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Ethics Interface

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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 was retained by a plaintiff attorney to develop a life care plan for a teenager with a spinal cord injury. During the interview, the evaluee disclosed s/he believed s/he was transgender and contemplating transition. This information has been shared with friends, however, the medical and legal communities, as well as the parents, were apparently unaware of the situation. I found no reference to this information in the medical records. While this may or may not impact the contents of the life care plan, I want to be respectful in my report with the use of correct pronouns. How should I proceed?

Response

Unless life care planners are very new to their primary professions, it is unlikely their educational backgrounds have prepared them to appropriately address the transgender population, as the public and professional discourse on this topic is relatively new. It can be difficult to know how to ethically handle this information with the evaluee and retaining counsel, and the information may impact the contents of the report and life care plan.

Beyond the use of the correct pronoun, there are many issues to consider when developing a life care plan for someone who presents as transgender, including:

- status or future plans for transitioning
- sexual orientation
- religious or cultural influences
- life expectancy
- healthcare disparities of transgenders who have transitioned
- discrimination or barriers to healthcare services, insurance coverage
- future job placement

Projection of life expectancy is important. "In 2011 the Institute of Medicine released a report on the health status of lesbian, gay, bisexual, and transgender populations. Their findings confirmed health disparities found within this population. The report identified the transgender community has having specific health issues that need further research in the areas of prevalence, defining who should be considered transgender, and the demographic characteristics of this population." (Ettner, Monstrey, & Coleman, 2016; Institute of Medicine, 2011; Manzetti & Leiningen, 2016)

Provisions within our standards prohibit any type of discrimination toward an evaluee, including gender and sexual orientation. Lack of knowledge may be considered a type of discrimination in that may not be possible to provide correct and/or adequate provisions for the life care plan. To properly present the needs of this evaluee, a thorough literature review is necessary.

The evaluee is a minor and with that there are important issues to consider. While this young person is "considering" transition, it does not appear a definite decision has been made. This teen may be in the process of not only choosing a sexual identity, but also deciding their place in numerous other parts of life.

This is a minor child and the parents' wishes, as guardians, must be considered. It is important to understand the legal boundaries of confidentiality and release of information within the jurisdiction where the teen lives. How the parents will process this information with their own values and beliefs is unknown and this is not your story to tell.

During the disclosure and informed consent process, at the time of the formal evaluation with the teen, the life care planner should cover the confidentiality rules under which the assessment is taking place, including the limits of such confidentiality. With this new information, it will be important to disclose to the evaluee your role in the assessment and the need for disclosure of the information to the retaining attorney who is the advocate for this young individual. Therefore, the potential impact of this information on the young person's life as well as the life care plan should be discussed. The attorney will need to decide how to proceed.

With adults, it is best to ask them what pronouns to use in their report. But if disclosing gender is not appropriate, other options include: using the person's name rather than a pronoun; while this can be cumbersome for the flow of the report, variety can be provided by using the first name, the first and last name, "the plaintiff," or "the evaluee."

For an individual with a spinal cord injury, psychological

support is a typical inclusion in the life care plan. While there are likely many disability adjustment issues, being transgender is certain to provide additional complexities. If the evaluee has not been engaged in mental health treatment yet, a referral should be made and the evaluee encouraged to share transgender and adjustment to disability issues with the provider.

Relevant Organizational Standards

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

III. STANDARDS OF PERFORMANCE

4. 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.

IV. STANDARDS OF PRACTICE

3. 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 in a systematic, comprehensive, and accurate manner.
b. Collects data about medical, health, biopsychosocial, financial, educational, and vocational status and needs.
c. Obtains information from medical records, evaluee/family (when available or appropriate), relevant treating or consulting health care professionals and others. If access to any source of information is not possible (e.g., denied permission to interview the evaluee), this should be so noted in the report.

From the International Commission on Health Care Certification (2015)

Principle 1 - Professional and Legal Standards

ICHCC certificants shall behave in legal, ethical, and professional manner in the conduct of their profession, maintaining the integrity of the Code of the Professional Ethics and avoiding any behavior which would cause harm to other entities and/or individuals.

