

*Freeing Individuals to Live Their
Most Independent Lives*

InterHab

January 17, 2023



Hello!
It's great to be here!



30 years experience in the DD field...

- **Lead Medicaid Policy Developer** - Ohio Department of Developmental Disabilities (Dep Director)
- **Managed Care Contract Manager** – Ohio Department of Medicaid
- **Section Chief HomeCare Waiver Clinical Services** – Ohio Department of Medicaid
 - Created Ohio's Private Duty Nursing Program
- **Director of Vocational Rehabilitation** – Licking/Knox Goodwill
- **ICF/IDD Administrator/Director** – 2 Agencies
- **Director of Residential Facilities Waiver Homes**
- **Metropolitan Housing Director**
- **Director of Services and Supports Administrator** – 2 County Boards of Developmental Disabilities
- **Project Manager for Ohio Department of Medicaid** - MMIS Managed Care System
- **Director of Provider Oversight - Ohio Medicaid HomeCare Waiver** – Public Consulting Group
- **ASI – Fiscal Management Services** in Missouri and Georgia
- **Advocacy & Protective Services (APSI)** Representative (Guardian Agency)
- **Community Employment Coordinator**
- **County Case Manager**
- **Activity Therapist** – Developmental Center



Sara Sherman Consulting:

- Nebraska Division of Developmental Disabilities
- Missouri Division of Developmental Disabilities
- Ohio Department of Developmental Disabilities
- Maryland Division of Disabilities Administration
- University of Missouri Kansas City
- Optum/United HealthCare
- Ohio Provider Resource Association (OPRA)
- Pennsylvania Advocacy and Resources for Autism and Intellectual Disability (PAR)
- Texas Provider Association – PACTX
- Kansas Provider Association – Interhab
- Arkansas Provider Association - DDPA
- Direct Service Providers and County Boards
- SafeinHome
- Norwich Consulting
- Quillo



Services:

- Training:
 - Frontline Supervisor Training
 - Ongoing Training Techniques
 - How to Create a Year's Worth of Activities from Just a Few Interests
 - How to Create an Internal Compliance Plan
 - Supported Decision Making: Freeing Individuals to Live their Most Productive Lives
 - Healthy Meal Planning for DSPs and the Individuals They Support
- Internal Operations Reboot
- Request for Proposal Response
- Strategic Planning
- Research
- Compliance/System Audits
- Customized Training
- Plans of Correction
- Workgroup Facilitation
- Etc.

www.ProviderPowerMoves.com



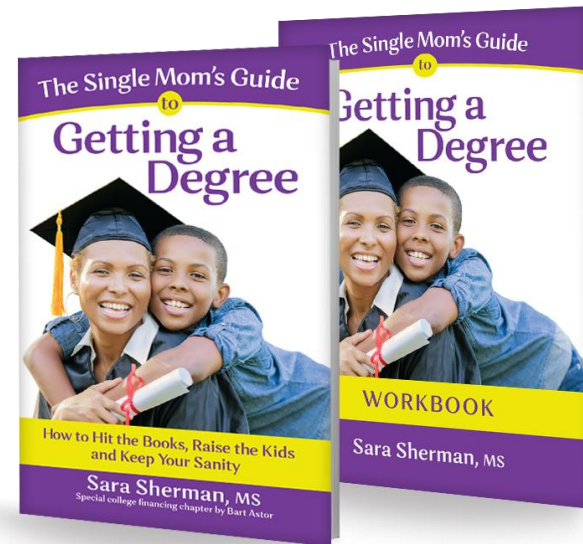
Other Projects...



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Today you'll learn:

- Overview of history of DD service
- How those outside the system make decisions
- How persons with disabilities are asked to make decisions
- How to bridge the Decision-Making Gap
- When decisions are made
- The elements of informed consent
- The Interdisciplinary Team's role
- How to document decision-making



Housekeeping:

- Ask questions at any time
- We'll take a break half-way through-ish
- You will receive a copy of the slides 😊
- Contact me at any time
sara@providerpowermoves.com



So....

Why do we have a DD system?



What does the “system” seek to accomplish?

