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Self-Direction & Mental Health

March 16, 2005 1:00PM – 2:30 PM (EST)

Free Men And Women Self-Determination & Mental Health

Thomas Nerney



401 East Stadium Boulevard Ann Arbor, Michigan



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Current Public Policy in Support of Individuals with Disabilities

- Low to no Expectations
- Irrational and Contradictory Eligibility Requirements
- No focus on Real Life Goals and True Quality
- Often Compromise Basic Citizenship



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History and Meaning of Self-Determination

- Based on a “principled” approach—a new foundation for supporting all individuals with disabilities
- Based on a new set of system requirements --the “tools” of Self-Determination



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Directed at Re-Thinking

- Quality
- The purpose of public funding
- The impoverishment of an entire class of individuals
- High costs of the public system create “The Perfect Storm”



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The Principles and History From 1993

- **Freedom** - *to live a meaningful life in the community*
- **Authority** - *over dollars needed for support*
- **Support**- *to organize resources in ways that are life enhancing and meaningful –*



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The Principles and History From 1993

- **Responsibility** - *for the wise use of public dollars*
- **Confirmation** - *of the important leadership that persons with disabilities must hold in a newly designed system*



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The Blending of These Principles lead To:

- A person determining one's own course to live a meaningful life
- Creating an ECONOMIC future
- Allowing the individual to allocate public and (private dollars) in ways that simply make sense to them



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The Blending of These Principles lead To:

- Crafting a highly personalized plan using personal preferences and peer support where assistance is needed
- Allowing traditional and non traditional supports and services
- Allowing the person to take the “responsibility” and acknowledge that they are the prime determiner in choosing their path.



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The Most Important Outcome of the Blending of These Principles :

- That individuals who experience a disability are the primary experts
- That changes to the “public system” should be led by individuals who experience the disability



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The Tools Of Self-Determination

- **Highly personal individual budgets**
- **Fiscal management assistance**
- **Unbiased assistance conflict-of-interest free**



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Individual Budgets

- • A line item expenditure summary that includes how the dollars will be spent based on the principle of “support”



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Fiscal Management Assistance

- The use of organizations that will accept the allocation/individual budget and arrange for bills to be paid and IRS, labor and benefit issues to be addressed based on the personal budget
- Report on a regular basis to both the funding authority and the person with a disability



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Unbiased Assistance

- • The provision when DESIRABLE of assistance in creating a life plan and securing the supports necessary to achieve the goals of recovery and the realization of a meaningful life



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Re-Thinking Quality

- Current system relies at best on the low standard of “satisfaction” with human services and interventions
- We need to move to quality of life in addition to services



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Re-Thinking Quality

- A strong focus on universal human aspirations for a meaningful life targeting at least: a safe place to live, connections with the community, long term committed relationships and the production of income
- In other words, we need to look at the whole person and recognize the primacy of relationships, personal control and the end of impoverishment



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The Purpose of Public Funding

- To enable individuals with disabilities to craft a meaningful life deeply embedded in the community, pursue committed relationships, become active members of their communities and generate income without penalty
- To incorporate into public policy the belief that public dollars should be targeted at notions of recovery that address essential issues around what it means to be a full human being and a citizen of this country



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The Promise of Self-Determination

From its inception self-determination was rooted in:

- ✓ increased quality
- ✓ increased power for individuals with disabilities
- ✓ increased status within the community
- ✓ more equitable distribution of public funds



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Policy and Organizational Change

- Self-Determination rests on the creation of new policy and systemic structural changes that embrace the basic human and civil rights
- The “Tools” of self-determination are essential in leading to these policy and structural changes
- Additional barriers must be removed that prevent persons with disabilities from enjoying a quality life based on universal human aspirations



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Self-determination in Mental Health

- It is important in Mental Health and other services systems to understand that taking responsibility for one's own recovery has emerged as a high standard.
- This important aspect of self-determination needs to be promoted.
- However promotion of recovery and personal responsibility is or should be inseparable from support for living quality lives.



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Self-determination in Mental Health

- If this notion of quality can be adopted and promoted for individuals living with mental illness then we will need to forge a public policy and financing agenda that will address the forced impoverishment of individuals with mental illness.



