

Healthcare Advocacy & Ethics

A Beginning Discussion



Healthcare Advocacy & Ethics Discussion

- The Big Picture
- Key Issues
- Vignettes, Questions & Considerations
- What Have YOU Experienced in Your Community?
- Planning for Further Discussion



Alameda County Developmental Disabilities Council June 2020

The Big Picture (1 of 5)

Every person must have access to comprehensive, timely, quality, affordable health care, dental care, and wellness services, and access to plain language information and supports to make informed decisions about their health care.



The Big Picture (2 of 5)

This requires informed consent, individualized, appropriate medication, treatments, and an adequate network of health professionals.



The Big Picture (3 of 5)

It also includes people with multiple health care needs, those who require routine preventative care, mental and/or behavioral health treatment, dental care, durable medical equipment, and reproductive health needs.



The Big Picture (4 of 5)

Service system complexities must not delay, reduce or deny access to services.



The Big Picture (5 of 5)



Disability is natural and a typical part of the human experience.

Rights

People with disabilities have healthcare related rights through:

- The ADA, Titles II and III
- Lanterman Act
- Section 504 of the Rehabilitation Act
- And more...



The 3 Cs

A few items about Consent and Capacity:

- Every 'competent' adult has the fundamental right of self-determination over his or her body and property. Individuals who are unable to exercise this right, such as minors or 'incompetent' adults, have the right to be represented by another who will protect their interests and preserve their basic rights.

-- CHA 2016 Consent Manual

- Medical and mental health care requires permission (consent) from patient; if they can't, then from someone legally authorized to consent on their behalf.



More about the 3 Cs

A few items about Consent and Capacity:

- California Health Care Decisions Law – Probate Code 4600 et seq.; Probate Code 4609:
 - Capacity means a person's ability to understand the nature and consequences of a decision and to make and communicate a decision, and includes in the case of proposed health care, the ability to understand its significant benefits, risks, and alternatives.



Examples of Code

- HIPAA – 45 CFR Parts 160 and 164 (federal)
- Confidentiality of Medical Information Act – CMIA – Civil Code 56.10 et seq. (physical health information)
- Civil Code 56.30 – Section 56.10 does not apply to criminal justice requests by law enforcement; those requests are covered by Penal Code 1543 (written authorization, court order or search warrant still generally required . HIPAA applies)
- LPS Act – Welfare & Institutions Code 5328 et seq. (mental health information from hospitals, CSUs or other programs including outpatient Medi-Cal)



Benefits and Advancements

People with disabilities have benefited from advancements in healthcare and medicine.

Examples include:

- Expansion of lifespan for many people
- Medications that can support wellness and functioning
- Adaptive devices, tools, and durable medical equipment for greater health and independence



Layers of Disparity Remain

And yet...

History tells of layers of discrimination against people with disabilities in medical and healthcare settings, including:

- Eugenics movement, which included forced sterilization and euthanasia
- Institutionalization
- Refusal of care
- The false belief that disabilities are only something to be cured
- The Ashley Treatment (removing one's sex organs, breast buds and stunting growth through hormone treatment)



Intersectional Disparity

Also, patients with disabilities may experience healthcare access and healthcare quality disparities related to their disability, their race or ethnicity, their gender, their age, and/or their income.

These overlapped identities mean that a person's experiences with inequity or lack of access may be more complex or look different than another's.



Key Issues (1 of 3)

Patients with disabilities experience unconscious bias when receiving care, and when discussing their care with their healthcare providers.

Some examples:

- False assumptions about quality of life
- Healthcare providers' lack of training and overall knowledge about disability
- Institutionalized ableism
- Healthcare providers' assumptions of capacity and consent



Key Issues (2 of 3)

- Bioethics is the study of the ethical issues emerging from advances in biology and medicine.
- It is moral discernment as it relates to medical policy and practice.
- Bioethics are concerned with the ethical questions that arise in the relationships among life sciences, biotechnology, medicine and medical ethics, politics, law, theology and philosophy.

<https://en.wikipedia.org/wiki/Bioethics>



Key Issues (3 of 3)

- Bioethics is a growing field.
 - Most medical groups and hospitals have bioethics departments or specialists
- People with disabilities are often affected by the biases and assumptions found in areas of bioethics.



Vignettes & Questions to Consider



What have YOU experienced?



Healthcare Advocacy & Ethics Topics for Further Discussion

- Who do we need to hear from?
- Who is helping?
- Tools We Can Use:
 - Person-Centered Planning
 - Supported Decision Making
 - Advance Medical Directive
 - Power of Attorney
- Welfare & Institutions Code
 - WIC 4655, WIC 4541, etc.
- Resources and Supports In Our Community



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