- Independence
- Choice
- Control
- Integration
- Good Life
- Self-sufficiency
- Empowerment

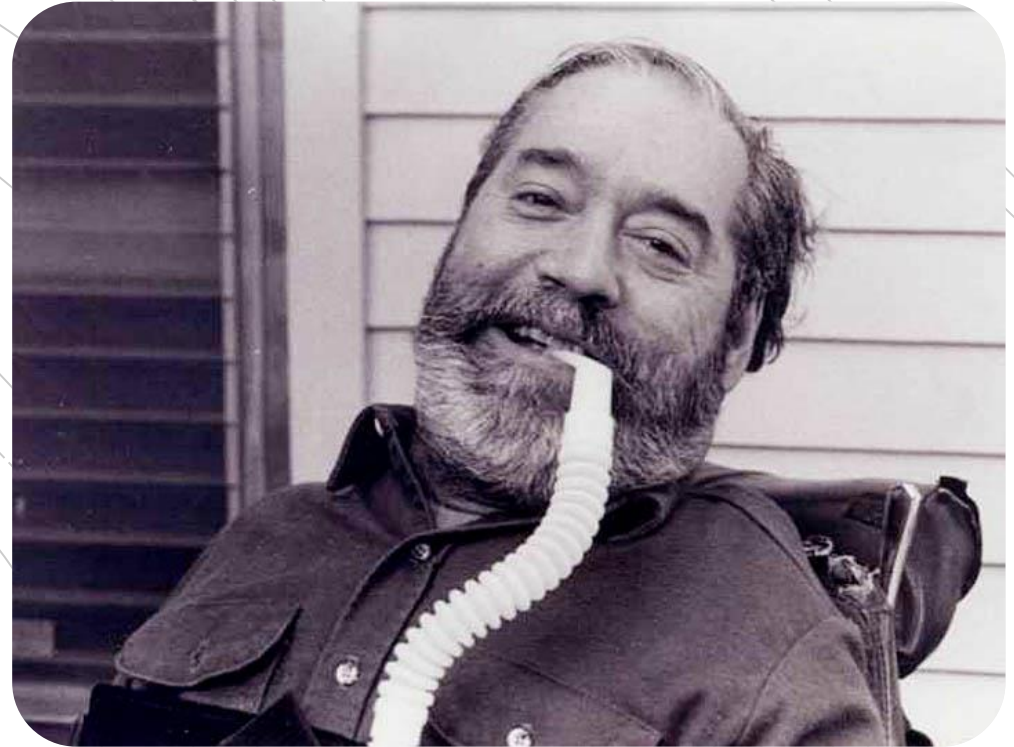


What do people with disabilities
tell us they want from us?



"People come to you and expect to be told what to do. It's your job to place that power back into their hands. You are there to help them find out what they want to do – not to decide what you think is best for them."

~Edward Roberts
Pioneer Self-Advocate



The background of the slide features a series of thin, curved lines in shades of gray, creating a sense of motion and depth. These lines are more prominent on the left side and fade towards the right.

35,000 Decisions
Each Day

(Psychology Today)

- This power give back happens at the DSP level
- In every interaction
- At every decision point throughout the day

DSPs need to
know...

How to help individuals:

- Expand their independence
- Develop decision making skills
- End unnecessary dependence on staff
- Celebrate success
- Work through typical trials and tribulations
- Gain confidence
- And more!

How's it going where you are?



What used to happen in DDLand?



It's been a long road to here...



1800 - 1950

1800

- “Poor houses”/wealthy kept their children at home
- Warning out or Passing on

1820

- As industrialization increased, people began speaking out on the treatment of those with disabilities

1820

- “Idiot” – incapable of thinking
- “Imbecile” – “almost perfect”

Ostracized



1850

- Europe begins schools for those with disabilities – overcrowding leads to abuse and neglect
- Therapy as a form of treatment; Montessori schools

1850

- Began to value all humans including those with disabilities
- Dorothea Dix lobbied Congress for better treatment – **Pres. Pierce vetoed this initiative**

1850

- More schools, training theories, focus on independence
- Government begins to count people with disabilities in the census



Civil War

- Schools closed but the demand for schools increased

1870

- Schools become asylums - “Dehumanization”
- Economic self-sufficiency of asylums

1890

- Separation of people by disability type; people with disabilities were considered a burden and counted in the same group as prostitutes, vagrants, etc.

1900

- Fear and suspicion leads to more institutions and deplorable conditions

Invisible



1913

- Binet IQ test given to immigrants at Ellis Island "79% of the Italians, 80% of the Hungarians, 83% of Jews, and 87% of the Russians are feeble-minded."

1927

- Perception that **having a disability was immoral and genetic**, forced sterilization (Bible idea: Whose fault is it? Who err'd?)

