

**From My Perspective... How Did The Day Shape Out?**

**Date:**

**WHAT I FELT WORKED BEST  
TODAY WAS...**

**WHAT WAS EITHER NEW LEARNING OR AFFIRMED  
LEARNING FOR YOU?**

**WHAT DIDN'T WORK**

**MY OVERALL REACTION TO  
, TODAY, IN ONE WORD IS...**

**HERE'S AN IDEA  
OF HOW TO  
IMPROVE THE  
DAY...**

**OTHER RECOMMENDATIONS FOR FUTURE  
SESSIONS...**

# Consumer Directed Services and Supports

9am-4pm

Unscramble exercise

Welcome/greetings

- Introduction
- Brief comments
  - Video "Jim and his Parents"
  - Update on Jim's life
  - Rock Jar Demonstration

What is Self-Determination?

## **Break**

National Efforts - Video "Individual Budgets"

Minnesota Efforts

## **Lunch**

Group exercise

Building a Life

1. Relationships
2. Dreaming
3. Budget
4. Planning
5. Getting Started
6. Making it Happen
7. Keeping it Going

## **Break**

Myths and Realities

Risk, Choice, and Doughnut

Wrap Up

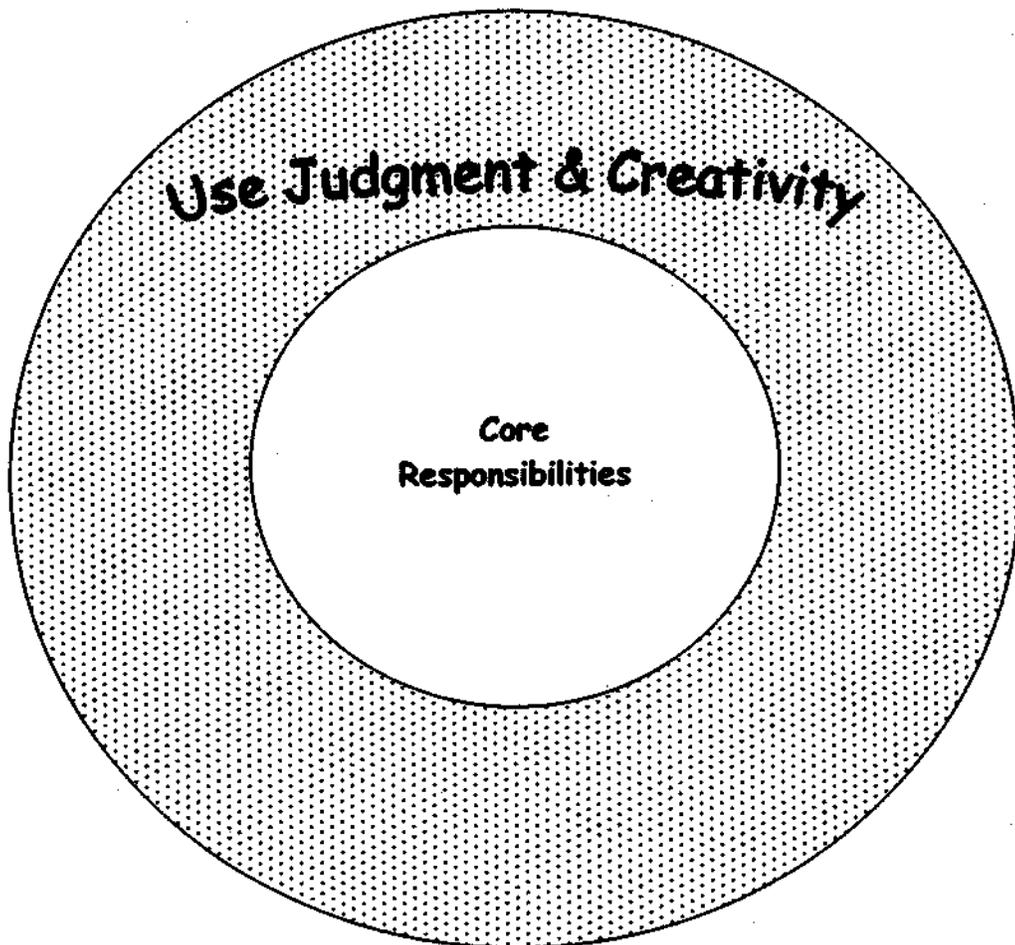
# Rock Jar Exercise

A philosophy professor stood before his class and had some items in front of him. When class began, wordlessly he picked up a large empty mayonnaise jar and proceeded to fill it with rocks, rocks about 2" in diameter. He then asked the students if the jar was full? They agreed that it was. So the professor then picked up a box of pebbles and poured them into the jar. He shook the jar lightly. The pebbles, of course, rolled into the open areas between the rocks. He then asked the students again if the jar was full. They agreed it was. The students laughed. The professor picked up a box of sand and poured it into the jar. Of course, the sand filled up everything else. "Now," said the professor, "I want you to recognize that this is like your life. The rocks are the important things - your family, your partner, your health, your children - anything that is so important to you that if it were lost, you would be nearly destroyed. The pebbles are the other things that matter like your job, your house, and your car. The sand is everything else. The small stuff."

"If you put the sand into the jar first, there is no room for the pebbles or the rocks. The same goes for your life. If you spend all our energy and time on the small stuff, you will never have room for the things that are important to you. Pay attention to the things that are critical to your happiness. Pay attention to the things that are critical to our happiness. Play with your children. Take time to get medical checkups. Take your partner out dancing. There will always be time to go to work, clean the house, give a dinner party, and fix the disposal. Take care of the rocks first - the things that really matter. Set your priorities. The rest is just sand.

