

# Promoting Self-Determination & Recovery through Self-Directed Services

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“The significant problems we face cannot be solved at the same level of thinking we were at when we created them.”

Albert Einstein (1879 -1955)



# Self Determination for People in Mental Health Recovery



“...self determination is achieved when people have maximal independence and educational opportunities to make meaningful decisions about their own lives, control their own money, and live and work where they choose...”

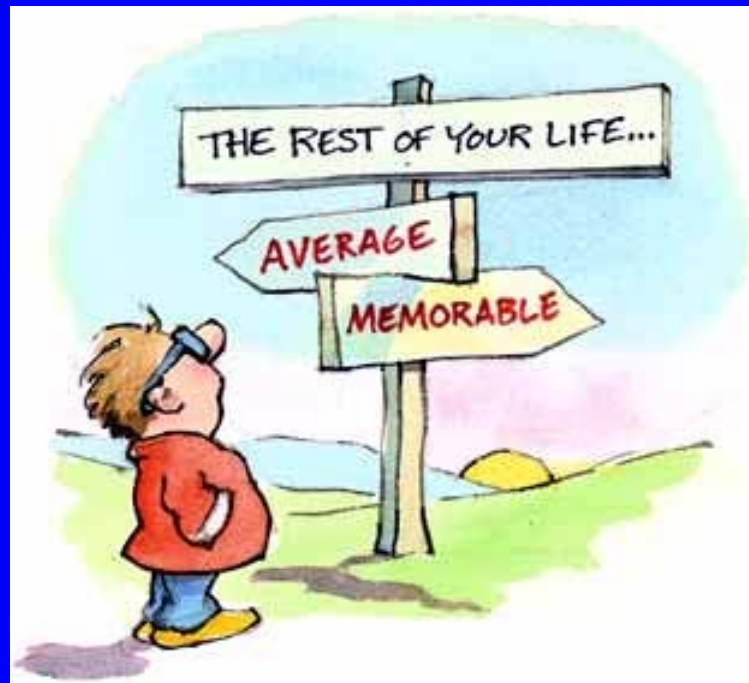
(Authors: Self-Determination Participatory Action Workgroup of the UIC National Research & Training Center on Psychiatric Disability, 2002)

**Too often, self-determination is viewed  
as a *privilege* to be earned rather than  
as a *right*  
(Chamberlin, 1999).**

**\* \* \***

**Consumers often are '*rewarded*' for  
treatment compliance by being given  
'*opportunities*' for self-determination  
(Unzicker, 1999).**

# Core Value: SDC Involves Having Choices



# Opportunities?

- New **federal mandates** (President's Mental Health Commission) for recovery & consumer/family-directed care
- **Rigorous research confirming success** of Self-Directed Care (SDC) initiatives for other groups raises the ? “why not for mental health?”
- Current federal/state programs present **sources of “cash-out” funds** for SDC
- Consumer-operated services present a **potential workforce available** for SDC functions

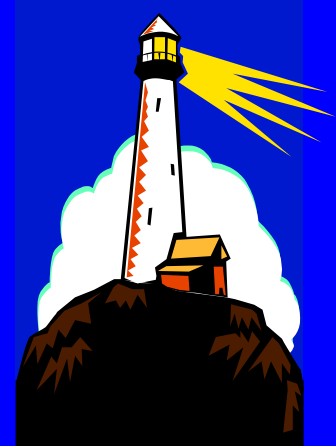
# Mental Health Service Delivery Dollars Should Follow the Person

From the *2003 President's New Freedom  
Commission on Mental Health Report...*

“... consumers and families will play a larger role in managing the funding for their services, treatments, and supports. Placing financial support increasingly under the management of consumers and families will enhance their choices. By allowing funding to follow consumers, incentives will shift toward a system of learning, self-monitoring & accountability.”

“All truth passes through three stages. First, it is ridiculed. Second, it is violently opposed. Third, it is accepted as being self-evident.”

