CHILD WELFARE PRACTICE: KEEPING CHILDREN WITH DISABILITIES IN THEIR HOME

By

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CalSWEC PREFACE

The California Social Work Education Center (CalSWEC) is the nation’s largest state coalition of social work educators and practitioners. It is a consortium of the state’s 18 accredited graduate schools of social work, the 58 county departments of social services and mental health, the California Department of Social Services, and the California Chapter of the National Association of Social Workers

The primary purpose of CalSWEC is an educational one. Our central task is to provide specialized education and training for social workers who practice in the field of public child welfare. Our stated mission, in part, is “to facilitate the integration of education and practice.” But this is not our ultimate goal. Our ultimate goal is to improve the lives of children and families who are the users and the purpose of the child welfare system. By educating others and ourselves, we intend a positive result for children: safety, a permanent home, and the opportunity to fulfill their developmental promise.

To achieve this challenging goal, the education and practice-related activities of CalSWEC are varied: recruitment of a diverse group of social workers, defining a continuum of education and training, engaging in research and evaluation of best practices, advocating for responsive social policy, and exploring other avenues to accomplish the CalSWEC mission. Education is a process, and necessarily an ongoing one involving interaction with a changing world. One who hopes to practice successfully in any field does not become “educated” and then cease to observe and to learn.

To foster continuing learning and evidence-based practice within the child welfare field, CalSWEC funds a series of curriculum modules that employ applied 

research methods to advance the knowledge of best practices in child welfare. These modules, on varied child welfare topics, are intended to enhance curriculum for Title IV-E graduate social work education programs and for continuing education of child welfare agency staff. To increase distribution and learning throughout the state, curriculum modules are made available through the CalSWEC Child Welfare Resource Library to all participating schools and collaborating agencies.

The module that follows has been commissioned with your learning in mind. We at CalSWEC hope it serves you well.

INTRODUCTION

The following six curriculum modules were developed to introduce social workers, students of social work, and child care workers to disability, specifically children with disabilities. In the last decade, researchers have indicated that social workers in general lack knowledge and skills concerning persons with disabilities. Formal and informal discussions with child welfare workers and directors of programs substantiate the need for increased knowledge and skills on the part of social workers working within the child welfare system. Studies indicate that there is a dearth of schools of social work dealing with the topic of disability. While schools of social work seek to increase content on ethnic cultures and on gender, it has only been in the last several years that social work curricula have begun to address the issue of disability. And within the schools, only a few faculty recognize disability as an issue of diversity rather than as an issue of dysfunction and medicine.

Recent scholars view disability as an issue of diversity. There is growing evidence of the existence of a minority disability culture. Evidence accumulates showing that the limitations of disability are by far a product of social definition rather than a product of natural dysfunction. The following six modules are designed squarely within that social/diversity model of disability. Therefore, these modules address the public child welfare competencies involving cultural skills and knowledge. In addition, the modules impact child welfare skills and knowledge around child abuse. And finally, these six modules address the seven principles for California's child welfare curriculum,
and in particular, the principles of caring for a child in the best and least restrictive environment, and available, accessible, timely, and effective services for children.

These modules can be used in a social work undergraduate or graduate class in practice or in HBSE. They can also be used in child welfare training workshops with the objective of increasing skills and knowledge around families and child abuse within the disability framework. These modules can be used together or individually, but it is strongly suggested that they be used sequentially as a total unit. The final module on resources can be used by itself as a resource guide or in conjunction with the other modules for wide-spectrum training. The modules draw from current theory and research on disability, and provide opportunities for students to discuss case studies and demonstrate critical thought processes. Please keep in mind that the modules represent only introductions to a very complicated and complex set of issues and skills. Each module could be a course by itself. Please note that the inconsistency in format relates to shifts in topics. The modules are designed so that they can be used as actual lecture notes, and the shifts in format help the instructor by symbolizing changes in content and/or emphasis.

Module I looks at the numbers of persons with disabilities both in the United States and in California. It seeks to have participants understand the complexity of counting people with disabilities and the forces in the process of the count. It is imperative that the instructor understand the politics of statistics and demographic accounting, particularly the elements that benefit by undercounting people with disabilities, especially children.

Module II is probably the most important module as it attempts to have the participant understand his/her own values and attitudes toward children with disabilities. It traces these values into the historical origins of the social paradigms that govern society's thoughts around disability. The instructor needs to be knowledgeable in both the history and social/diversity model of disability to effectively teach this module.

Module III is perhaps the most poignant as it addresses the issue of the physical and sexual abuse of children with disabilities. It seeks to explore some of the myths regarding abuse of children with disabilities and presents some practical ideas in terms of interviewing and assessing children with disabilities who may have been abused.

Module IV introduces the concept of families with children with disabilities. A primary theme centers on questioning the traditional assessment practices that assume that the introduction of a child with a disability into a family is automatically and naturally a negative occurrence.

Module V introduces a generic model of practice that includes children with disabilities and their families. This module deals with an empowerment practice technique that rests upon very strong assumptions about disability. The most important of these assumptions is that persons with disabilities, particularly children, have the right to control their own lives. If this assumption is not supported, children with disabilities will carry with them a particularly insidious component of oppression and dependency for the rest of their lives.

Module VI is a resource directory. It is designed to provide a practical guide to agencies serving children with disabilities and their families.

ACKNOWLEDGEMENTS

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MODULE I
THE NUMBER AND NATURE OF DISABILITY

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Goals:
Students will gain an understanding of the complexities in determining the number of children with disabilities both nationally and within the state of California. They will gain some understanding of the number of children with disabilities that child welfare agencies could potentially serve. Students will also gain insight to what needs to be done in terms of counting the children with disabilities in the state of California.

Objectives:
1. To articulate the complexities in defining disability and determining the number of children with disabilities in the state of California.
2. To articulate the myriad reasons why the various agencies and organizations dealing with children with disabilities have difficulty in defining and counting these children in the education and child welfare systems.
3. To articulate a beginning understanding of the extent of the problem of caring for children with disabilities in the state of California.

GENERAL NUMBERS (National Association of Disabled Persons)

- There are 48.9 million Americans with a disability. This represents 19.4% of the total population of the United States.

- Nearly 1 in 5 Americans has some type of disability. There are 24.1 million people who have a severe disability, which represents 9.6% of the total population. There are 29.5 million Americans with disabilities who are between the working ages of 15-64. Of these individuals, 13.2 million have a severe disability.

Questions for Class Discussion:
How do these numbers impact you?
Were you aware of the proportion of the U.S. population that is disabled?
Can you draw any conclusions about the nature of disability from these statistics?

Questions like these can be used to germinate several ideas. There are many people with disabilities in the United States. Disability is almost an everyday occurrence. Yet, people with disabilities remain an unseen issue. Why?

PROBLEMS IN COUNTING PEOPLE WITH DISABILITIES AND CHILDREN IN PARTICULAR (Overhead 1)

- There are no clear-cut statistics on children with disabilities in California or, for that matter, nationally. **There are several reasons for this:**

  1. Perhaps the most significant is the fact that professionals and persons with disabilities have not decided upon an exact definition of disability.

    - **The Americans with Disabilities Act** borrows its definition of disability from the Rehabilitation Act of 1973. It defines disability in terms of a functional limitation of one or more significant major life activities, having a record of physical or emotional barrier to major life activities, and/or being regarded as having an impairment preventing function.

    - This definition is purposefully vague and particularly difficult to apply to children because it is more oriented for adults in a working environment or older children in a school environment. Also, because of its vagueness, it is applied differently by different institutions.

    - On the other side of coin, **The Personal Responsibility and Work Opportunity Reconciliation Act of 1996** tightened the definition for children with disabilities under the Supplemental Security Income program. Welfare reform now requires that children can only be defined as disabled if they have a physical or mental condition that can be medically proven which results in marked and severe or functional limitations. This condition must be expected to last at least 12 months or result in death. The child cannot be considered disabled if he or she is working at a job that could be defined as substantial.

    - **The National Health Interview Survey** conducted in 1989 defines children with disabilities basically in terms of the school environment. It defines children with disabilities as those who cannot go to school, have limitations either in the amount or kind of school work they can do, or who are limited in activities other than school (Wenger, Kaye, & LaPlante, 1996).

Questions for Class Discussion:

What would be some reasons why these three entities would define disability in three different ways?

Definitions are a policy mechanism that can help reach political and economic goals. Vague definitions of disability allow flexibility in qualification for services, in counting (keep in mind that numbers translate into political power), and self-determination of disability rather than medical/official determination. Tight definitions of disability result in a stronger method to screen people away from services. Tighter definitions restrict entrance. Therefore, if an agency wants to save money, it supports a tight definition of disability. If a political power base fears the growth of another political group, it seeks to tighten definitions of eligibility.

2. Adding to the confusion is the growing acceptance of the social model of disability with its origins in the Independent Living Model.

✓ The Independent Living Model stands for the principal that there are more commonalities between people with disabilities than differences (Shapiro, 1993). **And many who are part of this movement believe that disability is a social and personal definition.** Therefore, it is either imposed by medical professionals, or it is self-defined from an ethnographic perspective. Although this view is gaining acceptance among researchers and academics and becoming more prevalent within the professional service realm, it leads to some difficulties in counting people with disabilities and particularly children with disabilities.

This would be an opportune time to introduce students to the Independent Living Movement. The Independent Living Movement started in the 1960s as a grassroots effort among people with disabilities to change societal attitudes toward disability and to open environmental, social, and political doors (Shapiro, 1993).

Why would the Independent Living Movement support a definition of disability that was inclusive?

Discussion could center around the question of how a group that has been historically isolated can gain a sense of identity and consciousness. Also, as addressed in an earlier discussion, vagueness of definition increases numbers.

NATIONAL NUMBERS AND CHILDREN (Overhead 2)

- Given these limitations, let's try to establish some idea of the number of children we are talking about in the United States.

  ✓ The latest statistics are old, coming from 1992 through 1997. In 1992, McNeil (1993) completed an in-depth analysis of national statistics on persons with disabilities in the United States. Using data from the U. S. Department of Commerce, the Economics and Statistics Administration, and the Bureau of the Census, McNeil determined that of the 56 million children between the ages of 0-14, **3 million are children with disabilities**. Of those, **529,000 had severe disabilities**. In addition, **9.3% of the population between 15-17 years of age were defined as disabled**.

  ✓ McNeil (1993) used a synthesis of definitions of disability. For children in the 0-14 age group, parents were asked if: (a) children manifested any limitations in the usual kinds of things children did, (b) if they “received therapy or other kinds of diagnostic services to meet developmental needs,” (c) if they had “limitations in their ability to do regular school work,” and (d) if they had a condition that “limited their ability to walk, run, or use stairs” (p. 2).

  ✓ These represented a somewhat narrower criterion for definition of disability than presented by the Americans with Disabilities Act, which defines a person with a disability as having either a “physical or mental impairment which substantially limits one or more of that person’s major life activities, has a record of such an impairment, or is regarded by the covered entity as having such an impairment” (Americans with Disabilities Act handbook, 1991, pp. 1-25). The McNeil analysis used autism, cerebral palsy, or mental retardation as examples of severe disabilities.

  ✓ Data from the 1992 National Health Interview Survey indicate that **approximately 4.0 million children and adolescents under 18 years of age have disabilities**. This is **about 6.1% of the United States population in this age category**. In this survey, disability was defined broadly and included any limitations in activity due to a chronic health condition or impairment.

  ✓ Using a general definition of disability, which included any reduced ability to perform tasks at a given stage in life development, the **Census Bureau** (1998) reports that **between 1994 and 1995, 313,000 children under 3 years old have a "developmental condition."** The same report **counts 652,000 children between the ages of 3-5, 4,462,000 children between the ages of 6-14, and over three million individuals between the ages of 15-21 as having a disability.** Of these, **12,000 have a severe disability**. If one is to believe the statistics, the numbers of children with disabilities are increasing in the United States.

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CALIFORNIA NUMBERS (Overhead 3)

- As with the national scenario, there is some difficulty in determining the number of disabled children residing in California.

  ✓ The lead agency concerning disability, the California Department of Rehabilitation, focuses primarily on adulthood and people eligible for employment.

  ✓ The datakeeping of schools concerning disability is haphazard at best.

  ✓ Social welfare agencies keep some statistics on disability that can be hidden in a variety of other fields within their databases.

- So the question of numbers regarding children with disabilities in California is indeed an open question.

- But there are some indicators of what is happening in California:


     ✓ In California, in the last decade, fewer children receive coverage through a parent's employer health insurance. California spends only one fifth of its available federal funding for children's health coverage. Poor health coverage can result in more children with disabilities.

     ✓ About 40% of California's toddlers do not receive immunization shots on time. Again, this puts them at risk for diseases that might result in permanent lifelong disabilities.

     ✓ In the last 10 years, an increased number of children are living in poverty. In 1998, 2.4 million children in California lived in poverty. Again, poverty increases the chances of disability because of lack of health care, safety issues, and crime issues.

     ✓ Child abuse reports have increased in the last decade. Child abuse can result in disability.

     ✓ In the last 10 years, the proportionate number of infants born at low birth weight has remained the same in California. Low birth weight can be an indicator of poor health, which is a factor in disability.
2. In 1998, there were over 9 million children in California (Children Now, 1998).

- In 1997, the number of children with disabilities under 18 years of age receiving SSI/SSP was 90,000 (California Department of Social Services, 1998).

- In 1998, the number of children with developmental disabilities between the ages of 0-21 known to the California Department of Developmental Services was almost 84,000; 17,305 were between the ages of 0-2, 43,216 were between the ages of 3-13, and 23,185 were between the ages of 14-21.

- Perhaps the most current aggregate count of the number of children with disabilities coming close to an accurate reflection of reality comes from The National Center for Education Statistics. NCES keeps track of the number of children served under the Individuals with Disabilities Education Act. The NCES (1998) reports that in California in the 1996-97 year, 604,075 children received services under IDEA. Their ages ranged from birth to 21.

- A more accurate, but out-of-date, aggregate count comes from a study by Dr. Paul W. Newacheck (1991). He estimated that 455,168 children between birth and 22 in the state of California had chronic conditions causing some activity limitation. These did not include institutionalized children.

1. There is a great need to determine an accurate number of children with disabilities for California with many unanswered questions:

- How many disabled children are not counted because of limited service provision in the rural area in which they live resulting in inaccurate reporting?

- How many children with disabilities are among the myriad of undocumented workers in California?

- How many children with disabilities are not counted by school districts because of a parent's unwillingness to register with the district?

- How many children with disabilities are not counted by social welfare agencies, by school districts, and other organizations because they do not fall into the various definitions these organizations and agencies used to define disability?

- How many children with disabilities are not counted by the various agencies because their parents are afraid that if the children get benefits or services, the family will lose other social welfare benefits?
What are the various types of disabilities that impact children in California? What are the possible variables connected to the types of disability?

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<td>What factors could contribute to the lack of numbers for children with disabilities in the state of California?</td>
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<td>Discussion would center around the low priority of children with disabilities because of low status within the society and the fact that caring for children with disabilities is more costly.</td>
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MODULE II

PROFESSIONAL AND SOCIETAL ATTITUDES ON DISABILITIES

MODULE II
PROFESSIONAL AND SOCIETAL ATTITUDES ON DISABILITIES

Goal:

For students to have a greater understanding of society’s attitudes and values concerning people with disabilities. Students hopefully will begin to understand their own attitudes and values toward people with disabilities that impact their practice with all people with disabilities, including children. A further goal is for students to understand the history and origin of the values they may hold toward people with disabilities.

Objectives:

1. To identify student’s own values and attitudes toward children with disabilities.

2. To be able to articulate the three models of disability which influence society’s attitudes toward people with disability.

3. To be able to articulate the connection between social work practice with children with disabilities and the myths and stereotypes harbored by society toward disability.

Educational Activity:
Pass out two copies of the handout (Module II Handout, located in Appendix B). Explain to the students that one is to be completed now and the other at the end of the module. Divide the class into manageable groups of four to eight members. After the students have formed groups, instruct them to take about 10 minutes to complete the survey. Then have the students discuss with their group members the hardest questions on which to make a decision.

After about 20 minutes call the class to your attention and ask members of each group to discuss one or two difficult questions in the survey.

Questions may include:

What about the question made it difficult to answer?

What were the issues for you?

Did anyone else in the group share this issue with you?

Never indicate an appropriate answer.

After the discussion, provide an overview analysis of each question based on the following insights:

**Question:**

1. Addresses the issue of the locus of disability and point of intervention.
2. Addresses the idea that some disabilities are moral in nature.
3. Addresses the issue that human beings should be physically perfect.
4. Addresses the issue of society's expectation for children with disabilities.
5. Addresses the issue of how children with disabilities can internalize society's expectations or lack of expectations.
6. Addresses the issue of internalized values.
7. Addresses society's views regarding disability.
8. Addresses societal myths regarding children with disabilities.
9. Addresses society's desire to contain children with disabilities because of stereotypes.
10. Addresses society's stereotypes of children with disabilities and the nature of learning.
11. Addresses society's myth that people want to be declared disabled to either get something or get out of something.
13. Addresses how society imposes its defined role on children with disabilities and their expected behavior around that role.
15. Addresses the use of “blaming the victim” on children with disabilities.

Addresses a radical concept of the social model of disability that particularly relates to the Independent Living Movement.

Addresses a common myth that parents with developmental disabilities make poor parents.

Have them save the completed survey so that they can compare it with the one completed at the end of the module.

- What you think of disability is influenced by three models of disability current in our culture: the moral, the medical, and the social/independent living.

THE MORAL MODEL (Overhead 1)

- The earliest way of looking at disability centers upon morality and sin.

- This ancient model is a part of American culture and is also dominant in many of the current world cultures (Ingstad & Wyte, 1995).

- The model sees disability as the direct result of sin and evil. Longmore (1993) concludes that the moral paradigm portrays disability as a state of existence in conflict with the very moral and spiritual center of the universe.

- Disability, according to this model, is the result of loss of control of the moral essence of the individual.

- A person with a disability represents an impaired spirit; a heart that is out of order.

- The moral model also reinforces the idea of noble suffering, that the person with a disability who can long suffer and endure the retribution from God is somehow noble and saintly.

- American culture shares the moral model of disability with a variety of non-industrialized cultures.

  1. Nicolaisen (1995) points out that the Punan Bah of Central Borneo in Malaysia directly connect disability to taboos committed by either the father or the mother of the person with the disability.

  2. The Maasai of Kenya believe that disability or illness is a sign of cosmic disorder. They believe that God causes disability because of inherited sin (Talle, 1995).
3. The peoples of Southern Somalia believe that the evil eye or the curse causes disability. Disability caused by the evil eye is the result of doing harm to another person. Disability caused by the curse is the result of not returning a favor or completing an obligation. For the Somalian, the greatest cause of disability is the evil eye (Helander, 1995).

4. Devlieger (1995) concludes that the Songyre of Zaire believe that sorcerers, either with or without the authorization of God, cause disability.

- Many subcultures, both Christian and non-Christian, in America also hold the beliefs of the moral paradigm concerning disability.
  1. Many Hispanics/Latinos believe that disability is a result of the sin of the parents of the person with a disability (Smart & Smart, 1991).
  2. African Americans may view disability, particularly psychiatric disability, as the result of a life of sin. But at the same time, a sense of spirituality helps many African Americans deal with the experience of disability (Ho, 1987).
  3. Like the Hmong, whose beliefs we will discuss shortly, Native American Indians may believe that disability is caused by a person losing his/her soul, the intervention of evil spirits, or immoral behavior (Farley, 1995).
  4. Peoples of Laos, Thailand, and Vietnam who have settled in the United States also share beliefs that may be construed to be a part of the moral paradigm. The Hmong, one of these peoples, recently immigrated to the United States as a result of the Vietnam War. They are a particularly strong people who only since the 1950s have developed a written language. They, like many other peoples, within their cultural construct, believe in a direct connection between disability and doing wrong. The Hmong believe that the self is made up of many souls. A soul or many souls leaving the person, sometimes for the reason of wrongdoing, causes disability and illness. Healing with the help of the Shaman seeks to reunite the soul or souls with the person (Livo & Cha, 1991).
  5. Arokiasamy, Rubin, and Roessler (1978) examine the beliefs of Hindus regarding disability. The life of suffering encountered by many persons with disabilities particularly in non-industrial societies is the result of a former life of sin.

THE MEDICAL MODEL (Overhead 2)

- Unlike the moral model, the medical model of disability is unique to western culture. Its origins stem from the Enlightenment era in Europe and America.
**Specific Characteristics**

- First, the focus of the problem of disability centers on the individual with the disability (DeJong, 1979).

- The second characteristic involves the concept of biological dysfunction. According to the medical model, there is something drastically wrong with the person with a disability. The biological organism is out of sync with the natural order of the universe (Longmore, 1993).

- The third characteristic centers on methodology. The medical model relies on the intervention of the professional. The solution to the problem lies with the knowledge and skills of the physician, physical therapist, occupational therapist, clinical therapist, professional counselor, certified teacher, etc. (DeJong, 1979).

- The fourth characteristic concerns the issue of who is in control. Related to the third characteristic, the medical model assumes the professional is the controlling factor in how the person with a disability is treated.

- The fifth and final characteristic relates to decided outcomes. The medical model seeks perfection, cure, the eradication of the physical or mental dysfunction (Whyte, 1995). For most people with disabilities, this is impossible.

**MYTHS ABOUT PERSONS WITH DISABILITIES THAT STEM FROM THE MORAL AND MEDICAL MODEL**

- The first image society sets aside for the person with a disability is that of a pitied or pitiful individual; a person that no one would envy; a person that no one would want to be (Shapiro, 1993). So if a child with a disability is born into a family the automatic response is grieving. Certainly no one would want a disabled child.

- Related to the above, the social image brought forth by the term “handicapped” or “crippled” is that of a perpetual child (Bogden & Biklen, 1993); the “Tiny Tim” image, a cute person but powerless and ineffectual whose only reason for being is to remind the able-bodied folks how well off and fortunate they are in not being crippled.

- Isolation and segregation most always color self-identity for persons with disabilities. Many persons with disabilities feel that they are always alone. They never quite fit in. They are forced to see themselves as different from everyone else. The institutionalization of persons with disabilities adds to this identity along with the segregation that occurs with group homes and other “special” accommodations (Mackelprang & Salsgiver, 1999).
• The stereotype of being **sick** creates an additional negative identity. In internalizing this stereotype, the persons with a disability may see themselves as **a person to be taken care of**. They may demand special treatment just because they are disabled. They may demand to be excused from commitments and responsibilities. They do not see themselves as serving but having the given **right to be served**. The internalized stereotype of sickness may prevent persons with disabilities from taking the **risks** so necessary for development, and leave the person with a self-image of that of a non-risk-taker (Devore & Schlesinger, 1991).

• **Many persons with disabilities see themselves as ugly and sexless**. How can a person be at odds with the spiritual and natural order and be beautiful and sexy?

• The final internalized stereotype for our purpose centers on persons with disabilities as a **menace to society; to be feared**. **Persons with a disability may feel deviant**. They may perceive themselves to be immoral if not criminal. They may see themselves as not worthy; to be shunned or worthy only of institutionalization because of the way the media portrays them in the movies, television, and literature (Bogden & Biklen, 1993).

• Rycus and Hughes (1998) identify **certain myths carried and perpetuated by child welfare workers** regarding children with developmental disabilities. These myths can be readily transferred to children with disabilities in general.

**MYTHS**

• **Disabilities within children are easily and clearly defined, are visible, permanent and constant, and as a consequence stifle and prevent children from embracing much of what is considered normal life activity.**

  1. As we discussed previously, it is not easy to define disability. The established definitions have more to do with the people defining than the actual disability.

  2. It is also important to keep in mind that disability is not constant. Disabilities change throughout the life cycle.

  3. A large part of involvement in life has to do with issues of acceptance, environmental accessibility, and social and policy access.

• **Disabilities are unfortunate accidents of nature and there’s little that can be done about it.**

  1. We have previously discussed the issue of pity, which can easily be transferred by the professional. We must within ourselves be aware of the negative stereotypes and prejudices that we have inculcated.
2. We must help educate parents on negative effects that societal attitudes toward disabilities can have on their children.

3. We must teach them how easy it is to internalize these negative values and myths.
4. In addition, we need to teach them about the disability and how to prevent it from becoming worse both at the early stage of development and later on.

- **Children with disabilities must be provided with all services by highly trained professional personnel.**

  1. Some components of the needs of children with disabilities need to be provided by highly trained medical or remedial professionals.

  2. But most other needs are similar to the endemic needs of all children. The services require no specific disability-related training. Too often the focus becomes unnecessarily the disability and the disability may have no bearing on the needs of the child.

  3. The above myth has become the rationale for special education and the resistance to inclusion. The disability becomes the focus rather than the need for children with disabilities developmentally to be with other children.

- **Much related to the previous myth, children with disabilities learn best in specialized settings with other children with disabilities so they don’t have to compete unfairly with children without disabilities. Also, they will not be exposed to cruel and nasty remarks of other children without disabilities.**

  1. This myth, as well as the one above, stems directly from the moral and medical model. At the basis of this myth is the idea that we really shouldn't associate with people with disabilities because they are either spiritually or naturally aberrant.

  2. In reality, the specialized programs whether they are in education or in recreation tend to promote the negative stereotyping and prejudice that exists in our society. They tend to increase the segregation and isolation of children and later of adults with disabilities.

- **Lastly, diagnostic labels are the best way of assessing and understanding the child with the disability.**

  1. Generally, diagnostic labels again support the segregation of people with disabilities and reinforce society's negative view of disability.

  2. The over-inclusive and absolute nature of some labels limits the potential development of children with disabilities.

3. We live in a medical model world and the use of these diagnostic labels is inescapable. We need to know and understand the use of diagnostic principles.

4. We also need to understand their limitations and their dangers in imposing an expectation of limitation and in some cases failure.

THE SOCIAL/MINORITY MODEL AND THE INDEPENDENT LIVING MOVEMENT (Overhead 3)

- The Independent Living Movement began to change the traditional way of looking at persons with disabilities.

- It manifested in political action from the 1960s until the present.

- In part, its philosophic roots came out of work by social psychologists in the mid-1940s. Researchers such as Roger Baker, Lee Meyerson, and Beatrice Wright, using the theoretical framework of Kurt Lewin, forged the foundation of a new way of looking at disability.

- They put forth the idea that rather than a characteristic of an individual, disability with its narrow stereotypes and limited identity was in fact a societal construct.

- Another component of the philosophic foundation of the social/minority model is rooted in conservative economics. Simply stated, it is the belief in free market theory and the concept that all individuals have the right to choose their life’s direction. All people should have the right to compete. None should be locked out of the marketplace (DeJong, 1979).

- The social/minority model of disability rests upon certain assumptions (Overhead 4):
  
  1. First, persons with disabilities are a minority group as ethnic minorities, women, gays and lesbians, and people who are older (Wright, 1960). Along with this minority status goes all the stereotypes of ableism and internalized ableism.

  2. Second, much related to the first assumption, the concept of disability is a social construct. This social picture of disability rests upon cultural tenants about disability. These beliefs manifest in the stereotypes and discriminations applied to persons with disabilities (Fine & Asch, 1993).

  3. Third, the “problem” with disability lies with the social construct of disability rather than with the individual (DeJong, 1979). There is nothing innately wrong with the person with a disability. He or she merely represents a

piece of the grand diversity that is human. Persons with disabilities belong in the spiritual and natural universe. Disability may only play a small part in a person's life.

4. Fourth, **when there is a problem concerning disability, the answer lies in addressing the social construct and the related barriers to individual and group fulfillment** (DeJong, 1979). In other words, intervention with persons with disabilities is an economic, political, and social intervention rather than an individual intervention.

5. Fifth, **persons with disabilities should be in control of their own lives just as people without disabilities.**

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**Instructional Questions:**

1. What do you think about these assumptions?
2. Can people with disabilities be considered a minority group?
3. How can you say that a person with a physical disability has a disability because of social constructs? Are they not obviously limited in one way or another?
4. How realistic is it to assume that you're going to change society's perspective on disability?
5. Isn't it easier to change the individual rather than change society? Hasn't new technology facilitated individuals adapting to the environment?
6. How can persons with a severe disability really be in control of their lives when they depend almost entirely upon other people? Can people with a severe emotional disability be relied upon to control their own lives?

These questions are designed to be the starting point for students to really discuss their views of these assumptions. The instructor needs to facilitate the expression of different viewpoints including ones that go against the assumptions. Students must examine what they believe within an open environment.

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- These assumptions have several implications:

  1. Persons with disabilities have a right to independence, but must take on the responsibilities that are a part of independence (DeJong, 1979). They must demand their political and economic freedom and continually work for it in both the political and economic arenas.

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2. This is not only the responsibility of persons with disabilities, it is also that of professionals who work with them. Professionals must teach persons with disabilities political and economic skills as well as participate in the political and economic process for the empowerment of persons with disabilities (Mackelprang & Salsgiver, 1999).

3. In addition, within professional treatment, independence means the absolute control of the person with a disability. The professional is merely a consultant. Persons with disabilities make the decisions of what happens in their lives particularly when they receive social services (Mackelprang & Salsgiver, 1999).

**Discussion Question:**

What does this mean specifically for the child welfare worker?

The discussion should contain the following points:

- It means that the child with the disability must be listened to. In order to do this, sometimes there is a necessity to make special effort with special skills.
- It means the child's family must be listened to. Sometimes this means training the family on how to ask the right questions. It also means helping the family to assess their needs.
- It means working with the family and teaching them how to advocate for themselves; how to advocate for their children; how to become politically active.
- It means that the child welfare worker must see himself or herself not necessarily as a controller but more as a consultant. Given policy in agency restraints, sometimes this is a tough one. But, if children with disabilities are truly going to reach their potential, this is a necessary step.

**Educational Activity:**

Divide the class into groups similarly to when the module began. Ask the students to complete the survey again and then compare their answers. Ask the students to discuss with one another answers that had an extreme differential between the pre- and postsurvey. Complete the module by asking students to share their changes in perspective, if any.

MODULE III
THE ABUSE OF CHILDREN WITH DISABILITIES

Goals:
Students will understand the limitations of practice-driven research concerning the abuse of children with disabilities. They will explore the various myths around children with disabilities. Students will gain some understanding of the extent of the problem. They will take a look at factors of vulnerability. Students will become knowledgeable about special assessment problems, generic interviewing techniques, and empowerment techniques centered on abuse and disability. Students will become knowledgeable concerning the special needs of particular disabilities.

Objectives:
1. To articulate some of the issues regarding practice-driven research.
2. To articulate the many myths around children with disabilities and abuse and to explore some of the origins of those myths.
3. To articulate some of the factors of vulnerability and apply them in a case scenario.
4. To articulate assessment problems and to utilize special assessment techniques in a case scenario.
5. To articulate special interviewing techniques and to apply them in a case scenario.
6. To articulate components of empowerment around the abuse of children with disabilities and to utilize these components in a practice/case scenario.

