our anger and our vision to motivate us toward new solutions and alternatives.

When we begin this planning process, people often feel that the obstacles in life seem to far outweigh the opportunities. This is why people feel stuck, oppressed, depressed, and angry. Sadly, the human service agencies that people depend on may hurt people rather than help by adding to the list of headaches. Opportunities in the community are hard to see because so many people with disabilities have been isolated. The strength of our personal network is often untested because we have been afraid to ask for help. Our own personal power is often untapped because no one believed in us.



This window of change helps us analyze the barriers we face and find some new opportunities for learning. Use this reflection task to identify barriers and additional action steps.

"For me, accepting help was part of the entire acceptance process. I was raised to believe that you should keep your troubles to yourself and handle your problems independently. And generally, one can endure a short-term problem and go on. However, when your life dictates one challenge after another, every day can be a struggle without relief in sight."

Laurie Allan



WHAT IS MY STRUGGLE? LISTING OBSTACLES AND OPPORTUNITIES

In this reflection process we seek to acknowledge our obstacles, while also learning more about the opportunities that may be available to us. When the opportunities in life begin to outweigh the obstacles, then we begin to feel more hope.

In this reflection task we encourage people to name the struggles they face, clarify new opportunities for learning, and explore ways to take action to change their situations.

WHAT DO I NEED TO LEARN? FINDING A FOCUS FOR ACTION

Once we have a clear idea of where we want to go, and a growing understanding of the obstacles we face, we often need to learn more about how things work in our communities, and systems. This learning process helps us find and create new opportunities and resources to help us realize our hopes.

This learning process is hard work because we must come face to face (once again) with the absurdities and complexities of most human service systems. We must confront (once again) the rejection and misunderstanding we often encounter in our communities. Additionally, we may seriously doubt our own ability (once again) to do this work while we also cope with the challenges of daily life. All the more reason for a formal or informal support network to help us sort through the complexity we face, stay focused on the future, and care with us in the present.

People often need to learn and explore in the following areas. The sixth window provides a list of common questions and points for exploration.



THE SIXTH WINDOW: What do I need to learn?

Task 6.1: This is my struggle:

Opportunities

- I have several people in my life who believe in me
- I have connections to a church community
 I can deepen
- I have some volunteer experiences that could become paid work

Obstacles

- There is no funding for the amount of personal assistance I need
- I lack transportation to community experience
- I'm afraid to try out some of these ideas

Reflection Task 62: What Do I Need to Learn?

What do I need to learn about my community?

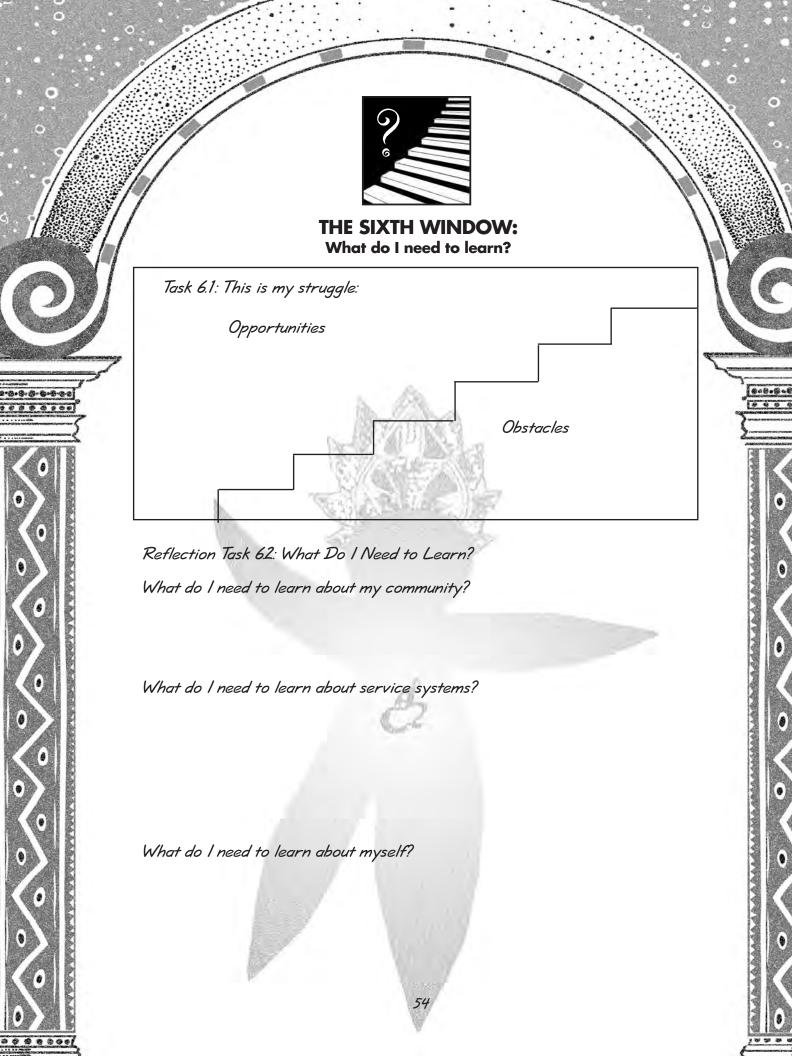
- What are the meeting times and schedules of possible networks, associations, groups, or places I would like to explore?
- Do I know anyone who has connections within these groups or places?
- Who are my neighbors? What are they interested in? How could I help them?

