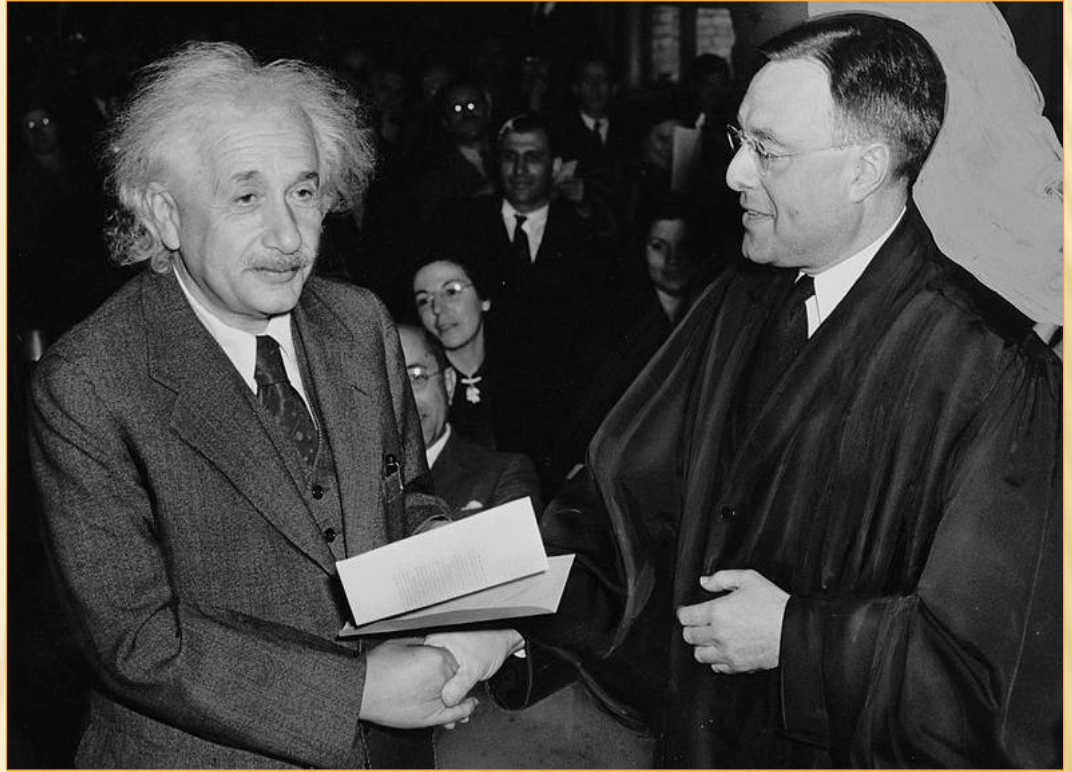


A SIMPLE PLAN...

..but not too simple

One Parent's Perspective
on Long-Term Care

Deanna Yost, November 2011



"Everything should be made as simple as possible, but not simpler."

Albert Einstein

SDS– EVOLUTION

Simple:

- ✘ People and families determine their lives
- ✘ Disability is diversity, people do not need to be fixed
- ✘ Power is shifted

But not too simple:

- ✘ Evolution from Inclusion to participation to contribution
- ✘ People and families have dreams and aspirations
- ✘ We change the equation from the agencies as the those who define and deliver, to the “users” as the decision makers.

EDGAR CAHN

“We should not be delivering services, we should only deliver pizza.”

SDS & MANAGED CARE COMPATIBILITY

- ✘ Full Citizenship principles as the underpinning structure



Full Citizenship

Citizens are fiscally responsible. Having “say” in your life is not what’s expensive, having inflexibility is.

