The Intersection Of Bioethics And Disability Right

La intersección de la Bioética y el Derecho a la Discapacidad

Ikechukwu Monday Osebor, Ph.D.[a]

Abstract:

The intersection of bioethics and the rights of people living with disabilities is complex and multifaceted, touching on issues of autonomy, justice, dignity, and quality of life. The intersection has led to debates that focus on healthcare, informed consent, genetic screening, and end-of-life decisions, aiming to ensure that medical practices and policies respect the dignity and rights of disabled individuals while advocating for their inclusion and equitable treatment. Using the method of philosophical analysis, this study argues that integrating ethics of care in disability care would promote a framework that challenges discriminatory practices and enhances participation upholding the values of diversity and human rights in healthcare settings. This study concludes that the ethics of care ultimately seeks to foster the inclusion of people with disabilities in society and an ethical approach to healthcare for all individuals, regardless of their abilities.

Keywords:

Disabilities, Bioethics, Intersection, Justice, Discriminatory ,Ethics of care

Resumen:

La intersección de la bioética y los derechos de las personas que viven con discapacidad es compleja y multifacética y toca cuestiones de autonomía, justicia, dignidad y calidad de vida. La intersección ha dado lugar a debates que se centran en la atención médica, el consentimiento informado, los exámenes genéticos y las decisiones sobre el final de la vida, con el objetivo de garantizar que las prácticas y políticas médicas respeten la dignidad y los derechos de las personas con discapacidad y al mismo tiempo aboguen por su inclusión y trato equitativo. Utilizando el método de análisis filosófico, este estudio sostiene que integrar la ética de la atención en la atención a la discapacidad promovería un marco *que* desafíe las prácticas discriminatorias y mejore la participación defendiendo los valores de la diversidad y los derechos humanos en los entornos de atención médica. Este estudio concluye que la ética del cuidado busca en última instancia fomentar la inclusión de las personas con discapacidad en la sociedad y un enfoque ético de la atención sanitaria para todos los individuos, independientemente de sus capacidades..

Palabras Clave:

Discapacidades, Bioética, Intersección, Justicia, Discriminación, Ética del cuidado

INTRODUCTION

The challenges of disability encompass a broad spectrum of physical, emotional, social, and economic obstacles that individuals with disabilities face daily (Groce, 2004). These challenges can vary greatly depending on the type and severity of the disability, as well as external factors such as societal attitudes and accessibility measures. Disabilities often result in intellectual impairment, and physical limitations, making everyday tasks such as mobility, self-care, and communication more difficult (Dowse, 2009). This can include challenges with walking, using stairs, or even holding objects. Chronic pain and fatigue are also common among individuals with certain disabilities, adding an extra layer of difficulty to daily life (Mitra, 2017). Living with a disability can lead to emotional struggles such as depression, anxiety, and low self-esteem (Rogers, 2007). These emotions may stem from a sense of loss or grief for the abilities they once had, frustration with limitations, or experiences of discrimination and stigma. Acceptance of one's disability and finding ways to cope with emotional challenges are ongoing processes for many individuals. Social interactions can be challenging for people with disabilities due to `prejudice,

[a] Autor de Correspondencia, Department of Philosophy, University of Delta Agbor | Agbor, Delta State | Nigeria https://orcid.org/0000-0002-2642-662X, Email: ikechukwu.osebor@unidel.edu.ng

misconceptions, and barriers to accessibility (Accariya, & Khalil, 2016). People with disabilities face social isolation, exclusion from activities, and difficulties in forming relationships. Additionally, communication barriers, such as difficulty speaking or understanding others, can further complicate social interactions and increase the risk of communication problems that are difficult to interpret and may be highly idiosyncratic (Smith, et al., 2020). Access to education can be a significant challenge for some individuals with disabilities. They may encounter barriers in mainstream educational settings, such as inaccessible buildings, lack of accommodations, or bullying from peers (Hanafin, et al 2007). Special education services are available in some places, but they may not always meet the diverse needs of students with disabilities (Bowen, & Rude, 2006). Despite legal protections against discrimination, people with disabilities often face barriers to employment (Ortoleva, 2010). These can include inaccessible workplaces, negative attitudes from employers, and limited opportunities for advancement. Many individuals with disabilities also struggle to find suitable employment that accommodates their needs and abilities (Baldwin & Johnson, 2006). The cost of living with a disability can be substantial, including expenses for medical care, assistive devices, and accessibility modifications to homes and vehicles (Morris, et al., 2022). Furthermore, limited employment opportunities and lower wages for people with disabilities can contribute to financial insecurity and dependence on government assistance programs. Access to quality healthcare services can be a challenge for individuals with disabilities, particularly in areas with limited resources or specialized care (Iezzoni, & O'Day, 2006). They may face difficulties finding healthcare providers who are knowledgeable about their specific needs or encounter barriers to receiving appropriate medical treatment and preventive care. While there have been advancements in legislation and policies aimed at protecting the rights of people with disabilities, enforcement and implementation can be inconsistent. Additionally, gaps in coverage and loopholes in existing laws may leave individuals with disabilities vulnerable to discrimination and inadequate support. Addressing these challenges requires a comprehensive approach that involves not only changes in policies and infrastructure but also shifts in societal attitudes and perceptions toward disability. Creating inclusive environments, promoting accessibility, and fostering opportunities for participation and empowerment are essential steps towards improving the lives of people with disabilities.

