



EMPOWERING ADVOCACY
Person-Centered Planning Meetings
Lanterman Regional Center

Defining Moments



- What **choice** did you make in that moment?
- What personal **strength** did you draw upon to give you the courage needed?
- What **action** did you take that lead to the profound and/or positive change this moment made in your life?

George's Story

- <https://www.youtube.com/watch?v=qn4pjuHfuGc>



Objectives

- To understand...
 - Person-centered concepts at the heart of advocacy.
 - Empowering your child through the meeting process.
 - Shared participation in planning.
 - How to recognize and respond to disempowering or “non” person-centered attitudes within the support team / planning meeting.



Defining Choices

Risk

Passion &
Experience

Finding Your
Voice



Are You In?



Dignity of Risk

Source: Opportunities for Independence, 2011

- Anyone who leads a life of dignity and meaning takes risks. Each of us, in the pursuit of jobs, our personal and romantic relationships, our leisure activities, and our adventures have stepped into the unknown and risked failure, rejection, and even our physical well-being.
- ***Anything any of us have ever accomplished has come from some level of risk-taking. The benefits of succeeding in these situations, or from learning from our mistakes, are a crucial element in our development as independent people.***
- Imagine for a moment what it would be like if you were never allowed to take a risk, if others made all of your decisions for you, if others, not you, had the last word on what you were capable of. You certainly wouldn't deserve such a life; nor do the people we support.



Definition of SAFETY

Safety is a state of being protected from potential harm or something that has been designed to protect and prevent harm.

The Hidden Harm

- Disempowerment
 - Helplessness
 - Hopelessness
- Failure to progress
- Diminished quality of life

Empathic Listening



- Seek to understand before being understood.
- Attempt to take the other person's point of view as you listen to them.
- Do not interrupt.
- Do not pass judgement.
- Withhold impulse to give advice, or tell your story. Always ask permission before you do.

Following the Person's Passion

- Listen and investigate more deeply
 - It isn't always what it appears on the surface.
- Explore natural supports, and community resources.
- Encourage experience informed decision making and reasonable risk, to increase life experiences.
- Know when to steer the conversation for specific information, and when to let it develop naturally into something more.



Meeting Preparation



- Preparing your family member before goal planning meetings can help to empower and build their confidence as their own advocate.
- Find out any major topics of interest or concern to them ahead of time. This can help focus the meeting, and information/resources can be readied.
- Recommend that the person brings an ally if needed.
 - Are they available to support the person in preparing for and attending their meetings or other important advocacy opportunities.
 - If the person would like, this ally might be able to act as a translator (not to speak for, but to translate and speak on behalf of the person if needed).

Finding Their Voice



- Find out how they wish to express their voice at their meeting
 - Gain support in preparing the tools necessary to do so if needed (i.e. a report, poster, slideshow, etc.). Find out who they may wish to help them to do this.
 - Sometimes practicing can be helpful.

Jacob's Voice

- “I want to move closer to my father.”



Put into Practice



- Practice Empathic Listening
- Follow your partner's passion without placing barriers or limitations
- Encourage experience