LIMITS OF RESEARCH

We must begin our discussion with an understanding of the limitations of studies around the abuse of children with disabilities.

- In terms of methodology, the study of the abuse of children with disabilities has been approached in two ways:
  1. Researchers can address a selection of children who have been abused and determine the percentage of these children who are known to be disabled before the abuse.

2. Another method is to look at a population of children with disabilities and try to establish the percentage that had been abused.

- The problem with both of these methodologies is that the possibility that the abuse caused the disability is not dealt with.

- The most serious issue with the vast majority of studies on the abuse of disabled children centers on their failure to utilize a control group of non-abused and/or able-bodied children that is matched in terms of gender, ethnicity, and socioeconomic position to the focused studied children. Without the use of a control group, it is impossible to determine the important variables.

- A significant second issue must be kept in mind when examining the issue of the abuse of children with disabilities. This is that there is a lack of a coherent underlying theory concerning the abuse of children with disabilities. This causes two problems:

  1. It allows the transfer of factors of abuse from children without disabilities to children with disabilities. We really don't know whether or not the factors such as isolation or severity of disability impact abuse although many writers will attest to this.

  2. Because of the lack of theory, we are unclear regarding the issue of cause and effect. Does disability cause abuse or does abuse cause disability? What are the combinations? A coherent underlying theory needs to emerge from the research that would clarify the relationship of the above two factors.

Social work practitioners and future social work practitioners need to keep the above limitations in mind when learning and using practice techniques developed to work with children with disabilities who have been abused or might have been abused.

**MYTHS**

- Children with disabilities are protected by their special nature.

**Discussion Question:**

What value system or way of looking at disability might support this particular myth?

Discussion needs to center on the moral model of looking at disability.

• Children with disabilities are "damaged goods." Therefore, their abuse is of the lesser consequence than the abuse of "normal" children.

**Discussion Question:**

What value system or way of looking at disability might support this particular myth? Discussion needs to center on the medical model of disability.

• Children with behavioral disabilities are responsible for their abuse. (Blaming the victim.)

**Discussion Question:**

Where did this particular myth originate? Blaming the victim is always a part of oppression and it comes both from the medical model and the moral model as well as the American idea that we should all be able to pick ourselves up by our bootstraps.

• Children with developmental and cognitive disabilities cannot be trusted in reporting abuse and besides the impact of abuse is less with them.

**Discussion Question:**

Where might the origin of this particular myth originate? Again, non-trust stems from imperfections and immorality. Also, the attributing of lesser impact of physical harm is again a part of oppression and the dehumanizing of entities of lower status.

• Professionals dedicated to the care of disabled children would not abuse them.

**Discussion Question:**

Finally, what is the origin of this myth? Discussion needs to center again on the “high moral calling” of working with children who are not spiritually or physically potentially perfect. People who work with children like these must be “really dedicated and ethical.”

THE NUMBERS

- The National Coalition on Abuse and Disabilities estimates that nationally over **18,000 children** per year are permanently disabled by abuse and neglect (Struck, 1999).

- In 1993, the National Center on Child Abuse and Neglect found children with disabilities nationally are abused at a rate of **1.7 times** that of children without disabilities (Struck, 1999).

- Children with disabilities are **1.6 times** more likely to be neglected (Struck, 1999).

- Children with disabilities are **1.8 times** more likely to be physically abused (Struck, 1999).

- Children with disabilities are **2.2 times** more likely to be sexually abused than children without disabilities. Some statisticians take that percentage much higher to **7 times** more likely to experience sexual abuse than non-disabled children (Struck, 1999).

- Children with developmental disabilities are at higher risk of sexual abuse. Up to **69%** of girls and **30%** of boys with developmental disabilities are sexually abused before the age of **18** (Briggs, 1995).

- **25%** of adolescent girls with developmental disabilities had experienced rape or attempted rape (Briggs, 1995).

- More than **half** of all deaf boys are sexually abused (Briggs, 1995).

- In general, the percentage of boys with disabilities who were the victims of child sexual abuse is consistently higher than the percentage of boys without disabilities (Briggs, 1995).

- More **boys** with disabilities between the ages of **6-11** were sexually abused than girls in the same age range (Briggs, 1995).

- **80%** or more of deaf children receiving treatment for emotional disability had experienced sexual abuse (Briggs, 1995).

FACTORS OF ABUSE CONCERNING CHILDREN WITH DISABILITIES (Overhead 1)

Sobsey (1994), using the ecological model of child abuse, points out a myriad of factors connecting disability and child abuse.

• The nature of specific disabilities directly relates to vulnerability to abuse.

1. Children with disabilities which impact motor skills find it difficult to fight back against physical or sexual abuse and in many cases cannot run from it.

2. Children with cognitive or language difficulties may have difficulty seeking help or defending themselves verbally.

3. Children with hearing-related disabilities may lack information important in protecting themselves or may be blocked from seeking help. The same is true for children with visual disabilities.

4. Children with emotional or behavioral disabilities may be subjected to abuse by caregivers related to their behavior:
   ✓ Corporal punishment may be rationalized as a necessary negative reinforcement.
   ✓ An overuse of medication may be rationalized as necessary because of the behavioral nature of the disability.
   ✓ Physical restraints and isolation could be construed as treatment modality for emotional and/or behavioral characteristics.

• Society and some of our educational/caregiving institutions teach learned helplessness and compliance to children with disabilities.

1. Treatment professionals consider compliance as an important skill for children with disabilities primarily because it makes them easier to manage.

2. Physicians and other medical professionals want children with disabilities to comply with treatment whether medication, counseling, or physical therapy.

3. Teachers want children with disabilities to comply with appropriate classroom behavior so that they learn.

4. Counselors want children with disabilities to comply with social norms.

5. Parents and foster parents want children with disabilities to comply with family norms.

Compliance and learned helplessness are factors in abuse.

1. Many times behaviors found in children with disabilities are a manifestation of their last remaining piece of control over their lives.

2. Children who are taught to be helpless and compliant are less likely to resist commands of adults maneuvering them into abusive situations.

3. Children who are taught compliance and learned helplessness have a lesser sense of personal space and therefore have difficulty in recognizing the violation of personal space.

4. Children who are taught compliance and learned helplessness through negative reinforcement and corporal punishment have difficulty recognizing the difference between negative reinforcement for the "good" (what somebody defines as socially appropriate behavior) and negative reinforcement that puts them in jeopardy of physical or sexual abuse.

Discussion Question:

How do you teach the child with a disability appropriate social interaction without teaching and reinforcing learned helplessness?

This is a particularly difficult issue with children with disabilities who act out because of their disability. The instructor should foster discussion but not stifle confusion. Don't give the students answers at this point but let them explore some of the issues and contradictions.

- **Society and some of our educational/caregiving institutions perpetuate dependency in children with disabilities.**
  
  1. Dependency produces the necessity for intensive interaction (sometimes physical) with caregivers. Some caregivers may be potential abusers.

  2. Dependency may teach children with disabilities to be more trusting of caregivers’ actions.

  3. Children with disabilities in dependent situations tend to trust caregivers explicitly.

  4. Children with disabilities in dependent situations may not express the abuse for fear they may be abandoned or left without needed services.

  5. Children with disabilities in dependent situations may develop a strong desire to please authority figures and thus acquiesce to the demands of a potential abuser.

Many children with disabilities find themselves in isolated situations either staying at home in special education programs, or institutions. This isolation tends to be a factor in their abuse.

1. Because of the safety of isolated situations, children with disabilities are easier targets for abuse without retribution.

2. Because of their isolation, some children with disabilities do not understand "non-abusive" or "abusive" behavior.

3. Because of their social isolation, some children with disabilities may respond more quickly to pressures to conform to behaviors not in their best interest.

4. Because of their social isolation, some children with disabilities may not understand the function, the technique, or the concept of sexuality. Thus they may not understand sexual abuse.

5. Because of their social isolation, some children with disabilities are starved for attention and affection, which makes them vulnerable to maltreatment and abuse. Sometimes they will endure the abuse in order to gain the attention.

WHO ABUSES CHILDREN WITH DISABILITIES

- Sexual abusers tend to be male; some reports indicate a 90% figure (Sobsey, 1994).

- They tend to be people that they know and that care for them. These include service providers (38%) and natural family members (17%). Only 8% of the abusers are strangers (Sobsey, 1994).

- They tend to be people who need to be in control.

- They tend to have been victims of abuse as children.

- They tend to "blame the victim." Their violence is justified because the child "provoked it."

- They tend to lack impulse control. Many are alcohol and drug users.

- Abuse of children with disabilities takes place in institutions with the following characteristics:

  1. Abuse of children with disabilities usually occurs in institutions where there is an extreme power differential between the caregivers and the children.

2. Generally, abuse of children with disabilities involves more than one caretaker and in some instances all the caregivers and all the children.

3. Generally, in institutions where abuse of children with disabilities occurs, there is a calculated cover-up of the phenomena. Administrators try to control it from within.

4. Abusive institutions tend to be institutions where few resources exist but caretakers have enormous power over the children.

SOME PRACTICE IMPLICATIONS

Assessment

- Problems in assessment

  1. Is it abuse or is it the disability? (Overhead 2)

     ✓ Many children with disabilities concerned with behavior or cognitive functioning exhibit self-abusive behaviors or are prone to accidents.

     ✓ Many children with disabilities concerned with emotional factors exhibit inconsistent behavior and antisocial behavior.

     ✓ Many children with severe physical disabilities require personal care that involves touching genitals.

- Some hints:

  1. Observe the injury. Determine if it is consistent with the types of injuries that are indicative of abuse.

  2. Determine what the child says about the situation. Listen carefully.

  3. Compare the injury with the explanation to determine consistency. Does the explanation make sense?

  4. Determine if the injury is consistent with the child's capacity to create the injury. Is the child at a point where he/she could do the thing explained in the statement?

  5. Try to find as many witnesses as possible. Think about who could potentially have seen what happened.

6. Read the medical reports and if possible interview the intervening nurse and/or physician.

7. Observe the child's behavior. Do you see the behavior that may have resulted in the injury?

- Getting a starting point (Overhead 3)

  1. Obtain a baseline of the child's behavior. Establish what is typical behavior for that particular child.
  2. Take a look at the history of the behavior.
  3. Compare historical behavior with current behavior. Has there been a change in intensity or duration of behavioral episodes?

- When collaborated with other evidence, the following behaviors may indicate sexual abuse:

  1. Increased masturbation;
  2. A new behavior of touching others;
  3. New and unusual behaviors related to a child's own genitals (e.g., pulling, punching, rubbing, etc.);
  4. Sexual drawings.

**Interviewing (Overhead 4)**

- General principles in interviewing a child with a disability

  1. The social worker needs to be aware of his or her own comfort level in talking to and interviewing children with disabilities. If the social worker is uncomfortable, he or she needs to find someone else to interview the child.

  2. Be sensitive to the child's developmental level. Very young children cannot conceptualize abuse, sexual abuse, or sexuality. This is particularly the case with children with disabilities. You need to develop a communication strategy that will accomplish your objectives.

  3. Follow the child's lead rather than adhering to a rigid interview protocol.

  4. Be objective and nonjudgmental.

5. Be empathetic and understanding.

6. In the beginning, explain the purpose of the interview.

7. Establish a positive rapport by asking questions that are relatively neutral and that will engage the child. These questions could include where the child lives, what the child’s birthday is, names of brothers and sisters, names of his or her favorite teacher, favorite television shows, what the child likes or dislikes, and what he or she did for fun this week.

8. Avoid any comments that would seem to blame or be critical of the child.

9. Limit your language to the developmental level of the child you're interviewing.
   - Always use simple words.
   - Use short sentences and short questions.
   - Use simple tenses.
   - Be as focused as possible on the who, what, when, and where.

10. In your language, avoid the following:
   - Abstract words.
   - The use of pronouns.
   - Complex questions with several possible answers.
   - Yes and no questions.
   - Negative questions.
   - Questions that go beyond the developmental level of the child.
   - "Why" questions.
   - Leading questions. Never ask a question in which the desired answer is located.

11. Be ready to use aids such as anatomically correct dolls or drawings.

12. Always bring your interview to closure and include the following:

Always thank the child for his or her help.

Always praise the child's effort. Never praise the content of the information he or she gave you.

Tell the child what will happen next.

Always try to educate the child regarding personal safety.

Explore possible safety options with the child.

Specific Disability-Related Interview Techniques

- Many disabilities impact language in communication. Disabilities can affect the ability to receive information, the ability to process information, and/or the ability to communicate information back.

Deaf or Hard of Hearing Children (Overhead 5)

- Prior to the interview, the social worker needs to ascertain what method of communicating the child utilizes. Does the child use American Sign Language, Cued Speech, or lip reading? The appropriate interpreter must be present. Make sure the interpreter is comfortable in communicating about sexuality and/or physical abuse.

- In interviewing children who are deaf or hearing impaired, always look directly at the candidate. Eye contact is crucial. Never look at the interpreter.

- The room should be well lit.

- For a child who can read lips, speak slowly and distinctly.

- Avoid gesturing around the face.

- Body language and facial expressions are important.

- If the child uses a sign language interpreter, the interpreter should be positioned next to the social worker doing the interviewing so that the child can shift back and forth from the interpreter to the interviewer.

- The social worker should always avoid the term “deaf and dumb.” It is inaccurate and offensive.

- It is not necessary for the interviewer to avoid using the word “hear” with a child who is deaf.

• If the social worker does not understand the comment or sentence, it is necessary to be honest and let the child and the interpreter know that he or she does not understand.

• It is appropriate for the social worker doing the interviewing to tap the child on the shoulder or to wave a hand to get visual contact.

• The reaction of speaking loudly around a person who is deaf or hearing impaired is not very helpful.

**Children With Visual Disabilities (Overhead 6)**

• For children with sight impairments, the social worker may extend an arm to help guide the child to a chair.

• If the child uses a guide dog, the interviewer should avoid petting the dog or distracting it in any way.

• It is appropriate to introduce all persons involved in the interview because a child who is blind may not be aware of all those present.

• In the introduction, indicate where other participants are sitting in the room.

• As with children who are deaf, children who are blind have little need for the social worker to speak in a loud voice.

**Children With Mobility-Related Disabilities (Overhead 6)**

• The social worker doing the interviewing should not assume that a wheelchair user or other child with a mobility impairment needs help. The interviewer should only provide assistance if the child requests it.

• The social worker should be prepared to tell the child the location of elevators, ramps, and accessible restrooms.

**Children With Speaking-Related Disabilities (Overhead 7)**

• In interviewing children with speech impairments, if the social worker does not understand a response to a question, it certainly is appropriate to ask the child to repeat the answer.

• The interviewer should not hesitate to follow up on an answer that does not make sense or seems confusing.

• Usually if the interviewer can relax while listening, the interviewer becomes more accustomed to the sound and pattern of the child's speech.

• Watch body language.

• Have readily available props and/or drawing boards.

• The room should be well lit.

• The room should be relatively quiet with limited distractions.

**Children with Cognitive Disabilities (Overhead 7)**

• The interview room must be well lighted and free from external distractions.

• Many children with cognitive disabilities have difficulty making generalizations from past events, which makes it difficult to draw connections with issues of a time development nature. This characteristic requires much patience on the part of the interviewer.

• Many children with cognitive disabilities have difficulty with picking up social cues. This means that the social worker must be very explicit in his or her speech, not relying on body language for expression.

• Many children with cognitive disabilities have difficulty expressing themselves in speech. Interviewing may take longer and points may be required to be repeated several times.

• In the interviewing process, communication must be direct and simple.

• The interview and follow-up sessions should be as short as possible and within an environment with minimal distractions.

**Children With Learning Disabilities (Overhead 8)**

• Children with learning disabilities will have difficulty receiving information from the senses. The social worker needs to be direct and explicit.

• The interview and session room must be without visual or auditory disturbance.

• Children with learning disabilities sometimes have difficulty processing information. Therefore, interview sessions may need to be longer than usual or more likely, need to be broken up into several sessions.

• Children with learning disabilities often have difficulty in communicating knowledge to others. This may require longer interview sessions or an increased number of sessions.

• Children with attention deficit hyperactivity disorder will have difficulty staying in one place with full attention on a task. The social worker may have to be creative in the interviewing process, and may have to break the session up into smaller sessions.

• One last word concerning interviewing, all social workers cannot be experts in disability and communicating with disabled children. Whenever possible, collaboration including finding assistance or advice in interviewing children with disabilities is important in getting the full picture of what happened.

FOSTERING THE EMPOWERMENT OF ABUSED CHILDREN WITH DISABILITIES

Some General Guidelines (Sobsey, 1994)

• Not only do we need to train children with disabilities to resist abuse, social workers must work to change the myriad social/legal conditions that perpetuate the abuse.

• Curriculum that teaches children with disabilities to resist abuse should include:
  1. Skills designed to enhance personal safety,
  2. Focused education regarding specific individual rights,
  3. Activities and exercises that foster self-esteem building and the teaching of how to be assertive,
  4. Activities designed to increase communication skills,
  5. Activities and exercises that promote development of social skills,
  6. Sex education, and
  7. Activities and exercises designed to foster self defense.

• In teaching and counseling, children with disabilities need help in understanding how to differentiate between when to comply and when to refuse to comply. Any program that a child with the disability participates in needs to reinforce noncompliance to unreasonable demands.

• Within any environment whether therapeutic or educational, children with disabilities need to increase their awareness that no one has the right to harm them.

• All interventions should minimize physical force. Physical force should never be used to overpower a child with the disability or to manipulate a child with the disability who is unresponsive.

• Adult service providers should always ask children with disabilities if it is all right for them to touch them. Children with disabilities should have the right to refuse to be touched when they do not want to be touched.

• Avoid the use of drugs and intrusive behavior management practices to modify behavior. Try to find the origin of the behavior, which usually has a function for the child. Try to teach a more acceptable behavior to accomplish the same goal. For example, disruptive physical behavior is usually a mechanism to draw attention to the child. Alternative appropriate behaviors to accomplish this goal can be taught.

• At any point in the intervention, including assessment, goal formation, plan development, plan implementation, and evaluation, the service providers need to facilitate active participation of the child with the disability.

• Goals for children with disabilities should always include some form of acceptance and encouragement of reasonable risks.

• In working with the child with the disability, accept the child for who he or she is. Avoid focusing on limitations and things he or she cannot do.

• Always interact with the child with the disability; avoid overpowering him or her.

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**Educational Activity:**

Divide the class into small groups of 4-7 members each. Distribute "Richard’s Vignette" (Appendix B, Module III Handout) and have the students read the entire vignette. After about 25 minutes, ask the groups to answer the following questions as a group:

1. Which incident in “Richard’s Vignette” could be considered abuse? Please give specific reasons for your choices.

   This question probes students’ ideas around the nature of abuse.

2. Pick one situation of abuse. What were the factors in the abuse? Did an extreme power differential exist in the situation? Did the abuse happen in isolation? Was learned helplessness a part of the process?

   This question begins to stir analysis of potential situations for abuse and the utilization of this analysis and intervention.

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3. If you were a social worker employed in this agency, and were called upon to investigate this situation, how would you proceed? Where should intervention take place?

Obviously, intervention must take place not only with the child with the disability, but also in the structure of the institution. The child depicted in this vignette certainly needs counseling and education in a variety of areas including assertiveness and self-esteem building. But clearly, the institution needs to address the power differential innate in its structure among other things. Intervention must happen at both those levels.

4. If you were called upon to interview Richard, what special considerations should be made?

There are some unanswered questions here. From the vignette, we are not clear on whether or not Richard may have a speech impairment because often children with cerebral palsy have both mobility issues and speech issues. But certainly accommodation in the interviewing process around these two areas must be addressed. Also we don’t know Richard’s age or developmental level.

After the groups have completed the questions, call the class together and ask each group to discuss their answers.
MODULE IV
FAMILIES AND DISABILITY

Goals:
Students will understand the importance of bringing a balanced perspective regarding disability and children with disabilities to interventions with families with members who have a disability. In addition, they will understand the needs of both parents of children with disabilities and the child members of the family.

Objectives:
1. To be able to articulate the negative components of traditional social work practice wisdom regarding disability and children with disabilities.
2. To be able to articulate some underlying factors in those negative components.
3. To be able to articulate the consequences of the negative components of traditional social work practice on the parents, siblings, and children with the disability.
4. To be able to articulate the wide range of responses by parents and siblings when children with disabilities enter families.
5. To be able to integrate positive practice modalities into intervention with families with children with disabilities and to utilize them in a case scenario.
6. To be able to identify potential stress points for families who have children with disabilities in a case scenario.
7. To be able to articulate a wide range of potential goals for families who have children with disabilities as members.
8. To apply various components of practice in a case scenario.

THE NUMBERS (LaPlante, Carlson, Kaye, and Bradsher, 1996)

- Approximately **20.3** million or over **29%** of the families in the United States have at least one member with the disability.
- Single-parent families have a higher percentage than partnered families with at least one member of the family having a disability.

• Over 2.3 million partnered families contain one or more children with a disability. This is 4% of all partnered families in the United States.

• 18.4% of single-male-headed families have at least one member with a disability. 5.9% have children with disabilities.

• 21.7% of single-female-headed families have members with a disability. 12.9% have children with disabilities.

• More than 3.8 million families contain one or more children with a disability. This is 5.5% of all families in United States.

• Most of the above families (89%) have one child with a disability. 0.5% contain more than one child with a disability.

• 29.1% of White families have a disabled member. 31.9% of African American families have a disabled member. 23.4% of Latino families have members with disabilities.

• The highest poverty rates in the United States of families with a disabled member are single-parent families with two or more children with disabilities.

• Families with members having disabilities have significantly higher than average number of hospital days experienced by members.

TRADITIONAL VIEWS ON FAMILIES AND DISABILITY

• Most traditional social work and human service-related professional literature and thought present negative consequences to the family as a whole and to the other “normal” family members upon the entrance into the family of an infant or child with a disability. Professional opinion generally views family responses to the disabled child as dysfunctional and negative, ultimately affecting the family as a whole, the disabled child, individual parents, and the siblings.

• The basic social work professional conceptualization of disability and family is the grief or bereavement model originally created to understand the adjustment process to death and dying (the Kübler-Ross-like Model). Equating disability to death, these stages generally include shock, disorientation, denial, guilt, shame, anxiety, hopelessness, blame, anger, and fear. Some models include the traditional bargaining phase with God. Eventually, parents reach the plateau of reorganization and acceptance according to the model.

• This stage model perspective utilized by many social workers places a child with a disability entering the family at birth or later in a potentially dysfunctional, negative

light. This negative perspective embraces the family as a whole, the child with the disability, the parents, and the siblings.

- Much of current professional social work thinking and practice wisdom puts forth the following: The whole family tends to move into a period of **deep depression**, particularly if the disabled child or chronically ill child does not die. Parents must deal with **issues of loss and disappointment** on an ongoing, unresolved basis. The family as a whole suffers a **disruption of communication** because members may be at different stages in the grieving process, and fear and guilt limit communication. Families generally become **isolated** from the larger society and community. This isolation impacts their seeking help. The disabled child may severely limit a family’s work time and leisure time, again decreasing the contact of the family with the outside world.

- Current professional literature presumes that the congenital or acquired disability will result in **negative consequences for the child with the disability**.
  1. Parental resentment of the child with a disability can result in the child being **punished, rejected, or ignored**.
  2. Parents develop unrealistically low expectations of the disabled child and adopt a custodial attitude according to much of the literature.
  3. Feelings of anxiety and uncertainty can produce overprotectiveness and overindulgence toward the child with a disability.
  4. The chronically ill or disabled child may also feel anxiety, shame, and failure. The child may feel guilty for bringing despair upon the family.
  5. The child with a disability can develop a sense of being “bad.” They generally are isolated from their peers.

- Much of current professional literature takes a negative stance regarding the impact of the child with a disability **on the parents**.
  1. Parents become preoccupied with their own feelings resulting in their inability to give support to the rest of the family.
  2. Mothers become involved in an intense dyadic relationship with the disabled child leaving father and the other siblings outside of the “magic circle.”
  3. Fathers seem to derive less satisfaction and gratification from disabled children.
  4. Both mother and father have increased psychosomatic illness and sleep disturbance.

• Much of current professional thought takes a negative slant regarding the **siblings** of the child with a disability.

  1. The sibling’s relationship to the parents may deteriorate.
  2. Siblings may develop psychosomatic illness and sleeping problems.
  3. They may develop pre-delinquent kinds of behavior such as fire-setting or experience increased problems at school.

### LIMITATIONS OF TRADITIONAL RESEARCH BEHIND PROFESSIONAL THOUGHT

• Several assumptions are misleading in traditional research about families with children with disabilities, and many studies have serious methodological flaws.

  1. Kazak (1986) stated that many studies have combined, as subjects, children with different disabilities. Different types of the disabilities and chronic illnesses may impact families differently. Family response, coping, and adaptation may be different with different disabilities.

  2. Most studies have not identified comparison groups. It is not known how families with children who are not disabled deal with particular kinds of stress. Without this comparison, the research may present an overly negative view of the impact on the family of the disabled child.

• There exist serious reservations regarding the “standard” view of developmental stages of grief of families with a child with a disability.

  1. Blacher (1984) indicated the lack of empirical research to support the stage paradigm.

  2. Some studies have been based on one family.

  3. Some studies used open-ended questions, which were not standardized in any way leading to increased susceptibility to subjective findings.

  4. Another limitation is that only mothers are interviewed and very rarely are fathers assessed.

  5. Another key limitation is that few studies address variables, which may influence family response such as

     ✓ Socioeconomic status of the family,

     ✓ Nature and number of supportive services available,
✓ The ethnicity of the family,

✓ The nature of the family (single-parent; double-parent; inclusion of grandparents, etc.), and

✓ The importance of religion and type of religion of the family.

• In terms of research concerning family isolation, Kazak (1986) concluded that:
  
  1.Investigators focused more on the size of the social network rather than its quality.

  2. Researchers have assumed that because parents of children with disabilities have fewer contacts and sources of support, this is a result of the negative impact on parents of the disabled child. Researchers have not fully investigated the quality of existing networks or the possible advantages of having smaller but more intense social networks.

ENTRENCHED NEGATIVE PERSPECTIVES

• Many social welfare professionals dismiss the reported positive consequences to the family of having a child with a disability as rationalizations. Both researchers and practitioners view the reporting of positive experiences with children with disabilities as a way to keep a family's defenses intact against the reality of the experience (based on the Kübler-Ross Model).

• Parents feel professionals emphasize the negative aspects of the experience and underestimate parents' capacity to adjust and cope with having a child with a disability.

• Practitioners, particularly ones who are not themselves disabled, harbor the same prejudices and stereotypes as the general culture.

• These prejudices and stereotypes form professional assumptions:
  
  1. Illness and disability are not normal.

  2. Because the child is ill or disabled, the child is not normal.

  3. Because the child is not normal, the child must be treated differently.

  4. The illness or disability is equated with great loss; the equivalent of death. This loss must be mourned.

THE CONSEQUENCES OF TRADITIONAL VIEWS

• The negative views of professionals regarding disability along with the dominance of professionals in treatment relationships have serious consequences in how families with children with disabilities are treated.

• Negative professional views on children with disabilities create feelings of anomie on the part of parents; they feel abnormal. Parents feel powerless in reaction to professionals’ attitudes of elitism, affective neutrality, impartiality, and dysfunctionalism.

Questions For Class Discussion:

1. How can such a negative view develop within the profession of social work that supposedly harbors empowerment and nonjudgment?

2. What sustains it?

Discussion of these questions needs to center on: how do professions integrate society’s values within their practice? How do research modalities also reflect values of the society? Once a practice perspective comes into being, how difficult is it to change the perspective? How influential is the medical model in social work practice and what does it mean?

DISABILITY-POSITIVE PERSPECTIVE (Overhead 1)

• A new perspective is beginning to emerge among practice professionals and researchers that challenges old negative perceptions of how children with disabilities impact families.

1. Darling (1988) and Kazak (1986) discuss research that presents the “normalcy” of families who have members who are children with disabilities.

  ✓ Parents of children with disabilities have similar hopes and expectations for themselves and their children as the parents of children without disabilities.

  ✓ The parents of children with disabilities believe that their children will have equal access to educational services as well as medical services.

  ✓ Parents of children with disabilities expect to continue pursuing their careers, participating in recreational and social activities with family and friends, and have as much financial security as others in their social class.

2. The introduction of a child with a disability can bring a family closer together as a unit, facilitating the development of a sense of family.

3. Individual family members can grow emotionally and expand their knowledge of the community and the world as a result of having a child with a disability.

4. Family members can increase their compassion and tolerance.

5. Families can develop deep and meaningful friendships with other parents of children with disabilities, and hospital and rehabilitation personnel.

6. The children themselves can gain an increase in self-esteem by quality and extensive relationships with both family members and professionals.

- Social work professionals specializing in children and families can no longer assume family reaction to disability on the negative side.

- Traustadottir (1991), using a qualitative research design, discovered a wide range of responses of mothers to the introduction of a child with a disability into their family.

- Responses to caring for a child with a disability ranged from feeling that the care disrupted other aspects of family member lives to that of others seeing it as an “empowering experience.”

- For mothers who saw having a disabled child as an empowering process, caring for the child was their major source of identity and pride.

- The middle territory was made up of mothers who saw little difference between caring for a child with a disability and a non-disabled child. From their perspective, the child’s disability was not their greatest concern.

**WHAT PARENTS OF CHILDREN WITH DISABILITIES ARE LOOKING FOR FROM SOCIAL WORKERS**

- Parents want social work professionals to see their child as a whole rather than the piece the professional is trained to look at.

- Parents want to eliminate the concepts of normalcy and dysfunction in social work professional care. They want their child to be evaluated and assessed on the basis of his/her own progress.

- Parents of children with disabilities want social work professionals to listen to them. They want their comments valued. They want professionals’ suggestions, not
mandates. They believe they know their child in many ways better than the professional.

- Parents want social work professionals to create an environment where they are not intimidated; where they feel comfortable enough to speak.

- Social work professionals must really believe that what the parent has to say is important and that the child who they are addressing is important and significant.

- Parents want social work professionals to drop the jargon, which they see as only a barrier between them and the professional.

- Parents want professionals to admit when they do not know something or the areas that are gray.

- Parents with children with disabilities want to be directed toward community resources and social resources rather than be given an empty diagnosis.

- Parents with children with disabilities want professionals to stop blaming the victim; stop blaming the parent for the child’s disability.

- Parents of children with disabilities want to learn how to be advocates; learn how to impact the system. They seek changes in the larger society, which require political action.

- Parents seek help meeting medical needs that in some cases are extensive. Parents request support for medical equipment and respite care. Many children with disabilities require special support into adulthood which society is more often than not reluctant to provide.

- Parents solicit ways of meeting educational, needs which can go well beyond the standard educational format.

- Parents seek changes in the human services establishment particularly in the area of access to services, an increase in the quality of services and a voice in the evaluation of those services.

