

## SELF-DETERMINATION AS AN EXPRESSION OF ENGAGEMENT

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*Luke sits alone in his darkened apartment. The curtains are drawn. The mood is as dreary as his apartment. He sits alone in his automatic wheelchair. His dirty laundry is piled at the rear of his chair. His face is sad, his shirt stained with food, and his red hair falls every which way.*

*Matthew and I came to his door and rang the bell. He opened the door and greeted us with momentary enthusiasm that sliced through the dreary space he called home. "He wants his independence," Matthew had told me before we entered. I did not know what independence meant—to live by yourself on your own with your network of friends or to live a lonely life punctuated by periodic lamentations of "I want my independence. I want to make all my choices. I have the right. I want the largest big screen television in the world and then I will be happy! If you don't let me have this, I will call recipient rights!"*

*We entered his house, more a tomb than a home of the living. Its darkness spoke a thousand words. Its musty, cold air wove its way through the air like a dark, damp, chilling embrace. Luke seemed to think, "I have my freedom. Now I have everything." Yet, he sat there alone with an empty face, eyes hungering for affection, and a wounded heart that he alone could not mend. He knew his rights. He had his autonomy. He was on his own, but very much alone.*

*"Let's go for a walk around the apartment complex," I asked. He did not seem to want to. He had not been out much during the three weeks he had lived in freedom. With some persuasion, he moved his machine-driven wheelchair through the narrow door and hall. We were soon in the bright summer sun moving across the broken asphalt parking lot. We headed for the pool as Luke wove in and out of the passing cars and up and down the broken curbs. Luke talked about his right to live alone but with a demanding tone devoid of joy or even meaning.*

*Luke was a shy young man, articulate with his palsied speech that took a while to understand. He gradually became more content as he started to feel safe with us and respected by us. His eyes took on a glimmer of contentment. He was with possible friends.*

*But, the walk ended all too soon for Luke. He rolled into his dark apartment. We hugged and said good-bye. The door swung shut. Luke was alone again. We left wondering what is freedom? It certainly must be more than being on your own, but alone. A house is made of bricks; a home is made of love. Freedom must be more than independence. It must be connectedness with others.*

As we grapple with gentle care giving and self-determination, we need to be clear regarding their common ground and how they can be integrated. They are not contradictory; they are complimentary. Both focus on the maximization of the fullness of each person's participation in community life.

Loneliness is not freedom. Decision-making is not freedom. Independence is not freedom. Autonomy is not freedom. These are only expressions of possible freedom. It is each person becoming the author of his/her own life-project, but in the context of being-with-others, feeling at home with others, feeling safe within oneself, and feeling connected and engaged with significant others.

### **WHAT IS SELF-DETERMINATION?**

Self-determination is a social change instrument aimed at fulfilling the need for and the right of each individual to choose her/his own destiny, to be autonomous, to be responsible for one's own actions, and to be free. It relates to the empowering role of engagement— enabling each person to become an active participant in his/her own life and in the life of the community. It places the person, instead of the system, as the author of change.

Self-determination is about each person defining and fulfilling his/her dreams with the degree of support each might need from those whom they trust. Dreams are not about buying things, having big screen televisions, or taking vacations at Disney World. These might be nice things to do or have, but they are not essential to the human condition. Dreams are aspirations that are critical to human well being and fulfillment. They are about deepening each person's self-esteem, happiness, pride, self-worth, and feeling safe on this earth, respected by others, and connected to them. They are about each person's capacity to actively engage in his/her own life-project.

Self-determination is about transforming social service systems so that each person is at the center of decision-making and, thereby, an active participant in his/her own life-project. It is about moving the person from passive participation to active engagement in his/her own destiny. It recognizes that systems of support have to be transformed to effectuate this. Instead of a person coming to an agency and begging for services, the person is seen as having an inherent right to essential services. It places decision-making in that person's hands. Without the freedom to decide one's essential dreams and having the resources to fulfill them, no can fully participate in his/her life-project.

*At the moment, Luke is served by a system he has to fit into. His needs are determined by what bed is available. His service provider holds the cards to his freedom. When others determine our freedom, we are only half-free. His connectedness with the community is next to nonexistent*

*because all his needs are identified as "services" designed to make him better or less disabled. Luke is not seen as the author of his own life-project; he is seen as a client dependent on a system. Because he has nothing else, his dreams shrivel. The center of his life becomes a big screen television.*

### **WHAT IS GENTLE CARE GIVING?**

Gentle care giving is about the foundations of the human condition—teaching, helping, and ensuring individuals who have been pushed aside by society to feel safe and loved and to become actively engaged in their own life-project. It is about the formation of a deep sense of companionship with others and the integration of each person into the fullness of community life based on this sense of companionship. It focuses on prerequisites to self-determination—especially the need to feel safe and esteemed within oneself and loved by others. It is about helping marginalized people feel grounded and connected. When a person feels safe within oneself and with others and loved within oneself and by others, he/she has the emotional foundation to move from a state of dependence to one of increasing autonomy and from a condition of loneliness to one of connectedness. Without these prerequisites, autonomy is hollow. With them, human engagement emerges in its wholeness and self-determination takes on a vibrant meaning.