THE CONCEPT OF DISABILITY

Disability is a deviation from the norm of biological functioning, focusing on impairments in the individual's body or mind (Douard, J. W. (1995). This definition emphasizes medical diagnosis and treatment but overlooks social and environmental factors influencing disability. Oliver, (2017) views disability as a consequence of societal barriers, discrimination, and lack of accessibility rather than inherent individual deficits. He

highlights the importance of social structures and attitudes in creating disablement and advocating for social change and inclusion. This perspective portrays disability as a minority group experience akin to ethnicity or gender, with its own culture, identity, and political movement (Thomas, 1999). It emphasizes empowerment, rights, and solidarity among people with disabilities. The social model theory views disability as a social construct resulting from the interaction between individuals with impairments and an inaccessible society (Burchardt, 2004). To address the societal barriers we advocate social justice for people with disabilities. The capabilities approach provides a framework for assessing well-being and social justice that is inclusive of people with disabilities (Morris, P2002). Individuals should have the opportunity to achieve a threshold level of certain capabilities, regardless of their impairments, and society should be structured to facilitate this (Morris, P2002). The concept of the "extraordinary body" challenges the normative understanding of disability (Pullin, 2018). The diversity of human bodies and identities, advocates for a more inclusive understanding of embodiment that celebrates difference rather than pathologizing it (Pullin, 2018). Kittay, (2011) focuses on the ethics of care and the moral significance of dependency. The traditional ethical theories often overlook the needs and experiences of people with disabilities, particularly those who rely on others for care (Kittay, 2011). The ethics of care recognizes the value of caring relationships and the dignity of all individuals. The international human rights frameworks, including the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), this model defines disability as a human rights issue, emphasizing equal rights, non-discrimination, and full participation in society for people with disabilities (Mannan, et al., 2012). Disability could be a dynamic interaction between biological, psychological, and social factors (Bøttcher, & Dammeyer, 2013). It highlights the interplay of individual experiences, coping mechanisms, and societal influences in shaping disability and well-being. It impacts on labor market participation and productivity. This model focuses on the costs of disability, including direct expenses for medical care and assistive devices, as well as indirect costs such as lost wages and reduced economic output (Bøttcher, & Dammeyer, 2013). The cultural model recognizes disability as a dimension of human diversity and creativity (Degener, 2016). This perspective challenges stigmatizing views of disability and celebrates the unique perspectives and contributions of people with disabilities to culture and society (Degener, 2016). The question is how disability intersects with other aspects of identity, such as race, gender, sexuality, and socioeconomic status, leading to unique experiences of discrimination and marginalization for individuals with multiple marginalized identities. It highlights the importance of accessible infrastructure, inclusive policies, and supportive communities in reducing barriers to inclusion. This acknowledges the interplay of biological, psychological, and social factors in shaping disability experiences and emphasizes

the need for comprehensive, interdisciplinary approaches to disability assessment and intervention.

TH BIOETHICS AND THE RIGHTS OF DISABLED PEOPLE

Philosophers explore the ethical implications of disability, including questions about justice, equality, and human rights (Barclay, 2018). They discuss issues such as access to healthcare, education, employment, and other social opportunities for people with disabilities. The moral implications of disability highlight the importance of recognizing the agency and identity of people with disabilities. The intersection of bioethics and the rights of disabled people is complex and multifaceted, touching on issues of autonomy, justice, dignity, and quality of life (King et al., 2022)

