PERSON-CENTERED APPROACHES in MINNESOTA: Where Have We Come From and Where Are We Going?

Angela Novak Amado, Ph.D. Institute on Community Integration, University of Minnesota

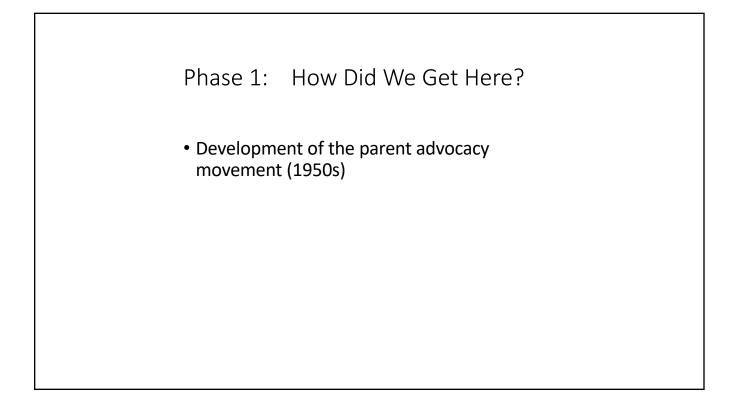
ERA's and PHASES

- 1. The roots of all this
- 2. Person-Centered Planning trainings
- 3. Organizational/Systems Change projects
- 4. How far have we come?
- 5. Where are we going?

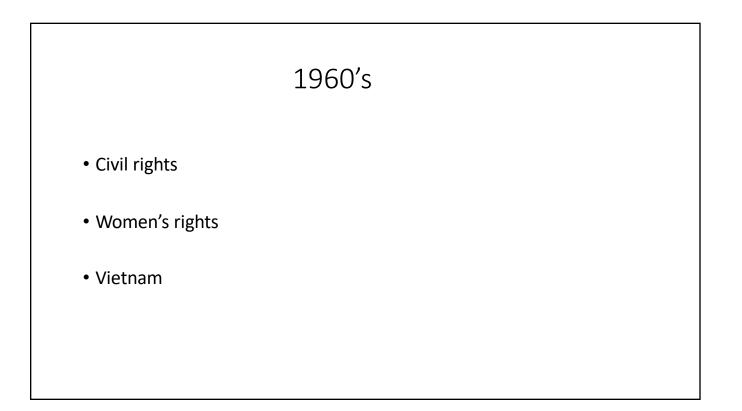
CAVEATS

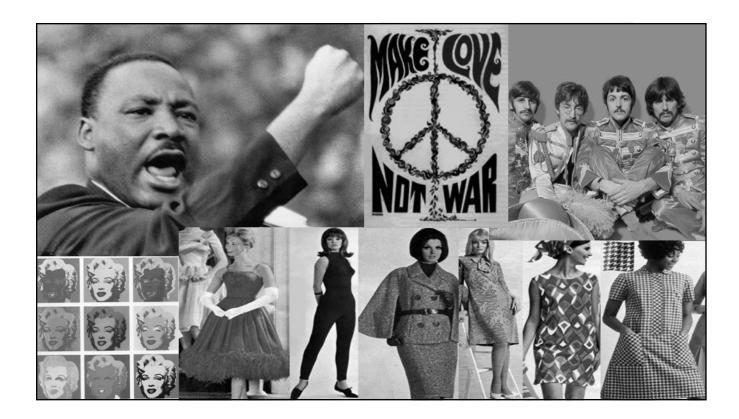
- 1. Can't capture everything that has gone on in all the different areas
- 2. Our memories are faulty and our collective memories are needed!
- 3. This presentation focuses on person-centered planning/implementation
 - foundation for other positive supports which have also developed

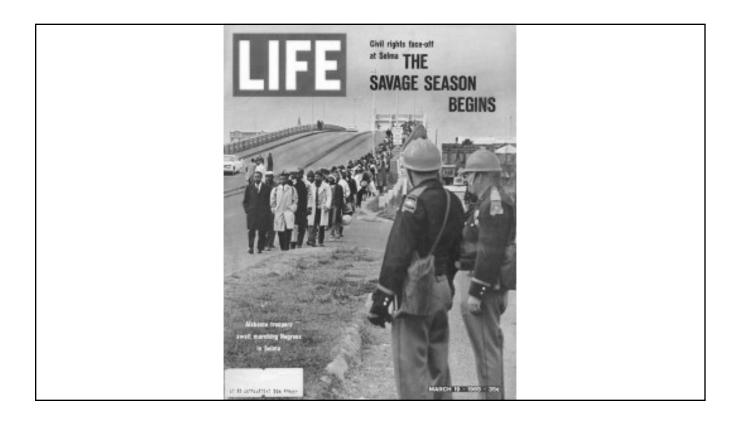
When was "person-centered" first used?













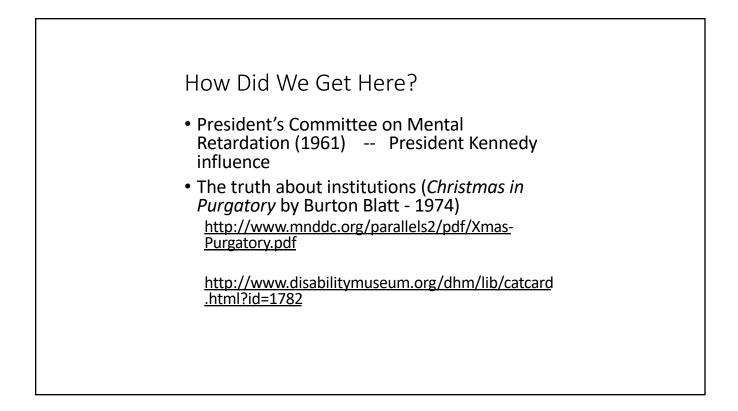


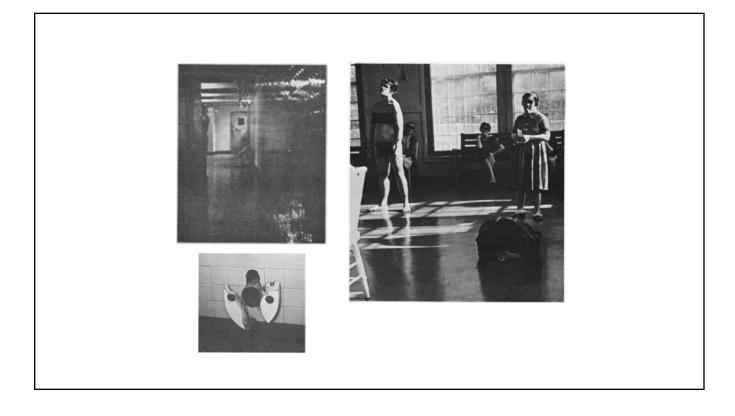


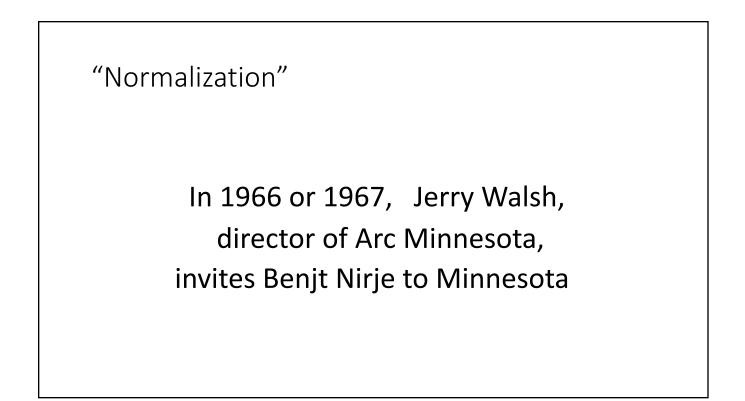












Swedish Expert Here to Help 'Bridge Gap'

Bengt Nirje, secretary general of the Swedish Association for Retarded Children, has been visiting Minnesota this month as a guest of the Minnesota Association for Retarded Children (ARC) and other organizations.

Other sponsors of his visit to the United States are the Minneapolis, St. Paul, Iowa and Wisconsin ARCs, the National ARC North Central Region, the Minnesota Welfare Association and the Minnesota Rehabilitation Association.

Nirje's visit is intended to help "bridge the gap between Europe's advanced methods of care and our outdated practices," said Gerald F. Walsh, Minnesota ARC executive director.

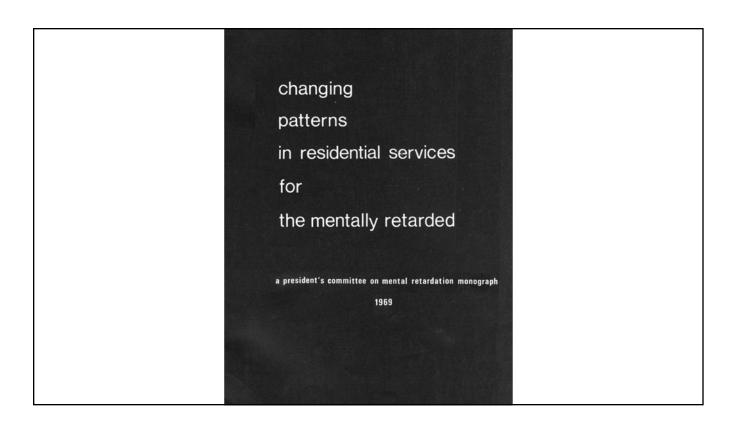
On Wednesday, March 15, Nirje was to address a joint meeting of the Minneapolis and St. Paul ARCs to which all metropolitan area chapters have been invited.

