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Date: 9/19/97

Pages (including cover): 14

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Subject/Remarks:

Do you mind taking a look
 at this ROUGH draft?

Appreciate it!
 Irene

Urgent? Yes No

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Rough Draft

THE ORIGINS OF SELF DETERMINATION

By: Irene Ward

Most disability historians will acknowledge that the concept of self-determination (determining for oneself) grew out of the Independent Living (IL) Movement in the late 1960's.

A young man by the name of Ed Roberts, a student at Berkeley¹ at the time, dared to question university policies related to access and housing. Roberts was soon joined by others on and off campus.

For a time, they were known informally as "the rolling quads." This ragtag group went on to form the first Center for Independent Living (CIL). By 1972, there were at least five CILs similar to Berkeley. Today, there are more than 400 centers throughout the U.S.

The Medical Model:

The IL Movement emerged, in part, as a reaction to the Medical Model (Table 1. below).

1. The condition of disability is an "illness."
2. Physicians and other practitioners are experts.
3. Care should be administered through a chain of authority where the physician/expert is the Principle decision maker.
4. The "patient/client" is expected to assume the sick role.
5. The purpose of medicine is to provide acute or restorative care.
6. "Illness" is muted primarily through ongoing treatment.
7. "Illness" can only be diagnosed, treated and certified by experts.

¹ DeJong, Carben (1979) "The Movement for Independent Living: Origins, Ideology and Implications for Disability Research"

People with disabilities were herded together in separate facilities and away from mainstream society. They were exempted from any responsibility for themselves.

There were no expectations of achievement. Life was to be spent being fixed and cared for. As "sick" people, social activities (other than those arranged for them) were discouraged or unattainable.

Practitioners and proponents of the medical model probably viewed their methods as humane and "best practice" at the time; after all, the U.S. Eugenics Movement of previous decades was really inhumane and intolerable by comparison. Besides, what could someone who was "impaired" mentally or physically really contribute to society as a whole? These poor unfortunates needed to be cared for and kept separate from the cruel world out there.

The Disability Rights Movement

The 1960's were also a time of great social changes in the United States. The Civil Rights Act of 1964 followed a decade or more of protests by African Americans. The Woman's Movement demanding equal rights and equal pay was in full swing. The Consumer Movement, lead by Ralph Nader, demanded product safety, truth in advertisement and government oversight of processes that posed potential harm to U.S. citizens.

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THE ORIGINS OF SELF DETERMINATION (Continued)

People with disabilities absorbed these issues, began banding together and raising questions about their own civil rights. There was no such thing as equal access and equal opportunity. People were excluded from society's mainstream, often as a direct result of the humane systems in place to care for them.

People wanted greater control over their own lives and over their own services. They wanted to have social lives, families, education, careers and respect. They wanted to take risks and participate in the American dream...

But most of all, they wanted to eliminate the dehumanizing processes and dead ends. They wanted a wide array of choices defined and limited only by their own creativity. And, they were willing to take responsibility for changing attitudes, eliminating barriers and coaching their peers through a new concept: organization run by people with disabilities, for people with disabilities.

Thus, the concept of self-determination was born and nurtured as the centerpiece of the Independent Living and Disability Rights Movement.

Central to these principles is the concept that we all need to be working together to change our society and our communities... not the person with a disability.

In an effort to achieve this, people with disabilities banded together over the past three decades to introduce and promote the passage of a series of laws in an attempt to level the playing field. At the same time, families and other advocates