1928

- Special Education starts in large cities

1930

- Hitler begins to murder people with disabilities as hygienic cleansing

1948

- 1948, Albert Deutsch wrote Shame of the States and the result was the invisible become visible again

Reappearing



Reawakening: 1950 to 1980 The Parent's Movement

1936

- **Cleveland Ohio establishes first CBDD – 169 Board because it was House Bill 169 that approved CBs**
- 88 such groups with a membership of 19,300 persons had been established in 19 states by 1950

1947

- The American Association on Mental Deficiency (AAMD) held its annual convention in St. Paul, Minnesota.

1950

- Governor of MN declares children with disabilities have rights
- ARC began in 1953

1955

- Congress gets involved and begins to pass laws that support people with disabilities

Visible



1960

- Institutions admissions increase and follow medical model - bathrooms had no doors for ease in monitoring, furnishings are designed for cleaning, etc.; residents were patients; disability was incurable

1965

- In 1964, the per diem rate for a person living in an institution was \$5.57, about one-half the amount devoted to tending animals in a zoo.
- Bobby Kennedy gets involved – Federal aid and “Acts” are approved

1974

- Federal government pledges to move 1/3 of the 200,000 in institutions, into the community
- “Developmental disability” becomes a term



So far...

Not a big need for people with developmental disabilities to make decisions.

It is certainly not occurring to anyone to really TEACH decision-making.



1980's and 1990's

New laws in:

- Education of children with disabilities
- Employment for those with disabilities
- Technology for those with disabilities
- The Americans with Disabilities Act (ADA)
- Home ownership for those with disabilities

1983 – The first HCBS Waiver in the U.S.



The focus was on Rights

Some talk of Responsibilities



June 22, 1999 - *Olmstead v. L.C.*



1st...

Institutional placement for people who can benefit from and handle community settings **perpetuates the idea that the people being isolated are incapable or unworthy of participating in community life.**



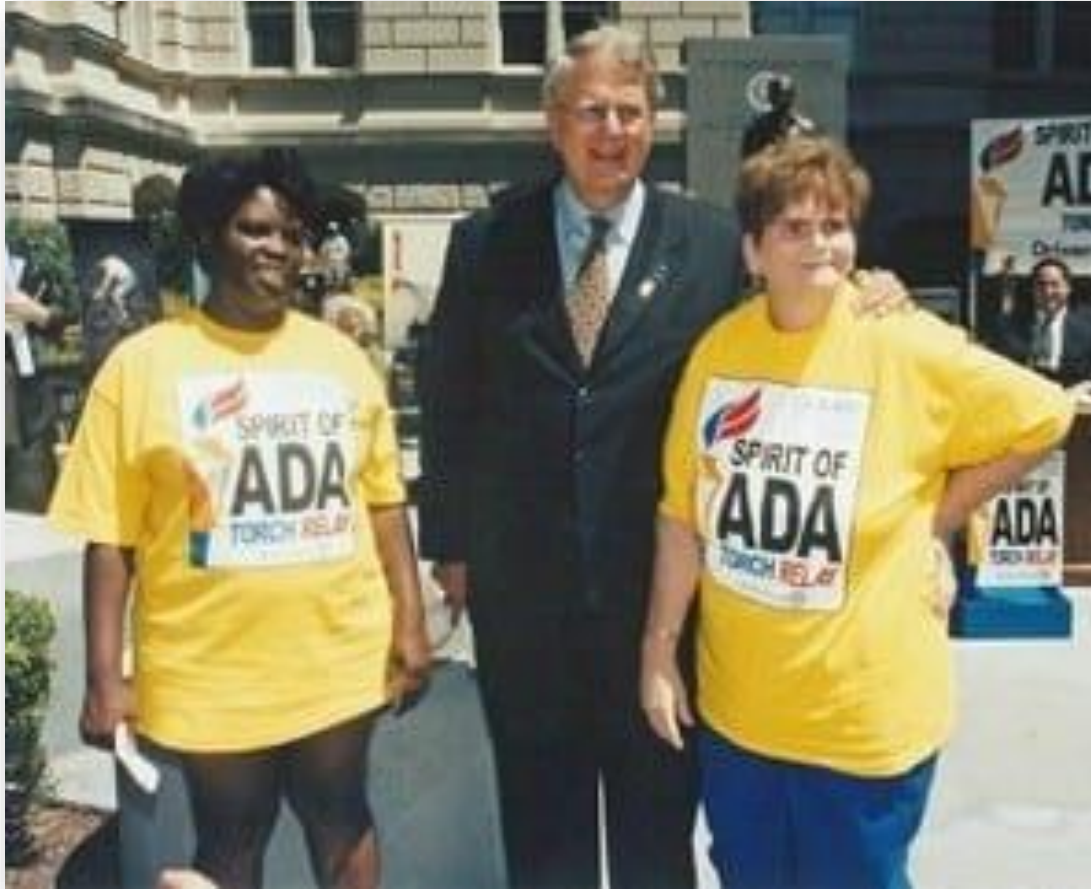
2nd...