SOME PRACTICE IMPLICATIONS (Overhead 2)

- **Values and Beliefs**: Social workers intervening in families with children with disabilities need to be aware of their own values and beliefs about disability. Negative stereotypical beliefs emanating from the larger society can be nothing but destructive to a family. If a social worker feels uncomfortable around disabled children in general or uncomfortable around a specific disability (e.g.,
developmental), then the child and family will know it and the social worker should not be working with those families.

- **Knowledge:** Social workers must be knowledgeable about disability. They must be aware of societal prejudice against people with disabilities, the stereotypes and myths about disability, and the resulting discrimination that people with disabilities face. It is imperative that social workers know about the civil rights movement in relationship to disability. It is also imperative that they know about the specific disability of the child in the family in which the social worker is intervening.

- Social work professionals need to be prepared to teach families about disability and the specific disability experienced by the child in the family. In this process, family social workers need to facilitate the view that the family's child is a child first and that the disability is a secondary characteristic.

- In the assessment process, plan development, plan implementation, and evaluation, social work professionals must inculcate the concerns and needs of parents with young children with disabilities. Parents want to be heard; they want control. Parents want to feel that human service professionals care in a holistic way about their child and respond to their child as a significant, important being. Parents with children with disabilities want human service professionals to see their child as different but normal, not abnormal and dysfunctional. Parents also want to learn how to become advocates for their child.

- In the assessment process, plan development, and plan implementation, social work professionals need to address the whole family rather than just the child with a disability. Some direct services may actually undermine family integrity, for example, prescribed institutionalization. Social work professionals must take into account the total family system in intervention and make increasing knowledge of family intervention techniques a part of continuing education goals.

- Individuals within the family need the opportunity to express their own feelings regarding the disability and assistance in developing individual and family potentials for adjusting to one another's needs. It is imperative that in this process the social worker does not impose a predetermined assumption that the family is grieving or experiencing loss or should be grieving or experiencing loss. But if the family is grieving and experiencing loss, this must be dealt with just as the family's potential excitement needs to be utilized.

- Based on family needs, referrals need to be made in terms of connecting the family to local resources which not only benefit the child but the family in general. These may include support groups for parents and children with disabilities, local independent living centers, the services of Regional Centers, respite centers, etc.

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• Potential Family Stress Points:

1. Family disruption because infants with disabilities may cry more, may cry harder, and may be more difficult to soothe.

2. Difficulties with parental attachment because of lack of smiling, eye contact, or desire to cuddle.

3. Interference in bonding because of long hospitalization in early infancy.

4. Frustration on the parents’ part because of inability of disabled child to reach developmental milestones.

5. Frustration by parents because of behavior difficulties of the child with the disability.

6. Parental burnout because of the daily care needs of the child with the disability; time pressure.

7. Financial strain because of the need for environmental adaptation in the home.

8. Financial strain because of increased medical and educational costs.

9. Family isolation because of the social stigma of having a disabled child.

10. Behavioral acting out of siblings because of lack of attention, resources, and/or psychological support.

• If father is part of the family, it is crucial that he participates in all components of family intervention. This may take some unique intervention approaches and scheduling.

• Social work family practitioners working with families with children with disabilities must remain in the political arena particularly today in light of the onslaught of the current political ideology. Petr and Barney (1993) found that family integrity depends on programs such as respite care. Normalization programs such as educational “inclusion” need continued political advocacy. Milestones in disability civil rights are in jeopardy without continued political support. And benefits such as SSI are crucial to families with children who are disabled, yet these programs are in constant jeopardy.

• Some Potential Goals for Family Intervention (Overhead 3):

1. The family views their child with the disability as a child first; the disability is secondary.

2. The family moves away from preoccupation with why the disability happened.

3. The family focuses on the positive characteristics and talents of the child with the disability rather than the negative, limited aspects of the disability.

4. The family seeks information about the child's disability and then uses that information to understand and work with the child.

5. The family is aware of the educational, emotional, and physical implications of the disability and is aware of available programs to support the child's needs.

6. The family is aware of support groups for parents of children with disabilities, children with disabilities, and siblings.

7. The family manages the needs and demands of the child with the disability within the framework of family life.

8. Both the mother and the father play an active role in parenting the child with the disability.

9. The family exhibits open communication including parents, siblings, and the child with the disability.

10. The family has support from friends and extended family.

11. Parents and other family members have the time and the resources to take care of themselves.

**Educational Activity:**

Divide the class into small groups of from 4-7 members each. Distribute "Chris's Vignette" (Appendix B, Module IV Handout) and have the students read it. If possible, distribute before session or class. After about 30-40 minutes, ask the groups to pick a developmental level designated by a color and arrows and answer the following questions as a group:

1. How did the group decide on that particular developmental piece of the vignette?

This question will give members of the group insight into some of their areas of interest regarding families and children with disabilities. It may give insight also into some of the member's values around disability and family.

2. In intervening with this family at the point you as a group have chosen, what values around disability seem to be more important?

3. What points of knowledge about disability would the social worker intervening with the family want to learn about?

One important point that needs to be stressed here is the interplay between culture and disability. Not only should the social worker need to learn about cerebral palsy, he or she needs to learn about the interplay between disability and Vietnamese culture.

4. At this point of intervention, what particular concerns and needs of parents need to be addressed?

5. What kinds of intervention techniques are applicable at this point (e.g., family counseling, case management, individual counseling with parents, individual counseling with the child, etc.)?

6. Does the father need to be involved? If yes, what kinds of things could be used to bring the father into the intervention process?

7. At this point of development, what goals might be appropriate for the family and the child?

8. Within the family, what are the stress points that need to be addressed?

After the groups have completed the questions, call the class together and ask each group to discuss their answers.

MODULE V

AN EMPOWERMENT MODEL OF SOCIAL WORK PRACTICE FOR PEOPLE WITH DISABILITIES INCLUDING CHILDREN WITH DISABILITIES AND THEIR FAMILIES

Goals:

Students will understand a generic practice model that is extremely useful in working with all people with disabilities including children with disabilities and their families. This generic model includes a strength-based assessment component. Also, students will understand basic social work roles in empowering people with disabilities. These roles include counseling, teaching, and advocacy.

Objectives:

1. Students will articulate components of the strength-based assessment model and utilize these components in a case scenario.

2. Students will both articulate social work empowerment roles and apply them in a case scenario situation.

3. Students will articulate pertinent federal laws regarding disability.

BASIC ASSUMPTIONS AND PRINCIPLES (Overhead 1)

The following assumptions form the foundation of this proposed generic empowerment practice model:

- People with disabilities, no matter what age, are capable or potentially capable.

  1. If people currently lack insight, knowledge, and skills, professionals are responsible to help them become insightful, knowledgeable, and skillful.

  2. When people lack the ability for the whole, we assume they are capable of parts of the whole.

- For example, children with intellectual disabilities may not be able to handle allowances the way their siblings can but they can manage the elements they are capable of handling.

Children with quadriplegia may be physically unable to dress themselves. However, they are capable of learning to direct who, how, and when attendant care is provided. Moreover, they should be supported in this move toward autonomy.

**Discussion Question:**

1. Do you really buy that people with disabilities are truly capable?
2. How can a child with a severe developmental disability be capable of learning in a school environment?
3. How can a child with severe cerebral palsy be capable of independent living?
4. How can an adolescent with a C-5 injury be considered capable of living his or her own independent life?

Once again, students need to be given the opportunity to discuss their doubts and their values discerning disability. There is no end to the necessity of providing opportunities for this kind of discussion.

- **The problem with disability lies not with the person.**

Again, students need to be allowed to explore their skepticism. This needs to be facilitated by the instructor.

- **Any model of practice applied to working with persons with disabilities must assume that disability is a social construct and that a primary emphasis on intervention must be political in nature.**

- **There is a disability history and culture.**

  1. Even though different people may have different disabilities, they have more in common than they have differences.

  2. Because of the shared experience of oppression, containment, and isolation of persons with disabilities, it is imperative that anyone working with persons with disabilities:

     ✓ Be knowledgeable of the history of oppression toward persons with disabilities.

     ✓ Be aware of political figures, advocates, and conveyors of disability culture and how they have contributed to the fight for disability respect and rights.

Be highly knowledgeable about political advocacy. They must be willing to help consumers to become politically involved themselves (Tower, 1994).

- Though persons with disabilities have experienced oppression, there is joy and beauty to be found in disability.

1. Models of practice applied to working with persons with disabilities, particularly children, must view disability as different and not necessarily dysfunctional. They will view disability as one more panel of color that makes up the glorious tapestry of human existence.

2. Disability is beautiful and most people with disabilities are actually happy with themselves and their lives (Hahn, 1993).

- Persons with disabilities have, without question, the right to control their lives (DeJong, 1979). This attitude needs to be particularly nurtured and fostered in children with disabilities.

1. This means that the consumer and the consumer’s family controls the professional’s involvement.

2. This means that the professional brings his or her expertise to the consumer to be rejected or accepted, or rejected in part or accepted in part.

3. The natural place for persons with disabilities, even if professionals disagree with their choices, is in control of their lives, living independently from custodial environments, and living freely within the American dream of freedom and equal opportunity.

**Discussion Question:**

How can a child with a disability who totally depends upon others for everything, including bodily functions, be in control of his or her own live?

Once again, the instructor needs to invite skepticism and at the same time begin to have students realize that how we define independence is culturally bound. An immediate example of this is the fact that an independent person in frontier America certainly is different than an independent person currently alive. The eventual goal centers on the person with the disability defining his or her independence.
ASSESSMENT

Traditional Models

- Traditional assessment models have focused on the presence or absence of pathology. There are several reasons for this emphasis.

  1. Persons seeking professional help traditionally have done so to receive assistance in treating or solving problems. For example, people see physicians to treat or cure illness.

  2. Professional training and sanctioning that centers on pathology have driven models of practice. Medical specialties (e.g., neurosurgery, cardiology, rheumatology) have heavily concentrated on treating pathological conditions with relatively little emphasis on preventive and health maintaining specialties (e.g., family practice).

  3. Similarly, mental health training has focused, not on maintaining mental health but on treating mental illness.

  4. The focus on pathology has been driven, in great measure, financially. Funding has been institutionally based in places such as hospitals and nursing homes. Service providers have been paid only after diagnosing and treating pathology.

Limitations of Traditional Models

- By attending primarily to problems, assessments fail to account for individual strengths.

- A deficiency focus can lead to devaluing, and in some cases, dehumanizing people.

- The individual pathology focus also fails to recognize the complexity of experiences and relationships.

An Alternative Model of Assessment: Strength-Based

- Strengths encompass the knowledge and skills that an individual possesses (Saleebey, 1996).

- Potentials are the abilities that people can develop with sufficient resources.

- Persons including children can identify their own strengths.
• Sometimes professionals can help them identify strengths they may not perceive that they possess.

• With consumer direction, professionals can also consult to help people develop their potentials.

• The practitioner needs to recognize strengths from a cultural perspective.

• Cowger (1994) presents 12 principles of strength-based assessment that underlie the need for the human service practitioner to seek the perception of the person with whom they are working (Overhead 2):

  1. The individual’s understanding of the facts and issues is of first importance.

  2. The human service practitioner must believe in the credibility and ability of the person.

  3. Look for what the person wants. Do not bring into the assessment process preconceived notions and biases.

  4. Move the assessment into personal and environmental strengths.

  5. Look for strengths on a multidimensional level. Address individual, family, and community strengths.

  6. Use language that the person understands and relates to. The use of professional jargon should be avoided.

  7. Make the assessment process a combined effort. This should be easy if you believe in the person.

  8. Much related to the last principle, reach a mutual agreement on the assessment.

  9. Do not “blame the victim.” It is easy to make their “laziness” or their “dependency” the cause of the problem that needs to be addressed.

  10. Avoid cause and effect analysis in assessment. Humans are far too complex for the social worker to figure out the “cause.”

  11. “Assess; do not diagnose.” Diagnosis assumes pathology and dysfunction.

  12. See difference and uniqueness as strengths. Cultural diversity must be not only recognized but valued.

ETHNOGRAPHIC PERSPECTIVE:

- When working with people with disabilities, an ethnographic perspective is imperative.

- Green (1982) defines an ethnographic interview as one used to determine a description of the problem of the person who the practitioner is working with from that person’s worldview.

- The person with whom the practitioner is working with becomes the teacher, guiding the practitioner into an understanding of his or her world.

- The ethnographic interviewing process assumes that language becomes the bridge to the understanding of the various cultures that are a part of the service provision. Words have common meanings within a culture but their definitions are not known outside that culture although the word may be in use outside of the culture.

- The social worker must explore the words of the culture of disability to get an understanding of the person’s life view. In the case of children with disabilities, they may be called upon to teach the children and their families about the culture of disability.

- Language is a significant component of any culture. It is the media by which humans translate reality.

- Language symbolizes reality and therefore becomes a part of the cultural values of groups of people (Norlin & Chess, 1997).

- Until the conceptualization of disability culture, the language around disability reflected the stereotypes and oppression of persons with disabilities. Terms such as (Overhead 3):

  *handicapped, deaf and dumb, epileptic, retarded or retard, and the disabled or the handicapped*

  reflected how society viewed persons with disabilities.

- These terms tended to separate persons with disabilities from “normal” people. Words such as:
affected, 
crippled, 
stricken, 
victim of, 
confined to a wheelchair, 
unfortunate, 
and diseased

placed persons with disabilities in powerless positions (Blaska, 1993).

- The development of disability culture has resulted in a language shift regarding and used by persons with disabilities.

1. Persons with disabilities have replaced the term “handicap” with the term "persons or people with a disability." Not all persons with disabilities are handicapped. To use the term handicap assumes immediate limitation, placing the person automatically in a victim role.

2. Persons with disabilities who are aware of the culture of disability use the term “persons with disabilities” because the use of this phrase was a decision of the leadership in the Independent Living Movement. It was a chosen terminology rather than an imposed one (Shapiro, 1993).

3. Disability cultural language reflects its worldview. We are persons first. We are not our disability. Our disability is merely one characteristic of ourselves. Therefore:

  ✓ A person with seizure disorder is not an "epileptic,"

  ✓ A person with cerebral palsy is not a "spastic," and

  ✓ A person with a developmental disability is not "retarded." A person with a disability is a person first (La Forge, 1991).

4. Disability cultural language reflects the worldview that disability is a part of the normal, natural condition of human beings. We are not the disabled. We are persons first to be included with rightful status within the human family.

5. Disability cultural language reflects the cultural worldview that persons with disabilities are in control of their lives (Mackelprang & Salsgiver, 1999).

  ✓ We are not afflicted or stricken or diseased or a victim.

  ✓ We are not confined to a wheelchair. We are wheelchair users or, if you live in San Francisco, wheelchair riders.

6. As with some other minority groups, some persons within the disability community have adopted the very words historically used in their oppression in order to eliminate the power of these words. Many persons with disabilities, particularly those with a more radical perspective, refer to themselves and other people with disabilities as:

“crips,”
“cripples,”
“crippers,” or
“gimps.”

It is truly an inside language not to be used by persons who are able-bodied (Johnson, 1991). But these are terms social workers working with people with disabilities need to be aware of.

7. Another term used within disability culture is “tab” which stands for temporarily able-bodied. This term refers to people without disabilities. It reflects the view that all able-bodied persons will one day have a disability due to circumstances such as aging, accident, and illness.

8. Terms like “supercrip” refer to persons with disabilities who try to overcompensate for their disability by constantly proving themselves capable (Mackelprang & Salsgiver, 1999).

Discussion Question:

1. How likely will it be that a new family with a new child with a disability is going to be aware of a culture of disability?

2. How would this knowledge of disability culture and language be helpful in assessment with the family?

Many people with disabilities and particularly children with disabilities are not aware of their connection with other people or other children with disabilities. In fact, the social worker may find a desire, particularly with children and their families, to avoid connecting themselves with other children with disabilities. What the social worker may find are feelings of isolation with little hint of its origins. In the assessment process, the knowledge of disability culture may give the social worker clues to potential planning objectives. Also, the social worker’s knowledge of disability culture and the use of appropriate disability terms becomes a model for both the child with the disability and his or her family.

SOCIAL ASSESSMENT

- In the social/environmental component of assessment, it is important to recognize the many societal elements impacting persons with disabilities (Norlin & Chess, 1997).

1. It is important to assess the social environment on three levels: micro, mezzo and macro.

- **Micro**: Family level. What is the cultural/ethnic background of the family? How does that ethnic culture look at disability? What roles does the disabled child play in the family structure? What are the socio/economic characteristics of the family? How is family defined and how is family support defined? What are the family members’ responses to the child's disability? What resources does the family need?

- **Mezzo**: Organization and agency level. Mezzo level assessment is also important. The prudent social worker is aware that many "helping" agencies carry societal bias toward people with disabilities, particularly children with disabilities.

  - Effective mezzo assessment is concerned with the impact of social systems on people's lives and the impact people can have on those same systems.

  - Mezzo assessment can include health care organizations, churches, schools, social agencies, and businesses in which people may be employed. It is critical that influences of these systems are addressed in assessment.

- **Macro**: Macro level assessment accounts for societal structures and their impact on persons.

  - Macro assessment for persons with disabilities starts with an acknowledgment of power differences and social conditions that disempower them and make them vulnerable to abuse and devaluation (Sobsey, 1994).

  - Macro assessment evaluates the impact of social structures and institutions on people’s lives.

The empowerment model proposes three functions or areas of intervention for social workers working with persons with disabilities: (a) counselor, (b) teacher, and (c) political activist or advocate.

1. The functions of counselor and teacher manifest primarily at all three areas: micro, mezzo, and macro levels.
2. The function of political activist or advocate plays out primarily in the mezzo and macro arenas.

**The Social Worker as Counselor**

- The function of counselor is multifaceted and goes well beyond the traditional role of clinical psychotherapist.
- Practitioners increase the awareness of consumers to the oppression that persons with disabilities experience and how oppression can impact sense of self, self-esteem, and the ability to gain personal and political power. This oppression is very real for many children with disabilities, particularly when they begin to interact with other children although most will not be able to articulate it.
- Sometimes awareness of oppression lies buried and prevents people from developing the self-concept necessary for success defined in their terms. Self-concept needs to be impacted early with children with disabilities.

**Discussion Question:**

How would a social work practitioner approach a child and/or his or her family about the issue of oppression?

He or she wouldn't directly. The negative stereotypes of people with disabilities usually in one form or another results in discrimination. Discrimination manifests in many ways including inability to gain necessary resources. At these points of discrimination, the social worker offers a context for the family and the child. But most importantly, the players need to understand that it is not personal deficiencies but artificial barriers placed in front of them that's resulting in the nonattainment of goals. The energy must be placed in removing the artificial barriers not in self-degradation.

Sometimes the denial which allows persons with disabilities to survive and mature (Wright, 1960) also can become a hindrance when later attitudinal, social, and environmental factors begin to destroy the “reality” found in the denial. With children, some components of this denial must be allowed for a period of time.

The counseling role of the human service practitioner allows understanding of that process and helps the person with a disability understand him or herself in a positive light as a person with a disability.

Wright (1960) discusses the psychological phenomena in detail. The instructor may want to refer to this work in order to illuminate the above concept further. Basically, Wright contends that the process of denial allows children with disabilities to progress along standard developmental passages. Thus through the use of denial, children with disabilities may not perceive their limitations which allows them to conceptualize themselves as being no different than anyone else. In the author's life experience as a child with a disability, he pretended that his crutches were actually a horse and that when he was using his crutches, he was actually riding a horse.

The problem with this denial centers on when it is no longer functional. In the author's case, the denial continued into middle adulthood allowing him to make inappropriate decisions about living arrangements, job responsibilities, etc. Of course, his denial became more sophisticated as he grew older to the point where he did not conceptualize himself as a person with a disability even though he had a relatively severe disability.

Understanding of the impact of oppression on persons with disabilities is crucial to the counseling role of social work practitioners.

1. Sometimes counselors and consumers must explore the personal effects of this negativity and stereotyping.

2. It may be especially difficult when people explore the effects of these perceptions on how their family members, loved ones, and others perceived and treated them.

   ✓ For example, children with physical disabilities whose parents subject them to surgeries and other painful procedures as advised by health care providers may harbor a multitude of feelings. They may acknowledge their parents' love but harbor resentment toward them for unnecessary pain.

3. Children with disabilities may struggle to form a positive disability identity.

4. Children with disabilities may also need help in reestablishing and redefining relationships with family and friends.

- **When disabilities are acquired later in a child's life**, counselors can help consumers in a number of ways:
  
  1. They can provide therapy to help children and loved ones cope with adjustment and the personal loss many experience.

  2. They can help them and their families understand ableist societal attitudes and help them and their families develop new perspectives on disabilities. Often, **peer counselors** can fill this valuable role by exposing them to competent persons with disabilities who can guide them in dealing with devaluation and stereotyping.

  3. **Group counselors** can facilitate groups of persons with children with disabilities in coming together to share personal experiences and life stories. Interaction and sharing help develop disability identity and culture.

  4. **Resource counseling** is a role in which practitioners help counsel and teach children and families about community resources and how to utilize them.

  5. **Family counselors** can help children and their loved ones understand and cope with the ups and downs of life.

- **It is critical that counseling be consumer driven and that it focus on children's and families' strengths and potentials.**

**The Social Worker as Teacher/Consultant**

- A second major function in social work practice encompasses the role of teacher/consultant.

- The social worker teaches the child and family about only those areas which the consumer seeks to learn about.

- The teacher is a **consultant** rather than the educational **director**.

- Teaching by the social worker takes place in three areas: **(a) personal techniques of dealing with the results of oppression, (b) self-management and self-advocacy, and (c) political advocacy.**

**Personal Techniques in Dealing with the Results of Oppression:**

- The first step in helping overcome dependency and passivity is teaching the child and family about the societal forces imposing negative stereotypes, to incorporate

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disability into the definition of self, and to develop assertiveness. The level and intensity of this instruction depends upon the developmental level of the child. And family members can benefit from assertiveness techniques.

1. Assertiveness training is very relevant in working with children with disabilities and their families.

   ✓ It involves teaching about the dynamics of guilt and shame and developing assertive verbal and behavioral skills.

   ✓ Assertiveness techniques include the “broken record,” defusing potentially negative confrontation.

   ✓ The next step in teaching assertiveness is helping children and families modify their expectations, to acknowledge and demand their rights.

**Self-Management and Personal Advocacy:**

- The second area of teaching lies with self-management and self-advocacy.

1. The social worker teaches personal management skills to children with disabilities so they can manage their lives themselves. This is a joint learning endeavor with the family involved.

2. Teaching in self-management and advocacy may include peer education and support, transportation, attendant care, accessible housing, and personal and family advocacy.

   ✓ **Peer Education and Support**

     - The sharing of the disabled experience is crucial in the lives of children with disabilities and their families.

     - There are some experiences that can only be understood by another child with a disability and/or his or her family.

     - Children with disabilities can derive great benefit from contact with peer counselors, role models, and others with disabilities.

     - The social worker must first have the knowledge of neighborhood and community resources offering peer support and disability advocacy groups.

     - They may need to show children with disabilities and their families how to link with services, in person, by phone and/or electronically.

At times, the social worker may be called upon to broker links and services. The social worker needs to be extremely careful in this process **not to reinforce dependency** upon the part of the child or the child's family. To the degree possible, the child and the family need to be involved in the brokering process.

**Transportation**

- Self-advocacy may also entail teaching a person with a disability to use public transportation. Because of the issue of dependency and children with disabilities, this is an extremely important role for the social worker.

- If public transportation is not available, the social worker may have to help arrange alternative transportation but the family must be fully involved with this process.

- When accessible transportation is problematic, the social worker may need to teach the family how to begin the political process of pressuring local government and government transit agencies to develop accessible transportation.

**Attendant Care**

- Some children with disabilities need attendant care beyond what the parents can provide, particularly if both parents work.

- Families may need to be taught how to access attendants through independent living centers, local government agencies, or privately.

- Families may request training in how to manage personal attendants. Children with disabilities need to be involved in this process to the extent that their developmental level will allow.

- Attendant management training includes interviewing, hiring, training, and firing attendants.

- The social worker must be knowledgeable of **management issues and techniques** in order to teach them to children and family.

- Families may need education to avoid problems such as **physical abuse**.

**Accessible Housing**

- In most places in the country, wheelchair accessible housing is at a premium.

- This means that families with children with disabilities may need to modify existing housing or seek out accessible housing.
- The social worker may need to be aware of or have access to existing accessible housing options.
- The social worker may be able to help the family access private contractors who provide modification services.
- Just as with the issue of transportation, it may be necessary for the social worker to help the family advocate for the addition of accessible housing and the enforcement of existing codes and laws requiring wheelchair accessibility by both public housing entities and private builders. The child with the disability should be involved in this process as much as possible.

✔ **Personal Advocacy**

- **Personal advocacy is basically asserting and acquiring the things that the child and family need or desire.**
  - Becoming a self-advocate begins with an understanding of the impact of oppression and lack of opportunity.
  - Secondly, family members need to develop assertiveness skills.
  - The family members need to work within and without the agency or organization providing the services to achieve their goals.
  - At times, self-advocacy involves going outside existing social agencies and institutions. The family may seek legal solutions or redress to force institutions to meet needs.

**Political Advocacy**

- The final teaching role for the social worker centers on political advocacy.

  1. This process begins by the social work practitioner being knowledgeable of the various political undertakings and communicating the importance of political activity to the consumer.
  2. The second step involves helping family members access the local groups involved with political advocacy around disabilities.

✔ There are hundreds of these groups across the country; many accessible by the Internet.

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Many are connected with the hundreds of independent living centers across the United States.

3. Social work practitioners can teach families about the political decision making process and how to connect with local, state, and national political representatives.

4. Social workers can provide families with lists of the politicians who represent them and help family members access them.

5. Strategies, ranging from cooperation to confrontation, can be taught to the family.

- Family members can be taught how to use strategies such as testifying before legislative bodies, interviewing with the media, and political demonstration.

**The Social Worker as Political Advocate**

- Social workers must work at the macro and mezzo levels for political change around issues relating to persons with disabilities.

- Traditionally, however, there have been conflicts of interests between professions and communities of disability.

- These conflicts must be acknowledged.

- Professionals may need to acknowledge that political advocacy on behalf of persons with disabilities can have negative effects on their traditional professional roles.

- Social workers can join forces with disability-directed organizations and movements.

- Collaboration between professional organizations and these groups will increase trust and understanding as interdependence is fostered.

- Social workers must access politicians to support policies and programs which empower and promote the independence of persons with disabilities.

**Laws That Social Workers Working With Children With Disabilities Need to Know About**

- There are several key pieces of legislation that are important in understanding disability.

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The Social Security Act of 1935

- **Social Security Disability Insurance (SSDI).** Based upon the individual’s prior payments into Social Security, SSDI expanded coverage to all persons with disabilities. SSDI defined physical or mental disability in terms of the inability to hold any employment at any geographic location in the country.

- Three general categories of persons with disabilities qualify for receiving benefits under SSDI.
  1. These include (a) insured workers who become disabled for a year or more and who are under 65 years of age, (b) widows, widowers, or divorced wives between the ages of 50-59 who are persons with disabilities and meet the qualifications for widows’ or widowers’ benefits, and (c) the disabled sons and daughters of entitled workers.

- **Supplemental Security Income (SSI)** provides an income floor for persons with disabilities and the elderly.
  1. SSI is paid from the general revenues of the federal government. Some states supplement this minimum income from state funds.
  2. Generally, to qualify for SSI, an individual must have little or no income or resources and must be considered medically disabled.
  3. People must be unemployed or if employed, their earnings must be less than limits set each year by the Social Security Administration. These limits are called "substantial gainful activity."
  4. Eligibility for SSI is determined by the state and payments are administered by the Federal SSA.

- SSI eligibility is especially important because most SSI recipients qualify for **Medicaid coverage and services.**
  1. Medicaid provides health care for people who are poor, aged, or disabled.
  2. Persons with disabilities who qualify for SSI automatically qualify for Medicaid, which provides physician and hospital services including inpatient and outpatient hospital care, laboratory, and X-ray services. Medical services are reimbursed by the government. MediCal is California's form of Medicaid.
  3. **Medicare** is a hospital and medical insurance plan. The hospital insurance is compulsory and the medical insurance is voluntary.
4. Benefits under the hospital insurance include hospital services and limited skilled nursing home care and home health care services.

5. The supplemental medical insurance provides physician services and outpatient hospital care.

**The Rehabilitation Act of 1973**

- The Rehabilitation Act of 1973 mandated services and civil rights for persons with disabilities involved in federally funded programs.

- The act established the Rehabilitation Services Administration within the Department of Health and Human Services.

- It established the policy that the most severely disabled persons should receive priority in rehabilitation services.

- The Rehabilitation Act of 1973 established the rule that all consumers receiving rehabilitation services must have an individualized written rehabilitation program (IWRP) to ensure they had input into their services.

- The act also created the Architectural and Transportation Barriers Compliance Board to facilitate the elimination of architectural barriers in public places to persons with disabilities.

- The act funded a national center for the deaf-blind and increased funding to rehabilitation research.

- The 1978 amendments to the Rehabilitation Act of 1973 established the National Institute of Handicapped Research, now called the National Institute on Disability and Rehabilitation Research, which then established funding for independent living centers and funding for employer incentives to train and hire persons with disabilities.

- **Section 503** of the Rehabilitation Act of 1973 required entities contracting with the federal government in excess of $2,500 to establish affirmative action plans for persons with disabilities. Recently updated to contracts of $150,000 with firms of 150 or more employees, Section 503 requires an employer to initiate affirmative action for all employment openings including administration.

- **Section 504** of the Rehabilitation Act of 1973 guaranteed that employers contracting with the Federal government could not discriminate against persons with disabilities.
The Individuals with Disabilities Education Act (PL 101--467) (IDEA)

- IDEA stipulates that education be provided at public expense for all children including children with disabilities.

- The age range of those covered under IDEA includes 3-21.

- The education of children with disabilities should be provided in the most open and “normal” environment possible (least restrictive environment).

- When children need to be diagnosed, evaluated, and prescribed for, the diagnosis, evaluation, and prescription should not produce stigmatization and discrimination.

- Parents and the child need to be primary players in any remedial or pedagogical plan established for the child’s education.

- The Individual Education Program (IEP) is the central process in the education of a child with a disability.

- These plans should include the current level of education of the child, the goals and objectives of the child’s educational process, specific services needed and when they need to be provided, and the method by which the plan will be evaluated.

- The educational environment in which the child is to be educated is established in the IEP.

  1. The IEP process addresses whether or not a child with a disability is placed in a regular classroom or special education.

  2. A key determinate in this educational environmental placement is the degree of benefit of the student with a disability in interacting with nondisabled students and the potential disruption of other students, which in effect, would make it impossible to meet the educational needs of the student with the disability.