Rules of Professional Conduct:

Rule 1.2: ICHCC Certificants shall be familiar with, observe and discuss with their evaluees as well as referral sources the legal limitations of their services.

Principle 2-Evaluee and ICHCC Certificant's 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.

Rules of Professional Conduct:

R2.3 ICHCC Certificants are obligated to clarify the nature of their relationship to all involved parties when providing services at the request of a third party. Similarly, and as expected, ICHCC Certificants have an obligation to provide unbiased, objective opinions regarding the evaluation results or care planning service regardless of referral source. ICHCC Certificants will clearly define through written or oral means, the limits of their relationship, particularly in the areas of informed consent and legally privileged communications to all involved individuals.

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.

Principle 3-Advocacy: 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.

Rules of professional conduct:

Principle 4-Professional Relationships: ICHCC Certificants shall act with integrity in their relationships with colleagues, other organizations, agencies, institutions, referral sources and other professions as to facilitate the contributions of all specialists.

Rules of Professional Conduct:

R. 4.1 ICHCC Certificants shall ensure that there is a mutual understanding of the evaluation

report by all parties involved.

R 4.3 ICHCC Certificants shall not commit the recipient of the case to any prescribed course(s)

of action which may be specified in the report.

Rules of Professional Conduct:

R9.1 ICHCC Certificants shall function within the limits of which they are professionally

qualified and competent.

R9.2 ICHCC Certificants shall continuously strive through reading, attending professional meetings and taking course instruction to keep abreast of new developments, concepts, and practices that are essential to providing the highest quality of services to their evaluees.

From the Commission for Case Manager Certification Code, Professional Conduct for Case Managers for Standards, Rules, Procedures, and Penalties (2015)

Section 4 – Confidentiality, Privacy and Recordkeeping

S 14 - Legal Compliance

Certificants will be knowledgeable about and act in accordance with federal, state, and local laws and procedures related to the scope of their practices regarding client consent, confidentiality, and the release of information.

S 15 - Disclosure

At the outset of the Certificant-client relationship, Certificants will inform the client that any information obtained through the relationship may be disclosed to third parties. Disclosure of information will be made only to clients, payors, service providers, and governmental authorities and limited to what is necessary and relevant, except that the Certificant must reveal information to appropriate authorities, as soon as and to the extent that the Certificant reasonably believes necessary, to prevent the client from: a) committing acts likely to result in bodily harm or imminent danger to the client or others; and b) committing criminal, illegal, or fraudulent acts.

From the CDMS Code of Professional Conduct (2015)

Principles

Principle 2: Certificants shall respect the integrity and protect the welfare of those persons

or groups with whom they are working.

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 1.10 – Records

This rule applies only to those records for which certificants have responsibility during the

course of their employment or practice.

c. Confidentiality

Certificants shall maintain any and all client medical records and/or documents, whether written or recorded using electronic technology or audio/video devices, using administrative, physical and technical safeguards to assure the confidentiality, integrity and availability of protected health and personal identification information.

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.

RPC 2.03 – Confidentiality

a. Disclosure

Certificants shall inform the individual client at the outset of the certificant−client relationship that any information obtained through the relationship may be disclosed to third parties. Disclosure of information shall be limited to what is necessary and relevant, expect that the certificant must reveal information to appropriate authorities, as soon as and to the extent that the certificant reasonably believes necessary, to prevent the individual client from (1) committing acts likely to result in bodily harm or imminent danger to the individual client or others or (2) committing criminal, illegal, or fraudulent acts.

From the Commission on Rehabilitation Counselor Certification, *Code of Professional Ethics for Rehabilitation Counselors* (2017)

Preamble

Rehabilitation counselors actively attempt to understand the diverse cultural backgrounds of the clients they serve and do not discriminate in their provision of rehabilitation counseling services. Rehabilitation counselors also explore their own cultural identities and how these affect their values and beliefs.

