Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities

Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

About the Community of Practice
The National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities will help five states develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities. The objective of the grant is to develop systems of supports for families throughout the lifespan of their family member.

Facilitating the Community of Practice
Grant partners include

- National Association of State Directors for Developmental Disability Services (NASDDDS)
- University of Missouri-Kansas City – Institute for Human Development (UMKC-IHD)
- Human Services Research Institute (HSRI)
- National Association of Councils on Developmental Disabilities (NACDD)

Goals of the CoP
The goals of the Community of Practice are:

- to create a model framework for supporting families that addresses the needs of families with a family member with I/DD across the lifespan and supports states to develop and sustain exemplary family support practices.
- to develop and facilitate a multi-level Community of Practice designed to build capacity within states and the nation to create policies, practices, and systems to better assist and support families that include a member with I/DD across the lifespan.
- to capture and share lessons learned and products to develop, implement and sustain exemplary practices to support families and systems

The Goal of Supporting Families

The overall goal of supporting families, with all of their complexity, strengths and unique abilities is so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.

from Building a National Agenda for Supporting Families with Member with I/DD 2011

Learn about policies and practices for supporting families, find resources connect with the Community of Practice, and share your ideas about supporting families:

Visit our website at **www.supportstofamilies.org**

Like us on Facebook at **facebook.com/supportstofamilies**

Sign up for our mailing list at **www.supportstofamilies.org**

Follow us on Twitter at **twitter.com/familieswithidd**

The Community of Practice (CoP) Supporting Families throughout the Lifespan is operated under a five year grant awarded to NASDDDS by the Administration on Intellectual and Developmental Disabilities (AIDD) beginning October 2012.

Goal: To create a model framework for supporting families that addresses the needs of families with a family member with ID/DD across the lifespan.

Wingspread Report
http://www.ct.gov/dds/cwp/view.asp?a=2042&Q=537862

GRANT STATES*
CONNECTICUT
DISTRICT OF COLUMBIA
*MISSOURI
OKLAHOMA
TENNESSEE
WASHINGTON

CHARTING the life course

What is Charting the Life Course?

Framework for Supporting Individuals and Families throughout the Life Course

Charting the Life Course is a framework that was developed to help individuals with disabilities and families at any age or stage of life think about what they need to know, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Individuals and families can focus on their current situation and stage of life but may also find it helpful to look ahead to start thinking about what they can do or learn now that will help build an inclusive, productive life in the future.

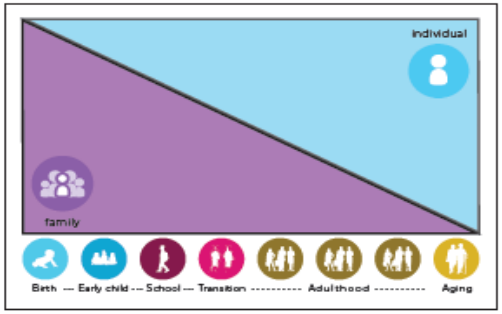
- Life is a journey – Our lives are not static, they change every day.
- It's all about vision – Anything is possible, with the right vision.
- Everything is connected – What you do today affects your life in the future.
- Our overall compass for people with disabilities and their families is "quality of life."

GOAL

Individual
Will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life

Families
Will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support the individual to achieve their goal

Recognizing that individuals exist within a family system



Caring About	Affection & Self-Esteem
	Repository of knowledge
	Lifetime commitment
Caring For	Provider of day-to-day care
	Material/Financial
	Facilitator of inclusion, recreation, spirituality and meaningful activities
	Advocate for support

Michelle "Sheli" Reynolds, PhD | UMKC-Institute for Human Development | mofamilytofamily.org

