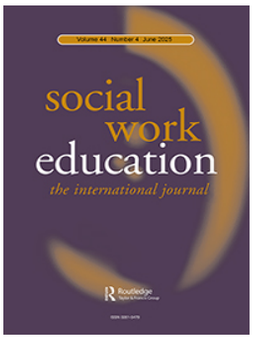

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Teaching social work students using a person-centered ethics of care model approach to working with individuals with intellectual/developmental disabilities and their caregivers

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ABSTRACT

The field of intellectual and/or developmental disabilities (I/DD) can encompass many conditions affecting the growth and maturation of children, including seizures, cerebral palsy, Down syndrome, traumatic brain injury, autism spectrum disorders, and others. Theoretical models that focus solely on the impact of physical disability are not always appropriate for individuals with I/DD. Individuals with I/DD are quickly sidelined in mainstream disability research and practice since these children have complex needs affecting them physically, cognitively, and/or behaviorally. The responsibility for lifelong assistance often falls on the caregiver to balance the challenges of caring for a severely disabled child across the lifespan. This paper discusses a model of care that places the individual with intellectual and developmental disabilities (I/DD) at the center of numerous forces shaping their development, including educational, medical, governmental, financial, and social service components. The Person-Centered Ethics of Care (PC-EoC) model described here illustrates the complex and interactive needs of individuals with intellectual and developmental disabilities (I/DD) and their caregivers. This paper focuses on educating social work students using the model to work with individuals with intellectual and developmental disabilities (I/DD).

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Introduction

Social work education prepares students to work with individuals, families, and communities to meet unique needs and challenges. However, disability-specific content is limited in most schools of social work. Graduating students rarely learn in a class dedicated to studying developmental disabilities (Bean & Krcek, 2012; Fuld, 2020; Laws et al., 2010). Disability coursework often uses a medical model that focuses on physical limitations rather than recognizing the abilities and strengths of this population (Fuld, 2020; Kattari et al., 2017). Recent changes in the National Association of Social Workers (NASW) Code of Ethics and the Council on Social Work Education (CSWE) Educational Policy and Accreditation Standards (EPAS) have helped shift the profession from a disability-based to an ability-based framework (NASW, 2006, preamble). Yet, despite

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these efforts, dedicated I/DD coursework remains limited in most curricula. Studies by Laws et al. (2010) showed that only about one-third of the 50 U.S. schools of social work they examined offered at least one course dedicated to the broad study of developmental disability.

Ironically, many vulnerable populations supported by social workers include I/DD (NASW, 2006). About 27% of individuals ages 15 and older have some form of disability (United States Census Bureau, 2021). Disability among older adults is protected in the NASW Code of Ethics (National Association of Social Workers [NASW], 2017, preamble), ensuring equity and support for clients with disabilities. Thus, social workers serve clients with disabilities of all ages and in various social service settings, primarily within a medical model (Kattari et al., 2017). Social workers trained in this model may offer limited support to families caring for an individual with intellectual and developmental disabilities (I/DD).

This paper introduces a model designed to help train social work students to address the critical needs of families caring for individuals with intellectual and developmental disabilities (I/DD). The goal is to employ a Person-Centered Ethics of Care approach in developing coursework for schools of social work dedicated to caring for individuals and families with developmental disabilities. Such knowledge may enhance social work practice with individuals with intellectual and developmental disabilities (I/DD) across various practice settings and age groups. It is essential to note that the model and this paper are based on a U.S. context. We begin by defining key terms in the study of I/DD, followed by a review of the literature regarding how intellectual and developmental disabilities have been modeled in different contexts. Next, the critical components of the proposed model will be examined. Finally, the implications for social work practice will be discussed, as well as how the proposed model can assist future social workers in supporting individuals with I/DD and their families.

Definitions

The Centers for Disease Control estimates that 1 in 6 U.S. children aged 3 through 17 May be developmentally disabled (CDC, 2019), or over 7 million Americans with I/DD. These numbers are increasing, and more service providers are needed to support the care of this population. Disability across the lifespan can manifest in many ways, ranging from learning difficulties in children to gait imbalance as adults. However, a crucial distinction is that developmental disabilities typically originate early in life and persist throughout a person's lifetime.