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We Must Address:

- “Homelessness”
- The incarceration of so many
- The inability to sacrifice meager federal benefits in the frequently vain hope that employment will eventually sustain the individual.
- The low per capita investment that many states still make for this population.



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Addressing Forced Impoverishment

- The convergence of different and unrealistic eligibility requirements for benefit programs serves to keep individuals with disabilities virtually totally impoverished in order to preserve often meager benefits.
- SSI
- Medicaid



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The High Costs of the Present System

- “The Perfect Storm”
- Medicaid retrenchment
- Overpowering demographics
- Shrinking workforce



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The System of the Future

- Merged Medicaid and Social Security waivers (for example, the Florida Freedom Initiative)
- Changes to what can be purchased with public dollars
- An end to the MONOPOLY of human services and the beginning of a free market system



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The System of the Future

- Safe and affordable housing
- A new priority for psychiatric disability in vocational rehabilitation
- New system crafted and led by individuals who experience disability



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The Dangers

- Research and data collection to date have been built around the old system values that lack an adequate foundation for determining what needs to be evaluated.
- Self-Direction has been marketed as the end product instead of as a necessary means to an end: a meaningful self-determined life.



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The Dangers

- Without a new and deep foundation for change based on important AMERICAN principles, the principles will be compromised
- Systems resist, are slow to change and easily sabotage these efforts.



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New Hope

- Self-Determination can offer a new sense of hope.
- It can augment and support progressive ideas about recovery.



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New Hope

- With support, antiquated laws, rules and regulations can be changed based on a new set of values that deeply respects individuals who experience disability.
- Self-Determination can add a foundation for addressing the need for working with the whole person and not some bifurcated, clinically isolated and labeled aspect of that person.



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Self-Determination Is About:

- The restoration of full citizenship
- The pursuit of the AMERICAN dream
- Part of the broad civil and human rights movement
- It is about free men and women who exercise those freedoms granted by the Bill of Rights and the Constitution and achieve full equality



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Skill-Building for Systems Change

Jean E. Tuller

Oregon Technical Assistance Corporation



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A Thought from Vaclav Havel

- A better system is not something that can be
 - introduced like a new car; it must become
 - more than just a new variation on an old
 - degeneration.
- A better system will not automatically ensure a
 - better life... In fact, it is through helping a
 - person create a better life that a better system
 - will be created.



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Three Variations on Systems Change

- Florida Self-Directed Care
- Piedmont 1915 (b)/(c) Concurrent
 - Waiver: Concord, North Carolina
- Empowerment Initiatives Brokerage:
 - Portland, Oregon



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Florida Self-Directed Care

- Created in 2001
- The program's mission is to create, maintain, and
 - enforce an environment in which participants can
 - navigate the road to recovery on their own terms and
 - make informed choices along the way
- Overseen by an advisory board composed of
 - participants and family members



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Florida Self-Directed Care

- 100 participants @ average of \$2,400 per participant per year)
- A fiscal mechanism that gives individuals with a psychiatric disability access to mental health services
- An independent brokerage service designed to support each individual's personal goals as each person navigates the road to recovery



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Piedmont 1915 (b)/(c) Concurrent

Waiver: Concord, North Carolina

- Functions as Prepaid Inpatient Health Plan
- Savings to be reinvested into consumers
- Free choice of providers within the PIHP
- Plan is to use savings in part as vehicle to
 - expand into consumer-directed services for
 - Medicaid-eligible people with MH and/or
 - substance abuse concerns



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Empowerment Initiatives Brokerage

- Funded by CMS Real Choice grant
- Based in Multnomah County, OR
- Partnership between OR Office of Mental Health and Substance Abuse, Portland State University and OTAC
- Consumer/survivor Board of Directors
 - and staff
 - 25 participants
- Started April 2004



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Seven Brokerage Functions

- Define goals and develop plans to achieve them
- Access opportunities, resources and supports to achieve goals
- Expand range of employment, housing, recreational and other opportunities through community development and networking
- Access information and education that increases capacity to make informed decisions, achieve goals and direct supports



