

NATIONAL CONSENSUS CONFERENCE ON PERSON/FAMILY CENTERED PLANNING

December 8, 2005

AM Breakout Sessions

Congressional Room AM

What essential principles and values need to be adopted in Person/Family/Youth Centered Planning?

It is intended that this list include the principles heard in the opening this morning.
All the discussion below refers to Person/Family/Youth Planning.

1. How do we reframe our principles and values so that we can recreate positive energy?
2. Balance of Power/Equality of Power
3. Address all the different things that contribute to the inequality.
4. The plan should be all about the person.
5. The Plan is not the outcome.
6. The Plan is owned by the Person.
7. Honor the commitments to the Plan with follow up.
8. Responsibility of the Person within the Plan.
9. We need to deal with the stages of Recovery. The professional needs to carry hope for the consumer.
10. The Plan is a "Living Plan" that is ever changing.
11. The Person and Family need to control the money. Services need to include those that are non-traditional - Flexible funds
12. The planning process has to create conditions for reciprocal learning and support.
13. Do no harm. No one should have to survive systems; should support people to thrive i.e. systems, schools.
14. Plan format is simple, practical and accessible written in PFY language.
15. Services support the vision and the Plan of Recovery.
16. Respect and honor of the person's and their dreams.
17. There is a role for formal, informal and natural supporters in the process
18. Person-Centered Planning is a Partnership

19. Providers have knowledge and expertise to contribute.
20. Family and youth experiences
21. Person centered practices involve partnership between consumers, families, and providers in which the experiences of adults as well as children, youth, and their families, their visions and goals, their perceptions of strengths and needs, and their guidance about what will make them comfortable steer decision making about all aspects of service and system design, operation, and evaluation.

What are the unique considerations for special populations?

1. Access to good integrated physical care.
2. A Person-Centered Plan should include the uniqueness of each person.
3. Person-Centered practices are universal principles and should be applicable to everybody.
4. The system has to reflect the diversity of people served.
5. Everyone is special and unique.
6. Person-Centered Planning emphasizes our similarities and common humanity and celebrates our differences.
7. Recovery is a universal process.

Plan ownership rests with the individual. What are the changes needed to support the principle of individual plan ownership?

1. Education for informed choice.
2. Time needs to be given for both the provider and the person to build a relationship.
3. Shared decision making tools.
4. Practical application of partnerships (shared learning).
5. Re-definition of professional ethics, culture, traditions, roles and boundaries
6. Provide information that is free of conflict of interest.

Director's Room AM

What essential principles and values need to be adopted in Person Centered Planning?

A drift from Pres NFC from consumer & family driven to consumer & family centered. The relationship of power & status of consumer/patient versus other or person who pays.

1. Is the person living where they want to live? i.e. State of WA - so many people in the State Hospital.
2. Even people within the community so little sufficient housing.
3. Doesn't the system have some responsibility to assist in this problem - code, Olmstead?

People need to be able to live in places of their choice. Look for points of leverage *Tenn.)

PC is an old term from DD community

Perversion to include family in the process for adult consumer without consent

Location/setting is a priority for consideration

Some states are still back in the older systems

No other options don't know what is available & what they have gotten used to

System is the maze and not a life plan and is in the way to a plan since life itself is in the way.

You can have a life plan

My person centered plan is like a machete to get thru the system or to get out of the system tapping into the resource & supports by the system. The problem is the bundling - some things you want and some you don't

Back to issue of power - social position of the person being described.

Difference being a public or private system.

Provider being a consultant and then up to consumer to determine which direction they want to travel.

System is set up on the medical model and that is what is getting paid for...

Certain states don't have the options of different types of care such as holistic.

Even when people have private funding they end up with restrictions from insurance.

Wraparound - some like it

Some feel you can have wrap around but not have services they want

The services at the community level does contain services that people want but it needs to be collaborative and cooperative. But it can still turn into what others want for the person/consumer due to funding streams.

So it gets back to the issue of who has power.

Too often (IL) even when families of children come into the system - they want the professional to give them the answers and give the power back to the system.

Cultural paradigm of who knows best *SP) -

So the push is known towards evidence based practice. Trying to sell something because we don't know what else to give.

Consultant - reciprocal relationship.

Person centered means surrounded by police.

What does the consumer want and how do they get them there.

Wraparound - the family tells them what is needed and then what are

All the other services. Experience is that if you let families dictate what they want and they get it and then they will cooperate.

Communication being sensitive and appropriate

If we all agree about what is necessary why can't we get to the ideal process

Tenn - ethical responsibility *difference with a consultant and IBM versus the client/consumer negotiating

With provider/insurance

Peer specialist - is a good solution to assist in the process when a consumer is exhausted

What is the business model that you put this into?

