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4-H 295 Working with Disabled Persons in 4-H

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Working with Disabled Persons in 4-H

Who is Disabled?

Everyone has a certain disability or difficulty with some task. All of us excel in certain skills while failing in others. We define the seriousness of our disabilities according to how we perceive they can be lessened or overcome. If persons experience a warm supportive environment at home, school, and in the community, difficulties with tasks may be minimized by learning adaptive and compensatory skills.

The feeling of disability in meeting social roles is called a handicap. Persons feel handicapped when they experience a disadvantage with other persons who achieve superior performance. For example, a late-maturing boy of eleven years is handicapped in playing basketball against taller peers who matured earlier. On the other hand, an early-maturing awkward twelve-year-old girl is handicapped in gymnastic competition with a late maturing, more agile peer. Social norms often are used in assessing one's level of handicap as compared with the ideal model.

The most serious kind of disability is called an impairment. This is an organic dysfunction caused by chronic physical or mental deficits. Impairments prevent individuals from doing certain tasks at levels comparable to persons without these deficits. While a blind person may never be able to see, he or she may become a great pianist or singer by greatly improving the sense of sound.

Acute impairment is a temporary dysfunction caused by illness or accident. On occasion physical limitations such as an injured foot or the sudden onset of influenza may prevent all of us from performing regular activities. Everyone with average abilities will have periods of acute disability during their lives and in their later years will most likely experience some permanent impairments.

Permanent or chronic impairment is an enduring disability which may become progressively limiting and last a lifetime. Although some organic impairments may not improve, individuals may be rehabilitated to function independently in daily living. They may learn to use mechanical devices which help them with routine tasks.

In the 1973 Rehabilitation Act the federal government defined a severely disabled person as one who has "a physical or mental impairment which substantially limits one or more of his or her major life activities including communicating with others, being physically mobile, being able to take care of yourself, being able to socialize, being able to learn and get an education, being able to use transportation, and being able to work."

It is estimated that about 13.5 million Americans over 15 years have severe impairments and cannot perform one or more major life activities.

Classification of Severe Disabilities

While it is not feasible to discuss all disabilities, it is crucial to learn the most common impairments affecting children. Disabilities may be classified into four categories: Physical impairments, crippling and neurological disabilities, mental retardation, and emotional disabilities.

Physical Impairment. This may include a range of physical impairments from loss of sight to loss of a limb. The visually impaired person experiences a range in severity from limited sight to total blindness. Children who were blind at birth or during their first five years are "congenitally blind" and have no visual memory. The hearing impaired child has a hearing loss in both ears severe enough to prevent hearing even with amplification. Deaf children learn to communicate through lip reading, finger spelling, and sign language. Amputations are the partial or total loss of one or more limbs. In most cases an artificial limb called a prosthesis is fitted to the stump to replace the missing arm or leg.

Crippling and Neurological Disabilities. Cerebral Palsy is caused by injury to the brain. It affects muscle and mental functioning and may cause abnormal sensations and perceptions and impairments of sight, hearing, or speech. Some of the most common types are: 1) spastic — inability to move smoothly with tense,
contracted muscles; 2) athetoid — constant uncontrolled motion intensified with excitement; 3) ataxic — difficulty with balance leading to many falls; and 4) tremor — constant shaking, especially in arms and hands.

Muscular Dystrophy is a group of diseases characterized by weakness and wasting of voluntary muscles. The most serious type, Duchenne's, usually results in death before age 20 since the body is unable to withstand respiratory infections.

Spina Bifida is a birth defect in which part of the backbone that covers the spinal cord fails to develop. A number of impairments occur in the body including paralysis of lower limbs, lack of bowel and bladder control, deformities and susceptibility to infection.

**Mental Retardation.** This is defined as "significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period." The following chart classifies mental retardation according to IQ scores and percentage frequency levels.

<table>
<thead>
<tr>
<th>Levels</th>
<th>IQ on Stanford-Binet</th>
<th>% MR in U.S.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>67-52</td>
<td>89.0%</td>
</tr>
<tr>
<td>Moderate</td>
<td>51-36</td>
<td>6.0%</td>
</tr>
<tr>
<td>Severe</td>
<td>35-20</td>
<td>3.5%</td>
</tr>
<tr>
<td>Profound</td>
<td>19-below</td>
<td>1.5%</td>
</tr>
</tbody>
</table>

*Estimates from President’s Committee on Mental Retardation

Down’s Syndrome is a type of mental retardation characterized by various physical deformities as well as intellectual deficits. Down’s children have an extra chromosome. They have poor coordination, tire easily, are very susceptible to infection, and rarely progress beyond the fifth grade level in intellectual functioning.

**Emotional Disabilities.** These are defined by the U.S. Department of Health and Human Services (1980) as "mental disorders that erode or prevent the development of functional capacities in primary aspects of daily life and economic self-sufficiency." The chronically mentally ill include persons with organic brain disease, schizophrenia, recurrent depressive and manic-depressive disorders, and paranoid or other psychoses.

From 5 percent to 15 percent of children from five to fifteen years suffer some forms of mental illnesses which are variously labeled emotional or conduct disorders, behavior problems, or delays in psychological development. It is important to avoid mislabeling some conditions which are confused with mental illness. A learning disability or hyperactivity may cause certain behavioral problems for parents, teachers, and 4-H leaders; however, these children should not be labeled as emotionally disturbed. Usually medication or social support can alleviate the disruptive behavior. It is likewise important to understand that mental illness does not necessarily mean lack of intelligence.

