# Ethical Issues in Social Work: Adults with Intellectual Disabilities

## What We Know

› Social workers frequently encounter ethical issues in their practice. These issues can be especially challenging for social workers when working with adults with intellectual disabilities[18]

› Developing ethical awareness and skills to navigate ethical issues is a critical component of social work training and practice. Professional social work organizations worldwide have ethical codes that guide their members in their work. The central features of these codes incorporate human rights, social justice, and professional integrity. The code of ethics of the National Association of Social Workers (NASW) in the United States emphasizes service, social justice, human dignity, the importance of human relationships, integrity, and competence. Each of these comes into play in the care of adults with intellectual disabilities[1,2,3,10,11,15]

• In the service of adults with intellectual disabilities, social workers should apply their knowledge and skills to address the challenges their clients face

• Ensuring that adults with intellectual disabilities have access to information, services, and resources is a matter of social justice

• Social workers should treat adults with intellectual disabilities respectfully, reinforcing their sense of dignity, worth, and self-determination

• Recognizing and helping to strengthen the relationships of adults with intellectual disabilities can enhance the well-being of entire family systems

• Social workers should work toward protecting and enhancing the integrity of the social work profession through expanding the knowledge base related to working with adults with intellectual disabilities

• Working within one's area of competence and continually striving to enhance knowledge on intellectual disability is an essential component of ethical social work practice

› Social workers who work with adults with intellectual disabilities may face ethical issues in the following areas[10,18]

• Confidentiality and privileged communication

– For example, when an adult client with an intellectual disability is considered unable to act in their own interest, the social worker may be required to disclose confidential information to third parties such as family members, physicians, teachers, and colleagues

• Self-determination versus professional paternalism

– Social workers may be involved in limiting a client's self-determination because adults with intellectual disabilities frequently do not fully understand the reasons for a proposed activity or action. For example, a client may fear a visit to a physician and refuse to keep an appointment. In the best interests of the client, the social worker may have to insist that they attend

– Researchers have found that social workers providing mental health services to adults with intellectual disabilities have difficulty promoting choice and autonomy[8]

– Increasingly, social workers have to justify their practices using evidence-based data, employing various auditing systems, and applying operational and administrative procedures, all of which may lead to a sense of detachment from their practice.

The ethics of care is a philosophy that promotes an alternative approach in which empathy and compassion are emphasized and a deep, committed form of listening is encouraged. By adopting the ethics of care, social workers may be better equipped to navigate ethical issues with which they frequently are challenged, such as self-determination versus paternalism[12]

- Laws, policies, and regulations
  - Ethical conflict may occur when laws and policies permit the physical restraint of a client with an intellectual disability even though this restraint use is contradictory to the official position held by social work organizations and the personally held beliefs of the social worker. For example, holding grips may be used by care staff to disable an aggressive individual in some environments
  - Globally, adults with intellectual disabilities are sometimes considered a burden on societal resources, which is entrenched in policy-making. Services for adults with intellectual disabilities are significantly underfunded in many countries, which impacts service delivery, accessibility, equity, and the quality of care of adults with intellectual disabilities[5,20,22]
  - Obligations to comply with laws, policies, and regulations may conflict with what a social worker considers to be appropriate and just. For example, policies that underfund housing options and support for independent or community living limit the social worker's ability to assist clients who want to become independent[5]
- Conflicts of interest and boundary issues
  - Issues of this kind can occur when social workers have dual or multiple relationships with clients. For example, a social worker in small community may see clients in activities of daily life and/or social settings as well as in the social worker's professional capacity
- Professional versus personal values
  - For example, a social worker may professionally support the use of contraception by asexually active, intellectually disabled client, yet privately consider their sexual relationship inappropriate
- Scarce or limited resources
  - Social workers may feel ethically conflicted when they are unable to provide services their intellectually disabled clients need because of inadequate resources or because clients do not meet eligibility requirements
- Inclusion in research
  - Social workers have a duty to encourage inclusion of individuals with intellectual disabilities in research studies so that their unique issues and viewpoints are represented in the research literature, yet doing so may give rise to ethical challenges concerning the ability of individuals to provide informed consent, the need to circumvent gatekeepers (e.g., family members who do not want the individual to participate), and the potential risk that individuals will feel coerced to join studies[9]

› Ethical issues may arise when cultural practices and values are misunderstood. It is critically important that social workers pay attention to cultural diversity and facilitate client preferences. Cultural competence involves the following overlapping activities[15]

- Assessing and accepting the personal identity of the client: asking about the client's life, family, work, social activities and hobbies, and ethnocultural heritage
- Learning about the client's family members and caregivers and the relationships of the people around them
- Understanding the power dynamics within the client's relationships with family members and caregivers by observing and exploring the interactions of the client's relations and caregivers, family roles, and perceptions
- Recognizing the rituals and symbols that embody meaning to the client. This may involve observing and affirming the client's religiosity and/or cultural practices and ensuring that cultural practices are supported as part of the client's care
- Recognizing the values that give the client's life meaning

