

**A PROVIDER'S HANDBOOK
ON
CULTURALLY
COMPETENT
CARE**



INDIVIDUALS WITH DISABILITIES

*Kaiser Foundation Rehabilitation Center, Vallejo, California
Kaiser Permanente National Diversity Council
Kaiser Permanente National Diversity Department*



KAISER PERMANENTE.

**A PROVIDER'S HANDBOOK
ON
CULTURALLY
COMPETENT
CARE**



TABLE OF CONTENTS

INTRODUCTION	1
DEFINITIONS AND DEMOGRAPHICS.....	2
Concepts and Scope	
Disability Rights Movement	
Americans with Disabilities Act	
Individuals with Disabilities Education Act	
Culturally and Linguistically Appropriate Services Standards	
Disability: Legal/Administrative Definitions	
Federal Definitions	
Public Health Definitions	
Clinical Definitions	
Prevalence	
Age and Gender	
Race and Ethnicity	
Education	
Income and Employment	
Mental Health Disability	
Cognitive or Intellectual Disability	
Health Care Coverage	
Implications for Kaiser Permanente Care Providers	
CULTURAL PERSPECTIVES, ATTITUDES, AND BELIEFS	14
Introduction	
Conceptual Models of Disability	
The Independent Living Movement	
Language Guidelines	
Attitudinal Barriers to Health Care	
Implications for Kaiser Permanente Care Providers	
ACCESS TO CARE	19
Access to Care: Barriers to Communication	
Introduction	
Accommodations for Communication	
Visual Disability	
Hearing Disability	
Accessible Formats for Individuals with Hearing and Visual Disabilities	
Speech Disability	
Cognitive Disability	
Implications for Kaiser Permanente Care Providers	
Access to Care: Primary Care	27
Introduction	

Barriers to Primary Care Access	
Primary Care Access for Children and Adolescents	
Information Technology	
Health Care Registries	
Primary Care, Specialty Care, and Primary Care Models	
Implications for Kaiser Permanente Care Providers	
Access to Care: Specialty Care and Rehabilitation.....	30
Introduction	
Barriers to Care	
Rehabilitation Treatment Teams for Specific Populations	
Rehabilitation Programs: Care Settings	
Assessment and Management of Secondary Conditions	
Implications for Kaiser Permanente Care Providers	
Access to Care: Community and Web-Based Services and Networks.....	35
Introduction	
Barriers to Care	
Community Resources	
Family and Caregiver Support	
Personal Assistance Services	
Durable Medical Equipment	
Preventive Services	
Advocacy	
Public Benefits	
Implications for Kaiser Permanente Care Providers	
RISK FACTORS	38
Stigma, Discrimination, and Disadvantage	
Introduction	
People of Color	
Social Networks	
Leisure Activity, Sports, and Recreation	
Environmental Barriers	
Abuse, Violence, and Neglect	
Implications for Kaiser Permanente Care Providers	
Behavioral and Lifestyle Risk Factors	40
Introduction	
Substance Use	
Sexually Transmitted Diseases	
Physical Injury	
Nutrition	
Implications for Kaiser Permanente Care Providers	

SPECIFIC AREAS OF CLINICAL FOCUS: REPRODUCTION, SEXUALITY, AND PREGNANCY44

- Introduction
- Barriers to Health Care
- Patient Assessment and Interview
- Pregnancy and Parenting
- Education
- [Implications for Kaiser Permanente Care Providers](#)

SPECIFIC AREAS OF CLINICAL FOCUS: PAIN48

- Introduction
- Barriers to Health Care
- General Patient Interview Principles
- Pain Conditions Associated with Physical Disabilities
 - Spinal Cord Injury
 - Multiple Sclerosis
 - Cerebral Palsy
 - Neuromuscular Disease
 - Post-Polio Syndrome
 - Amputations
 - Treatment Considerations
- [Implications for Kaiser Permanente Care Providers](#)

SPECIFIC AREAS OF CLINICAL FOCUS: CHILDHOOD AND ADOLESCENT HEALTH53

- Introduction
- Barriers to Health Care
- Clinical Practice Issues
- Important Considerations for Children and Adolescents with Disabilities
- Functionally-Oriented Approaches
- Developmental Disabilities Affecting Cognitive and Academic Functioning
- Screening and Assessment Tools
- Interacting with Parents
- [Implications for Kaiser Permanente Care Providers](#)

SPECIFIC AREAS OF CLINICAL FOCUS: BLADDER AND BOWEL MANAGEMENT60

- Introduction
- Barriers to Health Care
- Urinary Dysfunction and Classifications
- Bowel Dysfunction
- [Implications for Kaiser Permanente Care Providers](#)

SPECIFIC AREAS OF CLINICAL FOCUS: MENTAL HEALTH.....	65
Introduction	
Barriers to Health Care	
The Impact of Disability on Mental Health	
Individuals with Disabilities and Co-Morbid Mental Disorders	
Mental Health Disorders	
Mood Disorders	
Anxiety and Panic Disorders	
Psychoses	
Cognitive Disabilities	
Substance Use, Abuse, and Dependence	
Implications for Kaiser Permanente Care Providers	
CONCLUSION.....	72
APPENDIX	73
Appendix A: Neurogenic Bladder Dysfunction Table	
Appendix B: Neurogenic Bowel Dysfunction Table	
BIBLIOGRAPHY	75
ACKNOWLEDGMENTS	85
EVALUATION	89

INTRODUCTION

Kaiser Permanente is committed to providing the highest quality of care to our increasingly diverse membership. Kaiser Permanente's mission to provide personalized care and to improve the overall health of the communities we serve aligns with our commitment to “culturally competent care.” “Culturally competent care” refers to the delivery of health care services in a manner that acknowledges and understands cultural diversity in the clinical setting, respects members' health beliefs and practices, and values cross-cultural communication. Ensuring that a patient's cultural needs are considered and respected at every point of contact is essential. Consumers and regulatory authorities are evaluating health care organizations for their ability to provide such care.

The goal of the Provider's Handbook Series is to provide Kaiser Permanente's health care professionals with an overview of the cultural and epidemiological differences that characterize major cultural groups represented in our membership. Our intention is in no way to stereotype our members or patients by groups. Rather, the Handbooks focus on common characteristics of each group that may have implications for health care organizations and health care practitioners. The Handbooks present health care research, practical information, and tools that can help our providers become more aware and knowledgeable about the health care needs of our diverse membership. This Handbook is the first edition of the Provider's Handbook on Culturally Competent Care: Individuals with Disabilities.

This Handbook aims to raise awareness about this diverse cultural group and to provide guidance for the management of specific disability conditions. People with disabilities may require care from a wide range of health care professionals, and this care is best delivered through implementation of an interdisciplinary model, or at least with clear and consistent channels of communication. Kaiser Permanente's integrated health care delivery system, which allows our health care providers to work together and not in isolation, is in a unique position to provide the constellation of services necessary for persons with disabilities.

We chose the Specific Areas of Clinical Focus sections of this Handbook to provide information for clinicians in topic areas that may be underrepresented in health sciences educational curricula, but which are essential for improving the quality of care for our members with disabilities. Health science curricula in medicine, surgery, nursing, and other health care fields have for many years emphasized acute diagnosis and treatment, not the care of individuals with chronic diseases and disabilities. The additional clinical focus sections are provided to educate primary care and specialty care providers in all fields about the management of specific conditions underrepresented in health sciences curricula.

Kaiser Permanente is dedicated to establishing cultural competence through curricular enhancements, and believes that this is an important strategy to:

- Achieve the highest quality of care by promoting best practices.
- Improve the health status of the communities we serve.
- Promote high retention rates.
- Expand our membership.
- Promote cost containment through integrated, evidence-based practice.

The information provided in this Handbook comes primarily from four sources: 1) articles published in medical and health care journals, 2) state and federal publications, 3) vital statistics published on the Internet, and 4) Kaiser Permanente experts. An editorial board composed of Kaiser Permanente physicians, staff, and community experts reviewed this Handbook.

DEFINITIONS AND DEMOGRAPHICS

Concepts and Scope

At the outset, we must acknowledge that defining disability is complicated because of the multifaceted aspects represented within the concepts of disability, both theoretical and practical, and because of the evolution of these concepts over time. In light of this reality, it is not surprising that many different definitions, models, and classification systems have been devised, reflecting legal, public health, clinical and research perspectives. Each has different purposes and different philosophical or intellectual frameworks. This discussion highlights the legal, administrative, and clinical definitions that are useful to a clinician in practice in the health care setting.

The National Health Interview Survey (NHIS) is an annual, multistage, stratified survey of the health and health care of households in the United States. The Survey of Income and Program Participation (SIPP), on the other hand, is an annual household survey of the U.S. Bureau of the Census that serves to gather statistics on the economic status of U.S. households. These surveys collect information on impairments and disabilities, with a focus on activities within and outside the home, as well as limitations at work, including public transportation and taking care of personal needs.

According to U.S. Census data, people with disabilities comprise the largest single minority in the United States, numbering 52.6 million, or almost 20% of the population. The number of individuals with disabilities in the United States is thus approaching the combined populations of African Americans (12.3%), Latinos (12.5%), and Asians (3.6%). Almost one-third (29.2%) of families in the U.S. claim at least one member with a disability. In addition, approximately 6.5% of non-institutionalized children in the United States have a disability. Of the approximately 25 million people in the United States, ages 15 to 21, 12% report some degree of disability, while 3.2% report severe disability.

People with disabilities are a heterogeneous group. The disability community encompasses individuals from diverse religious groups, racial and ethnic backgrounds, sexual minorities, and socioeconomic strata. In addition, the reasons that an individual may be identified as having a disability include cognitive, mental, sensory (hearing or vision), or motor disability.

In addition, approaching individuals with disability as a demographic group is complicated for several reasons. Most importantly, different laws, sub-cultural groups, and health care systems define disability in different ways, making a shared definition of disability challenging. In addition, some individuals do not self-identify as having a disability.

Disability Rights Movement

The disability rights movement mobilized in the 1970s when civil rights activists sought to gain equal access and protection from discrimination in the workplace. The first federal law addressing equal access for individuals with disabilities was Section 504 of the Rehabilitation Act of 1973. Section 504 mandates: "No otherwise qualified handicapped individual ... shall...be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance." Since then, numerous federal and state laws have elaborated on the civil rights of people with disabilities to be free from discrimination and to obtain equal access to the goods and services available to the general public. Although legislation has been critical in advancing the legal rights of individuals with disabilities, discrimination, barriers to participation, economic disparities, and social stigmatization still remain.

Americans with Disabilities Act

The landmark 1990 Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act of 1973, are the principal federal laws that govern Kaiser Permanente's obligations to individuals with disabilities. Together these laws constitute a national mandate prohibiting discrimination on the basis of disability. These two pieces of legislation seek to ensure that people with disabilities have an equal opportunity to receive and benefit from health care programs and services by making it unlawful for public and private health care services, programs, and providers to treat people with disabilities in a discriminatory manner. These laws require Kaiser Permanente to make its facilities and health care services fully accessible to individuals with disabilities, and to provide persons with disabilities with health care services that are equally effective as those provided to others. Some states have developed their own disability civil rights laws and may have additional protections for consumers. Notably, California's civil rights laws provide even greater protections for people with disabilities than does federal law.

The ADA's core civil rights principles of non-discrimination, inclusion, and accommodation, with accommodation as the key ingredient, have reshaped the arena in which health care services are delivered for people with disabilities, offering a framework in which to deliver safe, effective, patient-centered, culturally competent health care services.

The ADA specifically states: "No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation." The term "full and equal enjoyment" has been interpreted to mean the right to participate and to have an equal opportunity to obtain the same results as others. All service establishments, including hospitals and the professional offices of health care providers and pharmacies, are considered places of public accommodation under the law. Also, as a recipient of federal financial assistance in the form of Medicare and Medicaid, Kaiser Permanente has similar obligations under Section 504 to provide accessible facilities and services to individuals with disabilities as a condition of continued receipt of federal financial assistance.

Medical equipment, such as examination tables, weight scales, x-ray, and mammography equipment that accommodates people with disabilities ensures accessibility to health care services. Accessible and effective medical care for patients with disabilities requires that health care providers be aware of the specific health care needs of each patient and be able to provide appropriate equipment that ensures proper diagnosis and treatment.

The law also recognizes the importance of effective communication with patients who have disabilities in order to provide accessible and effective medical care. The ADA and Section 504 require health care institutions to provide necessary auxiliary aids and services to individuals with disabilities, including those with hearing, visual, and speech impairments. These laws entitle patients to effective communication with health care providers and staff in order to ensure that they receive the benefits of Kaiser Permanente's services and programs on an equal basis with persons without disabilities. In addition to the requirements of these accessibility laws, effective communication with patients with disabilities is required for patient safety, quality of care, and informed consent.

Examples of auxiliary aids and services include qualified sign language interpreters, closed caption decoders, video text displays for patients who are deaf, and written material provided in alternative formats, such as audio recording, Braille, or large print for people with vision disabilities.

Individuals with Disabilities Education Act

It is also critical that health care providers understand the basic tenets of the Individuals with Disabilities Education Act (IDEA) and the Individual Education Plan (IEP) process, as providers may be asked to give supporting documentation for a student's IEP. Under IDEA, local school districts are required to provide evaluation, eligibility determinations, individualized education programs, appropriate placement, and other accommodations that ensure equal access to education for children with disabilities until they reach high school graduation or age 22. The IDEA also provides for early identification and intervention programs for children under the age of 3 who are considered at risk for a developmental disability.

Providers may also be asked to provide supporting documentation for accommodations for higher education, and for graduate school, professional, vocational, and other high-stakes exams. This access is protected not by IDEA, but by the ADA and Section 504 in post-secondary settings.

Culturally and Linguistically Appropriate Services Standards

Requirements for communicating with deaf and hard of hearing patients include the National Standards on Culturally and Linguistically Appropriate Services in Health Care, issued by the Office of Minority Health in the Department of Health and Human Services. The Culturally and Linguistically Appropriate Services Standards (CLAS Standards) require health care organizations to provide interpreter services for patients who communicate using sign language. In addition to American Sign Language (ASL), there are also other kinds of sign language, and the provider should identify the interpretation the patient requests. For example, some people use "Signed English," a form of sign language that, unlike ASL, is modeled on English grammar. In addition, there is tactile sign language for people who are deaf-blind, and there are sign languages used by non-English-speaking persons.

Disability: Legal/Administrative Definitions

Americans with Disabilities Act

The ADA defines disability with respect to an individual in three prongs as follows: 1) a physical or mental impairment that substantially limits one or more of the major life activities of such an individual; 2) a record of such an impairment; or 3) being regarded as having such an impairment. "Major life activities" include functions such as activities of daily living, walking, seeing, hearing, speaking, breathing, learning (including attending school), and working. State law and case law may further define "disability." The phrase "regarded as" is noteworthy, as the intent is to define discrimination based on stigma regardless of whether the individual actually has a disability that limits a major life activity.

U.S. Social Security Administration

The U.S. Social Security definition of disability requires that the individual demonstrate: "...the inability to engage in any substantial gainful activity by reason of any medically determinable physical or mental impairment which can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months." Thus, an individual may have a disability that is protected by the ADA, Section 504, and some state laws, but not qualify for Social Security Disability Income (SSDI). State disability programs may have different definitions and requirements, and the provider should be familiar with state disability statutes and procedures.

Public Health Definitions

Centers for Disease Control and Prevention

The Centers for Disease Control and Prevention (CDC) defines disability as "interactions between individuals with a health condition and barriers in their environment." People with disabilities are regarded as those "having an activity limitation or who use assistance or who perceive themselves as having a disability." The CDC further defines secondary conditions as "medical, social, emotional, family, or community problems that a person with a primary disabling condition likely experiences."

World Health Organization

The World Health Organization (WHO) published the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980. This classification included the terminology "impairment," "disability," and "handicap." The WHO has made revisions to this initial classification system to represent a shift in how health and disability are viewed, incorporating the concept that barriers to activity and participation are represented in the environment rather than the individual. The classification system is based on aspects of human functioning, and environmental and personal factors. During the 2001 World Health Assembly, the organization officially endorsed the revised system, the International Classification of Functioning, Disability and Health (ICF.) The ICF is intended to provide a common transcultural language for health care systems, to promote international data comparison, and to serve as a tool to measure health outcomes, quality, costs, satisfaction, and health disparities.

Clinical Definitions

Guides to the Evaluation of Permanent Impairment

The Committee on the Rating of Mental and Physical Impairment of the American Medical Association authorized the publication of the “Guides to the Evaluation of Permanent Impairment” (GEPI), beginning in 1958. These guides are intended to assist physicians in identifying the degree of impairment that a particular disorder represents, leaving the determination of disability to the administrative or legal system. The GEPI defines impairment as “loss, loss of use, or derangement of any body part, organ system, or organ function. A disability is considered permanent if it is unlikely to change substantially next year with or without medical treatment, and is not likely to remit despite medical treatment. An impaired individual who is able to accomplish a specific task with or without accommodation is neither handicapped nor disabled with regard to that task. This rating system has been criticized as being arbitrary, not substantiated by research, having poor inter-rater reliability, and being inadequate for assessing certain populations of individuals with disability, particularly individuals with cognitive impairments. These guidelines should, therefore, be used with caution, and should be used in conjunction with other functional measurement tools.

International Classification of Diseases Diagnostic and Statistical Manual of Mental Disorders

The International Classification of Diseases (ICD) and The Diagnostic and Statistical Manual of Mental Disorders (DSM) represent other frameworks in which diagnoses of disabling conditions are defined and classified. Both systems were created for data collection and statistical purposes, and provide a medical nomenclature for physicians and other providers. In the case of the ICD, a diagnosis may not necessarily result in an impairment of function, although with most diseases there is at least a temporary, i.e. acute, loss of function. In the case of the DSM, a mental disorder is defined as a behavioral or psychological syndrome or pattern that is associated with distress or disability, or with risk of suffering pain or death.

Prevalence

Health care organizations face many challenges in determining the prevalence of disability within populations. Coding systems used for medical information data collection, usually based on the ICD or DSM systems, only identify individuals by diagnosis, not by disability. These classification systems are not useful for determining the incidence or prevalence of disability, because diagnosis does not always mean loss of function or loss of work.

The U.S. government conducts a number of national surveys that estimate disability prevalence. A major concern with these surveys is that they rely on respondents to self-identify as having a disability but do not ensure that everyone is using the same definition of “disability.” The lack of standardization makes it difficult to estimate prevalence. Consequently, efforts to assess health care disparities and successful practices are limited. However, regardless of the definitions or classification systems utilized, there is a general consensus among governmental groups and health care organizations that the percentage of people with disabilities is in the range of 15-20% of the U.S. population.

The Survey of Income and Program Participation (SIPP) defines disability broadly, and includes an extensive set of specific questions on physical, mental, and work-related activities. The SIPP defines individuals as having a disability if they meet any of the criteria listed in Table 1. Statistics on specific disabilities can be found in Table 2. See Table 3 for a list of the top ten specific conditions of disability.

Table 1: Definitions of Disability Status, Functional Limitations, Activities of Daily Living, and Instrumental Activities of Daily Living.

1. Uses a wheelchair, a cane, crutches or a walker.
2. Has difficulty performing one or more functional activities (seeing, hearing, speaking, lifting/carrying, using stairs, walking, or grasping small objects).
3. Has difficulty with one or more activities of daily living (the activities include getting around inside the home, getting in or out of bed or a chair, bathing, dressing, eating, and toileting).
4. Has difficulty with one or more instrumental activities of daily living (the activities included going outside the home, keeping track of money and bills, preparing meals, doing light housekeeping, taking prescription medicines in the right amount at the right time, and using the telephone).
5. Has one or more specified conditions (a learning disability, mental retardation or another developmental disability, Alzheimer's disease, or some other type of mental or emotional condition).
6. Has any other mental or emotional condition that seriously interfered with everyday activities (frequently depressed or anxious, trouble getting along with others, trouble concentrating, or trouble coping with day to day stress).
7. Has a condition that limited the ability to work around the house.
8. If age 16 to 67, has a condition that made it difficult to work at a job or business.
9. Receives federal benefits based on an inability to work.
Individuals are considered to have a severe disability if they met criteria 1, 6 or 9; or have Alzheimer's disease, or mental retardation or another developmental disability; or are unable to perform or needed help to perform one or more of the activities in criteria 2,3,4,7 or 8.

Source: Adapted from McNeil, 2001. U.S. Census Bureau.

Table 2: Prevalence of Specific Types of Disabilities in the United States

Type of Disability	15 years and older (N=208,059,000)	65 years and older (N=32,064,000)
All Disabilities	23%	54.5%
Difficulty Walking/Using Stairs	12.1%	39.9%
Difficulty Lifting/Carrying 10 lbs/Grasping Objects	8.7%	27.6%
Difficulty Seeing/Hearing/Speaking	7%	22%
Has Activity of Daily Living Limitation	4.2%	14.2%
Uses Cane/Crutches/Walker	3.1%	13%

Source: Adapted from McNeil, 2001. U.S. Census Bureau.

Table 3: Prevalence of Top Ten Specific Conditions as the Main Cause of Disability Among Persons Age 18 and Older in the United States

Number	Main Condition	Total N=41,168,000	Men N=17,767,000	Women N=23,401,000
1	Arthritis or rheumatism	17.5%	11%	22.4%
2	Back or spine problem	16.5%	16.3%	16.6%
3	Heart trouble/hardening of the arteries	7.8%	9.4%	6.6%
4	Lung or respiratory problem	4.7%	5%	4.5%
5	Deafness or hearing problem	4.4%	6.7%	2.6%
6	Limb/extremity stiffness	4.2%	4.7%	3.9%
7	Mental or emotional problem	3.7%	4.1%	3.5%
8	Diabetes	3.4%	3.4%	3.4%
9	Blindness or vision problem	3.3%	3.5%	3.1%
10	Stroke	2.8%	3.3%	2.4%
11	Other conditions	31.7%	32.6%	31%

Source: Adapted from McNeil, 2001. U.S. Census Bureau.

The 2001 Behavioral Risk Factor Surveillance System reported that a third of the adult population has arthritis or chronic joint symptoms, which is consistent with the 34% figure represented by numbers 1 and 2 (combined) in Table 3.

Age and Gender

Older adults are more likely to have a disability than younger adults. According to the U.S. Census Bureau, 54% of individuals age 65 and older reported having a disability, compared to 19% of individuals, ages 25 to 64. The proportion of adults age 65 and older is growing significantly in the U.S. Factors such as decreased birth rates and a growing life expectancy are contributing to this trend. The number of adults age 65 and older in the United States is expected to double from 35 million in 2000 to 71 million by 2030. The growth of the older adult population is likely to have a dramatic effect on the prevalence of disability in the United States in the years to come.

Research on aging with a disability is one of the most important new developments in rehabilitation. Certain sub-populations of individuals with disabilities experience consequences of aging that may differ from non-disabled populations. For example, adults over the age of 50 with disabilities that limit mobility show functional changes that would not be expected until ages 70 to 75 in people without a disability. In addition, secondary health problems occur at three to four times the rate for individuals without a disability.

The U.S. Census Bureau reports that there is a greater prevalence of disability among males up to the age of 24, and females 25 and over. This statistic holds true for all severities of disability and all racial and ethnic groups. The greater prevalence of disability among boys and young adult men may be explained by physiological or maturational differences, and school bias or assessment bias, according to the U.S. Department of Education. High-risk activities and socioeconomic factors may also contribute to the higher prevalence rates in this group. A greater life expectancy among women may explain the higher prevalence of disability after the age of 25. Depending on the condition, prevalence may differ; for example, the prevalence rate of arthritis is higher in female populations, whereas disability secondary to spinal cord injury is more prevalent in male populations.

The Women's Health and Aging Study, a survey of a large sample of women age 65 and older with disabilities, documented that 24% reported financial difficulty obtaining food. In this study, nearly 50% of women of color reported financial difficulty obtaining food. The study also concluded that the need for personal assistance increases significantly with age. For those age 80 and over, 35% reported a need for personal assistance compared to 17% for those ages 75 to 79.

Race and Ethnicity

Among major racial and ethnic groups in the United States, African Americans report the greatest prevalence of severe disability consistently across all age groups. The prevalence of severe disability increases substantially in people age 65 and older in all groups and is significantly higher for people of color. See Table 4 below for specific prevalence rates. See other Kaiser Permanente Provider Handbooks on Culturally Competent Care for specific populations.

Table 4. Severe Disability by Race/Ethnicity

	African American	Asian and Pacific Islander	Caucasian (Non-Latino)	Latino
All Age Groups with Severe Disability	12.7%	8.5%	12.2%	9.7%
65 and Older with Severe Disability	51.8%	49.2%	35.3%	47%

Source: Adapted from McNeil, 1997. U.S. Census Bureau

Education

Educational status interrelates with and may influence socioeconomic status and health status. Level of education is closely linked to health, socialization, employability, and level of income for people with disabilities. Twenty-two percent (22%) of U.S. Americans with disabilities do not complete high school, compared with 9% of those without disabilities. Accommodations and transition planning for school-aged children with disabilities are still not consistently provided in all school systems, despite being mandated by legislation. Academic achievement provides a sense of participation and increased self-esteem, and classroom settings provide an opportunity for social interaction and networking for people with disabilities.

Young people living with disabilities are at increased risk for adjustment problems such as internalized symptoms (for example, anxiety, depression, and social withdrawal), externalized symptoms (for example, aggression, conduct disorder, and hyperactivity), and lower self-esteem. Associated consequences of these adjustment problems include higher school drop-out rates, unemployment, and high poverty rates. Approximately 25% of students with disabilities ages 16 to 21 drop out of school. Poverty rates are three times greater among students with disabilities when compared with students without disabilities.

Access to higher education is one of many challenges faced by individuals with disabilities. According to the 1997 SIPP survey, 9.4% of persons ages 25 to 64 with a severe disability were college graduates, compared with 28.5% of persons without a disability in the same age cohort. New technology and 'distance learning' have provided people with disabilities improved access to educational programs after high school.

Income and Employment

Due to high levels of unemployment, individuals with disabilities experience stark differences in income. In a recent study, for example, of people ages 25 to 64, 14% of those with a disability earned between \$20,000-\$39,000 annually, compared to 32.5% of those without a disability in the same age group. Only 32% of Americans with disabilities ages 18 to 64 were working, compared to 81% of those without disabilities in the same age category. Those with hearing disabilities are the most likely to be working. As would be predicted, severity of the disability is negatively correlated with employment status. Eighteen percent (18%) of adults without disabilities ages 21 to 64 are unemployed, compared with 23% with a non-severe disability and 73% with a severe disability. Of the total number of individuals with mental disabilities, 58% are unemployed, and among those who use a wheelchair, 78% are unemployed.

The poverty rate among people with disabilities is significantly higher than for individuals without a disability. In 1997, 8% of the U.S. population ages 25 to 65 without a disability lived in poverty, compared with 28% of those with a disability in the same age group. These data underscore the importance of the ADA and other legislation protecting access to services, and the need to provide workplace accommodations, employment programs, and preventative and ongoing health maintenance for people with disabilities.