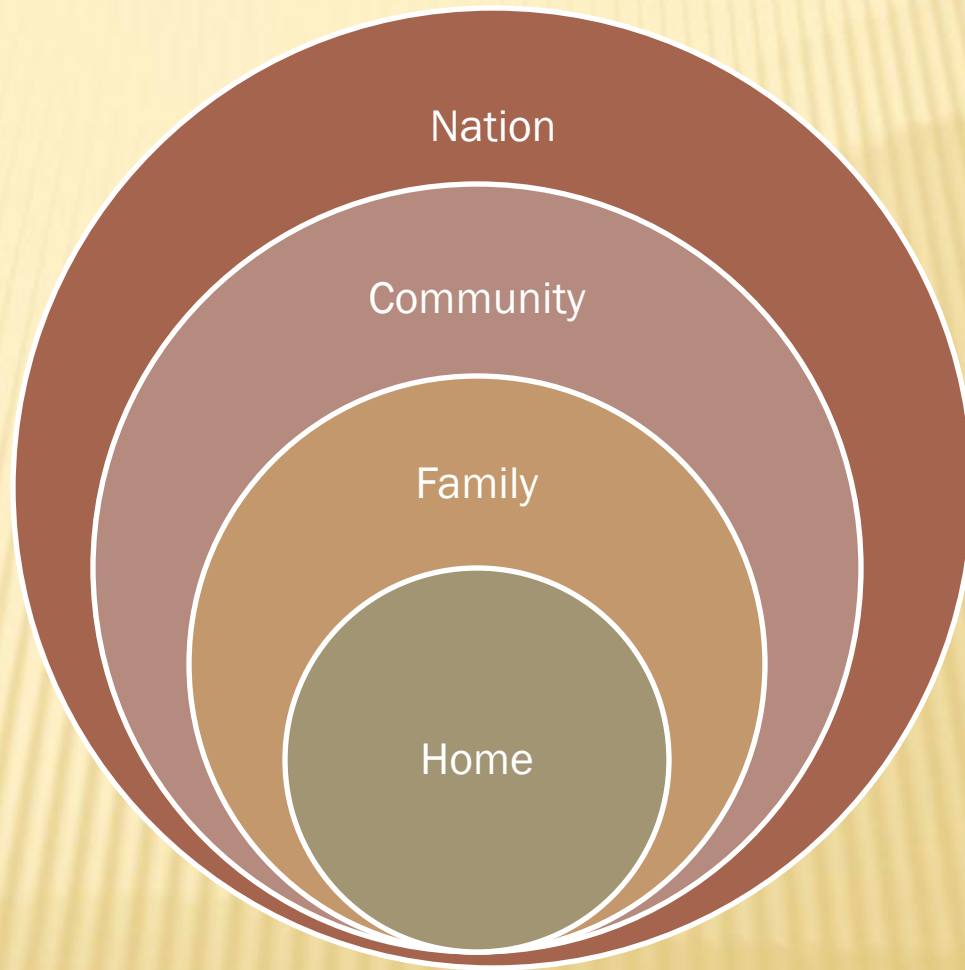
Self-directed Supports

Self-Determination
National movement

PEOPLE BELONG—FULL CITIZENSHIP

Move towards
universal design—

what usually works
for someone
without a disability
works for someone
with a disability, i.e.,
finding a job,
holding the lease,
affording the rent,
making friends,
being a leader...



REAL LIVES BETTER LIVES

Simple

Choices about:

- + Where to live, with whom
- + Work
- + Safety
- + Activities during the day
- + Support people
- + Other personal outcomes

But not too simple

Control over:

- + Individualized Budget
- + Direct support staff
- + Microenterprise, customized employment
- + Decisional capacity, safeguards
- + Contribution to the community
- + Star Rafts, Circles of support
- + Individualized supports

TOBY'S LIFE—HIS HOME

Simple:

- ✘ Home in Washburn with housemate
- ✘ 24/7 supports
- ✘ Has staff who help him

But not too simple:

- ✘ Pays rent, utilities and food out of SSI
- ✘ Supported Living—holds the lease, receives supports to live in home, funded through IRIS*
- ✘ Family began small non-profit “microboard” to hire 9 staff, *agency funded by IRIS.



Toby at his "Yellow" House

TOBY'S LIFE—HIS DAILY SUPPORTS

Simple:

- ✘ Gets day & overnight supports, receives personal care as needed
- ✘ Is learning and does many things throughout the day which staff and family review and discuss

But not too simple:

- ✘ Through Forward card which supplements his IRIS, self-directs medically necessary services—meaning person he/we choose can perform the care

Currently too complicated:

- ✘ Have to break down every area into categories of supports instead of a daily rate.



