

# Person Centered Planning: Individuals with TBI

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# Person Centered Planning (PCP)

- Initially utilized with individuals with DD.
- Primary emphasis was on transitioning individuals from institutional living back into the community
- PCP approaches:
  - Lifestyle planning (O'Brien, 1987, O'Brien & Lyle, 1987)
  - Whole life planning (Butterworth et al, 1993)
  - Essential Lifestyle Planning (Smull & Harrison, 1992)

# Person Centered Planning

- ...an approach for learning about people with disabilities and creating a lifestyle that can help people contribute in community life.
- ...it is an ongoing process of social change
- ...the effectiveness of the plan depends on the support group of concerned people who make a dream reality by learning to solve problems, build community and change organizations together over time.

From B. Mount (2002) in S. Holburn & P. Vietze (eds) *Person Centered Planning: Applications of Research to Practice*

# Person Centered Planning

- The most significant changes happen in people's lives when PCP creates a catalyst for the commitment of a small group of people who work toward many levels of change which usually lead to small, individualized service environments.
- When concentrated, committed listening to people incites the activism necessary to invent individualized supports, the preferences of people are most likely respected, and the responses lead to daring and imaginative connections in the community.

From B. Mount (2002) in S. Holburn & P. Vietze (eds) *Person Centered Planning: Applications of Research to Practice*

# Person Centered Planning

- Common features

- Primary direction from individual in shaping planning process
- Involvement of family and friends in planning process
- Focus on an individual's capacities and assets
- Emphasis on community resources rather than established services
- Planning process tolerates uncertainty, setbacks, false starts and disagreements

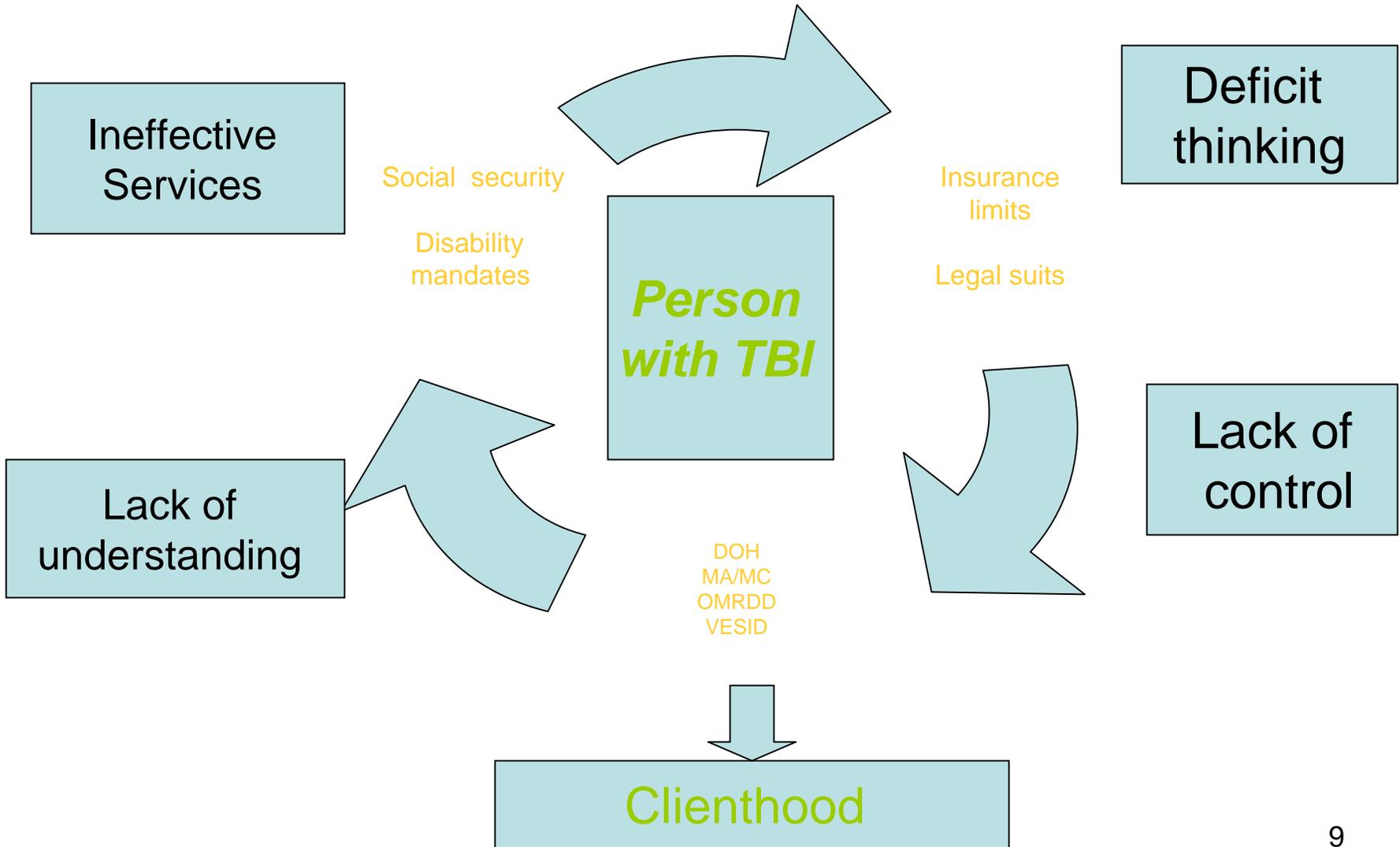
From: Hagner, D., Helm, D. & Buttersworth, J. (1996) "This is your meeting". A Qualitative Study of Person-Centered Planning. *Mental Retardation*. 34,(3), 159-171.