A.2.b. NONDISCRIMINATION. Rehabilitation counselors do not condone or engage in the prejudicial treatment of an individual or group based on their actual or perceived membership in a particular group, class, or category.

A.3. CLIENT RIGHTS a. PROFESSIONAL DISCLOSURE STATEMENT. Rehabilitation counselors review with clients, both orally and in writing, the rights and responsibilities of both the rehabilitation counselor and client. These are presented in a manner best suited to the needs of the client. Disclosure at the outset of the professional relationship minimally includes … (4) confidentiality and limitations regarding confidentiality (including how a supervisor and/or treatment team professional is involved) …

A.3.b. INFORMED CONSENT. … Rehabilitation counselors recognize that clients need information to make an informed decision regarding services and that professional disclosure must be an ongoing part of the rehabilitation counseling process so clients are able to provide informed consent.

A.3.d. INABILITY TO GIVE CONSENT. When counseling minors or persons who lack the capacity to give voluntary informed consent, rehabilitation counselors seek the assent of clients and include clients in decision-making as appropriate. Rehabilitation counselors recognize the need to balance the: (1) ethical rights of clients to make choices; (2) cognitive or legal capacity of clients to give consent or assent; and (3) legal rights and responsibilities of legal guardians, including parents who are legal guardians, or families (e.g., "next of kin" notification situations) to protect clients and make decisions on their behalf.

A.4. AVOIDING VALUE IMPOSITION: Rehabilitation counselors respect the diversity of clients and seek training in areas in which they are at risk of imposing their values onto clients, especially when the rehabilitation counselor's values are inconsistent with the client's goals or are discriminatory in nature.

A.8. TERMINATION AND REFERRAL: b. VALUES WITHIN TERMINATION AND REFERRAL: Rehabilitation counselors respect the diversity of clients and seek training in areas in which they are at risk of imposing their values onto clients, especially when the rehabilitation counselor's values are inconsistent with the client's goals or are discriminatory in nature.

B.2. EXCEPTIONS a. SERIOUS OR FORESEEABLE

HARM AND LEGAL REQUIREMENTS. The general requirement that rehabilitation counselors keep information confidential does not apply when disclosure is required to protect clients or identified others from serious and foreseeable harm, or when legal requirements demand that confidential information must be revealed. Rehabilitation counselors must be aware of and adhere to standards and laws that govern confidentiality. Rehabilitation counselors consult with other professionals when in doubt as to the validity of an exception.

B.5.c. RELEASE OF CONFIDENTIAL INFORMATION. When working with minors or persons who lack the capacity to give voluntary informed consent to the release of confidential information, rehabilitation counselors obtain written permission from legal guardians or legal power of attorney to disclose the information. In cases where there is no legal guardian or legal power of attorney, rehabilitation counselors engage in an ethical decision-making process to determine appropriate action. In such instances, rehabilitation counselors inform clients consistent with their level of understanding and take culturally appropriate measures to safeguard client confidentiality.

C.1. ADVOCACY a. ATTITUDINAL BARRIERS. Rehabilitation counselors address attitudinal barriers that inhibit the growth and development of their clients, including stereotyping and discrimination.

D.2. CULTURAL COMPETENCE/DIVERSITY c. NONDISCRIMINATION. Rehabilitation counselors do not condone or engage in the prejudicial treatment of an individual or group based on their actual or perceived membership in a particular group, class, or category.

From the Forensic Section: F.1. EVALUEE RIGHTS b. INFORMED CONSENT: When a minor or person unable to give voluntary consent is evaluated, informed consent is obtained from the evaluee's legally authorized representative.