### **WHAT IS THE COMMON GROUND?**

Both gentle care giving and self-determination focus on enabling the deepest sense of empowerment possible in each person. Self-determination emerges out of the each person's capacity to feel safe with a circle of others and loved by them. Self-determination meets a feeling of companionship and community at the crossroads of choice, autonomy, and freedom. We need to recognize and be deeply aware of this junction. If not, the path of self-determination is as dark and musty as Luke's apartment. His heart will break like the chunks of asphalt in the dreary parking lot. The television set will be his electronic lover. His life will be empty. If not, the cornerstone of companionship and community will crumble under the weight of nothingness.

The common ground is that both self-determination and gentle care giving see circles of friends and full community inclusion as bridges to justice, empowerment, and the fulfillment of essential human dreams. Both require us to have a deep understanding of the core needs of the human condition.

It is obvious that money is needed and must be assured for well-established human rights—education, health care, work, and housing. Other human needs are subtler, but just as essential, perhaps even more important. The homeless man or woman has an inherent right to a decent

place to live and the right to have work accessible. Once in his/her house, the person also has essential emotional needs that also must be fulfilled—to feel safe, loved, and engaged in the confluence of community life.

Many social service systems shell out a bed and head; they focus on meals, pills, toilet spills, and behavioral drills. The person is seen as a recipient and dependent. If whatever is offered does not fit the person's need for freedom, dignity, and autonomy, not much can be done. Self-determination enhances the possibility of these dreams becoming fulfilled in its call for bringing decision-making directly to the person with whatever degree of help the person might need. It calls for substantive change in the role of social service systems in order to help individuals become the authors of their own destiny:

<b>SELF-DETERMINATION CALLS FOR SYSTEMIC CHANGE</b>	
<input type="checkbox"/>	SOCIETY HAS A DUTY TO GUARANTEE THAT FINANCIAL RESOURCES ARE AVAILABLE FOR THE FULFILLMENT OF BASIC HUMAN NEEDS—MATERIAL, PHYSICAL, INTELLECTUAL, AND EMOTIONAL
<input type="checkbox"/>	ENSURING THE PRINCIPLE OF SUBSIDIARITY—THE BEST, MOST FRUITFUL, AND MOST LIBERATING DECISIONS ARE MADE AT THE LOWEST LEVEL POSSIBLE, I.E., THE CITIZEN AND COMMUNITY
<input type="checkbox"/>	RE-STRUCTURING SOCIAL SERVICE SYSTEMS TO ENABLE THE ACTUALIZATION OF THIS DUTY AND PRINCIPLE
<input type="checkbox"/>	SEEING HUMAN INTERDEPENDENCE AS CENTRAL TO THE HUMAN CONDITION AND ENSURING THAT EACH PERSON FEELS SAFE AND LOVED BY A CIRCLE OF SIGNIFICANT OTHERS IN THE PROCESS OF COMMUNITY INCLUSION

The fulfillment of essential human needs and the hunger for feeling safe, loved, loving, and engaged too often shrivel up like raisins in the sun. All too often, group homes are at best group houses with faceless staff, a posture of rigid compliance, and a disregard for the need to ensure that each person feels safe and loved. There are too many places where meals, pills, toilet spills, and behavioral drills form the foundation of what is seen as service delivery instead of creating faces of affection within and among individuals and, through this connectedness, empowering them to determine their own destiny. There are too many places where control over coffee, cookies, cigarettes, and cake are used as sources of professional power instead of a keen focus on the development of a sense of companionship and community.

*Luke's life is not at all complete if he has an apartment but no friends, job, or responsibility in his life. If Luke were to have control of his life, his house would more likely become a home with his friends invited over and his ability to be an active part of community life would more readily happen. The big screen television that Luke wants is nothing if it does not draw Luke's friends around him.*

The extent of anyone's self-determination depends on a person's sense of self and others, self-worth and self-respect, the ability and opportunity to reach out to others, and the capacity to be an active member of community life. Self-determination recognizes the degree to which an individual is able to participate actively in his/her own decision making at any given moment, and also recognizes the ever-enduring need for a circle of friends around each person— sometimes structured and formalized, sometimes more natural and free-flowing. It acknowledges that no one ever stands alone. A conceptual cornerstone shared by gentle care giving and self-determination is the need for a circle of friends in everyone's life.