What do I need to learn about service systems?

- What supports do I currently receive that work for me?
- Where are the gaps? What do I need that I do not have now?
- What would fix the problem? Where can I go visit people who have solved this problem or bridged this gap? Who can I call?
- Who could help me develop a concrete proposal for what would be better?
- Are there other groups working on the same problem that I could join?
- How could I arrange to give my proposal to someone who will listen?
- Is there pilot funding available to help me implement my idea?

What do I need to learn about myself?

- Who can I visit with a similar disability who has achieved a similar goal?
- What would it take for me to ask them to be my mentor?
- Can I really talk to someone about my fears and worries?
- How am I doing in asking for help from others?
- Can someone help me get more organized?
- Do I need help in breaking up these big tasks into manageable pieces?



The world to which we relate is a problem to be worked on and solved

"People are designed to be a Subject who acts upon and transforms the world, and in doing so moves towards ever new possibilities of a fuller and richer life both individually and collectively. This world to which we relate is not a given reality which we must accept and to which we must adjust; rather it is a problem to be worked on and solved. Every human being, no matter how submerged in the "culture of silence" he may be, is capable of looking critically at his world in a dialectical encounter with others. When this happens, people are no longer willing to be mere objects, they are more likely to decide to take upon themselves the struggle to change the structures of society which until now have served to oppress them. The reality of oppression must be perceived not as a closed world from which there is no exit or door, but as a limiting situation which can be transformed."

Pablo Freire

A Reflection on Organizational Change Using Person-Centered Planning

We wrote this poem to express what we have learned from changing our organization using person-centered planning. We realized how much we learned when we see things from the heart. We learned why we should not isolate people, and that we can make a difference whoever we are.

"Person-Centered support is like a house built on a firm foundation with the framework of supporting relationships, covered with the insulation of friendships that weather the storms. It creates an individual house which is protected under the roof of community."

From the Star Choices Leadership Change Team Facilitated by Gillian Grable in Macon, Georgia.

CONCLUSION



Life building encourages us to see people with disabilities as people with a sacred Self that deserves to be expressed and strengthened in the process of living. This Self cries out for freedom, particularly when people are oppressed by stereotypes, segregation, poverty, limited opportunities, and lack of understanding.



Personal Futures Planning provides a variety of tools to help people break the silence imposed by inner and outer limitations, and to express their hopes for themselves and their community. The voice for change is strengthened by building relationships with others who value people, see them as equals, and agree to work together to create new opportunities. Empowerment occurs as people are related to others who believe in them.



The Self is strengthened when people are reminded time and time again of their gifts-their unique abilities, life experiences, cultural identities, and qualities that influence who one is, and who one is meant to be in community life.



