

Until the last Breath (End of Life Series)...

By Ingrid M. Nelson, BA,BS,MS

Continuum of Care (CoC) will be sharing articles on various subjects, focusing on end of life issues. Such topics as the dying process, finding solace when there is a terminal condition, grieving, etc. This is the first article of this series, and it addresses *Advocacy* since we can't just talk about death without concentrating on the individual's life- especially the Quality of life. Advocacy is one way of supporting one's quality of life. This article will center on advocacy as it pertains to healthcare decision making.

“As Long as I have breath...I will advocate for you”

Practical Guide for Advocating for Healthcare

I recall an incident that had occurred a long time ago that prompted me to redefine my approach to advocacy. A Case Manager (CM) had a client who was in the ICU as he had become seriously ill – suddenly and unexpectedly. The CM was frantically trying to find someone who could make healthcare decisions for this patient since the hospital policy stipulated that a person who was “mentally retarded” needed to have a guardian [n.b. that policy has since been revamped after many discussions, educational trainings and negotiations]. Unfortunately, while the CM was making phone calls to locate a healthcare decision maker, the client passed away. This was disheartening to the CM as she wanted to be there with the client since his estranged family members had not yet arrived at the hospital and she felt he “died all alone.”

That incident forced me to take a closer look at the role healthcare decision making has on assuring good quality of life; and the importance of having plans in place while things are going well as opposed to waiting until conditions become critical. I know, oh too well, how easy it is to fall into the trap of taking the stance of *crossing that bridge when we come to it*, especially when there are no current emergencies and the individual is doing fairly well. Yet, we know that things can change overnight and that if safety nets are not in place- in this case-not having a healthcare decision maker – valuable time can be spent trying to put out the fire. Those moments could have been used, instead, to have quality time with the individual in the hospital or at his/her bedside.

I understood then that all my efforts, as an Advocate, should not be so much about sickness and/or death, but to work on assuring that the individual has sufficient supports to uphold a good *Quality of life*- throughout the time we work with each individual! Yet, I know down the road, time will have to be designated for end of life planning. However, for the most part- supports have to be available for a person’s *life*- ascertaining that the individual is happy, comfortable, and healthy. This needs to be within the realm of his/her physical/mental conditions; and that choices made by or for this person should be wholesome and sound. This also involves healthcare decision making.

Although, we strive to be omnipresent, reality dictates that we are not; and there is no guarantee that we will have the opportunity to say our proper good-byes to all of our clients. Nevertheless, it is incumbent upon us as team members to confirm that plans are in place, and to make sure that the healthcare decision maker is *actively and ardently* involved in the decision making process whether this role is carried out by the individual him/herself or a surrogate.

So let’s explore some premises or concepts to keep in mind:

- 1) Healthcare and Quality of life go hand-in-hand

- 2) It is imperative that **paid Interdisciplinary Team (IDT) members** (e.g. Case Managers, therapists, etc.) *are always guided by the fact that they do not ever make healthcare decision for the individuals they serve! We can advise, but not decide.*
- 3) *Keeping the above in mind, the identified healthcare decision maker or surrogate should be a regular participant at meetings (in –person, sending a designee or via conference calls) and that it is essential that a synergistic connection is developed among the healthcare decision maker(s) and the IDT members (paid staff)for the welfare of the individual they serve*
- 4) *Regardless of who the healthcare decision maker is, when it comes to communication, s/he should have a reciprocal and professional rapport with the other IDT members (individual, Case Manager, House Lead, etc.,) whereby information is effectively and securely shared at the appropriate time and with those who should be made aware of the information*
- 5) *Distinguish between when the Healthcare Decision Maker has the sole responsibility of making an informed **healthcare decisions** (captured on a Decision Consultation Form) vs. when the IDT, as a whole, can put their heads together to come up with a viable, **non-healthcare- related** decision as one unit (captured on a Team Justification Form)*
- 6) *Each member has his/her role, so no one is left out, but call it the nature of the beast or the luck of the draw... the Case Manager is responsible for generating and completing certain documents (e.g. Decision Consultation Form) or assuring that the documents exists (Plenary Guardianship Letters)and that a copy is at the residence, Day program, etc. in regards to Healthcare Decision Making*
- 7) *Forewarned is Forearmed- Have preliminary discussions with the individual when things are going well, especially when it comes to healthcare. Having the “we will cross that bridge when we come to it” approach is not often prudent-as you will come up on the bridge faster than anticipated. Of course, this does not mean that you have to have all the answers right then and there. What it does mean is that one can get peace of mind when the “what if “ forms and documents are in place. For example- what if a guardian were to get into an accident – who would make decisions in his/her stead? Having a designated person can help. Provisions of the NM Uniform Healthcare Decisions Act would allow a surrogate to be chosen in this instance. However, through a Power of Attorney, a guardian could choose an adult to take over the guardianship role and duties for 6 months while the guardian is recovering (check Probate Code section 45-5-104).*