That confinement in an institution severely diminishes the every day activity of those individuals.
Including their ability to:



**maintain family relations,
have social contacts,
have employment options,
economic independence,
educational advancement,
and experience cultural enrichment.**











CharlieBliss discussing Elaine Wilson transformation



Watch later



Share



MORE VIDEOS

Play (k)



0:00 / 2:49



YouTube



All of a sudden...

- We are asking people who have never had a chance to make decisions
- People who have no frame of reference for decision-making
- People who spent years having “compliance goals”

*What they want to do, and how and where
they want to do it*



How can people possibly tell us?



Think about how you make decisions

- Gather information
- Evaluate pros and cons
- Talk it over with trusted people in your circle
- Talk to experts
- Talk to people who have had to make the same decision
- Take your time
- Worry and fret
- Talk it over again
- Move forward with confidence/Move forward with trepidation



What do people say about your decision-making?

- Are you slow...too fast?
- Do you consult with lots of people?
- Do you talk about it over and over?
- Do you prefer to go away and ponder alone?
- What is your level of commitment to your decision?
- Do you get started in your new direction, and then change your mind?



*Do other people think you are a
good decision-maker?*



Think about other people in your life.
Spouse, parents, kids, friends.

How do *they* make decisions? Just like
you, or differently?



Who is the better decision-maker?

How do you decide?



Typically...the formula for
“*good decision-making*” is...

The most positive outcomes
Time



Or you might think of it as...

The fewest mistakes
Time





Self-Help Industry...

\$11 Billion Dollars in 2019

\$13.5 Billion by 2022



How many of you...

- Read self-help books?
- Talk over problems/challenges/etc. with a friend or family member?
- Are buoyed by your faith?
- Use inspirational quotes?
- Meditate?
- Go to therapy?
- Value alone time to ponder life?
- Grow and change as a result of the above?



Those we serve often don't have the same tools



We need to provide those tools for them



And...

If we think past decisions were not “good” decisions

We pull back on their ability and authority to make decisions

We don't tend to increase our support of decision-making



National Core Indicators Data Brief on Guardianship

April 2019

Respondents with guardians are less likely to:

- Live in their own homes or apartments and are more likely to live in group homes
- Be involved in making choices about their lives
- Be included in their community
- Have their rights respected
- Have community jobs or service plans with this goal
- Be supported to communicate with friends
- Be able to go on dates
- Be married



Preventive Care

- Women age 40+ with guardians are significantly less likely to have had a mammogram in the past two years than those without guardianship
- Women 21+ with guardians are significantly less likely to have had a pap test in the past three years than those without guardianship

Behavior Challenges

- Respondents with guardians are significantly more likely to take medications for behavior challenges than those without guardianship
- Respondents with guardians are significantly more likely to have a behavior plan than those without guardianship.




At the same time we recognize...



the most valuable
thing you can
make is a mistake.
you can't learn
anything from
being perfect.