#### **WHAT IS A CIRCLE OF FRIENDS?**

If gentle care giving and self-determination are to make a difference, we have to have a deep understanding of these more subtle and basic needs and find ways to ensure that they are met at any given moment in a person's life. The central structure for this is the formation of a circle of friends around each person. For the most marginalized individuals, a friend has to initiate a sense of trust-- a feeling of being safe with that person and loved by him/her. The friend needs to recognize and often initiate these feelings. The friend may even be rejected through acts of violence or withdrawal, yet must keep coming back— never provoking violence and always evoking peace. This is not solely a matter of choice; it is a basic human need.

Over time, a circle of friends forms— each having a sense of trust with the person and mutual giving and support. The role of a circle might be what we typically see friends doing—visiting one another, enjoying leisure time together, offering solace in difficult moments, and going out together. For those who are more marginalized and dependent, the circle engages in these activities, but plays a more self-initiating role that deepens and broadens a sense of companionship and community. These circles might have to deal with chronic issues such as extreme dependence due to physical or intellectual disabilities. Their roles might be simply involve visiting a person who might not even seem to recognize their presence and serving as their citizen advocates.

Some common challenges and the roles that a marginalized person can present to a circle of friends are:

COMMON CHALLENGES	VARIOUS ROLES OF THE CIRCLE OF FRIENDS
<ul style="list-style-type: none"> <li><input type="checkbox"/> SOMEONE WHO SEEMS TO KNOW BETTER BUT DOES NOT</li> <li><input type="checkbox"/> SOMEONE WHO HAS CHRONIC MENTAL ILLNESS</li> <li><input type="checkbox"/> SOMEONE WHO IS ALMOST TOTALLY DEPENDENT</li> <li><input type="checkbox"/> SOMEONE WHO HAS A FALSE IMPRESSION OF THE SOURCE OF WELL-BEING</li> <li><input type="checkbox"/> SOMEONE WHO DEMANDS WHAT HE/SHE WANTS BUT DOES NOT KNOW WHAT HE/SHE NEEDS</li> <li><input type="checkbox"/> SOMEONE WHO IS EXTREMELY DEPENDENT AND NEEDS OTHERS TO NURTURE</li> <li><input type="checkbox"/> SOMEONE WHO IS OBSESSED OR EVEN ADDICTED TO MATERIAL THINGS AND SEES LITTLE MEANING IN SELF OR OTHERS</li> </ul>	<ul style="list-style-type: none"> <li><input type="checkbox"/> FOCUS ON YOUR INITIATING A FEELING OF BEING SAFE AND VALUED WITH YOU AND OTHERS</li> <li><input type="checkbox"/> UNDERSTAND THAT THE PERSON HAS GOOD MOMENTS AND DIFFICULT ONES AND THAT YOUR ROLE WILL CHANGE WITH THESE VARIATIONS</li> <li><input type="checkbox"/> CENTER YOUR INTERACTIONS ON A FEELING OF COMPANIONSHIP AND COMMUNITY RATHER THAN ONLY FOCUSING ON CHOICE-MAKING RELATED TO MATERIAL POSSESSIONS</li> <li><input type="checkbox"/> HELP THE PERSON DISCERN HIS/HER RELATIONSHIPS AS CENTRAL TO THE HUMAN CONDITION—BEING WITH OTHERS, DOING THINGS WITH OTHERS, AND DOING THINGS FOR OTHERS</li> <li><input type="checkbox"/> BE ABUNDANTLY AND UNCONDITIONAL LOVING AND WORRY ABOUT NOTHING ELSE</li> <li><input type="checkbox"/> UNDERSTAND THAT YOU AND YOUR RELATIONSHIP WITH THE PERSON HAVE TO BECOME THE INITIAL CENTER OF THE PERSON</li> </ul>

**WHAT ARE THE BIGGEST DANGERS IN THIS PROCESS?**

The “self” in self-determination can be misleading. No person is an island— isolated and alone on this earth. No one is totally independent, free, or completely autonomous. Nor does anyone

always feel safe, loved, grounded, and connected. All are interdependent. The central questions are how much can any one person actively participate in his/her own life-decisions and life-project and, when this capacity is diminished, how can the individual be supported and maximally empowered to participate as actively as possible.

