

My Own World: Supporting People to Live Their Best Lives

*A Person-Centered Approach for Supporters,
Direct Service Professionals*

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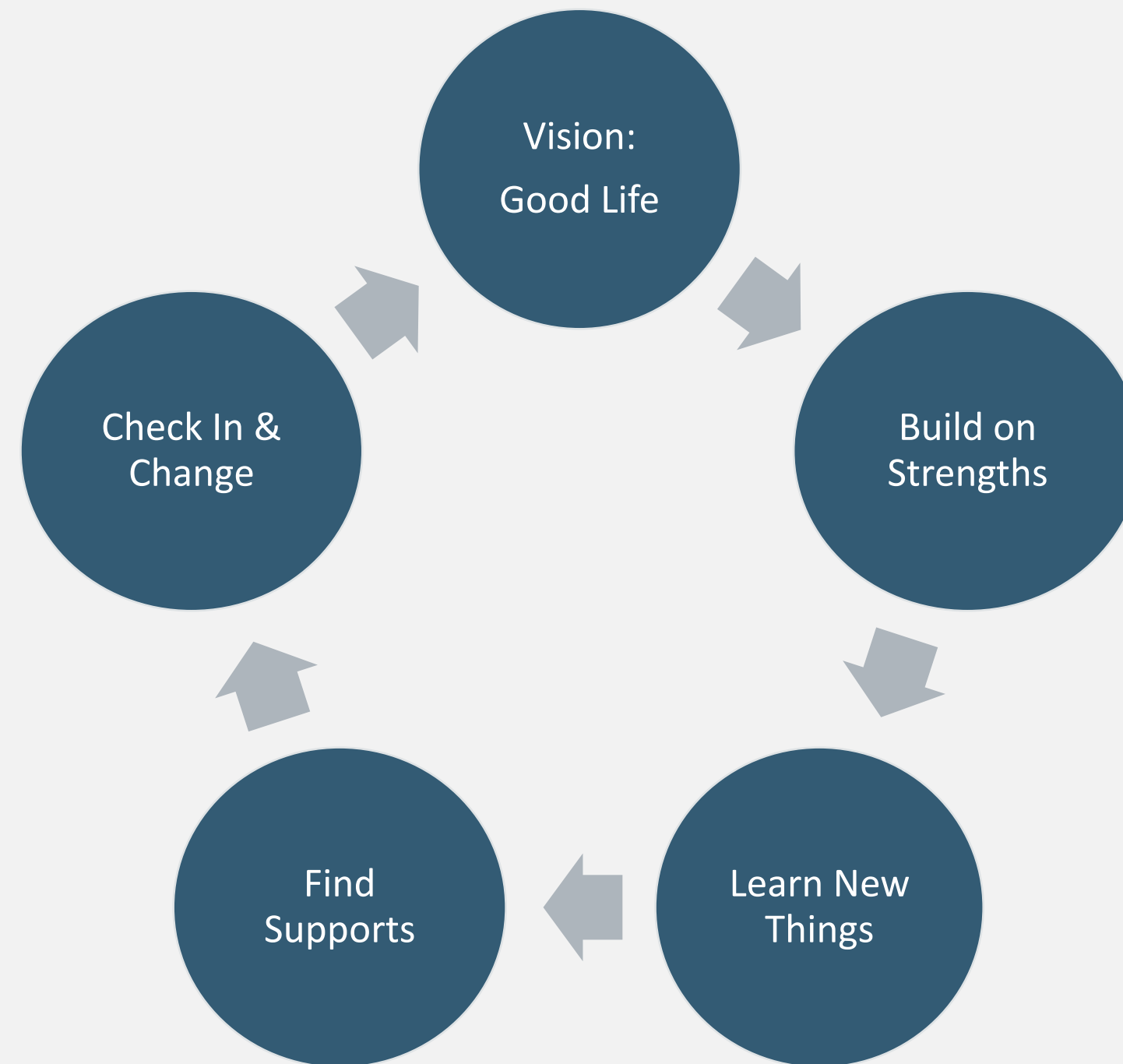
Louisiana's Office for Citizens with Developmental Disabilities



What are Your Personal Experiences ?