Life building assumes that every person has a unique and valued contribution to make in healthy community life. If this is true, then we are challenged to find multiple opportunities for each person to strengthen their presence and participation in community life. This task challenges us to strengthen the fabric of local community life so that people with disabilities can be active members.

As opportunities in community life emerge and unfold, so does one's personal vision for life fully lived. What begins as a seed of hope begins to ripen into a full grown and detailed focus for richer life in an increasingly healthy community.

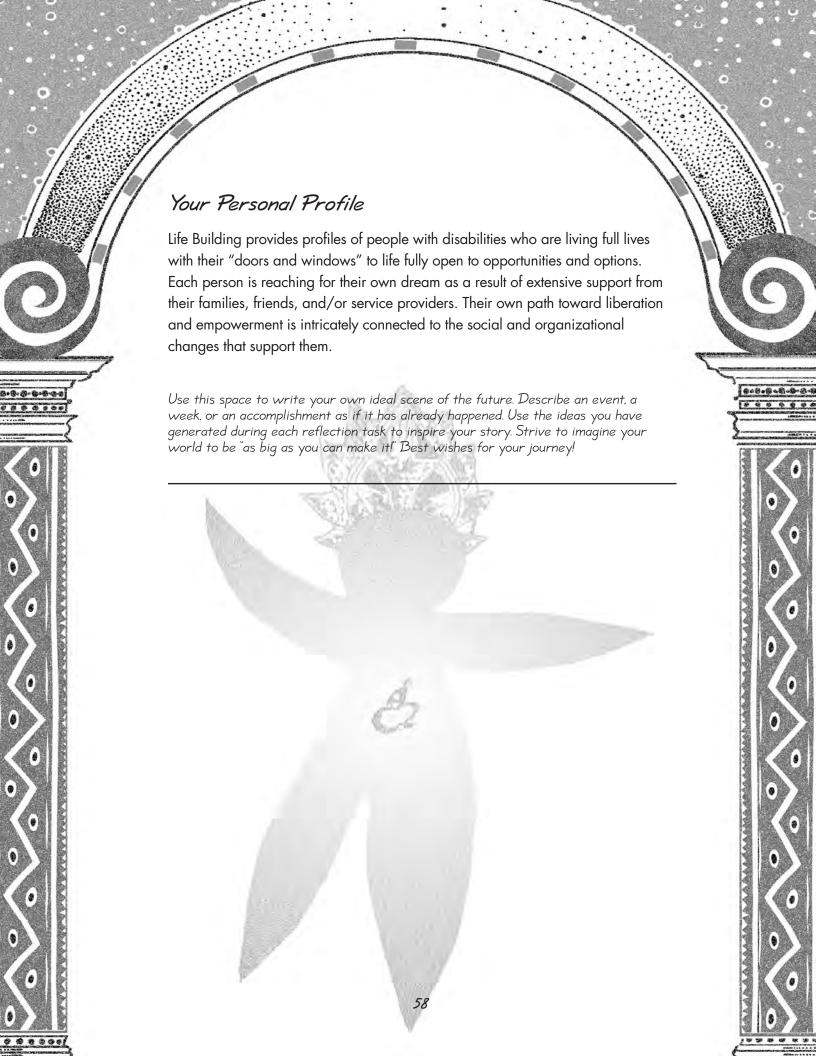


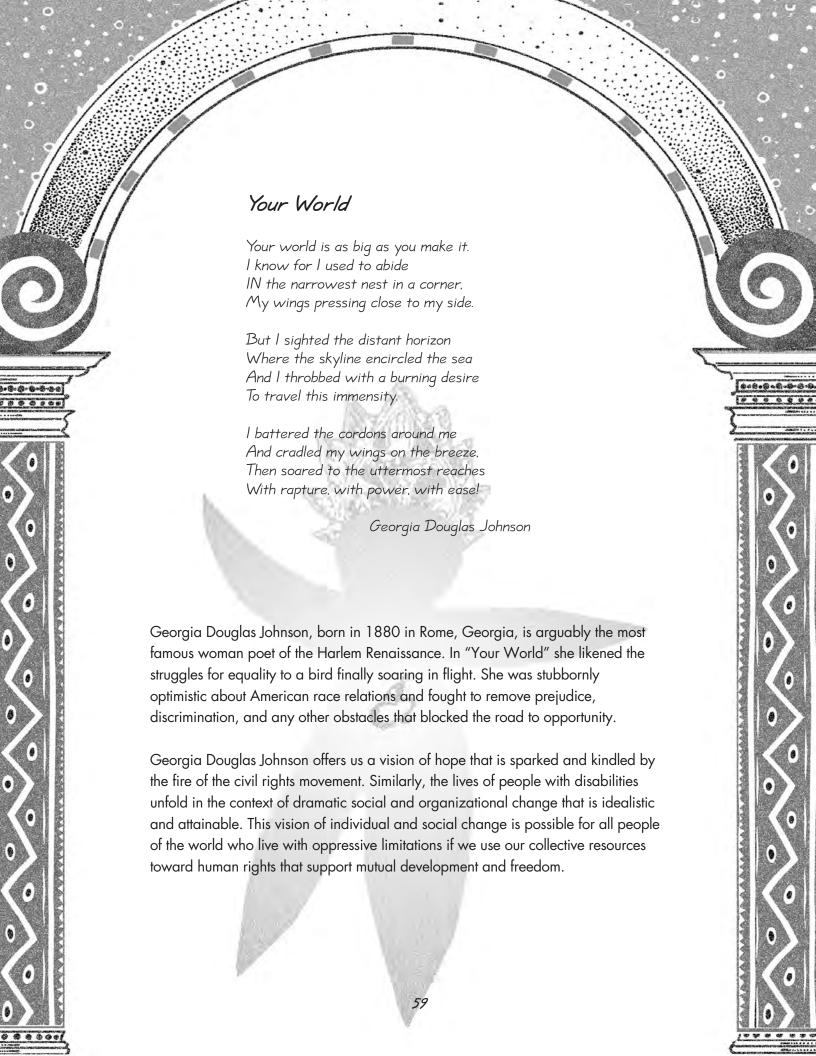
Throughout this journey, we continue to confront personal, community, service system, and political limitations. We might easily fall back into despair, hopelessness, and silence in the shadow of these looming limitations, yet we join with others to change these obstacles in whatever way we can. But because the magnitude of these limitations may still leave us frozen, enraged, depressed, or detached we seek to channel the energy hidden in these dark places into our work toward personal and social change.