Intellectual and Developmental Disabilities (IDD) are conditions characterized by impairments in physical, learning, language, or behavioral areas that arise during the developmental period and typically persist throughout a person's life (Masefield et al., 2020; Russo-Gleicher, 2008). It involves significant limitations in both intellectual functioning (e.g. learning, reasoning, problem-solving) and adaptive behavior (everyday social and practical skills), which typically originate before the age of 18 (American Association on Intellectual and Developmental Disabilities, 2021). Intellectual disability is a subset of developmental disabilities, which includes a broad range of chronic conditions due to intellectual, physical, or both impairments, such as autism spectrum disorders, cerebral palsy, and fetal alcohol syndrome (World Health Organization, 2001).

I/DD is the term often used to describe situations in which intellectual disability and other disabilities are present (Institute on Community Integration, n.d.)

According to the International Classification of Functioning, Disability, and Health (ICF) of the World Health Organization (WHO) (World Health Organization, 2001). International Classification of Functioning, Disability and Health [ICF]. n.d.), disability includes impairments, activity limitations, and participation restrictions that arise from the interaction between health conditions and contextual factors. These include environmental factors such as accessibility, social attitudes, policies, services, and technology, and personal factors such as age, gender, coping styles, education, and socioeconomic status, which shape the individual's experience of disability, highlighting the need for inclusive policies and support.

The medical model of disability in social work education

The practice of medicine in the U.S. often has a mechanical focus, where physicians search for an infection or other potential cause and attempt to correct it. This has proven helpful in addressing such illnesses as diabetes and heart disease, but less so in the care of individuals with I/DD. The medical model views disability as a defect that must be cured. Messages of pity or shame are often conveyed toward people with disabilities, even though many in the disability community consider their condition as integral to their self-identification (Dupré, 2012; Oliver, 2013). This same regime applies to social work education. The dominant view of disability in social work has been a medical model viewing disability as an individual dysfunction or pathology (Dupré, 2012; Hiranandani, 2005; Kattari, 2015).

Oliver (2004) emphasized that the medical model locates the problem of disability in the individual, which stems naturally from this deficit (Oliver, 2004, 2013). This is termed personal tragedy theory and suggests an inherent disadvantage for an individual with a disability when placed in competitive social situations. The medical model infers that a disabled individual has deficits that need 'fixing' (Quinn, 1996). Because schools of social work have traditionally addressed issues of grief and loss coupled with a disability, individuals with I/DD are often depicted as suffering from their circumstances. Recognizing and accepting disability are therefore viewed as the targeted outcomes of social work treatment (Hiranandani, 2005; Pease et al., 2017).

The medical model of disability is overly reliant on the individual as an agent of change rather than focusing on the rights and responsibilities of the person and the larger culture. Despite growth in the field of social work, the profession has done little to promote disability rights. Social work courses, literature, research, and practice in I/DD continue to lag behind other topics focused on oppressed groups (Fuld, 2020; Mackelprang, 2010). Nevertheless, the move toward empowerment and a perspective focused on an individual's strengths is slowly evolving in social work policy and research (Zastrow & Hessenauer, 2022).

The social model of disability in social work education

In the mid-1970s, a British disability rights organization began exploring a new theoretical approach called the social model of disability. Their work recognized that the

limitations experienced by people with disabilities often arise from the environments in which they work and live—and not solely the result of a person's diagnostic impairment (Oliver, 2013). The social model of disability acknowledges the existence of functional impairments but questions whether these impairments are best viewed as abnormal or simply different. A person using a wheelchair for mobility is often used to illustrate the key difference. In the medical model, a person's disability is a *deficit*, whose *loss* explains the person's limitation when accessing a building. In contrast, the social model of disability would point out that the person in the wheelchair is quite mobile; however, the lack of a ramp is what prevents an individual from entering a building. In the social model, walking is not considered superior to using a wheelchair.

While teaching social work students in the 1980s, Oliver (2013) coined the term 'social model of disability.' Early work in this field was spearheaded by the Union of the Physically Impaired Against Segregation (The Physically Impaired Against Segregation [UPIAS], 1976) as a way to assist students in understanding the social construct and best practices for working with individuals with I/DD. Gradually, disability studies emerged as a vibrant discipline in social work education. The relationship between social work and disability is complex and has evolved over the years (Morgan, 2012; Stainton et al., 2010).

With a social model of disability, the focus shifts from the individual to the environment and highlights an inherent bias regarding non-disabled behavior. Two terms evolved to capture this prejudice: ableism, which is discrimination in favor of the non-disabled, and disablism, which is discrimination against disabled people. Campbell (2008) argues that ableism reinforces the superiority of ability. This ableism bias spurred the development of a social model of disability by turning attention to environmental barriers.