# Inside a Person's Life

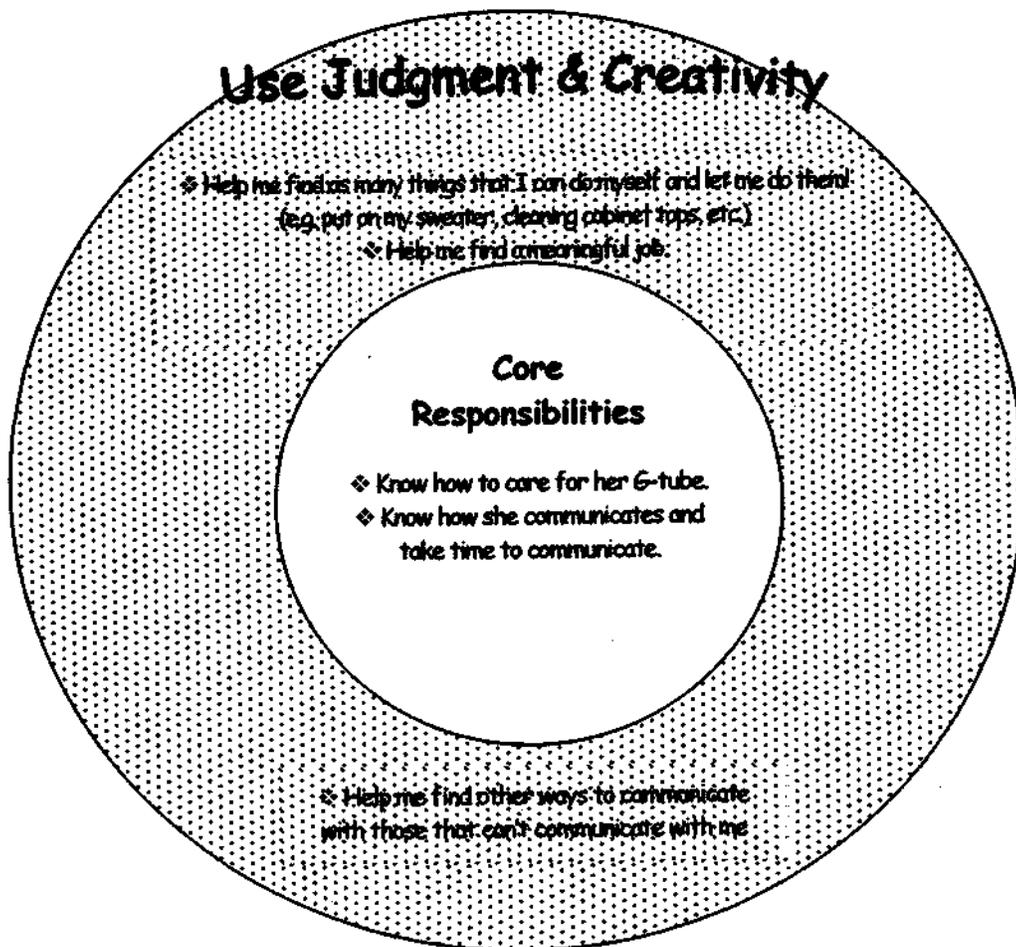
Not Our Responsibility



# Inside Elizabeth's Life

## Not our paid responsibility

- Don't interfere with the private time I spend with my friends. I don't need an interpreter, they *are*. my friends and we communicate.
- Don't interfere with how I choose to handle the love interests in my life, I will ask for any advice I want and from whom I want.



# The Origins of Self-Determination

The concept of self-determination grew, for the most part, out of the Independent Living movement in the last part of the 1960's. Ed Roberts, a student at the University of California at Berkeley protested the university policies regarding access and housing. At first they were known as "the rolling quads," for eventually formed the first Center for Independent Living (CIL). Today there are more than 400 centers throughout the United States.

The 1950's and 1960's were also a time of great social changes in the United States. The Civil Rights Act of 1964 was followed by the women's movement demanding equal rights and equal pay. Ralph Nadar led the consumer movement demanding product safety, truth in advertising, and more government oversight for potentially harmful processes.

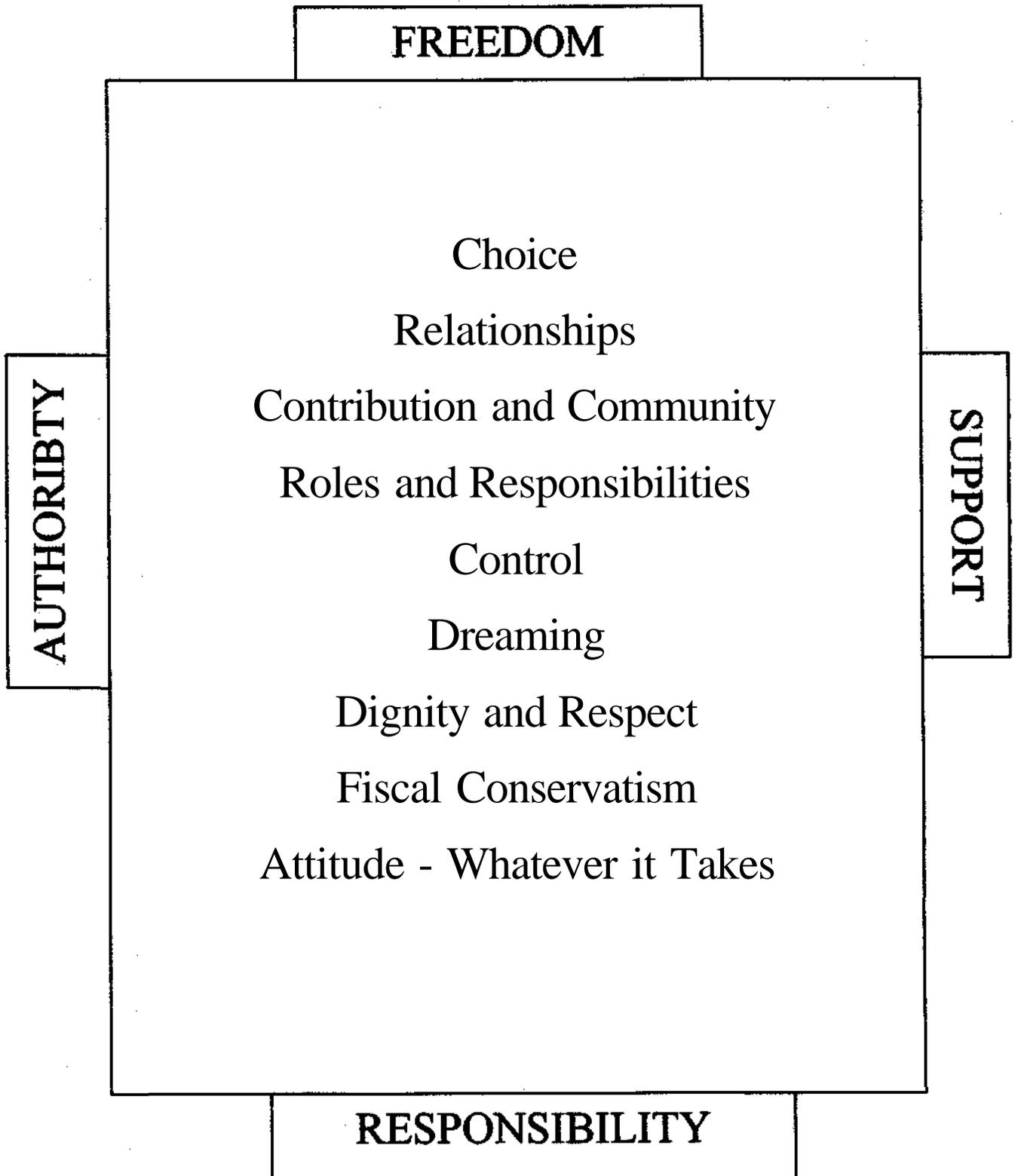
Africans refer to self-determination as part of the celebration of Kwanzaa. In a global sense, self-determination is a timeless fundamental aspect of natural law and natural rights. The Bill of Rights encompasses self-determination as one of it's founding principles.