- Personal experiences affect us throughout our entire lives
 - Shape our beliefs
 - Shape our actions and behaviors
- Thoughts and beliefs often direct our actions and behavior: If the thoughts change, so does the behavior
- Personal experiences with people who were “different”
 - How did you feel?
 - What did you think?
 - How did you behave?
 - How have these changed over time?

Building the Best Life: A Work in Progress



Who Do You Support?

Information Behind the Label

- Intellectual vs. Developmental Disability
- Type and severity of disability affect + unique characteristics of the person=
 - What services are provided
 - Amount of services provided
 - How services are provided
- 85% of people with intellectual disability have only a mild deficit
 - Mostly independent, receive little to no assistance from others
 - Live normal lives in their community, go to school, get jobs, social lives
- 15% of people with intellectual disability have moderate-profound deficits
 - Rely more on others for assistance, may need up to 24-hour care
 - Small percentage of this group may have more complex needs (behavioral, medical)

Supporting the Person to 'Get A Life!': Outcomes

- Belong to his/her community
- Variety of personal relationships
- Opportunity to advocate for self/others/causes
- Valued roles in family & community
- Support to make major lifestyle changes
- Express one's personal identity
- Support to manage aspects of life
- Plan reflects a life & supports designed by person & used to create positive image
- Maintain connection with his/her past
- Be understood & get a response
- Feel safe/emotional well-being
- Opportunity for physical wellness
- Live & die with dignity

Supporting the Person to 'Get A Life!': Outcomes



School
Work
Learning
Independence



Family
Friends
Community Connections
Valued Social Roles
Sense of Belonging



Healthy Lifestyle
Wellness
Positive Experiences



Health
Physical Well-being



Sense of self-identity
Drive plan and supports
Be understood
Live & Die with Dignity
Advocate for things that matter

Person-Centered Supports

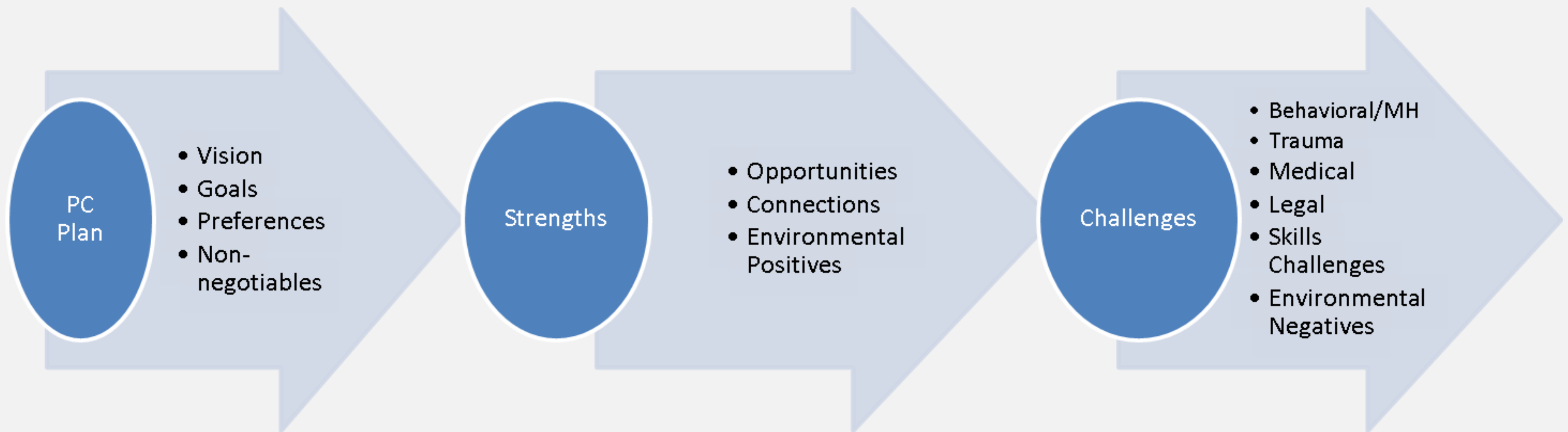
Person-Centered Thinking helps to establish the means for a person to live a life that they and the people who care about them have good reasons to value

Person-Centered Planning is a way to assist people who need HCBS and supports to construct and describe what they want and need to bring purpose and meaning to their life

Person-Centered Practice is the alignment of service resources that give people access to the full benefits of community living and ensure they receive services in a way that may help them achieve individual goals

<https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-training-series>

Learning Each Person's Story



Life Vision: What is it?

