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Ethics Interface

Nancy Mitchell

This column is the collaborative effort of Nancy Mitchell, Mary Barros-Bailey, Sherry Latham, Ann Neulicht, and Bobbi Dominick. The author is grateful for their editorial support, wisdom, and collective experience.

The column is meant to be an educational forum for life care planners. It is not designed to offer an authoritative opinion from the editor or editorial board of the Journal of Life Care Planning, the board of the International Academy of Life Care Planners, or the board of its parent organization, the International Association of Rehabilitation Professionals, nor is it designed to represent or replace official opinions from the certifying body or other organizations associated with the practice of life care planning.

Dilemma

I am developing a life care plan for an injured individual whose family has always rented their housing, as have previous generations of family members. Is it ethical to include architectural renovation costs if rental housing for people with disabilities is available in their home community?

Response

If the evaluee is living in accessible rental housing that meets that person's needs and has no intention to move, renting can be advantageous. Home maintenance, lawn care, and snow removal are not the responsibility of the person with a disability or the caregivers. Still, the average person living in the United States moves 11.7 times in their lifetime (www.census.gov/topics/population/migration/guidance/calculating-migration-expectancy.html), so, the life care planner must consider the evaluee's needs over a lifetime. Depending on the age of the person, it may be important to consider a move to another community where the accessible rental housing is limited or not available. Consider inclusion of home modifications in the typical section with the comment "as needed or list in the "potential complications" section of the report.

Relevant Organizational Standards

From the International Academy of Life Care Planning Standards of Practice (2015)

II. Philosophical Overview / Goals Of Life Care Planning

The life care plan is a document that provides accurate and timely information which can be followed by the evaluee and relevant parties. It is a detailed document that can serve as a lifelong guide to assist in the delivery of health care services.

Goals of Life Care Plans:

In life care planning, the evaluee is defined as the person who is the subject of the life care plan.

A. To assist the evaluee in achieving optimal outcomes by developing an appropriate plan of rehabilitation, prevention, and/or reduction of complications. This may include recommendations for evaluations or treatment that may contribute to the evaluee's level of wellness or provide information regarding treatment requirements.
B. To provide health education to the evaluee and relevant parties, when appropriate.
C. To develop likely alternatives for care that take into consideration developmentally appropriate and least restrictive options for the evaluee.
D. III. Standards of Performance

Standard: The life care planner uses the scientific principles of medicine and health care as a basis for life care planning.

Measurement Criteria:

a. Uses appropriate research findings in the development of life care plans.

Standard: The life care planner considers cultural and linguistic factors that may influence the assessment, development, and implementation of the plan.

Measurement Criteria:

a. Recommends care that is culturally sensitive.
b. Considers multiple evaluee-centered factors including ethnic, religious, sexual identity, and geographic.

Standard: The life care planner performs comprehensive assessment through the process of data collection and analysis involving multiple elements and sources.

Measurement Criteria:

a. Collects data about medical, health, biopsychosocial, financial, educational, and vocational status and needs.

Standard: The life care planner uses a consistent, valid and reliable approach to research, data collection, analysis,

and planning.

Measurement Criteria

a. Identifies current standards of care, clinical practice guidelines, services and products from reliable sources, such as current literature or other published sources, collaboration with other professionals, education programs, and personal clinical practice.
b. Researches appropriate options and charges for recommendations, using sources that are reasonably available to the evaluee.
c. Considers appropriate criteria for care options such as admission criteria, treatment indications or contraindications, program goals and outcomes, whether recommended care is consistent with standards of care, duration of care, replacement frequency, ability of the evaluee to appropriately use services and products, and whether care is reasonably available.
d. Uses a consistent method to determine available choices and charges.

From the International Commission on Health Care Certification (2020)

Principle 2 - Evaluee and ICHCC Certificants Relationship

"Principle 2 - Evaluee and ICHCC Certificants Relationship ICHCC Certificants shall respect the integrity and protect the welfare of people and groups with whom they work. The primary obligation of the certificant is to the evaluee outside of independent medical examinations and independent review of plans in which no physician/patient relationship exists." (ICHCC 2020)

Principle 3 - Advocacy

"R2.4 ICHCC Certificants' primary obligation and responsibility is to the catastrophically or non-catastrophically disabled person for whom assessment, evaluation, medical and vocational and rehabilitation needs are being determined." (ICHCC 2020)

ICHCC Certificants shall serve as advocates for fair and balanced reporting regardless of the referral source, with the health, care, and safety of people with disabilities not to be compromised as a result of a submitted respective report.

From the CDMS Code of Professional Conduct (2015)

Preamble

Certified Disability Management Specialists (certificants) recognize that their actions or inactions can either aid or hinder clients in achieving their objectives, and they accept this responsibility as part of their professional obligation. Certificants may be called upon to provide a variety of services and they are obligated to do so in a manner that is consistent with their education, formal training, and work experience. In providing services, certificants must demonstrate their adherence to certain standards. The CDMS Code of Professional Conduct (Code) has been designed to achieve these goals.

The fundamental spirit of caring and respect with which the Code is written is based upon five principles of ethical behavior. These include autonomy, beneficence, nonmaleficence, justice, and fidelity, as defined below:

Autonomy: To honor the right to make individual decisions. Beneficence: To do good to others.

Nonmaleficence: To do no harm to others. Justice: To act or treat justly or fairly.

Fidelity: To adhere to fact or detail.

The primary obligation of the certificant is to exercise independent judgment in offering appropriate recommendations that consider the client's needs and the parameters of the applicable disability management system. Regardless of whether direct client contact occurs or whether indirect services are provided, certificants are obligated to adhere to the Code.

