

In-Control Wisconsin

*AGING EMPOWERMENT
CONFERENCE*

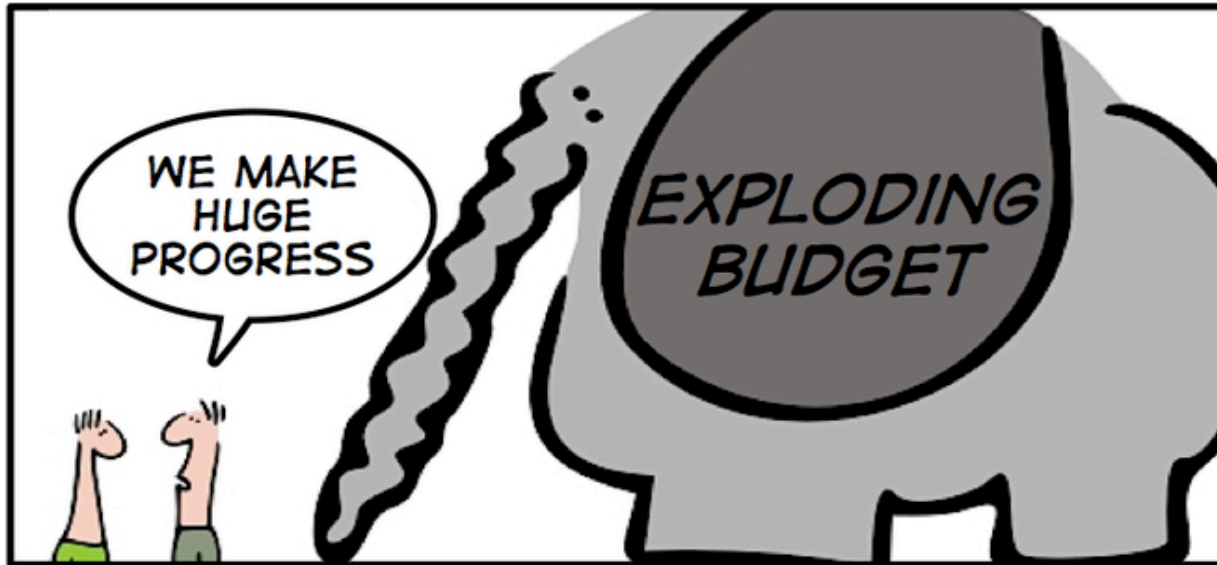
June 8, 2016

**LIVING A
SELF-DETERMINED LIFE**

Keynote Address:
Know *Your* Power, Embrace
***Your* Responsibilities,**
Lead the Life of *YOUR* Choice

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PROJECT MANAGEMENT STRATEGIES



STRATEGY 1: IGNORE

geek and poke

The **Why**, When & How

*Why did states decide to explore
Self-Directed services ??????????*

❖ Economics

❖ Demographics

❖ Preferences of Consumers/Families

❖ Improve Health Outcomes

❖ Selfishness (LOL) (HaHa)

The Why, **When** & How

- The “movement” to consumer-directed and controlled services began (in the USA) in Berkeley, California (early 70’s)
- The “deeper” roots lie in the Civil Rights Movement (1954)
- The Independent Living Model was adopted and ILC’s were created (1978)
- A National Research & Demonstration Project was Launched “Cash & Counseling” (1996)

In the Beginning

The Civil Rights March on Washington



In the Beginning . . .

- Ed Roberts



The Why, **When** & How

- We also recognize those with intellectual disabilities, who with the support of professionals & friends developed the Self Advocacy movement.
- In fact, the term “self-determination” comes directly from the DD world. They, too, were pioneers

The Why, When & How

- Beginning in 1996, the Robert Wood Johnson Foundation was interested in funding a large scale national research and demonstration project to test the efficacy of given consumers of long term care services access to funds to hire their own caregivers.
- After extensive interviews and visits four states were selected for the project: FL, NY, NJ & AK.

The Why, When & How

- Many decisions had to be made:
 - How to give funds to individuals without causing them to lose benefits
 - How to control potential fraud & abuse
 - How to include individuals with cognitive or intellectual disabilities
 - How to evaluate the impact of the program
 - And many other HOWS

The Why, When & How

- Should we permit people with substance abuse problems to enroll in the demo?
- **How** would our “participants” pay their staff?
- Should we permit family members to become paid employees? A spouse?
- **How** to control costs?
- **How** would participants find potential workers?