What people want whether in children or adults is not there -i.e. respite - baby sitting. It is the cheapest thing to provide but doesn't exist

It will not be paid for unless it is needed for the child.

DG - in some situations different people are at different levels - and some people may want and need something different.

What are the unique considerations for special populations?

Plan ownership rests with the individual. What are the changes needed to support the principle of individual plan ownership?

Realistic about power differences and some people more vulnerable and they need someone there

External to the system - an advocate from outside. If he/she is paid for by the system there is an underlying problem and so they need to be paid from outside the system.

We have know these things for 20 years but we still have the same problems -
Education, training and needs to be repeated.

Do you reward people for changing?

Financial incentives for making a difference

Peer support is good

People comes to late to the system - prevention, prevention

Address - discrimination to practicing

Ed - distrust the National level distrusts the States & the States distrust the
County

Time for clinicians to have the time to right the plan

Taking the time to do it well

Attitudes, beliefs, training....

They make you crazy - people don't want to go to the system

Medically dominated social construct & use it to sell the product that we want to
sell and we market them to people who don't want them and that is where the
money is tied.

What are we describing when we say someone is mentally ill - you have broken
too many rules.

MI is a discriminating label - they are troublesome and

S - The way we name it is detrimental to allowing the individual to get what they
want and need.

Recovery begins with hope

Tom - public & private systems are careening towards something - education,
trust building, you have rights and responsibilities and hope that the system

fundes need to see doing things in a different way

Evidence, peers

Dimension - how voluntary the system is & then you can have recovery

Workable business plans as toolkits

LD - having two systems is a result and creates discrimination and if you have
cancer you don't have a business plan. We shouldn't be adding on to the
cumbersome system but finding out what people want and to help people learn
some skills early on to deal with this.

Cabinet Room AM

What essential principles and values need to be adopted in Person Centered Planning?

There has been a drift since the President's Commission Report which stated it will be consumer and family driven to person and family centered which is a different concept.

The person and family centered concept implies that services are surrounding them, and it is based only on partnership and collaboration. In contrast person driven care is not only collaborative but the person and family hold the power in that collaboration. We should not drift from the original intent of person and family driven services.

People need to know what their choices are and be able to act on them.

The concept of family needs to be broadly defined. Youth and adults have different abilities to define their family.

There can be a censor of information and you need to make sure that there is limitless information in the person centered planning. Information is critical and the person and family need to know all their choices.

The family or persons involved need to be defined by the person and the family. Children and youth have a unique voice and it needs to be listened to.

We need to engage people with what they want and we need to be aware that this is important to the whole engagement process so they have the information and know their choices.

We need to provide this in a culturally appropriate way. There are many differences in cultural and this can lead to not understanding the person and/or family information. We need this at the individual level. This need to be linguistically sensitive. Culture needs to be defined broadly.

Funding (i.e. block grants) need to be in place to fund in a prioritized for the person and family centered approach. We need to reduce inconsistencies among the funders including Medicaid and Medicare.

We need to have consumer and family organizations involved. They have a critical role in driving this transformation. This would include legislation in addition how organizations implement the person and family centered planning.

We need to be aware and sensitive to the wholistic person that includes spirituality, cultural etc. Need to know how does spirituality help me in the person's recovery.

We need to have individualized plans that tap into the person and family choices within the context of the wholistic situation.

We need to redefine community. There needs to find a community where a person can be embraced.

We need to crossover boundaries. Community inclusion needs to precede recovery.

We need to recognize the gifts that the person and family have to give to the community.

What are the unique considerations for special populations?

We need to emphasize education. This education is for everyone including the person and the family. Once persons have information they know what services they can get. This is empowerment through education.

We need those who are not strong enough that they have an advocate and support.

There needs to be access to information and this initiative needs funding so that we are empowering both the person and the family. We need culturally appropriate advocacy.

For children there is special needs to educate the decision makers for the child to understand the information for the choices and this would be relevant to residential choices. There is a need to be aware of learning disability.

We need strength based and culturally appropriate assessments. WRAP is good system.

We need indigenous healers to be respected in the care process.

If we were listening and understanding this process as a whole we would not need the term special populations. We would not be focusing on unique needs based on cultural, diagnoses, mental stage etc. We would be looking at the person as a whole person.

Plan ownership rests with the individual. What are the changes needed to support the principle of individual plan ownership?

We need to reinforce staff competencies.

Everyone needs to have access to the same information. There needs to be transparency to the plans. There needs to be access to resources and money.

