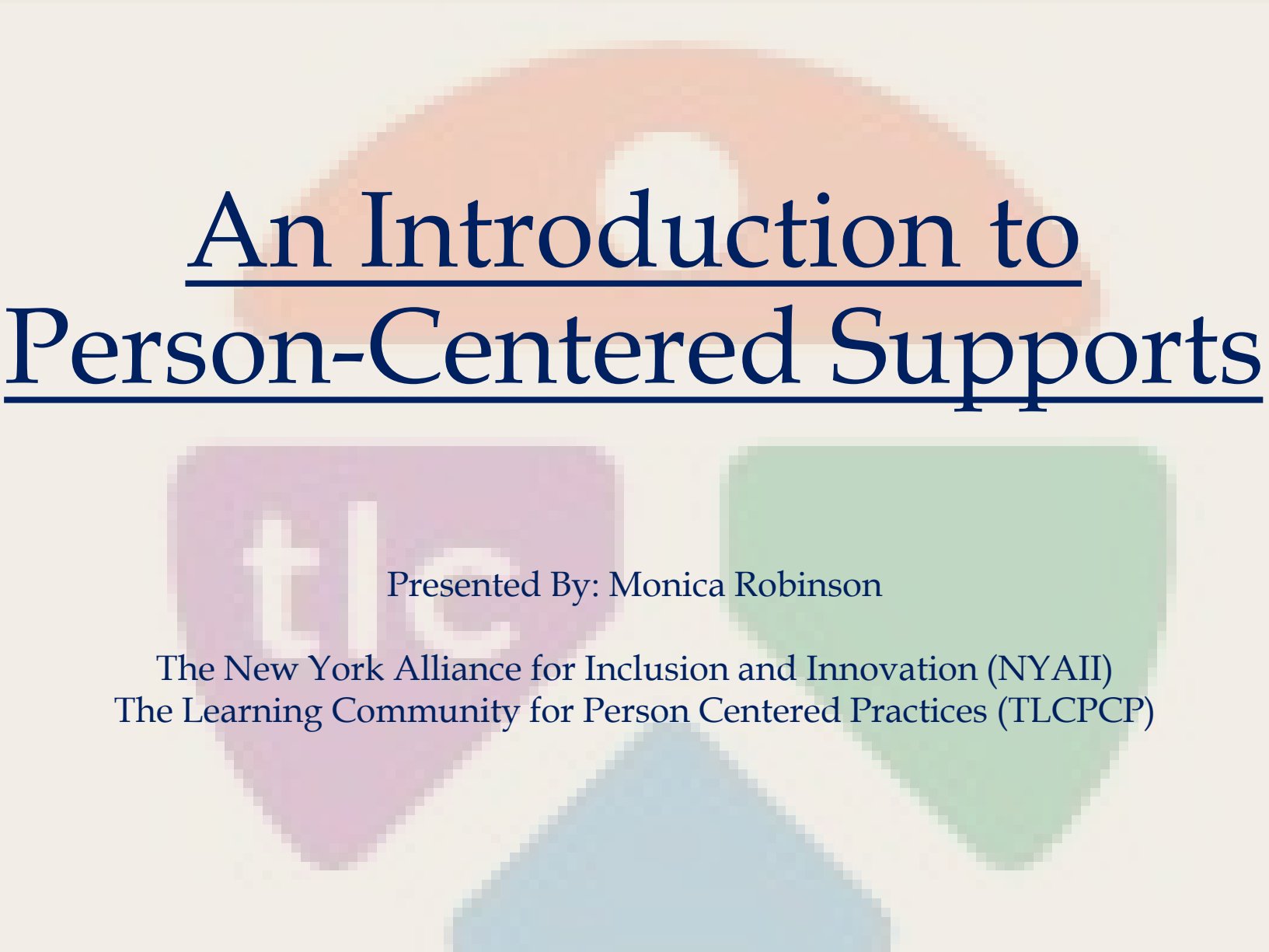




An Introduction to Person-Centered Supports

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The New York Alliance for Inclusion and Innovation (NYAII)
The Learning Community for Person Centered Practices (TLCPCP)

Person Centered Thinking

- Underlies and guides respectful listening, which leads to respectful action
- Supports people in having positive control over their life that is desired and satisfying
- Where people are:
 - Recognized and valued for our/their contributions (past, current, and potential) to our/their communities; and
 - Supported by a web of relationships, both natural and paid, within our/their communities

