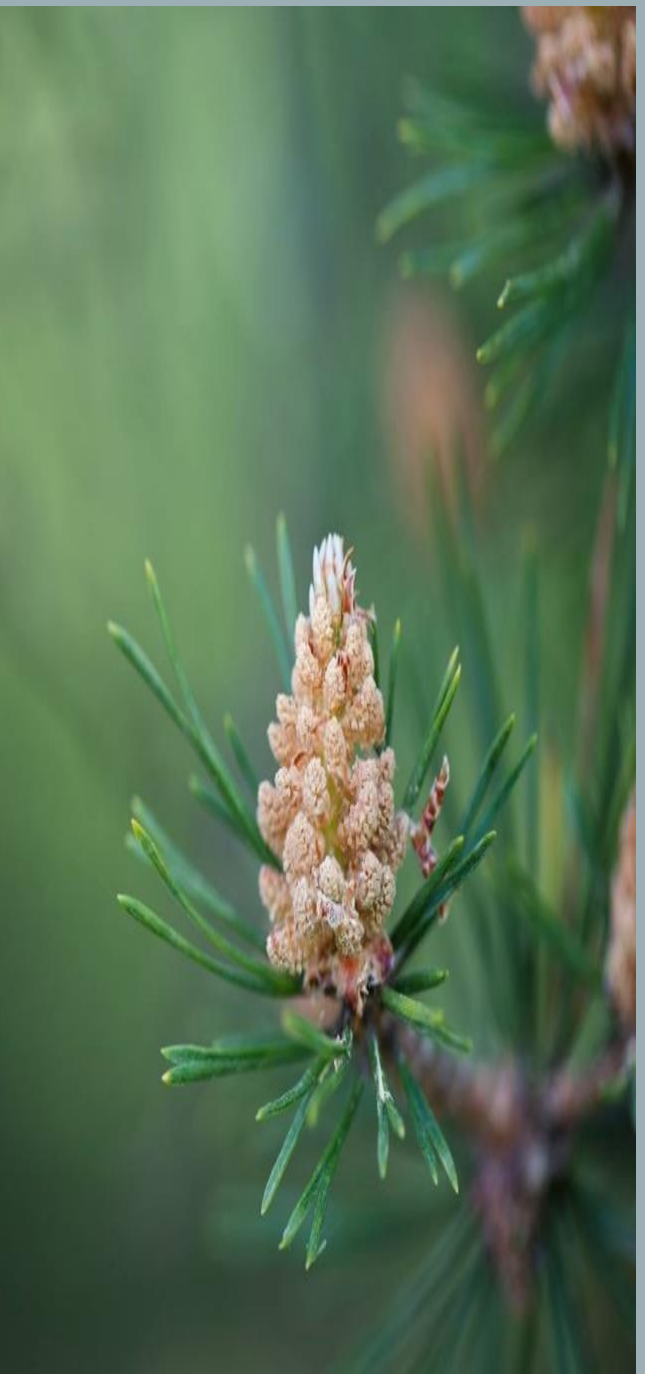

“ADVOCATING THROUGH HEALTHCARE FOR INDIVIDUALS WITH I/DD”

Continuum of Care Project

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OBJECTIVES: WHAT ARE THE TAKE AWAYS AND WHAT WE WILL DISCUSS:

Introspection- What is in your advocacy toolbox

NM Uniform Healthcare Decisions Act & Capacity (determinant)

Categories of Decision makers – Supporting Decision-Making

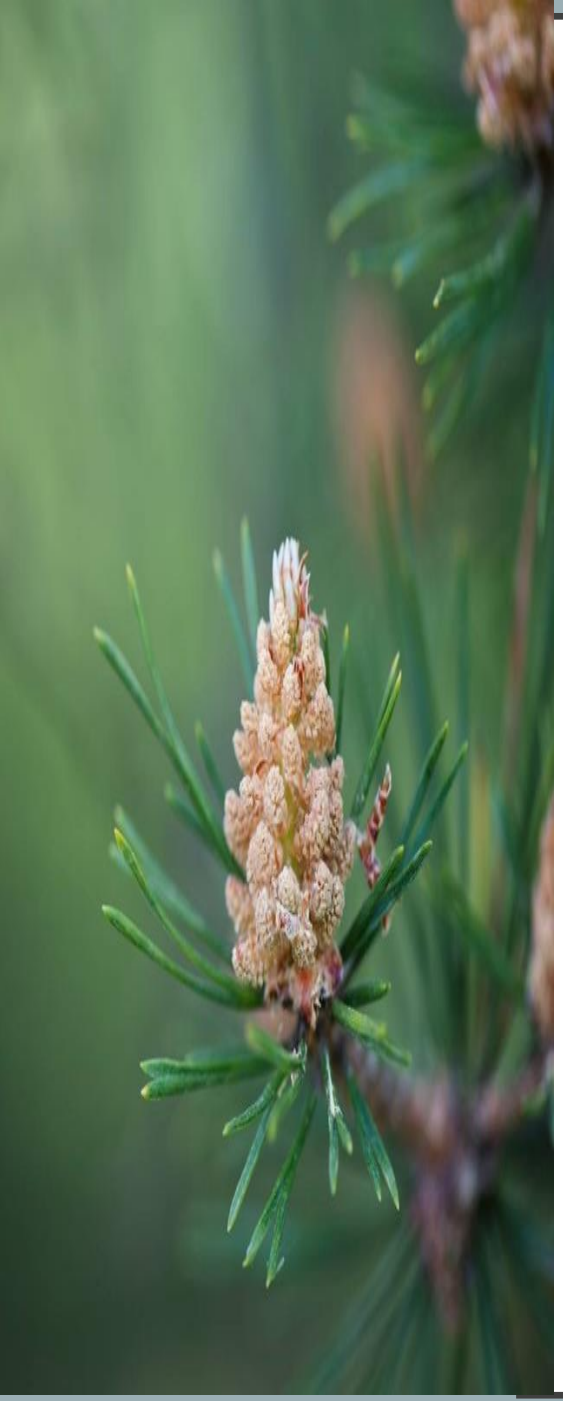
P.A.R.T.S: Planning, Advocating, Resources, Transition, Support