Basics in Healthcare Decision Making 101

I. Healthcare

Make appointments and keep regular check-ups. The Primary Care Physician or practitioner (PCP) should be the hub coordinating information between the PCP's office and the patient's Specialists/specialty clinics. This is the time when the left hand *should know* what the right hand is doing. It should also be clear why a person is going to an appointment so that the medical team does not have to use up valuable time guessing. Pertinent documents with current information should accompany the patient at the doctor's visit each and every time (e.g. **Health Passport including the MAR, Physician Consult Form, Referral Form**)

Regular check-ups are a must so that early detection of unforeseen diseases or conditions can be treated. In preparing for the doctor's visit, assist the individual in jotting down questions or concerns so that they can be addressed with the physician; check them off your sheet once the issue or question has been addressed. Believe it or not, patients or their representatives will come to our specialty clinics forgetting to inform us that the patient was in the hospital and was discharged only a few days prior. Healthcare Coordination is key (through an assigned IDT member to keep track appointments, confer with the nurse, etc.) as well as the MCO (Presbyterian, BCBS, United Health, etc.) Care Coordinator (which is a service that comes with that insurance and is complimentary to the Case Manager so an individual *should* and can have both since one does not replace the other).

IDT members must stay on top of things such as changes in health conditions whereby appointments and/or medical consultations should take place. We must find out what symptoms or signs should warrant a call to the physician's office. Continual communication with the healthcare decision maker can also make a difference so conditions are addressed in a timely manner and healthcare plans are developed or adjusted. Now, speaking of healthcare decision makers:

II. Healthcare Decision Makers

There are 4 main categories of healthcare decision makers and each must be an adult with "capacity" in order to be the rightful or legal decision maker. According to the New Mexico Uniform Healthcare Decisions Act- "**Capacity**": an individual's ability to understand and appreciate the nature and consequences of proposed health care, including its significant benefits, risks and alternatives to proposed health care and to make and communicate an informed health-care decision." In lay man's term- the person must be of sound mind and body or have his "wits about him."

- 1) The non-adjudicated adult – an individual 18 or older who is capable of making his/her own decisions (capacity).

Advocate – for the person's right to make informed decisions, have it on paper and filed (e.g. Advance Directives). Anyone can get into an accident or suddenly get sick. The non-adjudicated adult should have those documents in place giving another trusty adult (not a paid staff) the authority to carry out his/her medical preferences in the event that he/she were to become incapacitated. Use one of the forms listed:

Forms – *Advance Directives, Five Wishes, Living Will, Durable Power of Attorney, Decision Consultation Form* to capture the informed decision in writing (re: a recommendation), and to prompt modifications on documents (e.g. ISP, MERP) accordingly

Challenge to Advocacy - If it is not apparent that the Individual has capacity, testing and assessments should be looked into and scheduled. Do not confuse capacity with lack of good judgment. Just because a person does not agree with a medical recommendation, dabbles into risky behavior or may procrastinate when making healthy choices... does not necessarily imply that the individual lacks capacity. Assessments should be conducted by 2 medical professionals one of which ideally should be the PCP and familiar in working with the I/DD population. **Until there is an official determination that the individual lacks capacity, the individual should continue to make his/her own decisions.**

