1.1: Support Work- the Fundamentals

Introduction

Supporting individuals who have both an intellectual disability and a mental illness is rarely straightforward. Support work can be carried out by paid direct support workers, family members, or volunteers. Support can be offered in a variety of different environments including residential, vocational, and recreation and leisure. In all aspects of support work, fundamental knowledge from the field of disability studies can offer caregivers important direction. In this chapter, we identify guiding principles for support work, note historical struggles experienced by individuals with disabilities, and explain competencies expected of direct support workers.

Guiding Principles for Support Work

Four guiding principles are central to supporting people with disabilities. People with disabilities, just like people who do not have disabilities, have rights related to citizenship, individual control, equality and human rights, and universal design.

Citizenship means that people with disabilities have the same rights and responsibilities as people without disabilities. Socially constructed barriers, which prevent participation and discriminate against people with disabilities, must be eliminated.

Individual control signifies that people with disabilities must be involved in all stages of developing disability services and policies, and in all decision making that affects their lives. This is often missing in the way services have traditionally been provided, with services directed by professionals and directed to individuals. The shift to individual-controlled services has been a recent but very successful change.
Equality and human rights are pivotal in shifting approaches to providing service. In some countries, specific laws have been created to guarantee equal benefit and protection to all people. Laws prohibit discrimination based on disability. In some countries, legislation has been passed to promote employment equity. When employment equity laws are enforced, individuals cannot be denied employment for reasons related to ability. Employers are expected to make every reasonable effort to eliminate discrimination and barriers that have adverse impacts on people with disabilities.

Universal design requires that the environment be designed to be usable by people with various disabilities. Universal design highlights an important distinction between a disability and a handicap. An individual can have a disability but not experience a handicap. For example, an individual may have a physical disability and use a wheelchair. A ramp into a building would allow access to the building, removing a barrier that would handicap the individual with the physical disability. Universal design eliminates environmental barriers that handicap individuals who have a disability.

Guiding Principles for Support Work

Key Points for Caregivers

Guiding principles for support work state that people with disabilities have rights that relate to:

1. Citizenship, through freedom from discrimination
2. Individual control, through involvement in decisions related to their lives
3. Equality and human rights, through the benefits and protection of the law
4. Universal design, through barrier-free environments

“To deny people their human rights is to challenge their very humanity.”
— Nelson Mandela

Historical Struggles

People with disabilities have struggled for acceptance and equality for centuries. Historically, they have been ostracized. In ancient times, people with disabilities were often viewed as demonic or unique. Few survived and those who did were not typically part of the mainstream society. In Greek and Roman times, when able-bodied and able-minded soldiers were needed, people with disabilities were considered “defective” and exterminated. Later, in the Middle Ages, people with disabilities were positioned as servants or court jesters and fools; some were still put to death. The primary response to people with disabilities was ridicule for differences in physical appearance or behaviour.

The Renaissance brought an era of asylum for people with disabilities as the Catholic Church accepted them as wards of state. Although they were still cared for in isolation and without education, at least humane treatment was available. The Industrial Revolution introduced broader-based education, recognizing the need for a literate society and good workers. This vocational emphasis led to the emergence of sheltered workshops for people with disabilities.

The early 1900s introduced a biological emphasis to caregiving, and the primary service model was one of medical and institutional care. People with disabilities were warehoused in large congregate care facilities with a promise that training...
and education would be offered.

The mid-1900s shifted emphasis to the environment. Veterans returning from war spurred a rise in litigation and legislation to protect their rights to rehabilitation and employment. The civil rights movement in the 1950s and 1960s contributed to a much greater understanding of equality and rights, which trickled down to those with disabilities. The debilitating effects of institutionalization were acknowledged. Normalization, now known as social role valorization, became the widely held belief: that all individuals, regardless of any disability, should have as normal an education and living arrangement as possible (Wolfensberger, 1983, 2011).