People with disabilities have come together to ask theses same age-old questions. Shouldn't all people, including those with disabilities, have the rights of full citizenship? People want greater control over their own lives and over their own services. They want choices defined and limited only by their own creativity. They are willing to take responsibility for changing attitudes, eliminating barriers and coaching their peers through a new concept: organization run by and for people with disabilities. In the past three decades, people with disabilities and their allies have joined together to promote the passage of a series of laws to level the playing field.

During the same years, a grassroots family movement was emerging around the country. Many new laws were advocated for by the family movement such as school integration, deinstitutionalization and family-friendly services. Families wanted a greater say in how services were delivered. They wanted more flexibility and individualized supports that not only allowed their child to remain in the family home but for a typical life.

Self-determination has taken root and taken off. It has become both a service reform and a civil rights issue that will profoundly change our laws and service systems. We, as a field, must explore our own fears related to the changes that self-determination will necessitate and, instead, concentrate on using creativity and problem-solving techniques to build adequate safeguards in supports of people's choices.

# Self - Determination



## Self- Determination

Self-determination means that people have **freedom** to live their own lives and **authority** over how, where and with whom their lives will be lived. It means that people have control of the resources needed for their **support**, as well as **responsibility** for their decisions and actions.

### Guiding Principles

**Choice:** People have the right to choose how, where and with whom they will live their lives. When people need help, it is friends and family closest to them who assist them in broadening their experiences and exercising their right to choose. It is essential that each person choose their own network and circle of support.

**Relationships:** The relationships a person has with others must be treasured, nurtured, and protected. Those with whom the individual has close relationships provide the strength, assistance, and security, which ensures each person's well being.

**Contribution and Community:** Everyone has the ability to contribute to his or her community in a meaningful way. Giving of ourselves helps us establish a sense of belonging and identity. Community membership includes having an opportunity to be employed, to have your own home, to be truly involved in the routines of the community and to make a difference in the lives of others.

**Roles and Responsibilities:** Individuals assume greater responsibility for their decisions and actions, as they take greater control over their lives and resources. They must contribute to their supports, become self-advocates, and communicate their needs. Professionals and staff work for the individual rather than for the system. Families, friends, and staff assist people to create more meaningful relationships, link them with needed supports, remove barriers, develop safety networks, and help find ways to achieve the spirit of their dreams.

**Control:** People have the power to make decisions and truly control their lives. This includes authority over financial resources, as well as authority to determine what supports are needed, how they will be implemented, and by whom. People also have control of hiring those who will provide support.

**Dreams:** All People have hopes and dreams about something in their lives. Opportunities need to be created which instill hope and then enable the individual and their circle of support to begin the journey toward their dreams.

**Dignity and Respect:** All people have an inherent right to be treated with dignity and to be respected as a whole person. All people have the right to the dignity of taking risks. People have the right to make mistakes and be supported through their mistakes. The network of support makes risk possible by weaving a safety net, which provides for safety while supporting growth.

**Fiscal Conservatism:** making things happen does not always require money. It is imperative that alternatives to paid supports be found. When support must be purchased, people will get what they need, pay only for what they get, spend money efficiently, and make adjustments when necessary. Individuals are responsible to find the best quality for the most reasonable price.

**Attitude:** Nothing is impossible, as long as it is legal and causes no harm. Replace "No we can't" with "How can we?"

## **Systems Today**

- **Control over people's lives**
- **Staff often cast in the role of keepers or spectators in people's lives.**
- **Passive organizations that amplify the three D's: different, disconnected, and dependent.**
- **Central authority**
- **Deeply entrenched patterns of organization and policies.**

## **Systems Tomorrow**

- **People in control and doing things they want to do.**
- **Staff as community builders and brokers in partnership with people and families.**
- **Active organizations that amplify the three I's: individual, included, and Interdependent.**
- **Individual Choice (made to order).**
- **Mobile and flexible coordination and supports, that people need and want.**

## Managing the Tensions of Self-Determination

There are tensions between the "old way" of organizing services which was system driven and the "new extreme" which may be interpreted as the individual and family do everything. The challenge is to negotiate a middle ground between these two tensions to find a comfort level for that particular person and the system.