  3. The IEP must include the child, the parents, other individuals at the parents’ request, the student’s teacher, a school district representative, and other individuals at the school district’s request.

- IDEA mandates participating states to provide early intervention services to children with developmental disabilities from birth to their third birthday.

  1. The objective is to provide early intervention in the context of the child’s environment with maximum family involvement in the total care of the child with a disability.

2. The Individualized Family Service Plan (IFSP) is developed in a similar manner as the IEP.

- The child's parents and family play a crucial role.
- The IFSP team may include an advocate or person outside of the family at the parent's request.
- Other team members should include a service coordinator, the evaluations and assessment professional, and the service provider.
- Since the focus of the IFSP is both the child and the family, the IFSP may include services to the family, which will facilitate growth on the part of the child with a disability.
- As the child with a disability moves closer to the age of three, a plan of transition to Part B of IDEA or other preschool services should be included in the IFSP.

The Americans with Disabilities Act of 1990

- The ADA has five parts.

1. Title I addresses issues of discrimination in employment of persons with disabilities. It deals with the definition of disability, outlines reasonable accommodation in the workplace, defines undue hardship in not providing accommodation, and defines essential functions of the job.

2. Title II applies the ADA to public entities including public transportation. There are no funding limitations as with Section 504 of the 1973 Rehabilitation Act; all government activity is covered. Government agencies were required by the ADA to develop transition plans that assess physical barriers in the public entity's facilities and create a detailed plan to make the facilities accessible. Government agencies were required by the ADA to complete a self evaluation analyzing all services, policies, and practices to determine whether or not they comply with the ADA. Then a plan was to be formulated for bringing those things that did not comply with the ADA into compliance.

3. Title III brings the Civil Rights Act of 1964 and the Rehabilitation Act of 1973 into the private sector for persons with disabilities. Basically, it makes discrimination against persons with disabilities illegal in public accommodations and in commercial facilities. If services are provided, services must be made available to persons with disabilities. This includes children's services.

4. Title IV mandates the establishment of telecommunications relay services.

5. Title V contains several miscellaneous provisions and exclusions including alternate access to phone services.

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**Educational Activity:**

Divide the class into small groups from 4-7 members each. Distribute the case scenario (Appendix B, Module V Handout) and have the students read it. After about 10 minutes, ask the groups to answer the questions found on the handout as a group.

After the groups have completed the questions, call the class together and ask each group to discuss their answers.

1. What will your interview strategy be? What special considerations, if any, will you consider about the place and time of interview? What kinds of information will you be looking for? What kinds of questions will you be utilizing in order to glean that information?

The students need to address any special accommodations that Paul may need. Also, they need to determine whether or not they will focus on the complaints from the neighbors or look at other possible focal points. Finally, they need to see Paul as the primary source of information about himself and about what he wants.

2. What will your assessment strategy be? What kinds of information will you be looking for? From whom will you be requesting that information? How will you use the information?

Students in the assessment process need to focus on Paul's strengths and the barriers preventing him from utilizing the strengths.

3. What will your plan development and implementation strategy be? What roles will you utilize? What roles will Paul play? What roles will Paul’s family play?

Will the plan be a written contract? What parts will the social worker initiate? What parts will Paul initiate?

Students must recognize that all the players in Paul's life have roles. Also, all the roles described in the above model come into play. Counseling needs to take place; much teaching needs to take place; advocacy needs to take place. Depending upon the resources of the social worker's agency, many of these roles may have to be played out in other agencies with other service providers.

4. How will you evaluate whether or not the plan has been successful? Who will do the evaluation? How will you evaluate your practice? How will you change direction if you find the plan was ineffective?
A key compound here is the fact that Paul plays a very important role in determining whether the objectives of the plan have been completed.
ARC ORGANIZATIONS
"The Arc is the national organization of and for people with mental retardation and related disabilities and their families. It is devoted to promoting and improving supports and services for people with mental retardation and their families. The association also fosters research and education regarding the prevention of mental retardation in infants and young children" (http://www.TheArc.org/chapters.htm). Arc organizations are found in most larger communities. The organizations listed below are found on the Arc website noted above. Most Arc organizations offer employment training and employment. Many offer children's services and respite care for families.

Arc Riverside
8138 Mar Vista Court
Riverside, CA 92504-4324
Telephone: (909) 688-5141
Email: ArcRiverCA@aol.com

Parca (formerly the Peninsula Association for Retarded Children & Adults)
1650 South Amphlett Boulevard, Suite 213
San Mateo, CA 94402-2515
Telephone: (650) 312-0730
Fax: (650) 312-0737
Contact Us: parca@parca.org
Webmaster: chollen@parca.org

Desert Area Resources and Training
206 E. Ridgecrest Boulevard
Ridgecrest, CA 93555-3726
Telephone: (760) 375-9787
Fax: (760) 375-1288
Email: Phall@dartontarget.org
Web: www.dartontarget.org

The Arc of Alameda County
Facilities located throughout Alameda County, from Fremont to Berkeley, and Hayward to Pleasanton. For more information regarding ARC Alameda County Programs, please call: (510) 639-4680. Services: Work Activity Centers (also referred to as Production Centers)--facilities where clients receive individualized training (vocational, social, and personal development) that prepares them for transition into competitive and supported employment. Community Services--a program which provides competitive and supported employment in the form of

mobile work crews, enclaves, and individual placements within a wide range of businesses, such as nurseries, grounds maintenance, retail, and public institutions. The program also includes **Supportive Living Services**, where clients receive the support they need to live independently. Through this program, clients gain vocational and living independence, and the ability to meet job challenges. **S.C.O.P.E.**—a program designed to serve individuals with severe and profound disabilities. Program promotes domestic, vocational, recreation/leisure, and community access. **First Step Children's Center**—a program designed to serve children, 6 weeks old up to kindergarten age, who are experiencing developmental delays or have severe developmental disabilities.

**Marin County ARC**
18 Professional Center Parkway
San Rafael, CA 94903
Telephone: (415) 472-2373
Fax: (415) 472-5739
Email: marc@hooked.net
Web: Marinarc.org

**Services:** **Self-help skills training** in household management, grooming, nutrition, health, personal finances, and use of public transportation. **Group and individual counseling** to ensure that each client achieves his or her highest potential. **Support in acquiring social services and medical care.** **Instruction to prepare clients for independent living** in agency-supported apartments or with minimal supervision in their own homes in the general community. **24-hour supervised residential care** for mildly to profoundly disabled people living in nine agency-owned or leased homes. **Information and referral services** for other programs in the San Francisco Bay Area. **Education and awareness training** for the community.

**Ontario Pomona Association for Retarded Citizens**
OPARC is a non-profit organization located in the "Inland Empire" region of Southern California and dedicated to helping people with disabilities and their families. More than 400 adults with developmental and vocational disabilities utilize OPARC’s programs on a daily (Monday through Friday) basis. The Corporate office is in Montclair, California, with program facilities located in Montclair, Ontario, Upland, and Rancho Cucamonga.

**The Arc-South Bay in Gardena**
1735 W. Rosecrans
Gardena, CA 90249
Telephone: 310-532-6333
Fax: 310-532-0623
Email: arcsobay@lafn.org

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Orange County ARC  
225 Carl Karcher Way  
Anaheim, CA 92801  
Telephone: (714) 744-5301  
Fax: (714) 744-5312  
Services: Supported employment, community based, recreational, vocational, and foster family programs.

The Arc of San Diego  
9575 Aero Drive  
San Diego, CA 92123  
Telephone: (858) 715-3780  
Fax: (858) 715-3788  
Email: arcsandiego@msn.com  
Services: Employment training, community living, recreation, and respite family care.

Contra Costa Arc  
1340 Arnold Drive, Suite 127  
Martinez, CA 94553  
Telephone: 925-370-1818  
Fax: 925-370-2048  
Email: arcofcc@aol.com  
Web: Contracostaarc.org  
One of Contra Costa Arc’s programs is Lynn Center. Lynn Center provides an early intervention and preschool program for children 15 months to 5 years which begins with the concerns of the family. Programs include interventions and strategies that reflect a respect for racial, ethnic, and cultural diversity, as well as unique family differences. Lynn Center recognizes the family/professional partnership as the key to early intervention and preschool success. Some of the many services offered by Lynn Center include: family support, parent counseling, parent education, speech and language development, fine and gross motor development, sensory integration, social development, self-help skills development, play therapy, and transition support.

Foundation for the Retarded of the Desert  
73-255 Country Club Drive  
Palm Desert, CA 92260  
Telephone: (760) 346-1611  
Fax: (760) 773-0933

The Arc of Santa Maria Valley
2445 'A' Street
P.O. Box 1037
Santa Maria, CA 93456
Telephone: (805) 922-7381
Fax: (805) 922-9359
Email: vtc@utech.net

Arc Ventura County
5103 Walker Street
Ventura, California 93003
Telephone: (805) 650-8611
Fax: (805) 644-7308

STATE OF CALIFORNIA RESOURCES

UNITED STATES SENATORS

Honorable Dianne Feinstein (D)
United States Senate
331 Hart Senate Office Building
Washington, DC 20510-0504
Telephone: (202) 224-3841
Fax: (202) 228-3954
Email: senator@feinstein.senate.gov
Web: www.feinstein.senate.gov

Honorable Barbara Boxer (D)
United States Senate
112 Hart Senate Office Building
Washington, DC 20510-0505
Telephone: (202) 224-3553
Fax: (202) 228-0026
Email: senator@boxer.senate.gov
Web: www.senate.gov/~boxer

GOVERNOR

Gray Davis
Office of the Governor
State Capitol Building
Sacramento, CA 95814
Telephone: (916) 445-2841
Fax: (916) 445-4633
Email: graydavis@governor.ca.gov

STATE MENTAL HEALTH REPRESENTATIVE FOR CHILDREN & YOUTH

Dave Neilsen, Chief
California Department of Mental Health
Children and Family Services
1600 9th Street, Room 100
Sacramento, CA 95814
Telephone: (916) 654-2147
Email: dneilsen@dmhhq.state.ca.us
Web: www.dmh.cahwnet.gov

STATE MENTAL RETARDATION PROGRAM

Cliff Allenby, Director
Department of Developmental Services
Health & Human Services Agency
1600 9th Street, 2nd Floor
Sacramento, CA 95814
Telephone: (916) 654-1897
Email: callenby@dds.ca.gov
Web: www.dds.ca.gov

STATE DEVELOPMENTAL DISABILITIES PLANNING COUNCIL

Judy McDonald, Director
State Council on Developmental Disabilities
2000 "O" Street, Room 100
Sacramento, CA 95814
Telephone: (916) 322-8481
Web: www.scdd.ca.gov

PROTECTION AND ADVOCACY AGENCY

Catherine Blakemore, Executive Director
Protection & Advocacy, Inc.
100 Howe Avenue, Suite 185N
Sacramento, CA 95825
Telephone: (916) 488-9950
Toll-Free Telephone: (800) 776-5746 (In CA)
Email: legalmail@pai-ca.org
Web: www.pai-ca.org

CLIENT ASSISTANCE PROGRAM

Sheila Conlon Mentkowski, Chief
Client Assistance Program
2000 Evergreen Street, 2nd Floor
Sacramento, CA 95815
Telephone: (916) 263-7372
Toll-Free Telephone: (800) 952-5544
Email: smentkow@rehab.cahwnet.gov
Web: www.rehab.cahwnet.gov

PROGRAMS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Maridee Gregory, Chief
State Children’s Medical Services Branch
Department of Health Services
714 P Street, Room 350
Sacramento, CA 95814
Telephone: (916) 654-0832
Email: mgregory@dhs.ca.gov

PROGRAMS FOR CHILDREN AND YOUTH WHO ARE DEAF OR HARD OF HEARING

Fred Lewis, Chief
State Office of Deaf Access
Department of Social Services
744 P Street, MS 6-91
Sacramento, CA 95814
Telephone: (916) 653-8320
TTY: (916) 653-7651
Email: deaf.access@dss.ca.gov

STATE EDUCATION AGENCY RURAL REPRESENTATIVE

Ted Hawthorne, Consultant
Special Education Division
California Department of Education
515 L Street, Suite 270
Sacramento, CA 95814
Telephone: (916) 327-3505
Email: Thawthorn@cde.ca.gov

REGIONAL ADA TECHNICAL ASSISTANCE AGENCY

Erica Jones, Executive Director
Pacific DBTAC
Public Health Institute
2168 Shattuck Avenue, Suite 301
Berkeley, CA 94704-1307
Telephone: (510) 848-2980
TTY: (510) 848-1840
Toll Free Telephone: (800) 949-4232
E-mail: adatech@pdbtac.com
Web: www.pacdbtac.org

DISABILITY-SPECIFIC ORGANIZATIONS

Attention Deficit Disorder
To identify an ADD group in your state or locality, contact either:

Children and Adults with Attention-Deficit/Hyperactivity Disorder (CH.A.D.D.)
8181 Professional Place, Suite 201
Landover, MD 20785
Telephone: (301) 306-7070
Toll Free Telephone: (800) 233-4050 (Voice mail to request information packet)
Email: national@chadd.org
Web: www.chadd.org

National Attention Deficit Disorder Association (ADDA)
1788 Second Street, Suite 200
Highland Park, IL 60035
Telephone: (847) 432-ADDA
Fax: (847) 432-5874
Email: mail@add.org
Web: www.add.org

Autism
To identify an autism group in your state, contact:
Autism Society of America
7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814
Telephone: (301) 657-0881
Toll Free Telephone: (800) 3-AUTISM
Web: www.autism-society.org

Brain Injury
Claude Munday, President
Brain Injury Association of California
P.O. Box 160786
Sacramento, CA 95816-7305
Telephone: (916) 442-1710
Toll Free Telephone: (800) 457-2443
Email: csm4483@aol.com or biac@juno.com

Cerebral Palsy
Jo Gates, Executive Director
United Cerebral Palsy of Greater Sacramento
191 Lathrop Way, #N
Sacramento, CA 95815
Telephone: (916) 565-7700
Email: UCP@ucp.sacto.org
Web: www.UCPSacto.org

Epilepsy
Jackie Vella, Executive Director
Epilepsy Society of San Diego County
2055 El Cajon Boulevard
San Diego, CA 92104
Telephone: (619) 296-0161
Email: epilepsy@epilepsy-fnd-sd.org

Learning Disabilities
Betty G. Schiemenz, Administrative Director
Learning Disabilities Association of California
655 Lewelling Boulevard, #355
San Leandro, CA 94579
Telephone: (916) 725-7881
Email: office@ldaca.org
Web: www.ldaca.org

Mental Health
Rusty Selix, Executive Director
United Advocates for Children of California
1127 11th St , #830
Sacramento, CA 95814
P.O. Box 8900
Emeryville, CA 94662
Telephone: (510) 547-8754
Email: uacc@pacbell.net
Web: www.mhac.org

Mental Retardation
Laurie Shields, Executive Director
Arc California
1225 Eighth Street, Suite 590
Sacramento, CA 95814
Telephone: (916) 552-6619

Speech and Hearing
Robert Powell, J.D.
California Speech-Language-Hearing Association
825 University Avenue
Sacramento, CA 95825
Telephone: (916) 921-1568
Email: Rpowell@caspeechhearing.org
Web: www.caspeechhearing.org

Spina Bifida
Spina Bifida Association of Bay Area
P.O. Box 6015
Moraga, CA 94570
Telephone: (925) 210-6006

Spina Bifida Association of Greater San Diego
P.O. Box 232272
San Diego, CA 92193-2272
Telephone: (619) 491-9018

Visual Impairments
Gil Johnson, Director
American Foundation for the Blind-West
111 Pine Street, Suite 725
San Francisco, CA 94111
Telephone: (415) 392-4845
Email: sanfran@afb.net

UNIVERSITY AFFILIATED PROGRAMS

James T. McCracken, Director
University of California at Los Angeles, UAP
300 UCLA Medical Plaza, Suite 3310
Los Angeles, CA 90024-6967
Telephone: (310) 825-0470
E-mail: jmccracken@mednet.ucla.edu

Robert A. Jacobs, Director
Center for Child Development & DD
USC--University Affiliated Program
Children's Hospital Los Angeles
P. O. Box 54700, MS #53
Los Angeles, CA 90054-0700
Telephone: (323) 669-2300
E-mail: RJACOBS@chla.usc.edu

TECHNOLOGY-RELATED ASSISTANCE

Dennis Law, Project Coordinator
California Assistive Technology System
California Department of Rehabilitation
660 J Street, Suite 270
Sacramento, CA 95814
Telephone: (916) 263-8685 (Voice and TTY)
Toll Free Telephone: (800) 390-2699 (Voice and TTY, in CA)

PARENT TRAINING AND INFORMATION PROJECTS

Joan Tellefsen, Director
Team of Advocates for Special Kids (TASK)
100 West Cerritos Avenue
Anaheim, CA 92805
Telephone: (714) 533-8275
Email: taskca@aol.com

Jesse Coronel, Co-Director
Team of Advocates for Special Kids (TASK), San Diego
3750 Convoy Street, Suite 303
San Diego, CA 92111
Telephone: (858) 874-2386; (858) 874-2375
E-mail: tasksdl@aol.com

Mary Ellen Peterson, Chief Executive Officer
Northern California Coalition for Parent Training Information (NCC)
Parents Helping Parents
3041 Olcott Street
Santa Clara, CA 95054-3222
Telephone: (408) 727-5775
TTY: (408) 727-7655
Email: info@php.com
Web: www.php.com

Lois Jones, Director
Parents Helping Parents--San Francisco
594 Monterey Boulevard
San Francisco, CA 94127-2416
Telephone: (415) 841-8820
Email: sfphp@earthlink.com

Debbie Rowell, Executive Director
Exceptional Family Support Education and Advocacy Center
6402 Skyway
Paradise, CA 95969
Telephone: (530) 876-8321
Email: sea@sunset.net
Web: www.sea-center.org

Maryon Karian, Director
Exceptional Parents Unlimited
4440 North 1st Street
Fresno, CA 93726
Telephone: (559) 229-2000
Email: epu1@cybergate.com
Web: www.exceptionalparents.org

Diane Lipton
Disability Rights Education and Defense Fund, Inc. (DREDF)
2212 6th Street
Berkeley, CA 94710
Telephone: (510) 644-2555
Toll Free Telephone: (800) 466-4232
Email: dredf@dredf.org
Web: www.dredf.org

Deidre Hayden, Executive Director
MATRIX, A Parent Network & Resource Center
94 Galli Drive, Suite C
Novato, CA 94949
Telephone: (415) 884-3535
Toll Free Telephone: (800) 578-2592
Email: matrix@matrixparents.org
Web: www.matrixparents.org

Juno Duenas
Support for Families of Children with Disabilities
2601 Mission Street, Suite 710
San Francisco, CA 94110-3111
Telephone: (415) 282-7494
Email: sfcdmiss@aol.com

COMMUNITY PARENT RESOURCE CENTER
Theresa Cooper, Executive Director
Loving Your Disabled Child (LYDC)
4528 Crenshaw Boulevard.
Los Angeles, CA 90043
 Telephone: (323) 299-2925
Email: lydc@pacbell.net
Web: www.lydc.org

PARENT TEACHER ASSOCIATION (PTA)
Lavonne McBroom, President
California State PTA
930 Georgia Street
P.O. Box 15015
Los Angeles, CA 90015
Telephone: (213) 620-1100
Fax: (213) 620-1411
Email: ptacala@aol.com
Web: www.capta.org

OTHER DISABILITY ORGANIZATIONS

Susan Fisher, Executive Director
California Association of School Psychologists
1400 K Street, Suite 311
Sacramento, CA 95814
Telephone: (916) 444-1595
Email: memberservices@casponline.org
Web: www.casponline.org

Michael Pelfini, CEO/President
Easter Seals Bay Area
2757 Telegraph Avenue
Oakland, CA 94612
Telephone: (510) 835-2131
Email: mpelfini@esba.org
Web: www.esba.org

Ann Cirimele, Executive Director
Family Resource Network
5250 Claremont Avenue, Suite 235
Stockton, CA 95207
Telephone: (209) 472-3674
Toll Free Telephone: (800) 847-3030
Web: www.virtualstockton.com/families/home.htm

Christine Meinsen, Founder & Advocate
FOCUSED (For Our Children Under Stress with Educational Disabilities)
P.O. Box 417
Lakeside, CA 92040-0417
Telephone: (619) 390-HELP (4357)

Jan Schmidt, Board President
VSA (Very Special Arts) California
2800 North Main Street, Suite 2050
Santa Ana, CA 92705-6615
Telephone: (714) 835-8867
Email: vsacal@earthlink.net

CALIFORNIA CHILDREN SERVICES, DEPARTMENT OF MEDICAL SYSTEMS

CCS is a program that provides specialized medical care and rehabilitation for physically disabled children whose families are partially or wholly unable to provide for such services. Federal, state, and county tax funds finance the program. Family

enrollment fees supplement the program when applicable. The Civil Rights Act of 1964 governs CCS that rules that no person under the program may be discriminated against on the grounds of race, religion, color, or national origin. Payment covers only those services prior authorized by the program and will be made in accordance with CCS policies.

Wendy Schwartz, M.P.H. Program Chief Administrator
Samuel Yang, M.D. Medical Director
9616 Micron Avenue, Suite 640
Sacramento, CA 95827
Telephone: (916) 875-9900
Email: CCSMail@medsys.co.sacramento.ca.us
Web: http://medsys.co.sacramento.ca.us/ccs/index.htm

CCS ADDRESSES AND TELEPHONE NUMBERS

Department of Medical Systems, Case Management
9616 Micron Avenue, Suite 640
Sacramento, CA 95827
Telephone: (916) 875-9843
Program Coordinator
9616 Micron Avenue, Suite 640
Sacramento, CA 95827
Telephone: (916) 875-9900

Accounting
9616 Micron Avenue, Suite 850
Sacramento, CA 95827
Telephone: (916) 875-9766

Bowling Green Medical Therapy Unit
4211 Turnbridge Drive
Sacramento, CA 95827
Telephone: (916) 392-1480

Orchard Medical Therapy Unit
1040 Q Street
Rio Linda, CA 95673
Telephone: (916) 991-6063

Starr King Medical Therapy Unit
4848 Cottage Way
Carmichael, CA 95608
Telephone: (916) 485-8877
Fax: (916) 369-0639 or (916) 875-9784 for CCS Medical Case Management

INDEPENDENT LIVING CENTERS

One of the best resources for persons with disabilities is independent living centers which serve persons with all disability types. In many cases, they provide services that directly impact families and children with disabilities. A majority of the independent living centers offer attendant care registries, some form of peer counseling, accessible housing registries, and benefits advocacy. Many have special school programs for children and family counseling. Most services are free or based on a sliding scale. Centers are found in most areas of the state. If a particular center does not provide a service, they usually have access to an agency in the community or a nearby community that provides the needed service. Independent living centers are also an excellent place to find out the current happenings within a disability community and political and social connections locally, at the state level, and nationally around disability issues and services. The following is an alphabetical list of the independent living centers in the state of California taken from the Internet (http://www.cfilc.org/cgi-bin/lister.cgi). Some of the descriptions detail the services provided by particular centers.

Access Center of San Diego, Inc. (TASCD)
1295 University Avenue, Suite 10
San Diego, CA 92103
Telephone: (619) 293-3500
Fax: (619) 293-3508
TDD: (619) 293-7757
Executive Director: Bud Sayles
Email: budsayles@accesscentersd.org

The Center offers the following program services through its San Diego office as well as in North County: Financial Benefits Counseling: Mediation and assistance on behalf of individuals with disabilities who are seeking benefits and services from private and/or public agencies. Client Assistance Program: Assistance to individuals who are currently clients or who wish to become clients of the Department of Rehabilitation to obtain appropriate vocational training and services. Housing: Referral to emergency, temporary, and SRO shelters appropriate for disabled clients, maintenance of Section 8 Aftercare Certificate waiting list and process of certification of disability for such consumers. Assistance in applying for FEMA rental assistance and assistance in locating accessible/affordable living units. Personal Assistance Referral: Recruitment of individuals to assist persons who are disabled with personal care and housekeeping activities. Maintenance of registry of attendants and matching program between attendants and beneficiaries based on geographic location, type of care, and financial compensation. Independent Living Program: Coordination of services to aid individuals with disabilities to transition into the community and maintain an independent lifestyle. Employment Services: Prevocational training, job development, and employment referral/placement. Counseling and planning on how work will impact disability-related benefits. Information and Referral: Maintenance

of a reference library of disability-related information for public use, as well as responding to questions and making appropriate referrals with regard to disability-related issues. Peer Counseling: Provision of advice and support to disabled persons and their families who are coping with disability-related issues and problems. In addition to the above no-fee services, the Center operates The Spoke Shop, a small business enterprise for the sale and repair of durable medical equipment. The Center also offers ADA consulting services on a fee basis, as well as AccessTech, a program that offers assistive technology services for home or worksite modification to San Diego residents with disabilities.

Access Center of San Diego, Inc. North Branch (TASCD)
1562 Cherokee Street
San Marcos, CA
Telephone: (760) 591-9156
Fax: (760) 591-0171
TDD: (760) 591-0173
Executive Director: Bud Sayles
This is a branch office of the Center in San Diego.
Please note: After April 1, 2001 the center is moving to:
3355 Mission Avenue, Suite 131-132
Oceanside, CA 92054
The new telephone number is not yet available

Center for Independence of the Disabled, Inc. (CID)
875 O'Neill Avenue
Belmont, CA 94002
Telephone: (650) 595-0783
Fax: (650) 595-0261
TDD: (650) 595-0743
Executive Director: Kent Mickelson
Email: cidbelmont@aol.com
CID's Programs, from A to V: Accessibility Modification: Accessibility modifications such as ramps, grab bars, handrails, etc., are available. All modifications and installations are done by experienced professionals. Advocacy: When changes are needed to promote accessibility or provide services, for one person with a disability or thousands, CID assists in getting the need recognized and getting an appropriate response. Americans with Disabilities Act Consultation and Training: ADA consultation and training are available in all areas of the Act, including: Building Access Assessments, Public Accommodations, Employment, State and Local Government, etc. This service is available to individuals, groups, public and private agencies, businesses and community organizations. Personal Assistance Program: Attendants and Respite Workers are recruited and screened. Qualified applicants are listed on a roster available to consumers requesting this service. Client Assistance Program (CAP): Works with disabled clients, applicants,
or former clients (up to 1 year after case closure) of the Department of Rehabilitation, or other agencies funded under the Federal Rehabilitation Act. The program investigates complaints, negotiates settlements, represents consumers at administrative hearings and appeals, and informs consumers of their rights under the law. Will answer ADA questions. **Community Services:** CID conducts educational activities, (public speaking, workshops, sensitivity training, etc.) to promote an understanding of persons with disabilities and independent living. Experienced in working with public and private agencies, businesses, and community organizations. **Counseling and Peer Counseling:** CID offers help in overcoming emotional barriers to independence through individual, family and group counseling. Counseling is provided by peer and licensed professional counselors. **Financial Benefits Counseling:** Counseling, advocacy, information and referral, and explanation of rights regarding government benefits programs (e.g., Food Stamps, State Disability Insurance, Social Security, Supplemental Security Income, Medi-Cal) available to disabled consumers. **Independent Living Skills:** A registered Occupational Therapist (OT) provide evaluations and/or training to disabled/frail elderly consumers to increase or maintain independence in activities of daily living (personal care, household tasks, etc.) The OT also provides job, home & school site assessments, consultations for accessibility or modification requirements, assistance with medical and adaptive equipment needs, and training for homecare assistants and significant others. **Independent Living Skills First Step:** Counseling/training to gain the First Step towards further independence. Learn basic household skills, financial management, safety, social skills, effective communication, parenting, assertiveness, sexuality and problem solving. Services provided by an experienced professional. **Information and Referrals:** CID's Information and Referral specialist is available to assist anyone in need of material regarding disability and non-disability-related issues. Individuals requesting information or services not available through CID will be appropriately referred. **Shopping Assistance for Someone Who is Homebound (SASH):** SASH is a grocery shopping and delivery service for people of any age, with disabilities, who need a grocery shopping service due to disability-related limitations. **Volunteers in Money Management (VIMM):** CID recruits, trains, and supervises volunteers who help individuals with basic money management. VIMM volunteers visit assigned referrals at least once a month to help sort and pay bills, organize a simple bookkeeping system, and track health insurance claims. **Plan for Achieving Self-Support (PASS) Workshops:** CID offers the opportunity for consumers to advocate for themselves in achieving self-support. This seminar is offered once a month for the benefit of consumers who wish to learn how to write their own PASS Plan. This will enable the consumer to receive the funds necessary for employment, while receiving money from SSI and work. (The consumer must have an outside income and be on SSI in order to qualify for PASS). The workshop is led by CID staff.

**Center for Independence of the Disabled, Inc. North Branch (CID)**

355 Gellert Boulevard, Suite 256
Daly City, CA 94015

Telephone: (415) 991-5125
Fax: (415) 991-5182
Executive Director: Kent Mickelson
This is a branch office of the Center in Belmont.