adam osborne



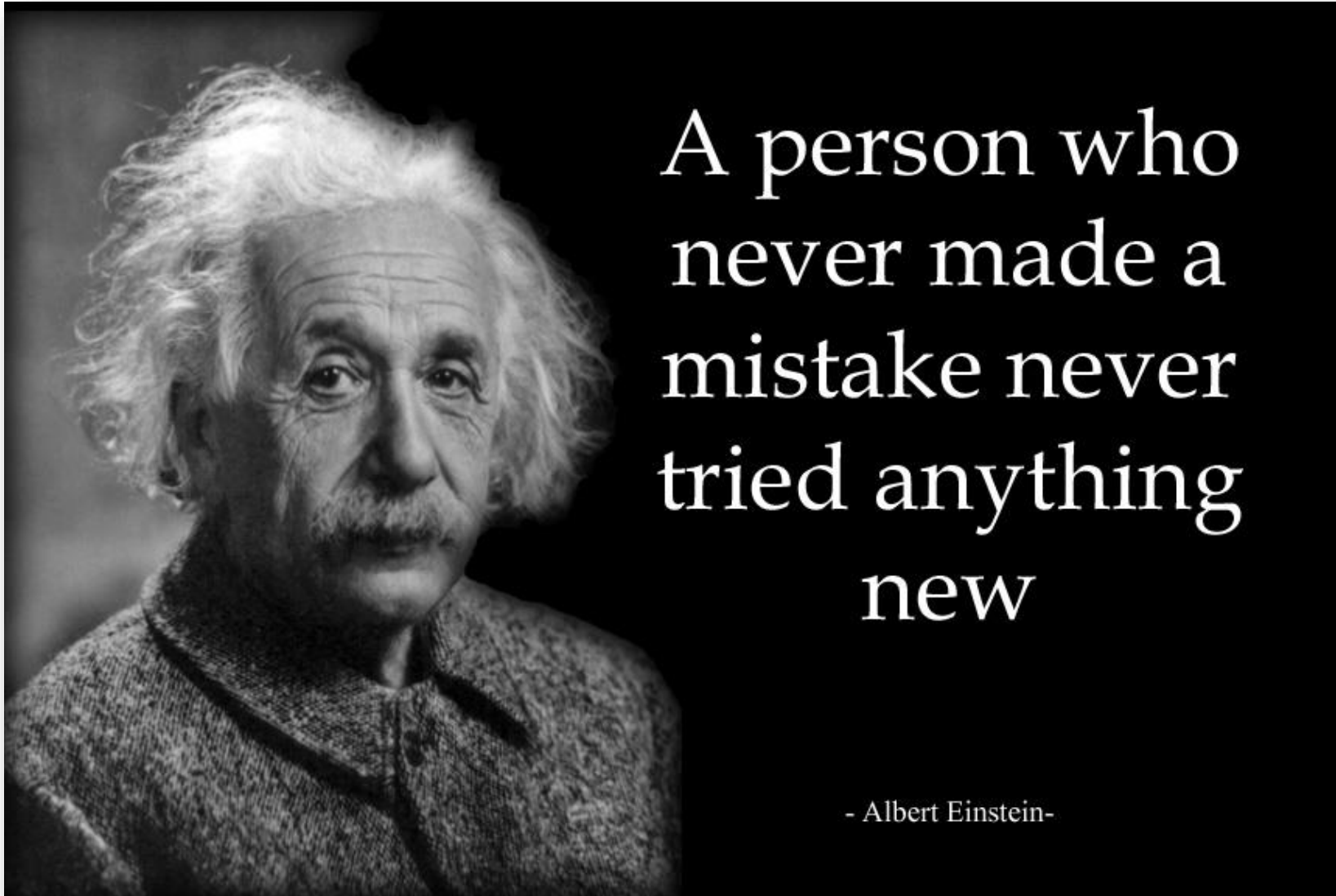


Mistakes are the stepping
stones to success.

John C. Maxwell

“quotefancy”







“Mistakes are
part of the
dues one pays
for a full life.”

Sophia Loren



Remember that
life's greatest
lessons are usually
learned at the
worst times and
from the worst
mistakes.





**I've never made a mistake.
I've only learned from
experience.**

Thomas A. Edison

EVERYDAY **POWER**



Basically...

*You gotta have experiences...
to learn from them.*



Foundational Principles of Self-Direction

- Individuals have the right to make decisions
- Individuals have the right to take part in decision-making process
- Individuals may need support to make decisions



Supporting decision-making (SDM) means:

- Help to understand
- Space to ask questions
- Provide explanations in a way that can be understood
- Communicate decisions to others
- Individualized



Self-Determination creates:

- Increased Independence
- Increased Integration
- Increased Health
- Increased Recognition and Resistance of Abuse



How do we want people to feel?

- Empowered
- Free
- Seen
- Heard
- Independent
- That they have choice
- That they have control
- That they are in charge of their destiny
- That they matter
- That they are the same as everyone else
- That they are respected



Think about how you make decisions

- Gather information
- Evaluate pros and cons
- Talk it over with trusted people in your circle
- Talk to experts
- Talk to people who have had to make the same decision
- Take your time
- Worry and fret
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- Move forward with confidence/Move forward with trepidation



How do we ask people with disabilities to make decisions?

- Do we go over the pros and cons with them?
- Do we make sure they understand the consequences of their decisions?
- Do we help them understand that they can change their mind?
- Do we help them research?
- Do we give them space to decide?
- Do we help them find friends and family to talk to?
- Do we give them plenty of time to hash and rehash and finally decide?



What are the differences?

What's different about the way we make decisions, and the way we ask those who receive services to make decision?



At every interaction:

Your job is to give back to the individuals you serve the power to run their own lives.

And the information they need in order to do that successfully.



Why do we struggle here?