PCT Beyond Requirements

It's the right thing to do AND:

- It is the foundation for meeting the Centers for Medicare and Medicaid Services (CMS) requirements for residential settings and service planning
- Person-centered service plans must be developed through a person-centered planning process

The HCBS Services Final Rule Requirements

- The setting is integrated in and supports full access to the greater community;
- Is selected by the individual from among setting options, including non-disability specific settings;
- Ensures individual rights of privacy, dignity and respect, and freedom from coercion and restraint;
- Optimizing autonomy and independence in making life choices; and
- Facilitates choice regarding services and who provides them.

Culture in PCT:

Supporting ALL People

- Embraces diversity and supports inclusion
- Considers the whole person
- Not one size fits all
- There is no one right way
- We are all made up of our unique strengths, gifts, skills, culture, and identity



What is a Person's Culture



A Culture of One

- In Person Centered Practices we avoid making assumptions about people's preferences related to their culture.
- Every person has their own beliefs, values, and preferences.
- Each person has a culture of one.

Person-Centered Supports

Providing services and support tailored to each individual's strengths, needs, preferences, facilitating the opportunity to achieve the outcomes they desire.



**IMPORTANT TO AND
IMPORTANT FOR AND THE
BALANCE BETWEEN THEM**

Important TO

What is important TO a person includes those things in life which help us to be satisfied, content, comforted, fulfilled, and happy.

It includes:

- People to be with/relationships
- Culture & Identity
- Purpose and Meaning
- Status and control
- Things to do and Places to go
- Rituals or routines
- Rhythm or pace of life
- Things to have

Important TO a Person

- Includes what matters the most to a person; their own definition of quality of life
- What is important TO a person includes only what people “say”:
 - with their words
 - with their behavior

When words and behavior are in conflict,
pay attention to the behavior and ask “why?”

Important FOR:



Health

- Prevention of illness
- Treatment of illness/medical conditions
- Promotion of wellness (e.g.: diet, exercise)

Safety

- Environment
- Well-being (physical and emotional)
- Free from Fear

Valued

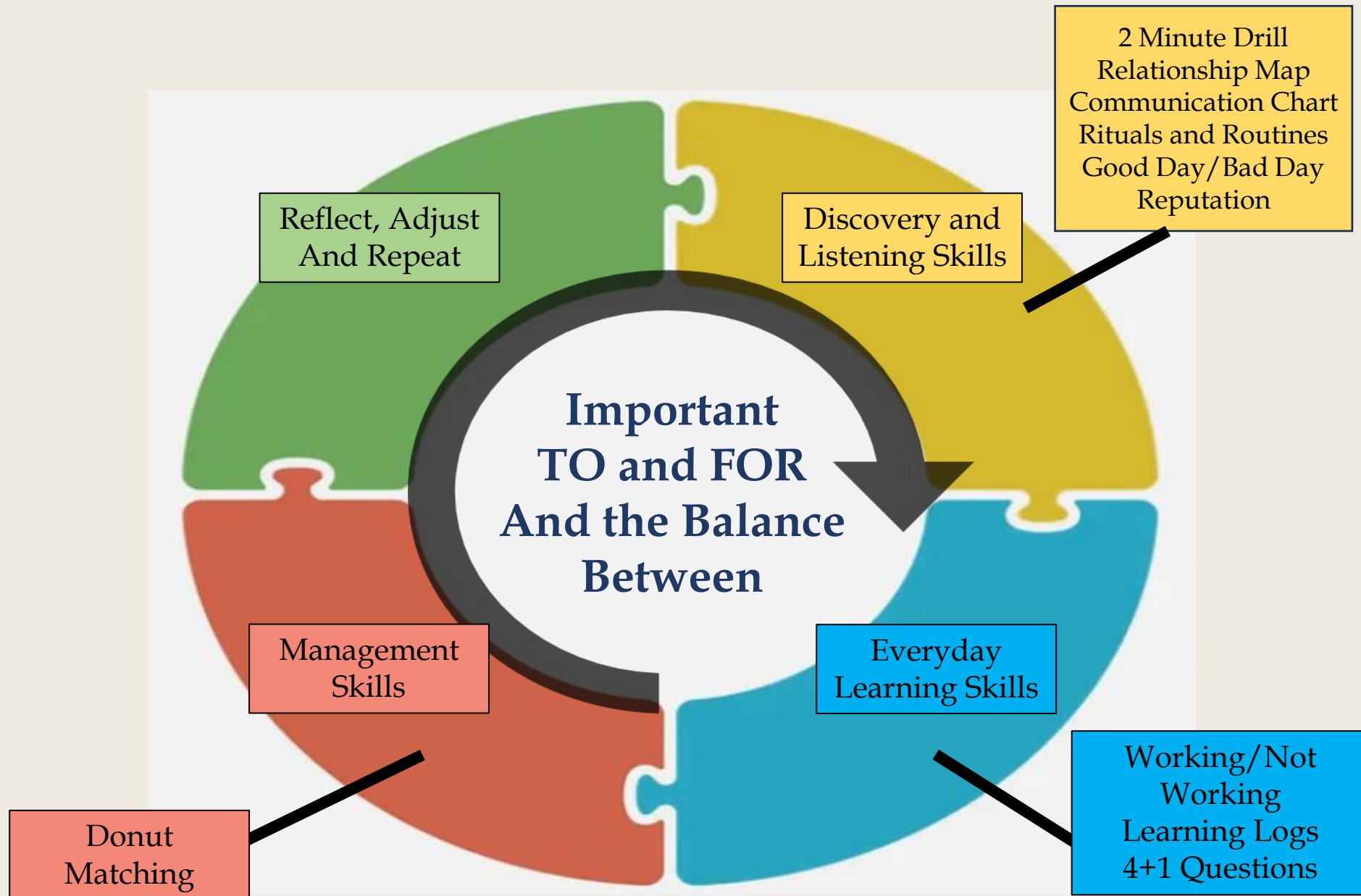
- Be valued
- Be a contributing member of their communities