- Should drive the whole PC planning process. This is **what the plan is all about!**
- The “**big picture**”: what I want my life to look like in the next 3-5 years
- The **ideal life** that has not yet been fully achieved
 - **May include:**
 - Home Life: where I would like to live, who I would like to live with, type of community
 - Relationships: people I want to have in my life, current relationships, new relationships
 - Meaningful day: school, jobs, other daytime activities, involvement in community
 - **Does *not* include:**
 - “I want to keep going to day program”; “I want to keep living here”
 - “I want to keep my behavior plan”; “I want to keep my 1:1 staff so I won’t have behaviors”

Life Vision: Does it pass the test?

- Should pass the “look at the future/not yet achieved” test
 - Statement = what person wants life to look like in next 3-5 years/ideal life/not achieved yet
- Should pass the “like you or me” test
 - Statement = something that we would say about you or me; not something that we say only about people with disabilities, people who receive services
- Examples:
 - I want to maintain my health
 - I need services to have around-the-clock supervision
 - I want to become more independent and have my own living environment
 - I want to continue to live in my group home with my friends
 - I want my provider to help me manage my finances
 - I want to live in my own rental home with 24-hour supports

Checking Our Understanding

Let's think about the examples we just reviewed and let's consider a few others.

Use the Life Vision section in your Competency Check document to write down your own responses about whether these meet the criteria for a good life vision.



Life Goals: What are they?

- Smaller accomplishments/outcomes we work on now to reach the Life Vision in the future: *Meeting our Life Goals will help us reach our Vision*
- Focused view of what things are like now, what we want to work on and achieve now (in the next year or so)
 - **Includes:**
 - Something that is personally meaningful
 - Something that can be “measured” (to see if progress is being made)
 - **Does *not* include** (unless important to Vision *and* at risk of losing):
 - “I want to keep my job”; “I want to maintain my health”
 - ***Never* includes:**
 - “I want to keep my behavior plan so I can have fewer behaviors”; “I want to keep seeing my doctors”; “I need a new wheelchair to get around safely”

Life Goals: Does it pass the test?

- Should pass the “personally meaningful” and “can be achieved in next year or so” test
- Should pass the “measurable” test (can tell if progress is being made)
- Should pass the “like you or me” test
- Examples:
 - I want rehabilitation services
 - I want to become more independent and have my own living environment
 - I will consistently manage stressful situations in a socially appropriate manner
 - I would like to have access to my belongings
 - I need assistance with money management
 - I want to participate in community activities and have staff to support me
 - I want to live free from abuse/neglect and have staff who ensure my daily needs taken care of

Checking Our Understanding

Let's think about the examples we just reviewed and let's consider a few others.



Vision and Life Goals:

Vision 1: I want to live in my own home near a park and library. I want a job working with animals.

- **Goal #1:** I will begin volunteering with the local animal shelter to get experience working with different kinds of cats and dogs.
- **Goal #2:** I will meet with different people that could be a good roommate (at least twice per month) and choose someone, so that I can afford to live where I want.
- **Goal #3:** I will start keeping a list of apartment complexes and typical rent prices in the preferred area I want to live, and will apply to a vacancy once I have a roommate.

Vision 2: I would like to earn my GED, and have a romantic relationship. I would like to live independently in my own apartment in the future.

- **Goal #1:** I will attend online classes and study every week in order to take the test later this year.
- **Goal #2:** I will join different dating sites and will invite someone over for dinner.
- **Goal #3:** I will work on some independence skills like learning to make simple meals and paying bills.