Disability rights refer to the rights and protections afforded to individuals with disabilities to ensure their full participation in society (Kayess & French, 2008). Central to this intersection is the principle of autonomy, which emphasizes an individual's right to make their own decisions about their body and health care (Weisstub, et al., 2008). The bioethical principle aims to ensure that people with disabilities have equal access to opportunities, services, and societal participation (Asch, 2001). However, in the context of disability, the bioethics principle of autonomy can be challenged by societal attitudes, medical paternalism, and the limitations imposed by the disability itself. For example, individuals with severe cognitive disabilities may have limited capacity to make complex medical decisions, raising questions about who should make decisions on their behalf and how those decisions should be made in their best interest. The principle of justice requires fair and equitable treatment for all individuals (Wright, 1999). In the context of disability, this means addressing disparities in access to healthcare, education, employment, and other social goods (Krahn, et al., 2015). Discrimination and ableism can result in systemic injustices that limit the opportunities and quality of life for people with disabilities. Bioethicists must grapple with how to promote justice for individuals with disabilities, including advocating for policies and practices that promote inclusion and accessibility (Asch, 2001). Dignity is a fundamental concept in bioethics, emphasizing the inherent worth and value of every human being (Sulmasy, 2008). However, debates exist about how to understand and respect the dignity of individuals with disabilities (Sulmasy, 2008). Some argue that certain medical interventions or treatments aimed at "fixing" or "curing" disabilities may undermine the dignity of individuals by suggesting that their lives are less valuable or worthy (Mitchell, & Entwistle, 2023). Others argue that dignity is upheld by respecting individuals' autonomy and providing support for them to live fulfilling lives according to their values and preferences. Bioethicists often grapple with questions about what constitutes a good or meaningful life, particularly in the context of disability. Discussions about quality of life can be highly subjective and influenced by societal attitudes and biases. People with disabilities may face stigma and discrimination that impact their perceived quality of life. Bioethicists ensure balancing individual rights with public health goals and must consider how to promote a more inclusive understanding of what it means to live a good life with a disability (Green, et al., 2005). Another area where bioethics intersects with disability is in reproductive decision-making. Advances in genetic testing and technology raise questions about the ethical implications of screening for and potentially selecting against certain disabilities. This raises concerns about eugenics, discrimination, and the value of diversity within the human population. In navigating the intersection of bioethics and disability, it's essential to center the voices and experiences of people with disabilities, recognize the diversity within the disability community, and strive for policies and practices that promote inclusion, dignity, and justice for all.

THE RELEVANCE OF ETHICS OF CARE

The ethics of care is a moral framework that emphasizes empathy, compassion, and the importance of relationships with disabled people (Held, V. (2006). The ethics of care offers an alternative approach that places value on caring for others and attending to the needs of disabled people, particularly in contexts of vulnerability and dependency (Branch, 2000). The roots of the ethics of care can be traced back to various philosophical and intellectual traditions, including feminist thought, existentialism, and certain strands of moral psychology (Laugier, 2015). It gained prominence as a distinct ethical theory in the 1980s through the influential writings of scholars such as Carol Gilligan, Nel Noddings, and Eva Feder Kittay (Serpe, 2024). Carol Gilligan's groundbreaking book "In a Different Voice" (1982) was instrumental in bringing attention to the moral voices of women and challenging the male-centered perspective that dominated traditional moral philosophy (Gilligan, 2018). Gilligan argued that women tend to approach moral dilemmas with a greater emphasis on relationships, care, and responsibility, in contrast to the abstract principles and rules often emphasized in traditional ethical theories (Gilligan, 2018). Nel Noddings, in her work "Caring: A Feminine Approach to Ethics and Moral Education" (1984), further developed the ethics of care by proposing that caring should be considered a foundational moral concept, on par with justice. She emphasized the importance of empathy and attentiveness to the needs of others, particularly in interpersonal relationships and caregiving roles (Noddings, 1986). Eva Feder Kittay's work in disability studies also contributed significantly to the development of the ethics of care. The traditional ethical theories often overlook the needs and experiences of individuals with disabilities and advocate for an ethics that recognizes the importance of dependency and interdependence in human life (Keller, & Kittay, 2017). The ethics of care centers on recognizing and valuing the inherent worth and dignity of all individuals, regardless of their abilities or disabilities. The traditional