Some individuals do not have capacity and never was deemed to have capacity even before he/she turned 18 years of age. Yet, families do not (or will not) petition for guardianship for various reasons (e.g.cost) and will resort to initiating a Power of Attorney (POA) form. The POA is not ethically or lawfully appropriate, in this case, because for a POA to be bona fide, the Principal has/had to have capacity at the time of signing the POA. Consider this- more and more hospitals, banks, establishments, etc., are protecting themselves from liability and are not going to play “Simon Says.” So, don’t be surprised if the administrative staff asks for alternatives, which may include requesting temporary guardianship, if there is a question of one’s ability to make informed decisions.

➤ Suggestion:

-If cost is an issue, contact **Office of Guardianship at DDPC** (505) 841-4519
To get information about the Guardianship program.

- Schedule **Assessments for determining Capacity**. Take care of this sooner than later- you don’t want to wait for a crisis to be the motivator.

2) Power of Attorney Agent, attorney-in-Fact, or Healthcare Proxy- an Agent (w/capacity) is authorized to act on behalf of another (Principal w/capacity) to make healthcare decisions and/or financial decisions (for the Principal)

Advocate- Ascertain that his form is used *properly* and that the Principal had capacity at the time this form was signed. Confer with Principal that the current Agent is still the person to make healthcare decisions for him/her. Durable POA is suggested so that in the event that the Principal was to become incompetent or lose capacity, the document would still be in effect. Although POA for healthcare does not require notary, it is *recommended* that it is signed, witnessed and notarized.

Forms – *Durable Power of Attorney, Power of Attorney for Healthcare & Finance, NMPOA, Decision Consultation Form* to capture the informed decision in writing (re: a recommendation), and to prompt modifications on documents (e.g. ISP, healthcare plans) accordingly.

Challenge to Advocacy -Since this tends to be the “go-to” or “fallback” form when a family does not want to take on the guardianship route, it is imperative that it is clear that the Principal- the Individual whose name is on the POA & ISP- has capacity. Please do not let this slide because one establishment chooses to look the other way. We are protecting the person when we make sure that the individual has capacity and can make his/her own decisions or give consent. When that is not the case, then we have to put the **safety nets** in place by identifying a surrogate who can be in that individual’s best interest while we arrange for capacity assessment and possibly seek guardianship. We never want to set up the individual where he/she will be targeted and taken advantaged of because of his/her lack of capacity. No one wants to remove anyone’s right to make decisions, but if s/he lacks capacity, then we do not want to leave them vulnerable and in a precarious situation. That is not advocacy!

If the Principal *does* have capacity, then please remind the Principal that he/she is in the driver’s seat and that the Agent should act on his/her behalf in the event that the Principal is unconscious, in surgery, etc. Otherwise, the Principal should be making his/her own decisions on a regular basis. POA typically kicks in when the Principal is incapacitated (unconscious) and unable to make healthcare decisions. Just because the form is a “Power” of attorney, does not mean that the Agent should be Powering- over the Principal. Nor is the POA a guardianship! So, as an advocate, we should promote independence on the part of the Principal (capacity). Do not give more authority than is indicated on the POA form- this is especially true when the Agent has always had a position of authority, as in the case of parents taking on the role as Agent. **Remember, we are there to serve the individual (the person whose name is on the ISP)!!!!!!**

➤ Suggestion:

- Getting official documents notarized is a good practice, (hopefully) it will reflect that the Principal initiated and signed the POA on his/her own volition. The Principal should not be under duress, threat, seduction, etc., in order to complete the POA. Check that information is current and accurate at least once a year (i.e. during the annual ISP) since oftentimes these documents have no expiration date and are still valid until revoked or changes are made with a new, updated POA.
- 3) Guardianship- An adult (capacity) who is appointed by the court to act on behalf of an individual (Ward) who has been deemed to lack capacity.

