
Health Care Treatment Decision-Making Guidelines for Adults With Developmental Disabilities

by the Midwest Bioethics Center and University of Missouri-Kansas City Institute for Human Development Task Force on Health Care for Adults with Developmental Disabilities

In December 1993, a multi-disciplinary task force convened by Midwest Bioethics Center and the University of Missouri-Kansas City's Institute for Human Development undertook the development of an ethically informed model by which adults with developmental disabilities could participate in their health care decisions. During twenty meetings over twenty-four months, the task force considered three issues.

- What health care decision-making model best serves the interests of adults with developmental disabilities?
- With respect to their health care, what are the rights of adults with developmental disabilities?
- What model best resolves questions about the decision-making capacity of adults with developmental disabilities?

Two paralleling activities informed the work of the task force.

- The Institute for Human Development sponsors a focus group in which adults with developmental disabilities discuss health care issues. Observations made in focus group meetings were brought to the task force and the focus group responded to the task force's preliminary conclusions.
- Midwest Bioethics Center sponsors a consortium of health care ethics committees. The consortium's work with the issue of decisional incapacity was reported to the task force and the "critical open process" that the consortium developed for finding decisional incapacity was adopted by the task force and incorporated into this document.

1.0 Decision-Making Model

The guidelines document reflects the task force's com-

mitment to a shared decision-making model which respects the important, distinct roles which health care providers, parents, guardians, and professional support staff may play in the health care decisions which adults with developmental disabilities make.

The health care decision-making model which the task force proposes for older adults with developmental disabilities has three components:

1.01 People who have decisional capacity have a right to make their own health care treatment decisions. When a person has decisional capacity, the fact that she also has a developmental disability is irrelevant;

1.02 When adults with developmental disabilities do not have decisional capacity, surrogates play a crucial role in their health care decision-making. In order to distinguish the authorization given or withheld by patients with decisional capacity (informed consent) from the authorization which surrogates give or withhold, the task force called such surrogate authorization, "informed surrogate permission." The task force concluded that giving or withholding informed consent is dispositive — that there is no ethical basis upon which a health care provider may resist it. However, the task force concluded that informed permission was less than dispositive and that health care providers have an ethical obligation to resist informed permission whenever they deem it to have been given or withheld against a patient's best interests.

1.03 When adult patients with developmental disabilities have what the task force called "incomplete decisional capacity," health care providers have an ethical obligation to solicit both patient assent and informed surrogate permission. Assent is the uncoerced expression of willingness to undergo a specific health care treatment which a person with incomplete capacity to participate in decision-making gives freely, based on his personal knowledge and understanding.

1.04 Both the second and third components of this decision-making model contemplate disagreements. Therefore, the model needs to provide conflict resolution.

1.05 Implementing this decision-making model challenges providers, parents, guardians, professional staff, health care providing organizations, and adults with developmental disabilities. To help them meet these challenges, the task force encouraged Midwest Bioethics Center and the University of Missouri - Kansas City Institute for Human Development to develop two instruments:

- a training video, *Health Care Choices: Health Care Decisions*; and¹
- a *Health Care Preferences Journal*.¹

2.0 Rights of Adults with Developmental Disabilities as Patients

When the task force began considering this issue, it assumed that people with incomplete decisional capacity necessarily had different rights than people with decisional capacity. However, the task force ultimately decided not to make this distinction. The task force's conclusion that individuals with complete and incomplete decisional capacity have identical rights to participate in their health care may suggest that the status of autonomy as bioethics' trumping principle is ebbing.

Although this document presents them in a hospital setting, the following rights pertain equally in every health care setting (that is, long-term care, home care, medical office).

As a patient you have the right to:

2.01 Know the names of the people who work here and how they will help you;

2.02 Be told who the doctor is that will be taking care of you;

2.03 Tell the nurses and doctors what you like, what you don't like, what's important to you, and what you believe in;

2.04 Know what the people who work here think is wrong with you, what they think can be done about it, and what they will be doing for you;

2.05 Be taken care of in a nice way by all the people who work here;

2.06 Help choose which treatments you will get;

2.07 Be told the hospital's rules for taking care of patients;

2.08 Ask questions about treatment. Some things you

may want to ask:

- Why do I need this treatment?
- What will be done to me?
- How will this treatment help me?
- What will happen to me after I have this treatment?
- Can the doctor do something else?
- Do I have anything to be afraid of?
- Can anything bad happen?
- Will this cost me anything?
- How do you expect me to pay (all at once, per/month)?