In coming full circle back to hope we change our world, even if in only some small way. Thus, we start the cycle anew, and slowly as our Self emerges, so also is the fabric of our community strengthened. Through small steps taken thoughtfully together with others we bring change to the world. This is then the challenge and goal of life building.







REFERENCES RELATED TO CAPACITY WORKS ASSUMPTIONS

Listening to Hope: Opening the Door

Achterberg, Jeanne. <u>Imagery in Healing</u>. Boston: New Science Library Shambhala, 1985.

Friere, Pablo. Pedagogy of the Oppressed. New York Continuum, 1982.

Ludlum, Catherine. <u>Tending the Candle: A Booklet for Circle Facilitators</u>. Available at The Community Place, 730 Main Street, Manchester, CT, 1993.

Kent, Deborah and Quinlan, Kathryn. Extraordinary People with Disabilities. New York: Grolier Publishing, 1996.

Malone, PT, and Malone, TP. <u>The Windows of Experience</u>. New York: Simon and Schuster, 1992.

Expanding and Deepening Relationships

Amado, Angela. Friendships and Community Connections between People with and without Developmental Disabilities. Baltimore, Paul Brooks Publishing Co., 1993.

Beeman, Pat and Ducharme, George. <u>One Candle Power</u>. Available from the Community Place, 730 Main Street, Manchester, CT, 1989.

Lyle, Connie. <u>To Boldly Go. . . Individualized Supports for Georgians with Severe Disabilities</u>. Available from the Developmental Disabilities Council, 2 Peachtree Street, 3rd Floor, Suite 210 Atlanta, GA 30303, 1992.