Though efforts have been made to implement coursework dedicated to individuals with I/DD (Barnes & Mercer, 2006; Morgan, 2012), educators in schools of social work still face outdated approaches that limit the scope of practice (Kattari, 2015; Morgan, 2012; Oliver, 2013). For example, Kim and Sellmaier (2019) argue that social work education must make disability visible by integrating the social model of disability into curricula and field placements. Despite the marginalization of individuals with disabilities (Morgan, 2012), the social model of disability guides policy and practice. It is essential that schools of social work adopt this framework so that students can better understand the challenges and strengths of individuals with disabilities early on in their careers, which can lead to more inclusive practice.

The bio-psycho-social approach and models of disability in social work education

The Bio-Psycho-Social (BPS) approach in social work education integrates biological, psychological, and social factors to provide a comprehensive understanding of disability. According to the World Health Organization (WHO), disability results from the interaction between health conditions and environmental and personal influences (World Health Organization, 2001). The BPS approach combines the medical and social models of disability, considering physical health, mental well-being, and the individuals within their social environment. For example, societal attitudes (ableism) and physical barriers (such as the lack of ramps) interact with health conditions, informing effective interventions (Tronto, 2020). Approaches to using the BPS model in social work education

involve developing curricula incorporating case studies and offering professional development (field placements) to better equip future social workers to address the complex needs of individuals with disabilities. This promotes inclusive practices that align with the ethical standards of the National Association of Social Workers (NASW) and the Council on Social Work Education (CSWE).

The moral theory of ethics of care

Many theorists have described Western culture and its care-delivery organizations as driven by individualism and a do-it-yourself approach (Oyserman et al., 2002; Schwartz, 1994) As resources are limited, these systems favor rationality over emotion in deciding who gets care. Ethics of justice (e.g. 'first come, first served') determines who deserves or merits help (Eisler, 2008). These attitudes differ from what this paper refers to as the 'ethics of care.' The model discussed differs primarily in its focus on caring, a concept that emerges from studies of relational feminism (Held, 1993).

The ethics of care approach stems from the understanding that women's emotions differ from those of men; girls, in general, are more socially gendered (Lappalaine & Motevasel, 1997). Women fundamentally differ in how they socialize and care for others compared with men, although these caring attitudes are universally accessible and not restricted by gender (Noddings, 2013/2013). A caring perspective prioritizes how we relate to the larger society (Eisler, 2008; Noddings, 2013). Ethics of care models define caring relationships as ontologically basic—they begin when our lives begin. Caring relationships are fundamental; every human feels this impulse to care (Noddings, 2013/2013). Vulnerability and dependence are essential to human life. From this vantage point, the ethics of care is crucial to all moral reasoning and action. Its value lies in emphasizing relationships with others and creating an urge to provide care in concrete ways that enhance the well-being of others (Gabriel, 2015; Noddings, 2013).

It is crucial to note that while the ethics of justice prioritize a detached and rule-based approach, the ethics of care focus on the needs and well-being of individuals within their specific relational contexts. This comparison highlights the ethics of care as a more flexible and compassionate approach, emphasizing relationships, empathy, and caring practices (Botes, 2000). It is particularly relevant in social work, where it is essential to understand and address the needs of individuals with intellectual and developmental disabilities (I/DD) within their social environments.

Perspectives of diversity in ethics of care

There is a growing need to integrate diverse perspectives and ethical frameworks in social work education to better address the complexities of vulnerable populations. Additional studies underscore the need for a more inclusive approach to social work education that incorporates the ethics of care and addresses issues related to disability. This includes feminist social work education, the inclusion of disability, and the application of the ethics of care versus the ethics of justice. For example, Soldatic and Meekosha (2012) argue that neoliberal policies marginalize disabled people in social work education and emphasize including their experiences to challenge these ideologies. Similarly, Kim and Sellmaier (2019) highlight that

disability is often overlooked in social work curricula and call for its integration to better prepare social workers for advocacy and support for clients with disabilities. Additionally, Botes (2000) contrasts the ethics of justice, which prioritizes fairness and impartiality, with the ethics of care, emphasizing relationships, empathy, and caring practices. In this sense—the ethics of care offers a deeper understanding of the complexities of social work, particularly in the context of vulnerable populations.