2.09 Have personal privacy;

2.10 Have your family and other important people with you as much as possible. When it isn't possible to have people with you, the people taking care of you will explain why;

2.11 Know that the people who work here won't talk about your care with anyone else unless you say it's OK;

2.12 Be treated fairly;

2.13 If it's OK, get what you ask for;

2.14 Be given help dealing with your

- pain
- uncomfortable feelings
- excitement, worry, fear, nervousness, and sadness
- spiritual matters

2.15 Get help from other doctors when you need it;

2.16 Get help regarding ethical issues surrounding your care from the hospital's ethics committee;

2.17 Have any of the following people help when you decide whether a treatment is right for you:

- chaplain
- your doctor
- your nurse
- patient representative
- social worker
- ethics committee

2.18 Not be moved to another hospital or facility without being told why and asked if it's OK;

2.19 Not be part of a new treatment or educational project unless you agree;

2.20 If you complain about your care, be listened to and when possible have your complaint taken care of;

2.21 Be told how to take care of yourself when you get home;

2.22 See your bill and be told what the charges mean;

2.23 See the papers which the people who work here have about you and have those papers explained to you;

2.24 Say what you want done if you have bad problems

in the future;

2.25 Choose someone to tell us what you want, if you can't tell us.

Whenever you have questions regarding your rights, or if you want to tell someone that you are not being given your rights, call (name or title) at (phone number)

3.0 Decisional Capacity

For some adults with developmental disabilities, questioned decisional capacity is a significant barrier to their participation in health care decision making. The guideline document addresses this issue in four ways:

3.01 By carefully defining decisional capacity.

3.02 By affirming the presumption that every adult, including adults with developmental disabilities, has decisional capacity. Respect for the autonomy of persons is central to clinical ethics. Among the principles of ethical conduct which derive from autonomy are respect for self-determination, shared decision making, informed consent, truth-telling, and confidentiality. Health care providers ought to honor these principles and accept the patient as an equal partner for making decisions.

3.03 By offering a values sensitive, critical open process for assessing the web of factors which influence whether adults with developmental disabilities lack decisional capacity. This process always includes the adult and the persons providing the care with respect to which decisional incapacity is an issue. In some cases it may also involve surrogates and professional staff. Since decisional capacity is a prerequisite to participation in an informed consent process, decisional incapacity is most problematic within the frame of a particular treatment decision. For providers, surrogates and professional staff, the elements of such a process include:

3.03.a Honoring the presumption that all patients have decisional capacity

3.03.b Identifying yourself and clarifying why you are there

3.03.c Explaining how assessments about decisional incapacity are made

3.03.d Identifying behavioral clues which suggest the absence of capacity

3.03.e Doing everything practicable to minimize your bias in interpreting such clues

3.03.f Being sensitive to the fact that cultural factors may influence a patient's ability to demonstrate capacity

3.03.g Being sensitive to the special communication

problems associated with some developmental disabilities

3.03.h Confirming conclusions of decisional incapacity with others who know the patient

3.03.i Doing everything possible to enhance decisional capacity

3.03.j Listening for authenticity during your conversations with the patient

3.03.k Recognizing that authenticity is a synthesis of cognitive and emotive processes

3.03.l Asking and carefully weighing the answer to this central authenticity question: "In their own terms or frame of reference, can this person share her understanding of the clinical issues involved in this decision?"

3.03.m Openly sharing your concerns with the patient about his or her decisional incapacity

3.03.n Considering offering the patient:

- the option of having assistance
- an advocate
- an opportunity to challenge a determination of incapacity
- the opportunity to refuse to participate in the process

3.03.o Documenting all determinations of incapacity in terms of the criteria of the critical open process

3.03.p Failing to conclusively find incapacity, leave the presumption of decisional capacity intact

3.03.q Explaining the meaning and significance of an assessment of decisional incapacity

3.03.r Supporting the patient's full participation in the process

3.03.s Using a multi-disciplinary, multi-perspectival process when assessing whether patients meet a minimum level of understanding (for example, nature of the health problem, treatment options [including non-treatment] and their consequences)

3.03.t When incapacity may practicably be reversed, (that is, when it is the result of medication or acute pain), attempting to restore capacity before making decisions.