*Luke needs his independence and his right to choose this. Yet, more basically, he needs to be grounded in a sense of self-worth that is found and fortified in his connectedness with others. If he lacks this, he has nothing other than the shrill scream of "I have my rights!" and then nothing but loneliness. He has the right to live on his own and this is good; but, he has the need to be connected with others who can help him feel safe and loved and who can help him become integrated into the fullness of community life.*

*Luke needs have his basic physical, intellectual, and emotional needs met through an array of supports that he and his circle of friends define and generate. His right to housing, education, health care and work has to be guaranteed. If they are not he has an empty autonomy. He has the need to feel connected with others and the right to the support to accomplish this. If not, he stands alone on this earth.*

Entitlement to the availability of sufficient resources to fulfill basic human needs is contradicted by long waiting lists, pervasive homelessness, and warehousing hundreds of thousands of children and adults in congregate care facilities. It is thwarted by tens of millions of persons without access to health care and hundreds of thousands denied an education.

Another significant danger lies in leaving behind those who are less strong and vocal than Luke. Luke can speak up and advocate for himself. We have to make sure that all who are marginalized have these same assurances, otherwise they will be left in the dust of the few.

## **WHAT IS EMPOWERING ENGAGEMENT?**

The person with his/her circle of friends enters into a process in which the person is at the center and is honored as the one who determines her/his destiny but in the context of his/her degree of engagement at any moment in time. Empowerment is vital in both gentle care giving and self-determination. The challenges are twofold:

1. To define the degree to which each individual is able to be engaged at any given moment and
2. To create and support a circle of friends for each individual across their life span that sustains and enhances each person's ability to be engaged in the context of community life.

The vehicle for empowerment is each person's circle of friends. The less the person is engaged, the more necessary it is to create, structure, and support a circle of friends. Human engagement involves the gradual unfolding of a sense of active participation as a companion with others and as a member of a community. It is a feeling of becoming an active participant in community life. It is not self-centered, but a shared feeling of "We are somebody because we are together and we are forming a better community." Its initial expression is found in the simple act of reaching out to others and drawing others into one's life. This first dimension of engagement is each person's circle of friends.

We need to see self-determination from the perspective of the most dependent person. What does it mean for the woman, who cannot see, hear, or move? She has difficulty chewing. Her breathing is labored. Her heart is failing. She has no language or even vocalizations. We need to define self-determination from this woman's perspective.

#### **WHAT DEGREE OF SUPPORT DOES A PERSON NEED?**

Engagement is like the widow's mite. The poor widow who gives a pittance gives as much as the rich person who gives millions. The woman who seems to have almost nothing to give has an even deeper need for self-determination. We need to see her mite—perhaps her smile, the movement of one finger, the turning of her face toward us. We need to see her as a full human being as valuable and valued as any other.

The person who has difficulty just moving his/eyes or even breathing needs to be supported in this engagement as much as the person who can and live on his/her own and form his/her own circle of friends. The circle has to be keenly aware of each person's needs and have a profound hope that feeling safe and loved will bring trust. And, trust will serve as the foundation for engagement with the circle and the broader community.

Engagement is each person becoming an active participant in the formation of companionship and community to the degree that each is capable. Caregivers have to be sensitive to the gifts and talents of each person, have high expectations, but also realize that, without the foundation of feeling safe and loved, no one is able to become an active participant in life. Engagement is a difficult process. It begins by enabling the person to move from being a passive participant in the world to a more active one. The first sign of engagement is a desire to be with others.

EMPOWERING ENGAGEMENT IS LEARNING...	SELF-DETERMINATION IS LEARNING...
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<input type="checkbox"/> It is good to be together	<input type="checkbox"/> To accept self as good and to understand the need to be with others
<input type="checkbox"/> It is good to do things together	<input type="checkbox"/> To reach out to others
<input type="checkbox"/> It is good to do things for oneself	<input type="checkbox"/> To feel trust of oneself and one's circle of friends
<input type="checkbox"/> It is good to do things for one another	<input type="checkbox"/> To participate to the maximum extent possible in the decision-making process regarding one's own well-being
<input type="checkbox"/> It is good to do things for others	

### WHAT IS THE FOUNDATION OF EMPOWERING ENGAGEMENT?

Engagement is found in trust and trust is rooted in feeling safe with others and loved by them. We look for meaning, a sense of connectedness and purpose, in our lives. For some, it might be family or friends. For others, it might be material possessions. For the powerless, life's meaning can often be found in the seemingly absurd act of rejection of self and others-- pushing others away as the last frontier of some dominion in their lives. We have to teach that there is meaning in being with us, doing things with us, and even doing things for others.