This article explores the various components of the ethics of care model, a versatile and adaptable framework that can be applied universally. It's essential for social work students to recognize that the ethics of care places a strong emphasis on relationships, empathy, and caring practices in moral reasoning, rather than being confined to rationality or gendered perspectives (Held, 2006). This approach, rooted in the works of Carol Gilligan (1982) and Nel Noddings (1986), challenges the traditional ethical theories that revolve around abstract principles and impartiality. Instead, it advocates for moral decisions that are based on the relational context and individual needs, a principle that can be applied universally.

Person-centered ethics of care for individuals with I/DD

An ethics of care model is defined as an approach in which different parties interact harmoniously in the interest of a specific individual, considering the needs of all parties when planning the choice of action. Person-centered ethics of care is particularly relevant in caring for an individual with I/DD. In the first few years of life, an individual with I/DD is usually identified as needing special attention. As the child ages, this individual and caregivers will interact with a network of entities seeking to influence the child's decision-making. The person-centered ethics of care model presented here aims to keep the focus on the person with a disability at the center (Weller & Rogers, 2013).

In the context of the person-centered ethics of care model, emotional connections are crucial for all involved. For individuals with I/DD, personal dignity is closely linked to independence and autonomy (Kittay, 2011). However, autonomy can be compromised when individuals rely on others for care. Individuals with disabilities often depend on societal, educational, political, and economic forces beyond their control (Oliver, 2013). Therefore, it's essential for individuals with intellectual and developmental disabilities (I/DD) to learn to make decisions independently and be afforded the same opportunities for decision-making as those without disabilities (Hakobyan et al., 2020). The person-centered ethics of care model is a community of service providers who share the common goal of caring for individuals with I/DD.

Consider the following example of how justice and dignity are compromised when a person with a disability's independence is impeded. A student with a developmental speech delay requires employment to live independently. The job requires effective communication skills, which can be enhanced using assistive technology. Yet, the technology may be limited by funding cuts, or the student may lack access to primary medical care for evaluation, or the school system may not offer the evaluations, or the student may not have the transportation to attend an assessment. This example points to the need for a person-centered ethics model, in which all parties collaborate to support individuals with intellectual and developmental disabilities (I/DD).

Empirical evidence that person-centered care is directly influenced by care coordination was recently reported by Hakobyan et al. (2020). They used the term 'co-creation of care' to describe productive interactions between patients and professionals. In their study of a cohort of 289 caregivers of persons with intellectual disabilities, findings showed that person-centered care and co-creation of care were positively related to caregivers' satisfaction with care ($p < 0.001$). In other words, when caregivers perceive that patients and professionals are interacting well, care for individuals with I/DD can be significantly improved.

From a person-centered ethics of care perspective, social work students examine the dynamic relationships between individuals with intellectual and developmental disabilities (I/DD) and their environment. This model focuses on an individual with I/DD as a person, rather than a patient with a diagnosis. Students learn to view the dynamic process in which a relationship exists between the person, the family, and the multiple care systems to improve the quality of life. The individual with I/DD is at the center, similar to the hub of a wheel. Considering the individual's needs, values, family, community, and medical history; understanding the barriers/challenges from the social environment teaches students how best to support the individual.

Patient-centered care is essential to the healing process and involves doctors and medical providers collaborating to treat illnesses, conditions, and injuries, sometimes with minimal input from patients and families. Person-centered care, by contrast, focuses on the active knowledge and involvement of the individuals receiving the care (Starfield, 2011). There are fundamental differences in how social workers must approach the care of individuals with disabilities, as described in Table 1. Person-centered care provides the foundation for a better understanding of connecting individuals with intellectual and developmental disabilities (I/DD) to resources that are independent of a medical setting. This approach teaches social work students to recognize that the individuals' needs and goals will evolve, yet they must always remain at the center of person-centered care.

The complex and interactive needs facing individuals with I/DD and their caregivers

Caregivers of individuals with I/DD often face steep challenges navigating healthcare and school systems. They find it difficult to transition from appropriate or necessary services due to the complexity of their needs and the general lack of care coordination. Previous studies identified strong service coordination as pivotal to successful service delivery and outcomes (Hiebert-Murphy et al., 2011; Hillis et al., 2016). Care coordinators, primarily social workers, provide families with resources and support tailored to an individual's needs. They often have an ongoing relationship with the family and are accustomed to being part of a care team (Hiebert-Murphy et al., 2011; Hillis et al., 2016).