TOBY'S LIFE, HIS EMPLOYMENT

Simple:

- ✘ Works, for himself and also for community employer

But not too simple:

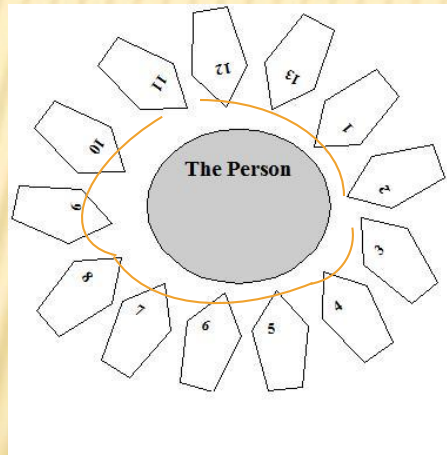
- ✘ Has microenterprise and customized employment



TOBY'S LIFE, COMMUNITY CONNECTING

Simple

- ✘ Has a circle of support



But not too simple

- ✘ A **Star Raft** which includes family, recruited community individuals, & staff who are connected to each other.
- ✘ Looks at assets, gifts, abilities of person, rather than deficits when cooking up connections.

TOBY'S LIFE-CONTRIBUTING

Simple:

- ✘ Helps other people while supported
- ✘ With supports began “Community Walking Club”

But not too simple:

- ✘ Is a Timebanker, member of TimeTraders North, began by ARC of the Northwoods



WHAT PARENTS ARE WORRIED ABOUT

- ✘ The budget will not be sufficient, cuts now or later
- ✘ Their family member will not get good care or not be safe
- ✘ Their perspective regarding what they think is best for their family member will be overridden
- ✘ No longer being able to take care of their family member, or seen as not able to
- ✘ Being lost in the bureaucratic system, learning a new way

PARENT'S RESPONSIVENESS TO FEAR

- ✘ Budget planning that involves spending full allocation
- ✘ “Keeping it in the family” (pay parents, siblings, cousins)
- ✘ Choosing “traditional” approaches that gained support from the grand deinstitutionalization of the 70’s, i.e., group homes, sheltered work
- ✘ Advocacy to Not change, or go back to the old county way, Or, to wait until the current way fails.