*The hunger for engagement is Luke screaming, "I have my rights! I have nothing else! I will yell for my rights!" Engagement found is Luke's eyes opening with hope. His words speaking of affection. His desires known without even being spoken. His rights fulfilled within his active participation in community life. It is Luke's whisper to his circle of friends, sometimes silent, sometimes spoken, "I now feel safe and loved. I am somebody because we have each other!"*

Self-determination is not the attitude of "Give him his big screen television and he will be happy!" The old saying "You cannot buy happiness!" rings true. It might good if each person has the power to acquire what he/she wants—own apartment, the ability to come and go as one please, and the opportunity to always say, "This is what I want to do!" Yet, our focus has to be grounded on more basic issues—ensuring that each person has what he/she needs—to feel safe, loved, loving, and engaged.

### WHAT IS COLLECTIVE DETERMINATION?

Self-determination and gentle care giving are about *collective determination and bringing decision-making to the most person-centered dimension possible*. They center on the

empowerment of the self while recognizing the need to structure and ensure a supportive network of friends around each person. *The more marginalized a person is, the more it is necessary to structure, enable, and empower this circle. The more self-reliant a person is, the more the individual him/herself generates his/her own support network.* In either case, we need to recognize the fundamental need for interdependence. If the circle of friends lacks the power and authority to empower the person as much as the person needs, then there is little self-determination.

### **WHO IS THE MOST AT-RISK OF BEING LEFT OUT?**

Devaluing is the process of society pushing people away from engagement in life. It is based on social injustice, prejudice against those seen as different or of lesser value, and a subconscious desire for those in power to be over those whom they devalue. Liberation is found in the recognition of one's own worth and the worth of others. It is expressed in our being-with-others, engagement with them, and being central in the definition of our own life-project.

Current social services systems unwittingly marginalize those whom they are designated to serve and support through almost total control and full decision-making authority. They define the people's needs, select what is good for "them", and watch over their system. Self-determination takes a different approach. The more the individual is central in his/her own life-project, the more self-esteem is strengthened and good choices are made. If self-determination is to have true freeing power it needs to lift all who are powerless.

Many individuals with strong intellectual skills also are burdened with hauntingly tragic life-stories as well as the inherent nature of various disabilities. For example, the individual still suffering from the trauma of years of institutionalization might need more support due to old memories based on fear and loneliness. The person with profound mental disability might require more support to understand and appreciate the world. The person who lives in an on-going nightmare of hallucinations or manic depression might need more support so that he/she remains feeling safe and loved during the worst moments of schizophrenia.

Liberation means having one's basic physical, intellectual, and emotional rights ensured. In one person, it might be sweeping the streets as if one is sweeping the heavenly stars. In another person, it might be leading a nation. In yet another person, it might be the mere act of smiling. For the homeless child, it might mean finding a home and becoming a member of a family. For the person with a severe intellectual disability, it might mean learning to communicate through sign language or gestures. For the teen-ager in a gang, it might mean slowly leaving the ways of the gang, finishing school, and starting a family. For the abused and neglected child, it might mean

learning to feel safe with a foster family. For the aged person wracked by senility, it might mean following a schedule that slows the loss of skills once found so easy.

There are many basic human needs that are obvious—nutrition, housing, education, work, and health care. Every individual is entitled to these; but, we also must recognize more subtle and essential emotional needs that are foundational to the human condition:

<b>LESS OBVIOUS BUT ESSENTIAL HUMAN NEEDS OF INDIVIDUALS</b>	
<input type="checkbox"/>	<b>THE NEED TO FEEL SAFE</b> —EACH PERSON NEEDS TO FEEL SAFE WITHIN HIM/HERSELF AND WITH OTHERS— THE RECOGNITION OF SELF AS MIND, BODY, AND SOUL FILLED WITH SELF-WORTH AND VALUE AND TO FEEL ACCEPTED
<input type="checkbox"/>	<b>THE NEED TO FEEL LOVED</b> — EACH PERSON HAS A NEED TO RECOGNIZE HIS/HER OWN VALUE, WORTH, CONNECTEDNESS WITH OTHERS, AND THE FULFILLMENT OF THE EMOTIONAL NEED TO BE AND TO FEEL SUPPORTED BY OTHERS
<input type="checkbox"/>	<b>THE NEED TO FEEL CONNECTED WITH OTHERS AND THE CAPACITY TO REACH OUT</b> — EACH PERSON NEEDS TO SEE SELF AS CONNECTED WITH OTHERS AND FIND ONE’S WORTH IN OTHERS
<input type="checkbox"/>	<b>THE NEED TO BE ENGAGED IN ONE’S WORLD</b> —EACH PERSON NEEDS TO FEEL THAT HE/SHE IS AN ACTIVE PARTICIPANT IN LIFE, CONNECTED WITH OTHERS, BRINGING MEANING TO SELF AND OTHERS, AND ENCOUNTERING A SENSE OF PRIDE IN ONE’S CONTRIBUTION TO OTHERS

We need to have a clear understanding of basic emotional needs, who are most at-risk of being further marginalized in this process, and how we can ensure true empowerment. In any movement to serve and support individuals with intellectual disabilities, there is a broad spectrum of needs that have to be recognized. These have to be distinguished from what individuals want. Society’s focus and constitutional guarantees have to ensure that each person has what he/she needs.

