
Project BRIDGE — People with Disabilities Participate in Their Health Care Decisions

by Don F. Reynolds

Project BRIDGE is a complex of activities through which individuals affected by major mental illness, developmental disability, or the effects of aging become engaged in their health care decision making. This article explains the development of BRIDGE through the profound stories of Julia Warren, Theresa Draper, and Jim Overstreet.

In 1991, Midwest Bioethics Center and Missouri's largest public guardianship office, the Jackson County Public Administrator, established BRIDGE as a service to more than 1,000 people for whom the office serves as guardian. In 1993, the Institute for Human Development at the University of Missouri — Kansas City and Midwest Bioethics Center extended BRIDGE to serve people with disabilities without respect to their guardianship status. BRIDGE is concerned with three health care decision-making situations:

1. When people with disabilities are capable, BRIDGE seeks to ensure that they are encouraged to participate in their health care decisions.
2. To prepare for those times when they cannot participate in their health care decisions, BRIDGE provides opportunities for people with disabilities to express their health care preferences to the people who help them.
3. When people with disabilities have not expressed their preferences and are unable to participate in their health care, BRIDGE seeks to ensure that appropriate surrogates and health care providers make thoughtful, compassionate, shared health care decisions.

The Julia Warren Story

When Julia Warren died in July 1993, she was a ward-protectee of the Jackson County (Missouri) Public Administrator. Her guardianship had been formed in March 1991, when she was seventy-three years old and hospitalized for a urinary tract infection and respiratory failure. She had other health problems: coronary artery disease, severe systemic arteriosclerosis, chronic anemia, hypothyroidism, and bedsores; and both her legs had been amputated above the knee. Less than two months after her guardianship was formed, Julia slipped into a persistent vegetative state.

In the 1990 decision of Nancy Cruzan's case (*Cruzan v. Director, Missouri Department of Health* [497 US 261]), the U.S. Supreme Court concluded that our Constitution allows surrogate decision makers, like Julia Warren's guardian, to direct life-prolonging care for people who cannot make or communicate their health care decisions. In the Cruzan case, the court assumed that participating in health care decisions is among the liberty rights protected by the U.S. Constitution.

Liberty rights are not absolute. The Missouri Supreme Court had limited the authority of health care surrogates in its 1988 decision of *Cruzan v. Harmon* (760 SW 2d 408 MO), by holding that in

some cases, surrogates cannot consent to the withdrawal or withholding of life-prolonging care unless the decision is based on a stated preference of the patient.

When Julia Warren's physician asked her public guardian to consent to a Do Not Resuscitate order, he placed her in a legal thicket almost as impenetrable as her health care situation. The Missouri and U.S. Cruzan decisions were rippling unevenly through Missouri. County-by-county, judges decided the extent to which they would become involved in the life-prolonging care of persons under guardianship. The judge who oversaw Julia Warren's guardianship required guardians to obtain his approval before consenting to the withdrawal or withholding of any life prolonging care.

Parallels with the Cruzan Case

Nancy Cruzan's guardian had requested the withholding of tube feeding. Whether the Missouri Cruzan decision required that every surrogate decision to withdraw or withhold life-prolonging care be based on the actual preferences of the patient, or only those involving tube feeding was unclear. The judge who oversaw Julia Warren's guardianship would not permit guardians to withdraw or withhold any life-prolonging care unless he was persuaded that withdrawing or withholding care furthered the ward's expressed preference.

Julia Warren had not asked her physician to write a Do Not Resuscitate order for her. No one knows if she had ever expressed any health care preferences.

While the last chapters of Nancy Cruzan's and Julia Warren's lives shared the bleakness of persistent vegetative state, their prior lives could not appear more disparate. Nancy Cruzan's family and friends remember and talk about the values that informed her life before a car accident reduced her to a persistent vegetative state. No one remembers the young Julia Warren. She was a stranger to the people who cared for her and an unbefriended biographical enigma to the courts that decided her case.