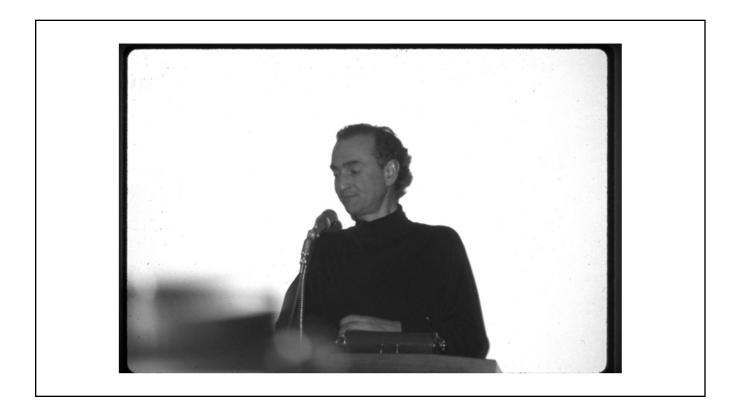
Nirje has been visiting various facilities for the retarded in Min-

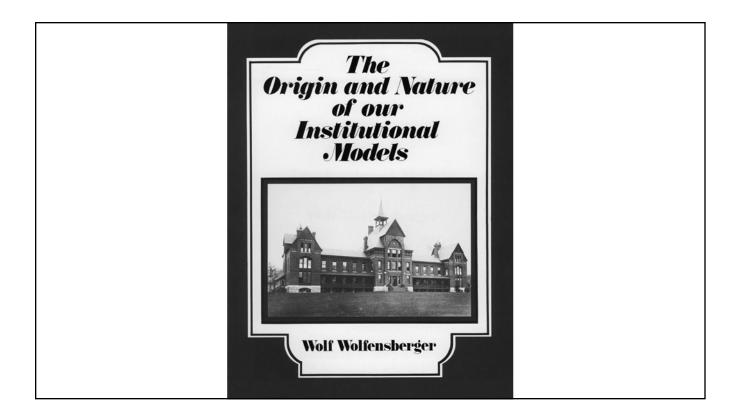


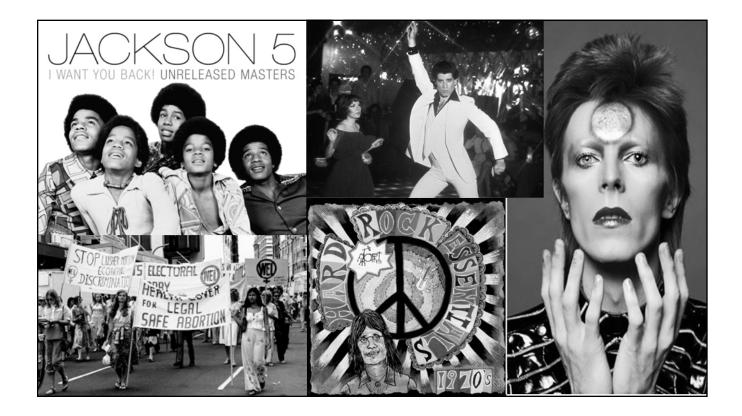
BENGT NIRJE

bers March 14 at the Minnesota Welfare Association conference; and the March 14 dinner meeting of the Minnesota Rehabilitation Association.

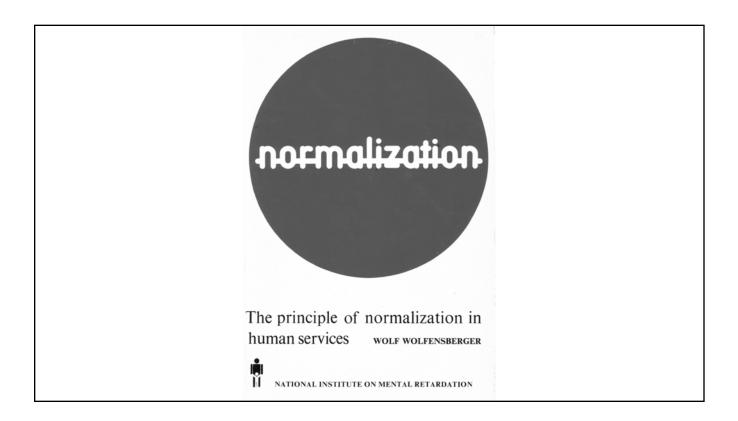


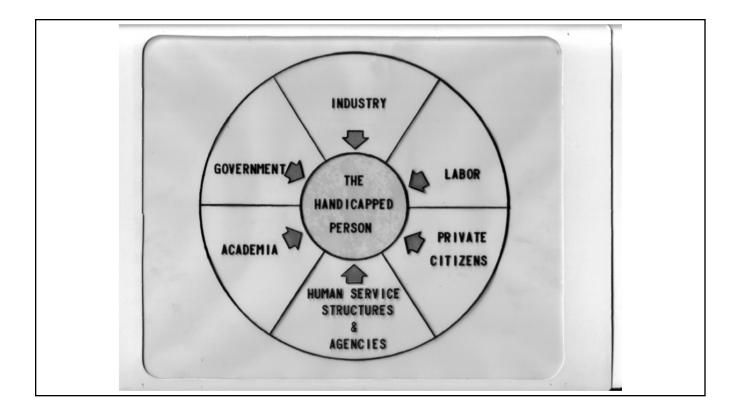




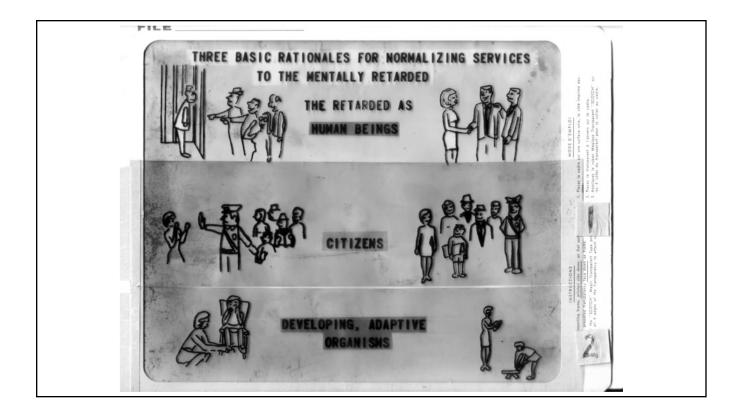


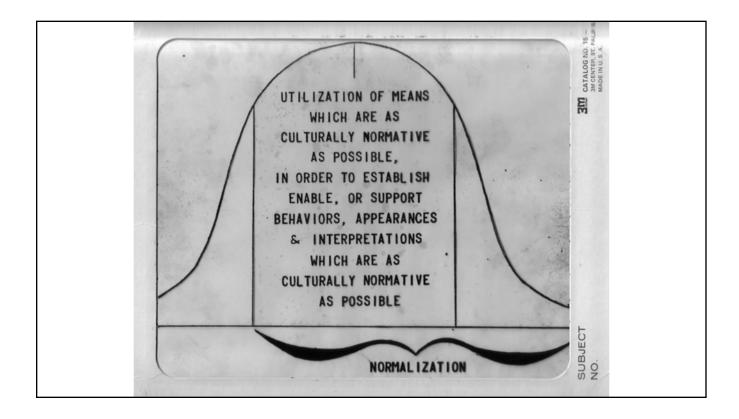
National	Minnesota
1972 - Cliff Poetz, first person with int	tellectual disabilities, testified to Congress –
DD Act first passed	
1975 - Public Law 94-142 passed – the	Education of All Handicapped Children Act
1977 - First national report on Commu	inity Residential Settings
1982 - Federal Medicaid waiver funding	g started
	1985 - Minnesota started planning for closing RTC's
1989 – First national conference on self	-determination
1990 - Americans with Disabilities Act	
	1993 - Last Regional Treatment Center closed
	1998-2003 - ICI study of Deinstitutionalization in Minnesota
1999 - Olmstead decision	
	2011 - Jensen settlement
2014 - HCBS regulations	











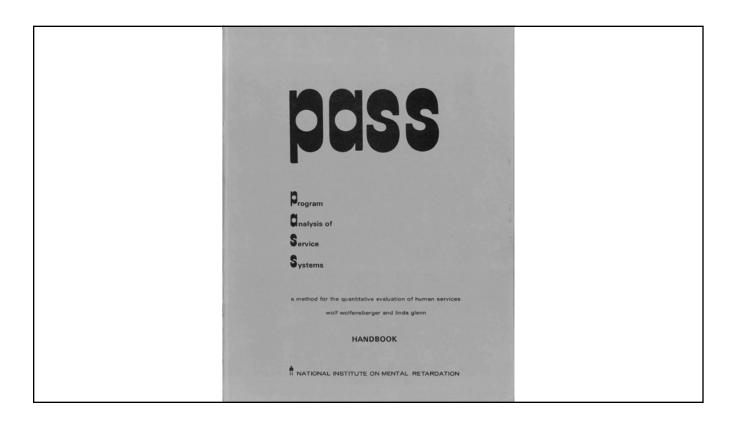
Traditional Roles

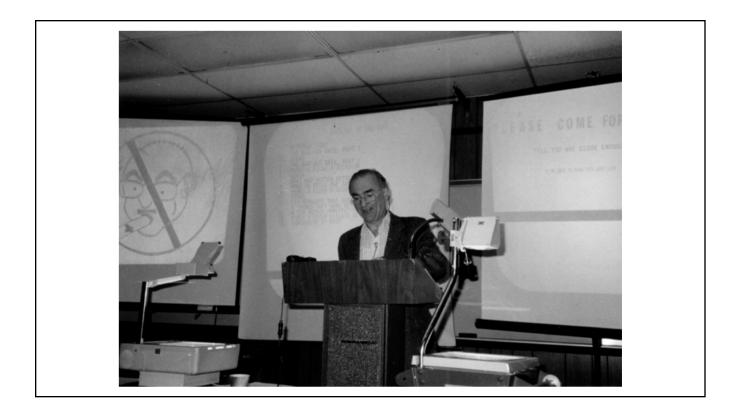
- Child
- Object of Pity
- Object of Charity
- Object of Dread/Dangerous
- Less than
- Object of Ridicule
- Not human
- Children of god, special

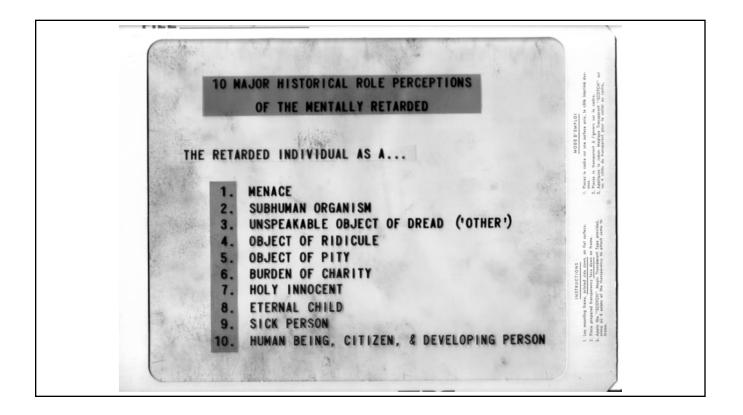
Valued Roles

- 1. Formally defined:
 - employee tenant business owner association board member political candidate actor/model

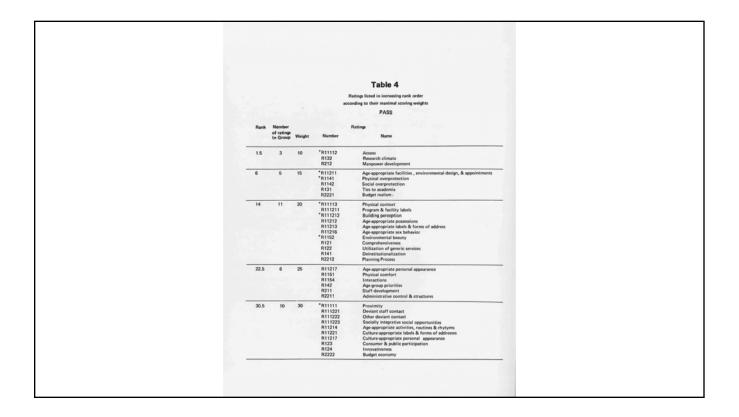
- 2. Informal roles:
 - co-worker
 - neighbor
 - classmate
 - unofficial advisor
- There's no comprehensive list of valued roles, but it's easy to recognize a person who has not found one