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Seven Brokerage Functions

- Pay bills and negotiate contracts necessary to
- implement plans
- Do employment paperwork, background checks and
- hiring, training and supervision of staff
- Monitor achievement of plan goals and quality of
- supports, and make adjustments as needed



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Support Brokerage Structure

- Consumer plans have up to \$3000 to
 - purchase needed supports
 - Brokerage dollars supplement current system
 - services
 - Consumer/survivor driven feedback on the
 - efficiency, effectiveness, and outcomes



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Evidence-Based Evaluation Tool

- Service Quality and Outcome Evaluation of Current Mental Health Services (completed by consumer)
- Service Quality and Outcome Evaluation of Empowerment Initiatives Brokerage (completed by consumer)
- Service Quality and Outcome Evaluation for EIB Consumers (completed by support brokers using evidence-based practices – Internal Survey)

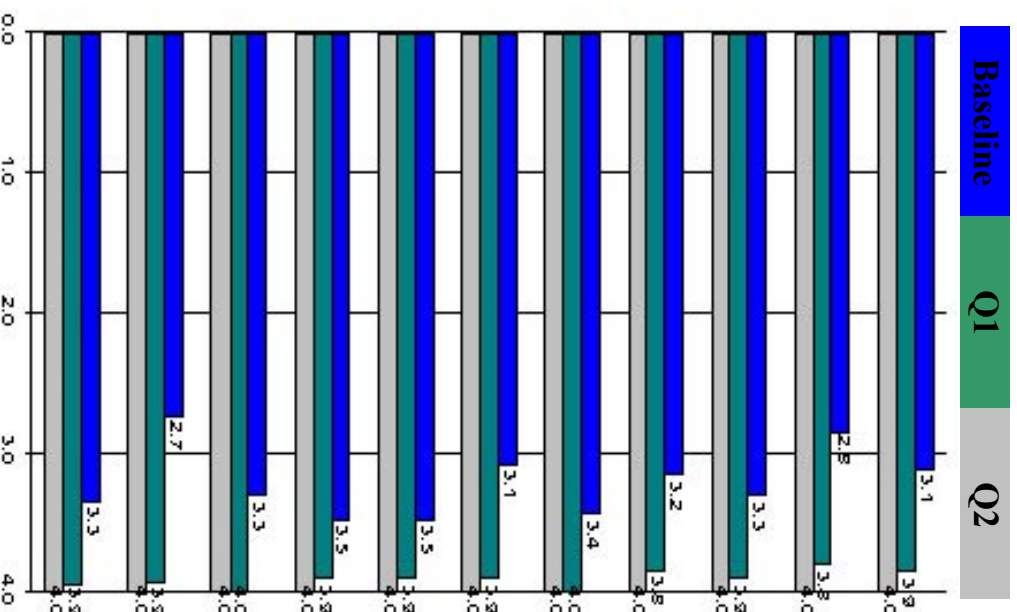


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Current or Traditional Mental Health Services/Brokerage Services

1. Service(s) provides access to information and resources.
2. Service(s) provides a range of options to make decisions.
3. Staff are available when I need them.
4. Staff understand my needs and wants.
5. Staff treat me as an equal.
6. Staff are sensitive to my cultural needs and preferences.
7. Staff encourage me.
8. Staff try to help and support me as best they can.
9. I feel comfortable speaking with staff.
10. I received the education and training I need to reach my goals.
11. Staff have helped me, or are helping me, to meet my goals.