Kantian and utilitarian approaches for their failure to adequately address the needs and vulnerabilities of certain groups, particularly those with disabilities (Becker, 2005). In her book "Love's Labor," Kittay. (2019). explores the caregiving experiences within families, particularly the care provided to individuals with disabilities. The moral significance of caregiving is portrayed not merely as a duty but as a deeply meaningful expression of love and commitment. It emphasizes the relational aspect of ethics or moral obligations to shape our interconnectedness with others (Kittay. 2019). The notion of the isolated, autonomous individual and instead emphasizes the importance of community and mutual dependence. Moreover, Kittay's work underscores the need for social and political structures that support caregivers and recognize the value of care work (Kittay. (2019). We argue for policies that provide adequate resources and support for caregivers, as well as for broader societal recognition of the importance of caregiving labor. This contribution to the ethics of care offers a compelling alternative to traditional ethical theories, emphasizing the centrality of care, empathy, and relationships in moral deliberation and social justice. The ethics of care prioritizes empathy and compassion towards others, recognizing the importance of understanding their perspectives and experiences (Frampton, et al., 2013). Moral judgments are seen as contextual and situational, rather than based on universal principles or rules. This allows for flexibility and responsiveness to the particular needs and circumstances of individuals and communities. The ethics of care acknowledges the inherent dependency and vulnerability of human beings and emphasizes the moral responsibility to attend to the needs of those who are most vulnerable (Held, 2006). The ethics of care offers a critique of traditional moral theories, such as utilitarianism and deontology, for their abstract and impersonal approach to ethics. Instead, it proposes a more relational and embodied understanding of morality. While care ethics initially focused on interpersonal relationships, it has since been expanded to address broader social and political issues, including injustices related to gender, race, class, and disability. In recent years, the ethics of care has continued to evolve and gained traction in various fields, including healthcare, education, social work, and environmental ethics. Its emphasis on empathy, relationships, and responsiveness to context resonates with many who seek a more holistic and inclusive approach to morality. However, the ethics of care also face critiques, including concerns about its potential to reinforce disability roles and its ability to address complex moral dilemmas associated with the intersection of disability and bioethics (Asch, 2001). Ethics of care challenges the traditional ethical frameworks that prioritize autonomy and independence. In the context of disability, where individuals may rely on others for support and assistance, the ethics of care recognizes the inherent interdependence among individuals. Caregivers and disabled individuals form interdependent relationships based on mutual care and support.

CONCLUSION.

Overall, the intersection of ethics of care and disability highlights the importance of fostering compassionate, responsive, and empowering relationships that uphold the dignity and well-being of disabled individuals within their communities and society at large. In conclusion, the ethics of care offers a compelling alternative to traditional moral theories, emphasizing the importance of relationships, empathy, and contextual responsiveness in ethical decision-making. Its principles have been shaped by feminist thought, moral psychology, and disability studies, and continue to evolve in response to contemporary social and ethical challenges. While it has generated significant interest and debate, its ultimate impact on moral philosophy and practice remains an ongoing question.

REFERENCES

Accariya, Z., & Khalil, M. (2016). The socio-emotional adjustment of learning-disabled students undergoing school transitions. Creative Education, 7(01), 139. 3-455.

Asch, A. (2001). Disability, bioethics and human rights. Handbook of disability studies, 307.

Baldwin, M. L., & Johnson, W. G. (2006). A critical review of studies of discrimination against workers with disabilities. Handbook on the Economics of Discrimination, 119-160

Barclay, L. (2018). Disability with dignity: Justice, human rights and equal status. Routledge.

Becker, L. C. (2005). Reciprocity, justice, and disability. Ethics, 116(1), 9-39.

Bøttcher, L., & Dammeyer, J. (2013). Disability as a risk factor? Development of psychopathology inchildren with disabilities. Research in Developmental Disabilities, 34(10), 3607-3617.

Bowen, S. K., & Rude, H. A. (2006). Assessment and students with disabilities: Issues and challenges with educational reform. Rural Special Education Quarterly, 25(3), 24-30.

Branch Jr, W. T. (2000). The ethics of caring and medical education. Academic Medicine, 75(2), 127-132.

Burchardt T. (2004). Capabilities and disability: the capabilities framework and the social model of disability. Disability & Society, 19(7), 735-751.

Degener, T. (2016). Disability in a human rights context. Laws, 5(3), 35.

Douard, J. W. (1995). Disability and the persistence of the 'normal'. Chronic illness: From experience to policy, 154-175.

Dowse, L. (2009). 'Some people are never going to be able to do that'. Challenges for people with intellectual disability in the 21st century. Disability & Society, 24(5), 571-584

Frampton, S. B., Guastello, S., & Lepore, M. (2013). Compassion as the foundation of patient-centered care: feminist philosophy (pp. 540-555). Routledge.