Caregivers of individuals with intellectual and developmental disabilities (I/DD) reported two essential qualities of care coordinators: relationship skills and practical skills. First, care coordinators must be caring individuals with strong interpersonal skills to promote trust and help build alliances. Second, care coordinators should be seen as 'organized, knowledgeable about the service delivery system, and able to stay on top of the services provided' (Hiebert-Murphy et al., 2011, p. 149). They should be trained to understand the various system logistics, locate available service providers, coordinate and

Table 1. Distinctions between the patient-centered care and person-centered ethics of care for individuals with disabilities.

Patient-Centered Care	Person-Centered Ethics of Care
• Primarily based on a medical model of disability, it focuses on the disability and impairment of the disabled person.	• Based on a social model of disability, it focuses on the disabled person and their social environment, specifically on the relationship between impairment and the larger society, acknowledging impairments as differences, not problems.
• Views individuals with disabilities and their body/mind as the problem.	• Empowers and unites the disabled individual and community by embracing the distinct differences between illness and caring. Focuses on social and community resources that may be age- or condition-specific.
• Focuses on diagnosis and treatment; examines the medical diagnoses in ag-related, healthcare, and mental health service settings.	• Recognizes care ethics as the key to aiding and connecting disabled persons to services. Connects the individual with I/DD across all service delivery entities and assists with access to care, ensuring appropriate needs are met.
• Doctors determine whether an individual is sufficiently impaired to qualify for disability benefits.	• Recognizes all factors (patients, families, caregivers, agencies, etc.) that may impact individuals with I/DD and their environment. Respects personal values, preferences, and expressed needs in a social environment.
• Doctors are independent in decision-making processes.	• Focuses on advocacy and rights of the disabled individual.
• The medical model treats disability as an individual problem that should be 'fixed.'	• Focuses on care coordination for the individual with I/DD within their social environment and family systems. Advocates for the strong involvement of all caregivers provide continuity of care and secure transition between all service delivery sectors.
• Less likely to coordinate care with providers and other service delivery members.	• Keeps the individual with I/DD at the center of the long-term goals and outcomes within the medical setting.
• Keeps the *patient* at the center, focusing on acute treatment plans, and tends to downplays social factors in recovery.	• Helps to develop individualized life plans focused on the social environment.
• Generally focused primarily on medical treatment; care coordination is less important in a medical model.	• Focuses closely on information sharing and education to individuals with I/DD and caregivers to become proactive partners and wise decision-makers. Provides emotional support to individuals with I/DD and caregivers.

monitor the delivery of services, inform families of the availability of services, and facilitate the development of necessary transitions as children grow. However, there are persistent challenges to the training and development of care coordinators in supporting families of individuals with intellectual and developmental disabilities (I/DD). Previous studies indicated a lack of provision for context-specific training (Au et al., 2011; Hillis et al., 2016). Therefore, a person-centered ethics of care approach will benefit social work students by thoroughly assessing individuals with intellectual and developmental disabilities (I/DD) and how best to address these complex needs.

Person-centered ethics of care: a model

The main components of the Person-Centered Ethics of Care (PC-EoC) model for individuals with I/DD include the family/individual with I/DD and key roles played by five distinct groups of workers. The key person in every child's growth and development