# Person Centered Planning

- Common features

- Utilizes social science portraiture (Lawrence-Lightfoot & Hoffman, 1997) to capture the complexity, dynamics and subtlety of human experience and organization of life.
- Utilizes facilitation techniques to involve groups in learning about the person and planning for a more positive future
- Assumes that traditional agency centered service planning has not fostered sufficiently productive relationships between paid providers and unpaid support resources nor has it served to maximize community inclusion

From: Hagner, D., Helm, D. & Buttersworth, J. (1996) "This is your meeting". A Qualitative Study of Person-Centered Planning. *Mental Retardation*. 34,(3), 159-171.



# Shifting PCP to Address TBI Challenges

- TBI creates sudden and abrupt changes in an individual's overall functioning
- Adolescents and adults acutely aware of changes in their “pre” and “post” abilities
- PCP needed to address unique TBI challenges

# Models of PCP with Individuals with TBI

- **Circles of Support**
  - Willer, Allen, Anthony & Cowlan (1993)
  - RTC on Community Integration of Individuals with TBI, Buffalo NY
  - Facilitator manual developed
- **Personal Futures Planning**
  - Mount, Brown, Hibbard et al, (1998, revised 2003)
  - RTC on Community Integration of Individuals with TBI, NY, NY
  - Consumer friendly workbook, facilitator guide and video developed
  - Materials revised and made web based for easy downloading
  - Designed to be used by consumers and circle of support independent of an established service system
- **Person Centered Treatment Planning**
  - McCarthy & Brenneke (ongoing)
  - Missouri Dept of Health, Head Injury Program
  - Designed to maximize opportunities for supports in the context of limited state resources

# Circles of Support

.....this process is referred to as  
**One Candle Power...**“A process  
enabling each person in the circle of  
support to empower each other, to light  
the way, and to build bridges to  
inclusion into community life for the  
person with disability”

From: Beeman, Ducharme & Mount (1989) One Candle Power: Building bridges into  
community life for people with disabilities. Manchester, Connecticut: Communitas, Inc.

# A Circle of Support

## IS NOT:

- An answer to a service system
- A way to have control over an individual
- A process involving persons unfamiliar with the focus person
- About titles, power or position

## IS ABOUT:

- Hope for options
- A way for individuals to gain control over their own lives
- Involves a network of persons who know the person best
- All members are equal

# Personal Futures Planning: the Mount Sinai Experience

Mount, B, Brown, M. Hibbard, M., O'Neill, J, Riggs D  
(2003) *Personal Futures Planning (PFP) for  
Individuals with TBI: 2nd Edition*. Research and  
Training Center on Community Integration of  
Individuals with TBI, Mount Sinai Medical Center

Original publication (1998) by the RTC on  
Community Integration of Individuals with TBI  
supported by funds from NIDRR (Grant No.  
H133B300038) to Mount Sinai School of Medicine,  
NY,NY