Gathering Information: Getting to Know the Person

- My Important Relationships and Connections
- Balancing “Important to” (what matters most to me) and “Important for” (what keeps me healthy and safe)
- My Routines and Non-negotiables
- Understanding My Communication Style
- Finding the Right Fit when I need Staff Support

Important Relationships & Connections

Close Family & Friends	Relationship (friend, family, connection, significant other)	What they do for me (emotional support, transportation, help at the store, support me at work/home, etc.)
Community Connections	People I Know There (Acquaintances)	Supports needed to go and participate
Important Paid Supporters	Relationship	What they do for me

Relationships: Spot the Differences

Me

- Close family & friends → Carrie, Weston, Ben, Thomas, Carla, Perry, Angela
- Connections & Acquaintances → Brittany, Matt, Michelle, Michelle, Mrs. Keene, Susan, Amy, Lance, Sherry
- Important Paid Supporters → Meagon, Dr. LaFleur, Dr. Manuel, Dr. Friedman, Mandy, Jason, Arnold

Susie

- Close family & friends → Mom, dad, Daisy
- Connections & Acquaintances → None
- Important Paid Supporters → Jill, Paula, Dr. Smith, Dr. Thompson, Theresa

Checking Our Understanding

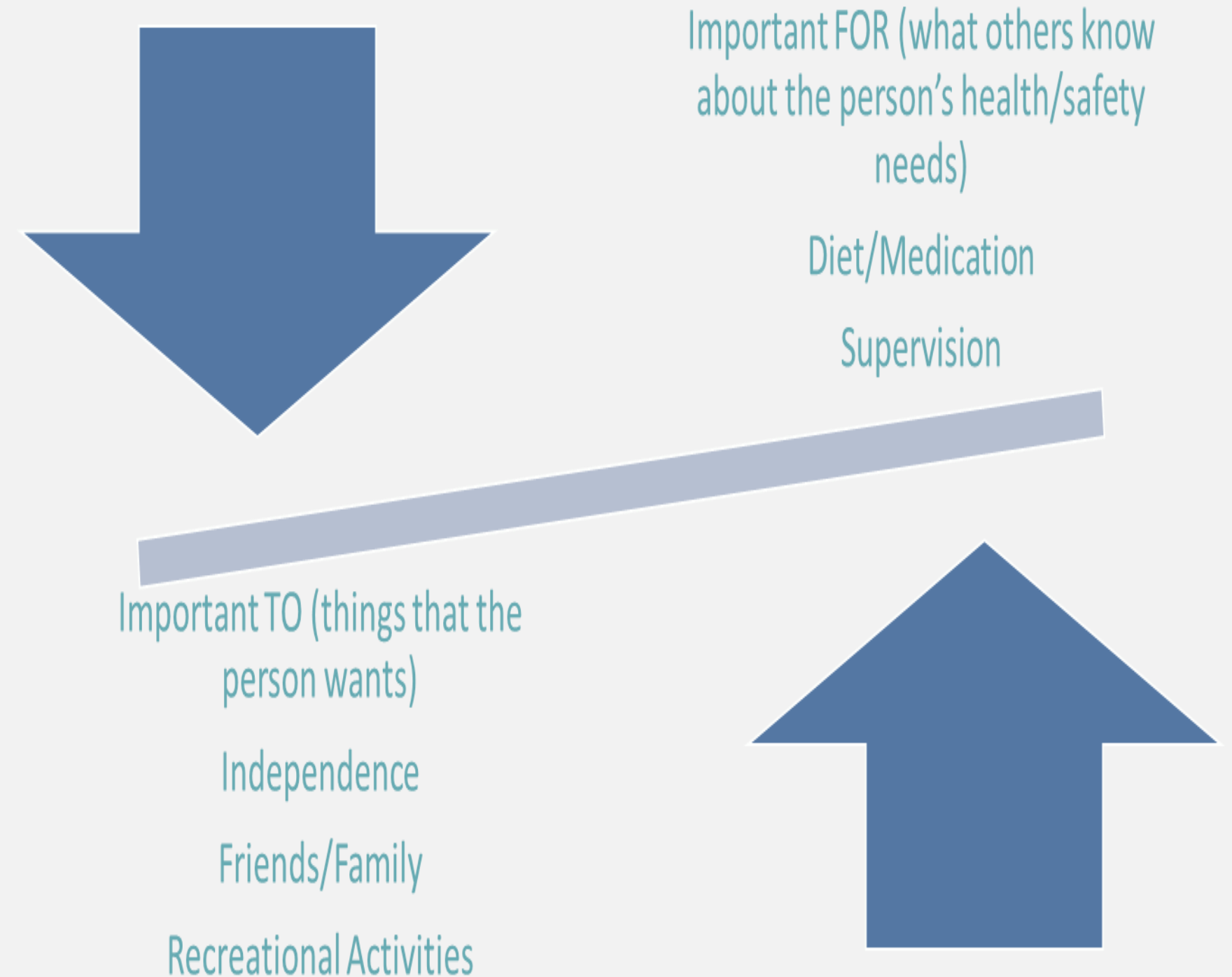
Let's think about the examples we just reviewed and let's consider another one.



