



Healthcare Treatment Decision-Making Guidelines for Adults with Developmental Disabilities

Center for Practical Bioethics
and University of Missouri-Kansas City Institute
for Human Development Task Force on Healthcare
for Adults with Developmental Disabilities

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Reviewed and Revised May 2015

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by the Center for Practical Bioethics and the University of Missouri–Kansas City Institute for Human Development Task Force on Healthcare for Adults with Developmental Disabilities

In December 1993, a multidisciplinary task force convened by the Midwest Bioethics Center, now the Center for Practical Bioethics, and the University of Missouri–Kansas City Institute for Human Development undertook the development of a decision-making model by which adults with developmental disabilities could participate in their healthcare 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 healthcare, 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 parallel activities informed the work of the task force.

- The Institute for Human Development sponsored a focus group in which adults with developmental disabilities discussed healthcare issues. Observations made in the focus group were brought to the task force and the task force sent its preliminary conclusions back to the group for additional comment.
- The Center for Practical Bioethics's Hospital Ethics Committee Consortium heard reports from the task force on healthcare for adults with developmental disabilities and developed a "critical open process" for determining decisional incapacity. This process was then adopted by the task force and incorporated into this document.

1.0 Decision-Making Model

These guidelines reflect the commitment of the task force to a shared decision-making model. The model respects the important and distinct roles that healthcare providers, parents, guardians, and professional support staff play in the healthcare decisions of adults with developmental disabilities.

The healthcare decision-making model that the task force proposes for older adults with developmental disabilities has four components, a process for conflict resolution, and two training instruments.

1.01 People who have decisional capacity have a right to make their own healthcare treatment decisions. When a person has decisional capacity, the fact that he or 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 the healthcare decision-making process. To distinguish the authorization given or withheld by patients with decisional capacity (informed consent) from the authorization that 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 — there is no ethical basis upon which a healthcare provider may resist it. However, the task force also concluded that informed permission is less than dispositive, and healthcare 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 "incomplete decisional capacity," healthcare pro-

viders have an ethical obligation to solicit both patient assent and informed surrogate permission. Assent is the uncoerced expression of willingness to undergo a specific healthcare treatment that a person with incomplete capacity to participate in decision making gives, based on his or her 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 a method for 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's Institute for Human Development to develop two instruments:

- a training video, *Healthcare Choices: Healthcare Decisions*; and a
- *Healthcare Preferences Journal*.

Information about these products is available from the sponsoring organizations.

2.0 Rights of Adult Patients with Developmental Disabilities

When the task force began its considerations, 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 conclusion that individuals with complete and incomplete decisional capacity have identical rights to participate in healthcare decisions suggests that the status of autonomy as bioethics' highest principle may be ebbing.

Although this document focuses on the hospital setting, the following rights pertain equally in every healthcare setting, including long-term care, home care, and medical offices.

As a patient in this facility, 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 your nurses and doctors what you like, what you don't like, what's important to you, and what you believe.

2.04 Know what 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 the treatments you will get.

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

2.08 Ask questions about your treatment. For example, 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 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 or per month)?

You also have other rights, for example, to

2.09 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 you or your care with anyone else unless you say it's O.K.

2.12 Be treated fairly.

2.13 Get what you ask for (if at times you can't have what you ask for, the people taking care of you will explain why).

2.14 Get help in dealing with your pain, uncomfortable feelings, and spiritual matters. (Uncomfortable feelings include excitement, worry, fear, nervousness, and sadness.)

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 you decide whether a treatment is right for you:

- your 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 O.K.

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

2.20 Have complaints about your care listened to, and when possible, to have your complaints taken care of.

2.21 Be told how to take care of yourself when you go home.

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

2.23 See the papers that the people who work here write or collect about you and have those papers explained to you.

2.24 Say what you want done if you have problems in the future.

2.25 Choose someone to tell your providers what you want, if you can't tell them yourself.

2.26 Have a number to call whenever you have questions regarding your rights, or if you want to tell someone that you are not getting your rights.

3.0 Decisional Capacity

For some adults with developmental disabilities, questioned decisional capacity is a significant barrier to their participation in healthcare decision making. These guidelines address 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. Healthcare 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 that influence whether adults with developmental disabilities lack decisional capacity. This process always includes the adult and the provider of 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 a critical open 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 the behavioral clues that suggest the absence of capacity.

3.03.e Doing everything possible 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 Being willing to confirm a finding 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 his or 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 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 Using a multidisciplinary, multiperspectival process to determine whether patients meet a minimum level of understanding (e.g., nature of their health problems, treatment options [including nontreatment] and the consequences of the treatment).

3.03.p Presuming an intact decisional capacity if incapacity cannot be found conclusively.

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

3.03.r When a perceived incapacity can be reversed, (i.e., when it is the result of medication or acute pain), attempting to restore capacity before making decisions.

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

3.03.t Using the criteria established by this critical open process to document all determinations of incapacity.

3.04 Communication can be the primary barrier preventing older adults who have a developmental disability from participating in their healthcare. The task force considered this barrier from two perspectives:

3.04.a Limitations stemming from the patient's receptive and expressive language. When individuals cannot clearly express their healthcare preferences, someone should be available to provide assistance. If limited reading skill is a problem, written materials appropriate to the individual's reading level should be used.

3.04.b Limitations stemming from the healthcare provider's receptive and expressive language. Informed participation in healthcare 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 that he or she has decisional capacity but 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 healthcare 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 healthcare.