Substance abuse among children is often treated as a mental disease. While behavioral symptoms of alcohol and drug abuse are similar to emotional illness, the chemically dependent child needs specialized therapy.

**Families of Persons With Disabilities**

Most of the estimated 35 million persons with disabilities in the United States live within a family setting. Well over 100 million Americans may be concerned family members of individuals with a disability. Nearly 2 million persons are institutionalized with severe disabilities and their families provide extra ordinary support in the task of rehabilitation.

Family members are the primary care givers to disabled children. Parents experience heavy tension and stress in caring for impaired children at the same time they encounter the normal pressures of rearing other children, housekeeping, and employment. Compared with others, families with disabled members suffer from the: 1) traumatic impact of learning there is an impairment; 2) lack of preparation for parenting a child with special needs; 3) limited social and cultural support from the community and extended family; 4) increased medical costs; 5) confinement and intensity of child care; and 6) increased feelings of guilt for their offspring's condition.

Parents often struggle for months by refusing to accept the diagnosis of their child's disability. They experience anxiety through denial of reality. They hold on to the hope for a less severe diagnosis or a magical cure. When parents accept the disability, they begin "systems of accommodation." Often this may be accompanied by anger and hostility openly expressed to other family members, including the disabled. After finally accepting reality, parents begin the final stage of assimilation. Parents will integrate the disabled child into the family and carry on with cohesion-building activities. It must be remembered that each family is unique with different patterns of adaptability. Only the family has the power to change itself into a fully energized functioning unit. Sometimes, after facing such a crisis, the family will become stronger and have more resources to encounter future challenges.

Community groups such as 4-H can help provide support for parents of children with disabilities. The next section examines how disabled persons can benefit from 4-H and how 4-H members can enrich their lives by working and playing with young persons with permanent impairments.

4-H leaders will need to become sensitive to each child's handicaps while remembering that these children are normal in most other ways. As all humans are unique, these children are unique and their special differences should be appreciated.
4-H Programs with Special Persons

4-H members and leaders may use several approaches to involve young persons with disabilities in 4-H programs. They may be mainstreamed into existing 4-H projects and activities just as they are integrated into schools. A second approach is to sponsor a special 4-H club or project group for severely disabled children in a school or institution. Either approach can be rewarding for 4-H members and leaders.

4-H Mainstreaming. The natural way to offer opportunities to special kids is to invite them to join an ongoing 4-H club or project group. They need to belong to a group to gain identity and recognition from their peers. Individuals need the stimulation of group life to feel accepted into wider society beyond the home, school, and church. Their special talents can be explored and their interests channeled into realizing a greater part of their human potential. Social skills can only be cultivated within group activities. Learning by doing needs the encouragement of friends, parents, and understanding leaders.

4-H clubs can accommodate several special kids without undue disruption of regular programs. They can attend events and participate in all activities to the extent of their capabilities. The following guidelines may be used in choosing a project:

- Arrange for immediate tangible accomplishment in the first meeting.
- Include tasks which become increasingly more challenging after learning basic skills.
- Adapt existing projects to the specific limitation of the person.
- Permit extra practice time with members at meetings and at home.
- Allow flexible and attainable completion requirements.
- Encourage exhibiting and showing accomplishments.
- Plan to individualize assistance.
- Using projects with plants or animals is recommended.

The existing 4-H club which admits special kids must learn about each handicapping condition. If possible, each child should present a club program on his or her disability. Often parents can help obtain visual aids.

Once 4-H club members understand the limits of each special child, they can learn how to help without becoming over solicitous. They can learn to appreciate the special child's strengths and begin to see the child as having more similar characteristics than differences.

There are several guidelines for club activities and recreation:

- Choose activities which enhance educational, social and emotional development.

- Use places that are free of barriers to members in wheelchairs.
- Consider transportation accessibibility to all events.
- Plan a variety of activities in which all may participate.
- Use spontaneous situations to draw special kids into activities that make them feel a part of the club.
- Do not place special kids into unfair competition.
- Find ways for special kids to gain recognition.

Organizing Special 4-H Clubs. A special 4-H group of disabled youth is an alternative to a mainstreamed 4-H club. This approach may be more feasible when a number of special kids attend school together or live in an institution. It works well when the level of functioning is homogeneous such as a moderate level of mental retardation.

The first step is to select a team of experienced 4-H leaders or junior leaders with a strong commitment to sharing their time and talents. When selecting a project, the team will need to have teachers or parents explain the special child's strengths and limits.

After the club is organized, a "normal" club atmosphere needs to be created with a balance of educational, recreational, social and service activities. Members should take trips and become involved in county activities with other members. Bring other 4-H'ers to their meetings to give demonstrations, lead singing, and provide other types of social recreation.

The most important goal is to help them develop to their full potential. Don't compare their accomplishments with those of others. All should be given participation ribbons for their exhibits and hugs for their willingness to try.

Other Programs with Special People

If it is not possible to involve special kids in 4-H, plan other programs to sensitize youth to the needs of handicapped people. These suggestions may fit into ongoing programs. A club can:

- "Adopt" a neighborhood child with a handicap.
- Conduct a service project for special kids, provide respite care for mothers, push wheelchairs or assist with transportation to activities.
- Bring special kids to your meeting to lead programs.
- Utilize disabled adults as 4-H leaders.
- Raise funds to support medical costs of neighbors.
- Show films of people overcoming their handicaps.
- Interview people to learn of architectural barriers.
- Organize a "Handicap Awareness Day" and let each 4-H'er play a role of having certain handicaps.