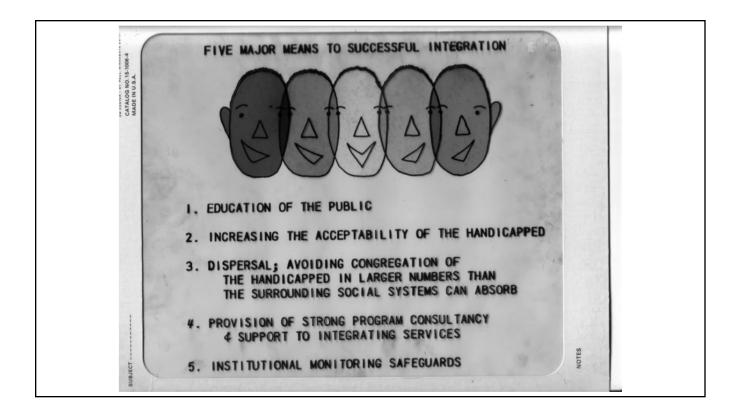






THE LANGUAGE OF DIFFERENTISM CATALOG NO.15-1006-4 MADE IN U.S.A. THEY, THEM, THE IR THESE, THOSE WE, US, OUR, I ERSUS HANDICAPPED, SICK, HEALTHY, WEALTHY, WISE, INTELLIGENT, ADJUSTED, RETARDED, AGED, MAJORITY, MINORITY, DIFFERENT, DEVIANT, NON-HANDICAPPED, NORMAL, WHOLE, CLIENTS, PATIENTS, PARENTS, STAFF, PROFESSIONALS, BAD ONES GOOD ONES





Normalization Training

PASS 3: Program Analysis of Service Systems: A Method for the Quantitative Evaluation of Human Services

by Wolf Wolfensberger and Linda Glenn (1975)

- Program-neighborhood harmony
- Congregation & assimilation potential
- Program, facility & location names
- Deviancy image juxtaposition
- Socially integrative social activities
- Model coherency

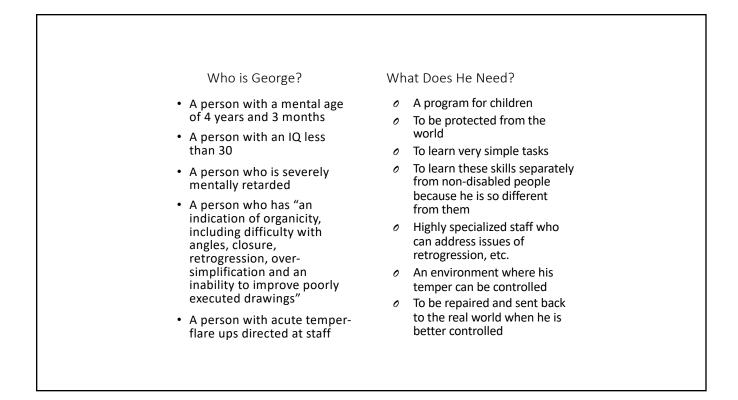
- How do we think about people?
- How do we think about what they need?
- How do we think about what services should provide?

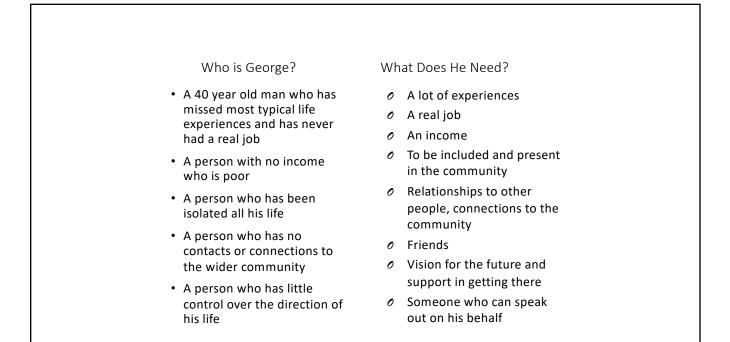
Service Perspective vs. Person-Centered Perspective

Who Is George? What Does He Need?







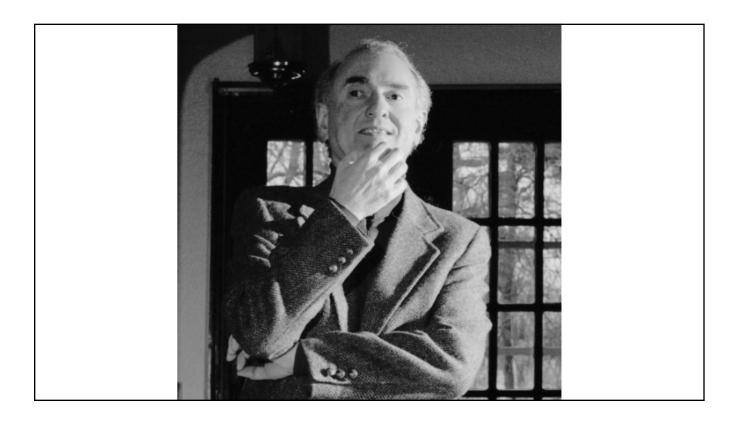


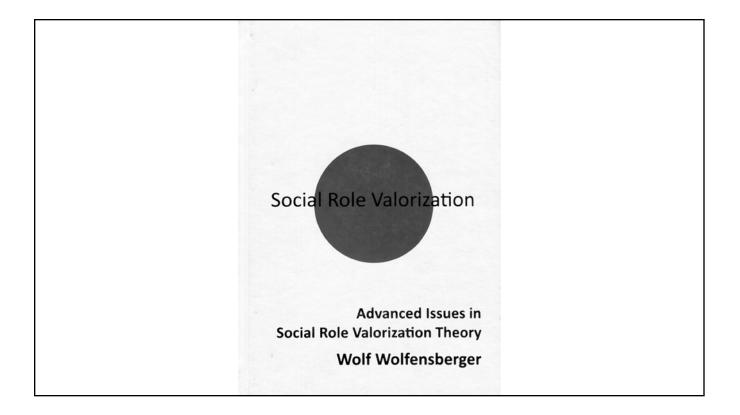


- A person who had more difficulty learning new skills than most people
- A person who is treated as a child by his mother
- A delightful man who makes a difference in the lives of those who care about him

What Does He Need?

- A lot of support for learning
- More people who see and treat him as an adult
- People who can enjoy being with him







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Early 1980's McKnight Foundation was tired of applications from individual developmental disabilities agencies. Funded three systems change projects – 1. ARRM 2. MnDACA 3. Vocational Rehabilitation ARRM: Jane Wells -- Program Analysis of Service Systems (PASS) – 1985-86



Early PASS attendees

- Ed Sootsman (Hennepin County)
- Val Sidlo
- Rick Amado
- Gerry Glomb (CCP)
- Terri Williams (Mains'l)
- Marijo McBride
- Luther Granquist

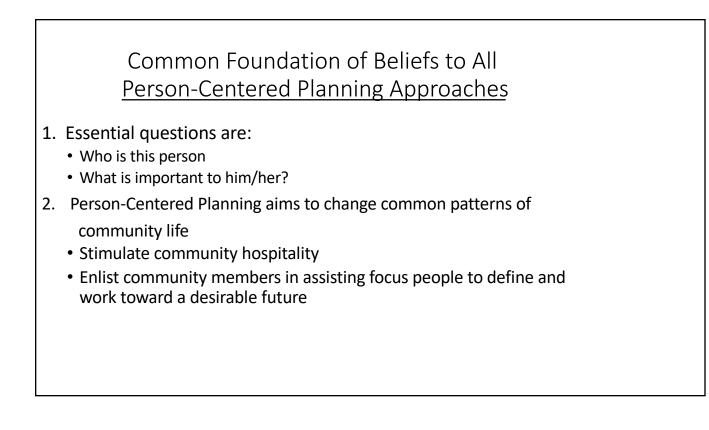
Phase 2: Person-Centered Planning formats develop

• Person-Centered Planning formats start to develop in the 1970's and by 1980 there are 4:

Getting to	Individual	Personal
Know You	Design	Futures
	Session	Planning

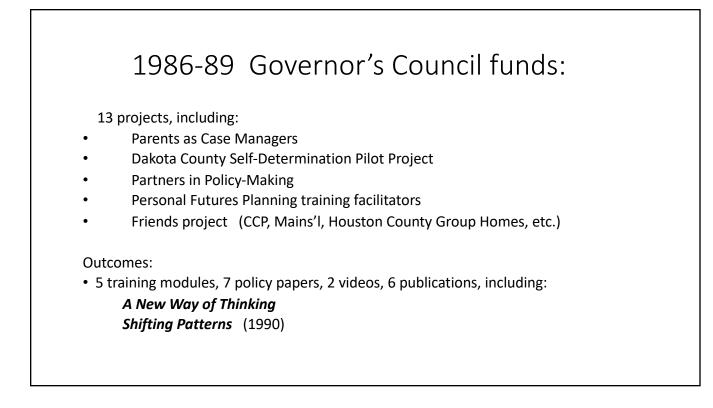
24 Hour Planning

	by 1990 -	- 4 beco	ome 12	
Personal Histories	Life	ential estyle nning	Whole Life Planning	PATH
	Families		Group	
New	First		Action	MAPS
Hats			Planning	
(Getting to Know Yo	u) (Individual Design Options)	(Personal Futur	es Planning)	(24 Hour Planning)



Common Foundation of Beliefs to All Person-Centered Planning Approaches

- 3. Person-Centered Planning fundamentally challenges practices that separate people and perpetuate controlling relationships
- 4. Honest Person-Centered Planning can only come from respect for the dignity and completeness of the focus person
- 5. Assisting people to define and pursue a desirable future tests one's clarity, commitment and courage





1988-90 Governor's Council funds

Metropolitan Council: produces 2 Beth Mount manuals

It's Never Too Early, It's Never Too Late Making Futures Happen

- Read My Lips (1989)
- It's My Choice
- The Heart of Community is Inclusion (1990)

Training in 3 Formats in Minnesota
 Personal Futures Planning – developing a dream from a deep understanding of a person (history, gifts) Variations: MAPS – especially used in schools Whole Life Planning (careers)
 Essential Lifestyle Planning – basic understanding of how a person wants to live now
 <u>PATH (</u>Planning Alternative Tomorrows with Hope) – North Star: goal Action steps toward implementation of a dream



A creative process designed to help a group of people craft a life of meaning and contribution for the person who is the focus of the planning

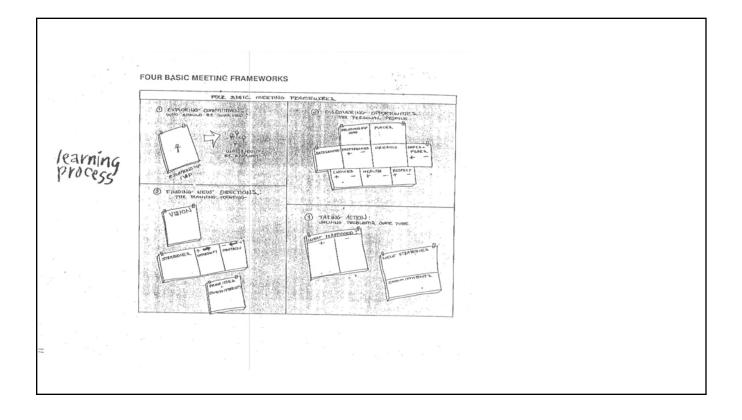
An effective plan should inspire people to act on behalf of the person with a disability