4.04 Adults with disabilities are too frequently unaware of their healthcare 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 ensure that their children enjoy their rights as members of society by teaching them how to live independent lives, promoting their decisional capacity by teaching them how to choose and set priorities, and by modeling the activities of independence. Though it is difficult when their children have incomplete decisional capacity, the refusal of parents to foster their children's autonomy is never morally permissible.

4.07 Professional support staff are expected to ensure that their adult clients with developmental disabilities have the resources they need to enjoy their rights as members of society. With respect to healthcare decision making, these support professionals act as interpreters during their clients' healthcare transactions. Some support professionals describe the deep relationship necessary to be an effective translator as "statutory" or "contract" surrogacy. Such expressions reveal the conflict inherent in the situation when work that is intended to make surrogacy unnecessary is performed by allowing staff to develop paternalistic relationships.

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 healthcare decisions, public guardians are expected to provide or withhold informed permission. Public guardians ought to seek the healthcare 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 adults with disabilities who lack or have incomplete decisional capacity. They do not, however, have absolute authority to make healthcare decisions on behalf of these adults.

4.10 Healthcare professionals' ethical obligation to act in their patients' 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 healthcare (i.e., through talking, drawing, writing) is an important component of their care, regardless of their decisional capacity.

4.12 A healthcare provider's role is complicated and made more time consuming when the adult patient has a developmental disability. Extra communication and administrative burdens manifest themselves and can be addressed in several ways:

4.12.a Taking extra steps to motivate regular self care (i.e., 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, (i.e., 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 histories from patients who have difficulty communicating orally or in writing. (This problem may be overcompensated for if professional support staff are too willing to provide such information.)

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

4.13 Providers of care to people with incomplete decisional capacity must be aware that some of these patients will 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 or 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 the providers' assessments of the adult's best interests).

4.15 Respect for people with incomplete decisional capacity requires explicit acknowledgment of their role in healthcare 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 healthcare decisions.

4.17 Healthcare 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 that pose an immediate threat to life.

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

4.19 Financial considerations tend to limit the opportunity for adults, particularly adults with disabilities, to participate in their healthcare. This tendency should be resisted.

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 healthcare during times when he or she cannot personally give that direction either because he or she cannot make those decisions or cannot communicate them. Written advance directives can take the form of Healthcare Treatment Directives, Durable Powers of Attorney for Healthcare Decisions, and Living Wills. Individuals with decision-making capacity may make any or all types of written advance directives including oral statements that 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 healthcare treatment. When given by a person whose capacity to participate in decision making is incomplete, this expression is based on a person's knowledge and understanding.

The process for soliciting assent includes

- helping a person understand the nature of his or her condition to the fullest extent of his or her ability;
- disclosing to the person the nature of the proposed treatment and what he or 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 autistic 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, the preservation or restoration of function, and the quality and extent of life to be considered.

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

5.07 Decisional Capacity: an individual's ability in a clinical setting to choose to do the following actions in sequence:

5.07.a Attend to the information disclosed by the provider.

5.07.b. Absorb, retain, and recall the information disclosed.

5.07.c. Appreciate that the information is significant. Understanding that one's decisions about healthcare have consequences for the future and reasoning well enough to connect present decisions with future consequences is *cognitive understanding*, an action that requires some nominally intact cognitive abilities.

5.07.d. Evaluate the consequences of one's decision on the basis of one's values and beliefs. This action can be called *evaluative understanding* and requires some nominally integrated sense of oneself.

5.07.e. Make a meaningful communication of one's cognitive and evaluative understandings.

5.07.f. Make a meaningful communication of the 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. Such development disabilities

- may be attributable to a mental impairment, a physical impairment, or a combination of mental and physical impairments;
- are likely manifest before the person attains age twenty-two;
- are likely to continue indefinitely;
- result in substantial functional limitations in two or more of the following major life activities, namely: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency;
- reflect the person's need for a combination and sequence of special interdisciplinary or generic care, treatment, or other services that are of lifelong or extended duration and must be individually planned and coordinated.

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

5.10 Dispositive: a factor that 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 on 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 has a history of seizures. Modern anticonvulsant medications can effectively manage and control seizures.

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

5.14 Informed Consent: voluntary, uncoerced agreement by a person with decisional capacity to accept a healthcare intervention based on an exchange of healthcare 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 and any alternative interventions or non-intervention.

Except in emergency situations, healthcare providers are obliged to obtain informed consent prior to a healthcare intervention. When a proposed healthcare intervention will occur over a period of time (e.g., 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 healthcare intervention for another person.

- Except in emergency situations, healthcare providers are obliged to obtain informed surrogate permission prior to a healthcare 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 healthcare intervention.

- If failure to provide a healthcare 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 ability to learn or think abstractly.

5.17 Provider: an umbrella term for all individuals who are involved in the direct provision of healthcare, 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 relate to the location and size of the spinal cord lesion.

5.21 Surrogate: a person who makes healthcare decisions for a patient who lacks decisional capacity with respect to a particular condition. An appropriate surrogate is a person with decisional capacity whom the patient designated when he or she had decisional capacity (e.g., in an advance directive). Alternatively, an appropriate surrogate is someone who is involved with the patient and knows and understands his or her personal values and preferences; or a person identified by the operation of law (e.g., a parent); or a person designated by a court (e.g., a guardian).

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