Supporting Families Community of Practice

http://supportstofamilies.org/cop/

10 Committees

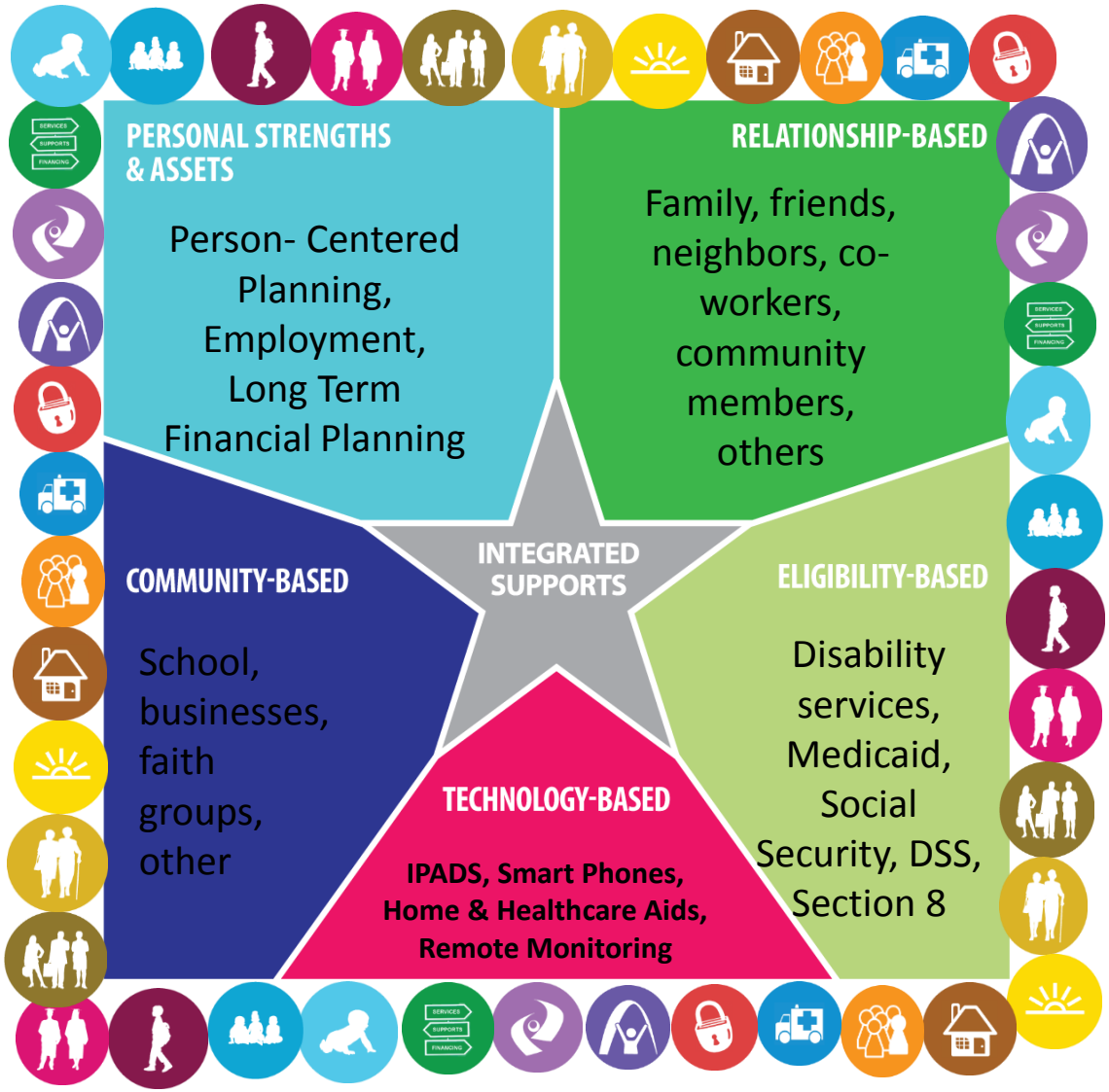
Family-to-Family Connections
Employment
Healthy Living
Housing/Home Supports
Information Navigation
Person-Centered Planning
Positive Behavior Support
Respite/Social Opportunities
Self-Directed/In-Home Supports
Technology

Re-evaluating current services – How many could we serve?

Type of Service	Cost per Person	Cost to Serve the Waiting List 122,870	People Served with $5 M
ICF/MR	$128,275 CT $383,316	**$15,761,114,925**	**39** **CT 13**
Non-family HCBS	$70,133 CT $140, 199	**$8,617,241,710**	**71** **CT 36**
Host Family	$44,122 CT $51,687	**$5,421,270,140**	**113** **CT 97**
Own Family	$25,072 CT $30, 390	**$3,080,596,640**	**200** **165**

Data Source: Lakin, K.C. MSIS and NCI data from 4 states (1,240 Individuals)

A GOOD LIFE


PERSONAL STRENGTHS & ASSETS
Person- Centered Planning, Employment, Long Term Financial Planning
RELATIONSHIP-BASED
Family, friends, neighbors, co-workers, community members, others
INTEGRATED SUPPORTS
COMMUNITY-BASED
School, businesses, faith groups, other
ELIGIBILITY-BASED
Disability services, Medicaid, Social Security, DSS, Section 8
TECHNOLOGY-BASED
IPADS, Smart Phones, Home & Healthcare Aids, Remote Monitoring