We need to assure that staff have the competency and value the approach to person and family centered planning. There needs to be accountability of the staff.

We need to ensure that the community and the staff moves beyond the medical model and truly believe in the Recovery process and that it really works.

We need to reduce stigma and "normalize" how persons with mental health problems are perceived. We need to encourage personal stories and sharing these with others to reduce the stigma.

Funding needs to support a person and family centered approach. The plans need to be portable between states. People need to be able to make choices backed by funding in that they can choose services to back up a person and family centered plan.

Funding needs to be consistent across the board.

We need to enhance self-directed tools such as WRAP.

Chairman's Room AM

What essential principles and values need to be adopted in Person Centered Planning?

- self determination - move control of financial resources directly to the person or family experiencing the disability

melding the principle of self determination with the resources

There are no expectations for achieving a meaningful life - discussion about what this means

Recovery seen in holistic way

Impoverishment of individuals with disabilities

Social security systems require poverty for services

- language - the need to crosswalk peoples talk with bureaucratic talk
- illness self-management
- recovery focused
- Education regarding resources
- NACBHD - regarding development of plan for individuals - need some information infrastructure to support fulfilling an ISP
- Strength-based
- Goal oriented
- Cultural and linguistic competence
- include youth culture
- Infrastructure development. Leadership, training, information systems, financing monitoring of outcome measuring
- We are in a Medicaid environment. CMS does not have the values we are discussing here. Medicaid is health insurance Company - values clash
- True partnership with youth
- need to build trust
- Relinquishment of power necessary
- Patient/professional relationship needs to become partnership
- Consumers/families have expertise which needs to be acknowledged
- have to be able to fund the contents of the plan, writing plan is not sufficient
- Professional person needs to trust in person; also trust that Medicaid will support tx.
- trust in support from regulatory systems that pcp efforts will be supported
- Self responsibility and autonomy
- Driven by the individual - can't write plan on behalf of someone else
- Self directed supports

- cost effectiveness
- Considerations of safety, team to recognize the family and the child, reduce blame - who are we serving? If the family has been a risk factor, need to take that into consideration
- Medicaid does encourage self determination. Unbiased assistance. It's not easy, but Medicaid does support pcp. Problem is with state mental health authorities - Medicaid is blamed when it is really a state issue.
- shared power among team members as well as with child/family.
- To get flexibility with CMS, need to do waiver process. CMS is going in state by state and disallowing the same services that are in state plan.
- (a lot of discussion about the role of CMS) - need for greater level of understanding at federal, state and local levels, and coordination among them. No one is autonomous.
- define the roles, within a care team
- Clarity regarding limitations of clinicians, care planners
- Principle of no blame. That doesn't mean "no conflict."
- Recognition that there are some inherent conflicts and tensions (i.e. CMS),
- Solution has to be relatively simple in order to ensure effective implementation. MH needs to be smart about this.
- Staff competency-based training- service substitution - use of community supports and non-disability focused services
- peer support and self help
- Family, youth, consumer involvement at all levels
- Workforce development - reform academic curricula to include pcp
- Consumer needs to have choice about who is on team. Hard to do in institutional settings.
- Definition of pcp - lots of people say they are doing it, but aren't really
- Microcosm of institution vs. community.

What are the unique considerations for special populations?

- Cultural considerations (who comes to the table - individualized)
- Evidence-based practices vs. practice-based evidence
- Unique advantages of pcp for different cultures. pcp will lead to discharge plan that will more likely be effective when cultural considerations taken into account
- Cultural competence will naturally occur if pcp effectively implemented
- age-appropriate involvement of all participants - even young children can participate to some level.
- It is an evolving process - level of involvement can increase as consumers become more educated and empowered.
- Even in prison, can make some choices. Unique consideration for incarcerated population is the extent to which pcp is possible

- Lay the foundation so pcp CAN be done. Transition planning should be pcp./b>
- Acknowledgement that sometimes choice not possible - a (ex. when there are legal parameters, such as incarceration).
- Legal rights of incarcerated people, child welfare consumers and other systems impact the rights that are available. Clarity around "rights"
- need to know what your parameters are if you are going to have a self-directed plan.
- pcp philosophies and practices need to exist in incarceration, residential and community settings
- how to teach person that they can have control over their life if in a setting that has no legal rights in practice, such as incarcerated people
- Clinicians need to state limitations, parameters up front so everyone understands available options.
- In prisons, can "lay the foundation" of pcp, but not actually do it.
- Confusing "respect" with pcp. Need to spell out standards and requirements.
- NEED DEFINITION OF PCP!!!
- pcp cannot be done in every environment
- promote pcp for discharge planning, not in an overly restricted environment
- caution about using in every setting, or will become one size fits all.
- Plan written and driven by individual with freely chosen assistance, when necessary
- Individual invites the circle of support
- Person has authority to stick to plan
- Resources be available to support the plan, resources under the control of the individual with the disability
- need to be concrete and really clear. Need to have ALL of these elements in pcp, not some.
- How do we achieve a pcp, driven by the person, that is across agencies? When there are safety issues for the person's children that have to be taken into account, can't have total choice. Mental health pcp has to be consistent with cw needs.