TABLE 2: Federal Laws Supporting the Independent Living Philosophy

1968	Architectural Barriers Act (designed to eliminate architectural barriers in all federally owned or leased buildings).
1970	Urban Mass Transit Act (required that all new purchases of mass transit vehicles be lift equipped; APTA sought and won a court injunction barring implementation of the proposed regulations).
1973	Rehabilitation Act (Section 504 and related non-discrimination provisions in programs receiving federal funds).
1975	Developmental Disabilities Bill of Rights Act (Protection & Advocacy or P&A agencies in each state established).
1975	P.L. 94-142, Education of All Handicapped Children Act , now titled Individuals with Disabilities Education Act or IDEA (written to require a free, appropriate integrated public education for children with disabilities; "mainstreaming" children with disabilities into regular classrooms).
1978	Rehabilitation Act Amendments (Title VII, Comprehensive Services for Independent Living , was created; Part B funded creation and operation of "centers").
1983	Rehabilitation Act Admendments (mandated that each state operate a Client Assistance Project or CAP ; Title VII Part A funded to buy services for IL clients - a concept parallel to the basic VR program).
1984	Voting Accessibility for the Elderly and Handicapped Act (provided that all polling places must be accessible).
1985	Mental Illness Bill of Rights Act (expanded P&As to cover mental illness).

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THE ORIGINS OF SELF DETERMINATION (Continued)

TABLE 2: Federal Laws Supporting the Independent Living Philosophy (Continued):

1986	Rehabilitation Act Amendments (advocates fought for and won "consumer control" for Title VII Part B center boards; supported work programs created and funded).
1988	Air Carrier Access Act (designed to provide for equal access on private airlines).
1988	Civil Rights Restoration Act (clarified that any organization or corporation receiving federal funds may not discriminate in any of their programs).
1988	Fair Housing Act Amendments (prohibits discrimination against people with disabilities in housing and created universal design in new construction provisions).
1990	Americans with Disabilities Act (created broad civil rights protections for people with disabilities modeled after the Civil Rights Act of 1964).
1991	Civil Rights Act (allows for punitive damages in a civil suit for discrimination on the basis of disability in employment; strengthens Title 1 of ADA).
1992	Rehabilitation Act Amendments (dramatically restructured Title VII to set standards for centers for independent living, to create an independent statewide independent living council responsible for statewide planning of center networks and independent living services, and establishes direct funding for centers in states where state funding for center operations is less than the federal allotment).

Source:

Shreve, M. (1995), "The Independent Living Movement: History and Philosophy to Implementation", Chicago.

Table 2 summarizes the progress made over the past 30-year period.

The Family Movement

At the same time that the disability movement was gathering steam, a grassroots family movement was emerging around the country. Many of the laws cited in Table 2. relate to the family movement that called for school integration, deinstitutionalization and family-friendly services.

Organizations formed and run by families sought and received Federal and state operating grants and demonstration funds. National organizations emerged with state chapters and local affiliates, much like the IL movement.

Information is power. Becoming organized resulted in family groups becoming powerful lobbying units in an effort to influence public policy. Laws and regulations either impeded or supported family issues. The family movement became a voice to be reckoned with.

A Meeting of the Minds

In some respects, the Family Movement has meshed with the concepts reflected in the self-determination movement. Families have certainly wanted to reduce the influence of the medical model. Families have also wanted a greater say in how services were delivered. They wanted flexibility and tailor-made supports that met their unique needs. They, like the disability movement, were frustrated by fragmented systems of generic service delivery.

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THE ORIGINS OF SELF DETERMINATION (Continued)

But, the last three decades have also produced an unintentional hodgepodge of laws, public policies and interwoven philosophies that clash (sometimes severely) with one another. There are decades of work yet to be done to resolve the fragmentation of our funding mechanisms and reform the vast industry that has sprung up around the condition of disability.

One bright contribution to our future is the development of the *Partners In Policymaking* training curricula in 1987 by the Minnesota DD Planning Council. Dr. Colleen Weick, MDDPC's Director, partnered with Ed Roberts, founder of the IL movement, along with a host of committed family and systems change advocates, to develop a comprehensive approach that had all stakeholders at the same table. Those states that have invested in *Partners In Policymaking* have reaped rich rewards, especially when it comes to implementing self-determination.

Parting Comments

Self-determination has its roots in the civil rights movement. It became the founding principle of the Independent Living Philosophy. Many elements of the Family Movement also embrace self-determination concepts.

However, the IL movement may frighten the family movement when it comes to issues of control, risk taking and choice making. Many parents want a final say in all issues associated with their family member, regardless of their age or level of functioning. It's natural to fear the unknown or see differences in the condition of disability and make functional comparisons.