Surveys report that the majority of persons with disabilities want to work, but individuals with disabilities have a long history of being excluded from the workforce. People with disabilities encounter a range of challenges in the workplace, including lack of on-the-job accommodations, low pay, and discrimination. Workers with disabilities earn less per hour and work fewer hours per week than workers without disabilities. The average household income of people with disabilities averages about 75% of the income of people without

disabilities. Supplemental income from disability or retirement benefits and the earnings of other household members do not compensate for the earnings gap between people with and without disabilities.

Employer accommodations and assistive technology are, in most cases, inexpensive and result in a productive and satisfied employee. The level of employer satisfaction with the need for job accommodations is increasing, and many employers are finding that the benefits of employing people with disabilities generally outweigh the expense. According to the U.S. Equal Employment Opportunity Commission, 78% of people with disabilities do not need accommodations at work. Another 7% require no-cost accommodations. Of the remaining 15%, roughly 56% of the accommodations cost between \$1 and \$500, 28% cost between \$501 and \$1,000, and only 16% cost more than \$1,000. Only 0.2% of accommodations cost more than \$5,000.

Mental Health Disability

Approximately 6.7 million U.S. citizens of working age have a mental health disability; 3.6 million people age 65 and older have a mental health disability. Nearly 20% of children and adolescents have mental health disabilities. Approximately 2.8% of the adults in the United States have a severe mental disorder. Primary mental disorders account for 3.3% of all disabling conditions.

According to a 1996 study conducted by the WHO, bipolar disorder, schizophrenia, and obsessive-compulsive disorder are among the 10 leading causes of disability in the United States and other developed countries. Major depressive disorder is the leading cause of disability in the United States and worldwide.

Providers should address mental health treatment issues in individuals with primary mental health disabilities, as well as patients with physical disabilities who may have coexisting mental health conditions. Substance abuse is a major problem in the United States and many industrialized countries. Lifetime prevalence rates of substance use disorders in adults are approximately 19.2%, with about two-thirds of these being related to alcohol. In children and adolescents, the most common disabilities are anxiety disorders (13%), disruptive behavior disorders (10.3%), mood disorders (6.2%), and substance use (2%). (See Specific Focus on Mental Health.)

Cognitive or Intellectual Disability

Mental retardation, a cognitive or intellectual disability, affects approximately 3% of the U.S. population; with 85% of individuals with mental retardation falling in the mild range. Individuals with mild mental retardation typically are able to develop social, communication, academic, and vocational skills that are adequate for independent or minimally supervised community living. According to the DSM IV, academic skills reach approximately the 6th grade level in this group.

Acquired brain injury, stroke, and dementia account for a significant percentage of the population in the United States with cognitive or intellectual disability. It is estimated that about 4 million Americans currently have a diagnosis of Alzheimer's disease. About 3% of men and women ages 65 to 74 have Alzheimer's disease, and nearly half of those age 85 and older may have the disease. The incidence of traumatic brain injury in the United States is 2 million per year, and 20-30% of individuals have severe enough injuries to result in lifelong disability. Annually, approximately 700,000 Americans are diagnosed with a stroke each year,

which often affects language or cognitive function. The incidence of autism is 1 to 2 per 1,000 people per year. Approximately 4% to 6% of the U.S. population has been diagnosed with attention deficit disorder.

Health Care Coverage

Low levels of employment and poverty are correlated with a lack of employer-based health care coverage. Disability itself may be a factor in preventing individuals from obtaining affordable health care insurance. The U.S. Census Bureau reported in 2001 that 17.2% of people with disabilities ages 25 to 64 did not possess health insurance coverage, and 16% of people with a non-severe disability in the same age group lacked health care coverage.

Implications for Kaiser Permanente Care Providers

- Recognize the diversity within the disability community.
- Understand that an individual may not self-identify as having a disability.
- Recognize a significantly higher prevalence of disabilities for people of color and that self-disclosure, pain, access, and other issues are affected by culture, ethnicity, and/or race.
- Be mindful of the stigmatization of persons with disabilities, and the added stress of being discriminated against based on disability status.
- Understand the interplay between social and economic factors, especially education, income, and employment, and the health of children and adults with disabilities.
- Identify individuals with disabilities who are at risk for accelerated effects of aging, and provide preventive care based on an assessment of these risks.
- Identify the cognitive and physical abilities in individuals with disabilities and assist them to achieve the highest quality of life with the greatest degree of independence.
- Identify appropriate on-the-job accommodations or modifications to promote job entry and re-entry, job retention, and retraining for individuals with disabilities.
- Encourage and assist with academic entry and re-entry, as well as academic achievement and retention through advocacy, including identification of appropriate accommodations or modifications.

CULTURAL PERSPECTIVES, ATTITUDES, AND BELIEFS

Introduction

Although a person may be born with a disability, the majority of individuals acquire disabilities later in life. An illness or injury that causes the disability can happen to anyone at any time in life. In contrast to most groups, this means that there is not an established cultural perspective of disability that is learned in early childhood. However, there is an emerging disability cultural perspective, evolving as the disability rights movement achieves milestones, that is predicated on the experiences of people with disabilities.

Conceptual Models of Disability

Disability scholars describe four conceptual and chronological models for understanding disability within our U.S. culture: 1) the moral model, 2) the medical model, 3) the rehabilitation model, and 4) the social or minority model. Of these, the moral and medical models are generally viewed as oppressive and outmoded ways of understanding disability.

The **moral model** of disability is derived from underlying notions of sinfulness and evil thought to be embodied by persons with disabilities, their families, or the culture at large. While this viewpoint has largely disappeared, its lingering effects may cause individuals with disabilities and their family members to experience guilt, shame, and self-loathing. The social ostracism of people with disabilities might be considered a legacy of this repudiated model.

The **medical model** of disability evolved during the 19th century, along with the professionalization of medicine. In this model, disability is considered the result of a defect or deficiency requiring alteration, eradication, or cure through medical intervention. The disability is seen as residing within the individual and a specific body part or system that requires medical intervention. The medical model exerted primary influence in the design and implementation of policies directed toward people with disabilities prior to the 1970s. While medical interventions may be needed for individuals with disabilities in some situations, as is the case for all individuals, the medical model is not an appropriate basis for the establishment of disability-related policy or legislation. Disability and health status are not synonymous, and many individuals born and living with a disability are healthy.

There are deleterious consequences that derive from the medical model's perspective concerning disability. An assumption that individuals with disabilities require expensive interventions may result in denial of insurance coverage or higher rate setting for people with disabilities, even in the absence of actuarial data demonstrating that the disability is expensive. Employers may be less likely to hire an individual with a disability because of a bias that there will be higher insurance costs. Another consequence of the medical model is that health care providers may be viewed as experts concerning disability by people with disabilities, when in fact little education concerning disability is included in most medical and nursing curricula.

The **rehabilitation model**, described as a permutation of the medical model, is based on the perspective that training, therapy, counseling, and other services may be designed to ameliorate the disability. This model gained acceptance after World War II when many veterans with disabilities needed to be re-introduced into society. The Vocational Rehabilitation system is based on this model.

In the last few decades, rehabilitation fields have incorporated concepts imbedded in the social model of disability, including the perspective that individuals with disabilities must be involved in decision-making about health care, as well as empowered to reach the highest levels of functioning in the home and community. Rehabilitation professionals with this view link individuals with community resources and programs that further promote the achievement of the highest levels of function and independence, including return to work and other meaningful life activities.

The **social or minority model** of disability identifies the key barrier for people with disabilities to be the inhospitality and inaccessibility of the social and physical (structural or built) environment. According to the social model, a disability is often disabling only because of a physical and social environment not constructed to accommodate it. Inadequate support systems or services, and attitudinal, architectural, sensory, cognitive, and economic barriers, may be the key disabling factor for an individual living with a physical or mental impairment. With the advent of the disability rights and independent living movements, the social model of disability has been promoted as a civil rights model that obligates society not to discriminate on the basis of disability, real or perceived. Disability is understood as difference, not deviance, and people with disabilities constitute a minority group equivalent to racial, ethnic, or sexual minorities. This model regards disability as a form of bodily difference. It rejects the notion that persons with disabilities are inherently "defective." It also acknowledges social discrimination as one of the most egregious problems experienced by persons with disabilities and the cause of many of the barriers to quality of life previously attributed to the disability itself. The primary goal of the social model is to eliminate social and structural barriers that impede the expression of ability and participation in all life activities, and that prevent opportunities for people with disabilities that individuals without disabilities take for granted.

Most individuals will experience some form of disability, either permanent or temporary, over the course of their lives. According to the Half the Planet Foundation, nearly 85% of Americans with disabilities acquire their disabilities after birth, through accident, injury, illness, disease, or aging. Given this reality, if disability came to be understood as likely, if not inevitable, then physical and social structures that are more flexible, accessible, and accommodating would be important to all individuals in our society.

Disability as a component of personal identity is not a consistently embraced concept by individuals living with a disability or their families. This may be due to differing cultural attitudes or beliefs, or because stereotypically negative attributes are associated with disability. People with disabilities often hide their condition out of embarrassment and shame. This is especially true for children and adolescents with disabilities, and "fitting in," especially at school, becomes an important goal. Difficulties achieving this may delay or impede the development of self-esteem and self-worth.

In contrast to most cultural groups, there is not an established cultural membership and value system that is learned in early childhood. People with disabilities are not usually born into and nurtured in a culture of disability in the same way as members of other cultural groups. An exception may be a child born with deafness whose parents are both deaf. Within the disability culture, there are many subcultures made up of people with different types of disability. For example, people with blindness have distinct cultural differences, and a different history of discrimination and activism, than people with mobility disabilities. In addition, while many people in the disability community view people who are deaf as having a disability, pre-lingually deaf individuals do not, by and large, think of themselves as people with disabilities.

Ethnic, religious, or other cultural issues also influence one's perceptions of disability. For example, members of some cultural groups may have views that reflect the "moral model" of disability, or may have views that promote dependence rather than independence for the individual with the disability. Understanding all these cultural issues and communicating with the patient about these issues when appropriate will help a provider determine the best treatment recommendations.

According to the National Organization on Disability/Harris 2000 Survey, only 47% of Americans with a disability share a sense of common identity with other individuals with disabilities. Sharing a very strong sense of common identity with others with disabilities is almost twice as likely (30% vs. 16%) to occur in people with severe disabilities as for those with less severe disabilities. People of color who also have disabilities may identify as members of a racial or ethnic group primarily, rather than as members of a disability cultural group. (See Providers Handbooks on Culturally Competent Care for specific racial/ethnic populations.)

The Independent Living Movement

The independent living movement began in the 1960s and was organized by individuals with significant disabilities who wished to establish community-based support services to ensure self-determination. Ed Roberts, a celebrated individual with a severe disability, established the first Independent Living Center in Berkeley, California, in 1972. Subsequently, Independent Living Centers were established in Boston, Massachusetts, in 1974 and in Houston, Texas, in 1975. There are now several hundred Independent Living Centers in the United States with at least one in every state. There are also similar centers in many other countries. A number of key values, in addition to self-determination, underpin the independent living movement, including self-advocacy, self-direction, consumer control, disability pride, a cross-disability focus, peer role modeling, the right to take risks and to fail, creative strategies to promote independence, equal access and equal justice, full societal participation, and quality of life with or without assistance.

For individuals with newly acquired disabilities, as well as for those living with life-long or long-term disability, asking for assistance may be difficult. The U.S. mainstream culture places great value on personal autonomy and independence. People who ask for help are often viewed as weak or demanding. The independent living movement understands independence differently. Independent living does not mean doing everything alone or without assistance, but rather it entails being in control of how, when, and with whom things are accomplished.

Language Guidelines

Use of language is a powerful tool for changing attitudes. By using outdated language, we support stereotypes that imply that people with disabilities are experiencing constant distress and hopelessness. Words or phrases to avoid include: "handicapped," "wheelchair bound," "cripple," "victim," "defective," "afflicted," "suffers from," "invalid," and "special." In addition, using words such as "brave," "courageous," or "inspirational" implies that skill in, and achievement by, people with disabilities is unusual, and these terms should thus also be avoided.

Attitudinal Barriers to Health Care

Questions of identity and status are at the heart of disability policy. One of the central goals of the disability rights movement is to promote a more positive understanding of what it means to have a disability. Many people, including health care professionals, assume that people with disabilities experience a poor quality of life. This culturally ingrained stereotype is not born out of science but rather from stigma. There is concern among disability activists that such long-held misconceptions by health care professionals might influence medical decision-making and ultimately undermine the health and welfare of persons with disabilities now and in the future. People with disabilities are poorly served when they receive care in an environment where this view persists.

Research reveals that people with disabilities rate their quality of life as average or better than average. Although 86% of patients with tetraplegia rate their quality of life as average or better than average, only 17% of emergency-room doctors, nurses, and technicians caring for these patients believe that they would achieve average or better than average quality of life if they were to become disabled in the same way. Rehabilitation patients with spinal cord injuries rate themselves on depression scales similar to the general population, but staff may consistently overestimate depression levels in this population.

The results of a European poll of attitudes toward disability suggest that a large majority of Europeans know someone with a disability, and 61% know a neighbor with a disability or have daily or weekly contacts with a person with a disability. Although 80% of respondents reported feeling at ease in the presence of people with disabilities, 44% think that "other people" do not feel at ease.

In another study, subjects reported more negative reactions (for example, pity and disgust) to people with disabilities if they also reported having no contact with anyone with a disability. These feelings were atypical for relatives of people with disabilities. In the survey, most respondents also reported a lack of understanding about different types of disabilities. Disability from cancer, asthma, diabetes, and arthritis obtained the highest awareness rates (more than 50%). Rates for neurologic disorders were 40% or less, with the lowest awareness rates being for brain injury, neuromuscular impairments, spinal cord injury, and cerebral palsy. These common conditions can cause disability and are familiar to rehabilitation professionals, but are less prevalent than the medical conditions listed above. Those surveyed agreed, almost unanimously, that more should be done to integrate people with disabilities into society, especially by spending more money on removing barriers to access.

As changes in health care delivery affect the relationship between the provider and the patient, both are learning to become partners in care. Providers can facilitate communication in order to learn about disabilities, learn about the way a person's disability interacts with health and affects the life of the individual, and determine the essential elements of the history. Individuals with disabilities are learning to ask questions and to educate providers about their conditions, and interventions that have been effective for them or for others with similar disabilities. They also can identify the accommodations that work best for them. The goal of the encounter should be mutual respect, which means acknowledging that the person with a disability may be an expert about his or her disability and is seeking to establish a collaborative relationship with a health care expert.

It is important that the health care community re-evaluate assumptions about disability and about people with disabilities, work to improve standards of care and eliminate stigma, raise expectation levels within and outside the family structure about the potential of children and

young adults with disability, and assist individuals and families to access community resources. In developing plans of care, health care professionals need to be cognizant of the physical, social, and structural challenges presented daily in the lives of individuals living with disabilities.

Persons with disabilities have the same goals, dreams, and desires as their non-disabled peers, that is, to be actively engaged in their communities, have friendships, lovers and committed relationships, become parents, and be gainfully employed. However, different life experiences, health status, cognitive capabilities, education levels, strengths, limitations, and identities may influence the specific goals for each individual with a disability.

Ascertaining a patient's self-understanding of disability is an important first step in developing an effective plan of care. Persons living with life-long or long-term disability may be experts in their own health care and can be a great resource in identifying problem areas and developing workable care plans. Health professionals should subscribe to the same treatment goals for all their patients, namely to ensure full participation, opportunity, and a sense of possibility. Medical professionals must develop the clinical knowledge and skills to care for patients with disabilities, and be able to refer patients to the community-based resources required to facilitate treatment goals.

Implications for Kaiser Permanente Care Providers

- Assess how your training in a health care field and your contact with people with disabilities may influence your attitudes toward people with disabilities.
- Use language that reflects positive views and attitudes in the context of discussing disability.
- Consider patients to be experts concerning their own function and disability, and respect their opinions and objectives in the treatment planning process.
- Regard the patient's health status as potentially unrelated to the disabling condition, although in some cases health status and disability may be related.
- Avoid assumptions that individuals with disabilities experience a poor quality of life.
- Consider the cultural context of your patient as this may influence the attitudes of the individual and his or her family in relation to disability.

ACCESS TO CARE

Access to Care: Barriers to Communication

Introduction

Communication between the health care provider and the patient is the cornerstone of good quality health care. The complexities of health care make this important process a challenge. The first step in assessing a patient involves constructing the history. This dialogue generates rapport, uncovers the presenting complaint and history of present illness, and leads to a tentative diagnosis. With further inquiry, an assessment of the disabling condition can be completed that identifies the functional consequences of the various diagnoses of the patient. Further evaluation includes a physical examination, and in some cases laboratory tests and other studies.

Health care providers can enhance the care provided to patients with disabilities by following the communication guidelines in the “Four Habits Model,” developed by The Permanente Medical Group’s Physician Education and Development Program, in partnership with the Institute for Culturally Competent Care. This model includes the following elements: 1) investing in the beginning of the visit by building rapport and understanding the patient’s life concerns; 2) eliciting the patient’s perspective and exploring the impact on the patient’s life; 3) demonstrating empathy by being open to the patient’s emotions, conveying empathy and being aware of one’s own reactions; and 4) investing in the end of the interaction by delivering diagnostic information, providing education, and involving the patient in decisions about care.

If the patient has an underlying disability that affects the process of communication, how does the practitioner diagnose or formulate a treatment plan? How are health education and preventive health care integrated into this individual's health care, given these barriers? The following section outlines the disabling conditions that may influence communication and methods of delivering high quality health care, and offers approaches to establishing best practices.

Accommodations for Communication

Visual Disability

Visual disability can be understood as:

- Limitation of one or more basic components of the visual system: the eye, optic nerve, and visual centers in the brain.
- Lack, loss, or reduction of the ability to perform certain tasks such as reading, writing, and driving.
- Social and environmental factors that result in disadvantage in areas such as education, employment, leisure, and recreation.

There are many different conditions and diseases that cause visual impairment. The most common are cataracts, glaucoma, macular degeneration, and diabetic retinopathy. While severe visual impairment can be present at birth, injury, infection, and conditions associated with aging are the more common causes. Approximately 80% of people with visual impairments are age 65 and older. According to the WHO, blindness is defined as visual acuity of less than 3/60 or corresponding visual field loss in the better eye with best possible

correction. Certain laws define legal blindness as less than 20/200 visual acuity or a visual field of 20 degrees or less, regardless of acuity, but the ADA requires a case-by-case analysis of disability. The WHO describes profound blindness as the inability to count fingers at a distance of three meters or less, and severe low vision as the inability to count fingers at six meters or less.

Severe visual loss can reduce the effectiveness of visual methods of communication, as many visual cues may be missed. However, very few individuals with visual disabilities are totally blind. The image of the person living in total blackness is true for only a very small proportion of those who are blind or visually impaired. In addition, a minority of blind people can distinguish only light. Most lack central or peripheral vision. The majority of people who are deaf-blind have some usable vision.

A range of visual disabilities that may not be readily apparent to other people are represented in the population of people with disabilities. For example, some individuals may be able to negotiate supermarket aisles, but not be able to read shelf labels. Others can read the labels but not negotiate the aisles. Visual disabilities may vary throughout the day due to lighting conditions or other factors.

The inability to read is the most notable of the functions affected by severe vision loss, as it can substantially affect the ways a provider can communicate complex or detailed information and instructions. Difficulties seeing visual demonstrations of self-care procedures can also affect patient care. In addition, restrictions on mobility because of blindness or visual disability can limit access to education, leisure, employment, and socialization opportunities. Individuals with visual disabilities are likely to depend upon public transportation systems because driving is often not an option. Safety may be an issue in negotiating the physical environment and using public transportation.

There are services and aids available to people with visual disabilities to help them to live more independently. They may meet their full potential through mobility training, independent living services, peer counseling, employment counseling and placement, service animals, and technology. Assistive devices used by a blind or visually disabled person include white walking canes; talking calculators; clocks and watches; talking, large print, and Braille books; talking and Braille computers; scanners that convert print into speech or electronic formats; Braille "typewriters" and writing slates; magnifying devices; page turners; audio-tapes; and book rests. Employees and members with visual disabilities may depend upon signage that meets their needs as well as those of all employees and members, that is, signage that is "universally designed."

Practical Considerations for Individuals with Visual Disabilities

People with visual disabilities require simple, straightforward design and architectural layout. Potential obstructions or physical hazards in circulation areas such as the lobby or corridors should be avoided. Low hanging signs or other potential hazards such as plants or suspended lighting could pose detection problems for the person with low vision and should be avoided. Facilities should avoid fixtures or structures that leave space exposed underneath them. People with visual disabilities who are cane users may experience great orientation difficulty and danger if they are unable to locate where an object or structure meets the floor. Floors on stairs and other public access should be finished with non-slip surfaces.

It is difficult to propose an ideal general lighting formula, as an individual's responses and needs may be highly individual and changeable. Adequate natural light, augmented by strategically placed, fixed electrical lights, is an essential element in making facilities environmentally suited to the needs of visually disabled people. Special care should be taken to ensure that the faces of staff are well-lighted and that individuals have an unobstructed view of a speaker's face at all times.

As a general principle, surfaces that are highly reflective or that can generate a lot of glare are not recommended. These may include highly polished floors or timbers, large expanses of glass, and laminated or glossy posters and displays. Sources of natural daylight such as large windows can supply useful levels of illumination but can also radiate high levels of glare. Adjustable blinds or curtains may be helpful for controlling light levels from these sources. To minimize glare, overhead lighting should be recessed wherever possible and light sources should not shine directly into the eyes. Ambient lighting should avoid patches or sudden changes from brightly lit to dark areas.

The location of signs is as important as the lettering used. For exterior areas, signs need to be located near the entrance, between the ground and eye level, and positioned where they will not cause injury. They should be in an accessible place, allowing close inspection and an unobscured view. Interior signs should be placed at eye level near doorways or traffic areas and clearly defined, with large print, bold text, and clear contrast such as black on white. Signs placed on glass panels or doors can be difficult to read and should be avoided. All signs should be simple and uncluttered. Signage in Braille is important in key areas such as elevators. Colored footprints and lines on the floor or lower walls can be useful to help guide patients out of exam rooms towards reception, lab, x-ray, or pharmacy areas.

Hearing Disability

Hearing disability can be understood as:

- Limitation of one or more basic components of the auditory system: the ear, auditory nerve, and/or the auditory center in the brain, that may affect an individual's ability to acquire language.
- Lack, loss, or reduction of the ability to perform certain tasks such as listening, using the telephone, and communicating depending on the nature and extent of the hearing loss.
- Societal and environmental factors that may result in reduced opportunities in areas such as education, employment, leisure, and recreation.

People who have a hearing loss or limitation do not hear at normal levels because of a variety of factors that affect the transference of sound. People with a hearing disability include individuals who are deaf and individuals who are hard of hearing. People who are deaf will usually communicate by using sign language and they may or may not wear hearing aids, use their voice, or read lips. On the other hand, people who are hard of hearing will usually wear hearing aids, use their voice, and read lips. Typically, people who are hard of hearing do not use sign language to communicate. The extent to which a person's hearing disability may affect their daily life depends on the degree of the hearing disability, the age at which it occurred, as well as other factors that influence communication.

Hearing disabilities may be hereditary or may be caused by a variety of factors including viral infections, noise, toxins, diseases of the ear, such as Meniere's disease and acoustic neuromas, strokes, and aging. The main causes of profound deafness at birth are genetic factors or exposure to the rubella virus in utero. The most common causes of a hearing disability are

aging or exposure to loud noise. The term “legally deaf” is not a correct term, and the ADA requires disability determinations to be made on a case-by-case basis.

Individuals Who Are Hard of Hearing

Hearing disabilities may be mild, moderate, severe, or profound. Persons with mild hearing disabilities may not even be aware of their inability to hear certain sounds. Hearing disabilities may be evident in certain situations and not in others. People with a mild to moderate hearing disability may be unaware of their hearing disability and may ascribe a lack of hearing to the speaker's articulation.

People with mild hearing disabilities who identify themselves as hard of hearing may or may not wear a hearing aid. Some individuals who are deaf or hard of hearing prefer not to acquire or wear an aid. There are many factors contributing to this reluctance, including the quality of sound reproduction, social stigma, cost, and cosmetic considerations.

Individuals with Profound Hearing Loss

Individuals with severe or profound hearing loss may only hear low-toned sounds even if the volume is raised much higher than normal. Consequently, they will not be able to hear well enough to follow speech or discern most environmental sounds such as a ringing telephone or smoke detector alarm. They may have difficulty monitoring volume and pitch when they speak and may instead use sign language to communicate.

Pre-Lingually Deaf Individuals

It is important to be aware that individuals who are profoundly deaf and use sign language as their preferred mode of communication may identify themselves as being a part of the “Deaf community.”

Individuals who are profoundly pre-lingually deaf are either born with insufficient hearing to enable them to acquire speech, or lose hearing prior to the age at which speech is acquired. These individuals may have difficulty communicating verbally and instead rely on sign language to communicate. However, some individuals who are pre-lingually deaf are raised in an oral setting, such that they are not taught sign language and are instead taught to lip-read and use voice communication. For these individuals, if their preferred mode of communication is verbal, the term "oral deaf" may be used. However, because different people have different communication abilities, ask the individual what form of communication is most effective for them.

American Sign Language (ASL), one of the most common forms of sign language in the United States, has its own grammatical rules that make it distinct from English. Accordingly, some people for whom sign language is a primary language may not be fluent in written English, making note-writing and using written communication, such as required on a Telecommunications Device for the Deaf (TTY/TDD), inappropriate for conversations in which important information is being exchanged.

Health care professionals should be aware that individuals who are deaf are legally entitled to the services of a qualified sign language interpreter, and these services should be provided in the health care setting at no cost to the patient. Family members should not be asked to interpret for patients, because of confidentiality concerns and because the emotional difficulty of conveying stressful or very personal information can burden the parties, creating poor communication and stress.

Late-Deafened Individuals

Individuals who become deaf after they have acquired speech are termed "late-deafened" and do not usually identify with the Deaf community or use sign language. Their own speech may not be affected, although they may have difficulty with voice modulation. They may rely on visual spoken language to communicate and may become highly proficient lip-readers. They may request the services of oral deaf interpreters or require information in written form. People with an acquired hearing disability usually retain some residual hearing ability and continue to communicate in a spoken language. While written language may not present a problem for people who have acquired a hearing disability in adulthood, their ability to access information relayed by television, film, or sound recordings may be restricted by their hearing loss.

General Considerations for People with a Hearing Loss or Limitation

The inability to communicate verbally with ease is the most obvious consequence of hearing loss, affecting all facets of human experience, from education to gaining employment to forming relationships. People with hearing disabilities function in an environment that is geared towards hearing and in which they must often use a second language to communicate. Accordingly, some individuals experience isolation and loneliness, which are important aspects of a hearing disability that are not always recognized by families, teachers, and health care professionals.

The invisible nature of a hearing disability means that it often goes unrecognized. However, it affects many aspects of everyday life for people who are deaf or hard of hearing. Indeed, simple interactions such as signing-in at the registration desk for an appointment may pose a challenge because patients may not identify themselves as deaf and the receptionist's attempts to communicate verbally may not be effective. Moreover, without an interpreter or other means of communication, specific directions given during medical encounters or procedures may be misunderstood or missed completely.

