

**Person Centered Planning and Communication of End-Of-Life Wishes With
People Who Have Developmental Disabilities**

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ABSTRACT

Person centered planning is a common practice in most developmental disability systems. As people with disabilities are living to old age and being supported in the community as they age and die, there is an ever increasing need for advance care planning for people who have developmental and intellectual disabilities. ; that is, the organizing of advance directives. Since many people already have a person centered plan, the author suggests that use of a good planning process might be a logical next step for helping people communicate their end of life wishes. The author is clear that this is not about active or passive euthanasia, but is about helping people clearly communicate their wishes in the context of increasing age, significant infirmity or terminal illness.

Key words: person centered planning, advance care planning, Essential Lifestyle Planning, PATH.

As more and more people with labels of developmental disabilities are welcomed into their communities and are living in communities of their choosing; as more and more people with disabilities are experiencing self-determination (or some attempt from the system to support the principles); and as more and more people with developmental disabilities are living to old age, the need to think about advance care planning, including wishes about extraordinary treatment, advance directives and health care agents/proxies increases. Disability or no, Americans are not generally well-prepared to address end-of-life issues. It is a subject we avoid until a crisis hits. Nationally, it is estimated that at least 50% of people have not made their wishes known to someone else (personal communication, Ellen Cameron, MSW, Lower Cape Fear Hospice, April 2002). For people with developmental disability labels (such as mental retardation), the assumption is that that figure is even higher. This issue is not just about becoming critically or terminally ill, or having a disability that compromises one's health. This is about being self-determined and planning for one's life...*from beginning to end*. Self-determination should not start and stop at some mythical age. It does not stop when one gets old or when one is diagnosed with a potentially terminal illness. Self-determination ought to be about one's entire life.

"Person-centered planning has become the norm" (personal communication. Michael Smull, July, 2001). In many states, person-centered planning is legislated. If done well, we include in individuals' person-centered plans their friends, families, paid and non-paid supporters, their hopes, dreams, fears, clinical concerns, support needs, etc. End-of-life wishes and plans ought to be an integral part of an individual's person-

centered plan, too, especially if that person is very ill, aging or old. Having a developmental disability is not a prerequisite either. Good person-centered planning is equally effective with people who have dementia or other acquired disabilities. To be clear, this is not about passive or active euthanasia. This is specifically about helping people communicate their wishes (advance care planning) should they be unable to do so at some point in their lives. Although we spend much of our lives figuring out “how to live”, we rarely figure out what we want the end of our life to look like (assuming we have some measure of control over that at all). In the field of developmental disabilities, we have championed person-centered planning as a means for people to convey what is important in their lives and convey the way they choose to live their lives. We know that the core values of person-centered planning include autonomy for the person, attempting to honor his or her wishes while balancing health and safety and supporting interdependence, companionship and relationships. In using person-centered planning to help someone communicate end-of-life wishes, those values do not change.

One of the many questions to be addressed, and certainly not to be answered entirely here, is “how do we remain ethical and mindful as we use person-centered planning to help someone communicate end of life wishes, especially someone who is dying”? Botsford and Force (2000) have addressed this question to a certain degree: “Despite the fact that we each may have unique views about end of life, we need a core set of values to guide our decisions and actions in supporting people with intellectual disabilities...(There are) four principles that are applied in bioethical dilemmas...1) respect for the autonomy of the person; 2) do no harm; 3) do what is good and; 4)

justice”. As mindful person-centered planners, we should expect to apply those same principles if we were helping someone document and communicate his/her end-of-life wishes and/or if we were helping to support someone who was dying. Knowing this, and knowing that many people receiving supports and services already have a planning process in place in their lives, it makes sense to use person-centered planning to help people identify their wishes; for example, whom the person would like to have present if they were dying, how the person would like to be made comfortable if he/she requires support to do so, what kinds of treatment/intervention he/she wishes to have or not have, what type of religious or spiritual support he/she wants, etc. For people who do not use words to communicate (people with the label “non-verbal”) and for people who use augmented communication devices, writing this information down ahead of time is crucial. Not using words to talk is not the same as not communicating or having nothing to say. Most of us know many people who communicate quite clearly with behavior. Planning ahead and establishing an on-going conversation with the people in the person’s life who may be called upon to make an end-of-life decision should the person be unable, is a critical step. It may never be words from which we learn the information needed; but knowing someone well over time, how they communicate with their behavior and having that information up-to-date and written down may be exactly the information that decision makers will need. It is imperative that the person who is dying has his/her physician as an ally, in addition to other clinicians, family members and friends. Anyone who has had the experience of trying to make end-of-life decisions at the eleventh hour knows that planning ahead of time is a much better alternative.