We struggle to allow people room to make decisions in their lives because:

- We are responsible for health and safety
- We recognize those we serve are vulnerable and it is our job to protect them
- We are afraid they won't understand
- We are afraid they will get hurt
- We are afraid they will be sad or disappointed
- We have so much personal baggage around decision-making; and around making mistakes – and we project



*We project our concerns
and our values*



Also because...

- We don't do enough preparing
- We don't have time to wait for the decision
- We don't have time to teach how to make the decision
- We don't support people to practice making decisions
- We don't help people analyze the decisions they have made
- We don't remind people of times they made decisions they were happy with
- We don't ask people how they came to be where they are in life
- We aren't comfortable walking people through the emotion of making decisions



Can't achieve it...

Until you define it



What if they make the “wrong”
decision?



We have to marry our wants, their wants,
and our responsibilities

And there's the rub...



What are our responsibilities as providers and team members?

- Support choice - *Empower*
- Ensure health and welfare
- Support dreams and desires – *Explore and Plan*
- Coordinator needed services – *Integrated Supports and Services*
- Facilitate planning - *Engagement*
- Establish service budgets



At every interaction:

Our job is to give back to the individuals you serve
the power to run their own lives.

And to provide the information they need in
order to utilize that power successfully.

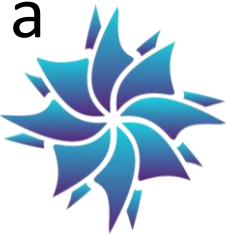


Support Decision Making



Balancing Rights versus Decision-Making

- People have the right to make decisions
- People have the right to make a decision that doesn't result in the outcome that was intended
- Rights restrictions should only be applied when there is no other way to support the person, and in accordance with the regulations
- The Team is responsible for creating a safe decision-making environment without restricting rights
- The stronger the decision-making process/support, the more access a person has to their rights.



Every decision must be
an *Informed Consent Decision...*



Informed Consent means....

- Voluntary
- Person has actual Choices
- Understands Consequences of each Choice

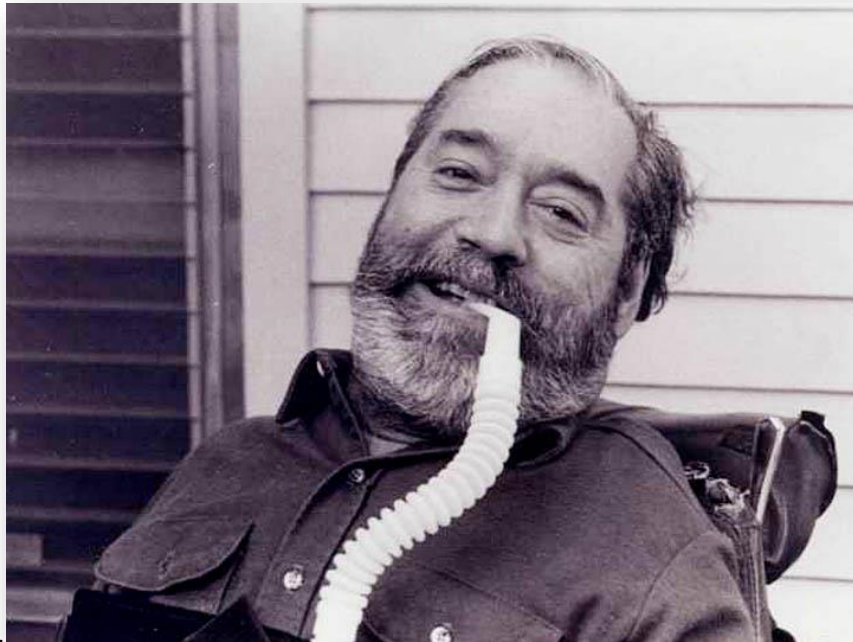


How do you make sure someone understands their choices and consequences?



Remember...

"People come to you and expect to be told what to do. It's your job to place that power back into their hands. You are there to help them find out what they want to do – not to decide what you think is best for them."



Edward Roberts, pioneer self-advocate



What is key here?



*“...place that power back
into their hands.”*



What are our responsibilities as service providers?

- Support choice
- Ensure health and welfare
- Support dreams and desires
- Identify needed services
- Participate in planning
- Support our people to participate in planning
- Implement plans
- Monitor and adjust for progress
- Track service delivery and response
- Contribute to the assessment process



What does this look like?



“Old way”:

- We tell people what to do.
- We share a lot about ourselves.
- We “discuss” people as if they aren’t there. Very personal information is discussed. Bathroom habits, sexual information, embarrassing moments.
- Individual hears others discuss him or her and may not understand what is happening. If asked, the individual is inclined to agree with statements made due to lack of understanding, fear to speak up, an understanding that there is no point in speaking up.
- Sometimes we talk to people about their hopes, dreams, and desires. And then we do nothing, or very little.
- We have an air of “we know best”. (Patriarchal)
- We remind people what they cannot do. “Remember...”