Because he thought attempted resuscitation would not be in her best interest, Julia Warren's guardian asked the court to approve a Do-Not-Resuscitate order for her.

Guardianship/Surrogacy

Public guardianship is the practical response of a community that is concerned for the welfare of its members who need help. Contemporary social phenomena have increased the demand for public guardianship. As the population ages, more people experience age-induced cognitive impairments.

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Scattered brothers and sisters, divorced spouses, and disaffected children are poor candidates to provide support. People with developmental disabilities are beginning to routinely outlive their parents. However, in the drive for community-based solutions to serious mental illnesses, the entire system of institutional supports was dismantled before a sufficient system of community supports was in place.

Poverty and public guardianship positively correlate. More than 90 percent of the ward-protectees whom the Jackson County Public Administrator serves as guardian are indigent. Care providers know they need to dot their *i*'s and cross their *t*'s before withholding or withdrawing life-prolonging care. However, the *i*'s and *t*'s are sometimes ambiguous. Sometimes health care providers seek public guardianships as a way to unload the responsibility of managing this ambiguity.

Surrogates are concerned with the health care situations of the patients for whom they make health

care decisions. The health care situation of a person with a disability consists of both an observed and an experienced story.

The "observed" story is the objective part of a person's health care status and the array of plausible responses to it. The observed story of a person with a disability includes those aspects of life that affect one's health care. These may include an underlying disability, guardianship, incapacity, and membership in a group that does not routinely participate fully in health care decision making (e.g., the frail elderly, mentally ill, or developmentally disabled).

The "experienced" story is the subjective part of a person's health care status and the way a person understands his observed story. Experienced stories reflect personal interests and values. They explain why one plausible response is most fitting. An experienced story relates a person's perception of health care to her observed story by expressing how she deals with life, including incapacity, disability, and guardianship.

The health care decisions that surrogates make are justified by the principles of best interest and substituted judgment.

Best interest decisions occur when surrogates, who do not know the patient's health care preferences and values, base their health care decisions on considerations of patient welfare such as relief of suffering, preservation or restoration of function, and the quality and duration of life. An *interest*, in the context of surrogate decision making, is the preference that a similarly situated patient who possesses complete information would express. A best interest decision reflects the patient's observed story, but not his experienced story.

Substituted judgment occurs whenever surrogates make health care decisions based on the health care preferences and values of the people they represent. Within the array of plausible responses to his or her health care situation, a patient will judge one to be most fitting. For that patient, this most fitting response is the right health care action. Right health care actions are the goal

of health care decision making. Substituted judgment permits surrogate decision makers to approximate right health care actions. A substituted judgment reflects the patient's experienced story in addition to her observed story.

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Right health care actions are plausible, fitting, and patient selected. Since personal participation is integral to right health care action, it is always good for people, including people with disabilities, to participate in their health care decisions. Since personal participation is not always possible, some surrogate decision making is necessary.

Assisting the Surrogate

When surrogates do not know the health care preferences and values of the people they represent, they use the best interest standard. Best interest is a problematic standard for surrogates who serve people with disabilities because it requires them to factor the disability itself into their decision making in order to construct the "similarly situated patient." A theme of the BRIDGE project has been the inability of surrogates and potential surrogates to predict the preferences of the people that they serve who have disabilities.

Based upon their observed inability to predict health care preferences, it seems likely that well-intended surrogates frequently make best interest decisions that are at odds with the unstated preferences of the people they represent. Therefore, health care surrogates who serve people with disabilities have a particular need to hear from the people they serve.

By inviting, listening to, and reporting the stories and health care preferences of people with disabilities, BRIDGE helps surrogates answer three questions:

1. As shaped by the health care situation, what are this person's views about health care and life-prolonging treatment?
2. Given the health care situation, which among the available health care actions are plausible for this person?
3. When measured by this person's views, which plausible health care action appears to be most fitting?