Practical Considerations for Individuals Who Are Deaf or Hard of Hearing

The key to communicating effectively with people who are deaf or hard of hearing is to engage in a dialogue to determine what works best for them. In addition to sign language interpreters, there are a variety of technological aides and services which may be helpful for people who are deaf or hard of hearing. These include:

- Closed captioning on television and videos, telephone typewriters, amplified telephones, computer technology, assistive listening devices, audio loops, real-time messaging devices, note-takers, and hearing dogs.
- Hearing aids, vibrating clocks, watches, pagers and alarms, and other telecommunication devices and services.

In addition, there are services available to help people who are deaf or hard of hearing to be more independent. These include vocational, educational, personal, and financial counseling; assessments and referrals for personal, daily living, educational and recreational need; and equipment advice.

The physical layout of the medical facility may also be an important factor affecting accessibility for people who are deaf or hard of hearing. Individuals with hearing disabilities may benefit from simple, straightforward design and layout. Breaking spaces up into smaller "capsules" by the use of portable screens may prove helpful as this isolates sounds and reduces distracting background noise and interference. Avoid the use of hard surfaces, especially on floors, as sound "bounces" off them, making it difficult to hear. Other sounds, such as chairs and tables being moved, are amplified. Hearing aids pick up and amplify all sounds that surround the wearer, not just the sounds they wish to hear. Use of carpet in walkways helps to reduce reverberation. It is important to remember that these adjustments may impact access for people with other types of disabilities. For example, carpets may pose access barriers for people with mobility disabilities and screens may pose access barriers for people with visual disabilities.

As with anyone, safety is an important issue for people who are deaf or hard of hearing. However, sound, which is used by hearing people to warn of possible danger (i.e., bells, alarms, sirens, horns, and even shouts) will not be effective to alert people who are deaf or hard of hearing to the emergency situation. Depending on the individual's degree of hearing impairment, such sounds may not be heard at all or, if heard, the person may not be able to locate the direction of the sound. Instead, individuals who are deaf or hard of hearing rely on visual indicators in an emergency situation. However, these visual indicators can be problematic if the emergency has resulted in poor visibility.

Nevertheless, in addition to auditory alarms, buildings must include flashing light alarms to warn people of fire danger or the possible need to evacuate for other reasons. Exits should be clearly marked with flashing red lights and flashlights or alternative lighting should be readily available. Emergency and evacuation procedures should be clearly displayed on appropriate signage and augmented by a public address system to help visually impaired people in an emergency.

Accessible Formats for Individuals with Hearing and Visual Disabilities

People with print disabilities are those who are unable to read standard print with ease, due to visual disabilities, a physical disability, or a learning disability. 'Accessible formats,' also known as 'alternative formats,' are formats other than print in which information can be delivered to and accessed by people with print disabilities. For people who are blind or low-vision, accessible formats include audio-cassette recordings, compact discs, telephone-based information services, large print materials, and Braille, and electronic formats such as computer disks, emails, electronic databases, and the Internet. A range of adaptive equipment can also be employed to make material in non-accessible formats accessible. Equipment can be low or high tech, and may include magnifiers, large computer monitors, text-enlarging software for visual display units, synthesized voice input and output for computers, Braille displays for computer scanners or optical character readers, and "reading machines."

Videos and video recordings can be helpful in providing material in an accessible format to deaf and hard of hearing individuals. These media can incorporate the use of subtitles, headings and graphics (sign language signs) and captions. They can also incorporate the use of sign language either by the main speaker or by including an interpreter. Where information is presented mainly in signs, written material should be used for people who are non-signing deaf and hearing impaired. In addition, by including voice-overs or video description, the videos can be made accessible for individuals who are blind or have low

vision. Accordingly, as a provider, the key to ensuring high quality care is to engage in a dialogue with patients to ensure that the services and information provided are accessible.

Speech Disability

Speech disabilities refer to limitations in producing speech sounds or limitations in voice quality during speech. These disabilities may be characterized by an interruption in the flow or rhythm of speech, such as stuttering (dysfluency). There may be difficulties with the way sounds are formed (articulation or phonological disorders) or with the pitch, volume or quality of the voice. Stroke, cerebral palsy and other neurologic disorders, or conditions resulting in deafness, may result in speech disabilities. Individuals who have speech disabilities may choose to use verbal expression, or they may prefer to communicate using writing, sign language, or an augmentative communication device.

People with speech disabilities experience numerous functional barriers, because speech is such an important aspect of ordinary daily routine for most people. Often people with speech disabilities are inappropriately assumed to have impaired intellect and may be infantilized by others. Those who are unfamiliar with different speech patterns, or who feel uncomfortable or impatient, may curtail conversations prematurely.

In the health care setting, meaningful interaction between the provider and the patient with a speech disability can be challenging. Short periods of time for appointments and time pressures contribute to the problem. Providers may miss important information from the patient, with potentially serious consequences. Extra time may thus be required for an appointment. It is important to remember that someone using a communication device does not necessarily have a cognitive disability. The provider should interact with the patient, not the attendant, and not interrupt or hurry the patient.

Cognitive Disability

Cognition is the process of reasoning, problem solving, learning, and remembering. The IDEA defines a cognitive disability as a "disorder in one or more of the basic psychological processes involved in understanding, or in using, spoken or written language, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations." The type and degree of cognitive impairment can vary widely from severe mental retardation to memory problems to absence or impairment of specific cognitive capabilities. Consequently, the types of functional limitations also vary. Conditions affecting the ability to attend to, store, process, or retrieve information can make it difficult to work and live independently, follow directions, solve problems, respond appropriately to social cues, attend school, and perform tasks that involve multiple steps. These difficulties undermine professional, educational, social, and personal opportunities.

Examples of cognitive disability-associated diagnoses include traumatic or anoxic brain injury, Down's Syndrome, stroke, dementia, autism, and various forms of developmental disabilities, including non-verbal and verbal learning disabilities. Causes of cognitive disabilities are numerous and include chromosome abnormalities, genetic disorders, cerebral vascular conditions, metabolic conditions, viruses, maternal infections, Rh incompatibility, traumatic brain injury, anoxia, birth injury, and early infant infection.

In the health care setting, many people with cognitive disabilities experience difficulties in finding providers with the necessary expertise, and the commitment to providing care for them. Some of this reluctance may be attributed to a lack of experience in providing primary

care to this population, and to the challenges presented in communicating that may make diagnosis and treatment difficult. The provider may find it difficult to obtain important basic information from patients with cognitive impairments or make erroneous assumptions about the person's capabilities or functioning at home or in the community. For example, clinicians may not ask a patient with mental retardation, or an obvious physical disability, about current sexual activity because they assume the patient to be asexual. (See Specific Areas of Clinical Focus: Reproduction, Sexuality, and Pregnancy.)

Health care professionals must be aware of the patient's cognitive capabilities, as well as deficits, and plan treatments and communication strategies accordingly. The patient may easily become overwhelmed with medical terminology or complex language and may not understand important instructions. There are many services and aids available to individuals living with a cognitive disability that can assist them to live independently. Current public policy advocates community-based services as opposed to institutional settings. As a result, many people with cognitive disabilities live in the community in small group homes or in apartments or homes of their own with assistance as needed. These services include residential programs with supervision and assistance provided as required, vocational training and coaching, social programs, including recreational activities, and personal assistance. Technological support may include communication boards, computerized speech and language equipment, and assistive technology for physical limitations.

Implications for Kaiser Permanente Care Providers

- Assess the structural environment in your clinical area to determine if it is accessible to people with communication (visual or auditory) or cognitive impairments.
- Assess your environment for safety risks and contact appropriate departments to correct any problems.
- Ask your patients what communication techniques and alternative formats facilitate optimal understanding.
- Know the rights of people with service animals to bring the animals into facilities. Providers and therapists should become familiar with the kinds of disabilities that benefit from having service animals.
- Avoid interacting with service animals that assist individuals who are visually impaired or blind. Service animals are an extension of the personal space of a person with a visual impairment or blindness.
- Be respectful of the potential differences in cultural perspectives of pre-lingually deaf and late-deafened individuals.
- Familiarize your office with the kinds of accommodations available to someone who is deaf-blind.
- Learn how to gain access to, and utilize, sign language interpreters and telecommunications devices (TTY/TDD) at your facility.
- Be proactive, and ensure that your staff is also proactive, in providing these services for regularly scheduled appointments.
- After speaking with your patients about the kinds of accommodation that work for them, familiarize yourself with your medical center's policies and procedures for making information available in formats that are accessible and understandable for the individual with a communication or cognitive disability.
- Ensure that the individual with a disability has appropriate access to emergency information such as visual and auditory alerts.

Access to Care: Primary Care

Introduction

Individuals with disabilities may have difficulty accessing health care systems and services. This population has been described by the Institute of Medicine as having a "thinner margin of health" because of vulnerabilities due to disability, such as compromised pulmonary function in some people with spinal cord injury. In addition, for some individuals with disabilities, there may be an earlier onset of health conditions such as osteoporosis or osteoarthritis. For others, another acute or chronic condition may increase functional limitations, leading to a requirement for more intensive treatment than a person without a disability might require. However, many people with disabilities are healthy and not in need of frequent health care interventions.

Barriers to Primary Care Access

Barriers to primary care may include.

- Transportation challenges due to mobility, cognitive, or visual disabilities.
- Inaccessibility of examination facilities and equipment-including examination tables, mammography machines, or slit-lamp examination chairs.
- Inaccessibility of communication systems due to visual, hearing, speech, or cognitive disabilities.
- Time constraints for individuals with disabilities, which increase history-taking and physical examination time-frames.
- Cultural barriers due to a lack of "disability literacy" among health care providers.

A key problem for many patients with disabilities is that primary care physicians may not be adequately trained about disability-specific conditions because they are infrequently seen in primary care settings (for example, autonomic dysreflexia in a person with a spinal cord injury). In addition, a primary care physician may be less familiar with prescribing orthotics, prosthetics, or durable medical equipment than a physical medicine and rehabilitation or orthopedic physician, yet these are essential aspects of the treatment and care of people with disabilities. Providers may need to adjust appointment timeframes to allow for the comprehensive, multifaceted approach required for some patients with disabilities.

Research has also indicated that providers may not pay sufficient attention to prevention for patients with disabilities because they are focusing on disability-related treatment issues. As a result, people with disabilities are more vulnerable to potentially preventable disorders, such as strokes and heart disease. In addition, secondary conditions, such as pressure sores, contractures, or deep venous thrombosis, are often preventable in individuals with disabilities. However, because primary care physicians may not be trained in, or focused on, preventative approaches, interventions to prevent these disability-related secondary conditions may not be considered.

Durable medical equipment (DME) such as wheelchairs, shower chairs, orthotic devices, and prosthetic limbs are among the most common requests for coverage that insurers deny. However, DME should be recommended as a preventive measure as well as a way to promote function. When it is not appropriately provided, there is an increased likelihood of morbidity, patient and family dissatisfaction, and, in some cases, additional costs.

Primary Care Access for Children and Adolescents

Children with disabilities are often in need of a complex array of services provided by teams of specialists and primary care providers. However, with few exceptions, chronic conditions management programs have been designed mainly for adult populations. Consequently, access to various pediatric specialists and sub-specialists may require families to attend multiple single appointments at various locations, placing more stress on an already over-extended family system. In addition, health care services delivered in this inefficient manner may prevent optimal communication among professionals. Without a designated care coordinator for the child's care, there is further fragmentation of care and delayed treatments. Specialty pediatric care, however, does not obviate the need for access to a primary care provider for children with disabilities to ensure timely, developmentally appropriate preventive health care.

Information Technology

Health systems that promote access through the telephone and web-based computer systems for communication with practitioners and health education may be of great benefit to people with disabilities. Kaiser Permanente members with disabilities may prefer 'telephone advice visits' if they do not need frequent examinations, but require follow-up to establish treatment efficacy following on-site appointments. TTY/TDD phones or relay services are available for telephone visits for patients who are deaf or hard of hearing.

In addition, Kaiser Permanente's automatic medical record with automated ordering features, including on-line prescription and refill services with a mailing option, provide additional benefits to individuals with disabilities who have difficulty traveling to appointments or to the pharmacy.

Health Care Registries

One of the difficulties faced by health care organizations is the identification of specific subpopulations of people with disabilities in order to implement health care prevention and treatment programs. Health care registries based on disability, rather than diagnostic categories, are potentially useful to a health system in planning for the needs of patients with disabilities. Researchers at the Kaiser Permanente Center for Health Research in the Northwest and Hawaii Regions and the National Rehabilitation Hospital Center for Health and Disability Research in Washington, DC, are developing an "Access Risk Registry" to identify high-risk populations with disabilities so that service delivery systems can be designed to meet the needs of these populations through appropriate access to services. Such registries will be helpful in health services research focused on accessibility, best practices, cost-effectiveness, outcomes, and delivery of care.

Primary Care, Specialty Care, and Primary Care Models

One of the priorities of both the modern disability movement and health care advocates is the advance of different models of coordinated care: case management, disease management, and other forms of coordinated care that promote patients' highest function while reducing office visits. For example, someone with diabetes, recent onset blindness, and osteoporosis may benefit from case management. The case manager might confer with a specialist to assess the patient's medical, functional (ability to perform basic activities of daily living), emotional, cognitive, environmental (safety of home and workplace), and social situation (social support,

personal attendant access, financial status). Providers may then assist the case manager to develop a plan that includes a recommended number of visits with an endocrinologist, nutritional counseling, advice about orientation and mobility training, and community support services such as peer counseling and assistive technology. Between visits, providers might coordinate to ensure that medicines, surgeries, and other treatments complement each other.

An ideal model for the patient with a disability as a result of a brain or spinal cord injury, post-polio syndrome, or amputation, links the physical medicine and rehabilitation physician and primary care physician. Such a linkage makes it more likely that most of the health care needs of the individual can be addressed through a coordinated approach that may also involve other service providers such as therapists or neuropsychologists. As noted earlier, modern rehabilitation philosophies do not stop at rehabilitation and medical interventions, but continue beyond rehabilitation to promote the patient's ongoing function and independence. In many cases the team approach, inherent in rehabilitation philosophy and practice now more prevalent in other kinds of case management models, is necessary to address the functional goals and preventive needs of individuals with disability.

Implications for Kaiser Permanente Care Providers

- Ensure access for people with all types of disabilities.
- Apply the same standards for promoting general health and disease prevention in the care of patients with disabilities as those without disabilities.
- Learn about the prevention and management of secondary conditions related to disability, as well as how conditions and medications not related to the disability may interact with the disabling condition.
- Refer to rehabilitation specialists or other specialists for co-management when additional expertise is required.
- Recognize that earlier onset of secondary conditions may occur in some individuals with disability as this is essential to developing prevention strategies.

Access to Care: Specialty Care and Rehabilitation

Introduction

Individuals with disabilities may have additional needs for specific subspecialty medical or surgical care, rehabilitation nursing expertise, nutritional advice, rehabilitation therapies, social service consultation, or neuropsychological evaluation. For certain individuals with disabilities, a referral to a specialist is indicated. For patients with multiple disabilities, consultation with the appropriate specialists may offer a coordinated and cost-effective approach to care, with fewer additional consultations required.

Barriers to Care

- People with disabilities may be less likely to have access to specialty care, including rehabilitation services, in managed care systems than in fee-for-service systems.
- Primary care physicians may be unfamiliar with the scope of practice, or expertise, of physiatrists, depending on the setting in which they trained, and may be less likely to make referrals to these physicians.
- Multiple referrals to subspecialists may tax the ability of an individual with a disability to travel to appointments, sometimes in multiple locations, unless a multispecialty clinic setting is available.
- Care may be fragmented if multiple specialists are consulted, unless there is coordination by a physiatrist, case manager, or primary care physician.

A recent study by Beatty indicates that only half of the respondents in a national survey of individuals with disabilities (spinal cord injury, cerebral palsy, and other physical disabilities) received needed rehabilitative services. Respondents receiving care within managed care organizations were less likely than fee-for-service covered populations to receive specialty and rehabilitative services.

Rehabilitation Treatment Teams for Specific Populations

An individual with a spinal cord injury may require attention from practitioners with special training in spinal cord injury medicine. This may be a physiatrist or a spinal cord fellowship-trained/spinal cord medicine board-certified physician. In addition, rehabilitation clinical nurse specialists, rehabilitation psychologists or social services staff, and physical and occupational therapists with knowledge and skills in spinal cord injury rehabilitation, may be recommended to assist with the care of persons with disabilities secondary to spinal cord injury. In the case of acquired brain disorders, physiatrists with expertise in brain disorders, rehabilitation clinical nurse specialists, neuropsychologists, cognitive therapists, or physical and occupational therapists may need to be consulted.

Physical Medicine and Rehabilitation Physicians

Physical medicine and rehabilitation (PM&R) physicians, or physiatrists, help patients to return to the highest level of function in the home, family, and work environment, and to engage in all aspects of community life. Physiatrists with training in pediatrics, or child neurologists specializing in rehabilitation, treat patients who are less than 18 years of age. Other PM&R

physicians may have specialty training beyond the required four years of residency, including fellowship training in musculoskeletal rehabilitation, brain injury, spinal cord injury, pain, or sports medicine.

Patient populations treated by physiatrists include individuals with stroke, traumatic brain injury, spinal cord injury, arthritis or joint replacement, amputations, spine disorders, cerebral palsy, multiple sclerosis, and neuromuscular disorders. Physiatric training emphasizes not only development of physical diagnostic skills, but assessment of function following acute or chronic disabling conditions, with a focus on identifying interventions to promote function that may be medical, pharmacological, surgical, or adaptive/assistive through the use of equipment and devices.

Physical medicine and rehabilitation medicine physicians understand recovery from disabling illness or injury to be a dynamic process over many years. Rehabilitation outpatient centers provide patients with follow-up appointments over the months and years following the initial acute hospitalization or acute episode. This commitment is an acknowledgement that the individual with the disability may need different interventions or assistance to promote independence in the home and community, at different times in the course of recovery or because of the effects of child development or aging.

Physical, Occupational, and Recreation Therapy

People with disabilities may have diminished functional abilities due to muscular weakness, decreased balance and range of movement, and poor coordination. They may have difficulties developing strategies for movement and grading the balance between stability and mobility required for efficient functional movement. Physical therapists assess and treat movement dysfunction, with the goal of returning optimal function and enhancing physical health and wellness. Neuromuscular re-education strategies are used to improve motor control for activities such as bed and wheelchair mobility, transfers, and walking. Physical therapists also assist in evaluating patients for appropriate assistive devices such as braces, canes, crutches, wheelchairs, and scooters. Patients can learn strategies to maintain functional gains and to prevent further disability.

Occupational therapists work with people with disabilities to improve their ability to perform activities of daily living, homemaking skills, and self-care activities such as grooming, bathing, and dressing. Occupational therapists assess and develop individualized treatment plans to address cognitive and sensory/perceptual deficits. Adaptive equipment and wheelchairs or other seating equipment are also areas of expertise for occupational therapists.

Home, community, and in some cases vocational re-integration is a focus of occupational as well as physical therapists. This focus becomes more important as the patient with an acquired injury or disorder becomes more medically stable and progresses to greater levels of independence. Therapeutic recreation staff in inpatient and outpatient settings can provide evaluations and recommendations for activities in both institutional and community settings.

Neuropsychology, Cognitive Rehabilitation, and Speech Therapy

Cognitive deficits are a common consequence of any insult or condition that affects the brain. The most common deficits following acquired brain injury involve memory, attention, speed-of-information processing, language, and problem solving. However, other cognitive functions such as visual-perceptual skills can also be affected. Neuropsychologists provide comprehensive evaluations of all aspects of cognitive function, and assist in establishing

whether the patient has capacity for decision-making. A comprehensive neuropsychological evaluation can assist in determination of fitness to return to work, accommodations for academic settings, or participation in other life activities, including driving. Speech-language pathologists evaluate patients for language disorders and recommend therapeutic interventions for language disorders, such as aphasia, and cognitive disorders.

Cognitive rehabilitation uses empirically-based interventions to assist an individual in compensating for cognitive deficits and learning new approaches to these areas of difficulty. The goal of treatment is to assist individuals to reach their full potential in daily life. Cognitive rehabilitation may be directed toward, but not limited to, improving memory, attention, concentration, comprehension, communication, perception, reasoning, problem solving, judgment, initiation, planning, self-monitoring, and awareness.

Cognitive rehabilitation services are provided across the continuum of care. This may include inpatient acute rehabilitation, outpatient treatment, day treatment, and home care. The treatment may be interdisciplinary or discipline-specific, depending on the setting and the patient's needs. It may include one or more aspects of treatment as defined above and may be provided by speech pathologists, occupational therapists, psychologists, or other rehabilitation professionals. Therapy involves education, strategies for decision-making, and planning for the transition to what may be a different life situation.

Rehabilitation Programs: Care Settings

After a catastrophic injury or disease process that results in multiple disabilities, physiatrists and other rehabilitation professionals can provide an assessment of current functional status to determine the appropriate level of care. Medical stability after the acute care hospitalization is a primary consideration in determining whether the patient can participate in a rehabilitation program. The appropriate eligible patient should be afebrile with stable vital signs, no significant changes in medical conditions in the preceding days, and an established route for hydration and nutrition. Whenever possible, the patient should be discharged to the home and community, and rehabilitation services and programs provided that optimize function in a non-institutional setting.

Interdisciplinary or multidisciplinary rehabilitation programs consist of rehabilitation services for children and adults, provided by a team of professionals who communicate regularly to assist in the evaluation and delivery of services. Interdisciplinary rehabilitation is most often provided in hospital settings and is termed "acute rehabilitation." This is distinguished from other rehabilitation service delivery, where regular communication and common goal-setting are less consistent and more often provided in non-hospital settings.

Studies measuring outcomes such as death rates, long-term function, and quality of life after stroke and traumatic injuries such as brain and spinal cord injury, strongly suggest that outcomes are superior for patients treated in interdisciplinary or multidisciplinary settings in acute hospitals or rehabilitation centers and hospitals. The components of care that appear to be most important, regardless of setting, are team-based practice with interdisciplinary team planning through conferencing, patient and family education, and staff education in the subspecialty area to promote best practices.

Rehabilitation hospitals for adults and children provide at least three hours of structured therapy per day. Rehabilitation medicine specialists (physiatrists), rehabilitation nurses, nutritionists, and physical, occupational, and speech therapists provide treatment and therapy 6-7 days per week. Neuropsychologists, social services personnel, and case managers in

some facilities are members of the treatment team in these hospital-based settings. Team conferences usually occur every week in acute rehabilitation programs. This model of service delivery may be operational in day treatment programs, although in such programs the patient is not an inpatient and does not receive 24-hour nursing care.

Comprehensive outpatient rehabilitation services and programs for children and adults are individualized and based on specific functional goals. Interdisciplinary approaches are more difficult to coordinate and physician oversight is more limited in the outpatient setting, except in day treatment or comprehensive programs with team conferencing.

Inpatient and outpatient services and programs should be directed towards returning the patient to the pre-injury or pre-existing level of function, or if that is not possible, to the highest level of function in the home, community, and workplace. Linkages to vocational, academic, and other community-based services are essential in facilitating the patient's optimal functional recovery. For patients who are born with a disability, as well as for those who have recovered from an injury, a disease process, or acute episode and remain disabled, health care systems should provide ongoing management, care coordination, and rehabilitation interventions throughout the lifespan.

Specialty Pediatrics Clinics

Specialty pediatric clinics administered by an interdisciplinary team, utilizing a biopsychosocial approach, can be highly effective in the delivery of services to children with multiple impairments who would otherwise require multiple appointments with many providers. Such interdisciplinary centers deliver medical, rehabilitative, and surgical interventions, and identify and address psychosocial and education concerns and needs. Pediatric specialty clinics often include essential case management services provided by registered nurses and social workers to assist families in the daily management of the child's care, in addition to identifying appropriate community-based resources.

Other Rehabilitation Settings

Skilled nursing facilities deliver rehabilitation care at a less intensive level than hospital-based rehabilitation programs. Physician and registered nursing hours in skilled nursing facilities are less than hospital levels. Physicians and nurses with rehabilitation training may not be on staff. Subacute rehabilitation programs and long-term acute care facilities offer a range of therapies at various levels of intensity, but usually less than 2-3 hours per day.

Home care services can be provided if the patient is being cared for at home. The advantage of home-based rehabilitation treatment is that rehabilitation takes place in the environment where skills will be utilized. The home or outpatient setting is not appropriate for patients who require frequent physician monitoring or who have the potential to make greater functional gains from a more intensive program, but eventual discharge to the home and community is the ultimate goal.

The Commission on Accreditation of Rehabilitation Facilities (CARF) accredits rehabilitation and human services programs, including adult day services, assisted living, behavioral health, employment and community services, and medical rehabilitation. Within the medical system, an organization may seek accreditation in the following rehabilitation programs: comprehensive integrated inpatient, spinal cord systems of care, interdisciplinary pain, brain injury, home- and community-based, outpatient medical, health enhancement, pediatric family-centered, occupational rehabilitation, and medical rehabilitation case management.

Assessment and Management of Secondary Conditions

Care coordination for people with disabilities must be a dynamic process. Changing life circumstances can affect support systems, which in turn may compromise physical and emotional well-being. For example, people with disabilities may be subject to periodic declines in function, or acute care episodes, that require a change in a treatment regimen or intensity of care. Accessibility to providers who are familiar with their medical, psychosocial, and functional history is essential for providing high quality care for this diverse population.

Health promotion interventions that focus on maintaining and improving functional abilities are effective in reducing secondary conditions and decreasing the number of medical interventions. Educational support is necessary to promote a capacity for independent living and to prevent secondary medical conditions. These educational and health promotion interventions, specifically designed for people with disabilities and their caregivers and families, are more likely to be a component of rehabilitation programs in an inpatient or outpatient setting than in primary care or acute hospital settings. However, these interventions are recommended in all settings that provide routine or episodic care.

For an older person with a disability, the focus is often on complications due to co-existing conditions. Mental health issues may arise due to deterioration in levels of independence and increasing dependence on others. Disease prevention and effective disease management with individualized interventions are vital for preventing functional decline. Case management and chronic care management programs can be very effective for preventive care and avoidance of re-hospitalizations.

Implications for Kaiser Permanente Care Providers

- Develop an individualized care plan for rehabilitation services, programs, and ongoing case management for each member with a disability after a severe disabling illness or injury occurs.
- Understand the criteria for referring patients with disabilities for inpatient and outpatient rehabilitation programs and services, particularly children and adults with catastrophic injuries and illnesses.
- Refer patients with disabling neurologic and musculoskeletal conditions, and complex multiple disabilities, to physical medicine and rehabilitation physicians for evaluation, treatment, and rehabilitation program planning.
- Refer patients in need of individualized services to physical, occupational, or speech therapists, neuropsychologists, social workers, rehabilitation nurses, nurse educators, or recreation therapists when appropriate.
- Refer patients with disabling medical conditions to appropriate care management and chronic conditions management programs.
- Remember that changes in function of any organ or system due to medical conditions or additional disabilities can significantly affect function, making preventive care and ongoing management crucial to the ability to participate in the home and community.
- Coordinate access to multiple specialties through a team approach. This may be necessary in both inpatient and outpatient settings for people with disabilities, particularly multiple disabilities.
- Provide educational materials and support as an integral part of health maintenance and prevention of secondary conditions for people with disabilities.