In the video, John O'Brien states that, "What people with disabilities can do is both unpredictable and amazing." Perhaps that is our greatest clue to sorting self-determination out.

- Let's concentrate on getting the safeguards in place.
- Let's take people as far as they can go.
- Let's insist that our systems stop amplifying differentness, dependency and disconnectedness and, instead, become a co-struggler with each individual.
- Let's also insist that we have adequate training support personnel in places where they are needed.
- Let's use our creative juices to solve problems in partnership with our communities.

Ultimately, real differences or fears between the disability and family movements fall by the wayside. What they both really want isn't all that different.

And, it's going to take some muscle power to retool outdated policies and redirect funding streams to places where they support (not compete with) self-determination.

A partnership between these two primary stakeholders would be a powerful and, perhaps, unstoppable combination.

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JOHN O'BRIEN'S FIVE VALUED EXPERIENCES & ACCOMPLISHMENTS

The 5 Valued Experiences	The 5 Valued Accomplishments
<p>1. Sharing ordinary places</p> <p>2. Growing in relationship</p> <p>3. Experiencing respect for who I am; having a valued social role</p> <p>4. Contributing (What am I here for?)</p> <p>5. Making choices</p>	<p>1. Supporting community presence</p> <ul style="list-style-type: none"> • What are we doing to promote opportunities to share ordinary places? <p>2. Supporting community participation</p> <ul style="list-style-type: none"> • What are we doing that gets in the way of people forging relationships with ordinary citizens? <p>3. Supporting valued social roles</p> <ul style="list-style-type: none"> • Are we taking direction from each person? • What are we doing to help people experience many possible roles? <p>4. Supporting contribution</p> <ul style="list-style-type: none"> • What are we doing to help people discover what they're good at? <p>5. Supporting Opportunities to Choose</p> <ul style="list-style-type: none"> • What kinds of supports do we provide for people to choose? • How are we helping people choose more wisely?

- Outcomes worth working toward.
- "Things that can't be purchased".
- Ways of belonging without compromising who people are.
- A social process.

- A way to audit ourselves.
- A way to reference our day-by-day actions in terms that help (or hinder) each person we work with.
- A political process.

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JOHN O'BRIEN NUGGETS

- "How it (self-determination) works depends on our capacity to solve problems together."
- "There is no road map. We need a compass. We're in uncharted territory."
- "We make the road by walking on it."
- "The hard part is moving out to change the patterns of disconnection, dependency, and differences that are built-in to our society, our culture and amplified by our service systems."
- "The only requirement (is) that we struggle together to make the way."
- "It's so easy to change our language without changing our structure and culture."
- "I don't think there are many incentives to change. People who have made changes do not talk about incentives. They say, "This is the right thing to do." They (typically) have concrete relationships with the people they serve."
- "Choice, all by itself, is a very slippery idea. People can fall prey to slick marketing campaigns that continue the patterns of segregation, disconnection and dependency, and still call it choice."
- "We are colonized in our choices by a whole set of social forces that want to make us consumers."

Hey . . . don't you think this is a good spot, perhaps, for a quotation?

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PATTERNS WE CAN IMPACT

John O'Brien discusses the three D's and the three I's in the video *What is Self Determination?* These concepts are reprinted below, along with clues related to how our systems fit in, now, and where we want to strive to be in the future:

The Three D's:	The Three I's:
Patterns practiced by our systems, society and culture.	New patterns worth working for to replace the Three D's.
1. DIFFERENT (not one of us).	1. INDIVIDUAL (like you and me).
2. DISCONNECTED (not part of our communities/culture).	2. INCLUDED (like you and me).
3. DEPENDENT (kept or managed).	3. INTERDEPENDENT (like you and me).

Systems Today:	Systems Tomorrow:
<ul style="list-style-type: none"> Control over people's lives until they get fixed or ready. 	<ul style="list-style-type: none"> People in control and doing things they can do and want to do.
<ul style="list-style-type: none"> Staff often cast in the role of being the keepers/spectators in people's lives. 	<ul style="list-style-type: none"> Staff as community builders and brokers in partnership with people and families (co-struggler).
<ul style="list-style-type: none"> Passive organizations that amplify the Three D's. 	<ul style="list-style-type: none"> Active organizations that amplify the Three I's.
<ul style="list-style-type: none"> Central Authority. 	<ul style="list-style-type: none"> Individual Choice (made to order).
<ul style="list-style-type: none"> Deeply entrenched patterns of organization and policies. 	<ul style="list-style-type: none"> Mobile and flexible coordination and supports, where people need them and want them.