After the probate court denied the request of Julia Warren's public guardian for permission to consent to her Do Not Resuscitate order, he appealed to the

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Missouri Court of Appeals. On July 13, 1993, the Court of Appeals reversed the probate court's decision and narrowed the range of cases to which the Missouri Cruzan Decision applies (*Murphy v. Wheeler*. 1993. 858 SW 2d 263). Because of Julia Warren's case:

1. Missouri guardians no longer need to obtain a court's permission before consenting to Do Not Resuscitate orders on behalf of their wards.
2. In Missouri, surrogates may consent to Do Not Resuscitate orders without knowing the preferences of the people they serve.

3. Missouri's requirement that a surrogate's decision to withdraw life-prolonging care be based on the patient's expressed wishes only pertains to cases involving artificially administered food and water. Other life-prolonging care may be withdrawn or withheld by a surrogate so long as the decision furthers the patient's best interests.

The Theresa Draper Story

Julia Warren is one bookend of the BRIDGE project and Theresa Draper is the other. On September 1, 1992, Theresa made the following statement.

I believe the better my life and my values are known, the more likely it is that health care decisions made on my behalf will accord with my wishes. Because my mental health condition threatens my ability to make such statements, it's important for me to express the following health care preferences now.

If my doctor believes a health care treatment or procedure can provide comfort, relieve pain, or lead to a significant recovery, I want my doctor to try that treatment or procedure. I'd want my doctor to try such a treatment or procedure even if it might cause me to lose my appetite, cause my breathing to slow down, or be habit forming. However, if a treatment or procedure doesn't do what my doctor believed it would, I want my doctor to stop it even if stopping the treatment or procedure might shorten my life.

If I have an irreversible, incurable illness or condition from which I'll soon die, I don't want my doctor to start any life-prolonging health care treatments or procedures. If such treatments or procedures are started, I want them stopped.

If I have an illness, condition, or injury from which there's no reasonable hope that I'll return to a life which will for me be better than death, I don't want my doctor to start any life-prolonging health care treatments or procedures. If such treatments or procedures are started, I want them stopped.

One life-prolonging health care treatment or procedure which I'd prefer not be started or if started, stopped, is tube feeding.

Other health care treatments or procedures which I'd prefer not be started or if started, stopped, are mechanical breathing and heart shock treatment.

If, while I have an illness, condition, or injury which is terminal or from which there's no reasonable hope that I'll return to a life which for me is better than death, I experience a potentially reversible acute illness or condition (such as a stroke, heart attack, or pneumonia), I'd prefer not to be resuscitated or transferred to a hospital for its treatment.

If acceptable for the purposes of transplantation or medical research, at my death I'd like to make the following organ donations which are listed on my organ donor card — eyes to be donated to the Kansas City Eye Bank; brain to be donated to the Brain Tissue Resource Center of the McLean Hospital in Belmont, Massachusetts.

To further explain my life, my values, and my health care preferences, I'm making the following comments.

I know how burdensome prolonged dying can be to a family because my father's final illness dissipated our family's finances. My chief health care concern is that a future illness will impoverish my daughters in the same way.

I hope my death will be a natural one.

I believe God has a plan for my life and for my death. I believe the time of my death is in God's hands. I do not want unnatural things, like being connected to machines, done to intervene in my dying.

In the future I hope my guardianship will be ended. However, while I'm a ward I trust my (public guardian) to make health care decisions for me.

The case of Karen Quinlan illustrates two things that I hope to avoid by expressing my health care preferences — the use of health care machines to prolong dying and the use of health care machines to make dying more burdensome to a family.

The case of Christine Busalacchi illustrates why I would prefer that tube feeding not even be started — the risk that having once been started, the procedure cannot be stopped.

Prior to expressing these health care preferences, I obtained information about advance directives from Midwest Bioethics Center and from the American Bar Association. Also, I've discussed making advance directive-like statements with my case worker and two hospital social workers.

An Unlikely Outcome

When Theresa Draper made her health care preference statement, she was forty-three years old, divorced, a mother, a grandmother, and hospitalized in a psychiatric unit. And, she had a public guardian.