Access to Care: Community and Web-Based Services and Networks

Introduction

Individuals with disabilities and their families and caregivers benefit from a variety of support services and networks that serve multiple needs and functions. Social workers, case managers, and discharge planners should be very familiar with local resources that enhance the individual's ability to participate in the community, access financial and entitlement programs, and adapt to the disability. Individuals with disabilities should be referred to social workers for assistance with these resources and networks. Web-based resources provide a wealth of information about health conditions, as well as programs to promote activities, participation, and independent living. (See Bibliography: Additional Resources and Suggested Readings.)

Barriers to Care

- Communication or cognitive impairments which result in a lack of knowledge of, or difficulty accessing, community and web-based resources.
- Family or caregiver responsibilities that challenge the family system and prevent the exploration of these support services and networks.
- Lack of transportation, which limits the person's ability to access community services.

Community Resources

Condition-specific agencies are located in the local yellow pages or on the Internet. These agencies provide education, information, advocacy, support, and practical assistance. Examples include the National Multiple Sclerosis Society, the National Mental Health Association, the National Spinal Cord Injury Association, and the Lighthouse for the Blind. Independent Living Centers provide practical services and advocacy for persons with disabilities to enhance community integration. Services include independent living skills training, information and referral, financial counseling, peer support, housing and employment referral services, and referrals for legal assistance and personal attendant services. In addition, local community colleges may offer special programs for cognitively or physically impaired adults, for example, adaptive physical education programs or independent living skills training. Social service departments should be familiar with what services Regional Centers provide for people with developmental disabilities. In addition, it is helpful to know what kinds of services school districts are required to provide for school-aged children with disabilities under the Individuals with Disabilities Education Act (IDEA).

It is essential that social service personnel and case managers develop relationships with community agencies and stay up-to-date concerning services, new educational and advocacy programs, and accommodations and resources that are available to individuals in the community or institutionalized in long-term settings. Social services departments serve as an outreach arm of the medical center, or long-term care facility, to link members to the community.

Area Agencies on Aging, a national organization, coordinates and provides services to help older adults live independently in their homes with the support of meal programs, information and referrals, including personal or homemaker assistance. Individuals with disabilities may also receive services provided by home health agencies, adult day health care agencies, and adult day care agencies. Depending on the level of care and supervision they require, individuals may benefit from intermittent nursing care, occupational, physical, or speech therapies, social services, respite services, supervision, and socialization.

Family and Caregiver Support

Family and caregiver support is critical for individuals who care for their loved ones with disabilities. Family caregivers confront feelings of isolation, financial burdens, lack of support from the community and from other family members, and at times overwhelming stress. Some condition-specific support groups are available for families dealing with Alzheimer's disease and multiple sclerosis, for example. National organizations, such as the Family Caregiver Alliance, offer written and web-based resources and weekend workshops. Family members should be encouraged to participate in support networks and activities.

Personal Assistance Services

Personal Assistance Services (PAS), or home care services, are programs that are critical for maintaining independence and community living, and are an essential component of independent living services for people with disabilities. Approximately 9 million disabled people in the United States, of all ages, use some form of home care or personal assistance services. PAS are defined as one or more persons assisting a disabled or elderly person with tasks that the individual would typically do if they did not have a disability. This includes such tasks as dressing, toileting, cooking, feeding, shopping, cleaning, or balancing a checkbook. PAS may also include tasks often considered to be nursing tasks, such as administering medication, tracheal suctioning, or urinary catheterization. Since the Independent Living Movement in the 1970s, the provision of PAS has enabled thousands of individuals with severe disabilities to live in the community, not in institutions, directing their own care in their own homes. Individuals can be referred to Independent Living Centers, which are operational in every state, for more information on PAS.

Durable Medical Equipment

Durable medical equipment may or may not be covered under an individual's health plan contract. Local organizations such as the Red Cross or Easter Seals may provide equipment loans. Previously owned durable medical equipment may also be purchased from clearing houses at a reduced price. Special transportation-related needs can be addressed by local or county transit agencies, adaptive driving schools administered by local medical centers or acute rehabilitation centers, and the provision of parking placards to persons with disabilities by the local Department of Motor Vehicles.

Preventive Services

Local public health centers and medical centers provide prevention education to the community. For people with complex conditions, preventive care may include not only standard physicals and health education, but also ongoing management of a disability. For example, a person with diabetes may need frequent monitoring of blood glucose to prevent a secondary condition, while a patient with cerebral palsy may need more frequent physical therapy to prevent disuse atrophy.

Condition-specific agencies such as the American Heart Association provide guidelines for prevention of disease and disability, while disability agencies can provide recommendations and training on providing accommodations, ongoing management of a disability, and information about the benefits and services that can promote a person's independence and participation in community life.

Advocacy

Individuals with disabilities may benefit from specialized advocacy programs, such as local ombudsman services, or referrals to local Independent Living Centers for benefits, counseling,

and community integration. In cases of suspected neglect or abuse, local protective services are available for assessment and intervention for children, dependent adults, and elderly individuals. The Disability Rights Education and Defense Fund and The World Institute on Disability are national advocacy groups for children and adults with disabilities. Another national advocacy group, Protection and Advocacy, is a resource for people with disabilities in need of advice and advocacy, with multiple sites around the country.

Public Benefits

Individuals with disability may qualify for specific programs and financial benefits administered by the state or Social Security Administration. These programs include entitlement programs such as State Disability Insurance, Social Security Disability Income, or needs-based programs like Supplemental Security Income. Individuals with disabilities may also be eligible for Medicare and Medicaid, which can pay for a variety of health care and services, including rehabilitation, nursing facility care, case management, home health, hospice, and long-term care. In addition to county offices, Independent Living Centers and local Protection and Advocacy agencies provide counseling on these subjects. Local, city, and county planning or housing departments can provide low interest loans or grants for homeowners and landlords who wish to make their homes more accessible or barrier free. Local Independent Living Centers offer the best source of information on these programs.

Implications for Kaiser Permanente Care Providers

- Be knowledgeable about accommodations and services people with disabilities need, and resources for additional information and training.
- Understand how people with disabilities from different cultures or socioeconomic backgrounds may view their disability in relation to lifestyle issues.
- Develop relationships with local disability agencies that are both cross-disability (such as Independent Living Centers) and specific to different kinds of disabilities.
- Refer patients to Centers for Independent Living and for resources and training in Personal Assistance Services.
- Develop a referral list and refer patients to appropriate services including prevention, wellness, peer counseling and support, therapy, rehabilitation, and in-home support programs.
- Be familiar with how the community resources and entitlement programs available to individuals with disabilities vary by condition, eligibility requirements, funding, and locality.
- Refer children, young adults and their parents to organizations that assist with academic assessment, educational and transition planning, and which can provide advice concerning the legal rights of children with disabilities.
- Utilize the specialized skills, knowledge, and networking ability of social workers to address the emotional and practical needs of this patient population.
- Ensure appropriate and necessary funding of services and programs, with accurate assessment and timely response.
- Assist in providing expert medical and functional assessments, and completion of referral information, for individuals with disabilities for disability benefits, academic integration, vocational integration, workers compensation, public assistance, and care in the most appropriate setting.
- Know the provisions of the Americans with Disabilities Act, Section 504 of the Rehabilitation Act, the Individuals with Disabilities Education Act, and the Culturally and Linguistically Appropriate Care Services Standards that apply to your practice with children, adolescents, and adults.

RISK FACTORS

Stigma, Discrimination, and Disadvantage

Introduction

People with disabilities may face stigma associated with the disability, as well as barriers to physical, social, emotional, environmental, health care, and financial resources required for full participation and opportunity. Individuals with disabilities may face discrimination on a daily basis. They may find themselves at a distinct disadvantage in the educational system, when seeking employment, or in the workplace. Other challenges include finding or accessing transportation to get to clinic or therapy appointments, securing housing, and negotiating architectural barriers in the community.

People of Color

People of color constitute a disproportionate share of the population with disabilities and may experience "multiple discrimination," placing them at a greater risk of acquiring a disability and at a greater risk of not receiving needed services if they have a disability. People of color are more likely than White individuals to identify primarily with race or ethnicity than other dimensions of their diversity (for example, gender, disability status, and sexual orientation). Some people of color with disabilities may experience conflict between a need to be a part of their racial or ethnic cultural group and the need to access support within the predominantly White disability community. In addition, because of experiences of discrimination, people of color with disabilities may be reluctant to access services.

Social Networks

Regular participation in social activities is necessary for living well. People with disabilities report significantly lower levels of social interaction and are more than twice as likely to live alone compared to people without disabilities. Social integration, which is improving slowly, requires accessibility to the community. However, nearly a third of people with disabilities report difficulties with transportation. Enabling opportunities for social interaction can improve the functional status and overall well-being of people with disabilities.

Leisure Activity, Sports, and Recreation

Studies indicate that leisure activity is one of the most important determinants of life satisfaction and psychological well-being. The dependency created by disability influences leisure behavior and relationships. Although people with disabilities report lower satisfaction with leisure activities, there has been an increase in leisure-time activity for this population in the last 10-15 years. Recreational activities provide an opportunity for self-expression and social interaction, and may promote a positive attitude. Through innovative adaptation, and increased awareness of the needs of people with disabilities to live integrated lives, more sports and leisure activities are becoming available to people with disabilities.

Exercise and fitness programs can promote optimum health, and for people with disabilities, as with people without disabilities, provide socialization. However, athletic facilities may not provide accessible exercise equipment for individuals with disabilities. In some cases, a physical therapist or exercise physiologist may be helpful in the design of an individualized program in the home, gym, aquatic, or other recreational facility program. Group activities

that promote fitness are often available in the community, and may include a variety of sports and recreational opportunities for children and adults with disabilities.

Environmental Barriers

Environmental barriers consist of the physical, social, financial, and attitudinal obstacles that result in decreased activity and participation of people with disabilities. In 1999, more than half of adults with disabilities age 18 and older reported encountering environmental barriers on a daily basis. Examples of these barriers include architectural or structural barriers, decreased access to technology, and exclusionary social program guidelines and attitudes. Identification and removal of physical barriers should be based on the concept of universal design, which refers to the design of products and environments that are usable by all or by most individuals without the need for adaptation or specialized design. Examples are curb cut-outs, wrist-blade control handles on faucets, flexible shower attachments, and ramps.

Abuse, Violence, and Neglect

Intimate partner violence can take different forms, including physical injury, sexual violence, isolation from loved ones, and financial and emotional abuse. People with disabilities are at significantly higher risk for intimate partner abuse than persons without disabilities. In one study of women with physical disabilities, 62% reported some type of emotional, physical, or sexual abuse. According to the CDC, the rates of sexual violence range from 51% to 79% for women with disabilities. In adults with cognitive disabilities, rates of sexual violence range from 25% to 67%, depending on the study.

Neglect by caretakers can also lead to increased risk of physical injury and medical complications. In addition to the vulnerability of persons with disabilities to intimate partner and caregiver violence, some individuals may incur a secondary disabling condition as a result of violent injury. For example, a recent study of battered women found that 92% sustained blows to the head and 40% lost consciousness during the assault, and thus may have incurred traumatic brain injuries.

Legal statutes in all states clearly outline the responsibilities of health care providers in the identification, reporting, and care of individuals who have been victims of abuse and neglect. Providers must not only be aware of these laws which vary by state, but also the increased risk for abuse, violence, and neglect in this population.

Implications for Kaiser Permanente Care Providers

- Use effective interviewing and communication skills to promote an open sharing of information, including both positive and negative aspects of the individual's life situation.
- Consider the impact of multiple discrimination for individuals with disabilities whose identity may be linked with various other cultural groups.
- Encourage patients with disabilities to participate in social activities, including recreational and leisure activities.
- Learn about national and local resources available to persons with disabilities.
- Complete timely documentation for appropriate adaptive equipment and assistive devices.

Behavioral and Lifestyle Risk Factors

Introduction

A broad range of behavioral and lifestyle risk factors may be associated with increased functional, health, and medical complications for individuals with disabilities as for all individuals, and these risk factors must be identified and appropriately addressed. With this information, providers will be able to minimize the negative impact of potentially modifiable behavioral and lifestyle risk factors such as substance use, sexually transmitted disease, physical injury, and malnutrition.

Substance Use

Substance use and abuse continue to cause some of the most prevalent, costly, and challenging health and societal problems in the United States, and are major risk factors for individuals with and without disabilities. Substance use includes ingestion of legal drugs (such as alcohol and nicotine), illicit drugs, and chemicals such as inhalants. Substance abuse generally refers to a maladaptive pattern of use that interferes with a person's functioning.

Individuals with certain kinds of disabilities are at an increased risk of developing substance use problems. The heterogeneity of this cultural group presents epidemiological obstacles for data collection and analysis, but estimates may be as high as 50% in some populations, such as individuals with traumatic brain injury. Some individuals with psychiatric disabilities such as bipolar disorder, schizophrenia, post-traumatic stress disorder, and depression have significantly higher rates of coexisting substance use disorders. In addition, stroke and other neurological disorders have been associated with substance abuse. Functional, social, and occupational limitations in the lives of some persons with disabilities, and chronic medical issues such as chronic pain can also lead to an increased risk of substance abuse.

Substance abuse can lead to a range of psychiatric conditions in individuals with and without disability. In addition, other consequences of substance abuse include falls, neglect of medical conditions, non-compliance with preventative daily care regimens, exposure to sexually transmitted diseases, unprotected sex, sexual assault, unwanted pregnancies, violence, and socioeconomic problems such as a loss of employment. Substance abuse compounds the effects of physical, social, economic, and health care barriers. It can interfere with recovery from acute medical conditions and rehabilitation. Individuals with alcohol abuse histories experience more complications during their recovery and rehabilitation after traumatic brain and spinal cord injuries.

Sexually Transmitted Diseases

The United States has one of the highest rates of sexually transmitted diseases (STD) in the world, with an estimated incidence of 15 million new cases per year. STDs include human papillomavirus, chlamydia, genital herpes, gonorrhea, syphilis, and human immunodeficiency virus (HIV) infection. The latter is not always sexually transmitted. Individuals at increased risk include women, people of color, adolescents, young adults, individuals with lower socioeconomic status, and substance abusers. In addition, individuals with HIV infection are at an increased risk of having coexisting STDs.

Individuals with disabilities are as likely as individuals without disabilities to contract an STD. However, because providers may incorrectly assume that individuals with disability are

sexually inactive, these individuals may not receive adequate screening, education, or treatment for STDs. In the National Study of Women with Disabilities survey, 94% of the subjects were found to be sexually active. These findings suggest that women with disabilities have an equal risk for acquiring STDs as women without disabilities. The rates are unknown for men with disabilities but it should be assumed that they have at least an equal risk for acquiring STDs as men without disabilities.

For individuals with disabilities, the associated features of the disability may mask the symptoms of an STD and delay diagnosis and appropriate treatment. For example, women with pelvic sensory impairment may not experience STD-related symptoms of discomfort but may experience increased spasticity or autonomic dysreflexia, and these symptoms may be misinterpreted as a bladder-related problem instead of a symptom of an STD. Individuals with cognitive or psychiatric disabilities may have poor memory or judgment, or have difficulties accurately describing their symptoms, and may therefore be misdiagnosed with a benign condition such as contact dermatitis when in fact they have an STD. These individuals may also be mistakenly assumed to be sexually inactive, but may be sexually very active and therefore at a high risk for contracting an STD or becoming pregnant. Some physical disabilities such as chronic pain, multiple sclerosis, and arthritis may limit an individual's manual dexterity, sensation, or movement such that they interfere with the ability to reach, see, or feel parts of the body to identify abnormalities. For individuals who rely on personal assistants, the attendant may not be aware of the symptoms of an STD and thus not bring it to the attention of the individual with a disability or health care professionals.

Symptoms of STDs may also closely resemble symptoms of other syndromes and be exacerbated or changed by medications the individual may be taking. In addition to these issues, physical and architectural barriers may limit access to appropriate medical care and thus may limit a provider's ability to correctly diagnose an STD. For example, an individual who uses a wheelchair may be unable to transfer onto an inaccessible examination table. The provider will be limited in the ability to perform an appropriate examination, and therefore may incorrectly diagnose and treat the individual. Given the risk and potentially serious impact of sexually transmitted diseases on individuals with disabilities, it is extremely important for providers to discuss these issues with patients and appropriately identify, treat, and educate individuals with sexually transmitted diseases.

Physical Injury

Individuals with physical or cognitive disabilities may have a significantly increased risk of physical injury. Physical injuries can greatly diminish an individual's level of independence, quality of life, and health status. Decreased muscle strength, decreased muscle function, impaired balance, visual-perceptual deficits, and poor safety awareness may place a person at risk for falls that then exacerbate a primary disability or create another disability such as a traumatic brain injury. Poor transfer techniques, lack of access to proper equipment, or inadequate education from therapists can also lead to an increased risk of falls and subsequent injury. Loss of skin integrity and wounds can be caused or exacerbated by poor nutrition, poor hygiene, and neglect of routine procedures such as weight shifts and skin checks.

The risks of developing overuse injuries and musculoskeletal dysfunctions can be significant among persons who use wheelchairs, assistive devices, and prosthetic devices because of the nature of the disability or the limitations of the technology. Therefore, the risks of physical injury among persons with disabilities are significant and should be identified and considered in the development of care plans.

Nutrition

Limited mobility, limited ability to self-feed, cognitive or communication impairment, decreased caloric need, or increased caloric requirements, are risk factors for nutritional imbalance in persons with disabilities. Nutritional imbalance can result in a decrease in function and further morbidity. The process of weight management must include careful attention to adequate nutrition. Education and assistance in management of eating behaviors encourages sustained weight goals. Monitoring of weight gain or loss can be difficult for individuals who are unable to stand to use a standard scale, so wheelchair scales in health care settings such as outpatient clinics should be readily available and accessible, and utilized at clinic appointments. Other methods of monitoring, for example using calipers to measure skin folds, or serum albumin or transferrin, may be helpful in some cases.

Diets lower than 1200 calories per day are rarely adequate in vitamins and minerals, and a supplement that meets the U.S. Recommended Daily Allowance is recommended at these caloric intake levels. The recommended caloric intake is 1600-1800 calories per day for women and 1800-2000 calories per day for men. Diets below 1200 calories per day are thus generally not recommended. In cases of small stature and reduced body mass, however, such a low calorie level may be appropriate. As with any weight management strategy, there must be an integrated approach with physical and occupational therapies. Caloric restriction should rarely be the sole means of weight reduction, and should be accompanied by an increase in activity whenever possible. Any impairment of mobility results in decreased caloric expenditure and presents a risk factor for obesity. Weight gain for a person with a disability can significantly affect functional level, independence, and caregiver burden. Ongoing evaluation of nutritional status and risk requires accurate baseline height and weight. Prudent weight loss is recommended as 0.5-1.0 lbs per week. Individuals should be monitored for a decrease of 10% of usual body weight in less than a month; weight loss greater than this amount is a risk factor for depletion.

Traumatic injuries such as brain injury and spinal cord injury increase caloric need in the acute phase. After the acute phase, loss of muscle mass in people with paraplegia and tetraplegia results in a reduction of ideal body weight, and caloric need is therefore reduced. This reduction in ideal body weight is 5-10% for a person with paraplegia and 10-15% for a person with tetraplegia. This population is at increased risk for development of diabetes mellitus type II, and the risk of diabetes is further increased for Latinos, African Americans, and Native Americans.

A number of other medical conditions require close monitoring of nutritional status. For example, nutritional assessment of an amputee must be based on accurate height and weight and should be performed by objective measurement, not estimation. Comparison of current weight to previous weight must take into consideration the weight of the lost limb. Accurate assessment of the level of amputation is important.

Adequate nutritional intake is essential to skin integrity. Pressure ulcers (Stage II and above) increase caloric and protein needs. A minimum of 30 kcal/kg ideal body weight and 1.5-2.0 gm of protein are required to maintain positive nitrogen balance and prevent skin breakdown. In cases of obesity, adjusted ideal body weight may be used. For some individuals with a disability, an inability to self-feed places individuals at risk, and lack of personal assistance has been correlated with poor nutritional status. Aphasia or cognitive impairments can also influence nutritional intake by impairing an individual's ability to communicate food preferences.

Recurrent hospitalizations and residence in an institutional setting are risk factors for nutritional depletion. Age and financial difficulties have also been shown to increase nutritional risk among persons with disabilities, and women are at a higher risk of inadequate intake than men. Unnecessary dietary restrictions and inappropriate diet levels can compromise meal selection and intake. These factors may prevent individual food choices, variety, and caloric adequacy. Individuals with disabilities may require close monitoring of their nutritional status, as well as referral to a registered dietitian to develop realistic nutrition goals when risk factors are identified.

Implications for Kaiser Permanente Care Providers

- Ask patients about how they are coping emotionally, and include non-threatening, non-judgmental questions about substance use, sexual functioning, nutrition, violence, abuse, and neglect.
- Look for signs of substance abuse, sexually transmitted diseases, physical injuries, and changes in general health status.
- When significant changes occur in the individual's ability to function independently or in their social, occupational, or financial status, make appropriate referrals to social or behavioral health services to assist the individual in maintaining the highest level of function.
- Where symptoms, historical data, or physical findings suggest an underlying issue, explore further and either treat the condition or provide an appropriate referral.
- If you suspect abuse or neglect, arrange to see the person alone, without his or her caregiver or partner.
- For situations that include sexual, physical, and emotional abuse, refer to Kaiser Permanente Clinical Practice Guidelines and Kaiser Permanente Domestic Violence Guidelines, available through the Kaiser Permanente Clinical Library online.
- Consider a referral to a registered dietitian to assess nutritional status and to develop treatment goals when nutritional risk factors are identified.

SPECIFIC AREAS OF CLINICAL FOCUS: SEXUALITY, REPRODUCTION, AND PREGNANCY

Introduction

Disabilities can influence an individual's life in many ways, and sexuality is a part of human life that is often overlooked by health care providers. If sexuality is not considered to be an important issue by providers, this area of human functioning is frequently not addressed. Provider attitudes, biases, and misunderstandings concerning the sexual desires and sexual activity of individuals with disability often reflect the erroneous societal view that people with disabilities are asexual. In addition, people with disabilities are viewed as not being able to, or not wanting to, become parents.

Many individuals with disabilities have no primary cause for sexual difficulties and have sexual satisfaction in intimate relationships. For others, the disabilities may affect sexuality, and the sexual dysfunction may be treatable. Many patients, with or without disabilities, do not feel comfortable discussing sexual concerns in a clinical setting unless the provider is perceived as trustworthy, knowledgeable, and willing to present the topic for discussion. Providers have an obligation to address concerns about reproduction, and pregnancy, as well as sexuality. Self-esteem, quality of life, sexuality, and parenting are all inter-related issues.

The nature of the disability will define many of the challenges and concerns. Potential physical, emotional, and psychological issues are influenced by the nature or cause of the injury or disability: Is the disability acquired or congenital, stable or progressive, visible or invisible? Age, sexual orientation, and culture may also be influencing factors. Parenting and genetic counseling may also be concerns that need to be addressed for the individual with a disability. It is important to recognize that there are many environmental, personal, social, and community barriers to accessible health care.

Barriers to Health Care

- The patient's difficulty, discomfort, or lack of trust to discuss with their provider topics and issues related to sexuality, reproduction, and pregnancy.
- The provider's lack of understanding that sexuality, relationships, pregnancy, and parenting are important issues for individuals with disabilities.
- Misinformation and myths related to the sexual potential and desires of individuals with disabilities.
- Unfamiliarity with how a patient's specific disability affects sexuality, reproduction, and parenting.
- Limited time during appointments to develop rapport and trust between the patient and provider.
- Physical barriers such as transportation to appointments, accessible exam tables, weighing equipment, radiology, and mammography equipment.
- The provider's lack of knowledge related to patient education information and resources not only in terms of the content, but also patient needs for alternative formats.
- Both the patient's and provider's lack of understanding regarding the importance of preventive care, prenatal care, and responsible sexual behavior.
- Both the patient's and provider's lack of awareness that pregnancy, sexually transmitted diseases, and HIV infection do occur in individuals with disabilities.
- The patient's social isolation or poor readiness to learn for a variety of reasons contributing to a lack of understanding and knowledge.

Patient Assessment and Interview

Assessment is the first important step in identifying and addressing concerns and problems, and a sexuality assessment should be an important part of a general assessment. Establishing rapport through respect, confidentiality, and trust is essential. It is much easier to begin addressing the topic of sexuality by asking a general open-ended question, which gives the patient permission to discuss the topic with the provider. This approach will also assess readiness to receive information.

A key topic to include in the history and physical is a medication profile, because many drugs such as cardiovascular or hypertensive agents, psychotropic agents, anxiolytics, anticonvulsants, antidepressants, and antispasticity and neuroleptic agents can have sexual side effects.

Abuse within the population of women with disabilities, including sexual abuse, occurs at approximately the same rate as in women without disabilities but is usually experienced for a longer duration. In addition, because of dependency for personal care and economic needs, there is less opportunity to escape or resolve the problem. Abuse may be perpetrated by spouses, parents, personal assistance providers, or other caregivers. It is important to ask patients discreetly if they wish others to be present during the evaluation, as this creates an opportunity for increased safety. Non-threatening questions related to the topic of abuse should be incorporated into the initial interview as well as on return visits. An exploration of possible abuse may start with the question, "Do you ever feel physically or emotionally threatened or hurt by your partner or by a caregiver?"

Begin the assessment by first explaining the need to ask some sensitive questions to provide the best possible care, at the same time giving the patient permission not to answer a question. A sexual assessment can begin with questions that use inclusive language such as "Who lives with you at home?" or "Tell me about your family." Follow these questions with additional questions such as "Are you sexually active?" More specific questions can then follow. A non-judgmental attitude concerning sexual issues, including same-sex relationships and sexual practices, is essential. If difficulties are identified, bridging statements such as "Has anyone explained to you how your disability can affect your ability to have sex?" can also be helpful. Address the partner, with permission of the patient, if this is important in the assessment. (See the Kaiser Permanente Provider's Handbook on Culturally Competent Care: Lesbian, Gay, Bisexual and Transgendered Population.)

Identify current functioning, positioning, history of sexually transmitted diseases, sensation, number and quality of relationships, history of sexual problems, and current problems and concerns. Mobility and sensory issues such as spasticity, pain, decreased range of motion, paralysis/paresis, weakness, changes/lack of sensation and proprioception difficulties can contribute to difficulties. Poor endurance and bladder and bowel dysfunction may interfere not only with sexual expression but also with developing relationships. The level of motor and sensory functioning, impaired cognition, and communication difficulties need to be considered. Social isolation as well as other psychosocial issues can also be present due to embarrassment, poor self-esteem, and shame.

Pregnancy and Parenting

For most women with disabilities, rates of infertility are similar to rates among women without disabilities. Medications that the individual with a disability may take for medical conditions can alter sexuality or may be teratogenic (i.e., detrimental to the developing fetus), for

example, some medications for spasticity and seizures. Pregnancy can have a significant effect on function for a woman with a disability if balance and mobility issues challenge her ability to continue ambulating safely during pregnancy. Temporarily returning to using a wheelchair can have a social and psychological impact. Imposed bed rest for complications of pregnancy can cause the woman to experience a functional decline. Physical and occupational therapists can help these individuals, not only by assisting them to achieve a high level of function, but also by addressing assistive and adaptive devices for breast feeding, seating, and parenting issues.

