

Self-Advocacy by People with Mental Health Conditions

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Inc.

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A Massachusetts-based consumer-directed and staffed quality improvement, evaluation and research organization (www.cqi-mass.org).

CQI evolved out of the consumer empowerment and recovery movement.

CQI's Mission

- To develop opportunities for meaningful involvement of consumers and family members in all aspects of mental health research and program evaluation.

What is a Serious Mental Illness?

■ Diagnostic Issues:

There are many mental illness diagnoses; diagnosing someone correctly is complex.

■ Concept of Recovery:

Recovery refers to the unique, personal process in which people are able to live a fulfilling and productive life and participate fully in their communities despite a mental health condition/ disability.

What is a Serious Mental Illness?

Recovering from the losses associated with a mental health condition:

- A loss of valued roles
- A loss of interpersonal connectedness
- A loss of sense of self
- A loss of power and self-efficacy
- A loss of hope

Challenges to Effective Self-Advocacy by People with Mental Health Conditions

- **Disabling effects of a mental illness diagnosis**
- **Learned dependency**
- **Coercion and involuntary treatment**
- **Perceptions of risk and dangerousness concerns**
- **Stigma and discrimination**

Foundations of Recovery and Transformation

- The Consumer-Survivor Movement
- Policy Support for the Recovery Paradigm and Consumer-Driven System
 - The President's New Freedom Commission Report
 - SAMHSA Consensus Statement on Recovery
 - CMS's endorsement of peer support services and peer specialists

The President's New Freedom Commission Report:

“In a consumer- and family-driven system, consumers choose their own programs and the providers that will help them most. Their needs and preferences drive the policy and financing decisions that affect them.”

“Increasing opportunities for consumers to choose their providers and allowing consumers and families to have greater control over funds spent on their care and supports facilitate personal responsibility, create economic interest in obtaining and sustaining recovery, and shift the incentives towards a system that promotes learning, self-monitoring, and accountability.”

<http://www.mentalhealthcommission.gov/>

SAMHSA National Consensus Statement on Recovery

Fundamental components:

Self direction

Person-centeredness

Empowerment

Holistic

Non-linearity

Strengths base

Peer support

Respect

Responsibility

Hope

<http://www.mentalhealth.samhsa.gov/publications/allpubs/sma05-4129/>

Transitioning from Institutions to the Community

Paying attention to agency (i.e., motivation) in early stages of transition and pathways (i.e., specific problem-solving and strategy interventions) in later stages of transition

A person who has become dependent on institutional services can experience increased agency through recovery-oriented services, such as peer support, peer specialist services

Creation of a Recovery and Empowerment Infrastructure

- Role of Peer Specialists
- Role of Recovery Learning Communities and consumer-run organizations
- Role of peer-led education and support programs in training peers, staff and policy makers to overcome self-advocacy challenges
- Role of advanced directives

Other Specific Concerns for Money Follows the Person programs

- Danger of self-advocacy challenges replaying themselves in Money Follows the Person programs
- Importance of “community liaison” understanding mental health issues
- Peer specialists and Recovery Learning Communities could play an important role in overcoming these challenges

Resources

- Pat Deegan & Associates, LLC,
www.patdeegan.com
- Mental Health Recovery and WRAP, Mary Ellen Copeland, www.mentalhealthrecovery.com
- Pathways to Recovery, Priscilla Ridgway et al.,
www.socwel.ku.edu/projects/SEG/pathways.html
- The Recovery Workbook, BU Center for
Psychiatric Rehabilitation,
www.bu.edu/cpr/products/curricula/recovery.html

Resources

- National Association of Peer Specialists, www.naops.org
- The Center for Self-Determination, www.self-determination.com
- National Empowerment Center, National peer-run TA center, www.power2u.org
- National Mental Health Consumers' Self-Help Clearinghouse, The Freedom Self-Advocacy Curriculum, www.mhselfhelp.org/training/view.php?training_id=7
- The Transformation Center, Mass. peer-run TA center, www.transformation-center.org

Contact Info:

- For more information please contact David Hughes from HSRI at 617-844-2527 or DHughes@hsri.org

A Parent's Perspective

Money Follows the Person

**Presenter:
Charlotte Cronin**

Daniel Cronin



What do I want for my son?

- I want him close to me.
- I want him in the community where he grew up, around the people who have known him and cared about him all of his life.
- I want him to be able to make friends with people who do not have disabilities in the same settings that people who do not have disabilities make friends.
- I don't care as much about him having a job as I do about him not being bored.

What do I want for my son?

- I want his job opportunities to be in the community along side people who don't have disabilities.
- I want him to be able to do things in which he has pride.
- I want to be able to interact with him naturally and often.
- Of course, I want him safe.
- I want him to have opportunities to learn in, grow in, and give back to his community.

What supports do I want for my son?

- I want to be able to be an active part of supporting him and his provider of services.
- I want to know he likes the people who support him.
- I want to know that the staff has the necessary training and abilities to support the challenges of his specific disabilities. This, of course, includes adequate funding to hire and retain quality staff.

What supports do I want for my son?

- I want the dental, medical, behavioral or psychiatric services he needs available in his home community. He should not have to travel unusually long distances for these services.
- I must know that there is a safety net in case the first placement fails.

How can you actively involve consumers?