It Works, It Can Be Replicated !

Evaluation revealed some real benefits:

Health Status Improved

Consumer/family satisfaction was high

Quality of Life Improved

It **DID NOT** cost more than traditional services

Participants Developed Employer Skills

Training is a KEY element

Cases of Fraud & Abuse were minimal

Models Now in Use

A. **Consumer Controlled model** where individual is employer of record, hires and fires employees, has an individual budget, counseling/training is available. Financial Management Services are provided.

B. **Agency with Choice model** Consumer co-manages employees, participates in selection of staff. Agency is employer of record, does payroll. Consumer can also use traditional agency services

Models Now in Use

C. **Managed Care Model.** Managed care company makes determination of budget and either contracts with another entity (state Agency, ILC, FMS, etc.) to manage the consumer-direction

D. **“Variations on A Theme” Model.** Many programs involve a combination of different models. States build what works best given their laws/regulations and the political (Big P) climate.

Characteristics of High Quality Self-Directed Programs

- The hallmarks of high performance consumer directed programs are:
- **Person-centered planning**
- **Availability of Financial Management Services**
- **Individualized budgets, controlled by participant**
- Training, support brokers, counselors at the consumer's request

Characteristics of High Quality Self-Directed Programs

- Goal Driven Outcome Measures
- Assistance in locating workers
- Continuous Quality Improvement
- Consumer Advisors & Periodic Satisfaction Surveys

Across our Great Nation



Across the Country

- All 50 states (and the District of Columbia) have at least one consumer directed program in Place. Many states have multiple consumer-directed programs for different populations.
- The Home Care Rules released by the Federal Government have created some major & minor changes in state consumer-Directed Programs

National Trends in 2016

- Much more interest in consumer-direction from individuals 65+
- Baby Boomers are entering the LTC arena
- Nursing home placement increasingly not the “default” setting for older persons needing assistance
- The relative ease of using consumer directed services, vs. agency services has made it more a more popular alternative.

Let's Look At Wisconsin

- Your Family Care/IRIS program is one of the largest consumer-directed programs in the country.
- “INCLUDE, RESPECT, I SELF-DIRECT”
I Love it!
- Changes are being Proposed to Family Care/IRIS 2.0
- YOU MUST MAKE YOUR VOICES HEARD

Let's Look At Wisconsin

- Family Caregiver Support Program
- Wisconsin Caregiver program looks like those in many other states that receive the Federal funding
- It is essential that programs of this type are expanded and financially stable
- Did you know that **non-paid** family & friend caregivers for people over age 60 number **34.2+ million** in the USA.

Non-Paid Caregiving

- **\$470 billion** represents the economic value of **unpaid caregiving** (2013 stat) More like **\$520 billion in 2016**.
- Robust “respite” programs are essential to the continuation of caregiving over time
- Education (orientation) for caregiving and Caregiver Support groups make a BIG difference.



How To Sustain & Grow Your Programs

- ❑ KNOW YOUR **FACTS & STATISTICS**
- ❑ WRITE TO YOUR GOVERNOR, **SHARE YOUR PERSONAL EXPERIENCES**, SAY “THANKS”
- ❑ **HARD FACTS IMPRESS**, DON'T RELY ON “IT'S THE RIGHT THING TO DO.”
- ❑ **POLITICIANS LIKE VOTES** – LET THEM KNOW IF THEY SUPPORT YOU, YOU'LL SUPPORT THEM
- ❑ **DATA DRIVES POLICY**

Paid Caregiving

- Treating your workers with respect is essential – You expect it, So do they!
- Do you remember to say “thanks” “good job” or “I feel glad that you are in my life” at least 2 times each day.
- Do you do everything in your power to support appropriate wage increases for your workers? **YOU HAVE POWER – USE IT.**

Questions & Comments

- ❖ Answers, if I have them.
- ❖ Heck, even complaints are OK with me.
- ❖ **Something to Think About:** If you could change one thing in the Wisconsin Self-Directed Programs, what would that be???
Why???

THANKS