Plan ownership rests with the individual. What are the changes needed to support the principle of individual plan ownership?

- Resources are under the control of the individual.
- Responsibility and accountability spelled out for all participants
- have to consider youth and family
- Infrastructure needs - how is plan made available to individual and those around them
- need partnership training, esp. for younger people and family members. Leadership training. Across agencies.

- needs to be consideration for the integration of the roles of individual child or youth and balance with their families.
- People are allowed to make mistakes and to have consequences.
- Workforce development.
- Major cross agency collaboration. Sharing resources, coming to table to provide resources
- Provision of freely available, unbiased assistance if necessary

Terrace Ballroom AM

What essential principles and values need to be adopted in Person Centered Planning?

Person driven vs. person centered - we prefer person driven, person better than consumer

Person is doing many things in the planning process, not just defined by using services - holistic view of the individual

Consumers can also be professionals - removed from role definition

DD and cross disability movement have been doing person centered planning for years

We have buy in from providers, but need to enhance this

Providers need to demonstrate how persons are driving the process

Person is center of circle, but should not be put in a position of opposition to others in team, person driven opens up concept more - driven also shows capability

- Person driven sets up the planning process - reminds everyone what this is about
- Person is inclusive of family or us both terms
- family differs from consumer role or adult role, be sensitive to fact that family needs to have some level of choice and gets really hard with kids
- need to be conscious of youth and young adults and the transition to adulthood, driving is important but equally important to ensure that is really what is happening

- education of family about core principles and values of recovery and the role of consumer and family dynamic changes and hard to get out of that role as you transition to the adult role, gets complicated because the individual is seen as the one who needs help, help family adjust with this transition
- Capacity needs to be addressed in principles and values - labels often undermine capacity

- some consumers did not have a great family life, sometimes they are a part of the problem, consumers are also often family members, not just biological family should be considered, kids can make choices, and create responsibility, build decision making

- need to expand choice, political correctness a concern, families can be source of abuse but still involved in treatment decisions, child and youth services and legal rights, kids should be empowered to make decisions, appreciate of a person's community and values, subgroup, culture, not everyone that looks like me has the same values,

- GLBT values needs to be included and put upfront

- Cannot have both a person driven plan and the definition of family - first must be driven by the consumer, not a requirement, except when it is legally required
- Part of the culture is involvement in the mental health system
- Family driven and youth guided care, youth at diff developmental levels can make decisions, youth board
- make it inclusive rather than divisive between persons and families
- Including the family when appropriate, wanted and desired - standard for inclusion
- funders can not be the ones who define person driven, now treatment planning is determined by funding, treatment to be person driven cannot be determined by funders, money follows the person
- Family with permission or legal responsibility
- must have strengths based concept in person driven
- cannot be driven by what programs that currently exist
- Peoples own sense of self and spirituality
- Benefit structures are diagnosis driven, diagnosis drives the care,
- peer support programs, teach use of person driven plan in programs, work with the person to help them develop their strengths, goals, needs, to facilitate recovery and resiliency, other states need to incorporate into their state plans and CMS to include peer support services for IPCs
- System principles, needs to put strengths first, put diagnosis in the back to get into the door and get paid,
- 2 values - treatment planning should be deep wide process, person centered should affect diff levels of system, and be a key process, recovery plans needs to infuse address key principles of recovery - hope, social connectedness,
- summary - idea that we need to look at , respect, choice, authentic, individual capacity, access, control, decision maker, culturally appropriate, principles and values should be seen at diff levels, person and provider level,
- move away from crisis driven, needs to be proactive self determination, accountability, quality of life, dignity, holistic, communication, responsibility, wellness,

- Community values and life experiences,
- Flexibility to incorporate individual experiences,

What are the unique considerations for special populations?