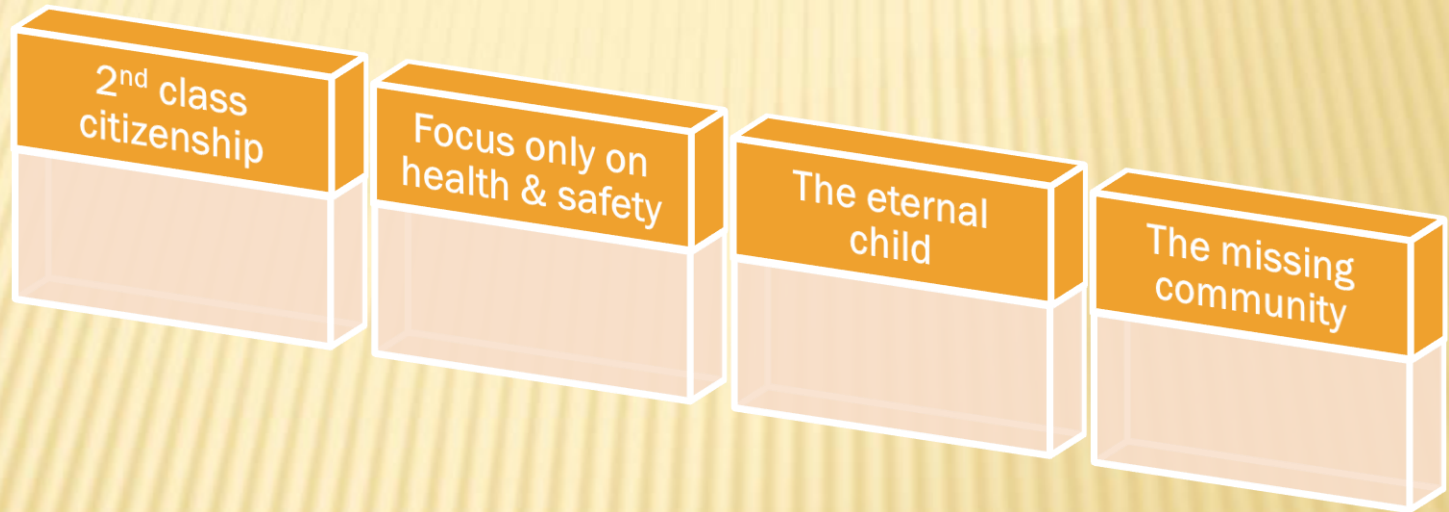
WHAT AGENCIES ARE WORRIED ABOUT

- ✘ Jobs going to family members
- ✘ Monthly vs. Annual budgets creates inflexibility, i.e., with seasonal employment
- ✘ Unclear roles with future and goal planning, good community agencies relegated to “clinical outcomes” rather than helping people get a life
- ✘ RATE SETTING, already hard to pay workers and give benefits

AGENCIES RESPONSE TO FEAR

- ✘ Non-compete clauses for employees
- ✘ Only hiring workers with degrees for “High Needs Clients” to justify higher rates
- ✘ Hyper-vigilance re: fraud, i.e., call-in requirements for personal care
- ✘ Public discussion of risk re: families who have no professional skills (but yet who are primary caregivers when the agencies aren’t there)

BARRIERS TO FULL LIVES



MANAGED CARE

- ✘ Care manager beginning sentences with “I will allow...”
- ✘ RNs thinking a person is not capable of living alone because she doesn’t do her dishes every night
- ✘ MCO Teams meeting to “RAD” supports without the person present
- ✘ Good percentage of services being coded as Supportive Home Care. Community Support agencies suspect SHC rate to plummet.



RED FLAGS RIGHT NOW

IRIS

- ✘ ICs either providing not enough or too much supports
- ✘ Information family receives to plan services is limited to knowledge of OC and IC
- ✘ Good percentage of the “workforce” is not covered by worker’s comp due to Household Employer/Domestic servant exclusion



BIGGER RED FLAGS



Both Managed Care and IRIS

- ✘ Few new supported living situations
- ✘ Still have program services, workshops, day centers, group homes. The “brand new day” did not arrive yet.
- ✘ Transition supports from school to adult continue to be poor or non-existent.
- ✘ Few new innovative providers but many supportive home care agencies (errands, cleaning, shopping, light tasks, supervision—”do for” type services.)
- ✘ Many family members, parents, siblings paid—DVR reporting decline in new cases. When told that payment for ongoing supports need to come out of budget families d/c pursuit with family member rather than advocate for ↑ allocation.

WHAT'S EMPOWERING

- ✘ To have a vision, a dream, a drive
- ✘ To know how to get there, the steps
- ✘ Or, to know who can help, who believes it too, and who has influence
- ✘ To have resources, like funding, to make it work
- ✘ To have the authority to put the right people on board
- ✘ To have the benefit of the doubt that you can try again if it didn't quite work out as planned

POSITIVE RESPONSES TO CHANGE

- ✘ Agency transformation, some due to the market economy
- ✘ Striving to turn the tables to SDS=more engagement of people with disabilities and families
- ✘ New approaches to explore community resources
- ✘ People First gaining headway
- ✘ Thinking outside the box & Proactively around issues like back up (Provider pools, co-ops, etc.)