#### **WHAT CAN HAPPEN IF THESE EMOTIONAL NEEDS ARE UNFULFILLED?**

Without this sense of connectedness, all dreams dry up like raisins in the sun. For example, unfulfilled needs are expressed in a multitude of ways in human beings— the mother who has lost her baby and wants to kill herself, the spouse who is being beaten and wants to soak her sorrow in booze, the homeless child who joins a gang to find meaning, the illiterate man or woman who is humiliated by the inability of not

being able to read or write, the person in a wheelchair who has much of the world closed and inaccessible due to lack of mobility, the person with mild intellectual disability who feels he/she is “different”, or even worthless, but can do nothing about it, or the child or adult who is totally dependent on others due to extreme physical or cognitive problems.

<b>BASIC HUMAN NEEDS UNFULFILLED CAN LEAD TO...</b>	
<input type="checkbox"/>	A SENSE OF WORTHLESSNESS BECAUSE THE PERSON FEELS “I HAVE NO ONE! I AM NOBODY! I WANT TO BE SOMEBODY!”
<input type="checkbox"/>	SELF-ISOLATION BECAUSE THE PERSON DOES NOT KNOW HOW TO REACH OUT, SOCIETY THWARTS THOSE WHO ARE SEEN AS DIFFERENT, AND IT IS EASIER TO WITHDRAW THAN REACH OUT
<input type="checkbox"/>	HAVING A HOUSE BUT BEING HOMELESS—A WALLOWING IN THE EMOTIONAL MUD OF LONELINESS
<input type="checkbox"/>	AGGRESSION TOWARD SELF OR OTHERS BECAUSE LASHING OUT IS A WAY TO DEAL WITH EMPTINESS AND FRUSTRATION

Choice-making in and of itself does not assure well being; it can only enhance it. Individuals who can articulate their wants do not necessarily communicate their needs. We all need others in our life whom we can trust and help us discern what we need to maintain or deepen our sense of self-worth. Individuals who cannot communicate their needs are at an extreme disadvantage in choice-making. Those who can communicate their needs are often vulnerable to the slightest hint of rejection. Many have to have trusted others surrounding them to be their advocates and spokespeople while they are in the process of becoming grounded with their circle of friends. Others are very articulate but latch onto what they see others as having, such as a house of their own, and reach the incorrect conclusion that these possessions will bring well-being in and of themselves.

There is also an inherent danger if government or its surrogates, such as managed care, decides that money is the driving force in self-determination. Control and authority over the financing of self-determination is a fragile right that needs to be clearly guaranteed, not just for housing, but for enabling a feeling of being-at-home. If it is not, future years will witness self-isolation instead of active and meaningful participation in the community, the evaporation of freedom and autonomy, and the making of decisions on one’s own a hollow victory.

#### **WHAT IS THE ROLE OF THE MONEY MANAGER?**

We have a duty to ensure that tax money is spent responsibly. A premise of self-determination is that a tool for personal autonomy is the implementation of a voucher system that assures the fulfillment of basic human needs. These needs are defined by the person and circle of friends within reasonable parameters set by society. The person and circle of friends, through a voucher system, access the financial support for the fulfillment of the person's essential needs. The voucher:

1. Cuts out the concept of agencies as middle-man deciding in cookie-cutter fashion what is right for everyone;
2. Lets each person with his/her circle of friends decide what is needed; and,
3. Through the above, places financing in the hands of the person and/or the circle of friends.

A voucher system ensures greater autonomy through the person's responsibility for defining and paying for his/her own needs. It also presents many vital questions related to each person's well being:

#### A VOUCHER SYSTEM IS MORE THAN INDIVIDUAL CHOICE

- If rights are to be preserved, each person who participates in self-determination needs to be organized with others so that their collective power will always be a strong reminder to government that the entitlement to basic human rights will spread to all marginalized people and will endure in the future.
- Service providers need to redefine their roles within this new reality, especially formulating ways to support each person and his/her circle without supplanting them and ensuring that access to a range of community services is available to meet complex human needs.
- Since financial empowerment is a key force, those who are most marginalized (e.g., chronic mental illness, severe medical and sensorial problems, and violent behaviors) need to be guaranteed equal empowerment through more structured approaches to circles of friends.
- A feeling of connectedness with others precedes individual choice-making and gives meaning to it.