Defining Strengths

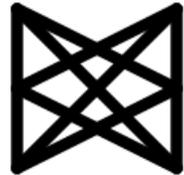
Respect

Model &
Educate

Reflect



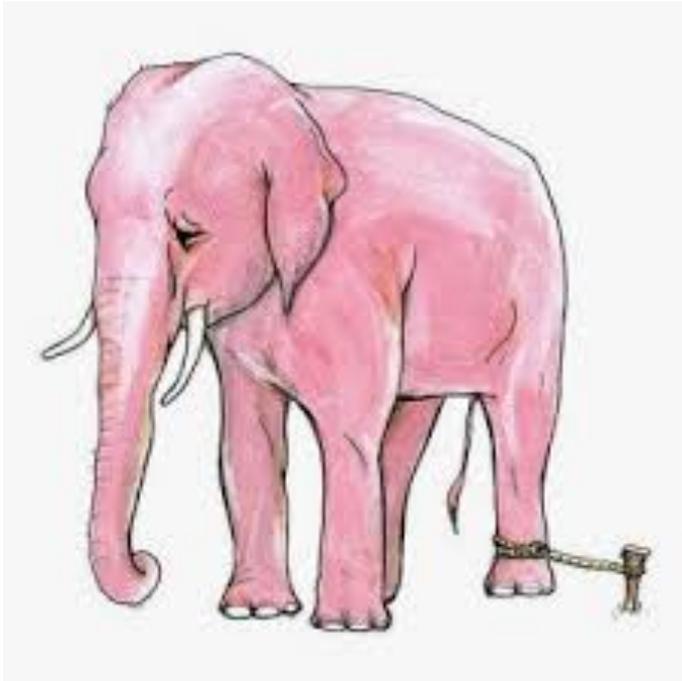
Easy Visual Puzzle



Learned Helplessness

- Google Definition: a condition in which a person suffers from a **sense of powerlessness**, arising from a traumatic event or persistent failure to succeed. It is thought to be one of the underlying causes of depression.
 - https://www.google.com/webhp?sourceid=chrome-instant&ion=1&espv=2&ie=UTF-8#q=learned+helplessness&*
- In this context the persistent failure to succeed is the failure to succeed in having choice or control over your own life.
- Sometimes a person's diagnosis is blamed for conditions that the service system has conditioned.

Results of Learned Helplessness



Possible Characteristics

- Rarely initiates choices or actions
- Consistent self-doubt
- Usually defers to others
- Completes tasks for other's approval, not own gratification
- Resistance to trying new things, or voicing opinion
- Compliant with unfavorable tasks or activities

Meeting Best Practices

Ensure your family member is driving their meeting (beginning to end)

- Find out from your family member if /when/where/who they want to support them in...
 - Filling out their progress assessments.
 - Preparing for their meetings.
 - Conducting their goal planning meetings.
- All discussions should be...
 - Conducted with their permission.
 - Centered around their input.
 - Inclusive of all those who love, care, and support them. With everyone's input valued in addition to (not in place of) their own input.
 - Give your family member the opportunity to have final say on all topics and comments.
- Is your family member being answered for or talked over? If so, listen, then redirect back to them.

Highlight Strengths

- Larger posters, visual aides and graphics can be very helpful.
 - We all want to know what is going on and what is being written about us.
- Environment should be comfortable and accessible to your family member and everyone they have invited.
- Either explain or refrain from using professional jargon. Make sure everyone understands what is being discussed.



The Support Team's Behavior Plan



Depersonalizing Tendencies

- Treachery
- Disempowerment
- Infantilization
- Intimidation
- **Labeling**
- Stigmatization
- **Outpacing**
- **Invalidation**
- Banishment
- Objectification
- **Ignoring**
- Imposition
- Withholding
- Accusation
- Disruption
- Mockery
- **Disparagement**

Source: Kitwood, 1997

Educating the Support Team

- **General rules:**
 - Use redirection, reflection, and paraphrasing to emphasize philosophical differences without correcting speaker.
 - Never embarrass anyone in front of the support team. Address major issues in private after meeting, so they are not repeated in future meetings.
 - Remember change doesn't happen in one day, baby steps...



Asking Person Centered Questions

Traditional Question

- How are you managing his diabetes?
- Is she allowed in the back garden?
- How many community outings does he go on a month?
- Are you happy at your day service? (asked in front of the day service providers)

Person Centered Question

- Can you show me what you do to maintain your blood sugar levels?
- Do you enjoy your back garden? How much time do you spend there?
- What were some of your favorite places that you have visited lately?
- What do you enjoy the most about your day service? What do you enjoy the least?

Put into Practice



- Discuss “non” person-centered support team behaviors.
- Asking person-centered questions.
- Reflect on ourselves!

Defining Actions

Meaningful
Balance

Paradigm Shift

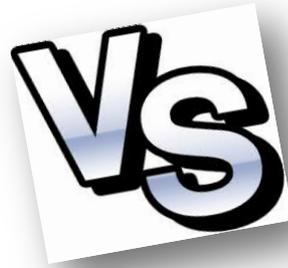
PC Goals



Quality of Life



Meaningful



Essential

Meaningful:

The things in life that make us happy and content. Things the person feels improves their QOL.

- Relationships
- Favorite Chair
- Morning Routine
- Knitting
- Going to the beach

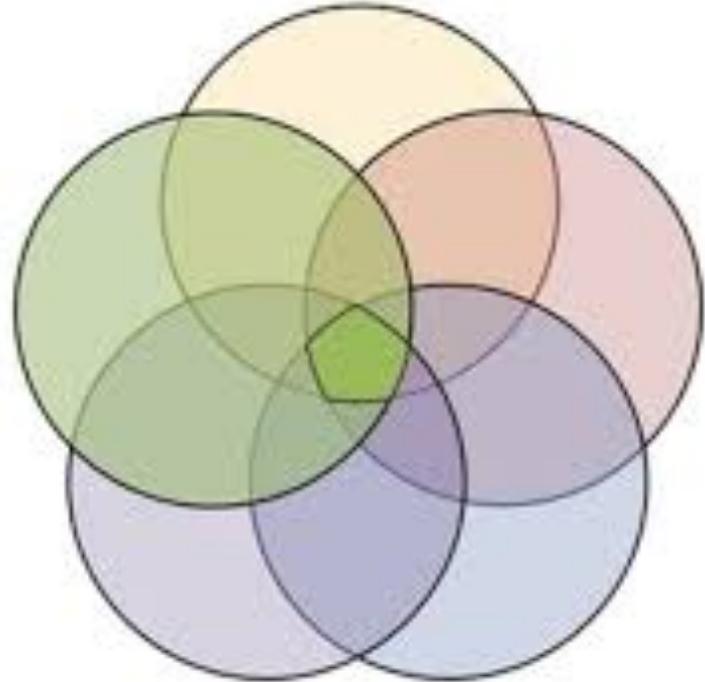
Essential:

Health, safety, and what others feel is necessary for the person's life. Includes regulatory requirements.

- Healthy Diet
- Safe Home
- Medications
- Earning Money
- Medical Appointment when needed

Listening for Themes

- Security
- Community
- Relationships
- Choices
- Goals



Person-Centered Then and Now

We think we know?

Where we have been:

- We (the professionals) have created a plan for Susan. We have gotten to know Susan well, and had her in mind as we created it. Now here is the daily strategy for Susan to achieve the goals set forth in the plan.

Where we want to go:

- We have talked with Susan and those she has indicated are central in her life. She let us know what is most important in her life right now, and we discussed with her any possible supports she might want to help her achieve those things. She will continue to direct her days as she sees fit.

Paradigm Shift

| | Focal Questions | Era of Institutions I | Era of Deinstitutionalization II | Era of Community Membership III |
|---|--------------------------------------|------------------------------------|---|---|
| A | Who is the person of concern? | The patient | The client | The citizen |
| B | What is the typical setting? | An institution | A group home, workshop | A person's home, local business, special school or classroom the neighborhood, school |
| C | How are services organized? | In facilities | In a continuum of options | Through a unique array of supports tailored to the individual |
| D | What is the model? | Custodial/medical | Developmental/Behavioral | Individual support |
| E | What are the services? | Care | Programs | Supports |
| F | How are services planned? | Through a plan of care | Through an individualized habilitation plan | Through a personal future plan |
| G | Who controls the planning decisions? | A professional (usually an MD) | An interdisciplinary team | The individual |
| H | What is the planning context? | Standards of professional practice | Team consensus | A circle of support |
| I | What has the highest priority? | Basic needs | Skill development, behavior management | Self-determination and relationship management |
| J | What is the object? | Control or cure | To change behavior | To change the environment and attitudes |

Person Centered Goals



- Goals build on strengths, skills, and autonomy.
- Ensure your family member is driving their goal development.
- Suggest pairing meaningful and essential aspects of life to find the right balance, and enhance motivation.
- Goals are directed towards your family member, are respectful, and empowers them. Written with the same principles as asking person centered questions.
- Goals speak to the lifestyle and community membership desired by your family member.

Person Centered Plan Effectiveness

Ratti et al. (2016) study also found...

- Care-givers constitute a major influencing factor on the success of PCP and they play a vital role in shaping the lives of people with ID through the quality of support that they provide. Heller et al. (2000) found that individuals with ID regarded staff's instrumental and emotional support as the single most important facilitator of goal attainment. Dumas, De La Garza, Seay, and Becker (2002) argued that ***individuals with ID do not perceive having a plan as the main cause of change, but in fact responsibility for change, achievements and failure to achieve is attributed to the PCP facilitators whose commitment to PCP has been considered the most powerful predictor of successful outcomes for people*** (Sanderson, Thompson, & Kilbane, 2006). (p. 79)



Focus on Building Relationships

- How strong are the relationships within the support team?
- Better relationships lead to...
 - More communication (both at the meeting, and throughout the year).
 - More open to each other's perspectives (including person centered concepts).
 - More support for your family member in advocating for what they really want at this time in their life.
 - More likely that the team will work together to reach real QOL outcomes.



Mission Accomplished?



- Created strategies to support the lifestyle your family member wants for themselves today.
 - Not focused just on health and safety, or even just on dreams and aspirations.
 - This has more immediate effects on QOL outcomes.
- Goals increase community membership, not just community observation.
- They have valued roles and relationships (if desired)
- Plan is unique, and clearly speaks of and represents them.
- Everyone is clear on next steps, and committed to their role in support of the plan.

Put into Practice



- Finding the balance desired.
- Create Person-Centered Goals
- Spirit of Building Relationships

References

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Celebrate, Don't Separate

- <https://www.youtube.com/watch?v=kln8npO7pEU>





Thank You!!!

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