› Worldwide, the majority of adults with intellectual disabilities live in developing countries, where information on the levels of intellectual disability and the number of individuals with intellectual disability is limited. In the United States, approximately 4.5% of adults have an intellectual disability. Many social workers will come into contact with adults with intellectual disabilities, ranging from mild to severe[19]

- Intellectual disability is determined when an adult has an IQ of less than 70 (the average adult IQ is 90–100)
- Intellectual disability limits functioning in learning, mobility, self-direction, independent living, and economic self-sufficiency
- Intellectual disability is not a temporary health condition or one that can be cured; rather, it is a permanent condition

- Intellectual disability also is referred to as developmental disability or severe cognitive disability; outdated terminology refers to mental handicap or mental retardation
- Intellectual disability is a term that may or may not include individuals with learning disabilities, developmental delays, behavior disorders, and autism

› Adults with intellectual disabilities in the United States tend to die at younger ages (on average 20 years younger)[16] than the general population, although the main causes of death are the same: cardiovascular disease and respiratory disease[6,16]

› Individuals with intellectual disability historically have been dehumanized, marginalized by society, and discriminated against. They frequently are denied rights, privileges, and services[8,11,22]

- In the early 20th century, many countries, including the United States, implemented eugenics policies such as sterilization programs for individuals with intellectual disabilities; these policies were most notable in Nazi Germany
- Some cultural and religious beliefs have been found to perpetuate negative attitudes toward persons with intellectual disabilities, resulting in marginalization, exclusion, and denial of fundamental rights of persons with intellectual disabilities[17]
- Enacted by the U.S. Congress in 1990, the Americans with Disabilities Act is a landmark law aimed at eliminating discrimination against individuals with intellectual disabilities[21]

› The quality of care received by individuals with intellectual disabilities is critical to their well-being and is a matter of ethical concern

- In the United States, there is an increasing and aging population of individuals with intellectual disabilities, and a decreasing numbers of caregivers
- Social workers providing mental health services often lack experience, training, and knowledge when working with adults with intellectual disabilities, which may impact the quality of care they provide to the client[8]
- Studies indicate that working with adults with intellectual disabilities is highly stressful, and staff (e.g., private caregivers; employees of adult day-care centers, care homes, nursing homes)have high rates of burnout. Indications are that quality care occurs when staff are supported emotionally by supervisors and receive adequate financial compensation for their work[13]
- In some cultures, mothers are blamed when a child is born with an intellectual disability. They frequently receive no assistance with the child's care during childhood and remain responsible for any care throughout adulthood. Mothers often blame themselves and feel stigma, guilt, and depression[4]
- Caregivers of individuals with intellectual disabilities report being unaware of available services and resources[22]

## What We Can Do

› Learn about ethical issues that may arise when working with adults with intellectual disabilities so we can accurately assess our clients' personal characteristics and health/mental health education needs; share this information with our colleagues

› Become knowledgeable about our professional associations' ethical guidelines[1,2,3,10,15]

› Become knowledgeable about the discrimination that adults with intellectual disabilities encounter to inform our ethical deliberations on interventions and treatments[7]

› Internationally, social workers should practice with awareness of, and adherence to, the social work principles of respect for human rights and human dignity, social justice, and professional conduct as described in the International Federation of Social Workers (IFSW) Global Social Work Statement of Ethical Principles,[10] as well as the national code of ethics that applies in the country in which they practice. For example, in the United States, social workers should adhere to the NASW Code of Ethics core values of service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence; and become knowledgeable of the NASW ethical standards as they apply to clients and practice accordingly[14]

› To inform ethical decision-making, become knowledgeable about one's own cultural values, beliefs, and biases and develop knowledge about the histories, traditions, and values of clients. Adopt treatment methodologies that reflect the culture of the client[10]

Coding Matrix

References are rated using the following codes, listed in order of strength:

| Code | Description |
|------|-------------|
| M | Published meta-analysis |
| SR | Published systematic or integrative literature review |
| RCT | Published research (randomized controlled trial) |
| R | Published research (not randomized controlled trial) |
| C | Case histories, case studies |
| G | Published guidelines |
| RV | Published review of the literature |
| RU | Published research utilization report |
| QI | Published quality improvement report |
| L | Legislation |
| PGR | Published government report |
| PFR | Published funded report |
| PP | Policies, procedures, protocols |
| X | Practice exemplars, stories, opinions |
| GI | General or background information/texts/reports |
| U | Unpublished research, reviews, poster presentations or other such materials |
| CP | Conference proceedings, abstracts, presentation |

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