Important To and For are Connected

- Important TO and Important FOR influence each other.
- It's not Important TO VS Important FOR. Both are important.
- No one does anything that is “Important FOR” them (willingly) unless a piece of it is “Important TO” them.

Balance is dynamic (changing) and always involves tradeoffs:

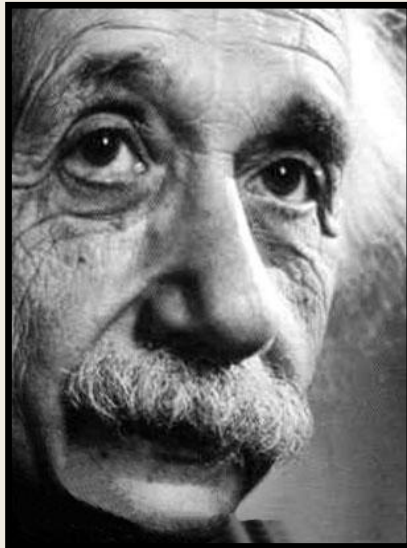
- Among the things that are “Important TO”
- Between Important TO and FOR.





**What you see
and/or hear
depends on
what you are
looking and
listening for**

Ask Yourself
“What do we know?”
Before asking
“What do we do?”

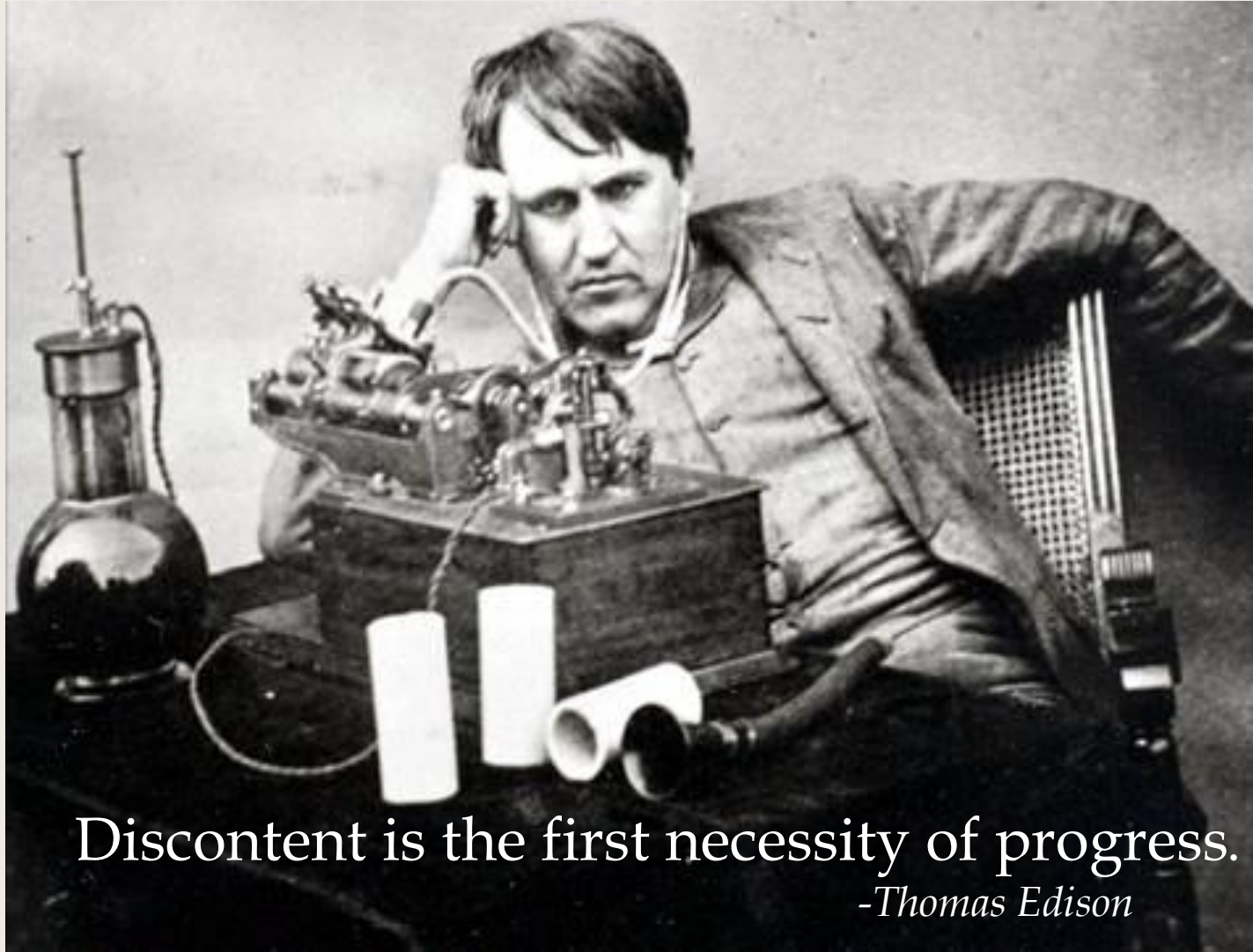


If I had an hour to save
the world, I'd spend 55
minutes defining the
problem.

~ Albert Einstein

Infographics





Optimistic Discontent

Requires hope based on trust that is created when there is:

- A history of acting on things that can be changed
- Honesty about those things that will take time to change
- Progress in acting on the things that take time

Where cynical discontent is dominant...

...trust must be created

Levels of Change

Level 1



Any changes that results in a positive difference in the lives of people who use services or in your own work life.

Level 2



Any changes an organization makes to its practices, structure or rules that result in positive differences in the lives of people.

Level 3



Any change in practice, structure and rules made at the system level. These changes have an effect on many organizations, and therefore many peoples' lives.

Changing our Language: Changes the Power

“Staff” (powerful) & “Individual” (not powerful) =Power **OVER**
OR

“Person to person” (equity and respect) =Power **WITH**



Learning about Support: Common Traps

Power OVER

- Assuming the person needs help
- You know best, making choices for a person without asking
- Answering questions for a person with you
- Bribing to get someone to do what you want
- Using shame or fear to manage behavior “Why would you do such a thing? ”
- People talking about the person as if they aren’t in the room
- Punishes the person for making mistakes

Power WITH

- Redirecting questions to the person when others ask you or someone else
- Ask don’t assume a person needs help
- Positive comments, helpful statements, and praise for actions “Wow, that is great work”
- Listening and asking “please tell me more” or “I am listening take your time”
- Promoting chances for making choices and decisions
- Asking what made it a bad day – paraphrase back “It’s hard when people misunderstand us”