Where People with Intellectual Disabilities Live: Housing Support Options

MINIMAL SUPPORT MODELS

Living Options	Current Available DDS Supports	Average Annual Cost *Supports only- Does not include rental assistance and SS funds	Community of Practice Supports	Most Common Barriers
Own Home, Condo or Apartment Person may live alone, be married, or live with a roommate of his/her own choosing (non DDS supported)	Minimal In Home supports	CT Average annual I.H.S. support cost= $3.876	• Assets Planning • Personal Networks • Technology • Community Resources • Other Eligibility	-Assets Management -Rental Assistance
Family or Other Loved One's Home Person lives with people who choose to provide natural supports	In-Home Supports Family Supports -Respite -Family Support Teams -Family Grants	CT Average annual support cost= *Respite-$1,821 *I.H.S. -$3.876	• Assets Planning • Personal Networks • Technology • Community Resources • Other Eligibility	-Social Supports -Family may rely on person's income/support -Aging Caregivers -People who have resources don't know where to go for supports

Typically LON 1 & 2

Ranges across all LON levels

Where People with Intellectual Disabilities Live: Housing Support Options

MODERATE SUPPORT MODELS

Typically LON 3-4

Typically LON 5-6

Living Options	Current Available DDS Supports	Average Annual Cost	Community of Practice Supports	Barriers
Shared Home -Live-In Companion -Community Companion Home -Shared Living (Provider Supported) -Cooperative Housing	Access to 24-hour support through paid providers and natural supports	CT Average annual CCH cost= $25,539	• Assets Planning • Personal Networks • Technology • Community Resources • Other Eligibility	-DDS Live-In Companion Rules -DOL Home Companion rules -Rental assistance -Families often don't want their child to live with another family -Shared living has been written into the waiver amendment which will implemented in January, 2015 subject to CMS approval Cooperative Housing is approved person by person

Where People with Intellectual Disabilities Live: Housing Support Options

COMPREHENSIVE SUPPORT MODELS

Typically LON 5-7

Living Options	Current Available DDS Supports	Average Annual Cost	Community of Practice Supports	Barriers
Group Living Waiver Funded -Continuous Residential Support (CRS)	Wrap-around skilled direct-support professional support available at all time	CT Average annual support cost= *$142,788 Average includes forensics costs, DCF individuals, higher need individuals costs	• Assets Planning • Personal Networks • Technology • Community Resources • Other Eligibility	High Cost -CRS are treated as CLAs-distinctions between CRS & CLA often unclear - More people that live together the less choice & control
Group Living-Waiver Funded Community Living Arrangement Licensed Setting (CLA)	Wrap-around skilled direct-support professional support present at all time Clinical team support as needed	CT Average annual Support cost= $116,304	• Assets Planning • Personal Networks • Technology • Community Resources • Other Eligibility	-High Cost -May have difficulty meeting CMS Final Rule guidelines

Where People with Intellectual Disabilities Live: Housing Support Options

INDIVIDUALIZED BUDGET

Typically LON 8

Living Options	Current Available DDS Supports	Average Annual Cost	Community of Practice Supports	Barriers
Group Living-Federal/State Funded ICF-IDD Institutions	Wrap-around skilled direct-support professional support present at all time Health or Behavioral staff available at all times	CT Average annual support cost= $349, 283	• Assets Planning • Personal Networks • Technology • Community Resources • Other Eligibility	-Very High Cost -High level of regulation

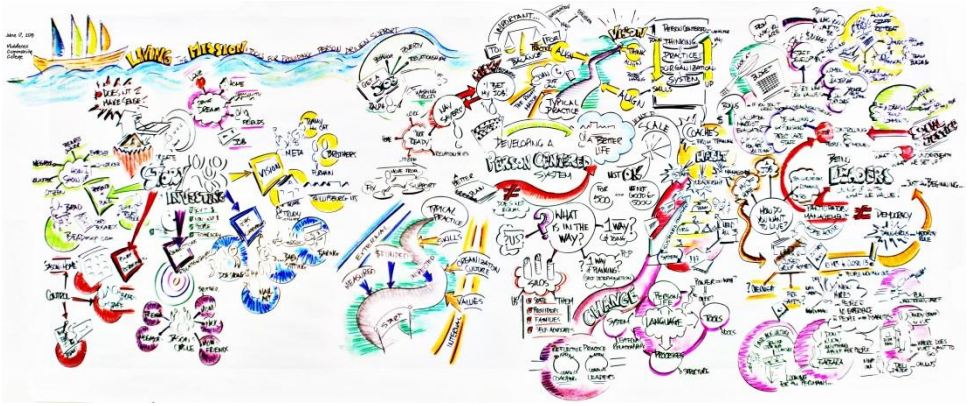
3 "Big Idea!" Changes
We've Learned Through the Supporting Families Community of Practice

