18. Social work practice with individuals with intellectual disabilities

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INTRODUCTION

Developmental disabilities or neurodevelopmental disabilities (including intellectual disabilities) are a diverse group of chronic disorders such as autism, cerebral palsy, Down syndrome, and other genetic disorders. Developmental disabilities are a group of disorders that influence the developing nervous system. Many of these conditions manifest before the age of two or in childhood as a developmental delay or limitation in one or more of the following domains, which include physical, learning, language, or behaviour (Petersen et al., 1998; Solarsh & Hofman, 2011; Schalock et al., 2021). Intellectual disabilities are a specific subset within the broader category of developmental disabilities (Schalock et al., 2021). They are defined explicitly by significant limitations in intellectual functioning—such as reasoning, problem-solving, learning, and adaptive behaviour, which includes social, conceptual, and practical skills needed for daily life (American Association on Intellectual and Developmental Disabilities, n.d.). Intellectual disabilities are characterized by notable limitations in intellectual functioning and adaptive behavior, originating before age 18 (Centers for Disease Control and Prevention [CDC], 2022). These conditions significantly impact an individual's daily functioning and typically last a lifetime.

This chapter will examine how social work and society approach an understanding of people with intellectual disabilities and how to address needs and advocate for support and services at the micro, mezzo, and macro levels. The chapter will begin with an overview of intellectual disabilities, an examination of social stigma and discrimination faced by people with intellectual disabilities, and how a shift in perspective from a medical model of disability to a social model of disability is needed to combat stigma, discrimination, and promote equity, belonging rights, and social justice. The chapter will then explore social work practice at the micro, mezzo, and macro levels, including considering working with caregivers of people with intellectual disabilities.

INTELLECTUAL DISABILITIES

Intellectual disabilities are among the most prevalent developmental disabilities, impacting around 1–3% of people worldwide (Olusanya et al., 2023). The origins of intellectual disabilities are varied, encompassing genetic disorders like Down syndrome, prenatal complications such as fetal alcohol spectrum disorders, birth-related issues such as oxygen deprivation, and environmental influences including lead poisoning or severe malnutrition (Eunice Kennedy Shriver National Institute of Child Health and Human Development [NICHD], n.d.).

Diagnosing intellectual disabilities requires thorough assessments utilizing standardized tests to evaluate intellectual functioning, often through IQ tests and assessments of adaptive behavior (*American Association on Intellectual and Developmental Disabilities*). Typically, an IQ score below 70–75 suggests the presence of an intellectual disability. Evaluations of adaptive behavior involve comparing an individual's abilities in areas like communication, social skills, and practical daily living skills with those of age-matched peers (Schalock et al., 2010). A multidisciplinary team often conducts assessments from infancy through adulthood, guides interventions, and adjusts support as individual needs change. They are an essential tool to inform educational plans (e.g., IEPs), behavioral interventions, transitions to adulthood, and support plans for adults in residential or vocational settings. For example, the Vineland Adaptive Behaviour Scales is one of the primary assessment tools used to assess individuals with intellectual disabilities across the life stages and serves as a guide for support and interventions (Chatham et al., 2018). Early interventions are vital to improving adaptive behavior; however, skills may plateau or decline, particularly in aging individuals with co-occurring conditions. Therefore, reassessments are needed to ensure that appropriate support continues to be provided as needs evolve. Types of assessments include:

1. *Adaptive Behaviour Scales:* Evaluate strengths and weaknesses in daily skills.
2. *Developmental Assessments:* Detect developmental delays in young children.
3. *Cognitive Assessments:* Measure intellectual functioning, often alongside adaptive behavior evaluations.
4. *Behavioral Assessments:* Focus on daily functioning and behavior management.

The benefits of assessment include:

1. *Access to Services:* A diagnosis provides opportunities for educational, medical, and therapeutic support.
2. *Individualized Planning:* Assessment can assist in tailoring interventions.
3. *Early Intervention:* Early assessments improve long-term outcomes.
4. *Informed Decision Making:* Data helps shape decisions regarding education and healthcare.
5. *Legal Protections*: A formal diagnosis ensures accommodations under laws such as IDEA (Individuals with Disabilities Education Act (IDEA), 20 U.S.C. § 1400 (2004)) and ADA (1990).