Instead of This:	Use this:
"Let" or "Allow"	Support or Assist
Toileting or Toileted	Supported person to use the restroom
Non-verbal	Doesn't use words to speak, uses a communication device
Transported, outing, had a behavior	Gave a ride, went out for fun, having a bad day
My guys, my program	Use the person's name
Handicapped parking	Accessible parking
Fluids	Something to drink, be specific (tea, water, soda, juice etc.)
Wheelchair bound, non ambulatory	Uses a wheelchair
Special needs, special assistance	Tailored assistance, support
Stranger danger, Go Potty	Do you need to go to the bathroom, Do you know them?
"suffers from" or "victim of" suggests poor quality of life or powerlessness	"has (a disability)" or "is [blind/deaf/deafblind]"
The term "help" portrays persons with disabilities as helpless and dependent.	"Support" and "assistance" are more empowering

Choice and Balance

As we think about choice, we must acknowledge:

- All choice can be irresponsible (happy and hurt)
- And dictating lifestyle is unacceptable (alive and miserable)

Good support means finding the balance:

- Finding the balance can create conflict
- We all have a right to make choices, even bad choices

Choice has Boundaries for Everyone

- Imposed by society
- My values
- Ripple effect
- Resource Driven
- Risk involved



Decision Making: Types and Processes

- Informed Decision Making
- Supported Decision Making
- Substitute Decision Making

What decisions have you made in the past 12 month?

Maybe it was a big decision like:

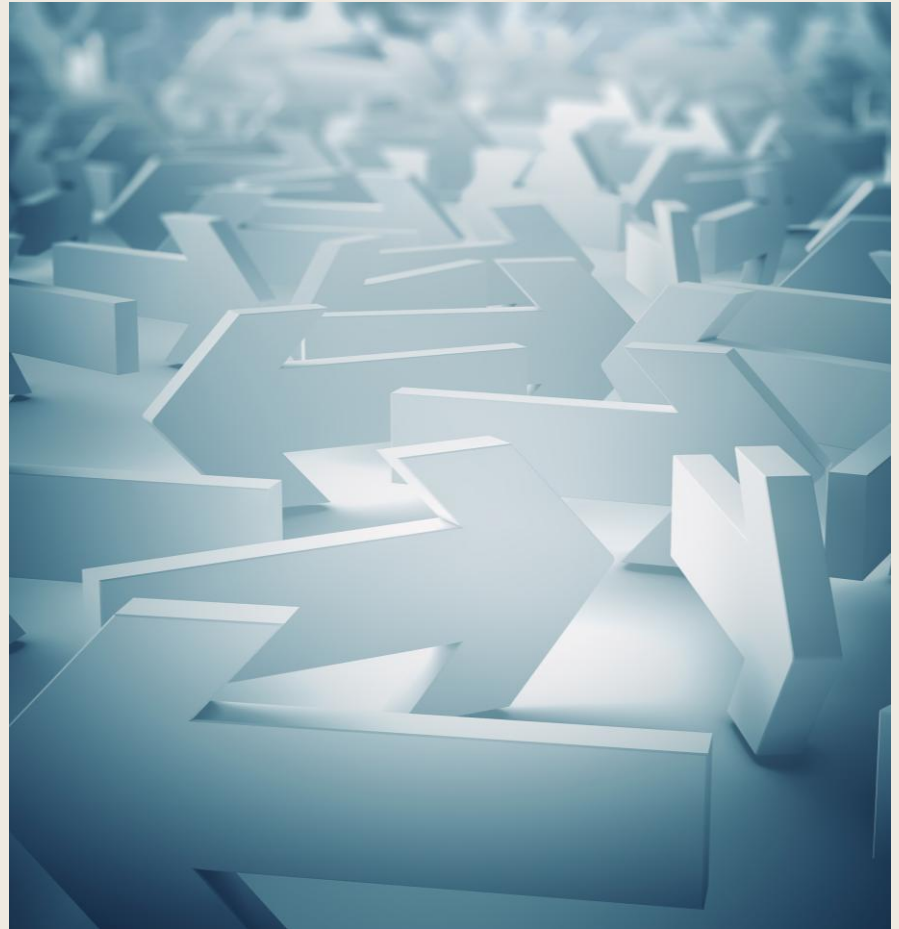
- Getting a new job
- Buying a new car
- Moving to a new home

Maybe it was a decision you went back and forth on:

- Switching banks
- Buying a TV

Maybe it was a decision you didn't even know you would have to make:

- Finding a new roommate
- Starting a new medicine



How did you go about making those decisions?