In 1970, following the birth of her first daughter, Theresa experienced a postpartum depression that was mistakenly diagnosed and treated for seventeen years as schizophrenia. They were rough years: twenty-two shock treatments, a divorce, too many of the wrong psychotropic drugs, lost custody of her daughters, long stays in state mental hospitals, depleted family relationships and, following a suicide attempt, six comatose weeks as "Jane Doe."

In 1987, Theresa got a public guardian and a new diagnosis, bipolar affective disorder and mixed personality disorder. Theresa evidences essential hopefulness in that she has been able to convert these modest gains into the foundation for a better life. She is, however, not always hopeful and her life continues to be filled with accommodations to her mental illness, including occasional hospitalizations for depression.

In the summer of 1992, Theresa's happiness about becoming a grandmother was overtaken by fear that she would physically harm herself, thereby, placing a financial burden on her daughters and somehow harming her new granddaughter. Theresa made her usual response

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to anxiety. She devised a plan, and she despaired. Before she could execute her plan to make an advance directive-like expression of her health care preferences, the despair led her to a hospital psychiatric unit.

It seems unlikely that Theresa could convince her case worker to cap a week spent dealing with the issues of homeless, broke, confused, ill, and recently arrested wards by paying a five o'clock Friday afternoon visit to a psychiatric unit to attend to her historically pointless act of expressing health care preferences. But she convinced him. It seems unlikely that Theresa could convince two social workers and a psychiatrist to affirm her health care decision-making capacity while she was hospitalized for depression. But she convinced them. And though the expectations of others were modest, Theresa delivered a powerful statement of her health care preferences.

It is not, however, the completeness, eloquence, or improbable setting of Theresa's statement that makes her story important. It's not that she has only been hospitalized once in the seven years since she expressed her preferences, and it's not even that a judge recognized her statement as a legal

advance directive. Theresa's story is crucial to BRIDGE because of how her public guardian responded to it.

Inviting and Welcoming the Ward's Participation

Before Theresa, BRIDGE was understood to offer public guardians a theory for increasing their power — allowing them to make health care decisions that the Missouri Cruzan decision would otherwise prohibit (*Matter of Jobes*. 1987. 529 A2d 434 [NJ]). Theresa's statement recast the BRIDGE methodology as a way to reduce a public guardian's power. It convinced her public guardian that by embracing a new way of thinking about how public guardians and their wards make health care decisions, he could participate in a steady stream of fitting health care actions. Wards ought to be invited to participate in health care decisions; and when they accept the invitation, the preferences they express ought to be decisive. Based on this insight, Theresa's public guardian adopted a simple approach to including his wards in their health care decisions — all would be invited to express their health care preferences, and any who expressed preferences would be welcomed participants in their health care decision making.

The Jim Overstreet Story

The third individual who most influenced BRIDGE is Jim Overstreet. With the permanently unconscious Julia Warren and the usually capable, always resilient Theresa Draper as bookends, the rich, complex stories of thousands of people like Jim Overstreet remain between the two.

Jim was born in 1970 with multiple disabilities including cerebral palsy, spastic quadriplegia, breathing problems, and seizures. He is an intelligent person who possesses only minimal ability to communicate, and who depends on the total care of others. He lives in a neurological long-term care center.

Jim's mother learned about BRIDGE and invited him to work with her to prepare a health care preference statement. On April 4, 1993, Jim's completed statement was delivered to Midwest Bioethics Center with the following letter from his mother.

I'm sorry we took so long in getting this finished, but here it is. I hope we did it properly. Jim was honored that you have so much faith in him and he worked very hard answering everything. It helped that I know him so well and so was able to present statements and thoughts for his approval a little easier than might be done otherwise.

The "values" went pretty smooth, but when we got to the actual health care preference statements, it was a lot harder for Jim to answer. He has already had many [life-prolonging] procedures done and he wasn't really excited by the idea of giving anyone a blanket "yes" or "no" to do or not do something to him. He's young yet and has a lot of living left to do. We finally decided that maybe the best solution was to try to put his preferences down on the "comment" section.