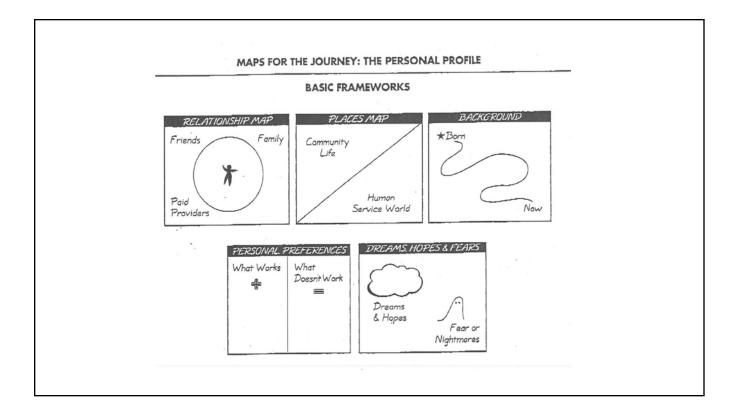
-- Beth Mount, Making Futures Happen

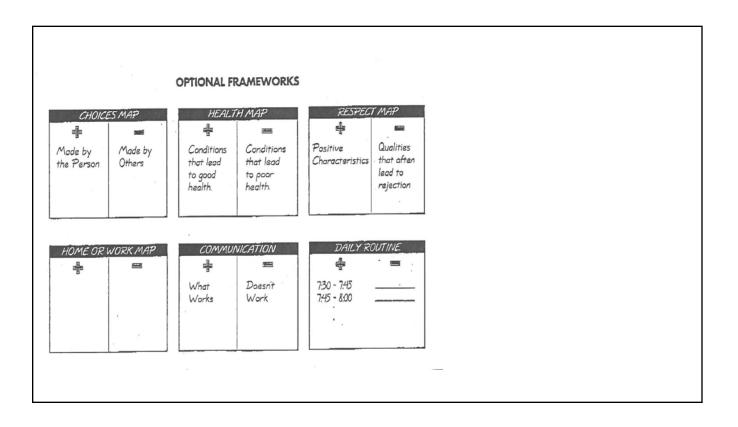


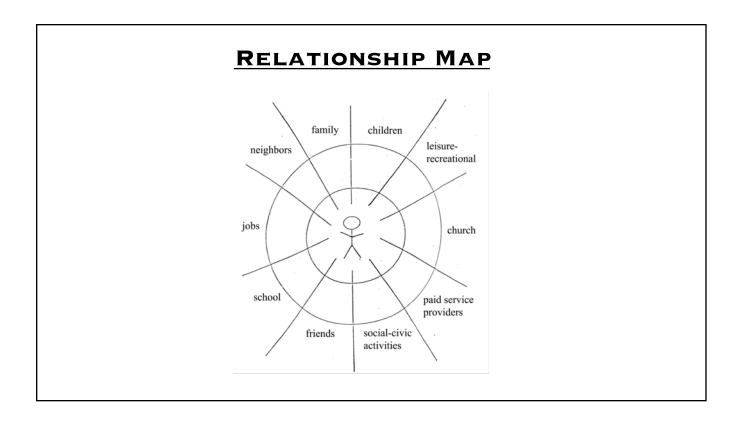
1. PERSONAL FUTURES PLANNING

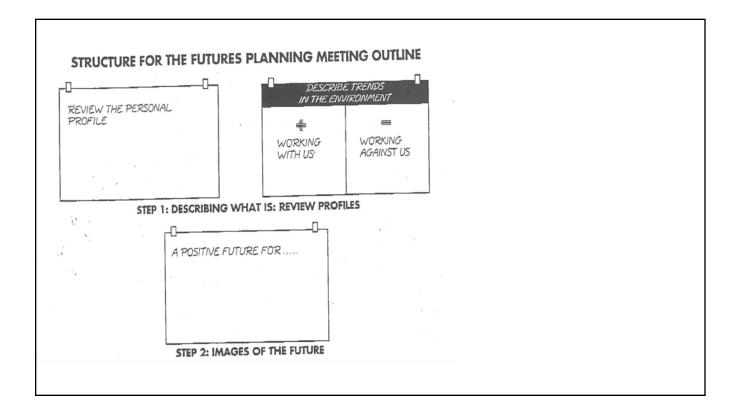
Developing a dream from a deep understanding of a person

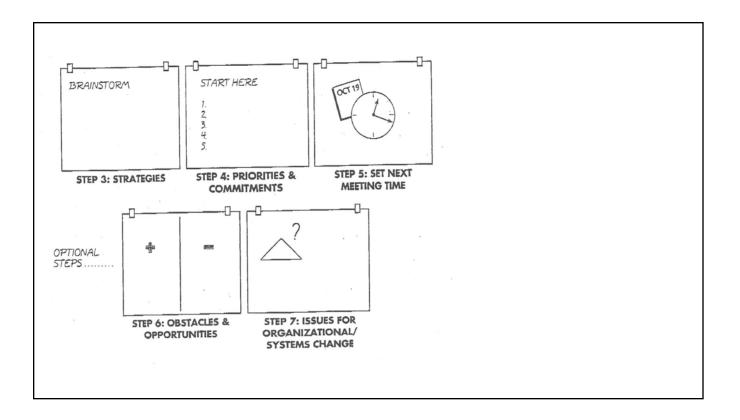


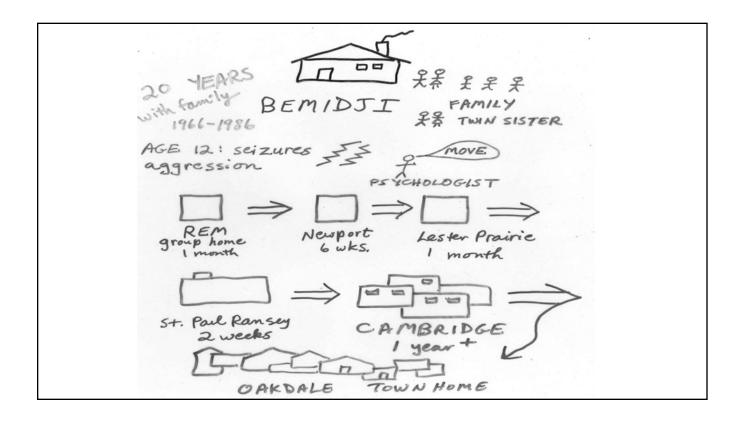


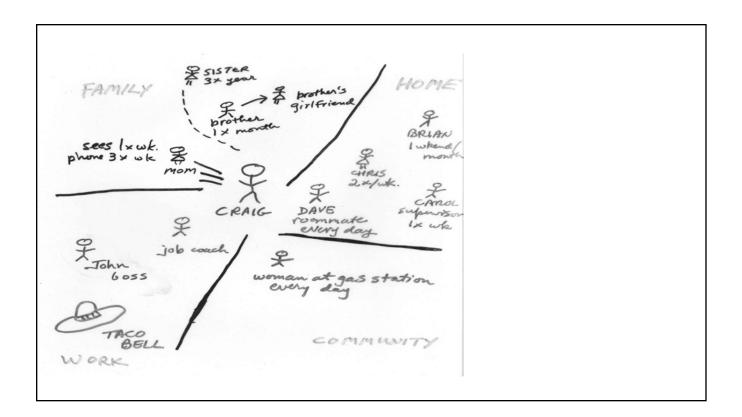


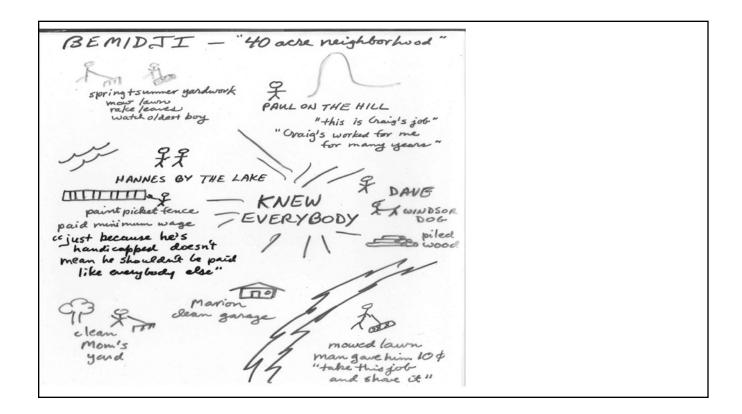


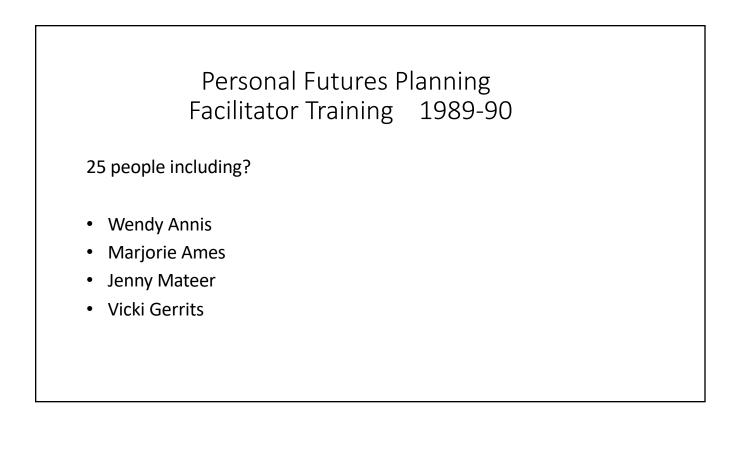












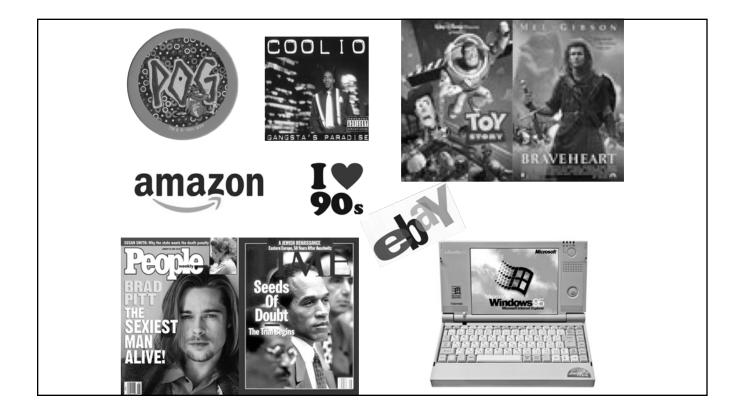
MAPS

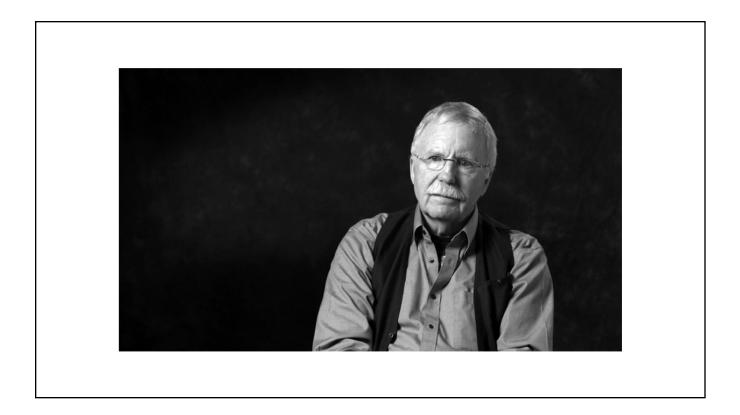
(started originally for school-age kids)

- 1. What is the individual's history?
- 2. What is your dream for the individual?
- 3. What is your nightmare?
- 4. Who is the individual?
- 5. What are the individual's strengths, gifts, and abilities?
- 6. What are the individual's needs?
- 7. What would the individual's ideal day at school look like and what must be done to make it happen?

