

BIOETHICS/HEALTHCARE – TOPIC SESSION

Topic: Dependency and Isolation in Healthcare
Convener: Michael McCarthy, Loyola University Chicago
Moderator: John Fitzgerald, St. John's University
Presenters: Lorraine Cuddeback-Gedeon, Mount St. Mary's University
Peter Fay, Boston College

The bioethics and healthcare topic session papers highlighted the importance of accounting for justice and community when considering the challenges facing both dependency care workers and those isolated because of mental illness. First, Lorraine Cuddeback-Gedeon's paper, "Tangled Dependencies: Healthcare, the Global Care Chain, and Justice for Direct Support Professionals", offered a description of dependency labor by drawing on her ethnographic research that allowed the voices of direct support professionals (DSPs) to interface with both moral philosophy and Christian ethics. Second, Peter Fay's, "Anthropology, Rights, and Justice: Catholic Social Teaching and the Victimization of Mental Illness in the United States", raised concerns around the victimization and isolation of individuals with schizophrenia and the need for a communitarian response grounded in Catholic social teaching (CST). Both papers lent themselves to a lively discussion around decision-making and formation within the disability community.

Cuddeback-Gedeon demonstrated that DSPs care for many of the everyday needs of their clients and play integral roles in the lives of the disability community. However, DSPs experience a high turnover rate, approximately 25-27% nationally. Cuddeback-Gedeon attributed this reality to three key factors: training and personal support, organizational culture, and low economic support. The unstable workforce not only affects employees but has a direct effect on the disability community itself.

Cuddeback-Gedeon critiqued the inequalities faced by DSPs and their clients by drawing on the thought of Eva Kittay and Sandra Sullivan-Dunbar. Cuddeback-Gedeon argued that an essential aspect of inequality resulted from an economic prioritization of curative efforts over recognizing the essential role of care within the disability community. The lack of prioritizing care results in economic, social, and emotional demands on DSPs. She drew on the narrative of a DSP, Sarah, to capture the complexity of the responsibilities she faced, particularly when caring for mentally ill patients. In closing, Cuddeback-Gedeon offered constructive suggestions that: (1) emphasize a living wage for DSPs, (2) consider the reality of "secondary dependencies" that face care workers, and (3) understand the ethics of being a care provider.

Peter Fay focused on the isolation and victimization of mental illness within the United States, particularly the 2.6 million people living with schizophrenia. He argued that a shift to a communitarian framework rooted in CST, grounded in the image of a triune God and gratuitous love, allows for inclusion rather than victimization of those with mental illness. The closing of mental health facilities beginning in the 1960s began a process that resulted in the isolation of many individuals living with schizophrenia within society. Today, many of these individuals find themselves homeless (100,000), incarcerated (200,000), or lacking access to treatment (over one million). These factors

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demonstrate the marginalization, victimization, and isolation of those with schizophrenia in need of a caring community.

Fay drew on Robert Bellah, et al., to critique an anthropology rooted in one's capacity to exercise autonomy and rationality. When lacking these characteristics, individuals with schizophrenia become restricted from participating in the community. This isolationist and individualist approach legitimizes structural violence in ways that disconnect them from the community essential for their care.

In contrast, Fay argued that a communitarian approach rooted in CST emphasizes the responsibility and privilege to care for those with schizophrenia in ways that protect their freedom to flourish. The prioritization of caring for those with schizophrenia as members of the human community requires further consideration about what social conditions are necessary for human flourishing, especially the right to access health care services. The paper concluded by noting that CST's conception of justice as commutative, distributive, and contributive provides a foundational understanding that affirms those with schizophrenia as integral to the human community.

Both Fay and Cuddeback-Gedeon responded to questions concerning the need to maintain a delicate balance between acting on behalf of those who lack capacity and respecting the agency of the individual. The session concluded by emphasizing a greater need for a disability ministry within the church and the importance of human and pastoral formation that respects both those in need of care and those providing the care.

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