# Personal Futures Planning (PFP)

- Consumer driven request
- Viewed as a tool to be used by consumers after traditional service delivery has ended
- PFP developed in collaboration with Beth Mount, consumers and RTC staff
- PCP shifted to incorporate the unique challenges after BI
- PFP implemented across New York State VESID offices
- PFP revised in 2003 and made available on the web ([www.tbicentral.org](http://www.tbicentral.org))

# Personal Futures Planning

- Overview:
  - Values underlying PFP approach
  - Challenges inherent in use of PFP
  - Who is ready to engage in PFP?
  - Who are good facilitators?
  - What is the structure of a planning team?
  - Goals of PFP
  - Key steps in the PFP process
  - Case presentation

# Values Underlying PFP

- Person with TBI is at center of all planning efforts
- Embraces self advocacy and self determination
- Utilizes a person centered approach
- Addresses

# Changing Assumptions: View of the Person with TBI

System Centered

Person Centered

Deficient

Able to contribute

Incompetent

Having capacities

Poor decision  
maker

Having interests

Having the right to  
choose

## *TBI Tension*

Discrepancy between “pre” and “post” self

Clear image of “pre” and  
negative image of “post” self

# Changing Assumptions: View of the Person's Future

System Centered

Person Centered

Isolation

Future of valued  
experiences

Segregation

In the mainstream  
community

Disability focused  
environments

*TBI Tension*

Building a new life may feel like  
a downward instead of upward journey

# Changing Assumptions: View of Decision Making

System Centered

Person Centered

Professionals “in charge”

Person makes decisions as much as possible

Decisions made for the person

## *TBI Tension*

Insight is critical to personal empowerment

Cognitive challenges may limit decision making skills

# Changing Assumptions: Beliefs about the Community

System Centered

Community is:

- rejecting
- intolerant of differences and disabilities

Person Centered

Community is:

- accepting
- involved
- supportive

*TBI Tension*

*Acceptance may happen easily;  
Accommodation is far more difficult*

# Changing Assumptions: Beliefs about Service Systems

## System Centered

System can't respond to individual preferences

Support options limited and inflexible

## Person Centered

System can respond to individual needs

Resources can be used in creative and flexible ways

### *TBI Tension*

*TBI services have some potential to be flexible but still are limited*

# Core Concepts of PFP

- Mental maps
- Readiness of focal person to engage in PFP
- Facilitator to help the planning process
- A planning (support) team to help the individual make things happen
- Use of a workbook, *Moving On*, to structure the planning process

# Mental Maps

- Provides a clear picture of what a person wants for him/herself
- Mental image convert to mental images.
- Mental maps help the person achieve desired goals

# Mental Maps after TBI

Persons with TBI may:

- Have dreams or hopes but are unclear of the actions needed to achieve these goals
- Dwell only on losses post TBI
- Ignore or minimize potential positives post TBI
- Feel they don't have the right to dream
- Lack mental images of what they want
- Lack mental maps to help achieve their goals

# Best Candidates for PFP

- Dissatisfied with parts of his/her life
- Aware that former goals are less than likely to be realized
- Some insight about pre and post changes, strengths and challenges
- Belief that change is possible
- Willing to accept help from others
- Committed to the long haul required in carrying out a plan
- Traditional treatment approaches have been less than satisfactory and/or are not longer available

# A Good Facilitator

- Has a personal interest in the life of the focal person
- Believes a person can *move on*
- Views the team as primary problem solvers
- Does not dominate the process
- Listens to others; is sensitive to individual differences
- Validates the feelings of the focal person
- Encourages dreams
- May or may not be a professional or related service provider
- Is a good resource person

# Members of The Planning Team

- Involved family members
- Meaningful persons in the focal person's life (friends, clergy, etc)
- Supportive people in the focal person's community
- Support service providers across multiple service delivery systems

# Scope: PFP Planning Team

- Autonomy of focal person emphasized
  - Facilitator and focal person develop plan
  - Focal person contacts others to be part of the person's network
  - Focal person able to initiate contacts
  - Focal person has a high level of control over his/her life