Center for Independent Living (CIL)
2539 Telegraph Avenue
Berkeley, CA 94704
Telephone: (510) 841-4776
Fax: (510) 841-6168
TDD: (510) 848-3101
Executive Director: Jan Garrett
Email: cil@hooked.net

CIL Services: Personal Assistance Services (PAS): Prospective personal assistants are recruited, interviewed, and referred to disabled and elderly consumers who require personal assistance services. Personal assistants assist consumers in housekeeping and personal care needs that enable them to live more independently. Independent Living Skills (ILS): Peer counselors provide workshops, support groups, and individual instruction in basic independent living skills/care, pre-vocational counseling and training, and socialization skills. Consumers are also advised about home modifications and aids. Employment Services: Job seekers with disabilities receive assistance in identifying job goals and in gaining interviewing and resume writing skills. Consumers are instructed in job search techniques and receive job referral and follow-up counseling. A support group is also available for consumers seeking employment. Financial Benefits Counseling: Benefits services such as counseling, education, and referral are provided to consumers. This service addresses issues of public cash assistance, private and public health insurance, and work incentive programs. Housing: Housing counseling services are available to consumers who live in Berkeley and Oakland, and for persons with psychiatric disabilities who are also homeless within Alameda County. CIL housing staff helps consumers find and keep affordable and accessible housing. Housing staff provides information about rental assistance programs and resources for emergency move-in cases, utility discount programs, and benefits information concerning GA and SSI/SS. Housing staff also maintains current housing listings and contact with local property owners as well as make referrals to emergency shelters when necessary. CIL staff help consumers with disability rights related to housing by giving information about local, state, and federal fair housing laws, making referrals to legal agencies, assisting with writing letters to landlords and agencies, negotiating with property owners, and assisting with other steps related to housing needs. For low income consumers who live in Berkeley, California, CIL provides housing modifications such as construction of wheelchair ramps/lifts and minor interior modifications to consumers' homes. Peer Support Services: Counseling and peer support are provided to assist individuals, couples, families, and groups with disability-related issues. Consumers are provided support to assist with various aspects of disability as it affects their daily lives. Blind Services: CIL provides blind

and low vision consumers with individual peer counseling, support groups, independent living skills, reader referral, and information on aids and equipment. Canes and Braille paper are sold and specialized equipment is available for rent or use. Certification for Recordings for the Blind and Books On Tape is also available. **Deaf and Deaf/Blind Services:** Deaf and Deaf/Blind Services provides services to individuals who are deaf, hard of hearing, and deaf/blind. Services include peer counseling, sign language interpretation, translation of written correspondence from English to American Sign Language (ASL) communications, interpreting referral, advocacy, independent living skills training, information and referral, and pre-vocational counseling to help identify career goals. **Youth Services:** Youth Services provides an array of services to disabled youth ages 14 to 22 and their families including: individual and family counseling; parent workshops and support groups, Disability Awareness Trainings in the schools for non-disabled students; and technical assistance to regular classroom teachers in accommodating youth with disabilities. Summer activities include opportunities to meet with positive role models, socialization through special events, career exploration and summer job placement, and a youth support group. **Information and Referral:** Information about disability issues and referral to other agencies with services for people with disabilities are provided to the public and to CIL consumers. **Client Assistance Project (CAP):** CAP is a federally-mandated program initiated by the Rehabilitation Act of 1973. CAP was established by Congress to advocate for applicants, consumers, and former consumers of the Department of Rehabilitation and all programs funded under the Federal Rehabilitation Act. CAP staff assists consumers in understanding the Department of Rehabilitation requirements and services available, helps to resolve communication problems between consumers and the Department, informs consumers of their rights and responsibilities, and represents consumers at administrative reviews and hearings. **Client Enhancement and Empowerment Project (Client Choice):** Client Enhancement and Empowerment Project is a 5-year U.S. Department of Education project to demonstrate methods of increasing consumer choice in the rehabilitation process for people with disabilities. This project is designed to serve individuals who have been traditionally underserved by the vocational rehabilitation process, including ethnic minorities and people with limited English language skills who have significant disabilities.

**Center for Independent Living - Fresno (CIL)**  
3475 West Shaw Avenue, Suite 101  
Fresno, CA 93711  
Telephone: (209) 276-6777  
Fax: (559) 276-6778  
TDD: (559) 276-6779  
Executive Director: Janet Carmichael  
**Services:** Personal assistance services, peer counseling, housing referral and assistance, community education and systems advocacy, individual advocacy, financial benefits counseling, communication assistance services, independent living skills training, information and referral, disabled student transition program. **Contact**

Information: Speak to the Counselor of the Day (C.O.D.), who can provide information about and referral to the numerous CIL-Fresno services, as well as other community resources. Hours of Operation: Monday through Friday, 8:30 a.m. to 5:00 p.m.

Center for Independent Living - Oakland (CIL)
375 15th Street, Suite 218
Oakland, CA 94612-2708
Telephone: (510) 763-9999
Fax: (510) 763-4910
TDD: (510) 444-1837
Executive Director: Mike Donnelly
This is a branch office of the Center in Berkeley

Central Coast Center for Independent Living (CCCIL)
234 Capitol Street, Suite A,
Salinas, CA 93901
Telephone: (831) 757-2968
Fax: (831) 757-5549
TDD: (831) 757-2968
Executive Director: Elsa Quezada
Email: cccil@cccil.org

Services: CCCIL provides the following services which promote independent living: Information and Referral; Advocacy; Housing Assistance; Personal Assistance Services; Peer Counseling; Independent Living Skills Training; and Systems Advocacy, to persons with disabilities who live in the counties of Santa Cruz, Monterey and San Benito. Additionally, CCCIL runs the New Options Traumatic Brain Injury Project, one of four demonstration project sites in California. All CCCIL services are provided in English, Spanish, and American Sign Language.

Information and Referral: Information on a wide range of topics related to disability. CCCIL connects people to other sources which provide the services they are seeking, and provides information to community agencies about how they can make their services more accessible to people with a variety of disabilities. Advocacy: Assistance to persons with disabilities in gaining access to financial and medical benefits and other services for which they may be eligible. Housing Assistance: Self-advocacy training in how to look for accessible, affordable and available housing, and about removal of architectural barriers. Personal Assistance Services: Guidance regarding programs; rights and procedures; personal assistant recruitment, hiring, and management; and registry/referral information. Peer Support: Ongoing peer support activities, as well as guidance and encouragement provided by CCCIL staff with disabilities to assist persons with disabilities to develop, clarify, and achieve their independent living goals. Independent Living Skills Training: Workshops, networking meetings and individualized sessions to develop social and organizational skills needed to live more independently. Systems Advocacy: CCCIL’s Board, staff, and volunteers advocate with private and

governmental entities to increase access to community services, improve quality of services, increase availability of low-cost, accessible housing, and expand awareness of and compliance with legislation which protects the rights of people with disabilities. **New Options Traumatic Brain Injury Project**: Direct services, case coordination and central coordination of a Consortium of local agencies and organizations which provide services to survivors of TBI; supported employment services; development of needed services. **Office hours**: 8:30 a.m. - 5:00 p.m. Monday through Friday (12:30 p.m. - 1:30 p.m. closed for the lunch hour).

**Locations:**

**Central office**
234 Capitol Street, Suite A
Salinas, CA 93901
Telephone: (831) 757-2968
Fax: (831) 757-5549
Email: cccil@cccil.org
Contact person: Olivia Quezada, IL Program Manager

**Branch office**
1395 41st Avenue, Suite B
Capitola, CA 95010
Telephone: (831) 462-8720
Fax: (831) 462-8727
Email: cccilcap@cccil.org

**Central Coast Center for Independent Living San Benito Office (CIL)**
300 West Street
Hollister, CA 95024
Telephone: (831) 638-0826
Fax: (831) 638-1728
Executive Director: Elsa Quezada
This is a branch office of the Center in Salinas

**Central Coast Center for Independent Living Santa Cruz Office (CCIL)**
1395 41st Avenue, Suite B
Capitola, CA 95010
Telephone: (831) 462-8720
Fax: (831) 462-8727
Executive Director: Elsa Quezada
This is a branch office of the Center in Salinas

Community Access Center (CAC)
4960 Arlington Avenue, Suite C
Riverside, CA 92504
Telephone: (909) 637-6900
Fax: (909) 637-6906
TDD: (909) 637-6902
Executive Director: Lucille Walls

Advocacy: This office acts as an ombudsman for the rights of disabled people and assists in mediation with government and social service agencies. Attendant Registry: Recruitment and referral of personal care attendants to help with homemaking, shopping, driving and/or personal care; information about how to hire, train and manage attendants. Information & Referral: A clearinghouse of information and resources about services, products and activities in the community. Systemic Advocacy: The Community Access Center will work with Local and State organizations to promote change within systems, agencies, jurisdictions, etc.; implement strategies to increase availability and accessibility of services and resources; raise public awareness and create opportunities for people with disabilities. Peer Support: Peer support for people with disabilities and their families by others who share similar experiences. Communications: Interpreters may be scheduled through Dayle McIntosh Center's sign language interpreter service. To request a sign language interpreter, please call (909) 682-6579. Housing Assistance: Help in locating affordable rental units through housing referrals; advice to landlords and property owners regarding housing modification. For More Information, call weekdays from 9 a.m. - 5 p.m. Telephone: (909) 682-0230, TDD: (909) 682-0232, Fax: (909) 682-5224. Appointments are recommended. While Community Access Center welcomes any individual with disability-related concerns, it is best to make an appointment beforehand. If sign language assistance is needed for the interview, please mention this when making the appointment.

Community Rehabilitation Services (CRS)
4716 Cesar E. Chavez Ave. Bldg A
Los Angeles, CA 90022
Telephone: (323) 266-0453
Fax: (323) 266-7992
TDD: (323) 266-3016
Executive Director: Al Rivera
Email: crsela@icnt.net

Any person who is 18 years of age or more with a physical, sensory, mental/emotional or developmental disability can work with us to become more self-sufficient. Our intake procedures provide an orientation to the staff, facilities, and services at CRS. Information and Referral: Knowledge of local resources and services is vital for persons with disabilities to remain active and involved. We have a Resource Center to provide direct access to information and telephone assistance as well. Our Newest Services: We now have staff members who speak Chinese (Mandarin and Cantonese) and Korean as well as many staff members who speak

Spanish and English. Inclusion of people from all cultures is very important to us at CRS. Persons with hearing disabilities now have access to staff members trained in American Sign Language. Our interpreter registry can be used by community businesses and organizations. CRS is proud to offer **Job Club services** for persons with disabilities in three locations: El Monte, East Los Angeles and San Gabriel. The Job Club program provides support and information to people with disabilities who are ready to search for employment.

**Community Rehabilitation Services Downtown Office (CRS)**
3325 Wilshire Boulevard, Suite 850
Los Angeles, CA 90010
Telephone: (213) 427-9090
Fax: (213) 427-0172
TDD: (213) 427-0173
Executive Director: Al Rivera
This is a branch office of the Center in Los Angeles
Branch/Site Manager/Coordinator: Yolanda Ramirez, Director

**Community Rehabilitation Services San Gabriel Office (CRS)**
844 E. Mission Drive
San Gabriel, CA 91776
Telephone: (626) 614-1570
Fax: (626) 614-1590
TDD: (626) 614-1591
Executive Director: Al Rivera
This is a branch office of the Center in Los Angeles
Branch/Site Manager/Coordinator: Pat Torres, Director

**Community Rehabilitation Services, Inc. (CRS)**
980 N. Fair Oaks, Room 16-17
Pasadena, CA 91103
Telephone: (626) 794-9860
Fax: (626) 794-9884
Executive Director: Al Rivera
E-Mail: crspas@pacbell.net
This is a branch office of the Center of East Los Angeles.
Branch/Site Manager/Coordinator: Alicia Espinoza, Manager

**Community Resources for Independence (CRI)**
980 Hopper Avenue
Santa Rosa, CA 95403
Telephone: (707) 528-2745
Fax: (707) 528-9477
TDD: (707) 528-2151
Executive Director: Mike Humphrey

Here's how CRI can help: **Benefits Advocacy**: issues with SSI (Supplemental Security Income) or SSDI (Social Security Disability Insurance), Medi-Cal, in-Home Supportive Services (IHSS). **Communications**: sign language and Spanish interpreters at work, at school, doctors, emergencies. **Housing**: help finding affordable and accessible housing and modifications if required. **Independent Living Skills**: task management training (money, shopping, self-care) and other trainings as requested. **Information and Referral**: support groups, adaptive equipment, publications, the Americans With Disabilities Act (ADA) and much more. **Peer Support**: training for volunteers who will share experiences, knowledge, skills with individuals and groups requesting peer support. **Personal Assistants**: referrals to individuals who help with daily living activities, attendant management skills training, recruitment and orientation for attendants. **Systems Advocacy & Community Education**: bringing about changes in our community that promote full inclusion for all persons with disabilities.

**Community Resources for Independence Ft. Bragg Office (CRI)**
310 East Redwood Lane
Ft. Bragg, CA 95437
Telephone: (707) 964-6714
Fax: (707) 961-1761
TDD: (707) 964-2599
Executive Director: Mike Humphrey
This is a branch office of the Center in Santa Rosa.
Branch/Manager/Coordinator: Mike Johnson

**Community Resources for Independence Napa Office (CRI)**
1040 Main Street, Suite 301
Napa, CA 94559
Telephone: (707) 258-0270
Fax: (707) 258-0275
TDD: (707) 258-0274
Executive Director: Mike Humphrey
This is a branch office of the Center in Santa Rosa.
Branch/Manager/Coordinator: Tim Fallis

**Community Resources for Independence Ukiah Office (CRI)**
1040 N. State Street, Suite E
Ukiah, CA 95482-3414
Telephone: (707) 463-8875
Fax: (707) 463-8878
TDD: (707) 463-4498
Executive Director: Mike Humphrey
This is a branch office of the Center in Santa Rosa.
Branch/Manager/Coordinator: Tanner Silver

Community Resources for Independent Living (CRIL)
439 A Street
Hayward, CA 94541
Telephone: (510) 881-5743
Fax: (510) 881-1593
TDD: (510) 881-0218
Executive Director: Jack Chapman
Email: CrilSvc4u@aol.com

Core services include: Resources to find accessible and affordable housing, personal care assistant registry and resources, independent living skills training, information & referral to community resources, peer support—both individually and in groups, and advocacy—both individual and systems. Other programs and services may include: Pre-employment skills, workshops, financial benefits counseling, resources and information on home modification for accessibility, job resource board, youth training programs, active participation in the community to change attitudes about people with disabilities, Activities to remove barriers to full participation in the community, and voter's registration.

Dayle McIntosh Center for the Disabled (DMC)
150 West Cerritos, Building 4
Anaheim, CA 92805
Telephone: (714) 772-8285
Fax: (714) 772-8292
TDD: (714) 772-8366
Executive Director: Margaret Drda

Directory of Programs and Services. Advocacy: DMC acts as an ombudsman for the rights of individuals with disabilities and assists in mediation with government and social service agencies. Americans with Disabilities Act Consultation. Attendant Registry: Recruitment and referral of potential employees to help with homemaking, shopping, driving and/or personal care; training in attendant management. Client Assistance Program (CAP): A state-mandated service, advocates work to resolve differences and liaison between the Department of Rehabilitation and people receiving services from the Department. The Clubhouse: People with Traumatic Head Injury and similar disabilities participate interactively in a model community to restore social and vocational skills. Located in Anaheim, the Clubhouse is completely member-run and ideal for those transitioning from medical rehab into the community. Communications: Hearing and visually impaired individuals receive assistance through sign language interpreters, readers, transcription services and the provision of alternate format material. Also serves Long Beach/Los Angeles County and Riverside. COMMEND (Communication Medical Emergency Network for the Deaf): Links deaf people experiencing health crises with hospital emergency rooms through interpreter services. Community Living Program: One-to-one independent living training for adults with disabilities who have the ability and desire to live in their community with some additional assistance. Counseling: Professional counseling and peer support help individuals,

families, and groups to cope with disability-related problems. **Equipment Loan:** Wheelchairs, walkers and other equipment may be borrowed free of charge for people who are newly injured or in need of temporary equipment. **Emergency Services:** DMC operates a fully accessible, six-bed temporary shelter called HEARTH in Garden Grove for homeless people with disabilities. The Center also provides financial assistance and non-perishable food to those who qualify based on need. **Housing Assistance:** Help in locating accessible rental units through housing referrals; advice to landlords and property owners on housing modification. **Information and Referral:** A clearinghouse of information concerning disabilities and related resources and programs is available to the public. **Independent Living Skills Training:** Classroom work in sign language and basic academics, along with instruction in practical skills needed for self-sufficiency and employment, for people who need help with cognitive and communication skills; special emphasis on people with hearing impairments. **Mature Adult Blind Services:** Offers mature adults with visual impairments one-to-one independent living skills training to enhance their self-sufficiency in their own homes or relevant community setting.

**Dayle McIntosh Center for the Disabled**
Laguna Niguel Office (DMC)
27782 El Lazo, Suite 100
Laguna Niguel, CA 92677
Telephone: (949) 643-7275
Fax: (949) 643-7284
TDD: (949) 643-7282
This is a branch office of the Center in Anaheim.

**Disability Resources Agency for Independent Living (DRAIL)**
221 McHenry Avenue
Modesto, CA 95354
Telephone: (209) 521-7260
Fax: (209) 521-4763
TDD: (209) 521-1425
Executive Director: Dwight Bateman
Email: dwight@drail.org

**Services Include:** **Information and Referral:** The dissemination of information and/or referrals on current services and resources for persons with disabilities regarding employment, transportation, support groups, adaptive aids and equipment and/or supplies, education, counseling, accessibility public awareness, Civil Rights information under the Americans with Disability Act (ADA) and other related information. **Care Provider Referrals:** Provides a referral list of potential care providers. Assist persons with disabilities with finding appropriate care providers. Train employers with disabilities and consumers in interviewing, supervision, assertiveness techniques and understanding one’s own specialized needs. **Housing Referrals:** Provides information, education, outreach, and advocacy on accessible housing. Consultation with government agencies, housing

management companies, landlords and non-profit housing providers. Assist consumer with locating low-income accessible housing and provide support for developing these skills. **Advocacy:** Action by an individual or group in support of a cause, ideal, or policy to effect change, advance a cause, raise public awareness. Action to achieve these goals may take the form of demonstration, lobbying for legislative change, conducting educational activities, or organizing others. Teach consumers how to gain access to services, benefits, and to understand their civil rights which may have been denied or are endangered. **Individual Advocacy:** Action on behalf of, for, and, most importantly, with an individual. Focuses on providing training, information, referral, and intervention with individuals. An effective individual advocate seeks to help people develop knowledge and skills for effective future advocacy activities. **Systems Advocacy:** Develops a partnership between the ILC and the consumer working to create change within a system, agency, jurisdiction, etc; implementing broad base strategies to increase availability and accessibility of services and resources and creating equal opportunities for independent living for large numbers of people. **Peer Advising:** Provides to the consumer peer counseling designed from personal life experiences that would deal with disability related issues, such as socialization, emotional adjustment, accessing resources and family related. **Peer Support Volunteer Training:** Volunteers with disabilities trained as Peer Counselors to provide one on one support to consumers, their friends and families. **Volunteer Services:** Opportunities for community involvement in program services fund raising and special projects; gain new skills and work experience. **Independent Living Skills:** Consultation and training on an individual or workshop basis to acquire practical daily living skills for home and community accessibility, includes use of adaptive aids or equipment, local transportation system, and management of other community resources. **Benefits Counseling:** Provides benefits counseling to consumers and their families about their rights and responsibilities involving possible or actual benefits, and individual and or group counseling to obtain these benefits. **Disability Awareness Sensitivity Training:** Provides training to the community and other organizations in the area of employment, interaction and the civil rights of people with disabilities. **Americans with Disability Act (ADA) Technical Assistance & Evaluation:** Provides on site assessment and evaluation to public and private organization to assist in complying with the ADA. **Motor Voter Registration:** Offers the opportunity to persons with disabilities the option of becoming a registered voter and to assist if requested.
Disability Resources Agency for Independent Living (Motherlode ILC) (DRAIL)
67 Rinelberg Street
Sonora, CA 95370
Telephone: (209) 532-0963
Fax: (209) 532-0963
TDD: (209) 532-0963
Executive Director: Dwight Bateman
This is a branch office of the Center in Modesto
Branch/Site Manager/Coordinator: Barry Smith

Disabled Resources Center, Inc. (DRC)
2750 E. Spring Street, #100
Long Beach, CA 90806
Telephone: (562) 427-1000
Fax: (562) 427-2027
TDD: (562) 427-1366
Executive Director: Jeanette Nishikawa

DRC Services: Attendant Registry: Screens and refers personal care attendants to persons with disabilities who require assistance. Consumers are matched with their attendants to provide the most effective care. Without this service, many persons with disabilities would be at risk of institutional living. Benefits Counseling & Advocacy: Assists people with disabilities seeking public benefits to which they are entitled such as Social Security Administration, Department of Rehabilitation and other benefit providers. Representation at Fair Hearings for Benefits Denial
Community Advocacy. Housing: Housing search-assistance, information on rental practices, listing of rentals and property management companies, homeless/crisis assistance. Peer Counseling Services: Paraprofessional counseling, peer support groups, workshops on topics related to disability, peer counseling training program
Information & Referral Requests: For information about services, products, and community resources of interest to people with disabilities, their families, professionals, and others. Independent Living Services (ILS): Teach people with disabilities needed skills for optimum Independent Living (Life Skills), includes budgeting, transportation, employer skills, pre-employment training, self-care, etc. Community Outreach: Outreach, information, and referral for the unserved and underserved people with disabilities living in the cities of Lakewood, Artesia, Downey, Signal Hill, Hawaiian Gardens, Avalon and Long Beach. Linkage of people with disabilities to appropriate services. Volunteer Services: Many opportunities exist for community involvement in program services, fund-raising, special projects, development of new skills, and work experience.

Foundation of Resources for Equality and Employment for the Disabled (FREED)
154 Hughes Road, Suite 1
Grass Valley, CA 95945
Telephone: (530) 272-1732
Fax: (530) 272-7793
TDD: (530) 272-1732
Executive Director: Ann Angeria
Headquartered in Nevada County, but serving Yuba, Sutter, Sierra, and Colusa Counties. Core services: Housing assistance, independent living skills, individual and systems advocacy, information and referral, peer support, personal assistance referral. Special programs include: Americans with Disabilities Act consultations, fix-it program (minor home repairs for seniors and people with disabilities), senior companions, self-advocacy training, Yuba/Sutter Community Development Project, California Assistive Technology System (CATS) Database Management, and host site for Nevada County Community Network's Senior Internet Docent Program.

FREED Marysville Office
508 J Street
Marysville, CA 95901
Telephone: (916) 742-4474
Fax: (916) 742-4476
Executive Director: Tony Sauer
This is a branch office of the Center in Grass Valley.
Branch/Site Manager/Coordinator: Tonya Rhoades

Humboldt Access Project (HAP)
955 Myrtle Avenue
Eureka, CA 95501
Telephone: (707) 445-8404
Fax: (707) 445-9751
TDD: (707) 445-8404
Executive Director: Gay Larsen
Email: hap@northcoast.com

Independent Living Center of Kern County (ILCKC)
1631 30th Street
Bakersfield, CA 93301
Telephone: (661) 325-1063
Fax: (661) 325-6702
TDD: (661) 325-4143
Toll Free Telephone: (800) 529-9541
Executive Director: Juanda Ridgway
Email: ilckc@ilcofkerncounty.org
Hours: 8:00 a.m.-5:00 p.m., Monday–Friday.

The Independent Living Center of Kern County provides the following services: Individual Advocacy: helping consumers learn and develop self-advocacy skills, provide assistance with the resolution of conflicts that impede service delivery, investigation of discrimination claims, and dissemination of information regarding entitlement programs. Systems Advocacy: efforts to affect positive change in laws and programs affecting people with disabilities to ensure access, quality life, and independence for all people with disabilities. Peer Counseling: support for individuals and their families who are struggling with disability-related issues and problems. Personal Assistant Referral: provision of viable personal care options for individuals with disabilities, develops skills and knowledge in interviewing, hiring, management and self-evaluation of a personal assistant, interpreters, readers, and drivers, and a registry of persons looking for assistants is maintained. Housing Referral and Assistance: provides assistance in locating affordable, accessible housing in the community and advocates with landlords and realty companies. Information and Referral: provision of relevant information and resource referral to consumers and the general public regarding activities and services that are available in the community. Independent Living Skills Training: provides group or one-on-one training and demonstrated techniques that will enable persons with disabilities to achieve a higher degree of self-reliance in their everyday lives. These include money management, mobility, nutritional, homemaking, cooking, education, communication skills, etc. Cross Disability Peer Counseling: assistance and support designed to increase skills and knowledge with interpersonal, family, social, financial, and interagency services that bring increased trust and a reduction of isolation. Services other than core services: Emergency food and shelter referrals, equipment loans, client assistance program (CAP), pre-employment training, and social programs.

Independent Living Center of Southern California (ILCSC)
14407 Gilmore Street
Van Nuys, CA 91401
Telephone: (818) 785-6934
Fax: (818) 785-0330
TDD: (818) 785-7097
Executive Director: Norma Vescovo
Email: ilcsc@aol.com

Independent Living Center of Southern California Lancaster Office (ILCSC)
356 B East Avenue, K-4
Lancaster, CA 93535
Telephone: (661) 945-6602
Fax: (661) 945-5690
TDD: (661) 945-6604
Executive Director: Norma Vescovo
Branch/Site Manager/Coordinator: Kurt Baldwin
This is a branch office of the Center in Van Nuys.

Independent Living Resource Center (ILRC)
649 Mission Street
San Francisco, CA 94105
Telephone: (415) 543-6222
Fax: (415) 543-6318
TDD: (415) 543-6698
Executive Director: Kathy Uhl

Services: Peer Counseling/Peer Counselor Training: ILRC's peer counselors are people with disabilities, trained to provide counseling and support to individuals having difficulty adjusting to the disability-related challenges they encounter. Potential peer counselors are evaluated and provided with intensive training. ILRC has peer counselors at its offices on Tenth Street, R.K. Davies Hospital, San Francisco General Hospital, and at several community programs. Personal Assistance Services: Many people with disabilities employ personal assistants to assist them with a variety of activities such as personal care, household maintenance, communicating and accessing information. ILRC not only matches people with potential personal assistants, but also provides counseling and training on how to manage assistants. Independent Living Skills Training: Living independently as a person with a disability requires special skills and strategies to deal effectively with physical, societal, and system-based barriers. ILRC provides training and guidance so individuals who have a disability can achieve maximum potential for living independently in the community. Employment-Related Services: Many people with disabilities want to work but are frustrated by the obstacles they face when seeking employment. ILRC's employment services provides workshops and counseling to assist people with disabilities to explore the personal, professional, and financial aspects of going to work. Housing Services: ILRC's housing services works with consumers who have disabilities to understand their rights and responsibilities as tenants. Education and informational services are provided to building owners to help them understand their rights and responsibilities to provide fair housing for people with disabilities. Information and Referral: Individuals with disabilities, family members, and others can contact ILRC to find out where to go for particular services, how to deal with public agencies, where to find assistive technology, or what to do if disability-related discrimination occurs. Individual and Systems Advocacy: ILRC acts as an advocate for individuals who experience disability-related barriers or discrimination, and also serves in an advocacy role to promote needed systems and community change so people with disabilities have full access to services, physical structures, and activities. Programs: Pathways to Independence: Provides needed services as identified by the consumer to travel the road to independence and meet the many challenges of having a disability. Services include independent living skills training, personal assistant services, housing services, peer counseling, information & referral services and advocacy. Access to Employment: Explores the implications of pursuing a career for a

person with a disability. Financial benefits, health, time management, self-esteem, impact on relationships, and self-employment are covered in workshops and one-on-one sessions. **Services for Deaf and Hearing Impaired Persons:** Culturally appropriate and disability specific services are provided in American Sign Language and English, with attention paid to the particular needs of late-deafened adults. **Mission Outreach Program:** Services and advocacy are provided in Spanish and in a culturally appropriate manner to consumers with disabilities who are members of San Francisco’s Latino Community and who use Spanish as their primary mode of communication. Program staff is bilingual, bicultural service professionals who have disabilities. **Chinatown Outreach Program:** Services and advocacy are available in Chinese and are provided in a culturally sensitive manner. Program staff is bilingual, bicultural service professionals who have disabilities, which enhances their ability to assist Chinese-speaking consumers to effectively access community and governmental services and other community organizations.

**Independent Living Resource Center Santa Barbara Office (ILRC)**
423 W. Victoria Street
Santa Barbara, CA 93101
Telephone: (805) 963-0595
TDD: (805) 963-8265
Fax: (805) 963-1350
VP-200: (805) 963-0595 or 207.71.193.185
Client Assistance Program (CAP) Direct line ~ Toll-Free (888) 963-0595 or (805) 884-8423. Both numbers are Voice or Text (TTY/TDD). Open Monday – Friday, 9 a.m. – Noon and 1 p.m. – 5 p.m.

**Independent Living Resource Center Santa Maria Office (ILRC)**
327 East Plaza Drive #3A
Santa Maria, CA 93454
Telephone: (805) 925-0015
Fax: (805) 349-2416
TDD: (805) 925-0015
Executive Director: Jo Black
This is a branch office of the Center in Santa Barbara
Branch/Site Manager/Coordinator: Mandelena Nieto

**Independent Living Resource Center Ventura Office (ILRC)**
1802 Eastman Avenue, Suite 112
Ventura, CA 93003
Telephone: (805) 650-5993
Fax: (805) 650-9278
TDD: (805) 650-5993
Executive Director: Jo Black

Independent Living Resource Programs and Services: Individual and Systems Advocacy & Benefits Services. We assist with the following areas of concern: Social Security Disability Insurance (SSDI), Supplemental Security Income (SSI), Veterans Benefits, Medi-Cal, Medicare, Workers Compensation, State Disability Insurance, Education/Special Education, Transportation, Housing. Personal Assistant Referral & Training: Services include a registry of screened personal assistants who provide care for people with disabilities and the frail elderly residents of Contra Costa and Solano Counties. We provide training for both the employee (personal assistant) and employer (consumer) to improve their skills and working relationship. ILR is a member of the In-Home Supportive Services Task Force for the improvement of in-home personal assistant services. If you are interested in volunteering to assist with advocacy efforts to improve these services please call ILR. Housing Referral Services: Assists consumers by maintaining a registry of accessible, adaptable, affordable apartments and houses. We provide training on how to adapt a living environment to a disabled individual's needs, and assistance on obtaining low income housing subsidies. We offer training on becoming a self advocate in relating to landlord/tenant conflict resolution and negotiation. Information and Referral Services: We provide community resources information on subjects requested by individuals with disabilities, as well as non-disabled members of the community. Using an office computer database, current referrals are made which offer the fullest possible information and assistance. Peer Counseling: Peer counseling is available to disabled consumers and their families and friends. It is offered on a group or individual basis and is intended to assist individuals to cope with various issues, including communication, disability awareness and sensitivity, and other independent living skills. Independent Living Skills Training: Services are offered on a group or individual basis to assist consumers with daily living skills, including resource (money) management and informing consumers regarding adaptive technology. Pre-Employment Counseling: Services include counseling to consumers interested in entering the job market. Counseling is provided in resume writing, interviewing skills, and researching the job market. We provide information regarding the rights and responsibilities of both employers and employees and technical assistance on issues surrounding adaptive technology. ADA/ACCESS—Assistive Technology: Services on consultation include all titles of the American with Disabilities Act (ADA). We provide individual services as well as group

presentations on accessibility issues. Our ADA-trained staff is able to consult for a nominal fee. We also have an extensive library on Technical Assistive Devices and can provide information on a variety of equipment. **Empowerment Team Leaders:** The empowerment team leaders organize and train individuals within the community to become a unifying force regarding disability related issues. **Sign Language and Bi-Lingual Services:** These services are provided with written information in alternative formats.

**Branch Office ILR Locations:**

**Solano County Branch Office**
1545 Webster Street, Suite. C
Fairfield, CA 94533
Telephone: (707) 435-8174
Fax: (707) 435-8177
TDD: (707) 435-8174
Monday-Friday, 9:00 a.m. - 5:00 p.m.
Branch/Site Manager/Coordinator: Bill Pelter

**East Contra Costa County Office**
301 West 10th Street
Antioch, CA 94509
Telephone and TTY: (510) 754-0539
Tuesday-Friday, 9:00 a.m. - 5:00 p.m.

**West Contra Costa County Office**
402 Harbour Way
Richmond, CA 94806
Telephone and TTY: (510) 232-4942
Tuesday-Friday, 9:00 a.m. - 5:00 p.m.