Arthur Schopenhauer (1788-1860)



# What is Self-Directed Care?

- Pioneered in the RWJF *Self-Determination Initiative* & CMS *Cash and Counseling* program
- Funds ordinarily paid to service provider agencies are **controlled by service recipients**
- **Person-centered plans** for recovery are developed by the person him/herself
- **Individual budgets** are developed to allocate dollars to achievement of the plan's goals
- Support is provided (if needed) to “broker” services and **help a person manage their plan**
- **Fiscal intermediaries** handle billing, payroll, taxes, & other administrative functions

# How Well Does SDC work?...

- **Randomized evaluation of Cash & Counseling programs (for people with developmental & physical disabilities & the elderly) by Mathematica found that...**
  - ✓ **Outcomes of SDC participants were as good or better than regular fee-for-service (FFS)**
  - ✓ **SDC participants received more services than their FFS counterparts**
  - ✓ **Budget neutrality prevailed by end of 2<sup>nd</sup> year**
  - ✓ **Consumer satisfaction was significantly higher among those served in SDC**
  - ✓ **Incidences of fraudulent behavior were low**
  - ✓ **Hiring (& firing) friends/family members not problematic**

# Is SDC the only way to achieve self-determination?

**No, other ways include...**

- Consumer-run services (drop-in centers, support groups)
- Illness self-management (WRAP, Recovery, Inc)
- Advance directives for mental health care (ADMaker)
- Peer-to-peer services (Certified Peer Specialists)
- Employment of peer providers in traditional programs & mental health systems
- Advance crisis planning (seclusion & restraint reduction/elimination)
- Advocacy & political activism

# Core Value: SDC Participants Take Control



UIC Center on Mental Health  
Services Research & Policy

# Person-Centered Plan

Helps people to identify...

- ⌘ Who they are & how they want to live
- ⌘ Future goals based on how they want to live
- ⌘ Barriers to their goals
- ⌘ Supports & services that can facilitate success
- ⌘ Action plan & timeline related to their goals



# Individual Budget



- ⚙️ Budget flows from the person-centered plan
- ⚙️ Line items relate directly to goals specified in the plan
- ⚙️ Direct connection between budgeted goods, services, or supports & achievement of a goal
- ⚙️ Participant monitors budget on ongoing basis