	<b>Old Way: System Leads</b>	<b>Middle Ground</b>	<b>New Extreme</b>
<b>Who Makes Decisions?</b>	Service system makes all decisions	People work together to find common interests and agendas <ul style="list-style-type: none"> <li>• Building relationships</li> <li>• Conversation</li> <li>• Mediation</li> <li>• Conflict resolution</li> </ul>	Person and family make all decisions
<b>How are people supported in managing life choices?</b>	Overprotection	Interdependence: Create support to navigate the complexity of choice <ul style="list-style-type: none"> <li>• Building natural supports and community support</li> <li>• Supporting self-advocacy</li> </ul>	Abandonment
<b>How do we pay for the support needed for meaningful lifestyles?</b>	The system pays for everything:  "High costs"  Paperwork demands	Arrangements are negotiated <ul style="list-style-type: none"> <li>• Everyone "plays their cards" up front</li> <li>• We learn about individual budgets and flexibility</li> <li>• We know more about the funds available for support.</li> </ul>	Families pay for everything  "Low costs"  Natural support demands realities
<b>How do we manage the responsibility and risks of real choice?</b>	The system carries the responsibility  "High Control"	<ul style="list-style-type: none"> <li>• We work together to share the complexity and create new safeguards</li> </ul>	Families and people carry the burden of risk: "Abandon Control"

## FORMAL PLANNING PROCESSES

### CIRCLES OF SUPPORT

A circle of support is a group of people who agree to meet on a regular basis to help an individual accomplish personal visions or goals. The individual is unable to reach, his/her goals alone so s/he asks a number of people to work with him/her to overcome obstacles and to open doors to new opportunities. Members of a circle are usually friends, family members, coworkers, neighbors, church members, and sometimes service providers. The majority of members are not paid to be there. This process also uses a facilitator, who may play any number of roles from helping organize meetings to assistance locating resources.

### ESSENTIAL LIFESTYLE PLANNING

Essential Lifestyle Planning helps people discover their choices and those choices honored. It is focused on an individual and what that person values. This process was first developed to support people with challenging behaviors in their communities. The process looks at choices in three categories: non-negotiables, strong preferences, and highly desirables. Non-negotiables are those lifestyle choices which are essential to a reasonable quality of life for a person. Strong preferences are those choices which make a major contribution to a reasonable quality of life but are not critical to it. Highly desirables are things the person would like to have in their life. A facilitator helps a person with a disability, along with people who care about the person, explore and make plans. Graphic illustrations record this process.

### MAPS (Making Action Plans)

MAPS is a process that places primary emphasis on inclusion, participation, and learning in integrated settings. This process identifies action steps that move in the direction of inclusion in all aspects of life. Originally developed for use in schools, the MAPS process has been used with adults and families as well. A facilitator guides a process of discussion and planning. A graphic recorder illustrates the process.

### PATH (Planning Alternative Tormorrows with Hope)

PATH is an eight step process that helps a person identify his/her dreams, what life now is like, and action steps to get from now to where s/he wants to be. All eight steps and their particular order are integral to a successful experience using this planning method. This process is a way for people to align their purpose, their understanding of the situation and the possibilities for hopeful action. They commit to change, mutual support, personal and team development, and learning. PATH is led by a facilitator and graphically illustrated.

### PERSONAL FUTURES PLANNING

Personal Futures Planning is an individualized, possibility-based approach to life planning. A Personal Futures Plan represents a vision for a more desirable future. The plan is developed by a group of people who care about an individual and will assist in making the plan a reality. A facilitator helps organize a group to listen to the dreams and desires of a person and take action over time to accomplish these dreams. Graphic recording often accomplishes this process.

# SELF DETERMINATION

"Self-determination is a philosophy of service delivery that assists people to have more choices about who helps them, where and with whom they live and work, and how to have the life they want."

## Why are we doing this?

Individuals are asking for more flexibility and control

People have specific needs that may not fit into a *"pre-packaged" program*

Staff shortages *are* forcing the system to think more creatively

## Freedom

To choose where and with whom to live

To choose what important things to do with your life

To have necessary help, not a "program"

## **Support...**

From family, friends, and others  
who care

To grow, live, and work in  
communities, not "programs"

To live a life of choice not  
compliance to a system

## **Aid...**

Over a targeted amount of  
dollars sufficient to provide  
necessary supports

## **Responsibility...**

To accept the consequences of  
choices made

To spend money wisely

To be safe and healthy

## How is this different?

People are viewed as people with real lives, not clients in a program

People plan and get their support with whomever *they* choose

There are many more choices and people have a lot more control in their lives \_\_\_\_\_

## SELF-DETERMINATION IS...

- > Living a life that is always changing & growing & never fixed.
- > Deciding what I want in life & setting my own goals.
- > Learning to trust my feelings; having others trust your feelings.

## SELF-DETERMINATION IS...

- > Controlling service decisions & the money that buys those services.
- > Honoring & respecting me, my choices, my ways of expressing myself.
- > Having enough support to not be confined by my disability.

## **SELF-DETERMINATION IS...**

- > Becoming more confident & feeling better about myself as I do things on my own.
- > Having a purpose to my life & being successful in working toward it.
- > Having freedom to make choices & taking responsibility for choices I make.

## **SELF-DETERMINATION IS...**

Having the help I need for the choices I make.

## **Self-Determination is Impeded by...**

People thinking their main job is to protect me through restrictions, rules, & regulations.

Having too little information to know & choose different options.

Having too little self-confidence.

## Self-Determination is Impeded by...

Being surrounded by people who do not respect me & who underestimate what I can do.

Being pushed by people who want me to decide quickly & once & for all.

Being surrounded by people who think they should make the decisions about me & for me.

## Self-Determination is Impeded by...

Having people expecting me to fit into their system & same old way of doing things.

Having limited resources & more importantly, limitations on how those resources are used.

## Self-Determination is Impeded by...

Having too few creative people in my life to help me solve my problems.

Having no one who has or will give me the time it takes to help set me up the way I want.

# Building a Life



*Understanding Consumer  
Directed Community Supports*

## Begin Dreaming

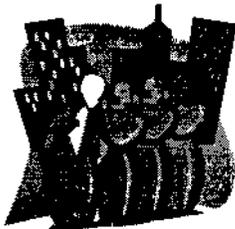
What do we want our  
house to look like?



*What do I want  
out of my life?*



## Relationships



We all need people to  
support us and to  
care.

Who do you need to  
achieve your  
dreams.

## Look at Your Budget

Applying for a loan



What funds are available?



## Planning

an architect can help



Person-Centered Planning



## Getting Started

Where do I want to build my house?