Supporting individuals with intellectual disabilities involves a range of essential services, including educational programs, vocational training, social skills development, and personalized healthcare plans. Adaptive behavior assessments are key to diagnosing intellectual disabilities and ensuring appropriate support for a fulfilling, independent life. Early intervention is critical in helping individuals with intellectual disabilities reach their full potential, while community-based services and family support are vital components of a comprehensive support system. This chapter discusses specific social work practice approaches in more detail.

Social Stigma and Discrimination

Historical, cultural, and systemic factors shape society's views on individuals with intellectual and developmental disabilities. Stigma surrounding intellectual disabilities affects all ethnic groups but is particularly pronounced among ethnic minorities (Scior, 2011; Scior et al., 2013). Cultural beliefs and misconceptions can lead to shame, social isolation, and reluctance to seek diagnosis or services. Barriers such as language, limited healthcare access, and systemic inequities further contribute to delayed diagnoses and lack of support. Additionally, cultural expectations of caregiving can intensify pressure to care for individuals at home without seeking professional help. For example, families may experience internalized stigma, feeling guilt or shame, which often prevents them from advocating for their loved ones with intellectual disabilities.

Increased contact and awareness are linked to reduced stigma and should be key targets in efforts to address stigma associated with intellectual disabilities. Therefore, challenging stereotypes, raising awareness, and advocating for inclusive policies are essential for promoting acceptance, respect, and equality for individuals with disabilities. Common perceptions towards individuals with intellectual disabilities often include:

1. *Lack of understanding* or awareness about the capabilities and contributions of individuals with disabilities portrays them as incompetent, dependent, or burdensome. This often contributes to marginalization and discrimination (Scior et al., 2020).
2. *Normalizing* the authentic experiences of individuals with intellectual disabilities, which are often overlooked or normalized, especially if they are not visibly apparent. This normalization often leads to the invisibility of their needs, challenges, and contributions within society, resulting in the perpetuation of systemic barriers to inclusion and participation (Kattari et al., 2017).
3. *Attitude of pity and infantilization* towards individuals with intellectual or developmental disabilities, which often diminishes their agency, autonomy, and dignity. This paternalistic view often manifests in well-intentioned disempowering behaviors, such as condescendingly speaking to individuals with disabilities or assuming they are incapable of making decisions for themselves (Davis, 2016).
4. *False narratives* that often portray individuals with intellectual and developmental disabilities as inspirational figures, emphasizing their resilience, courage, and ability to overcome adversity. While these narratives can assist in promoting positive attitudes and awareness about individuals with intellectual disabilities, they may also tokenize individuals with disabilities, reducing them to sources of inspiration rather than recognizing their full humanity and diverse experiences (Watermeyer and Görgens, 2014).
5. *Misleading views* of individuals with intellectual disabilities emphasize their dependency on others for support and care. This perspective often reinforces attitudes of paternalism, perpetuating systems of dependency rather than recognizing and fostering the abilities, aspirations, and rights to self-determination of individuals with intellectual disabilities (Davis, 2016).

Stigma and discrimination against individuals with intellectual disabilities often limit their access to education, employment, and social integration. Stigma surrounding intellectual

disabilities significantly limits access to education, employment, and social integration, particularly among marginalized groups. Scior et al. (2013) revealed that negative perceptions towards individuals with intellectual disabilities persist globally, affecting individuals' opportunities. These include the following:

1. ***Education***: Stigma frequently leads to exclusion from mainstream education and restricted access to specialized programs. Children with disabilities are twice as likely to be out of school compared to their peers (Arakelyan et al., 2020).
2. ***Employment***: Individuals with intellectual disabilities frequently face enduring challenges in obtaining and retaining employment, as employers often underestimate their capabilities, leading to lower employment rates (Jacob et al., 2023).
3. ***Social Integration:*** Individuals with intellectual disabilities often experience social isolation due to stigma, which leads to exclusion from community activities and worsens mental health outcomes. This reinforces and perpetuates the cycle of marginalization (Rizzo et al., 2024).
4. ***Cultural Competence:*** Cultural services, community education, and advocacy are crucial to dispel myths and reduce stigma. Support networks for families within minority communities can also help reduce stigma and provide a safe space to share experiences and access resources. This can promote greater acceptance and inclusion for individuals with intellectual disabilities in minority communities.

Stigma restricts opportunities for individuals with intellectual disabilities; however, interventions targeted to combat stigma can enhance inclusion and equality. Key strategies for reducing stigma include public awareness campaigns, inclusive education, supported employment programs, and policy advocacy.

