

“All In Together Now...”

A PERSPECTIVE ON GUARDIANS AS ADVOCATES

Continuum of Care Project

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Objectives



This is what we will go over today:

- ▶ Capacity – determinant for decision making
- ▶ Main categories of Decision Makers
- ▶ Focus on Guardians as a healthcare decision maker
- ▶ Types of Guardianship
- ▶ Guardians & Advocacy
- ▶ Decision Consultation Form & Team Justification Form – Brainstorm solutions
- ▶ Food for thought – Scenarios, Cases & Tips for Advocacy – open your mind and heart

Right to choose



- ▶ The laws were made to protect citizens
- ▶ Provisions for adults to make their own decisions
- ▶ Adults or emancipated adolescents must have capacity in order to exercise their right to choose

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



- ▶ A Doctor's order is a recommendation. Because an individual refuses treatment/recommendation is not a determinant or 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 UHDA, 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

Who has the right to make Healthcare Decisions



- ❑ 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 and look into assessments

- ❑ 2 professionals credentialed to make this type of an evaluation and who is familiar with I/DD population; one should be the primary care provider (PCP)
- ❑ Seek assistance through regional office, APS, DHI, etc.

Paperwork...

- ▶ 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

Don't Get Confused

“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

Paperwork... Five Wishes 1-888-5-Wishes

- ⦿ Holistic document (in over 26 languages) honored in many states (e.g. New Mexico) which gives you the opportunity to capture your healthcare wishes and needs in a way that lets others know officially:
- ⦿ What procedures you want or don't want
- ⦿ Who you want to make decisions for you
- ⦿ Comfort Measures

Paperwork...1-888-5-Wishes

- ◎ Preferred approach
- ◎ What you want friends and family members to know
- ◎ How you would like to be treated

Note: [Copyright regulation -Original Five Wishes Form! (can make copies of completed form for family, etc.) Can replace old AD, living wills as long as you tear up the old and alert PCP, etc. The form is good from state to state that honor them]

Additional form for Special Consideration



- ▶ *My Wishes* is based on the Five Wishes
- ▶ For Children/Minors- gives them a voice
- ▶ Does not require signature and is not a legally binding document
- ▶ Addresses how one wants to be treated and this completed form can be shown to family, friends, healthcare professionals and IDT members

More Paperwork

Don't be confused

“Power of Attorney”

(the form with this name on the top)

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

- Healthcare
- Finance or business

Paperwork...POA

The person initiating this document (Principal) has to have capacity at the time that these papers are signed

The majority of POAs are activated when a person loses capacity (e.g. coma, surgery, recovery, out of the country, variable (early) dementia (durable), etc.)

More Paperwork...

Don't be confused

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.

However, for Finance- this form must be notarized * in order for it to be a legal document. For Healthcare- witness & notary is recommended, but not required.

*This includes POAs that are used to cover both health and finance

Paperwork - POA



The Principal should not complete this form under duress, threat, seduction or coercion

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

POA can be revoked at anytime *by the* Principal

Updates should be given to those who need to know w/new Agent named, 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

Surrogates



- ▶ In the interim, while a family and or IDT is trying to secure a guardian, someone has to make healthcare decisions...