Advocate – Wards should have a voice and should be appropriately involved in activities and situations that can impact their lives. Even though they have a guardian, they still have human and some civil rights and should be treated with respect and dignity. We should promote and encourage the Ward to be independent and self-reliant in those areas where they can make progress and achieve success.

Develop a rapport and foster open communication with the guardian. Provide education and information so that the guardian can make informed decisions. Ask questions for clarification more so than to be judgmental. There are different types of Guardianship (Full or Plenary, Limited, Testamentary, Treatment, + Conservatorship/finance/property). You should ask the guardian to see his/her “Letters of Guardianship” from the court so that you know to what degree of authority the guardian has in making decision for the ward. For example, there is a big difference between a Limited guardian and a Plenary guardian (check www.nmddpc.com for the types and description of guardianship).

Forms – *Decision Consultation Form* to capture the informed decision in writing (re: a recommendation), and to prompt modifications on documents (e.g. ISP, MERP) accordingly.

Challenge to Advocacy – Full/Plenary guardians and guardians for Healthcare have the **sole** decision making authority in healthcare – consensus amongst the IDT is neither required or necessary. There may be times when one is not in agreement with a healthcare decision. Disagreements should not bring about disrespect. Discuss with your supervisor the appropriate course of actions you can take if (ethically, morally, etc.,) you cannot implement a healthcare decision. Please note that supporting a healthcare decision does not always mean that you are in *total* agreement of that decision. However, if one believes that the guardian is not in the best interest of the ward or there is suspicion of abuse, neglect, etc., you **MUST** take proper steps to report this matter (APS, DHI, Office of Guardianship, District court).

Even though paid staff are not healthcare decision makers for the ward, they are instrumental in educating and presenting materials to the guardian in order to make informed decisions. This is why it is imperative to establish open communication at the onset of forming the IDT so that sharing information is a regular occurrence. Emotions tend to escalate during serious medical trauma and it is ideal when the guardian can see the paid IDT members as a resource and vice versa. It is not easy being the guardian and healthcare decision maker- nor is it easy to be an IDT member...so work together, talk matters out and have empathy especially during these stressful times.

➤ Suggestion:

-Work with guardians - since it appears that out of all of the healthcare decision maker categories- this tends to have the most disparity- with the unfortunate potential of IDT gravitating to the circle (or on one side), while the guardian stays on the periphery (or other side). When we should be advocating for the IDT to consist of the Case Manager, guardian, therapist, etc. – with all members working towards inclusion, uniformity, two-way communication, and so on.

-Advocate for the team to discuss and resolve communication glitches-at the very first time that you notice them. If you allow things to steep, it may then result in miscommunication or information being given **conditionally** or the passive-aggressive

lag time in sharing information (“Oh, I thought you knew that...”) just to cite a few obstacles.

-It is poetry in motion when you have a strong and collaborative IDT. Aim for that and you will reap the utmost in synergy, resourcefulness, respect, two-way communication and superior quality of care. Fortunately, the one who benefits the most from this -is the Ward – the individual we serve! This helps the ward attain a wholesome quality of life with assurance that we/IDT are going to do right by and for him/her. Plus, the guardian does not have to feel “alone” when making those heavy healthcare decisions. If the guardian so prefers it, s/he can *consult* with the IDT members, mull over options and then, make an informed decision. That’s powerful!!

- 4) Surrogate Healthcare Decision Maker- when the individual does not have a guardian, a POA, or the adult lacks capacity, according to the *NM Uniform Healthcare Decisions Act*- a person (e.g. spouse, significant other, adult child, parent, sibling, etc.) can be asked to make healthcare decisions for the individual.

Advocate: Again, if there is concern of capacity, proceed to getting testing and assessments done. In the interim, contact Lisa Storti (505) 476-8972 at DDSD/Office of Constituent Affairs for a copy and instructions on the *DDSD form on Surrogate Healthcare Decision Makers*. You may also contact Ingrid M. Nelson, MS (505) 925-2374 at CoC as she has been deputized to explain and provide a copy of this same Surrogate form to the CM/IDT.