Meetings & Processes -DDSD forms to capture concepts/discussion

Vignettes & Scenarios – groups to share perspectives

Assessing the Needs during the life span – youth to seniors– expanding your Toolbox to keep in step

Navigating a path, tracking for continual advocacy and support



YOU CAN'T GIVE WHAT YOU DON'T HAVE

Start with yourself by examine any biases, thoughts, philosophy and influence regarding your approach when advocating for I/DD patients

Do you have your healthcare & paperwork in order? If you do, then you can lead; if you don't... how well do you think you can help I/DD patients with theirs? Better Fake it to you make it.

Getting familiar with Standards, policies, procedures, etc.- use them as a guide, a foundation, governing factor

Respecting cultures, seeing individuals as a whole person and not their symptoms, honoring their values (if known). This above all, to thine ownself be true...

WHAT'S COMING DOWN THE PIKE

- More minors/ youngsters are allocated on the waivers
- More individuals with I/DD are living longer
- More individuals w/IDD are experiencing the same co-morbidities as the rest of the population- just in different degrees

What's coming down the Pike

- Supported Decision Making – passed through legislature and active
- More Research includes I/DD population
- Laws of Guardianship Courts toughening up & Status Review
- Bill of Rights- supports
- Elizabeth Whitefield End of Life option; and understanding relief from terminal illness

BE IN THE KNOW…

- **Practical Tips**
- Know the individual's diagnoses, chronic conditions; treatments, etc.
- Confirm who are the clinicians/clinics that regularly treat the individual
- Read the individuals' most current Service Plan, Healthcare plans, therapeutic plans…
- Let's look at how to make the most of visiting the doctors, clinics, specialty clinics
- Assist by preparing the individual for the doctor's appointment- Including asking about why the appointment was made and if the individual knows why; jot down any questions, symptoms, meds, etc. to address at the appointment; ask that follow up information be in a form that the individual can comprehend.

BE IN THE KNOW…

- **Practical Tips**
- Request for a longer appointment session if needed when making the appointment
- Utilize Patient Portals, summaries, create medical journals (e.g. schoolbook tablets) to capture what was or will be discussed
- Ascertain who, if anyone, will accompany the individual to the appointment; & do they have the Necessary paperwork to bring to appt.
- Tap into Care Coordination with the MCO's Care Coordinator
- Look into Station MD when there is a situation that could lead to a hospital visit