New Way:

- We come to serve
- We follow up
- We push ourselves to be creative
- We keep our word
- We provide options
- We encourage trying new things
- We support mind changing
- We hand people the power to learn how to run their own lives, how to make decisions, and how to live their highest purpose with the greatest joy
- Other?



How to handle “Bad decisions”



Reframe “Bad Decision”:

unpleasant choice
error
fumble
miscalculation
misjudgment
misstep
mistake
blooper

blunder
gaffe
howler
screw-up
slip-up
Oops!
do over
practice round



Often times we think of bad decisions as:

- Not in line with *our* values
- Mistakes *we believe we've* already made
- Things *we believe* are dangerous

We often come to our conclusions about their decisions with a very clear personal bias



Ask...

What can be learned from this experience?



Overarching Goal:

Help people move from...

Dependence on the system

To...

Use of the system with dependence on self
and natural supports



Paradigm Shift

From: What can we do?

To: What will it take?



What *DOES* it take?



System support

- Agency policy
- Staff support
- Supervision lines

Intention and focus



What if we thought that those who have made the most “mistakes” are especially well-positioned to create a rich and fulfilling life?



System support

Team Level:

- Discuss levels of support needed
- Strengths and ways to increase decision-making skills
- How to practice decision-making
- How to increase decision-making opportunities
- How to increase decision-making confidence
- *Evaluate risk level and needed safeguards*



Benefit to you...

- Company Culture
- Selling point to use in recruiting employees
- Selling point to use when interviewing with individuals
- Better team involvement
- More on target ISPs



Guidelines for interacting:

- Address the individual at all times
- Give the individual time to ponder, reflect, process, and ask questions
- Maintain a neutral tone
- Ask...Don't tell
- Ask the individual to repeat information, to explain what they understand, to explain the next steps given the information, offer scenarios for them to think through



Guidelines for interacting:

- Table decisions as necessary, and break down decisions into smaller pieces wherever necessary
- Create a space that allows the individual to object and/or change their mind
- Help the individual to express their opinions, desires, wants
- Keep private topics...private



Phrases to try...

- Tell me about...
- Help me understand...
- How do you feel about...
- If you do that, what will happen next?
- What would you like to see happen?
- How will that help you _____?
- Is there anything else you could try?
- You said you wanted to _____, how will doing _____ get you there?
- If I weren't here, what would you do?
- Why do you think _____ didn't work? How can you change that part?



After a conversation:

- Follow up with the individual to see how they feel about the decisions made in the conversation
- Do they still understand the conversations in the meetings
- When asked again, does the individual make the same decision/have the same opinion. If not, why not?
- How did it feel to the individual to participate in the conversation in that way? What does the individual think he/she needs to get better at/understand better when conversing/problem solving/making decisions.



Train and Monitor Decision-Making Support

- Train the concept
- Retrain the concept
- Model the concept
- Train to document on the concept
- Evaluation performance on the concept
- Reward implementation of the concept



Training for DSPs

- Train DSPs that is how services are delivered
 - Case study – use in house stories, be sure to include success stories
 - Practice – role play, question and answer
- Goals
 - Person decides as much as possible, and still gets their services in
 - Person gets better and better at the decision-making process



Training for Supervisors

- **Goals**

- Person decides as much as possible, and still gets their services in
- Person gets better and better at the decision-making process
- Model this behavior

- **Look for and Reinforce**

- Facilitated conversation
- Staff and individual successes
- Documentation



Professional Boundary Concerns:

- Staff are too close
- Staff get to know people in the wrong way
- Staff create a “best friend” scenario

Comes from an unclear definition of their role



Remedy

- Staff become a Coach
- Staff become an Empowerer
- Staff become a Facilitator

The focus simply shifts



Celebrate wins for Individuals

- Micro decisions
- Macro decisions
- New understanding of decision-making
- New understanding of self
- New items for “What I don’t want to do, feel, experience, try, etc.”
- New items for “What I want to do again, what made me feel happy, successful, content, independent, confident, connected, etc.”



Celebrate wins for Staff

- New ways to present information
- New ways to support in decision-making
- Helping someone to learn new skills, experiences, new dislikes, new confidence, increase generalization
- Celebrations of trying, learning (mistakes)
- Celebrations of victories



Agency Processes

- Have a formal process to share accomplishments
- Take decision-making insights and progress to the team
- Create a company culture around supported decision-making



What if you can't convince the person?