3.04 Communication can be the primary barrier between older adults who have a developmental disability and the opportunity to participate in their health care. The task force considered this barrier from two perspectives:

3.04.a Limitations to the patient's receptive and

expressive language. When individuals cannot clearly express their health care preferences, someone should be available to provide assistance. If limited reading skill is a problem, written material which is appropriate to the individual's reading level should be used.

3.04.b Limitations to the health care provider's receptive and expressive language. Informed participation in health care cannot occur if mismatches between the provider's and the patient's receptive and expressive language are not addressed. It is the provider's responsibility to ensure that someone is available to mediate communication mismatches.

3.05 When an adult with a developmental disability believes she has decisional capacity but the providers disagree, conflict resolution should be provided.

4.0 Conclusion of the Task Force

4.01 All persons with decisional capacity have the right to make health care treatment decisions.

4.02 A person's developmental disability may be irrelevant to a determination of his decisional incapacity.

4.03 Adults, especially those with disabilities, are frequently neither encouraged nor permitted to participate in their health care.

4.04 Adults with disabilities are too frequently unaware of their health care decision making rights and opportunities.

4.05 Adults with disabilities are full members of society; they have the same right to life, liberty and justice as any other member of society.

4.06 Parents are expected to provide the necessary requisites for their children to enjoy their rights as members of society by teaching them how to live independent lives, promoting their decisional capacity by teaching the skills of choosing and prioritizing, and by being models for activities which are incidental to independence. Though it is problematic when their children have incomplete decisional capacity, the refusal of parents to foster their children's autonomy is never licit.

4.07 Professional support staff is expected to assure that their adult clients with developmental disabilities have the resources they need to enjoy their rights as members of society. With respect to health care decision-making, these support professionals act as interpreters during health care transactions to which the individuals they support are parties. Some support professionals describe the deep relationship necessary to be an effective translator as "statutory" or "contract" surrogacy. Such expressions reveal the inherent conflict when work which is intended to make surrogacy unnecessary is performed

by developing relationships in which paternalistic practices flourish.

4.08 Public guardians are expected to help adults with developmental disabilities who are incapacitated, disabled, and for whom no other person naturally appears to provide that help. Public guardians help their ward-protectees by accessing services on their behalf. With respect to health care decisions, public guardians are expected to provide or withhold informed permission. Public guardians ought to seek the health care preferences of the people they serve and when preferences are expressed they should treat them as dispositive.

4.09 Parents and guardians are the primary guardians of the rights, welfare, and health of those adults with disabilities who lack or have incomplete decisional capacity. However, they do not have absolute authority to make health care decisions on their behalf.

4.10 The ethical obligation which health care professionals have to act in their patient's best interest is heightened when the patient lacks or has incomplete decisional capacity.

4.11 Inviting adults with developmental disabilities to express themselves concerning their health care (that is, through discussing, drawing, writing) is an important component of their care, regardless of their decisional capacity.

4.12 A health care provider's role is complicated and made more time consuming by extra communication and administrative burdens when her adult patient has a developmental disability. Some ways in which this burden manifests itself and in which it can be addressed are as follows:

4.12.a Taking extra steps to motivate regular self care (that is, having the patient practice and critique an in-home therapy);

4.12.b Relieving patient apprehensions;

4.12.c Using simple adaptive aids or props, (that is, pillboxes, punch lists, and egg timers [to confirm the length of an in-home therapy]);

4.12.d Motivating support staff and surrogates to support the adult's practice of an in-home therapy;

4.12.e Establishing a patient's *de novo* Medicaid eligibility;

4.12.f Accommodating a patient's transportation problems;

4.12.g Obtaining history from patients who have difficulty communicating orally or in writing. This problem may be overcompensated for by professional

support staff persons who are too willing to provide such information;

4.12.h Explaining and demonstrating the importance of compliance with care plans.

4.13 Providing care to people with incomplete decisional capacity requires providers to be sensitive to the fact that they may experience the world very differently from the provider. Attempts to implement these guidelines require flexible, developmentally appropriate, and individualized approaches.

4.14 When an adult with a disability lacks the capacity to make or communicate treatment decisions, such decisions are frequently based on the best interests standard. It is presumed that a parent/guardian is the individual's appropriate surrogate decision-maker. An appropriate surrogate should be allowed to determine which course of treatment is in the adult's best interests (this authority is subject to challenge by providers when the course of action chosen by the surrogate is clearly contrary to providers' assessment of the adult's best interests).

4.15 Respect for people with incomplete decisional capacity requires explicit acknowledgment of their role in health care decision making and treatment.