<u>From the American Association of Nurse Life Care Planners-Code of Ethics 2015</u>

Ethics Guideline

1. The nurse life care planner does not discriminate against any person based on age, gender, sexual orientation, ethnic background, religious beliefs or practices, social or economic status, lifestyle choices, functional status, health status or disability.
   - An individual's differences or beliefs are respected. Personal attitudes do not influence or interfere with professional performance.
   - Each individual's inherent worth, dignity and human rights are respected by the nurse life care planner without prejudice, regardless of whether the nurse agrees with or condones certain individual choices.
   - The nurse life care planner performs in a nonjudgmental and nondiscriminatory manner.
3. The nurse life care planner incorporates high standards of professional conduct through the continuum of then nurse life care planning services.
   - The nurse life care planner demonstrates honesty, integrity, responsibility, accountability, timeliness and respect for human dignity.
   - The nurse life care planner will not knowingly engage in unethical or unlawful activities nor will they knowingly misrepresent their background or credentials, or promote personal interests for personal gain.
   - The nurse life care planner remains objective and does not impose individual values on others.
4. The nurse life care planner safeguards privacy rights.
   - The nurse life care planner exercises responsibility, discretion and respect in handling and use of all protected or sensitive information and materials.
   - The nurse life care plan considers the rights, well-being and safety of the individual should be the primary factors in arriving at any professional judgment concerning the disposition of confidential information.
5. The nurse life care planner assumes responsibility and accountability for all actions, opinions, recommendations, and commitments.
   - The nurse life care planner assumes accountability for his/her life care plan, as well as their actions, opinions and decisions.
   - The nurse life care planner relies upon his/her specialized education, body of knowledge, level of competence and experience when accepting and completing an assignment.
   - The nurse life care planner's professional services are delivered in a competent, concise and timely manner.
6. The Nurse Life Care Planner provides professional services with objectivity.
   - The nurse life care planner demonstrates critical thinking in decisions, recommendations and opinions.
   - All functions of the nurse life care planner are void of personal opinion, prejudice and conflict of interest or any such other consideration that could interfere with or influence objectivity, performance or outcome.

References

Barros-Bailey, M., (2017) "Cultural Experiences and International Practices of Life Care Planners: Results of an Exploratory Research Study" *Journal of Life Care Planning,* Vol. 15, No. 2, 2017, (7-12).

Certification of Disability Management Specialists Commission. (2015). *Code of professional conduct with disciplinary rules procedures and penalties*. Schaumburg, IL: Author. Retrieved from:

www. http://cdms.org/uploads/files/CDMS_Code of Professional_Conduct.pdf

Commission for Case Manager Certification. (2015). *Code of professional conduct for case managers for standards, rules, procedures, and penalties*. Retrieved from http://www.Code of professional conduct for case managers/CCMC

Commission on Rehabilitation Counselor Certification. (2017). *Code of professional ethics for rehabilitation* counselors. Schaumburg, IL: Author. Retrieved from https://www.crccertification.com/filebin/pdf/Final_CRCC_Code_Eff_20170101.pdf

Ettner, R., Monstrey, S., & Coleman, E., (2016). *Transgender health program*. Retrieved from http://www.lgbthealtheducation.org/wpcontent/uploads/COM-2245-The-Medical Care of Transgender Persons.pdf

Institute of Medicine. (2011). *The health of lesbian, gay, bisexual, and transgender people: Building a foundation for better understanding*. Retrieved from http://www.nationalacademies.org/hmd/Reports/2011/The-Health-of-Lesbian-Gay-Bisexual-and-Transgender-People.aspx

International Association of Rehabilitation Professionals. (2009). *Code of ethics, standards of practice, and competencies*. Retrieved from http://www.rehabpro.org/publications/standards-ethics/12.2007.pdf/view

International Academy of Life Care Planners. (2015). *Standards of practice for life care planners*. Third Edition. International Academy of Life Care Planners, The Life Care Planning Section of The Association of Rehabilitation Professionals. Retrieved from https://higherlogicdownload.s3.amazonaws.com/REHABPRO/Standards%20of%20Practice%20for%20Life%20Care%20Planners%2

International Commission on Health Care Certification. (2015). *Standards and examination guidelines*. Retrieved from: www.http://ICHCC.org/PDF.s/ICHCC_StandardsandGuidelines.pdf.

Manzetti, C., & Leiningen, C. (2016). Lesbian, gay, bisexual and transgender population; ensuring cultural competency for the transgender population when developing a life care plan. *Journal of Life Care Planning Volume 14*(3), 3-9.