- Provide us opportunities to give each other informal support. For example, coffee clutches, e-mail conversations, newsletters or other activities where we can share our successes and strategies.
- Ways must be found to connect family members with each other. If they don't know each other they can't help each other.

Other ways to actively involve consumers?

- We must be respected.
- We must not be pandered to.
- We must lead and not follow.
- We must know that our efforts will have real outcomes.

Other ways to actively involve consumers?

- We must have the necessary knowledge to feel confident that we are making a meaningful contribution.
- We need to know that others see us as the experts and that our opinions matter as much as those of the professionals in the room.
- We need to have our time and expenses reimbursed.

Self-Advocates in the Lead

Money Follows the Person

**Presenter:
Eric Guidish**

The type of disability doesn't matter

We all want the same things.

We want to:

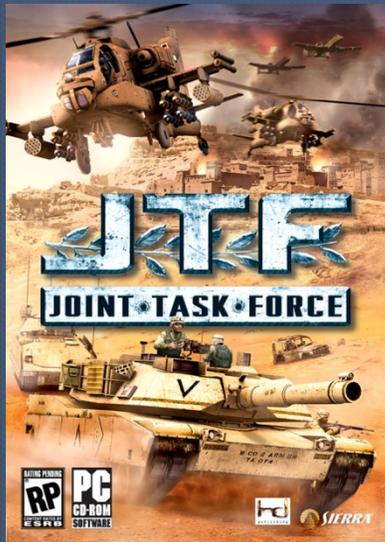
- ◉ Be a part of the community,
- ◉ Be able to live our full potential,
- ◉ Have privacy and personal choice,
- ◉ Have equal access to opportunities,
- ◉ Have personal preferences,
- ◉ Have equal rights.



Maximizing Consumer Input



- People with disabilities are people with their own goals, ambitions and desires.
- We deserve to be in control of what happens to our own lives.
- So, I suggest involving people with disabilities at every level of the decision making process. For example:
 - Quality assurance teams,
 - Local and state task forces,
 - Local and state advisory committees.



Self-advocates helping each other...

- Peer support, peer connections definitely.
- Work with your local Centers for Independent Living.



Self-Advocates in the Lead

Money Follows the Person

Presenter:
Nancy Ward

Self-advocates want the same things you do

They want:

- To be respected
- A home
- A job
- Some friends
- A way to get around
- Interesting things to do, and
- To give back to their friends and the community.

The Difference is Night and Day

Self-advocates living

in institutions:

- Do not have privacy
- Have few choice in their lives
- Are seen as different because they live in those big, segregated places
- Aren't members of their community

in the community:

- Have jobs
- Pay taxes and contribute to the community
- Have a social life and friends
- Are seen as a valued member of their community

Sally taught me many lessons...



Sally was my friend. She was 28 years old and lived in a nursing home when I met her. I was paid to be her friend.

Sally taught me many things during our friendship. I want to share some of those with you.

Lesson #1



All self-advocates, even those with severe disabilities, can live in the community with the right support.

Lesson #2

We want respect and we want to be valued for what we can do. In an institution people are numbers and you don't see what they can do.

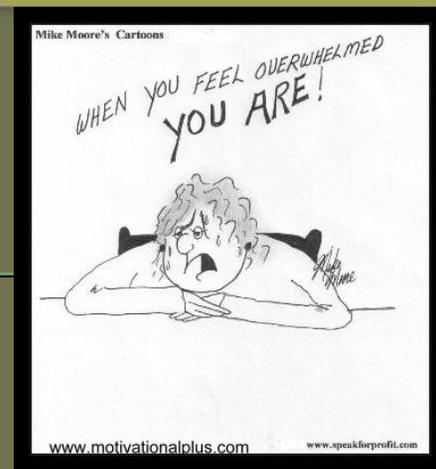


Lesson #3



People who live in institutions don't have many friends. Most of the people in their lives are paid to be there. You can't pay someone to be a friend.

Lesson #4



Be patient with people when they move into the community. They could be overwhelmed with the choices and new things around them. They need time to get used to things.

Lesson #5

Self-advocates need opportunities to make informed decisions.

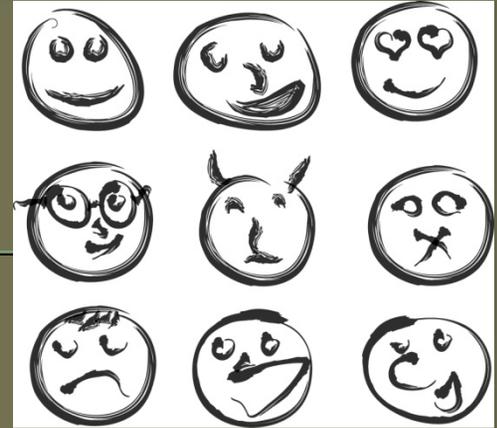


Lesson #6

Watch out! You can make rules that can give self-advocates less choice in the community.



Lesson #7



To me, quality of life is definitely more important than quantity of life.

Finally, ask yourself...

How would you like to be treated?

Most likely, people with disabilities want to be treated with the same respect.

Maximizing Consumer Input

At the individual level:

- ◎ You can listen to what people say.
- ◎ Give them an opportunity to make an informed decision.

At the state level:

- ◎ Work with the self-advocacy group in your state and include them in the decision making process.



Peer Connections

Self-advocates are very good at helping each other because we have similar experiences.