Gilligan, C. (2018). Revisiting" In a Different Voice". LEARNing Landscapes, 11(2), 25-30.

Green, S., Davis, C., Karshmer, E., Marsh, P., & Straight, B. (2005). Living stigma: The impact of labeling, stereotyping, separation, status loss, and discrimination in the lives of individuals with disabilities and their families. Sociological Inquiry, 75(2), 197-215.

Groce, N. E. (2004). Adolescents and youth with disability: Issues and challenges. Asia Pacific Disability Rehabilitation Journal, 15(2), 13-32.

Hanafin, J., Shevlin, M., Kenny, M., & Neela, E. M. (2007). Including young people with disabilities: Assessment challenges in higher education. Higher education, 54, 435-448.

Held, V. (2006). The ethics of care: Personal, political, and global. Oxford University Press.

Iezzoni, L. I., & O'Day, B. (2006). More than ramps: A guide to improving health care quality and access for people with disabilities. Oxford University Press, USA.

In The Journal of Medicine and Philosophy: A Forum for Bioethics and Philosophy of Medicine (Vol. 48, No. 1, pp. 33-49). US: Oxford University Press.

Kayess, R., & French, P. (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. Human rights law review, 8(1), 1-34.

Keller, J., & Kittay, E. F. (2017). Feminist ethics of care. In The Routledge companion

King, N. M., Henderson, G. E., & Churchill, L. R. (2022). Bioethics reenvisioned: A path toward health justice. UNC Press Books.

Kittay, E. F. (2011). The ethics of care, dependence, and disability. Ratio juris, 24(1), 49-58.

Kittay, E. F. (2019). Love's labor: Essays on women, equality and dependency. Routledge.

Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. American journal of public health, 105(S2), S198 S206.

Laugier, S. (2015). The Ethics of Care as a Politics of the Ordinary. New Literary History, 46(2), 217-240.

Mannan, H., MacLachlan, M., McVeigh, J., & EquitAble Consortium. (2012). Core concepts of human rights and inclusion of vulnerable groups in the United Nations Convention on thrights of persons with disabilities. Alter, 6(3), 159-177.

Mitchell, P., Cribb, A., & Entwistle, V. (2023, February). Patient safety and the question of dignitary harms.

Mitra, S. (2017). Disability, health and human development. Springer Nature.

Morris, P. M. (2002). The capabilities perspective: A framework for social justice. Families in Society, 83(4), 365-373.

Morris, Z. A., McGarity, S. V., Goodman, N., & Zaidi, A. (2022). The extra costs associated with living with a disability in the United States. Journal of Disability Policy Studies, 33(3), 158-167.

Noddings, N. (1986). Caring: A feminine approach to ethics and moral education. Legal Evolution (pp. 460-480). Edward Elgar Publishing.

Oliver, M. (2017). Defining impairment and disability: Issues at stake. In Disability and equality law (pp. 3-18). Routledge.

Ortoleva, S. (2010). Inaccessible justice: Human rights, persons with disabilities and the legal system. ILSA J. Int'l & Comp. L., 17, 281.

Pullin, G. (2018). Supernormal design for extraordinary bodies: A design manifesto In Manifestos for the future of critical disability studies (pp. 166-176). Routledge.

Rackley, E. (2006). From Arachne to Charlotte: an imaginative revisiting of Gilligan's in a different voice.

Rogers, C. (2007). Disabling a family? Emotional dilemmas experienced in becoming a parent of a child with learning disabilities. British Journal of Special Education, 34(3), 136-143.

Serpe, A. (2024). Ethics of care: Its evolution and significance for law. In the Research Handbook on

Smith, M., Manduchi, B., Burke, É., Carroll, R., McCallion, P., & McCarron, M. (2020). Communication difficulties in adults with Intellectual Disability: Results from a national cross-sectional study. Research in developmental disabilities, 97, 103557.

Sulmasy, D. P. (2008). Dignity and bioethics: history, theory, and selected applications. Human dignityand bioethics, 1, 469-501.

Thomas, C. (1999). Female forms: Experiencing and understanding disability. McGraw-Hill Education (UK).

Weisstub, D. N., Pintos, G. D., & Rendtorff, J. D. (2008). The limitations and accomplishments of autonomy as a basic principle in bioethics and biolaw. Autonomy and human rights in health care:An international perspective, 75-87.

Wm. & Mary J. Women & L., 13, 751. the importance of compassion in action. Journal of comparative effectiveness research, 2(5), 44

Wright, R. W. (1999). Principles of justice. Notre Dame L. Rev., 75, 1859.