Whole Life Planning

- Developed for transition-age students (Boston: employment RTC)
- Same maps, except "Ideal Job" added
- Available from www.trninc.com





2. Essential Lifestyle Planning

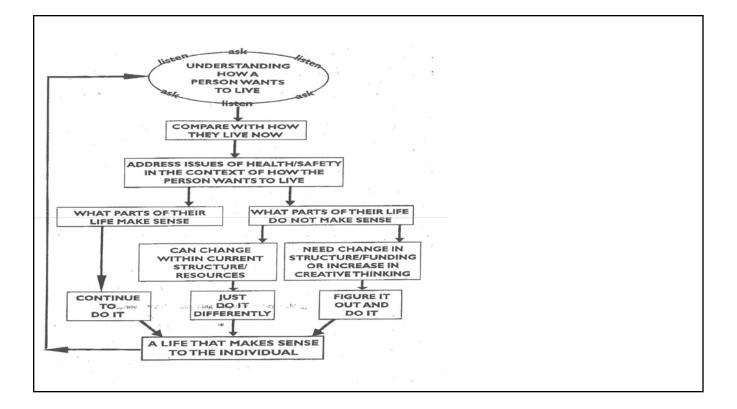
- Discover CORE VALUES and preferences (not superficial choices)
- How a person WANTS to live (person by person)

Essential Lifestyle Planning exercises

- 1. Positive Reputation (who listen to)
- 2. Important To/Important For
- 3. Routines (morning, evening, etc.)
- 4. Good Day/Bad Day
- Communication Chart (especially good with people who don't use words to communicate)
- 6. Doughnut

Parts: ESSENTIAL LIFESTYLE PLAN

- 1. Positive reputation
- 2. Non-negotiables
- 3. Strong preferences
- 4. Highly desirables
- 5. To be successful in supporting (person)
- What does and does not make sense in the life of this person
- 7. What we need to do to maintain those things that make sense
- 8. Action plan to change those things that don't make sense



Essential Lifestyle Planning training in Minnesota

1997-2002

• Fore-runner of Person-Centered Thinking

3. PATH

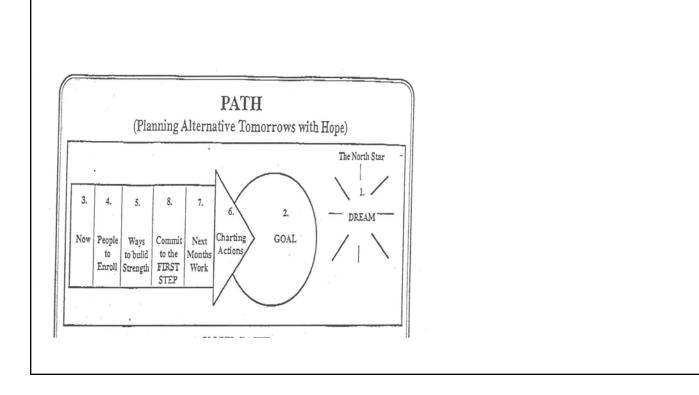
(Planning Alternative Tomorrows with Hope)

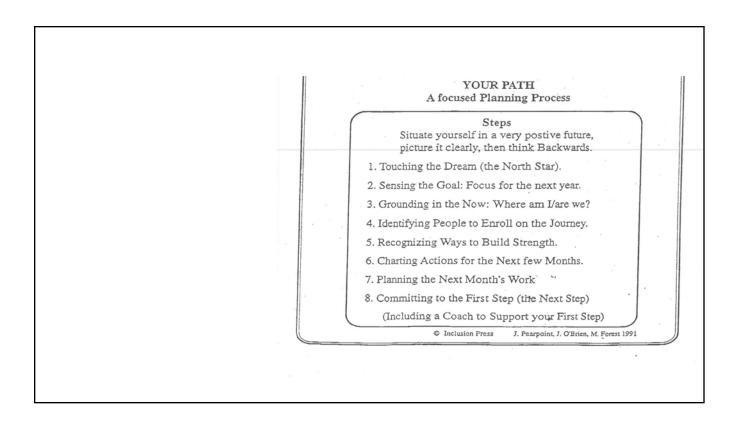
Steps:

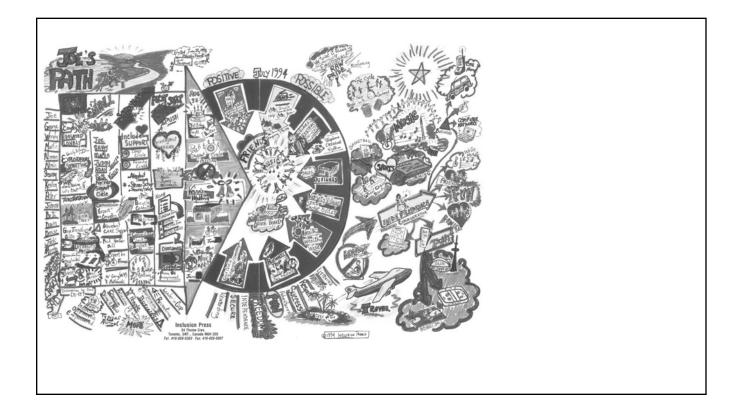
Situate yourself in a very positive future,

picture it clearly,

then think Backwards







EARLY adopters 1986 ARC MN convention -- Al Pendergast led a day-long person-centered planning workshop in Duluth Hammer hired Beth Mount to come Lifeworks, LSS, and Trillium -- brought in Jack Pealer & Lynda Kahn for PATH and MAPS training People (e.g., Betsy Gadbois, Marjorie Ames, Vicki Gerrits, etc.) went to Toronto - for PATH and MAPS training, Toronto Summer Institute

Creative Options Conferences 1989-2013

Brought in many national leaders, including:

Lou Brown Norman Kunc Herb Lovett Beth Mount John & Connie O'Brien Jack Pearpoint

David Pitonyak Ed Roberts Michael Smull Jeff Strully Judith Snow David & Faye Wetherow

"People are IN the community but not OF the community"

"Friends" (Social Inclusion) projects

- 1989 Friends project
- 2003-2008 5 year project with LSS & MSOCS
- 2008-2013 MSOCS project
- 2013-2018 Project with families

Myths about Person-Centered Planning

- 1. "We're already doing it."
- 2. Person-centered planning means asking the person, "What do you want?"
- 3. A good plan means a good life.
- 4. Person-centered planning is a different kind of planning process that can be done separate from more significant organizational change.

Evaluation of Personal Futures Planning training -- from families

"It was wonderful, but there was no follow-through"

"I have beautiful charts rolled up in my garage (car trunk, etc.)"

A GOOD PLAN

DOES NOT EQUAL

A GOOD LIFE

"Almost every personal futures plan that is true to the person challenges the existing organizational structure and process in some way."

Mount, 1994



"Like other efforts for social change, person-centered planning has been used and misused, complicated and simplified, lengthened and shortened, trivialized, legalized, and lionized."

"The Origins of Person-Centered Planning: A Community of Practice Perspective" by Connie Lyle O'Brien and John O'Brien, 2000

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PHASE 3: ORGANIZATIONAL CHANGE

NationalMinnesota1972 - Cliff Poetz, first person with intellectual disabilities, testified to Congress –
D Act first passed1975 - Public Law 94-142 requires Education of All Handicapped Children1975 - Public Law 94-142 requires Education of All Handicapped Children1977 - First national report on Community Residential Settings1982 - Federal Medicaid waiver funding started1989 - First national conference on self-determination1989 - First national conference on self-determination1990 - Americans with Disabilities Act1991 - Olmstead decision1992 - Olmstead decision2014 - HCBS regulations

Person-Centered Agency Design 1991-94 8 agencies

- Clay County Diversified Services (Moorhead)
- Cooperating Community Programs (CCP Washington County)
- Dakota Inc. (now Lifeworks)
- Houston County Group Homes
- Linnea Residence -- Chisago City
- LSS -- International Falls ICF/MR
- MBW, Inc. -- New Ulm
- STEP, Inc. -- Fairmont and Blue Earth

Framework for Accomplishment

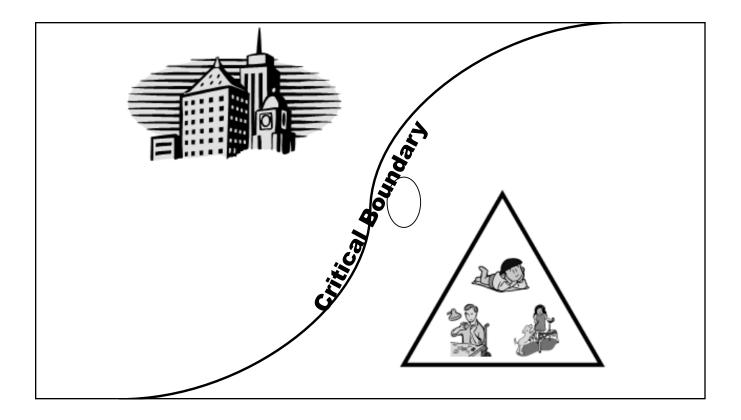
5 – day workshop

John & Connie O'Brien

adapted for agency self-evaluation:

How person-centered an agency are we?



