

*People Planning Ahead:
Communication of
Healthcare and End-of-
Life Wishes Through
Person-Centered
Planning*

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*If we have these
conversations, the
person will die....if
we do not have these
conversations, the
person will still die!"*

Ellen Cameron, Lower Cape
Fear Hospice

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**The Answer is:
Sex and End of
Life!**

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**Why We're Having This
Conversation**

- ◆ People with disabilities are living longer and aging
- ◆ Self determination is about all of one's life.....from beginning to end
- ◆ We help people plan their lives....why would we not help people plan the end of their lives?
- ◆ It makes no sense to wait until the 11th hour

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*We must consider that death is not
always "an incident"...only to be
investigated and documented on a
form.*

It is the final passage of one's life...

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Communication

- ◆ With the Person
- ◆ With Guardians
- ◆ With Spouses
- ◆ With Families
- ◆ With Staff
- ◆ With Friends
- ◆ With Physicians

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Critical Issues to Consider

- ◆ **Competency**
- ◆ **Capacity**
- ◆ **Perceived Incompetence**
- ◆ **Guardianship**

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Competency and Capacity

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Competency

- ◆ Competency is a *legal term*...it is determined by the courts
- ◆ Document how the person routinely makes decisions and what decisions he/she makes
- ◆ Ensure that the primary physician and/or therapist knows that the person is legally competent
- ◆ Start helping the person to have end-of-life-planning conversations with the doctor...well in advance of the need to do so
 - ◆ the doctor and/or any therapeutic clinicians *must* be an ally

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Capacity

Capacity is a *clinical term*...it is determined by *health professionals* in clinical settings by performing a "decision-making capacity assessment"

But.....

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But the problem is...

- ◆ not only "health professionals" can determine capacity
- ◆ There are currently NO *decision-making capacity assessment* tools for people with intellectual disabilities (not that we would want them...?)

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Four Components of Capacity

Catholic Lutheran Medical Foundation, 2000

1. The ability to understand that one has authority—that there is a choice to be made
2. The ability to understand information—elements of informed consent
3. The ability to communicate a decision and the rationale for it
4. The ability to make a decision which is consistent with one's values and goals and which remains consistent over time

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10 Myths of Capacity

Ganzini, Volicer, Nelson Fox and Derse, JAMDA – July/August 2004

1. Decision-making capacity and competency are the same thing
2. Lack of capacity can be presumed if the person doesn't follow medical advice
3. There is no reason to assess capacity unless the person goes against medical advice
4. Capacity is a "all or nothing" phenomenon

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10 Myths, continued

Ganzini, Volicer, Nelson Fox and Derse, JAMDA – July/August 2004

5. Having a cognitive impairment is equal to "lack of decision-making capacity"
6. Lack of capacity is a permanent situation
7. People who do not have relevant and consistent information about their situation and treatment lack capacity

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10 Myths, continued

Ganzini, Volicer, Nelson Fox and Derse, JAMDA – July/August 2004

8. People with certain psychiatric diagnoses lack decision making capacity
9. People who are involuntarily committed to a psychiatric facility lack capacity
10. Only mental health experts can assess a person's capacity

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Perceived Incompetence

- ◆ This is one reason not to do this at the 11th hour
- ◆ You need the person's doctors and therapists as allies
- ◆ Be able to demonstrate how the person makes decisions and again, what decisions the person routinely makes

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Guardianship

- ◆ Based on your state statutes, know what the guardian's role is (e.g., decision maker?)
- ◆ Know *ahead of time* what the guardian's wishes are
- ◆ Ensure that you have a good working relationship with the guardian...*even if you disagree with his/her decision*

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Five Points to Consider When Having End-of-Life Conversations

1. Choose the setting where you can have a one-on-one conversation with few distractions
2. Ask permission to have the conversation—you may be ready, but the person may not be

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Five Points, continued

3. *Talk about it—support the person to set the pace; be warm and caring; share that you're scared if need be*
4. *Be a listener—this is not a debate—truly hear what the person is telling you*
5. *Do your homework! Learn about end-of-life care options in your community and share what you learn with the person.*

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What We're Learning

- ◆ Future healthcare and end of life conversations are really emotional
 - we must build in a process for following up and staying connected to the person with whom we're planning
- ◆ People's experiences are frequently quite limited—we need ways to better explain what we're talking about
- ◆ Some people with disabilities have very clear ideas about what they want or do not want

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Learning, continued:

There are *HUGE* issues surrounding surrogate decision making

- ◆ People who have no non-paid support in their lives
- ◆ People who are capable but deemed incompetent
- ◆ People who are perceived to be incompetent

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Learning continued...

- ◆ Issues of faith, culture and religion are not being considered well
- ◆ Medical professionals are unsure of the "rules"...and even more so, the rights of people with disabilities

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Learning continued...

- ◆ Having future healthcare and end of life conversations takes practice...it can be anxiety producing for the facilitator and others involved
- ◆ As a facilitator, it is imperative to have a mentor the first few times to work through the process, the kinks, the nerves!

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"If we have these conversations, the person will die....if we do not have these conversations, the person will still die"

Ellen Cameron, Lower Cape Fear Hospice

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For information or assistance with training/development of facilitators and/or planning:

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