**South Solano County**
575 Sacramento Street
Vallejo, CA 94590
Telephone: (707) 643-1797 by appointment

**Independent Living Services of Northern California (ILSNC)**
1161 East Avenue
Chico, CA 95926-1847
Telephone: (530) 893-8527
Fax: (530) 893-8574
TDD: (530) 893-8527
Executive Director: Rocky Burks
Email: ilsnc@maxinet.com

Marin Center for Independent Living (CIL)
710 Fourth Street
San Rafael, CA 94901
Telephone: (415) 459-6245
Fax: (415) 459-7047
TDD: (415) 459-7027
Executive Director: Bob Roberts
Email: bob@ihss.org

Marin-CIL Services: Personal Assistance Services: Attendants work with seniors and people with disabilities in their homes assisting in a wide range of services including housework, daily chores; such as shopping, driving to medical appointments and providing personal assistance with tasks like dressing and bathing. Marin-CIL interviews all workers for HCCM attendant data base. Housing: Assistance in finding affordable/accessible housing, helping find funds for moving costs etc. Access Modification: Installation of ramps, grab bars, and other access modifications to make housing accessible. Advocacy: Works to train self-advocacy skills or find mediation or refer to legal counsel to resolve physical and programmatic access issues. Works with students and parents to assure schools provide full and equal access for all students. Employment: The Job Match program finds jobs from wood splitting to entry level bookkeeping. Benefits: Assist people on SSI and SSDI to achieve their education and employment plans. The Employment Benefit Program: Works with consumers of the department of Rehabilitation to assist them through the testing, training, and job placement process. Drug and Alcohol Recovery: Works with people in recovery or who have the goal of achieving recovery with life skills and money management. SSI Rep. Payee: Marin-CIL is the financial counselor for people with drug and alcohol and mental illness disabilities. We assist them to better manage their money and learn self-reliance and money management skills. Loans-to-Independence: Allows people who are able to work and would rather not take charity to repay a "loan" to repay the charitable institutions which would otherwise give the money as charity to Marin-CIL consumers by arranging jobs through the Marin CIL Job Match Program. (Any other Non-profit or church is welcome to become a part of Loans to Independence to help their employable consumers build self-reliance. Please call Bob Roberts at Marin-CIL if your agency is interested in more information.) Home Care Consortium of Marin: is a group of agencies dedicated to promote and improve affordable, quality home.
attendant services to Marin County residents. The Division on Aging, The Division of Social Services, Marin Center for Independent Living, Senior Access, and West Marin Senior Services work collaboratively to train, screen, and refer quality home attendants to support, foster, and ensure the independence of the older adult and person with disabilities. All screening of workers is done by Marin-CIL staff. **Low Vision Clinic of Marin:** Marin-CIL hosts the Low Vision Clinic of Marin. The Clinic screens test and refers people with vision loss to appropriate low vision aides which assist them in their daily activities. These aids may include, magnifying devices, special lighting, as well as referral to appropriate agencies which provide instructions in the skills necessary to live in the world with reduced vision. Fee-based service, services provided by licensed ophthalmologists. **Peer Counseling:** Assist people with developing strategies to cope with their disabilities and developing independence. People receive support in one-on-one counseling sessions or in supportive group environments. Alcohol and drug recovery counseling is offered individually and in groups. The agency sponsors a Sobriety meeting geared to address the concerns of people with disabilities. **Advocacy and Public Education:** Works to increase public understanding of people with disabilities, community resources available, existing and proposed legislation and the impacts on individuals and the community. **Advocacy and System Change:** Working with Disability Rights Advocates, an Oakland California Law firm. **Benefits Counseling:** Assist people to identify locate and obtain public and private benefits and resources for which they may be eligible. This includes instruction in working through difficult bureaucracies to obtain SSI, SSDI, MediCal and General Assistance. Assistance may also be provided in completing the extensive application forms required. **Drug and Alcohol Services:** Recovery related information and referral and short-term counseling is offered to people with disabilities. A Representative Payee Program is administered to assist people mandated to have a payee manage their funds. For more information visit www.marincil.org

**Placer Independent Resource Services (PIRS)**
11768 Atwood Road, Suite 29
Auburn, CA 95603
Telephone: (530) 885-6100
Fax: (530) 885-3032
TDD: (530) 885-0326
Executive Director: Tink Miller
Email: tmiller@pirs.org

**Personal Assistant Referral:** PIRS maintains a registry of screened applicants for referral to be employed in-home by persons with disabilities. Consumers are trained in interviewing, hiring, and supervision skills. **Housing and Transportation Coordination Assistance:** PIRS advocates for affordable and accessible housing and assists consumers in locating such housing. Consultations for home and business modifications are offered. PIRS advocates for changes in transportation to better meet the varied needs of people with disabilities. **Information and Referral:** PIRS provides basic information about issues and community resources relating to

people with disabilities, including employment, benefits, accessibility, medical information, public awareness, among others. **Independent Living Skills Training:** PIRS enhances the ability to live independently, at home, and in the community. In self-advocacy training, consumers learn how to access services, benefits and other rights, as well as practical day-to-day living skills. **Peer Support:** PIRS provides support for individuals and their families who are experiencing disability-related difficulties, either in a group or one-on-one. **Individual and Systems Advocacy:** PIRS assists people to obtain services from various agencies and advocates for systems changes to remove any barriers which may inhibit access. **Peer Support Group:** Every Wednesday from 1:00-2:30 P.M. Come share concerns, experiences, support, and information with other people with disabilities. **New Dawn:** Every Thursday from 2:00-4:00 P.M. Support for people with depression. Call (916) 663-9449 to register for **Deaf Awareness Workshop:** Every Thursday from 10:30-11:30 A.M. (Please call to confirm attendance.) Attend Sign Language Class and ADA Awareness sessions. **Communication Advocacy Meeting:** Second Thursday of every month from 11:30 A.M.-12:30 P.M. (Please call to confirm schedule.) **Training for People with Disabilities Self Advocacy Training:** learn how to get started.

- What are your rights?
- What are your responsibilities?
- How can you write effective letters?
- How can you make effective phone calls?
- Why should you keep a record of your activities?

**Resources for Independent Living (RIL)**

1211 H Street, Suite B
Sacramento, CA 95814
Telephone: (916) 446-3074
Fax: (916) 446-2443
TDD: (916) 446-3074
Executive Director: Frances Gracechild
Email: ril@sna.com

**Rolling Start, Inc. (RSI)**

570 West 4th Street, Suite 103
San Bernardino, CA 92401
Telephone: (909) 884-2129
Fax: (909) 386-7446
TDD: (909) 884-7396
Executive Director: Frances Bates

**Services Offered:** Personal Assistance Referral, Systems and Individuals Advocacy, Independent Living Skills Training, Information and Referral, Housing Assistance, Cross Disability Peer Support, Helpline Program, ADA Technical Assistance, Community Workshops, Interpreter Services, Benefits Counseling

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San Joaquin Independent Living Center (SJILC)
4555 Precissi Lane, Suite 2
Stockton, CA 95207
Telephone: (209) 477-8143
Fax: (209) 477-7730
TDD: (209) 477-7734
Executive Director: Dwight Bateman
This is a branch office of the Center in Modesto
Branch/Site Manager/Coordinator: Dino Wallen

Service Center for Independent Living (SCIL)
109 South Spring Street
Claremont, CA 91711
Telephone: (909) 621-6722
Fax: (909) 445-0727
TDD: (909) 445-0726
Executive Director: Carol Lane
Email: scilclmt@tstonramp.com

**Operating Hours:** Monday - Friday 9:00 a.m. - 12:00 noon, and 1:00 p.m. - 5:00 p.m.

**Services:**
- **Advocacy:** The SCIL advocacy program includes both individual and systems advocacy. SCIL assists consumers in obtaining their correct government benefits. The Advocate also provides representation in administrative proceedings or informal negotiations before other agencies on complaints of discrimination. SCIL will also advise employers and public entities of their responsibilities under the ADA and assist local cities in acquiring consumer input and reasonable goals in developing and implementing their ADA transition plans.
- **Attendant Care:** SCIL recruits and maintains an up-to-date registry of attendants that consumers may interview and hire to perform non-medical services. Full-time, part-time, or live-in attendants assist in the home with personal care, housekeeping duties, transfers, meal preparation and feeding, or as a companion, where supervision by a nurse or physician is not required.
- **Communications:** The communications component provides assistance to consumers with sensory impairments. It includes a referral program of sign-language interpreters for job interviews, doctor appointments, and any other situation requiring communication between Deaf or Hard of Hearing signers and hearing persons who are not fluent in sign language. Additionally, SCIL assists hearing impaired persons on a walk-in basis with a variety of needs such as interpreting mail and filling out various applications.
- **Community Outreach:** SCIL staff, board, and volunteers regularly give presentations to schools, community centers, and service organizations and participate in local community events as part of SCIL’s commitment to increase community awareness of disability and disability-related issues.
- **Housing Assistance:** The SCIL housing program maintains a housing registry and provides referrals to consumers for low income housing within the San Gabriel/Inland Valley. Consumers can apply through SCIL to the Los Angeles County Aftercare Program for long-term housing assistance.

**Independent Living Skills:** Independent living

skills training is available to assist consumers in learning to master a whole array of skills necessary to live independently. Some of these are nutrition, cooking, cleaning, budgeting, banking, problem solving, hiring and managing an attendant/employee, negotiating terms, and asserting oneself. These are skills people with disabilities must learn in order to retain control over decisions and live in their own home. **Information and Referral:** In the past year, SCIL staff and volunteers answered over 6,000 requests for information or referral. SCIL maintains a resource file on a wide range of disability issues and services available throughout the San Gabriel/Inland Valley cities. **Newsletter:** "Out and About" provides valuable information to persons with disabilities about benefits, services, and other disability issues. Recipients receive information about available SCIL services, recent accomplishments, and community resources. Over 3,500 copies of the quarterly newsletter are distributed to community agencies, consumers, and supporters of SCIL. **Peer Counseling:** SCIL provides individual peer counseling by telephone and in person to help people cope with stresses frequently encountered. Specific strategies are developed which address successful employment, continuing relationships, and an independent lifestyle.

**Service Center for Independent Living Covina Office (SCIL)**
963 West Badillo Street, Covina, CA 91722
Telephone: 626-967-0995
Toll Free Telephone: 1 (800) 491-6722
Fax: 626-967-3132
TDD: 626-967-4401
Executive Director: Carol Lane
Email: scilcovn@tstonramp.com
This is a branch office of the Center in Claremont
Branch/Site Manager/Coordinator: Christie MacDonald

**Silicon Valley Independent Living Center (SVILC—formerly AIDC)**
2306 Zanker Road
San Jose, CA 95131
Telephone: (408) 985-1243
Fax: (408) 985-0671
TDD: (408) 985-9243
Executive Director: Cheryl Cairns

**Services:** As a consumer-governed human services agency, SVILC provides a variety of independent living support services and programs to enhance the self-reliance of individuals with disabilities: Vocational Counseling, Job Preparation and Job Placement, PASS Writing & Benefits Counseling, Computer Skill Training, Personal, Family and Group Therapy, Peer Counseling, Neuro-Psychological Assessments, Vocational Occupational Therapy, American Sign Language Interpretation, Residential and Group Independent Living Skills Training, Legal Assistance, Housing Services, Personal Assistant Services, Therapeutic Recreation Services, Equipment Rental & Loan, and Information and Referral.

Silicon Valley Independent Living Center (SVILC--formerly AIDC)
7415 Eigleberry Street, Suite C
Gilroy, CA 95020
Telephone: (408) 847-1805
Fax: (408) 847-5595
TDD: (408) 847-1845
Executive Director: Cheryl Cairns
This is a branch office of the Center in San Jose.
Branch/Site Manager/Coordinator: Bertha Morreira

Southern California Rehabilitation Services (SCRS)
7830 Quill Drive, Suite D
Downey, CA 90242
Telephone: (562) 862-6531
Fax: (562) 923-5274
TDD: (562) 869-0931
Executive Director: Mary Rios
Email: scrsmary@aol.com

Peer Counseling and Support Groups: One-on-one peer counseling services are provided to any consumer. Peer counseling covers issues related to disabilities. Support groups for persons with a disability and support groups for family members are held twice per month. Presentations from service providers cover topics such as: adaptive driving, wheelchair repair, sexuality, self-defense, and more. Independent Living Skills Instruction: Instruction in areas such as managing a bank account, enrolling in college or other classes, personal care, and more is offered to any consumer. Each individual develops his or her own plan depending on specific needs and situations. In-Home Attendant Registry Referral: Many qualified in-home attendants register to assist persons with disabilities and seniors in their homes through SECIIL. Attendants assist with shopping, cleaning, personal care, and more, depending on specific needs. Benefits Advocacy: Applying for financial programs such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medi-Cal, and Medicare can be confusing and frustrating. SECIIL offers a full range of assistance in this area, from filling out the paperwork to providing representation at hearings. Housing Assistance: Assistance with filling out the paperwork and seeing through Section 8 Aftercare program is available to anyone needing this service. A list of available housing in the area is provided when needed. Referrals to homeless shelters and accessible apartments are also available. Community/Systems Advocacy: To assure that the voices of people with disabilities are heard, community education and advocacy is essential. SCRS contacts local policymakers, businesses, schools, churches, and more to get the word out about the needs and contributions of individuals with disabilities. Americans with Disabilities Act (ADA) and Disability Sensitivity Training: SCRS provides employers, community groups, and others with presentations on the ADA and training. Disability Sensitivity Training helps undo some myths held by many individuals surrounding disabilities in general. These presentations help

explain terms and conditions in a non-threatening manner. Presentations can be tailored to fit the needs of any group. **Southern California Project With Industry (SCPWI):** SCPWI assists job-ready consumers from the California State Department of Rehabilitation in finding jobs. Consumers receive training in job hunting, resume preparation, interview skills, negotiating job offers, and sometimes, on-the-job training. Each consumer gets individual attention from a job developer.

**Westside Center for Independent Living (WCIL)**
12901 Venice Boulevard
West Los Angeles, CA 90066
Telephone: (310) 390-3611
Fax: (310) 390-4906
TDD: (310) 398-2204
Executive Director: Mary Ann Jones
Email: wcil@wcil.org

**Benefits Advocacy:** Experienced staff provide information, referral, intervention and representation for people who are having difficulties with benefits programs that serve people with disabilities and seniors, including the Department of Rehabilitation, Social Security Administration, In-Home Support Services, General Relief, and MediCal. **Community Advocacy:** WCIL consumers are assisted in developing self-advocacy skills to assert their rights under the Americans with Disabilities Act (ADA) and other civil rights protection. Staff members advise and assist people with disabilities and seniors to eliminate practices and barriers that prohibit access and inclusion in the community. **Housing Advocacy:** WCIL Advocates provide information, education, outreach, and advocacy in support of consumers who are having problems locating accessible housing. Advocates act as liaisons with government agencies, housing management companies, landlords, and non-profit housing providers. **Employment Services:** WCIL is committed to providing people with disabilities and seniors the opportunity to achieve financial independence and personal fulfillment through competitive employment. **Hispanic Employment Services (HES):** Bilingual staff provides counseling, training, and job placement opportunities to Spanish-speaking people with disabilities and seniors who are looking for work. Services include a 6-week job strategies training course, personal counseling, and individual placement assistance. The HES Advisory Council includes Hispanic business leaders, government agency representatives, and other concerned volunteers who act as advisors, assisting with job placement. **Computer Training Project (CTP):** This rigorous program is designed to train people with disabilities and seniors as computer specialists. Successful graduates of the 1-month programming course qualify as entry-level programmers. The 7-month PC Specialist course trains students in data entry and word processing for database career positions. A Business Advisory Council of executives, from major Southern California companies design coursework, assist with student selection and evaluation, provide student mentors, and actively hire students when their coursework is completed. The project also offers job placement services to people with disabilities having marketable skills in non-computer fields. **Peer Counseling:**

Peer counseling is designed to support the emotional needs of people with disabilities and seniors. Consumers learn to deal with the problems of personal and social adjustment, social skills, and inter-personal relationships. Services include individual, family, and group counseling. **Personal Assistance Services:** WCIL provides referrals of personal assistants who perform personal care/homemaking services. WCIL also provides information to help people successfully employ personal assistants. An emergency referral hotline is always available. Visit the Westside Center for Independent Living Website! (http://www.wcil.org)

**NATIONAL INFORMATION CENTER FOR CHILDREN AND YOUTH WITH DISABILITIES**

NICHCY is the national information and referral center that provides information on disabilities and disability-related issues for families, educators, and other professionals regarding children and youth from birth to age 22. Visit the web site (http://www.nichcy.org). NICHCY provides information and makes referrals in areas related to: specific disabilities, early intervention, special education and related services, individualized education programs, family issues, disability organizations, professional associations, education rights, and transition to adult life.

NICHCY
P.O. Box 1492
Washington, DC 20013
Telephone or TTY: (202) 884-8200
Toll Free Telephone or TTY: 1 (800) 695-0285
Fax: (202) 884-8441
Email: nichcy@aed.org
Web: www.nichcy.org

NICHCY’s services include: **Personal Responses to Specific Questions:** 1-800-695-0285, or email nichcy@aed.org. **NICHCY Publications:** NICHCY makes available a wide variety of publications, including fact sheets on specific disabilities, state resource sheets, parent guides, bibliographies, and our issue papers, "News Digest" and "Transition Summary." Most publications can be printed off the internet. Documents may be requested in print. Publications are also available in alternative formats upon request. **Referrals to Other Organizations and Sources of Help:** Connections can be made with disability organizations, parent groups, and professional associations at the state and national level. **Information Searches of Databases and Library:** NICHCY can provide an information search to your unique needs and concerns. Materials are also available in Spanish, on disk, and as camera-ready originals.

**Regional Centers:** The Department of Developmental Services is responsible for designing and coordinating a wide array of services for California residents with developmental disabilities. These services are provided through a statewide system of 21 locally-based regional centers. Regional centers are nonprofit private corporations that have offices throughout California to provide a local resource to

help find and access the many services available to individuals with developmental disabilities and their families. Both geographic accessibility and population density were considered when selecting locations for the 21 regional centers. The catchment area boundaries for the regional centers conform to county boundaries or groups of counties, except in Los Angeles County, which is divided into seven areas, each served by a regional center. Website: http://www.dds. cahwnet.gov/regctrs/main/rclist.cfm

**Alta California Regional Center** serves the counties of Alpine, Colusa, El Dorado, Nevada, Placer, Sacramento, Sierra, Sutter, Yolo, and Yuba.

2135 Butano Drive  
Sacramento, CA 95825  
Telephone: (916) 614-0400  
TDD: (916) 924-0645  
Fax: (916) 929-1036  
Director: James F. Huyck  
Web site: www.altaregional.org

**Field Offices**

Auburn  
560 Wall Street, Suite B  
Auburn, CA 95603  
Telephone: (530) 885-8447  
Fax: (530) 885-9148

South Lake Tahoe  
2489 Lake Tahoe Boulevard.  
South Lake Tahoe, CA 96150  
Telephone: (530) 542-0442  
Fax: (530) 542-3436

Grass Valley  
908 Taylorville Road, Suite 101  
Grass Valley, CA 95949  
Telephone: (530) 272-4231  
Fax: (530) 272-4637

Woodland  
250 West Main Street, Suite100  
Woodland, CA 95695  
Telephone: (530) 666-3391  
Fax: (530) 666-3831

Placerville  
344 Placerville Drive, Suite 1  
Placerville, CA 95667  
Telephone: (530) 626-1353  
Fax: (530) 626-0162

Yuba City  
1506 Star Drive  
Yuba City, CA 95993  
Telephone: (530) 674-3070  
Fax: (530) 674-7228

Roseville  
807 Douglas Boulevard  
Roseville, CA 95678  
Telephone: (916) 786-8110  
Fax: (916) 786-0621

Central Valley Regional Center serves the counties of Fresno, Kings, Madera, Mariposa, Merced, and Tulare.

5168 North Blythe Avenue
Fresno, CA 93722
Telephone: (559) 276-4300
Fax: (559) 276-4360
Director: David Reister
Web site: www.cvrc.org

Field Offices

Merced
676 Loughborough Drive, Suite A
Merced, CA 95348-2601
Telephone: (209) 723-4245
Fax: (209) 723-2442

Visalia
1945 East Nobel Avenue
Visalia, CA 93292-1516
Telephone: (559) 738-2200
Fax: (559) 738-2265

Regional Center of the East Bay serves Alameda and Contra Costa counties.

7677 Oakport Street, Suite 1200
Oakland, CA 94621
Telephone: (510) 383-1200
TDD: (510) 383-1206
Fax: (510) 633-5020
Director: Elian Howe
Web site: www.rceb.org

Field Office

Contra Costa County
2151 Salvio Street, Suite 365
Concord, CA 94520
Telephone: (925) 798-3001
Fax: (925) 674-8001

Eastern Los Angeles Regional Center serves the health districts of Alhambra, East Los Angeles, Northeast, and Whittier within the county of Los Angeles.

1000 South Fremont Avenue
Alhambra, CA 91802
Telephone: (626) 299-4700
Fax: (626) 281-1163
Director: Gloria Wong

Field Office

Whittier
13215 Penn Street, Suite 410
Whittier, CA 90602-1718
Telephone: (562) 693-0146
Fax: (562) 693-0158

Frank D. Lanterman Regional Center serves the health districts of Central, Glendale, Hollywood-Wilshire, and Pasadena within the county of Los Angeles.

3303 Wilshire Boulevard, Suite 700
Los Angeles, CA 90010
Telephone: (213) 383-1300
Fax: (213) 383-6526
Director: Diane Campbell Anand
Web site: www.lanterman.org

Far Northern Regional Center serves the counties of Butte, Glenn, Lassen, Modoc, Plumas, Shasta, Siskiyou, Tehama, and Trinity.

1900 Churn Creek Road, Suite 319
Redding, CA 96002
Telephone: (530) 222-4791
Fax: (530) 222-8908
Director: Laura Larson
Web site: members@aol.com/fnrc

Field Offices

Chico
1377 East Lassen Avenue
Chico, CA 95926-1381
Telephone: (530) 895-8633
Fax: (530) 895-1501

Shasta
421 Chestnut Street
Mt. Shasta, CA 96067
Telephone: (530) 926-6496
Fax: (530) 926-6499

Susanville
170 Russell Avenue, #H
Susanville, CA 96130-4216
Telephone: (530) 257-5317
Fax: (530) 257-5526

Golden Gate Regional Center serves the counties of Marin, San Francisco, and San Mateo.

120 Howard Street, Third Floor
San Francisco, CA 94105
Telephone: (415) 546-9222
Fax: (415) 546-9203
Director: J. F. Gaillard
Web site: www.ggrc.com

Field Offices

San Mateo
3130 La Selva Drive, Suite 202
San Mateo, CA 94403
Telephone: (650) 574-9232
Fax: (650) 522-8901

Marin
5725 Paradise Drive
Building A, Suite 100
Corte Madera, CA 94925
Telephone: (415) 945-1600
Fax: (415) 945-1630

Harbor Regional Center serves the health districts of Bellflower, Harbor, Long Beach, and Torrance within the city of Los Angeles.

Del Amo Business Plaza
21231 Hawthorne Boulevard
Torrance, CA 90503
Telephone: (310) 540-1711
Fax: (310) 540-9538
Director: Patricia Del Monico
Web site: www.hddf.com

Inland Regional Center serves the counties of Riverside and San Bernardino.

674 Brier Drive
San Bernardino, CA 92408
Telephone: (909) 890-3000
Fax: (909) 890-3001
Director: Verlin Woolley
Web site: www.inlandrc.org

Field Offices

San Bernardino
1855 Business Center Drive
San Bernardino, CA 92408
Telephone: (909) 890-4700
Fax: (909) 890-4709

Ontario
3602 Inland Empire Boulevard, C-100
Ontario, CA 91764
Telephone: (909) 481-4720
Fax: (909) 481-4815

Riverside
4361 Latham Street
Riverside, CA 92501
Telephone: (909) 826-2600
Fax: (909) 826-2609

Kern Regional Center serves the counties of Inyo, Kern, and Mono.

3200 North Sillect Avenue
Bakersfield, CA 93308
Telephone: (661) 327-8531
Fax: (661) 324-5060
Director: Michael C. Clark
Web site: www.kernrc.org

Field Offices

Bishop
819 North Barlow Lane
Bishop, CA 93514
Telephone: (760) 873-7411
Fax: (760) 873-5435

Lamont
10501 Main Street
Lamont, CA 93241
Telephone: (661) 845-2286
Fax: (661) 845-2287

Ridgecrest
815 North Downs, Suite A
Ridgecrest, CA 93555
Telephone: (760) 375-9512
Fax: (760) 375-1271

Taft
29 Emmons Park Drive
Taft, CA 93268
Telephone: (661) 765-7294
Fax: (661) 765-1468

Tehachapi
21030 Mission Street, Suite A
Tehachapi, CA 93561
Telephone: (661) 822-1288
Fax: (661) 822-1286

Shafter
428 James Street, Suite 5
Shafter, CA 93263
Telephone: (661) 746-3918
Fax: (661) 746-1468

North Bay Regional Center serves the counties of Napa, Solano, and Sonoma.

10 Executive Court
Napa, CA 94558
Telephone: (707) 256-1100
TDD: (707) 257-0213
Fax: (707) 256-1112
Director: Nancy Gardner
Web site: www.nbrc.net

Field Office

Santa Rosa
2351 Mendocino Avenue
Santa Rosa, CA 94503
Telephone: (707) 569-2000
Fax: (707) 542-9727

North Los Angeles County Regional Center serves the health districts of East Valley, San Fernando, and West Valley within the city of Los Angeles.

15400 Sherman Way, Suite 170
Van Nuys, CA 91406-4211
Telephone: (818) 778-1900
Fax: (818) 754-6140
Director: George Stevens
Web site: www.nlacrc.com

Field Offices

Antelope Valley
43210 Gingham Avenue, Suite 6
Lancaster, CA 93535-4512
Telephone: (661) 945-6761
Fax: (661) 942-4050

Santa Clarita Valley
25031 W. Avenue Stanford, #30
Santa Clarita, CA 91355-4543
Telephone: (661) 775-8450
Fax: (661) 775-8454

Regional Center of Orange County serves Orange County.

801 Civic Center Drive West, Suite 300
Santa Ana, CA 92701-4206
Telephone: (714) 796-5222 or
Toll Free Telephone: (800) 244-3177
Fax: (714) 547-4365
Director: William J. Bowman
Web site: www.rcocdd.com

Field Offices

East/Central Area Office
801 Civic Center Drive West, #100
Santa Ana, CA 92701
Telephone: (714) 796-5100
Fax: (714) 973-0336

North Area Office
3111 North Tustin Street, Suite 150
Orange, CA 92865-1752
Telephone: (714) 685-5555
Fax: (714) 282-7910

South Area Office
24012 Calle de la Plata, Suite 200
Laguna Hills, CA 92653-7623
Telephone: (949) 206-8840
Fax: (949) 699-3366

West Area Office
13950 Milton, Suite 200
Westminster, CA 92683
Telephone: (714) 889-7200
Fax: (714) 990-7222

Redwood Coast Regional Center serves the counties of Del Norte, Humboldt, Mendocino, and Lake.

525 2nd Street, Suite 300
Eureka, CA 95501
Telephone: (707) 445-0893
Fax: (707) 444-3409
Director: Phil Bonnet
Web site: www.redwoodcoastrc.org

Field Offices

Crescent City
875 5th Street
Crescent City, CA 95531
Telephone: (707) 464-7488
Fax: (707) 465-4230

Ukiah
1116 Airport Park Boulevard
Ukiah, CA 95482
Telephone: (707) 462-3832
Toll Free Telephone: 800-281-3832
Fax: (707) 462-3314

San Andreas Regional Center serves the counties of Monterey, San Benito, Santa Clara, and Santa Cruz.

300 Orchard City Drive, Suite 170
Campbell, CA 95008
Telephone: (408) 374-9960
Fax: (408) 376-0586
Web site: www.sarc.org
Director: Santi Rogers

Field Offices

Salinas
344 Salinas Street, Suite 207
Salinas, CA 93906
Telephone: (831) 759-7500
Fax: (831) 424-3007

Gilroy
7855 Wren Avenue, Suite A
Gilroy, CA 95020
Telephone: (408) 846-8805
Fax: (408) 846-5140

Watsonville
1110 Main Street
Watsonville, CA 95076
Telephone: (831) 728-1781
Fax: (831) 728-5514

South Central Los Angeles Regional Center serves the health districts of Compton, San Antonio, South, Southeast, and Southwest within the county of Los Angeles.

650 West Adams Boulevard, Suite 200
Los Angeles, CA 90007
Telephone: (213) 763-7800
Fax: 213-744-8444
Web site: www.sclarc.org
Director: Dexter A. Henderson

San Diego Regional Center serves the counties of Imperial and San Diego.

4355 Ruffin Road, Suite 110
San Diego, CA 92123-1648
Telephone: (858) 576-2996
Fax: (858) 576-2873
Web site: www.sdrc.org
Director: Raymond M. Peterson

Field Offices
El Centro
1073 Ross Avenue, #B
El Centro, CA 92243
Telephone: (760) 353-2830
Fax: (760) 353-4201

La Mesa
4215 Spring Street, Suite 104
La Mesa, CA 91941
Telephone: (619) 464-4580
Fax: (619) 464-4068

San Marcos
135 Vallecitos De Oro, Suite F
San Marcos, CA 92069
Telephone: (760) 736-1200
Fax: (760) 736-1262

National City
2602 Hoover Avenue
National City, CA 91950
Telephone: (619) 336-6600
Fax: (619) 477-6248

San Gabriel/Pomona Regional Center serves the cities of El Monte, Monrovia, Pomona, and Glendora within the county of Los Angeles.

761 Corporate Center Drive
Pomona, CA 91768
Telephone: (909) 620-7722
24 hour information line: 1 (888) 882-0433
Fax: (909) 622-5123
Web site: www.sgprc.org
Director: R. Keith Penman

Tri-Counties Regional Center serves the counties of San Luis Obispo, Santa Barbara, and Ventura.

520 East Montecito Street
Santa Barbara, CA 93103
Telephone: (805) 962-7881
Fax: (805) 884-4696
Web site: www.tri-counties.org
James L. Shorter, Director

Field Offices

Atascadero
6005 Capistrano, Suite E
Atascadero, CA 93422
Telephone: (805) 461-7402
Fax: (805) 461-9479

Santa Maria
302 W. Carmen Lane
Santa Maria, CA 93458
Telephone: (805) 922-4640
Fax: (805) 922-4350

Oxnard
500 Esplanada Drive, Suite 500
Oxnard, CA 93030
Telephone: (805) 485-3177
Fax: (805) 988-9521

Simi Valley
1919 Williams Street, Suite 201
Simi Valley, CA 93065
Telephone: (805) 522-8030
Fax: (805) 522-8142

San Luis Obispo
3450 Broad Street, Suite 111
San Luis Obispo, CA 93401-7102
Telephone: (805) 543-2833
Fax: (805) 543-8725

Valley Mountain Regional Center serves the counties of Amador, Calaveras, San Joaquin, Stanislaus, and Tuolumne.