A Realtor can help us, navigate



Making connections between people and resources. Your case manager can help make connections

## Making It Happen

Using a contractor  
or sub-contractor  
it out-



Putting the plan  
into action



*FISCAL INTERMEDIARY,  
EMPLOYER OF RECORD  
HOME OF CHOICE.*

## Keeping it Going

Finding the right  
resources



Expanding your  
support group



## WHAT IS CHOICE REALLY ABOUT?

The concept of "choice" is discussed frequently in the field of developmental disabilities these days. Yet the concept means different things to different people, and is used to justify radically different visions of the place of people with developmental disabilities in society. This article presents some thoughts on the concept of choice.

### Why is choice important?

Historically, people with disabilities and their families were offered few, if any, choices in their lives. Families of children labeled with severe disabilities had two options: to place their children in institutions or keep them at home with no publicly funded assistance or education. Adults labeled with severe disabilities could be placed in public institutions or live in the community with no services or supports.

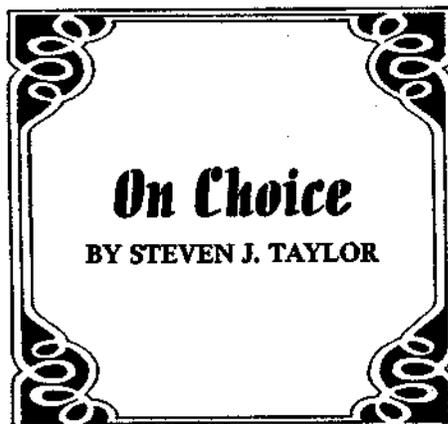
With the establishment of a federally guaranteed right to education and the expansion of community services, the options available to people with disabilities and their families slowly started to expand. Nevertheless, many people continue to be denied the opportunity to make choices about the most basic aspects of their lives.

### What is choice really about?

In my view, choice means that people with disabilities, regardless of the severity of the disability, should be able to enjoy the same choices and options available to other people in society. A public commitment to choice means that public funds and programs should support people in making these choices and selecting these options. It does not mean that public funds and programs should support lifestyle choices and living conditions other people do not enjoy.

### What are some important choices that people should be able to make?

All people should be able to make decisions over various aspects of their



lives. For adults, major choices include decisions about:

- In which communities and neighborhoods to live
- Whether to live alone or with others and, in the case of the latter, the specific person or persons with whom to live
- Friendships and participation in community activities and associations
- From whom and how to receive personal assistance and support
- Sexuality and sexual relations
- Where to work
- Medical treatment and therapeutic interventions

Choices about these matters determine the degree to which people can make decisions about day-to-day things such as:

- Meals and mealtime routines
- Bedtime routines
- How to spend leisure time
- Dress and personal appearance

### What public policies and approaches are consistent with choice?

Public policies and service approaches should maximize personal control and choice. The following are some current approaches consistent with this principle:

© Individualized funding. Sometimes referred to as "self-determination" or "cash and counseling," individualized funding provides individuals with funds to arrange for their services and supports. A fiscal intermediary and service coordinator may be used to assist people in managing funds allocated to them.

© Person-directed personal assistance. Under this approach, people are able to select, hire, supervise, and, if necessary, fire their support staff or personal assistants.

© Person-centered planning. This is a planning approach designed to identify people's capacities, needs, and desires.

© Home of Your Own. This involves innovative financing schemes to enable people with disabilities to own their own homes as opposed to living in agency operated facilities.

© Family-centered support services. For children, in particular, families should control the services offered to them.

*People without disabilities can make poor choices. Some people pursue unhealthy lifestyles or spend their money unwisely. Disability is not a reason for depriving any person from making the same choices other people have the right to make.*

### Are all people capable of making choices?

All people should be presumed competent to make choices about their lives. Some people, however, may be limited in their ability to express their decisions. In these instances, every effort must be made to ascertain their preferences and choices by people who know them well. Surrogates — parents, family members, and guardians — will sometimes need to

make decisions on peoples' behalf when it is impossible to determine what they want. The choices that surrogates make in such circumstances should be limited to the range of choices and opportunities available to people without disabilities.

### **What about people who make bad choices?**

People with or without disabilities can make bad choices. Some people pursue unhealthy lifestyles or spend their money poorly. Disability is not a reason for depriving any person from making the same choices other people have the right to make. Nor is disability a reason for supporting people with disabilities to make decisions (e.g., physician-assisted suicide) that persons without disabilities are not entitled to make.

Family members, friends, and loved ones can and do influence the behavior of others. The strongest safeguard of the well-being of any person is to be involved in caring relationships in which people influence each other in non-coercive and non-manipulative ways.

Choice should never be used to justify neglect, poverty, or an absence of realistic options. People do not choose to go hungry or be homeless. To people who might make bad lifestyle or spending decisions, we should be magnanimous.

Although family members can play an important role in supporting people with developmental disabilities, they are not entitled to substitute their own interests and wishes for those of people with disabilities.

How has the concept of choice been misused?

Increasingly, choice is used by some individuals and groups as a justification for the continued institutionalization of some people with developmental disabilities. What is usually meant by this is that parents and family members should have the option of deciding where and how their sons and daughters with disabilities should live. Although family members can play an important role in supporting people with developmental disabilities, they are not entitled to substitute their own interests and wishes for those of people with disabilities. The condemnation of institutions by organized self-advocacy groups testifies to the fact that people with developmental disabilities do not wish to be put away.

The phrase "one size fits all" is sometimes quoted by proponents of institutions to characterize the policy of community inclusion. Yet, it is the institution — with well-documented patterns of "block treatment" and rigidity of routines — that epitomizes "one size fits all." In the community, there is unlimited variety and opportunity to pursue lifestyles based on individual needs and preferences.

Any adult has the right to decide with whom to associate. Some groups have chosen to segregate themselves from the wider society based on religious, ethnic, and other grounds. Some parents choose to send their nondisabled children to boarding schools where they can be with students of similar ethnic, religious, or economic backgrounds. In a democratic society people have the right to choose segregation — to associate with only those persons presumed to be exactly like themselves. But society has no responsibility to subsidize segregation. Public policy toward people with disabilities should support opportunities to make the same choices other people make — nothing more and nothing less.