P.A.R.T.S

PLANNING

ADVOCATING

RESOURCES

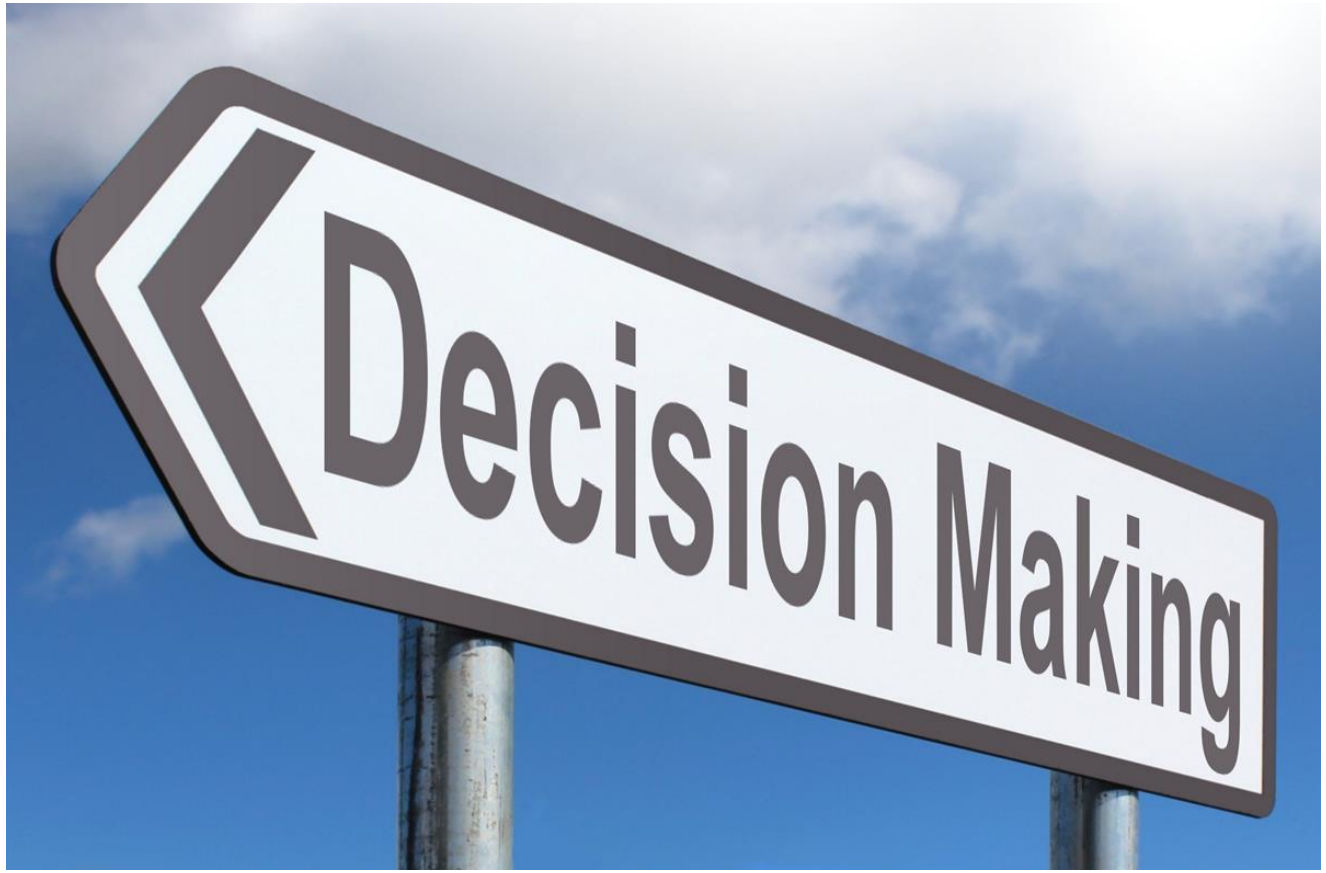
TRANSITIONING

SUPPORT

AUTHORIZED HEALTHCARE DECISION MAKER

NM UNIFORM HEALTHCARE DECISIONS ACT

The laws were made to protect citizens so they may
exercise their right to choose and provide guidance for medical professionals and institutions



NM UNIFORM HEALTHCARE DECISIONS ACT

- Capacity

As addressed in the NM Uniform Health-Care Decisions Act, capacity refers to "an individual's ability to understand and appreciate the nature and consequences of proposed health care, including the significant benefits, risks and alternatives to proposed health-care and to make and communicate an informed health-care decision."

Capacity…keep in mind

A Doctor's order is a recommendation. Just because an individual refuses treatment/recommendation- it is not an indicator that the individual lacks capacity.

Nor can a lack of capacity be based solely on patient's disagreement with the doctor.

Determination of a lack of capacity, according to the NMUHCDA, requires that 2 healthcare professionals make an assessment- one of which *should* be the PCP.

If there is a mental health or developmental disability, one of the health care professionals must have expertise in assessing functional impairment.

NM UNIFORM HEALTHCARE DECISIONS ACT

- The Authorized Decision Maker is at the helm for individuals with I/DD
- A) Capacity is the main ingredient! Each Authorized Decision Maker MUST have capacity!
- B) Context/person's values and preferences to the highest possible degree upon asking, knowing or observing what they are
- C) Capacity is not determined by one's agreement or disagreement with a medical professional or expert in that field

WHO HAS THE RIGHT TO MAKE HEALTHCARE DECISIONS

- With Capacity… you can make decisions for yourself, or you can make decisions for another via proper paperwork and procedure (sometimes Notary)

- This is what is referred to as the Authorized (Healthcare) Decision Maker

- Within the I/DD System – The Main Four:

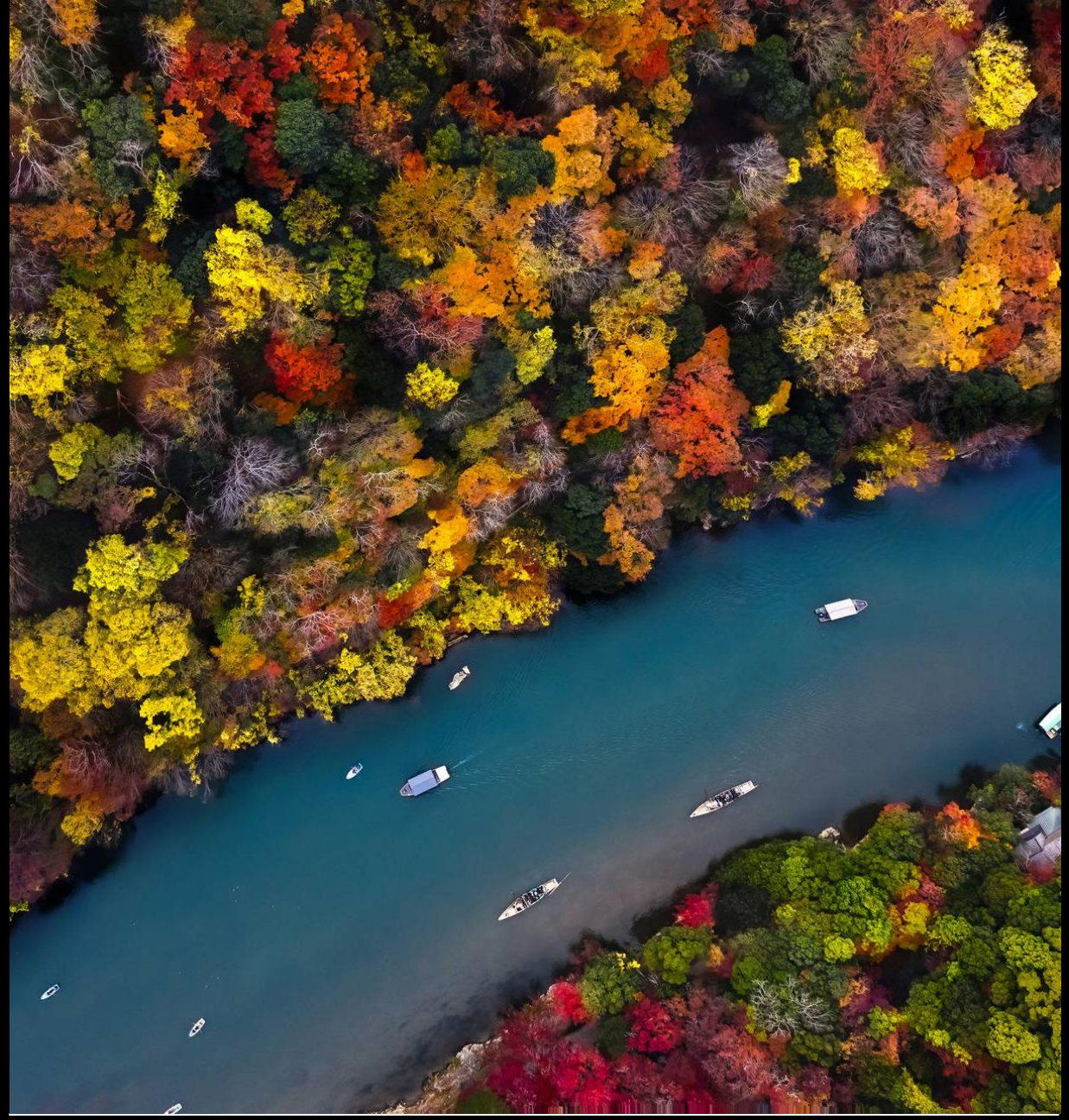
1. Non- Adjudicated Adult
2. Power of Attorney
3. Surrogate
4. Guardians