- Researched online
- Talked to a trusted friend or family member
- Made a list of pros and cons with a trusted person
- Got more information about your options
- Got advice from a professional or expert
- Talked to someone who has more experience than you
- Talked to someone who made the same or a similar decision recently

Informed Decision-Making

- A choice that you make
- Once you have all the information related to the decision topic
- Involves analyzing possible outcomes, benefits and risks associated with each option
- Deciding which choice is the best for you
 - You know what you want
 - You know what is possible
 - What is possible includes what is desirable
 - You know about any “trade-offs” (e.g., getting this keeps you from having that)

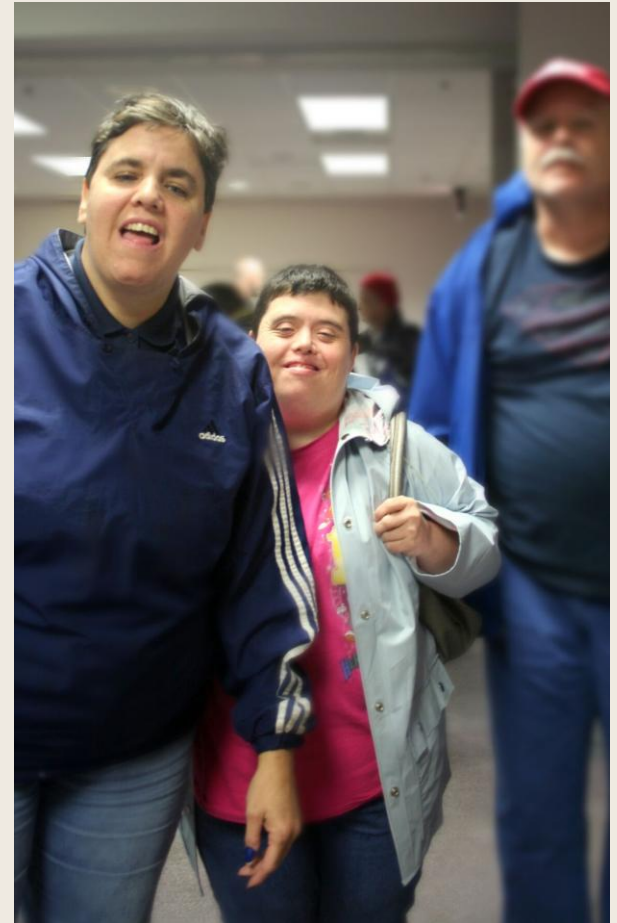


Substitute Decision-Making



What about when a person has a legal guardian?

- It is important that the guardian understands the difference in the roles of guardian and supporter.
- Guardians can be encouraged to participate in supported decision-making with the person.



Supported Decision-Making



What is Supported Decision-Making (SDM)?

- A process in which people make their own decisions with the assistance of a trusted person they select
- A method that empowers people to make their own informed decisions rather than someone else making decisions for them
- A tool that helps people receiving services and supports to exercise their right to self-determination

Who uses Supported Decision Making?

- People with Intellectual and Developmental Disabilities for whom decisions may be difficult to make autonomously
- People with mental health diagnoses who may be having difficulty making decisions
- People who are elderly who may need help making decisions
- We ALL do!

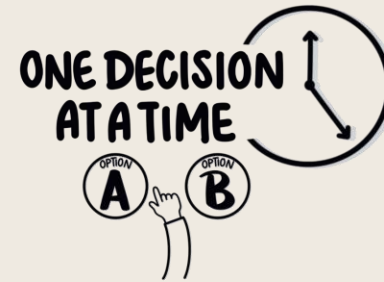


Principles of SDM



ASSUME
I CAN! 

UNDERSTAND
ME AND MY
PREFERENCES



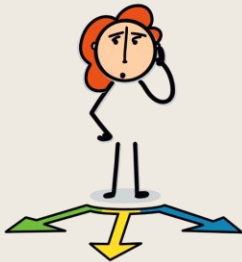
I CAN CHANGE
MY MIND

SUPPORTED DECISION MAKING PRINCIPLES



EXPLORE
ALL OPTIONS



IT'S UP TO ME TO
MAKE DECISIONS
ABOUT MY LIFE



EXPERIENCE
TO EXPLORE



UNDERSTAND THE
RIGHT ASSISTANCE
FOR ME



Who makes the ultimate decision?