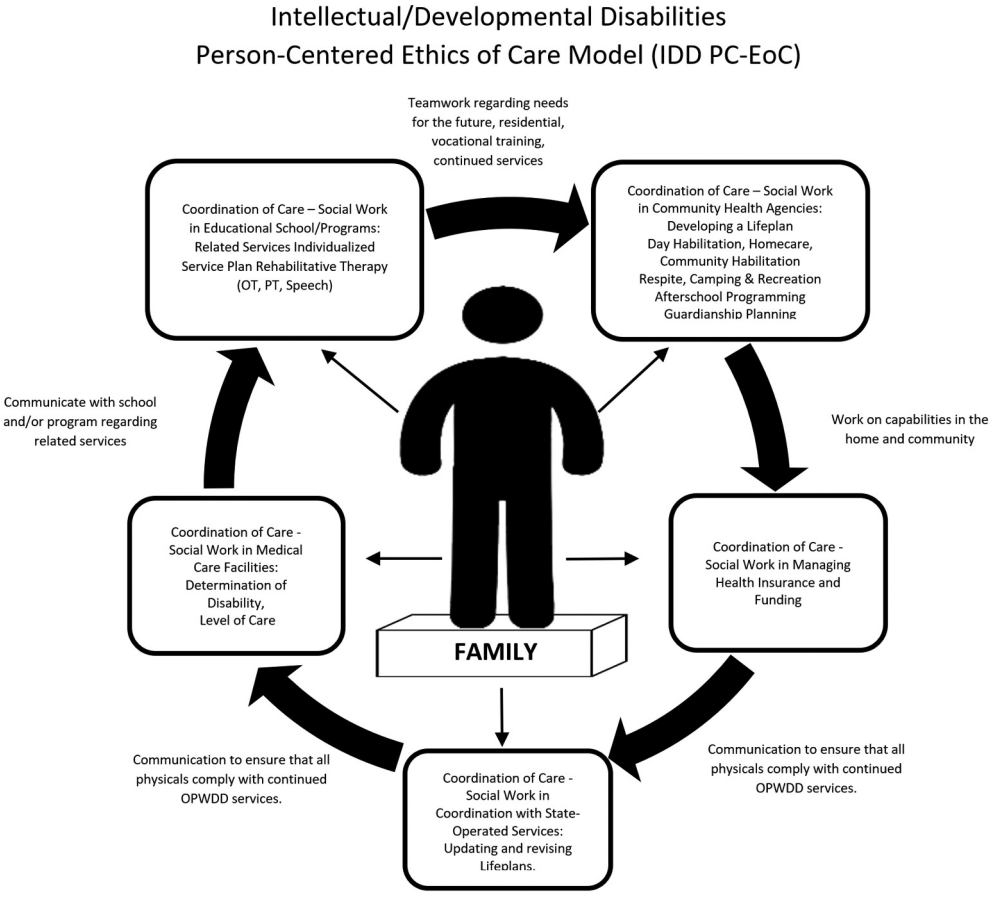

Figure 1. Intellectual/Developmental Disabilities Person-Centered Ethics of Care Model (IDD PC-EoC).

is nearly always a social worker (SW). Figure 1 depicts these supporting roles as Coordination of Care—S.W./Educational School/Programs; Coordination of Care—S.W./Community Health Agencies; Coordination of Care—S.W./Health Insurance Funding; Coordination of Care S.W./Governmental and State Agencies Liaison; and Coordination of Care—S.W./Medical Care Facilities. A vital component of Figure 1 indicates a necessary flow of information between each part of a person's team.

Teaching social work students, the components of the PC-EoC model for individuals with I/DD

Understanding the interactions between the various elements of the PC-EoC model can guide social work students and inform their training for future practices. The model uses case studies to understand the full array of service delivery systems; works with parents and caregivers in how to best seek services that may be required for their family members; works with agencies, offices, and education and healthcare providers in effective decision-making; and emphasizes communication skills to integrate the separate

entities shown in Figure 1. It should be noted that this model is rooted in a U.S.-based framework, primarily in areas such as care coordination, health insurance management, and the reliance on state-run services (i.e. agencies and services operated by and under OPWDD in New York City), and the use of care models often linked to different levels of health coverage.

Individuals with intellectual and developmental disabilities (I/DD) and their caregivers must be fully informed about the multiple professionals involved in their care. The person-centered process respects and responds to the individual's preferences with intellectual and developmental disabilities (I/DD). The approach requires close communication and shared decision-making beyond the simple provision of information (Epstein & Peters, 2009; Rowland & Politi, 2016). The productive collaboration between professionals and the person's preferences and desires lead to more satisfying outcomes (Hakobyan et al., 2020). The collaborative role of the social worker is described below.

Coordination of care - social work in school settings

Children with I/DD will likely be flagged early in their lives as needing more attention than typically developing individuals, thereby eliciting a referral to an Early Intervention (E.I.) program. Thus, we will begin a decades-long interaction with school-based professionals and teachers. These programs are usually operated under the aegis of the Department of Education. Here, a child with I/DD will first encounter specialists to provide physical, occupational, and speech evaluations and therapies. However, it is essential to note that the duration and nature of these interactions may evolve over time, depending on the individual's changing care needs.

Social workers collaborate with the school-based team to evaluate the child who may require special services. They play a significant role in creating an Individualized Education Plan (IEP) to meet the child's needs. An IEP is a legal document that provides information on how the student learns best. The team recommends the best professionals (teachers and service providers) who can be used to help the child learn. Additionally, school social workers can provide individualized counseling to children in groups or classroom settings.