7109 Danny Drive
Stockton, CA 95210
Telephone: (209) 473-0951
Fax: (209) 473-0256
Web site: www.vmrc.net
Director: Richard W. Jacobs

Field Offices

Modesto
1620 Cummins Road
Modesto, CA 95351
Telephone: (209) 529-2626
Fax: (209) 529-5763

San Andreas
52 North Main Street
San Andreas, CA 95249
Telephone: (209) 754-1871
Fax: (209) 754-3211

Westside Regional Center serves the health districts of Inglewood and Santa Monica-West within the county of Los Angeles.

Westside Regional Center
5901 Green Valley Circle, Suite 320
Culver City, CA 90230
Telephone: (310) 258-4000
Fax: (310) 649-1024
Website: www.westsiderc.org
Michael Danneker, Director

United Cerebral Palsy
United Cerebral Palsy agencies provide a wide range of services to children and adults diagnosed with cerebral palsy. The services include information and referral, educational training programs, recreation and sports programs, health training, family respite services, and travel information. Nationally, the organization supports social and medical research concerning cerebral palsy including research on aging and disability. Visit the web site at http://www.ucp.org/search.cfm.

UCP of Central California
4224 N. Cedar Avenue
Fresno, CA 93726-3700
Telephone: (559) 221-8272
Fax: (559) 221-9347
Email: ucpcc@aol.com

UCP of Orange County, CA
3010 West Harvard Street
Santa Ana, CA 92704
Telephone: (714) 557-1291
Fax: (714) 546-0943
Email: jminer@ucpaoc.org

UCP of Greater Sacramento
191 Lathrop Way, Suite N
Sacramento, CA 95815
Telephone: (916) 565-7700
Fax: (916) 565-7773
Email: ucpsacto@aol.com

UCP of San Diego County
8525 Gibbs Drive, Suite 100
San Diego, CA 92123
Telephone: (858) 619-571-7803
Fax: (858) 619-571-0919
Email: ucpsd@pacbell.net

UCP of Los Angeles & Ventura Counties
7630 Gloria Avenue
Van Nuys, CA 91406
Telephone: (818) 782-2211
Fax: (818) 909-9106
Email: ucpla@aol.com

UCP of San Joaquin, Calaveras & Amador Counties
333 W. Benjamin Holt Drive, Suite 1
Stockton, CA 95207
Telephone: (209) 956-0290
Fax: (209) 956-0294
Email: jschumacher@ucpsj.org

REFERENCES


DEFINITIONS OF DISABILITY

The Americans with Disabilities Act: Disability is defined as a functional limitation of one or more significant major life activities, having a record of physical or emotional barrier, and/or being regarded as having an impairment preventing function (Wenger, Kaye, & LaPlante, 1996).

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996: The act defines children with disabilities under the Supplemental Security Income program. Welfare reform now requires that children can only be defined as disabled if they have a physical or mental condition that can be medically proven which results in marked and severe or functional limitations. This condition must be expected to last at least 12 months or result in death. The child cannot be considered disabled if he or she is working at a job that could be defined as substantial (Wenger, Kaye, & LaPlante, 1996).

The National Health Interview Survey: The survey defines children with disabilities as those who cannot go to school, have limitations either in the amount or kind of school work they can do, or who are limited in activities other than school (Wenger, Kaye, & LaPlante, 1996).

Appendix A
Module I Overhead 2

THE NUMBERS

NATIONAL:

- 4 million children and adolescents under 18 years of age have disabilities. This is about 6.1% of the United States population in this age category (Wenger, Kaye, & LaPlante, 1996).

- 313,000 children under 3 years old have a "developmental condition" (Wenger, Kaye, & LaPlante, 1996).

- 652,000 children between the ages of 3-5 have a disability (Wenger, Kaye, & LaPlante, 1996).

- 4,462,000 children between the ages of 6-14 are reported to have a disability (U.S. Bureau of the Census, 1998).

- 3,000,000 individuals between the ages of 15-21 are reported to have a disability, of which 12,000 have a severe disability (U.S. Bureau of the Census, 1998).
THE NUMBERS

CALIFORNIA:

- 90,000 children with disabilities under 18 years of age receiving SSI/SSP (California Department of Social Services, 1998).

- 84,000 children with developmental disabilities between the ages of 0 and 21 are known to the California Department of Developmental Services (1998).
  
  17,305 are between the ages of 0-2, 
  
  43,216 are between the ages of 3-13, 
  
  23,185 are between the ages of 14-21.

- 604,075 children receive services under IDEA. Their ages range from birth to 21 (National Center for Education Statistics, 1998).

- 455,168 children between birth and 22 in the state of California had chronic conditions causing some activity limitation (Newacheck, 1991). These did not include institutionalized children.
THE MORAL MODEL

- The earliest way of looking at disability centers upon morality and sin.

- This ancient model is a part of American culture and is also dominant in many of the current world cultures.

- The model sees disability as the direct result of sin and evil.

- Disability, according to this model, is the result of loss of control of the moral essence of the individual.

- A person with a disability represents an impaired spirit; a heart that is out of order.

- The moral model also reinforces the idea of noble suffering. The person with a disability who can long suffer and endure the retribution from God is somehow noble and saintly.

- American culture shares the moral model of disability with its many ethnic cultural components.

THE MEDICAL MODEL

• Specific Characteristics:

1. The focus of the problem of disability centers on the individual with the disability.

2. According to the medical model, there is something drastically wrong with the person with a disability. The biological organism is out of sync with the natural order of the universe.

3. The medical model relies on the intervention of the professional. The solution to the problem lies with the knowledge and skills of the physician, physical therapist, occupational therapist, clinical therapist, professional counselor, certified teacher, caseworker, child welfare worker, etc.

4. The medical model assumes the professional is the controlling factor in how the person with a disability is treated.

5. The medical model seeks perfection, cure, the eradication of the physical or mental difference it defines as dysfunctional. For most people with disabilities, this is impossible.

THE SOCIAL/MINORITY MODEL AND THE INDEPENDENT LIVING MOVEMENT

• The Independent Living Movement began to change the traditional way of looking at persons with disabilities.

• It manifested in political action from the 1960s until the present.

• In part, its philosophic roots came out of the work done by social psychologists in the mid 1940s.

• They put forth the idea that rather than a characteristic of an individual, disability with its narrow stereotypes and limited identity was in fact a societal construct.

• In free market, all individuals have the right to choose their life’s direction. All people should have the right to compete. None should be locked out of the market place.
THE SOCIAL/MINORITY MODEL OF DISABILITY ASSUMPTIONS

• Persons with disabilities are a minority group as ethnic minorities, women, gays and lesbians, and people who are older. Along with this minority status go all the stereotypes of ableism and internalized ableism.

• The concept of disability is a social construct. This social picture of disability rests upon cultural tenants about disability. Current beliefs manifest in the stereotypes applied to persons with disabilities and the resulting discrimination.

• The “problem” with disability lies with the social construct of disability rather than with the individual. There is nothing innately wrong with the person with a disability. He or she merely represents a piece of the grand diversity that is human.

• When there is a problem concerning disability, the answer lies in addressing the social construct and the related barriers to individual and group fulfillment. Intervention with persons with disabilities is an economic, political, and social intervention rather than an individual intervention.

Persons with disabilities should be in control of their own lives just as people without disabilities.

FACTORS OF ABUSE CONCERNING CHILDREN WITH DISABILITIES
(Sobsey, 1994)

1. The nature of specific disabilities directly relates to vulnerability to abuse.

- Motor skills
- Cognitive or language
- Hearing
- Emotional or behavioral

2. Society and some of our educational/caregiving institutions teach learned helplessness and compliance to children with disabilities.

- Treatment professionals
- Physicians and other medical professionals
- Teachers
- Counselors
- Parents and foster parents

3. Society and some of our educational/caregiving institutions perpetuate dependency in children with disabilities.

- Dependency produces the necessity for intensive physical interaction
- Dependency may teach children with disabilities to be more trusting
- Fear of abandonment
- A desire to please

Many children with disabilities find themselves in isolated situations either staying at home, in special education programs, or institutions. This isolation tends to be a factor in the abuse of children with disabilities.

IS IT ABUSE OR IS IT THE DISABILITY?

• Many children with disabilities concerned with behavior or cognitive functioning exhibit self-abusive behaviors or are prone to accidents.

• Many children with disabilities concerned with emotional factors exhibit inconsistent behavior and antisocial behavior.

• Many children with severe physical disabilities require personal care that involves touching sexual parts of the body.

SOME HINTS:

• Observe the injury. Determine if it is consistent with the types of injuries that are indicative of abuse.

• Determine what the child says about the situation. Listen carefully.

• Compare the injury with the explanation to determine consistency. Does the explanation make sense?

• Determine if the injury is consistent with the child's capacity to create the injury. Is the child at a point where he or she could do the thing explained in the statement?

• Try to find as many witnesses as possible. Think about who could potentially have seen what happened.

• Read the medical reports and if possible interview the intervening nurse and/or physician.

• Observe the child's behavior. Do you see the behavior that may have resulted in the injury?

GETTING A STARTING POINT

• Obtain a baseline of the child's behavior. Establish what is typical behavior for that particular child.

• Take a look at the history of the behavior.

• Compare historical behavior with current behavior. Has there been a change in intensity or duration of behavioral episodes?

When collaborated with other evidence, the following behaviors may indicate sexual abuse:

• increased masturbation;

• a new behavior of touching others;

• new and unusual behaviors related to a child's own genitals (e.g. pulling, punching, rubbing, etc.);

• sexual drawings.

GENERAL PRINCIPLES IN INTERVIEWING A CHILD WITH A DISABILITY

- The social worker needs to be aware of his or her own comfort level in talking to and interviewing children with disabilities.

- Be sensitive to the child's developmental level. Very young children cannot conceptualize abuse, sexual abuse, or sexuality.

- Follow the child's lead rather than adhering to a rigid interview protocol.

- Be objective and nonjudgmental.

- Be empathetic and understanding.

- In the beginning, explain the purpose of the interview.

- Establish a positive rapport by asking questions that are relatively neutral and that will engage the child.

- Avoid any comments that would seem to blame or be critical of the child.

- Limit your language to the developmental level of the child you're interviewing.

- In your language, avoid abstract words, the use of pronouns, complex questions with several possible answers, yes and no questions, negative questions, questions that go beyond the developmental level of the child, "Why" questions, and leading questions.

- Be ready to use aids such as anatomically correct dolls or drawings.

- Always bring your interview to closure.

INTERVIEWING DEAF/HARD OF HEARING CHILDREN

- Prior to the interview, the social worker needs to ascertain what method of communicating the child utilizes. The appropriate interpreter must be present. Make sure the interpreter is comfortable in communicating about sexuality and/or physical abuse.

- In interviewing children who are deaf or hearing impaired, always look directly at the candidate. Eye contact is crucial. Never look at the interpreter.

- The room should be well lit.

- For a child who can read lips, speak slowly and distinctly.

- Avoid gesturing around the face.

- Body language and facial expressions are important.

- If the child uses a sign language interpreter, the interpreter should be positioned next to the social worker doing the interviewing so that the child can shift back and forth from the interpreter to the interviewer.

- The social worker should always avoid the term “deaf and dumb.” It is inaccurate and offensive.

- It is not necessary to avoid using the word “hear” with a child who is deaf.

- If the social worker does not understand the comment or sentence, it is necessary to be honest and let the child and the interpreter know that he or she does not understand.

- It is appropriate for the social worker doing the interviewing to tap the child on the shoulder or to wave a hand to get visual contact.

- The reaction of speaking loudly around a person who is deaf or hearing impaired is not very helpful.

INTERVIEWING CHILDREN WITH VISUAL DISABILITIES

- For children with sight impairments, the social worker may extend an arm to help guide the child to a chair.

- If the child uses a guide dog, the interviewer should avoid petting the dog or distracting it in any way.

- It is appropriate to introduce all persons involved in the interview because a child who is blind may not be aware of all those present.

- In the introduction, indicate where other participants are sitting in the room.

- As with children who are deaf, children who are blind have little need for the social worker to speak in a loud voice.

INTERVIEWING CHILDREN WITH MOBILITY-RELATED DISABILITIES

- The social worker doing the interviewing should not assume that a wheelchair user or other child with a mobility impairment needs help. The interviewer should only provide assistance if the child requests it.

- The social worker should be prepared to tell the child the location of elevators, ramps, and accessible restrooms.

INTERVIEWING CHILDREN WITH SPEAKING-RELATED DISABILITIES

- If the social worker does not understand a response to a question, it certainly is appropriate to ask the child to repeat the answer.

- The interviewer should not hesitate to follow up on an answer that does not make sense or seems confusing.

- Usually if the interviewer can relax while listening, the interviewer becomes more accustomed to the sound and pattern of the child's speech.

- Watch body language.

- Have readily available props and/or drawing boards.

- The room should be well lit.

- The room should be relatively quiet with limited distractions.

INTERVIEWING CHILDREN WITH COGNITIVE DISABILITIES

- The interview room must be well lit and free from external distractions.

- Patience is important because many children with cognitive disabilities have difficulty making generalizations from past events.

- The social worker must be very explicit in his or her speech because many children with cognitive disabilities have difficulty picking up social cues.

- Interviewing may take longer because many children with cognitive disabilities have difficulty expressing themselves in speech.

- In the interviewing process, communication must be direct and simple.

- The interview and follow-up sessions should be in a comfortable environment.
Interviewing Children with Learning Disabilities

- Children with learning disabilities will have difficulty receiving information from the senses. The social worker needs to be direct and exclusive.

- The interview and session room must be without visual or auditory disturbance.

- Children with learning disabilities sometimes have difficulty processing information, therefore interview sessions may need to be longer than usual, or more likely, need to be broken up into several sessions.

- Children with learning disabilities often have difficulty in communicating knowledge to others. This may require longer interview sessions or an increased number of sessions.

- Children with attention deficit hyperactivity disorder will have difficulty staying in one place with full attention on a task. The social worker may have to be creative in the interviewing process. He or she may have to break the session up into smaller sessions.

THE PLUS SIDE OF CHILDREN WITH DISABILITIES

1. Parents of children with disabilities have similar hopes and expectations for themselves and their children as parents of children without disabilities.

2. Parents of children with disabilities expect to continue pursuing their careers, participating in recreational and social activities with family and friends, and have as much financial security as others in their social class.

3. The introduction of a child with a disability can bring a family closer together as a unit, facilitating the development of a sense of family.

4. Individual family members can grow emotionally and expand their knowledge of the community and the world as a result of having a child with a disability.

5. Family members can increase their compassion and tolerance.

6. Families can develop deep and meaningful friendships with other parents of children with disabilities, and hospital and rehabilitation personnel.

7. The children themselves can gain an increase in self-esteem by quality and extensive relationships with both family members and professionals.

IMPORTANT POINTS IN PRACTICE

• Social workers intervening in families with children with disabilities need to be aware of their own values and beliefs about disability and not impose or sustain negative stereotypes.

• Social workers must be knowledgeable about disability.

• Social work professionals need to be prepared to teach families about disability and the specific disability that is experienced by the child in the family.

• In the assessment process, plan development, plan implementation, and evaluation, social work professionals must inculcate the concerns and needs of parents with young children with disabilities.

• In the assessment process, plan development, and plan implementation, social work professionals need to address the whole family rather than just the child with the disability.

• Individuals within the family need the opportunity to express their own feelings regarding the disability and assistance in developing individual and family potentials for adjusting to one another's needs.

• Based on family needs, referrals need to be made in terms of connecting the family to local resources which not only benefit the child but the family in general.

• If father is part of the family, it is crucial that he participates in all components of family intervention. This may take some unique intervention approaches and scheduling.

• Social work family practitioners working with families with children with disabilities must remain in the political arena, particularly today in light of the onslaught of the current political ideology.

SOME POTENTIAL GOALS FOR FAMILY INTERVENTION

- The family views their child with the disability as a child first; the disability is secondary.

- The family moves away from preoccupation with why the disability happened.

- The family focuses on the positive characteristics and talents of the child with the disability rather than the negative, limited aspects of the disability.

- The family seeks information about the child's disability and then uses that information to understand and work with the child.

- The family is aware of the educational, emotional, and physical implications of the disability, and is aware of available programs to support the child's needs.

- The family is aware of support groups for parents of children with disabilities, children with disabilities, and siblings.

- The family manages the needs and demands of the child with the disability within the framework of family life.

- Both the mother and the father play an active role in parenting the child with the disability.

- The family exhibits open communication including parents, siblings, and the child with the disability.

- The family has support from friends and extended family.

- Parents and other family members have the time and the resources to take care of themselves.

BASIC ASSUMPTIONS AND PRINCIPLES

1. People with disabilities, no matter what age, are capable or potentially capable.

2. The problem with disability lies not with the person.

3. Any model of practice applied to working with persons with disabilities must assume that disability is a social construct and that a primary emphasis on intervention must be political in nature.

4. There is a disability history and culture.

5. Though persons with disabilities have experienced oppression, there is joy and beauty to be found in disability.

6. Persons with disabilities have, without question, the right to control their lives.
12 PRINCIPLES OF STRENGTH-BASED ASSESSMENT

(1) The individual’s understanding of the facts and issues is of the first importance.

(2) The human service practitioner must believe in the credibility and ability of the person.

(3) Look for what the person wants. Do not bring preconceived notions and bias into the assessment process.

(4) Move the assessment into personal and environmental strengths.

(5) Look for strengths on a multidimensional level. Address individual, family, and community strengths.

(6) Use language that the person understands and relates to. The use of professional jargon should be avoided.

(7) Make the assessment process a combined effort. This should be easy if you believe in the person.

(8) Much related to the last principle; reach a mutual agreement on the assessment.

(9) Do not “blame the victim.” It is easy to make their “laziness” or their “dependency” the cause of the problem which needs to be addressed.

(10) Avoid cause and effect analysis in assessment. Humans are far too complex for the human service practitioner to figure out the “cause.”

(11) “Assess; do not diagnose.” Diagnosis assumes pathology and dysfunction.

(12) See difference and uniqueness as strengths. Cultural diversity must be not only recognized but valued.

INAPPROPRIATE AND APPROPRIATE TERMS

<table>
<thead>
<tr>
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<th>Appropriate</th>
</tr>
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<tr>
<td>deaf and dumb</td>
<td>deaf</td>
</tr>
<tr>
<td>epileptic</td>
<td>person with a seizure disorder</td>
</tr>
<tr>
<td>retarded or retard</td>
<td>person with a developmental disability</td>
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<td>the disabled or the handicapped</td>
<td>person with a disability</td>
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</tr>
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<td>crippled</td>
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<tr>
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<td>unfortunate</td>
<td>person with __________</td>
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<tr>
<td>diseased</td>
<td>person with __________</td>
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APPENDIX B

HANDOUTS
Appendix B
Module II Handout

DISABILITY SURVEY

You have been provided two copies of the following questionnaire. Take about 5 minutes and complete the first copy. The questionnaire helps participants explore underlying stereotypes and values they hold regarding persons with disabilities. It focuses on subjective feelings and thoughts rather than attempting to objectively ascertain individual or group values around disability. The questionnaire uses a 4-point Likert-type scale (1 = strongly agree, 2 = agree, 3 = disagree, 4 = strongly disagree) to ascertain the extent to which participants agree or disagree with following statements:

Please rank the extent to which you agree or disagree with the following statements.
(1 = strongly agree, 2 = agree, 3 = disagree, 4 = strongly disagree)

1. It is more beneficial to teach a child using a wheelchair to jump curbs rather than to convince the city to install curb cuts.  
2. Teaching a child to walk, if possible, is better than teaching a child to use a wheelchair.  
3. People with histories of drug and alcohol abuse should be considered persons with disabilities.  
4. A severely physically disabled child in a restaurant makes others dining uncomfortable when their eating is sloppy and is perceived as disgusting.  
5. Children with severe disabilities should not be expected to go to school.  
6. A child with an amputated limb should wear his/her prosthesis in social situations including school and play.  
7. The biggest factor in preventing children with disabilities from accomplishing their goals is the fact that they do not take risks.  
8. Few children with disabilities are ashamed of their disabilities  
9. In spite of all the publicity and activism, children with severe disabilities can never really be included in a regular classroom  
10. It is a tragedy for parents to have a child with a disability, either at birth or in childhood.

11. It is common for children with disabilities to be angry and resentful toward able-bodied children.

12. Children with severe developmental disabilities should be prevented from socializing with non-disabled children because they get picked on.

13. Severely developmentally disabled children will not benefit from schooling.

14. Given the choice, parents with children who act out would declare them learning disabled to get extra benefits for them at school.

15. For a child to acquire a disability from an injury is a tragic event.

16. Children with disabilities are usually friendly and receptive to being helped.

17. The new “inclusion” movement in primary and secondary education causes more harm than good to both the disabled student and the non-disabled student.

18. The Individuals with Disabilities Education Act gives special privileges to children with disabilities.

19. The biggest factor in preventing children with disabilities from accomplishing their educational goals is their dependency on their parents.

20. Children with disabilities can not produce as much in the school environment as an able-bodied child.

21. Only persons with disabilities should provide human services to other persons with disabilities.

22. Persons with severe developmental disabilities should be prevented from having children.

23. Civil rights laws like ADA take away rights from productive able-bodied students and workers.

I was born in Pennsylvania. At the age of about two, my family began to become alarmed that I was not progressing physically the way that I should. As time moved forward, I failed to move from crawling to standing; from standing to walking. Our family physician said to my mother that I was simply a late walker. In a sense, his diagnosis was correct. With consultation with several specialists, his diagnosis was later expanded to cerebral palsy. Doctors never determined when the brain damage occurred, but I would use crutches and later a wheelchair for the rest of my life.

Years of consultation with physicians by my parents eventually resulted in my institutionalization for 6 years in the Industrial Home for Crippled Children. The Industrial Home for Crippled Children in Pittsburgh, Pennsylvania was 60 miles from my home. My first view of it reminded me of a prison I had seen in an old film. The “Home” appeared to be made up of two sections. The older section, built probably in the early 1900s, was located facing Denniston Avenue and its brick was old and dirty. The newer section, probably no more than 5 years old, formed an “L” and faced both Wilkins Avenue and Shady Avenue. A paved courtyard occupied the center bordered on the Northumberland side by a huge Presbyterian church. The older section was particularly foreboding. It housed the administrative offices and dining hall. The second floor of the combined sections housed the dorms where they housed the “little” girls and boys, and the “middle” girls and boys. The “older” boys and girls had small individual rooms in individual sections. The isolation room was located in the new section.

Professionals at the Industrial Home for Crippled Children believed that a period of isolation for about 3 weeks was necessary for a successful transition to the environment of the “Home.” So on the day of my arrival, after the admissions counselor had completed all the paperwork, my parents and I--with a counselor--went up to the isolation room. It was a small, gray-tiled room with one hospital bed. The window looked out over a grassy area. A small bathroom about the size of a broom closet occupied one corner. My parents helped me undress and once again they put me in a hospital gown. They turned to leave. I felt hollow and alone. After about a minute, I got out of bed, holding onto the cold gray-tiled walls, I walked out into the hallway crying. Through my tears I saw my father, dressed in his Sunday best brown suit with a brown silk tie, the collars of his white shirt turned toward the sky; my mother with her navy blue suit almost too tight to fit and her blue and white pillbox hat, turning the corner to leave. I cried, “Please don’t leave me; don’t leave me here. Take me home with you!!!!” They turned toward me for a moment and then disappeared into the hall that led to freedom. I sobbed, “I want to go home; I want to go home!” Two attendants came and put me back into bed and strapped me into the bed. Once again I was left to myself--alone.

The attendants unstrapped me after I had promised to not get out of bed. I lay there looking up at the ceiling. There were two lights. Both were these futuristic designs consisting of four metal rings around a silver globe in the middle. In front of me across the room was a window. The only people I saw in those weeks were the attendants who brought me my meals and changed my clothes and bed. The others I saw passed by the door to my room. The isolation room was just around the corner from the gym and an indoor pool. Daily a parade of children with disabilities passed by the door. Some

walked with crutches, but most used some kind of device like wheelchairs or three-wheeled carts. The wheelchairs were made of wood with high-caned backs and caned seats. The big wheels were in the front and the small wheels in the back. This strange parade seemed curious to me and occasionally one of the young girls would stop and say “hi” or give me a broad smile. This was extremely comforting to me.

The 3 weeks passed very slowly. Physical exams and orthopedic evaluations broke the monotony but I dreaded them just the same. The nurses would undress me completely and then stand me next to the bed. Parades of physicians both male and female would march past me, occasionally to stop and take a closer look. At the end of the ordeal, on the fourth Sunday of my incarceration, my mother and father visited me. The majority of their visit I spent attempting to bargain with them about taking me home, of course to no avail. At the end of the visiting hour, they left. My only consolation was a model of an old-fashioned car they had brought me.

My integration into the “Home” went quickly. After isolation, the administration placed me in the “little” boys’ section that went up to the age of 6, which I was. The little boy’s section overlooked Denniston Avenue with three standard windows looking out on huge maple trees and well-kept brick homes. It was a fairly large room painted institutional green. It housed 20 beds in which 20 boys from the ages of 3-6 slept. I can recall specifically none of the names of these early boys. I remember only their faces and their disabilities. Several of the young boys had cerebral palsy but much worse than mine. Straps held them in their wheelchairs or three-wheeled carts. They had no control of their saliva and their drool constantly dripped from their mouths. Some could not feed themselves or dress themselves. They spoke but could barely be understood. Many of

the boys had contracted polio. They seemed to be the best off of the entire group, particularly the ones that the polio had impacted only one arm or one leg. Most of these used only crutches to help them in their mobility or nothing at all. Some had no apparent disability and I often wondered why they were institutionalized. One young man had purple lips and purple fingernails. His skin had a purple tint to it. Someone later told me that he had a hole in his heart. One night he mysteriously disappeared. No one seemed to know what happened to him.

I learned quickly to pick the boys that I could trust to be friends with and the ones that I could not. You didn’t mess with the “middle” boys. Many of them had hardened faces, used vulgar language, and would smack you upside the head as quick as look at you if none of the counselors were around. So when you made contact with one of them, you made sure there was an adult present. Some of the little boys had that same look about them. I did not deal with them much at all. Interestingly, the older boys were usually very nice and understanding. I liked to hang out with them although they treated my presence with a certain ambiguity. The little boys with whom I became friends generally had kind faces and easy-going demeanors. They generally liked me and I would develop trust with these boys.

I played two roles in the social stratification of the institution. The one role was that of leader and coordinator. For many of the adventures that I embarked on in the next 6 years, I led the way. I would think up an adventure, convince other boys of its rewards, coordinate its implementation, and carry it out. The other role I played was that of scapegoat, both by the boys and by the staff. Many of the streetwise boys would pick on me and took great delight in either getting me in trouble or making me cry by beating

on me or teasing me. The staff found in me a convenient answer to all that was going wrong with the place. Whenever something happened, I would be sure of an immediate hauling into Mrs. Budd’s office. Mrs. Budd was the head supervisor and dreaded by both staff and children.

Adventures were many as was abuse. "Bob the Hobby Man" came on Monday nights. He was a local hobby store owner who would come and bring models for us to build. I don’t know if this was his contribution to the "home" or if he was paid. Sometimes parents would subsidize his visit for their child. On one occasion, a child received a Super Erector Set. My idea was to build a robot monster on wheels and use it to scare the "little" girls. Late one night, when everybody was in bed, myself and several other boys pushed "the monster" from the “little” boys’ dorm across to the “little” girls’ dorm to scare the hell out of them. This was quite a feat because in order to do so, you had to pass the head counselor’s office, which was in between the two dorms. This is where the night counselor stayed. She always kept the door open. We successfully executed our plan but at the culmination of the event when the “little” girls reacted, we were all caught.

I don’t remember my specific punishment for this but I do recall spending many Saturday mornings confined to the room called “solitary.” I was confined to a particular chair. The room was above the “big” boys section of the institution (the “big” boys section was partitioned off into little rooms where individual boys stayed). That room had big windows that looked out over another brick building. The floor was made up of black and green linoleum squares. The chair was a big old wooden office chair. It was hard. Usually by lunch time, a counselor or another "inmate" would come and tell you

that you could go.

The newer section housed the "middle" boys area of the institution. The "middle" boys slept in a dorm with huge windows looking out over a courtyard. One night, it snowed about a foot. I had a brilliant idea. I thought that opening all the windows, rolling up in covers at the bottom of our beds, and pretending that we were out camping in the wilderness would create great excitement. I convinced the rest to join me. The next morning, there was about two inches of snow on the beds and the floors--the place was freezing. Two "inmates" caught severe colds. And of course, the guilty finger was pointed directly at me.

I remember my "just deserts" for this one explicitly. Mrs. Williams, the staunch woman from England, locked me in a closet for 2 days. This was a small closet about the size of a coffin. The only time I was allowed out was to go the bathroom. They would leave the door of the closet open for me to eat my meals.

Mrs. Williams relished in my torture. She would rally other boys against me by saying that if I was in England, they would teach me a thing or two. She couldn't stand my complaining and continually made life difficult for me. When she facilitated retribution through the other boys, I was powerless--there was no escape. I suffered many a punch in the stomach because of her, and I carry to this day a chipped tooth from being kicked in the face.

Mrs. Williams believed that children could train their bodily functions. So every morning after breakfast, boys in her command sat on the toilet until they had produced a bowel movement. You did not leave until you produced. She would periodically come in and inspect. Many a time, after producing, a bigger boy would force me off my

production facility to claim the fruits of my labor. I would spend the morning on the "John" unable to produce more.

Sometimes, justice would prevail. The "home" housed its own school. Only a few "big" boys went to school on the outside in Pittsburgh public schools. I loved to draw and spent my extra hours doing so in school. One of my arch enemies was Jim--I don't remember his last name. His disability had something to do with his hip and his means of mobility was a three-wheeled cart. He was not allowed to move his hip. He was nasty and would continually make fun of my drawings. On one occasion, I left the room. Upon returning, I had found he had destroyed my art. I had had it. I went over to him and punched him so hard he fell out of the cart and had to be hospitalized. I'll never forget the teachers commenting about how I didn't realize my strength--I needed more self control. To the "solitary" I went again.

After all group members complete reading the vignette, as a group, answer the following questions:

1. Which incidents in “Richard’s Vignette” could be considered abuse? Please give specific reasons for your choices.

2. Pick one situation of abuse. What were the factors in the abuse? Did an extreme power differential exist in the situation? Did the abuse happen in isolation? Was learned helplessness a part of the process?

3. If you were a social worker employed in this agency, and were called upon to investigate this situation, how would you proceed? Where should intervention take place? What important information is lacking?