In the spinal cord injury population with a level of injury at T-6 thoracic level and above (and in some rare cases as low as T-8), pregnancy and labor can trigger autonomic dysreflexia. Providers need to know how to identify, prevent, and treat autonomic dysreflexia, and understand the maternal risks, including stroke and death from cerebral complications. Symptoms of autonomic dysreflexia may be similar to those of pre-eclampsia, so accurate differential diagnosis is critical. In addition, because of a lack of sensation, women with spinal cord injuries may not feel contractions or fetal movement.

Assisted reproductive technology and management of infertility are important topics for women and men with disabilities. Advances in the treatment of ejaculatory dysfunction and other strategies to increase conception rates can assist individuals with disabilities in becoming parents, for example, through artificial insemination.

Education

The **PLISSIT** model, described by Annon, can guide sexuality education and counseling. Asking open-ended questions during the history to identify if there are any concerns, clearly gives the individual the sense that you are giving **P**ermission to speak about the topic. **L**imited **I**nformation can include some factual information as to how the disability affects sexual functioning. **S**pecific **S**uggestions may include information about problem solving or when to seek medication attention/intervention. **I**ntensive **T**herapy is individualized treatment provided by sex therapists and counselors.

Parents and primary care providers should provide sexual information to children and adolescents with disabilities prior to their becoming sexually active. It is especially important for children and adolescents to understand what constitutes inappropriate touching. Neufeld notes several key challenges regarding adolescent sexuality and disability, such as the barriers to health care and more specifically to gynecologic care. Health care providers may lack knowledge of community resources that can "support the healthy development and exercise of responsible and satisfying sexuality." For all populations, Independent Living Centers (ILCs) are a resource for education, peer support, and mentoring. In addition, ILCs are an excellent resource for information on adaptive and assistive technologies and the use of personal care assistants. Sex education may also include not only basic information on sexuality but also topics such as consensual sex, communicating assertively, developing a mutually-satisfying intimate relationship, self-pleasuring/masturbation, and the use of sexual aids.

Prevention of HIV/AIDS and STDs is important not only for adolescents, who may be experimenting with sexuality, but also for all individuals with disabilities. Address the use of non-latex supplies when there is a latex sensitivity. Mobility impairment, cognition, and memory issues can influence contraceptive choices. (See Risk Factors: Behavioral and Lifestyle Risk Factors: Sexually Transmitted Diseases.)

The disability rights movement supports the rights of women, with and without disabilities, both to bear and to parent children and to resist prenatal diagnosis and selective abortion. Self-determination of assistance needs should be addressed by asking the individual with a disability what assistance she needs rather than imposing assistance. Once there is a clear understanding of the concerns and problems that the individual with a disability is having related to sexuality and reproduction, the health care professional may provide interventions, education, and consultation as well as act as an advocate for medical and psychological needs.

Implications for Kaiser Permanente Care Providers

- Avoid making assumptions about the patient's sexual behavior or sexual health needs.
- Realize that persons with disabilities are sexual, and acknowledge sexuality as an important area for assessment and interventions.
- Discuss confidentiality and ask if the individual prefers to have their intimate partner present during the evaluation.
- Listen carefully and be open and non-judgmental, using gender-neutral language, and ask the patient to give an account in his or her own language.
- Understand how the patient's disability affects sexuality, reproduction, and pregnancy.
- Consider sexuality issues and concerns for the intimate partner of the person with a disability.
- Validate and clarify an understanding of the information provided and allow adequate time for a response; provide extra time for appointments when indicated for discussions of sexuality and reproduction.
- Provide educational materials and resources concerning sexuality to adults and adolescents prior to their becoming sexually active, including written, audio and visual materials as appropriate, taking into consideration the patient's preferred learning style, and other disability-related needs.
- Incorporate inclusive language related to sexual orientation on information and history forms.
- Assure routine prevention and reproductive health care is provided, and address issues of safe sex, sexually transmitted diseases, and contraception.
- Refer to appropriate specialties such as physical medicine and rehabilitation, urology, obstetrics and gynecology, genetic counseling, and sexual counselors.
- Link with peer counselors, support groups, and community resources for additional information on sexuality, reproduction, and parenting with a disability.
- Consider referral to physical and occupational therapy during and after pregnancy to maintain/restore the individual to her highest level of functioning and independence and to assist with adaptations necessary for positioning, mobility, and breastfeeding.
- Recognize autonomic dysreflexia and be familiar with its dangers, as well as the interventions necessary during pregnancy, examinations, and labor.

SPECIFIC AREAS OF CLINICAL FOCUS: PAIN

Introduction

Pain is the most common symptom of people seeking medical care with and without disabilities, and is the second leading medical cause of work absenteeism. Both acute and chronic pain, regardless of etiology, can be disabling. Pain may accompany a disability as a secondary condition, or be defined as an individual's primary impairment or disability. Primary pain conditions are fibromyalgia/myofascial pain, and complex regional pain syndrome. Complex regional pain syndrome Type I, or reflex sympathetic dystrophy, can occur in association with neurologic conditions such as stroke. Complex regional pain syndrome Type II or causalgia is a pain syndrome that often occurs in association with traumatic injuries. The cause and pathogenesis of these disorders is poorly understood.

Pain more frequently occurs as a secondary condition and may be associated with a wide range of conditions, both acute and chronic. Chronic pain is a disorder with high prevalence in this country. Approximately 20% of older adults take analgesics several times a week or more, and 63% of those take pain medications requiring a prescription for more than 6 months. In a large nursing home study, 25% of the subjects reporting pain were not ordered pain medications. The most likely groups to receive inadequate treatment for pain were patients older than 85, women, members of racial minorities, and cognitively-impaired patients.

Barriers to Health Care

- Inadequate assessment techniques contributing to inadequate treatment or mismanagement.
- Untreated or inadequately treated pain, resulting from concerns about addiction or dependence, or legal or regulatory sanctions for overuse of analgesics.
- Cultural, gender, and age-group differences regarding pain that are not understood by the provider or communicated by the patient.
- Professional knowledge and approaches among providers that vary depending on the degree of formal education in pain assessment and management and provider beliefs and attitudes.
- Lack of knowledge among patients, influencing both assessment and treatment of pain.
- The different approaches, strategies, and interventions required to evaluate and treat acute and chronic pain.
- A tendency to either over-treat acute pain or under-treat chronic pain.
- A lack of knowledge concerning strategies and interventions required to evaluate and treat pain in pediatric, adult, geriatric, and specific disabled populations.
- The diverse representation of painful conditions within populations and subpopulations, even those with similar primary diagnoses or disabling conditions.
- The requirement of on-going management, often with a team of providers, which is time-consuming and resource-intensive.
- Unrecognized depression or other mental health disorders, which have a high prevalence in the chronic pain population, and go unrecognized and untreated, contributing to the inadequate treatment of pain.
- The high costs of medications and treatments.

General Patient Interview Principles

The biopsychosocial model of pain identifies biological factors as central to the experience of pain but acknowledges psychosocial factors, such as family or cultural responses to pain behaviors, beliefs, coping behaviors, depression, and disability as being important factors as well. Dimensions of pain include physiological, sensory, cognitive, affective, behavioral, and sociocultural factors.

Inadequate pain assessment may be due to the patient's stoicism or lack of pain behaviors, fear that the primary condition will not be treated, fear of pain treatment or addiction to medications, or fear that the pain will not be taken seriously by the provider. Some patients think their providers will assume that pain related to physical disability is unavoidable and something the patient will just have to get used to. In fact, the pain may have had very recent onset, may or may not be related to the disability, and may be able to be managed or resolved through a range of treatment options. Patients also may assume that they will have pain because of the disability and that it is something they have to endure, not realizing that there are interventions available.

A patient's perception of the cause, meaning, or intensity of the pain may vary because of cultural background, age, or gender. Various studies suggest that cultural factors influence an individual's experience of pain. The patient's racial or ethnic background or cultural group identity should not lead to stereotyping or assumptions, however. The individual's emotional response and behavior as related to pain and response to pain treatment may also differ depending on various other factors.

Treatment considerations also vary depending on factors such as age, gender, ethnicity, or culture. There is some evidence that there may be ethnic differences, for example, in regard to the use of certain pharmacologic agents. Children and the elderly, and those on more complicated medication regimens, must be carefully monitored for appropriate doses and agents, at the same time being given adequate relief through a comprehensive, multimodality approach. Alternative methods of administration of medications may need to be considered in disabled populations, with the goal of achieving independence whenever possible. Alternative modalities should also be explored for pain management, for example, meditation, bio-feedback, and acupuncture, when indicated.

Use of a pain scale and a pain management log is essential to identify the intensity of the pain at a point in time, or over a specific time interval, and the effectiveness of pain management interventions. Some patients with a disability require education and assessment materials in a different format, such as Braille or large print, or assistance with communicating about pain because of visual, hearing, mobility, cognitive, or communication impairments.

The Kaiser Permanente Care Management Chronic Pain Guidelines recommend the following key messages when interacting with patients who experience chronic pain:

- "I understand that you are in pain. It's not all in your head. It is a real medical condition."
- "Your active role in the management of your chronic pain will help improve your quality of life."
- "Let's talk about setting realistic treatment goals. We can aim to decrease your pain and suffering to improve your day-to-day functioning."
- "You will have better and worse days in your daily activities, but there are things you can do to feel better."

- "Some people worry about their pain treatment and medications. Tell me your concerns."
- "Often, we involve behavioral medicine or a behavioral medicine specialist because we recognize chronic pain affects so many aspects of your life. It does not mean that your pain is not real or that you have a psychiatric problem."

Pain Conditions Associated with Physical Disabilities

The nature, scope, and prevalence of chronic pain in children, youth, and adults with physical disabilities are poorly understood. In addition, the extent to which pain interferes with functioning apart from the primary disability has not been studied. Very few studies have adequately addressed the efficacy of treatments for people with disability who experience acute or chronic pain. Studies have been cross-sectional rather than longitudinal in most cases.

Spinal Cord Injury

Chronic pain occurs after spinal cord injury at a high frequency, with 77-79% of patients reporting having pain or unpleasant sensations, according to one study; allodynia (pain or discomfort with non-noxious stimuli) was reported in 48% of respondents. More than half (52%) of patients with spinal cord injury, in another study, reported that pain interfered with daily activities, and 60% reported that pain caused sleep disturbance. Pain was associated with depressive symptoms, more perceived stress, and poorer perceptions of health.

Pain that occurs in individuals with spinal cord injury may be neuropathic in origin, occurring above and below the site of injury, or musculoskeletal, due to stresses on joints, muscle imbalance, or spinal deformity. Subjects being asked to number sites of pain averaged 3.4 sites in one study. Unfortunately, over time, painful conditions do not resolve in most individuals with spinal cord injury; only 7% of persons reported resolution, with others reporting no change or worsening of the condition. Subjects ages 30 to 59 (when compared with subjects 18 to 29, and 60 years and older) reported more pain. Upper extremity pain may increase over time, and lower extremity pain may decrease. There appear to be no differences based on gender or between individuals with tetraplegia or paraplegia. However, spinal cord injury, secondary to gunshot wounds rather than other causes, may be associated with a higher incidence or more severe pain. A classification system for spinal cord injury pain has been developed that includes subtypes of pain, such as spinal cord injury pain, transition zone pain, radicular pain, visceral pain, mechanical spine pain, and overuse pain.

Multiple Sclerosis

Individuals with multiple sclerosis may experience pain from a variety of causes, including neuropathic pain from acute exacerbations, trigeminal neuralgia, spasticity, or postural abnormalities. Surveys suggest that up to 82% of people with multiple sclerosis experience a painful condition. Longitudinal studies suggest that the prevalence of chronic pain problems increases two- or three-fold over a five-year period. In one survey, only 36% of respondents had received pain treatment, suggesting that pain is not adequately treated in the multiple sclerosis population, so providers should be attentive to the special needs of this population.

Cerebral Palsy

Chronic pain was reported by 84% of respondents in a survey of women with cerebral palsy, and in 67% of a sample of adults with cerebral palsy. The hip, knee, and foot were the sites of pain most common in children with cerebral palsy, most likely due to joint stress from spastic muscles, dislocation, and overuse. In adults with cerebral palsy, pain interference with daily activities was rated on average at a level of 2 on a 0-10 scale. Half of the respondents reported that pain did not interfere at all with activities, in contrast to other populations with disabilities such as individuals with spinal cord injury. Coping responses, when compared to persons without disabilities who had chronic pain, were more often cognitive (diverting attention, task persistence) rather than physical strategies (such as resting or changing posture); this information may suggest strategies that are more efficacious in terms of daily functioning. This study did not examine the use of physical therapeutics such as anti-spasticity medication, or ice or heat in the treatment of pain, which may be alternative treatments for patients with neuromuscular or musculoskeletal pain.

Neuromuscular Disease

Neuromuscular disorders include disorders of muscle or muscle units such as myopathies, myasthenia gravis, or neuropathies. Many individuals with neuromuscular disorders report significant pain problems. For example, 89% of patients with Guillain-Barre syndrome and 71% of patients with Charcot-Marie-Tooth disease report pain as a symptom. In a large survey of individuals with neuromuscular disorders, 70% of persons with spinal muscular atrophy, 82% of individuals with Charcot-Marie-Tooth disease, and 96% of respondents with muscular dystrophy reported pain.

Post-Polio Syndrome

Post-polio syndrome is a disorder that affects individuals many years after a polio infection. New weakness, fatigue, and pain involving muscles and joints may occur. In some cases these symptoms are accompanied by muscle atrophy, breathing and swallowing difficulties, and cold intolerance. Pain may occur because of musculoskeletal stress or secondary conditions (such as carpal tunnel syndrome, progression of scoliosis, degenerative joint disease, or radiculopathy) or from weakness and atrophy, most likely secondary to degeneration of motor neurons and motor axonal sprouts. In a large study of the late effects of polio, 80% of patients reported muscle pain and 79% reported joint pain. In another study, 91% of respondents report pain in more than one location, and pain may worsen or involve increasing numbers of sites over time. Predictive factors were female gender, longer duration of stability after polio, younger age at interview, greater weakness at acute infection, weaker lower-extremity strength, and more compromised general health.

Amputations

Pain may occur in as many as 85% of individuals who undergo limb amputation. Both residual limb pain or "stump pain," and phantom limb pain occur in over 70% of individuals with amputation. Back pain is also a common problem for individuals with lower limb amputations, as is pain in other locations, such as an unamputated foot, or in the hips, neck, and shoulders. Children may not experience phantom limb pain as often as adults who have acquired an amputation in adulthood.

Treatment Considerations

Treatment of the primary condition causing the pain may, in some cases, result in elimination or amelioration of the pain. However, if this is not possible, as is the case with many chronic pain conditions, treatment interventions should be focused on pain treatment and management. Pharmacologic agents include simple analgesics, non-steroidal/anti-inflammatory agents, tricyclic-antidepressants, anticonvulsants, and opioids. Non-pharmacologic approaches include physical modalities (e.g., exercise, heat, cold, transcutaneous electrical nerve stimulation, etc.), cognitive/behavioral interventions (e.g., relaxation, redirected thinking, psychological support, counseling, biofeedback, hypnosis, etc.), complementary and alternative medicine techniques (e.g., acupuncture, topical agents, etc.) Invasive interventions (e.g., nerve blocks, other procedural and surgical techniques such as sympathectomy) may be recommended in some patients with intractable pain.

Treatment of pain in patients with disabilities requires additional considerations by the provider. For example, treatment of pain after amputation may include specific physical modalities such as desensitization. Preventive approaches, including epidural anesthesia at the time of surgery, are under investigation. As in all conditions, identifying the specific origin of the pain is the goal. Pain in persons with history of polio or spinal cord injury, for example, may be due to musculoskeletal (e.g. degenerative joint disease or scoliosis) and neurologic causes (e.g. neuropathic pain due to the spinal cord injury or neuromuscular overuse syndromes).

Implications for Kaiser Permanente Care Providers

- Understand the reasons for inadequate pain management, including inadequate assessment techniques, or a lack of understanding of the impact of cultural factors such as age, race, gender, and disability.
- Provide sufficient time and resources to evaluate the patient's pain and emotional well-being, using other members of the team when possible.
- Utilize pain questionnaires and assessment instruments to assist in data collection, and use alternative formats and the individual's primary language when required.
- Appreciate the specific nature, causative factors, and dimensions of pain in disabled populations, and refer to specialists in rehabilitation when necessary.
- Provide educational materials from health education centers that utilize alternative formats and in the patient's primary language to enhance knowledge and facilitate best practices.
- Remember that patients are the best judges of their pain, but assessment of pain can be especially challenging when an individual has cognitive or communication impairments.
- Ensure that your colleagues are using the same tools consistently when assessing pain.
- Reassess responses to treatment at each clinical encounter.
- Reinforce the importance of non-pharmacological modalities as effective modes of pain management.
- Clearly review with the patient and caregiver that musculoskeletal and neuropathic pain often respond to pharmacologic interventions, but are subtypes of painful conditions that may require different approaches.
- Recognize that chronic pain has an impact not only on the patient, but also on family members, work life, and quality of life.

SPECIFIC AREAS OF CLINICAL FOCUS: CHILDHOOD AND ADOLESCENT HEALTH

Introduction

Children and adolescents with disabilities and their families experience many challenges. Some of these challenges include physical, social, cultural, emotional, environmental, and financial issues. Although adults and children with disabilities may face similar barriers to care and to full participation, the unique vulnerabilities of children and the challenges within the family context present additional issues that must be considered by providers of care to children and youth. This section highlights approaches to lessen the impact of these stressors on the individual and the family.

Barriers to Health Care

- Inadequate number of chronic conditions management programs for children and families dealing with complex medical conditions.
- A lack of multidisciplinary specialty services for children requiring appointments with a variety of specialists in multiple locations.
- Financial challenges, such as multiple co-pays, transportation expense, and time away from work for families.
- Logistical difficulties of traveling with a child or adolescent with a disability.
- Inconsistent communication among pediatric specialty providers, resulting in fragmentation of care and services.
- Time constraints on busy primary care pediatric practices, preventing comprehensive approaches necessary for children with complex chronic conditions and disabilities.
- A frequency of disability-related, specialty appointments, resulting in a lack of preventive health care services for children.
- A lack of familiarity with interventions to prevent the development of secondary conditions frequently associated with having a physical disability, such as pressure ulcers, pain, and contractures.
- A lack of knowledge of community-based resources to promote full participation and opportunity.
- A lack of knowledge concerning federal laws governing access and academic inclusion of children with disabilities.
- A child's or adolescent's lack of understanding and adherence to therapies and treatment plans because of the developmental stage or cognitive capabilities that affect information processing or a willingness to follow adult direction.
- A tendency to "pathologize" everyday developmental stage responses, feelings, and behaviors as "disability-related" rather than considering them age-appropriate.
- Inadequate provider, parent, and patient support for the debilitating effect of societal stigma on the child's disability, contributing to feelings of depression, hopelessness, denial, and shame.

Clinical Practice Issues

Clinicians who work with children and adolescents with disabilities need to be aware of the variability of physical, sensory, and cognitive disability. For some patients, social and structural barriers, more than the disability itself, prevent optimal health outcomes. For others, the specific medical condition and its effect on multiple bodily systems and functions may be challenging. The intersection of the physical, social, emotional, and cognitive effects associated with disability can make independent living difficult. An important role for the clinician is to determine what factors, such as medical, social, emotional, and structural, may facilitate or undermine overall health.

First, a plan of care targeting transition needs over the lifespan, with particular emphasis on developmental and functional skill sets and abilities, must be established. Children living with a disability are frequently the only member of the family with the disabling condition. Most families are under-prepared with regard to the biological, social, and physical (architectural) challenges that lie ahead. A family's initial understanding of disability tends to mirror their cultural viewpoint. Therefore, providing patients and their families with resources and empowerment is an important first step in reframing how they may understand disability. Such information is designed to promote self-determination and self-care through education, advocacy, support, and modeling in order to achieve empowerment, for example, in regard to a successful school and vocational experience.

Health care providers for children with disabilities should be aware of, and anticipate, developmental issues over the course of the life span. Evaluation of the individual's and the family's understanding of issues and events and the attached meanings, and understanding the family structures for coping and adaptation, lay the groundwork for planning interventions. Critical transition periods and triggering events may include planned or unplanned surgeries, hospitalizations, a sudden health crisis, entry into middle school or high school, and transition from puberty into adulthood. These transitions may trigger a change in self-care and self-care agency demands. During periods of transition, patients or families may be presented with challenges, both related to and unrelated to the disability.

Because children born with certain kinds of physical, sensory, and cognitive disabilities may experience frequent episodes of illness, hospitalizations, and surgeries, there may be an erroneous assumption of "routine" by health care professionals caring for these children. Both the parent and the child may try to protect one another from feeling guilt or burden, keeping their concerns, worries or complaints hidden. Parents, children, and health care professionals may interpret these silences as a lack of stress or concern about the illness, hospitalization, or surgery. Failure to ensure adequate briefing and debriefing during appointments may have negative consequences on a child's health and well-being in the future. In addition, youth exposed to traumatic stressful events, such as chronic illness added to another disabling condition, are at risk for post-traumatic stress disorder. Staying attuned to a disabled youth's affective states, not always overtly demonstrated, is essential to promote overall well-being, recovery, and healthy development. Encouraging greater vigilance and emotional support by the family before, during, and after a perceived stressful and traumatic event, including hospitalization and surgery, is also crucial.

Children with physical disabilities are often presumed to have cognitive disabilities. In fact, such assumptions are usually unfounded. Careful evaluation is necessary to determine the specific physical and cognitive disabilities of a given individual. Different individuals may exhibit varying degrees of disability, despite having the same medical diagnosis. In some cases, no specific diagnosis can be ascribed, even when a cognitive disability is documented.

On the other hand, children with cognitive impairments, but no physical impairments, may not be perceived as having a disability at all. These children are at risk of being labeled as lazy, defiant, or unmotivated.

Children with cognitive disabilities may have trouble processing information and, for example, understanding and remembering instructions. Information processing is a key skill in academic areas such as mathematics, science, reading comprehension, and writing. The difficulty is not limited to school work, however, but also applies to processing day-to-day information from parents, siblings, school classmates, and health care providers. Children with disabilities may exhibit problems in several areas, such as completing assignments in a timely manner, finding and getting to the classroom in the allotted time, remembering to take medication, and performing required treatments, such as catheterizations, at the prescribed time. They may experience difficulty making meaningful contact and friendships with peers, resulting in social isolation. Parents may report difficulty promoting independence and self-care and may find it necessary to repeat seemingly straightforward directions.

Health needs of children with physical disabilities are broad in scope, and management of these conditions can sometimes be overwhelming for the child and family. Despite the many different conditions that can result in disabilities, children with disabilities have a number of basic needs that require attention. Basic health maintenance; promotion of proper nutrition, physical fitness, socialization, peer relations, and academic progress; coordination of services; support for the family; and communication among health care professionals are vital. Teamwork among family, clinicians, schools, and community agencies is also required to deal with the challenging needs of children with disabilities.

Important Considerations for Children and Adolescents with Disabilities

The path leading from childhood to adulthood is predicated on developing a sense of personal identity honed through recognition of one's abilities and achievements by self and others. During adolescence, youth venture forth from the home environment, the security and dependency of parents, and begin to replace it with a peer group. The peer group, club, best friend, girlfriend, or boyfriend, provide a feedback system helping to promote a sense of self through mirroring or modeling. The opportunity for this kind of psychosocial reciprocity, so critical to identity formation in adolescence, is sometimes lacking for disabled youth as a consequence of peer neglect, isolation, or rejection in response to the stigma associated with a physical difference. Beginning in middle school, disability poses a greater social liability when differences become more highly charged and tolerated less, placing early adolescents, in particular, at risk for alienation from their peers. In some cases, children with disabilities can be victims of verbal threats and even violence, usually beginning in adolescence.

Peer ridicule and rejection as a consequence of physical or other differences may exaggerate already existing feelings of inadequacy in relation to self-concept and body image common during early adolescence. Even youth with "hidden" or less obvious disabilities may be influenced by these pressures. Left un-addressed by families, school, and health care professionals, disturbances in self-perception and self-esteem may build, eventually overwhelming the adolescent whose sense of self is not yet strong enough to ignore the negative messages from peers.

Early and middle adolescents often downplay or withhold feelings of personal suffering, insecurity, and emotional pain from family, friends, as well as health care providers, even when given the opportunity to voice them. The adolescent may not yet have the cognitive

capability or sophistication to be self-reflective or introspective in order to know what it is they are feeling. They may already see themselves as a "burden" by virtue of their physical dependency on others and be unwilling to demonstrate further need. In addition, they may be embarrassed about their physical condition and not want to risk further humiliation by appearing vulnerable.

Challenges with respect to friendship and intimacy are likely to cross over into the sexual arena as well. In addition to feeling embarrassed and self-conscious about their specific disability, there may be other obstacles precluding physical closeness such as bladder and bowel incontinence and physical scarring, making the prospect for sexual intimacy highly charged with anxiety. Clinicians need to be aware of these issues, creating an environment whereby youth with disabilities may feel comfortable discussing their concerns.

Socialization, play, and peer culture allow children to gain control over their lives, their world, and one another. Through play and interaction, children practice, problem-solve, negotiate, reject, and perfect the behaviors, skills, and rhetoric necessary for successful entree into the adult world. Disabilities that impact mobility, physical appearance, and continence may result in reduced social contacts, interfering with peer interactions and friendship development, and hence modeling opportunities. As a consequence, youth with disabilities are more likely to experience delays in transitioning from one developmental stage to another. Peer-support and recreational activities are essential aspects of the lives of children with disabilities. Providers should be aware of resources in their communities in order to make appropriate referrals.

Functionally-Oriented Approaches

The goals of health evaluation are to promote physical, mental, emotional, and social growth and development. Assessment of functional abilities and adaptive behaviors of the child within the environment is crucial. It is important to promote the viewpoint that, although there may be physical, emotional, and social challenges, most children can develop a meaningful and productive life as adults with appropriate guidance and intervention. Emphasis on abilities and assets is essential during assessment. An interdisciplinary team is helpful for comprehensive assessment and planning and is recommended for children with moderate to severe disabilities.

Initial interactions with the family and the child will lead to important first impressions. The goal is to establish rapport and reduce fear and anxiety in the child. Upon entering the room, the practitioner should acknowledge everyone in the room and establish the relationship of each person to the child. Establishing good rapport is critical, especially when difficult care decisions must be made. For a new evaluation, the complaints typically fall into the categories of physical difference, altered function, or pain. Proper evaluation is important in establishing a diagnosis. Every condition requires a clinical impression, and some require active management. Keep in mind that "functional disability" is more significant than diagnosis or physical difference, although in order to qualify for some public services, a diagnosis is likely to be necessary. It is not always in the best interest of the child to have surgical interventions to correct physical differences without clear goals to improve function or reduce pain.

Observations of behaviors (for example, level of alertness, interactions, and adaptive behaviors) provide crucial information for parents, so that they can appreciate the uniqueness of the child and understand the clinician's perspective and recommendations. Complete screening for evidence of scoliosis should include inspection of the thoracic and lumbar

spine, as well as performance of the forward bending test. Gait assessment should include observation of the child's ambulation in shoes, and then again on toes and heels, without shoes and socks.