#### HOW CAN WE PUT EVERYTHING TOGETHER?

Self-determination and gentle care giving are marked by a *process of empowerment*. The key is not possessions, but *authorship of one's own life-project*. Their synthesis ensures:

A SYNTHESIS OF GENTLE CARE GIVING AND SELF-DETERMINATION ENSURES THAT...

- EACH PERSON IS WELL-GROUNDED IN A SENSE OF SELF AND CONNECTEDNESS TO OTHERS
- EACH PERSON HAS A CIRCLE OF FRIENDS
- THE PERSON WITH HIS/HER CIRCLE OF FRIENDS IS AT THE CENTER OF THE DECISION-MAKING PROCESS
- A VOUCHER SYSTEM PLACES EMPOWERMENT AND DECISION-MAKING IN A CONCRETE FORM BY MAKING THE PERSON AND CIRCLE OF FRIENDS THE RESPONSIBLE AGENTS FOR THE INDIVIDUAL'S WELL-BEING
- EACH PERSON PARTICIPATES TO THE MAXIMUM EXTENT POSSIBLE IN HIS/HER OWN DECISION-MAKING PROCESS
- THE DEGREE OF SUPPORT A PERSON REQUIRES IS BASED ON A SHARP SENSITIVITY TO WHAT THE PERSON NEEDS EMOTIONALLY AT ANY GIVEN MOMENT
- NECESSARY SUPPORT IS AVAILABLE AND ACCESSIBLE TO EACH PERSON AT THE MOMENT HE/SHE NEEDS THE SUPPORT— A FLEXIBLE AND QUICKLY RESPONSIVE GRADIENT OF SUPPORT DEPENDING UPON THE PERSON'S VARYING EMOTIONAL NEEDS AND SENSE OF CONNECTEDNESS
- THE CENTRAL FOCUS IS TO DEEPEN AND BROADEN THE NECESSARY SENSE OF COMPANIONSHIP AND COMMUNITY IN EACH PERSON

In practice, this common ground requires new thinking about the role of professionals and service agencies. The practical central issue is the *locus of control*. Current practice gives almost complete control to agencies and professionals. This leaves the individual almost totally dependent and subservient. An opposite tendency would be a hedonistic posture of "Let them make their own decisions. Give them what they want and they will be happy!" Self-determination does not mean dumping people into the community and proclaiming, "Sink or swim!" A sole focus on the individual outside the context of companionship and community will lead invariably to a sense of emptiness. No one is capable of formulating and fulfilling his/her dreams without having significant others in their life such as family, parents, spouses, girl/boyfriends, advocates, and companions.

The center of control and authority needs to move from professionals and agencies to the person and his/her circle of friends, but within the context of broadening and deepening a sense of connectedness. As time

evolves, self-determination calls for all those involved in supporting marginalized individuals to move from the center of decision-making authority to a secondary, supportive role and the repositioning of the person and circle of friends from the fringe to the center.

### **WHAT ARE THE CHALLENGES?**

The challenges to facilitating each person's self-determination are many. The road is strewn with debris. A substantial shift in thinking and common practices needs to occur:

<b>ROADBLOCKS TO EMPOWERMENT...</b>
<input type="checkbox"/> <b>REPOSITIONING OF THE LOCUS OF CONTROL</b>
<b>FROM AGENCY-BASED TO PERSON-CENTERED AND FRIENDS-CENTERED</b>
<input type="checkbox"/> <b>CREATING A VOUCHER SYSTEM BY RE-POSITIONING THE CONTROL OF MONEY</b>
<b>FROM AGENCY-BASED TO PERSON-BASED AND, THEREBY, MAKING THE PERSON THE AUTHOR OF HIS/HER OWN CHANGE PROCESS</b>
<input type="checkbox"/> <b>REDEFINING THE ROLE OF AGENCIES</b>
<b>FROM AN AUTHORITARIAN CONTROL OF DECISION-MAKING TO AUTHORITATIVELY ENSURING A SUPPORTIVE NETWORK</b>
<input type="checkbox"/> <b>REDEFINING THE ROLE OF PROFESSIONALS</b>
<b>FROM BEING IN CONTROL OF DECISION-MAKING TO BEING SUPPORTIVE OF EACH PERSON AND/OR THE PERSON'S CIRCLE OF FRIENDS</b>
<input type="checkbox"/> <b>REDEFINING THE ROLE OF GOVERNMENT—COUNTY, STATE, FEDERAL</b>
<b>FROM HEAVILY REGULATED OVERSIGHT TO A VOUCHER SYSTEM TO EACH PERSON</b>
<input type="checkbox"/> <b>REDEFINING THE ROLE OF CAREGIVERS</b>
<i>FROM AUTHORITARIAN FIGURES SEEKING COMPLIANCE TO COMPANIONS ENABLING FEELINGS OF BEING SAFE, LOVED, LOVING, AND ENGAGED IN THE FULLNESS OF COMMUNITY LIFE</i>