WHO HAS THE RIGHT TO MAKE HEALTHCARE DECISIONS

- DO NOT CALL ALL DECISION MAKERS "GUARDIANS"-
- Keep in mind that sometimes the Individual is the Authorized Decision Maker
- It is incumbent of the Authorized Decision Maker to check-in and discuss about decisions with the Individual "Guardian/Individual" is kinda oxymoronic
- DO CHECK TO SEE THE TYPE OF GUARDIANSHIP OR HEALTHCARE DECISION MAKING POWER THE PERSON HAS- Official documents, please!
- Make Copies and Place in Folder-DON'T ASSUME or Give more authority than what is due- especially when person is outspoken

LET'S START BY WORKING WITH THE YOUNGER WAIVER RECIPIENTS

TRANSITION: GPS-like Approach: Assessing the needs based on age and quality of life, values…all at the period of the Individual's life. When adjustments need to be made- you re-calibrate, tap into viable/effective resources.



Advocating & supporting young adults

- Some Services through the Waiver others through straight Medicaid –
- Work with the High School counselors/social worker, nurse and staff. EPSTDT (Early and Periodic Screening, Diagnostic and Treatment) benefits – Children on Medicaid up to 21were eligible to cover dental, mental health and therapies along with specialty services.
- Keep documents especially if Individual/Student is in special ed with IEPs, IQ testing results

Advocating & supporting young adults

- Once they graduate, they are Young Adults- some of the securities that they had will most likely be reduced or cease – some will be happy some anxious – even the parents

- New adventure whereby they may be Non-adjudicated Adults; other with Limited Guardianship while stil other have pleanary guardianship

- Transition -Focus on having them as safe and independent as possible, develop strength and skills, explore early levels of adulthood, what is the most appropriate services, etc.