**The
PERSON!**



Supporters Role

- Help people identify options.
- Provide information in a way that can be understood.
- Possibly assist in communicating to others.



Choice Includes

- Preference: What people like AND what they desire and dream
- Opportunity: An array of people to spend time with, things to do during that time, places to spend that time. Also includes being able to spend time by yourself
- Control: The authority to make use of an opportunity to satisfy a preference
- A balance of *Important To* and *Important For*

The Quality Of Choice Versus The Quantity

Quantity of choices
doesn't matter if none
of the choices are
desirable or connected
to what is important to
the person.



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Too many choices is also overwhelming.



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“...As the number of choices grows..., the negatives escalate until we become overloaded. At this point, choice no longer liberates but debilitates.” The Paradox of Choice, Barry Schwartz

Culture and Choice

- We also see (and process) choice through the lens of our culture
 - Those that support choice are challenged to understand and honor culture while navigating any conflicts that arise
- How choice is presented influences the choices that are made



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When there is a risk present . . .



As we think about risk

- Choice without boundaries can lead to harm
- Choice with too many boundaries leads to misery



The right to make bad choices has to be balanced against our obligations to address health and safety of the person and others

You Cannot Eliminate all Risks

- Some risks are just a part of life.
- There are risks that we create or contribute to by –
 - Not listening, or
 - Not understanding, or
 - Both
- (and some risks you just have to manage)
- Some risks cannot be supported and an alternative must be found.



Supported Decision Making in New York State



The Supported Decision-Making (SDM) law in New York was signed by Governor Hochul on July 26, 2022. On the 32nd anniversary of Americans with Disabilities Act (ADA).

"The commissioner of the Office for People with Developmental Disabilities shall promulgate within one year of the passage of this act the rules and regulations necessary to implement this article for adults who receive or are eligible to receive services that are operated, certified, funded or approved by the Office for People with Developmental Disabilities."

MHL Section 82.15 (a)

On August 20, more than 3 years after the law was signed by Governor Hochul, **THE REGS WERE PUBLISHED!**

90 days later, on November 18, 2025, Decision-Makers with SDMNY-facilitated SDMAAs are able to use those SDMAAs to require third parties to accept their decisions regardless of their disability.

AAIDD Recommendations:

"emphasiz[ing] that all people, inclusive of people with IDD, have a human and civil right to autonomy and self-determination."

What this Means

- Everyone over 18 who is not under guardianship is presumed to have capacity
- The Regulations recognize that a facilitated Supported Decision-Making Agreement (SDMA) now legally requires third parties to accept and act on that capacity
- There is no such legal obligation for those with informal SDMAs or who practice SDM with no written agreement;
- However, the statute and the Regulations recognize and encourage all forms of SDM including informal SDMAs;
- The unique provision of the New York statute is that legal recognition is not conferred unless there has been meaningful facilitation in accordance with the Regulations
- All SDMAs previously completed with SDMNY facilitation are covered by the statute and Regulations

PCT Resources

The Learning Community for Person Centered Practices

<https://tlcpcp.com>

PCP Resource Library

https://www.health.ny.gov/health_care/medicaid/redesign/person-centered_planning/index.htm

One-Page Descriptions

<https://onepageprofiles.wordpress.com/>

NYS OPWDD Person-Centered Planning Guidance

<https://opwdd.ny.gov/providers/person-centered-planning-and-community-inclusion>

HCBS Final Rule Transition

https://www.health.ny.gov/health_care/medicaid/redesign/home_community_based_settings.htm

nydohpcptraining.com/events

SDMNY Resources

Supported Decision-Making New York (sdmny)

[SDMNY – Supported Decision-Making New York](#)

Office for People With Developmental Disabilities (OPWDD)

SDM Pilot Program

[Supported Decision-Making Pilot Program | Office for People With Developmental Disabilities](#)

OPWDD Supported Decision-Making Regulation

[Supported Decision-Making Regulations](#)

AAIDD Inclusion Article

[Recommendations of the Consent and Decision-Making Strand](#)

[From the National Goals 2024 Conference](#)



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