## Scope: PFP Planning Team (cont.)

- Multiple person-individual planning team
  - Facilitator and focal person convene planning team and select its members
  - Team members collectively plan and contribute to solving of problems
  - Focal person needs support in order to reflect on current abilities and challenges
  - Focal person needs to depend on others to assist with planning and implementation

# Structure of PFP Planning Meetings

• Session maps provide script and structured focus of a given meeting

- Session agenda is planned in advance
- Time limits and clear boundaries are established by facilitator
- Key points of discussion, themes and action steps summarized
- Records kept of each meeting

# Frequency: PFP Planning Meetings

- Initial meetings with small team more frequent
- Members of planning team may shift over time
- Meeting frequency typically declines over time
- Frequency of meetings determined by the focus person

# Goals of PFP

- Feel whole again
- Feel good about one's self
- Regain hope in the future
- Create a vision of a “good” life
- Develop “maps” to follow to reach this vision

# Four Paths of PFP

- Path I: Beginning my journey
- Path II: Expanding and deepening my relationships
- Path III: Re-defining myself
- Path IV: Realizing my vision
- Each path includes:
  - unique goals
  - several maps
  - structured questions for the planning team
  - focused discoveries and strategies
  - Identified challenges in achieving the plan

# The PFP Process for Charles

- 50 year old male, seeking to re-focus his life 25 years after his TBI
- Prior to TBI, he was a college student planning to go to either graduate or law school
- Never finished his college degree
- Prior interests: economics, politics, social justice and teaching
- Felt “traditional” rehabilitation interventions had failed in helping him achieve his potential
- Interested in trying PFP to reshape future and procure a more satisfying vocational direction

# Structure of PFP for Charles

- Preferred privacy; was skilled in self reflection
- A high autonomous approach to PFP was selected
- Meetings were scheduled every 3 weeks for 2 hours
- Charles left each session with a “to do” list
- Planning team gradually expanded to include his wife, the men in his church and a former college professor

# Path I: Beginning the Journey

- Goals
  - Begin plans for *moving on*
  - Determine who will help in the process
  - Explore focus person's issues
  - Affirm focus person's hopes
- Map I: People willing to listen
- Map II: What I want to change in my life
- Map III: What are my hopes

# Path I: Beginning the Journey

- Discoveries and Strategies
  - Affirm the important people in the focus person's life
  - Explore losses and opportunities to rebuild
  - Link the focus person's experience with that of the wider community
  - Reassure the focus person that PFP will help re-organize life
  - Stay focused on things that can change

# Path I: Beginning the Journey

- Challenges
  - Managing the balance between real and false hopes
  - Managing different agenda of the focus person and the planning team
  - Bringing more persons into the process

# Path I: Beginning Charles' Journey

- **Negatives:**
  - Periodic bouts of unemployment post TBI
  - Attempted a wide variety of jobs that were either menial and unchallenging, or required processing speed or organization skills beyond his abilities to succeed
  - Result = strong sense of personal and work related failure
- **Positive:**
  - Had assumed a central role in managing home and children
  - Enabled his wife to work full time
  - Had become active in his local church
  - Was involved in TBI self-advocacy group in the community

# Path I: Beginning Charles' Journey

- Important people – wife, children, church members
- Obvious lack of service providers included in his planning team
- Past vocational failures and their meaning were explored
- Future hopes explored
  - finding work that better matched to his interests and abilities
  - finding a work environment that offered greater dignity and respect
  - consider a return to school to complete college

# Path II: Expanding Relationships

- Goals
  - Understand the focus person's relationships
  - Expand existing relationships
- Map 4: My current relationships
  - Family, friends, community and service providers
- Map 5: “Ins” and “Outs” of my relationships
  - What relationships worked and didn't work before and after TBI
- Map 6: Working on my relationships

# Path II: Expanding relationships

- Discoveries and Strategies
  - Realize that relationships exist
  - Realize that one can improve relationships
  - Allow honest labeling of poor relationships and “letting go” of these
  - Permit grieving lost relationships
  - Strive to balance interactions between people
  - Provide opportunities for constructive action

# Path II: Expanding Relationships

- Challenges
  - No one is “there” for the person
  - Focus person uncomfortable disclosing TBI to others
  - Focus person’s life is highly segregated

## Path II: Expanding Charles' Relationships

- Wife asked to outline Charles' interests, abilities and strengths
- Feedback validated his valuable contributions to his family's success
- Exploration of his leadership role and strong affiliation with his church; validation of his contribution to the community
- Increased insight into his competence as father, husband and community participant which countered his sense of failures as a worker
- Insights allowed moving on to more careful analysis of job issues and vocational redirection

# Path III: Redefining Self

- Goals
  - Clarify person's struggles, interests and capacities
  - Clarify person's limitations and challenges
  - Delineate positive and negative aspects both pre and post TBI experiences
- Map 7: My interests and strengths
  - Before and after TBI
- Map 8: My challenges and problems
  - Before and after TBI
- Map 9: Who am I now?