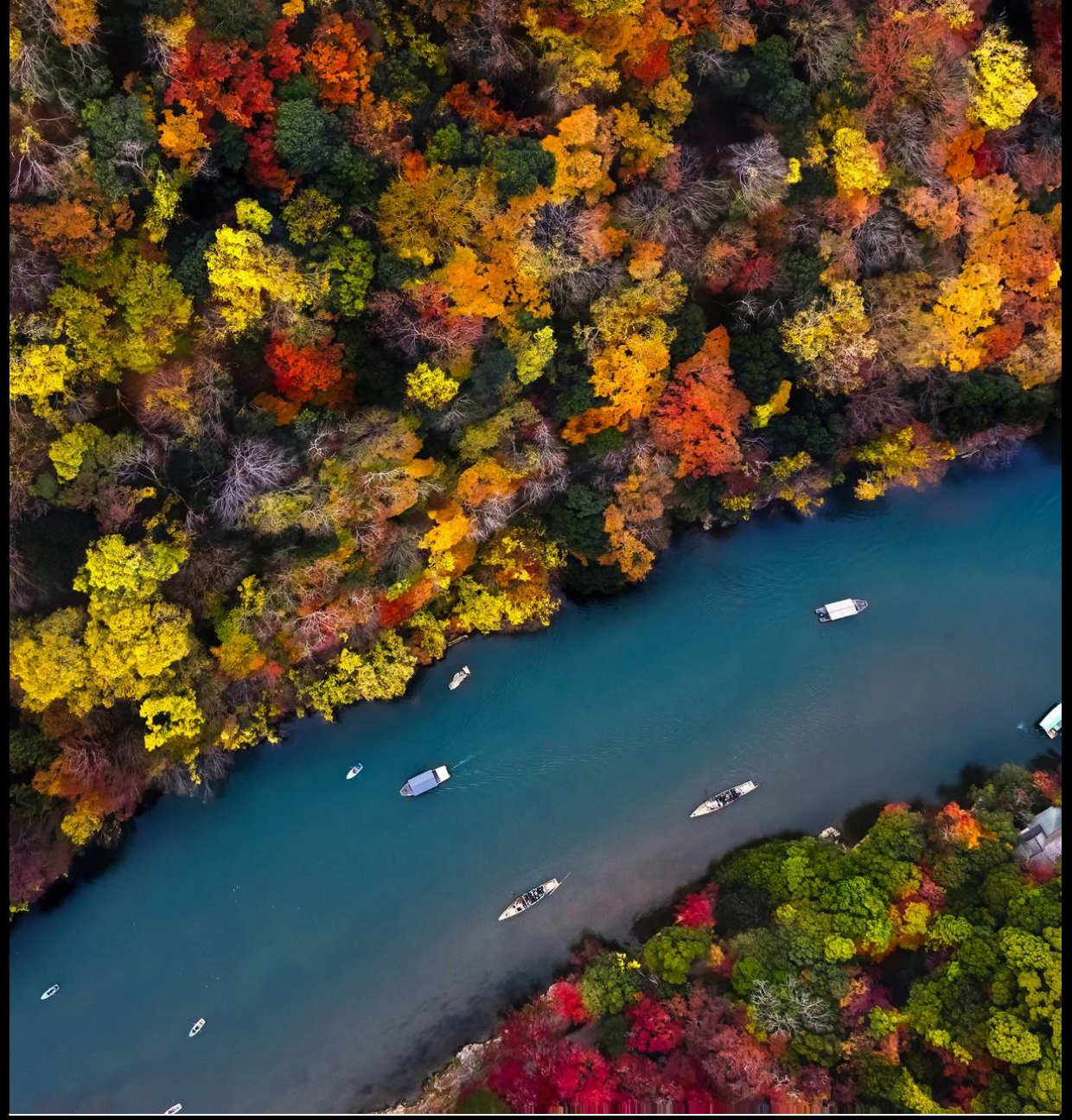
Advocating & supporting young adults

- Young Adults are going to make tons of mistakes- the majority of us did
- Allowing some slack especially when decisions have to be made
- Figuring ways to allow independence with safety nets that gradually get removed as the Young adult reflects maturity
- Parents and careivers learning to wear more than one hat
- Supporting without hovering or over-indulging yet being there when requested
- No "I told you so…" pressure statements- tough love when it is most effective
- Love and guidance is the best way to promote learning by example and experience
- Promoting goal development and achievement

SUPPORTED DECISION-MAKING ACT

- **Governor signs SB 535:** April 2025 which included the Supported Decision Making
- **Promoters:** Office of Guardianship collaborating with ALTSD (Aging and Long-Term Services Department) to collaborate with Office of Guardianship to identify and promote supported decision-making resources
- **Goal:** Alternative to guardianship especially for Adults with disabilities and older adults who could have more autonomy in making decisions for themselves.

3 VIGNETTES: DEMONSTRATE HOW YOU WOULD GUIDE PARENTS WITH A YOUNG ADULT AT A DOCTOR'S OFFICE



NON-ADJUDICATED ADULT

- Self advocate with capacity (non-adjudicated adult)
  - Remember that a non-adjudicated adult makes
  - his/her own decisions starting at 18 years old

- If there is a question about the person's capacity, discuss with IDT or Supports and look into assessments, seek assistance through regional office, APS, DHI, Specialty Clinics, etc.

- 2 professionals credentialed to make this type of an evaluation and who are familiar with I/DD population; one of whom should be the primary care provider (PCP)

Advance health-care directive-

is an individual's instructions as to the kind of medical treatment s/he would or would not want in the event that s/he becomes incapacitated or unconscious or so ill that s/he is unable to express health choices or wishes.

A person has to have capacity in order to have an Advance Directive- solely about him/herself. A "Me" Thing Document!

No one can put in an Advance Directive for you- this is your decision about You and your wishes(think autobiography).

****Guardians/Surrogates cannot devise an Advance Directive for another they make "Healthcare decisions" (think biography)**

NON-ADJUDICATED ADULT – CAN HAVE…

- **Advance Directives**
- **Power of Attorney**
- **Limited Guardianship whereby the courts determine particular area of jurisdiction, so non-adjudicated adult may be independent in all other areas**
- **Supported Decision Making- processes for assisting and supporting self-determination- safety net promotion of this guidance and supports for individual's right to make choices.**

"Advance Directive"

(the form with this name on the top)

Through this form, you can name an Agent or Attorney–in-fact(POA). The Agent will make healthcare decisions for you.

However, this form **does not** need to be notarized.

[It makes sense - as this form is a requirement at hospitals and surgery cannot be held up because we are waiting around for a notary.]

Copy is as good as the original in New Mexico

POWER OF ATTORNEY
(THE FORM WITH THIS NAME)

Through this form, you, the Principal, can name a person (Agent or Attorney-in-fact, healthcare proxy) to take care of your affairs which covers two categories:

- Healthcare

and/or

- Finance or business (Notary)

POA

The person initiating this document is called the “Principal” and must have capacity at the time that these papers are signed; the Agent also must have capacity

The majority of POAs are activated when a person is unable to make decisions or out of commission(e.g. coma, surgery, recovery, out of the country, variable (springing) dementia (durable), etc.); *but when indicated…*may start immediately.

POA

Best option is to have a “durable” POA or one that states “…this document will not be affected by my incapacity…” so, if you should lose your wits about you, the document is still in effect, otherwise it would be null and void.

For Healthcare- witness & notary is recommended **but not required.**

However, for Finance- this form **must be notarized.*** This includes POAs that are used to cover both health and finance

POA

Principal is in the driver's seat – This information is not emphasized enough!

POA is good indefinitely until the Principal changes it or until his/her passing (agent may need time with finishing up a task/process, before the Will kicks in)

POA can be revoked at anytime *by the* Principal

Updates should be given to those who need to know w/new Agent, date, etc.

SAFEGUARDS

When a person lacks capacity (or capacity is of question), s/he is vulnerable and can be the target of abuse, neglect or exploitation.

Surrogates or guardians are put in place to be responsible for assuring that the person lacking capacity is “protected” and is in a healthy and safe environment.

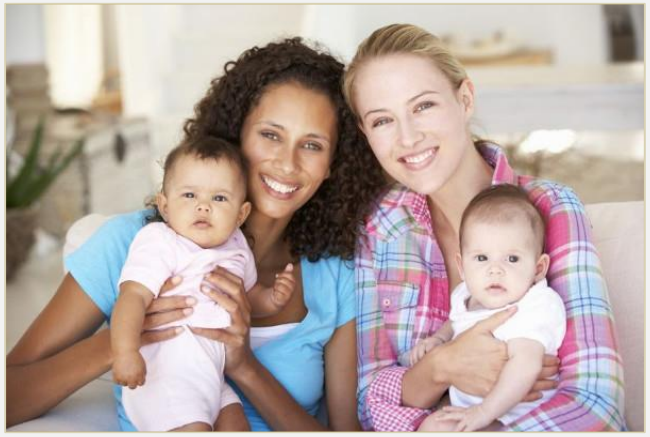
SAFEGUARDS

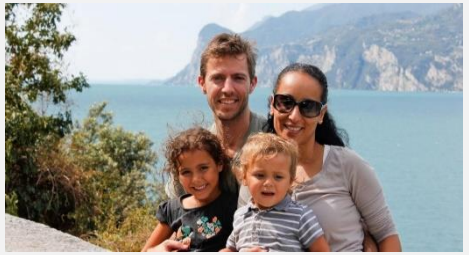
In the interim, while a family, an IDT, or both are trying to secure a guardian, someone has to make healthcare decisions...