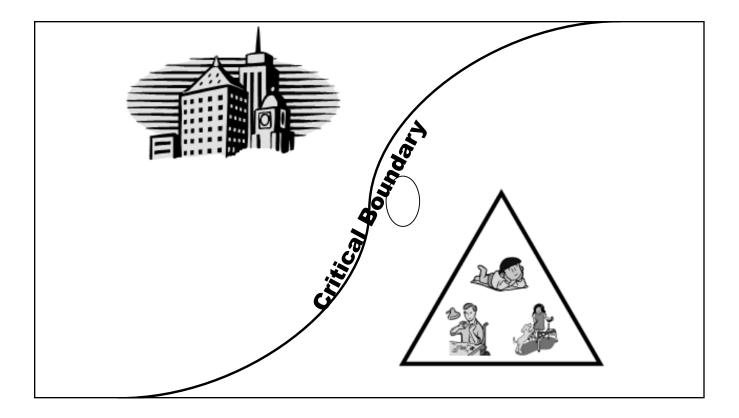


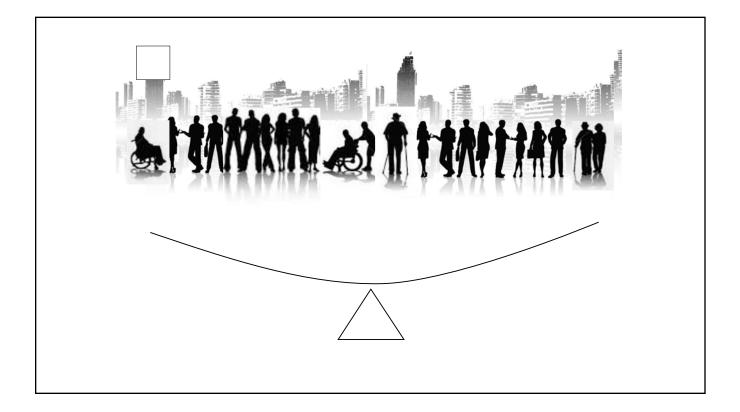
"What Is Person-Centered Planning"

The term "Person-Centered Planning" refers to:

A family of approaches to organizing and guiding community change in alliance with people with disabilities and their families and friends

- O'Brien & Lovett, 1998





FRAMEWORK for ACCOMPLISHMENT

(John & Connie O'Brien 5-day workshop)

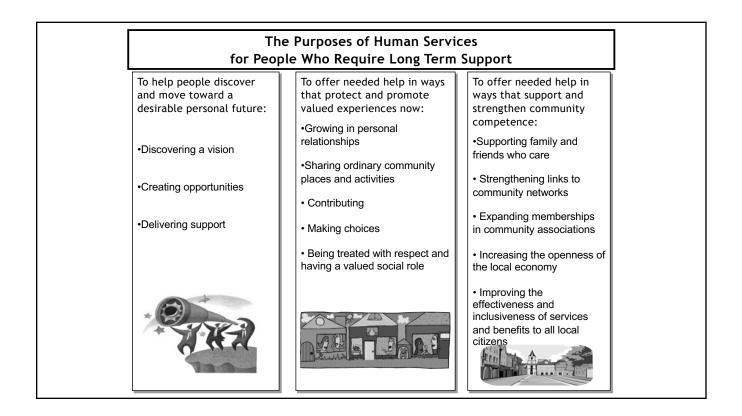
FRAMEWORK

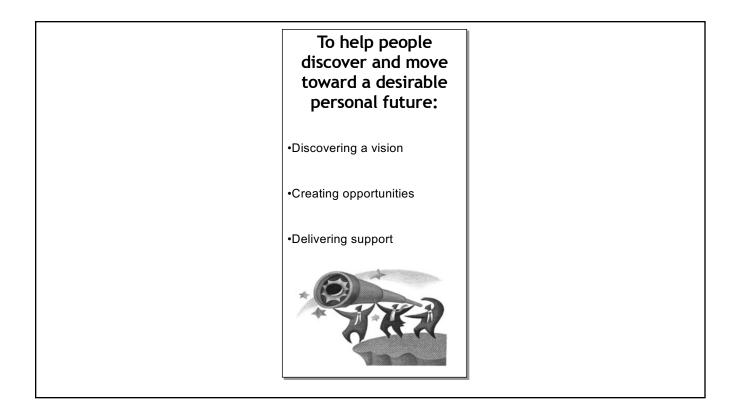
- 1. The supporting frame of a building or other construction
- 2.The basic structure (of an idea, treaty, etc.)

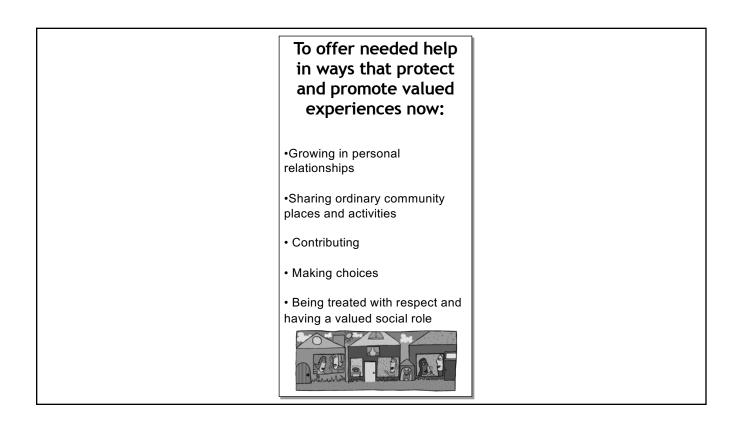
<u>ACCOMPLISHMENT</u>

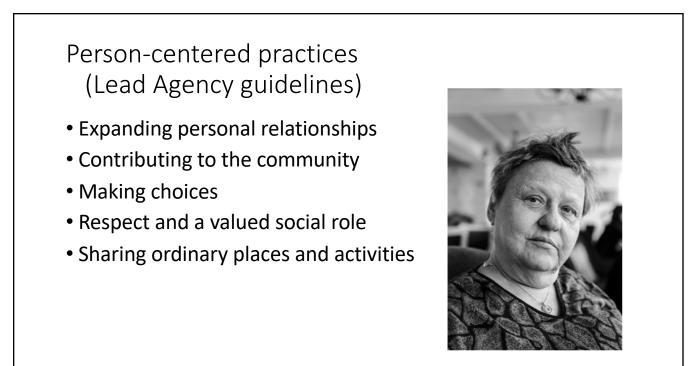
1. Worthy performance

2.Results that give meaning to activity

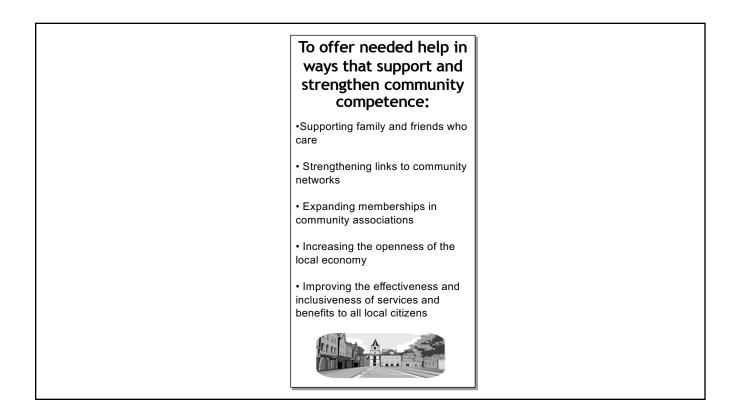


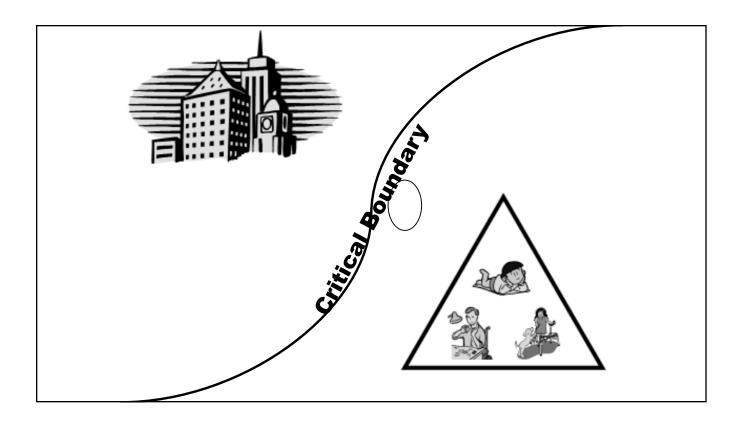


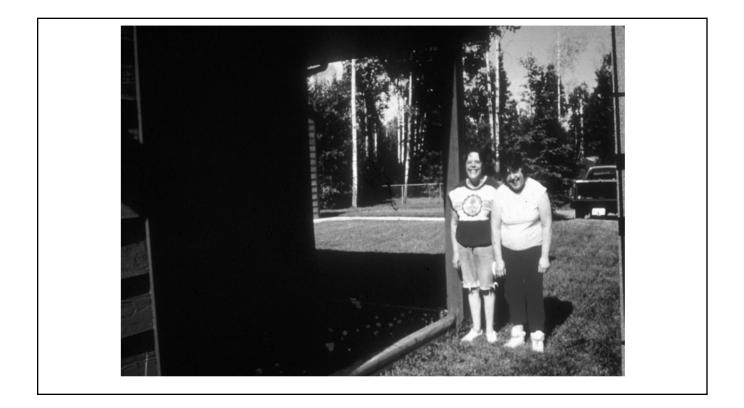




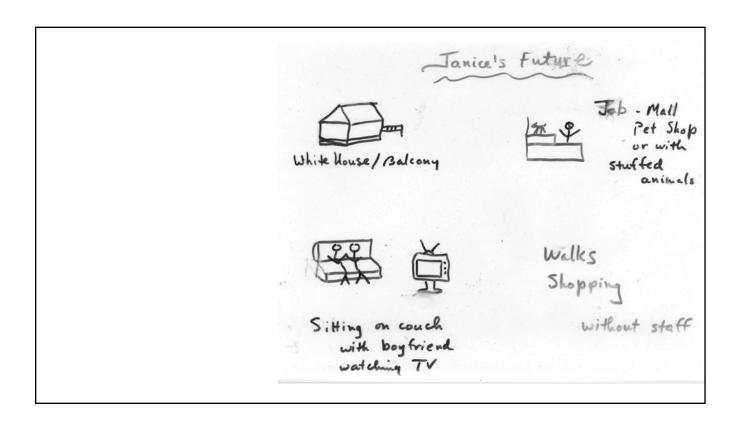
Minnesota Department of Human Services | mn.gov/dhs







How people Janice dislike see her Rude! No fun! avior Violent! threatens people Basketholds Timeout peopl Hits Selfish! Mean Timeconsuming roblem t P Be Rule 40 === 1 -Rule + C C 9 "Thetwins X together, no thousa limited -High risk Earned outside activities - age 19 left home -mom couldn't handle her or sister Brainerd State Hosp. meds/ Mech. restraints Janice Lack of friends, real experiences L labelled Northome with sister suparated because of Janice's behavior Grand Rapids (2 wks.) Moose Lake State Hasp. - phys./mech. restraints I meds REM group home Bemidy i - meds, behavior home (fence, no neighborg) International Falls - "behavior," Rule 40