Surrogates



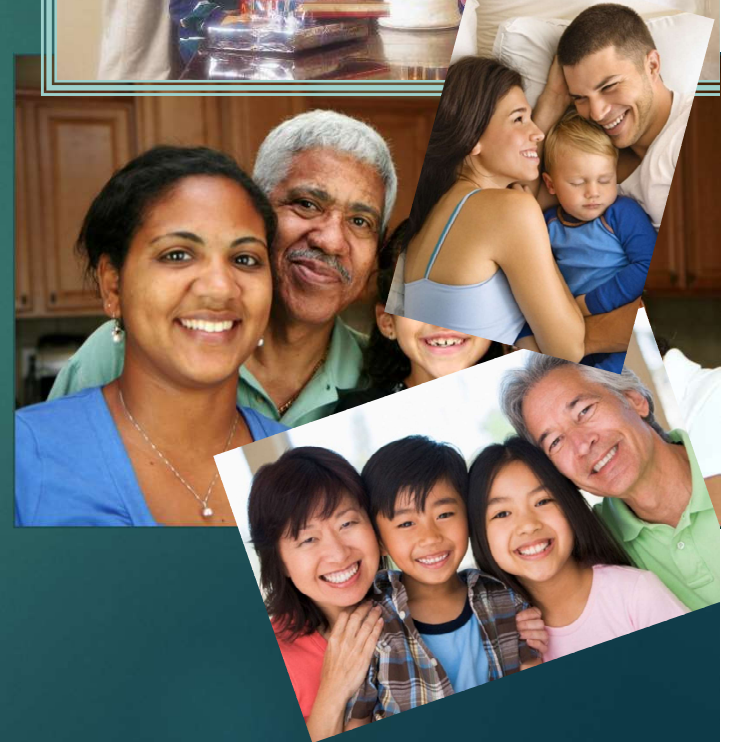
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- An individual, other than a patient's agent or guardian, authorized under the NM UHDA to make a health-care decision for the patient
- Surrogate can be appointed if the agent or guardian is not “reasonably available” and there is an urgency in treating the health-care needs
- Alternates can also be chosen based on their availability and willingness to be a surrogate
- Safety net for those who do not have advance directives, living wills, etc.

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 Healthcare Decision 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, MD,)
- To receive info: Please contact Lisa Storti, Office of Constituent Supports (505) 476-8972 or (Deputized) Christine Wester or Ingrid Nelson at CoC (505) 925-2350

Paperwork - Guardians

- ⦿ A guardian is a person appointed by the court to make personal and/or health care decisions for a person (protected person) 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

Paperwork - Guardians

- ▶ *If you are serious about becoming a guardian you must first petition the court, either by filing it out yourself or through an attorney. Petitioning Attorney puts in official document*
- ▶ Evaluations will be based on 1) Visitor (Social worker/Case Worker for the court); 2) medical assessment of capacity- PCP should be one of two medical professionals making this evaluation; and 3) any notes or observations by the Guardian ad Litem
- ▶ A Hearing will determine if guardianship will be granted or denied (process can take a *few* months, but getting shorter in recent times starting 2018)
- ▶ Average cost - \geq \$3,600 (uncontested)

Paperwork - Guardians

◎ Types of Guardianship

I. Family or Corporate

II. Full or Plenary

Limited

Treatment*

Temporary

Kinship

Testamentary

Guardian ad Litem

* *Mental Health & Developmental Disabilities Code*

Paperwork - Guardians

- ▶ Full or Plenary –responsible for making all major decisions for the protected or incapacitated person. Functions under New Mexico Uniform Probate Code
- ▶ Limited –This is granted when the protected person can make *some* decisions, but not all. Court order will specify- *Ideal when appropos
- ▶ Temporary – Usually appointed for 60 days and is initiated if the physical health of the person is in jeopardy. Can be extended via the court for 30 days

Paperwork - Guardians

- ▶ Treatment Guardian - at the request of a facility or treatment center, to assure compliance with medication and to make decisions regarding mental health issues. Functions under the *Mental Health & Developmental Disabilities Code*
- ▶ Testamentary Guardian - named in the will of either a parent or spouse* who is also the guardian of the PP). Must be done through filing at court - Probate)
- ▶ Guardian ad Litem - assigned to protect the rights of the alleged incapacitated person while waiting for a court proceeding (e.g. to determine guardianship)
- ▶ Kinship Legal Guardian (KLG) - extended family (connected to biological parents) who are granted permanent guardianship to children.

Paperwork - Guardians

- ▶ There will be times when you 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)

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 Sandy, CIRS – Intake Coordinator
DDPC Office of Guardianship (505) 841-4549
625 Silver Avenue, SW Suite 100
Albuquerque, New Mexico 87102
www.nmddpc.com
- ▶ Advocacy Inc.