4.16 The presumption of decisional capacity applies to adults with disabilities. A clear demonstration of incapacity is necessary to override their health care decisions.

4.17 Health care providers should avoid coercion, deception, and force in caring for adults with disabilities. These tactics should be seen as a last resort to be used only in situations which pose an immediate threat to life.

4.18 Whenever a health care intervention is to be undertaken against the expressed wishes of an adult with a disability, she is entitled to an explanation and a justification.

4.19 Financial considerations tend to limit the prospects for adults, particularly adults with disabilities, to participate in their health care.

5.0 Definitions

5.01 Advance Directive: an umbrella term for the oral statements and written instruments by which an individual seeks to direct the course of his or her health care during times when s/he cannot personally give that direction either because s/he cannot then make those decisions or because s/he cannot communicate them. Written advance directives can take the form of Health Care Treatment Directives, Durable Powers of Attorney for Health Care Decisions, and Living Wills. Individu-

als with decision-making capacity may make any or all types of written advance directives as well as oral statements which have directive authority. Typical directives cover refusing treatment, being or not being placed on life support, and stopping life-prolonging treatment at a point chosen by the individual.

5.02 Assent: the free, uncoerced expression of willingness to undergo a specific health care treatment based on a person's knowledge and understanding, when given by a person whose capacity to participate in decision making is incomplete.

The process for soliciting assent includes:

- assisting the person to the fullest extent of his ability to understand the nature of his condition;
- disclosing to the person the nature of the proposed treatment and what she is likely to experience when undergoing it; and
- soliciting the person's willingness to accept the proposed treatment.

5.03 Autism: a condition that results in major disturbances of communication, socialization, and learning. Observed abnormalities include delay, cessation, or deterioration in developmental rates; abnormal responses to sensory stimuli; absent or limited verbal communication; and incapacity to appropriately relate to people events, or objects. The condition has a prevalence of about five per 10,000 and occurs more commonly in males. Intellectual development varies, but most individuals function in the subnormal range of mental ability.

5.04 Best Interests: the standard of surrogate decision making wherein a surrogate uses an incapacitated patient's welfare as the criterion for giving or withholding informed permission. The best interests standard permits factors such as relief of suffering, preservation or restoration of function, and the quality and extent of life to be considered.

5.05 Cerebral Palsy: a nonprogressive disorder of muscular control and sensory deficits. Characteristics of cerebral palsy include a reduction in muscle tone, abnormal motor movements, and orthopedic deformity, occurring as individual deficits or in combination. The condition has a prevalence of approximately one per 1,000. Commonly associated conditions include epilepsy, learning disability or mental retardation, and deviation of the eye. The extent of dysfunction is highly variable.

5.06 Conflict Resolution: a model of shared decision making supported by a variety of mechanisms for resolving ethical issues. These mechanisms include additional medical consultation; efforts to mediate the con-

flict with assistance from clinical ethicists, patient representatives, social workers, pastoral care professionals, and others; and case management conferences. Most health care providing organizations have ethics committees which may be of assistance. As a last resort, conflict resolution may require appeal to the courts.

5.07 Decisional Capacity: an individual's ability to choose in a clinical setting by doing (in sequence) the following:

- 5.07.a attend to the information disclosed by her or his provider
- 5.07.b absorb, retain, and recall the information disclosed
- 5.07.c appreciate that the information has significance in her life and the lives of others. That is, she understand that her decisions about health care has consequences for the future and she reasons well enough to connect present decisions with future consequences. This can be called *cognitive understanding* and requires some nominally intact cognitive abilities
- 5.07.d evaluate those consequences on the basis of values and beliefs. This can be called *evaluative understanding* and requires some nominally integrated sense of self
- 5.07.e make a meaningful communication of their cognitive and evaluative understandings
- 5.07.f make a meaningful communication of a decisions based on such understanding

As a general rule, individuals with decisional capacity should be regarded as having the capacity to provide informed consent to medical treatment.

5.08 Developmental Disability: a severe, chronic disability of a person which

- is attributable to a mental impairment, a physical impairment, or a combination of mental and physical impairments
- is manifested before person attains age twenty-two
- is likely to continue indefinitely
- results in substantial functional limitations in two or more of the following areas of major life activity:
 - self-care
 - receptive and expressive language
 - learning
 - mobility
 - self-direction
 - capacity for independent living
 - economic self-sufficiency
- Reflects the persons need for a combination and sequence of special interdisciplinary or generic care,

treatment, or other services which are of lifelong or extended duration and are individually planned and coordinated.