Jim's mother introduced his statement as follows.

Here at the beginning I would like to point out that since Jim is nonverbal, these are not his exact words, but my interpretation of his communications. The way we approached this was I explained to Jim what this was for, then I verbally presented a series of statements I thought he might want to say. He then communicated YES (by looking up and smiling) or NO (by looking down or shaking his head) or if he wanted to add or subtract something he would look at me and verbally try to make me understand. Then I would try to figure out what he wanted to say and he would instruct me by communicating YES or NO. After I felt I had it down I read it back to him for his approval. He was very cooperative and pointed out some potential problems for someone who is severely disabled like him.

Because of Jim's disabilities and condition he is concerned that the statements on the pages I have marked 1 and 2 could easily be misinterpreted by someone who doesn't understand him. He does not want to be experimented on by well-meaning doctors,

but if necessary he does want corrective treatments for his health and comfort and he does want treatment to save his life, if need be. Major surgeries are life-threatening in themselves because of Jim's brain damage and should only be considered as a last resort. Also he is so terrified of being unable to make doctors and nurses understand he goes into panic attacks. He has trouble breathing when these attacks hit, and he looks and sounds terrible; but he needs reassurance and to be calmed down.

He feels he has a quality of life that may not be apparent to the casual observer. He feels that life with disability, no matter how severe, can be good and fulfilling if you have a good attitude and a sense of humor.

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Jim's statement consists of his responses to eleven cues designed to elicit values that inform health care preferences.

- Some enjoyable things about my life are my family and friends, living at (this facility), social outings, teasing people, watching and visiting with friends.
- My chief present concerns are [that] I have no particular concerns at this time.
- My hopes for the future include getting to travel and maybe get a job.
- Some of my fears are going to the hospital alone, having surgery, not knowing or understanding what to expect or what is going to be done to me. Not knowing if I'm going to be taken care of in a particular situation. Being unable to make people understand what I need.

- My overall attitude toward my health is good right now. I don't usually worry about my health.
- My thoughts about personal independence and control include having my own room with my personal things in it. I like living at (the facility) and I don't want an apartment or anything like that. I don't care about controlling my environment (i.e., TV, radio, lamps). I might like to be more mobile, so I could go where I wanted to when I wanted to.
- My thoughts about personal and family relationships are [that] they are very important to me. I have lots of friends and really enjoy doing things with them. I really love my family and enjoy going home and visiting my relatives at family get togethers, especially July Fourth and Christmas.
- Some thoughts about the general circumstances of my life include [the following]: If I could have a choice, I suppose I wouldn't have been disabled, but since I was born with cerebral palsy, I have learned to accept it. There are worse things, lots of people have problems. I have had a lot of love and support during my life. I have a loving family and a lot of special friends. I enjoy my life.
- Some of my ideas about illness, dying and death are [that] I don't like illness, but it happens. I really don't like death, but it happens too. In 1992 I lost four of my friends to death in a six-month period. Two were roommates, two were especially close to me and I was with one roommate when he died. I went to his funeral and it was very hard on me. When my next good friend died, I couldn't bring myself to go to hers. She and another girl died in the same week. I was afraid that I was going to die too. Some counselors talked to me and gradually I came out of my depression and overcame my grief. I try not to think about it too much now.
- Some of my thoughts about faith and religion are [that] I believe in God, but I don't understand a lot of things.

- My thoughts about being a ward-protectee include [the following]: I need someone to help me communicate my needs and wants, and I like having help in making decisions so I am not taken advantage of. My guardian will usually ask my opinions and let me make my own decisions if she can so I feel more secure about being a ward-protectee.