Forms: “*The Uniform Healthcare Decisions Act: General Information Regarding Capacity and the Designation of a Surrogate Healthcare Decision Maker –DDSD*”

Challenge to Advocacy: Temporary form – short term use. By activating this form, either a family member or friend of the family should step up to the plate to make healthcare decisions. *Simultaneously*, guardianship should be pursued either via family member or CM/IDT should look into acquiring a corporate guardian.

➤ Suggestion:

-When in doubt about capacity... use this form as opposed to utilizing a POA or looking the other way and going along with a person being his/her own guardian – when we could possibly be placing that individual in a very vulnerable situation. Do the right thing and advocate to keep the person safe.

Remember:

Healthcare decision makers should be accessible and alert the Case manager/IDT when a phone number or address has changed. CM and Direct Support Professionals (DSP) should periodically

confirm that the contact information is accurate and current. It's disconcerting to find out, in an emergency, that the contact information is not correct and you have no way of reaching them.

IDT should always request, read and keep a copy of the necessary documents that *verify* that the person has the legal authority to make healthcare decisions. Do not assume or loosely take anyone's word- stay vigilant as this is for *everyone's* protection.

Discussing healthcare options can be both a delicate and difficult topic for some. It is important to be mindful and respectful of cultures and values when broaching this discussion.

Support the individual in adopting healthy habits in regards to getting good sleep, eating a balanced diet and having regular exercise (in tandem with his/her health and physical condition).

Best way to encourage a good habit is to be an example of the good habit- if all IDT members had Advance Directives or Healthcare Decision forms in place on a **personal level**, they would most likely invest, on a **professional level**, in assuring that their clients have these forms, too.

Educate yourself on the laws and statutes that impact healthcare decision making. Knowledge is always power: read materials and attend as many trainings on this topic as much as possible- to get more tools in your advocacy tool box. Continue to advocate with integrity...for as long as you have breath!

A few resources to consider:

Resources

“*Guidelines for Community Programs, Case managers & IDT Members Regarding Advance Directives and Healthcare Decisions*” coc.unm.edu→ Advance Directives “**guidelines**”

“NM Uniform Healthcare Decisions Act” - UNM HSC Institute of Ethics (505) 272-4566
hsc-ethics@salud.unm.edu

“*Guardianship & Conservatorship for Adults in New Mexico*” (505) 216-1133
www.guardianshipalliancenm.org

Disability Rights New Mexico 1-800-432-4682

Office of Guardianship (505) 841-4549

Medical Consultations:

DDSD Regional Offices – Nursing, Case Management, Behavioral supports

TEASC (Transdisciplinary Evaluation and Support Clinic) – (505) 272-5158

COC (Continuum of Care) – coc.unm.edu (505) 925-2350

CDD (Center for Development and Disability) (505) 272-3000

HDR (Healthcare Decisions Resource) via CoC (505) 925-2350

DDSD BBS (Bureau of Behavioral Support) (505) 841-5500

DDSD/ CSB (Clinical Services Bureau) (505) 841-5500

Additional Forms (Search internet)

Ethics/Values- Values History UNM HSC Institute of Ethics (505) 272-4566
hsc-ethics@salud.unm.edu

Funeral Funds/Trusts

NM MOST (Medical Order for Scope of Treatment) www.nmmost.org

NM EMS/DNR EMS Bureau (505) 476-8200 www.nmems.org

Decisions Consultation Form- coc.unm.edu → Advanced Directives→ Informed Decisions regarding medical, healthcare, therapeutic services

Team Justification Form – coc.unm.edu →Advanced Directives→Decisions made regarding non-medical services and situations (e.g. vocation)

<http://nmhealth.org> (go to CoC Decision Consultation Info)

Respectfully Submitted _____ *Ingrid*

Ingrid M. Nelson, MS
Continuum of Care Sr. Program Manager