Today, inclusion is the focus for most governments and services. In the United States, Rosa’s Law (2010) has changed the way an intellectual disability is conceptualized. Rather than the older term mental retardation, the term intellectual disability is now used. The focus is on providing supports to individuals in the least restrictive environment possible.

Despite increasing attention to including individuals with disabilities in mainstream society, it would be a mistake to believe that persons with disabilities are part of their communities. Many still spend much of the day in environments that are not inclusive. All those who provide support to people with disabilities play a key role in discovering, organizing, and supporting them toward physical and social inclusion.

### Historical Struggles

#### Key Points for Caregivers

Historically, people with disabilities were rejected, laughed at, and even put to death. Today, disability services emphasize the importance of including people with disabilities in communities. Social role valorization encourages communities to provide normal living, education, and employment opportunities whenever possible. Rosa’s Law requires that the term mental retardation is replaced with the term intellectual disability.

### Competencies Expected of Support Workers

What does it take to be informed and competent when supporting someone with a disability? A competency is an attribute, knowledge, skill, ability, or other characteristic that contributes to successful job performance. Competencies give rise to observable and measurable behaviours that contribute to individual success in an organization (e.g., teamwork and cooperation, communication). Direct support workers, regardless of the service that is provided, require competencies in working with others, assessing strengths and needs, planning and providing services, linking to resources, advocacy, documenting and report writing, professionalism and ethical behaviour, and individualizing support requirements.

**Working with others** is an expectation for direct support workers. The typical approach is to work collaboratively with others to plan and implement support plans. A multidisciplinary team might include professionals such as psychologists, occupational therapists, physical therapists, medical professionals, and social workers. Parents, guardians, and family members are also integral to the team. Teams promote coordination and communication, and add to relationships. They
may also identify service gaps and raise awareness of strategies, resources, and approaches that might be of benefit in direct support. Teams are extremely valuable in furthering positive outcomes for clients who are in difficult or complex situations.

**Assessing strengths and needs** is a significant part of the direct support worker’s job. The approach that is most favoured first identifies the talents, gifts, and skills of the individual being supported, with a view to using those to manage any needs the individual might have. An individualized strengths-based assessment then focuses on the complex interplay of risks and strengths among individual family members, the family as a unit, and the broader neighbourhood and environment. The individualized strengths-based approach is an overall philosophical view supported by policies and standards. It refers to practice methods and strategies that identify and draw upon the strengths of individuals, families, and communities.

Strengths-based practice requires a shift from a deficit approach, which emphasizes problems and pathology, to a positive approach (Rapp, Saleebey & Sullivan, 2005; Saleebey, 2006). A strengths-based approach values the capacity, skills, knowledge, connections, and potential in individuals and communities. Focusing on strengths does not mean ignoring challenges or spinning struggles into strengths. It does require that people work collaboratively.

**Planning and providing services** follows assessing strengths and needs. Most services have adopted a person-centred process to assist people with disabilities and their families to build their capacities and capabilities. This planning effort is typically a series of discussions or interactions among the person with a disability, his or her family, and other members of the multidisciplinary team.

The team assists the individual in developing a description that includes a preferred place to live, favourite people with whom to socialize, and preferred types of daily activities, including preferred jobs. This description is based on the individual’s strengths, capabilities, preferences, lifestyle, and cultural background. The planning team decides what needs to be done, by whom, when, and how the individual is to work toward the preferred future. An individual program plan serves as a record of the decisions made by the planning team. This plan forms the foundation for the work of the direct service worker.

**Linking to resources** requires the direct support worker to have comprehensive knowledge of the community in which the supported individual lives. Community asset mapping is one approach to acquiring this knowledge. The community asset mapping process (Asset Based Community Development Institute, n.d.) is intended to initiate full mobilization of a community and its assets around an individual vision. It allows mapping of relationships with other organizations for funding, referrals, access to resources, joint service planning, or collaborative projects with contributed staff. Once a community’s assets have been identified, the direct support worker is in a good position to begin linking the assets with the supported individual based on the individual’s strengths and needs.