Balancing “Important to” and “Important for”

Topics for Discussion:

- Acceptable substitutes
- All or nothing vs. Moderation
- Exercise – can it help reduce risk?
- Education and self-monitoring: options to teach rather than restrict
- Budgeting – teaching rather than restricting; also, consider: separate ‘fun’ account from ‘bills’ account (allow for learning natural consequences)
- Risk conversations – are risks greater than for you/me? Is it related to cognitive understanding? Are the risks realistic?
- Opportunities for “appropriate relationships?”
- Explore: What is MOST important in the relationship?



Non-Negotiables: Importance of Routine and Rituals

- What are your important routines/rituals?
 - Daily Routines (morning, bedtime, etc.)
 - Birthdays/Anniversaries/Deaths
 - Cultural/Holiday
 - Spiritual/Religious
 - Vacation
 - Comfort
- Why are these routines/rituals important?
- What happens to your well-being if they go away?

Non-Negotiables: Considerations

Things We Might Say

- Bath/shower preference (time preference)
- Beverages (coffee, tea, coke) & time preferred
- Work times/schedules
- Morning routines/after work routines/bedtime routines
- Exercise (type, when)
- Need for quiet/alone time
- Ways we celebrate certain things/events

Things We Would Never Say

- Structured setting & routine
- Positive Behavior Support/Behavior management
- Supervision
- Diet
- Medication
- ADLs/Assistance with ADLs

Non-negotiables are ALWAYS from the person's perspective: What matters to them?

How do we help someone have the best day?

- Helps caregivers to recognize that all people are different and what makes them “tick” is different
- Helps identify what is important to a person
- Allows us to identify areas where people need support
- Supporting the person vs. “fixing”
- Maximize the good days and minimize effect of bad days

Is this Your “Good” Day or “Bad” Day?

Schedule 1

- Get up at 5 a.m.
- Shower & dress for the day
- Leave home at 5:30 a.m. for hour commute
- Grab coffee on way to office
- Begin work at 6:30 a.m.
- Meetings most mornings with minimal breaks
- Eat lunch at desk while working
- Intense work in afternoon with minimal breaks
- Leave work at 4:00 p.m. for hour commute
- Watch/check news
- Eat dinner at 6:30 p.m.
- In bed by 9:00 p.m.

Schedule 2

- Get up at 6:30 a.m.
- Eat breakfast
- Dress for the day
- Leave home at 7:30 a.m. for 15-minute drive to office
- Arrive early for check-in/chatting with colleagues
- Begin work at 8 a.m.
- Activities scheduled to allow for morning break
- Lunch with colleagues
- Afternoon activities – walking meetings with staff
- Leave work at 4:30 p.m. for 15-minute drive home
- Spend time – outdoor activities with family/friends
- Eat dinner at leisure
- In bed by 10 p.m.

Checking Our Understanding

Let's think about the important to/for and routines and non-negotiables discussions we had. Remember that non-negotiables are important for an individual to have a balance of "important to" and "important for" things and to have the best day possible.