Surrogate decision making may be challenging enough without the burden of not knowing someone's clear wishes and having a means to support those wishes. Again, this article is not intended to answer all these questions, but rather open a dialogue for thinking about ways to address them.

Additionally, holding conversations about end-of-life wishes with legal guardians is critical. For the many people who receive supports and services away from their family's or guardian's home, and especially people who have little or no family involvement in their lives, paid direct support professionals are likely to be providing the day-in and day-out support. Those professionals and usually care deeply about the individual with disabilities. They may even describe their relationship as "we're like family". They may also have a very clear idea of what they believe the person's wishes would be because they know the person well or because they have actually engaged in that conversation with the person. If however, the legal guardian's wishes differ from the person's (assuming the person's wishes are known); and if the guardian chooses to act on his/her wishes, direct care staff and others who know and love the person may be deeply saddened, angry and confused over the choices that are made. Several years ago I had the experience of providing support to a group of direct support professionals when someone they cared deeply for had died. Unbeknownst to them, the guardian made the decision to end nutrition and hydration. When the staff, who at that point were visiting the man in a nursing home, showed up and discovered this situation, they were terrified. Some agreed with the decision; some did not. That was not this issue; they clearly had no decision making authority....they're only role at that point was

to visit and provide companionship; but having supported the gentleman for many years, they loved him dearly and they just did not understand. They had no information. It is unfair to the person receiving supports and services and the people who support and love the person to not have end-of-life wishes conversations well before the time comes to act upon those wishes. Even if everyone intimately involved in the care and support of the person is not on the same page or does not hold the same beliefs, it is helpful for everyone to have a clear understanding of what to expect when the time comes. This is not to imply by engaging in advance care planning that “when the time comes”, everything will go smoothly or that it will be “easy”. A dear friend died of brain cancer several years ago; it was a slow and devastating process in his and his family’s life. When he died, a little more than 3 years after his diagnosis, his wife said “no matter what I thought about ‘how ready’ we were...we were not. I was absolutely not ready to lose my spouse...and no amount of planning (which we did a lot of) would have made me any more ‘ready’”.

Advanced care planning and communication of end-of-life wishes involves numerous parties: the person, the spouse, the family, the guardian, the provider, caregivers, friends, medical professionals, etc. We need to understand that end-of-life decision-making, like good person-centered planning, is not an *event* but an *on-going process*, and there must be a series of conversations, ultimately leading to decisions, based on the person’s, family’s, guardian’s experiences, values and beliefs. Trying to have these conversations, and make decisions and plans when people are under extreme stress, when they are sad and frightened makes no sense. One of the keys to

ensuring that this already-stressful-time is not made even tougher is good, on-going communication. One means of ensuring that communication is to recognize the person's and family's (or guardian's) wishes in the individual's person-centered plan.

One of the cornerstones of person-centered planning is action planning; a way to ensure that the people involved in helping to implement the plan follow through and are communicating with each other. One of the many ways that person-centered planning has always differed from traditional habilitation or treatment planning is that meetings are not just held annually to meet regulatory requirements. By coming together as needed and when it makes sense for the person and his/her family, on-going communication is supported and encouraged and the person's ever-changing life can be supported.