The child with I/DD can begin receiving all related services at a very young age, starting from early intervention (0-when the child turns 3 years), preschool (3–5 years), and continuing through the school years to young adulthood (5–21 years). Often, the child receives services when their teacher realizes they are needed. The roles of school social workers vary from state to state, but they often talk with parents when their child is considered for special education.

Coordination of care - social work in community health agencies

Social workers trained in intellectual and developmental disabilities (I/DD) work closely with community health agencies. They assist in identifying individuals with developmental disabilities such as intellectual disability, autism, Down syndrome, cerebral palsy, and other conditions. These social workers help manage their day-to-day activities. Like other social workers, they evaluate clients through psychological and psychosocial assessments, explore community resources, and recommend services that benefit the individual. They assist parents in understanding their rights so their child can receive the services they are entitled to.

Trained social workers assess their clients' needs and strengths to determine which support system or program may help them achieve their goals. When the assessment is complete, the social worker develops a person-centered Individualized Family Service Plan (for children aged 0–3) and an Individualized Service Plan (for children aged three and up) to assist the client in obtaining the necessary services. The IFSP and ISP aim to promote the individual's autonomy and self-esteem. For example, an I/DD-trained social worker evaluates community resources, such as governmental programs like Medicaid and Food Stamps/SNAP, to secure the most suitable programs. They advocate for the rights of their clients and their caregivers. Once the services are implemented, regular follow-up is maintained to ensure that they remain in place and continue to meet the client's needs. Additionally, social workers offer individual and family counseling, as well as facilitate support groups. One of the primary goals of disability social workers is to teach parents how to advocate for their children, thereby assisting the child in becoming as independent as possible. For older individuals with I/DD, disability social workers connect them with services and support groups and help maintain their independence as they age. They also work with physicians and other healthcare professionals to explain how the client's disability may influence their emotional and mental health.

Coordination of care - social work in managing health insurance and funding

The most critical and contentious component of receiving services is often the availability of funding. Most programs for individuals with I/DD are historically funded by Medicaid. Funding levels vary significantly from state to state, affecting the range of services available to any individual. The social worker's role in this area is to understand the importance of health insurance and the availability of Medicaid funding, as well as how these factors impact individuals throughout their lifespan. For Medicaid purposes, a child with I/DD must be identified as having special needs early in life, ideally in the first 1–2 years, but certainly before age 21. Without Medicaid funding, the child will likely be denied participation in many of their programs. The disability social workers also help determine whether an individual with I/DD has access to specially trained physicians and clinics that understand the unique needs of this population (Hiebert-Murphy et al., 2011; Hillis et al., 2016).

Coordination of care - social work in collaboration with state-operated services

For families with an individual with an intellectual or developmental disability (I/DD), many programs and services are operated and licensed by a state agency. In New York, this agency is known as the Office for People with Developmental Disabilities (OPWDD). Similar entities exist in other states throughout the U.S. Within these various agencies, budgets for various programs and services are established, criteria and requirements are set for participation in these programs, and rules for oversight and accountability are established. Social workers meet with all agencies involved in the individual's care and continually update life plans tailored to the individual's needs with intellectual and developmental disabilities (I/DD). The goal of proper training of social work students who wish to work in this field is to ensure that individuals with I/DD have access to person-centered supportive services throughout adulthood.

As with other state-operated services, a social worker's training in developmental disability is pivotal in assisting and counseling families in developing a life plan for a child

with I/DD. A social worker is often the first person a family will turn to when seeking help with a child with special needs, and this role often remains constant throughout the years. While schools, programs, and clinics come and go, the social worker may often be the same person guiding the family and individual through the process of receiving state-operated services. Social workers in this role provide person-centered care using an interdisciplinary approach. They identify community-based resources and connect them to community services and support, social services, housing, and family services.

Coordination of care - social work in medical care facilities

In most aspects of a child with a disability's life, services will depend upon the availability of a physician or other medical practitioner to document and prescribe a person's developmental disability and ultimately approve their services. In many cases, a child's pediatrician will play this role, and it is common for a family to depend on a child's pediatric practitioner well into a person's adult years. However, special needs clinics have arisen in many cities to help provide I/DD-sensitive healthcare. The social worker in this role may facilitate and document the appropriate level of care. This individual will assist in the transition to adult medical care, focusing on the complex needs of an individual with I/DD.