Communication

- Very important to learn and record how people communicate and respond appropriately
- Especially important for persons who communicate in atypical ways
 - People who do not use words to communicate
 - People who communicate more clearly with behavior
- Allows people to get to know someone more quickly
- Effective communication can impact behavioral issues significantly
- Critical to record how people communicate and use the information that is learned

Active Listening

- Be aware of the individuals communication style and approaches; use easy to understand language
 - Visual/other cues
 - Use technology
- Balance open and closed ended questions to ensure consideration of response bias
- Give sufficient time to hear, process & respond
- Focus on one issue at a time
- May need observation as more important component
 - Inconsistencies
 - Limited in communicating verbally
- Reflect back to be sure you understood



Communication Plan/Log

Sharing How You Communicate and What Matters to You

I do this....	Because this happened...	It means ...	I need you to do this....

Communication Log: Example

I do this....	Because this happened...	It means ...	I need you to do this....
Pace and mumble things you cannot hear	My request is not heard or seems to be ignored	I am frustrated or angry about something important to me	Ask me to share what I would like to happen; Respond to my request
Lie in bed and refuse to get up	Migraines Constipation	I am not feeling well	Give me some space until I feel better. Sometimes a dark room and music helps. Ask me if I need my medication

Communication: Considerations

Things We Might Include

- Pacing and repeating your name → restroom
- Wraps pillow around head; refuses to eat or shower → has migraine
- Grabs your arm as you pass close by → wants to sit and talk (this is NOT “aggression”)

Things We Would Never Include

- Smiles → happy
- Cries → sad
- Slam doors/yells/stomp feet → angry
- Use my first finger to gesture towards me → come here

Checking Our Understanding

Let's think about the discussion we had about the unique communication and the communication log.



Finding the “Right Fit”: Matching People to Staff

- Look at what skills, interests, personality characteristics make for good matches
- Look at what characteristics make for bad matches
- Helps people think about the kind of caregiver they want/need
- Helps agencies to hire the best matched caregiver(s)
- Increases satisfaction for caregiver and service participants

NOTE: This information can also be used to enhance shared supports/roommate situations and improve success.

Who will support YOU best?

What supports and approach works best for me?	Things I like to do with others
Planning my week on Sunday Knowing ahead of time if something changes Space and quiet in my home	Sharing books Gardening Puzzles
What supports and approach do not work well for me?	Things (characteristics and actions) about people I want to have relationships with and do fun things with
Someone talking to me a lot/being chatty Doing things for me instead of giving me time and space to do it myself	Book club/talking about and sharing books People who can share time quietly and do not talk too much People who like to be active (walking, trying new things)

Finding the Right Fit: Considerations

Things We Might Say

- Shared Interests
 - Enjoys outdoor activities/gardening
 - Loves sports (playing & attending)
 - Enjoys exercise/yoga/etc.
 - Likes animals/pets
- Interaction Style
 - Loves talking and socializing
 - Is ok with some quiet/down time
- Skills/Knowledge to teach me _____
- Someone connected to organizations that do _____

Things We Would Never Say

- Positive Things That Should Be Given
 - Trustworthy
 - Kind
 - Reliable
 - Patient
 - Calm voice
- Negative Things That No One Should Experience
 - Someone who does not yell at me
 - Being told what to do/corrected
 - Talking down to me

Checking Our Understanding

Let's think about the discussion we had about staff matching.



You Will Always Be Needed

- There are thousands of people who have long-term care needs in Louisiana
 - People with developmental disabilities
 - People who are elderly
 - People with physical support needs/limitations in mobility
- Even if people become more independent, start using more technology, and/or rely more on community resources/natural supports, many people will always need support from paid staff
- How you do your job may change over time, but you will always be needed!

Words We Should Leave Behind

If we are serious about being Person-Centered, let's re-think:

- “Outing” or “Going Into the Community”
- Move away from “integration” and focus more on real “connections” and “belonging”
- “Noncompliance” (unless we are talking about failure to comply with treatment recommendations in the way a professional would use to describe you or me)



Thank you

