

Individuals with Profound Disabilities¹

Part 1

¹The following information was taken from Sternberg et al. (1994). Individuals with Profound Disabilities: Instructional and Assistive Strategies. (3rd ed., pp. 5-16, 22-34). Austin, TX: PRO-ED.

Definition

Definition provides direction in terms of assessment and delineation of specific services and includes the following:

- Exhibits profound developmental discrepancies in cognition, communication, social skills development, mobility, and self help skills; includes people with profound mental retardation.

- Have accompanying sensory and/or physical disabilities and significant medical problems.
- Requires a pervasive level of support; service structure with continuous monitoring and observation.

Characteristics

- Don't assume individuals with profound disabilities necessarily follow the same developmental progression as non-disabled individuals.
- Does not imply that individuals with profound disabilities will display equal levels of discrepancy across all areas of functioning.

- When multiple handicapping conditions are present, characteristics within each area will likely reflect the effects of the central nervous system dysfunction and sensory or physical disabilities.

- An interactive effect is likely between areas such that functioning within one area will interact with and affect functioning within another.
- Discussion of characteristics does not preclude the potential use of functional models of service delivery or expectations of functional types of behaviors.

Cognitive Characteristics

- The presence of a cognitive impairment affects both the manner in which and the degree to which an individual interacts with the environment, as well as the impact the environment has on that individual.

Communication Characteristics

- In that communication skills are precursors to the development of language skills, they have both receptive and expressive components. As with language skills, receptive and expressive communication behaviors often develop in a type of parallel fashion.

Social Skills Characteristics

- The ability to exhibit appropriate and observable reactions to pleasant and unpleasant stimuli.

Motor-Mobility Characteristics

- Includes fine motor (hands and arms which are used to facilitate hand use), gross motor (head, trunk, and arms for postural control), and mobility (behaviors that must be committed when wanting to change position in space).

Self Help Characteristics

- Four skills that typically receive the most attention are eating, toileting, dressing, and personal grooming.

Other Behavioral Characteristics

- Behavioral excesses include stereotypy (defined as ritualistic and repetitive), self-stimulatory behavior (a subset of stereotypy in which movements are reinforced by perceptual consequences produced by the behavior), and self injurious behavior.

Creating Environments that Support and Enhance the Lives of all Participants

Physical placement is but one aspect of an inclusive environment; other characteristics may either support or interfere with the overall quality of a person's life.

Real change in the realities of persons with profound disabilities can happen by improving the ways in which their personal care, social relationships, communication, and emotional needs are met.

Developing Environments Based On Desired Outcomes

First, consider what outcomes are desirable.
Second, affect the way in which others perceive people with disabilities – people with disabilities are full fledged human beings with the same needs as others.

Environmental Characteristics

- Physical: Includes accessibility, programs and supports, medical services, and provision of adaptive equipment (glasses, hearing aids, etc.).

Assistive technology and adaptations are not an end unto themselves; they are a means to greater natural participation and opportunity for personal choice.

- Learning and Participation: Includes where and how the person learns and participates.

It includes motivation, responsiveness, and initiation (i.e., engage others by crying or prolonging or preventing an activity through gross body movement – this is often overlooked, deliberately ignored, or targeted as behaviors to be eliminated).

As preferences are observed, it becomes clearer as to how the environment should be arranged to reflect those preferences.

As individuals with profound disabilities begin to realize that the preferences they exhibit are understood and are respected, they may begin to realize for the first time that they have an ability to control the environment.

This awareness can be the basis for the development of choice-making skills for the person.

The acquisition of choice-making skills can enable those supporting the person to create environments that are based upon that person's needs, preferences, and desires.

One of the most common features identified as contributing to the quality of life of persons with and without disabilities is that of control.

We tend to view people with the most complex needs as vulnerable and in need of constant supervision.

This supervision often translates into control rather than support.

Although the need for support for people who are vulnerable must be recognized, a characteristic of desirable environments is that people receive the supports that *they* require and desire, not those determined by service providers and regulatory agencies.

In situations where people have things done to them rather than for them, the issue of control is obvious.

A more subtle form of control involves who is in control of determining what supports will be provided for an individual, and how those supports will be implemented.

The issue becomes whether the person is satisfied with the type of support and the manner in which it is delivered.

- Social: The concept of creating a circle of friends or support circles. However, for a support circle to be successful, the person must be perceived as a full-fledged human being.

An inclusive environment is one with a capacity to reach out and embrace each member regardless of differing needs and abilities, thereby creating a true sense of community.

An inclusive environment encourages respect and understanding among its members.

It provides opportunities for persons to interact with and support one another in a climate where diversity is recognized and celebrated and where membership is shared in a manner that creates friendships, networks, and associations.

The responsibility to initiate and nurture the person's entry into the environment may fall to those who provide services and supports – the person who is paid to provide supports must extend invitations to other community members to provide natural supports, and to facilitate opportunities to form relationships between the person with the disabilities and other members of the community.

Personnel

The key to creating appropriate supportive environments for individuals with profound disabilities rests with those who will assume the responsibility of providing those supports.

Crucial Concerns

Attitudes: A support person's attitudes will ultimately determine how his or her skills and knowledge will affect the quality of life of the individual being served.

If a support person has a respectful attitude toward the individual being served, then he or she will find ways to learn whatever is essential to support that person, or will assist the person in finding someone else to provide for that particular need.

Attitudes of those providing support to a person with complex needs will ultimately determine the quality of life for that person.

Team Models

Present models include transdisciplinary models of assessment and delivery of integrated therapy services, and the use of person-centered planning processes that focus on identifying the capabilities, gifts, and talents of the individual.

The common elements in each of these models includes broadening the team to include the person with disabilities, friends, and others who support and understand the person; listening to what the person has to say; and identifying ways to assist the individual in achieving what he or she wants and needs.

Teamwork

Calling a small group of people a team does not make them so...a fundamental aspect of optimal team functioning is mutual understanding of and respect for the skills and knowledge of each individual member.

For persons with profound disabilities, it is essential that the team focus on identifying who the person really is through identifying personal characteristics, capabilities, and gifts.

To accomplish these ends, teams must include those who know the person well and who are most likely to be able to interpret the person's communication.

Creating Positive Work Environments

People who work directly with persons with disabilities are often the lowest paid and have the least power in their organizations.

As agencies attempt to invert the structure of relationships and power for people with disabilities, they must also find ways to empower and support their staff.

Relationships that develop between people with disabilities and support staff must be respected.

References

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For more information, see
Individuals with Profound Disabilities
Part 2.