Raising awareness and increasing contact with individuals with intellectual disabilities helps reduce stigma and requires public education, advocacy, and legal protection. Social workers play a key role by challenging stereotypes, educating communities, and advocating for inclusive policies. They also collaborate with policymakers to ensure full societal participation for individuals with disabilities. For example, legislation such as the Americans with Disabilities Act (1990) are crucial for advancing the rights and inclusion of individuals with intellectual disabilities in the United States.

A Shift from the Medical Model to the Social Model of Disability

Beyond direct services, the evolution in the disability field from a medical model of disability (Brosco, 2010), focused on diagnostic labels, to a social rehabilitation approach emphasizing community integration has created avenues for social workers to advocate for inclusive policies and programs for individuals with intellectual disabilities. For example, the medical model of disability views disability as a problem within the individual, focusing on diagnosis and treatment aimed at 'fixing' impairments. This approach often emphasizes deficits and reinforces dependency (Zaks, 2023). In contrast, the social model of disability sees disability as the result of societal barriers rather than individual limitations, advocating for accessible environments and full societal participation for people with disabilities (Dirth and Branscombe, 2017). Initiatives such as the Americans with Disabilities Act (Americans with Disabilities

Act of 1990, 1990) have shifted the focus toward the social model of disability (Kattari et al., 2017), creating universally accessible social environments. This allows social workers to contribute to establishing equitable communities that include individuals with intellectual disabilities so they can thrive within their social environment. The social model of disability aligns closely with the core social work values of justice, equity, and empowerment, providing several key benefits:

1. ***Advocacy for Inclusive Policies:*** Social workers can advocate for systemic changes, such as enforcing the Americans with Disabilities Act (ADA), to ensure accessibility in public spaces and services (Kattari et al., 2017).
2. ***Community Integration***: This model encourages the creation of inclusive environments, allowing individuals with intellectual disabilities to participate fully in society.
3. ***Empowerment***: The social model emphasizes empowering individuals to advocate for themselves and make informed choices, shifting away from a deficit-based approach.
4. ***Challenging Ableism***: It challenges institutionalized ableism by fostering acceptance of disability as a natural aspect of human diversity.

Adopting the social model of disability is a social work practice that can foster inclusive communities, advocate for systemic change, and empower individuals with intellectual disabilities to thrive and fully participate in society.

The Nature of Social Work Practice with Individuals with Intellectual Disabilities

Disabilities affect approximately 26% of adults in the United States, spanning various demographic groups (CDC, 2024a; CDC, 2024b). Social workers routinely serve individuals with disabilities; however, the broad spectrum of disabilities often presents numerous unique challenges for social workers (Oliver et al., 2012; Clarke and Westmore, 2022). One significant challenge is communication barriers for individuals with intellectual disabilities. For example, communication efforts may require assistive technology or adapted communication methods to navigate complex systems such as healthcare, education, and social services. Among this population, individuals with intellectual disabilities require even more specialized care due to the complexities of their condition, which often involve significant challenges in cognitive functioning, communication, and adaptive behavior. This can necessitate tailored support in daily living, decision-making, and accessing services, as well as a need for higher levels of supervision, personalized interventions, and long-term care plans to ensure their well-being and integration into society. Therefore, social workers must be prepared to address these heightened needs, advocating for appropriate resources and fostering an inclusive, supportive environment.

Practice at the Micro, Mezzo, and Macro Levels

At the micro level, social workers provide direct services such as early intervention and transition planning for individuals with intellectual disabilities. At the mezzo level, they facilitate individual skills and support groups for families. At the macro level, they advocate for supportive policies and programs (Rubin and Johnson, 1984). In addition, the unique needs of

caregivers of individuals with intellectual disabilities require a range of support needs relevant to social work practice (Gutowska, 2022). For example, practice can include early intervention services, K–12 education services, transition support into postsecondary settings (i.e., work, employment, and adult daily living), and family counseling. Moreover, the heightened prevalence of homelessness (Brown and McCann, 2021), abuse (Collins and Murphy, 2022), and poverty (Emerson, 2007) among individuals with intellectual disabilities highlights the critical demand for support and the need for social workers to offer assistance. Ways in which social workers can offer assistance can include the following:

1. *Conduct assessments* to identify strengths and needs, develop person-centered plans with individuals and families, and advocate for rights, such as inclusive education and accessible healthcare.
2. *Provide case management*, which links clients to essential resources like healthcare, education, and vocational programs while offering crisis intervention and behavioral support during challenging times.
3. *Provide education and training* for individuals, families, and communities to promote awareness and inclusion while counseling addresses emotional and behavioral challenges.
4. *Assist with skill development* to enhance independence, provide family support, and advocate for improving care systems.
5. *Promote community integration*, collaborate with interdisciplinary teams to ensure holistic care, and help a family navigate healthcare services while advocating for the client's inclusion in community programs.