- Assess risk
- Assess understanding of consequences
- Prepare team, staff, etc., for how to support the person



Sometimes...

People just aren't
ready yet



6 Steps to assess Risk

1. Identify the risks – what are the risks?
2. Analyze the risk – why are the risks there?
3. Determine the level of risk – Slight to severe, and why so?
4. Who might be hurt, and to what degree?
5. Treat/Mitigate the risk – what can you put into place to lessen the risk?
6. Monitor the risk – as the person moves forward, is the risk staying the same, lessening, getting worse?



Key Elements of supporting decision-making

- Ongoing
- Fun!
- Teaching people how to make decisions
- Increases freedom
- Increases confidence
- Increases self-empowerment
- Increases self-understanding
- Expands understanding of the world
- Creates a great frame of reference
- Helping people to be their full and best self



Document!!

You don't want all this good stuff to get missed!

- What issues came up
- What choices were made
- What points were considered
- What the person liked/didn't like
- Who they talked too
- Challenges, concerns, barriers
- Any revelations, insights, surprises, new skills
- Follow up needed? Where are things now?
- Tell the story



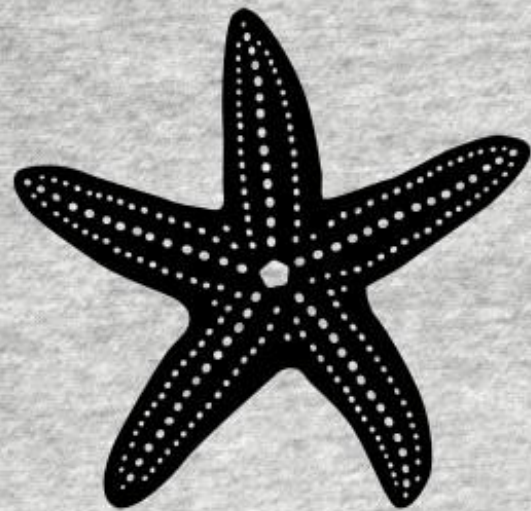
Don't Panic!!



Just try...



...it matters
to this one.



It's been said...

“People won’t remember what you say, they will remember how you made them feel.”

~Maya Angelou



It takes time...



The wonderful thing about our field is that...



Progress counts



Person-Centered Planning



Agency-Centered Planning



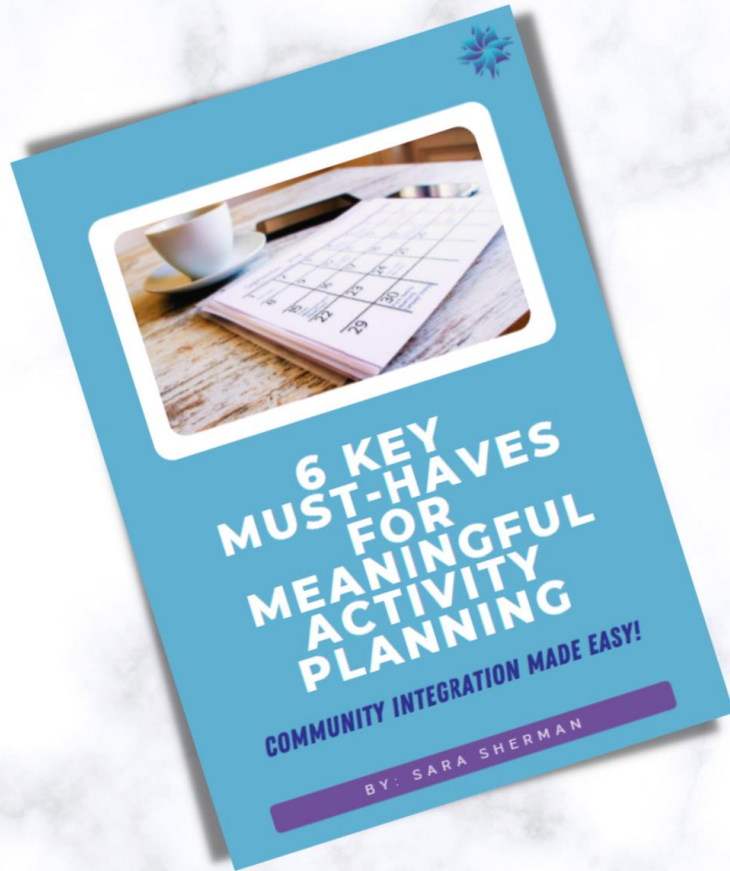


Questions?

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