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THE SLIPPERY, SCARY ELEMENTS OF CHOICE

John O'Brien speaks eloquently about choice and how slippery the concept can be, when cleverly packaged and promoted around FEAR. Fear has the potential to motivate families to choose segregation, disconnection and dependency, all under the guise of choice.

However, an elementary review of the dictionary (Table 1.) has revealed several interesting aspects related to the term *choice*, but in a slightly different light than O'Brien presented.

In ancient times, European and Mediterranean mariners used to mark the open ocean sections of their maps with the phrase, "*Here be Monsters.*"

We, as human beings, have always tended to fear the unknown. And, there are many unknowns attached to the notion of self-determination and choice that deserve earnest discussion.

For example, there are underlined passages contained in Table 1. that apply more to our systems than the individual act of choice-making. Are we, as a system, fearful that we wouldn't be chosen if people had the real right and power to choose? Do we offer a great variety of services from which people wish to select? Are our services of special excellence?

Have we dared to discuss the WIIFM (What's In It For Me?) aspects of our own fears and how that translates into our own motivations and actions? Are our fears more a product of not knowing or understanding the current or future role we could possibly play in support of a choice-driven system?

Are we afraid of the potential lack of structure and flexibility that "real choice" will require? Are we fearful of our future ability to support notes due on costly infrastructure (bricks and mortar) purchased with taxpayer funds (a.k.a.: we choose not to do choice because we have no choice...)? Are we afraid that someone is going to force us to deal with this because we're not quite ready?

Whose choices and fears are we really talking about here? Perhaps Franklin D. Roosevelt said it best, "*The only thing we have to fear is fear itself...*"

TABLE 1: Choice Defined	
Choice, n. [ME. <i>chois</i> , <i>choise</i> ; OFr. <i>chois</i> , <i>choix</i> , choice from <i>choisir</i> to choose]	
1.	The act of choosing; determination of the mind in preferring one thing to another; selection.
2.	The right or power of choosing; having options.
3.	A variety from which to choose.
4.	A supply that is well chosen.
5.	An alternative.
Syn. – Election, option, preference, selection	
Choice, a.	
1.	Worthy of being preferred; select; of special excellence.

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SAFEGUARDS

John O'Brien published a series of thoughtful safeguards in his 1990 paper, *What's Worth Working For?* The five basic concepts are reprinted in Table 1 (on the right of this page). O'Brien discusses safeguards as being a necessity "because many people are vulnerable."

Safeguards are a two-edged sword. On one side, fear of inadequate safeguards can become the primary reason systems or families fear risk taking. It becomes the excuse to block real choice making and self-determination efforts.

On the other side, failure to institute a balanced array of back-up mechanisms leaves people vulnerable to neglect.

But, one does not wield a sword by grasping the sharp edges of the blade. A sword is grasped by the handle. And, the "handle" in this case relates to getting a handle on the supports, policies and funding allocated by the systems that serve people.

Below is a brief checklist of questions that relate to O'Brien's safeguards. These are leadership and administrative policy questions that impact how safeguards are provided.

- To cut down on turnover, do the staff who have direct support responsibilities earn a living wage, with benefits?
- Do support staff have values that honor self-determination philosophy?
- Have support staff been adequately trained?
- Does the agency have a culture that supports innovation and creativity?

- Are staff supported by middle and upper-level management in resources, policies and procedures?
- Does the agency project an image that supports integration and inclusion in its community?
- Are the people served by the agency represented on its governing board?