4. If you were called upon to interview Richard, what special considerations should be made?

CHRIS’ VIGNETTE
By
Claude Edmond Christopher

I was born on December 11, 1969. I was born during the Vietnam War in a small village called Vinh-Long, about 60 miles south of Saigon. My mother was born and raised in this village, while my father was in the United States Army as an enlisted soldier. My father was born and raised in Lexington, Kentucky. He joined the military at the age of 17. His mother had to sign for him so that he could join. The military had always been his passion since he was a child.

I have one sister named Susan. Susan is a year and 9 months older than me and was born in Vinh-Long as well. My parents were married in Vietnam in 1967. Because of my father’s citizenship, my sister and I were born American citizens. My mother had to go through the naturalization process, which began upon our arrival in November of 1970. I was 11 months old. My mother eventually became a citizen of the United States in July of 1977. When we moved to the U.S., we lived in Lexington, Kentucky, close to my father’s family. In Lexington, my father’s family consisted mostly of his extended family; aunts, uncles, nephews, cousins. His mother and his biological father divorced when he was around 4 years old. From what my grandmother had told me many years ago, his father would physically abuse him and my grandmother. My father and grandfather, which we all carry the same name, have not spoken in over 25 years. My father wishes to have no contact with his father at all!

Upon our arrival in Lexington, my father settled us in long enough to familiarize my mother with her surroundings and family members so that he could return to

Vietnam for a last tour of duty of the Vietnam War. Prior to returning to Vietnam, he had already spent 5½ years in combat. I later asked him why he returned to Vietnam knowing that he could have possibly left his wife a widow and his two children fatherless. His response was, “My only objective was to earn the Congressional Medal of Honor.” In that regard, he came back empty-handed. Although, throughout his 5½-year tour in Vietnam, he did come back very decorated with over 30 medals from the United States Army and the South Vietnamese Army, as well.

During this time when he was in Vietnam, my mother was left with little money to buy food, clothes, rent, utilities, and other necessities of everyday life. My mother told stories of times she had enough money to buy one piece of meat that was to be shared three ways, my mother, my sister and me. She would accompany the meat with rice and vegetables given to her by family members. My mother expressed to me that she feels guilty for me being disabled because she feels like if she hadn’t been so “prideful” about getting food stamps, that I might not be disabled now if we had more food to eat.

While my father was in Vietnam, my mother learned what English she could from relatives, children, and TV shows like Sesame Street and Captain Kangaroo. My relatives were good at teaching her how to swear. They would tell her that a swear word meant totally something different than what it really meant. After spending a year in Lexington, my father returned from Vietnam due to my grandmother’s letter to President Johnson stating that, “her son had more than fulfilled his obligation to his country and that she wants him home with his wife and children.” President Johnson personally wrote my grandmother back saying that he will have direct orders from him that he return on the next available flight back home.

When my father returned, he received orders for Fort Knox, Kentucky. Fort Knox was only 4 hours from Lexington. We moved into a mobile home park in a nearby town called Radcliff. With the return of my father, the ups and downs were starting to show between my parents. One of the major issue(s) was regarding me. I was 3 years old and showing no signs of beginning to either walk or speak clearly enough for anyone to understand except my sister. My father expressed little concern while my mother was beginning to worry and on the verge of panic.

Coming from a multicultural family, there were significant differences between my parents' views on such things as discipline, religion, culture, and the simple daily tasks of chores, cooking, taking care of the children, etc. It wasn't long after my father’s return that he too, had begun to see that I was slow in my developmental process. At the age of 3½, I was still unable to walk without leaning on furniture and I could not sit on the floor without assistance or I would fall, mostly face first. This was enough to convince my father that I needed to see a specialist, and I had more serious problems than slow development.

My father’s aunt who happened to work for the Shriner’s Crippled Children’s Hospital in Lexington, Kentucky advised the family to see an orthopedic specialist. My great aunt made an appointment for me to see one of the best child specialists in the area of children’s orthopedics and disabilities. I was around 4 years old when I made my first visit to Shriner’s. There were many questions asked by the doctor about my history since birth. My parents revealed to the doctor that I was approximately 6 weeks premature and that around 2 weeks after birth I was critically ill with Yellow jaundice. I was unable to keep food down, so the Vietnamese doctors fed me through an IV in my arm.
right ankle. Vietnam is a third world country and in the middle of a war, the medical facilities were comparable to the “Dark Ages,” so to speak. It has been questioned amongst the doctors and especially myself, whether if I had the opportunity to have the phototherapy treatment, that I would have Cerebral Palsy today. Phototherapy is a procedure of putting jaundiced infants under special blue lights that break down bile pigments, preventing them from building up and threatening the brain. My mother, again, hypothesized that having an IV could have brought on the Cerebral Palsy as well. While I was in the hospital in Vietnam, my mother and grandfather would go to the Buddhist temple every day to pray that either I survive or pray that I would die if that was in my best interest. I truly believe that they didn’t think that I would survive.

There are various types and degrees of Cerebral Palsy, which affects each person with Cerebral Palsy differently in a minor or major way. Because my Cerebral Palsy is “congenital,” due to the jaundice, I am very fortunate that the bile pigment did not damage my brain to the extent of causing any mental disability or retardation. At the Shriner’s hospital, my father asked if there was anything that could be done to improve my condition. According to my father, the doctor stated that he could surgically cut the muscle(s) near the ankles of both feet to release some of the tension so that I wouldn’t be walking on my toes. But the doctor said that there is a real high chance that as I got older, my body would correct itself. And for the most part it did until my early twenties.

I lived out my childhood like most “normal” children. I climbed trees, rode bicycles, ran, played with other children, etc. My active childhood had my parents at

odds. My mother, being Vietnamese and very protective of me, wanted me to stay indoors to lessen the chances of me getting hurt. My father was the opposite. He told my mother that I wasn’t any different than the “other” children. He encouraged me to be like the other children. My father once told me that my mother asked him, “what if Chunky (my nickname) gets hurt?” My father told her that, “all boys get hurt once in a while.” I got my share of the bumps and bruises that my father was certainly talking about.

I also remember a time when I was around 6 years old while we were still living in a trailer court when I came home crying to my father because another kid “beat me up.” My father immediately spanked me and told me to never come back home crying because “I got beat up.” Even at that young age, my father was teaching me that even though I had some physical problems, “I was no different than these other children.” The next time I was being picked on, I made sure that I got the upper hand on the situation so that it wouldn’t be me coming home crying.

When my father came home in the evenings, we would often wrestle with each other. I remember vividly of he and I slapping each other in the face open-handed until one of us gave up. Of course my father didn’t use half of his strength but I tried like hell to slap him as hard as I could so that he would give up first. He never left marks or bruises on me during our “playtimes.” I understand and thank him now that he did what he did to toughen me up and prepare me for life later on when he knew that there would be times where I would have to defend myself from the teasing of being “different.” This laid the foundation for me to this day, to never give up in the face of adversity.

My father was only stationed at Fort Knox for 2 years after returning from Vietnam when he got orders to get stationed in Germany. My father decided to go “unaccompanied” meaning without his family. By doing this, a soldier can cut his tour from 3 years to only 1 year. This was a very strenuous year for the whole family. It was especially hard for me because I missed him and our “playtimes” together in which my mother never partook.

After my father left for Germany, my mother got a job at the Officer’s Club on Ft. Knox as a bartender. Around this time, I was entering the first grade, and my sister the third grade. We never had any formal babysitter(s). Our neighbors would check up on us every so often. My mother would leave for work around 7:30-8:00 p.m. and wouldn’t come home until three or four in the morning.

Even at this early age, there was friction between my mother and me. She never thought that I was of average intelligence, therefore she never expected much from me; this went on up through high school. Since I have a speech impediment, I could remember feeling that she never had the patience to take a moment to listen to me. Rather, she would turn to my sister and ask her, “Susan, what did Chunky say?” This was an everyday event. During supper my mother would ask my sister what I wanted to eat rather than asking me. I was beginning to feel resentful towards my mother, which some of it is still carried on today.

Since my father was in Germany, and my mother worked nights, this basically left my sister and me together a lot. Asians believe that family is very important and my mother put a lot of emphasis and pressure on my sister to take care of me. In a sense, my sister was more than a sister. She was also my caregiver. Before I would go to...

parents first, I would always go to my sister. My sister would always watch after me and made sure that I was protected from other kids who might have picked on me. This put a lot of responsibility on my sister and yet she never complained. Since my sister and I spent most of our growing up years together, we were able to build a very strong bond that is still there today.

Upon my father’s return from Germany in 1977, it was apparent that my parent’s marriage was irreconcilable. During my father’s tour in Germany, we moved into a very large house in which my mother worked over 50 hours a week just to maintain the house payments and other bills. Also during this time, my mother met a captain in the army, who is currently my stepfather. When my father returned from Germany, my parents were fighting a lot. One afternoon, my sister and I were standing outside of the house when we heard our parents screaming and fighting. We could hear my mother being thrown around in the bedroom for at least an hour. Suddenly, my mother ran outside carrying my father’s pistol in her hand. She was able to get in her car and lock the doors. As she was about to leave, my father picked up the rear end of the car so she couldn’t leave. My sister and me ventured into their bedroom to discover blood all over the walls and several broken objects. Due to all off this mayhem, my mother developed lead poison from digging her polished nails in her skin from her nervous impulses.

It had come out that my mother had been seeing my future stepfather. A few days later, our parents sat us down at the kitchen table to inform us that they were getting a divorce. It was the summer between my second and third grade year. Our parents asked us who did we want to live with. Immediately, I said “my dad,” and my

sister said, “my mom.” This was a very devastating circumstance especially for my sister and I because we realized that we were going to be living apart for the first time and I would no longer have my big sister at my side to watch and look over me.

About a week or two later, my mother, sister and stepfather moved to Phoenix, Arizona to my stepfather’s new army station. This separation was made a little easier for my sister and I because every Sunday we took turns calling each other. And for me, I now had to learn to take care of myself without having my big sister around. During this year, my father worked very long days. Oftentimes, I would go 3 or 4 days without seeing him. Sunday nights I would say “goodnight” to him and wouldn’t see him again until Wednesday or Thursday evenings. Since he went to work before I got up for school and I would be in bed before he got home, we communicated by writing notes to each other.

Being a Staff Sergeant, he was responsible for almost 60 other soldiers. In addition, he spent a lot of the time in the field. He asked me early on if I wanted a babysitter and I said, “no.” My daily routine was to go to school, which was walking distance, come home and do my homework and go next door where there was an older couple in their late forties or early fifties to have snacks and often times eat supper with them. They treated me like their “adopted son.” Rachel (the neighbor) and I would work on my homework, bake cookies, and go on errands together. I would come home around eight at night to get ready for bed.

There was a deal between my father and I. Every Friday night we had two rituals. When he got home, we would go to McDonald’s. Sometimes we would eat there or

bring it home so that we could watch TV together. Then after the dinner had settled, we would throw on the boxing gloves and box. There was only one rule: the first sign of blood would be the end of the boxing. My father would get on his knees, as I would stand so that we were eye-to-eye. I remember punching him with all my might just so that I could get him to bleed first. As I recall, it came out pretty even. Some nights I would bust his lip and other times he would bust mine. This was absolutely the best quality time that I spent with my father in my life!

At the end of my third grade year, my stepfather received orders to go to Hong Kong to attend a Chinese language school to learn Chinese. I was encouraged to go, even though I didn’t want to, so that I could be reunited with my sister. My parents knew that it was important for the both of us to be together and grow up together because “we” were all we had and that it was tearing us apart emotionally being separated from one another. Against my father’s wishes, I went.

Hong Kong was a very good learning experience as well as an eye-opener for me. I learned about many different cultures because of the school I attended. I went to a private Protestant school, which had students from the first to the twelfth grade. The name of this school was called “Hong Kong International School.” This school was composed of almost all races and nationalities. I had crushes on girls that extended from Greece to Japan. We were in Hong Kong for 2 years during my fourth and fifth grade years. It was while in Hong Kong that I became consciously aware of my disability.

The community of apartments that we lived in had a lot of British families. Even though I knew that I was disabled, it was hardly ever an issue to other children or

friends of mine. It was when I would venture out to play with the British kids that my disability came out in the open. To begin with, the “Brits” weren’t too fond of Americans invading their “community.” So when I would ask the British kids if I could play soccer with them and if they couldn’t understand me, they would call me “spastic.” To the British, “spastic” meant “mentally retarded.” Even though I knew I wasn’t “spastic,” I was now reminded that in fact I was “different” than the other children and that I did have something wrong with me. None of my friends or teachers treated me any differently, but I “knew” that I was. In fact, a lot of my friends joined the community Little League baseball teams and so did I. I wasn’t good enough to play on the “A” league, which was for more advanced kids in my age group, so I played on the “B” league. The “B” league was comprised of younger kids than I was. However, I was good enough to be a starting player as a left fielder. Deep inside, I was beginning to understand that my disability was beginning to impact “who” I was because I wasn’t advanced enough to play with most of my other friends in the same upper division league that they were playing in.

During Physical Education (PE), I was almost the last person to be picked for teams. I was beginning to question why wasn’t I good enough, or what is wrong with me. No one needed to explain to me “why” or “how come” because I knew why. I compensated for my lack of physical abilities by being the class clown and developing a likeable personality. I never had trouble making friends after a person got to know me, could understand me, and got to know the “real” me.

During these two years in Hong Kong, the relationship between my mother and I was definitely taking its toll. I was very defiant and did the opposite of everything she told me to do. I resented my mother because I could just feel that she saw my disability as a burden.
as being bothersome to her and interfering with her life plans. She felt as if I was going to be a burden to her for the rest of her life to where she would have to take care of me for the rest of my life. She was beginning to reveal that she saw me as “crippled” and unable to have achievements like a normal child would be expected to. An example of this is when I played baseball. We had a game every Saturday during the season, a total of 25 games. Between her and my stepfather, they probably attended anywhere from seven to nine games. It was normal for my sister and I to take the 45-minute bus ride to the baseball park so that I could play my game. Needless to say, my parents showed little support in their “crippled” child’s life. My mother’s lack of involvement in my life played a major role in how I felt about her. About this time in my life, I hated her!

When my stepfather’s 2 years was up in Hong Kong, my sister and I lived with my father for a while in Kentucky, which could not have come a day sooner for me.

The 4 months of living with my father and future stepmother, who he was only married to for 8 months, changed my life forever. One afternoon, Pam (my soon-to-be stepmother) and sister took off to go shopping. My father was at work and I was left at home to watch Pam’s two children. Kelly, the little boy, was about 3 years old. Margaret, the little girl was about two. When Pam and my sister took off to go shopping, Kelly was outside on the porch crying and throwing a fit. At 12 years of age, I wasn’t much bigger than he was. I was doing everything I could to get him inside. Meanwhile, his sister, after watching him cry, started crying herself. After about 20 minutes of trying to get him to come in, I gave up and went inside, leaving the front door open in case he decided to come in. Meanwhile, the neighbor across the street called social service and the police on me. Next thing I knew there were two police cars with sirens blaring and a social

worker, not to mention the nosy neighbor across the street. I frantically called my father at work but he was in the field, so I called my kindergarten teacher who lived in the next town. Before my kindergarten teacher arrived, the neighbor stood just outside of the screen door yelling at me in front of the social worker. The social worker did absolutely nothing, allowing the neighbor to continue his rampage on me, and the social worker himself took the side of the neighbor, making accusations at me as well for beating Kelly without even asking me for my side of the story. During this time of complete chaos, I was so scared and frightened that my only saving grace was an African American police officer. This policeman took the time to isolate me from the commotion going on in front of the house and took me for a walk in the back yard to calm down. He assured me that I had done nothing wrong and that nothing bad was going to happen to me. When my kindergarten teacher arrived, she happened to know this police officer and they both assured me that everything was going to be all right.

Even at the age of twelve, I knew that the social worker was supposed to be on my side as well, but he wasn’t! It was at this point that I decided that “when I grow up, I wanted to be a social worker.” This incident traumatized me for a long time because I knew that the one person who should have been on my side wasn’t. Wanting to become a social worker started out as just being a career, but now since my disability is more prevalent and I am continuously dealing with new health issues because of my cerebral palsy, my career as a social worker is taking on new meaning(s) as every day goes by. Social work is now becoming a lifelong passion where my goals and objectives have different meanings than they did even a year ago.
Since I didn’t see my future stepmother as a “stepmother” figure, and my father just received orders to go back to Germany, I decided to move back with my mother, sister, and stepfather in New York after finishing the first half of my sixth grade year in Kentucky. The difficult part of this new living arrangement for me was that I was no longer getting my father’s “sole” attention.

My stepfather was stationed at West Point (The United States Military Academy), teaching cadets Chinese. We lived on an Air Force base about 30 minutes from West Point called Stewart Air Force Base. This base was basically a bedroom community. There were a lot of kids in my sister’s age group as well as mine, where we all went to the same schools together. There were two major activities that I involved myself in. They were bowling and bicycle riding. There were about 30 of us kids aging in grades from 8th to the 10th grade that were on the same bowling league. We were a tight clique in which we supported each other on and off the lanes. Everyone knew that I was “handicapped” but all of my friends and teammates were supportive and encouraged me to do my best. I even received several bowling plaques and trophies. One of the trophies was for “most improved bowler.” In order to receive this particular trophy, the other bowlers had to vote for the person that they thought deserved it.

Throughout the 2½ years in New York, I was developing my physical abilities by doing a lot of bike riding, bowling, playing football, basketball, and baseball with the neighborhood kids. My body was beginning to develop like “normal” adolescent kids my age. The cerebral palsy was playing a lesser part in my life due to my active lifestyle. This proved to be the foundation of decreasing the effects of the cerebral palsy that impacted me later in life.

When my stepfather’s 3-year assignment was up in New York, we moved to Fort Leavenworth, Kansas for a year. In Kansas, I attended a junior high school in which all of the kids were “military brats” including myself. Most of these kids were officers’ kids. Since I was the new kid on the block, I went through a very rough “initiation” process. A week into the school year, I was jumped in the boys restroom by three of my peers. I was able to take care of myself until the third one jumped in and slammed my head against the urinal. I stumbled out with a black eye, a busted lip, a fractured rib, and a big knot on my head. I never reported this to any authority figure(s), such as teachers or the principal. I kept in mind what my father had said to me many years ago about standing up for myself. Throughout the school year, I sought revenge on each of the three boys in various ways. From this experience, I realized that I now had to take care of myself; in a way, I was on my own!

I did not do well at all, especially academically because I hated this school and the kids who attended there. My issues at home were also very troublesome as well. I was beginning to become rebellious toward my mother and stepfather. I found myself being grounded a lot from my bowling league and my motorcycle. My parents knew that these were the only two things that were important to me. My grades in school were barely good enough for me to graduate to the 10th grade. I was very unhappy with the school I was attending and the environment as a whole. I feel that this is why I didn’t excel academically.

During our year in Kansas, I did get my first job. I was a paperboy for the local Leavenworth newspaper and the Kansas City Times newspaper. I would get up at four in the morning seven days a week to deliver the Kansas City Times and when I came

home from school, I would deliver the Leavenworth times. This allowed me to gain important work experiences. I now had a responsibility and it also gave me the freedom to earn my own money without having to depend on my parents, which was the last thing I wanted to do. I also joined the school’s wrestling team but I had to make a choice of either delivering papers or wrestling. I couldn’t do both because I was just too exhausted from doing both. I chose keeping my two paper routes because of the money and the extra freedom of having my own money.

In the summer of 1985, we moved to Castroville, California. My parents heard from various people that the high school that I was about to enter as a 10th grader was an excellent high school academically. Since I did poorly in the school that I attended in Kansas, my parents were concerned about my ability to “achieve” in this tough academic setting. I remember one evening at the dinner table, before the new school year, my mother turned to me and said, “Chunk, I don’t think you’re smart enough to graduate from this high school (North Monterey County High School).” I just looked at her and bit my tongue, not saying a word. Looking back now, maybe this is what I needed in order to prove to my mother, but most importantly, to myself, that I could do it! This was the biggest turning point in my life thus far. I remember telling myself, “OK Chunk, you’re on your own!” At this point, I decided that I was on my own as far as not having the advantage of having the support of my parents, especially my mother! I got the feeling that I was doing everything for myself. My biggest objective was proving my mother wrong by showing her that “I can do it and graduate with honor role capabilities.”

My first 9-week grading period, I did make the honor role. When I came home from school, my mother was in the kitchen cooking. I walked in with my report card in

hand and I tossed it on the counter and I said, “Here is my report card from your stupid ass son,” as I walked out. She never did congratulate me or acknowledge my achievement. It was clearly my sister who got the praises for her “good” grades.

I decided that I wanted to join the wrestling team once again. This time I stuck with it through the next 3 years. My very first tournament where I was going to be wrestling was at my high school, which was less than 2 miles from where we lived. I told my mother weeks before the tournament that it was going to be at home wrestling and that I would like her to come, even if it was just only going to be for a couple of hours. The tournament was an all day event. I wrestled four times that day. I received my first win and I was voted the “wrestler of the week.” I kept looking out to see if my mother was there, but she never showed up. When I came home that evening, she was in the kitchen keeping herself occupied. She barely acknowledged my coming in and never did ask me how I did or show any type of interest. Not one word was brought up about my day or about my wrestling. Therefore, I didn’t say anything myself even though I was really hurt, disappointed and angry. I just could not comprehend why she couldn’t have taken a few hours out of her kitchen to see her only son wrestle. This event only added to my already hostile attitude towards my mother. Throughout my first year of wrestling, neither my mother nor stepfather took time to see me wrestle. The atmosphere at home continued to get worse as each wrestling match or tournament went by and my parents were “no shows.” At home, I took great effort in avoiding my mother just as she did with my wrestling endeavors. Little or no words were spoken between my mother and I. It seemed like every time we did speak, it would end up in an argument or that there was an exchange of hurtful words said by both of us. Besides the physical advantages of

wrestling was keeping me in top physical shape, it served as a therapeutic outlet allowing me to vent my frustrations on other wrestlers in a “legal” manner.

After a year and a half of my parents not seeing me wrestle, they sat me down to ask me why was I so angry and mean-spirited every time they would try to talk to me. My response was, “do you remember ever seeing me wrestle, because I don’t! I’m not asking you guys to come to every single one of my matches, but damn at least make a fucking effort.” So after our little talk, the rest of my junior year and senior year, they came to roughly four of my matches; 4 out of 80 matches that I wrestled in 3 years. From my point of view, I still feel that my parents did not see the importance of the most important activity of my life. It is not very often that a teenager with cerebral palsy is successful in playing on high school athletic teams like I was, and I was excellent at. My parents were so out of tune with my life that they had no idea that I was using steroids all through my junior year of wrestling. The only reason why I did steroids, like most other athletes, was so that I would be bigger, stronger and meaner than my opponents were.

Other than my family problems, I excelled in school academically and socially. I almost always had girlfriends and had friends that I would hang out with and go to parties. There was only one time where I got into a little trouble. During my junior year, my girlfriend and I were walking on the beach in Monterey when an opponent of mine from another school was trying to pick a fight with me. To make a long story short, he was doing his best to get me to fight him. He got me turned around to where I was facing the ocean. He apparently saw two policemen approaching us. He pushed me in the chest and just as I was about to swing, I felt someone grabbing my arm. At that
same moment, I saw the other police officer jump in front of the other kid. It ended up that when the policeman that was holding me back and then released me, I took a swing at the other kid. The kid’s head flew back and hit the other policeman square in the glasses pushing them into his nose, hence, making his nose bleed and making his eyes watery. Next thing I knew, I was face down in the sand with two cops on my back handcuffing me. Since I was a juvenile and times were different in the ‘80s regarding juvenile laws, I was able to see a judge immediately upon my arrival at the Monterey County Municipal Court. While standing in front of the judge, she asked me, “Mr. Christopher, is there anything that you would like to say before the court?” Of course she was expecting me to apologize, which I didn’t. My response was “yes, I only wished I would’ve punched the cop harder than I did.” Not appreciating my response, the judge immediately slammed her gavel and said, “not only are you getting a $350 fine but you just bought yourself 50 hours of community service. Would you like to say anything else, Mr. Christopher?” I politely responded with, “No your honor, have a good evening.” I am not telling this story to share my stupidity, or my “manly image,” but rather something more deeply. I was under the influence of steroids. Like any drug, steroids affect people differently. For me, my level of patience was very minimal, I had a nasty temper and I often resorted to throwing punches, rather than being civil. A simple dirty look from somebody was enough to set me off enough to start fighting.

At home, this also added to the already existing stresses between my mother and I. My parents both knew that there was a change in my mood(s), but they could never figure out why. My mother would often go through my room to try to find any signs

or evidence of me using drugs. I never brought home the vials of steroids or the syringes. I would keep them at a fellow teammate and friend’s house.

For the three years of being on the wrestling team, I wrestled at the 100-pound weight class. It wasn’t uncommon that when I stepped on the mat to wrestle that the referee would look at me and tell me that this match is for the 100 pounders. I would assure him that I am the “100 pounder.” Some referees would call both wrestling coaches to make sure. I don’t blame those referees because I looked more like a 114 pounder with the build and muscularity that I had. Doing the steroids undoubtedly caused health problems that continue even today, 12 years later. Since steroids increase muscle mass, I found myself every week being at least 25 pounds over my weight class. Our weekly league matches were on Thursday nights. Starting on Sundays, I would start running every evening and mornings and would not eat during those four days. I would drink just enough water to keep me from dehydrating.

There was one incident when I found myself being over 20 pounds overweight on a Thursday. I had to lose around 23 pounds, and I had four hours to do it in. A friend of mine had a sister who worked in a pharmacy. I asked him to have his sister give him some prescribed water pills. I ingested about six water pills at one time. When I weighed in that evening, I was two pounds under my weight class. My heart was beating so fast and I was ignorant of what water pills do to the body internally. I didn’t know what was going on with me and I wasn’t about to tell anyone. That night when I got on the mat to wrestle, I was definitely dehydrated, shaky and dizzy. That match only lasted for half of the first period. Each period is two minutes long, and there are three periods in a match. When I got off of the mat after being pinned, I walked outside to catch my breath. I don’t

know exactly how long it actually took me to catch my breath, but it seemed like an eternity. I believe that if I wasn’t in such good physical health that this idiotic stunt I pulled probably and should have killed me. If there are such things as angels, I know they were working double time that night keeping me alive.

During the 3-year course of wrestling, I wrestled in two state semi-final tournaments. I was wrestling against the best wrestlers in the state of California. My first of these tournaments was during my junior year. In the second match of this tournament, I wrestled the number 2 wrestler in the state. Needless to say, it was a very tough match. I was trying to flip the wrestler over my shoulder and head. During my move, the wrestler countered my move by hooking his leg around mine so that I couldn’t flip him. Since I didn’t have the momentum to successfully flip him, he landed, or fell on top of me, as I had my neck bridged throughout the flip. So when we hit the mat, his weight and my weight were isolated on my neck. I heard a couple of cracks in my neck as my head hit the mat. Immediately I felt numbness throughout my body, especially in my neck, arms, and fingers. Knowing that I wouldn’t be able to wrestle at this pace, I body hugged him as hard as I could in order to flip him over on his back so that I can pin him. After this match, the pain was almost unbearable. To help alleviate most of the pain, I resorted to injecting myself with 5ccs of steroids. I continued to wrestle through the duration of the tournament with a 4th place finish. I was very discouraged with myself and unconcerned with the injury that I had incurred. I remembered for months after this injury, I was injecting more steroids than usual and I was taking around 20 capsules of extra strength Tylenol a day to keep the swelling down from the back of my neck. I wanted to keep the swelling down because if my parents discovered my injury, they

would have made me quit wrestling. Again, I am not glorifying the use of steroids, or any other drugs for that matter. But for me, I saw what I did as the “solution” to my immediate problems. Looking back now, I realized what I had put my body through and as I stated earlier, I am still paying the consequences of my actions.

As a group, answer the following questions:

1. In intervening with this family at the point you as a group has chosen, what values around disability seem to be more important?

2. What points of knowledge about disability would the social worker intervening with the family want to learn about?

3. At this point of intervention, what particular concerns and needs of the parents need to be addressed?

4. What kinds of intervention techniques are applicable at this point (e.g., family counseling, case management, individual counseling with parents, individual counseling with the child, etc.)?

5. Does the father need to be involved? If yes, what kinds of things could be used to bring the father into the intervention process?

6. At this point of development, what goals might be appropriate for the family and the child?

7. Within the family, what are the stress points that need to be addressed?

CASE SCENARIO: PAUL ANDERSON

You are a social worker in child protective services. You have been given this case to follow up on after an initial phone assessment. Neighbors have called police several times about hollering and screaming coming from the apartment where Paul and his family live. The following has been recorded:

Paul Anderson is an African American male, age 14, with an average IQ who was severely injured in a motorcycle accident. He was illegally driving, without a license or helmet. Paul refuses to return to school. His injury has resulted in partial paralysis of both his arms and legs. He has limited hand movement. Paul suffers chronic depression for which he takes medication. In-home education has been arranged for but to date, neither Paul nor his family has taken the initial steps to begin.

Paul is severely limited in his mobility. He uses a manual wheelchair. His mobility in the chair is hampered because of lack of strength in his hands and arms. His parent's medical insurance does not allow for an electric wheelchair. Family members prepare his food, bath him, attend to his bowel program, etc.

His family is uncooperative in his rehabilitation. Both he and his family miss appointments. They did not follow through on suggestions to make the apartment more accessible. Paul appears to have limited ambition towards education or future employment.

Paul lives with his mother and his younger brother in a modest apartment. Paul is very angry and many times takes his anger out both on his mother and his younger brother. He seems to get along better with his father but his father is away from home.

for long periods of time because of his work as a truck driver. Mother works some days at a local restaurant waiting on tables. Several of his relatives live in the same area of the city and they stop in frequently to visit. His family is very close. They agreed that he will stay with them rather than be institutionalized.

Paul gets along well in the neighborhood. The apartment building is wheelchair accessible for the most part and he visits other family members frequently. He gets out into the neighborhood quite often and various storeowners “watch out for him.” Paul visits the local Radio Shack where Ralph Henderson, the owner takes time to show him how to use a computer on display. Paul is giving Ralph $10 a week towards a computer. Paul is thinking about someday going to computer school to learn programming.

As a group, discuss and answer the following questions:

1. **What will be your interview strategy?** What special considerations, if any, will you consider about the place and time of interview? What kinds of information will you be looking for? What kinds of questions will you be utilizing in order to glean that information?

2. **What will be your assessment strategy?** What kinds of information will you be looking for? From whom will you be requesting that information? How will you use the information?

3. **What will be your plan development and implementation strategy?** What roles will you utilize? What roles will Paul play? What roles will Paul's family play? Will the plan be a written contract? What parts will the social worker initiate? What parts will Paul initiate?

4. **How will you evaluate whether or not the plan has been successful?** Who will do the evaluation? How will you evaluate your practice? How will you change direction if you find the plan was ineffective?