### *THE FOLLOWING BULLETINS AND FACT SHEETS RELATED TO CHOICE ARE AVAILABLE FROM THE CENTER ON HUMAN POLICY:*

Policy Bulletin on Safeguards (1993) addresses how safety can be increased by strengthening community and improving the assistance people receive. It also discusses the paradox of regulations. (18 pages)

Fact Sheet on Self-Advocacy (1999) by Mair Hall briefly defines what self-advocacy is, provides a brief history of the Self-Advocacy/People First Movement, and includes a brief list of resources. (2 pages)

Fact Sheet: Summary of Self-Determination (1998) by Michael X Kennedy and Lori Lewin summarizes what self-determination is and is not, the principles of self-determination, the values supported by self-determination, and a call for changes in the system in order for self-determination to truly succeed. (2 pages)

Fact Sheet: In Support of Families and Their Children (2000) by Nancy Rosenau discusses why children belong in families and how to assure families for all children. (2 pages)

Feature Issue on Institution Closure (Winter 1995/96) edited by Mary F. Hayden, K. Charlie Lakin, and Steve Taylor contains national information as well as a variety of articles on closing institutions written from the perspectives of self-advocates, professionals, parents, researchers, and policy makers. This bulletin was published through the Impact series of the Institute on Community Integration at the University of Minnesota in cooperation with the Center on Human Policy.

## A Self-Advocate's "Before and After" of Self-Determination

-By Clare Zimmerman and Nancy Richards, Delaware, Ohio

Clare is a participant of the Self-Determination initiative in Delaware, Ohio, and presently lives with her sister while she is looking for her own place. Unable to use her arms and hands since birth, Clare has developed her feet and toes to take their place. At a recent conference, Clare presented her thoughts about how self-determination has changed her life. She asked Nancy Richards, a Self-Determination Project Coordinator at the Delaware County Board of MRDD to assist her in this "before and after self-determination" comparison.

Before: I had to ask if I could do something.

After: I tell them that I am going to do it.

Before: I was usually told "No, you can't,"

After: I tell them "Yes, I want to try".

Before: I was dependent on the goodwill of others.

After: I'm dependent on the understanding of others.

Before: People got mad at me if I didn't like something.

After: If they get mad at me I can tell them "so what!"

Before: Nobody asked me what I wanted. They talked to each other and decided what I should do.

After: People ask me what I want now. They talk to me.

Before: Other people decided what I was able to do and how smart I was and what I should learn.

After: I know how smart I am and now I can tell people and they listen. I know what I am able to do and what I want to learn and people help me do it.

Before: I was afraid to show if I was mad. They might stop helping me or make me do things I don't want to do or not let me do something I want.

After: I'm not so afraid to show if I'm mad. People understand better and won't take things away.

Before: Other people decided if and how I could spend my money or if I could even keep it

After: I decide how to spend my money and what I can do with it I don't have to give it to anyone else unless I want to.

Before: I didn't get to go out very much when I wanted to.

After: I get to go out most of the time when I want to and go places I want to go.

Before: I was treated like a child or a really dumb person.

After: I get treated like a smart person by more people. I tell them I know things.

Before: I was afraid I'd have to live somewhere I didn't want to, like a nursing home, if I was too much trouble for people.

After: I'm still afraid of that but not so much. I know I do the best I can and it's hard for me, so people should help and not get mad.

Before: I thought my Mom could do anything she wanted to with me and my money.

After: My sister says nobody can do anything to me or my money unless I want to.

Before: My Mom took me to the doctor or dentist and let them do things to me without telling me what was going to happen or why, or asking me if I wanted to.



(left to right) Nancy Richards, Clare Zimmerman



Clare Zimmerman

After: My sister says it's up to me if I want to go to the doctor or dentist and won't let anybody do anything to me unless I know what it is and say it's okay.

Before: People made me work at workshops when I didn't want to. People wanted me to work all day every day even if there was no work to do, and would get mad at me if I didn't come every day.

After: Nobody makes me work at a place I don't want to. They're trying to find me a place and the kind of job I want. Now they let me decide that I only want to work part time and nobody is trying to make me work more.

Before: People made me socialize and spend time only with people who were not very smart

After: Now more people know I'm smart and they don't make me stay all the time with people who aren't as smart as me.

Before: People would talk to my mother and not to me.

After: Now people talk to me.

Before: Sometimes I wasn't very happy.

After: I'm happy more now, but I will be happier when I have a stair lift and a laptop computer talker.

Clare says, "Self-determination means that I get to decide about myself just like regular people. Self-determination means that the rights of liberty and the pursuit of happiness are my rights, too. Self-determination means that I'm not a second class citizen, an object of pity and charity, but a real person. I'm not a 'disabled' person; you can't turn me off or put me in storage like a 'disabled' vehicle or machine. I'm a member of a minority, that's all. I have problems that the majority of people don't share. Self-determination means that other people can't decide what my problems are and how to deal with them anymore. I do"

Clare's sister, Ann Plassenthal, adds, "For family members, self-determination means that our people are finally being treated the way we want them to be treated. It means that the professionals are listening to us and we're getting more of the kind of help we really need. It means that we're not being told what to do or how to do it or how we should think about it. It means we're being listened to and our experience and opinions are respected."

# Self-Determination Stories from Across the Country —Maryland—

Editors note: The following stories appear in a booklet prepared by a joint effort of the Families Training Committee of the Maryland Robert Wood Johnson Foundation Self-Determination Initiative and the Governor's Waiting List Initiative of the Maryland Developmental Disabilities Administration. For more information about the Maryland Self-Determination Initiative or to order the booklet, contact Jean Tuller, Self-Determination Project Director, 301-663-0909.

## The Spechts

Denny waits for his mother to come walking through the front door at any moment. He has been waiting for more than two years. William Specht, Denny's father, knows that Tilly will not come home because she died in 1996. Denny, who is 44 years old, does not understand his mother's death and continually asks where she is. Mr. Specht, 84, deals with the reality of his wife's death every day. It was hardest in the beginning. Not only did he lose



Photo by P. Sue Kullen

## The Spechts at home

his companion of more than 61 years, but he is facing an increasing inability to care for his son. Initially, Mr. Specht believed that he had no choice but to put Denny into a group home while he moved into a veteran's home in West Virginia. Separating the son from his father seemed to be the only way Denny would receive the care he needed.