# Role of the Support Broker



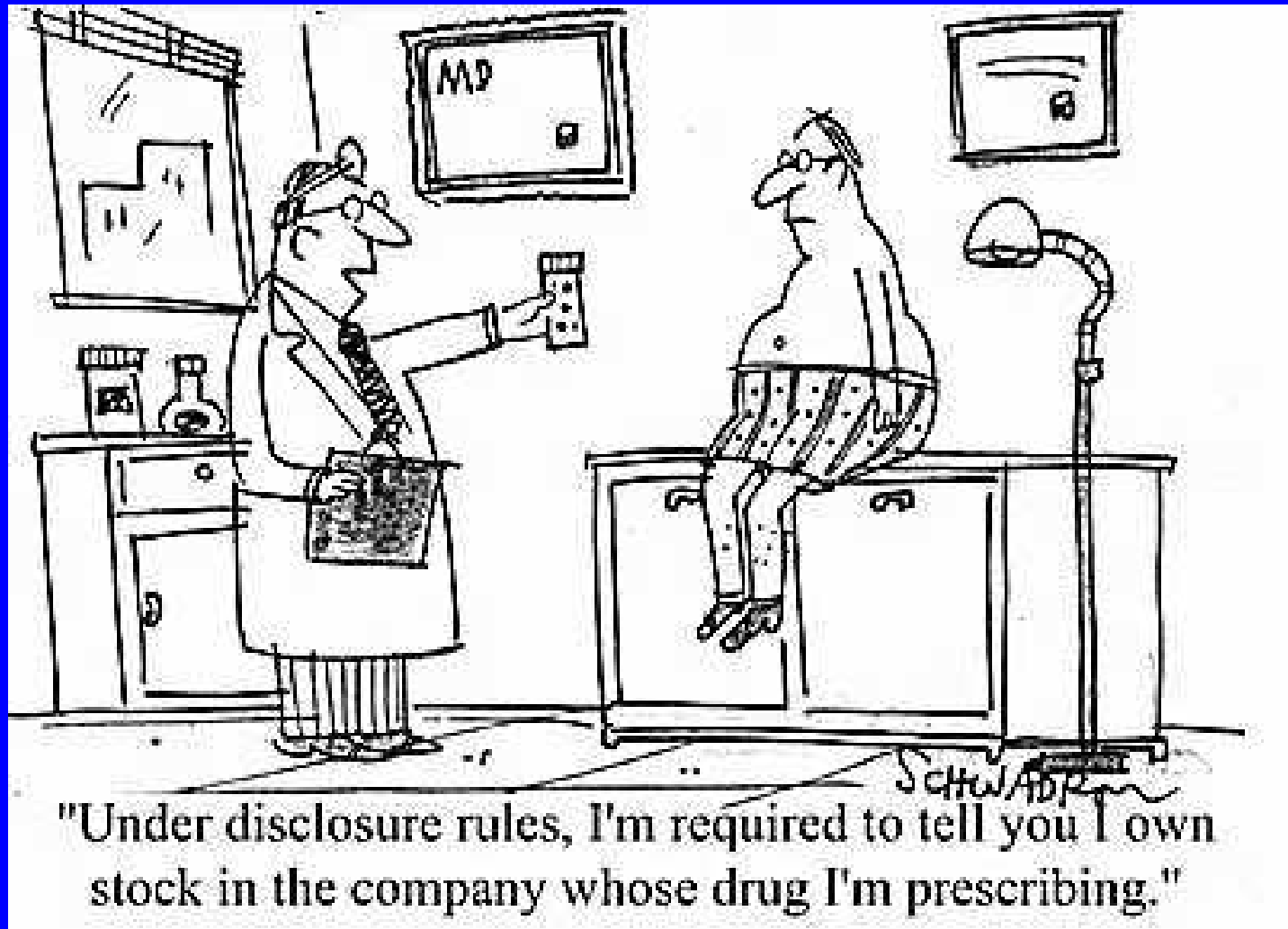
- ✿ May help develop person-centered plan
- ✿ Help ensure plan is implemented & modified
- ✿ Help navigate community resources & form connections
- ✿ Assist with managing the individualized budget
- ✿ Help recruit, hire, & negotiate rates with providers
- ✿ Help train & supervise (if requested) & discharge providers (if requested)
- ✿ Help develop & implement emergency plan
- ✿ Assist with billing through the Fiscal Intermediary
- ✿ Always a co-pilot - never the pilot

*(Adapted from My Voice/My Choice, Idaho Dept of Health & Welfare)*

# Who Can Provide SDC Supports? Consumers!

- Many mental health consumers already know what kinds of formal and informal supports people need to recover
- Consumers can help SDC participants learn about and access peer services & supports
- Consumers may know which traditional agencies do and do not deliver high quality services
- Consumers can act as role models, instilling hope and showing that recovery is possible

# Core Value: Absence of Conflict of Interest



# What Does An SDC Program Cost?

- Decide what you want to spend/what's available
- Remember that cost neutrality is an option since SDC can be a supplement to (OR, IA) or a replacement for (FL) traditional services
- Decide whether the program is time-limited vs. ongoing
- Decide how to finance the fiscal intermediary
- Decide how to staff the program
- Decide where to locate the program
- Funds for staff training may be necessary



# How Much \$ Should Be Available to Consumers in Individual Budgets?

Different costing formulas...

- Average annual per capita cost of outpatient services
- Above minus administrative expenses (10%)

Examples:

**Florida SDC (original program)** - \$2,776/year ongoing

**Empowerment Initiatives** - \$3,000/year for 2 years only

**Iowa Program** - \$2,000 ongoing



# Fiscal Intermediaries

## *Role of Fiscal Intermediaries*

- Hold, manage, & account for funds
- Independent, 3rd party administrator
- Manages employee payroll, tax withholding & reporting

## *Common Fiscal Intermediary Administrators*

- Colleges & universities
- Larger non-profits
- Managed care organizations
- Insurance groups
- Disability service cooperatives

# What Is A Purchasing Policy?

A policy document describing how people can spend their money in accordance with their own individual budgets