SURROGATES -THROUGH THE NM UNIFORM HEALTHCARE DECISIONS ACT*

Hierarchy of Surrogates

- Spouse
- Significant Other
- Adult Children
- Parents
- Adult Siblings
- Grand parents
- Person showing Special care





SURROGATE DECISION MAKER FORM

- DDSD Form for stating that a surrogate has been identified to take on the role as decision maker
- Temporary – in cases of serious/delicate medical situations when a decision is needed
- IDT/Family should also be *actively pursuing guardianship* if it is determined that the individual lacks capacity (consult with individual's PCP, CNP...)
- To receive info: Please contact Regional Office or Office of Constituent Supports
- (Deputized) Christine Wester or Ingrid Nelson at CoC Main (505) 925-2350

GUARDIANS

A guardian is a person appointed by the court to make personal and/or health care decisions for a person (protected person -PP) who has been deemed “incapacitated.”

Conservators» finances

Guardianship is governed by the NM Uniform Probate Code

Guardians are to submit an Annual report to the District Court which issued the guardianship to assure commitment.

PAPERWORK - GUARDIANS

- Those who seek to be a guardian, but fall below the poverty line should contact the Office of Guardianship to get on the waiting list for the Guardianship Program where the fee is free or nominal

- Contact the Intake Coordinator
  DDC Office of Guardianship
  625 Silver Avenue, SW Suite 100
  Albuquerque, New Mexico 87102
  www.nmddpc.com (505) 841-4549

- Advocacy Inc.
  Tammy Vigil – Intake/Coordinator
  6301 4th Street NW
  Albuquerque, New Mexico 87107
  (505) 266-3166

⦿Types of Guardianship

Δ Family or Corporate

Δ Conservatorship – finance, fiduciary oversight

- Full or Plenary
- Limited (court states what area of oversight)
- Treatment* *Mental Health & Developmental Disabilities Code*
- Kinship (family connection) or Permanent
- Temporary (critical medical situation)
- Testamentary (name a successor in a Will)
- Guardian ad Litem (decision maker in the interim of court proceedings)

PAPERWORK - GUARDIANS

- There will be times when a guardian may need to take a break, go on vacation, leave the country, etc.
- Delegation of powers by guardian (45-5-104 of Uniform NM Probate Code)
- By an official POA, guardian may appoint (delegate) an adult (with capacity) to carry out any of his/her powers as guardian (except power to consent to marriage or adoption of a minor ward). The duration of this POA can be *up to 6 months*
- Can be renewed for another 6 months via a new POA (repeatedly- want another 6 months… new POA)

WHAT YOU NEED TO KNOW

- All Guardians and conservators must complete Reports (90 days after a new appointment; Annual Report – due 30 days after the 1st anniversary and every year thereafter)

- Courts can fine a guardian or conservator $25 for each day the report is late

- Annual report will not be waived, but can be extended only up to 60 days- one must put in request to the courts for this extension

WHAT YOU NEED TO KNOW

- Every 10 years, any time after the appointment of a guardian, or Receipt of a Review Request… the court can hold a Status Hearing
- To check the status of the PP's capacity and if there remains a need for a guardian
- Appoint a Court Investigator who will submit a detailed report to the court regarding the capacity and the level of need for guardianship

PROBLEMS HAVE SOLUTIONS- TAP INTO RESOURCES

- Grievance Form 4-999

This should be done after all other efforts have not been successful. Please refer to form for directions

- Contact Courts to request a Review

Compose letter with dates, times and facts - Send certified letter to courts/judge

- Document, document, document all interventions and plans of action

DECISION CONSULTATIONPROCESS/FORM MAKER FORM

DECISION CONSULTATION PROCESS

[SIMPLY]

- To guide teams or network of supports on the value of discussion –respect of different opinions to reach outcomes.
  - A means of letting the IDT members or Network of Supports to know what the final decision was regarding a recommendation.
- Helps to get into a rhythm/pattern of discussing, educating, future planning…while encouraging the Authorized decision maker to consult w/PCP, experts, etc., It is a *Process.*
- Supporting the decision maker in arriving at an *informed decision* & communicating that decision.

KEEP IN MIND

Although the case manager is the one who generates the forms, and helps facilitate, it is through the team collaboration that these forms are made complete with all the elements to reflect what has lead up to the final decision.

The member who has been most involved with the situation should be a fulcrum: connecting with CM and ascertaining that the information contained in the form is accurate, sequential and so forth.