Theresa Draper reached through her mental illness and her guardianship to insist on respect for her health care preferences. Neither her guardian, her psychiatrist, nor her judge could resist. Not all

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BRIDGE stories are so clear cut. Because of cerebral palsy, Jim Overstreet cannot speak. The way he communicates is very limited. Looking up and smiling is "yes." Looking down or shaking his head is "no." He expands or reduces statements by looking at the listener and making sounds. He only communicates with his mother and a few people at the facility where he lives. Those who communicate with Jim must be very patient and extraordinarily attuned to Jim's methodology.

After Jim expressed his health care preferences, a psychologist met with Jim and his communication partners to learn their practices. Over the course of eight hours of meetings, Jim persuaded

the psychologist that he values his life and wants to receive life-prolonging care that a surrogate applying the best interest standard might licitly withhold. To that extent, the psychologist confirmed Jim's health care preference statement. Two aspects of relying on such a synchronistic communication methodology are problematic. The receiving parties' opportunities to discern are restricted and the expressing party has few tools with which to correct a misunderstanding. According to the psychologist, Jim's methodology cannot reliably produce such long and complex messages.

Coordinated acts of inviting and listening can overcome the barriers that disability and guardianship present to people who participate in their health care decision making.

When expressive and/or receptive ability is materially diminished, communication can be an overwhelming barrier between an individual and his health care decisions. Jim and his mother spent twenty-four hours over six weeks creating his statement. The psychologist spent eight more hours evaluating it. Jim's story demonstrates that persons with the most limited communication ability have and can express health care preferences. However, his story also demonstrates that the BRIDGE methodology has limitations. If persons with profoundly limited communication ability are going to regularly participate in their health care decisions the methodology will need to be refined in ways that help listeners to discern and expressing parties to correct misunderstandings.

The Bridge Methodology

As Project BRIDGE continues, we have reached some conclusions. When BRIDGE was started, Jackson County's Public Administrator had

modest expectations. He thought one ward in ten might participate in some health care decision making. He hoped the health care preferences that ward-protectees expressed would occasionally bolster his authority to make health care decisions for them. When he left office, the public guardian believed seven in eight wards want to participate in their health care decision making. He had helped Theresa Draper's expressions of health care preference transcend her guardianship and achieve independent legal significance. Some public guardians now conduct their office on the basis that a ward-protectee's expressed health care preferences are decisive — that failing to honor them amounts to failing to act in the ward's best interests.

When people with disabilities are invited to express health care preferences, when they are determined to make their preferences heard, the people become participants in their health care decisions. Coordinated acts of inviting and listening can overcome the barriers that disability and guardianship present to people who participate in their health care decision making.

The methodology of inviting, listening, and respecting is person-centered, but not person-initiated. The presumption that persons with disabilities routinely have allies who will invite them to express health care preferences, listen to their responses, and bring the responses forward to inform health care situations is unproved. Whenever the allies of a person with a disability — family, friends, staff, guardian, health care professionals, incorrectly believe the disability or guardianship evidences an absence of valuable health care information, the person's participation in his health care decision making can be thwarted. Based on the pilot work of Midwest Bioethics Center, UMKC's Institute for Human Development, and a group of seven older adults who have developmental disabilities, integrating health care preferences into a mandated practice of person-centered-planning may be a partial answer to this problem (St. Clair 1996).

The messy, time-consuming BRIDGE methodology of inviting people to tell their stories and listening when someone accepts the invitation ensures that invitations are not perceived as commands and that listening does not favor any particular preference. The methodology was suggested by the pastoral care practices of professional chaplains.

The court orders that form guardianships do not extinguish the rights of ward-protectees to be informed of and involved in decisions affecting their health care, to assent to or dissent from treatment, to express preferences in anticipation of

future decisional incapacity, and to be dealt with honestly and truthfully. Notwithstanding, incapacity, disability, and the imposition of guardianship, personal dignity commands respect, including recognition that the person may know better than anyone how to respond to a health care situation. People with disabilities own their lives; the people who help them, including guardians, are just managing some of the details.

Reference

St. Clair, Becky. 1996. "People with Developmental Disabilities Focusing on Their Own Care." *Bioethics Forum* 12(3): 48-49.