Principles

Principle 2: Certificants shall respect the integrity and protect the welfare of those persons or groups with whom they are working.

Rules of Professional Conduct

RPC 1.08 – Objectivity

Certificants shall maintain objectivity in their professional relationships and shall not impose their values on their clients

RPC 1.09 – Reports

Certificants shall be accurate, honest, unbiased, and timely in reporting the results of their professional activities to appropriate third parties.

RPC 1.13 – Human Relations

a. Discrimination:

Certificants shall:

1. demonstrate respect for clients with diverse populations regardless of age, color, culture, disability, ethnicity, gender, gender identity, race, national origin, religion/spirituality, sexual orientation, marital status/partnership, language preference, or socioeconomic status.

2. develop and adapt interventions and services to

incorporate consideration of individual clients' cultural and/or religious perspectives and recognition of barriers external to clients that may interfere with achieving effective outcomes.

From the American Association of Nurse Life Care Planners- Code of Ethics (2015)

Standard 1. Assessment

The nurse life care planner performs comprehensive data collection pertinent to the healthcare consumer's health and unique situation.

Competencies: The nurse life care planner:

- Collects comprehensive data including but not limited to physical, functional, psychosocial, emotional, cognitive, sexual, cultural, age-related, environmental, spiritual/transpersonal, and economic assessments in a systematic and ongoing process while honoring the uniqueness of the person.
- Includes the healthcare consumer, family, and healthcare providers in data collection when possible and as appropriate.

Standard 2. Diagnosis

The nurse life care planner analyzes assessment data to determine diagnoses and issues.

Competencies: The nurse life care planner:

- Identifies actual and potential risks to the healthcare consumer's health, safety, and barriers to health, including but not limited to interpersonal, systematic, and environmental circumstances.

Standard 3. Outcomes Identification

The nurse life care planner identifies expected outcomes for a life care plan individualized to the healthcare consumer or situation.

Competencies: The nurse life care planner:

- Involves the individual, family, healthcare providers, and others, when possible and appropriate, in formulating expected outcomes.
- Develops culturally appropriate outcomes. (For example, referrals to providers with similar language and culture whenever possible).
- Considers the healthcare consumer's age, developmental stage, values and culture, ethical considerations, and environment when formulating expected outcomes. (For example, a child with life-long needs receives age-appropriate occupational therapy in the home, community, or facility appropriate setting)

Standard 4. Planning

The nurse life care planner develops a plan that prescribes strategies, interventions, and alternatives to attain projected outcomes.

Competencies: The nurse life care planner develops a plan that:

- Considers the individual's characteristics and situation, including, but not limited to, values, beliefs, spiritual and health practices, preferences, choices, developmental level, coping style, culture and environment, and available technology.
- Explores suggested, potential, and alternative options and establishes the plan's priorities with the healthcare consumer, healthcare providers, and others as possible and appropriate.
- Provides for continuity.
- Includes an analysis of the economic effect on the healthcare consumer, family, caregivers, or other affected parties.
- Integrates current scientific evidence, trends and research.
- Provides alternatives, associated costs, and benefits.

Standard 5B. Health Teaching and Health Promotion

The nurse life care planner employs strategies to promote health and safety.

Competencies: The nurse life care planner:

- Addresses health and safety issues using data collected in the assessment, diagnosis, and planning processes.
- Provides for health teaching to address such topics as healthy lifestyles, risk reducing behaviors, developmental needs, activities of daily living, restorative measures, intended effects and potential adverse effects of proposed therapies, and preventive care.
- Provides for health teaching methods taking into account values, beliefs, health practices, developmental level, learning needs, readiness and ability to learn, language preference, spirituality, culture, and socioeconomic status.
- Provides for education about informed decision-making related to plan options.

Standard 6. Evaluation

The nurse life care planner evaluates progress toward plan outcomes.

Competencies: The nurse life care planner:

- Incorporates a systematic and evidence-based process for outcomes evaluation in the life care plan.
- Collaborates with the healthcare consumer and other involved persons in the evaluation process when possible and appropriate.
- Uses evaluation findings to revise the nursing diagnoses, outcomes, life care plan, and implementation as needed.
- Communicates the life care plan results to the healthcare consumer and other involved persons as reasonable and appropriate, in accordance with state and federal law and regulations.
- Reviews the life care plan for responsible and

appropriate interventions to minimize unwarranted or unwanted treatment and healthcare consumer suffering.

- Documents the results of the evaluation.

Commission on Rehabilitation Counselor Certification (2017)

A.1. Welfare of Those Served

d. Avocational and Independent Living Goals. Rehabilitation counselors work with clients to develop avocational and independent living goals consistent with their abilities, interests, culture, needs, and welfare.

C.1. Advocacy

b. Empowerment. Rehabilitation counselors empower clients, parents, or legal guardians by providing appropriate information to facilitate their self-advocacy actions whenever possible. Rehabilitation counselors work to help clients, parents, or legal guardians understand their rights and responsibilities, speak for themselves, and make informed decisions. When appropriate and with the consent of a client, parent, or legal guardian, rehabilitation counselors act as advocates on behalf of that client at the local, regional, and/or national levels.

e. Advocacy and Confidentiality. When engaging in advocacy on behalf of clients, should circumstances require the disclosure of confidential information, rehabilitation counselors obtain and document consent from the client and disclose only minimal information.

f. Areas of Knowledge and Competency. Rehabilitation counselors are knowledgeable about systems and laws, as well as organizational policies, and how they affect access to employment, education, transportation, housing, civil rights, financial benefits, medical services, and mental health services for individuals with disabilities. They keep current with changes in these areas in order to advocate effectively for clients and/or to facilitate self-advocacy of clients in these areas.

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