WHAT IF “THEY” IS “US”

- ✘ John O’Brien’s pivotal question
- ✘ Locally we formed a grassroots group to take the lead in LTC changes in 2007-2008.
- ✘ Although the participants were for the most part on the same page of full citizenship, we lacked two important ingredients:
 - + Department representation
 - + Recognized equality with county rep stakeholders

GETTING THERE—MOVE AWAY FROM PROGRAMS

Simple: Just say “no”



Congregate/sheltered work



Day programs



Group homes/
Congregate living

But not too simple: Be cautious of:

- ✘ The shredding scene
- ✘ Community activities with staff
- ✘ “Care for the body” paradigms—where homes become mini-institutions even though people hold the lease

TAKING IT TO THE NEXT LEVEL

Simple:

- ✘ People are part of the community
- ✘ People live in the community
- ✘ People or parents have say about what providers they use and their staff
- ✘ People's outcomes determine their funding

But not too simple:

- ✘ People contribute to the community, have associational life
- ✘ People have threshold control*, sense of place, control, ownership
- ✘ People and parents are the employers, co-employ or co-evolve with agencies
- ✘ Adequate funding provides a springboard for a good life

*John O'Brien

EMBRACE THE PARADOX OF RIGHTS VS. NEEDS

“Achieving self-sufficiency under a supports paradigm may be best judged by noting how much power a person yields in directing their support services, not by how quickly someone stops uses those services.”

Thomas M. Reischl, Witnessing the Possible for People with Disabilities

ROLE OF A GOOD AGENCY PARTNER

- ✘ To infuse ideas, energy and connections into a person's life
- ✘ To change community culture, to educate
- ✘ To support innovation, to make room for ideas outside the norm, allow risk
- ✘ To influence and to be influenced (M. Sweet)
- ✘ To handle the mundane (billing, payroll, coding)

WHEN FAMILY MEMBERS ARE PAID

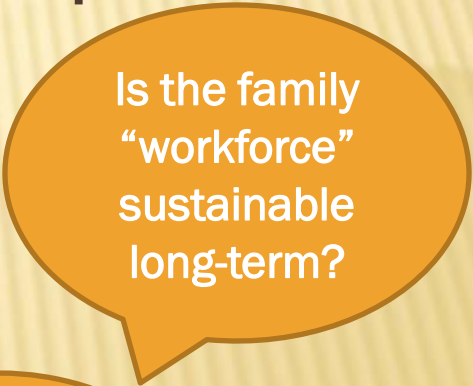
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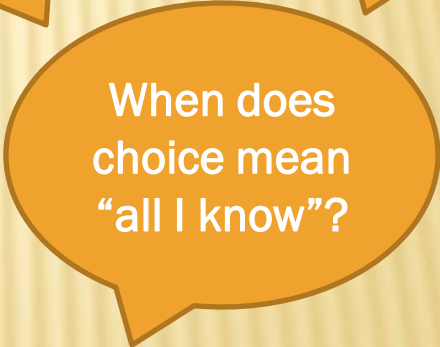
- ✘ Low-cost, efficient
- ✘ Often no training costs
- ✘ Families are the back up plan in most cases
- ✘ People with disabilities often choose or prefer family members. SDS is about choice.....



Are we creating financial dependence?



Is the family "workforce" sustainable long-term?



When does choice mean "all I know"?

- ✘ Is there value in diversity other paid supports?

CREATING THE FUTURE WE WANT TO SEE

Simple:

- ✘ Partner with parents
- ✘ Partner with agencies
- ✘ Partner with the community



But not too simple

- ✘ Get to the kitchen tables, i.e., Family Mentoring Project
- ✘ Co-evolution means some chaos and paradox
- ✘ Tap the abundance of community

ADVOCACY NOW & LATER

Simple:

- ✘ Passion, still the main ingredient
- ✘ Representation for more than ourselves
- ✘ Transparency

But not too simple:

- ✘ Yet we need to admit our biases upfront
- ✘ Yet we acknowledge that there are 5 sides to every story
- ✘ At the risk of scrutiny

NEXT STEPS

Simple:

- ✘ Have a workgroup
- ✘ Have help in place with the employment of workers
- ✘ Think about back up, instead of putting it on the person's shoulders
- ✘ Don't use a check box for natural supports

But not too simple:

- ✘ Keep it grassroots, if possible
- ✘ Explore multiple options of co-employment, leasing, microboards, coops, co-evolution with agencies
- ✘ Explore ABCD organizing, the Star Raft or other patterns with families

THANK YOU



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