**Advocacy** in all its forms seeks to ensure that people, particularly those who are most vulnerable in society, are able to have their voice heard on issues that are important to them. Advocacy supports and enables people to access information and services, defend and promote their rights and responsibilities, and explore choices and options (Support Empower Advocate Promote, n.d.).

**Documenting and report writing** takes many forms. Most common is documenting history and needs, services, individual outcomes, and service information. Any documenting should be concise, accurate, current, meaningful, and
consistent. Reports can include case notes, plans, assessment results, letters to parents, referrals to other community services, letters to funders, and reports to supervisors, to mention just a few. Documentation serves six primary functions: assessment and planning, service delivery, continuity and coordination of services, supervision, service evaluation, and accountability. In documentation, caution should be used with personal opinion and conclusions; defamatory and negative language should be avoided; over-documentation should be avoided; and the documentation should be directed to a specific audience.

**Professionalism and ethical behaviour** is a cornerstone for direct support worker practice. Professionalism is the conduct, aims, or qualities that characterize or mark a profession or professional person. In 1996 in the United States, the Council for Standards in Human Service Education adopted *Ethical Standards for Human Services Professionals*, which are a set of standards of conduct that human service professionals and educators consider in ethical and professional decision making (National Organization for Human Services, n.d.).

Section 1 of *Ethical Standards* is targeted to the human services professional and contains 37 statements in five responsibility areas: client, employer, community and society, colleagues, and the profession. Section 2, incorporating statements 38 to 54, outlines standards for human services educators. The National Organization for Human Services, a U.S. organization that publishes the standards, has done much to expand professional development opportunities, enhance communication, promote professional and organizational identity through certification, and advocate for a social policy agenda both in the United States and in other countries.

In Canada, the Developmental Services Human Resource Strategy is currently working on developing core competencies for direct support workers. With the intent of “positioning employment in the developmental services sector as a career of choice,” the DSHRS continues to examine models for training and best practice that will strengthen professionalism among those who work in the field (DSHRS, n.d.). In Ontario, as part of quality assurance measures mandated in the Social Inclusion of Persons with Developmental Disabilities Act, 2008, developmental service agencies now have set standards to guide their policies and procedures (Government of Ontario, 2011).

**Individualizing support requirements.** Every person is different and may have individual support requirements that necessitate the support worker having specialized competencies. Often these competencies are specific to the environment, such as household management, budgeting, health and wellness, food safety, or job coaching. Other times they are skills that directly respond to individual needs and may include medication administration, crisis management, and non-violent crisis intervention or behaviour management. All individuals who are being supported will present with strengths, needs, and characteristics that require specialized knowledge.

---

**Competencies Expected of Support Workers**

**Key Points for Caregivers**

Caregivers who support individuals with disabilities, particularly caregivers who are employed as direct support workers, are expected to be competent and able to work with others to:

1. Assess the strengths and needs of clients
2. Plan and provide services
3. Link to resources
4. Advocate
5. Record information and write reports
6. Demonstrate professional and ethical behaviour
7. Tailor support requirements in relation to unique requirements of clients

Conclusion

This chapter has provided a snapshot of fundamental knowledge that caregivers can build on as they support individuals with disabilities. In the chapters that follow, we extend these fundamentals to explain support that is specific to individuals with both intellectual disabilities and mental illness.

Those who support people with disabilities are in a unique position to ensure that those individuals are included in their communities. To maximize the possibilities, it is important for caregivers to be guided by principles grounded in citizenship, individual control, equality and human rights, and universal design. Further, it is important to appreciate the historical struggles endured by people with disabilities. Knowing the competencies expected of support workers can assist caregivers, particularly those employed in direct support work positions, to develop and strengthen their skills.

Chapter Audio for Print

This chapter contains a number of short audio clips. If you are reading this in print, you can access the audio clips in this chapter by scanning this QR code with your mobile device. Alternatively, you can visit the book website at opentextbc.ca/caregivers and listen to all the audio clips.

References