- Special consideration of unique needs,
- How does system meet individual needs?
- How can this be delivered and operationalized,
- Special populations are the providers
- System needs to be flexible
- Person has access to the supports they need
- need to look at the cross disability movement that have been providing effective services without us, they exist, and we can't expect something different
- Providers need the right tools
- CMS approval of recovery plans and peers support change
- Peer support incorporated into recovery system
- look at the plan and have them collaborate with providers to make it work, no one solution, operationalize psychosocial principles into the work that is done, then we can inform the service system

Plan ownership rests with the individual. What are the changes needed to support the principle of individual plan ownership?

- Ownership is one thing, responsibility is shared, not just the individual responsibility
- Staff education is needed to explain what this means
- Staff training for collaborative approach
- Power of knowledge

- The planning process is person driven end up with document that is an agreement, person must have copy, empowered, the tool for recourse,
- Control, traditional therapist model balance with person driven, both sides must come to agreement,
- identify the role of the clinician as the facilitator, outline that everyone has a role in the implementation of the plan
- The plan must look beyond the clinical setting, lifestyle planning, life goals
- Real role for education, kids, families, adults can educate their own constituents and providers, bureaucracies,
- providers become physical therapists for folks that have been allowed to atrophy for decades, people are afraid that they are going to be kicked out of services, older adults afraid that they have to work as a part of recovery plan,
- Plan should look more like an MOU
- Professional orgs needs to reevaluate their roles or members as they have dual roles, consumer providers,
- system must believe that the plan is based on self determination and providers have to let go of control and work collaboratively, providers must spend their time teaching the tools for empowerment and recovery
- Fear of liability for providers, suicide,
- Treatment plans must be organic, living documents, person driven plan must allow that goals may change,
- make sure there is an ally in the process, peer ally, to help maintain consumer ownership
- Liability is a natural issue as a result of change, clinicians must maintain ethical behavior
- must sign for pres drugs, some people are afraid to ask for copy of records, who owns, the plans must be clear in who has what rights, who does what, who has resp for what actions in the treatment plan, if an indiv fails, who is responsible, accountability
- Open a dialogue, staff person and consumer disagree, must trigger a dialogue not a no response,

- Treatment planning document, advance directives
- Team meetings,
- need to have a good safety net, effective accountability and monitoring, outcomes are usually provider determined,
- need to believe in people's potential
- risk and liability, concern about failure, consumers should be allowed to fail if that is what happens, what happens when consumers adhere and get Tardive Dyskenisia, must be equal partner,
- Liability can be reduced when you enter into a partnerships
- Communication and meaningful information, and evaluation
- literacy and terminology must be addressed

PM BREAKOUT SESSIONS

Congressional Room PM

What are the most promising practices in person/family/youth-centered planning?

1. Administrative and fiscal integration
2. Universities for participation for workforce development.
3. Workforce coaching rather than just training.
4. Technical assistance for new business models for provider and organization conversion.
5. National wrap around initiative with active participation from PFY
6. Development of the Family Driven Care
7. Permeable system to include real world natural supports.
8. Break down walls around mental health service system.
9. developing collaborative at communities and local levels. (It takes a village.)
(Do asset mapping.)
10. Self-directed care approach, i.e., budgeting, brokering, money follows the person, etc.
11. Next friend approach (VA) (families of the heart)
12. Peer support specialist; Medicaid reimbursable.
13. Reconciliation of PCP and medical necessity (Adams, Grieder)
14. peer developed wellness models, i.e. WRAP
15. Relationship building required with in PCP
16. PCP helps us develop/understand a person's vision of recovery.

What steps can be taken now to begin to address ownership issues and other barriers?

1. Create conditions where diverse communities can appropriate and translate person centered planning.
2. Integrate person centered plans across systems and phases of care.
3. Challenge medical necessity definitions.
4. Ensure CMS funds can be use flexibility to support recovery/community based success.
5. Measure outcomes consistently and regularly - Life, financial, satisfaction, recovery

6. Developed shared learning, include all
7. Accrediting organizations need to Kick Butt
- 8.
9. Develop guidelines for PCP form development - develop forms with PFY
10. PCP forms can circumvent relationships so in development of forms have to overcome this issue.
11. Ensure electronic records tools to support PCP.
12. Tap into and support with resources existing PFY and networks for development, training and mentoring re PCP.
13. Pilot PCP projects that promote innovations for non-traditional approaches.
14. Pay for performance.

Director's Room PM

What steps can be taken now to begin to address ownership issues and other barriers?

When you have a research piece it is based on data and not on people - a fallacy to say that

Evidenced Based Research

qualitative research methods should be viewed as important as quantitative research

CMS change mechanism for reimbursement so that the service/activity is aligned with the principles of recovery and consumer driven.

Top down mandates create a problem in which the staff then don't buy in or the top leaves the position.