In looking at two of the most tried and true methods of person centered planning, Essential Lifestyle Planning (ELP), and Planning Alternative Tomorrows with Hope (PATH), one can see where each of these processes would be helpful to an aging or dying individual and the people who are supporting him or her. ELP helps people who are planning with and supporting someone to listen, learn, understand and act on what is both important *to* and important *for* the individual with whom planning is being done (Smull, 2001). In the context of planning with someone who is aging and or dying, ELP can help the person and caregivers specifically identify the important rituals, routines, supports, treatments and wishes of the aging or dying person. In *Twelve Weeks In Spring (1986)*, June Callwood tells the story of Margaret and her "care team", the men and women who circle around Margaret to support her to die at home. Throughout

Twelve Weeks In Spring, Callwood recounts numerous examples of rituals that bring Margaret comfort and allow for some consistency in her life, as her care team members come and go on a daily basis. There is way the birds must be fed; the way Margaret's tea must be fixed; the blanket Margaret uses as she curls up on her loveseat in the living room (even though some care team members believe her bed upstairs would be so much more comfortable); the ways Margaret wishes her care team members would keep her kitchen organized (as she did when she was well). Through the implementation of ELP, daily rituals that are vitally important to the person for a sense of routine and comfort, such as special mugs for tea and feeding the birds are not only identified, but are explained and understood as being *important to* the person in his/her daily life. A terminal illness might change the importance of those rituals, but it also may not. Understanding their role in the person's everyday life and how they should be carried out is one important aspect of an ELP. For a little more than seven years, I had the joy (and adventure) of supporting my grandmother in my home. With support from a wonderful husband and my mother, my grandmother was able to stay home with the support she needed following a severe stroke. For nearly the 80 years prior to her stroke, "Granny" drank Sanka coffee. Following her stroke, her tastes changed and she no longer enjoyed coffee. Short-term memory losses combined with a strong Scottish stubbornness however, meant that the ritual of coffee after dinner was usually not to be denied. So, for many of the seven years that she lived after the stroke, we fixed a cup of coffee after dinner. Reminding her "but you don't like coffee anymore" was futile. This was not so much about the flavor of coffee as it was a ritual of comfort. It is just

what “you did after dinner”. Since it always went down the drain, I suppose we were fortunate it was Sanka and not Starbucks brand!

In PATH, one begins the process with the “north star”; or the “where are you going...what is your dream?” question. Faye Wetherow, a gifted PATH trainer and facilitator says “when you ask people their dreams, you are walking on sacred ground” (personal communication, Faye Wetherow, May 2000). When people choose to share their dreams with us, they become vulnerable. What if we laugh? What if we disagree? What if we say it is impossible? When someone is aging, slowing down, becoming sick more frequently, or when someone is dying, it is easy to become more focused on the clinical aspects of life: medications, pain management, trips to the doctor, therapeutic treatments, etc. This is not to say that those aspects are not important; in fact, it may be impossible to focus on anything else until one’s pain is reduced. How often though, do we ask someone who is aging or dying what his/her dreams are? Would we feel uncomfortable asking that question of someone who was dying? In the context of end-of-life, dreams will likely look very different than they do for someone who, for example, is moving into his/her first apartment or looking to move from sheltered employment to a job in the community. As people age and sometimes slow down, we may forget about the question of dreams. We may wrongly assume that the person is “content” in their daily life and routine; which he/she may be; but maybe not? Does this mean we should not ask then? Why not ask differently? Why not spend some time exploring the person’s dreams? There may be dreams for their loved ones (e.g., a dying woman I knew had a dream that her daughter would always “be okay”); there may be dreams of

an afterlife or afterworld. There may be dreams of connecting with loved ones who have already died. Facilitating a PATH with someone who is aging or dying may bring comfort, a sense of respect for the person's wishes and concerns, and perhaps even a sense of inclusion or feeling valued; a sense of "even though I am old or critically ill or dying, what's important to me still matters." Recently I was asked to provide some guidance for staff supporting a young, dying mother with disabilities. The staff was concerned about helping the young woman "accept" the fact that she was dying and address the questions of healthcare power of attorney, extraordinary treatment, interventions, etc. The young mother had only one concern: her daughter. Although the other questions were important and need to be addressed sooner than later, clearly what was most important to the young woman was her concerns about her daughter. Those concerns had to be addressed first, before she was going to entertain any other topic of conversation. Her end-of-life decisions needed to be addressed in the context of her most pressing concern: what was going to happen to her daughter?