Keep in Mind- Guardians

- All guardianship in New Mexico –family/private or corporate- can go through the Office of Guardianship for information and for pointing them in the right direction. However, this office does oversee the Corporate Guardianship Agencies.*
- “Guardianship and Conservatorship for Adults in New Mexico: A decision-Maker’s Manual”
 - * * GuardianshipAllianceNM.org (download a copy)
- Guardians are to be in the Best Interest of the PP and protect the PP’s rights.
- Guardians should ask the PP what his/her wishes are and try to grant those wishes in the most practical and reasonable way. Guardians have the final decision. (Decision Consultation form).

Keep in Mind- Guardians should, for the most part, base decisions on the PP's wishes (if *known* or in accordance w/the PP's values)

- ▶ Generally, they are responsible for maintaining and enhancing their PP's quality of life by:
- ▶ Making sure the PP's basic needs are being met
- ▶ Making sure that the PP is involved in recreational activities that he/she likes and can enrich his/her life
- ▶ Making sure the PP has good training and education
- ▶ Making sure the PP stays healthy; Remembering that as guardians, they should be actively involved in making informed health care decisions (may include consenting/refusing medical treatment)...in alignment with the PP's values.

Another form 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 or*
- ⊙ *AND* - *Allow Natural Death*

Another form 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)

While on the Waiver

HEALTHCARE DECISIONS ARE DOCUMENTED SO THAT THE TEAM AND ANY REVIEWING ENTITY(S) ARE AWARE OF THE DECISION(S).

IDT CAN ALSO DISCUSS WAYS TO ASSIST IN CARRYING OUT THE HEALTHCARE DECISION, WHEN/ IF THIS IS NEEDED

IDT MEMBERS DO NOT MAKE HEALTHCARE DECISIONS FOR THE INDIVIDUALS THEY SERVE

DOCUMENTS SHOULD BE UPDATED WHEN CONDITION OR DECISION CHANGES

Decision Consultation Form (DCF)-

The main form for
acknowledging a decision

Decision Consultation Form (DCF)

[DDSD Policy on Team Decision Documentation]

- ❖ Used to...
- ❖ Document medical/health related or clinical decisions whether agreeing or disagreeing
- ❖ Document each and every time when disagreeing with or deferring from a medical recommendation
- ❖ Respond to a health or medical recommendation, Case Manager completes the DCF - may require assistance from IDT

Decision Consultation Form (DCF) [DDSD Process and Form]



❖ THIS INCLUDES

Medical orders or recommendations from:

√ PCP, specialists or licensed medical or
healthcare practitioner (e.g ACNP, DDS, PA)

Medical orders are usually for routine care,
medications, services or treatment

Medical recommendations include discussion,
advice, options, referral, etc. Regarding a life-
style change, procedure, surgery...or end of life

Decision making

Decision Consultation Form (DCF)

[DDSD Process and Form]



❖ THIS ALSO INCLUDES...

CLINICAL RECOMMENDATIONS:

MADE BY A REGISTERED/LICENSED
CLINICIANS, THERAPISTS, ETC. WHO ARE
MEMBERS OF THE IDT

OR

MADE BY CLINICIANS WHO HAVE
PERFORMED AN EVALUATION (SUCH AS A
VIDEO FLUOROSCOPY)

Decision Consultation Form (DCF)



❖ THIS ALSO INCLUDES...

HEALTH-RELATED RECOMMENDATIONS
OR SUGGESTIONS:

FROM OVERSIGHT ACTIVITIES SUCH AS -

✓ JACKSON COMMUNITY PRACTICE
REVIEW (IQR)

✓ DOH REVIEW

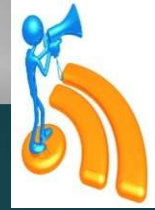
Decision Consultation Form (DCF)

DDSD Policy on Team Decision Documentation

Once a decision has been made by the healthcare decision maker, the Practitioner/consultant, etc., who made the recommendation, is notified and then the Case Manager files this form along with the report that contains the recommendation.