With funding guaranteed, a service coordinator saw an alternative plan and began working with the family. The service coordinator introduced

## THE SPECHTS

- CONTINUED FROM PAGE 1-

Denny and Mr. Specht to the concept of receiving supports in their home. Mr. Specht was not aware that this was a possibility and jumped at the opportunity. He and Denny could continue living in their own home and Taneytown community of 63 years and receive the supports they needed. Denny would be with his father and continue working at the day program he had been attending for more than 20 years. Father and son could continue worshipping at the same church and living close to friends and family.

Mr. Specht chose to receive services from a nearby agency. Denny receives 45 hours a week of support. Someone comes to the home every weekday morning for one hour to help Denny get up and ready for work. Someone else comes in the afternoon and evening for six and a half hours a day, six days a week to help with meal preparation, transportation, shopping, banking, medication, and leisure activities. The hours are flexible enough to include professional appointments as needed.

Although Denny and Mr. Specht are on their own on Sundays, family and friends stop by to help. The pastor of their church picks them up for services. After church, they always visit Tilly's grave.

"This certainly has made life better for us, I know that," said Mr. Specht. "This is 100 percent better than a group home because it keeps us together," he adds. Mr. Specht is still planning for the future. He does not want his own death to change Denny's life and routine. Denny will continue to live in the family home after his father dies and receive the support he needs. Denny has two sisters who live nearby who will keep a protective eye on him. The Spechts also have many friends in the area who care about Denny and will help out as needed. "This is Denny's home and he is happiest here," says his father.

## The Goldens

When they walk back into the house, it is both a strange and wonderful feeling. Strange in that it is no longer their home but their son's home. Wonderful because it promises a secure future for Joshua. Jackie and Mike Golden moved out of their home and gave it to their son. In doing so, they did more than ensure a permanent home for their 16-year-old son. They also made sure that Joshua would always be surrounded by people who cared about him.



The Goldens with their son, Joshua

Photo by P. Sue Kullen

Although Jackie and Mike Golden moved out of their home in Lutherville, they have retained management of the building and direct influence over who works with their son. They recruited, interviewed, selected, trained, and built a team of people who will provide Joshua with the full-time supports he needs.

Fortunately, most of the support staff have known Joshua for many years. Jackie fills in for staff when they are sick or not available to work. When they are short-staffed, it is Jackie, again, who provides the support. Jackie stops by the home every evening to check on Joshua, coordinate appointments, grocery shop, talk with staff, and generally keep things running smoothly. Good communication with the people who work with Joshua seems to be the cornerstone of successful support

## Words of Advice

- **Never give up on your dream.**
- **Balance daily risks with long term gains.**
- **Seek and use all available resources in the community.**
- **Paid staff are not the only means of support for your child.**

The Goldens know what works for Joshua from past experience. "We have learned from the good and the bad. We need to do all that we can to control who comes in and out of Joshua's life," says Jackie. When they did not have control over the staff members who supported Josh in traditional settings, such as the hospital and a group home, the effects on the quality of Joshua's life were negative. Some staff members were neglectful and unpleasant with Joshua; others took advantage of him. Since he moved back to his home in June 1998, the Goldens have noticed a new and delighted expression on Joshua's face; he looks like a child again. Because their son does not speak, they rely on facial expressions to gauge his emotions. "We took extreme measures to remove negativity from Joshua's life," says Jackie.

The Goldens, with the help of their service coordinator, wrote a plan for their son which redistributed the funds that Joshua previously received to support him in a group home

setting. They contributed time, money, and their home while the State provided staff support, backup staffing, home modifications, and administrative costs. The plan also called for a house mate with disabilities who would make the entire support plan more economical for everyone. The plan projects a cost savings to the State given the family's management of the home and supervision of support services.

One of the most critical elements in the plan was finding a provider to carry out the State's portion. They needed an agency they could trust, one that could work with them, support them, and allow them direct involvement in their son's life. They interviewed agencies and entered into a partnership with the agency they felt could work best with them. "Then it became a team process because we all brought our expertise to the table," said Jackie.

Not everyone can do what we have done. We simply did what we could do to ensure a better life for our son. We made use of the assets, resources, and energy that we have at this point in our lives to invest in Joshua's future. Our son now has his home, and is close to his neighbors, and his family. It has created the best for Joshua, and it means peace of mind for us."

## The Banks

Maude Banks and her husband built a beautiful stone house in Churchville in 1963. He was a landscaper by trade, so the yard is expansive and serene. They designed their home to



Maude Banks and son, Walter

Photo by P. Sue Kullen

house and protect their entire family. When Mr. Banks passed away a few years ago, Maude was left alone to care for their only son, Walter. Increasing health concerns challenged her ability to provide a safe and supportive environment. Mrs. Banks' niece, who lives nearby, stepped in to assume responsibility for both Mrs. Banks and Walter.

The family was eligible to receive some assistance through family and individual support services. Initially they benefitted from 20 hours of support each week. Over time 20 hours was not enough. Maude's increasing problems threatened Walter's ability to stay safely in his home. A major intervention was needed to protect both Mrs. Banks and Walter. A group of concerned family members and professionals met with Walter to decide his future. Walter did not want to move into a group home, and the family wanted to honor Mr. Banks' desire to keep his wife and son together. Maude was adamant that her son needed to stay with her and be near his family.

An individualized plan of support was developed and submitted to the Developmental Disabilities Administration for approval. The plan called for a staff person to be in the home every waking hour that Walter was in the home. The plan also called for the house to be licensed as an agency residential site with the agency and the family assuming a shared responsibility for the upkeep of the home. Staff support would increase from 20 hours a week to 80 hours a week. Much to everyone's surprise and delight, especially Walter's and his mom's, the plan was approved.

The home was licensed, and the increased supports began in July 1998. Staff assist Walter with personal care, professional appointments, cooking, shopping, leisure activities, cleaning, and laundry. Walter is learning to do as much for himself as possible. Mrs. Banks' niece manages the finances and keeps a watchful eye on both Walter and his mother. She plays a critical role in the success of the supports that Walter receives.

Mrs. Banks hopes that Walter will not have to leave his home under any circumstances in the future. "He grew up here, this is his home," says Mrs. Banks. With the help of lawyers, the family has ensured that Walter will have the financial means to stay in his home. Although he eventually may need a house mate to share expenses, Walter will cross that bridge when the time comes. For now he is happy to be home.