By asking someone what his/her dreams are, people who are supporting the person have a mission and a focus. It may even be that using any good person-centered planning process with someone who is aging or dying may also bring comfort to the caregivers; by establishing a clear set of expectations, defined by the person and those who love that person, caregivers may find that they feel more competent and more useful because they know they are doing something that is clearly important to and important for the individual, as defined by that individual. Using PATH, some of those things could be clearly laid out for the caregivers/supporters. Under the category

of “first steps”, very specific tasks are identified and participants in the PATH can claim responsibility. Using person-centered planning as the springboard for advance care planning absolutely requires courage and it absolutely requires that one be thoughtful and mindful. The first time I had an end of life conversation with a family whose son was dying (and a family I knew well), I was well prepared, had all my ducks in a row and was sure I was ready to go. Upon opening my mouth to begin the conversation, a different scenario emerged. My palms were sweaty, my heart was racing, and one would have thought I had a mouth full of peanut butter and crackers. “Person-centered planning raises, and can productively contain, many difficult ethical issues...Practitioners have an obligation to be thoughtful and courageous about when and how they plan with people” (O’Brien and O’Brien, 2000). Very few issues will raise one’s discomfort in the way that discussions around death and dying will. It used to be sex that made us uncomfortable and was a taboo subject, now it is end of life!

In Washington D.C. this year, with support from the Quality Trust for People with Disabilities and the District’s MR/DDA, we have just begun the *Life Choice Planners Project (LCP)*. LCP was conceived because of the need to address the aging and end-of-life issues that are facing a growing number of people with developmental and intellectual disabilities who currently receive services in the District. The project will use the six core skills of person-centered planning and coaching as established by The Learning Community for Essential Lifestyle Planning and using those skills as the foundation for planning, will then layer over that foundation information about aging and end-of-life issues. From there, in year one, we will develop a small cadre of planners

who will receive hands-on support and mentoring to become skilled coaches around aging and/or end-of-life issues, including such topics as how to balance what is important *to* a person while also ensuring that what is important *for* is addressed; the importance of daily, cultural, spiritual, etc. rituals; how to address issues of grief and bereavement; supporting people who have dementia, etc. Because each end-of-life scenario is unique to the dying person, the coaches' skills will be around good planning and access to resources, not specifics about diseases and terminal illness (though some of that learning will naturally occur). One of the issues that seems to matter a lot to agencies and staff is "what do we do once we know someone is dying"? We hope that through LCP we will develop a network of people who feel somewhat more at ease with this question and have a toolbox of skills and resources to coach the people who are actively supporting the dying individual.

Why should we help people who have developmental disabilities communicate end of life wishes? They have a right to be active participants in their healthcare, just as people without disability labels. People with disabilities, their spouses, loved ones, friends, family members, guardians, provider staff, etc., need to know and understand what the options are. Physicians and other medical care providers need to have a greater understanding of the abilities of people with developmental disabilities and their right to be an active part of this planning process. Advance care planning should be a part of everyone's life, whether one has a disability label or not. Without communicating one's wishes, loved ones are left to make decisions of which they are often unsure and which could be in conflict with what the individual would desire. Use of a person-

centered planning process should not, and in many places cannot preclude the use of a specific form or process for one's advance directives and the naming of one's health care agent (durable power of attorney, healthcare proxy, etc.), but a thoughtfully considered person-centered plan can be the foundation for developing more formal directives.

Clearly one of the issues that must be addressed on an individual basis is that of decision making and informed consent. The purpose of this article is not to sort through that specific issue, however it bears mentioning as we learn more about how people with disabilities wish to participate in advance care planning. The Gunderson Lutheran Respecting Choices Program on Advance Care Planning suggests there are four components to capacity.

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.

Though not developed specifically for people with developmental or intellectual disabilities, the components may be one reasonable set of standards with which to begin the discussion. Furthermore, there is much additional literature on evaluating the capacity of individuals without mental retardation which can be used as a guideline for assessing "capability" for those with intellectual disabilities (personal communication,

Barbara Wheeler, 2004). Overlaying that knowledge with the issues of advance care planning is one next logical step in this discussion.

The use of person-centered planning ought to support conversations around what is important to and important for the person; what matters in everyday life; what the person's values are; what their hopes, dreams and fears are; what supports are needed for the person to have a meaningful and quality life on their terms; and how all of those elements can be supported and honored as the person ages, acquires a disability and/or is dying. Self-determination applies to one's whole life---and advance care planning, which can be accomplished as part of trusting and mindful person-centered planning, must be a part of the process.

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