Relevant support plans should be revised accordingly—especially the Health and Safety Action Plan page of the ISP, healthcare plans, MERP, Therap, etc.

DCF- Keep in Mind



- The healthcare decision maker has the sole responsibility for health related decisions
- (IDT DOES NOT MAKE HEALTHCARE DECISIONS)**
- Issues of concern are communicated and addressed in a timely manner
- IDT members make themselves available for information and answering questions
- Clinical and healthcare resources are identified or provided, if requested
- Informed decisions are *made, documented and honored (implemented)*

Decision Consultation Form (DCF)

[Simply]



- ❖ To guide and document team discussion in a manner that promotes informed decision making
- ❖ A means of letting the IDT members know what the final decision was regarding a recommendation
- ❖ Helps IDT to get into a rhythm/pattern of discussing, educating, while encouraging healthcare decision maker to consult w/PCP, experts, etc.,
- ❖ Supporting the decision maker in arriving at an *informed decision* & communicating that decision
- ❖ IDT should advocate & honor the decision to promote the individual's Quality of life



TJF - Team Justification Form
Another acknowledgement form

Team Justification Form (TJF)

[DDSD Process and Form]



- ❖ This process and form is used when the individual w/capacity, guardian, poa...and/or team (usually through a facilitated meeting) has given due consideration to a non-health related recommendation and as a result, has made a determination to either-
 - a) Implement the recommendation
 - b) Create an action plan, revise ISP in order to implement the plan *OR*
 - c) Not to implement the recommendation

Team Justification Form (TJF)

[DDSD Process and Form]



- ❖ To be used when...
- ❖ The team determines that a non-health related recommendation is not in the best interest of the individual
- ❖ For ex. -Use when it involves an employment recommendation
- ❖ In conjunction to above, IDT should develop goals and state what will be the more preferable alternative (e.g. Volunteering instead of working)
- ❖ For responding to (IQR) recommendations or any other non medical audit



Case Manager holds the key

CM has ultimate responsibility for the decision consultation process & team justification process

- ❖ Convenes the meeting, *if necessary, (e.g. Phone)*
- ❖ Assures that the form is completed
- ❖ Instrumental in accessing resources
- ❖ Updates health and safety action plan page whenever a DCF is completed
- ❖ Retains the form and files it appropriately
- ❖ Makes sure a copy is available for individual, guardian, pertinent IDT members

For both forms



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.

For both forms

[DDSD

Policy on Team Decision Documentation]



These forms are appropriate for all inter-disciplinary teams who support adults on the Waiver (individuals 21 or older who are no longer eligible for EPSDT benefits)

For both forms



It has been suggested that all members are given the form ahead of time to become familiar and do some “prep” work before the actual meeting occurs to discuss the situation or particulars

This can encourage IDT member’s full participation, their careful thought to the issue at hand, research, inviting the experts and resources to attend the meeting. It can move the discussion and team process to efficacy and productivity (as opposed to the mundane, un-involved, unaware, one-way meeting.

LET'S REVIEW



There are 4 main legal decision makers (capacity) w/DDW
Let's name them

1 _____ 2 _____ 3 _____ 4 _____

PLEASE CLASSIFY THE HEALTHCARE DECISION
MAKER APPROPRIATELY AND ACCURATELY
(1 OF THE 4)

DO NOT CALL ALL DECISION
MAKERS "GUARDIANS"

▣ Let's Review...

Use Decision Consultation Form for Medical, healthcare therapeutic or health-related recommendations

Healthcare decision maker makes → informed decision

*** IDT does not make healthcare decisions for the Individual, but supports and implements the decision(s)*

Team Justification Form is for non-health or non-medical related recommendations (e.g. vocational)

IDT discusses and makes Determination (which most likely will include a “justification” along with alternative(s))

LET'S REVIEW...