LEARNING	BARRIERS	What we hope will change…
System Change Learning takes time 	We are moving into a new generation of services. It is hard to let go of the familiar.	**Partnerships:** Stakeholders move from fear-based responses to hope-based action planning
Communication! **Communication!** **Communication!** 	Moving from a provider system of support to a network system of support is a whole new way of thinking and doing business.	**Networking Tools:** Legal, IT, and other decision-makers become less risk averse and social media tools and other networking resources are made more available and accessible
Community Engagement & Reciprocal Contribution 	DDS stakeholders often ask for help from the community without showing how reciprocal contributions will occur.	**Training:** Stakeholders learn the art & science of "crossing thresholds" and develop community partnerships based upon equality & mutual reward

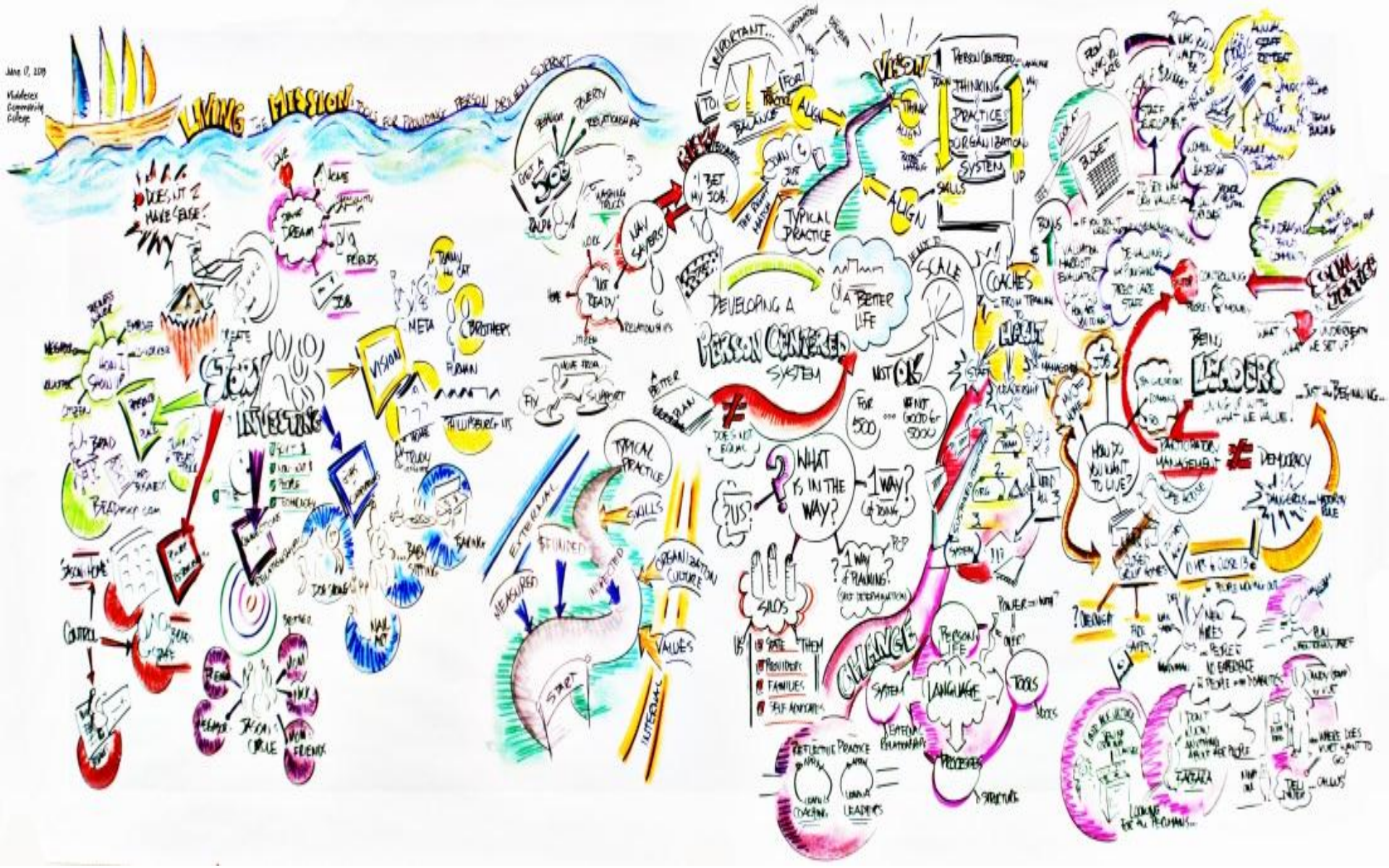
3 Values Change Ideas
We've Learned Through the Supporting Families Community of Practice