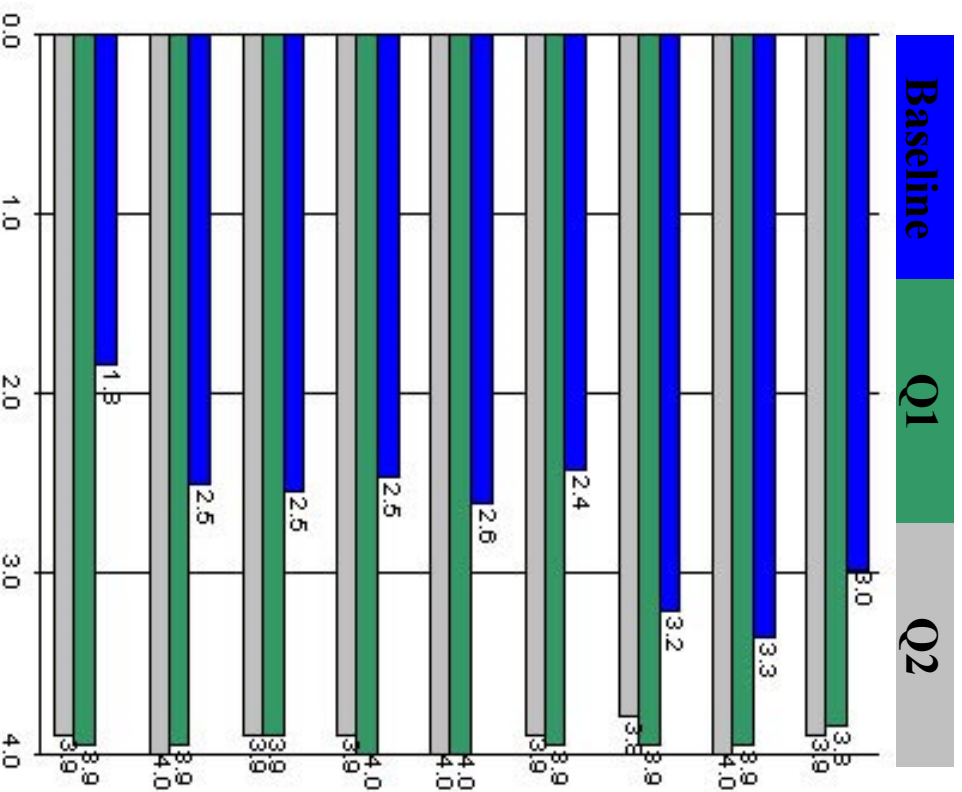


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Goal Attainment Planning and Service Budgets

1. I felt in charge of the planning process.
2. My plan reflects what is important to me.
3. My plan reflects my decisions
4. I have a copy of my plan.
5. The planning process was helpful in providing direction or setting priorities.
6. My current service(s) budget process was explained to me.
7. My current mental health service(s) budget reflects my choices.
8. My current mental health service(s) budget meets my needs.
9. I have a copy of my current mental health service(s) budget.