5.09 Disability: a functional limitation which interferes with a person's ability, for example, to walk, lift, hear, or learn. It may refer to a physical, sensory, or mental condition. Used as a descriptive noun or adjective, such as "persons who are mentally and physically disabled" or "man with a disability." Impairment refers to loss or abnormality of an organ or body mechanism, which may result in disability.

5.10 Dispositive: something which instantly and conclusively decides a matter.

5.11 Do Not Resuscitate Order (DNR): a physician's written order not to initiate cardiopulmonary resuscitation (CPR). Such orders may be based upon the physician's determination that resuscitation would be futile, ethically inappropriate, or inconsistent with the patient's overall values, wishes, and goals.

5.12 Epilepsy: a condition of the central nervous system in which seizures or involuntary motor movements occur. These episodes, vary in frequency, cause, and severity. Epilepsy is not associated with intellectual deficit. About one in 100 individuals have a history of seizures. Modern anticonvulsant medications can effectively manage and control seizures.

5.13 Expression of Health care Preference: a communication by which an individual provides information which she hopes will assist another person to make health care decisions on his or her behalf.

5.14 Informed Consent: voluntary, uncoerced agreement by a person with decisional capacity to accept a health care intervention based upon an exchange of health care treatment information between the person being asked to consent and the provider who will provide the intervention. The exchanged information must include:

- the nature of the patient's medical condition and prognosis
- the nature and purpose of the proposed intervention
- the risks, benefits and side-effects of the proposed intervention, any alternative interventions or non intervention.

Except in emergency situations, health care providers are obliged to obtain informed consent prior to a health care intervention. When a proposed health care intervention will occur over a period of time (i.e., treatment for a chronic condition), continuing consent should be periodically confirmed. Only individuals with decisional capacity can give informed consent.

5.15 Informed Surrogate Permission: the process by which one person (the surrogate) gives or withholds permission to provide a recommended health care intervention for another person.

- Except in emergency situations, health care providers are obliged to obtain informed surrogate permission prior to a health care intervention.
- Informed surrogate permission involves all the "informational" elements of informed consent.
- When a person has incomplete decisional capacity, both informed surrogate permission and patient assent must be sought.
- When a person lacks decisional capacity and has not previously expressed his preferences, surrogates may give or refuse permission to initiate or terminate a health care intervention.
- If failure to provide a health care intervention would constitute a significant burden or risk to a patient's health or welfare, and if permission is withheld by the surrogate, providers may seek authorization from appropriate state agencies or the legal system.

When coupled with patient assent, informed surrogate permission approximates informed consent.

5.16 Mental Retardation: a significantly below average general intellectual function and adaptive behavior. Adaptive behavior is the degree to which an individual meets standards of personal independence and social responsibility for his or her age. Mental retardation is the most common developmental disability and occurs in about two out of 100 people. It is characterized by limited learning and abstract ability.

5.17 Provider: an umbrella term for all individuals who are involved in the direct provision of health care, for example, physicians, nurses, social workers, therapists, and chaplains.

5.18 Middle Aged Adult With a Developmental Disability: a person between the ages of forty-five and fifty-five who has a developmental disability.

5.19 Older Adult With a Developmental Disability: a person over the age of fifty-five who has a developmental disability.

5.20 Spina Bifida: a congenital defect in the closure of the spinal canal with a hernial protrusion of the meningeal sheath of the spinal cord. The overall incidence is estimated to be one per 1,000. Individuals with spina bifida may have several associated problems that include hydrocephalus, vertebral and spinal column malformations, loss of sensation and motor function to lower extremities, and urinary tract and bowel dysfunction. The number and extent of these problems is related to the location and size of the spinal cord lesion.

5.21 Surrogate: a person who makes health care decisions for patients who lack decisional capacity with respect to that particular decision. An appropriate surrogate may be a person with decisional capacity who:

- The patient previously designated when she had decisional capacity (e.g., in an advance directive)
- Is involved with the patient and well knows his personal values and preferences
- Has been identified by operation of law (for example, a parent)
- Has been designated by a court (for example, a guardian)

Endnotes

1. For information about these instruments, contact Don Reynolds at Midwest Bioethics Center (816•221•1100) or Becky St. Clair at the Institute for Human Development (816•235•1750).

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