- Lays out what expenses are allowed and not allowed
- Describes the process of having one's budget approved
- Specifies the manner in which goods and services can be purchased (cash, voucher, debit card, reimbursement)
- Specifies limits on amounts that can be spent within line items
- Describes the individual's ability to shift \$ between line items
- Explains sanctions in the event of policy violations
- Explains what will happen with unspent monies (carried forward, returned to the system)

<http://www.dhhs.state.nc.us/mhddsas/rfa9/rfa9-attach1policyquestions4-04.pdf>

# Service Substitution



Less restrictive, more flexible goods & services, that the participant chooses, to achieve similar traditional service recovery goals

- Replace formal services with informal services
- Replace services with “normal” community activities
- Replace public services with private services
- Replace services with goods

**Examples from Florida SDC** - attending Weight Watchers, yoga classes, martial arts classes, joining the “Y”, taking college courses, certification courses, correspondence courses, buying self help books and classes, school supplies, clothes for job interview

# Most Common Funding Sources for SDC

## *Medicaid*

- Medicaid State Plan – under Rehab Option (person-centered planning as part of treatment planning, financial management & supports brokerage approved as administrative expenses)
- Waivers - 1915(c), 1915 (b), 1115
- System Change Grants – Independence Plus programs

## *State General Revenue*

- Monies re-directed from traditional to SDC programs
- Combined with MHBG funding & other state funding
- May require state legislation

## *CMHS/SAMHSA State MH Block Grant*

- Included in a state plan along with its relationship to the current system & fiscal intermediary arrangements

# What other systems have the potential to support self-directed care?

- State Vocational Rehabilitation
- Ticket to Work
- WIA One-Step Career Centers
- Individual Development Accounts (asset accumulation)
- Social Security Administration (SSI/SSDI)
- HUD (public housing)
- Fiscal agents & intermediaries
- The Internet & other information technology
- Consumer-operated & consumer-centered programs

**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\***

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# What systems change is needed to promote the spread of SDC?

- *Find the money* – identify publicly funded sources of cash-outs for SDC
- *Develop the infrastructure* – define SDC model; identify support for person-centered planning, individual budgeting, & support brokerage; choose fiscal intermediary
- *Change laws & policies* – eliminate laws & policies that deny people with psychiatric disabilities the same opportunities for SDC given to people with other disabilities
- *Provide education* – little is known about these models, their efficacy, & their potential utility for MH service users

# A Multi-Systemic Approach is Required

As acknowledged in the 2003 report of the President's New Freedom Commission on Mental Health...

“...states will have the **flexibility** to combine, federal, state, and local resources in **creative, innovative, & more efficient** ways, overcoming the bureaucratic boundaries between health care, employment supports, housing & the criminal justice system.”

# An Impossible Task?



# System Change: The Realities

- Systems will revert to old ways of doing things; one must be prepared for that inevitability & resist discouragement
- Actions speak louder than words
- Performance is everything
- Never give up

**(Carolyn Russell, Former Florida SDC Director)**

# A Closing Thought...

"It's kind of fun to do the impossible."

Walt Disney (1901-1966)



# Advocacy & Other Resources

1. Fact sheet on SDC in public mental health

<http://www.upennrrtc.org/var/tool/file/137-CI%20Tool%20-%20Self-Directed%20Care.pdf>

2. Fact sheet on the evidence base for SDC

<http://www.cmhsrp.uic.edu/download/SDCResearchFactSheet.pdf>

3. Report on the state of SDC for people with mental illness

<http://www.cmhsrp.uic.edu/download/sdconfdoc09.pdf>

4. Philosophy and funding of mental health SDC programs

<http://www.cmhsrp.uic.edu/download/sdsamhsaconfsentver3.pdf>

5. Competency issues in SDC

<http://mentalhealth.samhsa.gov/publications/allpubs/NMH05-0195/default.asp>

6. Models of self-direction in mental health: Archived webcast

<http://www.connective.com/events/samhsa040605/#>

# Learn more by visiting our website...

## [www.psych.uic.edu/uicnrtc/](http://www.psych.uic.edu/uicnrtc/)

- **New manual on starting SDC programs!  
(coming soon)**
- **First ever collection of papers on self-determination for people in MH recovery**
- **Tools developed for and by consumers to enhance self-determination**
- **Bibliography on self-determination**
- **Links to relevant sites**

