

END OF LIFE PLANNING FOR RC CLIENTS

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NBRC's Clinical Team

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- ▶ Oran Hutton, PhD
- ▶ Mila DeWitt, PhD, BCBA
- ▶ Debra Kircher, BCBA
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NBRC'S Clinical team-Medical

- ▶ Gayatri Mahajan, MD
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- ▶ Leslie Crisostomo, RN
- ▶ Monica Smith Braun, Senior Nurse (SDC)
- ▶ Nayeli Hidalgo, Senior Nurse (SDC)
- ▶ Jeff Newton, Senior Nurse (SDC)
- ▶ Joan Etchandy, Nurse Santa Rosa

What do our clinicians do?

- ▶ Physician role/nurses role
- ▶ Behaviorist's role
- ▶ Diagnostic/clinical evaluations/CAD clinic
- ▶ Intake/Eligibility
- ▶ Forms/legal reports
- ▶ Parent support/counseling
- ▶ Psycho-sexual education project
- ▶ Professional development/Staff training
- ▶ Community outreach

Physician Role

- ▶ Questions regarding medical or psychiatric treatment
- ▶ New medical consultation service/Clinical consults
- ▶ Treatment consents for unconserved clients without available family
- ▶ Consultation with clients' medical providers
- ▶ Bioethics meetings, advance directives and POLST requests
- ▶ Weekly medical consultations with nurse
- ▶ Evaluations/CAD
- ▶ Intake and eligibility



Clinical Consultation Team

- ▶ Meets weekly to discuss complex issues; often where behavioral, psychiatric, and medical issues interact
- ▶ MDT with a physician, psychologist, BCBA (and a sometimes a nurse)- meets with clients, families, caregivers, providers



Advance Planning For Medical Decision Making

- ▶ What happens if I can't speak for myself?
- ▶ Who makes my decisions?
- ▶ Do they know me or my wishes?
- ▶ How do I make decision when in a crisis situation?
- ▶ What happens when we need to make decisions for others ?
 - ▶ **Do we know their wishes?**

Reality for Individuals with Intellectual and Developmental Disabilities

- ▶ Many individuals are denied the opportunity to exercise choice
- ▶ There is insufficient emphasis on supported decision making for people, amplified when facing complex end of life decisions
- ▶ Lack of understanding for the persons capacity to make his or her own choices and decisions
- ▶ Rarely is there an advance directive
- ▶ Physicians in hospitals often:
 - ▶ Take a conservative approach and refer to hospice
 - ▶ Do not consider a team meeting or a bioethics meeting unless asked
 - ▶ Consider perspectives of caregivers
 - ▶ Can be emphatic and treat appropriately when supported by NBRC team or families

NBRC Initiatives

- ▶ Staff training twice a year
- ▶ Using Thinking Ahead workbook
- ▶ Advance Directives/POLST for every client
- ▶ Starting conversations-IPP, medical consults
- ▶ ARCA workgroup

ARCA End of life Workgroup

- ▶ 12 members from various RC's, meet monthly, facilitated by Sidney Jackson from ARCA
- ▶ Drafting recommendations which will be shared with Clinical Directors, final draft to Executive Directors in March
- ▶ Includes the law, definitions, resources, steps to be taken when there is no family and client is not conserved (or when family cannot be reached or does not want to be involved).
- ▶ Seeking perspectives from families and clients, religious and cultural perspectives, Disability Rights.

Questions?

List of References:

- ▶ <http://coalitionccc.org/tools-resources/people-with-developmental-disabilities/>
- ▶
- ▶ <https://www.dds.ca.gov/ConsumerCorner/ThinkingAhead.cfm>
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- ▶ <http://odpc.ucsf.edu/advocacy/supported-health-care-decision-making>
- ▶
- ▶ https://coalitionccc.org/tools-resources/partners-in-caring-toolkit/10_pictoolkit2015_easy-to-read_advance_directive/
- ▶
- ▶ <https://www.aclu.org/other/how-make-supported-decision-making-agreement>
- ▶
- ▶ <https://health.ucdavis.edu/mindinstitute/centers/cedd/sdm.html>
- ▶
- ▶ <https://aaid.org/news-policy/policy/position-statements/caring-at-the-end-of-life#.WrpgW2aZNBw>
- ▶ Supported decision-making and personal autonomy for persons with intellectual disabilities: article 12 of the UN convention on the rights of persons with disabilities. Devi N, J Law Med Ethics. 2013 Winter; 41(4):792-806, Table of Contents. doi: 10.1111/jlme.12090