Social work practice with individuals with intellectual disabilities involves a multifaceted approach encompassing micro, mezzo, and macro interventions, each addressing separate but interconnected aspects of support and advocacy. For example, at the *micro level*, social workers engage directly with individuals with intellectual disabilities, providing personalized support to address their needs, enhance their daily functioning, and promote self-determination (Mumbardó-Adam et al., 2020). Services may include comprehensive assessments to understand strengths and needs, developing person-centered plans, providing counseling and therapeutic support, and offering crisis intervention and behavioral support (Bigby and Frawley, 2018). Social workers also assist individuals with intellectual disabilities in developing skills, such as communication, self-care, and social skills, to enhance their independence and quality of life (Nota et al., 2007).

The *mezzo level* involves working with families, groups, communities, and organizations, providing support systems, and ensuring that individuals with intellectual disabilities can access community resources and networks that foster social inclusion and well-being (Kwan, 2021). Social workers facilitate group interventions, such as employment skills and training programs for individuals with intellectual disabilities and support groups for families, which provide social support, education, and resources (Kwan, 2021). This helps individuals with intellectual disabilities build social networks, gain peer support, and develop a sense of belonging.

At the *macro level*, social workers engage in systemic advocacy and policy work, striving to influence legislation, funding, and public perceptions to create an environment that promotes the rights and inclusion of individuals with intellectual disabilities on a broader societal scale

(Tören and Aslan Açan, 2024). These areas of practice are critical for delivering comprehensive care and allow social workers to address the unique and complex needs of individuals with intellectual disabilities across various domains of their lives. For example, social workers advocate and work to influence policies to create supportive environments for individuals with intellectual disabilities. This includes advocating for inclusive policies and programs, participating in policy development, and promoting legislative changes that support the rights and inclusion of individuals with intellectual disabilities (Rothman, 2018). In addition, social workers raise awareness and challenge societal attitudes and stigma surrounding intellectual disabilities, promoting a more inclusive and accepting society (Rimmerman, 2013).

Social work practice with individuals with intellectual disabilities involves a comprehensive approach through micro, mezzo, and macro interventions rooted in empowerment, inclusion, and social justice. Each level addresses distinct yet interconnected areas of support and advocacy, ensuring holistic care. This approach allows social workers to serve as key advocates for the rights and well-being of individuals with intellectual disabilities, addressing their unique needs and strengths in supportive, inclusive environments (Knevel et al., 2023; Smith-Hill et al., 2023).

Reflection of Society in Social Work Practice with Individuals with Intellectual Disabilities

As demonstrated in the previous section, social work practice with individuals with intellectual disabilities is multifaceted, reflecting and shaping societal attitudes, policies, and norms. Social workers are crucial in advocating for and providing services addressing the various needs of individuals with intellectual disabilities, from direct care to systemic advocacy. These include the following:

1. ***Attitudes and Stigma:*** Social workers frequently encounter and address negative stereotypes and misconceptions about intellectual disabilities. Negative societal views can influence how services are provided and how individuals with intellectual disabilities are perceived and treated within various systems (Finkelstein and Gross, 2024). Social workers are critical in challenging these stigmas and promoting more inclusive and accepting attitudes.
2. ***Legal and Policy Frameworks:*** Social work practice is heavily influenced by the legal and policy frameworks that govern the rights and protection of individuals with intellectual disabilities. Policies such as the Americans with Disabilities Act (1990) reflect societal values regarding inclusion and accessibility and shape the work of social workers advocating for the rights of individuals with disabilities.
3. ***Cultural and Social Norms:*** Social work practice with individuals with intellectual disabilities reflects broader cultural and social norms. This includes the shift from institutional care to person-centered care to allow greater inclusion and recognition of the rights of individuals with intellectual disabilities (McCausland et al., 2022; Isvan et al., 2023).
4. ***Intersectionality and Diversity:*** Social work practice acknowledges and addresses the intersectionality of individuals with intellectual disabilities such as race, gender, socioeconomic status, and more. This reflects a broader social understanding of how multiple forms of oppression and privilege intersect to impact individuals' experiences and access

to resources (Wickenden, 2023). Social workers strive to provide culturally competent services that recognize and address these intersecting factors.

