Who Decides?

Health Care Decisioning-Making for Adults with Development Disabilities

Kathy McReynolds Ph.D

Director of Academic Studies

Christian Institute on Disability

Joni and Friends International Disability Center

Professor, Biola University

Disclosure

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- **This Presentation is Dedicated to Wolf Wolfensberger (1934-2011) Who Has Profoundly Shaped by Thoughts on Human Services**

Outline

- Who Are Those Who Are Perceived To Be Devalued in Today's Society?
- Special Dangers the Devalued Population Can Encounter in a Hospital Setting
- Health care Decisions for Adults with DD: General Guidelines
- Measures for Protecting Adults with DD in a Hospital Setting

A Perceived Devalued Population

Who Are The "Devalued" in Today's Society?

- **There are those who are perceived to be devalued in society precisely because of their disability and/or their social status.**

Who Are The Devalued in Today's Society?

- **In Western society today, groups that are devalued may include the following:**
- **Those with intellectual disabilities**
- **The physically handicapped**
- **The blind and the deaf**
- **The elderly**
- **The poor; racial minorities**
- **Those believed to be dying**
- **Prisoners and those accused of a crime**
- **Drug addicts and alcoholics**

Who Are the Devalued in Today's Society?

- Homeless people
- People perceived to have certain highly contagious and dangerous diseases
- People whose consciousness is believed to be permanently impaired
- People with more than one of these conditions or characteristics, such as the elderly poor, the impaired infants of the poor, retarded minorities, homeless people with AIDS.

Bad Things that Can Happen to Devalued People

- **1) Devalued because of impairment. People may become impaired as a result of poverty, poor nutrition, unsafe living conditions, poor health care, being assaulted.**
- **2) Devalued because of low functioning.**
- **3) Devalued people are relegated to low social status; considered second-class citizens.**

Bad Things that Can Happen to Devalued People

- **4) As a result of low social status, devalued people can be rejected by society and family.**
- **5) Devalued people get cast into roles that are devalued in society.**
- **6) Services to devalued people get placed in locations where valued people do not want to be. (Next to garbage dumps or cemeteries)**
- **7) Devalued people become society's scapegoat.**

Bad Things that Can Happen to Devalued People

- **8) Devalued people lose control over their lives. Other people make decisions for them.**
- **9) Devalued people tend to get deindividualized. They are subjected to mass management.**
- **10) Devalued people also suffer impoverishment in the world of pleasant experiences: cultural events, movies, theme parks.**

Common Expressions of a Devalued Person

- 1) Self-conscious; aware that they do not fit in.
- 2) Dislike themselves; feel worthless.
- 3) Feelings of insecurity.
- 4) Feelings of complete failure.
- 5) Distrustful of relationships.
- 6) Feelings of bitterness and anxiety.

Special Dangers A "Devalued" Population Can Encounter in a Hospital Setting

Bad Things that can Happen to Devalued People in **Hospital**

- **Staff maybe unsure of themselves because they have never interacted with a person with a disability and may be distant.**
- **Staff may see certain patients in stereotyped negative ways and respond to them negatively.**

Bad Things that can Happen to Devalued People in **Hospital**

- **Staff may even be afraid of the devalued patient.**
- **Staff and medical students may find the devalued patient less interesting than the more valued patient.**
- **Staff may even outright dislike a patient, or consider the patient loathsome, and then either mistreat or avoid the patient.**

Bad Things that can Happen to Devalued People in **Hospital**

- **Staff can interpret a patient's condition in much less favorable terms than the clinical realities warrant.**
- **Hospitals are "cure-oriented," but people with devalued conditions are often seen as "incurable" and "chronic" and their treatment as "futile."**
- **Even when staff do not behave so drastically, they are still more apt to pronounce a devalued person as terminal, or brain dead when he or she is not, or as having a poor quality of life.**

Bad Things that can Happen to Devalued People in **Hospital**

- **Out of a perverted sense of compassion, some staff may attempt to withhold or withdraw treatments from a devalued person much earlier than for a valued person (death-making).**
- **Hospitals implement cost saving measures in order to get a better reimbursement. Many of these cost-saving measures affect devalued people first and foremost, which makes the need for their protection more urgent.**

Health Care Decisions for Adult with DD: General Guidelines

Three Fundamental Issues:

- 1) What health care decision making model best serves the interests of adults with DD?
- 2) What are the rights of adults with DD with regard to health care decisions?
- 3) What model best resolves questions about the decision-making capacity of adults with developmental disabilities?

1) HC Decision-making Model & Best Interests

- 1) People who have capacity have a right to make their own healthcare decisions. When a person has capacity, the fact that he or she also has a development disability is irrelevant.
- 2) When adults with DD do not have capacity, surrogates play a crucial role in the HC decision-making process.

Informed Consent vs. Informed Surrogate Permission

- Informed consent from patient is dispositive---there is no ethical basis upon which a healthcare provider may reject it.
- Informed surrogate permission is less dispositive, and healthcare providers have an ethical obligation to resist informed permission if withholding or administering the treatment is not in the patient's best interests.