You cannot mandate a value.

MEASUREMENT TOOL - empowerment or decision making scale so that it measures how involved the patient/consumer is involved in the decision making.

How this concept is operationalizing it and identifying what isn't recovery.

Instead of saying recovery use community integration... let people define what they need to integrate into the community. This would be culturally competent.

The training for staff and people assisting with integration must be inherent in the process or staff and providers will not be accepting of the change/transformation.

We have been doing this for 20 years and the system hasn't changed.

So maybe we have been doing this wrong and we need to analyze at what the barriers and problems

existed in the past before moving forward.

Kindling hope and unleashing it and people embrace it they have a lot of power and the power must be nurtured and then you have recovery. Empowerment, self-determination, recovery are 3 different things.

People can be given power by giving them information.

Consumer & providers trained together.

Flexible dollars so that people/consumers can use the system effectively.

Then help consumers who have taken control of their lives assist in working with providers to change the system.

How do we capitalize on the similarity of providers being coerced into taking these classes and training

and their anger with consumers being mandated to do whatever.

Self-determination and control which is the basis of recovery accounts.

People/consumers need to control their resources and get what they want.

Whoever controls is the golden rule. And ensure that it is enacted.

Staff resistency - loyalty is a better word than resistance.

Models of how to give up power. Come up with paradigms on how to deal with the problems of getting administrators and providers understand that they need to give up power to consumers.

Mandatory retirement for the older providers.

Who we sell this to are the legislators and the public. Show that people do recover and that the process of being involved is a parcel of the process. Good practice...

The same thing that foster individual recovery fosters system recovery.

You lead the way and tell us where to go as a model.

Sharing power - outcomes, outcomes and if no outcomes no income.

How to measure a system when the providers have no control is not fair.

The answer - measure death!!

The more external funding = killing the community.

What is the pay-off of sharing power = share hope. They may feel more effective.
The ethical question of it's the right thing to do.

Train families and give them the skills to be part of the community integration.

Need to get to the position in which families, consumers and providers are all part of the team.

Promising practice of partnerships which foster this model of recovery centered planning.

If you operate more efficiently then you get to keep the funds.

Self-determination: ask the consumer what they need and they will be able to use services that are more cost efficient.

Using peer specialist as promising practice - also cost effective and cost efficient.

Access To Recovery is being used in tandem with MHSIG Grants - Conn.

State and Federal partnership related to impacting CMS.

CA: a component of full service partnerships which requires recovery training. Whatever it takes so if a person needs clothing to go to a job the money can be used for it.

Strong development of advocates is necessary.

Need to equip consumers to participate in these processes i.e. -CA

Need to evaluate the CA process to determine if it truly reflects what consumers want.

Cabinet Room PM

What steps can be taken now to begin to address ownership issues and other barriers?

We need to think of personally defined action steps to get to person and family centered care. This can encompass the person stating where they want to be.

The agency incorporates outcomes that are congruent with the outcomes valued and expressed by individuals and families. How do we get there? Is the agency determined outcomes what counts, how do we sanction productivity and success as defined by the person.

Medical Necessity can be defined as what the person has determined as goals. We need to redefine medical necessity and this would require fiscal realignment.

We need to change language in some of mandates, this may require legislative changes and we will need advocacy to change this.

We need a strategy to not over promise and under deliver. We need consumer and families voices in the language of mandates which is not currently there.

We should not spend time reinventing the wheel. We need to be assertive that we are going to do things in a person and family centered way. We do however need to meet the agency needs. This balance will require education and showing how we can fund person and family centered approaches.

Need public service announcements and a widespread dissemination of information, personal stories are important pieces of this awareness.

More dollars for consumer and family leadership development as well as building the infrastructure of their organizations and we need to partner with a broad range of stakeholders.

All other organizations and systems are doing the same thing and we need to go out to vocational rehabilitation, school system etc and we need to coordinate and integrate these processes. This will help so we do not have fractionalized service. The federal agencies need to coordinate.

We need to make the system simple for persons and families to negotiate the system.

The involvement of peers and advocates can be helpers to the person and family to negotiate the system.

We need some pilots in different states that uses a broad set of standards that make person and family centered practices policies. This will need funding. This might be guidelines and best practices that need to be used and then this should be reported. This should be the first phase of transformation so it goes beyond a typical pilot.

We are not looking for one standardize model but a variety that are flexible. There should be standards but within this there needs to be flexibility.

Everyone that has a plan, they need to see their plan within a specified period of time and then people need to review and approve this plan. We need to remove barriers to access.

Require organizations that are doing person and family centered care have had an evaluation of how they are culturally competent.