Discussion

The theoretical concept of person-centered care primarily originated in healthcare as a 'patient-centered model' and referred to 'care that is respectful of and responsive to individual patient preferences' (Epstein & Peters, 2009). A patient-centered approach was empirically sound and improved outcomes in various study settings (Anderson, 2002; Hakobyan et al., 2020). However, the person-centered ethics of care model discussed here is similar to patient-centered care yet different in several key ways. First, person-centered ethics of care is not based on an illness or procedure, as in a healthcare setting. Instead, the model aims to teach social work students how to best address the complex needs of individuals with I/DD. Students are taught that individuals with intellectual and developmental disabilities (I/DD) and their families require coordination of all systems, including caregivers, in the sole interest of the individual with I/DD at the center of the hub, as shown in Figure 1.

Second, a person-centered ethics of care relies on the mutual awareness of all team members, including social workers, doctors, therapists, teachers, state officials, Medicaid agents, and others. As Hakobyan et al. (2020) state, this model requires 'co-creation of care.' Like the spokes of a wheel, the individual with I/DD cannot flourish if any component is missing. Students are taught the benefits of this person-centered approach before starting a career. Thus, social workers can help meet the complex needs of individuals with I/DD and improve job satisfaction if they choose to work with individuals with I/DD (van der Meer et al., 2018).

However, changing to a person-centered ethics of care model in social service and healthcare delivery systems can pose a challenge for social workers. These include policies that often prioritize efficiency over personalized care, resulting in inequality and hindering implementation (Held, 2006; Shakespeare, 2006), as well as a lack of resources, agency constraints, systemic barriers, and resistance to

change. The model requires more time, patience, staff, financial resources, and a shift in mind-set to meet resistance due to entrenched norms. Educating social work students early on and highlighting the benefits can help overcome the challenges, promoting positive outcomes in care. Furthermore, prior studies have highlighted the need for social workers to receive more context-specific training (Au et al., 2011; Hillis et al., 2016). Delivering this training using the PC-EoC model (e.g. case studies and role-playing) can effectively diminish systemic barriers and resistance to change. This model aims to educate future social workers to be organized, well-versed in the service delivery system, and updated on the services offered. Finally, social workers involved in the I/DD world play a dual role: they help families locate the required services and assist them in understanding the various components of their care. Social workers gain satisfaction from connecting individuals with other professionals on the team. The person-centered ethics of care model provides social work students with insights into the 'working parts' of the I/DD world, emphasizing the interconnectedness of the different team members. This is a key component of a social worker's education.

Implications for social work education

Social work students must understand their roles in coordinating care for individuals with Intellectual and Developmental Disabilities (I/DD) early in their careers. Using the Person-Centered Ethics of Care (PC-EoC) model, students learn that ongoing support systems are required throughout the lifespan (Hakobyan et al., 2020; van der Meer et al., 2018). For example, young adults with intellectual and developmental disabilities (I/DD) who previously received services through the Department of Education must now navigate new systems, such as Care Coordination, Waiver Services, and Self-Determination. Understanding the interconnected nature of these systems can lead to higher satisfaction for individuals with I/DD and their social workers (van der Meer et al., 2018).

Focusing on curriculum development, field placements, and ongoing professional development is crucial to enhancing the implementation of the PC-EoC model in social work education. Curricula should include comprehensive modules within the PC-EoC model, as well as case studies, role-playing exercises, and guest lectures. Field placements should provide hands-on experience in agencies serving individuals with intellectual and developmental disabilities (I/DD), allowing students to work directly with clients with I/DD, their families, and service providers.

In addition, ongoing professional development should include workshops, seminars, and continuing education courses on the PC-EoC model, focusing on developing interpersonal skills, including empathy, navigating social service agencies, understanding financial assistance options, and advocating for individuals with I/DD. This approach helps social work students connect with unfamiliar services, navigate interconnected social service systems, assist families in applying for funding programs, understand financial assistance options, and advocate in community and work organizations where adults with I/DD may lack opportunity and representation.

Conclusion

The Person-Centered Ethics of Care (PC-EoC) model provides social work students with crucial knowledge of 'best practices' in caring for individuals with I/DD early in their careers. They will learn that the social worker is always key in advising families of individuals with I/DD to navigate a complex path. This proposed model will help social work students stay person-centered by enhancing their interpersonal and practice skills and knowledge through increased learning experience if they choose to work in the I/DD field.

Disclosure statement

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