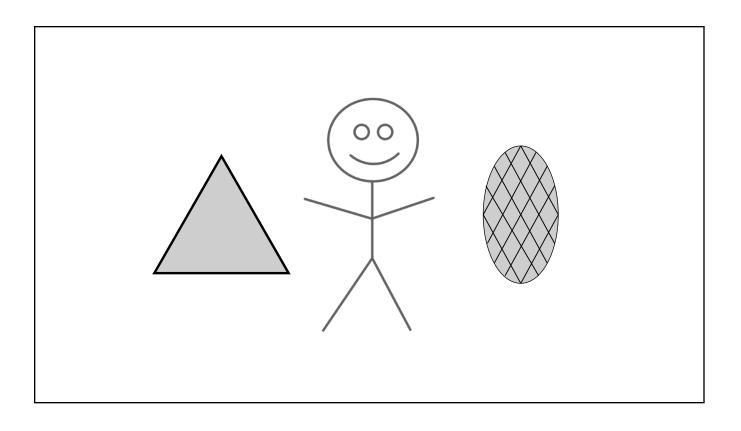


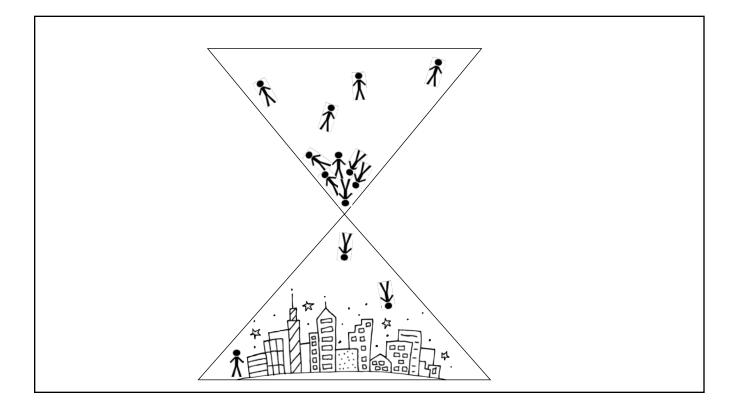


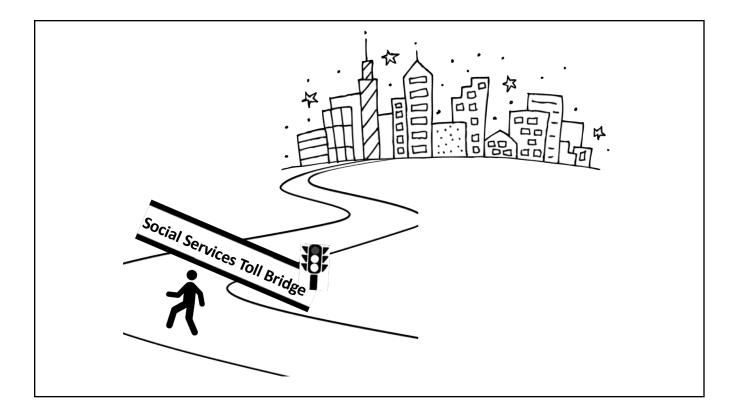


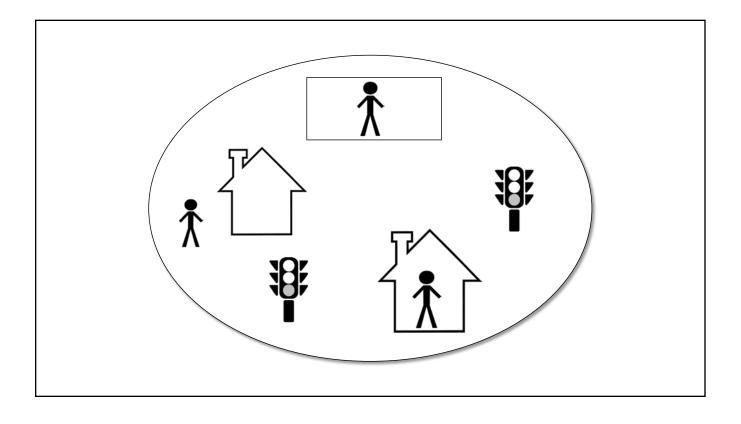


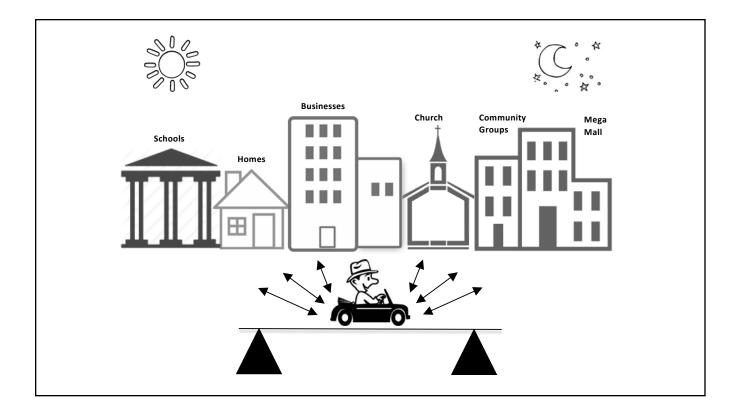
Janice Howpeople doing very see her Happy! ing growi Funto be with. E Aning 5000 -0% in Rule yd Sept. Behavior label being/broken boking smiles! Her room good 1-1 Job at Special Bedspread + curtains she picked Has TV saving for VCR Touch Excellent worker Problemsolving Making decisions Jokes choices compliments pleasant helpful C Road more separation House Line dancing siste dance at VFW Local bar she Happy ing Comm. Ed. w/o staff Not a high risk pecor fres own perso Roadtrips to shop

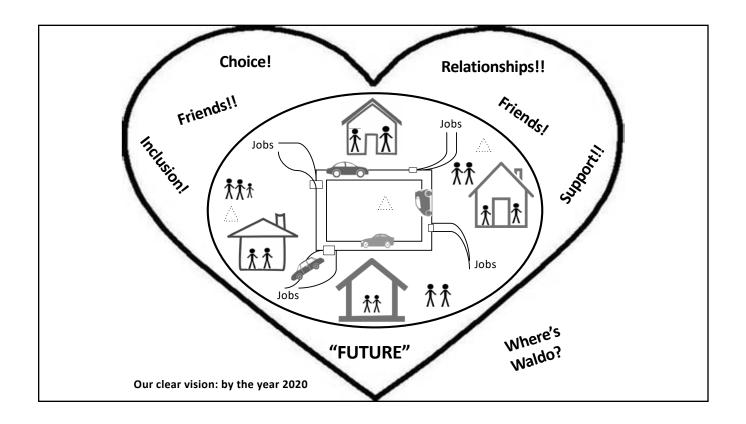














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Person-Centered Agency Design 1991-94 8 agencies

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- Cooperating Community Programs (CCP Washington County)
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- Houston County Group Homes
- Linnea Residence Chisago City
- LSS - International Falls ICF/MR
- MBW, Inc. -New Ulm
- STEP, Inc -- Fairmont and Blue Earth led to Systems Design project

Person-Centered Systems Design 1994-96

11 agencies in Faribault-Martin Counties, including:

Residential:

- Friendship Haven, Inc
- REM-Fairmont
- REM-Southwest Services
- Assissi Residences
- Habilitative Services Inc (HSI)

Day Training/Employment:

- STEP, Inc.
- MRCI-Fairmont
- Department of Rehabilitation Services

OTHER:

Human Services of Faribault & Martin Counties Martin County Special Education Cooperative ARC

Performance-Based Contracting Project 1993-96

- Council for Quality and Leadership outcomes standards
- Lots of person-centered planning training: Personal Futures Planning

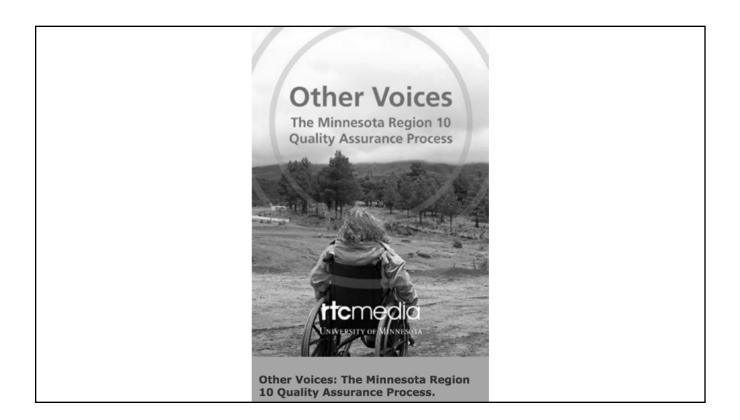
4 agencies: Nekton Heartland Homes

Bristol Place New Directions

Region 10 Quality Assurance pilot starts 1997

• Alternative quality assurance system

• Developed "VOICE" for quality assessment



NEW DIRECTIONS

WRAP (Wellness Recovery Action Plan) starts 1997

Personal Futures Planning for individuals with Brain Injury (Mount, 2003)



National	Minnesota
1972 - Cliff Poetz, first person with in	tellectual disabilities, testified to Congress –
DD Act first passed	
1975 - Public Law 94-142 requires Ed	lucation of All Handicapped Children
1977 - First national report on Comm	nunity Residential Settings
1982 - Federal Medicaid waiver fund	ing started
	1985 - Minnesota started planning for closing RTC's
1989 – First national conference on se	elf-determination
1990 - Americans with Disabilities Ac	t
	1993 - Last Regional Treatment Center closed
	1998-2003 - ICI study of Deinstitutionalization in Minnesota
1999 - Olmstead decision	
	2011 - Jensen settlement
2014 - HCBS regulations	

From: Michael Smull

We need not just person-centered planning but person-centered THINKING --

at all levels

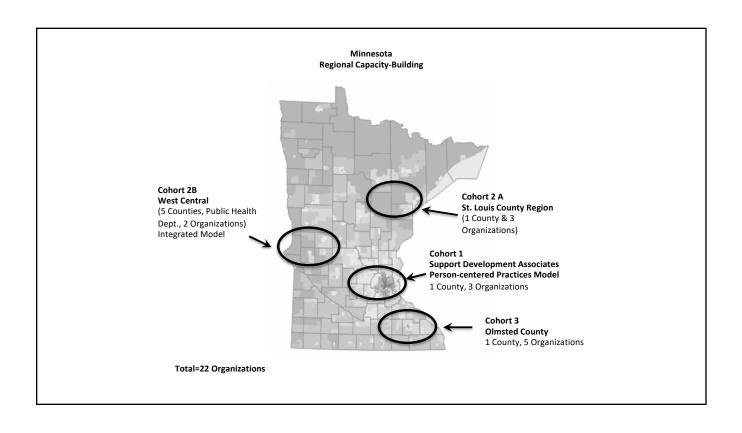
Person-Centered Thinking

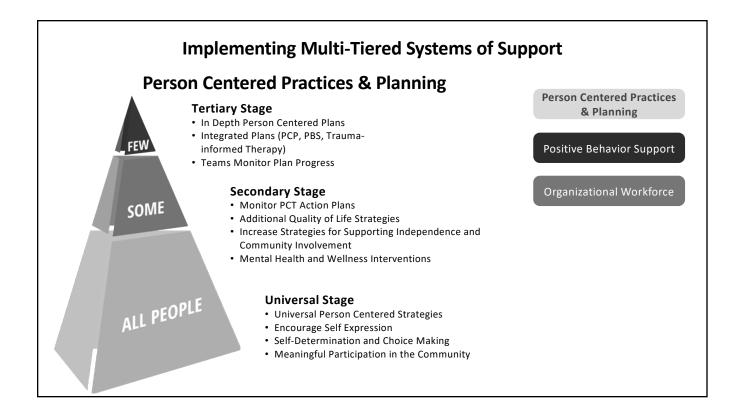
2010: Direct Care & Treatment started Person-Centered Organizational Change (Dakota County also participated)