Recognizing and Developing Personal Preferences

Alexander, Christopher. <u>The Timeless way of Building</u>. New York: Oxford University Press, 1979.

Bolles, Richard. The New Quick Job Hunting Map. Ten Speed Press, 1990.

Bolles, Richard. What color is your Parachute? Ten Speed Press, 1993.

Briggs Myers, Isabel. <u>Gifts Differing</u>. Palo Alto, CA: Consulting Psychologist Press, 1985

Keirsey, David, and Bates, Marilyn. <u>Please Understand Me</u>. Del Mar, CA: Prometheus Nemesis Book Company, 1984.

O'Brien, John. <u>A Guide to Life-style Planning</u>. <u>A Comprehensive Guide to the Activities Catalog</u>. Baltimore; Paul Brooks Publishing Company, 1987.

Starhawk. <u>Truth or Dare</u>. San Francisco: Harper and Row, 1987.

Steinem, Gloria. Revolution from Within. Boston: Little, Brown and Co., 1992.

Building Community

Center on Human Policy. <u>Annotated Bibliography on Community Integration</u>. Available from Syracuse University, 200 Huntington Hall, Syracuse, NY 13244, 1990.

Gretz, Sharon, Editor <u>The Common Thread</u>. Available from The Community Building Project, 17 Eisele Road, Cheswick PA 15024. Published quarterly.

Kretzmann, John, and McKnight, John. <u>Building Communities from the Inside Out</u>. Center for Urban Affairs and Policy Research. Northwestern University, and the Department of Rehabilitation Services, State of Illinois, 1988.

Moses, Joseph, Merrill, Sam, and Divers, Mary. <u>Lives of Our Own</u>. A video documentary of Joseph Moses. Available from: Lives of Our Own, 898 North Main Street, Laconia, New hampshire 03247. Phone: 603-524-8570.

Wetherow, David. <u>The Whole Community Catalog</u>. Available from The Community Place, 730 Main Street, Manchester, CT, 1991

Building a Vision for a Positive Future

Hilman, James. <u>Re-Visioning Psychology</u>. New York: Harper Colophon Books, 1975.

Ludlum, Catherine. <u>Stories of the Heart: Inclusion Taking Hold Connecticut</u>. The Community Place, 730 Main Street, Manchester, CT, 1991.

Forest, Marsha, and Pearpoint, Jack. <u>Everyone Belongs: Building the Vision with MAPS- The McGill Action Planning System</u>. Toronto, Center for Integrated Education. 1990.

Mount, Beth. <u>Person-Centered Planning</u>. Available from Capacity Works, 25 West 81st Street, New York, NY, 1992.

Learning from Our Experience

Freire, Pablo. Pedagogy of Hope. New York: Continuum, 1994.

Macy, Joanna. <u>Despair and Personal Power in the Nuclear Age</u>. Philadelphia: New Society Publishers, 1983.

Clinton, Catherine. <u>I, Too, Sing America</u>; <u>Three Centuries of African American Poetry</u>. Boston: Houghton Mifflin Company, 1998.

NOTES:



THE ART OF CAPACITY

For 25 years, my professional work has been based on the belief that people with disabilities are valuable members of our human community. For just as long, I have had an artistic interest in graphics, leading me to incorporate group graphics

into the process of creating life plans with people. I also have a passion for textile arts, creating my own artwork using fabrics from throughout the world. The Art of Capacity brings these themes together in artworks which express the path of empowerment for people with disabilities, and others who are finding their way toward meaningful lives and responsive communities.

Throughout time, people from all cultures have used images and symbols to communicate with one another...make meaning of their experience...represent their inner and outer worlds...and map life journeys. I draw on these universal symbols – the star, the spiral, the house, the woman with a basket – and combine them with text to tell stories of hope and freedom, personal and social change.

My interest in this work is inspired by the courage and determination of people with disabilities and the families who work with them to develop optimistic ideals in the face of limiting constraints. It is my hope that each image here will serve as a reminder of the capacity that we have, both individually and together, to overcome challenges, celebrate our differences as well as our similarities, build lives of meaning and worth, and create communities that encourage and nurture our dreams.

BETH MOUNT