# Path III: Redefining Myself

- Discoveries and Strategies
  - Identify patterns in personal qualities, interests and abilities pre and post TBI
  - Clarify that life was not perfect pre TBI and that new opportunities may arise after TBI
  - Deepening understanding of frustrations 2<sup>nd</sup> to TBI
  - Identify additional supportive strategies

# Path III: Redefining Myself

- Challenges
  - A distorted view of abilities and challenges by the focus person
  - Conflicting views of focus person's abilities and challenges within support circle
  - Capacity themes before and after TBI difficult to identify

# Path III: Redefining Charles' Self

- Focus on vocational goals
- Review prior job experiences
  - “green” list summarizing settings, skills and tasks that were positive and worked
  - “red” list summarizing problems and experiences that did not work
- Joint review of prior job evaluations
- Summary of job strengths, interests and characteristics most fitting (social justice and interest in helping other)
- Beginning exploration of work in the area of helping professions
- Beginning exploration of continued study in social service arena

# Path IV: Realizing My Vision

- Goals
  - Integration of prior discussion
  - Creation of personal “vision”
  - Development of action plan
- Map 10: My vision
- Map 11: My action plan
- Map 12: Keeping track and keeping moving

# Path IV: Realizing My Vision

- Discoveries and Strategies
  - Creation of a vision based on:
    - Interests and characteristics of the person
    - Resources and richness of person's support network and community
    - Connections and friend network of support
    - Resources and services that can support opportunities
  - Focus of vision:
    - Increasing presence in the community
    - Expand/deepen friendships
    - Enhance dignity and reputation
    - Increase choice and control over one's life

# Path IV: Realizing My Vision

- Common visions:
  - Better days
  - Better living arrangements
  - Better social and community ties
  - More focused and meaningful work
  - Active pursuit of interests

# Path IV: Realizing My Vision

- Challenges
  - A distorted view of abilities and challenges by the focus person
  - Conflicting views of focus person's abilities and challenges within support circle
  - Capacity themes before and after TBI difficult to identify
  - Establishing a plan is difficult
  - Carrying out steps overtime becomes problematic
  - Re-emergence of former stumbling blocks for the person or within planning team

# Keeping Track and Keeping *Moving On*

- Ongoing meetings with planning team to review final map: Keeping track and keeping moving
  - What worked and why
  - What didn't work and why
- Review and revise until vision achieved
  - Expand
  - Revise
  - Refine
  - Achieve

## Path IV: Realizing Charles' Vision

- Charles found a job in lg. human service agency
- In PFP, critique of new job and brainstorming how to make it better
- Charles selected as Employee of Month affirming his growing self confidence
- Charles sought another position within the same agency
- Short term vision (keep current job and advance within agency) and long range vision (begin social work school) discussed
- Sessions continued 1x month for 4 months to problem solve and modify long term vision

## In Charles' own words...

...following my brain injury, society seemed to say to me...drop out of life, take your medication and maybe we can find a job in a file room somewhere.... PFP helped clear this psychosocial logjam which blocked the flow of my personal development. I was finally able to move on and the process helped me to do so...

# Mission: Head Injury Program of Missouri

... to provide for the identification and integration of resources for all eligible Missouri residents who sustain a TBI, thereby enhancing their opportunity to obtain the necessary supports that will enable them to return to a productive lifestyle in their community...

From McCarthy, Brenneke & Shields (2006). Adapting Person Centered Approaches: Implications for Values, Policy and Practice.