DECISION CONSULTATION PROCESS & FORM

The Process

Education – Context – advocating for as much information as possible (knowledge is power)

Risks vs Benefits

Calling in the Experts (via Zoom)

Exploring alternatives and "what ifs"

DECISION CONSULTATION PROCESS & FORM

The Process

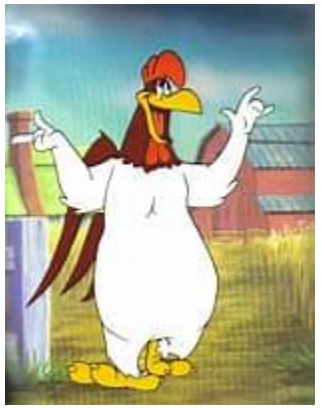
Members are Whole Hog

Every Voice Heard

Creativity (fishbone, brainstorm)

Exploration of *Viable* Options

May take more than one meeting



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DECISION CONSULTATION PROCESS & FORM

The Form

Capturing the discussion points, concepts and education for an informed decision

Review the form to familiarize yourself -link to be used as template for decision making

Assist with completion or clarification if needed

- Action items – assignments
- Check point of an Informed Decision and if additional or follow-up steps are needed
  - Stating Resources
  - May take more than one meeting
  - Takes more than just a facilitator

OTHER FORMS TO CONSIDER

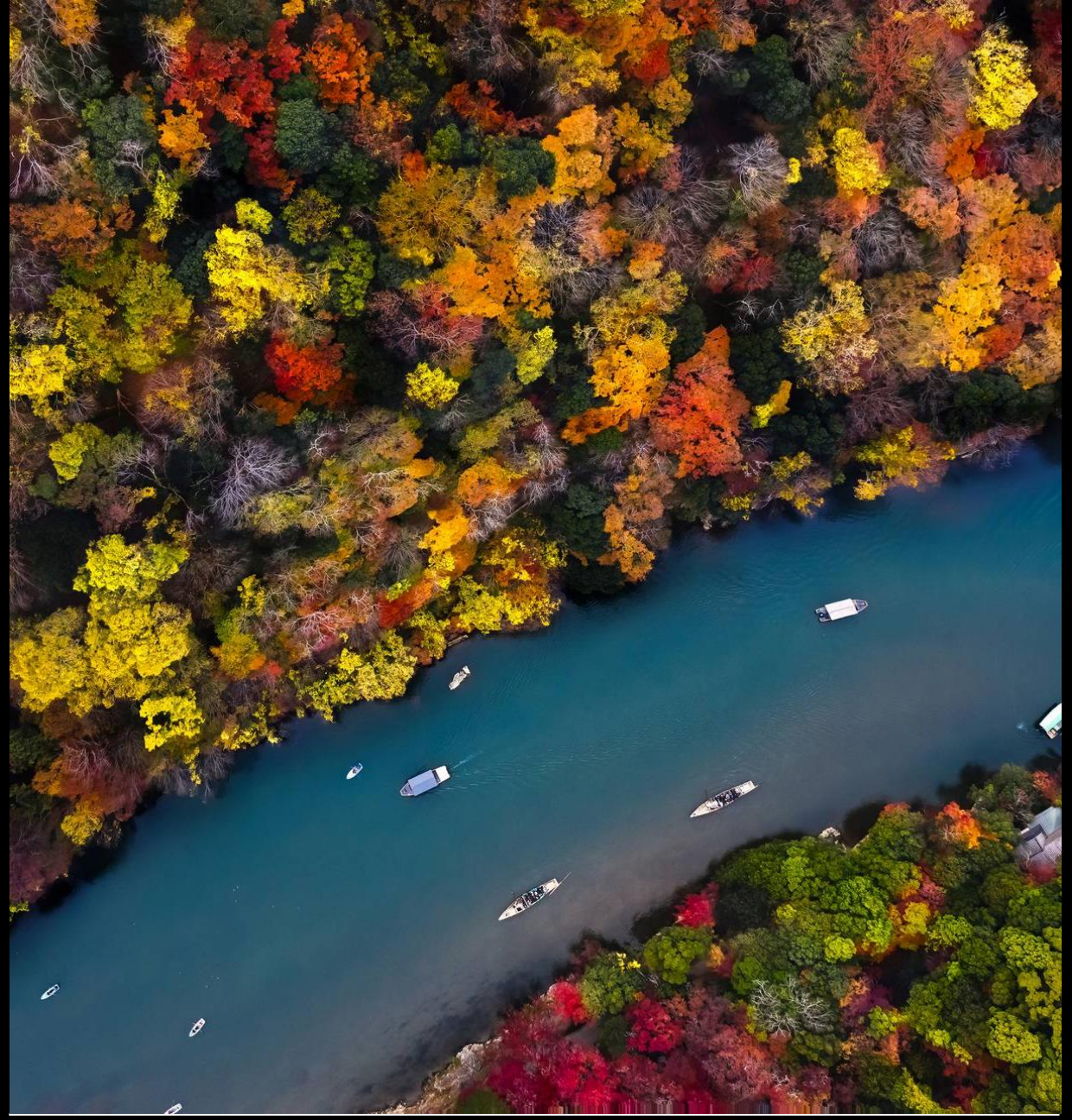
- Do Not Resuscitate (DNR) or In-tubate (DNI)
- These are special orders and please note that they cross categories:
- DNR/DNI orders, when initiated by a person with capacity, it is *part* of an *Advance Directive*
- However, when a Surrogate Decision Maker initiates a DNR/DNI order, for another, it is a *healthcare decision*
- *DNAR – Do Not Attempt Resuscitation (osteogenesis imperfecta, med frag,)*
- *AND – Allow Natural Death*

OTHER FORMS TO CONSIDER

- Standardized EMS –DNR Form (Only form they will honor)
- Statutory Form for New Mexico
- Transporting to and from Residence, Group homes, Assisted Living, etc.
- Place it where it is conspicuous, freezer/bag, carry order w/you (medical bracelet) Copies are OK.
- Use authorized Medical medallions, bracelets, etc.,
- * NM Medical Orders for Scope of Treatment (M.O.S.T)

2 SCENARIOS:

BREAKOUT SESSION APPLYING ADVOCACY TOOLS



FOOD FOR THOUGHT-

Advocacy

Get into <u>Guardianship Planning-</u> don't have a false sense of security:

What if the guardian became ill

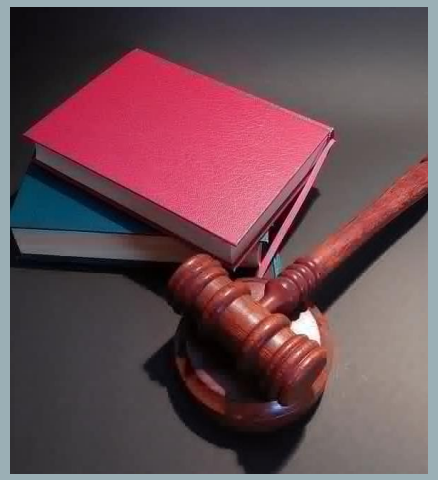
What if the guardian passed away

What if the guardian is elderly, and now showing signs of dementia

What if they are very hard to reach (e.g. rarely keeping in touch)

FOOD FOR THOUGHT-

Advocacy



Utilize simple suggestions/tools

When a guardian passes away…someone must notify/alert the courts - so they can aid/identify: the appointment of a guardian. Logically it falls on the shoulders of the CM – for DDW documents to get signed.

Seek *guidance* from Office of Guardianship, counsel, etc. they may have emergency funding to identify a guardian

Surrogate Decision Maker Form can be used while securing a guardian

FOOD FOR THOUGHT- ADVOCACY

Utilize simple suggestions/tools

CM (either one-on-one or smaller group setting) should gently ask about successor guardian and this can be prompted by the annual ISP or if incident occurs with guardian that warrants this to be broached- can be peace of mind for current guardian and for IDT (things are in place/order)

If a guardian is ill, utilize the delegation POA for a 6-month term- this takes the weight off of a guardian (find the temp sub and/or permanent successor)

Contact the courts so they can look into this and determine if a guardian ad litem, successor, Corp Guardian, etc. is needed (Yes, Corp. Guard. is a viable choice sometimes)

FOOD FOR THOUGHT-

Advocacy

- Check for medical or physical causes re: behaviors. There is a reason for everything
- Present Parameters if an answer is needed by a specific time (ex. Can you give me an answer by next Tuesday 5/26? Pull out the calendar to demonstrate)
- Get the person(s) who knows the individual well to get to the heart of the matter to have a meeting of the minds for solutions. Share with guardian – no one has all the answers
- Consider Supported Decision Maker
- Maybe its time to explore Resources, Bureau of Behavior Supports, Regional Office (I'm just sayin'...)

SOME SEPARATE AND SOME IN CONJUNCTION W/WAIVER PROGRAMS

Station MD – Station MD is a telehealth company dedicated to serving individuals with I/DD. All Station MD clinicians are board-certified and specially trained to treat individuals with I/DD. Clinicians are available 24/7 via telemedicine for urgent and non-urgent medical matters. Station MD enables individuals with IDD faster access to high quality care. Aim to hopefully cut down on ER visits and time spent in the ER.

NM START /CDD- Systemic-Therapeutic-Assessment-Resources-Treatment. Provide mental health assessment, crisis response, behavioral intervention, coordination, therapeutic coaching, training, and linkage of systems to address complex needs.

AGING

Caregivers now- in a few decades-will need to have care given to them

How to stay independent yet safe and realistic as faculties are not the same – Can you really drive at 85 or at night?

Are you, as my advocate, accepting my aging or thinking of me when I was 40?

Dementia- I'm different, but can I still have some of my routines? Can you work with me with my (wild) moods?

If I have hearing loss, will you make sure I get aid because there's a correlation of hearing loss and cognitive decline despite me fighting you about this?

OTHER MEANS FOR PROMOTING EARLY INTERVENTION AND TRACKING PROGRESS- CONTINUAL CONNECTION, IN THE LOOP

Following Waiver Standards – DDSD Regional Office

RORAs

NM START

Making the Most of Your Doctor's Visit

MCO Care Coordination

UNM Specialty Clinics, TEASC, CoC, CDD,

- SAFE , Seating Clinic, Adult Special Needs Clinic
- Consultation
- Reports, Summaries, recommendations
- Monthly Check-ins- to include the health component – you are not a robot

MINDFUL MEETINGS – COMMITTED WHOLE HOG

Establish the *Purpose* of the meeting- don't assume (note taker, timekeeper)

Ground rules (what is respectful and permissible for a productive meeting)

Person Centered – be present for whole meeting since this is about someone's life- not the time for multitasking – ADD-fake it to you make it

Roles defined so all can participate – Consensus – Level playing field

Don't work in fear or live in fear~ TRUST (Fear vs Faith)

Priority ◊ Collaboration , truthful, assertive, good eye contact, be brave

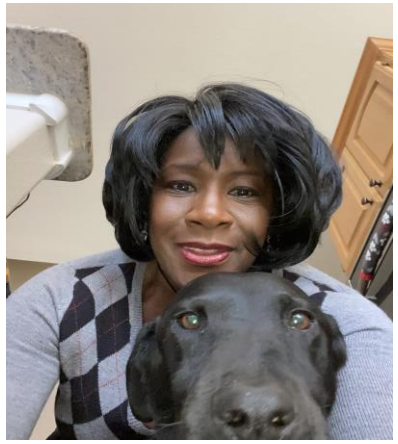
Realistic expectations- how do you measure success?

No "All or Nothing" Attitude or choosing sides (don't be wishy-washy)

How are you when we don't agree? Can you agree to disagree, and still be open to suggestions? Hmmm? Serenity Prayer in tow

Be Your own Best Advocate- a powerful way to enforce is to do so by example

Take good care of yourself…you are valuable!
Get good sleep, eat well, take breaks during work, reduce stress, meditate, pray, etc. – Calm/soothe the mind and body, be loving & be kind; exercise – take long walks, walk your dog, add resistance workouts (ladies), take the staircase, have continual cycles of “me time” with no guilt or excuses.



THANK YOU

Ingrid