CARF is certifying a lot of the right things. Surveyors should include consumers and families.

Chairman's Room PM

What steps can be taken now to begin to address ownership issues and other barriers?

- Establish definition for pcp; the context has already been done in the pub "Free to Choose" on the SAMHSA website.
- Change the title from "person centered" to "person directed" or something stronger.
- As per the NFI, this is not a separate issue but imbedded within mh transformation.
- Define the tension between having the resources in the hands of the consumer and the marketplace where the resources are.
- build on peer supports, provide assistance in brokering supports when necessary
- explore the role of peer supports/consumer movement as support brokers.
- develop a market place where services and supports can be purchased.
- provide an educational document for helping consumers understand the system, acronyms, etc. - a guide to the system
- Must have family members and youth at all tables!!-
- Before developing consensus, need to get the opinion and experiences of people who have been through the process.
- define the application of pcp concepts, values, principles, etc. to people in institutional settings (MH and Jails)
- BRING THE VALUES OF PCP IN PEOPLE IN INSTITUTIONAL SETTINGS, but don't pretend tht it's pcp
- look at what services are going to be available regardless of whether the individual wants to purchase them as part of his plan - i.e., emergency care, safety nets. we need to have the safety issues addressed as we look at broader picture - a person can get what he needs before/until he is ready to participate in pcp. those services will stay on the table.
- go to universities and training places to instill the pcp values in the curricula.,
- explore what pcp means for persons who do not want to control finances and resources.
- establishment of fiscal management agencies even if the individual does not want to control his/her finances
- explore difference between person centered and person driven or controlled.
- it is bad public policy to tell people that they have the ability to give up their freedoms (if they don't want to control their resources)
- develop and disseminate performance criteria, fidelity, outcome measures, so we know how things will work.

- integrate stages of change to accommodate people's ability to participate in pcp.
- educate, from a peer perspective, what pcp can do for the individual, that they don't have to be dependent on the system.
- develop education about self-directed care from a peer perspective for people at different stages of change.
- develop knowledge, skills, attitudes and competencies for staff who are going to do pcp support.
- recognize that people are at different stages. pcp can be temporary or partial delegations of responsibility to someone other than the consumer
- ensure that when someone declines to participate in the plan it's not because they've been told they aren't capable.
- recommend that the income disregard level for SSI be increased.
- need clarity about what responsibilities will be delegated to someone else - need to make sure that all parties understand, that what rights or options they are delegating and how they can get them back. In youth friendly language.
- creation of circles of support for those that are incapacitated, or have demention or otherwise not capable of creating them themselves. Circles should include people who care about the individual.
- call into question the notion of incompetence and replace with various forms of assisted competence.
- create the workplan to address the action steps, as a follow-up to this conference. It would be most effective if a follow-up conference were planned for February in Hawaii.
- Meld "free to choose" with pcp to create more comprehensive and cohesive public policy decisions.
- Create pubic policy at the SAMHSA level. SAMHSA to model pcp in block grants and other SAMHSA pgms.
- Encourage the adoption of pcp in state block grants programs.
- create consumer and family involvement and input at the local, state and federal levels. youth and family members should be at all levels, including at the executive level.
- develop cross walks with concepts that seem to be related to pcp, such as wrap, wraparound etc. - how are they related?
- develop methods, models and procedures to use pcp for families of young children.
- don't create another process oriented thing that doesn't have real outcomes. constant vigilance that process isn't driving the bus.
- explore and disseminate formalized processes of individual budgeting.
- explore policies and procedures that enable individuals to retain all or some part of unspent moneys or resources.

Terrace Ballroom PM

What are the most promising practices in person centered planning?

- psychiatric advance directives
 - wellness recovery action planning
 - wraparound
 - certified peer specialists
 - self directed care - Florida model
 - treatment plan structures that support person driven - formats
 - accreditation standards that require person centered planning - CARF has these, JCAHO
 - consumers are creating their own progress notes
 - Essential Lifestyle Planning, PATH, MAPS - place to start
 - separating the assessment from the provider - so it is geared on person's needs and not what providers provides
 - fidelity applies to practitioner, not the participant
 - peer specialists as facilitators of person centered planning specifically
 - integration vs. collaboration - good practice, cant have system where people can fall through the cracks
 - family-driven care for youth, families actively engaged - fcmh.org, definition of family driven
- now developing curriculum to train the trainers and tool to measure if it is happening at the practice and system level
- youth guided care definition is also happening now, to youth directed, to youth driven
 - self directed care - person controls the budget, wraparound has flexible dollars and integrated services
 - users self assessment guided by the person and assessment of the system
 - consumers/survivors active at all levels of management, board, staff, planning, implementation
 - leadership development meaningful
 - rethinking vac rehab guidelines, employment guidelines, break through these barriers, experiential expertise must be valued
 - any practices that are based on the principles of self determination, or provide choice, community integration
 - systems of care, include all descriptors
 - money follows the person, rebalancing
 - flexible spending accounts, wraparound, cross disability, DD, physical disabilities, RWJ grants