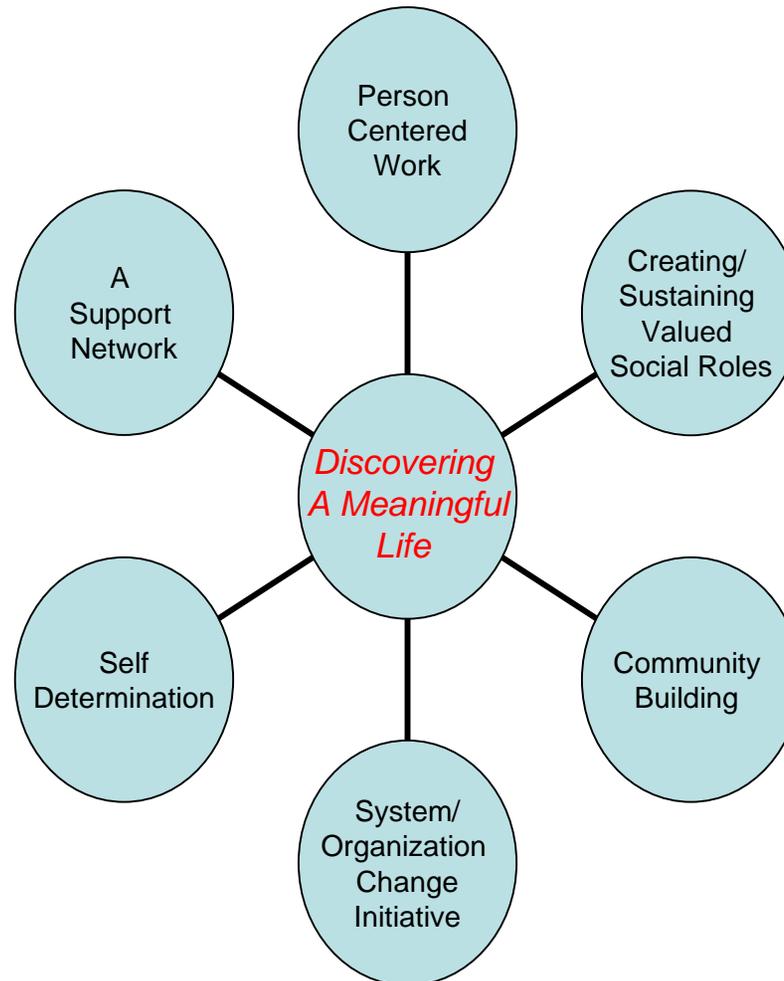
# PCP Treatment Planning: The Missouri Experience

- Inadequate services available in the community
- No state TBI Medicaid waiver
- Paid agencies have limited resources and can't follow people for indefinite time periods
- Need to identify community resources to augment limited state resources
- Need to collaboration with independent living centers
- Increased need to rely on natural community supports

Personal communication, R. Zotto, Missouri TBI Service Coordinator (2006)

# Needed Supports after TBI

Modified from McCarthy, Brenneke & Shields (2006). Adapting Person Centered Approaches: Implications for Values, Policy and Practice.



# Missouri's TBI Program Values

Modified from McCarthy, Brenneke & Shields (2006).

- Person centered
- Outcome oriented
- Community inclusion
- Family involvement in immediate and long term planning
- Personal responsibility for functional improvement
- Resumption of a productive life style
- Responsible resource management
- Supportive partnerships

# PCP is successful when...

- The entry point is clear
- Important information is shared
- Realistic and consistent messages are given
- A comprehensive and coordinated plan is developed that includes timelines and responsibilities
- Outcomes are achieved efficiently

Modified from McCarthy, Brenneke & Shields (2006). Adapting Person Centered Approaches: Implications for Values, Policy and Practice

# Typical PCP Support Team Members

- “Champions” of the focal person
- Department/division directors
- Case managers/service coordinators
- Hospital discharge planners
- Service providers
- Community organizations

Modified from McCarthy, Brenneke & Shields (2006) *Adapting Person Centered Approaches: Implications for Values, Policy and Practice*

## The PCP Process for John

- John, age 28, injured in MVA 4 years prior
- Residing in nursing home for past 3 years
- Prior relationships “burned”
- Strong desire to return to the community and live on his own
- Representatives from family and differing agencies brought together as a PCP planning meeting to design steps needed to help John achieve his dream