TABLE 1: Providing Safeguards

1. Establish clear ways to identify people who are vulnerable and need protection. Keep revising procedures to balance between neglect and overprotection.
2. Budget time and money for ongoing back-up from someone the person knows. Be sure that people who are able have someone to call and someplace to go when problems arise. Be sure that someone regularly visits people who are not able to call for themselves.
3. Be active in finding out what's happening for people. Don't assume that no news is good news. Ask questions and listen carefully to people. Don't be afraid to identify or anticipate problems.
4. Be sure people know it's OK to decide something isn't working. Don't blame people for failures; learn by reflecting on mistakes and failures.
5. Be open to "outsiders". Learn from critics. Pay the costs of actively involving people with different interests and points of view.

AN OPEN MESSAGE

(To Organized Labor and Civil Servants)

expand to all helping people

Draft

I respect you and need you.

I know you only want to do your best.

I know that the policies and supports provided by your managers can be frustrating at times.

I get frustrated, too.

I know you want to grow, learn new skills and make the most your career.

Most of all, I understand that you need to earn a living wage to support yourself and your family.

I do not want to see you having to scrape by without adequate healthcare or retirement benefits.

I know about these things. I'm in the same boat.

So...Here is my pledge to you...

I will fight at your side to help you achieve these things.

I'll testify and urge my family and friends to help you too.

I'll make phone calls and write letters to politicians, policymakers, administrators and board members, if it will help you.

I'll even join your picket lines with placards and signs, if that's what it takes.

You can count on me to be there, as your partner.

But, here is what I expect in return...

See me as your fellow co-struggler.

Forget the labels and programs and hoops I've been made to jump through.

See me as a human being who has frequently been kept away and denied the everyday experiences you take for granted.

Argue with me if you must, but make it about respectful matters, not about controlling me.

And...when I'm ready to leave the comfortable, seperate world you work in, don't attempt to hold me back.

Follow me, support me and encourage me in places I want to be.

Listen to my hopes and dreams, even if the only way I'm able to communicate with you is through the sparkle in my eyes.

Believe in me.

Use your creativity and knowledge in support of my quest.

Please be my partner, and not my foe...

For if you are not, you must surely go.

--Author Unknown--

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NEW ROLES - NEW WAYS

Old Ways/Roles:	New Ways/Roles:
<ul style="list-style-type: none"> • Separate Schools. 	<ul style="list-style-type: none"> • P.L. 94-142 and IDEA.
<ul style="list-style-type: none"> • Commensurate wages in sheltered workshops. 	<ul style="list-style-type: none"> • REAL work and REAL wages.
<ul style="list-style-type: none"> • No access to post-secondary education and training. 	<p><i>Attending college</i></p> <ul style="list-style-type: none"> • A growing cadre of well-educated people with disabilities in responsible positions of authority.
<ul style="list-style-type: none"> • Institutions, ICF/MR's and nursing homes. 	<ul style="list-style-type: none"> • Supported living, CASA and ADA lawsuits.
<ul style="list-style-type: none"> • Yellow school buses or no transportation. 	<ul style="list-style-type: none"> • Accessible trains, vans, planes, regular buses and paratransit.
<ul style="list-style-type: none"> • "Retarded Bowling" and field trips. 	<ul style="list-style-type: none"> • Integrated recreation of all types.
<ul style="list-style-type: none"> • Political Action Committees (PAC's) and organized lobbying efforts by the disability industry. 	<ul style="list-style-type: none"> • Public testimony and organized lobbying efforts by people with disabilities and family advocates.
<ul style="list-style-type: none"> • Compliant consumers. 	<ul style="list-style-type: none"> • ADAPT, SABE, CILs and others.
<ul style="list-style-type: none"> • Inservices for staff 	<ul style="list-style-type: none"> • Inservices for people with disabilities • Skill building and new roles for staff.
<ul style="list-style-type: none"> • Facility-based everything. 	<ul style="list-style-type: none"> • Community-based everything, with supports.
<ul style="list-style-type: none"> • Control, differentness, segregation, dependency. 	<ul style="list-style-type: none"> • Self-determination, diversity, integration, interdependence.
<ul style="list-style-type: none"> • Fragmented funding and capitated service systems. 	<ul style="list-style-type: none"> • Federalism, states' rights and choice under managed care.

Amelia