CM is responsible for assuring that the forms are complete

IDT member with the most knowledge should assist with filling in the details

CM files form accordingly- makes it available for pertinent IDT members

Update relevant documents

Group Scenarios



Food For Thought- Advocacy



Your philosophies or belief systems will impact your approach on the delivery of care and how you advocate for your clients.

If you keep bringing your guns out...you are going to continually be in a battle or gun fight

Guardians are in the drivers seat- you ride with them (educate, communicate and support) or get off the bus

You have the power to set the tone- are we going to fight or are we going to negotiate and work out a solution that helps the Individual

You are going to get a lot more flies with honey, than you can with vinegar

Food For Thought- Advocacy

- ▶ Guardianship should not be used and abused either- and *please* don't resort to Guardianship because:
 - a. The individual refuses to take Meds
 - b. The individual takes too long to make decisions
 - c. The Individual seems to have no morals
 - d. The Individual is testy and resistant to following parts of the program “She appears to never agree w/any of the Therapy plans...”

Food For Thought- Advocacy

e. “...the very nature of the Waiver implies that *those* people need a guardian. C’mon, the average person is not on a Waiver, so, of course they need a guardian!”

f. “All of these questions and recommendations from the Individual Quality Review Process (we see why it was formerly called CPR)...I think we need a Guardian!”

g. With all those behaviors...he needs a guardian”

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.
- ▶ Maybe its time to explore Resources, Bureau of Behavior Supports, Regional Office (I'm just sayin'...)

Food For Thought- Advocacy

- ▶ Least Restrictive and in the best interest of the individual -
Dignity of Risk -don't forget safety nets
- ▶ Courts are doing more monitoring, home visits, checking after 10 years to see if status needs to change, fines for late annual reports- more checks and balances
- ▶ Have a game plan and follow your philosophy on the best way to advocate - catch everyone being good vs. catching when they are bad -with all eyes open (TEAM) you will discern when praise and when admonishment is needed.
- ▶ Explore Limited guardianship - let's not be hasty with the full/plenary* * (do right by the person & lighten up responsibilities of the guardian- as appropriate- let's not forget about the Rights & Responsibility of the individual)

Food For Thought- Advocacy

- ▶ Work from the Individual's strengths - as building blocks-to include pace and the best format to present things to him/her (e.g. When you assist Granny with crossing the street you don't tell her to hurry up...)
- ▶ Question- is this about making it easier or less "liability" for the team as opposed to what is best for the individual with I/DD
- ▶ Be creative...utilize skills of the IDT
- ▶ Progress (human nature) takes time...but in the long run it can be beneficial for all involved
- ▶ Annual Check points and assess status

Food For Thought- Advocacy

- ▶ Let the impetus of your actions be about advocating for the individual! (not about being right)
- ▶ Our main focus should be supporting Quality of Life and assuring Quality Care for the Individuals we serve
- ▶ Incumbent on each team member to be available for the whole IDT meeting to contribute information that promotes to the Individual's Quality of life (no multi-tasking)

Food For Thought- Advocacy



Get into Guardianship Planning- 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- Knowing Policy

- ▶ Fitting in the Family Living Provider- Remember- must be connected by blood, marriage or adoption to be a healthcare decision maker (sanguinity or affinity)
- ▶ Repayee - who determines this?
- ▶ Make no assumptions
- ▶ Educate *all* IDT members (this includes the guardian) and always promote 2-way communication

Food For Thought- Advocacy

- ▶ Developing a Rapport
- ▶ Keeping communication open, honest and wholesome
- ▶ Courts are making home visits
- ▶ Empathy, yet have accountability
- ▶ Creating a “trusting” relationship
- ▶ Synergy amongst IDT members- (CM, Guardian, RN, Therapists, etc.,)

Food For Thought- Advocacy

Integrity, resourcefulness, perseverance, sense of humor, resilience, get relief through confidantes; and say the Serenity Prayer (not everything will go as planned all the time - so have plan B, C...) and stay positive! We are here for our clients/individuals/patients through...**TEAMWORK!**



▶ Thank You