5. ***Advocacy and Social Change:*** Social workers engage in advocacy efforts that reflect societal values of social justice and equity. This includes pushing for systemic changes that benefit individuals with intellectual disabilities and working toward societal changes that promote inclusion and equality (Jones, 2023). The advocacy work done by social workers is both a reflection of and a catalyst for broader societal change.

Social work practice with individuals with intellectual disabilities aims to influence societal attitudes, structures, and systems to promote inclusion, equity, and empowerment. Addressing the interaction between individual needs and broader social contexts fosters more inclusive and supportive communities for individuals with intellectual disabilities.

Experiences and Voices of Individuals with Intellectual Disabilities and Their Caregivers

Individuals with intellectual disabilities and their caregivers frequently report diverse experiences with service delivery, reflecting a range of satisfaction and outcomes. Positive outcomes are often linked to person-centered approaches that respect individuals' preferences, involve them in decision-making, and customize services to meet their needs (Schalock and Luckasson, 2021). Many individuals with intellectual disabilities value service providers who show respect, patience, and understanding. This enhances dignity, self-worth, and self-esteem (Assouline and Morin, 2024). However, challenges remain prevalent. Common issues include lack of accessibility, insufficiently trained staff, and limited opportunities for meaningful participation in community activities (Bogenschutz et al., 2014). Individuals with intellectual disabilities often express frustration with bureaucratic processes and inflexible service structures that fail to adapt to their changing needs (Traci et al., 1999; Test et al., 2003; Seavey, 2004). Therefore, advocating for person-centered approaches involving decision-making and tailoring services to their unique needs is essential. Promoting staff training to enhance respect and understanding, streamlining bureaucratic processes, and supporting flexible service structures are also essential. This would ultimately assist in increasing opportunities for meaningful community participation and inclusion for individuals with intellectual disabilities and their families.

Caregivers of individuals with intellectual disabilities also play a crucial role in providing feedback on the effectiveness of service delivery. They stress the importance of integrated, holistic approaches that address the entire family's needs and ensure continuity of care. They often highlight the physical, emotional, and financial burdens of caregiving and the crucial role that supportive services play in alleviating these pressures and frequently emphasize the physical, emotional, and financial challenges of caregiving, as well as the vital role supportive services play in reducing these burdens (Truong et al., 2021). They value services that offer respite, provide comprehensive information, and facilitate access to resources. However, despite the availability of services, caregivers frequently encounter obstacles such as long waiting lists, fragmented service systems, and inadequate communication from service providers (Serres, 2015). These barriers can exacerbate caregiver stress and negatively impact their overall well-being. Caregivers emphasize the need for integrated, holistic approaches that consider the entire family's needs and promote continuity of care.

Social work approaches to these issues, prioritizing family-centered care and addressing individual and caregiver needs, are critical to the needs of individuals with intellectual disabilities and their caregivers. For example, coordinating services to reduce system fragmentation can improve the health and well-being of caregivers who require assistance navigating a complex system of services. Assessing caregivers' challenges to ensure their feedback shapes service delivery can promote trust and unity. In addition, advocating for respite care and frequent communication about resources can positively influence caregiver perspectives towards receiving care.

Overall, the experiences and voices of individuals with intellectual disabilities and their caregivers are crucial in understanding the effectiveness of service delivery outcomes. Their perspectives provide valuable insights into the challenges faced, the quality of services received, and the areas needing improvement.

CONCLUSION

Social work practice with individuals with intellectual disabilities is essential for promoting well-being, inclusion, and empowerment. Social workers are grounded in social justice, empowerment, and inclusion principles and address the unique challenges individuals with intellectual disabilities face on all levels. Social workers' knowledge about direct services, such as early intervention, transition planning, and advocacy for inclusive policies, plays a pivotal role in improving the quality of life for individuals with intellectual disabilities. They also challenge societal attitudes and policies that perpetuate stigma and marginalization, working to create a more equitable and supportive environment. Ongoing research, education, and policy reforms are vital to ensuring that social workers are equipped to meet the complex needs of individuals with intellectual disabilities, ultimately fostering greater societal understanding, acceptance, and inclusivity.

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