LEARNING	BARRIERS	What we hope will change…
Life Course Principles Helping families build upon life stages is more effective then waiting for people to arrive at the door of adult services	IDD services are not as effective or efficient as they can be when provided in a silo, or when services are separated from previous developmental stages	**Staffing:** Partnering with practitioners from each life stage reduces duplication of services & helps lead to better outcomes for people with IDD. Appropriate staffing is available at each life stage.
Family Engagement Families benefit from collaborations with other families	Isolated families result in increased needs over-time	**Funding for family networking,** mentoring, training and care-giving supports are available to assist families to be resilient and to support new ideas
Caring For and Caring About "Caring about" people with ID/DD is the responsibility of all. It is not just a family concern.	Separating "caring about" and "caring for" increases the probability of abuse & neglect	The Community of Practice concepts are infused in all aspects of the agency's operations. This will require **shifting of resources and flexible funding practices**.

3 Infrastructure Changes We've Learned Through the Supporting Families Community of Practice



LEARNING	BARRIERS	What we hope will change…
Organizational Design Many new best practice models have been identified but need to be made scalable.	The majority of resources in current organizational design focus on maintaining the current provider structure	More "Blue Space" innovation opportunities **(pilots/prototypes)** will evolve and be funded to help management re-think what systems need to move from provider design to network design of services
Waiver Assurances Waivers can help and can hinder depending on how they are perceived.	There are many "myths" about what the waivers allow and don't allow	**Waiver amendments** may need to be amended to allow for new models of services to be implemented.
Quality Assurance Quality practices need to keep paces with societal changes.	Current quality measures and designs are based on a legacy model of services.	**Quality assurance best practices** are incorporated into continuous quality improvement activities. QA staff are both "finders" AND "fixers".



June 17, 2019
Middlesex Community College
LIVING THE MISSION
TOOLS FOR PROVIDING PERSON DRIVEN SUPPORT
DOES IT MAKE SENSE?
DREAM
FRIENDS
JOB
CREATE
STORY
INVESTING
VISION
META
BROTHERS
FURMAN
THILLIPSBURG NJ
TRUDY
BRAD
BEADmap.com
CONTROL
JASON'S CIRCLE
NAIL ART
BABY SITTING
BAKING
GET A JOB
RALPH
NAV SAVERS
"NOT READY"
FIX
SUPPORT
NOVE FROM
IMPORTANT...
TO
BALANCE
FOR
ALIGN
JOHN
JUST CALL
THE RIGHT MATCH
"I BET MY JOB!"
TYPICAL PRACTICE
VISION
PERSON CENTERED
THINKING
PRACTICES
ORGANIZATION
SYSTEM
UP
SKILLS
ALIGN
DEVELOPING A
PERSON CENTERED
SYSTEM
A BETTER LIFE
SCALE
NOT OK
FOR 500
NOT GOOD for 5000
COACHES
FROM TRAINING TO
HABIT
STAFF
LEADERSHIP
BUDGET
BONUS
VALUATION
HARRIOTT
EVALUATION
DEVALUING
PRESS CARE STAFF
CONTROLLING
PEOPLE'S MONEY
BEING
LEADERS
WHAT WE VALUE!
...JUST AN BEGINNING...
HOW DO YOU WANT TO LIVE?
PARTICIPATORY MANAGEMENT
DEMOCRACY
DANGEROUS
MAJORITY RULE
TYPICAL PRACTICE
SKILLS
EXTERNAL
FUNDED
MEASURED
INSPECTED
ORGANIZATION CULTURE
VALUES
START
INTERNAL
DOES NOT EQUAL
WHAT IS IN THE WAY?
1 WAY?
US?
1 WAY of PLANNING?
SILOS
US
THEM
PROVIDERS
FAMILIES
SELF ADVOCATES
CHANGE
PERSON LIFE
SYSTEM
LANGUAGE
TOOLS
PROCESSES
STRUCTURE
REFLECTIVE PRACTICE
COACHING
LEADERS
POWER
FIX
SAFETY?
NEW HIRES
PEOPLE
NO EMPEROR
NO PEOPLE
NO DOMINATOR
FARBARA
WHERE DOES WORK WANT TO GO?
CALLOUS