Developmental Disabilities Affecting Cognitive and Academic Functioning

Developmental disabilities most often significantly affect an individual's cognitive and/or emotional development. Some may persist into adulthood while others may resolve as the child develops. The essential feature of mental retardation is below-average intellectual functioning and impaired adaptive behavior functioning in communication, self-care, social and interpersonal skills. Although individuals with moderate or severe mental retardation are sometimes placed in institutional settings, most mildly affected individuals live either independently or in supervised living situations.

Another disabling developmental disorder is autism. The characteristics of autism initially appear prior to age three and include abnormalities or marked delay in reciprocal social interaction and communicative language. In addition, the child demonstrates significant restricted repetitive stereotyped behaviors. Autism is three times more common in males than in females, and 70% of these individuals also function in the mentally retarded range. Approximately 15% to 30% can eventually live independently and have some type of employment. Communicative language skills and intellectual function correlate best with prognosis.

Asperger's disorder is a condition similar to autism, but individuals with this disorder exhibit relatively normal language and cognitive development. Both conditions include significant impairment in social interaction skills and repetitive, stereotyped behavior patterns. Age of onset of Asperger's is variable, but may not be recognized until pre-school age when the social challenges are more likely to highlight peer differences. Both autism and Asperger's disorder are usually defined as spectrum disorders.

Although mental retardation, autism, and Asperger's impact learning, some other conditions primarily impact academic functioning. Learning disorders are disorders characterized by academic achievement or functional status which is substantially below that which would be expected given the individual's age, level of intellectual functioning, and schooling. The areas of involvement include reading, writing skills, and mathematics but also may include visual perceptual processing, memory, or other areas of cognitive functioning that significantly impact academic performance.

Verbal and non-verbal learning disorders are types of learning disorders that are associated with academic difficulty. Another condition that influences learning is attention deficit/hyperactivity disorder (AD/HD). Symptoms include inattention, impulsivity, and hyperactivity that significantly interfere with a child's ability to function in many settings, including school, home, and social situations. These individuals have significant difficulties completing tasks and following through with projects, and directions, for example. The symptoms begin before age seven and may continue throughout life.

Although the initial symptoms of a learning disorder or AD/HD may include a behavioral or emotional disturbance, some children may only exhibit academic problems. This is not only true for learning disabilities but also can be seen in the child with the inattentive type of AD/HD. These children may be seen as "daydreamers" and are often disorganized and forgetful. Providers should always inquire about not only behavioral and emotional functioning but also academic and school functioning.

Screening and Assessment Tools

Areas that need assessment include a child's gross motor function, fine motor function, cognitive and language ability, personal-social behaviors, and academic skills. Avoidance of subjective methods in obtaining data is strongly encouraged. Instead of making generalized impressions about the child, more specific clarification about the child's behavior is needed. For example, instead of saying that the child is distractible, the professional can quantify the child's behavior and state how many times the child looked at the object, how many times the child reached for the object, how often the child followed through with the requested tasks. Longitudinal data allow for comparison with the child's earlier performance. Gathering information from parents and school staff using structured questionnaires or rating forms is an important component of the assessment in children. Examination in the clinic alone is often not sufficient.

Providers are encouraged to tell parents about specific behaviors that they need to monitor. General health areas that should be addressed in a child with a disability include growth and development, nutrition, immunization, sleep patterns, bladder and bowel patterns, safety and injury prevention, and physical fitness. Disability-related health issues that should be addressed include vision, hearing, oral health, contractures, spasticity, spinal pathology, seizures, pressure ulcers, and fractures. Technology needs, psychosocial development and support, environmental access, and acute and chronic pain management should also be evaluated and addressed with specific interventions.

Interacting with Parents

Keep in mind that the child's family is part of the team. Conveying information to the parents constitutes an important part of treatment. Instead of inundating the parents with a long list of problems, clinicians are encouraged to pace the information and provide resources to allow the parents to absorb the information. Childcare professionals should learn to respond comfortably to the parents' needs and not to impose their views. Rather than thinking in terms of limited goals, childcare professionals need to consider lifetime goals and include the parents and child in realistic planning. Instead of intervening during a crisis, clinicians should concentrate on giving anticipatory guidance. Effective care requires full participation of the parents.

When communicating with the child and parents regarding a diagnosis or condition, discussions of behaviors should emphasize strengths and challenges in ability. Clinicians are encouraged to be specific in clarifying behaviors that need to be increased, decreased, or disregarded. For example, instead of referring to medical terms such as "mentally retarded" or "learning disabled," explain to the family what they can expect regarding functional abilities and challenges. Labeling is not necessarily useful to the parent or the child, although it is required under IDEA in order for services to be provided. Stereotyping affects how everyone views the child and his abilities and will most likely affect the plan of care. No matter how much the child progresses developmentally, she or he will be subject to being stigmatized because of the label. Labeling perpetuates a negative image of an individual, and this may tend to diminish a positive self-image. Although using medical diagnoses accomplishes a practical purpose in obtaining public services, medical terms tell little about the child's current functional abilities and adaptive behaviors.

The needs of adolescents take on additional importance. Encounters for the adolescent population should allow for the establishment of rapport and for fostering continued discussions in areas of sexual activity, nutrition, and emotional development. Because the

adolescent is no longer a child but is not yet an adult, there are a few suggestions to keep in mind during the encounter. Much of the history should be obtained directly from the adolescent, without the parents present. A sense of confidentiality should be established at the beginning of the health care encounter. There should be adequate time spent alone with the adolescent, with the parent(s), and with the family as a unit. There should be time at the end to summarize the evaluation and answer questions, and discuss sensitive areas, such as risk-taking behaviors.

Implications for Kaiser Permanente Care Providers

- Recognize that children and adolescents with disabilities possess the right to full participation and opportunity in life.
- Empower families to maintain healthy family dynamics and advise them of resources such as support groups and family therapy.
- Give parents permission to define their own needs and avoid intervention until the family's needs are clarified.
- Establish the purpose of the visit, and encourage the child and family to ask questions and actively organize their own medical health care records at home.
- Offer to provide follow-up or telephone appointments if the family appears to need continued reassurance, and be available on a long-term basis to provide guidance.
- Avoid stereotypic language or labels to describe the child, and explain diagnostic terms.
- Be sensitive when you describe the patient to other providers in the presence of the patient, and remember that clinical terms may be misinterpreted or considered offensive by the family.
- View the family as resourceful rather than passive recipients, and give them credit for their role, emphasizing family members' strengths instead of perceived inadequacies.
- Provide educational intervention at an understandable level and pace at an age-appropriate level for the child or adolescent.
- Actively seek the input of other clinicians and specialists, and refer to interdisciplinary clinics when available.
- Limit the child's activities only when the child will be placed at risk, as recreation is an important part of childhood development.
- Consider lifetime goals and include the parents and child in realistic planning.
- Avoid excluding a child in discussions, as children may often understand more than would be expected.

SPECIFIC AREAS OF CLINICAL FOCUS: BLADDER AND BOWEL MANAGEMENT

Introduction

Depending on the nature of the disability, bladder or bowel dysfunction may be either neurologic or non-neurologic in origin. The challenges may be due to mobility issues such as spasticity, paresis or paralysis, or contractures resulting in impairments in hand function or transfer abilities; speech issues such as ability to communicate needs; or cognitive impairments such as memory, attention, and initiation; and accessibility of bathroom facilities, equipment, and assistive devices.

Regardless of the specific problem or cause, bladder and bowel dysfunction can impose burdens, not only on the individual with disability, but also on the caregiver and family. Physical consequences and complications such as infection can result in hospitalizations. Financial burdens may be incurred due to medical expenses, cost of supplies/equipment, and lost wages due to time off from work. Emotional difficulties may include depression, anxiety, fear of accidents, and embarrassment. Social relationships, intimacy, and sexuality may also be affected.

Barriers to Health Care

To better understand bladder and bowel management, it is critical to recognize that there are many environmental, personal, social, and community barriers to accessible health care:

- The patient's difficulty, discomfort, or lack of trust around discussing topics related to incontinence and bladder and bowel dysfunction.
- The provider's lack of training in sensitive approaches to raising this stigmatized topic and reducing patient anxiety.
- The provider's lack of understanding of the types of interventions available for neurogenic bladder and bowel issues.
- Limited time during appointments to develop rapport and trust between the patient and provider.
- Physical barriers such as transportation to appointments, accessible exam tables, weighing scales, and radiology equipment.
- The provider's lack of knowledge related to patient education/information/resources, not only in terms of the topics, but also in terms of alternative formats.
- Lack of readiness or ability by the patient to receive information on the topic.
- The patient's social isolation as a contributing barrier to receiving information.

Many studies have identified the significant impact that bladder and bowel dysfunction may have on the quality of life. Research has indicated that the secondary conditions of bladder and bowel dysfunction, experienced after the primary or first disability, can significantly influence both the health status and the quality of life for women with disabilities. Individuals with spinal cord injury who were functionally dependent for bladder and bowel management reported a lower quality of life in several domains than the matched sample group of individuals who were functionally independent with bladder and bowel management.

Moderate to severe depression was associated with urinary incontinence in 43% of 668 elderly Americans, versus 30% without incontinence. Embarrassment, shame, and social isolation were felt to be contributory to the depression.

Incontinence is a marker for stroke severity because of its association with death and disability and its influence on the place to which stroke survivors are discharged. Genitourinary consequences of disabling conditions such as incontinence, retention, and urgency may not be life-threatening. However, psychosocial consequences and morbidity may affect quality of life and employability. Bowel dysfunction is a significant co-morbid condition after spinal cord injury, and there is a high incidence of bowel symptoms in individuals aging with spinal cord injury.

Despite the challenges of bladder and bowel dysfunction, many problems can be managed through accurate identification, implementation of the correct interventions, education of the patient, family, and caregiver, and routine follow-up care with adjustment in bladder and bowel management programs. Access to prevention and wellness programs is also an important factor.

Urinary Dysfunction and Classifications

Urinary incontinence affects 13 million Americans. The National Institute of Diabetes and Digestive and Kidney Diseases and partner organizations have a campaign both to increase the reporting of urinary incontinence and to raise health care professionals' knowledge on the topic of incontinence in women. They suggest that at routine visits, providers should ask about incontinence to destigmatize the issue and to offer optimism and a problem-solving approach. Health care professionals may not feel they have expertise in handling some of the more complex problems, but should refer the patient to the appropriate specialist in urology or physical medicine and rehabilitation, or to rehabilitation nurses or clinical nurse specialists.

Patients may be embarrassed to talk about bladder and bowel issues, and providers need to include questions related to this during routine visits. It is estimated that less than half of those persons with urinary incontinence who live in the community consult with health care professionals about this issue.

There are several classifications of voiding dysfunction based on neurologic lesions and functional classifications (i.e., failure to store, failure to empty, and failure of storage and emptying.) An incontinence classification system identifies types as urge, stress, reflex, and overflow with additions including mixed and functional incontinence. Functional incontinence is not related to the genitourinary tract but is related to cognitive, communication, environmental, and physical limitations. Aphasia, immobility, architectural barriers, and altered mental status are a few causes. Interventions can include behavioral and noninvasive management techniques such as time voiding, prompted voiding, bladder training, pelvic muscle exercises, fluid balancing, bathroom accessibility, and communication aids.

There are five categories of neurogenic bladder dysfunction: uninhibited, reflex (spastic), autonomous (flaccid), sensory paralytic, and motor paralytic. Neurogenic conditions may result from traumatic injuries such as spinal cord injury, non-traumatic conditions such as stroke, multiple sclerosis, and diabetes mellitus, and congenital conditions such as cerebral palsy and spina bifida. Interventions are based on the type of neurogenic bladder, functional abilities of the individual and their caregivers, and psychosocial issues and lifestyle preferences. It is important to tailor the bladder management program to the individual.

Components of a bladder management program may be intermittent catheterization, external catheters, indwelling foley/suprapubic catheter, and fluid balancing. (See Appendix A: Neurogenic Bladder Dysfunction Table.)

A complete assessment to identify the urinary dysfunction includes genitourinary symptoms and history; medications, both prescription and over-the-counter; herbal supplements; environmental factors; functional abilities; cognitive and affective status; medical and surgical history; urinalysis; post-void residual; rectal exam including perianal sensation, sphincter tone, and bulbocavernous reflex. A voiding diary, with a log of voiding/incontinence patterns and fluid intake/choices is helpful in identifying problems and interventions. Additional urodynamic and imaging studies may be necessary to identify the type of neurogenic bladder dysfunction and the best management program. Problems such as detrusor sphincter dyssynergia, which occurs when bladder contraction and bladder neck/sphincter relaxation do not occur simultaneously, need to be identified through these studies.

Guidelines need to be outlined for catheterization frequency/volumes, fluid choices, parameters, and balancing guidelines. Adequate fluid intake must be reinforced because some patients limit fluid intake to relieve bladder symptoms and to decrease frequency of catheterization. Excessive fluids will influence the frequency of catheterization based on the maximum volume (usually 450-500cc).

A life-threatening complication that can be seen in spinal cord injury at T-6 level and above (some studies indicate as low as T-8) is autonomic dysreflexia (AD). Bladder distention, urinary tract infection, stones, blocked catheter, detrusor sphincter dyssynergia, urologic instrumentation, catheterization, and shock wave lithotripsy are some of the major potential causative factors related to the urinary system. This hypertensive emergency may present with only an increase of systolic blood pressure of 20-40 mm Hg above baseline in adults and 15-20 mm Hg in adolescents. Average systolic blood pressure in spinal cord injury can range between 90-110 mmHg. Autonomic dysreflexia may be present without any other symptoms, but nasal congestion, pounding headache, flushing of skin above the level of injury, anxiety, and piloerection can occur. Other triggers of this medical emergency are bowel distention, skin problems, fractures, pregnancy/labor, ingrown toenails, and tight clothing. Immediate actions must be taken to decrease the blood pressure. Sit the patient up, dangle legs if possible, and remove constrictive clothes, elastic stockings and abdominal binder, and then identify and remove the cause. If the cause cannot be quickly determined and the blood pressure is not reduced, medications may be indicated. Autonomic dysreflexia can result in stroke or death.

Medications may be helpful in bladder management programs. Drugs from appropriate categories can be prescribed to increase bladder capacity and/or storage or to improve bladder emptying and sphincter contraction. Antibiotic treatment of urinary tract infections should be used judiciously, and not simply to treat colonization in patients with indwelling catheters. Indwelling catheters are associated with more frequent infections than is intermittent catheterization. Surgical procedures for neurogenic bladder such as bladder augmentation, continent diversion, urinary diversion, vesicostomy, urinary conduit, and sphincterotomy may be alternatives.

Bowel Dysfunction

Bowel dysfunction, similar to bladder dysfunction, may be present due to functional problems similar to those that cause urinary incontinence. Neurogenic bowel dysfunction can occur with results such as fecal incontinence or difficulty with evacuation. Types of neurogenic bowel are uninhibited, reflex (spastic), autonomous (flaccid), motor paralytic and sensory paralytic. (See Appendix B: Neurogenic Bowel Dysfunction Table.)

Assessment of the type of bowel dysfunction includes complete evaluation of bowel symptoms and history, pre-injury bowel pattern, medications (including prescription and over-the-counter), diet, environmental factors, medical and surgical history, and rectal exam including perianal sensation, sphincter tone, and bulbocavernous reflex. In addition, functional abilities, ability and tolerance to sit up, spasticity, transfer skills, cognitive and affective status, and ability to direct care are other elements to include in the assessment. Providers should identify bowel program components such as suppositories, digital stimulation, frequency, time of day, time to complete the program, assistance required, assistive devices, and complications. Lab studies may be necessary to assess the causes of diarrhea. A bowel diary, with a log of bowel patterns /incontinence and fluid and dietary intake completed before the office visit can be very helpful in identifying problems and interventions.

Predictable and effective elimination are the key goals of a bowel program. Medications can be added to soften or firm the stool and to trigger defecation. In rare instances, surgical diversion by ileostomy or colostomy may be recommended. Keys to preventing complications are to monitor the outcomes of the bowel program and make adjustments as needed. The Consortium for Spinal Cord Medicine includes a comprehensive Clinical Practice Guideline on the Management of Neurogenic Bowel in Adults with Spinal Cord Injury. (See Bibliography: Additional Resources and Suggested Readings)

Bladder and bowel management programs can successfully manage urinary and bowel dysfunction. The programs must be individualized, taking into consideration the abilities of patients and their support systems, cultural beliefs and attitudes, pre-disability habits, lifestyle, and age and developmental level. It is important to know both the patient and family expectations and motivation to adhere to recommendations. Commitment and compliance are essential for bladder and bowel management programs to be effective. For health care professionals, as important as the knowledge of medical issues related to urinary and bowel dysfunctions is a sensitivity to the impact that these dysfunctions can have on self-esteem, quality of life, return or entry to work, school, and community, and satisfaction with life. Health care professionals who work with individuals with disabilities need to coordinate the interdisciplinary care and services required, take a holistic approach to needs, and act as advocates, not only with health care, but also with schools and communities.

Implications for Kaiser Permanente Care Providers

- Monitor voiding and bowel dysfunction and the quality of life issues that may be present for individuals with disabilities.
- Remember that bladder and bowel management programs are contingent on a realistic plan for the patient, family, and personal attendant within functional abilities and tailored to work and school schedules, lifestyles, and preferences.
- Coordinate regular long-term follow-up care to minimize complications.
- Provide important education related to prevention and recognition of urinary tract infection, prevention and treatment of autonomic dysreflexia, components of individualized bladder and bowel management programs, adherence to a consistent schedule for programs, care of supplies and equipment, and how and when to contact their health care professional
- Check post-void residuals by intermittent catheterization or bladder ultrasound because voiding may occur but emptying may be incomplete with high pressure and volumes.
- Ask the patient to keep a bladder and bowel log that includes frequency and

components of their program, fluid intake and choices, diet, and outcomes to facilitate identification of problems and interventions.

- Change only one component of the bladder or bowel program at a time in order to assess if the change is effective or if an additional change is needed.
- Enhance the effectiveness of bowel programs by incorporating a consistent time of program, sitting up on commode, and timing the program when the gastrocolic reflex is triggered after eating.
- Identify and facilitate the acquisition of assistive and adaptive equipment for bladder and bowel programs that contribute to independence and safety.
- Consult with specialists such as physical medicine and rehabilitation physicians, urologists, gastroenterologists, and rehabilitation nurses/clinical nurse specialists to assist with diagnosis and management strategies.
- Advocate for patients not only in the health care setting but also in school, workplace, home, and community.

SPECIFIC AREAS OF CLINICAL FOCUS: MENTAL HEALTH

Introduction

The term "mental disorder" has been applied to a range of diagnoses and disabling conditions. In fact, the Diagnostic Statistical Manual (DSM) IV Classification system now encompasses: 1) cognitive and behavioral disorders such as dementia and delirium; 2) developmental disorders such as attention deficit hyperactivity disorder, autism, and mental retardation; 3) the more commonly-associated psychiatric disorders such as mood, psychotic, and adjustment disorders; 4) mental disorders due to a general medical condition; and 5) an assortment of other conditions such as substance-related disorders, enuresis, sexual and gender identity disorders, and sleeping and eating disorders. This should remind us that the fields of psychiatry and neurology, as well as internal medicine and other fields of medicine, do indeed have domains of knowledge and practice that overlap.

Barriers To Health Care

- Mental health concerns presenting indirectly as somatic complaints.
- Syndrome-overlap in mental disorders.
- Lack of appreciation of the distinction between feelings of grief and loss, and depression.
- Assumptions that people with disabilities must have associated depression or other mood disorders because of projection of the feelings of the provider onto the patient.
- Assumptions that the cause of the patient's mood disorder is the disability, not another life circumstance or a biological factor.
- Social stigma, shame, and feelings of isolation or inadequacy associated with mental disorders preventing a discussion of mood symptoms or adjustment issues.
- Social withdrawal, resulting in the individual not seeking treatment.
- Poor social support networks influencing ability to access health care services.
- Communication or cognitive impairments that prevent a full evaluation of a mental health condition.
- Insufficient communication by the provider with the patient about the full range of treatment options.
- The complex relationships between mental and other health conditions.
- Inadequate financial resources due to lack of income, or other socioeconomic factors related to disability.
- Cultural, gender, and age-cohort differences in symptoms, knowledge, and acceptance of disability.

The Impact of Disability on Mental Health

This section discusses the broad range of psychological symptoms and reactions including emotional symptoms, primary psychiatric disabilities, and co-morbid psychiatric conditions in people with another disabling condition. Providers may not appreciate that individuals with disabilities can and do experience the same wide range of emotional experiences as do people without disabilities. To feel sadness or anxiety when a difficult situation arises is part of the human experience and is not a pathological reaction, or a symptom leading to a diagnosis.

The DSM-IV defines a mental disorder as a disturbance that causes clinically significant distress or impairment in social or occupational functioning. For some individuals, the severity and scope of the symptoms may be the basis for a primary disabling condition, but for others the symptoms may not cause an impairment. Symptoms in children and adolescents may appear differently than in adults. Behavioral disturbances and significant changes in school and social settings may be the initial signs and symptoms of a psychiatric condition.

The challenges and discrimination experienced by people with disabilities may or may not result in emotional or psychological symptoms that are disabling. For some individuals, these stressors have become part of a life experience and are responded to as any other life experience. For others, these stressors may facilitate the development of psychological symptoms or a secondary condition. How the disability occurred or developed, what functions are lost or impaired, and other factors not directly related to the disability, can have a significant impact on psychological functioning. For individuals who acquired a disability in adolescence or adulthood, psychological adjustment is common but may take many different forms. Although depression can occur, individuals with loss of function experience a mourning or grief reaction similar to the loss of a loved one or a job. For others, the psychological adjustment to a newly acquired disability may appear as a changed perspective on life with new opportunities and challenges. It is imperative for providers to examine the degree and impact of emotional response in any given individual to determine what, if any, interventions are necessary.

Individuals with Disabilities and Co-Morbid Mental Disorders

For individuals with disabilities who have coexisting mental disorders, few statistics are available. However, primary risk factors for many mental disorders include medical conditions, chronic pain, life circumstance problems, and substance use. These factors suggest that individuals with disabilities are at increased risk to develop a co-morbid mental disorder. Co-morbid conditions have been recognized in specific populations such as people with traumatic brain injury, spinal cord injury, multiple sclerosis, and stroke. These populations have significantly higher rates of depression than the general population.

Depressive symptoms are also common in individuals with chronic pain. Chronic pain itself can either be a primary disabling condition or it can be an associated feature of another disabling condition. Substance abuse may coexist in individuals with psychiatric disorders, physical disabilities, and multiple disabling conditions, such as spinal cord injury, traumatic brain injury, and acquired immunodeficiency syndrome. It has been estimated that 40% of individuals in substance abuse treatment programs may have coexisting disabilities. (See Specific Area of Clinical Focus: Pain.)

Providers may be unfamiliar with these co-existing conditions and their associated features. Studies indicate that primary care providers do not recognize the symptoms of major depressive disorder in as many as 50% of their depressed patients.

The severity, scope, and impact on functioning are what distinguish normal emotional responses from psychiatric conditions and disabling psychiatric conditions. Inquiring about a person's emotional, cognitive, and behavioral symptoms may or may not uncover a disorder. The symptoms of a psychiatric disorder in a person with another disabling condition may be misinterpreted, or the symptoms may not be as overt, for example, in individuals with cognitive disabilities. They may not be able to articulate feelings when questioned, and may

only identify feelings of irritation or frustration. Depressive symptoms may overlap with medical symptoms or mask symptoms of another condition. In addition, psychological symptoms may fluctuate in severity and frequency, and may not appear until many months after the onset of the disabling condition. In addition, there are cultural differences in the manifestations of psychiatric conditions, and how individuals from a particular culture express feelings. (See other Kaiser Permanente Provider Handbooks on Culturally Competent Care for specific populations.)

Mental Health Disorders

Mood Disorders

Mood disorders are characterized by mood disturbances accompanied by other symptoms. Individuals with depressive disorders, the most common type of mood disorders, may report increased somatic symptoms, pain and sleep problems, poor appetite, concentration and memory difficulties, and anxiety. Depression can worsen the prognosis of other health conditions and decrease treatment adherence.

Major Depressive Disorder and Dysthymia

Major depressive disorder is defined by depressed mood or loss of interest or pleasure for two or more weeks, and four or more of the following: significant weight or appetite change, sleep disturbance, loss of energy, feelings of worthlessness or excessive inappropriate guilt, suicidal ideation or a plan to carry out the suicide, agitation, decreased libido, and reduced ability to concentrate or think. Asking about hopelessness and loss of interest in usual activities (anhedonia) may be helpful in screening for depression. Uncharacteristic irritability may be the presenting symptom in children and adolescents. Dysthymia is a condition similar to major depression but the symptoms are chronic (two or more years in adults; one year in children) and with less severe sleep, appetite, weight change, and psychomotor symptoms.

Bipolar Disorder and Cyclothymia

Mania is defined as a distinct period of expansive (elevated or irritable) mood accompanied by at least three of the following: grandiosity, decreased need for sleep, extreme talkativeness (pressured speech), distractibility, delusions, racing thoughts, agitation, or involvement in high risk behaviors such as spending sprees or sexual indiscretions. The typical course is one of fluctuating mood states. The manic episode determines the diagnosis and distinct treatment implications.

A Type I diagnosis requires a manic or mixed (manic and depressive) episode. Individuals with bipolar II and III lack full mania. Traits of impulsivity and co-morbid substance abuse contribute to social and occupational impairment and risk of suicide. Many people may not recognize mania or hypomania, and these states and the associated behaviors, if recognized, may not be viewed by the patient as a problem for which to seek treatment. Therefore, the disorder may go undiagnosed in the absence of direct inquiry about manic symptoms. Psychotic symptoms, school problems, substance abuse, and antisocial behavior can be seen in adolescents. Cyclothymia is a condition similar to bipolar disorder but the symptoms are chronic (two or more years in adults; one year in children) and less severe. The condition usually is undiagnosed until late adolescence, so it is often difficult to have the child approved for special education services.

Anxiety and Panic Disorders

Anxiety disorders occur at a yearly prevalence of approximately 13% (childhood to 55 years of age). Anxiety disorders may coexist with mood disorders or substance abuse. Anxiety disorders are more common in women. Panic disorder is characterized by recurrent, unexpected panic attacks, followed by fear or worry about potential future attacks. Panic attacks are defined as episodes of intense fear accompanied by physical symptoms (e.g., trembling, sweating, palpitations, sensations of shortness of breath, chest pains, dizziness, abdominal distress, or paresthesias) and most often a fear of dying. Agoraphobia, a fear of being in a place where escape may be difficult, leading to avoidant behavior, may accompany panic disorder or occur alone. Depressive disorders may also accompany panic disorder.

Generalized anxiety disorder manifests as persistent, excessive worry and physical symptoms of anxiety (restlessness, irritability, difficulties with concentration, and muscle tension). The disorder may begin as early as childhood and may extend throughout life, influenced by life stressors. The worry is out of proportion to circumstances and interferes with functioning.

Obsessive-Compulsive Disorder

This disorder is characterized by intrusive, unwanted, obsessive thoughts, or compulsive, repetitive, or ritualistic behaviors. These thoughts and behaviors are time-consuming, significantly debilitating, and recognized by the individual to be excessive or unreasonable. The disorder may begin as early as childhood and tends to run throughout life. Obsessive-compulsive disorder is equally common in men and women. Individuals may have a personality trait that does not interfere with functioning, and is not disabling, but may have behavioral features that are similar to the disorder, such as excessive neatness.