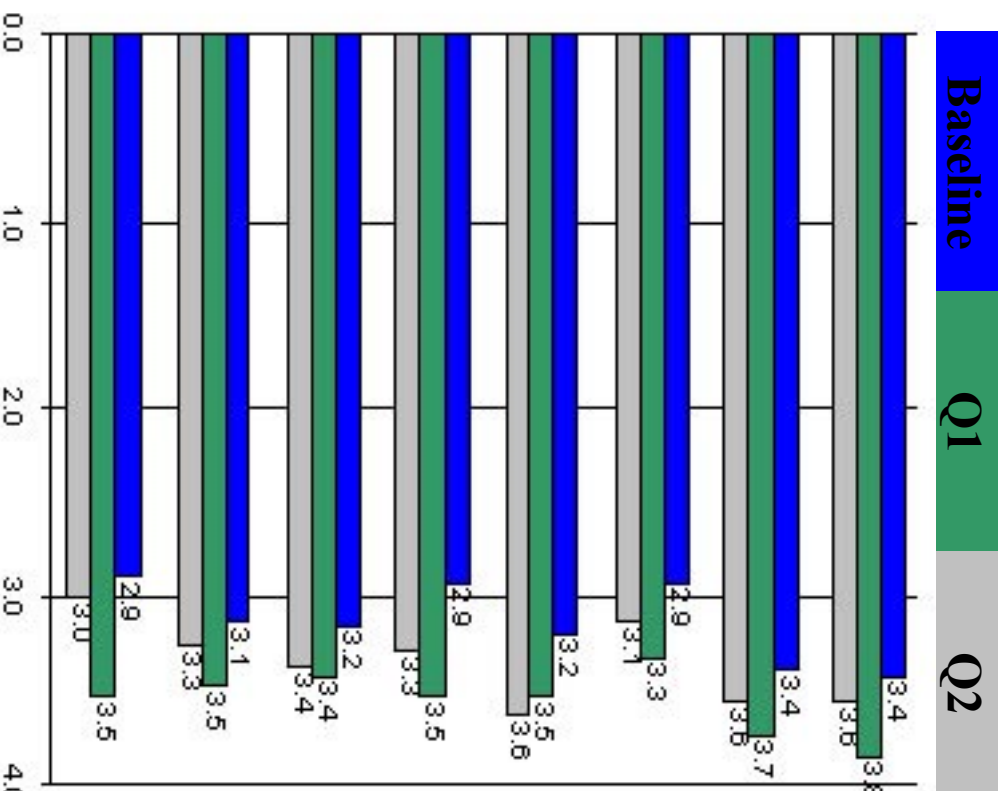


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Individual Empowerment

1. I make my own decisions.
2. I am able to assert my will.
3. I know I am an equal member of my community.
4. I feel comfortable speaking up for my rights and myself.
5. I am able to manage my supports.
6. I am confident as an individual.
7. I am confident in my independence.
8. I feel in control of my own life.





Service Quality and Outcome Evaluation for EIB Customers Summarized as of January 26, 2005

Total Customers: **25**

- Customers working in a competitive job - **9**
 - (Competitive employment means a job for which anyone may apply that pays at least minimum wage)
- Current living arrangements:
 - Live with relatives but is largely independent – **1**
 - Independent Living – **24**
- Customer's Educational Status:
 - Enrolled in formal educational courses in college - **11**
 - No educational participation - **14**



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Some Great References

- Competence Issues in Self-Directed Care: Susan Stefan [March 2004]
- Promoting Self-Determination for Individuals with Psychiatric Disabilities through Self-Directed Services: A Look at Federal, State and Public Systems as Sources of Cash-Outs and Other Fiscal Expansion Opportunities: Cook, Terrell and Jonikas [March 2004]
- History, Principles and Definitions of Consumer-Direction and Self-Determination: Unzicker [October 1999]



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RECLAIMING OUR LIVES: Peer-to-Peer Services and the Importance of Self-Direction in Mental Health Systems

Judi Chamberlin

**Director of Education and Training
National Empowerment Center, Inc.
Lawrence, MA**



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What Are Peer-to-Peer Mental Health Services?

- Programs which are run and controlled by their users
- Also known as peer support, mutual support or self-help
- Programs include support groups, drop-in centers, “warm lines,” crisis programs, housing programs, and more



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Who Uses

Peer-to-Peer Services?

- Adults who have been diagnosed with serious mental illness
- Living in the community
- may or may not also be participating in formal mental health programs
- Participation is voluntary



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Peer-to-Peer Services:

An Example of Self-Direction

- They are grass-roots and evolve from expressed needs
- Their members set the direction and underlying philosophy
- Their members become forceful advocates for their continuation and expansion



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Basic Principles of Peer-to-Peer Services And of Self-Direction

- Having a diagnosis should not limit the right to make choices about one's life
- People have inherent value and their choices should be respected
- People in peer-to-peer services experience the value of contributing as well as receiving
- Peer support helps people to take responsibility for their lives
- Recovery is real and possible for all people diagnosed with mental illness



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Peer-to-Peer Services:

An Example of Self-Direction

- Professionals are trained that the existence of serious mental illness impairs decision-making
- Paternalistic assumptions that professionals know best
- Coercion is inherent in the system, both in-patient and out-patient



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Barriers to Self-Direction

- The “brain disease” theory of mental illness
- Perception of people diagnosed with mental illness as inherently unable to make “good” decisions
- Recovery is not seen as a real possibility for most people
- Separation of mental health from general health and from disability



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Support for Self-Direction In Mental Health

- Surgeon General's Report (1999)
- *From Privileges to Rights*, National Council on Disability (2000)
- President's New Freedom Mental Health Commission Report (2003)



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- # **Self-Direction Is The Future of Mental Health**
- Growing recognition of the rights of people with all disabilities to control their own lives
 - Organizing by people with disabilities to change systems to meet their self-defined needs
 - Mental health is **NOT** separate and apart



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NOTHING ABOUT US, WITHOUT US!