Incomplete Decisional Capacity and Assent

- When an adult with DD has incomplete capacity, healthcare providers have an ethical obligation to require both patient assent and informed surrogate permission
- Assent is the uncoerced expression of willingness to undergo a treatment that a person with incomplete capacity gives, based on his or her personal knowledge and understanding.

2) Rights of Adults with DD as Patients

- **As a patient, you have a right to:**
- 1) know the names of the people who work at the facility and how they will help you.
- 2) Be told who the doctor is that will take care of you.
- 3) Tell the nurses and doctors what you like, what you don't like, what's important to you, and what you believe in.
- 4) 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.
- 5) Be taken care of in a nice way by all the people who work here.
- 6) Help choose the treatments you will get.

2) Rights of Adults with DD as Patients

- 7) Be told the hospital's rules for taking care of patients.
- 8) Ask questions about your treatment. You may 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?**

2) Rights of Adults with DD as Patients

- You also have other rights:
- **Personal Privacy**
- **Have your family or friends with you**
- **Know that people in the facility would talk about your care unless you say it is OK**
- **Be treated fairly**
- **Get what ask for when time is appropriate**
- **Get help with your pain**
- **Get help in spiritual matters**

2) Rights of Adults with DD as Patients

- **Get help from your doctors when you need it.**
- **Get help from the hospital's ethics committee.**
- **Have any of the following people help you decide about treatment:**
- *Chaplain*
- *Doctor*
- *Nurse*
- *Social Worker*
- *Ethics committee*

2) Rights of Adults with DD as Patients

- 9) Not be moved to another facility without your permission
- 10) Not be part of a new treatment or research project unless you agree
- 11) Have complaints about your care listened to
- 12) Be told how to take care of yourself when you go home
- 13) See your bill and be told what the charges mean
- 14) See the information about your treatment and about what they found in their tests
- 15) Say what you want to have done if you have problems in the future
- 16) Choose someone to tell your providers what you want
- 17) Have a number to call whenever you have questions about your rights.

3) Decisional Capacity

- For some adults with DD, questioned decisional capacity is a significant barrier to their participation in their own health decisions.

3) Decisional Capacity

- These guidelines address this issue in the following four ways:
- 1) By carefully defining decisional capacity.
- 2) By affirming the presumption that every adult, including adults with DD, has decisional capacity. Respect for autonomy of persons is central to clinical ethics. Autonomy presumes self-determination, shared decision-making, informed consent, truth telling, and confidentiality.

3) Decisional Capacity

- 3) By offering a values sensitive, **critical open process** for assessing the many factors that influence whether adults with DD lack decisional capacity.
    - This process always includes the adult and provider, but may involve a surrogate as well.

3) Decisional Capacity

- Since decisional capacity is a prerequisite to informed consent, incapacity poses the greatest problem within the framework of a particular treatment. For all involved, the critical open process involves the following:
  - **Presuming that patients have capacity**
  - **Identifying yourself**
  - **Explaining how assessments about incapacity are made**
  - **Identifying the behavioral clues that suggest the absence of capacity**
  - **Doing everything to eliminate bias in your assessment of clues**
  - **Being sensitive to cultural factors that may influence a patient's ability to demonstrate capacity**

3) Decisional Capacity

- **Being sensitive to the special communication problems associated with some DD**
- **Being willing to confirm a finding of decisional incapacity with others who know the patient**
- **Doing everything possible to enhance decisional capacity**
- **Listening for authenticity during your conversations with the patient**
- **Recognizing that authenticity is a synthesis of cognitive and emotional processes**

3) Decisional Capacity

- **Asking and carefully weighing the answer to this central authenticity question:**
  - **"In their own terms, can this person share his or her understanding of the clinical issues involved in this decision?"**

3) Decisional Capacity

- **Openly sharing your concerns with the patient about his or her decisional incapacity.**
- **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) Decisional Capacity

- **Using a multi-disciplinary approach**
- **When a perceived incapacity can be reversed, attempting to restore capacity before making decisions.**
- **Using the criteria established by this critical open process to document all determinations of incapacity.**

3) Decisional Capacity

- 4) Communication can be the primary barrier preventing adult with DD from participating in health care decisions.
- **This barrier can be analyzed from two perspectives:**
  - 1) Limitations stemming from the patient's receptive and expressive language. When Adults with DD cannot clearly express their preferences, someone should be available to provide assistance. If limited reading skills is a problem, written material appropriate to the their reading level should be used.

3) Decisional Capacity

- 2) 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

Measures to Protect Adults with DD in a Hospital

Measures to Protect Devalued People in Hospital

- **Keep environment clean**
- **Provide bedside care**
- **Uplift patient's spirit**
- **Promote patient's mobility and independence**
- **Promote patient's rest**
- **Oversee food and water more carefully**

Measures to Protect Devalued People in Hospital

- **Orient patients to reality: give them anchors: date, time, season, name of hospital.**
- **Monitor quality of nursing care: ex. be sure patients understand consent forms.**
- **Be wary of "death-making."**

Sources

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