Acute/Post-Traumatic Stress Disorder

These disorders occur in response to an extremely traumatic event. Symptoms include re-experiencing the traumatic event (flashbacks, intrusive thoughts, and nightmares); avoidance of stimuli associated with the event; intense distress when faced with reminders of the event; emotional numbing; and other symptoms of anxiety such as difficulties with concentration and sleep, or hypervigilance. Acute stress disorder begins within one month of the event and lasts for at most one month. Post-traumatic stress disorder (PTSD) is termed "delayed onset" type if the onset occurs beyond six months of the event. The duration may be acute (less than three months) or chronic (greater than three months). This disorder is common in individuals who have disabilities following traumatic injury, such as spinal cord injury or brain injury. A past traumatic experience, such as a war experience or child sexual abuse, may become manifest again after another traumatic event, producing intense reactivation of symptoms of PTSD.

Phobias

Specific phobias are intense fears and avoidance associated with exposure, or fear of exposure, to a specific stimulus such as an animal, environmental condition (heights, storms, etc.) situation (airplanes, elevators, and closed spaces), blood, injection, injury, or other condition. Social phobia describes excessive fear of exposure, scrutiny, embarrassment, or humiliation in social or performance situations. The identified situations are either avoided or endured with tremendous anxiety. In children, crying or tantrums may be a presenting feature of a phobia but because some fears are common in many children a diagnosis should only be made when the fear significantly interferes with functioning, such as an unwillingness to participate in necessary activities.

Psychoses

Psychosis refers to a disorder of thought, but it may refer more specifically to a disorder of perception (hallucinations) or beliefs (delusions). Broader definitions include disorganized, referential, or paranoid thinking, distortions in speech, and disorganized behavior. Psychosis can occur in the context of delirium, dementia, substance use, cognitive disability, and mood disorder. In schizophrenia, psychosis can be the defining feature of an illness.

The estimated lifetime prevalence rate of schizophrenia is approximately 1%. Usually beginning in adolescence or during early adulthood, and accompanied by a deterioration in social and occupational functioning, the subsequent lifelong course of schizophrenia is typified by chronic waxing and waning of residual positive and negative symptoms. Positive symptoms include hallucinations, delusions, disorganized or bizarre speech, and disorganized or bizarre behavior. Negative symptoms include restricted or flattened affect, reduced production of speech or thought (alogia), and poor initiation of goal-directed behaviors (avolition). Approximately 20% of individuals with schizophrenia attempt suicide, half of them successfully.

Schizoaffective disorder is also a primary psychotic disorder, similar to schizophrenia, but with the addition of mood episodes (manic, mixed, or major depressive). Delusional disorder is characterized by fixed, false, or erroneous beliefs that are not bizarre, although under some circumstances they could occur.

Cognitive Disabilities

The range of cognitive disabilities include: 1) in children: mental retardation, learning disorders, pervasive developmental disorders, attention-deficit disorder, and communication disorders; 2) in adults: delirium, dementia, amnesia, language disorders, and other acquired cognitive disorders. Cognitive disabilities affect an individual's ability to think, attend, reason, process, and remember information. These conditions often have a significant negative impact on a person's ability to live independently and function in social, academic, and occupational settings. There are many types of cognitive disabilities, associated with many different medical diagnoses. Many are not readily apparent to a casual observer, such as language disorders or attention deficits due to a stroke or brain injury.

Dementia involves the development of cognitive deficits in memory and at least one other area of cognitive functioning, such as language, perception, or executive functioning, and represents a decline from a previous level of functioning. In addition, the deficits must cause significant impairment in social and occupational functioning. Alzheimer's disease and vascular dementia are examples of progressive dementias that, over time, lead to profound impairments in all areas of functioning.

Amnesia disorders are characterized by difficulties learning new information or recalling previously learned information. The characteristic cognitive deficits seen in traumatic brain injury may include, but are not limited to, concentration, learning and memory, visual perception, language, and executive functions. Similar cognitive deficits may be found in members who have experienced a stroke or anoxia. In addition to cognitive deficits, many of these individuals may experience personality changes, frustration, behavioral dyscontrol, impulsivity, perseveration, disinhibition, poor initiation, or depression.

Substance Use, Abuse, and Dependence

Substance use is more common in males than females. Individuals with other psychiatric disorders or a physical disability are at increased risk of developing substance use disorders. Substance abuse is a maladaptive pattern of use that is associated with persistent interpersonal, occupational, social, and legal problems. In addition to the features of substance abuse, dependence includes tolerance (using increased amounts to achieve the same level of intoxication), withdrawal symptoms when substance is not used, a constellation of behaviors associated with compulsive use, or difficulties stopping use. Types of substances used vary widely but include alcohol, amphetamines, hallucinogens, cannabis, cocaine, sedatives, and opioids.

Implications For Kaiser Permanente Care Providers

- Be aware that the range and severity of symptoms in many disorders can vary and fluctuate with stress.
- Ask the individual about changes in target symptom severity or frequency.
- Avoid assuming that transient emotional expressions, such as sadness, are symptoms of a mental health condition; take into account severity, scope, and degree of impact on functioning.
- Individuals living with long-standing primary psychiatric disabilities may benefit from mental health or chemical dependency services.
- Use of open-ended questions and active listening skills will increase the member's comfort level and convey concern.
- Questions about emotional states and substance use should be a routine part of examinations.
- Inquire specifically about intimate partner abuse, or about abuse in other settings, and provide opportunities for the issue to be raised in the context of the clinical encounter.
- When providing health information and education, tailor the presentation format to accommodate an individual's disability.
- If concerned about depression in any context, ask directly about suicide and inquire about suicidal thoughts, impulses, plans, history of prior suicide attempts, and family history of suicide.
- If suicidal ideation exists, ensure safety and involve mental health providers directly.
- If an individual is exhibiting psychotic behavior, or presents a danger to others, ensure safety and involve mental health providers directly.
- Remember that psychiatric symptoms may exacerbate symptoms of other medical conditions.
- The treatment plan should include appropriate referrals to mental health professionals and chemical dependency programs. Kaiser Permanente Best Practices/Clinical Guidelines (KP Online Clinical Library) offers more information about identifying and managing mental health disorders.
- Consider that many patients with a mental health diagnosis who present with valid physical complaints may not be diagnosed because their symptoms have been ascribed to a mental health diagnosis.
- Consider factors that affect emotional functioning such as chronic pain, significant changes in general health status, significant changes in ability to function independently, emotional coping, substance use, abuse by partner or caregiver, and changes in social, occupational, and financial situations.
- Where symptoms, historical data, or physical findings point to an underlying medical

disorder as a possible cause of mental symptoms, consult with other medical professionals and mental health professionals.

- Assessment of cognitive disabilities and dementias should include a specialized medical work-up to address treatable underlying causes of the condition.
- For individuals with neurologic disabilities, referral to a neurologist or physical medicine and rehabilitation physician may be beneficial.
- For children and adolescents with possible developmental disabilities, referral to a developmental pediatrician may be beneficial.
- Refer to the Kaiser Permanente Provider's Handbook Series on Culturally Competent Care for information regarding the health beliefs and behaviors in the expression of mental illness across cultures.

CONCLUSION

Individuals with disabilities, comprising 20% of the U.S. population, are a diverse group in terms of race, ethnicity, religious beliefs, sexual orientation, gender identity, and socioeconomic status. In addition, as our U.S. population ages over the next decade, the percentage of the population with a disability is expected to rise proportionately. Within our membership, the percentage of individuals who are most likely to frequent our clinics and hospitals with a disabling condition, acute or chronic, is no doubt much higher than 20%.

People with disabilities have endured a long history of legal discrimination and exclusion, but the disability community is making progress toward removing barriers to full activity and participation in our society. Kaiser Permanente's commitment is to provide the highest quality of care, by removing architectural and attitudinal barriers, and educating providers about best health care practices that address the needs of people with disabilities. We hope that all providers, regardless of professional training or practice setting, will find the information presented in this Handbook useful in daily encounters with patients. As providers, we must educate ourselves now to prepare for a future in which this information and training are even more essential.

APPENDIX A: NEUROGENIC BLADDER DYSFUNCTION

Dysfunction	Level in Neuraxis	Possible Etiology	Voluntary Control	Saddle Sensation	Bulbo-cavernous Reflex	Signs and Symptoms	Management
Uninhibited neurogenic	Cortical and subcortical	Newborn child, CVA, MS, cerebral arteriosclerosis, brain tumor, pernicious anemia, trauma	Initiation or inhibition diminished	Normal	Normal	Frequency, urgency, urge incontinence, nocturia, decreased bladder capacity	Scheduled voiding, anticholinergic drugs Male: external collection device Female: "padding"
Reflex neurogenic	Spinal cord above conus medullaris	Trauma, tumor, vascular disease, MS, syringomyelia, pernicious anemia	Absent	Absent or impaired	Hyperactive	Unpredictable voiding: stream starts and stops (may initially appear as areflexic during spinal shock)	Reflex voiding with alpha blocker or IC with anticholinergic drugs, or surgery
Autonomous (areflex) neurogenic	At conus medullaris or cauda equine	Spina bifida, myelomeningocele, tumor, post-operative radical pelvic surgery, herniated intervertebral disk	Absent	Absent	Absent	Increased bladder capacity, high residual, dribbling incontinence, no bladder contractions, overflow (stress) incontinence with straining or compression	IC, Valsalva maneuver (strain), Crede's methods (if permitted)
Motor paralytic	Anterior horn cells or S2, S3 or S4 ventral roots	Poliomyelitis, herniated intervertebral disk, trauma, tumor	Absent	Normal	Absent	Voiding similar to clients with symptoms of 'prostatism' strain to void, incontinence rare	IC, Valsalva maneuver (strain), Crede's methods (if permitted)
Sensory paralytic	S2, S3 or S4 dorsal roots or cells of origin or dorsal horns of spinal cord	Diabetes mellitus, tabes dorsalis	Normal initially-becomes impaired with chronic overdistention	Absent	Absent	Voids only 1-3 times daily, overflow incontinence rare	Timed voiding, IC

Source: *Rehabilitation Nursing: Process, Application, and Outcomes, 3rd ed, Pires M, 2002, with permission from Elsevier, Philadelphia, PA and Rancho Los Amigos Medical Center, Downey, CA.*

APPENDIX B: NEUROGENIC BOWEL DYSFUNCTION

Diagnosis	Level of Lesion	Possible Etiology	Bulbocavernous Reflex	Anal Reflex	Pattern of Incontinence	Bowel Program
Uninhibited	Brain	Cerebrovascular accident, multiple sclerosis, brain injury	Intact or increased	Intact or increased	Urgency, poor awareness of desire to defecate	Consistent habit and time according to premorbid history, physical exercise, high fluid intake, high fiber foods, stool softener, suppository as needed
Reflex	Spinal cord above T12 To L1 vertebral level	Trauma, tumor, vascular disease, syringomyelia, multiple sclerosis	Increased	Increased	Infrequent, sudden, unexpected	Consistent habit and time, physical exercise, high fluid intake, high-fiber foods, suppository program, digital stimulation, stool softener as needed
Autonomous	Spinal cord at or below T12 to L1 vertebral level	Trauma, tumor, spina bifida, intervertebral disk	Absent	Absent	Frequent, may be continuous or induced by exercise or stress	Consistent habit and time, physical exercise, high fluid intake, high-fiber foods and bulk agents as necessary for firm stool consistency, suppository program, Valsalva maneuver, manual removal

Source: Rehabilitation Nursing: Process, Application, and Outcomes, 3rd ed, Gender A, 2002, adapted with permission from Elsevier, Philadelphia, PA.

BIBLIOGRAPHY

Definitions and Demographics

American Deficit Disorder Association. Fact sheet on attention deficit hyperactivity disorder. Available on the World Wide Web (accessed April 20, 2004): add.org/content/abc/factsheet.htm

American Heart Association. About stroke. Available on the World Wide Web (accessed April 12, 2004): www.strokeassociation.org/presenter.jhtml?identifier=11402

Centers for Disease Control and Prevention. Healthy people 2010: disability and secondary conditions. 2001.

Centers for Disease Control and Prevention. Prevalence of disabilities and associated health conditions among adults - U.S. 1999. MMWR 2001;50(07):120-125.

Centers for Disease Control and Prevention. Prevalence of self-reported arthritis or chronic joint symptoms among adults - U.S. 2001. MMWR 2002;51(42):948-950.

Centers for Disease Control and Prevention. Trends in aging - US. and worldwide. MMWR 2003;52:100-106.

Cocchiarella L, Anderson G. Guides to the evaluation of permanent impairment. American Medical Association, 2002.

Klesges L, Pahor M, Shorr R, Wan J, Williamson J, Guralnik J. Financial difficulty in acquiring food among elderly disabled women: results from the Women's Health and Aging Study. Am J of Public Health 2001;9(1):68-75.

Lipson JG, Dibble, SL, Minarik PA, editors. Culture & nursing care: a pocket guide. San Francisco: UCSF Nursing Press; 1996.

McNeil JM. Americans with disabilities:1994-95. Department of Commerce, Bureau of the Census, Current Population Reports, P70-61. Washington (DC): U.S. Government Printing Office; 1997

McNeil JM. Americans with disabilities: household economic studies,1997. Department of Commerce, Bureau of the Census, Current Population Reports, P70-73. Washington (DC): U.S Government Printing Office; 2001

National Organization on Disability. Methodology for the 2000 NOD/ Harris Survey of Americans with Disabilities 2001. Available on the World Wide Web (accessed on April 12, 2004): www.nod.org

Stoddard S, Jans L, Ripple J, Kraus L. Chartbook on work and disability in the United States, 1998. An InfoUse Report. Washington (DC): U.S. National Institute on Disability and Rehabilitation Research.

U.S. Department of Education, Office of Special Education and Rehabilitative Services, 1998. Twentieth annual report to Congress on the implementation of the Individuals with Disabilities Education Act. Washington (DC): U.S. Department of Education; 1998.

Waxweiler RJ. Monitoring the impact of traumatic brain injury: a review and update. J of Neurotrauma 1995;12(4). Available on the World Wide Web (accessed April 12, 2004): www.neuro.pmr.vcu.edu/FAQ/answer.asp?FAQ=65

World Health Organization. ICF as the new member in the WHO family of international classifications. Available on the World Wide Web (accessed on April 12, 2004): www.who.int/icf/icftemplate.cfm

World Health Organization. International Classification of Functioning and Disability. Available on the World Wide Web (accessed April 12, 2004): www.who.int/classification/icf

Cultural Perspectives, Attitudes, and Beliefs

Dejong G. Independent living: from social movement to analytic paradigm. Arch Phys Med Rehab 1979;60:435-446.

Kailes J. Centers for independent living. Playa del Rey (CA): KAILES Publications; 1997.

Los Angeles Times. Help the disabled work. Lead editorial. 1998 Dec 13: Sect. M:4.

Louvet E, Rohmer O. The impact of affect on social judgment toward handicapped people depending on familiarity with disability. Cahiers Internationaux de Psychologie Sociale 2000 Sep-Dec;47-48:95-109.

O'Day B, Palsbo S, Dhont K, Scheer J. Health plan selection criteria by people with impaired mobility. *Medical Care* 2002;40(9):732-742.

Pfeiffer D. The disability paradigm and federal policy relating to children with disabilities. Honolulu: Unpublished;1998.

Pfeiffer D. The problem of disability definition. Honolulu: Unpublished; 1998.

Zawaiza T, Gordon, C. Outreach and people with disabilities from diverse cultures: a review of the literature. National Council on Disability 2003. Available on the World Wide Web (accessed May 13, 2004): www.ncd.gov/newsroom/advisory/cultural/cdi_litreview.htm

Access to Care: Barriers to Communication

Frankel RM, Stein T. Getting the most out of the clinical encounter: the four habits model. *Permanente Journal* 1999 fall;3(3):79-88.

Iezzoni LI, Davis RB, Soukup J, O'Day B. Quality dimensions that most concern people with physical and sensory disabilities. *Archives of Internal Medicine* 2003;163(17):2085-2092.

Access to Care: Primary Care, Subspecialty Care, and Rehabilitation

Beatty PW, Dhont KR. Medicare health maintenance organizations and traditional coverage: perceptions of health care among beneficiaries with disabilities. *Arch Phys Med Rehabil* 2001;82:1009-17.

Beatty PW, Hagglund KJ, Neri MT, Dhont KR, Clark MJ, Hilton SA. Access to health care services among people with chronic or disabling conditions: patterns and predictors. *Arch Phys Med Rehabil* 2003;84:1417-1425.

Bockneck W, Mann N, Lanig I, et al. Primary care for persons with disability. In: DeLisa JA, Gans BM, Bockenek WL, editors. *Rehabilitation medicine: principles and practice*. 3rd ed. Philadelphia: Lippincott Williams & Wilkins; 1998:905-28.

Center for an Accessible Society. Research on definitions of disability from NIDDER; 2002.

Wilber N, Mitra M, Walker DK, Allen D, et al. Disability as a public health issue: findings and reflections from the Massachusetts survey of secondary conditions. *The Milbank Quarterly* 2002 Jun;80(2):393-421. Available on the World Wide Web (accessed on April 12, 2004): www.accessiblesociety.org

Centers for Disease Control and Prevention. Healthy people 2010: disability and secondary conditions, 2001. Available on the World Wide Web (accessed on April 12, 2004): www.healthypeople.gov

Clancy CM, Andresen EM. Meeting the health care needs of persons with disabilities. *The Milbank Quarterly* 2002;80(2):381-391.

DeJong G, Basnett I. Disability and health policy: the role of markets in the delivery of health services. In: Albrecht G, Seelman K, Bury M, editors. *Handbook of Disability Studies*. Thousand Oaks (CA):Sage; 2001.

DeJong G, Jones GC, Beatty PW. Prescription drugs for working-age Medicare beneficiaries with disabilities. Health and disability policy brief. Washington (DC): National Rehabilitation Hospital Center for Health and Disability Research; 2000.

DeJong G, Palsbo S, Beatty P, Jones G, Kroll T, Neri M. The organization and financing of health services for persons with disabilities. *Milbank Quarterly* 2002;80:261-301.

European Opinion Research Group for the Education and Culture Directorate. Attitudes of Europeans to disability. Manuscript completed in 2001. Available on the World Wide Web (accessed on June 2, 2004): http://europa.eu.int/comm/public_opinion/archives/ebs/ebs_149_en.pdf

Gold M, Nelson L, Brown R, et al. Disabled Medicare beneficiaries in HMOs. *Health Affairs* 1997;16(5):149-62.

Halvorson GC, Isham GJ. *Epidemic of care*. San Francisco: Jossey-Bass; 2003.

- Hogan DB. Effects of aging and disease on disability in the very elderly. *Clinical Geriatrics* 2000.
- Iezzoni LI. Using administrative data to study persons with disabilities. *The Milbank Quarterly* 2002;80(2):347-379.
- Jette AM, Keysor JJ. Uses of evidence in disability outcomes and effectiveness research. *The Milbank Quarterly* 2002;80(2):325-345.
- Kaiser Permanente Northern California Department of Quality and Utilization. Stroke. Available on KP intranet (accessed May 26, 2004): http://cl.kp.org/pkc/ncal/clib/guidelines/cpg/Stroke_portal/StrokeCPG.htm
- Kaiser Permanente Northern California Department of Quality and Utilization, TPMG Stroke Work Group. Stroke-Portal: easy access to all stroke guidelines, tools, and clinical resources. Available on KP intranet (accessed May 26, 2004): http://cl.kp.org/pkc/ncal/clib/guidelines/cpg/Stroke_portal/index.htm
- Kemp BJ, Campbell M. Health, functioning and psychosocial aspects of aging with a disability. Rehabilitation Research and Training Center on Aging. Downey, CA: Rancho Los Amigos Medical Center; 1993.
- Lawrence D. From chaos to care: the promise of team-based medicine. Cambridge, MA: Da Capo Press; 2002.
- Louvet E, Rohmer O. The impact of affect on social judgment toward handicapped people depending on familiarity with disability. *Cahiers Internationaux de Psychologie Sociale* 2000;47-48:95-109.
- Marge M. Health promotion for people with disabilities: moving beyond rehabilitation. *Am J Health Promot* 1998;2:29-35.
- National Information Center for Children and Youth with Disabilities. Severe and multiple disabilities. Washington (DC): U. S. Department of Education 2001. Available on the World Wide Web (accessed on April 12, 2004): www.nichcy.org
- Neri MT, Kroll T. Understanding the consequences of access barriers to health care: experiences of adults with disabilities. *Disabil Rehabil* 2003;25:85-96.
- Perrin J. Health services research for children with disabilities. *The Milbank Quarterly* 2002;(80):303-324.
- Richardson M. The Health Security Act of 1993 and health care for persons with disabilities. *Health Care Manag* 1994;1:145-55.
- Scheer J, Kroll T, Neri M, Beatty P. Access barriers for persons with disabilities: the consumers' perspective. *J Disabil Policy Stud* 2003;13(4):221-30.
- Sutton J, DeJong G. Managed care and people with disabilities: framing the issues. *Arch Phys Med Rehabil* 1998;79:1312-6.

Access to Care: Community and Web-based Services and Networks

- American Association of Community Colleges. Available on the World Wide Web (accessed April 12, 2004): <http://www.aacc.nche.edu/>
- Americans with Disabilities Act of 1990. 42 U.S.C. §§12101, et seq.
- Centers for Medicare and Medicaid Services. Available on the World Wide Web (accessed April 12, 2004): <http://cms.hhs.gov/>
- DeJong G. Independent living: from social movement to analytic paradigm. *Arch Phys Med Rehabil* 1979;60:435-446.
- Iezzoni LI, Davis RB, Soukup J, O'Day B. Quality dimensions that most concern people with physical and sensory disabilities. *Archives of Internal Medicine* 2003;163(17):2085-2092.
- Litvak S, Kennedy J. Policy issues affecting the Medicaid personal care services optional benefits. *World Institute on Disability*; 1991.
- National Standards on Culturally and Linguistically Appropriate Services (CLAS) in Health Care, 65 Fed. Reg. 80865-79; Dec. 22, 2000.

Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794.

Risk Factors

Cates W, Am. Health Assoc. Panel. Estimates of the incidence and prevalence of sexually transmitted diseases in the United States. *Sexually Transmitted Diseases* 1999 Apr;26(4) Suppl S2-S7.

Center for Research on Women with Disabilities. National study of women with physical disabilities. Available on the World Wide Web (accessed June 7, 2004): www.bcm.tmc.edu/crowd/national_study/SPECIALS.htm

Despouy L. Human Rights and Disabled Persons: human rights study series, 6. United Nations Division for Social Policy and Development; 2002.

Hubbard JR, Martin PR. Substance abuse in the mentally and physically disabled: an overview. In: Hubbard JR, Martin PR, editors. New York: Marcel Dekker 2001;(1-10).

Jackson H, Philip E., Nuttall RL, Diller L. Traumatic brain injury: a hidden consequence for battered women. *Prof Psych Res Pract* 2002;33(1):39-45.

National Center for Injury Prevention and Control. Sexual violence against people with disabilities. Centers for Disease Control; 2003.

National Council on Disability. Meeting the unique needs of minorities with disabilities: a report to the President and the Congress; 1993.

National Organization on Disability. Methodology for the 2000 NOD/Harris Survey of Americans with Disabilities 2001.

Nosek MA, Howland CA. Abuse and women with disabilities. Violence against women online resources; 1998.

Sparadeo FR, Barth JT, Stout, CE. Addiction and traumatic brain injury. In: Stout CE, Levitt JL, Ruben DH, editors. *Handbook for Assessing and Treating Addictive Disorders*. New York: Greenwood Press; 1992.

Turpin L, Rice DP. Health status, medical care use and number of disabling conditions in the United States. San Francisco: Disability Statistics Center at UCSF; 1995.

Weinstein DD, Martin PR. Neurological disorders and head injuries. In: Hubbard JR, Martin PR, editors. *Substance Abuse in the Mentally and Physically Disabled*. New York: Marcel Dekker 2001:277-305.

Welner SL. Sexually transmitted infections in women with disabilities: diagnosis, treatment, and prevention: a review. *Sexually Transmitted Diseases* 2002;27(5):272-277.

Specific Areas of Clinical Focus: Reproduction, Sexuality, and Pregnancy

Annon J. The PLISSIT model: a proposed conceptual scheme for the behavioral treatment of sexual problems. *J Sex Ed Therapists* 1976;5:1-15.

Arnold L. Talking about sex. Slide presentation. Southeast Permanente Medical Group, Georgia Region; 2003.

Carmine H. Sexuality. In: Derstine J, Drayton Hargrove S, editors. *Comprehensive Rehabilitation Nursing* 2001:170-192. Philadelphia: WB Saunders.

Center for Research on Women with Disabilities. National study of women with physical disabilities. Available on the World Wide Web (accessed June 7, 2004): www.bcm.tmc.edu/crowd/national_study/SPECIALS.htm

Cole SS, Gray DB, Haseltine FP, editors. *Reproductive Issues for Persons with Physical Disabilities*. Baltimore: Brookes; 1995.

Consortium for Spinal Cord Medicine. Acute management of autonomic dysreflexia: individuals with spinal cord injury presenting to health care facilities. 2nd ed. Washington (DC): Paralyzed Veterans of America. 2001 Jul.

Duchame SH, Gill KM. *Sexuality After Spinal Cord Injury: Answers to Your Questions*. Baltimore: Brookes; 1997.