- accreditation, CPRP - USpra, principles, certification, 12 states have reimbursable, based on degree and experience
- one stop shopping, no wrong door, - resource navigator who knows how to work with individual and has sub specialties knowing available resources, seamless system for individuals
- case manager with lived experience
- levels of self directed care, some not ready for much, some may relapse, person decides who will assist them and not assigned
- crisis planning to actually prevent crisis not call 911
- incentives - like residential care homes in OK, to buy into recovery, that reach certain capacity in their homes, meet 4 of 7 criteria, ample parking for personal care, can have personal phone line, transportation to work, etc...then they get extra money as being a recovery home, small tweak to break down resistance
- involve consumers in research, in design, planning, implementation, and evaluation
- involving consumers in education professionals
- ongoing stigma training about stigma in mh treatment
- consumers in eval of treatment
- enforcing ADA and Olmstead
- having consumers survivors creating the evaluation tools, implementing them, analyzing the data
- CQI, ROSI,
- work on wait times, not asking for same info more than once, customer service not burdensome
- technology could be used better to leave more time for human interaction
- concurrent documentation, write notes in the room
- performance based contracting, setting up time for providers to present new ideas, setting up competitive systems between providers, need protections in rural communities, competition must be driven by quality
- consumer driven market
- eliminating catchment areas
- include person driven in contract with service providers

What steps can be taken now to begin to address ownership issues and other barriers?,

- include this language on person driven in SAMHSA RFAs, contracts, etc
- Medicare Medicaid billing incorporate this language
- process to improve Medicaid services, need to be clearly defined
- SAMHSA Access to Recovery building in effectiveness outcomes and potential for re auth of grants based on outcomes,

- forbid funding for contracts that are not person centered, such as housing restrictions, can't live there except under certain circumstances
- take questions about barriers and obstacles to stakeholders, providers, families with kids, consumers, beaurocrats, etc...get richer product
- money, investment is major barrier, program may want to change but faces little funding to do so
- must target people in services right now, to get input on this issue
- backdoor financial practices to get reimbursement is cumbersome for providers and takes away from time with consumers
- get better input,
- streamlining of practices, electronic health records, funding, increase productivity,
- movement toward on federal level toward collaboration, on grants, step now is to have a comprehensive planning approach across federal agencies that affect supports for consumers
- ownership, very medical oriented, providers must look at what they are offering to consumers for recovery, supported employment, b waiver modality, if provided on more statewide basis, more consumers would respond and get involved instead of just faced with med compliance
- paperwork could be increased by this, if consumers are going to do their own care plans and peer specialists could do that with consumer,
- eliminating the entitlement barriers, disincentives to recovery,
- academic institutions need to do a better job on training, key elements in job description that includes recovery competencies
- need to build relationships between providers and consumers during planning process for real collaborations, guidelines, and orientation for both
- don't let this become the issue of the day, wonderful new plans, no follow through
- in kids MH, families have taken over the train and it is not going to stop, keeps it going when sharing decision making
- advocacy
- need strategic plan at all levels, goals and action steps
- need federal regulatory support to maintain and sustain recovery orientation
- leadership, changes in leadership, how to support leaders who take a risk
- how do we get more Garys by gosh
- what actions do we need to engage in to be more successful
- congressional leadership, beaurocratic structures
- update State mental health plan, MH Sigs should be a platform for person centered care across the country
- make this a requirement of block grants
- fund a demo grant to any state that would test the model, person centered planning that is integrated, CMS, federal level,

- fund an entire service delivery system and test that
- get prof organizations, NASW, APA to include this in their ethical standards
- carrot and the stick - incentives and penalties, change provider
- include in state codes, licensing
- technology grants, electronic health records, save time money
- fund the creation of peer specialists across the US, using lessons learned from existing models, research base to assure providers,
- educating politicians about funding priorities
- education of staff, providers of services, never heard of recent policy shifts, NF commission, academic organizations, institutions, med schools,
- education of those assisting in the development of person centered plans, to transition from clinical medical goals to recovery goals
- educating legal and policy advocates, and policymakers,
- get more feedback from youth and families and information out to them