### The Swartzentrubers

Well-intentioned professionals were asking me to be realistic and accept my daughter's disabilities," says Lois Swartzentruber of Oakland. Her daughter, Laurie, lived in a group home and was very unhappy. "I had a dream of something better, but I couldn't do it on my

own," she adds sadly.

Laurie, 26, also had a dream. As one of three women who lived in an agency-owned home, Laurie wanted her own apartment and support that made sense to her. She endured getting up early on Saturday mornings to ride to her housemate's doctor appointments because there was no extra staff to stay with her at

home, she endured staff's unruly children in the home, and she endured a houseful of fat-free food because all of her housemates were on diets. "I want my own apartment," Laurie pleaded at numerous yearly planning meetings.

Only through drastic measures could mother and daughter realize their dream. In a desperate attempt to gain as much control as possible, Lois decided to pursue guardianship for her daughter. In this process she met a service coordinator who showed

them a different path. The service coordinator helped Laurie develop a person-centered plan and find resources that could make the dream a reality. Laurie's plan involved renting her own barrier-free apartment near her mom, receiving 24 hours a week of personal assistance through the health department, and 10-12 hours a week through a local agency's family and individual support services. This amount of support, teamed with Laurie's going home every weekend, was enough to make it work.

Since Laurie needs daily support, they initially decided on a live-in housemate who did not have disabilities. The person received reductions in room and board in exchange for supporting Laurie Monday through Friday. This worked for the first six months, but Laurie's seizures were too much for the person to handle. Again, with the help of her service

### Words of Advice

- **Rely on your family to help out where they can.**
- **Use a lawyer to set up trust funds and final wishes.**
- **Rely on your children's preferences in planning their future.**
- **Explain what you want; ask for assistance.**

coordinator, Laurie was able to find a young woman with disabilities, nearer her age who agreed to be trained to understand and respond to Laurie's seizures. She agreed to live with Laurie and provide support to her when needed, in exchange for reductions in room and board. The two young women compliment each other and support each other. They also discuss eligible young men to date and keep track of how many times they have each seen "Titanic."

"We had to walk away from the group home," says Lois. "The services that Laurie gets now are less expensive and better for Laurie. We combed the community for the supports that Laurie needs. The services are not as neat and tidy, but they work for Laurie," Lois says. Lois admits that the plan has risks but she is comfortable with the risks balanced with the longer range goals of happiness, control and improved self-esteem. Laurie likes her own place. She likes to sleep in, likes to eat what she pleases, and especially likes having her mom around and helping out "I love my mom," Laurie adds with a smile, when her mom is out of earshot.



The Larmore Family

### The Larmores

David Larmore, 28, volunteers 40 hours a week at the Peninsula Region Medical Center in Salisbury. He has been a volunteer there for seven years. He also volunteers for the March of Dimes, The Magi Fund, and visits schools to talk to third graders about issues facing people with disabilities. He received a Governor's Award for Independence, a Maryland You Are Beautiful Award, and has been featured on a local TV show to honor his commitment to volunteering. David is happiest when he contributes to his community and when he is out of the house and around people. David lives at home with his parents, Sara and Sheldon Larmore. They have devoted their lives to caring for their only child and are proud of



Photo by P. Sue Kullen

Mike is learning to do more for himself, but the learning process includes a lot of mistakes. Mike has learned that you can't cook spaghetti in a plastic bucket, that you need a key to unlock a door, that liquid soap is not a good substitute or dishwasher powder, and that you cannot vacuum soap bubbles. Mike's service coordinator notes that in spite of some bumps in the road, nothing has held back the learning process. Mike has been allowed to make mistakes and learn from those mistakes. "You need to try and learn to live on your own," says Mike. "Having his own place has made a world of difference," says his mom.



Nicole and her mom, Kelly McElwain

Photo by P. Sue Kullen

## Nicole and Amy

Nicole and Amy were classmates at the Maryland School for the Blind. They are now housemates in a charming home in Harford County.

"We know our daughters better than anyone else" says Kelly, which is why Kelly and Nancy, the girls' moms knew that their daughters could not live in a traditional group home. Too many people would create too much stimulation and excessive noise. So careful pairing with a housemate would be the most important factor in a successful support plan after Nicole and Amy left school.

Kelly McElwain started planning for her daughter's future almost 13 years ago. She visited group homes and vocational workshops and knew that they would not work for Nicole. She needed something different. Nancy McKee started planning for her daughter about four years ago. She knew that she wanted something different for Amy once she left school. Through the Maryland School for the Blind, Nancy and Kelly met and joined forces. They hoped that if they could do something extra for the girls, the State would fund a support plan for their daughters.



Nancy McKee and daughter, Amy

Photo by P. Sue Kullen

They began sharing their story and dream with decision makers at the Developmental Disabilities Administration. "We knew that we had to sell them on our daughters' needs," says Kelly. "I put a lot of effort in the strategy of selling the idea to people who could fund it." The plan was to jointly purchase a small, comfortable home for the girls; find a flexible agency to share the responsibilities of full-time support; and move the girls to their new home,

in a series of transition steps during their last year of school.

And that is exactly what happened, although the first year was not easy. At first, it took a while for everyone to adjust to their new roles. Patience was the key. Kelly and Nancy learned that it was difficult for a parent to let go. Amy still comes home every weekend, but Nancy believes that this will change in the future. "My comfort level will change over time," says Nancy.

The moms formed more than a formal, legal partnership in a home; they also formed a partnership of support with each other. "We talk a lot, vent frustrations, and share information," said Kelly. When asked about their motives, they responded that they did not want their other children to be responsible for caring for Nicole and Amy. They firmly believe that all of their children need and deserve to live their own lives. Kelly compared it to saving for college for her other kids.

"It is an investment in your child's future," she stated, "We wanted to set up our daughters' futures now while we are healthy and able to enter into a partnership for support."



Jean Tuller

For more information about the Maryland Self-determination Initiative or to order the booklet, contact Jean Tuller, Self-Determination Project Director, 301-663-0909.

These stories were written by P. Sue Kullen with assistance by Tim Quinn and Joyce Lipman.

IF YOUR CHILD IS MISERABLE,  
YOU ARE MISERABLE.

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