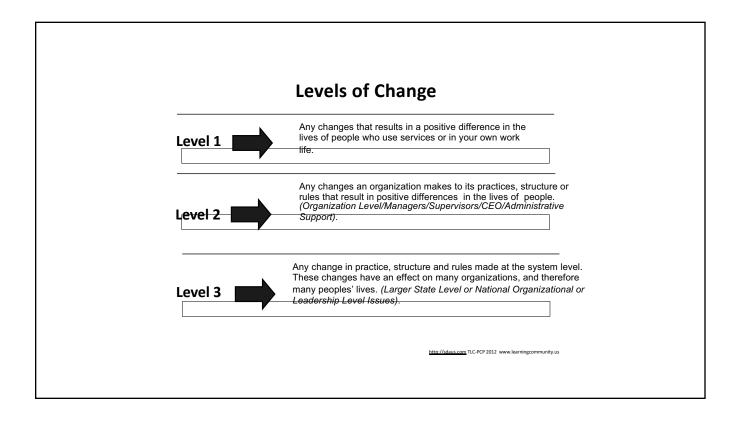
2012: DHS funded ICI to start PCT training with community agencies

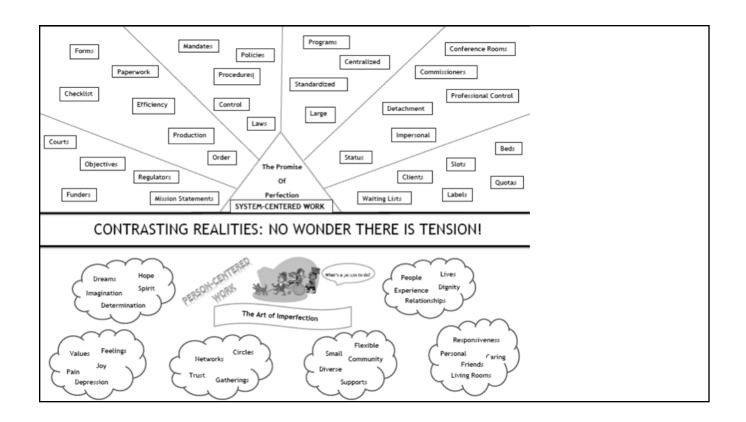
2015: First Cohort for Organizational Change (ICI with community agencies)

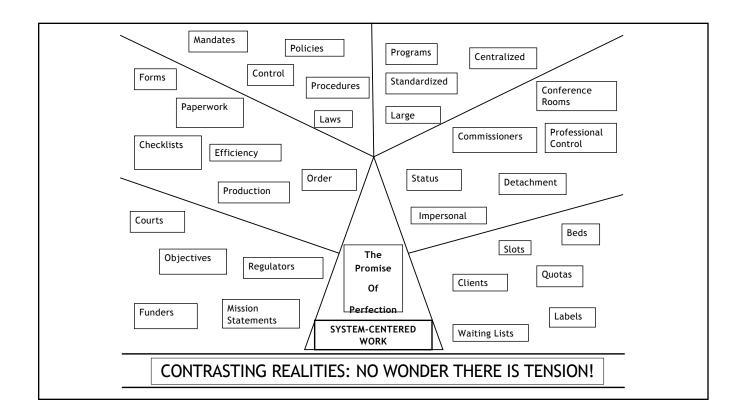
2016 and 2017: Second and Third Cohorts

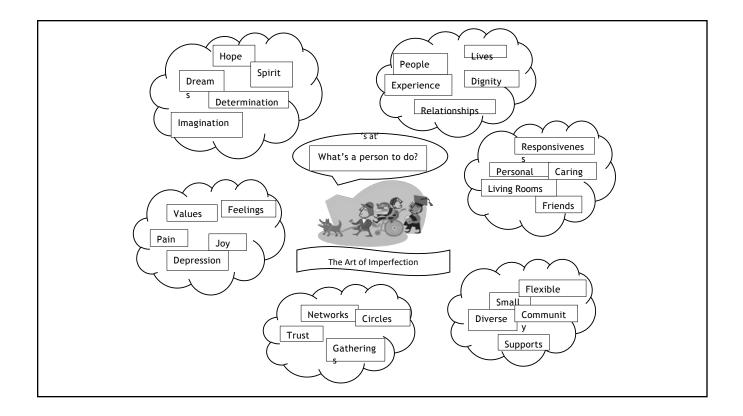


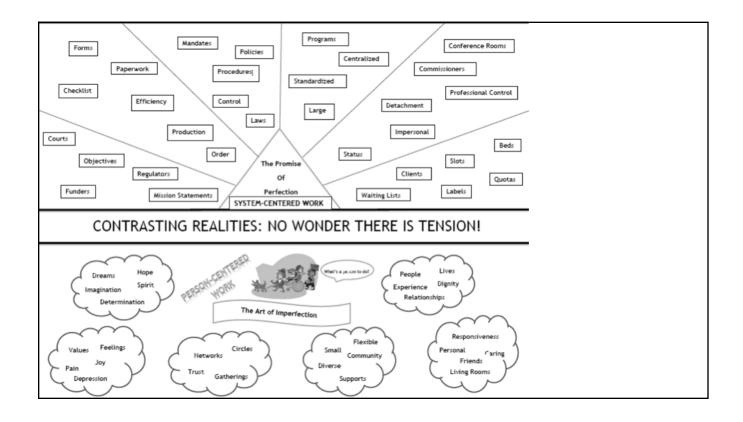


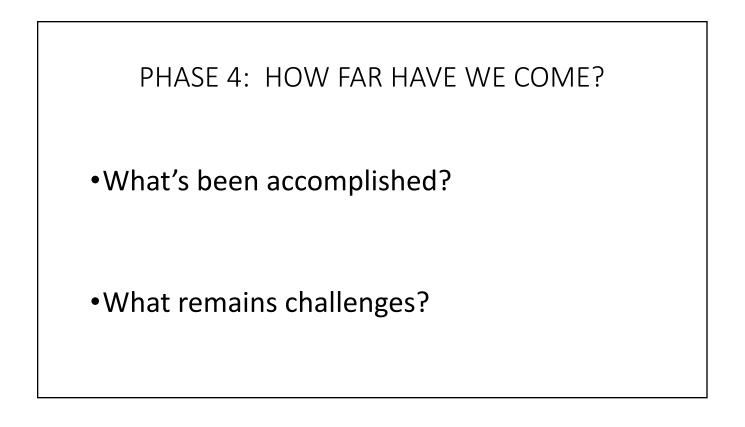












RECOMMENDATIONS -- WHAT YEAR?

- The financing system should be redesigned to eliminate existing inequities and irrationalities
- Greater flexibility in housing options
- Active state and county support of person-centered themes

In What Year Did These Recommendations Appear in Different Reports?

- Incentives to increase affordable housing options
- Increase housing options
- Development of housing cooperative options
- Promoting consumer home ownership

What Year

• Incentives to increase affordable housing options (2017)

• Increase housing options (2017)

• Development of housing cooperative options (1994)

• Promoting consumer home ownership (1994)

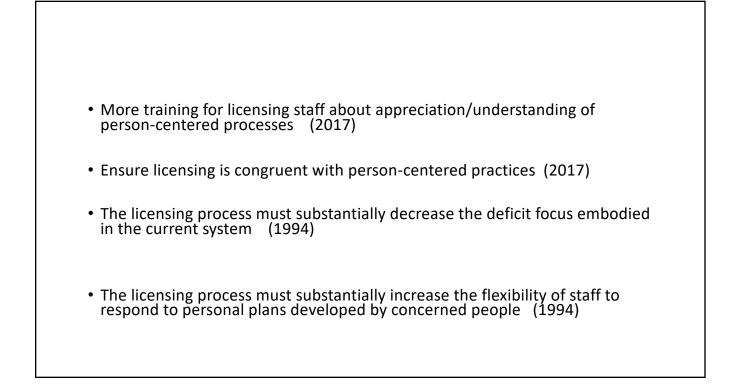
IN WHAT YEAR WERE THESE RECOMMENDATIONS MADE?

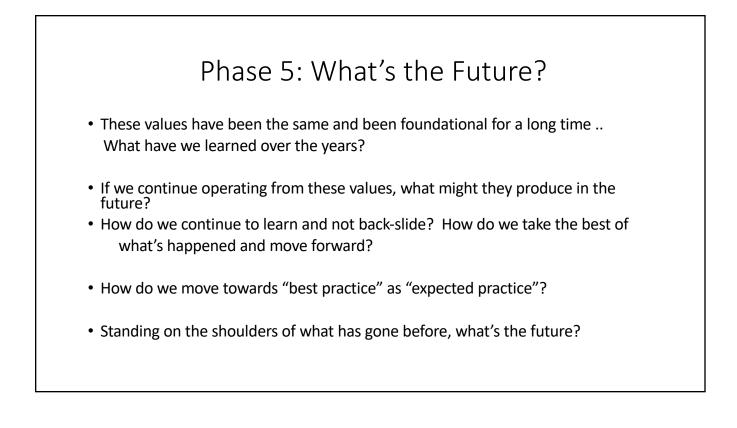
- Annual planning and other processes should be based on celebration of people's strengths, not a system based on their weaknesses and "fixing" things
- Continue support for on-going organizational and culture change processes
- Systems management should make a statewide commitment to involvement of providers in all counties and county case management to person-centered themes
- Expand learning and competencies about person-centered practices
- The financing system should substantially increase the flexibility with which funds can be used

- Annual planning and other processes should be based on celebration of people's strengths, not a system based on their weaknesses and "fixing" things (1994)
 - Continue support for on-going organizational and culture change processes (2017)
 - Systems management should make a statewide commitment to involvement of providers in all counties and county case management to person-centered themes (1994)
 - Expand learning and competencies about person-centered practices (2017)
 - The financing system should substantially increase the flexibility with which funds can be used (1994)

IN WHAT YEAR WERE THESE RECOMMENDATIONS MADE?

- More training for licensing staff about appreciation/understanding of person-centered processes
- Ensure licensing is congruent with person-centered practices
- The licensing process must substantially decrease the deficit focus embodied in the current system
- The licensing process must substantially increase the flexibility of staff to respond to personal plans developed by concerned people





THANK YOU

- Building on learning/foundation from the past
- Never one individual
- Always partners -- learning together
- Shared values, passion, commitment
- Where will we be in another 30-40 years?