## John's PCP Planning Team

- Facilitator
- Public Advocate
- Select nursing home staff
- Family Guidance Center rep. (procure needed mental health services)
- Senior Service Provider rep. (expedite funding of PCA)
- ILC rep. (identify community supports and resources)
- Divorced parents

## Progress of PCP Planning Team

- Planning team meeting once per month
- Multiple funding streams slowly being established
- Short term goals:
  - increase John's socialization skills
  - increase John's ADL skills
- Build upon and/or create new relationships in the community to provide support for John after discharged

# The PCP Process for Miriam

- Miriam, age 55, injured 5 years prior
- Former textile worker, now unable to work or drive
- Returned to her home in rural setting after rehab; initially required oversight for safety
- Daughter and two small children moved into Miriam's home to provide care
- Over time, patient became totally dependent on daughter; daughter taking unfair advantage of mother
- No public transportation, increased social isolation
- Miriam contacted the TBI Head Injury Program for help

# The PCP Process for Miriam

- Miriam's Dreams:
  - Wanted to stop being a prisoner in her own home and “doing nothing” with her life
  - Wanted to relocate to an urban setting where she could be more independent with paid help
  - Wanted to meet new people...needed to decrease her isolation
  - Wanted additional skills training so she could live more independently

# Miriam's PCP Planning Team

- TBI Case Manager
- Representative from Section 8 housing
- Medicaid representative to ensure home attendant and transportation
  
- DOH TBI Head Injury Service Staff
- New Neighbors
- New Contacts at Church
- BIA staff

# Progress of Miriam's PFP Planning Team

- Section 8 apartment in urban setting located
- MA provided P/T aide to supervise and increase ADL skills
- Relocation to urban setting with p/t help and transportation
- Began socialization in DOH TBI program
- Developed new friends in the TBI group
- Slowly met new community members
- Befriended a woman who ran a pottery shop; relationship developed into a friendship and eventual travel companion
- Introduced to friend's local temple; Miriam now volunteering at temple
- Miriam now fund raising for local BIA

# PCP Common Themes

- Individual many years post TBI onset
- Traditional service supports have ended
- Desire to increase independence or maintain current lifestyle
- Creative use of family, community and service systems to expand person's activities and functions
- Minimal use of traditional “assessments” or “therapy”

*Do our basic values about helping people  
need to be challenged?*

# Values Gaps

Modified from M. Mccarthy, Brenneke & Shields (2006)

- Everyone belongs
- Persons/families at center of all planning
- Agencies should respect and be responsive to persons
- Self-determination
- Some persons are not ready for the community
- The agency selects where persons live and who they live with
- The agency is at the center of planning

*How might we incorporate PCP  
into what we do?*

# Practice Gaps

Modified from M. McCarthy, Brenneke & Shields (2006)

- Person centered planning
- Ownership or rental of living space
- Supported community based employment
- Community collaboration
- Who owns the plan?
- Who controls the housing budget?
- Agencies pre-select job trials within their networks
- WE do not get involved in community coalitions

*What are the policy implications at the service, state and federal levels?*

# Policy Gaps

Modified from M. McCarthy, Brenneke & Shields (2006)

- Money should follow the person
- People should have control over how monies are spent
- People should live where they want; supports should come to them
- Natural supports are preferable to service support
- Communities need to be empowered to provide needed support for its citizens
- Agencies have budgets
- Agencies determine what services are offered and to whom
- Liability issues often drive decisions about where, when and why services are rendered
- People come to agencies for services not vice versa
- It is not the agencies job to educate or empower the community

# Ideal Goals of PCP Support Systems

Modified from M. McCarthy, Brenneke & Shields (2006)

- Value
  - Self-determination
  - Contribution
  - Respect and dignity
- Practice
  - Self directed services
  - Person centered planning
- Policy
  - Independence +/- Waivers
  - Consumer developed plans for employment

# Needed Shifts

- Value shifts
  - Belief about a person with TBI
  - Beliefs about the differences that services alone can really make
  - Beliefs about the role of communities
- Practice shifts
  - Beliefs about who controls decisions
  - Beliefs in consumer involvement
  - Beliefs in self-determination and negotiation
- Policy shifts
  - Rethinking of organizational structure
  - Rethinking of how limited funds are best utilized
  - Rethinking goals and objectives of treatment

Thank you