**CREATING CIRCLES OF FRIENDS**

*ENSURING THAT THE PERSON AND HIS/HER CIRCLE OF FRIENDS ARE AT THE CENTER OF DECISION-MAKING AND CONTROL AND THAT THESE CIRCLES ENDURE AND EXPAND OVER TIME*

**WHAT IS THE NEW PARADIGM AND WHAT IS IT NOT?**

Self-determination and gentle care giving need to be understood as a whole cloth. Each is dependent on the other and gains deeper meaning from the other. A shallow or narrow grasp of either one will only serve to further marginalize vulnerable individuals.

WHAT IT IS NOT...	WHAT IT IS...
<p><input type="checkbox"/> IT IS NOT DUMPING</p> <p><input type="checkbox"/></p> <p><input type="checkbox"/> IT IS NOT PRIMARILY ABOUT INDEPENDENCE</p> <p><input type="checkbox"/> IT IS NOT "A DO WHATEVER YOU WANT AND YOU WILL BE HAPPY" POSTURE</p> <p><input type="checkbox"/> IT IS NOT ABOUT PROFESSIONALS TELLING OTHERS WHAT TO DO</p>	<p><input type="checkbox"/> IT IS A WAY TO ASSURE THAT BASIC HUMAN NEEDS ARE MET</p> <p><input type="checkbox"/> IT IS ABOUT THE RECOGNITION OF HUMAN INTERDEPENDENCE AS THE FOUNDATION OF INDEPENDENCE, AUTONOMY, AND FREEDOM</p> <p><input type="checkbox"/> IT IS THE RECOGNITION THAT THE BEST DECISIONS ARE MADE BY THE PERSON AND CIRCLE OF FRIENDS</p> <p><input type="checkbox"/> IT IS ABOUT PLACING THE PERSON IN THE CENTER WITH CLINICIANS PLAYING A SUPPORTIVE ROLE AT THE REQUEST OF THE PERSON AND CIRCLE OF FRIENDS</p> <p><input type="checkbox"/> IT ABOUT ENABLING PEOPLE WHO ARE MARGINALIZED TO BECOME THE AUTHORS OF THEIR OWN LIFE-PROJECT</p> <p><input type="checkbox"/> IT IS ABOUT THE USE OF MONEY AS A TOOL TO PLACE DECISION-MAKING IN</p>



<ul style="list-style-type: none"> <li><input type="checkbox"/> IT IS NOT ABOUT CONTROLLING OTHERS</li>   <li><input type="checkbox"/> IT IS NOT PRIMARILY ABOUT MONEY</li>   <li><input type="checkbox"/> IT IS NOT ABOUT INDIVIDUALS IN SOCIAL SERVICE SYSTEMS</li> </ul>	<p style="text-align: center;">THE HANDS OF THE PERSON INVOLVED</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> IT IS ABOUT INDIVIDUALS FORMING THEIR OWN CONNECTEDNESS WITHIN THE LARGER COMMUNITY, DEFINING THEIR OWN DREAMS, AND MAKING THEMSELVES ACTIVE PARTICIPANTS IN THEIR LIFE-PROJECT</li> </ul>
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**WHAT DOES THE FUTURE HOLD?**

The future holds much promise. However, we need to recognize that promise is also accompanied by anxiety. Change is hard. We need to be the servant leaders in this promise by bringing a sense of hope and being creative. If our focus stays on the well-being of those whom we serve, we will forge deeper and broader ways to help the most marginalized become more active participants in their own life-project and we will help ourselves strengthen our commitment to others.

In the future, Luke’s dreams will be fulfilled. He will have a roommate who is his friend and companion. He will have significant others in his life who will make him feel connected and included. His friends will take joy in being his companions. He will have people to call and visit. He will go out and discover others who want to be his friend. He will not be dependent or beholdng on others to beg for what he desires. His circle of friends will help him discern how he can continue to grow in self-esteem and connectedness.

*Luke eyes will be filled with warmth. His arms will reach out to others. His words will be penetrated with hope. His dreams will become reality.*