- Greco S. Sexuality education and counseling. In: Hoeman S. *Rehabilitation Nursing: Process, Application, and Outcomes*. 3rd ed. St. Louis: Mosby; 2002:507-541.
- Herson L, Hart K, Gordon M, Rintala D. Identifying and overcoming barriers to providing sexuality information in the clinical setting. *Rehabilitation Nursing* 1999;24(4):148-151.
- Jans L, Stoddard S. *Chartbook on women and disability in the United States: an InfoUse Report*. Washington (DC): US Department of Education, National Institute on Disability and Rehabilitation Research; 1999.
- Kaiser Permanente National Diversity Council and Kaiser Permanente National Diversity Department. *A provider's handbook on culturally competent care: lesbian, bisexual and transgendered population*; 2000.
- Krotoski D, Nosek M, Turk M. *Women with Physical Disabilities: Achieving and Maintaining Health and Well-Being*. Baltimore: Brookes; 1996.
- Lefebvre K. Performing a sexual evaluation on the person with a disability or illness. In: Sipski M, Alexander C, editors. *Sexual Function in People with Disability and Chronic Illness*. Gaithersburg, MD: Aspen; 1997;3:19-45.
- Lipson J, Rogers J. Pregnancy, birth, and disabilities: women's health care experiences. *Health Care for Women International* 2000;21:11-26.
- McBride K, Rines B. Sexuality and spinal cord injury: a road map for nurses. *SCI Nursing* 2000 spring;17(1):8-13.
- Neufeld JA, Kingbell F, Byren DN, Silvermam B, Thomas A. Adolescent sexuality and disability. *Phys Med and Rehab Clinics of No Amer* 2002;13(4):857-873.
- Nortvedt MW, Riise T, Myhr K, Landtblom AM, Baake A, Nyland HI. Reduced quality of life among multiple sclerosis patients with sexual disturbance and bladder dysfunction. *Multiple Sclerosis* 2001;7:231-235.
- Nosek M, Howland CA. Breast and cervical cancer screening among women with physical disabilities. *Arch Phys Med Rehabil* 1997;78 Suppl 5:S-39-44.
- Nosek M, Howland C. Sexual abuse and people with disabilities. In: Sipski M, Alexander C, editors. *Sexual Function in People with Disability and Chronic Illness*. Gaithersburg, MD: Aspen; 1997;28:577-594.
- Rehabilitation Nursing Foundation of the Association of Rehabilitation Nurses. Sexuality and disability. In: *Faculty Manual for Basic Rehabilitation Nursing Practice*. 3rd ed. 1995;17:225-246.
- Sandel ME, Delmonico RD, Kotch MJ. Sexuality, reproduction and neuroendocrine disorders following traumatic brain injury. In: Zasler N, Katz D, Zafonte R, editors. *Brain Injury Medicine*. New York: Demos Medical Publishing; in press.
- Saxton M. Commentary: disabled women's view of selective abortion: an issue for all women. *JAMWA* 1999;54(1):26-28.
- Sipski M, Alexander C, editors. *Sexual Function in People with Disability and Chronic Illness*. Gaithersburg, MD: Aspen; 1997.
- Tan J. Problems in human sexuality. In: *Practice Manual of Physical Medicine and Rehabilitation*. St. Louis: Mosby; 1998;580-606.
- Taleporos G, McCabe M. Physical disability and sexual esteem. *Sexuality and Disability* 2001;19(2):131-148.
- Thomas P, Curtis P. Having a baby: disabled women's reproductive experiences. *Midwifery* 1997;13(4):202-209.
- Turk N, Scandale J, Rosenbaum P, Weber R. The health of women with cerebral palsy. *Physical Medicine and Rehabilitative Clinics of North America* 2001 Feb;12(1):153-166.
- Walter L, Nosek M, Langdon K. Understanding of sexuality and reproductive health among women with and without physical disabilities. *Sexuality and Disability* 2001 fall;19(3):167-176.
- Weiner D, Rosen R. Medications and their impact. In: Sipski M, Alexander C, editors. *Sexual Function in People with Disability and Chronic Illness*. Gaithersburg, MD; 1997;6:85-118.

Whipple B, Richards E, Tepper M, Komisaruk B. Sexual response in women with complete spinal cord injury. In: Krotoski DM, Nosek M, Turk M, editors. *Women with Physical Disabilities: Achieving and Maintaining Health and Well-Being*. Baltimore: Brookes; 1996;5:69-80.

Specific Areas of Clinical Focus: Pain

Abresch RT, Jensen MP, Carter GT, Kilmer DD. Assessment of pain and health-related quality of life in slowly progressive neuromuscular disease. *Am J Hospice Palliat Care*; in press.

Bach S, Noreng MF, Tj'ellden NU. Phantom limb pain in amputees during the first 12 months following limb amputation, after preoperative lumbar epidural blockade. *Pain* 1988;33:297-301.

Cardenas DD, Turner JA, Warms CA, Marshall HM. Classification of chronic pain associated with spinal cord injuries. *Arch Phys Med Rehabil*; in press.

Cardenas DD. Pain in spinal cord injury: causes and treatments. *Spinal Cord Inj Update* 2001;10.

Carter GT, Jensen MP, Galer BS, et al. Neuropathic pain in Charcot-Marie-Tooth disease. *Arch Phys Med Rehabil* 1998;79:1560-4.

Ehde DM, Czerniecki JM, Smith DG, Campbell KM, Edwards WT, Jens MP, Robinson LR. Chronic phantom sensations, phantom pain, residual limb pain, and other regional pain after lower limb amputation. *Arch Phys Med Rehabil* 2000;81:1039-44

Ehde DM, Jensen MP, Engel JM, Turner JA, Hoffman AJ, Cardenas D. Chronic pain secondary to disability: a review. *Clinical Journal of Pain* 2003 Jan/Feb;19(1):3-17.

Ehde DM, Smith DG, Czerniecki JM, Campbell KM, Malchow DM, Robinson LR. Back pain as a secondary disability in persons with lower limb amputations. *Arch Phys Med Rehabil* 2001; 82:731-4.

Engel JM, Schwartz L, Jensen MP, Johnson DR. Pain in cerebral palsy: the relation of coping strategies to adjustment. *Pain* 2000; 88:225-30.

Feldt KS. The checklist of nonverbal pain indicators (CNPI). *Pain Management Nursing* 2000;1(1):13-21.

Finnerup NB, Johannesen IL, Sindrup SH, Bach FW, Jensen TS. Pain and dysesthesia in patients with spinal cord injury: a postal survey. *Spinal Cord* 2001;39:256-62.

Goodin DS. Survey of multiple sclerosis in Northern California. Northern California MS Study Group. *Mult Scler* 1999;5:78-88.

Halstead LS, Rossi CD. New problems in old polio patients: results of a survey of 539 polio survivors. *Orthopedics* 1985;8:845-50.

Kaiser Permanente Care Management Institute. Key messages for chronic pain patients guideline rationale statement. Available on KP intranet (accessed June 10, 2004): <http://cl.kp.org/pkc/national/cmi/programs/chronicpain/con-keymessages.html>

Kassirer M. Multiple sclerosis and pain. *Int J MS Care* 2000;2:30-38.

Lambert AW, Dashfield AK, Cosgrove C, Wilkins DC, Walker AJ, Ashley S. Randomized prospective study comparing preoperative epidural intraoperative perineural analgesia for the prevention of postoperative stump and phantom limb pain following major amputation. *Reg Anesth Pain Med* 2001;26:316-21.

Long TM, Hart KA. Pain in children. *Orthop Phys Ther Clin N Am* 1995;4:503-17.

McGuire DB. Comprehensive and multidimensional assessment and measurement of pain. *J of Pain and Symptom Management* 1992;7:312-319.

Moulin DE, Foley KM, Ebers GC. Pain syndromes in multiple sclerosis. *Neurology* 1988;38:1830-4.

Moulin DE, Hagen N, Feasby TE, Amireh R, Hahn A. Pain in Guillain-Barre syndrome. *Neurology* 1997;48:328-31.

Novy DM, Nelson DV, Francis DJ, Turk D. Perspectives of chronic pain: an evaluative comparison of restrictive and comprehensive models. *Psychol Bull* 1995;118:238-47.

- Putzke JD, Richards JS, DeVivo MJ. Quality of life after spinal cord injury caused by gunshot. *Arch Phys Med Rehabil* 2001;82:949-54.
- Putzke JD, Richards S, Dowler RN. The impact of pain in spinal cord injury: a case-control study. *Rehabil Psychol* 2000;45:386-401.
- Rintala D, Loubser PG, Castro J, Hart KA, Fuhrer MJ. Chronic pain in a community based sample of men with spinal cord injury: prevalence, severity, and relationship with impairment, disability, handicap, and subjective well-being. *Arch Phys Med Rehabil* 1999;79:604-614.
- Schwartz L, Engel JM, Jensen MP. Pain in persons with cerebral palsy. *Arch Phys Med Rehabil* 1999;80:1243-6.
- Siddall PJ, Taylor DA, McClelland JM, Rutkowski SB, Cousins MJ. Pain report and the relationship of pain to physical factors in the first six months following spinal cord injury. *Pin* 1999;81:187-197.
- Siddall PJ, Yezierski RP, Loeser JD. Pain following spinal cord injury: clinical features, prevalence, and taxonomy. *IASP Newslett* 2000;3.
- Smith DG, Ehde DM, Legro MW, Reiber GE, del Aguila M, Boone DA. Phantom limb, residual limb, and back pain after lower extremity amputations. *Clin Orthop* 1999;361:29-38.
- Stenager E, Knudsen L, Jensen K. Acute and chronic pain syndromes in multiple sclerosis: a 5-year follow-up study. *Ital J Neurol Sci* 1995;6:629-32.
- Stormer S, Gerner HJ, Gruninger W, et al. Chronic pain/dysaesthesiae in spinal cord injury patients: results of a multicentre study. *Spinal Cord* 1997;35:446-55.
- Turk MA, Geremski CA, Rosenbaum PF, et al. The health status of women with cerebral palsy. *Arch Phys Med Rehabil* 1997;78(Suppl 5):S10-7.
- Turner JA, Cardenas DD, Warms CA, et al. Chronic pain associated with spinal cord injuries: a community survey. *Arch Phys Med Rehabil* 2001;82:501-9.
- Vasilidalis HM, Collet JP, Shapiro, Venturini A, Trojan DA. Predictive factors and correlates for pain in postpoliomyelitis syndrome patients. *Arch Phys Med Rehabil* 2002 Aug;83(8):1109-15.
- Widar M, Ahlstrom G. Experiences and consequences of pain in persons with post-polio syndrome. *Adv Nurs* 1998 Sep;28(3):606-13.
- Widerstrom-Noga EG, Felipe-Cuervo E, Yezierski RP. Relationships among clinical characteristics of chronic pain after spinal cord injury. *Arch Phys Med Rehabil* 2001;82:1191-7.
- Weitzenkamp DA, Joes RH, Whiteneck GG, et al. Aging with spinal cord injury: cross-sectional and longitudinal effects. *Spinal Cord* 2001;39:301-9.
- Wilkins KL, McGrath PH, Finley GA, et al. Phantom limb sensations and phantom limb pain in child and adolescent amputees. *Pin* 1998;78:7-12.
- Won A, Lapane K, Gambassi G, Bernabei R, Mor V, Lipsitz L, et al. Correlates and management of nonmalignant pain in the nursing home. Systematic assessment of geriatric drug use via epidemiology. *J Am Geriatr Soc* 1999;47(8):936-42.

Specific Areas of Clinical Focus: Child and Adolescent Health

- Adams PF, Marano MA. Current estimates from the National Health Interview Survey, 1994, vital and health statistics, series 10, No. 193. Hyattsville, MD: U.S. Public Health Service, National Center for Health Statistics; 1995.
- Betz CL, Redcay G. Lessons learned from providing transition services to adolescents with special health care needs. *Issues in Comprehensive Pediatric Nursing* 2002;25:129-149.
- Blum RW. Sexual health contraceptive needs of adolescents with chronic conditions. *Archives of Pediatric and Adolescent Medicine* 1997;151:290-297.

- Fadiman A. *The Spirit Catches You and You Fall Down*. New York: Noonday Press; 1997.
- Hogan DP, Msall ME, Rogers ML, et. al. Improved population estimates of functional limitation among American children age 5-17. Population Studies and Training Center, Working Paper #97-16. Brown University; 1994.
- Lararus, PJ, Strichart SS, editors. *Psychoeducational Evaluation of Children and Adolescents with Low-Incidence Handicaps*. Grune & Stratton; 1986.
- Lewis M, Volkmar F. *Clinical Aspects of Child and Adolescent Development*. 3rd ed. Philadelphia: Lea & Ferbigger; 1990.
- McNeil JM. *Americans with disabilities: household economic studies, 1997*. Department of Commerce, Bureau of the Census, Current Population Reports, P70-73. Washington (DC): U.S Government Printing Office; 2001.
- Moos RH. Life stressors, social resources, and coping skills in youth: applications to adolescents with chronic disorders. *Journal of Adolescent Health* 2002;305:22-29.
- Neinstein LS. *Adolescent Health Care*. Baltimore: Urban & Schwarzenberg; 1991.
- Newacheck PW, Halfon N. Prevalence and disabling chronic conditions in childhood. *Am J Public Health* 1998;88(4):610-17.
- Powell ML. *Assessment and Management of Developmental Changes and Problems in Children*. 2nd ed. St. Louis: Mosby; 1981.
- Stein REK, Silver EJ. Operationalizing a conceptually based noncategorical definition. *Arch Pediatr Adolesc Med* 1999;10(1):20-30.
- Thain WS, Casto G, Petersen A. *Normal and Handicapped Children*. PSG Publishing Company, Inc; 1980.
- Turk MA, editor. *Health and Function in Childhood Disability in Physical Medicine and Rehabilitation Clinics of North America*. WB Saunders 2002;13(4).

Specific Areas of Clinical Focus: Bladder and Bowel Management

- Agency for Health Care Policy and Research. Update: Urinary incontinence in adults: acute and chronic management. *Clinical Practice Guideline*; 1996:2.
- Agency for Health Care Policy and Research. Prevention and management of urinary tract infection in paralyzed persons. Summary, Evidence Report/Technology Assessment: Number 6. MD: Publication No. 99-E007 1999 Jan.
- Brittain K, Peet S, Castleden C. Stroke and incontinence. *Stroke* 1998;29(2):524-528.
- Consortium for Spinal Cord Medicine. *Clinical Practice Guideline. Acute Management of Autonomic Dysreflexia: Individuals with Spinal Cord Injury Presenting to Health Care Facilities*. 2nd ed. Washington (DC): Paralyzed Veterans of America 2001 Jul.
- Consortium for Spinal Cord Medicine. *Clinical Practice Guideline. Neurogenic Bowel Management in Adults with Spinal Cord Injury*. Washington (DC): Paralyzed Veterans of America 1998 Mar.
- Coyle C, Santiago M, Shank J, et al. Secondary conditions and women with physical disabilities: a descriptive study. *Arch Phys Med Rehabil* 2000;81(10):1380-1387.
- Craig Hospital. *SCI and Aging: Bladder Cancer*; 1996.
- Dougherty D, editor. *Urinary and Fecal Incontinence: Nursing Management*. 2nd ed. St. Louis: Mosby; 2000.
- Dugan E, Cohen S, Bland DR, Preisser JS, Davis CC, Suggs PK, et al. The association of depressive symptoms and urinary incontinence among older adults. *J of the American Geriatrics Society* 2000;413-416.
- Gender A. Bowel regulation and elimination. In: Hoeman S. *Rehabilitation Nursing: Process, Application, and Outcomes*. 3rd ed. St. Louis: Mosby 2002;20:422-444.

Hinken B, Putzke J, Richards J. Bladder management and quality of life after spinal cord injury. *American J of Phys Med and Rehab* 2001;80(12):916-925.

Hixon AK, Joseph AC, Giroux J, Briggs D, Gardenhire M, Diaz D, Wells J; Bladder Management Content Development Group. Nursing clinical practice guideline: neurogenic bladder management. (Revised) *SCI Nursing* 1998 Aug;15(2):21-56.

Kirshblum S, Gulatim M, O'Connor K, et al. Bowel care practices in chronic spinal cord injury. *Arch Phys Med Rehabil* 1998;79:20-23.

Litwiler SE, Frohman EM, Zimmer PR. Multiple sclerosis and the urologist. *J of Urology* 1999;161(3):743-757.

Mandzak Fried K, Fried G, Farnan C. Elimination. In: Derstine J, Drayton Hargrove S, editors. *Comprehensive Rehabilitation Nursing*. Philadelphia: WB Saunders; 2001;11:153-162.

Menter R, Weitzendamp D, Cooper D, et al. Bowel management outcomes in individuals with long-term spinal cord injuries. *Spinal Cord* 1997;35:608-612.

Multiple Sclerosis Council for Clinical Practice Guidelines. Urinary dysfunction and multiple sclerosis: evidence-based management strategies for urinary dysfunction in multiple sclerosis. Washington (DC): Paralyzed Veterans of America; 1999.

National Institute of Diabetes and Digestive and Kidney Diseases. What your female patients want to know about bladder control. Publication No 02-4183; 2002 Apr.

National Institute of Health. Neurogenic bladder. Publication no. 99-4560; 1998.

Nortvedt M, Riise T, Myhr K, et al. Reduced quality of life among multiple sclerosis patients with sexual disturbance and bladder dysfunction. *Multiple Sclerosis* 2001;7:231-235.

Office of Disease Prevention and Health Promotion. Disability and secondary conditions in healthy people 2010; 2000;6.

Pires M. Bladder elimination and continence. In: Hoeman S. *Rehabilitation Nursing: Process, Application, and Outcomes*. 3rd ed. St. Louis: Mosby; 2002;19:383-421.

Tan J, Horn S. *Practical Manual of Physical Medicine and Rehabilitation*. St. Louis: Mosby; 1998.

Specific Areas of Clinical Focus: Mental Health

American Psychiatric Association. Diagnostic and statistical manual for mental disorders, 4th edition (DSM IV). Washington (DC): American Psychiatric Press; 1994.

Bryson SE, Smith, IM. Epidemiology of autism: prevalence, associated characteristics, and implications for research and service delivery. *Mental Retardation and Developmental Disabilities Research Reviews* 1998;4:97-103.

Maxmen JS, Ward NG. *Essential psychopathology and its treatment: 2d edition revised for DSM - IV*. New York: W.W. Norton & Company; 1995.

Murray, CJL, Lopez AD, editors. *The Global Burden of Disease: a Comprehensive Assessment of Mortality and Disability from Diseases, Injuries, and Risk Factors in 1990 and Projected to 2020*. Cambridge, MA: Harvard School of Public Health; 1996.

National Mental Health Association. Alcohol and drug abuse, addiction and co-occurring disorders. 2003. Available on the World Wide Web (accessed April 16, 2004): www.nmha.org/substance/factsheet.cfm

National Mental Health Association. The autistic child. 2003. Available on the World Wide Web (accessed April 16, 2004): www.nmha.org/infoctr/factsheets/73.cfm

National Mental Health Association. Supported employment for persons with psychiatric disabilities: a review of effective services. Alexandria, VA: National Mental Health Association; 2003.

Regier DA, Rae DS, Narrow W.E., Kaelber CT & Schatzberg AF. Prevalence of anxiety disorders and their comorbidity with mood and addictive disorders. *British Journal of Psychiatry - Supplementum* 1998;(34):24-8.

Shaffer D, Fisher P, Dulcan MK, Davies M, Piacentini J, Schwab-Stone ME, et al. The NIMH diagnostic interview schedule for children version 2.3 (DISC - 2.3): Description, acceptability, prevalence rates, and performance in the MECA study. *Methods for the epidemiology of child and adolescent mental disorders study. J of the Am Academy of Child and Adolescent Psychiatry* 1996;35:865-877.

Stoddard S, Jans L, Ripple J, Kraus L. Chartbook on work and disability in the United States. An InfoUse Report. Washington, DC: U.S. National Institute on Disability and Rehabilitation Research; 1998.

Substance Abuse and Mental Health Services Administration. Substance abuse: people with disabilities at high risk. 1999. Available on the World Wide Web (accessed on April 16, 2004): www.samhsa.gov/media/content/990113nr.htm

U.S. Preventative Services Task Force. Screening for depression: recommendations and rationale. *Annals of Internal Medicine* 2002 136:760-4.

Additional Resources and Suggested Readings

For a list of additional resources and suggested readings, KP staff may access the following Kaiser Permanente websites: diversity.kp.org or kpnet.kp.org/ada/index.html. All others should contact National Diversity at Kaiser Permanente, (510) 271-6663.

ACKNOWLEDGMENTS

The Kaiser Permanente National Diversity Council wishes to acknowledge the following individuals for their invaluable contributions and personal commitment to the development of this handbook:

Physician Champion

M. Elizabeth Sandel, MD, Medical Director and Chief of Physical Medicine and Rehabilitation, Kaiser Foundation Rehabilitation Center/Kaiser Foundation Hospital, Vallejo, CA; Director, Center of Excellence in Culturally Competent Care: Individuals with Disabilities, Northern California.

Major Contributors

Richard Delmonico, PhD, Chief, Neuropsychology, Kaiser Foundation Rehabilitation Center, Northern California.

Benton Giap, MD, Medical Director, Neurorehabilitation, Redwood City Medical Center, Northern California.

Timothy Josten, PT, Director, PNF Program and Rehabilitation Physical Therapy, Kaiser Foundation Rehabilitation Center, Northern California.

Deborah Kaplan, JD, Executive Director, World Institute on Disability, Oakland, CA.

Christine Kinavey, RN, CNS, PhD, Nurse Coordinator, Department of Genetics, Regional Spina Bifida Program, Oakland Medical Center, Northern California.

Mary Jean Kotch, MSN, CRRN-A, Clinical Nurse Specialist, Kaiser Foundation Rehabilitation Center, Northern California.

Valerie Thomas, MSW, LCSW, CPHQ, Quality Director, Napa Solano Service Area, Northern California.

Contributors and Reviewers

Ujwala Agharkar, MD, Child Psychiatry, Fremont Medical Center, Northern California.

Phyllis Bergeron Bouvier, MD, Otolaryngology, Co-Chair, Regional Diversity Council, Co-Chair, Diversity Steering Committee, Franklin Medical Center, Colorado.

Mary Lou Breslin, MS, Senior Policy Advisor, Disability Rights Education and Defense Fund, Berkeley, CA.

Irene Brown, RN, MS, CNRN, CRRN, Clinical Nurse Specialist, Redwood City Medical Center, Northern California.

Wendy Byrnes, Parent Advocate, Disability Rights Education and Defense Fund, Berkeley, CA.

Diona Cheng, MPH, Service and Diversity Director, East Bay Service Area, Northern California.

Nilda Chong, MD, DrPH, MPH, Director, Institute for Culturally Competent Care, National Diversity, Program Offices.

Bernie Collins, PhD, MS, Administrative Assistant, Institute for Culturally Competent Care, National Diversity, Program Offices.

Katie Cornwall, RD, Dietitian, Kaiser Foundation Rehabilitation Center, Northern California.

Robert Czeck, CRNA, Chief/Manager, Anesthesiology, San Francisco Medical Center, Northern California.

Jose De Anda, Assistant Medical Group Administrator, ADA Advisory Committee, San Francisco Medical Center, Northern California.

Sharon Eastman, Assistant Regional Medical Group Administrator, ADA Advisory Committee, Northern California.

Julia Epstein, PhD, Director of Communications and Development, Disability Rights Education and Defense Fund, Berkeley, CA.

Mark Gaines, Project Coordinator, ADA Compliance Sub-Committee, San Francisco Medical Center, Northern California.

Anthony Gately, Vice President and Regional Medical Group Administrator, Executive Sponsor, ADA Compliance Committee, Northern California.

Anne Grey, MPH, Disability Project Manager, Inland Empire Health Plan, San Bernardino, CA.

Saleena Gupte, MPH, Consultant, Institute for Culturally Competent Care, National Diversity, Program Offices.

Carol Havens, MD, Director, Clinical Education, Northern California.

Gayle Hunt, Project Manager, Institute for Culturally Competent Care, National Diversity Program Offices.

Caroline Jacobs, Esq., Senior Staff Attorney, Disability Rights Advocates, Oakland, CA.

June Isaacson Kailes, Associate Director, Center for Disability Issues and the Health Professions, Western University of Health Sciences, Pomona, CA.

Pamela Kearns, RN, Patient Transfer Coordinator, Quality Resource Management, Colorado.

Ronald Knox, Vice President, National Diversity, Program Offices.

Helen Levy, MS, Genetic Counselor, ADA Advisory Sub-Committee, San Francisco Medical Center, Northern California.

Susan Lindheim, MD, Assistant Chief, Pediatrics, Richmond Medical Center, Northern California.

Gabi Marcus, Outreach Coordinator, Disability Rights Advocates, Oakland, CA.

Tina Martelon, Diversity Trainer and President, KP Persons with disAbility Staff Association, Colorado.

Charles McAvoy, Jr., Network Telephony Lead and Vice-President, Kaiser Permanente Employees with disAbilities Association, Northern California.

Brigid McCaw, MD, MS, MPH, Clinical Lead, Family Violence Prevention Services, Northern California.

Susan Palsbo, PhD, MS, Senior Research Associate, National Rehabilitation Hospital, Washington, DC.

Brenda Premo, MBA, Director, Center for Disability Issues and the Health Professions, Western University of Health Sciences, Pomona, CA.

Rona Renner, RN, Parent Educator, Pediatrics, Richmond Medical Center, Northern California.

Cristine Richards, Staff Specialist, Kaiser Foundation Rehabilitation Center, Vallejo Medical Center, Northern California.

Judith E. Roberts, Project Manager, Institute for Culturally Competent Care, National Diversity, Program Offices.

Joan Sage, MD, Pediatrics, Mount Scott Medical Office, Northwest.

Shari Samuels, CSP, CPHRM, Program Manager, ADA Compliance, California.

Kadavil Satyanarayan, MD, Physical Medicine and Rehabilitation, Central Interstate Clinic, Northwest.

Marsha Saxton, PhD, Research Associate, World Institute on Disability, Oakland, CA.

Mary Staunton, MD, Psychiatry, Walnut Creek Medical Center, Northern California.

Cheryle Sullivan, MD, Family Practice, KP Persons with disAbility Staff Association, Colorado.

Gayle Tang, MSN, RN, Director, National Linguistic and Cultural Programs, National Diversity, Program Offices.

Marian TeSelle, MD, Sub-Chief, Physical Medicine and Rehabilitation, Sacramento Medical Center, Northern California.

Sue Tico, Project Manager, Institute for Culturally Competent Care, National Diversity, Program Offices.

Malcolm Trifon, Esq., Senior Counsel, ADA Advisory Committee, Program Offices.

Lynn Van Houten, MLIS, Manager of Library Services, Kaiser Vallejo.

Anvarali Velji, MD, Chief, Infectious Disease, South Sacramento Medical Center, Northern California.

Nicolaas Versteeg, Assistant Medical Group Administrator, ADA Advisory Committee, Riverside Medical Center, Southern California.

Wendy Zerín, MD, Developmental Pediatrics, Boulder Medical Offices, Colorado.

THE CULTURALLY COMPETENT CARE HANDBOOK EVALUATION

1. In what context did you receive the handbook(s)?

____ Training/Workshop ____ Individual Request ____ Other (specify ____)

2. Please rate the effectiveness of the handbook(s) as learning tools:

	Not at All	Somewhat	Extremely		
Latino	1	2	3	4	5
Disability	1	2	3	4	5
African American	1	2	3	4	5
Asian and Pacific Islander (API)	1	2	3	4	5
Lesbian, Gay, Bisexual and Transgendered (LGBT)	1	2	3	4	5

3. Please rate the effectiveness of the handbook(s) in improving cross-cultural clinical skills:

	Not at All	Somewhat	Extremely		
Latino	1	2	3	4	5
Disability	1	2	3	4	5
African American	1	2	3	4	5
Asian and Pacific Islander (API)	1	2	3	4	5
Lesbian, Gay, Bisexual and Transgendered (LGBT)	1	2	3	4	5

4. Describe what you like about the handbook(s):

Latino: _____

Disability: _____

African American: _____

Asian and Pacific Islander: _____

LGBT: _____

5. Describe how we could improve the handbook(s):

Latino: _____

Disability: _____

African American: _____

Asian and Pacific Islander: _____

LGBT: _____

6. Other comments?

**Please FAX to 510-271-5757 or mail to the address
printed on the opposite side of this page.**

**If you are interested in obtaining additional copies of this handbook, please contact
the National Diversity Hotline at 510-271-6663.**

Thank you

Fold Here



Kaiser Permanente National Diversity Department
One Kaiser Plaza, 17 Lakeside
Oakland, CA 94612

Fold Here

*Sponsored by
The Kaiser Permanente National Diversity Council
and the Kaiser Permanente National Diversity Department
Copyright© 2004 Kaiser Foundation Health Plan, Inc. All Rights Reserved.*



KAISER PERMANENTE®